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FACULTY OF HEALTH SCIENCES
SCHOOL OF PUBLIC HEALTH

Factors associated with timely referral of cancer patients for palliative care services at Chris Hani Baragwanath Academic Hospital, Johannesburg

By

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A research report submitted to the Faculty of Health Sciences in partial fulfillment of the requirement for a Master of Science degree in Epidemiology in the Field of Implementation Science.

August 2024

DECLARATION

I, Sabelo Msomi, declare that this research report is my original work. It is being submitted for the degree of Master of Science in Epidemiology at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at any other university.



_____

(Signature of Candidate)

Date: 11August2024

DEDICATION

This research is dedicated to my late mother Nokuthula Adelaide Msomi who transcended November 2023. This is for her resilience, undisputed love, and support throughout my life and academic endeavors.

ACKNOWLEDGEMENTS

Glory to God and my forefathers for the strength to persevere and the wisdom to conquer this academic training. Firstly, I would like to appreciate and thank supervisors Prof. Latifat Ibisomi and Dr.Mpho Ratshikana for their unmatched guidance, wisdom, and mentorship throughout my academic training for the degree.

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ABSTRACT

Background: In a South African context, palliative care (PC) is defined as a holistic approach to care and support for patients and their families facing life-threatening illnesses. Referral of cancer patients to PC tends to happen late, especially when the disease has progressed significantly due to various referral factors, with 14%-30% being the prevalence of timely referrals to PC. This study aims to investigate factors associated with timely referrals of cancer patients to PC services at CHBAH, August 2021 – July 2022. The main objective is to determine the prevalence of timely referrals.

Method: A retrospective cross sectional study design and secondary data analysis were used to address the aim and objectives. STATA SE version 17 was used to conduct statistical analyses to determine the prevalence of timely referrals. The trend in referral time from diagnosis to PC for cancer patients was assessed using Kaplan-Meier survival analysis. This analysis was stratified by sex, referral place, cancer type, and healthcare provider. Significant differences between groups were evaluated using the log-rank test. Referral times within 90 days of diagnosis were categorized as "timely referral" while those occurring after 90 days were considered "no timely referral" Logistic regression analysis was performed to identify the influence of sociodemographic and clinical factors on the likelihood of a timely referral.

Results: The probability of a cancer patient not being referred decreased steadily over the study period; of the 459 patient records that were analyzed, only 63 (13.7%) cancer patients were timely referred to PC. Forty-four (44) (69.8%) of patients who were timely referred to palliative care were from CHBAH wards as opposed to 21(30,2%) those referred timely from the 3 places of referral. The results from this category were significant, with a p-value <0.01. The log-rank test indicates

that the time it takes for a patient to be referred significantly depends on the place of referral (p-value < 0.01), and this is supported by the logistic regression results.

Further, the odds of referring cancer patients with stage 4 cancer to PC are 1.49 times (OR:2.49, 95%CI (1.01-6.17)) more likely than of Stage 1& 2 cancer patients in the adjusted model. This indicates that stage 4 cancer patients are more likely to be referred to palliative care than stage 1 cancer patients. In the unadjusted model, lung cancer patients are 1.81 times (OR:2.81, 95%CI (1.03-7.60)) more likely to be referred to PC compared to breast cancer patients.

Conclusion: Healthcare providers play an important role in aiding timely referrals. PC knowledge and acceptability from healthcare providers can exert a positive impact on increasing the number of cancer patients referred timely. This study contributes to the body of knowledge relating to PC and provides insights into significant factors for referring cancer patients to PC services. CHBAH must prioritize and institutionalize referral guidelines that encourage timely referrals to PC to ensure that cancer patients receive timely access to PC.

Keywords: Palliative care, Timely referral, Cancer patients, Life-threatening illnesses, Cancer staging, Quality of life

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LIST OF ACRONYMS

ACP	Advance Care Planning
AIDS	Acquired Immuno-Deficiency Syndrome
ART	Antiretroviral Treatment
CFIR	Consolidated Framework for Implementation Research
CHBAH	Chris Hani Baragwanath Academic Hospital
ECOG	Eastern Cooperative Oncology Group
NDoH	National Department of Health
HCPs	Healthcare Professionals
HIV	Human Immunodeficiency Virus
HREC	Human Research Ethics Committee
NPFSPC (2017-2022)	National Policy Framework and Strategy for Palliative Care 2017-2022
OPD	Outpatient Department
PC	Palliative care
PLHIV	People living with HIV
WHA	World Health Assembly
WHO	World Health Organization

DEFINITIONS OF KEY TERMS

Palliative Care: refers to the holistic multi-disciplinary care of a patient and family affected by a life-threatening illness, applicable from the time of diagnosis for all adults and children across the life span and includes bereavement care for the family(1)(2).

Life-threatening illness: Refers to a condition in adults where there is a greater chance of death for which curative treatment is feasible but may not work(1)(3).

Terminal Illness: Refers to an irreversible life-limiting illness for which there is no cure and will result in an inevitable decline in function until the end of life(1).

Non-communicable condition: Refers to a medical condition or disease that is non-infectious or non-transmissible(1).

Advance care planning: entails discussing and preparing for future decisions about the patient's medical care as the patient becomes seriously ill or unable to communicate their wishes(1).

Outpatient department: Refers to the day clinic for patients who visit the hospital for diagnosis or treatment, but do not require a bed or to be admitted for overnight care(4).

Palliative care intervention: Refers to mediation that is introduced as the patient approaches end-of-life care during a life-threatening illness and addresses total pain which includes physical, social, emotional, and spiritual pain(1)(5).

Malignancies: Refers to the presence of a cancerous tumour (6,7).

Pain management: Refers to a multi-dimensional approach using an interdisciplinary team to address total pain of a patient. This includes pharmacological, non-pharmacological, physiotherapy, and occupational therapy interventions to reduce pain from acute and minor to chronic illnesses(1, 8).

National Policy Framework and Strategy for Palliative Care (NPFSPC)-2017-2022: Refers to the national policy framework that provides guidance and a framework for planning the improvement and delivery of palliative care services in South Africa(1, 3).

Quality of life: Refers to an individual's perception of their position in life, in respect to their culture and value systems in which they live and relating to their goals, standards, expectations and concerns(9, 10).

Holistic palliative care treatment refers to a comprehensive treatment approach that addresses the physical, psychosocial, and spiritual aspects of palliative care (11).

Cancer staging: refers to the extent and severity of your cancer, including the size of the tumor and how much it has spread (6).

Timey referrals: refers to the referrals conducted within 90 days from the time of diagnosis for patients with life threatening illnesses(12**,** 13**,** 14).

CHAPTER 1 – INTRODUCTION

1.0 Introduction of the chapter

This chapter provides a background on palliative care services (PC) globally and from a South African context. It further explains the need and impact of PC services amongst cancer patients. The problem statement, justification, research question, aim, and specific objectives of this study are also outlined.

1.1 Background

According to the World Health Organization (WHO), PC is a comprehensive patient care approach that enhances the quality of life of patients and their families, who face life-threatening illnesses by preventing and relieving needless suffering (15). PC covers the physical, psychosocial, and spiritual aspects of illness and provides people with a voice in determining their care at the end of life (1) (10)(3). In South Africa, PC is a holistic approach to care and support for patients and their families facing life-threatening illnesses(3). The main aim of PC is to improve the quality of life by preventing and reducing suffering through early identification, assessment, and management of pain and other physical, spiritual, or psychosocial conditions from the time of diagnosis to the end of life (3).

Non-communicable diseases are prevalent in South Africa, where there has been a notable increase in reported cancer cases (5). The most prevalent cancers among South African men are prostate (25%), basal cell carcinoma(BCC) (21%), squamous cell carcinoma(SCC) of the skin (15%), colorectal (6%), and lung (4%) (15, 5). The top five cancers in women are breast (23%), cervix (16%), basal cell carcinoma (BCC) (15%), squamous cell carcinoma (SCC) of skin (7%) and colorectal (4%) (5, 15).

The Wits Centre of Excellence for Palliative Care located at Chris Hani Baragwanath Academic Hospital (CHBAH) in Johannesburg provides PC services to many patients diagnosed with life-threatening illnesses (16). Seventy percent (70%) of patients are diagnosed with only cancer, 25% are diagnosed with both cancer and Human Immunodeficiency Virus (HIV), and 5% are diagnosed with other non-cancer life-threatening illnesses (17). These patients have a significant number of symptoms, and without PC intervention, most of the patients suffer physically, emotionally, and spiritually (17).

There is an urgent need to close the gap in accessing PC and management of pain around the world, which is now in crisis (18). South Africa is no different as it is faced with the same challenge. The National Policy Framework and Strategy for Palliative Care (NPFSPC) 2017-2022 was approved and implemented in 2017 by the National Department of Health (NDoH) to address the disparities in access to and the provision of comprehensive PC (1). The NPFSPC aims to improve the quality of life of patients who need PC through mitigating suffering and ideal PC assessment (3). According to the NPFSPC, life-threatening conditions have a long trajectory, and patients' and caregiver's needs differ throughout an illness. Providing PC earlier improves the quality of life of the patients and their families while allowing patients to communicate their wishes and live longer with a life-threatening illness (3).

The NPFSPC is meant to assist policymakers, health programs, professionals, and workers in the health department and Non-governmental organizations (NGOs) by providing guidance for the provision of PC and understanding the need for such services (1,3,19). Furthermore, the NPFSPC acts as a road map and planning framework for the development of PC services in South Africa,

while highlighting the population's need for PC and the difficulties in providing it (3). Planning includes providing a step-by-step approach to the need for PC, its provision, who is eligible, and where to access services. The NPFSPC addresses the structural challenges and burden of life-threatening diseases in line with the 2014 World Health Assembly (WHA) Resolution 67.19 on PC, which states the importance of the provision of palliative care across all levels of healthcare (1, 20).

Care and support needed for a PC patient is from the time of diagnosis and varies according to the patient's needs. This includes different levels of support consisting of physical, psychosocial, and spiritual care (19). Key personnel who provide a basic package of care for a PC patient include nurses, doctors, social workers, and spiritual counselors. Other healthcare providers can be called in, depending on a patient's need and the level of function (1).

Timely referral to PC is considered effective in supporting advanced care planning that helps patients and their families with symptom management (12, 21). The early involvement of PC allows for the identification of symptoms such as pain and depression which are detected through PC assessments. Early detection of these symptoms assists with avoiding the risk of symptom crises needing emergency interventions which are particularly experienced at the end of life (22, 23).

1.2 Problem statement

According to the WHO, about 40 million people need PC worldwide, but only 14% of people receive PC (24). Only 14-30% of patients are referred timeously to PC (25). Referral of cancer patients to PC tends to happen late when the disease has progressed significantly (26, 25). PC services have been available for the past 23 years at Chris Hani Baragwanath Academic Hospital, with cancer patients being referred from various areas in the hospital (17). However, a low

prevalence of timely referrals has been noted (there is some evidence, but more is needed), leading to cancer patients receiving PC later in the disease course.

There is an urgent need to increase the prevalence of timely referrals and bridge the gap between cancer diagnosis and referral to PC to ensure that patients are referred in time (3, 17, 27). This study aims to investigate and identify factors associated with the timely referral of cancer patients for PC services at Chris Hani Baragwanath Academic Hospital.

1.3 Justification

PC is intended to increase the comfort of patients and their families by alleviating the effects of life-threatening illnesses and reducing pain and stressful symptoms. This study will provide evidence on the factors that affect timely referral of patients to PC. If the factors are identified and addressed, then the timely application of PC services may be enhanced, leading to increased utilization of the services by patients and their families, resulting in an improved quality of life and better health outcomes (28). The results of this study will provide insights into bridging the gap between cancer diagnosis and referral to PC services. Furthermore, the findings of this study will be used to prioritize and institutionalize referral guidelines that encourage timely referral to PC services.

1.4 Research question

What are the factors associated with timely referral of cancer patients for palliative care services at Chris Hani Baragwanath Academic Hospital, Johannesburg?

1.5 Aim

To investigate factors associated with timely referral of cancer patients for palliative care services at Chris Hani Baragwanath Academic Hospital from August 2021 – July 2022.

1.6 Specific Objectives

1. To determine the time taken for a cancer patient to be referred for palliative care at CHBAH, from August 2021-July 2022.
2. To determine the prevalence of timely referrals by the sociodemographic and clinical factors of cancer patients for palliative care at CHBAH, from August 2021-July 2022.
3. To identify factors associated with timely referral of cancer patients for palliative care at CHBAH, from August 2021-July 2022.

