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'Navigating the Fog': A reflection on epistemic injustice in epilepsy treatment and care

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Introduction

This reflective article draws on findings from my qualitative doctoral research project, conducted between 2012 and 2016. The project explored perspectives and subjective experiences of adults living with epilepsy and their caregivers in a marginalised urban township in Cape Town. The study revealed a range of health system factors that impede access to appropriate treatment and care. These included factors such as language barriers and communication difficulties, dismissal of patients' concerns, loss of patients' records and negative attitudes of healthcare professionals (HCPs). Consequently, some patients reported experiencing medication side effects and undesirable physical symptoms that affect their lives (Keikelame & Swartz 2013).

Adults with epilepsy, who took part in the study, received their treatment and care from a local Community Health Centre (CHCs) in Cape Town and support from the local branch of the national epilepsy organisation. The CHCs are typically staffed by multidisciplinary primary health care (PHC) teams – comprising nurses, doctors, pharmacists and allied health workers and often operate 24/7 with emergency and obstetric services (Bresick, Von Pressentin & Mash 2019).

The strengths of the South African (SA) public health sector are that it comprises primary, secondary and tertiary health services, which are managed by the different provincial departments and monitored by the National Department of Health. It also has different policies, strategies and charters that are aimed at strengthening the public health system performance and enhancing quality service delivery. However, the sector continues to face major health system factors. These factors include negative staff attitudes, long waiting times, unclean facilities, fragmented services, inadequate supply of medicines and poor infection control and standards, which can compromise the safety and security of both staff and patients (Abrahams, Thani & Kahn 2022; Malakoane et al. 2020).

Concerning epilepsy, approximately 500 000 individuals in SA live with the condition, highlighting the urgent need for increased awareness and the availability of effective, affordable treatment options accessible treatment (Epilepsy SA, Intersectoral Global Action Plan [IGAP] 2023). This includes efforts to combat stigma and improve access to care by the World Health Organization (WHO) IGAP 2022–2031 (Leitinger et al. 2025). The challenge is further exacerbated by a shortage of neurologists and insufficient training among general practitioners, which hampers effective management and care for patients (Epilepsy SA IGAP 2023; Rosenberg & Leichter 2019).

To improve epilepsy management at the PHC level in SA and to address the knowledge gap among HCPs, the Standard Treatment Guidelines (STGs) have been revised. These STGs now emphasise treatment based on epilepsy types that are classified by the International League Against Epilepsy (ILAE), rather than on specific population groups (SA Department of Health 2025).

Despite advances in epilepsy treatment, the epilepsy treatment gap (ETG) remains alarmingly high. This gap is wider in lower- and middle-income countries (LMICs) than in high-income countries and more pronounced in rural than urban areas. This persistent disparity underscores the ongoing challenges in ensuring effective epilepsy care for all populations (Wagner et al. 2020). To address this, a regional pilot course called Epilepsy Training in Adult Medicine (ETAM) will be rolled out across Africa. The goal is to enhance the knowledge and skills of primary care providers. Organised by ILAE-Africa, this training is part of a broader effort to improve epilepsy care across the continent. It involves participation from SA and other African countries (SA Department of Health 2025).

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In this critical reflection, I use the metaphor of the 'fog' – which, from my reflection, vividly symbolises the challenges within the CHC from which my study participants accessed their treatment and care. These obstacles are reflected in participants' stories, which, from my reflection, align with the literature on epistemic injustice. I argue that recognising and addressing these health systems barriers can lift this fog and can enable an inclusive and equitable healthcare that addresses the holistic needs of people with epilepsy and those with other impairments.

Research design and methodology

I employed a qualitative exploratory design guided by Kleinman's Explanatory Models framework (Kleinman 1980; Kleinman & Benson 2006) and Bronfenbrenner's Socio-ecological Model (Bronfenbrenner 1979, 1989). Participants included adults with epilepsy, their carers (spouses, siblings, friends, neighbours), home-based carers and traditional healers, purposively and conveniently sampled. The recruitment process was conducted with the assistance of two field assistants and through my direct personal interactions with adults living with epilepsy and their carers during their follow-up visits at the CHC, and through the snowball approach.

Consent procedures included translating the consent leaflet into participants' languages, engaging local interpreters familiar with the spoken language, clearly explaining the study's purpose, and allowing sufficient time to support informed decision-making. Participation was voluntary, with rights explained, and signed consent obtained and reaffirmed before interviews and focus group discussions. For direct observation, verbal consent was secured, and ethical and cultural considerations were considered.

Data collection was carried out between 2012 and 2013. Methods included direct observation of clinical encounters between patients with epilepsy and a clinical nurse practitioner, pharmacist, and health educator from the local epilepsy organisation at the CHC; face-to-face, in-depth interviews conducted in participants' homes; and focus group discussions held at accessible venues within the study setting. Thematic analysis was conducted following Braun and Clarke's (2006, 2022) approach, and strategies to enhance trustworthiness included reflexivity, member checking and peer debriefing with relevant stakeholders at each phase of the project. Ethical approval was obtained from the local Health Research Ethics Committees.

To better understand these complex health system factors and epistemic injustices, I reflect on the methodological influences that shaped my approach and interpretation.

Mentorship and methodological influence

Leslie Swartz's mentorship has been instrumental in shaping my research approach and fostering ongoing critical self-reflection. I often described him as 'an elephant' in my YouTube video talk entitled 'My PhD Supervisor Was like an Elephant' (Keikelame 2018a) – a metaphor capturing his impactful presence and unwavering support. This metaphor, shared on YouTube, reflects both his influence and the strength of his mentorship. He emphasised principles of genuine collaboration, respect for community knowledge and social justice – values that profoundly shaped my interactions with participants and community partners directly affected by this research.

He encouraged me to adopt a manuscript-style thesis, comprising published peer-reviewed articles (Keikelame 2016). This approach enhanced the visibility and accessibility of my findings, allowing my research to reach a broader audience across various journals and thereby increasing its impact.

Throughout the research process, Leslie urged me to remain inquisitive during fieldwork, fostering ongoing reflection to ensure meaningful data interpretation. This inquisitiveness reminded me that cultural factors – though often overlooked in research (Smith 2021) – were central to how participants understood and experienced the phenomena under investigation (Keikelame 2018b).

By co-constructing knowledge with Leslie, local field researchers and participants, I was also prompted to engage with decolonising research literature from scholars such as Smith (2021) and Chilisa (2020). This engagement helped me to draw critical lessons from the fieldwork that could inform a decolonising research process – particularly with respect to power dynamics and the centrality of respect (Keikelame & Swartz 2019).

This personal reflection on mentorship and methodology leads into a broader discussion of epistemic injustice, a key theoretical lens through which I critically reflect on these health systems' factors and how they align with epistemic injustice literature.

Overview of epistemic injustice in healthcare

Epistemic injustice, as defined by Fricker (2007) in Alcalay (2024:115), involves the unfair dismissal or devaluation of individuals' knowledge claims, which undermines their credibility and capacity to contribute meaningfully. Okoroji et al. (2023) note that such injustices are common among marginalised and vulnerable populations, whose lived experiences and insights are often ignored or dismissed. These dismissals can lead to misunderstandings of patients' realities, inadequate care and the reinforcement of social inequalities.

Fricker (2007), as cited by Hunt and Blease (2024:2–3), identifies two key types of epistemic injustice in healthcare that serve as significant barriers: testimonial injustice and hermeneutic injustice. Testimonial injustice occurs when healthcare providers dismiss or underestimate patients' experiences because of biases, thereby undermining their right to proper care. Hermeneutic injustice arises when individuals or groups struggle to articulate or interpret their experiences because of a lack of appropriate language, concepts or interpretive resources (Carel & Kidd 2014). The scenarios provided below exemplify the two types of epistemic injustice.

Scenario 1: Ignoring patients' concerns

One adult male whom I interviewed expressed how he raised his concerns about the medication side effects and the physical symptoms that he experiences from living with epilepsy, and how have affected him:

> 'Since I started seeing the doctors, it's as if they are not interested. That's the way I see it … I tell the doctor about my fatigue … but I don't know if they take note of that or not. Another one said, when I told him I feel weak. I just become dizzy sometimes when I take these tablets … He said that it is something that is common …' (Male participant aged 42). (Keikelame & Swartz 2013)

In this scenario, the patient raised his concerns as illustrated in his personal account, and the response that his concerns are common is inadequate. This, from reflection, exemplifies testimonial injustice – a type of epistemic injustice where patients' concerns are dismissed or ignored. Such dismissals can result in some patients not adhering to seizure treatment, particularly when side effects and physical symptoms significantly affect person's quality of life.

By not receiving adequate counselling, such patients may disengage from formal healthcare and may seek alternative treatment from traditional healers. However, seeking healthcare from traditional healers is a fluid practice shaped by a variety of cultural factors, rather than merely a response to dissatisfaction with the biomedical system. This fluidity highlights how patients' decisions to consult traditional healers vary according to individual circumstances, illness experiences, cultural influences, and personal preferences. Interpreting such practices solely through the lens of dissatisfaction risks pathologising them and overlooking their cultural significance. These healers play a vital role in epilepsy treatment and care despite challenges in collaboration with biomedical practitioners (Keikelame & Swartz 2015).

Scenario 2: Language barrier between a Xhosa-speaking patient and a healthcare professional

I observed a language barrier between a Xhosa-speaking patient and a Xhosa-speaking nurse. The patient used a metaphor – 'I want to wash the heart' [*ndifuna kuhlamba intliziyo*] – to describe his illness experience. The clinical nurse practitioner did not understand the metaphor, even after the patient repeated it, nor did she seek clarification or consult another professional (Keikelame & Swartz 2013:39).

This scenario highlights how dialect differences, regional expressions or cultural metaphors – common in rural communities – can create interpretive barriers. Such barriers may also stem from a lack of resources, like interpreters or professional inaction, leading to miscommunication and compromised care. In sum, this scenario suggest that when patients leave consultations feeling that their concerns have not been listened to, or are ignored or misunderstood, underlying epistemic injustices may be at play. Systemic issues such as language barriers and the absence of interpreters align with the concept of epistemic injustice (Wilmot 2024). Addressing these issues is crucial, as they can leave patients feeling confused, unheard and unsupported, underscoring the need for strategies aimed at mitigating epistemic injustices within healthcare systems.

The following section proposes approaches aimed at 'lifting the fog' and fostering more inclusive healthcare.

'Lifting the *fog*' – Proposed approaches to address issues of epistemic injustice in healthcare

While strategies such as integrated Person-Centred Care (Coulter & Oldham 2016), Asset-Based Approaches (Wreford et al. 2024) and Decolonising methodologies (Chilisa 2020) are essential for addressing health systems' factors that may be suggestive of epistemic injustice, their effective implementation must be understood within the broader systemic context.

Healthcare providers operating in resource-constrained environments such as the public health system in SA, face structural barriers – such as high patient loads, limited staffing and inadequate resources – that can impede the realisation of these approaches. Recognising and leveraging patients' resources and knowledge requires systemic reforms, including supportive policies, equitable resource allocation and organisational change (Abrahams et al. 2022; Malakoane et al. 2020).

Without addressing these underlying systemic issues, any efforts risk remaining superficial or unfeasible. By tackling these structural challenges, we can create healthcare environments that truly empower providers to deliver inclusive, respectful, and culturally sensitive care – transforming clinical encounters from sites of injustice into spaces of equity and agency.

Concluding thoughts and call to action

In this article, I employed the metaphor of 'fog' to critically reflect on how the health system factors contribute to epistemic injustice, emphasising the urgent need to lift this obscuring barrier. Achieving this requires adopting a resolute commitment to a person-centred approach and shifting the focus from deficits to personal strengths and resources. Crucially, decolonising approaches must be embraced not only to challenge entrenched power imbalances and ensure cultural relevance, but also to expose and dismantle epistemic injustices, thereby fostering genuine collaboration grounded in humility, respect, and social justice.

Furthermore, active engagement from passionate advocates, activists, HCPs and researchers is vital to catalyse collaborative efforts toward transformative change within the healthcare systems. To realise this vision, targeted reforms are necessary to improve resource allocation, infrastructure and service integration, thereby ensuring equitable access and high-quality care for all. Equally essential is investing in comprehensive epilepsy management training and transforming the healthcare system into one that respects individual agency and delivers fair, just care for marginalised populations and those living with epilepsy.

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Data availability

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