EXPERIENCES OF WOMEN WITH BREAST CANCER DURING THE COVID-19 PANDEMIC IN NAIROBI, KENYA.

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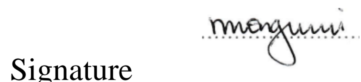
A RESEARCH PROJECT SUBMITTED TO THE DEPARTMENT OF SOCIOLOGY, SOCIAL WORK AND AFRICAN WOMEN'S STUDIES IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE AWARD OF MASTER OF ARTS IN WOMEN LEADERSHIP AND GOVERNANCE IN AFRICA OF THE UNIVERSITY OF NAIROBI

JULY 2023

DECLARATION

This project report is my original work and has not been presented for examination for a degree in any other university or institution.



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DEDICATION

This research project is dedicated to my parents Mr. and Mrs. Peter Ngumi Gichoho and my husband Samuel Kariuki Kuria who have believed in me and constantly provided advice and financial support. To my children Njeri, Wanjiru, and, Kuria for being so helpful to me in finding my place in online classes. To the Late Pauline Githugu, who was one of my Key Informants who bravely battled breast cancer during the COVID-19 pandemic but passed away in June 2022.

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I acknowledge, the Department of Sociology, Social Work, and Women's Studies for providing an online platform and academic space that focuses on Women's studies not only for Africa but for the rest of the World. I am honored to be a student in this department and to benefit from this rich and rigorous academic environment. I am indebted to the Senate of the University of Nairobi for braving the challenge as a result of the declaration of COVID-19 as a pandemic in March 2020. The Department provided a robust online class environment that allowed me to take the entire course from Abuja, Nigeria.

I am indebted to my supervisors Dr Marygorety Akinyi and Dr Josephine Muthami who worked tirelessly to guide me in this project.

"Don't let the fear of the time it will take to accomplish something stand in the way of you doing it. The time will pass anyway; we might as well put that passing time to the best possible use" Earl Nightingale (nd.). I am grateful to my friend Mrs. Lydia Magutsa who inspired me to seize the day while performing my triple roles in settling my family in a new land. I consider the relocation to Nigeria as part of my success where success is defined as the progressive realization of a worthy goal or ideal (Nightingale, UD). It presented me with ample time and significantly few distractions to be able to focus on enriching my skill, knowledge, and capacity. "All things work together for good to them that love God, to them who are the called according to his purpose. Romans 8:28" Indeed all things have worked together for my good.

ABSTRACT

The global cancer burden is increasing and Breast Cancer is now the top cause of death among women, most in the prime of their lives, the majority of whom are from the poorer nations of the world. Cancer is therefore ranked the number two global leading cause of fatality among non-communicable diseases Every aspect of life as we know it changed drastically when COVID-19 was declared a pandemic in March 2020. Governments across the world instituted stringent measures in order to curb the rapid spread of the COVID-19 virus. The daily briefings in Kenya and in the world concerning the risk for citizenry with comorbidity, women living with breast cancer were at higher risk. The mixed method approach used in this study lends an ear to the voices of these women and records how the pandemic presented new and exciting training and employment opportunities leading to a positive impact of the COVID-19 pandemic on their socio-economic status. This study looked at the impact of the COVID-19 pandemic on the livelihoods of a select number of women with breast cancer living at the epicenter of the pandemic in Nairobi, Kenya during the period from March 2020 to September 2021. The study found that majority of these women were empowered by the unique opportunities presented by virtual upskilling, and many more job opportunities that allowed them to work despite their comorbidity. While some of the lockdown measures resulted in closures, re-prioritizing, and reduction of 'in-person' interaction it also presented flexibility and new approaches to psycho-social support and socio-economic support to women living with breast cancer.

TABLE OF CONTENTS

DECLARATION i

DEDICATION ii

ACKNOWLEDGEMENT iii

ABSTRACT iv

ABBREVIATIONS AND ACRONYMS viii

LIST OF FIGURES AND TABLES ix

CHAPTER ONE 1

INTRODUCTION 1

- **1.1 Background of the study** 1
- **1.2 Statement of the Problem** 2
- **1.3 General objective of the study** 4
  - **1.3.1 Specific Objectives** 4
- **1.4 Research Questions** 4
- **1.5 Justification of the study** 5
- **1.6 Scope of the study** 6
- **1.7 Limitations of the study** 7
- **1.8 Definition of Terms** 7
- **1.9 Organization of the study** 12

CHAPTER TWO 13

LITERATURE REVIEW 13

- **2.1 Introduction** 13
- **2.2 Breast cancer and the role of timely access to health care provision** 13
- **2.3 Pandemics and Breast Cancer** 15
- **2.4 Effects of WHO Protocols during COVID-19 pandemic** 17
  - **2.4.1 Access to health care** 20
  - **2.4.2 Impact of COVID-19 pandemic on healthcare** 23

2.5 Psycho-social impact of the COVID-19 pandemic 25
2.5.1 Uncertainty caused by the COVID-19 pandemic 25
2.5.2 Psycho-social support required by WBC 27
2.6 COVID-19 pandemic and how it impacted socio-economic status of women 28
2.6.1 Unpaid care and economic imbalance 30
2.7 Theoretical Framework 31
2.8 Conceptual Framework 34
2.9 Summary of Literature Review 35
2.10 Research Gap 36
CHAPTER THREE 37
RESEARCH METHODOLOGY 37
3.1 Introduction 37
3.2 Research Area 37
3.3 Research Design 39
3.4 Study Population 41
3.5 Sample Size and Sampling Technique 41
3.6 Data Collection Instrument 43
3.7 Data Processing Analysis 44
3.8 Ethical Consideration 44
CHAPTER FOUR 45
4.1 Introduction 45
4.2 Demographic Characteristics of the respondents 45
4.2.1 Age of the respondents 45
4.2.2 Marital status 46
4.2.3 Education Level 46

4.2.4 Occupation 47

4.3 Breast cancer Management during COVID-19 pandemic 48

4.3.1 Breast cancer management challenges 48

4.3.2 Coping mechanisms of the participants 50

4.3.3 Access to health care based on online need assessment 50

4.3.4 Psychosocial challenges faced 53

4.3.5 Psycho-social outcomes of the pandemic presented 55

4.4 Facing the fear of contracting COVID-19 57

4.5 Social distance created space to process breast cancer 58

4.6 New opportunities in the digital space 59

4.7 Employment and training in the digital space 60

4.8 Coping with financial challenges during COVID-19 62

CHAPTER FIVE 64

SUMMARY CONCLUSION AND RECOMMENDATION 64

5.1 Introduction 64

5.2 Summary of findings 64

5.3 Conclusion 64

5.4 Recommendations 68

REFERENCES 69

Appendix I 77

Appendix II 82

Appendix III 83

ABBREVIATIONS AND ACRONYMS

BC	Breast Cancer
CDC	Centre for disease control and prevention
COVID-19	Corona Virus Disease 2019
GLOBOCAN	Global Cancer Observatory
GOK	Government of Kenya
IARC	International Agency for research on cancer
KNBS	Kenya National Bureau of Statistics
MOH	Ministry of Health
NCCS	National Cancer Control Strategy 2017-2022
NCD	Noncommunicable diseases
SARS-CoV-2 virus	Severe Acute Respiratory Syndrome Coronavirus 2
SDG	Sustainable Development Goals
UN	United Nations
WB	World Bank
WBC	Women with Breast Cancer
WHO	World health organization

LIST OF FIGURES AND TABLES

Figure 1: Number of cumulative COVID-19 cases as at Oct 27, 2021. Source: Ministry of Health 17

Figure 2: Graphic representation of confirmed COVID-19 cases in Kenya as at Oct 31st, 2022..... 18

Figure 3: Number and distribution of cancer treatment centres in Nairobi, Kenya as at Oct 31st, 2021 19

Figure 4: Conceptual framework 34

Figure 5: Map of Kenya indicating COVID-19 epicentre 37

Figure 6: Detailed outline of Nairobi Metropolitan lockdown boundaries..... 38

Table 1: Marital Status..... 46

Table 2: Education Level 47

Table 3: Demographic statistics with codes..... 48

Table 4:Year of diagnosis, phase and location of treatment 52

CHAPTER ONE

INTRODUCTION

1.1 Background of the study

According to World Health Organization (WHO) cancer was a primary cause of death and a significant impediment to extending life expectancy globally and it was estimated that cancer was the first or second leading cause of death before the age of seventy (70) in 112 of 183 countries in 2019. Countries in the Maghreb region, Kenya and Malawi rank it as second in Africa and another 23 countries rank it as third or fourth (*World Health Organization*, 2021).

The cancer burden in 2020 in terms of incidence and mortality against the full impact of the coronavirus disease (COVID-19), was yet to be fully captured because it was based on estimates that were derived from studies done in previous years (*World Health Organization*, 2021). According to a previous report "In 2020, there were 2.3 million women diagnosed with breast cancer with 685,000 fatalities globally"(*World Health Organization*, 2021).Not all diagnosis needs to be fatal it can be treated if detected early. Between 2015 and 2020, WHO reported that breast cancer had been diagnosed on over 7.8 million women who were still alive. It is not only the most common cancer among women worldwide it is also referred to as the world's most prevalent cancer by end of 2020.

The burden continues to grow across the world and Breast cancer is leading cancer both in incidence and mortality among women globally. (*World Health Organization*, 2021) According to previous research findings, breast cancer struck Kenyan women at a younger age (35-50 years) than it does in Western countries (50-55 years). Only 5-10% of instances

could be related to hereditary susceptibility, while 90% of cases occurred spontaneously meaning that breast cancer was more likely in families with no history of the disease.

A woman could be diagnosed with cancer at any time, regardless of their social, economic, or physical circumstances. *World Health Organization*, (2021) found breast cancer in Kenya, to be the most frequently occurring and ranked at number three (3) of highest occurring deaths related to cancer. Chronic illnesses and pandemics disproportionately impact women, and found that women have the highest breast cancer risk factor, with men accounting for only 0.5-1 percent of breast cancer cases.

The daily COVID-19 cases globally as of January 25th, 2022 according to WHO was at over 3.65 million people, with a 7-day average at over 3.4 million people. The cumulative cases were close to 347 million with deaths reported at over 5.5 million globally. In Kenya, the number of new cases stood at just slightly over 1000 with deaths recorded at 47 people on 24th January 2022 and Nairobi County was taking the lead.(*World Health Organization*, 2021) (*World Health Organization*, 2022)

The study recorded how the COVID-19 pandemic resulting from the corona virus and lockdown measures impacted women with breast cancer in Nairobi, Kenya.

1.2 Statement of the Problem

Breast cancer accounts for over 16 percent of all cancers in Kenya. A total of 6799 cases were reported in 2020, an increase from 5985 reported in 2018.Deaths from breast cancer rose from 2553 in 2018 to 3107 in 2020 (Sung et al., 2021). According to the National Comprehensive Cancer Network in Kenya, about half of all BC patients are under the age of 50 and most of them are mothers, working adults, or even owners of small businesses.

The expectations placed on them by their families and society, the side effects of treatment, and the symptoms of cancer require a lot of care and support (*National Cancer Control Strategy*, 2017). Research on the various aspects of breast cancer globally continued to grow in leaps and bounds. In Kenya, various studies have been carried out recently on breast cancer awareness among Kenya women, breast self-examination and the prevalence of breast cancer in Kenya (Mwenda et al., 2021; Antabe et al., 2020). Others were on how testing and treatment of cancer could be improved in Kenya (Makau-Barasa et al., 2018), breast cancer analysis and challenges in tackling the disease. However, the experiences of living with breast cancer during the COVID-19 pandemic are relatively unknown. The numbers of diagnoses and morbidity in both breast cancer and COVID-19 are alarming and behind those numbers are women. The full extent COVID-19 pandemic in various geographic locations globally is yet uncertain, with delays in identification and treatment due to patient and health-care system concerns. Closures, including temporary stop to screening programs, limited access and provision of much required medical intervention were predicted to result in a temporary reduction in incidence of cancer followed by rises in late-stage diagnosis, prognosis and fatality in some situations (Sung et al., 2021).

Cancer patients were found to be more vulnerable during the pandemic(Zhang et al., 2020) and capturing the experience of and the impact of COVID-19 from the perspective of women living with breast cancer (WBC) is an essential part of increasing awareness, useful in the provision of care for cancer patients in Kenya and other low and middle income (LMIC) countries as well as in building solutions that best meet the needs of the patients.

