Original Article:

Screening female refugees in Sudan’s challenging Settings: A simple, feasible, and affordable telemedicine framework.

Alaaddin Salih¹², Mohamed Mohamed³, Momen Norealdaim⁴, Abubkr Khalifa⁵⁶, Dafalla Alam-alhuda⁷⁸

1. PhD Applicant, FHS, University of Cape Town, Cape Town, South Africa.
2. Research Associate, Academy of Health Sciences, Khartoum, Sudan.
3. Assistant Professor, University of Gazira, Wad Madani, Sudan.
4. OB/GYN Consultant, Central Police Hospitals, Khartoum, Sudan.
5. Medical Director, The Commissioner for Refugees (COR), Khartoum, Sudan.
6. Assistant Professor, Omdurman Islamic University, Khartoum, Sudan.
7. Sr. Consultant, Academy of Health Sciences, Khartoum, Sudan.
8. Associate Professor, Neelain University, Khartoum, Sudan.

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Corresponding author:

Alaaddin Salih

PhD Applicant, FHS, University of Cape Town, Cape Town, South Africa. Email: alaaddinsalih@yahoo.com

Abstract

Background and Aims:
Cancers often go unnoticed during emergencies; exacerbating underdiagnoses and late presentations. Telemedicine-driven screening systems emerge as effective and economical alternatives, particularly crucial amidst Sudan’s current refugee situation.

Methods:
Using the 3-step process: First, cancer burden was assessed using Refugees Commission data and presented as per 100,000 period prevalence. Second, case definitions for malignancies under study were then created as a screening base. Third, the telemedicine framework was built following user-centered design’s (UCD) 4 steps (analysis of stakeholders’ needs; design using the MAIA model; implementation according to BPMN flowchart; and users’ feedback evaluation).

Results:
The most common tumor was breast followed by ovarian cancer (median=16.45 and 3.19 per 100,000). UCD’s four steps shaped our framework, with MAIA aiding the management plan’s design for suspected cases. BPMN guaranteed seamless implementation, and our model scored 6.83 out of 7 on a Martinez-Alcalá inspired Likert system upon evaluation.

Conclusions:
Designing a telemedicine-based screening system for refugees necessitates incorporating epidemiological mapping, clinical presentations, contextual and cultural dimensions, and ensuring overall feasibility.

Keywords:
Cancer, breast, gynecological, refugees, telemedicine, screening, framework.
Introduction

Cancer stands as a formidable global challenge, ranking high among causes of morbidity and mortality, exerting an immense strain on health systems worldwide. This burden becomes even more profound during humanitarian crises, where cancer problems are compounded by acute crises, rendering early detection, diagnosis, and management exceedingly challenging. Jozef Suvada's compelling report reveals a higher cancer incidence rate among refugees (2.6%) compared to migrants (1.89%) and inhabitants (0.97%), which underscores the role of environmental factors such as carcinogenic viruses.

The intricacies of humanitarian emergencies exacerbate the complexities associated with cancer diagnosis and management. Crises typically prioritize acute injuries and outbreak control over chronic conditions such as cancers. Additionally, the scarcity of reliable statistics on the burden of malignant diseases in fragile contexts, which is pervasive, hampers the much-needed effective planning. Perone et al. emphasize the need for intensive scrutiny in managing cancer in special situations, urging further research to assess factors such as disaster nature, disease complexity, feasibility, health system reliability, and cost-effectiveness.

A lack of a proficient screening system jeopardizes cancer outcomes, prompting the proposal of a simple, integrated, and cost-effective screening protocol based on case definitions. This study advocates for telemedicine as a precise identification tool, mitigating risks and associated costs. The current acceleration of digital transformation in healthcare, spurred by the COVID-19 pandemic, reinforces telemedicine adoption, a trend constrained primarily by access and infrastructure limitations.

