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The assessment of patient-centred care among diabetic patients in southern Malawi.

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Dissertation submitted in fulfilment of the requirements for the degree of

Doctor of Philosophy in Public Health

The University of the Witwatersrand, Johannesburg, South Africa.

Supervisor: Professor Jude Igumbor

Co-Supervisors: Prof A Muula and Dr Felix AnyanwuDate:

26th October 2024

Declaration

I, Martha Thokozani Makwero, make this declaration that this thesis is a product of my original intellectual work. The study has been conceptualized and done independently, except where I have explicitly declared in the thesis or references. It is being submitted in fulfillment for the degree of Doctor of Philosophy at the University of the Witwatersrand, Johannesburg, South Africa. It has not been submitted in part or whole before for any degree or examination at any other University or institution.



Signature: Date: 26th October 2024

Thesis materials

The following are the original pieces of publications and presentations arising from this work

1. Makwero M, Muula A, Anyanwu FIJ. The conceptualization of patient-centred care: A case study of diabetes management in public facilities in southern Malawi. African J Prim Health Care Fam Med [Internet]. 2021;13(1):1–10. Available from: https://phcfm.org/index.php/PHCFM/article/view/2755
2. Makwero M, Muula AS, Anyanwu FC, Igumbor J. An insight into patients' perspectives on barriers affecting participation in shared decision making among patients with diabetes mellitus in Malawi. BMC Prim Care [Internet]. 2022;23(1):1–8. Available from: https://doi.org/10.1186/s12875-022-
3. Makwero M, Muula AS, Anyanwu FC, Igumbor J. The Development and Psychometric Evaluation of a Patient-Centred Care Tool for Diabetic Patients in Southern Malawi. Manuscript submitted to Malawi Medical journal, November 2023
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5. Makwero M, Muula AS, Anyanwu FC, Igumbor J The perception of patient centred care and, its relationship with management outcomes and complications among patients with DM in Malawi (unpublished)
6. Makwero M, Muula AS, Anyanwu FC, Igumbor J 'Assessment of patient centred care among diabetic patients in Malawi' is accepted as a poster pitch, The European and Dutch Societies for Global Health and Tropical Medicine Congress, Netherlands 20-23 November 2023

7. Makwero M, Muula AS, Anyanwu FC, Igumbor J. Patients' perception of patient-centred care: does it matter in low-resourced contexts? Oral presentation at the WONCA Sydney World Conference, Sydney, Australia 26-29 October 2023
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Fellowships and awards

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2. SIDA Covid-19 Mitigation Grant: Fellowship Support valued at $57000 (May 2021)
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4. A number of travel awards

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2021-Date External examiner for Reproductive health, Malawi College of Health Sciences

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2. **George Washington public Health Institute:** Characterizing the uses of primary health care performance information in El Salvador, Malawi, and Lebanon. Co-investigator and lead investigator for the Malawi sub-award (Grant #CIN U74900TG2007NPL055085)). Funded by The George Institute of Global Health, on behalf of the PHC Research Consortium and the Gates Foundation. Published two articles
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4. **SEED Global Health:** Supporting the Family Medicine Specialty in Malawi. Serving as an implementing partner.
5. **CDC HEALERs** project as implementing partner within the School of Public Health and Family Medicine

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Global peace Corps Volunteer program

Abstract

Introduction: Patient centred care (PCC) is gaining recognition in various quality care reforms, especially in the growing era of chronic care where its effects are palpable yet its functional elements are unknown and hardly measurable. PCC has been shown to improve care processes and patient reported outcomes among chronic care patients such as Diabetes Mellitus (DM). While the Malawi Quality management Directorate (QMD) and the Non-communicable disease and injury (NCDI) policies mention PCC as a strategic quality reform, its functional elements are hardly known and, if it matters, in mediating patient experiences and outcomes. It is clear that the vagueness is thwarting PCC's implementation, assessment, and advocacy. Thus, as the burden of chronic diseases, including DM grows, there is a need to optimize PCC through the elicitation of its functional elements, its objective assessment, and its recommended implementation strategies.

Aim: This study aims to assess the functional elements of PCC and its relationship to outcomes in diabetic patients.

Methodology: I conducted a cross-sectional, exploratory mixed methods study in southern Malawi. Sequentially, I employed qualitative and quantitative methods in order to enrich the contextual understanding of the complex PCC construct and its correlates. Therefore, we initially explored the common elements of PCC in LMIC through a scoping review. Building on the findings, in the next phase, I explored PCC conceptualization among three stakeholders (patients, health care providers and policy makers) further, breaking down the PCC construct to its functional elements through a qualitative inquiry. The qualitative themes identified were used to build a tool on important elements of PCC from the same population. A psychometric analysis was done in order to confirm the structure and consistency of the tool to improve the validity of results obtained. Thereafter, I quantitatively measured the current PCC practice

among patients with DM and its association with baseline adherence to DM care plans, self-efficacy, glycaemic control, and some complications.

The study used Covidence to manage the scoping review and Nvivo version 11 for the qualitative data, which was analyzed through the thematic analysis. The quantitative data was analyzed using STATA version 18 and R-studio version 4.2.3. The psychometric analysis employed exploratory and confirmatory factor analysis. Dichotomization of study participants into those who perceived low and high PCC scores was done through K-means clustering was done in R studio. Similarly, correlational studies and Path analysis were conducted to determine the nature and direction of relationships between the perception of PCC during the encounter and adherence, self-efficacy and glycaemic control.

Results: The study confirmed the paucity and fragmentation of literature on PCC in LMIC especially in Africa and therefore, the need to situate the elements in our context. The themes identified were interrelated, and differences in expression and emphasis of some of the elements compared to the Eurocentric ones were highlighted. The recurring themes included the facilitating ambience, sharing of information, and patient involvement, the wider organization of care and the macroenvironment in which care takes place.

Although they are similar to the Eurocentric themes, our qualitative inquiry identified eight themes and proposed a working definition. Thus, in the Malawian context, PCC was conceptualized as an expected care process that incorporates warm patient reception, where the healthcare provider consciously aims to reduce the patient-HCP power gap to harness a good long-term relationship. This creates a conducive atmosphere that allows the gathering of information that holistically identifies the individual specific problems and all possible interacting factors, ensuring timely access to care and medication. While patients highlighted the value of PCC encounters, particularly shared decision-making, the study documented the

challenges and vulnerabilities faced in an attempt to engage their providers in shared decision making.

The psychometric analysis identified three latent themes underlying the PCC elements namely 1) relational aspects of care, 2) individualization and shared decision making and, 3) organizational aspects of care highlighting what is important and the hierarchical nature of the PCC construct. While acknowledging the need for further refinement, the tool exhibited acceptable reliability and validity properties to be used as a measurement framework in the study.

The study showed significant deficiencies in the delivery of PCC with 55.8% of patients perceiving low levels, particularly, in the area of individualization and shared decision-making. Higher PCC scores did not have a significant relationship with self-efficacy. Both the perception of PCC and self-efficacy were positive predictors of adherence independently. Having perceived higher PCC scores was associated with a marginal 0.03-point increase in one's adherence scores ($\beta = 0.03$; 95% CI: 0.01 to 0.04, p-value <0.001). Self-efficacy and adherence were both positive predictors of blood sugar control independently. Better self-efficacy was associated with a 0.03 unit decrease in the level of HbA1c ($\beta = -0.03$; 95% CI: -0.04 to -0.022, p-value <0.001). Additionally, as adherence scores went higher, there was a 0.15 unit decrease in HbA1c ($\beta = -0.15$; 95% CI: -0.25 to -0.02, p-value <0.05). The results highlight that PCC can affect glycaemic control only indirectly through adherence.

Conclusion

The study has confirmed the complexity of the PCC construct and the paucity of literature in LMIC. It has highlighted that above and beyond creating a conducive ambiance, medical encounters ought to evoke support and capacitation for patients to undertake self-care behaviors confidently to be able to produce patient outcomes. Even though this study is cross-

sectional, the initial patterns are promising for the value of PCC in mediating patient-reported experiences and outcomes among DM patients.

Keywords: *patient-centred care, shared decision making, adherence, self-efficacy, chronic care, glycaemic control*

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GLOSSARY OF TERMS

NCD non-communicable diseases

UHC Universal Health Coverage

SDM Shared Decision Making

NGO non-governmental organizations

HSSP Health Service Strategic plan

HCP Health Care Provider

DALYs Daily Adjusted Life Years

PFP Private for Profit

PFNP Private for Non-Profit

DM Diabetes Mellitus

WHO World Health Organization

IOM Institute of Medicine

QMD Quality Management Directorate

NCDI Poverty Network: Non- Communicable Diseases and Injuries Poverty Network

NCD BRITE: Building Research Implementation, and Translation Expertise for Noncommunicable Diseases consortium)

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SECTION A: CHAPTERS 1-3: INTRODUCTION, BACKGROUND AND METHODS

CHAPTER 1: Introduction and Outline of Thesis

1.1 The Malawi context and organization of care

Malawi is a landlocked country with a population of 19.4 million and a life expectancy of 65.6 years (1). The country has an average annual urban population growth rate of 4.2% that is expected to exert pressure on urban healthcare delivery systems. Climate change and increased demand for healthcare systems pose challenges that necessitate resilient and responsive healthcare delivery systems that are adaptable and effective(1). Malawi's Universal Health Coverage (UHC) aims to improve the health status of its population, reduce financial risk, and deliver care that is satisfying to the target population(2). According to the WHO Country Cooperation Strategy 2017 -2022, Malawi had registered some progress towards UHC in terms of accessibility quality to equitable and affordable health care while improving health status, financial risk protection and client satisfaction(2,3). However, challenges still existed in enabling and sustaining the expansion of and access to quality essential health services(1–3).

Malawi aims to achieve its UHC through the health benefit package as a prioritization mechanism to maximize targets for 2063(1). The country's healthcare delivery is through a three-tiered healthcare delivery space, namely primary (community and facility), secondary, and tertiary levels. The services are delivered through a network of public, non-governmental organizations (NGOs), private-not-for-profit (PFNP), and Private-for- Profit (PFP) providers. The public sector is comprised of four central hospitals and 26 district hospitals that serve as referral centres for primary care facilities. District hospitals offer outpatient clinics and inpatient services, surgical procedures, and a bed capacity that can reach up to 300(1,4). Each district hospital has 11 to 40 health centres in its catchment area. Some districts have an intermediary level of community hospitals that are public, PFP or PFNP facilities. District hospitals serve

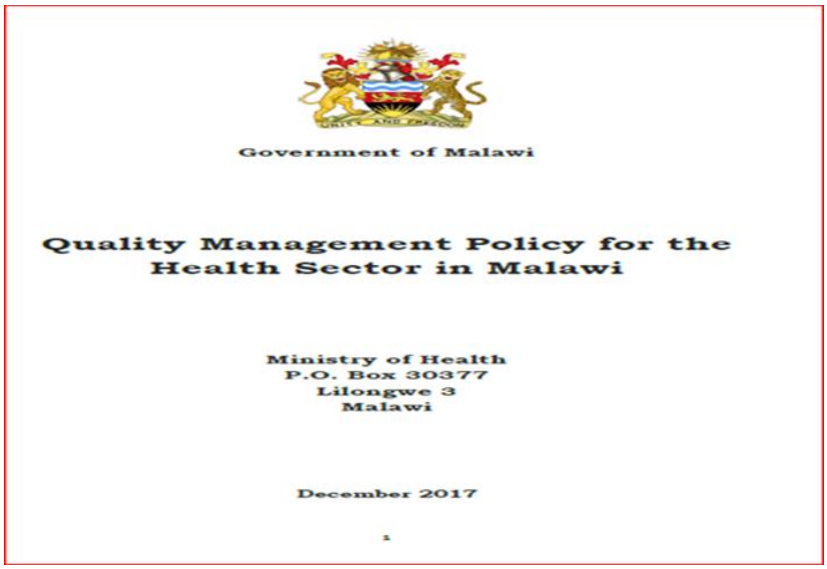
populations ranging from 140,000 to 1,400,000. The primary care level includes health centres with their constituent clinics, dispensaries, and village clinics. Health centres offer ambulatory and maternity services and they are meant to serve an average population of 10,000 people. Some urban facilities, however, serve up to 237,000 people. Primary care facilities are designed to link with community-based services although, practically, there is often fragmentation between facility-based curative and community-based preventive activities(4).

Malawi has shown commitment to promoting UHC by extending its original essential health care package to include non-communicable diseases and by continuing to be free to all Malawians within public and most PFNP sectors. The capability of the primary healthcare sector to deliver this package is being strengthened beyond access and coverage and quality improvement. In its current Health Service Strategic Plan (HSSP) III, covering 2202-2030, Malawi pledges a value-based equitable, and holistic service provision that is able to meet patients at their point of need(1). Among other strategies, Malawi promotes client-centredness; empowering patients and communities to participate in their care under "one plan, one budget, one monitoring and evaluation (M&E)" reform.

Malawi is facing a shifting global disease burden from acute to chronic and the associated multi-morbidity (1,5). The contribution of Non-Communicable Diseases (NCD) to the current burden of disease and mortality in the country stands at 26% and 16% respectively(5). The multi-morbidity entails growing complexity in disease management, which has necessitated movement of care delivery from traditional acute, episodic, and biomedical models to more patient-centred care (PCC) values (6,7).

1.2 The global and Malawian quality of care delivery landscape

Figure 1.1: The quality management policy document cover page



Government of Malawi

Quality Management Policy for the Health Sector in Malawi

Ministry of Health
P.O. Box 30377
Lilongwe 3
Malawi

December 2017

Like other developing countries, Malawi strives to improve the quality of health service delivery. Ironically, various advancements in achieving quality care delivery, such as increased technology, access to care, diagnostic tools, and wide pharmaceutical options, have not necessarily resulted in better care processes and/or outcomes and satisfied users(8–10). Inadequate dialogue between patients and their providers and limited participation between the dyad make care unresponsive to the needs and preferences of its beneficiaries (11,12). This situation calls for consideration in the way health care services are planned and delivered, and for improvement of quality efforts beyond mere access to care and coverage(13). Both the World Health Organization (WHO) and the Institute of Medicine (IOM) highlight patient-centred care (PCC) as one of the essential components of quality care delivery in that it incorporates the perspectives of key players in care, including patients (7,8). Therefore, PCC has been deemed an equally essential driver in striving for the delivery of quality care and satisfied users in Malawi.

The need for chronic care delivery to be patient-centred had never been more urgent than at the time this research was being conducted due to the growing complexity of disease management and amidst rising patients' expectations(5). After all, the World Health Organization Primary

Health Care monitoring framework requires that care be person-centred, and responsive to the health goals of the person(s) accessing it(7,8).

The establishment of the Quality Management Department (QMD) within the Ministry of Health (MOH) in 2017 was an effort to improve the efficiency of health service delivery quality assurance at all levels and accelerate the attainment of universal health coverage through the provision of high-quality care that is responsive and satisfying to the end users(12). The QMD mandate is to set standards, implement, monitor, and evaluate its policies and strategies. The QMD and Non-communicable disease and injuries (NCDI) Poverty network policies further recognize the fundamental role of PCC in accelerating UHC goals. Therefore, there is a great need for care delivery policies and strategies to be organized around patients' needs and perspectives. This further entails that patients are regarded as essential care partners. Their capabilities are incorporated into care processes to improve care delivery and attain outcomes. Malawi's MOH, through this initiative, is committed to the highest standards of patient-centred care, thus, ensuring that all users at all levels report satisfaction in all dimensions of health services delivery by 2024(5,12).

1.3 Problem statement

Practicing PCC has been challenging and its influence is hardly noticeable in routine healthcare delivery despite growing advocacy and professed adoption of quality-of-care policy reforms(14,15). This is largely because evidence regarding functional elements of PCC, especially in Africa, is lacking(16). Existing variations and ambiguity make the PCC concept less expressible and measurable in routine care(17). In Malawi, there is a growing burden of chronic diseases, including diabetes mellitus (DM), whose prevalence is 3.0% and 1.7% (for urban and rural populations respectively) with associated high rates of complications(18,19). Reportedly, DM care delivery in the country is suboptimal, as appraised by Assayed et al. using

International Diabetes Federation (IDF) guidelines, whose notable facet is the organization of care around the patients' needs and preferences(20,21). Despite the NCDI and QMD policies advancing PCC as one of the strategies for improving the quality of chronic care, there is lack of clarity concerning its functional elements and standardized measures. Current efforts have focused on complaint reporting, using suggestion boxes, and promotion of patient charters, and patient satisfaction surveys, which do not effectively elicit patients' perceptions towards care design and delivery, thereby falling short of allowing safe spaces for patients to be effective partners in care(16).

1.4. Justification of the study

It is imperative to delineate the contextual functional elements and to objectively assess patients' perceptions of PCC delivery in the chronic care context. Similarly, there is a need to elucidate what elements are important in day-to-day PCC medical encounters and their associated factors in order to implement the set policies in an adequately informed manner thereby creating a plausible advocacy case. Most African health systems profess to be people and community-centred, however, they are characterized by deficiencies in access and communication between the health care delivery systems and their beneficiaries(16,22–25). There is, therefore, a need to adapt PCC within the confines of its own values, enablers, and socio-economic confines if one is to be realistic(26).

1.5 Aim

The aim of this study, is to assess the functional elements of the Patient-centred care construct, the extent of diabetes Mellitus patients' perceptions of PCC, and its correlates

1.6 Objectives

1. To conduct a scoping review and synthesis of evidence on key dimensions and drivers of PCC for chronic care patients in the Low and Middle-Income context.

2. To explore the understanding of Patient-centred care among diabetes mellitus patients, Healthcare providers, and policymakers in public facilities in southern Malawi.
3. To explore the experiences, enablers, and challenges of PCC practice among patients with Diabetes Mellitus in southern Malawi
4. To develop and psychometrically evaluate a Patient-Centred Care Tool for patients with Diabetes Mellitus in Southern Malawi
5. To assess the level of patient-centred care perception and the association between patient-centred care and self-efficacy, patient adherence, and glycaemic control in Diabetes Mellitus patient management in public facilities in southern Malawi.

1.7 Structure of the thesis

The structure of this Ph.D. thesis follows the divided block format, one of the thesis formats recognized by the University of the Witwatersrand Thesis Style Guide.

In chapter one, I present the background and contextual issues related to this study. Particularly, I discuss the NCD landscape and how it has challenged the traditional way of approaching health and healthcare delivery. Additionally, I bring forth the justification, including the aim and objectives of the study.

Chapter two focuses on the definition and relationships among concepts related to this study and how they are operationalized. Further, I situate my study in priori works of other scholars through conceptual and theoretical frameworks. Therefore, I am allowing readers to conceptualize my work through the lens of healthcare delivery as a process (structure, process, and outcome framework) that is intended to produce patient outcomes.

Chapter three focuses on the general methodological approaches to this study and why they were used. I relate to the phases of the study and how each component contributed to the next.

Chapters four to eight highlight key findings for each component and how they contribute to the understanding of the whole study. In line with University of the Witwatersrand thesis submission styles, each of these chapters is a complete report in the form of a manuscript. It includes two published papers and ones under review. Each manuscript has its respective abstract, introduction, methods, discussion, and conclusion. All references have been appended at the end of the thesis.

- **Chapter four** focuses on the findings of a scoping review of PCC in low- and middle-income countries, particularly, in Africa. It highlights key elements of PCC in the context of chronic care.
- **Chapter five** presents findings from the qualitative inquiry on what stakeholders think PCC means and the peculiarities of the study context, and proposes a working definition for the study and its practical elements.
- **Chapter six** discusses one crucial aspect of PCC, namely shared decision making (SDM), highlighting the challenges and vulnerabilities that patients face in trying to engage healthcare providers (HCP) in the same during medical encounters.
- **Chapter seven** discusses the psychometric analytical processes and structure of the contextual PCC assessment tool we developed and used.
- **Chapter eight** showcases the quantitative measurement of the extent of PCC itself and its correlates. In this chapter, I present PCC perception and its relationship with adherence, glycaemic control, and self-efficacy. Particularly, it highlights some unexpected results and how that allows us to think differently as we approach PCC delivery.

- **Chapter nine** consolidates all the findings in the respective manuscripts in a discussion chapter and proposes a working definition, implications for practice, and highlights the Ph.D.'s contribution to science, recommendations, and areas for further study.

CHAPTER 2: Background: Theoretical and Conceptual Frameworks

2. Introduction

This literature review chapter aims to offer an initial contextual understanding and operationalization of the concepts used in this study through the theoretical and conceptual frameworks highlighted in this chapter. It serves as an extended background for the study. Additionally, a comprehensive scoping review of relevant literature is presented in Chapter 4 to further supplement this chapter.

2.1 The Theoretical framework

This theoretical framework sets the stage for conceptualizing the PCC construct empirically as a process of care leading to patient outcomes. While acknowledging the multiplicity of PCC themes in literature, we highlight and define some common practical dimensions further, and situate the PCC concept in the context of chronic care in low and middle-income countries. In addition, we present PCC surrogate terms as used by other authors in order to guide the reader in their review of this work.

The chapter further argues on perceptions that matter in the conceptualization and assessment of PCC. Finally, the chapter explores from priori works in this field and how they have been used to inform the theoretical and conceptual framework for this study.

2.2 The conceptualization of PCC

Differing definitions of PCC exist in literature across contexts, which results in inconsistencies in the conceptualization of the concept. The variation in conceptualization depends on context and whose perspective is being represented; whether patients or providers(27–29). Conceptualization refers to the process of breaking down concepts into common functional meanings(30).

Patient centred care refers to a complex set of phenomena involving the interaction between the provider and the patient (often in a medical encounter context) that is characterized by responsiveness to patient needs and preferences, using the patient's informed wishes to guide activity, interaction, and information-giving, and shared decision (29). Responsiveness brings a balance to the extent to which both the patients and providers' wishes and needs can and should influence the activities within the encounter. While Kitson et al describes the basis of PCC as an encounter, Castro in her concept analysis, aligns with the definition and adds that "patient-centredness is a bio-psycho-social approach and attitude that aims to deliver care that is respectful, individualized and empowering" (page 1930)(31). Furthermore, she observes that there is "individual patient participation that is built on a relationship of mutual trust, sensitivity, empathy, and shared knowledge" (page 1930)(31). Castro's definition additionally highlights comprehensiveness and mutual relationships in care, describes PCC from the providers' responsibility perspective, and explains that, as much as PCC is an approach, it is an attitude and moral value. Her definition further acknowledges the role of individual patient competencies in such care. In contrast, Mead and Bower's PCC conceptualization proposes practical elements as tasks to be fulfilled during the encounter (32) . These functions include therapeutic patient-HCP relationship building, bio-psychosocial care provision, individualizing the patient as a unique person, sharing power and responsibility, and realism in the expectations of the encounter. This narrative highlights the complexity of the PCC construct and the multiplicity of expressions across authors and contexts.

The existence of a multiplicity of PCC conceptualizations hinges on implementation models of PCC. According to the Australian Agency for Clinical Innovation (ACI), a model of care outlines best approaches and practices on how service is delivered(33) . While Marshal et al argues for a unified model across contexts like the Eurocentric ones, Pluut asserts that the

multiplicity is healthy and it forces stakeholders to reflect on the relevance of the models in respective contexts(34,35).

In constructing an action model for any context, Pluut et al. advise that it must be integrative, drawing on perspectives from the patient, Health care providers (HCP), and policymakers through consensus building, and working through the respective differences(35). Hugo adds that the model of practice for a given context should consider enablers and barriers in its interaction at individual patient–provider interaction, institutional/community, and wider policy levels(28). The World Health Organization attests to the aforementioned layers of interfaces as noteworthy to the construction of a system for innovative care for chronic conditions framework(36). The foregoing views are all reasonable; it is imperative to elucidate from stakeholders how PCC is conceptualized locally.

While it is acknowledged that terms like "patient-", "client-" "people-" centred care are used interchangeably in literature, we posit that all these terms represent the "individual" who is the central object of care and, in the context of medical encounters, is often the patient(s)(29,37). Therefore, in this study, the term "patient" has been used. For the quantitative phase, therefore, we assessed only patients' perceptions of PCC because the patients are beneficiaries and the central object of care(38).

One could safely summarize that patient-centred care is a complex and responsive approach to healthcare. It involves healthcare providers and patients working together in a relationship based on trust and mutual understanding. This approach aims to deliver care that is respectful, individualized, and empowering, considering the unique needs and circumstances of each patient. It involves shared decision-making and the active involvement of patients in their own care. Patient-centred care addresses the physical, emotional, and social aspects of health and

well-being and considers the values, beliefs, and preferences of patients. It also recognizes the strengths and abilities of patients, empowering them to actively participate in their own care.

2.3 Description of the functional elements of patient centred care

PCC attributes have been adapted and described in various ways to suit variable contexts and settings(39,40). Whilst some attributes are emphasized more than others in different contexts, five of the seminal themes are biopsychosocial perspective, patient as a person, sharing power and responsibility, patient provider relationship, and being realistic(32). In this section, therefore, we aim to describe some of the attributes in PCC and how they may serve as initial signposts in our work.

2.3.1 Biopsychosocial perspective (Understanding the Whole Person)

This dimension is about looking at a patient holistically, acknowledging that a person is more than their biomedical aspects (52, 53) and understanding their context in terms of culture, family, work, religion, social support, life history, developmental stages, and how these affect illness and health(32,40,41). In other words, it asserts the willingness to help patients with a wide range of problems beyond the biomedical aspects of care.

2.3.2 Patient being known as a person (Exploring both disease and illness)

This dimension is also known as exploring disease and illness experience, or “starting from the patient” (32,40,42). It highlights that patients with illnesses experience personal meaning that is unique to each individual, hence the need to individualize to cater for unique illness experiences and consequences.

2.3.3 Sharing power and responsibility (Finding Common ground)

Shared power and responsibility acknowledge that, in a provider-patient encounter, there are power differences that may affect the nature of the interaction (31,43). This dimension, therefore, aims to make the provider aware of how he needs to recognize and deal with existing power imbalances in order to facilitate the formulation and attainment of mutual goals in care(44). Practically, it calls for mutual participation and negotiation in the care to any possible extent. Furthermore, it acknowledges that a patient has the expertise to manage their own health.

2.3.4 Enhancing provider-patient relationship

Enhancing an alliance between patient and provider is critical to effective provider-patient interaction. The relationship is a continuous commitment based on trust, access, and continuous effective communication, both verbal and non-verbal(41,45,46). It is also known as the therapeutic alliance because its goal is to develop and reach mutual goals in care, which is fundamental in any provider-patient encounter, whether psycho-social or physical(47).

2.3.5 Being realistic

Mead and Bower refer to this dimension as “provider as a person”(32). Several authors agree that it is a multifaceted dimension in that it acknowledges the provider as a human being with limitations, a value system, and a set of skills that may affect the care rendered(41,45,46). Hudon et al. add the perspective of being aware that both parties in the interaction are affecting each other (40). Additionally, the authors caution providers concerning realism about what care can be rendered within the confines of their resources.

2.3.6 Incorporation of health prevention and promotion

Stewart et al posit that all provider-patient interactions need to incorporate aspects of anticipatory health prevention and promotion(48). Actually, they explain that the interaction

provides a supportive platform for screening new health problems and monitoring old ones to improve health.

2.4 PCC outcomes and chronic care context

Regardless of existing inconsistencies in documented PCC outcomes, PCC interactions affect patient outcomes through a number of motivational and cognitive processes underlying health-related behaviors thereby improving health outcomes (49,50). In DM care, PCC has been shown to impact biomedical outcomes such as better glycaemic control and reduced emergency visits(51). PCC also impacts on patient reported outcome measures (PROMs) and Patient experience measures (PREMs) (46). Better still, apart from PROMs and PREMS, improving the effectiveness of technical aspects of care, Black et al demonstrated that PROMS and PREMS have the potential to impact each other positively in a reciprocal manner(52). While PROMS highlight the patients' perceptions of the effectiveness of care on their own health status and, PREMS highlight patients' perceptions of the experiences concerning the process of care as they are receiving it and the impact of such experiences on the given care. Important PROMs in diabetic patients include adherence to self-care, self-efficacy, emotional and physical wellbeing (perceptions of general health), functional status, reduced emergency visits and complications(51,53,54). The PREMs describe both relational and functional rating of the interaction(52,55). Relational aspects of PREMs highlight issues to do with the quality of the actual encounter such as shared decision-making whilst functional rating relates to systemic issues of the healthcare system.

Chronic disease management is amenable to PCC efforts, and its significance is palpable(7,50,56,57). Patient-centred care complements the biomedical aspects of care in facilitating the attainment of patient-reported experience and outcomes as well as health status outcomes(56). Literature highlights the contribution of a functional patient-provider interaction

leading to an activated patient and proactive health provider team facilitating better patient experiences of care, self-efficacy, and adherence with the HCP as a resource(58,59). MacMillan et al. in their review of thirty randomized control trials on outcomes of PCC in chronic care patients, found that PCC was associated with better-perceived quality of care, patient satisfaction, and some health outcomes such as glycaemic control(51) . Patient and HCP factors, as well as contextual factors, all affect the attainment of such outcomes (42,52).

PCC outcomes are mediated through direct or interlinking causal pathways. Glanz et al theorizes that PCC mediates outcomes through proximal, and intermediate outcomes(49). For instance, in the context of DM care, PCC interaction that portrays therapeutic provider-patient alliance facilitates patients' feelings of being involved in care as a proximal outcome, thereby giving them the ability to participate in shared decision-making about healthcare goals as an intermediary outcome. Mutual care plans between the provider and patients are likely to be adhered to, which leads to improved glycaemic control and quality of life (53,60). Pathways linking PCC to quality outcomes may not be direct but through intermediary outcomes or factors such as disease profile, self-efficacy, and adherence (51).

2.5 Patient-centred care, self-efficacy, adherence, and glycaemic control in chronic care

Adherence, as the main outcome of this study, is a construct that recognises patient participation and capabilities in following mutually agreed plans(53). It is key to chronic patient care and a marker of effective provider-patient interaction that has facilitated trust building, information sharing, patient involvement, and support(49). Without adherence to management plans and appointment keeping, it would be difficult to attain patient outcomes, glycaemic control, prevention or delay of DM complications, and the cost-effective use of health resources(61).

Important aspects of adherence are the ability to follow a medication regime, health behavior, and appointment-keeping (38).

One other key cognitive resource to attaining outcomes is self-efficacy for specific self-care activities. It relates to the acknowledgment and support for the mastery of self-care activities within the encounter(62,63). One key function of medical encounters ought to be the capacitation of patients towards confidence and mastery of self-care activities if we need to achieve patient goals and outcomes.

Long term glycaemic control is ultimate goal of DM care among others to prevent the development and progression of complications. The International Diabetes Federation (IDF) defines the glycaemic goal is HbA1c of =<7%(64). Achieving glycaemic control among patients with DM is multifactorial, individualized and requires multifaced efforts that includes the patient. Disease, patient and system factors can affect attainment of glycaemic control. For instance, patient factors such as multimorbidity and presence of complication, self-efficacy and adherence levels have been shown to correlate glycaemic control among patients with DM(63,65). Therefore, any efforts tailored to mitigate these factors have potential to optimize glycaemic control and its resultant effects

2.6 PCC in low middle and income countries

While it is acknowledged that PCC cannot be determined entirely by Gross Domestic Product (GDP), the models and typologies differ across countries' socioeconomic developmental states because GDP, in part, facilitates (or does not) the healthcare models that support PCC. It is clear that the levels of health expenditure, the extent of shared financial responsibility (between the patient and the system), and human resources determine the success factors and bottle-necks faced in implementing PCC and, ultimately, how it would be perceived and experienced (66–68). Benshib et al. conceptualizes PCC as humanistic health systems that thrive at the nexus of

quality and accessibility of care rendered and communication between its players (69). In other words, health systems are about relationships, mediated by social, political, and cultural happenings. The Low Middle Income countries (LMIC) context is often characterized by low GDP and its associated low expenditure on health, high burden of disease and, constrained and/or inequitable human and material resources(13,66,70). The patients in these contexts are often underprivileged, economically vulnerable, and the limited access to resources that often results in poor-quality care delivery. These dynamics indicate that the interactions between the patient-provider dyad are moderated in the expressions of what working PCC frameworks should mean within those resource constraints(71).

In Malawi, through UHC, the public healthcare system is free for the patient at the point of delivery, and this has a bearing on what care is accessible and the bargaining power dynamics among its actors during medical encounters. Patients often view the care rendered as a privilege and not a right and thus have little or no say in the care they prefer. While PCC is being advocated through service charters and the presence of an Ombudsman it is imperative to understand how these dynamics are negotiated at the interactional level in coming up with a working conceptual model and approach while embarking on this PCC study(67).

2.7 The assessment of patient-centred care

Patient-centred care is an abstract social construct that is important in care processes. It is important to measure as it relates to important aspects of quality that need to be appraised and assessed in order to assess the responsiveness of care, its quality, and benefits. According to da Silva, assessing of PCC with fidelity starts with standardizing the variables we are measuring. in whom how, and where.

Different authors have measured PCC can be done at definitions, thus, how different stakeholders in care regard as important variables in their study population, and what they value

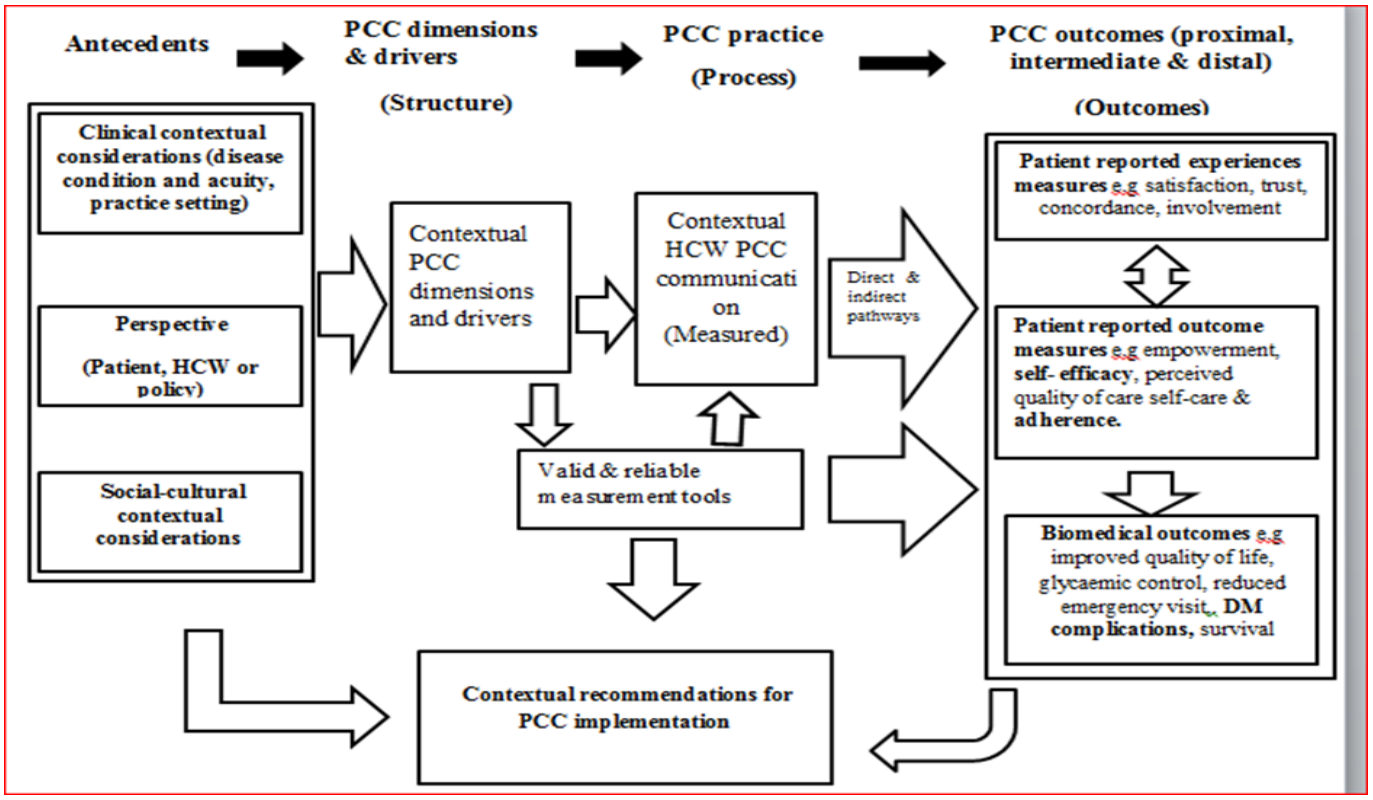
or prefer. Experiences of PCC are important measures of PCC and its resultant patient-reported- and biomedical- outcomes make the circle complete.

While conceptualization requires multiple perspectives, in as far as measuring the extent of PCC practice in any context is concerned, Hudon et al. heavily incline toward patients' perceptions when it comes to assessing what matters because they are PCC's beneficiaries and central object of care(43). Tzelepis et al. agree with the same view and add that a measure of patient perception of PCC is a good proxy of whether a PCC encounter has taken place or not (72,73). In this study, therefore, the patient was the judge of whether PCC had taken place or not.

2.8 The conceptual framework

This study was informed by composite conceptual frameworks adapted from Glanz et al. Louw et al. da Silva et al, Donabedian et al and Bressers et al. who highlight that in any given context, PCC conceptualization is driven by contextual factors and stakeholders' perceptions (antecedents) (28,49,74). These factors further determine important dimensions or elements and how PCC can be implemented to mediate patient outcomes and, be assessed in a structure-process-outcome model(75). The framework also highlights what, on whom, and how to measure in the assessment of PCC; stressing that patients' (or their proxies') perceptions should ideally be utilized as input into the measurement tools because they are the central beneficiaries and the central object of care. An appreciation of the contextual considerations and perspectives shaping PCC, its valid measures, and its relationship to outcomes has the potential to inform recommendations for implementation. The framework (Figure 2.1) summarizes research gaps, the scope of work and how research questions were addressed in this study.

Figure 2.1: The Conceptual framework governing the study



The study therefore explores and measures operational definitions of PCC patients' preferences and experiences whilst receiving care, and patient-reported- and biomedical outcomes and highlights some of the PCC benefits.

2.9 Conclusion

The chapter embraces the multiplicity of elements in defining PCC as a process of care in different contexts. It, particularly, sets forth some seminal elements that served as a signpost in the conceptualization of the complex PCC concept in this study. Furthermore, it highlights the value of PCC in patient care delivery and outcomes and how stakeholders' perceptions and contextual considerations must define its practice, and guide its implementation (to effect desired outcomes) and assessment in a given context. Finally, I highlight how the theoretical and conceptual frameworks inform the approach, scope, and phases of the study to effectively answer the research questions.

CHAPTER 3: METHODS

3.1 Introduction

This section describes the methods used in the study and provided its justification. Each phase of the study is clearly outlined sequentially and how each feed into the next (the three successive phases as highlighted in Table 1). Detailed methodological approaches for the respective phases of the study are described in the respective manuscripts. The three phases are as follows:

Phase 1: A scoping review

Phase 2: Qualitative inquiry

Phase 3: Tool development: Psychometric assessment of perception of PCC tool t

Phase 4: Quantitative assessment and analysis of PCC and its correlates

The section further describes the study setting, its population, and how they were selected. Data collection procedures and tools are clearly outlined, and scientific rigor and ethical standards were maintained throughout the study. The section also describes data management and analytical steps that were followed in the study. Finally, it describes the strengths and weaknesses of the study and how they were mitigated to maintain scientific rigor.

3.2 The general study approach

This was a cross-sectional mixed methods study that employed an exploratory sequential design in order to complement, triangulate and converge research findings(76) . The term mixed methodological approach refers to the art of concurrent or sequential employment of qualitative and quantitative methods in order to achieve a deeper understanding of a research topic than using one approach (76,77). The need for mixing methods in this study was considered in order to enrich our contextual understanding of the complex PCC construct. Thus, initially exploring PCC meanings and breaking it down to its functional elements and later, being able to measure it

precisely. Specifically, the qualitative inquiry was used in this study to explore the PCC construct and to build a tool on important elements of PCC from the same population and, in turn, assess the extent of PCC to which the measures are contextually relevant. We further did a psychometric analysis in order to confirm the structure and consistency of the tool and obtain valid results. Thereafter, we quantitatively assessed the current PCC practice in Malawi and its association with baseline adherence to DM care plans, self-efficacy and glycaemic control. The methodological phases are shown in Figure 3.1 below.

