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"Out of the Shadows": The Transformation of Epilepsy Stigma in Mahenge, Tanzania, 19th–20th Century

"Out of the Shadows": The Transformation of Epilepsy Stigma in Mahenge, Tanzania, 19th–20th Century

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Abstract
The 1997 "Out of the Shadows" campaign, led by the International League Against Epilepsy (ILAE), the International Bureau for Epilepsy (IBE), and the World Health Organisation (WHO), sought to improve the well-being of people with epilepsy worldwide by combating stigma. However, the campaign treated stigma as a uniform problem, ignoring the local social and historical contexts in which stigma emerged and operated. Drawing on oral life histories, illness narratives, and in-depth interviews with 23 informants from four villages in Mahenge, this paper examines the root causes of stigma as well as the transformation of stigma brought by increasing inter-community interactions and the growing pressures of the money economy during the colonial period. The study found that in the pre-colonial period, both men and women with epilepsy faced stigma as the Wapogoro believed both sexes could transmit the condition through reproduction. During the early colonial period, however, many men migrated to distant villages, married, and fathered unaffected children, revealing that paternal transmission was rare. At the same time, the colonial money economy placed new pressures on men to earn cash wages. Consequently, the root cause of stigma for men shifted from reproduction to a poor economic base. Women, by contrast, continued to experience stigma based on the belief that women transmit epilepsy to their children and that seizures incapacitate them from performing daily gender roles. These findings demonstrate that the 'Out of the Shadows' campaign's assumption of uniform stigma is contextually incomplete. Effective intervention against stigma requires building on local knowledge relating to epilepsy accumulated over centuries.

Introduction

The 1997 "Out of the Shadows" campaign, led by the International League Against Epilepsy (ILAE), the International Bureau for Epilepsy (IBE), and the World Health Organisation (WHO), was launched with the primary aim of combating stigma and social exclusion and changing attitudes and myths about epilepsy through increasing awareness of the condition worldwide (World Health Organisation, 1997). The campaign treated stigma as a uniform experience to be reduced through awareness. However, there are inadequate historical studies on stigma relating to chronic illnesses such as epilepsy. Using the case study of Mahenge, this paper examines the root causes and the transformation of epilepsy stigma across the 19th and 20th centuries. Mahenge is an effective case study since it has a long history of epilepsy and a high prevalence rate compared to other regions in Tanzania.

The largest study conducted across 15 European countries, involving 5,100 patients, reported that 18% experienced a high degree of stigma and 51% experienced exclusion and marginalisation (Baker et al., 2000). Stigma has been influencing access to employment, education, marriage, and driving opportunities. While providing a broad European perspective on stigma, the study revealed significant variation in the degree of stigma and exclusion across countries. This suggests that local contexts influenced the experiences of people with epilepsy. However, the quality of life for people with epilepsy in Europe has demonstrated significant improvement in recent decades. This progress is attributed to a multifaceted approach, including sustained public campaigns which have been credited with 'bringing epilepsy out of the shadows' by changing attitudes and reducing stigma (Little, 2013).

Stigma relating to epilepsy is a well-documented experience across sub-Saharan Africa. In this region, stigma has been complicated by cultural beliefs. In Mahenge, Tanzania, a recent KAP survey found that 51% of community members held negative attitudes toward the condition (Mmbando et al., 2024). This aligns with qualitative findings from other East African communities where epilepsy is attributed to spiritual causes (Kaddumukasa et al., 2020). The World Health Organisation (2019) acknowledges that the stigma of epilepsy can be more difficult to address than the seizures themselves, reflecting a paradigm shift from the biological dimension of the disease to the recognition of the social, economic, and cultural dimensions of the disease.

It has also been noted that the stigma of epilepsy is gender based. Gender issues shape the experiences of people with epilepsy in distinct ways (Ntaimah, 2008; Teuwen et al., 2024). Key gender disparities in stigma include the unique forms of social rejection faced by women relating to menstruation, pregnancy, birthing, and child rearing (Maiga et al., 2010; Teuwen et al., 2024). Women bear the burden of being stigmatised for transmitting epilepsy to offspring and face marital rejection as a consequence (Birbeck et al., 2008). Men, by contrast, experience stigma in the form of a crisis of masculine identity when the condition impairs their ability to fulfil traditional roles as breadwinners, leading to social marginalisation (Kleinman et al., 1995; Ntaimah, 2008). In response to these gendered dimensions of stigma, the World Health Organisation (2019) declared that the burden of epilepsy is determined by gender norms, representing a fundamental shift from gender-blind models toward the social basis of epilepsy.