Sudan hosts one of Africa's largest refugee populations, shaped by decades of serving as either the final destination or a crossing point for millions of East African refugees. The continuous influx, driven by political upheavals and environmental disasters, is evident in the generations of passers-by or settlers for over 4 decades, complicating Sudan's humanitarian landscape that becomes even more so with its current situation. Faced with a significant gender imbalance among new arrivals, predominantly women, and an over 75% funding gap, unconventional approaches become particularly imperative. As such, the purpose of this study was to suggest a framework-designing approach for screening according to the specific circumstances and needs of refugees in Sudan. Following the outcome of the needs assessment, a case definition-based, WhatsApp-aided
teledmedicine screening tool was recommended to address the clinical, technical, and feasibility needs, respectively.

**Material and methods**

**Study Design:**

This mixed methods pilot study employed epidemiological data from COR records to establish evidence-based case definitions in line with the best available evidence. The telemedicine screening framework inspired by User-Centered Design (UCD), also known as participatory design (PD), ensured comprehensive investigation.

![Map of Sudan showing refugee and IDP distribution](image)

*Fig.1: Numbers (in hundreds of thousands) and distribution map of refugees and IDP across Sudan (data are courtesy of UNHCR*).  

**Study settings and population**

Preceding the present crisis, Sudan occupies a unique role as both the origin and transit hub for refugees from East and Central Africa. Persistent regional disputes have forced large communities to seek refuge in Sudan, both within and outside designated camps, with Khartoum serving as the predominant urban center. Syrians, Ethiopians, and Eritreans constitute the majority of nationalities.

Prominent among the refugee settlements is Shagarab, a longstanding complex of three interconnected camps located approximately 70 km southeast of New Halfa and 105 km northeast of Qadarif, the capital city of Qadarif state. Administered by the Commissioner for Refugees (COR), these camps receive support from the United Nations High Commissioner for Refugees (UNHCR) and Sudan’s Humanitarian Aid Commission (HAC). Alalgaia camp, another notable example, has become a haven for South Sudanese newcomers displaced by the 2013 civil war.

The eligibility criteria for our study were: UNHCR registration, official refugee status in Sudan, COR registration with a valid permit card, engagement with COR’s Consultancy Services Administration for medical services, willingness to participate in the study with signed informed consent, age between 18 and 75 years, and a histopathological-confirmed diagnosis of one of the six cancer types (breast, ovarian, uterine, cervical, vaginal, and vulvar) as evident by COR records and histopathology results.
Data collection:
In pursuit of robust and credible data, proficient local research assistants, adept in refugee camp dynamics, were selectively chosen, prioritizing linguistic familiarity with the refugees’ native languages. Meticulously trained, these assistants underwent a two-phase training regimen. Phase one encompassed mastery of study design, data tools, sampling techniques, interview skills, and research ethics. The subsequent phase involved the practical application of these skills in the real world.

To ascertain the prevalence of cancer cases among refugees in Sudan, investigators meticulously scrutinized records from COR’s Consultancy Services Administration, the entity overseeing medical care provision to all refugees. Rigorous evaluation against standard case definitions was conducted to ensure accuracy.

The telemedicine screening system’s conceptualization adhered to UCD’s 4 steps. First, face-to-face interviews with key stakeholders ensured a robust analysis phase. Second, designing followed Modelling Agents based on the Institutional Analysis (MAIA) model to identify our system’s functions and components. Third, for seamless implementation, Business Process Modeling and Notation (BPMN) was adopted, detailing functional design, testing, and debugging. Fourth, model evaluation employed a modified Martínez-Alcalá Likert system, executed by six independent assessors.

Statistical analysis:
The statistical analyses were performed using the STATA/IC 15 (StataCorp LLC., Texas, US). Categorical variables were reported in numbers and percentages (N, %). Epidemiological variables were expressed per 100,000 population.

Ethical considerations:
Ethical clearance number 6-1-19 was obtained from the National Research Ethics Committee (NREC), Federal Ministry of Health, Sudan. Approvals of The Commissioner for Refugees (COR) office and its Consultancy Services Administration were also secured (number CCR/44/A/1). Subjects involved have also signed informed consent once recruited.