1.3 General objective of the study

To establish the experiences of women living with breast cancer in Nairobi during the COVID-19 Pandemic.

1.3.1 Specific Objectives

The specific objectives were as follows: -

i) To assess the effect of COVID-19 pandemic on access to healthcare for WBC in Nairobi, Kenya.

ii) To examine the psycho-social effect of the COVID-19 pandemic on WBC in Nairobi, Kenya.

iii) To explore the socioeconomic experiences of COVID-19 pandemic on WBC in Nairobi, Kenya.

1.4 Research Questions

The research questions in this study were as follows: -

i) How did COVID-19 pandemic influence the experience of WBC in accessing health services in Nairobi, Kenya?

ii) What psycho-social consequences were experienced by WBC during the COVID-19 pandemic in Nairobi, Kenya?

iii) What socio-economic experiences did WBC handle during the COVID-19 pandemic in Nairobi, Kenya?

1.5 Justification of the study

Many patients and their families bear the impact including shifting roles, fear of death and in this study the fear of contracting COVID-19 and often times a patient who has family and friends around them to support them during the diagnosis and treatment fairs better than one without the support. Behind the WBC figures are women and families that had to deal with the medical and social ramifications of an illness that strikes people in their prime, and the COVID-19 pandemic and lockdown measures complicated matters even more.

The study findings were to create an opportunity for future studies about the impact of pandemics on WBC who were considered as having comorbidity that made them more vulnerable and more likely to catch COVID-19 and becoming severely ill(Zhang et al., 2020).

According to Antabe et al., (2020) future research would be beneficial on educating the public on breast cancer and screening. Community awareness and information about breast cancer screening had the capacity to generate demand required a well-prepared healthcare system to provide breast cancer screening(Mwenda et al., 2021).

Access to healthcare, availability, and access to psychosocial support and socioeconomic support changed quickly and were investigated from an academic and policy perspective.

However, there was little research available of how COVID-19 in Nairobi, Kenya impacted WBC. The aim of this study was to explore the experiences of WBC in Nairobi during the COVID-19 pandemic. The findings of the study were to provide valuable and timely information on how the quality of life of WBC could be improved based on the findings and the recommendations derived from the study.

The findings were useful for the fulfillment of my studies in Women Leadership and Governance in Africa as the voice of women in critical decision making. The findings were also to be useful to both Government and non-governmental organizations involved in the provision of healthcare, psycho-social support, and socio-economic support of women living with breast cancer in Kenya.

Participation of member countries and non-governmental organization alongside the engagement of individuals who have lived with breast cancer to be critical in ensuring that the new Global Breast Cancer Initiative (GBCI) was successful in its integration of initiatives in place and that they were tailor made country specific solutions(*GBCI*, 2021).

It added to the body of knowledge of pandemics that was to move to address the identified challenges that touch on the lives of WBC and their dependents. It was to come up with appropriate measures and guidelines for the Kenya in the event of a pandemic of the similar or different nature. The findings were to improve the emergency response and ensure the right sizing of containment measures while at the same time move to address the identified challenges that touch on the lives of WBC with strategies to improve the quality of care.

1.6 Scope of the study

The study was carried out in Nairobi, Kenya. The Nairobi Metro Vision 2030 in a bid to create a world-class African metropolis, formed the Nairobi Metropolitan Area. During the COVID-19 Pandemic the area was designated in a Presidential Statement on 6th April 2020 to include the county of Nairobi, parts of Kiambu, parts of Machakos county and parts of the county of Kajiado (*Kenyatta*, 2020). For the purpose of this study Nairobi included the above-mentioned areas. The target was women living with breast cancer within the Nairobi

Metropolitan Area during the COVID-19 pandemic. The scope of the study was limited to experiences of selected WBC in the said region.

1.7 Limitations of the study

It was worth noting that beyond the COVID-19 lockdown measures and the physical travel restrictions during the period of study, the nature of the breast cancer disease and its physical and psychological burden posed a challenge while carrying out the study. The interviews were conducted online and because of the sampling technique, some participants declined to be interviewed on what they felt were very personal issues to a stranger. Thus, the generalization of conclusions may not necessarily apply to all WBC living within Nairobi and beyond.

1.8 Definition of Terms

Breast Cancer: uncontrolled division of abnormal cells in the mammary glands and this study in women in Nairobi during the COVID-19 pandemic. Often viewed with fear and seen as a very private matter due to the intimate connection of the breasts

Cancer: a condition brought on by the uncontrolled division of aberrant cells in a specific bodily region, in this case, the female mammary glands.

Comorbidity: the simultaneous occurrence of two or more medical conditions in a patient, in this case, breast cancer patients in Nairobi, Kenya, during COVID-19 pandemic were

	considered to be more vulnerable due to their already compromised immunity.
COVID-19	a respiratory infection that causes severe symptoms and, in some cases, death. In this study following the declaration of COVID-19 as a pandemic by WHO due to its rapid global spread became a concern to governments and individuals alike.
Curfew	a law mandating individuals to stay indoors during certain times, usually at night "dusk to dawn curfew," and in this study between 8 pm and 4 am or as instituted by the government of Kenya through Presidential directive and enforced by the police.
Lockdown	a security mechanism that imposes a condition of isolation or restriction of movement, in this case within the established boundaries of the Nairobi Metropolitan Region and other regions as deemed necessary based on the data available by the MOH concerning the reported COVID-19 infections. The lockdown was enforced by law enforcement that were feared by many.
Pandemic	Widespread epidemic of an infectious disease that may be throughout an entire nation, continent or the world, in this

case, the COVID-19 Pandemic in Kenya that saw the cases increase exponentially after the first case was reported.

Phase One treatment	This is the initial screening, diagnosis and either Surgery, chemotherapy and radiotherapy and in this study that which is fully administered by medical personnel in a hospital environment due to the nature of the protocols for treatment.
Phase Two treatment	This is the treatment that follows completion of Phase one and in this study requiring spaced-out consultation with the oncologist and systemic chemotherapy or hormone therapy in tablet (self-administered) format and needed fewer visits to the hospital for routine testing.
Psycho-social support	is the interrelation between social factors and individual thought and behavior. Psycho-social support in this study is therefore how a patient who has been diagnosed with breast cancer interacts with a diagnosis that is emotionally and physically distressing.
Quarantine	isolation of individuals exposed to infectious disease under strict measures to reduce or curb the spread of the disease. In this study quarantine was a measure given to those who were found to have the COVID-19 virus. The period was ranging from 14 days as required by the WHO and the Government

of Kenya and could be increased if after the initial quarantine the patient was tested and found to still be having the virus.

Social distance — the practice of keeping a greater-than-usual physical distance to reduce exposure and infection transmission. In this case the WHO prescribed the physical distance to be maintained at a minimum of 1 Meter whether or not the other person was exhibiting symptoms of the Corona Virus. In this study plays out in its application in transportation, access to health care services, number of people that can received both public and private services in a day

Socio-economic support — relates to the interaction of social behaviour and economic factors. Social economic support is therefore in this study the interaction when one's social behaviour is challenged by diagnosis of a terminal illness like breast cancer and its implication on their ability to continue to earn sharpened by the COVID-19 pandemic demand for all people with pre-existing conditions requirement to stay at home. In this case the capacity to afford the basic needs of food, shelter and clothing while still coming to terms with a breast cancer diagnosis and now being faced with the new dynamics of the COVID-19 pandemic.

Support for WBC	Support is crucial to women who have been diagnosed with breast cancer, as the treatment is not only time consuming but also a financial burden to the women and their care giver. In his study it is the ability to work and provide for the needs of her family and have access to NHIF and other forms of insurance to cater for the treatment and the rigor of the treatment can be daunting. On top of the that the women had a double challenge to also live through the Covid-19 pandemic.
Telemedicine	Online or virtual consultation by multi-disciplinary team collectively or individually and in this study the first response during the COVID-19 pandemic. Also used to review scans, MRI, x-ray and blood tests results and offering prescription. Helped to reduce long queues in waiting rooms where the breast cancer patients felt even more vulnerable.
Timely access to healthcare	in breast cancer care is the capacity to provide medical care in a quick unhindered manner to reduce morbidity and mortality of Cancer. In this study it refers to access to consultation in person or virtually, access to surgery, radiotherapy, chemotherapy both oral and intravenous, palliative care, diet and nutritional support prescription. The ability to access can be impacted by availability of the

healthcare facilities, the financial capacity to procure the service and the physical capacity to contract the services.

1.9 Organization of the study

This project was arranged into five chapters. Chapter one introduced the study. Chapter two captured the study literature review. Chapter three described the research methodology. Chapter four captured data analysis, presentation, and discussion. Chapter five presents the summary of research findings, discussion of the findings, conclusion, recommendations derived from the findings, and finally suggestions for further research.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter covered the empirical literature review, theoretical and conceptual framework. The researcher reviewed the work of other researchers that border around breast cancer and the role of timely access to health providers and systems in cancer management, pandemics and women with breast cancer, COVID-19 pandemic lockdown on women with breast cancer. The theoretical framework guided and provided assumptions of the study, determined appropriate questions for the study, in the selection of the research design and appropriate data collection methods too. The Conceptual framework

2.2 Breast cancer and the role of timely access to health care provision

Cancer is the body's unchecked cell division that has the ability to invade surrounding tissues. In the glandular tissue of the breast, breast cancer forms in the lining cells of the ducts or lobules. Initially, tumors develop within the lobule or duct, where there are normally no symptoms, with low probability of spreading. These tumors then grow over time into the breast tissue, lymph nodes, or other body organs. Women who die from breast cancer typically do so due to widespread metastases (*WHO*, 2018).

Women should seek medical assistance as soon as they see an unusual mass in their breast, even if there is no pain associated with the mass. When a potential symptom is identified as soon as feasible, medical assistance can be sought for a more successful course of therapy. Breast cancer symptoms include breast lumps, altered nipple appearance, redness,

pitting, or other skin abnormalities, as well as alterations in breast size, shape, or appearance (*WHO*, 2018).

Radiation therapy, medicine, and surgical removal are all used to treat breast cancer. Such therapy can halt the development and spread of cancer. Chemotherapy, radiation and surgery are breast cancer treatments that can have negative effects on a person's physical, mental health and finances (UN,2015). Through the use of support networks, which may include family, community, and healthcare providers, the social, economic and psychological effects of breast cancer could be minimized. Understanding how support systems mitigate the effects of breast cancer and related medicines is therefore crucial in dealing with the disease (Bigatti et al., 2011).

The United Nations (UN) in its third goal towards development aim at ensuring that people of all ages around the world can enjoy living well and being healthy, delves further into that particular goal by outlining that by 2030 their objective was to reduce the number of people who die young due to diseases that are not communicable by 30% through prevention and treatment of those NCDs while at the same time promoting wholeness and mental health (United Nations, 2015).

This has been mirrored through the constitution of Kenya which "confers on every person the right to the highest attainable standard of health, which includes the right to health care services" (Constitution of Kenya, 2010, p. Art. 43). This right has been further expounded on through the establishment of a specific mechanism towards prevention and control of cancer as priority amongst NCDs at both national government and county level (Ministry of Health, 2015).

There is a protocol aimed at ensuring that due service per level of care and prompt referral to the appropriate management facility is available to any suspected case of cancer. The guidelines to deliver a well-coordinated effort for the evaluation, treatment, rehabilitation and continued care through to survivorship or palliation are well outlined (Ministry of Health, 2017; Ministry of Health, 2019).

The objectives of the government in a 5-year strategy through that cover "Prevention, early detection, and cancer screening, cancer diagnosis, registration, and surveillance, cancer treatment, palliative care, and survivorship. The strategy also looks at coordination, partnership, and financing for cancer control. This worked in hand with ensuring there is adequate information through monitoring, evaluation, and research" (Ministry of Health, 2017, p. 12)

All of these and more did not factor in the occurrence of a pandemic that would have an impact so globally devastating as COVID-19 (WHO, 2020) with guidelines being issued by the WHO in a bid to contain the rapid transmission of the disease. These were both pharmacological and non-pharmacological including wearing masks, washing hands with clean running water, and maintaining a specified social distance (WHO, 2020). In Kenya, there was the issuance of interim guidance on the provision of services for NCDs during COVID-19 in July 2020 (MOH, 2020).

