

**ASSESSMENT OF LIVED EXPERIENCES, SELF EFFICACY, AND QUALITY OF LIFE
AMONG TUBERCULOSIS PATIENTS IN NAIROBI COUNTY, KENYA**

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**A THESIS SUBMITTED TO THE SCHOOL OF HEALTH SCIENCES IN PARTIAL
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I. DECLARATION

This thesis is my original work and has not been presented for an award of a degree or diploma in any other university or institution.

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III. ABSTRACT

Tuberculosis program effectiveness is majorly measured by disease severity and treatment response without integrating patient perspectives, yet, it's a critical dimension in clinical decision-making that enhances health worker-patient interactions and increases individuals' sustained engagement with treatment thereby benefiting not only the people affected by tuberculosis but also the wider public by mitigating the infection risk. This study assessed tuberculosis patients' lived experiences, level of self-efficacy, and quality of life in Nairobi County, Kenya. A cross-sectional study design with mixed-method research, triangulation design, and convergence model was used, employing a partially mixed, concurrent, dominant design. Interviews were conducted between May and June 2023 in five sub-counties namely: Ruaraka, Dagorretti, Langata, Starehe, and Embakasi East among drug-sensitive tuberculosis patients in the continuation phase of treatment. Additionally, a phenomenology approach was used to explore the lived experiences of the patients in focused group discussions and key informant interviews, which were audio recorded and transcribed verbatim followed by coding and thematic analysis. A two-stage cluster sampling was done based on the 2021 county tuberculosis workload. First, five sub-counties with the highest cases were purposively selected. Secondly, facilities with the highest cases were also purposively selected. Participants were then selected through simple random sampling($n=392$) from a population of 2961. *R* statistical software and Microsoft excel were used for descriptive and inferential statistics where Spearman's correlation was used to assess the association of the different domains to the overall self efficacy and quality of life levels, while analysis of variance was used to measure the mean differences across the domains of self efficacy and quality of life. Different themes were identified including low knowledge level on prevention and control strategies, perceived wellness, facility preference, missed appointments among the special population, food insecurity stigma, side effects, pill burden and economic effects of tuberculosis. The overall self efficacy level was low 349 (89.03%) with a moderate positive correlation between the different domains (knowledge, collective, psycho-emotional, functionality) and the overall level. All the domains were statistically significant ($p < 0.05$). The overall quality of life level was also low, 97(50.26%) with the domains (physical, socioeconomic, psychosocial) having a strong positive correlation with the overall level except the spiritual domain which had a weak positive correlation. All the domains were statistically significant($p < 0.05$) except the spiritual domain. These findings suggest that patients' experiences may affect treatment outcomes and that improving their levels of self efficacy, and quality of life may help improve treatment outcomes. Therefore, in addition to the clinical outcomes, the tuberculosis program should consider adding patients' perceptions in the monitoring and evaluation tools, include the socio-economic and psychological dimensions that impact the disease and its treatment in the treatment package, including nutritional support for street families and vulnerable groups. They should also consider using self efficacy and quality of life more frequently and perhaps include them in forthcoming guidelines.

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VI. DEFINITION OF TERMS

Quality of life: refers to the individuals' perception of their position in life in the context of the culture and value system in which they live and in relation to their goals.

Self-efficacy: refers to the self-confidence or a judgment about one's capacity for self-organization and the ability to perform a particular activity.

Patient centered care: refers providing care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions

Intensive phase of treatment: refers to the period from initiation of treatment up to eight weeks of treatment.

Continuation phase of treatment: refers to the period from eight weeks of treatment to end of treatment period (six months for drug sensitive TB)

Validity: the accuracy and meaningfulness of inferences based on the research results, and it's enhanced by absence of systematic errors in the data collected

Pre-test: small-scale preliminary study that is carried out before implementing a full-scale study.

Knowledge: information, and skills acquired through experience or education; the theoretical or practical understanding of a subject.

Microbial outcomes: treatment outcomes based on the measured bacterial load in the system of the patient.

VII. ABBREVIATIONS AND ACRONYMS

ANOVA	Analysis of Variance
CHP	Community Health Promoter
DOTS	Directly Observed Therapy
EPTB	Extra Pulmonary tuberculosis
FGDG	Focus Group Discussion Guide
GDP	Gross Domestic Profit
HBM	Health Belief Model
HIV	Human Immunosuppressive Virus
HSD	Honestly Significant Difference
ICS	Individualized Care Scale
KIIG	Key Informant Interview Guide
KSH	Kenya shilling
MDR	Multi-Drug Resistant TB
MMR	Mixed Method Research
MOH	Ministry of Health
NACOSTI	National Commission for Science Technology and Innovation
QOL	Quality of Life
RR	Rifampicin Resistant
SE	Self-Efficacy
TB	Tuberculosis
TBSES	Tuberculosis Self Efficacy Scale
TWG	Technical Working Group
TWG	Technical Working Group
UN	United Nations
WHO	World Health Organization
XDR	Extra Drug Resistant

1.0 CHAPTER ONE: INTRODUCTION

1.1 Background Information

Until the Covid 19 pandemic, tuberculosis (TB) remained the leading cause of death from a single infectious agent, ranking above HIV/AIDS (Global Tuberculosis Report, 2022) with 10.6 million infections and 1.6 million deaths, of which 82% occurred in World Health Organization (WHO) African and South-East Asia regions in 2022 (Global Tuberculosis Report, 2022). Additionally, the WHO estimates Kenya's incidence rate at 133,000(MOH-NTLP, 2022).The report further shows that the county reported 90,560 drug sensitive cases in 2022 with Nairobi County contributing 12,163 (15%) of the cases (Nairobi county TB report, 2022) (Nairobi county TB report 2022, n.d.).Even with free treatment in all public facilities, Nairobi still leads in all TB reported cases nationally, as well as a high loss to follow-up rate of 6%,against the recommended less than 5%(MOH-NTLP, 2022; Nairobi county TB report, 2022).

Patient centered care, which has been defined as “providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions”(Kuipers *et al.*, 2019) is greatly advocated for by the WHO to not only end the TB epidemic by 2035, but also reduce its morbidity and mortality, and eliminate economic and social burdens (Global Tuberculosis Report, 2022). In addition, a systematic review by (Cazabon *et al.*, 2020) and (Alipanah *et al.*, 2018) as well as a report by the Lancet commission (Reid *et al.*, 2019) demonstrated that providing individualized care that is specifically suited for individual patient needs can lead to improved treatment outcomes.

However, TB programs have leaned towards the universally applicable interventions, prioritizing case detection, TB notification and treatment adherence over the specific needs of individuals affected (Horter *et al.*, 2021), with a “one size fit all approach” regardless of the different social and cultural contexts (Megerso *et al.*, 2020). For instance, the Kenya national TB guidelines (2021) attempts to give a patient centered approach to TB care through new diagnostic technologies, shorter term regimens for treating latent TB and more individualized care for drug resistant TB patients (MOH TB guidelines, 2021).However, the fact that the perceptions of the patients are not captured has led to scarce evidence on what works and how to implement this approach since, these perceptions are neither part of the routine data collected nor routine care, leading to a lack of

understanding of the inward perceptions of the patients that may drive them to continue or discontinue medication.(Ivaylo *et al.*, 2018)..

Previous studies indicate that treatment success or failure of TB patients depends on their level of self efficacy (SE) (Setiyowati *et al.*, 2021). A systematic review by Choliq *et al* showed that patients with high SE are known to have the confidence to complete different tasks and difficulties during treatment (Choliq *et al.*, 2020). These patients have stronger motivation and execution, are more accurate in decision-making, and have better health-promoting behaviors(Chuang *et al.*, 2021). When TB patients have low SE, they may not adhere to treatment protocols and may develop negative health behaviors (Nuwa & Kiik, 2021).

Not only are people rendered jobless by TB, but it also cuts down on productivity (Saqib *et al.*, 2018) with studies showing that this can affect any organ in the body leaving lesions in the lungs which may lead to physical disability, and opportunistic infections, which all decrease the quality of life(QoL) of patients (Abiz *et al.*, 2020). And upon diagnosis, a number of psychological reactions can be seen (Aggarwal, 2019) with some patients showing reduced self-esteem, depression, anxiety, disappointment, and refusal to accept the diagnosis (Alfian 2020).These psychosocial burden ,as suggested by some evidence, may have a greater impact than clinical symptoms in TB patients (Álvarez-López *et al.*, 2020) and this can affect treatment adherence (Alfian 2020).

Therefore, understanding constructs associated with specific patient-level needs and values is needful to guide tailored interventions (Furin *et al.*, 2020). There is need for a multifaceted approach, that takes into account patients' perspectives, psychological, social and economic factors that affect adherence. This will help the patients in adapting, changing, and maintaining behavior due to the long treatment process of TB as well as being centered on individual care to balance the rights and needs of patients, including the responsibility for their recovery (Parwati *et al.*, 2021). This study was therefore conducted to explore the lived experiences of patients who are on TB treatment, and to determine their level of SE and QoL to help explain how they may impact the overall treatment outcome

1.2 Problem Statement.

Even though the national TB guidelines has attempted to implement a patient centered approach towards the management of TB, through provision of use of newer and more sensitive TB diagnostic techniques, use of the newer shorter-term regimen for treatment of Latent TB infection and provides for individualized care of DR TB patients (MOH TB guidelines, 2021), Kenya is still ranked among the 30 high burden countries by the WHO (Global Tuberculosis Report, 2022). The national 2022 report shows 90,560 cases (MOH-NTLP, 2022) with Nairobi county bearing the greatest burden in all reported cases at 12,163 (Nairobi county TB report, 2022) with a high loss to follow up rate of 6% against the recommended less than 5% (MOH-NTLP, 2022).

Additionally in the local setting, patients' perceptions and psycho-cognitive experiences are not part of the current monitoring and evaluation tools in the TB program and so they are neither part of the routine data collected nor care provided. This therefore means that these perceptions which are highly varied, have remained largely understudied (Aggarwal 2019) leading to a lack of understanding of may drive them to continue or discontinue medication (Ivaylo *et al.*, 2018). Further, even though studies have associated SE and QoL for chronically ill patients including TB (Lim *et al.*, 2021), there have been less focus on these aspects as a components of treatment (Chuang *et al.*, 2021)

1.3 Objectives of the Study

General Objective

This study sought to explore the lived experiences, assess the level of self-efficacy, and quality of life of tuberculosis patients on treatment in Nairobi County.

Specific Objectives

- i. To explore the lived experiences of tuberculosis patients on treatment in Nairobi County.
- ii. To determine the level of self-efficacy among tuberculosis patients on treatment in Nairobi County.
- iii. To determine the level of quality of life in tuberculosis patients on treatment in Nairobi County.

Research Questions

- i. What are the lived experiences among tuberculosis patients on treatment in Nairobi County?
- ii. What is the level of self-efficacy of tuberculosis patients during the treatment period in Nairobi County?
- iii. What is the level of quality of life among tuberculosis patients during the treatment period in Nairobi County?

1.4 Justification of the Study

Nairobi county being an urban area, bears a high burden of TB (MOH NTLP, 2016), and is also the leading county in TB burden nationally (Nairobi county TB report, 2022). Further, the WHO introduced the directly observed therapy (DOTS), which is the recommended treatment approach for TB for improved adherence and treatment outcomes (MOH TB guidelines, 2021). Though extremely important, this is not anchored on the patient centered approach that requires the patients to own treatment and that their perceptions guide clinical decisions (WHO, 2015). And also, there is still very little understanding of how this patient centered approach should be implemented, with assumptions that once they are put on DOTs, the patients will be well empowered to transition to self-care and own treatment. Additionally, SE is less studies with inadequate evidence available to show its level or gaps that may act as a basis of empowering the patients, while lack of adequate information on QoL leads to a lack of understanding of the patient as a whole, where gaps associated with QoL such as the physical, social ,economic and psychological are less understood

1.5 Significance of the Study

This study findings demonstrates, first, individual, psycho-cognitive, social and economic factors that drive patient treatment behavior responses. This will inform improvement strategies for TB programs towards adoption of the patient-centered approach in line with the WHO End TB strategy(*Global Tuberculosis Report, 2022*), as adopted in the Kenya strategic plan for TB 2019-2023 that aims for a patient-centered approach in TB management (Kenya Ministry of Health, 2019), and secondly the interplay of personal factors, disease severity and QoL. This understanding will enable the design of personalized care to achieve better outcomes, in line with Vision 2030 which aims to achieve a globally competitive and prosperous Kenya with a high QoL (MOH NTLP, 2016).Further, these findings inform policy formulation on the psychosocial needs of patients and

help plan mitigation measures as well as help improve practice by including psychosocial care to the routine care that may ultimately help improve treatment outcomes.

1.6 Limitations of the Study

This was a hospital-based study that interviewed the participants who came to the facility, thereby missing the inputs of those who did not come to the facility.

2.0 CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

Even with the sustained efforts in TB eradication, including free treatment in public facilities, Kenya reported a 16.6% increase in drug sensitive TB cases, reporting 90,560 cases up from 77,854 in 2021, a sustained upward trend since 2020 (MOH-NTLP, 2022). The management plan for the drug sensitive TB treatment involves two phases namely intensive (which lasts two months and usually consists of four drugs) and continuation (which lasts four months to ten months and usually consists of two drugs) (MOH TB guidelines, 2021). This treatment is offered DOTS as recommended by the WHO, is aimed at helping patients improve adherence, thus achieving cure and preventing the development of drug resistance (MOH TB guidelines, 2021). Response to treatment in pulmonary bacteriologically confirmed TB patients is monitored by sputum smear examination with the patients expected to make weekly visits during the intensive phase and twice weekly during the continuation phase of anti-tuberculous therapy (MOH TB guidelines, 2021). Additionally, the Kenya national TB guidelines (2021) attempts to give a patient centered approach to TB care through new diagnostic technologies, shorter term regimens for treating latent TB and more individualized care for drug resistant TB patients (MOH TB guidelines, 2021).

2.2 Patient Experiences

Patient experiences are described as a direct report by the patients, of the health outcomes concerning an illness or treatment (Forestier *et al.*, 2019). According to Stinger *et al.*, they are an important tool in the evaluation of the effectiveness of treatment interventions from a patient's perspective and ensures that the patients are involved in the decision-making process (Stringer *et al.*, 2021). Previous studies have indicated that TB patients have varied experiences (Ting *et al.*, 2020), with negative experiences being associated with non-adherence (Cazabon *et al.* 2020) which leads to significant impacts including delayed sputum conversion, drug resistance, prolonged infectiousness in the community, high mortality rate, and prolonged treatment course resulting to economic and psychosocial affliction (Suliman *et al.*, 2022). No one other than the patients themselves, are best placed to provide evidence from their experiences that then allows for a deeper understanding of how treatment impacts their overall health, care, and daily life (Araia *et al.*, 2021). It's therefore crucial that as recipients of services, their perceptions are explored as associates of adherence to help develop ideal and alternative interventions through a patient-centered approach (Sahile *et al.*, 2018).

Personal factors such as low TB knowledge, perceived wellness and honoring treatment appointments have been associated with treatment outcomes (Aibana *et al.*, 2020). Knowledge on the disease, its mode of transmission, the TB drugs as well as the standard treatment duration are key for achievement of desired outcomes (Megerso *et al.*, 2020). Some patients once they feel relief after taking medications for a while, stop it all together leading to grave consequences such as incomplete adherence, which may result in increased relapses and multidrug-resistant TB. Educating patients have been found to significantly reduce the risk of treatment nonadherence (Appiah *et al.*, 2023) which then improves treatment outcomes.

Secondly health service-related factors such as accessibility, medication burden waiting time, patient-provider interaction and patient preference have been shown to determine treatment outcomes (Sahile *et al.*, 2018). Patients take four take 4 tablets daily on average and this, in addition to the unpleasant taste of the drugs, makes medication consumption difficult and can discourage compliance and thereby affect clinical outcomes negatively (Ting *et al.*, 2020). Patients have also additionally reported pain and fatigue as a side effect which limits their ability to perform daily tasks (Angwenyi *et al.*, 2018). In additional, accessibility of the facilities have been shown to affect adherence to clinic appointments, where patients not only travel to seek the services but they also spend resources in the process (Marahatta *et al.*, 2020).

The TB patients further experience the social effects such as stigma and discrimination which is a risk factor for early treatment interruption (Suliman *et al.*, 2022). Some patients have had materials they use separated from other people in addition to letting them live alone in a separate home (Megerso *et al.*, 2020). Some patients have also reported missing out on social activities due to treatment appointments while others have been restricted to travel for work or leisure, because of the need to take medications in addition to being forced to adjust work, study, sleeping patterns and even meal times (Ting *et al.*, 2020). Another social effect is the nutritional impact with the disease mainly being shown to affect the most vulnerable members of society including the street families and drug users, with malnutrition further worsening their susceptibility and treatment outcomes (MOH-NLTP, 2022). Further, mental has also been reported in TB patients who report worry and anxiety, which all increase the likelihood of negative health outcomes by exacerbating poor health seeking behavior and ability to adhere to treatment (Mainga *et al.*, 2022).

Poverty is a risk factor for TB disease, and its treatment has been shown to enhance the already existing financial hardships which then impairs treatment adherence (Aibana et al., 2020). This disease causes economic burdens from the onset of symptoms through to the post-treatment period, usually due to (Furin et al., 2020) direct costs include among others costs of traveling to the facility, costs for additional tests and ancillary medicines which may be commonly prescribed to mitigate the toxic effects of TB drugs, while the indirect cost includes the amount of time taken off to go to the hospital which translates to lost income (Ting et al., 2020).

2.3 Self-efficacy of TB Patients

The theory of self-efficacy (SE) was derived from the social cognitive theory of Bandura in 1977 and is defined as self-confidence or a judgment about one's capacity for self-organization and the ability to perform a particular activity (Chuang et al., 2021). To achieve better treatment outcomes, patients with chronic illnesses need to be willing to enter and stay in treatment (Danielson et al., 2019) as well as be responsible for their disease and health, perform daily disease management tasks like taking medicine, quitting smoking and alcohol, leaving unhealthy psychological conditions, and seeking social support (Cao et al. 2019). According to Belil et al (2018), self-efficient patients can accept their illnesses, are open to behavior change, and show adaptive behaviors such as adherence to treatments (Belil et al., 2018) and in TB management, studies show that it greatly improves compliance and further plays an important role in adapting to challenging situations and improving resilience when setbacks arise (Choliq et al., 2020; Nott et al., 2021; Volz et al., 2019). And therefore, to improve the self-care skills of patients, you need to strengthen their SE (Chuang et al. 2021).

As a chronic disease, TB has a long treatment period and several side effects which may impede better treatment outcomes (Li et al. 2021) in addition to causing several challenges to the patients such as different psychosocial problems, changing their roles and lifestyles, and making them unable to fulfill their daily needs (Belil et al. 2018). This may reduce their SE (Sukartini et al., 2019) which then places them at risk of transmitting pulmonary TB up to five times compared to patients with high SE (Herdianti et al., 2020).

Previous studies indicate that treatment success or failure of TB patients depends on their level of SE (Setiyowati et al., 2021). A systematic review by Choliq et al showed that patients with high SE are known to have the confidence to complete different tasks and difficulties during treatment

(Choliq et al., 2020). These patients have stronger motivation and execution, are more accurate in decision-making, and have better health-promoting behaviors (Chuang et al., 2021). A study in Uganda attributed better treatment outcomes to SE in people living with human immunosuppressive virus (HIV) (Lim et al., 2021). When TB patients have low SE, they may not adhere to treatment protocols and may develop negative health behaviors (Nuwa & Kiik, 2021). Existing studies show that when faced with obstacles, individuals with higher SE sustain self-care longer than those with lower SE and the likelihood of success is reduced if an individual loses confidence in their ability to perform tasks such as taking drugs (Chuang *et al.*, 2021).

One of the ways of increasing SE in TB management is by increasing the knowledge level of patients (Parwati et al., 2021). To achieve better treatment outcomes, patients need to be knowledgeable about TB causes, curability, transmission, and prevention (Sahile *et al.*, 2018). Knowledgeable patients are aware and have positive attitudes about the importance of treatment completion (Choliq et al., 2020) compared to those who are not knowledgeable who tend to have wrong perceptions of the control and prevention thus making it difficult to reduce the burden of TB (Sahile *et al.*, 2018).

Emotions such as fear, anxiety, tension, anger, and depression have been shown to reduce the SE of chronically ill patients (Belil *et al.*, 2018). Patients who are not self-efficient cannot control their disease, its consequences, and complications as well as have the ability to identify factors that may worsen their conditions such as negative emotions, anger, and depression (Belil *et al.* 2018). The patients with high SE, after the acute phase of illnesses, tend to accept their illnesses, can change their behaviors, accept the fact that they are ill, and can tolerate disruptions to cope with their illness as part of achieving faster recovery and continuity of their lives. (Belil *et al.* 2018)

Another aspect of SE is functionality which is the ability of TB patients to plan their life and self-care activities while trusting their abilities which emphasizes the importance of the patients deliberately taking care of themselves and their families to stay healthy, protect their physical and mental health, fulfill their psychosocial needs, and maintain their post-illness health (Belil *et al.* 2018). When patients are self-efficient, they can understand that without thoughtful planning, there may be challenges experienced in life, and therefore they are then able to plan their daily activities including adhering to medication house tasks, daily rest, and avoiding unhealthy foods in addition to performing their family and parental roles (Belil *et al.* 2018)

There is growing recognition that self-efficacy does not only depend on the individual alone but that it requires collective support provided by members of the patient's social network (Ivaylo *et al.*, 2018). Family plays a crucial role in effective patient self-management, and this leads to better health outcomes for chronic illnesses (Li *et al.* 2021). When patients continually interact with their social network, they develop familiarity, a sense of association, and trust (Ivaylo *et al.* 2018). Studies have shown that patients will more easily change their behavior if they feel the availability of social support during the period of and maintenance of behavior change, which then helps improve long-term success (Choliq *et al.*, 2020). This collective support can be expressed in different ways such as food and financial assistance, emotional encouragement and counsel as well as assistance with medication and clinic visits. (Angwenyi *et al.* 2018). Additionally, interacting with healthcare providers is an important resource that helps the patients to understand their condition and perceive medical advice as helpful (Danielson *et al.*, 2019).

It is therefore important to integrate SE into routine TB clinic services for newly diagnosed people together with their social or family support in order to strengthen the patient's self-confidence to be compliant in treatment and for better outcomes (Choliq *et al.*, 2020).

2.4 Quality of Life of TB patients

Quality of life is a multidimensional concept that incorporates physical, social, psychological, economic, spiritual and other domains, and may be described as an individual's perception of their position in life (Mbuti *et al.*, 2019). It is influenced by the duration of TB treatment and the side effects which may be affected throughout the disease duration and even after treatment completion (Datta *et al.*, 2020). Patients suffer not only because of the symptoms of the disease, but also because of the resultant general deterioration in their QoL (Alfian, 2020).

Physically, studies have shown that TB can affect any organ in the body. This infection leaves lesions in the lungs which may lead to physical disability, and opportunistic infections, which all decrease the QoL of patients (Abiz *et al.*, 2020). Physical pain has been shown to prevent patients from performing their desired daily activities which may cause them to feel incompetent and a burden to their families (Araia *et al.*, 2021). Other physical effects include lack of sufficient rest and sleep, lack of enough energy and mobility, and poor capacity for work. In addition, symptoms such as cough and weight loss, are commonly seen in TB patients (Alfian 2020) and paves way

for the emergence of social and family problems (Abiz *et al.*, 2020). As for the TB patients with comorbidities, they experience more symptoms and pain, which affects their QoL (Alfian 2020).

