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Poopedi, Machuene Ananias

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EVALUATION OF HEALTH REFERRAL UPTAKE AND LINKAGE TO HEALTH CARE AFTER COMMUNITY-BASED DISEASE SCREENING IN URBAN INFORMAL SETTLEMENT, SOUTH AFRICA

Machuene Ananias Poopedi

Student No: 0601257p

A research report submitted to the School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Masters of Science in Epidemiology

October 2019

DECLARATION

I Machuene Ananias Poopedi declare that this dissertation is my own, unaided work. It is being submitted for the research report of Master of Science at the University of the Witwatersrand, Johannesburg. It has not been submitted for any degree or examination at any other University.

_____07_____day of _October____2019__in Parktown, Johannesburg_____



…….

DEDICATION

In Loving Memory of my Mother
Chuene Abrina Poopedi (nee Tsiri)
1945 – 2016
Your departure from this earth was unexpected, sudden and painful. RIP Mme-Sekiele I will love you till the end.

ACKNOWLEDGMENTS

-Supervisor (**Dr Jabulani Ncayiyana**) and Co-Supervisor (D**r Ntombizodwa Ndlovu**), thanks for providing me with the inside knowledge of epidemiology and public health. It was a bit of a challenge to serve many masters while studying for this degree and for that I would like to thank you for your patience.

-My father **Petrus Poopedi** and my siblings (**Ezekiel, Gideon, Salome, Petunia, and Selina**), thank you for your support and encourage throughout my years of studying.

-Buti Mapadi Mafisa, Rangwane Lazy, and **Buti Washington Maupye** – a million thanks for your support, this journey started in 1994 and it is still continuing…

-My friends **Drs Longologo and Muteba** and **Mr Steve Blam**, we studied together, and our friendship just blossomed. You were God's gift to me. May Almighty God continue to bless you in abundance.

-My Wife **Dr Kgomotso W Lebogo**, thanks for your tolerance and always wanting what is best for me.

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DEFINITIONS

Community health worker – "is a member of the community in which she/he works and who serves and response to the health needs of the community"[1].

Spatial access – Access to healthcare which is terrain related, referring to distance, rivers, forest, and mountains which separate health facilities and the population in need of healthcare services.

Health referral in the healthcare system – "The practice of sending a patient to another program or practitioner for services or advice, which the referring source is not prepared or able to provide" [2].

Health referral uptake - Percentage of participants who were referred that completed the referral process.

Millennium Development Goals – "United Nations (UN) goals signed by the 191 UN member states in September 2000 termed the United Nations Millennium Declaration which commits to combat poverty, hunger, disease, illiteracy, environmental degradation and discrimination against women by 2015 "[3].

Non-spatial access - Access to healthcare which is related to demographic, socio-economic and organizational factors which include sex, age, education, income, religion and other related factors.

Linkage to healthcare - an essential step in engaging patients into healthcare by putting them on treatment.

LIST OF ABBREVIATIONS

ADA	American diabetes association
aHR	Adjusted hazard ratio
ANC	Antenatal care
ART	Anti-retroviral therapy
BMI	Body mass index
CVD	Cardiovascular disease
CHWs	Community health workers
DBP	Diastolic blood pressure
HA	Hazard Ratios
HBCT	Home based care test
HIV	Human immunodeficiency virus
HREC	Human research ethics committee
LMICs	Low and middle income countries
mmHg	Millimeter mercury
MTSD	Median time of stay in Diepsloot
KZN	KwaZulu Natal
NCDs	Non-communicable diseases
NGO	Non-governmental organization
NHLS	National health laboratory services
PHC	Primary healthcare
PPD	Purified protein derivative
SA	South Africa
SD	Standard deviation
SES	Socio-economic status
SBP	Systolic blood pressure
SSA	Sub-Saharan Africa
STI	Sexually transmitted infections
TB	Tuberculosis
TST	Tuberculin skin test
US	United States
VCT	Voluntary counseling and treatment

WC	Western Cape
WHA	World Health Assembly
WHO	World Health Organization

OVERVIEW OF THE RESEARCH REPORT

Introduction: The present research report paints a picture of a household survey of disease screening in an informal settlement of Diepsloot in Johannesburg, South Africa. Like any other informal settlement or slum in developing and low and middle-income countries (LMICs), the studied population was exposed to various undiagnosed disease conditions due to a lack of access to healthcare services.

Study aim: To assess healthcare referral uptake and linkage to healthcare and factors associated with health referral uptake and linkage to healthcare in an informal settlement in Johannesburg.

Methods: The baseline study consisted of primary data that was collected from 2000 households and the present study was a prospective cohort of 429 randomly selected participants from the baseline study suspected to have diseases. Data on demographic, mobility, physical activity, mental health, health-seeking behavior, food security and children's health, women and men's health was collected. Participants suspected of having disease were given health referral letters to visit the nearest health clinic for medical attention. The participants were further called after 14 days has elapsed to check if they visited the healthcare facility, with an overlap in time for those not found at the required time.

Manuscript statistical analysis: Median and interquartile ranges were calculated for continuous variables, frequencies and percentages were calculated for categorical variables. The relationship of health referral uptake, linkage to care and their predictors (socio-demographic status and disease conditions) was assessed by univariate and multivariate Cox proportional hazards regression models. In all associations, statistical significance was considered when the p-value was < 0.05. The time taken for participants to visit the nearest healthcare center was assessed by Kaplan-Meier (KM) survival curve.

Results: Of the 429 participants, only 109 (25%) took the referral letter to the clinic and from 109 participants 77 (71%) were linked to care and 32 (29%) not linked to care. The 77 participants were linked to care within a period of approximately 3 months (median = 11.4 days, inter quartile range (IQR) (1 – 84 days). There were also 240 (56%) participants who failed to visit the clinic and stated health system problems 17 (7%), patient problems 213 (89%) and health worker problems 10(4%) as their barriers to access healthcare and 80 (19%) participants were not reached. The association of health referral uptake and linkage to care with socio-demographic factors and disease conditions were mixed (Hazards Ratio (HA) < 1 or HA > 1), with no statistical significant ($p > 0.05$).

Conclusion: Overall, there was a low uptake of healthcare services (31%) and linkage to healthcare (20%) in Diepsloot. The majority of the participants were lost to follow up with 80 (19%) of the participants not reached and other 240 (56%) participants were reached but failed to visit the healthcare center, hence studies with larger sample sizes are not only suggested but warranted.

CHAPTER 1 INTRODUCTION

This section gives a summary of the background and introduction to the reader.

Studies in low and middle-income countries (LIMCs) including sub-Saharan Africa (SSA) have estimated that millions of people die annually from chronic non-communicable diseases such as cardiovascular disease, hypertension and diabetes and while many more are dying from tuberculosis (TB) and HIV/AIDS (Human immunodeficiency virus/Acquired immunodeficiency syndrome). Evidence has indicated that the majority of these conditions are not screened at a community level by community healthcare workers (CHWs). The present study has reflected on the importance of disease screening in an urban informal settlement by evaluating the health referral uptake and linkage to healthcare after community-based disease screening. Disease screening is used as a way of bringing healthcare service delivery to marginalized communities because of the emergence of quadruple burden of diseases i.e. high maternal and child health, growing burden of NCDs (Non-communicable diseases), HIV/AIDS and TB and high level of violence and injuries. Studies conducted in informal settlements, slums, and rural areas have reported that community members are at a disadvantage in terms of accessing healthcare. As a result, there is poor uptake of healthcare services and the failure of community members to healthcare linkage. This has often led to late disease presentations at healthcare facilities which may result in disease complications and high mortality.

Lack of resources in terms of healthwork force has prompted most governments in developing countries to introduce community healthcare workers (CHWs) so that people with suspected disease conditions can be screened at community level and those needing further treatment be given referral letters to visit the nearest healthcare facility. The limitation of CHWs in other developing countries has been a high attrition rate due to the search for better remuneration. Overall, health referral uptake and community linkage into healthcare has been reported to be affected by factors such as patient problems, health system problems, and health worker problems. In evaluating health referral uptake and linkage to healthcare, the present study has described disease conditions in terms of healthcare referral uptake and linkage to healthcare in the Diepsloot community. The study has further described barriers to healthcare and determined factors associated with healthcare referral uptake and its linkage to healthcare in the Diepsloot community.

1.1 Background

South Africa (SA) is in the league of developing countries challenged by quadruple burden of diseases which are a combination of life-style-related non-communicable diseases (NCDs), poverty-related infectious disease and violence-related trauma [4]. Developing countries have reported increased rates of NCDs namely, cardiovascular diseases (CVD), diabetes mellitus, and hypertension as part of the disease burden that result from a change in nutritional epidemiological transition [5]. Furthermore, reports have found NCDs to be the main cause of death worldwide and are placing the greatest burden on developing countries namely concerning to costs in medical treatment [6-8]. Unfortunately, the health departments in developing countries are constrained by a lack of formally trained health professionals, which hinders the effective screening and adequate management of those in need of healthcare. In general, the lack of essential skills in the health sector has affected the delivery of healthcare services [9].

Another factor is the HIV epidemic which has contributed to the burden of disease and is more evident in populations of developing countries where per capita incomes are under two Unites States (US) dollars a day [10-13]. Developing countries are unable to provide basic quality healthcare due to high HIV prevalence and the additional burden of scaling up antiretroviral therapy (ART) [14, 15], which in itself requires additional staff training and expertise. As HIV treatment is becoming available worldwide, ARTs have to find their way into developing countries' weak health systems, which is a challenge. This is because HIV/AIDS condition is no longer viewed nor perceived as deadly but as lifelong disease affecting millions of people that will need care and continuous adherence to treatment. In the majority of developing countries with high HIV prevalence in SSA, the major thorny issue in the provision of ART and managing compliance of chronic ART care is shortage of health personnel with proper skills [16], as a result of brain drain [17], among other reasons**.**

Due to a lack of health personnel in the health system, governments especially in developing countries have introduced the model of CHWs. In most settings, the CHWs are "individuals who live within the community they serve, understand the culture and speak the language of the people who live around them" [18]. As a way of delivering service to the communities, CHWs are reported to play a crucial role in multiple disease screening and health awareness so that community members with health problems are issued with health referral letters [19, 20]. Health referral letters are used to link patients to healthcare when given to health personnel at the health clinic to access healthcare. However, access to healthcare has been reported to be affected by health system problems, patient problems and health worker problems [21, 22].

South African health system like any of the developing countries has been faced with challenges associated with low referral uptake and low linkage to care. Common challenges encountered in other studies were long queues at the healthcare centers, financial challenges (lack of transport), lack of disease knowledge, poor relationship between healthcare center and patient, etc [23-31]. Studies in SA on referral uptake and linkage to care were reported in the province of KwaZulu Natal (KZN) and Western Cape (WC) [32-37]. More studies are warranted in other parts of SA on CHWs in showing the importance of bringing healthcare to the needy communities, through improvement of patient's referral uptake and linkage to healthcare.

1.2 Literature review

1.2.1 Access to healthcare in developing countries

Sub-Saharan African (SSA) countries are in a transition of change in lifestyle which is associated with increased communicable and non-communicable diseases [38-40]. Furthermore, SSA falls under the umbrella of low and middle-income countries (LMICs),

which are faced with many factors that are associated with poor healthcare access [41-43] and South Africa is not exempted [21]. One way of collating health information on specific disease conditions in countries is when governments and non-governmental organizations (NGOs) are conducting community screening of diseases [5, 44-46].

Researchers have categorized access to healthcare access into two distinct dimensions namely spatial and non-spatial. Spatial access is terrain-related which refers to distance, rivers, forest, and mountains which separate health facilities and the population in need of healthcare services. Non-spatial access refers to demographic, socio-economic and organizational factors which include sex, age, education, income, religion, satisfactory utilization of human resources (matched professional skills to needs) and collaborative approaches to programs and services delivery (community engagement) [47, 48]. The most common major contributing factors to poor healthcare in LMICs is poor infrastructure, long distances between the health facilities and communities, poverty and famine, political instability, poor socio-economic status (SES), cultural factors, high illiteracy rate, communicable diseases and greater emergence of non-communicable diseases including poor maternal health [13, 49-51]. As a result, community screening for disease awareness and prevention is drastically affected. This has made health referral uptake and linkage to healthcare not fully attainable in most countries because of constraints related to access to healthcare [52]. Hence, limited access to healthcare and late presentation to healthcare facilities in SSA have been associated with unnecessary deaths that could have been prevented [53]. This has been evidenced by the fact that approximately 500 000 maternal deaths happen worldwide with 4 million newborn deaths and an additional 3 million stillborn births; unfortunately, the majority of the percentages of these deaths are in developing countries [54].

Poor access to healthcare has been a contributing factor for inability to attain the Millennium Development Goals (MDGs) for health by end of 2015 in poorly resourced settings [9, 41, 55, 56]. MDG four (reduction in child mortality under five years) and MDG five (improved maternal health) were reported to be affected by the inability to access healthcare [57]. To address the challenge of poor access to healthcare, governments have introduced community healthcare workers (CHWs) into health systems as a way of linking disadvantaged communities with relevant healthcare providers [58]. In a situation whereby a patient is found to have a disease, the CHW will advise the patient to visit the nearest healthcare center by giving a patient the referral letter [59, 60]. The term referral in the health care system is defined as "the practice of sending a patient to another program or practitioner for services or advice, which the referring source is not prepared or able to provide" [2].

