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POSTER

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Designing Accessible Educational Services: A Human-Centered Framework from Sub-Saharan African Student Communities

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Abstract

The study used an embedded netnographic methodology to explore the lived experiences of students with epilepsy across twelve Sub-Saharan African countries. This was done to develop a human centred assumptions map to guide the creation of sustainable technological solutions like small language models aimed at solving education challenges in low resource contexts. Through systematic analysis of some digital narratives collected during a one-year period of embedded fieldwork as a communications officer with the International Bureau of Epilepsy (IBE) African Region, the researcher analysed a total of 24 digital narratives from WhatsApp groups, podcast interviews, and organizational reports. The study highlights several key themes which can be summed up in one major overarching theme of the cascade effect of missed learning opportunities by students with epilepsy. Firstly, the study found that academic failure amplifies the stigma these students face in classroom settings. Secondly, parents and carers of children with disabilities are forced by a different factors to make difficult trade-offs when determining their child's educational path. Thirdly, the students themselves create communities which help them adapt especially using digital technologies. Based on these findings the researcher has proposed some design recommendations for future technological interventions which seek to counter the effects of epilepsy and other neurological disorders in education by specifically focusing on these existing digital resilience networks. Our proposed design framework the low resource setting and the challenges that other educational technological interventions have faced as highlighted by other authors. The study brings more attention to the nuances from the human experiences angle which are informing the technology design methodology.

CCS Concepts

• **Human-centered computing** → Accessibility; Accessibility design and evaluation methods.

Keywords

Accessibility, Human-centered computing, Ethnographic studies, User studies, HCI design and evaluation methods, Educational technology, Participatory design, User experience design, Sub-Saharan Africa, Epilepsy

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1 Introduction and Background

Epilepsy affects more than 50 million people globally with a substantial number living in Africa. with the highest burden among school-age children⁸. The intersection of chronic conditions and education in Africa presents unique challenges that traditional educational support systems have struggled to address. While previous research has documented the medical and some social dimensions of epilepsy in Africa², limited attention has been paid to how these challenges specifically impact educational trajectories especially through the lens of the lived experiences of the students and their families or caregivers.

The intersection of epilepsy and education presents significant barriers to achieving genuine inclusive educational practices. Students with epilepsy face multifaceted challenges that substantially compromise their educational experiences and outcomes. These barriers manifest through several interconnected dimensions that collectively undermine educational participation and success. They include stigma and social exclusion [10], knowledge gaps and lack of preparedness by teachers⁶, sporadic class attendance and bullying [5], systematic and structural barriers [17] other secondary effects from seizures [4]. Some studies have also discussed the stories of resilience and coping strategies for example [16]. While it's possible to live seizure free due to several advances in diagnosing and treating the condition there is a wide treatment gap in low and middle income countries [9]. Most people living with epilepsy in Africa still have challenges accessing medication and as such still have seizures which impact their life and education. It is also worth noting that epilepsy as a condition manifests differently across individuals, existing on a spectrum from invisible, severely affected and some symptoms which are unclassified [14]. This is why the issue needs to be approached from several angles not just the medical.

The COVID-19 pandemic accelerated digital adoption across Africa, with other scholars describing this advancement in adoption of different technologies as a big quantum leap that has not been seen before [11]. WhatsApp was one such platform becoming the primary platform for educational communication in many African communities. This digital transformation created new opportunities for understanding and addressing educational challenges through technology. While the digital divide remains an issue in African countries it seems that social factors and the urgent need created



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by the pandemic greatly influenced the adoption especially for those students who were seeking learning support outside of the classroom.