Socially, studies have shown that up to 36% of these patients remain socially secluded (MOH-NTLP, 2022) with patients facing isolation from members of the community (Sartika *et al.*, 2019) in addition to losing support networks as a result of hospitalization, stigma, and difficulties in maintaining family life (Araia *et al.*, 2021). Stigma has been specifically reported, with the disease being associated with HIV infection or low socio-economic status, and traditional myths (Aggarwal, 2019)

Upon diagnosis, a number of psychological reactions can be seen (Aggarwal, 2019) with some patients showing reduced self-esteem, depression, anxiety, disappointment, and refusal to accept the diagnosis (Alfian 2020). These psychosocial burden, as suggested by some evidence, may have a greater impact than clinical symptoms in TB patients (Álvarez-López *et al.*, 2020) and this can affect treatment adherence (Alfian 2020). Studies have shown that patients with depression or anxiety have lower overall QoL scores as compared to patients without. (Aggarwal 2019)

Spirituality has been reported as a coping mechanism for these patients with chronic illnesses. This includes the belief in the existence and power of God in healing diseases (Gyimah & Dako-gyeke, 2019). Studies have associated spirituality with improved self-esteem, the generation of positive emotions, and the promotion of positive self-care practices by encouraging individuals to refrain from unhealthy lifestyle practices, which then fosters well-being (Abu *et al.* 2018). Spirituality has further been shown to have a favorable influence on an individual's QoL by fostering a deeper sense of meaning when faced with life-threatening or chronic debilitating conditions (Abu *et al.* 2018). In addition, intrinsic religiousness, spiritual well-being, and attending to one's spiritual needs have been related to better physical, mental, and emotional functioning while spiritual constraint and lower spiritual well-being were associated with poorer physical and emotional well-being (Abu *et al.* 2018)

Not only are people rendered jobless by TB, but it also cuts down on productivity (Saqib *et al.*, 2018). Economically, TB has been shown to have negative effects with up to 30% of patients experiencing a decline in productivity during the treatment, with the greatest burden in the economically productive age groups (MOH NTLP, 2016). The Kenya national TB program further indicates the catastrophic costs of TB, with over KES 25,000 incurred per household with drug-

sensitive TB patients and a further 62.5% of people losing their jobs, in addition to 9.3% of children in the TB households being disrupted from school(MOH-NTLP, 2022). All these factors lead these patients to employ different coping strategies with 27.8% employing strategies such as loans, selling assets, and using savings or even taking their children out of school(Murphy *et al.*, 2019).

The assessment of QoL using patient-reported outcomes allows for a comprehensive understanding of how health, disease evaluation, and treatment impact individuals' overall health condition, patient care, and daily life (Datta *et al.*, 2020) in addition to providing distinctive evidence and experience on different aspects of living with the disease and their importance and values to the patients (Araia *et al.* 2021). Figure 2.1 shows the conceptual framework, explained in the theoretical framework above.

2.5 Conceptual Framework

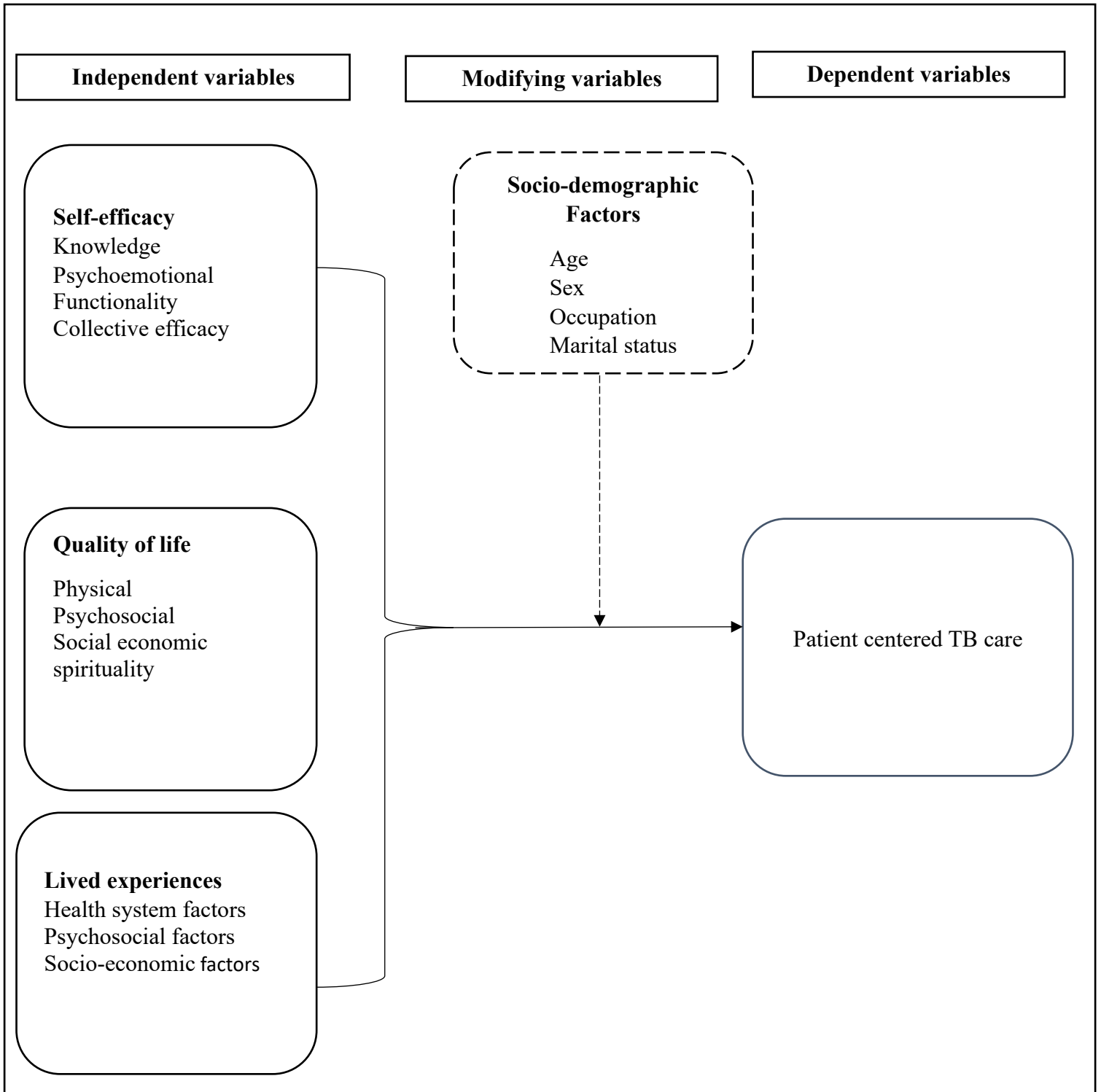


Figure 2.1: Conceptual framework

3.0 CHAPTER THREE: RESEARCH METHODOLOGY

3.1 Research Design

The study employed cross-sectional, mixed-method research (MMR) using the triangulation design, and convergence model (Creswell 2006). A partially mixed, concurrent, dominant design (Leech & Onwuegbuzie, 2009) of the MMR was used. The quantitative aspect of the study was accomplished by the use of a semi-structured questionnaire with a Likert scale to assess the experiences, level of SE and QoL. The qualitative data collection, used the phenomenological study approach based on the inductive approach (Moser & Korstjens, 2018). Semi structured questionnaires were used to collect quantitative data that included lived experiences, SE and QoL of the TB patients in Nairobi County during the course of treatment. For the KII and FGD, semi structured guides were used. Figure 3.1 shows the convergence model of the triangulation design used to explain the mixed method design graphically (Creswell 2006).

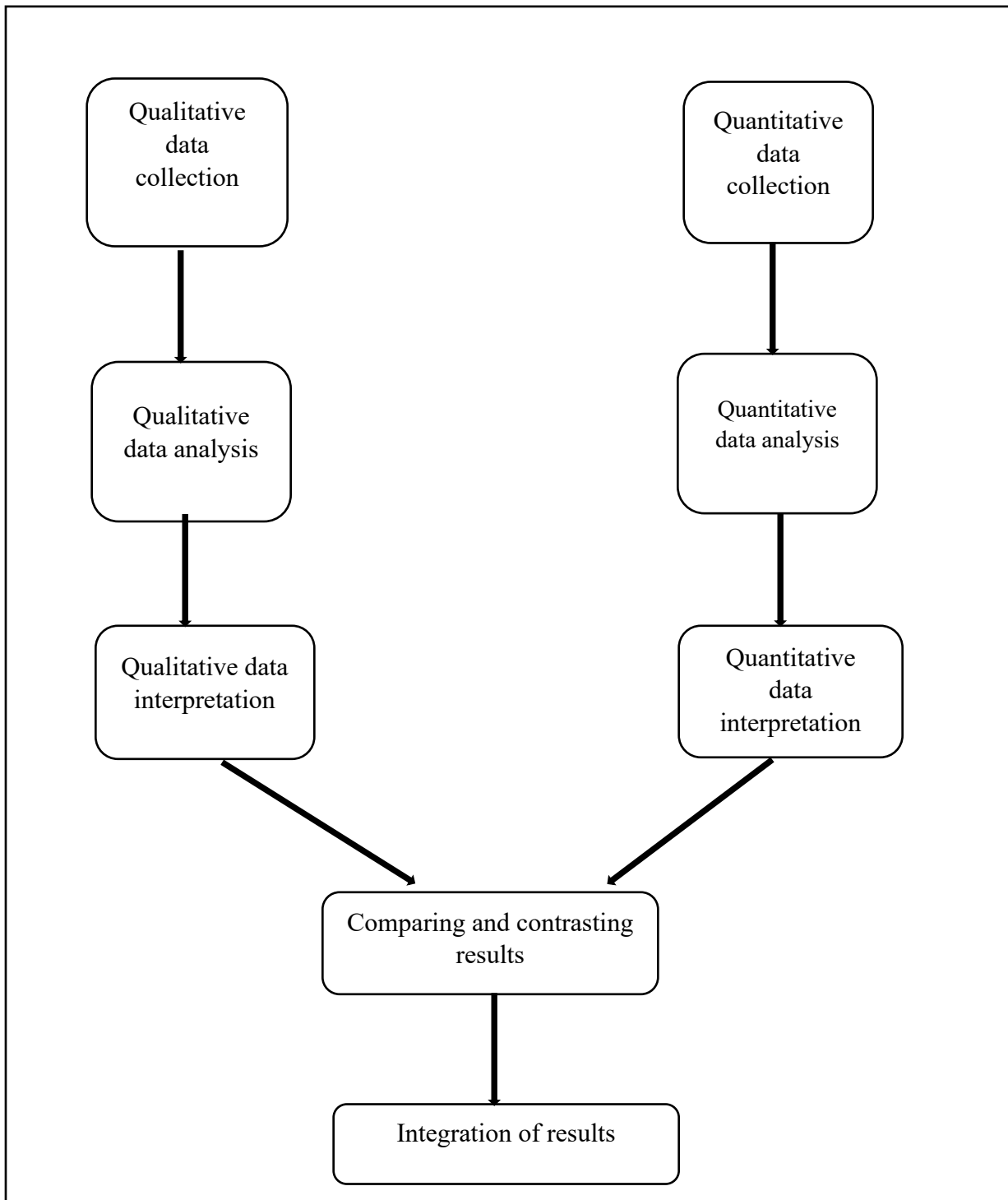


Figure 3.1: Convergence model of the triangulation design.

Source: (Creswell, 2006)

Figure legend: a drawing of the mixed methods design, showing how data was collected and findings triangulated were triangulated

Study Population

The study population which totaled to 11485 according to the TB report 2021, included drug sensitive pulmonary TB patients in the continuation phase of treatment in public health facilities within Nairobi County. The target population was 77,854, who were all the TB patients in Nairobi County based on the TB report 2021(MOH-NTLP, 2022).

Study Setting

This study was conducted in Nairobi County which is one of the 47 counties of Kenya as well as the capital city of Kenya. It's located at 1°17' South ,36°49' East in South-Central Kenya and 140 Kilometers south of the Equator It is the most populous of all the counties with a total population of 4,397,073 (NCCG health report, 2023). Nairobi County bears the greatest burden in all reported TB cases at 11,485 in 2021(Nairobi county TB report, 2022).

3.2 Sampling

3.2.1 Sample Size Calculation

The desired sample size was determined using the Raosoft online sample size calculator (Sample Size Calculator by Raosoft, Inc., n.d.) with a 5% margin of error and a 95% confidence interval giving a sample size of 341. The sample size for each health facility was made proportionate to the entire sample size and sex of the respondents. Further, a 10% adjustment was made to this sample size to cater for incomplete responses and any other survey that cannot be analyzed, which provided a final sample size of 375 respondents. A simple random sampling procedure was then used to select study participants from the TB patients. The study realized a sample size of 392 respondents. Table 1 below shows a summary of the study sample size where “N” is the study population, and “n” is the calculated sample size. For qualitative data, FGD (n=4) was conducted, each with six participants as well as KII (n=4) (Moser & Korstjens, 2018). Participants who already participated in the quantitative survey were not included in the qualitative survey.

3.2.2 Sampling Procedure

Out of the 119 operational public health facilities, those with a TB clinic in Nairobi County were selected. A two-stage cluster sampling procedure was adopted to cluster health units using the county TB caseload data for January 2021 to December 2021. In the first stage, five sub-counties (out of 10 health administrative sub counties), with the highest TB cases were purposively selected.

These are; Embakasi, Langata, Ruaraka, Starehe and Dagoretti. They represent 74% of all TB cases recorded in public health facilities within Nairobi County in the year 2021(NLTP – National Leprosy, Tuberculosis & Lung Disease Program n.d.) with 65% of the cases being men. The second stage again involved the purposive selection of facilities with the highest TB cases within the selected sub-counties, giving a sample frame of 2961. Participants were then selected using the simple random sampling criteria where from the TB clinic, patients who had come for their clinic appointments were randomly selected and requested to take part in the survey. Private facilities with high patient volumes were excluded from the study because most of them are not located in the informal settlements where the TB burden is high, and secondly, they offer treatment at a cost, therefore locking out some patients.

Table 3.1: Sample size distribution in Nairobi County facilities

Sub-county	Health Facility	N	n	Adjusted n	Male sampled	Female sampled	Total
Embakasi East	Mama Lucy Kibaki Hospital	1,477	170	187	123	75	198
Langata	Mbagathi District Hospital	627	72	79	52	33	85
Ruaraka	Mathare North Health Centre	118	14	15	10	5	15
Starehe	Rhodes Chest Clinic	470	54	60	38	22	60
Dagoretti	Riruta Health Centre	269	31	34	22	12	34
Total		2,961	341	375	245	147	392

Table legend: Table showing the sample size distribution in 5 selected sub counties with the highest Tb burden in Nairobi County

3.2.3 Inclusion and Exclusion Criteria

Inclusion criteria

1. All pulmonary TB patients including children within the respective selected facilities who were in the continuation phase of treatment were included in the study. The parents/guardians of the children consented and responded on their behalf. No child was interviewed directly.

Exclusion criteria

Patients who did not give consent, as well as those who were too weak to answer questions were excluded from the study.

3.3 Data Collection Methods and Instruments

An array of tools was used to collect data that meet objectives of this study. These included;

Questionnaires (in English and Kiswahili except the KIIG which was administered in English since the respondents mainly use English) were administered to the patients and were mainly used for collecting data at individual level from the study respondents. The questionnaire captured patients' experiences, SE level and QoL level. Prior to its administration, the questionnaire was pretested at Chandaria health center, a facility which was not part of the sampling frame, to avoid contamination of results by respondents who may have had prior contact with the tool during the pre-test phase. The study engaged 12 research assistants who were trained for one day before being sent to the field for the study.

The Hospital Consumer Assessment of Healthcare Providers and Systems CAHPS 2022 survey tool: (Lavela & Gallan, 2014). This tool has 29 items with questions focusing on the personal views regarding healthcare, experience with HCW, hospital environment and hospital experience and has demonstrated excellent hospital-level reliability of the single-item measures of 0.716 to 0.994 in a Chinese study (Hu et al., 2021). The tool was adopted and modified to fit the assessment of patient experience.

The Individualized Care Scale (ICS) (Suhonen et al., 2007) that assesses the patients' views on the level of individual support received from HCW through specific interventions (Suhonen et al., 2007) was also adopted and modified to form the final tool. The tool has previously demonstrated good properties of homogeneity and construct validity for its use in practice and research in health care systems (Rodríguez-Martín et al., 2022). The tool was used to collect demographic data such as age, sex, occupation, education level and income. It also measured patient experiences classified into healthcare system factors (treatment duration, missed appointment, interaction with HCW, pill

burden, facility preference and facility turnaround time) and social life experiences (limited interaction, effects on spousal relationships, stigma), all totaling to 22 questions.

The TB self-efficacy scale (TBSES) (Cao et al., 2019): a tool that is validated for assessing the level of SE in TB patients containing 21 items was adapted and modified (two questions were dropped) to collect data on SE. Studies have shown that the tool has a good construct validity with both exploratory and confirmatory factor analysis proving that scale has a good construct validity (Cao et al., 2019). The modified tool contains 19 items that represent four domains namely; knowledge, collective efficacy, psycho-emotional and functionality. All the questions were positively framed with the answers in a Likert scale ranging from strongly agree, agree, neutral, disagree and strongly disagree with five representing strongly agree and one strongly disagree.

The knowledge domain assessed the level of understanding in prevention and control strategies using six questions including masking, ventilation, curability and early treatment. The collective efficacy domain involved five questions that measured the level of support from the social networks of the patients (family and friends) such as help with clinic appointments, food support, hope and encouragement as well as financial support. The psycho-emotional efficacy was assessed through five questions that looked at the patient's ability to manage stressful situations, taking responsibility for personal to avoid infecting others, having a positive mindset towards curability, taking responsibility for medication adherence. Functional efficacy was measured through three questions that assessed the effect of TB on the daily economic activities, social activities and personal care activities. The total score was calculated by averaging all the responses.

The WHO QOL BREF questionnaire: which captures broader domains, including physical capacity, psychological, social relationship, and environment (Sartika et al., 2019) was adapted and modified (by removing equations for computing domain scores) for data collection on QoL. The tool in previous studies gave a Cronbach's alpha coefficient of 0.896 with internal reliability for all domains above 0.70 (Ilić et al., 2019). The new tool had 14 items and four domains namely: physical, socio-economic, psychosocial, and spiritual.

All the questions were positively framed with the answers in a Likert scale ranging from strongly agree, agree, neutral, disagree and strongly disagree with five representing strongly agree and one strongly disagree. This scale indicated the level of confidence in the different thematic areas which were captured as strongly disagree, disagree, neutral disagree strongly disagree. The physical

domain assessed was measured through six questions that assessed the effects of the disease such as pain and fatigue, reduced mobility, time spent on daily chores, time spent on economic activities and change in body appearance. The socio-economic domain aimed to bring out the effects of the disease on the socio-economic aspects of the patients. It was assessed by four questions including effect of the disease on the social network, income, participation in social networks and productivity.

The psycho-social domain focused on the effects of the disease on the mental health of the patients and was assessed using four questions that assessed level of worry on missing daily economic activities, stigma, losing social network and being a burden to the family as a result of the disease. Additionally, the spiritual domain assessed how the religious/spiritual beliefs and practices influence coping strategies during the period of chronic illness (Abu et al., 2018). This was measured through seven questions including membership to a religious group, help received from the group, how much sense of belonging the patients feels in the group, effects of the teachings on the patient, effects of spiritual counselling and the availability of the spiritual group when needed for any support.

Focus group discussion (FGD) guide was a semi structured tool, with open ended questions and was available in both English and Kiswahili and was used to gain an in-depth understanding of the other aspects of the study which the quantitative data could not comprehensively explain (Moser & Korstjens, 2018). Where early themes developed, they were used as guides for subsequent sessions. Audio recorders were used during the interview with the consent of the respondents. The participants included parents, patients with comorbidity (with HIV, hypertension and diabetes), youth and return to follow-up.

Key informant interview (KII) guide was employed to collect data from individuals who have specific information relevant to the study. The tool was semi structured with open ended questions. The KIIs targeted; the County TB coordinator, TB clinic staff and Community Health Assistant. Audio recorders were used during KIIs and FGDs. Audio recorders were used during the interview with the consent of the respondents

3.4 Instruments Validity and Reliability

Cronbach's alpha was used to determine the internal consistency of items in the questionnaire, yielding an excellent score of 0.92 for SE and 0.93 for QoL (Gliem & Gliem, 2003). According to

Cronbach (1957) a coefficient of between $0.7 \leq \alpha < 0.9$ is considered to be good while that of $\alpha \geq 0.9$ is taken to be excellent (Gliem & Gliem, 2003). The questionnaire was pretested using 10% of the total sample size from Chandaria health center that was not part of the study. This was ensured by going through the questionnaire with the respondents to ascertain that each of the items was framed in the least ambiguous way. This study also assisted in identifying the problems that the respondents may have encountered in the process of answering the questions put across to them. Through the help of supervisors, the questionnaire was revised and ambiguous items either dropped or modified. Reliability was tested using Cronbach alpha, yielding an excellent score of 0.92 for SE and 0.93 for QoL.

3.5 Data Collection Procedure

The researcher/research assistant sought an appointment with respondents prior to administering the instruments. The questionnaire was administered by the researcher and the trained research assistants through an interview session following the inductive approach. The hard copy questionnaire was transcribed into an open data kit (ODK) from where the research assistants administered it using android devices. The procedure for data collection from respondents at the facility was as follows: the data collectors introduced themselves and provided detailed explanations why the study was being carried out. They then sought the consent of the respondents. The interview commenced ONLY when consent was provided. The assistants then went ahead to ask questions. The interviews lasted between 30 to 45 minutes. The data was then submitted to the kobo collect application where it was stored in soft copy and downloaded as an excel sheet for analysis. The FGDs were carried out in secluded places within the facility and were audio recorded on the interviewer's android device recorder, which is password protected. Each group consisted only of one gender, to take care of the cultural diversity. The FGDs took between 1 hour 30 minutes to 2 hours. The KIIs, which took between 45 minutes to 1 hour were conducted at the TB clinics except for the county TB representative which was conducted online.

3.6 Data Analysis and Reporting

Data analysis was carried out using computer assisted *R* software version 4.3.2 and Ms excel 2016. For objective one, descriptive statistics including measures of central tendency (frequency, percentages, means) and measures of dispersion (standard deviation) were used to describe sample statistics such as age, gender, level of education and marital status, occupation and income. For

quantitative analysis, data was first cleaned before any manipulation and exploration. Analysis included reasons for; missing appointments, facility preference and visiting different facilities as well as the pill burden such as the taste, size and side effects, experience with the HCW and the socio-economic effects of the disease. Qualitative data was manually analyzed using data from the FGD and the KII.

For objective two, analysis of SE was conducted quantitatively with both descriptive and inferential statistics utilized. For descriptive statistics, measures of central tendency (e.g. frequency, percentages, means of the scores across the domain) and measures of dispersion (e.g. standard deviation) were used. The SE was measured on four sub scales (knowledge, collective efficacy, psycho-emotional, functionality) with each item being measured on a five-point Likert scale ranging from one to five. Domain scores was calculated as mean by summing the scores for each observation and dividing by the number of variables per domain. The overall SE level was calculated by adding the mean scores for each SE domain (Bravo et al., 2020). To categorize SE into three levels of “high”, “medium” and “low”, the “neural” score represented by three in the Likert scale was taken as the mean (Bravo et al., 2020). All patients who scored less than three (1& 2) in all the response categories were grouped as “low”, those who scored three (3) categorized as medium while the patients with scores greater than three (4&5) were categorized as high.