CHAPTER 2 – LITERATURE REVIEW

2.0 Introduction of the chapter

In this chapter, a review of the literature is provided, outlining the need for PC amongst cancer patients globally and from a South African context. Furthermore, the current prevalence of timely referrals has been explored, which includes factors associated with timely referral of cancer patients for PC are explored as well. The conceptual framework used for this study research is adapted from the socio-ecological model by Mosley and Chen, used to study the determinants of child survival (29).

2.1 Palliative Care in South Africa

Since 1979, South Africa has been actively involved in delivering PC and has a thriving PC community (3, 30). PC stemmed from a hospice concept responding to the need to alleviate pain and suffering for patients with life-threatening illnesses, thus providing patients with a voice to determine their care at the end of life (3). PC focuses on physical comfort, alleviation of symptom distress, as well as social and emotional needs to improve health outcomes. Patients who are diagnosed with cancer and receive integrated PC early, have a better quality of life and prolonged survival (12). Based only on mortality data of natural deaths, most of the reported deaths are due to illnesses that requires PC (3, 31).

South Africa strives toward the vision to provide critical PC services to all adults and children, including their families, who are faced with difficulties associated with life-threatening illnesses (3). Many hospitals have developed PC services and further initiatives to integrate services into primary healthcare setting has been established (2, 3, 32).

The focus of multidisciplinary PC is on patients and their families. It incorporates providing treatment to patients and supporting their families as the disease progresses, in its advanced stages,

and leading to the final hours before death. PC ought to be made available as soon as a diagnosis is made and is based on the fusion of conventional medicine with alternative and holistic treatment (33). The main goal of PC is to enhance the patient's quality of life by improving their ability to achieve personal goals, such as symptom control and social support while setting realistic expectations. This is achieved through a holistic PC approach which includes clinical assessments, counseling and communication (3, 34). PC includes assisting patients to make informed decisions about their treatments to ensure that they receive the best possible care (3).

2.2 Palliative continuum of care

As shown in Figure 1, the concept of PC has evolved beyond the end-of-life service to encompass a holistic approach from diagnosis of a life-threatening illness. This includes disease management and support for families and caregivers. The old concept of the PC continuum showed that PC was offered when curative treatment was not an option, whereas the new concept shows that PC must be offered from diagnosis (34). This progression came through an increased awareness that life-threatening illnesses may have a long trajectory, while patients and their families may have different needs over the disease course (30).

The shift to provide PC at diagnosis has been influenced by evidence that PC can alleviate unnecessary hospital admission and use of healthcare services , ultimately reducing the cost burden in the health system (3).

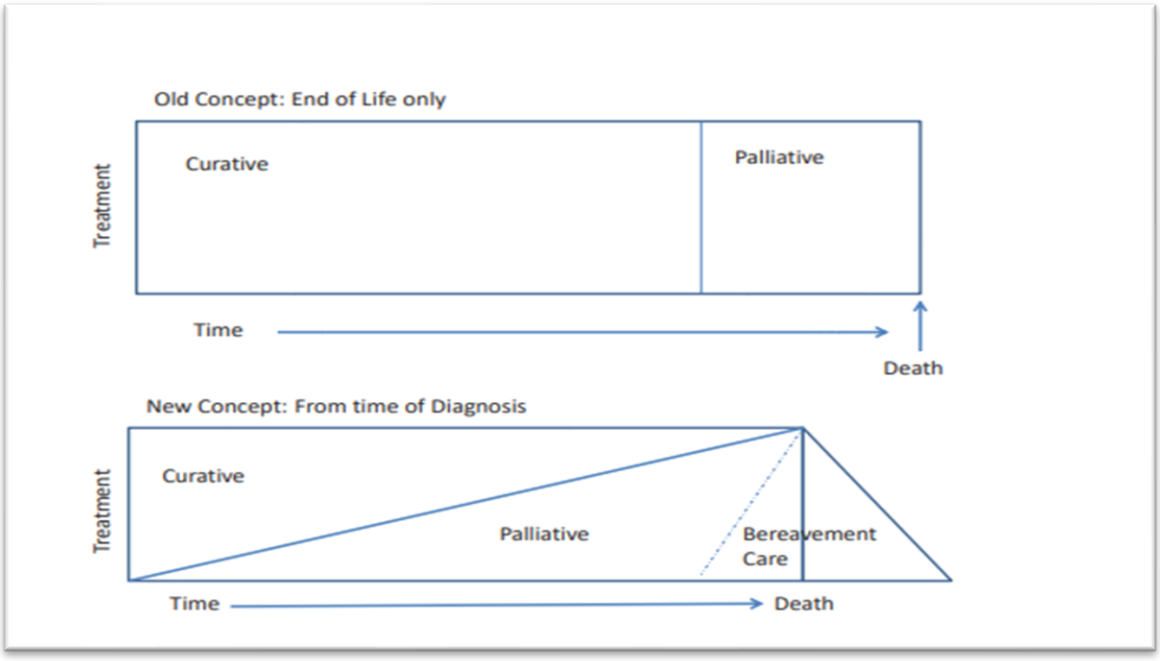


Figure 1: Old and new concept of the palliative continuum of care. Source Lynn et al. 2003.

2.3 Palliative care gaps

Large gaps in the continuum of PC result from a serious lack of efficient communication and well-defined care routes between service providers (35). To provide continuity of treatment throughout the illness, individuals in need of PC must be identified early and enrolled into a particular care pathway with clear referral protocols. Regardless of the prognosis, early identification of individuals in need of PC can be accomplished by understanding when the patient is eligible for PC and where are the services offered (3).

2.4 Referrals factors

Many factors are considered when it comes to referrals to PC services. Referral factors such as the health facility where the cancer diagnosis was confirmed and the health care provider who initiates the referral are considered to be crucial in aiding the referrals (36). Clinicians or healthcare providers who are aware of PC play a vital role in initiating the referral for PC at diagnosis (37).

Referrals to PC facilitate discharge planning, clarify goals of care, offer psychosocial and spiritual support, and enhance symptom management (36). Incorporating PC into active oncologic treatment at the right time has been linked to many advantages, including increased survival rates and improved quality of life, symptom burden, prognostic awareness, patient and family satisfaction, and cost-effectiveness of care (14).

2.4.1 Timely Referral

The National Policy Framework and Strategy for Palliative Care (NPFSPC)-2017-2022 states that referral to PC must occur from the time of diagnosis and should not be delayed to the end of life where curative treatment becomes less important as the health function of the patient deteriorates over time (3). According to Hausner and colleagues, 14%-30% is the prevalence rate of early referrals to PC (25). The timing of referral is categorized according to the date of diagnosis and cancer staging (38). According to Hui and colleagues, what constitutes a timely referral has not been established. However, early PC typically involves referring patients within 2–3 months from diagnosis. Care

Timely referral to PC is considered effective at minimizing the patient's and caregiver's distress to ensure a moderate quality of life and that appropriate health and social support measures are taken at end-of-life care. Early referrals are essential for improving treatment outcomes since both curative treatment and PC are provided concurrently(12, 25). Social support including ongoing counseling for both patient and family tends to be beneficial since holistic services are offered from the beginning of the life-threatening illness (39). Patients who are well informed about their prognosis and are given the chance to express their preferences for care are more likely to receive

chemotherapy and a strong emphasis on symptom management that best matches their preferences as reported by the patient or their caregivers (14).

2.5 Socio-demographic factors

2.5.1 Race of a patient

Socio-demographic disparities among the previously disadvantaged groups of patients, such as Blacks, Hispanics, and Indians have been highlighted when addressing the course of delays in timely referral as compared to White patients (40). In a study by Koffman et al, aimed at exploring awareness of PC and analyzing the relation between demographic characteristics, knowledge and awareness of Pc is low among the black and Indian ethnic groups. The lack of knowledge and awareness contributes to the low number of patients timely referred for PC related services (41).

2.5.2 Age and sex of a patient

The relationship between demographic characteristics and knowledge of PC was further explored in the study by Koffman et al, based on the study results, sex and age appear to be a critical factor when it comes for palliative care referrals. Females and elderly patients are more likely to be referred to PC related services as compared to males and younger patients (41).

2.5.4 Healthcare provider and place of referral

Healthcare providers are the pillars in aiding timely referrals for PC, and their role is to ensure that patients receive the best possible treatment following their confirmed diagnosis (42, 43). In a study by Enguidanos et al, exploring healthcare provider perceived challenges to PC patient referral, barriers included lack of PC knowledge, clarity regarding referral processes, inadequate communication skills , healthcare provider culture and reluctance to refer to PC (43). As part of continuity of care and managing the healthcare needs of patients, timely referrals are crucial from

the initiating facility to the next facility that can better provide the appropriate level of care required (44). In the NPFSPC, PC referrals are mandatory from the initiating facility, to ensure that patients diagnosed with life-threatening illnesses receive timely PC services (3).

2.5.5 Other demographic factors

In other studies, socio-demographics which are frequently tied to race, marital status, employment status, level of education, and health literacy, have been linked to a high volume of referrals that occur at advanced stage of the disease and the end-of-life care (45, 46). Significant implications of initiating PC referrals based on social and economic status have been highlighted by many research studies. Most commonly noted disparities are among socially and economically marginalized groups of people, such as Blacks, Hispanics, and Indians when compared to Whites. Healthcare disparities are well documented across the healthcare sector and dissimilarities in quality of service, access to care, and health outcomes continue across demographic groups. Socioeconomic status, including education, and health literacy, and often linked with race, have been associated with higher intensity end-of-life care and decreased engagement.

This practice perpetuates a negative stereotype against certain populations, leading to health provider bias in the provision of healthcare(45, 40).

2.6 Clinical characteristics

2.6.1 Cancer type

In South Africa, breast, cervical, basal cell cancer, colorectal, and lung cancers are the most frequently diagnosed cancers among women, whereas prostate, basal cell cancer, colorectal, and lung cancers are the most frequently diagnosed cancers among men (47). There are more than a

hundred different kinds of cancer, each with a unique behavior and response to treatment(48). Since cancer results from the abnormal multiplication of any type of cell in the body(48), It is best practice that once the cancer diagnosis is confirmed, PC should be offered although tumor-specific treatment can be given in parallel(49). Different cancer types have specific symptom clusters and disease trajectories and some of the healthcare providers have reported that these aspects influence their decisions to refer patients for PC (50).

2.6.2 Cancer staging

Cancer is described according to stages which inform where the cancer is located and its size (51). Staging further refers to the extent of the cancer, such as how large the tumor is, how far it has grown into nearby tissues, and if it has spread to other sites of the body (51, 52). Cancer staging is categorized into four (4), stages 1-4 and plays an important role in ensuring that suitable treatment modalities are described at diagnosis (51). Patients who are diagnosed at an advanced stage suffer from the weight of weakening symptoms that were not addressed early, even after modern curative treatment has been offered (53). Many studies show that patients diagnosed with advanced cancer are more likely to be referred immediately for PC services, which has proven to be beneficial to patients, especially with late presentation referred to a metastatic cancer where curative treatment is no longer an option (54). Majority of patients present late with cancer and are diagnosed at advanced stages (52). This has proven to be one of the contributing factors to late referral to palliative care (13).

2.6.3 HIV status

Historically, PC has been associated with cancer and in the 1900s ,PC organizations mobilized to respond to the Human Immunodeficiency Virus(HIV) pandemic and allow PC services to be provided to people living with HIV (PLHIV) (3). According to a study by Islam and partners, patients who are diagnosed with both cancer and HIV are more likely to be referred for PC services as compared to HIV-negative cancer patients (55). In 2004, antiretroviral treatment (ART) was introduced in South Africa, and an increase in longevity amongst PLHIV has been notable leading to an increase in co-infection of cancer and HIV (56). HIV-positive individuals have an elevated risk of developing cancer, and some PC patients are diagnosed with both HIV and cancer (57).

2.6.4 ECOG Performance Score

The Eastern Cooperative Oncology Group performance score (ECOG PS) scale is one of the important indices in adult cancer care(58). The scale describes the level of function for a patient in terms of the ability to care for themselves from a score of 1-5 (58). It is an important factor in therapy choices and a stand-alone prognostic predictor for patients with cancer (58, 59). Many healthcare decisions are based primarily on the careful assessment and accurate documentation of performance scores to determine suitable cancer treatments for each patient (59).