In South Africa, CHWs have been introduced countrywide as part of the program to re-engineer primary healthcare (PHC) in the management of chronic conditions, to improve healthcare outcomes [18]. The ultimate goal of CHWs is to contribute significantly towards increasing life expectancy, combating HIV and AIDS and strengthening health system effectiveness [21].

1.2.2 Community healthcare workers and their role in the public health system

The history of CHWs dates back to centuries where their important functions were to provide healthcare to vulnerable, disadvantaged, and marginalized communities. Various communities, countries, regions, and villages which are resource deficient, have their version or relevance of CHWs due to the nature of their public health demands. Other names for CHWs are "health auxiliaries, barefoot doctors, health agents, health promoters, family welfare educators, health volunteers, village health workers, community health aides and community health volunteers" [39, 42, 61, 62]. The earlier reports by Perez and Martinez

showed that CHWs were brought into the health system in Russia due to a shortage of doctors in the early 17th century [63]. During that era, they were called "feldshers," and they were trained to provide basic medical care to military personnel [64]. Over time, a similar model was used in Asia (China), where farmers with minimal education were given basic minimal medical training and were named "barefoot doctors" to provide basic primary healthcare, including vaccinations and treatment of minor illnesses, to rural underserved regions [65]. Currently, many nations across the globe are using CHWs due to a lack of health personnel to bring healthcare to the people [66-68].

The World Health Assembly (WHA) of 1974 noted the striking disparities in health and health services between countries and decided to explore possibilities for more effective action to bring appropriate equity in healthcare services. This culminated in the Alma Ata Declaration of 1978, which was in PHC [69]. As the majority of the countries were overburdened by diseases, the countries signatory to the declaration, including many African countries, considered the introduction of the CHW model as synonymous with the PHC approach [70].

In the late 1980s, PHC gave rise to a mass training of CHWs in many developing countries [71]. This made PHC available to remote and previously inaccessible parts of the world [72]. The WHA specified that the focal social target of governments and World Health Organization (WHO) in the next decades was to achieve healthcare to all world citizens by the year 2000 [73], however, this will still be a pipe dream in some years to come [74]. Political instability, wars, and famine especially in LMICs are still a worrying factor for healthcare services to reach the people in remote rural areas [75-77].

Internationally, a global shortage of medical workers to treat and manage the spread of diseases has led to the introduction of CHWs. Because of a lack of resources, significant skilled healthcare workforce shortages are present in approximately 57 countries, including countries in SSA and Asia, due to imbalances in the health worker patient ratio [78]. The number of physicians per 100,000 people range from as low as 2 in Malawi, 256 in the United States, to a high of 591 in Cuba [79]. These figures explain the reality that is faced by LMICs in accessing quality healthcare. The shortage of the healthcare workforce to cater for communicable diseases in relation to non-communicable diseases in LMICs and the world over has renewed interest in the role of CHWs. CHWs have become efficient as health foot soldiers, or as the face of public health, by strengthening healthcare systems and increasing availability of primary healthcare services [57, 80].

1.2.3 Community Health Workers in Low and Middle-Income Countries (LMICs)

Many countries in SSA face an enormous challenge of organizing healthcare service delivery in a way that provides quality and accessible healthcare to their communities against a background of economic hardships and resource constraints. In reaction to these challenges, various governments have been implementing health sector reforms for healthcare accessibility to their population. Hence, some countries in the East, West and Southern Africa (Kenya, Uganda, Ghana, and South Africa) have implemented community health workers' national programs [21, 81-83].

Lack of healthcare force or personnel in public health sectors mainly in LMICs has prompted health programs to recruit and train CHWs in the field of health promotion, case-control, and service delivery undertakings or activities at the community level for several decades. CHWs can help communities to establish and address their own health needs. They can provide health system managers and their associates with essential health facts or information that

may otherwise never reach them and can support those in the health system to understand and help with community needs [84].

Ghana (as a typical example) like South Africa has some imbalances in terms of healthcare service delivery and hence the introduction of CHWs in the country to bridge the gap between the vulnerable members of the society and adequate healthcare [81]. Due to the complexity of the scope of practice in Ghana by the CHWs, they have uniquely divided CHWs into two categories. The first category is informal, where CHWs are an unofficially integral part of the healthcare system, and supervisors/administrators for healthcare work together as developmental partners e.g. non-profit organizations take responsibility for their employment and training, incentives and remuneration, where appropriate. The next category of CHWs' existence is felt when they represent communities and act in favor of the communities. CHWs' jurisdiction under this category is formally aligned with the healthcare system, and also at the forefront of community-operative preventive healthcare activities. Irrespective of the difference, there is a hybrid form of CHWs in the former Gold Coast (Ghana) [81].

In developed countries like the USA, CHWs are regarded as frontline public health workers who work closely with their communities. This "relationship enables CHWs to serve as a liaison, link, or intermediary between health/social services and the community to facilitate easy access to healthcare services and improve the quality and cultural competence of service delivery healthcare. CHWs also build individual and community capacity by increasing health knowledge and self-sufficiency through a range of activities such as outreach, community education, informal counseling, social support, and advocacy" [84].

1.2.4 Challenges and constraints faced by CHWs

The challenge with CHWs programs is the high rate of employee turnover which is commonly called attrition, with varying rates of approximately 3% to 77% [85]. The main cause of higher attrition rates has been reported to be associated with volunteers because they are not accountable fully to the system due to lack of career path or signing of job contracts. Such dropout rates negatively affect the ongoing relationship between CHWs and communities, elevate costs in selecting and training CHWs, and result in missed opportunities to build on experience. This means that the effectiveness of CHWs' work usually depends on retention [61]. The main challenge in retaining CHWs is the lack of incentives or stipends which cause CHWs to move from job to job in search of better remuneration [86].
Attrition rates of approximately 30% and 50% were reported in Senegal and Nigeria respectively over two years [87]. This was found to be dependent on factors such as community and government funding. CHWs who are funded by the community had twice the attrition rate as compared to their counterparts who are on government payroll [88]. High attrition gives rise to a plethora of problems. Repeated replacement of CHWs means poor continuity in the relationships established among CHWs, communities, and health systems. In safeguarding CHWs status, considerable undertaking is made in each CHW and program costs for identifying, screening, selecting, and training of the CHWs rise alongside high attrition rates. When CHWs render their resignation due to better remuneration elsewhere, they leave with much needed gained experience and opportunity is lost to build on experience. The success of CHWs depends on retention. CHWs programs are exposed to massive challenges such as lack of political support, financial difficulties, limited oversight and technical support, lack of a common and well-funded research agenda, and strategies to enhance and sustain CHWs performance [89, 90].

1.2.5 CHW work environment model

For CHWs to be productive and deliver services effectively there are the number of factors or inputs that need to be taken into consideration (Figure 1 next page).

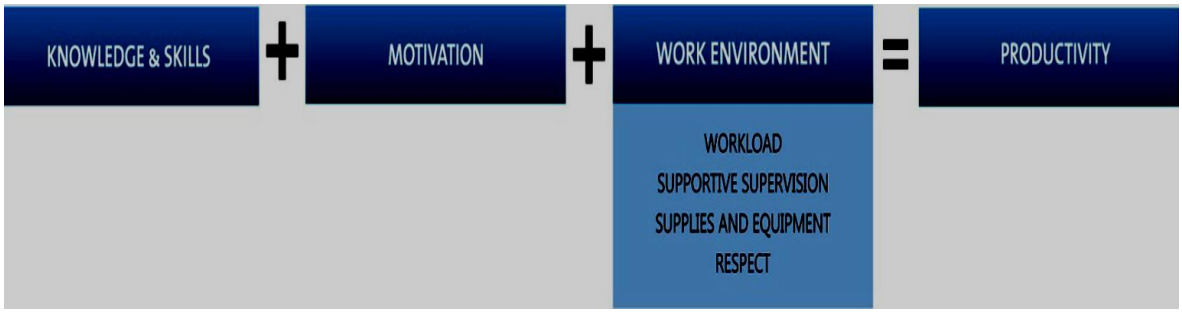


Figure 1: Work environment as a key determinant of community health worker productivity (Jaskiewicz et al.[91])

The knowledge and skills of CHWs are built through training on communicable and non-communicable diseases together with basic medical knowledge. Unfortunately, their training is usually short. As a result, their knowledge of skills and attitude towards patient care may be limited by the fact that there is not enough time given to learn about different diseases [66, 82]. In a South African study, a constraining factor was being unable to learn from the native language (isi-Xhosa) to the preferred language (English) [18]. Motivation of CHWs by supervisors is required to build their confidence, competence, and delivery of healthcare services [92]. Besides, incentives and payment of stipends have been shown to ensure maximum performance for reaching their healthcare targets [93]. Timely coordination of daily activities by supervisors for CHWs has been proven to be effective in bringing healthcare closer to the communities [92].

1.2.6 Model for CHW workload

The workload in most settings in LMICs or developing countries is often heavy resulting in attrition of CHWs and inadequate delivery of healthcare services to communities [88]. The components of the CHW workload are summarized in Figure 2 (next page).

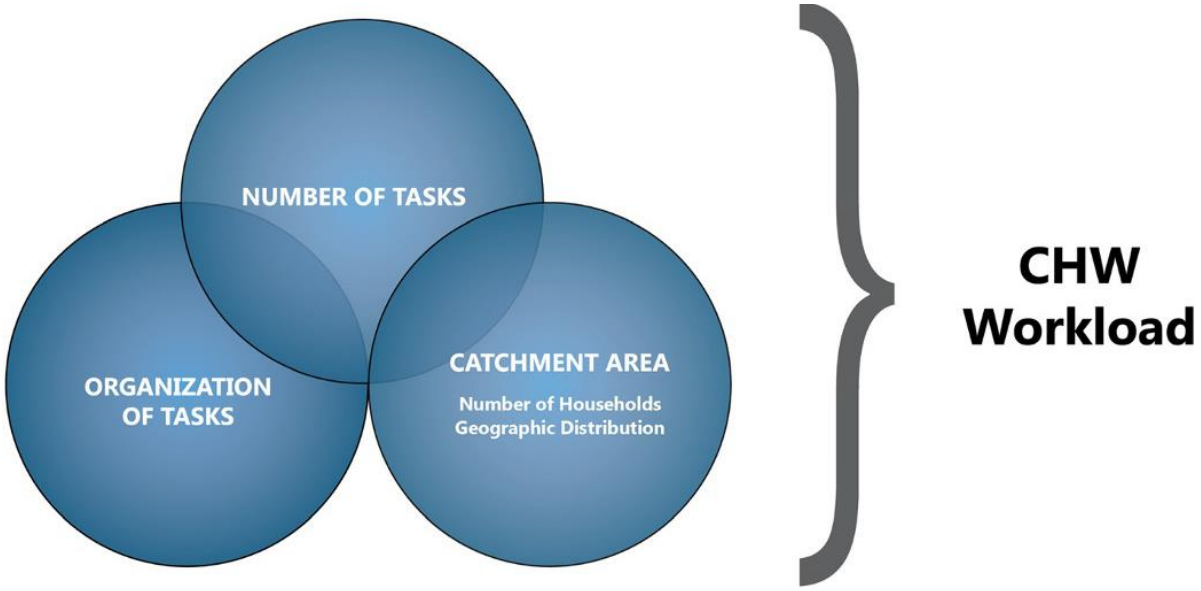


Figure 2: Components of CHW (Jaskiewicz et al.[91])

The three components catchment area, organization of tasks and number of tasks are inter-linked. The catchment area comprises two of aspects namely; household numbers to be attended and their geographic dispersion. The depths and core work of CHW's catchment area depend on the household's number of CHWs that are responsible for it, for example, the chosen group within the confines of the family and geographical distribution. The way in which tasks are organized by supervisors affects the CHWs potential to deliver on targets and maximize productivity. The number of tasks allocated to CHWs often fluctuates based on the need for healthcare services at a particular time. Hence, in some circumstances the CHW's can be "overwhelmed by a very broad range of tasks which may have negative effects on the overall quality of performance" [94].

1.2.7 Health referral

Referral systems are an essential component of health systems in developing and LMIC countries since the introduction of PHC [60]. The referral system normally assumes a one-way referral process of moving patients "up the pyramid" of care (Figure 3), from less specialized primary healthcare services to more specialized care, as appropriate [2].

