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# Towards Mapping the Problem Space of Cervical Cancer Patients' Journeys in Sub-Saharan Africa

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## Abstract

Access to cervical cancer care remains limited in sub-Saharan Africa, where women face compounded socio-cultural, gendered, and structural barriers. This qualitative study explores the lived experiences of nine women diagnosed with cervical cancer in Ethiopia and develops an empirically grounded patient journey map as a design and process artifact based on semi-structured interviews. The journey map reveals fragmented, non-linear care pathways, showing how barriers accumulate from symptom recognition through diagnosis, treatment, and post-treatment support. By visualizing breakdowns and transitions across the care path, the artifact supports problem framing, reflection, and identification of design opportunities. These disruptions intensify emotional and practical burdens, highlighting critical gaps in health literacy, information access, and continuity of care in the healthcare structure. The journey map defines a design-relevant problem space for context-sensitive digital health interventions. This work provides evidence for HCI researchers and practitioners to address accessibility barriers in cervical cancer care in low-resource settings.

## CCS Concepts

• **Human-Centered Computing**; • **Accessibility**; • **Empirical Studies in Accessibility**;

## Keywords

Accessibility, Cervical Cancer Care, Patients' Experience, Patients' Journey Map

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## 1 Introduction And Background

Healthcare accessibility, as defined by John & Karly [1], refers to the ability to obtain and use health services when needed. Despite the preventability of cervical cancer through cancer control and management strategies [2], [3], women in sub-Saharan Africa (SSA) continue to face substantial barriers to accessing timely care for cervical cancer [4], [5]. These barriers stem from both users of healthcare services [6], [7], [8] and health system provider inefficiencies [9], [10], which collectively limit women's engagement along the cervical cancer care pathway. To systematically identify where and how these accessibility barriers arise along the care pathway, tools that make women's experiences visible are essential. One such tool is patient journey mapping (PJM) [11]. In healthcare, PJMs help visualize patients' experiences to improve communication, identify gaps in the care pathway, and support a patient-centered approach by highlighting needs, pain points, and failures in addressing gaps [12], [13]. Such mappings not only reveal breakdowns in existing healthcare systems but also point to opportunities for the (re)design of healthcare services [14], [15], [16], [17].

Despite extensive research on cervical cancer burdens in SSA, systematic application of PJM to understand women's lived experiences remains limited, particularly in Ethiopia. Technology, including digital health solutions, can play an important role in improving access to healthcare. In the field of Human-Computer Interaction (HCI), numerous studies have examined the design and application of digital health services to support accessibility across domains such as cancer care [18], [19], maternal and child health [20], [21], diabetes [22], [23], hypertension [24], and mental health [25]; however, in Ethiopia, the application of digital health services to support cervical cancer care remains largely uninvestigated [26], [27], [28], [29], [30], [31], [32], [33]. Existing digital health solutions are often informed by expert judgment rather than patient experiences, limiting their accessibility and contextual relevance.

To date, few studies have examined patients' experiences of cervical cancer care [8], [34], [35], [36], [37], and even fewer have begun to leverage PJM, revealing an evidence gap in generating

**Table 1: Characteristics of the Study Participants'**

Participants	Number (N)
Women newly admitted to the hospital	3
Women undergoing treatment at the hospital	3
Women under follow-up at the hospital	3

insights to inform the (re)design of health services addressing accessibility barriers. To address this gap, we conducted semi-structured interviews with nine Ethiopian women about their experiences with cervical cancer care and synthesized these accounts into a PJM, defining a design-relevant problem space for accessible care. Our research question is: *How do women experience access to cervical cancer care services across their journey in Ethiopia, and how can these experiences inform the design of accessible digital health services?*

## 2 Methodology

### 2.1 Study Approach: Patient's Experience Perspective

In this study, we adopt a patient experience perspective [38], focusing on the human experience of healthcare services across care pathways rather than relying solely on aggregated satisfaction metrics such as overall or average patient satisfaction scores from a post-visit survey. We situate participants' narratives as central to interpreting healthcare access barriers and health behaviors. Drawing from a Human-Centered Design (HCD) perspective [39], this approach centers the lived experiences of women as a key source of insight for improving accessibility.