2.7 Conceptual framework

Adapted from the socio-ecological framework by Mosley and Chen, the modified conceptual framework is constructed to show a pictorial representation of various factors associated with timely referrals as shown in Figure 2. The framework shows how various socio-demographic, clinical, and referral factors operate together to exert an impact on PC timely referrals(29, 60). The adaptation included rewording the proximate determinants from the original model to suit this

study and adding factors to ascertain association. The factors were grouped according to socio-demographic, clinical characteristics and referral factors.

Socio-demographic factors such as (age, sex, race, marital status, employment status and level of education), clinical characteristics (cancer type, cancer staging, HIV status, and ECOG performance score) and referral factor such as healthcare and place of referral, directly influence the outcome (timely referral).

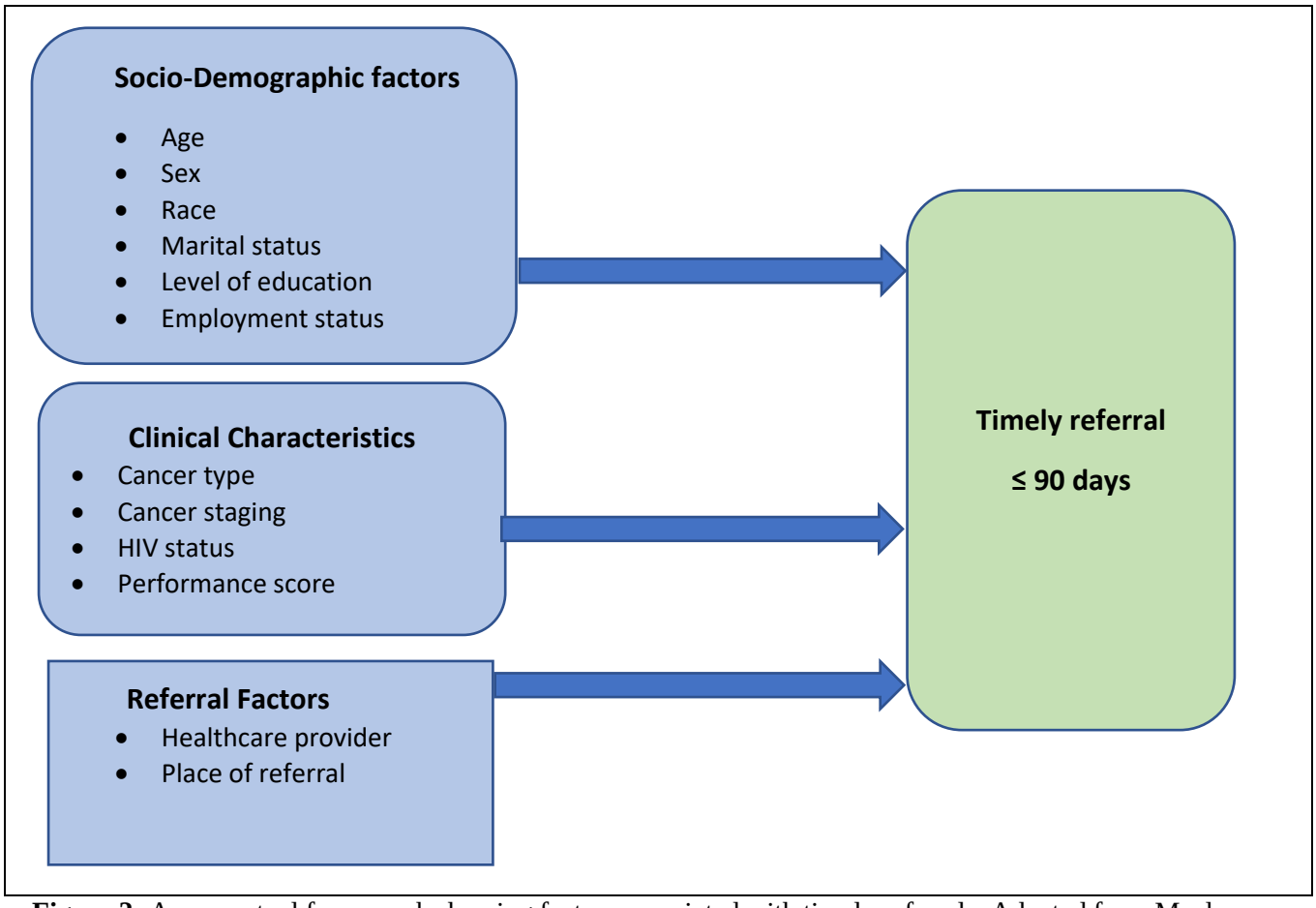


Figure 2: A conceptual framework showing factors associated with timely referrals, Adapted from Mosley and Chen's model (29).

CHAPTER 3 – METHODOLOGY

3.0 Introduction of the chapter

This chapter describes the methodology that was used in this study. It includes the description of the study design, study site, study population, study sample, data collection. and data management. Additionally, a detailed plan for data analysis and ethical considerations is provided.

3.1 Study site and setting

At Chris Hani Baragwanath Academic Hospital (CHBAH), the palliative care unit operates in several settings which includes hospital wards, special clinics, and PC Outpatient Department (OPD). The unit is historically placed within the internal medicine cluster and has been operating for 23 years (17). CHBAH is the largest hospital in South Africa and the African continent, and one of the top ten largest hospitals in the world in terms of size and beds with approximately 3200 beds(61, 16). CHBAH is a teaching hospital for the University of Witwatersrand Medical School and is located in Soweto, Johannesburg with over 6,000 employees (62).

The PC unit has a multi-disciplinary team of personnel ranging from doctors, professional nurses, social workers, and spiritual care counselors. The main focus of the PC team is to provide holistic patient care through the management of symptoms and supporting the family right through the disease course (63). The team is responsible for addressing all physical, emotional, social, and spiritual needs of the patient. The PC unit receives referrals from various departments within the hospital such as OPD clinics, CHBAH hospital wards, and the new medical oncology unit, with some of the patients being walk-ins to the department(63, 17).

From a PC context, a timely referral is defined as a referral that occurs at diagnosis and is initiated by the diagnosing unit and supported by the NPFSPC 2017-2023, stating that timely referral to PC

occurs from the time of diagnosis. Referrals that occur within 90 days of diagnosis are considered timely and those made after 90 days are considered late (3).

3.2 Study design

A cross-sectional study design (retrospective) was utilized for the study. Cancer and referral data were collected at the same time, where secondary data were analyzed from CHBAH.

3.3 Study population

The study population were men and women, aged 18 and above diagnosed with cancer, who were referred to palliative care at CHBAH's palliative care unit.

3.4 Study data

A data use approval letter (Appendix 3) was obtained from the PC unit at CHBAH. Permission and access to data was granted by the PC unit Director. The de-identified CSV Excel dataset file was received via email from the PC at CHBAH. The dataset was imported to STATA and the original CSV Excel file was password-protected, only accessible to the researcher. A total of 459 data records were analyzed from the original dataset of 607 records as shown in Figure 3.

3.4.1 Data flow chart of palliative care patient records

Records included and excluded in the analysis for palliative care patient's records collected at CHBAH, from August 2021 to July 2022.

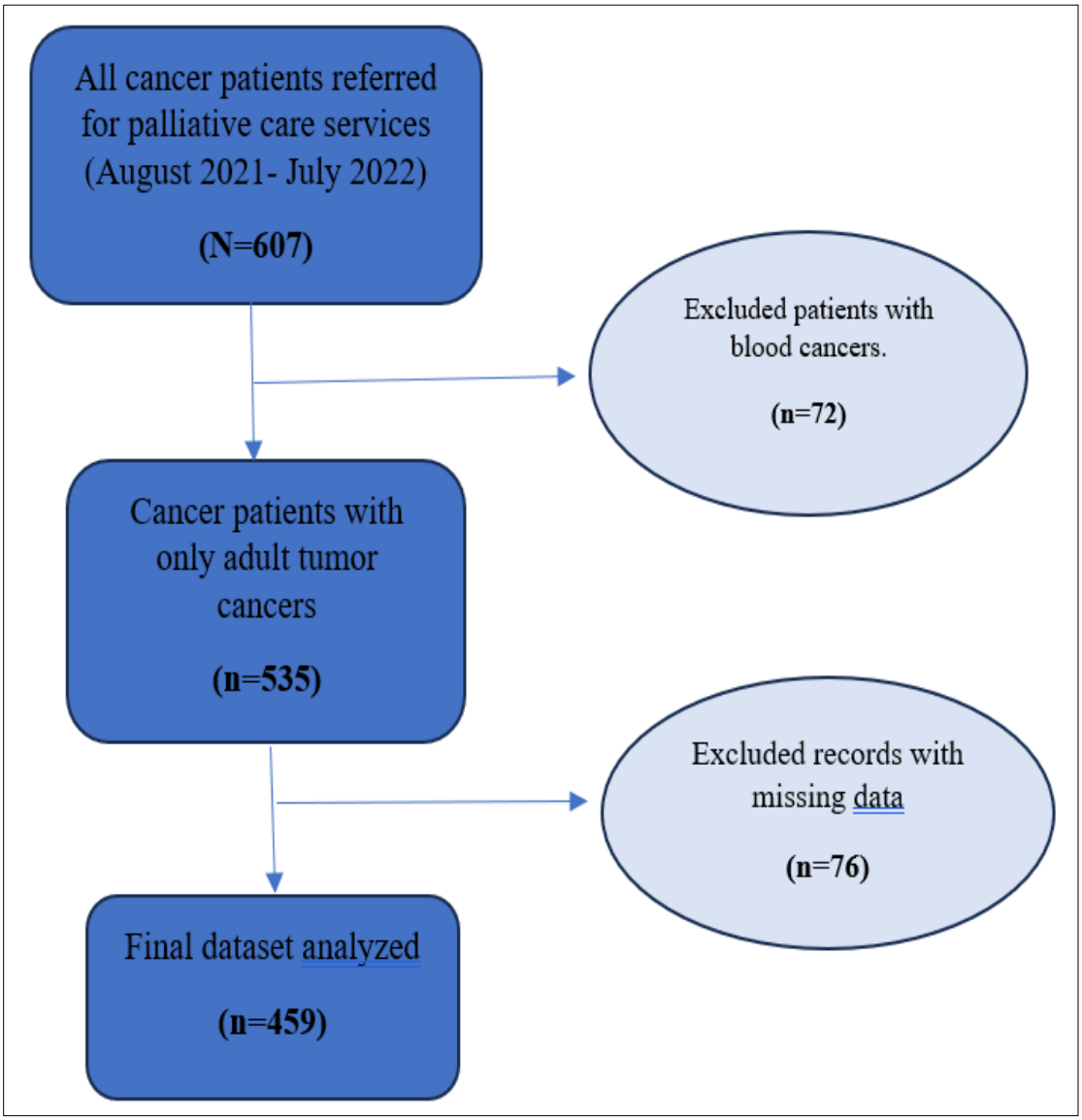


Figure 3: Dataflow chart of palliative care patients at CHBAH.

3.4.2 *Inclusion and Exclusion Criteria*

- *Inclusion:* Men and women, aged 18 and above diagnosed with cancer, referred to palliative care at CHBAH, palliative care unit, from August 2021- June 2022.

  Exclusion: Patients diagnosed with blood cancers were excluded since the study focus is only on tumor cancers. Records with incomplete data were excluded since data completeness on variables such as cancer type, staging, date of referral and date of diagnosis was vital for conducting the analysis.

3.5 Data source

The dataset for this study is from the CHBAH palliative care unit database, for patient data collected from August 2021 to July 2022.