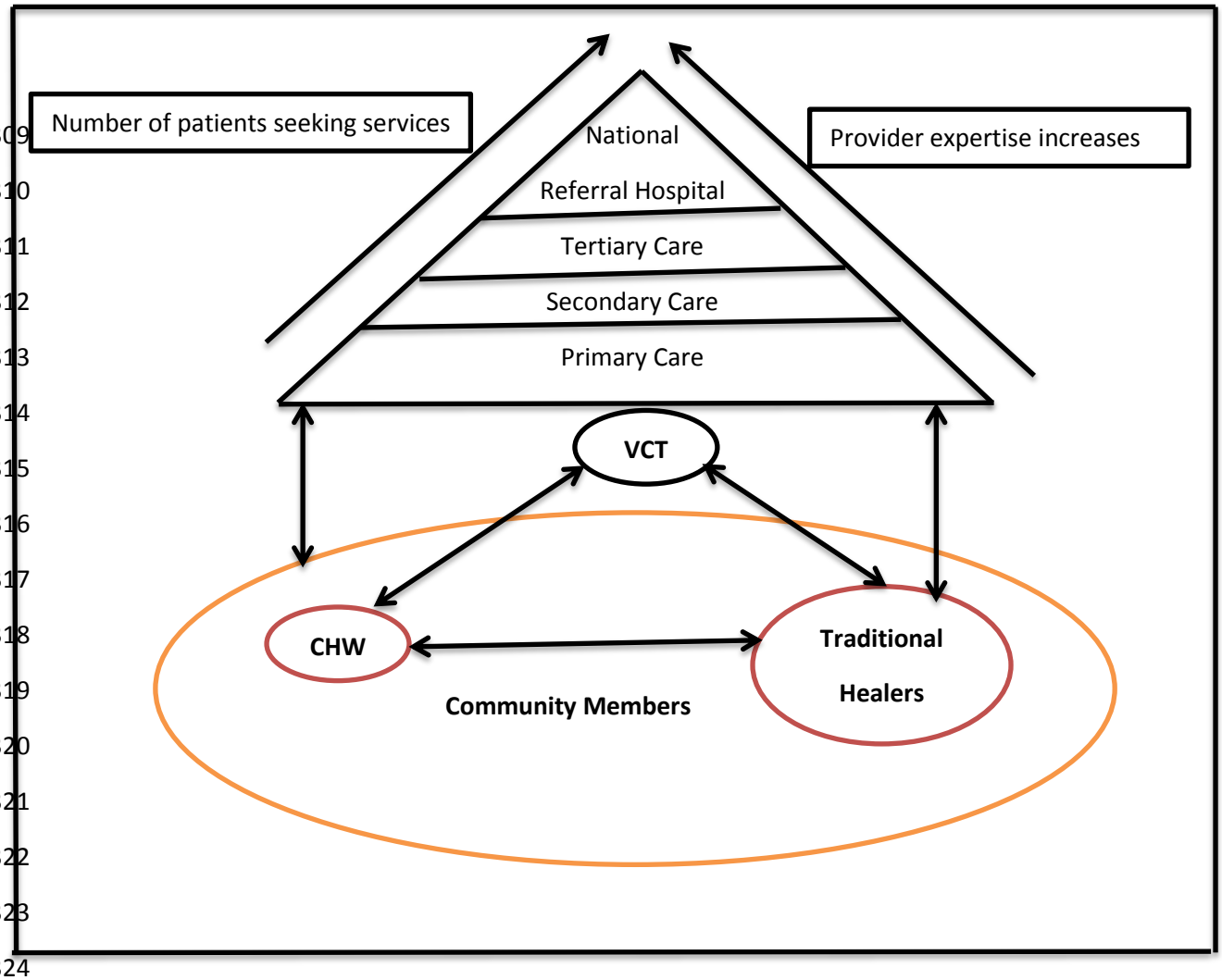


Figure 3: Levels of health care according to referrals (MacIntyre et al.[95])

At the bottom of the pyramid are community members that utilize the services of CHW's and traditional healers. Both the service providers can refer patients for voluntary counseling and treatment (VCT) in patients infected with HIV to primary healthcare facilities. Depending on the healthcare at primary care level, patients needing specialized medical care are referred to secondary, tertiary and high-level care at national health referral hospitals.

1.2.8 Factors affecting referral

The referral process is also hampered by "three delays" (Figure 4): delays in making the resolution to seek health care, delays in arriving at appropriate health facility once the decision has been made, and lastly, delays in receiving sufficient and suitable care once the healthcare facility has been reached [96].

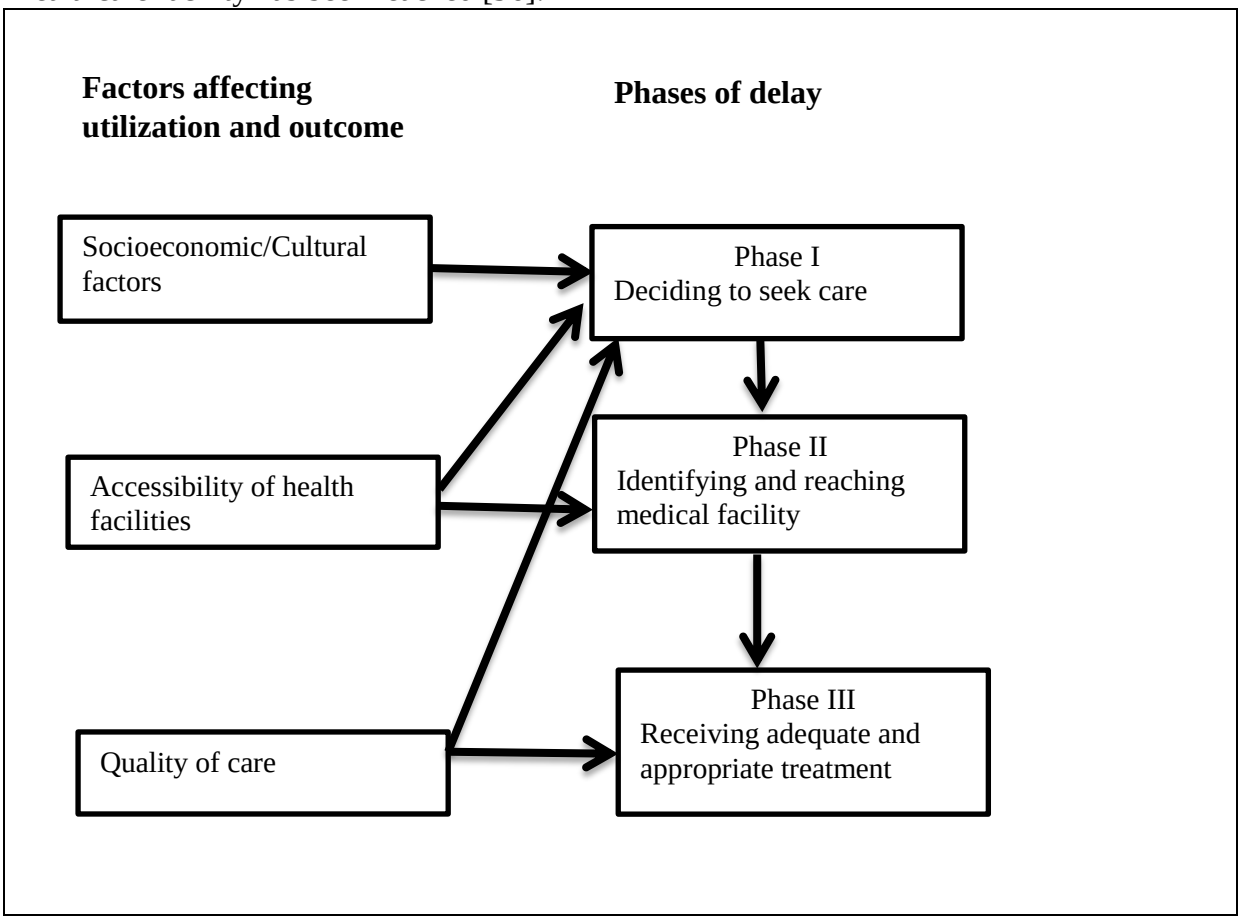


Figure 4: The three delays model in accessing healthcare (Thaddeus et al.[97])

A good functioning health system is characterized by appropriate and timely referral of patients to access quality healthcare. Regrettably, this is one of the weakest links in the health systems of economically poor countries [98]. The researchers have categorized factors affecting the referral system into health system issues, patient problems, and cultural practices. Health system issues include poor communication by CHWs, unpleasant prior experiences with the health system e.g. rudeness of healthcare workers/facility, healthcare workers not being patient-friendly and no drugs at the healthcare facility. Besides, in some communities, families may take longer time to seek healthcare for sick female children compared to male children [95, 99-102].

1.2.9 Linkage to healthcare

Linkage to healthcare is an essential step in engaging patients to care by putting them on treatment [103]. Linkage to healthcare can lead to a decreased in morbidity and deaths, as well as improvements in life expectancy and quality of life [104]. Linkage to healthcare is accomplished when patients are given proper information about the importance of receiving care at a health facility and also when the hierarchy in public health system is intact (i.e. from CHWs to the clinical specialist) [105]. However, linkage to healthcare has been reported to differ based on the nature of disease (communicable and non-communicable diseases) or perception of diseases [15, 45, 106].

1.2.10 Barriers to healthcare linkage

In low resource settings, barriers to healthcare make linkage to care and retention in care a major challenge [107].

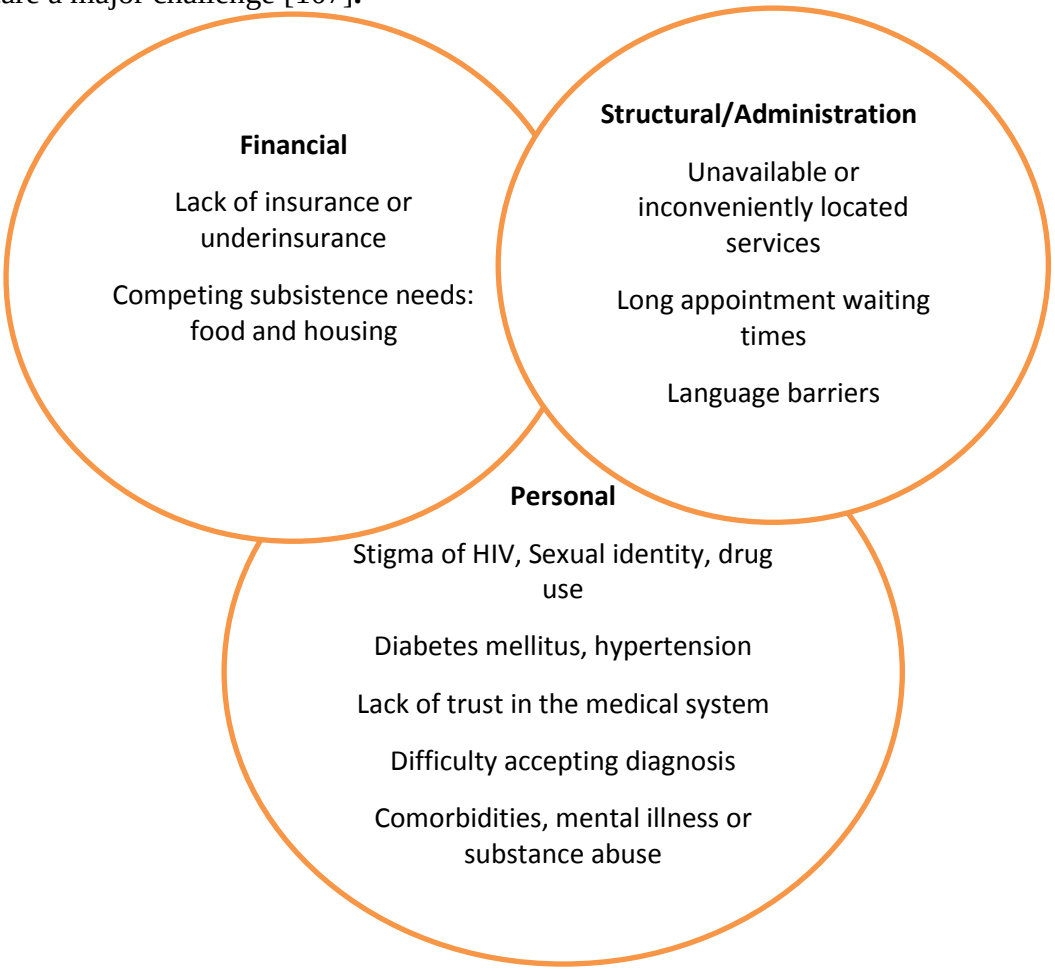


Figure 5: Barriers to healthcare linkage (Dombrowski [107]).

Figure 5 shows the consensus based on the published literature, that the barriers to linkage to healthcare ideally revolve around financial constraints, structural terrains or poor administrations of health management services and personal factors. However, all the three factors are inter-related. Studies in developing countries have proposed that addressing financial barriers, efficient patient communication, and education may ameliorate linkage, retention, and medication adherence in diseases [25, 108, 109].

1.2.11 Communicable diseases and linkage to care

Poor linkage to healthcare in most instances has been reported in SSA, which is part of the world that is grossly affected by the global HIV epidemic [110]. A disturbing factor is that attrition to care often happens before ARV treatment, and this has been attributed to barriers to healthcare [13, 111]. The importance of linking patients to care is crucial for successful HIV treatment. However, in a situation where there is delayed linkage, it impacts heavily on medical outcomes resulting in longer periods of viral suppression in the human body, increased risk of hospitalization, increased costs to treat the disease and death when the virus is resistant to antiviral drugs. There is also a high possibility of increased HIV transmission risk [15].