One striking thing that is clear in the literature on epilepsy is the relationship between epilepsy, stigma, and life-altering disabilities. Stigma increases the vulnerability of people with epilepsy to health risks and disability (Buck et al., 1997; Lawn et al., 2004). Injuries relating to seizures range from minor bruises to severe trauma, including fractures, burns, and head injuries (Camilo & Goldstein, 2004; Persson & Söderfeldt, 1997). In sub-Saharan Africa, injury related to seizures has been complicated by inadequate health services (Mbelesso et al., 2013; Ndoye et al., 2005). The burden of disability in poor areas has been higher due to unsafe living and working conditions and inadequate treatment. In addition, stigma complicates these injuries by leaving people with epilepsy hidden and untreated. In Mahenge, a study found that 75% of adults and 31% of children with epilepsy lived with a physical disability from seizure-related injuries (Bhwana et al., 2023). Physical disability is not merely a medical condition but also a consequence of stigma and associated social exclusion from adequate healthcare, seizure management, and injury prevention services.

Also addressed in many studies are the experiences of people with epilepsy in the education sector (Brabcová et al., 2021; Mbuba et al., 2009). In high-income countries, specialised health services, suitable learning environments, and legal protections have mitigated extreme forms of exclusion (Devaux & Sassi, 2013; Thompson & Kerr, 2012). In sub-Saharan Africa, however, there have been reports of the denial of educational opportunities to people suffering from epilepsy (Atadzhanov et

al., 2006; Mushi et al., 2011). With limited resources in the era of cost sharing, children with epilepsy were more likely to stay home for domestic chores (Birbeck & Kalichi, 2004; Chomba et al., 2008). In addition, the absence of teacher training on seizure first aid means schools are not safe for people with epilepsy (Kaddumukasa et al., 2020; Nuhu & Bada, 2013). A study by Magili et al. (2023) highlights an alarmingly high rate of school dropout and non-enrolment among children with epilepsy in Mahenge. Among the 203 participants with epilepsy, 30.5% had never enrolled in school. Furthermore, among those who enrolled, 54.6% dropped out before completing primary education. Only a single participant in the entire cohort (0.5%) had attained a secondary school education (Magili et al., 2023). Denial of educational opportunities represents one of the most damaging forms of social exclusion, as it limits the future opportunities of children with epilepsy. The saying that 'poverty breeds poverty' is true for people with epilepsy in sub-Saharan Africa, where epilepsy has been a trap. The documented physical disabilities from untreated seizures and denial of education are not isolated facts. They are interlinked symptoms of the "poverty breeds poverty" trap, where each element reinforces the others, leaving individuals and families with few avenues for escape.

Despite this rich body of literature on experiences of epilepsy, gaps remain. There is no systematic historical scholarship on people who lived with epilepsy in Mahenge. People with epilepsy in Mahenge have been studied mainly from socio-anthropological (Mmbando et al., 2022) and biomedical perspectives (Jilek-Aall, 1979). These works did not present the evolution of stigma and social exclusion in the experiences of people with epilepsy. Early colonial works on medical history concentrated on institutional histories of disease and healing. For instance, David Clyde's work (1962) and Anne Beck's (1977) examined the establishment of colonial medicine as a civilising mission and did not document how Africans negotiated foreign medical systems. This stimulated studies that analysed the influence of colonial operations on disease outbreaks (Turshen, 1986; Packard, 1992; Kjekshus, 1977). In addition, scholars such as Lesley Doyal (1981) and Steven Feierman (1995) analysed the socio-economic and political economy of disease and healing, arguing that social factors such as poverty, oppression, and exploitation are more significant than germs in disease causation and healing practices. Contemporary works on medical history focused on the analysis of politics, cultural factors, agency, and the co-existence of African and biomedical perspectives of disease and healing. From the 1990s onward, scholarship on medical history called for attention to African perspectives on health, disease, and healing (Vaughan, 1991; Feierman & Janzen, 1992). Recent historical scholarship in the 2020s has continued this attention. However, even these recent works have not specifically examined the experiences of chronic illness in the pre-colonial, colonial and post-colonial periods.

