

## Getting Close to the Context and Experience of Illness: Critically Reflexive Fieldwork in Qualitative Health Research

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### Abstract

Since more than three decades, the perspectives of critical health psychology and new cross-cultural psychiatry within the field of health sciences have renewed the focus on experiences of illness and healing. Such an impetus to research exploring the person's life experiences was based on the imperative of how the cultural and structural processes intricately shape the diverse experiences of illness, distress, or healing. The task of getting close to the person's experiences of illness or healing inherently requires a qualitative researcher's orientation or motivation to unravel the hierarchies or power positions (related to gender, religion, caste, class, or academic expertise) surrounding not only the participant's life context but also the researcher-participant relationship. In order to understand these hierarchies and build a trust- or compassion-based research-participant relationship and to explore the participant's experiences within context, this paper illustrates the use of critical reflexivity, i.e., researcher's critical and continual awareness of his or her personal, theoretical, epistemological and ideological assumptions behind research and the researcher-participant relationship. Examples from our ethnographic studies (on caregiving of children diagnosed with Autism Spectrum Disorder, transgenerational trauma, disability experience, 'personal' recovery among severely mentally ill persons, social suffering of homeless mentally ill people, and institutionalized care for mental health) indicate how doing critically reflexive fieldwork not only helped us comprehend the socio-political and cultural contexts of participants' lives but also enabled us to develop an empathic understanding of their distress or healing.

*Keywords:* critical reflexivity, experience, health, illness, qualitative research

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It is well-established that the advent and growth of qualitative research in the field of health sciences were endorsed and advocated by psychologists, psychiatrists, and other social scientists who adopted critical and interdisciplinary perspectives such as critical health psychology (Hepworth, 2006; Lykes, 2000; MacLachlan, 2000; Murray & Poland, 2006; Stam, 2006) or new cross-cultural psychiatry (Kleinman, 1987; 1988a, 1988b, Lewis-Fernandez & Kleinman, 1994). These critical and interdisciplinary perspectives are premised on reaching out to or getting close to the voice, i.e., subjective experiences and identity (Sampson, 1993) that are often subdued or silenced by the positivist approach to research in health sciences. It is paradoxical that this approach uses implicit Eurocentric assumptions such as mind-body dualism, egocentric view of selfhood, and considering culture as a by-product of biological processes (Lewis-Fernandez & Kleinman, 1994), alongside its claims of doing objectivist and universalist science. It is not surprising then that qualitative health research (QHR) generally adopts what may be understood in Gergen's (2015) terms as its *deconstructive* and *reconstructive* features. The former is about being critically aware of Eurocentric (as well as objectivist) assumptions that underlie the positivist research approach, while the latter entails research creating research spaces where the researcher and participants may form a trust-based relationship in order to enter into a genuine dialogue about their experiences and standpoints.

*Reflexivity* is a process that facilitates the learning of deconstructive and reconstructive features of QHR. It is defined as the orientation of the researcher to be consistently critical and conscious of the implicit premises, assumptions, ideologies, and human relations associated with research (Chamberlain, 2004; Priya & Dalal, 2015). Chamberlain (2004) posited that researchers are not independent of their research and are, in fact part of the social world that they seek to

investigate; they are intimately involved in the research practices that they conduct. This raises questions about the nature of the effect of their involvement, and reflexive researchers attempt to address such issues—who is the researcher (female, black, middle class, and so on), what do they bring to the research (values, assumptions, and so forth), and how has all that impacted the practices, findings and outcomes of the research?” (p. 125)

Despite the apparent incorporation of the ideological or hierarchical aspects of research and the human relationship associated with it in the definition of reflexivity, Gemignani (2017) and Gergen (2015) have called for *critical reflexivity* as they emphasize the researcher to be critical of one’s own status or authority that one brings to the researcher-participant relationship. Critical reflexivity also accentuates the need to outgrow the narcissistic approach to research that may blind the researcher to look beyond the theoretical and motivational standpoints that he or she had at the beginning of research, as if the researcher remains unchanged as a scholar and a person throughout the research. Indeed, these methodological as well as ethical questions that critical reflexivity invites researchers to address are not entirely new. The works of social scientists such as Charmaz (2017), Frank (2000, 2001), and Radley (2004) have addressed these indirectly or in parts. Yet, we contend that researchers seldom find systematic and illustrative examples of research that highlight the role that critical reflexivity may play in adopting the deconstructive as well as reconstructive features of QHR. Keeping this in mind, this paper addresses the following questions:

1. How does a researcher prepare motivationally as well as academically to be critically reflexive about the QHR one plans to undertake?
2. How do reflections about the researcher-participant relationship address the hierarchy often ingrained in it?