Concerning TB, despite medical intervention efforts by governments to treat and control TB through community screening, TB remains a dominant public health problem globally. Furthermore, in 2015, approximately 9.6 million individuals around the globe were reported to have suffered from the ripple effects of TB and around 1,5 million individuals are demising from TB every year [112]. This is often seen in people living in overcrowded

ghettos or squatter camps especially with a high prevalence of HIV/AIDS. Adherence to treatment is especially important because non-adherence to treatment leads to resistance to *mycobacterium bacillus* [113]. A similar trend has also been reported in TB/HIV co-infection [114]. Sexually transmitted infections (STIs) play a crucial part in the transmission of HIV through unprotected practice of sexual activities and unfaithfulness of the partners [115]. While much is known about effective interventions (condom use and adherence to treatment), the execution of these measures remains disappointing in South Africa [116].

1.2.12 Non-communicable diseases and linkage to care

1.2.12.1 Hypertension and diabetes

High blood pressure is a killer disease and a global risk factor for more deaths because of diseases such as ischemic heart diseases, heart failure, and stroke. Its treatment and control rate has been reported to be low across the globe [117, 118]. Delay in seeking or linking to healthcare may lead to fatalities especially in vulnerable groups such as the elderly and pregnant women [40, 106]. Hypertension in its nature is asymptomatic, hence linkage and medication adherence are always a serious challenge. As a result linkage to high blood pressure care and successful retention of clinical services are critical elements of high blood pressure control [119].

The emergence of high prevalence of diabetes mellitus in SSA is attributed to factors such as increased in individual lifespan, economic development, change in lifestyle (low physical activity and high sugar/high-fat diet), which has resulted in a rise of burden of diabetes mellitus [38, 120, 121]. The ripple effects of poor linkage to continuum of care in most instances have led to limb amputations, blindness and multiple organ failure [122, 123].

1.2.12.2 Antenatal care (ANC)

This is a special care provided to expectant mothers during pregnancy to ensure that delivery is harm-free and the mother of the child is healthy. Under normal conditions, four visits to an ANC clinic are required for the safe delivery of the new-born [124]. The first visit is for screening and treatment of conditions such as anemia, sexually transmitted infections, and medical conditions that should be taken into consideration during pregnancy and also to start preventative treatment when necessary. The second, third and fourth visits are scheduled at 24 - 28, 32 and 36 weeks respectively [28]. Increased child and maternal deaths in developing countries have been reported to be due to the failure of pregnant women to be linked to ANC [125, 126]. This may explain why MDG 4 (child mortality reduction) and MDG 5 (maternal health improvement) were not reached by the year 2015 in SSA and LMICs [127].

1.2.12.3 Depression

The causes of depression are often multifactorial and might be due to low SES and HIV/AIDS. Depression is the most common mental health disorder among those diagnosed with HIV & AIDS, affecting 22% of the population [128]. Furthermore, people with HIV/AIDS conditions have an increased prevalence of depression as compared to their HIV-negative counterparts [129, 130].

1.3 Problem Statement

Communities located in informal settlements often have a large percentage of undiagnosed diseases due to a lack of routine medical check-ups. This is because healthcare centers are far away from communities and community members may lack transport money [21]. The majority of people have little or no disease knowledge and often seek medical treatment only when there are disease complications and these may lead to a high incidence of mortality [131, 132]. The problem is that there is a high burden of both communicable diseases and

NCDs in SA [6]. Although CHWs are there in communities in SA, many community members might still not be utilizing their services. Studies in SA have found that patients still need to be educated on the importance of referral uptake and linkage to care, with patient's problems, health system problems and health worker problems being the contributors [32-37]. Furthermore, communities should be made aware of the consequences that are associated with failure to take referral letters to the healthcare center and failure to healthcare linkage. Studies have shown that although health care facilities exist, many people do not access these facilities for reasons already stated and hence many treatable diseases are not being treated [12, 29]. Lack of access to healthcare services has prompted the SA government to introduce CHWs to act as a middleman between community and healthcare services as a way of re-engineering PHC. The present study will show the importance of CHWs in multiple disease screening, awareness and offer counseling to participants diagnosed with diseases to access healthcare.

1.4 Justification of the study

In developing countries, reports have found that most disease conditions are presented late at healthcare clinics which often lead to an increase in disease transmission, complications and premature deaths, [99, 100] due to poor uptake of health referrals. There is insufficient information on health referral uptake and linkage to healthcare in South Africa, with few studies being conducted in a peri-urban (uptake of neonatal and young infant referrals) and urban informal settlement (referrals on non-acute child health conditions) of Kwa-Zulu Natal [32, 33]. Another study investigated linkage to healthcare among adults in underprivileged urban and peri-urban townships within the Western Cape Metropolitan region of South Africa [34]. To improve health outcomes in informal settlements (underprivileged communities), it is of essence to understand the factors that affect their utilization of healthcare services after screening by CHWs. Health referral uptake and linkage to care in children and adults is important especially in poorly resourced communities where there is a lack of access to healthcare due to low socio-economic status (SES), as reported by other researchers [131].

1.5 RESEARCH QUESTION

What are the factors associated with healthcare referral uptake and linkage to healthcare following community-based screening in an informal settlement in Johannesburg?

1.6 STUDY AIM

To assess healthcare referral uptake and linkage to healthcare and factors associated with health referral uptake and linkage to healthcare in an informal settlement in Johannesburg.

1.7 STUDY OBJECTIVES

1. To describe disease conditions and healthcare referral uptake and linkage to health care in adults in Diepsloot, Johannesburg.
2. To describe barriers to linkage to healthcare in adults in Diepsloot, Johannesburg.
3. To determine factors associated with healthcare referral uptake and its linkage to healthcare in adults in Diepsloot, Johannesburg.

CHAPTER 2 METHODOLOGY

This part of the dissertation gives the reader a comprehensive description and explanation of the study methods that were not fully covered in the manuscript.

2.1 STUDY SITE AND SETTING

The study site was the densely populated, Diepsloot informal settlement, which is an area located in the north-western peripheral part of the Johannesburg Metropolitan Area, approximately 40 kilometres from the inner city and 20 kilometres north of Sandton City, close to Fourways and the Midrand corridor (Figure 6).

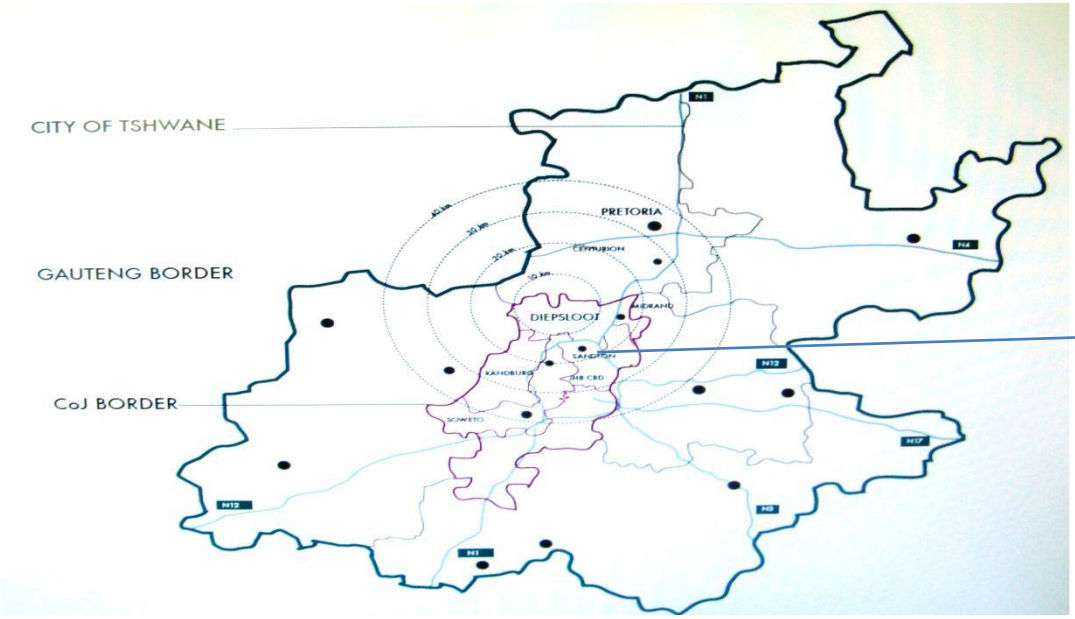


Figure 6: Map of Gauteng province showing the study area (Diepsloot) (Adopted from Agency [133]).

The study population comprises of over 500,000 residents based on a statistical survey conducted in 2013 in Diepsloot [134].

2.2 THE PRIMARY STUDY (MAIN SURVEY)

The primary aim of this study was to define the burden of disease and develop a geographic risk profile for the Diepsloot community. The study was a cross-sectional household survey, conducted on 2000 households (based on the sample size calculation) using a geographically-weighted random sampling framework [134]. The survey started in April 2013 and ended in May 2013, using study questionnaires. During the survey, trained CHWs administered a primary study questionnaire on demographics (age, sex, partnership status, country of origin, employment status, educational status, and medical aid coverage), mobility (length of stay in Diepsloot), physical activity (running, walking heavy lifting, aerobics), mental health (emotional problems and witness of violence), health-seeking behaviour (frequency of visiting healthcare facilities, traditional healers, church healer/faith-based healer), food security and children's health (availability of food in the house), women and men's health (reproductive health and history of sexually transmitted infections (STI). Professional nurses administered a questionnaire in a random household survey of spatial distribution of health needs in Diepsloot. Participants who were found to have suspected disease conditions were given a referral letter to visit the nearest healthcare facility. Telephonic follow-up of

participants was after two weeks in 2013, with an overlap in time for those who were not found at an expected time. Information on the disease referred (high blood pressure, anemia, high blood sugar, body weight, Tuberculin skin test, STI symptoms, HIV, and mental health) was recorded on the referral enrolment tracking questionnaire, wherein participants were called four times on the landline and lastly on a mobile phone if not available. The participants were assessed on their health referral uptake by asking them about the referred disease, days taken to visit a healthcare provider, and the name of the health provider.

During the follow-up at the clinic the following findings of concern were elicited during the clinical examination of the subjects being referred; blood pressure, body mass index (BMI), blood tests, and urine glucose and ketones, hemoglobin, mental health, ANC, TB and STI.

For blood pressure measurements, systolic (SBP) (mmHg) and diastolic (DBP) (mmHg) blood pressures were measured on the right upper arm using an automated oscillometric device. Blood pressure measurements were taken three times with the subject seated. The average of the three readings was used as the systolic and diastolic blood pressure. High blood pressure was diagnosed as having SBP and DBP of 140 mmHg and 90 mmHg or greater respectively [135]. In assessing anthropometrical measurements, height was measured barefoot to the nearest 0.1 cm using a rigid stadiometer and weight was measured with subjects wearing light clothes and barefoot to the nearest 0.1 kg using a calibrated scale balance. BMI was calculated by dividing weight in kilograms by height in meters squared (kg/m^2). Bodyweight status was categorized as normal (BMI $\leq$ 25 kg/m^2), overweight (BMI 25 to < 30 kg/m^2) and obese ($\geq$ 30 kg/m^2) [135].

Fasting blood glucose (< 7 mmol/l-normal) was tested using a rapid test by a Glucometer machine [136]. Diabetes mellitus diagnosis was based on the American Diabetes Association (ADA) which defines diabetes as having a fasting blood sugar of 7 mmol/l or greater [137]. The test was done by first cleaning the participant's fingertip with an alcohol swab to eliminate micro-organisms. The participant was then pricked on the fingertip and the droplet of blood transferred from the test strip into the glucometer for glucose measurements. The outcome of the test results was in 60 seconds. For fasting urine glucose and ketone tests, a urine dip stick was used. The dip stick was inserted in and out of the participant's urine sample and left to stand in the open for 60 seconds. A positive urine glucose and ketone corresponds with the color on the dip stick bottle. Anemia assessment was done on blood samples wherein hemoglobin (reference range 12.0 – 15.5 g/dL) was tested by sending blood specimens to the National Health Laboratory health Services (NHLS) [138]. TB was assessed by the tuberculosis skin test which uses a purified protein derivative (PPD). In the test procedure, a participant's skin is cleaned first with an alcohol swab and during a PPD test a small amount of antigen is injected in the skin. The PPD test leaves a small amount of killed, purified mycobacteria material in the skin, but no significant amount gets into the bloodstream. The immune system reacts within 48 to 72 hours if it has "seen" similar material before. The test is "positive" if a bump of about the size of a pencil eraser or bigger (at least 10 mm induration) appears on the participants' arm [139].