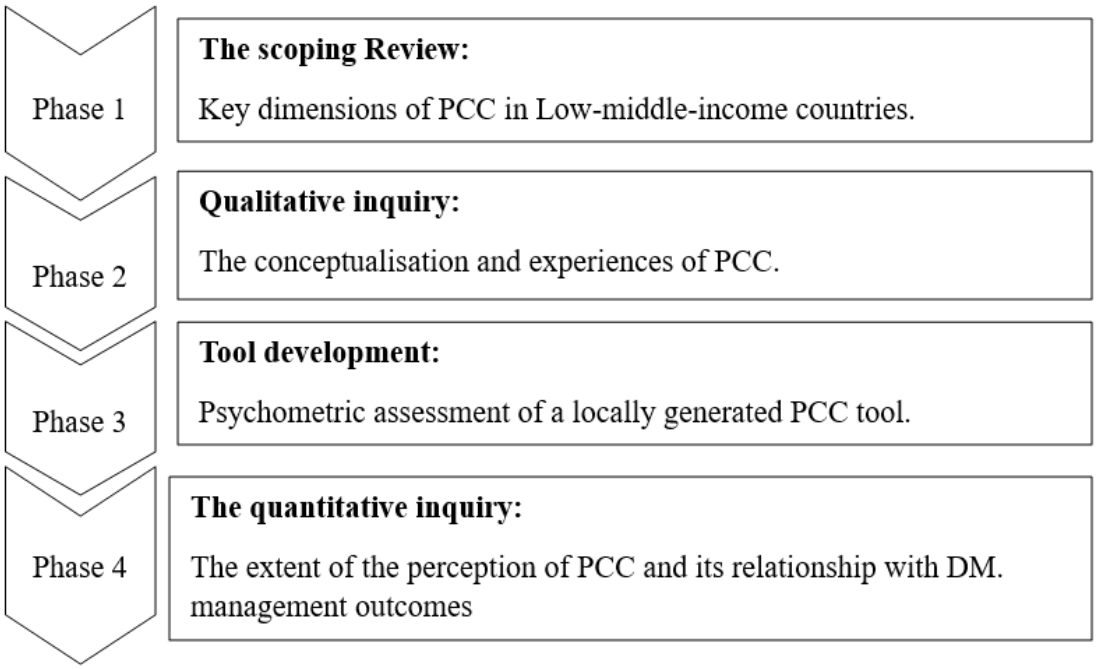


Figure 3.1: Methodological phases of the study

3.3 Participants and study setting

Participants were DM patients, their health providers, and policymakers from southern region of Malawi (Refer to Figure 3.2). Healthcare providers encompass nurses, clinical officers, and medical doctors who are directly involved in DM care by defining the problem and rendering

care. For the quantitative phase, we only collected data from patients with DM who had patronized the facility for more than six months.



Figure 3.2: The Map of Southern Malawi

We collected data from four public hospitals' DM clinics in the Southern Region of Malawi and the Ministry of Health headquarters since, logistically, it was geographically close to where the researcher operates. The four public hospitals were Blantyre, Zomba, Mulanje, and Chikwawa. Piloting of the qualitative tool was done at Chiradzulu District Hospital within the Southern Region. These districts were conveniently selected to highlight a mix of both urban and rural views. We selected policy-makers from the QMD and the Non-Communicable Diseases and Injuries (NCDI) because of their influence in the development of quality of care and NCD policies.

Diabetes care is largely centralized in Malawi; it happens in district hospitals on designated days. Usually, patients have to travel long distances to access care. DM district hospital clinics are usually run by nurses and clinical officers, while specialized DM care is only obtainable at central hospitals. There is usually no 'regular' healthcare provider (HCP) for a given clinic, although an HCP can be assigned for variable periods of time as an NCDs coordinator.

3.4 Phases of the study

The descriptions of the methodological phases were as follows:

3.4.1 Phase 1: The scoping Review

We conducted findings from published and unpublished literature following Arksey and O'Malley's steps (78).

Search strategy and information sources

We iteratively developed a search strategy using the research question **"What are key dimensions of patient-centred care among chronic care patients in low-middle income countries?"** A published literature search was obtained from all available databases, including PubMed, EBSCO host platform (CINHAL, Medline), EMBASE, Cochrane library, Hinari, Scopus, Researchgate, Google Scholar, and Africa journal online. Grey literature was also identified from Google Scholar, Sabinet (> Theses & Dissertations > African Digital Repository > African Journal Archive), government websites, and non-governmental organizations (NGO) reports. The inclusion and exclusion criteria are detailed in chapter four. The search was carried out between June-September 2019.

> *("chronic care" OR "non-communicable disease*" OR "chronic management" OR "chronic patient*" OR "long term care") AND ("patient-centred care" OR "patient-centred care" OR "patient-centredness" OR "client-centred" OR "client-centred" OR "person-centred" OR "person-centred") AND (dimension* OR attribute* OR element**

OR function) AND ("developing country*" OR "third world country*" OR "low-income country*" OR " low resource country*" OR Africa)*

Selection and data analysis

We used the Covidence data management tool to manage and extract the data from relevant articles. The Covidence tool did an initial practical screen to remove duplicates, and later, a more detailed screen and data extraction process followed. Two reviewers did the title, abstract and full-text screening, and data extraction, and conflicts between them were resolved at every step. We employed thematic data analysis and synthesis, which involved the interpretation and explanation of themes identified(79,80). This scoping review phase informed the direction of data collection and analysis of the qualitative inquiry through semi-structuring the data collection tools and relating the findings we obtained to existing functional elements in the literature. Particularly, this phase provided the initial framework and operationalization of the elements of PCC in the chronic care context; a step that provided a framework for organizing ideas in the analysis of the qualitative inquiry.

3.4.2 Phase 2: PCC qualitative inquiry

Study design

This was an exploratory qualitative inquiry. The qualitative exploratory approach seeks to understand the complexity and dimensionality of perspectives of a construct, in this case, the perceptions and experiences of PCC.

Sampling and study population

The study population involved patients with DM. This is because they are chronic patients who are often stable clinically have repetitive contact with the healthcare system and, are amenable to

PCC efforts. Therefore, they were better able to give insights on the functioning of the healthcare delivery systems and its providers. Likewise, HCP and policy makers that work in DM care are better placed to comment on the expectations, processes of care and have power to influence its functioning.

We interviewed 37 patients with DM, 33 HCPs, and two policy-makers through in-depth interviews (IDIs) and Focus group discussions (FGDs). There were 31 individual participant IDIs (16 patients, 13 HCPs, and two policy-makers) and four FGDs (two for patients and HCP each). Each FGD had 10 participants except one. The sample size was determined by the saturation of responses to meet the study objectives. Sampling was purposive. We approached the clinic-in-charge to identify patients who had patronized the clinic for more than six months and were willing to participate in the study. We made deliberate effort to vary sex, age, and duration of disease to ensure diversity of perspectives. For HCP, we conveniently recruited nurses, clinical officers, general doctors, and specialists who were involved in direct DM care and they were involved in formulating management plans for their patients in the respective health facilities for at least 6 months. We purposely selected heads of the QMD and NCDs units as our policymakers due to their experience in policy formulation in regards to PCC and NCDs care. Of all participants approached, only one specialist doctor declined participation because they had limited time to commit to the study.

Data collection tools and procedures

We used a semi-structured interview guide (Appendices 7.1- 7.5). The author, alongside a research assistant who was a note-taker, conducted individual In-depth Interviews (IDIs) and Focus Group Discussions (FGDs) to obtain both individual and collective perceptions of PCC. One FGD comprised of 10-11 participants was conducted at each facility. Patients and HCPs

were in separate FGDs. Due to logistical challenges concerning getting enough policy-makers together, no FGD was conducted with them.

Data management and analysis

Research assistants translated audio data from Chichewa into English, transcribed them verbatim, and imported them into NVivo software version 11. Data analysis involved familiarization, coding inductively, and mapping data against Mead and Bower's framework and those obtained from our scoping review.

Trustworthiness and reflexivity

We ensured the trustworthiness of data through the triangulation of data collection methods (IDIS and FGD's) and views presented in this study by collecting data from three participant categories, namely, patients, their HCPs, and policy-makers. The research process as documented is repeatable.

Reflexivity involves acknowledgement of the role of researcher's subjectivity and context in the research process(81). The researcher, being a family physician, who engages with the PCC construct in teaching and practice, acknowledged the priori assumptions and hypothesis that may bring potential bias whilst engaging with the topic. The researcher employed bracketing in order to approach the exploration of the construct with an open mind, permitting sensitivity to alternative perspectives while maintaining focus. Although the definitions and approaches of bracketing are fluid, according to Tufford et al, bracketing, as a reflexive process, refers to the art of earnestly suspending the researcher's own pre-existing thoughts and beliefs, and hypotheses about a topic at the conceptualization of the research topic, data collection and analysis stages(82). In this study, bracketing was achieved by writing memos and reflecting on them as we drafted interview guides, data collection and analysis. Triangulation and member -

checking ensured that views of participants are prioritized. Further, the engagement of persons such as other research team members and non-team members in the coding and analysis mitigated the preconceptions that the researcher might have held.

3.4.3 Phase 3: The Development and Psychometric Evaluation of a Patient-Centred Care Tool for Diabetic Patients

Study approach and design

This phase employed a quantitative methods approach to develop a tool de novo. The study involved use of the PCC thematic domains identified earlier in the study through qualitative inquiry to develop items that would be used to measure the perception of PCC during a medical encounter. These items were then psychometrically assessed quantitatively to determine the structure and validity of the PCC construct.

Study population and sampling

We used DM patients' data on PCC to assess the psychometric properties of the tool. We used data from 607 subsequent patients in accessing care in DM clinics. This was actually the same study sample used in Phase 4; therefore, the sample size was determined through the requirements of Phase 4 of this study).

Data collection

We used an interviewer-administered five-point Likert type 28 item-tool (Appendix 8). The tool had eight domains, highlighting functional tasks that ought to happen during a PCC encounter. The domains were generated locally from the initial phase of qualitative inquiry of this study.

Data management and analysis

The data was cleaned, and all outliers were removed. Don't know or missing variables were managed as a "mode" which is the most frequently occurring number in order not to affect the mean(83). The tool had undergone face validity testing with a panel of experts and was piloted

among participants and it was administered to a pilot sample of 30 patients, with identified problems being rectified accordingly. The pilot sample was not included in the study because there were significant changes to the likerting style of the tool. We then proceeded to administer it to 607 patients.

The psychometric analysis was done using STATA version 17. The adequacy of the sample was determined using the Kaiser–Meyer–Olkin (KMO) and Bartlett's test of sphericity (84). The Bartlett's test for sphericity assesses the hypothesis to ensure that the correlation matrices of all variables are all at zero; a measure of variables relatedness. A chi-square value of <0.05 indicates significant variable collinearity (relatedness) and is desirable for exploratory factor analysis and data reduction(85). Kaiser–Meyer–Olkin test assesses the proportion of variance among variables that might be attributable to common underlying factors. It indicates adequacy of sampling, hence, suitability of data in the model for factor analysis. A high value between 0.8-1.0 is desirable(84,86) .

Internal consistency and reliability of the tool were determined using Cronbach's Alpha which is the amount of shared variance; measuring how closely related the items are as a group, pegged at >0.70(86,87). Identification and extraction of latent factors was done through exploratory factor analysis (EFA). Exploratory factor analysis is a method for investigating a large set of observed and related measures to find the latent themes and interrelationships among its variables(86). We further confirmed the number of latent themes using parallel analysis to determine and visualized them on a Scree plot(86,88). We iteratively assigned items to each factor using factor loadings, uniqueness and conceptual mindfulness in the respective factors. Factor loading of >0.3 was deemed acceptable(86). Finally, we used confirmatory factor analysis with goodness of fit studies to confirm the number and structure of the final tool(89,90). To confirm construct validity, we used the same data to determine if the tool could determine

groups of individuals with different PCC levels and if it related to outcomes. Details of the psychometric analytical procedures and the determination of latent factors are provided in chapter five.

3.4.4 Phase 4: The quantitative assessment of PCC among patients with DM

Study approach and design

This was a quantitative, cross-sectional analytical study. In this approach, the researcher measures the exposure and the outcome at one particular point in time (91). The purpose is to measure the nature and strengths of associations between the exposure and the outcome among the participants. Since experimental studies on PCC are sparse, especially in Malawi, the cross-sectional analytical approach was ideal in this case in order to create theories and hypothesis that can be tested in future experimental research.

Study Population and sampling

The sample size was 607 patients with DM who were 18 years old or older. The study sample determination was based on comparing two means. The sample size (n) was therefore calculated using the standardized coefficient for the relationship between PCC and adherence in DM at 0.16, effect size (ES) with the power of 80% to detect 5% difference, and design effect (DE) of 1.5(92). The standard value for DE was two (2) but due to budgetary constraints, the study used an acceptable value of 1.5. Therefore;

n= (1.96+0.84) ^ (2) [(p(1-p))/(p1-p0) ^ (2)] = $((1.96+0.84)/0.136589)^2$ = 420.2 x 1.5=632

Accounting for 10% non-response rate the n (new) = n (old)/0.9= **703 patients**. However, due to the COVID pandemic, we only managed to recruit about 86 % of the intended sample size because DM clinics were running at half capacity. Therefore, the final sample size (n) was 607.

Data collection tools and procedures

For this phase of the study, we used data from the 23-item three-factor model that was psychometrically tested in the earlier phase of the study.

Self-efficacy was measured using the Stanford self-efficacy for diabetes tool (Appendix 9). This ten point 8-item tool had high internal consistency, with Cronbach alpha scores of 0.828 (n = 189 DM patients)(93). The tool had been adapted for use in Malawi in DM patients in a similar population and shown to be suitable (94). Adherence was measured using an adapted 10-item Hill-Bone compliance tool(95). The tool uses a time bound 4-point Likert scale an, ranging from 1 "none of the times" to 4 being "all of the time" (Appendix 10). Although the tool was developed for hypertension, it was adapted for DM care because the two conditions share similar care components, namely adherence to medication, lifestyle modification, and appointment-keeping. The tool was preferred because it was validated in a culturally similar setting (black South African population) with Cronbach alpha scores of 0.79.

Reported diabetic complications were assessed as a proxy of DM control through recall if they had experienced any of the DM complications in the last six months (96). The DM complications we considered were eye problems, neuropathy, kidney problems, DM limb ulcers and amputations, hypoglycaemia, hyperglycaemia, heart problems, and loss of consciousness because they were common and easy to elicit from recall (96). Long-term glycaemic control was measured using point of care HBA1c test. The rapid test has good acceptability, comparable use, and is stable in Malawi temperatures (19). Haemoglobin A1c (HBA1c) >7.1% were considered poor glycaemia(64) .

Quantitative management and analysis plan

We used STATA version 17 software for all data management and analysis except clustering, which was done using an R-studio version 4.2.3. We did normality checks to ascertain the most suitable inferential statistics to be used. All the models that we used showed a Hosmer-

Lemeshow goodness-of-fit chi-square value of > 0.05, indicating that the regression models fitted well with the data (97). Ordinal variables from the Hill-Bone, self-efficacy and PCC tools were coded as numbers and summarized as scores. PCC scores were clustered using unsupervised k-means and analyzed as binary variables in low and high score clusters. For the sake of adherence and self-efficacy, the mean scores were analyzed as a continuous variable because we had lost a lot of detail in reducing it to a binary variable.

We utilized multivariate logistic regressions using a t-test; with chi-square and p-values for levels of significance pegged at <0.05(97). In order to further describe the effect of confounders in the pathway between PCC and socio-demographic characteristics, disease profiles, self-efficacy, adherence, and DM complications, we employed a path analysis to further clarify the nature and direction of these relationships(90). A path analysis with continuous variables was conducted using a conceptual framework to identify and evaluate the relationships between variables and their mediating factors in a specific direction as highlighted in the theoretical model. We ran an adjusted regression analysis for individual factors and for the tool as a whole.

3.5 Strengths and Limitations of the study

While the study methodology records some strengths to maintain integrity and scientific rigor, it was faced with some limitations too.

3.5.1 Strengths

One major strength of our study was the mixing of methods that served to triangulate the findings of what's important as functional elements of PCC. Through qualitative inquiry and psychometric analysis, we were able to validate the elements that matter and measure them quantitatively. Other strengths included:

1. The scoping review ensured that the study was informed by existing literature and identified key dimensions of patient-centred care in low-middle-income countries.

2. The qualitative inquiry allowed for in-depth exploration of the perceptions and experiences of patient-centred care among patients, healthcare providers, and policymakers.
3. The psychometric assessment of the contextual tool provided evidence of its reliability, validity, and factor structure in the study population.
4. The quantitative assessment of patient-centred care allowed for the examination of its associations with self-efficacy, adherence, and diabetic complications, providing insights into potential clinical outcomes.

3.5.2 Limitations

One of the limitations was that the quantitative phase of the study was not interventional due to time and logistical constraints thereby falling short of causal conclusions. Below are other limitations that were identified.

1. The scoping review may have missed some relevant literature, despite using an extensive search strategy, which could limit the scope of the findings.
2. The qualitative inquiry was conducted in a specific context (Malawi) and may not be fully generalizable to other low-middle-income countries, although similar themes and dimensions may be applicable. The validated tool may then require further testing across other geographic, economic, and cultural settings.
3. The psychometric assessment of the contextual tool was conducted using data from patients with diabetes, and its applicability to other chronic conditions and populations may be limited.
4. The quantitative assessment of patient-centred care relied on self-report measures, which may be subject to bias and may not fully capture the complexity of the

concept. Additionally, the cross-sectional design limits the ability to establish causal relationships between patient-centred care and outcomes.

5. Data collection methods within hospital facilities may pose bias in the way participants respond. They may not have been truthful thus skewing the results.
6. The COVID-19 pandemic affected the recruitment process, leading to a smaller sample size than initially planned, which may limit the generalizability of the findings and conclusions.

Although the study is marked with some limitations as outlined, we strived to mitigate them as highlighted in the corresponding manuscripts thereby, improving the validity of its findings and setting the groundwork for further study in PCC in Malawi.

3.6 Ethical considerations

The study was of minimal to no risk to the participants as it did not disrupt the usual DM care. Ethical considerations anticipated and acknowledged in this study were participants' time, and dealing with people and patients. More importantly, some of these patients could be poor, hence the creation of unbalanced power in the interaction, which could, in turn, indicate coercion. However, the benefits of the evidence from the study outweighed these risks.

Ethical clearance to undertake the study was sought from the Malawi College of Medicine Research and Ethics Committee (COMREC) and University of Witwatersrand (UW) Research Ethics (HREC) boards in order to allow scrutiny of any ethical concerns before the commencement of data collection. Further, approval was obtained from the respective study district hospital research and ethics boards (Appendices 4.1-4).

In an effort to respect participants' autonomy, all participants recruited to participate in the study were 18 years of age or older and with a sane mind. Informed written consent was sought from

all individuals for the interviews and for the audio recording separately after the individuals had been made aware of the general information, anticipated risks, and benefits of the study. An information leaflet in Chichewa, the local language, and/or English was explained to participants and administered by the interviewers (Appendix 5)

Particularly, attention was given to vulnerable patient respondents. Among some patients, who by virtue of their low socio-economic status, destitute health needs, and the inherent power imbalance between them and the interviewers, there existed the potential to compromise the efficacy of the consent given(98). This vulnerability was managed by lengthy vernacular explanations about the aim, risks, and benefits and, managed their expectations of the study. Interviews were done in one consultation room to ensure privacy. The risk of coercion was low because the researcher worked in a department that is geographically and functionally far removed from the DM clinic where the study took place. She had no contact with patients or HCPs in the DM clinic, reducing the undue hierarchical superiority interference to the HCP. The interviewers were trained to ensure that data were collected in a respectful and non-coercive manner, openly stating that participation in the study was voluntary and that withdrawal from it was acceptable without negative consequences to the patient's care or HCPs' work dynamics. No other ethical dilemmas were encountered during this study.

Data were managed and protected using good clinical practice guidelines. Participants' anonymity and confidentiality were ensured at every step. No names were used; instead, study identification numbers were assigned to each participant. Additionally, all personal identifiers, such as date of birth, from the data sets were removed. Hard copies of field notes and consent forms were surely stored in the University of Malawi buildings. Data query resolution and retrieval procedures will follow the policies stipulated by Witwatersrand University and the University of Malawi (UNIMA) to allow proper follow-up of audit trails. Soft copies of data

were stored in a password-protected form with limited access, and data ownership rights were granted by the research team and UNIMA, respectively.

Participants (both patients and HCWs) time was reimbursed at the end of the interview as a token of appreciation following the standard Government of Malawi (GOM) minimum hourly approved rates, namely 3000 Malawi kwacha (75 Rands).

3.7 Conclusion

This chapter has provided an overview of the study's scope and approach. The study's methodological approach was ethical, scientific, and traceable to improve scientific rigor and reduce bias. Where necessary, complementary analytical approaches were used to improve validity of the results. Strengths and limitations have been highlighted to allow the reader to interpret the results with the necessary considerations.

Section B: CHAPTERS 4-9: THE STUDY FINDINGS AND SYNTHESIS

Introduction

In the following chapters, I present findings concerning functional elements in Malawi, a psychometrically tested tool, an objective assessment of the Malawi specific elements, and their correlates. The results are presented as individual manuscripts, both published and unpublished. Each of chapters 4-8 represents a manuscript that highlights a key finding in the study, thereby sequentially responding to the research objectives and, ultimately, the aim. Each manuscript is presented with its own abstract, introduction highlighting the research gap, methodology, key findings, discussion, and conclusion. At the end, I consolidate the key findings from the individual manuscripts of the study into a synthesis chapter in order to show the study's key findings, scientific contribution, methodological innovations, and policy and practice implications. The key findings are summarized in Table 4.1.

Table 4.1: Summary of findings

Objectives	Key findings	Outputs
Objective 1 **To conduct a scoping review and synthesis of evidence on key dimensions and drivers of PCC for chronic care patients in the LMIC context**	The paucity of evidence on PCC elements especially in Africa Differing expressions of and emphasis on some key functional elements	**Paper I:** The Scoping Review of the Key Functional Elements in Chronic Care in the Low- and middle-income Context (LMIC) (Unpublished manuscript)
Objective 2 **To explore the understanding of PCC among DM patients, HCPs, and policymakers in public facilities in southern Malawi.**	Key functional elements from three stakeholders elucidated A working definition of PCC for the Malawi DM care context	**Paper II** The Conceptualization of Patient-Centred Care: A Case Study of Diabetes Management in Public Facilities in Southern Malawi
Objective 3 To explore the experiences, enablers, and challenges of PCC practice among patients with Diabetes Mellitus in southern Malawi	Experiences and Vulnerabilities of patients while in pursuit of a basic tenant of PCC (Shared decision-making)	**Paper III** An insight into patient perspectives on barriers affecting participation in shared Decision-making among patients with Diabetes Mellitus in Malawi (published)

Objective 4. **To assess the level of PCC perception in DM patient management in public facilities in southern Malawi.**	Distillation of key elements that matter quantitatively Validation of a contextual PCC tool Objective assessment and scientific categorization of PCC score that matters for outcomes	**Paper IV** The Development and Psychometric Evaluation of a Patient-Centred Care Tool for Diabetic Patients in Southern Malawi (submitted for publication)
Objective 5 **To describe the association between PCC and self-efficacy, patient adherence, and glycaemic control among DM patients in public facilities in southern Malawi**	Low levels of PCC PCC relationship to DM patients' experiences and outcomes of care self-efficacy and adherence. Showcasing that PCC matters! Methodological innovations in assessing the associations between PCC and outcomes Advocacy for PCC: Policy Brief for sharing with Policy Makers	**Paper V** The perception of patient-centred care and its relationship with management outcomes and complications among patients with DM in Malawi (Submitted for publication) Paper VI Policy Brief: Patient-centred care (PCC) interactions among patients with Diabetes Mellitus

CHAPTER 4: PAPER I

Manuscript: The Scoping review of the key functional elements in chronic care in the low- and middle-income context (LMIC) (unpublished)

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Abstract

Introduction: Patient-centred care (PCC) implementation still remains a gap, especially in LMIC. The functional elements or dimensions at the interactional level especially in chronic care are either poorly understood or lack clarity. The lack of clarity in what it constitutes in the low and middle-income context thwarts its understanding, implementation and objective assessment. Therefore, understanding PCC's contextual key dimensions or elements is core to its successful implementation.

Aim: This scoping review aimed to discuss the availability and descriptions of the key functional elements of PCC among chronic care patients in Low-middle-income countries.

Results: There is a paucity of literature concerning explicit definitions of key functional elements within the chronic care context. However, the identified key elements in the chronic care context include information sharing, support for self-care, comprehensiveness, patient involvement and shared decision-making, optimal patient-provider communication, good interactional ambiance, cultural sensitivity, reasonable waiting times, meeting needs, individualization of care, and organizational culture for PCC.

Conclusion: While the literature describing PCC in the LMIC is sparse, within the chronic care context, it is defined beyond the realms of interactional definitions to include organizational elements.

Background

The implementation of PCC has been challenging; therefore, its influence is hardly noticeable in routine healthcare delivery despite growing advocacy and professed adoption of quality-of-care policy reforms. This could largely be attributed to the fact that functional elements of PCC are largely undefined, especially in Low- and Middle- income countries (LMICs) where documentation of what it means in practice is sparse. The absence of clear functional elements of PCC makes it hard for PCC to be expressible and measurable in routine care(14).

Additionally, the multiplicity of frameworks, most of which have origins in well-resourced contexts, makes us question whether the elements would be applicable to LMIC, where resource limitations and cultural constructions of complex phenomena such as PCC may affect the dynamics and expectations of medical encounters (23,99,100). It is known that the construction of self in different cultures and settings determines what we think of ourselves and what to expect in medical encounters. In most African societies, the interdependent view of self is prevalent. In reference to the Botswana socio-cultural context, Selthare et al contend that the view of self includes significant others in defining who we are and how we behave in different situations(23). This means that these dynamics might manifest themselves cognitively, emotionally, and in the expressions of motivations and mannerisms during medical encounters. For example, a grown patient's seemingly reluctance to engage in shared decision-making with the provider may actually imply that he would like to consult and make decisions that should serve the interests of not just himself but also significant others, or implicitly delegating power to the HCP. This calls for contextual sensitivity in conceptualizing and defining PCC. Again, healthcare resource availability (especially human resources) and the sharing of financial responsibility between the patient and system have an impact on the extent to which care can be

accessed. Patients who access free services are likely to view healthcare as a privilege, therefore, they are unlikely to exercise their decisional freedom(71). These factors have the potential impact on power dynamics, ultimately, the expressions and expectations of PCC encounters(101). Thus, the seminal definitions may differ significantly between western and non-western contexts, including LMIC's.

The PCC necessitates that care responds to the holistic needs and preferences of the patient as a functional approach to medical encounters in different contexts. Practically, this approach, therefore, outlines tasks that need to be fulfilled in the medical encounter. Such approaches to care improve quality of health service delivery and can be implemented at individual provider-patient interaction, institutional and broader system, and contextual levels (11,31,102).

The significance of PCC is palpable in chronic disease management. Wagner's chronic care implementation framework highlights the contribution of a functional patient-provider interaction, leading to an activated patient and proactive health provider team in achieving better outcomes in care(40). Patient centred care among chronic patients has been linked to better-perceived quality of care, patient satisfaction, and some health outcomes, such as glycaemic control(103).

The rising burden of chronic non-communicable diseases (NCDs) that often exist with multi-morbidity such as psychosocial problems, contributes to the growing complexity of disease management plans(5). Therefore, care delivery needs to shift from the traditional acute, episodic, and biomedical models to embrace more PCC models in which provider-patient encounters are capable of integrating both technical and interpersonal aspects of care and dealing with bio-psychosocial patient demands over time(8,104). Additionally, the WHO emphasizes that such interactions should be able to foster partnerships with patients, leveraging their capabilities towards health promotion. This being the case, PCC interactions would be fundamental to

quality management of chronic patients, especially in limited resource contexts such as Malawi, particularly, in this era of growing chronic NCDs as Malawi tries to maximize value for money in its healthcare service delivery(50). It, therefore, becomes imperative to understand what it should mean in day-to-day life.

The PCC approach, however, is poorly understood and executed(16). In this regard too, there is paucity of information abo functional elements and contextual considerations(17). Thus, specific initiatives and products to be integrated into routine care to promote PCC are elusive(105). It was through this scoping review that the study sought to identify and map the evidence regarding key dimensions or components of PCC in LMIC in order to understand PCC's functional elements. Understanding what PCC is would help one assess it and advocate its implementation in LMICs such as Malawi.

The Aim and review question

The aim of the study was to understand the key dimensions of PCC in chronic care context in low and middle-income context in order to inform the subsequent interrogation of the topic. To fulfil the aim, the study endeavored to answer the research question, **"What are key dimensions of Patient centred care among chronic care patients in low- and middle-income countries?"**

Methods

We conducted a scoping review of information synthesized from LMIC context literature in order to explore the spread and descriptions of key dimensions of PCC in LMIC in chronic care.

Study approach and design

The study was approached as a scoping review of findings from published and unpublished literature within the LMIC context. The study followed Arksey and O'Malley's steps in a scoping review (78). A Scoping review is appropriate in this study because it allows narrative

synthesis of evidence from different sources to come up with a quick understanding and breadth of evidence on dimensions or elements of PCC that are in low middle-income countries. Furthermore, as an approach, a scoping review that uses multiple sources offers rigor and the potential to unearth real-world hidden gaps and controversies that exist in the implementation of PCC(106) . The findings guided the direction of subsequent qualitative inquiry in the same study. To improve clarity, the study procedures have been explained in stages, as stipulated below.

Stage 1: Preparation and planning

Search strategy and terms

To enable an effective literature search, we iteratively developed a search strategy using the research question provided by the principal investigator. The research question is derived from the research gap and negotiated for clarity and relevance by first and last authors. Once the research question had been agreed upon, a search framework was used to build a search strategy.

The initial search followed the population, concept, and context framework to enable a wider search of the PCC concept in LMIC (107). Therefore, the population was chronic care patients, with the concept being patient-centred care dimensions and, context being LMIC. Later, the findings obtained from the initial search findings were used to iteratively refine the search strategy using common antonyms and surrogate terms for all keywords, either singularly or as a combination to create a more targeted search string to improve the yield.

To build the search strategy, we used the Boolean operators to connect search terms in order to narrow or broaden the search. The Boolean operators “AND” denoted a combination of all search words, while “OR” was used to use either or both of the words in question. The operator “NOT” was used in instances where a word ought to be excluded from a search. Parentheses ()

or [] was used to direct the application of searches that were enclosed in parenthesis first before the rest of the string. A truncation operator asterisk (* or?) was added to some nouns such as patient, person, client, and country to represent terminal character (s) or(ies) in order that both singular and plural forms of the search term were included. Both American and British versions of each term were taken into consideration. Here too, alternative but commonly used or alternative (thesaurus) terms for respective key words were applied as appropriate.

Throughout the search period, the search strategy was iteratively reviewed and revised, and appropriate filters were applied as agreed by the team for maximum yield. Examples of the search strings are presented below.

((chronic patient [MeSH Terms]) AND ((patient centred care[Title/Abstract]) OR patient centered care[MeSH Terms])) AND ((low middle income countries[Title/Abstract]) OR developing countries[MeSH Terms]

("chronic care" OR " non-communicable disease*"OR "chronic management" OR " chronic patient*" OR "long term care") AND ("patient centred care" OR "patient centered care" OR "patient centredness" OR "client centred" OR "client centered" OR "person centred" OR "person centered") AND (dimension* OR attribute* OR element* OR function*) AND ("developing country*" OR "third world country*" OR " low income country*"OR " low resource country*" OR Africa)

The search term was evaluated for clarity and then piloted by the author before the search began.

Information sources and location

A published literature search was obtained from all available databases, including PubMed, EBSCO host platform (CINHAL, Medline), MBASE, Cochrane Library, Hinari, Scopus,

ResearchGate, Google Scholar, and African Journal Online. Grey literature, if found, was also included from Google Scholar; Sabinet (> Theses & dissertations > African digital repository > African Journal Archive), and government websites and non-governmental organizations (NGO) reports that work in areas such as quality health care, patient satisfaction, and patients' rights.

Additional identification of relevant articles was done through snowballing by tracking references for identified articles based on the PI's judgement regarding their relevance during literature review.

The study search was carried out from June to September 2019.

The Research Team

A review team comprised of a librarian, and the authorship team was created, with the role of each team member clearly defined. The first author was responsible for defining the research question and building keywords and surrogate terms into the search framework. The librarian assisted with building the search strategy. Article or record reviews were carried out by the first and second authors. If incongruities occurred, then the librarian stepped in as a tiebreaker. These individuals were chosen for their expertise in academia, research, and scoping reviews.

The reviewers had a half-day virtual training to ensure consistency and concordance in the review process.

Table 4.1: showing the inclusion and exclusion criteria

	Criteria	Inclusion	Exclusion	Notes
1	Population	Chronic NCDs patients, disease-specific NCDs papers e.g. DM, cancer, hypertension	Non-chronic patients	Context of study

2	Type of study	qualitative, quantitative, mixed methods	Other	
3	Context	LMIC or describes both LMIC & high income	Only high income	Defined by world Bank
4	Outcome	Patient-centred care dimensions and surrogate terms	PCC mentioned in passing	Surrogate terms: "Client", "person", "people"
5	Language	English	Non-English	
6	Publication or grey literature	Ten years or less	More than 10 years	relevance & currency
7	Sources	Free abstract and full text studies and reports (published and unpublished).	No full text, or have to pay for the paper	No funds to buy articles

Stage 2: Searching and the article selection process

Data inclusion and exclusion criteria

We reviewed literature that included people-, patients- and clients- centred care in this study as the central object of study while seeking care. The literature search followed inclusion and exclusion criteria as outlined in the table below.

Table 4.2: Showing the search hits

The search string was as shown below and the hits for the respective search engines were as follows: -

Database	Search strategy	hits
PUBMED	((((Chronic care[Title/Abstract] OR non-communicable disease*[Title/Abstract] OR non communicable disease care[Title/Abstract] OR chronic management[Title/Abstract] OR chronic patient*[Title/Abstract] OR long term care[Title/Abstract] OR Care, Long-Term[Title/Abstract] OR diabetes Mellitus care[Title/Abstract] OR diabetes Mellitus management[Title/Abstract] OR hypertension care[Title/Abstract] OR Asthma care[Title/Abstract] OR epilepsy care[Title/Abstract] OR cancer care[Title/Abstract] OR heart disease* care[Title/Abstract] OR chronic disease* care[Title/Abstract] OR chronic disease* management[Title/Abstract))) AND ((Patient-Centred care[Title/Abstract] OR patient centred care definition[Title/Abstract] OR patient centred care theme* [title/Abstract]OR *Patient Centred care element*[Title/Abstract] OR patient centred care review of concepts[Title/Abstract] OR Nursing care, Patient-centred	160

	elements*[Title/Abstract] OR Nursing, Patient Centered dimension*[Title/Abstract] OR patient centred care attribute*[Title/Abstract] OR patient centred care definition*[Title/Abstract] OR patient centred care definition* OR patient centered care theme* [title/abstract] OR Patient-centred Nursing[Title/Abstract] OR Patient Centered Nursing[Title/Abstract] OR Patient-Focused Care[Title/Abstract] OR Care, Patient-Focused[Title/Abstract] OR Patient Focused Care[Title/Abstract] OR Medical Home[Title/Abstract] OR Home, Medical[Title/Abstract] OR Homes, Medical[Title/Abstract] OR Medical Homes[Title/Abstract] OR Patient centred care[Title/Abstract] OR patient centeredness[Title/Abstract] OR client centred[Title/Abstract] OR person centred[Title/Abstract] OR person focused[Title/Abstract] OR people centred care[Title/Abstract] OR people centered care[Title/Abstract] OR client centred[Title/Abstract] OR client centred[Title/Abstract] OR patient centeredness[Title/Abstract] OR client centeredness)OR patient-physician communication element*[Title/Abstract] OR patient provider communication[Title/Abstract] OR patient nurse communication[Title/Abstract] OR patient doctor communication dimension*OR patient centred care interaction*OR	

	patient centred care interaction*OR provider patient interaction[Title/Abstract))) AND ((Developing Countries OR Africa OR Africa, OR third world countr* OR Low middle income countr*OR POOR countr* OR Northern Africa OR South of the Sahara Africa OR Central OR Africa, Eastern OR Africa, Southern OR Africa, Western Asia OR Asia, Central Asia OR South-eastern Asia, Western OR Caribbean Region OR West Indies OR South America OR Latin America OR Central America OR Afghanistan OR Albania OR Algeria OR American Samoa OR Angola OR "Antigua and Barbuda" OR Argentina OR Armenia OR Azerbaijan OR Bahrain OR Bangladesh OR Barbados OR Benin OR Belarus OR Belize OR Bhutan OR Bolivia OR Bosnia-Herzegovina OR Botswana OR Brazil OR Bulgaria OR Burkina Faso OR Burundi OR Cambodia OR Cameroon OR Cape Verde OR Central African Republic OR Chad OR Chile OR China OR Colombia OR Comoros OR Congo OR Costa Rica OR Cote d'Ivoire OR Croatia OR Cuba OR Cyprus OR Czechoslovakia OR Czech Republic OR Slovakia OR Djibouti OR "Democratic Republic of the Congo" OR Dominica OR Dominican Republic OR East Timor OR Ecuador OR Egypt OR El Salvador OR Eritrea OR Estonia OR Ethiopia OR Fiji OR Gabon OR Gambia OR	

	"Georgia (Republic)" OR Ghana OR Greece OR Grenada OR Guatemala OR Guinea OR Guinea-Bissau OR Guam OR Guyana OR Haiti OR Honduras OR Hungary OR India OR Indonesia OR Iran OR Iraq OR Jamaica OR Jordan OR Kazakhstan OR Kenya OR Korea OR Kosovo OR Kyrgyzstan OR Laos OR Latvia OR Lebanon OR Lesotho OR Liberia OR Libya OR Lithuania OR Macedonia OR Madagascar OR Malaysia OR Malawi OR Mali OR Malta OR Mauritania OR Mauritius OR Mexico OR Micronesia OR Middle East OR Moldova OR Mongolia OR Montenegro OR Morocco OR Mozambique OR Myanmar OR Namibia OR Nepal OR Netherlands Antilles OR New Caledonia OR Nicaragua OR Niger OR Nigeria OR Oman OR Pakistan OR Palau OR Panama OR Papua New Guinea OR Paraguay OR Peru OR Philippines OR Poland OR Portugal OR Puerto Rico OR Romania OR Russia OR "Russia (Pre-1917)" OR Rwanda OR "Saint Kitts and Nevis" OR Saint Lucia OR "Saint Vincent and the Grenadines" OR Samoa OR Saudi Arabia OR Senegal OR Serbia OR Montenegro OR Seychelles OR Sierra Leone OR Slovenia OR Sri Lanka OR Somalia OR South Africa OR Sudan OR Suriname OR Swaziland OR Syria OR Tajikistan OR Tanzania OR Thailand OR Togo OR Tonga OR "Trinidad and Tobago"	

	OR Tunisia OR Turkey OR Turkmenistan OR Uganda OR Ukraine OR Uruguay OR USSR OR Uzbekistan OR Vanuatu OR Venezuela OR Vietnam OR Yemen OR Yugoslavia OR Zambia OR Zimbabwe))			
CIHNAL	Chronic care OR non-communicable disease OR non communicable disease care OR chronic management OR chronic patient OR long term care OR Care, Long-Term OR diabetes Mellitus care OR diabetes Mellitus management OR hypertension care OR Asthma care OR epilepsy care OR cancer care OR heart disease care OR chronic disease care OR chronic disease management) AND (Patient-Centred care OR patient centred care definition OR patient centred care theme OR Patient Centred care element OR patient centred care review of concepts OR Nursing care, Patient-centred elements OR Nursing, Patient Centered dimension OR patient centred care attribute OR patient centred care definition OR patient centred care definition OR patient centered care theme* OR Patient-centred Nursing OR Patient Centered Nursing OR Patient-Focused Care OR Care, Patient-Focused OR Patient Focused Care OR Medical OR Home, Medical OR Homes, Medical OR Medical Homes OR Patient centred care OR patient	298	25	

	centeredness OR client centred OR person centred OR person focused OR people centred care OR people centered care OR client centred OR client centred OR patient centeredness OR client centeredness OR patient-physician communication element OR patient provider communication OR patient nurse communication OR patient doctor communication dimension OR patient centred care interaction OR patient centred care inte) AND (Developing Countries OR Africa OR Africa, OR third world countr* OR Low middle income countr*OR POOR countr* OR Northern Africa OR South of the Sahara Africa OR Central OR Africa, Eastern OR Africa, Southern OR Africa, Western Asia OR Asia, Central Asia OR South-eastern Asia, Western OR Caribbean Region OR West Indies OR South America OR Latin America OR Central America OR Afghanistan OR Albania OR Algeria OR American Samoa OR Angola OR "Antigua and Barbuda" OR Argentina OR Armenia OR Azerbaijan OR Bahrain OR Bangladesh OR Barbados OR Benin OR Belarus OR Belize OR Bhutan OR Bolivia OR Bosnia-Herzegovina OR Botswana OR Brazil OR Bulgaria OR Burkina Faso OR Burundi OR Cambodia OR Cameroon OR Cape Verde OR Central African Republic OR Chad OR Chile OR China OR Colombia OR Comoros OR Congo OR Costa Rica			

	OR Cote d'Ivoire OR Croatia OR Cuba OR Cyprus OR Czechoslovakia OR Czech Republic OR Slovakia OR Djibouti OR "Democratic Republic of the Congo" OR Dominica OR Dominican Republic OR East Timor OR Ecuador OR Egypt OR)(Search as Keyword)added things explodes “PCC and continuity of care”			
Lilacs	patient centred care in chronic care patients and low-middle income countries	16	1	
Grey lit: Open Grey	(((Chronic care OR non-communicable disease* OR chronic management OR chronic patient* OR long term care OR Care, Long-Term OR diabetes Mellitus OR hypertension care OR Asthma care OR epilepsy care OR cancer care OR heart disease* care OR chronic disease* care OR chronic disease* managementâ€)) AND (Care, Patient-Centred care OR Patient Centered care elements - Care OR Nursing, Patient-centred elements OR Nursing, Patient Centered dimension* OR patient centred care attribute*OR Patient-centred Nursing OR Patient Centered Nursing OR Patient-Focused Care OR Care, Patient-Focused OR Patient Focused Care OR Medical Home OR Home, Medical OR Homes, Medical OR Medical Homes OR Patient centred care OR patient centeredness OR client centred OR person centred OR person focused OR	90	4	

	people centred care OR people centered care OR client centred OR client centred OR patient centeredness OR client centeredness)OR patient-physician communication element* OR patient “provider communication Or patient nurse c			
Clinical trials	Non communicable diseases AND patient-centred care	20	6	
Total			92	

Article selection:

We used the Covidence data management tool and we developed the data extraction tool. Relevant articles obtained from the search were imported from Mendeley software selection criteria. The Covidence application did a practical screen to remove duplicates and then the two raters did the title and abstract screening. We then uploaded the respective PDF versions of the articles that were selected. In turn, a more detailed screen of the title and abstract was done. See flowchart (Table 2) highlighting the steps for screening and data extraction processes.