### 2.2 Study Design And Participant Recruitment

We conducted in-person semi-structured interviews with women diagnosed with cervical cancer recruited at Tikur Anbessa Specialized Hospital (TASH), a tertiary cancer treatment center in Addis Ababa, Ethiopia, to gather accounts of their experiences in accessing cervical cancer care. Participants were identified through snowball sampling in the TASH oncology ward. This approach was appropriate given the sensitive nature of the condition and the difficulty of reaching women undergoing cancer treatment in this context. Recruitment continued until no substantial new insights emerged from the interviews. In total, nine participants were included in the study and were assigned to P1–P9 using random assignment (See Table 1).

The participants ranged in age from 40 to 66 years. Five of the nine participants lived in urban areas, while four lived in rural settings. Regarding health insurance coverage, financial protection was limited, and most treatment-related expenses were paid out-of-pocket, even though most had community-based health insurance. In terms of educational background, most had low formal education. Additionally, eight of the nine participants were housewives, a circumstance that may have contributed to financial challenges and potentially influenced their understanding of the disease and treatment process.

### 2.3 Data Collection And Analysis

Interviews were conducted using an interview guide co-developed by all authors and refined by experts with medical backgrounds in gynae-oncology. The interview guide explored participants' experiences across different stages of cervical cancer care, from pre-diagnosis through diagnosis and treatment to post-treatment, and was informed by previous literature to ensure alignment with the cervical cancer care pathway. Each interview set contained participants representing different stages of cancer diagnosis and treatment and diverse residential backgrounds. Interviews lasted between 25 and 45 minutes and were conducted in-person. Interviews were first audio-recorded in Amharic<sup>1</sup>. Then followed transcribing into Amharic and, later, translating into English using translation tools compliant with the General Data Protection Regulation (GDPR), the European Union's data protection framework. Translations were then manually reviewed and corrected.

Data were analyzed using reflexive thematic analysis [40], chosen for its suitability in exploring participants' experiences and meanings through an interpretive, flexible process. Analysis began with repeated, familiarization-based review of the data, followed by inductive coding without a predefined codebook. Codes were iteratively reviewed and refined, resulting in four broad analytic themes that capture patterned meaning across the dataset. These themes were continuously revisited and refined throughout the analytic process.

### 2.4 Ethical Considerations

This study was conducted in accordance with ethical review and approval by the Human Research Ethics Committee (HREC) at Delft University of Technology (application number 5489) in the Netherlands and Addis Ababa University, College of Health Sciences Institutional Review Board (AAU-CHS-IRB; protocol number 056/25/Onco) in Ethiopia. Written informed consent was obtained from all participants prior to the interviews, and participants were informed that participation was voluntary.

### 2.5 Positionality Statement

This study draws on interviews with women diagnosed with cervical cancer, interpreted by a multidisciplinary research team with expertise in HCI, inclusive healthcare design, and artificial intelligence. As such, the analysis reflects a socio-structural and experiential perspective that may differ from biomedical interpretations of care pathways and disease processes. The corresponding author has prior research experience in Ethiopia and is familiar with the local context, which may have influenced aspects of data collection and interpretation. Although none of the authors has lived

<sup>1</sup>The national and working language of Ethiopia

experience with cervical cancer or its diagnosis, two authors have experience conducting research in healthcare settings. The team engaged in ongoing reflexive practices throughout data collection and analysis to critically examine how these positionalities and disciplinary backgrounds informed interpretations and to foreground participants' accounts and meanings in the findings.

### 3 Results And Discussion

Our analysis identified four themes characterizing women's experiences in accessing cervical cancer care services in Ethiopia: themes highlight experienced barriers related to health literacy, socio-economic disruption, gendered burdens, and structural inequalities in the healthcare system.

#### 3.1 Low Health Literacy

Participants demonstrated limited health literacy regarding cervical cancer, including limited understanding of the disease, its prevention, and available treatment options, with gaps in knowledge and beliefs that shaped care-seeking behavior.

**Limited awareness and knowledge of cervical cancer:** Participants primarily reported insufficient knowledge of early signs and symptoms of cervical cancer, as well as limited awareness of preventive measures and treatment services. Many were unaware of early symptoms, prevention strategies, and treatment options, often interpreting persistent vaginal bleeding as irregular menstruation, which delayed care-seeking: *"I was bleeding for more than nine months... I thought I started menstruation at the age of 60. [P3]"* and *"...it seemed like irregular menstruation. [P6]"* An analysis of three participants' shared perception indicated that fatalistic beliefs about cancer shaped their perceptions, with some viewing the disease as inevitably deadly: *"I assumed it is a completely deadly disease that can't be cured. [P3, P5, P9]"* These responses suggest that participants' interpretations of early symptoms were shaped by gaps in public health education and cultural norms around discussing reproductive health. From a reflexive standpoint, this highlights how societal taboos, limited delivery, and access to accurate health information may delay recognition of cervical cancer symptoms and engagement with healthcare services.