2.3 Pandemics and Breast Cancer

Pandemics have been there throughout history and appear to be increasing due to advancements in human travel and population. Cholera, Bubonic plague, smallpox, and Influenza have been some of the deadliest pandemics in the world's history. Morbidity and

mortality increase when there is a large-scale infectious disease outbreak leading to a major interruption of socioeconomic and political environment of an affected geographical area (Madhav et al., 2017).

The Coronavirus causing infectious disease known as COVID-19 led to the declaration of a pandemic on 11th March 2020 by WHO. It continues to affect just about every single aspect of life. Research is still ongoing on how it as affected breast cancer patients from an epidemiologic perspective, the socio-economic impact, health policy perspective, the links between cancer and COVID-19 infections, and immunity among many other aspects (WHO, 2020).

Restrictions imposed by respective authorities through lockdown measures may have caused an increase in the severity of cancer cases and even complications. Several studies carried out opined that the global health crisis spurred fast state-imposed lockdowns, causing significant and sudden disruptive challenges to the global labour scene, cost of living, supply networks and worldwide, and resulting in a large number of people migrating Kabeer et al., 2021; Nikoloski et al., 2021).

It goes down in recent history as a time when extensive restrictions were deliberately imposed on economic livelihoods by governments globally for the protection of their people. According to data available on COVID-19 infections in 112 countries that even though the rate of fatality was higher in men than women, fear was more prevalent in women than in men. People with underlying medical conditions like cancer and those undergoing active treatment are more likely to get severely ill from COVID-19 because the treatment weakens their body's ability to fight off the disease (*CDC*, 2021);Kabeer et al., (2021)

2.4 Effects of WHO Protocols during COVID-19 pandemic

When COVID-19 was declared a pandemic by the WHO in March 2020 they issued a protocol that was to be adopted around the world with an aim to curb the rapid spread of the Corona Virus. The protocol included wearing of masks, social distancing prescribed at a minimum of 1 meter, restriction of movement and public gatherings, hand washing and sanitization and vaccination. As of 7th October 2021, the cumulative number of confirmed covid cases in Kenya stood at 250,728 with 243,337 having recovered and 5,178 fatalities country-wide. (MOH 8th October 2021 brief) Nairobi was the epicenter of the pandemic in Kenya with an estimated 100,965 cases reported as of the end of September 2021. The first case was reported on 12th March 2020. Initially, governments across the globe put guidelines and restrictions in a bid to curb the virus from rapidly spreading and Kenya was one of them.

Search: Records: 13

Characteristic	Number of cumulative cases
Nairobi City	101,643
Kiambu	16,380
Mombasa	15,523
Nakuru	13,122
Uasin Gishu	8,487
Kisumu	6,509
Machakos	6,497
Kajiado	6,302
Kilifi	6,159
Busia	5,898
Kericho	4,480
Nyeri	4,119
Siaya	3,600

Showing entries 1 to 13 (47 entries in total)
Previous Next

Details: Kenya; Ministry of Health Kenya; October 27, 2021

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Figure 1: Number of cumulative COVID-19 cases as at Oct 27, 2021. Source: Ministry of Health

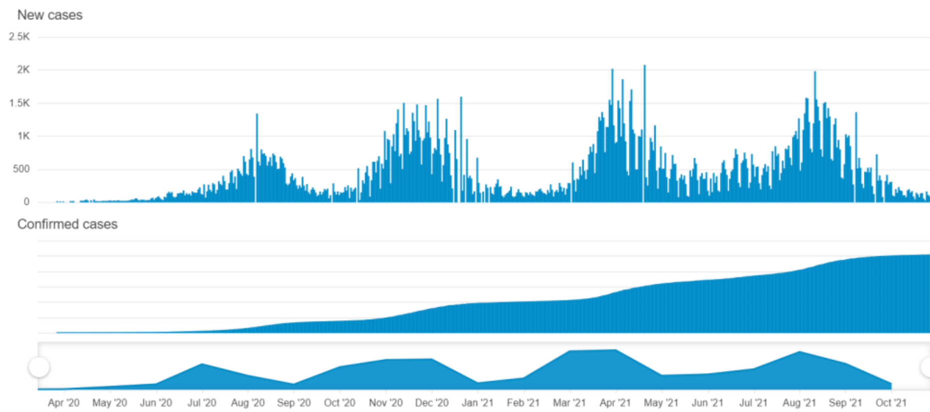


Figure 2: Graphic representation of confirmed COVID-19 cases in Kenya as at Oct 31st, 2022

Source: Statistics 2021

Worldwide healthcare centers and hospitals tried to halt the rapid spread of infections. The majority of global citizens were still vulnerable to the virus. Families and communities continued to bear the increased healthcare burden on their shoulders. As a result of the initial reaction to the pandemic, most healthcare systems were overstretched and it saw a significant reduction in the provision of health and social services for non-COVID-19 cases. Also referred to as non-essential services as reported by the WHO (WHO, 2021).

Many families had little choice but to bridge the gap in care and support of their loved ones who had any other illnesses including chronic illnesses. As the default unpaid family caregiver many forerunners in the pandemic response were women and the majority went with no pay or were poorly paid community health workers (WHO, 2020) (*United Nations*, 2021). This was emphasized in the statement "*COVID-19 is not only a challenge for global health systems but also a test of our human spirit"* (*United Nations*, 2021, p.2)

In Kenya the Government, through Presidential directives and statements by the Ministry of Health began issuing guidelines from 13th March 2020to date. The MOH in a letter to

all the County Executives of Health in April 2020 emphasized the need to keep NCD clinics open to their patients' following reports that some of them had been closed following the pandemic (MOH, 2020).

Facility	Ownership	Radiotherapy	Brachytherapy
Kenyatta National Hospital	Public	3	1
Kenyatta University Hospital	Public	1	0
Aga Khan University Hospital	Private	2	1
Nairobi Hospital	Private	2	1
Cancer Care Kenya-HCG	Private	2	0
Texas Cancer Centre	Private	2	0
Equra Cancer Centre, Eldoret	Private	1	1
Nairobi West Hospital	Private	1	0

Figure 3: Number and distribution of cancer treatment centres in Nairobi, Kenya as at Oct 31st, 2021

Source: MOH (2020)

According to Grossheim et al., (2021)majority of the currently functioning radiotherapy centers are located in Nairobi with five out of six being private facilities and the only public one being at the Kenyatta National Hospital. The government made effort to ensure that many of the level V hospitals have existing chemotherapy units. It noted that they risked not only having fatalities but also gains made in terms of the management of the patients before the pandemic.

MOH also issued Interim guidelines on the Provision of services for NCDs in July 2020 wherein they outlined measures on how to continue to provide for Cancer Patients. In the guidelines, they recommended the adoption of innovative solutions to be adopted to overcome health system challenges during this period such as telemedicine, home delivery

of drugs, keeping active communication, and giving social support via phone with clients and their families (MOH, 2020).

This was especially critical for those in palliative care and to extend liberties such as allowing relatives to come and pick up prescriptions for a longer period to reduce the number of times the WBC needs to make a physical visit to the hospital. (Martei et al., 2021) noted that some African countries like Congo, Egypt, Kenya, Nigeria, and Rwanda applied new innovative technologies to collect and even deliver samples and medication.

The lockdown measures within the Nairobi Metropolitan area were lifted and re-introduced based on the number of infection cases since March 2020 with the lift on the majority of the measures in October 2021. The President of Kenya H.E Uhuru Kenyatta instituted a 'shift of focus from survival to co-existing with the disease' during his ‘Mashujaa’ Day speech in October 2021.

In a bid to fully reopen the economy, the disruptions caused to cancer care by the temporary closure of many chemotherapy centers outside of Nairobi earlier in the pandemic led to more cancer patients being able to access treatment at the largest teaching and referral hospital in Nairobi (Grossheim et al., 2021). However, WHO continues to encourage as many people as can be reached to get vaccinated but still maintain the no-pharmacological mitigation measures that were; need to wear a facial mask, keeping social distance, and cleaning of hands (WHO, 2021).

2.4.1 Access to health care

In many societies women and girls are discriminated when it comes to access to health often based on deep rooted social cultural factors. Women from marginalized groups and

low-income households were found to have suffered to a greater extent during the COVID-19 pandemic. This is in addition to the fact that globally, the economic sectors that took the hardest hit had larger numbers of women employed in them compared to men leaving them with a bigger risk of exposure to the disease (Kabeer et al., 2021)

Studies conducted in different parts of the world confirm that those who were already predisposed to another health condition like breast cancer were more likely to get sick or critically ill from COVID-19 and die than those without an underlying condition (CDC, 2021). These findings point to the urgency of instituting measures that would help cancer patients to receive continued care while at the same time reducing the risk of them getting sick in the process (Kassaman et al., 2020)

From March 2020 Kenya, the MOH put containment guidelines including curfews, complete or partial lockdown, social distancing, mask-wearing, and prohibition of all public gatherings including churches, political rallies and eventually learning institutions. Additional measures over the Nairobi Metropolitan (NM) area being lifted or enforced based on the positivity rate throughout March 2020 to October 2021 because the NM was leading in the number of cases being reported daily, (*MOH*, 2020) (*Office of the President*, 2020-2021)

The travel bans into and out of the capital of Nairobi had a significant impact on the county and metropolitan area as well as other towns and cities across the country. Because of the population and dynamics of life in Nairobi and the large infection rate, most of the measures put directly impacted the County.

The majority of the cancer services are in Nairobi with the only functional radiotherapy centers being located there (Grossheim et al., 2021). The Kenya Cancer registry notes that the needs of the most immune-compromised members of the community needing quicker and more sophisticated medical care were not put into consideration when the government issued a blanket statement on its strategy to contain the spread of the virus.

The few facilities able to offer cancer treatment faced immense pressure that saw them modify their hours of operation to fit in the revised staff rotation schedules, staff isolation, and their fear of getting the virus especially where personal protective gear was scarce or ill fitting. They were therefore not operating at optimum both in staff and patient numbers (Martei et al., 2021).

In Ghana as well as in Nigeria the impact of lockdown measures on breast cancer patients was not easily available data as testing for COVID-19 was for those with symptoms

Telemedicine has drastically lowered the barriers to healthcare access. The implementation of telemedicine is one method of making sure that Universal Health care becomes accessible to all. According to Wambalaba et al., (2019) approximately 70-80% of cancer patients in Kenya are diagnosed usually at the advanced stages because they are unaware of what to look out for in terms of symptoms and indicators.

That is coupled with inadequate screening, little or no access to the prerequisite diagnostic and treatment services. Some of the significant challenges brought about by the pandemic have been directly on the demand, and capacity of healthcare facilities to provide cancer services across the different phases in prevention and control. Health workers across all

levels of care should continue to prioritize cancer symptom recognition and referrals for diagnosis and management while implementing COVID-19 infection prevention measures.

The MOH set out Interim guidelines for the response to NCDs during the COVID-19 Pandemic that included the adoption of virtual consultations encouraged for patients not requiring a physical exam, or in-office diagnostics. This included regular surveillance in patients who have finished treatment or who are on active surveillance and are thought to be at low risk of recurrence or disease progression and those who are asymptomatic during the follow-up period (*MOH*, 2020)

In the context of COVID-19, facilities were encouraged to establish digital diagnostic platforms to allow for telepathology and virtual reporting of pathology specimens to mitigate against longer waiting times for cancer diagnosis that may worsen should cancer diagnostic services be halted. Telepathology offers an innovative solution for prompt diagnosis, knowledge exchange, and sharing among the relevant pathologists and in the setting of multidisciplinary team meetings as it was noted that already, in Kenya, the majority of cancer patients are detected late resulting in poor prognosis and potentially higher fatalities (*MOH*, 2020) (Kenyatta University Teaching Referral and Research Hospital, 2021).

2.4.2 Impact of COVID-19 pandemic on healthcare

Every citizen in Kenya has the right under the Constitution to the best health that is reasonably attainable. The agenda 2030, outlines audacious goals with attainable markers of having a healthy life and for the well-being of all people of all ages globally. This includes working towards reducing the number of people who die prematurely from NCDs by 30% by the year 2030 (*GBCI*, 2021)

This being done through the concerted effort of governments, non-governmental organizations, and players in the field of research and advocacy (*Sustainable Development Goals*, 2012). Kenya's Vision 2030 was set to see all Kenyans benefit from seeking a reasonable and high standard of living this is also mirrored in the Kenya Health Policy which strives to achieve the best feasible level of health in a way that is sensitive to the health requirements of the people (*MOH*, 2014)

A significant number of cancer patients at Kenya's top referral hospital were not able to attend to switch to telemedicine to enable them to access with ease the continuity of quality patient-centered cancer care by addressing the unique needs of cancer patients during the pandemic (Umar et al., 2022). In other parts of the world like Australia, many patients reported overall satisfaction with switching to telehealth (Edge et al., 2021).