Two reviewers did a full text review, and conflicts between them were reviewed while reading the articles together. Articles would be rejected if they did not fit the inclusion criteria or did not answer the research question. The author had the final say in including or excluding any controversial article. The articles were then retained and saved in the Mendeley library for data extraction and analysis. The remaining articles were kept in a "delete folder" in case inter-rater inconsistencies necessitated the re-assessment of articles for re-inclusion would be required. Reasons for the exclusion of each article were documented accordingly.

To ensure that we included articles that met the required standards at every level, an automated quality appraisal tool built into the system was used. The system was built in such a way that it would not allow one rater to proceed with data extraction if an article did not fulfill the inclusion criteria. Again, it served as a practical second-line check of the exclusion criteria. Two initial screening questions were asked namely: "Are there clear research questions? and "Did the collected data allow for addressing the research

questions?". Quality appraisal of grey literature only involved authentication of a source organization/individuals through a Google search.

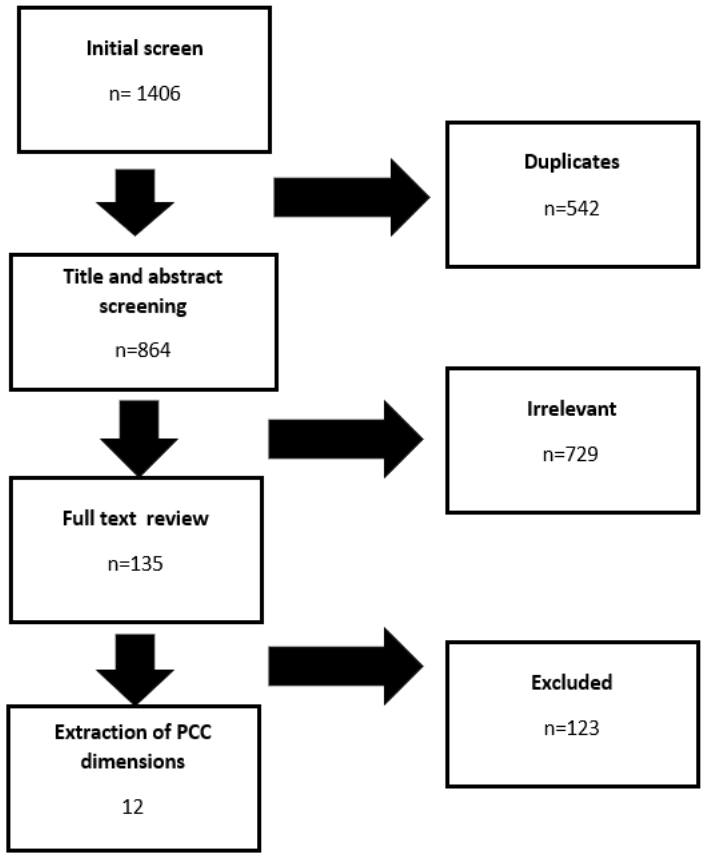


Figure 4.3: Showing the procedure for article screening and data extraction

Almost half (n=64) of the exclusions were based on articles not written from LMICs and the other half of the articles were not based on chronic diseases.

Stage 3: Data extraction

Table 3.1 Data extraction

The first author extracted data in accordance with the research question. The data included the article title, authors, methodology, geographical location, disease, PCC functional elements, and authors' conclusions.

Stage 4: Data analysis

Data analysis and synthesis

Data analysis and synthesis involved the interpretation and explanation of themes identified in the articles. Thereby, breaking down the identified themes to practical levels and, isolating from the data, the practical thematic elements that refer to PCC(79,80). We, in turn, deductively extracted the emerging themes and documented them.

Trustworthiness and scientific rigor

We ensured trustworthiness of the review through thorough documentation of the review process to make it transparent, rigorous, and repeatable(108). The team reviewed the research question for clarity and iteratively refined the search strategy, which led to a focused and yet comprehensive yield. Again, the Covidence application ensured that all the quality checks were attended to before proceeding to the next level. The sensitivity and specificity of the search were improved by the use of Boolean terms. A clear audit trail of this iterative process improved the trustworthiness of the results as well(79)

Objectivity and coverage in interpretation were ensured by all co-authors independently analysing randomly selected articles or records.

Ethics

Ethical clearance was done as part of a larger study about the review of PCC. No specific application for this phase of the study was made to the College of Medicine Research and Ethics Committee (COMREC) in Malawi (P.04/19/2654) or the Health Research Ethics Committee for Witwatersrand University Health Research Committee (M190550).

Results

This review highlighted the paucity of literature in the LMIC. Of the 135 articles retrieved, only 12 met the inclusion criteria. Most of the articles were on asthma and diabetes mellitus. Almost half of the results were from Africa (See table 4.6)

We reviewed literature that included people-, patient(s)- and client(s)-centered care as the central object of study while seeking care. Some literature, especially about Africa, describes PCC as what is wished for. We elucidated several themes that are interrelated (See Table 4.4).

Interactional / Relational ambience

The first dimension relates to PCC having a good interactional ambience when patients and their provider are receiving/ delivering care. The ambience being referred to is an atmosphere marked with warm welcome, friendliness, empathy, privacy, dignity, attentiveness, and caring attitude portrayed by the healthcare provider(16,22,25,109–111). It further explained the notion of the HCP-patient dyad exercising cultural and contextual sensitivity in their interactions, reducing power differences(111)

Support for self-care

This was discussed in the context of informational sharing and activities that support and empower the patient to care for themselves. It was, actually, an important element in the expression of PCC within the chronic care found in three of the 12 articles (50,112,113)

Holistic care

Holism referred to all aspects of health, including psychosocial elements. It defined care that was able to meet all health needs (25,50,112,114). The dimension places this responsibility on the need for holistic and comprehensive care on the HCP.

Access to care

Access to care was a concept that mainly encompassed timely care and availability of management options especially in the South African context(16,50,109,112). Generally, untimely care was perceived as poor access. In the Malaysian context discussed improved access as a dimension of PCC, there was no further description provided (109).

Information sharing

Eight of the 12 sources had strong focus on communication, specifically information and access reciprocal information sharing between the patient and the provider including their families(16,22,50,109,110,112,115,116). Cubaka et at emphasizes that patients have the right to know pertinent issues about the disease and its management thereby placing information sharing as a patients' right(22). The information sharing would go further to support patients' ability to self-care. The dimension further describes the information shared between the dyad as being empowering to recognize and between the providers and the patient/their proxies(109).

Patient involvement and collaborative care

Collaborative care was a major theme in seven of the sources(8,16,25,50,111,113,114). This element emphasized patients or their proxies as effective care partners; additionally, patients and their families are empowered, given responsibility, and space to participate in their care plans and decisions. Particularly, the El Salvador, Rwandan, Tanzanian and South African contexts highlight the notion of patients and their families as equal partners in health and experts in their own care(109). This meant facilitating their involving them in the design, delivery and goal setting in care. It also included teamwork among the providers.

Individualized and responsive care

Concerning the delivery of care, only three of the sources described the dimension of individualized care in which the individual is acknowledged(16,110,112). This meant that care considers, cultural and individual preferences, expectations, and needs while assisting

patients(111,114). In the Zambian context there was an angle that articulated PCC as being responsive to a patient's needs and ensuring that the needs are met comprehensively and holistically(16).

Organizational aspects of care

Eight sources extended the definition from the interactional realm for PCC to include organizational cultures and activities that foster provider attributes highlighted above(16,50,109–111,113,114) . The dimension also included the organization of services that improve awareness of work challenges and dealing with them, the practice of PCC through community orientation of services, and the enhancement of patient care experiences such as reducing waiting times and community orientation.

Two sources from middle east quoted continuity of care as a functional of PCC, However, in this context, continuity lacked adequate contextual characterization(50,113).

Table 4.3: showing the articles and the key functional elements

No	Lead Author	Title	country	Context	Year	PCC dimensions
1	World Health Organization (WHO) Report of meeting held 5 May 2010	People-centred care in low- and middle-income countries	WHO collation	Meeting proceedings: experiences in implementing people-centred care in low- and middle-income countries	2010	**El Salvador-** participation in care **Malaysia-** improving access to care, patient and family feedback, caring & teamwork **Rwanda-** families are effective health partners **Tanzania-** alteration in patient-provider interactions (involving patients in goal setting and decision making)
2	Tzeng, Li-Fen; Chiang,	A preliminary study to evaluate a patient-centred asthma education program on parental control of home environment and asthma signs and symptoms in children with moderate-to-severe asthma.	Taiwan	Qualitative among Asthma patients	2010	Asthma education about the disease and its treatment

3	Masoud Mirzaei	entred approach to health service nproving health outcomes for people c illness	Iran	Qualitative research	2013	1) The need for improved communication and information delivery on the part of HCPs; 2) Well-organized health services and reduced waiting times to see HCPs; 3) Help with self-care; 4) Greater recognition among professionals of the need for holistic and continuing care; and 5) Inclusion of patients and carers in the decision-making processes
4	Nayiga et al	Strengthening patient-centred communication in rural Ugandan health centers: A theory-driven evaluation within a cluster randomized trial	Uganda	Cluster Randomized control trial	2014	Rapport building, respect, welcoming, individualization, provider self-reflection, active listening in busy environments, information sharing empowering patients to recognize challenges at work and deal with them, meeting patients' need, timely care, fairness
5	Kühlbrandt, Charlotte	In search of patient-centred care in middle-income countries: The experience of diabetes care in the former Soviet Union	The former Soviet Union territories	Qualitative	2014	Continuity of care, Information sharing, Support for self-care, Access to care, Individualization of care, Comprehensiveness, Shared decision making

6	Trishul Siddharthanet al	Implementation of Patient-centred Education for Chronic-Disease Management in Uganda: An Effectiveness Study	Uganda	Mixed methods among heart failure patients	2016	Information, facilitation of provider-patient communication; Information about the disease
7	Jeroen De Man et al	Patient-centred Care and People-Centered Health Systems in Sub-Saharan Africa: Why So Little of Something So Badly Needed?	Systematic Review of African Literature	Systematic review	2016	Largely described PCC for what it is not **Zambia:** Responsive care, professionalism **Ghana:** respect & Privacy, Information **Sierra Leone**- P-P relationship **Nigeria**-Involvement in SDM, **Nigeria**- Timeliness, respect for patients' rights, **South Africa's** friendliness, confidentiality, availability of options

8	Paulo, Marília Silva;	The primary health care in the Emirate of Abu Dhabi: Are they aligned with the chronic care model elements	United Arab Emirates	Systematic Review	2017	Self-management support, task sharing, decisional support, community orientation, delivery of organizational change
9	Vincent K. Cubaka,	He should feel your pain': Patient insights on patient-provider communication in Rwanda	Rwanda	Qualitative	2018	Welcoming, attention, empathy and friendliness, Right to Know, Power balance
10	Sihaam Jardien-Baboo	Perceptions of patient-centred care at public hospitals in Nelson Mandela Bay	South Africa	Qualitative	2019	Awareness of the importance of the patient's culture in patient-centred care, Involving the patient's family, Incorporating values of love and respect Optimal communication, Patient accountability
11	Sihaam Jardien-Baboo	Best Practice Guideline for Patient-Centred Care in South African Public Hospitals	South Africa	Scoping review	2019	(1) Embracing values and beliefs foundational to patient-centred care; (2) Optimal communication in all facets of care; (3) Rendering of basic nursing care practices; (4) Family involvement; (5) Awareness of the importance of culture in patient-centred care, (6) Organizational and managerial support; (7) Organizational champions; (8)

						Positive work environment; and (9) Organizational structure that promotes interprofessional collaborative practice
12	Waweru et al	Stakeholders' perception of PCC at primary healthcare at rural Uganda: a qualitative inquiry	Uganda	Qualitative inquiry in Primary Health care	2019	(1) Exploring both disease and illness (Responsibility for health, health-seeking behaviors); (2) Discussing psychosocial & emotional issues; (3) Understanding HCW as a person; Finding common ground: factors affecting SDM & health literacy); (4) Information sharing; (5) Awareness of patients' rights, Professional training & competencies; (6) Patient as a person, Respect trust/ empathy; (7) Cultural competencies (Choice and empowerment, dignity and respect, patient involvement, information sharing access and support)

Table 4.4. Showing the summary emerging themes and their descriptions

	Key dimension	Descriptions	References
1	Information sharing	Reciprocal sharing of information between patient and provider	(16,22,50,109,110,112,115)
2	Support for self-care	Includes activities that support and empower patient to self-care	(113,115)
3	Holism and meeting all health needs	Care that encompassed all aspects of health, biopsychosocial	(16,50,112,114)
4	Patient Involvement and shared decision making	Involvement of family and friends in decisions about care & sharing responsibility, collaborative care	(16,24,25,50,109,113,114)
5	Optimal patient-HCP communication and information sharing	Two-way communication that allows informational sharing	(16,22,50,109,110,112,116)
6	Good interactional ambience	Good ambience marked with respect, privacy, confidentiality.	(16,22,24,25,109,110)
8	Cultural sensitivity	Awareness of cultural and contextual sensitivities	(24,114)
9	Individualization	Awareness of individual context	(16,110,112,114)
10	Organizational culture for PCC including reasonable waiting times, continuity, comprehensiveness and access	Professional competencies and organizational culture and values	(16,24,50,109,110,112–114)

Discussion

The review elucidates paucity of patient- or person- centred care literature in the LMIC context, especially in Africa, with six out of the 12 studies documenting PCC in Africa among chronic care patients (16,24,25,110,114,115). The few studies identified revealed fragmented

definitions which are hard to put into use(16). Other authors such as Waweru et al have adopted Eurocentric models highlighted in work by Mead and Bowers and by Stewart et al (25). The paucity in the documentation of functional elements of PCC is confirmed by WHO in their meeting proceedings, in which they highlight the need for health care systems that are struggling with meeting their UHC targets to practical examples of PCC models they use (38). Furthermore, De Mann et al lament lack of contextual meanings in African Healthcare systems and calls Africa to explore contextual PCC frameworks, respective assessment tools and innovative ways to improve its practice (16).

This review further articulates the spread and common expressions of PCC dimensions in the LMIC chronic care context. The components were based on what PCC delivery should contain and what it should not were interrelated, and had the following 7 themes: favorable interactional ambience, information sharing, support for self-care, collaborative care, comprehensiveness, individualism in care delivery, organizational context of care, including timeliness and a positive work environment, and continuity of care. The themes seemed to be concentrated around a warm supportive ambience that facilitates the sharing of information between the patient and provider dyad. This allowed for power sharing within the encounter, and for collaboration with the patient to support them for self-care within the confines of their own individualized context and capacities, and a positive work environment (29,91). These themes resonate with Thórarinsdóttir et al.'s PCC framework which, by highlighting incremental basic tasks within the encounter experience, culminates into a patient who has control over their own care(117) .

While similar in many ways, the recurring themes in the chronic care context are expressed significantly differently from Mead and Bower's thematic domains (32). We find, for example, that the theme "starting from the patients' situation, though expressed differently,

acknowledges patients' uniqueness and individualization and calls for the provider to explore the whole individual experience. The fundamentals of this theme resonate with other authors in showcasing contextual intelligence and individualized care(16,24,110,112,114).

Although PCC is expressed in so many facets, all the articles extensively describe collaborative care as a significant task in PCC encounters. The theme acknowledges that patients as capable and willing partners in their own care, and that supporting patients towards self-care is prominent in our review. It is expressed as deliberate acknowledgement of a patient's expertise and capacities for self-care, power imbalance, as well as support for shared decision-making and self-management roles. Contrary to the biomedical view of care, this aspect has been shown to be important in mediating several outcomes in chronic care(70,103). Thus, its prominence in this review is not surprising.

Legitimizing patients' illness and continuity of care seemed less expressible in this review. This may possibly be due to the LMIC medical encounters being characterized by time pressures and power imbalances whereby patients' expectations are moderated, power is sometimes delegated, and the patients accept, at the minimum, having been given an opportunity to be attended to as opposed to being heard(118,119). The expression of moderated expectations as portrayed by patients in this study are reportedly prevalent in LMIC contexts(16,22,115). This is possible due to limited human and therapeutic resources against health care demand. Furthermore, while they consider a privilege opportunity to be seen, it appears asking for continuity of the HCP sounds too ambitious and unattainable, thereby making the continuity element appearing not very expressible in LMICs.

The review, in a nutshell, showcases the differences in the expression and application of some of the PCC elements within the LMIC context which will inform the next phase of the study as we interrogating what the PCC construct actually entails in a qualitative inquiry.

Strengths and limitations of the study

We had a limitation of the study with retrieval of articles/records. The Malawi College of Medicine library (now KUHES) had few paid-up databases to search from. This hurdle could have impacted the extensiveness of the search. To mitigate it, we requested the Witwatersrand University librarian to help us with articles that we could not find in Malawi, which they did.

Conclusion

The study has shown the paucity of PCC literature in LMICs, especially in Africa. The studies are fragmented and their lack a holistic definition. The paucity of literature confirms the inexpressibility and the impact of PCC at chronic care practice and policy levels. The lack of data on PCC dimensions also means that advocacy efforts at policy level would be difficult to achieve.

The recurring themes include the facilitating ambience, sharing of information, patient involvement, the wider organization of care and the macroenvironment in which care takes place. Although the themes are similar to Eurocentric ones, the review confirms that they are different in their level of expression and emphasis in some of the elements of chronic care. There is, thus, a need to situate the elements and what they would mean in LMIC context.

The next phases of the study endeavor to understand what PCC elements are important empirically and how they would be expressed among Malawian stakeholders on the one hand, and to highlight patients' experiences concerning them and their objective measurement, on the other.

CHAPTER 5: PAPER II

Manuscript: The Conceptualization of Patient-Centred Care: A Case Study of Diabetes Management in Public Facilities in Southern Malawi (Published).

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AOSIS
Page 1 of 10 Original Research

The conceptualisation of patient-centred care: A case study of diabetes management in public facilities in southern Malawi

Abstract

Background: Patient-centred care (PCC) is one of the pillars of Malawi's quality of care policy initiatives. The role of PCC in mediating quality service delivery is well documented and its importance may heighten in chronic disease management. Yet, PCC conceptualization is known to be context specific.

Aim: The study aimed to understand the conceptualization of PCC among patients, healthcare providers and policy-makers in Diabetes Mellitus (DM) management.

Setting: This study was conducted in DM clinics in southern Malawi.

Methods: Our qualitative exploratory research study design used in-depth and focus group interviews. We interviewed patients with DM, healthcare providers and policy-makers. The study used framework analysis guided by Mead and Bower's work.

Results: PCC conceptualizations from patients, HCP and policy-makers showed convergence with minor differences in emphasis in some elements. Prominent themes emerging from

participants' conceptualization of PCC included the following: meeting individual needs, goals and expectations, accessing medication, supporting relationship building, patient involvement, information sharing, holistic care and timeliness. Though they yearn for these elements in their encounters, they expressed their expectations moderated realism.

Conclusion: Patient-centred care conceptualization in Malawi goes beyond the patient–healthcare provider relational framework to include the technical aspects of care. Contrary to the global view, accessing medication and timeliness are major elements in PCC conceptualization in Malawi. While PCC conceptualization is contextual, meeting expectations and needs of patients is fundamental.

Background

The shifting global disease burden from acute to chronic, and the associated multi-morbidity, has necessitated that care delivery moves away from the traditional acute, episodic and biomedical models to embrace more patient-centred care (PCC) values (7,11). The World Health Organization (WHO) innovations for chronic care advances PCC delivery as an approach that promotes the ability for patient-healthcare provider (HCP) encounters to deal with the complex bio-psychosocial determinants of health and enhance care experiences whilst meeting needs and expectations of people seeking care over time (36).

In Malawi, the chronic disease burden is growing with Diabetes Mellitus (DM) disease prevalence now at 3.0% and 1.7% for urban and rural areas, respectively, and accounts for 2.4% of the Daily Adjusted Life Years (DALYs) (120). Notably, DM care in Malawi is reportedly suboptimal as appraised by Assayed et al. in Malawi district using International Diabetes Federation (IDF) guidelines whose notable facet is the organization of care around the patient (20,64). Consequently, the Malawi government promotes the PCC approach in chronic

disease management (5). However, PCC conceptualization is not homogenous across contexts making it difficult to objectively appraise its performance.

Markedly, the success of PCC implementation and appraisal lies in the clarity of its functional elements. For example, in the National Health-Care quality report by the Agency for Health Research and Quality (AHRQ), PCC showed a modest improvement of 1.9% increase in its contribution to overall improvement in quality of care, lagging behind patient safety (10.3%) and efficiency (3%) (14). The lag was largely related to vagueness of what constitutes PCC, which thwarted its implementation and appraisal. Most African literature offers no specific conceptualization. However, some elements such as "people first", accountability to the patient, holism, communication, HCP attitudes of friendliness, respect and empathy, and family involvement do emerge in describing PCC (16,24,121). This makes PCC conceptualization blurry, and hampers its successful implementation.

Literature notes variations in PCC conceptualization, largely depending on context and whose perspective is being represented; whether patients or HCPs (31,32,38,40). Conceptualization refers to the process of breaking down concepts into common functional meanings (30). The Institute of Medicine (IOM) conceptualizes PCC as care that is responsive to individual patient preferences, needs and values, ensuring that patient wishes guide all clinical decisions (122). The reliance on patients' perspectives, values and wishes to guide all clinical decisions may appear consumeristic and would promote unhealthy patients' agenda, falling short of scientifically sound patient care decisions. Marshall et al. advise that good conceptualizations should be co-constructed using the perspectives of both the patient and healthcare providers (123). Fundamentally, PCC meaning should include elements that go beyond following patients' wishes by balancing patients' preferences with contextual evidence, available resources and HCP considerations in a favorable interaction.

Mead and Bower's PCC conceptualization highlights practical elements as functions to be fulfilled during the encounter. These functions include the following: therapeutic patient-HCP relationship building, bio-psychosocial care provision, individualizing the patient as a unique person, sharing power and responsibility, and being realistic of the doctor as person (32). While close to the epitome, this conceptualization may not apply wholesale especially in health contexts which are paternalistic, with marked low patient medical literacy and limited human and therapeutic resources that may affect interactional behaviors (67,124).

In chronic diseases, it is important to understand PCC interactions as they facilitate better care experiences and reported outcomes leading to patient empowerment and a proactive patient-HCP team (125,126). Some stated outcomes include patient satisfaction, perceived quality of care, patient adherence to management plans, reduced emergency visits, complications, patient empowerment and self-care and glycaemic control (49,126). In their meta-analysis of 109 correlational studies and 21 experimental studies, Haskard and Dimatteo found that HCP training on PCC was associated with 0.16 higher odds of patient adherence (53). It is vital to note that the evidence in literature is favorable to a patient-centred interaction in the management of chronic conditions such as DM. As we strive to advocate for PCC in chronic care encounters, it becomes imperative to gain its conceptual understanding. The study therefore set out to understand the conceptualization of PCC and highlight its functional elements in Malawi.

Methodology

Study design and setting

The study employed a qualitative exploratory approach. We collected data from four public hospitals' DM clinics in the southern region of Malawi and the Ministry of Health headquarters. Since the public health sector is the biggest service HCP in Malawi, it was

purposively chosen to highlight what PCC might look like in the sector. The four public hospitals included Queen Elizabeth central hospital, Zomba Central hospital, Mulanje and Chikwawa, and these were conveniently selected to highlight a mix of both urban and rural views. We selected policy-makers chosen from the Quality Management Directorate (QMD) and the Non-Communicable Disease and Injuries (NCDI) Directorate because of their influence in the development of chronic care policies.

Study population and sampling

We interviewed 37 patients with DM, 33 HCPs and two policy-makers. Healthcare providers encompassed nurses, clinical officers and medical doctors who are directly involved in DM care in defining the problem and rendering care.

The nurse in-charge purposively selected participants who were at least 18 years old, clinically stable and able to give a verbal and/or written consent to interviews and/or audio recording. Participants who could not give a written consent were excluded from the study.

Data collection tools and procedures

The author collected data using a semi-structured interview guide (Appendix 1). To encourage participants to open; we initially asked them to describe their typical patient-healthcare provider interactions. We later zeroed in to discuss their understanding of PCC.

The author conducted individual In-depth Interviews (IDIs) and Focus Group Discussions (FGDs) to obtain both individual and collective meanings of PCC. One FGD was conducted at each facility and each FDG included between 10 and 11 participants. Patients and HCPs were in separate FGDs. Due to logistical challenges of getting enough policy-makers together, no FGD was conducted with them. FGD participants' selection followed the stated inclusion criteria.

We interviewed patients during their routine visit after obtaining care for that day, while clinicians were interviewed after their clinic duties. All interviews took place in secure rooms within the facility to maintain privacy. Data was collected from September 2019 to December 2019.

Data management and analysis

Three research assistants translated audio data from Chichewa into English and transcribed them verbatim. Later, we imported the data into NVivo software version 11.

The data analysis process started in the field by making notes and exploring further on the themes that came out recurrently. Further analytical processes involved familiarization, coding, and mapping data against Mead and Bower's framework. Familiarization with the data set was done through reading transcripts repetitively by the author. Through this step we identified the recurrent themes inductively from participants' accounts until saturation. With input from the last author, themes were grouped manually to come up with the initial codebook, which was iteratively refined through further discussion with the third and last authors. Exemplar extracts were then mapped against the codes.

We ensured the triangulation of views presented in this study by collecting data from three participant categories namely; patients, their HCPs and policy-makers. Additionally, member checking and the use of two data collection methods (FGDs and IDIs) allowed triangulation of individual and collective viewpoints. For quality assurance purposes, two randomly sampled transcripts were coded by the first and the third authors concurrently. The identified differences in coding were discussed and resolved. We achieved conformability by counterchecking the codes. The counterchecking process was done by an individual who was not in the study group to mitigate the effect of researchers' prior predispositions about PCC.

Findings

We conducted 31 individual participant IDIs (16 patients, 13 HCPs and two policy-makers) and four FGDs. The distribution of the participants' socio-demographic profile is shown in (Table 1).

Table 1: Participants Socio demographic characteristics

Variable	*Patients (n=37)*	*Healthcare providers (n=33)*	*Policy makers (n=2)*
Age in years (Average)	50.4†	34.5‡	38.5§
Sex			
Male	12	22	2
Female	25	11	-
Level of education			
None	10	-	-
Primary	7	-	-
Secondary	10	-	-
Tertiary	10	33	2
Type of DM			
Type 1	3	-	-
Type 2	34	-	-
Duration DM (years)			
< 2	7	-	-
2–5	10	-	-
> 5	14	-	-
Current facility use (years)			-
< 2	5	-	-
2–5	21	-	-
> 5	5	-	-

Health care provider cadre			
Nurses	-	6	-
Clinical officers	-	19	-
Medical officers	-	5	-
Specialist doctors	-	3	-
Healthcare provider service years			
< 2	-	9	-
2–5	-	6	-
> 5	-	7	2

Average (years) s.d.: †, Patients = 13.1; ‡, Healthcare providers = 11.5; §, Policy makers = 1.4.

The general conceptualization of PCC

Regarding the general understanding of PCC, the HCPs seemed to express some familiarity with the term and offered meanings similar to what literature offers. Conversely, some patients expressed difficulty in understanding PCC and, consequently, attempted to simplify the term in their own understanding and provided alternative terms. This is exemplified by the following participant response:

> "… I think you asked that how do I see that I have been satisfied with the care we receive here once we have entered into the hospital premises". (37-year-old, urban-based, female patient)

Not all conceptualizations were presented explicitly as meanings, but also as experiences and expectations of care. Further, participants stated that PCC is care that satisfies the patient,

brings happy emotions and signifies government's commitment to 'best care' delivery. In that regard, one participant observed the following:

> "In my opinion, I think the government wants the patient to be centred. Evidence of that the government wants the patient to be centred is that 3 weeks ago I was also selected to be part of a certain research. So that research is trying to find out the exact drugs meant for Africans. So, on that I think the government is very much interested to give the best care to its people". (62-year-old, urban-based, male patient)

Even though challenging, the emergent themes and their functional elements are summarized in Table 2. It is noted that most of the themes were validated by all stakeholder groups with minor expression differences. To highlight the study findings' comparability with prior works, the results are mapped against Mead and Bower's framework (32).

Table 2: Qualitative elements of PCC by patients, healthcare providers and policy makers

Functional element	***The study's conceptualization of PCC***		
	Patients	**Healthcare providers**	**Policy makers**
Bio-psychosocial approach	Adequate equipment for thorough bodily exam.	Bio-psychosocial approach. All health problems addressed. Team approach including the patient.	Bio-psychosocial care.
Individualizing care to the patient as a unique person	-	Addressing unique needs and expectations.	Achieving biomedical goals.
Sharing power and responsibility	Being consulted on care decisions. Leveraging patients' capacities.	Active participation in- and empowering patients to make decisions. Sharing responsibilities.	Involve patients in design of health care services. Shared decision making.
Enhancing the patient-doctor relationship	Respect, dignity, friendliness, being listened to. Allowing time to talk	Respect, dignity, Being listened to. Friendliness.	Respect, dignity.
The doctors as person: Being realistic	Patients acknowledging the HCP/system has challenges to care delivery.	Recognize contextual limitations to care delivery.	Recognize contextual limitations to care delivery.
-	Medication availability and access.	Essential medication availability access.	Better medicine supply chain.

-	Timeliness of care.	Timeliness of care.	-
-	Informing, educating, support, feedback, validation, reprimand.	Educating patients for informed choices.	-

HCP, patient-healthcare provider; PCC, Patient-centred care.

Meeting individualized needs, goals and expectations

Healthcare workers reported that PCC meant tailoring care with unique individual needs, life circumstances and expectations. In that vein, one participant, observed the following:

> "I think each and every patient has his/her own expectations when coming to the hospital. As a result, when delivering the care to the patient, we have to deliver in a way that we will be able to meet the patients' expectations and that will be patient centred.' (63-year-old, HCP, female)

From the perspective of the HCPs, meeting biomedical goals of care, such as glycaemic control, can be considered as being patient centred, as observed by another HCP:

> **"**So, if we have assessed that a patient is doing good in terms of his diabetes or hypertension, I think that can mean patient centred care.' (29-year-old, urban-based, male)

Accessing diabetes medication

Both patients and policy-makers conceptualize PCC as receiving medication. This was a prominent theme as one patient participant explains:

> "[PCC] … It's what I have already explained. I should leave here with all the drugs that have been prescribed for me, that way I would feel so happy.' (58-year-old, rural-based, female patient)

Accessing medication seems to be the gauge for PCC. When the senior policy-maker is asked about his vision for PCC, he emphasized the following:

> "I'll be happy to see a patient coming to the facility for a refill and drugs are available. That could be ideal because [...]. I'd be happy if our supply chain is up to date.' (40-year-old, MOH, male policy-maker).

Receiving medicine was highlighted as both availability and access; and was expressed as a basic need, expectation and requirement for appraising a patient-centred care encounter.

Supporting relational aspects of care

Both patients and HCPs conceptualize PCC as relationship building; stating it as a process of care, that should start with a warm welcome and being listened to with friendly and dignifying conversations. More desired elements of PCC encounters are presented as friendliness, dignity, respect, and the opportunity for patients to express themselves. These are, in part, reflected in the following verbatim responses:

> "We should have a peaceful and amicable conversation. [...] If you have done something wrong, you should be told in an amicable manner what you were supposed to do with dignity.' (18-year-old, urban-based, male patient).
>
> "… I feel like patients need to feel like we are interested to talk with them […] by actions and words.'
>
> (27-year-old, male HCP, rural).

Harsh and hurried encounters are reported by patients. Again, patients highlight those warm receptions and friendly environments can create trust and openness that facilitate the building of therapeutic relationships even in the face of limited therapeutic resources.

Given the relational power dynamics that exist during patient encounters, HCPs recommend that relationship building, recognition and minimizing the power gap should be their initiative using simple and socially appropriate strategies. In that regard, one participant observed the following:

"... I was telling, just two days ago, [*t*]he colleagues hear simple concepts on how to put chairs in consultation rooms. Put the chairs in a way that you tell the patient that I am your friend [...]. So that is something very simple, the way you are going to set your encounter, furniture so to establish that friendship.' (50-year-old, urban-based, male HCP).

Patient involvement in care

Though expressed differently between patients and HCPs, the theme depicts a spectrum of tasks in shared responsibility and decision making; from a mere assent from patients to empowering patients with information for decision making. Patients expressed the desire to be consulted before care decisions are made, as illustrated in the following verbatim response:

"…But just making decisions without the knowledge of the patient, sometimes it becomes a problem.' (38-year-old, urban-based, female patient).

Even though patients wish to be involved in major care decisions, they perceive difficulty and inappropriateness to debate or reason with the HCP. Most passively accept the proposed care based on the understanding that their HCP knows it all. This is, in part, reflected in the following verbatim response:

"My suggestions, if you are [*a*] patient and you are meeting the doctor, there is no way you can be exchanging ideas. The doctor just tell[*s*] you that depending on your results, follow this this and this […]. I do not think a patient can have the audacity to be telling the doctor what to do as if you know about health. You just listen and take whatever the doctor has told you.' (48-year-old, urban-based, male patient).

On the other hand, and for HCPs and policy-makers, PCC goes beyond assent and involves the patient from designing the need-based services to negotiating care choices with mutuality. HCPs agree that patients should be active recipients of care and their capabilities leveraged, as observed in the following participant response:

> "So, I am saying that patient-centred care is all about putting the patient at the center of the care. [...] So when you are designing systems, or programmes, the programmes should be based on the needs of the patient, not making your patient follow the system or making the patient to be a passive recipient of care but should be in a position that is driving the care to them.' (37-year-old, MOH, male policy-maker).

Informing, educating and counselling

This theme was very prominent both for HCPs and patients. It captures that PCC encounters should be an opportunity for information sharing. The information could be shared through counselling and when educating patients about disease, its treatment and prognosis, and the expectations of care. In light of this, a patient observed the following:

> "When they counsel us on which foods to eat and not to eat … they counsel us on marriages because, sometimes, there is a decrease in libido. […] Also, as diabetic patients, we are advised bathe every day because we develop a very pungent odor due to the diabetes.' (60-year-old, rural-based, female patient)

Further, emphasizing PCC as an information-sharing function, it empowers patients to make informed choices, as reflected by one HCP:

> "So, patient-centred [*care*] now will be, after giving the patient such information, what will she choose? What would she feel that is better or feasible, practical to more adapt to her lifestyle, or whatever is linked or concerns her, but based on, what you have

shared with her, so I think that is what I would feel about patient-centred[*ness*].' **(**35-year-old, urban-based, male HCP)

Information sharing is further depicted to serve as support towards self-care through giving hope, feedback, reprimand and validation. In that vein, one patient had this to say:

"You should tell us the procedure on how we are to take medicine because, sometimes, we forget […] from there they should give us feedback on how we are progressing. Is our diabetes condition improving or not? […] Because it is like you give hope to patients.' (65-year-old, rural-based, male patient)

Receiving wholesome care

Both patients and HCPs alluded to PCC being wholesome, and that reflects care that thoroughly assesses bio-psychosocial aspects of life, as recollected by one participant:

"Patient centred means a holistic approach to the patient. Once you have approached him/her holistically, it means it is part of the patient centred […]. It means we are seeing the patient physically, mentally, as well as spiritually.' (27-year-old, rural-based, male HCP)

This view was shared by another participant who recollected the following:

"In my opinion, I think it [*PCC*] means patients must receive the necessary and holistic care […]. So, when they talk of patient-centred care, the care must be wholesome […] and be thoroughly examined.' (47-year-old, rural-based, female patient)

The participant verbatim responses further highlight PCC as comprehensive assessment and management of patients' problems over one or several encounters. Wholesomeness also extended to include managing patients throughout their illness by a team that includes the patient, as reflected in the following response:

> "Patient-centred care is basically the total care given to a patient as a team. Everyone has a part to play. Be it doctors, nurses, patients as well as guardians.' (34-year-old, urban-based, male HCP).

Timeliness of care

Untimely care was expressed as an expected yet failed element of PCC among patients and HCPs. Timeliness referred to how urgent care is delivered and the length of time patients spend at the clinic. This is, in part, reflected in the following participant response:

> "Sometimes the reception we receive is not good. A patient might come here in the morning without being attended to until evening, and that disappoints us. We should properly be received and the HCPs should attend to us […]. What we want is punctuality.' (18-year-old, urban-based, male patient)

Additionally, HCPs also expressed awareness that delays in service provision affects patients' perception of patient centeredness. In that regard, one participant observed the following:

> "… Even sometimes they [*patients*] become angry because they have been waiting for a longer time and for the conversation to be OK, it becomes very difficult because they feel like they are not being taken care of because […] the clinic started late.' (25-year-old, urban-based, male nurse).

Being realistic and pragmatic

Most HCPs related their conceptualization of PCC with realism, further articulating their frustration with the systemic constraints, as illustrated in the following verbatim response:

> "We want the care to be patient-centred such that we want to make plans with the patient, but it has not possible because of human resources. Sometimes, HCPs look at

> the queue that is outside, maybe 40 to 50 patients. I think that is why we are failing because we want to finish the line but not necessarily having enough time to manage the patients.' (40-year-old, MOH, male policy-maker).

While acknowledging challenges in realizing PCC, HCPs suggested simple practical tips for improvement.

Discussion

This paper discusses functional elements in the conceptualization of PCC, its similarities with prior frameworks and peculiarities to this context. The centrality of meeting patients' needs and expectations of care, and relationship building, is highlighted. Furthermore, the study reveals how patients and HCPs perceive some failed elements of PCC and their realistic approach in the face of limited human and therapeutic resources. Based on the collective meanings, this paper proposes a working definition.

We conceptualize PCC as the meeting individual patients' needs, goals and expectations, especially as it relates to health systems responsiveness (126–128). This is consistent with Tolib et al.'s systematic literature review of literature, in which the authors noted how receptivity to patients' needs and expectations were core to appraising quality from patients' perspectives (128). Patients, in our study, expressed receptivity by narrating or rating experiences of their care. Individual patient needs included supportive diabetic education, amicable relationships and glycaemic control, while expectations consisted of access to medication. Overall, we found that measuring experiences of the interaction may be a proxy for measuring the quality of PCC.

Receiving DM medication is an emphasized and peculiar element in this context. Even though it falls outside the conventional patient-HCP interactional-based definition, it is not surprising. The emphasis is likely because medication is a basic need for every patient with DM and, therefore, the most sought-after aspect and gauge for appraising PCC (129,130). More so in this resource-constrained setting like Malawi, the prominence of this element is heightened by medication shortages that are prevalent (131). Functionally, the finding stresses the centrality of meeting the basic patient needs, be it technical or interpersonal.

Even in the face of limited medicinal resources, patients stress that relationship building is a valued element in PCC encounters over infrastructure and doctors' knowledge (22). The positive role of perceived quality of relational dynamics in DM patient-HCP interaction is confirmed (132–134). A multi-country Diabetes Attitudes, Wishes and Needs (DAWN) study reported a positive association between better patient-HCPs relationship and patient outcomes (135). Specifically, the emotional elements of the unrushed encounters based on HCP attentiveness, warmth, empathy, trust and opportunity to respond to patient questions were highly associated with reduced diabetes-related distress and hyperglycaemic symptoms, better glycaemic control and general well-being, lifestyle and medical regimen adherence and, perceived diabetes control (135). This confirms the proposition that investments made in relationship building can improve health-seeking behaviors and patient outcomes.

Patients' active involvement in care is a desired element of PCC among patients with DM (136–138). While HCPs conceptualize active involvement from design to delivery of care, patients largely experience assent. This is partly explained by the difference in how patients and HCPs approach the interaction in this context. Due to the social and power gaps between patients and HCPs (12,139), patients often approach the interaction from an uninformed and powerless perspective (119), and this reduces their propensity to actively participate. Again,

while HCPs report patients' involvement with normative standards but, in practice, they often make contextually negotiated decisions as the extent to which patients can be involved (140). Consequently, patients' experience and perception of involvement is often limited to assent and being grateful recipients of care.