Furthermore, participants' limited knowledge extended beyond the disease itself to the treatment process. For example, one participant feared that treatment would involve removal of the uterus and loss of bladder control: *"I felt embarrassed when I heard I had cervical cancer. When the doctor referred me to the treatment center, I was thinking my uterus would be removed, and I couldn't control my urine. [P5]"* This illustrates how misinformation and anxiety about invasive procedures shape perceptions of cervical cancer care and potentially delay engagement with treatment services. Women's accounts highlighted not only a lack of accurate information about cervical cancer but also the influence of cultural beliefs and stigma on their understanding of the disease. For instance, one participant associated her symptoms with personal wrongdoing: *"I think I have this disease because of my sins. [P3]"* Others noted that while public health messaging focused on other diseases, cervical cancer was unfamiliar: *"...my kids talk about HIV/AIDS and kidney failure, but cervical cancer is even new to my ears. [P4]"* highlighting healthcare system inefficiencies in cancer control and management.

Four participants linked these consequences to structural shortcomings in the health system, which they believed a lack of public health education and awareness contributed to delayed diagnosis, as reflected in their shared perception: *"I live in the city and am educated, but I had very little knowledge... If I had known earlier, I would have been diagnosed sooner and avoided this much damage and cost. [P6-P9]"* This suggests that earlier awareness could have enabled diagnosis and treatment at local health centers, reducing physical, emotional, and financial strain. Three participants also shared common suggestions that health authorities provide targeted education, particularly in rural areas, to address both informational and cultural barriers to awareness: *"We don't even know if this type of disease (cervical cancer) exists....If they [healthcare providers] had told us earlier, we might have sought care sooner, before it worsened. [P1, P2, P9]"*

**Beliefs:** Many perceived a cervical cancer diagnosis as a death sentence, reflecting widespread fatalistic beliefs about cancer: *"I only heard cancer kills immediately. I thought I was going to die right away. I woke up early and was so excited to find myself alive. [P1]"* Others interpreted symptoms through the lens of spiritual beliefs, seeing illness as a result of an evil spirit: *"I felt an evil spirit possessed me. Why am I bleeding at this age? [P3]"* Additionally, one participant expressed complete denial of biomedical treatment and preferred religious healing rituals due to negative attitude development against modern medical treatments, stating: *"It might be better to go to church and take a holy bath. What can medicine do for me? [P4]"*

#### 3.2 Socio-Economic Disruptions

Participants described significant socio-economic disruptions resulting from cervical cancer, reflecting how illness can compromise daily productivity and financial independence.

**Economic Disruption:** Participants highlighted disruption to economic activities, as the illness affected their daily productive routines, thereby reducing their capacity to produce what they were used to. Three participants conveyed a shared perception of severe financial strain, noting dependence on family or social support groups for basic subsistence and treatment-related costs: *"...we are now with an empty pocket. We spent all our savings and sold what we left. This place prevented us from quitting the treatment and getting back home. [P1-P3]"* From a reflexive perspective, these illustrate how late-stage diagnosis amplifies economic vulnerability, highlighting the interplay between health literacy, access to care, and financial resilience. Notably, these financial pressures were exacerbated by the centralization of services in major cities, which required women to incur additional indirect costs, such as transportation and accommodation.

**Disruption of Social Relations:** It was also evident that the participant experienced isolation due to long-distance travel for treatment, fear of judgment based on physical changes, and disease recurrence post-therapy: *"I traveled for more than a hundred kilometers for this treatment, and I felt very lonely in that locked room hotel. [P2]"* Similarly, another participant described profound social isolation and uncertainty about survival, explaining: *"...I don't want to socialize at all...I think people see me and know I have cancer. I don't fully believe I will survive anymore; every morning is a surprise for*

me. [P9]” These experiences reflect that socio-economic burdens are deeply compounded with structural and health system barriers, as well as the emotional impacts of prolonged illness.