Services were also reconfigured so that telehealth can be adopted with specific adaptations for pandemic response and therefore giving it good value in the bigger scope of care management. (Bahn et al., 2020) opined that in the context of COVID-19 there was a risk that telecommuting would disproportionately affect women and that institutionalizing telecommuting through job sharing, flextime, policies that are becoming more easily accessible and acceptable may put a premium on much-needed domestic help.

The reorganization of cancer care, including restricting the number of people and the number of times an admitted patient could be visited, changes to the frequency and length of visits to the doctor during an appointment, the capacity of those who care for them to adjust, and give even the most basic support because of an increased psychological and practical burden on their caregivers. COVID-19 has made an already stressful and uncertain time for patients and caregiver become even worse.

2.5 Psycho-social impact of the COVID-19 pandemic

The COVID-19 pandemic produced considerable interruptions in cancer care, and early research indicates that these disruptions are linked to higher levels of psychosocial distress among cancer survivors (Soriano et al., 2021). This disruption were on a complex scale for WBC and it was crucial to look for what the practical and psycho-social impacts of COVID-19 were. These include the uncertainty caused by the COVID-19 pandemic and support needed by WBC during the pandemic

2.5.1 Uncertainty caused by the COVID-19 pandemic

Public Orders issued by the government continued to guide the government response. Some orders included nationwide dusk-to-dawn curfews, closure and eventual opening of International and local airports, limited ground transport, closure of businesses' limitation and delineation of 'essential' goods and services among others (*MOH*, 2020) (*National Emergency Response Committee on Coronavirus*, 2021), EOP Presidential Statements and Addresses 2020, 2021 all of which impacted the access and availability of psycho-social support by caregivers and healthcare workers too.

A study in Nigeria revealed that both patients and healthcare workers were in fear of contracting COVID-19 and the duty roster put in place in an attempt to reduce exposure of the staff led to a reduction in the number of healthcare workers on duty (Olabumuyi et al., 2020). A Study noted that in China, Cancer patients with flu-like and other symptoms closely resembling those of the infection caused by the coronavirus were great fear, more anxiety, and for some even depression and made many trips to the hospitals

This was even after they had been confirmed to not have the infection through several tests carried out. Some cancer patients picked up mannerisms that were overprotective like putting on rain protection gear and covers on their shoes, and disinfecting their homes on re-entry (Liu et al., 2020)

According to (Hwang et al., 2020) individuals with cancer social experience during the pandemic included decreased interaction with other people, loneliness which may have increased severe anxiety due to social isolation, and where they were required to quarantine over a long period were notable in potentially buffering vulnerability to psychological distress. (Sigorski et al., 2020) espoused those individuals with breast cancer primarily being women had higher levels of fear compared to individuals with other forms of cancer.

Pandemics have been shown to cause significant distress and many reported cases of anxiety and fear-related behaviors, sleep disturbances, and an ever lower perceived state of health due to the actual or perceived threat of the corona infection. Other fear factors like fear of being caught on the wrong side of the law with reports such as (Ombuor, 2020) where Kenyan Police Forces were accused of using excessive force and for killings recorded while enforcing COVID-19 curfew rules.

(Wasike, 2020) also reported of injuries and death by police offices in Nairobi while implementing curfews and safety measures. The fear to venture out even for treatment or to have family and loved ones come and offer psycho-social support was easily felt. The harshness of the police impacted access to hospitals beyond curfew hours.

2.5.2 Psycho-social support required by WBC

Studies undertaken indicate that support from members of one's family, community and health care professionals is critical for positive treatment outcomes for breast cancer patients and others with terminal illness. The support by providing information, giving of money, offering a listening ear and helping in other practical ways. For a patient to enjoy their existence and increase the chances of living longer especially if they have a terminal illness both quality medical intervention and psycho-social support are important.

WHO outlined the requirement to help contain the virus that included ensuring a physical distance of between 1.5 Meters to 2 meters, wearing face masks, and washing of hands (*World Health Organization*, 2021) Many patients rely heavily on their family members who may or may not be living together with them and would need to travel to come to their aid. Dependent on the nature of help required social distance was difficult to maintain where the patient needs to be nursed or ferried to the hospital.

(Liu et al., 2020) noted that for cancer patients there was an increase in anxiety and depression due to the restrictions on travel and instructions to stay at home, isolate, quarantine that led to delays in treatment and as a result increased demand for social support. "While Nairobi is considered the epicenter of the pandemic in Kenya, little is known regarding the transmission dynamics within the city meaning the formal and informal settlements in the city.

Subcounty level data are available, but not for informal settlements specifically". Insufficient information was available to show if there was any particular advantage of being in Nairobi where transport options include self-drive, taxi including online taxi-hailing services like Uber, Bolt among others, both public and private ambulances were

easier to access when public transport was limited and there was fear of contracting COVID-19 and increase in bus fare to compensate for the non-occupied seats as a result of social distancing (Pinchoff et al., 2021).

Breast cancer data available indicated that because nine out of ten women diagnosed have no family history of cancer it is sporadic and cuts across social demographics. Not enough data is available about the interaction of WBC and COVID-19 in both the formal and informal settlement.

Limited data was available regarding the informal settlements in Nairobi while the guidelines provided by the MOH were aimed at minimizing the fatal health impact of COVID-19. The pandemic caused food insecurity and unemployment. Those able to work having to break the laws in order to put food on their table and provide for their families (Pinchoff et al., 2021).

2.6 COVID-19 pandemic and how it impacted socio-economic status of women

While seeking to understand the nature of paid and unpaid work (Bahn et al., 2020) notes a huge upheaval both socially and economically as a result of the pandemic. The International Labour Organization reported a projection of a drop-in productivity and production worldwide as partial or total lockdown in 2020 was affecting billions of workers. This would likely result in global recession that is strikingly different from recessions in years past (*ILO*, 2020).

As the impact of COVID-19 continues to emerge it would seem that the productive and economic life of women will be disproportionate from men. Globally the gender wage gap sees women earning less, saving less holding less secure jobs and most likely as informal

sector employees. “They have less access to social protection and are the majority of single-parent households. Their capacity to absorb economic shocks is, therefore, less than that of men” .

According to (Kabeer et al., 2021), Women account for the majority of domestic workers globally in the millions who undertake all house hold cores like cooking and cleaning and caring for their families, frequently outside of the realms of labour laws and without any social protection, because they have to fill voids and gaps formed by governments and markets.

Domestic worker unions and groups have raised several complaints regarding infringement of employees’ rights since the beginning of the pandemic. Some of the issues ranging from being locked down in their place of work to being terminated without proper compensation (*WIEGO*, 2022).

According to (*United Nations*, 2021), Women and girls bear the brunt of the economic consequences, as they have lower earnings, have less savings, work in precarious employment or live in poverty. With the disruption of markets and supply chains many businesses were forced to close, to halt or to reduce their operations and as a result millions of people lost or continue to lose their economic livelihoods.

According to (*World Health Organization*, 2021) women pick up the bigger share of unpaid care responsibilities of family members because schools were closed and they had to provide and nurture for children heightened care needs of older persons due to significant change in routine, and a health care system that was struggling to stay afloat during the lockdown. Some of the challenges that was unique to women is that while they were

affected disproportionately by job cuts and lay-offs while at the same time were facing bigger demands to care for their families at home. The unpaid care provided by women increased.

(Hurren et al., 2023) looked into how women with breast cancer interacted with the healthcare system. Breast cancer management is challenging. Teams within the healthcare sector are best positioned to support patents with breast cancer. These officials could enhance the experience of patients through empathy and clear communication. Nurses, doctors, and numerous other healthcare professionals are involved in the management of breast cancer. The usual provision of supportive and oncological treatment to breast cancer patients is faced with unprecedented challenges due to COVID-19 epidemic. Healthcare facilities should consider risk of patients, long-term oncological outcomes from the treatment choices and the use of resources diverted from healthcare to support a coordinated response.

2.6.1 Unpaid care and economic imbalance

While the female labour force made it still remains fragile and therefore the adverse impact of COVID-19 continues to threaten the progress made. Female-headed households are particularly at risk of not meeting the needs of their homes in the pandemic. The first round of layoffs where the labour market has an overrepresentation of women was seriously impacted.

While early reports showed that funds allocated for sexual and reproductive health services were in most cases re-assigned to the pandemic and that affected the general health of women more (*United Nations*, 2021) Those considered unemployed yet perform many necessary and important tasks in the household were critical to timely and efficient

response to the pandemic in ways difficult to quantify. This is because most homes have women doing more than thrice as much unpaid work in the household than me.

Disparities therefore have always been there by gender when it comes to allocation of those duties, the pandemic widened this gap due to the increase in demand for care work. This economy though no visible to most has substantial consequences for the formal economy and the lives of women, unfortunately continues to be hidden(Dugarova, 2020)

2.7 Theoretical Framework

Feminist theory was looking at a set of ideas that attempt to explain women's experiences, women's inequalities and show limitations of the popular assumption of gender sex, and race. What was known, and how it was known, reflected the knower's circumstances and viewpoint. Individuals have first-hand awareness of their own body and mental states as well as information about themselves, which varies from third person knowledge about them. It also recognizes that the challenges faced by these women are influenced by multiple interconnected factors and can vary based on their specific social identities and contexts.

The use of African feminism aimed to give a clear way to working through how these women with breast cancer may have experienced COVID-19 in a unique way. This research will be based on African Feminism theory. (Mama & Abbas, 2014)refers to African feminisms as being diverse having many angles that help incorporates the liberation of women both theoretically and practically in the African context. Historically, women, migrant workers and refugees have been least served and most harmed during a pandemic(*United Nations*, 2021)

Women's health outcomes are impacted by various factors and the African feminist theory aids in bringing to light both structural and systemic inequalities that affect WBC. It helps to examine the disparities in the allocation of healthcare resources, encompassing restricted availability of cancer screenings, treatment centers, and affordable medications. African feminist also explores the impact of poverty, colonial legacies, and socio-economic disparities on women's experiences of cancer and barriers they face in accessing adequate healthcare.

African customs and beliefs paint a backdrop to how most women process the information about breast cancer. According to (E. P. Morse et al., 2014) women in urban parts of Tanzania still believed in myths and taboos regarding the likelihood of being diagnosed with cancer including the will of God, putting money in the brassiere, witchcraft amongst others. Many were unaware of breast self-examination or were too occupied with household chores, fearful or forgetful to be consistent and not any changes in appearance leading to delayed seeking of medical assistance.

While accessing the social-economic impact of COVID-19 on Kenya the KNBS (2020) found that there is a heavy and unequal responsibility of care and domestic work born by women and girls. These women already have to contend with a terminal illness and the reality of being referred to as more vulnerable due to the comorbidity brought about by their illness. There was an intersectionality of illness and care that amplified the harmful impact of the lockdown measures on WBC.(Bahn et al., 2020) (*WIEGO*, 2022)

Women had to deal with higher with job losses while at the same time experiencing a higher demand on care for other members of their families that sometimes led to delayed seeking of treatment (Castaldi et al., 2022) (Dugarova, 2020) (*ILO*, 2020) African feminist

frameworks promote women's agency and activism. In the context of cancer, this means empowering African women to assert their rights, challenge stigmas, and advocate for improved cancer care and support services.

The harshness or fear brought about by police brutality all of which bring about the feminization of poverty as many women feared getting out to look for casual or other forms of labour to supplement their meagre income to meet the growing demand form family that were indoors all day long. Their stories need to be heard.

The feminist theory is applicable to the study as it explained the nature of gender inequality is society. The theory looked at avenues of mobilizing women's networks, creating safe spaces for sharing experiences, and engaging in policy advocacy to address the specific needs of WBC by helping to highlight their experiences, including the social-economic impact of the COVID-19 protocols and unequal responsibility of care and domestic work borne by women. According to (Steinberg & Halperin-Kaddari, 2020)these realities would not only be addressed, but also acknowledged as significant and necessary contributions to socio-economic disparities and psycho-social strain (Kinoti & Kelleher, n.d.). African women with breast cancer face challenges unique to being African.

