Self-care behaviours in Ghanaian adults with type 2 diabetes: adherence and barriers

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Submitted for the degree of Doctor of Philosophy August 2019

This research was supported by an Australian Government Research

Training Program (RTP) Scholarship

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DECLARATIONS

Statement of originality

I hereby certify that the work embodied in the thesis is my own work, conducted under normal supervision. The thesis contains no material which has been accepted, or is being examined, for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made. I give consent to the final version of my thesis being made available worldwide when deposited in the University's Digital Repository, subject to the provisions of the Copyright Act 1968 and any approved embargo.

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Thesis by Publication

I hereby certify that this thesis is in the form of a series of papers. I have included as part of the thesis a written declaration from each co-author, endorsed in writing by the Faculty Assistant Dean (Research Training), attesting to my contribution to any jointly authored papers.

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16/07/2019

CONTRIBUTION STATEMENT

By signing below, I confirm that **Mr. Victor Mogre** contributed and led manuscript conceptualisation, study design, data collection, data analysis and interpretation, and drafting and final preparation of the following manuscripts:

- Mogre V, Johnson NA, Tzelepis, F, Shaw, JE, & Paul, C. Systematic review of adherence to diabetes self-care: evidence from low-and middle-income countries. Accepted for publication by the Journal of Advanced Nursing (Acceptance date: 05/10/2019).
- Mogre V, Abanga Z. O., Tzelepis F, Johnson NA, & Paul C. Psychometric evaluation of the Summary of Diabetes Self-Care Activities measure in Ghanaian adults living with type 2 diabetes. Diabetes Research and Clinical Practice 2019;149:98-106
- Mogre V, Abanga ZO, Tzelepis F, Johnson NA, Paul C. Adherence to and factors associated with self-care behaviours in type 2 diabetes patients in Ghana. BMC Endocrine Disorders 2017; 17 (1):20.
- Mogre V, Johnson NA, Tzelepis F, & Paul C. Barriers to diabetes self-care: a qualitative study of patients' and health care providers' perspectives. Journal of Clinical Nursing. 2019; 1-13.
- Mogre V, Johnson NA, Tzelepis F, Paul C. Attitudes towards, facilitators and barriers to the provision of diabetes self-care support: A qualitative study among healthcare providers in Ghana. Diabetes and Metabolic Syndrome: Clinical Research and Reviews 2019;13 (2019):1745-51
- 6. Mogre V, Johnson NA, Tzelepis F, Hall A, Paul C. Barriers to self-care and their association with poor adherence to self-care behaviours in people with type 2 diabetes in Ghana: a cross sectional study. Submitted to Diabetes Research and Clinical Practice (Submission date: 05/08/2019). Currently under editorial review.

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ACKNOWLEDGEMENT

Firstly, I thank the Almighty God for His blessings, guidance and protection throughout my life and educational career up till this point. He is truly a living God who never forsakes those who call on Him.

Secondly, I would like to thank my supervisors, Prof. Christine Paul, A/Prof. Flora Tzelepis and Dr. Natalie A. Johnson for their support, insightful supervision and direction to make my research productive and stimulating. I am grateful to all of them for their trust and confidence in me that I could collect my data, perform data analysis and write up my manuscripts from my home in Ghana as an off-campus student. I would like to thank Professor Christine Paul in a special way for her ability to always see the 'big picture'; her quick understanding of what I really want to convey and always going out of her way to support me in non-academic areas of my studies such as scholarship and VISA related matters. These efforts have helped me greatly to complete my PhD research.

Next, I would like to thank my wife, Patience for her love, support, words of encouragement and motivation for me to aspire to higher heights and to realise my dreams and always allowing me to stay awake during most nights to work on my research. She is a demonstration of the saying that "behind every successful man there is a woman". I am also thankful to my two sons, Bangya and Naamkulna for always allowing Daddy to be on his computer instead of playing with them.

Also, I would like to thank my Dean Prof. Francis A. Abantanga for granting me permissions and the opportunity to travel to the University of Newcastle whenever the need arose.

I would also like to thank my HOD, Dr. Anthony Amalba for his support and kind words to work harder as well as allowing me to take some time off to work on my PhD research.

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I also would like to thank in a special way the heads of all the hospitals and the diabetes clinics for granting me the time and space in their hospitals to enable me to collect data for my PhD research.

I would also like to make special mention of A/Prof. Juventus Ziem for his words of encouragement and motivation to pick up the opportunity to do the PhD even when there were serious challenges regarding how to get permission to travel to Australia. I thank him immensely for giving me ideas on how to go about getting permissions and finally helping me get a part-time study leave to enable me to undertake my PhD research.

Throughout my educational career my dad, the Chief of Tindongo, NAAB MELUGSUNG KUPASAAH MOGRE I has been a strong pillar, and I thank him so much for the support all these years.

In addition, I would like to thank my siblings, Dominic, Sylvester, Joseph, Moses and Anselm as well as John Paul who are always happy with my progress as well as their love and support for my dreams and aspirations. I say 'mpuuhiha'!

Furthermore, I would like to thank my Ghanaian friends I met in Newcastle, Mathew and Gideon for their support and words of encouragement throughout my PhD study. I also specifically like to thank Emmanuel Olabode (Bode), my Nigerian brother ('bros! how far now'), who was my housemate during my stay in Newcastle, for being a reliable and dependable friend during my stay in Newcastle. He together with my Ghanaian friends made my stay in Newcastle a wonderful experience.

Finally, I would like to thank my desk mates aka 'my hommies', Martine and Emma, for making my office experience at HMRI exciting.

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LIST OF ABBREVIATIONS

ADA: American Diabetes Association
ASCBQ: Adherence to Self-Care Behaviours Questionnaire
BMI: Body Mass Index
CFA: Confirmatory Factor Analysis
CFI: Comparative Fit Index
CI: Confidence Interval
COREQ: Consolidated Criteria for Reporting Qualitative Research
CPD: Continuous Professional Development
DAWN: Diabetes Attitudes, Wishes, and Needs
DHPSC: Diabetes Health Promotion Self-Care Scale
DSCS: Diabetes Self-Care Scale
D-SMART: Diabetes Self-Management Assessment Tool
DSMI: Diabetes Self-Management Instrument
DSMS: Diabetes Self-Management Scale
GFI: Goodness-of-Fit Index
GHS: Ghana Health Service
GNI: Gross National Income
GPs: General Practitioners
HbA1c: Glycated Haemoglobin
HBM: Health Belief Model
HCPs: Health Care Providers
HICs: High Income Countries
IBM: International Business Machines Corporation
IDF: International Diabetes Federation

IOM: Institute of Medicine IPAQ: International Physical Activity Questionnaire IQR: Interquartile Range LMICs: Lower- and Middle- Income Countries MESH: Medical Subject Headings MHPE: Masters in Health Professions Education MOH: Ministry of Health MMAS: Morisky Medication Adherence Scale NCDs: Non-communicable Diseases NFI: Normed Fit Index NHLBI: National Heart, Lung and Blood Institute PBC: Perceived Behavioural Control PCDS: Perceived Competence for Diabetes Scale PhD: Doctor of Philosophy **PMT: Protection Motivation Theory** PNFI: Parsimonious Normed Fit Index PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses PROSPERO: International Prospective Register of Systematic Reviews PWD: Person with Diabetes QR: Quantile Regression RMR: Root Mean Square Residual RMSEA: Root Mean Square Error of Approximation SCAQ: Self-Care Activity Questionnaire SCI: Self-Care Inventory SCT: Social Cognitive Theory

SD: Standard Deviation

SDH: Social Determinants of Health

SDSCA: Summary of Diabetes Self-Care Activities

SMBG: Self-Monitoring of Blood Glucose

SPSS: Statistical Package for the Social Sciences

SRM: Self-Regulated Model of Illness

SSA: Sub-Saharan Africa

TDAQ: Diabetes Activities Questionnaire

TLI: Tucker Lewis Index

TPB: Theory of Planned Behaviour

TRA: Theory of Reasoned Action

TTM: Trans-Theoretical Model

UK: United Kingdom

UNICEF: United Nations Children's Fund

USA: United States of America

WC: Waist Circumference

WHO: World Health Organization

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THESIS ABSTRACT

There is a dearth of data regarding adherence to self-care behaviours, and associated barriers among people with type 2 diabetes in Sub-Saharan Africa including Ghana, as described in **Chapter 1**. The remaining Chapters of the thesis sought to address this major gap in the literature.

Chapter 2 contains a systematic review of the literature on adherence to diabetes self-care from low-and middle-income countries (LMICs), describing self-reported adherence rates for the following self-care behaviours: diet, exercise, self-monitoring of blood glucose (SMBG), medication taking and foot care. Twenty-seven quantitative studies from 18 LMICs were included in the systematic review. Adherence was described in two ways: number of days people with diabetes adhered to a self-care behaviour in the past week and the proportion of diabetes patients adhering to a recommended self-care behaviour. Adherence ranged from 2.3 to 4.6 days per week for diet, 5.5 to 6.8 days per week for medication taking, 1.8 to 5.7 days per week for exercise, 0.2 to 2.2 days per week for SMBG and 2.2 to 4.3 days per week for foot care. Proportions of participants adhering to a recommended self-care behaviour varied from 29.9 to 91.7% for diet, 26.0 to 97.0% for medication taking, 26.7 to 69.0% for exercise, 13.0 to 79.9% for SMBG and 17.0 to 77.4% for foot care. It was concluded that adherence to self-care behaviours was generally low and varied widely across studies.

In **Chapter 3**, an evaluation of the psychometric properties of the Summary of Diabetes Self-Care Activities measure (SDSCA) was undertaken, as a potentially feasible tool for population-level use in Ghana. The SDSCA was administered to 187 adults living with type 2 diabetes from three diabetes clinics in Ghana. The analyses showed that people with type 2 diabetes found the items of the SDSCA to be understandable, readable, easy to use, clear, unambiguous and relevant to diabetes self-care. However, a revision of the diet-related item 4 may improve

further the understanding of this item in a Ghanaian context. The results of a confirmatory factor analysis indicated that the four-factor structure of the SDSCA was maintained.

The study presented in **Chapter 4** describes self-reported adherence to the following self-care behaviours: diet, exercise, SMBG and foot care among people with type 2 diabetes people. In addition, factors associated with adherence to diabetes self-care among people with type 2 diabetes were investigated. Consenting type 2 diabetes patients (n=187) attending diabetes outpatient clinic appointments at three hospitals in the Tamale Metropolis of Ghana completed a cross-sectional survey comprising the SDSCA, demographic characteristics and diabetes history. Participants reported exercising 4.8 days on average and followed diet, foot care and SMBG for an average of 4.4, 2.9 and 2.2 days per week, respectively. Increased level of education was associated with higher adherence to exercise, diet and foot care. In addition, women were less likely to perform SMBG compared to men. It was concluded that relatively low adherence was evident in relation to diet, SMBG and foot care; and that interventions should include special attention to women and to people with a low level of education.

Having identified that many people with type 2 diabetes report low adherence to diabetes selfcare, **Chapter 5** explored barriers to diabetes self-care as perceived by people with type 2 diabetes and their healthcare providers (HCPs). Semi-structured interviews were conducted with 23 people living with type 2 diabetes and 14 HCPs recruited from the diabetes clinics of three hospitals in Tamale, Ghana. Potential barriers were conceptualised in accordance with the constructs of the Theory of Planned Behaviour (TPB). The analysis showed a number of barriers relating to attitudes including the misconception that diabetes was caused by spiritual forces or curses, intentional non-adherence and lack of motivation to exercise. Barriers relating to subjective norms included inadequate family support, social stigma and cultural beliefs. Perceived behavioural control barriers included low income levels, lack of glucometers, and inadequate access to foods due to erratic supply or seasonality. Described in **Chapter 6** are the attitudes, facilitators and barriers to the provision of self-care support as perceived by the 14 HCPs interviewed for chapter 5. Although HCPs perceived self-care was the responsibility of the individual with diabetes, they also felt a sense of urgency and responsibility to provide diabetes education. They perceived their role to be one of information sharing rather than building motivation or confidence in relation to self-care behaviours. Barriers that hindered self-care support included language barriers and poor inter-professional collaboration. Furthermore, HCPs discussed that they felt inadequately trained to provide self-care support. Other barriers included inadequate office space, inadequate staff numbers, insufficient supplies and lack of equipment in the hospital.

Chapter 7 provides a quantitative evaluation of the prevalence of barriers and their association with adherence to self-care behaviours. This cross-sectional study was conducted in adults (n=252) with type 2 diabetes recruited from the diabetes clinics of three hospitals in Ghana. The most commonly reported barriers to self-care were: lack of knowledge on how to use a glucometer (59.8%); finding it difficult to change dietary habits (58.7%); and lack of money to purchase a glucometer (55.2%). The only significant association was between adherence to foot care and subjective norms barriers.

Chapter 8 provides a discussion of the main findings and implications of the thesis.

CHAPTER 1

INTRODUCTION

1.1 BRIEF DESCRIPTION OF LITERATURE SEARCH METHODS

The literature was derived from multiple topic-specific non-systematic searches of electronic databases such as MEDLINE, SCOPUS, EBSCO, PUBMED. Grey literature available via Google scholar was also sourced. Key words used were self-care behaviours, type 2 diabetes, adherence, diet, physical activity, exercise, self-monitoring of blood glucose, foot care, sub-Saharan Africa, Ghana

1.2. GLOBAL PREVALENCE OF DIABETES

Diabetes is one of the largest medical emergencies of the 21st Century ⁽¹⁾. According to the World Health Organization (WHO), 422 million adults had diabetes in 2014 ⁽²⁾. High blood glucose is the third most prevalent risk factor for premature death worldwide after high blood pressure and tobacco use ⁽³⁾. Over the years the prevalence of diabetes has increased dramatically rising from 108 million in 1980 to the current figures which is about four times higher ⁽²⁾. The International Diabetes Federation (IDF) estimates that by 2040 the number of adults with diabetes will rise to 642 million i.e. 1 in every 10 adults ⁽¹⁾; 40% of this rise is as a result of population growth and increased life expectancy; 28% due to increases in age-specific prevalence, and 32% due to a combination of the two ⁽⁴⁾.

The rise in the prevalence of diabetes is occurring globally. About 58 million people are living with diabetes in the European region and this is estimated to rise to 67 million people by the year 2045 ⁽⁵⁾. An estimated 4.5 million people are living with diabetes in the UK ⁽⁶⁾. In the US, 30.3 million Americans (9.4% of the US population) had diabetes in 2015 of which 13.4% were non-Hispanic blacks ⁽⁷⁾. An estimated 96 million people have diabetes in WHO's South-East Asian Region ⁽⁸⁾. Based on self-report about 1.2 million Australian adults (6.1% of the Australian population) have diabetes ⁽⁹⁾. About 87% to 91% of all individuals with diabetes are estimated to have type 2 diabetes ^(10; 11; 12; 13).

1.3. ROLE OF SELF-CARE BEHAVIOURS IN THE MANAGEMENT OF TYPE 2 DIABETES

The rate of development and progression of diabetes complications reduces considerably when individuals with diabetes participate in their own care ^(14; 15; 16) i.e. by changing behaviours such as diet. People with diabetes need to perform certain tasks of their own accord to reduce diabetes-related complications ⁽¹⁷⁾. Self-care and self-management are closely related concepts and are used interchangeably. While self-care refers "to the task that individuals must undertake to live with one or more chronic conditions" ⁽¹⁸⁾, self-management refers to the process by which the individual develops the knowledge and skills required to take care of their condition ⁽¹⁹⁾. Consistent self-care requires the knowledge and confidence to deal with medical, behavioural, and emotional aspects of the diabetes condition ⁽¹⁸⁾. Recognised national and international guidelines recommend diabetes-self-care behaviours to include consuming an appropriate diet, doing sufficient exercise, self-monitoring of blood glucose (SMBG), foot care, and in some patients taking medication ^(20; 21; 22; 23; 24; 25; 26; 27).

Evidence suggests participation in these self-care behaviours can result in improved health outcomes for type 2 diabetes patients ^(28; 29; 30; 31). Table 1 provides an overview of reported benefits of these self-care behaviours.

Self-care behaviour	Reported benefits
Diet	Reduces glycated haemoglobin (HbA1c) levels of -0.5% to -2% (^{14; 32; 33; 34; 35; 36; 37; 38; 39; 40; 41; 42; 43; 44; 45)} .
Exercise	Decreases HbA1c by 0.7% per 8mmol/mol, reduces long-term morbidity and mortality and increases insulin sensitivity ^(28; 29; 30; 31) .
Medications	Improves glycaemic control, fewer emergency department visits, reduces hospitalizations and lower medical costs ⁽⁴⁶⁾ .
Self-monitoring of blood glucose	Decreases HbA1c levels by 0.3%, reduces microvascular complications ⁽⁴⁷⁾ .
Foot care	Reduces the risk of diabetic foot complications by 49% to 85% ^(48; 49) .

Table 1: Benefits of participating in self-care behaviours

1.4. CONCEPT OF ADHERENCE TO SELF-CARE BEHAVIOURS

Diabetes is a challenging disease for one to successfully manage ⁽⁵⁰⁾, however, patients who adhere to self-care behaviours can realise excellent glycaemic control ⁽⁵⁰⁾. Following the definitions of Haynes ⁽⁵¹⁾ and Rand ⁽⁵²⁾, the WHO defines adherence as "the extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider ⁽⁵³⁾."

Despite adherence being usually used interchangeably with compliance in the medical literature ^(54; 55) there is a need to differentiate these two terms. Adherence involves the patient's agreement to treatment recommendations, while compliance conceptualises the goodness of fit between a patient's behaviour and a prescribed treatment regimen ⁽⁵⁶⁾ whereby self-care behaviours are recommended solely from the perspective of the healthcare provider. The underlying assumption of compliance is that the healthcare provider always knows what type of treatment is good for the patient ⁽⁵⁴⁾ and medically-defined goals become the focus of

treatment ⁽⁵⁷⁾. Under a compliance-based model, the patient's sense of control and role is limited in decision making, which may make the patient a passive partner in her/his care. For adherence, patients are encouraged to be active partners with their healthcare providers in their own care and good communication between the patient and the healthcare provider is essential for effective clinical practice ⁽⁵³⁾. According to Hentinen ⁽⁵⁸⁾ "adherence to self-care is an active, responsible and flexible process of self-management in which the patient strives to achieve good health by working in close collaboration with healthcare staff, instead of simply following rigidly prescribed rules", p.72 – 73.Terms such as collaborative diabetes management ⁽⁵⁹⁾, patient empowerment or self-care behaviour management ^(60; 61; 62) have been used to conceptualise adherence.

1.5. PREVALENCE OF ADHERENCE TO RECOMMENDED SELF-CARE BEHAVIOURS

Given that adherence to one self-care behaviour may be unrelated to adherence to other self-care behaviours ^(53; 63; 64), it is important to independently evaluate the level of adherence to each self-care behaviour separately ⁽⁵³⁾.

Diet: In a study in India, 37% of type 2 diabetes patients regularly followed dietary prescriptions ⁽⁶⁵⁾, while a little above half (52%) followed a meal plan in a study in the US ⁽⁶⁶⁾. Results of the Cross-National Diabetes Attitudes, Wishes, and Needs (DAWN) study in the US found that type 2 diabetes patients reported adherence rates of 37% for diet ⁽⁶⁷⁾. The results of a systematic review in which the majority of the studies originated from high income countries found adherence to diet ranged from 50 to 81% in type 2 diabetes patients ⁽⁶⁸⁾. This review also reported that the average number of days type 2 diabetes patients participated in healthy eating ranged from 3.5 to 4.4 days ⁽⁶⁸⁾. Given that diet is generally difficult to assess ⁽⁶⁹⁾, these may be imprecise estimates of adherence to dietary recommendations.

Exercise: Studies evaluating type 2 diabetes patients' adherence to exercise vary in their definition of sufficient levels of exercise ⁽⁶⁸⁾, ranging from 30 minutes three or more times per week ⁽⁷⁰⁾ to 150 minutes of moderate or higher-intensity exercise weekly ⁽⁷¹⁾. Notwithstanding the lack of consistency in defining sufficient exercise, adherence to long-term exercise programs ranges between 10% and 80% ⁽⁷²⁾. In the US a survey among type 2 diabetes patients showed that only 26% of the participants adhered to an exercise plan ⁽⁶⁶⁾. A survey among Chinese Americans with type 2 diabetes showed that 39.7% of the participants exercised on 5 or more days ⁽⁷³⁾. Among immigrant Filipino Americans living with type 2 diabetes ⁽⁷⁴⁾ only 56.2% exercised 30 minutes \geq 4 days per week.

SMBG: Results from the third National Health and Nutrition Examination Survey in the US showed that 24% of insulin-treated type 2 diabetes participants reported never monitoring their blood glucose or doing so once per month ⁽⁷⁵⁾ as compared to the recommendation of daily checks. Performing SMBG once per day occurred in only 39% of insulin-treated participants and 5-6% in those on oral medications or diet alone ⁽⁷⁵⁾. Similarly, a cross-sectional study among a sample of 44,181 diabetes patients from the Kaiser Permanente Northern California Region, showed that 67% of those with type 2 diabetes reported frequencies of SMBG lower than the recommended levels ⁽⁷⁶⁾. African American diabetes patients reported an average of 4.7 days per week of performing SMBG in the US ⁽⁷⁷⁾. A study of low-income urban Puerto Ricans in the US found 60% of type 2 diabetes patients performed SMBG once or twice daily ⁽⁷⁸⁾.

Medications: Research shows that diabetes patients demonstrate better adherence to medication regimens than to other self-care behaviours ⁽⁷⁹⁾. A recent review of adherence to self-care behaviours by Coyle et al ⁽⁶⁸⁾ found that adherence to medications ranged from 70% to 99%, which was higher than for other types of self-care behaviours. Definitions of adherence

and methods of measuring adherence vary considerably across studies, as do the study results, suggesting that medication adherence for some patients may be as low as 4.0% ($^{80; 81; 82}$).

Foot care: It is widely acknowledged that adequate foot self-care is not undertaken by the majority of individuals with diabetes ^(48; 83; 84; 85). In a national outcomes research program among 3,564 patients with type 2 diabetes enrolled in diabetes outpatient clinics and general practice in the US, only 49% reported having their feet examined in the last year ⁽⁸³⁾. A study in Jamaica showed that 60% performed daily foot inspection; 85% reported wearing shoes and slippers both indoors and outdoors, although over 40% reported walking barefoot sometimes ⁽⁸⁶⁾. A recent study in Brazil found that 38.7% of type 2 diabetes patients checked their feet 5 to 7 days a week ⁽⁸⁷⁾.

1.6. MEASURES OF ADHERENCE TO DIABETES SELF-CARE BEHAVIOURS

A variety of measures exist for assessing adherence to diabetes self-care behaviours. These methods can be categorised as direct and indirect methods ⁽⁸⁸⁾. The direct methods, which apply mainly to medication adherence and sometimes SMBG, provide proof that the drug has been taken by the patient or the patient is self-testing accurately. This can be done by: 1) the identification of the drug or its metabolite or a biologic marker that is given with the drug, in urine or blood and 2) direct observation of taking the medication or performing the recommended self-care behaviour ⁽⁸⁸⁾. Biochemical tests to identify the availability of the drug or biomarker can randomly be done or at specific time intervals ⁽⁸⁸⁾. Although this approach may be accurate, it is not without drawbacks as its findings can be influenced by several individual factors including diet, absorption, and rate of excretion ^(53; 89). It is also expensive and may not be feasible in low-income settings. In addition, direct observation provides an assessment approach that is particularly specific and may not be influenced by the health status of the person with diabetes ^(88; 90). This approach is used frequently in closely monitored clinical

trials ⁽⁸⁸⁾ and as a strength is able to steadily identify deficits in performing a self-care behaviour that can accidently result in non-adherence ^(91; 92) e.g. technical skill deficits in self-testing blood glucose or administering insulin. Notwithstanding the usefulness of direct observation, it is labour intensive as it requires one to carefully identify and train observers to accurately assess the behaviours of interests ⁽⁹⁰⁾. Direct observation is also prone to measurement reactivity ^(53; 88; 90). For instance, if an individual with type 2 diabetes feels he/she is being monitored by the family members or a healthcare provider (HCP), he/she may become unusually adherent, or make it difficult for the observer to observe the behaviour ⁽⁹⁰⁾.

Indirect methods of measuring adherence to self-care behaviours are more common and involve forms of assessment which do not directly measure the behaviour but serve as proxies to the actual behaviour ⁽⁹⁰⁾. Using Johnson's classification, they can broadly be categorised into health status indicators, health-provider ratings, permanent products (e.g. electronic devices that record the opening of pills) and patient self-reports ⁽⁹⁰⁾. Health status indicators such as metabolic control have been used as measures of adherence to diabetes self-care behaviours (90; ⁹³⁾. Metabolic control and adherence have been treated as interchangeable constructs as it is presumed that patients in good metabolic control denotes good adherence and those with poor metabolic control shows non-adherence (90). However, metabolic control as a measure of adherence has numerous faults and the findings may be misleading. There is, for example, no clear dose-response or 1:1 relationship between metabolic control and adherence in the literature ^(90; 94; 95; 96). The lack of a clear relationship may be due to the fact that metabolic control is related to several factors other than adherence i.e. appropriateness of the prescribed treatment regimen, presence of comorbidities, changes in hormones, duration of the disease, family history and other factors (88; 90) . Adherence is just one of the factors that affects metabolic control but not the only factor. Both should thus be measured independently and concomitantly. Furthermore, the use of health status indicators for assessing adherence does

not allow one to determine the problem areas relevant to the multiple aspects of diabetes care ⁽⁹⁰⁾. Poor glycaemic control may show that something is wrong but it is unable to determine what is specifically wrong, be it the providers' recommendations or that the patient is not following the recommendations well.

Subjective ratings of adherence by HCPs involve asking providers to rate patients' level of adherence to self-care behaviours. This approach is widely reported in the literature ^(53; 90) as being unreliable because providers generally overestimate the degree to which they think patients adhere to their recommendations ^(97; 98). According to Johnson et al ⁽⁹⁰⁾ measures of HCP ratings of adherence are limited by the same methodological and conceptual issues as for health status indicators. The providers' awareness of the health status of the patient (such as HbA1c levels, lipid levels, blood pressure) is likely to influence his/her ratings of the patient's adherence. In addition, provider rating of adherence to diabetes self-care has been global in nature ⁽⁹⁰⁾ (either adherent or non-adherent) without taking into consideration the complexity of adherence to self-care behaviours. Evidence indicates that diabetes adherence is a multidimensional construct involving several unrelated behaviours ^(90; 99; 100; 101).

Generally applied to medication adherence, counting permanent products has been used as a measure of adherence when the behaviour is associated consistently with a permanent product and the product can be counted as an indirect assessment of the associated adherence behaviour ⁽⁹⁰⁾. Examples includes pill counts (arguably the most well-known use of permanent products as a measure) ^(53; 88; 90), prescription record review, weighing bottles of insulin ⁽⁹⁰⁾, counting glucose tests tablets or test strips ⁽¹⁰²⁾. Counting permanent products has a number of limitations such as counting inaccuracies which can lead to overestimation of adherence behaviour ⁽¹⁰³⁾ and loss of important information such as timing of dosage and patterns of missed dosages. This approach may allow patients to indulge in behaviours that may invalidate pill counts as an evaluation of medication adherence ⁽⁹⁰⁾. For example, patients may remove a

pill from a bottle without taking it or give the pills to others. Other behaviours include taking prescribed medications from other pharmacies or dispensers or taking the medication at wrong times. Counting permanent products as an assessment of general adherence is also of limited usefulness in the fact that many diabetes self-care behaviours such as diet and exercise are not associated with any permanent product. ⁽⁹⁰⁾ Taking these limitations into consideration other forms of permanent product measures that are electronic have been introduced to overcome some of these inaccuracies. They include electronic monitoring caps that record the timing of pill bottle openings, current blood glucose monitors that records dates, times and result of glucose test ^(88; 104) and insulin pumps that also store dates, times and amount of basal and insulin bolus doses, carbohydrate entries and blood glucose readings. Although these electronic devices may be able to reduce the inaccuracies associated with pill counts the expense associated with their use limits widespread application and adoption ⁽⁵³⁾.

Another strategy of assessing adherence, is to ask patients to rate their adherence to recommended diabetes self-care behaviours. This could be done through patient interviews with specific questions regarding adherence to diabetes self-care behaviours, or through patient kept-diaries ⁽⁸⁸⁾. Patient self-reports however are generally seen as an unreliable method which are often prone to bias ^(53; 99; 105). Patients may report what they believe is of interest to the healthcare provider, although they may not actually be doing it. Evidently, patients tend to report more accurately on non-adherence to behaviours than they do for adherence ^(53; 88; 90). A number of other factors also influence the accuracy of adherence assessed through self-reports including the type of self-reporting method and the form in which it is used; how the questions are constructed; the communication skills of the interviewer; the wording of the questions; and the timeframe given to patients to recall their adherence behaviour ⁽⁸⁸⁾. Notwithstanding the limitations, patient self-reports are less expensive than objective measures, feasible and less labour-intensive ^(88; 99). Patient self-reports can be made more reliable if the questions in the

interviews and questionnaires are specific and non-judgemental about self-care behaviours ^(106; 107)

Given that patients tend to report more accurately on specific behaviours, one of the ways that has been suggested to overcome some of the limitations of self-reports is to have patients report their adherence to specific behaviours such as diet, exercise, medication taking, SMBG, and foot care ⁽¹⁰⁵⁾. Several patient self-report tools have been developed to assess the self-care behaviours of diabetes patients, including the Summary of Diabetes Self-Care Activities (SDSCA) ⁽⁰⁹⁾, the Adherence to self-care behaviours questionnaire (ASCBQ)⁽¹⁰⁸⁾, diabetes health promotion self-care scale (DHPSC)⁽¹⁰⁹⁾, diabetes self-management instrument (DSMI)⁽¹¹⁰⁾, diabetes self-management scale (DSMS)⁽¹¹¹⁾, diabetes self-care scale (DSCS)⁽¹¹²⁾, self-care activity questionnaire (SCAQ), self-care inventory (SCI) ⁽¹¹³⁾, and the diabetes activities questionnaire (TDAQ)^(114; 115). The ASCBQ, DHPSC, DSMI, DSMS and TDAQ have only been tested psychometrically on one sample ⁽¹¹⁴⁾, and have limited available information. This limits the wide application of these tools in diverse populations. Limited psychometric properties have been reported for the SCI, it does not include foot care, a key self-care behaviour ⁽¹¹⁴⁾.

The SDSCA, a self-report instrument which measures diabetes patients' adherence to a number of self-care behaviours, is arguably the most widely used self-report instrument for assessing diabetes self-care in adults ^(99; 101). The original version comprised 12-items assessing five components of diabetes self-care ⁽¹¹⁶⁾: diet, exercise, medication taking, and blood glucose testing. A review of seven studies by the authors of the SDSCA ⁽⁹⁹⁾ resulted in a revised version that included items for foot care and smoking status. The revised version consisted of 11 core items and an expanded list of 14 additional items yielding 25 items ⁽⁹⁹⁾. However, given there is little or no data on the reliability and validity of these additional items ⁽⁹⁹⁾, the 11-item revised

SDSCA is recommended for use by the authors. Furthermore, the revised version of the SDSCA does not include items on medications due to their strong ceiling effects and low test-retest reliability ⁽⁹⁹⁾. According to the authors of the SDSCA, strengths of the 11-item revised SDSCA include its brevity and ease of use in both clinical and research settings and evidence for its validity and reliability ⁽⁹⁹⁾.

The psychometric properties of the SDSCA have been shown to be satisfactory among diabetes populations in European ^(99; 101), Asian ^(117; 118) and African American settings ^(77; 99). However, the psychometric properties of the SDSCA are yet to be investigated among diabetes patients in a sub-Saharan African context despite being used to assess self-care behaviours in this setting ⁽¹¹⁹⁾. It is important to assess the psychometric properties of the SDSCA among a diabetes patient population in a sub-Saharan African context because of the socio-cultural, socio-economic and ethnic differences between African populations and other populations. This will provide important data on the suitability and applicability of the SDSCA for assessing self-care behaviours among sub-Saharan African people who have type 2 diabetes.

1.7 CRITIQUE OF THE ADHERENCE TO DIABETES SELF-CARE BEHAVIOURS LITERATURE

The adherence to self-care behaviours literature has a number of limitations. First, there is no 'gold standard', widely accepted accurate method of assessing adherence to self-care behaviours ^(88; 120) resulting in the adoption of varied measures by researchers. The large number of measures reported in the literature ⁽⁵³⁾ makes it difficult to compare findings across studies ^(68; 116). Self-report is the most widely used measure of adherence, due to ease of application and low cost ^(105; 121), but may be vulnerable to social desirability and recall bias ^(116; 122). Accurate measurement of adherence to self-care behaviours may be improved by using instruments that meet adequate psychometric standards of reliability and validity ^(107; 123).

Another important limitation is the lack of a common strategy for quantifying levels of adherence. While some authors assessed adherence in terms of the relative frequency of performing self-care behaviours (i.e. never, sometimes, often, always, etc)⁽¹²⁴⁾, others reported on the number of times patients performed self-care behaviours in a day or a week, while others enumerated the percentage of time patients adhered to a recommended self-care behaviour. A number of studies also used terms such as regular/irregular⁽⁶⁵⁾ and good/bad⁽¹²⁵⁾ to describe the frequency of adhering to self-care behaviours without providing clear definitions of these terms. While this is a shortcoming of the existing data, it is not appropriate to provide definitions which were not used by the original data source. It is important to interpret these data in the context of the limitations of self-reported diet. For example, what is considered as adequate may not be the same for two individuals, hence classifying adherence into good or adequate may be misleading especially for diet. Self-report is liable to under-reporting due to social desirability bias, especially for diet ⁽¹²⁵⁾. Evidence has shown that under-reporting is an important limitation of self-report especially for energy intake ^(125; 126). Individuals with type 2 diabetes may also underreport their energy intake given their awareness of the recommendations for them to limit the consumption of energy-dense foods or high carbohydrate diets. In addition, self-reports especially for diet are also prone to participant burden, and reactivity (i.e., the participant changes behaviour to ease the burden or in light of the information) $^{(126)}$.

The patient's adherence to one self-care behaviour may not be associated with his/her adherence to another self-care behaviour ⁽⁹⁰⁾. Accordingly, it is important to measure each self-care behaviour separately rather than combining scores to yield a single adherence score ^(90; 116). However, a number of studies summed responses across the self-care behaviours assessed to yield a total adherence score to determine adherers and non-adherers ^(127; 128). Given these

limitations the reported adherence rates for diabetes self-care behaviours should be interpreted with caution.

Regarding sampling and recruitment of subjects, most of the studies reported using random sampling ^(65; 78; 86; 129) with a few using convenience sampling ^(73; 74). However, these authors fell short of describing the processes/procedures through which the random sampling or convenience sampling was done.

1.8. BARRIERS TO SELF-CARE BEHAVIOURS

Low or insufficient adherence to self-care behaviours has been attributed to several barriers to self-care. These barriers can be grouped into patient-, provider- and health care system-based barriers ^(130; 131).

1.8.1. Patient-/personal barriers to diabetes self-care

Educational status: Findings from three cross-sectional studies among Chinese Americans, African-Americans and Taiwanese people showed that higher educational status was associated with higher exercise and regular performance of SMBG in type 2 diabetes patients ^(73; 77; 132). Level of education was also found to be associated with adherence to exercise in type 2 diabetes patients in Kenya ⁽¹¹⁹⁾. Having some form of formal education might help people with type 2 diabetes understand the need and role of self-care activities such as SMBG in their diabetes management. Also, most individuals with high level of education are usually associated with high levels of income who are usually more likely to adopt healthy behaviours including diabetes self-care behaviours ^(133; 134). However, those with lower level of education might have less income and may also be dealing more stressful job environments which may not encourage adherence to diabetes self-care behaviours ^(134; 135).

Income levels: Level of income is an important social determinant of adherence to diabetes self-care and can affect adherence to self-care behaviours such as diet, SMBG and medications. The individual requires income to purchase some foods that may not be grown by the person with type 2 diabetes. This barrier to following a recommended diet may be even more significant for people with type 2 diabetes who live in urban cities and have to purchase all their food. Particularly for low income individuals and those without health insurance, the cost of treatment may be an important barrier to diabetes treatment ⁽¹³⁶⁾. A study of 908 Mexican Americans showed significant associations between inadequate health insurance and inconsistent use of medications among a sample of type 2 diabetes patients ⁽¹³⁷⁾. The high cost of drugs and recommended healthy foods has been reported to prevent Ghanaian people with type 2 diabetes from seeking medical care from hospitals ⁽¹³⁸⁾. The Mexican study did not explore why people with type 2 diabetes had inadequate health insurance and also diabetes was diagnosed by self-report.

Culture, religion and language: Often defined as a learned set of values, beliefs, norms and patterns of behaviour ⁽¹³⁹⁾, culture can affect one's perceptions and behaviours in relation to diabetes self-care ^(140; 141). Cultural factors may include food and dietary preferences, lifestyles, traditional and religious beliefs, and beliefs about general health ⁽¹³⁶⁾. Religion can influence eating habits ⁽¹³⁹⁾. Fasting, for example, is common in Islamic religious practice and diabetes patients may not necessarily consider themselves sufficiently 'ill' to exempt themselves from fasting ⁽¹³⁹⁾. In sub-Saharan Africa, the concept of diabetes being curable is promulgated by traditional and folk healers, resulting in reluctance to attend conventional medical practitioners ^(142; 143). A substantial number of patients in the sub-Saharan region still express spiritual theories about the causes of diabetes such as witchcraft and sorcery ⁽¹⁴⁴⁾. Poor language proficiency can also be a major barrier for accessing effective diabetes care. A retrospective US study that compared self-care behaviours in Spanish speaking type 2 diabetes patients with
English-speaking or bilingual patients, found 22% of Spanish-speaking patients reported no comprehension of their prescriptions versus 3% of English-speaking patients not comprehending their prescriptions ⁽¹⁴⁵⁾.

Lack of family and social support: There is some evidence that lack of family and social support is a barrier to self-care, however the evidence reported in the literature has been inconsistent. A sample of Mexican-American women with type 2 diabetes reported that the most difficult aspect of diabetes self-care was its disruption of their ability to take care of their family responsibilities ⁽¹⁴⁶⁾. Social support was not significantly associated with diabetes self-care in a study of Hispanic adult type 2 diabetes patients who had fairly large networks, primarily composed of family members ⁽¹⁴⁷⁾. Wing and colleagues reported that spousal participation in weight loss education groups for diabetes patients had a negative impact for men but resulted in more weight loss for women ⁽¹⁴⁸⁾.

Treatment regimen: Generally, the more complex the treatment recommendations, the less likely the patient will adhere ⁽⁵³⁾. Patients who were prescribed a single medication reported better short-and long-term adherence rates than those prescribed more than one medication ⁽¹⁴⁹⁾ while more frequent doses were associated with lower adherence ⁽¹⁵⁰⁾. People with type 2 diabetes are more likely to forget or get confused with the recommendations when they are multiple and complex.

Lack of knowledge: Qualitative studies have identified lack of knowledge as a common barrier to diabetes self-care ^(151; 152). Knowledge about diabetes and its causes and symptoms has been quantitatively associated with the prevention of diabetes related complications ⁽¹⁵³⁾. However, knowledge does not necessarily result in the adoption of risk-reducing behaviour ⁽¹³⁶⁾. A study among insulin-treated type 2 diabetes patients showed higher knowledge scores correlated positively with lower perceived barriers to SMBG but there was no significant association between diabetes knowledge scores and perceived adherence to diet, exercise or medication

⁽¹⁵⁴⁾. However, knowledge may still be necessary to help people with diabetes understand their treatment region and the reason to adhere to recommendations.

Low self-efficacy: Self-efficacy refers to belief in one's competence to successfully perform a given task/activity/behaviour ⁽¹⁵⁵⁾. Higher self-efficacy was associated with adherence to a prescribed treatment regimen in a cross-sectional study of adults with type 2 diabetes ⁽²³⁾.

Attitudes and beliefs: Individuals with type 2 diabetes have a wide range of attitudes and beliefs about diabetes and its treatments which in turn influence the way they perceive and adhere to self-care recommendations. These attitudes and beliefs may influence the choice of treatment the individual with type 2 diabetes may choose (either to seek biomedical care or to seek herbal medicine). Aikens in a qualitative study among Ghanaian adults living with diabetes reported the occurrence of healer shopping in which people with type 2 diabetes engage in healer shopping (the use of a second healer without referral from the first for a single episode of illness ⁽¹⁵⁶⁾ between biomedicine, ethnomedicine, and faith healing ⁽¹³⁸⁾. This study comprised of only participants from the southern part of Ghana, that varies socio-economical from northern Ghana, affecting the generalizability of the findings.

1.8.2. Provider-based barriers

Attitude of healthcare providers to support patient self-care: Healthcare providers are in an important position to promote patients' abilities to successfully manage their diabetes ⁽¹⁵⁷⁾. The attitudes of healthcare providers have also been found to influence diabetes patients' adherence to self-care behaviours. A systematic review reported that patients' adherence to the recommended treatment regimen is influenced by clinicians' beliefs and attitudes ⁽¹⁵⁸⁾. Another study ⁽¹⁵⁹⁾ showed that diabetes patients' attitudes towards insulin therapy were influenced by their healthcare provider's attitudes regarding the efficacy of diabetes treatment regimens. Thus, they were reluctant to recommend such treatment regimens to patients. The attitude of

the health care provider can either promote or decrease patient-provider communication, a factor that has been shown to improve adherence to diabetes self-care recommendations.

Lack of knowledge: Healthcare providers' lack of knowledge about recent evidence-based guidelines can affect patients' diabetes care and self-care behaviours ⁽¹³⁶⁾. Specifically, healthcare providers may be unclear about when to start insulin and how much insulin they should prescribe ⁽¹⁶⁰⁾. They may also lack the knowledge to support patients to self-care. A qualitative study among healthcare professionals in the Netherlands identified lack of awareness of lifestyle programs and preventive initiatives for individuals with diabetes as major barriers to diabetes care ⁽¹⁶¹⁾. Inadequate knowledge regarding treatment guidelines may result in patients not receiving optimum care for their disease condition. Adequate knowledge will help the healthcare provider choose the most appropriate treatment option for the patients and also support the patient overcome challenges that may arise from the treatment recommendations.

Provider-patient communication: There is evidence that quality patient-provider communication is associated with higher adherence to diabetes self-care, better diabetes outcomes or both ^(162; 163). Patients often report communication-related barriers that affect collaborative diabetes management with their provider, which may influence their adherence to self-care behaviours ⁽¹⁶⁴⁾. Some healthcare providers report that they lack effective communication tools and skills in counselling and shared-decision-making ⁽¹⁶⁵⁾. Effective communication may motivate people with type 2 diabetes to adhere to self-care recommendations and may also help patients feel at ease to share their experiences and challenges to the healthcare provider to offer support to overcome those challenges.

1.8.3. Healthcare system-based barriers

Lack of access to trained specialists: An important aspect of diabetes care is access to diabetes specialists or healthcare professionals specially trained for diabetes ^(131; 139). In the US it is estimated that over 90% of diabetes patients' visits to the clinic are with primary care providers or general practitioners ⁽¹⁶⁶⁾. There is evidence that care provided by diabetes specialists compared to generalist physicians is associated with higher use of preventive services and improved glycaemic control ^(167; 168; 169; 170; 171).

Inadequate systems: Other health system related barriers that have been shown to influence access to diabetes care include lack of reimbursement ^(172; 173; 174; 175); organizational constraints such as the absence of organizational systems to support diabetes management (i.e. registries, automatic recall systems and reminder systems) ⁽¹⁷³⁾ and the lack of an individualized plan of care ⁽¹⁷⁶⁾.

1.9. BARRIERS AND FACILITATORS TO HEALTHCARE PROVIDERS' PROVISION OF SELF-CARE SUPPORT

Self-care constitutes approximately 95% of diabetes care ⁽¹⁹⁾. However, the term self-care should not be misconstrued as suggesting that people with diabetes should be left alone to solely do everything for their diabetes; rather that HCPs, family and friends all play a part in supporting the person with diabetes ^(177; 178; 179). Supporting self-care involves making it possible for people with diabetes to have the confidence, knowledge and skills to effectively deal with day-to-day activities associated with living with diabetes ^(19; 180; 181; 182). According to the American Diabetes Association (ADA), diabetes self-care support is that needed for carrying out and encouraging coping skills and behaviours required to self-care for diabetes on a day-to-day basis beyond or outside of formal self-management training ⁽¹⁸³⁾. It provides a stepping stone upon which people with diabetes are assisted to go through self-care decisions

and activities to successfully manage their diabetes ⁽¹⁸⁴⁾. Self-care support comes in a number of forms including behavioural, educational, psychosocial and clinical and has been shown to improve health outcomes including behaviour change such as healthy lifestyle, improved quality of life, reduced hospital admissions and re-admonitions ^(19; 183).

Notwithstanding the fact that family members, friends and peers can provide self-care support to people with diabetes, the HCP is very key to the self-care support process and may be required to play a lead and coordinating role. However, a number of barriers prevent HCPs from providing effective self-care support to their patients. Just like the barriers to diabetes self-care among patients, barriers of HCPs can also be categorised into three levels; patientrelated, the individual healthcare provider and healthcare system-related.

Patient-related barriers: A number of patient-related barriers that prevent HCPs from providing effective self-care support and care to people with diabetes have been reported in the literature. In a qualitative study that explored the role of patient, physician and systemic factors in the management of type 2 diabetes mellitus among Canadian family physicians, Brown et al found that participants reported a number of patient-related barriers including lack of adherence; lack of acceptance of diabetes as a chronic illness; feeling fatalistic, denial, passivity, and unrealistic perspectives; and the presence of co-morbid diseases ⁽¹⁶⁰⁾. In another qualitative study among Belgian general practitioners, Wen et al found that GPs' provision of diabetes care including self-care support was hindered by social isolation; patients' inadequate knowledge about diabetes; patients minimising their diabetes; patients opposition to change/modify their lifestyle and patients reliance on using medication for every complaint instead of adopting healthy dietary habits ⁽¹⁶⁵⁾. Other patient-related barriers reported in the literature include patients misunderstanding the role of diabetes educators ⁽¹⁸⁵⁾; lack of motivation ^(160; 186); and patients' lack of trust in some HCPs ⁽¹⁸⁵⁾; and patients' unwillingness to spend time with the HCP ⁽¹⁸⁵⁾.

Provider-related barriers: Goderis et al undertook a qualitative study among 20 GPs who were part of a quality improvement programme and found that GPs were less likely to adhere to diabetes care guidelines if they had inadequate knowledge in diabetes care; lack of awareness of the provider's performance; lack of confidence in evidenced based treatment and collaborative care; and lack of time ⁽¹⁸⁶⁾. Other provider-related barriers reported in the literature include inadequate skill set ⁽¹⁶⁰⁾; poor self-efficacy in diabetes care; the need for education ⁽¹⁸⁷⁾; complexity ⁽¹⁸⁸⁾; competition among different groups of HCPs ^(165; 189); lack of effective communication tools ^(136; 160); lack of counselling and collaborative care skills ⁽¹³⁶⁾; poor patient-provider relationships and frustration with patients' poor adherence ⁽¹⁸⁹⁾.

Health system-related barriers: Regarding healthcare system related barriers Rushforth et al in a qualitative systematic review of 32 studies reported a number of barriers including workload and time pressures; inadequate funding and staff numbers; mixed relationships and communication with specialists teams and inadequate financial compensation ⁽¹⁸⁹⁾. In a qualitative study aimed at identifying systemic barriers to primary care diabetes management among physicians in a small office practice in Delaware in the US ⁽¹⁹⁰⁾, participants identified a number of systemic barriers including a greater emphasis for acute care and less regard for chronic care; lack of proactive population-based patient management; lack of adequate selfmanagement education; lack of universally available clinical information and lack of public health support for prevention awareness. A wide range of other systemic barriers have also been reported and include a lack of a structured approach to diabetes management ⁽¹⁸⁹⁾; lack of team work and multidisciplinary support (165; 186); financial barriers such as out-of-pocket payments for education, dietary advice; limited services available for special populations such as the elderly ⁽¹⁶⁰⁾; the lack of organisational systems such as registers, automatic recall and reminder systems to support effective diabetes care (160; 186) and the unavailability of an individualised plan of care (176).