Spearman’s correlation was used to examine the relationship between each SE domain and the overall SE level (Bravo et al., 2020). The scores were categorized as strong (1 to 0.7/-1 to -0.7), moderate (0.6 to 0.4/-0.6 to -0.4), weak (0.3 to 0.1/-0.3 to -0.1) and no correlations (zero) (Akoglu, 2018). A one-way Analysis of Variance (ANOVA) with Fishers’ test (Henson, 2015) was used to measure the mean difference between the domains with the overall SE level being the dependable variable measured on a continuous scale while the domains (knowledge, collective efficacy, psycho-emotional and functional) being the categorical independent variable with three levels (low, medium and high). All patients who scored less than three (1&2) in each domain were grouped as “low”, those who scored three (3) were categorized as medium while patients with scores greater than three (4&5) were categorized as high. The post hoc test, Tukey method was further performed to identify magnitude of group means differences and their significance at 5%.

And for objective three: analysis of QoL involved both descriptive and inferential statistics. For descriptive statistics, measures of central tendency (e.g., frequency, percentages, means of the

scores across the domain) and measures of dispersion (e.g. standard deviation) were used. The QoL was measured on four sub scales (physical, socioeconomic, psycho-social, spiritual) with each item being measured on a five-point Likert scale ranging from one to five. Domain scores was calculated as mean by summing the scores for each observation and dividing by the number of variables per domain. The overall QoL level was calculated by adding the mean scores for each QoL domain. To categorize QoL into three levels of “high”, “medium” and “low”, the “neutral” score represented by three in the Likert scale was taken as the mean (Bravo et al., 2020). All patients who scored less than three (1& 2) in all the response categories were grouped as “low”, those who scored three (3) categorized as medium while the patients with scores greater than three (4&5) were categorized as high.

Spearman’s correlation was used to examine the relationship between each QoL domain and the overall QoL level (Bravo et al., 2020). The scores were categorized as strong(1 to 0.7/-1 to -0.7),moderate (0.6 to 0.4/-0.6 to -0.4,weak(0.3 to 0.1/-0.3 to -0.1) and no correlations(zero) (Akoglu, 2018). A one-way ANOVA with Fishers’ test (Henson, 2015) was used to measure the mean difference between the domains, with the overall QoL level being the dependable variable measured on a continuous scale while the domains (physical, socioeconomic, psycho-social, spiritual) being the categorical independent variable with three levels (low, medium and high). The post hoc test, Tukey method was further performed to identify magnitude of group means differences and their significance at 5%. Appendix one shows the definition of variables.

3.7 Ethical Requirements

Ethical approval was obtained from the board of post graduate studies and the ethical review committee of Jaramogi Oginga Odinga University of Science and Technology (ERC 35/12/23-15/06). Additional approval was received from the National Commission for Science Technology and Innovation (License No: NACOSTI/P/23/23921). Permission to conduct the study was received from the health directorate of Nairobi City County (NCCG/HWN/REC/344).The purpose and importance of the study was explained to each study participant. The confidentiality and privacy of participants was secured by omitting any personal identifiers and by conducting the interviews in a secluded area within the facilities. Data was securely stored in the kobo collect application with only the principal investigator having access through passwords. A written consent was obtained from each participant. Participants were informed of their full rights to

withdraw from the study at any time they wished. Parents or guardians consented and answered on behalf of the children who were interviewed. This study categorized children as persons below 18 years of age. To minimize interviewer bias, all the research assistants were trained and asked to strictly ask the questions as they were in the questionnaire.

This information was disseminated at the African Medical Research Foundation (AMREF) primary health care conference in November 2023, a thesis report, a manuscript is currently under peer review at Biomed central public health journal and a copy of the final work will be delivered to the research department of Nairobi County.

4.0 CHAPTER FOUR: RESULTS

4.1 Respondents' characteristics

The sample consisted of 392 patients where 245 (62%) were male while the rest 147(38%) were female. The mean age was 35 years with a range of 3 years and 74 years. In terms of education, 152(39%) patients had secondary level while 115 (29%) were casual laborers. Business people were 109 (28%) while half of the respondents 195 (50%) were married. Given age is equal or greater than 18 years, the respondents median income was Ksh 9000.00. In addition, the mean treatment period of the patients interviewed was 4 months (mean=4). Marital status, occupation and income were statistically significant while age and education were not statistically significant. The patients' demographics are summarized in table 4.1 as shown below.

Table 4.1: Patients demographic characteristics

Characteristic	Overall, N = 392	Female, N = 147	Male, N = 245	p-value
Age				0.2
<i>Mean (SD)</i>	35(14)	34(15)	35(13)	
<i>Median (IQR)</i>	35(17)	32(17)	36(16)	
Education Level				0.8
<i>Secondary Level</i>	152 (39%)	60 (41%)	92 (38%)	
<i>Tertiary Level</i>	96 (24%)	33 (22%)	63 (26%)	
<i>Primary Level</i>	79 (20%)	32 (22%)	47 (19%)	
<i>University</i>	46 (12%)	15 (10%)	31 (13%)	
<i>No formal education</i>	19 (4.8%)	7 (4.8%)	12 (4.9%)	
Marital Status				0.021***
<i>Married</i>	195 (50%)	69 (47%)	126 (51%)	
<i>Single</i>	137 (35%)	46 (31%)	91 (37%)	
<i>Children</i>	23 (5.9%)	15 (10%)	8 (3.3%)	
<i>Divorced</i>	18 (4.6%)	7 (4.8%)	11 (4.5%)	
<i>Widowed</i>	12 (3.1%)	8 (5.4%)	4 (1.6%)	
<i>Widowed</i>	7 (1.8%)	2 (1.4%)	5 (2.0%)	
Occupation				0.050***
<i>Casuals</i>	115 (29%)	42 (29%)	73 (30%)	
<i>Businessman/woman</i>	109 (28%)	38 (26%)	71 (29%)	
<i>Not employed</i>	62 (16%)	34 (23%)	28 (11%)	
<i>Formally employed</i>	55 (14%)	16 (11%)	39 (16%)	
<i>Student</i>	49 (13%)	16 (11%)	33 (13%)	
<i>Other</i>	2 (0.5%)	1 (0.7%)	1 (0.4%)	
Income				0.013***
<i>Mean (SD)</i>	12,835(15,003)	10,391(12,933)	14,301(15,965)	
<i>Median</i>	9,000	6,000	10,000	
<i>Significant codes***</i>				

Table legend: table showing the demographic characteristics of the respondents

4.2 Lived experiences of TB patients

The study established themes that made up experiences for TB patients namely, patient related, health system, social and economic factors as shown in table 4.2 below.

Table 4.2: Summary of emerging themes

Key themes	Sub themes	Quotes from patients
Patient related factors	Knowledge on TB	<i>“I wasn’t shocked with the diagnosis because this is a family disease to us. I am the fourth one in the family to get infected”-Male TB patient, 31 years old.</i>
	Perceived wellness	<i>“In the beginning, they will do everything the doctor says. But later on, when they begin feeling well, the appetite improves and the weight is restored, they start missing medication”-Male KII, TB clinic”</i>
	Missed appointment	<i>“The special population, including the street families and the drug users form a big part of the loss to follow up patients. Other than being mobile, most of them do not have mobile phones” -County TB program representative, Nairobi</i>
Health system factors	Courtesy and respect	<i>“They are courteous and respectful. They listen well too. They give all the relevant information about TB, the means of transmission, how to avoid it, like when using public transport, they tell you that you should open the windows. When it comes to taking medicine, they advise you that you should not miss any day because it’s going to cost you much, like starting all over again”-Male TB patient,20 years old.</i>
	Medication burden	<i>“In the first phase, the tablets were big and difficult to swallow. I would vomit whenever I took them. But the ones I am taking in this second phase are good in size”-female TB patient 58 years old”</i>
Social factors	Food insecurity	<i>“When you come for the drugs, they ask you to eat a balanced diet, including fruits, but there are times I</i>

don't get anything to eat at all, because I don't have the money to buy. I have been forced to take drugs on an empty stomach several times"-Female TB patient, 47 years old.

Stigma

"I stayed for three months without going to church because I didn't know what people would say when they saw how I looked because I had lost much weight. I decided to pray in the house until the time when I will feel and look better"-Female TB patient, 27 years old.

Economic factors Effect on income Reduced income, inability to work

Table legend: factors affected treatment outcomes namely patient related, health system, social and economic factors.

4.2.1 Patient related factors

To begin with, these findings show a low level of knowledge on the prevention and control of TB strategies. For all the areas assessed, 274 (70%) strongly disagreed, 98(25%) disagreed that TB is curable, 239(61%) strongly disagreeing, 133(34%) disagreeing that early diagnosis and treatment is a measure of control, 208(53%) strongly disagreeing, 157(40%) disagreeing that spitting in the open among those with TB can enhance spread of TB, 220(56%) strongly disagreeing, 153(39%) disagreeing that covering mouths while coughing can help minimize spread. Half of the patients 196(50%) strongly disagreed, 176(45%) disagreed that proper ventilation houses can help minimize spread of TB. On wearing of mask among those with TB illness as a way of minimizing spread of TB, 212(54%) strongly disagreed while 157(40%) disagreed as shown in figure 4.1 below.

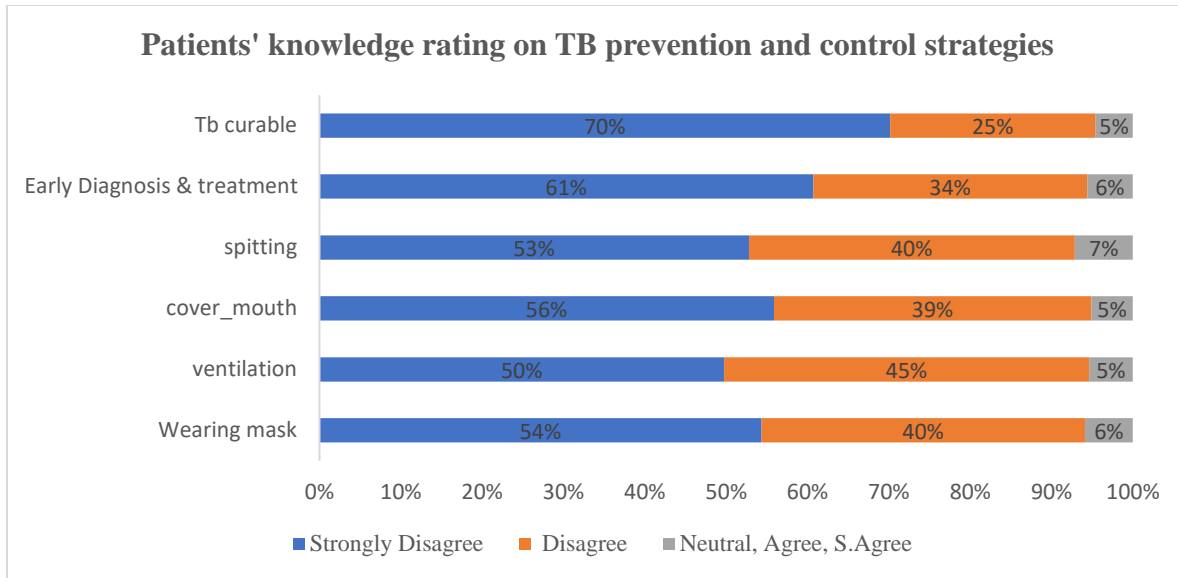


Figure 4.1: Patients' knowledge rating on TB prevention and control.

Table legend: Patients' knowledge level on TB prevention and control strategies including masking, early diagnosis, spitting, ventilation and mouth covering

Some patients had a misconception on the cause and mode of transmission, with some patients still having separate household items from the rest of the family such as utensils, while another patient believed that TB was hereditary as explained by a respondent:

“We don't share cups and plates and bathing basin. I have mine separated and well known by everybody so that we don't mix them up. My food is served in specific utensil. My clothes are also washed separately, and they put a detergent in the water”-male TB patient 47, years old.

Another said:

“I wasn't shocked with the diagnosis because this is a family disease to us. I am the fourth one in the family to get infected”-Male TB patient, 31 years old.

Additionally, perceived wellness was found as a reason for failing on adherence. Patient who felt better were reported to stop adhering to the treatment.

“In the beginning they will do everything the doctor says. But later on, when they begin feeling well, the appetite improves and the weight is restored, they start missing medication”-Male KII, TB clinic”.

Facility preference was also identified as a factor affecting treatment. Patients gave different reasons for choosing facilities such as accessibility 28 (59%), availability of drugs 27(57%), friendly HCW 26 (55%), and availability of equipment in the laboratory and x-ray departments 17(36%) as shown in Figure 4.2 below.

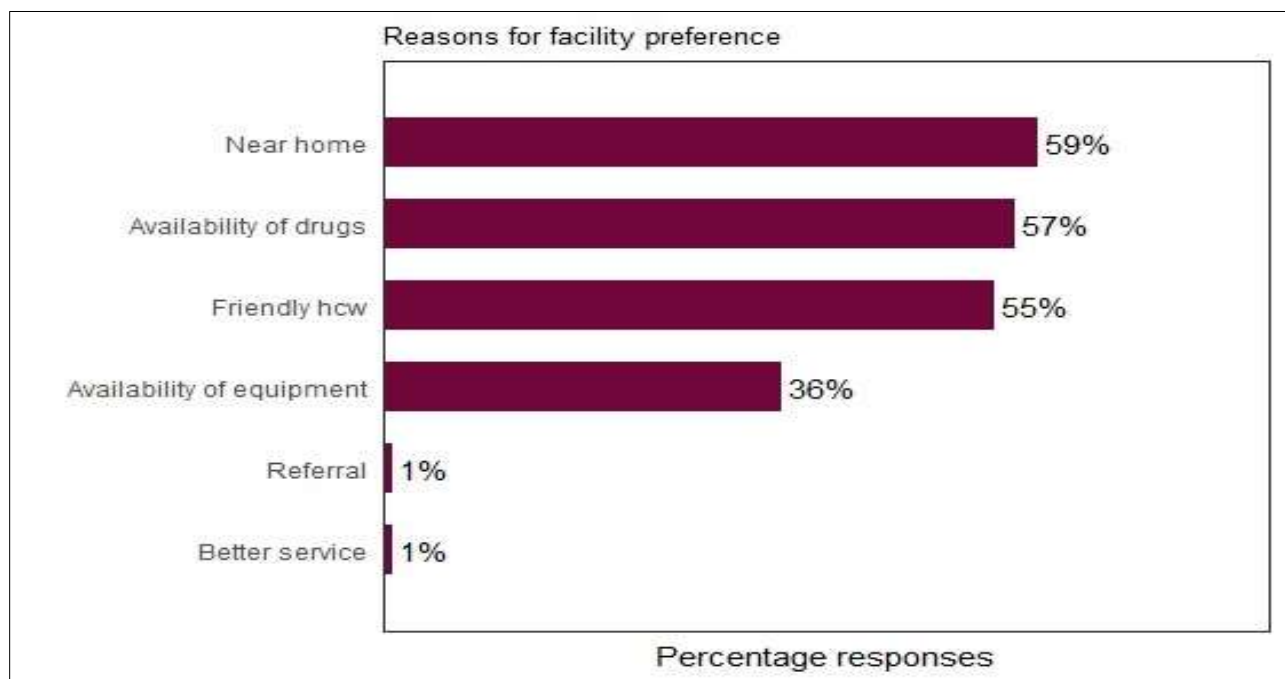


Figure 4.2: Reasons for facility preference

Figure legend: reasons for facility preference including accessibility, availability of drugs and friendly health care workers.

This was further demonstrated by 113 (29%) patients who changed facilities in between treatment (mean=2) with 44 (30%) women visiting more facilities than men, 69 (28%) mainly as a result of relocation 41 (52%), facility accessibility 25 (32%), lack of laboratory services 16 (21%), and poor staff attitude 8 (10%) as shown in figure 4.3 below.

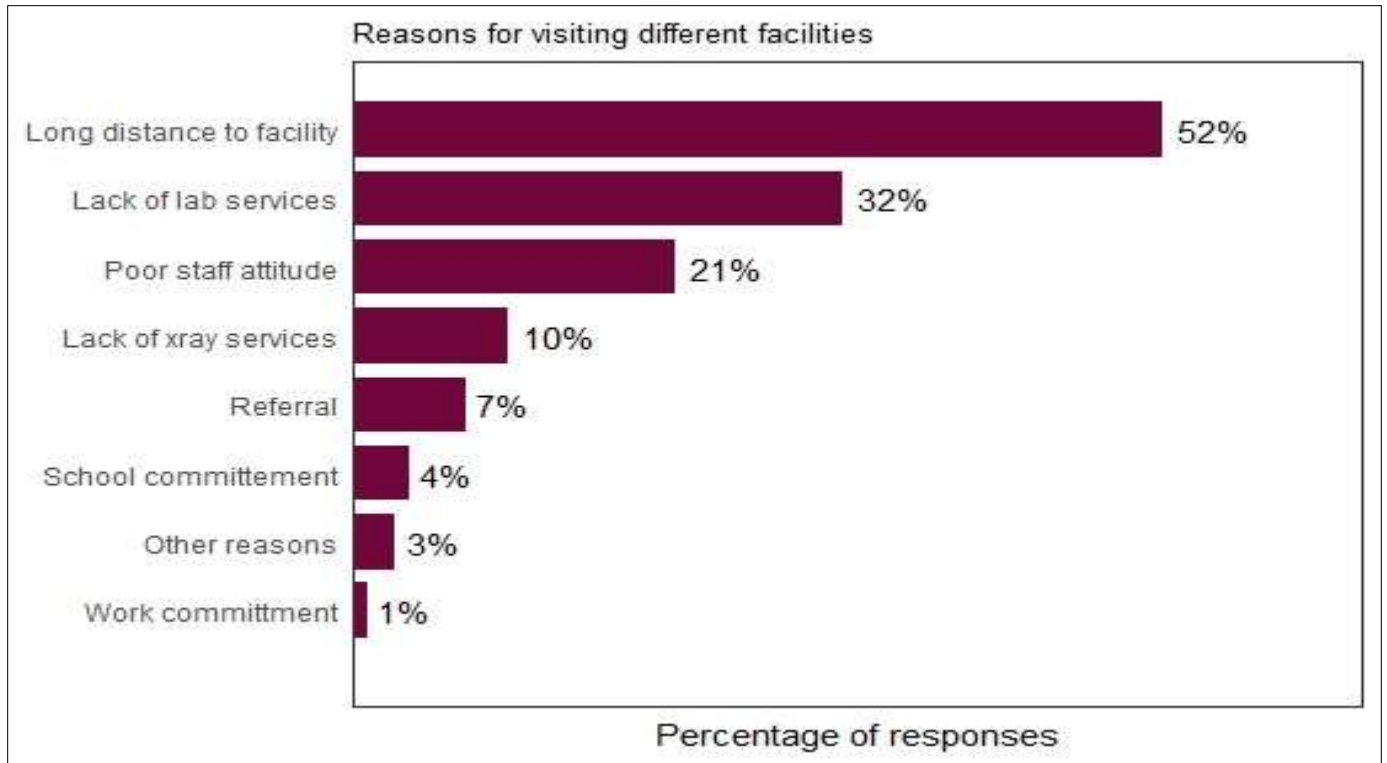


Figure 4.3: Reasons for different many facilities

Figure legend: reasons for visiting different facilities including accessibility, lack of laboratory services, lack of x-ray services, referral and poor staff attitude.

This study established that 55 (14%) patients missed their appointments, with women 23 (16%) missing more than men 32 (13%). Relocation 29 (34%), long distance to facility 28 (32%), patient condition 23 (26%), work commitment 5 (6%), and school commitment 4 (4%) were identified as the main reasons as shown in figure 4.4.

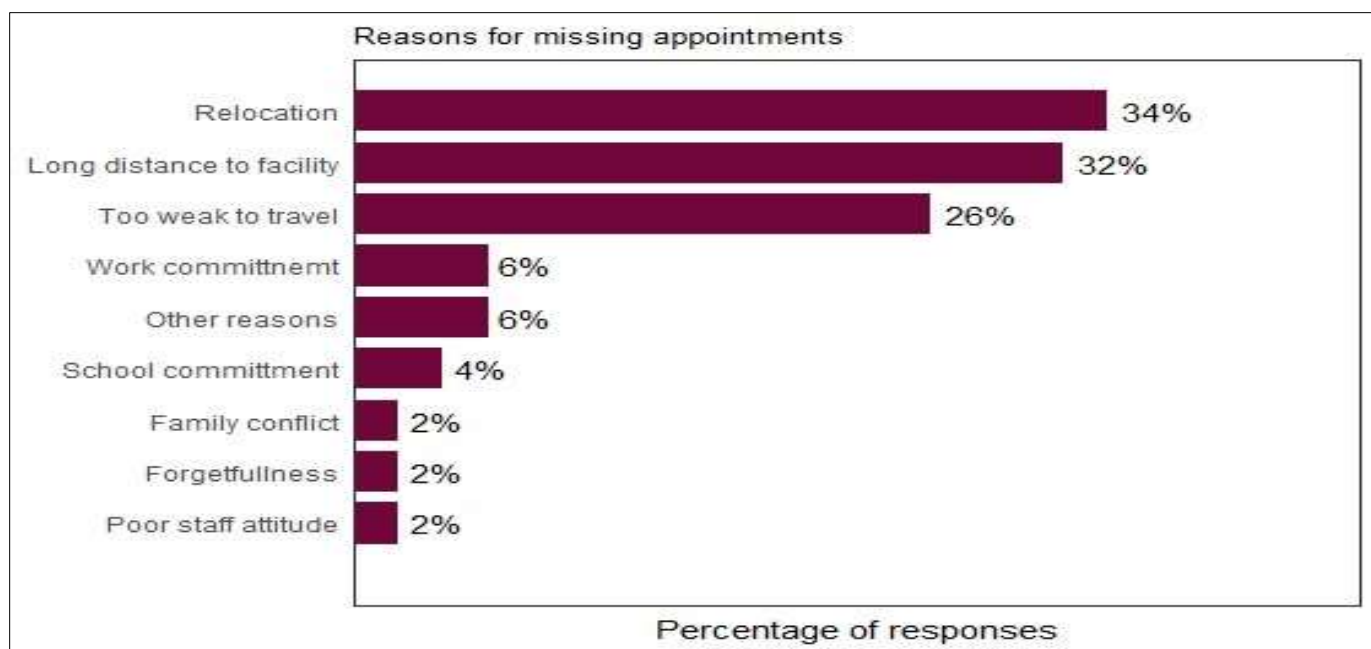


Figure 4.4: Reasons for missed appointments

Figure legend: reasons for missing appointments such as relocation, long distance to the facility, too weak to travel, work and school commitment and forgetfulness

In addition, the findings show that the current loss to follow up rates in Nairobi County is at 6%, higher than the acceptable level of less than 5%, with the special population including the street families and the drug users being the majority. This was attributed to their mobile nature. Following them up was noted as a big challenge, considering that majority of them do not own mobile phones;

“The special population, including the street families and the drug users form a big part of the loss to follow up patients. Other than being mobile, most of them do not have mobile phones” -County TB program representative, Nairobi

The use of drugs such as alcohol was also identified as another reason for missing appointments;

“They start well and do everything you tell them including stopping alcohol, but when they feel better, they forget and go back to drugs. This then makes them to miss their clinic appointments” -KII, Community Health Assistant

4.2.2 Health system factors

An assessment of the attitude of the health workers showed that the patients rated the courtesy of the HCW as follows: 176 (45%) excellent, 82 (21%) very good and only 12 (3%) rated it as bad-worse. Listening was rated as 157 (40%) excellent, 98 (25%) very good and 118 (30%) good while 20 (5%) rated it as bad-worse. As for explanations regarding the disease, the patients rated them at 157 (40%) excellent, 98 (25%) very good, 118 (30%) and 20 (5%) bad-worse. On the knowledge of the HCW when describing medicine usage, dosage, and possible side effects in an understandable manner, they were rated at 167 (42%) excellent, 94 (24%) very good, 118 (30%) good, and only 16 (4%) bad-worse. On the question of the effectiveness of the dialogue session held by the HCW, it was rated at was rated at 153 (39%) excellent, 110 (28%) very good and good while 20 (5%) rated it as bad-worse as shown in figure 4.5 below.