3.6 Power calculation

The sample size calculation was computed to determine the appropriate sample size to answer the research question and sample size for a single proportion equation was used. According to the literature approximately 14% of cancer patients are timely referred for palliative care, therefore (**pq**) is the standard deviation of the outcome of interests (timely referral) where, ^**p** = 0.14, ^**q** =0.86, **E** (margin of error) =0.05 and Z^2 (value from the table of probabilities =1.96

$$n = \frac{Z^2_{\alpha/2}\hat{p}\hat{q}}{E^2}$$

$$\mathbf{n} = \frac{(1.96)^2\,(0.14 \times 0.86)}{0.05^2}$$

$$\mathbf{n} = \mathbf{185}$$

At least a sample size of 185 participants is required to ensure that this study has enough power. The total number of observations of this study was n=459. Stata SE version 17 software was used to estimate power for one sample proportion at 5% significance level. The stata command used was: power **one proportion 0.14, diff(0.05) n(459)**.The overall power of the study was calculated at **84%.**

3.7 Data cleaning and management

Data management was conducted using STATA SE - version 17 to check for errors and omitted values. One hundred and eight (148) erroneous data were excluded from the final dataset, this included patient records with missing date of birth, date of diagnosis, date of referral, level of education, marital status, and ECOG performance score, and records of patients with blood cancers. The variables used in the analysis of the study and how they are derived are presented in Table 1.

3.7.1 *Outcome variable*

The outcome variable for this study is "timely referral" of cancer patients for PC services. This is a binary categorical variable that answers the question of whether the patient was referred timely for PC services at diagnosis. "Yes" (1) depicts that the patient was referred timely which is within ≤ 90 days from the time of confirmed diagnosis. "No" (0) depicts that the patient was not referred timely which confirms referral that occurred after (>) 90 days from the time of confirmed diagnosis. Timely referral is a new variable created from the variable "time taken to refer" which stipulates the number of days taken to refer a patient. This variable is created out of the date of referral and date of diagnosis from the study dataset.

3.7.2 *Exposure variables*

The exposure variables are factors associated with timely referral of cancer patients for palliative care services. There are three (3) groups, referral, socio-demographic, and clinical characteristics.

3.7.3 *Referral factors*

Referral factors are exposure variables that outline referrals of cancer patients for PC services. "Referral" is a binary variable with 2 options, "No" (0) depicts a patient who was not directly referred, and this was a walk-in patient. "Place of referral" is a categorical variable with options, "Palliative care walk-ins" (0), "Medical oncology clinic" (1), "CHBAH OPD clinics" (2), and CHBAH wards" (3). "Referred by" is a categorical variable that stipulates the healthcare professional or person who referred the patient. These categorical options are "Doctor" (1), "Nurse" (2), Social worker" (3) "and "Other" (4).

3.7.4 Socio-demographic factors

The socio-demographic variables for this study were "age" which stipulates the age of the patient. The sex variable is a categorical variable with "female" (0) and "male" (1) ". Race variable is a categorical variable with options, "white" (0), "black" (1), "colored" (2) and "Indian" (3). Marital status is a categorical variable with options, "married" (0), "single" (1). Employment status variable is a categorical variable with options "unemployed" (0) and "employed" (1). Lastly, Level of education is a categorical variable with options "primary school & below" (0), "high school education" (1) and "higher education" (2).

3.7.5 Clinical characteristics

The clinical variables for this study were “cancer type” which is a new variable created from cancer diagnosis from the dataset. “Cancer type” is a categorical variable with options “Breast cancer” (1), “Cervical cancer” (2), “Lung cancer” (3), and “Other” (4). “Cancer staging” is a categorical variable with options “Stage 1 &2” (1), “Stage 3”, (2) and “Stage 4” (3). “HIV status” is a categorical variable with options “HIV-negative” (0), and “HIV-positive” (1). Lastly, “ECOG performance score is a categorical variable with options, “ECOG 1” (1), “ECOG 2” (2), “ECOG” 3(3), and "ECOG 4” (4).

Table 1: Data management of variables used in the study.

	Table of variables		
Variable name	**Definition**	**Original dataset coding**	**Application (Categories and Codes)**
	Dependent /Outcome variable		
Timely referral*	Refers to PC referrals that occur within 90 days of being diagnosed with cancer. This new variable was obtained from subtraction the date of referral from the date of diagnosis. For walk-in patients, their time of referral will be the date of walk-in minus the date of diagnosis. This binary variable with two categories i.e. Yes or No**.** Yes: refers to palliative care referrals that occur within 90 days from the time of diagnosis. **N**o: refers to PC referrals that occur after 90 days from the time of diagnosis. The outcome variable will be operationalized differently for Objective 1,2 and 3.	**New variable*	1, Yes (≤90 days) 0, No (> 90 days)
	Independent /Exposure variables: Socio-demographic		
Referral*	Refers to confirm whether or not the patient was referred for PC. This variable includes walk-in patients	**New variable*	0, No (not referred) 1 Yes (Referred)

	who were not directly referred by a healthcare provider. This is a new variable was obtained from "*place of referral"* variable. This binary variable with two categories i.e. Yes and No. Yes: state that the patient was referred to PC. No: state that the patient was not directly referred to palliative care, this was a walk-in patient. This variable will be used in the Kaplan Meier analysis to determine the event of interest (success or failure) to refer a PCpatient within 90 days of diagnosis.		
Days taken to refer *	Refers to the number of days it took for the patient to be referred to PC from the time of diagnosis. This new variable was created from two variables "*date of referral"-"primary disease date of diagnosis".* This is a continuous variable that shows each number of days it took to refer a patient. Ranges from 1 day to 14059 days	**New variable*	Days
Place of referral	Refers to a health facility that referred the patient for PC. This variable has 4 categories i.e. PC walk-in patients, medical oncology clinic clinics, CHBAH OPD clinics, and CHBAH wards. Categories were combined due to sample size.	1, SCCC 2, PC OPD 3, Clinics 4, Medical wards 5, Surgical wards 6, Gynaecology wards 7, Orthopaedic wards 8, Radiation oncology 9, Medical oncology	0, PC walk-ins 1, Medical oncology clinic 2, CHBAH OPD clinics 3, CHBAH Wards
Referred by	Refers to the healthcare provider who referred the patient for PC. This variable has 4 categories i.e. doctor, nurse, social worker, and other (social auxiliary workers, Community Healthcare Workers and spiritual counsellors. Categories were combined due to sample size.	1, Doctor 2, Nurse 3, Social Worker 4, Other 5, Social Auxiliary Worker 6, Community Healthcare Worker 7, Spiritual Counsellor	1, Doctor 2, Nurse 3, Social Worker 4, Other[1]

[1] Other: Social Auxiliary Workers, Community Healthcare workers and Spiritual Counsellors

Age	Refers to the age of a patient.		In years Rangefrom 20 to 106
Sex	Refers to the sex of a patient. This variable has 2 categories i.e. female or male	1, Male 2, Female	0, Female 1, Male
Race	Refer to the race group of a patient. This variable has 4 categories i.e. white, black, colored and Indian	1, White 2, Black 3, Coloured 4, Indian	0, White 1, Black 2, Colored 3, Indian
Marital status	Refers to the marital status of a patient. This variable has 3 categories i.e. married, single, and divorced. Categories were combined due to sample size.	1, Married/partnered 2, Widowed 3, Single 4, Divorced 5, Refused to say	0, Married 1, Single
Employment status	Refers to whether the patient is employed or not. This variable has 2 categories i.e. Unemployed and employed. Categories were combined due to sample size.	1, Employed full-time 2, Employed part-time 3, Informal employment 4, Unemployed 5, Retired	0, Unemployed 1, Employed
Level of education	Refers to the level of education the patient has acquired. This variable has 3 categories i.e. primary school education, high school education, and higher education. Categories were combined due to sample size.	1, No formal education 2, Primary school education 3, High school education 4, Technical school education 5, Graduate-Tertiary education	0,Primary-school & below 1, High school education 2,Tertiary education
	Independent /Exposure variables: Clinical characteristics		
Cancer type	Refers to the type of cancer the patient has been diagnosed with. This variable has 4 categories i.e. breast cancer, cervical cancer, lung cancer, and other cancers.		1, Breast cancer 2, Cervical cancer 3, Lung cancer 4, Other cancers[2]
Cancer staging	Refers to the cancer stage of the patient. This variable has 3 categories i.e. stage 1&2, stage 3, and stage 4. Stage 1 and 2 were combined due to sample size.	2, Stage 1 3, Stage 2 4, Stage 3 5, Stage 4 6, Unknown	1, Stage 1 and 2 2, Stage 3 3, Stage 4
HIV status	Refers to Human Immunodeficiency Virus (HIV) status of a patient, whether diagnosed or not. This variable has two categories i.e. HIV-negative, HIV-positive	1, Negative 2, Positive 3, Unknown	0. HIV Negative 1, HIV Positive
ECOG Performance score (ECOG PS)	Refers to a scale that describes the level of function for a patient in terms of the ability to care for themselves	1, ECOG 1 2, ECOG 2 3, ECOG 3	1, ECOG 1 2, ECOG 2 3, ECOG 3

[2] Other cancers: Prostate and Colorectal cancers

	from a score of 1-5. This variable has 5 categories: ECOG 1**:** Restricted in physically strenuous activity but ambulatory and able to carry out work. ECOG 2: Ambulatory and capable of self-care but unable to carry out work activities. Up and about more than 50% of waking hours. ECOG 3: Capable of limited selfcare, confined to bed/chair more than 50% of waking hours. ECOG 4: Disabled, unable to perform any self-care, and totally confined to bed or chair.	4, ECOG 4 5, ECOG 5	4, ECOG 4

3.8 Data analysis

3.8.1 Data Analysis of Objective 1

The demographic and exposure characteristics were described using means and standard deviations for the normally distributed age variable, and frequencies and percentages for the categorical variables. To determine the time, it takes for a cancer patient to be referred for palliative care at CHBAH from August 2021 to July 2022, the Kaplan Meier curve was used to analyse the time to the event of interest and determine the time taken for a cancer patient to be referred to PC from diagnosis. The Log-rank test was also applied to examine differences in hazard functions.

3.8.2 Data analysis of Objective 2

To determine the prevalence of timely referrals of cancer patients for palliative care at Chris Hani Baragwanath Academic Hospital, August 2021 -July 2022. Using the STATA SE version17. The outcome variable (timely referral) was used to determine the prevalence of patients that were referred timely. Tables of frequencies and percentages were used to outline the prevalence of timely referrals.

3.8.3 Data analysis of Objective 3

To identify factors associated with timely referral of cancer patients for palliative care at CHBAH from August 2021- July 2022.A binary logistic regression analysis was conducted to identify factors associated with timely referral of cancer patients for PC. Adjusted and unadjusted odd ratios were reported at a 95% confidence interval.

3.9 Ethical considerations

Ethical approval was obtained from the University of Witwatersrand Human Research Ethics Committee (HREC) and received on the 29th of May 2023, clearance certificate no: M230323 (Appendix 1). Permission to use the data was also obtained from the Medical Advisory Committee (MAC) at CHBAH, written approval was received on the 2nd of May 2023, approval letter reference number GP_202304_053 (Appendix 2). None of the identifiers such as patient names and identification numbers were included in the data provided for the study. The original dataset was securely kept in a password-protected Excel sheet and stored in an external drive kept safe in a lockable cabinet only accessible to the researcher.

CHAPTER 4 – RESULTS

4.0 Introduction of the chapter

In this chapter, the main results are presented according to the study objectives. Tables and graphs were used to illustrate the results. This section provides a descriptive summary statistic of the study participants and highlights the prevalence of timely referrals various variables. Kaplan Meier curves are used to the time taken for the patient to be referred to PC. Adjust and unadjusted odds ratios models, confidence interval and p-values were used to illustrate the results of univariable and multivariate logistic regression.

4.1 Description of socio-demographic and clinical characteristics of the study. (Table 2).

Table 2 shows the results in frequencies and percentages of the variables analyzed in this study. The mean (SD) age for patients timely referred to PC was 57.02(14.1) in years.

The final sample size analyzed for this study was n=459 comprises of women and men, 298(64.9) and 161(35.1%) respectively. Of the 459 patients, 10(2.2%) were White, 423(9.2%) were Black, 21(4.6%) and 5(1.1%) were coloured. Only 73(15.9%) patients were employed and 147(32.0% being married. The majority of patients were referred by doctors at 190(41.4%), followed by 171(37.3%) nurses and 47(10.2%) social workers. Of the 459 cancer patients referred to PC, 171(37.3%) were diagnosed with lung cancer and 248(54.0%) had stage 1 and 2 combined.

Table 2: Characteristics of cancer patients referred to palliative care.

