# **ONCOAFRICA**

#### ISSUE NO. 2 - 30.09.2024

#### **CANCER RESEARCH IN KENYA:**

The need for basic science infrastructure

#### **OVERCOMING BARRIERS:**

Bottlenecks in drug development for brain tumors

#### **RADIOTHERAPY:**

Understanding the painless path of cancer treatment



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## THE POWER OF RNA TECHNOLOGY

CONNECTING THE DOTS: Endometriosis and ovarian cancer

CHILDHOOD CANCERS AFRICA: The 'sore' in cure attempts

Integrated Cancer Research Foundation of Kenya

## TABLE OF CONTENTS

The power of RNA technology Page 16

Kenya needs to develop basic science infrastructure for cancer research Page 4

How nature's pharmacy may be the answer to cancer Page 14

Radiotherapy: From fear of to understanding the painless path of cancer treatment Page 18

What is Palliative Care? Page 8

Expanding Role of Primary Health Care in Addressing Cancer Burden in Kenya Page 22

Hereditary Cancers Page 10

Treatment Abandonment: The "sore' in the efforts to improve childhood cancer cure in Africa Page 24 Cancer in Kenyan families: sociobiological interruptions and victories Page 20

Honors and Awards Page 11

Connecting the dots: Endometriosis and Ovarian Cancer. Is there a possible association? Page 12

Overcoming the blood-brain barrier: bottleneck in drug development for brain tumors Page 6

Prostate Cancer Page 26

Cancer Genomics Data Sharing Stakeholder Conference Page 30

Caring for the caregiver: a forgotten stakeholder in cancer management Page 26

Cancer Awareness / Research Symposium Page 30

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## FOREWORD

ICRF Kenya is a vibrant research organization committed to enabling groundbreaking discoveries in cancer and disseminating evidence-based cancer information to the public. In the face of rising cancer cases and high mortality rate in Africa, our mission is to ensure that the waves of accurate, up-to-date information on cancer management reaches all corners of the continent. Through this, we can bridge the gap between scientific research and public's understanding of cancer prevention, diagnosis and treatment. In this spirit, we are pleased to introduce the second issue of OncoAfrica for the year 2024.

In this issue, we delve into a wide array of topics that reflect both the complexities and the opportunities in today's cancer management. From exploring the foundational need for Kenya to invest in basic science infrastructure to drive cancer research, to the expanding role of primary health care in addressing our growing cancer burden, we spotlight the areas where focused effort is necessary. We also explore the blessings of nature pharmacy, which may hold the answers to cancer treatment, explore the emotional and socio-economic dimensions of cancer, from the link between endometriosis and ovarian cancer to the issue of treatment abandonment, particularly in childhood cancer - a sore point in Africa's cancer journey. Importantly, we highlight the challenges of crossing the blood-brain barrier in drug development for brain tumors, a bottleneck that continues to inhibit effective treatment to these life-threatening tumors. Moreover, we explore the revolution of RNA technology as an indispensable tool in discovering new ways to diagnose and treat cancer.

At ICRF Kenya, we believe that cancer research and education should run in parallel if we are to move closer a healthier and cancer resilient continent. Through OncoAfrica, our goal is to provide you with emerging cancer research and management insights, and foster informed choices of cancer prevention and management. We invite you to engage deeply with these articles, each one rooted in the belief that, we have the collective responsibility to reshape the future of effective cancer management and care on the continent.

Thank you for your continued support.

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Hudson Alakonya, Ph.D. CEO, ICRF Kenya.

## Kenya Needs to Develop Basic Science Infrastructure for Cancer Research

#### By Dr. Vivian Tuei, Ph.D.

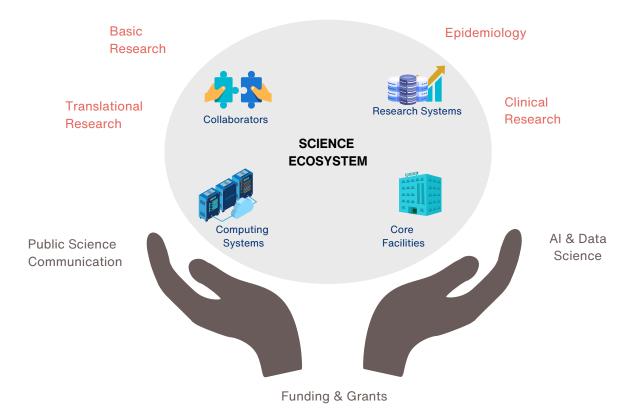
Kenya has seen a significant rise in cancer cases over the past few decades. According to Global Cancer Observatory (GLOBOCAN), Kenya reported 44,726 new cancer cases and 29,317 deaths in 2022. Given the rising cancer prevalence in Kenya, it is important that the country invests in health and research systems to meet this challenge. Basic science research, which focuses on understanding the causes and molecular mechanisms of cancer, is fundamental for advancements in cancer diagnosis and treatment. This foundational research has enabled global progress over the last three decades as evidenced by several Nobel Prize-winning discoveries including, precision therapies, cancerinducing viruses, retroviral oncogenes, and DNA repair mechanisms.

Despite these global advancements, Kenya's infrastructure for basic cancer research remains inadequate. Enhancing this infrastructure is crucial for Kenyan scientists to conduct robust basic and translational cancer research and produce groundbreaking discoveries.; While the country has over forty universities, very few of them are well equipped with basic research infrastructure. Basic and translational cancer research cannot occur without the right laboratory infrastructure supporting culture, molecular biology, biochemistry, cell histopathology, animal models, imaging, and drug discovery studies. Also, establishing at least biosafety level-2 laboratories in universities and research institutions is critical. These labs should have adequate working space, proper ventilation, and safety equipment to allow researchers to conduct experiments safely and effectively, and ensure the integrity of their findings.

The cancer research landscape in Kenya, and Sub-Saharan Africa by extension lacks the state of the art equipment needed to support different research programs. Access to advanced research equipment such as biosafety cabinets, PCR machines, centrifuges, spectrophotometers, flow cytometers, biobanking infrastructure, and various types of microscopes such as confocal, fluorescence, and electron microscopes are essential for detailed and molecular analyses. Additionally, cellular cryopreservation and sequencing platforms are vital for storing biological samples and analyzing detailed genetic, transcriptomic, and epigenetic information. Improving the regulations and the supply chains for laboratory consumables and equipment is also necessary. Streamlined procurement processes and reliable supply chains will ensure that researchers have continuous access to the tools they need without unnecessary delays.

The increasing reliance on computational and datadriven approaches in cancer research underscores the need for robust bioinformatics and artificial intelligence resources. Computational infrastructure for data analysis, software tools for genomic, proteomic, and metabolomic analysis, and databases for storing and sharing research data are essential components. In addition, strengthening population-based cancer registries is important for tracking cancer incidence, mortality and guality of life outcomes. Currently, Kenya has only three functional registries based in Nairobi, Eldoret, and Kisumu. Expanding and enhancing these registries will provide valuable epidemiological data that can inform research and public health strategies.

Establishing operationalizing regulatory and committees and frameworks for biosafety. biosecurity, animal experimentation, and research ethics are necessary to ensure the responsible conduct of research to safeguard the welfare of research subjects and the integrity of the research process. Also, coordinated research regulatory functionalities involving government organizations the National Commission for Science, like Technology and Innovation (NACOSTI), the National Cancer Institute of Kenya (NCI-Kenya), the National Biosafety Authority (NBA), and the Ministry of Health should be enhanced. These organizations must work



Cancer research requires a robust and interdisciplinary ecosystem supported by shared core facilities, computing and research systems. These systems promote collaborative research disciplines anchored by funding, grants, science communication, artificial intelligence, and data science.

together to streamline approval processes and provide clear guidelines for researchers and institutions.

Cancer research funding landscape in Kenya and the rest of SSA is constrained. While infectious diseases such as HIV/AIDS, tuberculosis and malaria get substantial funding from the government and other philanthropic organizations, cancer research in Kenya is barely funded. Competitive grant programs, fellowships, and research awards can help attract and retain talented researchers, innovation and progress in cancer fostering research. Grants tailored solely for individual basic scientists for cancer research, and infrastructural development grants, need to be incorporated. Institutions such as the Kenya National Research Fund (NRF), the Kenya Medical Research Institute (KEMRI) and NCI-Kenya should prioritize these funding mechanisms in their mandates as seen in successes driven by the National Institute of Health (NIH) in the United States. Expanding small basic science grants programs for early-career scientists and creating long-term grant funding opportunities for researchers at all career stages are crucial.

These initiatives will support the development of new research ideas, propel discoveries to translatable clinical products and drive promising projects. In addition, training programs and professional development opportunities should be provided to cultivate expertise in new emerging technologies and encourage cross border collaborations., These programs will equip researchers with the skills and knowledge needed to conduct cutting-edge cancer research. Finally, dedicated fiscal management systems for research grants at the institutional level need to be operationalized and made technically supportive to grantees. By investing in these areas, Kenya can create a conducive environment to promote significant advancements in cancer biology, preclinical studies, new cancer diagnostic and therapeutic approaches, and collaborative networks, ultimately improving outcomes for cancer patients. Strategic investment in basic science infrastructure, as outlined in Kenya's Vision 2030, is essential for achieving these goals.

