Effects of Gender Roles on Caregiving Experiences and Support Networks of Parents with Autistic Children in Voi, Taita Taveta County

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ABSTRACT

Many African societies historically assign caregiving roles to women, a responsibility intensified when a child presents with autism spectrum disorder (ASD). This study explored how traditional gender roles, positioning men as providers and women as caregivers, influence the lives of families in Voi, Taita Taveta County. Motivated by the constant emotional, social and medical support demands of autism, the survey addresses the disproportionate burden on mothers that restricts their labour market participation and reinforces patriarchal inequities. Utilizing a qualitative phenomenological research design, the study documented the experiences of fifty-three married women and ten key informants, including healthcare professionals. Findings demonstrated that 46.3% of children frequently engage in repetitive behaviors, while 37.0% experience significant social communication challenges. Stigma remains a severe barrier, with 42.6% of parents experiencing overt labelling and 53.7% avoiding public spaces entirely. Formal support systems are profoundly inadequate; 38.9% of participants strongly disagree that government social protection is accessible. Spousal physical involvement is minimal, leaving mothers with a disproportionate physical burden. Conversely, peer WhatsApp groups and informal networks serve as critical emotional coping mechanisms. The study concludes that patriarchal divisions of labour worsen caregiver marginalization, recommending targeted gender-sensitive county policies and community sensitization.

Keywords: Autism Spectrum Disorder, Gender Roles, Unpaid Care Work, Social Stigma, Structural Inequalities, Taita Taveta County

INTRODUCTION

Background to the Study

The sociological architecture of contemporary African family units continues to be governed by deep-rooted traditional gender roles that dictate distinct behavior, performance and institutional expectations for men and women (Tamunomiegbam & Arinze 2024). Reinforced continuously by cultural systems, religious codes and socio-structural institutions, these norms firmly position men as authoritative providers, breadwinners and households heads (Gyan & Ossom 2026). Conversely, women are consistently socialized to be nurturing, compassionate, emotionally resilient, and singularly responsible for domestic management, child rearing, and household caregiving duties (Sharma et al., 2016).

While these gendered binaries are frequently normalized across cultural discourses as "natural" biological traits, they are socially constructed performance parameters. They establish a rigid structural distribution of labour that penalizes women by enforcing an unequal baseline of unpaid domestic duties (Schneiders 2020). This systemic allocation of responsibilities persists unabated even when women manage competing demands, including formal employment, entrepreneurship or personal health crises (Mussida & Patino 2020).

The introduction of a chronic developmental disability within the family structure dramatically compounds these labour inequities. Autism Spectrum Disorder (ASD) is a complex neurodevelopmental condition characterized by persistent challenges in social communication, verbal and non-verbal interactions, alongside highly restricted, repetitive patterns of behavior, interests, or activities (Hodis et al., 2025). The clinical manifestations of ASD vary significantly across a wide spectrum; some individuals can build independent lives, while others exhibit severe functional impairments that require intensive, lifelong, around-the-clock physical and behavioural support (Hodis et al., 2025).

When a child exhibits severe sensory and behavioural dependencies, the daily operational management of these needs falls almost exclusively on the nuclear family. This reality is magnified in developing nations due to a systemic scarcity of state-sponsored support, therapeutic infrastructure, and respite care options (Aldersey et al., 2020).

Globally, the multi-layered caregiving burden associated with autism is skewed by gender, with mothers carrying the vast majority of physical care, therapeutic planning, and emotional coordination (Herrero et al., 2024; Zaidi 2026). Realistically, this unequal distribution of labour directly causes chronic parental distress, clinical anxiety, physical exhaustion, and long-term exclusion from the formal economy for female caregivers (Zaidi 2026).

Mothers of children with autism report considerably higher subjective strain, lower mental health indices, and elevated instances of systemic role conflict compared to fathers in the same households. This imbalance forces mothers to continuously negotiate the friction between institutional labour demands, intensive home-based medical management, and patriarchal family expectations (Picardi et al., 2018).