Covariate	**Mean (SD)**
Age	57.02 (14.1)
Factors	**Total n (459) n (%)**
Sex	
Female	298 (64.9%)
Male	161 (35.1%)
Race	
White	10 (2.2%)
Black	423 (92.2%)
Coloured	21 (4.6%)
Indian	5 (1.1%)
Marital Status	
Married	147 (32.0%)
Single	312 (68.0%)
Employment Status	
Unemployed	386 (84.1%)
Employed	73 (15.9%)
Level of education	
Primary School & below	51 (11.1%)
High School	311 (67.8%)
Higher Education	97 (21.1%)
Referred by	
Doctor	190 (41.4%)
Nurse	171 (37.3%)
Social Worker	47 (10.2%)
Other[1]	51 (11.1%)
Place of Referral	
PC OPD Walk-Ins	83 (18.1%)
Medical oncology	124 (27.0%)
CHBAH OPD clinics	57 (12.4%)
CHBAH wards	195 (42.5%)
Cancer Type	
Breast Cancer	171 (37.3%)
Cervical Cancer	32 (7.0%)
Lung Cancer	30 (6.5%)
Other Cancers[2]	226 (49.2%)
Cancer staging	
Stage 1 & 2	248 (54.0%)
Stage 3	172 (37.5%)
Stage 4	39 (8.5%)
HIV Status	
Negative	360 (78.4%)
Positive	99 (21.6%)
Performance Score	
ECOG 1	180 (39.2%)
ECOG 2	147 (32.0%)
ECOG 3	63 (13.7%)
ECOG 4	69 (15.0%)

4.2 Prevalence of timely referrals to palliative care.

Figure 4 shows the overall prevalence of timely referrals to PC. Of the 459 patient records that were analyzed, 63(13.7%) cancer patients were timely referred to PC As shown in Table 3 and narrated in section (4.2.1 and 4.2.2), the prevalence varied across different explanatory variables of this study.

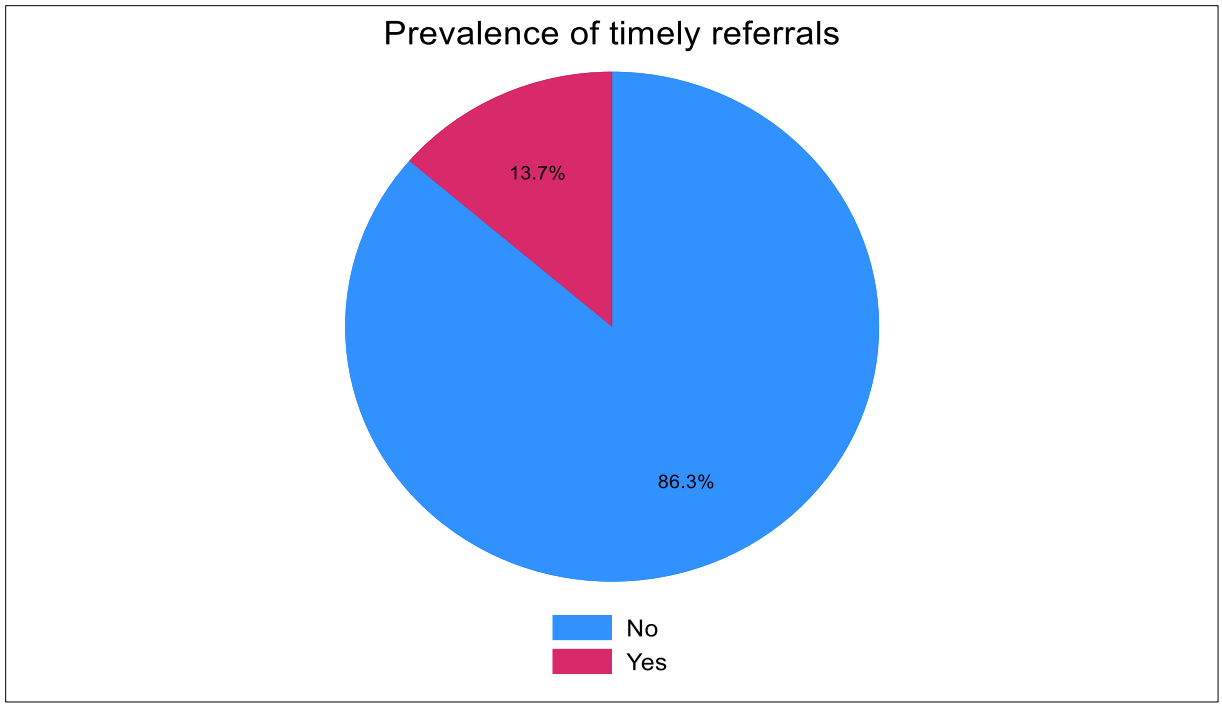


Figure 4: Pie graph showing the overall prevalence of timely referrals.

4.2.1 Prevalence of timely referrals by socio-demographic.

Male patients who were referred timely to PC had a higher prevalence of 14.9% as compared to female patients with 13.1% prevalence. Indians had a higher prevalence of 40% compared to other races with a prevalence of (14%) Black, (10%) White and (4.8%) Coloureds. Patients who are married had a higher prevalence of 17.0% compared to patients that are single with 12.2% prevalence. There was no apparent difference in prevalence of timely referral between employment category (13.7% employed and 13.7% unemployed).

Patients with high school education have a higher prevalence of 16.1% compared to 9.3% prevalence from patients with higher education and 7.8% from patients with primary school education and below. Timely referrals initiated by nurses had a higher prevalence of 17.5% as compared to other healthcare providers. Doctors, social workers and other healthcare providers have a prevalence of 13.7%, 4.3% and 9.8% respectively. The place of referral variable was categorized into 4 categories: palliative care OPD walk-ins, medical oncology clinic, CHBAH OPD clinics, and CHABH wards. Patients who were timely referred from CHBAH wards had a higher prevalence of 22.6% compared to other places of referral.

4.2.1 Prevalence of timely referrals by clinical characteristics

Clinical characteristics analyzed included cancer type, cancer staging, HIV status, and performance score. Of the 63 patients who were referred timely, patients diagnosed with lung cancer had a higher prevalence of 23.3% compared to other cancers[2] with a prevalence of 15.0%, breast cancer (11.1%) and cervical cancer (9.4%). Patients with stage 4 cancer had a higher prevalence of 25.6% compared to patients with stage 3 cancer with a prevalence of 12.8% and stage 1& 2 combined with a prevalence of 12.5%.

HIV positive patients who were referred timely to PC had a higher prevalence of 16.2% as compared to negative patients with a prevalence of 13.1%. Patients with ECOG performance score of 3 had a higher prevalence of 20.6% compared to patients with other ECOG performance scores.

Table 3: Prevalence of timely referral of cancer patients by selected characteristics.

Variable	NO (86.3%) n (%)	YES (13.7%) n (%)	TOTAL
Sex			
Female	259 (86.9%)	39 (13.1%)	298
Male	137 (85.1%)	24 (14.9%)	161
Race			
White	9 (90.0%)	1 (10.0%)	10
Black	364 (86.0%)	59 (14.0%)	423
Coloured	20 (95.2%)	1 (4.8%)	21
Indian	3 (60.0%)	2 (40.0%)	5
Marital Status			
Married	122 (83.0%)	25 17.0%)	147
Single	249 (87.8%)	38 (12.2%)	283
Employment Status			
Unemployed	333 (86.3%)	53 (13.7%)	386
Employed	63 (86.3%)	10 (13.7%)	73
Level of education			
Primary &below	47 (92.2%)	4 (7.8%)	51
High School	261 (83.9%)	50 (16.1%)	311
Higher Education	88 (90.7%)	9 (9.3%)	97
Referred by			
Doctor	164 (86.3%)	26 (13,7%)	190
Nurse	141 (82.5%)	30 (17.5%)	171
Social Worker	45 (95.7.4%)	2 (4.3%)	47
Other[1]	46 (90.2%)	5 (9.8%)	51
Place of Referral			
PC OPD Walk-Ins	76 (91.6%)	7 (8.4%)	83
Medical oncology	116 (93.6%)	8 (6.4%)	124
CHBAH OPD clinics	53 (93.0%)	4 (7.0%)	57
CHBAH wards	151 (77.4%)	44 (22.6%)	195
Cancer Type			
Breast Cancer	152 (88.9%)	19 (11.1%)	171
Cervical Cancer	29 (90.6%)	3 (9.4%)	32
Lung Cancer	23 (76.7%)	7 (23.3%)	30
Other Cancers[2]	192 (85.0%)	34 (15.0%)	226
Cancer staging			
Stage 1 & 2	217 (87.5%)	31 (12.5%)	248
Stage 3	150 (87.2%)	22 (12.8%)	172
Stage 4	29 (74.4%)	10 (25.6%)	39
HIV Status			
Negative	313 (86.9%)	47 (13.1%)	360
Positive	83 (83.8%)	16 (16.2%)	99
Performance Score			
ECOG 1	155 (86.1%)	25 (13.9%)	180
ECOG 2	129 (87.8%)	18 (12.2%)	147
ECOG 3	50 (79.4%)	13 (20.6%)	63
ECOG 4	62 (89.9%)	7 (10.1%)	69

4.3 Kaplan Meier analysis showing time taken to refer a cancer patient to palliative care.

Figure 5 shows the overall Kaplan Meiser analysis showing the time taken to refer a cancer patient for PC. Further analysis across different explanatory variables is shown in Figure 6 – 9 and narrated in section [4.3.1- 4.3.5)] respectively.

4.3.1 Overall Kaplan Meier curve showing the time taken to refer to palliative care.

As shown in Figure 5, the probability of a patient not being referred decreases steadily over time, suggesting that referrals are happening at a relatively constant rate over the 120-day period. Of the 459 patients who were diagnosed with cancer and eligible for PC referral, only 19(4,1%) were referred within the first 15 days of diagnosis. Only 13.7% were referred within 90 days, and 86.3% were referred after 90 days of diagnosis.

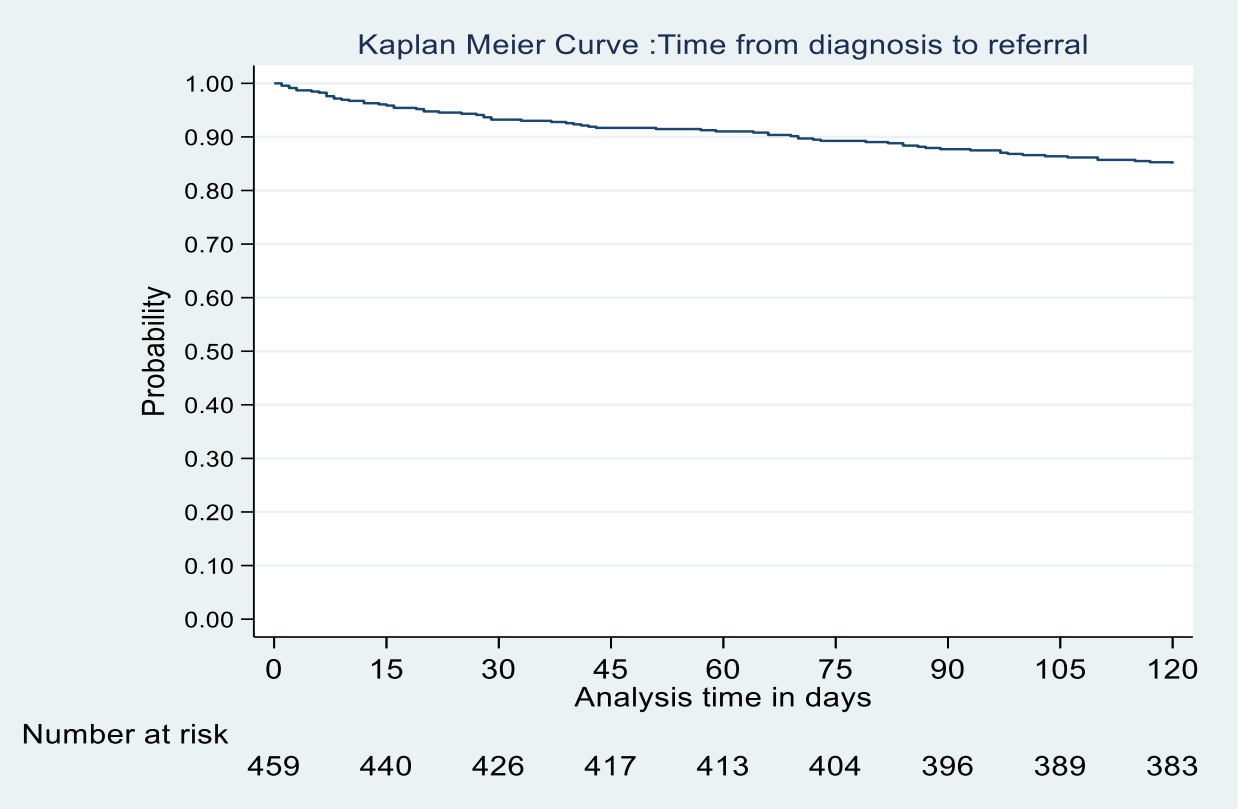


Figure 5: Overall Kaplan Meier curve showing the time taken to refer to palliative care.