Facilitators to diabetes self-care support: Notwithstanding the barriers, there are also a number of facilitators at the patient, provider and healthcare system level that facilitate HCPs' provision of self-care support to people with type 2 diabetes. At the patient-level some of the facilitators reported in the literature include patients' assumption of responsibility and control for their diabetes; early educational interventions; initial anxiety following diagnosis presenting an opportune time to motivate patient behaviour change; significant positive changes in health outcomes or treatment plan; cooperating with HCPs in shared and collaborative care; and having knowledge and awareness about the disease condition ^(160; 185). Goderis et al identified GPs' enhanced knowledge, improved motivation and a greater sense of responsibility as facilitators of greater adherence to diabetes care guidelines in a qualitative study of barriers and facilitators of evidenced based care of type 2 diabetes patients ⁽¹⁸⁶⁾. Other HCP related facilitators reported from previous studies include improved communication skills ^(165; 185); team work and multidisciplinary collaboration ^(165; 191); positive attitudes towards diabetes care; availability of on-going continuous medical education; and improved information technology facilities (160). At the level of the healthcare system, facilitators of effective diabetes self-care support and care include working in multidisciplinary teams (165; ¹⁹¹); allocating time for patient education ⁽¹⁶⁰⁾; re-orientation of the care system; financial support and creating opportunities for HCPs to participate in continuous education programmes (175)

1.10. CRITIQUE OF THE BARRIERS TO SELF-CARE BEHAVIOURS LITERATURE

Few studies of barriers provided detailed information regarding the sampling and recruitment of study participants ^(137; 192). Furthermore, some studies did not provide an adequate description of the context of the studies ^(140; 143; 152), which limited their ability to identify a wide range of barriers. Among studies^(147; 153) that utilised author-designed questionnaires, the authors did

not assess the psychometric properties of the instrument, making it difficult to assess the adequacy of the validity and reliability of the reported data.

1.11. CONCEPTUAL MODEL/THEORETICAL FRAMEWORK

Understanding behaviours such as adherence to self-care and developing effective interventions to promote behaviour change require choosing an appropriate theory and methods for a particular situation ^(193; 194). Commonly reported behaviour change theories in the literature include the Health Belief Model (HBM) ⁽¹⁹⁵⁾; the Theory of Reasoned Action (TRA) ⁽¹⁹⁶⁾; the Theory of Planned Behaviour (TPB) ⁽¹⁹⁷⁾; Bandura's Social Cognitive Theory (SCT) ⁽¹⁹⁸⁾; the Transtheoretical Model (TTM) ⁽¹⁹⁹⁾; Protection Motivation Theory (PMT) ⁽²⁰⁰⁾ and Self-regulated Model of Illness (SRM) ⁽²⁰¹⁾.

The TPB, which will be used in this thesis, conceptualises that intention influences one's adherence to self-care behaviours ⁽²⁰²⁾. The TPB is an extension of the TRA through the inclusion of the perceived behavioural control component ⁽²⁰³⁾ in addition to attitudes and perceived social norms. Intention to adhere to a self-care behaviour is influenced by the individual's attitudes; subjective norms; and perceived behavioural control ⁽¹⁹⁷⁾.

Attitude is influenced by one's beliefs and it is conceptualised in the TPB model as one's appraisal of the outcome of performing a behaviour ⁽²⁰⁴⁾, which could either be positive or negative. Influenced by normative beliefs, *subjective norms* can be conceptualised as one's perception of social pressure from his/her significant other(s) to adhere or not to adhere to recommended self-care behaviours ⁽²⁰²⁾. One's motivation to adhere to the opinion of important people/groups influences one's normative beliefs which subsequently affects one's adherence to self-care behaviours ⁽²⁰⁵⁾. Associated with beliefs of control (e.g. self-efficacy), *perceived behavioural control* refers to one's perception of the ease or difficulty of adhering to the recommended self-care behaviours ⁽²⁰²⁾. Belief about control is influenced by the availability

of resources and opportunities to perform the recommended self-care behaviours. These resources and opportunities could relate to having enough finances to perform the behaviour, or having access to the specialised care. The TPB also recognises the indirect influence of background factors such as demographics, personality and psychological factors, previous experience and knowledge ⁽²⁰⁶⁾.

When using the TPB it is important to acknowledge its limitations. The TPB emphasizes the responsibility of the individual actor rather than social and physical environments along with the collective effort of the community in which the individual lives ⁽²⁰⁷⁾.

In addition, the TPB does not allow for cooperative behavior but is tailor-made for individual behavior ⁽²⁰⁷⁾. This may not fully account for adherence to diabetes self-care as some of the recommended behaviours such as diet might require the cooperation of family members (e.g. spouses, children) to prepare appropriate meals for the individual with type 2 diabetes.

Furthermore, critics of the TPB argue that attitudes and subjective norms (important concepts of the TPB) exist at the community level but is ignored in the TPB model and as a result does not provide a community-based explanation of social behavior ⁽²⁰⁸⁾. They argue that these community level attitudes and subjective norms that are as a result of social construction are potentially more influential at behavior change than individually-held cognitions ⁽²⁰⁸⁾.

Another drawback of the TPB is its assumption that the behavior of individuals operates in a rational systematic manner depicted by somewhat linear and rational decision-making processes ⁽²⁰⁹⁾. Dutta-Bergman argues that the strong emphasis of the TPB on cognitive orientation lends itself to ignoring the affective nature of individuals that is critical in decision making processes ⁽²⁰⁷⁾. Kippax and Crawford insist that norms and beliefs do not necessarily determine or precede behaviour or action especially for a number of recommended diabetes self-care behaviours such as SMBG, diet and medication ⁽²⁰⁸⁾. The linearity of the TPB may fail to account for why people with type 2 diabetes may not adhere to recommended self-care

behaviours although they may have appropriate beliefs and norms regarding diabetes self-care. For instance, an individual with type 2 diabetes may have adequate knowledge, attitudes and beliefs regarding the need to eat adequate diet but may not have adequate income to do so. Thus, the linearity of the TPB may not allow the theory to fully capture the complex and dynamic nature existing between practice, beliefs and normative structures.

The TPB has also been criticized as being insufficient to explain behaviour change ^(210; 211; 212; 213). Critics argue that variables in addition to attitude, subjective norms and perceived behavioural control are needed to fully explain behaviour, resulting in calls for an extension of the theory ^(210; 211; 212; 213).

Notwithstanding the drawbacks, the TPB is a useful tool for helping (at least in part) to explain adherence to diabetes self-care and identify why individuals with type 2 diabetes may not adhere to their self-care recommendations. Individuals with type 2 diabetes have attitudes, norms and values that will shape and influence their decision-making processes regarding adherence to recommended self-care behaviours.

The TPB has been used to explain adherence to a number of self-care behaviours in diabetes. A recent study showed that positive attitudes and perceived behavioural control predicted a stronger intention to perform physical activity in a study among type 2 diabetes patients ⁽²¹⁴⁾. Furthermore, intention to do physical activity was the strongest predictor of adherence. Explaining 60% of the variance in intention, all TPB variables were found to be associated to intentions to perform physical activity in a study that evaluated exercise adherence in a sample of type 2 diabetes patients ⁽²¹⁵⁾. A cross-sectional study of type 2 diabetes patients ⁽²¹⁶⁾, found that attitudes, subjective norms and perceived behavioural control were predictors of intention to adhere to self-care behaviours, with the strongest being perceived control that predicted actual adherence. The findings of a meta-analysis in 2001 showed that 39% of the variance of intention and 27% of actual behaviour were explained by TPB variables ⁽²¹⁷⁾. Regarding the

SMBG a study among adults living with type 2 diabetes found that social norms, adherence and partner support predicted self-monitoring of blood glucose ⁽²¹⁸⁾. Concerning adherence to diet, a study among individuals diagnosed with type 2 diabetes and cardiovascular disease, revealed that intentions to eat foods low in saturated fats were predicted by attitude and subjective norms ⁽²¹⁹⁾. Given the fact that no single behaviour change theory can account for all health-related behaviours, not all studies report support for all TPB variables. In a sample of individuals at risk of diabetes, Blue et al found all TPB variables predicting intention to perform exercise and diet but attitude was not found to be associated with any of the self-care behaviours ⁽²²⁰⁾.

Although a number of behavioral models exist which take into consideration the role of social and physical environments including the social ecological model ⁽²²¹⁾, social cognitive theory ⁽²²²⁾, diffusion of innovation theory ⁽²²³⁾, value belief system ⁽²²⁴⁾, and the WHO conceptual framework for action on the social determinants of health ⁽²²⁵⁾, the TPB was chosen due to the following reasons. Informed by the researcher's empirical framework, academic background and research training the thesis perspective is focused on the health-care -provider - patient relationship (ie the individual perspective) rather than a societal perspective. Therefore, the TPB is an important model to conceptualise the studies presented in this thesis. Against the context of societal and environmental factors, the individual needs to make a personal decision to respond to conditions at the systems or social level. Focusing on the individual may bring about changes within the short-term, given the immediate decision to change - to some extent - still rests with the individual. It is thus reasonable to address the individual level factors in relation to diabetes self-care behaviours. Notwithstanding this assumption, the role of the social and system level factors is recognized in the thesis work through the classification of barriers into individual, provider and organizational or environmental level barriers. The researcher's acknowledgement of factors outside the individual also influenced the design of data collection tools especially for the qualitative studies, along with the way data have been analysed and presented in this thesis. Accordingly, the social determinants relevant to diabetes self-care are discussed next.



Figure 1: Conceptual framework ⁽²⁰⁴⁾ (Modified by VM to include perceived barriers to self-care)

1.12 UNDERSTANDING AND MEASURING SOCIAL DETERMINANTS OF DIABETES AND ITS CARE

Although the focus of this thesis is on the individual, it is important to acknowledge that physical and social environments have an influence on adherence to diabetes self-care. Poor diabetes-related health outcomes are not adequately explained solely by the contributions of clinical factors and individual behavioural practices ^(226; 227; 228). A number of interventions to improve diabetes care fail to adequately account for the impact of physical and social factors (such as low income, employment insecurity, low educational attainment, and poor living conditions) on behavioral practices ^(227; 229; 230). These factors beyond the individual are broadly referred to as the social determinants of health. The WHO framework for the social determinants of health (SDH) defines social determinants as "the conditions, in which people are born, grow, work, live, and age and the wider set of forces and systems shaping the conditions of daily life"⁽²³¹⁾. These may include the social environment, the physical

environment, health services, and structural and societal factors ⁽²³²⁾. At both the individual and population level, these factors can broadly be considered as influencers and predictors of health outcomes ^(226; 233). Social determinants such as income, education, housing and access to nutritious food are relevant to diabetes care including adherence to self-care recommendations ⁽²²⁸⁾. The cost of diabetes care presents a high financial burden to individuals with poor income levels which can further magnify the effects of poverty given that it expends a larger part of income. In addition, an individual who is disadvantaged as a result of poverty may not also have adequate access to important resources needed to manage the diabetes including adequate housing, nutritious food and health care services ^(228; 234). Depictive of a cyclical process, type 2 diabetes can cause poverty and change the income status of the person living with the condition as it can decrease productivity at work or educational achievement if left unmanaged ⁽²²⁸⁾. Such an exacerbation of the cycle of inequality may result in further poverty, material deprivation and social exclusion ^(228; 235).

While measuring SDH is challenging ⁽²³⁶⁾, education is one of the universal indicators of socioeconomic status ⁽²²⁸⁾. Education acts via a complexity of pathways and may be related to other key SDH variables such as income and occupation ⁽²²⁸⁾. Education is associated with the ability to access and use health-related knowledge, appropriate health care and health services ⁽²²⁸⁾. People who are highly educated are more likely to have employment that will earn them adequate income to be able to manage their diabetes condition ^(228; 233). As noted above, education plays an important role in the adoption of health behaviour practices such as diabetes self-care behaviours. For clinical interventions to have a positive and sustainable impact it is essential to invest in social support polices that aim to improve income instability, low education attainment, inadequate access to healthcare and food insecurity ⁽²²⁸⁾. Given the relevance of education to SDH, it is important to include the assessment of education wherever possible, even in studies which have an individual rather than a systemic or societal focus.

1.13 BURDEN OF TYPE 2 DIABETES IN SUB-SAHARAN AFRICA

In this section, a description of the burden of diabetes is provided detailing why there is a need to focus research about adherence to diabetes self-care, barriers to self-care and the provision of diabetes care in Sub-Sharan Africa (SSA).

1.13.1 Why should research focus on diabetes in Sub-Saharan Africa?

Reports of the global prevalence of diabetes from the IDF and WHO concur that the largest increases of the prevalence of diabetes are expected to occur in regions where economies are moving from low-income to middle-income levels ^(1; 2) in which sub-Saharan Africa is included. As with other parts of the world, the prevalence of non-communicable diseases such as type 2 diabetes, heart diseases, cancer and obesity is on the ascendency in sub-Saharan Africa, as more people in the region consume processed foods, become physically inactive, live in urban centres and live longer ⁽²³⁷⁾. From 4 million people living with diabetes in 1980 in the sub-region, the WHO reports that 25 million people constituting 7.1% had diabetes in 2014, an increase of more than four-fold during the period ⁽²⁾. The sub-Saharan Africa region also has the highest rate of undiagnosed diabetes; 66.7% of individuals are unaware they have diabetes. Type 2 diabetes is the most common form of diabetes in sub-Saharan Africa. It accounts for over 90% of all cases ⁽¹⁴⁴⁾. The remainder is constituted by type 1A or autoimmune type 1 and type 1B or idiopathic or alternatively ketosis-prone type 2 diabetes, gestational diabetes, and malnutrition-related diabetes ^(144; 238).

Data sources for estimating the prevalence of diabetes in the region are limited to a small number of countries. More than three-quarters of countries in sub-Saharan Africa lack nationwide data on diabetes ⁽¹⁾. Therefore, the current estimates of diabetes prevalence in sub-Saharan Africa may be an underestimation. In a systematic review of the prevalence of diabetes

in Sub-Saharan Africa Hall et al found only nine countries reported surveys on the prevalence of type 2 diabetes ⁽²³⁸⁾.

Diabetes was considered a rare disease in sub-Saharan Africa until about 50 years ago. Between 1960 and mid-1985, the reported prevalence of diabetes was 1% based on studies in localised settings of Ethiopia, Ghana, Lesotho, Uganda and Malawi, that used urine analysis to diagnose diabetes except in Ivory Coast (5.7%) and South Africa (2.2 - 2.7%) that had comparatively higher prevalence $(^{239; 240})$. In Eastern and Western Africa, low prevalence of diabetes was still apparent using the standardised WHO criteria for the diagnosis of diabetes in cross-sectional studies during 1985-1995 $(^{239; 241; 242; 243})$. However, the prevalence ranged from 4-8% in different cities and one peri-urban area from South Africa $(^{244; 245; 246)}$. This could be due to the higher rates of obesity in the South African population than in other countries of the region $(^{144})$.

According to the WHO Non-communicable disease profile for Ghana, in 2014 2% of adults aged 30-70 years were living with diabetes ⁽²⁴⁷⁾. Non-communicable diseases including diabetes accounted for 42% of total deaths in Ghana ⁽²⁴⁷⁾. In 2002, a cross-sectional study of a sample of 4733 Ghanaians aged \geq 25 years reported a prevalence of 6.4% in which 70% were undiagnosed ⁽²⁴⁸⁾. According to the IDF, diabetes affected 3.3% of Ghanaian adults aged 20-79 years in 2014 and was responsible for 8528 deaths ⁽²⁴⁹⁾. In Accra, Ghana, a study among participants from both rural and urban communities reported a diabetes prevalence of 6.0% in the late 1990s, while another study reported a prevalence of 9.1% among civil servants in the same city in 2006 ⁽²⁵⁰⁾.

The variations found in the prevalence of diabetes have been attributed to between-study variations in type of population, methods, diagnostic criteria and small sample sizes. The very limited data available indicates that type 2 diabetes accounts for over 90% of all diabetes cases in Ghana ⁽¹⁴⁴⁾.

1.13.2 Adherence to diabetes self-care in sub-Saharan Africa

As discussed previously, the majority of diabetes care is borne by the person with diabetes i.e. adherence to self-care behaviours. A limited number of studies in Sub-Saharan Africa have investigated adherence to diabetes self-care behaviours among people with type 2 diabetes. In sub-Saharan African countries, similar results of low adherence rates have been seen. In a sample of 104 type 2 diabetes patients (Female, 58.7%) in Botswana, 37% of the participants were non-adherent to diet recommendations ⁽¹²⁷⁾. In Nigeria, 67% of type 2 diabetes patients from a secondary public healthcare facility adhered to dietary treatment ⁽²⁵¹⁾. In a clinical setting in Kenya, 74% of type 2 diabetes patients had a diet adherence level of 80% and only 22% adhered completely to the healthcare provider's recommendation ⁽¹²⁸⁾.

A study among a convenience sample of 65 type 2 diabetes patients receiving care from a diabetes clinic at an academic hospital in Pretoria, South Africa found 46% of the participants achieved a high level of physical activity, 28% a moderate level and 26% a low level ⁽²⁵²⁾. In a cross-sectional study of adult type 2 diabetes patients seeking care from a primary care clinic of a tertiary hospital in Nigeria, 22.5% adhered to physical activity recommendations ⁽²⁵³⁾.

The few sub-Saharan African studies available indicate a low adherence to SMBG. A recent retrospective cohort study of 164 type 2 diabetes patients (59% female; 76% rural) with poor glycaemic control enrolled into a home glucose monitoring (HGM) program in Kenya ⁽²⁵⁴⁾ showed 34%, 17%, 15% and 10% reported good adherence to SMBG during 0-6, 7-12, 13-18, and 19-24 months respectively. In a sample of type 2 diabetes patients in Harari, Eastern Ethiopia, 2.6% of the participants performed SMBG daily ⁽¹²⁰⁾. In Nigeria, only 32% of type 2 diabetes patients seeking care from a diabetes clinic reported using SMBG ⁽²⁵⁵⁾.

In the sub-Saharan African context, a recent study in Uganda reported a medication adherence prevalence of 83.3% in a sample of 521 patients with diabetes in two hospitals ⁽²⁵⁶⁾. In type 2 diabetes patients seeking diabetes care in Tanzania, 60.2% and 71.2% of the participants were

found to adhere to their anti-diabetic drugs at one week and three months respectively ⁽¹²⁴⁾. In Ethiopia, one study found that 51.3% of participants adhered to their medication strategy daily and 36.6% frequently missed their daily doses ⁽¹²⁰⁾.

Evidence from the limited studies in sub-Saharan Africa regarding adherence to foot care is similar to that in other countries. A cross-sectional study conducted on a convenience sample of 313 diabetic patients in Ethiopia showed 41.2% of the participants checked their feet daily ⁽²⁵⁷⁾. In South Africa ⁽²⁵⁸⁾, 31% of the patients attending an outpatient diabetic unit did not inspect their feet for one week, 45.8% did not inspect their shoes before wearing and 94.2% never consulted a podiatrist. Among type 2 diabetes patients attending public diabetes clinics in Dar es Salaam, 48% had received advice on foot self-care, 37.9% undertook foot self-inspection regularly (6-7 days per week) and 27.5% had their feet examined by a doctor at least once since diabetes diagnosis ⁽²⁵⁹⁾.

The few studies from sub-Saharan Africa have relatively small sample sizes (n=65-425) $^{(127;}$ $^{129;252;253)}$. In addition, information about recruitment and sampling procedures for participants in the majority of the studies is scant.

1.13.3. Health system care for diabetes care in sub-Saharan Africa

In sub-Saharan Africa, healthcare is state-funded, oriented towards the needs of acute care and priority is given to infectious diseases ⁽¹⁴⁴⁾. The health workforce is small, such that the African region has access to only 3% of the world's health workforce ⁽²⁶⁰⁾. A typical country in sub-Saharan Africa has two physicians and 11 nurses and midwives per 10, 000 population compared to 32 physicians, and 72 nurses and midwives per 10, 000 population in the European region ⁽²⁶¹⁾. There are also 10 hospital beds per 10, 000 patients in the Africa region and 63 per 10, 000 patients in Europe ⁽²⁶¹⁾. This overstretched healthcare system in SSA is expected to meet the needs of patients with infectious diseases as well as those with chronic, non-infectious

diseases like diabetes. Infectious diseases are thus given priority over diseases that require long-term care ⁽²⁶²⁾.

Diabetes care is part of the general health delivery system in most countries of sub-Saharan Africa ⁽²³⁷⁾. In countries where specialised diabetes care centres exist, they may only be present at a few hospitals or be inadequately funded, rendering diabetes care to levels well below what might be considered optimal ⁽²⁶³⁾. In Ghana for instance, diabetes clinics are non-existent at the primary level of care, they are only present at tertiary care, and a few secondary levels of care ⁽²⁶⁴⁾. Lack of training for diabetes care may result in patients being misdiagnosed ^(262; 265), receiving late diagnosis of diabetes ⁽²⁶⁶⁾ or poor management resulting in the development of diabetes complications. In many countries of the sub-region, 21-25% of people with diabetes are already blind at the time of their diabetes diagnosis ⁽²⁶⁷⁾. In sub-Saharan Africa up to 34%, 65%, and 83% of type 2 diabetes patients have nephropathy, retinopathy and microalbulimia respectively ^(238; 268; 269). Access to hypoglycaemic agents, insulin and equipment such as glucometers and syringes is frequently inadequate ⁽²⁶²⁾.

1.14 THE HEALTH SYSTEM IN GHANA AND DIABETES CARE

Just like other sub-Saharan African countries, the health system in Ghana is government funded. Health services are provided by the Ministry of Health through its agency the Ghana Health Service. The delivery of health services is provided through a three-tier system of primary, secondary and tertiary care. At the base (i.e. primary health care) of the health delivery system is the Community-based Health Planning and Services (CHPS) centres, which serve as a first point of call at the community level. There are also health centres at the community level that provide primary health care. CHPS and health centres are usually staffed by nurses and physician assistants respectively. Diabetes care is almost non-existent at the CHPS and health centres. Hospitals are present at the district level to provide secondary level of care to patients. Complicated cases and chronic diseases such as diabetes are referred from the CHPS and health centres to the district hospitals. District hospitals provide primary and some level of secondary level of health care. A typical district with a population of 100 000 inhabitants has 1 hospital, 5 health centres and 10–15 CHPS zones. Most districts lack specialised diabetes clinics for individuals with diabetes. At the regional level are regional hospitals that provide secondary and some tertiary health care. They are currently 10 hospitals corresponding to the 10 regions of the country. Specialized diabetes clinics are usually present at these hospitals. The tertiary level of healthcare is provided by five teaching hospitals including the Tamale Teaching Hospital, Korle-bu Teaching Hospital in Accra, Komfo Anoakye Teaching Hospital in Kumasi, the Cape Coast Teaching Hospital in Cape Coast and the Ho Teaching Hospital in Ho.

Apart from the five teaching hospitals that provide specialist care, the rest of the hospitals (i.e. regional and district hospitals) treat diabetes through out-patient clinics. Thus, specialist care is limited which is symptomatic of a universal lack of specialist care for chronic disease management in Ghana and other SSA countries ⁽²³⁴⁾. This presupposes that the majority of people with type 2 diabetes in Ghana do not have access to specialist care. A large proportion of the care is provided by nurses, physician assistants and other allied health care professionals such as nutritionists and dieticians. This cadre of healthcare professionals most often do not have specialist training in diabetes care except what they acquired during school, which is frequently inadequate ⁽²⁷⁰⁾.

Similar to other SSA countries, there is a general lack of facilities and resources for diabetes care as well as an erratic supply of essential products for diabetes care in the health facilities in Ghana ⁽²³⁴⁾. In addition, national data on diabetes prevalence, mortality, morbidity and disability is non-existent with the only data available being from a few community- and institution-based studies ⁽²³⁴⁾.

The Ministry of Health in 2012 enacted a national policy for the prevention and control of chronic non-communicable diseases (which includes diabetes) proposing an integrated approach to NCDs programs ⁽²⁷¹⁾. However, its implementation is faced with a lot of challenges, given that in Ghana a national guideline specifically for diabetes care does not exist and as a result diabetes care in the country is fragmented and uncoordinated ⁽²³⁴⁾.

The cost of diabetes care is also high for all income groups but is particularly difficult for poor individuals in rural and urban areas of Ghana ⁽¹³⁸⁾. Although the National Health Insurance Scheme (NHIS) established in 2006 covers some diabetes medication, the initial payment of a premium to access the NHIS may be too expensive for individuals with low income levels. The NHIS is also affected by delayed reimbursement of healthcare costs which has negatively impacted the availability of diabetes medications, thus affecting continuity of care ⁽²³⁴⁾ for people with diabetes. Poverty is an important barrier to receipt of quality care in Ghana ⁽²⁷²⁾. Poor communities have inadequate access to medical care increasing their risk of developing complications ⁽²⁷²⁾. The health disadvantage situation of poor communities can be experienced at a number of levels: "beliefs about health and actual behavior, presentation, screening, negotiation, risk assessment, negotiation, participation, programme persistence and treatment adherence"⁽²⁷³⁾.



Figure 2: Map of Ghana

1.15. GAPS IN THE LITERATURE

There is a dearth of data regarding adherence to self-care behaviours, associated barriers and health outcomes among diabetes patients in Sub-Saharan Africa including Ghana. As a recommendation for future research in a study that investigated self-care behaviours, barriers and health outcomes, Daly et al ⁽²⁴⁾ noted that future research is needed from more diverse populations. Nam et al ⁽¹³⁶⁾ in a recent systematic review also observed a limited understanding of how the different barriers to self-care behaviours relate to each other and mediate to produce an effect. They further observed that the included studies predominantly consisted of Caucasian populations with a few underserved ethnic minorities who are noted to have high morbidity and mortality for diabetes.

In two separate systematic reviews of patient and provider barriers to diabetes care including self-care behaviours, Pun et al ⁽¹⁵⁷⁾ and Nam et al ⁽¹³⁶⁾ observed that there are limited studies examining the perspective of both the patient and provider regarding barriers to self-care. In the Pun et al ⁽¹⁵⁷⁾ review, authors noted that only two studies examined the perceptions of both the patient and the provider concurrently. They observed the need for further studies to investigate this because both patients and providers should recognize and understand these barriers to enable them to work as a team to overcome them.

To the best of our knowledge no study has investigated with an African type 2 diabetes population the psychometric properties of any of the abundant self-report measures of adherence to self-care behaviours in the literature. Evaluation of the psychometric properties of such a measure is essential to accurate assessment of adherence which in turn, is necessary to inform treatment decisions and the design of interventions to improve adherence to self-care behaviours. It is also necessary to assess the psychometric properties of a self-report measure among the Sub-Saharan diabetes population because of the unique socio-cultural and socio-economic characteristics of these populations, as well as poor health systems for diabetes care between African populations and other populations. Few studies have addressed the issue of which barriers are associated with which self-care behaviours. In a review, Glasgow et al ⁽¹³⁰⁾ observed a well-established finding of low inter-correlations among different self-care behaviours, and recommended further research into the relationship between specific barriers and specific self-care behaviours. This thesis intends to fill these gaps in the literature by investigating the following objectives.

1.16 THESIS OBJECTIVES

The broad aim of this thesis is to evaluate adherence to recommended self-care behaviours (diet, exercise, SMBG, medications, and foot care) among Ghanaian adults with type 2 diabetes and to determine the barriers to diabetes self-care.

The specific objectives are to:

- 1. Systematically review the literature on adherence to recommended self-care behaviours among people with type 2 diabetes in low-and middle-income countries (Chapter 2).
- To evaluate the psychometric properties of the Summary of Diabetes Self-Care Activities Measure (SDSCA) among Ghanaian adults with type 2 diabetes (Chapter 3).
- 3. To describe adherence to, and the factors associated with, recommended self-care behaviours in Ghanaian adults with type 2 diabetes (Chapter 4).
- 4. To qualitatively explore barriers to the performance of recommended self-care behaviours among Ghanaian people with type 2 diabetes (Chapter 5)
- 5. To qualitatively explore barriers to the provision of diabetes self-care support among healthcare providers (Chapter 6).
- 6. To determine the prevalence of patient perceived barriers to diabetes self-care and their association to adherence to diabetes self-care behaviours (Chapter 7).

1.17 REFLEXIVITY OF THE RESEARCHER

The researcher is a Senior Lecturer with the School of Medicine and Health Sciences of the University for Development Studies, Ghana. He has a background in nutrition and health professions education. He has a research interest in diabetes care and has previously investigated overweight, obesity, weight perception and weight management behaviours in people with type 2 diabetes. His research was influenced by his long-term vision to design interventions to improve adherence to self-care behaviours, which requires an understanding of diabetes self-care behaviours relating to adherence rates, barriers to adherence, and enablers/facilitators of adherence. The research presented in this thesis is informed by this vision. In addition, as a result of his training and academic role, the researcher's perspective is focused on the health-care –provider – patient relationship (i.e. the individual perspective) rather than a societal one, and hinges on empirico-analytical framework ⁽²⁷⁴⁾. Importantly, the researcher is a Ghanaian and has been working in the setting for a number of years. The disciplinary focus of the thesis is Behavioural Science.

1.18 THESIS STRUCTURE

This is a thesis by publication and it comprises an introduction (Chapter 1), six papers formatted as journal articles (Chapters 2-7) and a general discussion (Chapter 8) that situates the entire findings within the literature, the strengths and limitations of the included studies, implications for practice and recommendations for future research. The papers presented in Chapters 3, 4, 5 and 6 have been published. Chapter 2 has been accepted for publication and Chapter 7 is currently under consideration with a peer-reviewed journal.

1.19 REFERENCES

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CHAPTER 2

A SYSTEMATIC REVIEW OF ADHERENCE TO DIABETES SELF-CARE BEHAVIOURS: EVIDENCE FROM LOW-AND MIDDLE-INCOME COUNTRIES

This manuscript is published in 'Journal of Advanced Nursing'

Mogre V, Johnson NA, Tzelepis, F, Shaw, JE, & Paul, C. Systematic review of adherence to diabetes self-care: evidence from low-and middle-income countries. Journal of Advanced Nursing 2019; 75:3374–3389.

ABSTRACT

Aims: To determine diabetes patient's adherence to five self-care behaviours (diet, exercise; medication, self-monitoring of blood glucose [SMBG] and foot care) in low- and middle-income countries

Design: Systematic review

Data sources: We searched MEDLINE, CINAHL, PUBMED, SCOPUS, PsycINFO, EMBASE, Cochrane library, and EMCARE for the period January 1990 to June 2017.

Review methods: Title, abstract and full text screening were done according to an eligibility criteria. A narrative synthesis of the literature was conducted.

Results: A total of 7,109 studies were identified of which 27 met the review eligibility criteria and were included. All the studies used self-report of adherence to diabetes self-care. Studies reported adherence rates in two major forms: 1) number of days participants performed a recommended dietary behaviour/activity during the past week and 2) proportions of participants adhering to a recommended self-care behaviour. Adherence rates ranged from 29.9 to 91.7% for diet, 26.0 to 97.0% for medication taking, 26.7 to 69.0% for exercise, 13.0 to 79.9% for self-monitoring of blood glucose and 17.0 to 77.4% for foot care.

Conclusion: Although most diabetes patients do not adhere to recommended self-care behaviours, adherence rates vary widely and were found to be high in some instances.

2.1 INTRODUCTION

In the recent three decades there has been a four-fold rise in the number of people with diabetes, with the prevalence rising from 108 million people in 1980 to 422 million in 2014 ⁽¹⁾. The rise in the prevalence of diabetes has been linked to increasing levels of physical inactivity, excess body weight, unhealthy dietary habits and an aging population ^(2; 3). Within the last decade, the number of people living with diabetes has increased at a faster rate in low-and middle-income countries (LMICs) compared to higher income countries (HICs) ⁽¹⁾. The WHO has projected that non-communicable diseases including diabetes will have a higher prevalence than infectious diseases, malnutrition and infant and maternal mortality combined in LMICs by the year 2030 ^(4; 5). Globally, type 2 diabetes mellitus is the most prevalent, constituting over 90% of all diabetes cases ^(6; 7; 8). In LMICs, people with diabetes are prone to poor glycaemic control, frequent hospital admissions, diabetic complications and premature deaths resulting from hyperglycaemia ^(1; 9; 10).

Diabetes is a life-long condition and its proper management requires the active participation of the individual with diabetes through the performance of self-care behaviours such as exercise, diet, self-monitoring of blood glucose (SMBG), medication taking and foot care ⁽¹¹⁾. Adherence to diabetes self-care behaviours has been shown to improve patient health outcomes such as reduced risk of diabetic complications, decreased emergency admissions at the hospital, and improved quality of life outcomes. It is thus not surprising that clinical practice guidelines from the USA, UK and globally ^(12; 13; 14; 15) have recommended that diabetes patients should regularly adhere to their self-care behaviours.

2.2 BACKGROUND

Given the improved health outcomes associated with adherence to self-care behaviours, it is important to have a clear understanding of the extent to which people with diabetes adhere to their recommended self-care behaviours ⁽¹⁶⁾. Adherence to self-care behaviours is likely to be of particular importance in LMICs given very scarce resources are available for managing complex health conditions such as diabetes complications, the lack of trained staff for diabetes management, inadequate equipment and resources, and the lack of facilities for the diagnosis and management of diabetes ^(5; 17).

To our knowledge, only two reviews have evaluated diabetes patients' adherence to self-care behaviours ^(15; 18). Although, the review by Coyle et al included studies from LMICs, the authors did not evaluate data from LMICs separately. In addition, Coyle and colleagues' review contained studies published up to August 2012. The review by Stephani et al ⁽¹⁸⁾ included studies from 10 countries in Sub-Saharan Africa (SSA); and as acknowledged by the authors, this limited the generalisability of the review findings to LMICs outside SSA. A review which includes studies from both SSA and non-SSA LMICs will provide a much wider synthesis of the evidence regarding adherence to diabetes self-care behaviours, making available findings that will be relevant to developing countries globally. As a result, a systematic review of the published literature from LMICs regarding adherence to self-care behaviours is needed to identify the extent of the challenge regarding self-care adherence among persons living with diabetes. These data can assist diabetes care planning in LMICs to target scarce resources where the need or benefit is likely to be greatest.

2.3 THE REVIEW

2.3.1 Aims

This systematic review evaluated the level of adherence to five self-care behaviours recommended for people with type 2 diabetes: diet, exercise, medication taking, SMBG and foot care.

2.3.2 Design

This systematic review is reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) ⁽¹⁹⁾. A protocol was registered at PROSPERO, an international prospective register of systematic reviews (registration number CRD42016035406) and subsequently published ⁽²⁰⁾.

2.3.3 Definition of key terms

Low-and middle-income countries: We defined low-and middle-income countries using the World Bank's 2016 Gross National Income (GNI) per capita of \leq US\$1,025 for low-income countries and a GNI per capita of \geq US\$1,026 but <US\$12,475 for middle-income countries ⁽²¹⁾. This is a slight revision from our published protocol ⁽²⁰⁾ where we indicated we would use the 2015 World Bank's classifications.

Adherence: Following the definitions of Haynes ⁽²²⁾ and Rand ⁽²³⁾, the WHO defines adherence as "the extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes – corresponds with agreed recommendations from a health care provider". We adopted this definition in this review.

2.3.4 Search methods and search strategy

We searched eight electronic databases: MEDLINE, CINAHL, PUBMED, SCOPUS, PsycINFO, EMBASE, Cochrane library, and EMCARE. We searched EMCARE instead of The British Nursing Index listed in our published protocol ⁽²⁰⁾ because our medical librarian advised us that the EMCARE database would contain more relevant information. All searches were completed on 20th June 2017. The search strategy was developed by VM and reviewed by the research team and a medical librarian. As shown in additional file, the search strategy had terms relating to the following: self-care behaviours, diet, exercise, self-monitoring of blood glucose, medication taking, foot care, type 2 diabetes, low-and middle-income countries.

Appropriate MESH headings of these terms as well as relevant free text words were used. Boolean operators were applied where necessary to cater for the different use of terms in the literature. Search results were limited to English and 1990 to present given that diabetes was being recognised during this timeframe as a disease that affects populations of developing countries or LMICs ⁽²⁴⁾. The search strategy was initially used in MEDLINE and subsequently used for the syntax and subject headings of the other databases. All searches were conducted by VM and the results reviewed by all members of the research team.

2.3.5 Search outcome

All search results were downloaded into the reference manager, ENDNOTE version X7 for screening purposes. Titles and abstracts were screened independently by two reviewers (VM and (FT or NJ or CP)) according to the eligibility criteria. The results of the two reviewers were compared and differences were resolved through discussions. Using the Cohen kappa, interrater agreement was k=0.334 demonstrating fair agreement. For articles where eligibility could not be determined through title and abstract screening, full text review was independently completed by two reviewers (VM and (FT or NJ or CP)). Where discrepancies arose, these were resolved through discussion. The reference lists of all eligible articles and systematic reviews were searched to identify any additional relevant articles. We selected studies for inclusion based on the following eligibility criteria.

Study designs: All study designs were included (cross-sectional studies, baseline data from experiments [i.e. randomised or non-randomised trials], retrospective studies, prospective cohort studies and case control studies).

Type of data: Only quantitative studies.

Study participants: Studies that had type 2 diabetes patients from any of the LMICs were included. Those that had the majority (\geq 50%) of participants having type 2 diabetes were included. Studies that did not clearly state the type of diabetes participants had but reported the

mean age of onset of diabetes of the participants to be ≥ 30 years and/or the mean age of participants to be ≥ 40 years were also included.

Time frame: From January 1990 to June 2017.

Setting: Population-based, community-based and clinical or hospital-based studies.

Outcomes: Studies that reported on adherence to diabetes self-care behaviours (either one or multiple self-care behaviour).

Language: Studies written in English.

To ensure the replicability of findings, only published studies were included.

Studies were excluded if they were case reports, conference proceedings, non-peer reviewed papers, opinion pieces, letters to the editor, commentaries, abstracts, did not report on adherence and/or barriers to any of the diabetes self-care behaviours, and/or had majority of the participants being younger than 18 years. Although we intended in our published protocol ⁽²⁰⁾ to investigate in one review adherence and barriers to diabetes self-care, the barriers component is now a subject of another review and will be reported separately. However, the search terms/exclusion criteria still refer to the barriers component.

2.3.6 Data extraction

Data extraction was done using a standardized data extraction form similar to those used in previous reviews ^(15; 25; 26; 27). Information regarding the following was extracted: author(s) name, year of publication, study objectives, study design, country of study, participants, sample size, sampling, recruitment procedures, methods, inclusion/exclusion criteria, type of self-care behaviour (s) investigated, how self-care behaviour was investigated, type of tool used to assess self-care behaviour, data analysis, theoretical underpinning, response rate, demographic characteristics, adherence rates,, and reported conclusions. VM and CP independently extracted the data and discussed among themselves the findings in which differences were

resolved. The outcome of the data extraction process was then discussed with the other members of the review team.

2.3.7 Quality appraisal

We used the National Heart, Lung and Blood Institute (NHLBI) Quality assessment tool for Observational and Cross-sectional studies to undertake quality appraisal ^(28; 29). This tool is widely used and has been recommended by Cochrane for the quality assessment of observational and cross-sectional studies ⁽²⁵⁾. Each study was graded using 14 criteria (a score of one was awarded if the response was 'Yes' and zero if the response was 'no', 'not applicable", 'not reported' or 'cannot determine' and each study was awarded a global score out of 100% (e.g., 7/14 = 50%). A score >80% was considered high quality; 60-80% and <60% considered medium and low quality respectively. All studies that were graded as poor quality were excluded from the review.

2.3.8 Data analysis and synthesis

Given the heterogeneity of the studies a systematic narrative synthesis was conducted. In presenting the characteristics and findings of studies, we used tables and narrative summaries. The analysis and synthesis process was informed by the Guidance of the Conduct of Narrative Synthesis in Systematic Reviews ⁽³⁰⁾. VM conducted all data analysis and synthesis and discussed the findings with the other members of the review team.

2.4 RESULTS

Figure 1 presents the PRISMA flow chart. Our database searches identified 7,109 studies (PubMed = 3008; CINAHL = 312; MEDLINE = 630; SCOPUS = 579; PsychINFO = 37; EMBASE = 1160; Cochrane library = 924; EMCARE = 459) and 2,956 duplicates were removed. Title and abstract screening resulted in 145 studies for full text review. The most

common reasons for exclusion were: not being about diabetes; reporting in other languages other than English; originating from a high income country; following a qualitative approach. Full texts of these articles were retrieved and evaluated against the eligibility criteria from which 48 studies were retained. Review of the reference lists of eligible studies resulted in the inclusion of 6 additional studies yielding a total of 54 studies. Data was extracted from these 54 studies for quality assessment from which 22 studies were excluded for having poor quality. Three studies were excluded for using qualitative approaches to assess adherence to diabetes self-care, 2 for reporting inconsistent adherence rates and the remaining 27 studies were included in this review.



Figure 1: PRISMA flow chart for the selection of studies

2.4.1 General characteristics of included studies

The general characteristics of the included studies is presented in additional file 2. All the studies were published after 2006. The included studies were carried out in a number of LMICs. Five were from Ethiopia, five from Nigeria, three from Uganda, two Tanzania, one each from Belize, Brazil, Cameroun, China, Ghana, Honduras, India, Jordan, Libya, Malaysia, Nepal, and Zambia. Twenty-four studies used a cross-sectional design and one each employed the following designs: case-control, single group pre-post and non-randomised controlled trials (only baseline data was used).

Two of the included studies recruited participants from the community while the remainder (n=25) recruited from institutions (i.e. hospitals). The included studies had 7620 participants (women = 4272 vs. men = 3348) with a mean (SD) and median sample size of 282 (165) and 230 (Interquartile range (IQR): 25 - 806) participants respectively. Most of the included studies (n=22) had more women participants than men. Twenty-four studies reported the mean ages of study participants, the majority (n=19) of which had mean ages between 50 and 60 years. The rest of the studies that reported age categories of participants found a large majority of the participants were aged within the 50 to 60 years age category. Among the 13 studies that reported participants' mean duration of diabetes, all but one study ⁽³¹⁾ reported that participants had been living with their diabetes for 5 or more years.

2.4.2 Self-care behaviours and prevalence of adherence

The majority of the included studies, 16 out of 27 investigated and reported on more than one self-care behaviour. Of the 11 studies that reported on only one self-care behaviour, seven reported on medication taking only, two foot care practice only, and one each reported on SMBG only, diet only and physical activity only. Items of the questionnaires were either author-designed (n=6) or derived from previous studies (n=5) or adopted existing scales (n=16). Among studies that used existing questions, six used the Summary of Diabetes Self-Care Activities Questionnaire (SDSCA); four studies used the eight-item Morisky Medication Adherence Scale (8-MMAS) (all of which assessed medication taking only); two studies used the International Physical Activity Questionnaire (IPAQ); and one each used the Diabetes Self-Management Assessment Tool (D-SMART), the Self-Care Inventory Tool, and Self-Reported Medication Adherence and Self-Care Dietary Adherence Scale.

Two studies combined adherence rates for all self-care behaviours investigated. Ayele et al ⁽³⁶⁾ found 39.0% of a sample of 222 diabetes patients adhered to recommended self-care practices. Using the SDSCA to evaluate adherence to self-care behaviours among a sample of 230 type 2 diabetes patients from Nepal, Bhandari and Kim, ⁽³⁹⁾ reported a total mean (SD) adherence score of 3.6 (0.89) (maximum score = 7.0).

2.4.2.1 Diet

Fourteen studies evaluated adherence to diet (Shown in Table 1); all of which evaluated diet with other self-care behaviours except for one study $^{(54)}$ that investigated diet only. These studies reported adherence in varied forms: 1) number of days participants performed a recommended dietary behaviour/activity during the past week (n= 6); 2) percentage and/or number of participants adhering to a recommended diet, eating a particular type of food, or avoiding/limiting/minimising the intake of particular diet(s) (n=3); 3) number of times within a week participants followed a type of diet or meal (n=1); and 4) percentage of participants

having good, fair or poor dietary adherence based on cut-off scores generated from participants' responses to items of a self-care questionnaire, the majority of which were Likert scales (n= 4). The mean number of days participants adhered to their dietary recommendations ranged from 2.3 days per week to 4.6 days per week. Regarding the percentage of participants adhering to a recommended dietary practice, rates ranged from 29.9% of a sample of persons living with diabetes from South Western Nigeria reportedly having outstanding adherence ⁽³²⁾ to 91.7% of Nepalese diabetes patients avoiding sweets ⁽³⁸⁾. Among these studies the median adherence was 58.0% (IQR = 29.9% – 88.4%). Dekker et al ⁽⁴²⁾ found a sample of persons living with diabetes from Belize eating fruits and vegetables an average of 3 times per week.

Author(s)	Year	Country	Sample	Measure	Adherence
Bhandari and Kim ⁽³⁹⁾	2016	Nepal	230	Mean (SD) number of days participants adhered to diet during the last one week	4.3(1.45)
Mosha and Rashidi ⁽⁴⁷⁾	2009	Tanzania	121	Mean (SD) number of days participants adhered to general diet during the last one week	4.6(2.6)
Al-Amer et al ⁽³³⁾	2016	Jordan	220	Mean (SD) number of days participants adhered to specific diet in the last one week Mean (SD) number of days participants adhered to general diet during the last	1.4(2.2) 2.3(2.4)
Ashur et al., ⁽³⁴⁾	2016	Libya	523	one week Mean (SD) number of days participants adhered to general diet during the last one week	2.9(2.6)
Assah et al	2015	Cameroun	192	Mean (SD) number of days participants adhered to general diet during the last one week	3.8(2.4)
Mogre et al	2017	Ghana	187	Mean (SD) number of days participants adhered to general diet during the last one week Mean (SD) number of days participants adhered to specific diet in the last one week	4.4(1.5)

Table 1: Adherence to diet

Dekker et al (42)	2017	Belize	25	Mean number of times participants ate fruits and vegetables in the past week	3 times
Hintsa et al	2017	Ethiopia	409	% Using vegetable oil to cook % Adherent to diet	68.0% 43.5%
Huang et al (57)	2014	China	364	% Having good adherence % Having fair adherence % Having poor adherence	55.2% 25.6% 19.2%
Emmanuel and Otovwe (55)	2015	Nigeria	350	% Having partial adherence to diet treatment % Having strict adherence to diet treatment	32.6% 67.4%
Worku et al (54) Adisa and Fakeye ⁽³²⁾	2015 2014	Ethiopia Nigeria	403 176	% Having poor dietary practice % Having outstanding adherence (≥8 self-reported dietary adherence score)	51.4% 29.9%
Ayele et al (36) Baumann et al ⁽³⁸⁾	2012 2010	Ethiopia Uganda	222 340	% Having poor dietary adherence (<8 SRDAS) Adherence to dietary recommendation in the last 3 days Avoid sweets	70.1% 58.0% 91.7%
				Limit fatty food Eat what I can afford/what is available	88.4% 27.3%

2.4.2.2 Medication use/taking

As shown in Table 2, 19 of the included studies reported on diabetes medication, making it the most frequently reported self-care behaviour. Three studies reported adherence as the mean number of days participants adhered to their diabetes medication during the last 7 days, all of which found participants adhering at least 5 days a week. Medication adherence rates ranged from 26.0% to 97.0% (median = 71%; IQR = 59.0% - 83.0%). Regarding good/high/strict adherence, rates ranged from 59.0% to 71.0%. Two studies investigated and reported treatment/anti-diabetic non-adherence ($^{(31; 52)}$). The study by Kalyango et al ($^{(31)}$ reported a non-adherence of 29.0%, while the study by Piette et al ($^{(58)}$ found 85.0% of persons with diabetes not adhering to their diabetes medication at least once during the past year. One study reported on the proportion of persons with diabetes using insulin only, insulin with oral agents, oral agents and those not using medication ($^{(38)}$). This study did not investigate whether participants adhered or not.

