UNIVERSITY OF THE WITWATERSRAND
JOHANNESBURG

The Faculty of Humanities
School of Social Sciences
Department of Sociology

Program: MA in Health Sociology
Master's Research Report

Topic: Exploring the involvement of HIV patients in person-centred care: The case of Nancholi Youth Organization (NAYO) in Blantyre, Malawi

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Submitted to the School of Social Sciences

July 2024

Abstract

This research report explored the involvement of HIV patients in person-centred care (PCC). PCC is the collaboration between healthcare providers, patients, and their support system to achieve the desired goals of quality treatment and care. PCC has been implemented in high-income countries where definitions, theories, and frameworks have been made.

The literature review focuses on six major concepts namely PCC, expert patient, Greater Involvement of People with HIV/AIDS (GIPA), community-based care, patient support system, and stigma. PCC, expert patient and GIPA are core to understanding community-based initiatives and the need to implement PCC and community-based care. Community care, patient support systems and stigma drive person-centred care implementation, especially in low-income countries.

The main research question was: What is the involvement of HIV patients in the Malawian Nancholi Youth Organization (NAYO) Programmes in Blantyre?

In its methodological considerations, the study used the following research approaches: (1) A qualitative design to explore the involvement of HIV patients in NAYO Programmes; (2) A purposive sampling technique in the identification of seven respondents from NAYO staff and five community volunteers; (3) A stratified sampling technique in recruiting 11 HIV patients on the first line of HIV treatment; (4) Semi-structured interviews to gather information from NAYO staff members, HIV patients, and community volunteers; (5) Adopted the participant observation method in observing interactions between patients and healthcare providers; (6) Thematic analysis was adopted to draw themes based on research-specific questions and NAYO programmes.

Findings reveal that NAYO uses a community-based approach for the implementation of its services and much of the involvement of patients is on a community level. NAYO Community volunteers facilitate and coordinate the collaboration between patients and healthcare providers. NAYO relies on community volunteers to implement its programmes. Finally, the research revealed that patients' support system includes family relations, friends, church members and community leaders who provide psychosocial-moral support. Felt and enacted stigma are barriers to the implementation of community-centred care. Financing programmes and services is a major challenge for NAYO in the implementation of its activities.

Declaration

I Delipher Magola (Student number: _2613399) am a student registered for MA in Health Sociology in the year 2023. I hereby declare the following:

- I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledge source) is wrong.
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Signature: ____ Magola **Date: 27/07/2024___**

Dedication

I dedicate this research to my beloved mother, Amayi Esnart Chirambo whose love, prayers and encouragement have always been a pillar of strength in my academic journey.

Acknowledgements

My profound gratitude to my supervisors Prof. David Dickinson and Dr. Kezia Lewins whose unwavering support, constructive and efficient feedback, objective comments, encouragement, and accompaniment produced the dissertation.

Special thanks to my academic mentor Prof. Clement Majawa for his support, guidance, critique, and encouragement which made this journey possible.

A vote of appreciation to my friend and sister Dr. Maureen Mzuza for her unwavering support and encouragement throughout this research endeavour.

My bountiful gratitude goes to the Director of Nancholi Youth Organisation (NAYO) Mr. George Nedi who supported me during my research at NAYO. Special thanks to Anne Magoli who selflessly supported me throughout my data collection. Thanks to Mathews Katete, Chikumbutso Chimphamba, Teresa Namboya, Flossie Chikwakwa, Rabecca Nanungu, Maria Masalika, and the entire staff of NAYO for the support I received during my research period.

Sincere gramercy to my friend Sr. Martha Spoon for her support and encouragement throughout this study. Finally, I am indebted with applauding gratitude to my beloved Mom and siblings, nephews, and nieces for their support and understanding during this cognitive journey.

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Abbreviations/Acronyms

AGYW: Adolescent girls and young women

ART: antiretroviral therapy

CBC: Community Based Care

CCC: Community Centred Care

CFL: Community facility linkages

CHAM: Christian Health Association of Malawi

CHBC: Community Health Based Care

CHWs: Community health workers

COPC: Community-Oriented Primary Care

DHS: District health system

DOT: Direct observation therapy for TB and HIV treatment

EPP: Expert patient Programmes

GIPA: Greater involvement of people living with HIV

GWM: GIPA workplace model

HCW: Healthcare workers

HIVST: HIV self-test

HSA: Health Surveillance Assistants

HTC: HIV testing and counselling

LTFU: Losses to follow-ups

MASM: Medical Aid Society of Malawi

MCH: Medical Council of Malawi

MoH: Ministry of Health

MPHIA: Malawi population-based HIV impact assessment

NCDs: Non-communicable diseases

OPD: Outpatient department

PCC: Person centred Care

PHAM: Private hospital association of Malawi

PITC: Provider-initiated testing and counselling.

PLWA/PLHIV: People living with HIV/AIDS

PMTCT: Prevention of mother-to-child transmission

SSA: Sub-Sahara Africa

UHC: Universal healthcare

UNAIDS: The joint United Nations program on HIV/AIDS

VHC: Village Health Committees

WHO: World Health Organization

Definition of Terms

Person-Centred Care

Kitwood and McCormack (2004 as cited by Calisi et al., 2016) defined person-centred care (PCC) as “an approach to practice that is established through the formation and fostering of therapeutic relationships between all care providers, service users, and others significant to them, underpinned by values of respect for persons, individual right to self-determination, mutual respect, and understanding”.

2.1.2 Expert Patients: Patients having significant knowledge of their disease and treatment in addition to self-management skills (Guell, 2012)

2.1.3 Stigma: A powerful discrediting and tainting social label that changes the way individuals view themselves and how they are viewed by others (Alonzo and Reynolds 1995).

2.1.3 Community: A collective body of individuals identified by common characteristics such as geography, interests, experiences, concerns, or values (McKenzie et al., 2017).

2.1.4 Losses to follow-ups (LTFU) refers to patient attrition, defaulting, and death within six months to one year after Anti-retroviral therapy enrolment (Tweya et al., 2013).

1.0 Chapter One

1.1 Chapter Overview

This chapter presents background information, the problem statement, the purpose of the study, and research questions. The background information focuses on the need for the implementation of person-centred care to achieve the 95-95-95 project targets as set by UNAIDS. The problem statement is based on the definition of PCC from first world (developed) countries, challenges the medical model, and the need for implementation of PCC to integrate cure and care through partnership between healthcare providers, patients, and patients' support system. The main research question focuses on exploring the involvement of HIV patients in NAYO programmes and activities.

1.2 Background of the study

The fight against HIV/AIDS has been enhanced by the United Nations Joint Programme on HIV/AIDS (UNAIDS) which launched Project 95-95-95 targeting 95% of people living with HIV (PLHIV) knowing their status, 95% of PLHIV receiving antiretroviral therapy (ART), and 95% of PLHIV on ART to achieve viral suppression by 2030 .. To increase HIV status awareness, link PLHIV with treatment, and achieve viral load suppression, there is a need to increase the involvement of PLHIV in care because they are managing the illness, know their needs, and have the capacity to take necessary actions toward the achievement of the above-mentioned goals.

Ghana adopted a patient-centred approach through the implementation of community-based adherence support programmes and networks aiming at addressing challenges faced by PLHIV to improve ART retention and adherence. Through the implementation of support Programmes and networks, Ghana successfully improved the treatment and retention of PLHIV on ART with positive outcomes (Boakye & Adjorlolo, 2023). The adoption of patient-centred approach provided solutions to problems such as stigma, transportation and defaulting to treatment and enhanced better care for PLHIV.

According to a study by Orel et al. (2022), more than half of PLHIV are from Eastern and Southern Africa. These regions are overburdened with 20.7 million PLHIV. As of 2020, 87% of PLHIV in these regions were aware of their HIV status and 83% were on ART (Orel et al., 2022). Cancer Care Ontario (CCO) describes person-centred care (PCC) as an approach to providing care that involves a partnership between patients and healthcare providers to actively involve patients in the design and delivery of care (Calisi et al., 2016).

In its efforts to fight against the epidemic, the Ministry of Health and other non-governmental partners have implemented strategies. These include prevention of mother-to-child transmission (PMTCT), provider-initiated testing and counselling (PITC), HIV self-test (HIVST), community facility linkage (CFL), street testing, youth-friendly reproductive services, and expert patients, among others. These programmes were initiated because the medical model is limited in that it only addresses physical and health needs while neglecting social, psychological, emotional and safety needs of patients. Chronically ill patients become their own caregivers through experience and involving them in care can inform effective management of illness.

In a study by the Ministry of Health (2022), Malawi has interesting observations on the same. Malawi’s HIV prevalence rates have been categorized regionally and according to age groups. HIV prevalence is at 20.8% among adults of 45-49 years. Prevalence among adults of 15 years and older in Central East and Central West regions of Malawi is above 5% whilst it peaked in South West and Blantyre City at 14.2%. Nationwide, 88.3% of PLHIV adults are aware of their HIV status, 86.6% are on ART and 83.8% have achieved viral load suppression (Ministry of Health, 2022). NAYO is a suitable research site because it is in the Hills of Blantyre which has highest prevalence rate.

In 2018, Malawi was estimated to have one million PLHIV and 13,000 deaths from HIV-related illnesses (Conan et al., 2021). Despite efforts such as accessibility to condoms, scaling up of tests, treatment and male circumcision and use of PrEP among those at risk after exposure to reduce HIV transmission, Blantyre still has the highest HIV prevalence rate at 14.2% (Ministry of Health, 2022).

Demographic statistics show that Malawi’s total population is at 20.8 million and its general HIV prevalence rate is above 8%. In 2020-2021, Malawi had 20,000 HIV new infections among adults above 15 years. Puleni and Nyondo-Mipando (2022) researched strategies for optimizing the uptake of assisted partner notification services among newly diagnosed HIV-positive adults at Ndirande Health Centre in Blantyre Malawi, and their findings revealed that lack of information on ART services, poor contact profiling, and intimate partner violence were barriers to service uptake. They suggested client contact profiling for tracing, sensitization on the benefits of ART services, screening for intimate partner violence, provider training, home testing and funding for the implementation of service as strategies to enhance the uptake of services among the tested adults (Puleni & Nyondo-Mipando, 2022). In 2018, the government of Malawi through the Ministry of Health showed that 86% of HIV youthful patients were on ART but 20% of these had not attained viral suppression and therefore at a higher risk of infecting others (Zgambo et al., 2021).

Nancholi Youth Organization (NAYO) is a community-based organization that started as a youth club offering youth-friendly Information and services aiming at reducing the spread of HIV/AIDS among the youth. NAYO started its operations in 2002 and was registered as a community-based organization under the CBO Act in 2004. NAYO is in the hills of Blantyre which has the highest HIV prevalence rate, making it a suitable research site. It is specifically located in the Green Corner ward and currently serves 25 villages.

As time went, it upgraded its services to serve all age groups found within its catchment area. NAYO offers services including voluntary counselling and testing (VCT), self-test kits, pre-exposure prophylaxis (PrEP), post-exposure prophylaxis (PEP), palliative care, ART, and youth recreation services. Furthermore, NAYO provides PMTCT, animal pass-on (in which HIV patients are given goats or pigs to breed and once they deliver, they pass on the young goat or piglet to another patient, nutrition education and supplements and education support. NAYO was chosen as the research case because it is found in Blantyre which has the highest HIV prevalence rate, and it offers a wide range of services aiming to reduce the spread of HIV/AIDS using a community-based approach. Initially, the researcher wanted to explore if what NAYO is offering is within Person centred care (PCC).

1.3 Problem statement

Most studies on the implementation of PCC have been done in high-income settings such as the UK, Sweden, Netherlands, Norway, Ireland, Poland and Greece among others where existing definitions, frameworks, and measures have been developed. There is a need to develop PCC definitions and frameworks that fit lower-income contexts (Wachira et al., 2023).

HIV service engagement is influenced by a wide range of factors such as individual circumstances and structures influencing a person’s agency to engage in HIV services. The structure of the biomedical model compels patients to fit within the system when in a healthcare institution. Those who find it difficult to fit in resort to seeking alternative healing practices (Skovdal et al., 2017). Exploring the implementation of PCC will help in designing interventions that address the needs of HIV patients in Malawian communities.

1.4 The purpose of the research

A study by Bristowe et al (2019) revealed that PLHIV have complex physical, psychological, and social needs and poorer health-related quality of life (HRQoL). PCC's approach to care is respectful and responsive to the needs of the individual and enables professionals to deliver quality care. A person-centred approach to care can address the multidimensional concerns of PLHIV. PCC provides a platform where patients, healthcare providers and support providers collaborate to assist patients manage their illness by involving them in the decision-making about their disease and illness. This calls for a need to explore the satisfaction of HIV patients with services and benefits. The purpose of this study is to contribute to the body of knowledge that integrates cure and care by involving a range of systems to manage disease and illness. The research could aid the design of a person-centred model for low-income community contexts like those of Nancholi in Malawi.

1.5 Research questions

1.5.1 Main research question

What is the involvement of HIV patients in care within NAYO Programmes?

1.5.2 Specific questions

1. What is NAYO's understanding of [PCC] care for HIV patients?
2. How is PCC put into practice within the context NAYO?
3. What needs of HIV patients does NAYO seek to address?
4. How are patients involved in NAYO?
5. What factors facilitate NAYO's approach?
6. What factors challenge NAYO's approach?

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Chapter two

Literature review and theoretical framework

Chapter Three

Research Methodology Research design, research site, population, sampling and sample, data collection, data analysis and management.

Chapter four

Study findings and discussion

Chapter five

Conclusion and recommendations

2.0 Chapter Two: Literature Review and Theoretical Framework

2.1 Chapter Overview

This chapter presents the literature review and theoretical framework. The literature that is reviewed is on person-centred care, expert patients, greater involvement of PLHIV, stigma, patient's support system, the Malawi healthcare system and community care. The PCC section focuses on the definition, evolution, implementation, and benefits realized through the implementation of person-centred care. The expert patient section focuses on the significant roles of expert patients in implementing PCC and areas in which patients are assumed to be experts in the management of illness. It also highlights the limitations of the implementation of expert patient programmes. The greater involvement of PLHIV emphasizes promotion of HIV patients' participation in treatment and care.

In this study, stigma is observed to be an obstacle to the implementation of PCC that needs to be dealt with to pave a way for effective care provision. Patient support systems play a significant role in the provision of psychosocial support to enhance quality care. COPC has been advocated to reach the underserved populations in hard-to-reach communities. Community care is facilitated and coordinated by community health workers whose roles include assessment of patient needs, linking the patient with healthcare services, provision of psychosocial support to patients through visits and follow-up to track patients' progress. The Malawian healthcare system provides a background and structure of healthcare provision in Malawi focusing on a community level.

2.2. Person-Centred Care

2.2.1 Evolution of PCC

The PCC concept originated from the care of older persons with chronic illnesses in nursing institutions and homes. Kitwood (1997) developed the theory of PCC in the context of dementia care. He emphasized the importance of understanding the needs of a person besides being a patient. The PCC approach to care considers people's historical and family context, their strengths, and weaknesses. PCC requires a shift from the healthcare system that views the patient as a passive target to a model where the patient actively participates in decision-making about his or her care (Eklund et al., 2019).

Individual capacity and determination are considered vital to achieving personal goals in PCC. PCC focuses on the whole person by considering mental, emotional, and situational aspects beyond sickness (The American Geriatrics Society Expert Panel on Person-Centered Care, 2016). These considerations are made through the involvement of patients in illness management processes.

2.2.2 Similar Terms

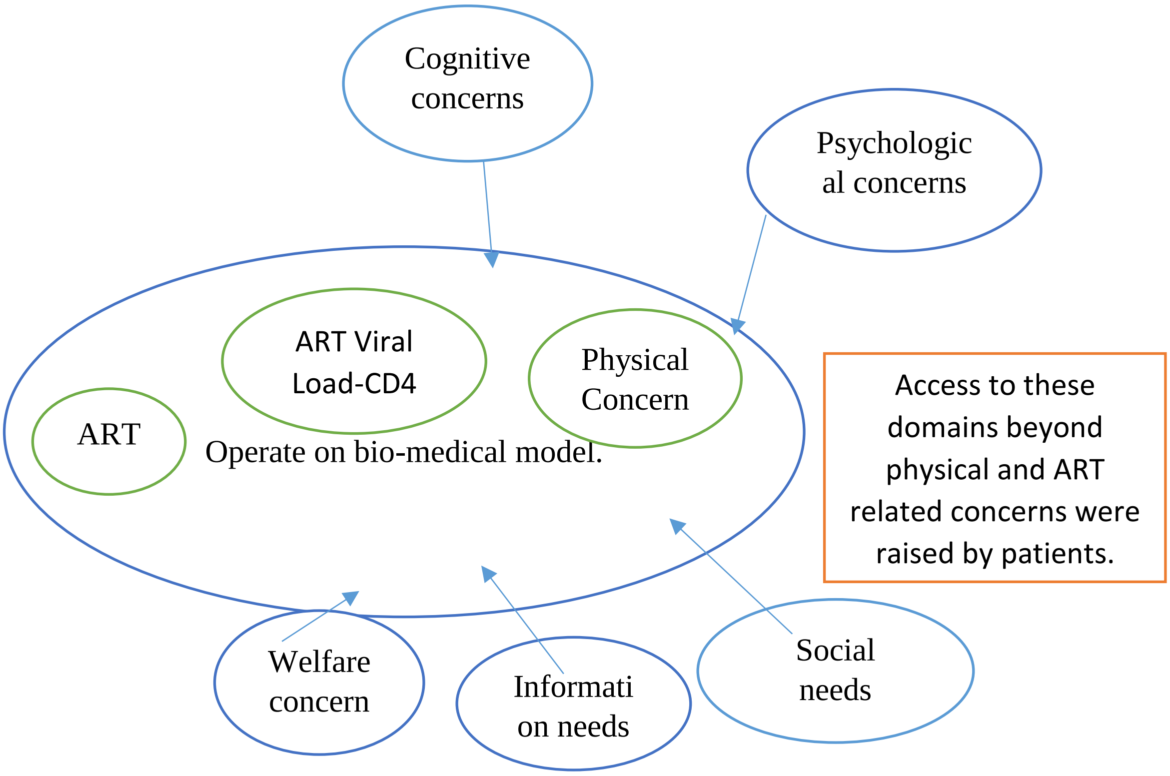
PCC has evolved in different settings of interventions within medicine, social work, psychology, and sociology. There are a range of similar terms to PCC used such as patient-directed, person-focused care, personalized medicine, person-directed, individualized care, client-centred, user-oriented care, and people-centred care (The American Geriatrics Society Expert Panel on Person-Centered Care, 2016; McCormack, 2004; White et al., 2008; Chappell et al., 2007; Eales et al., 2001; Kajonius & Kazemi, 2016;Kazemi & Kajonius, 2015). The use of similar terms suggests efforts to involve persons by considering their preferences in interventions to achieve the desired change.

2.2.3 Components of PCC

Calisi et al (2016:311) identified components of PCC based on what patients deemed to be important in their treatment. These include "care that is caring, compassionate, and empathetic, person or patient is the centre of focus, care that is respectful and/or dignifying, person or patient is a part of their care, and care is unique to the individual's needs." Involving patients in care management could lead to positive results and effective achievement of goals because interventions are directed toward addressing their contextual needs.