While technology seems to be a promising tool to counter some of the effects of education, most technologies that aim to be accessible or address these problems are often adapted from other contexts. The challenge with adaptations is that the designers of these tools often have implicit understanding that by simply ticking boxes and following accessibility guidelines for example those by Web Content Accessibility Guidelines (WCAG) 2.1 will mean that their technology will universally accessible which is usually not the case. Several authors have examined the quality and usefulness of design guidelines, standards, and resources for technology accessibility among people with disabilities [12]. These challenges are particularly pronounced in developing contexts like Africa, where technological solutions may achieve technical compliance but fail to address real-world usability. One of the reasons that this happens is that these approaches often overlook the lived experiences of students with disabilities in resource-constrained environments. Furthermore these demographics rarely fall on the radar of for profit ventures as the primary users, creating a gap between accessibility standards and user reality. This disconnect is exacerbated by insufficient documented research on the experiences of people with different disabilities. This study takes advantage of the unique access to the digital epilepsy communities to understand the lived educational experiences. The need for inclusive technology design has been emphasized by accessibility researchers who argue for moving beyond compliance-based approaches [1]. Incorporating accessibility into service design requires moving beyond compliance-based approaches to deeply understanding the lived experiences from the beginning. This embedded netnographic study demonstrates how service design for students with epilepsy in Sub-Saharan Africa must begin with their existing digital resilience networks rather than imposing external solutions [15].

The interconnected nature of African societies fundamentally challenges traditional market segmentation that positions people with epilepsy and neurological disorders as a "minority" group unworthy of design attention. This reveals how digital connectivity amplifies what [13] termed "bottom of the pyramid" markets as the families and students with epilepsy are embedded within extended families and community networks, multiplying the actual number of people affected by and invested in accessible educational solutions [7]. The organic emergence of cross-border peer support networks documented in this study demonstrates what [3] calls "pro-poor innovation" where excluded communities become early adopters and co-creators of solutions that eventually benefit broader populations. This network effect transforms accessibility from a compliance requirement into inclusive and sustainable innovation.

2 Research Questions and Objectives

This study was guided by two primary research questions:

1. How do digital community narratives confirm or reveal the educational challenges faced by students with epilepsy in Sub-Saharan Africa?
2. What implications do these experiences have for accessible technology design approaches?

The study objectives were to:

- Document and analyse the lived educational experiences of students with epilepsy and their caregivers across twelve IBE chapter countries in Africa
- Develop a human centred assumptions map that can be used in future human centred design frameworks for technology developers seeking to create solutions.

3 Methodology

3.1 An Embedded Netnographic Approach

This study employed an embedded netnographic approach, ethically leveraging the researcher's two-year tenure as Communications Consultant with the International Bureau of Epilepsy (IBE) African Region. This position granted access to digital epilepsy communities across twelve countries: Zambia, Tanzania, Cameroon, Lesotho, Eswatini, Malawi, South Sudan, Kenya, South Africa, Sierra Leone, Ethiopia, and Mauritius.

Netnographic methodology was chosen because the research questions specifically target digital community narratives within online epilepsy support networks. The embedded approach allowed the researcher to capture authentic, naturally-occurring discussions about educational challenges and community-developed coping strategies that would be difficult to access through traditional interviews, while avoiding the observer effect common in ethnographic research.

3.2 Ethical Considerations and Data Access

Permission was obtained from IBE African Region leadership, with all participating organizations having existing data use agreements for research purposes. All narrative data utilized was subsequently made publicly available through IBE's official channels. Data was anonymized, and direct quotes were used only with explicit participant permission.

3.3 Data Collection Through Embedded Participation

Data collection occurred through three primary channels over 12 months:

1. WhatsApp Group Participation (n=6 groups) across youth, parent, adult, and NGO coordination groups, generating 24 educationally-focused narrative threads for analysis.
2. Podcast Series: "Talks on Epilepsy Lived Experience" (n=6 episodes) featuring interviews with 4 youth and 2 parents discussing educational experiences.
3. Organizational Reports and Documentation (n=22 documents) providing contextual data to triangulate personal narratives with organizational perspectives.

3.4 Data Analysis

Analysis employed a three-stage approach addressing each research question:

3.4.1 Stage 1: Educational Challenge Documentation (RQ1). Using ATLAS.ti, the researcher conducted thematic analysis of all digital narratives, focusing on the challenges which aggregated to the

themes of missed learning opportunities, stigma experiences, and academic consequences. Codes were refined through iterative review to capture the domino effects and educational amplification patterns described by participants.

3.4.2 Stage 2: Cross-Platform Pattern Analysis. The researcher compared themes across WhatsApp, podcast, and report data to identify consistencies and platform-specific discourse patterns, revealing how different mediums shaped the expression of educational challenges.

3.4.3 Stage 3: Technology Design Implication Analysis (RQ2). Based on identified challenges and community coping strategies, the researcher conducted systematic review of existing technological interventions in accessible education, evaluating their potential adaptation for this context and identifying gaps where new approaches might be needed. The systematic analysis was mainly done to guide the matching of the assumptions that were going to come out of the study with potential solutions to avoid leaving it too open ended and to narrow the scope of the interpretation.

4 Preliminary Themes

Analysis revealed three interconnected themes describing the educational landscape for students with epilepsy in Sub-Saharan Africa:

4.1 Theme 1: The Cascade Effect of Lost Learning

Digital narratives consistently described education loss as a cascading failure where each absence to class compounds previous absenteeism. A WhatsApp voice note from an Ethiopian student captured this vividly: "It's not just missing one class. When I have seizures and miss a week, I come back lost. The next lessons build on what I missed, so I'm lost there too. By exam time, I'm drowning."

Podcast interviews also revealed the hidden curriculum loss. A mother from Lesotho explained: "My daughter doesn't just miss math lessons. She misses learning in the context of other people, how to relate to friends, how to share, how to work in groups, how to take notes, dealing with conflict and disagreements, how to ask questions. Other children learn these things naturally by being there every day."

This cascade effect was also quantified in organizational reports showing that students with epilepsy in the region are more likely to repeat grades or drop out before completing secondary education. The digital narratives helped explain these narratives through lived experience.

4.2 Theme 2: Stigma's Educational Outcomes Amplification

Educational failure becomes a potential multiplier for epilepsy-related stigma and other misunderstandings. A viral WhatsApp forwarded text shared across multiple groups included the narratives of a Kenyan student who graduated, and they were looking for a job. All the job applications they had sent out had been rejected and they suspected that employers assume cognitive impairment due to poor grades on their transcript, not recognizing that frequent absences caused the academic struggles. The student lamented that for them to even graduate considering the amount of self-learning

they had to do would probably mean they are resilient which was actually part of the job advert on what the recruiter was looking for. Most job advertisements in Africa do not explicitly mention accommodations for disabled individuals.

Another powerful podcast testimony from a Malawian recent graduate revealed the long shadow of educational stigma: "Even now, with my degree, some colleagues doubt my abilities because they know I struggled in school. They don't understand that I struggled because of seizures, not intelligence."

Parent WhatsApp groups revealed agonizing decisions about disclosure. One Zambian mother's message, which sparked a lot of responses, asked: "Do I tell the school and risk my child being labelled, or stay quiet and watch him fail without support?"

4.3 Theme 3: Digital Resilience and Informal Learning Networks

The analysis uncovered extensive informal learning networks that have emerged organically within the student communities. These networks demonstrate innovative community-driven solutions:

WhatsApp Study Circles: Youth groups in Kenya and Zambia developed buddy systems where members record voice notes explaining lessons for peers who missed school or are having challenges understanding the content. One group created a repository of over 300 voice note lessons covering the national curriculum. Their biggest challenge was the WhatsApp group membership limits which was circumvented with creating multiple numbered groups with the same name. Some students also work out their math problems in their notebooks share a picture of the page and hope to get feedback and possible explanations or recommendations for further study.

Digital Mentorship Networks: Older students with epilepsy who successfully navigated education mentor younger students through WhatsApp video calls. A Kenyan university student mentored 4 secondary school students, helping them develop catch-up strategies for a small fee charged per hour.

5 Technology Design Implication Analysis

Drawing on Stickdorn et al.'s service design methodology, we developed a novel implications matrix that translates lived experiences into specific design requirements as illustrated in Table 1.

6 Discussion

This embedded netnographic study reveals a noticeable shift in how we tend to position ourselves as we understand accessibility in educational technology design for Sub-Saharan Africa. Rather than viewing students as passive recipients of externally designed interventions, our findings demonstrate they are active creators of sophisticated digital learning ecosystems with existing tools and these solutions transcend national boundaries and formal institutional structures. The findings also challenge and show that there is potential for uptake and utilisation of technological tools as communities find ways around the digital divide and connectivity challenges.