According to (Tetteh & Faulkner, 2016) it is important to emphasize the cultural context in understanding women's experiences therefore African feminism frameworks come in handy. When applied to cancer, this approach takes into account cultural beliefs, norms, and practices related to illness and healthcare-seeking behaviours. It recognizes that cultural factors can impact women's perceptions, access to information, treatment choices, and support systems.

2.8 Conceptual Framework

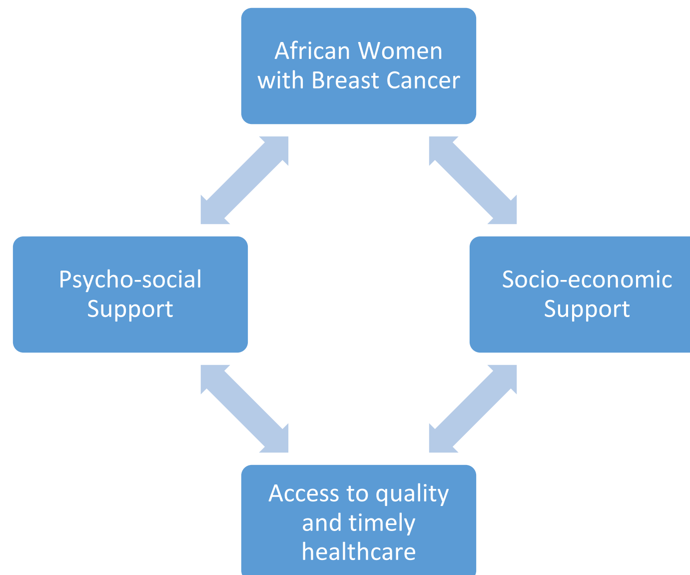


Figure 4: Conceptual framework

The study looked at three major factors that have influenced the experiences of WBC during the COVID-19 pandemic in Nairobi, Kenya. These are availability and access to health care, (ii) psychosocial support, (iii) socio-economic support. These are sub-themes of the independent variable whose properties will be investigated and will serve as the study's primary objectives. The dependent variable, on the other hand, will represent WBC's quality of life.

However, while it was assumed that the link between the dependent and independent variables is straightforward, this is not always the case. Other factors, known as moderating or intervening variables, are generally present between the two variables. If necessary, these factors can be explored independently. The government policies are on cushioning of the economy in a pandemic, mitigation of job losses, limitation of movement etc.

The conceptual paradigm also excludes the behavior of seeking medical assistance and diagnosis when it is too late which frequently contributes to discouraging outcomes (Karbakhsh, 2021),(Lehmann et al., 2020)

The independent variable was women with breast cancer, while the dependent variable was access to quality and timely healthcare, access to psycho-social support, and access to socio-economic support. The intervening variable was the COVID-19 pandemic and the lockdown measures.

2.9 Summary of Literature Review

The researcher has established from the literature that the COVID-19 pandemic disproportionately impacted Women with Breast Cancer especially the containment measures set by the various governments in the world and in Kenya too. The COVID-19 pandemic that was still ravaging the world and continued to unveil new and evolving information. The researcher observed from the literature review that the gap between the rich, well-off nations and the poor nations in breast cancer mortality rate continued to be large(Karbakhsh, 2021).

Access to healthcare was critical for WBC so as to succeed and attain the goal set out in the sustainable development goal number 3 and reduce the mortality rate especially in the low-income countries (*Sustainable Development Goals*, 2012) (*World Health Organization*, 2021). The researcher also observed that in a bid to adjust to the challenging times during the pandemic efforts were made to introduce telemedicine. It was in a bid to bridge the gap caused by among others, the overstretched healthcare facilities.

Other factors that saw telemedicine become a preferred mode of consulting doctors were fear for contraction of COVID-19, transport challenges due to lockdown measures, and how the pandemic lockdown measures have had an impact on the socio-economic support and psycho-social support pillars that were critical in improving the survival rate of women with breast cancer.

The research endeavored to establish how the lockdown measures affected Women with breast cancer at the epicenter of the pandemic, Nairobi.

2.10 Research Gap

The researcher observed during the literature review that there is a gap between the data available on Women with breast cancer in Nairobi and the COVID-19 pandemic. The Sustainable development goal 3 and the Global Breast cancer Initiative have an ambitious objective to reduce the deaths caused by breast cancer worldwide rate by 2.5% per year until 2040 in a bid to avert 2.5 million deaths (*GBCI*, 2021)

More research needed to be done to establish the impact of the lockdown measures during the pandemic and the lived experiences of WBC in Nairobi, Kenya (Karbakhsh, 2021). It was essential to elicit feedback from individuals who live with breast cancer and to have more Women-led research to capture the voices of the Women in all areas of life.

CHAPTER THREE

RESEARCH METHODOLOGY

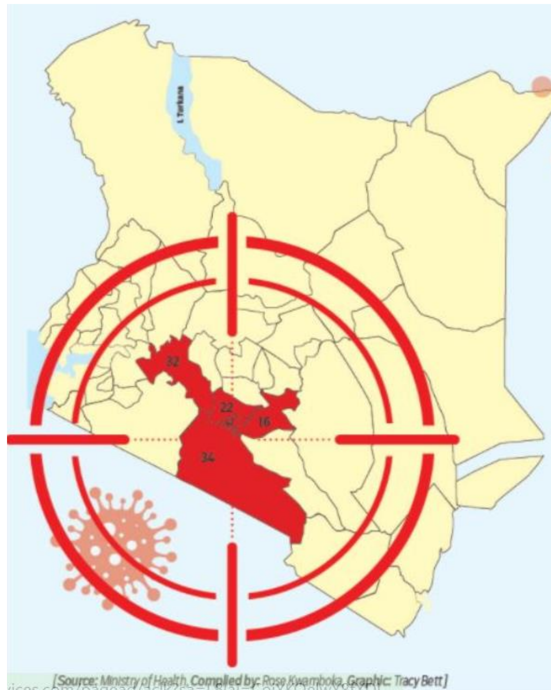
3.1 Introduction

This chapter describes procedures to be used in the collection, analysis, and presentation of data. These are Research Area, Research Design, Target Population, Sampling Design, Data Collection Procedures, Data Analysis, Techniques of data collection, and Ethical Considerations.

3.2 Research Area

The study was conducted in the Nairobi Metropolitan Region also referred to as the zoned area or infected area in Kenya.

Infected area lockdown boundaries



County by number	Name
47	Nairobi
22	Kiambu
32	Nakuru
16	Machakos
34	Kajiado

Figure 5: Map of Kenya indicating COVID-19 epicenter

Source: The Standard Newspaper March 27th, 2021

Nairobi Metropolitan Region as demarcated during COVID-19 pandemic

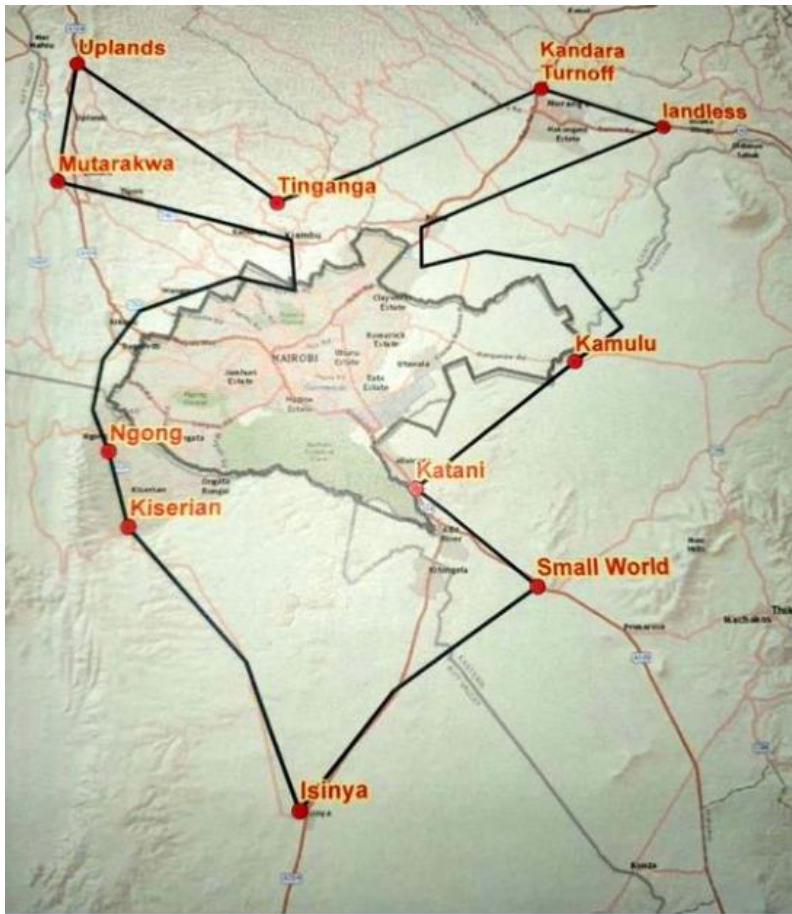


Figure 6: Detailed outline of Nairobi Metropolitan lockdown boundaries

Source: @Karanjakibicho twitter 4:09 pm · 7 Apr 2020·Twitter for iPhone

Nairobi, the capital city of the Republic of Kenya and is situated in the South-Central part of Kenya. It stands elevated at 1795m above sea level and boasts a cool highland climate. It lies 480kms North West of the country's biggest coastal city of Mombasa. It plays an important role in the East African Community is the gateway to the landlocked nations of Uganda, Rwanda, Burundi, and South Sudan.

Nairobi, considered as a melting pot of people from all walks of life and ethnicities and its cosmopolitan nature has led to the creation of a Nairobi Metropolitan area. This was to

support its fast-growing population which stood at approximately 9.34 million as per 2019 Census, while the city proper was estimated to 4.39 million. It is well served by road, rail, and air transport hubs. It is also the only capital city in the world to host a national park within minutes of the central business district.

According to (Wambalaba et al., 2019) majority of the facilities that offer complete services for cancer care are to be found within close proximity to each other within Nairobi. Accessing services such as screening and treatment should have been one less hurdle for WBC within Nairobi during the pandemic lockdown period because few women from outside of Nairobi could travel.

The questions sought to find if, by any chance being within the NMR offered an advantage to them or if the capacity to diagnosis and treat Women with breast cancer was limited during the COVID-19 lockdown. It sought answers as to what the implications were on issues of access, proximity, and availability. Being a qualitative study taking a narrative approach the study will be target only 6 WBC.

The study will employ purposive sampling and the findings may not be generalized but will be varied to other women. The key focus will be to capture the experiences through individual case narratives.

3.3 Research Design

The study used mixed methods of research. Qualitative methods were applied to establish the demographics of the participants while qualitative research was employed using the narratological approach with the selected participants to explore their experience in accessing healthcare, psycho-social support, and socio-economic support during the

COVID-19 pandemic. Qualitative data was collected during in-depth interviews using open ended questionnaires.

According to (Anas, 2022) "*the purpose of qualitative research is to promote greater understanding of not just the way things are, but also why they are*" He further opined that using substantial and rigorous interviews, discussions and observation, research of qualitative nature hopes to describe and derive findings that will increase the level of understanding of how and why people respond and behave in a particular way.

The study was planned to take place over two weeks. Open-ended questionnaires were administered to six (6) Women with Breast Cancer to collect data on their experiences. Although the participants selected were of various ages and diagnosed at different stages in their lives all the women who will take part in the study have had a breast cancer diagnosis. As such, we selected the narratological design as most appropriate to elicit and describe the meanings the WBC gave to their experiences during the pandemic on accessing healthcare, socio-economic and psycho-social support.

According to (Creswell & Creswell, 2018) the use of both open- and closed ended questions in mixed method design aid in data collection. The nature of a breast cancer diagnosis greatly impacts on the number of participants willing and able to share their personal experiences (E. P. Morse et al., 2014) The work was emotive and required that we get first-hand information from the participants. It was noted that the interviews were conducted while the country was still under COVID-19 restrictions with extra measures still applicable to WBC due to comorbidity.

3.4 Study Population

Breast cancer was the third leading cause of all cancer deaths. According to (*GBCI*, 2021). Kenya, Breast Cancer leads in incidence with 6,799 new cases annually with 50% of the cases being diagnosed late. The death rate is considerably higher in lower income countries than in higher income countries. Participants were a select few WBC in Nairobi, Kenya due to the nature, stigma of talking about breast cancer, the fear of contracting the deadly corona virus, privacy of a disease affecting what is considered by general a private and intimate part of a woman's body and period of study happening with COVID-19 prevention protocols were still in place.

