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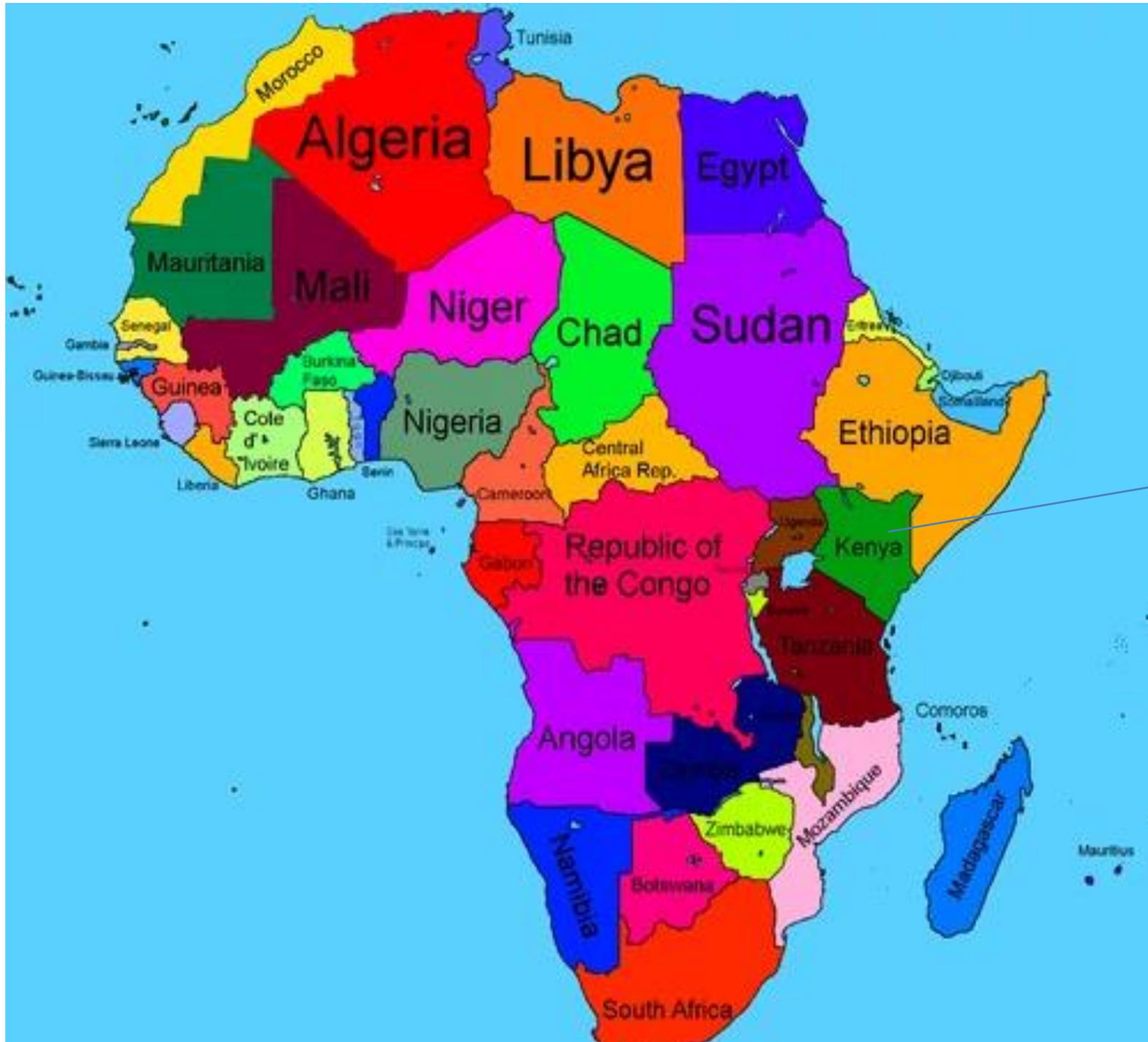


# Health Literacy: A Qualitative Study of Information & Educational Needs of Kenyan Patients Diagnosed with Breast/Cervix Cancer

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**Kenya**

**Kenya-East African  
country  
Capital city : Nairobi  
Population: 48.46  
million (2016)  
National  
language:Kiswahili**