An analytical study by Lowther et al (2018) on active ingredients of a person-centred intervention for people with HIV using mixed methods was conducted in Mombasa Kenya. This qualitative analysis identified four active ingredients: appropriate medication, health education, counselling, and having time to talk. Appropriate medication and health education improved adherence to treatment while having time to talk allowed the patients to talk about their problems and improved their mental health (Lowther et al., 2018). These ingredients are contextualized to PCC application within a clinical setup with healthcare providers playing a key role. It however left out the direct involvement of patients as a driver of their care system which is core to the implementation of PCC.

In figures below, Figure 1 shows a traditional medical model that ignores the social, cognitive, information and welfare needs of PLHIV while Figure 2 shows that PCC considers the diverse needs of PLHIV and adopts a collaborative approach to care.



Access to these domains beyond physical and ART related concerns were raised by patients.

Figure 1: *Model of current HIV care*

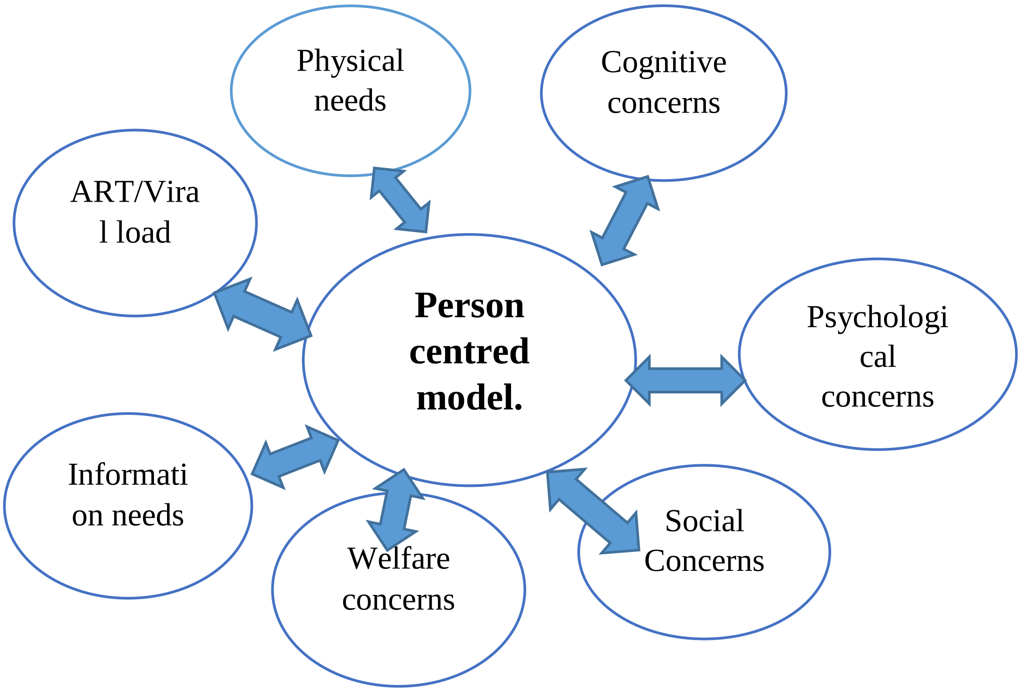


Figure 2: *Model of person-centred care*

2.2.4 Person-centred framework

Implementing PCC requires redesigned and re-structured services and roles to create a conducive environment for patients' involvement (Granström et al., 2020). Santana et al (2018) suggest a three-stage process in the implementation of PCC. First is the structure and system, which focus on the organisation and interrelationship of health sectors; the second process focuses on the interaction between patients, health care providers and support that embraces communication, respect, compassion, and engaging patients in illness management; and the third is the outcome based on evaluation and reviews. This focuses on the effects of health system organisation and interaction between providers and users as key drivers of quality health care (Santana et al., 2018). PCC sets an atmosphere where patients can participate in their care.

2.*2*.5 The need to implement PCC

People report experiencing good health care when they receive timely access to treatment and care and the quality of the relationship between patients with health and social care providers in managing health problems (Kuluski, 2020). This is a shift from medical models to a more collaborative relationship that actively engages patients and considers their needs and preferences in illness management.

Patients need to be involved in care by engaging them in decisions about their treatment and care. This is because patients take specific actions to manage illness and improve their health. Patients have preferences and values that must be considered in care. A study by Offei et al. (2020) on community-based enhanced care to improve person-centred outcomes for people living with HIV in Ghana, revealed that patients expressed the feeling that healthcare professionals were more interested in their HIV and not in them as persons. They recommended the need to involve patients in their care (Abboah-Offei et al., 2020)This can be done through the proper implementation of PCC, which considers all aspects of the individual rather than physical or disease alone.

Patient-centred care requires prioritizing patients rather than benefits or profits for institutions. It requires quality care in which healthcare workers give patients enough time to express their concerns and needs and involve them in decision-making. This is a challenge to healthcare systems which are under-resourced because the ratio of healthcare professionals to patients is high. This puts pressure on healthcare providers who also consider those waiting for consultation and diagnosis. There is a need to increase human and material resources to achieve person-centred care (Santana et al., 2018).

Patient-centred care at the facility level requires adjustments of the structure to accommodate the needs of patients. The system needs to be flexible enough to accommodate patients' needs by understanding how patients can participate and connect with health systems that enhance their care (Morolake et al., 2009). Allowing patients to facilitate the interaction and providing medicine refill options such as home delivery, community centre and facility refills on both weekdays and weekends could provide flexibility.

Individualized care requires adherence to the principle of individuality. This is the principle of taking and treating each person as unique in terms of his or her needs and preferences. This could be enhanced through meaningful partnerships between patients, healthcare professionals and their support systems. Healthcare providers need to communicate with patients about their disease and care. This could enhance the active participation of all stakeholders in patient treatment and care (Brown et al., 2019).

Person-centred care emphasizes care rather than cure. This requires healthcare providers and patients' support systems to empower patients to take an active role in self-care and adopt practices that enhance care such as making necessary adjustments in their diet, activities and lifestyle choices to promote positive living with chronic illness (Guell, 2012). Empowered by experience, patients with chronic illness learn to manage their illness better and become their own caregivers. Involving them in care would yield positive results because they focus on getting their needs met and life enhancement styles and activities for their benefit.

Patient-centred care requires a commitment to being empathetic; humanized care that values and involves the service user. The emphasis is on knowing the motivation of individuals who join the medical profession because they deal with human life (Scammel, 2016). Scammel emphasizes that people need to have good reasons for joining the medical profession so that they can empathize with patients. This is one of the main ethical dimensions of person-centred care implementation.

The collaboration between healthcare professionals, community workers and social workers enhances positive outcomes in the sense that each category makes a valuable contribution to support an aspect of patient life. This is enhanced through communication and assessing of functional abilities for each category realizing its importance in care (Joubert, 2023). This collaboration is done better through the implementation of PCC which emphasizes collaboration between patients, healthcare professionals and patient support systems to achieve quality care.

Wachira et.al (2023) conducted a study on promoting patient-centred care in HIV settings in Sub-Saharan Africa (SSA). Their findings reveal that HIV care providers in the SSA region lack adequate training on the key components of PCC with a major focus on communication and shared decision-making because healthcare providers expect patients to act in a certain way when interacting with health systems that lean towards the medical model. Their research further recommends that the SSA region would benefit from studies on the implementation of PCC in disease burden health systems (Wachira et al., 2023).

Malawi implemented HIV self-testing (HIVST) to increase HIV testing uptake by men because traditionally men seek help less as compared to women. This is because hospital settings compel patients to depend on healthcare provider`s decision and men do not take illness seriously as compared to women. Self-testing was facilitated by promoting privacy and convenience. A qualitative study using interviews was conducted by Hubbard et al. (2022) on improving ART initiation among men who use HIV self-testing in Malawi. Their research findings revealed that there is a lack of external motivation to support and link people to care where health workers give guidance to support treatment and care after diagnosis. Secondly, there is lack of post-test counselling due to the unavailability of health workers to support patients as they experience disbelief and shame, fear of lifelong medication and unwanted disclosure. These factors were major barriers to ART initiation. These findings reveal that the implementation of HIV self-testing did not consider how to address these psychosocial needs and the follow-up of HIV patients after the self-test or how to initiate them into ART and care programmes. This calls for a need for PCC implementation in HIV services (Hubbard et al., 2022).

2.2.6 Benefits of PCC

PCC's approach seeks to make the institutional environment more comfortable and home-like for patients. In a homelike environment, people thrive because their needs are met, have strong familial support and acceptance. Patients take an active role in illness management decisions through implementing needed actions to improve their health. Involving patients in their treatment decisions ensures sustainability and could lead to the achievement of positive outcomes (Granström et al., 2020).

There are many benefits of PCC ranging from helping to foster healthy relationships, improving self-management support and shared decision-making. These lead to an increase in patient satisfaction, self-efficacy and empowerment, leading to a change in self-care behaviours including better medication and treatment adherence (Balqis-Ali et al., 2022). Wherever PCC has been well explained, introduced, and implemented, significant improvements and change have been achieved through disease management and patients performing an active role in illness management.

2.3 Expert Patients

The concept of expert patient originates from the Stanford Chronic Disease Self–Management Program (CDSMP) launched in the 1980s which aimed to provide support to patients with non-communicable diseases (NCDs) through patient participation in short workshops. The management of NCD emphasizes collaborative care through a partnership between patients and professionals with self-management education which requires changes in the culture and structure of service delivery (Boulet, 2016).

A study by Xiao (2015) unveiled the challenge of changing the behaviour of healthcare workers who assume expert roles in the care of patients as per medical models. Studies indicate that expert patient strategy reduces severe symptoms and pain in patients in the UK. Expert patient review studies show that medical professionals make decisions for patients using their medical knowledge and therefore remain expert in care and not all patients would want to take illness management responsibility because of choice and competency factors (Xiao, 2015). There is a need to contextualize PCC frameworks by considering circumstances and factors that could motivate patients to participate in their care.

Expert patients help at the facility level. They assist in tasks such as taking vital signs, temperature, heights, weight, counselling, and record keeping and follow ups. This volunteering is beneficial to patients because they receive services such as animals, food items and farm inputs (Tenthani et al., 2012). This is like Kato et. Al. (2011) whose research also emphasized the roles expert patients play at the facility level. Expert patients contribute much towards person-centred care, especially in HIV treatment and care. They provide appropriate care based on their knowledge and experiences on living with HIV.

Malawi implements a three-tier Community Facility Linkage (CFL) model in public health facilities. It includes Expert patient, Mentor Mothers (Mothers who are living with HIV, have followed advice on prevention of vertical transmission and provide counselling to pregnant women and postnatal mothers on safety measures to avoid vertical transmission. , and CHWs who are initiated and overseen by non-governmental organizations (NGOs) to provide support in the prevention of mother-to-child transmissions (PMTCT) program. These use a combination of facility and community-based strategies to deliver counselling, accompaniment, testing, tracing, follow-ups, education visits, and established peer-to-peer networks (Topp et al., 2020). This provides a variety of options for patients to choose from if they want to be assisted at the facility or within their communities. This was meant to provide opportunity, especially to those who are not comfortable with clinic visits.

Expert patients and mentor mothers were recruited from PLWA to connect with clients living with HIV and to function as role models. CHWs were trained to provide counselling and education on pregnancy and breastfeeding and to address pregnant women's fears, stigma, and uncertainty of PMTCT. Topp et al's. (2020) research findings revealed that CHWs play a vital role in improving human resource capacity, reducing workload, enhancing social connectedness and patient participation, and promoting a strong link between community and facility. The engagement of a broader social network, such as family members and spouses were an important source of emotional and material support for mothers. These interventions improved ART uptake and retention. These models considered the psychosocial and physical needs of pregnant mothers through collaboration between healthcare providers, HIV-pregnant women, and their support networks such as family members. However, it employed a medical model in practice to achieve treatment rather than integrating cure and care (Topp et al., 2020).

2.3.1 Debate and Criticisms of Expert Patient Programmes

The criticism of expert patient programmes (EPP) is based, firstly, on the one-size-fits-all conceptualization which assumes that it can be implemented in all contexts and places (Kendall & Rogers, 2007). Secondly, expert patient programmes perpetuate the medical model because they rely on the decisions made by healthcare workers (Greenhalgh, 2009). Finally, expert patient program implementation is linked to social class which benefits those who have and disadvantage the have-nots because it places the cost burden on patients (Lindsay, 2008; 2009). The implementation of PCC must be put in the correct and right context by considering factors that affect its applicability.

Proponents of self-management for chronic diseases, such as Carr and Moffett (2005), Gallant (2003), Kendall and Rogers (2007), and Korp (2008) promote the social model of illness in theory not in practice because they suggest an individualistic approach that risks victimization and ignore the social context of illness (Taylor & Burry, 2007). To potentially solve problems arising from the implementation of EPP as these criticisms reveal, a collaborative approach between healthcare providers and HIV patients in decision-making about care is needed to ensure better management of chronic illness (Lindsay & Vrijhoef, 2009).

2.4 Greater involvement of people living with HIV/AIDS (GIPA)

The Paris AIDS Summit in 1994 with 42 countries declared that the principle of the Greater involvement of people with or affected by HIV/AIDS was critical to ethical and effective national responses to the epidemic. It aimed to assist different sectors involved in a partnership to fight against AIDS through the application of the GIPA principle (Simon-Meyer & Odallo, 2002). The partnership was a way of acknowledging the complexity of solving the HIV/AIDS problem which is influenced by many overlapping aspects. Collaboration through involving a wide range of sectors entails efforts to address the needs of PLHIV.

Kato et al's (2011) study revealed that feedback from HIV patients to health care services improves service quality and participation of PLHIV and leads to a reduction of stigma and discrimination (Kato et al., 2011). South Africa developed the GIPA workplace model (GWM) aiming at selecting, training, and placing field workers in partnership with organizations to enrich workplace policies and programmes on HIV/AIDS. In their situational analysis, they realized that PLHIV plays a key role in designing and implementing interventions and use their experience in giving face to and normalizing HIV infection by creating a productive workforce and supportive work environment for PLHIV. It was also reported that evidence from the implementation of GWM revealed that motivating and involving PLHIV in interventions results in reducing stigma and discrimination (Simon-Meyer & Odallo, 2002).

2.5 Community-based care and community health workers (CHWs)

Luker and Orr (1992) as cited by Johnson & Brown (1995) conceptualize the term community as locality, social activity, social structure, and sentiment. This write-up will adopt the term community as a locality and social structure. Locality is marked by geographical location and structure entails the social and political organization of people within a specific place (Johnston & Brown, 1995)

Community-oriented primary care (COPC) is a primary care delivery approach that originated from Sidney L. Kark and Emily Kark's work in Pholela, South Africa, in the 1940s and 1950s and extended worldwide. This approach is characterized by the integration of clinical care and public care. Pholela health unit in KwaZulu Natal, South Africa called the community health centre integrated individual-based care with community health activities. The health care team conducted activities such as the identification of community health needs, promotion of community participation, and integration of primary care and public health in the care of individuals and communities. Health centre services integrated curative, preventive, and promotional activities in the fight against diseases (Gofin & Gofin, 2011).

A study by Bam et al. (2013) on COPC in Tshwane, South Africa and the health post model revealed that the COPC engages the socioeconomic and political-cultural determinants of health and disease to enhance health literacy and social capabilities leading to the growth of individuals. COPC is a type of formalized community-based care that provides opportunity to reach people in rural areas. Health care could be achieved through the empowerment of community members to improve service delivery (Bam et al., 2013).

The study of community health care aids in understanding how community health needs affect patients and their caregivers (Johnston & Brown, 1995). Understanding the community would help in the identification of the health needs of the community. This would result in the provision of effective care that addresses the needs of the community within the locality.

Community health workers are both community volunteers who work informally to improve their community's health and those who are paid for providing these services. Those recruited to work in formal organizations are paid on a contract basis while those working voluntarily are chosen from the community and serve their community without pay. It should be made clear that in non-governmental organizations volunteers sign agreements and are trained to provide community services. They are frontline health and social service workers and are often a community member's first contact with a health or social service agency. CHWs have distinct roles, statuses, and recognition in different contexts. They come from the communities they serve and are therefore uniquely prepared to provide culturally and linguistically appropriate services. They provide a wide range of services, including outreach, home visits, health education, client counselling and case management (Berthold et al., 2009).

CHWs play various roles including cultural mediation between communities and the healthcare providers and social services systems. Intimate knowledge of the communities they work with permits CHWs to serve as cultural brokers between their clients and health and social services systems through counselling and social support by providing direct services and referrals. They also play various roles such as providing culturally appropriate health education, advocating for individual and community needs, ensuring that people get the services they need and building individual and community capacity (Berthold et al., 2009).

The roles played by community health workers form part of team care model which was introduced by Thomas Bodenheimer (2006) as cited in Berthold et al (2009) from the University of California in San Francisco. In this model, CHW is a critical component with four significant roles to play namely: improving quality, access and patient-centeredness, reducing health care costs for high-cost patients and changing primary care from a doctor `game to a team game` (Berthold et al., 2009).

Community health workers play a vital role in the implementation of care approaches for patients with chronic illnesses. In limited resource setting communities like Nancholi, community volunteers provide personal and community care. This necessitates a shift from a physician-centred model to non-physician health workers in the provision of care (Wools-Kaloustian & Kimaiyo, 2006). The investigation noted that Malawi's public health system and non-profit organizations have limited healthcare workers due to lack of financing and they do not charge fees. It is from this background that community health workers and community volunteers are trained and engaged to fill this gap.

Community volunteers are key in the facilitation of person-centred care. This is because they are trained, and they are committed to serving others within their community. Community volunteers assess patients' needs and provide medical, psycho-social, material, and spiritual support to patients. These are key drivers of patient-centred care because they adhere to ethics by respecting patients' autonomy and choices (Batte et al., 2021). Patient-centeredness and empowerment are important in working with resource-constrained populations. This gives patients the power to manage their illness and disease. This could be done by allowing patients to take the lead in their care through the expression of their needs and concerns to enhance better care (De Lourdes Arrieta-Canales et al., 2023).

2.6 Stigma as a barrier to HIV management

Goffman (1963) defined stigma as a significantly discrediting attribute. Stigma destroys the image of PLHIV because it makes them have a lowered self-esteem. Sex is a key method for HIV transmission in Africa and stigma is caused by society's perception that links HIV and sexual immorality. Goffman's definition resonates with Alonzo and Reynolds (1995) as cited by Holzemer et al. (2007) who defined stigma as a powerful discrediting and tainting social label that changes the way individuals view themselves and how they are viewed by others (Holzemer et al., 2007).

Holzemer et al. (2007) report further asserts that when HIV positive diagnosis has been revealed, HIV patients go through a grieving process before acceptance and make necessary adjustments to cope with the disease. HIV/AIDS is viewed as a life-threatening, dirty disease, and people who are diagnosed with HIV/AIDS are called bad names. For example, Dlamini et al. (2007) in their study on verbal and physical abuse and neglect as manifestations of HIV/AIDS stigma in five African countries reported that in Tanzania, PLWA are called *maiti inayotembeyea* (walking corpse) and *marehemu mtarajiwa* (expected to die).