Results
Epidemiological and demographic features:
Breast cancer prevalence varied among Eritrean, Ethiopian, and Syrian refugees was 9.57, 58.79, and 16.45 per 100,000 populations, respectively. Gynecological malignancies included ovarian, uterine, and cervical cancers; no vaginal or vulvar cases were identified. The first two, ovarian and uterine cancers, were reported among Eritreans exclusively (3.19 per 100,000).
The sole case of cervical tumor occurred in an Ethiopian woman (29.39 per 100,000).

**Standard case definitions and clinical presentations:**

We aimed to identify studies with sound symptomatology and presentation analysis. That means the list of symptoms should be comprehensive to minimize spectrum bias, and at the same time, all reference standards should be unified to adjust for verification bias.

Case definitions that we created for the sake of this study were as follows:

**First: Case definition for breast cancer:**

(A) **Clinical description:**

A malignant outgrowth of breast tissue in any of its five areas (four quadrants plus retro-areolar), that is characterized by the presence of 1 major OR 2 minor criteria:

- Major criteria:
  - Palpable breast lump on clinical examination.

- Minor criteria:
  - Breast changes (e.g. pain, size or shape changes, swelling, etc.).
  - Nipple discharge (e.g. discharge, retraction, inversion, etc.).
  - Skin changes (discoloration, tethering, peau d’orange, fungating wounds, etc.).
  - Regional lymphadenopathy.
  - Signs of metastasis to chest, abdomen, back, pelvis or head and neck.
  - General: Malaise, weight loss, etc.

(B) **Laboratory criteria for diagnosis:**

Histopathology showing signs of malignant transformation (Grade I-III).

(C) **Case classification: Suspected:**

Any case compatible with the clinical description.

- Probable: Supportive cytological or radiological (including mammography or USS screening) findings.
- Confirmed: Positive histopathology signs of a Tru-cut or excisional biopsy.

**Second: Case definition for ovarian cancer:**

(A) **Clinical description:**

A malignant neoplasm originating from a single or both ovaries and surrounding tissues. A minimum of 1 major OR both of the minor criteria are needed for the diagnosis:

- Major criteria:
  - Goff et al. suggested that any woman experiencing at least one of the following symptoms >12 times per month for <1 year should be suspected based on the Goff Symptom Index (GSI).
  - Abdominal pain.
  - Pelvic pain.
  - Increased abdominal size.
  - Bloating.
  - Feeling full.
  - Difficulty eating.
Minor criteria:
Shetty et al.19 have found out the following two symptoms take sensitivity up from 71.6% to 77% without compromising specificity (88.5%).
- Loss of appetite.
- Weight loss.

(B) Laboratory criteria for diagnosis:
Histopathology showing signs of malignant transformation and histopathological subtyping.

(C) Case classification: Suspected:
Any case consistent with the clinical description.
Probable: Suggestive radiological findings.
Confirmed: Positive histopathology findings of an excisional biopsy.

Third: Case definition for uterine cancer:
(A) Clinical description:
It is a malignant tumor of the uterine endometrium or body. The presence of the single major OR a minimum of 2 minor criteria is needed:
- Abnormal vaginal bleeding (this is the primary presentation in 80% of women with endometrial cancer, which accounts for 95% of all types of uterine cancer combined20. It is usually post-menopausal, intermenstrual, or menorrhagia21).

Minor criteria:22,23
- Abnormal vaginal discharge.
- Pelvic pain or pressure.
- Pressure symptoms (troubled urination).
- Painful intercourse.

(A) Laboratory criteria for diagnosis:
Histopathology showing malignant changes in a transvaginal ultrasound-assisted endometrial biopsy. Hysteroscopy and hysterectomy are options when endometrial biopsy is not feasible.