### 3.3 Gendered Burdens

Gendered roles further constrained women’s ability to seek timely care. These roles positioned women as primary caregivers and as responsible for household tasks. Participants often prioritized family responsibilities over their own health: *“Two or three years ago, I was screened for cervical cancer... I didn’t go [for diagnosis] because I have to take care of my sick son. [P6]”* These accounts reveal how societal expectations of women’s caregiving can delay engagement with healthcare, reinforcing gendered health inequities in access to timely treatment. On the other hand, long-distance travel to urban treatment centers, caregiving responsibilities, and financial burdens uniquely constrain women’s engagement with care. In some regions, armed conflicts further restricted women’s safe travel to healthcare facilities due to fear of forced rape and abduction, deepening disengagement from care and creating bottlenecks not observed in higher-resource settings, underscoring the lack of accessible healthcare services.

### 3.4 Healthcare Structure Inequalities

Structural inequalities shaped participants’ access to cervical cancer information and care services. A participant from a rural setting reported limited exposure to health education and diagnostic services: *“I haven’t heard of cervical cancer before I was diagnosed...my sister died of this disease without knowing it. [P2]”* In contrast, urban participants had greater opportunities for screening: *“Yes, I sometimes heard of cervical cancer from health workers, television, and radio advertisements. I also screened before being diagnosed with cervical cancer four or five years ago. [P9]”* Three of the participants also indicated distance to healthcare services and unavailability of diagnosis and treatment services nearby to their residential location as a barrier for not seeking treatment after they were diagnosed with cervical cancer: *We were living very far from Addis Ababa [around 400 kilometers], which made me to fly due to the current armed conflicts in the area. I had to wait until I had enough money for transportation and accommodation during my treatment in Addis Ababa. [P1-P3]”* These highlight how geographic disparities, concentration of treatment centers in urban areas, and inequitable distribution of health resources contribute to delayed diagnosis and reinforce negative perceptions about the disease. These structural barriers intersect with socio-economic and gendered challenges, underscoring the complex context in which women navigate cervical cancer care in Ethiopia. As a result, gaps within the healthcare system significantly hinder individuals’ ability to seek early diagnosis and appropriate treatment.

### 3.5 The Patient’s Journey Map

The PJM synthesizes individual narratives into a collective care trajectory, illustrating how informational, structural, and emotional barriers accumulate across the cervical cancer care path (See Figure 1). By mapping the experience of interactions into the healthcare system, decision points, and disruptions in care continuity, the

PJM highlights critical transitional moments that shape women’s experiences across phases.

The pre-diagnosis phase of the patient journey reflected how limited health literacy and misinterpretation of symptoms contributed to delays in care-seeking. These gaps in awareness and knowledge were evident as women described uncertainty about the meaning of persistent vaginal bleeding, what to do about it, where to go, and whom to consult. They often attributed symptoms to normal aging, irregular menstruation, or spiritual causes, reflecting belief-driven interpretations of illness. This uncertainty prolonged decision-making and encouraged initial reliance on self-management or alternative healing practices before accessing formal healthcare services. As a result, the diagnosis occurred at a later stage, when symptoms became severe.

During the diagnosis and treatment phase, women experienced significant emotional distress characterized by anxiety, confusion, fear, and hope for recovery. These emotional burdens were intensified among women who traveled from rural areas for care, as separation from family and social support increased feelings of loneliness. In addition to psychological strain, healthcare structure barriers such as long travel distances, centralized treatment services, and financial hardship compounded difficulties in accessing and navigating care. The convergence of economic constraints and healthcare structure barriers created cumulative obstacles during this critical stage of treatment initiation and continuation.

In the post-treatment phase, women continued to experience emotional instability characterized by persistent uncertainty about the future, fear of disease recurrence, altered self-perception, and feelings of hopelessness. These emotional challenges were intensified by limited psychosocial support systems and inadequate follow-up counseling. For many women, recovery extended beyond physical healing to negotiating changes in identity, body image, and social roles. The absence of structured psychological support within the healthcare system further complicated adjustment during survivorship.

The red-lined emotional curves depicted in the PJM illustrate the fluctuating, often unstable nature of women’s emotional experiences across the phases of care mentioned. Rather than progressing in a smooth and straightforward manner, emotional reactions often manifested in fear, anxiety, and frustration in response to informational gaps, healthcare structure constraints, and critical decision points.