4.3.2 Kaplan Meier curve showing time from diagnosis to referral by sex.

As shown in Figure 6, of the 298 female patients who were diagnosed with cancer and eligible for PC referral, only 39(13.1%) were referred within 90 days of diagnosis. Of the 161 male patients eligible for PC referral, only 24(14.9%) were referred within 90 days of diagnosis. Overall, the log-rank test indicates that the time from diagnosis to referral does not significantly differ between male and female patients.

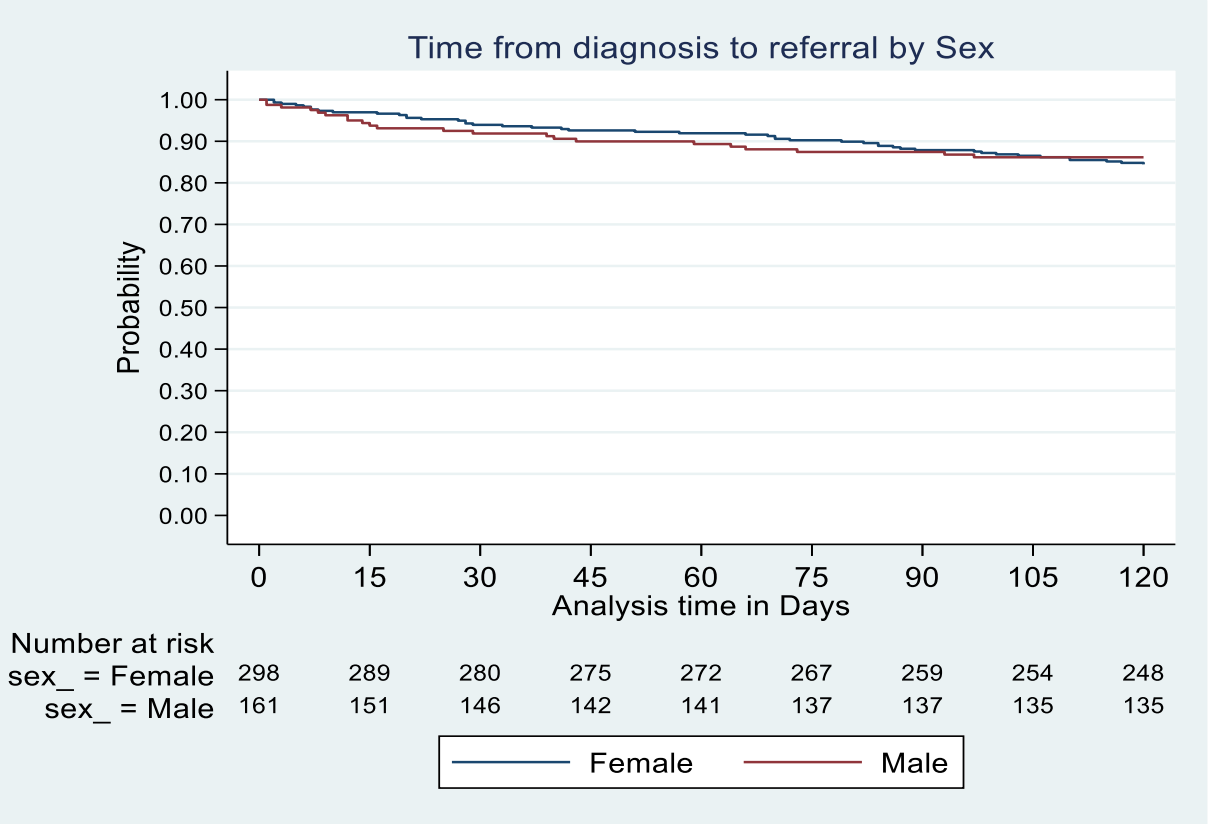


Figure 6: Kaplan Meier curve showing time from diagnosis by sex.

4.3.3 Kaplan Meier curve showing time from diagnosis to referral by healthcare provider.

Figure 7 also shows that referral time did not vary significantly by healthcare provider. Of the 190 cancer patients referred by a doctor, only 26(13.7%) were referred within 90 days. Nurses, social workers and other healthcare providers had referred 30(17.5%), 2(4.3%) and within 90 days respectively.

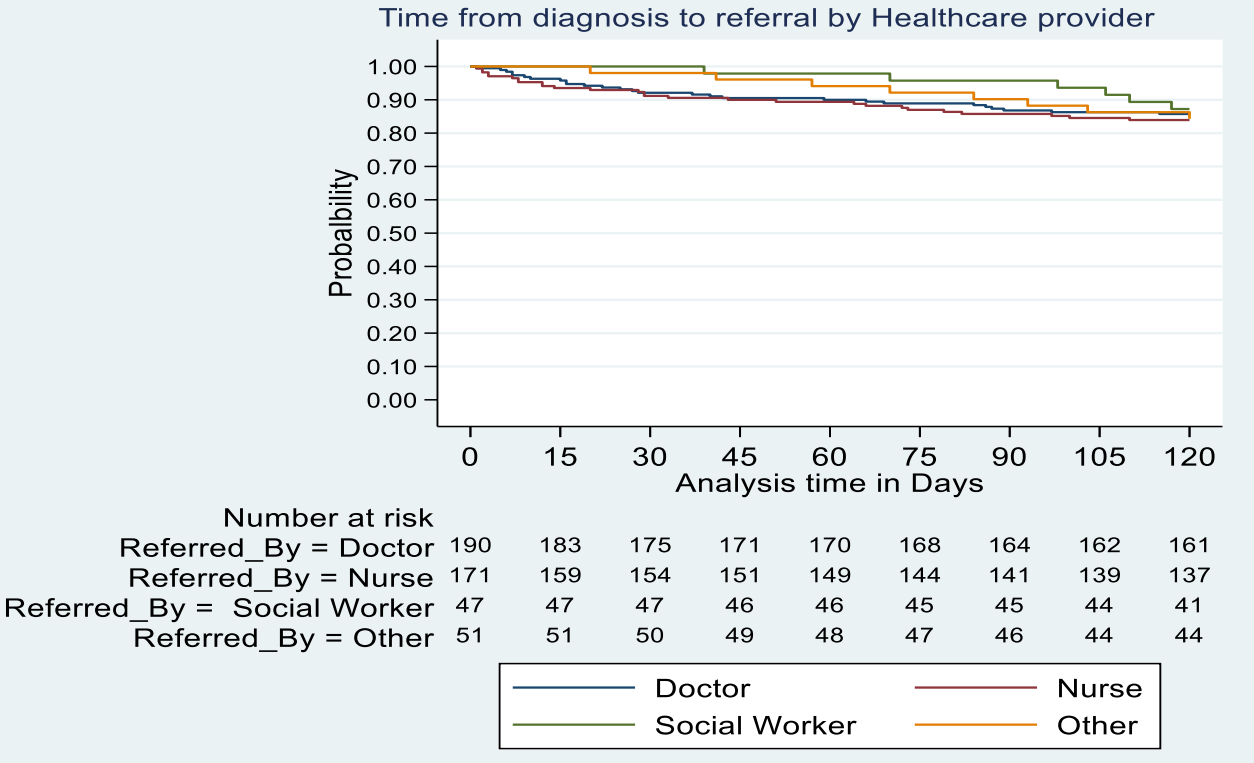


Figure 7: Kaplan Meier curve showing time from diagnosis by healthcare provider.

4.3.4Kaplan Meier curve showing time taken from diagnosis by place of referral

As shown in Figure 8, of the 63(13.7%) patients referred within 90 days across different places of referral, 44(69.8%) were referred from CHBAH wards as compared to 19(30.1%) patients referred

from other places of referral, As shown in Figure 6. The log-rank test results provided a P<0.01 showing a statistically significant pattern between places of referral.

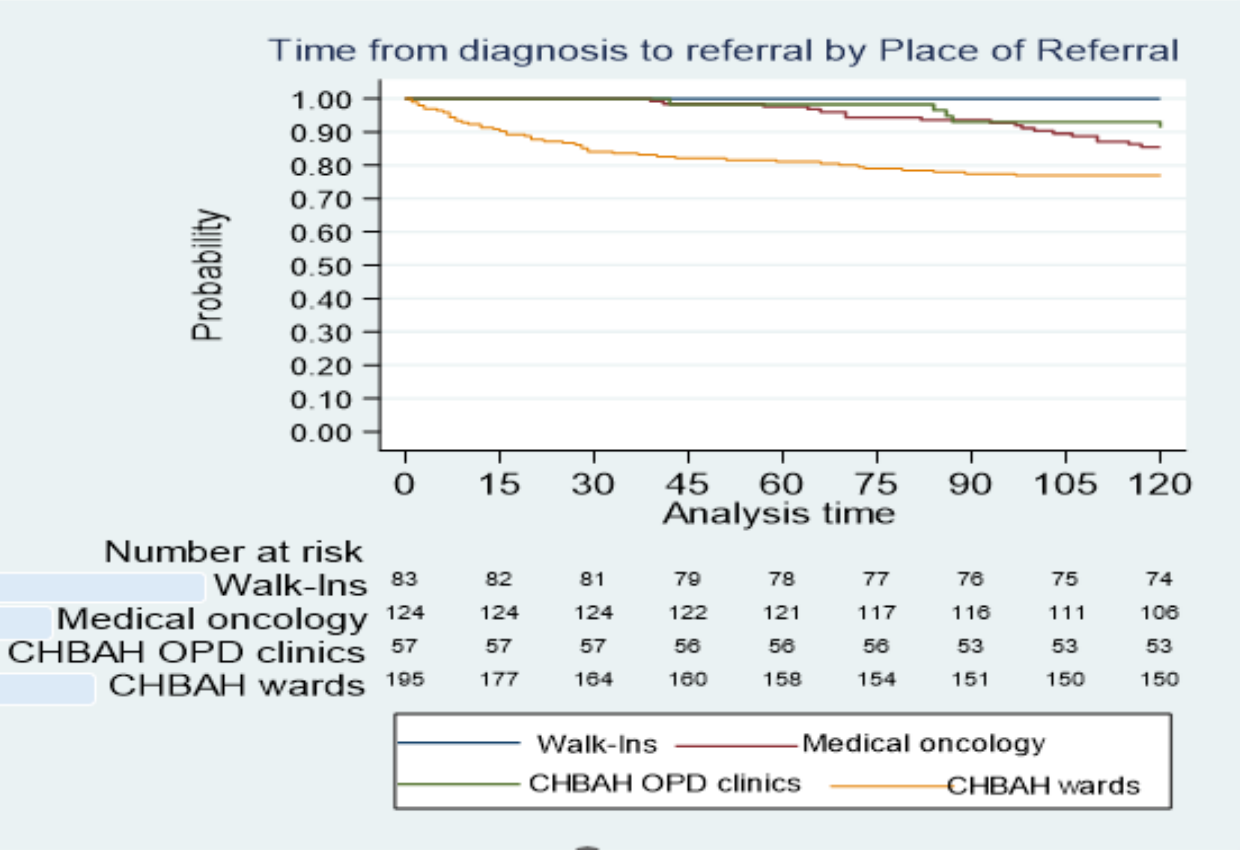


Figure 8: Kaplan Meier curve showing time from diagnosis by place of referral.

4.3.5 Kaplan Meier curve showing time from diagnosis to referral by cancer type.

As shown in Figure 9, of the 195 cancer patients referred from CHBAH wards, only 44(22.6%) were referred within 90 days and 19(7.2%) were referred within 90 days of diagnosis across other places of referral.