In low- and middle-income countries (LMICs), the baseline vulnerabilities of female caregivers are further worsened by absent policy execution and underdeveloped institutional protection mechanisms. Sub-Saharan African contexts present unique structural challenges; cultural paradigms deeply entrench the feminization of care, making the birth of a child with a neurodevelopmental disorder a isolating female trial (Chen et al., 2025). Regional data from nations such as South Africa (Torres & Ohajunwa 2025) and Nigeria (Azubuike et al., 2025) confirm that mothers frequently must downscale formal employment or withdraw entirely from the workforce to stabilize an autistic child's environment. In stark contrast, fathers' career projection and labour choices are rarely altered by these developmental diagnoses (Torres & Ohajunwa 2025).

In these regions, patriarchal ideologies often define hands-on childcare as incompatible with the male provider status, limiting paternal involvement to fluctuating financial provisions while avoiding physical care routines.

In Kenya, families raising children with autism operate within a landscape defined by significant social stigma, high costs for therapy, and fragmented neurodevelopmental care networks. Studies conducted within urbanized zones like Nairobi County indicate that the high care demands of ASD, combined with weak community support, lead to psychological distress, physical exhaustion, and severe social isolation for mothers (Masaba et al., 2021). However, the vast majority of autism research in Kenya remains concentrated within the capital city or highly specialized research hubs along the coast, such as Kilifi. This geographic concentration leaves a critical gap in empirical literature regarding semi-urban, transit-proximate settings like Taita Taveta County.

Voi Sub-County in Taita Taveta County represents a distinct socio-cultural environment that blends urban healthcare access with deep-rooted rural traditions. As a primary regional transit hub along the Mombasa-Nairobi corridor, Voi is undergoing rapid socio-demographic changes. Yet, traditional cultural assumptions regarding gender roles and domestic expectations remain influential.

While clinical awareness of neurodevelopmental disorders is growing among local medical staff, there is scarcity of localized, empirical data documenting how gendered labour divisions shape the everyday lives, economic independence, and mental health of married women in this community. Evaluating these micro-level dynamics is crucial for developing targeted, context-appropriate interventions that support equitable parental care and improve developmental trajectories for children with autism.

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MATERIALS AND METHODS

Study Area

The study was conducted within Voi Sub-County, located in Taita Taveta County, Kenya. Voi functions as the principal commercial, logistical, and administrative centre of Taita Taveta County. It contains a diverse array of administrative wards, including Voi Central, Mbololo, Sagalla, and Kaloleni. Geographically and socially, Voi is a relevant location for this study because it combines a bustling, transit-proximate urban hub with semi-rural periphery zones where traditional cultural codes and gendered expectations remain influential.

The urbanized areas give families proximity to regional health infrastructure, such as the Voi County Referral Hospital. Meanwhile, the surrounding rural wards present the resource limits and community stigma typical of remote Kenyan environments. This mixed setting provides a useful context for analysing how autism caregiving is experienced across varying socio-economic levels and cultural conditions.

Research Design

This study utilized a qualitative, phenomenological research design. The primary purpose of phenomenology is to investigate, document, and describe the detailed "lived experiences" of individuals who share a common life situation or phenomenon (Oluka 2025). In this research, that shared situation is being a married woman caring for a child with a formal clinical diagnosis of autism.

A qualitative phenomenological framework was highly suited for this study because it prioritizes the subjective perspectives of the participants. This allows the researcher to explore emotional nuances, role negotiations, and personal challenges that standard quantitative surveys often miss. By focusing on *how* these women perceive and navigate their daily caregiving responsibilities within traditional patriarchal structures, the design provides a rich, context-specific analysis of the maternal care burden.

Target Population and Selection Criteria

The primary target population consisted of married women actively caring for an autistic child within Voi Sub-County. This group was chosen because they experience the direct intersection of traditional marital expectations and the heavy daily demands of neurodevelopmental care. To ensure full legal capacity for informed consent, all primary participants were aged 18 years and older.

Additionally, fathers were included as secondary participants to provide a comparative perspective on paternal roles and household labour division. Healthcare professionals, including; paediatricians, occupational therapists, and psychiatric nurses were engaged as key informants to provide institutional context regarding local diagnostic pipelines and systemic support gaps. To maintain clinical integrity, strict inclusion and exclusion criteria were enforced:

Inclusion Criteria

Primary caregivers (both men and women) of children with a formal clinical diagnosis of Autism Spectrum Disorder (ASD), residing within the selected wards of Voi Sub-County, with at least six months of continuous caregiving experience. Key informants had to be practicing health professionals or centers managers directly involved in ASD diagnosis, therapy, or caregiver support in the region.