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## Overcoming the blood-brain barrier: Bottlenecks in drug development for brain tumors

#### By Lucy Macharia, Ph.D.

Brain tumors occur when abnormal cells grow in the brain or nearby tissues, such as the pituitary gland, nerves, pineal gland, or membranes that cover the brain. Brain tumors that begin in the brain are called primary brain tumors, while those that spread to the brain from other sites are called metastatic brain tumors. Glioblastoma (GB) is the most common and malignant type of primary brain tumor, accounting for 55% of all primary brain tumors (Rodriguez et al., 2022; Louis et al., 2019). Despite advances in understanding the biology of brain tumors, much has remained the same in their treatment in the past decade. Conversely, the overall prognosis remains dismal for patients with GB due to a local recurrence standard treatments despite the such as chemotherapy, radiotherapy, and surgery (Stupp et 2009). To date, the Food and Drug al., Administration (FDA) has approved only four systemic therapies for GB, including temozolomide (TMZ), lomustine, carmustine, and bevacizumab. Temozolomide lomustine, and carmustine are simple alkylating agents (they add an alkyl chemical group DNA, interfering with replication). while to bevacizumab is an antibody therapy that blocks a growth factor (vascular endothelial growth factor -VEGF) that promotes the development of tumorassociated blood vessels. Even with the current treatment options, the median survival of patients with GB is approximately 14.6 months, and their 5year survival rate is less than 5% (Stupp et al., 2009; Gilbert et al., 2013).

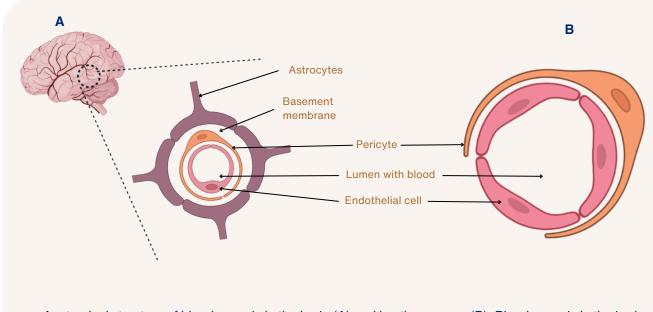
The origin of GB is still unclear. Initially, it was thought that central nervous system (CNS) cells develop mutations that give rise to GB (Geraldo et al., 2019; Visvader, 2011). Others have suggested that GB arises from neuronal cells (Liu et al., 2011; Alcantara et al., 2016), but the cellular heterogeneity of GB makes it extremely hard to accurately identify its cell of origin. More recently, glioblastoma stem cells (GSCs), which represent a subpopulation of self-renewing cells involved in tumor initiation and maintenance, have emerged as the culprits as they have shown to have the ability to self-renew and differentiate into a heterogeneous population of cancer, to be responsible for cancer relapse and drug resistance (Rodriguez et al., 2022; Ciurea et al., 2014; Singh et al., 2004).

All organisms with a well-developed CNS have a blood-brain barrier (BBB) (Abbott, 2005; Zhou et al., 2018). The BBB is a membrane barrier that separates blood from the extracellular fluid of the brain in the CNS of most vertebrates, thereby protecting the brain from foreign substances in the blood that may damage the brain, thus keeping a constant brain environment (Zhou et al., 2018; Mayer et al., 2009). Due to the presence of the junctions between cells in the BBB, the passage of the many molecules, including drugs, is primarily restricted (Sandoval and Witt, 2008). The BBB markedly limits brain distribution of many cancer pharmaceuticals, including monoclonal antibodies and hydrophilic molecules that do not readily cross

...'The delivery and release of drugs into the brain is a challenging topic, and various strategies have been developed to efficiently improve the release of drugs into the brain.'...

the cell membrane. For molecules that readily go across the cell membrane into the cells, endothelial cells express pumps that get rid of these molecules (Sarkaria et al., 2018). Only small molecules such as water, some gasses, and some lipid-soluble compounds can easily penetrate through the BBB by passive diffusion.

On the other hand, transporting large molecules with high electric charge, polarity, and hydrophilicity (i.e.,



Anatomical structure of blood vessels in the brain (A) and in other organs (B). Blood vessels in the brain are made up of endothelial cells, pericytes, basement membrane, and astrocytes, which together make up the blood-brain barrier. This barrier, unlike in other organs, has tight junctions that selectively allows the passage of different molecules into the brain microenvironment.

glucose, amino acids, and most drugs) has to rely on specific proteins via active transport routes (Zheng et al., 2003). Thus, the delivery and release of drugs into the brain is a challenging topic, and various strategies have been developed to efficiently improve the release of drugs into the brain. These strategies include chemical modification of the drugs to allow them to cross the BBB. Second, temporary disruption of the tight junctions that hold the BBB in place can also permit entry of drugs into the brain. Finally, neurosurgery- and nanoparticle-assisted drug delivery into the brain are additional options (Koo et al., 2006). Of these methods, nanoparticleassisted drug delivery across the BBB is a relatively optimistic approach. It offers advantages such as non-invasiveness, low cost, long-term stability in circulation, ease of synthesis, high targeting efficiency, and high controllability to load and release drugs across the BBB (Zhou et al., 2018; Nance et al., 2014).

The contribution of the BBB to treatment failure in GB raises the need for improved efforts to develop BBB-penetrating agents, optimize BBB-disruption technologies, and refine implantable drug delivery technologies that bypass the BBB and deliver therapeutic concentrations throughout an infiltrating tumor volume.

References for this article are available on the online version at oncoafrica.org

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### What Is Palliative Care?

#### By Elliot Abbott, Ph.D.

Palliative care is a specialized medical approach focused on relieving symptoms, pain, and stress in patients with serious illnesses. Its primary goal is to enhance the quality of life for both patients and their families, regardless of the stage of the illness. The need for palliative care in Sub-Saharan Africa (SSA) is high yet many countries on the continent have no identifiable hospice or palliative care services integrated in their healthcare systems. This is despite SSA having the highest burden of chronic diseases such as HIV/AIDS, diabetes, chronic respiratory disease, and cancer.

In Kenya, late diagnosis of cancer often means that patients present with advanced stages of the disease. where curative treatments are less effective. This increases the need for palliative care to manage severe symptoms, control pain, and provide psychosocial support, ultimately improving the quality of life for patients and their families. Despite being a relatively new concept in Kenya, the demand for palliative care is overwhelming given the high burden of acute infectious diseases and noncommunicable diseases like cancer. Kenva's Ministry of Health data shows that over 800,000 Kenyans require palliative care annually, yet less than 15,000 receive these services.

Despite its importance, palliative care faces significant cultural barriers in Kenya, impacting its accessibility and acceptance. In many communities, serious illnesses, especially cancer, are stigmatized, leading patients and families to avoid palliative care services to prevent social ostracism. There is a common misconception that palliative care is only for the dying, causing reluctance to seek these services, as many believe it means giving up hope for recovery. Nonetheless, through the Kenya Hospices and Palliative Care Association (KEHPCA), there is a multifaceted approach towards sensitizing patients with chronic diseases, their families, and the general public about the value of palliative care.

Additionally, a significant portion of the Kenyan population relies on traditional healers and

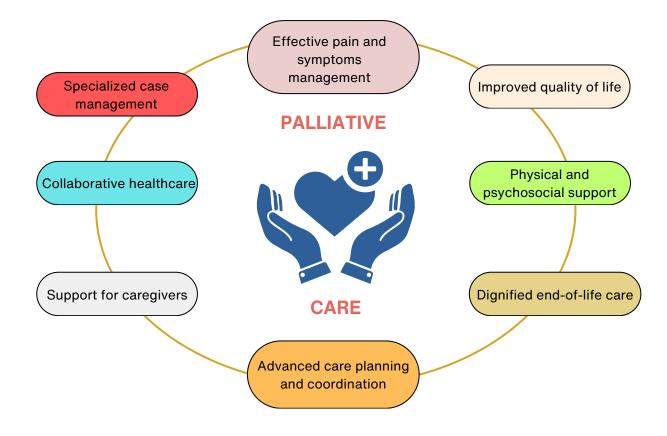
remedies, which can delay or prevent the utilization of modern palliative care services. Some communities living in remote parts of Kenya believe illnesses are caused by supernatural forces or divine punishment, preferring spiritual healing over medical interventions, including palliative care. In such communities, healthcare decisions are often made collectively by the family rather than by the individual patient, complicating or delaying decisions about seeking palliative care. Traditional gender roles can also influence access, with women sometimes having less autonomy in making healthcare decisions and facing barriers in accessing services due to dependency on male family members.

#### **Delivery of palliative care**

A number of different professionals support the delivery of palliative care services. Here is a list of some of them:

- Home care team
- Community palliative nurses
- General practitioners
- Hospice doctors
- Marie Curie nurses
- Social workers
- Specialists in palliative care

There is also a widespread lack of awareness about what palliative care entails and its benefits. Many people are unfamiliar with the concept and thus do not seek out these services. This is because palliative care is a relatively new concept in Africa with evidence informing its delivery and quality borrowed from high-income countries where it is integrated in the healthcare system. Therefore, increasing awareness through community outreach programs can help dispel myths and educate people about the benefits of palliative care. Organizations



The benefits of palliative healthcare system

like ICRF-Kenya aim to bolster awareness through outreach events, social media posts, webinars, and research into cancer care engagement. Stronger advocacy and policies that promote palliative care can help overcome these cultural barriers. Training healthcare providers on cultural competence and collaborating with traditional healers to incorporate culturally sensitive practices can bridge the gap between traditional beliefs and modern palliative care.