The type of stigma could be enacted (from others) or felt (from within) by the person. Enacted stigma is discrimination that PLHIV experiences for example, telling them to use different chairs and toilets (Holzemer et al., 2007). Mbonu et al. (2009) conceptualize internal stigma as a survival mechanism that helps PLWA to protect themselves from imagined discriminatory acts. For example, HIV-infected patients choose to isolate themselves for fear of rejection.

HIV stigma is common in Sub-Saharan Africa where communal life poses a dilemma. HIV patients are stigmatised, and this makes them unable to interact with others due to fear of being exposed. On the other hand, communal life also ensures that sick people get help and care. Studies done in Malawi, Lesotho, Botswana, South Africa, and Ghana reveal that HIV patients suffer psychological isolation and condemnation from their families, friends, and society due to the connection between HIV and immorality. Stigma acts as a policing mechanism because HIV status is perceived to have resulted from sexual immorality although sex is not the only means of HIV transmission (Mbonu et al., 2009).

These findings resonate with Letamo’s (2003) research, as cited by Holzemer et al. (2007), which reveal the correlation between stigma and access to care. Letamo’s study in Botswana revealed that nurses stigmatize patients due to lack of personal experience in caring for HIV patients as opposed to those with friends and families with HIV/AIDS (Holzemer et al., 2007). Involving them in care would help to reduce stigma.

HIV patients just as any chronically ill patients experience emotional distress from the disease and self-isolation, and avoidance of interaction that leads to stigma (Angwenyi et al., 2018). The involvement of HIV patients in treatment and care could be instrumental in the fight against stigma. The presence of the disease negatively affects the self-esteem of HIV patients through their perceptions of what others think about them.

Person-centred care can be enhanced through the implementation of strategies that address stigma and discrimination. This is because PCC provides opportunity for patients to take active roles in care by addressing various patient needs. Stigma on the other hand is a barrier to the implementation of PCC because it makes patients isolate themselves for fear of the community’s judgement. Stigma reduction programmes include community education, awareness campaigns and engaging healthcare providers and community leaders (Boakye & Adjorlolo, 2023).

2.7 Patient support system

NAYO`s ART programme forms a basis for the provision of a wide range of services such as psychosocial support, home-based care, palliative care, and assistance with school fees to students whose parents are on palliative care and ART. The identification of these support services is based on the assessment of individual needs of each patient. These are done better through the implementation of PCC which emphasises on meeting needs of individual patients.

Patients’ support systems include those who spare time to visit patients in their homes or at the facility to encourage, give emotional support, provide reassurance and share information about their condition (Lavoie et al., 2013). Patients need proper accompaniment in their treatment and care journey. The provision of patient support can be enhanced by the collaboration between patients, healthcare providers and the patient’s support system to enhance quality care.

This discussion has highlighted that collaborative care between healthcare providers, patients and their support system can assist patients to achieve communication and capabilities thereby enhancing health outcomes. Each of the parties play a significant role in care and these are interdependent to promote quality care for patients. Research by Joubert (2023) on PCC within community-based domains revealed that collaborative care between nurses, community health workers and social workers helps patients achieve communication and functional abilities thereby improving health outcomes for patients (Joubert, 2023).

HIV patients need a safe space where they can comfortably share their experiences with others. Often emotional support is provided by support groups where patients meet to share and listen to one another. PCC encourages collaboration between healthcare workers and the patient support system to provide psychosocial support which enhances care for HIV patients and those with chronic illnesses. HIV patients need attention and the fulfilment of psychosocial needs in their communities. Healthcare professionals need to encourage HIV patients to find a safe space in a community where they can share and find companionship and home-based care where attention and emotional support are given to them (Ginting et al., 2022). Person-centred care provided through collaboration between patients and their support system would enhance the provision of psychosocial support to HIV patients.

2.8 Malawi’s healthcare system

For many years, Malawi has had a poor healthcare system. Statistics prove that large parts of Malawi’s population especially in rural areas lack access to health care. A high burden of disease, chronic poverty and a growing population accelerate the need for extending and improving health care (Benson Chilima – PHIM, 2023). Malawi’s healthcare system faces multiple obstacles including poor infrastructure**,** the dire shortage of drugs, depleted equipment in many health facilities, de-motivated health personnel, etc. Thus, in 2017, the WHO conducted timely research on healthcare in Malawi. The intense study revealed that 70 percent of all child deaths are due to preventable causes, including malaria, diarrhoea, pneumonia, anaemia, HIV, and malnutrition.

Malawi's health sector has two major parts: namely the modern and traditional. Before independence, the traditional sector was mostly utilized by Malawians in rural areas due to lack of infrastructure and traditional views and practices which favoured traditional healing. It is important to note that 85% of Malawians live in rural areas. By 1964 (independence), Malawi had two major financing sources for health services: government and churches. The government owned public health institutions while churches formed the Private Hospital Association of Malawi (PHAM) which was later renamed as Christian Health Association of Malawi (CHAM).

This investigation disclosed that the traditional sector also had gone through a transformation from being called witch doctors to traditional healers or herbalists, traditional birth attendants and health counsellors. The Ministry of Health (MoH) develops policies and planning strategies and programmes for healthcare while the CHAM secretariat in consultation with MoH formulates operational policies in the interests of the church organizations it represents (Banda & Simukonda, 1994).

Malawi has five levels of services namely community level, health centres, rural hospitals, district hospitals and special hospitals. This hierarchy is based on referral roles where patients are moved from lower to higher institutions. However, this is not what is entirely practiced because CHAM and private hospitals do not fall under this 'ladder' or hierarchy and the lack of medical equipment and medicine on the lower rungs of the ladder makes people bypass it to district and central hospitals. Healthcare institutions and services are mostly available in urban areas. This is because the urban population is concentrated making a hub of business and people can afford to pay for health services thereby supporting institutions to sustain the provision of services (Makwero et al., 2021). This leaves rural areas neglected from healthcare services. Community-based organizations like NAYO fill this gap.

The major challenge in public healthcare provision is financing. MoH hospitals have three sources of funds namely public, foreign donations and fees. CHAM hospitals have four sources namely subsidies from the government, the churches, fees, and donations from overseas entities. Revenues from MoH institutions are sent to MoH headquarters while revenues generated in CHAM hospitals are returned for the running of its programmes and services (Banda & Simukonda, 1994). This gives an advantage to CHAM hospitals in terms of funding and sustainability for quality services as compared to public health services which are underfunded coupled with poor management of its funds and resources.

To provide universal healthcare amidst funding challenges, the government's health policy is flexible allowing the participation of non-governmental organizations and traditional health practitioners to support governmental organizations. The government encourages the private sector by permitting medical personnel to retire early and set up private surgery facilities. It allows non-medical professionals to set healthcare businesses for minor health complaints, it encourages parastatal organizations to adopt medical schemes for its employees and set up bodies such as Medical Council of Malawi (MCM) and Nurses and Midwives Council of Malawi to regulate the healthcare profession (Banda & Simukonda, 1994).

Most rural communities in Malawi access their healthcare needs through the essential health package consisting of healthcare interventions provided by a multidisciplinary team of healthcare professionals within the district health system (DHS). The DHS consists of community, health centres and district hospitals which focus on the delivery of secondary and primary healthcare services through preventive healthcare implemented by health surveillance assistants (HSAs) and village health committees (VHCs) (Masangwi et al., 2012).

People in rural areas have limited access to healthcare services due to a lack of transportation, healthcare costs and unavailability of medicines (Harrison et al., 2020: Chirwa et al., 2023). MoH funds are mostly utilized at central hospitals and trickle to district hospitals but rarely reach health centres and community interventions. Community health centres are neglected in terms of resource allocation and funding for their programmes and services.

Malawi depends on non-governmental organizations such as private hospitals and CHAM institutions to complement the government in the delivery of health services. Despite community healthcare levels being praised for their contribution to the achievement of universal healthcare (UHC), their involvement in the design, implementation, management, and monitoring of interventions is limited (Van Niekerk et. al, 2023). Community-based organizations need the capacity to reach vulnerable rural populations especially in hard-to-reach areas due to poor road infrastructure.

2.9 Theoretical Framework

This section focuses on the theoretical framework of the study which adopts Habermas and Foucault's theoretical underpinnings. PCC implementation would require a shift from the medical model to a more partnership approach to allow patients to take an active role in their care and treatment. Foucault argues that people with chronic illnesses integrate treatment and care activities into their everyday life. HIV patients adjust in lifestyles and food diet to manage their illness through treatment and care.

2.9.1 Colonization of life worlds (Jurgen Habermas)

Habermas (1981) argued that the power of the medical profession, given to healthcare providers, derives from collective strength sanctioned by a society which is reflected in three assumptions of traditional healthcare relationships with patients. These assumptions are that the professional is an expert, the profession itself is the legitimate gatekeeper to all healthcare services, and the ideal patient is both compliant and self-reliant. Self-reliant in the sense that each patient has to take active role in adhering to doctor`s advice regarding treatment to achieve desired outcome (Silva, 2019). This may be true from an acute disease perspective, but when focusing on illness management, this may not be so because chronically ill patients become experts through experience in the management of their illness.

2.9.2 Bio power: Locating self in practice (Michael Foucault)

Bio-power or power over life constitutes power employed to control individual bodies and populations. Individuals adopt behaviours and lifestyles that promote health (Bunton & Petersen, 1997). The sociological perspective and approach to health emphasize care rather than cure. Kohn and McKechnie (1999 as cited by Guell 2012) argued that the shift from cure to care necessitates new norms and renders self-caring individual responsibility and a daily practice for patients as they manage chronic illnesses. This also resonates with Mol (2008) who suggested that care is framed as a consumer choice in which patients are expected to assume an empowered role rather than accepting paternalistic decisions made by healthcare providers. Mol sees patients becoming caregivers who manage their chronic illnesses and integrate care into their daily practices (Guell, 2012).

Promoting quality care among patients requires transitioning from medical models through effective changes in principles, policy, and practice with capacity building for healthcare providers to enhance engagement and build trusting relationships with clients (Lazarus et al., 2023). This can be done through the implementation of person-centred care which emphasizes patients' involvement in rational discernment and decision-making regarding management of disease and illness.

Sociologists conceptualize self-care by focusing on locating the self in practices, embracing everyday discipline that chronically ill patients adopt to achieve their desire for health. Foucault (1990) sees the care of self as a self-reflective practice to achieve freedom. Foucault argues that physical exercises to maintain a healthy body makes one an autonomous citizen (Guell, 2012). As much as healthcare providers diagnose and treat diseases, the management of illness is patients' responsibility.

Person-centred care requires shared decision-making through the involvement of patients in their care. This means that healthcare providers and patient support systems must allow some degree of autonomy and empower patients to take an active role in their treatment and care (Eklund et al., 2019). At the facility level, much power is vested in healthcare providers as per the medical model, which assumes that the healthcare professional is an expert and gatekeeper to a patient's life thereby having legitimate authority to make decisions about patients' lives, treatments, and care.

In the context of this study, Habermas' theory of colonization of life worlds explains the problem in clinical settings where healthcare providers play expert roles with minimal or no involvement of patients in decision-making about care. This is because the structure of healthcare institutions uses a medical model that assumes that healthcare providers are experts and gatekeepers and have the power to decide for patients. On the other hand, Foucault's theory explains how chronically ill patients integrate treatment and care into their everyday practices by making necessary adjustments in their lifestyle and food diet to manage illness and disease.

This complex theory entails the necessary shift from the medical model to a more collaborative approach where patients and their support systems are involved in care and treatment. This partnership is required because healthcare providers are experts at managing disease while patients and their support systems manage illness. Patients with chronic illness integrate care into their everyday lives through their illness management by making choices that benefit them. These theoretical conceptualizations fit in this study as it focuses on the need to integrate cure and care through a collaborative approach in the implementation of PCC.

2.10 Conclusion

Chapter Two reviewed literature on PCC, expert patient, GIPA, community care, Patient support system, stigma, and Malawi health care system. It also explored theoretical concepts of colonization of life worlds by Habermas and locating the self in practice by Foucault. The following chapter focuses on research methodology.

3.0 Chapter Three: Methodology

3.1 Chapter Overview

Chapter three describes the research methodology used for this study. The research site was Nancholi Youth organization (NAYO). The research used stratified and purposive sampling techniques to select ART patients on the first line and NAYO staff directly working with ART patients. The study used semi-structured interviews and participant observation for data collection and developed themes from the research schedule. NAYO was chosen as a research site because it is found in Blantyre, which has the highest HIV prevalence rate of 14.2%, and it is implementing programmes and activities such as ART, palliative care, nutrition education, VCT and education support aimed at reducing the spread of HIV/AIDS.

The study targeted ART patients enrolled at NAYO, the staff members directly working with HIV patients and community volunteers who implement NAYO services in the 25 villages within NAYO's area of operation. A stratified sampling technique was used to categorize NAYO's 530 HIV patients on ART based on the treatment line. The clinician in charge, HCT providers and the project officer have access to ART information and files for HIV patients and assisted the researcher in selecting HIV patients on first-line treatment regimes. Purposeful sampling was used to select key informants from NAYO staff and community volunteers working directly with patients. Semi-structured interviews and participant observation were used to collect data using interview and observation guide. Verbatim was used to transcribe audio for data analysis.

The researcher translated all Chichewa (vernacular language) quotes into English using the same words of participants to retain originality. Chichewa is the lingua franca and national language of the linguistically pluralistic Malawi. Chichewa is the researcher's first language because she was raised in the suburb of Blantyre where it is spoken to the extent that Chichewa has influenced her more and she communicates in it better than the official language, English. Themes were generated based on specific research questions using thematic analysis.

3.2 The Study Design

This study adopted qualitative design using case study approach. This design was adopted based on the fact that involvement of patients and person-centred care are qualitative variables.

3.3 Study Area

Nancholi is a rural area in the hills surrounding the city of Blantyre in Malawi. NAYO's catchment area covers 25 villages within the Green Corner Ward with about 23,000 people

(MPHIA, 2018). NAYO started as a youth club offering youth-friendly services in 2004. NAYO has a wide range of programmes in health care, education, nutrition, and economic empowerment which were initiated based on the needs of PLHIV.

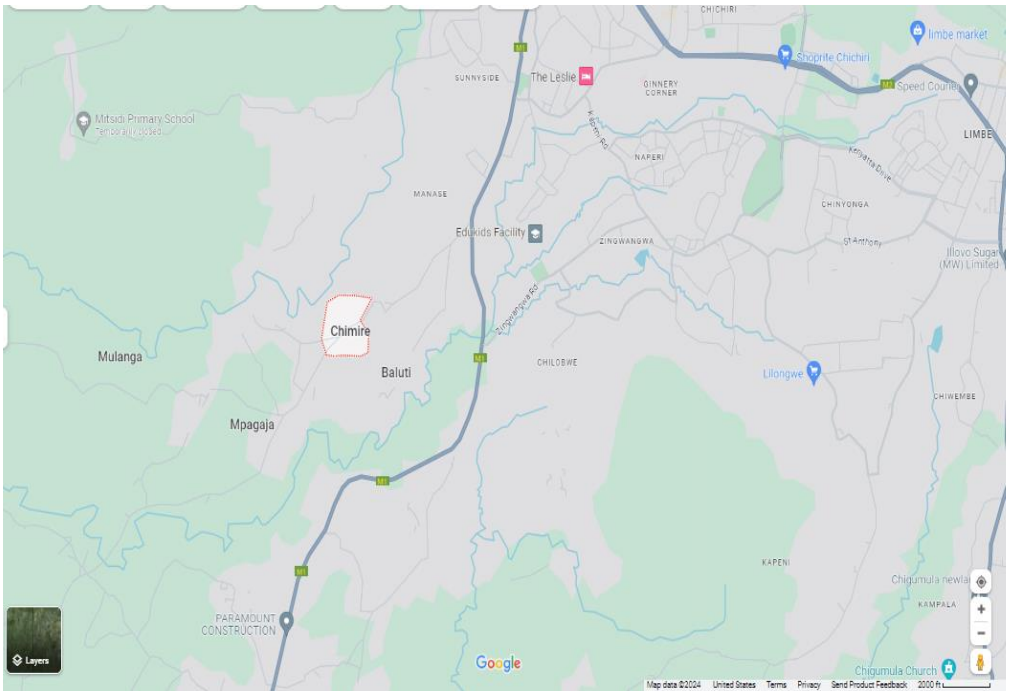


Figure 3: *Nancholi Map*

3.4 Study population

I was referred to NAYO by a friend who gave me the director's contact details. I wrote to the Director requesting him if I could do my study with his organisation. He formally responded and informed the project officer to help me throughout my study. During working hours, I assisted with dispensing medicines and tracing defaulters using ART files and cards. I worked with the nurse in charge and HCT providers who helped with the list of those on the first line of treatment in their ART program. NAYO has over 600 registered ART patients and about 530 active patients on ART (those who regularly come to the facility for refill of their ARVs). Most ART patients are on the first line of treatment. NAYO has 19 staff members working in administration, facility management, and the community. The target was staff members working with community volunteers and those administering ART at facility level. Community volunteers administer to ART patients at the community level.

3.5 Sampling Techniques and Sample Size

This research adopted a qualitative study design using a case study approach to explore the involvement of HIV patients in PCC within NAYO programmes and activities. The research used a stratified sampling technique to categorize HIV patients based on the line of ART treatment and age. The clinician in charge, HCT providers and the project officer assisted in the selection of HIV patient respondents and community volunteers because they directly work with them. Fifteen patients and five community volunteers were contacted through phone calls and requested to come for interviews. All contacted women came for interviews, but most men contacted did not come. This is because of the limited participation of men in ART and community volunteer work.

The challenge was getting male respondents to participate in the study. Male participants were contacted through phone calls twice, but they did not pick the phone calls and only a few participated in the study. NAYO staff members who assisted in the identification of respondents explained that it is generally difficult to get men to participate in their programmes, and they were hoping that I would get some when they came for ARV refill, but it turned out that they sent their wives to get the medicines for them. Most respondents from patient and volunteer categories are females making it a female voice dominated study.

3.6 Data collection

The researcher used semi-structured interviews and participant observation methods to collect data. Interview and observation guides were used to collect data from three categories of respondents which were the ART patients - adults on the first line of treatment, community volunteers, and NAYO staff members. The researcher had a full week orientation to NAYO facility and activities. The researcher administered an interview guide to 23 respondents in total. An audio recorder was used to record all interview sessions and a notebook was used to write notes during observation.

Research observation also revealed that men do not come to the clinic to collect their ARVs. Rather, they give cards to their wives, community volunteers or women guardians to collect for them. The researcher interviewed 11 ART patients (nine females and two Males), five community volunteers (four women and one male), and seven staff members (five females and two males). In total, the researcher interviewed 23 participants (19 females and four Males). HIV patients provided information about their experience and participation in care through activities provided by NAYO programmes.