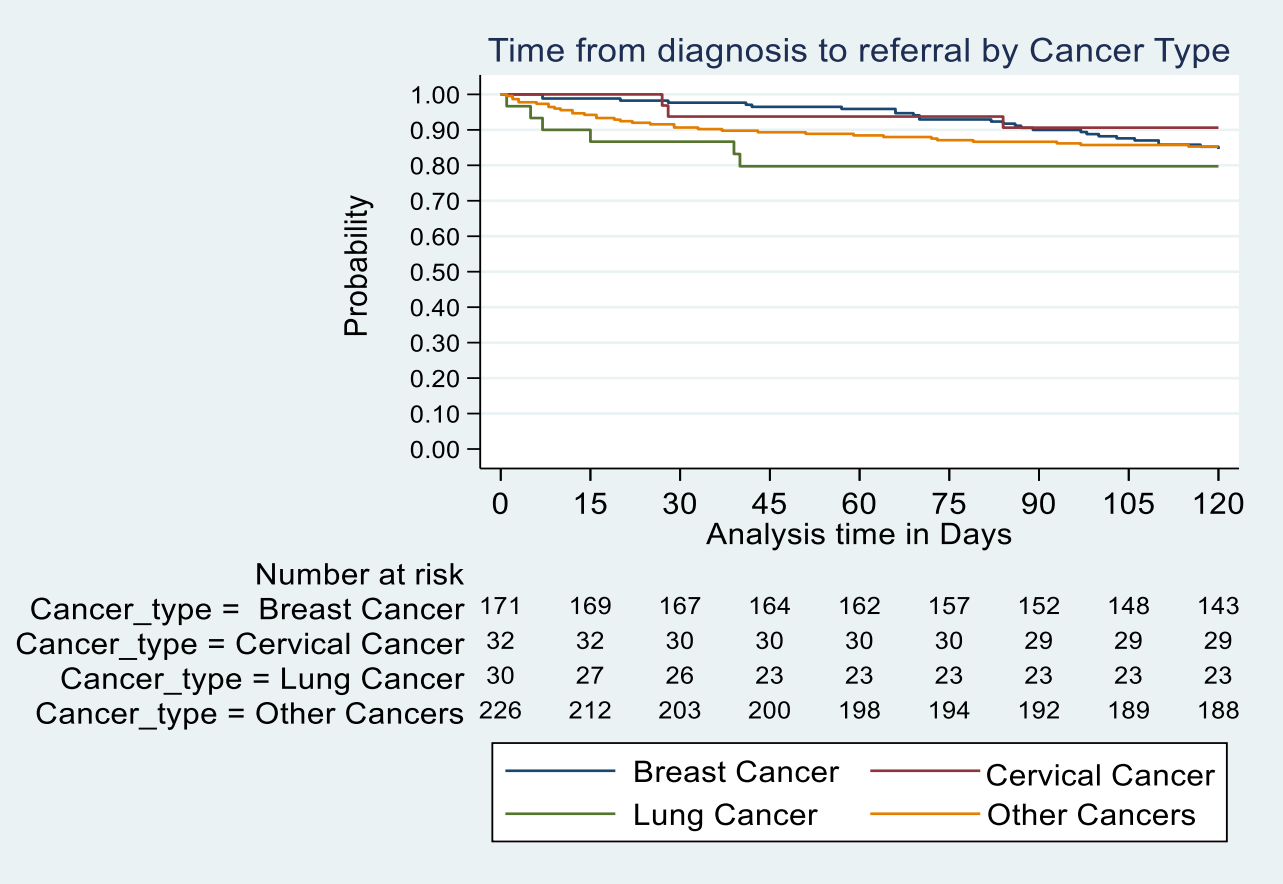


Figure 9: Kaplan Meier curve showing time from diagnosis by cancer type.

4.4 Factors associated with timely referral of cancer patients to palliative care.

Table 4 shows the overall results of the univariable, and multivariable logistic regression analysis conducted. All the variables were fitted in the unadjusted model. Only two (2) variables showed a statistically significant association with timely referral at 95% CI and P<0.05. The significant variables were “place of referral”, for the CHBAH wards category, and “cancer staging” for the stage 4 cancer category as shown in Table 4. In the adjusted model, four (4) variables showed a statistically significant association with timely referral at P<0.05 and 95% CI. The significant variables were “referred by”, for the nurse category, “place of referral” for the CHBAH wards category, “cancer type” for the lung cancer category, and “cancer staging” for the stage 4 cancer category.

4.4.1 Referral factors associated with timely referral of cancer patients for PC services.

In the unadjusted model, the results showed a statistically significant association at P<0.01,95% CI, between timely referral and place of referral for the CHBAH wards category. The odds of referring cancer patients to PC are 2.16 times (OR:3.16, 95%CI (1.36-7.36)) for CHBAH wards as compared to CHBAH OPD and medical oncology clinics. This indicates that CHBAH wards are more likely to refer cancer patients timely to PC than CHBAH OPD.

In the adjusted model, the results showed a statistically significant association at P<0.001, 95% CI between timely referral and place of referral for the CHBAH wards category. In CHBAH wards, the odds of referring cancer patients to PC are 4.76 times (OR:5.76, 95%CI (2.25-14.75)) higher than in CHBAH OPD clinics. In CHBAH wards, the odds of referring patients are 3.22 times (OR:4.22, 95%CI (1.73-10.28)) higher than in CHBAH OPD clinics. This indicates that CHBAH wards are more likely to refer cancer patients to palliative care than the CHBAH OPD clinics.

In the adjusted model, the results showed that nurses are 0.99 times (OR:1.99, 95%CI (1.06-3.74)) more likely to refer cancer patients to PC than doctors. This indicates that nurses are more likely to refer cancer patients than doctors, this model showed a significant association at P<0.05, 95% CI between timely referral and healthcare providers.

4.4.2 Socio-demographic factors associated with timely referral of cancer patients for PC services.

Table 4 shows the socio-demographic factors associated with timely referral of cancer patients for PC services. In the unadjusted model, the results show that the odds of male patients being referred timely to PC are 0.16 times (OR:1.16, 95%CI (0.67-2.01)) more likely than of female patients. However, there was no significant association between sex and timely referral. The results also indicate that the odds of Indian patients being referred timely to PC are 5 times (OR:6.00, 95%CI

(0.39-92.28)) more likely than of white patients and black patients are 0.46 times (OR:1.46, 95%CI (0.18-11.73)) more likely than white patients.

Single patients are 0.33 times (OR:0.67, 95%CI (0.18-11.73)) less likely than married patients to be referred timely to PC. The odds of patients with a high school education being referred timely to PC are 1.25 times (OR:2.25, 95%CI (0.78-6.52)) more likely than of patients with primary school and below education. There was no significant association across all socio-demographic variables in either the unadjusted or adjusted models.

4.4.3 Clinical characteristics associated with timely referral of cancer patients for PC services.

In the unadjusted model, the odds of referring cancer patients with stage 4 cancer to PC are 1.41 times (OR:2.41, 95%CI (0.54-5.43)) more likely than of Stage 1& 2 cancer patients. This indicates that stage 4 cancer patients are more likely to be referred to PC than stage 1 cancer patients. There was a significant association at P<0.05,95% CI between timely referral and stage 4 cancer.

In the adjusted model, the odds of referring cancer patients with stage 4 cancer to PC are 1.49 times (OR:2.49, 95%CI (1.01-6.17)) more likely than of Stage 1& 2 cancer patients. This indicates that stage 4 cancer patients are more likely to be referred to palliative care than stage 1 cancer patients. There was a significant association at P<0.05,95% CI between timely referral and cancer staging.

The odds of referring patients with ECOG 3 performance scores to PC are 0.61 times (OR:1.61, 95%CI (0.77-3.39)) more likely than of patients with ECOG 1 performance scores.

In the unadjusted model, lung cancer patients are 1.81 times (OR:2.81, 95%CI (1.03-7.60)) more likely to be referred to PC compared to breast cancer patients. The association was significant at P<0.05, 95% CI between timely referral and cancer type.

Table 4: Adjusted univariate and multivariable analysis showing factors associated with timely referral of cancer patients for palliative care services at CHBAH.

Variables	Unadjusted OR | 95% CI	Unadjusted P-value	Adjusted OR |95% CI	Adjusted P-value
Age	0.99(0.97-1.01)	0.19	0.98(0.96-1.00)	0.12
Referred by				
Doctor (*Reference group*)	1.00		1.00	
Nurse	1.34(0.76-2.38)	0.31	1.99(1.06-3.74)	**0.03***
Social worker	0.28(0.06-1.23)	0.09	0.61(0.12-2.93)	0.54
Other[1]	0.69(0.25-1.89)	0.47	1.50 (0.49-4.58)	0.47
Place of referral				
PC OPD (*Reference group)*	1.00		1.00	
Medical Oncology	0.75(0.26-2.15)	0.59	0.97(0.32-2.96)	0.96
CHBAH OPD clinics	0.82(0.23-2.94)	0.76	1.16(0.30-4.54)	0.82
CHBAH wards	3.16(1.36-7.36)	**<0.01****	5.76(2.25-14.75)	**<0.01****
Sex				
Female (*Reference group*)	1.00		1.00	
Male	1.16 (0.67-2.01)	0.59	1.03 (0.58-1.83)	0.90
Race				
White (*Reference group*)	1.00		1.00	
Black	1.46 (0.18-11.73)	0.72	1.44 (0.17-11.86)	0.73
Coloured	0.45 (0.03-8.03)	0.59	0.46 (0.02-8.38)	0.60
Indian	6.00 (0.39-92.28	0.20	7.47 (0.44-125.15)	0.16
Marital status				
Married (*Reference group*)	1.00		1.00	
Single	0.67 (0.39-1.17)	0.16	0.72(0.41-1.29)	0.27
Level of Education				
Primary & below (*Reference group*)	1.00		1.00	
High School Education	2.25 (0.78-6.52)	0.14	2.11 (0.72-6.20)	0.17
Higher Education	1.20(0.35-4.11)	0.77	1.12 (0.32-4.00)	084
Employment status				
Unemployed (*Reference group*)	1.00		1.00	
Employed	0.99 (0.48-2.06)	0.99	0.88 (0.42-1.85)	0.74
Cancer-type	1.00		1.00	

Breast Cancer (*Reference group*)				
Cervical Cancer	0.82 (0.23-2.98)	0.77	1.09 (0.29-4.13)	0.89
Lung Cancer	2.43 (0.92-6.43)	0.07	2.81 (1.03-7.60)	**0.04***
Other Cancers[2]	1.42 (0.78-2.58)	0.256	1.50 (0.78-2.90)	0.22
Clinical staging				
Stage 1 & 2 (*Reference group*)	1.00		1.00	
Stage 3	1.03(0.57-1.8)	0.93	1.06 (0.58-1.94)	0.82
Stage 4	2.41 (0.54-5.43)	**0.03***	2.49 (1.00-6.17)	**0.04***
HIV status				
Negative (*Reference group*)	1.00		1.00	
Positive	1.28 (0.69-2.38)	0.42	1.06 (0.53-2.11)	0.85
Performance status				
ECOG 1(*Reference group*)	1.00		1.00	
ECOG 2	0.87 (0.45-1.66)	0.66	0.81 (0.41-1.61)	0.56
ECOG 3	1.61 (0.77-3.39)	0.21	1.23 (0.54-2.78)	0.61
ECOG 4	0.70 (0.28-1.70)	0.43	0.55 (0.21-1.43)	0.22

Note: *p < 0.05, **p<0.01 UAOR =Unadjusted Odds Ratio, AOR= Adjusted Odds Ratio, CI 95%=95 % Confidence Interval. Other[1] "referred by" include social auxiliary workers and spiritual counselors. Other[2] "other cancers" include prostate and colorectal cancers.

CHAPTER 5 - DISCUSSION

5.0 Introduction of the chapter

This study sought to determine the prevalence of timely referrals and factors associated with timely referral of cancer patients for palliative care at CHBAH.

In this chapter, the prevalence of timely referral of cancer patients to PC and associated factors are discussed in detail. The chapter further explains how the results and interpretation support or differ from other studies. Furthermore, the strengths, limitations, and conclusions of the study are discussed, and the study recommendations are also highlighted.

5.1 Prevalence of timely referral of cancer patients for palliative care.

This study investigates and identifies factors associated with timely referral of cancer patients for PC services. The study results show a low prevalence of timely referrals of 13.7%, implying that most cancer patients are not timely referred to PC at CHBAH. The finding is supported by existing evidence collected from the various research studies including a recent study by Hausner and partners highlighting a 14%-30% prevalence of PC referrals conducted within 90 days of diagnosis(25, 64, 65).