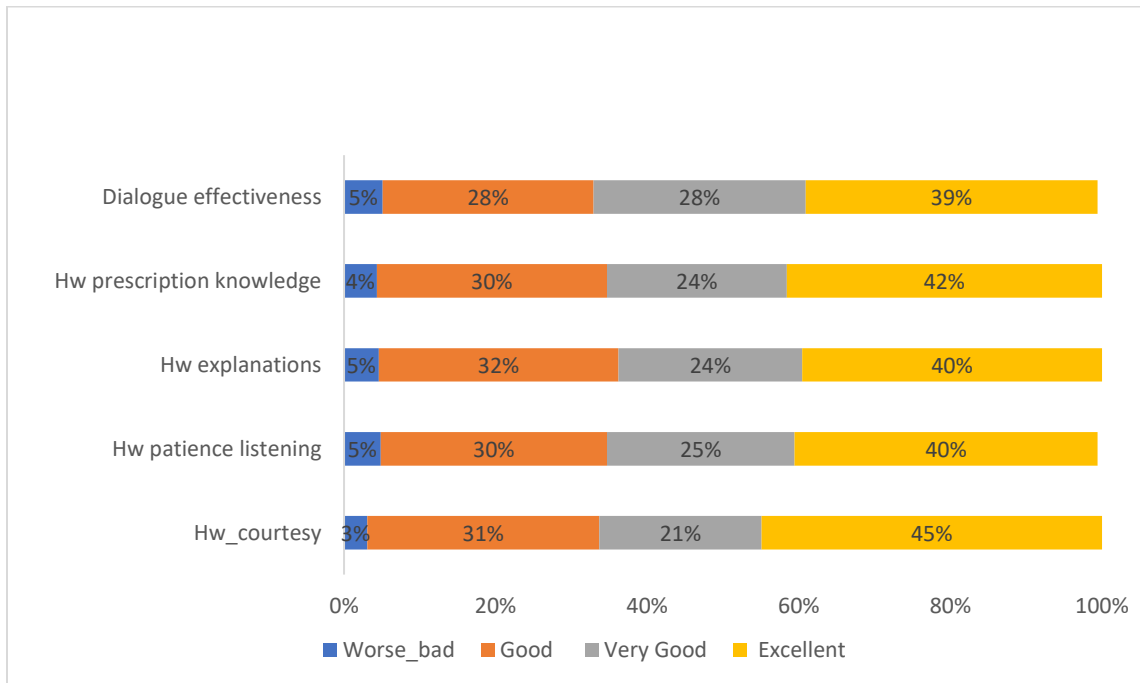


Figure 4.5: Patient experiences with healthcare workers

Figure legend: response distribution on HCW interaction with the patients

A patient explained that:

“They are courteous and respectful. They listen well too. They give all the relevant information about TB, the means of transmission, how to avoid it, like when using public transport, they tell you that you should open the windows. When it comes to taking

medicine, they advise you that you should not miss any day because it's going to cost you much, like starting all over again"-Male TB patient,20 years old.

As for the diagnostic capacity, it was established that the county has 262 public and 803 private facilities offering services with 17 gene xpert machines, out of which 16 are in public facilities. As for the x-ray services, the county has four digital and two card machines.

The medication burden was also identified in this study as a barrier to treatment compliance. The pill burden findings show that more than half of the patients, 198 (51%) reported as big the size of the drugs, where the drugs in the first phase of treatment were deemed to be big in size compared to those in the second phase.

"In the first phase, the tablets were big and difficult to swallow. I would vomit whenever I took them. But the ones I am taking in this second phase are good in size"- female TB patient 58 years old"

The findings are also similar for the taste, where more than half of the patients, 205 (52%) noted that the drug was bitter with only 17 (4%) saying they are sweet. A patient said:

"The white one, the one we take throughout the treatment period is bitter compared to the rest of the drugs, and it leaves a very bad taste in the mouth. You always feel like you need to take something sweet after taking it"-Female TB patient;30 years old"

Another experience with the pill was the number of tablets that the patients were expected to take, which were perceived to be many, especially for patients with other existing conditions. Most TB patients take between four to five tablets. This number increases when the patients have other coexisting conditions;

"I am diabetic and hypertensive. When you add me the TB drugs, I end up taking up to ten tablets at a go. I feel these tablets are too many for me"-Female TB patient,57 years old"

As for the street families, storage of drugs was found to be a challenge during the treatment period. They not only lose the drugs but they also get wet during the rainy season as explained by a KII:

"Storage is the main issue. These persons do not live in a permanent place, not even semi-permanent, they are just in the streets. We usually show them how to pack their drugs well,

but they will still come back to you and tell you that they were rained on and the drugs got wet. Other times, they come back and say the drugs got lost”-Male KII, TB clinic

Further, 166 (42%) of the patients reported having experienced side effects in the first month (mean=1.5) compared to 226 (58%) who hadn't. The most reported side effects were vomiting and nausea. Among them, 25(11%) failed to take drugs due to the side effects. Majority of the patients 192 (85%) reported that they received help from HCW to deal with the side effects.

Additionally, it was the view of the patients that the current treatment duration was long. The preferred duration for 172 (44%) patients was between 1-3 months;

“Six months is not short, it's half of a year. When the duration is long, there are high chances of repeating some mistakes like taking your drugs late. I would suggest the period be shortened.”-Male TB patient,21 years old.

4.2.3 Social factors

Patients reported how the disease impacted on their social lives in different ways including stigma, food insecurity and limited interaction. Some of the TB patients reported stigma both perceived and experienced stigma where 78(20%) reported to have experienced stigma and discrimination always,74(19%) very often,106(27%) often while 71(18%) said they had never experienced it as described in figure 4.6 below.

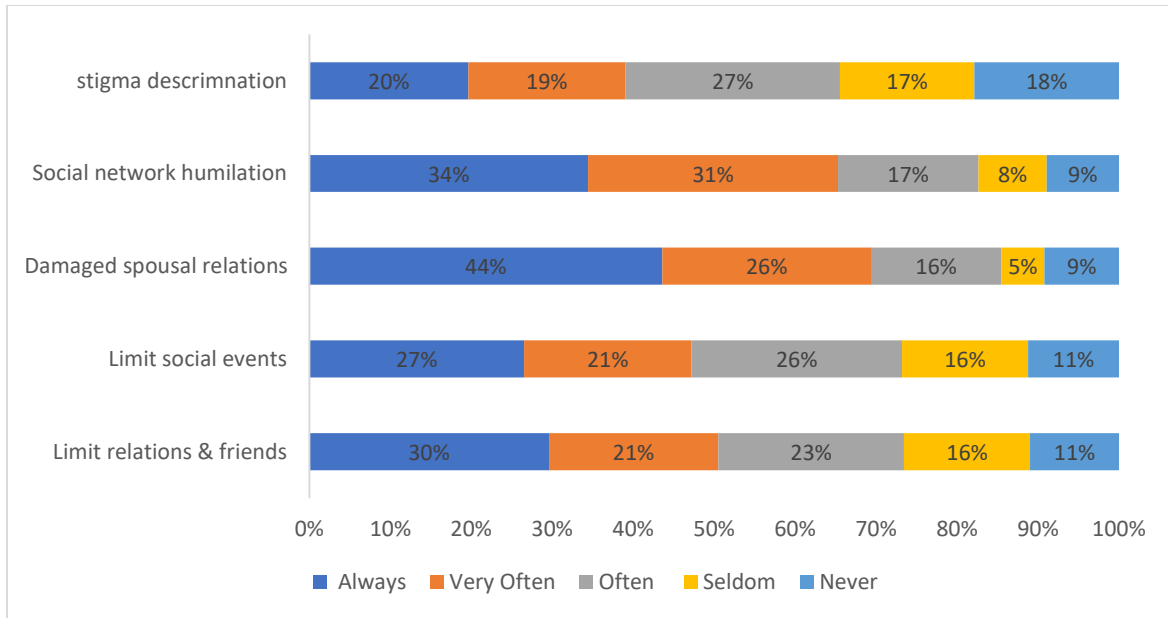


Figure 4.6: Patients Social life experiences with TB

Figure legend: response distribution on the effects of the disease on their social life

In further interviews, a patient said that:

“When I was diagnosed with this disease, my daughter said that they would put aside a cup, and a plate for me. She told me not to get near her. When she gets home, she climbs on her bed with her bread. She says it’s up to the three of us who are on TB drugs to take care of ourselves. When I tell her I am going to the clinic for drugs, she asks when I will be done with the treatment. ”-Female TB patient,45 years old

Another patient said:

“I stayed for three months without going to church because I didn’t know what people would say when they saw how I looked, because I had lost much weight. I decided to pray in the house until the time when I will feel and look better”-Female TB patient,27 years old.

The disease was also shown to limit social interactions with the patient network with 122 (31%) saying it always did and 133 (34%) saying it was very often as shown in figure 9. A patient explained that:

“I can no longer hang out with my friends like we used to do before. I have to first finish my treatment” -male TB patient,48 years old

The study also highlighted the food insecurity experienced by TB patients. The need for a balanced diet came with an extra cost that most respondents could not afford:

“When you come for the drugs, they ask you to eat a balanced diet, including fruits, but there are times I don’t get anything to eat at all, because I don’t have the money to buy. I have been forced to take drugs on an empty stomach several times”-Female TB patient, 47 years old.

Food insecurity was further found to be a driver of non-treatment adherence for street families as explained by a KII;

“If they feel they are not getting food in the area where they live, they are forced to move. When they move, they might disappear even for a month. When they come back, you start from zero”- KII, TB clinic

4.2.4 Economic factors

The findings showed that the disease had no effects on the productivity level of the patients where 78(20%) strongly disagreed, 125(32%) disagreeing with the fact that the disease had an effect, 86(22%) neutral, 57(15%) and 43(11%) agreeing and strongly agreeing respectively. Additionally, 71(18%) respondents strongly disagreed that the disease resulted in reduced income, while 118(30%) disagreed, 82(21%) expressed neutrality, with only 86(22%) agreeing and a mere 39(10%) strongly agreeing as shown in figure 4.7. However, further interviews revealed the impact of the disease such as loss of income, loss of jobs, and reduced productivity. Most of the respondents were casuals who depended on physical strength to work. The patients reported having experienced physical weakness at the beginning of their treatment which incapacitated them from working. This led to the interruption of careers or the source of livelihood for clients.

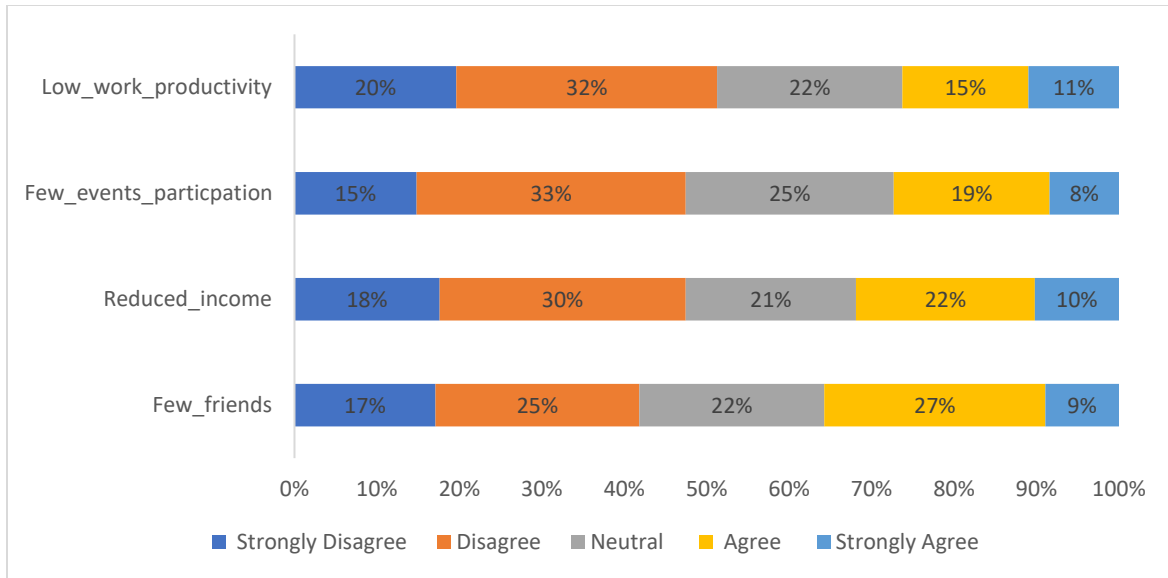


Figure 4.7: Socio economic effects of TB on patients.

Figure legend: response distribution on the economic effects of the disease on the patients.

A patient said:

“My job involves walking. I had to stay away from work. That meant that my source of livelihood is affected” male TB patient,42 years old.

Another one said;

“I am a businesswoman. From the time I was diagnosed with TB, some of the businesses stalled. My body is still weak so I cannot go back to work now”-Female TB patient,57 years old

4.3 LEVEL OF SELF EFFICACY

4.3.1 Descriptive statistics and visualizations for self-efficacy

In terms of total SE, the majority of patients 349 (89.03%) exhibited low level, 38 (9.69%) medium level, while only 5 (1.25%) showed high level. Also, the same trend was observed in the different domains, with 374(95.41%) patients having low levels in knowledge domain,316 (80.61%) collective, 312(79.59%) psycho-emotional and 188(47.96%) functionality domain as shown in table 4.3 below.

Table 4.3: Patients self efficacy scores in different domains

Self-Efficacy Domains Levels	Frequency (%)	Frequency (%)	Frequency (%)
	Low	Medium	High
Overall scores	349(89.03)	38(9.69)	5(1.28)
Knowledge	374(95.41)	12(3.06)	6(1.53)
Collective	316(80.61)	65(16.58)	11(2.81)
Psycho-emotional:	312(79.59)	63 (16.07)	17 (4.34)
Functionality	188(47.96)	117(29.85)	87(22.19)

Table legend: Scores of the self efficacy domains shown in three levels of low, medium and high

Collective efficacy in supporting treatment was further revealed through a patient who said that;

“In the evening after supper, the first thing my children do is to bring me water. If I want to take the drugs with porridge, they make it immediately. If I forget to take my drugs, they wake me up. They ensure I have taken my drugs”-Female TB patient, 62 years old.

Another patient said;

“My sister-in-law has been very supportive with words of encouragement. Every Sunday, she sends my child ksh 50 for yogurt as a motivation for completing treatment”-Mother of a TB patient, 7 years old.

For street families, it was also revealed how important collective efficacy for successful treatment is. Not only do they accompany each other to the clinic, but also the leader is tasked with ensuring treatment adherence for any group member who is on TB treatment:

“The good thing about this group is that they care for each other. When one of them is unwell, they all accompany him/her to the hospital. They always come as a group when it’s a clinic day for one of them”-KII, TB clinic

The role of the CHP in treatment adherence for TB patients especially the street families was also emphasized in this study.

“When we get a TB patient from the streets, we identify their base. We then send a community health promoter to find out the base leader. The base leader is then tasked with ensuring that the patient adheres to appointments”- KII, TB clinic

Another one said;

“We had one male patient;40-year-old from the street. He was not adhering well to treatment. We sent the CHP to trace the family. We found the mother who came and took him home. He is now under her care and continuing with treatment”- KII, TB clinic

The study further revealed the financial struggles of the CHP during the patient follow-up. It was revealed that they at times run out of resources to continue tracking these patients

“We had a client from another county. The CHP followed him for a while but was not able to continue because she run out of transport at some point” KII, community health assistant

Most TB patients in this study had a low psycho- emotional level and this was further expressed in the FGD which indicated the shock and worry by patients at the time of diagnosis;

“When the doctor gave me results, I was so shocked. I felt dizzy and could not think straight. I called my brother who had accompanied me to come and listen to what I was being told. I could not believe that I had been infected with TB”-Male TB patient,35 years old

Another patient said;

“I am a worried man. I had personal plans for the year. Because of this disease, I had to put them on hold because I am not feeling well”-male TB patient,48 years old

Another patient also said that

“I am worried about the outcome. I don’t know what they will say at the end of the treatment period, whether I will be declared healed or that I will have to continue with the treatment”- male TB patient,21 years old

Children were also shown to suffer emotionally

“She keeps asking how long she will be on drugs. When we are out for a birthday party, we have to leave early so that she can take her drugs at 7pm. This makes her very sad”- Mother of 7-year-old TB patients

Figure 4.8 below shows boxplots that visualize the overall distribution of the TB patient’s responses on the different SE domains. On the collective efficacy, most respondents (25th to 75th percentile) rated their satisfaction with the support from family and friends between "strongly

disagree" and "disagree." The median fell closer to "disagree" and had only two respondents with very high satisfaction levels with the support from family and friends.

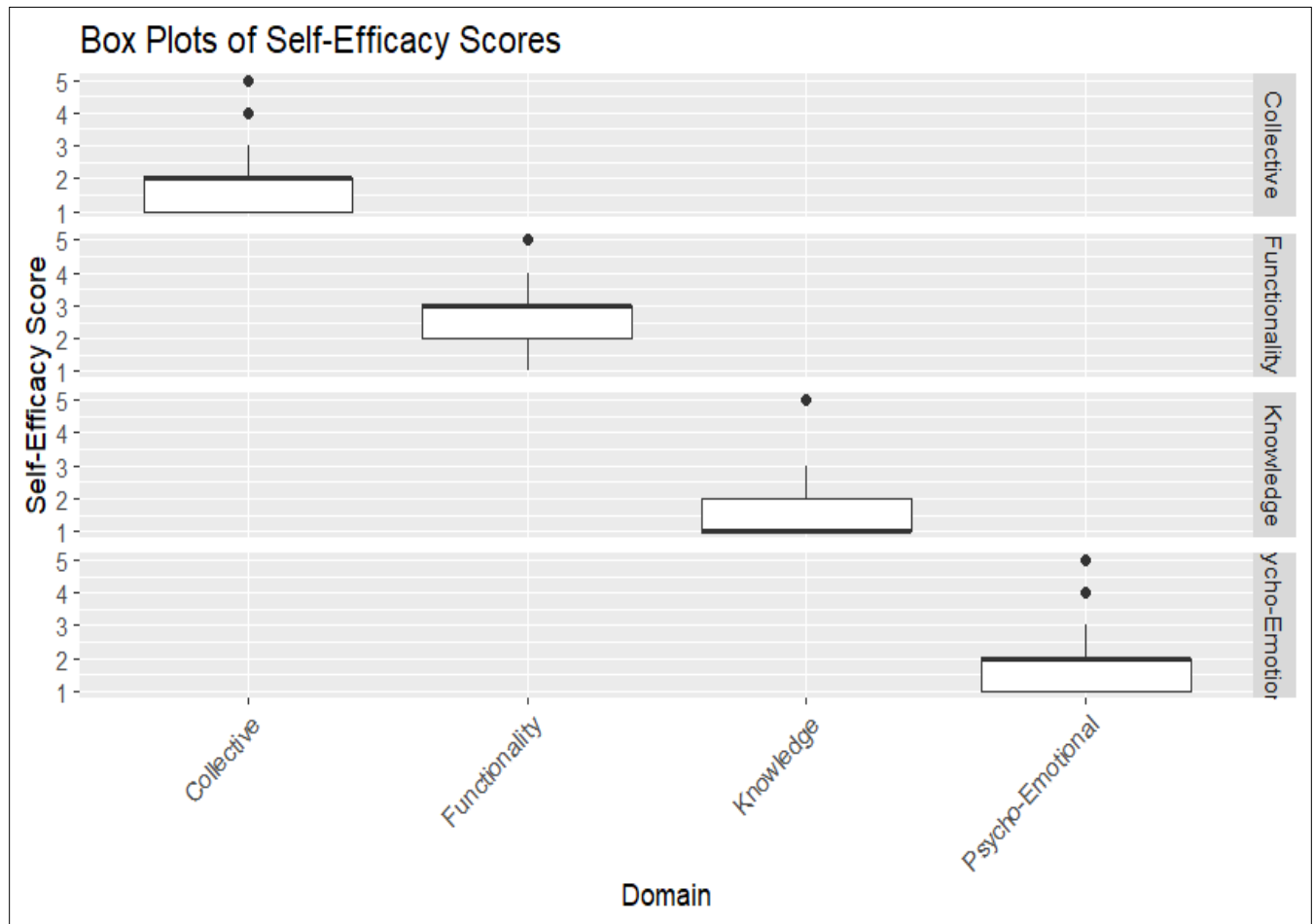


Figure 4.8: Boxplots showing distribution of patients' responses on the different SE domains

Figure legend: distribution of the TB patient's responses on the different SE domains.

Even though most of the respondents scored high in the functionality level, most of the respondents rated it between "disagree" and "neutral" with median falling on "neutral" and only one respondent strongly agree with the statements.

In regard to the knowledge efficacy, median fell on "strongly disagree" and most of the respondents rated it between "strongly disagree" and "disagree." This indicated that most of them were not informed about TB prevention and control strategies. Also, most respondents rated psycho-emotional efficacy between "strongly disagree" and "disagree." The median fell closer on

"disagree" and there only two respondents with very high satisfaction levels with the psycho-emotional efficacy statements.

4.3.2 Correlations within the self-efficacy domains.

To examine the relationship between each SE domain and the overall SE level, a Spearman's correlation, a non-parametric test which is suitable for ordinal, non-normally distributed, or non-linear data was used as visualized in figure 4.10. The SE domains were not strongly correlated with each other though there existed some positive correlation. However, it was noted that there was a moderate positive correlation between the SE domains and the overall SE levels.

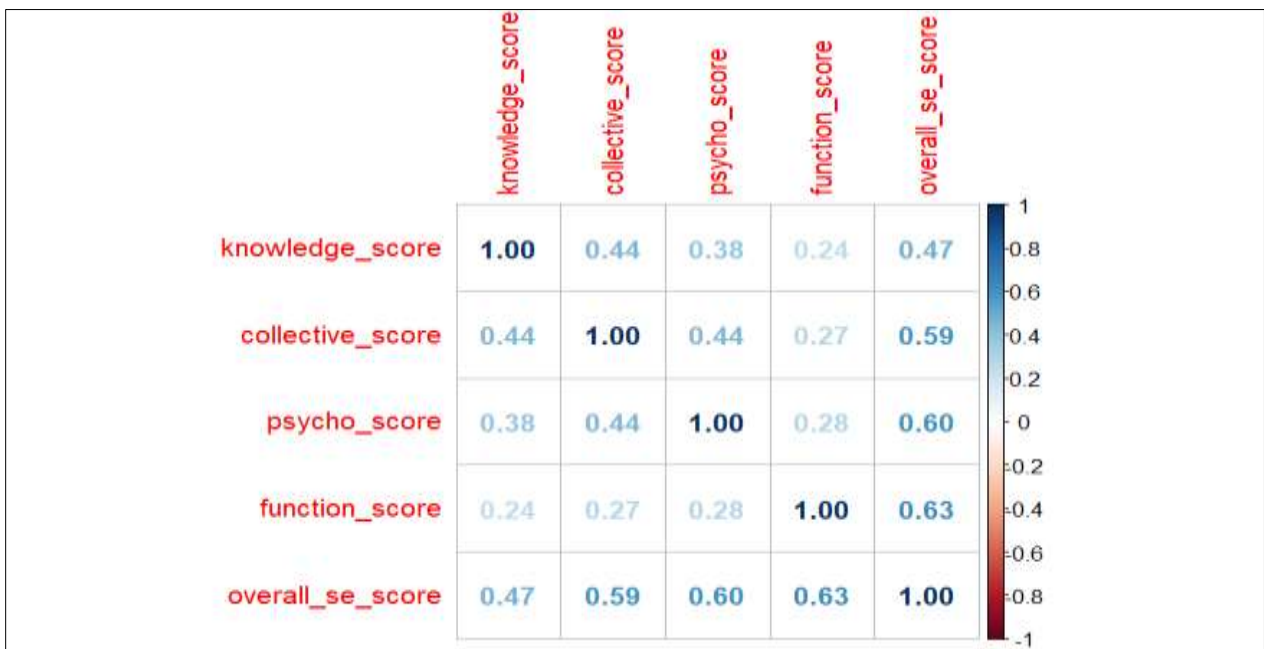


Figure 4.10: Correlation between the self efficacy domains

Figure legend: Correlations scores between the overall level and the different SE domains, showing that all the domains were moderately positively correlated to the overall level

4.3.3 ANOVA results for Self Efficacy domains.

To test whether there was significant difference in SE score means across the different groups of each domain, One-way ANOVA was used at 95% confidence interval as shown in table 4.4 below.