Palliative care is increasingly recognized as essential in Kenya's healthcare system, particularly for common chronic conditions like cancer and HIV/AIDS. Key aspects include the availability of services through hospitals, NGOs, and community health programs, though access is limited in rural areas. Organizations like KEHPCA train healthcare providers and advocate for palliative care integration. The government includes palliative care in strategies like the National Cancer Control Strategy.

In conclusion, palliative care is crucial for improving the quality of life for patients with chronic diseases such as cancer and diabetes. Continued efforts to expand access, train providers, and raise awareness are necessary to ensure comprehensive and compassionate care for all patients. However, such services are only useful if the public is aware of their presence and benefits.

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It is widely acknowledged that the risk of developing certain cancers is hereditary. Examples of hereditary cancers include cancers of the breast, ovary, lung, brain, endometrium, kidney, stomach, blood (leukemia) and prostate (Fig. 1). Approximately 5-10% of all diagnosed cancers are linked to an inherited faulty or mutated gene. These inherited mutated genes are important drivers in certain tumors but much less in others, and increase the risk of developing specific cancers. Ovarian cancer leads with the highest percentage of inherited genetic mutations at 19%, followed by lung and brain tumors at 15% and 12%, respectively (Fig. 2).











Kidney



Breast

Stomach Prostate

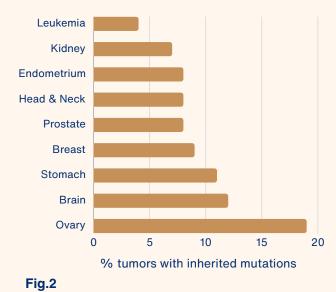
Endometrium

Lung

Ovarian

#### Fig.1

For example, women with BRCA1 mutation have between 50-80% risk of developing breast and 24-40% of getting ovarian cancer. Individuals with APC mutation have upto 100% risk of developing colorectal cancer compared with a 4% risk in the normal population. Similarly, those with VHL mutations have upto a 70% risk of developing kidney cancers compared to the normal population that has a 1-2% risk.



Gene	Cancer	Risk in normal population	Risk in cases of mutation
BRCA1	Breast	12%	50-80%
BRCA1	Ovarian	2%	24-40%
BRCA2	Breast	12%	40-70%
VHL	Kidney	1-2%	Upto 70%
APC	Colorectal	4%	Upto 100%

#### WHAT YOU NEED TO KNOW

If you think that you may have a strong family history of cancer, talk to your GP. Your GP will ask you about your family and how many members have had cancer, so it is important to have as much information about your relatives' cancer diagnoses as possible. If they think that you might be at increased risk, they can advice you on your next steps and provide you with more information.



### EXCELLENCE HONORS AND AWARDS

#### The East Africa Biosciences Studio Fellowship by Villgro Africa

Dr Jeremy Okonjo, Ms Olive Chege, and Dr. Fiona Okonjo (Head of Research Division, ICRF-Kenya) were recently awarded the East Africa Biosciences Studio Fellowship, sponsored by Villgro Africa, for their project on "Modelling a Regulatory Sandbox for Biotechnology Research and Innovation'. Regulatory sandboxes are tools or frameworks that provide 'a safe environment for testing new technologies, products, services or business models, under the supervision of a regulator.' This concept which was first developed in the financial technologies (FinTech) sector is currently being implemented in other sectors including healthcare. Kenya's health sector has experienced a rise in health-tech innovations, including the adoption of novel technologies like artificial intelligence for cancer diagnosis and precision medicine. However, the regulatory frameworks have yet to fully address or evaluate while these emerging technologies. This project aims to design a health-tech regulatory sandbox in Kenya. This will be achieved through engaging with stakeholders to understand the challenges of undertaking and regulating research and innovation in health-tech in Kenya, and whether a regulatory sandbox can address some of these challenges. We hope to generate a healthtech regulatory sandbox model that will drive collaboration between Kenya's health-tech regulators and innovators. The project will run from 2nd September 2024 to 30th November 2024.

#### Dr. Stella Irungu, Ph.D. Senior Scientist, Kenya Institute of Primate Research (KIPRE) Scientist, Integrated Cancer Research Foundation of Kenya (ICRF-Kenya)

Diseases of the female reproductive tract contribute significantly to the global burden of diseases. This makes them an important target for the development of better diagnostic, prognostic, and therapeutic strategies. My research on endometriosis has underscored the importance of early diagnosis, which is essential for early disease detection and treatment, ultimately leading to better outcomes for these women.

I was honored to receive the Merck Foundation Best African Researcher Award emerging as the overall winner in the 2023 category of Best African Women Researchers for my work entitled Identifying biomarkers for the non-invasive diagnosis of endometriosis. This award was in partnership with The African Union Scientific Technical Research Commission, International Federation for Fertility Societies (IFFS), Africa Reproductive Care Society (ARCS) and Manipal Academy of Higher Education, India. This recognition was awarded for my contributions to the theme of Women's' Health and infertility. The Merck Foundation's award aims to empower young African researchers and specifically encourages African women in STEM disciplines by advancing their capabilities and promoting their contributions.

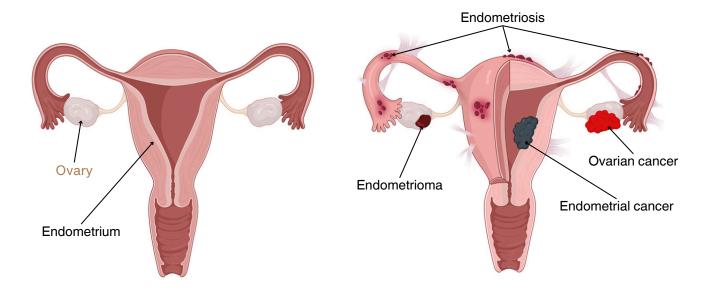
This award not only acknowledges my work but also highlights the importance of increasing representation and support for African women scientists. It serves as a platform to inspire and motivate other young women in Africa to pursue careers in science, technology, engineering, and mathematics, fostering a more inclusive and diverse scientific community.

## Connecting the Dots: Endometriosis and Ovarian Cancer. Is there a possible association?

#### By Stella Irungu, Ph.D.

The human endometrium (layer of tissue that lines the uterus) is a unique tissue that undergoes important changes during the menstrual cycle. Due to the exposure of different risk factors in a woman's lifetime, normal endometrial tissue can give rise to multiple pathological conditions including endometriosis. The cause and disease mechanisms behind such conditions remain largely unclear. Endometriosis is a common, estrogen-dependent disease that affects ~20% of women of child-bearing age. It occurs when endometrial tissue grows outside the uterus mostly in the abdominal and pelvic cavity. The tissue may sometimes be found outside the pelvis such as in the lungs, gut, and brain. Most women with endometriosis experience chronic pelvic pain and infertility, which impacts their quality of life, reproductive function and causes a significant economic burden.

While endometriosis is considered a benign disease (non-malignant), it possesses some characteristics that are similar to malignant tumors. These include invasion of other tissues with subsequent damage to target organs, resistance to programmed cell death, local and distant metastases. angiogenesis (generation of own blood vessels for tumor maintenance) and responsiveness to hormones of the menstrual cycle. Different types of endometriosis are characterized by distinct biological and clinical features. Disease classification also depends on the anatomic location of the lesion and depth of infiltration. For example, superficial endometriosis usually appears on the surface of the peritoneum or visceral organs, deep infiltrating endometriosis (DIE) typically occurs in the muscle layer of the bladder, rectum, vagina, and diaphragm, while ovarian endometriosis (endometriomas) usually presents as



Female reproductive organ with healthy endometrium and ovaries. Genetic abnormalities in the normal uterine epithelium leads to the developing of endometriosis, the growth of endometrial tissues, outside their primary location. While the link between endometriosis and ovarian cancer is still unclear, there are cases of endometriomas growing in the ovaries to develop into ovarian cancer.

large blood-filled cysts commonly known as "chocolate cysts." Standard diagnosis involves clinical examination and imaging (ultrasound, MRI) but the gold standard remains surgery (laparoscopy) and histological examination of the resected tissue to confirm the disease.

Research into the molecular behavior of endometriosis have reported a potential risk for developing epithelial ovarian cancer mainly ovarian clear cell carcinoma (OCCC) and ovarian endometrioid carcinoma (OEC). These forms of ovarian cancers thought to arise predominantly due to endometriosis are collectively referred to as endometriosis-associated ovarian cancers (EAOC). Pathology examination of resected endometriosis tissue enables the identification of patients with hyperplastic (increase in cell production in a tissue or organ) endometriosis who could be at an increased risk of developing EAOC. To differentiate between EAOC and benign cysts, we use the Sampson and Scott diagnostic criteria to establish presence of endometriosis and cancer within the same ovary, to confirm a similar histological structure to that of endometrial tissue, to exclude the possibility of a metastatic tumor affecting the ovary and to show proof of progression from benign endometriosis to a malignant tumor.