Table 2: Adherence to medication taking

	Year	Country	Sample size		Adherence
Author(s)				Measure	Rates

Al-Amer et al ⁽³³⁾	2016	Jordan	220	Mean (SD) number of days participants adhered to medications in the last 7 days	6.5(1.4)
Bhandari and Kim ⁽³⁹⁾	2010	Nepal	230	Mean (SD) number of days participants adhered to medications in the last 7 days	6.8(1.1)
Mosha and Rashidi ⁽⁴⁷⁾	2009	Tanzania	121	Mean (SD) number of days participants adhered to diabetes medications	5.5(2.8)
Bagonza et al ⁽³⁷⁾	2015	Uganda	521	Adherent to anti-diabetic medication	83.0%
Jackson et al ⁽⁴⁵⁾	2015	Nigeria	303	Highly adherent to diabetes medications	68.0%
Kalyango et al	2008	Uganda	402	Prevalence of non- adherence	29.0%
Kassahun et al	2016	Ethiopia	309	High medication adherence Medium adherence	37.0% 38.0%
Duvergement of al	2014	Tanzania	216	Good adherence at one week	23,0% 60.0%
(50)			- -	months	71.0%
Piette et al ⁽⁵²⁾	2011	Honduras	85	Taking diabetes medication Having at least one-	89.0%
				episode of cost related non-adherence in the prior year	85.0%
Adisa and Fakeye ⁽³²⁾	2014	Nigeria	176	Medication adherence	53.0%
Ayele et al ⁽³⁶⁾	2012	Ethiopia	222	Adherence to drugs	78.0%
Baumann et al	2010	Uganda	340	Insulin Insulin + Oral medication	62.9% 27.9%

Ashur et al., ⁽³⁴⁾	2016	Libya	523	Oral medication No medication Low medication adherers Moderate and high medication adherers	3.9% 5.3% 36.1% 63.9%
Hintsa et al ⁽⁵¹⁾	2017	Ethiopia	409 84 325	Medication adherence Cases Controls	95.0% 97.0%
Huang et al ⁽⁵⁷⁾	2014	China	364	Good adherence Fair adherence	65.4% 28.6%
Emmanuel and Otovwe ⁽⁵⁵⁾	2015	Nigeria	350	Poor adherence Partial medication adherence Strict medication adherence	9.0% 40.0% 59.0%
Bueno et al ⁽⁴⁰⁾ Gelaw et al ⁽⁴⁴⁾	2017 2014	Brazil Ethiopia	806 270	Average use of drugs per elderly Adherence to anti- diabetic regimen	2.2 72.2%
Musenge et al ⁽⁴⁸⁾	2016	Zambia	198	Adherence to treatment regimen as prescribed	26.0%

2.4.2.3 Exercise

Fourteen included studies evaluated patients' adherence to exercise (Table 3). All of these included studies used self-reports. Adherence to physical activity or exercise was reported in varied forms including number of days of adhering to recommended exercise or physical

activity in the last 7 or 3 days; and frequency/number of times participants engaged in physical activity or exercise within a week, percentage or number of participants engaging in exercise or type of physical activity. Six studies reported the number of days participants adhered to exercise in the last 7 days, and the majority of these studies (n=4) found participants engaging in physical/exercise for less than 3 days in a week. Adherence rates ranged from 26.7% of elderly persons with diabetes from Brazil reportedly being sufficiently active ⁽⁴⁰⁾ to 69.0% of a sample of Nigerian type 2 diabetes individuals being physically active ⁽⁴⁹⁾. The median adherence among these studies was 41.2% (IQR = 29.5% - 50.1%).

 Table 3: Adherence to exercise

Author(s)	Year	Country	Sample size	Measure	Adherence rates
Al-Amer et al (33)	2016	Jordan	220	Mean (SD) number of days participants adhered to exercise in the last 7 days	1.8(2.0)
Ashur et al., ⁽³⁴⁾	2016	Libya	523	Mean (SD) number of days participants adhered to exercise in the last 7 days	2.5(2.3)

Assah et al ⁽³⁵⁾	2015	Cameroun	192	Mean (SD) number of days participants adhered to exercise in the last 7 days	2.3(1.7)
Bhandari and Kim ⁽³⁹⁾	2016	Nepal	230	Mean (SD) number of days participants adhered to exercise in the last 7 days	4.2(2.8)
Mosha and Rashidi ⁽⁴⁷⁾	2009	Tanzania	121	Mean (SD) number of days of participating in at least 30 minutes of physical activity in the last 7 days	5.7(2.4)
				Mean (SD) number of days of participating in a specific exercise session in the last 7 days	1.2(2.3)
Mogre et al ⁽⁵³⁾	2017	Ghana	187	Mean (SD) number of days participants adhered to exercise in the last 7 days	4.8(2.1)
Ayele et al ⁽³⁶⁾	2012	Ethiopia	222	Had exercise for 30 minutes per day in the last three days Did not exercise for 30 minutes per day in the	31.1%
				last three days Being active	25.7%
Baumann et al	2010	Uganda	340	Regular program of exercise	39.0%
				Activities of daily living	54.0%
				Limited ability to	7.0%
Hintsa et al ⁽⁵¹⁾	2017	Ethiopia	409	Adherence to exercise	42.0%

Huang et al ⁽⁵⁷⁾	2014	China	364	Exercise management	
-				Good	50.8%
				Fair	41.8%
				Poor	7.4%
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	2017	Brazil	806	Prevalence of active and	26.7% and
Bueno et al ⁽⁴⁰⁾				inactive individuals	73.3%
Musenge et al	2016	Zambia	198	Did not engage in any	
(48)				type of regular exercise	59.6%
	2017	Belize	25	Engage in activities that	
Dekker et al ⁽⁴²⁾				increases their breathing	
				including walking or	
				domestic work for at	
				least once a week	48.0%
Oyewole et al	2014	Nigeria	350	Physically inactive and	31.0% and
(49)				active	69.0%

2.4.2.4 SMBG

As shown in Table 4, 13 included studies investigated SMBG from which six studies ^(33; 34; 35; 39; 47; 53) reported the mean number of days participants performed SMBG in the last 7 days. The mean number of days on which SMBG was performed ranged from 0.2 to 2.2 days per week. Four studies reported on the percentage of participants that performed SMBG without indicating the number of times per day or within a week ^(32; 38; 48; 57). These studies reported rates from 13.0% to 79.9% (median = 18.5%; IQR = 14.5% - 51.5%). Two studies investigated the number of times participants monitored their blood glucose in a day and/or within a week ^(36; 56). Ayele et al ⁽³⁶⁾ found 18.0% of a sample of persons with diabetes from Ethiopia performing SMBG more than once a week. However, Mastura et al ⁽⁵⁶⁾ reported 16.4% performing SMBG once per day, 47.1% more than once per week and 36. 5% less than once a week.

	Year	Country	Sample		Adherence
Author(s)			size	Measure	rates
Al-Amer et al (33)	2016	Jordan	220	Mean (SD) number of days of self-monitoring blood glucose in the last 7 days	2.1(2.3)
Ashur et al., (34)	2016	Libya	523	Mean (SD) number of days of self-monitoring	1.2(1.9)

Table 4:	Adherence	to	SMBG
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				blood glucose in the last 7	
Assah et al ⁽³⁵⁾	2015	Cameroun	192	Mean (SD) number of	1.2(1.5)
				days of self-monitoring	
				blood glucose in the last 7	
Bhandari and	2016	Nepal	230	Mean (SD) number of	0.6(0.9)
Kim ⁽³⁹⁾		- · · I · · ·		days of self-monitoring	()
				blood glucose in the last 7	
Mosha and	2009	Tanzania	121	days Mean (SD) number of	0.2(0.5)
Rashidi ⁽⁴⁷⁾	2007	1 anzania	121	days of self-monitoring	0.2(0.3)
				blood glucose in the last 7	
				days	
Mogre et al ⁽⁵³⁾	2017	Ghana	187	Mean (SD) number of	2.2(0.7)
C				days of self-monitoring	()
				blood glucose in the last 7	
				days	
Ayele et al ⁽³⁶⁾	2012	Ethiopia	222	Monitored blood glucose	42.0%
D (1	2010	TT 1	240	once a week	15 00/
(38)	2010	Uganda	340	glucose at home	13.0%
	2014	China	364	% performing blood sugar	79.9%
Huang et al ⁽⁵⁷⁾				monitoring	
Musenge et al	2016	Zambia	198	% Reporting SMBG	13.0%
(48)	2014	NT	176		22.00/
Adisa and	2014	Nigeria	1/6	% Self-monitoring blood	22.0%
Fakeye ⁽³²⁾				grucose	
				0/1 1 1 0	
				% Keeping record of measurements	92.0%
Mastura et al	2007	Malaysia	170	Performance of SMBG	15.0%
(56)		-		% Performing SMBG at	16 40/
				least once per day	10.4%
				% Performing SMBG	47.1%
				more than once per week	
				% performing < once per	36.5%
				week	201270

2.4.2.5 Foot care

Ten included studies evaluated foot care among diabetes patients from which two studies investigated foot care only (Shown in Table 5). Six studies $^{(33; 34; 35; 39; 47; 53)}$ reported foot care adherence according to the mean number of days diabetes patients adhered to foot care recommendations; mean days ranged from 2.2 days to 4.3 days in a week. Huang et al $^{(57)}$ reported a mean foot care practice score of 77.47% among Chinese persons with diabetes (higher scores indicate better self-perceived overall foot-care). Three studies $^{(38; 43; 59)}$ reported on regular feet inspection from which rates ranging from 37% to 41% were reported. The study by Desalu et al $^{(43)}$, investigated a wide range of foot care practices including feet inspection, washing of feet with warm water and inspection of the inside of foot wear. Responses from these were used to classify participants into good, fair and satisfactory foot care practice. They found only 10.0% of participants had good foot care practices. In a study among a sample of persons with diabetes from India, Chellan et al $^{(41)}$ reported a good foot care practice (with a different classification of factors considered to be good practice) prevalence of 36.0% among those without diabetic foot ulcer and 17.0% among those with diabetic foot ulcer disease. The median adherence was 36.5% (IQR = 13.6% - 59.2%).

Author(s)	Year	Country	Sample size	Measure	Adherence rates
Ashur et al	2016	Libya	523	Mean (SD) number of days participants practiced foot care during the last 7 days	2.3(2.6)
Assah et al	2015	Cameroun	192	Mean (SD) number of days participants practiced foot care during the last 7 days	4.3(2.6)
Bhandari and Kim ⁽³⁹⁾	2016	Nepal	230	Mean (SD) number of days participants practiced foot care during the last 7 days	2.2(2.4)

Table 5: Adherence to foot care

Mosha and Rashidi ⁽⁴⁷⁾	2009	Tanzania	121	Mean (SD) number of days participants practiced foot care during the last 7 days	3.6(2.8)
Mogre et al (53)	2017	Ghana	187	Mean (SD) number of days participants practiced foot care during the last 7 days	2.9(2.2)
Al-Amer et al ⁽³³⁾	2016	Jordan	220	Mean (SD) number of days participants practiced foot care	2.4(2.5)
Huang et al (57)	2014	China	364	% Foot care practice	77.4%
Chellan et al	2012	India	203	Diabetic Foot Ulcer group	
				Poor practice of foot care	40.0%
				Average practice of foot care	44.0%
				Good practice of foot care	17.0%
				Without Diabetic Foot Ulcer group	
				Poor practice of foot care	9.0%
				Average practice of foot care	55.0%
				Good practice of foot care	36.0%
Desalu et al (43)	2011	Nigeria	352	Mean foot care practice score	5.7
				% Having regular inspection of feet	40.9%
				% Regularly washing their feet with warm	46.0%
				water % Inspecting the inside of their foot wear	47.7%
				% Having good foot care practice (Score ≥70)	10.2%
				% Having satisfactory foot care practice	40.3%

				(Score = 50-69%)	
				% Having poor foot	
				care practice	
				(Score<50)	49.4%
Baumann et	2010	Uganda	340	% Having feet	41.0%
al ⁽³⁸⁾		-		checked	

2.5 DISCUSSION

This review identified that many diabetes patients from LMICs fail to adhere to self-care behaviours as recommended or agreed between the patient and healthcare provider. This is concerning given that poor adherence to diabetes self-care could lead to poor glycaemic control and subsequently development of acute and chronic complications ^(9; 10).

The dietary adherence rates of 29.9 to 91.7% (median 58.0%, IQR: 29.5 - 88.4%) are similar to the 33 to 87% rate of adherence reported by Stephani et al in a systematic review of studies from Sub-Saharan Africa (SSA) ⁽¹⁸⁾. Although the adherence rates reported in this study for diet do not greatly differ from those reported among diabetes patients from high income countries (HICs) ⁽¹⁵⁾, the capability of LMIC health services to manage diabetes complications are likely to differ from HICs, which suggests diabetes self-care adherence is an urgent challenge facing LMICs. It is also pertinent to note that the accuracy of the data regarding adherence to diet may also be weaker than some of the other self-report data.

It is unsurprising that self-care adherence to diet is poor, given the long-term nature of the behaviour $^{(60; 61)}$; the complexity of changing both daily food choices and daily eating patterns $^{(62)}$; social pressure $^{(63; 64; 65; 66)}$ and the cultural meaning of food $^{(60; 62)}$.

The review identified medication taking as the self-care behaviour with the highest frequency and rates of adherence. This is consistent with the data from HICs ^(11; 15; 67). The range of medication adherence rate of 26.0 to 97.0% (median = 71.0%; IQR: 59.0 – 83.0%) appears similar to the 36.0 to 93.0% reported from a systematic review of 11 retrospective studies from HICs ⁽¹¹⁾ and the 38.5 to 93.1% reported from a systematic review of 27 studies, most of which

were from HICs ⁽⁶⁷⁾. A review of studies from SSA reported a medication adherence rate of 39.0 to 88.0% ⁽¹⁸⁾. Although the adherence rates for medication taking are higher than those for the other self-care behaviours in this review, the wide variations among the studies and between the lowest and highest estimates show that many diabetes patients do not regularly adhere to their anti-diabetic medications in LMICs. Adherence to anti-diabetic medications may be more challenging for diabetes patients from LMICs due to a myriad of factors including lack of health insurance, poor income levels, and lack of medicines, among others ^(59; 68).

Guidelines for glucose monitoring vary by individual and by medication, making it difficult to evaluate adherence rates, particularly in terms of frequency ⁽⁶⁹⁾. The non-frequency data (i.e. the proportion of patients adhering to their recommended SMBG) suggests adherence is low (13-79%) in LMICs relative to most other behaviours. In HICs adherence to SMBG appears to be similarly variable and perhaps higher, varying from 40% to 97% ^(15; 69). Stephani et al ⁽¹⁸⁾ reported SMBG adherence rates of 0 to 43% in SSA. Evidently, suboptimal adherence to SMBG is a particular concern in LMICs. Strategies for addressing this issue are essential given the findings that the frequency of performing SMBG is associated with improved HbA1c levels in diabetes patients ^(70; 71).

Just like the other self-care behaviours, varying rates of adherence to exercise was reported ranging from 26.7% to 69.0% (median = 41.2%; IQR: 29.5 – 50.1%). Similar varying rates have also been reported from HICs in which several studies have described patients' adherence to exercise as suboptimal ^(66; 72; 73). A number of reasons could be responsible for the current situation including lack of time, social/cultural beliefs, poor perception of obesity as a health issue, non-receipt of self-care support to exercise, and lack of exercise facilities, among others ^(72; 74).

Foot care was the least explored in the literature and one of the least adhered self-care behaviours. This finding is also similar to a review by Coyle et al ⁽¹⁵⁾ which had majority of the

included studies from HICs. As has been widely reported in the literature ^(75; 76; 77; 78), the included studies found patients reporting poor adherence to foot self-care. Inadequate foot care knowledge has been identified previously as a contributing factor to poor foot care practice among type 2 diabetes patients ^(79; 80). Foot care education has been shown to improve foot care knowledge, foot care practice and decreased diabetic foot complications and amputations ^(80; 81).

Limited access to support services has been reported as a barrier to adherence to diabetes selfcare in the literature from LMICs ^(5; 82; 83; 84) and it is likely to affect diabetes knowledge and adherence ^(85; 86). Limited access to support services may result in patients' poor understanding of the causes, symptoms and management of diabetes which is critical to the performance of recommended self-care behaviours ^(85; 86). An important aspect of diabetes care is access to diabetes specialists or healthcare professionals specially trained for diabetes ^(87; 88). Critical to diabetes care is lifestyle advice including dietary advice. However, most diabetes patients from Sub-Saharan Africa do not receive such care largely due to the unavailability of specialists such as nutritionists and dieticians. Access to other specialists such as eye specialists, endocrinologists, and even general diabetes educators is also inadequate in several LMICs ^(31; 37; 54). There is evidence from middle/high income countries that access to specialist care is associated with improved diabetes knowledge, improved SMBG, and improved glycaemic control ^(89; 90; 91; 92; 93).

There is evidence that affordability is directly linked to consumption of fruits and vegetables in the general population. In a prospective study that investigated consumption, availability and affordability of fruits and vegetables in 18 countries including LMICs, Miller et al found that consumption was associated with affordability of fruits and vegetables ⁽⁹⁴⁾. There is however limited evidence evaluating the association between affordability and consumption of fruits and vegetables in people with type 2 diabetes and future studies should explore this relationship. Notwithstanding this, unaffordability has been frequently reported by previous studies as a barrier to dietary recommendations (including the consumption of fruits and vegetables) in people with type 2 diabetes ^(54; 68; 95). Expectedly, unaffordability is associated with poor income levels and having low income levels may result in inability of people with type 2 diabetes to purchase recommended fruits and vegetables, thereby affecting consumption. The situation is even more precarious in LMICs in that unaffordability co-exist with issues of accessibility and availability of fruits and vegetables ^(96; 97).

2.5.1 Strengths and Limitations

The review by Stephani et al ⁽¹⁸⁾ provides a firsthand overview of adherence to diabetes selfcare behaviours among diabetes patients from SSA, providing a platform for future studies to build upon. However, authors reported adherence rates, only from studies that described adherence in terms of proportions but not those that described adherence in terms of frequency or number of days or times patients adhered to a self-care behaviour within a day or a week. Given that a good proportion of published studies adopt these approaches of reporting adherence, the Stephani et al ⁽¹⁸⁾ approach does not provide a complete picture of the situation of adherence to self-care behaviours among diabetes patients from SSA and other developing countries, the focus of the current review. The current review quantifies the extent to which people in LMICs with diabetes adhere to each of the recommended self-care behaviours and also identifies the variability in methods of measuring and reporting adherence. Our review thus provides a comprehensive, broader and varied synthesis of the adherence data recognising the nuances and complexity of the literature on adherence to diabetes self-care.

The adherence literature in general has a number of limitations. First, there is no 'gold standard', widely accepted accurate method of assessing adherence to self-care behaviours ^(98; 99) resulting in the adoption of varied assessment measures by the authors. This made it difficult

to make comparisons across studies ^(15; 100). Self-reports were the most widely used measures of adherence, due to their ease of application and low cost ^(101; 102), but may be vulnerable to social desirability bias ^(100; 103). Reliability could be improved by adopting specific items in interviews ⁽¹⁰⁴⁾ or questionnaires ⁽¹⁰⁵⁾ and also by adopting instruments that meet psychometric standards of reliability and validity ⁽¹⁰⁶⁾.

Our findings are also limited by there being only a fair level (rather than high level) of agreement showing some level of disagreement among the reviewers. However, this was minimised by discussions among the independent reviewers regarding inclusion/exclusion of studies and subsequent adjudication by another member of the review if required. We also note that all the included studies were published from 2006 onwards with none published between 1990 and 2005. This was due to pre-2006 studies being relatively few in number (17% of the total citations identified in the search strategy) and not meeting the review inclusion criteria.

Another important limitation in the literature was the lack of a common strategy of quantifying levels of adherence. While some authors assessed adherence in terms of the relative frequency of performing self-care behaviours (i.e. never, sometimes, often, always, etc) ⁽¹⁰⁷⁾, others reported on the number of times patients performed self-care behaviours in a day or a week, while others enumerated the percentage of time patients adhered to a recommended self-care behaviour. A number of studies also used terms such as regular/irregular ⁽¹⁰⁸⁾ and good/bad ⁽¹⁰⁹⁾ to describe the frequency of adhering to self-care behaviours without providing clear definitions of these terms. These point to the high heterogeneity of the included studies, a limitation that did not allow for us to conduct a meta-analysis. Given that a patient's adherence to one self-care behaviour may not be associated with his/her adherence to another self-care behaviour, it is important to measure each self-care behaviour separately rather than combining scores to yield a single adherence score ^(100; 110). It is important to note that the median adherence rates reported in this systematic review for the ranges of adherence rates should be

interpreted with caution as they do not originate from primary data but from secondary data (i.e. the included studies) with varying sample sizes.

2.6 CONCLUSION

Adherence to diabetes self-care behaviours is inadequate among persons with diabetes LMICs especially for diet and SMBG. This is a concern given the poor health outcomes associated with poor self-care (for example, blindness, amputations etc) particularly in countries where health-care resources are inadequate and/or scarce. There is also the need to understand the barriers, facilitators of, and diabetes patients' attitudes towards self-care in order to inform the design of interventions. In addition, the measurement variability identified in the review also makes it clear that health services must monitor these behaviours rather than expect adherence; and that large-scale accurate monitoring of adherence in a health district or nation requires a considered approach to choice of measurement tool.

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RELATIONSHIP OF CHAPTER 3 TO CHAPTER 2

As described in Chapter 2, adherence to diabetes self-care behaviours in LMICs is low, albeit with substantial variability in the data. Given adherence to self-care behaviours is critical to patient outcomes, it is important that:

- i) Health services monitor diabetes self-care behaviours, and
- Large-scale accurate monitoring of diabetes self-care occurs at a health district or population level in sub-Saharan countries.

Both the above purposes require a measurement tool which balances the need for accurate measurement with the need for a tool which is appropriate for widespread use at minimal cost. The Summary of Diabetes Self-Care Activities (SDSCA) measure is arguably the most widely used and comprehensive self-report instrument for assessing diabetes self-care in adults, and has been found to have satisfactory psychometric properties among diabetes populations in European and Asian settings and with African American people living in the USA. However,

the psychometric properties of the SDSCA among diabetes patients in a Sub-Saharan African context have not been established, although the SDSCA has been used in this setting. Chapter 3 describes an exploration of the psychometric properties of the SDSCA in the Ghanaian setting.

CHAPTER 3

PSYCHOMETRIC EVALUATION OF THE SUMMARY OF DIABETES SELF-CARE ACTIVITIES MEASURE IN GHANAIAN ADULTS LIVING WITH TYPE 2 DIABETES

This manuscript has been published in "Diabetes Research and Clinical Practice".

Mogre V, Abanga Z. O., Tzelepis F, Johnson NA, & Paul C. Psychometric evaluation of the Summary of Diabetes Self-Care Activities measure in Ghanaian adults living with type 2 diabetes. Diabetes Research and Clinical Practice 2019;149:98-106

ABSTRACT

Aims: We evaluated the content validity, factorial structure, internal consistency, construct validity, and floor and ceiling effects of the SDSCA among Ghanaian persons with type 2 diabetes.

Methods: The Summary of Diabetes Self-Care Activities measure (SDSCA) was administered to 187 adults living with type 2 diabetes from three diabetes clinics.

Results: A confirmatory factor analysis maintained the four factor structure of the SDSCA. However, two items, 3 (fruit and vegetable servings) and 4 (red meat or full-fat dairy products) had factor loadings of 0.26 and 0.16 respectively. The model also had a statistical power of 0.72 (below acceptable criteria). Modification of the model by removing item 4 resulted in an improved revised model with a power of 0.82. Construct validity was found for the exercise and diet subscales of the SDSCA but not for the self-monitoring of blood glucose and foot care subscales. The internal consistency of the SDSCA measure was 0.68, below acceptable criteria for internal consistency. No floor effects were present but the exercise subscale had ceiling effects.

Conclusion: The SDSCA measure had content validity, maintained its multidimensionality and met the criteria for floor effects but not for construct validity, internal consistency and ceiling effects. The SDSCA measure may require improvements to evaluate self-care behaviours of adult type 2 diabetes patients in Ghana and probably in other Sub-Saharan countries.

3.1 INTRODUCTION

Approximately 30 million people in Africa had diabetes, more than half of which live in Sub-Saharan African and estimated to rise by 162% by the year 2045 ^(1; 2). More than 90% of all cases of diabetes globally and in the sub-region is type 2 diabetes ^(1; 2). The Sub-Saharan region has the highest prevalence of undiagnosed diabetes in the world (69.2%) and 6% of all mortality is attributed to diabetes ⁽²⁾. In Ghana, a Sub-Saharan African country, the prevalence of diabetes increased from 0.3% in 1986 to 3.6% in 2017 ^(2; 3; 4).

Patients with Type 2 diabetes are expected to follow a number of recommended self-care behaviours ^(5; 6; 7). These self-care behaviours include regular participation in physical activity, healthy eating, weight management, self-monitoring of blood glucose (SMBG), and adherence to medications ⁽⁸⁾. Evidence indicates that regular participation in these self-care behaviours may result in improved glycaemic control, reduced risk of developing diabetes complications, improved quality of life and dietary habits ^(5; 9; 10; 11; 12).

Given the significant role of self-care behaviours in improving health outcomes of Type 2 diabetes patients, a brief, valid and reliable instrument to assess diabetes self-care behaviours is necessary. Such instruments are useful to both clinicians and other healthcare professionals who provide care to diabetes patients and for researchers interested in evaluating the effectiveness of interventions to improve diabetes self-care behaviours ⁽¹³⁾.

The Summary of Diabetes Self-Care Activities (SDSCA) measure [13], is arguably the most widely used self-report instrument for assessing self-care behaviours in adult diabetes patients ^(13; 14). The original version comprised 12-items assessing five components of diabetes self-care ⁽¹⁵⁾: general diet, specific diet, exercise, medication taking, and blood glucose testing. A review of seven studies by the authors ⁽¹³⁾ of the SDSCA resulted in the addition of items for foot care and smoking status. The revised version comprised 11 core items and an expanded list of 14 additional items yielding a total of 25 items ⁽¹³⁾. However, due to little or no data on the

reliability and validity of the additional items [13], the authors recommend using the 11-item revised SDSCA measure. Furthermore, the revised version of the SDSCA does not include items on medication because they had strong ceiling effects and low test-retest reliability ⁽¹³⁾. According to the authors ⁽¹³⁾, strengths of the 11-item revised SDSCA measure include its brevity and ease of use in both clinical and research settings and evidence for its validity and reliability.

The psychometric properties of the revised SDSCA measure has been evaluated among diabetes populations in Europe ^(13; 14), Asia ^(16; 17) and African Americans ^(13; 18). Using a cut-off point of 0.50, Toobert et al ⁽¹³⁾ reported an average inter-item correlations of 0.47 which they described as acceptable in a sample of 7 individual studies. The rest of the studies except one (alpha=0.62) [14] showed adequacy of internal consistency with Cronbach's alphas between 0.74 and 0.93 ^(16; 17). However, psychometric properties of the SDSCA are yet to be investigated among type 2 diabetes patients in a Sub-Saharan African context despite being used to assess self-care behaviours in this setting ⁽¹⁹⁾. It is important to assess the psychometric properties of the SDSCA measure among a Sub-Saharan African Type 2 diabetes patient population because of the socio-cultural, socio-economic, and ethnic and health system differences between African populations and other populations.

This study aimed to assess content validity, factorial structure, internal consistency, construct validity, and floor and ceiling effects of the SDSCA measure in adult Ghanaian type 2 diabetes patients.

3.2. METHODS

3.2.1 Participants and Procedure

3.2.1.1. Content validity

Semi-structured interviews were conducted with type 2 diabetes patients recruited from weekly diabetes clinics from three hospitals in the Tamale Metropolis, Ghana. Tamale is approximately

500km North of Accra, Ghana's capital city. These clinics undertake weekly diabetes clinics to provide diabetes care to patients, who come from both urban and rural settings. Participants were either asked to read the items of the SDSCA measure or listen carefully to the items translated to them in the local dialect by a research assistant. Using an interview guide they were then asked to comment on the ease of use of the SDSCA measure, clarity of its items, readability of the items, understanding and relevance of the items to diabetes self-care. Research assistants had the option of probing further to clarify comments. All interviews were conducted by a research assistant who recorded the interviews digitally and transcribed them verbatim.

3.2.1.2 Psychometric evaluation of the SDSCA measure

To assess the internal consistency, construct validity, and floor and ceiling effects of the SDSCA measure, it was administered to another group of type 2 diabetes patients recruited from these hospitals. Patients were eligible to participate if they had a confirmed diagnosis of type 2 diabetes or self-reported a healthcare professional diagnosis of type 2 diabetes or were identified by the healthcare professional as seeking care for type 2 diabetes and were registered with the specific hospital and had sought care from its diabetes clinic at least twice during the last 12 months. Patients were not eligible if they were: identified by the healthcare professional as having type 1 diabetes; or were younger than 18 years of age and/or were diagnosed with diabetes clinic days to collect data. While patients waited for their medical consultation, the research assistants approached them to introduce the study and seek their consent to participate. Consenting participants were given a self-completed paper survey. For those who could not read nor write in English, trained research assistants assisted them to

complete the survey by verbally translating the questions into their respective local dialects. This occurred for less than 10% of the participants.

The research was approved by the research department of the Tamale Teaching Hospital, the Ethics Committee of the School of Allied Health Science of the University for Development Studies, Ghana and the Human Research Ethics Committee of the University of Newcastle, Australia. All data collection procedures were completed during May 2015 to June 2017.

3.2.2 Measures

3.2.2.1 Summary of Diabetes Self-Care Activities Measure

As shown in Table 1, the SDSCA consists of 11 items assessing participants' frequency during the last 7 days or month of engaging in diabetes self-care behaviours including diet (general and specific), exercise, self-monitoring of blood glucose (SMBG), foot care and smoking status. Participants are asked to indicate the number of days on which the respective self-care behaviour was performed using an eight point Likert scale (0-7). The greater the number of days reported for a behaviour the better the self-care. The first ten items are summed to correspond with the four subscales: diet (items 1-4), exercise (items 5-6), SMBG (items 7-8) and foot care (items 9-10). The eleventh item, which investigates tobacco use by assessing the number of cigarettes smoked per day ^(13; 20), was not included in the factor analysis because it is one item which is consistent with previous studies investigating the psychometric properties of the SDSCA measure ^(14; 21; 22).

Item	Description
Diet	
Q1	How many of the last SEVEN DAYS have you followed a healthful eating plan?
Q2	On average, over the past month, how many DAYS PER WEEK have you followed your eating plan?
Q3	On how many of the last SEVEN DAYS did you eat five or more servings of fruits and vegetables?
Q4	On how many of the last SEVEN DAYS did you eat high fat foods such as red meat or full-fat dairy products?
Exercise	
Q5	On how many of the last SEVEN DAYS did you participate in at least 30 minutes of physical activity? (Total minutes of continuous activity, including walking).
Q6	On how many of the last SEVEN DAYS did you participate in a specific exercise session (such as swimming, walking, biking) other than what you do around the house or as part of your work?
SMBG	
Q7	On how many of the last SEVEN DAYS did you test your blood sugar?
Q8	On how many of the last SEVEN DAYS did you test your blood sugar the number of times recommended by your health care provider?
Foot care	
Q9	On how many of the last SEVEN DAYS did you check your feet?
Q10	On how many of the last SEVEN DAYS did you inspect the inside of your shoes?
Smoking status	
Q11	Have you smoked a cigarette—even one puff—during the past SEVEN DAYS? 1. No 2. Yes.
	If yes, how many cigarettes did you smoke on an average day?

Table 1: The revised version of the SDSCA measure

3.2.2.2. Demographic characteristics

Demographic characteristics such as age (continuous), gender, duration of diabetes since diagnosis (years), family history of diabetes (yes/no), educational status (years), marital status (married and not married) and religious status (Christianity, Islamic and African traditional religion) were self-reported.

3.2.3 Statistical analysis

IBM SPSS and AMOS 23.0 were used to perform all data analysis. Means and standard deviations were used to describe continuous variables while frequencies and percentages were used to present categorical data. Confirmatory factor analysis (CFA) was undertaken to confirm the four factor structure of the SDSCA measure using AMOS version 23.0. CFA evaluates the extent to which the data fits into a predetermined and constructed model ⁽²³⁾. The maximum likelihood (ML) estimation method with bootstrapping was used. As recommended by Nevitt and Hancock ⁽²⁴⁾, bootstrap samples were placed at 250. A bias-corrected interval of 95% confidence level was set. To determine model fit the Bollen-Stine bootstrap p was adopted together with Chi-Square to determine model fit ⁽²⁵⁾. Bollen-Stine estimates fit without normal theory limitations, and p>0.05 was considered indicative of model fit ⁽²⁵⁾. Other model fit indices adopted were goodness-of-fit index (GFI), normed fit index (NFI), and a comparative fit index (CFI)⁽²⁶⁾. The parsimonious normed fit index (PNFI), Tucker Lewis index (TLI), root mean square residual (RMR) and a root mean square error of approximation (RMSEA) were also calculated. For the GFI, CFI, TLI, NFI and PNFI indices, values ≥0.90 were considered acceptable model fit $^{(27;\,28;\,29;\,30)}$. RMR values of \leq 0.05 and RMSEA values of \leq 0.06 represent acceptable model fit ^(28; 29; 31). Sampling adequacy was determined using Kaiser-Meyer-Olkin (KMO) test and Bartlett's test of sphericity. KMO values ≥ 0.5 is considered sample adequacy ⁽³²⁾. Post-hoc power analysis for RMSEA was performed using Preacher and Coffman online statistical power calculator ⁽³³⁾ based on an alternative RMSEA of 0.08 at an alpha value of 0.05. A power >0.80 was considered adequate ⁽³⁴⁾.

To assess the construct validity of the SDSCA measure we compared subscale scores by participant educational levels using one-way analysis of variance. Previous studies conducted among diabetes populations in Sub-Saharan Africa have found level of education to be associated with adherence to self-care behaviours ^(19; 35). We thus hypothesised a positive

correlation between number of years in formal education and participants' adherence to diabetes self-care behaviours scores. Construct validity was acceptable if \geq 75% of the hypotheses were supported ⁽³⁶⁾. Pearson correlation analysis was thus conducted.

Internal consistency of the SDSCA measure was determined using Cronbach's alpha ⁽³⁷⁾. To determine the influence of each of the individual items on the internal consistency of the total score, item-total correlations were computed. This provides an assessment of the correlation between an item and the sum of the rest of the items in the scale. Values >0.2 are considered acceptable ⁽³⁷⁾. To determine Cronbach's alpha if an item is deleted, Cronbach's alpha was computed with the removal of each item in turn.

To determine floor and ceiling effects the proportion of participants with the lowest and highest scores respectively were calculated. Floor and ceiling effects were present for factors for which >15% of participants obtained the lowest or highest score, respectively ⁽³⁶⁾.

3.3 RESULTS

3.3.1 Content validity

Of the 27 patients approached, 23 completed an interview. During the semi-structured interviews the majority of the participants found all the items of the SDSCA measure to be clear and unambiguous; readable and understandable, and easy to use. They also found the items to be relevant to their diabetes self-care behaviours. Only two participants had difficulty understanding the phrase 'full-fat dairy products' which is used in item 4. Participants' required further explanation of this phrase to enable them determine their adherence to this self-care behaviour. Participants also found the response options to be appropriate.

3.3.2 Psychometric evaluation

3.3.2.1 Demographics

One hundred and ninety patients from the 201 patients who were approached consented to participate in the study and 187 (93%) surveys contained sufficient data for inclusion in the analysis. Participants had a mean (SD) age of 54.83 (13.32) years; were mainly female (72.2%, n=135), had a mean duration of diabetes of 5.43 (4.92) years, and only 2 participants reported smoking with an average of 5.00 ± 1.00 cigarettes per week. The majority of participants were married (64%, n=120), had low level of education (75%, n=140) followed the Islamic religion (84%, n=154) and 38.5% had a family history of diabetes.

3.3.2.2 Factorial structure using Confirmatory factor analysis

Applying the KMO measure of sample adequacy, an overall index of 0.576 was obtained, making factor analysis appropriate. Bartlett's test of sphericity had an approximated Chi-Square of 657.43, p<0.001, also indicative of the sample being appropriate for factor analysis. Confirmatory Factor Analysis was conducted to confirm the four factor structure of the SDCSA measure. With an X^2 value of 36.97 (p= 0.15), degrees of freedom of 29 and a Bollen-Stine p=0.287. The model had a goodness-of-fit index of 0.96, a normed fit index of 0.94 and a comparative fit index of 0.98. In addition, the model had a parsimonious normed fit index of 0.61; a Tucker Lewis index of 0.98; a root mean square residual of 0.18, a root mean square error of approximation of 0.04 and model power of 0.72. Correlations between the factors were generally low ranging from 0.07-0.34. The model is displayed in Figure 1, along with the latent variable correlations, standardised parameter estimates and squared multiple correlations.



Figure 1: CFA model of the SDSCA measure including factor loadings, squared correlations and latent variable correlations.

Exer = Exercise; SMBG = Self-monitoring of blood glucose; and FC = Foot care

Although, majority of the indices showed a good fit, the power of the model did not meet acceptable criteria. We thus evaluated the factor loadings of each of the items and item 4 had a very low factor loading of 0.16. Theoretically, we also noted from the content validity that participants found it difficult to understand some terms used in item 4. We thus proceeded to test an alternative model (Shown in Figure 2) in which item 4 was deleted. The revised model had an X^2 value of 22.72 (p=0.359), degrees of freedom of 21 and Bollen-Stine p=0.482. With a power of 0.82 (indicative of adequate power), the revised model had a goodness-of-fit index of 0.97, a normed fit index of 0.96 and a comparative fit index of 1.00. In addition, the model had a parsimonious normed fit index of 0.56; a Tucker Lewis index of 1.00; a root mean square residual of 0.14 and a root mean square error of approximation of 0.02.



Figure 2: Revised CFA model of the SDSCA measure including factor loadings, squared correlations and latent variable correlations.

Exer = Exercise; SMBG = Self-monitoring of blood glucose; and FC = Foot care

3.3.2.3. Internal consistency

The overall Cronbach's alpha value of the SDSCA measure was 0.68 with the values of the subscales ranging from 0.61-0.84 (Shown in Table 2).

Domain	Items	Cronbach's alpha
Diet	1-4	0.61
Exercise	5-6	0.63
SMBG	7-8	0.72
Foot care	9-10	0.84
Overall	1-10	0.68

Table 2: Cronbach alpha values for the revised SDSCA

The mean scores of the individual items, item-total statistics and internal consistency if an item is deleted is shown in Table 3. Apart from items 4, 7 and 8, the deletion of any other item resulted in a decrease of the Cronbach's alpha of the SDSCA measure. Item 4 had the lowest item-total correlation of 0.04 and the internal consistency of the SDSCA measure improved to 0.71 following its removal. Also, the deletion of items 7 and 8 resulted in the improvement of the Cronbach's alpha of the SDSCA measure to 0.69.

Item	Mean (SD) item scores	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
Q1	4.79 (2.09)	0.45	0.65
Q2	3.94 (1.97)	0.54	0.63
Q3	3.25 (2.11)	0.29	0.68
Q4	5.63 (1.67)	0.04	0.71
Q5	4.19 (2.31)	0.46	0.64
Q6	4.98 (2.00)	0.38	0.66
Q7	2.17 (0.71)	0.13	0.69
Q8	2.12 (0.65)	0.17	0.69
Q9	3.02 (2.16)	0.49	0.64
Q10	2.43 (1.99)	0.44	0.65

Table 3: Mean (SD) item scores, item-total statistics and internal consistency in case of deletion

3.3.2.4. Construct validity

Table 4 presents the construct validity of the subscales of the SDSCA measure. Except for the SMBG subscale, the diet, exercise and foot care subscales were significantly associated with the number of years participants spent schooling.

 Table 4: Construct validity of the SDSCA measure subscales with number of years in school

	Diet	Exercise	SMBG	Foot care
Number of years in school	0.199^{**}	0.182^{*}	0.115	0.165^{*}
Diet		0.229^{**}	0.105	0.234**
Exercise			0.104	0.258^{**}
SMBG				0.058
** 0 1	0.011 1.(2)	· ·1 1)		

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

3.3.2.5. Floor and Ceiling effects

As shown in Table 5, only the exercise subscale had a ceiling effect with >15% of the sample obtaining the highest possible score. There were no floor effects.
	Diet	Exercise	SMBG	Foot care
Mean (SD)	4.40 (1.52)	4.78 (2.09)	2.15 (0.65)	2.86(2.16)
Median (Min-Max)	4.53 (0.50 - 7.00)	4.63 (1.00 - 7.00)	2.00 (1.00 - 7.00)	2.17 (1.00 - 7.00)
Floor - Frequency				
(% with lowest				
possible score)	0(0)	0 (0)	0 (0)	0 (0)
Ceiling - Frequency				
(% with highest	5 (2 70/)	40 (21 40/)	1 (0 50/)	10(0(0))
possible score)	3 (2.7%)	40 (21.4%)	1 (0.5%)	18 (9.0%)

Table 5: Floor and ceiling effects of the subscales of the SDSCA measure

3.4 DISCUSSION

This is the first study to evaluate the psychometric properties of the SDSCA measure in a type 2 diabetes population in Sub-Saharan Africa. It provides information about the psychometric properties of the SDSCA measure in an area where the prevalence of diabetes is rising and outcomes are generally poor ⁽²⁾. We found that the SDSCA measure met the recommended criteria for content validity as it measured what it was designed to assess ⁽³⁶⁾. Nonetheless, revision of the phrase "full-fat dairy products" to a more familiar phrase in the Ghanaian context such as 'full milk products' may improve patients' understanding of this item.

The findings among these type 2 diabetes patients having low levels of education; frequently being female; reporting general low use of tobacco and being middle-aged are similar to those of previous studies conducted in Ghana and other parts of Africa ^(4; 19; 38; 39; 40; 41; 42; 43; 44; 45; 46; 47; 48). Our finding that majority of the diabetes patients practiced the Islamic religion differ from studies from other parts of Ghana ^(3; 4; 38) but similar to those previously reported from the study setting ⁽⁴⁹⁾. The differences may be due to the fact that the study setting is dominated by those who practice the Islamic religion ⁽⁵⁰⁾.

Consistent with previous studies ^(14; 22), the four factor structure of the SDSCA measure was maintained using the model fit indices to demonstrate acceptable level of internal consistency. Although the four factor structure of the SDSCA measure was maintained, item 4 (red meat or full-fat dairy products) had an extremely low factor loading consistent with previous studies ^(14; 21; 22). In addition, the power of the model did not also meet acceptable criteria. In theory, participants also had difficulty understanding item 4, providing us further justification to revise the model by removing item 4. The revised model without item 4 showed improvements of the χ^2 value, model fit indices and model power. Our findings are similar to those of Kamradt et al in which authors reported improvements of the relevant model fit indices and the X^2 value of a revised model of the SDSCA measure ⁽¹⁴⁾ after removing item 4 in a psychometric evaluation of the SDSCA measure among German type 2 diabetes patients. Revision of item 4 by replacing dairy products with full milk products may help improve its factor loading.

Item 3 (fruits and vegetables) of the SDSCA also had a factor loading < 0.40.

The low factor loading of item 3 (fruits and vegetables) could be because these adult Ghanaian type 2 diabetes patients may have found it difficult to understand, interpret and quantify serving sizes due to the lack of uniformly accepted portion sizes in Ghana ⁽⁵¹⁾ for estimation of how much food is eaten. Generally, vegetables are not eaten alone but included in thicken soups and stews making it difficult for the participant to estimate portion/serving sizes. In addition, the size of kitchen utensil (i.e. ladle) that is used to fetch soups or stews vary in households. Notwithstanding the low factor loading of item 3 (fruits and vegetables), we did not remove item 3 to modify the model because we did not have theoretical justification to do so. For CFA, decisions as to which models should be assessed should be hypothesis-driven, based on strong empirical evidence, informed by theoretical knowledge and therefore, should not be entirely data driven or solely on the basis of modification indices to realise an acceptable goodness of fit ⁽⁵²⁾.

Overall, the low correlations between the factors in both models demonstrate the multidimensional nature of the subscales of the SDCSA measure. This finding suggests that self-care activities are independent of each other ^(14; 22).

Another important finding was that the SDSCA measure did not meet acceptable criteria for construct validity ⁽³⁶⁾. However, the exercise, diet and foot care subscales met the hypothesis and differentiated adherence by number of years participants spent schooling. Despite not meeting the criteria construct validity we note our limitation that we only conducted four tests, and thus recommend that future research is needed to assess further the construct validity of this scale by assessing differences between other known groups.

Although the Cronbach's alpha coefficients of the SDSCA were found to be lower than some of the more commonly recommended criteria for assessing internal reliability ⁽³⁷⁾, they were similar to previous studies assessing the reliability of the SDSCA scale, with previous alphas ranging from 0.62 to 0.69^(14; 21; 22). As the Cronbach's alpha coefficients are influenced by the number of items in a scale it is possible that the low number of items in each of the subscales of the SDSCA may be influencing the low alpha coefficient seen here. However, as the lowest Cronbach's alpha value was found for the diet subscale, which contains 4 items, it is also likely that the reliability of this scale is also in need of improvement. Furthermore, low alpha coefficient value of the SDSCA measure once again demonstrates the multidimensional nature of the SDSCA and the independence of the individual self-care activities as reported by authors of the SDSCA and other researchers ^(13; 14; 53). For example, a patient reporting high adherence to foot care may not report high adherence for diet, exercise or SMBG. Importantly, item 4 had an extremely low-item-subscale and item-total correlation contributing to the low internal consistency of the SDSCA measure and the diet sub-scale. This finding is consistent with previous reports ^(14; 21; 54). Authors of the SDSCA measure have also reported similar difficulties regarding item 4 and the internal consistency of the SDSCA measure ⁽¹³⁾. These findings suggest that the reliability issues of the SDSCA measure may not be unique to the Ghanaian context but may exist in other context/settings around the world.

Items 7 and 8 which constitute the exercise subscale had item-total correlation lower than 0.2, contributing to the low internal consistency of the subscale and that of the entire SDSCA measure. Revision of these items may be necessary as previous studies have reported findings similar to ours ^(14; 54). Also, addition of more items into the SDSCA may also help improve its internal consistency.

Ceiling effects were present for the exercise subscale of the SDSCA which may affect the responsiveness of the SDSCA measure ⁽³⁶⁾. There were no floor effects for any SDSCA subscale.

This study is not without limitations. In assessing our sample adequacy using KMO, a cut of value of 0.5 was used as originally classified by Kaiser as a borderline of acceptability ⁽³²⁾. We however recognize that some authors use >0.6 as acceptable level of KMO. Our value of 0.5 may suggest that the factorability of the items could be improved. There is also the need for future studies to use larger samples. This study did not assess measurement error and test-retest reliability thus the stability of the SDSCA measure on this sample of type 2 diabetes patients is unknown. The cross-sectional design also made it impossible to assess the predictive validity of the SDSCA measure. Nonetheless our findings present information about the performance of the SDSCA on sample of diabetes patients from Sub-Saharan Africa that may be relevant to future studies evaluating adherence to self-care behaviours in these populations.

3.5 CONCLUSION

The multidimensionality of the SDSCA measure was maintained and it met the acceptable criteria for content validity, and floor effects but not for construct validity, and ceiling effects. Accordingly, although the SDSCA measure could be an important tool for assessing self-care

behaviours in Ghanaian adult type 2 diabetes patients it requires further development which includes, but is not limited, to the revision of items 3 and probably the removal of item 4 and development of its construct validity. Further validation studies of the SDSCA in this population is also needed.

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RELATIONSHIP OF CHAPTER 4 TO CHAPTERS 2 AND 3

As described in Chapter 2, there is a need to explore adherence to diabetes self-care behaviours among people with diabetes in LMICs. The study described in Chapter 3 indicated that the SDSCA may be an appropriate tool for monitoring adherence to diabetes self-care behaviours in a low-resource setting, given it is brief and met the criteria for acceptable content validity and floor effects, albeit some limitations were identified. The data reported in Chapter 3 also indicated that the multidimensionality of the SDSCA measure was maintained, confirming the need to explore diabetes self-care behaviours separately to each other, rather than in terms of global adherence to self-care.

It is acknowledged that the SDSCA does have shortcomings and requires further development including the revision of items 3 and 4; along with development of its construct validity. While further validation studies of the SDSCA in Sub-Saharan Africa are needed, such work is outside the scope of the current thesis. Therefore, the SDSCA was considered to be sufficiently useful for increasing knowledge about adherence to diabetes self-care behaviours in Sub-Saharan Africa, while being mindful of its limitations. Chapter 4 describes the use of the SDSCA to explore adherence and factors that are associated with adherence to recommended self-care behaviours.

CHAPTER 4

ADHERENCE TO AND FACTORS ASSOCIATED WITH SELF-CARE BEHAVIOURS IN TYPE 2 DIABETES PATIENTS IN GHANA

This manuscript has been published in "BMC Endocrine Disorders".

Mogre V, Abanga ZO, Tzelepis F, Johnson NA, Paul C. Adherence to and factors associated with self-care behaviours in type 2 diabetes patients in Ghana. BMC Endocrine Disorders 2017;17(1):20.

ABSTRACT

Background: Previous research has failed to examine more than one self-care behaviour in type 2 diabetes patients in Ghana. The purpose of this study is to investigate adult Ghanaian type 2 diabetes patients' adherence to four self-care activities: diet (general and specific), exercise, self-monitoring of blood glucose (SMBG) and foot care.

Methods: Consenting type 2 diabetes patients attending diabetes outpatient clinic appointments at three hospitals in the Tamale Metropolis of Ghana completed a cross-sectional survey comprising the Summary of Diabetes Self-Care Activities Measure, and questions about

demographic characteristics and diabetes history. Height and weight were also measured. Multiple linear regression analyses were conducted to identify the factors associated with adherence to each of the four self-care behaviours.

Results: In the last 7 days, participants exercised for an average of 4.78 ± 2.09 days and followed diet, foot care and SMBG for an average of 4.40 ± 1.52 , 2.86 ± 2.16 and 2.15 ± 0.65 days, respectively. More education was associated with a higher frequency of reported participation in exercise (r=0.168, p=0.022), following a healthy diet (r=0.223, p=0.002) and foot care (r=0.153, p=0.037) in the last 7 days. Males reported performing SMBG (r=0.198, p=0.007) more frequently than their female counterparts.