The participants were also assessed (using the primary study questionnaire) on their mental health status by asking them of their experiences with emotional problems (felt downhearted and blue, felt so down and in the dumps, feeling calm and peaceful) and if they had witnessed violence (someone been violently attacked, being threatened with a knife, gun or weapon, or being slapped, punched or kicked), in Diepsloot. For ANC, the participants were asked about their pregnancy status and their last date of menstruation. They were also asked if they were adhering to their antenatal consultation at their nearest healthcare centre. Participants were

also asked on STI symptoms, and experiences with sores or ulcers on the penis or vagina, abnormal discharge from the penis or vagina and warts in the genital area.

2.3 Secondary data analysis

2.3.1 Study design

This was a prospective cohort study that followed up 429 participants (from a sample size of 2000 participants) who were screened for suspected disease conditions and given health referral letters by CHWs.

2.3.2 Data collection procedures

The data was collected on the study questionnaire by CHWs and professional nurses and was entered into a Microsoft Excel spreadsheet by trained data capturers.

2.3.3 Data management

Data cleaning was conducted on Microsoft Excel before data was transferred to STATA software (version 11.0, StataCorp, NY., College Station, TX, USA, 2009) for statistical analysis [140]. The STATA duplicate command (drop if Var ==id) was used to eliminate duplicates and, where appropriate, categorical ordinal variables were generated and coded, using the STATA commands generate and recode. Frequencies and percentages were used to represent categorical variables. The socio-demographic factors and disease conditions variable were divided into categories, lowest reference category (code = 0), second category (code = 1), third category (code = 2) and fourth category (code = 3), depending on the number of categories of a variable. The outcome variables were healthcare referral uptake and linkage to healthcare which were both categorized as binary variables, Yes (Code = 1) for present or No (Code = 0) for absent.

2.3.4 Statistical analysis

Numerical data were tested for normality of the distribution by visual inspection of the histograms and Shapiro-Wilk tests. Normally distributed variables were represented as means and standard deviations (SD) and non-normally distributed variables were represented by medium and range.

2.3.5 Study Objectives

Objective 1: To describe disease conditions in terms of healthcare referral uptake and linkage to health care in the Diepsloot community, Johannesburg.

The health referral uptake/linkage to care refers to the number of participants who were referred/linked to care for a particular disease, divided by the total number of participants referred or linked to care for all diseases multiplied by hundred, to give a percentage (Health referral uptake/linkage to care$= \frac{\text{No of participants referred/linked tocare}}{\text{Total number of participants referred/linked tocare}} x\ 100\%$). This calculation was repeated for all 10 health conditions.

Objective 2: To describe barriers to linkage to healthcare in the Diepsloot community, Johannesburg.

Barriers to linkage to healthcare were divided into health system problems (long queues at the clinic), patient problems (reluctance to go to the clinic, the condition cannot be cured, referral not received or lost, personal problems, out of Gauteng province, and health worker problems (rude health workers).

Objective 3: To determine factors associated with healthcare referral uptake and its linkage to healthcare in the Diepsloot community.

The relationship of dependent variables (health referral uptake and linkage to care) and predictor variables (socio-demographic factors and disease conditions) were assessed by univariate and multivariate Cox proportional hazards regression models. Hazard ratios (HR) and p-values were used as measures of association with a p-value of < 0.05 being considered for a statistically significant relationship at the 95% confidence level.
Kaplan-Meier survival curves estimated the time taken for the participant to visit the healthcare clinic after being diagnosed with a disease condition.

2.4 ETHICAL CONSIDERATIONS

The data were provided to the principal researcher with permission from Witkoppen Health and Welfare Centre. Ethical approval was obtained from the Human Research Ethics Committee (Medical) (HREC) of the University of the Witwatersrand, Johannesburg (clearance certificate no. M151178).

CHAPTER 3 PAPER IN A SUBMISSIBLE FORMAT

This manuscript has been prepared for submission to BMC Public Health (see Appendix i for author guidelines).

Health referral uptake and linkage to healthcare after community-based screening in Gauteng, South Africa: A prospective cohort study

Machuene A Poopedi[1], Ntombizodwa Ndlovu[1], Jabulani Ncayiyana[1]

Corresponding author

Poopedi MA

School of Public Health

Faculty of Health Sciences

University of Witwatersrand, Johannesburg

Work Telephone: +27 15 2875400

Mobile Telephone: +27 72 1764530

Fax No: 0865532750

Email:ananiaspoopedi@gmail.com

Keywords: Community health workers, Human Immunodeficiency Virus, Tuberculosis, Sexually transmitted infections, Non-communicable diseases, Communicable diseases, Obesity, Blood pressure, Psychological problems

DECLARATION BY AUTHORS

The authors; Machuene Ananias Poopedi, Ntombizodwa Ndlovu and Jabulani Ncayiyana declare that the contents of paper are their own original work. The authors of the paper had no conflict of interest to declare.

LETTER TO BE SIGNED BY ALL CO-AUTHORS

Machuene Ananias Poopedi – M.Sc Epidemiology Student; Data analysis, interpretation of the data and writing of the initial drafts of the manuscript.

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Signature

Jabulani Ncayiyana - Supervisor; Project supervisor was responsible for substantial contributions in conception and designed of the study, data acquisition, interpretation of the data, reviewed and edited the drafts.

…….

Signature

Ntombizodwa Ndlovu - Co-Supervisor- Project Co-Supervisor was responsible for interpretation of the data, drafting the manuscript and revising it critically for important intellectual content.

…….

Signature

All Authors were responsible for the final approval of the submitted version. The authors agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

672 **ACKNOWLEDGEMENTS**
673 The authors unreservedly thank community healthcare workers and professional nurses of
674 Witkoppen Health and Welfare Centre for helping with data collection.

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676

677

Abstract

Background: The high burden of undiagnosed communicable and non-communicable diseases is a major public health challenge in developing countries. Community-based multi-disease screening campaigns using community health workers (CHWs) offer great potential for disease awareness and medical treatment. However, little is known about health referral uptake and linkage to healthcare following such campaigns. The present study investigated the health referral uptake, linkage to healthcare and associated factors after a community-based multi-disease screening campaign in a peri-urban, informal settlement in Johannesburg.

Methods: A cohort of 429 participants diagnosed with non-communicable diseases, communicable disease, and mental health problems, were provided with health referral letters and were followed-up telephonically over two weeks. The relationship of health referral uptake, linkage to care and their predictors (socio-demographic status and disease conditions) was assessed by univariate and multivariate Cox proportional hazards regression models. The time taken for participants to visit the nearest healthcare center was assessed by Kaplan-Meier (KM) survival curves.

Results: Of the 429 participants, only 109 (25%) took the referral letter to the health clinic and from 109 participants, 77 (71%) were linked to care and 32 (29%) not linked to care. The 77 participants were linked to care within a period of approximately 3 months (median = 11.4 days, interquartile range (IQR) 1 – 84 days). There were also 240 (56%) participants who failed to visit the clinic and stated health system problems 17 (7%), patient problems 213 (89%) and health worker problems 10 (4%) as their barriers to accessing healthcare and 80 (19%) participants were not reached. The association of health referral uptake and linkage to care with socio-demographic factors and disease conditions were mixed (Hazards Ratio (HA) < 1 or HA > 1), with no statistical significant ($p > 0.05$).

Conclusions: Overall, there was a low uptake of healthcare services and linkage to healthcare in the Diepsloot community. It suffices to notice that, majority of the participants were lost to follow up, hence studies with larger sample sizes are not only suggested but warranted.

Keywords: Community health workers, Human immunodeficiency virus, Tuberculosis, Non-communicable diseases, Communicable diseases, Obesity, Blood pressure, Psychological problems.

Background

Sub-Saharan Africa (SSA) carries one-quarter of the world's burden of illness, with only three percent of the global health workforce, and less than one percent of the world's financial resources [1, 2] resulting in overburdening of the health system. Diseases are often undiagnosed due to a lack of awareness by community members [3]. Undiagnosed and untreated disease undermines public health prevention and treatment interventions, often leading to late disease presentation at healthcare facilities, complications, and death [4].

In many countries, CHWs (Community Health Workers) have been introduced to bridge the gap between communities and healthcare services. CHWs are the extension of primary healthcare services and are trained to screen for diseases in communities [5] and to issue health referral letters [5-10], encourage sick community members to access healthcare at the nearest health clinic. However, the benefits of community disease screening such as early disease detection and linkage to healthcare are often minimized by poor uptake of health referrals [11].

A handful of studies in South Africa investigating health referral uptake after single disease screening in childhood illnesses have shown differences in referral uptake [12, 13] and poor linkage to healthcare [14]. High uptake of CHWs referrals was observed by Nsibande et al. in acute childhood illnesses [12], whereas Uwedimo et al. [13] showed poor uptake of referrals in children with non-acute illness. Other results were reported in adults wherein patients were diagnosed for HIV (Human Immunodeficiency Virus), TB (Tuberculosis) and non-communicable disease cases but there was poor linkage to care as reported by Govindasamy et al. [15] which was attributed to lack of time to access the healthcare clinic and no disease symptoms. Poor linkage to healthcare in communities may lead to unnecessary deaths that were supposed to have been prevented because linkage to care in primary healthcare is regarded as the backbone of public health advancement [10].

Barriers to healthcare access such as poor roads, long queues at the health facilities, lack of financial resources, difficulty in securing appointments, negative clinic-patient interactions, asking permission from the husband to access medical treatment are stumbling blocks to access healthcare thus resulting in poor health referral uptake [16-21]. In South Africa, studies investigating uptake of health services after multi-diseases screening in the community are still lacking. Understanding factors associated with poor health referral uptake and linkage to healthcare after community-based multi-disease screening will help inform strategies to reduce barriers to referral and linkage to care [17-19, 22, 23]. Hence, the present study has assessed health referral status and linkage to care with respect to disease conditions and evaluated the association of health referral uptake and linkage to care with predictors (socio-demographic status and disease conditions). Furthermore, barriers to healthcare were assessed in participants issued with referral letters for their medical conditions during community screening of diseases.

METHODS

Study setting

The study was conducted in Diepsloot Township, a low-income informal settlement which is located in the city of Johannesburg, South Africa. It is a densely populated township in the north-western periphery of the city and has a population of over 500,000 residents in an area of approximately 12 km^2 [24].

Study Design

This was a prospective cohort study of 429 participants who were diagnosed with disease conditions or found to be pregnant during multi-disease screening. This study was a sub-study of a large community-based household survey; the details of a community-based household survey have been described elsewhere [25, 26]. Briefly, CHWs administered the study questionnaires developed on population demographic status, health profile status, and referral enrolment tracking during the household surveys. The professional nurses conducted participant's clinical assessments, namely blood pressure assessments, tuberculin skin test (TST), blood sugar test, pregnancy assessments, and HIV status. Participants with suspected disease conditions were given health referral letters to visit the nearest clinic.

Follow-up

Participants were contacted by telephone after two weeks have elapsed since they were given referral letters, and participants not found after 14 days were further called once using a mobile phone. During follow-up (referral uptake assessment), the participants were asked about the type of disease/condition they were referred, days or weeks taken to visit the healthcare provider. Participants were further asked on the following, whether they received prescribed medication, staff took further tests, and counseling being received. Participants with non-communicable diseases (NCDs) were advised to follow a prescribed diet and exercise plan, and those who were HIV positive were asked on whether they are receiving medication to prevent TB.

Statistical Analysis

Study variables comprised of continuous and categorical variables. Variable age and MTSD were continuous, not normally distributed and were represented by the median and range. Categorical data were presented as frequencies and percentages. Referral uptake was coded as zero (code = 0) when the participant who was given the health referral letter has not visited the healthcare facility and one (code = 1) when the participant who was given the health referral letter has visited the healthcare facility. Participants not linked to healthcare (no treatment nor counseling received) were coded as zero 0 (code = 0) and participants linked to healthcare (treatment nor counseling received) were coded as 1 (code = 1). The socio-demographic factors and disease conditions variable were divided into categories, lowest category- reference (code = 0), second category (Code = 1), third category (code = 2) and fourth category (code = 3), depending on the number of categories on a variable.

The relationship of dependent variables (health referral uptake and linkage to care) and predictor variables (socio-demographic factors and disease conditions) were assessed by univariate and multivariate Cox proportional hazards regression models. Hazard ratios (HR) and p-values were used as measures of association with a p-value of < 0.05 being considered for a statistically significant relationship at the 95% confidence level.

Kaplan-Meier survival curves estimated the time taken for the participant to visit the healthcare clinic after being diagnosed with a disease condition. All statistical analyses were conducted using STATA software, version 11.0 (StataCorp, NY, College Station, TX, 2009).