Quantifying cancer risk in women with endometriosis has important public health implications for women in terms of cancer screening and prevention and for clinicians in terms of long term management of women with endometriosis. Epidemiological reports that support an association between endometriosis and EOC estimate that women with endometriosis have two to three times higher risk of developing ovarian cancer and that a high proportion of women with OCCC and OEC also have endometriosis. For instance, a study involving 7911 women with invasive epithelial ovarian cancer in the Ovarian Cancer Association Consortium showed significant association between history of endometriosis and specific histological subtypes of epithelial ovarian cancer including OCCC and OEC. Findings from genetic studies also propose a possible link suggesting that similar genetic factors may increase the risk for both endometriosis and these types of ovarian cancer. Studies that have shed light into disease mechanisms have reported common molecular pathways, including abnormalities in the immune response, inflammation and hormonal regulation, in endometriosis and ovarian cancer that may influence malignant transformation.

Despite advancements in precise diagnostic, prognostic and treatment modalities. data on malignant association between endometriosis and ovarian cancer are still conflicting and there is still no acceptable tool to clinically identify patients at risk of developing endometriosis-associated carcinomas. The relationship between these two diseases warrants in-depth investigation to properly identify the mechanisms and risk factors underlying the transformation of endometriosis to ovarian cancer. This requires a better understanding of the pathophysiology of the disease, histology, genetics, and proteome changes. The development of biomarkers based on molecular alterations identified in endometriosis-associated carcinoma will benefit the clinical evaluation, diagnosis, and management of patients at various stages of malignancy development.

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## How nature's pharmacy may be the answer to cancer

#### By Carolyn Muruthi, Ph.D.

Most of the mainstream cancer treatment options, such as chemotherapy and radiation, have shown tremendous efficacies. However, these approaches are associated with a spectrum of adverse effects, including cardiotoxicity and myelosuppression, some of which are attributable to the nonspecific nature of chemotherapeutic drugs. Chemotherapeutic drug resistance also presents an emerging obstacle, with outcomes and side unsatisfactory effects compromising the quality of life. Moreover, belligerent metastatic cancers pose a risk of relapse after remission.

The quest for effective therapies with the ability to improve survival outcomes and quality of life has increased research into natural products, most of which remains untapped. Historically revered for their medicinal properties, natural products from plants, marine organisms, and microorganisms are emerging as powerful allies in the fight against cancer. Their applications in medicine date back to ancient civilizations, with their first use reported in Mesopotamia in 2600 BC. The basis of traditional medicine systems, including Indian Ayurveda, Traditional Chinese Medicine (TCM), and indigenous knowledge systems is sculpted on the therapeutic potential of natural products, particularly those from medicinal plants.

In African communities, medicinal plants have long been integral to healthcare, largely due to their accessibility, efficacy perceived safety. and Integration of medicinal plants cancer in management within the African communities is driven by their therapeutic potential and by socioeconomic factors. The high costs and limited accessibility of conventional chemotherapies pose significant barriers for many patients in these regions. In this regard, medicinal plants offer a viable alternative that aligns with local healthcare practices and economic realities. Moreover, cultural acceptance of and belief in traditional medicine ensures a greater adherence to treatment protocols.

Medicinal plants such as Prunus africana, Withania somnifera, Carissa edulis and Moringa oleifera have been demonstrated to suppress cancer cell proliferation. The primary plant parts employed are and bark, leaves, roots, each with unique pharmacological composition. The therapeutic potential of these plants in cancer management is supported by a growing body of scientific evidence. Their anti-cancer properties have been attributed to various bioactive compounds, such as alkaloids, flavonoids, terpenoids, and phenolic compounds. These phytochemicals exhibit a range of biological activities, including antioxidant, anti-inflammatory, and cytotoxic effects, which inhibit cancer cell proliferation, induce cancer cell death, and prevent metastasis.

Modern science has validated some of the phytocompounds, leading to the discovery of several anti-tumor agents. Paclitaxel (Taxol), a diterpenoid derived from the Pacific yew tree (Taxus brevifolia) has been successfully incorporated into mainstream oncology for the treatment of ovarian, breast, and lung cancers. Taxol stabilizes cellular microtubules and inhibits cell division, making it a cornerstone in cancer treatment. Vincristine and vinblastine, alkaloids from the periwinkle plant (Catharanthus roseus), are also essential in treatment of leukemia and other malignancies. Several bioactive compounds, including roscovitine from Raphanus sativus, noscapine from Paper somniferum and pomiferin, an isoflavonoid from Maclura pomifera, are currently in clinical trials, reflecting their potential in cancer treatment.

Adopting integrative healthcare models that combine conventional medicine with complementary and alternative therapies will exert significant anti-cancer effects. For example, regular consumption of turmeric, which contains the bioactive compound curcumin with anti-inflammatory and antioxidant properties, should be encouraged. Similarly, garlic, rich in organosulfur compounds like allicin, and



ginger, containing gingerol and shogaol, can be integrated into meals to exploit their anticarcinogenic effects. Additionally, promoting daily intake of green tea, high in epigallocatechin gallate (EGCG), can provide a steady source of polyphenols that modulate cellular processes associated with cancer prevention. Adopting integrative healthcare models that combine conventional medicine with complementary and alternative therapies will exert significant anti-cancer effects. For example, regular consumption of turmeric, which contains the bioactive compound curcumin with anti-inflammatory and antioxidant properties, should be encouraged. Similarly, garlic, rich in organosulfur compounds like allicin, and ginger, containing gingerol and shogaol, can be integrated into meals to exploit their anticarcinogenic effects. Additionally, promoting daily intake of green tea, high in epigallocatechin gallate (EGCG), can provide a steady source of polyphenols that modulate cellular processes associated with cancer prevention.

Traditional cancer phytotherapy has led to the discovery of important compounds that have revolutionized cancer prevention and treatment. However, data on anticancer properties of medicinal plants is not comprehensive. Additionally, most of the anti-cancer agents from medicinal plants are yet to be subjected to clinical trials. Despite these limitations, exploration of medicinal plants for cancer treatment and bridging ancient traditional knowledge with contemporary scientific research is paramount. As multidisciplinary approaches continue to evolve, integrating advanced technologies and methodologies, the therapeutic potential of these natural compounds will become increasingly accessible. To fully realize the potential of medicinal plants in oncology, studies should focus on high throughput screening of bioactive compounds and large-scale clinical trials. By harnessing the biochemical diversity of the plant kingdom, we can uncover novel treatments that offer improved efficacy and reduced toxicity, significantly contributing to advancement of cancer therapy.

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### The Power of RNA technology

#### By Faith Mokobi Zablon

The RNA revolution, now beyond its infancy, is in an exciting phase of evolution with vast potential in cancer diagnosis and treatment. The science of RNA, which begins with understanding the central dogma (DNA to RNA to proteins), is driving innovative medical approaches and improved patient outcomes in cancer. In the previous issue, 'The power of your RNA in cancer,' we have elucidated the myriad spectra of RNAs that can be used in detecting and monitoring cancer, citing specific examples of these RNAs, which demonstrate how

RNA is transforming the cancer landscape and engaging the audience in the potential of RNA from diagnosis to treatment.

In this new issue, we explore the advent and power of RNA technology and its revolution. We focus on the technology that makes these advancements possible. We aim to explain why this technology is considered the gold standard for discovering new ways to diagnose and treat cancer by looking at a widely used technique in clinical and research settings.

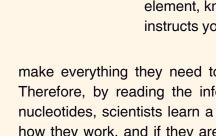
Have you ever wondered how scientists classify cancers? How do they identify the genes to target in cancer treatments? For instance, how do doctors classify the subtype of breast cancer? This classification is crucial because it helps doctors effective select the most treatments. The classification of breast cancer types has been significantly advanced by a technology known as **RNA-sequencing** (RNA-seq). This technique examines the expression of thousands of genes at once providing scientists with а detailed understanding of which genes are turned on or off in a cell. In the context of breast cancer, RNA-seq plays a crucial role in identifying specific patterns

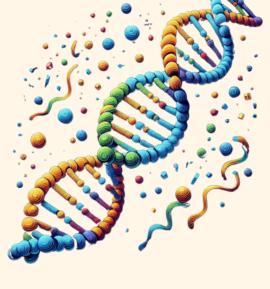
that distinguish different subtypes of tumors, thereby aiding in developing personalized therapies.

