

# An Intersectional Analysis of Quantitative Patient-Centered Care Metrics and Qualitative Themes in the Healthcare Decision-Making Practices Among Fistula Surgery Candidates in Kenya

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## Abstract

Genitourinary fistula is a stigmatizing injury primarily affecting women with poor access to high quality emergency obstetric care. Western Kenya is a region which continues to observe fistula incidences among women, particularly in remote areas, who undergo labor outside of and far from emergency obstetric care facilities. Existing research on genitourinary fistulas have outlined several sociocultural, socioeconomic, and infrastructural factors which have both facilitated fistula development and served as barriers to accessing care for surgical fistula repair. While fistulas are observed in various global communities, the purpose of this study is to qualitatively interview fistula patients living in Western Kenya to better understand how patient mobilization can be modified to improve access to quality fistula treatment in the region. We seek to delineate the various socioeconomic, sociocultural, and infrastructural barriers that impact a women's access to reconstructive fistula surgery through in-depth interview among approximately 30 women who will undergo reconstructive fistula surgery at the Gynocare Fistula Centre in Eldoret, Kenya. Study participants will be asked to describe patient decision-making processes and eventual care access, including the role of various facilitators and barriers at each step, attitudes and experiences with healthcare before and after developing fistula, and patient recommendations for overcoming the identified barriers to improve access to fistula care. The results of this study will contribute to the evidence base on the challenges patients face in accessing fistula care in Western Kenya. We hope to offer insightful findings to local and international programs, such as the Fistula Foundation, to assist in the work currently underway that aims to improve access to fistula care for Kenyan women. Furthermore, the project hopes to contribute to the narratives of a urogynecological issue underrepresented in scientific research.

## Introduction

Since the early 2000s, access to surgery has tripled; however, many women still face challenges obtaining the care they need. In spite of growing improvements in maternal health, emergency obstetric care remains the least equitably distributed in many low and middle income countries worldwide.

Eliminating obstetric fistulas will require a dual focus on increasing the quality of maternity care in conjunction with the sociocultural norms of early marriage, early childbirth, and low literacy rates which contribute to disparities in access to quality care and greater complications at childbirth, thus resulting in higher incidence of obstetric fistulas. Additionally, there remain incidences of sexual violence contributing to traumatic fistulas whose causes are also rooted into sociocultural dynamics.

Beyond the complexities of sociocultural circumstances which play a role in enabling traumatic and obstetric vaginal fistulas, there are a multitude of layers which serve as barriers to care. At the individual level, barriers include lack of awareness of vaginal fistulas and treatment options. There may be financial costs associated with travel, treatment, and the inability to earn household income when undergoing surgery. Moreover, healthcare systems may be inadequate in terms of trained surgeons, facilities, and supplies to allow for successful fistula repair.<sup>19</sup> Finally, there is the dynamic between the individual and the healthcare facility, involving individual perspectives and subjective norms regarding healthcare utilization.

The proposed study seeks to contribute to the evidence base through a qualitative assessment of key factors influencing women's access to fistula care and examination of the role of prior healthcare experiences in fistula care-seeking. Furthermore, the qualitative interview will identify recommendations at the domestic, community, and national level from fistula survivors to improve patient mobility and access to fistula care.

**Impact.** Since the founding of Gynocare Women's and Fistula Hospital, staff have consistently reported barriers to patient mobilization due to specific sociocultural norms prevalent among communities where fistula is prevalent. The goal of this analysis is to provide data-driven insight into patient-reported challenges to accessing fistula care. The study will also seek to integrate information from participants' lived experiences with enduring and seeking treatment for fistula to outline recommendations for improving access to care.