Stigma and social exclusion were embedded in pre-colonial societies long before the arrival of European colonial powers. Lorne Larson reports on social exclusion in Mahenge based on accusations of witchcraft and adultery (Lorne Larson, 1975). Larson revealed the continuation of stigma and social exclusion in the colonial period based on leprosy (Larson, 2021). Although Larson did not study epilepsy directly, his work is valuable because it reveals parallel patterns of stigma and spatial isolation in Mahenge in the period under consideration (Lorne Larson, 1975; Larson, 2021). This study examines the transformation of the root causes of epilepsy stigma in Mahenge over the 19th and 20th centuries.

Theoretical Framework

This study is grounded in Erving Goffman's (1963) stigma theory and the social theory of disease and healing by Steven Feierman and John Janzen (1992). Goffman's stigma theory explains how stigma operates in everyday life. The theory conceptualises stigma as an individual experience that destroys identity and discredits a person in the eyes of society. Although Goffman's work is foundational to

the study of stigma, it analyses stigma as if it occurs in a social vacuum. The theory cannot explain how or why stigma evolves over time or varies across different social and historical contexts.

The social theory of disease and healing, in contrast, insists on the influence of historical circumstances and socio-economic realities on disease and healing. While acknowledging individual experiences of illness, this theory extends its analysis to kinship networks and their involvement in disease and healing (Feierman & Janzen, 1992). Drawing on this perspective, the present study extends Goffman's insight by demonstrating that stigma is not a universal or static phenomenon but rather a product of specific historical and social circumstances. Stigma is not merely an individual problem; its influence extends to other kinship members. This study applies these insights to understand how men's stigma shifted from reproduction to economic failure. Although both theories were developed to analyse contemporary phenomena, they provide analytical tools for examining stigma and social exclusion across the 19th and 20th centuries. These two theoretical frameworks enable this study to move beyond the biomedical and socio-anthropological approaches that have dominated epilepsy research in Mahenge for several decades.

Methods and Contexts

Research Design

This study employs a qualitative research design to solicit, analyse and interpret the illness narratives of people, families, and clans with a history of epilepsy in Mahenge. It draws on the theoretical frameworks of Arthur Frank (1995) and Arthur Kleinman (1988) to understand how individuals construct their experience of illness within a specific socio-cultural context.

Study Area

Mahenge has emerged as a critical case study for understanding epilepsy in sub-Saharan Africa due to its long-documented history of the condition and high prevalence rates compared to other regions in Tanzania. Fieldwork was carried out in the villages of Mdindo, Msogezi, Mzelezi and Sali to capture perspectives of epilepsy in rural areas.

Study Population

The study employed a purposive sampling technique to solicit information from individuals who had experienced epilepsy in the 20th century and from young informants who could recall stories passed down from their grandparents and great-grandparents. The Wapogoro had maintained strong traditions of intergenerational oral transmission, particularly regarding epilepsy. Oral histories collected in 2023 capture intergenerational memory, as Wapogoro traditions of oral transmission have preserved knowledge of epilepsy across the 19th and 20th centuries. To access reluctant individuals, snowball sampling was employed as a supplementary technique. Initially, purposive sampling identified participants and provided trusted referrals to others within their networks. Throughout the recruitment process, the final selection of participants continued to be guided by the strategic aim of purposive sampling, ensuring the sample maintained the study's historicity. Recruitment continued until theoretical saturation was achieved, resulting in a final sample of 23 participants, all of whom were adults with direct personal or familial experience of epilepsy.

Data Collection Methods

Multiple methods were employed in data collection. Life histories traced family history across generations, establishing patterns of inheritance, experiences, and adaptations to the condition over time. Illness narratives were employed to capture the personal, subjective experience of epilepsy, exploring how individuals interpreted symptoms and negotiated identity. In-depth interviews were conducted with persons with epilepsy using open-ended prompts. Oral traditions were employed to

access the shared, collective knowledge and belief systems that informed the experiences of epilepsy in Mahenge.

Data Analysis

Data were analysed using content and thematic analysis frameworks. This process involved examining primary and secondary sources, identifying key recurring themes relevant to the research questions, and synthesising evidence from different data sources. The interpreted findings were then used to draw conclusions.

Ethical Considerations

The study received ethical approval from the Mwalimu Nyerere Memorial Academy (MNMA) and relevant local authorities in Mahenge and Morogoro Region. Informed consent was obtained from all participants, and the research protocol respected the community's oral traditions and cultural sensitivities.

The Root Causes of Epilepsy Stigma in the 19th–20th Century

This section presents findings on the root causes and transformation of epilepsy stigma among the Wapogoro of Mahenge across the 19th and 20th centuries. The findings are organised into two main parts. The first part traces the root causes **of** epilepsy stigma, and the second part examines the transformation of epilepsy stigma experienced in the 20th century.

The Stigma of Hereditary Epilepsy

During this period, the Wapogoro conceptualised epilepsy in three frameworks: hereditary, active, and dormant. Each framework carried different implications for the evolution of stigma and social exclusion in Mahenge. The hereditary conceptual framework claimed that epilepsy arises within a clan and can pass from one clan to another through direct or indirect contact. In addition, this conceptual framework suggests that epilepsy is a permanent health condition. Oral histories of the Wapogoro traced patterns of epilepsy, indicating that the condition appeared across successive generations within particular families and clans, affecting children, parents, and grandparents. These clans were few in number and widely known in Mahenge (Lazaro Mfanyakazi, personal communication, November 2023).

According to this conceptual framework, epilepsy could be prevented through restricted contacts. As a result, interaction with vulnerable clans, including intermarriage and social relations, was restricted (Lazaro Mfanyakazi, personal communication, November 2023).

This long-term observation by the Wapogoro is now supported by scientific empirical evidence from Mahenge, where 36.1% of persons with epilepsy had a family member with epilepsy (Bhwana et al., 2019). Genetic analysis further revealed that first-degree relatives of affected individuals had about 15% risk of developing epilepsy (Neuman et al., 1995). The term "hereditary or traditional epilepsy" was adopted locally to acknowledge this intergenerational connection (Lazaro Mfanyakazi, personal communication, November 2023).

The Wapogoro feared this intergenerational pattern of epilepsy. Their fear was based on day-to-day observation of the recurrence of epilepsy across generations. During this period, epilepsy was interpreted through the frameworks of traditional religions and broken social relationships. It was placed in the same category as leprosy. Both diseases were highly stigmatised (Thomas Nginanga, personal communication, November 2023).

Fear of stigma led to the segregation of vulnerable clans in Mkolongo, a segregated village where people with epilepsy and leprosy were isolated from mainstream society. The process began with community leaders identifying affected clans and supervising their relocation to a designated village.

Interactions with other villages were not permitted, and they were neither allowed to abandon Mkolongo nor expand beyond its borders. They were instructed to live, cultivate, and collect firewood, herbs, water, and building and other materials only from the areas allocated to them (Thomas Nginanga, personal communication, November 2023). Thomas Nginanga, a community member, recalled that some of his grandmothers lived in this village and had to adhere **to** restrictions that controlled their mobility, production, and reproduction. However, in Mkolongo village, people with epilepsy enjoyed freedoms they might not have experienced in other villages – they could marry each other, share local beers, and lead what was considered a normal life (Thomas Nginanga, personal communication, November 2023).

Active Epilepsy in Women and Reproductive Blame

The concept of active epilepsy also influenced stigma and social exclusion among the Wapogoro people. As Leticia Mpondela explained, active epilepsy is a form of the condition specific to women that can be transmitted from one generation to another through pregnancy, childbirth, and the daily acts of child-rearing. The concept gained momentum after the observation that women with epilepsy consistently bore affected children, even when they married healthier partners from distant villages (Leticia Mpondela, personal communication, November 2023). This observation reinforced the belief that women, not men, were the primary transmitters of epilepsy in society. The Wapogoro understanding of active epilepsy was not limited to transmission alone. It also encompassed the broader reproductive consequences for women. As Raphael Kalumila Lyenge explained:

> "In women, epilepsy stays in their wombs and affects reproductive processes. It limits chances of getting pregnant, increases the number of seizures during pregnancy, and the increasing seizures affect the unborn child. Active epilepsy attacks women's offspring and passes down from one generation to another." (Raphael Kalumila Lyenge, personal communication, November 2023)

This testimony reveals that the Wapogoro saw active epilepsy as affecting women at every stage of motherhood. From menstruation through conception to childbirth and child-rearing, the womb was understood as the site where epilepsy resided and from which it attacks offspring and is transmitted to the next generation.

The concept of active epilepsy could be regarded as unscientific, but the perception anticipates biomedical research on maternal transmission of epilepsy (Dreier et al., 2021; Bolton et al., 2015). The Wapogoro framework demonstrates that local knowledge systems can arrive at empirically observable patterns through constant reasoning, observation, and reflection on social reality. This belief in maternal transmission carries significant implications for women's lives. Lyenge explained:

> "If epilepsy attacked the mother, all children from affected women were viewed as vulnerable to epilepsy. These women with epilepsy were often considered unsuitable for marriage, as their condition was seen as a threat not only to themselves but to future generations" (Raphael Kalumila Lyenge, personal communication, November 2023).

According to Hatia Choma, active epilepsy represented a societal problem, not an individual problem. This challenges Goffman's (1963) view of stigma as an individual experience whose mitigation depended on individual efforts. Among the Wapogoro, the leakage of knowledge regarding a woman's epilepsy status could lead to stigma and exclusion for entire clans. This leakage could result in the termination of marital relationships not only for the affected woman but also for other healthy family members (Hatia Choma, personal communication, November 2023).

The belief in maternal transmission was consolidated during the colonial period. Women who remained in Mahenge and those who migrated to distant places continued to mother children affected by epilepsy. The root cause of stigma for active epilepsy in women was reproductive blame based on observed maternal transmission. This root cause persisted across the colonial period because empirical evidence continued to confirm that affected mothers bore affected children, regardless of where they lived.

The story of Leticia Mpondela illustrates how families with an affected woman were treated in the Wapogoro community. Leticia, a mother of six children, experienced her first seizure in adulthood following prolonged headaches. According to Leticia, people in her village, including her own husband, considered her useless, as she could no longer participate effectively in domestic chores, particularly cooking, for fear of burns if a seizure occurred during cooking.

Goffman's hypothesis that stigma spoils social status was true for Leticia. Friends who had previously lent her money and other resources during times of difficulty now refused to lend her money during periods of economic hardship. Leticia, therefore, turned to her relatives and children for food, clothing, and critical cash. However, the support she received was insufficient; sometimes it was not given on time, and it declined over time. She came to believe she was burdening her relatives excessively while her health deteriorated. Eventually, Leticia requested her husband's permission to go to Sali Mission, where she could join other women who had taken refuge in the 1950s.

The consequences of Leticia's condition extended to her children, particularly her daughters. They began to be treated with caution as prospective victims of epilepsy in adulthood. The husband of one of her daughters decided to marry another woman in search of healthy children, explicitly acting on the belief that daughters of an affected mother might carry active epilepsy. While Leticia and her daughters experienced these various forms of marginalisation, her husband, though at an advanced age, married another woman to replace Leticia. This story illustrates that stigma was not only an individual phenomenon but also a social phenomenon.

Dormant Epilepsy in Men: Rare Paternal Transmission

A second concept that influenced stigma and social exclusion during the period under discussion focused on the notion of dormant epilepsy. Justine Mhenga defined dormant epilepsy as a form of epilepsy in men that can rarely be transmitted to their offspring (Justine Mhenga, personal communication, November 2023). In other words, dormancy refers specifically to transmissibility, not clinical manifestation. Men were viewed as carriers who came from infected clans and inherited the condition, but they could rarely transmit it to other people through marriage.

The Wapogoro observed this pattern before increasing interactions. As Hatia Choma explained, there were some men who experienced seizures yet fathered unaffected children. But most people considered this knowledge to be mere rumours (Hatia Choma, personal communication, November 2023). Although the Wapogoro arrived at the concept of dormant epilepsy through empirical observation, the community did not readily accept this knowledge.

Thus, despite the rumours that men rarely transmit epilepsy, it was difficult for a man with epilepsy to marry a seizure-free partner, even when that partner came from a family with a history of epilepsy. Albert Mhenga remembered a story of his grandparents who wanted to marry a lady who had no epilepsy, but whose clan comprised people with epilepsy. He recalled that his relatives deserted the lady to a distant village while they were in the process of arranging the marriage (Albert Mhenga, personal communication, November 2023). This experience aligns with Goffman's (1963) view that stigma is embedded in cultural beliefs, not merely in factual knowledge.

Scientific research confirms that paternal transmission of epilepsy is rare, aligning with the Wapogoro understanding that men rarely transmit the condition. Where the Wapogoro framework diverges from biomedicine is not in the pattern of transmission but in the explanation for it. The Wapogoro attribute the rarity of paternal transmission to the biological nature of men, whereas biomedicine explains it through genetic mechanisms.

The Transformation of Epilepsy Stigma in the 19th–20th Century

Although it is difficult to document the full history of transformation in Wapogoro conceptions of epilepsy following colonial processes, it is clear that inter-community interactions increased from the mid-19th century and accelerated rapidly during the colonial period. However, scholarly attention has focused predominantly on the political and economic implications of these interactions. The influence of increased interactions on stigma and social exclusion has received relatively little attention. This study addresses that gap by examining how pre-colonial and colonial interactions transformed the stigma surrounding epilepsy in Mahenge.

Pre-colonial Interactions and Transformation of Epilepsy Stigma

A study conducted in Mahenge by Lorne Larson reports that Mahenge's geography, particularly its rivers, valleys, and mountains, delayed interactions between the Wapogoro and outsiders. However, in the last quarter of the 19th century, Mahenge was opened through the invasion and migration of the Mbunga, Ngoni, Ngindo, and Bena peoples, resulting in intermarriage and increased interactions (Larson, 1976, pp. 10-25). Through intermarriage with these ethnic groups, the Wapogoro confirmed what had previously been dismissed as rumoured: that men with epilepsy could father healthy children. As Lyenge explained:

> "Because of recurrent breaking of relationships due to his health conditions, my grandparents went to marry among the Wangindo and got healthy children, including my mother. This is said to happen to many men with epilepsy" (Raphael Lyenge, personal communication, November 2023).

The confirmation that men with epilepsy could father healthy children had profound implications for stigma and social exclusion. The fear of reproductive transmission gradually diminished, allowing men to marry and establish their families. Yet this opportunity came at a cost: men who could not meet the family's economic expectations faced marginalisation. This reality aligns with Foucault's (1977) argument that knowledge and power are inseparable. The concepts of active and dormant epilepsy were not neutral; they produced distinct forms of stigma for men and women.

While the notion of rare paternal transmission became **a** widespread phenomenon and mitigated extreme forms of exclusion for men, women, by contrast, could not escape epilepsy transmission blame. They continued to mother affected children, thereby reinforcing beliefs about maternal transmission.

The Impacts of Missionaries' Work on Stigma and Social Exclusion

Missionaries challenged the exclusion of people with epilepsy in Mkolongo village by offering refuge and services regardless of health status. Mission centres, particularly Sali, became spaces where people with and without epilepsy could interact, slowly breaking down the spatial and social barriers that had previously segregated affected clans (Rev. Kuandika, personal interview, November 2023). Sali Mission was established near Mkolongo village by the Benedictine fathers in the early colonial period and represented an important milestone in the history of epilepsy in Mahenge.

Initially, only chronically ill men and women went to Sali Mission, where they received accommodation, spiritual services, and other health services (Hatia Choma, personal communication,

November 2023). They were later followed by people with epilepsy who had poor social networks, infertile men and women, and those who had lost their partners in old age**.** Later, even able-bodied people with epilepsy chose to live at the church, indicating that Sali Mission had transformed from a place of last resort to a desirable community (Rev. Kuandika, personal interview, November 2023). The agency of people with epilepsy in their quest for a decent life is evident in their migration to Sali Mission, where most of them spent their entire lives. This pattern reveals that people with epilepsy were not passive victims of stigma; they actively sought refuge and community where they could live with dignity.