3. How does the research process foreground different aspects of the roles, relationships, and identity of the researcher in order to create an empathy- and trust-based researcher-participant relationship?
4. How is a researcher able to connect or empathize with the participants' experiences if he or she might not have had similar experiences in life?

We utilize the reflexive accounts on ethnographic studies conducted by the first six authors of this paper on caregiving of ASD children, transgenerational trauma, disability experience, 'personal' recovery among severely mentally ill persons, social suffering of homeless mentally ill people, and institutionalized care for mental health respectively to address these questions related to the use of critical reflexivity. It is noteworthy that the question '3a' is addressed through the inclusion of the first three research reflections where the researcher had a similar experience (with herself, a family member, or a close friend) as that of the participants, while the last three instances involve the researcher who did not have a similar experience. In our account of their research journey presented below, we have highlighted, (a) 'locating the researcher' while proposing the study and while addressing the hierarchy within the researcher-participant relationship, (b) being aware of the cultural and structural contexts of participants' lives, and (c) insights about experiences of illness or healing through empathic connections with the participants.

### **Research Reflection 1**

#### **"Can I Remain an 'Ordinary' rather than a 'Special' Parent": Listening to the Voices of ASD Parents**

Autism Spectrum Disorder (ASD) is considered as one of the most demanding childhood developmental disabilities that a family can face, primarily because of the tribulations or distress

its characteristics (i.e., limitations in social communication and interaction, and restricted and repetitive behavior) can bring about in its members. The notion of growing as a ‘normal’ family gets disrupted with the advent of ASD. My doctoral research aimed to explore the parents’ potential experiences of self-growth along with those of intense distress, from an interdisciplinary approach of new cross-cultural psychiatry that focuses on subjective experiences of suffering and healing through ethnography and other qualitative approaches. Thirty sets of parents were interviewed in Lucknow and Kanpur, tier II cities of Uttar Pradesh. Interview sessions were carried out in the home setting. Access to parents was gained through special schools and therapy centers.

### **My Motivation to Explore the Lived Experiences of ASD Parents**

The idea of my doctoral research can be traced back to a time when I was a part of a multidisciplinary team in Child development and Guidance Clinic (CGC) in Delhi. During my interactions with patients, I came close to an ASD family for the first time only during a home visit. In the clinic, however, everything used to be seen from the professionals’ end; appeared to be the only story which was ‘complete’, where the broad aim was to diagnose the case, psycho-educate the parents and recommend intervention, irrespective of the fact that parents didn’t have any say or voice in that (the way it should have been). As a professional, I often felt trapped in the hierarchy of a systemic world; at the professional’s desk no matter that I would claim that I was doing the required, but, in reality, I was always bound by space and time that seldom allowed seeing the world of parents from their own perspective. Thus, my professional role would never let me come close to the parents in the clinic. Though inwardly I wished to be more humane, but, the hierarchical spaces I was bound in did not let me act as per my virtues.

Once I visited the home of a family, where I witnessed the ‘incompleteness’ of the child’s case-history taken in our clinic, i.e., CGC. The experience at home—its settings, its little things, the interactional space being ‘home’ where a parent resides—elucidated the reality of being a parent to an ASD child. This home-visit was not about extracting the case-details from parents, but it was more about *knowing* them. There was ‘something more’ to every little thing; here the child’s case-history was not merely a case-detail, but a story. This story made me see that as a professional, one was just ‘giving’ with no ‘care’ in it, and this caregiving was incomplete. It often made me wonder what was happening at my place, with people who are residing in places with scarcity of resources (Lucknow and Kanpur). I wanted to *understand the seen-incompleteness*. I wanted to bring forward the *complete story* of those invisible and unheard parents, and this became a major research goal in my doctoral research.