Key research informants working closely with HIV patients were selected using purposeful sampling techniques from NAYO staff and community volunteers. These provided information about the structure, NAYO’s approach to care and the implementation of programmes and activities for PLHIV. Patient support personnel (community volunteers) provided information about their participation and experiences in NAYO programmes. All participants filled out consent forms before interviews as a formal agreement to participate in the study. Verbal consent for recording interviews was sought and all participants approved the recording of interviews.

The semi-structured interviews were conducted from 23rd October to 14th December 2023 at NAYO Health Centre. All participants agreed and signed the consent form before the interview. The participants also agreed to have the interviews recorded after knowing the purpose and use of the audio files. All the interviews were recorded using an audio recorder. The minimum duration of the interview was 18 minutes, and the longest interview took 107 minutes.

The researcher assisted with dispensing medicines during OPD activities and helped with tracing defaulters during ART clinic days.

During interactions, the researcher observed resistance to answering questions in English. This was also noted during chats. Participants were given a chance to choose their preferred language for comfort. Most participants chose Chichewa, the local language. This is because most patients and community volunteers are not fluent in English. Most staff members also preferred Chichewa citing that English is a foreign language and they speak it when necessary and in a compelling situation. Two interviews were conducted in English while 21 were in Chichewa.

3.7 Participants Demographics

3.7.1 NAYO Staff Participant Table

Pseudonym	**Position**	**Qualification**	**Duration at NAYO**	**Gender**	**Age**
Nanyoni 1	HCT-Provider	HCT-Counsellor	2 Years	Female	42
Nanyoni 2	Project Officer	Advanced Diploma in Community Development	8 Years	Female	27
Nanyoni 3	Bachelor	Advanced Diploma in Food Nutrition	4 Years	Female	29
Nanyoni 4	HCT-Provider	HCT-Counsellor	5 Years	Female	41

Nyoni 1	Monitoring and Evaluation Officer	Bachelor’s in Development Studies	9 Years	Male	30
Nanyoni 5	In-Charge	Diploma in Nursing	2 Years	Female	47
Nyoni 2	Director	Master’s in Business Administration and Bachelor’s in Development Studies	22 Years	Male	40

The qualifications of NAYO staff reflect their specific areas of focus which include clinical, nutritional education and supplements, economic empowerment, and youth friendly services. These specializations are in line with NAYO’s programmes and activities and professionals play a specific role in designing and implementation of interventions in areas of their specialization. These staff members define needs of PLHIV with specific programmes and activities to address those needs.

3.7.2 HIV Patients Participants Table

Pseudonym	**Duration with NAYO**	**Gender**	**Age (Years)**	**Village**
Naphiri 1	19 years	Female	48	Baluti
Phiri	5 Years	Male	19	Baluti
Naphiri 2	19 Years	Female	41	Baluti
Naphiri 3	19 Years	Female	61	Kampala
Naphiri 4	8 Years	Female	53	Chilunduka
Naphiri 5	18 Years	Female	54	Sumani 1
Naphiri 6	19 Years	Female	60	Chilunduka
Naphiri 7	7 Years	Female	46	Chilunduka
Naphiri 8	1 year	Female	35	Baluti
Naphiri 9	21 Years	Female	50	Chilunduka
Naphiri 10	12 Years	Female	61	Nancholi

3.7.3 NAYO Community Volunteers

Pseudonym	Duration with NAYO	Gender	Age	Village
Natsonthi 1	4 years	Female	53	Nancholi
Natsonthi 2	2 Years	Female	59	Nancholi
Natsonthi 3	1 year	Female	49	Manase
Natsonthi 4	8 years	Female	53	Sumani 2
Natsonthi 5	22 years	Male	60	Mpagaja

3.7 Data analysis and Management

All recordings were transcribed verbatim. Once the transcription was done, the researcher listened to all recordings to correct spellings and errors. The transcripts were anonymized with pseudonyms and numbers to hide the identification particulars of respondents. All research participants and the researcher speak Chichewa fluently. The 21 Chichewa transcriptions were translated into English by the researcher. Data has been categorized into themes using research questions. Daily report notes were useful as complementary sources and enhanced interview records, aiding memory in filling the timing gap between interview and transcription. Themes have been coded manually using the flow of specific questions (Bless et al., 2013). The researcher did data coding, processing, and interpretation.

3.7 Ethical Considerations

The research risk level was low (Wits Risk Table from Human research Ethics …) because the focus was on the experience of patients being involved in care. An ethics application was made to Wits University through the School of Social Sciences. The ethics approval certificate was given under the number SOCL-2023-02. Provisional access to the NAYO organization was granted in a formal letter from the director. NAYO directly provided formal access to interview staff, patients, and community volunteers. Participant consent was sought through verbal request and signing the consent form. Anonymity was ensured using pseudonyms in the form of clan names such as Naphiri or Natsonthi (female) and Phiri or Nguni (male). Participants were assured of confidentiality through an explanation of the research’s academic purpose. All interviews were conducted in a private room within NAYO premises. NAYO provided support in case of emergency and HCT providers were available in case respondents felt discomfort. None of the respondents expressed discomfort during interview sessions.

3.8 Conclusion

Chapter three details research methodology. The study adopted qualitative design to explore the involvement of HIV patients in person-centred care at NAYO. The target population includes NAYO staff directly working with ART patients, ART patients on first line of treatment and community volunteers. The study used purposive and stratified sampling methods to select research participants. Semi-structured interviews and observation methods were used to collect data while thematic analysis was used for coding and interpretation of data. Consent forms were used in seeking participants' approval while pseudonyms were used to enhance the anonymity principle. Research approval certificate was given by the Research Ethics Committee from the Faculty of Humanities and a formal access letter was given by the NAYO Director. Chapter four discusses the study's findings and recommendations.

4.0 Chapter Four: Study findings and discussion

4.1 Chapter overview

This chapter presents key findings and discussion of the study. It presents the organizational structure of NAYO in its operation, the process involved in the identification of patients' needs by community volunteers at the village level and the healthcare providers at the facility level. Community volunteers are at the centre of collaboration between patients and healthcare workers. The community volunteers link patients with support systems, the healthcare system, and professionals. They are key drivers of community-based care in the context of NAYO programmes and services. HIV patients are actively involved at the community level whilst minimally not involved at the facility level. Research findings reveal that NAYO implements community-centred care, not person-centred care, because it focuses on the community rather than individual patients. Both felt and enacted stigma are experienced by patients in the process of accessing benefits and services at NAYO. Patients' support system includes family members, friends, community leaders, religious leaders, and community volunteers. Funding is the major challenge impeding the running of everyday activities at NAYO.

4.2 NAYO's Structure

At the top of NAYO's structure is the board of trustees who are custodians of the organization. Under these comes the director who implements decisions by the board of trustees using donor funds to run the programmes/activities. Under the director are key personnel in charge of implementing activities, including the finance officer, human resource manager and monitoring and evaluation officer, working hand in hand with chiefs (traditional leaders) and religious leaders to ensure that human and material resources are available for the activities and programmes. Under these, a team that works closely with beneficiaries is followed to ensure that every activity is done according to plan. These include the programmes officer, the project officer, the clinician in charge and HIV counselling and testing (HCT) providers.

Furthermore, the study findings revealed that field officers work hand in hand with community volunteers in administering the health, social, physical, emotional, and psychological needs of patients. Under the field, workers are community volunteers who are key to providing needed services to the patients in the villages. Most community volunteers are expert patients (as described in Chapter 2) in ART and palliative care. They have lived with the disease for more than ten years and are trained in ART and palliative care to help other patients. Under these are program beneficiaries who are patients and end service users. See Figures 4 and 5 below:

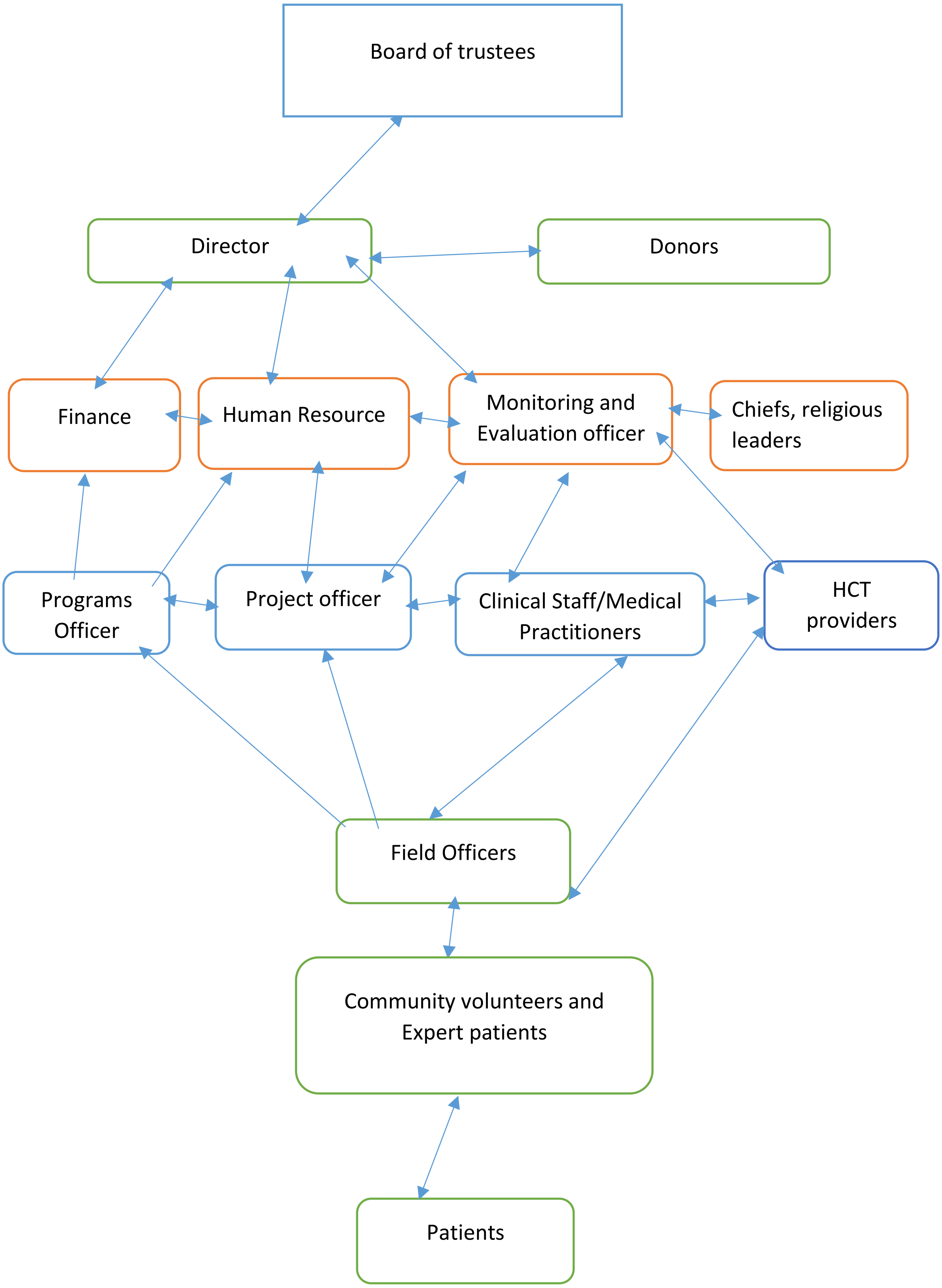


***Figure 4**: NAYO Structure (Source: NAYO Report)*

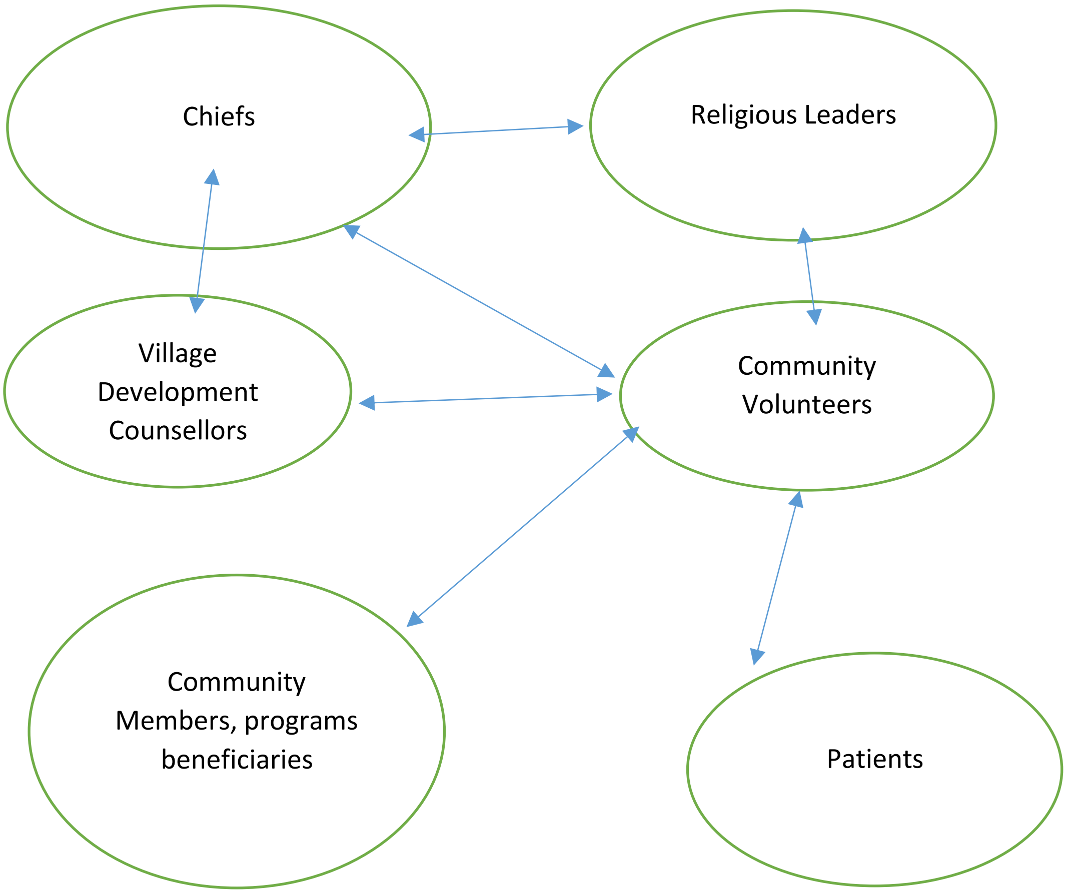


Figure 5: *Community /Village Set up (Source NAYO Report)*

Nancholi Youth Organization (NAYO) is in Nancholi within the green-corner ward in Blantyre, Malawi. NAYO's catchment area includes 25 villages namely: Baluti, Chigwaja, Chilunduka, Chimire, Kampala, Kamtukule, Lesteni, Luso, Lundu, Manyowe, Manyenje Mpagaja, Martin, Mkoka, Mpemba, Mulanga, Manase, Maliro, Mwandika, Mwandambe, Mzeru, Nancholi, Pensulo, Sumani and Zingwangwa. It started as a youth club offering youth-friendly services aiming at reducing the spread of HIV/AIDS and deaths among youth. Currently, it offers services including palliative care, Outpatient department (OPD), Maternal and child health care (MCH) Anti-retroviral therapy, nutrition education, youth empowerment, agricultural inputs, livestock farming and educational support.

In the village, village-headmen or traditional chiefs provide leadership and have authority over the people. They are custodians of people's culture, including ethnic ethos, conventional wisdom, heritage, and traditional land under the Tradition Authority Act. They make decisions regarding land, benefits, and services and oversee the selection of beneficiaries for welfare programmes and services from government and non-governmental organizations. Chiefs appoint Village Development Counsellors (VDCs) who communicate with community members and coordinate the distribution of benefits. When NAYO plans to implement any program or project, it first consults with the chiefs and religious leaders. If they approve, they call for stakeholder meetings where decisions about the implementation of services and selection of beneficiaries are made. The VDCs disseminate the information from chiefs to the villagers and from the villagers back to the chiefs (Nyoni 2, Interview 2023).

Community volunteers are chosen during village meetings where chiefs oversee and recommend who should be selected for various leadership positions and benefit from the services. This is because the chiefs know the families of the selected leaders and beneficiaries. Most community volunteers are expert patients with knowledge of ART and palliative care. Community volunteers are trained in caregiving, ART, adherence, follow-up, diagnosis of non-communicable diseases based on signs, giving first aid, and home-based care. These assess, diagnose, give first aid, contact medical personnel regarding cases, and make necessary recommendations about cases. Patients on ART and palliative care are registered with community volunteers for easy follow-ups. NAYO healthcare providers trust community volunteers because they are trained to support patients. In the case where a patient visits the clinic directly, they are referred to community volunteers after treatment and or the community volunteers are notified about new cases within their villages for follow-ups (Nanyoni 2, interview 2023).

4.3 Theme one: NAYO's Community Approach to Intervention

A community approach to caring for individual patients living in a specific locality requires engagement with various stakeholders so that intervention implementers know the community's perception and understand its priority needs. This helps implementers design interventions that are relevant to the community. The structure of the Nancholi community influenced NAYO's community approach to interventions. In an integrated community where an individual is defined by the community, focusing on the community produces desirable outcomes.

This approach corresponds with Howard et al. (2002), whose research revealed that community care can facilitate the meeting of community needs because it involves stakeholders from the community in assessing the perceptions of community health and community priorities. Community members can lobby local service providers to put primary healthcare workers in the community and identify community volunteers for training to provide health services.

Healthcare providers should be acceptable to the community and have access to the population to ensure effective healthcare delivery (Howard et al., 2002).

This study also discovered that person-centred care in communities requires case management and coordination efforts in care through the appointment of CHWs and health facility-based healthcare providers. This necessitates the integration of community and facility care. This is because HIV patients require constant monitoring to ensure psychosocial support and patients' adherence to ARVs. Upon being asked about their role, Nanyoni 3 responded:

> *We have community volunteers who manage cases in the community, and they inform us when they need our help. These volunteers assist a lot in communication with our medical team especially if there is an emergency requiring the attention of the medical team. They are in the community, we are at the facility and our link is strong in managing cases and doing follow-ups* (Nanyoni 3, interview 2023*).*

This finding corresponds with Chaukos et al. (2024) whose research on improving patient-centred care for HIV and mental illness revealed that PLHIV requires case management that could be facilitated through the integration of community-based and hospital care models. Person-centred care requires an integration of community and facility services to ensure that HIV patients get what they need primarily in communities that are far from health facilities.

Community-centred care is enhanced by community-based ART programmes yielding positive adherence results. This is because follow-up systems in community-based care are efficient. They aid in tracking patients' progress and management of illness. Upon being asked about their activities in the community, one respondent explained:

> *We offer community-based services to enhance care for PLHIV. This is because we rely on community volunteers who support patients through home visits, follow up, and provision of psycho-social support to our ART client (Nyoni 2 interview 2023).*

This research finding corroborates Kelly et al. (2018), whose research revealed a positive correlation between community-based ART and adherence to ARVs. This correlation is a result of CHWs support, guidance, and home visits (Kelly et al., 2018).