Results

Of the 429 participants who were given healthcare referral letters, 109 (25%) visited the healthcare centers (clinics), 240 (56 %) did not visit and 80 (19%) could not be reached for follow-up. Of the 109 participants, 77 (71%) were linked to healthcare services and 32 (29%) were not linked to care. **(Figure 1)**

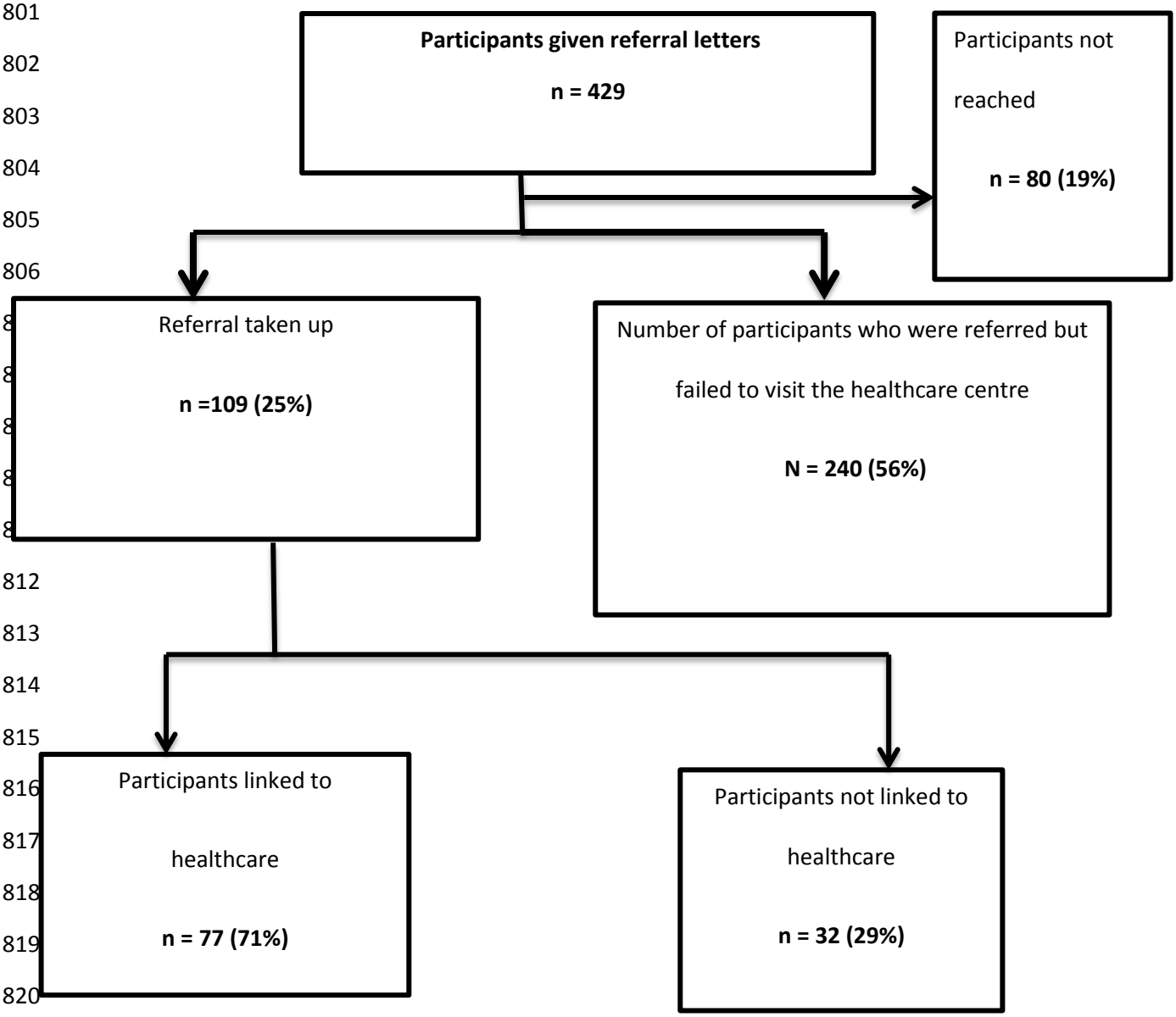


Figure 1: Flow chart of study participants

828 **Table 1: Socio-demographic characteristics of the study population**

Variable	(N = 429)	(%)
	Median (Range)	
Age (Years)	33 (15 - 72)	
	Median (Range)	
MTSD*	9.9 (0 – 27)	
Age Categories		
≤ 20 years	28	7
21 – 30 years	139	32
31 – 40 years	128	30
> 40 years	134	31
Gender		
Male	201	47
Female	228	53
Partnership Status		
Non-Disclosure	114	27
Married	70	16
Co-Habiting	101	33
Not Married	141	24
Country of Origin		
South Africa	347	81
Foreign Nationality	82	19
Employment status		
Unemployed	250	58
Self/Temporary	105	20
Formal Employment	73	17
Not Stated	1	0.23
Educational status		
None	22	5
Primary School education	107	25
Secondary School education	272	64
Tertiary School Education	27	6
Not Stated	1	0.2
Medical Aid Coverage		
Yes	15	4
No	391	94
Not Stated	8	2

829 *MTSD (**Median Time of Stay in Diepsloot**)

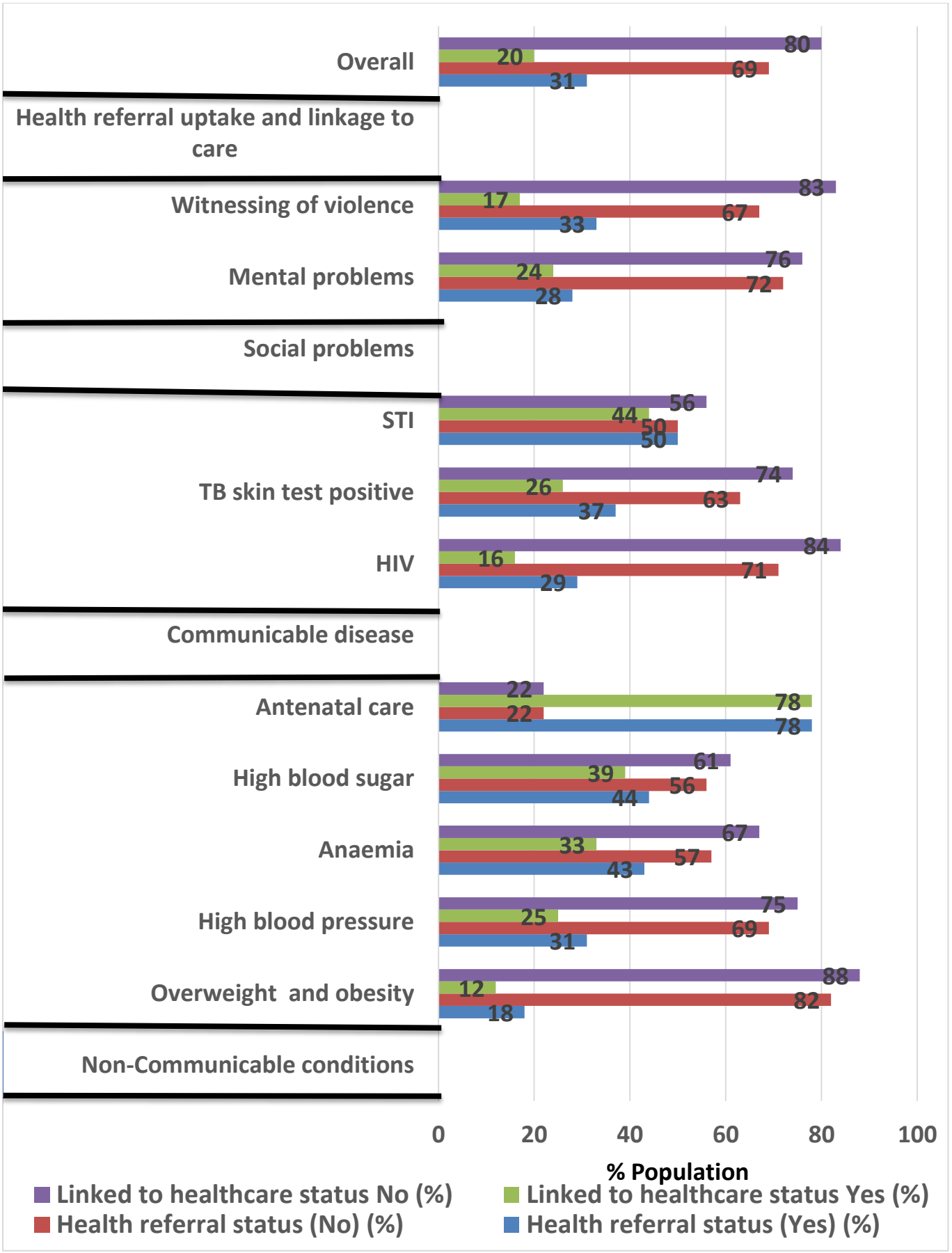
830 The population comprised both young and adult population, with the proportion of male
831 participants being less (47%) as compared to females (53%). The majority of the participants
832 were of South African origin and minority being foreign nationals. Some participants did not
833 disclose their relationship status, and more participants were in long-term relationships
834 (married and cohabiting). The majority of participants had a secondary school education, with
835 few having formal employment and majority were without medical aid cover.

836

837 **Table 2: Health profile of the study population**

Variable	(N = 429)	(%)
Non communicable disease conditions		
Body Mass Index (BMI) (kg/m2)		
Underweight (<18.5)	36	9
Normal (18.5 – 24.9)	171	41
Overweight (25 – 29.9)	110	26
Obese (> 30)	105	25
Blood pressure (Systolic mmHg)		
Normal (< 120)	111	26
Prehypertensive (120 - 139)	197	46
Hypertension (> 140)	117	28
Blood pressure (Diastolic mmHg)		
Normal (< 80)	111	26
Prehypertensive (80 - 89)	197	46
Hypertension (> 90)	117	28
High blood sugar (mmol/l)		
Yes (Abnormal)	18	4
No (Normal)	411	96
Anaemia		
Yes	82	19
No	346	81
Antenatal care (ANC)		
Yes	9	2
No	420	98
Not Stated	1	0.2
Communicable diseases		
Human Immunodeficiency Virus (HIV)		
Positive	58	14
Negative	371	87
Sexually Transmitted Infections (STI) symptoms		
Yes	16	4
No	413	96
Tuberculosis (TB) Skin Test positive		
Yes	19	4
No	416	96
Social problems		
Witnessing of violence		
Yes	12	3
No	417	97
Emotional Problems		
Yes	25	6
No	404	94

838 Under non-communicable disease conditions, approximately 50% of participants had morbid
839 obesity, with a higher proportion (46%) of pre-hypertensive subjects and 28% with higher
840 blood pressure and other disease conditions were less than 20%. In communicable disease
841 conditions, participants with HIV positive were more as compared to those with STI
842 symptoms and TB. Few participants experienced social problems (<7%).

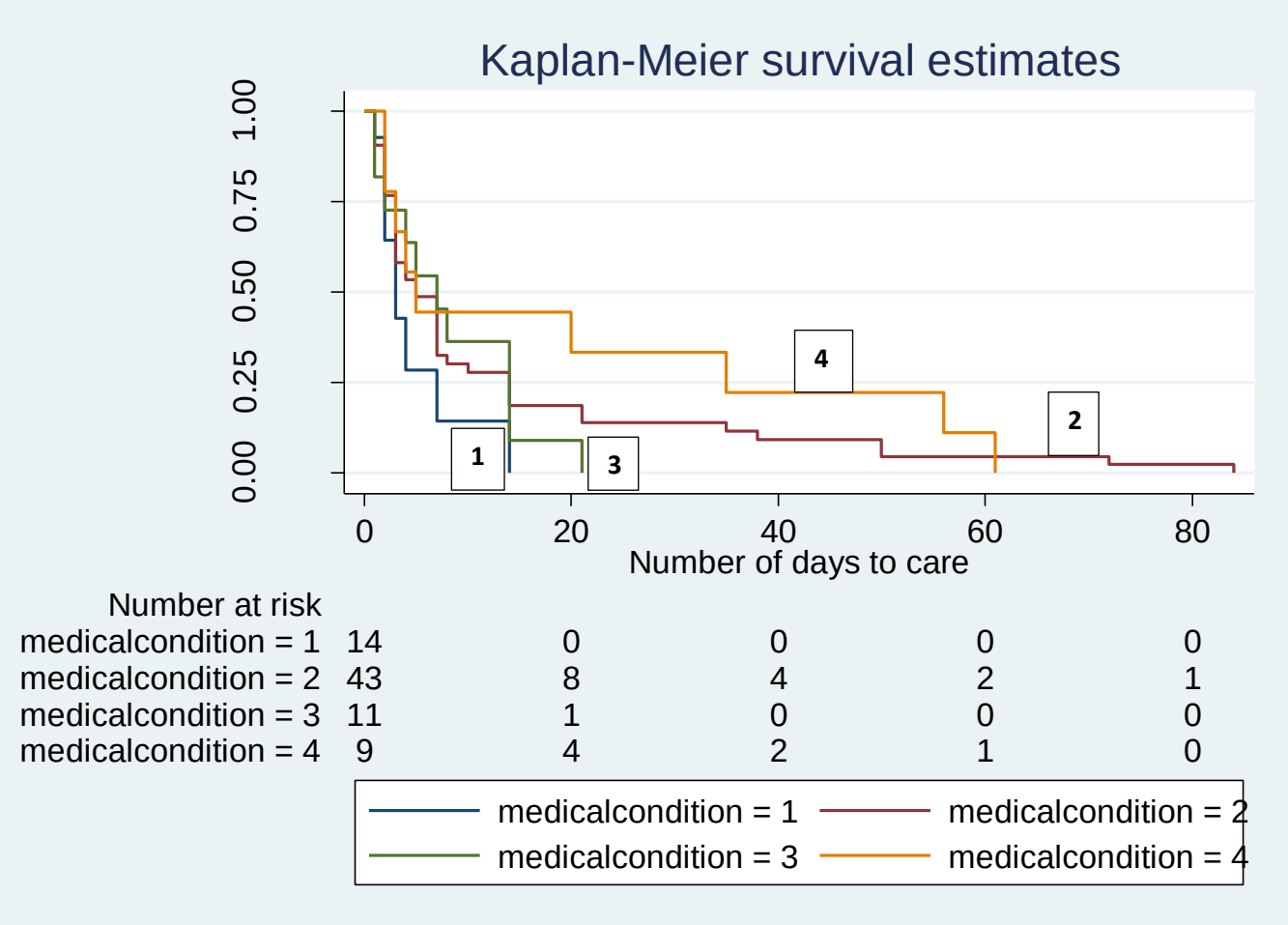

Overall
80
20
69
31
Health referral uptake and linkage to care
Witnessing of violence
83
17
67
33
Mental problems
76
24
72
28
Social problems
STI
56
44
50
50
TB skin test positive
74
26
63
37
HIV
84
16
71
29
Communicable disease
Antenatal care
22
78
22
78
High blood sugar
61
39
56
44
Anaemia
67
33
57
43
High blood pressure
75
25
69
31
Overweight and obesity
88
12
82
18
Non-Communicable conditions
0
20
40
60
80
100
% Population
Linked to healthcare status No (%)
Linked to healthcare status Yes (%)
Health referral status (No) (%)
Health referral status (Yes) (%)