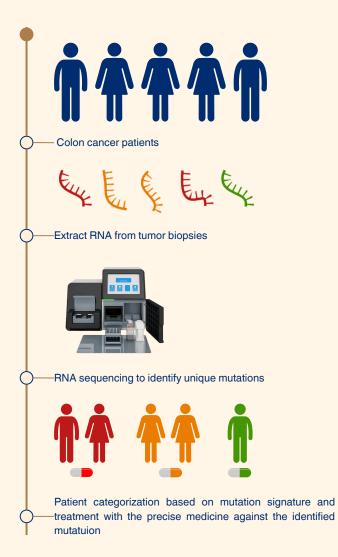
How does RNA sequencing work? The process begins with collecting tumor/tissue samples from breast cancer patients. The doctors/scientists extract the RNA from the sample and prepare it for 'sequencing'. Sequencing is a process that scientists use to determine the order of the building blocks of your DNA/RNA. Our genome is very long made up of sentences with millions of letters. Just like reading a

> long sentence letter by letter, sequencing is like figuring out the order of the letters in a book to understand the message. Figuring out this message helps you to understand the story. In this case, your genome (DNA or RNA), is the book made up of letters called 'nucleotides,' which are the building blocks of your DNA RNA. and These nucleotides form a sequence that carries important information message) (the regarding your biological element, known as gene. A gene instructs your body on how to

make everything they need to function (the story). Therefore, by reading the information about these nucleotides, scientists learn a lot about your genes, how they work, and if they are involved in diseases like cancer. Therefore, sequencing allows us to understand the expression and function of various genes. 'nucleotides,' which are the building blocks of your DNA and RNA. These nucleotides form a sequence that carries important information (the message) regarding your biological element, known as a gene. A gene instructs your body on how to make everything they need to function (the story). Therefore, by reading the information about these nucleotides, scientists learn a lot about your genes,







#### Tumor RNA sequencing profiles cancer patients based on actionable mutation signatures, which subsequently determines the most effective therapy.

how they work, and if they are involved in diseases like cancer. Therefore, sequencing allows us to understand the expression and function of various genes.

After sequencing, we use computational tools to assemble these genes into patterns usable for understanding their functions and quantifying their expression levels. It is through these analyses that various genes are identified as overexpressed or under-expressed. The presence of overexpressed genes in cancer indicates the cancer-promoting properties of those genes, and depending on their known functions, they are implicated in causing and/or promoting cancer. Moreover, identifying these over-expressed genes by RNA sequencing has contributed to classifying cancer and cancer stages, prompting accurate and unique ways of approaching the disease treatment and response to therapies. For example, the well-known breast cancer type is Luminal A, which is known for its high activity of hormone-related genes but has a good prognosis and responds well to hormone therapy. In contrast, Luminal B, has higher activity of genes linked to cell growth, is more aggressive than Luminal A, and may need additional treatments like chemotherapy. On the other hand, HER2-breast cancer is more aggressive, with high activity of the HER2 gene, but has better responses to HER2targeted therapies such as Herceptin. Basal-like breast cancer has hyperactivity of genes found in basal cells (all types of cells in the breast), such as TP53 (tumor protein p53) genes that are normally mutated in basal-like breast cancer. This leads to loss of tumor suppressive function and enhances uncontrollable cell growth and resistance to apoptosis (natural cell death).

RNA sequencing has improved our understanding of genetic events that underpin cancer consequently informing personalized therapy. With the advent of precision (individualized or personalized medicine), RNA-seq analysis has enabled the study of millions of cancer samples available in The Cancer Genome Atlas (TCGA) database, providing valuable data for ongoing research for the development of better personalized treatments for cancer patients. From technology to practical applications at the point of care (POC) of patients, RNA sequencing has transformed how we understand and treat many types of cancers. It provides comprehensive insights into an individual's genes and the genetic and molecular mechanisms underlying different cancers. The technology has paved the way for opportunities for not only categorizing cancers but also early detection of these cancers with improved prognosis and timely interventions, treatment monitoring, and personalized medicine while minimizing adverse side effects. All these advancements in RNA-seq have transformed the cancer research landscape, contributing to improved patient outcomes.

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## Radiotherapy: From fear of to understanding the painless path of cancer treatment

#### By Christine Kili

'Nimekuja kuchomwa' This is a very common statement in most cancer centres across the country with patients undergoing radiation therapy. Most new patients still have not come to terms with their various diagnoses and are very apprehensive, with fear written all over their faces. They are always in the company of relatives who appear sicker than the patients. Patients go through various psychological stages after a cancer diagnosis. Others even have their daily lives changed completely. The role of stakeholders involved in the patient journey cannot be ignored and specifically the support from relatives and friends. In Kenya, where Swahili is the national language, most patients will be heard referring to radiotherapy as 'kuchomwa' a Swahili word directly translated to being burnt. As a result, patients are usually frightened of the whole process. It is not 'kuchomwa'. There is a need for people to have a better understanding of this modality in cancer management and an overview of what it entails.

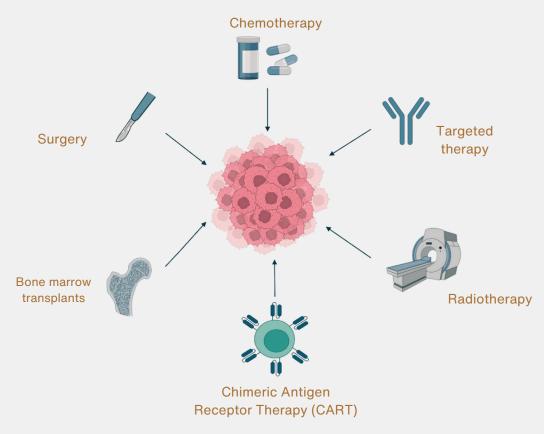
Radiotherapy uses ionizing radiation delivered at high energies to either treat or control the symptoms of a disease, including cancer. The radiation may be from photons (X-rays) or particles such as protons, electrons and gamma radiation. Radiation is energy in transit that is neither seen nor felt hence, the treatment process is completely painless. Radiotherapy may be used to debulk a tumor before surgery, reduce recurrence of a disease after surgery or chemotherapy, suppress the immune system before organ transplant or to control the symptoms of a disease in the case of metastasis. It can also be used in emergency conditions such as spinal cord compression, airway obstruction, superior vena cava obstruction, bleeding and brain metastasis.

Radiotherapy can be delivered from outside the body by a machine that rotates around the patient as in external beam radiation therapy. It may also be delivered from a source placed on or near the tumor (brachytherapy) or can be ingested (radionuclide therapy). The choice of the modality depends on the tumor type, stage at diagnosis, the patient's general health, availability of the treatment modalities and the patient's preferences. Radiotherapy can be applied as an individual treatment or it can also be combined with radiosensitizers such as radionuclides and chemotherapy.

Before administering radiotherapy, the patient receives a general explanation of the procedure and expected outcome and side effects. In addition, any arising concerns by the patient are addressed. Radiotherapy involves *three major steps*, including simulation, treatment planning and actual treatment delivery.

Simulation is a mock treatment process and involves obtaining images for treatment planning. With improved technology, 4-D images are preferred but 3-D images are the most commonly used. These images are obtained using a CT scanner. The patient is placed in the treatment position and documentation accurate is done to ensure reproducibility, accuracy and precision during the dose delivery. actual Special customized immobilization devices are used to ensure patient comfort. Semi-permanent marks and tattoos are made on the patient's skin to help in positioning. The images obtained in simulation are forwarded to the treatment planning system.

During *treatment planning*, dedicated computer systems are used to guide the machine on how to direct the radiation to the target. The healthy organs in the beam's path are delineated together with the target. Margins are given around the target organ to account for clinically obscure disease and a margin for error during daily treatment. Various body organs have different tolerance levels of radiation. A multidisciplinary radiotherapy team consisting of a radiation oncologist, dosimetrist, radiation therapist, and a medical physicist work jointly to ensure that a tumoricidal dose is delivered to the target organ and



Types of cancer therapies used in clinical settings today.

as low as reasonably achievable radiation reaches the surrounding healthy tissue. Once the best plan has been agreed upon by the team, the patient is scheduled to start treatment.

Before the *actual treatment delivery*, the patients' details are confirmed. The machine's performance status is confirmed by quality checks to ensure proper functioning, precision and accuracy during dose delivery. The patient assumes the same position as in the simulation throughout their course of treatment. The radiation therapists are guided by the skin marks made during the simulation. This procedure takes about 20 minutes from the time the patient walks into the room to discharge. Treatment sessions are usually five (5) times a week, allowing the patient to rest on weekends.

Follow-up on patients undergoing radiotherapy is done during weekly appointments with their oncologists. Lab works are ordered to monitor the prognosis and the patient's general health. Patients may experience some side effects, which are both patient- and site-specific. The common ones include fatigue, loss of appetite, unintentional weight loss, pain, and discomfort. Appropriate advice is usually given on managing the various side effects, medications may be prescribed, and in extreme cases, treatment may be suspended. After completing the full course of radiotherapy, patients are seen periodically for up to 5 years, with the first appointment after three (3) months. Imaging tests may be ordered together with lab work to monitor recurrence and prognosis.

Radiation therapy may also be indicated in other benign conditions such as blood irradiation to prevent transfusion associated with graft versus host disease, treatment of keloid scars, gynecomastia, and acoustic schwannomas among others.

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## Cancer in Kenyan families: socio-biological interruptions and victories

By Tyrus Swaya, Ph.D.

Cancer is a disease with diverse epidemiology and characterized by uncontrolled growth of cells that can invade beyond their primary organ and spread to distant organs. It is a genetic disease that is caused by changes in genes that control cell growth and multiplication. In Kenya, cancer is the third leading cause of death (7% of deaths per year), after infectious diseases and cardiovascular diseases placing a great burden on families, communities, and the health system. According to GLOBOCAN, in 2022, Kenya reported an annual incidence of cancer of 44726 with 29317 cancer-related deaths. Breast cancer is the most common cancer at 16.2%, followed by cervical cancer (13.1%), prostate cancer (8%), esophageal cancer (7.5%) and colorectal cancer (6.9%). Projections from Kenya's Ministry of Health suggest that from 2028, there will be more than 58000 new cancer cases diagnosed annually. However, data on the prevalence of first degree relative cancers in Kenya remains undocumented.