Integrating CHWs into the care team requires restructuring, redefining, and differentiating professional roles and embracing policy changes. This requires a shift from medical models of care to partnership models to engaging other stakeholders such as community leaders, family, and friends of patients to deliver effective care. This research reveals that NAYO's structure which is based on the medical model limits patients' participation because they are expected to fit into the established healthcare system. Participant observation revealed that the clinical environment had an atmosphere that limits patients' autonomy because healthcare providers speak more, give instructions, ask questions, and make decisions for patients. Upon being asked what would promote patient involvement in care, two participants said:

> *We will need a paradigm shift in the way healthcare is provided so that we accommodate patients and other significant stakeholders such as relatives, friends, and religious leaders in ensuring that patient's needs are met (Nanyoni 5, interview, 2023).*

> *We need to change our way of functioning as an organization because right now our focus is on the community and not much on the patient. We engage community volunteers and chiefs and other leaders in the implementation of our services, but the challenge is that we do not see them as partners although we consider their contributions and suggestions (Nanyoni 3, interview 2023).*

This finding corresponds with (Martinez et al., 2021 p.8) observations on HIV/AIDS site visits which revealed that "integrating community health workers in care teams necessitates revising, redefining as well as making necessary changes in professional roles and policies". This shift is necessary for successful partnerships between patients, healthcare providers, and support systems.

4.4 Theme two: Community care

4.4.1 Roles of Community Health Workers

At its initiation stage, NAYO called for the enrolment of community volunteers to guide and facilitate its establishment. Community volunteers imparted knowledge to NAYO staff about the organization of Nancholi community and the approach that could be used to engage the leaders. This is because leaders are gatekeepers of the community and oversee outsiders' access the community. Upon being asked about their enrolment with NAYO, a participant said:

> *When the NAYO youth club started, they called for volunteers who would be trained to facilitate activities in the villages. I was among the first volunteers to be trained to work with NAYO in mobilizing community members for the programmes. I was among those chosen to oversee the establishment of NAYO centres in villages. These centres were*

> *turned into nursery schools for children whose parents died of HIV/AIDS. We were trained and given bicycles for transportation (Natsonthi 5 interview 2023).*

This result correlates with findings by Butt et al (2023)'s study on addressing disparities in pre-exposure prophylaxis (PrEP) access in a community-centred mobile PrEP program in South Florida which revealed that engaging community health workers in the initiation of community-based programmes would help program implementers understand the communities and facilitate communities' buy-in.

This revelation also corroborates findings by Rodrigues et al. (2022) which revealed that community health workers understand community culture and language. They can provide culturally appropriate health-related services to support the community and facilitate community networks (Rodrigues et al., 2022). CHWs are members of the community who know how relationships operate and can facilitate effective change through the implementation of health services.

Community volunteers are trained to provide health services to patients in the community. Upon being asked about community volunteers, a respondent said:

> *Community volunteers are trained to assess patients' conditions and cases, provide first aid, and inform us about new cases and the condition of the patients. There is also [re]fresher training for community health workers that government and some organizations like Egg Puff and Globe provide. During these trainings, volunteers benefit knowledge and allowances which motivate them and increase competency in their work (Nanyoni 3, interview 2023).*

This corresponds with findings by Kakande et al. (2023), who found that training and capacity building, coupled with support and supervision, enhance community health workers' effectiveness in the intervention. CHWs are supported by healthcare providers such as clinicians, nurses, and counsellors because they are trained, compared to traditional birth attendants, who rely much on Indigenous knowledge and experiences.

CHWs enhance community-centred care because they take a holistic approach to interacting with individual patients. They engage family, friends, church members, colleagues, and community leaders to ensure that patients' needs are met.

Upon being asked about their roles, Natsonthi 2 said:

> *It is our role to support HIV clients manage their treatment and care. We move to the villages to encourage our patients and also let them share concerns so that they are free from worry caused by the HIV status. We have to be there for patients so that their burden becomes light. Patients are happy when we visit them (Natsonthi 2, interview 2023).*

This finding agrees with Sturmberg and Njoroge (2017) whose research on people-centred health systems revealed that CHWs support families of patients by providing them with coping skills. In the case where guardians are not available, CHWs become guardians for children with HIV to ensure that they get the necessary help and support (Sturmberg & Njoroge, 2017). The roles of community volunteers go beyond healthcare provision because they take a holistic approach to addressing the social, psychological, emotional as well as spiritual needs of patients, their friends, and relatives.

CHWs play vital roles in the provision of person-centred and community-centred care because they can work in various settings. Community volunteers are trained to support patients and provide various services and benefits in addressing the needs of individual patients and the community. Upon being asked about their service to the communities and individuals, a participant said:

> *We conduct follow–up home visits to check if HIV patients are adhering to ARVs and report on their progress. We also impart knowledge to community members during community gatherings where we share information about how to prevent and manage diseases, promote hygiene and sanitation, and encourage patients to report perpetrators of stigma. We also come to assist at this facility on PMTCT and palliative clinic days (Natsonthi 3, interview 2023).*

This corresponds with findings by Rodrigues *et al* (2022) whose study revealed that community health workers are beneficial to communities and individual patients because they are trained to work in a variety of settings such as public, non-profit organizations, private and public health care systems to provide services that address patients' needs. This makes CHWs general facilitators in the provision of health services in various settings.

It should be professionally appraised with scientific research that community care and familial engagement coordinate care and connect patients with services within their area. Community care is facilitated by CHWs who are trained to provide health services within communities. CHWs link patients with healthcare providers and health services available within their communities. Community care centres provide access to care, especially for underserved populations in rural areas of developing nations like Malawi. Upon being asked about how they got to find out about NAYO, two participants said:

> *I got to know about NAYO through community volunteers who were moving in our villages telling people about the NAYO clinic and the programmes they offer. They encouraged those on ART to register with NAYO so that they could receive their medication nearby because Queens and Zingwangwa are far away. So, I decided to transfer from Zingwangwa to here (Naphiri 3, interview 2023).*

> *I was approached twice by a community volunteer who told me about NAYO. I used to meet this volunteer at Queen Elizabeth Central Hospital when I went for an ARV refill. So, I decided to come and enrol here at NAYO because Queens is far and sometimes I used to walk [to the] clinic due to lack of transport (Naphiri 2, interview 2023).*

These responses resonate with Rector and Stanley (2022) who argue that community care programmes coordinate and connect patients to services in their communities. These also provide access to care for hard-to-reach areas of developing nations, especially in rural areas.

From this study, community volunteers play a vital role in offering prevention services to the community. This is because community volunteers live within the villages, know the language, and easily relate with community members. They offer behaviour change advice, support, counselling, adherence to ARVs and health education. These assist in filling the gaps such as the lack of qualified healthcare providers and resources to facilitate community-centred care. Being asked about their roles in the community, Natsonthi 3 said:

> *Sometimes we engage the community in campaigns where we impart knowledge on prevention of diseases and how to care for people with chronic illnesses. This is because there are still many people at risk of getting HIV due to carelessness. We also have HIV patients who are bitter and would want to infect others as a way of revenge because they were also given the disease (Natsonthi 3, interview 2023).*

These sentiments echo Kakande et al. (2023), whose study revealed that CHWs offer prevention services and care for people living with HIV and other non-communicable diseases. They engage in behaviour change, counselling, health education, ART adherence, and defaulter tracing. Community volunteers offer needed services because they are embedded in the community, and the services they deliver are tailored toward meeting community needs.

NAYO has more than 50 active CHWs who support activities at the facility and in the community. These facilitate HIV patients' access to care and provide psychosocial support to patients in the community. They also assist in taking vitals such as weight, blood pressure, and temperature and registering patients, especially on clinic days.

Upon being asked about their roles, two participants: a community volunteer and patient said:

> *Much of our work is in the community where we visit patients to track their progress in the management of the disease and offer psychosocial support to our patients. But we also participate here on clinic days because NAYO is understaffed so we help in taking vital signs such as weight, temperature, BP, and malaria tests. We also give oral drops to children who come for vaccination (Natsonthi 2, interview 2023).*

> *Our community volunteers support us a lot because they fill the gap of lack of qualified personnel. We just inform them, and they come to assist us at the clinic and in outreach activities, especially in MCH activities. So, because these volunteers are there, lack of qualified staff gap is not seen (Nanyoni 4, interview 2023).*

A study by Ivers et al. (2011) on task-shifting in HIV care in rural Haiti equally corroborates these findings. It revealed that CHWs formed large components of staff in the implementation of healthcare services and Programmes such as HIV testing, patient visits, ART initiation, PMTCT, patient management, and follow-up. Community-based care relies on CHWs in implementing healthcare services, especially in low-income countries with a limited number of healthcare professionals (Ivers et al., 2011).

CHWs accompany HIV patients in their care journey through community care. This is because community health workers become part of the patient's life through the process of administering services and integrating. CHWs can help patients change their perception of diseases through information sharing and their interactions with HIV patients, leading to a reduction of stigma. Participant observation revealed that NAYO's CHWs facilitate the transportation of patients from the community to the facility and conduct home visits to track patients' progress and report outcomes to the medical team.

Upon being asked of roles she plays when administering to patients, Natsonthi 2 said:

> *We support family members and relatives of HIV patients. We encourage close friends and relatives of patients to give them necessary support to enhance their care. Some family members get worried especially when they see their patient deteriorating in health or the sickness becoming more serious. We provide counselling for family members and guardians when we see that they are worried about their patients. We encourage them to be a pillar of strength for patients (Natsonthi 2, interview 2023).*

This corresponds with Ivers et al. (2011), whose research revealed that CHWs become part of patients' lives as accompaniers by administering to them. It also corresponds with Kelly et al. (2018), whose evaluation of a community-based ART program in rural Sierra Leone revealed that community health workers provide support, forming enduring relationships with patients.

4.4.2 Healthcare in Community

Effective tracking system of community-oriented primary care can retain most ART patients on treatments. Community volunteers are engaged in monitoring tracking and reporting the progress of patients for follow-ups of HIV patients in villages. Upon being asked what they do, two respondents: a community volunteer and a patient said:

> *We live in the villages with the patients. If anything happens, they alert us, but we also conduct follow-ups where we visit patients to check their progress. Apart from that, relatives and neighbours of patients also report to us if the patient needs our attention or assistance (Natsonthi 3, interview 2023).*

> *In the communities, we have community volunteers who are our eyes in terms of doing follow-up and monitoring client progress. We rely much on them because they are trained and are on the ground. Having them in the village means that the communities are sorted and well connected in case of any emergencies (Nanyoni 3 interview 2023).*

This finding corresponds with Massavon et al. (2014) whose cohort study in Kampala, Uganda among HIV-infected children and adolescents revealed that decentralization, counselling and testing and ART refills within communities have a more effective tracking system than at the facility. Community-centred care also helps overcome barriers such as transport, long waiting hours at facilities and stigma that hinders HIV patient's access to ART. Community care models are effective because patients receive their ARVs within community centres and community volunteers can trace them if they default ART and need attention. Participant observation revealed that NAYO's CHWs call medical professionals to communicate about the situation so that the healthcare team knows what to take when visiting the patients. Upon being asked about having their medicines refilled, a participant said:

> *Community volunteers assist us to get our medicines in case we are unable to come to the facility for the refills. We have contacts of community volunteers whom we call when we have a problem needing their attention. These are very supportive in terms of getting the necessary medical support we need Naphiri 7, interview 2023).*

This research finding corresponds with Kakande et al. (2023), who revealed that community-based provision of HIV care can overcome barriers such as transport costs, long waits, and stigma that hinder access to health services. It also corroborates a study by Adrawa et al. (2020: p8) on alcohol consumption and non-adherence to ART in rural northern Uganda, which revealed that "A community-based ART delivery model overcomes barriers to ART adherence and improves access to HIV care. The model is effective because it provides support to PLHIV." In developing countries such as Malawi where the doctor-patient ratio is low, the community's health workers are trained to provide care services to patients within their communities as a means of filling the gap in the lack of healthcare professionals and resources in low-income countries.

Additionally, community-centred care models necessitate cultural integration within community settings. The healthcare system is embedded in local structures where community leaders such as chiefs, village development counsellors, and religious leaders are part of key stakeholders in community approaches to care. These stakeholders build lasting relationships and partnerships to ensure the provision and sustainability of services when funding ceases.

Upon being asked about their key stakeholder, NAYO staff members responded:

> *Our key stakeholders are community leaders such as chiefs who own the people and culture, religious leaders who assist us with the spiritual aspects and mobilization of community members, and our community volunteers who work tirelessly in ensuring that healthcare services and support services are administered to our clients. We rely on them because we are here today and tomorrow is another day and we do not know, but they are there with their people (Nyoni 2, interview 2023).*

> *In the monitoring and evaluation of our programmes, we engage chiefs, religious leaders, community volunteers and teachers who support us in these exercises to know what is on the ground and what people feel regarding our activities and programmes. If there are necessary changes to be made, we go back to our initial plan and redesign together the required changes (Nyoni 1 interview, 2023).*

This finding corresponds with Sbaffi et al. (2023) who studied the promotion of well-being among informal caregivers of people with HIV/AIDS in rural Malawi. They found that community-based participatory design allows full integration of the intervention with the culture. They equally found such a design facilitates trust-building between researchers and local communities and consequently enhances the sense of ownership among community members (Sbaffi et al., 2023).

Community-centred care models effectively help clients manage their treatment and care. This is because they allow HIV patients to ask questions and express their concerns. Patients adhere to advice regarding lifestyle changes, hygiene, and food from community volunteers. Participant observation also revealed that patients are more open and share their concerns with community volunteers than healthcare providers. This is because community volunteers give more time to patients to express their concerns than healthcare providers who have long queues of people waiting to be seen. Upon being asked about the airing of their concerns, Naphiri 4 said:

> *I go to see community volunteers especially when I have a reaction on my body from ARVs. I go to express my concerns and they usually encourage me and sometimes advise me to see the doctors if the problems continue. Community volunteers listen to our concerns and express their empathy towards our suffering (Naphiri 4, interview 2023).*

These findings are like those of Sbaffi et al. (2023), in which patients valued advice from community volunteers and integrated it into their diet, personal hygiene, and medication to improve their health. Community-centred care is more effective because the engagement between HIV patients and community volunteers enhances positive living among HIV patients; hence, most community volunteers are expert patients who speak from their experience.

Community-centred care facilitates the shift from medical models of practice where patients are simply recipients of services, to active participants in treatment and care through collaboration. This is because community-centred care practices enhance the participation of patients and key personnel from communities. Community leaders such as chiefs, religious leaders, and local development leaders play significant roles in implementing healthcare services in rural settings where leadership is embedded in activities and programmes.

Upon being asked about key stakeholders in the implementation of activities and Programmes. Nanyoni 4 said:

> *We do community mobilization where we engage community leaders such as chiefs, religious leaders, and village development counsellors. We rely on their input about programmes and how we should implement them to benefit the people in the communities. We also follow their advice because they know their people and they assist us very much in the implementation of our programmes (Nanyoni 4, interview, 2023).*

This also corresponds with Sbaffi et al (2023) who suggest the shift of patients from being recipients of services to active participants. They recommend the involvement of leaders in guiding the processes based on their visions, building trust through interactions and the use of participatory engagement strategies. The engagement of key personnel in the community intervention results in the effectiveness of the intervention because leaders know the pressing needs of people and can direct interventions towards addressing those needs.

4.5 Theme Three: Identification of Patient Needs at NAYO

NAYO uses several criteria to identify beneficiaries of the services at the facility level. Clinical assessment forms the backbone of all assessments of the patient's primary needs including physical, health, nutritional and security. This is because NAYO's programme's primary beneficiaries are HIV-positive and chronically ill patients. ART, palliative care, PMTCT, immunization and VCT Programmes determine extension services such as youth-friendly services, nutritional education and supplements, agricultural farm inputs, livestock farming and education support. NAYO uses an allopathic medical model with a community health centre and activities extended to community outreach with the help of community health workers.

The allopathic medicine model is modern medicine which relies on the knowledge of health professionals in the diagnosis, prescriptions, treatments, and lifestyle of patients. Medical personnel usually take the weight of each HIV patient when they visit the clinic for the refill of ARVS. When a patient is found to be of low weight, he/she is enrolled in the nutrition supplements program and given nutritional education. Farm inputs are given to experienced farmers to boost their harvest. Those who do not have land for cultivation are given pigs or goats to breed on their homestead.

The investigation of NAYO's programmes also found that teachers in various secondary schools within the NAYO catchment area help in identifying needy students to benefit from school tuition fee support. Those needing psychosocial support are referred to pastors and counsellors at the facility level and community volunteers at the village level. Although the interventions are holistic, NAYO does not provide holistic care to each PLHIV because patients can only benefit from a maximum of one programme at a time, and assessors ensure that a beneficiary is enrolled in only one programme. Most beneficiaries of these programmes are community volunteers who are expert patients. Upon being asked about the assessment of the patient's needs, Nanyoni 5 responded:

> *When the ART client comes for ARV refill, we check how they are adhering to the drugs. We ask them about the number of tablets remaining in their bottles. We encourage them to adhere to taking ARVs and engage in community activities. Then we check their weight so that we know if there is an improvement. If the weight is higher than the previous visit and the number of remaining drugs corresponds with the dates, then we know there is good adherence, so we encourage them to continue. If the weight is lower than the previous visit, we enquire more about how they take medication and how many times they missed taking drugs (Nanyoni 5 interview, 2023).*

Patients are an important stakeholder in health care and therapeutic ministry (Majawa, 2020). NAYO patients play a passive role in the identification of their own needs because medical personnel dominate the decision-making process. This is because the medical model gives power to healthcare providers who are assumed to be experts and gatekeepers of health. This corresponds with findings by Bristowe et al. (2019), who recommended person-centred care as putting the client at the centre of care and having their needs addressed by actively involving them in decision-making about their treatment.

At the community level, the needs of HIV patients are identified through the collaboration between HIV patients and community volunteers. Community volunteers are the first point of contact for patients in the villages. They ask questions about the sickness history, interact with the patient's guardians or relatives, and engage the authorities if the case requires their intervention for the benefit of the patient. Upon being asked about how the needs of patients are identified, Natsonthi 4 responded:

> *We enquire about the sickness from neighbours and relatives. We mostly engage those close to the patient. We empathize with the patient and try to encourage them to give them hope. We seek consent from the patient for our interaction regarding the sickness so that we avoid intruding on the patient's life. We ask questions to the guardian regarding the sickness. Dealing with patients requires a humanistic approach to understanding their situation and also encourages the church's involvement in assisting patients. We do this to give hope to the patient and guardian ensuring that they take an active role in seeking medical help. We assess the patient's sickness through history and symptoms of sickness. We also assess hygiene and psychosocial support that a patient gets from relatives and neighbours (Natsonthi 4 interview, 2023).*

In line with these findings, a study by Twungubumwe et al. (2020) recommends PCC that emphasizes health workers' respect and listening as most important in facilitating the opportunity to work together with the patient so that they manage their illness (Twungubumwe et al., 2020).