843

Figure 2: Health referral uptake and linkage to care in different disease conditions

Health referral uptake and linkage to healthcare were classified according to non-communicable disease conditions, communicable disease conditions, and social problems. The health referral status has shown that a higher proportion of participants diagnosed with NCDs, CDs, and social problems did not visit the healthcare clinic. This was complemented by a low proportion of participants that were not linked to healthcare. In overall disease conditions, the participant's uptake of healthcare services was 31% and only 20% were linked to healthcare.

A total of 240 participants gave reasons for failure to adhere to healthcare referral, with patient problems 213/240 (89%) contributed more to barriers to healthcare as compared to health system problems 17/240 (7%) and health worker problems 10/240 (4%) (Supplementary Table 4.1). There were 21(66%) of participants with NCDs, 9 (28%) NCDs, and communicable diseases and 2 (6%) with mental health problems not linked to care due to reasons mentioned (Supplementary Table 4.2)**.**



1 = **Communicable diseases (CD)**, 2 = **Non- Communicable diseases (NCD)**, 3 = **Communicable diseases (CD) and Non-Communicable diseases (NCD)**, 4 = **Social problems and other medical conditions**

Figure 3: The Kaplan-Meier survival curve of participants visiting the healthcare clinics

In total, 77 participants were linked to healthcare within a period of 84 days (median = 11.4 days, IQR = 1 – 84 days) as shown by the Kaplan Meier survival curve. Within the first 20

days of receiving the health referral letters, 14 (18%) participants with CD, 43 (56%) participants with NCD, 11 (14%) participants with CD and NCD, and 9 (12%) participants with social problems and other medical conditions were linked to healthcare. Only one participant under the category of CD and NCD was linked to healthcare on day 21. Participants with social problems and NCD were linked to healthcare within 60 and 84 days respectively.

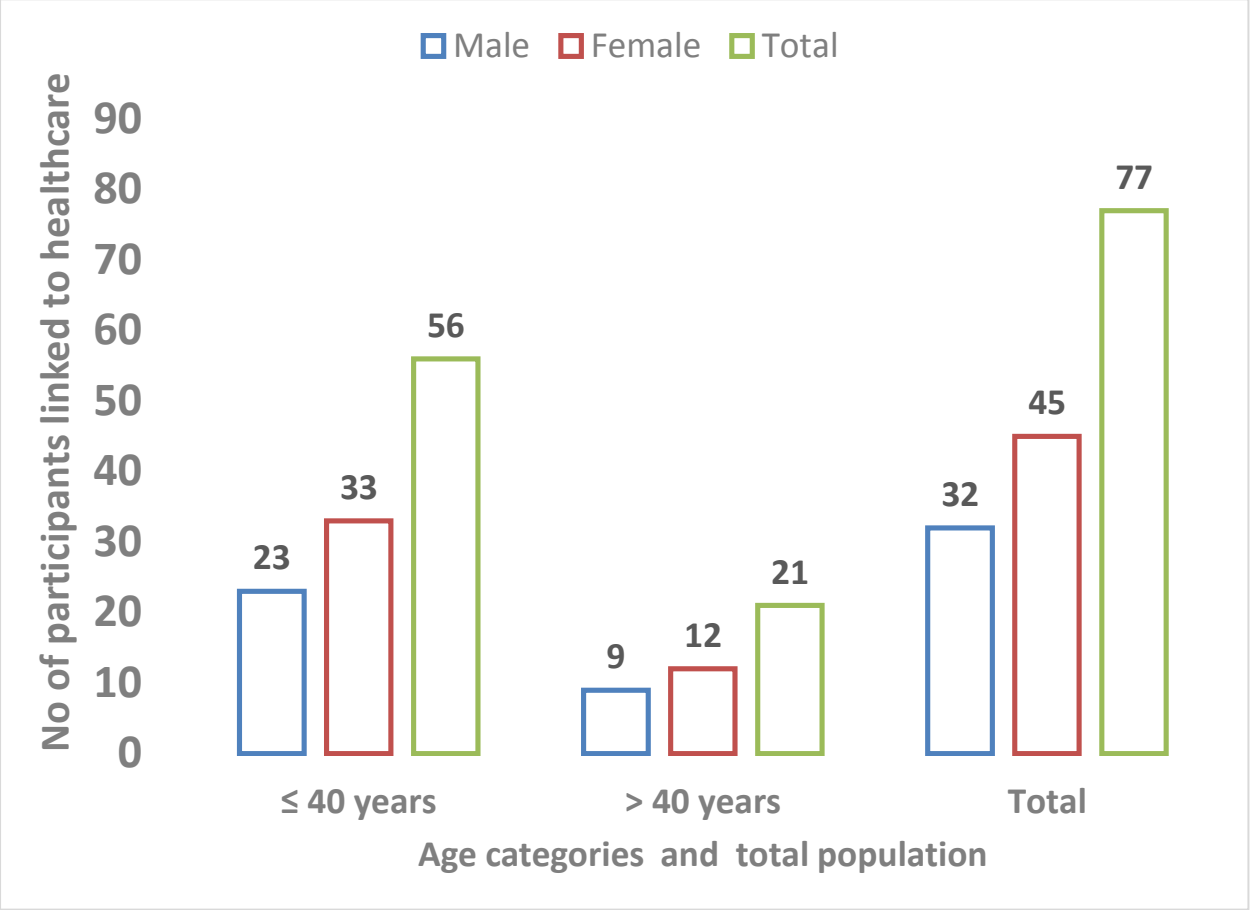


Figure 4: Age and gender population linkage to healthcare

Of the total population linked to healthcare (N = 77), younger participants were more in number with respect to their older counterparts. Irrespective of age, the number of female participants linked to healthcare was more as compared to their male counterparts.

877 **Table 3: Association of health referral uptake, linkage to healthcare with demographic status and disease conditions**

	Health referral uptake						**Linkage to healthcare**					
	Univariate Cox regression			Multivariate Cox regression			Univariate Cox regression			Multivariate Cox regression		
	Unadjusted Hazard ratio (HR)	P-Value	95% CI	**Adjusted Hazard ratio (aHR)**	P-Value	95% CI	**Unadjusted Hazard ratio (HR)**	P-Value	95% CI	**Adjusted Hazard ratio (aHR)**	P-Value	95% CI
						Socio-demographic factors						
Reference (≤ 40 years)	1						1					
Age (> 40years)	0.89	0.63	0.58 – 1.39	0.98	0.96	0.59 – 1.64	0.89	0.66	0.53 – 1.50	0.94	0.84	0.51 – 1.71
Reference (Female)	1			1			1					
Gender (Male)	1.16	0.44	0.79 – 1.72	1.14	0.60	0.68 – 1.92	1.13	0.62	0.71 – 1.79	0.99	0.54	0.54 – 1.81
Reference (Non-Disclosure)	1			1			1					
Married	0.54	0.09	0.26 – 1.11	0.58	0.18	0.26 – 1.29	0.45	0.09	0.18 – 1.13	0.47	0.14	0.17 – 1.29
Co-Habiting	0.77	0.31	0.47 – 1.27	0.90	0.74	0.49 – 1.64	0.73	0.30	0.41 – 1.32	0.75	0.44	0.36 – 1.55
Not-Married	0.96	0.88	0.57 – 1.61	0.93	0.82	0.50 – 1.73	1.02	0.95	0.56 – 1.87	1.18	0.63	0.58 – 2.42
Reference (Foreign Nationality)	1			1			1					
South African	1.42	0.17	0.86 -2.36	1.89	0.07	0.96 – 3.75	1.65	0.12	0.88 – 3.11	2.15	0.07	0.95 – 4.89
Reference (Unemployed)	1			1			1					
Self/Temporary Employment	0.77	0.29	0.47 – 1.25	0.75	0.31	0.43 – 1.31	0.98	0.95	0.57 – 1.69	1.13	0.70	0.60 – 2.12
Formal Employment	0.88	0.68	0.50 – 1.57	1.58	0.22	0.75 – 3.30	0.76	0.47	0.37 – 1.59	1.97	0.14	0.81 – 4.81
Reference (No Formal Education)	1			1			1					
Primary School Education	1.38	0.51	0.53 – 3.12	1.35	0.55	0.50 – 3.63	1.21	0.73	0.41 – 3.57	1.29	0.65	0.42 – 4.01
Secondary School Education	1.29	0.59	0.51 – 3.21	1.44	0.46	0.55 – 3.78	1.13	0.81	0.41 – 3.18	1.49	0.46	0.51 – 4.42
Tertiary School Education	1.69	0.35	0.56 – 5.07	1.16	0.81	0.34 – 3.94	1.39	0.61	0.39 – 4.97	1.15	0.85	0.28 – 4.77
Reference (No Medical Aid)	1			1			1					
Medical Aid available	2.21	0.09	0.88 – 4.67	1.34	0.18	0.73 – 5.34	1.77	0.34	0.55 – 5.74	1.53	0.53	0.44 – 5.36
Medical conditions												
Reference (Communicable Diseases)	1						1					
Non-Communicable Diseases	1.19	0.46	0.74 – 1.93	1.01	0.96	0.51 – 1.05	0.87	0.68	0.47 – 1.64	0.63	0.24	0.29 – 1.35
Emotional problems	0.79	0.62	0.32 – 1.97	0.93	0.89	0.30 – 2.86	1.08	0.87	0.43 – 2.73	1.57	0.46	0.47 – 5.20
Pregnancy	0.88	0.83	0.28 – 2.80	0.62	0.55	0.12 – 3.07	0.79	0.74	0.19 – 3.25	1.04	0.95	0.17 – 5.90

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In health referral uptake models, the univariate Cox regression results shows that married participants (HR = 0.54, 95% CI 0.26 – 1.11, p = 0.09) were less likely to take referral letter to healthcare center, while those with medical aid insurance (HR = 2.21, 95% CI 0.88 – 4.67, p = 0.09) were 2.21 times more likely to take referral letters to healthcare centre. In multivariate Cox regression, to be a South African citizen (aHR = 1.89, 95% CI 0.96 – 3.75, p = 0.07) was 1.89 times more likely of taking referral letters to healthcare center. With respect to linkage to care models, the univariate Cox regression results shows that married participants (HR = 0.45, 95% CI 0.18 – 1.13, p = 0.09) were less likely to link to healthcare. Being a South African citizen (aHR = 2.15, 95% CI 0.95 – 4.89, p = 0.07) was 2.15 times more likely to link to care. However, all variables association with health referral uptake and linkage to care did not reach 5% level of statistical significant.

DISCUSSION

Key findings

The present study showed the results of community multi-screening of diseases in an urban informal settlement of households survey in Diepsloot. A small percentage of participants 25% (109/429) took health referral letters to the clinic and linked to care 71% (77/109). Over 55% (240/429) of the study participants did not visit the healthcare facilities and fewer than 20% (80/429) were lost to follow-up. The majority of the participants have highlighted patient problems 89% (213/240) as their main barrier for low uptake of healthcare services. Participants were linked to care in a period of approximately three months, but participants with NCDs took a long time to link to care as compared to other disease conditions. The association of health referral uptake and linkage to care with socio-demographic factors and medical conditions were mixed, but with no statistical significance.

