OPINION EDITORIAL

Improving Retinoblastoma Care and Outcomes in Kenya

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INTRODUCTION

Cancer is a leading cause of childhood mortality, with approximately 300,000 new cases diagnosed each year worldwide, and recorded incidents increasing over time [1]. In high-income countries (HICs), medical surveillance has enabled earlier detection and treatment of cancer, leading to a survival rate of approximately 80%, representing the percentage of children who are alive five years or more after their diagnosis [2,3]. Despite the advancements in HICs, nearly 90% of children with cancer reside in low- and middle-income countries (LMICs) and are four times more likely to die of the disease than children in HICs [1,3]. Explanations for this discrepancy include delayed diagnoses, low-resource hospitals, and a lack of specialized training among healthcare professionals [2]. In 2018, the World Health Organization announced the 'Global Initiative for Childhood Cancer', aiming to reach a 60% survival rate by 2030 [1]. This article will demonstrate how a shift towards eHealth can advance cancer care and outcomes in LMICs, specifically using retinoblastoma in Kenya as a case study.

RETINOBLASTOMA AND THE GLOBAL DISEASE BURDEN

Retinoblastoma (RB) is a rare cancer that typically develops before the age of five in the light-sensitive tissue at the back of the eye called the retina [4]. RB accounts for about 4% of all cancers in children younger than 15 years [4,5]. As the eyes develop, progenitor cells called retinoblasts divide and fill the retina [5]. If a mutation occurs in the RB1 gene of the immature progenitor cells, the retinoblasts grow out of control and form an RB tumour. The most common presenting sign is a white pupil, or leukocoria, followed by misaligned eyes, or strabismus [6,7]. Several therapeutic options for RB include enucleation (removal of the affected eye), local or systemic chemotherapy, and focal treatments with laser and cryotherapy [6]. In HICs, these therapies have led to a >90% survival rate [7]. Even though RB treatment can be curative when diagnosed early, families in LMICs face the consequences of delayed presentation, including an aggressive invasion of the optic nerve and brain or secondary metastases in the body, which can be fatal [6].

Approximately 9,000 cases of RB are diagnosed annually worldwide [8]. Although the global incidence of RB is constant, at one in 15,000-20,000 live births, the condition has a significant burden on LMICs [6]. Data shows that 11% of children with RB live in HICs, while 89% live in LMICs [8]. Even though the prevalence of RB is evidently greater in LMICs, most treatment centers are in middle- and HICs, demonstrating a discrepancy in facility distribution [8]. Access to RB treatment is the greatest barrier to survival in most LMICs, where patient survival has historically been <30% [6]. Outcomes are worsened due to low public awareness and inadequate financial resources [6].

IMPROVING RB DIAGNOSES IN KENYA

The age of RB diagnosis is influenced by (1) the molecular basis, where heritable RB presents earlier than the non-heritable form and (2) the medico-social response, where contextual factors such as public awareness impact the recognition of signs [8]. In HICs, photoleukocoria (a white pupil in photographs) is commonly a feature that directs

caregivers to seek readily available medical advice. Unfortunately, children in LMICs whose signs are missed continue to suffer through advanced disease forms like colour change of the iris, an enlarged cornea and eye, or non-infective orbital inflammation [8]. In fact, proptosis (protrusion of the eye from the socket due to the tumour's expansion) is a common presentation in Asia and Africa, demonstrating the deadly effect of delayed diagnoses in LMICs [8].

In Kenya, approximately 90 new cases of RB are documented annually [9]. As a result of Kenya's referral-based healthcare system, the cumulative three-year survival rate was historically very low, at 26.6%, mainly due to the delay between disease presentation and treatment [9,10]. Research that explored the knowledge, attitudes, and experiences of RB patient families showed that they expressed a desire to better understand their diagnosis and receive more comprehensive service delivery [11]. Diagnostic delays and mortality rates led to the formation of the Kenyan National Retinoblastoma Strategy (KNRbS) group, which has successfully implemented several efforts to improve survival such as publishing the KNRbS Best Practice Guidelines and creating a system of centralized pathology for RB [12]. With such fruitful changes, the age of children receiving bilateral and unilateral RB diagnoses has changed from 25.2 to 16.8 months and 35.9 to 24 months, respectively [13]. These figures are more akin to those of HICs and associated with a better prognosis [14]. It is currently necessary to implement and assess studies that test intervention efficacy for RB patient families, such as genetic testing and counselling using eHealth.

INCREASING ACCESSIBILITY WITH EHEALTH IN KENYA

Kenya is a modern hub for information and communication technologies (ICTs); thus, it is an appropriate location for assessing eHealth as a cancer service delivery mechanism [15]. eHealth-driven initiatives can respond to access-related issues by providing interventions from any setting, given that over 93% of Kenyan households own a mobile phone and mobile internet penetration is greater than 100% [15,16].

Some researchers suggest using 'WhatsApp' as a cost-effective and convenient eHealth tool for data collection, as shown in Lebanon (a LMIC), where the platform was used for qualitative surveying [17]. WhatsApp is a free multi-function messaging application used by 88.6% of Kenyans [16]. Further research showed that mobile-phone technology can be effective for delivering educational interventions to parents of children with sickle cell disease, another genetic disorder [18]. A third study used WhatsApp in a medical setting to increase medication adherence in hypertension and diabetes patients, showing that this mechanism of information transfer can be feasible in a healthcare environment [19]. In alignment with these studies, educational interventions for RB patient families could be mobile-phone-based, using WhatsApp to gather valuable data surrounding attitudes and knowledge about their experience with RB. eHealth can harness ICTs for improved healthcare delivery in the face of rising healthcare costs, higher demands for quality services, and a shortage of trained personnel [15].

In Guatemala, another LMIC, mobile phones were provided to community facilitators as an eHealth intervention to communicate with pregnant women [20]. This strategy enabled continuous training, medical consultations, and community health promotion, leading to a significant decrease in maternal and child mortality [20]. Evidently, eHealth can be successfully employed to increase healthcare accessibility and outcomes in an LMIC; however, this tool must be applied in a culturally sensitive manner. One study evaluated factors associated with knowledge gain in a sample of African American women diagnosed with early-onset breast cancer [21]. Researchers determined that culturally targeted material given through multiple modalities (e.g., phone call, visual aid, personalized letter) may improve relevance and acceptability of information as compared to traditional material [21]. To respond appropriately to the cultural variations and expressed needs unique to the Kenyan RB population, it is necessary to design, implement, and study several eHealth

modalities that can educate families about RB as well as its genetic causes and consequences [9,11].

CONCLUSIONS

In LMICs, services for RB such as genetic testing and counselling are largely unavailable and/or inaccessible, meaning that RB patient families are not supported in undergoing surveillance, accessing timely care, and coping with their diagnoses. Although eHealth does not come without challenges, it is a potential solution to the gap in cancer care within LMICs, thus its efficacy must be assessed through further implementation studies.

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