3.5 Sample Size and Sampling Technique

One unit of analysis was one WBC so as to weave the narratives of experiences with a focus on how these women made sense of their experience during the COVID-19 pandemic. The narrative approach of this descriptive study influenced the sample size and while (Creswell & Creswell, 2018)proposed one or two people, and (Saunders et al., 2018)opined that one can halt data collection when the study becomes saturated and no new information is being generated. (J. M. Morse, n.d.)opined that the nature and complexity of the study can assist in determination of the sample size.

This study had four (4) key informants including one oncology breast surgeon and 3 breast cancer survivors aged 46 and below at the point of diagnosis. Two of these informants were past ten (10) years since diagnosis. One key informant passed away barely 3 months after the interview testing. The in-depth interview was conducted using open ended questions designed to obtain as much detail about a topic from the participant and to explore the point of view of the respondent to a great extent, their feelings, experiences and perspective.

There were 8 participants approached for the interview, 6 responded and saturation achieved by the 5th participant, when no new insights were available.

Grounded theory informs the concept of saturation. The study employed purposive sampling style since the targeted population was already self-selecting due to the snowballing applied with the first participant. The sample size for the narratives was six (6) Women with breast cancer from Nairobi. Five (5) participants accepted to be interviewed while the 6th participant declined when the key informant had not contacted her before sharing her contacts with the researcher and she felt the nature of the study was too personal to share with a total stranger.

According to (Creswell & Creswell, 2018) *"Qualitative approach seeks a transformative worldview using narrative design, and open-ended interviewing to examine an issue related to the oppression of individuals. To study this, stories are collected of individual oppression using a narrative approach. Individuals are interviewed at some length to determine how they have personally experienced oppression."* Other researchers lend their voice to the fact that numbers do not matter to a great extent where the research is intended to capture each woman's experience as unique. According to (Vasileiou et al., 2018), it is appropriate to evaluate data adequacy in light of characteristics that are essential to the prevailing investigation. Qualitative studies are characterized by small samples that give an in-depth and case by case analysis that is relevant to such studies. Samples for qualitative studies re more often purposefully selected as they are focused on in depth elements of the population under study. In the same vein, (Saunders et al., 2018) point out that operationalizing saturation in a manner that is in line with the research question, the theoretical perspective, and the analytic framework chosen should be adhered to. In light

of this, data saturations can be achieved with a sample size of five to fifteen respondents (Saunders et al., 2018); (Vasileiou et al., 2018) This study, therefore, collected the stories of these women first hand so as to understand their experience of COVID-19 pandemic. (Bingley et al., 2008) found that to understand the individual and also the cultural experience then, the use of narrative research is both innovative and very specific as it lends itself to the continual growth of qualitative research by augmenting the robust analytical methods therein.

3.6 Data Collection Instrument

The study employed a questionnaire with closed-questions to guide the collection of the demographic data while the open ended questions were used to capture the narratives as the stories collected were the primary data to learn about their experiences

During the study contact was established with the respondent and the nature of study explained. Next, consent to participate in the study was sent explaining the extent of the study and option to participate or refrain in answering the questions highlighted. A link was then sent in advance to the respondents requesting for the interview date and time most convenient to them. The respondents need to have sufficient charge on their phone and data bundles to conduct the interview.

During the actual interview there was an introduction of self and of the study objects, then verbal consent sought in order to commence on the interview. Emphasis was made that the participant was not required to answer any question they felt they were not able or willing to answer. The study captured the narratives using open-ended questions and the recording of the conversations via zoom/google meet and WhatsApp calls to reduce the risk of spreading the corona virus and in compliance with the stipulated protocols that were in

enforcement at the time of the interview. Notes were also taken during the interview. These recordings were listened to and transcribed and analyzed.

3.7 Data Processing Analysis

The data collected in this research was divided into quantitative and qualitative data. The Quantitative data was analyzed using demographic data analysis while the qualitative data was analyzed using thematic analysis following the themes identified while analyzing the data.

3.8 Ethical Consideration

A letter issued by the University of Nairobi, Department of Sociology, social work and African women's studies served to identify and authorize the researcher to seek approvals from the National Commission of Science and Technology (NACOSTI). NACOSTI then issued a research permit ref NACOSTI/P/22/16819 dated 9th April, 2022.

At the beginning of each interview verbal consent was sought from each participant. The researcher fully identified herself to the participants and explained what the research was bout and why it was being carried out before seeking their consent to participate. The study sought to appropriate both respect, consideration, privacy and confidentiality throughout the interview. All the participants names were replaced with codes to reduce the probability of their identity being known.

CHAPTER FOUR

DATA PRESENTATION AND ANALYSIS

4.1 Introduction

This chapter presents the research findings on the experiences of women living with breast cancer in Nairobi during the COVID-19 pandemic. The chapter contains a presentation of the demographic characteristics of the respondents and a representation of the findings of the study based on the study objectives. The broad themes that were analyzed included Breast cancer management during COVID-19 pandemic, psycho-social impact of the pandemic and new socio-economic opportunities in the face of COVID-19 pandemic from the lens of WBC in Nairobi.

4.2 Demographic Characteristics of the respondents

Respondents' age, marital status, education level, occupation and residence were sought. These were found to be significant in the study as they had an overall implication on how the participants experienced the COVID-19 pandemic especially the lockdown period.

4.2.1 Age of the respondents

Respondents were aged between 31 and 55 years of age. 20% of the respondents were aged between the age of 30 and 40 while 40% were aged between 40 and 50 while the remaining 40% were above 50 years. Respondents age helped capture the respondents' diversified experiences. According to American cancer.org the median age at the time of breast cancer diagnosis is 62 with a very small number below the age of 45 while in Kenya the median age is 47 years (Sung et al., 2021) (*World Health Organization*, 2021).

4.2.2 Marital status

It was established that of the participants two were married and received socio-economic and psycho-social support from their spouse. The pandemic presented unprecedented strain on one of the households. *"Due to the nature of my husband's work in the event industry, the pandemic and lockdown measures meant fewer social events were taking place and many of the pre-booked events were either cancelled totally or numbers revised down significantly. So, I had to step in and share a bigger burden of our financial obligations*"

Of the other participants one was widowed, one was separated and one was single. Two relied heavily on their children for psycho-social support and siblings while the one who was single relied on her parents and siblings. The marital and family status was found to be important during the study because of the restrictions on movement and social distancing regulations where people formed some form of family bubble. Breast cancer treatment requires input from family members and often times their support is all they have.

Table 1: Marital Status

Marital Status	
Single	1
Married	2
Separated/Divorced	1
Widowed	1

4.2.3 Education Level

The participants in the study were all degree holders and this helped them to synthesize the data available to them during COVID-19 and all were able to access and use digital technology in their cancer treatment journey. *"I was able to work from home and in the*

process even change jobs from the comfort of my home whilst receiving treatment" said participant W05 who felt that the world of opportunities opened up to them.

Another participant who was a retired civil servant and was able to access free training by an international organization based in another continent. "*I did the training through an international organization who then approached me to do training with them under 'train the trainer'(TOT) programme and I have been able to earn a living through the training opportunities they provided. I became a sort after trainer. It renewed my hope of finding meaningful and financially rewarding work"* She was already in retirement but because she was a graduate the TOT opportunity was within her reach.

Table 2: Education Level

Education Level	
University	3
Post Graduate	2

4.2.4 Occupation

Majority of the participants were employed in formal sector while two are self-employed. The nature of work involved professional skills and all were able to continue to work remotely until such a time as the government eased out the rules and regulations regarding resumption of work. Two participants were government employees and therefore they had some form job security while many others faced job losses. All the participants in the study remained gainfully in employment.

Table 3: Demographic statistics with codes

Code	Age	Marital Status	Number of Children	Education level	Occupation	Residence
W01	55	Widowed	2	Graduate	Private sector	Kahawa West
W02	50	Separated	3	Graduate	Public sector	Thika
W03	47	Married	2	Postgraduate	Private sector	Ridgeways
W04	49	Single	0	Postgraduate	Public sector	Upper hill
W05	31	Married	Miscarried	Graduate	Private sector	Langata

4.3 Breast cancer Management during COVID-19 pandemic

The participants of the study were found to have made several adjustments towards the management of breast cancer in line with the COVID-19 protocols issued by the Government of Kenya and trickled down to their health care providers during the COVID-19 pandemic. Based on the phase of treatment in which they were in changes were made to their breast cancer management and how they coped with the changes

4.3.1 Breast cancer management challenges

The majority of the participants were initially diagnosed with Cancer well before the COVID-19 pandemic with 1 patient being diagnosed and treated between September 2021 to April 2022. The remaining 4 had received their initial treatment of chemotherapy, surgery and radiotherapy and were already in the 'second phase' of treatment mainly requiring longer term hormonal treatment and non-urgent intervention.

Patient W05 was diagnosed with Cancer after two miscarried pregnancies, the first being in the first trimester at the point of miscarriage while the second was a twin pregnancy miscarried at the onset of the third trimester. She said *"I thought it was a blocked milk duct because I had miscarried a twin pregnancy at 7 months, only for the biopsy to be carried*

out and I was diagnosed with breast cancer. I was in shock especially because I am just 31 years of age." She was diagnosed early because she was already seeing a gynaecologist.

Her cancer was detected early and the prognosis of early detection is fairly good. According to the National Cancer Protocol (Ministry of Health, 2019) 'patients confirmed with cancer should be referred without delay to the appropriate multi-disciplinary team'. She was able to access an oncologist, radiologist, gynecologist, and fertility expert in various facilities to help her with the cancer management.

According to the (WHO, 2021) NCD's of which breast cancer is one of, can be sometimes life-long in nature and requiring multiple interfacing with the healthcare systems over lengthy periods of time. The management of these types of disease involves freely accessing medicines that are essential and rehabilitation services. According to (Martei Y, 2021) (Ministry of Health, 2017) (WHO, 2021) COVID-19 disrupted health care services in multiple countries across the world, Kenya included

Like many other health conditions during the COVID-19 pandemic at the initial phase Cancer of the breast has several treatment routes depending on the type and also the spread all starts with the access to screening services and speed of the beginning of the treatment. (Antabe R, 2020) COVID-19 put a strain on healthcare facilities all over the world and diseases begun to categorized in terms of urgency and risk.

Kenya responded by initially by providing interim guidelines on non-communicable diseases (MOH, 2020) in a bid not to reverse gains made on early detection of breast cancer by recommending the use of alternative to in person consultations and ranking of some of the procedures as life-saving. This brought about changes that allowed the participants to remotely access their medication as Participant W02 noted *"Most of the medication could*

be bought using a scanned prescription and with the COVID medication a friend was able to buy in Nairobi and send it to me"

4.3.2 Coping mechanisms of the participants

Based on the outcome of the study, majority of the participants were in the second phase of treatment meaning they were on some form of long-term medication not requiring urgent intervention. Access to health care was therefore a carefully calculated move. Many relied heavily on tele-consulting to determine the urgency of the next appointment

4.3.3 Access to health care based on online need assessment

Participant W01 said *"I did not have to go see the doctor for over 1.5 years during the start of the pandemic but continued with the prescription medication I was already on following advice from the doctor"* she was able to have a tele-consulting session with her doctor every 6 months. She had to do some lab tests and the results transmitted directly to the doctor which aided in her review.

Participant W05 said *"I was diagnosed with breast cancer at the height of the pandemic and I was able to meet and consult with a multi-disciplinary team in person by observing the COVID-19 protocols. My consultation meetings were limited to 2 or 3 people per consultation and my husband and alternately a member of my immediate and in-law family was in attendance"*

She did not mind the limitation of guests and social distancing *"I am a private person and I did not mind the movement restriction as I was able to process the start of my cancer journey with just my immediate family. Since we had to limit the interaction with people, we were extra careful in selecting where we went and with whom we interacted."* The

participants were able to develop coping mechanisms that allowed them to manage during the pandemic. This was aided by the 'work from the home' directive and the movement restriction.

The term 'people with underlying conditions' or 'comorbidities' brought both fear and courage to the participants. Participant W02 said *"the terms 'comorbidities and people with underlying conditions stigmatized me because each time the two were used it was about critical illness and death. I was terrified and felt very vulnerable. I tried to remain as secluded as possible, but when I required to replenish my food pantry, I was very careful and observed strict covid measures. I felt the lockdown measures restricted my access to cheaper and fresher vegetables from the Murang'a county which I could previously access due to the proximity to my workplace. I stayed at home until the government re-opened the borders within the counties*". Her residence is located within the Nairobi Metropolitan Area and therefore received the same access as one within the boundaries of Nairobi County.