Conclusion: Adherence to diet, SMBG and checking of feet were relatively low. People with low education and women may need additional support to improve adherence to self-care behaviours in this type 2 diabetes population.

4.1 BACKGROUND

Diabetes has emerged as an important non-communicable disease in Sub-Saharan Africa ⁽¹⁾. According to the International Diabetes Federation, about 50% of all deaths attributed to diabetes were in less-developed regions like Sub-Saharan Africa ⁽²⁾. Over three-quarters of these deaths occurred in individuals under 60 years old, affecting the productive work force of the sub-region. The prevalence of diabetes in adults aged 20-79 years in Ghana has increased from a prevalence of 0.2% in 1958 ⁽³⁾ to an estimated prevalence of 3.3% in 2014 ⁽⁴⁾. Similar

to other regions of the world, type 2 diabetes is the most common form of diabetes in Ghana ⁽¹⁾.

The recommended self-care regimen for type 2 diabetes patients generally includes regular physical activity, healthy eating and foot care as well as self-monitoring of blood glucose (SMBG) ^(5; 6). Adherence to these self-care behaviours improves glycaemic control ⁽⁷⁾; sustains blood pressure ⁽⁸⁾; reduces the severity of complications ⁽⁷⁾ and health costs ⁽⁹⁾.

Consistent implementation of recommended self-care behaviours for individuals with type 2 diabetes requires collaboration between the patient and the provider in an enabling health care system with adequate facilities and resources ⁽¹⁰⁾. This is a major challenge for many sub-Saharan countries in the wake of the rising prevalence of diabetes ^(1; 11; 12) because Sub-Saharan Africa is faced with inadequate facilities/resources, inadequately skilled staff, and lack of resources for diabetes education ^(11; 12; 13; 14).

There is, however, limited data regarding the frequency of adherence to self-care behaviours in individuals with type 2 diabetes in the Sub-Saharan region including Ghana. The few studies in Ghana and other parts of the region suggests that diabetes patients adherence to self-care behaviours is low ^(15; 16; 17; 18; 19). Ayele et al ⁽¹⁵⁾ reported self-care behaviour adherence of 39.2% in a sample of type 2 diabetes in Ethiopia. A cross-sectional study among a sample of type 2 diabetes patients in Nigeria found 67.4% reporting complete adherence to dietary treatment regimens ⁽¹⁹⁾.

A number of factors have been shown to be associated with adherence to self-care behaviours. Previous research has found an association between self-care behaviours and patients' demographic characteristics such as age, gender, and education; doctor-patient relationships; psychological stress; and social support/context ^(20; 21). Most of these studies were conducted in western countries. Our understanding of how patient demographic characteristics may be associated with self-care behaviours in type 2 diabetes in the Sub-Saharan African settings is limited.

One other factor that could also influence adherence to self-care behaviours in individuals with type 2 diabetes is excess weight. Overweight and obesity are common in individuals with type 2 diabetes $^{(22; 23)}$. However, only one study $^{(24)}$ has evaluated the association between self-care behaviours and body mass index (BMI) and waist circumference (WC) in type 2 diabetes patients in which those with BMI \geq 35 Kg/m² compared to those with BMI < 35 Kg/m² were less likely to achieve healthy diet and exercise targets. Consequently, there is limited data regarding the influence of body weight on adherence to self-care behaviours in type 2 diabetes. The aims of this study are to describe:

- Ghanaian type 2 diabetes patients' adherence to the following self-care behaviours: diet, exercise, SMBG and foot care.
- 2. The association between adherence to self-care behaviours and patients' demographic characteristics (including age, gender, education, and religion)
- 3. The association between adherence to self-care behaviours and body weight measured by body-mass index (BMI) and waist circumference.

4.2 METHODS

4.2.1 Participants and setting

Participants in this cross-sectional study were type 2 diabetes patients seeking care from the out-patient diabetes clinics of the Tamale Teaching Hospital, Tamale West and Central Hospitals located in the Tamale Metropolis of Ghana. These hospitals have weekly diabetes clinics to provide care to diabetes patients. Tamale is located approximately 500km north of

Accra, Ghana's capital. It is the administrative capital of the Northern Region of Ghana and inhabited by people of both urban and rural backgrounds.

Patients were eligible to participate if they: had a confirmed diagnosis of type 2 diabetes; selfreported healthcare professional diagnosis of type 2 diabetes; and sought care from the diabetes clinic at least twice during the last 12 months and were registered with the specific hospital. Patients were excluded if they: had type 1 diabetes; were younger than 18 years and/or were diagnosed with diabetes before the age of 30 years.

4.2.2 Procedures

Letters were written to the heads of the diabetes clinics through the heads of the hospitals to seek permission for the study to be conducted on the premises. From May to June, 2015, trained research assistants visited the outpatient diabetes clinic weekly on days scheduled by the hospitals for the purposes of providing care to out-patient diabetes patients to recruit patients for the study. The research assistants approached patients while they waited for their medical consultation or after their consultation, to introduce the study to them and seek their consent to participate. Participants who agreed to participate were taken through the consent processes and subsequently given a survey to complete. Participants were advised that participants who could read and write in English. For those who could not read nor write in English, trained research assistants assisted them to complete the survey by translating the questions into their respective local dialects. This was observed in less than 10% of the participants. The survey took approximately 20 minutes to complete.

Weight, height and waist circumference were also measured by the trained research assistants after participants had completed the survey. These measurements were conducted in a secluded room at the hospital. The research was approved by the research department of the Tamale Teaching Hospital, the Ethics Committee of the School of Allied Health Sciences of the University for Development Studies and the Human Research Ethics Committee of the University of Newcastle.

4.2.3 Measures

Self-care behaviours: The revised version of the Summary of Diabetes Self-Care Activities Measure (SDSCA)⁽²⁵⁾ was used to measure participants' self-reported frequency of adhering to self-care behaviours. The SDSCA assesses participants' frequency of engaging in diabetes self-care behaviours such as following a general diet (i.e. following healthy eating plan) and a specific diet (i.e. consuming fruits and vegetables and reducing the consumption of high fatty foods); exercising at least 30 minutes per day; SMBG ; foot care; and not smoking cigarettes. Participants were asked to indicate the number of days they engaged in each of the self-care behaviours for the past seven days. The greater the number of days reported for a behaviour the better the self-care. The validity and reliability of the SDSCA have been found to be acceptable with both European and African American diabetes patients ^(25; 26). The SDSCA has demonstrated adequate test-retest reliability and evidence of validity and sensitivity to change in a number of studies ^(27; 28; 29; 30; 31; 32; 33). Previous studies that investigated adherence to self-care behaviours using the SDSCA did not report not smoking cigarette as a self-care behaviour ^(26; 34). Hence, not smoking cigarette was not reported as a self-care behaviour but as a demographic factor.

BMI: Weight was measured without shoes and wearing light clothing to the nearest kilogram using the United Nations Children's Fund (UNICEF) electronic scale manufactured by Seca. Height was measured without shoes to the nearest centimetre using a wall-mounted standardized microtoise manufactured by Seca. BMI was calculated as body weight in kilograms divided by the squared value of body height in meters (kg/m²) and categorized into

underweight (BMI ≤ 18.5 Kg/m²), normal weight (18.5–24.9 Kg/m²), overweight (25.0–29.9 Kg/m²) and obese (≥ 30 Kg/m²) based on the World Health Organization (WHO) criteria.⁽³⁵⁾

Waist circumference (WC): was measured midway between the inferior angle of the ribs and the suprailiac crest ⁽³⁶⁾ to the nearest 1 cm using a non-stretchable fibre-glass measuring tape (Butterfly, China). Participants stood in an upright position, with arms relaxed at the side, feet evenly spread apart and body weight evenly distributed in accordance with the WHO expert consultation report on waist circumference and waist-to-hip ratio ⁽³⁶⁾. Abdominal obesity was determined as a waist circumference >102 cm in men and >88 cm in women according to the WHO cut-off points and risk of metabolic complications for waist circumference.⁽³⁶⁾

Demographic characteristics: Age (continuous), gender, duration of diabetes since diagnosis (years), family history (yes/no), educational status (years), marital status (married and not married) and religious status (Christianity, Islamic and African traditional religion) were self-reported.

4.2.4 Statistical analysis

All data were analysed using IBM SPSS version 20.0. Means and standard deviations were used to describe all continuous variables including self-care behaviours, age, duration of diabetes since diagnosis, number of cigarettes smoked per day, weight, and height. Categorical variables were reported as frequencies and percentages. Univariate associations were examined between demographic or anthropometric variables, and self-care behaviours using independent t-tests (for categorical variables) and Pearson correlations (for continuous variables).

To identify factors associated with self-care behaviours, variables that were significant in the univariate associations were entered as independent variables into stepwise regression models using forward selection. Each of the four self-care behavior scores (i.e. diet, exercise, SMBG and foot care) were included as dependent variables in separate regression models (i.e. four models in total). In all statistical analysis, a p<0.05 was considered significant.

4.3 RESULTS

4.3.1 Demographic and anthropometric variables

Of 201 patients approached, 190 (95%) consented, however, only 187 (98%) contained sufficient data for inclusion in the analysis. The demographic characteristics and anthropometric measurements of the sample are presented in Table 1. The majority of participants were female, older than 50 years, married, and followed the Islamic religion. One-third reported having diabetes for over 5 years and 38.5% had a family history of diabetes. Only three participants reported smoking cigarettes.

Gender	Frequency (%)		
Male	52(27.8%)		
Female	135(72.2%)		
Mean ±SD age (years)	54.83 ± 13.32		
\leq 50 years	69(36.9%)		
> 50 years	118(63.1%)		
Religious following			
Islam	154(82.4%)		
Christianity	32(17.1%)		
African Traditional Religion	1(0.5%)		
Mean number of years schooling	6.63 ± 7.23		
\leq 12 years	140(74.9%)		

Table 1: Participant demographic and anthropometric characteristics (n=187)

>12 years	47(25.1%)		
Marital status			
Single	67(32.8%)		
Married	120(64.2%)		
Mean duration of diabetes (years)	5.43 ± 4.92		
\leq 5 years	125(66.8%)		
> 5 years	62(33.2%)		
Family history			
Yes (Parent, brother, sister or own child)	21(11.2%)		
Yes (grandparent, aunt, uncle or first cousin			
(but no own parent, brother, sister or child)	51(27.3%)		
No	115(61.5%)		
Anthropometry	Frequency (%)		
Mean BMI (kg/m ²)	29.27 ± 6.87		
Obese	75(40.1%)		
Overweight	61(32.6%)		
Normal weight	51(27.3%)		
Mean WC (cm)	98.60 ± 14.14		
Abdominally obese	123(65.8%)		
Smoking status			
Non Smoker	184(98.4%)		
Smoker	3(1.6%)		
Mean number of cigarettes smoked per day	5.00 ± 1.00		

4.3.2 Adherence to self-care behaviours

Table 2 presents the mean number of days each diabetes self-care behaviour was reported as being performed during the last 7 days. It also specifies the percentage of participants that reported performing each of these behaviours daily. The most commonly performed diabetes self-care behaviour was participation in a specific exercise session $(5.19 \pm 2.24 \text{ days per week})$ and the least was testing blood sugar level according to the number of times recommended by a health provider (2.12 ± 0.69 days per week). Only 1 patient performed self-monitoring of blood glucose (SMBG) daily; 26 (13.9%) checked their feet daily and 18(9.6%) inspected the inside of their shoes every day.

Table 2: Participant frequency of adhering to self-care behaviours (n=187)

		Performed self-care
Self-care behaviours (0 to 7 days)	Mean (SD)	behaviour daily (n, %)
General diet	4.37 (1.96)	16(8.6%)
Follows a healthful eating plan	4.79 (2.09)	56(29.9%)
Follows eating plan	3.94 (1.97)	16(8.6%)
Specific diet	4.44 (1.31)	13(7.0%)
Eats five or more servings of fruits and		25(13.4%)
vegetables	3.25 (2.11)	
Eats high fat foods (red meat or full fat dairy		3(1.6%)
products)	1.34 (1.62)	
Total diet score per week	4.40 (1.52)	5(2.7%)
Exercise	4.78 (2.09)	40(21.4%)
Participates in at least 30 minutes of physical		50(26.7%)
activity	4.37 (2.56)	
Participates in a specific exercise session	5.19 (2.24)	62(33.2%)
SMBG	2.15 (0.65)	1(0.5%)
Tests blood sugar level	2.19 (0.74)	1(0.5%)
Tests blood sugar the number of times		
recommended by your health care provider	2.12 (0.69)	1(0.5%)
Foot care	2.86 (2.16)	18(9.6%)
Checks feet	3.17 (2.40)	26(13.9%)
Inspects inside of shoes	2.54 (2.22)	18(9.6%)

Data are Mean (SD) or n (%). Mean refers to the average number of days participants adhered to a particular self-care behaviour in the last 7 days. SD= Standard deviation. Only the adherent cells are presented for brevity. All 187 participants completed all self-care items.

4.3.3 Associations between participant characteristics and self-care behaviours

4.3.3.1 Univariate associations among participant characteristics and self-care behaviours

Frequency of participation in a diabetes self-care behaviour defined by number of days per week was analysed according to demographic variables. Men (2.36 (1.02) days per week) reported greater mean (SD) days per week for blood glucose testing than women (2.07 (0.40) days per week), t (184) = 0.007. Age, marital status, duration of diabetes, family history, religious following, BMI (normal/overweight/obese) and WC (abdominally obese vs not) were not associated to frequency of participation in any of the self-care behaviours.

4.3.3.2 Multivariate associations between participant characteristics and self-care behaviours

Table 3 presents the regression models of factors associated with adherence to the four selfcare behaviours. Number of years in school was associated with frequency of adhering to diet (r=0.223, p=0.002), exercise (r=0.168, p=0.022), and foot care (r=0.153, p=0.037). Male gender was associated with higher frequency of performing SMBG (r=0.198, p=0.007).

Variable	В	SE of B	p-value	Partial correlation	Adjusted R ²
Diet					0.053
Number of years in school	0.226	0.02	0.002	0.223	
Exercise					0.023
Number of years in school	0.168	0.021	0.022	0.168	
SMBG					0.034
Gender ^a	0.198	0.104	0.007	0.198	
Foot care					0.023
Number of years in school	0.153	0.022	0.037	0.153	

 Table 3: Factors associated with participant frequency of adhering to self-care behaviours

a. Gender: Male = 1, Female=0. Diet includes both specific and general diet.

4.4 DISCUSSION

This study described-the frequency of adhering to four self-care behaviours in adult Ghanaian type 2 diabetes patients and factors associated with performing these self-care behaviours. Exercise was the most commonly performed self-care behaviour and SMBG was the least adhered to by the participants. More education and being female were associated with adherence to self-care behaviours. Given that self-care is a multidimensional concept, factors associated with each of the four self-care behaviours were investigated separately using multivariate analysis: diet; exercise; SMBG and foot care.

4.4.1 Self-care behaviours

4.4.1.1 Exercise

The frequency of exercise reported in this study is one of the highest reported among type 2 diabetes patients. Participants performed physical activity of at least 30 minutes for an average of 4.37 days per week. This is higher than the 2.7 days reported among both African American type 2 diabetes patients ⁽²⁶⁾ and diabetic patients from three rural Appalachian communities ⁽³⁴⁾. These findings are however consistent with those among type 2 diabetes patients in Ethiopia ⁽³⁷⁾ and among immigrant Filipino Americans living with diabetes ⁽³⁸⁾. The relatively high exercise adherence in this study could be due to most patients generally having to walk for transport. Despite the relatively high mean number of days of performing physical activity in this study, less than 35% of the participants exercised for 30 minutes daily or participated in a specified exercise session every day during the past week. Several barriers may have prevented daily adherence to physical activity including the risk of hypoglycaemia; inadequate access to conducive environment and facilities to perform physical activity and fear of increasing blood pressure ^(38, 39; 40; 41).

4.4.1.2 Diet

The frequency of following general (4.37 days per week) and specific diet (4.44 days per week) in these type 2 diabetes patients is similar to the 4.1 days per week found among a rural population of diabetes patients ⁽³⁴⁾; and 4.37 days and 4.09 days per week following general and specific diets respectively among diabetes patients with a rural background ⁽⁴²⁾. These findings are however lower than those reported among African American type 2 diabetes patients ⁽²⁶⁾; in type 2 diabetes patients from an urban setting in the US ⁽⁴²⁾ and Chinese American type 2 diabetes patients ⁽⁴³⁾. The patients' performance on specific self-care behaviours for diet were less desirable: less than 15% of them ate fruits and vegetables on a

daily basis and less than one-third followed a healthy eating plan daily. Seasonality of fruits and vegetables and cost might have contributed to the low adherence to diet.

4.4.1.3 Self-monitoring of blood glucose

Decreased ability to adjust medication dosages, dietary intake and physical activity could arise, if SMBG is not performed as recommended ⁽³⁸⁾. Despite this, SMBG was the least performed self-care behaviour in these Ghanaian type 2 diabetes patients with only 1 patient doing SMBG daily. This is among the lowest frequency of performing SMBG among type 2 diabetes patients in Sub-Saharan Africa and other parts of the world. In type 2 diabetes patients in Harari, Eastern Ethiopia, 2.6% of a sample of type 2 diabetes patients performed SMBG daily ⁽⁴⁴⁾. African American diabetes patients reported an average of 4.7 days per week of performing SMBG in a cross-sectional study in the US⁽²⁶⁾. Furthermore, a study of type 2 diabetes in low-income urban Puerto Ricans in the US, found that 60% of the participants performed SMBG once or twice daily ⁽⁴⁵⁾. The current findings are only similar to those reported among rural diabetes patients in the US in which participants reported an average of 2.15 days per week of performing SMBG ⁽³⁴⁾. Inadequate access to glucose monitoring machines, cost of test strips and needles, lack of requisite knowledge and skills to perform and interpret SMBG readings; lack of provider support; fear of testing and pain and preference for traditional and alternative medicine ^(46; 47; 48; 49; 50) may be responsible for the low SMBG in Ghanaian type 2 diabetes patients.

4.4.1.4 Foot care

Participants' frequency of checking their feet in the last 7 days was lower than the 4.33 ⁽⁴²⁾ and 4.8 days ⁽²⁶⁾ per week, and the 42.1% who checked their feet per day ⁽⁴³⁾ reported in previous research. Similar low levels of foot care practices have been reported previously ^(17; 51) in Sub-

Saharan diabetes patients. Several factors could contribute to the low practice of foot care in these type 2 diabetes population including lack of knowledge on how to perform foot care ^(17; 51); poor provider-patient communication; inconvenience for work; and poverty affecting patient's inability to purchase appropriate footwear ⁽¹⁷⁾.

4.4.2 Factors associated with self-care behaviours

The study results suggest that number of years of education plays an important role in diabetes self-care behaviours such as diet, exercise and foot care. These findings concur with those of previous studies reported among type 2 diabetes patients in Sub-Saharan Africa ^(37; 51) and from China ^(43; 52). Patients with more years of education may be more likely to comprehend recommended self-care behaviours than their less educated counterparts because they may be able to read and become more informed of the benefits of adherence. This is a cause of concern since the majority of the Ghanaian adults with type 2 diabetes and those reported previously are usually less educated ^(23; 53; 54). Unavailability of linguistically and culturally relevant diabetes self-care education resources in the Ghanaian setting, as well as patients' inability to interact with healthcare providers due to low literacy may be some of the factors that makes it difficult for effective counselling on self-care behaviours. Inadequate awareness of health concepts may also be another contributing factor.

It was also found that gender plays an important role in SMBG in that men were more likely than women to perform SMBG. A qualitative study from Canada ⁽⁵⁵⁾ reported that while women were more concerned with their fears and anxieties, men focused on the technical aspects of SMBG and were more likely to experiment with SMBG. Thus, women may have less confidence to use glucometers resulting in their reluctance to perform SMBG. Furthermore, women also receive less family support for self-care; may lack confidence; may self-blame themselves more for the condition and may also allow the needs of children and spouses to take precedence over their needs ^(26; 56; 57). It is imperative that providers are aware of the gendered dimensions in diabetes self-care and address these in their counselling sessions with patients ⁽⁵⁶⁾.

4.4.3 Association between adherence to self-care behaviours and body weight

Contrary to the findings of Dixon et al ⁽²⁴⁾ in Australia, BMI and WC were not significantly associated to any of the self-care behaviours investigated in this study. The diabetes populations of the Dixon et al study and the current study could differ in their perception of the health risks of excess body weight. Excess body weight is generally considered as a sign of beauty, affluence and well-being in most parts of Sub-Saharan African countries including Ghana ^(58; 59) but generally considered a health risk in many developed countries including Australia. Thus the diabetes population of the current study might not be less concerned about their body weight and may be less likely to adopt strategies to control their weight.

4.4.4 Strengths and Limitations

This is the first study to investigate more than one self-care behaviour in type 2 diabetes patients in Ghana. Another strength of the study is the use of a reliable, valid and widely used instrument for the assessment of self-care behaviours in diabetes patients. The main limitations of the study are the cross-sectional design, which cannot establish causality, and use of self-report to measure adherence, making it liable to social desirability bias. Although social desirability bias might have occurred, the self-reported self-care behaviours were, in general, low. In addition, our findings regarding SMBG would have been easier to interpret if we had collected information as to how many of our type 2 diabetes patients owned glucometers. Women and those with less education appeared to be over-represented in the sample, which may limit the generalizability of the results. However, our diabetes patient population had similar characteristics with diabetes populations reported in studies from other parts of Ghana ^(23; 60).

4.4.5 Implications and future research

Given the link between self-care behaviours and health outcomes of diabetes patients, the low adherence found in this study is a concern. Effective strategies are needed to help improve the diabetes self-care behaviours of adult Ghanaian type 2 diabetes patients. Our findings could be relevant to the type 2 diabetes patient population of several developing countries with challenged health systems like Ghana. Future research should explore both patient and provider barriers to performing effective self-care behaviours in diabetes patients. Such data will inform the design of tailored interventions to improve adherence to self-care behaviours. There is also a need to conduct more research about how to effectively communicate about self-care behaviour with populations who have low literacy or health literacy. In addition future studies should explore the effect of performing recommended self-care behaviours on clinical outcomes of diabetes patients in the Ghanaian setting.

4.5 CONCLUSION

This study has shown that the performance of self-care behaviours, SMBG and foot care in particular, are sub-optimal among Ghanaian adults with type 2 diabetes. The sociodemographic factors associated with poor adherence were lower levels of education and female gender. Further research to identify the barriers to effective self-care behaviours, particularly among those with a lower educational level and women, is warranted.

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RELATIONSHIP OF CHAPTER 5 TO CHAPTERS 2 AND 4

The findings presented in Chapter 2 showed that many people with type 2 diabetes from LMICs do not frequently adhere to self-care behaviours. The findings in Chapter 4 indicated variable

levels of adherence to recommended self-care behaviours among Ghanaian people with type 2 diabetes with gender and education playing a role in adherence. Collectively, the findings presented in Chapters 2 and 4 showed that adherence to diabetes self-care behaviours among people with type 2 diabetes from Ghana and other LMICs is not likely to optimise health outcomes or minimise morbidity among this patient group. Therefore, it is important to take a more in-depth approach to understanding the potential reasons for non-adherence to each diabetes self-care behaviour. The qualitative study presented in Chapter 5 seeks to identify the range of barriers that may hinder adherence to self-care among people with type 2 diabetes from the perspectives of both patients and their HCPs using the Theory of Planned Behaviour as a conceptual guide.

CHAPTER 5

BARRIERS TO DIABETES SELF-CARE: A QUALITATIVE STUDY OF PATIENTS' AND HEALTH CARE PROVIDERS' PERSPECTIVES

This manuscript has been published in "Journal of Clinical Nursing".

Mogre V, Johnson NA, Tzelepis F, & Paul C. Barriers to diabetes self-care: a qualitative study of patients' and health care providers' perspectives. Journal of Clinical Nursing. 2019; 1-13.

ABSTRACT

Aims and Objectives: We explored patient and health care provider (HCP) perspectives about patients' barriers to the performance of diabetes self-care behaviours in Ghana.

Background: Sub-Saharan African urban populations are increasingly affected by type 2 diabetes due to nutrition transition, sedentary lifestyles, and ageing. Diabetes self-care is
critical to improving clinical outcomes. However, little is known about barriers to diabetes self-care (diet, exercise, medication taking, self-monitoring of blood glucose and foot care) in Sub-Saharan Africa.

Design: Qualitative study that followed the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines.

Methods: Semi-structured interviews were conducted among 23 people living with type 2 diabetes and 14 HCPs recruited from the diabetes clinics of three hospitals in Tamale, Ghana. Interviews were audiotaped and transcribed verbatim. The constant comparative method of data analysis was used and identified themes classified according to constructs of the theory of planned behaviour (TPB): attitudes/behavioural beliefs, subjective norms and perceived behavioural control.

Results: Barriers relating to attitudes included misconceptions that diabetes was caused by spiritual forces or curses, use of herbal medicines, intentional non-adherence, difficulty changing old habits, and feeling or lacking motivation to exercise. Barriers relating to subjective norms were inadequate family support, social stigma (usually by spouses and other members of the community) and cultural beliefs. Perceived behavioural control barriers were poor income levels, lack of glucometers, busy work schedules, long distance to the hospital, and inadequate access to variety of foods due to erratic supply of foods or seasonality.

Conclusions: Both patients and HCPs discussed similar barriers and those relating to attitude and behavioural control were commonly discussed. Interventions to improve adherence to diabetes self-care should focus on helping persons with diabetes develop favourable attitudes and how to overcome control barriers. Such interventions should have both individualised and community wide approaches.

5.1 INTRODUCTION

Diabetes was responsible for five million deaths in 2015, and has become a disease of global importance affecting 1 in 11 adults ^(1; 2). The prevalence of type 2 diabetes is rising rapidly in lower-and middle-income countries. In 2015, 3.2% of adults aged 20-79 years were diagnosed with diabetes in sub-Sahara Africa ⁽¹⁾ and it has been estimated that by 2030, non-

communicable diseases (NCDs) will surpass infectious diseases, maternal, perinatal and nutritional diseases in the sub-region ^(1; 2). Sub-Saharan African urban populations are the most affected due to nutrition transition, sedentary lifestyles, and ageing ^(2; 3; 4). Type 2 diabetes is the most frequently occurring type of diabetes in Sub-Saharan Africa and worldwide ^(1; 2). However, access to recommended diabetes care in Sub-Saharan Africa is limited by a shortage of adequately trained HCPs, inadequate diagnostic tools and lack of medications for the treatment of diabetes ^(5; 6). Diabetes care requires patients to navigate an interactive model of HCPs, healthcare systems, families and communities ⁽⁷⁾. With the support of the provider the patient is expected to follow recommended self-care behaviours such as self-monitoring of blood glucose (SMBG), dietary change, exercise, foot care, and medication. Adherence to these self-care behaviours has been shown to improve glycaemic control, lower long-term morbidity, mortality, and increased insulin sensitivity ^(8; 9) as well as decreased risk of foot ulcers ^(10; 11).

5.2 BACKGROUND

Most studies investigating patient barriers to self-care are from developed countries such as the United States, Canada and the United Kingdom ^(12; 13; 14; 15). These studies have found that potential barriers to self-care behaviours among patients with type 2 diabetes include poor patient-provider communication, lack of support from family, inadequate understanding or knowledge of the disease, lack of motivation to change ^(16; 17), a need for education ⁽¹⁷⁾, cultural and psychological factors ^(18; 19). Given these settings generally have well established health care systems for diabetes care, the generalizability of these findings to Sub-Saharan Africa, where the health systems are limited, is questionable. The few studies conducted in Sub-Saharan Africa have largely adopted quantitative approaches ^(20; 21; 22; 23; 24; 25), which provides limited insight into how to develop interventions which account for local or cultural beliefs ⁽²⁶⁾. Furthermore, the limited studies from Sub-Saharan Africa, explored a single self-care

behaviour (i.e. either diet only, diabetic foot care only or physical activity only) ^(20; 21; 23; 24; 27). A more comprehensive approach to understanding barriers to adherence is essential to the development of interventions which are effective for the full-suite of diabetes self-care behaviours.

Both patient and provider perspectives are relevant when exploring barriers to self-care. Increased participation of patients in treatment decisions and satisfaction with provider communication have been reported to result in improved adherence to self-care behaviours ^{(28;} ²⁹⁾ and better health outcomes in patients ^(30; 31). Conversely, patients' and HCPs' discordance in health goals, targets, and barriers may result in poor health outcomes ⁽³²⁾. There is evidence that patients and HCPs can differ in their perception of barriers to adherence to self-care behaviours ^(32; 33). HCPs may be able to identify barriers that are not apparent to patients. A number of studies have investigated patient only and provider only barriers to self-care ^(33; 34). Other than one study from the United Kingdom which concurrently investigated HCP and patient perceptions of barriers to diet and physical activity self-care behaviours ⁽¹²⁾; no study has concurrently explored patient and provider perceptions of barriers to adhering to self-care behaviours. A better understanding of patient and HCP barriers to self-care behaviour is needed to guide the design of interventions to improve self-management and quality of diabetes care. This study qualitatively explored provider and patient perceptions of barriers to the performance of five diabetes self-care behaviours (diet, exercise, SMBG, medication taking and foot care).

5.3 METHODS

Design: Semi-structured in-depth individual interviews, informed by the Theory of Planned Behaviour (TPB) ⁽³⁵⁾ were conducted with Ghanaian type 2 diabetes patients and their HCPs.

5.3.1 Theoretical framework

TPB conceptualises that behaviour is determined by *intention* to act and perceived behavioural control (PBC) ⁽³⁵⁾. According to the TPB, intention to perform a self-care behaviour is determined by three components: the individual's attitudes (one's evaluation of the potential or expected outcome of performing a self-care behaviour); subjective norms (one's perception of social pressure to perform or not perform a self-care behaviour); and PBC (one's perception of the ease or difficulty in performing a self-care behaviour) ^(35; 36). Latent to attitudes, social norms and PBC are beliefs that are useful targets for interventions to help change behaviour ⁽³⁷⁾. These beliefs include behavioural beliefs, normative beliefs and control beliefs.

5.3.2 Setting and sample

Patients: Patients were recruited from the diabetes clinics of the Tamale Teaching Hospital, Tamale West and Central Hospitals located in the Tamale Metropolis of Ghana. Patients attending these hospitals are primarily from urban and semi-urban areas. These hospitals have weekly diabetes clinics to provide care to diabetes patients. Patients were eligible to participate if they: were older than 18 years; self-reported a healthcare professional diagnosis of type 2 diabetes; sought care from the diabetes clinic at least twice during the last 12 months and were registered with the hospital. Patients were excluded if they: had type 1 diabetes or were diagnosed with diabetes before the age of 30 years.

HCPs: HCPs were recruited from the diabetes clinics of the three hospitals where doctors, nurses, nutritionists and dietitians provided diabetes care. Eligible HCPs were those having a primary role in diabetes care and who had worked in the diabetes clinic for at least three months.

5.3.3 Procedures

Patients: All recruitment and data collection procedures were completed by a trained research assistant (RA). Patients waiting for their consultation with their provider were approached by the RA and invited to participate. After signing a consent form, an appointment for the study interview was made with the patient at a convenient time and venue. Noting that patients may feel vulnerable while in the waiting area we adopted a number of strategies to prevent coercion. Patients were assured that their participation was voluntary and they were at liberty to withdraw at any time during the interview without any consequences. In addition, patients were also assured that their decision whether or not to participate was not going to affect the availability of care to them. Finally, the research assistant who collected the data was not involved in the provision of care to the patients, thereby reducing the likelihood of coercion. Most interviews were conducted face-to-face at the patients' homes and all were audio-recorded. Interviews with patients were conducted in English or in a local dialect (i.e. Dagbani) if patients were unable to speak English. Interviews that were conducted in the local dialect were translated to English by the interviewer. Forward-and back-translations were adopted. All interviews with patients had a duration of 20-30 minutes. Interviews were conducted till the point of saturation.

HCPs: Participants were recruited using a combination of purposive sampling and snow balling techniques. All recruitment procedures and interviews were conducted by VM. Potential participants were approached on diabetes clinic days. Those who agreed to participate were interviewed in the hospital at a mutually agreed time. All interviews with HCPs were conducted face-to-face in English, audio-recorded and lasted for a duration of 15-30 minutes. The study was approved by the University of Newcastle Human Research Ethics Committee and the Tamale Teaching Hospital Ethics committee.

5.3.4 Measures

The interview discussion guide included open-ended questions and covered all components of the TPB. Specifically, for patients, topics relating to the diabetes patients' barriers to self-care were considered (Appendix 1). For the HCPs, the discussion guide covered topics, based on a literature review ^(12; 15) relating to general diabetes care and barriers they perceived hindered patients' adherence to diabetes self-care behaviours (Appendix 2).

5.3.5 Data analysis

All interviews were transcribed verbatim into English. Transcripts were checked for errors in conjunction with the digital audio recordings by VM. The coding procedures and constant comparative method of qualitative data analysis developed by Strauss ⁽³⁸⁾ was used to analyse the interview transcripts. Following an inductive, bottom up approach, this method has been widely used for analysing qualitative data ⁽³⁹⁾. Transcripts of the individual interviews were read and re-read and assigned a series of codes by the principal investigator. VM and a colleague, who has experience in qualitative research coded a sample (i.e. 25%) of interview transcripts independently. These were compared and differences resolved through discussion between the coders, and with other members of the research team if required. The codes were grouped into similar themes/concepts. Themes/concepts were presented according to the constructs of TPB and augmented with illustrative quotes. Nvivo software version 12.0 was used for processing, ordering and comparing the codes.

5.4 RESULTS

5.4.1 Demographic characteristics

From the three diabetes clinics, 26 type 2 diabetes patients were approached in which 23 agreed to participate and were interviewed. Most patients were female (17/23) with a mean (SD) age of 60.9(12.6) years. Duration of diabetes ranged from one year to 20 years and most (18/23) had lived with the condition for less than ten years. Eighteen of the 23 patients either had no formal education or had attained low levels of education. Out of the 17 HCPs approached 14 agreed to participate and were interviewed. Nine of the 14 HCPs were male. The HCPs were nurses (n=8), physician assistants or prescribers (n=2), nutrition officers (n=2) and dieticians (n=2). The HCPs had been working in the diabetes clinic for an average of 3 years.

5.4.2 Barriers to self-care

Both patients and HCPs identified a number of perceived barriers to patients' adherence to self-

care behaviours as described in full below. These barriers are summarised in Table 1.

TPB Construct	Barrier
Attitudes/behavioural	
beliefs	
	Misconception and use of herbal medicines
	Difficulty changing old habits
	Intentional non-adherence and fatalism
	Worrying about the continuous taking of medication
	Feeling lazy to perform exercise
	Side effects of medication
	Fear of pricking the finger
Subjective	1 5 5
norms/normative beliefs	
	Inadequate family support
	Culture and beliefs
	Social stigma
Perceived behavioural	e e e e e e e e e e e e e e e e e e e
control/control beliefs	
	Non-receipt of self-care support to perform SMBG
	Inadequate knowledge and skills to operate the glucometer

 Table 1: Barriers to diabetes self-care categorised according to the constructs of the

 Theory of Planned Behaviour

Patients' having comorbid conditions
Old age and body pains
Poor income levels
Inadequate access to a variety of foods
Diet recommendations are too restrictive
Busy work schedules

5.4.2.1 Attitudes/behavioural beliefs

Misconceptions and use of herbal medicines: According to the HCPS, diabetes patients had misconceptions regarding diabetes and its care. These misconceptions related to the causes of diabetes and dietary care. HCPs suggested that most diabetes patients misconstrued that diabetes was caused by the consumption of high carbohydrate diets and as a result should avoid such foods.

...most of them think it is sugar ... that causes diabetes, a lot of them have that misconception. Which is not true. – Participant 10, Nutrition Officer.

Some HCPs also noted some of these misconceptions as they usually advised diabetes patients not to take high carbohydrate diets making it difficult for some patients to make the right choice of meals.

Some do come here saying some nurses told them not to eat protein foods. ... I'll tell them that you're not supposed to avoid anything, even sugar, if you get a dietician involved. We call it carbohydrate counting....-Participant 5, Dietician.

HCPs perceived that some patients have the misperception that diabetes was caused by spiritual forces. This misperception usually resulted in such diabetes patients seeking care from other places such as prayer camps and/or from herbalists instead of visiting the hospital. Those that visit the hospital may not trust the diabetes self-care recommendations provided to them by their HCPs, may not adhere to them and only come to the hospital when they develop complications.

Those people that I was talking about were those who were reporting of local medications and spiritual healings. Majority of them were those who claim it was related to the culture. That some spiritual things or certain things and even up to now some people were even changing their medications. I think we even investigated, that was when we were told that they were having the mentality that it is due to some spiritual happenings. Because of that they were not also taking the drugs. Once they have that mentality that it is spiritual, somebody somewhere is working on them, they will not take our medications. Later they will come to the hospital worse. – **Participant**

12, Prescriber.

... Some of them will tell you that - they say with local medication it can be cured. With herbs, they can be cured. That is cure - which is one of their misconceptions. Sometimes, because they hear the condition is curable with herbs, they stop and they go in to buy those medications that is perceived to cure the condition. – **Participant 3, Nurse.**

HCPs further intimated that some patients misperceived that diabetes is a curse and once you are cursed with the condition there is nothing one can do about it and as result they do not follow recommended self-care behaviours.

They say its 'baari' as in it's a cursed sickness. So once it has affected the family, it means that it will affect everybody [in the family]. There's nothing you can do. –

Participant 6, Nutrition Officer.

HCPs thought that misconceptions that the use of herbal medicines could cure diabetes was rampant among patients. This misconception originated from patients' misconception that diabetes can be cured. Generally this misconception usually hindered patients' adherence to their diabetes medications as well as their dietary recommendations.

Yes. Some of them will tell you that - they say with local medication it can be cured. With herbs, they can be cured. That is cure - which is one of their misconceptions. Because diabetes is not curable. Sometimes, because they hear the condition is curable with herbs, they stop and they go in to buy those medications that is perceived to cure the condition.-Participant 3, Nurse.

A lot. Someone even came and said he met an herbalist who gave them some medicine which should be taken with alcohol. Meanwhile it is not advisable for diabetics to take alcohol and that is what they were doing. **–Participant 5, Dietician.**

Difficulty changing habits: HCPs were concerned that some patients usually found it difficult to change certain habits. Most of these habits were dietary related. Confirming the perceptions of the HCPs, some patients said they have been eating some foods for almost all of their lives and have developed a taste for such foods. As a result they found it difficult to follow recommendations that required them to either avoid such foods altogether or reduce the quantity or frequency of consuming such foods.

There are some particular food that you tell the patient not to take and the patient will be telling you that for this one, I'm used to it. I can't stop taking it- Participant 4, Enrolled Nurse.

My morning breakfast like this. I can't seem to be able to take it without sugar. It's very

difficult. Participant 11, Patient.

Intentional non-adherence to self-care and fatalism: HCPs noted that while most patients were cooperative and eager to do something about their condition, some seemed not to care about their condition. These patients have poor attitudes towards self-care in general and some have a fatalistic belief that they will die whether they adhered to their diabetes self-care behaviours or not. HCPs suggested that some patients even prefer to die with the condition instead of making changes to their lifestyle.

It's also a misconception. Or is it - I might put it - self-endured something. Some of them will tell you, if you eat whatever you like and die, it's still the same death. Whether you eat

good diet and die, its death. And if you eat what you are supposed to eat and you die - yes, they will tell you that slogan, "all die be die". So no matter what you tell the person, the person will still go back and do what she feels like doing. **–Participant 3, Nurse.**

Worrying about the continuous taking of medication: Some patients found it difficult to follow the new routine of taking diabetes medications every day for the rest of their lives. Those patients said they found it worrying and felt concerned about the chronic nature of diabetes and the continuous intake of diabetes medications for the rest of their lives. This barrier was also shared by the HCPs.

Am often worried about the chronic nature of the disease. Because how long can one continue to take these drugs. I sit down and I reflect, at my age can I continue taking these medications till thy Kingdom come. It is also a challenge. I know one guy, a colleague, the last two weeks we met, he said he had thrown away his drugs. He said we are too young to be taking these drugs. He wants to wait and see the reactions before he starts taking them. **Participant 10, Patient.**

The problem is when you take it. You are always swallowing medicine. In the morning you take, afternoon you take and evening you take. **Participant 6, Patient.**

It's because sometimes the person has taken their medication for quite too long. And because of that, she can't - she just ignores or stops taking the medication. – Participant 3, Nurse.

Feeling lazy to perform exercise: HCPs discussed that some patients were unable to exercise as required because they felt lazy to do so.

The exercises too has to do with attitude, some of them their barriers could be laziness.-

Participant 14, Nurse.

Some too are just lazy or they don't see the importance of exercise.-Participant 10, Nutrition Officer. *I don't do any physical activity or work I am just lying down.* **Participant 21, Patient Side effects of medications:** Both patients and HCPs alike explained that the medications have side effects that usually prevented them from adhering to the recommendations. Some of these side effects as identified by the patients included hunger, nausea, dizziness, shivers, and among others.

Yes, it causes a lot of hunger and when you take it in the morning and evening, you become very hungry and your body starts shaking. So that is why I take it only in the morning. Participant 18, Patient.

There are some they will give you to take and you will not feel your head. When you take the B.P medication plus the diabetes one, your head will be aching. So I find it difficult. Participant 5, Patient.

Some of them especially the men; they do the defaulting. They believe that when you are taking the medications one of its bad effects is slowed libido. So when they take it for some time they complain that they are not able to "perform" the way they used to. So they start defaulting and won't come for the drugs.-Participant 4, Enrolled Nurse.

The fear of pricking the finger: Both patients and HCPs opined that some patients have glucometers and can also afford glucose strips to self-test but are unable to perform SMBG because of the pain of pricking themselves.

The difficulty is just the pricking part of it. **Participant 22, Patient.** Some patients find it difficult to prick themselves.-**Participant 5, Dietician.**

5.4.2.2 Subjective norms/normative beliefs

Inadequate family support: HCPs and patients recognised that family support was key to successful diabetes self-care. They thought that family support was especially important for diet self-care behaviours and patients may not be able to adhere to their dietary

recommendations at all if family support is inadequate.

They don't give me any support. It is 'cry your own cry'. Participant 11, Patient. The barriers to receipt of adequate family support were generally gender specific as expressed by HCPs. Male patients visited the dietician or nutritionist without their spouses or those responsible for preparing their dishes. HCPs thought that this may have resulted in male patients' inability to adhere to any dietary advice because they may forget some of the advice or may not relay it to those responsible for their diets. HCPs also opined that female patients who found themselves in polygamous marriages found it difficult to adhere to some of the selfcare behaviours such as diet and medication as they competed with the other wives to meet the needs of the husband.

During consultation, when a man who is living with the wife comes alone but he is not the one who cooks the food at home. So that is one of the barriers, so normally when it comes to consulting it is better for them to come with the person who prepares the meals for you. If the person comes alone, the question is what they tell their wives when they get home or do tell them what you instructed at all. **–Participant 8, Dietician.** Some of them come with a lot of family issues. Because many of them, their husbands have many wives. So they are rather competing to please the husband instead of caring for themselves. So when you tell them to eat well, they get home and rather concentrate on taking care of their children and their husbands to the neglect of their own diabetes.

- Participant 6, Nutrition Officer.

In most households of northern Ghana the entire family (which sometimes can be more than 10 members) eat meals cooked by one person or from a common pot. This arrangement sometimes makes it difficult for those who prepare the meals as they may not have time to prepare special meals for the diabetic patient or take into account the needs of the diabetic patient in the preparation of the family meal.

As for the diet and exercise; when you ask most of them, they either tell you their children are not around or their daughter in-laws won't help. Their daughter in-laws cook the family meal and the patients are usually old women or old men and can't cook for themselves. Their daughter-in-law worries about cooking for the entire family to eat and seldom has time for their special needs. **Participant 11, Nurse.**

Culture and beliefs: Given that the Ghanaian society generally associates being plump with a sense of a good living and wealth, plump patients who begun to lose weight as a result of adhering to their self-care behaviours usually complained of their friends, family and significant others perceiving them to be sick. This perception usually resulted in these patients defaulting on the recommendations. In addition, culture influences their adherence to dietary advice as it influences the kind of foods they eat.

Yes, culture might have an influence. There was this woman who came and she was morbidly obese and we were trying to bring her weight down. We started and she was doing very well. At a point she said a lot of people see her and question her why she was losing weight like that. So she came to tell us that we should add to her food. She didn't want to lose weight any longer. Because people are complaining that her weight is getting down and down and down. You know this part of the country, they always believe that if you are fat and plumpy it's a sign of good living. So once your weight is getting down, they think you have a problem. – Participant 5, Dietician.

Culture is the way we dress, the food we eat, ... So, like I said, the food we eat in my area if, basically, we farm only cassava, definitely affects how we adhere because that's what I have been eating from childhood.- Participant 7, Senior Nursing Officer.

Culturally, others perceived that exercise is for the rich or it's a western culture and hence will not participate in it if they think they are poor.

"The practice of exercising in the Northern culture is low or non-existent if I should put it bluntly. So if someone sees you exercising (e.g. jogging), it appears strange."-Participant 13, Nurse.

Social stigma: Due to patients' perception that they may be stigmatised as a result of their condition they usually do not want friends, family members, spouses and other close relations to know about their condition. Women in polygamous marriages dreaded being abandoned by their spouses if they were found to have diabetes. This perception usually affected their adherence to self-care behaviours and attendance to the diabetes clinic for regular checks and consultations.

There was an instance a lady was diagnosed and we asked her to assist us to call the husband and inform him to be supporting her among other things; she said "no" she won't allow that. After being told it was a part of hospital protocols to get guardians informed she still refused. So some don't even want relatives and friends to know about it; when they get diagnosed diabetic. **Participant 3, Nurse.**

I think stigmatization too; you come and then....some people don't even want to come for consultation. They don't want people to know that they are diabetic. They rather rely on over the counter medication.-Participant 8, Dietician.

5.4.2.3 Perceived behavioural control/control beliefs

Non-receipt of self-care support to perform SMBG: Some patients said they were not told to self-test their blood glucose and did not know the recommended blood glucose level.

They have never told me anything like that but the lowest I have ever had is 5.6. I have never had lower than 5. Participant 5, Patient.

Inadequate knowledge and skills to operate a glucometer: HCPs also thought that patients who are able to afford a glucometer found it difficult to either operate it or had challenges doing the unit conversion as some of the machines are calibrated in different units. Patients shared similar difficulties.

And besides that, some are finding it difficult to operate it themselves. –Participant 5, Dietician.

Others too, they have the money, but when they buy the machine, the one to check it for them will be the problem. **-Participant 4, Enrolled Nurse.**

And when the children are not there I can't check because when I check I can't record

the number. Participant 16, Patient.

Patients having comorbid conditions: According to the HCPs, some patients were unable to exercise due to the presence of other chronic conditions such as hypertension and other cardiovascular diseases.

The exercise, there are a few who come with an arthritis and they will tell you any time they try walking they feel pain, and some of them don't do. Those who come with multiple conditions, some of them it's not only diabetes, they're all age-related conditions.-Participant 5, Dietician.

Old age and body pains during exercise: Old age also prevented some patients from participating in exercise. Both patients and HCPs explained that due to their advanced age anytime they participated in any form of exercise they usually felt pains.

Sometimes with my age, the exercise is not easy. Participant 11, Patient. Most of them are unable to exercise as a result of old age.-Participant 6, Nutrition Officer. Yes how to bend down, the waist. To bend down, I have been struggling. When you want to flex and touch the ground, you will see that my waist will be in severe pains.

Participant 5, Patient.

Poor income levels: HCPs opined that they frequently came across patients who did not have enough finances to cover the cost related to self-care. This barrier was more pronounced when patients had to buy drugs that may not be covered by health insurance. Other self-care behaviours affected by this barrier were diet and SMBG.

Another thing is financial barriers. The patient wants to comply but she/he tells you "look, I don't even get food to eat and much less the type of food you warn me not to eat?" "So if I get anything I eat". So all those things are barrier. – Participant 14, Nurse.

If not because of the price I would be checking everyday but the test strips are expensive for one to be self-testing every day. **Participant 15, Patient.**

At home, one has to check but if you don't have the machine how do you check.

Participant 17, Patient.

Inadequate access to a variety of foods: HCPs were concerned that some patients do not have access to a variety of foods that will aid in their adherence to self-care behaviours. As a result, patients ate what was available to them. Furthermore, access to a variety of foods for patients to choose from was also related to seasonality. Some foods were available during the wet/rainy season but non-existent during the dry season. Also, some patients agreed with the HCPs that the foods recommended to them by their HCPs may not always be available. They said the supply of such foods is usually erratic in that they may get it at some times but not other times.