ELSA

# Background & Significance

- Health literacy is defined as the degree to which individuals have the capacity to obtain, communicate, process & understand basic health information & services needed to make appropriate health decisions (Oldach & Katz,2014).
- Breast & cervix cancer have high mortality rates worldwide
- Kenya-among the top 3 causes of death after cardiovascular and infectious diseases (Ferlay et al., 2015)
- 80% late presentation due to lack of awareness & perceived low health literacy (Ferlay et al., 2015)
- Cancer diagnosis as stressful experience for individual, family & community
- Patients & families should be able to access, understand & use health information to make decisions(McCormack, Thomas, Lewis, & Rudd, 2017)

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Kenya-among top 3 causes of death from cancer in women  
(Ferlay et al., 2015)

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Cancer diagnosis as stressful experience for individual, family & community

Health literacy plays crucial role in healthcare outcomes  
(Nutbeam, 2017)

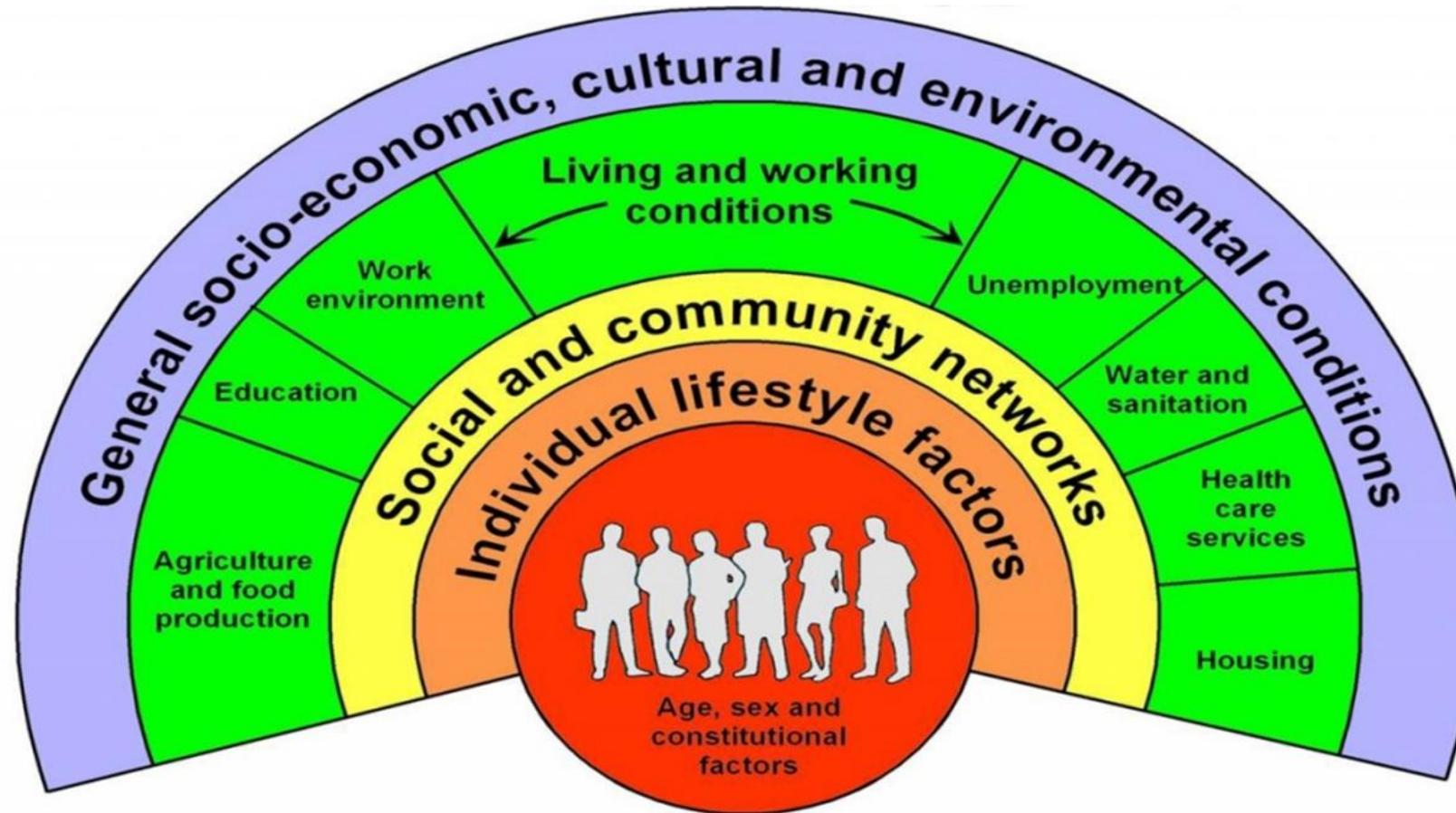
Significance: Understanding women's source of information & knowledge needs will help target effective health information & education