Exclusion Criteria

Caregivers of children exhibiting developmental delays without an official, verified clinical diagnosis of ASD were excluded. Caregivers with less than six months of experience, those living outside Voi Sub-County, and healthcare workers without direct involvement in neurodevelopmental management were also excluded.

Sampling Technique and Sample Size

This study utilized a combination of purposive and snowball sampling techniques to recruit participants. Purposive sampling was used to identify information-rich cases by accessing official medical records from Voi County Referral Hospital and local paediatric clinics. This process identified families with verified diagnoses of ASD, ensuring the sample met the clinical criteria required for the study.

To expand the study's reach, snowball sampling was integrated. Initial participants referred the researcher to other families within their personal networks. This technique was valuable for connecting with isolated or hidden populations who may avoid formal hospital networks due to community stigma or lack of funds for therapy.

The final sample size reached data saturation with 54 primary participants and 10 key informants, yielding a total sample of 63 individuals. This sample size ensured qualitative depth and data richness within the geographic boundaries of the study.

Instruments and Data Collection Procedures

Data collection relied on multiple qualitative tools to achieve methodological triangulation:

Semi-structured In-depth Interview Guides

Semi-structured In-depth Interview Guides were used to gather detailed information regarding mothers' personal caregiving routines, financial sacrifices, emotional wellbeing, and household role negotiations.

Focus Group Discussion (FGD) Schedules

FGDs were conducted with separated groups of caregivers to explore community norms, shared encounters with public stigma, and collective coping strategies.

Key Informant Interview (KII) Guides

KII guides were designed for healthcare professionals and local administrators to evaluate institutional barriers, county resource limits, and service delivery gaps.

Structured Demographic Questionnaires

Questionnaires were used to collect basic descriptive data, such as age, education levels, and employment status.

All the data was collected through face-to-face sessions by the primary researcher and trained research assistants. Sessions were held in quiet, private spaces within local health centers or participants' homes to protect confidentiality and encourage open sharing. Every interview and FGD lasted between 45 and 60 minutes and was audio-recorded with written consent.

To ensure data integrity during recruitment, eligibility was verified by checking the child's official medical clinic card or a diagnostic report signed by a qualified specialist. This step eliminated unconfirmed cases and maintained a consistent sample. Detailed field notes were also taken to document non-verbal cues and context.

Piloting, Validity and Reliability

A pilot study was conducted in a comparable setting within Kilifi County, using a sample equal to 10% of the target size. Kilifi was selected because it shares similar coastal cultural dynamics and neurodevelopmental awareness levels with Taita Taveta, allowing for an effective pre-test. The pilot phase helped clarify ambiguous terminology in the interview guides and adapted the tools to be culturally sensitive.

Rigid qualitative validity was maintained through methodological triangulation (combining interviews, FGDs, and questionnaires) and regular peer debriefing. Standardized data collection protocols were followed throughout the study to ensure reliability.

Data Analysis

The demographic data collected from questionnaires were coded, cleaned, and entered into the Statistical Package for Social Sciences (SPSS) Version 27. This software generated basic descriptive statistics, including frequencies, means, and percentages, to profile the sample.

The qualitative audio data from interviews and FGDs were transcribed verbatim and analyzed using Atlas software for thematic analysis. The analytic process followed Braun and Clarke's six-stage framework: familiarizing with the data, generating initial codes, searching for broader themes, reviewing and refining themes, defining and naming themes, and producing the final report. This approach systematically linked raw narrative responses to the study's core objectives.

RESULTS AND DISCUSSION

Socio-Demographic Characteristics of Caregivers

Socio-demographic profiles are important for understanding the variations in caregiving capacity, economic stability, and coping strategies among families managing autism. A caregiver's age, education level, and employment status shape their access to information, financial resources, and social support networks.

Age of Caregivers

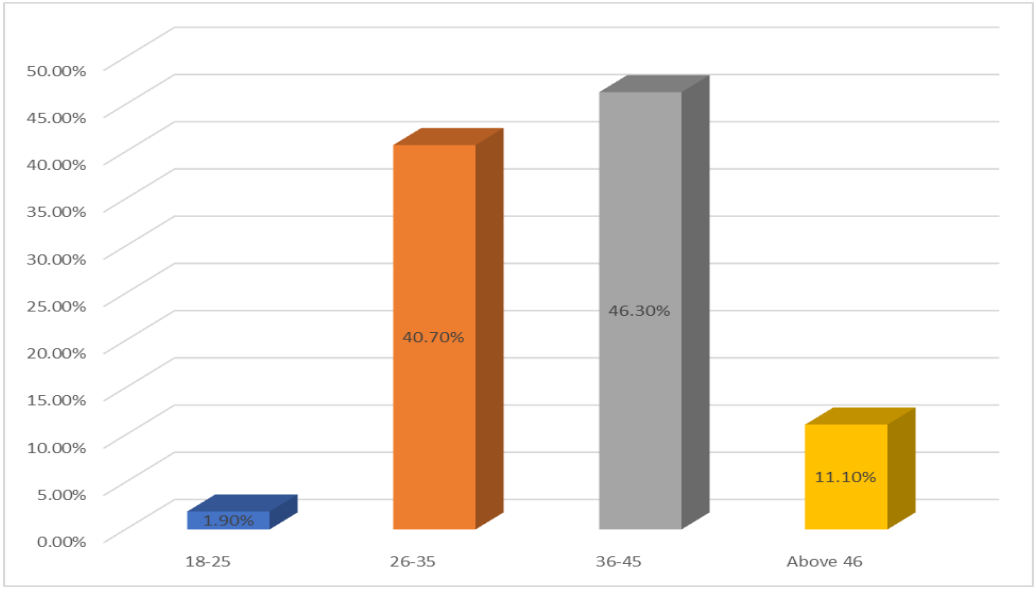

Figure 1: Age of Caregivers

The quantitative analysis showed that the majority of primary caregivers (46.3%) were aged between 36 and 45 years, while 40.7% fell within the 26 to 35 age range. Combined, 87% of the primary caregivers were between 26 and 45 years old, representing their prime working and economically productive years. This concentration highlights a significant societal challenge: the demanding daily schedule of autism care directly conflicts with the years when parents would typically build financial security and advance their careers.

This finding aligns with regional literature showing that neurodevelopmental care burdens are primarily borne by young and middle-aged adults, creating a dual challenge of managing home-based therapy alongside economic pressures (Xie et al., 2022).

Level of Education, Employment and Marital Status of caregivers

Table 1: Level of Education, Employment and Marital Status of Caregivers

Socio-Demographic Indicator	Frequency	Percentage (%)
Level of Education Attained		
None	3	5.6
Primary	12	22.2
Secondary	28	51.8
Tertiary	11	20.4
Total	54	100%
Employment Status		
Formal	4	7.4
Informal/Self-employed	24	44.4
Unemployed	26	48.2
Total	54	100%
Marital Status		
Married (Co-habiting)	45	83.3
Single / Separated / Widowed	9	16.7
Total	54	100%

Regarding formal education, 51.8% of the primary caregivers had completed secondary school, 20.4% held tertiary credentials, 22.2% had primary schooling, and 5.6% had no formal education. While the sample showed basic literacy, their employment status revealed severe economic vulnerability. Nearly half (48.2%) of the mothers were unemployed, while 44.4% worked in volatile informal sectors or small-scale self-employment. Only 7.4% held stable formal jobs.

In qualitative interviews, mothers noted that their unemployment was a direct consequence of their caregiving responsibilities rather than a lack of skills. Many explained that the unpredictable behavioural patterns and high supervision needs of their children forced them to resign from formal positions or downscale their business activities, increasing their financial dependence within the household.

Behavioural and Sensory Profiling of Autistic Children

This survey profiled the behavioural and sensory characteristics of children with autism in Voi Sub-County, as these needs dictate the intensity of parental care.

Perception of caregiver on the behavioural and sensory profiling of autistic children

Table 2: Perceptions of Caregivers on the Behavioural and Sensory Profiling of Autistic Children

Behavioural/Sensory Characteristic	Never	Rarely	Sometimes	Often	Always
Difficulty making eye contact or responding to their name.	5.6%	13.0%	37.0%	37.0%	7.4%
Engagement in repetitive movements (e.g., rocking, hand-flapping).	9.3%	9.3%	22.2%	46.3%	13.0%
Extreme distress when daily routines are slightly changed.	5.6%	16.7%	33.3%	22.2%	22.2%
Hypersensitivity to loud noises, bright lights, or certain textures.	7.4%	14.8%	29.6%	29.6%	18.5%
Preference for isolation over social play with peers/siblings.	7.4%	13.0%	22.2%	44.4%	13.0%

The data showed that 46.3% of the children frequently displayed repetitive movements, such as body rocking, hand-flapping, and pacing. Additionally, 37.0% consistently exhibited severe deficits in social communication, including avoiding eye contact, failing to respond to their names, and displaying limited verbal capacity. Sensory processing sensitivities were also widespread, with 50.0% of parents reporting that their children experienced intense distress or public meltdowns when exposed to loud noises, bright environments, or specific clothing textures.

Qualitative entries from focus groups emphasized how these combined behavioural and sensory profiles affect daily life. One mother in Voi Central shared:

"My child cannot tolerate the sound of a motorcycle or the noise at the open-air marketplace. The moment a loud vehicle passes, he starts screaming, hitting his ears, and throwing himself to the ground. Because I cannot predict what will trigger his distress, I am forced to stay inside the house with him all day. I cannot leave him with anyone else because neighbours think he is cursed or possessed by bad spirits."

These intense behavioural patterns require constant maternal surveillance, leaving mothers with little time for outside activities or personal rest. The need for continuous monitoring links directly to the high rates of maternal unemployment observed in the sample, demonstrating how the child's clinical needs reinforce gender inequalities under traditional divisions of labour.

Social Interaction and Stigma on Parenting Experiences

The second specific objective examined how social interaction barriers and community stigma affect parenting experiences. The quantitative data revealed high levels of social exclusion. Overt labelling and discrimination were reported by 42.6% of primary caregivers, while 53.7% admitted they actively avoided public spaces, community gatherings, and religious services to protect their children from judgment and harassment.

Perceptions of caregivers on the Social Interaction and Stigma on Parenting of Autistic Children

Table 3: Perceptions of Caregivers on the Social Interaction and Stigma on Parenting of Autistic Children

Social Interaction/Stigma Statement	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
I feel that community members blame me for my	9.3%1	4.8%	35.2%	35.2%	5.6%

child's condition.					
I avoid public gatherings/church to prevent my child's social exclusion.	9.3%	9.3%	11.1%	53.7%	16.7%
My extended family treats my child differently due to their disability.	14.8%	18.5%	24.1%	37.0%	5.6%
I have experienced "labelling" or derogatory comments in Voi.	9.3%	16.7%	24.1%	42.6%	7.4%

A significant portion of the stigma originates within the extended family. Nearly half (48.1%) of the mothers stated they were blamed by their husbands' relatives for the child's condition. These relatives often claimed the autism was a result of maternal genetic flaws, moral failings, or a failure to respect traditional taboos.

This maternal blame reflects the social construction of disability, where atypical neurodevelopmental presentations are viewed through a spiritual lens rather than recognized as medical conditions. This dynamic isolates the mother within her marital home, turning caregiving into a lonely struggle and eroding her emotional resilience.

Evaluation of Formal and Informal Support Systems

The study also evaluated the types, availability, and frequency of support received by families. The results showed a major gap in formal state assistance. A substantial 38.9% of primary caregivers strongly disagreed that government social protection programs, such as cash transfers or disability funds, were accessible to them.

Key informants from local health centers confirmed that while the national government provides funds for severe physical and intellectual disabilities, the registration process requires formal clinical assessments that are often unavailable or too costly for families in Voi Sub-County.

Support from religious institutions was also limited; only 29.6% of participants reported receiving meaningful emotional or financial assistance from their local churches or mosques. Many mothers noted that while religious leaders offered prayers for spiritual healing, they rarely provided practical respite care or tailored programs to help integrate children into religious activities, leading families to gradually withdraw from their congregations.

Perception on the Types and Frequency of Support Received by Parents of Autistic Children

Table 4: Perceptions on the Types and Frequency of Support Received by Parents of Autistic Children

Support and Gender Role Statement	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
My husband provides hands-on care (feeding, bathing) daily.	22.2%	14.8%	14.8%	29.6%	18.5%
Financial support is the only way my spouse assists in caregiving.	24.1%	22.2%	13.0%	33.3%	7.4%
Local religious groups provide meaningful emotional/spiritual support.	18.5%	27.8%	20.4%	29.6%	3.7%
Government social protection programs are accessible to my family.	38.9%	27.8%	9.3%	14.8%	9.3%

Paternal involvement within the household was highly skewed along gender lines. While 74.1% of mothers agreed that their husbands provided intermittent financial contributions for medical fees or food, 74.1% strongly disagreed that fathers participated in daily, hands-on physical care tasks, such as feeding, bathing, or managing behavioural meltdowns. This distribution confirms the provider-caregiver binary described by Gender Role Theory (Woo et al., 2023). Fathers often consider their duties fulfilled through financial support, leaving the physical and emotional weight of daily behavioural management exclusively to mothers.