### **Whether to Align with the Institutionalized ‘Care’: Negotiating My Identity as a Researcher**

I wanted to interview parents in their most comfortable setting, i.e., home. But, due to hierarchal settings, I was expected to interact with them via designated centers. Parents could only be located through special schools or therapy centers. As a researcher, it was important to know the quality of relationship that these parents had with the center. My decisions were to be based on what was primarily seen through parents’ eyes and therefore my ways of relating with the system (clinic or center) relied heavily on parents’ relationship with it. Thus, since the beginning, I tried to remain as neutral as possible and tried my best not to get soaked in the identity of being a ‘part of the system’. In order to understand parents’ perception of the center, I decided to do a brief focused group discussion with them. The outcome of the discussion gave various points of consideration. One of the most important points was that parents of many

centers were not that satisfied with its working style. The dissatisfaction they had from the system made me reconsider my role of associating with the center. I became sure that if my identity had to be aligned with the centers, it would hamper my relationship with the parents and it would become difficult for me to establish any kind of close relationship with them. The parents would always be apprehensive about discussing things about centers. As my priority was to '*get closer to the parent*', I decided not to be a part of the center because parents' dissatisfaction with the system is also a *part of their story* which I wanted to listen to in detail. My predominant motivation was to bring forward their complete story of being a parent to an ASD child.

### **Listening to the 'Gendered' Nature of Parents' Experience**

The society we reside in has its own norms and culture. Being a mother and being a father, both hold different meanings in our culture. Thus, being aware of these aspects of culture and 'getting closer' to them required a different set of understanding and instant awareness during interview sessions. As a routine, I was permitted by all the parents to tape-record interview sessions. I observed that mothers were comfortable with getting their experiences recorded, but most fathers hesitated to talk in the presence of the recorder. I noticed that during the first few interviews, whenever I switched off my recorder, many fathers started to open up more, because in the presence of the recorder they had this 'feeling of being reported'. They knew that the interview was over, but still wished to complete an on-going conversation. Some critical aspects of their emotions came out *only* in the absence of the recorder, especially the vulnerable side of them. Some of them even cried during those moments. To allow them to be comfortable with their emotions, I recorded initial parts of the interview session, but, after about half an hour, I purposely switched off the recorder. I recorded the remaining details in a diary immediately while travelling back from the sessions. Allowing fathers to be comfortable in their settings helped me to explore their emotions in a more comprehensive manner.

### **My Personal Engagement in Caregiving as a Bridge to Parents' Experience**

My curiosity to hear the real voices of parents deepened during the second phase of the fieldwork, when my whole being as a researcher got affected due to personal experiences. The feeling of associating with the participants amplified when my close friend's child (Ananya) started showing symptoms of ASD. Being very close to Ananya's mother, I started my journey as a virtual family member to Ananya, where my friend and I were busy figuring out the puzzles of ASD. Though we were residing in different geographies (USA and India), we started to have detailed conversations around Ananya. Internal difficulties—How to proceed? Where to go? What to do? Whether to accept it (the diagnosis)? How to stay strong? How to keep moving ahead?—had started affecting my friend. I tried to absorb the experience as a professional but I could not, because Ananya was so close to me that it was impossible not to see it through a parent's eyes. My interaction with the other parents in the field shaped up from being just a part of a research to an expansion of my own being like a family member to an ASD child who was wanting to understand the experiences of similar parents more closely. I genuinely got involved in the world of parents with an ASD child and tried to *go closer* to each of them. It was more about experiencing what it is to be a parent to an ASD child rather than analyzing their emotions from a far angle. Thus, in subsequent phases of fieldwork, I started living the experiences of my participants' story. What they said took me back to the struggle that I and my friend had gone through—our constant worry of finding a pathway to diagnosis, persistent denial to see some obvious signs of ASD, questioning God and His motives, and becoming conscious of society's judgement for this condition. This empathetic connect not only changed the whole course of my being a researcher, but also taught me the real meaning of *categories* like 'fear of labelling' that emerged in my analysis of parents' narratives. These parents are craving for normalcy in their life and calling them '*special parent*' is not what they wish to hear. They want to remain just an '*ordinary parent*'!

## **Research Reflection 2**

### **Studying Trans-generational Transmission of Trauma: My Reflections on Ethnographic Fieldwork**

Trans-generational transmission of trauma (TGT) as a concept is understood as intense distress that the second or subsequent generations experience due to the direct (verbal) or indirect (observational) impact of traumatic experiences of the parents who survived ethnic or political violence. These impacts of parents' traumatic experiences on their offspring have been predominantly studied in terms of distinct psychopathological symptoms. This limited focus on pathology radically undermines the lived experiences of distress that might not just be associated with the transfer of pathology, but also the everyday distresses that are rooted in contemporary socio-political realities. It is therefore critical to address the impact of these potentially distressing socio-political conditions in the post-violence period that may affect the relational dynamics between the two generations and lead to the probable transfer of distress as well as healing. In my study, I have attempted to understand the phenomenon of TGT within the context of the 1984 violence against the Sikh community living in New Delhi (that erupted in the aftermath of the killing of the then Prime Minister of India, Mrs. Indira Gandhi, by her Sikh security guards) to study its resonances and ramifications in the lives of survivors and their families.