Cancer affects Kenyans of all ages and socioeconomic backgrounds but has a disproportionate effect on the most vulnerable groups. As in many low- and middle-income countries (LMICs), 70-80% of cancer cases in Kenya are diagnosed at an advanced stage, when treatment options are limited and families make huge sacrifices, often with poor results. Late diagnoses of cancer in Kenya are limited attributed to awareness. inadequate diagnostic facilities, under-resourced treatment facilities, high cost of treatment, and systemic poverty. Less than 20% of Kenya's households have health insurance, trapping these families in dire financial fixes forcing them to borrow, selling assets and Whatsapp-initiated fundraisers to meet treatment costs. Behind each cancer, is a person and a family struggling to cope with the medical and socioeconomic consequences of this disease. There is a need for more comprehensive counseling and access to genetic testing; recognizing the added clarity it would bring to these families' risk of cancer.



When a family member is diagnosed with cancer, shock, fear, disbelief, and numbress are some of the emotions that close family members mav experience. Households with a cancer patient face many difficult choices often taken in a situation of physical pain and great uncertainty about the treatment outcome and survivorship. Patients and family members are forced to decide about treatment modalities, whether to sell assets or take out loans, caregiving and cutting back on routine spending. The choice of treatment is particularly sensitive, as both under- and over-treatment are risky and costly in diverse ways. At times there is lack of proper communication from health care providers leading to confusion and anxiety, which impedes timely decisions. Mixed messages delays health-seeking behavior as well as fueling health care costs as patients and family members consult multiple providers. Families affected by cancer are often paralyzed by emotional distress, uncertainty, and lack of clear information around the consequences of different options. In some circumstances, a decision must be made quickly due to a deteriorating health situation: hence, access to accurate information is critical.

Family and friends play a critical role in supporting cancer patients and hence need to be well-informed. They help patients make critical decisions about whether to pursue treatment, which facility to access, how to cope with the financial costs, and the available health insurances. Patients with wellinformed, strong, functional family structures, collectively make decisions about financing and fundraising. Well-intentioned family members and friends, who are not fully informed, can lead patients in the wrong direction; hence, it is important to raise awareness more broadly beyond health care professionals. Socio-economic analyses of the effect of cancer reveals economic losses due to lost wages, sold assets, and in some cases growing debts, as well as significant spending on cancer care.

Families where breadwinners are engaged in formal employment and benefit from employer-provided social welfare schemes are better equipped to cope with the economic burden. Likewise, families with assets such as savings, land, livestock, and real estate are in a position to cater for urgently needed diagnostic procedures, costly medications, and expensive treatments in private health facilities usually unavailable in level 1-3 facilities. By contrast, families with breadwinners with limited assets and no health insurance often struggle with mounting debts and intergenerational consequences on household finances, mental health, and children's well-being. Fear of stigma from a cancer diagnosis (especially for reproductive cancers) may lead patients not to discuss their conditions or to seek health care. In some socio-cultural settings, reproductive cancers for both genders are perceived to be a "divine punishment for acts of infidelity." Additionally, embarrassment related to menstrual bleeding causes female patients to hide their condition and delay seeking care. While many people may want to help, it is sometimes best to be in a safe place with authentic, compassionate, non-judgemental people who have "been there" and can offer reassurance, companionship, and practical support.

Children living with a parent with cancer always find their social and interpersonal relations change. They may exhibit acting-out behaviors, emotional distress, and physical pain, which affects their wellbeing. In addition, adolescents may be more vulnerable because thev are at а more advanced developmental stage with more cognitive abilities than younger children. Regardless of the prognosis, it is crucial to talk with children openly and honestly. Adolescents and teens may reject talking about the situation and seem withdrawn. It doesn't mean they're not interested or don't care but simply need more time to process information.

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## Expanding Role of Primary Health Care in Addressing Cancer Burden in Kenya

#### By James Kiilu

Like many other low- and middle-income countries (LMICs), Kenya has undergone a significant epidemiological transition over the past decade. Originally designed to combat communicable diseases, the country's health system now faces an increasing burden of non-communicable diseases (NCDs). Globally, NCDs account for two-thirds of all premature deaths, with cancer as the second leading cause among NCDs after cardiovascular diseases. Presently, 54% of deaths in Kenya are due to communicable diseases, while deaths from NCDs have risen from 27% in 2014 to 39%. By 2030, deaths from NCDs are projected to increase by 55%.

According to GLOBOCAN 2022, Kenya reported an annual cancer incidence of 44,726 cases and 29,317 cancer-related deaths. The most prevalent cancers include breast, cervical, colorectal, prostate, and esophageal cancers, which collectively account for 51.7% of all new cancer cases and 48.2% of cancerrelated deaths. Given the rising cancer burden and Kenya's economic status, there is a pressing need for efficient and effective cancer management Primary health care strategies. (PHC), the cornerstone of Kenya's healthcare system, is crucial in addressing the cancer burden and achieving universal health coverage.

Kenya's healthcare system is organized into six levels with PHC services predominantly delivered at levels 1 to 3. PHC serves as the initial point of contact for individuals, families, and communities with the healthcare system, offering essential medical services directly where people live and work. It encompasses disease prevention, health promotion, and addressing social determinants of health, including health education, family health services, environmental health, first aid, communitybased surveillance, psychosocial support, rehabilitation, and palliative care.

Kenya's Ministry of Health recently conducted a health facility census to enumerate all health



facilities, determine service availability, and identify system gaps. According to the census, 92% of assessed facilities were level 2 or 3, indicating that these are our primary access points to healthcare. However, significant challenges still need to be addressed, including an uneven distribution of healthcare facilities, with a national average of 2.4 facilities per 10,000 people, primarily concentrated in major towns within specific counties. Some counties have only one facility that serves 10,000 people. Furthermore, only 55% of primary health facilities were accredited by the public health insurer, the National Health Insurance Fund (NHIF). Additionally, many PHC facilities do not offer basic laboratory and imaging services.

Within Kenya's economic and social context, primary health care is pivotal in addressing the cancer burden as these facilities are most accessible to the population. Despite their importance, several challenges hinder effective cancer care in these settings. Late detection remains a significant issue due to low screening rates and limited diagnostic capacity. Integrating screening into routine services can mitigate the barriers patients face, such as embarrassment, discomfort, or fear. It's concerning that despite most Kenyans seeking initial healthcare from primary facilities, cancer diagnoses in these facilities are rare, prolonging the time between symptom development and treatment initiation. Lowering the threshold of suspicion among healthcare workers in these facilities is crucial to improving early detection and timely intervention.

Primary healthcare facilities often lack essential diagnostic tools and adequately trained personnel to detect and manage cancer effectively. Investing in advanced diagnostic technologies, providing comprehensive training for healthcare providers, and implementing evidence-based triage protocols can enhance early detection and facilitate timely referrals. Integrating cancer screening tools such as mammography, PSA tests for prostate cancer, CEA tests for colorectal cancer, pap smears, VIA/VILI for cervical cancer, and colposcopy with biopsy into primary health facilities, particularly at level three, is crucial. Increasing public awareness of the benefits of screening and ensuring that screenings are affordable and accessible can lead to better treatment outcomes and a reduction in the overall cancer burden. These can only be achieved with responsive funding mechanisms that account for screening costs for the target groups and the required frequency.

Subsequently, health education is crucial for addressing risk factors like tobacco use, alcohol consumption, and sedentary lifestyles. Community health promoters are vital in disseminating health information and raising awareness about cancer prevention and screening. Public awareness campaigns and education programs can demystify cancer, promote proactive health behaviors, and empower individuals to take ownership of their health.

Of significance is the vaccination against human papillomavirus (HPV). This is pivotal in preventing cervical cancer, particularly when administered to girls by age 15. Community health promoters are promoting HPV instrumental in vaccination, addressing safety concerns, and ensuring no missed vaccination. opportunities for Strong recommendations from healthcare providers significantly influence vaccination uptake. highlighting the effective importance of communication about HPV vaccination as a preventive measure against cancer.

Lastly, Integrated care, an organizational principle that aims to improve patient care and experience through coordinated service delivery, is critical in comprehensive cancer management. It ensures seamless coordination among healthcare providers and services, optimizing patient outcomes and care delivery. This approach relies heavily on effective referral systems and coordinated care across multiple levels. We need to rethink the primary healthcare system's expanded role as the first line of defense in addressing the cancer burden, leveraging its accessibility and community-centered approach to ensure comprehensive cancer screening, early detection, and timely intervention become standard practice across all healthcare facilities. This proactive strategy, backed by strong diagnostic capabilities, ongoing healthcare provider training, and targeted public education campaigns, is critical to lowering mortality rates and improving the quality of life for all Kenyans affected by cancer.