(B) Case classification:
Suspected: Any case consistent with the clinical description.
Probable: Suggestive radiological findings.
Confirmed: Positive histopathology findings of an excisional biopsy.

Fourth: Case definition for cervical cancer:
(A) Clinical description:
Dysplasia of the epithelial lining of the cervix. The widely adopted screening modalities have made it easier to detect the disease well before recognizing any symptom24. However, many studies have reported the following triad on presentation25,26:
- Abnormal vaginal bleeding (postictal, inter-menstrual, or post-menopausal).
- Unusual vaginal discharge.
- Lower abdominal AND/OR back pain.
(B) **Laboratory criteria for diagnosis:**

Histopathology showing signs of dysplasia in a colposcopy-assisted biopsy (punch, endocervical curettage, loop electrosurgical excision procedure (LEEP), or cold knife cone biopsy (CKC)).

(C) **Case classification:**

Suspected: Any case with predisposing factors that is consistent with the clinical description.

Probable: Abnormal Papanicolaou (Pap) Smear findings as demonstrated by The Bethesda System (TBS).

Confirmed: Positive histopathology findings of a colposcopy-assisted biopsy.

**Fifth: Case definition for vaginal cancer:**

(A) **Clinical description:**

It is a malignant tumor of the female vagina. It takes time to have a distinctive clinical picture but in general, it is close to that of cervical cancer. Both tumors share a common viral etiology for most cases of vaginal cancer. A minimum of 1 major OR 2 minor criteria are needed:

**Major criteria:**
- Lump in the vagina.

**Minor criteria:**
- Abnormal vaginal bleeding (post-menopausal, inter-menstrual, menorrhagia, coital, or postictal).
- Unusual vaginal discharge.
- Persistent vaginal soreness, pruritus or itchiness.
- Pelvic or back pain.
- Burning micturition.
- Blood in urine ± stool.
- Increase urine frequency or urgency.
- Constipation.

(B) **Laboratory criteria for diagnosis:**

Histopathology showing signs of malignant transformation.

(C) **Case classification:**

Suspected: Experiencing any of the symptoms above in a case with multiple risk factors.

Probable: Any case consistent with the clinical description of an elderly woman in general.

Confirmed: Positive histopathology findings of a colposcopy-assisted vaginal biopsy.

**Sixth: Case definition for vulvar cancer:**

(A) **Clinical description:**

It is the cancer of vulvar skin. Out of the exhaustive list of symptoms published by Cancer Research UK29,30, we will consider the presence of masses or ulcers as major criteria, because both are associated with cancer among women with vulvar conditions (12.8% vs 1.3%)31.

For the provisional diagnosis to be made, a minimum of 1 major OR 2 minor criteria are required.

**Major criteria:**
(B) Laboratory criteria for diagnosis:

Histopathology showing signs of malignant transformation in a vulvoscopy or colposcopy-assisted vulvar biopsy. The two common modalities are excisional or punch biopsy, when the lesion is sizable, using the 4-6mm Keyes or cervical punch forceps.

(C) Case classification:

Suspected: Experiencing any of the symptoms above in a case with multiple risk factors.

Probable: Any case consistent with the clinical description of an elderly woman in general.

Confirmed: Positive histopathology findings of a vulvoscopy or colposcopy-assisted vulvar biopsy.

Telemedicine screening protocol:

To develop this telemedicine protocol, investigators have used the UCD/PD, which considers users’ characteristics and options when crafting the solution. UCD/PD has 4 steps: analysis, design, implementation, and evaluation.