Like other frameworks, information sharing is an important element and serves communicative roles such as informing, educating, counselling, reprimanding, validating, supporting and empowering patients to make informed choices (141–143). Whereas most of these facets of information sharing are important, HCPs, in our study, uniquely identify that PCC is about information that empowers the patient to choose what is ideal for self-care. Mulder et al. confirm the role of transformative education as a basic tenet of diabetic PCC (143). Mulder et al. point out that transformative education empowers patients to be active participants within the provisions of PCC.

Holistic care in this study encompassed attending to bio-psychosocial aspects of patients' life throughout the illness journey. It also encompassed holistic management of the patients' bio-psychosocial aspects by a multidisciplinary team that includes the patients themselves. Holism is validated as coordinated care that addresses patients' needs at the juncture of the bio-medical 'pathology', the person experiencing the pathology, their context (bio-psychosocial), and the nature of the interaction between the person and their context (144). Even though holism sounds complex, the acknowledgement of the patient as an active partner in the team is commendable in this context.

Untimely care is perceived as a failed element of PCC. Timeliness of care gives the perception of better healthcare care organization and access which is core to PCC experience (118). Even though WHO highlights timeliness of care as a distinct element of quality, understandably,

participants, in this study, pointed out to long waiting times as undermining efforts towards PCC. This, therefore, needs to be addressed.

Being realistic is a crucial contextual element in PCC operationalization. It is expressed as the frustration of the HCPs of knowing the elements of PCC, yet being unable to practice, or employing workaround behaviors and alliances in order to be pragmatic. From the perspective of an optimist, it is a sign of acknowledgement of shortcomings and positive attempts towards advancement of PCC in the face of systemic challenges (145). Contextual challenges purportedly explain the employment of workaround strategies and the redefinition of PCC to what is practically possible (140). Thus, as we continue to advocate for government's commitment towards conducive environment for PCC, we ought to view contextual moderations as a crucial element of any PCC conceptualization.

Limitations of the study

This study obtained insights from one single chronic disease which may not be representative. However, it was envisaged that patients with DM's repetitive contact in a non-acute setting gathers important elements around PCC conceptualization. Due to limited time, we did not do ethnographic observations to examine the individual patient-HCP interactional dynamics which could have enriched our findings. Finally, owing to the paucity of PCC frameworks in Africa, there is potential that the Western-oriented analytical framework, which guided our analysis, might have created a Western inclination in interpreting the results.

Conclusion

The study confirms the complexity and interrelatedness of PCC elements. In the Malawi[-an] context, we conceptually understand PCC as an expected care process that incorporates warm patient reception, where the healthcare provider consciously aims to reduce the patient-HCP

power gap to harness a good long-term relationship. This creates a conducive atmosphere that allows gathering of information that holistically identifies the individual specific problems and all possible interacting factors, ensuring timely access to care and medication.

The functional elements of PCC are, in many ways, similar to those in literature. However, its expressions go beyond the patient-HCP interactional realm to include wider organization themes such as access to medication, among others. We hope that these findings will contribute to the actionable dialogue around PCC to clearly communicate its transformative vision. Further, it provides basis for its objective measures highlighted in the next phases of this study.

Recommendations

Whilst Malawi is striving to be patient centred in its chronic care delivery, it needs to address the wider organizational issues in the work environment and the supply chain to realize PCC practice. HCP's pre-service education must include skills in relationship building and information sharing which essentially empower the patient to demand and participate in PCC.

CHAPTER 6: PAPER III

An insight into patient perspectives on barriers affecting participation in shared decision making among patients with Diabetes Mellitus in Malawi (published).



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Background

Investing individual or collective patients' participation in shared decision making (SDM) is a fundamental step in enhancing patient centred care (PCC) experience because it enables patients to be active recipients of their care (136,146,147). in practice, however, patients' experiences of participation in medical decisions has been reported to lack deserved

consideration and, often are limited to informing patients about providers' care plans and expecting them to comply with them (59,148,149). In Malawi, insufficient communication between patients and providers and, patients' passivity around their care decisions are reported to impede PCC and its resultant benefits (12). Yet, there is limited understanding of barriers that impede engagement in the SDM process in Malawi(12,20).

Patient participation in shared decision-making refers to interactional elements between a patient and a provider where a patient provides information, asks questions, and shares experiences that contribute to collaborative problem exploration, identification of management options that meet a patient's needs, preferences and priorities in a conducive space for dialogue (31,150). Optimal participation therefore culminates into collaborative patient management plans, a proactive and empowered patient-provider dyad that potentiates the patient to reach their personalized goals with the provider as a resource (8,146). Evidently, SDM facilitates the provision of care that meets at the nexus of patient preferences, provider experiential practice, available resources, and evidence(8). Particularly, in patients with Diabetes Mellitus (DM), participation in decision making enhances positive patient' experiences of care, treatment goal setting, medication adherence, safety, glycaemic control and lifestyle modification through enhancement of patient self-efficacy (146,151,152). Therefore, patient participation is a key element in DM care as patients have to constantly make decisions to accommodate their complex individual situations, recurrent hospital visits, the disease, its treatment and goals (8).

Castro et al identifies key dynamic process in the patient-provider interaction as key antecedents to patient participation in SDM (31). The processes include deliberate effort to solicit a patient or their proxies to participate in a supportive dialogue; engaging the patients in meaningful dialogue about the disease and the individualized treatment options available; and providing a supportive and safe interactional environment aimed at activating and empowering

a patient to actively participate to their desired extent, refraining from merely validating providers' agenda (31). The process further requires acknowledgement of a patient as an expert of their disease (153). The highlighted process engenders a well informed and activated team of patients and providers that is better placed to meet the demands of DM care (22,59).

Despite the documented positive gains from patient participation, DM care practice is marked with failings (8,12,71,148). An interplay of patient, provider, system and contextual factors has been reported as affecting individualized levels of participation in SDM (31,154). At the patient-provider interactional level, factors known to influence DM care dynamics include patient's disease and socio-economic profiles, patients' educational status, health literacy, past experiences, patients' views and cultural values (155). For example, a patient's low socio-economic status and socio-cultural backgrounds with centralized repressive government power that excludes potential challengers are reported to have lowered the likelihood of initiating engagement with a medical authority (71,151), This element has been observed to create variability in observed patterns of SDM among different populations. Similarly, providers' communication skills, attitudes towards shared decision making and conflicting roles are known to affect observed levels of patient participation (31,71,150). Shortus et al report that providers often are ambivalent about the extent which they can engage their patients towards personalized versus protocol-based biomedical goals (150).Often, their ambivalence leads to non-solicitation of SDM around goals of care and expectation of trust from their patients(156). At institutional level, interactional time constraints, and at systems level, contextual issues such as an authoritarian socio-political context affect participation in SDM (71).

The attention given to user active participation in SDM is increasingly becoming fundamental to quality service delivery discourses in Malawi's chronic care settings (5,12). As Malawi endeavors to achieve greater active individual or collective participation especially in chronic

patients, this paper uniquely presents patients' perspectives regarding barriers precluding their participation in SDM. This narrative can improve understanding of the interactional failings and highlight patients' expectations of their participation, thereby, enhancing targeted strategies towards improvement of the participation.

Aim

In the light of the foregoing observations, the study sought to describe perspectives concerning barriers to participation in shared decision making among DM patients in Malawi.

Methods

Research Design

The study employed the qualitative approach to understand patients' perspectives concerning barriers precluding their participation in SDM.

Study setting

The study was conducted at 2 tertiary health facilities and 2 secondary ones, namely Queen Elizabeth Central Hospital and Zomba Central Hospital (ZCH), and Chikwawa and Mulanje District hospitals respectively. The facilities were selected based on an understanding that they would generate diverse views about the subject matter because they were different in terms of geographical location and offered care levels.

Study Participants

Through the clinic in-charges, we purposively identified 39 participants who came for their routine DM care visits who we, in turn, asked to participate in the study. In order to diversify views obtained, we further tasked the clinic in-charge to purposively select participants' who varied in age, sex, and DM type and duration. The eligibility of the participants depended on

their willingness to participate in the interviews; ability to provide informed consent; their patronage of the facility for more than six months, which implied that they had long enough contact with the health facility to significantly contribute to the study. We explained the purpose of the study to the potential participants; two of the them refused participation due to time constraints. We, in turn, obtained informed consent for interviews and audio-recoding from all the participants who met the criteria and agreed to participate.

Data collection

For data collection, we used in-depth interviews (IDIs) and focus group discussions (FGDs) guided by an unstructured questionnaire (supplementary file attached). There were 15 IDIs and two FGDs of 12 participants each. Two of the patients that participated in IDIs were also included in FGDs. The author conducted all interviews in the local language within the clinic. Apart from exploring perceptions about patient centred care, participants were asked to narrate their experiences and barriers around participation in common decisions in recent care. Saturation of responses was arrived after 13 IDIs but we continued with two more IDIs to verify saturation points. After each interview and focus group discussion, main issues arising from them were noted and summarized to participants for data verification.

Data management and analysis

For purposes of this paper, we focused our analysis on patients' perceptions and barriers to their engagement in SDM. We purposively chose the public sector to reflect patients' insights from the largest healthcare provider in Malawi. We conducted the study from September to December 2019.

The data analysis process started during data collection in the field by noting and exploring further recurrent themes. Following the data collection, we transcribed the audio data verbatim and imported it into NVivo software version 11 for analysis.

We employed Content Analysis where we familiarized, coded the data and clustered emerging thematic patterns(157). The analysts read the transcripts repetitively to familiarize themselves with the data set. Through this step we identified the perceptions and barriers to the SDM process

We ensured credibility by triangulating individual views in IDIs with collective ones from FGDs (108). Transferability of the results was enhanced through diversifying the patient profiles within the DM group studied (108). Also, as a way of quality check, two random transcripts were coded by the first and the third authors concurrently almost at the beginning of the coding process. Differences in coding were discussed and resolved by negotiating dominant meanings in the controversial quotes. Then we placed quotes in the rightful thematic context. We then updated the codebook and re-coded the transcripts using the new codebook. Conformability was achieved through counterchecking the codes by another individual of a different background to help mitigate the effect of researcher's prior predispositions that might have affected the analysis(108).

Results

Two themes were identified; the perceived value and benefits of participating in SDM, and challenges associated with patients' engagement towards SDM which has subthemes

Perceived value and benefits of participating in SDM

Participants generally felt that adherence to decisions made pertaining to diabetic care would be enhanced if the clients' themselves were part of the decisions made:

> 'A patient should be asked and should be allowed to give his/her suggestions, that way it would be easier for him/her to follow the decisions made [...]. So it is very important

to inquire from us first. […] But just making decisions without the knowledge of the patient sometimes becomes a problem.' **(Male participant 2 rural FGD)**

Further, the participants yearned for adequate dialogue as pre-requisite meaningful engagement towards SDM.

'However there has to be a good motivation, you [the provider] should ask questions, I should answer. I should ask questions and you should explain to me that for your problem to be over, you should do this and I should try that. "How are you feeling now?" "Everything is well." By doing that we have helped each other questions and seeking clarifications from patients.' **(Female participant 2 FGD urban)**

This theme describes the patients' expectation and perceived value of engaging them in SDM.

'Sometimes history can be said by a patient and care can be derived from that. […] So sometimes providers can make a decision which a patient is not in support of and the patient says it is better to die than to follow what the providers are saying […] A patient should be asked and should be allowed to give his/her suggestions, that way it would be easier for him/her to follow the decisions made [...]. So it is very important to inquire from us first. […] But just making decisions without the knowledge of the patient sometimes it becomes a problem.' **(Male participant 2 rural FGD) DELETE}**

The excerpt highlights the benefits of involving patients to arrive at collaborative care plans. Further, the participants yearn for adequate dialogue as pre-requisite meaningful engagement towards SDM.

'However there has to be a good motivation, you [the provider] should ask questions, I should answer. I should ask questions and you should explain to me that for your problem to be over, you should do this and I should try that. "How are you feeling

now?" "Everything is well." By doing that we have helped each other questions and seeking clarifications from patients.' **(Female participant 2 FGD urban)**

Challenges associated with patients' engagement towards SDM

The theme expresses patients' struggles and vulnerabilities faced in trying to ask questions in pursuit to engage their providers in SDM. The hostility of the interactional atmosphere and their own perceptions towards provider-patient interactions are testified. The following subthemes emerged from the theme:

a. Fearful and dismissive ambience

Some patients reported that they were unable to contribute to the discussion because the patient -provider interactional atmosphere was so fearful and dismissive that they assumed a submissive and unknowledgeable role.

> 'What scares us is, whenever you are talking too much and suggesting ideas to the doctor, they just ask you one question, "Are you the doctor? Just go and do whatever you are told." And then we don't have anything to say'. **(Female participant 9, urban FGD)**

The feeling of fear in patients was perpetuated by the possibility of being denied the day's intended service for that if they asked questions aimed at achieving engagement. Notably, patients noticed providers' unspoken cues around paternalistic inclinations, and their reluctance to involve them in care decisions.

> '…when you start asking the doctor too many questions, they leave you because they assume that you know everything. It is just out of luck when they write a prescription for you and that is why we are resilient to answer back. You can even tell that this doctor is angry at me and you don't ask any more questions. You just wait for the prescription and then off you go. We should say the truth, a patient should not be wise

more than the doctor. Just listen to whatever s/he is saying even though s/he is wrong.' **(Female Participant 9, FGD urban)**

Patients also perceived dismissive interactions as a deterrent to engagement towards SDM. They, reported their experiences with service providers who did not listen to patients' ideas.

> 'There are some provider[s], especially doctors, before you finish explaining, they have already written in your book so what can you do? Can you continue talking with them? Doctors are the ones who are supposed to listen to our complaints but most of them dispose us off even before we finish talking'. **(Female participant IDI urban)**

b. Insufficient opportunities for dialogue

The theme highlights sufficiency level of dialogue between the patients and the provider regarding the problem and its management to enable sound participation in SDM. With regards to alternative treatment options, patients expressed their potential to offer experiential insights into their diseases and their management, however, they confirmed that providers missed opportunities to tap into patients' expertise through dialogue.

> 'Just imagine a fresh doctor coming from College of Medicine trying to tell a patient who has been diabetic for 18 years. Who knows much there? It is us patients. That is why there is a need for that good doctor-patient relationship. Just because they learnt theory doesn't mean that they know everything. We are the ones who know much because we are the patients and they are supposed to listen to us. They should tell us what they learnt, the new technologies coming in but we should also tell them about our disease because we have an experience of the condition and by doing that we will help each other.' **(Female participant 7, urban FGD)**

Some patients with experiential knowledge, ironically, found it difficult to engage with their providers in dialogue and when they did, they felt that it would be futile for them to propose options because the options could not be heard.

> 'It is very difficult to have an opportunity to sit down with the doctor and discuss because mostly they feel like those issues should be left with the researchers and the diet which they have given us is ideal. So, I don't think that even if we sit down and discuss, it won't change anything.' **(Male participant, IDI urban)**

Patients' own perceptions towards dialogue and SDM

It was noted that patients' perceived inappropriateness of exchanging ideas, asking questions about their care with their providers contributed to their passivity in the interaction.

> 'My suggestions [are] if you are [a]patient and you are meeting the doctor, there is no way you can be exchanging ideas. The doctor just tells you that depending on your results, follow this, this and this. I will prescribe these drugs for you. I don't think a patient can have the audacity to be telling the doctor what to do as if you know about health. You just listen and take whatever the doctor has told you. **(Participant 5 urban FGD)**

The data analysis revealed that patients' possession of inadequate health literacy deterred their engagement in meaningful dialogue with providers. Similarly, patients believed that the providers were their sole help hence their need to trust whatever they said and to gratefully receive and comply with care packages without questioning anything.

> 'I would like to comment on what number 5 [participant 5] said, that we so much put our trust in the doctors. When they tell us this is how you are going to be taking your medicine, we listen and we do not disagree because we know that the doctor knows

his/her job and we don't have a right to disagree. That is why I said even if you have been prescribed the wrong medicine, there is nothing you can do unless if there is someone who also knows about medicine'. (**Female participant 8, urban FGD)**

'So, whenever we come here, we take the doctors as our help. We trust whatever they say.' **(Female participant 2, urban FGD)**

Discussion

While patients seem to value and yearn for engagement in SDM in clinical encounters, the narratives highlight that active participation among patients with DM is hampered by a non-inviting interactional atmosphere, insufficiency of dialogue, and patients' predispositions towards SDM. The themes overlap greatly, hence the need for the results and interpretations to be considered in the context of sensitivities of interactional power imbalances between the patients and their service providers.

Our study highlights the non-inviting, fearful and power imbalanced atmosphere as a deterrent to SDM. Furthermore, the unfavorable ambience compels patients to assume passive, subservient and unknowledgeable roles during medical encounters. Especially in the African context, this finding is supported by records of chronic care encounters being largely paternalistic with power imbalances that tilt against the patient (12,16,139). The interactional power imbalances are reportedly prominent where patients are socially and medically disadvantaged, among populations with low patient medical literacy and, those accessing non-fee-paying services. These factors have been reported to further reduce patient awareness of decisional freedom and assertiveness to initiate participation (71,151). Particularly, in resource-limited contexts, patients opt for passivity due to fear of risking their only opportunity to receive care upon asking questions that anger providers who perceive them as challenging their

authority and trust (156). Thus, passivity concerning patient care decisions also reflects poor patient provider relationship and patients' way of navigating felt hostility.

The reported contradiction between patients' desire for SDM and presumed trust towards their providers is not surprising and yet an important finding to this study. Patients' accounts about powerlessness and futility regarding decisional control during clinical encounters are not only profound but they also partly explain the apparent contradiction. Thus, due to futility perceived while trying to engage their providers in SDM, the patients portray their presumed trust out of deep vulnerability and helplessness by playing the role of good patient to win provider favors. Meaner et al supports this finding, arguing that it is patients' vulnerability, feeling unsafe and destitute that push them into blindly trusting their providers or risk being denied a services or being treated badly (158,159). Additionally, the results in our study show that patients' presumed trust in their providers hardly emanates from sufficient information shared or good interactional relationship in the dyad. To make SDM a reality, Joseph-Williams et al purports that patient provider trust must be born out of positive relations to the extent that the patient and the provider should have a "shared mind" (160). This implies the existence of enough opportunities for dialogue with optimal exchange of information and investment into relationship building over time(161). Although having total trust in their providers can lead to patients' passivity concerning SDM, providers in the low resourced context need to interpret patients' trust regarding SDM with caution to clear the ambivalence.

Concerning inadequate informational exchange through dismissive and hurried interactions deterring meaningful participation in SDM, Ringdal et al confirms that time pressed interactions hardly promote patients' medical literacy (159). Medical literacy does not only facilitates access, appraisal and application of information; it also fosters patients' feeling of decisional control and responsibility for meaningful SDM(159). Within the time constrained

DM care settings of Malawi, the perception that information sharing is time consuming may seem legitimate. However, providers should consider that the additional interactional time spent on dialogue is, usually, marginal (162) yet its value in reducing unwarranted retreatments, improving self-efficacy and tilting power balances towards the patients with DM is significant (31,163). Therefore the cost-effectiveness of the extra time must be weighed against potential gains of setting and attaining personalized goals especially in poorly controlled diabetic patients (152,164). Considering that DM medical encounters are repetitive, it would ease time pressure if providers could delegate or task shift information sharing to other cadres, and consider building patients' medical literacy as a longitudinal task over several encounters. These acts could, over time, capacitate patients along the SDM participation ladder(119,152).

Patients' attitudes about engagement in SDM need investigation if meaningful SDM is to be achieved in clinical encounters. It is a known fact that a patient's past experiences, disease condition and socio-cultural inclinations can shape their perception, abilities and attitudes towards SDM. Particularly, previous studies show that patients' perceptions that providers knowledge and authority is supreme over theirs, hence non-contestable. Consequently, patients assume passivity because they think that their health knowledge, experience is less important in the dialogue (161,165). While we acknowledge that patients' attitudes that are deeply engraved in socio-cultural sensitivities are hard to change, patient education strategies that focus on patient empowerment and enablement towards SDM are urgent in Malawi's chronic care context.

It is evident that patients with DM are likely to participate in SDM if they are solicited within a conducive environment where they genuinely feel safe and empowered to contribute to the discussion (146,166). While interactional time is an important constraint in SDM, it remains the providers responsibility to create a conducive ambience for SDM (158,159). Unfortunately,

medical training in Malawi is still largely biomedically oriented with emphasis and reward given to technical rather than interpersonal skills (16). This has perpetuated the paternalistic tendencies among providers. Thus, in order to effect the paternalistic professional culture, attitudes and routines needs to change among providers through transformative medical and nursing education that fosters active participation, relinquishing power to the patient to the necessary extent. These soft skills and competencies are urgently needed.

In Malawi, while some clinical specialties such as family medicine and nursing are working towards providers' culture change, the initial step for starting the relinquishing of power to patients is conducting a review of models of delivery and accreditation of evidence-based medicine in all specialties. Specifically, there is need to review practical ways of integrating personalized attributes to care, rapport building and participatory skills as longitudinal competencies in pre-service and in-service medical and nursing training (137). In order to improve on accountability concerning these important skills and attitudes, training institutions ought to make deliberate effort to assess and accredit the stated skills and attitudes during student and staff appraisals in training and clinical institutions.

In an effort to facilitate effective partnerships and safe spaces for dialogue, we advocate the use of participatory approaches to patient education that encourages provider-patients dialogue and asking questions(137). Through medical transformative education, we need to challenge provider attitudes to regard patients as active partners possessing complementary knowledge.

Limitations of the study

The study was conducted in the diabetic population of Southern and Eastern Regions of Malawi. Therefore, the perspectives that transpired in it may not be generalizable to the general patient population. However, due to the repetitiveness of the health interactions between the

healthcare system and DM patients we were of the opinion that their perspectives may enrich the goals of this study.

The narratives in this paper are limited to patients' perspectives on barriers precluding patients' participation in SDM. Therefore, the gaps presented may not be comprehensive, falling short of comparative analysis with perspectives from their providers.

Conclusions

The patients' perspectives narrated in this paper have unearthed the perceived value, relevant challenges and deep vulnerabilities associated with patients' participation in their medical decisions during clinical encounters. Even though most Malawian patient-provider encounters are time pressed, it is evident that patients yearn to be effective partners in their care. While the reasons may be numerous; from individual to contextual issues, the findings can guide the needed practical changes in culture and care routines that strengthen patient participation in decision making in DM care.

The findings from this study, helps reflect on the challenges PCC efforts would have to overcome. It allows for deep reflection of HCP practice and, a platform for improvement that is suggested in later chapters

CHAPTER 7: PAPER IV

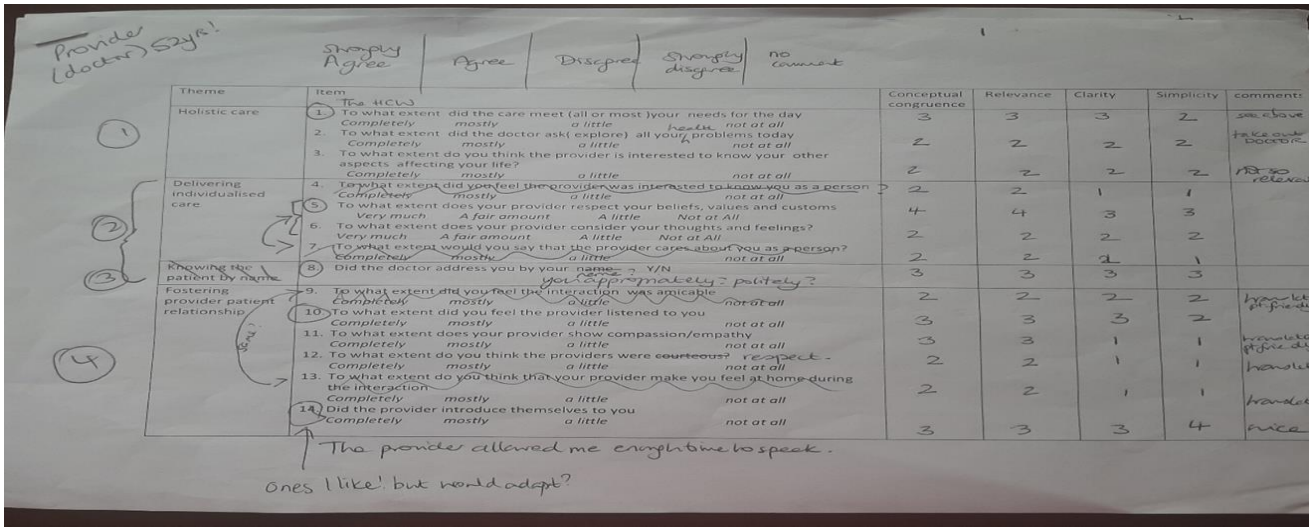
The Development and Psychometric Evaluation of a Patient-Centred Care Tool for Diabetic Patients in Southern Malawi (under peer review since November 2023)

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Abstract

Background: Whilst Malawi nurtures the policy and humanistic initiatives towards PCC, the ambiguity in definition and the complex nature of the construct calls for a local contextualization and the use of psychometrically sound measurement tools if one is to assess its extent and potential impact on patient outcomes with fidelity.

Aim: We aimed to assess the psychometric properties and structure of a PCC tool usable among diabetic patients in Southern Malawi.

Methods: This was a psychometric properties assessment study of a novel tool that was administered to 607 consecutive patients with DM in Malawi. The process consisted of assessing the face validity of items derived from a prior qualitative inquiry phase. Subsequently, we performed correlational studies to assess the consistency of the items in the tool. Finally, we used exploratory and confirmatory factor analysis in STATA 17 to identify and confirm the latent factors in the tool and determine their properties and goodness of fit of the model used. We assessed the construct validity through unsupervised K-means clustering.

Results: The exploratory factor analysis yielded a three-factor, 23-item solution that fit the data. The three factors included 1) relational ambiance, 2) individualization and involvement in care, and 3) organization of care. We found the tool to be an acceptably reliable measure of PCC with a Cronbach's Alpha of 0.94 and discriminately identified participants who perceived high and low PCC scores. Although the chi-square was significant due to large sample size, the df was 392 and RMSEA was 0.48 square and CFI was 0.969, PCLOSE was 0.633 indicating goodness of fit with the data. The classes of PCC identified correlated to patient outcomes showing good discriminant and

Conclusion: Despite some limitations in the psychometric assessment processes of the tool, it exhibited acceptable reliability and validity properties to serve as an empirical framework for

measuring PCC in this study population. It highlights the key practical elements that matter in PCC and serves as a starting point in the development of a tool among patients with DM in Malawi. Further refinement is needed to improve its usability.

Introduction

Patient-centred care (PCC) is a widely discussed concept, yet it has no agreed definition, and its functional elements are context-specific (167–169). It follows, therefore, that its measures would be highly dependent on local conceptualization and the actors' perspectives (167). The growing policy and humanistic drive towards the promotion of PCC in the African context is obvious, hence its need for objective assessment(16). The available tools or instruments are, however, often Western and have the potential to lack relevance due to the different expressions of the PCC construct across social, cultural, and linguistic contexts (11). To improve the PCC application and interpretability of appraisal results, one ought to use elements that are specific to the population in question(16). Reliable instruments or assessment approaches are, therefore, needed to measure its context-operationalized elements and the extent to which patients perceive PCC, and to identify what is important in day-to-day empirical practice (167). The paucity of psychometrically rigorous tools is obvious in African contexts make reliable measurement of PCC a challenge(102). Thus, the fact that tools that exist in Africa are largely Western makes it difficult to draw generalizable conclusions for a construct that has the potential to manifest itself differently across context(23,167)

Patient-centred care is a complex behavioral science construct in healthcare delivery, and its functional elements may not be directly observable(167). In the Malawian context, we conceptually understand PCC as an expected care process that incorporates warm patient reception, where the healthcare provider consciously aims to reduce the patient-HCP power

gap to harness a good long-term relationship. This creates a conducive atmosphere that allows the gathering of information that holistically identifies the individual's specific problems and all possible interacting factors, ensuring timely access to care and medication (170). Patient-centred care is not about giving patients whatever they want. The concept is about considering patients' preferences, values, family situations, social circumstances, and lifestyles; seeing people as individuals; and, in turn, working together with them to develop appropriate solutions(29,37,171). In other words, person-centred care is about facilitation of the encounter and co-production of knowledge as opposed to consumerism. It is clear that some of the concepts in the definition may not be observable, making them difficult to be measured directly.

Instruments used to measure the PCC construct use scales with items that are observable manifestations of the underlying latent constructs in the definition from a variety of perspectives(43,102). Thus, the instruments have the potential to measure the definition, the experience (process of care), the expectation or preference, and the outcome of PCC(167) (1,12). Comprehensive tools highlight key processes within the encounter at nano and micro levels (102,172). Yet again, most existing tools have focused on measuring the perspectives of either the provider, the patient, or both, which is less than ideal as patients or clients are the rightful judge (38). While PCC can be measured through in-depth interviews, observational studies, and patient surveys, with well-designed instruments, it is less intrusive and more cost effective to do patient surveys(37) . Measurements can happen longitudinally, episodically, in healthcare facilities, or in community contexts. Hudon et al contend that when it comes to perceptions, patients' perceptions matter as a gauge of the PCC process of care in a specific care receiving context (29,173). Thus, instruments that take into consideration the patient's perspective are therefore recommended.

Complex constructs such as PCC can be assessed wholly or only for their components and for specific disease contexts(167). Chronic care is one ideal context for assessing the extent of PCC manifestation largely because it can be expressible and improvements of quality in care are amenable to PCC(56,70). Additionally, chronic care patients or clients have repetitive contact with the health care providers thereby offering valuable insights concerning the extent and nature PCC. Chronic patients are defined as patients that have a life-long illness for more than 6 months (40).

Patient-centred care approaches in NCD management harness collaborative care and empower patients for effective self-care and improved patient outcomes. Most particularly in Malawian contexts where therapeutic and human resource constraints are prevalent, PCC approaches can potentially improve the value of medical encounters, rendering care cost effective for its players (patients, their families, providers, and the healthcare system)(174). Thus, there is a call for care to be patient-centred by adapting and innovating care interventions for Malawi(5). Yet, Malawi offers no specific operational instrument that can validly measure PCC and monitor its implementation. It is acknowledged that, breaking down the complex PCC phenomenon to its functional elements and, understanding its structure and properties, is a crucial step towards reliably assessing the concept. It is clearly the government of Malawi's priority to measure the perception of PCC to gauge how medical encounters are responsive to the needs and values of the community.

Valid measures of PCC experiences have the potential to inform elements that are attributable to outcomes, and that inform quality initiatives that matter, and ascertain the quality strides attained. Validated tools assess the extent to which PCC rendered for chronic care patients is non-existent (33). Existing PCC efforts have focused on patient charters, Ombudsman, community score-cards and suggestion boxes, which fall short of describing PCC experiences

of care at the interactional level. This manuscript, therefore, outlines the process in the psychometric assessment of the tool we developed to assess its suitability and performance in evaluating the extent of PCC in this study. We also highlight the process's shortfalls, how they may have impacted the scientific rigor, and how we mitigated them.

Aim

We aimed to develop and assess the psychometric properties of a PCC tool usable in this context among diabetic patients in southern Malawi.

Methods

This was a mixed methods study using a sequential exploratory approach that involved the initial identification of PCC thematic domains through qualitative inquiry which was followed by quantitative determination of the psychometric properties of the PCC construct, its ability to discriminate, and reliability measurement of the extent of PCC in our target population. The data collection procedures are described below.

Item generation

PCC thematic and functional element generation

Through an earlier qualitative inquiry output from chapter 5 of this study, thematic analysis was used to generate PCC thematic and functional elements that highlighted the lived experiences and preferences of the study population (86,167) as defined in Table 7.1. The thematic areas are adequately defined to reflect all possible connotations of the theme. This process generated 30 items. Other literature perceptions of PCC tools were referred to identify the similarities in the wording of items and their likerting styles.

Table 7. 1. Thematic areas and their respective items

Initial Theme	Definitions	Item description
Relational aspects	Amicable encounter/ humanistic Empathy, love/ warm welcome Relationship building Dignity, Listening\Allowing time to express Managing power differences	1. The interaction with my provider was amicable. 2. I felt the provider listened to me during the interaction, 3. The provider showed compassion/empathy. 4. The providers were courteous/ respectful, 5. The provider allowed me enough time to speak. 6. The provider made me feel comfortable during the interaction. 7. The provider introduced him/herself to me 7a. The provider called me by my name/relevant.
Holism	All patients' problems addressed Care to complete healing Thorough assessment and examination Total care given by the whole team	8. The care met most / almost all my needs for the day. 9. The provider explored all my health-related problems today e.g. Asthma, BP. 10. The provider is interested to know the other aspects affecting my life.
Individualization	Care based on/ addressing unique needs and expectations Being known as a unique person	11. The provider respects my beliefs, values and customs in managing my illness. 12. The provider considers my thoughts and feelings in managing my illness.

Information sharing	Health education/teaching Advising / counselling Explaining about disease, meds, prognosis Emotional support; Validation, encourage, reprimand	13. The provider gave me the opportunity to ask questions. 14. I am satisfied with the information given to me about my condition. 15. The provider explained the disease and its treatment to me. 16. My provider motivated and supported me to manage my illness. 17. There are opportunities to share feedback about care that I receive.
Shared decision making	Ask /inquire from us patients Not making decisions without the patients" knowledge Involve patient and family in planning Support patients to make informed decisions	18.The provider involved and engaged me (or relevant carers) in decisions about my care. 19. My provider supported me to make decisions concerning my health.
Accessing medication	Availability and access of care, Coordination of care Being realistic about care hurdles	20. The medicine I need for my illness was available. 21. There is coordination between the prescriber and pharmacy. 22. I understand when they explain that there is no medication.
Timeliness	Start work early (early defined as "reasonable") Waiting times too long	23. The waiting time was reasonable. 24. The time I spent at the clinic for care was reasonable.
Meeting expectations of care	Biomedical outcomes; Glycaemic control Meeting needs & expectation	25. The provider examined thoroughly for my illness. 26. The care meets my expectation

		27. I am satisfied with the care.

Face and content validity

The list of items was taken to an expert panel, which deliberated and rated individual items. Scores ranged from one to four, with one being the poorest and four being on point concerning conceptual congruence, clarity, and relevance to this setting. The panel consisted of two patients, two nurses, two clinical officers, two academics, and one social scientist. The panel was purposely chosen based on their expertise and interest in the topic and their involvement in DM care at different facets of healthcare delivery within the university and teaching hospital and study clinics (86). The author further refined the questions into a questionnaire. Items that rated poorly on the stated domains on the scales or were vague and did not correspond well with the context were either left out or improved for clarity to reliably reflect and measure the lived experiences of the study population. The questionnaire was developed on a 5-point (positive) Likert scale from strongly agree to strongly disagree. Items not fitting well with the context or lacking cultural conceptual congruence were reworded or not included. Two items were removed from the tool because they lacked conceptual congruence with the construct in question and they were contextually not befitting what happens in typical medical encounters. This process then, yielded 28 from the original 30 items, falling into eight domains.

Pre-testing and pilot

The tool was administered by research assistants to 30 adult consecutive patients with diabetes Mellitus in two of the four diabetic clinics we used for the study through face-to-face survey interviews. This was done to ensure consistency in administration and the validity of the

responses to the questions retained(167). Again, this ensured consistency among the interviewers. Emergent problems that we identified were remedied by the researcher, research assistants (interviewers), and supervisors. Some of the problems identified were: 1) the scale items were challenging to articulate in vernacular language; 2) there was confusion about the recall period; and 3) some questions had multiple possible answers. To improve the tool, we identified better alternative vernacular terms and changed the perception scale to a time-bound Likert scale with a 6-month recall period which is deemed ideal(175). The pilot cohort was not included in the data analysis because the response scales changed dramatically from the original. Some items were further clarified and a four-point Likert scale; of one denoting "never" and four denoting "all the time" was adopted, with five assigned to a null answer namely, "no comment" or "I don't know"

Data collection

Sampling and administration of the tool

The tool was later administered at a single point to the subsequent 607 patients who attended the DM clinic within the study sites. The sample size determination was based on the number of respondents per item in the tool to achieve adequate validity. According to Clark et al who recommended ratio is ten respondents in the target population per item(176). In this study, the sample size was 607. We used a large sample size beyond the ideal of at least 10 participants per item to adequately highlight generalizable patterns in the data and, in turn, reduce measurement errors during the psychometric analysis(86). After the clinic staff explained the nature of the study, we approached individual patients to explain the study, ask for their willingness to participate, and screen if they met the inclusion criteria. We then obtained both verbal and written consent for both interviews and HBA1c testing through a finger prick. All patients who were too sick to take a survey did not give verbal consent, or used the facility for

less than 6 months were excluded from the study because they may not have been familiar with the HCPs long enough to comment on the quality of the care they receive.

The study was carried out at four study sites in the Southern region. Four DM clinics were chosen; two urban and two rural. The urban sites were purposely chosen as they were the only urban centres in the Southern Region.

Data management and statistical analysis

Duplicates were removed while data and null responses ("no comment or not sure") were assigned a mode because they accounted for less than 5% of the whole dataset. A mode was preferred because the modes occur at random and they do not really affect variance of string object data (177). There was one extreme outlier that was removed from the data set. Normality checks were done by using box plots and histograms to ascertain the most suitable inferential statistics to be used. Finally, categories were created and labelled accordingly.

The data were analyzed using STATA version 17. We used exploratory factor analysis (EFA) to determine the latent dimensions in the data and this was, in turn, confirmed using parallel analysis(88). Confirmatory factor analysis (CFA) was subsequently used to confirm the structure of the latent constructs underlying the items in the tool(86,178). This was done in the following highlighted steps: -

a. Internal consistency and reliability testing

We conducted classical test theory on all items using correlation analysis to measure the internal conceptual consistency between the items and the tool as a whole. We used Cronbach's alpha of >0.7 to be acceptable in ascertaining sufficient conceptual correlation amongst the items and the tool (86,179). Clark & Watson et al. suggest that, for complex social-behavioral phenomena, a correlation of > 0.3 is acceptable(176,180). Thus, items that in EFA correlated less than 0.3 to other items in the pool were flagged for potential elimination.

Due to logistical challenges, we did not test and retest reliability. Factorability and adequacy of the sample for factor analysis was pegged at the KMO values of >0.8 and Bartlett's test for sphericity with a chi-square of <0.05 were desirable(86). Bartlett's test for sphericity confirmed that a significant linear combination existed between the items in the tool(86).

b. Extraction of latent factors and item reduction

To extract latent constructs that define the interrelationship among items in the tool and to improve the interpretability of the model, we used principal factoring and an oblique rotational iterative process. We further employed Horn's parallel analysis based on random data simulation to determine a number of factors at 100 iterations, using the p95 estimate to confirm the number of factors we are to retain(88). Factor extraction was both theoretical and statistically driven. We used the scree plot, item uniqueness to the factor, and the pattern of the factor loadings to determine the factors and items to be retained(181). Factor loadings indicate the correlation between individual items (variable and respective factors). Factor loadings of >=0.3 indicate acceptable correlation(84). Uniqueness refers to the variance that is unique to the variable in question and not shared by other variables, and is equal to one minus communality, that is, the uniqueness shared with other variables in the model. Uniqueness of >0.6 indicates significant lack of specificity for the item(182). Eigenvalues > 1, factor loadings of >0.3, and uniqueness of <0.6 determined the number of factors (subscales) and which items were assigned to a respective subscale. While factor loadings of >0.3 are acceptable, in the light of Whittaker and Carpenter caution that the assignment of the items needs to make conceptual and theoretical sense, we assigned items based on both (161).

Firstly, we ran a principal factor analysis and chose factors based on Eigenvalues >1.0(178). A scree plot was further utilized to visualize and reduce the number of plausible latent factors

above the elbow. The factor solution was obliquely rotated to get a clearer interpretation of the factors and their respective observed variables.

Item reduction was then done by iteratively examining and retaining functional items that had factor loadings of more than a coefficient of >= 0.3 into a specific factor. Items that cross-loaded were assigned to where they loaded most or where they made conceptual sense, although they may have loaded higher in an alternative factor (86).

Once again, we flagged for elimination items that had a uniqueness of less than 0.6, as it indicated that the item was to a greater extent exclusive to that specific latent factor. The greater the 'uniqueness', the lower the relevance of the variable in the factor model. Some factors that had high uniqueness were still retained due to conceptual importance in the factor in question.