Table 4.4: One way ANOVA scores for self-efficacy domains

Domain	Low (Mean &SD)	Medium (Mean & SD)	High (Mean &SD)	ANOVA (F, p value)
Knowledge	8.83 ± 2.08	11.91 ± 1.31	17.50 ± 5.4	59.441 , 2.2e-16 ***
Collective	8.45 ± 1.96	11.02 ± 1.24	14.90 ± 5.16	90.92 , 2.2e-16 ***
Psycho-emotional	8.46 ± 1.99	11.00 ± 5.08	12.82 ± 5.09	65.98 , 2.2e-16 ***
Functionality	7.59 ± 1.85	9.85 ± 1.44	11.15 ± 2.61	113.3, 2.2e-16 ***

*Significant codes: ****

Table legend: One way ANOVA results showing that all the domains were statistically significant and that they all impacted the overall level.

The ANOVA table 4.4 shows that the " Knowledge ", "Collective", "Psycho-emotional", and "Functionality" variables, grouped into "low," "medium," and "high" categories, had a highly significant effect on the overall SE score." The F-statistic is large, and the associated p-value is < 0.05, suggesting that there are statistically significant differences among these categories. To explore specific nature of these differences, a Tukey honestly significant difference (HSD) post-hoc tests was performed as shown in table 4.5 below.

Table 4.5: Tukey HSD test for Self-Efficacy

Domains	Group Comparison	Mean Difference (Diff)	Confidence Intervals (CI)	Adjusted p- value (p adj)
Knowledge	medium-low	3.085	[1.60, 4.562]	3.9e-00***
	high-low	8.668	[6.596, 10.741]	0.00e+00***
	High -medium	5.58	[3.06, 8.101]	9.0e-07***
Collective	medium-low	2.538	[1.915, 3.209]	0.000***
	high-low	4.361	[4.999, 7.913]	0.000***
	High -medium	1.823	[2.344, 5.443]	0.000***
Psycho-emotional	medium-low	2.538	[1.851, 3.225]	0.000***
	high-low	4.36	[3.123, 5.600]	0.000***
	High -medium	1.823	[0.464, 3.182]	0.0049***
Functionality	medium-low	2.258	[1.720, 2.797]	0.00e+00***
	high-low	3.553	[2.960, 4.1468]	0.00e+00***
	High -medium	1.295	[0.6470, 1.942]	1.06e-0.5***

*Significant codes****

Table legend: Turkey HSD results showing that all the domains were statistically significant, and that they all impacted the overall SE level

From the post hoc test (Tukey HSD) it was observed that, the confidence intervals for the differences did not contain zero, and the adjusted p-values were all reported as 0, indicating strong evidence of differences between these groups. Thus, all three pairs of groups ("medium-low," "high-low," and "high-medium") across each domain were statistically significantly different from

each other in terms of their impact on the overall SE score with high SE total score being associated with high levels of each domain.

4.4 LEVEL OF QUALITY OF LIFE

4.4.1 Descriptive Statistics

Half of the TB patients who responded, 197(50.26%) demonstrated low levels of total QoL, 129 (32.91%) scored medium while only 66(16.84) demonstrated high levels. Based on the domains, it can be seen that 154 (39.29%) patients in the physical domain exhibited low levels, half the patients 194(49.49%) having low socioeconomic levels, 228(58.16%) low in psychosocial level and majority of the patients 230(81.56%) having a low level in the spiritual as shown in table 4.6 below.

Table 4.6: Patient’s quality of life scores in the different domains

Category	Frequency (%) Low	Frequency (%) Medium	Frequency (%) High
Overall quality of life	197(50.26)	129(32.91)	66(16.84)
Physical	154(39.29)	100(25.51)	138(35.20)
Socio-economic	194(49.49)	8(21.68)	113(28.83)
Psychosocial	228(58.16)	72(18.37)	92(23.47)
Spiritual	230(81.56)	44(15.60)	8(2.84)

Table legend: Results of the analysis of the overall level of the QoL and the domain scores showing that the overall level was low.

The low QoL in the physical domain was also explained through the FGD where a patient said;

“I am not healthy as before. This disease makes you weak. I cannot work like I used to. Sometimes my friend will call me and tell me that he is somewhere working, yet I am just in the house. If I was healthy, I would have joined him”-male TB patient, 38-year-old

The disease was also shown to affect the body appearance as expressed during the FGD:

“Before the infection, I was big in size. When got infected with TB, I lost a lot of weight. I was ashamed of going outside the house. Whenever I met people, they would comment on how I had lost weight and became very thin and this made me hate myself. Sometimes after preparing myself for church, I am not able to go, because the women there keep telling me that I am not eating well”

Some patients were also shown to rely on their spiritual belief to cope with treatment challenges as shown below

“God has taken care of me throughout this journey, even when things get tough, I turn to him. He has seen me through together with my two children who are also on TB treatment”- female TB patient, 25-year-old

The low socio-economic level was explained further, revealing the economic effects of TB on patients such as loss of income, loss of jobs and reduced productivity as a result of clients quitting their jobs at the commencement of treatment period. Most of the respondents were casuals who depended on physical strength to work. The patients experienced physical weakness which incapacitated them from working. This led to the interruption of career or the source of livelihood for clients. Respondents revealed the challenge of inadequate material support owing to their inability to work as shown below:

“My job involves walking. I had to stay away from work. That meant that my source of livelihood is affected” male TB patient, 42 years old.

Another one said

“I am a businesswoman. From the time I was diagnosed with TB, some of the businesses stalled. My body is still weak so I cannot go back to work now”-Female TB patient, 57 years old

The figure 4.11 shows distribution of patient responses in the different domains of QoL. Most of the respondents rated physical quality of life between “disagree” and “agree” with median falling on “neutral” showing some mixed reactions with half of them agreeing with the statements while the rest disagreeing. In regard to the psychosocial quality of life, median fell on “strongly disagree” and most of the respondents rated it between “disagree” and “neutral.” Indicating that the most of respondents were not sure of the psychosocial information asked.

Also, most of the respondents rated socio-economic quality of life between “disagree” and “agree” with median falling on “neutral” showing some mixed reactions with half of them agreeing with the statements while the rest disagreeing. For the spiritual, most of the respondents disagreed with the given statements regarding quality of life, with a few agreeing with the statements

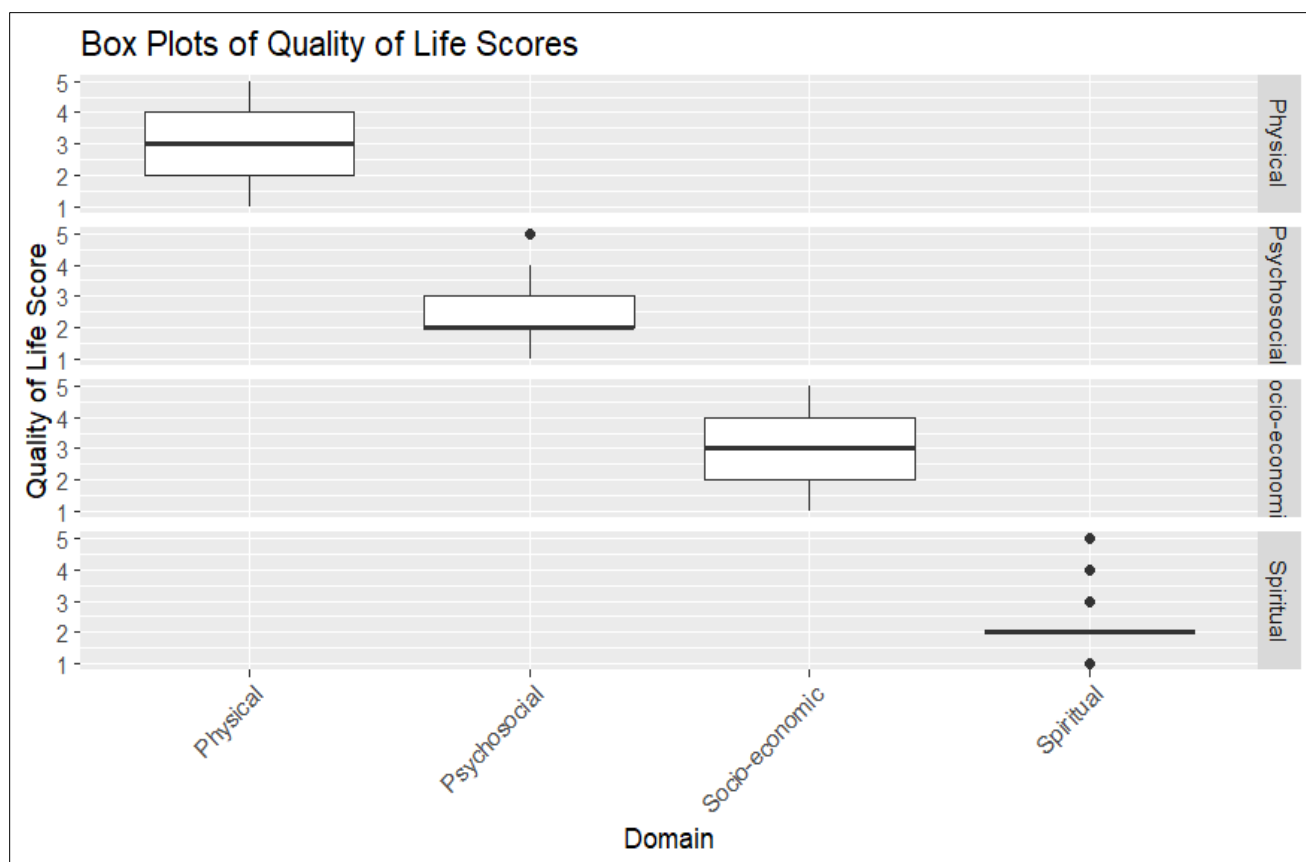


Figure 4.11: Boxplots showing distribution of patients' responses on the different QoL domains

Figure legend: distribution of patient responses in the different domains of QoL.

4.4.2 Correlations between the QoL domains

The QoL domains were strongly correlated positively with the overall QoL level except for the spiritual domain which showed a weak correlation. Moreover, there existed a moderate positive correlation among the domains with exception of spiritual domain which showed weaker correlation with other domains as shown in figure 4.12 below.

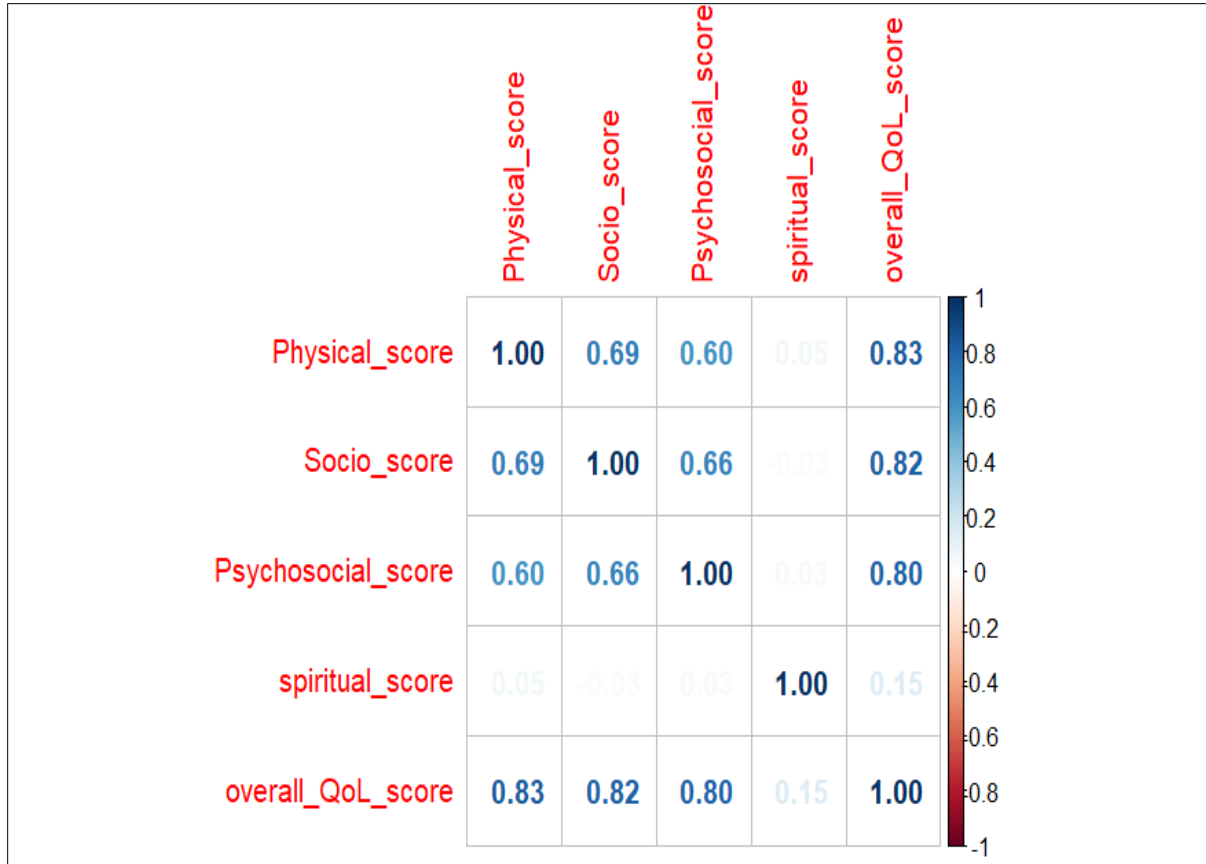


Figure 4.12:Correlations between the QoL domains

Figure legend: Correlation results showing that all the domains had a strong positive correlation with the overall QoL level except the spiritual domain which had a weak positive correlation.

4.4.3 ANOVA Results for Quality of Life

To test whether there was significant difference in total quality of life score means across the different groups of each domain, One-way ANOVA was used at 95% confidence interval as shown in table 4.7 below.

Table 4.7: One way ANOVA results for the quality-of-life domains

Domains	Low (n= 66) (Mean & SD)	Medium(n= 97) (Mean & SD)	(High n=129) (Mean & SD)	ANOVA (F, p value)
Physical	7.00 ± 2.36	9.7 ± 1.48	12.54 ± 2.49	225.06, 2.2e-16 ***
Socio-economic scores	7.38 ± 2.29	10.36 ± 1.57	13.00 ± 2.36	241.64, 2.2e-16 ***
Spiritual scores	9.93 ± 3.27	10.84 ± 1.82	14.75 ± 4.97	10.10, 5.79e-05 ***
Psychosocial scores	7.84 ± 2.43	10.71 ± 1.84	13.31 ± 2.39	191.68, 2.2e-16 ***

*Significant codes:****

Table legend: One way ANOVA results showing that all the domains impacted the overall QoL level.

The ANOVA results show that the "physical", "socio-economic", "spiritual", and "psycho-social" variables, grouped into "low," "medium," and "high" categories, had a highly significant effect on the overall QoL total score." The F-statistic is large, and the associated p-value is very close to zero, suggesting that there are statistically significant differences in the overall total QoL among these categories. To explore specific nature of these differences, a Tukey HSD post-hoc tests was performed as shown in table 4.8.

Table 4.8: Tukey HSD test for quality of life

Domains	Group Comparison	Mean (Diff)	Difference	Confidence Intervals (CI)	Adjusted p-value (p adj):
Physical	medium-low	2.723		[2.051, 3.396]	0.000***
	High-Low	5.536		[4.923, 6.151]	0.000***
	High-medium	2.813		[2.125, 3.501]	0.000***
Socio-economic	medium-low	2.978		[2.309, 3.646]	0.000***
	High-Low	5.613		[5.613, 6.221]	0.000***
	High-medium	2.635		[1.897, 3.37]	0.000***
Psychosocial	medium-low	2.871		[2.132, 3.601]	0.000***
	High-Low	5.477		[4.083, 6.15]	0.000***
	High-medium	2.606		[1.747, 3.466]	0.000***
Spiritual	medium-low	0.910		[-0.310, 2.131]	0.1860
	High-Low	4.819		[2.151, 7.488]	0.0008***
	High-medium	3.909		[1.057, 6.760]	0.0039***

Significant codes***

Table legend: Turkey HSD results, showing that all domains significantly impacted the overall QoL level except the spiritual domain

From the post hoc test (Tukey HSD), it was observed that the confidence intervals for the differences did not contain zero, and the adjusted p-values were all reported as almost 0 except for the ("medium-low" in the spiritual domain), indicating strong evidence of differences between these groups. Thus, all three pairs of groups ("medium-low," "high-low," and "high-medium") across each domain of physical, social-economic and psychosocial and spiritual were statistically significantly different from each other in terms of their impact on overall total QoL score except for the spiritual domain where medium & low were not significantly different, with high QoL total score being associated with high levels of each domain.

5.0 CHAPTER FIVE: DISCUSSION

This study explored the lived experiences and assessed the level of SE and QoL among TB patients in Nairobi County. The study identified several factors that form part of the experiences of TB patients in Nairobi County such as food insecurity, mobile street family members, pill burden, side effects, loss of income, long treatment duration, insufficient knowledge of TB knowledge level, insufficient diagnostic services, perceived wellness and facility accessibility. The overall level of SE and QoL was low with all domains impacting the Overall SE. For QoL, all the domains impacted the overall level except the spiritual domain.

5.1 Patients Lived Experiences

These findings indicate that there is still a low knowledge level on TB among the patients, observations which have earlier been made in a study in Kenya (Kenya Ministry of Health, 2019; Msoka et al., 2021). Some patients still believed that TB is hereditary while others thought that TB can be transmitted through shared items. This low knowledge level suggests that the patients were not given adequate health talk before treatment was initiated, which could be attributed to the fact that most TB clinic staff still have other duties assigned to them such as administrative or other routine patient work, leaving them with only limited time to attend to the patients. A study in urban communities of Indonesia indicated that patients with low level of TB knowledge have a risk of dropping out of treatment 5.28 times (Malisngorar *et al.*, 2023). The TB clinic staff should therefore make deliberate efforts and allocate time for counselling before and during treatment with key messages, made simpler to cater for the patients with low education levels (Wekunda *et al.*, 2021)

Perceived wellness was noted as a contributing factor to treatment interruption, where patients tend to stop treatment when they feel better, and have a sense of having been cured, observations that were also made in Kilifi and Kiambu, Kenya (Chebet et al., 2022; E. Kimani et al., 2021). This is a concern since studies other studies have shown that poor adherence is a contributor to drug resistance which may increase community transmission (Tok *et al.*, 2023). There is need for enhanced counselling with a strategy that offers more personalized health talks in a way that is easily understood by the patients, considering their diverse background.

Facility preference was revealed as another major factor towards honoring clinic appointments. Patients chose facilities that are easily accessible to them, those that had drugs, those with friendly

HCW and those with equipment in the laboratory and x-ray departments, observations that are similar to a cross sectional study done in Kenya, Uganda and Tanzania (Msoka *et al.*, 2021). Nairobi county is the most populated in Kenya, with a day population of seven million (NCCG health report, 2023) yet it only has 803 TB clinics, out of which 262 are public. This not only makes the patients travel for long in search of these services but also increases the out-of-pocket expenditure on health. With the higher demand for health services as a result of the huge population in the city, these numbers seem to be low, and therefore, to enhance service delivery and patient experience, the county government should consider opening up more TB clinics through multisectoral collaboration, expansion of diagnostic capacity and training healthcare workers.

Majority of the patients who missed appointment were found to be among the special population including the homeless and the drug users, similar to studies Eldoret, Busia and Transnzoia, Kenya (Embleton *et al.*, 2023; Koros *et al.*, 2023). This population has been shown to not only have a high prevalence of TB but also has the ability to transmit the disease up to 48 to 67 times compared to the general population (Scholze *et al.*, 2022). Further, the living conditions for this population puts them at risk of infections with challenges that include poor education, which leads to ignorance on primary health care, poor healthcare access, poor hygiene and eating habits, stigma, prejudice, conflicting or nonexistent family ties, and the lack of a life project, among others (Embleton *et al.*, 2023; Scholze *et al.*, 2022). The TB program should therefore put in place strategic measures that includes the availability of health services and social assistance in an effort to improve treatment outcomes of this group. This study identified challenges of the homeless on TB treatment which makes drug storage a challenge for them. They not only lose their drugs at times during the rainy season, the drugs get wet. This particular group of persons are a high risk of infection with TB compared to the general population not only due to their low-income status but also as a result of other risk factors such as poverty, overcrowding, malnutrition, HIV infection, smoking, alcoholism, and drug abuse (Shamebo *et al.*, 2023). There needs to be policies that specifically address their plight, including social protection programs.

The majority of HCW were found to have a good relationship with the patients. This differs from a study in Ukraine (Aibana *et al.* 2020) which showed that the patients had a striking negative attitude towards the nurses. As reported by a study in Kisumu, Kenya, (Mulaku *et al.*, 2023), good

provider-patient communication after diagnosis is essential so patients are well prepared for the long course of treatment.

Medication burden including adverse treatment effects were found to be another factor that affects TB treatment, similar to results seen in Uganda and Ghana (Appiah *et al.*, 2023; Nabisere-Arinaitwe *et al.*, 2023). Responses from some patients indicated that the side effects led them to miss drugs for some days, though most of them reported that the side effects were reduced after they adapted to treatment. Its therefore important to continually educate the patients on the expected common side effects and also inform them on what to do once they occur.

These findings show that the TB patients were still experiencing stigma both from the community and the family members, similar to findings reported in Kenya (Mbothia *et al.*, 2020; Mulaku *et al.*, 2023). This was shown when some of the family members refused to share items with them or come near them. Even though the patients disclosed their condition to close family members, they did not disclose it to the community because of the stigma associated with TB. Mostly this stigma is a result of the perceived risk of transmission from patients to other susceptible community members (Aggarwal 2019). As suggested by (Addo *et al.*, 2022) in their study, there is need for more education at the public level to raise TB awareness.