Patients & families should be able to access, understand & use health information to make decisions(McCormack, Thomas, Lewis, & Rudd, 2017)

## Research Objectives

- To describe experiences of getting cancer-related information before & after cancer diagnosis & how information is used along illness trajectory
- To explore what Kenyan women understand about breast/cervix cancer, including words and numbers used in their communication with healthcare providers
- To identify information/education needs and how these needs are/are not met
- To describe perceptions of women towards the information given by healthcare providers

# Theoretical Framework: Socio-Ecological Model



Source: Dahlgren and Whitehead, 1991

# Methodology

## Design

- Design :Qualitative- phenomenology
- Ontological stance :Intepretivist
- Study sites :Aga Khan University Hospital (AKU) and Kenyatta National Hospital (KNH)
- Ethical approval :AKU,University of Salford,NACOSTI,KNH

## Sampling Data Collection

- Purposive sample 8-15 -stop at **saturation**
- Inclusion/exclusion criteria
- Audiotaped semi structured face-face individual interviews-English and Kiswahili
- Interview guides

## Data analysis

- Ongoing during data collection
- Nvivo for coding
- Thematic content analysis

(Creswell,2015; Houser, 2013).

# Sub themes Emerging from Interviews

- Breast lump, abnormal discharge &/or bleeding as a gateway to health facility
- Church as an avenue for cancer information sharing
- Despair & agony at diagnosis
- Doctors as main source of information
- Not understanding treatment regimens
- Insufficient information on cancer
- Need for patient psychosocial support
- Faith in a higher being (God) as a coping strategy
- Stigma associated with a cancer diagnosis
- Cancer treatment financial burden

# Breast Lump, Abnormal Discharge &/or Bleeding as Gateway to Health Facility

Excerpts from interviews

- *Actually am the one who diagnosed my condition. I was doing my monthly check. So when I was doing my checkup them I noticed there was something on the left breast. When I felt like there was something, I went to the Nairobi hospital (AF01BC)*
- *I was bathing when I realized I had a lump in my breast, I went to hospital the following day (AF07BC)*
- *I had been bleeding but I thought it was due to the Norplant (AF10CC)*

# Despair & Agony at Diagnosis

- *..the word cancer, what comes to your mind is that the disease can not be cured (TAF0BC1)*
- *I had some information but the worst was that it can kill...there was a lot of fear(AF03BC)*
- *..the results were not good those are the words he used...So I started to cry because I sympathized with myself (AFBOBCC)*

# Not Understanding Treatment Regimens

- *He said even though I may tell her she will not understand anything. So they explain to my husband and he told us to go and make the decision (AF01BC)*
- *People need to be told the importance of continuing with treatment (AFB08CC)*
- *Need to use language that patients understand most people don't understand pap smear and chemotherapy language*

# Insufficient Cancer Information

- *...some information that the doctor will not give you... like where to get the bra after operation (AF03BC)*
- *When you ask what to eat they just say eat balanced diet some people do not know what this is; am lucky because I go to the net to get more information (AF07BC)*
- *So I reached a point and stopped attending clinics, I was not told not to go. I saw I was OK and stopped (AF08CC)*

# Some words used by participants

- Zero stage cancer
- I had cystectomy - my uterus was removed
- Zero stage cancer
- My husband saw his gynecologist
- I had meat removed taken to South Africa
- “*Nilichinjwa*”-Swahili for “I was slaughtered”-meaning-they had surgery
- Cancer feeds on red meat

# Recommendations

- Need for Health literacy assessments
- Individualize patient teaching
- Adoption of health literacy best practices to enhance breast & cervical cancer screening, diagnosis & treatment
  - Health literacy assessment as newest vital sign
  - Concept of ‘expert patient’ – focus on knowledge transmission & support
  - Patient education interventions to increase participation in decision making
- Curriculum review to incorporate guidelines for teaching healthcare professionals
- Inform public policy on cancer awareness campaigns
- Provide psychosocial support for adherence to treatment

Thank you  
Asante sana  
Whakawhetai koe

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