Table 1: Design Implications

Community Challenge	Existing Community Solution	Technology Gap/Limitation	Technology Enhancement Opportunity
Cascade Effect: Missing sequential lessons	Voice note lesson recordings by peers	Limited searchability; no curriculum alignment; inconsistent quality	Prerequisite mapping algorithms Cascade gap identification tools
Hidden curriculum loss (social learning)	WhatsApp group discussions and peer support	Lacks systematic guidance; informal mentorship	Collaborative problem-solving tools Virtual study group formation Peer interaction simulation
Academic stigma from peers and teachers	Parent disclosure dilemmas; student self-advocacy	No teacher education tools especially on how to deal with disabilities; reactive rather than proactive	Alternative assessment pathways Skills-based competency tracking Flexible disclosure controls Employer education resources
Grade repetition/dropout risk	Informal mentorship by successful students	Limited mentor availability; no systematic tracking	Micro-payment integration to attract committed mentors Quality rating systems Community knowledge curation
Inconsistent lesson quality from peers	voice note repositories for example in Kenya/Zambia groups	No quality control; curriculum gaps; language barriers on the African continent and mismatch in curriculums in different countries	Social learning analytics Co-design processes with peer evaluation systems Digestible universal curriculum
Isolation during absence periods due to seizures and medication side effects	WhatsApp and physical check-ins and emotional support from friends and family	Reactive support; no predictive intervention	Mentor-mentee matching algorithms AI enhanced predictive attendance tracking
Low bandwidth/connectivity	Voice notes & texts	Limited multimedia learning; delayed responses	AI-enhanced peer explanation matching Voice or text priority learning interfaces with references to text-books

6.1 Implications for Educational Policy

Our findings challenge the conventional approach to disability inclusion in African educational systems, which typically focus on physical accommodation and teacher training. The organic emergence of cross-border peer learning networks documented in this study suggests that educational policy must evolve from national to regional frameworks that recognize and help to build these existing digital communities.

6.2 Technology Design Considerations

Rather than retrofitting existing educational technologies with accessibility features, our findings suggest a "Community-First Design Methodology" that begins with the sophisticated solutions already developed by users.

The success of voice note repositories and mentoring systems reveals a previously undocumented design pattern and a true amplification approach calls for a design of technologies that maintain the intimacy and peer connection of small groups while enabling knowledge sharing across unlimited participants.

Our analysis reveals an opportunity for a novel AI application that could match knowledge with context. Unlike general-purpose

educational AI, this approach could use machine learning to connect students who missed similar lesson sequences, match peer explanations with individual learning styles, and predict which community-generated content will be most effective for specific learning gaps.

This means AI is not a teacher replacement but rather a community connection facilitator. The technology could become an invisible infrastructure supporting human connection rather than the primary educational delivery mechanism.

6.3 Limitations and Future Research

While our embedded netnographic approach provided unprecedented access to authentic community discourse, it was limited to digitally-connected communities. This creates both a limitation and a research opportunity. Future research should investigate this further to include students with limited or no internet access.

While our study documented visible digital communities, there is evidence that suggests extensive "invisible networks" of learning support that occur through SMS, offline peer tutoring, and family

knowledge sharing. Future research should develop methodologies for documenting these invisible networks, potentially revolutionizing our understanding of how learning happens in resource-constrained environments.

7 Conclusion

This study fundamentally reframes accessibility in educational technology from a compliance-based challenge to an innovation amplification opportunity. By documenting the sophisticated digital learning ecosystems that students with epilepsy have created across Sub-Saharan Africa, we reveal that the foundation for educational transformation already exists within communities.

The key insight driving our recommendations is that technology should amplify human connection and community wisdom rather than replace it. The WhatsApp study circles, cross-border mentoring networks, and peer support systems we documented demonstrate that students are not waiting for external solutions and they are creating their own. The question for technology designers and policymakers is whether they will recognize and build upon this existing innovation or continue developing solutions in isolation from the communities they aim to serve.

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