We further subjected the reduced tool and each factor (subscale) to correlational analysis to assess and confirm its internal consistency. According to Keith et al and Mohsen et al Cronbach's alpha of> 0.7 was considered acceptable for reliability testing for social constructs like PCC(179,183). Similarly, item-total correlations of at least 0.3 were acceptable to retain an item in that factor. Some items did not make a difference on the Cronbach's alpha within their respective factor. Being redundant, they were removed from the tool.

c. Model of fit analysis

Model of fit testing was done to check if the observed constructs matched with identified latent constructs derived from earlier EFA using structural equation modelling (SEM). This model specification was evaluated iteratively by conducting confirmatory factor analysis in STATA 17. This analysis determined the likelihood of a variable coming from a specified distribution (chi-square), allowing for better comparison between observed and expected results (85). The SEM model was built based on the EFA output and tested with the output maximum likelihood

report on standardized coefficients and values, maximization history, and modification indices. To obtain the goodness of fit of the structure model, we used a combination of the chi-square test of >0.05, the root mean squared error of approximation (RMSEA) pegged at a significant value of <0.05 as good fit and <0.08 as fair. fit, and the comparative fit index (CFI) of 0.>950 as acceptable fit. RMSEA estimates model fit assuming optimal parameters, were used, and reports chi-square and degrees of freedom. A significant RMSEA of less than 0.05 signifies a good model fit between the model and the data. CFI was acceptable if it was greater than 0.9 because it signifies the minimal difference between the independent model and our model(85).

d. Construct validity: The determination of PCC scores

We used the tool on the same dataset to do unsupervised K-means cluster analysis in R Studio version 4.2.3 to ensure that the tool measured what it purported to measure in the index population discriminately. This was done to determine the number of clusters of the population that have statistically distinct PCC scores(184). The difference between the mean scores in the clusters (groups) identified were compared and the statistical significance determined using sample t-test and proportions by chi-square of<0.05.

Ethical considerations

The study underwent scrutiny and approval from the Wits and Malawi COMREC as part of the larger study.

Results

Socio-demographic characteristics

The study interviewed 617 participants and after data cleaning, the number was reduced to 607. The study sample had more males than females 36% vs 64% respectively. The mean age was

51.6 (SD-14.5). The study population was comprised of a statistically significantly high proportion of patients (86.8%) with type 2 diabetics (p value 0.018) who had stayed with the disease for an average of 6.9 years (SD 5,8) with no significant difference between sexes (Table 2).

Table 7.2: The socio-demographic characteristics of the participants by sex

Variable	Characteristic	Male	Female	Overall	p-value*
Proportion	n%	202(36%)	358(64%)	560	
Age (years)	Mean (SD)	51.58 (14.5)	54.7 (12.5)	53.6(13.6)	0.008
Level of education (n%)	None	12(14.0)	82(7.9)	94(21.9)	<0.000
	Primary	78(2.9)	185(1.6)	263(4.5)	
	Secondary	86(12.4)	78(7.3)	164(19.4)	
	Tertiary	26(8.6)	15(4,8)	41(13.4)	
Type of DM (n%)	Type 1	37(17.7)	42(10.8)	70(13.2)	0.018
	Type 2	172(82.3)	348(89.2)	520(86.8)	
Type of treatment (n%)	OHA	148(70.8)	311(79.7)	459(76,6)	0.024
	Insulin	43(20.6)	60(15.3)	103(17.2)	
	OHA Insulin	13 (1.4)	15(1.0)	30(5.0)	
	None	3 (6.2)	4(1.0)	7(1.2)	
Duration of disease (years)	Mean (SD)	6.97 (5.6)	6.79(5.7)	6.87(5.7)	0.3608
Duration of facility use (Years)	Mean (SD)	6.89(5.6)	6.80(5.6)	6.86(5.6)	0.3608
Facility location(n%)	Urban	118(41.6)	227(62.1)	345(61.5)	0.280
	Rural	84(57.4)	133(36.9)	217(38.5)	

SD: standard deviation * Chi-square for categorical variables and t=test for continuous variables

Tool internal consistency and reliability

The 23-item tool showed good internal consistency with a Cronbach's alpha of 0.94. The average item-item correlation which tests which measures how closely related each item is to the others was 0.37. Item-total that measures how closely related each item is to the rest total score of the scale was between 0.35-.0.70. Few items that had internal item-item correlation of less than 0.3 were flagged for elimination in the subsequent analysis. The item's correlations are shown in Table 3.

Table 7.3: Correlations indices of the tool

Item	Item test	Item-rest	Average inter-item	Alpha	Mean	Std. dev.	Min	Max
The interaction with my provider was amicable	0.639	0.596	0.391	0.934	3.13	0.98	1	4
I felt the provider listened to me during the interaction	0.656	0.616	0.390	0.934	3.32	0.82	1	4
The provider showed compassion/empathy	0.706	0.669	0.387	0.933	3.21	0.90	1	4
The providers were courteous/ respectful?	0.693	0.655	0.388	0.933	3.23	0.90	1	4
The provider allowed me enough time to speak	0.6693	0.630	0.399	0.934	3.23	0.89	1	4
The provider made me feel comfortable during the interaction	0.671	0.631	0.389	0.934	3.26	0.88	1	4
The provider called me by my name/relevant title	0.728	0.694	0.386	0.933	2.31	1.26	1	4
The care met most/almost all my needs for the day	0.697	0.660	0.388	0.933	3.05	0.94	1	4
The provider explored all my health-related problems today e.g. Asthma, BP	0.631	0.588	0.392	0.934	2.91	1.01	1	4
The provider is interested to know the other aspects affecting my life	0.687	0.650	0.388	0.933	2.00	1.19	1	4
The provider respects my beliefs, values, and customs in managing my illness	0.695	0.658	0.388	0.933	2.70	1.11	1	4
The provider considers my thoughts and feelings in managing my illness.	0.714	0.678	0.387	0.934	2.61	1.12	1	4
I am satisfied with the information given to me about my condition	0.650	0.609	0.391	0.934	3.28	0.86	1	4
The provider explained the disease and its treatment to me.	0.652	0.611	0.391	0.934	3.25	0.82	1	4
There are opportunities to share feedback about the care that I receive	0.651	0.610	0.390	0.933	2.60	1.16	1	4
The provider involved and engaged me (or carers) in decisions about my care	0.606	0.561	0.394	0.935	2.43	1.14	1	4

My provider supported me to make decisions concerning my health	0.687	0.649	0.388	0.933	2.65	1.13	1	4
The medicine I needed for my illness was available	0.517	0.465	0.399	0.936	3.07	0.87	1	4
There is coordination between the prescriber and the pharmacy	0.643	0.601	0.391	0.934	2.57	1.17	1	4
The waiting time was reasonable	0.401	0.342	0.407	0.938	1.98	0.91	1	4
The time I spent at the clinic for care was reasonable	0.436	0.379	0.405	0.937	1.91	0.86	1	4
The care meets my expectation	0.717	0.682	0.386	0.933	3.05	0.94	1	4
I am satisfied with the care	0.715	0.679	0.387	0.932	3.10	0.92	1	4
Total				0.937				

Factor extraction, item reduction and interpretation

Our sample was adequate for EFA with the Bartlett test of sphericity test with KMO Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) of 0.924. We obtained a three-factor solution that was able to explain most of the variation in the sample size using minimum Eigenvalues of 1, using EFA and Horn's parallel analysis based on random data simulation using the p95 estimate and, visualized on a screen plot (figure 7.1). It was found out that the two complementary methods (EFA and Parallel analysis) produced the same number of factors consistently.

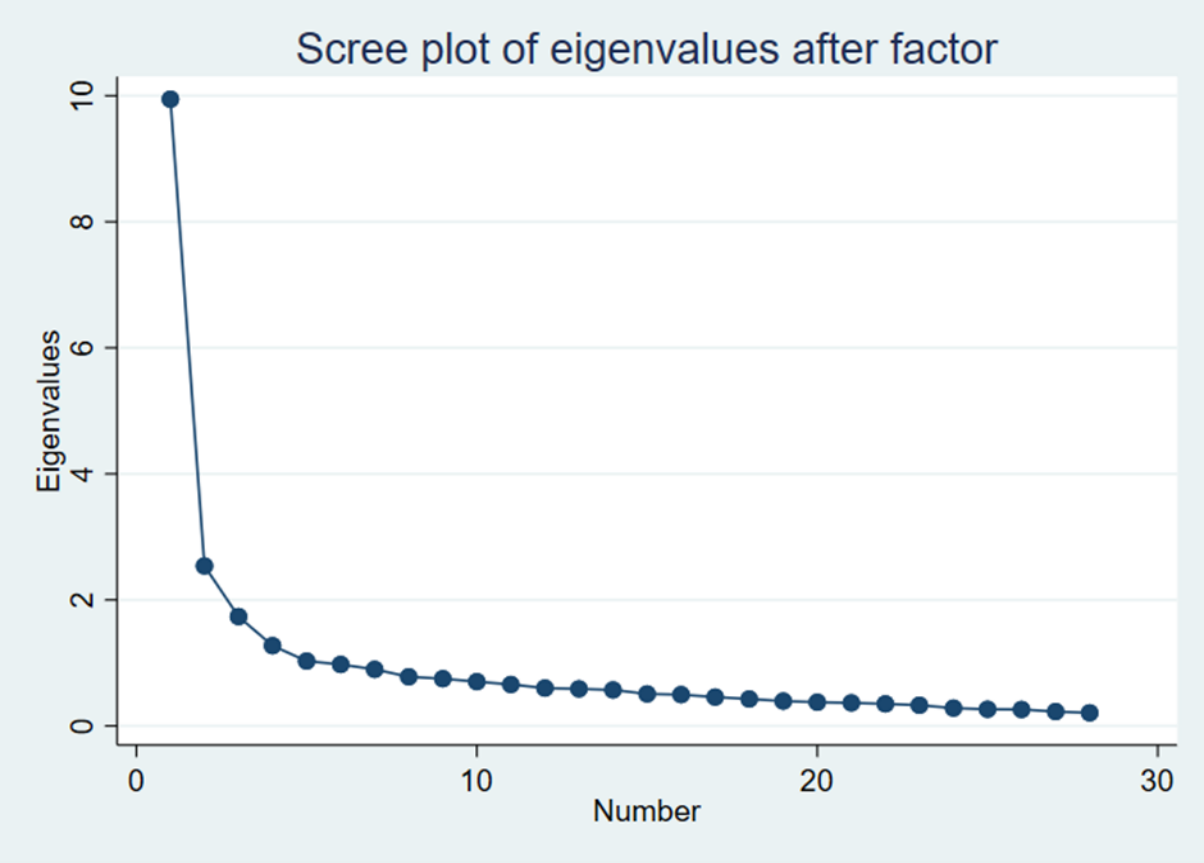


Figure 7.1: The Scree plot showing number of factors retained

The factor loadings after oblique rotation for each factor were as shown below. Those with factor loadings of an >0.3 were retained.

Table 7.4: Rotated factor loadings and uniqueness values for items in the instrument

Item	FACTOR 1	FACTOR 2	FACTOR3	UNIQUENESS
1. The interaction with my provider was amicable	0.6225			0.5426
2. I felt the provider listened to me during the interaction	0.7011			0.4570
3. The provider showed compassion/empathy	0.7829			0.3381
4. The providers were courteous/respectful?	0.7985			0.3244
5. The provider allowed me enough time to speak	0.7016			0.4485
6. The provider made me feel comfortable during the interaction	0.6736			0.4709
7a the provider introduced him/herself to me		0.4519		0.7681
7. The provider called me by my name/relevant title		0.6862		0.3854
8. The care met most/almost all my needs for the day	0.5362	0.4047		0.5303
9. The provider explored all my health-related problems today e.g. Asthma, bp	0.3090	0.4843		0.6133
10. The provider is interested to know the other aspects affecting my life		0.6160		0.4760
11. The provider respects my beliefs, values, and customs in managing my illness	0.3004	0.6158		0.4869
12. The provider considers my thoughts and feelings in managing my illness.		0.7442		0.3695
13. The provider gave me the opportunity to ask questions	0.3587	0.5174		0.5994
14. I am satisfied with the information given to me about my condition	0.5817	0.3291		0.5494
15. The provider explained the disease and its treatment to me.	0.4770	0.4586		0.5608
16. My provider motivated and supported me to manage my illness	0.3131	0.4782		0.6376

17. There are opportunities to share feedback about the care that I receive		0.7680		0.3732
18. The provider involved and engaged me (or carers) in decisions about my care		0.7831		0.3725
19. My provider supported me to make decisions concerning my health		0.8273		0.2910
20. The medicine I needed for my illness was available		0.3674		0.7668
21. There is coordination between the prescriber and the pharmacy	0.3388	0.4010	0.4153	0.5519
22. I understand when they explain that there is no medication				0.7926
23. The waiting time was reasonable			0.7479	0.4109
24. The time I spent at the clinic for care was reasonable			0.7144	0.4471
25. The provider examined thoroughly for my illness	0.5128			0.5855
26. The care meets my expectation	0.5531	0.4347		0.4796
27. I am satisfied with the care	0.5866	0.3700		0.4770

Through correlational analysis, we noted that items 7, 16, and 22 were eliminated as they both correlated poorly (<0.5) with the rest of the tool and, had very high uniqueness values of 0.6 or more, indicating a lack of specificity and cohesiveness to the tool as highlighted in Table 3(86). Item 7 was about the provider introducing themselves to the patient which had very low scores as it hardly happens. Even though item 16 talked about support and motivation for self-care, it did not load in any of factors or subscales. It is possible that it conceptually covered other issues or it might have been vague without highlighting the type of support in question. While items 8, 9,11, 13-15, 21, 25-27 cross loaded, we noted that, on the one hand, items 8, 14,15, 26, and 27 loaded highly onto the relationship subscale while items 9,11,13 loaded more onto individualization and collaboration of care subscale. On the other hand, item 21 loaded highly in the organizational subscale. Even though items 8,9, and 20 loaded in the other factors, they conceptually and theoretically related the organizational subscale discussing comprehensiveness in the care and timeliness. Item 13; "the provider gave me the opportunity to ask questions" and was removed as it was redundant and did not contribute much to the overall Cronbach's alpha in the subscale and possibly conceptually related to question 17. It is likely that item 13 was redundant and most of its aspects which covered opportunity for dialogue in the encounter were captured by item 17. Though Patient's understanding of access hurdles was represented by question 22, it would seem that it was not conceptually related to the PCC construct, hence its being dropped out. Although item 25 "the provider examined thoroughly for my illness loaded highly in relational subscale, it did not relate conceptually with other items in the tool and its uniqueness (0.59) was pretty high, therefore, it was dropped. Items 13 and 25 did not change the Cronbach alpha when they were deleted from their respective subscales. This indicated that the two items may have been redundant.

The global scale, therefore, was reduced to 23 items and we labelled the three factors as shown in table 3 with their respective items that were loaded. When we correlated the items in the

individual factors, all showed acceptable internal consistency (Cronbach's Alpha 0.937).

The description of subscales (factors)

Following factor analysis, the relational and interactive ambience subscale had ten items which had an average inter-item correlation of 0.51 and a Cronbach's alpha of 0.91 as shown on the table 5 below. The subscale was related to PCC facets marked with relational ambience and communication with exchange of information between the patient-provider dyad.

Table 7. 5: Item-test scale correlations matrix for the relational ambience subscale

ITEM	ITEM-TEST	ITEM-REST	AV. INTER ITEM	CRONBACH'S ALPHA
1. The interaction with my provider was amicable	0.7251	0.6455	0.5131	0.9046
2. I felt the provider listened to me during the interaction	0.7635	0.6980	0.5041	0.9015
3. The provider showed compassion/empathy	0.8270	0.7687	0.4923	0.8975
4. The providers were courteous/ respectful?	0.8156	0.7623	0.4933	0.8976
5. The provider allowed me enough time to speak	0.7615	0.6956	0.5040	0.9016
6. The provider made me feel comfortable during the interaction	0.7556	0.6884	0.5053	0.9021
14. I am satisfied with the information given to me about my condition	0.6991	0.6201	0.5175	0.9061
15. The provider explained the disease and its treatment to me.	0.6691	0.5786	0.5247	0.9086
26. The care meets my expectation	0.7236	0.6495	0.5124	0.9044
27. I am satisfied with the care	0.7385	0.6676	0.5093	0.9033
Subscale			**0.5077**	**0.9116**

The individualization and shared decision-making sunset had seven items. The average inter item correlation was 0.58 and a Cronbach alpha value of 0.91. The subscale investigated the interactional aspects that regard the patient as a unique person, take into account their unique individualities and, support patient involvement and participation in care (See Table 6).

Table 7.6: Item-test scale correlations of the individualization and SDM subscale

ITEM	ITEM-TEST	ITEM-REST	AV. INTER ITEM	CRONBACH'S ALPHA
7a. The provider introduced him/herself to me	0.7892	0.7052	0.5850	0.8943
10. The provider is interested to know the other aspects affecting my life	0.7528	0.6574	0.5986	0.8095
11. The provider respects my beliefs, values, and customs in managing my illness	0.7660	0.6742	0.5937	0.8976
12. The provider considers my thoughts and feelings in managing my illness.	0.8376	0.7688	0.5672	0.8872
17. There are opportunities to share feedback about the care that I receive	0.8070	0.7288	0.5784	0.8917
18. The provider involved and engaged me (or carers) in decisions about my care	0.3030	0.7234	0.5799	0.8923
19. My provider supported me to make decisions concerning my health	0.8483	0.7845	0.5629	0.8854
Subscale total			0.5802	0.9064

The organization of care subscale had a total of six items with an overall Cronbach's alpha of 0.74 while the inter-item correlation was 0.32. This subscale discusses the organizational context in which care is taking place which is outpatient clinic, principally about comprehensiveness, coordination, timeliness of care and access to medication. Here timeliness was considered in relation to the waiting times and the time spent at the clinic in an effort to receive care (See table 7).

Table 7.7: Item-test scale correlations for the organization of care subscale

Item	Item-test	ITEM-REST	AV. INTER ITEM	CRONBACH'S ALPHA
8. The care met most / almost all my needs for the day	0.6647	0.4834	0.3222	0.7038
9. The provider explored all my health-related problems today e.g. Asthma, bp	0.6499	0.4635	0.3281	0.7094
20. The medicine I needed for my illness was available	0.5892	0.3849	0.3521	0.7310
21. There is coordination between the prescriber and the pharmacy	0.7355	0.5806	0.2941	0.6757
23. The waiting time was reasonable	0.6473	0.4601	0.3291	0.7104
24. The time I spent at the clinic for care was reasonable	0.6778	0.5003	0.3171	0.6990
SUBSCALE TOTAL			**0.3228**	**0.7418**

Overall, all the three subscales showed acceptable item-test, item-rest and the average inter-item correlation values of >0.3. This showed acceptable conceptual relatedness of the items in each subscale and the overall instrument.

Confirmatory Factor Analysis

The three-factor model obtained from EFA produced a satisfactory goodness of fit after five iterations to confirm the structure of the latent factors. Co-variation of the observed variables was done for those items that had high modification indices to improve the fitness. Thus, the model produced latent factors, namely 1) ambience, 2) individualization and involvement in care and, 3) organizational aspects of care. Although the chi-square was significant due to large sample size, the df was 392 and RMSEA was 0.48 square and CFI was 0.969, PCLOSE was 0.633 indicating goodness of fit with the data.

Figure 2 below highlights the structure and the psychometric properties of the factors. The results highlight acceptable fit of the model to our data.

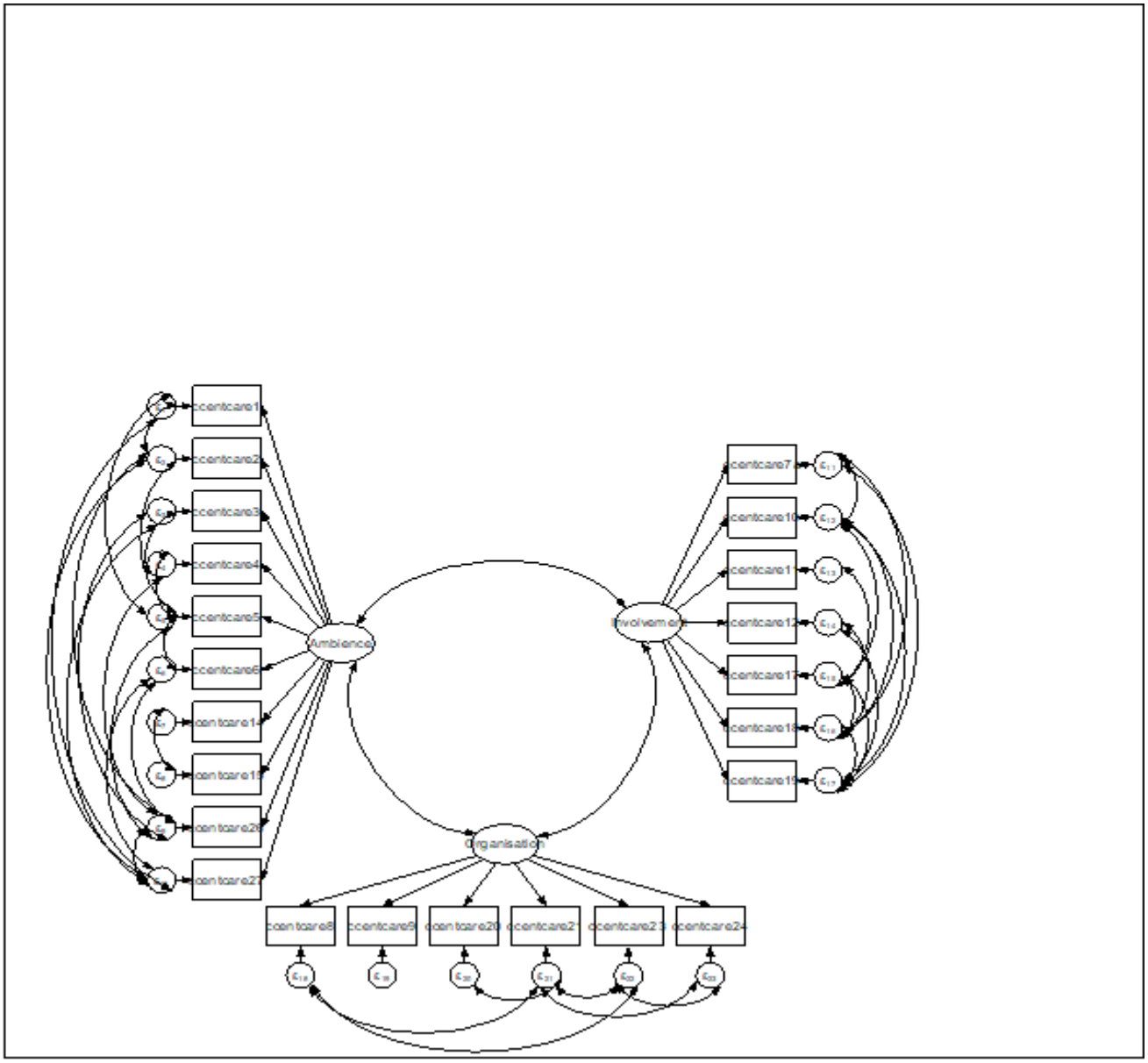


Figure 2: showing the three-factor solution for the perception of the PCC Measurement Tool

Goodness of fit indices

The goodness of fit indices shows acceptable Gof. The chi-square is significant >0.05 due to the large sample size See Table 8).

Table 7.8: Goodness of fit indices for the three-factor solution

Fit statistics	*Value*

Likelihood Ratio	Chi-square	0.000
Population Error 90%CI	Root mean squared error of approximation (RMSEA)	0.48
	Lower bound	0.042
	Upper bound	0.055
	P-Close (probability RMSEA <=0.05)	0.633
Information criteria	Akaike (AIC) Information Criterion	22315.82
	Bayesian Information Criterion (BIC)	22753.34
Baseline Comparison	Tucker Lewis Index (TLI)	0.959
	Comparative Fit Index (CFI)	0.969
Size of Residuals	Standardized Room Mean Squared Residual (SRMSR)	0.42
	Coefficient of determination (CD)	0.990

Measures of PCC (Construct Validity).

Measures of discriminant validity were done with the same sample population (607 participants). The tool was able to discriminate those with high PCC and low scores through cluster analysis, and through regression analytical models, we were able to correlate with some of the outcome variables. This is explained in the next chapter.

Discussion

This paper concerns itself with describing the psychometric analytical process and the structure of the PCC contextual tool in this study to generate an understanding of the operational definition and its functional elements or tasks before using it for assessment in the next phase of the study. The tool purports to assess the extent to which providers' PCC behavior is perceived by patients at interactional and context of care levels. While most tools exist, very few reportedly consider patients' perspectives in their conceptualization and measurement. This study, therefore, acknowledges patients as judges of whether PCC has been responsive to the target population; it serves as a proxy of care responsiveness (38,72).

The 23-item three-factor solution discovered in this analysis demonstrated sufficient reliability and validity measures, thus providing a suitable framework for assessing patient-centred care

among diabetic patients in this particular setting. Its internal consistency was high (0.94) and was similar to other studies examining the similar construct scales with Cronbach Alpha scores of 0.84- 0.96(43,167,168). The high internal consistency confirms the interrelatedness and unidirectionality of the items in the tool. While Some authors such as Tavkol and Streiner et al argue that high Cronbach's Alpha of >0.90 may mean low specificity, redundancy and that the tool may offer limited reliability interpretations (165,167), however, in this study we employed multiple complementary tests to mitigate the redundancy. The employment of tools such as uniqueness, item total correlations for the whole tool, and the respective subscales helped to mitigate redundancy and confirm the conceptual distinctiveness of each item while maintaining the conceptual relatedness between the items(86,87,179). Additionally, as outlined in Boateng et al.'s best practices, they contend that tool validation is an iterative process with both theoretical and statistical underpinnings(86). In that regard, researchers in this study, through a panel of experts, looked at the conceptual relevance of the items to the tool and removed items that did not add value contextually but also looked redundant. Again, as Cortina et al. argue, that for socio-behavioral constructs such as PCC, a high Cronbach's Alpha is acceptable provided that there are enough items in each subdomain(185). Our initial tool had at least three items for most thematic areas to support the high levels of certainty in the interpretation of the Cronbach alpha (86,95). Due to large sample size, the chi square is significant (<0.05), which is common in such scenarios and therefore, does not negate the validity of the tool(85).

It is important to note that the strength of the study is that it followed nearly all the steps in the process of scale development. Firstly, the identification of domains and items, content validity, piloting, and administration of the tool from a large enough sample, ensured that the tool was parsimonious (86). Secondly, we ensured the identification of a latent factor and item reduction, validating the hypothetical structure matched with the data(186). Even though the study acknowledges that some steps are missing, such as test and retest reliability and convergent

validity testing as defined by Boateng et al., due to time and resource limitations, we reckon that the process was sufficiently rigorous and, does not render the tool unempirical for this study in this context(186). We, therefore, assert that for the purposes of this study, the scale development processes were of adequate scientific rigor as a starting point to be used to assess the extent of PCC. The authors acknowledge that further refinements would be necessary to improve its specificity for adoption as well as for routine monitoring use in the future. Thus, further studies can be done to see how it correlates with other scales measuring different but similar constructs among this population and at different times.

As regards the broad definitions of processes in care, the tool covers the fundamental broad subscales of the definition, namely relational aspects, patient participation, and the context of care such as access, timeliness, and coordination of care. This is corroborated with other definitions in literature, which highlight measuring tools with the same subscales(43,102,168). Hugo et al. and Hudon et al. frameworks, which are provider-patient relationships that facilitate patients, the biopsychosocial approach (comprehensiveness), common ground that facilitates collaborative care between the patient and the provider, and context of where the care is taking place(43,102,167) (27,54). However, when it comes to the focused tasks in chronic care encounters as deemed important by Hudon et al., we notice that some tasks did not map well with our framework(40,43). For instance, while other tasks seem relevant, legitimizing patient illness and offering realist hope did not seem to be contextually relevant in our study. This may be because the tasks are not well-defined in our context, while others have different contextual explanations (48,65). For instance, finding common ground is an important but hardly expressible subscale in our context due to both patients' own restrictive attitudes and providers orientation to SDM, as found in this study (169).

Items in the relationship (interactional ambience) subscale touched on the important relational aspects that underlie the PCC construct, namely empathy, respect, dignity, and ambience for information sharing, and they corroborate with other tools. Items 26 and 27 highlight the ultimate fulfilment of satisfaction and of the care that meets the expectations patients have. While the subscale talked about relational ambience, item 25 did not add much to the scale and was less fitting conceptually in this subscale, as it focused more on thoroughness and holistic care delivery. Although it was important in the qualitative inquiry its inclusion in the subscale hardly made a difference; rather, it spoke more comprehensively of care than the interactional ambience between the dyad, therefore, it was removed.

The second subscale of being known and managed as a unique person holistically is paramount in the definition of PCC, as highlighted in other tools(43,168). It was interesting to know further that the subscale covers the involvement and support for patients to participate in their care decisions. While item number 13 discusses the importance of asking questions, it does not align with the overall theme of this subscale. We, however, see peculiarities and lack of prominence in relation to some PCC concepts documented as important for chronic care by Hudon et al. For instance, relational continuity and provider advocacy roles across care transitions were not emphasized in our study and were thus left out of the operational framework. It is possible that while our patients yearn for high level interactional needs, they struggle to access the basic interactional and organizational issues for their care, such as medication access and timeliness, to the extent that their yearning for high levelled needs is very moderated(131,170)

Although the organizational subscale falls outside of the interactional realm it highlights the importance of the broader PCC organizational culture, namely timeliness and coordination of care and access to medication. The timely organization of care delivery in this case relates to the reasonableness of waiting time and time spent at the hospital without sacrificing other

obligations in order to access care. In this context, untimeliness stands out because it is an important domain in the PCC process as it relates to perceived barriers to access at the point of care, and improvements have the potential to enhance positive experiences of care and service utilization (39,50,118). While not part of the interactional realm of PCC, it has been shown to be both a practical and relevant part of the PCC organizational culture and an indicator of quality care(16,50).

While the framework is unique to this study population in many ways, it has thematic similarities with earlier studies in its general approaches(35,123,171,187,188). First is its emphasis on relationship building with the patient through an inviting, respectful atmosphere. Secondly, is its attempt to know the patient as a unique individual, to co-design care, and to share power and responsibility (12,43,189)(10,17,22). The third similarity concerns issues around the organization of care related to access, coordination, timeliness, and perceived barriers(16,110,111,190). In a way, the framework identifies with Thoˊrarinsdoˊttir et al.'s hierarchical view of PCC processes that are interdependent and incremental(117). Stating that provider-patient relationship building harnesses a good interactional environment marked with sensitivity and respect is a fundamental step that allows for optimal communication, individualization of care, and support for patients' involvement and participation in care that is supported by optimal systemic enablers.

We found that the tool is able to discriminate between study participants who had low and high PCC scorers. Further, the correlation between each of the subscales and outcomes, namely self-efficacy, adherence, and glycaemic control, is a proxy for construct validity of the tool. Thus, the tool is, to an extent, able to do what it is developed to do, which is in line with similar tools(167,168). Therefore, while we are aware that some forms of validity were not defined in this study, there is adequate evidence to ascertain that the tool is stable and discriminatory.

Limitations and conclusions

Since the tool was tested among DM patients, it may not be generalizable to other diseases. The absence of test and retest reliability testing may mean low consistency and reproducibility of the results across a time interval. Therefore, we acknowledge that it may require some more refinement. On a positive note, however, although it sets the groundwork for further studies, the tool was derived de novo, thus it represents (captures) the views of providers and patients in the study context. Actually, the tool measures the important elements that underlie the PCC construct from both patient and provider perspectives. The process that followed was traceable and showed scientific rigor. The tool exhibited adequate psychometric properties, specificity, and sensitivity to discriminately assess PCC in this study's context. I, therefore, conclude that the tool suffices as an operational framework for the measurement of PCC for the subsequent phase of the study.

Recommendations for future research

While the authors acknowledge the need for further refinement of the tool and subsequent adaptation for other settings, it is a good starting point for quality improvement efforts in PCC implementation in Malawi.

CHAPTER 8: PAPER V

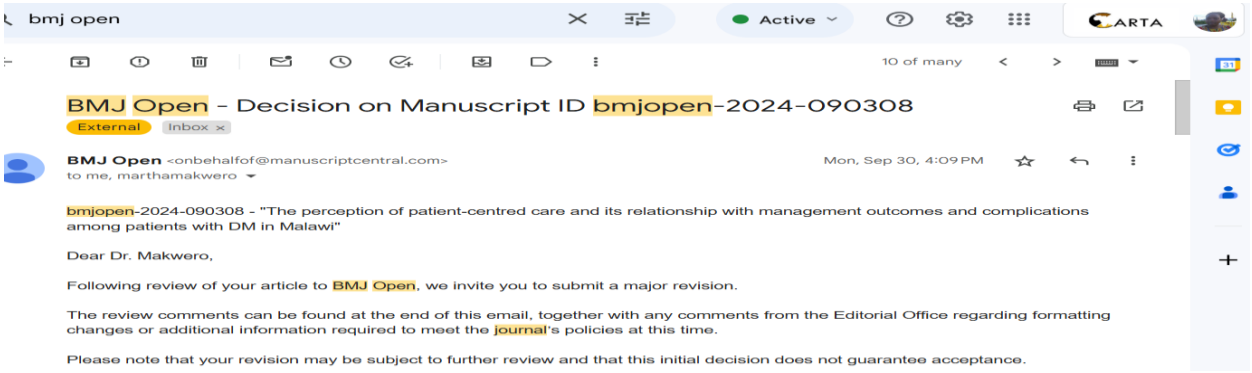
The perception of patient-centred care and its relationship with management outcomes and complications among patients with DM in Malawi

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Abstract

Background: Patient-centred care (PCC) is associated with better experiences for chronic care encounters and better outcomes, yet its assessment and resultant management outcomes have not been well-documented in Malawi. As Malawi strives to institutionalize PCC in its quality-of-care initiatives, documenting its correlates and outcomes is a good starting point in the

implementation and advocacy of PCC among chronic care patients, particularly those living with Diabetes Mellitus (DM)

Aim: We sought to assess the level of diabetic patients' perception of PCC and its relationship to self-efficacy, adherence, and glycaemic control among patients with DM.

Research Design and Methods: This was a cross-sectional analytical study. We assessed the level of perception of PCC and its correlation with self-efficacy, adherence, and long-term glycaemic control among patients with DM during medical encounters in Malawi. We used K-means clustering, linear and logistic regression, and path analysis in the analysis.

Results: Overall, the mean score for the perception of PCC was 62.86 (SD 14.78). The study highlighted two groups of patients who had statistically distinct mean perception of PCC scores of 51.6 (7.8) vs 77. 1(7.2) out of a possible 92. The difference between the two means was statistically significant (p-value <0.001). More patients (n=234 out of 436) 55.7% belonged to the cluster with an average score of 51.56, highlighting that more patients perceived less (poor) PCC and that low perception was more prominent in the patient individualization and involvement subscale. Path analysis showed that female sex and those with the presence of complications had lower PCC scores than males and those without complications. We found a non-significant relationship between PCC and self-efficacy. Having tertiary education was associated with a 6.4 increase in efficacy scores (β = 6.36; 95% CI: 1.96 to 10.76, p-value <0.05). Both PCC and self-efficacy were positive predictors of adherence independently. Having perceived higher PCC scores was associated with a marginal 0.03-point increase in one's adherence scores (β = 0.03; 95% CI: 0.01 to 0.04, p-value <0.001). The effect of efficacy on adherence was of similar magnitude. Self-efficacy and adherence were both positive predictors of blood sugar control independently. Better self-efficacy was associated with a 0.03 unit decrease in the level of HbA1c (β =-0.03; 95% CI: -0.04 to -0.022, p-value <0.001).

Additionally, as adherence scores went higher, there was a 0.15 unit decrease in HbA1c (β = -0.15; 95% CI: -0.25 to -0.02, p-value <0.05).

Conclusion: Although this study did not find a direct correlation between Patient-Centred-Care (PCC) and glycaemic control, it has demonstrated that PCC medical encounters could potentially improve glycaemic control by enhancing patients' adherence to their diabetes management plans. Even though PCC is not an end in itself, medical encounters that prioritize good relational ambience, patient involvement, and capacitation are promising interventions in DM care, especially for patients with or at risk of DM complications. The general lack of patient individualization and involvement elements found in the medical encounters in our study could explain why PCC hardly has an impact on self-efficacy. The study highlights the importance of PCC in DM patient management and outlines important innovative adaptations towards transforming medical education to equip and appraise interpersonal skills that have an impact on patient-reported experiences and outcomes.

Introduction

Patient-Centred-Care (PCC) in medical encounters is associated with better experiences of care and outcomes, yet the extent to which patients perceive PCC and its associated outcomes have not been well-documented in healthcare reform literature(16). Literature, which is largely from high-resourced contexts, represents documentation concerning objective assessment of PCC and causal studies that highlight its value in routine care(42,43,48,53,103,191). Some of these studies have highlighted the causal links and how PCC can impact patient-reported experiences and mediate outcomes such as adherence to care medication, lifestyle, appointment keeping, and glycaemic control in the chronic care context (48,53,54). While these studies may be high quality, there is a scarcity of studies on such kinds of objective assessment and causal links between PCC and management outcomes in LMIC context such as Malawi, particularly among

chronic care patients, where such care approaches could make a difference in patient management(7,16,56).

Perception refers to the way in which a construct is regarded, understood, or interpreted and, ultimately, experienced by the respective actors(192). Individual actors' sociodemographic characteristics, culture, prior experiences, and disease conditions have the potential to shape perceptions about PCC (41). While debate regarding whose perceptions between health care providers or users matter in the assessment of PCC is on-going, studies have shown that measuring patients' perceptions of PCC is a reliable gauge of the delivered of care, and its responsiveness(38). Evidence suggests that patients' perceptions are more predictive of outcomes than are providers' perceptions and interaction observation (38,41,43,193). Therefore, in any context, the heavy inclination on patients' perceptions in assessing what matters in PCC and to what extent it is being delivered is justifiable since they are beneficiaries and the central object of care.

As an approach to care, PCC entails that patients are active participants in their care and that healthcare systems and their respective teams respond to patient needs and preferences. Patient-centred care is underpinned by a functional provider-patient interaction during medical encounters (59). In the Malawi context, PCC is conceptually understood as an expected care process that incorporates warm patient reception, where the healthcare provider consciously aims to reduce the patient-HCP power gap to harness a good long-term relationship. This creates a conducive atmosphere that allows gathering of information that holistically identifies the individual's specific problems and all possible interacting factors, ensuring timely access to care and medication (170). Such interaction thrives within different organizational layers, namely individual provider-patient interaction, institutional and broader system, and contextual levels(11,28,31) .

Patient-centred care complements the biomedical aspects of care by facilitating the attainment of better patient-reported experiences and health status outcomes(42,56,110). Documented evidence on PCC outcomes is not consistent because of poor conceptualization of PCC and challenges with randomization of the studies, however, the results on the same are still largely promising(103). Some outcomes include patient satisfaction, perceived quality of care, patient adherence to management plans, reduced emergency visits, complications, patient empowerment, and self- efficacy(42,65,103). Attainment of such outcomes is affected by patient factors, HCP and contextual factors. Likewise, pathways linking PCC to quality outcomes may not be direct but through intermediary outcomes or factors (52).

Amidst increasing NCDs burden and its associated multi-morbidity, the growing complexity of management plans and rising patient' expectations, care delivery needs to shift from the traditional acute, episodic, and biomedical models to embrace more PCC approaches. In the latter, provider-patient encounters are capable of integrating both technical and interpersonal aspects of care , thereby, better placed to dealing with biopsychosocial patient demands over time with the provider as a resource (8). Furthermore, emphasis should be placed on the fact that, such interactions should foster partnerships with patients, leveraging their capabilities towards individual and population health promotion(8). This being the case, PCC interactions would be fundamental to quality management of chronic patients, especially in limited resource contexts such as Malawi's, particularly in this era of growing chronic NCDs(5). Thus, interactional elements of medical encounters ought to be given due attention, assessing their value in impacting outcomes explored.

While Malawi in its Quality Management Directorate (QMD) for the health sector and the non-communicable disease and injury (NCDI) policies strive to improve the delivery of quality care through people engagement and consideration of patients' perspectives in care design and

delivery. Current efforts in this area are, however, found wanting(5) Actually, documentation of perceptions about the quality of received DM care is sparse (16,25,110). The current QMD efforts have focused on suggestion boxes, promotion of patient charters, and patients' satisfaction surveys, which do not effectively elicit patients' perceptions towards care design and delivery, thereby falling short of allowing safe spaces for patients to be effective participants in care(12,22). It is, therefore, imperative to assess patients' perceptions of PCC in the chronic care context and its associated factors in order to adequately inform the implementation of the set policies. The study, therefore, aimed to assess the extent of the perception of PCC and its correlates among patients with DM as a case study.

Aim

To assess the extent to which patients with DM in Malawi perceive PCC during their medical encounters and its relationship to self-efficacy, patient adherence to management care plans, and glycaemic control.

Methods

Study design and setting

This was a quantitative observational analytical study. We collected data from DM clinics in two central hospitals (Queen Elizabeth and Zomba) and two district hospitals (Chikwawa and Mulanje).