Healthcare providers need to engage patients in communicating about the diagnosis so that patients understand what is happening in their bodies. This way, they take the necessary action to enhance their health. Healthcare providers and patients must engage in meaningful communication so that each understands their role to enhance patient care. Upon being asked about their engagement with patients, one participant member of NAYO staff said:

> *We normally have a conversation with patients before we enrol them in ART. We try to explain to them so that they know what is happening in their body and what they should do to enhance positive living. We also engage with them so that they do not take long before they accept their condition. Nowadays we encourage them that having HIV does not mean end of life. They can still live many years if they take necessary action such as eating healthy diet and adherence to ARVs (Nanyoni 1, interview 2023).*

The sentiments in this response echo existing research. For example, Verbiest et al. (2022) found that patients' understanding of their situation helps them to take necessary action to better their life. Patients' knowledge regarding their bodies is paramount to enhancing changes that may improve their lives. This can be done through the implementation of person-centred care.

4.6 Theme Four: Patients' satisfaction with NAYO services

Patient satisfaction with treatment and care is key to achieving quality care. The quality of health care is measured by patient satisfaction since patients are the primary beneficiaries of healthcare. NAYO staff had mixed responses regarding their satisfaction with patients' involvement in their care.

> *Am somehow satisfied because most ART patients adhere to our advice by doing what we tell them. Also, their retention in ART programmes makes me think that they are satisfied with what we give them. However, I would like them to take a more active role in their care, especially by opening up (Nanyoni 5, interview 2023).*

> *We are not there yet; I am not satisfied because of two reasons: lack of resources and lack of technical support. Those clients come with complaints and those complaints need resources to be addressed. There is a day when our medical people see over 150 people. We are looking at issues to do with collaboration; we need new partners to come in to support us so that we give our clients what they need (Nyoni 2, interview, 2023).*

A study by Yaya et al (2017) on urban-rural differences in satisfaction with primary healthcare services in Ghana revealed the importance of patient satisfaction as an indicator of quality healthcare, corroborating the present study's findings.

A holistic approach to health care that considers dimension of patients' needs is enhanced in the implementation of PCC. PCC considers the social, psychological, emotional, health, physical and economic needs of patients and considers the patient's preferences. Through collaboration, patients are given a chance to express their needs and concerns. They engage in actions that benefit them and care enhancement. A respondent had the following to say:

> *At NAYO we offer services that address health, nutritional, educational, psychological, and physical as well as spiritual needs of patients. Here at the clinic, we provide medical services, the VCT providers give psychosocial support, the youth department provides education and recreational needs, and we have a lady pastor who usually comes in the morning to encourage our patients spiritually (Nanyoni 5, interview 2023).*

These findings reiterate findings by Ginting et al (2022) whose study on a patient-centred medical home care model for older adults in Singapore revealed that relationship-based care helps healthcare providers understand patient's needs, respect their preferences, and treat them holistically.

The understanding of a patient's needs through listening and providing information are necessary to improve care. In the implementation of PCC, listening skills are required to enhance the understanding of patients and provide needed information to enhance patient care. Upon being asked about how they understand patients, one of the respondents said:

> *I normally take time to listen to patients so that they express their worries and concerns. Having the burden of HIV diseases makes the patients go through psychological and emotional distress. Listening to them helps us to understand their situation and sympathize with them. I'm also a client and sometimes I just need someone to talk to (Natsonthi 3, Interview 2023).*

This is a reiteration of what Stojan et al. (2016) found in a study on assessing patient-centred care through direct observation of clinical encounters. Their study revealed that listening to patients, sharing information, and understanding promote quality because it makes patients feel satisfied with care.

4.7 Theme Five: Involvement of HIV patients

This section presents the involvement of patients at community and facility level. Findings reveal that much of patients' involvement happen at the community level. This is to say that person-centred care is practiced at community level where patients' autonomy is respected and their participation in decision making is core to practice. On the other hand, there is minimal involvement of patients at facility level because facility practice uses the medical model which invests much power on healthcare providers.

4.7.1 Patients involvement at the community level

At the village level, patients are involved in their care through the guidance of community volunteers whose voluntary work is permanent as long as NAYO programmes exist. Community volunteers assess the condition and present options for the patients to choose what is best for him or her in care. HIV patients participate in decision-making about who should be involved in the care and management of the disease. Patients are expected to give consent to community volunteers before any assessment, test, or treatment is given to them. This is done because community volunteers are trained in ethics and must respect rights of patients, which guides their practice.

The respondents shared about the involvement of HIV patients at the community level as follows:

> *As NAYO volunteers, villagers approach us when they have a case. We go and help those around our villages. We collaborate with patients and their guardians or relatives to help the patients. We present options available and let the patient choose what is good for him or her. We cannot force patients even if they don't want to take medication because sometimes men resist taking medication or enrolling in ART programmes. We let the patient choose the option they want, or think is fit for their health. We are trained to respect the patient's choices even if it's contrary to what we would prefer for them. We then follow up if the patient is enrolled in the ART program and continue engaging their support system. We also encourage patients to take part in community activities and request community leaders to appoint them in various leadership positions (Natsonthi 5 interview, 2023).*

> *We engage the patients in all assessment plans, processes, and decisions we make about their conditions. Even when we want to engage church leaders to support the patient, we ask their permission first before we engage their church leaders and community authorities. We respect their options because they have the right to choose what is best for them though we provide information and guide them as well. We share information about their condition with them so that they understand their condition better and make informed decisions (Natsonthi 4, interview, 2023).*

This finding corresponds with findings by Bristowe et al. (2019), who emphasized a person-centred approach to care to enable professionals to deliver quality care that respects patients and responds to their individual needs. Patients' involvement in decisions about their condition yields positive results because it addresses their real problems and enhances quality care.

This study found that NAYO's community volunteers make enquiries from a patient's neighbours, relatives, and church members to get information about the patient and the chain of sickness. They also encourage patients, giving them hope and motivating them to consider treatment by focusing on the benefits of ART. Community volunteers persuade those suspected to have HIV to go for VCT. Field officers visit those who do not want to visit the facility at community volunteers' houses. This is because suspected HIV patients fear enacted stigma.

Community volunteers engage and encourage patients’ support systems, such as relatives and guardians, to be actively involved in assisting patients. Community volunteers collaborate with the chiefs for support in case they experience reluctance from the patients. They also assess how the condition affects the patient and his or her reaction to it and engage service providers such as counsellors, religious leaders, relatives, and clinical teams. However, community volunteers did not know that they give person-centred care as evidenced in the two responses below:

> *In a certain case we found, we observed that the guardians have no love for the patient. We were told that the relatives had abandoned the patient. [However,] The church also was very supportive of the patient. As NAYO, we collaborated with the church members to assist the patient get medical, material, financial, and social support. We had to buy everything for the patient and the relatives now wanted to start helping the patient because they had seen us assisting the patient, but we did not allow them because they had abandoned the patient. The chief and we from NAYO collaborated in rebuking the relatives who abandoned the patient (Natsonthi 4 interview, 2023).*

> *The people in the village know us as community volunteers. So, the villagers approach us when they have patients. We go to assess the patient’s needs and we link with the medical personnel for further assistance. We work with patients, community members, and the medical team from NAYO in the provision of patients’ needs and care. So, we link the patient with community support and NAYO medical personnel in ensuring that patient gets the needed help (Natsonthi 2 interview, 2023).*

These findings are equally reflective of extant literature. For example, Tenthani et al. (2012) found that HIV patients felt treated fairly by expert patients who had similar life experiences. Similar sentiments were expressed by expert patients who felt valued and gave hope to positive living. Most community volunteers are expert patients who are also on ART programmes and palliative care. They share experiences with HIV patients and are best at caring for PLHIV because they can easily relate to their experiences and understand the patients.

Likewise, a study by Horter et al. (2020) revealed that patients asserted that they had a right to know and be involved in the decision-making processes regarding treatment options. Patients felt left out in the decisions regarding their care and treatment. Patients are rational beings and involving them in their care results in positive benefits for care. When a patient's self-autonomy is respected, it yields positive results.

There is a need to engage CHWs in implementing person-centred care because they can share information with patients more easily. Communication is key to the implementation of PCC in communities. The link between CHWs and healthcare providers can assist bridge the knowledge gap between healthcare providers and patients. Upon being asked about the interaction between patients and healthcare providers, Naphiri 5, responded:

> *When we are meeting the doctors, we just listen to what they tell us to do and go where they want us to be although it's a pity that they do not tell us what is happening in our body. Even what they write in our books, we do not understand because it is in English (Naphiri 5, interview 2023).*

This experience contradicts existing recommendations based on what various studies have found. In a study on the acceptability of patient-centred hypertension education delivered by the community, for example, it was discovered that CHWs are a strong link between patients and healthcare providers to enhance the implementation of PCC (Batte et al., 2021).

In the context of NAYO practice, community volunteers work without remuneration. However, most of them are expert patients in ART and palliative care, which makes them automatically the primary beneficiaries of NAYO programmes and services. A few who are not expert patients benefit from livestock farming and agricultural inputs.

The present study also found that the community health workers in developing countries are engaged in the delivery of care to communities to ensure sustainability in health care delivery, especially in hard-to-reach areas. When choosing community health workers they consider dedication to community services. The community members are involved in the appointment of community health workers because they choose dependable people. One community volunteer had this to say when asked about their motivation to serve their communities.

> *We volunteered to serve our communities. When NAYO engaged us, they explained to us that we are volunteers so we will work without remuneration. We are far from the government hospitals and NAYO brought their services near us. So, we keep volunteering because it is God who calls us to serve our communities. Most of our friends left volunteering especially during COVID-19 because NAYO did not have funding and the benefits we used to receive are no longer there. For me, volunteering*

> *has become part of me because even in the village I’m known as a NAYO man. Am happy to be identified with NAYO and it feels good to serve my community (Natsonthi 5, interview 2024).*

The question of dedication and commitment is not an unfamiliar occurrence in similar studies. To illustrate this, Batte et al. (2021) equally found that community health workers dedicate themselves to community service which becomes their passion to serve communities as they perform their roles.

The involvement of patients in decision-making about their care and treatment is necessary so that they take responsibility for taking necessary action and sustaining care. Enhancing ownership is key in the implementation of PCC. Once enlightened about what is happening and what needs to be done, patients engage in health-seeking behaviours to keep fit. Community volunteers engage patients in the decision-making process. They provide options and guide where necessary, but in most circumstances, they let patients decide what they want. Upon being asked about patients’ engagement, respondents said:

> *We engage patients in all processes and decision-making. When we assess the patients’ situation, we inform them about their condition and options available for treatment. They decide what would help them heal but sometimes we also guide them in choice making especially when their choices are not the best options (Natsonthi 2, interview, 2023).*

This echoes a study by Ginting et al. (2022), whose findings revealed that patient-centred care emphasizes patient engagement in decision-making so that patients take an active role in planning and care, resulting in the promotion of symmetrical partnerships between patients and their care providers.

4.7.2 Patient’s involvement at facility level

At the facility level, patients are not involved in decisions regarding their tests and treatment. This is because healthcare professionals assume an expert role in healthcare provision. Healthcare professionals decide for patients because much power is vested in them as per allopathic medicine. Participant observation revealed power relation imbalances in the interaction between healthcare professionals and HIV patients. HIV patients are passive recipients of services who are told what to do, how to do it, and when. Healthcare professionals make decisions on tests, nutritional supplements, and treatment for patients. The clinical staff takes the patient’s weight, does a physical count of tablets, and recommends viral load testing for patients. They also inform the patients about the benefits of adherence to medication and the negative consequences of default. Upon being asked how HIV patients are involved at the clinic, Naphiri 5 said:

> *When we come to the clinic, we just have to follow what our doctors tell us because we believe that through their training, they know what is happening in our bodies and assist us accordingly. Sometimes we have questions, but we fail to ask because of fear that they might scold us (Naphiri 5, interview 2023).*

Abboah-Offei et al. (2019) also found that PLHIV were not actively involved in decision-making about their care and consequently felt that person-centred care was not implemented. Makumba et al. (2023) also note that health facilities are hierarchical, directive and characterized by domination without eliciting client input on treatment. Consequently, Moreau et al. (2020) recommend system-level changes and improvement of care processes to accommodate PCC. They also emphasize that clinical processes should centre on the patient's needs.

4.8 Theme Six: Patient Support System

Patient support systems include chiefs, religious leaders, friends, relatives, and community volunteers. NAYO relies much on community volunteers as the patient support system. This is because community volunteers are trained to assess, link, and provide needed patient support. They also recognize chiefs as the first point of reference for patients at the village level. This is because chiefs own people, are informed about cases in their community, and approve activities in the village. Chiefs are in the lineage of legitimate traditional authority in the Malawian communities. NAYO had support groups for patients on ART and palliative care. They used to meet at the facility once a month to share their concerns, play games together and have conversations. However, establishing support groups was linked to receiving nutritional supplements such as soybeans, ground nuts, maize flour, and cooking oil. When funding ended and patients were not getting food items, there was low attendance and consequently, the support groups ceased to exist. Currently, patients meet every quarter for group therapy where they interact, share concerns, and listen to one another. Patients interface with NAYO staff members in this forum and express their concerns. These meetings facilitate patients' interactions and sharing of their concerns.

Upon being asked about their support systems, two respondents gave the following answers:

> *My support system is my relatives and friends. But my best friend knows about my status. When it comes to adherence to medication, we engage in activities to keep ourselves busy and refrain from worry. My strongest support system is my best friend because relatives were isolating me and talking badly about my HIV status. But my friend walks with me everywhere. She is always there for me, provides for my needs, encourages me, and accepts me as I am. When I'm sick, she escorts me to the hospital for treatment and medication. My friend has more genuine love than my relatives (Naphiri 4 interview, 2023).*

> *My support system is my church and a support group from our village. In the church, we have well-wishers who always assist the needy, especially the sick. At the church, they also pray for our positive living and support us with items from well-wishers. The people know us, and they assist us because we do not hide our HIV status. We have a support group for PLHIV, and we move in organizations and industries sensitizing people about positive living with HIV/AIDS. The aim of this group is for us to encourage positive living, share concerns and listen to one another. We also contribute monthly to assist each other with loans and share the money at the end of the year. We also support and guide those newly enrolled in ART. We encourage them to live positively by sharing our experiences with them. Aside from these, my strongest support system is my children who encourage me and are always there for me (Naphiri 3 interview, 2023).*

Similarly, Duffy et al. (2022) propose psychosocial support as a sub-domain of the person-centred care framework. They emphasize the importance of support given by friends, relatives, groups, caregivers, and disclosure support, which facilitates treatment improvements and retention of patients on ART. These findings also resonate with Kazemi and Kajonius (2021), who contend that knowing and valuing the person, being attentive and adapting care to the client's needs are core to person-centred approaches. Companionship plays a significant role in patient care because HIV patients are encouraged, motivated, and cared for by their significant other. This gives them hope because they know they are not alone in their care journey.

Patient support systems are required in the implementation of PCC through the involvement of family members and friends of patients. However, this is affected by structural constraints of the power imbalance between patients and healthcare professionals (De Lourdes Arrieta-Canales et al., 2023). At NAYO, healthcare workers decide who they interact with as patients' support system. NAYO prefers to interact with community volunteers because they are trained in patient caregiving. The power imbalances of the healthcare providers' professional roles and beliefs affect the interaction between patients, the support system and healthcare providers.

Healthcare providers need to be open to listening to patients in the implementation of PCC so that they learn the meaning of the patient's description of their situation, how they are reacting to the situation, and how it affects them. Listening to patients will help healthcare providers understand patients as people and empower them to manage their illnesses and treatment. Upon being asked how they are engaged at the facility level, one of the respondents said:

> *When we come to get our ARVs, we meet our doctors, who tell us what to do. We just have to follow their instructions. Sometimes, I wish to express concerns or worries about how the medicines are affecting me, but I fail because the doctors are fast, and they also have other patients waiting for them. I end up not saying what I want to tell them (Naphiri 3, interview 2023).*

The revelation above is a sad realization that runs counter to the understanding that providers learn from patients by listening to their experiences and views on the disease (De Lourdes et al., 2023). De Lourdes further argues that providers can learn key concepts and ideas used by patients to better explain and clarify their situation of sickness.

4.9 Theme Seven: Collaboration at NAYO

Person-centred care is given by community volunteers whose roles include inquiry and assessment of health conditions for each case, taking patients to the hospital, engaging the relatives and friends of the patients to understand health conditions, helping and supporting patients to manage their conditions and linking patients with the clinical team, chief and support system such as church and relatives. Community volunteers manage each case individually based on the illness's historical presentation, signs and symptoms and provide immediate help to the patient. They also assess the living conditions and provide home-based care services such as bathing the patient, cleaning the patient's house, and preparing the patient for medical team intervention.

Much of the collaboration is initiated and championed by community volunteers who link patients with their support system and NAYO staff based on an assessment of patient needs. Community volunteers are the first point of reference and contact for the patients because they live in villages with the patients and are in contact with their support system. The relatives or family members of patients report a case to the community volunteers, who then visit the patient, assess the situation, and communicate with the field workers on what is required in the treatment and care of the patients.

Community volunteers collaborate with patients' support systems, including the chief, religious leaders, friends, and patients' relatives, to ensure that the patients' various health, emotional, psychological, and spiritual needs are met. This is because each collaborator addresses a particular need of patients which is unique but complementary. Two community volunteers shared their coordination experiences as follows:

> *We collaborate with patients by doing follow-ups in our village and recommend them to link with the medical team for further assistance. We also link with their support system so that their needs are met. The patients know our contacts and where we live, so they approach us when the need arises (Natsonthi 3 interview, 2023).*

> *Our collaboration is based on programmes and target groups. We collaborate with youth leaders for friendly health services so that the youth have access to these services. If we are targeting HIV patients, we engage the church leaders, community leaders, teachers, and businesspeople to practice safe methods so that they prevent HIV transmission. People know about NAYO, so they contact our community volunteers, the chief, and the medical team if in need of assistance. We also have referees within NAYO programmes and activities. Our department handles the youth population; patients are tackled by the clinic department (Nyoni 1, interview 2023).*

Eklund et al. (2019) emphasize the theme of shared decision-making. Patients and professionals engage in decision-making to promote care for the patients. This theme highlights the importance of empowerment, autonomy, and involvement of patients in their care. All partners providing care to PLHIV must respect individual choices and preferences to enhance ownership and self-management.

Person-centred care emphasizes the partnership between patients, healthcare professionals and their support system. However, healthcare professionals usually assume an expert role in their practice environment. Participant observation also revealed that patients are passive spectators.

Upon being asked about collaboration, HIV patients expressed that much of the partnership is done at the community level. Two of the respondents said:

> *When community volunteers visit us, they try to find out what is important for us because they ask us, our relatives, and friends questions regarding the sickness. Sometimes, they also involve chiefs and church leaders in ensuring that we get the help we need. But they engage these stakeholders and after explaining and requesting our approval to engage them (Naphiri 2, interview).*

> *When we come to this clinic, we are told what to do and we just have to follow instructions in doing what healthcare professionals want us to do. We are told to go to that room, come after, and then enter that door opposite. We just follow what they say, and we can't refuse what they tell us because we believe that it is for our own good (Naphiri 4 interview, 2023).*

Crawford et al. (2021) also emphasise community-level partnerships' prevalence and importance arguing that healthcare providers must work in partnerships with other caregivers in client-centred care because problems are solved through the cooperation between healthcare providers, patients, and patients' support system. Likewise, Bristowe et al. (2019) posit that PCC care should value and recognize individuality and approach care decisions as a partnership between the patient and provider. All these key stakeholders have a significant role in care and their roles are interdependent in that they complement each other. To enhance collaboration through the implementation of PCC, healthcare providers need to distinguish powers to and powers over to foster the implementation of PCC (Riding et al., 2017). It is necessary to shift the approach from healthcare providers being expert decision-makers to empowering patients to have a say in decisions that affect their lives.