It's the setting that they are coming from. Some of them, where they are coming from will affect - will be a barrier. For example, you go from the Konkonba site. They mostly farm Konkonte. That is their stable. It's just there. So such a person when you advise him don't eat this don't eat that but when they go back that is what is just available. So it makes it difficult for them to resist. But that is what they see every day to eat. So the setting affects then. – Participant 7, Senior Nursing Officer.

Diet recommendations are too restrictive: Some patients rather felt that the limited variety of foods for them to choose from resulted from HCPs' recommendations being restrictive. They indicated that the recommendations limited them to only certain types of food. The regular consumption of such foods makes them become fed up and subsequently lose their appetite for such foods.

Yes, it's not easy. Some of the foods they advise us to eat I become fed up with it and I don't have taste for it. For instance they advised us to take porridge but as I speak I don't have taste for the porridge again because I've taken it for long time. And even bread, am not supposed to take because it is heavy. So if you want to eat bread you have to toast it. **Participant 18, Patient.**

Busy work schedules: Both patients and HCPs explained that some of the participants reportedly said their work schedule made it difficult for them to adhere to some of the self-care activities such as exercise and diet.

I think most of those we interact with are able to exercise. It is just a few. What they complain of is lack of time. They rise up early to go to work and come back late. We try to tell them to make time, it starts slowly. For exercising you can start with 5 minutes and progress from there. – Participant 10, Nutrition Officer.

The soup they want me to eat sometimes I don't get to eat it because by the time I would leave here for the house it is late and I just have to eat what they have prepared. Participant 24, Patient.

5.5 DISCUSSION

The current study explored patients' and HCPs perspectives on the performance of diabetes self-care behaviours in which varied barriers were identified and conceptualised into the TPB constructs of attitudes/behavioural beliefs, subjective norms and perceived behavioural control. The TPB served as a framework to understanding the reasons why patients do not adhere to their recommended diabetes self-care behaviours.

5.5.1 Attitudes/behavioural beliefs

Misconceptions relating to the causes of diabetes and its care were commonly expressed by the participants. These misconceptions hindered a number of self-care behaviours including diet (in which patients' avoided carbohydrate rich foods because they felt diabetes was caused by high sugar intake), adherence to diabetes medications (seeking care from prayer camps or herbalists because they believed diabetes was caused by spiritual forces or it's as a result of curses), and diabetes self-care in general (as they believed the disease can be cured). The misconceptions reported in this study regarding the causes and treatment of diabetes differ from the poor understanding of diabetes and its treatment that is usually reported as a barrier to self-care among studies from high income countries (¹²; ¹³; ¹⁴; ¹⁵; ¹⁶; ¹⁷). The misconceptions found in this study are consistent with previous studies from Ghana (⁴; ⁴⁰) and other parts of Africa that have identified such barriers to diabetes care including self-care (⁴¹; ⁴²; ⁴³; ⁴⁴). Self-care support and counselling sessions should thus focus on assisting patients to overcome these misperceptions regarding the causes and management of diabetes. Community-based interventions should also be implemented to help improve attitudes towards the disease at the community level.

Patients reported finding it difficult to modify entrenched dietary habits. This barrier was reported by both patients and HCPs. Our finding is similar to those reported by Booth et al ⁽¹²⁾ among newly diagnosed diabetes patients from a hospital in the UK; the qualitative report by

Ebrahim ⁽⁴⁵⁾ among diabetes patients from South Africa; and the qualitative report by Abioye-Akanji ⁽⁴⁶⁾ about West African Immigrant diabetes patients having challenges modifying their traditional West African diets. It is imperative that HCPs should endeavour to make dietary modifications more appealing, manageable, less daunting and achievable for patients ⁽¹²⁾. This may mean suggesting locally-relevant and successive small improvements to diet rather than abrupt major changes. These should be incorporated during individualised counselling and group diabetes self-management education.

In addition, we found that intentional non-adherence and fatalism affected patient's adherence to self-care behaviours. Intentional non-adherence related to patients refusing to follow any recommendations given to them to cater for their condition. This may be due to a number of factors including denial or non-acceptance of being diagnosed with diabetes or the seriousness of the condition, feeling of wellness, worrying about the continuous intake of drugs, misconceptions and lack of trust in the effectiveness of the recommended treatment ^(47; 48). Other factors may include the lack of motivation to adhere to the recommendation, cultural motives, and side effects of drugs ⁽⁴⁹⁾. In a qualitative study of diabetes patients from Southern Ghana, Aikins ⁽⁵⁰⁾ identified chronic suffering characterised by financial difficulties, increasing complications, and inadequate family and social support as major contributing factors to intentional non-adherence (i.e. passive withdrawal from drug and dietary management) reported by patients. Aikins ⁽⁵⁰⁾ added that patients desired death as an alternative to chronic suffering from diabetes. HCPs should continuously counsel patients to note that diabetes is a manageable disease and not a life sentence.

Fear of pricking the finger hindered patients' adherence to SMBG similar to the findings of Abioye-Akanji et al in a qualitative exploration of barriers to diabetes management among West African immigrants in the United States of America ⁽⁴⁶⁾ and those of Ong et al among type 2 diabetes patients from a primary care clinic of a teaching hospital in Malaysia ⁽⁵¹⁾. HCPs

should provide information and support to people with diabetes regarding appropriate procedures of pricking the finger less painfully such as using the lateral side of the finger, limiting the use of the thumbs and index fingers, using needles that have shallower depths, and using alternative site of testing (e.g. the arm, abdomen and thigh) ^(51; 52).

Lack of motivation or feeling lazy to exercise is consistent with other studies reported from developed countries ^(53; 54) but has not been identified in other studies originating from Sub-Saharan Africa. HCPs may be able to reinforce patients' motivation and commitment by educating them on the benefits and need for regular performance of exercise and also supporting them to adopt exercise strategies that are easy, low cost and able to be performed at home.

5.5.2 Subjective norms/normative beliefs

Family members are the significant sources of both instrumental (e.g. assisting patients to selftest) and emotional support (e.g. encouraging diabetes patients) for people with diabetes ^(55; 56). Family support has also been shown to improve adherence to diabetes self-care ⁽⁵⁵⁾. Both patients and HCPs perceived a lack of family support required for diabetes self-care. For instance, we found that women in polygamous marriages struggled to adhere to their diabetes self-care due to competing interests to meet the needs of the husband. Inadequate family support hindered adherence to dietary recommendations and medication taking. Poor understanding of the causes of diabetes and its care at the family and community level were discussed as the reasons for the inadequate family support. This finding suggests that where possible, diabetes patients should be actively encouraged to involve family members in diabetes education programs and family support should be incorporated as part of the diabetes care plan as has been recommended by a number of care guidelines ⁽⁵⁶⁾.

Contrary to studies from high income countries but consistent with previous studies from Ghana and other parts of Sub-Saharan Africa (44; 57) we identified social stigma as a barrier to diabetes self-care. We found that some diabetes patients did not want family members to know they have diabetes and may not seek support to self-test their blood glucose for fear of being stigmatised. In addition, we found that women in polygamous marriages did not want their spouses to know they have diabetes for the fear of being stigmatised or deserted, particularly if they are seen to be taking medication. Another aspect of social stigma was the fear of losing weight as family members or friends may believe their health condition to be very serious. In the Ghanaian setting as well as in several African countries, being plump is generally considered as a sign of wellness and prosperity although this notion may be changing as more people are becoming aware of the health consequences of being overweight ^(58; 59). To the best of our knowledge, the perceived lack of family support and social stigma reported in this study have not been previously identified in other diabetes populations. These findings suggest the need to include family members in diabetes self-management education. It is also likely that culturally-relevant community-level interventions are required to address these social and cultural issues.

5.5.3 Perceived behavioural control

As per previous qualitative reports of studies from Sub-Saharan Africa; barriers to SMBG included non-receipt of self-care support to perform SMBG and inadequate knowledge and skills to operate the glucometer ^(40; 43; 60; 61). There is the need for HCPs to continuously provide information and support regarding SMBG to persons with diabetes for them to be empowered ^(13; 62). Empowerment based diabetes self-management education interventions have previously been shown to improve adherence to SMBG ⁽⁶³⁾. HCPs should also implement individualised training regarding the use of a glucometer, continuous guidance and regular follow-up

evaluations of the SMBG technique to improve patients' knowledge and skills in operating the glucometer.

Both patients and HCPs identified inadequate income levels as a common barrier to diabetes self-care. Our findings support those of previous studies from other parts of Sub-Saharan Africa that report patients' inability to perform SMBG due to the high cost of glucose strips and the unaffordability of personal glucometers ^(43; 64). In agreement with previous studies from Ghana ^(50; 57) and elsewhere in Africa ^(43; 65), inadequate income levels made it difficult for diabetes patients to purchase medicines and to buy appropriate foods such as fruits and vegetables. Expanding the current national health insurance to increase the quantities of drugs given to patients and to cover more effective drugs as well as the introduction of subsidies for glucose test strips and needles may help reduce the financial burden for persons living with diabetes which may subsequently result in improved adherence to self-care.

Another barrier within the perceived behavioural control construct was patients' inadequate access to a variety of foods. Patients discussed that they did not have regular access to a variety of foods that they are required to eat to meet their dietary recommendations. Similar to our findings two studies ^(61; 66) reported limited availability of a variety of food items in the local market as a barrier that hindered dietary self-care practices among diabetes patients from Ethiopia.

Both patients and HCPs alike discussed that busy work schedules hindered patients' adherence to their diet, medication taking and regular participation in exercise. These findings are similar to those of Abioye-Akanji et al ⁽⁴⁶⁾ in which West African immigrants reportedly found it difficult integrating their exercise recommendations to their daily work schedule and child care. Similarly, a study among African- Americans reported that participants found it difficult to integrate complex diabetes management regimen into their day-to-day activities ⁽⁶⁷⁾. People

with diabetes should be educated on suitable strategies, areas and times for performing selfcare behaviours during work hours. The benefits of regular adherence to self-care behaviours should be emphasized.

Consistent with reports of previous studies from Sub-Saharan Africa, barriers such as old age, body pains and having comorbid conditions hindered patients' adherence to exercise ^(43; 61). Walking is a common form of transport (relative to diabetes patients in HICs), but the presence of other conditions and old age may significantly decrease patients' ability to exercise. Participation in daily exercise regimens such as going to the gym may be unfeasible due to cost and other barriers. Patients should thus be given appropriate guidance and support to adopt exercise regimens that can easily be done in the home.

5.5.4 Limitations

The study may not represent the perspectives of those who do not seek biomedical care. The use of face-to-face semi structured interviews with an independent interviewer may result in limited social-desirability bias. The use of a convenience non-probability sample might have led to the selection of patients who were interested in improving diabetes self-care.

5.5.5 Implications for future research

This study is a contribution to the holistic perspective of self-care and serves as a foundation for future research. Our use of a theory-driven approach and literature search to derive the items in the discussion guide is worth noting as such an approach provides a conceptual framework to align the findings of the study. Future research could adopt similar approaches. Future research should also explore further the influence of polygamy on diabetes self-care and also how diabetes patients from large households adhere to diabetes self-care recommendations especially those relating to diet.

5.5.6 Relevance to clinical practice

Interventions should focus on assisting patients develop favourable attitudes towards self-care, and support their ability to perform priority self-care health behaviours. Such interventions will need to take careful account of the cultural context of patients' existing belief systems and therefore, may need to have a community-wide approach rather than solely focussing on the education of individual patients. Furthermore, HCPs should encourage and support diabetes patients through targeted counselling to motivate and empower them to overcome barriers they perceive to be beyond their control.

5.6 CONCLUSION

A wide range of barriers that hindered diabetes self-care were identified by both patients and HCPs. Barriers relating to attitudes and perceived behavioural control were more prominent than those relating to subjective norms. This is the first study to qualitatively explore diabetes self-care and its barriers in Ghana thereby increasing our understanding of diabetes self-care and its barriers within the context of a resource poor environment. The findings of this study highlight important areas that have not been previously reported which can inform the design of interventions in low and middle income countries to help improve adherence to diabetes self-care behaviours.

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RELATIONSHIP OF CHAPTER 6 TO CHAPTER 5

In Chapter 5, Ghanaian people with type 2 diabetes and their health care providers described a number of barriers which were perceived to hinder patient adherence to diabetes self-care behaviours. These barriers were categorised into the constructs of the Theory of Planned Behaviour (TPB): attitudinal, subjective norms and perceived behavioural control barriers. One of the barriers identified in Chapter 5 was inadequate self-care support from HCPs. In order for people with type 2 diabetes to effectively adhere to their self-care recommendations, they may require support from their HCPs. **Chapter 6** is a qualitative study among healthcare providers from Ghana involved in the provision of care to people with diabetes. It describes the views of health care providers about factors which promote the provision of self-care support as well as barriers experienced by HCPs in their quest to provide self-care support to people living with type 2 diabetes.

CHAPTER 6

ATTITUDES TOWARDS, FACILITATORS AND BARRIERS TO THE PROVISION OF DIABETES SELF-CARE SUPPORT: A QUALITATIVE STUDY AMONG HEALTHCARE PROVIDERS IN GHANA

This manuscript has been published in "Diabetes and Metabolic

Syndrome: Clinical Research and Reviews".

Mogre V, Johnson NA, Tzelepis F, Paul C. Attitudes towards, facilitators and barriers to the provision of diabetes self-care support: A qualitative study among healthcare providers in Ghana. Diabetes and Metabolic Syndrome: Clinical Research and Reviews 2019;13 (2019):1745-51

ABSTRACT

Statement of the problem: Self-care support provided by healthcare providers (HCPs) is critical to diabetes self-care. However, a number of barriers prevent HCPs from providing self-care support to people with diabetes as well as facilitators of the provision of self-care support. We explored attitudes towards, barriers and facilitators of the provision of diabetes self-care support among Ghanaian HCPs.

Methods: Fourteen semi-structured interviews were conducted among HCPs recruited from three diabetes clinics in Tamale, Ghana. All interviews were digitally recorded and transcribed verbatim. Transcripts were coded and analysed thematically.

Results: HCPs reported a sense of responsibility and urgency to provide self-care education to diabetes patients; while believing it was the patients' responsibility to self-care for their diabetes condition. Accordingly, HCPs perceived their role to be limited to information sharing rather than behaviour change interventions. Facilitators to the provision of self-care support included patients' motivation, and team work among healthcare professionals. Barriers that hindered self-care support included language barriers and poor inter-professional collaboration. Furthermore, HCPs discussed that they felt inadequately trained to provide self-care support. Healthcare-system-related barriers were inadequate office space, lack of professional development programmes, high patient numbers, inadequate staff numbers, inadequate health insurance and a lack of sufficient supplies and equipment in the hospital.

Conclusion: HCPs attitudes were generally favourable towards supporting self-care, albeit with a focus on information provision rather than behaviour change. Training in effective strategies for providing self-care support are needed, and better use of the resources that are available.

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6.1 INTRODUCTION

Diabetes is one of the most frequently occurring diseases worldwide, increasing from a prevalence of 366 million adults in 2011 to 425 million in 2017 $^{(1; 2)}$. The rapidly increasing prevalence of diabetes is pronounced in middle- and low-income countries $^{(3; 4)}$. It is a systemic disease that requires regular and quality medical care to prevent the development of complications such as heart attack, stroke, kidney failure, amputations, loss of vision and nerve damage $^{(5; 6)}$. To reduce the risk of developing these life-threatening complications, diabetes patients are required to follow self-care behaviours which include, but are not limited to, appropriate diet, sufficient exercise, taking medication, self-monitoring of blood glucose and foot care $^{(7; 8)}$.

Health experts and international diabetes organisations agree that individuals with diabetes should receive self-care support to assist them to effectively manage their condition ⁽⁹⁾. As defined by the Institute of Medicine, self-management/care support refers to 'the systematic provision of education and supportive interventions by health care staff to increase patients' skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting, and problem solving' ⁽¹⁰⁾. Self-care support goes beyond the mere provision of information by healthcare providers (HCPs) and includes building patients' confidence and assisting them to make choices that will result in improved self-care and health outcomes ⁽¹¹⁾. The Chronic Care Model ^(12; 13) and several diabetes treatment guidelines ^(14; 15; 16) strongly emphasise the role of self-care support and consider it a key dimension of quality care for individuals with chronic diseases including diabetes.

Supporting patients to self-care has been shown to decrease hospitalisations, emergency department visits and costs of care ^(9; 11; 17). However, patient adherence to self-care is often poor ⁽¹⁸⁾. For instance, a recent study from Tamale, Ghana found diabetes patients reporting

poor adherence to four recommended self-care behaviours i.e. diet, exercise, self-monitoring of blood glucose (SMBG), and foot care ⁽¹⁹⁾.

The HCP plays a critical role in supporting diabetes patients to self-care ^(20; 21). However, studies of HCPs, primarily in high-income countries, indicate that HCPs often report they lack the knowledge and skills to properly support patients with the challenges of self-care ^(22; 23). Other barriers to supporting self-care which have been reported by HCPs in high-income countries include lack of motivation ⁽²³⁾, lack of an enabling healthcare team to support self-care ⁽²²⁾, provider non-compliance to treatment guidelines ⁽²⁴⁾, lack of confidence in clinical skills ⁽²⁵⁾, lack of effective communication tools, lack of reimbursement for preventive care ^(20; 23; 24), organizational constraints such as the absence of organizational systems to support diabetes management (i.e. registries, automatic recall systems and reminder systems); and the lack of an individualized plan of care ⁽²⁶⁾. Facilitators of self-care support have also been reported including effective provider-patient communication ⁽²⁷⁾, continuing professional education in diabetes for HCPs ⁽²⁵⁾, patients' responsibility for their self-care activities ⁽²⁸⁾, patients' awareness about diabetes and its complications ⁽²⁹⁾, working in multidisciplinary teams ⁽²⁸⁾ and adherence to treatment guidelines ⁽³⁰⁾.

It is plausible that the attitude HCPs bear towards their role of providing self-care support can either promote effective self-care support or forestall it. While a number of studies have investigated HCPs' attitudes towards diabetes care in general ^(29; 31; 32) those specifically reporting HCPs' attitudes towards self-care support are limited ⁽³³⁾. Although studies from high income countries have identified a number of facilitators and barriers to HCPs supporting diabetes care ^(34; 35; 36), the barriers experienced by HCPs and facilitators that promote self-care support in resource-challenged healthcare systems like those in Sub-Saharan Africa are largely unstudied. Given the growing prevalence of diabetes in Sub-Saharan Africa, such data are needed to guide health service planning in order to maximise the effectiveness of the very

limited resources. Qualitative data are likely to be valuable for providing an in-depth understanding of the experiences and perspectives of HCPs in Sub-Saharan Africa. The study aimed to explore attitudes towards and facilitators and barriers to the provision of diabetes selfcare support among Ghanaian HCPs.

6.2 METHODS

6.2.1 Design, setting and participants

A qualitative study was conducted in the diabetes clinics of the Tamale Teaching Hospital, West Hospital and Central Hospital located in Tamale, Ghana. Tamale is approximately 500km North of Accra, Ghana's capital. HCPs were eligible to participate if they provided diabetes care in these hospitals (e.g. nurses, nutritionists/dietitians) and had worked in the diabetes clinic for at least 3 months.

6.2.2 Recruitment

All staff of the diabetes clinics were invited to participate in the study. VM visited the hospitals on days scheduled for the diabetes clinics. Potential participants were approached prior to the start of the clinic and the purpose of the study explained to them. Those that agreed to participate were given an information sheet detailing the consent process and introduction to the interview. They were subsequently asked to sign a consent form if they agreed to participate in the study. Our purposeful approach in selecting participants was informed by our aim to choose participants who will provide rich information that will represent broad views concerning the provision of self-care support to diabetes patients ⁽³⁷⁾. The study was approved by the University of Newcastle Human Research Ethics Committee and the Tamale Teaching Hospital Ethics committee.

6.2.3 Data collection

Semi-structured interviews were conducted using a discussion guide informed by open-ended questions to explore general diabetes care, attitudes towards self-care support, facilitators and opportunities to improve self-care support and barriers to the provision of self-care support. The questions of the interview guide were derived from the literature ^(30; 32) and were evaluated by all members of the research team who have varying levels of experience in qualitative research, chronic disease care and nutrition. The discussion guide was pilot tested on a group of four participants to ensure clarity, comprehension and understanding of the questions. The data generated from the pilot sessions were not included into the main data analysis. To ensure uniformity, VM conducted all interviews, which were individual and face-to-face, in a private room at the diabetes clinics. Interviews were digitally recorded. Participants were allowed to give detail and in-depth information about their opinions and experiences regarding self-care support and its provision enabling them express their own understanding and point of view rather than assuming generalizations. Wherever necessary, VM probed, clarified or sought for elaboration of participants' responses. Participants were also granted the opportunity to express unsolicited opinions and experiences.

6.2.4 Data analysis

All interviews were transcribed verbatim. VM checked for transcription errors by comparing transcripts with the digital audiotapes. Coding of transcripts was done by VM following the constant comparative method of qualitative data analysis developed by Strauss ⁽³⁸⁾. Following an inductive, bottom up approach this method has been widely used for analysing qualitative data ⁽³⁹⁾. Transcripts of the individual interviews were read and re-read and assigned a series of codes. Another member of the research team coded a sample (i.e. 25%) of interview transcripts independently. These were then compared and any differences resolved through

discussion between the coders, and with other members of the research team if required. The codes were grouped into similar themes/concepts. Data collection and analysis were conducted simultaneously until thematic saturation was realised. Results are presented as themes/concepts and augmented with illustrative quotes. Nvivo software was used for processing, ordering and comparison of codes.

6.3 RESULTS

6.3.1 Participants

Seventeen HCPs were approached to participate and 14 (82%) agreed to be interviewed. This number was realised upon reaching a point of saturation whereby collection of further data and analysis did not yield new evidence. Nine of the participants were male (n=9). Most were nurses (n=8) and two each were physician assistants/prescribers, nutrition officers and dieticians. The only doctor who worked at one of the diabetes clinics was on leave at the time of data collection. The mean (SD) number of years working in the diabetes clinic was 3.2 (1.9) years.

6.3.2 Self-care behaviours HCPs usually recommend

Diet, exercise, SMBG and medications were the self-care behaviours that were consistently identified by HCPs.

We try to educate them on how they can monitor their blood glucose by themselves. We also try to educate them on what to eat and at what time. We educate them to how to take the diabetes medication and if they have any problem anytime to call on us. - Participant 12, Prescriber.

HCPs rarely mentioned foot care as one of the self-care behaviours/activities they recommend to diabetes patients. When foot care was mentioned, the issues addressed generally related to how patients could prevent getting wounds and cuts.

They should not be walking barefooted because if there's any nail or a needle they may get them pricked and the wound will be difficult to heal.... they should avoid all those home accidents so they don't get any wound that will become a challenge to take care

of. – Participant 5, Dietician

6.3.3 Attitudes towards self-care support and self-care

HCPs expressed the following attitudes towards the provision of self-care support.

Sense of responsibility: All the HCPs considered it their responsibility to support diabetes patients to follow their recommended self-care behaviours. They recognised that self-care was very important in helping the patient maintain normal blood glucose levels in order to prevent complications. Furthermore, they recognised that they had a responsibility to facilitate or support diabetes patients to self-care for their condition i.e 'help them to help themselves'.

I have a very important role in treating patients and helping them to be able to help themselves at home to care for themselves in order to avoid any complications. –

Participant 9, Principal Physician Assistant.

...it's our responsibility to ...let them understand what they need to do to have them improve upon their conditions. – Participant 5, Dietician.

Information-centric role: HCPs perceived self-care as the responsibility of the patient and that the provider's responsibility is to deliver the self-care message to the patient. They described their roles as providing information and encouragement (as opposed to behaviour change management) to the diabetes patients.

The things they are supposed to do on their own, ours is to find out whether they know and if they don't know, ours is to tell them and encourage them how they themselves are supposed to take the role to be doing it. So ours is just to encourage them and throw more emphasis on the fact that if you do this, this is what you will get. ... I will tell that if you try to take breakfast between 6:00 to 8:30, these are the benefits you'll get. And upon telling you all this, I don't follow you to your home so it's up to you then ... –

Participant 5, Dietician.

For us, what we see as our responsibility is to get them informed. ... They spend very little time in the clinic as compared to their general life, so most of the things we encourage them to do by themselves, and that is even the objective of health care... So if the person can do those things, what you just need to do is give the patient guidelines as to how to do them. – **Participant 1, Nurse**

6.3.4 Facilitators to the provision of self-care support

Patients' motivation and enthusiasm: HCPs were motivated by some patients' enthusiasm and eagerness to know about their condition and to receive counselling as to what to do to remain healthy. Furthermore, participants noted that over time they build relationships and a sense of belonging to the patients and vice versa.

The enthusiasm with which our patients come. Like, we see ourselves as a family. If you don't see a patient for a while we'll ask – even remind a patient, they know themselves, and say well, we haven't seen this person and we'll try to trace to find out what is it. –

Participant 1, Nurse.

Team work: HCPs felt their ability to provide quality self-care support was influenced by team work and cooperation among their colleagues.

We do meetings from time to time, especially to discuss about how best to manage our clients.-Participant 3, Nurse.

... It is very common to come across a condition and when we are facing something, we all come together to bring our heads together and come to a consensus on how to manage the case. – Participant 5, Dietician.

6.3.5 Barriers to the provision of self-care support

6.3.5.1 Patient-related barriers

Language barrier: As shown in the quotes below, self-care support was hindered by the lack of a common language and translation difficulties.

That is my main problem because I don't understand Dagbani and they don't also understand English ..., so I try to call somebody to explain. – Participant 2, Enrolled Nurse.

Also the language; it is a problem because sometimes some of the terms it's quite difficult to put it in the layman local language. ...sometimes you have to make away with some of the technical terms and use really basic terms so that the fellow will understand. – Participant 14, Nurse.

6.3.5.2 Provider-related barriers

Poor inter-professional collaboration: Team work and cooperation was more likely to occur among healthcare professionals of the same type, such as among nurses, than among healthcare professionals of different types. Some HCPs were particularly concerned about the poor interprofessional collaboration between nurses and dieticians/nutritionists. Furthermore, competition and lack of sharing ideas did not also foster inter-professional collaboration.

...But if we could also talk about how each personnel involved in the clinic could work as a team. I don't know. ...But this staff feels he is more important than the next one. If you are not there, I will do my work and do it well. Our system is such that sharing is difficult. People find it difficult to share what they know.. – Participant 6, Nutrition Officer.

People can be difficult, when it comes to those colleagues who are naturally rude, such people you don't even go to them. However, you can go to those who are willing to share knowledge with you on the problem. –Participant 13, Nurse, Male.

They can't just understand the dietary management of the disease. Yes. Because of that, it's like if you are the one who identifies a case, it brings some controversies. They feel that they're the only people who should. And they feel that we are only assisting them. So when we identify cases and refer to them, they sometimes feel bad [They perceive that we are only assisting them but are not part and parcel of diabetes care].-

Participant 10, Nutrition Officer.

Healthcare professionals feeling inadequately trained: Some HCPs were not confident of their skills and felt inadequately trained. These HCPs felt that they needed more training on diabetes care and self-care support but this was not forth coming due to the unavailability of continuous professional development programmes.

... no one has gone in to do any special training on diabetes. Yes. It is just on the job training. – Participant 3, Nurse.

So I feel I need more training regarding the clinical aspect of diabetes. –Participant

6, Nutrition Officer, Male

6.3.5.3 Barriers related to organisation of healthcare and the environment

High patient numbers: HCPs reported that their ability to provide self-care support was often hindered by high patient numbers. This usually resulted in HCPs spending less time with a patient than they felt was necessary.

The first barrier is time, because of the numbers. At times you wish that every clinic you will be able to spend at least 15 minutes with your patient so that they will also talk

to you about their experiences. The equipment we are also using are too small in number. So usually when they are many like that you don't feel comfortable. You see them in that small space and they will be waiting for their turn. At times when you look at the numbers too, you can't ask any questions about the current problems that are affecting them. Even what they present to you as a problem is what you discuss with them. So I think time is a barrier.- Participant 12, Prescriber.

Ok, when there are too many cases for example, you may not have time to ask further questions or educate the client further because of the number of patients. – **Participant 14, Nurse.**

HCPs also noted the high patient numbers affected the scheduling of follow-up appointments: *That's why we give our patients two month periods of review. So usually if we are going to give them one month you come and the whole place is flooded. But we give each patient two months.* –**Participant 1, Nurse.**

Inadequate office space: HCPs discussed that they lacked a permanent adequate space to conduct the diabetes clinic. This situation resulted in the diabetes clinic being carried out for a limited number of days during the week as they are required to use the consulting rooms interchangeably with other units of the hospital.

At the moment, we don't have a place of our own. ... they will tell you that they need their consulting room to do some other things when you also need it to care for your clients... Participant 3, Nurse.

In one of the diabetes clinics those providing counselling shared the same office space with those who were taking the vital signs of the patients. For instance, the prescriber/physician assistant shared office space with the nutritionists such that two diabetes patients were usually inside the consulting room at every point in time.

Then also, it's still with work conditions. The setting, the atmosphere. We are sitting together with a prescriber and there's a nurse, and then another patients come in, they seem to join. So sometimes, it's difficult to get a person to talk about personal issues. –

Participant 6, Nutrition officer.

Health insurance does not cover some medications: HCPs indicated that most of the diabetes medications were covered by Ghana's National Health Insurance Scheme. However HCPs were concerned that not all the medications (generally more efficacious drugs) were covered by the scheme leading to patients purchasing some medications from their pockets which may be challenging for patients who have inadequate levels of income.

So mostly they are dependent on the health insurance covered medication so when you are prescribing anything outside that you can be sure that they may not buy it. –

Participant 1, Nurse.

HCPs were also concerned that the insurance scheme does not provide an adequate quantity of drugs to be used by the patients until their next scheduled visit. HCPs thought this was due to the rationing of drugs by the insurance scheme.

With this health insurance system, you know they do rationing. ... They give the client two vials and that is it, whether it will take the client for a month or not. So most of the time, you find them coming to weep that they're not able to afford the rest of the medication.– Participant 3, Nurse.

Health insurance does not cover nutrition and dietetic care: The nutrition and dietetic care which is required by all diabetes patients was not covered by the health insurance scheme. Given that most patients have low incomes this limits their access to this kind of care.

Finance is also another barrier. The services we are rendering is cash and carry. It's not covered by health insurance. ...Some can and others cannot afford so that's another barrier. –Participant 5, Dietician.

Inadequate staff: The diabetes clinic did not have all the required kinds of healthcare professionals needed for diabetes care such as diabetologists, endocrinologists, podiatrists, public health nurses, dieticians and nutritionists. Some diabetes clinics had some of these types of healthcare professionals but they were inadequate in number or were not directly associated with the diabetes clinic. There were also insufficient dieticians and only one hospital had a diet therapy unit. The rest had nutritionists who were undertaking the roles of dieticians.

Ideally, we are supposed to have public health nurse and a dietician attached to the diabetes clinic. As at now we have none. –Participant 3, Nurse.

... Currently we are just three dieticians in the three regions.... Every patient that is on admission is supposed to get some nutritional advice. But because we are limited we rather concentrate on cases that are referred to us..... Because of the numbers, we try to overlook some of those things and handle only the serious ones. –Participant 5, Dietician.

Inadequate teaching and learning aids: HCPs discussed that their self-care support was hindered by limited availability of teaching and learning aids such as pictures, demonstration cards, and banners.

I really would have preferred if there are pictures or videos or things of that sort that I could use. And we would have also preferred pictures of diets especially localized. It should ... be... something that is Ghanaian that patients can use. Then I would have also preferred pictures of the complications of diabetes or maybe pictures of how the steps should also be done. – Participant 14, Nurse.

High turnover of staff: Some HCPs were replaced frequently at some of the diabetes clinics and may not always have been trained before they commenced work at the clinic. At some places there were no permanent HCPs for the diabetes clinic and any nurse could be called to work in the diabetes clinic at any time.

Like I said, we don't have a particular nurse.....So in the absence of this person, the next person will do -... So you can be there consulting sometimes, and then a patient will ask for something and you won't even know. –Participant 4, Enrolled Nurse.

Inadequate continuous professional training programmes or workshops: Most HCPs were concerned that they did not get the opportunity to attend continuous professional programmes such as in-service training workshops, and educational tours.

You know, every day they revise the modes of drugs that were used previously and are outdated. ...They are supposed to provide workshops so that you will attend and upgrade your knowledge and skills set. To be up to the task. But lack of workshops for the staff to constantly upgrade is always a problem. – Participant 11, Nurse.

Furthermore, HCPs attempts to self-educate were affected by inadequate access to both hard copy and electronic resources.

We don't have internet access in the wards and we don't also have a library to go and read about diabetes. – **Participant 13, Nurse.**

We do a lot of reading, going to the internet, you do that on your own. You're not given credit to go onto the net.-Participant 3, Nurse.

Lack of medications and other diabetes-related supplies and equipment: HCPs discussed that their ability to ensure patients adhered to their self-care behaviours was sometimes hampered by the hospital's pharmacy running out of medications and other important supplies resulting in patients buying medicines out of their pockets from private pharmacies.

Also, from time to time, we run out of medication and clients will have to buy on their own. **Participants 1, Nurse**

A lot of the times also, we run out of strips to monitor their glucose. Sometimes our machines are down.-Participant 3, Nurse.

At times we also run short of drugs and we have to pick pharmacy shops that patronize health insurance. When they go to pick the drugs from those pharmacy shops, you don't even know the quality of those drugs.–**Participant 12, Prescriber.**

6.4 DISCUSSION

We found that HCPs usually recommended the self-care behaviours of diet, exercise, SMBG and medications but that foot care was rarely mentioned. Both primary studies and systematic reviews have previously reported that foot care is sparingly investigated in the literature ⁽⁴⁰⁾. HCPs felt that it was their responsibility to provide self-care support to diabetes patients but adopted information-centric approaches instead of building patient-provider teams and patients' confidence for behaviour change. This is similar to the findings of Fransen et al ⁽³³⁾ in a qualitative study of HCPs and patients with low health literacy from the Netherlands in which HCPs adopted information-centric approaches. Such an approach is not consistent with the Institute of Medicine (IOM) definition, which makes it clear that the role of the HCP in self-care support goes beyond sharing information but includes building the confidence and ability of patients to make important choices about their self-care ^(11; 41; 42).

HCPs identified that self-care was the responsibility of the diabetes patient and expressed a desire for patients to take greater responsibility for their diabetes care. This perception demonstrated by the HCPs is consistent with the literature regarding patient empowerment that encourages patients to be responsible for their diabetes care with some level of support from their HCPs ^(32; 43). Funnel and Anderson suggests the need to change the typical orientation of the patient from "the doctor is responsible for my health" to "I am responsible for my own health" ⁽⁴⁴⁾. However, patient empowerment can be misconstrued by healthcare HCPs and instead of building patient-provider teams ⁽³³⁾, HCPs offload their responsibility to that of the patients, especially if they are overstretched ⁽¹¹⁾.

HCPs identified patients' motivation and enthusiasm to care for their diabetes as one of the things that facilitated their provision of self-care support to diabetes patients. This is encouraging as patient motivation is significant in the diabetes care process ⁽⁴⁵⁾. Given that self-care is a process and a lifelong one, its effectiveness is largely dependent on the patients' initiation and maintenance of self-care activities in the context of daily life events ⁽⁴⁶⁾ in which motivation is a strong denominator.

Frequently cited in qualitative research as a facilitator of improved diabetes care including selfcare support ^(47; 48), HCPs discussed that the existence of team work, motivated and facilitated their self-care support of diabetes patients. However, team work was common among HCPs of the same profession (e.g. nurses) but an apparent poor inter-professional collaboration existed among the various types of healthcare professionals required to provide diabetes care (especially between nurses and nutritionists/dieticians). The situation of poor inter-professional collaboration was probably borne out of poor communication and sharing of ideas and information among the various healthcare professionals. Some types of healthcare professionals felt they were more competent than other types or perceived that they had a more important role to play in diabetes care which did not foster inter-professional collaboration. In consonance with our findings, two previous studies, one from Belgium and the other from the Netherlands reported competition among specialists, dieticians, physical therapists, family physicians and primary care nurses as barriers to evidenced-based diabetes care ^(27; 30).

An important patient-related barrier that was discussed by HCPs was language barrier. The basis of self-care support is effective communication between the patient and the HCP, and a language barrier hinders this process as well as health literacy regarding diabetes and may also affect patients' trust in HCPs to manage their diabetes ⁽⁴⁹⁾.

Effective diabetes care including self-care support hinges on the availability of trained healthcare professionals, however the diabetes clinics had insufficient HCPs. The majority of

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these healthcare professionals felt inadequately trained in diabetes care which may be due to the little attention given to diabetes and its treatment in the curriculum of healthcare professionals from this setting ⁽⁵⁰⁾. We also found that there was a lack of key healthcare professionals such as endocrinologists, diabetologists, emergency specialists, and pharmacists, which are required for effective diabetes care including self-care support. It is concerning that except in one hospital, all the diabetes clinics had no doctors to provide patients with medical consultations. There was also a general lack or inadequacy of continuous professional development programmes for HCPs to enrol and equip their competencies regarding diabetes care. Opportunities to learn more about diabetes through the internet were also limited as internet connectivity was non-existent in almost all of the hospitals. These barriers place HCPs in a precarious position in which they may be willing to support patients to self-care for their diabetes but do not have the knowledge, skills, resources and opportunities within the healthcare system to do so. This situation also makes it difficult for the HCPs to create full time specialised teams solely devoted to diabetes care.

Self-care support was also hindered by inadequate office space. Although HCPs said they had a conducive environment to run the clinics, they felt it was inadequate. The inadequacy of the office space meant that the diabetes clinics could not be run daily, and they provided two or more services in one consulting room (e.g. taking vital signs of patients and providing counselling to patients). Scheduling of the diabetes clinic did not allow for patient flexibility regarding their appointments. This may affect patients' motivation to visit the clinic regularly to receive self-care support. The provision of two services in one consulting room may create privacy and confidentially issues for the patients which may make it difficult for patients to fully express themselves and share information that they may not want other patients to know about. Services such as nutrition and dietetic care were not insured and patients had to pay from their pockets to receive such care. This negatively affected the receipt of self-care support regarding diet especially for patients who did not have enough income to pay for such care. We also found HCPs reported that their self-care support was frequently hindered by the inadequacy of consumables such as glucose strips and medicines in the hospital as well as the lack of regular access to basic diagnostic tools to test for important clinical variables such as HbA1c. This hampered the provision of evidenced-based diabetes care. All of these inadequacies create avoidable inconveniences for both patients and HCPs and may make patients feel less inclined to make regular appointments. The orientation of the healthcare system in Ghana and in several Sub-Saharan Africa countries in which more emphasis is placed on acute conditions than chronic conditions may be an important contributor to the myriad of barriers hampering the provision of effective self-care support to diabetes patients.

6.4.1 Limitations, strengths and implications

Recruiting participants from only three diabetes clinics might not represent the views of all HCPs from Ghana thereby affecting the generalisability of our findings. Also, the exclusion of doctors due to their unavailability during the time of data collection might have limited the scope experiences and perspectives explored. The majority of the participants in this study being nurses depicts the situation of inadequate set of HCPs for diabetes care in most developing countries like Ghana ^(51; 52; 53; 54; 55). Nurses are the majority of HCPs of the healthcare system and it is not surprising that majority of the HCPs responsible for diabetes care are nurses. A typical country in Sub-Saharan Africa has 2 physicians, and 11 nurses and midwives per 10, 000 population compared to 32 physicians, and 72 nurses and midwives in the European region ⁽⁵⁶⁾.

An important strength of the study is our use of semi-structured interviews which granted us the chance to collect in-depth information and to understand varied perspectives and experiences of providing self-care support to patients. It is also one of the first studies from Sub-Saharan Africa to explore HCPs attitudes, perspectives and experiences of providing selfcare support to diabetes patients thereby increasing our understanding of diabetes self-care support in the sub-region and also serves as a basis for future research in this area.

The current study brings to bear important areas that can be utilised by researchers, policy makers, hospital administrators, and practitioners to design interventions to improve diabetes care particularly in low- and middle-income countries. To allow for transferability of the findings of the current study, future research should explore further the barriers identified in this study that hampered the provision of self-care support. Future quantitative studies should also be conducted to determine the magnitude of these barriers and how those barriers affect patients' adherence to their self-care recommendations.

6.5 CONCLUSION

There is the need to create enabling conditions and opportunities for health care professionals to continuously develop and update their competencies in diabetes care. More resources should be committed to diabetes care and the healthcare system should place more emphasis on chronic disease management such as diabetes self-care support. HCPs should also endeavour to work in multidisciplinary teams to promote effective self-care support to diabetes patients.

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RELATIONSHIP OF CHAPTER 7 TO PREVIOUS CHAPTERS

Having investigated adherence to diabetes self-care (**Chapters 2 and 4**) as well as developing an understanding of the range and type of barriers that hinder adherence to diabetes self-care in people with type 2 diabetes (**Chapters 5 and 6**), it is important to quantify the prevalence of each of these barriers and their relative importance to adherence in Ghanaian people with type 2 diabetes. **Chapter 7** describes a study of the prevalence of barriers to self-care and their association with self-reported adherence to self-care behaviours in people with type 2 diabetes.

BARRIERS TO SELF-CARE AND THEIR ASSOCIATION WITH POOR ADHERENCE TO SELF-CARE BEHAVIOURS IN PEOPLE WITH TYPE 2 DIABETES IN GHANA: A CROSS SECTIONAL STUDY

This manuscript has been published in "Obesity Medicine".

Mogre V, Johnson NA, Tzelepis F, Hall A, Paul C. Barriers to self-care and their association with poor adherence to self-care behaviours in people with type 2 diabetes in Ghana: a cross sectional study. Obesity Medicine 2020. 100222

ABSTRACT

Aim: We evaluated the prevalence of barriers to self-care and associations between these barriers and adherence to self-care behaviours among people with type 2 diabetes.

Methods: Cross-sectional study among persons with type 2 diabetes recruited from the diabetes clinics of three hospitals. A survey assessed barriers to self-care conceptualised into the constructs of the theory of planned behaviour (i.e. attitudes, subjective norms, perceived behavioural control). The Summary of Diabetes Self-care Activities scale was used to assess adherence to self-care.

Results: The study included 252 (90% response rate) participants. Prevalent barriers included: lack of knowledge on how to use a glucometer (59.8%, n=150); difficulty in changing dietary habits (58.7%, n=148); and lack of money to purchase a glucometer (55.2%, n=139). Attitudinal barriers were commonly reported for diet, exercise and foot care; perceived behavioural control barriers were frequently reported for self-monitoring of blood glucose (SMBG); and subjective norm barriers for medication taking. The only significant association was between adherence to foot care and subjective norms barriers.

Conclusions: The commonly-reported types of barriers varied according to the type of selfcare behaviour but specific type of barrier was associated with poor adherence to diabetes self-care behaviours.

7.1 INTRODUCTION

Diabetes mellitus affects more than 382 million adults globally and has been estimated to increase to 592 million in the next 25 years with low-and middle-income countries experiencing over 80% of this epidemic ⁽¹⁾. Being a chronic metabolic disease, diabetes mellitus is associated with increased risk of developing microvascular and macrovascular complications, decreased quality of life, increased healthcare costs and premature death ^(2; 3; 4). Type 2 diabetes, the most common form of diabetes, is a complex condition that requires a high degree of self-management in order to improve outcomes and reduce hospitalisations ⁽⁵⁾. Recommended self-care behaviours for people with diabetes include diet, exercise, medication taking, self-monitoring of blood glucose (SMBG) and foot care.

However, adherence to the recommended self-care behaviours is often poor ^(6; 7), which is thought to be largely due to barriers such as low income, poor patient-provider communication, lack of family support, and inadequate understanding or knowledge of the disease ^(8; 9). According to the Theory of Planned Behaviour (TPB), intention to perform a self-care behaviour is determined by three components: the individual's attitudes (one's evaluation of the potential or expected outcome of performing a self-care behaviour); subjective norms (one's perception of social pressure to perform or not perform a self-care behaviour); and perceived behavioural control (PBC), one's perception of the ease or difficulty in performing a self-care behaviour) ^(10; 11). Latent to attitudes, social norms and PBC are beliefs that are useful targets for interventions to help change behaviour ⁽¹²⁾. These include behavioural beliefs, normative beliefs and control beliefs.

Attitudinal barriers reported in the diabetes literature include misperceptions regarding the potential seriousness of the condition ⁽¹³⁾ and difficulty changing lifestyle habits ^(14; 15). Diabetes self-care barriers relating to subjective norms may include cultural, traditional and religious beliefs ^(16; 17); inadequate family and social support ^(17; 18)). Perceived behavioural control

barriers to diabetes self-care include poor health literacy regarding diabetes ^(13; 17), the presence of other health conditions ^(19; 20), poor socio-economic status, healthcare providers' (HCPs) perceptions ^(21; 22; 23), HCP cultural biases ⁽²⁴⁾, poor patient-provider communication ^(24; 25; 26) and service-related issues such as availability, accessibility and acceptability ^(24; 27; 28). Despite the availability of substantial data on self-care for diabetes and barriers to self-care (24; ^{25; 26; 29)}, largely from western populations, there is a dearth of data regarding the prevalence of self-care barriers among diabetes patients in Sub-Saharan Africa. This is an important gap in the literature given the rising prevalence of type 2 diabetes among populations in Sub-Saharan Africa ^(1; 30). A qualitative study that explored barriers to self-care among people with type 2 diabetes in Ghana reported a number of barriers relating to attitudes, subjective norms and perceived behavioural control such as misconceptions that diabetes was caused by spiritual forces or curses; difficulty changing dietary habits; the use of herbal medicines; lack of motivation to exercise; social stigma, cultural beliefs; lack of glucometers; and inadequate access to a variety of foods ⁽³¹⁾. The qualitative study did not address the prevalence of such barriers. The current study fills this gap. In addition, Nam et al (17) in a recent systematic review reported provider and patient barriers to diabetes care but noted there was a limited understanding of the association between barriers and adherence to self-care behaviours. These data are likely to be valuable for prioritizing future interventions in sub-Saharan Africa where health service resources and cultural factors may differ from those in high-income countries.

7.1.1 Aims

 To determine the prevalence of patient-reported barriers to diabetes self-care (diet, exercise, medication taking, SMBG and foot care) according to attitudes, subjective norms and perceived behavioural control among Ghanaian adults with type 2 diabetes. To determine the associations between adherence to self-care and barriers (i.e. attitudes, subjective norms and perceived behavioural control barriers) while controlling for possible confounders among Ghanaian adults with type 2 diabetes.

7.2 METHODS

7.2.1 Setting and study participants

A cross-sectional study informed by the Theory of Planned Behaviour ⁽¹⁰⁾. This study was conducted among persons with type 2 diabetes recruited from the outpatient diabetes clinics of the Tamale Teaching Hospital, Tamale West Hospital and Tamale Central Hospital from October to December 2018. Tamale is the capital city of the Northern Region of Ghana. It has an urban population with people from all parts of Ghana living and working in the city. Individuals were eligible to participate if they: had a confirmed diagnosis of type 2 diabetes or self-reported healthcare professional diagnosis of type 2 diabetes; were 18 years or older; and had visited the diabetes clinic to consult their provider in the last 6 months. The exclusion criteria were: having type 1 diabetes; being younger than 18 years and/or being diagnosed with diabetes before the age of 30 years.

7.2.2 Recruitment and data collection procedures

During the study period, trained research assistants recruited participants from outpatient diabetes clinics. All participants waiting for their medical consultation were approached, the study introduced to them and their consent to participate was sought. The paper-based survey was self-administered by participants who were able to read and write in English. For those who could neither read nor write in English, trained research assistants assisted them to complete the survey by verbally translating the questions into their respective local dialects. The survey took approximately 20 minutes to complete. Ethical approval for the study was

obtained from a Human Research Ethics Committee of the University of Newcastle, Australia. Permission from the participating hospitals was also obtained.

7.2.3 Measures

Adherence to self-care behaviours: This was assessed using the Summary of Diabetes Self-Care Activities (SDSCA) questionnaire ^(32; 33). The SDSCA is a brief, 14 item, self-report measure of the frequency of adhering to five key diabetes self-care behaviours (diet, exercise, blood glucose testing, medication taking, foot care) ⁽³²⁾. Participants are asked to indicate the number of days out of the last seven days they performed a self-care behaviour. The total scores for each of the self-care behaviours are computed by summing responses for each of the items and weighting them by the number of items to obtain scores ranging from 0 to 7. The SDSCA has been widely used to measure diabetes self-care behaviours among people living with type 2 diabetes mellitus ^(34; 35; 36), and has adequate internal consistency, test-retest reliability, construct validity and sensitivity to change ⁽³²⁾. A previous psychometric evaluation of the SDSCA on Ghanaian type 2 diabetes patients showed the SDSCA had acceptable content validity, was multidimensional consisting of four subscales, including: diet, exercise SMBG and foot care. Cronbach alpha values for the four subscales ranged from 0.61 for diet to 0.84 for foot care ⁽³⁷⁾.