## Methods

### STUDY SETTING

The Gynocare Women's and Fistula Hospital was established in 2009 and began providing genital fistula surgery in 2011. It has a 100-bed capacity, and 49 clinical and administrative staff members. Its mission is to provide quality and excellent clinical care for women, giving hope to vulnerable and marginalized populations through preventing and treating obstetric fistula. A referral facility for a patient population of approximately 10 million, the facility provides a broad variety of care for women's health, and it is heavily focused on meeting the local need for female genital fistula surgery in western Kenya. Gynocare offers the following services: inpatient, consultant outpatient, pharmacy and laboratory, ultrasound diagnostics, accident and emergency, maternity and postpartum care, counseling, surgery, and fistula center. Female genital fistula surgical services are provided for free to patients, with funding provided for these services from varied stakeholders including Dr. Hillary Mabeya, Fistula Foundation, Direct Relief, and ADRA Germany through Waldfriede Hospital. It is certified as a fistula surgery training center by the International Federation of Gynecology and Obstetrics (FIGO). On arrival at the hospital for treatment, women are provided with at least three free counseling sessions. One counseling session is conducted before surgery during which the counselors get to know the patients and prepare them psychologically for the procedure, one counseling session is conducted after surgery during which they begin discussing reintegration, and a final session on discharge during which they discuss reintegration plans with patient and review important self-care instructions.

### STUDY PARTICIPANTS

Our study participants were women and girls who awaited genital fistula surgery at Gynocare Women's and Fistula Hospital (n= 30 qualitative interview participants). Given this particular patient population, we expected that our study participants would be of low socioeconomic status and come from different parts of the country. We did not implement restrictions based on participant age: we expected that the majority of participants will have obstetric or childbirth-related iatrogenic fistula, and thus potential participants under the age of 18 had meet the criteria for emancipation under Kenyan law.

### RECRUITMENT AND ENROLLMENT

We recruited our cohort for study participation at Gynocare after diagnosis is confirmed. Prior to approaching potential participants, the research assistant consulted the primary care providers regarding patients' mental state to ensure that partaking in this study at the current time will not cause distress. During the time that women are waiting surgery at least one day prior to their scheduled surgery date, the program assistant invited them to participate in the study, explaining the purpose, the time investments and data to be collected. The women had the opportunity to ask questions about the study and their participation, and if they are interested in participating, they provided written/thumbprint confirmation of informed consent. We followed this informed consent process with all participants above the age of majority and all emancipated minors. Where potential participants are non-emancipated minors (e.g., if fistula is congenital), informed consent was sought from a parent or guardian and assent sought from the minor, following a similar process.