4.10. Theme Eight: Implementation of PCC at NAYO

The PCC implementation at NAYO is influenced by two main factors: the implementer's knowledge of PCC and Malawi's healthcare structure. Findings reveal that NAYO staff's limited knowledge of PCC accounts for the lack of PCC recognition. As Malawi's community healthcare system adopts a community approach, this contributes to how PCC is practiced at NAYO.

4.10.1 NAYO staff knowledge of person-centred care

No NAYO staff members knew about person-centred care. They said it was their first-time hearing about the concept when asked. During the orientation period one afternoon at NAYO's premises, the researcher shared information about PCC with the staff, explaining that it is the collaboration between healthcare providers, patients, and the patient support system to ensure that patients' needs are met. The emphasis is to integrate cure and care through partnerships between patients, healthcare providers, and patients' support systems. The preference for using the word "person" is since HIV patients are persons with full human dignity, as opposed to the word patient which places them in a clinical need. The researcher also discussed with the staff how PCC relates to what NAYO is doing through implementing programmes and services. There were also question-and-answer sessions regarding PCC.

Upon being asked about their knowledge of PCC, four NAYO staff members responded in the following ways:

> *Person-centred care, in short, is more about the collaboration between patients, health care providers and caregivers. I learn about person-centred care from here and that is what we are doing as per your explanation. It was my first time to hear about it and I didn't know that we are doing person-centred care here at NAYO (Nanyoni 4, interview 2023).*

> *Of course, I don't know it well but I heard about person-centred care that it is self-care, when you put yourself first in caring for your body and getting your needs met, person-centred care is like the care that an individual is supposed to receive without considering other factors attached to giving that care but just focusing on the individual as he/she is (Nanyoni 5, Interview 2023).*

> *Am not a medical practitioner so I don't know about it but maybe our medical people will know (Nyoni 2, interview 2023).*

> *I have never heard about it (Nyoni 1, interview 2023).*

In such contexts, Kazemi and Kajonius (2021) advance the need to consider training healthcare workers on administering person-centred care. Healthcare providers need to be trained in caregiving that reflects person-centred care and reflects the structural changes to accommodate the needs of HIV patients (Kazemi & Kajonius, 2021)Once training is given to key PCC implementers, such as healthcare providers and community health workers, effective PCC could be achieved in low-income settings like Malawi.

4.10.2 Health care system influence the implementation of PCC

The implementation of person-centred care is influenced by the health system within various social settings since it emphasizes the involvement of patients and their autonomy in the process of treatment and care. The health system and structure of the organization affect how health is managed. Some systems are open, and they allow autonomy, but some systems are closed, making it difficult to respect the autonomy of HIV patients. Participant observation revealed that in closed health systems, patients' autonomy is not respected because patients are expected to be passive recipients of healthcare services. Healthcare professionals dominate the conversation and decide for patients. Upon being asked about the involvement, a participant (Naphiri 6) responded:

> *I am not involved because the nurse tells us what to do. When we come to the clinic, we are told to step on the scale so that they check our weight. When they check our weight, they ask us questions if we are adhering to the ARVs, and we explain to them about the remaining tablets and the challenges we face when taking the drugs. Then they encourage us to interact with friends and family members so that we are not stressed due to the HIV burden. But they do not ask us to share our views about care and treatment although I would wish to make care suggestions (Naphiri 6, Interview 2023).*

In the same light, Crawford et al. (2021) note that the system influences healthcare. Person-centred care emphasizes seeking an understanding of what is important to the person, understanding the person, and building trust, respect, and partnerships. These work well in an open system, not in closed systems like health facilities and healthcare delivery settings, which give much power to medical professionals and disempower patients.

Crawford et al. (2021) further argue that the transformed person-centred care within highly integrated communities requires healthcare providers to use appropriate language in addressing HIV patients and admit when they are wrong. This could foster trustful relationships between patients and healthcare professionals. Upon being asked about their experiences in interaction with healthcare providers, respondents referenced indirect language and the professionals' failure to admit wrongs.

> *I had friends and my husband who used to receive their medication from here, but they left because these staff members disrespected them. Sometimes they could call us (a date la lero) and that all for today's appointment should go to that room. People see us going there, and they talk a lot about our HIV status. I used to volunteer here, but the experience of being disrespected pushed me off, and I decided to leave the group of community volunteers (Naphiri 5, interview 2023).*

> *During our support group meetings, clients expressed their dissatisfaction with care and indirect language used by some staff members. Imagine they call us those for today's appointment should come here or go there. They call when other OPD patients are there, and we feel disrespected. As a chair of community volunteers, I approached the staff members who were known to disrespect ART clients they told me that they would improve but still, these incidences occur, and it's sad that others requested for transfer because of the way they are handled(Natsonthi 4, interview 2023).*

Crawford et al. (2021) contend that healthcare providers must use appropriate language and admit when they have done wrong to enhance client-centred care. The use of inappropriate language and not accepting corrections are barriers to implementing person-centred care because patients feel disrespected and end up withdrawing from facility visits.

Person-centred care within highly integrated communities embraces the multi-dimensional preferences of patients. Some patients would need healthcare providers to decide for them while others would want to take an active part and wish healthcare providers to respect their preferences. This is where collaboration can be enhanced to clarify who does what and when. Some clients want to seek advice from healthcare providers while others wish to facilitate their care. Healthcare providers need to consider the preferences of HIV patients and assist them according to their areas of need and preference. Upon being asked about their preferences, Naphiri 3 said:

> *I would rather prefer to be involved in my care but here I'm told what to do and decisions are already made by medical people about how we are supposed to live our lives. [Although] sometimes we have concerns especially if their advice does not work. We are different people, and our preferences and needs may differ. Therefore, we are supposed to interact with healthcare providers on how best each individual's preferences affect the way healthcare is administered (Naphiri 3, interviews 2023).*

The sentiments uncovered here support Crawford et al. (2021)'s argument that a client-led model of care respects client preferences. Patients' preferences must be respected to enhance the ownership from clients' perspective.

Person-centred care for chronic illness helps overcome barriers to HIV care and optimize health system efficiency because the core of the intervention is addressing the needs of each patient after assessment. The focus on each client's needs ensures that care is based on addressing each client's individual needs.

Upon being asked how person-centred care could be implemented in the NAYO context, a participant responded in the following way:

> *We need to abandon this community approach of dealing with individuals in the community and prioritize individuals' needs so that we serve them better in the way of promoting person-centred care. This is because each individual is unique in the way the disease affects them and how they react to the disease (Nanyoni 5, interview 2023).*

As argued by Chamie et al. (2019), a patient-centred approach to chronic care helps to overcome barriers to HIV care and optimize health system efficiency.

4.11 Theme Nine: Stigma

Stigma appears to be the major impediment to implementing PCC and CCC. Both enacted and felt stigma are common at NAYO, as observation and interviews revealed. At the facility level, the integration of ART and OPD services exposes ART patients to other people on OPD. The separation of rooms for general and ART medicines exposes patients to be seen by other villagers. Poor handling of ART cards and files for HIV patients results in stigma among the patients. Calling of names of patients on ART when they come for refills fuels enacted stigma. Healthcare providers take ART cards and call patients names. This is because ART providers search for the patient's card when they come to the clinic rather than earlier. This is done because staff do not keep track of records on patients' next visiting days.

The government of Malawi has a socio-moral-political obligation to take a leading role in addressing the national health care issue. The government initiated the integration of the ART clinic with the Out-Patient Department to reduce enacted stigma. However, this is challenged by poor handling of patients' cards and files, insensitivity, and indirect language among community members. The government further warned the public and introduced a law to punish perpetrators of enacted stigma and ART clients are encouraged to report stigmatizing incidences to the chief and police station.

A lack of communication between NAYO staff and patients on the changes led to felt stigma. Initially, NAYO had a specific day for ART clinic and palliative care only. Through seminars, NAYO staff learnt that this was stigmatizing patients. NAYO integrated ART with OPD aiming at de-stigmatizing HIV patients. However, the reasons necessitating the changes were not communicated to patients. Patients thought that this integration was exposing them to other villagers, resulting in felt stigma. Society perceives PLHIV as a burden to society, especially when PLHIV are not economically independent. NAYO's economic empowerment through the distribution of farm inputs, piglets and village savings and loans is meant to fight enacted stigma. Some respondents shared experiences of stigma:

> *For a long time, we used to receive our medication on Tuesdays. But nowadays, they just mix us on ART and OPD and we are stigmatised. People talk about us when we come to receive ARVs. We are easily identified because we have cards in our hands and our weight is checked. It would be good if they revert to a specific day for the ART programme. People knew that Tuesdays were for that ART programme, and this was respectful. Now people are taking transfers because they are being stigmatised when they come for their medication (Naphiri 4 interview, 2023).*

> *The time I was very sick, I was very thin, and people were talking that I have HIV. My children wanted to beat those people in the village because they were talking bad about me, but I told them not to revenge. People talk ill about HIV conditions. I have passed through a lot in my life because of this disease. It is better now because the majority of those who used to talk ill about my HIV status are also on the ART programme. They are also experiencing what I experienced and now they are quiet. But we just have to persevere because of HIV since people still talk ill about being HIV positive (Naphiri 8 interview, 2023).*

> *Sometimes they call us 'those for today's date' while everyone is hearing. This is exposing us to be known by OPD patients. Some of these patients are from our villages and they talk about our status in the village. The way they handle our files also exposes us to be known by others. We follow the clinician taking the file and it becomes obvious*

> *that people know about our HIV status. We feel disrespected through the way our files are handled (Naphiri 6, interview 2023).*

The respondents also shared the following about felt stigma:

> *We created a forum where these HIV clients meet quarterly. In these forums, they interact and express their concerns in group therapy discussions. There are also times when HIV clients isolate themselves. Instead of sitting with others and chatting, some isolate themselves and do not mingle with other people. We encourage them not to isolate themselves. We call and challenge their isolation techniques (Nyoni 2 interview 2023).*

In their study, Kato et al. (2011) argue for the participation of PLHIV to reduce stigma. Lack of communication from staff to patients about the changes in clinic days for ART and combination with OPD was received negatively by patients because the purpose of the change was not communicated.

Stigma is a barrier to the implementation of community-centred care for HIV patients. Community centres for refilling ARVs were initiated. However, most HIV patients did not come to get their medicine for fear of being seen by community members. Patients stated that they prefer getting their ARVs from distant clinics where people do not know them for fear of being stigmatised. Participants expressed their fear of stigma:

> *I come from Mpemba, but I was getting my ARVs from Queen Elizabeth Central Hospital in Blantyre. This is because many people were talking about my HIV status and my relatives and friends did not want to associate with me due to my HIV status. When I got married, I came to stay here in Nancholi, and I got transferred from Queens to NAYO. I'm fine with getting my medicines here because people do not know me. But my husband goes to Queens still because he has friends from this area (Naphiri 5, interview 2023).*

This is congruous with Zakumumpa et al's. (2020) study on understanding implementation barriers in the national scale-up of differentiated ART delivery in Uganda. Their findings revealed that stigma impedes community ART pick-up points and pushes patients to use pharmacies for ARV refills. Community members are fond of talking behind people with HIV status sometimes using indirect language. Participant observation also noted that HIV patients were uncomfortable in getting their ARVs when they noticed a village member at the facility.

Some resorted to leaving their medicines and returning later to wait for villagers to leave the clinic first.

Attending an HIV clinic exposes HIV patients to be seen by people visiting the clinic. Those who see HIV patients at the clinic gossip about them and may spread rumours about their HIV status. HIV patients also expressed their concerns regarding fencing of facility premises so that their visit to the clinic is confidential. This results in HIV patients withdrawing from social interactions.

> *I'm not happy with the arrangement that we come on Tuesdays and together with the OPD patients. The way staff manage our files and ART cards exposes us to other people who start talking about our status especially when they are from our village, we feel stigmatised. For a long time, we used to have our clinic on Tuesdays and OPD patients were not allowed, we used to feel respected but now mixing us all is disrespectful for us on ART because we have the whole village looking at us (Naphiri 5, interview 2023*).
>
> *Natsonthi 3 said:*
>
> *We have been requesting NAYO administration to fence the facility premises, as you see this clinic is within people`s houses. People around see us coming to the clinic and they talk about out HIV status with other people. Our visit to the clinic is personal and privacy is an issue here. However, the Director told us that there is no funding for constructing a fence. We will continue to express this issue because many of our HIV patients get transfers due to lack of privacy (Natsonthi 3, interview 2023).*

Likewise, Chamie et al. (2019) argue that attending an HIV clinic fuels rumours, stigmatizes PLHIV and creates social isolation. The structure of healthcare facilities, which separate rooms and structures based on services being offered, makes people aware of PLHIV whenever patients' clinic visit is associated with the disease.

The psychological impacts of HIV status do not hinder the implementation of person-centred care in highly cohesive societies because, in these societies, everyone is alert and minds other people's business. However, HIV stigma is hard to contain in homogeneous societies where a community determines how an individual should live their life. HIV-related factors such as depression, anxiety, and sleep disturbances are psychological negative effects of living with HIV.

A respondent expressed her fears about living with HIV in the village setup:

> *I can try to live positively with HIV by adhering to ARVs, minding my business, and ignoring everyone else. But here in our community, it is hard to ignore because people even speak metaphorical language, but you will just know that they are talking about you. Sometimes I don't want to think about it, but it comes to my mind, and I fail to control it; then, I find myself cursing God for the burden of this disease Naphiri 10, interview, 2023).*

From these sentiments, it is evident that challenges faced by HIV patients comprise their quality of life compared to the general population due to psychological impacts such as depression and fear, anxiety and the disturbance in sleep which they experience (Crawford et al., 2021). Observation also revealed fear and anxiety due to HIV status because once one tested positive, one had the whole community judging, stigmatizing, and discriminating against them.

4.12 Theme Ten: Challenges to the implementation of community-based care

The medicalization of HIV emphasizes clinical treatment in the management of the disease and neglects the social, emotional, psychological, and spiritual aspects in which HIV affects patients. Community-based interventions effectively address these neglected aspects by engaging local authorities to achieve effective care for PLHIV. However, the community-based organization lacks funding, and their services are at risk in terms of continuity. During COVID-19, funding agencies redirected their programmes and activities to COVID-19 prevention and treatment initiatives. NAYO's funding ceased, and this led to a cut-off OF their nutritional programmes, home visits and youth activities, as well as reducing the number of staff and those who were willing to work were given half of their salary.

Upon being asked about challenges, most respondents bemoaned financing activities as a major challenge:

> *We rely on donor funding from the Steven Lewis Foundation in Canada, NAYO UK fundraisers and the Government which supports us with medicines. Much of the stress in the implementation of our programmes comes from lack of funding and this makes us worry about the sustainability of our services (Nyoni 2, interview 2023).*

> *The main challenge we constantly face as an organization is funding. We rely on our funders and when they tell us that they do not have funds, we do not implement programmes and activities. Now that we have no funding, we are just operating as a*

> *mere clinic providing OPD, palliative care and ART. All other programmes for nutrition, farm inputs, education, youth recreation and economic empowerment stopped due to lack of funds (Nyoni 1, interview 2023).*

Similarly, Fakoya et al. (2019) found that the medicalization of the HIV response threatens the funding of community interventions. However, engaging community leaders in community intervention brings hope of reaching those in rural areas. Another challenge threatening the funding of community interventions is that donors want to see impact after funding a project or activities.

Another challenge to the implementation of person-centred is the complexity of communication between healthcare providers and patients. The extent to which patients are involved in decision-making is influenced by the patient's level of education and enhanced by trust and respect between healthcare providers and patients. Communication is enhanced by familiarity with concepts and terms used in disease and illness management. Healthcare providers need skills in communication with patients considering these factors. Upon being asked how communication is done, one respondent said:

> *When our viral load results come, we are just told that we are at risk or there is no change. We would prefer that we know about how they interpret viral load results (Naphiri 9, interview 2023).*

Waweru et al. (2019) contend that communication between patients and healthcare providers is complex because it is affected by patients' literacy level, respect, and trust. These require healthcare providers to gain skills in communication, respect, and trust building to better interact with patients.

Enacted stigma is a challenge to the implementation of person-centred care in community settings. The community stigmatizing HIV patients affects the sufferers whose fears hinder them from active participation in community activities. Upon being asked about the experience of stigma, a respondent said:

> *We who have the HIV disease are the talk of the community. People in the community backbite us on our HIV status and some discriminate against us. When my relatives heard about my status, they stopped to eat my food because they thought that I could infect them. So, I have few friends and relatives who still interact with me and encourage me to live positively though but not easy (Naphiri 3, interview 2023).*

From the lamentations above, it becomes obvious that stigma is a powerful determinant of how people living with HIV manage their lives (Pepper, 2023). HIV patients live in constant fear of being judged by community members. This is because HIV is assumed to be linked to immorality in most cases; people blame those suffering from the disease by attributing irresponsibility to them, for the contraction of the disease.

A lack of necessities could impede person-centred care in communal settings. This is because the community expects visitors to bring gifts when visiting them. Community volunteers are expected to carry something when visiting patients in the village. This is a tradition in communal settings like Nancholi. The challenge is that NAYO does not have funds to give to community volunteers, so they buy some things to carry for patients when they visit them for a follow-up. Poverty also hinders retention and adherence to HIV treatment. This is because taking ARVs requires healthy eating so that the system is conducive for ARVs to work and retain patients' strength. The unfortunate part is that most ART patients cannot afford all six nutritional groups of food to have a balanced diet. The majority live in rural areas where they depend on subsistence farming on ancestral land for survival.

Upon being asked about the changes since NAYO enrolment some of the respondents said:

> *It was worse when I came because I had lost much weight. I had started getting my ARVs from Queen Elizabeth Central Hospital, but most of the time, I was not taking the drugs because I did not have food to accompany it. Also, the drugs were making me feel weak and I had dizziness (Naphiri 2 interview, 2023).*

> *Sometimes, I fail to go and visit ART clients because I have nothing to carry for them, especially when I have seen that the client is in a pathetic situation and needs our help in terms of food and soap. This is because I think a lot about the client's situation and how best I can help them. I cannot encourage a client to take medicines if they have not eaten because I know that ARVs are strong and they work better when a client has eaten (Natsonthi 3, Interview, 2024).*

This is in line with Pepper's (2023) argument that poverty is found to be a barrier to maintaining adherence to ARVs. Lack of necessities such as a balanced diet makes ARV adherence difficult for patients. Financial struggles make it difficult for patients to acquire food items necessary for taking medication. Patients resort to defaulting or withdrawing from ART.