Barriers to self-care: Items regarding barriers to self-care were informed by the findings of a previous qualitative study among Ghanaian type 2 diabetes patients ⁽³¹⁾ and were grouped according to the TPB domains ^(10; 11) and by each self-care behaviour. A multidisciplinary team of experts including behavioural scientists, nutritionists and researchers collaborated to develop and refine the final list of 33 barriers. For each barrier, participants were asked to indicate the extent to which that barrier affected their ability to self-care using a 5-point Likert scale (1-totally disagree to 5-totally agree). For example, participants were asked the extent to

which they agreed with the statement: "I see no harm in replacing my diabetes medications with herbal medicines. In reporting the frequencies, strongly agree and agree were combined to yield agree and strongly disagree and disagree combined to yield disagree. Participants' responses to the items for each of the constructs of the TPB classified by individual self-care behaviours were summed and weighted by the number of items to yield a barriers score ranging between 1.0 and 5.0 for each of the self-care behaviours within each of the constructs of the TPB (e.g. attitudes for diet, subjective norms for diet and perceived behavioural control for diet).

7.2.4 Potential confounders

Socio-demographic characteristics: These included age, sex, marital status, occupation (self-employed, retired, public/private employed, unemployed), duration of diabetes, and educational status. Smoking status was self-reported using the responses: current smoker, former smoker and non-smoker.

Competence in diabetes self-care abilities: This was assessed using the Perceived Competence for Diabetes Scale (PCDS) ⁽³⁸⁾. The PCDS is a 4-item validated scale that assesses the degree to which patients feel they can manage daily aspects of their diabetes care ⁽³⁸⁾. Patients were asked to indicate their level of agreement to each item using a 7-point Likert scale ranging from 1 (strongly disagree) to 7 (strongly agree).

Receipt of recommendation to adhere to self-care behaviours: Patients were asked: "Has your health care provider or nurse ever told you to regularly [insert self-care behaviour] to manage your diabetes? Yes/No. Participants were also asked to indicate whether they had ever attended a diabetes education class.

7.2.5 Statistical analysis

All data were analysed using SPSS version 23 and Stata 15.0. Means, standard deviations, frequencies and proportions were used to describe the data. Separate analyses assessing the

association between adherence to self-care behaviours and the TPB self-care behaviour specific barriers were carried out. The data was initially assessed for its suitability for linear regression analysis checking for homoscedasticity, normality of residuals and multicollinearity. However, as most models did not meet the assumptions for linear regression analysis, quantile regression (QR) at the 50th percentile was used for the self-care outcomes: diet, exercise and foot care, as QR is robust to outliers and appropriate for analysing and interpreting data that has a nonnormal distribution ^(39; 40). The association between TPB barriers and the self-care outcomes of medication taking and SMBG were not assessed due to little variation in these outcomes with most participants having the same value. The coefficients derived from QR are interpreted similarly to those of traditional ordinary least squares linear regression (i.e. the coefficient shows that a change in the dependent variable represents a unit change in the predictor variable), except that QR coefficients denotes the change in the value at the modelled percentile, instead of the mean of a continuous dependent variable ⁽⁴¹⁾. All three models were adjusted for the following variables that have been previously shown to be associated with adherence to self-care behaviours: age ^(42; 43), gender ^(7; 44), level of education ^(45; 46), marital status, income levels ^(45; 47), duration of diabetes ^(43; 48), competence in self-care abilities ^(14; 49), receipt of diabetes education and receipt of healthcare provider support to adhere to a recommended self-care behaviour ^(15; 44; 48). The quantile regression models were bootstrapped (due to non-constant variance) at 500 replications and 95% confidence interval. In all statistical analysis, barriers identified at a p-value of <0.05 were considered significantly associated with self-care behaviours.

7.3 RESULTS

7.3.1 Socio-demographic characteristics

Of 280 people approached, 253 (90% response rate) agreed to participate. One questionnaire was incomplete and was discarded yielding 252 participants. Table 1 presents the sociodemographic characteristics of participants. The participants had a mean age of 56.0 (13.3) years and having been living with type 2 diabetes for an average of 6.1(5.5) years. The mean numbers of days per week on which participants reported adherence to each self-care behaviour were: diet (3.6, SD=1.5), exercise (4.22, SD = 2.7), SMBG (0.6, SD=1.3), medication taking (3.7, SD = 1.5) foot care (2.8, SD = 3.1).

Tał	ole	1:	Socio-d	lemographic	characteristics	of t	he participants	(n=252)
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Variable	Frequency	%
Gender (n=252)		
Female	200	79.4
Mean (SD) age	56.0(13.3)	
Duration of diabetes (n=252)		
5 years or less	154	61.1
more than 5 years	98	38.9
Mean (SD) duration of diabetes (years)	6.1(5.5)	
Marital status (n=252)		
Never married	5	2.0
Married	154	61.1
Separated/divorced	12	4.8
Widowed	81	32.1
Number of people in household (n=252)		
1 person	5	2.0
2 people	14	5.6
3 people	15	6.0
4 people	18	7.1
5 or more people	200	79.4
Level of education (n=252)		
No formal education	158	62.7
Primary education	21	8.3
Secondary/vocational	41	16.3
Tertiary education	32	12.7
Annual income level (n=221)		
<ghc (<usd="" 100)<="" 500="" td=""><td>71</td><td>32.1</td></ghc>	71	32.1
GHC 500 – 900 (USD 100 – 180)	49	22.2
GHC 901-1400 (USD 181 – 280)	29	13.1

GHC 1401-1900 (USD 281 – 380)	26	11.8
>GHC 1900 (> USD 380)	46	20.8
Employment status (n=250)		
Employed full time	40	16.0
Employed part-time	10	4.0
Casual worker	87	34.8
Unemployed	92	36.8
Not in labour force/retired	21	8.4
Family history of diabetes (n=252)		
No	154	61.1
Yes (parents, grandparents, brother and sisters)	98	38.9
Smoking status (n=252)		
Current smoker	10	4.0
Non-smoker	242	96.0
	5 00 41 OUO (D 1	(C1)

PWD = Person with diabetes. As at 13/02/2019 1 USD = 5.0041 GHC (Bank of Ghana)

7.3.2 Barriers to diabetes self-care

The prevalence of each of the barriers investigated is shown in Table 2. Within the attitude construct the most commonly reported barriers were: finding it difficult to change dietary habits (58.7%, n=148); feeling worried about one's diabetes (47.2%, n=119), and misperception that high carbohydrate foods should be avoided (45%, n=113). For the subjective norms construct, the most commonly reported barriers were: no one follows all the rules for managing diabetes (47.6%, n=120); and not having enough family support (39.3%, n=99). For the perceived behavioural control construct the most commonly reported barriers were technical difficulties in operating a glucometer (59.8%, n=150); lack of money to purchase a glucometer (55.2%, n=139); and not having one's own glucometer (41.3%, n=104).

TPB Construct/Item	Ν	Agree	Neutral	Disagree
Attitude				
Difficulty changing dietary habits	252	148(58.7%)	5(2.0%)	99(39.3%)
Worrying about having diabetes	252	119(47.2%)	3(1.2%)	130(51.6%)
Misperception of avoiding high	251	113(45.0%)	15(6.0%)	123(49.0%)
carbohydrate diets				
Afraid to exercise due to pain	249	106(42.6%)	34(13.7%)	109(43.8%)
during exercise				
Difficulty adopting habits of	250	80(32.0%)	33(13.2%)	137(54.8%)
regular feet check				
Replaces diabetes medicine with	252	60(23.8%)	32(12.7%)	160(63.4%)
herbal medicine				
Takes diabetes medicine with	251	57(22.7%)	3(1.2%)	191(76.1%)
herbal medicine		· · · · ·	× ,	~ /
Difficulty adopting habit of regular	252	48(19.0%)	13(5.2%)	191(75.8%)
SMBG			- (-)	()
Medication has side effects	252	47(18.7%)	17(6.7%)	188(74.6%)
Becomes fed-up with continuous	252	40(15.9%)	6(2.4%)	206(81.7%)
intake of medicines			•()	
Do not believe in exercise	251	34(13.5%)	8(3.2%)	209(83.3%)
A fraid to prick the finger	249	31(12.4%)	2(0.80%)	216(86.7%)
Non-acceptance of being diabetic	252	24(9.5%)	4(1.6%)	224(88.9%)
Feels cured and no need to self-care	252	3(1.2%)	0	249(98.8%)
Subjective norms	202	5(1.270)	Ū	217(70.070)
No one follows all self-care	252	120(47.6%)	28(11.1%)	104(41.3%)
recommendations	202	120(17.070)	20(11.170)	101(11.570)
Inadequate family support	252	99(39.3%)	4(1.6%)	149(59.1%)
Social stigmatisation against	252	34(13.5%)	8(3.2%)	210(83.3%)
diabetics	232	54(15.570)	0(3.270)	210(05.570)
Lack of family's understanding of	252	30(11.0%)	2(0.80%)	220(87.3%)
diabetes	232	50(11.770)	2(0.0070)	220(07.370)
Negative societal perception of	251	21(8/1%)	10(7.6%)	211(8/ 0%)
weight loss	231	21(0.470)	19(7.070)	211(04.070)
Inconventional foods	252	10(7 59/)	0	222(02 50/)
Exercise is for foreigners	252	19(7.570) 17(6.794)	0 8(2,2%)	233(92.376) 227(00.197)
Democized behavioural control	232	17(0.770)	8(3.270)	227(90.170)
Technical difficulties in using a	251	150(50 90/)	1(0,40/)	100(20.90/)
lechnical difficulties in using a	231	130(39.8%)	1(0.4%)	100(39.8%)
	252	120(55 20/)	$\Omega(2, 20/)$	105(41 70/)
Inadequate income to purchase	252	139(55.2%)	8(3.2%)	105(41.7%)
glucometer	252	104(41 20/)	0	1 40(50 70()
Lack of glucometer	252	104(41.3%)	0	148(58.7%)
Seasonality of foods	252	59(23.4%)	4(1.6%)	189(/5.0%)
Inadequate income to buy	250	47(18.8%)	16(6.4%)	18/(/4.8%)
recommended foods	250			
Inappropriate work schedules to	250	46(18.4%)	2(0.8%)	202(80.8%)
dietary requirements			-	
Long distance to diabetes clinic	252	42(16.7%)	0	210(83.3%)

Inadequate income to buy	252	37(14.7%)	19(7.5%)	196(77.8%)
recommended medicines				
Too old to exercise	249	21(8.4%)	4(1.6%)	224(90.0%)
Inadequate access to wide variety	251	19(7.6%)	4(1.6%)	228(90.8%)
of foods				
Tight work schedules to meet	252	18(7.1%)	4(1.6%)	230(91.3%)
dosage recommendations				
Tight work schedules to exercise	251	16(6.4%)	9(3.6%)	226(90.0%)

In computing frequencies; strongly agree and agree were combined to yield "Agree". Strongly disagree and disagree were combined to yield "Disagree". Some responses do not add up to 252 due to non-response.
Table 3 shows the mean (SD) and median barrier scores for each of the self-care behaviours within the TPB constructs. While attitudinal barriers had higher scores for diet, foot care and exercise, perceived behavioural control barriers were higher for SMBG. The scores were fairly consistent across the self-care behaviours for subjective norms barriers.

Self-care behaviours	At	titude	de Subjective norms		Perceived behavioural control	
	Mean (SD)	Median (25%, 75%)	Mean (SD)	Median (25%, 75%)	Mean (SD)	Median (25%, 75%)
Diet	2.62(0.39)	2.60 (2.40, 2.80)	2.42(0.40)	2.33 (2.17, 2.67)	2.06(0.52)	2.20 (2.00, 2.60)
Exercise	2.42(0.45)	2.40 (2.00, 2.80)	2.36(0.37)	2.29 (2.14, 2.57)	2.06(0.52)	2.00 (1.67, 2.33)
Medication taking	2.33(0.40)	2.29 (2.00, 2.57)	2.42(0.40)	2.33 (2.17, 2.67)	2.21(0.57)	2.00 (2.00, 2.57)
SMBG	2.32(0.37)	2.40 (2.00, 2.40)	2.42(0.40)	2.33 (2.17, 2.67)	2.81(0.79)	3.00 (2.00, 3.50)
Foot care	2.43(0.46)	2.50 (2.00, 2.75)	2.42(0.40)	2.33 (2.17, 2.67)	2.17(0.96)	2.00 (2.00, 2.00)

Table 3: Mean (SD) and median barriers score for each of the self-care behaviours within the constructs of the TPB

7.3.3 Association between barriers and adherence to diabetes self-care for diet, exercise and SMBG

Table 4 shows results of the QR models testing the relationship between TPB barriers and diet, exercise and foot care self-care behaviours. In the univariate analysis, there was a negative association between attitude barriers (exercise) ($\beta = -2.50$; 95% CI = -3.78, -1.22; p<0.001, perceived behavioural control barriers (exercise) ($\beta = -3.60$; 95% CI = -3.09, -0.91; p<0.001) and adherence to exercise as well as between attitude barriers (foot care) and adherence to foot care ($\beta = -3.00$; 95% CI = -4.31, -1.69; p<0.001). However, the associations became non-significant after adjusting for potential confounders. Subjective norms barriers were significantly associated with increased adherence to foot care in the univariate analysis ($\beta =$

2.27; 95% CI = 0.16, 4.53; p=.048) and after adjusting for potential confounders (β = 2.42; 95%

CI = 0.68, 4.16; p=0.007).

Table 4: Unadjusted and adjusted quantile regression estimates between TPB barriers and adherence to diet, exercise and foot care at the 50th percentile.

Variable	Unadjusted estimate	p-value	Adjusted estimate	p-value
	(95% CI)		(95% CI)	
Diet	•		· · ·	
Attitude (diet)	-0.80(-1.61, 0.01)	0.052	-0.61(-1.29, 0.08)	0.081
Subjective norms (diet)	-0.34(-1.20, 0.51)	0.432	-0.62(-1.35,0.10)	0.092
Perceived behavioural control (diet)	-0.33(-0.84, 0.18)	0.200	-0.57(-1.32,0.19)	0.139
Exercise				
Attitude (exercise)	-2.50(-3.78, -1.22)	< 0.001	-1.02(-2.37,0.34)	0.142
Subjective norms (exercise)	1.16(-0.68, 3.00)	0.215	0.57(-1.08,2.21)	0.497
Perceived behavioural control	-3.60(-3.09, -0.91)	< 0.001	-0.75(-1.98,0.48)	0.231
(exercise)				
Foot care				
Attitude (foot care)	-3.00(-4.31, -1.69)	< 0.001	-1.17(-2.48,0.13)	0.078
Subjective norms (foot care)	2.27(0.16, 4.53)	0.048	2.42(0.68, 4.16)	0.007
Perceived behavioural control (foot care)	-0.33(-1.30, 0.64)	0.499	-0.36(-0.87,0.15)	0.169

Note. Models adjusted for age, gender, duration of diabetes, marital status (married vs. not married), level of education (no formal education, some form of formal education, and high education), annual income (>900GHC vs. \leq 900GHC), perceived confidence in self-care abilities, receipt of self-care support (yes, no, unsure), and attended diabetes education classes (yes, no, unsure)

7.4 DISCUSSION

This study aimed to determine the prevalence of patient-reported barriers to diabetes self-care (diet, exercise, medication taking, SMBG and foot care) and determine the associations between the barriers identified and adherence to self-care behaviours. Although many barriers were identified, only one significant association was found (and it was not in the expected direction). The lack of significant associations between attitudinal barriers, and PBC barriers identified in this study and adherence is a challenge for considering the importance (or non-importance) of the data about barriers. It may be possible that patients' reported barriers are

truly unrelated to their actual self-care barriers. However, given that a previous study ⁽⁵⁰⁾ found barriers to be associated with decreased adherence to diabetes self-care, it may be that measurement error or insufficient statistical power may have played a role in the study findings. In addition, the lack of significant associations in the current study compared to the previous study could be due to differences in study settings, population characteristics and methods used to assess barriers to diabetes self-care. The Daly et al⁽⁵⁰⁾ study was conducted in the US and participants were predominantly White and were college educated, whereas the participants in this study were Ghanaians and most had no formal education. Daly et al⁽⁵⁰⁾ used items from an existing barriers questionnaire known as the Environmental Barriers to Adherence Scale⁽⁵¹⁾, the items of which vary from the items of the barrier questionnaire used in this study that were derived from a previous qualitative study⁽³¹⁾ with a Ghanaian type 2 diabetes population, to make the items context-dependent. The Daly et al study determined the association between individual barriers and adherence to diabetes self-care whereas in the current study the individual barriers were grouped and analysed according to the constructs of the TPB. The specific individual barriers may be more critical than an overall concept like attitudes or PBC of the TPB. Finally, a prior psychometric evaluation of the SDSCA with Ghanaian type 2 diabetes patients ⁽³⁷⁾, found that its SMBG scale did not meet the criteria for construct validity. Further investigation using more robust or more sensitive measures should be conducted to clarify whether the hypothesised association between barriers and adherence to diabetes selfcare can be identified or definitively ruled out in a Ghanaian setting. Taking account of these limitations and the evidence from previous studies that barriers are associated with decreased adherence to diabetes self-care behaviours (50), it is pertinent to recommend strategies to HCPs, as has been done in the current study to support people with type 2 diabetes to overcome barriers they have reported.

Attitudinal barriers were commonly reported among the study population. These were: having difficulty changing dietary habits; feeling worried about one's diabetes; misperception that high carbohydrates foods be avoided; feeling afraid to exercise due to pain when exercising; and difficulty adopting new habits such as regular feet checking. Even though the attitude barriers were not associated with adherence to diabetes self-care behaviours, we recommend that during individual counselling sessions and group diabetes education it is important for healthcare professionals to adopt strategies that will improve attitudes towards self-care among people with type 2 diabetes by specifically correcting misconceptions regarding the type of diets people with type 2 diabetes should eat; reducing the fears about the negative consequences of diabetes, encouraging people with type 2 diabetes that if they adhere to their self-care recommendations risk of developing complications may be minimised; discussing forms of exercise that may reduce pain, and letting people with type 2 diabetes understand the need to adopt recommended lifestyle habits and how to maintain such habits.

Barriers relating to perceived behavioural control, mostly in relation to SMBG, were also reported. These included having technical difficulties operating a glucometer (59.8%), inadequate income to purchase a glucometer (55.2%) and not having a glucometer (41.3%). SMBG interventions should aim to provide access to glucometers and build the technical skills of people with type 2 diabetes to operate a glucometer. In addition, the inclusion of glucose strips into the Ghana National Health Insurance may also help reduce the financial barrier of persons with diabetes not having the income to purchase glucose strips or the glucometer.

It is critical to build upon the self-efficacy (which relates not perceived behavioural control of the TPB constructs) and skills of people with type 2 diabetes to be able to adhere to recommended self-care behaviours using strategies that promote patient activation and engagement⁽⁵²⁾. There is evidence that activated individuals are more likely to adhere to healthy lifestyle behaviours such as consumption of healthy diet and participating in regular exercise

⁽⁵³⁾. Healthcare providers could adopt a number of strategies including individualized counselling, peer diabetes education and group diabetes education to help build the self-efficacy and confidence of people with type 2 diabetes. In addition, team-based care and the use of community-health workers could be a targeted way to provide support and personalized care ⁽⁵³⁾. Given the significance of family support it is important to encourage the activation participation of family members such as spouses and children.

Given the significance of family support it is important to encourage the activation participation of family members such as spouses and children. In terms of the subjective norm construct, two frequently-reported barriers were the perception that no one follows all recommended selfcare behaviours and inadequate family support. People with type 2 diabetes may think it is socially acceptable for one not to adhere to self-care behaviours. Therefore, it is important for healthcare professionals to convey the message that it is possible for people with type 2 diabetes to adhere to all the self-care behaviours and that it is important to do so, reiterating the fact that doing so may reduce the risk of developing diabetic complications. This could be done through peer led education in which individuals with type 2 diabetes who adhere to all the self-care recommendations lead the diabetes education in order to encourage others that it is possible for them also to adhere to all the self-care recommendations. Inadequate family support has been reported as a common barrier to diabetes self-care in previous studies from Sub-Saharan Africa ^(14; 15) and in other parts of the world ^(42; 43; 49). Given the important role of the family in diabetes care healthcare providers should encourage and support people with type 2 diabetes to involve their family members in the self-care process. It was expected that barriers relating to the subjective norm construct would result in poor adherence to self-care behaviours. However, we found a counterintuitive positive association between subjective norm barriers for foot care and adherence to foot care recommendations and no association for diet and exercise. This finding could be attributed to chance or measurement error, but requires further investigation.

7.4.1 Strengths and limitations

This is the first study to use the constructs of the TPB to conceptualise barriers to self-care and assess whether they are associated with adherence to self-care behaviours among persons with type 2 diabetes. Our theory-driven approach enabled us to conceptualise the barriers to self-care and how they contributed to adherence to self-care behaviours.

Another strength was that the barriers used in this study were identified from the findings of a previous qualitative study ⁽³¹⁾ among members of this population allowing for the contextualisation of the study and its findings.

The study also had some limitations. The use of self-report to assess adherence to self-care behaviours make the findings liable to social-desirability bias and recall bias as well as measurement error. However, given the relatively low rates of adherence to self-care behaviours reported the effect of these biases may be minimal. The SDSCA measure has also been psychometrically tested with Ghanaian type 2 diabetes patients ⁽³⁷⁾ and found to be reliable and valid for assessing adherence among a Ghanaian type 2 diabetes population with the exception of diet. Consistent with previous reports from other sub-Sharan African countries (15; 54; 55; 56; 57; 58; 59; 60; 61; 62; 63; 64; 65), females were over-represented in our sample, affecting the generalisability of our findings to males. We also note the limitation of not being able to determine the association between barriers and adherence to SMBG and medication taking, due to lack of variation in the data. This may stem from ambiguity in the study items or from factors other than those reported in this study affecting adherence to diabetes self-care. This may stem from participants having varying views, ambiguity in the study items or from factors other than those reported in this study affecting adherence to diabetes self-care. Although the SDSCA is a useful omnibus measure, a more thorough and robust assessment of each individual self-care outcome variable (e.g. a 3-day diet diary) may be required in order to fully test the study hypotheses. Additionally, we note the limitation of some of the items having double negatives, which may have resulted in some items being unclear to some participants.

7.5 CONCLUSION

Prevalence of barriers to diabetes self-care differed by type of self-care behaviour in which attitudinal barriers were prevalent for diet, exercise and foot care and perceived behavioural control barriers were frequently reported for SMBG. Barriers were not associated with poor adherence to diabetes self-care behaviours. Further research that addresses the measurement issues in the current study is required to elucidate further whether there is an association between barriers to diabetes self-care and adherence to self-care. In the meantime, it may be prudent for HCPs to consider discussing the barriers identified in this study when educating their patients with type 2 diabetes in Ghana and other Sub-Sharan African countries about diabetes self-care.

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CHAPTER 8

DISCUSSION

8.1 BRIEF INTRODUCTION

Given the independence and importance of each diabetes self-care behaviour, the discussion chapter focuses on the findings for each behaviour in turn. Following on from the discussion of findings in relation to each behaviour, the limitations and implications of the work are discussed.

8.2. KEY FINDINGS FOR EACH SELF-CARE BEHAVIOUR

8.2.1. Medication taking

Adherence to medication taking among type 2 diabetes patients from low-and middle-income countries varied widely ranging from 26.0% to 97.0% (Chapter 2). Comparatively, adherence to medication taking was relatively higher than that for other self-care behaviours (diet, exercise, SMBG and foot care). This finding is consistent with the findings of a recent systematic review of studies from sub-Saharan Africa (SSA)⁽¹⁾ and those from higher income countries ^(2; 3; 4). The relatively higher adherence rates for medication taking may be due to people with type 2 diabetes accepting medication taking as a usual part of treating illness including diabetes ⁽⁵⁾. Medication-taking may also be perceived as relatively easy to adhere to compared to other forms of self-care such as changes to diet that may require more ongoing personal commitment and support from others ^(6; 7). Given that the adherence rates ranged from 26.0% to 97%, it demonstrated that many people living with diabetes in LMICs including Ghana did not adhere to their diabetes medication. As discussed in Chapter 7, the most prevalent barriers for medication taking were within the attitude construct of the Theory of Planned Behaviour (TPB). Specifically, 24% of Ghanaian type 2 diabetes patients replaced their diabetes medication with herbal medicines and another 23% took their diabetes medication together with herbal medicines. These findings demonstrated that the use of herbal medicines was common enough to warrant the attention of health care providers and health services as has been reported among previous studies from elsewhere in SSA ^(8; 9; 10; 11; 12; 13; 14).

As discussed in Chapter 5 ⁽¹⁵⁾, some people with type 2 diabetes used herbal medicines because they believed diabetes was the result of curses and spiritual inclinations; a finding that is unique to developing countries. Studies from high income countries (HICs) ^(16; 17; 18) rarely report spiritually-related misconceptions of the causes and treatment of type 2 diabetes and the use of herbal medicines as barriers to medication taking. People with type 2 diabetes used herbal medicines partly due to the belief that diseases due to curses or spiritual-inclined causes can only be treated using herbal medicines provided by a traditional healer ⁽¹⁹⁾. Consistent with studies from HICs ^(20; 21; 22) and other LMICs ^(23; 24; 25), side effects of medications were also frequently reported within the attitude construct of the TPB as a barrier to medication taking. Unpleasant side effects such as fainting, fatigue, palpitations, nausea, vomiting and itching ⁽²⁰⁾ ^{23; 24; 26)} can be a barrier to adherence to medication taking. Healthcare providers should regularly educate patients on the possible side effects of the medications given to people with type 2 diabetes as diabetes self-management education interventions have been shown to improve adherence to medication taking ^(27; 28). This could be done at the point at which the medications are prescribed and provided to people at the clinic.

Another unique barrier that was found to limit adherence to medication taking was women in polygamous marriages not wanting their husbands to know they had diabetes for fear that they may be divorced if their husbands saw them taking their diabetes medications. Further studies should explore from both the husbands' and wives' perspectives whether and how women can be safely supported to disclose to their husband that they have type 2 diabetes. A systematic review that evaluated the effects of family interventions on diabetes outcomes showed evidence for improved diabetes self-care including medication adherence across studies ⁽²⁹⁾.

Future research could also include family members in diabetes education classes for people with diabetes and also implement community-based interventions aimed at educating community members about the causes and management of diabetes.

Within the PBC concept of the TPB, as described in Chapters 5 ⁽¹⁵⁾ and 7, a common barrier reported by participants was inadequate income to purchase diabetes medications. This finding is consistent with previous research ^(30; 31; 32; 33) showing that the majority of people with type 2 diabetes in low-and middle-income countries do not have adequate income to purchase drugs. Furthermore, the health insurance schemes in SSA do not cover the majority of diabetes medications; and people with type 2 diabetes may still have to bear the financial burden of purchasing recommended drugs not on the insurance scheme ^(34; 35).

8.2.2. Diet

Adherence rates for diet also varied widely. Among people with type 2 diabetes from LMICs adherence rates for diet ranged from 29.9 to 91.7% and the mean number of days participants adhered to diet ranged from 2.3 to 4.6 days per week (Chapter 2). In a study among Ghanaian people with type 2 diabetes 2.7% adhered to their diet recommendations daily, with the mean number of days of adherence being 1.5 days per week (Chapter 4)⁽³⁶⁾. It is important to be cautious in interpreting the diet adherence rates especially those assessed using the SDSCA measure because, as discussed in Chapter 3⁽³⁷⁾, the diet scale of the SDSCA did not meet the criteria for internal consistency and two items had poor factor loadings: Item 3 (On how many of the last SEVEN DAYS did you eat five or more servings of fruits and vegetables?) and item 4 (On how many of the last SEVEN DAYS did you eat high fat foods such as red meat or fullfat dairy products?). Previous psychometric evaluations of the SDSCA also found these two items had poor factor loadings (5; 38; 39; 40). Furthermore, Ghanaian type 2 diabetes patients reported limited understanding of some words and phrases for item 3 and difficulty putting vegetables and fruits together as these are eaten separately in the Ghanaian setting (Chapter 3). Further testing of the psychometric properties of the SDSCA is needed with diverse Sub-Saharan African populations. In addition, there is a need to revise item 3 and item 4 for a Ghanaian type 2 diabetes population and conduct further psychometric testing of the SDSCA.

For item 3, the revision could include replacing the term 'full-fat dairy products' with 'full-fat milk or full-fat milk products' and also having a separate item for participants' consumption of 'red meat'. Item 4 could also be revised by having separate items for fruits and vegetables. It may also be the case that an alternative approach is necessary such as supplementing the SDSCA with reliable and valid diet-specific scales (e.g. food diaries or other measurement tools that assesses levels of urinary nitrogen, amino acids) ^(41; 42).

Many people with type 2 diabetes do not adhere to diet recommendations as evidenced by the adherence rates of 2.7% of Ghanaian type 2 diabetes patients adhering to dietary recommendations $^{(36)}$ and 29.9 to 91.7% of type 2 diabetes patients from other LMICs (Chapter 2). These findings are similar to those of previous reviews from SSA $^{(1)}$ and higher income countries $^{(2)}$. As presented in Chapter 5 $^{(15)}$, adherence to dietary recommendations may be particularly difficult for people with diabetes compared to other self-care behaviours as a result of the need for them to change life-long dietary habits $^{(43; 44)}$. This barrier was found to be prevalent with 58.7% of Ghanaian people with type 2 diabetes reporting that it was difficult to change their life-long dietary habits (Chapter 7).

Another commonly reported barrier for diet was the misperception that people with type 2 diabetes should avoid almost completely foods high in carbohydrates. This misconception was not only expressed by people with type 2 diabetes but also some healthcare providers (Chapter 5) ⁽¹⁵⁾ who advised patients to avoid high carbohydrate diets. HCPs' lack of training in the treatment and management of diabetes (especially for dietary management of diabetes), as presented in Chapter 6 ⁽⁴⁵⁾ and other previous studies ⁽⁴⁶⁾ from Ghana and South Africa ⁽⁴⁷⁾ may be a cause of HCPs' misconceptions about diet. There is a need for in-service training programmes for HCPs in SSA to improve their knowledge and skills regarding general diabetes care and specifically the dietary management of diabetes as lack of training opportunities was reported as a barrier by HCPs in the qualitative study presented in Chapter 6 ⁽⁴⁵⁾. Patients'

misperceptions could also be corrected through individual counselling provided by nutritionists and dietitians. This will only be possible if more nutritionists and dieticians are employed into the Ghana Health Service as the findings in Chapter 6 showed that there are an inadequate number of such HCPs and that nutrition care is inadequately provided.

Two other barriers that were common included seasonality of some of the recommended foods and inadequate income to purchase some foods (Chapter 7). The seasonality of foods presents a significant challenge to the ability of Ghanaian people with type 2 diabetes to adhere to dietary recommendations, limiting the variety of available foods. Inadequate income has been reported in previous studies from other SSA countries ^(48; 49) as a barrier to dietary adherence as it affects type 2 diabetes patients' affordability of recommended foods. These barriers could be minimised by HCPs being aware of the seasonality of recommended foods and the financial situation of people with type 2 diabetes and identifying alternative low-cost foods that are locally available to people with type 2 diabetes ⁽⁴⁹⁾. There is thus the need for HCPs to take a comprehensive social history of the individual with type 2 diabetes helping to identify the pertinent barriers to adherence to diet.

8.2.3. Exercise

Adherence rates for exercise were also generally less than optimal in that 21.4% of Ghanaian people with type 2 diabetes performed exercise daily (Chapter 4) ⁽³⁶⁾ and rates ranged from 13.0% to 79.9% among type 2 diabetes patients from other low-and middle-income countries (Chapter 2). Ghanaian people with type 2 diabetes exercised for a mean of 2.1 days per week ⁽³⁶⁾ while the mean number of days ranged from 1.8 to 5.7 days per week among those from LMICs.

A psychometric evaluation of the SDSCA presented in Chapter 3 ⁽³⁷⁾ showed that its exercise subscale did not meet recommended criteria for internal consistency but met criteria for content

and construct validity. These findings are similar to those of previous studies from a HIC ⁽⁴⁰⁾ and LMIC ⁽⁵⁰⁾. Further psychometric evaluations of the SDSCA in relation to the reliability of its exercise subscale with people with type 2 diabetes from LMICs are needed. Comparison of adherence measured by the SDSCA with objective measures of exercise ⁽⁴¹⁾ using accelerometers is also warranted in future research.

A number of barriers were found to affect adherence to exercise recommendations among Ghanaian people with type 2 diabetes. People with type 2 diabetes frequently reported that the fear of discomfort during exercise served as a barrier to their regular adherence to exercise recommendations (Chapter 5) ⁽¹⁵⁾. This finding is similar to those of previous findings from SSA and other parts of the world ^(16; 51). During individual counselling and group diabetes education sessions, it is important for HCPs to allay the fears of people with type 2 diabetes. Walking, for example, is a , convenient, and widely recommended form of aerobic activity for health and fitness in all age groups ^(52; 53) including people with diabetes^(54; 55).

A substantial proportion of Ghanaian people with type 2 diabetes did not believe in the benefits of exercise and some even considered it to be part of western culture (Chapters 5 and 7) ⁽¹⁵⁾. This misperception may reflect poor health literacy regarding the role of exercise in diabetes treatment and management. Through individualised counselling and group diabetes education sessions people with type 2 diabetes may understand the role of exercise and identify personal options for making exercise part of their diabetes treatment and management. Peers who have been able to successfully manage their diabetes and have experienced the benefits of exercise in their diabetes self-care could be used as role models to lead the education. Peer-led self-care education or peer support can be useful in promoting adherence to self-care behaviours as it utilises the benefits of receiving and providing social support ^(56; 57; 58). There is evidence that peer support assists in improving self-care behaviours such as diabetes medication adherence, diet, exercise and SMBG ^(59; 60; 61).

8.2.4. SMBG

Less than 1% of Ghanaian people with type 2 diabetes adhered to their SMBG recommendations (Chapter 4) ⁽³⁶⁾. Among LMICs, adherence rates for SMBG ranged from 13.0 to 79.9% (Chapter 2). While Ghanaian people with type 2 diabetes adhered for a mean of 2.2 days per week, for those from LMICs the mean ranged from 0.2 to 2.2 days per week. These findings are consistent with those from SSA ⁽¹⁾ and other parts of the world ^(2; 62; 63; 64; 65; 66; 67).

A psychometric evaluation of the SDSCA showed that its SMBG subscale met the criteria for internal consistency and was also found to meet content and construct validity ⁽³⁷⁾. These findings are similar to previous reports from Korea⁽³⁸⁾, Spain⁽³⁹⁾ and Germany ⁽⁴⁰⁾.

Some barriers were found to contribute to the poor adherence to SMBG among Ghanaian people with type 2 diabetes. Ghanaian people with type 2 diabetes and their HCPs reported that adherence to SMBG was hindered by non-receipt of self-care support (e.g. education) to perform SMBG and lack of technical skills to operate the glucometer (Chapter 5)⁽¹⁵⁾. As shown in Chapter 7, lack of technical skills to operate the glucometer was the most prevalent barrier reported by participants. These findings have been corroborated by previous studies from Ghana ⁽⁹⁾, Ethiopia ⁽⁶⁾, and Kenya ⁽¹²⁾. Diabetes self-care was also found to place a financial burden on most Ghanaian adults with type 2 diabetes, which may affect adherence to diabetes self-care especially among those with low income levels (Chapter 5)⁽¹⁵⁾. Chapter 7 reported that 55.2% lacked money to purchase a glucometer as well as glucose test strips and 41.3% did not own a glucometer. These findings are similar to reports from other parts of SSA ^(12; 19; 68; 69; 70). To minimise the financial burden associated with diabetes self-care on people with type 2 diabetes, the government of Ghana could include into the National Health Insurance Scheme aspects of diabetes care (such as glucose test strips, glucometers) that are not already in the insurance scheme. Given these findings, specific training and monitoring of patients' skills in

operating the glucometer is essential. Such interventions should be done early following diagnosis.

Being afraid of the pain when the finger is pricked to test blood sugar was also reported by a substantial proportion of people with type 2 diabetes as a barrier to SMBG (Chapter 7). This finding is consistent with those of previous studies among migrant West African diabetes patients living in the US ⁽⁷¹⁾ and diabetes patients from Malaysia ⁽⁷²⁾. HCPs should provide information and support to people with diabetes regarding appropriate procedures of pricking the finger less painfully such as using the lateral side of the finger, limiting the use of the thumbs and index fingers, using needles that have shallower depths, and using alternative site of testing (e.g. the arm, abdomen and thigh) ^(72; 73).

8.2.5. Foot care

Along with SMBG, foot care was one of the least adhered to self-care behaviours. Chapter 4 ⁽³⁶⁾ reported that 9.6% of Ghanaian adults adhered to their foot care recommendations daily and the average was 2.9 days per week. Foot care adherence rates from other low-and middle-income countries ranged from 17.0% to 77.4% (Chapter 2) and the average ranged from 2.2 to 4.3 days per week. These findings were consistent with those from other parts of the world ^(2; 62; 63; 64; 65; 66; 67).

Arguably foot care is one of the easiest self-care tasks for people with type 2 diabetes but it was one of the least adhered to self-care behaviours. This could be because HCPs in Ghana may not regularly recommend foot care during their discussions with people with type 2 diabetes(Chapters 5 and 6)^(15; 45). This finding is consistent with those of a previously published systematic review.

The current findings demonstrate the need for HCPs to include foot care alongside discussion of other self-care behaviours, and adopt strategies that will facilitate adherence to foot care.

This should be done at the point of first diagnosis and reinforced during each visit to the diabetes clinic. There is evidence that early adherence is associated with continued adherence ^(74; 75).

8.3. BARRIERS RELATING TO THE SOCIAL DETERMINANTS OF HEALTH IN DIABETES CARE

In Chapter 5, a number of barriers were identified within the perceived behavioural control construct of the TPB. People with type 2 diabetes as well as their providers discussed that adherence to SMBG was hindered by non-receipt of self-care support to perform SMBG and inadequate knowledge and skills to operate the glucometer. These findings have been corroborated by previous studies ^(6; 9; 12; 76). These two barriers are interrelated in that adequate receipt of self-care support will result in improved knowledge and skills to perform recommended diabetes self-care behaviours such as SMBG. High patient numbers coupled with inadequate numbers of healthcare providers may be responsible for the poor provider support for diabetes self-care and poor diabetes self-care knowledge reported by Ghanaian people with type 2 diabetes. Community health workers (CHWs) could be an important alternative to help address these challenges at the primary healthcare level. CHWs could be empowered through training to provide diabetes care to people with type 2 diabetes.

We found that diabetes care places a financial burden on most Ghanaian adults with type 2 diabetes, which hinders adherence to diabetes self-care especially among those that have poor income levels. Inadequate income levels affected a number of self-care behaviours including SMBG (as they had inadequate income to purchase personal glucometers and glucose test strips); medication taking (inadequate income to purchase medications not covered by health insurance) and diet (poor income to purchase fruits and vegetables required for their diabetes). This is a recognized social barrier that has been reported by previous studies in other parts of sub-Saharan Africa ^(12; 19; 68; 69; 70).

As reported in Chapter 5, other social and environmental barriers that were discussed by people with type 2 diabetes included inadequate access to a variety of foods due to limited availability and seasonality of such foods consistent with reports from other developing countries ^(6; 12; 77). Availability and seasonality of foods also affects affordability as the prices of such foods will be affected by whether a food is in season. Given that low income levels have been reported to affect adherence to diabetes, non-availability and seasonality may aggravate the situation of type 2 diabetes patients who have a low income. Unaffordability is associated with poor income levels and having low income levels may result in inability of people with type 2 diabetes to purchase recommended fruits and vegetables, thereby affecting consumption. The situation is even more precarious in LMICs in that unaffordability co-exists with issues of accessibility and availability of fruits and vegetables ^(6; 77).

Physical barriers such as poor access to diabetes clinics to receive regular care was also a significant barrier reported by people with type 2 diabetes. Having CHWs available in health centres and clinics across the country could be an important option to help resolve this barrier. CHWs live in the community and are easily accessible at the community level. The CHWs would need to be trained, empowered and supported to provide such care to people with type 2 diabetes in order to work with people to improve their diabetes self-care behaviours.

In such scenarios it is imperative to activate the individual with type 2 diabetes through patient engagement to be able to adhere to recommended self-care behaviours. Individual activation of people with type 2 diabetes refers to emphasising the willingness and ability of the individual with type 2 diabetes to adopt independent actions (e.g. recommended self-care behaviours) to manage their diabetes ⁽⁷⁸⁾. Activation relates to improving the knowledge, understanding, skills, and self-efficacy of the individual to manage his/her diabetes. As noted earlier targeted and personalised care through individualized counselling, team work, peer and group diabetes education as well as the use of community health workers to provide generalist diabetes care

could be ways by which the individual with type 2 diabetes can be activated to adhere to recommended self-care behaviours.

8.4. LIMITATIONS AND STRENGTHS

The studies which comprise this thesis have a number of limitations. The studies presented in Chapters 3, 4, and 7 used a cross-sectional design and therefore causality could not be established.

The research presented in Chapters 5 and 6 used qualitative approaches which may be liable to social desirability bias. Also, the studies presented in Chapters 3, 4, 5 and 6 used self-report to assess adherence to self-care behaviours and to explore barriers to diabetes self-care. As noted earlier this approach has potential for social-desirability and recall bias, however the low adherence to self-care behaviours reported by the participants suggest this bias might have had a minimal effect. Evaluation of the validity and reliability of the SDSCA (Chapter 3) ⁽³⁷⁾, showed the SDSCA could be used in a Ghanaian type 2 diabetes population to assess exercise, SMBG and foot care but the items for diet require revision for this population. Further, the psychometric evaluation presented in Chapter 3 would have been enhanced if it had been possible to assess test-re-test reliability. This may be the subject of future research.

Apart from the systematic review (Chapter 2), all data collected for this thesis was from people with type 2 diabetes seeking care from three hospitals in Tamale, Ghana, a low income SSA country. This may limit the generalisability of the findings to people with type 2 diabetes who do not seek care from these diabetes clinics in Ghana. Nonetheless, the findings may have relevance for people with type 2 diabetes attending similar challenged healthcare systems like Ghana.

In addition, our findings presented in Chapter 5 that explored the perspectives of HCPs and people with type 2 diabetes regarding barriers to self-care is limited by the over-representation

of the perspectives of HCPs compared to those expressed by people with type 2 diabetes. A fairer balance between the perspectives for patients versus healthcare providers would have provided a more balanced representation of the situation.

Another limitation of this thesis regarding the results presented in Chapter 7 was that a number of the barriers could be categorized into more than one TPB constructs. However, this was resolved by consensus among the authors, with the classification of the variables in Chapter 7 informed by our findings in the qualitative papers. In addition, the case definition of excluding those younger than 30 years as not having type 2 diabetes in the studies reported in Chapters 4 and 7 is a limitation worth noting, given that there is a likelihood of younger people having type 2 diabetes but were excluded.

The main strengths of this thesis have been described below. One important strength is that the findings presented in this thesis, when taken together provide a comprehensive view of adherence and barriers to diabetes self-care and how they are or not associated with each other. This thesis helps us to understand adherence to self-care behaviours among people with type 2 diabetes from low-and middle-income countries. Also, the exploration of the psychometric properties of the SDSCA, showed that the SDSCA could be used for the evaluation of adherence to self-care behaviours in a Ghanaian type 2 diabetes population with the likely exception of diet.

The thesis work provides unique data indicating that perceived social stigmatization of women in polygamous marriages living with type 2 diabetes may be a threat to adherence to self-care behaviours such as medication taking. This relates to pre-existing socio-cultural norms and beliefs at the social and community level. In the majority of Ghanaian settings decisions to seek healthcare are generally controlled by the husband as the funds required to access health care are under male control and cost is critical in the decision-making process. The fear of stigmatization may result in a woman with type 2 diabetes (who may not be in paid employment) not discussing the condition with her husband, or choosing not to seek healthcare, presupposing that finances to seek care or purchase medication may not be provided. Such scenarios have the potential to cause poor adherence to self-care behaviours especially for medications that may require purchase. In addition, it appears that there may be competition among women in polygamous marriages to win the favour of the husband. The quest to achieve such favour may result in the woman with type 2 diabetes prioritizing other actions over adhering to recommended diabetes self-care behaviours. Community-level interventions may be necessary to overcome some of these social barriers. Encouraging the participation of community members through community health workers who facilitate awareness and health literacy regarding the causes and treatment of diabetes could be an important way of bringing about an activated community, family and individual.

The use of both qualitative and quantitative approaches is another strength of the study. The qualitative approach allowed participants to express their opinions and preferences by which new knowledge was generated concerning barriers to diabetes self-care. The evidence from the qualitative approach also informed the design and content of the barrier items used in Chapter 7. The quantitative approach helped us to understand the extent to which participants adhered to diabetes self-care behaviours and quantify the barriers to diabetes self-care with a Ghanaian type 2 diabetes population. The two approaches complemented each other resulting in the generation of rich data.

From the systemic review of the literature presented in Chapter 2, 22 ^(23; 24; 25; 32; 33; 36; 79; 80; 81; 82; 83; 84; 85; 86; 87; 88; 89; 90; 91; 92; 93; 94) out of the 27 included studies from LMICs investigating adherence to diabetes self-care did not state any theoretical underpinning, demonstrating majority of studies from LMICs lack theoretical underpinnings. The theory-driven nature of this thesis is worth noting as it explicitly stated the conceptual framework to derive and describe the findings ^(95; 96). The conceptual framework guided the design of interview questions for the

two qualitative studies (Chapters 5 and 6), the design of the barrier items (Chapter 7) and the reporting of the results of those studies. The conceptual framework also provided a guide and context as to how to interpret the findings. It is however important to note the TPB does not fully account for the wide range of factors that influence health behaviours. As described in the introduction, the broader social determinants of health are needed to fully understand health behavior. For example, the individualistic nature of the TPB vis-a-vis the social determinants of diabetes care. Therefore, the limitations of the TPB must be considered when interpreting the thesis data.

8.5. POLICY AND PRACTICE IMPLICATIONS

The thesis findings provide policy makers with information regarding the level of adherence to diabetes self-care and barriers that hinder patients' ability to adhere to their self-care recommendations in the Ghanaian context and SSA as a whole. Ghana shares similar health-related characteristics with several SSA countries such as being a lower-income country ^(97; 98), having a rising prevalence of diabetes co-existing with infectious diseases like malaria ⁽⁹⁹⁾, and a challenged healthcare system especially for diabetes care and other chronic non-communicable diseases⁽¹⁰⁰⁾. Hence the findings may be generalizable to other SSA countries.

Furthermore, it provides data that can inform the design of future interventions to improve adherence to self-care. Such interventions should be self-care behaviour specific, and theory-driven. They could be driven by strategies and activities that are behavioural, educational and affective depending on the individual needs and perceived reasons for poor adherence in a culturally acceptable manner ⁽⁷⁴⁾.

There is the need for the development and publication of diabetes care guidelines for Ghana to promote diabetes care and to also serve as a benchmark of quality care. These guidelines should emphasise the role of the HCP in providing self-care support and strategies. HCPs should develop their skills to provide effective self-care support to promote adherence. Our finding in Chapter 6 ⁽⁴⁵⁾ that HCPs do not have access to continuous professional development (CPD) programmes demonstrates the need to set guidelines that require HCPs to regularly attend continuous professional development programmes on diabetes care in order to improve their competencies in providing such care to diabetes patients. Of course, such guidelines can only be implemented effectively if the CPDs are available to HCPs.

Chapter 6 ⁽⁴⁵⁾ reported that Ghanaian HCPs perceive their role as being information sharing rather than supporting patients to build confidence and skills in diabetes self-care. HCPs could adopt strategies such as motivational interviewing which has been shown to have positive effects on adherence ^(101; 102). Motivational counselling training could be instituted and coordinated by the hospitals, with policy direction from the Ministry of Health (MOH).

Financial barriers to self-care were reported by Ghanaian people with type 2 diabetes. Financial barriers could be reduced through the expansion of the current Ghanaian National Health Insurance Scheme (NHIS) to cover additional diabetes cost related activities such as medications, glucometers and glucose strips. This could be made possible by engaging with relevant stakeholders such as the National Health Insurance Authority, the Ministry of Health and the Ghana Health Service (GHS) to advocate for people with type 2 diabetes. It is however, worth noting that the NHIS is also affected by delayed reimbursement of healthcare costs which has negatively impacted the availability of diabetes medications, thus affecting continuity of care ⁽¹⁰³⁾ for people with diabetes

The evidence presented in this thesis denotes that patient-provider collaboration is necessary and may be the stepping stone towards patients' acceptability and implementation of interventions to improve adherence to diabetes self-care $^{(104)}$. It is thus important for HCPs to

aim towards building positive relationships with their patients so as to improve patients' trust and confidence in an effort to improve adherence to self-care behaviours and clinical outcomes.