Participant W04 relied on a combination of the telehealth offered by her doctor in the USA *"together with my employer's clinic here in Kenya, where the doctor gave me some form of preferential treatment so that on the day I was scheduled for 'bloodwork' then my clinic appointment was expediated to reduce my risk exposure. I could access my doctors both in Kenya and the USA and they were able to make decisions on my prescriptions without me travelling"* so whereas there was limited cross continental and other border crossing she could access telehealth that was without boundaries and aided by technology.

Participant W02 was required to have her chemo port flushed every 3 months but because of fear

"*By the time COVID-19 was declared a pandemic, I was on hormonal treatment which did not require me to frequent the hospital. However, I have a chemotherapy port that needs to be flushed, but I kept away from the hospital for fear of contracting the disease. I stayed for 1 ½ year without it being attended to but was careful and looking out for any infection symptoms."* This participant was afraid of contracting COVID-19 in the hospitals or on her way there and remained in close contact with her healthcare provider in order to look out for symptoms of infection.

Patient	Year of Diagnosis	Phase of treatment during COVID-19	Location of initial treatment	Location of treatment during COVID-19
W01	2015	Phase II	India	Online
W02	2016	Phase II	India and Kenya	Online
W03	2015	Phase II	India	Online
W04	2018	Phase II	USA	Online
W05	2021	Phase I	Kenya	In person -Kenya

Table 4:Year of diagnosis, phase and location of treatment

The boundaries were lifted virtually as the physical boundaries were enforced but not without its challenges. For participant W04 "*The medication was couriered from the US or I would use people traveling back to Nairobi. The hospital said they would not ship the medicine to me. I was required to be in the US but I was stuck in Kenya. They could not allow me to purchase more than one month's worth of medicine at a go.* The challenge of limited quantity on prescription medication seemed to temporarily cause a strain on finances as there was need to be on medication for several months subject to monitoring.

She noted that, *"as the pandemic continued, they allowed me to get a 2-month supply at a time. I used postal services ad except on one occasion where the medication was held back for 3 weeks by customs officials all other deliveries were seamless so I never missed out on*

my medication" I was able to receive my phase 1 of treatment in the US while I have continued to receive medication and reviews based on tests carried out here. I have not traveled back for review since COVID but hope to go back if necessary." Postal services were listed as essential services and were therefore at hand to assist this patient to receive her prescriptions efficiently and hence reduce the anxiety experienced with delays.

Another challenge was the continuity of treatment where the initial or immediate prior treatment was done out of the country. Participant W03 who had just returned to Kenya from India barely 2 weeks before international borders said "*I had to get a local oncologist while the one in India was via email. All earlier treatment was done in India. In India, it is very easy to access oncologists. I am in my second phase of treatment. The experience was not as good as I expected.* Due to the interpersonal relationship built over time since she started treatment there was some anxiety in now finding a local doctor to understand her needs.

"When it was time for my review, I made my way there and went to the receptionist but found that the doctor was not in and I could not get his number. I was very disappointed there was no personal touch and till now they have not called back. I am doing my part but the doctor has no personal touch. No empathy or follow-up. I hope when I go do the next blood work in three weeks, I will be able to see him" The participant experienced a slight delay and a lowered level of attention in comparison to her previous experience because of the restriction in out of the country travel.

4.3.4 Psychosocial challenges faced

For W02 being diagnosed with breast cancer and having received treatment both in Kenya and in India, COVID-19 pandemic and the lockdown period proved to be a time of 'testing

and redefining' her marital status. *"I was diagnosed in 2016 and my husband would take me to the treatment center in Nairobi but with time he started getting tired and losing interest and I had to call a friend to pick me up after the chemotherapy or radiotherapy session to take me home.* Cracks begun to appear in the relationship and the strain was evident in his response.

She went on to say that "*COVID-19, I would say was the straw that broke the camel's back. He would occasionally visit and this one time he came and he was not feeling well and I perhaps caught COVID-19 from him. I got tested but he did not. He asked the children to keep away so as not to catch it from me. Our 'relationship' of over 30 years ended like that. He moved his few belongings and has not been back"* Between the fear of catching and transmitting COVID-19 she felt exposed to the virus by her intimate partner and ostracized at the same time.

The realization that psycho-social support can also take a different dimension when stretched to new limits made her say "*It was tough but it gave me the freedom to finally realize that I am a cancer and covid survivor by the grace of God alone and that I will be alright. "I am stronger than I think"* She came out stronger by relying on her children and on her faith in God.

Psycho-social support seems to primarily come from nuclear family as was for W03 who said *"having parents living outside of the Nairobi metropolis was difficult 'because my mum was not feeling well and we could not travel to see her. The proximity to her in-laws, however, proved both beneficial and challenging. Because of their age (Above 80 years) they could not go anywhere and were more vulnerable and depended on her and her family much more to provide psycho-social support to them*.

Family dynamic shifted significantly and those that had lived a fairly independent life before COVID-19 were now more dependent on their children irrespective of the fact that this daughter in law was a breast cancer patient. She said "*I now had to fit in their Sunday afternoon routine into mine in order to spend time with them.* This new routine just like the orders from governments and health official had an impact as identified by W03 who referred to it as burnout.

"*As the year 2020 went along with the new routine now in a place I felt burn-out because I no longer had the freedom of what to do on Sunday which was my much-needed rest day due to increased workload since my work schedule run into Saturday*. She had to take on the role of a very active daughter-in-law. As soon as the borders re-opened, she traveled to Nyeri to see her parents, and what she initially planned as a one-day visit turned into a three-day visit. She had to juggle the multiple roles that African women play even when faced with a challenging illness like Cancer

4.3.5 Psycho-social outcomes of the pandemic presented

It was easy and convenient for participant W01 who is widowed and whose daughters are adults, take an active role in the care and psycho-social support unhindered by distance or other logistics. *"Both my daughters now in their 30's was 'over-protective' and insisted that I should not leave the house at all. So, for over a year, I did not leave the house. I do not own a vehicle and when I finally needed to leave the house, I used the easily available 'cab hailing' services like Uber and Bolt to get around.*

By the time of the interview, she had not gone back to using public transport or resumed attending church service in person as she was still scared about her compromised immunity.

Between her getting a new job as a trainer and her daughters she was able to comfortably afford the cost of a taxi to and from her occasional hospital visits

For W04, who is single and whose larger nuclear family is based in the United States of America, COVID-19 meant she had to become creative and keep her social ties as tight and as frequent as she possibly could said that "*When the government issued a stay-at-home directive we were required to work from home.* Their jobs were secured there was no mention of job losses in the public sector despite of the shift in work place policies.

She continued to say that "*My organization further submitted a list of those with underlying conditions and even when the return-to-work formula was being implemented we were requested to continue to work from home which worked very well for me.* Special attention was given to those with underlying conditions and in this instance the doctors in the 'staff clinic' made regular follow-up on phone to those in the list. With extension of work from home schedules for them.

She said "*If we got used to having virtual meetings for all our office tasks I reckoned that it could as well work for a weekly virtual family time. The meeting gave me a lot of emotional and spiritual support while undergoing oral chemotherapy and helped to cope well. It was structured starting with Prayer, time of worship, sharing time – where we all got to share how our week went and any challenges we were facing, then end with prayer.* The psycho-social support was not just limited to immediate family but was replicated with one other social group.

4.4 Facing the fear of contracting COVID-19

According to Participant W02 who was able to stay home and remain socially distanced initially the biggest fear was contracting the COVID-19 virus. Unfortunately, even with all the precautions in place, she was diagnosed with COVID-19. "*I was very afraid of the impact of the virus on me and also that of passing on the virus to others near me*. She needed to go to the market to buy food and to the pharmacy to buy medicine after being diagnosed with COVID and was extremely cautious and tried to keep her distance.

Tasks that she had begun to master doing amidst all the restrictions now became even harder when she was diagnosed with COVID-19 "*While in the market on one of the days the vendor expected me to select tomatoes and carrots amongst others as is the norm and she found it strange that I asked her to select them on my behalf. I could not imagine disclosing to her or the pharmacist that I had just been diagnosed with COVID-19.* The fear was real.

She felt extremely vulnerable and the reality of being in the category of people with comorbidity was in every daily briefing from the Ministry of health. *"I was very afraid that if I caught COVID it would be fatal. It is as though no one thought I would pull through. Now that in my neighborhood social media group when someone died of COVID the first question asked was if there were underlying issues. So, I felt extremely anxious knowing very well I had underlying issues.*

Knowing the risks that she and her immediate family took to stand by her during the extremely difficult times makes her grateful to God for being alive "*I thank God I pulled through. My spouse had told the children not to visit me because I was sick with COVID-19. My daughter come and stayed with me for a couple of days and thankfully did not get*

sick. Her 'spouse' deserted her at that point. She said *"I had to be strong for myself and I realized that God is there for me and that was enough"* and mused that she is happily single thanks to COVID-19.

4.5 Social distance created space to process breast cancer

A positive impact of social distancing was experienced by W03 who said *"I consider herself an introvert and is more than happy and comfortable being in her own space*" She was able to exercise social distance to her advantage. Being single and having the majority of her nuclear family residing out of the country allowed her to be innovative to keep connected with her parents and 2 siblings who were thousands of miles away.

Another participant W05 who was diagnosed and began treatment during the COVID-19 said *"My husband and immediate family were the ones who walked with her through the journey. During the initial consultations with the doctor, all their family members wanted to be at the consultations but they were restricted to herself and a maximum of 2 people."* Both her family and her in-laws wanted to be there at the consultations. During Chemotherapy, her visitors were also restricted so her primary support was her husband and family.

When speaking about support groups she noted that "*when I was referred to a popular support group, I did not quite get the answers to her questions. Being diagnosed at such a young age of 31 years I specifically asked if I can be placed in a smaller age-specific group but was told they do not have one for those below the age of 45.* She was diagnosed with breast cancer at a fairly young age and she struggled to get a group of women in her age. The median age of diagnosis in Kenya is 47years and so she felt lost.

That lose led her to seek alternative groups mostly of people in other countries. *"I was looking for a group where I would find guidance and have a wider opportunity to hear more stories of hope other than one where 'messages of hope were mainly bible verses or spiritual messages.* This quest led her to explore what social media had and she found groups where there was ready information sharing on advanced medical procedures or the latest technology.

In those *groups "I found many people young and old and it gave me hope. People openly shared about challenges they are facing and how to overcome them. I also got to learn that there is hope for me who wed recently and still held on to the hope of starting my own family. I came across information regarding fertility treatment and preservation of my ova and ovaries because the chemotherapy would very likely reduce the chance of having a successful conception*." The groups had close to real-time sharing of information from specialists and cancer survivors as well.

4.6 New opportunities in the digital space

Participant W01 was still going through hormonal treatment and did not go to the hospital because her caregivers restricted her movement strictly for 3 months. In that period of time she said *"I learnt what to do on zoom including the exercises and continue to dutifully carry them out. I was able to get all my medication using the previous prescriptions at a faith-based hospital and it was all within my NHIF cover and at an even subsidized price compared to the major hospitals.*

Being able to get her prescription at the outlet of her choice meant that she could be able to save on out-of-pocket expenses which would have arisen if she was restricted to buying

the same drugs at a more are ‘convenient or closer location’ She would send an image of her prescription to the pharmacy who would in turn bill her and provide online /mobile payment options then dispatch the medicine via courier to her doorstep.

All the participants of the study were meaningfully employed during COVID-19 and did not suffer directly from any salary cuts during the same period. The majority of the participants had already undertaken the first phase of treatment before COVID-19 struck in March 2020.

4.7 Employment and training in the digital space

Participant W05 said *“I was diagnosed during the year 2021 was able to apply for a different job with a different organization in a role that allowed me to comfortably work from home much to my delight as it allowed me flexibility to be away when I needed to be in hospital to undergo a procedure and also be able to take a nap when and if needed to remain productive during the day”.* She experienced great flexibility and opportunity as a result of the COVID-19 pandemic dynamics.

Participant W01 said *“I had been retrenched from her employment just before being diagnosed with breast cancer in 2016 and was therefore not in formal employment when COVID-19 struck.* It proved to be a blessing in disguise when her virtual support group opened up so many opportunities to learn and be inspired and encouraged in her journey with breast cancer. It renewed her hope and made her feel there was a reason to still be alive.