#### **My Sense of 'Loss' as a Precursor to Exploring TGT**

My journey as a qualitative researcher began with an interaction that I had with my professor (under whom I wanted to pursue my doctoral work). During our conversation, I had briefly shared how I have been intrigued by the experience of ‘loss’ that has shaped varied aspects of my selfhood. I was then asked to reflect further and pen down about this ‘experience of loss’ which became the starting point for my doctoral work.

My first exposure to the lives of 1984 anti-Sikh violence survivors was when a poignant article titled, *Our Work to Cry: Your Work to Listen*, by an eminent scholar Veena Das (1990) was introduced as a part of a course on ‘Disaster Mental Health’ at IIT Kanpur. It was the same year that marked the 30<sup>th</sup> anniversary of the tragic event of the 1984 violence; the print and electronic media were filled with cover stories on the survivors and their families. What intrigued me was their sense of loss that was ‘personal’ yet shared by a whole community. I was further engaged with the topic when I found out about a personal connect wherein my father had saved a Sikh neighbor family by hiding them in our home. My parents told me that the extent of the event was such that no one who had witnessed the event would have remained untouched by the unprecedented violence that was unleashed in the streets of Delhi for three days. Their memory of the event brought to the fore horrifying details and evoked strong emotions not only in them but in me as well. The topic was especially meaningful since it was the same time when I had lost my maternal grandparents. My own experience of loss led me to extend myself and relate to the people who too had experienced loss. Following further discussions with my doctoral thesis supervisor, our initial focus on the experience of loss in the context of 1984 violence extended and took the form of the study of TGT among the families of the survivors.

### **Negotiating Survivors’ Suspicion over My Motives**

To gather a rich understanding of their life-worlds, I used ethnography to immerse myself in the field and develop close familiarity and empathic relationships with them. In doing so, I interacted with 27 dyads (one parent and his/her offspring as a *family unit* of the study) and conducted semi-structured interviews with the participants.

My first field visit was more or less foundered, mainly because of my identity as a stranger that led them to perceive me with grave suspicion. Nonetheless, my initial experience made me mindful of the prevailing socio-political context as I realized that after 30 years of endurance, while many had lost the will to engage any further, others were still willing to share their stories, though they were gravely concerned over the purpose and use of their stories due to their prior experiences of exploitation. I also became aware of the multiple hierarchies that exist within the researcher-participant relationship itself wherein I as a researcher was being looked upon as one of the ‘reporters’ who had come to ‘cover a story’ for my vested interests. These initial experiences made me aware of the significance as well as the need to ‘break the ice’ and establish a mutual relationship of trust with my research participants. In my subsequent field visits, I keenly started observing their day-to-day activities and routines. One evening as I was exploring the field site, I found a group of women who were doing *yoga asanas*. As a yoga practitioner myself, I got intrigued. As I approached them and introduced myself, we started having a casual conversation wherein they also informed me about their concern about their physical and mental health. When I shared my own experience of practicing yoga and meditation and how it had personally helped me over the years, they expressed their desire to learn these practices in a better way. We mutually decided and started meeting in the mornings for our daily practice together. Gradually, I was made a part of their everyday conversations and was being referred to and introduced in the locality as a girl who teaches yoga. I started visiting their homes, meeting their families, and slowly formed a bond that got deepened through our practice. The practice of yoga and meditation had given us a common ground to connect.

### **Insights about How Victimhood is Normalized**

Over the course of my relationship with different families, I became acutely aware of the socio-cultural and structural contexts of their lives. I became mindful of their difficult life experiences associated with 30 years of denial of voice, care and justice due to the apathetic attitude of various political, legal and judicial systems. As a researcher as well as a person, it was important to be sensitive to their experiences of loss, marginalization and victimization that they experienced in the aftermath of violence. It was during the interactions with participants that I became especially mindful of not using the word 'riot'. The characterization of 'violence' as 'riot' aroused strong emotions in them as they recounted the painful memories of the violence as 'a well-planned and politically organized event'. While there was a marked similarity in their narratives and retellings, it was also important to acknowledge and bring forth the 'alternate reality' that exists amidst the dominant portrayal of their identity as 'victims'. This alternate reality became glaringly visible when I came across families who voiced their concerns on being defined as 'victims' because their life stories defy these labels; particularly when these labels became a tool to simply erase their voices from public memory. From my field visits, I got a clear sense that such families have not been provided a means to articulate their voices amidst the distressing dominant socio-political and structural forces wherein it largely remains undermined and underrepresented. When provided with an experiential space to express and assert their sense of 'agency', many participants expressed a sense of relief on being listened to.

### **Empathizing with Survivors' Loss and Healing**

Driven by a period of struggle and quest to find a resolve, my own experience of loss provided me with a 'space' to connect with my participants. The loss that they experienced not only stemmed from the loss of their loved ones but was also the loss of 'valued' aspects of their lives that was rooted in their everyday struggles. Being mindful of such aspects, my empathic connect not only came from me as a person but also as a qualitative researcher who has been sensitized to study the contextualized experiences of distress and healing. The voices from the field not only recounted the lived experiences of distress but also conveyed enabling experiences of healing. Throughout my fieldwork, many participants shared their experiences of healing through their unshakeable faith and connection with their Gurus. My close connection with my own Guru and my faith in the existence of a Supreme power led me to relate with my participants. The mutuality of our experiences facilitated enriching disclosures around the healing power of 'faith'.

### **Research Reflection 3**

#### **Being a Witness to the Disability Experience: My Journey as a Daughter and a Researcher**

Disability experience in India is situated within the larger socio-political context of poverty, deprivation, and marginalization. World Bank Report 2003, states that India has about 70 million persons with disabilities (PwDs), and the majority are marginalized as they live in rural areas with disabling barriers (Chaudhry, 2012). My doctoral research focuses on the experiences of suffering and healing in accident survivors with loco-motor disabilities. By focusing on the stories of this population who are embodied people, with rich, unique and diverse lived experiences, I attempted to look into their narratives of meaning-making, courage and agency. My second goal was to have a situated understanding of disability experience within the socio-political context that shapes everyday challenges of PwDs. I interviewed forty participants (amputees and spinal cord injury patients) in Delhi and Kanpur for my study.

#### **When My Father Met with an Accident!**

My initial interest in this area stemmed primarily from my similar personal experience at home. My father met with a disastrous accident, and that was a challenging phase for him as well as for our whole family. An accident is a sudden event, often traumatic that shatters the life-world of the person and those related to him or her. Seeing my father closely and being able to recognize the challenges that a person goes through after an accident gave me some insights about life after an accident as I developed my interest further in this area. However, I was still concerned because I am a non-disabled person and was trying to work on disability. But my personal and up-close experience with my father encouraged me to explore this domain. I had observed not only my father's tryst with pain in plenitude ways, but also how the accident changed a lot within him and consequently our whole family's relational network. I knew that my standpoint was a good starting point to dwell deeper into this area, and it gave me hope and confidence to move forward with the topic. It did not make me an insider per se, but it did open up possibilities to share a connection with accident survivors, their worldviews and experiences. During interviews, when being asked about my motivation for this topic, I would often disclose about my father's accident and this in many ways used to become a connecting point for building an emphatic bond with my participants. Being a witness to my father's journey after accident helped me connect not only with the participants at various levels but also on many occasions with the family members too.

### **Being an 'Insider' as well as an 'Outsider' in the Field**

The process of knowledge production in ethnographic fieldwork is an embodied practice where the researcher's body affects the research process as it is manifested in terms of its positionality, the way it looks like and how it is perceived to be belonging in one social group or the other (Coffey, 1999, cited in Ellingson, 2006). During my visits to camps and other centers for the persons with disabilities, I was often asked questions as to what I was doing in a center/place meant for persons with disabilities and what difficulty I had (with a curious glance to see any signs of disability in my body), together with the curiosity to know my motivation for the topic, and at times, attempts to categorize me either as an 'insider' or an 'outsider'. Being a non-disabled researcher was not the only challenge I had when I entered the field. I realized that I was perceived mostly as an educated and privileged female researcher. As most of my participants were male and from low socioeconomic status, it was challenging for me to gain their trust and work towards creating a space where they could share their personal stories. Being aware of the embodied nature of my interactions with my participants, I was sensitive to each participant's body language and observant of the hindrances my identity might have posed. Accordingly, I was aware and sensitive of minute details during interviewing, like sitting at the same level as my participant, matching my pace of walking with them, going for home visits so that their routine was not disturbed (especially in spinal cord injury patients). Their body language would often show signs of discomfort, low confidence, and they were often intimidated by my identity. I had to negotiate my way through this challenge by trying to diffuse the inherent hierarchies. On being questioned about the importance of interviewing them, I would often tell them that their experiences were very important in helping me know more about disability experience, as my limited understanding regarding disability through books could only be complete if they shared their own experiences. This, on many occasions, immediately changed the body posture of my participants, and they would be more confident and eager to share their stories. They felt being worthy of attention and care, and the fact that they were contributing to

the disability discourse through me often initiated a dialogical discussion with them.

### **Whose Choice Counts: My Unlimited and Their Limited Freedom to Exercise Agency**

Initially, I thought that my non-disabled identity might come as a serious hurdle in getting closer to the participants and their contexts, but I realized it helped me instead. The difference in identity between my participants and me kept me curious and drove me to know more about them, their lives and experiences, which were different from mine. This demanded genuine engagement where my identity acted as a background guiding force, but the focus was on the 'other'. The clear demarcation between what I was able to do or take for granted because of my sense of agency and what they were unable to do due to the limits on their agency because of altered functionality of the body on some occasions and architectural barriers on the other was a point of both reflection and revelation for me. The recognition of the absence of embodied agency in things important to them in comparison to my unlimited freedom to exert agency in ways such as being able to eat with a spoon, or plan a random outing, or being able to access most public places made me pause, think and eventually connect with them (Radley, 2004). While this point of difference might take the form of pity for some, apathy for others and nothing to yet many others, for me it became a major point of empathetic connection with my participants.

### **The 'Daughter' in Me and the Unseen Bonding with the Participants**

There were many instances during my fieldwork where my participants' experiences would take me back to my father's experiences of being an accident survivor. Like his initial days of irritation over lack of agency due to complete immobility, how his self-concept was affected due to this helplessness and inability to do things, and what was in store for him in an uncertain future regarding his career gave him sleepless nights. On many occasions, I could connect to the similar voices in my participants' stories, and this made me connect to them and their families in a much deeper way. When my participants expressed how their confidence was

affected because of the inability to do things which they could do independently earlier, like self-care and leisure activities, it brought back memories of my father's similar struggle as he was caught between the need to assert his agency by doing things important to him and the helplessness of not being able to do it. The lost embodied agency of my participants in terms of the mundane daily tasks, which we often take for granted, made me compassionate towards their sense of suffering. During such occasions, self-disclosure about the proximity with which I had witnessed similar things in my family created an unspoken bond with not only the participants but also with the family members on many occasions.

#### **Research Reflection 4**

##### **'Recovery in'<sup>1</sup> Severe Mental Illness: Interpreting the Shades of Structural Violence**

Severe Mental Illnesses (SMIs) include psychotic disorders that are chronic, debilitating, and associated with complex needs (Ruggeri, Leese, Thornicroft, Biscoffi, & Tansella, 2000). Images of altered personhood, social and personal inaccessibility, and economic dependency are dominant in society. Psychiatric explanations and familial narratives of caregiving burden further validate these understandings. Yet, the subjective and experiential nature of living with SMI often gets disparaged. For instance, loss of self and identity, employment opportunities, relationships, and future due to mental illness (Baker, Procter, & Gibbons, 2009) is often overlooked while focusing on symptoms and support needs.

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<sup>1</sup> 'Recovery in' SMI is a more optimistic view than 'recovery from' SMI (Davidson & Roe, 2007) as it helps look beyond symptom elimination, reduction, or management, and facilitates a vision of hope and personal growth by accepting the existence of illness.

### **Redefined Role as a ‘Clinician’: The Foundational Motivation to Study SMI**

My clinical psychology training at Central Institute of Psychiatry brought me closer to the marginalized world of SMI. I observed the constant struggle and helpless despair of people with SMI in the psychiatric setup. The inadequacy of clinical tools and positivistic methodologies in facilitating recovery fueled my decision to engage in a phenomenological inquiry of SMI for my doctoral research. I chose to value the first-person accounts of illness and experiential subjectivity (e.g., Strauss & Estroff, 1989). The qualitative approach facilitated a continual dialogue between my research stance, voices of participants, and also the silences from the field. As a clinical psychologist, I might exclusively prescribe to a medical, person-focused stance vis-à-vis SMI. However, as a qualitative researcher, I could look beyond my pre-existing assumptions about SMI and appreciate the influences of structural hierarchies on experiences of illness, treatment, and life at large.

### **Exposure to the ‘Gendered’ Research Space**

I realized that my study, the participants, and I as ‘the researcher’ existed within patriarchal hierarchies. I found male participants more agential while contacting me, fixing an appointment, or even refusing to participate in the study. Women, however, always had a father, a husband, a brother, or a son speaking or deciding for them. Despite growing feminism and ‘#MeToo’ moments, Indian women are still voiceless; more so, at the margins of mental health.

### **Meeting Everyday Violence Faced by Sukanya instead of Her Illness Narratives**

One of the silenced voices is that of Sukanya Devi (pseudonym). She was a 37-year-old, graduate, housewife when we first met. She was being prescribed antipsychotics for ten years. She was married off 12 years ago, to a high-school educated man from a village, while pursuing her postgraduate studies, maybe due to early signs of psychosis. Resultantly, she had to abandon

her education and any dreams of a job. Presently, she was made to visit a private psychiatric clinic, on her father's insistence; every time she visited her maternal home. It was here that I would meet her. Every conversation I had with her was marked by an absence of illness narrative, despite repeated attempts of the father as well as me, making me question her suitability for the study. She narrated the disparity in her living conditions and that of her parents, the everyday violence she had to live with, and experiences of the loss of respect, voice, and agency.

*"Everybody screams at me. They hit me. My brother-in-law grabbed my throat one day."*

*"I only know how I am living in that house. They found a very simple and straight (wife in me). My younger sister-in-law keeps scolding me. She fights with me unnecessarily. She treats me like a child. Keeps telling me to do like this, to do like that. Do I not know anything?"*

Even though Sukanya Devi refused to talk about her 'illness', she voiced how 'being ill' facilitated experiences of disrespect and violence. Yet, these accounts were just a source of unrest and doubts about her fitness as a research participant until I came across a documentary on 'paros' or bridal slaves of India (Al Jazeera, 2011). Poverty facilitates slavery for 'paros' who end up losing respect, social status, and claims over property. Just like Sukanya Devi, who lost respect as well as any rights to opine, decide, or refute after marriage because of her illness. However, 'being a woman' seems to increase manifold the experiences of marginalization and voicelessness either in the context of mental illness or poverty.

### **Connecting with Sukanya: Outgrowing the Typical Clinician's Role**

Holliday (2010) says that a researcher needs to submit to data to allow findings to emerge, and use personal knowledge to engage with the process (cited in Flogen, 2011). I realized that excluding the patriarchal context while focusing on losses related to SMI created hurdles in getting closer to the subjective experiences of the participants. I recognized that focusing on symptom amelioration, like a clinician, meant losing an opportunity for a meaningful connection. I also realized that Sukanya was being impacted by the same patriarchal norms that I frequently came across in the responses of male and female participants, as they responded differently to my role as a *female researcher*. I was able to not ‘lose the complexity of illness experience’ (Pascal & Sagan, 2016), by submitting to Sukanya Devi’s narrative, and using my knowledge of power and politics of patriarchy to engage with her.

Critical reflexivity during fieldwork and beyond brought forward awareness of multiple complexities related to SMI. I realized that clinical knowledge might not always be the answer to the sufferings of people with SMI. I understood gendered experiences of SMI by accessing personal experiences with patriarchy, theoretical underpinnings allowing to look beyond biomedical explanations, academic belief in a transactional epistemological stance, and an ideology attuned to acknowledging ‘participants as experts’. This insight has facilitated my understanding of the narratives of loss, coping, ability, and hope of participants in their journeys of recovery and meaning making.

### **Research Reflection 5**

#### **Listening to the Sound of Silence: Reflections on My Research with the Homeless Mentally**

### **III**

I belong to a city that outsiders perceive as the ‘city of joy’, Kolkata. My city never sleeps, always bustling with colors and festivities. Within that, parallelly runs another city which

struggles daily against poverty, crime, homelessness; and amidst that darkness, some are invisible lingering like shadows—the homeless mentally ill (HMI). HMI has always been one of the most vulnerable sections of the society. Involuntarily marginalized, homeless people are susceptible to enter the vicious cycle of mental illness and poverty, succumbing to its atrocities and trapped in it due to lack of resources. However, the process of ‘medicalization’ of such a social problem like homelessness has not only made ‘symptom reduction’ its focus but has also limited our understanding of this population holistically, restricting it only to the disability lens.