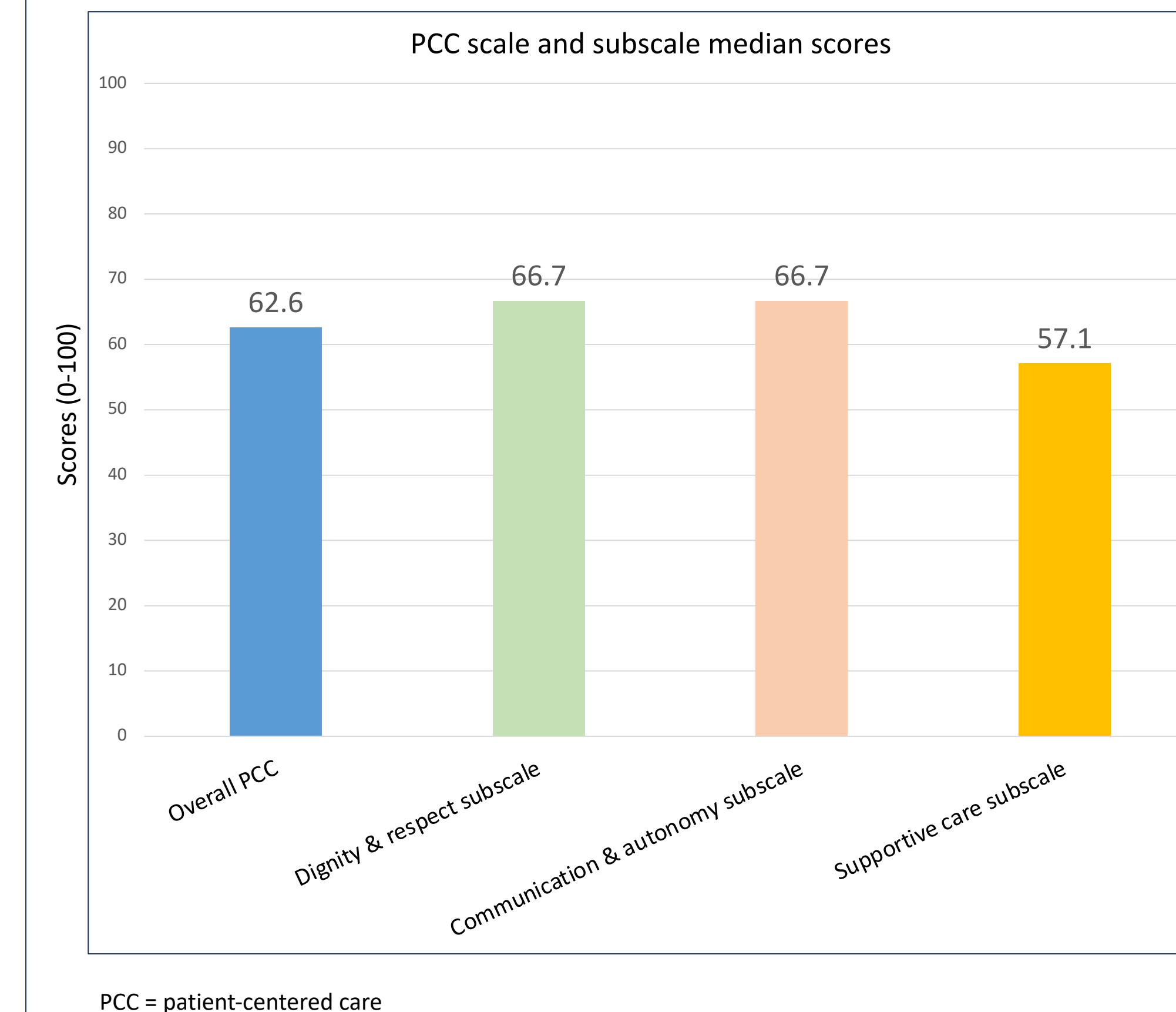
### STUDY PROCEDURES

After the informed consent process, participants were scheduled for the interview with the research team. The interviews took place in a private location at Gynocare where confidentiality can be maintained. Women were first asked to complete a brief interview on sociodemographic characteristics and prior healthcare experiences, particularly through the Patient-Centered Maternity Care questionnaire developed by Afulani et al. Subsequently, in-depth interviews were conducted within the participant's preferred language and were anticipated to take approximately one hour. Participants were asked for their permission to audio-record the interviews, and interviews were be transcribed and translated into English (as necessary) for analysis.

Table 1. Study Measures

Category	Measures	Questionnaire	Interview
Sociodemographic characteristics	Age, place of origin, household status, socioeconomic status, educational attainment, and languages spoken	X	
Decision-making factors	Identity of primary decision-maker, open-ended identification of challenges, social network		X
Perceptions of healthcare systems	Prior experience with healthcare, community perception of healthcare, personal perception of healthcare, how healthcare perception has changed since deciding to seek care at Gynocare	X	X
Recommendations for improving patient mobilization	What was done well in the home, in the community, and at the national level to support access to fistula surgery; what could be improved in the home, in the community, and at the national level to support access to fistula surgery		X