Continuous monitoring, provision of feedback on patients' adherence efforts and reinforcement are strategies that could also be employed by HCPs to improve adherence to diabetes self-care. A cost-effective way of achieving this is to adopt information communication technology ⁽¹⁰⁵⁾.

In Ghana, a reorientation of the current model of care is needed: away from an emphasis on infectious diseases towards investing in non-communicable diseases; and a healthcare system that is structured to support chronic care, rather than solely visit-based, acute care. The current infectious disease and acute care approach makes it difficult for HCPs to vary their style of communication or to implement multicomponent and integrated intervention strategies. This could be achieved by a remodelling of the healthcare system that is conducive and supportive of a team-based, multidisciplinary approach and structured work processes to yield proactive, coordinated care for chronic disease ⁽¹⁰⁶⁾.

Given that self-care support is hindered by the inadequacy of critical HCPs for the provision of diabetes care, HCPs' lack of time, high patient numbers and inadequate staff numbers relevant authorities such as the GHS and MOH should recruit and train more dieticians, diabetes educators and other relevant healthcare professionals to improve staff capacity and the quality of care given to people with type 2 diabetes. In addition, community-based health workers could be an important avenue to improve patient activation, empowerment and confidence to perform recommended self-care behaviours. There is evidence that CHW interventions improve health outcomes of individuals with type 2 diabetes given their potential to address not only individual level challenges but community-level factors as well ^(107; 108). CHW are able to do so because they work in their own communities, and share similar cultural, economic and linguistic values with individuals with diabetes. This enables individuals with type 2 diabetes to trust them and build close relationships with them ⁽¹⁰⁹⁾. CHWs thus present

an important opportunity to help improve adherence to diabetes self-care among Ghanaian people with type 2 diabetes. The capacity of CHWs to support quality diabetes care could be built through training and empowerment which can take a number of forms including technical assistance, in-depth consultations, virtual and in-person training sessions, digital/online learning courses, guidance materials in the form of knowledge and products and skills-based courses such as coaching and mentoring ^(110; 111; 112). In the Ghanaian circumstances and situations especially with poor internet connectivity and infrastructure, virtual and digital/online learning courses may not be feasible. Training programs such as technical assistance, in-depth consultations, in-person training sessions and guidance materials in the form of knowledge and products and skills-based courses such as technical assistance, in-depth consultations, in-person training sessions and guidance materials in the form of knowledge and products and skills-based courses and situations.

At the health systems level the following could be done to assist people with type 2 diabetes adhere to recommended self-care behaviours: planning and care provision should be evidence-based; reorganization of practice systems and provider roles, improvement of support for patient self-care and increasing access to expertise and clinical information ⁽¹¹³⁾.

Educational campaigns that aim to improve awareness and understanding of the causes, treatment and management of type 2 diabetes at the community-level are necessary to help reduce the social stigma around the disease. This could be done by encouraging the participation of community members through CHWs who will facilitate awareness and health literacy regarding the causes and treatment of diabetes. This may result in an activated community, family and individual.

8.6. FUTURE RESEARCH DIRECTIONS

The exploration of the facilitators and barriers to the provision of self-care support by HCPs, indicated a need for future empirical studies to evaluate the magnitude of facilitators and barriers to the provision of self-care support in a larger sample of HCPs. This future research

should be expanded to other hospitals in Ghana that provide diabetes self-care in order to increase the generalisability of the findings.

The lack of inter-professional collaboration among HCPs identified as one of the barriers to the provision of self-care support deserves further investigation. Future studies should explore further the factors that could be contributing to the poor inter-professional collaboration among HCPs involved in the care of people with type 2 diabetes.

Longitudinal designs could also be adopted to examine causality and the stability of adherence to self-care behaviours and barriers to self-care among people with type 2 diabetes in Ghana. Another important future research direction is to design and pilot interventions informed by the findings of this thesis to investigate their effects on improving adherence to self-care behaviours. Such interventions should be theory-driven and should be integrated in nature and scope incorporating strategies for education as well as behaviour change. Evidently, behavioural interventions may improve adherence to self-care behaviours and patient outcomes by modifying motivational, emotional, behavioural and cognitive outcomes ⁽¹¹⁴⁾.

Given the lack of significant association between barriers and adherence to diabetes self-care in the findings presented in Chapter 7, it is important for future research to investigate further to determine if barriers are associated with adherence to diabetes self-care recommendations.

8.7. CONCLUSION

The evidence provided in this thesis showed that the majority of Ghanaian people with type 2 diabetes struggle to adhere to recommended self-care behaviours. A number of barriers were commonly reported including lack of technical skills to operate a glucometer; difficulty changing dietary habits; lack of a glucometer and inadequate income to purchase a glucometer.

There is the need for action within the sub-Saharan subregion to help encourage people with type 2 diabetes to adhere to recommended self-care behaviours. It is particularly important for the healthcare authorities in LMICs to implement appropriate interventions towards improving adherence to diabetes self-care behaviours; given the limited-resources of the healthcare systems for managing diabetes-related morbidities in such settings. It may be more cost-efficient for SSA countries to invest in improving self-care rather than funding expensive treatments for diabetes-related morbidities or suffering the economic losses which would likely result from rising rates of poorly-managed or untreated type 2 diabetes. Such interventions should aim at identifying and improving adherence as early as during the first diagnosis of diabetes or at the early stage of a treatment recommendation ⁽⁷⁴⁾. This recommendation is premised on the evidence that early adherence is associated with continued adherence ^(74; 75).

Interventions may also be more effective if effort is directed toward a community-wide approach focusing on the cultural context of patients' existing belief systems. It may be that wide and long-term community education campaigns are needed to address these critical cultural beliefs ^(115; 116). HCPs should also endeavour to identify people with type 2 diabetes who are struggling with their diabetes self-care and support them to overcome barriers they perceive to be beyond their control, such as individuals who are more likely to regularly miss appointments; are non-responsive to treatment; and tell the HCP they are struggling when they are asked ^(74; 117).

The Government of Ghana through the Ghana Health Service and the Ministry of Health should actively and consciously promote the need for people with type 2 diabetes in Ghana to adhere to recommended self-care behaviours as well as devote more resources and interventions that will make the Ghanaian healthcare system conducive for HCPs to effectively provide self-care support to people with type 2 diabetes.

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APPENDIX A

Author contribution statements

Contribution statement

By signing below I **Professor Christine Paul** confirm that **Mr. Victor Mogre** contributed and led manuscript conceptualisation, study design, data collection, data analysis and interpretation, and drafting and final preparation of the following manuscripts:

- Mogre V, Johnson NA, Tzelepis, F, Shaw, JE, & Paul, C. Systematic review of adherence to diabetes self-care: evidence from low-and middle-income countries. Accepted for publication by the Journal of Advanced Nursing (Acceptance date: 5/08/2019).
- Mogre V, Abanga Z. O., Tzelepis F, Johnson NA, & Paul C. Psychometric evaluation of the Summary of Diabetes Self-Care Activities measure in Ghanaian adults living with type 2 diabetes. Diabetes Research and Clinical Practice 2019;149:98-106
- Mogre V, Abanga ZO, Tzelepis F, Johnson NA, Paul C. Adherence to and factors associated with self-care behaviours in type 2 diabetes patients in Ghana. BMC Endocrine Disorders 2017;17(1):20.
- Mogre V, Johnson NA, Tzelepis F, & Paul C. Barriers to diabetes self-care: a qualitative study of patients' and health care providers' perspectives. Journal of Clinical Nursing. 2019; 1-13.
- Mogre V, Johnson NA, Tzelepis F, Paul C. Attitudes towards, facilitators and barriers to the provision of diabetes self-care support: A qualitative study among healthcare providers in Ghana. Diabetes and Metabolic Syndrome: Clinical Research and Reviews 2019;13 (2019):1745-51
- 6. Mogre V, Johnson NA, Tzelepis F, Hall A, Paul C. Barriers to self-care and their association with poor adherence to self-care behaviours in people with type 2 diabetes in Ghana: a cross sectional study. Submitted to Diabetes Research and Clinical Practice (Submission date: 05/08/2019). Currently under editorial review.

	15/07/2019		
Professor Christine Paul (Supervisor and co-author)	Date		
	16/07/2019		
Victor Mogre (Candidate)	Date		
	6/08/2019		
Dr. Lesley MacDonald-Wicks (Assistant Dean Research Tr	aining) Date		

By signing below I, **Dr. Natalie A. Johnson,** confirm that **Mr. Victor Mogre** contributed and led manuscript conceptualisation, study design, data collection, data analysis and interpretation, and drafting and final preparation of the following manuscripts:

- Mogre V, Johnson NA, Tzelepis, F, Shaw, JE, & Paul, C. Systematic review of adherence to diabetes self-care: evidence from low-and middle-income countries. Accepted for publication by the Journal of Advanced Nursing (Acceptance date: 5/08/2019).
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- 6. Mogre V, Johnson NA, Tzelepis F, Hall A, Paul C. Barriers to self-care and their association with poor adherence to self-care behaviours in people with type 2 diabetes in Ghana: a cross sectional study. Submitted to Diabetes Research and Clinical Practice (Submission date: 05/08/2019). Currently under editorial review.

	19/07/2019			
Dr. Natalie A. Johnson (Supervisor and co-author)	Date			
	16/07/201			
Victor Mogre (Candidate)	Date			
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Dr. Lesley MacDonald-Wicks (Assistant Dean Research Training	J) Date			

By signing below I, Associate Professor Flora Tzelepis, confirm that Mr. Victor Mogre contributed and led manuscript conceptualisation, study design, data collection, data analysis and interpretation, and drafting and final preparation of the following manuscripts:

- Mogre V, Johnson NA, Tzelepis, F, Shaw, JE, & Paul, C. Systematic review of adherence to diabetes self-care: evidence from low-and middle-income countries. Accepted for publication by the Journal of Advanced Nursing (Acceptance date: 5/08/2019).
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By signing below I **Mr. Osman Z. Abanga** confirm that Mr. Victor Mogre contributed and led manuscript conceptualisation, study design, data collection, data analysis and interpretation, and drafting and final preparation of the following manuscripts:

- Mogre V, Abanga Z. O., Tzelepis F, Johnson NA, & Paul C. Psychometric evaluation of the Summary of Diabetes Self-Care Activities measure in Ghanaian adults living with type 2 diabetes. Diabetes Research and Clinical Practice 2019;149:98-106
- Mogre V, Abanga ZO, Tzelepis F, Johnson NA, Paul C. Adherence to and factors associated with self-care behaviours in type 2 diabetes patients in Ghana. BMC Endocrine Disorders 2017;17 (1):20.

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4th April, 2019 Date

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Mogre V, Johnson NA, Tzelepis, F, Shaw, JE, & Paul, C. Systematic review of adherence to diabetes self-care: evidence from low-and middle-income countries. Accepted for publication by the Journal of Advanced Nursing (Acceptance date: 5/08/2019).

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22/07/2019

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Dr Lesley MacDonald-Wicks (Assistant Dean Research Training) Date

By signing below I, **Dr. Alix Hall**, confirm that **Mr. Victor Mogre** contributed and led manuscript conceptualisation, study design, data collection, data analysis and interpretation, and drafting and final preparation of the following manuscript.

Mogre V, Johnson NA, Tzelepis F, Hall A, Paul C. Barriers to self-care and their association with poor adherence to self-care behaviours in people with type 2 diabetes in Ghana: a cross sectional study. Submitted to Diabetes Research and Clinical Practice (Submission date: 05/08/2019). Currently under editorial review.

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- Mogre V, Johnson NA, Tzelepis, F, Shaw, JE, & Paul, C. Systematic review of adherence to diabetes self-care: evidence from low-and middle-income countries. Accepted for publication by the Journal of Advanced Nursing (Acceptance date: 12/02/2019).
- Mogre V, Abanga Z. O., Tzelepis F, Johnson NA, & Paul C. Psychometric evaluation of the Summary of Diabetes Self-Care Activities measure in Ghanaian adults living with type 2 diabetes. Diabetes Research and Clinical Practice 2019;149:98-106
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- 6. Mogre V, Johnson NA, Tzelepis F, Hall A, Paul C. Barriers to self-care and their association with poor adherence to self-care behaviours in people with type 2

diabetes in Ghana: a cross sectional study. Submitted to the Diabetes Research and

Clinical Practice (Submission date: 05/08/2019). Currently under editorial review.

Co-author	Publications	Signature	Date
Victor Mogre	1, 2, 3, 4, 5, 6		16/07/2019
Osman Z. Abanga	2,3		4/04/2019
Natalie A. Johnson	1, 2, 3, 4, 5, 6		19/07/2019
Flora Tzelepis	1, 2, 3, 4, 5, 6		19/07/2019
Alix Hall	6		19/07/2019
Jonathan E. Shaw	2		
Christine Paul	1, 2, 3, 4, 5, 6		15/07/2019

Endorsed by the Faculty of Health and Medicine Assistant Dean (Research Training)

Signature:

30/07/2019

APPENDIX B 1: RELATED INFORMATION FOR CHAPTER 2

2.1 Published systematic review protocol

Mogre et al. Systematic Reviews (2017) 6:39 DOI 10.1186/s13643-017-0436-4

PROTOCOL

Systematic Reviews



Adherence to self-care behaviours and associated barriers in type 2 diabetes patients of low-and middle-income countries: a systematic review protocol

Victor Mogre^{1,2*}, Natalie A. Johnson^{1,3}, Flora Tzelepis^{1,3,4}, Jonathan Shaw⁵ and Christine Paul^{1,3}

Abstract

Background: Diabetes has become a global health emergency affecting high-, middle- and low-income countries. Previous systematic reviews have either focused on patients' adherence to diabetes self-care behaviours only or barriers to diabetes care (including self-care) only in the published literature and have not also analysed data separately for low- and middle-income countries (LMICs). Thus, none have focused on adherence with, and barriers to, self-care behaviours from the perspectives of both patient and providers in low- and middle-income countries (LMICs). This systematic review will evaluate the published literature on adherence to five diabetes self-care behaviours (i.e., diet, exercise, self-monitoring of blood glucose, medication taking and foot care) and associated barriers in type 2 diabetes patients in LMICs. Healthcare providers' barriers to the provision of diabetes self-care support will also be reviewed.

Methods: This narrative review will be reported in accordance with the guidelines of the Preferred Reporting Items for Systematic review and Meta-Analysis Protocols (PRISMA-P). The electronic databases, MEDLINE, EMBASE, CINAHL, SCOPUS, PsycINFO, Cochrane Library and the British Nursing Index will be searched. Qualitative and quantitative studies reporting on type 2 diabetes patients' adherence to self-care behaviours and associated barriers in LMICs will be included. Studies also reporting on barriers encountered by providers in LMICs providing diabetes care and supporting patients to adhere to self-care behaviours will also be included. Cross-sectional studies, observational cohort studies, baseline data of randomised controlled trials and qualitative studies will be eligible. Two independent reviewers will screen articles for inclusion, undertake quality assessment of included studies and execute data extraction using standardised forms. Discrepancies will be discussed to reach consensus, and another reviewer will adjudicate if the need arises. The Guidance of Narrative Synthesis in Systematic Reviews will be employed to explore relationships within and between included studies.

Discussion: This review will provide evidence on adherence to self-care behaviours by type 2 diabetes patients in LMICs. Barriers experienced by patients in LMICs to adhere to recommended self-care behaviours will also be identified. Barriers experienced by healthcare providers in LMICs in providing self-care support patients will also be determined.

Systematic review registration: PROSPERO CRD42016035406

Keywords: Adherence, Barriers, Self-care, Type 2 diabetes, Low- and middle-income countries

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Ghana

Background

Diabetes affected 422 million adults in 2014 compared to 108 million in 1980 [1]. The increasing prevalence is associated with an increase in the prevalence of risk factors such as excess body weight, sedentary lifestyle, diet and ageing populations [2, 3]. In the last 10 years, the prevalence of diabetes has risen faster in low- and middleincome countries than in high-income countries [1]. The World Health Organization (WHO) anticipates that infectious diseases, maternal and infant mortality and malnutrition will be overtaken by non-communicable diseases such as diabetes mellitus (DM) in low- and middleincome countries (LMICs) by 2030 [4, 5]. Characterised by hyperglycaemia, insulin resistance and relative insulin deficiency, type 2 DM is the most frequently occurring form of DM globally [6–8].

Diabetes patients of LMICs are at increased risk of late diagnosis, poor diabetes control, hospitalisations and the development of diabetes-related complications [9, 10]. Also a higher proportion of premature deaths due to high blood glucose occurred in LMICs than in highincome countries [1].

Being a complex chronic disorder, diabetes care requires regular attention to diet, physical activity, monitoring of blood sugar, medications and foot care to attain positive health outcomes [11]. As has been advocated by clinical practice guidelines from the USA, UK and globally [12–15], these activities are referred to as diabetes self-care behaviours requiring the active participation of the patient in his or her care [15]. As each of these behaviours is important to health outcomes, it is essential to have a clear understanding of the level of adherence to each self-care behaviour and barriers to the performance of each of them for LMICs.

A number of reviews have examined adherence to selfcare behaviours among type 2 diabetes patients [15] and barriers to diabetes care [16-18] including self-care [19]. The review by Coyle et al. included studies from lowand middle-income countries (LMICs) but only evaluated patients' adherence to self-care behaviours (i.e. did not report on patients' barriers to self-care) and did not analyse data from LMICs separately. The reviews by Pun et al. and Nam et al. [16-18] also included studies from LMICs, examined patient and provider barriers to general diabetes care including self-care but did not consider barriers to self-care behaviours separately and did not analyse LMICs data separately. Also, they did not undertake quality assessment of the included studies. The review by Sohal et al. evaluated patient and provider barriers and facilitators to diabetes management using only studies conducted in South Asia [18]. Wilkinson et al. [19] reviewed the literature to identify factors that influence patients' ability to self-care for their diabetes, but only included qualitative studies, considered both type 1

and type 2 diabetes patients, did not include studies among providers and did not analyse LMICs data separately. Accordingly, a systematic review of the published literature from LMICs on patient adherence with, and the barriers to, self-care behaviours from the perspectives of both the patient and providers is warranted.

This systematic review will examine both qualitative and quantitative studies conducted in LMICs related to:

- Type 2 diabetes patients' adherence to five self-care behaviours: recommended diet, sufficient exercise, diabetes medications, self-monitoring of blood glucose and foot care.
- b. Barriers to self-care behaviours among patients with type 2 diabetes
- c. Barriers to the provision of appropriate care to patients with type 2 diabetes among healthcare providers.

Methods

This systematic review will be reported in accordance with the guidelines of the Preferred Reporting Items for Systematic review and Meta-Analysis Protocols (PRISMA-P) 2015 [20]. Details of this can be found in an additional file (see Additional file 1).

Definition of low- and middle-income countries

Based on the 2015 Gross National Income per capita (GNI), low-income countries are those with a GNI per capita of \leq US\$1,045 and middle-income countries are those with a GNI per capita of >US\$12,045 but <US\$12,736 [21]. Any country listed by World Bank as a LMIC at any point during the review period will be included.

Information sources

Electronic databases including MEDLINE (OVID interface, 1948 and beyond), EMBASE (OVID interface, 1980 onwards), CINAHL, SCOPUS, PsycINFO, Cochrane Library and the British Nursing Index will be searched. The websites of relevant organisations such as the International Diabetes Federation (IDF), WHO and other diabetes-related institutions will also be examined for other potentially relevant studies. To ensure relevant publications are captured, the reference lists of relevant studies or systematic reviews will be hand searched.

Search strategy

The databases will be searched using medical subject headings (MeSH) and free text words relating to the themes of this review (Table 1). Truncation and appropriate Boolean operators will be incorporated into the search strategy to cater for the different use of terms. Limitations pertaining to the inclusion and exclusion

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Tab	le '	1.5	Search	stra	tegy
-----	------	-----	--------	------	------

1	diabetes mellitus.mp. or Diabetes Mellitus/
2	Diabetes Mellitus, Type 2/or Diabetes Mellitus, or diabetes mellitus type 2.mp.
3	(non insulin*dep* or noninsulin*dep*).mp. [mp = title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
4	1 or 2 or 3
5	self-care.mp. or Self Care/
6	self-manage*.mp. or Patient Education as Topic/
7	self-care behaviours.mp.
8	5 or 6 or 7
9	diet.mp. or Diet/
10	Food Habits/or dietary habit*.mp.
11	nutrition.mp.
12	9 or 10 or 11
13	exercise.mp. or Exercise/
14	physical activity.mp.
15	13 or 14
16	Blood Glucose Self-Monitoring/
17	Self Care/or blood glucose testing.mp.
18	16 or 17
19	Self Care/or foot care.mp.
20	Patient Compliance/or medication taking.mp. or Self Administration/or Medication Adherence/
21	adherence.mp.
22	20 or 21
23	barrier.mp.
24	Health Services Accessibility/or Health Personnel/or patient barrier.mp. or "Attitude of Health Personnel"/
25	23 or 24
26	Developing Countries/or Socioeconomic Factors/or Low- income countries.mp.
27	Developing Countries/or middle-income countries.mp.
28	26 or 27
29	4 or 8 or 12 or 15 or 18 or 19 or 22 or 28
30	25 and 29
31	limit to (english language and yr = *1990 -Current" and "all adult (19 plus years)")

criteria will be set. An Ovid MEDLINE strategy will be developed by VM and other members of the research team under the guidance of a librarian with experience in systematic review searching. The finalized Ovid MED-LINE strategy will be adapted to the syntax and subject headings of the other databases. The search strategy will be reviewed by another librarian in accordance with the Peer Review of Electronic Search Strategies (PRESS) checklist. The execution of the search strategy will be done by VM.

Eligibility criteria

Studies will be included in accordance with the criteria outlined below.

- *Type of data*: Studies using quantitative, qualitative or both approach(es) will be included. Included studies will be limited to published papers including published theses/dissertations.
- b. *Study design:* Cross-sectional studies, cohort studies, baseline data from randomised controlled trials (RCTs) and qualitative studies (e.g. in depth interviews, focus groups) will be eligible for inclusion.
- c. Study participants: (i) Adults with type 2 diabetes from LMICs. Studies where the majority (≥50%) of participants are from a LMIC will be included. (ii) Studies that report on the barriers faced by healthcare professionals who deliver care to type 2 diabetes patients in LMICs will also be eligible for inclusion.
- d. *Search limitations:* All studies published from January 1990 onwards will be included. This time frame is informed by global estimates of diabetes that recognised diabetes as a global disease affecting adult populations of developing countries or LMICs [22].
- e. *Study focus*: Studies that are concerned with patient adherence to self-care behaviours and barriers to self-care. Also, studies that report on barriers experienced by providers to support patients to self-care for their diabetes will be included.
- f. *Setting*: Both population- and clinic-based studies will be eligible for inclusion.
- g. Language: Due to funding constraints, only studies published in English will be eligible for inclusion

Exclusion criteria

Studies will be excluded if the majority of participants were younger than 18 years or had gestational diabetes. Conference proceedings, non-peer reviewed papers, opinion pieces, commentaries, case reports, abstracts and systematic reviews will be excluded.

Data management, screening and selection

All search results will be downloaded into the reference manager ENDNOTE version X7 for screening. The liberal accelerated screening method for the screening of the literature search results will be adopted [23]. Firstly, VM will screen the title, abstract and subject headings of the citations in accordance with the eligibility criteria. Those that meet the eligibility criteria will be included and moved into the next level of assessment as well as those that were unclear. Those that are excluded as per the eligibility criteria will be reviewed by another member of the review team to confirm exclusion or otherwise. Secondly, full-text screening will be carried out by two members of the review team independently. Discussions and consensus building between the two reviewers will be used to resolve discordance and one or two arbitrators will adjudicate unresolved disagreements. In accordance with the PRISMA flow diagram, the entire selection process and reasons for exclusion will be recorded [24, 25]. Questions for screening will be developed in accordance with the eligibility criteria for the two-stage assessment of potentially eligible studies. The screening questions will be piloted, prior to the formal screening processes.

Characteristics of included studies

The content of each included study will be extracted by two independent reviewers and recorded on a standard data collection form utilised in other reviews [24]. The following data will be extracted:

- Publication details: author(s) names, year of publication, country of study and years data were collected
- b. Study setting: population based, clinic-based
- Study design: cross-sectional, cohort, baseline data from RCT, qualitative (focus groups, in-depth interviews)
- d. *Details of study population*: demographics, sample size, eligibility criteria
- e. Sampling methods: consent rates
- f. Measures
- g. Results

During the data extraction process, disagreements will be resolved through discussion and consensus building and one or two arbitrators will adjudicate if needed.

Quality assessment

All quantitative studies will be assessed using the National Heart, Lung and Blood Institute (NHLBI) standardised quality rating tools for quality assessment [26]. The NHLBI standardised tools are study-design specific [26, 27]. Studies having observational cohort and crosssectional designs will be assessed using the NHLBI standardized Quality Assessment Tool for Observational Cohort and Cross-sectional studies. Data only from the baseline phase of RCTs will be included in this review because adherence to self-care behaviours and reporting of barriers may change at follow-up as a result of an intervention. Baseline data only from an RCT represents a cross-sectional assessment and therefore the NHLBI standardized Quality Assessment Tool for Observational Cohort and Cross-sectional studies will also be used for such studies.

The NLBI tools will allow for assessment of potential flaws in study methods including sources of bias, sampling, confounding, study power and other relevant factors. Each study will be judged as "good", "fair" or "poor" quality based on ratings of a list of items included in the tools. Globally, a good study has the least risk of bias and is considered valid. A fair study is prone to some bias but insufficient to invalidate its findings, varying in its strengths and weaknesses. A poor study has high risk of bias and is considered invalid. Quality assessment will be conducted independently by two members of the review team. Differences will be resolved through discussions between these two and if unresolved the other members of the team will be consulted for adjudication.

Qualitative studies will be assessed according to quality assessment categories adopted by Popay, Rogers and Williams [28]. These categories will pertain to relevance and appropriateness of research design, study context, use of convenience/purposive sampling, richness of data, thoroughness of data analysis and clarity of interpretation and logical generalisation of findings based on theoretical underpinnings. This tool has been used widely for assessing the quality of qualitative studies in several systematic reviews [29–31]. It has been reported to be applicable across a wide range of qualitative methods [30, 32].

Data analysis and synthesis

A systematic narrative synthesis will be conducted. Tables and narrative summaries will be used to present the characteristics and findings of included studies. Relationships within and between included studies will be explored as well as assessment of the robustness of the synthesis, in accordance with the Guidance of Narrative Synthesis in Systematic reviews produced by the Economic and Social Research Council (ESRC) methods programme [33]. This guidance provides a framework for the execution of narrative synthesis using both broad and specific techniques and tools. It has been used widely in several systematic reviews [34–38]. VM will conduct the synthesis in consultation with the rest of the review team members.

Discussion

Systematically reviewing the published literature from LMICs will increase knowledge on the self-care behaviours that are commonly adhered to and those that are not among type 2 diabetes patients in LMICs. It will also provide data relating to barriers faced by patients to selfcare for their diabetes and providers to support patients to self-care in LMICs which will assist with the design of interventions to improve care planning and delivery in this population. The inclusion of both qualitative and quantitative studies will allow for a comprehensive review of the published literature.

Additional files

Additional file 1: PRISMA-P checklist. This checklist provides a list of recommended items to include in a systematic review protocol and the pages upon which those items are covered in the protocol. (DOCX 30 kb)

Abbreviations

ESRC: Economic and social research council; GNI: Gross national income per capital; IDF: International diabetes federation; LMICs: Low- and middleincome countries; NHLBI: National Heart, Lung and Blood Institute; PRESS: Peer review of electronic search strategies; PRISMA-P: Preferred Reporting Items for Systematic Review and Meta-Analysis Protocol; RCTs: Randomised controlled trials; WHO: World Health Organization

Acknowledgements

The authors wish to thank Debbie Booth, a Senior Research Librarian at the University of Newcastle for her assistance in identifying the key words of the review. The authors also wish to acknowledge infrastructure support from the Hunter Medical Research Institute, Australia.

Funding

VM was supported by the Research Training Scheme of the University of Newcastle, Australia. CP was supported by an NHMRC career development fellowship.

Availability of data and materials Not applicable

Authors' contributions

VM conceived and designed the study, and drafting of manuscript; FT, NAJ, CP and JS jointly undertook critical revision of the manuscript. All authors approved the manuscript for publication.

Competing interests

The authors declare that they have no competing interests.

Consent for publication

Ethics approval and consent to participate

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Received: 6 December 2016 Accepted: 17 February 2017 Published online: 27 February 2017

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2.2 Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies used for data presented in Chapter 2 Study title:

Author(s) and year of publication:

Critaria	Vos	No	Other (CD, NR, NA)*
1. Was the research question or objective in this paper clearly	105	110	
stated?			
2. Was the study nonvelotion alconfy specified and defined?			
2. Was the study population clearly specified and defined?			
3. Was the participation rate of eligible persons at least 50%?			
4. Were all the subjects selected or recruited from the same or			
similar populations (including the same time period)? Were			
inclusion and exclusion criteria for being in the study			
specified and applied uniformly to all participants?			
5. Was a sample size justification, power description, or			
variance and effect estimates provided?			
6. For the analyses in this paper, were the exposure(s) of			
interest measured prior to the outcome(s) being measured?			
7. Was the timeframe sufficient so that one could reasonably			
expect to see an association between exposure and outcome if			
it existed?			
8. For exposures that can vary in amount or level, did the			
study examine different levels of the exposure as related to the			
outcome (e.g., categories of exposure, or exposure measured			
as continuous variable)?			
9. Were the exposure measures (independent variables)			
clearly defined, valid, reliable, and implemented consistently			
across all study participants?			
10. Was the exposure(s) assessed more than once over time?			
11. Were the outcome measures (dependent variables) clearly			
defined, valid, reliable, and implemented consistently across			
all study participants?			
12. Were the outcome assessors blinded to the exposure status			
of participants?			
13. Was loss to follow-up after baseline 20% or less?			
14. Were key potential confounding variables measured and			
adjusted statistically for their impact on the relationship			
between exposure(s) and outcome(s)?			
Total score			

*CD, cannot determine; NA, not applicable; NR, not reported

Quality Rating (Good, Fair, or Poor)

Rater #1 initials:

Rater #2 initials:

Additional Comments (If POOR, please state why):

APPENDIX B 2: RELATED INFORMATION FOR CHAPTERS 3 AND 4

3.1 Information concerning data used for Chapters 3 and 4

The data used for the papers presented in Chapters 3 and 4 were collected via multiple substudies which had separate ethical approvals; such that some of the data collected for chapters 3 and 4 occurred immediately prior to enrolment in the PhD, and UON subsequently provided ethical approvals for inclusion of these data in the thesis. 3.2 Discussion guide used for assessing the face validity of the Summary of diabetes selfcare activities measure for Chapter 3



A/Prof Christine Paul NHMRC Career Development Fellow School of Medicine and Public Health University Drive Callaghan NSW 2308 University of Newcastle Australia Phone: +61 2 4042 0693 Email: chris.paul@newcastle.edu.au

Assessing the face validity of the Summary of diabetes self-care activities measure

Now that you finish answering the questions of the questionnaire I will like to ask you the following questions

Ease of use

Do you consider each of these statements easy to answer?

(If not – which ones are not easy to answer and can you tell me why they are not easy to answer?

How could these questions be improved to make them easier to answer?

Clarity

Are the questions clear to you?

If not – How could these questions be made clearer?

Are the instructions clear to you?

If not- How could these instructions be made clearer?

Is the response scale clear to you?

If not – How could the response scale be made clearer?

Readability

Are there any words, phrases or statements that are difficult for you to understand?

If so, please indicate which one(s)

Of the statements that you find difficult to understand, what do you think they meant?

How could the wording of these questions be improved?

Relevance:

Do these items relate to how you care for your diabetes?

Are there any new questions that you would also include that relate to how you care for your diabetes?

General comments

Do you think that your answers to each of the items accurately reflect your experiences in the last seven days?

If not – tell me what you think might not have been accurate (and if possible, why)

Is there anything about how you care for diabetes that is not captured in the questions that you would like to add?

3.3 The SDSCA tool used for assessing adherence to diabetes self-care used in Chapter 3

A/Prof Christine Paul

NHMRC Career Development Fellow School of Medicine and Public Health University Drive Callaghan NSW 2308 University of Newcastle Australia Phone: +61 2 4042 0693 Email: chris.paul@newcastle.edu.au



The following are questions intended to assess the frequency with which you follow self-care activities as recommended by your doctor. Can you answer these items and then I will ask you some questions about how you found this survey.

SELF-CARE BEHAVIOURS MEASURE

- How many of the last SEVENDAYS have you followed a healthful eating plan?
 0 1 2 3 4 5 6 7
- On average, over the past month, how many DAYS PER WEEK have you followed your eating plan? 01234567
- On how many of the last SEVEN DAYS did you eat five or more servings of fruits and vegetables? 01234567
- 4. On how many of the last SEVEN DAYS did you eat high fat foods such as red meat or full-fat dairy products? 0 1 2 3 4 5 6 7
- 5. On how many of the last SEVEN DAYS did you participate in at least 30 minutes of physical activity? (Total minutes of continuous activity, including walking).
 0 1 2 3 4 5 6 7
- 6. On how many of the last SEVEN DAYS did you participate in a specific exercise session (such as swimming, walking, biking) other than what you do around the house or as part of your work?
 0 1 2 3 4 5 6 7

- 7. On how many of the last SEVEN DAYS did you test your blood sugar? 0 1 2 3 4 5 6 7
- On how many of the last SEVEN DAYS did you test your blood sugar the number of times recommended by your health care provider? 0 1 2 3 4 5 6 7

On how many of the last SEVEN DAYS did you check your feet? 0 1 2 3 4 5 6 7

9. On how many of the last SEVEN DAYS did you inspect the inside of your shoes?

 $0 \quad 1 \; 2 \; 3 \; 4 \; 5 \; 6 \; 7 \\$

10. Have you smoked a cigarette-even one puff-during the past SEVEN DAYS?

1. No 2. Yes.

If yes, how many cigarettes did you smoke on an average day?

Number of cigarettes:

3.4 Questionnaire for assessing adherence and associated factors among people with type 2 diabetes used in Chapter 4 and 5

I would like to have an interview with you about your condition and I would appreciate your participation. The information you would provide will be used to assess the self-care behaviours and perception of risk of developing cardiovascular complications among diabetes patients. This interview will takes 15 minutes to complete. All of the answers you will give will be confidential and be used for the intended purpose only.

May we begin the interview now?

- 1. Yes
- 2. No

SOCIO-DEMOGRAPHIC CHARACTERISTICS

- 1. Gender [1] Male [2] Female
- 2. Age:
- 3. What is your religion?

[1] Christianity [2] Islam [3] A.T.R [4] Other (specify):

4. What is your highest education level completed?

[1] None [2] Primary [3] Middle/J.H.S [4] S.H.S/Vocational T. [5] Tertiary

[6]Other(specify):

5. Number of years spent schooling.....

6. Marital status: [1] Single [2] Married [3] Divorced [4] Widowed [5] Separated

7. What is your occupation? [1] Civil servant [2] Businessman/women [3] Unemployed [4]Others(specify):
8. How many years have been living with this condition.....

9. Have any of the members of your immediate family or other relatives been diagnosed with diabetes (type1 and type 2)?2. No1. Yes (grandparent, aunt, uncle or first cousin (but no own parent, brother, sister or child)3. Yes (Parent, brother, sister or own child)

SELF-CARE BEHAVIOURS

Diet

- 11. How many of the last SEVENDAYS have you followed a healthful eating plan?0 1 2 3 4 5 6 7
- 12. On average, over the past month, how many DAYS PER WEEK have you followed your eating plan? 0 1 2 3 4 5 6 7
- 13. On how many of the last SEVEN DAYS did you eat five or more servings of fruits and vegetables? 0 1 2 3 4 5 6 7
- 14. On how many of the last SEVEN DAYS did you eat high fat foods such as red meat or full-fat dairy products? 0 1 2 3 4 5 6 7

Exercise

- On how many of the last SEVEN DAYS did you participate in at least 30 minutes of physical activity? (Total minutes of continuous activity, including walking).
 0 1 2 3 4 5 6 7
- 2. On how many of the last SEVEN DAYS did you participate in a specific exercise session (such as swimming, walking, biking) other than what you do around the house or as part of your work? 0 1 2 3 4 5 6 7

Blood Sugar Testing

On how many of the last SEVEN DAYS did you test your blood sugar? 0 1 2 3 4 5 6

2. On how many of the last SEVEN DAYS did you test your blood sugar the number of times recommended by your health care provider? 0 1 2 3 4 5 6 7

Foot Care

- 1. On how many of the last SEVEN DAYS did you check your feet? 0 1 2 3 4 5 6 7
- On how many of the last SEVEN DAYS did you inspect the inside of your shoes?
 0 1 2 3 4 5 6 7

Smoking

1. Have you smoked a cigarette—even one puff—during the past SEVEN DAYS?

1. No 2. Yes.

If yes, how many cigarettes did you smoke on an average day?

Number of cigarettes:

Anthropometry

Weight:

Height:

Waist circumference:

APPENDIX B 3: RELATED INFORMATION FOR CHAPTERS 5 AND 6

5.1 Participant information statement used for data collection in Chapter 5

Information statement

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Information Statement for the Research Project:

Barriers to self-care study

Dear Sir/Madam,

You are invited to participate in the above identified research project conducted by Victor Mogre who is undertaking the research as part of his PhD studies at the University of Newcastle. The chief investigator, A/Prof. Christine Paul, from the School of Medicine and Public Health at the University of Newcastle, Dr. Flora Tzelepis and Natalie A. Johnson both from the School of Medicine and Public Health, University of Newcastle, are co-investigators.

Why is the research being done?

- The purpose of the research is to explore Ghanaian type 2 diabetes patients' barriers to the adherence of recommended diabetes self-care behaviours.
- Furthermore, it aims to evaluate the face validity of the revised Summary of Diabetes Self Care Activities questionnaire.
- The findings of the study will increase our understanding of barriers experienced by patients in their quest to adhere to self-care behaviours.
- The evidence will help in the design of interventions to improve adherence to self-care behaviours among type 2 diabetes patients.

Who can participate in the research?

- People with Type 2 diabetes aged 18 years and older, registered with the selected diabetes clinic and have sought for care from the selected diabetes clinics twice during the last 12 months.
- Those with type 1 diabetes and/or younger than 18 years will not be eligible to participate in the study.

What would you be asked to do?

- If you agree to participate, you will be asked to participate in a semi-structured interview that will be audio-taped.
- The interviews will be conducted in a secluded room at the diabetes clinic by a trained research assistant.
- The interview will cover issues relating to your understanding of diabetes and how you self-care for your diabetes.
- Furthermore, you will be asked to assess the face validity of the revised Summary of Diabetes Self Care Activities questionnaire.

What choice do you have?

- Participation in this research is entirely your choice.
- Only those people who give their informed consent will be included in the project.

- Whether or not you decide to participate, your decision will not disadvantage you.
- If you do decide to participate, you may withdraw from the project at any time without giving a reason.

How much time will it take?

• The interview will take about 20 minutes to complete.

What are the risks and benefits of participating?

- There will be no benefit to you in participating in this research.
- No risks to participating in this study have been identified

How will your privacy be protected?

- All audiotaped interviews will be transcribed without identifying information.
- All results will be reported as themes and all codes will be presented de-identified
- Data will be retained for at least 5 years on the University of Newcastle's ownCloud secure server.
- All the audio recordings will be stored on the University of Newcastle's ownCloud secure server.
- Research assistant will sign a confidentiality agreement for the transcribing of the interview data.
- Data will be securely destroyed in line with UON policy provisions for research conducted by University staff and students at least a copy of the data used for analysis is to be held at the University of Newcastle.

How will the information collected be used?

- The results will be used to show the kinds of barriers experienced by type 2 diabetes in their quest to self- care for their condition.
- This will enable us to determine what can be done to improve type 2 diabetes patients' adherence to self-care behaviours.

- The findings of the research will be presented in scientific journals as peer reviewed publications and at conferences.
- They will be included in the thesis of Victor Mogre as part of his PhD. Individual participants will not be identified in any reports arising from the project.
- Given the fact that the interviews will be audiotaped and transcribed, you will be able to review the recording and transcripts to edit or erase your contribution.
- Non-identifiable data may be also be shared with other parties to encourage scientific scrutiny, and to contribute to further research and public knowledge, or as required by law.
- If you would like a copy of the summary of the results, please email the Chief Investigator through <u>chris.paul@newcastle.edu.au</u> after 30th October, 2017.

What do you need to do to participate?

- Please read this Information Statement and be sure you understand its contents before you consent to participate.
- If there is anything you do not understand, or you have questions, contact Victor Mogre (PhD Candidate) via 0208442438 or Christine Paul (Chief Investigator) through <u>chris.paul@newcastle.edu.au</u>.
- If you would like to participate, please complete the attached informed consent form and we will proceed to arrange for a convenient place to have the interview.

Further information

• If you would like further information please contact Victor Mogre (Phd Candidate) via 0208442438 and Christine Paul (Chief Investigator) via chris.paul@newcastle.edu.au.

Thank you for considering this invitation.

THE RESEARCH TEAM

A/Prof. Christine Paul	Victor Mogre
NHMRC Career Development Fellow	PhD Candidate

Dr. Flora Tzelepis

Dr. Natalie A. Johnson

Post-Doctoral Research Fellow

Senior Lecturer

Complaints about this research

This project has been approved by the University's Human Research Ethics Committee, Approval No. **H-2017-0118.**

Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Human Research Ethics Officer, Research Services, NIER Precinct, The University of Newcastle, University Drive, Callaghan NSW 2308, Australia, telephone (02) 4921 6333, email: <u>Human-Ethics@newcastle.edu.au</u>.

5.2 Participant information statement for healthcare providers used to collect data for papers presented in Chapters 5 and 6

Information Statement

A/Prof Christine Paul NHMRC Career Development Fellow School of Medicine and Public Health University Drive Callaghan NSW 2308 University of Newcastle Australia Phone: +61 2 4042 0693 Email: chris.paul@newcastle.edu.au



Information Statement for the Research Project:

Patient barriers to self-care and healthcare providers' barriers to self-care support

Dear Sir/Madam,

You are invited to participate in the research project identified above which is being conducted by Victor Mogre who is undertaking the research as part of his PhD studies at the University of Newcastle. The chief investigator A/Prof. Christine Paul, from the School of Medicine and Public Health at the University of Newcastle. Dr. Flora Tzelepis and Natalie A Johnson both from the School of Medicine and Public Health, University of Newcastle, are coinvestigators.

Why is the research being done?

- The purpose of the research is to explore barriers experienced by healthcare providers in the provision of self-care support to type 2 diabetes patients.
- The findings of the study will increase our understanding of barriers experienced by providers as they strive to provide self-care support to diabetes patients.

• The evidence will help in the design of interventions to improve adherence to self-care behaviours among type 2 diabetes patients.

Who can participate in the research?

- Health care providers (HCPs) will be recruited from the diabetes clinics of the three hospitals.
- HCPs will be selected based on their primary role in diabetes care.
- Also HCPs will be eligible to participate if they have worked in the diabetes clinic ≥ 3 months.

What would you be asked to do?

- If you agree to participate, you will be asked to participate in a semi-structured interview that will audio-taped.
- The interviews will be conducted in a secluded room at the diabetes clinic by a trained research assistant.
- The interview will cover issues relating to challenges you experience in providing self-care support to diabetes patients

What choice do you have?

- Participation in this research is entirely your choice.
- Only those people who give their informed consent will be included in the project.
- Whether or not you decide to participate, your decision will not disadvantage you.
- If you do decide to participate, you may withdraw from the project at any time without giving a reason.

How much time will it take?

• The interview will take about 20 minutes to complete.

What are the risks and benefits of participating?

- There will be no benefit to you in participating in this research.
- No risks to participating in this study have been identified

How will your privacy be protected?

- All audiotaped interviews will be transcribed without identifying information.
- All results will be reported as themes and all codes will be presented de-identified
- Data will be retained for at least 5 years on the University of Newcastle's ownCloud secure server.
- All the audio recordings will be stored on the University of Newcastle's ownCloud secure server.
- Research assistant will sign a confidentiality agreement for the transcribing of the interview data.
- Data will be securely destroyed in line with UON policy provisions for research conducted by University staff and students at least a copy of the data used for analysis is to be held at the University of Newcastle.

How will the information collected be used?

- The results will be used to show the challenges faced by healthcare providers in the provision of self-care support to diabetes patients.
- This will enable us to determine what can be done to improve healthcare providers' performance of self-care support to patients.
- The findings of the research will be presented in scientific journals as peer reviewed publications and at conferences.
- They will be included in the thesis of Victor Mogre as part of his PhD. Individual participants will not be identified in any reports arising from the project.
- Given the fact that the interviews will be audiotaped and transcribed, you will be able to review the recording and transcripts to edit or erase your contribution.
- Non-identifiable data may be also be shared with other parties to encourage scientific scrutiny, and to contribute to further research and public knowledge, or as required by law.

• If you would like a copy of the summary of the results, please email the Chief Investigator through <u>chris.paul@newcastle.edu.au</u> after 30th October, 2017.

What do you need to do to participate?

- Please read this Information Statement and be sure you understand its contents before you consent to participate.
- If there is anything you do not understand, or you have questions, contact Victor Mogre (PhD Candidate) via 0208442438 or Christine Paul (Chief Investigator) through <u>chris.paul@newcastle.edu.au</u>.
- If you would like to participate, please complete the attached informed consent and we will proceed to arrange for a convenient place to have the interview.

Further information

• If you would like further information please contact Victor Mogre (Phd Candidate) via 0208442438 and Christine Paul (Chief Investigator) via chief.paul@newcastle.edu.au.

Thank you for considering this invitation.

THE RESEARCH TEAM

A/Prof. Christine Paul

NHMRC Career Development Fellow

Dr. Flora Tzelepis

Post-Doctoral Research Fellow

Victor Mogre

PhD Candidate

Dr. Natalie A. Johnson

Senior Lecturer

Complaints about this research

This project has been approved by the University's Human Research Ethics Committee, Approval No. **H-2017-0118**.

Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Human Research Ethics Officer, Research Services, NIER Precinct, The University of Newcastle, University Drive, Callaghan NSW 2308, Australia, telephone (02) 4921 6333, email: <u>Human-Ethics@newcastle.edu.au</u>.

5.3 Consent form for patients (used in Chapter 5)

Consent Form for patients

A/Prof Christine Paul NHMRC Career Development Fellow School of Medicine and Public Health University Drive Callaghan NSW 2308 University of Newcastle Australia Phone: +61 2 4042 0693 Email: chris.paul@newcastle.edu.au



Consent Form for the Research Project:

A qualitative study of Ghanaian type 2 diabetes patients' barriers to self-care behaviours and barriers to health care providers' provision of self-care support

Christine Paul, Victor Mogre, Flora Tzelepis, and Natalie A Johnson

I agree to participate in the above research project and provide my consent freely by signing this form.

I understand that:

- The project will be conducted as described in the Information Statement, a copy of which I have retained.
- I can withdraw from the project at any time, and do not have to give any reason for withdrawing.
- My personal information will remain confidential to the researchers

I have also had the opportunity to have questions answered to my satisfaction.

I consent to:

1. Participating in an interview and having it recorded

2. Assess the face validity of a self-care adherence questionnaire

Print Name:

Contact:	
Signature:	Date:
THE RESEARCH TEAM	
A/Prof. Christine Paul	Victor Mogre
NHMRC Career Development Fellow	PhD Candidate
Dr. Flora Tzelepis	Dr. Natalie A. Johnson
Post-Doctoral Research Fellow	Senior Lecturer

5.4 Consent form for health care providers (used in Chapters 5 and 6)

Consent Form for healthcare providers

A/Prof Christine Paul NHMRC Career Development Fellow School of Medicine and Public Health University Drive Callaghan NSW 2308 University of Newcastle Australia Phone: +61 2 4042 0693

Email: chris.paul@newcastle.edu.au



Consent Form for the Research Project:

A qualitative study of Ghanaian type 2 diabetes patients' barriers to self-care behaviours and barriers to health care providers' provision of self-care support

Christine Paul, Victor Mogre, Flora Tzelepis, Natalie A Johnson

I agree to participate in the above research project and give my consent freely.

I understand:

- That the project will be conducted as described in the Information Statement, a copy of which I have retained.
- I can withdraw from the project at any time, and do not have to give any reason for withdrawing.
- My personal information will remain confidential to the researchers.

I have also had the opportunity to have questions answered to my satisfaction.

I consent to:

- 3. Participating in an interview concerning barriers to the provision of self-care support.
- 4. Having the interview recorded.