Health referral uptake and linkage to healthcare

Multi-screening of diseases is an essential tool in public healthcare for disease awareness so that people suspected of diseases can access healthcare at the nearest healthcare center. However, there has been a mixed bag of results with regards to health referral uptake and linkage to healthcare reported from SSA and elsewhere [27-33]. Interestingly, studies with better referral uptake and linkage to healthcare were reported in areas where participants were given transport money and accommodation at healthcare center [30], in medical adherence clubs where participants have knowledge of disease conditions [28] as compared to areas with no knowledge of disease conditions [27] and low economic resources to access healthcare [34, 35]. In the present study, participants were told about the importance of their disease conditions by CHWs but there was still low health referral uptake (31%) and low linkage to healthcare (20%), which is a finding commonly found in low resource settings [34, 36, 37].

In terms of disease conditions, non-communicable diseases have been reported to have low referral uptake and linkage to care [13, 27], whereas communicable diseases have better health referral uptake and linkage to healthcare [31, 38, 39]. Researchers have attributed differences in health referral uptake and linkage to healthcare between NCDs and CDs to their differences in symptoms [40-42]. However, low referral and linkage to healthcare is often found in CDs like HIV in situation where participants are asymptomatic [14], stigmatize and in denial [43-45] or in fear of disclosing sickness to family or spouse [46]. In the present study health referral uptake of NCDs, CDs and social problems were approximately 30% and linkage to healthcare was approximately 20%. The exact reasons for low health referral uptake and low linkage to care are not known. But a study in Tanzania have found that low access to healthcare in people suspected of diseases was due to unawareness of the ripple effects of their disease conditions [27].

Factors associated with health referral uptake and linkage to healthcare

Uptake of healthcare services and linkage of patients into healthcare is influenced by several factors. Health referral uptake and linkage to healthcare were found to be significantly associated with older age, high socio-economic status (SES), increased educational level, knowledge, broader media information channels, partnership status, medical condition to name but a few [13, 47-50]. In contrast to other studies, health referral uptake and linkage to care of the present study were not significantly associated with socio-demographic factors and medical conditions. Authors suggest that lack of association of health referral uptake with old age may be due to the

fact that, older individuals may not have time to go to clinic due to household chores or taking care of grandchildren or knocking late at work as reported by other researchers [8, 15] and may also be related to low SES [34, 36]. There was also a lack of association of referral uptake with medical conditions, which authors are speculating that some study participants may not have taken their disease conditions seriously hence not visiting the healthcare centers [27] or decide to look for healthcare elsewhere [51].

Linkage to healthcare has been reported to differ by disease conditions, with CDs been associated with better linkage to care as compared to NCDs [29, 48, 49]. Concerning CDs, patients diagnosed with HIV and TB were found to have increased linkage to care which was attributed to social support [29, 49]. On the contrary, poor linkages to care to patients diagnosed with NCDs have been viewed as a huge public health challenge [51, 52]. In the present study, the association of linkage to care with disease conditions did not reach statistical significance, which was in contrast to other studies [48, 49, 51]. Overall, authors are suggesting that low referral uptake may have contributed to compromised linkage to care.

Duration of healthcare linkage

Time to healthcare linkage has been reported as crucial in disease treatment to avoid disease complications and infections [15]. In the present study, linkage to healthcare in participants was in approximately 3 months, which showed delayed linkage to care in participants diagnosed with diseases. Linkage to healthcare was more in the younger age group ($\leq$ 40 years) as compared to the older age group. Besides, females were more linked to healthcare as compared to male counterparts, which are findings reported by other researchers [53, 54]. These may refer to a situation where men are not eager to be screened for suspected medical conditions or are not enrolled due to work-related commitments [51].

Barriers to healthcare access

In low resource settings, access to healthcare is a serious challenge because of numerous barriers to healthcare. In most settings, transport challenges, long-distance to healthcare centers, agricultural work, ill-equipped health facilities, lack of formal education, poverty, difficulty in getting money for treatment and dilapidated infrastructure form part of the top list of inadequate access to healthcare [20, 55-59]. Barriers to healthcare were similar to those reported in SSA, however, in the present study the groups were divided into health system problems, patient problems, and health workers' problems. The patient problems (reluctant to go to clinic, condition cannot be cured, referral not received or lost, personal problems, out of Gauteng Province, financial problems) were found to have contributed approximately 213/240 (89%) of inadequate access to healthcare as compared to other barriers (health system problems and health worker problems). Furthermore, 66% of participants with NCDs, 28% with communicable and NCDs, and 6% with mental problems were not linked to healthcare. Common stated reasons were, reluctant to take medicine, no cure and participant denial of the disease condition. These may result in premature deaths that can be prevented and controlled through the treatment of taking drugs at the nearest healthcare facility [60-62].

The strength and limitation of the study

The strength of the present study was due to its prospective cohort design, its ability to comprehensively screen many diseases and the ability to control potential confounders by

multivariate Cox regression analysis. Unlike other studies that had followed-up participants for a maximum of 6 months or more [31, 63], the present study was limited by a short period of participant's follow-up of a minimum of 14 days. These might have contributed to a loss of follow-up of participants in the study. Authors are anticipating that if the period of follow-up was longer, more participants would have linked to healthcare. Furthermore, authors are speculating that loss to follow-up might be due to the migration of participants, which may be another limitation of the present study.

Conclusion and recommendations

There was low uptake of healthcare services and low linkage to healthcare, which may result in devastating medical conditions and mortality in the future.

It is recommended that more resources should be directed towards CHWs empowerment in terms of multi-disease training, in-depth disease knowledge for better patient-counseling, health seminars and better reimbursement. This would help in reducing patient problems and may stop CHWs from seeking employment elsewhere, which will result in communities benefiting from their experience. The authors further recommend that CHWs should educate community members on the importance of accessing healthcare services at the nearest healthcare center, to avoid complications of late disease presentation. CHWs should conduct multi-disease screening and awareness in disadvantaged communities on a yearly basis to improve healthcare uptake and linkage to healthcare.

CHAPTER 4 SUPPLEMENTARY RESULTS

This section of the dissertation comprises of the supplementary results that were discussed in the paper.

Supplementary Table 4.1. Reasons for not adhering to health referral letters

Reasons	Number (N = 240)	Percentage (%)	Overall percentage (%)
Health System Problems			
Long queues at the clinic	17	7	7
Patient Problems			
Reluctant to go to clinic	114	48	89
Condition cannot be cured	35	15	
Referral not received or lost	22	9	
Personal problems	19	8	
Out of Gauteng Province	11	4	
Financial problems	12	5	
Health Worker Problems			
Rude health workers	10	4	4

Patient problems (89%) formed a major bulk of reasons why participants did not honor their health referral letters. Specifically, reluctance to go to clinic (48%) and conditions cannot be cured (15%) were found to be common. Health system problems and health worker problems contributed to less than 12% of the reasons.

Supplementary Table 4.2. Reasons for failure to link to healthcare according to disease conditions

Disease conditions	Number (%)	Number	Reason for not linked to health care.
NCD	21 (66%)	5	Test normal at the healthcare facility.
		5	Patient reluctant to take medication.
		5	No cure.
		4	Patient opted for an alternative treatment.
		1	Patient still thinking of starting treatment.
		1	Patient doesn't believe in treatment.
Communicable and NCD	9 (28%)	3	Patient still thinking of starting treatment.
		3	Patient denial of disease condition.
		1	Patient reluctant to visit healthcare facility.
		1	Patient still searching for information on treatment.
		1	No medication at the clinic and patient advised to come after one week.
Social problems	2 (6%)	2	Patient doesn't believe in counselling.

Common reasons for not linking to healthcare were test normal at the healthcare facility, patient reluctant to take medication and no cure, which were found in participants with NCDs (66%). Participants with a combination of communicable and NCDs were less than 30% with common reasons for not linking to healthcare being patient still thinking of starting treatment and patient denial of disease condition. Participants with social problems did not believe in counseling.

CHAPTER 5 OVERALL CONCLUSION

Reports have shown that communities in informal settlements and slums are not easily accessing healthcare services [27, 30, 31, 64] but not in all studies [31, 65]. In strengthening the health system, developing countries have introduced CHWs to their governments in order give a helping hand to healthcare [18, 66]. The present study has showed the importance of CHWs and nurses in bringing healthcare services closer to the people in Diepsloot informal settlement through multi-disease screening in their various households. However, the main barriers to healthcare access in the present study were reported to be patient problems (89%), health system problems (7%) and health worker problem (4%). Although the community was concertized about their various disease statuses, there was low healthcare referral uptake and low linkage to healthcare in majority of the participants. More studies with larger sample sizes are warranted to unravel the gray areas associated with healthcare referral uptake and linkage to care.

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Appendix i – BMC Public Health Authors Guidelines

Title page

The title page should:

- present a title that includes, if appropriate, the study design e.g.:
    - "A versus B in the treatment of C: a randomized controlled trial", "X is a risk factor for Y: a case control study", "What is the impact of factor X on subject Y: A systematic review"
    - or for non-clinical or non-research studies a description of what the article reports
- list the full names, institutional addresses and email addresses for all authors
    - if a collaboration group should be listed as an author, please list the Group name as an author. If you would like the names of the individual members of the Group to be searchable through their individual PubMed records, please include this information in the "Acknowledgements" section in accordance with the instructions below
- indicate the corresponding author

Abstract

The Abstract should not exceed 350 words. Please minimize the use of abbreviations and do not cite references in the abstract. Reports of randomized controlled trials should follow the CONSORT extension for abstracts. The abstract must include the following separate sections:

- **Background:** the context and purpose of the study
- **Methods:** how the study was performed and statistical tests used
- **Results:** the main findings
- **Conclusions:** brief summary and potential implications
- **Trial registration:** If your article reports the results of a health care intervention on human participants, it must be registered in an appropriate registry and the registration number and date of registration should be in stated in this section. If it was not registered prospectively (before enrollment of the first participant), you should include the words 'retrospectively registered'. See our editorial policies for more information on trial registration

Keywords

Three to ten keywords representing the main content of the article.

List of abbreviations

If abbreviations are used in the text they should be defined in the text at first use, and a list of abbreviations should be provided.

Declarations

All manuscripts must contain the following sections under the heading 'Declarations':

- Ethics approval and consent to participate
- Consent for publication
- Availability of data and material
- Competing interests
- Funding
- Authors' contributions
- Acknowledgements
- Authors' information (optional)

Ethics approval and consent to participate

Manuscripts reporting studies involving human participants, human data or human tissue must:

- include a statement on ethics approval and consent (even where the need for approval was waived)
- include the name of the ethics committee that approved the study and the committee's reference number if appropriate

Studies involving animals must include a statement on ethics approval.

See our editorial policies for more information.

If your manuscript does not report on or involve the use of any animal or human data or tissue, please state "Not applicable" in this section.

Consent for publication

If your manuscript contains any individual person's data in any form (including individual details, images or videos), consent for publication must be obtained from that person, or in the

case of children, their parent or legal guardian. All presentations of case reports must have consent for publication.

You can use your institutional consent form or our consent form if you prefer. You should not send the form to us on submission, but we may request to see a copy at any stage (including after publication).

Appendix ii – Plagiarism Declaration



PLAGIARISM DECLARATION TO BE SIGNED BY ALL HIGHER DEGREE STUDENTS

SENATE PLAGIARISM POLICY: APPENDIX ONE

I _____ (Student number: _____) am a student

registered for the degree of _____ in the academic year _____.

I hereby declare the following:

- I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledging the original source) is wrong.
- I confirm that the work submitted for assessment for the above degree is my own unaided work except where I have explicitly indicated otherwise.
- I have followed the required conventions in referencing the thoughts and ideas of others.
- I understand that the University of the Witwatersrand may take disciplinary action against me if there is a belief that this is not my own unaided work or that I have failed to acknowledge the source of the ideas or words in my writing.
- I have included as an appendix a report from "Turnitin" (or other approved plagiarism detection) software indicating the level of plagiarism in my research document.

Signature: _____ Date: _____

Appendix iii – Human Research Ethics Committee (Medical)

R14/49 Mr Machuene Ananias Poopedi

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

CLEARANCE CERTIFICATE NO. M151178

NAME: (Principal Investigator)	Mr Machuene Ananias Poopedi
DEPARTMENT:	Public Health University of the Witwatersrand
PROJECT TITLE:	Evaluation of Health Referral Uptake and Linkage to Health Care After Community-Based Disease Screening in Urban Informal Settlement, South Africa
DATE CONSIDERED:	27/11/2015
DECISION:	Approved unconditionally
CONDITIONS:	
SUPERVISOR:	Jabulani Ncayiyana and Zodwa Ndlovu
APPROVED BY:	Professor A Dhai, Co-Chairperson, HREC (Medical)
DATE OF APPROVAL:	14/12/2015

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

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Secretary in Room 10004, 10th floor, Senate House, University.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated, from the research protocol as approved, I/we undertake to resubmit the application to the Committee. **I agree to submit a yearly progress report.**

Principal Investigator Signature

Date 15/12/2015

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES