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“Like Bananas with Brown Spots”: Epilepsy, Embodiment, Vulnerability and Resilience in South Asia

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Abstract: Employing an analytical autoethnographic methodology, this paper examines how the polysemic meanings and punctuated character of epilepsy produces social and corporeal vulnerabilities in an Indian childhood. The paper further establishes the importance of the family in influencing individual perceptions and constructions of chronic illness as well as in building resilience or increasing vulnerabilities. In examining the process of research, this paper also makes an argument that disabled researchers in the field can become vulnerable in multivalent ways but also argues that the act of disclosure of epileptic/disabled identities during the research process can become central to building community and resilience. This paper also complicates the often North-centric narrative of disability studies and underlines the importance of social contexts around individual categories of disability or chronic illness.

Keywords: epilepsy, embodied, India, resilience, vulnerability, autoethnography

“Like Bananas with Brown Spots”: Epilepsy, Embodiment, Vulnerability and Resilience in South Asia

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I exited one of the offices of the crowded neurology clinic where I was doing my fieldwork and enter the waiting room where I saw a knot of curious and chattering people surrounding her as she lay on the old, clean floor of indeterminate color. A patient at the clinic, she was maybe six or seven years old. I was unable to see much of her figure, obscured as it was by people around her but her long green dress fluttered around her as her thin unconscious body convulsed violently. I averted my gaze immediately—without understanding why I did so. I focused instead on her clearly distraught yet oddly resigned parents who quickly cleared the space of all sharp edges and objects with the ease of long practice; while nurses scurried from their stations with tranquilizers and gurneys. The faces around the young girl expressed the spectrum of emotions from fear to avid—almost morbid—interest and my stomach congeals and twitches with the effort it took to curb the visceral need to tell everyone watching to stop staring, to give her privacy. The nurses and orderlies saw to her and the crowd trickled back to their seats, talking desultorily. I too turned and walked back into the room from where I had come; shaken by what I had observed but with the uneasy sense that I did not really comprehend why I was so disturbed.

This incident had occurred within the first few weeks of a seventeen-month long (2010-2011) research project aiming to explore the experience of epilepsy in a large tertiary care hospital located in the Indian state of Kerala. Recent calls have been made for scholars to be cognizant of the role embodiment plays in the research process: to understand how their own bodies are implicated and imbricated within research at all stages (Ellingson, 2007; Sharma, Reimer-Kirkham and Cochrane, 2009). Brown and Boardman (2011) urge disabled scholars to reflect on their disabled subjectivities in the research process. Taking these prompts and employing an analytical autoethnographic approach (Anderson, 2006), this paper traces this researcher’s trajectories from illness to diagnosis and after and interprets epilepsy as social and corporeal vulnerability. I also utilize and demonstrate the concept of resilience (which is often conceptualized alongside vulnerability as part of a continuum) and can be broadly understood as a dynamic set of processes through which individuals acclimatize and adapt to adverse experiences (Fleming and Ledogar, 2008). The act of research itself is analyzed as empowering and risky for both researcher and participant, but I also argue that the research process builds resilience while also engendering new kinds of vulnerabilities. In doing so, this paper nonetheless presents a strong argument for peer participation in research among people with chronic illnesses or corporeal difference in South Asia. The methodological contributions in this essay are pertinent for scholars interested in autoethnography in general, but specifically in the global South. Further, as Andermann (2000) argued, these lived experiences of difference are crucial complementary narratives for those whose interests lie in the biomedical diagnosis and/or management of chronic illness.[1]

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[1] This paper employs both memory as well as written notes maintained during fieldwork as the data for this autoethnography. While this project involved survey instrument, I also kept a diary recording the process of requesting consent and any additional information volunteered to me during the interview. Employing recollections

Setting the Scene: Autoethnography as Method

Recent examinations of epilepsy from within disability studies have argued that as a category of experience, epilepsy occupies an ambiguous position both in popular and academic notions of disability (Rhodes, et al, 2008). Indeed, by its trajectory where seizures are punctuated with periods of remission, epilepsy challenges the binaries of disabled and non-disabled as those who live with epilepsy can move between illness and impairment. As Rhodes et al argued, epilepsy and disability both need to be conceptualized and analysed through 'multidimensional conceptions' and 'pluralist approaches.' Certainly, this sense of the importance of the social worlds in determining the experience of epilepsy is clear in the existing sociological and ethnographic research. For regions as disparate as the United Kingdom, Cameroon, Chile, Ethiopia and Benin, sociological research underscores that the physical symptoms and manifestations of epilepsy are overwhelmed by the felt and enacted stigma around the illness; to which the ubiquitous response was to remain 'in the closet' whenever possible (Scambler, 1998; Scambler and Hopkins, 1986; Scheider and Conrad, 1980; Jacoby, 1994; Schneider and Conrad, 1980, 1983; Jacoby, Snape and Baker, 2005; Baskind and Birbeck, 2005; Yang et al, 2007). However, this emphasis on stigma has the tendency to ascribe considerable passivity to individuals (Kleinman, 1992; Kleinman, 1997:61; Faircloth, 1998). Ethnographers' explorations of epilepsy take a different tack and have consistently underlined the importance of understanding the 'local moral worlds' within which individuals experience epilepsy. For instance, in both China and Turkey, the role of the family and community in the experience of

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from the past in research is problematic, but here I argue that since the events of illness onset and diagnosis were so transformative that recollection may be relatively reliable.

epilepsy has been emphasized in a socio-somatic model of disease and disability distinct from the more individualized model of illness articulated for the ‘Western’ worlds (Kleinman et al, 1995; Good and Good, 1994; Good, 1994). In various regions across Africa, scholars have demonstrated how people with epilepsy were forced into liminal social spaces—such as being refused access to communal eating spaces and prevented from passing on inheritances (Whyte, 1995; Baskind and Birbeck, 2005). Despite this body of work and the fact that close to ten million individuals are estimated to live with epilepsy in India alone, ethnographic explorations of epilepsy in South Asia are still rare.

Commanding rigorous self-reflexivity from the researcher, autoethnography hinges on the critical use of the researcher’s own experiences and history to generalise and theorise about the wider world (Ellis, 2004; Ellis and Bochner, 2000; Anderson, 2006). Autoethnography possesses immense potential in the study of chronic illness and disability, particularly when we take into consideration the fact that illness as framed within both biomedicine and anthropology continues to perpetuate the ‘professional transformation’ of human experience and suffering: often losing ‘the complexity, uncertainty and ordinariness of some man or woman’s unified world of experience— (which) is also missing when illness is reinterpreted as social role, social strategy, or social symbol…anything but human experience’ (Kleinman and Kleinman, 1991: 276). Told as they are through the voice of ‘wounded bodies’, autoethnography can counter the ‘interpretive dilemma’ of the anthropologist as well as shift the dominant cultural perception of the ill person away from ‘passivity…toward activity’ (Frank, 1995:2).

Autoethnography has been deployed to the study of a broad range of illnesses, disabilities and corporeal experiences ranging from cancer (Karnilowicz, 2011; Doshi, 2014), HIV (Spieldenner, 2014), chronic pain (Birk, 2013), bulimia (Tillmann-Healy, 1996), obsessive-compulsive disorder (Fox, 2014), kidney failure (Richards, 2008; Etherington, 1991) and hospitalization (Uotinen, 2011) although this is far from an exhaustive list. Scarfe and Marlow (2015) recently used this method to explore the transformations in the life of an athlete that followed a diagnosis of epilepsy and followed her experience of returning to her sport. With a compelling use of narrative, they establish how diagnosis of illness can impinge upon the researcher’s sense of self and identity. Further, the authors argued that such methods are a necessary complement to the quantitative approach that often dominates the study of epilepsy in addition to underlining the value of such narrations as a coping mechanism for individuals living with chronic conditions. In the context of South Asia, Chaudhry’s recent work engages with the meanings, possibilities and limits of disability as researcher identity in the field (Chaudhry, 2018).

By virtue of its particularities, analytical autoethnography can be very useful in understanding and analysing the experience of disability or illness in the global South for many reasons. This method permits researchers some room to avoid the academic reduction of objectification of experience while also serving to counter being ‘colonized’ by others (Falah, 2012) particularly when it is utilized as an emancipatory discourse; and has been employed as such by indigenous scholars (Bainbridge, 2007; Whitinui, 2013). Further, autoethnography is an effective means of countering the critique that is often levelled at contemporary disability studies—primarily that it is dominated by the experiences, voices, theories and perspectives of the global North (Meekosha, 2011; Grech and Soldatic, 2015).

Growing Up ‘Wrong’: Ruptures in an Indian Childhood

> *First time:This was the last carefree me.It had been a terribly warm summer. School was out and I was visiting India from my home in Abu Dhabi. I was eleven years old. I loved*

those gloriously carefree summers and always looked forward to going back to India. Those were times best remembered for monsoon rains, family reunions and afternoons buried in the local libraries. One afternoon, I had been kneeling on the cream and brown mosaic floor in front of the ancient television in my grandparents' house; trying to adjust the image on the fuzzy screen. I don't recall what I had been watching, but I remember the heavy, pounding rain outside that was interfering with the reception and leaching the afternoon of light. Suddenly, the flickering grainy images took on an odd hypnotic quality; a quietly buzzing black and white vortex was drawing me in. I couldn't take my eyes off the screen. The television receded as I fell backwards in what felt like slow motion. For the first time, I became a visitor in my own body as something else--a strange but soon to be familiar enemy—took over. Soon, I was floating, but it was not a pleasant feeling—it felt surreal and disturbing. The next thing I remember is waking up with a headache pounding through me, my body simultaneously exhausted and in pain; my shocked family standing around me.

For two years following my first seizure, I had little idea what was ‘wrong’ with me as I was not told why I had fallen that day and why I had to take those purple and white pills daily, or get my blood drawn so frequently. I only knew that something was wrong, and whatever it was made my parents profoundly upset. I was told the diagnosis when I was thirteen:

Neurologist (speaking to me): You have a condition of the brain. It's called epilepsy. Your brain, the neurons in your brain, you must have studied that in school, haven't you? There is something that makes them fire when they shouldn't. That's why you faint and fall. It's ok (to my crying mother). If she takes the medication she should be fine. It will be *fine (also to my mother).*

As he continued to speak mostly over my head to my mother in that grey room with the green metallic table, my limbs became cold and my feet felt like they were welded to the floor. He kept talking as if I understood. But I didn’t. I didn’t dare to ask any more.. All I knew is that what he said clearly scared my parents. My father, a doctor himself, could scarcely meet my eyes.

I had always known vaguely that there was something ‘wrong’ since my first seizure. But this moment of diagnosis was different. I knew with a gut wrenching certainty that I was profoundly and irretrievably altered. My body had betrayed me. I did not belong; not anymore.

But it was illness, rather than diagnosis, had rung the death-knell to my childhood; which I remember most as punctuated by seizures and spent in reversals and revivals. Every respite from seizures was riven by unhappy and uncertain expectation of the next ‘episode’. In a brief, rather puny, gesture of rebellion against this dark, moody and unpredictable entity that now occupied my body against my will, I stopped taking my anticonvulsants. Following two seizures and several fraught visits to the doctor, my parents’ anger and bewilderment washed over me, but I was benumbed.

How could you? You know how important it is! Why would you not take your medicines? Why?

I had no answer.

The early onset of chronic illness has often been identified as being a transformative event in the lives of children and adolescents; one that immediately impinges on multiple domains of individual and social domains, including personhood and notions of self (Pinquart, 2012). In the instance of conditions like epilepsy, the onset and diagnosis of illness can also render entire families both ‘othered’ and isolated. Epilepsy came to signify a most profoundly undesirable corporeal difference and marked my family and myself as being socially non-normate (Garland-Thomson, 1997, 10-12). While my family’s caste and class locations provided social protection and economic support to counter the corporeal and social risks posed by chronic illness, my family nonetheless struggled to accept epilepsy in their midst. From the moment I first fell to the ground in a seizure, illness became the dominant narrative in my life and in the lives of my family. My mother sought comfort and answers in her faith; temples, *poojas* and prayers became more common than before my illness. My father lost his faith and could not bear to even pronounce the word ‘epilepsy’, let alone discuss it. For my middle-class Hindu family, epilepsy was not understood in terms of karma, but as a somatic difference, albeit a difference that was accompanied by negative social connotations. ‘Perceived’ stigma thus played a powerful role in my family’s responses to epilepsy (Jacoby, 1994). Unsurprisingly, I kept my illness hidden from the world around me for decades after my diagnosis; a choice shaped by my parents’ almost desperate urging (Schneider and Conrad, 1980). It is a conversation from my adolescence that I remember with some disquiet. My parents, quietly and sternly telling me that I would be thought ‘wrongly’ to be ‘sick’ when I was actually ‘normal’.

> *‘Never tell any one of your friends, understand? They would never understand. And they would talk about you. People don’t understand.’*

Sociologists have termed this ‘stigma coaching’ (Schneider and Conrad, 1980; Scambler, 2011). In retrospect, it is imminently easy to understand why my middle-class and educated family reacted so strongly to chronic illness in their midst. For my parents, the costs of visibility and disclosure outweighed the benefits (Tierny, 2001; Rhodes et al, 2008). India was and is a harsh and unforgiving place for people with epilepsy. For instance, Indian civil codes pertaining to marriage had clung tightly to constructions of epilepsy that underlined it as an undesirable and hereditary trait until the end of the twentieth century. (Mani, 1997; D’Souza, 2003; Thomas and Nair, 2010). Similar constructs existed around procuring driving licenses as well as qualifying for insurance. Concealment and silence therefore allowed my family to negotiate and militate the potential negative consequences and stigma associated with epilepsy.

Out of the Closet: Ceasing to ‘Pass’ and Constructing ‘Sameness’

Nearly twenty years after my first brush with epilepsy, I returned to the very same clinic where I had been diagnosed with the illness; soliciting interviews and researching the experience of illness. My return to the clinic was complicated, fraught and problematic: this was the place where I was diagnosed and treated as a child.

> *The clinic was located within a large tertiary care hospital which was an odd hodgepodge of differing architectural styles, all piled on top of each other with less aesthetic concern than convenience; as the building had been renovated and extended in multiple eras. I stood in line outside the ground floor entry, guarded by a bear of a man with a lush, impressively groomed mustache. A Cerberus-like guardian to the inner clinics, he was gruff and fierce. I waited for him to scan my security permit to access the hospital. Although it was all in order, my mouth was dry, my stomach flutters and I could not calm my nerves. But when I got to the head of the line, the security guard just skimmed my permit, asked some desultory questions and then waved me through enthusiastically.*

Inside, the spaces of the hospital were intimately familiar, yet simultaneously strange. I entered the out-patient areas of the hospital and the heat and the humidity hit me in the face while a few solitary fans spin pointlessly. As I made my way through, I am consumed by memories, all of them painful, none of them easy. I could still recall the smells of disinfectant, sweat, the occasional metallic tang of blood and heat in the hospital corridor where I had waited for doctors, examinations, scans and EEGs as a child; the patterns on the ceiling of the room where I resentfully had blood tapped from my veins; the pounding and clanging of the MRI machine around me.

The intensely crowded waiting rooms were still crammed with chairs. Gurneys lined the walls, covered with sheets and also hold patients too frail to sit or stand. Despite the overt air of chaos, there was an underlying order to the milling crowds. Nurses manned their desks with fierce concentration and gravitas, all the while sorting through the mass of queries from anxious patients and harried junior doctors. Doctors sailed through the crowds like ships parting the waves, trailing in their wake residents, junior doctors, social workers, research assistants. Their arrival galvanized the crowd, many of whom had come to the hospital hours in advance; some from neighbouring states. The clinic itself was in a tiny room leading off from the waiting room and was equipped with two tables, several chairs and an examining table.

I sat down and wondered to myself, slightly panicked: What am I doing here?It was in a clinic such as this that I too had been poked, prodded, tested and diagnosed with epilepsy. Now, though, I was 'Dr. Nair', the researcher. This is *how the staff at the clinic referred to me, and how they introduced me to potential respondents. But I heard the curious appellation and felt like an impostor. I knew I sat on the threshold; one foot in and one foot out.*

There is no denying the affective toll of the hospital as a research site and obtaining consent for interviews proved even more challenging. The women attending the clinic inevitably arrived with family members who served as gatekeepers to the patients themselves. When I began to solicit interviews in the tense, emotive atmosphere of the clinic, responses were routinely negative and often scuttled by ‘bystanders’ who worried that hitherto the routinely concealed ‘epileptic’ identities of the patients would be outed by a conversation with an outsider/stranger. It did not help that my last name simultaneously marked me as ‘Hindu’ and belonging to a non-Dalit caste community—such markers could potentially have put some participants even more unlikely to consent. Further, although chosen for their coolness and serviceability rather than fashion, my usual research garb of cotton *salwar-kameez* marked me as belonging to the middle classes. When I spoke, my accented Malayalam (the result of having grown up in the Middle East and speaking Malayalam only at home) underlined additional class differences between myself and any potential participants. In these initial steps of the research process, I was silent about my own encounters with epilepsy. Although I had been a citizen of the ‘kingdom of the sick’ (Sontag,1978) since the age of eleven, I nonetheless had routinely concealed my own encounter with epilepsy from much of the wider world, out of a fear of social and individual vulnerability. And as long as I chose not to reveal my epilepsy, these were the identities that were foregrounded in my interactions; but most dominant was that of ‘Dr Nair’, the researcher. These markers only exacerbated the distance between them and me, diminishing any rapport I sought to create. Yet, as most autoethnographers should, I did possess those ‘qualities of often permanent self-identification and full internal membership’ with the group I chose to study: people with epilepsy (Hayano, 1979). This eventual realization is certainly a (not entirely conscious) part of the reason I came to choose to disclose my epilepsy to potential participants when I was explaining the nature of the project. Up to that point, I was still careful about whom I told about my illness. As much as I had acknowledged how it had shaped my sense of self, I still chose to conceal it for the most part.

I will focus on one interaction here to explore how researcher disclosures of invisible disabilities can generate vulnerability but also build resilience. Sajitha[2] was the second participant to whom I disclosed my epilepsy as being the motivation for my research.

> *Ravi was a lean, wiry and animated man in his late 50s; whose presence initially tended to dominate the interview despite his rather small stature. His daughter Sajitha resembled her father physically. Her personality, however, could not have been more different from that of her father—she was quiet and reserved. When we sat down to talk, Ravi peppered me with questions. When I explained why I was working on the subject and disclosed my own encounters with epilepsy, Ravi was struck to silence. Nothing was said for a couple of minutes. I sat in front of them, waiting. Ravi watched me with shocked curiosity; clearly critical. Sajitha was the first to break the silence that had fallen. Eagerness in her eyes, she leaned towards me and asked: ‘Can you tell me something? How did you study? How did you get your degrees? I mean, with this? I explained that it had not been easy. But it had been possible.*

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[2] The institutional ethics board in the hospital had extensively interrogated the application for research among women with epilepsy, and informed consent (in Malayalam) had been gathered from every participant. Every attempt was made to respect the patients’ need for privacy, and their names are changed here to further protect them.

> *Speaking for the first time since I had stated I too lived with the illness, Ravi asked frowning and apparently disapproving: ‘So do you just go about telling everyone about it?’*
>
> *Yes, I said, discomfited but wanting to be truthful. I used to not say much, but now I did. My response seemed to further silence him, but Sajitha began to talk to me, and was almost garrulous. She continued to talk very openly about the role epilepsy played in her life.*

Through this act of disclosure, I was able to signal to participants that that I too had crossed the threshold into the ‘kingdom of the sick’, levelling at least one invisible yet previously impassable wall between myself and my participants (Sontag, 1978). Ceasing to pass as ‘normal’ in the research setting transformed the space between the researcher and subject and rendered epilepsy my dominant, master identity, if at least for that moment. While interviews had previously been stilted, stalling and largely unproductive, the act of disclosure as part of my introduction served to remove their undeniable fear of the ‘stranger’-interviewer; who was always distant and alien to them. I had become familiar and known and did not represent the danger of unintended disclosure and loss of status; for I too carried the ‘mark’ of epilepsy. Through the act of disclosure, I had become ‘just like them’. Further, in such research constructing the illness (Good, 1994), researcher disclosure possesses particular effectiveness in drawing out the women’s individual narratives. By choosing to disclose my experience with the same illness, I found that women were provided with the space to present their own narrations of illness, rather than letting their families do the narration for themselves. I often found that women who were otherwise initially silent or limited in their narrations of illness were more eloquent subsequent to my disclosure; while their families simultaneously became more comfortable with the conversation. Researcher disclosure of disabled subjectivities can thus be instrumental in the erasure of *some* of the inevitable power asymmetries inherent in fieldwork. But, as important as the act of disclosure came to be in terms of my research, personally, the very processes of research built resilience through the act of communicating a part of myself that I had more often hidden from the world. As I articulated epilepsy as part of my rationale for the research, I also began to construct a new narrative for my illness and what it meant in my life. Yet this act of disclosure can also render the researcher uniquely open and vulnerable to the gaze of others. For instance, after I revealed my epilepsy to potential participants, my body was immediately reduced to being 'epileptic' over all else. Ravi's reaction in the narrative above illustrates how disclosure did leave me socially vulnerable. Once revealed as epileptic, my body also often became a site of reference for most of the participants; which was sometimes discomfiting. Interlocutors now defined and narrated their experience of epilepsy using my body as an example or exception. Further, while the response to my disclosure of epilepsy was almost uniformly positive with other individuals who shared my diagnosis, responses to my decision to talk openly about my epilepsy outside the clinic often had difficult and unforeseeable consequences. One of the more striking was an exchange between myself and a fellow academic and social scientist.

> *Standing in the corridors, having one of those conversations-in-passing that characterize university life, we chatted about our respective work. I describe the project at the epilepsy clinic to my colleague, what we hoped to achieve; also adding why I was interested in the subject—my own brushes with the illness. My listener nods seriously through the entire recital and asked the question that had troubled him throughout:*

‘So how do the families get them (the women who were my research respondents) married off then?’

Me: Well, for many of the women I speak to, they say they cannot tell anyone who comes to them with a ‘proposal’ for an arranged marriage. Many women report that they confront many rejections because they revealed they had epilepsy.

He continues to nod vigorously, rubbing his chin, apparently pondering what I had said. Then he pauses, laughs uproariously and then says:

‘Well, it would be difficult, isn’t it? It’s like buying bananas with brown spots’.

Struck speechless, I could say nothing much in response.

In the same way that self-advocacy and disability communities have occasionally been paths towards producing and accentuating resilience, the act of conducting research in the hospital where I had been diagnosed provided me with an opportunity to seek and build a sense of sameness, if not community. This in turn engendered a tenuous resilience, complicated by the vulnerabilities resulting from the affective toll of the research process.

Doubly Deviant: Disability, Divorce and Disclosure

It was neither ‘arranged’ nor a ‘love’ marriage. Contracted on the cusp of both and yet neither. Through my fear of being alone and my parents’ fear that I would never find a ‘suitable boy’ because of my epilepsy. I did not know much about him, but was willing, like so many women in my family had before me, to learn to live with him. Before the marriage, he was loving and friendly. He wanted to be with me, or so it seemed. I went ahead with the marriage; and *don’t remember much about that day—a blur of impressions. Silencing the voice inside that told me something was wrong.*

Two days after the marriage:

He breaks out into an angry rage so powerful that he pushes and breaks the TV in my parents’ home.

Two weeks into the marriage:

I wait late in the night for him to arrive. He returns, reeking of marijuana and alcohol. Aggressive and abrasive, he starts off. An unpleasant, long fight, well into the early hours of the morning. I spend most of the night listening to him rage on. Such anger. Why was he so angry? I’m a mouse, I tell myself. Say something. But I listen to his rage and cannot speak. At three in the morning, I am exhausted. My hands are shaking. This pattern repeats itself for weeks.

Finally, he says what I fear. He never wanted to be married to a ‘sick woman’.

Why did he marry me then?

Money.

Dowry.

To my shame, I am even willing to live with that.

Until it becomes physical. It started small, and then ended with him grabbing my neck.

I filed for divorce, and had to defend my decision to a scowling, black-clad judge who asked me whether I could not ‘adjust a little more’.

Returning to fieldwork in India, it had been nearly a decade since my divorce. I was confronted with the realization that divorce was significantly stigmatizing—particularly for women. In a society where marriage and motherhood are still perceived as necessary milestones for women my status as a childless divorcee often transcended my identity as a woman with epilepsy (Reissman, 2000, 128-53). Marriage and motherhood have been conceptualized as central to Indian women's domestic citizenship (Das and Addlakha). This sense that divorce had 'othered' me in a far more pronounced way than epilepsy had not became self-evident through the research process. As I narrated key life events including illness onset, diagnosis, education and career into the introductions I made to the participants, I was often asked about my marital status openly.

I had cordoned off Mary and her mother, Padmaja from the stream of patients for a private interview. I explain the project and introduce it briefly. They listen and Padmaja, who is a determined and vocal woman of some will who speaks for the two of them.

She asks me: 'So what about you, Doctor? Are you married?

I can see she anticipates no other answer other than a positive one; and I can almost sense the second question hovering on her lips: How many children do I have? Instead, I gird myself for her reaction and tell her I'm divorced, and have been for nearly ten years. Padmaja is startled, as is her daughter, by the mention of divorce. She hesitates to speak, her previous assurance gone. She looks me over with some shock in her eyes and says: 'Well why? Why did it happen?'. Familiar with the blunt question, I responded that my ex-husband was not a good man, and that he decided to use my epilepsy to get dowry from my family. "sometimes people like you (gesturing to me and her daughter) need to do that to stay married." I responded that he got violent. She still looked unbelieving, and then burst out with: 'Why haven't you gotten married again?' After some hesitation, she then says: 'Don't you want to get married?'

I am intensely uncomfortable with the line taken by the conversation and say instead rather vaguely: 'Well there is time yet'.

'You should get married you know. Find someone, get married, and take the burden of your illness off your parents'.

Even more uncomfortable, and beginning to get angry, I mumble a vague assent and then move the conversation back towards the interview.

Mine is not an unusual story in India. Dowry harassment is all too common, and for women who are considered to be 'different', a dowry becomes the literal price of marriage (Singh, 2013). For my respondents, my divorce was a mark of personal failure, a disastrous event for my family, an undesirable social label from which there was no recovery but remarriage (Singh, 2013). For many of my respondents, divorce was more stigmatizing than epilepsy itself—indeed in some ways, my participants conveyed the perception that epilepsy could be mitigated or 'managed' through marriage. These interactions underscored the importance of an intersectional approach to disability, as others have pointed out before (Hussain, 2015). Certainly, epilepsy does not exist in a vacuum and is not experienced as such. It necessarily intersects with income, caste, gender and marital status to transform the social experience of disability/chronic illness; but equally important were the cultural constructions around gender roles. If anything, these interactions underscored how disability/chronic illness can never be considered in isolation but must always be contextualized.

Concluding Remarks

Epilepsy in India is both ubiquitous and understudied, despite the fact that the region is home to at least ten million people with epilepsy (Santhosh, Sinha and Satishchandra, 2014). Largely explored through biomedical perspectives, the humanities and social sciences have yet to explore what it means to live with this often 'invisible', yet significantly disabling neurological disease in South Asia. This paper uses the author's experiences to describe the vulnerabilities resulting from epilepsy and specifically examines how the disruptive, punctuated nature of epilepsy has the power to influence families and their worlds as well as the ways in which disability is complicated by other axes of difference. This paper establishes that people with epilepsy in India routinely practice concealment because of the stigma ascribed to corporeal non-normativity, even when the category of disability/illness is not widely understood. This paper also makes a broader argument for the use of autoethnography in disability studies in the Global South, despite criticisms of the method being individuated, self-indulgent and narcissistic (Atkinson, 2006; Delamont, 2009).

As a researcher living with epilepsy and working on disability, engaging with my embodiment as an 'epileptic' researcher is crucial to understanding the limits and possibilities of my work. This article attempted this self-reflexivity through narrative and explores my tenuous stance in the field as I shifted uneasily between patient and ethnographer. I also reflected on the consequences of disclosure in the field and the difficulty of negotiating stigmatized social labels in the field. To a lesser extent, this article was also in some way an attempt to explore how my silenced body was given a voice, although it is not intended as a celebratory 'coming out'. The clinic and the narratives I collected served not only to provide me with a space for articulating my own subjectivity as a person living with illness; but were equally a space for reflection on my own experiences. In the clinic, I was confronted by the corporeal manifestations of epilepsy through reiterated narrations of symptoms, injuries, medicines and lifestyle regimens as well as by the social constructions of the illness. Listening to the women who shared their accounts of illness progression, biomedical procedures, social trajectories and responses often triggered an almost atavistic and physical response, in addition to eliciting memories of my own previous status as a patient rather than a researcher. Equally important was my eventual realization that through the repeated disclosure in the clinic, my own narrative of illness was rendered both more coherent and comprehensible in a way I had not expected (Bochner, 1994; Bochner, Ellis and Tillmann-Healy, 1996). This disclosure created the space for interlocutors and their families to feel comfortable with discussing an illness that was otherwise systematically and broadly concealed. For many of my participants, disclosure served as a powerful if not absolute equalizer in the usually asymmetrical relationship between ethnographer and subject. The resulting 'enhanced rapport' has its costs; for it does render the researcher particularly vulnerable and bare.

For me, disclosure was equally a sigh of relief as much as it was a statement of belonging in a community no one wishes to claim.

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