## Results



### QUALITATIVE DATA FINDINGS

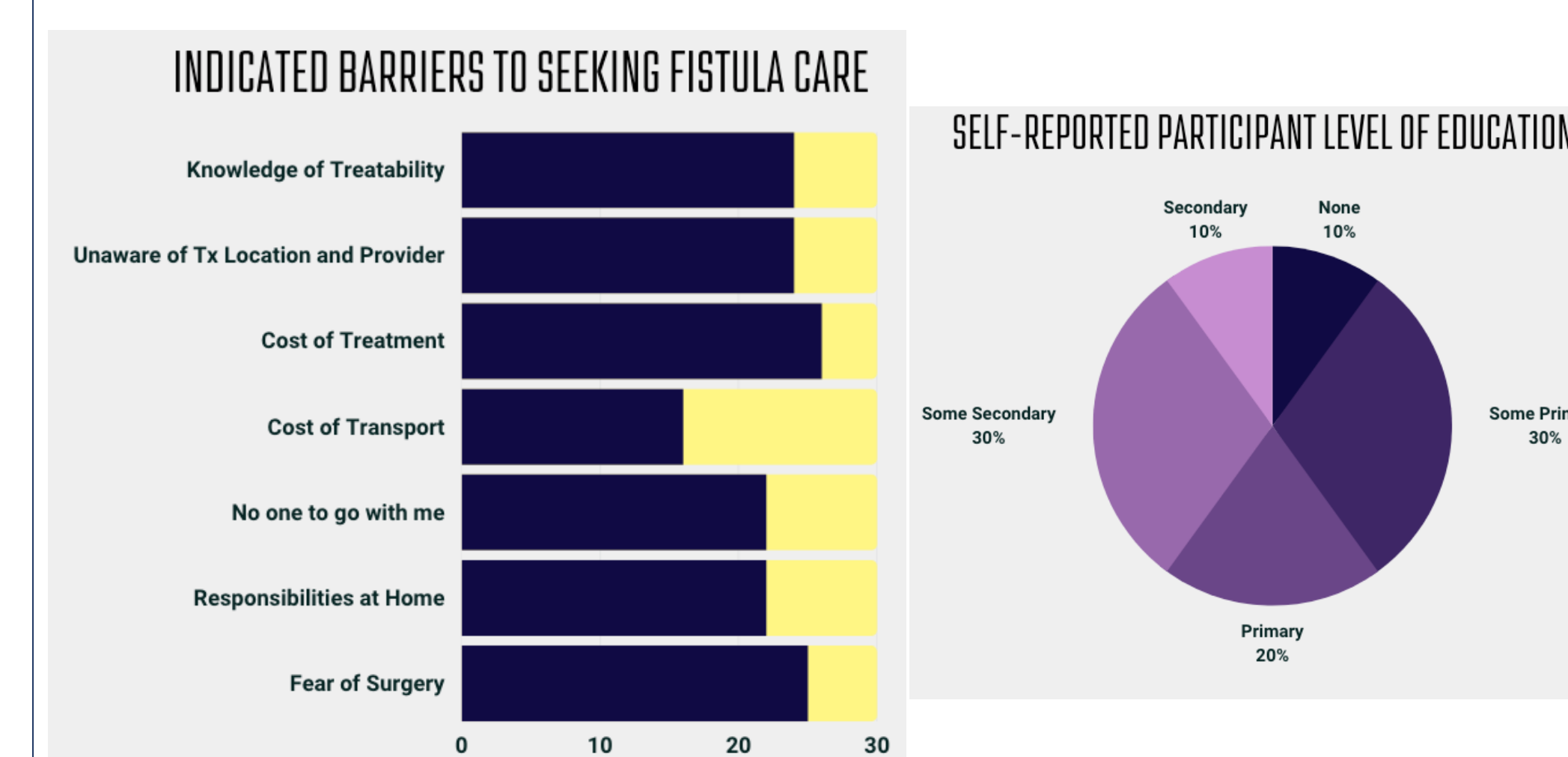
Thematic codes were organized and applied across the translated interview transcripts of the 30 study participants. Of note, the women's individual health experiences as a component of their healthcare-seeking behaviors was explored and summarized.

Individual Health Experiences appeared in participants' discussions following the types of healthcare facilities available to participants in their hometowns, to highlight their typical healthcare preferences given what is accessible. In addition, the code appeared later on in the interview during the discussions of fistula development and care-seeking. This code serves to illustrate participants' preference in utilizing hospital-based medicine over traditional medicine, or vice-versa, as a means to draw parallels to participants' healthcare-seeking behaviors regarding fistula repair.