1) Analysis:

We identified three different types of beneficiaries. Below is the result of the needs assessment:

Table I: An overview of the needs assessment of our end users’ categories

<table>
<thead>
<tr>
<th>Users</th>
<th>Needs/problems</th>
<th>Solutions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 COR’s Consultancy Services Administration</td>
<td>An efficient and cost-effective cancer screening tool for refugees living in the camp.</td>
<td>An affordable telemedicine application that exchanges data through free or open-source platforms that take into account the limited data transfer capacity.</td>
</tr>
<tr>
<td>2 Healthcare services providers/Alrhma Healthcare Center</td>
<td>A simple tool to classify patients in an absence of specialized services.</td>
<td>Create case definitions.</td>
</tr>
<tr>
<td>3 Refugees</td>
<td>Proper diagnosis and treatment of their conditions. Privacy and security of their clinical data.</td>
<td>Use encrypted platforms like WhatsApp. Use coded identifiers as the refugee ID number that is only known to both receiver-sender ends, instead of direct names.</td>
</tr>
</tbody>
</table>
2) Design:

To navigate these problems and needs, investigators used Modelling Agents based on Institutional Analysis (MAIA), which is a simulation approach to study the relation meta-model to identify both components and tasks of all elements involved in our telemedicine system.

MAIA model is a computer simulation method that studies interactions between various parts of a process (persons, parts, etc.), which in our case is a simplified design of refugees’ referral process. On the left, a demonstration of the relationship between the two organizations involved (COR’s Consultancy Services Administration that is in charge of the whole process and Camp’s Healthcare Center as the field’s clinical and operational arm). 4 subject personas are involved in healthcare process (patients, Healthcare providers, CSA staff, specialists/oncologists) who interact with one or more of the 4 mediums/roles (attending HC facility, images/photos, clini-
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3) Implementation:

This phase is all about functional design, testing, and debugging. We chose Business Process Modelling and Notation (BPMN) to demonstrate the end-to-end workflow of our telemedicine system. Fig. 3 below demonstrates the refined version of our model as a BPMN after all amendments were completed.

Upper Camp’s healthcare provider kicks off the process by inquiring about the database’s basic data. If not available, the practitioner has to first add the necessary data, otherwise, he or she can proceed directly to add the consultation information before contacting COR’s CSA, where another process starts (below).

Lower COR’s CSA receives the consultation data and reviews it, COR’s CSA staff and consultants can always ask for more if the information is not enough before making the clinical recommendations and decisions. The final recommendations are
sent back to the camp’s healthcare center.

4) **Evaluation:**

During this phase, we mainly focused on building a framework that is consistent with the primary designs, and at the same time, it should reflect users’ feedback and reviews.

In total, we had six participants who evaluated the model. They were in total agreement with all of the five parameters except for the functionality element (average score=6.83 out of 7). Only one respondent scored it at 6, questioning the feasibility and security of transferring ultrasound scans (USS) through the WhatsApp application.

**Discussion**

*Epidemiological and demographic features:*

Cancer, like other non-communicable diseases, is often overlooked among refugee populations\(^34\). The need to screen breast and gynecological malignancies stemmed from their predominance among refugees\(^35\).\(^{38,39}\), including our cohort, which implies a favorable outcome. Our screening program serves as a strategic model for resource allocation towards screening rather than exorbitant management.

Gynecological cancers, predominantly cervix uteri, stand as the second most prevalent tumors among refugees. Remarkably, East Africa deviates from global trends, with cervix uteri surpassing breast cancer as the primary female malignancy\(^40\). Despite this, African and Arab refugee women demonstrated lower screening service utilization compared to their Bhutanese and Myanmarese counterparts in the US\(^41\). The same pattern was observed in Norway when screening rates of immigrants and nationals were considered\(^42\). To resolve this issue, Møen et al.\(^43\) suggested that encouraging physicians to recommend voluntary screening to their patients can impact utilization rates considerably.

*Standard case definitions and clinical presentations:*

Role of telemedicine can be fully realized in unstable regions ravaged by war, terrorism, violence, and natural disaster\(^44\). Instability creates the perfect conditions for refugee crises, and telemedicine can be a powerful humanitarian tool in such settings\(^35,46\). Telemedicine in Africa is often described as being in the infancy stage\(^47\).
In LMIC it is hard to build a comprehensive telemedicine program that includes screening, treatment, and prevention altogether. For the sake of this study, the investigators identified early detection and follow-up consultations as the two areas in need of improvement as stated by officials in charge of refugee health in the country.