Together, these findings indicate that both systemic and socio-cultural barriers influence accessibility. Limited public health education, limited awareness and knowledge of cervical cancer, and communication constraints within the healthcare system are compounded by taboos and cultural perceptions surrounding reproductive and sexual health. Spiritual interpretations and prevailing social norms further shape women’s emotional responses and health-seeking behaviors. This underscores the importance of examining the patient experience as a continuous, dynamic journey rather than isolated stages of care. For the HCI and digital health communities, these insights underscore the need for culturally sensitive and human-centered interventions. Such interventions could integrate educational initiatives, myth correction, and trusted community channels to support women throughout the cervical cancer care journey. Interventions should also focus on critical transitional

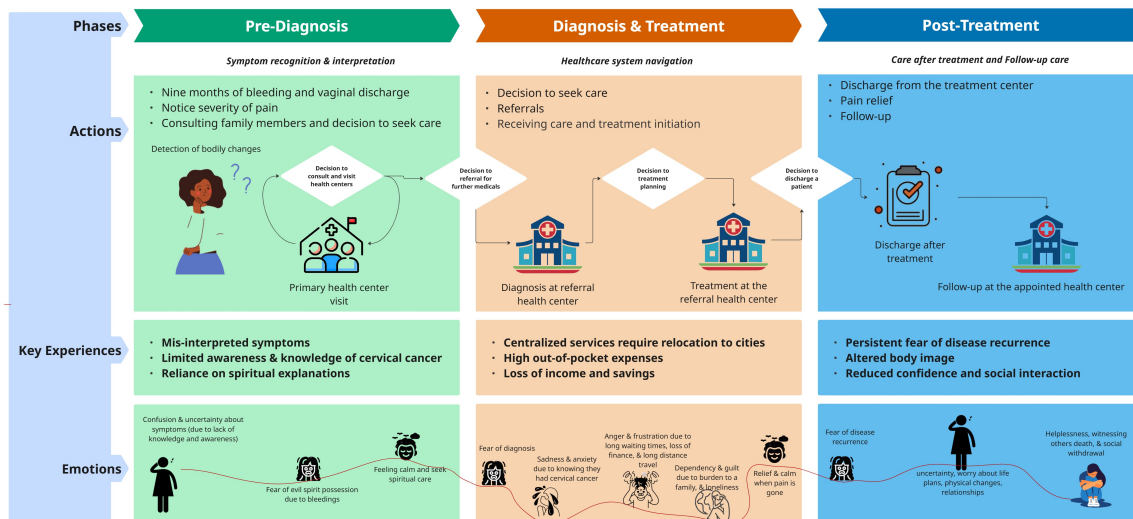


Figure 1: The Cervical Cancer Patients' Journey Map in Ethiopia

points identified in the PJM, including health literacy, awareness, and knowledge before, during, and after diagnosis; and on the continuity of psychosocial support. Future research could build on these findings by including women from other cancer treatment centers, caregivers, and social support groups to provide multi-stakeholder insights into accessibility barriers.

#### 4 Conclusion And Future Work

By foregrounding women's lived experiences and mapping their care journeys, this study provides insight into how cumulative sociocultural, gendered, and structural barriers shape engagement with and access to cervical cancer services across the care pathway. We position the PJM as a design and process artifact that operates as both an analytic synthesis of patient experiences and a boundary object for facilitating generative design discussions among stakeholders. In contrast to prior journey maps that primarily document experiences, our PJM integrates intervention points and design implications directly into the representation, thereby extending its role beyond documentation toward actionable design inquiry. Informed by our findings, future HCI research can investigate digital health interventions to address the aforementioned barriers throughout the care pathway. First, culturally and linguistically tailored digital public health literacy tools could support earlier symptom recognition and counter stigma and misinformation, particularly in low-resource and rural settings. Second, digital monitoring and tracking tools may help women report symptoms, treatment side effects, and support needs remotely, reducing socioeconomic, gendered, and mobility-related burdens. Finally, telehealth and remote consultation services may help mitigate geographic and systemic inequalities by reducing travel, costs, and time away from paid and unpaid labor, while supporting continuity of care and post-treatment psychosocial support. In this study, rather than proposing standalone digital health applications, future work

could explore low-bandwidth approaches that could accommodate intermittent connectivity and varying literacy levels.

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