Study Population and sampling

Our study population consisted of patients with DM seeking care at DM clinics. We employed simple, convenient sampling to achieve high generalizability and representativeness to the population under study(194) . Again, convenient sampling within the DM clinics facilitated the

ease of finding participants with the inclusion criteria. Being an observational study that was comparing two independent means (PCC clusters), the sample size for the study was based on the assumption that the effect size (ES) for the difference in adherence between two clusters was 0.16 among diabetics (60)**.** The study assumed an alpha value of 5% and a minimum power of 80%. To offset some sample dependence that may exist in the clinics, we scaled the sample size by a design effect of 1.5(195). Accounting for a 10% non-response rate, the final sample size was 703. However, we only managed to get 607 due to the Covid-19 pandemic as DM clinics were running half full. Less than 10% response rate was registered.

All subsequent patients, who accessed DM care from providers between September and December 2021 were approached to participate. Those who were less than 18 years old, those too unwell to respond, and those who patronized the clinic for less than six months were excluded from the study.

Data collection tools and variable scoring

Patient centred care

Patient centred care was collected using a locally generated and validated tool (Appendix1). The tool had 23 Likert-type, time bound five-point Likert scale; The scores were as follows: - one=never, two=occasionally, three=often, four=all the time and five was assigned to a null answer such as “no comment” or “I don’t know”. The tool had three subscales, namely relational ambience (ten items), individualization and shared decision-making (seven items), and organizational subscale (six items). The tool exhibited acceptable reliability and validity in psychometric properties, with a Cronbach’s alpha of 0.94.

Self-efficacy

Self-efficacy was measured using the Stanford self-efficacy for diabetes tool (Appendix 2). This 8-item tool had high internal consistency with Cronbach alpha scores of 0.828 (n=189 DM patients). The tool has been adapted for use in Malawi with DM patients in a similar population and it was shown to be suitable (94). It has a 10-point numerical scale and the rating used was one to ten, depicting the least and most confidence in patients' ability to perform certain tasks related to DM self-care, including dealing with hypoglycaemic states (93).

Adherence to management plans

Adherence was measured using an adapted 10-item Hill-Bone compliance tool that uses a time bound 4-point Likert scale (95), ranging from 1 "none of the times" to 4, "All of the time" (Appendix 3). Although the tool was developed for hypertension, it was adapted for DM care because the two conditions share similar care components, namely, adherence to medication, lifestyle modification, and appointment-keeping. The tool was preferred because it was validated in a comparable cultural setting; a black South African population with a Cronbach alpha score of 0.79(95) . To conform to the rest of the variables in the study, the scoring in the Hill-Bone adherence scoring was reversed. Thus, one was the least desirable response, and 4 was the best score in PCC and adherence, with 1 representing "never" and 4 representing "always".

Long-term glycaemic control

Long-term glycaemic control was measured using point of care HbA1c test. The rapid test has good acceptability, is easy to use, and is stable in Malawi's temperatures. The test was used in a comparable situation in the country(19).

Diabetic comorbidities and complications

Reported co-morbidities and diabetic complications were assessed as a proxy of DM control(96). Participants were asked to report through recall if they had experienced any of the DM complications in the last six months, and the response was a "Yes" or "No". We considered the following DM complications: eye problems, neuropathy, kidney problems, DM limb ulcers and amputations, hypoglycaemia, hyperglycaemia, heart problems, loss of consciousness, and erectile problems(96).

Quantitative data management and analysis

General data management

Initial data exploration was done in STATA version 17 to ensure quality, completeness and, to transform some variables, create and assign labels. We explored the data elements for normality, appreciated the patterns and assumptions, and then applied the required constraints. Duplicates were removed while missing data and, "not applicable", "no comment" and/or "don't know" responses, which were less than 5% of the total dataset, were assigned a Mode because they occurred at random and do not really affect the variance of string object data (177). Extreme outliers were identified using box plots, and seven entries were removed, representing 1.2% of the total dataset. The data normality checks helped to ascertain the most suitable inferential statistics to be used.

Sociodemographic and disease characteristics

Descriptive analysis was done on socio-demographic and disease characteristics and PCC scores. Summarization was done using means, medians, and standard deviations or medians for continuous data, while frequencies and proportions were used for categorical data and, presented in tables. Inferential statistics of associations between dependent and independent variables such as socioeconomic variables, comorbidities, complications, self-efficacy, adherence scores, and

reported DM complications were performed. The results were expressed as p-values fixed at <0.05 and confidence intervals(196). For descriptive analysis, presence of complications and comorbidities was analyzed as a binary variable (present or absent). Linear and logistic regressions, as well as structural equation models, were further used to assess relationships.

Patient-centred care scoring and categorization

We used unsupervised K-means cluster analysis to identify the number and properties of the PCC clusters among our study population using R-Studio version 4.2.3. The clustering allowed us to probabilistically discriminate patients who perceived low and high PCC scores based on responses to 23 items in the PCC scale. The individual patient classification into either high or low PCC was then used to determine the effect on self-efficacy and health outcomes, viz-a viz adherence and glycaemic control. The R output was transferred back into STATA and, in turn, used to determine if the means between the two clusters were statistically distinct using an independent t-test. The PCC scores were, therefore, reported as both categorical variables (frequencies and percentage frequencies were used) and as continuous variables (means, standard deviation, minimum-maximum and interquartile range were used) for the initial exploratory analysis. The clusters were labelled high and low depending on the mean values for individual patients identified through K-means cluster analysis. This categorization highlighted the extent to which PCC delivered might be adequate apart from determining the level at which it makes statistical differences in outcomes, a dimension that is essential in mediating outcomes clinically(53,54).

The scores were aggregated on a global scale, subscales, and per individual. The possible minimum and maximum PCC scores were 23 and 92, respectively, for an individual.

Self-efficacy scoring

For self–efficacy, 1 meant the least confident, while 10 denoted the most confident. Self–efficacy scores per individual ranged from 8-80 and were analyzed as a continuous variable in order not to lose detail and were summarized as aggregates using means, standard deviation, median and interquartile range.

Adherence to management scoring

For adherence, the mean scores per individual ranged from 10-40 and they were analyzed as a continuous variable. Thus, the possible maximum and minimum adherence scores were 10 and 40 respectively.

Long-term glycaemic control measures

The HbA1c machine provided a number from 4-13.8%. For clinical descriptive categorization purposes, HbA1c <=7% was considered good control while >7.1% was considered poor control (the higher the number, the poorer the glycaemic control)(21). However, for regression and path analysis we analyzed long-term glycaemic as a continuous variable.

Inferential statistical analysis

Univariate and multivariate regression analysis

We used regression analysis to find the strength and direction of the link between how patients felt about PCC, on the one hand, and outcome variables such as self-efficacy, adherence, and glycaemic control, on the other. The outcome variables were related to the patient's sociodemographic and disease profiles. Logistic regression was used for PCC since it was analyzed as a binary variable. In this study, the PCC clusters that have been derived from the K-means clustering analysis are presented as a binary variable of either poor or better individual average scores of the perception of PCC. For self-efficacy, adherence, and glycaemic control

(HbA1c); which were all analyzed as continuous variables using linear regression. We chose adherence as the main outcome variable because it is a cornerstone to the attainment of patient outcomes, mainly glycaemic control and, prevention or delay of DM complications(53,54,60)

In the light of the complex nature of the PCC construct and its covariates, and in order to further describe the effect of potential confounders in the pathway between PCC and socio-demographic characteristics, disease profiles, self- efficacy, adherence, and DM complications, we used a multivariate logistic regression model adjusting for other variables; and the t-test with chi-square and p-values for levels of significance at <0.05(90). A conceptual framework highlighting the possibility and direction of relationships between variables and their mediating factors guided the inferential statistical analysis. We reported unadjusted (OR) and adjusted (aOR) odds ratios for logistic regression and unadjusted and adjusted beta (β) coefficients for linear regression. We ran an adjusted regression analysis for individual factors or subscales and the aggregate scale.

It is important to note that the assumption for using linear regression was based on data being normally distributed and that the observations under review were independent of each other and were met before linear regression was used. Logistic regression was used on the premise that there was no significant collinearity among the independent variables and that it was assumed that the independent variables were linearly related to the dependent variables. Additionally, all influential outliers were removed from the dataset(197).

Path analysis to show the interrelationships between PCC, self-efficacy and adherence

To further clarify the magnitude and significance of predicted and observed relationships among the variables, we conducted a path analysis. A path model was iteratively built based on the theoretical hypothesis of the nature and directions of associations obtained from the initial regression output. The model was iteratively adjusted based on the magnitude of the modification indices and theoretical judgement(90). Our endogenous variables were PCC,

efficacy, adherence, and glycaemic control (as continuous variables), while exogenous variables included the sociodemographic and disease profile characteristics that were shown to affect the exogenous variable in the normal regression models. All endogenous variables were fed into the model as continuous variables. These exogenous variables included sex, age, tertiary education, type of diabetes and duration of disease. The path analysis β coefficients were used to judge the magnitude and direction of the predicted effect between the exogenous and the endogenous variables.

Model goodness-of-fit and effect size

We used show to determine goodness of fit for the binary regression models with a Hosmer-Lemeshow goodness-of-fit chi-square value of > 0.05 indicating that the regression models used in the analysis fitted well with the data (85). To determine if the hypothesized structural equation model fitted our data and the theoretical model, we assessed the following goodness of fit (Gof) indices of fit and their respective acceptable values; CFI: >0.9, TLI > 0.9, SRMR< 0.08, RMSEA <0.05.

The R^2 was used to determine how much of the effect on the endogenous variables is attributable to the predictor variables in the path analysis model. The R squared of> 10% was deemed acceptable in empirical social science research as long as the linear relationships were statistically significant(198).

Results

Participants' sociodemographic characteristics and disease profile

The study population had significantly more females (n= 390; 65%) than males. The mean age for males (51.6 years; SD 14.5) was significantly lower than that of females (54.5 years, SD 13.8). Nearly half (46.7 %) of the respondents had attained at least primary education. There

were significantly more females (n=91, 23.3%) with no formal education compared to males (n=11,5.3%). The majority of respondents had type 2 DM (n=520, 86.8%) and the rest had type 1 DM.

The respondents had their DM disease for an average duration of 6.9 years (SD 5.8) and had used the index facility for nearly the same period of time; 6.3 years (SD 5.5). The majority of patients (n=520, 86.7%) were type 2 diabetes and the most common comorbidities were hypertension (n=364, 60.8%) followed by HIV (n=93, 15.5%). Overall, there were significant levels of reported complications by the respondents. Numbness of the feet was the commonest reported complication (n=465, 77.6%), followed by visual problems including blindness (n=315, 52.6%), and DM related limb ulcers or amputations (n=161, 26.9). The study reported high levels of poor long-term glycaemic control with 69.5% of the respondents having HbAc1>7%.

The perception of PCC, self-efficacy and adherence scores

The unsupervised K-means cluster analysis highlighted two distinct groups of patients with different scores of PCC. Refer to Figure 8.1

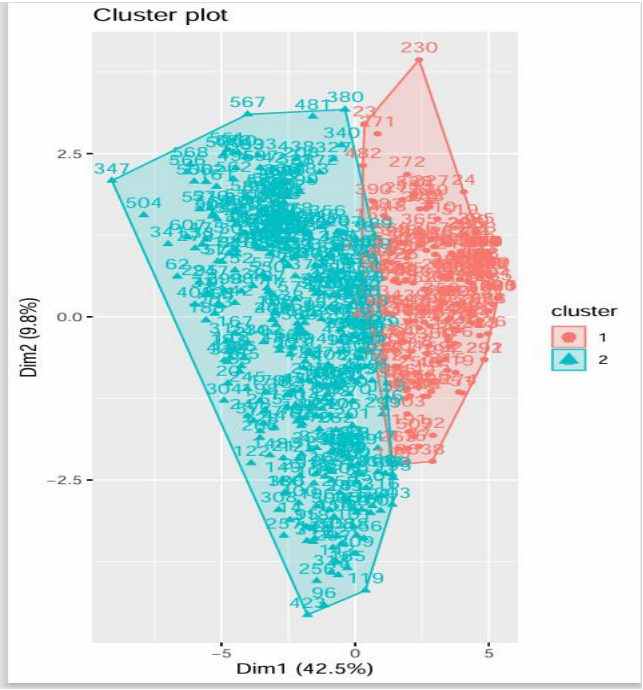


Figure 8.1. Cluster Plot

The first group had statistically significantly lower PCC scores than the second with mean scores of 51.6 (7.8) vs 77.0 (7.2) out of a possible score of 92 (p-value <0.001). More patients (55.7%, n=234 over436) belonged to the cluster with an average score of 51.56. Overall, slightly over half of the patients perceived low PCC during medical encounters highlighting inconsistencies in the delivery of PCC. Women were more likely to experience low levels of PCC than men (aOR-.48; 95% CI-.86 -.10, p-value <0.05). Further segregation of the perception of PCC by age, disease type, duration of disease, and facility did not show any significant differences (see table 8.1)

Table 8.1: The PCC clusters and their relationship to patient and disease profile and outcomes

		PCC CLUSTERS			
VARIABLE	**Characteristic**	**High**	**Low**	**Overall**	**P-Value***
PATIENT CHARACTERISTICS					
NO. OF PATIENTS	n (%)	193(44.2.)	243 (55.8)	434 (100)	-
PCC SCORES	Mean (SD)	77.1(7.2)	51.6 (7.8)	62.9(14.8)	**<0.001**
INTERQUARTILE RANGE(MEDIAN)	IQR (median)	63-88(79)	22-64(80)	22-88(61)	-
SEX (N%)	M	70 (36.3)	67(27.6)	137(31.4)	**0.048**
	F	123(63.7)	126(72.4)	299 (69.6)	-
AGE (YEARS)	Mean (SD)	53.5	53.7	53.6	0.912
LEVEL OF EDUCATION N (%)	None	32(16.6)	51(20,9)	83(19.1)	0.243
	Primary	88(45.6)	117 (48.1)	205 (47.1)	-
	Secondary	54(28.4)	60 (24.6)	114(26.2)	-
	Tertiary	19(9.4)	15 (6.2)	33(7.6)	-
TYPE OF DIABETES MELLITUS (%)	Type 1	26(13.5)	33(13.6)	59(13.5)	**0.004**
	Type 2	167(86.5)	210(66.4)	377(86.5)	-
FACILITY LOCATION N (%)	Urban	119(61.7)	142(58.4)	261(75.4)	0.465
	Rural	74(38.3)	101(41.6)	175(24.6)	-
DISEASE CHARACTERISTICS					-

TYPE OF MEDICINE N (%)	OHA	151(78.2)	183 (75.4)	334(76.6)	0.370
	Insulin	35(18.1)	43 (17.7)	78(17.9)	-
	OHA and Insulin	7(3.7)	15 (6.1)	22 (5.0)	-
	None	0(0)	2 (0.8)	2(0.05)	-
DURATION OF DISEASE (YEARS)	Mean (SD)	5.7(4.9)	6.3(5.5)	6.3(5.2)	0.039
DURATION OF USE OF CURRENT FACILITY(YEARS)	Mean (SD)	6.4(5.6)	7.3(6.0)	7.0(5.8)	0.112
COMORBIDITIES: HIGH BP	No	183(94.8)	227(93.2)	410(94.0)	0.387
	Yes	10 (5.2)	16(6.8)	26(6.0)	-
COMORBIDITIES: OSTEOARTHRITIS	No	191(98.1)	230(94.5)	421(96.6)	**0.014**
	Yes	2(1.9)	13(5.5)	15(4.4)	-
LIMB ULCERS AND AMPUTATIONS	No	163(84.5)	140(57.6)	303(69.4)	**<0.001**
	Yes	30(15.5)	103(42.4)	133(29.6)	-
VISION PROBLEMS & BLINDNESS	No	112(58.0)	91(37.4)	203(46.6)	**<0.001**
	Yes	81(42,0)	152(62,8)	233(53,4)	-
OUTCOMES					-
SELF-EFFICACY	Mean (SD)	54.9(16.0)	57.6(14.8)	56.1(14.8)	**0.015**
ADHERENCE	Mean (SD)	38.2(1.6)	33.7(2.4)	37.9(2.1)	**0.008**
GLYCAEMIC CONTROL	Poor	134(69.4)	172(70.8)	305(88.2)	0.091
	Good	59(30.6)	71(29.2)	130(11.8)	-

SD=Standard Deviation, *t-test for continuous variables, and chi-square test for categorical variables.

The factors that were least perceived were: - patients' involvement in care and organization of care with a comparatively low score. The individualization and involvement subscale had only 40% of patients experiencing the high mean scores compared to 55.7% for the global scale (Figure 8.2)

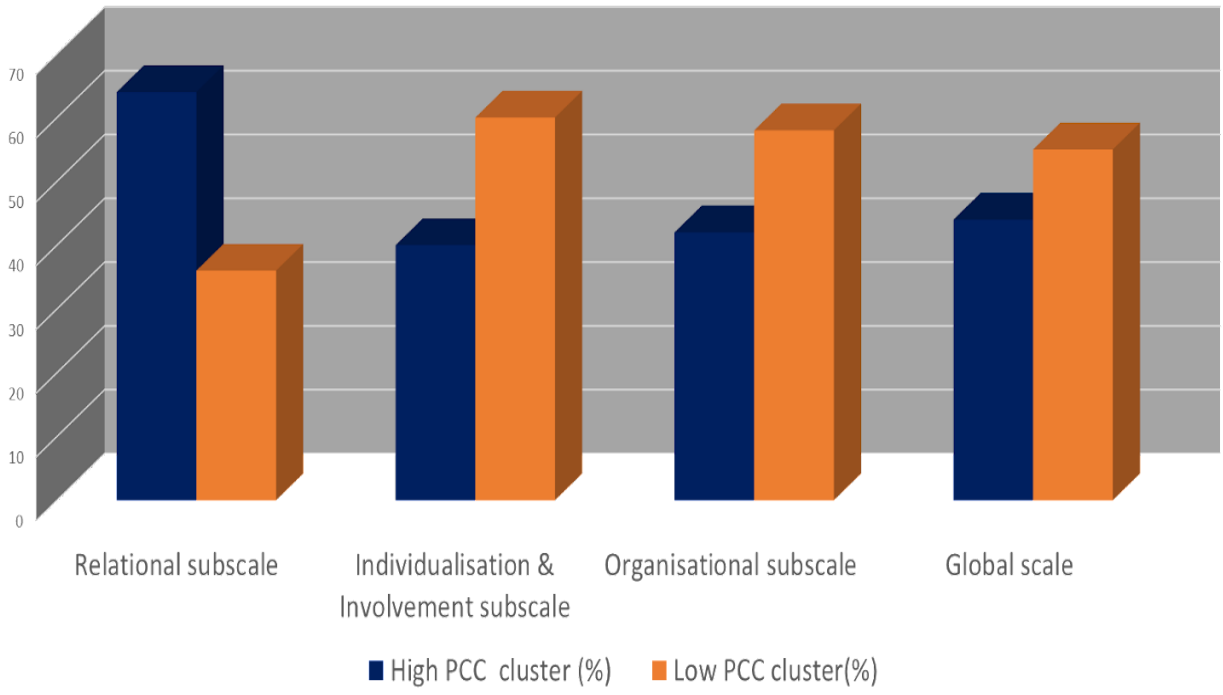


Figure 8.2: Showing the statistics for the global PCC scale and individual subscales

The efficacy scores ranged from 17-80 with a median score of 57 (mean 56.1 SD 14,6). The reported levels of adherence scores ranged from 23-40 with median 38 and mean of 37.8 (SD 2,1) respectively.

Univariate and multivariate regression analysis

The perception of PCC

Table 8.2 shows adjusted and unadjusted relationships between PCC and some sociodemographic characteristics, disease profile, comorbidities, self-efficacy, adherence and glycaemic control.

In the multivariate model, patients' perception of PCC was significantly associated with adherence to management plans, serious DM complications with p-values <0.05. Although the odds of perceiving low PCC were 1.49 higher if one were female compared to male (aOR=1.49;

95% CI: 1.00 to 2.24, *p*-value <0.05) in the univariate model, after adjusting for other variables the relationship was no longer significant. The study also reported significantly higher odds of perceiving low PCC among patients who reported to have osteoarthritis (aOR=7.72 95% CI: 1.62 to 37.38 *p*-value <0.005,) and also reported limb ulcers or amputations and, comorbidities such as joint problems (aOR =4.67 95% CI 0.2.66 to 4.67 *p*-value <0.001) compared to those who did not report these complications. There was no significant relationship between the perception of PCC with age, education status, the type of DM, type of medication and facility location (whether rural or urban).

The odds of experiencing low PCC were 1.02 higher if your self-efficacy was high (aOR=1.02 95% CI: 1.00 to 1.04 *p*-value <0.005), and the odds lower if you were adherent (aOR=0.75 95% CI: 0.66 to 0.85 *p*-value <0.001). See Table 8.2.

Table 8.2: Univariate and multivariate regression analysis of the perception of PCC

		UN-ADJUSTED OR				ADJUSTED OR			
		OR	**p-value**	**95% CI**		**aOR**	**p-value**	**95% CI**	
PATIENT CHARACTERISTICS									
SEX	Male (Ref)								
	Female	1.49	0.053	1.00	2.24	1.52	0.101	0.92	2.51
AGE	Years	1.00	0.912	0.99	1.01	1.00	0.616	0.98	1.01
LEVEL OF EDUCATION	None (Ref)								
	Primary	0.83	0.496	0.55	1.41	0.71	0.259	0.39	1.29
	Secondary	0.70	0.219	0.40	1.24	0.54	0.085	0.27	1.09
	Tertiary	0.50	0.089	0.22	1.11	0.40	0.070	0.15	1.08
FACILITY LOCATION	Urban (Ref)								
	Rural	1.14	0.496	0.78	1.68	0.98	0.948	0.62	1.57
DISEASE CHARACTERISTICS									
TYPE OF DIABETES MELLITUS	Type 1 (Ref)								
	Type 2	0.99	0.974	0.57	1.72	0.95	0.922	0.38	2.43
TYPE OF MEDICINE	OHA (Ref)								
	Insulin	1.01	0.957	0.62	1.66	1.37	0.469	0.58	3.22
	Insulin & OHA	1.77	0.226	0.70	4.45	2.15	0.144	0.77	6.03
DURATION OF FACILITY USE	Years	1.04	**0.042**	1.00	1.08	1.02	0.288	0.98	1.07
COMORBIDITIES									
HIGH BLOOD PRESSURE	No (Ref)								
	Yes	1.29	0.540	0.57	2.91	1.01	0.984	0.39	2.61
OSTEOARTHRITIS	No (Ref)								
	Yes	5.34	0.028	1.20	24.22	7.72	0.011	1.60	37.38

HIV ON ANTIRETROVIRAL TREATMENT	No (Ref)								
	Yes	0.67	0.483	0.22	2.04	0.48	0.355	0.10	2.29
COMPLICATIONS									
NUMBNESS OF FEET	No (Ref)								
	Yes	1.54	0.070	0.97	2.46	1.14	0.656	0.65	2.01
LIMB ULCERS & AMPUTATIONS	No (Ref)								
	Yes	4.00	**<0.001**	2.51	6.36	4.67	0.000	2.66	8.21
VISION PROBLEMS & BLINDNESS	No (Ref)								
	Yes	2.31	**<0.001**	1.60	3.40	1.52	0.078	0.95	2.43
OUTCOMES									
SELF-EFFICACY	Score	1.02	**0.016**	1.00	1.03	1.02	0.016	1.00	1.04
ADHERENCE	Score	0.88	**0.009**	0.79	0.97	0.75	0.000	0.66	0.85
GLYCAEMIC CONTROL	Score	1.00	0.901	0.99	1.01	1.00	0.741	0.99	1.01

Self-efficacy

In the adjusted regression model, being female was associated with low self-efficacy with having a 2.99 unit decrease in self-efficacy scores (β=-2.99 95% CI: -5.89 to-0.07, p-value<0.05) while having a tertiary level education was associated with an 8.76 - point increase in efficacy scores (β=8.76 95% CI: 3.08 to 14.4, p-value <0.05). Reported visual complications are paradoxically associated with 3.45-point increase in self-efficacy scores compared to none (β=3.45, 95% CI: 0.66 to 6.25, *p*-value<0.05). The study did not find any relationship between age, facility location, type of DM and its treatment (See table 8.2).

The perception of low PCC was associated with a 3.13-point increase in self-efficacy scores (β=3.13 95% CI: 0.33 to 5.94, p-value <0.05). Those that portrayed better adherence were also likely to have better self-efficacy (β=2.0, 95% CI: 1.32 to 2.69, *p*-value <0.001) while better glycaemic control (lower HbA1c levels) was associated with a 0.96-point decrease in self-efficacy as well (β=-0.96, 95% CI: -1.46 to -0.45, *p*-value <0.001). Refer to Table 8.3

There was no significant relationship between self-efficacy and DM type, its treatment, comorbidities and other complications.

Table 8.3: The Univariate and multivariate analysis for self-efficacy

		UNADJUSTED				ADJUSTED			
		β	**p-value**		**95% CI**	**β**	**p-value**		**95% CI**
PATIENT CHARACTERISTICS									
SEX	Male (Ref)								
	Female	-3.20	**0.012**	-5.70	-0.70	-2.99	0.045	-5.89	-.07
AGE (YEARS)		-.025	0.576	-0.11	0.06	-	-	-	-
LEVEL OF EDUCATION	None (Ref)								
	Primary	1.54	0.376	-1.87	4.94	2.06	0.251	-1.47	5.60
	Secondary	4.78	**0.011**	1.12	8.45	3.61	0.075	-.36	7.59
	Tertiary	7.86	**0.004**	2.56	13.16	8.76	0.003	3.08	14.44
TYPE OF DIABETES MELLITUS (%)	Type 1(Ref)								
	Type 2	3.79	0.039	0.19	7.39	1.67	0.553	-3.86	7.21
FACILITY LOCATION	Urban (Ref)								
	Rural	-0.78	0.539	-3.25	1.70	-	-	-	-
DISEASE CHARACTERISTICS									
TYPE OF MEDICINE	OHA (Ref)								
	Insulin	-3.86	**0.018**	-7.06	-.66	-1.12	0.660	-6.11	3.87
	Both Insulin & OHA	-6.19	**0.028**	-11.73	-0.66	-4.97	0.115	-11.15	1.21
DURATION OF CURRENT FACILITY (YEARS)		0.23	0.051	-.00	0.45	0.17	0.187	-0.08	0.41
COMORBIDITIES: HIGH BP	No (Ref)								
	Yes	0.07	0.953	-2.39	2.54				

COMORBIDITIES: OSTEOARTHRITIS	No (Ref)								
	Yes	-3.96	0.176	-9.70	1.78	-	-	-	-
LIMB ULCERS & AMPUTATIONS	No (Ref)								
	Yes	7.27	**<0.001**	4.64	9.91	2.91	0.080	-0.35	6.16
VISION PROBLEMS & BLINDNESS	No (Ref)								
	Yes	3.84	**0.002**	1.44	6.23	3.45	0.016	0.66	6.25
<u>OUTCOMES</u>									
SELF-EFFICACY	Score								
ADHERENCE	Score	2.03	**<0.001**	1.48	2.58	2.00	0.000	1.32	2.69
GLYCAEMIC CONTROL	Score	-1.21	**<0.001**	-1.66	-0.77	-0.96	0.000	-1.46	-0.45
PERCEPTION OF PCC	High (Ref)								
	Low	3.30	**0.025**	0.42	6.17	3.13	0.029	0.33	5.94

Adherence to DM management plans

In a univariate linear regression, having type two DM was associated with 0.91 unit increase in adherence scores (β=0.91; 95% C: 0.13-1.70, p-value <0.05). Being female was significantly associated with an average increase of 0.31 increase in the odds of having better adherence scores than male counterparts (β =0.31; 95% CI 0.017-0.74 p- < 0.05). However, when we adjusted for other variables, the relationship was no longer significant. Likewise, those patients who were older and had better adherence scores with every increase in age (years) reported corresponding average increase of 0.031 in adherence scores (β =0.03 95% CI: 0.013-0.03, p-value <0.001). See table 8.4 below

Having experienced low PCC levels in medical encounters also significantly associated with poorer adherence with a corresponding unit decrease of -0.88 in adherence score (β=-0.88; 95% CI: -0.26 to -0.49, p-value <0.001) as PCC score goes down. Patients that portrayed better efficacy scores had better adherence with every unit increase in self-efficacy score being related to 0.04 unit increase in adherence score (β =0.04 955, CI 0.03-0.05, p-value <0.001). There was a marginal unit decrease of 0.07 in adherence scores if there were increased HbA1c values (β=-0.07; 95% C: -0.15 to -0.00, p-value <0.001). Thus, the better the adherence score, the better the glycaemic control. Notably, level of education and hospital location did not have any significant relationship with being adherent to management care plans.

Table 8.4: Showing univariate and multivariate analysis of adherence

		UNADJUSTED				ADJUSTED			
		β	**p-value**		**95% CI**	**β**	**p-value**		**95% CI**
PATIENT CHARACTERISTICS	**Category**								
SEX	Male (Ref)								
	Female	0.38	**0.040**	0.017	0.74	0.31	0.120	-0.08	0.70
AGE (YEARS)	Years	0.03	**<0.001**	0.013	0.03	0.01	0.074	-0.00	0.03
LEVEL OF EDUCATION	None (Ref)								
	Primary	-.09	0.720	-.57	0.41	-	-	-	-
	Secondary	-0.37	0.174	-.90	0.16	-	-	-	-
	Tertiary	0.01	0.972	-0.76	0.79	-	-	-	-
TYPE OF DIABETES MELLITUS (%)	Type 1(Ref)								
	Type 2	1.08	**<0.001**	0.57	1.60	0.92	0.022	0.13	
DISEASE CHARACTERISTICS									
TYPE OF MEDICINE	OHA (Ref)								
	Insulin	0-.75	**0.001**	-1.21	-0.30	0.48	0.185	-0.23	1.19
	Both Insulin & OHA	-1.34	**0.001**	-2.14	-0.55	0.19	0.666	-.66	1.03
DURATION OF DISEASE (YEARS)	Years	-0.01	0.403	-.04	0.01	-	-	-	-
COMORBIDITIES: HIGH BP	No (Ref)								
	Yes	0.29	0.106	-.06	0.65	-	-	-	-
COMORBIDITIES: OSTEOARTHRITIS	No (Ref)								
	Yes	-1.02	**0.015**	-1.85	-.20	-0.30	0.554	-1.30	0.70
NUMBNESS OF FEET	No (Ref)								
	Yes	0.46	**0.031**	0.04	0.88	0.09	0.708	-0.38	0.56

LIMB ULCERS & AMPUTATIONS	No (Ref)								
	Yes	1.08	**<0.001**	0.70	1.46	1.08	0.000	0.64	1.527181
VISION PROBLEMS & BLINDNESS	No (Ref)								
	Yes	0.06	0.736	-0.29	0.41	-	-	-	-
OUTCOMES									
SELF-EFFICACY	Score	0.04	**<0.001**	0.03	0.05	0.04	0.000	0.03	0.05
GLYCAEMIC CONTROL	Score	-.16	**<0.001**	-0.22	-0.09	-0.07	0.049	-0.15	-0.00
THE PERCEPTION OF PCC	High (Ref)								
	Low	-0.41	**0.045**	-0.81	-.01	-0.88	0.000	-0.26	-0.49

Long-term glycaemic control

Notably, those that had better glycaemic control been older, had better adherence and higher self-efficacy scores (*p*-value <0.01) in the unadjusted model although the relationship was no longer significant after controlling for other variables. The adjusted regression model reported better glycaemic control if you were older (β =-0.04, 95%; CI: -0.07 to -0.02 p-value <0.001). Thus, younger patients exhibited poorer glycaemic control than older patients. There was no significant change in glycaemic control among those who perceived high PCC compared to lower ones. Self-efficacy was the only independent predictor of glycaemic control with a marginal 0.04 unit decrease in HbA1c when efficacy scores increased (β =-0.04 95% CI: -0.06 to -0.02, p-value <0.001). Refer to table 8.5 below.

Although there was a -0.98 unit decrease in HbA1c if one had type 2 DM compared to type 1 DM (β = -0.81; 95% CI: -1.63 to - 0.33, p-value <0.005), after adjusting for other variables, the relationship was no longer significant. Likewise, the type of treatment and presence of complications seemed to correlate with glycaemic control in the unadjusted models but the relationship was not significant after adjusting for other variables.

Table 8.5: Univariate and multivariate regression analysis for glycaemic control

		UNADJUSTED				ADJUSTED			
		β	**p-value**	**95% CI**		**β**	**p-value**	**95% CI**	
PATIENT CHARACTERISTICS									
SEX	Male (Ref)								
	Female	-0.120	0.605	-0.57	0.33	0.17	0.525	-.36	0.70
AGE (YEARS)		-0.035	**<0.001**	-0.05	-0.02	-0.04	0.000	-0.07	-0.02
LEVEL OF EDUCATION	None (Ref)								
	Primary	0.42	0.185	-0.20	1.04	-	-	-	-
	Secondary	0.25	0.460	-0.42	0.92	-	-	-	-
	Tertiary	0.55	0.264	-0.42	1.52	-	-	-	-
TYPE OF DIABETES MELLITUS (%)	Type 1(Ref)								
	Type 2	-0.98	**0.003**	-1.63	-0.33	0.80	0.139	-0.26	1.85
DISEASE CHARACTERISTICS									
TYPE OF MEDICINE	OHA (Ref)					-	-	-	-
	Insulin	1.16	**<0.001**	0.59	1.74	0.48	0.319	-0.47	1.42
	OHA & Insulin	1.10	**0.029**	0.11	2.10	0.25	0.674	-0.90	1.39
DURATION OF DISEASE	Years	0.04	**0.046**	0.00	0.08	0.05	0.016	0.01	0.10
DURATION OF USE CURRENT FACILITY	Years	0.04	0.060	-0.00	0.08	-	-	-	-
COMORBIDITIES: HIGH BP	No (Ref)								
	Yes	-0.81	**<0.001**	-3.63	-1.25	-0.38	0.188	-0.96	0.19
COMORBIDITIES: OSTEOARTHRITIS	No (Ref)								
	Yes	-0.47	0.376	-1.51	0.57	-	-	-	-
NUMBNESS OF FEET	No (Ref)								
	Yes	0.05	0.845	-.47	0.58	-	-	-	-

LIMB ULCERS & AMPUTATIONS	No (Ref)								
	Yes	-0.15	0.549	-0.64	0.34	-	-	-	-
VISION PROBLEMS & BLINDNESS	No (Ref)								
	Yes	0-.02	0.942	-0.45	0.42	-	-	-	-
OUTCOMES									
SELF-EFFICACY	Score	-0.04	**<0.001**	-0.05	-0.03	-0.04	0.000	-0.06	-0.02
ADHERENCE	Score	-0.24	**<0.001**	-0.35	-0.15	-0.12	0.084	-0.25	0.02
PERCEPTION OF PCC	High (Ref)								
	Low	-0.16	0.525	-0.67	0.34	-0.28	0.290	-0.80	0.24

The analysis of individual subscales with self-efficacy, adherence and long-term glycaemic control

With regards to individual subscales, collaborative care was positively associated with adherence (β=0.66; 95% CI-0.04-0.09, p-value <0.05). There was no statistically significant relationship between the relational subscale and the organizational scale with adherence. Notably, there was a negative association between organizational subscale and self-efficacy. Thus, the predicted score of self-efficacies was reduced by a factor of 0.47% if the patient perceived better organizational aspects in their care (β=-0.47; 95% CI-0.79-0.18 p-value <0.001). There was no significant relationship between self-efficacy and perceiving better relational and collaborative aspects in their care. None of the subscales independently showed any significant relationship with glycaemic control. Refer to table 8.6.

Table 8.6: The analysis individual subscales with self-efficacy, adherence and glycaemic control

	Self-efficacy				*Adherence*				*Glycaemic control*			
Subscale	β	p-value	95% CI		β	p-value	95% CI		β	p-value	95% CI	
Relational Ambience	0.08	0.958	-2.36	2.51	0.34	0.59	-0.01	0.07	-1.62	0.385	-5.29	2.04
Individualization and involvement	-1.69	0.163	-4.06	0.69	0.043	0.16	0.078	0.77	-0.77	0.673	-4.35	2.81
Organizational	-5.85	0.000	-8.17	-3.35	-0.03	0.858	-0.38	-0.31	1.29	0.476	-2.27	4.85

Path analysis: The relationship between PCC and other variables

The endogenous variables in this model included the perception of PCC, self-efficacy, adherence and blood sugar level (HBA1c) while the exogenous variables included age, sex sugar type, presence of complications, concomitant hypertension and hospital location (urban Vs. rural). We

had other endogenous variables predicting other endogenous variables such as adherence and self-efficacy in the model (see Figure 8.3).

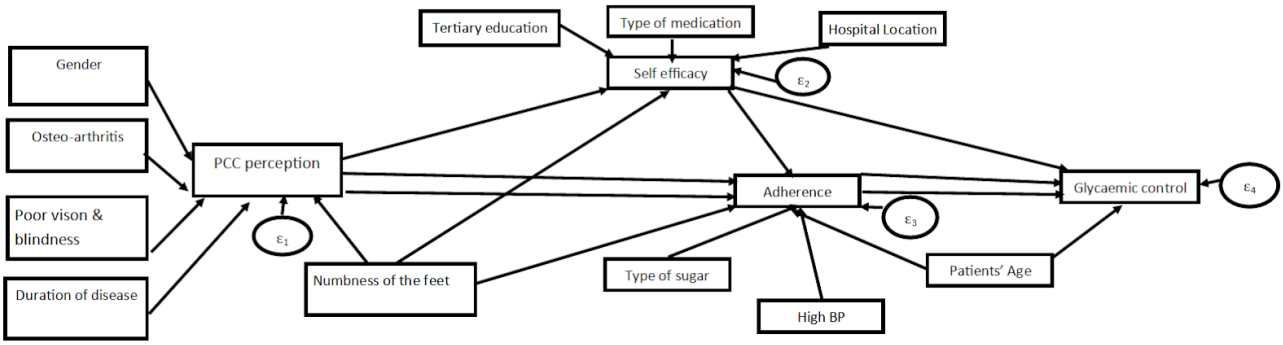


Figure 8.3: Path analysis model showing the statistical and theoretical relationship among variables

The model was guided by observed relationships obtained from the initial regression model outputs. It was iteratively adapted to get maximum goodness of fit indices guided by theoretical plausibility. The statistical coefficients are as shown in Table 8.7 below.

Table **8.7: Showing the nature of relationships, coefficients and p-values between variables**

ENDOGENOUS VARIABLES	EXOGENOUS VARIABLES	BETA COEFFICIENT	P-VALUE	95% CONFIDENCE INTERVAL	
PERCEPTION	Gender(female)	-3.26	0.004	-0.51	-1.01
	Comorbidities	-7.38	0.005	-12.50	-2.27
	Complications	-4.62	<0.001	-6.87	-2.38
	Complications	-8.18	**<0.001**	-10.72	-5.65
	Duration of	-0.17	**0.112**	-0.37	0.04
SELF-	PCC	0.02	0.693	-0.07	0.10
	Complications	7.31	**<0.001**	4.56	10.06
	Level of	6.36	**0.005**	1.96	10.76
	Medication type	-3.18	**0.001**	-5.08	-1.27
	Hospital location	-2.30	0.062	-4.72	0.12
ADHERENCE	PCC	0.03	<0.001	0.01	0.04
	self-efficacy	0.04	**<0.001**	0.02	0.05
	Complications	0.93	**<0.000**	0.54	1.31
	Age	0.02	**0.010**	<0.00	0.03
	Type of sugar	0.49	0.079	-0.06	1.03
	Comorbidities	0.49	0.168	-0.21	1.19
LONG-TERM	PCC	0.01	0.347	0.02	0.01
	self-efficacy	0.03	**<0.001**	0.05	0.02
	Adherence	-0.15	**0.007**	-0.25	-0.04

Age	0.03	**<0.001**	0.06	0.02

Table 8.7 shows that female sex, presence of complications and comorbidities are significant negative predictors of the perception of PCC. There was a predicted 3.26 decrease in the perceiving PCC if one were female compared to male (=β -3.26.95% CI -0.51, -1.01, *p*-value< 0.005). Having reported complications predicted 4.62 decrease in odds of perceiving higher PCC scores (β =-4.62; 95% CI: -6.87, -2.38, *p*-value <0.001).

Although PCC was, theoretically, expected to predict better self-efficacy, we found no significant linear relationship between them (p-value >0.05). The presence of complications, tertiary education seemed to predict better efficacy in this study population. Having a tertiary education predicted a 6.4 increase in efficacy scores (β= 6.36; 95% CI 1.96-10.76, p-value <0.05). Those on complicated management regimes were less self-efficacious with a predicted point reduction of self-efficacy scores of 3.1 if one is moves from OHA to more complicated regimes such as insulin and a combination of both (β= -3.71; 95% CI -5.1, -1.23, p-value <0.05). Hospital location (urban vs. rural) where patients accessed care did not seem to predict any significant differences in self-efficacy.

Both PCC and self-efficacy were positive predictors of adherence independently. Having perceived higher PCC predicted a marginal 0.03-point increase in adherence (β= 0.03; 95% CI: 0.01-0.04, p-value <0.05) The predicted effect of efficacy on adherence was of similar magnitude. Similarly, those that were older, seemed to portray better adherence with every unit increase in age predicting a 0.02 increase in adherence scores (β= 0.02; 95% CI 0.03-0.03, p-value <0.05). Disaggregating PCC perception by factor revealed that the subscale which had patient engagement elements, was associated with adherence to a greater degree (β= 0.07; 95% CI 0.4-0.9, p-value <0.001) than the other two.