5.2 Factors associated with timely referrals of cancer patients for PC services.

The following sections discuss at length the factors associated with timely referrals of cancer patients for PC services. There are 3 sections which are as follows: referral factors [section 5.2.1], socio-demographic [section 5.2.2], and clinical characteristics [section 5.2.3]

5.2.1 Referral factors and timely referrals

Across different levels of healthcare providers, doctors, nurses, and social workers seem to be the key healthcare providers that champion PC referrals among cancer patients. Our results have

shown that nurses are more likely to refer patients as compared to doctors. The finding is supported by literature, confirming that most PC and hospice services are nurse-driven due to the evolution of cancer nursing and palliative nursing over the past few years. Newly diagnosed patients have extended survival and treatment benefits that were not before possible(8, 66). Referrals by nurses are mostly associated with timely referrals of cancer patients to PC compared to other healthcare providers. At CHBAH, the PC unit is historically placed under the internal medicine cluster, and doctors may find it challenging to make early recommendations for PC based on the understanding that PC is end of life care (67). This is due to uncertainty about the disease course, ignorance of PC lack of communication skills, and inadequate knowledge about palliative care(68, 66, 69).

Evidence from a study by Schroeder and partners supported that nurses spend more time with patients and families than any other healthcare professional as they face serious illness. Various studies have shown that expert nursing care lessens the distress and burdens of the disease to patients, and provides support for the physical, social, psychological, and spiritual needs of the patients and their families(70, 71, 64). Healthcare providers are crucial factors to aid timely referrals.

The findings of the study show that the place of referral is a significant factor in timely referral of cancer patients to PC. The results show a significant buy-in to PC services from CHBAH wards contributing to a large number of PC timely referrals as compared to points of referral (67).The results shown are from all wards at CHBAH combined, making it difficult to comment comprehensively on each specific ward since breast cancer patients are from the surgical wards and lung cancer from the medical wards. Timely referrals from special OPD clinics are expected to be higher since they are diagnosing clinics. This is in contrast with evidence provided by

Rodrigues and colleagues, stating referrals to PC are much less common from surgical wards than medical services. Other studies indicated a delay for surgical patients to be referred early for PC (72). Characteristics of surgical cancer patients suggest that PC services are designated for elderly patients and those critically ill who are closer to the end of life(73) Other studies stated that PC services are underutilized by surgical patients (72, 49).

5.2.2 Socio-demographic and timely referral

The results from the study showed that the mean age of cancer patients referred timely to PC is 55 years. This finding is supported by common misconceptions that PC services are designed for the elderly (74). This is misleading and incorrect since the mandate of PC is to improve the quality of life and must be offered from diagnosis as stated in the PC policy and strategic framework (12,, 3, 75, 76). Further evidence from a study by Pal and Manning shows that now it is widely acknowledged that PC should be offered to everyone irrespective of age (77). The results have also illustrated that female patients are more likely to receive timely referrals compared to men. This can be attributed to the fact that women are more likely to seek healthcare services than men which is notable by the proportion of women patients who are found in healthcare facilities(78, 76).

Despite the NPFSPC being in place, the evidence is still showing bias associated with some of the socio-demographic factors to refer patients. There are still not many defined methods or criteria for allowing patients to receive PC treatments. The lack of standardization aids inequity to which patients are referred to PC services (79). Age of patients, sex, and marital status appear to be factors in being referred to PC even though findings were not significant. Other studies have supported

the evidence showing sex and race or ethnicity are used as determining factors by healthcare providers to refer patients (79). Other earlier studies have shown that Blacks , Asians and those with low socioeconomic levels are less likely to obtain inpatient PC consultations and hospice care among patients with serious illnesses (80).

5.2.3 Clinical characteristics and timely referral

The findings of this study show that advanced cancer stage 4 patients are the significant group most likely to be timely referred to PC. Our results also show that patients diagnosed with lung cancer are significant to timely referrals as compared to other cancers. This finding is supported by evidence that lung cancer patients are diagnosed late and patients with advanced cancer are often referred for PC especially when curative treatment is no longer an option. These patients often experience symptoms of the disease that contribute to distress and diminish their quality of life (22). PC has been shown to improve patient's quality of life and contentment with their treatment and perhaps increase survival for those with advanced disease. However, inadequate PC referrals continue to stand in the way of advanced cancer patients receiving high-quality care (81).

5.5 Summary of discussion

In this study, the results show a low prevalence of timely referrals to PC. Nurses are more likely to refer patients as compared to other healthcare providers. Despite the mandate that PC services must be provided from the time of diagnosis, as stated in the PC policy and strategic framework, regardless of contributing socio-demographic factors and clinical characteristics, misleading and incorrect misconceptions still exist.

The results also show that CHBAH wards contribute mostly to timely referrals at CHBAH. This contrasts with the literature reviewed to support this study, which claims that PC services are underutilized and frequently delayed among surgical patients.

The results show that patients diagnosed with lung cancer represent a significant group of people who are timely referred to PC at CHBAH. The findings also show that stage 4 advanced cancer patients are more likely to be referred timely as compared to patients with other stages. PC is frequently recommended for patients with advanced cancer, especially when curative treatment is no longer an option. These patients frequently encounter disease symptoms that are distressing and lower their quality of life.

5.6 INFLUENCE OF THE LIMITATIONS OF THE STUDY RESULTS

In considering the findings of this study, the following limitations were noted: Data was limited to records available from the PC database since the analysis is based on secondary data. Some of the records did not the date of diagnosis and referral making it difficult to ascertain whether they were referred timely or not, however, since we had sufficient statistical power, we are confident that we were able to detect true differences. According to the literature, what constitutes a timely referral to PC has not yet been fully established, However, a 90-day window from the time of diagnosis is used to ascertain timely referrals (25). This study took place in a large academic hospital, although generalizability to a smaller hospital setting is still uncertain and needs to be explored. A large number of records were excluded considering the final dataset had 459 data records. Evidence from incomplete records could have provided support for other factors that we not supported by the results of this study. The majority of patients in the study were black which made it difficult to ascertain association from race.

5.7 STRENGTH OF THE STUDY

This study was the first to identify factors associated with timely referral of cancer patients for palliative care services at CHBAH. Cancer patients with various types of cancers and staging were analyzed in this study and the analysis provided insight into how PC referrals are prioritized by each diagnosing unit at CHBAH. The findings of this study can be used to strengthen PC services and streamline referrals to PC across different levels of care at CHBAH. The significant factors showed evidence that was aligned with the current literature.

5.8 CONCLUSION

In conclusion, this study shows a low prevalence rate of timely referrals to PC services and provides supporting evidence that the majority of cancer patients are referred late. Healthcare providers play an important role in aiding timely referrals. PC knowledge and acceptability from healthcare providers can exert a positive impact on increasing the number of cancer patients referred timely. PC must be offered from diagnosis and initiating facilities regarded as places of referral are key contributors to timely and effective PC referrals.

Socio-demographic and clinical characteristics are the contributing factors for referrals. These factors must not be used as determining factors for PC referrals, it is important for the Department of Health in South Africa to strictly enforce to healthcare providers the usage of the National Policy Framework and Strategy for the Palliative 2017-2022 guidelines when making health care decisions for patients diagnosed with cancer.

This study contributes enormously to the body of knowledge relating to PC and provides insights into significant factors for referring cancer patients to PC. When patients are referred timely, better symptom control and less discomfort endured during the disease course, leading to an improved

quality of life and positive patient health outcomes. Further research is still required on this topic to ascertain enablers and barriers to timely referrals of cancer patients.

5.9 RECOMMENDATIONS

CHBAH must prioritize and institutionalize referral guidelines that encourage timely referrals to PC to ensure that cancer patients receive timely access to PC. Training of healthcare professionals on PC must be intensified to ensure implementation of the NPFSPC, for all patients with life-threatening illnesses to be referred to PC at diagnosis, which will lead to most patients being referred timely. Sensitizing workshops that target healthcare providers must be conducted to instill knowledge and awareness of PC.

The role of each healthcare provider must be documented and linked to the PC team. A compulsory PC module must be integrated into the academic curricula of all healthcare professional training to ensure adequate and appropriately trained healthcare professionals at all levels of healthcare(82). Further research is required to investigate the barriers and enable PC referrals among health providers. This will provide insights into generating a strong body of evidence.

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APPENDICES

Appendix 1: Ethics approval certificate

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG

R49 Mr S Msomi

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
CLEARANCE CERTIFICATE NO. M230323

NAME: (Principal Investigator)	Mr S Msomi
DEPARTMENT:	School of Public Health Medical School University
PROJECT TITLE:	*Factors associated with timely referral of cancer patients for palliative care services at Chris Hani Baragwanath Academic Hospital, Johannesburg*
DATE CONSIDERED:	2023/03/31
DECISION:	Approved unconditionally
CONDITIONS:	
NOTE:	If contact information regarding student study participants is required, please contact the Registrar's office - <Nicoleen.Potgieter@wits.ac.za>
SUPERVISOR:	Professor L Ibisomi and Dr M Ratshikana
APPROVED BY:	Dr CB Penny, Chairperson, HREC (Medical)
DATE OF APPROVAL:	2023/05/29

This Clearance Certificate is valid for 5 years from the date of approval. An extension may be applied for.

DECLARATION OF INVESTIGATORS

To be completed in duplicate and **ONE COPY** returned to the Research Office secretariat on the 3rd floor, Phillip Tobias Building, Parktown, University of the Witwatersrand, Johannesburg.

I/we fully understand the conditions under which I am/we are authorized to carry out the above-mentioned research and I/we undertake to ensure compliance with these conditions. Should any departure be contemplated from the research protocol as approved, I/we undertake to submit details to the Committee. **I agree to submit a yearly progress report**. When a funder requires annual re-certification, the application date will be one year after the date when the study was initially reviewed. In this case, the study was initially reviewed in **March** and therefore reports and re-certification will be due in the month of **March** each year. Unreported changes to the study may invalidate the clearance given by the HREC (Medical).

Signature of Principal Investigator

Date 29/05/2023

Appendix 2: Permission to conduct the study from Medical Advisory Committee at CHBAH

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

MEDICAL ADVISORY COMMITTEE

CHRIS HANI BARAGWANATH ACADEMIC HOSPITAL

PERMISSION TO CONDUCT RESEARCH

Date: 2nd May 2023

TITLE OF PROJECT:

Factors associated with timely referral of cancer patients for palliative care services at Chris Hani Baragwanath Academic Hospital, Johannesburg.

UNIVERSITY: Witwatersrand

Principal Investigator: Dr S Msomi

Department: INTERNAL MEDICINE

Supervisor : Prof L Ibisomi/ Dr M Ratshikana

NHRD Number: GP_202304_053

Permission Head Department (where research conducted): Yes

The Medical Advisory Committee recommends that the said research be conducted at Chris Hani Baragwanath Academic Hospital. The CEO / management of Chris Hani Baragwanath Academic Hospital is accordingly informed and the study is subject to:-

- **Permission having been granted by the Committee for Research on Human Subjects of the University of the Witwatersrand.**
- The Hospital will not incur extra costs as a result of the research being conducted on its patients within the hospital
- The MAC will be informed of any serious adverse events as soon as they occur
- Permission is granted for the duration of the Ethics Committee Approval.

.....
Recommended
(On behalf of the MAC)
Date: 02/05/2023

.....
Approved/Not Approved
Hospital Management
Date: 03/05/2023

Appendix 3: Permission to use palliative care data



GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

Gauteng
Centre of Excellence
for Palliative Care

10 June 2022

To: Wits University

Permission to use palliative care data for a research study

This serves to confirm that Mr Sabelo Msomi, student number **2484798** has been granted permission to use our palliative care data at Chris Hani Baragwanath Academic Hospital, Palliative care unit to conduct his MSc research study.

Yours faithfully

Dr MJA Ratshikana

Director / Principal Investigator

Gauteng Centre of Excellence for Palliative Care

Appendix 4: Plagiarism Declaration Report

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG

FACULTY OF HEALTH SCIENCES

PLAGIARISM DECLARATION TO BE SIGNED BY ALL HIGHER DEGREE STUDENTS

SENATE PLAGIARISM POLICY: APPENDIX ONE

I **Sabelo Msomi** (Student number: **2484798**) am a student registered for the degree of **MSC Epidemiology: Implementation Science** in the academic year **2024.**

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: 25 /03/2024

Appendix 5: Turnit report