Most patients in this study indicated that the food available in the households was not enough to provide for the extra nutritional needs while others revealed that they could not afford to buy food and that they struggled to buy even the most basic food. This finding is similar to that in South Africa (Id Karina Kielmann *et al.*, 2018). It's important to note that people suffering from TB tend to have an increased demand for energy, which often causes them to lose a significant amount of weight, and this undernutrition leads to increased risk of death and relapse of the disease (Tadesse *et al.*, 2023).. In addition, the search for food was noted as the main reason for the loss to follow up for the street families. The TB program should therefore include nutritional support which will not only play a big role in enabling them to continue their treatment and get healthy again but can also support the TB-affected households to strengthen their resilience and support their ability to care for household members with TB.

5.2 Self efficacy of TB Patients

The findings show that the overall level of SE of the patients was low, similar to findings in Indonesia (Setiyowati *et al.*, 2021). For chronic disease like TB, studies have shown that success

in treatment requires the patients to be fully confident and commit to performing self-care tasks (Kainat et al, n.d.). The confidence can be instilled through counselling at the time of diagnosis and throughout the treatment period. This is important since patients with high SE scores have been shown to cope better with the negative consequences of their disease and with its treatment (Szczepańska-gieracha *et al.*, 2022) compared to patients with a low level who are likely to transmit TB up to 5 times (Herdianti *et al.*, 2020). A patient-centered approach is therefore necessary because such interventions enable individuals to make informed decisions about their condition, resulting in better health outcomes, and a positive impact on their health

The findings indicate that physical domain scores were low, and that it has an impact the overall SE level. Studies have shown that patients with a higher SE have lesser physical symptoms, which may probably lead to better treatment adherence and tolerance, ultimately leading to better outcomes (Trille K. Kjaer *et al.*, n.d.) while patients with a lower self efficacy tend to have a harder time dealing with challenging situations in life, which may end up affecting their help-seeking efforts and communication with health staff regarding the symptoms and adverse effects that may occur during treatment. As established in this study, improving the physical domain SE level by enhanced counselling throughout the treatment period is necessary to for improved overall SE outcome.

The collective efficacy domain level was also found to be low with the post hoc scores showing that it had had an impact on the overall SE scores. Previously, it has been shown that communities that have a higher collective efficacy have low rates of morbidity and mortality as well as risky behaviors in comparison to similar communities with low levels of collective efficacy (Butel & Braun, 2019). In this study, collective efficacy was demonstrated through help with reminders to take drugs, words of encouragement, accompanying the patient to the clinic visits, and preparing food for them by family and social circle of the patients. The street families were shown to implement this strategy better where they would all accompany anyone of them who had an appointment at the clinic. In Ghana and Ethiopia, studies have shown that support systems are a protective factor for treatment adherence while a lack of such support is a major hindrance as seen in Ethiopia and Ghana (Appiah *et al.*, 2023; Gebremariam *et al.*, 2021). And therefore, targeting the specific components of this domain including reminders of clinic days and drug time, words of encouragement, preparing food, support with transport to the clinic, support with food as well

as gifts after treatment completion, especially for children, can be used as to help improve the outcomes in this domain and general SE level.

This study demonstrates the mental distress that patients go through at the time of diagnosis and during treatment. The respondents were worried about their jobs, their families, their appearance and the final treatment outcome. This distress as observed in the study, is mainly due to individual, socio-economic and health system level factors, highlighting the need for multilevel solutions to address mental health needs of TB patients during treatment and investigation. The findings are consistent with observations in Zambia, South Africa, Zimbabwe and Tanzania which showed that participants with higher levels of mental distress were more than two times more likely to be non-adherent than those with lower levels of distress (Mainga *et al.*, 2022). Therefore, to better address mental distress amongst TB patients, it is important to expand beyond a biomedical framework and examine the role that social context plays, employing interventions that address the drivers including counselling, nutritional support, cash transfers and improved user experience in the healthcare system.

5.3 Quality of Life of TB Patients

The overall QoL was found to be low in TB patients in this study, similar to findings in Indonesia (Alfian 2020). The study also showed that activities such as lifting heavy objects and long-distance walking were a challenge to some of the TB patients, which was similar to findings reported in Pakistan (Malik *et al.*, 2018). A study in Kenya (H. Kimani *et al.*, 2022) demonstrated that health education can help improve pain and discomfort, anxiety, sleep and usual activities of the TB patients. The patients should therefore be continually educated on the coping strategies throughout the treatment period.

The socioeconomic domain was also found to be low, attributable to the effects of the disease on this domain. Reduced income was a major effect identified in this study. This agrees with findings in Ghana and Zimbabwe (Addo *et al.*, 2022; Tigrigi *et al.*, 2023) which found financial constraints and food insecurity are predictors of low QoL levels. Even though in Kenya TB is publicly funded, the potential loss of income due to indirect costs during TB investigation and treatment, in addition to notable reduction in productivity, may lead to catastrophic health costs for individuals with TB and their families. The TB program could consider interventions that can cushion the patients such as cash transfers, and assistance with food to increase treatment success rates.

The findings also revealed the mental distress experienced by TB patients who are on treatment. This was similar to results from a study in Zambia (Mainga *et al.* 2022) which showed economic and social factors as the main causes of the mental distress that was experienced by the participants. This study revealed that at the point of diagnosis, some patients are shocked at the results, some have the fear of social seclusion, others deny the results and others even think about death. These negative emotional states have been shown to contribute to non-adherence (Aibana *et al.* 2020). Even though the patients need mental health services, the study revealed a gap in the counseling skills of the TB clinic staff. All the staff interviewed had not been trained in counseling. There is a need to integrate psychological care into the care and treatment package with counsellors assigned to the TB clinic. This may help patients to better handle the challenges they may experience during treatment as well as training the TB clinic staff on counselling to help bridge the gap that the study identified.

Even though the findings showed that spirituality did not affect the QoL, some patients revealed that in addition to the provided treatment, depended on spiritual coping mechanisms like the belief in the existence and power of God in coping with the disease. These findings are similar to those in Ghana (Gyimah & Dako-gyeke, 2019) which revealed that some patients relied on the spiritual belief to cope with treatment challenges.

6.0 CONCLUSION AND RECOMMENDATION

6.1 Conclusion

First, the findings indicate that food insecurity, mobility of street families, pill burden, side effects, loss of income, long treatment duration, insufficient knowledge of TB knowledge level, insufficient diagnostic services, perceived wellness and facility accessibility have an effect on treatment adherence and outcomes.

Secondly, the overall SE level was low across the domains. All the domains were found to be moderately positively correlated with the overall SE level. The ANOVA analysis showed statistical significance in all domains indicating that all they affected the level of the overall SE. Therefore, improving the knowledge, collective, psycho-emotional and functional efficacy of the TB patients may help improve the overall SE which then leads to better adherence and treatment outcomes.

Additionally, the overall QoL was low with all the domains having a strong positive correlation with the overall level except the spiritual domain which had a weak positive correlation. The ANOVA analysis showed statistical significance in all domains (except spiritual) indicating that they affected the level of the overall QoL. Therefore, improving the physical, socio-economic and psycho-social efficacy of the TB patients may help improve the overall QoL which then leads to better adherence and treatment outcomes.

6.2 Recommendation for TB programming / policy

In order to attain patient centered approaches, the TB program should

- i. First, consider going beyond the clinical aspects, and try to include socio-economic and psychological dimensions that impact the disease and its treatment. Nutritional support should be considered for street families, drug users and vulnerable groups, counselling should be a key component of the care and treatment package, health education with key messages should be sustained throughout the treatment period and patients' perceptions included in the monitoring and evaluation tools.
- ii. Secondly SE and QoL could be used more frequently in addition to the available routine disease outcome indicators, and perhaps included into forthcoming guidelines. This can assist health care providers to target specific mental and physical health components that are adversely affected by the disease or treatment.

6.3 Recommendation for research

Future research should focus on a community study, to help get the perspectives of the patients who did not visit the facility as well as those who may have poor health seeking behaviors.

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APPENDICES

6.4 Appendix 1: variable definition table

Variable	Operational definition	Level of measurement
Age	Age in years	Integer
Sex	Physiological orientation	Nominal <ul style="list-style-type: none"> • Male • Female • Other
Educational level	Highest education attained	Ordinal <ul style="list-style-type: none"> • No formal education • Primary level • Secondary level • Tertiary level • University
Marital status	Relationship status	Nominal <ul style="list-style-type: none"> • Single/ never married • Married • Widowed • Widowered • Divorced
Occupation	Current source of livelihood	Nominal <ul style="list-style-type: none"> • Businessman/woman • Casual laborer • Formal Employment • Student • None • Other (Please specify)
Income	Average monthly income in ksh	Integer
Healthcare System Factors		
Treatment duration	Length of treatment period(months)	Integer
Facilities visited	Number of TB clinics visited since diagnosis	Integer
Reasons for visiting many facilities	Reasons for visiting different facilities	Nominal <ul style="list-style-type: none"> • Poor staff attitude • Long distance to facility • Relocation • Lack of medicines • Lack of laboratory services • Others (please specify)
Missed appointment	Number of times patient did not honor clinic appointment	Nominal <ul style="list-style-type: none"> • Yes • No
Reasons for missed appointment	Reasons for missing clinic appointment	Nominal

			<ul style="list-style-type: none"> • Facility is too far for me • Lacked transport • Lacked cost of medication • Changed residential area • Was too weak to travel o Others (specify) _____
Number of clinic visits	Number of clinic visits in the last one month	Integer	
Travel time	Time spent travelling to the clinic	Ordinal	<ul style="list-style-type: none"> • 1 - 30 minutes • 31- 59 minutes • 1 hour to 2 hours • More than 2 hours
Turnaround time	Time taken on queue in the facility	Ordinal	<ul style="list-style-type: none"> • 1 - 30 minutes • 31- 59 minutes • 1 hour to 2 hours • More than 2 hours
Transport cost	Money spent on travel to the clinic in ksh	Integer	
Facility preference	Reasons for choosing facility over others	Nominal	<ul style="list-style-type: none"> • It is nearer to my home/house • It is affordable • Healthcare workers are friendly • It has drugs for my condition • It has equipment for managing TB patients • Others (please specify)

Experience with HCW

Courtesy	How the patients rated the HCW on courtesy	Ordinal	<ul style="list-style-type: none"> • Worse • Bad • Good • Very Good • Excellent
Patience	How the patients rated the HCW on patience	Ordinal	<ul style="list-style-type: none"> • Worse • Bad • Good • Very Good • Excellent

Clarity of explanations	How the patients rated the HCW on clarity during explanations on drugs	Ordinal <ul style="list-style-type: none"> • Worse • Bad • Good • Very Good • Excellent
Effectiveness of dialogue	How the patients rated the HCW on clarity during explanations on drugs	Ordinal <ul style="list-style-type: none"> • Worse • Bad • Good • Very Good • Excellent
Challenges	Some of the challenges experienced during treatment	Nominal
Pill burden		
Side effects	Effects of drugs experienced by the patient	Nominal <ul style="list-style-type: none"> • Yes • No
Months of side effect	The month of treatment when side effects were experienced	Integer
Days of missed drugs	Number of days patient missed drugs due to side effects	Integer
HCW support	Support received from HCW to handle side effects	Nominal <ul style="list-style-type: none"> • Yes • No
Effectiveness of support	How effective the support from the HCW is	Ordinal <ul style="list-style-type: none"> • Very Ineffective • Ineffective • Neutral • Effective • Very Effective
Taste of drugs	Patients' assessment of the drug taste	Ordinal <ul style="list-style-type: none"> • Extremely bitter • Bitter • Tasteless • Sweet • Extremely sweet
Size of drugs	Patients' assessment of the drug size	Ordinal <ul style="list-style-type: none"> • Extremely big • Big • Neither big nor small • Small • Extremely small
Time of discharge	Knowledge on discharge time	Nominal <ul style="list-style-type: none"> • Yes

Desired medication period	Patients' ideal treatment period	Ordinal	<ul style="list-style-type: none"> • No • Less than 1 month • 1 – 3 months • 3 – 6 months • 6 – 9 months • Over 9 months
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Socio-Economic Experiences

Limited social relationships	How the disease limited interactions	Ordinal	<ul style="list-style-type: none"> • Never • Seldom • Often • Very Often • Always
Limit attending social events	How the disease limited attendance of social events such as church, family gathering	Ordinal	<ul style="list-style-type: none"> • Never • Seldom • Often • Very Often • Always
Spousal relationship	Effect of disease affected relationship with spouse	Ordinal	<ul style="list-style-type: none"> • Never • Seldom • Often • Very Often • Always
Unfair treatment	Patient's experience (insults, humiliation) with neighbors	Ordinal	<ul style="list-style-type: none"> • Never • Seldom • Often • Very Often • Always
Not discussing condition	Avoided discussing condition with family and friends due to stigma and discrimination	Ordinal	<ul style="list-style-type: none"> • Never • Seldom • Often • Very Often • Always

Determination of self efficacy level

Levels of SE	Categorization of SE based on the patient scores	Ordinal	<ul style="list-style-type: none"> • Low • Medium • High
--------------	--	---------	---

SE domains

Knowledge	How much information patient has on control and prevention of TB such as masking, ventilation, curability and early treatment	Ordinal <ul style="list-style-type: none"> • Strongly Agree • Agree • Neutral • Disagree • Strongly Disagree
Collective	The level of support from social networks, five questions measuring; help with clinic appointments, food support, hope and encouragement and financial support	Ordinal <ul style="list-style-type: none"> • Strongly Agree • Agree • Neutral • Disagree • Strongly Disagree
Psycho-emotional	Ability to manage stressful situations, assessed through five questions: ability to take personal responsibility to avoid infecting others, positive mindset towards curability and taking responsibility for medication adherence.	Ordinal <ul style="list-style-type: none"> • Strongly Agree • Agree • Neutral • Disagree • Strongly Disagree
Functionality	Three questions that assessed the effect of TB on the daily economic activities, social activities and personal care activities.	Ordinal <ul style="list-style-type: none"> • Strongly Agree • Agree • Neutral • Disagree • Strongly Disagree

Determination of the level of Quality of Life

Level of QoL	Categorization of QoL based on the patient scores	Ordinal <ul style="list-style-type: none"> • Low • Medium • High
QoL domains		
Physical	Assessed through six questions looking at:pain and fatigue, reduced mobility, time spent on daily chores, time spent on economic activities and change in body appearance.	Ordinal <ul style="list-style-type: none"> • Strongly Agree • Agree • Neutral • Disagree • Strongly Disagree
Socio-economic	Effects of the disease on the socio-economic aspects of the patients, four questions including effect of the disease on the social network,	Ordinal <ul style="list-style-type: none"> • Strongly Agree • Agree • Neutral • Disagree • Strongly Disagree

income, participation in social networks and productivity.

Psycho-social

Effects of the disease on the mental health of the patients, assessed using four questions: level of worry on missing daily economic activities, stigma, losing social network and being a burden to the family as a result of the disease.

Ordinal

- Strongly Agree
- Agree
- Neutral
- Disagree
- Strongly Disagree

Spirituality

Assessed how religious/spiritual beliefs and practices influence coping strategies during the period of chronic illnesses

Ordinal

- Strongly Agree
 - Agree
 - Neutral
 - Disagree
 - Strongly Disagree
-

6.5 Board of post graduate studies approval letter



JARAMOGI OGINGA ODINGA UNIVERSITY OF SCIENCE & TECHNOLOGY

BOARD OF POSTGRADUATE STUDIES
Office of the Director

Tel. 057-2501804
Email: bps@jooust.ac.ke

P.O. BOX 210 - 40601
BONDO

Our Ref: H153/P/2551/21

Date: 1st November 2022

TO WHOM IT MAY CONCERN

RE: JOAN ONDIRO - H153/P/2551/21

The above-mentioned person is a bonafide postgraduate student of Jaramogi Oginga Odinga University of Science and Technology in the School of Health Sciences, pursuing Master of Science in Epidemiology and Biostatistics. She has been authorized by the University to undertake research on the topic: "*Assessment of Lived Experiences, Self-Efficacy and Quality of Life among Tuberculosis Patients in Nairobi County, Kenya*".

Any assistance accorded her shall be appreciated.

Thank you.

The stamp is circular with a blue border. The text inside the stamp reads: 'JARAMOGI OGINGA UNIVERSITY OF SCIENCE & TECHNOLOGY' around the top edge, 'BOARD OF POSTGRADUATE STUDIES' around the bottom edge, and 'NOV 2022' in the center. Below the stamp, the text '210 - 40601 BONDO' is visible.

Prof. Dennis Ochiudho
DIRECTOR, BOARD OF POSTGRADUATE STUDIES

6.6 Appendix 2: ERC research approval letter



**JARAMOGI OGINGA ODINGA
UNIVERSITY OF SCIENCE AND TECHNOLOGY
DIVISION OF RESEARCH, INNOVATION AND OUTREACH
JOOUST-ETHICS REVIEW OFFICE**

Tel. 057-2501804
Email: erc@jooust.ac.ke
Website: www.jooust.ac.ke

P.O. BOX 210 - 40601
BONDO

OUR REF: JOOUST/DVC-RIO/ERC/E4

10th January, 2023

Joan Ondiro
SHS
JOOUST

Dear Ms. Ondiro,

RE: APPROVAL TO CONDUCT RESEARCH TITLED "ASSESSMENT OF LIVED EXPERIENCES, SELF-EFFICACY AND QUALITY OF LIFE AMONG TUBERCULOSIS PATIENTS IN NAIROBI COUNTY, KENYA"

This is to inform you that JOOUST ERC has reviewed and approved your above research proposal. Your application approval number is ERC 35/12/23-15/06. The approval period is from 10th January, 2023– 09th January, 2024.

This approval is subject to compliance with the following requirements:

- i. Only approved documents including (informed consents, study instruments, MTA) will be used.
- ii. All changes including (amendments, deviations and violations) are submitted for review and approval by JOOUST IERC.
- iii. Death and life threatening problems and serious adverse events or unexpected adverse events whether related or unrelated to the study must be reported to NACOSTI IERC within 72 hours of notification.
- iv. Any changes, anticipated or otherwise that may increase the risks of affected safety or welfare of study participants and others or affect the integrity of the research must be reported to NACOSTI IERC within 72 hours.
- v. Clearance for export of biological specimens must be obtained from relevant institutions.
- vi. Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. Attach a comprehensive progress report to support the renewal.
- vii. Submission of an executive summary report within 90 days upon completion of the study to JOOUST IERC.

Prior to commencing your study, you will be expected to obtain a research permit from National Commission for Science, Technology and Innovation (NACOSTI) <https://oris.nacosti.go.ke> and also obtain other clearances needed.

Yours sincerely,

for
Prof. Francis Anga'wa
Chairman, JOOUST ERC

Copy to: Deputy Vice-Chancellor, RIO

Director, BPS

DEAN, SHS

6.7 Appendix 3: NACOSTI research approval letter


REPUBLIC OF KENYA


NATIONAL COMMISSION FOR
SCIENCE, TECHNOLOGY & INNOVATION

Ref No: 766647

Date of Issue: 20/March/2023

RESEARCH LICENSE



This is to Certify that Ms. Joan Ondiro Ondiro of Jaramogi Oginga Odinga University of Science and Technology, has been licensed to conduct research as per the provision of the Science, Technology and Innovation Act, 2013 (Rev.2014) in Nairobi on the topic: ASSESSMENT OF LIVED EXPERIENCES, SELF EFFICACY AND QUALITY OF LIFE AMONG TUBERCULOSIS PATIENTS IN NAIROBI COUNTY, KENYA for the period ending : 20/March/2024.

License No: NACOSTI/P/23/23921

766647

Applicant Identification Number


Director General
NATIONAL COMMISSION FOR
SCIENCE, TECHNOLOGY &
INNOVATION

Verification QR Code



NOTE: This is a computer generated License. To verify the authenticity of this document,
Scan the QR Code using QR scanner application.

See overleaf for conditions

6.8 Appendix 4: Nairobi county research approval letter

NAIROBI CITY COUNTY

Telephone 020 344194

Web: www.nairobi.go.ke



City Hall,
P. O. Box 30075-00100,
Nairobi,
KENYA.

HEALTH, WELLNESS & NUTRITION

REF: NCCG/HWN/REC/344

DATE: 11th April 2023

JOAN ONDIRI

JARAMOGI OGINGA ODINGA UNIVERSITY OF SCIENCE AND TECHNOLOGY

Dear Ms. Joan,

RE: RESEARCH AUTHORIZATION

This is to inform you that the Nairobi City County – County Health Research Ethics Committee (REC) reviewed the documents on the study titled "ASSESSMENT OF LIVED EXPERIENCES, SELF EFFICACY AND QUALITY OF LIFE AMONG TUBERCULOSIS PATIENTS IN NAIROBI COUNTY, KENYA"

I am pleased to inform you that you have been authorized to carry out the study in Nairobi County. The researcher will be required to adhere to the ethical code of conduct for health research in accordance with the Science Technology and Innovation Act, 2013 and the approval procedure and protocol for research for Nairobi.

On completion of the study, you will submit one hard copy and one copy in PDF of the research findings to the REC. In addition, you will disseminate recommendations of the research at a virtual meeting organized by the REC. By copy of this letter, the Sub County Medical Officers of Health - Embakasi East and West, Langata, Starehe, Ruaraka, Dagoretti Sub Counties are to accord you the necessary assistance to carry out this research study.

Yours sincerely,

DR. IRENE MUCHOKI

CHIEF OFFICER MEDICAL SERVICES &

Ag. CHIEF OFFICER NUTRITION, WELLNESS & SCHOOL FEEDING PROGRAM

Cc: Chief Officers – Public Health and Health Facilities
the Sub County Medical Officers of Health - Embakasi East and West, Langata,
Starehe, Ruaraka, Dagoretti Sub Counties

6.9 Appendix 5: patients' questionnaire

ASSESSMENT OF LIVED EXPERIENCES, SELF-EFFICACY, AND QUALITY OF LIFE AMONG TB PATIENTS IN NAIROBI COUNTY, KENYA

Thank you for agreeing to participate in this survey. This interview is part of a survey titled: Assessment of patient's lived experiences, self-efficacy, and quality of life of TB patients in Nairobi County. My name is Joan Ondiro and this is part of the requirements for the fulfilment of the award of a Master's degree in Epidemiology and Biostatistics by Jaramogi Oginga Odinga University of Science and Technology. I will be asking you some questions about your journey with TB treatment.

Your opinions and experiences will help us improve the services we provide. This interview will take about 30 to 45 minutes. I would like you to answer the questions as best as you can. There is no right or wrong answer. Your answers will not be linked to your name and will not affect the type of treatment or care you receive. If there are any questions that you are uncomfortable answering, we can skip to the next question or stop the interview.

Before we begin, please let me know if you have any questions. If not, we can start the interview.

SOCIO-DEMOGRAPHIC INFORMATION

SUB COUNTY NAME	
WARD NAME	
NAME OF FACILITY	

1. How old are you currently? (Insert number) _____
2. What is your sex?
 Male Female Other
3. What is your highest completed educational level?
 No formal education Primary level Tertiary level
 Secondary level University
4. What is your current marital status?
 Single/ never married Married Divorced
 Widowed Widowed
5. What is your current occupation?
 Businessman/woman Student
 Casual laborer None
 Formal Employment Other (Please specify) _____
6. What is your average monthly income (KES)? _____

PATIENTS EXPERIENCE

Healthcare System Factors

7. How long have been on TB treatment? (Enter the number of months) _____
8. i) How many different health facilities have you visited for treatment since your diagnosis with TB?
ii) Why have you sought treatment from the different health facilities?
 Poor staff attitude Long distance to facility Relocation
 Lack of medicines

- Lack of laboratory services
- Other (please specify)

9. i) Have you ever missed any of your appointments since you were diagnosed with TB?
 Yes No

ii) What prompted you to miss your appointment?

- Facility is too far for me
- Lacked transport
- Lacked cost of medication
- Changed residential area
- Was too weak to travel
- Others (specify) _____

10. How many visits did you make to the TB clinic in the last 30 days, to meet with a nurse or health care worker? (Enter a number) _____

11. How much time does it take to travel to the TB clinic?

- 1 - 30 minutes
- 31- 59 minutes
- 1 hour to 2 hours
- More than 2 hours

12. How long do you normally take in the queue before seeing a healthcare worker at the health facility whenever you visit for TB treatment?

- 1 - 30 minutes
- 31- 59 minutes
- 1 hour to 2 hours
- More than 2 hours

13. On average, how much money does it cost you to travel to the TB clinic? (Insert figure in Ksh) _____

14. Why do you prefer this facility for your TB medication?

- It is nearer to my home/house
- It is affordable
- Healthcare workers are friendly
- It has drugs for my condition
- It has equipment for managing TB patients
- Others (please specify)

15. I would like to ask you about your experience with the interaction with healthcare workers on their attitudes towards you whenever you visit a healthcare facility for TB treatment services.

Kindly rate healthcare workers' attitudes on a scale of 1 – 5 where 5 = worse while 1 = excellent on the following aspects

Experience with HW	Worse	Bad	Good	Very Good	Excellent
(i). During your visits to the clinic, how would you rate the health care worker's courtesy and respect towards you?	1	2	3	4	5
(ii). During your visit to the clinic, how would you rate the healthcare worker's patience and listening towards you?	1	2	3	4	5
(iii). During your visits to the clinic and interaction with healthcare worker(s), how would you rate the staff's explanations to you in a way you could understand?	1	2	3	4	5
(iv). Before giving you any medicine, how would you rate the healthcare workers' description of the medicine usage, dosage, and possible side effects in a way you could understand?	1	2	3	4	5
(v). During your visits to the clinic, how would you rate the effectiveness of the dialogue session you've attended with other TB patients that HCW conducts on TB management?	1	2	3	4	5

16. What are some of the challenges you've experienced about your illness since you were diagnosed with TB?

Pill/Medication Burden

17. Have you ever experienced any side effects with your TB drugs since you began medication?

Yes

No

ii). During which month(s) of treatment did you experience these side effects?

(iii). Did you fail to take your drugs because of the side effects?

(iv). How many days did you miss to take drugs?

18. (i). Have you received any support from the healthcare workers in managing these side effects?

Yes

No

(ii). How effective is this support towards managing these side effects?

Very Ineffective

Neutral

Very Effective

Ineffective

Effective

19. Given your experience with the TB drugs, how would you describe their taste?

Extremely bitter

Tasteless

Extremely sweet

Bitter

Sweet

20. Given your experience with the TB drugs, how would you describe their size?

Extremely big

Neither big nor

Small

Big

small

Extremely small

21. Do you know when you are supposed to be discharged from the TB clinic?

Yes

No

22. What would be your ideal period for attending a TB clinic for treatment and medication?

Less than 1
month

1 – 3 months

3 – 6 months

6 – 9 months

Over 9 months

Socio-Economic Experiences

23. Now I'd like to ask you about your social life experiences as impacted by TB since you were diagnosed with TB. During this period and due to your TB illness, how often did you...

Social Life Experiences	Never	Seldom	Often	Very Often	Always
(i). Limit your social relationships and friendships	5	4	3	2	1
(ii). Limit attending social events e.g. church, wedding, family gathering, social gathering, etc	5	4	3	2	1
(iii). Experience deteriorated relationship with your spouse	5	4	3	2	1
(iv). Experience unfair treatment from your neighbors (e.g. humiliation, abuse, insults tease or mocking)	5	4	3	2	1
(v). Avoided discussing your illness openly with friends due to stigma & discrimination	5	4	3	2	1

SELF-EFFICACY

24. I am now going to read for you a list of statements, For each statement, I'd like you to rate your level of agreement on a scale of 1 – 5, where 1= strongly disagree while 5 = strongly agree with the statement.

How do you agree with the following statements?					
Knowledge:	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
(i). Wearing of mask among those with TB illness can minimize the spread of TB	5	4	3	2	1
(ii). Proper ventilation in our houses can help minimize spread of TB	5	4	3	2	1
(iii). Covering our mouths while coughing can help minimize the spread of TB	5	4	3	2	1
(iv). Spitting in the open among those with TB can enhance the spread of TB	5	4	3	2	1
(v). Early diagnosis and treatment initiation can help control the spread of TB	5	4	3	2	1
(vi). TB is curable	5	4	3	2	1
Collective Efficacy:					
(i). I have received sufficient support from my family in promptly honoring my clinical appointments and taking medication. e.g. clinic days reminder, transport, company to the facility, etc	5	4	3	2	1

(ii). My social network (friends & family) has supported me with regular food assistance for myself and my family during this period of my illness.	5	4	3	2	1
(iii). My social network (friends & family) has supported me with relevant information on TB management during this time of my illness	5	4	3	2	1
(iv). My social network (friends & family) has provided me with hope, companionship, encouragement, and optimism of getting health of TB	5	4	3	2	1
(v). My social network (friends & family) has supported me with financial assistance to take care of my health and family obligations during this time of my illness	5	4	3	2	1
Psycho-emotional:					
(i). I can manage the effects of depression, anger, stigma, and/or other negative emotions on my treatment and life.	5	4	3	2	1
(ii). I can accept the fact that I have tuberculosis and talk openly about it with people	5	4	3	2	1
(iii). I can maintain a positive attitude and believe that my illness will be cured	5	4	3	2	1
(iv). I am able to take responsibility of my health to prevent infecting others with TB	5	4	3	2	1
(v). I am able to take responsibility of adhering to my medication & hospital appointments as required	5	4	3	2	1
Functionality:					
(i). daily economic activity has NOT been affected since being diagnosed with TB	5	4	3	2	1
(ii). I am able to attend my usual social network (<i>church, friends, family gathering etc</i>) since being diagnosed with TB	5	4	3	2	1
(iii). My self-care (personal hygiene, grooming) has not been affected since being diagnosed with TB	5	4	3	2	1

QUALITY OF LIFE

25. How do you agree with the following statements?					
Physical	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
(i). I always experience pain associated with TB illness	5	4	3	2	1
(ii). I always experience fatigue or lack of energy due to TB illness	5	4	3	2	1
(iii). I always experience limited mobility due to TB illness	5	4	3	2	1
(iv). I always experience reduced time spent on my usual daily household chores due to TB illness	5	4	3	2	1

6.10 Appendix 6: dodoso la mgonjwa

TATHMINI YA WAGONJWA, UFANISI BINAFSI, NA UBORA WA MAISHA WA WAGONJWA WANAUGUA KIFUA KIKUU KATIKA KAUNTI YA NAIROBI

Asante kwa kukubali kushiriki katika utafiti huu. Mahojiano haya ni sehemu ya utafiti wenye kichwa” Tathmini ya wagonjwa, ufanisi binafsi, na ubora wa maisha wa wagonjwa wanaougua kifua kikuu katika kaunti ya Nairobi”. Ni sehemu ya mahitaji ya kutimiza kwa tuzo ya shahada ya uzamili kwa Epidemiolojia na Takwimu za kibayolojia katika chuo kikuu cha Jaramogi Oginga Odinga cha Sayansi na Teknolojia

Maoni yako na uzoefu wako utatusaidia kuboresha huduma ambazo tunapeana. Mahojiano haya yatachukua mda wa dakika 30 hadi 45. Ningependa ujibu maswali haya kadri uwezavyo. Hakuna jibu sahihi au baya. Majibu yako hayataonyesha jina lako na hayataathiri huduma ambayo unapokea. Kama kuna maswali ambayo unahisi hauwezi yajibu, uko huru kuyapita ama pia kusitisha haya mahojiano.

Kabla ya kuanza, tafadhali nifahamishe kama uko na swali lolote. Kama hakuna, tunaanza anza mahojiano.

IDADI YA WATU KIJAMII

JINA LA KAUNTI NDOGO	
WODI	
JINA LA KITUO CHA AFYA	

27. Uko na miaka mingapi kwa sasa? (weka namba) _____

28. Jinsia yako ni ipi?

- Mume Mke Ingingine

29. Kiwango chako cha juu cha masomo ni kipi?

- Hakuna Shule ya upili Chuo kikuu
 Shule ya msingi Chuo cha kiufundi

30. Hali yako ya ndoa iko vipi kwa sasa?

- Sijaolewa Mjane
 Nimeolewa/nimeoa Tumetengana

31. Kazi yako ni ipi kwa sasa?

- Biashara wanafunzi
 Juakali Hakuna
 Nimeajiriwa Nyingine(fafanua) _____

32. Mapato yako ya wastani kila mwezi ni ngapi? (KES)

UZOEFU WA WAGONJWA

Vipengele vya mfumo wa afya

33. Umekuwa kwa matibabu ya ugonjwa wa kifua kikuu kwa miezi mingapi? (enter number of months) _____

34. (i) Umeenda hospitali ngapi tangu ugunduliwe na ugonjwa wa kifua kikuu? _____

(ii) Mbona umeenda hospitali tofauti kutafuta matibabu?

- | | |
|--|--|
| <input type="radio"/> Tabia mbaya ya wafanyikazi | <input type="radio"/> Ukosefu wa dawa |
| <input type="radio"/> Umbali wa kituo | <input type="radio"/> Ukosefu wa maabara |
| <input type="radio"/> Kuhama | <input type="radio"/> Sababu nyingine(fafanua) |

35. (i) Umewahi kosa kwenda kwa kliniki siku ambayo uliagizwa?

- Ndio
- La

(ii) Nini ilifanya ukose kwenda kliniki siku ambayo uliagizwa

- | | |
|--|--|
| <input type="radio"/> Hospitali iko mbali sana | <input type="radio"/> Nilikua mnyonge sana sikuweza kusafiri |
| <input type="radio"/> Nilikosa nauli | <input type="radio"/> Sababu nyingine (eleza) |
| <input type="radio"/> Nilibadilisha makao | |

36. Ulienda kliniki ya kifua kikuu mara ngapi kwa siku 30 zilizopita kukutana na mhadumu wa afya (weka namba) _____

37. Je, inachukua mda gani kusafiri hadi hospitali

- | | |
|------------------------------------|--|
| <input type="radio"/> Dakika 1-30 | <input type="radio"/> Saa 1 hadi masaa 2 |
| <input type="radio"/> Dakika 31-59 | <input type="radio"/> Zaidi ya masaa 2 |

38. Huwa inachukua mda gani ukiwa kwenye foleni kabla uweze kumuona mhadumu wa afya?

- | | |
|------------------------------------|--|
| <input type="radio"/> Dakika 1-30 | <input type="radio"/> Saa 1 hadi 2 |
| <input type="radio"/> Dakika 31-59 | <input type="radio"/> Zaidi ya masaa 2 |

39. Kwa wastani, unatumia pesa ngapi wakati unasafiri ukienda kwenye kliniki ya kifua kikuu? (weka kiwango cha pesa KES) _____

40. Mbona unapendelea hii hospitali kwa matibabu yako ya kifua kikuu?

- Iko karibu na nyumba yangu/nyumbani kwangu
- Bei yake ni nafuu
- Wahudumu wa afya ni wazuri
- Ina dawa ambazo nahitaji kwa hali yangu ya afya
- Iko vifaa maalum vya kuhudumia wagonjwa wa kifua kikuu
- Sababu nyingine (fafanua) _____

41. Ningependa kuuliza uzoefu wako kuhusiana na jinsi wahudumu wa afya wanavyo kuhudumia kila unapotembelea hospitali kutafuta huduma ya afya. Tafadhali wape alama wahudumu wa afya kulingana na mtazamo wao katika kipimo cha moja hadi tano ambapo tano ni mbaya zaidi na moja ni nzuri Zaidi kwa vipengele vifuatavyo.

Uzoefu na wafanyikazi wa afya	Mbaya sana	Mbaya	Vizuri	Vizuri sana	Bora
(i). Wakati wa ziara zako za kliniki,ungekadiria vipi ukarimu na heshima ya wahudumu wa afya kwako	1	2	3	4	5
(ii). Wakati wa ziara zako za kliniki,ungekadiria vipi subira na kusikilizwa na wana afya	1	2	3	4	5
(iii). Wakati wa ziara zako za kliniki,ungekadiria vipi jinsi ambavyo wahudumu wa afya wanavyo kupea maeleza kwa jinsi ambayo unaelewa?	1	2	3	4	5
(iv). Ungekadiria vipi maelezo ambayo mhudumu wa afya alikupa kukusu matumizi ya dawa,kiwango cha dawa na athari za dawa kwa namna ambayo ungeelewa	1	2	3	4	5
(v). Wakati wa ziara zako za kliniki,ungekadiria vipi manufaa ya mazungumzo ambayo umehudhuria kati ya mhudumu wa afya na wagonjwa wengine wa kifua kikuu kwa ajili ya kusaidia kudhibiti huu ugonjwa	1	2	3	4	5

42. Ni changamoto zipi ambazo umepitia,ambazo zinahusiana na ugonjwa wako,tangu ugunduliwe na ugonjwa wa kifua kikuu?

Mzigo wa dawa/tembe

43. (i) Je, umepata athari zozote na dawa za kifua kikuu tangu uanze kizitumia?

Ndio

La

(ii). Je, ulishuhudia adhari hizi katika mwezi upi wa matibabu?

(iii). Je, ulikosa kumeza dawa kwa sababu ya hizi athari?

(iv). Je, ulikosa kumeza dawa kwa siku ngapi?

44. (i). Je, muhudumu wa afya amekupa usaidizi katika kudhibiti athari za dawa hizi?

Ndio

La

(ii). Je, ni vipi msaada ambao umepata kutoka kwa wahudumu wa afya umekuwa na ufanisi katika kidhibiti hizi athari za dawa?

Isiyofaa sana

Inayofaa

Isiyofaa

Inayofaa sana

Upande wowote

45. Kulingana na ujuzi wako na dawa za kifua kikuu, una lipi la kusema kulingana na ladha ya dawa hizi?

Kali sana

Haina ladha

Kali

Tamu

Tamu sana

46. Kulingana na ujuzi wako, unaweza kueleza aje ukubwa ya dawa ya kifua kikuu

Kubwa sana

Kubwa

Upande wowote

Ndogo sana

Ndogo.

47. Je, unajua ni lini unafaa kumaliza matibabu katika kliniki ya kifua kikuu?

Ndio

La

48. Wewe ungependelea haya matibabu yachukue mda upi

Chini ya mwezi
mmoja

Miezi 1 – 3

Miezi 3 – 6

Miezi 6 – 9

Zaidi ya miezi 9

Ujuzi wa kijamii na kiuchumi

23. Sasa ningependa kukuuliza maswali kuhisiana na jinsi uzoefu wa maisha yako ya kijamii yameathirika na ugonjwa wa kifua kikuu. Katika hiki kipindi, na kwa sababu ya ugonjwa wako, je ni mara ngapi.....

Uzoefu wa Maisha ya kijamii	Kamwe	Mara chache	Mara nyingi	Mara kwa mara	Kila mara
(i). Upungufu wa mahusiano yako ya kijamii na urafiki	5	4	3	2	1
(ii). Umepunguza kuhudhuria mikutano ya kirafiki kama kanisa, harusi, mikutano ya kifamilia	5	4	3	2	1
(iii). Umeshuhudia kuharibika kwa uhusiano kati yako na mchumba wako?	5	4	3	2	1
(iv). Umeshuhudia kudhulumiwa kutoka kwa majirani wako kwa mafano kudhalilishwa, matusi, dhuluma?	5	4	3	2	1
(v). Umekosa kujadili ugonjwa wako kwa uwazi na marafiki kwa sababu ya kutengwa?	5	4	3	2	1

UFANISI BINAFSI

24. Sasa naenda kukusomea baadhi ya sentensi. Kwa kila sentensi, ningepenga uelezee kiwango chako chako cha kukubaliana nayo katika kipimo cha moja hadi tano (1-5), ambapo moja = Nakubali sana, mbili = nakubali, tatu = Sikubali na sijakataa, nne = nakataa, tano = nakataa sana.

Je, unakubaliana vipi na semi hizi?					
Maarifa	Nakubaliana sana	Nakubaliana	Upande wowote	Kutokubaliana	Kutokubaliana kabisa
(i). Uvaaji wa barakoa miongoni mwa wagonjwa wa kifua kikuu unasaidia kuzuia maabukizi ya kifua kikuu	5	4	3	2	1
(ii). Kuwa na hewa safi kwa nyumba zetu inasaidia kupunguza kusambaa kwa kifua kikuu	5	4	3	2	1
(iii). Kufunika midomo yetu tunapo kohoa kunasaidia kupunguza maambukizi ya kifua kikuu	5	4	3	2	1
(iv). Kutema kikohozi peupe ni mojawapo ya njia zinazoeneza usambazaji wa ugonjwa wa kifua kikuu	5	4	3	2	1
(v). Kugunduliwa mapema na kupata matibabu mapema kunaweza saidia katika kudhibiti ugonjwa wa kifua kikuu	5	4	3	2	1
(vi). Kifua kikuu kina tiba	5	4	3	2	1
Ufanisi wa Pamoja					
(i). Nimepokea usaidizi wa kutosha kutoka kwa familia yangu kunisaidia kwenda kliniki wakati unaofaa na pia kunisaidia kumezaa dawa inavyofaa (kwa mfano kunikumbusha siku ya kliniki, kunipa nauli, kunizindikisha hospitalini)	5	4	3	2	1
(ii). Mtandao wangu wa kijamii (marafiki na jamaa wangu) wamenipa usaidizi wa kila mara wa chakula kwangu mimi na kwa familia yangu katika kipindi hiki cha ugonjwa wangu	5	4	3	2	1
(iii). Mtandao wangu wa kijamii (marafiki na jamaa wangu)	5	4	3	2	1

wamenipa ujumbe wa kunielimisha kuhusu maambukizi ya kifua kikuu wakati huu wa ugonjwa wangu					
(iv). Mtandao wangu wa kijamii (marafiki na jamaa yangu) wamenipa tumaini, wakuwa wenza, na wamefanya niwe na matumaini kwamba nitakuwa na afya njema	5	4	3	2	1
(iv). Mtandao wangu wa kijamii(marafiki na jamaa wangu)wamenisaidia kifedha na kuniwezesha kushughulikia afya yangu na majukumu yangu kwa familia yangu wakati huu wa ugonjwa wangu	5	4	3	2	1
Hisia na mawazo					
(i). Ninaweza kudhibiti makali ya msongamano wa mawazo ,kutengwa na mambo mengine ambayo yanaweza athiri matibabu yangu na Maisha yangu	5	4	3	2	1
(ii). Naweza kukubali kwamba nina kifua kikuu na niongee wazi wazi na watu juu yake	5	4	3	2	1
(iii). Naweza kuwa na mtazamo mzuri na imani kwamba ugonjwa wangu utapona	5	4	3	2	1
(iv). Naweza kuwajibikia afya yangu ili kuzuia kuambukiza wengine na kifua kikuu	5	4	3	2	1
(v). Naweza kuwajibika ili nizingatie kemeza dawa na kuenda hospitalini kila wakati nikihitajika	5	4	3	2	1
Utendakazi					
(i). Kazi yangu ya kujikimu kimaisha haijaathirika tangu ningunduliwe na ugonjwa wa kifua kikuu	5	4	3	2	1
(ii). Ninaweza kuhudhuria hafla ya jamaa na marafiki(kwa mfano kanisa,harusi,mikutano ya familia) tangu nigunduliwe na ugonjwa wa kifua kikuu	5	4	3	2	1
(iii). Kujijali(usafi wa kibinafsi,urembo) kwangu	5	4	3	2	1

haujaathirika tangu nigunduliwe na ugonjwa huu wa kifua kikuu					
---	--	--	--	--	--

UBORA WA MAISHA

25. Unakubaliana vipi na kauli zifuatazo?					
Kimwili	Nakubaliana sana	Nakubali	Upande wowote	Kutokubaliana	Kutokubaliana kabisa
(i). Huwa ninahisi uchungu unaohisishwa na ugonjwa wa kifua kikuu	5	4	3	2	1
(ii). Huwa ninahisi kuchoka au kukosa nguvu kwa sababu ya ugonjwa wa kifua kikuu	5	4	3	2	1
(iii). Huwa ninahisi kama siwezi kutembea sana kwa sababu ya ugonjwa wa kifua kikuu	5	4	3	2	1
(iv). Huwa ninahisi kwamba kwa sababu ya ugonjwa wa kifua kikuu, muda ambao ninatumia kufanya kazi za nyumba umepungua	5	4	3	2	1
(v). Ninahisi kwamba muda unaotumika kazini umepungua kwa sababu ya ugonjwa wa kifua kikuu	5	4	3	2	1
(vi). Kuonekana kwa mwili wangu umebadilika kwa sababu ya ugonjwa wa kifua kikuu	5	4	3	2	1
Kijamii na kiuchumi					
(i). Mtandao wangu wa marafiki umepungua tangu kugunduliwa kwa ugonjwa wa kifua kikuu	5	4	3	2	1
(ii). Mapato yangu yanayotoka kwa kazi yangu yamepungua tangu kugunduliwa kwa ugonjwa wa kifua kikuu	5	4	3	2	1
(iii). Uwezo wangu wa kushiriki katika matukio ya kijamii umepungua tangu	5	4	3	2	1

kugunduliwa kwa ugonjwa wa kifua kikuu					
(iv). Tija yangu kazini imepungua tangu kugunduliwa kwa ugonjwa wa kifua kikuu	5	4	3	2	1
Saikologia					
(i). Huwa nina wasiwasi kuhusu kukosa kutimiza majukumu yangu ya kujikimu kimaisha kutokana na ugonjwa wangu	5	4	3	2	1
(ii). Huwa nina wasiwasi kuhusu kudhulumiwa au kubaguliwa na watu kwa sababu ya ugonjwa wangu	5	4	3	2	1
(iii). Huwa nina wasiwasi kuhusu kupoteza mtandao wa marafiki wangu kwa sababu ya ugonjwa wangu	5	4	3	2	1
(iv). Huwa nina wasiwasi kuhusu mimi kuwa mzigo kwa jamaa na marafiki wangu kwa sababu ya ugonjwa wangu	5	4	3	2	1
Maisha ya Kiroho					
Je, wewe ni mmoja wa kikundi chochote cha kiroho kama vile kanisa,msikiti?			Ndio	La	
Je, unapata msaada wowote wa kutoka kwa kikundi chako cha kiroho kama vile mahimizo, maombi ama msaada mwingine wowote?			Ndio	La	Wakati mwingine
Unakubaliana vipi na semi hizi kwa maisha yako ya kiroho?					
(i). Ninahisi kuwa mtu katika jumuiya yangu ya kidini	5	4	3	2	1
(ii). Ninahisi hali ya matumaini kupitia mafundisho ya dini na sala	5	4	3	2	1
(iii). Ninafurahia ushirika wangu na wakristo, waislamu wenzangu	5	4	3	2	1
(iv). Ninapata faraja na amani ya akili kupitia ushauri wa kiroho	5	4	3	2	1
(v). Jumuiya za kidini zinapatikana kila mara ninapohitaji msaada	5	4	3	2	1

6.11 Appendix 7: key informant guide – county tb coordinator

A STUDY ON LIVED EXPERINCES SELF-EFFICACY AND QUALITY OF LIFE AMONG TB PATIENTS IN NAIROBI COUNTY

RESPONDENT'S DESIGNATION	
DATE OF INTERVIEW	

Thank you for agreeing to participate in this survey. This interview is part of a survey titled: Assessment of patient's experiences, self-efficacy, and quality of life of TB patients in Nairobi County, Kenya. My name is Joan Ondiro and this is part of the requirements for the fulfillment of the award of a Masters degree in Epidemiology and biostatistics by Jaramogi Oginga Odinga University of Science and Technology. I will be asking you some questions about the journey of TB patients who are on treatment.