The majority of participants expressed preference for hospitals and dispensaries over traditional medicine, such as herbal medicine and community healers. Some of the main reasons provided were the availability of medication when going to large community hospitals as well as its overall efficiency. Despite acknowledging that there are flaws to the medical system, participants generally mentioned that they "trust hospitals because they help. However, there are good doctors and not so good ones. The not so good ones are the ones that cause problems." Many participants noted that they have only previously gone to hospitals and dispensaries for medical attention. The lack of personal experience seeking traditional healers and herbalists contributed highly to participants' general preference for hospitals and dispensaries.

Related to seeking fistula care, several of the participants noted various experiences at hospitals for fistula care prior to their final referral to Gynocare. Some of the women acknowledged that the cause of their fistulas occurred in the hospital during treatments or procedures for other conditions. Many of them retained their trust in the hospital system and accepted the reality that incidents can occur, rather than placing blame on the institutions for causing the fistulas or resenting the medical team for being unable to repair the fistula that resulted. Several participants mentioned doctors who facilitated their advancement in fistula repair, by referrals and/or financial assistance for transport.

### ADDITIONAL DEMOGRAPHIC DATA



## Discussion

The PCC questionnaire is a series of 30 questions pertaining to participants' previous healthcare experiences as it relates to patient-centered care. Apart from the overall PCC score generated from the overall questionnaire responses, the survey is further divided into 3 subscales: Dignity & Respect, Communication & Autonomy, and Supportive Care. Each participant's overall PCC scores were calculated, as well as their subscale scores in each sub-category.

In this patient population seeking surgical repair for their gynecologic fistulas, 62.6% of respondents indicated that they felt their previous healthcare experience(s) were patient-centered overall. More specifically, 66.7% felt that they were treated with dignity and respect by their healthcare providers. Another 66.7% felt that they witnessed satisfactory communication regarding their care from their providers and could exercise autonomy as part of their hospital stays. A mere 57.1% of participants reported that they were provided supportive care as a patient.

The coded interviews of study participants highlighted their individual healthcare experiences and preferred modes of healthcare institutions prior to their admission at Gynocare. While a small minority mentioned blame and distrust of their former healthcare providers particularly surrounding their fistula diagnosis, the vast majority expressed continued trust in the healthcare system and persisting hope for repair.

## Future Prospects

The eventual aim of this project is to incorporate the quantitative findings from the PCC survey results that explores participants' previous healthcare experiences and how they factor into the healthcare seeking practices that have led them to Gynocare Fistula Centre—the anticipated final destination for fistula repair. While an overall summary of all participants' descriptions of individual health experiences has been summarized, this study aims to conduct a deeper analysis relating each participant's PCC responses with their individual recollections of the healthcare experience. Within our in-depth interviews, we will seek to understand participants' previous experiences with the healthcare system and how this experience may have facilitated or hindered their fistula-related care-seeking. We will also seek to understand subjective norms through querying the healthcare perspectives of influential individuals (e.g. family members, friends, community).

As the study's analysis remains ongoing, a potential direction for the project could be conducting a linear regression analysis of a possible correlation between the study respondents' PCC scores and the "time to care-seeking" variable, in which we measured the amount of time a participant decided to seek fistula care since the time of fistula onset. Additional options could be an analysis of PCC scores against other demographic features, such as level of education obtained, domestic status (married, single, widowed, etc.), and income-level (as determined by types of assets currently owned).

While a variety of quantitative studies could be generated from the current pool of data, the predominant core of this study is the qualitative interview. The qualitative interview provides the in-depth narrative of each woman's story in her care-seeking endeavor, exploring the healthcare facilities that are readily accessible in her hometown and how her autonomous healthcare decisions are made in the cultural context of the patriarchal family structure that predominates in Kenya. The exploration of these themes and the interview's direct inquiry of participants' recommendations for broadening the access to fistula care is projected to inform current structures in place to make fistula repair a simple reality for those who need it.

## Acknowledgements

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