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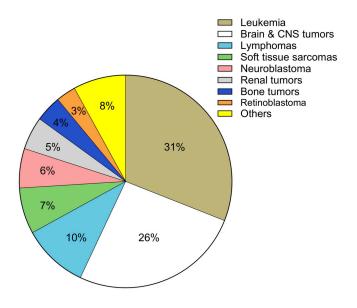
## Treatment Abandonment: The "sore' in the efforts to improve childhood cancer cure in Africa

#### By Gilbert Olbara, MD

Childhood cancers are a global health priority. Annually, 400,000 children and adolescents 0-19 years will be diagnosed with cancer. Out of this, 90% live in low- and middle-income countries (LMICs). While advancements in treatments have improved survival rates in high-income countries (HICs), the same has not been realized in LMICs, including Sub-Saharan Africa (SSA). These resource-constrained countries, in aggregate, have only 10% of the total global resources to fight childhood cancers. For these and many other reasons, only 3 out of 10 children diagnosed with cancer living in LMICs are likely to survive their cancer. This would be different if the child was born in a HIC, where 8 out of the 10 children diagnosed will survive their cancer.

At the start of June this year, over 500+ healthcare workers from Africa and other parts of the world met at the SIOP AFRICA 2024 conference in South Africa to share lessons and opportunities for improving childhood cancers management in Africa. This year's conference theme was "Towards 2030", referencing the goal of WHO's Global Initiative on childhood cancer of increasing the survival rate of children with cancer globally to at least 60% by the year 2030 while reducing suffering and improving their quality of life. On a light note, the conference Hotel": was "Indaba venue the remarkably appropriate by chance or convenience. I later learnt that "Indaba" is a Zulu word for "important meeting', which seeks to gather the right people together at the right time to discuss the right issues." It was no surprise, therefore, that one of the recurrent themes in most of the presentation was the urgent need to address "treatment abandonment," a common cause for cancer treatment failure in Africa.

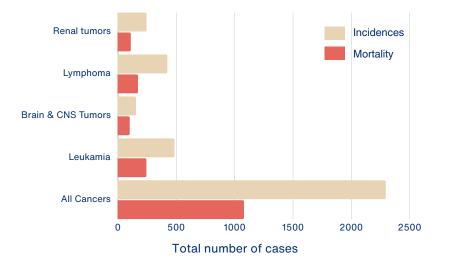
"Treatment abandonment" or " treatment refusal" is not new. As far back as the late 1970s in the US, there were sensational newspaper articles, journal case reports, and even court cases about teenagers and their families refusing life-saving cancer treatment for their curable cancers.



Age adjusted (0-19 years) of the most common types of childhood cancers at diagnosis worldwide (2012)

One such case was the Virginia v Cherrix court case in 2006, where the state of Virginia sued to force Abraham Cherrix, then a 16-year-old with Hodgkin's lymphoma, to undergo further conventional medical treatment for a highly treatable cancer. So protracted was the case that it resulted in a new law, dubbed the Abrahams Law, that increased the rights of patients aged 14 to 17 years in Virginia to refuse medical treatment. The ambiguity in differentiating refusal','treatment 'treatment abandonment', treatment non-adherence and 'lost to follow up' persisted for a while, leading to what most experts in this field termed this 'semantic chaos'. This lasted until 2006 when the International Society of Paediatric **Oncology-Paediatric** Oncology in Developing Countries (SIOP-PODC) presented a definition to harmonize terms consensus for documenting, quantifying, and comparing treatment abandonment across the globe.

In line with SIOP recommendations, treatment abandonment is defined as the termination of care by the parent/caregiver and/or not presenting for scheduled treatment for four weeks or more from the scheduled treatment date at the time of data record.



Incidence and mortality of childhood cancers (0-19 years) in Kenya in 2022 (Source: GLOBOCAN)

In a systematic review by Friedrich and colleagues conducted in 2015, which included 101 countries globally, 99% of the cases of treatment abandonment were common in LMICs. In a way, the total number of children abandoning treatment in LMICs annually equaled the total number of new cases of childhood cancers in children under15 years expected in HICs. Most studies done in Africa indicate 10% to 60% abandonment rates of all children diagnosed, significantly impacting survival rates and overall outcomes. While this definition is universallv accepted. more recently. some researchers have argued that the term 'treatment abandonment" should be avoided as it is derogatory and puts all the blame on the parent and caregivers, which is not the case. In some instances, treatment non-compliance may be due to health systemrelated factors or healthcare providers themselves. In Vietnam, for example, the use of the term "treatment abandonment" is prohibited in preference for treatment non-completion.In Vietnam, for example, the use of the term "treatment abandonment" is prohibited in preference for treatment non-completion.

The causes of treatment abandonment in Africa are multifactorial and complex. More recent studies have grouped them into supply-side barriers like high cost of care (associated with treatment, diagnostics, and hidden costs like transportation and lodging). Other supply-side barriers include lack of insurance, long travel time to cancer centers, long waiting times, and lack of social support for the family. On the demand side (patient/caregiver), low income or poverty, cost of transport, poor public awareness, and knowledge on cancer contribute to abandonment. The interplay of these factors in Africa is always complex. Even in countries like Zambia and Malawi, where cancer care has been provided for free, there are still high rates of abandonment. It is thought that while the patients do not have to pay for treatment, other indirect costs like opportunity cost of labor income lost while caregiver is away from home, perceptions of cancer as an incurable disease, and preference for complementary and

alternative medicine highly influence the family choice to abandon conventional cancer treatment. In most low-resource settings, treatment abandonment is a significant "sore" to achieving optimal outcomes in childhood cancers. Nevertheless, it remains the most modifiable risk factor for treatment failure. This calls for concerted multi-sectorial efforts to address these challenges and develop sustainable and context-appropriate interventions. This will require addressing all factors involved along the cancer continuum from the community to the policy-making level in a bid to prioritize access to affordable quality care. promote community engagement, and strengthen health care systems using innovative interventions.

It is, therefore, imperative that addressing noncompletion of childhood cancer treatment should be one of the strategic priorities in all cancer control plans in Africa. Just as the word "indaba" from the Zulu community emphasizes "deep talk" and acknowledges that we all have something important to say, all stakeholders have a role to play if 60% of the children in Africa are to survive their cancer by the year 2030.

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## Caring for the caregiver: A forgotten stakeholder in cancer management

By Peninah Wairagu, Ph.D.



~A helping hand can be a ray of sunshine in a cloudy world~

A cancer diagnosis marks the beginning of a journey often fraught with fear of the unknown, anxiety and despair, but which many hope will end in cure. Many factors determine the course of treatment adopted, including the type of cancer, the stage at diagnosis, economic status of the patient and the available technology and expertise. The journey for a cancer patient involves multidisciplinary personnel that may include surgeons, oncologists, radiologists and nurses, who form part of the medical team. In addition to the medical personnel, family members or close friends may act as caregivers in a non-medical capacity. The role of a caregiver usually befalls an individual without warning, and finds one unprepared mentally, financially and skillswise. Unfortunately, in some cases, the burden of caregiving is carried disproportionately by one individual, with little or no support from other members of the family. According to the American Cancer Society, the roles of caregivers are many and vary depending on various factors such as whether treatment is inpatient or outpatient, and whether the patient is undergoing treatment or has finished the course of treatment, among others. Some of the roles include giving of medicines, monitoring side effects, preparing meals and feeding the patients, grooming the patients, arranging doctor's appointments, and keeping doctors and other family members informed on the

patient's progress. In many cases, this involves the caregiver being with the patient full time for many months or even years. Since these roles touch on all aspects of a patient, caregivers have a huge influence on the wellbeing of the patient.

Caregivers face many challenges that can negatively affect their ability to carry out their roles. Since most caregivers are not professionally-trained, they often have limited skills or expertise to handle the patients. For instance, if a patient is bedridden, the patient will need to be turned every so often, may require administration of medicines through injections, will probably be on adult diapers and may need assistance with feeding. Some of these tasks such as administration of injections and turning the patient may require skill and can be overwhelming for the caregiver, especially if the caregiver is not as physically endowed as the patient. Some patients may not be very cooperative with the caregivers. Cases have been reported of patients refusing to eat. take medication or even follow routines prescribed by medical professionals. There are even cases where patients have been reported to be abusive and physically violent to their caregivers. Finances can also pose a great challenge to caregivers. In addition to treatment costs, other costs such as purchase of adult diapers, provision of special diets, and payment of home-based professional care is a major burden to caregivers. The situation is made worse in cases where the caregiver is forced to take time off from work to take care of the patient, with little or no support from other parties. There is also the mental toll that most caregivers go through. Helplessly watching a loved one endure pain and/or deteriorate, coupled with the stress associated with the many challenges they face, can drive most of us to the edge.

However, all is not lost. Caregivers are cognizant of the critical role they play in the wellbeing of the patient. Thus, they seek to take care of themselves first, before they can take care of the patients. There are many support groups and organizations that have set up programs to train and support caregivers. Some of these organizations double up as patient advocacy groups to lobby policymakers and government agencies to lower cost of treatment and other essential supplies for patients. Other organizations have set up campaigns to raise funds to support treatment of patients who meet certain eligibility criteria. Sometimes all one needs is to vent to feel rejuvenated. Other times one needs information or links to resources available for patients and/or caregivers. This can only happen if one deliberately reaches out to those around them that are willing to support. It is also a challenge to family members or friends of caregivers. Do we check on the wellbeing of the caregiver? Do we offer support in terms of finances, time or even psychosocial support? We can offer to watch the patient for one day as the caregiver takes time off to unwind or to run personal errands. We can buy that one pack of adult diapers, or the special foods that the patients require. Once again, the role of a caregiver usually befalls an individual without warning, and finds one unprepared mentally, financially and skillswise. It would be unfortunate if we were to lose a caregiver because of lack of support.