Your opinions and experiences will help us improve the services we provide. This interview will take about 30 to 45 minutes. I would like you to answer the questions as best as you can. There is no right or wrong answer nor will they be linked to your name. If there are any questions that you are uncomfortable answering, we can skip to the next question or stop the interview.

1. How many government facilities have TB clinics in Nairobi County?
 - Would you know the current TB prevalence rate in Nairobi County?
 - Are there specific groups who are more vulnerable? E.g. men, women, children? Why?
2. How would you describe the current coverage of TB clinics especially in the informal settlement?
 - What plans are in place to improve coverage of TB services, especially within the informal settlement?

3. How has the government supported constant TB supply/equipment in these facilities?
 - How rampant are cases of supply stockouts within our facilities? (all commodities s.a lab reagents, registers, drugs)
4. Do all the TB clinics in the county have a TB nurse/clinician?
 - Are these personnel sufficient in their respective facility to serve TB patient volumes enrolled in those facilities?
 - How frequently does the government organize staff training on new guidelines or other TB-related pieces of training?
5. Do we have a specific funds allocation from the government exchequer or county government to support TB services in the county?
 - How much is this allocation per fiscal year?
 - How sufficient is it for all the TB clinics in the county?
 - How do you meet this budgetary insufficiency relating to TB treatment & management?
6. What kind of government interventions are currently being implemented to minimize the spread of TB and support TB patients within the county with their treatment?
7. What mechanisms has the county put in place to support TB management among street family/ drug users?
8. How effective are the current policies, regulations, and strategies in addressing TB management in the county?
 - Are there any policy gap you think needs to be addressed? Which ones?
9. What challenges do you experience with TB management in this county?
10. What recommendation would you give for the improvement of TB treatment outcomes in this county?

6.12 Appendix 8: key informant guide – TB nurse/ clinician

ASSESSMENT OF EXPERINCES, SELF-EFFICACY, AND QUALITY OF LIFE AMONG TB PATIENTS IN NAIROBI COUNTY

SUB-COUNTY NAME	
ZONE NAME	
FACILITY NAME	
RESPONDENT'S DESIGNATION	
DATE OF INTERVIEW	

Thank you for agreeing to participate in this survey. This interview is part of a survey titled: Assessment of patient's experiences, self-efficacy, and quality of life of TB patients in Nairobi County, Kenya. My name is Joan Ondiro and this is part of the requirements for the fulfillment of the award of a Masters degree in Epidemiology and biostatistics by Jaramogi Oginga Odinga University of Science and Technology. I will be asking you some questions about the journey of TB patients who are on treatment.

Your opinions and experiences will help us improve the services we provide. This interview will take about 30 to 45 minutes. I would like you to answer the questions as best as you can. There is no right or wrong answer neither will they be linked to your name. If there are any questions that you are uncomfortable answering, we can skip to the next question or stop the interview.

EXPERIENCES

1. Averagely how many TB patients are currently enrolled in this facility?
 - Kindly disaggregate by sex.
2. Based on your interaction with the TB patients at this facility, what is their general behavior towards health-seeking services in this facility?
 - Do they promptly heed their clinical appointments?
 - Follow medication as recommended?
 - What hinders their health-seeking behaviors?
3. What would be the reasons behind some TB patients defaulting on their clinical appointments as recommended?
 - How is the default rate in this facility like in this facility? (high/low)
4. What are some of the complaints/concerns you've heard from patients about the TB drugs they take?
 - Duration of medication
 - Pill taste & size
 - Side effects
5. Based on your interaction with the TB clients, how has their illness changed their socio-economic life?
 - Loss of friends, livelihoods
 - Depression/ stress/ worries
 - Change of body appearance/ QOL

FACILITY

6. How well is this facility stocked with the right equipment, tests, and drugs required by all your TB patients at all times?

- Are the drugs sufficient and supplies timely replenished
 - Are all tests conducted within the facility and equipment available for such?
7. How many TB clinicians/nurses are currently deployed in this facility? Based on your clients' volumes, do you feel that this is an optimal number to handle cases reported?
- How is service delivery affected by the low number of staff handling TB patients?
8. When was the last time you attended a TB-related training?
- How frequently do you or your colleagues attend such training?
 - How relevant are these trainings to your work?
9. What support do you or this facility require to enhance TB service delivery to patients seeking such services here?

SE & QOL

10. During your interaction with these TB patients, would you tell if they are affected emotionally (angry, depressed, or stressed)?
- How do they normally react to these negative emotions?
11. What would be your comment on the effect of TB illness on a patient's social life?
- Are they discriminated against?
 - Do their social network and events change?
 - Do their occupation change?
12. During your interaction with these TB patients, would you tell if their physical body or look is affected (emaciated, fatigued)?
- How do they normally react to these bodily changes?

6.13 Appendix 9: key informant guide – community health assistant

ASSESSMENT OF LIVED EXPERIENCES SELF-EFFICACY AND QUALITY OF LIFE AMONG TB PATIENTS IN NAIROBI COUNTY, KENYA

SUB-COUNTY NAME	
FACILITY NAME	
RESPONDENT'S DESIGNATION	
DATE OF INTERVIEW	

Thank you for agreeing to participate in this survey. This interview is part of a survey titled: Assessment of patient's experiences, self-efficacy, and quality of life of TB Patients in Nairobi County, Kenya. My name is Joan Ondiro and this is part of the requirements for the fulfillment of the award of a Masters degree in Epidemiology and biostatistics by Jaramogi Oginga Odinga University of Science and Technology. I will be asking you some questions about the journey of TB patients who are on treatment.

Your opinions and experiences will help us improve the services we provide. This interview will take about 30 to 45 minutes. I would like you to answer the questions as best as you can. There is no right or wrong answer nor will they be linked to your name. If there are any questions that you are uncomfortable answering, we can skip to the next question or stop the interview.

1. What's the role of CHA in supporting TB patients in this facility/ locality?
 - How many CHVs do you currently work within this locality?
 - Averagely how many TB patients do you support currently?
2. Based on your observation, what is the general behavior of TB patients towards health-seeking services in this facility?
 - Do they promptly heed their clinical appointments?
 - Follow medication as recommended?
3. What would be the reasons for some TB patients defaulting on their clinical appointments and subsequently prompting your follow-up?
 - What is the default rate in this facility like? (high/low)
4. What are some of the complaints/ challenges that you have heard from TB patients seeking medication in this facility
 - Health facility-related challenges
 - Home/personal related challenges
5. In your capacity as a CHA in this area, what kind of facilitation/ support would you require to enhance your work in supporting TB patients in this facility/ locality?
6. During your interaction with these TB patients, would you tell if they are affected emotionally (angry, depressed, or stressed)? How do they normally react to these negative emotions?
7. During your interaction with these TB patients, would you tell if their physical body or look is affected (emaciated, fatigued)? How do they normally react to these bodily changes?
8. What recommendations would you make to help improve the outcomes of TB treatment among patients?

6.14 Appendix 10: patients focus group discussion guide

ASSESSMENT OF LIVED EXPERINCES, SELF-EFFICACY, AND QUALITY OF LIFE AMONG TB PATIENTS IN NAIROBI COUNTY

SUB-COUNTY NAME	
FACILITY NAME	
NAME OF GROUP INTERVIEWED	
DATE OF INTERVIEW	

Thank you for agreeing to participate in this survey. This interview is part of a survey titled: Assessment of patient's experiences, self-efficacy, and quality of life of TB Patients in Nairobi County, Kenya. My name is Joan Ondiro and this is part of the requirements for the fulfillment of the award of a Masters degree in Epidemiology and biostatistics by Jaramogi Oginga Odinga University of Science and Technology. I will be asking you some questions about your journey with TB treatment.

Your opinions and experiences will help us improve the services we provide. This interview will take about 30 to 45 minutes. I would like you to answer the questions as best as you can. There is no right or wrong answer. Your answers will not be linked to your name and will not affect the type of treatment or care you receive. If there are any questions that you are uncomfortable answering, we can skip to the next question or stop the interview.

EXPERIENCES

1. What has been your experience with healthcare workers in this hospital since you were diagnosed with TB?
 - How do they treat you with courtesy, listen to you and provide you with satisfactory feedback/ information?
 - Attend to you promptly during clinic visits, assist with managing drug side effects,
2. What has been your experience with the TB medicine you take?
 - How bitter, big, and how has the frequency/duration of taking them been like?
3. How has your experience been whenever your treatment require tests or drug in this facility?
 - Are the drugs/test always available? Cost?
4. How has your relationship with your social friends been/changed since your diagnosis with TB?
 - Do you still spend your leisure time or attend social gatherings together (i.e go for chamaas, watch favorite sports, attend a family gathering, church, etc.)
 - Do you experience any unfair treatment from your friends/ family due to your illness condition? What kind of unfair treatment are these?

SELF-EFFICACY

5. What level of support have you received from family and friends in relation to your treatment?
 - Do they remind you of your clinic days, offer transport, and/or accompany you to the facility, etc.)
 - Do they offer hope, companionship, or reassurance towards healing?
6. How has your ailment affected your emotion on anger, depression or stress?
 - How do you cope with such negative emotion during this time?

7. How has your ailment affected your usual daily activities/ chores or occupation?
- How do you cope with changes in your daily activities as a result of your ailment?

QUALITY OF LIFE

8. How has your ailment affected your physical body or ability to perform some tasks?
- Do you experience physical/body pains, fatigue? What kind?
- Has your medication left some scars on your body, or emaciation? Expound.
9. How has your ailment affected your productivity at your workplace?
- Do you have to spend less time than usual? Or seek for time off to attend to your medication?
10. How has your ailment affected your psychological life? What are you constantly worried about in life as a result of your ailment?

i.e missing, social events, occupation, being burdensome to friends/family or losing your social networks.
11. How has your ailment changed your spiritual life? Do you frequent church/ mosque or any holy place you consider receiving spiritual nourishment from? Associate more with spiritual people or feel closer connected to God?
12. In general, what are some of the challenges you've experienced as a patient since your diagnosis with TB?

***** END *****

Thank you very much for your time and valuable response. This is the end of our interview please feel free to ask me any questions that you would like to know about this study.

6.15 Appendix 11: majadiliano ya kikundi yenye umakini

TATHMINI YA WAGONJWA UFANISI BINAFSI NA UBORA WA MAISHA WA WAGONJWA WANAOUUGUA KIFUA KIKUU KATIKA KAUNTI YA NAIROBI

JINA LA KAUNTI NDOGO	
JINA LA HOSIPITALI	
JINA LA KIKUNDI	
TAREHE YA MAHOJIANO	

Asante kwa kukubali kushiriki katika utafiti huu. Mahojiano haya ni sehemu ya utafiti wenye kichwa “Tathmini ya wagonjwa ufanisi binafsi na ubora wa maisha wa wagonjwa wanaouguua kifua kikuu katika kaunti ya Nairobi”. Ni sehemu ya mahitaji ya kutimiza kwa tuzo ya shahada ya uzamili kwa Epidemiolojia na Takwimu za kibayolojia katika chuo kikuu cha Jaramogi Oginga Odinga cha Sayansi na Teknolojia.

Maoni yako na uzoefu wako utatusaidia kuboresha huduma ambazo tunapeana. Mahojiano haya yatachukua mda wa dakika 30 hadi 45. Ningependa ujibu maswali haya kadri uwezavyo. Hakuna jibu sahihi au baya. Majibu yako hayataonyesha jina lako na hayataathiri huduma ambayo unapokea. Kama kuna maswali ambayo unahisi hauwezi yajibu, uko huru kuyapita ama pia kusitisha haya mahojiano.

Kabla ya kuanza, tafadhali nifahamishe kama uko na swali lolote. Kama hakuna, tunaanza anza mahojiano.

UZOEFU

1. Uzoefu wako umekuaje na wahudumu wa afya katika hospitali hii tangu ugunduliwe na ugonjwa wa kifua kuu?
 - Heshima yao iko vipi? Wanakusikiza vipi, na wanakupa majibu au habari ya kuridhisha
 - Unahudumiwa kwa wakati unapoenda kwenye kliniki, wanakusaidia vipi kudhibiti madhara ya madawa?
2. Uzoefu wako umekuaje na madawa unazo meza?
 - Ukali wao, ukubwa na muda wa kuzimeza umekuwa vipi?
3. Uzoefu wako umekua vipi wakati unahitajika kufanya vipimo ama unahitaji dawa kwa hii hospitali?
 - Je, dawa na vipimo huwa zinapatikana? Bei?
4. Uhusiano wako na marafiki wa kijamii umekuwa aje ama umebadilika vipi tangu ugunduliwe na ugonjwa wa kifua kuu?
 - Bado unatumia wakati wako wa burudani au unahudhuria mikusanyiko ya kijamii (kwa mfano chama, kutazama michezo unayoipenda, kuhudhuria mukutano wa familia, kanisa na kadhalika)?
 - Je unapata utanzi wowote usio wa haki kutoka kwa marafiki au familia kwa ajili ya hali yako? Je utanzi huu ni wa aina gani?

UFANISI BINAFSI

1. Umepata kiwango kipi cha msaada kutoka kwa familia na marafiki inayoambatana na matibabu yako?
 - Je, wanakukumbusha siku yako ya kliniki, wanakupa nauli ama wanaandamana na wewe kwenda kwa kliniki na kadhalika?
 - Je wanakupa matumaini, wenzi na uhakikisho kuelekea kwa uponyaji wako?
2. Ni vipi ugonjwa huu umekuathiri na hasira, huzuni ama mkazo?
 - Unakubaliana aje na hisia hasi wakati huu?

3. Ni vipi ugonjwa huu umeathiri kazi zako za kila siku
 - Ni vipi unakabiliana na mabadiliko katika kazi yako ya kila siku kama matokeo ya ugonjwa wako?

UBORA WA MAISHA

4. Je,ugonjwa huu umeathiri mwili wako wa kimwili au uwezo wa kufanya majukumu mengine
 - Je,unapata maumivu ya mwili,kuchoka?Wa aina gani?
 - Ugonjwa huu umeacha makovu yoyote mwilini mwako au unyogovu
5. Ni vipi ugonjwa huu umeathiri tija yako kazini kwako
 - ?Je unatumia muda kidogo kuzidi wa kawaida?Ama unaomba muda wa ziada kuenda matibabu?
6. Ni vipi ugonjwa huu umeathiri maisha yako kisaikolojia?Ni lipi daima una wasiwasi nalo maishani mwako kwa sababu ya ugonjwa wako?(kama vile kukosa matukio ya kijamii,kazi,kuwa mzigo kwa jamii na marafiki ama kupoteza mtandao wa kijamii)
7. Ni vipi ugonjwa huu umebadili maisha yako ya kiroho?Je unaenda kanisa/msikiti ama mahali pako pa kuabudu mara kwa mara?Je unashirikiana zaidi na watu waliokomaa kiroho ama kuhisi ukiwa karibu sana na Mungu?
8. Kwa ujumla, ni changamoto zipu umekumbana nazo kama ngonjwa wa kikua kikuu tangu kugunduliwa kwa huu ugonjwa

***** **MWISHO*******

Asante sana kwa muda wako na majibu yako.Huu ndio mwisho wa mahojiano yetu.Unaeza kuniulliza swali lolote ambalo uko kuhusiana na utafiti huu kama unalo.

6.16 Appendix 12: consent form

SUB-COUNTY NAME	
FACILITY NAME	
UNIQUE ID NO.	
DATE OF INTERVIEW	

My name is Joan Ondiro, a student at Jaramogi Oginga Odinga University of Science and Technology studying for an MSc. In Epidemiology and Biostatistics. I invite you to carefully read this document (or understand its contents as read by a literate witness) before accepting to participate in this study.

This study has been cleared by the Board of Postgraduate Studies and the Ethical Review Committee of Jaramogi Oginga Odinga University of Science and Technology No and National Commission for Science, Technology, and Innovation No

PURPOSE OF STUDY

This study seeks to find out the experiences of TB patients, their level of self-efficacy, and their quality of life while on treatment in Nairobi County. Your facility is one of the facilities selected to participate in this study

INCLUSION/EXCLUSION CRITERIA

All pulmonary TB patients in the continuation phase of treatment will be included in the study. Patients in the initiation phase of treatment, those with multidrug-resistant TB, extra drug-resistant TB, extrapulmonary TB, those who do not consent as well as those who are mentally unstable will be excluded from the study

STUDY PROCEDURES

If you agree to participate in this study, first you will sign this form, then, I will ask you questions regarding your experience while on treatment for TB. I will also ask you questions that will help assess your level of self-efficacy and quality of life while on treatment for TB. I expect the interview to take about 30-45 minutes.

POTENTIAL RISKS

By participating in this research, you are not likely to experience any discomfort. We will try to decrease the chances of any uncomfortable events. You may decline to answer any or all questions and you may terminate your involvement at any time if you choose.

BENEFITS

If you participate in this research, you will not get any personal benefits or incentives. However, we hope that the information obtained from this study will help the government in formulating patient-centered policies and will help improve TB treatment outcomes.

CONFIDENTIALITY

The facts, information, and data that we will collect in this study will be kept private to the extent allowed by law. The information we collect will be stored in locked cabinets that will be accessed only by the principal investigator, and password-protected computers. Only our research team will have access to this information. Your name will not be used on any of the study reports or study samples.

YOUR RIGHTS TO PARTICIPATE, SAY NO, OR WITHDRAW

Your participation in this interview is entirely voluntary. You are not under any obligation to participate, and you have the right to refuse this invitation. If at any time during the interviews, you decide that you will not participate further, you are free to withdraw immediately, with no further discussion. This will have no adverse consequences for you.

COSTS AND COMPENSATION FOR BEING IN THE STUDY:

There are no costs to participate in this study.

CONTACT INFORMATION

If you have any questions from the interview, you can contact **Joan Ondiro, the principal investigator of this study** by phone number **0736 679 453** or send an email to **joanondiro@gmail.com**. If you want to talk about the study with someone who is not part of this research project or your rights regarding participation in this study, please contact **The Board of**

**Postgraduate studies or the Ethical Review Committee of Jaramogi Oginga Odinga
University of Science and Technology**

CONSENT

I have read and understand the provided information and have had the opportunity to ask questions. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason and without cost. I understand that I will be given a copy of this consent form. I voluntarily agree to take part in this study.

Participant's signature _____ Date _____

Investigator's signature _____ Date _____

6.17 Appendix 13: fomu ya kibali cha habari

Jina la kata Ndogo	
Jina la hospitali	
Kitambulisho cha kipekee	
Tarehe ya mahojiano	

Jina langu ni Joan Ondiro, mwanafunzi wa shahada ya uzamili kwa Epidemiolojia na Takwimu za Kibayolojia katika chuo kikuu cha Jaramogi Oginga Odinga cha Sayansi na Teknolojia. Nakualika usome waraka huu kwa makini kabla ya kukubali kushiriki katika mahojiano haya (ama uelewe maelezo yaliyomo jinsi utakovyosomewa na shahidi mtafsiri). Utafiti huu umeidhinishwa na kamati ya bodi ya masomo ya baada ya kuhitimu na kamati ya kupitia maadili katika chuo kikuu cha Jaramogi Oginga Odinga cha Sayansi na Teknolojia Pamoja na tume ya kitaifa ya sayansi, teknolojia na ubunifu.

KUSUDI LA UTAFITI

Utafiti huu unasaka uzoefu wa wagonjwa wa kifua kikuu, ufanisi binafsi na ubora wa maisha wa wagonjwa wa kifua kikuu walio kwenye matibabu katika kauli ya Nairobi.

Hospitali yako ni mojawapo ya hospitali ambazo zimechaguliwa kishiriki katika utafiti huu.

VIGEZO VYA UJUMUISHAJI/VIGEZO VYA KUTENGWA.

Wagonjwa wote wanaouguza kifua kikuu cha mapafu walio kwenye awamu ya muendeleo watashirikishwa katika utafiti huu. Wagonjwa walio kwenye awamu ya kufudhwa, wagonjwa walio na TB sugu dawa, ziada ya mapafu, watia sahihi ya kuhojiwa, na walio na upungufu wa kiakili hawatahusishwa katika mahojiano haya

TARATIBU ZA UTAFITI

Ukikubali kushiriki katika utafiti huu, kwanza utaweka sahihi katika fomu hii, baadaye nitakuuliza maswali kuhusiana na uzoefu wako katika matibabu ya ugonjwa wa kifua kikuu. Pia nitakuuliza maswali ambayo yatasaidia kutathmini kiwango ufanisi binafsi na ubora wa maisha wakati unapokea matibabu ya kifua kikuu.

Natarajia mahojiano haya kuchukua dakika 30-45.

HATARI ZINAZOWEZEKANA

Kwa kushiriki katika huu utafiti, hukuna uwezekano wa kupata madhara yoyote ama usumbufu wowote. Tutajaribu kupunguza nafasi ya matukio yasiopendeza. Unaweza kukataa kujibu maswali mengine ama yote na pia unaweza sitisha mahojiano haya wakati wowote utakaochagua

FAIDA

Ukishiriki katika utafiti huu, hautapata motisha ama faida zozote za kibinafsi

Hata hivyo, tunatumai kwamba habari zitakazotokana na utafiti huu zitasaidia serikali kutengeneza sera ambazo zitaweka mgonjwa katikati na zitasaidia kuboresha matokeo ya matibabu.

USIRI

Ukweli, habari na takwimu ambazo tutakazo kusanya zitawekwa kwa siri kwa kiwango ambacho kinakubaliwa na sheria. Habari ambazo tutakusanya zitawekwa kwenye kabati itakayofikiwa tu na kiongozi wa utafiti. Wanakikundi cha utafiti pekee ndio wataweza kupata jumbe hizi. Tarakalishi ambayo itatumika italindwa na nenosiri. Jina lako halitatumika katika ripoti zetu.

HAKI YA KUSHIRIKI, KUSEMA LA NA KUJIONDOA

Kushiriki kwako katika mahojiano haya ni kwa hiari. Haujashurutishwa kushiriki na una haki ya kukataa huu mualiko. Wakati wowote katika haya mahojiano ukuhisi kwamba hautashiriki zaidi, uko huru kujiondoa mara moja bila majadiliano Zaidi. Hii haitakuwa na madhara yoyote kwako.

GHARAMA NA FIDIA YA KUSHIRIKI KWA UTAFITI

Hakuna gharama ya kushiriki katika mahojiano haya

MAWASILIANO

Kama una swali,unaweza wasiliana na Joan Ondiro, kiongozi wa utafiti kwenye nambari ya simu **0736 679 453 ama utume barua pepe kwa joanondiro@gmail.com**

Kama ungependa kuongea na mtu mwingine ambaye hayuko mmjua wa kundi la watafiti,ama haki yako ya kushiriki katika utafiti huu,tafadhali wasiliana na bodi ya masomo ya baada ya kuhitimu ama kamati ya kupitia maadili katika chuo kikuu cha Jaramogi Oginga Odinga cha Sayansi na Teknolojia

KIBALI

Nimesoma na nimeelewa maelezo yaliyopeanwa na nimepata nafasi ya kuuliza maswali.. time,Naelewa kwamba kushiriki kwangu ni kwa hiari na kwamba niko huru kujiondoa wakati wowote bila kupeana sababu na bila gharama. Naelewa kwamba nitapwewa nakala ya kibali hiki hii.Nakubali kushiriki kwa mahojiano haya kwa hiari.

Sahihi ya mshiriki _____ Tarehe_____

Sahihi ya mtafiti _____ Tarehe _____