By providing accommodation for people with leprosy and epilepsy, along with a school, a church, and a health centre, the mission created vital services that attracted other people to settle on its periphery. This transformed the site from a refuge into an important centre for social and economic interactions. The church became a meeting point where people with and without epilepsy could gather, slowly integrating these previously divided communities (Christopher Benignus, personal communication, November 2023).

Christian values such as equality, love, and kindness mitigated the extreme forms of stigma that had prevailed in traditional Wapogoro society, creating conditions conducive to marriage, education, and respectful burial ceremonies. It is said that many of those who migrated to Sali did not marry. Education opportunities were also not fully exploited, partly because seizures disrupted attendance and partly because accessing the nearby school required crossing the river, viewed as a daily risk for people with epilepsy. However, people hosted at Sali Mission were few and had no great influence on the widespread phenomenon of people with epilepsy in Mahenge.

Despite these positive changes, discrimination persisted even within the church. In the event of an epileptic episode, congregants were likely to run away, leaving the patient alone in fear of contagion (Rev. Kuandika, personal interview, November 2023). Even Christian devotees were not spared from exclusion. Young men who wished to join the priesthood could not do so as long as they had epilepsy or a family history of epilepsy (Christopher Benignus, personal communication, November 2023). In addition, the general requirements for the priesthood systematically excluded these people from joining the holy rank. From the compendium of missionary hygiene, we read:

> "Anyone wishing to embrace this life of priesthood should possess strong health and should receive medical confirmation of the same…. In case of doubt of the aspirants' health, the doctor is strictly bound in conscience to cast a negative vote, and it is preferable that this happens more often than not seldom" (Burton & Wagner, 1963).

This pattern of the Church providing social services for the chronically ill is a global phenomenon (Gussow & Tracy, 1970; Vaughan, 1991). In essence, during the German colonial period, the Church acted as the implementer of epilepsy policy in East Africa.

5.3 Colonial Interactions and the Transformation of Epilepsy Stigma

Colonialism transformed African societies, particularly through economic restructuring. Colonial taxes, cash crop production, and migrant labour fundamentally altered how men and women lived and worked. These changes reconfigured social identity, especially for men, whose traditional status depended on providing for their families through subsistence production.

In Mahenge, these colonial economic pressures transformed the root causes of epilepsy stigma. In many African societies, a man's identity and power depend on his ability to control economic resources and provide for his family. A man who cannot work, farm, or earn an income loses his identity and prestige as a husband, father, and head of household. Men from well-to-do families, by

contrast, can use economic resources to mitigate severe forms of stigma. The literature on epilepsy and gender has highlighted the crisis of masculine identity that men face when the condition impairs their ability to fulfil traditional roles as breadwinners (Kleinman et al., 1995). The growing pressures of the money economy during the colonial period intensified this economic basis of stigma, as men were increasingly expected to earn cash wages rather than merely provide for subsistence needs. Larson (1976) provides detailed evidence of how colonial economic policies created new pressures on men in the Mahenge district.

Goffman (1963) theorised stigma as a static individual experience, but the Mahenge case reveals that stigma is a dynamic phenomenon. As Feierman and Janzen (1992) argue, local knowledge systems are not static superstitions but rational inferences drawn from accumulated experience.

Conclusion

This study examined the root causes and transformation of epilepsy stigma in Mahenge across the 19th and 20th centuries. To understand the complexity of epilepsy stigma, the study employed Goffman's (1963) stigma theory and Feierman and Janzen's (1992) social theory of disease and healing. The study concludes that stigma is a dynamic phenomenon shaped by day-to-day experience, cultural factors, and economic pressure. Understanding it requires an approach that integrates micro-level social interaction with macro-level historical forces.

The 1997 "Out of the Shadows" campaign viewed stigma as a static and uniform experience. This study has shown otherwise. Therefore, public health interventions must adopt a historically informed and context-based approach. Interventions should consider the gender dimension of epilepsy stigma and should build on local knowledge of epilepsy and associated stigma and social exclusion.

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