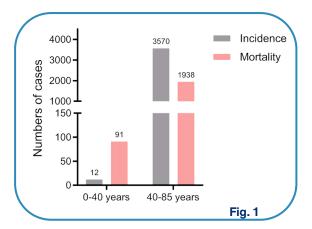
Are you a caregiver out there struggling in the journey with your patient? Do not walk the journey alone. Look for support around. Ask the medical professionals to recommend support groups that you can join. When you go for doctor's appointments, interact with other individuals in the waiting area. You will be surprised at the wealth of valuable information and knowledge that you can gain from others walking the same journey. Are you a friend or family member to a caregiver? Check on them once in a while.

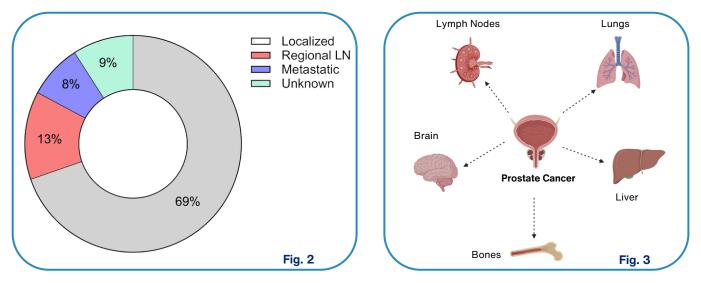
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#### **Prostate Cancer In Kenya**

Prostate Cancer is the most prevalent cancer in Kenyan men with 3582 new cases and 2029 deaths reported in 2022 (IARC - GLOBOCAN 2022). While there were only 12 newly diagnosed cases reported in men under 40 years, surprisingly it was the third highest cause of cancerrelated mortality in men under 40 years (91 deaths) after leukemia (228 deaths) and Non-Hodgkin lymphoma (150 deaths) in 2022. For men over 40 years, prostate cancer remains the most common malignancy based on new diagnoses and cancer-related deaths (**Fig. 1**).





Yet, this disease should not be a death sentence if discovered early. Existing data demonstrates that 69% of newly diagnosed prostate cancer cases are localized meaning that they have not spread beyond the prostate, with 13% in the regional lymph nodes and 8% spread to secondary organs (**Fig. 2**). The common sites of metastasis for prostate cancer are the bones, lungs, liver, lymph nodes, and brain (**Fig. 3**). However, the bones are most dominant site for metastatic prostate cancer accounting for over 85% of all metastases.

#### Why Is Screening Important?

In Kenya, many patients are diagnosed with advanced metastatic disease with limited treatment options. A recent study in looking at screening in Kenya found out that only 2.4% and 4.1% of participants in rural areas and in Nairobi city respectively had been screened for prostate cancer. Why is screening important?

- If prostate cancer is discovered early, in most cases, it will usually be localized or in the regional lymph nodes.
- Early detection can lead to less aggressive treatment.
- Reduced Mortality: The 5-year survival rate for localized or regional prostate cancer is over 90% compared to 34% for metastatic disease.

Prostate cancer is NOT A DEATH SENTENCE if we encourage men to go for regular screening. This is a call to action for all stakeholders involved to raise awareness about prostate cancer.



#### CANCER AWARENESS AT

#### INTEGRATED CANCER RESEARCH FOUNDATION

Cancer education and awareness lies at the core of the Mission of ICRF which is to empower communities through cancer awareness and education. ICRF carries out this mission through organising in person awareness forums across the country and on social media platforms.



Cancer Awareness in Machakos County



Cancer Awareness in Mumias Sub-County



Outreach Division members out for an awareness session

## MAISHA NA CANCER

The Maisha Na Cancer Project is a cancer literacy research project In the CaLioS that seeks to better understand cancer education and the cancer-related health literacy among cancer patients in Kenya. The website aims to support newly diagnosed cancer patients and their family members in Kenya to improve their cancer literacy, such as the ability to understand the disease, treatment, and living with it, and to get ideas on how to cope and improve their quality of life.



maishanacancer.co.ke



youtube.com/@cancerresearchkenya



#### SECOND

#### **CANCER RESEARCH SYMPOSIUM**

21st - 24 October 2025 | Venue: TBD

Building on the success of our inaugural Cancer Research Symposium in 2023, we are excited to announce an even more comprehensive and impactful event for 2024. This year's symposium will feature an expanded lineup of renowned speakers, thought-provoking presentations, insightful masterclasses, and engaging talks. Open to all stakeholders in the cancer field, from academic researchers to industry leaders, policymakers, and corporate representatives, our symposium aims to foster meaningful discussions, collaborations, and innovative thinking. By bringing together diverse perspectives, we seek to drive groundbreaking research in cancer prevention, diagnosis, and treatment."

For More Information: symposium.cancerresearchkenya.org

#### C O N F E R E N C E R E P O R T

## CANCER GENOMICS DATA SHARING STAKEHOLDER CONFERENCE

University of Warwick, Coventry, UK | 19th-20th June 2024

#### Introduction

Cancer genomics research has significantly transformed our understanding and treatment of cancer, leading to the development of targeted therapies and advancements in precision medicine. However, these studies have predominantly focused on individuals of European ancestry, with those of African descent being largely underrepresented. This disparity has created a significant gap in research and development of cancer treatments that are effective for individuals of African ancestry. Addressing this lack of ethnic diversity in cancer genomics is crucial to providing precision treatments for all populations. In this context, we selected Kenya as a case study, to understand the barriers that impede cancer genomic research and data sharing within an African population. Our objective is to provide recommendations that could help to overcome these challenges, thereby facilitating the acceleration of cancer genomics research in Kenya, and across the African continent.

To identify these barriers and formulate recommendations, we organized '**The Cancer Genomic Data Sharing Stakeholder Conference**', on 20th June at the University of Warwick in the United Kingdom. This conference brought together experts from diverse fields across Kenya, South Africa, and the UK to exchange knowledge on cancer genomics data sharing and its potential to drive innovation in cancer research, diagnosis and treatment.

The conference aimed to:

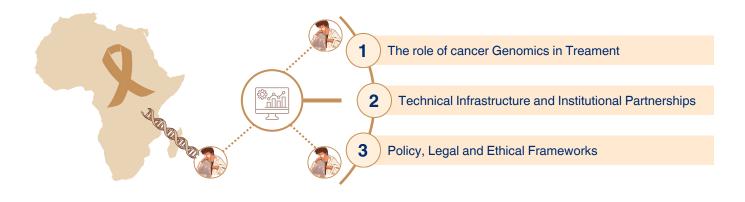
- Establish a network of interdisciplinary experts in health research and innovation, with a focus on cancer genomics, from both the UK and Kenya.
- Facilitate knowledge exchange between UK and Kenyan stakeholders on the development and maintenance of a genomic data-sharing ecosystem for promoting research and innovation in cancer treatment in Kenya.
- Develop a roadmap on the research, policy, legal, regulatory, institutional, and infrastructural best practices for establishing cancer genomics databases in Kenya and across Africa, based on the insights from UK-Kenya knowledge exchange.

The program covered a wide range of topics, including the role of genomics in cancer treatment and health innovations, technical infrastructure and institutional partnerships, as well as the policy, legal and ethical frameworks necessary to establish a robust and sustainable cancer genomic data-sharing ecosystem.

#### Key Challenges in Conducting Cancer Genomic Studies in Kenya

The primary challenges identified as barriers to cancer genomics research in Kenya include:

- 1. Researchers working in isolation and not collaborating.
- 2. Limited access to sequencing instruments and dedicated laboratory space for sequencing.
- 3. High costs associated with genomic sequencing.
- 4. Limited patient awareness and understanding of cancer genomics.
- 5. Limited expertise in genomics and bioinformatics.
- 6. Concerns about data sovereignty and a lack of trust in data management.
- 7. Insufficient funding for research initiatives.



#### **Recommendations For Accelerating Cancer Genomic Research In Kenya**

During the conference stakeholders proposed several recommendations to increase the number of genomic studies conducted in Kenya:

- 1. Promote stakeholder engagement and collaboration to build partnerships and facilitate knowledge transfer.
- 2. Develop infrastructure by establishing centres of excellence to enhance the capacity for cancer genomic research.
- 3. Begin with simpler genomic technologies before advancing to more complex methods.
- 4. Increase patient and public engagement to encourage participation in cancer genomic studies.
- 5. Train Kenyan scientists in the use of sequencing technologies and bioinformatic analysis.
- 6. Implement effective data management practices for genomic research.
- 7. Establish ethical, legal, regulatory and policy frameworks to support cancer genomic data sharing.

#### Conclusion

Adopting these recommendations is anticipated to significantly enhance cancer genomics research in Kenya, leading to the generation of substantial amounts of data. This data needs to be efficiently stored, managed, and utilized to foster innovation in cancer diagnosis, treatment, and care. Consequently, there is a strong argument for establishing a Kenyan and African cancer genomics database, which would be a vital tool in advancing our understanding of cancer progression and treatment within African populations. By enabling personalized medicine, advancing research initiatives, and promoting international collaboration, such a database has the potential to markedly improve patient outcomes and contribute to the global battle against cancer.



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Integrated Cancer Research Foundation of Kenya

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