4.13 Conclusion

Chapter four provided and discussed the research findings, which were organised into themes including the identification of patient needs, the NAYO approach to care, the involvement of patients at the community and facility level, and factors influencing the implementation of PCC at NAYO. These were namely staff knowledge and the healthcare system which are geared towards CBC. The patient support system, collaboration, stigma, and limited finances are also major challenges to the implementation of NAYO's activities. Chapter five concludes the discussion and offers recommendations based on the study's findings.

5.0 Chapter Five: Conclusion and Recommendations

5.1 Conclusion

This study explored the involvement of HIV patients in person-centred care (PCC) at the Nancholi Youth Organization (NAYO) in Blantyre, Malawi. The study's literature review was guided by significant concepts including PCC, expert patients, GIPA, CCC and stigma. The study adopted Habermas's theory of colonization of life worlds in problematizing the dominant medical model and Foucault's theory of bio-power along with the concept of locating the self in practice. This study argues that patients with chronic illnesses, like HIV, make necessary adjustments in their lifestyle to enhance the management of illness. The study used stratified and purposive sampling techniques to identify HIV patients on the first line of ART. It also used purposive sampling to recruit NAYO staff members working with ART patients. Interviews and participant observation were used to collect data, and themes were developed using research questions.

The study's findings revealed that NAYO uses a community approach (CCC) in its interventions by integrating facility care and community-based care. At the facility level, patients' needs are assessed clinically and linked to extended services such as nutritional supplements, agricultural inputs, and livestock farming. NAYO uses the medical model at the health facility, making it difficult for patients to participate in care. NAYO's community interventions use the community model as coordinated by community volunteers who collaborate with patients, healthcare providers, and patients' support systems to meet patients' needs. Patients' support systems include community volunteers, community and religious leaders, family and friends who work in collaboration to provide for the needs of HIV patients.

Stigma, however, is an obstacle to the implementation of both PCC and CCC. NAYO is dissatisfied with patients' participation, and financing is a major challenge in implementing its programmes. NAYO's approach, structure and stigma hinder the involvement of patients in care. Nonetheless, patients are involved at the community level, where community health workers coordinate the provision of services. Therefore, the major finding is that NAYO is practising community-based care rather than PCC, as the researcher initially wanted to explore.

5.2 Recommendations

5.2.1 Recommendations by the Researcher to NAYO

The findings revealed limited knowledge of person-centred care by NAYO professionals. There is a need to facilitate training opportunities for NAYO staff to fill the knowledge gap in person-centred care by training and organizing workshops and seminars.

The research findings also revealed that much of the collaboration occurs between community volunteers and healthcare providers. Strengthening collaboration between healthcare providers and patients is needed to better implement person-centred care.

The findings further reveal that the organization's key stakeholders, such as the Chief, In-charge, and Monitoring and Evaluation officers, mostly interact with the local leaders in communities who decide or are consulted about programmes/activities to be implemented while patients are left out. However, there is an expectation that PLHIV, as beneficiaries will participate in decisions that concern them. There is, therefore, a need for improved engagement between patients and the organization’s key stakeholders.

The study also reveals the low involvement of HIV patients at the facility level due to power imbalances between healthcare providers and patients. There is also a need to improve patient involvement at the facility level.

The results reveal that patients are not given enough time to express their needs and concerns. This is because only one medical professional attends to all patients, which puts pressure on the nurse in charge. There is a need to create a forum to listen to patient concerns.

The study also reveals that NAYO’s implementation of activities with a limited budget resulted in a shortage of staff. The catchment area of 25 villages with its population does not correspond to the number of NAYO staff. NAYO needs to request additional finances and human resources from the government because they deliver primary health care on behalf of ministry of health in filling the gap of public health institution shortage in Malawi.

The study findings also revealed the importance of societal ethos and the moral obligation of community members to provide holistic support. They use indirect language, which demeans HIV patients by making fun of their status should be actively discouraged and prevented. There is a need for moral and civic education to sensitize community members on the use of language or oral traditions that are more inclusive to ART clients.

5.2.2 Recommendations from Participants

The findings report that NAYO staff makes changes about the days for ART days and the integration of ART with OPD patients without consulting the patients about the change. Despite NAYO’s intentions, the patients had negative assumptions about these changes. Therefore, NAYO staff needs to improve its communication to avoid negative assumptions.

The study's findings also reveal that NAYO staff's poor file handling exposes clients to OPD patients, resulting in patients feeling stigmatized. NAYO staff needs to be more sensitive in handling ART client files and cards.

Third, the results of this research revealed that HIV patient respondents expressed their concerns about the need to fence the clinic for security and privacy. They recommended fencing the facility premises, arguing that this could enhance the privacy and security of patients.

The study also reveals that support groups ceased to exist because they were linked to the distribution of food items. As such, when funding ceased, these groups died a natural death. Considering the importance of support groups in terms of offering psycho-social support to patients, there is a need to revive the support groups. This can be done through establishment of ART support groups coordinated by CHW within traditional authorities in NAYO catchment area.

5.2.3 Recommendations for further research

Findings reveal that implementing person-centred care requires changes in the structure, roles, and communication patterns to accommodate patients' needs. Research is needed to determine how healthcare systems in communal settings could accommodate PCC.

Further, the study reveals that the lack of involvement of HIV patients in care is caused by power imbalances between healthcare providers and patients coupled with HCWs' beliefs about their role. There is a need for further research to find ways of increasing patients' autonomy at the facility level.

The study's results also revealed little collaboration between patients and healthcare providers. This is because the presence of community health workers links healthcare providers and patients through NAYO. Engagement is needed to improve collaboration between patients and healthcare providers better.

The study's results also reveal an overlap between community-based care and person-centred care in highly integrated communities. There is a need to research the link between community-based and person-centred care in low-income countries.

This study also uncovered the importance of community-based healthcare reaching the majority in rural areas and addressing the lack of professionals and resources. However, community healthcare programmes are less funded and not included in funding mainstream healthcare programmes. There is a need to research on the financing of community healthcare programmes.

Also, the study findings reveal that healthcare provisions rely on medical models rather than community models of care despite community-based care practices yielding positive results. Research is needed on how to promote community models of care in healthcare provision practices in rural areas.

Lastly, the study reveals the constructive collaboration between facility and community care. NAYO has integrated two systems well, and they fit together because one complements the other. Community volunteers and healthcare providers work together. A study that explores the integration of the two systems in other contexts is recommended.

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II. Appendices

1. Participant Consent Form

Title of project: Involvement of HIV patients in person-centred care in NAYO Programmes

Name of researcher: Delipher Magola

I, ……………………………………….., agree to participate in this research project.

I agree to the following:

(Tick in the box of relevant options below)

The research study was explained to me. I understand what this study is about the involvement of HIV patients in person-centred care.	YES ☐	NO ☐
I understand that I can volunteer to take part in the study.	YES ☐	NO ☐
I agree that the interview may be audio recorded.	YES ☐	NO ☐
I agree that direct quotations from my interview activity may be used by the researcher in their research report.	YES ☐	NO ☐
I agree that my participation will remain anonymous (my name or other identifying data will not be used by the researcher in their research report.	YES ☐	NO ☐
With your permission, the data collected from this research study could be made available to other researchers.	YES ☐	NO ☐

………………………………… (Signature)
…………………………………… (Name of participant)
…………………………………… (Date)

…………………………………… (Signature)
…………………………………… (Name of researcher/person seeking consent)
……………………………………. (Date)

2. Participant Information Sheet (PIS)

Dear Sir / Madam

My name is Delipher Magola, a student in MA in Health Sociology at the University of the Witwatersrand, Johannesburg. My supervisor is Dr Kezia Lewins and Prof. David Dickinson. I am conducting a research study about person-centred care. The study title is “The involvement of HIV patients in NAYO programmes.” I am conducting research on HIV patients’ involvement in care. I am inviting you to take part in an interview. Your participation in this research study will last about an hour. The interview will take place at Nancholi Youth Organization in person.

With your permission, I would like to audio record the interview. The data will be stored in computer. Only the researcher and the supervisors will have access to the data.

During the research activity, I will need to ask for some personal information about you, including HIV patients’ participation in NAYO programmes.

The interview record will be confidential and anonymous. When I share the results of the research study, I will not include your name or anything else that could identify you. With your permission, other researchers may use the data collected from this research study, but your name and any personal information will not be used or passed on. I guarantee anonymity.

If you decide to take part in the research study, it should be because you want to volunteer. You do not have to take part. You can stop being in the study at any time. You do not have to answer any questions if you do not want to, and this will not have any negative consequences. You will not get any direct benefits if you choose to join the research study. You will not lose any services, benefits, or rights you would normally have if you decide not to join. Taking part in the research study will not cost you anything. You will not be paid for being in this research study. Your travel/data costs to attend the interview will be reimbursed.

The risks for this research study are no more than what happens in everyday life / some of the questions asked may make you feel sad or upset. If this happens, I will stop the interview and continue another time. If you need some support or counselling services following the interview, these are available free of charge at NAYO. The name of the counsellor is NAYO staff and the contact details for the counselling service are………...

Patients may feel sad

This research study will be written up as a research report. The report will be available on the university library website. If you would like to receive a summary of this report, I will be happy to send it to you.

If you have any questions during or afterwards about this research study, feel free to contact me at +265996795086 or my supervisor on the details listed below. If you have any concerns or complaints about the ethical procedures of this research study, you are welcome to contact the University Human Research Ethics Committee (Non-Medical), telephone +27(0) 11 717 1408, email: hrecnon-medical@wits.ac.za or my supervisor.

Yours sincerely,

Magda

Researcher: Delipher Magola, 2613399@students.wits.ac.za, 0692039506 or +265996795086

Supervisor: Professor David Dickinson, David.Dickinson@wits.ac.za, +27827891265

Supervisor: Dr. Kezia Lewins,
Kezia.Lewins@wits.ac.za, +27793528989

The involvement of HIV patients in person-centred care: The case of Nancholi Youth Organization (NAYO) in Blantyre, Malawi.

Delipher Magola-2613399

Research Tool

3. Interview Guide for HIV patients

Section A: Introduction

Thank you for taking the time to participate in this interview. My name is Delipher Magola. I am a Wits University Master's student conducting research about the involvement of HIV patients in person-centred care, as a requirement for the award of a Master's Degree in Health Sociology. I will appreciate honesty in your answers because your responses will be reported in the final analysis to answer research questions.

Section B: Instructions

- Please answer the following questions
- Your participation in this interview is voluntary
- You are free to withdraw from the interview at the point of discomfort

I request to audio record the interview so that I can refer to the recording when writing the report to ensure that I correctly and accurately represent your words.

Section C: Questions about yourself

1. Where do you live?
2. What is your gender?
3. What is your age?
4. How did you learn about NAYO?
5. How long have been with the NAYO organization?
6. Have you participated in any other HIV&AIDS programmes before coming to NAYO?
7. What is your highest qualification attained?

Section D: Items

8. Which Programmes/activities do you participate in?
9. What roles do you play through participation in NAYO programmes?
10. What do you get from participating in NAYO programmes?
11. What factors affect your participation in NAYO programmes?
12. What do you benefit from participation in NAYO programmes?
13. How do you collaborate with healthcare providers in NAYO programmes?
14. How do you collaborate with your support system?
15. How are you involved in decision-making for NAYO programmes?
16. What changes have you experienced after joining NAYO?
17. What could you do to improve the involvement of HIV patients in NAYO programmes?
18. What is NAYO doing to fight against Stigma?

Section E: Conclusion

Thank you for your participation in the study. Your responses are valuable. The information will be used for academic purposes, and I will not reveal your identity in reporting.

The Involvement of HIV Patients in Person-centred Care

Delipher Magola: 2613399

Research tool:

4. Interview Guide for patient support system

Section A: Introduction

Thank you for taking the time to participate in this interview. My name is Delipher Magola. I am a Wits University Master's student conducting research about the involvement of HIV patients in person-centred care, as a requirement for the award of a Master's Degree in Health Sociology. I will appreciate honesty in your answers because your responses will be reported in the final analysis to answer research questions.

Section B: Instructions

- Your participation in this interview is voluntary.
- Please answer all questions.
- You are free to withdraw from the interview at any point you feel discomfort.

I request to audio record the interview so that I can refer to the recording when writing the report to ensure that I correctly and accurately represent your words.

Section C: Questions about yourself

1. Where do you come from?
2. What is your gender?
3. What is your age/When were you born?
4. What is your relationship with the patient?
5. How long have you been involved in the patient's life?

Section D: Supply Items

6. What are your roles in NAYO programmes and activities?
7. What needs of HIV patients are addressed in NAYO programmes?

8. How are HIV patients involved in NAYO programmes?

9. What factors affect your participation in NAYO programmes?

10. How do you collaborate with HIV patients as a support system?

11. How do you collaborate with NAYO staff as a patient support system?

12. How are you satisfied with HIV patients' participation in NAYO activities?

13. What can motivate patients to participate in person-centred care?

14. How do you help HIV patients manage stigma?

Section E: Conclusion

Thank you for your participation in the study. Your responses are valuable. The information will be used for academic purposes. I will not reveal your identity in my report.

The Involvement of HIV Patients in Person-centred Care

Delipher Magola-2613399

Research tool

5. Interview Guide for NAYO staff

Section A: Introduction

Thank you for taking the time to participate in this interview. My name is Delipher Magola. I am a Wits University Master’s student conducting research about the involvement of HIV patients in person-centred care, as a requirement for the award of a Master’s Degree in Health Sociology. I will appreciate honesty in your answers because your responses will be reported in the final analysis to answer research questions. The information you provide will not be shared with anyone, and I will not reveal your identity in the report.

Section B: Instructions

- Please answer the following questions.
- Your participation in this interview is voluntary.
- You are free to withdraw from this interview at any point of discomfort.

I request to audio record the interview so that I can refer to the recording when writing the report to ensure that I correctly and accurately represent your words.

Section C: Questions about yourself

1. Where do you come from?
2. What is your gender?
3. What is your age/when were you born?
4. How did you learn/hear of NAYO?
5. How long have you been working with the NAYO organization?
6. What is your position and role within the NAYO organization?

Section D: Items

7. What are your roles in NAYO programmes and activities?
8. What are the objectives of NAYO programmes?
9. What needs of HIV patients are addressed in NAYO programmes?
10. How are HIV patients involved in NAYO programmes?
11. What factors affect patients’ participation in NAYO programmes?
12. How do you collaborate with patients in decision-making about NAYO programmes?
13. How do you collaborate with the patient support system in NAYO programmes?
14. How satisfied are you with HIV patients’ participation in NAYO activities?
15. How can patients be motivated to participate in person-centred care?
16. What is your knowledge about person-centred care?
17. How did you learn about person-centred care?
18. How is NAYO fighting stigma among HIV patients?

Section E: Conclusion

Thank you for your participation in the study. Your responses are valuable and will be used for academic purposes. I will not reveal your identity in the report.

The Involvement of HIV Patients in Person-centred Care

Delipher Magola-2613399

Research tool

6. Observation guide

Section A: Introduction

Thank you for allowing me to observe your interaction. My name is Delipher Magola. I am a Wits University Master's student conducting research about the involvement of HIV patients in person-centred care, as a requirement for the award of a Master's Degree in Health Sociology. I will be observing as I participate in the activities taking place.

Areas to observe

1. Interaction between healthcare providers and patients
2. Activities happening in different rooms
3. Management of HIV patients files
4. Storage and pharmacy for HIV medicines
5. Interaction between patients

7. Ethics Certificate

UNIVERSITY OF THE
WITWATERSRAND,
JOHANNESBURG

DEVELOPMENT STUDIES AND SOCIOLOGY ETHICS COMMITTEE
CONSTITUTED UNDER THE UNIVERSITY HUMAN RESEARCH ETHICS COMMITTEE (NON-MEDICAL)

8. Clearance Certificate Protocol Number: Socl-2023-02

PROJECT TITLE	The involvement of HIV patients in person-centred care in Nancholi Youth Organization, Blantyre, Malawi
INVESTIGATOR	Magola, Delipher
SCHOOL/DEPARTMENT OF INVESTIGATOR	Sociology, School of Social Science
DATE CONSIDERED	26 June 2023
DECISION OF THE COMMITTEE	Approved unconditionally
RISK LEVEL	Minimal Risk
EXPIRY DATE	27 June 2024
ISSUE DATE OF CERTIFICATE	06 July 2023

CHAIRPERSON
____
(Dr Obvious Katsaura)

cc: Supervisor: Prof David Dickinson and Dr Kezia Lewins

DECLARATION OF INVESTIGATOR

To be completed in duplicate and **ONE COPY** returned to the Chairperson of the School/Department ethics committee.

I/we fully understand the conditions under which I am/we are authorized to conduct the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure be contemplated from the research procedure as approved, I/we undertake to submit an amendment of the protocol to the Committee.

___________________________ ______/______/______

Signature **Date**

PLEASE QUOTE THE PROTOCOL NUMBER ON ALL ENQUIRIES

9. Access to NAYO

Nancholi Youth Organisation
P.O. BOX 2057
Blantyre, Malawi
Email: nancholiyouthorganisation@gmail.com
Cell: +265999762724 / +265888194007

Human Research and Ethics Committee (HREC)
Wits University
Senate House Building, Research and Innovative
Braamfontein, East Campus
Johannesburg 2050

Dear Human Research and Ethics Committee (HREC),

Recommendation Letter

I am writing to you on behalf of the Nancholi Youth Organization to provide an update regarding Delipher Magola's research project titled "The involvement of HIV patients in person-centred care: The case of Nancholi Youth organization" which is being conducted in collaboration with our organization. We would like to express our strong recommendation for her to continue and complete the research with us.

Delipher Magola's research focuses on exploring the involvement of HIV patients in person-centred care within the context of the Nancholi Youth organization, located in Blantyre, Malawi. This study holds significant importance as it aims to shed light on the experiences and perspectives of HIV patients and how they are engaged in their own care within our organization.

By expanding the scope of her research to include the specific context of the Nancholi Youth organization, Delipher Magola has the opportunity to uncover valuable insights into the challenges and successes of implementing person-centred care practices for HIV patients. This information will not only benefit our organization but also contribute to the broader understanding of effective care models for individuals living with HIV in resource-limited settings.

We believe that our collaboration with Delipher Magola will enhance the validity and relevance of her research findings. Our organization has been actively involved in providing comprehensive support and services to HIV patients, and our experience in this field will greatly contribute to the success of the study. Furthermore, our close relationship with the HIV patient community in Blantyre will facilitate access to the necessary participants and ensure the research is conducted in an ethical and culturally sensitive manner.

We assure you that our organization is fully committed to supporting Delipher Magola throughout the research process, providing her with the necessary resources, guidance, and access to our network of HIV patients. We strongly believe that her findings will not only contribute to academic knowledge but also have practical implications for improving person-centred care practices and the overall well-being of HIV patients in our community.

We kindly request your endorsement and support for Delipher Magola to continue her research with the Nancholi Youth organization. We are confident that her study will make a meaningful contribution to the field of healthcare and further advance our understanding of person-centred care for HIV patients.

Thank you for considering our recommendation, and we look forward to your favourable response.

Sincerely,

George Nedi

Executive Director