Self-efficacy and adherence were independent positive predictors of blood sugar control. Better self-efficacy predicted 0.03 unit increase in the level of HbA1c (β= 0.03; 95% CI:0.04-0.02, p-value <0.001). Additionally, higher adherence scores were associated with a 0.15 unit decrease in HbA1c (β= 0.15; 95% CI:0.25-0.47, p-value <0.05). Thus, better self-efficacy and adherence both independently predicted better glycaemic control. The younger one is the worse the glycaemic control with predicted increase of 0.03 in HbA1c as one gets younger. Thus, younger patients who also had type 1 diabetes, had a predicted poor glycaemic control generally.

Model goodness of fit and Variance

The model we used for path analysis statistically fit well our data in predicting endogenous variables using multiple goodness of fit (Gof) indices. The Gof indices showed the following values: - RMESA: 0.37, CFI: 930 and TLI: 880 and SRMR: 0.25. The model was able to explain 30% of the variance in the observed data as explained in table 8.8.

Table 8.8: The variance for Equation level goodness of fit

VARIABLE	Variance				Correlation	
	Fitted	Predicted	Residual	R-squared (%)	Dep Vs. Pred	B-T corr.
THE PERCEPTION OF PATIENT CENTRED CARE (PCC)	201.58	29.61	171.97	14.68	0.38	0.15
SELF-EFFICACY	211.70	17.50	194.20	8.27	0.29	0.08
ADHERENCE	4.39	0.74	3.64	16.97	0.41	0.17

LONG-TERM GLYCAEMIC CONTROL	6.96	0.68	6.28	9.80	0.31	0.10
OVERALL				**30.07**	-	-

Regarding the dependent observable variables, namely PCC, self-efficacy, adherence and blood sugar control, the overall R squared (R^2) was 0.30 indicating the variance explained by the model. Therefore, the model was able to explain 30% of the relationships in this prototype. The endogenous variables in the model were PCC, self-efficacy, adherence and blood levels which were able to explain 14%, 17% and 10% of the relationships respectively in our study population. The R^2 was low at just about 8% for self-efficacy. There could be other endogenous variables not considered in this model that may explain the portrayed relationships especially for self-efficacy and glycaemic control.

Discussion

Using the contextual operational framework, we found that most patients perceived low PCC as defined by fearful interactional ambience, less individualization and involvement, and a poor organization of care context. The extent of the low PCC perception standing at 55.7% in this study was comparable with the Ethiopian studies (Bahir City and Addis Ababa) which found the perception of low PCC scores at 53.7% and 51% respectively(199,200). Both these studies showed significantly poorer PCC in public health facilities compared to private ones. This is possibly due to comparable resource challenges in the two contexts, where HCPs hardly have time to interact with their patients except to finish the queue(170). Malawi's proportions of low PCC (55.7%) are considerably higher compared to the South African (SA) study (16%)(199). This is possibly due to the differences in the type of scales and the method used to dichotomize the scores. In the SA study, the dichotomization of PCC scores was largely qualitative, while in our study, the categorization of the scores was statistical and scientific with an unsupervised K-

means clustering technique. Furthermore, it indicated cut off points that made a statistical difference in eliciting management outcomes (184). This adds value to the construct validation of the tool which this study considers a strength because it further dictates the level at which PCC would matter for improving outcomes.

Principally, the result highlights the inadequacies and inconsistencies in the delivery of PCC by providers during medical encounters, most deficient in the individualization and patient involvement subscales. This finding is further corroborated by De Mann et al., who in their systematic review of literature from sub-Saharan Africa lament the overly biomedical orientation of medical training and incentivization in most African healthcare delivery systems(16) . Medical training and healthcare delivery systems hardly value PCC approaches, therefore, most medical interactions in African contexts are overly paternalistic, with no due attention given to quality partnership building(22). While most studies mention organizational, structural, and patient barriers as accounting for low PCC experiences in medical encounters, the biomedical orientation of service delivery, lack of time, and overworked providers stand out in low resource contexts (22,170).

The presence of complications and comorbidities predicts a negative perception of PCC. In their study, Kuipers et al., show that people with multi-morbidities and complications have compromised physical comfort and are therefore likely to report having perceived less PCC, especially if it does not respond to their current physical needs(201). Conversely, the results highlight the need to tailor PCC to those that need it most and the extent to which they need it because it matters in the realization of PREMS and PROMS. The presence of complications and comorbidities comes with both emotional and physical discomfort, creating more complex patients' care needs, hence the perceived need for a more tailored PCC(202). The finding confirms that PCC, by its nature, should help healthcare providers unearth patients' health needs

and be responsive to them in unique ways that are satisfying to each patient's situation. Concurrently, in our study population, there is a predominance of women who also have complications, which can explain the preponderance for women to perceive less PCC, just as Kuipers et al., found in their study(201). The fact that location (rural vs urban), education status, type of diabetes, and duration of disease did not affect the perception of PCC confirm that PCC is a need for all patients' regardless of a social background; only the emphasized elements may evolve across visits.

The individualization and involvement subscale ware notably, the least experienced, with lower mean scores than factors (relational and organizational) comparatively. Although patients perceived that their provider's interactions were a little bit more relational, the human connection during the encounter was not adequate enough to create an environment for invitation and support for participation in care. Patients' experiences of being acknowledged as unique individuals and involved in care in our study population are gloomy(203). Malawi alludes to the same in its quality management policy (QMD) where deficiencies in patient involvement in care were identified(12). Fearful interactional ambience, power imbalances, insufficient dialogue, and patients' own restrictive attitudes towards engagement with their providers deters patient involvement(203) . There is a need for an adequate build-up from the creation of a good relational ambience to acknowledging patients, tailoring their care to their unique experiences and empowering and supporting them towards self-care behaviors (117). The human connection process therefore ought to manage power imbalances and patient vulnerabilities related to patient involvement. It makes sense, therefore, that without the enabling interactional environment in the encounters, patient involvement would hardly happen.

The perceptions of PCC as being positively associated with adherence is not surprising. PCC interactions in medical encounters have the potential to build health literacy and support and

capacitate patients towards adherence to self-care behaviors(54,204). Thus, adherence is, in part, a marker of effective provider-patient interaction that has facilitated trust building, information sharing, patient involvement, and support (38,170). Additionally, adherence is a cornerstone to the attainment of patient outcomes, glycaemic control, and the prevention or delay of DM complications(104). The finding validates that PCC is not just a quality issue, it also impacts intermediate outcomes, including glycaemic control. Especially when patients are active partners in their care, they are better able to adhere to mutually agreed-upon goals of care. While we understand that glycaemic control and the reduction of complications is multifactorial, adherence to care management plans is an effective starting point if we are to achieve some gains in DM patient outcomes.

Surprisingly, the relationship between PCC and self-efficacy was not statistically significant in the path analysis. As a social cognitive resource, self-efficacy, especially as it relates to specific health related self-care activities requires a significant level of support during medical encounters through verbal persuasion by the HCP or peers, acknowledgment and validation of patients' capabilities, and mastery of the activities(62,205). The general absence of empowering and supportive elements in the perceived PCC in this study may explain the non-significant relationship to start with. Patient-centred care goes beyond good relational ambience or friendliness to include support towards mastery of self-care competencies with the provider as a resource (206). Therefore, in contexts where there's marked power imbalances between the patients and their providers, poor medical literacy, and patient self-confidence is low or is hardly harnessed, PCC supportive efforts during medical encounters need to acknowledge, validate, and leverage patients' capabilities in self-care for attainment of better outcomes (65,205,207). The absence of a relationship between the PCC and self-efficacy may, in part, also be attributable to the fact that the study did not include other related or medicating constructs such as social

support, health literacy, and outcome expectations (person's estimate that a given behavior will lead to certain outcomes) which also impact self-efficacy(65,94,208).

Self-efficacy and adherence independently predict better long-term glycaemic control in our study, which resonates with most studies (53,63,208). Haskard et al., in their meta-analysis, highlight how PCC provider behaviors can enhance adherence by helping patients understand their illness, the treatment and its benefits, enhance collaborative partnerships and, support for self-care (53). Thus, PCC that prioritizes patient involvement works by capacitating patients to adhere to their treatment plans, thereby yielding better glycaemic control(42,56,60). Even though in our study PCC does not predict better self-efficacy, we see that self-efficacy itself is a predictor of better glycaemic control. According to social cognitive theory, self-efficacy has the potential to impact outcomes independently (63,65,208). In addition, our study found better glycaemic control among older patients compared to younger ones. Likely, with increasing age comes experience and mastery of self-care activities. Tertiary educational status being a predictor of self-efficacy in our study population is not surprising, as it may be regarded as a proxy for health literacy, an important element in the development of self-efficacy behaviors(209).

Over two-thirds (70%) of the patients had poor long-term glycaemic control reported. It may be that there is general poor glycaemic control reported in this study and other studies emanate from other reasons, such as the chronic shortage of drugs alluded to through the qualitative phase of this study context (131). Within the study population, we concurrently found that access to DM medication was a yearned for and yet lacking aspect of PCC. Thus, even though PCC predicts some marginal increases in adherence, patients may only be taking their drugs as and when they are available. Likewise, there may be more determinants of glycaemic control that this study did not elicit apart from adherence to drugs and lifestyle(204). Therefore, we advocate that PCC

delivery must spill over beyond the interactional realm to stimulate larger organizational improvements if we are to make a significant difference in patient outcomes. Notably, therefore, in implementing PCC, healthcare delivery systems ought to strive to address the basic organizational issues such as access to medication and timeliness of care which matter to patients with DM.

The study confirms that the perception PCC has potential to predict outcomes such as adherence and glycaemic control. The pathway linking PCC to glycaemic control is not direct but, rather, through adherence. The absence of a link between PCC and self-efficacy in this study has been attributed to the general absence of empowerment aspects of PCC in the study, which capacitates patients to feel confident in themselves to undertake self-care activities. The finding still validates the need for chronic PCC encounters to be supportive and empowering towards mastery of self-care.

Strengths and limitations

Some of the study's strengths are use of multiple methodological and analytical approaches in elucidating what PCC should mean, development of a measurement framework, and the assessment of PCC and its correlates. The use of exploratory qualitative methodologies to elucidate meanings and measure PCC quantitatively validates to the study findings. The use of multiple perspectives of patients, HCP, and policymakers in coming up with what PCC should mean is a strength that tries to reduce consumerism when defining PCC.

This is not an interventional study therefore; it falls short of describing causal relationships between PCC and related outcomes. Some aspects of the conceptual model that may mediate PCC and outcomes were not measured, hence the study's inability to explain some associations or absence of others.

Furthermore, considering the study was done in Malawi, on one disease condition, the results of this study may not be generalizable to other chronic conditions. The results may also not be transferable to other geographical contexts.

PCC being a socio-behavioral phenomenon, it has other determinants that explain the relationships between itself and outcomes that were not considered in this study, such as social support and health literacy. Nevertheless, the results have highlighted potential relationships within the PCC- DM management pathway that can be further studied. This is significant because this is the first time a Malawian study has objectively assessed how patients perceive PCC. In other words, since the study has elucidated some patterns in the PCC-DM management pathway, the findings have set a platform for subsequent exploration.

Conclusion

While PCC is not an end in itself, the initial patterns show that it is a potential intervention in the improvement of DM care, especially for patients with or at risk of complications. Above and beyond creating a conducive ambience, medical encounters ought to evoke support and capacitation for patients to undertake self-care behaviors confidently. While it is obvious that patients with DM in Malawi perceive low PCC, we must ride on the political commitment that is currently within the country's Ministry of Health's documented policies to advance these interpersonal aspects of quality of care because they matter. PCC largely remains the providers' responsibility, hence the urgent need to invest in medical education that cultivates PCC competencies and attitudes. Appraising and incentivizing PCC elements will help improve its advocacy.

Implications for practice

This baseline evaluation of patient-centredness and timeliness measures contributes to our understanding of the current state of quality of care. Our operational framework can inform the development of PCC interventions and care innovation models that effectively improve medication adherence and patient outcome in DM care. Medical encounters need to foster interactions that improve patient involvement, leveraging on patient capabilities thereby improving adherence to management care plans. We recommend further interventional studies using this validated framework to elucidate feasibility of such studies and causal relationship of PCC and outcomes.

CHAPTER 9: Discussion, limitations, conclusions and recommendations

9.1 Introduction

The chapter focuses on the synthesis of key findings, proposes a working framework, makes some recommendations, and signposts areas for future research. The following are the key messages drawn from this research study.

Key messages

- Studies on the objective assessment of chronic patients' perception of PCC are sparse in Africa
- The perception of PCC is known to improve patient experiences of care and has the potential to mediate outcomes among patients with DM
- Better perception of PCC is associated with better adherence which, in turn, predicts long-term glycaemic control
- There is need to prioritize patient-centred care delivery, especially for poorly controlled patients or those at risk of or with DM complications
- There need to modify and operationalize the current policy frameworks to make PCC more expressible and measurable.

9.1.1 The vague yet important concept

Patient centred care is a known concept, especially in family medicine, where a humanistic approach to care is emphasized. In my career as a medical educator, I was challenged to teach the concept to medical students and apply it to my daily clinical practice. This challenge aroused my quest to find out what it means functionally and the PCC process really matters in patient

care. I, therefore, set out to understand what it means, why I should care about teaching and reinforcing it in clinical teaching and assessments. Patients living with chronic conditions came to mind as a case study since they are frequent users of the health services and offer a "well patient" set of patients to interrogate the aim of this study. The aim of the study, therefore, was to assess the functional elements of PCC construct, the extent of patients' perceptions of PCC, and its correlates using patients with DM as a case study. The specific objectives included: -

1. To conduct a scoping review and synthesis of evidence on key dimensions and drivers of PCC for chronic care patients in the LMIC context.
2. To explore the understanding and experiences of PCC among DM patients, HCPs, and policymakers in public facilities in southern Malawi.
3. To assess the level of PCC perception in DM patient management in public facilities in southern Malawi.

The study has shown that humanistic medical care encounters matter in chronic patients in the continuum of care process towards attainment of PREMS and PROMS. Therefore, the pursuit to understand and innovate PCC interventions should be implemented with urgency in all health systems, regardless of their economic and developmental status. Locally, what PCC means, on the one hand, and measuring the humanistic experiences of the person receiving care, on the other, continue to dominate the quality of healthcare delivery discourses in Malawi. While the definitions are largely context-specific, requiring tailor- made measures, the links between PCC practice and PREMs and PROMs in chronic care are promising (50,52,55). In this synthesis, I bring out the elements of PCC in this context and why they matter. I further highlight how PCC would mediate outcomes and recommendations for future research, policy, and practice.

In chapters 4–9, I have highlighted key results. Chapter four sought to illuminate the PCC functional elements, which would later serve as a basis for the interrogation of what PCC means

in our context. The multiplicity and multi-layered nature of PCC definitions are not unexpected. The review of literature challenged my synthesis and taught me how similar meanings were present across contexts, yet there were differing areas of expression and emphasis. The apparent lack of prominence of some elements, such as continuity of care, highlights the systemic shortcomings in PCC implementation peculiar to our context. It does not mean that patients do not cherish humanistic interactions with continuity; rather, due to limited access to basic care, they are simply happy to have an opportunity to meet the HCP. Thus, the review brings to reality how expectations of care are moderated without negating the importance of some elements.

In chapter five, I highlight the elements of PCC pertinent among stakeholders in the interaction of care, and further in chapter six, I endeavor to describe some experiences of PCC and the barriers to one core element; shared decision making. It highlights the value of patients' engagement, further challenging the notion of "biomedical thinking" and the supremacy of the HCP in the medical encounter that medical education ought to address. It calls for the use of innovative ways to reduce power imbalances and engage patients in medical encounters.

Chapter seven represents my effort towards the development of a tool to measure PCC de novo from the elements highlighted in chapter five. The employment of EFA and CFA leads to the filtering of functional elements that matter contextually to patients in their medical encounters while eliminating redundant ones. In this narrative, I first highlighted the scientific steps, strengths and, challenges of developing and validating a tool *de novo* and how the tool offers a three-latent-factor solution as a working measurement framework for the study. Finally, the synthesis talks about an objective evaluation of how patients feel about PCC and how it affects outcomes in the DM pathway, such as self-efficacy, adherence, and long-term glycaemic control. It confirms that patient-centred care is valued and, it matters even in resource constrained

settings such as Malawi, where access to therapeutics is limited. Further, the synthesis looks at the conflict between the theoretical and conceptual frameworks in the study and possible reasons for it. Ultimately, I propose a working framework.

9.1.2 The working PCC framework and practical applications among patients with DM

In the Malawian context, we conceptually understand PCC as an expected care process that incorporates warm patient reception, where the healthcare provider consciously aims to reduce the patient-HCP power gap to harness a good long-term relationship. This creates a conducive atmosphere that allows gathering of information that holistically identifies the individual's specific problems and all possible interacting factors, ensuring timely access to care and medication (170). Reflecting on the definition, the study highlights that the PCC concept is complex and multi-layered in nature.

As Hugo et al alludes, practically, the definition highlights the core principles and takes into consideration the enablers for the expected interactional activities to make PCC possible(102). The principles that were emphasized in this study are relational ambience (emotional elements), holism, individualization and empowering care, and organization of care, which are multi-layered as shown in Table 9.1 below

Table 9.1: Practical applications of PCC principles; enablers and expected behaviors

Principle	**Enabler actions**	**Expected HCP behaviors**
Relational ambience	Friendliness, openness, respect and dignity, being listened to, unrushed	Empathy, relationship building, and creating a conducive atmosphere for

	encounters	interaction
Holist care	Biopsychosocial approach,	Thorough body check, all health needs addressed, and all possible factors considered in care. Achieving patients' biomedical needs and targets
Individualization (personalized care)	Meeting unique care needs and expectations of an individual Acknowledging uniqueness	Exploring individual needs and expectations, addressing expectations of care, Knowing the individual patient
Collaboration	Sharing power and responsibility, Information sharing, teaching, feedback and reprimand Informed choices, support for shared decision-making and self-care	Patients being consulted in medical decisions Reducing the power gap and creating safe spaces for dialogue between the patient and HCP dyad Support for active participation, self-care Leveraging patients' experimental knowledge
Organizational aspects	Access to medication, comprehensiveness, timeliness, coordination, and acknowledging the HCP/system have challenges to care delivery.	Ensure availability of medicine, equipment to check all bodily ailments, spaces, being on time, Patients being realistic & understanding the HCP limitations and contextual challenges,

		being open to employing work-around strategies, knowing when medicine is not available

The study highlights the multiplicity of the elements and differing expression principles expressed in literature and yet it brings out what is important in this population. The expression of PCC as an expectation of care confirms the centrality of meeting patients' care expectations in the conceptualization of the construct. Patients' needs are hardly met; therefore, they are expressed as a moderated set of expectations from the interaction, thereby questioning the responsiveness of the care we render. Especially in Africa, where care is verticalized into programs, fragmented, and characterized by short-staffing, limited one-on-one time, and poor funding for healthcare services PCC encounters are rare (210).

The prominence of relational ambience is acknowledged as a basic tenet for productive medical encounters in most studies, even in the context where resources are constrained(16,210). Patients acknowledge and appreciate a warm interactional environment as a facilitator of effective care delivery. In a similar study done among patients living with chronic conditions in Malawi, good relational ambience was reported to facilitate openness, exploration of contextual issues relating to care, and opportunities for support (22,40). In spite of organizational challenges highlighted in this study, deliberate efforts by HCP to be warm to the extent that is possible in their interactions should, therefore, be fostered through modelling, mentorships and medical education.

It is clear, however, that some peculiarities and a lack of prominence in some functional elements are documented to be important for chronic care(115). For instance, relational continuity and provider advocacy roles across care transitions were not emphasized. It is possible that they were deemed unattainable elements by participants of our study, thus they were left out

of the operational framework. It is also possible that while our patients and HCP yearn for high level interactional needs, they struggle with basic interactional and access issues in delivering care, such as medication and timeliness thereby hardly highlighting these as most important(110). Consequently, when patients visit for check-ups, whilst they may value having relational continuity, they are merely grateful to have someone attend to them. This confirms the realistic approach to PCC that is needed in that while relational continuity cannot be achieved due to human resource pressures in our context, we can strive for other forms of continuity such as documentation through the master cards which fosters a feeling of being known as a unique person by the system over time.

Availability of DM medication is an important and peculiar element of PCC in this context. Although it falls outside the conventional patient-HCP interactional-based definition, that is not surprising because it relates to access to a basic need for every patient with DM, making it the most sought-after aspect and a gauge for appraising PCC(114,121). More so, in this resource-constrained setting like Malawi, the prominence of this element is heightened by the chronic medication shortages that are prevalent and expressed as an access issue(122). Functionally, the finding stresses the centrality of healthcare delivery systems in meeting the basic patient needs, be it technical or interpersonal.

Our operational framework further highlights the notion of timely organization of care delivery. In this context, untimeliness stands out because it is an important domain in the PCC process as it relates to perceived barriers to access at the point of care and that improvements have the potential to enhance positive experiences of care and service utilization(60,211) (53,94). While not part of the interactional realm of PCC, it has been shown to be both a practical and relevant part of the PCC organizational culture and an indicator of quality care (70).

Support for patient involvement in care as a desired element is yet marked with failings due to the interplay of provider, patient and contextual factors(203). Coming from a destitute perspective, patients' deep vulnerability (for fear of losing the only care opportunity), insufficiency of informational exchange, and patients' own restrictive attitudes towards SDM are highlighted. Improvements in health literacy and awareness of decisional control need reinforcement. What institutional and organizational innovations can be employed to improve patient involvement in SDM among such vulnerable groups? The creation of a safe space for dialogue by HCPs is one important investment through relationship building. Strategies on how this can be modelled in medical education are a recommendation for future research.

I reckon that the framework depicts the incremental nature of the PCC construct, where a favorable interactional ambience is a requisite for the patient's involvement in care. Thus, patients need to feel welcome and comfortable in encounters to engage and be effective partners in their own health care. Patients in this study unanimously agree that it helps to be effective partners only if they can be invited into supportive spaces to participate. Health care providers need to be trained to value human interactions. After all, the health care system is a human interaction service at the most vulnerable times of human life.

The study has further confirmed that PCC requires conducive micro and macro context enablers. Healthcare systems are waking up to realize that interactions do matter in the continuum of healthcare delivery. Thus, responsive medical education curricula ought to place value on and install attitudes that align with this responsibility. Medical education delivery innovations that teach learners to value and leverage the wealth of knowledge and experience patients may bring to the table to enhance their own care are urgent. This means inclusion of aspects of health systems and ethical expectations to what future HCP learn thereby, improving their accountability to PCC.

The constrained human resources in the Malawi health delivery system against the number of patients to be attended to is known and, in part, is responsible for the rushed and inhumane encounters that are reported in this study. Enabler suggestions would be improving the work standards, such as staffing norms, so that HCPs report for duties timely and have adequate time to interact meaningfully with patients. Work setups that improve the PCC organizational cultures, such as teamwork, quality appraisals, and incentivization of PCC, are urgently needed(17). Even in resource constrained settings, simple techniques such as sets of consultation chair setups have been suggested to improve the relational ambience by the participants of this study(203). Equity in resource allocation within the system, particularly medicines, improves the sense of access among beneficiaries and it is alluded to by the participants of this study. At the core of PCC, patients will have to experience and acknowledge that equitable access to basic care is prioritized by the system.

9.1.3 Patients' experience of PCC: the measures and its correlates

While suggestion boxes, posted patients' rights and charters, complaints' processing by the Ombudsman, and community scores are available, the documentation of patients' experiences of PCC show a lot of gaps. The experiences in this study seem to fall short in capturing what really matters to patients (even the illiterate ones) from their own perspective (12). Particularly, the inadequacy in meeting patients' needs ought to be urgently addressed especially in contexts where the power balance is tipped against the patient.

The paucity in objective measures for the implementation of PCC in our context is highlighted, and, the absence of global definitions that may be transferable across contexts justifies the need for context specific measures(16). Therefore, as Malawi nurtures the drive for PCC medical encounters, the necessity for a tool to measure what really matters to patients heightens too. In

chapter 5 therefore, I have offered elements that matter and how we can measure them objectively. Although the development of tools de novo is marked by cautions, the validation of the tool to a three-factor solution scientifically sifts out what matters (both at interactional and organizational levels) and links to outcomes. Therefore, while I acknowledge its further refinement, it provides a starting point to measure PCC objectively among this study population.

While the low PCC levels are not surprising in this context, they reflect the general paternalistic approaches to care prevalent in Malawi. Particularly the lack of involvement and acknowledgement that patients are active partners that is lamented(12,203). It is clear that we owe it to HCP provider attitudes and to the poor organizational aspects of healthcare. Some of the policymakers agreed that patients feel that since healthcare is free, the HCP is doing them a favour and that they ought to be grateful recipients, whether care is responsive to their needs or not. Would a shared cost-sharing health financing model better the situation? That is difficult to know, however, I argue how that may be valid because patients are already in their vulnerable state (illness encounter), yet they are not bringing anything to the table. Thus, they feel destitute and without decisional freedom during encounters. This is an area where HCP attitudinal change through transformational medical education becomes core to changing this even in the face of free public service provision. Job aids serve to remind HCP of this responsibility thereby fostering SDM behaviors and reduce power gaps during medical interactions ultimately, a culture change(137). This is an additional strategy that can be used.

9.1.4 Does PCC matter in the management of patients with DM?

Most of the relationships between PCC and its correlates (self-efficacy, adherence, and glycaemic control) are not surprising. The strikingly positive relationships were between PCC and adherence, particularly, the acknowledgement and involvement subscale. In the broader

sense of the evidence on the effect of PCC and patient reported outcomes, most studies have been inconclusive due to ununified definitions of PCC and randomization issues in the causal studies. This finding supports early indications regarding the value of PCC in medical encounters between patient and HCP in advancing adherence. Thus, if PCC is empowering, it drives the zeal in patients to perform and master the mutually agreed care plans. The absence of the relationship between PCC and self-efficacy is unexpected, as is the negative association between the involvement subscale and self-efficacy. While we acknowledge that the study probably did not include other co-determinants in the pathway between PCC and self-efficacy, I argue in Paper 2 that a general lack of acknowledgement and involvement in aspects of care in this population may be a contributing factor. The fact that high self-efficacy is positively associated with better glycaemic control speaks to the fact that the PCC that invests in building self-efficacy among its beneficiaries is a winning formula. While it is challenging to establish a direct relationship pathway between PCC and glycaemic control, there is an indirect one through adherence and self-efficacy. Suffice it to say that achievement of glycaemic control is multifactorial; at least the study finds that, independently, self-efficacy and adherence may have a part to play. Therefore, this finding, actually, substantiates the need for PCC to achieve better self-efficacy and adherence in achieving better glycaemic control rather than negating it.

In view of the foregoing, I assert that PCC matters in the management of patients with DM. It is worth repeating here that although the theoretical and statistical models used in this study explain only 30% of the variance in the observed relationship among variables in the model, it is still acceptable considering that PCC is a social construct that may have other determinants that were not considered in the model influencing the relations. As well, the goal of this analysis was not necessarily to predict human behavior but rather to explain the significance of predictors or explanatory variables that have an effect on the dependent variables in this case(196). Thus, the relationships in the model can be interpreted theoretically and statistically with an acceptable

degree of confidence, especially that the individual pathways were indeed statistically significant(36).

9.2 Methodological innovations in this study

The use of mixed methods is particularly a strength and an innovation in the study. When one uses a scoping review, qualitative inquiry, and quantitative methods in that order, one gets three sets of facts and incremental evidence, which help with the formation, validation, and the objective look at PCC construct scientifically and its related concepts. Firstly, since PCC is a social behavioral construct, the use of three groups of stakeholders (patients, HCP, and policymakers) in deconstructing the PCC concept ensures comprehensive meanings while reducing consumerism(212). The qualitative inquiry methodology deconstructs PCC as a complex phenomenon and brings up a balanced, yet empirical view of reality in the definition. This process sifts out the contextual elements that matter and are vetted through an expert panel in the study topic. Secondly, the scientific validation of the tool brings a layer of scientific crystallization of the elements into a usable form to measure what matters to patients(73). Very few studies have developed and validated similar tools de novo in Africa.

The use of complementary statistical methods in assigning patients' individual Perceptions of PCC average scores into subgroups (Parallel analysis and unsupervised K-means clustering) ensured the dichotomization of PCC levels was scientific and used cut-offs that mattered in the determination of patient outcomes. The optimal number of clusters was statistically determined through the number of clusters on the sum of squares plot (scree plot) or silhouette test above the elbow which was two(213) The finding seems to suggest a probable minimum level of PCC that is required to mediate patient outcomes. Further interventional studies are required to validate this proposition.

Given the complex nature of PCC as a social behavioral construct, the determination of associations between variables and their covariates, and the use of both statistical and theoretical underpinnings from a logistical regression into a path analysis to ensure that the effect of covariates is considered in the analysis models are novel. The hierarchical nature in the employment of statistical methods ensured that the results were scientific and reliable(77).

9.3 Limitations and conclusions

Due to limited time, we did not do ethnographic observations to examine the individual patient-HCP interactional dynamics, which could have enriched our findings.

This is not an interventional study, hence its inability to describe causal relationships between PCC and related outcomes. Some aspects of the conceptual model that may mediate PCC and outcomes were not measured, causing the study to be unable to explain some associations or absence of others. Likewise, this being a cross-sectional study, we fell short of measuring PCC experiences over time. These limitations notwithstanding, this is the first Malawian study to objectively assess how patients perceive PCC. As the study has elucidated important elements and patterns in the PCC-DM management pathway, the findings set the platform for subsequent studies.

The validation of the tool used a once-off measurement due to logistical and resource constraints in the study. Thus, the test- and retest- reliability process did not happen. Therefore, we were unable to assess the consistency and reproducibility of results among our subjects over time. This limits the usability of the tool in other settings, hence my recommending it for future research.

Overall, the findings suggest that although PCC is not an end in itself, the initial patterns show that it can easily help improve DM care, especially for patients with or at risk of complications. Above and beyond creating a conducive ambience, medical encounters ought to evoke support and motivation for patients to undertake self-care behaviors confidently and participate in their

care effectively. While it is obvious that patients with DM in Malawi experience less PCC, there is a need to ride on the political commitment that is currently within our Ministry of Health to advance the interpersonal aspects of care because it matters.

The recurrent issue in this study is that the practice of PCC leaves a lot to be desired, with patients feeling like guests in a healthcare system that is professed to be designed for them. The study draws our attention to patients' unfulfilled needs. While PCC is the provider's responsibility, there is a call for the healthcare systems and respective governments to create a conducive micro- and macro-environment where PCC can thrive. The renewed commitment to personalized care in policy documents in Malawi is a good starting point and is highly commended. The issue of limited interactional time and shortages of staff who are always firefighting, thereby having no time to create meaningful relationships that involve patients in their care, is well-known. Appeals to improve HCP working conditions should not be ignored by policymakers. While it is true that medical education is biomedically oriented, and that health systems hardly value and reward PCC outputs, the policy and medical education innovations have to start with pedagogical changes that transform attitudes towards the creation of enabling PCC interactional environments.

9.4 The unique contribution to science and future research

My study offers insights regarding how to isolate practical elements of PCC that matter and how to measure them. It helps one to adapt and innovate what they have to be able to make a difference in patient outcomes for patients with DM in southern Malawi. It is also a starting point in medical education transformation and policy in defining what PCCs should mean and include in the Malawi setting.

I have elucidated perspectives on what PCC should mean, what's important in day-to-day practice, and how to objectively assess PCC in Malawi. The study has proposed a working

framework that is psychometrically tested, creating a platform for further refinement that can be used as a framework for implementation and certification for those desiring excellence in PCC. Further refinement of the tool that we developed and validated in Malawi is urgently needed.

There is a need for interventional longitudinal studies that examine the relationship between PCC and outcomes. Future research should touch on interventional packages that are required to advance PCC among HCPs and patients with DM. Further study is needed to determine the feasibility of such packages.

9.5 Policy and practice recommendations

In light of the discourse and experiential evidence obtained from this study, I suggest the following practice and policy recommendations at the interactional (micro-), facility (meso-), and, wider organizational health system (macro-)levels. I make an effort to highlight some practical and cost-effective ways in which these recommendations can be integrated into the already existing care structures, QMD, and educational interventions. While I will describe a few examples, the wider set of recommendations has been summarized in Table 9.2.

Table 9.2: Summary of suggested practical recommendations in advancing PCC implementation.

	Micro-level (interactional level)	**Meso-level (facility level)**	**Macro-level (health systems level)**

Practice implications	Fostering attitude change among HCPs Modelling and mentorship of PCC interactions Job aids that remind HCPs to support patients' involvement and safe care such as decision aids (DAs) Continued Professional Development modules through cultural role plays to improve their communication and patient-centred care skills.	Feedback mechanisms Pasting rights and charters and innovating on how to reach out to illiterate patients Patients charts to include a section on shared goals for next visit	Equitable resource allocation & access Use of data & feedback for improvement Creating safe spaces for patients to be involved in care, and contribute to goals Clarifying the roles of Ombudsman in actual practice beyond complaint processing
Policy implications	Using the existing patient interactional forums such as village health committees, patient support groups to foster HCP-patient relationships and reduce power imbalances, reminding them of their decisional and constitutional rights at the medical interactional level	Use of patient feedback, including expectations of care Use of valid patient satisfaction surveys Work standards (privacy) and Human resources for Health (HRH)	Research & practice standards for PCC Medical education innovations to foster PCC Incentivization of PCC in monitoring and evaluation tools Accountability mechanisms and equitable Health financing models Feasibility and interventional research on the value of PCC as an advocacy and financing tool.

In medical education, modelling PCC communication behaviors by educators is a very important. One practical way is observed consultations following practical role play sessions that is common in Family Medicine where medical students are observed during a consultation process with a patient. Grades are rewarded for not only the technical bits of the task, but also

the interpersonal tasks at the interactional level. This fosters attitudinal changes among students to value relational aspects of care(119).

At facility level, medical encounter decisional aids are one practical tool that can be tried in our setting. As a conversational instrument, it facilitates exchange of information between the patient and HCP around evidence, preferences and values pertaining to care(167). Although it increases interactional time marginally (by three minutes), its value on adherence is unclear, it has been shown to improve communication and patient health literacy that is key in improving self-efficacy and adherence(53).At health systems level, it is clear that facility performance appraisals and funding is heavily weighted towards technical outputs such as number of patients served or mortality trends. I am aware that facilities are currently being rated based on some indices such as cleanliness, access, and presence of patient charters, however, patients' voices in this rating process are still lacking. It would be useful to use both qualitative and quantitative patient feedback. The feedback can be in the form of surveys with emphasis on specific measurable parameters that patients find important such as SDM to gauge the actual responsiveness to the needs of patients and communities being served. Furthermore, indices of responsiveness could be correlated to some of the emphasized performance outcomes. A summary policy brief is attached in Appendix 12.

9.6 Conclusion

The synthesis has highlighted the important elements and how they relate to PREMS and PROMS. Most importantly, the implications for practice, policy and research in order to optimize PCC implementation and advocacy based on practicality and impact. Further, I have highlighted the unique contribution to science in terms of the science, methodological innovation, recommendations and suggested areas for future research.

SECTION C: CHAPTERS 10-11: BIBLIOGRAPHY AND APPENDICES

CHAPTER 10: BIBLIOGRAPHY

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CHAPTER 11: APPENDICES

Appendix 1: College of Medicine Research approval certificate



CERTIFICATE OF ETHICS APPROVAL

This is to certify that the College of Medicine Research and Ethics Committee (COMREC) has reviewed and approved a study entitled:

P.04/19/2654 - STAKEHOLDERS PERCEPTIONS AND EXPERIENCES OF PATIENT CENTRED CARE, AND RECOMMENDATIONS FOR IMPLEMENTATION: A CASE STUDY OF DIABETES MELLITUS MANAGEMENT IN SOUTHERN MALAWI. VERSION 1.1 DATED 16TH MAY 2019 by Martha Makwero

On 15-Jun-19

Approved by College of Medicine

As you proceed with the implementation of your study, we would like you to adhere to international ethical guidelines, national guidelines and all requirements by COMREC some of which are indicated on the next page for your study

18-Jun-2019

15-Jun-19

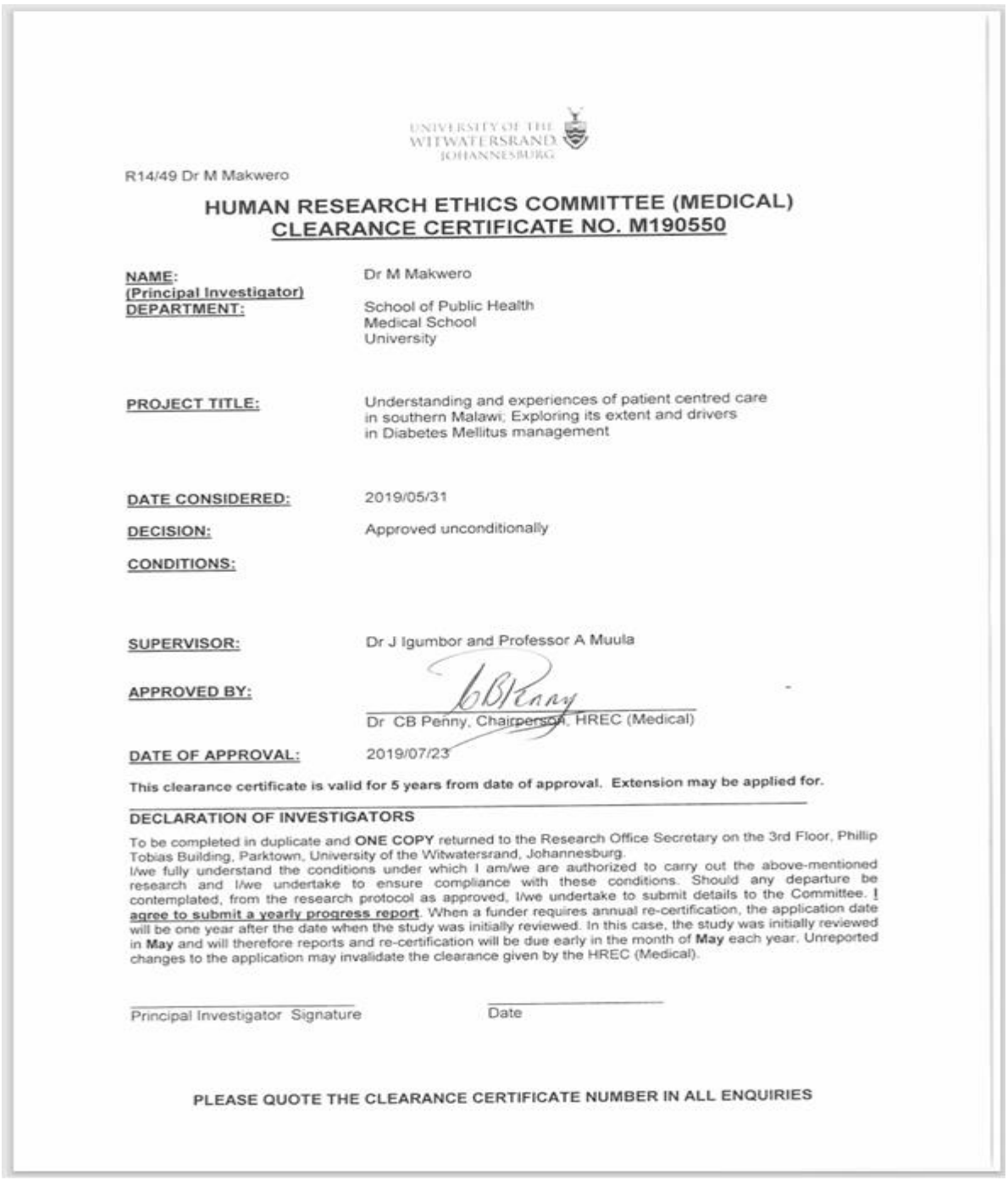
Dr. YB. Mlombe - Chairperson (COMREC)

Date

(COMREC) Research and Ethics Committee

Appendix 2: Witwatersrand HREC Faculty approval

Appendix 3: Witwatersrand Health Research (HREC) approval committee



UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG

R14/49 Dr M Makwero

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M190550

NAME: (Principal Investigator)	Dr M Makwero
DEPARTMENT:	School of Public Health Medical School University
PROJECT TITLE:	Understanding and experiences of patient centred care in southern Malawi; Exploring its extent and drivers in Diabetes Mellitus management
DATE CONSIDERED:	2019/05/31
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Dr J Igumbor and Professor A Muula
APPROVED BY:	Dr CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	2019/07/23

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

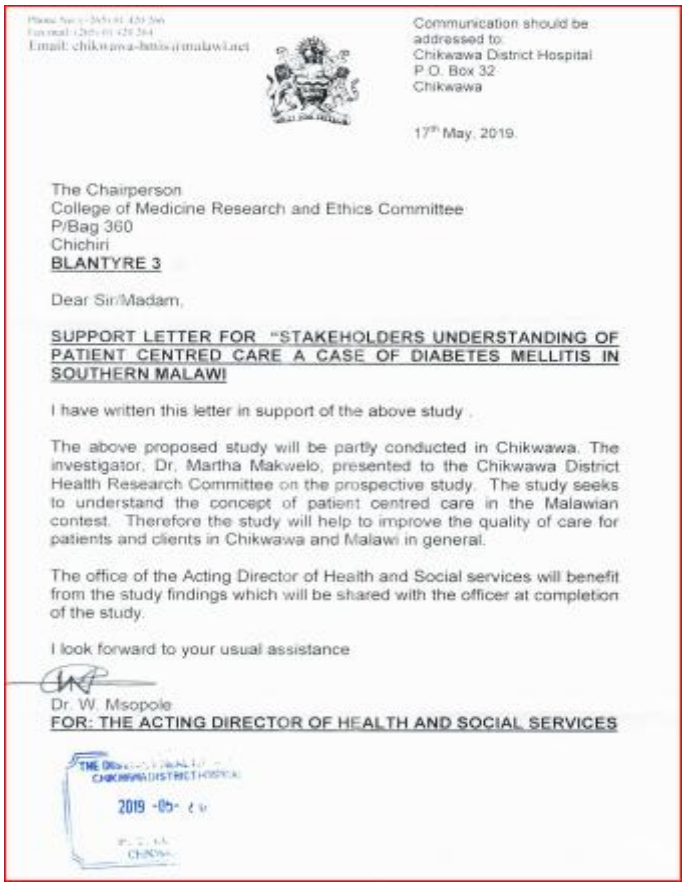
DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office Secretary on the 3rd Floor, Phillip Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.
I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to submit details to the Committee. **I agree to submit a yearly progress report**. When a funder requires annual re-certification, the application date will be one year after the date when the study was initially reviewed. In this case, the study was initially reviewed in **May** and will therefore reports and re-certification will be due early in the month of **May** each year. Unreported changes to the application may invalidate the clearance given by the HREC (Medical).