In response to weak formal services and limited spousal assistance, mothers rely heavily on informal networks. A majority (68.5%) of caregivers reported that peer networks and localized caregiver support groups were their primary source of emotional support and practical coping strategies.

In qualitative sessions, participants frequently highlighted community-led WhatsApp groups as vital resources. These digital spaces allow mothers to share advice on tracking sensory triggers, swap details on friendly healthcare providers, and offer mutual encouragement without facing public judgment. These findings show that while formal safety nets remain weak, informal peer networks provide critical emotional support for isolated caregivers.

CONCLUSION AND RECOMMENDATIONS

Conclusion

This survey demonstrates that the caregiving experiences of parents raising children with autism in Voi Sub-County are shaped by an unequal division of labour rooted in traditional patriarchal gender roles. The complex behavioural needs and sensory sensitivities of these children require intensive, long-term monitoring. Under prevailing cultural expectations, the physical and emotional weight of this care falls almost entirely on mothers. This unbalanced burden forces women out of the formal labour market, limiting their financial autonomy and reinforcing structural gender inequalities within both the family and the wider community.

Furthermore, maternal strain is worsened by persistent community stigma, social isolation, and widespread moral blame from extended family networks. Formal support systems, including county health resources and national social protection initiatives, remain fragmented and hard to access for most families. Spousal support is generally limited to basic financial provision, leaving fathers detached from daily physical caregiving routines.

Ultimately, the findings indicate that raising an autistic child in this semi-urban environment remains an isolating female challenge. Addressing these disparities requires targeted policy design, increased institutional support, and community interventions to challenge gendered caregiving assumptions and promote parental equity.

Recommendations

Recommendations for Practice

1. Establish Localized Caregiver Training Programs: The Taita Taveta County Department of Health, in partnership with local community health volunteers (CHVs), should set up continuous, neighbourhood-level training workshops for parents. These programs should focus on positive behavioural management, alternative communication strategies, and sensory integration techniques to help mothers navigate daily challenges and reduce role strain.

2. Formalize and Expand Peer Support Networks: Community health workers should actively formalize and expand informal caregiver support groups, including digital platforms like WhatsApp. Connecting these groups with primary health centre staff will ensure families have steady access to accurate medical information, emotional support, and organized respite care options.

Recommendations for Policy

1. Enhance Access to Social Protection Initiatives: The national and county governments should streamline registration processes for cash transfer programs and disability funds specifically targeting neurodevelopmental conditions. Subsidized occupational therapy services, specialized speech therapy, and inclusive educational resources must be integrated into local health centers to ease the financial pressure on low-income families.

2. Launch Sex-Informed Public Sensitization Campaigns: County social development offices should design and implement targeted public education campaigns to dismantle supernatural myths and combat discrimination surrounding autism. These initiatives should engage community elders, religious organizations, and extended kinship networks to reduce maternal blame, foster public inclusion, and encourage men to take a more active role in household caregiving.

Recommendations for Further Research

1. Conduct Longitudinal Impact Appraisals: Future researchers should conduct longitudinal studies to track how the maternal caregiving burden changes over time as children reach adolescence and adulthood, measuring the long-term impact on maternal health and career development.

2. Perform Cross-County Comparative Work: Comparative research should be expanded across different counties and rural-urban settings in East Africa to assess whether the patriarchal care divisions observed in Voi Sub-County reflect broader regional patterns or vary based on local socio-economic configurations.

Ethical Approval

Ethical approval was sought from Egerton University Research Ethics Committee (EUREC) and National Council of Science Technology and Innovation (NACOSTI). Additional authorization was sought from Hola Sub County hospital for recruitment of healthcare staff in the study.

Conflicts Of Interest

The authors of this study declare that they have no conflict of interest concerning the work reported in this study.

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