She continued to say that *“I attended a virtual training on moving from just coping with a cancer diagnosis to thriving and finding purpose. Through the training, I was able to come*

on board and take on a train the trainer course with the organizers and was given a paid opportunity to help contextualize the course. Now I am employed as a facilitator." COVID-19 allowed her to be up-skilled, earn a living, and positively influence other cancer survivors towards a fresh chapter of their lives.

Participant W03 had a mix of tidings during COVID she said *"my husband and I run an event business that suffered serious blows with the lockdown and limitation of public gatherings. This meant that the otherwise stable income took a nosedive when weddings and events were either completely canceled or drastically downsized in light of compliance.*" The restrictions placed on the sizes of public gatherings especially weddings resulted in many weddings being cancelled and it impacted their family source of income.

Her main source of income as a trained counselor took an interesting turn. Initially, most of her clients canceled the in-person counseling sessions but some adopted fairly fast to the virtual sessions. This presented an opportunity to offer more virtual counseling and hence more pay and more workload. She said *'Suddenly there were so many more people needing counseling help and that could be done virtually. I took on more clients to help us meet our financial obligations. Almost all Pre-COVID financial plans needed to be put on hold but I am happy to say it brought along many tidings'*

The COVID-19 pandemic was unexpected and caught many by surprise. It introduced new levels of mental health challenges to individuals and families some of which required psychological help to navigate

4.8 Coping with financial challenges during COVID-19

The cost of breast cancer treatment can be prohibitive and many may not have information about the National Health Insurance Fund Cancer scheme. For participant W05 she said "*I am lucky that I am one of the few Kenyans who have utilized my NHIF. I also had private insurance cover but during chemotherapy and radiotherapy, it covered about half of the sessions I am thankful for NHIF.*

When she was diagnosed with breast cancer, she was able to take on a new job and have access to both private and national insurance coverage. *I did not feel the strain even when I had to undergo fertility treatment and conservation of my ovum.* The private medical cover was useful while seeking fertility preservation treatment. Even when NHIF covers majority of cancer costs there may be out of pocket expenses like those experienced by this participant that are not classified as direct cancer treatment costs.

What COVID-19 pandemic did was reduce the 'distance between people and places and instead increase the access to the much-needed resources required for cancer treatment in new and ingenious ways including online fundraising with people from all over the world chipping in. Participant W04 said that "*I remained employed but the medical cover did not cover my treatment or the trip to the USA. Her international friends raised funds on GoFundMe while those in Kenya created a mobile fundraising platform with a 'pay bill' number that people wishing to contribute could use.*

She said *"I was also fortunate to get an 'angel-sponsor' who sponsored part of the treatment."* The cost of cancer treatment abroad can be prohibitive. NHIF covers for part treatment in some countries like India under very stringent rules and with pre-approvals. Too often Time is of essence and many have found it easier to just fundraise for their loved

one to get speedier treatment. COVID-19 made fundraising efforts easier with many virtual platforms and mobile money options in pulling their resources together.

CHAPTER FIVE

SUMMARY CONCLUSION AND RECOMMENDATION

5.1 Introduction

The objective of this study was to establish the experiences of women living with breast cancer in Nairobi during the COVID-19 Pandemic. In line with the research objectives, this chapter summarizes the study findings. The chapter presents the study findings and conclusions drawn from the study. It further makes recommendations from the study findings. The final section of this chapter includes suggestions for areas of future research to add to the body of knowledge

5.2 Summary of findings

The objective of the study was to explore and describe the experiences of women living with breast cancer during the COVID-19 pandemic in Nairobi Kenya. Specifically, the experiences during the COVID-19 lockdown period have been themed according to the research objectives of access to healthcare, socio-economic support, and psycho-social support using an interpretive theory so as to understand their experience. Whilst there has been a wide selection of literature available regarding breast cancer and its interaction with COVID-19 there has not been sufficient research on women's experiences with breast cancer in Nairobi, Kenya during the pandemic.

5.3 Conclusion

During the study, one of the objectives of the research was to find out how COVID-19 Pandemic influenced the experience of WBC in accessing health services in Nairobi, Kenya. The research questions were to understand how the COVID-19 pandemic

influenced the experience of WBC in their access to health services in Nairobi, Kenya, experiences that are unique to these women due to the intersection of breast cancer and COVID-19.

The study established that the experiences were varied and the majority were not in a crisis during the pandemic. They complied with the preventative measures that were adopted by the Government of Kenya and whereas their freedom of movement was curtailed during the initial phase of the lockdown all were able to access their medication and health services with some being able to consult their doctors virtually.

It was noted that those who were not in active treatment were able to access virtual consultations and use electronic prescriptions to get medication at their convenience. The study also established that the majority of the participants expressed satisfaction in the follow-up done by the oncology department to guide them in rescheduling and prioritizing in-person visits. The majority were in phase two cancer treatment that did not require them to visit the health care facilities frequently and were able to use prescriptions to access their medication promptly.

One of the participants was diagnosed and started her cancer treatment at the height of COVID-19 and was able to access 3 different cancer centers for Oncologist consultation, Chemotherapy, and radiotherapy with little or no challenge. The age of this particular participant required the additional services of a fertility clinic to undergo IVF treatment before the onset of her chemotherapy in order to preserve her ovary for the future with the hope of starting a family.

The study did not however dwell on the impact of chemotherapy on the hope of starting a family in the future for women diagnosed with breast cancer during childbearing age. This was an extra precautionary measure to preserve her ovary since she was of childbearing age and had not given birth. She remained hopeful to achieve a quality of life after the cancer treatment.

The study established that majority of the participants had immediate family offering psycho-social support by providing company, much-needed help to access food and medication. Where family members were far away then technology came in handy in bridging the gap for physical meetings. Some of the participants did not mind the social distance and stay-at-home orders because it allowed them the privacy to process the diagnosis and at the same time helped to curb the risk of infection from COVID-19.

Psycho-social support was mainly provided by nuclear family members and in particular spouses and children and where the spouses were deceased or absent the adult children carried the full weight. Women with breast cancer were in some instances required to play the role of offering psycho-social support to their own family and aging parents as well as in two instances to clients and fellow patients.

Socio-economically all the women interviewed remained employed or were able to access new opportunities as a result of COVID-19 pandemic restrictions that triggered work from home orders. The study established that the flexibility to work from home cut on normal work commute time and increased the available flexible employment and training opportunities.

The study also established a link between women's economic empowerment to those who had already been empowered with education indicating a direct co-relation with their ability to take on the push to move to more virtual meetings, trainings etc. for their benefit even amidst such a gloomy pandemic that brought in its wake death, loss and heartache. "*Patient narratives of survivorship have the potential to complement the more general medical knowledge with their nuanced and multifaceted stories of breast cancer"* (Mohlin & Bernhardsson, 2021)

We concur with Mohlin (2021) who espouses that these narratives may indeed be a path to becoming more and more aligned to breast cancer patient's individual needs and preferences during a pandemic or medical crisis like the world has been through. These narratives may provide the much-needed help and guidance to patients, their caregivers, and even researchers in order to gain a greater understanding of how COVID-19 impacted women with breast cancer in Nairobi.

Rehabilitation, support and individualized information to survivors of breast cancer could enable them effectively handle their situations in life. This would promote wellbeing after diagnosis and promises better life trajectories for the survivors. Women living with breast cancer in Nairobi Kenya during the COVID-19 pandemic were able to access healthcare, grow socio-economically and experience limited but meaningful psychosocial support from beyond the confines of the physical boundaries set in a bid to curb the spread of COVID-19.

The economic opportunities did not discriminate against the women on grounds of being breast cancer patients. COVID-19 while instilling boundaries and restrictions also offered boundaryless and non-restricted work opportunities that also allowed the said women to

play their triple roles. The health care systems were able to quickly set up a robust follow-up system and schedule in a bit to reduce the claw back on the progress made to reduce breast cancer morbidity by early detection and treatment.

Socially, a majority of the participants had joined new online groups both locally and internationally that allowed them to access more information about women with breast cancer but also life skills training that even led to an international job opportunity for one while another was able to take on more counseling clients because the demand for psychotherapy significantly increased. The knowledge base widened for each of the participants when it moved from the traditional way of receiving psycho-social support.

5.4 Recommendations

- Further research to collate the voices of women in every single county in Kenya in order to provide a women centric response in the event of another pandemic.
- Empowering women with education places them in a better position to cope with curveballs in life like pandemics. The message of breast cancer prevention and treatment needs to be pushed through in our education systems early detection and treatment will save more lives.
- Information is power. There should be a push to have information transmitted speedily to special groups like women with breast cancer during times of crisis for example through a dedicated helpline

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APPENDICES

Appendix I

QUESTIONNAIRE

My name is Mercy Wambui Ngumi, a Master of Arts in women leadership and governance in Africa student at the University of Nairobi. I am undertaking an analysis of how Women living with breast cancer were impacted by the COVID-19 pandemic and the lockdown measures. With your permission I would like to interview you and document your narrative/story about your experience as a breast cancer warrior in Nairobi, Kenya. Please feel free to give as much information as you feel most comfortable. When you are through, I may ask for further information in case I need some clarification. The key objective of this study is to hear your experience as narrated by yourself.

All the information given during this interview will be treated with confidentiality

Section A: Demographic Data

Age

(i)18-25 [ ] (ii) 25-35 [ ] (iii) 35-50 [ ] (iv) 50 and above [ ]

b. Marital status

(i) Married [ ] (ii) Single [ ] (iii)Divorced [ ] (iv)Widow [ ]

c. Level of Education

(i) Primary [ ](ii) Secondary [ ](iii)Tertiary [ ](iv)University /College [ ] (v) None [ ]

d. Do you have children?

Yes [ ]

i) how many (alive or not)

ii) what are their ages?

No [ ]

e. What is your occupation?

i) Formal employment: Public [ ] or Private sector [ ] or both [ ]

ii) Self-employed [ ] what is the nature of business……………………………………….

iii) Informal [ ] what sector

iv) Not employed [ ]

f. Where do you live?..

1. With whom do you live?..

SECTION B:

1. When were you diagnosed with breast cancer and at what stage was it? How has that impacted your life?

2. Tell me about the treatment options that were available to you before COVID-19 and what may have changed during the pandemic.

3. How did the lockdown measures (curfews, cessation of movement, social distancing affect your treatment during the pandemic and decision making?

4. Can you describe some of the thoughts or feelings you experienced when you heard about COVID-19?

5. Can you tell me who has been with you in your breast cancer journey and how did the COVID-19 protocols and lockdown measures affect those relationships (Social distancing, movement restrictions, curfew, reference to Nairobi as the epicenter of the pandemic, etc.) What new connections did you make?

6. Tell me how did breast cancer impact your economic livelihood and how that may have changed during the pandemic?

7. Can you describe how the COVID-19 protocols like wearing face masks, social distancing, and washing/sanitizing hands affected your social life and economic livelihood?

Appendix II

UNIVERSITY OF NAIROBI
DEPARTMENT OF SOCIOLOGY, SOCIAL WORK & AFRICAN WOMEN STUDIES

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January 31, 2022

TO WHOM IT MAY CONCERN

SUBJECT: INTRODUCTION LETTER FOR MS. MERCY WAMBUI NGUMI (MA STUDENT)

This is to confirm that Ms. Mercy Wambui Ngumi (M10/38232/2020) is a registered Master of Arts student at the Department of Sociology, Social Work & African Women Studies, University of Nairobi.

She is currently working on her research project entitled, ***"Analysis of Impact of the Covid-19 Pandemic on African Women with Breast Cancer in Nairobi, Kenya"***

Any assistance accorded to her during her research period is highly appreciated.

Dr. Kathleen Anangwe
Ag. Chairperson
Department of Sociology, Social Work & AWS

Appendix III

REPUBLIC OF KENYA

NATIONAL COMMISSION FOR SCIENCE,TECHNOLOGY & INNOVATION

Ref No: 684552

Date of Issue: 09/April/2022

RESEARCH LICENSE

This is to Certify that Ms.. Mercy Wambui NGUMI of University of Nairobi, has been licensed to conduct research in Nairobi on the topic: Experiences of women with Breast Cancer during the COVID-19 Pandemic in Nairobi, Kenya for the period ending : 09/April/2023.

License No: NACOSTI/P/22/16819

684552

Applicant Identification Number

Director General
NATIONAL COMMISSION FOR SCIENCE,TECHNOLOGY & INNOVATION

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