Principal Investigator Signature Date

PLEASE QUOTE THE CLEARANCE CERTIFICATE NUMBER IN ALL ENQUIRIES

Appendix 4: Approval letters from respective hospitals



Email: chikwawa-hmis@malawi.net

Communication should be addressed to:
Chikwawa District Hospital
P.O. Box 32
Chikwawa

17th May, 2019.

The Chairperson
College of Medicine Research and Ethics Committee
P/Bag 360
Chichiri
BLANTYRE 3

Dear Sir/Madam,

SUPPORT LETTER FOR "STAKEHOLDERS UNDERSTANDING OF PATIENT CENTRED CARE A CASE OF DIABETES MELLITIS IN SOUTHERN MALAWI

I have written this letter in support of the above study .

The above proposed study will be partly conducted in Chikwawa. The investigator, Dr. Martha Makwelo, presented to the Chikwawa District Health Research Committee on the prospective study. The study seeks to understand the concept of patient centred care in the Malawian contest. Therefore the study will help to improve the quality of care for patients and clients in Chikwawa and Malawi in general.

The office of the Acting Director of Health and Social services will benefit from the study findings which will be shared with the officer at completion of the study.

I look forward to your usual assistance

Dr. W. Msopole
FOR: THE ACTING DIRECTOR OF HEALTH AND SOCIAL SERVICES

CHIKWAWA DISTRICT HOSPITAL
2019 -05-

Telephone: +265 (0) 1 525 816
Fax: +265 (0) 1 524 538
E-mail:
All communications should be addressed to:
The Hospital Director

In reply please quote No Ref.....

MINISTRY OF HEALTH
ZOMBA CENTRAL HOSPITAL
P.O. BOX 21,
ZOMBA

Ref. No.....

20th March, 2019

The Chairman
College of Medicine Research and Ethics Committee
P. Bag 303
Chichiri
Blantyre

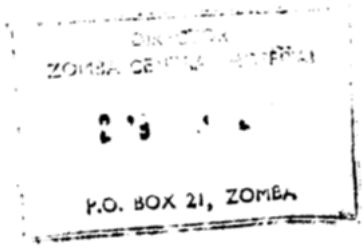
Dear Sir,

LETTER OF NO OBJECTION

The Management of Zomba Central Hospital is pleased to inform you that Martha Makwero would like to conduct a study at the facility as a study pilot site and the management has no objection. COMREC approval will allow officer to do the study.

The title of research is **"STAKEHOLDERS' PERCEPTIONS AND EXPERIENCES OF PATIENT CENTRED CARE, AND RECOMMENDATIONS FOR IMPLEMENTATION: A CASE STUDY OF DIABETES MELLITUS MANAGEMENT IN SOUTHERN MALAWI.".**

Your consideration will be greatly appreciated.
Thanks in advance



Yours faithfully

Martias Joshua (Dr)
HOSPITAL DIRECTOR

Appendix 5: Information sheets

STUDY: STAKEHOLDERS' UNDERSTANDING AND EXPERIENCES OF PATIENT CENTRED CARE: A CASE STUDY OF DIABETES MELLITUS MANAGEMENT IN SOUTHERN MALAWI.

Dear Sir/Madam,

I, Dr Makwero and my research team are doing a study that aims to explore what patient centred care for diabetic patients is through understanding the perceptions and experiences of patients, providers and policy-makers and to assess the its practice and outcomes of patient centred care for diabetic patients in Malawi. This study will be done in Zomba, Chikhwawa, Mulanje and Blantyre districts diabetic clinics. The results will help us find out what diabetic's patients actually expect from the health care system in order to inform quality improvement efforts in Malawi

Invitation to Participate and What is involved in the study? I invite you to participate to a focus group discussion to describe your perceptions and experiences of the care you receive at this facility. It is a study which will be incorporated into your routine care. On your regular appointment date, you will be asked to describe your experiences, expectation of care through an interview with myself. The interviews will be audio-recorded. Your visit may be one hour longer than usual.

Risks and benefits: There are no anticipated risks in the study since you will not be subjected to any strange drugs and tests. It will be beneficial that you to participate since your opinions will provide contributions to the understanding of what patient centred care is at this facility. You will be informed of the study results if you so wish.

Participation is voluntary and refusals to participate will not result in penalties or compromise to your entitled care for the day. You are free to withdraw from the study at any time without negative effects in the care rendered to you.

Reimbursement: As a token of appreciation, your transport today will be reimbursed using the Malawi standard rate of 3000 Malawi kwacha.

Confidentiality: Efforts will be made by the researcher to keep your personal information confidential unless if required by the law or governing bodies such as ethics committee for medical research or quality assurance purposes. However, confidentiality may not be fully guaranteed as information may be leaked by other members of the team. In case the results of this study are published, that is when it may lead to cohort identification.

Ethical approval: Permission to conduct the study and ethical approval has been obtained from COMREC and respective hospital boards. The respective letters are available if you need to have a copy.

Contact details: Should you have any questions or clarifications about the study, please contact the researcher or the COMREC Secretariat using the contact details written below:

Dr Martha Makwero

College of Medicine (COM), Private Bag 360, Malawi

+265 1871911 (O)

+265 884111312(C)

The Research and Ethics Committee

COM Research Ethics committee

University of Malawi, P/Bag 360

Blantyre Tel: +265 1871911

FOCUS GROUP DISCUSSION INFORMED CONSENT LEAFLET FOR DIABETIC PATIENTS

RESEARCH STUDY: STAKEHOLDERS' PERCEPTIONS AND EXPERIENCES OF PATIENT CENTRED CARE, AND RECOMMENDATIONS FOR IMPLEMENTATION: A CASE STUDY OF DIABETES MELLITUS MANAGEMENT IN SOUTHERN MALAWI

(To be translated into Chichewa)

Good day sir/madam/colleague

You have been asked to participate in this Focus group discussion and audio-recording of the same.

You have been informed about the study by Dr M. Makwero (*or Edina Kabudula and Esther Dambula*). You have been given an opportunity to ask questions about the discussions and have been answered satisfactorily. You have been made aware you are free to withdraw from the study at any time. You have been made aware of the risks and benefits of the study and you are satisfied with the information provided.

If you have questions about the way the study is being conducted or your rights as a research subject you may contact any of the following

- Dr M Makwero at College of Medicine on telephone number 01871911 or cell phone 0884111312 at any time
- Dr Mlomba, The Secretariat of the Ethics Committee of the college of Medicine (COMREC), UNIMA on 01871911

- The chairperson of the human research ethics committee (HREC), Witwatersrand University; Professor Clement Penny on +27 11 717 2301, or by e-mail on Clement.Penny@wits.ac.za. Alternatively, the committee secretariat on +2711 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za

Your participation in this study is voluntary, and you will not be penalized or lose benefits if you refuse to participate or decide to terminate participation.

If you agree to participate, you will be given a signed copy of this document as well as the participant information sheet, which is a written summary of the research.

The research study, including the above information, has been verbally described to me. I understand what my involvement in the study means and I voluntarily agree to participate in the ***interview****.*

…… ……..

Signature of participant *Date*

The research study, including the above information, has been verbally described to me. I understand what my involvement in the study means and I voluntarily agree to be ***audio-recorded.***

Signature of Participant Date

…… ……

Signature of researcher (or assistant) administering the patient information.

Appendix 5.1 Information leaflet for HCWs' Focus group discussion

STUDY: STAKEHOLDERS' UNDERSTANDING AND EXPERIENCES OF PATIENT CENTRED CARE: A CASE STUDY OF DIABETES MELLITUS MANAGEMENT IN SOUTHERN MALAWI.

Dear colleague,

I, Dr Makwero and my research team are doing a study that aims to explore what patient centred care for diabetic patients is through understanding the perceptions and experiences of patients, providers and policy-makers and to assess the its practice and outcomes of patient centred care for diabetic patients in Malawi. This study will be done in Zomba, Chikhwawa, Mulanje and Blantyre districts diabetic clinics. The results will help us find out what diabetic's patients actually expect from the health care system in order to inform quality improvement efforts in Malawi

Invitation to Participate and What is involved in the study? I invite you to participate in a focus group discussion to describe your perceptions and experiences of the care you receive at this facility. It is a study which will be incorporated into your routine care. On your regular appointment date you will be asked to describe your experiences, expectation of care through an interview with myself. The interviews will be audio-recorded. Your visit may be one hour longer than usual.

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Participation is voluntary and refusals to participate will not result in penalties or compromise to your entitled care for the day. You are free to withdraw from the study at any time without negative effects in the care rendered to you.

Reimbursement: As a token of appreciation, your transport today will be reimbursed using the Malawi standard rate of 3000 Malawi kwacha.

Confidentiality: Efforts will be made by the researcher to keep your personal information confidential unless if required by the law or governing bodies such as ethics committee for medical research or quality assurance purposes. However, confidentiality may not be fully guaranteed as information may be leaked by other members of the team. In case the results of this study are published, that is when it may lead to cohort identification.

Ethical approval: Permission to conduct the study and ethical approval has been obtained from COMREC and respective hospital boards. The respective letters are available if you need to have a copy.

Contact details: Should you have any questions or clarifications about the study, please contact the researcher or the COMREC Secretariat using the contact details written below:

Dr Martha Makwero

College of Medicine, Private Bag 360, Malawi

+265 1871911 (O)

+265 884111312(C)

The Research and Ethics Committee

College of Medicine Ethics Research and committee

University of Malawi, P/Bag 360

Blantyre Tel: +265 1871911

Appendix 6: Informed Consent form for interviews and audio-recording

Informed consent form for patients, HCWs and policy makers

(To be translated into Chichewa)

You have been asked to participate in this research study interview and audio-recording of the same).

You have been informed about the study by Dr M. Makwero (*or name of research assistant*)

If you have questions about the way the study is being conducted or your rights as a research subject you may contact any of the following

- Dr M Makwero at College of Medicine on telephone number 01871911 or cell phone 0884111312 at any time
- The Secretariat of the Ethics Committee of the college of Medicine (COMREC), UNIMA on 01871911
- The chairperson of the human research ethics committee (HREC), Witwatersrand University; Professor Clement Penny on +27 11 717 2301, or by e-mail on Clement.Penny@wits.ac.za. Alternatively, the committee secretariat on +2711 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za

Your participation in this study is voluntary, and you will not be penalized or lose benefits if you refuse to participate or decide to terminate participation.

If you agree to participate, you will be given a signed copy of this document as well as the participant information sheet, which is a written summary of the research.

The research study, including the above information, has been verbally described to me. I understand what my involvement in the study means and I voluntarily agree to participate in the ***interview****.*

…… ……..

Signature of participant *Date*

The research study, including the above information, has been verbally described to me. I understand what my involvement in the study means and I voluntarily agree to be ***audio-recorded.***

Signature of Participant Date

…… ……

Signature of researcher (or assistant) administering the patient information.

Appendix 7: Interview guides

Appendix 7.1: Interview guide for In Depth interviews for DM patients

Probes for DM patients' In-depth Interviews and focus group discussion which are subject to adaptation from the scoping review findings

- Please tell me about the care that you received at this clinic recently
    - Please explain in detail about the kind of interaction had between you and your provider
    - Tell me about the expectations of the care you want to receive at this clinic?
    - If you were to share with somebody your experiences about the care you received at this clinic, what would you say?
- For the care to be "centred on you", what does that entail to you? What should happen during the interaction with your provider to make such care "centred on you", What key elements of the interaction with your provider would make such care "centred on you?" (including cues that point to some important elements of PCC) or (use case vignettes of some PCC dimensions)

· Please tell me about the practice of care that is "centred on you" among HCWs at this facility:

- In your opinion, what do you think are the factors (both positive and negative) that are influencing the type of patient-provider interactions that you experience?
- What do you think are the enabling factors for the HCWs to render care that is deemed to be "centred on you"?
- (In case providers already do provide care centred on you) What do you think would help reinforce the interactions that you have at this facility?

· Do you have any questions?

Appendix 7.2: Semi structured interview guide for In-depth interviews for HCPs

Probes for HCWs in-depth interviews and focus group discussion which are subject to adaptation from the scoping review findings

- Tell me about the care you render to the patients that come to this clinic?
    - How do you go about interacting with the patients that receive care at this facility?
    - Can you describe to me a typical interaction with a patient?
- Tell me about care that you think your patients would like to receive?
    - What do you think are the expectations of your patients in your interaction with them?
- In your opinion, if the interaction is to be described as patient centred, what would it entail?
- In your opinion, what do you think are the factors (Both positive and negative) influencing the type of interactions that you experience?
- What do you think are the enabling factors for you to render care that is deemed to be "centred on you"?
- (In case providers already do provide care that centres on patients) What do you think would help reinforce the interactions that you have at this facility?
- Tell me about what would it take to practise care that is centred on the patient
    - What would motivate you to render care and interactions that focus on the patient?

(*An example of motivation; what is the value of care that centres on patients" in your care delivery if any? How do you think it contributes to the goals of quality care?)*

- What do you think is required for you to be able to render care that focusses on the patient?
  - *An example: what specific information, skills and attitudes do you require to render care that is centred on patients?*
- Do you feel empowered to render care that is centred on your patients (self-efficacy)?
  - How and from where do you get the empowerment
  - If not empowered, why?
- What is your opinion of the power differences between the implements (HCWs & policy makers) and patients in the implementation of care that centres on patients?

· Further questions as necessary, Do you have any questions?

Appendix 7.3: Semi structured interview guide for In-depth interviews for Policy makers

Probes for HCWs in-depth interviews which are subject to adaptation from the scoping review findings

- Tell me about the care rendered to the patients in this clinic?
    - How do you go about interacting with the patients that receive care at this facility?
    - In your opinion, can you describe to me a typical interaction with a patient ought to look like?
- Tell me about care that you think your patients would like to receive?
    - What do you think are the expectations of your patients with your HCWs (including yourself) interaction with them?
- In your opinion, if the interaction is to be described as patient centred, what would it entail?
- In your opinion, what do you think are the factors (Both positive and negative) influencing the type of interactions that you experience?
- What do you think are the enabling factors for you to render care that is deemed to be "centred on you"?
- (In case providers already do provide care that centres on patients) What do you think would help reinforce the interactions that you have at this facility?
- Tell me about what would it take to improve practice care that is centred on the patient
    - What would be the motivation to render care and interactions that focus on the patient?

        (*An example of motivation; what is the value of care that centres on patients" in your care delivery if any? How do you think it contributes to the goals of quality care?)*
    - What do you think is required for HCWs to be able to render care that focusses on the patients at the facility?

- § *An example: what specific information, skills and attitudes do you require to render care that is centred on patients?*
- o Do you think the HCWs feel empowered to render care that is centred on patients?
  - § How and from where do you get the empowerment
  - § If not empowered, why?
- o What is your opinion of the power differences between the implements (HCWs & policy makers) and patients in the implementation of care that centres on patients?

· In your opinion, what are policy recommendations that are required to facilitate rendering care that is centred on the patient?

· Further questions as necessary

· Do you have any questions?

Appendix 7.4: Focus group discussion probes for DM patients

STUDY: STAKEHOLDERS' UNDERSTANDING AND EXPERIENCES OF PATIENT CENTRED CARE: A CASE STUDY OF DIABETES MELLITUS MANAGEMENT IN SOUTHERN MALAWI.

- For the care to be "centred on you", what does that entail to you? What should happen during in the interaction with the provider to make such care "centred on you",

  What key elements of the interaction with your provider would make such care "centred on you?" (Including cues that point to some important elements of PCC obtained from the scoping review) or (use case vignettes of some PCC dimensions)
- What do you think helps to deliver such care? Or make such interactions centred on the patients views

What do you think hinders you from receiving such care?

Appendix 7.5: Focus group discussion probes for HCPs

For the care to be "patient or person centred", what does that entail to you? What should happen during in the interaction with the patient/ or client

would such care "centred on them?" (Including cues that point to some important elements of PCC obtained from the scoping review) or (use case vignettes of some PCC dimensions)

- What do you think helps to deliver such care? Or make such interactions centred on the patients' views
- What do you think hinders you from delivering such care?
- Do you have anything else to add?

Appendix 8: The Malawi Patient centred care Tool

DATA COLLECTION TOOL (Chichewa)

Dzina LA chipatala: _____ Facility code _____

A: Sociodemographic information **For official Use**

screening questions

Have you answered this questionaire before

☐ Yes (If Yes, Do not proceed(

☐ No

Nthawiyaitali bwanji pomwe munayambira kulandira chithandizo pano (If less than 6 months -exclude from study)

1 Nambala ya wodwala ☐☐☐ 1,2,3

2 chaka lobadwa ☐☐☐☐ 4,5,6,7

3 Sex ☐ 8

☐ Mwamuna

☐ Wamkazi

4 Maphunziro a pamwamba kwambiri ☐ 9

☐ Sindinapite ku sukulu

☐ Pulayimale sukulu

☐ Sekondale sukulu

☐ Ndinafika ku koleji 0

5 Mtundu wa matenda a shuga (type 1=young (oftenless than 30 , lean, on insulin only)) ☐ 10

☐ Type I

☐ Type II

☐ Zina……

1 Zaka kuchokera pomwe matenda anapezeka mthupi ☐☐☐☐ 11,12,13,14

3 Mtundu wa mankhwala ☐ 15

☐ Mankhwala akumwa otsitsa shuga- Oral Hypoglycaem

☐ Insulini

☐ Ndimasakaniza insulin and mankhwala akumwa otsits

☐ Palibe mankhwala omwe ndimamwa

4 Matenda ena okhazikika mthupi (Cormorbidities)

☐ HIV ndipo ali pamankhwala ☐ 16

☐ HIV koma sali pamankhwala ☐ 17

☐ Matenda a mtima ☐ 18

☐ Kuthamanga kwa magazi ☐ 19

☐ Sitiroku ☐ 20

☐ Matenda a mphumu ☐ 21

☐ Matenda a impso ☐ 22

☐ Other…… ☐ 23

5 Zovuta zakudza chifukwa cha matenda a shuga (kukumbuki

☐	mavuto a mapazi dzanzi	☐ 24
☐	mavuto odulidwa ziwalo	☐
☐	Mavuto a kusaona	☐ 25
☐	mavuto a impsyo	☐ 26
☐	mavuto okomoka kamba ka kuchepa shuga	☐ 27
☐	Mavuto okomoka kamba ka kuchuluka shu	☐ 28
☐	abambo kufooka kuchipinda	☐ 29
☐	amayi chikazi chodabwitsa chosatha	☐ 30
☐	Zina……	☐ 32

C. Patient centred care

Mafunso otsatirawa ndimafuna akufunsa za mmene mwakhalira mukulandira chithandizo cha anthi a shuga pa chipatala pano kuyerekeza miyesi 6 yapitayi

1 Nkumano wathu ndi othandiza umakhala mwa chibale

☐	Palibe (Never)	☐ 33
☐	Nthawi zina (some of the time)	
☐	Nthawi zambiri (Most of the time)	
☐	nthawi zonse (All of the time)	
☐	Ndilibe chonena (No comment)	

2 ondithandiza amandimvetsera bwino lomwe mwa chidwi ku zomwe ndimalankhula

☐	Palibe (Never)	☐ 34
☐	Nthawi zina (some of the time)	
☐	Nthawi zambiri (Most of the time)	
☐	nthawi zonse (All of the time)	
☐	Ndilibe chonena (No comment)	

3 ondithandiza anandiotsera chifundo

- [ ] Palibe (Never)
- [ ] Nthawi zina (some of the time)
- [ ] Nthawi zambiri (Most of the time)
- [ ] nthawi zonse (All of the time)
- [ ] Ndilibe chonena (No comment)

→ [ ] 35

4 Ondithandiza amandithandiza mwa ulemu

- [ ] Palibe (Never)
- [ ] Nthawi zina (some of the time)
- [ ] Nthawi zambiri (Most of the time)
- [ ] nthawi zonse (All of the time)
- [ ] Ndilibe chonena (No comment)

→ [ ] 36

5 Ondithandiza amandipatsa mpata okwanira olankhula za mavuto anga

- [ ] Palibe (Never)
- [ ] Nthawi zina (some of the time)
- [ ] Nthawi zambiri (Most of the time)
- [ ] nthawi zonse (All of the time)
- [ ] Ndilibe chonena (No comment)

→ [ ] 37

6 ondithandiza amandikhalitsa momasuka pamene takumana.

- [ ] Palibe (Never)
- [ ] Nthawi zina (some of the time)
- [ ] Nthawi zambiri (Most of the time)
- [ ] nthawi zonse (All of the time)
- [ ] Ndilibe chonena (No comment)

→ [ ] 38

7 Ondithandiza amandiuza dzina lawo

- [ ] Palibe (Never)
- [ ] Nthawi zina (some of the time)
- [ ] Nthawi zambiri (Most of the time)
- [ ] nthawi zonse (All of the time)
- [ ] Ndilibe chonena (No comment)

→ [ ] 39

8 Ondithandiza amnditana ndi dzina langa kapena nfunda oyenerera

- ☐ Palibe (Never)
- ☐ Nthawi zina (some of the time)
- ☐ Nthawi zambiri (Most of the time) → ☐ 37
- ☐ nthawi zonse (All of the time)
- ☐ Ndilibe chonena (No comment)

8 Chithandizo chimakwaniritsa sosowa zanga za thanzi makamaka pa matenda a shuga

- ☐ Palibe (Never) → ☐ 40
- ☐ Nthawi zina (some of the time)
- ☐ Nthawi zambiri (Most of the time)
- ☐ nthawi zonse (All of the time)
- ☐ Ndilibe chonena (No comment)

9 ondithandiza kuchipatala amaunikira mavuto anga onse okhunza thanzi langa (e.g BP, asthma etc)

- ☐ Palibe (Never) → ☐ 35
- ☐ Nthawi zina (some of the time)
- ☐ Nthawi zambiri (Most of the time)
- ☐ nthawi zonse (All of the time)
- ☐ Ndilibe chonena (No comment)

10 Ondithandiza amaonetsa chidwi pa zina zamoyo wanga kupatula za nthazi(e.g banja, ntchito, chpembezo)

- ☐ Palibe (Never) → ☐ 36
- ☐ Nthawi zina (some of the time)
- ☐ Nthawi zambiri (Most of the time)
- ☐ nthawi zonse (All of the time)
- ☐ Ndilibe chonena (No comment)

12 Ondithandiza amaunikira zikhumbo zanga pondithandiza za vuto langa

- ☐ Palibe (Never) → ☐ 38
- ☐ Nthawi zina (some of the time)
- ☐ Nthawi zambiri (Most of the time)
- ☐ nthawi zonse (All of the time)
- ☐ Ndilibe chonena (No comment)

18 Ondithandiza amandilola ine (kapena achibale) kutengapo mbali poika maganizo pa za chithandizo changa

- [ ] Palibe (Never)
- [ ] Nthawi zina (some of the time)
- [ ] Nthawi zambiri (Most of the time)
- [ ] nthawi zonse (All of the time)
- [ ] Ndilibe chonena (No comment)

[ ] 44

19 ondithandiza amandilimbikitsa kutengapo mbali poika maganizo pa za chithandizo changa

- [ ] Palibe (Never)
- [ ] Nthawi zina (some of the time)
- [ ] Nthawi zambiri (Most of the time)
- [ ] nthawi zonse (All of the time)
- [ ] Ndilibe chonena (No comment)

[ ] 45

20 Mankhwala othandizira mavuto anga analipo

- [ ] Palibe (Never)
- [ ] Nthawi zina (some of the time)
- [ ] Nthawi zambiri (Most of the time)
- [ ] nthawi zonse (All of the time)
- [ ] Ndilibe chonena (No comment)

[ ] 46

21 Panali kulumikizana kwabwino pa nkhani ya mapezekendwe a mankhwala pakati pa olemba mankhwala ndi kolandira mankhwala

- [ ] Palibe (Never)
- [ ] Nthawi zina (some of the time)
- [ ] Nthawi zambiri (Most of the time)
- [ ] nthawi zonse (All of the time)
- [ ] Ndilibe chonena (No comment)

[ ] 47

22 Ndimakhala owanvesetsa ondithanndiza akafotokoza kuti mankhwala ashuga palibe

- [ ] Palibe (Never)
- [ ] Nthawi zina (some of the time)
- [ ] Nthawi zambiri (Most of the time)
- [ ] nthawi zonse (All of the time)
- [ ] Ndilibe chonena (No comment)

23 Nthawi yodikira kuonana ndi ondithandiza imkhala ya saizi yabwino

- ☐ Palibe (Never)
- ☐ Nthawi zina (some of the time)
- ☐ Nthawi zambiri (Most of the time)
- ☐ nthawi zonse (All of the time)
- ☐ Ndilibe chonena (No comment)

☐ 48

24 nthawi yomwe ndimafikira ndi kuchoka pa chipatala tsiku la clinic imakhala ya muyezo wabwino

- ☐ Palibe (Never)
- ☐ Nthawi zina (some of the time)
- ☐ Nthawi zambiri (Most of the time)
- ☐ nthawi zonse (All of the time)
- ☐ Ndilibe chonena (No comment)

☐ 49

25 ondithandiza anandiyeza za matenda anga mokwanira

- ☐ Palibe (Never)
- ☐ Nthawi zina (some of the time)
- ☐ Nthawi zambiri (Most of the time)
- ☐ nthawi zonse (All of the time)
- ☐ Ndilibe chonena (No comment)

☐ 50

26 Chithandizo cha lero chamafikira pa zomwe ndimayembekezera

- ☐ Palibe (Never)
- ☐ Nthawi zina (some of the time)
- ☐ Nthawi zambiri (Most of the time)
- ☐ nthawi zonse (All of the time)
- ☐ Ndilibe chonena (No comment)

☐ 51

27 Ndine wokhutira ndi chithandizo chomwe ndimalandira

- ☐ Palibe (Never)
- ☐ Nthawi zina (some of the time)
- ☐ Nthawi zambiri (Most of the time)
- ☐ nthawi zonse (All of the time)
- ☐ Ndilibe chonena (No comment)

☐ 52

(Self Efficacy) Kudziyerekeza kuthekera

Tifuna tidziwe za momwe mumamasukira kupanga zina ndi zina. pakuthekera kopanga zotsatira:
Pa manfunso ali m'musiwa, chonde sankhani nambala yokhuzana ndi momwe mumazionera nokha

1 Mukuzidalira bwanji kuti mutha kudya chakudya pama ola 4-5 ali wonse, tsiku lili lonse, kuphatikizapo chakudya cha mmawa?

☐	1 (Not Confident)Sindikuzidalira	☐ 54
☐	2	
☐	3	
☐	4	
☐	5	
☐	6	
☐	7	
☐	8	
☐	9	
☐	10 (Confident)Ndikuzidalira kwam	

2 Mukuzidalira bwanji kuti mutha kukonza chakudya chanu mwandondomeko panthawi imene mukumonza kapena kugayirana ndi anthu opanda matenda a shuga?

☐	1 Sindikuzidalira	☐ 55
☐	2	
☐	3	
☐	4	
☐	5	
☐	6	
☐	7	
☐	8	
☐	9	
☐	10 Ndikuzidalira kwambiri	

3 Mukuzidalira bwanji kuti mutha kusankha chakudya choyenera pa nthawi yomwe muli ndi njala (mwachitsanzo chakudya chotolatola?)

☐	1 Sindikuzidalira	☐ 56
☐	2	
☐	3	
☐	4	
☐	5	
☐	6	
☐	7	
☐	8	
☐	9	
☐	10 Ndikuzidalira kwambiri	

4 Mukuzidalira motani kuti mungakwanise kupanga ma ekisasayizi kwa mphindi 15-30 , kanayi kapena kasanu pa sabata ili yonse?

☐	1	Sindikuzidalira	☐ 57
☐	2		
☐	3		
☐	4		
☐	5		
☐	6		
☐	7		
☐	8		
☐	9		
☐	10	Ndikuzidalira kwambiri	

5 Mukuzidalira bwanji kuti mutha kusamala kuti shuga yanu itsatsike kwambiri pa nthawi yomwe mukupanga ma ekisasayizi?

☐	1	Sindikuzidalira	☐ 58
☐	2		
☐	3		
☐	4		
☐	5		
☐	6		
☐	7		
☐	8		
☐	9		
☐	10	Ndikuzidalira kwambiri	

6 Mukuzidalira bwanji kuti mukuziwa chochita pa nthawi imene shuga yanu yakwera kapena kutsika kuposa mulingo wake?

	1 Sindikuzidalira	59
	2	
	3	
	4	
	5	
	6	
	7	
	8	
	9	
	10 Ndikuzidalira kwambiri	

7 Mukuzidalira bwanji kuti mutha kuziwa panokha kuti pano matends anu afunika mupite kuchipatala kukaonana ndi a dokotala?

	1 Sindikuzidalira	60
	2	
	3	
	4	
	5	
	6	
	7	
	8	
	9	
	10 Ndikuzidalira kwambiri	

8 Mukuzidalira bwanji kuti mutha kuzisamala bwino kuti matenda anu a shuga asamasokoneze ndi zinthu zina zamoyo wanu?

	1 Sindikuzidalira	61
	2	
	3	
	4	
	5	
	6	
	7	
	8	
	9	
	10 Ndikuzidalira kwambiri	

E HILL-BONE compliance scale Item

1 Ndikangati kamene mumayiwala kumwa mankhwala a shuga?

	Palibe (Never)	62
	Nthawi zina(some of the time)	
	Nthawi zambiri (Nthawi Zambiri)	
	Nthawi zonse (all of the time)	
	Sizikundikhuza (Not applicable)	
	Sindikuziwa (I don't know)	

2 Ndikangati kamene mumapanga chitsankho chosamwa mankhwala a shuga?

	Palibe (Never)	63
	Nthawi zina(some of the time)	
	Nthawi zambiri (Nthawi Zambiri)	
	Nthawi zonse (all of the time)	
	Sizikundikhuza (Not applicable)	
	Sindikuziwa (I don't know)	

3 Ndikangati komwe mumadya zakudya zopezeka ndi shuga?

- ☐ Palibe (Never)
- ☐ Nthawi zina(some of the time)
- ☐ Nthawi zambiri (Nthawi Zambiri)
- ☐ Nthawi zonse (all of the time)
- ☐ Sizikundikhuza (Not applicable)
- ☐ Sindikuziwa (I don't know)

☐ 64

4 Ndikangati akmene mumalephera kubwera kuchipatala pa nthawi ya apoyintimenti?

- ☐ Palibe (Never)
- ☐ Nthawi zina(some of the time)
- ☐ Nthawi zambiri (Nthawi Zambiri)
- ☐ Nthawi zonse (all of the time)
- ☐ Sizikundikhuza (Not applicable)
- ☐ Sindikuziwa (I don't know)

☐ 65

5 Ndikangati kamene mumapezeka kuti mankhwala a shuga akutherani?

- ☐ Palibe (Never)
- ☐ Nthawi zina(some of the time)
- ☐ Nthawi zambiri (Nthawi Zambiri)
- ☐ Nthawi zonse (all of the time)
- ☐ Sizikundikhuza (Not applicable)
- ☐ Sindikuziwa (I don't know)

☐ 66

6 Ndikangati kapene mulalephera kumwa mankhwala patatsala tsiku limodzi, awiri akapena atatu kuti mupite kuchipatala?

- ☐ Palibe (Never)
- ☐ Nthawi zina(some of the time)
- ☐ Nthawi zambiri (Nthawi Zambiri)
- ☐ Nthawi zonse (all of the time)
- ☐ Sizikundikhuza (Not applicable)
- ☐ Sindikuziwa (I don't know)

☐ 67

7 Ndikangati kamene simumwa mankhwala chifukwa mukumva bwino mthupi?

- ☐ Palibe (Never)
- ☐ Nthawi zina(some of the time)
- ☐ Nthawi zambiri (Nthawi Zambiri)
- ☐ Nthawi zonse (all of the time)
- ☐ Sizikundikhuza (Not applicable)
- ☐ Sindikuziwa (I don't know)

☐ 68

8 Ndikangati kamene simumwa mankhwala a shuga pamene mukumva kudwala?

- ☐ Palibe (Never)
- ☐ Nthawi zina(some of the time)
- ☐ Nthawi zambiri (Nthawi Zambiri)
- ☐ Nthawi zonse (all of the time)
- ☐ Sizikundikhuza (Not applicable)
- ☐ Sindikuziwa (I don't know)

☐ 69

9 Ndikangati kamene mumapezeka mukumwa mankhwala anzanu a shuga?

- ☐ Palibe (Never)
- ☐ Nthawi zina(some of the time)
- ☐ Nthawi zambiri (Nthawi Zambiri)
- ☐ Nthawi zonse (all of the time)
- ☐ Sizikundikhuza (Not applicable)
- ☐ Sindikuziwa (I don't know)

☐ 70

10 Ndikangati kamene simumamwa mankhwala chifukwa chonyozera?

- ☐ Palibe (Never)
- ☐ Nthawi zina(some of the time)
- ☐ Nthawi zambiri (Nthawi Zambiri)
- ☐ Nthawi zonse (all of the time)
- ☐ Sizikundikhuza (Not applicable)
- ☐ Sindikuziwa (I don't know)

☐ 71

F. Blood sugar control (HBA1c)

☐ ☐ 72

Appendix 9: Stanford self-efficacy tool

We would like to know how confident you are in doing certain activities. For each of the following questions, please choose the number that corresponds to your confidence that you can do the tasks regularly at the present time.

1.	How confident do you feel that you can eat your meals every 4 to 5 hours every day, including breakfast every day?	1 Not confident	2	3	4	5	6	7	8	9	10 Totally confident
2.	How confident do you feel that you can follow your diet when you have to prepare or share food with other people who do not have diabetes?	1	2	3	4	5	6	7	8	9	10
3.	How confident do you feel that you can choose the appropriate foods to eat when you are hungry (for example, snacks)?	1	2	3	4	5	6	7	8	9	10
4.	How confident do you feel that you can exercise 15 to 30 minutes, 4 to 5 times a week?	1	2	3	4	5	6	7	8	9	10
5.	How confident do you feel that you can do something to prevent your blood sugar level from dropping when you exercise?	1	2	3	4	5	6	7	8	9	10t
6.	How confident do you feel that you know what to do when your blood sugar level	1	2	3	4	5	6	7	8	9	10

	goes higher or lower than it should be?										
7.	How confident do you feel that you can judge when the changes in your illness mean you should visit the doctor?	1	2	3	4	5	6	7	8	9	10
8.	How confident do you feel that you can control your Diabetes so that it does not interfere with the things you want to do	1	2	3	4	5	6	7	8	9	10

Appendix 10: Hill Bone adherence scale

HILL-BONE compliance scale Item		None of the time	Some of the time	Most of the time	All of the time	Not applicable	Don't Know
1	How often do you forget to take your DM medicine?						
2	How often do you decide not to take your DM medicine?						
3	How often do you take sugary food?						
4	How often do you miss scheduled appointments?						
5	How often do you run out of DM pills?						
6	How often do you skip your DM medicine 1–3 days before you go to the clinic?						
7	How often do you miss taking your DM pills when you feel better?						
8	How often do you miss taking your DM pills when you feel sick?						
9	How often do you take someone else's DM pills?						
10	How often do you miss taking your DM pills when you do not feel like taking them						

Appendix 11: Plagiarism declaration report (submitted as a separate file)

Appendix 12: Policy Brief under peer review since April 2024

Title: Patient-centred care (PCC) interactions among patients with Diabetes Mellitus

Highlights

- PCC care is a quality imperative yet it is hardly expressible in care
- PCC improves experiences of care and patient-reported outcomes
- Consistency is key

Background and introduction:

Patient-centred care (PCC) is becoming increasingly recognized in various quality care reforms, especially in the era of chronic care where its benefits are evident. PCC has improved care processes and patient-reported outcomes in chronic care patients, like those with Diabetes Mellitus (DM). While the Malawi Quality Management Directorate (QMD) and Non-communicable Disease and Injury (NCDI) policies mention PCC as a strategic quality reform, its functional elements are not well-known, and it's unclear whether it has any impact on patients' experiences and outcomes. This lack of clarity is hindering the implementation, assessment, and advocacy of PCC. Therefore, as the burden of chronic diseases, including DM, increases, there is a need to optimize PCC by identifying its functional elements, objectively assessing it, and recommending effective implementation strategies.

Methodology

The study used exploratory mixed-methods to investigate patient-centred care (PCC) in low- and middle-income countries (LMIC) in southern Malawi. The study was conducted in multiple phases. Firstly, a scoping review was done to identify the common elements of PCC in LMIC. Secondly, qualitative inquiry was used to break down the PCC construct into its functional

elements among patients, healthcare providers, and policymakers. The identified qualitative themes were then used to develop a tool that captures the important elements of PCC from the same population. A psychometric analysis was conducted to confirm the structure and consistency of the tool to improve the validity of the results obtained. Finally, a quantitative assessment was done to measure the current PCC practice among patients with DM and its association with baseline adherence to management plans, self-efficacy, glycaemic control, and some complications

Key findings:

- Patients valued PCC encounters, particularly shared decision-making (SDM).
- 55.8% of patients perceived low PCC scores, particularly in individualization and SDM.
- Higher PCC scores did not significantly correlate with self-efficacy.
- Both PCC and self-efficacy independently predicted adherence.
- Perceived higher PCC scores marginally increased adherence.
- Both self-efficacy and adherence independently predicted better blood sugar control.
- Better self-efficacy is associated with decreased HbA1c levels.
- Higher adherence scores correlated with decreased HbA1c, highlighting the indirect impact of PCC on glycemic control through adherence.

Conclusions:

This study has confirmed that the concept of Person-Centered Care (PCC) is complex and that there is a lack of literature on this topic in Low and Middle-Income Countries (LMIC). Medical encounters that follow the principles of PCC should not only create a positive environment but also provide patients with the necessary support and skills to confidently engage in self-care behaviors that will lead to better patient outcomes. Although this study is cross-sectional, the initial results suggest that PCC can positively impact patients' reported experiences and

outcomes in individuals with Diabetes Mellitus (DM). The synthesis of the study identifies key elements that are important in PCC and how they relate to patients' reported experiences and outcomes of care.

Policy implications

1. Interactional Level (Micro):
   - Incorporate modeling of PCC communication behaviors into the medical education curriculum.
   - Reward grades for both technical and interpersonal tasks to instill PCC principles among students.
2. Facility Level (Meso):
   - Implement medical encounter decisional aids to facilitate information exchange between patients and HCPs.
   - Decisional aids enhance communication and patient health literacy, improving self-efficacy and adherence.
3. Organizational Health System Level (Macro):
   - Revise facility performance appraisals and funding mechanisms to include patient-centred metrics.
   - Incorporate qualitative and quantitative patient feedback, emphasizing measurable parameters such as shared decision-making (SDM).
   - Ensure care responsiveness to the needs of patients and communities by aligning evaluation metrics with PCC principles.
4. Integration Strategies:
   - Integrate PCC communication modeling into educator training programs.

- Provide resources and training for implementing decisional aids in routine medical encounters.
- Adapt performance appraisal systems to incorporate patient-centred metrics and feedback mechanisms.
- Foster collaboration between policymakers, healthcare providers, and patients to ensure alignment of policies with patient needs and preferences.

Recommendations

The study recommends PCC to be included in preservice education, further be included in the quality performance management frameworks

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