To screen remote refugee populations, workable case definitions should be established in the first place so as to objectively stratify individual risks. No single case definition can encompass all needs of researchers and clinicians. In the same time, there are no rules on how to pick the most appropriate case definition out of the available many, which makes the whole process not so straightforward. Katz et al. tried to come up with a potential solution that is based on an expert clinician’s opinion in ambiguous cases. For this study, our experts have put together the case definitions discussed earlier.

**Telemedicine screening protocol:**

In telemedicine model design, UCD/PD is the go-to option as it caters to (a) the context, (b) stakeholder needs, and (c) the outcomes. Réseau en Afrique Francophone pour la Télémedecine (RAFT) recommends this triad, drawing from a decade of LMIC telemedicine project expertise.

Designing with the MAIA framework helped identify the right participants for the telemedicine screening, revealing dynamics and relationship interactions within social construct. It was crucial to investigate the reactions of our disadvantaged population coming from such a conservative background. Beyond assessing feasibility, our team was concerned with practical aspects such as privacy issues and reactions to sensitive clinical questions.

The evaluation was done with the adopted Martinez-Alcalá’s method that utilizes a 1 to 7 Likert scale, with the latter representing total agreement, to gauge respondents’ agreement with parameters like navigation, learnability, satisfaction, operability, and functionality. Results, comparable to Martinez-Alcalá et al., highlighted functionality as a major concern in our study.

In the absence of a dependable internet source at the camp, an evaluator initially questioned the efficacy of such a WhatsApp-centric model for enhancing his role without real-time interaction with other parties involved in evaluating suspected cases. However, his skepticism waned after three compelling points were presented:

- Firstly, consensus acknowledged suboptimal protocols for clinical information exchange, deemed the best given the absence of alternatives. The research team...
emphasizes improved decision-making for camp doctors, with subject matter experts and specialists providing case-specific recommendations, enhancing overall patient care.

- Secondly, this telemedicine solution exhibits promise in positively impacting lives and pains of refugees. It holds the potential to spare them on average 2-days travel time of arduous, risky journeys spanning hundreds of kilometers.

- Thirdly, as noted earlier, reducing referral trips significantly cuts costs. This efficiency extends to managing COR’s budgets allocated for logistics, boarding, and lodging. Additional unforeseen benefits emerged later, reminiscent of the telehealth boom during the COVID-19 pandemic. These systems, transcending intra-country lockdowns, fostered a secure platform uniting doctors and patients, minimizing the risk of virus transmission to our vulnerable cancer patients.

The use of WhatsApp in telemedicine sparks considerable debate. Giordano et al.\textsuperscript{58} reported “promising” outcomes in tele-education and teleconsultation, aligning with our framework. Conversely, Ashfaq et al.\textsuperscript{59} raised doubts about its efficiency, particularly in telediagnosis, especially for psychiatric assessments.

**Conclusion**

The increased global cancer incidence affects regions worldwide, including the developing world, the primary source of refugees. Establishing a tailored screening system for this population is imperative. The feasibility and acceptance of remote options, such as teleconsultations, are well-documented in the literature. In Sudan, where challenging circumstances prevail, investigators, recognizing telemedicine’s reliability, began by assessing the cancer burden. They then devised practical case definitions for at-risk individuals, culminating in the adoption of a screening framework that is both practical and feasible, addressing the unique challenges of the local context in Sudan.

Additionally, as is the case with other clinical public health studies, engaging the right stakeholders early on was imperative for the success of this research project. Our close collaboration and coordination with the government arm, COR, and COR-CSA, has eased some of the usually bureaucratic steps; field healthcare providers have provided us with the access and insights needed; and finally, the refugee community was incredibly understanding and willing to participate and open up once we gained their trust.
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Disclosure statement

The authors report there are no competing interests to declare.

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