Print Name:

Contact:	
Signature:	_Date:
THE RESEARCH TEAM	
A/Prof. Christine Paul	Victor Mogre
NHMRC Career Development Fellow	PhD Candidate
Dr. Flora Tzelepis	Dr. Natalie A. Johnson
Post-Doctoral Research Fellow	Senior Lecturer

5.5 Organisational consent form for the Tamale Teaching Hospital used in Chapters 5

and 6

Consent Form (Organisational)

A/Prof Christine Paul

NHMRC Career Development Fellow School of Medicine and Public Health University Drive Callaghan NSW 2308 University of Newcastle Australia Phone: +61 2 4042 0693 Email: chris.paul@newcastle.edu.au



Consent Form for the Research Project:

A qualitative study of Ghanaian type 2 diabetes patients' barriers to self-care behaviours and barriers to health care providers' provision of self-care support

Christine Paul, Victor Mogre, Flora Tzelepis, and Natalie A Johnson

On behalf of the Tamale Teaching Hospital (TTH), I agree to the diabetes clinic of TTH participating in the above research project and provide my consent freely by signing this form.

I understand that:

- The project will be conducted as described in the Information Statement, a copy of which I have retained.
- TTH or any diabetes patient can withdraw from the project at any time, and do not have to give any reason for withdrawing.
- The personal information of patients will remain confidential to the researchers.
- I have also had the opportunity to have questions answered to my satisfaction.

I consent to the TTH diabetes clinic staff:

5. Assist in identifying diabetes patients to be approached to participate in interviews.

- 6. Assists with scheduling a convenient time to approach diabetes patients to participate in interviews.
- 7. Assists in identifying and providing a secluded room to interview consented diabetes patients.
- 8. Participating in interviews to assess barriers to providing self-care support to diabetes patients.

Print		Name:
Contact		Details
Signature:	Date:	
THE RESEARCH TEAM		
A/Prof. Christine Paul	Victor Mogre	
NHMRC Career Development Fellow	PhD Candidate	
Dr. Flora Tzelepis	Dr. Natalie A. John	son
Post-Doctoral Research Fellow	Senior Lecturer	

5.6 Organisational consent form for the Tamale Central Hospital used for data

collection in Chapters 5 and 6

Consent Form (Organisational)

A/Prof Christine Paul NHMRC Career Development Fellow School of Medicine and Public Health University Drive Callaghan NSW 2308 University of Newcastle Australia Phone: +61 2 4042 0693 Email: chris.paul@newcastle.edu.au



Consent Form for the Research Project:

A qualitative study of Ghanaian type 2 diabetes patients' barriers to self-care behaviours and barriers to health care providers' provision of self-care support

Christine Paul, Victor Mogre, Flora Tzelepis, and Natalie A Johnson

On behalf of the Tamale Central Hospital, I agree to the diabetes clinic of the hospital participating in the above research project and provide my consent freely by signing this form.

I understand that:

- The project will be conducted as described in the Information Statement, a copy of which I have retained.
- TTH or any diabetes patient can withdraw from the project at any time, and do not have to give any reason for withdrawing.
- The personal information of patients will remain confidential to the researchers

I have also had the opportunity to have questions answered to my satisfaction.

I consent to the TTH diabetes clinic staff:

1. Assist in identifying diabetes patients to be approached to participate in interviews.

2. Assists with scheduling a convenient time to approach diabetes patients to participate in interviews.

3. Assists in identifying and providing a secluded room to interview consented diabetes patients.

4. Participating in interviews to assess barriers to providing self-care support to diabetes patients.

5.7 Organisational consent form for the Tamale West Hospital used for data collection

in Chapters 5 and 6

Consent Form (Organisational)

A/Prof Christine Paul

NHMRC Career Development Fellow School of Medicine and Public Health University Drive Callaghan NSW 2308 University of Newcastle Australia Phone: +61 2 4042 0693 Email: chris.paul@newcastle.edu.au



Consent Form for the Research Project:

A qualitative study of Ghanaian type 2 diabetes patients' barriers to self-care behaviours and barriers to health care providers' provision of self-care support

Christine Paul, Victor Mogre, Flora Tzelepis, and Natalie A Johnson

On behalf of the Tamale West Hospital, I agree to the diabetes clinic of the hospital participating in the above research project and provide my consent freely by signing this form.

I understand that:

- The project will be conducted as described in the Information Statement, a copy of which I have retained.
- TTH or any diabetes patient can withdraw from the project at any time, and do not have to give any reason for withdrawing.
- The personal information of patients will remain confidential to the researchers.

I have also had the opportunity to have questions answered to my satisfaction.

I consent to the TTH diabetes clinic staff:

1. Assist in identifying diabetes patients to be approached to participate in interviews.

2. Assists with scheduling a convenient time to approach diabetes patients to participate in interviews.

3. Assists in identifying and providing a secluded room to interview consented diabetes patients.

4. Participating in interviews to assess barriers to providing self-care support to diabetes patients.

Print		Name:
Contact		Details
Signature:	Date:	

THE RESEARCH TEAM

A/Prof. Christine Paul

NHMRC Career Development Fellow

Dr. Flora Tzelepis

Victor Mogre

PhD Candidate

Dr. Natalie A. Johnson

Post-Doctoral Research Fellow

Senior Lecturer

5.8 Discussion guide for patients used for data collection for the paper presented in Chapter 5

DISCUSSION GUIDE

A/Prof Christine Paul NHMRC Career Development Fellow School of Medicine and Public Health University Drive Callaghan NSW 2308 University of Newcastle Australia Phone: +61 2 4042 0693 Email: chris.paul@newcastle.edu.au



A qualitative study of Ghanaian type 2 diabetes patients' barriers to self-care behaviours

Discussion guide for patients' interview

Demographics

Gender:

Age:

Level of education:

Living with diabetes

Tell me about when you were first diagnosed with diabetes

Probes:

How long ago was that?

Now I would like to ask you about the information you have received about diabetes since you were diagnosed.

Knowledge about lifestyle modifications in diabetes and source of information What changes can you make in your life to keep your diabetes from making you sick?

How did you find out about these changes?

What do you think about the information you received?

Probes:

How useful was the information you received?

What could be improved about the information you received?

What (if any) information about your diabetes do you find hard to understand?

Probe:

What makes the information confusing?

Next I would like to find out how you manage your diabetes

Attitude towards diabetes self-care

What do you think about making changes in your life as a result of your diabetes?

Probes: (*Physical activity, diet, self-monitoring of blood glucose, medication taking and insulin, risk of hyper/hypoglycaemia, etc*).

Now I would like to talk one by one about these things - diet, then exercise and so on.

Adherence to self-care behaviours and associated barriers

Diet What is your diet like?

What advice/information have you received regarding what you eat and diabetes?

Have you been able to follow such advice?

Probe – if not, why not or what has made it difficult to follow that advice?

Are there any areas you feel you are struggling with?

What are they?

Why do you think you are finding it hard?

Probe for: Cost, access to healthy foods and availability, family support

What type of assistance would help you to improve your diet?

Do you think you will follow the recommended dietary advice in the future?

Why/why not?

Physical activity

What advice/information have you received regarding physical activity/keeping active and diabetes? How helpful was it?

Have you been able to follow such advice?

Probe – if not, why not or what has made it difficult to follow that advice?

Are there any areas you feel you are struggling with?

What are they?

Why do you think you are finding it hard?

Probes: Time, places to exercise, family support

What type of assistance would help you to improve your physical activity?

Do you think you will follow the recommended advice in the future?

Probe: Why/why not?

Medication taking

Do you take medications as part of the treatment for your diabetes? (If no skip the rest of the questions regarding medication taking)

Have you received any advice regarding your diabetes medication?

What advice/information have you received regarding taking medications for your diabetes?

How helpful was it?

Have you been able to follow such advice of taking your medications?

Probe – if not, why not or what has made it difficult to follow that advice?

What are some of the difficulties you face in taking your diabetes medications?

Are there any areas you feel you are struggling with?

What are they?

Why do you think you are finding it hard?

Probe for: Cost, taking dosage correctly, family support, forget

What type of assistance would help you to improve your medication taking?

Do you think you will follow the recommended advice in the future?

Why/why not?

SMBG

Have you been advised to check your blood glucose?

Probes: Did anyone tell you / show you how?

What advice/information have you received concerning checking of your blood glucose? How helpful was it?

Have you been able to follow such advice of checking your blood glucose?

Probe – if not, why not or what has made it difficult to follow that advice?

What blood sugar level has your doctor suggested is good for you?

Have been able to achieve it? **Probe:** Why/why not

Are there any areas you feel you are struggling with? What are they?

What makes it hard for you to check your blood sugar?

Probe for: cost of glucometers, availability of glucometers, operation of glucometers, etc

What type of assistance would help you to improve the self-monitoring of your blood glucose?

Do you think you will follow the recommended advice in the future?

Why/why not?

What do you do when you feel shaky, hungry and sweaty or

What do you do when you feel thirsty, tired and weak?

Foot care

Have you been advised to check your feet?

Probe: What advice/information have you received?

Have you been able to follow such advice of checking your feet?

Probe – if not, why not or what has made it difficult to follow that advice?

Are there any areas you feel you are struggling with?

What are they?

Why do you think you are finding it hard?

Probe for: Time, lack of podiatrist, family support

What type of assistance would help you to improve your foot care?

Do you think you will follow the recommended advice in the future?

Probe: Why/why not?

We have discussed each of the self-care behaviours one by one. Now I would like to go back to talking more generally about managing your diabetes self-care.

Subjective norm: social pressure Do the opinions or actions of your family and friends affect the way that you carry out your self-care?

If so, how?

What support, if any, does your family/friends give you to help you care for your diabetes?

Perceived control and self-confidence to perform the behaviour

How confident do you feel about managing your diabetes?

In which aspects of your diabetes self-care do you perceive that you have control?

Probe: Why?

In which aspects of your diabetes self-care do you perceive that it is outside your control?

Are you trying to make any changes to your diabetes self-care behaviour in the next month?

Are you using any strategies or aids to try and help you make those changes?

(E.g. pill box with days of week, a set shopping list, a friend to exercise with).

What are those strategies?

Conclusion

That's all the questions I have for you.

Is there anything else about managing your diabetes that you would like to talk about?

5.9 Discussion guide for healthcare providers used for data collection for papers

presented in Chapters 5 and 6

A/Prof Christine Paul NHMRC Career Development Fellow School of Medicine and Public Health University Drive Callaghan NSW 2308 University of Newcastle Australia Phone: +61 2 4042 0693 Email: chris.paul@newcastle.edu.au



Perception of patient barriers to self-care and barriers encountered in providing selfcare support to patients

Discussion guide for providers

Demographics

Gender:

Type of healthcare provider:

Number of years working in the diabetes clinic:

Age:

General questions

I would like to ask some general questions relating to the self-care support you provide to type 2 diabetes patients who visit this clinic

- 1. Please describe your responsibilities with regard to type 2 diabetes care.
- 2. What type of self-care behaviours do you usually recommend to type 2 diabetes patients?
- 3. What type of advice or assistance do you usually offer to type 2 diabetes patients to help them manage their diabetes? Probe: advice, education or information
- 4. How often do you talk to type 2 diabetes patients about their self-care behaviours?

Provider attitude

Now I would like to ask you questions regarding what you think about your role in providing self-care support and the benefits of patients' adherence to self-care behaviours

- 5. Do you think it is part of your health care professional role to provide self-care support to type 2 diabetes patients? Probe for reasons
- 6. How important do you think it is that type 2 diabetes patients perform self-care behaviours?

Patient level barriers Next I would like to ask you about what your patients encounter when they are trying to manage their diabetes.

- 7. How well do you think your patients understand type 2 diabetes?
- 8. What type of self-care advice do your patients ask for most frequently? Probe to find out whether patients have misconceptions regarding self-care behaviours.
- 9. How well do you think your patients with type 2 diabetes follow self-care advice? Prompt regarding each of:
 - Dietary
 - Exercise
 - SMBG
 - Medications
 - Foot care
- 10. (If non-adherence): What do you think are the reasons why some type 2 diabetes patients do not follow self-care advice?
- 11. What barriers do you think your patients with type 2 diabetes encounter when trying to follow self-care advice?
- 12. How do you think culture influences your type 2 diabetes patients' ability to self-care for their disease?
- 13. To what extent do you think your type 2 diabetes patients get support from their family and/or society to self-care for their disease? Probe for explanations

Provider level

Now I would like to know the barriers you experience in providing diabetes self-care support to type 2 diabetes patients.

- 14. What things assist you with providing diabetes self-care support to type 2 diabetes patients?
- 15. What do you think are some things that make it difficult for you to provide diabetes selfcare support to type 2 diabetes patients?
- 16. What barriers do you encounter in terms of your skills and expertise for supporting patients to self-care for their diabetes? Probe for all the self-care behaviours
- 17. What barriers do you encounter when providing self-care support to patients in terms of the following (allow participant to provide barriers to each of the items listed below)
 - a. During the consultation when providing self-care support

- b. In accessing comprehensive and up-to-date information about self-care support
- c. Seeking advice and support from other healthcare providers
- d. Any other areas that were not covered above

Practice level

Next our discussion will focus on barriers you experience at the institutional level when providing self-care support to type 2 diabetes patients.

18. What barriers do you encounter at the practice level while providing self-care support for your patients (e.g. barriers with organization of diabetes care, insurance policies, guidelines for diabetes self-care, etc)?

APPENDIX B 4: RELATED INFORMATION FOR CHAPTER 7

7.1 Participant information statement for patients used for data collection in Chapter 7

Information statement

Prof Christine Paul Co-Deputy Director, Hunter Cancer Research Alliance Associate Dean (Research) SMPH School of Medicine and Public Health University Drive Callaghan NSW 2308 University of Newcastle Australia Phone: +61 2 4042 0693 Email: chris.paul@newcastle.edu.au



Information Statement for the Research Project:

Cross-sectional study of prevalence of barriers

Dear Sir/Madam,

You are invited to participate in the above identified research project conducted by Victor Mogre who is undertaking the research as part of his PhD studies at the University of Newcastle. The chief investigator, A/Prof. Christine Paul, from the School of Medicine and Public Health at the University of Newcastle, Dr. Flora Tzelepis and Natalie A. Johnson both from the School of Medicine and Public Health, University of Newcastle, are co-investigators.

Why is the research being done?

• The purpose of the research is to determine the prevalence of patient barriers to diabetes self-care among type 2 diabetes patients in Tamale.

- The findings of the study will increase our understanding of the prevalence of barriers experienced by patients in their quest to adhere to self-care behaviours.
- The evidence will help in the design of interventions to improve adherence to self-care behaviours among type 2 diabetes patients.

Who can participate in the research?

- People with Type 2 diabetes aged 18 years and older, registered with the selected diabetes clinic and have sought for care from the selected diabetes clinics twice during the last 12 months.
- Those with type 1 diabetes and/or younger than 18 years will not be eligible to participate in the study.

What would you be asked to do?

- If you agree to participate, you will be asked to complete a 20-minute survey using a paper questionnaire that will be handed out to you after consultation with your healthcare provider. The survey will ask you questions about your diabetes relating to barriers to self-care, attitudes towards diabetes self-care, alcohol consumption, and competence for diabetes self-care, depression, and receipt of self-care advice.
- Information regarding you blood pressure, fasting blood glucose and/or HbA1c results will also be recorded from your health folder during the survey.
- Your weight and height will also be measured after completing the survey. This will be used to compute your BMI.

What choice do you have?

- Participation in this research is entirely your choice.
- Only those people who give their informed consent will be included in the project.
- Whether or not you decide to participate, your decision will not disadvantage you.
- If you do decide to participate, you may withdraw from the project at any time without giving a reason.

How much time will it take?

• The interview will take about 20 minutes to complete.

What are the risks and benefits of participating?

- There will be no benefit to you in participating in this research.
- No risks to participating in this study have been identified

How will your privacy be protected?

- All data will be de-identified and analysed without any identifying information
- All results will be reported as frequencies and proportions
- Data will be retained for at least 5 years on the University of Newcastle's ownCloud secure server.
- All data will be stored on the University of Newcastle's ownCloud secure server.
- Research assistant will sign a confidentiality agreement for the transcribing of the interview data.
- Data will be securely destroyed in line with UON policy provisions for research conducted by University staff and students at least a copy of the data used for analysis is to be held at the University of Newcastle.

How will the information collected be used?

- The results will be used to show magnitude of barriers that hinder patients' adherence to self-care behaviours.
- This will enable us to determine what can be done to improve type 2 diabetes patients' adherence to self-care behaviours.
- The findings of the research will be presented in scientific journals as peer reviewed publications and at conferences.
- They will be included in the thesis of Victor Mogre as part of his PhD. Individual participants will not be identified in any reports arising from the project.
- Non-identifiable data may be also be shared with other parties to encourage scientific scrutiny, and to contribute to further research and public knowledge, or as required by law.
- If you would like a copy of the summary of the results, please email the Chief Investigator through <u>chris.paul@newcastle.edu.au</u> after 30th October, 2017.

What do you need to do to participate?

- Please read this Information Statement and be sure you understand its contents before you consent to participate.
- If there is anything you do not understand, or you have questions, contact Victor Mogre (PhD Candidate) via 0208442438 or Christine Paul (Chief Investigator) through <u>chris.paul@newcastle.edu.au</u>.
- If you would like to participate, please complete the attached informed consent form and we will proceed to arrange for a convenient place to have the interview.

Further information

• If you would like further information please contact Victor Mogre (Phd Candidate) via 0208442438 and Christine Paul (Chief Investigator) via <u>chris.paul@newcastle.edu.au</u>.

Thank you for considering this invitation.

THE RESEARCH TEAM

A/Prof. Christine Paul	
NHMRC Career Development Fellow	

Dr. Flora Tzelepis

Post-Doctoral Research Fellow

Dr. Natalie A. Johnson

Senior Lecturer

Victor Mogre

PhD Candidate

Complaints about this research

This project has been approved by the University's Human Research Ethics Committee, Approval No. **H-2018-0400**

Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to the Human Research Ethics Officer,

Research Services, NIER Precinct, The University of Newcastle, University Drive, Callaghan NSW 2308, Australia, telephone (02) 4921 6333, email: <u>Human-Ethics@newcastle.edu.au</u>.
7.2 Informed consent form for patients used for data collection in Chapter 7

Consent Form

Prof Christine Paul

Co-Deputy Director, Hunter Cancer Research Alliance Associate Dean (Research) SMPH School of Medicine and Public Health University Drive Callaghan NSW 2308 University of Newcastle Australia Phone: +61 2 4042 0693

Email: chris.paul@newcastle.edu.au



Consent Form for the Research Project:

Barriers to diabetes self-care: A survey among Ghanaian type 2 diabetes patients Christine Paul, Victor Mogre, Flora Tzelepis, and Natalie A Johnson

I agree to participate in the above research project and provide my consent freely by signing this form.

I understand that:

- The project will be conducted as described in the Information Statement, a copy of which I have retained.
- I can withdraw from the project at any time, and do not have to give any reason for withdrawing.
- My personal information will remain confidential to the researchers

I have also had the opportunity to have questions answered to my satisfaction.

I consent to:

- 1. Participating in a survey that will last for 20 minutes
- 2. Having my health information retrieved from my health folder
- 3. Having my weight and height measured to compute BMI.

Print Name:

Contact: _____

Signature: _____ Date:

THE RESEARCH TEAM

Prof. Christine Paul

NHMRC Career Development Fellow

Dr. Flora Tzelepis

Post-Doctoral Research Fellow

Victor Mogre

PhD Candidate

Dr. Natalie A. Johnson

Senior Lecturer

7.3 Organisational consent form for Tamale Central Hospital used for data collection in Chapter 7

Consent Form (Organisational)

Email: chris.paul@newcastle.edu.au

Prof Christine Paul

Co-Deputy Director, Hunter Cancer Research Alliance Associate Dean (Research) SMPH School of Medicine and Public Health University Drive Callaghan NSW 2308 University of Newcastle Australia Phone: +61 2 4042 0693



Consent Form for the Research Project:

Barriers to diabetes self-care: A survey among Ghanaian type 2 diabetes patients

Christine Paul, Victor Mogre, Flora Tzelepis, and Natalie A Johnson

On behalf of the Tamale West Hospital, I agree to the diabetes clinic of the hospital participating in the above research project and provide my consent freely by signing this form.

I understand that:

- The project will be conducted as described in the Information Statement, a copy of which I have retained.
- Tamale Central Hospital or any diabetes patient can withdraw from the project at any time, and do not have to give any reason for withdrawing.
- The personal information of patients will remain confidential to the researchers.

I have also had the opportunity to have questions answered to my satisfaction.

I consent to the Tamale West Hospital diabetes clinic staff:

1. Assist in identifying diabetes patients to be approached to participate in the survey.

2. Assists with scheduling a convenient time to approach diabetes patients to participate in the survey.

3. Allow the retrieval of patients' clinical information from their health folder.

4. Assists in identifying and providing a secluded room to interview consented diabetes patients.

Print	Name:
Contact Details	
Signature:	_ Date:
THE RESEARCH TEAM	
A/Prof. Christine Paul	Victor Mogre
NHMRC Career Development Fellow	PhD Candidate
Dr. Flora Tzelepis	Dr. Natalie A. Johnson
Post-Doctoral Research Fellow	Senior Lecturer

7.4 Organisational consent form for the Tamale West Hospital used data collection in Chapter 7

Consent Form (Organisational)

Email: chris.paul@newcastle.edu.au

Prof Christine Paul

Co-Deputy Director, Hunter Cancer Research Alliance Associate Dean (Research) SMPH School of Medicine and Public Health University Drive Callaghan NSW 2308 University of Newcastle Australia Phone: +61 2 4042 0693



Consent Form for the Research Project:

Barriers to diabetes self-care: A survey among Ghanaian type 2 diabetes patients

Christine Paul, Victor Mogre, Flora Tzelepis, and Natalie A Johnson

On behalf of the Tamale West Hospital, I agree to the diabetes clinic of the hospital participating in the above research project and provide my consent freely by signing this form.

I understand that:

- The project will be conducted as described in the Information Statement, a copy of which I have retained.
- Tamale West Hospital or any diabetes patient can withdraw from the project at any time, and do not have to give any reason for withdrawing.
- The personal information of patients will remain confidential to the researchers.

I have also had the opportunity to have questions answered to my satisfaction.

I consent to the Tamale West Hospital diabetes clinic staff:

1. Assist in identifying diabetes patients to be approached to participate in the survey.

2. Assists with scheduling a convenient time to approach diabetes patients to participate in the survey.

3. Allow the retrieval of patients' clinical information from their health folder.

4. Assists in identifying and providing a secluded room to interview consented diabetes patients.

Print	Name:
Contact Details	
Signature:	Date:
THE RESEARCH TEAM	
A/Prof. Christine Paul	Victor Mogre
NHMRC Career Development Fellow	PhD Candidate
Dr. Flora Tzelepis	Dr. Natalie A. Johnson
Post-Doctoral Research Fellow	Senior Lecturer

7.5 Organisational consent form for the Tamale Teaching Hospital used for data collection in Chapter 7

Consent form (Organisational)

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Consent Form for the Research Project:

Barriers to diabetes self-care: A survey among Ghanaian type 2 diabetes patients

Christine Paul, Victor Mogre, Flora Tzelepis, and Natalie A Johnson

On behalf of the Tamale Teaching Hospital (TTH), I agree to the diabetes clinic of TTH participating in the above research project and provide my consent freely by signing this form.

I understand that:

- The project will be conducted as described in the Information Statement, a copy of which I have retained.
- TTH or any diabetes patient can withdraw from the project at any time, and do not have to give any reason for withdrawing.
- The personal information of patients will remain confidential to the researchers.

I have also had the opportunity to have questions answered to my satisfaction.

I consent to the TTH diabetes clinic staff:

1. Assist in identifying diabetes patients to be approached to participate in the survey.

2. Assists with scheduling a convenient time to approach diabetes patients to participate in the survey.

3. Allow the retrieval of information from patients' health folders.

4. Assists in identifying and providing a secluded room to interview consented diabetes patients.

Print		Name:
Contact Details _		
Signature:	Date:	

THE RESEARCH TEAM

A/Prof. Christine Paul

NHMRC Career Development Fellow

Dr. Flora Tzelepis

Post-Doctoral Research Fellow

Victor Mogre

PhD Candidate

Dr. Natalie A. Johnson

Senior Lecturer

7.6 Questionnaire for assessing prevalence of barriers to diabetes self-care and adherence to self-care

Prof Christine Paul

Co-Deputy Director, Hunter Cancer Research Alliance

Associate Dean (Research) SMPH

School of Medicine and Public Health

University Drive

Callaghan NSW 2308

University of Newcastle

Australia



Please answer each of the following questions by filling in the blanks or by choosing the best answer.

Demographics

Q1. Age: ____years old

Q2. Sex: \square_1 Male \square_2 Female

Q3. When were you first told you have diabetes?

 \Box_1 Less than 3 months ago

 \square_2 3-6 months ago

 \square_3 more than 6-12 months ago

4 more than 1-3 years ago

 \Box_5 more than 3-5 years ago

 \Box_6 more than 5 years ago

Q4. How many months or years have you been diagnosed with diabetes?

.....YearsMonths

- Q5. What is your marital status? (Check one box)
 - \square_1 Never married
 - \square_2 Married
 - 3 Separated/Divorced
 - 4 Widowed
- Q6. How many people live with you? (Check one box)
 - \Box_0 I live alone
 - \square_1 1 person
 - \square_2 2 people
 - \square_3 3 people
 - \square_4 4 people
 - \Box_5 5 or more

Q7. How much schooling have you had? (Years of formal schooling completed) (check one box)

\Box_1 No f	ormal education
---------------	-----------------

- 2 Primary-compulsory school
- 3 Secondary/vocational training or high school
- 4 Tertiary (university or technical college)
- Q8.Which of the categories best describes your total annual <u>combined</u> household income from <u>all</u> sources? (Check one box)
 - \Box_{01} Less than GHC 500

____02 GHC500 to GHC 900

 \Box_{03} GHC901 to GHC 1400

05	GHC	1901	and	over
05	one	1701	unu	0,01

Q9. What is your current employment status?

 \Box_1 Employed full time

2 Employed part-time

3 Casual worker

4 Unemployed

□ 5 Not in labour force (E.g. retired)

Q10. What is your religion?

\square_1 Christianity
2 Islam
□ ₃ A.T.R [4]
4 Other (specify):

Q11. Which town, suburb or area is your usual place of residence.....

Q12. Have any of the members of your immediate family or other relatives been diagnosed with diabetes (type1 or type 2)?

 \square_1 No

 \Box_2 Yes (grandparent, aunt, uncle or first cousin (but no own parent, brother, sister or child)

3 Yes (Parent, brother, sister or own child)

Health status

Q13. Do you take medications as part of your diabetes treatment?

 $\Box_1 \text{ No} \quad (\text{If no Go to Q15})$ $\Box_2 \text{ Yes}$

Q14. Which of the following medications do you take?

1 Oral anti-diabetic (OAD) medications of	only
---	------

- \square_2 Insulin only
- 3 Oral anti-diabetic (OAD) medications and insulin
- 4 Do not know

Q15. Do you know what your last blood test said about your blood sugar level?

- \square_1 No (If No Go to Q17)
- \square_2 Yes (If Yes Go to Q16)
- \square_3 Don't know (If Don't Know Go to Q17)

Q16. If yes: 'what was the result OR

 \Box_1 Within normal range

 \Box_2 A bit high

 \Box_3 Very high

4 Don't know

Q17. Smoking status:

- 1 Current smoker
- 2 Former smoker
- 3 Non-smoker

Q18. How often do you have a drink containing alcohol?

 \square_1 Never

- \square_2 Monthly or less
- $\square_3 2 4$ times a month

 $\square_4 2 - 3$ times a week

 \Box_5 4 or more times a week

Q19. How many standard drinks containing alcohol do you have on a typical day?

 $\Box_1 1 \text{ or } 2$

- \Box_2 3 or 4
- 3 5 or 6
- _4 7 to 9
- **5** 10 or more

Q20. How OFTEN do you have six or more drinks on one occasion?

 \square_1 Never

 \Box_2 Less than monthly

3 Monthly

4 Weekly

5 Daily or almost daily

Barriers to diabetes self-care

Q20 Part I. Please indicate how much you agree or disagree with the following statements.

Attitudes/behavioural beliefs

Barrier	Response options					
	Strongly	Disagree	Neither	Agree	Strongly	Not
	disagree		agree nor		agree	applicable
			disagree			
a. I often avoid foods high in	1	2	3	4	5	6
carbohydrates (e.g. yam, fufu, corn						
TZ, etc) because they are generally						
not good for my diabetes						
b. I find it difficult to change my old	1	2	3	4	5	6
eating habits to manage my diabetes						
c. I see no harm in replacing my	1	2	3	4	5	6
diabetes medications with herbal						
medicines						
d. I sometimes take my diabetes	1	2	3	4	5	6
medications together with herbal						
medicines						
e. My diabetes medications have side	1	2	3	4	5	6
effects that interfere with my life						
f. I have become fed up with taking						
my medications every day						
g. I feel pains anytime I exercise	1	2	3	4	5	6

h. I am unable to exercise due to my	1	2	3	4	5	6
old age						
i. Fear of pain stops me from	1	2	3	4	5	6
pricking my finger to check my						
blood sugar						
j. I find it easy to make new habits	1	2	3	4	5	6
like checking my blood glucose						
k. I find it easy to make new habits	1	2	3	4	5	6
like checking my feet						
1. I no longer need to be careful with	1	2	3	4	5	6
my health (careful eating, exercising,						
checking feet) because my diabetes						
is cured						
m. I don't accept that I have diabetes	1	2	3	4	5	6
n. I do not want to worry about my	1	2	3	4	5	6
diabetes						

Q20 Part II. Please indicate how much you agree or disagree with the following statements.

Subjective norms/normative beliefs

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree	Not applicable
a. I don't have enough family support to help me look after my diabetes	1	2	3	4	5	6
b. My family understand what I need to do to manage my diabetes	1	2	3	4	5	6
c. People from my culture don't usually eat the kinds of foods that are 'good' for my diabetes	1	2	3	4	5	6
d. I do not want to lose weight because people will think there is something wrong with me	1	2	3	4	5	6
e. I do not want people to know I have diabetes	1	2	3	4	5	6
f. Exercise is meant for people in developed countries	1	2	3	4	5	6
g. Hardly anyone with diabetes follows all the rules for managing their diabetes	1	2	3	4	5	6

Q20 Part III. Please indicate how much you agree or disagree with the following statements.

	Strongly disagree	Disagree	Neither agree nor	Agree	Strongly agree	Not applicable
			disagree			
a. I do not check my blood sugar regularly because I don't have my own glucometer	1	2	3	4	5	6
b. I need to use a glucometer but I do not have enough money to buy it	1	2	3	4	5	6
c. I know how to use a glucometer to check my blood sugar	1	2	3	4	5	6
d. I sometimes miss my diabetes appointments because the hospital/clinic is too far from where I live	1	2	3	4	5	6
e. I don't have enough money to buy the right foods to improve my diabetes	1	2	3	4	5	6
f. There is nowhere I can get the variety of foods I am supposed to eat for my diabetes	1	2	3	4	5	6
g. The right foods for diabetes are not available all year long	1	2	3	4	5	6
h. My work schedule interferes with the timing of my meals	1	2	3	4	5	6
i. I don't have enough money to buy my diabetes medications	1	2	3	4	5	6
j. My work schedule interferes with taking my diabetes medications on time	1	2	3	4	5	6
k. My work schedule interferes with my exercise	1	2	3	4	5	6
1. I am too old to exercise	1	2	3	4	5	6

Perceived Competence for Diabetes

Q21. Please respond to each of the following items with respect to dealing with your diabetes. Use the scale: $1\ 2\ 3\ 4\ 5$

	Strongly	Disagree	Neutral	Agree	Strongly
	disagree				agree
Items	1	2	3	4	5
a. I feel confident in my ability to manage	1	2	3	4	5
my diabetes					
b. I am capable of handling my diabetes	1	2	3	4	5
now.					
c. I am able to do my own routine diabetic	1	2	3	4	5
care now.					
d. I feel able to meet the challenge of	1	2	3	4	5
controlling my diabetes					

Depression

Q22. Please indicate for each of the 5 statements which is closest to how you have been feeling over the past 2 weeks. Response scale: 5. All of the time 4. Most of the time 3. More than half the time 2. Less than half the time 1. Some of the time 0. At no time

Over the past 2 weeks: (circle one answer for each line)	All of the time	Most of the time	More than half the time	Less than half the time	Some of the time	At no time
a) I have felt cheerful and in good spirits	5	4	3	2	1	0
b) I have felt calm and relaxed	5	4	3	2	1	0
c) I have felt active and vigorous	5	4	3	2	1	0
d) I woke up feeling fresh and rested	5	4	3	2	1	0
e) My daily life has been filled with things that interest me	5	4	3	2	1	0

Level of satisfaction

Q23. Generally speaking, were you satisfied with the overall quality of the diabetes clinic?'

\square_1 Very dissatisfied
 Dissatisfied Neither satisfied nor dissatisfied
4 Satisfied
5 Very satisfied
Q24. If dissatisfied – what would you like to see improved or changed at the diabetes clinic?

.....

Education / Advice Received for self-care

Note: For this survey, a <u>Health Care Provider</u> refers to a doctor, nurse practitioner, or physician assistant.

Q25. Has your health care provider or nurse ever told you to take special care of your feet to manage your diabetes? (Check one box)

□ 1 No □ 2 Yes □ 3 Not Sure

Q26. Has your health care provider or nurse ever told you to follow an exercise program to manage your diabetes? (Check one box)

□ 1 No □ 2 Yes □ 3 Not Sure Q27. Has your health care provider or nurse ever told you to follow a meal plan or diet to manage your diabetes?

(Check one box)

 \Box_1 No

2 Yes

3 Not Sure

Q28. Has your health care provider or nurse ever told you to always take medications to manage your diabetes? (Check one box)

 $\square_1 \text{ No}$ $\square_2 \text{ Yes}$ $\square_3 \text{ Not Sure}$

Q29. Has your health care provider or nurse ever told you to regularly check your blood sugar to manage your diabetes? (Check one box)

□ 1 No □ 2 Yes □ 3 Not Sure

Q30. Have you ever received diabetes education? (For example: attended classes or meetings with a diabetes educator) (Check one box)

□ 1 No □ 2 Yes □ 3 Not Sure

Attitudes toward Diabetes and self-care

For the following questions, please <u>circle</u> the appropriate response.

(Circle one answer for each line)

		Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
Q31.	I am afraid of my diabetes.	1	2	3	4	5
Q32.	I find it hard to believe that I have diabetes.	1	2	3	4	5
Q33.	I feel unhappy because of my diabetes.	1	2	3	4	5
Q34.	I feel I'm not as good as others because of my diabetes.	1	2	3	4	5
Q35.	I find it hard to do all the things I have to do for my diabetes.	1	2	3	4	5
Q36.	Diabetes doesn't affect my life at all.	1	2	3	4	5

Q37.	I am able to: (circle one answer for each line)	Strongly Disagree	Disagree	Neither agree nor disagree	Agree	Strongly Agree
	a) keep my blood sugar in good control.	1	2	3	4	5
	b) keep my weight under control.	1	2	3	4	5
	d) handle my feelings (fear, worry, anger) about my diabetes.	1	2	3	4	5

Q38.	I think it is important for me to: (circle one answer for each line)	Strongly Disagree	Disagree	Neither agree or disagree	Agree	Strongly Agree
	a) keep my blood sugar in good control.	1	2	3	4	5
	b) keep my weight under control.	1	2	3	4	5
	d) handle my feelings (fear, worry, anger) about my diabetes.	1	2	3	4	5

Adherence to self-care behaviours

The questions below ask you about your diabetes self-care activities during the past 7 days. If you were sick during the past 7 days, please think back to the last 7 days that you were not sick.

Diet

1. How many of the last SEVENDAYS have you followed a healthful eating plan?

0	1	2	3	4	5	6	7				
2. On eating	n averag g plan?	e, over 0	the pas	st month 2	n, how r 3	nany D. 4	AYS PI 5	ER WE 6	EK have 7	you followed y	our
3. On	n how m	any of	the last	t SEVE	N DAY	S did yo	ou eat fi	ive or n	nore servi	ngs of fruits?	
0	1	2	3	4	5	6	7				
4. On	n how m	any of	the last	t SEVE	N DAY	S did yo	ou eat fi	ive or n	nore servi	ngs of vegetabl	les?
0	1	2	3	4	5	6	7				
5. On foods	n how m s? 0	any of 1	the last 2	t SEVEI 3	N DAY 4	S did yo 5	ou eat h 6	igh fat 7	foods suc	h as red meat o	r oily

Exercise

1. On how many of the last SEVEN DAYS did you participate in at least 30 minutes of physical activity? (Total minutes of continuous activity, including walking).

0 1 2 3 4 5 6 7

2. On how ma	any of	the last	SEVE	N DAY	S did yo	ou parti	cipate in	n a speci	fic exercise	session
(such as swim	nming,	walkir	ıg, bikiı	ng) othe	r than v	what you	u do arc	ound the	house or as	part of
your work?	0	1	2	3	4	5	6	7		

Blood Sugar Testing

1. On how many of the last SEVEN DAYS did you test your blood sugar?

0 1 2 3 4 5 6 7

2. On how many of the last SEVEN DAYS did you test your blood sugar the number of times recommended by your health care provider?

0 1 2 3 4 5 6 7

Medication

3. On l	how ma	ny of th	e last S	EVEN I	DAYS,	did you	take yo	our reco	mmend	ed diabetes
medica	ation or	pills?	0	1	2	3	4	5	6	7
4. On l	now ma	ny of th	e last S	EVEN I	DAYS o	lid you	take yo	ur recor	nmende	d insulin
injectio	ons?	0	1	2	3	4	5	6	7	
Foot C	Care									
1. On l	now ma	ny of th	e last S	EVEN I	DAYS a	lid you	check y	our fee	t?	
0	1	2	3	4	5	6	7			
2. On l	now ma	ny of th	e last S	EVEN I	DAYS o	lid you	inspect	the insi	de of yo	our shoes?

0 1 2 3 4 5 6 7

Anthropometric measurements

I will now like to take your weight, height and waist circumference. Remove your sandals and step on the weight scale. The information taken will be used to compute your body mass index to allow for classification into normal weight, underweight, overweight and obesity.

Weight (Kg)..... Height (m).... Waist circumference.... Blood pressure (To be taken from patient's folder) Systolic.... Diastolic....

That's the end of the interview now. Thank you very much for your time. Do you have any questions or comments?

LIST OF SUPPLEMENTARY MATERIALS

Additional file 1: Medline search strategy (Chapter 2)

#	Searches
1	self care.mp. or Self Care/
2	Health Behavior/ or health behavio?r*.mp.
3	Patient Compliance/ or self efficacy.mp. or Self Efficacy/
4	self monitor*.mp.
5	patient* monitor*.mp.
6	self manage*.mp.
7	self-care.mp.
8	1 or 2 or 3 or 4 or 5 or 6 or 7
9	Diabetes Mellitus, Type 2/ or diabetes mellitus type 2.mp. or Diabetes Mellitus/
10	NIDDM.mp.
11	(Non insulin* dep* or noninsulin* dep*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
12	(typ* II diabet* or typ* 2 diabet* or diabet* typ* 2 or diabet* typ* II).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
13	9 or 10 or 11 or 12
14	Exercise/ or Exercise.mp.
15	exercise*.tw.
16	physical activity.mp.
17	physical activit*.tw.
18	physical inactivi*.tw.
19	14 or 15 or 16 or 17 or 18

20	Diet/ or diet.mp. or Healthy Diet/
21	dietary pattern.mp.
22	Feeding Behavior/ or diet* pattern*.mp.
23	eating behaviour.mp.
24	eating behavio*.mp.
25	dietary habits.mp.
26	diet* habit*.mp.
27	Food intake*.mp.
28	Food pattern*.mp.
29	Food habit*.mp.
30	Food behavio*.mp.
31	20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30
32	Blood glucose self-monitoring.mp. or Blood Glucose Self-Monitoring/
33	(Self monitor* adj5 (blood glucose* or blood sugar*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
34	(test* adj5 (blood glucose* or blood sugar*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
35	32 or 33 or 34
36	((foot or feet) adj care).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
37	Diabetic Foot/ or foot care.mp.
38	Podiatry/ or foot health.mp.
39	(Feet adj3 health).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]

40	36 or 37 or 38 or 39
41	medication adherence.mp. or Patient Compliance/ or Medication Adherence/
42	diabetes medication.mp.
43	(Medicat* adj3 (adher* or complian* or persist*)).tw.
44	41 or 42 or 43
45	barriers.mp.
46	barrier*.mp.
47	Communication Barriers/ or communication barrier*.mp.
48	factors.mp.
49	factor*.mp.
50	45 or 46 or 47 or 48 or 49
51	Developing Countries/ or low-income countries.mp.
52	middle-income countries.mp.
53	middle income countr*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
54	low income countr*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
55	low income nation*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
56	Middle income nation*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
57	Developing nation*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol

	supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
58	Under developed nation*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
59	under developed countr*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
60	least developed nation*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
61	least developed countr*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
62	underdeveloped nation*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
63	underdeveloped countr*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
64	Sub-Saharan Africa.mp. or "Africa South of the Sahara"/
65	Africa, Southern/ or South Africa/ or Africa, Western/ or Africa.mp. or Africa, Central/ or Africa, Northern/ or Africa/ or Africa, Eastern/
66	51 or 52 or 53 or 54 or 55 or 56 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65
67	8 or 19 or 31 or 35 or 40 or 44
68	50 or 67
69	Adherence.mp.

70	treatment adherence.mp.
71	69 or 70
72	67 or 71
73	correlate*.mp.
74	predictor*.mp.
75	73 or 74
76	50 or 75
77	72 or 76
78	13 and 66 and 77
79	limit 78 to (english language and yr="1990 -Current" and "all adult (19 plus years)" and english and medline)

Author(s) name	Country	Study design	Sample size	Setting	Self-care behaviours evaluated	Instrument	Demographic characteristics	Quality rating
Adisa and Fakeye ⁽³²⁾	Nigeria	Cross- sectional study	176	2 teaching hospitals	Medication treatment adherence; diet; SMBG	SRMA and SRDA	Women=108; duration of diabetes =6.3 years	HIGH
Al-Amer et al, ⁽³³⁾	Jordan	Cross- sectional study	220	1 teaching hospital	diet, exercise, medication, blood sugar testing, foot care, smoking habits	SDSCA	Women=52% (n=115); age = 58.2(10.8); duration of diabetes=9.7(8.0); 86%married;72% completed high school	HIGH
Ashur et al., (34)	Libya	Cross- sectional study	523	National Centre for Diabetes and Endocrinology (NCDE)	diet, exercise, medication, blood sugar testing, foot care,	SDSCA	Mean age=54.4 years; 59% were women; 58% had primary education; mean duration of diabetes = 9.4 years	HIGH

Additional file 2: General characteristics of the included studies

Assah et al., (35)	Cameroun	non- randomized controlled trial	192	1 Hospital	diet, exercise, blood sugar testing, foot care,	SDSCA	Women=51; mean age=57.1; mean duration of diabetes=10.4	HIGH
Ayele et al., (36)	Ethiopia	Cross- sectional study	222		physical exercise, diet, medication, and blood glucose measurement	Self-care inventory	Women=134; mean age = 49.7 years; 42% could neither read nor write;	Medium
Bagonza et al., ⁽³⁷⁾	Uganda	Cross- sectional study	521	2 general Hospitals	Medication adherence	Items from previous studies	Women=259, mean age = 50.9 years; 46% had no formal education	Medium
Baumann et al., ⁽³⁸⁾	Uganda	Cross- sectional study	340	2 Hospitals	Being active, healthy eating, taking medication, monitoring blood glucose, problem solving, reducing risk of complications, and coping with diabetes	D-SMART	Men=144; mean age = 53.5(11.5); mean duration of diabetes = 5 years; primary level of education or below=47%	Medium

Bhandari and Kim ⁽³⁹⁾	Nepal	Cross- sectional study, using a mixed method approach	230	Private and public hospitals	Diet, exercise, medication, blood sugar testing, foot care,	SDSCA	Mean age = 56.9 years; mean duration of diabetes = 8.7(6.7) years; women = 139, no formal education = 31%;	Medium
Bueno et al., (40)	Brazil	Cross- sectional study	806	Community- based setting	Physical activity	IPAQ	61% were women (n=526); mean age = 70.7 years.	Medium
Chellan et al., ⁽⁴¹⁾	India	Cross- sectional	203	Podiatric clinic	Foot care practice	Items from previous studies	66% were men; mean age = 59.9 years; 59% completed high school and 41% completed graduate education	Medium
Dekker et al., ⁽⁴²⁾	Belize	Cross- sectional	25	Primary health care facility	Diet, physical activity	Author designed	Women = 72%; family history = 68%	Medium
							Mean age = 59 years	
Desalu et al., ⁽⁴³⁾	Nigeria	Cross- sectional	352	3 tertiary hospitals	foot care practice	Author designed	Women=136; mean age = 44.0 years; 56% had none/primary education	Medium

Gelaw et al., (44)	Ethiopia	Cross- sectional	270	1 tertiary hospital	medication non- adherence	Morisky index	Women= 131; mean age = 55.11 years; 27% had no formal education	Medium
Jackson et al., ⁽⁴⁵⁾	Nigeria	Cross- sectional	303	2 teaching hospitals	Medication adherence	Morisky index	Women = 171; 68% older than 50 years; 50% tertiary education; 35% living with diabetes for the past 1-5 years; smoking = 1%; alcohol use = 16%	Medium
Kalyango et al., ⁽³¹⁾	Uganda	Cross- sectional study	402	1 tertiary hospital	medication adherence	Author designed	Mean age = 50 years; women = 70%; 49% had primary education; Median duration of diabetes = 4 years	Medium
Kassahun et al., ⁽⁴⁶⁾	Ethiopia	Cross- sectional	309	1 teaching hospital	Medication adherence, alcohol consumption, smoking	Morisky index	Women=120; 36% had completed grade 1-8; 3% current smokers; 5% drank alcohol	Medium

Mosha and Rashidi ⁽⁴⁷⁾	Tanzania	Cross- sectional study	121	4 general hospitals	Diet, exercise, foot care and SMBG, smoking	SDSCA	Women = 74; mean age = 53 years; 51% had primary level of education; 3% smoked and 64% took alcohol; mean duration of diabetes = 6.1 years	Medium
Musenge et al., ⁽⁴⁸⁾	Zambia	Cross- sectional	198	1 teaching hospital	medication, exercise and SMBG	WHO Steps Survey	Women= 119, men = 79; median age = 55, 89% aged 30 and above; 63% had secondary/college education; 35% overweight; 27% obese; 93% had type 2 DM, 61% had poor glycaemic control	Medium
Oyewole et al., ⁽⁴⁹⁾	Nigeria	Cross- sectional study	119	1 teaching hospital	Physical activity	IPAQ	Women =72; mean age = 61.8 years; 53% had primary/secondary level of education	Medium

Rwegerera et al., ⁽⁵⁰⁾	Tanzania	Cross- sectional	216	1 teaching hospital	Antidiabetic medications	Author designed	Women = 144; median age = 55 years; 73.4% had primary/secondary education; 63% had been living with diabetes >5 years	Medium
Hintsa et al., (51)	Ethiopia	Case-control study	409	1 tertiary hospital	Diet, medications	Author designed	Mean age (cases) = 52(1.34), controls = 42.4(0.8). Men (cases) = 58%, controls=55%. Majority of cases and controls were literate (cases = 86%, controls = 80%)	HIGH
Piette et al., (52)	Honduras	A single- group, pre- post study	85	A number of primary health clinics	Medication adherence	Morisky index	Women = 70%; mean age = 55.7 years; >half had five or fewer years of formal education	HIGH

Mogre et al., (53)	Ghana	Cross- sectional study	187	1 teaching hospital and 2 secondary hospitals	diet, exercise, foot care and SMBG, smoking	SDSCA	Women = 72% (n=135) mean age = 54.84 years; mean duration of diabetes = 5.43 years; mean number of years of schooling=6.63; 1.6% smoked cigarette	Medium
Worku et al., ⁽⁵⁴⁾	Ethiopia	Cross- sectional	403	l teaching hospital	dietary practice,	Items from previous studies	Women = 198, mean age = 55.19 years; 43% had no formal education	Medium
Emmanuel and Otovwe., (55)	Nigeria	Cross- sectional	350	1 secondary hospital	diet regimen, medication	Author designed	Women = 213; mean age = 57.9 years; 28% had post-secondary education	Medium
Mastura et al., ⁽⁵⁶⁾	Malaysia	Cross- sectional	170	2 primary care clinics	SMBG	Author designed	54% women; mean age = 54.7 years; age of onset of diabetes = 46.5years; mean duration of diabetes =	Medium

8.2 years; majority had secondary and tertiary level of education (67%)

Huang et al., China Cross- 364 A number of ⁽⁵⁷⁾ sectional community health centre	DrugItems frommanagement,previousblood sugarstudiesmonitoring, foot-care, sports-management,-prevention and-treatment of-hyperglycaemia/-hypoglycaemia,-and total-behaviour-management,-	Women = 208; mean age = 67.87 years; 77% had below junior college-level of education; 56% had diabetes for 5 or more years	Medium
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