### **HMI: Intrigued by the Dark Corners of the ‘City of Joy’**

All my life, every day, I had come across them at almost every corner but never knowing who they were, where they came from, why they were on the streets or whether anyone really cared! I chose to indulge myself in the quest of seeking these answers through my doctoral research project by studying their lived experiences through an exploration of their life-stories. Being critically reflexive while conducting life-story interviews in two shelter-houses in Chennai and Kolkata became an eminent source of data which not only enriched my research experience, but also helped me understand the context of my participants amongst the varied socio-political-cultural dynamics. I initiated my fieldwork in Kolkata with the help of a non-governmental organization (NGO). This NGO had been struggling for a decade trying to provide community-based rehabilitation to the HMI population despite all odds to make them once again *be a part of* the society and live with dignity.

### **Receiving a Blunt ‘No’ to an Entry into Ms. R’s World**

I entered the field with confidence. Having the tag of a ‘clinical psychologist’ made me believe that I have in my reservoir all that were required to make my participants open up in interactions with me. Was I aware of the hierarchy that I carried with myself? Yes. Was I doing anything to get rid of that? No. Because it was multifaceted, it would not be possible to get rid of the hierarchy or deny it, in the system where we belong. One could just be critically reflexive to

let it not interfere, but one could not do away with it. Thus, being an ethnographer trained in clinical psychology when I attempted to interview Ms. R, a resident of the shelter-house at Kolkata, I was looking forward to collecting 'rich data'. There were primarily two reasons: first, I was already having a good flow of data from my other participants that boosted my belief. Second, Ms. R, a 48-year-old Bengali speaking woman had clinically recovered, running her own tea stall with support from the NGO. She met my 'inclusion criteria', and her current status made me hopeful about a 'good interview'.

"I do not want to talk to you. I don't like you. You can sit here all day long if you want, but I will not talk to you," said Ms. R. I was speechless! I did not know how to convince her for the interview. I modestly mumbled, "It's okay if you do not want to talk about your past life. Can we just chat about your tea shop, this business that you run?". "No!" she retaliated. Muttering a soft "thank you", I left her tea shop. This was the first time that I got rejected by a potential participant during fieldwork. I felt insulted; a burning sensation in my eyes. On my way back from the tea shop to the female shelter-house at Kolkata, I kept pondering on what exactly went wrong! What was so unacceptable in my demeanor that provoked her. After all, I was a qualified clinical psychologist, trained in 'building rapport' and 'breaking the ice'. I needed to understand where that 'No' was coming from. I had to understand the source of that strength which let her spontaneously overcome the 'researcher-participant hierarchy' that was subtly but fiercely established in all strata of the system (institutions that provide care).

### **'No' as a Symbol of Fight against Structural Violence**

I started going through her case files to have my bewilderment answered and understand her context but got little in return. She vaguely recalled fragments of her past life but had no recollection of how her illness started and how her life ended up being lived on the streets. She was identified at Sealdah Railway Station in West Bengal in April 2009, and diagnosed with schizophrenia. She had been one of those few individuals with whom the NGO at Kolkata started its journey. She was the first person to speak about the necessity of a shelter for homeless women like her. “She was one of the spokespersons for the outreach clients... took the initiative to cook their meals... acquired utensils and fuel on her own and prepared meals to the exact proportion for 18 people so that nothing was wasted,” shared Ms. C, the then outreach social-worker. She was also one of the founders of a self-help group of the NGO, and had been running the roadside tea stall along with two other fellow residents.

### **Connecting with Ms. R’s Sense of ‘Autonomy’**

These new insights into her social and personal context encouraged me to re-evaluate my empathic connection with her from a fresher perspective. I chose to respect her ‘decision’ not to revisit those traumatizing days of suffering. I made a conscious choice of acknowledging the ‘autonomy’ that had been core to her survival. I could realize that I *had a choice* to initiate exploring the world of an extremely vulnerable group (HMI). Similarly, *she also had a choice or resolve* not to talk to a person like me who belonged to the ‘other’ world (oppressive state, society, and family) whose hegemony she had been fighting against.

Ms. R was another reverberating example of the coerced ostracism that the HMI have been living through under the hegemony of the ‘disability lens’ imposed upon them by the state, the society, and the family. Fighting against that current, she had been able to come back to the mainstream with that same vigor and strength which provided her the courage to deny me an interview. Her zeal to establish an identity of an empowered woman, outwitted many of the challenges faced on her way. And thus, even her silence had the power to make her voice be

heard in her own way, not the way I or the society at large, needed her to speak (Sampson, 1993).

## **Research Reflection 6**

### **Institutionalized Clinical Care for Mental Illness: Reflections on Adopting a Critical Interdisciplinary Perspective**

#### **The Epistemic View of Patient as ‘Person’**

This piece of writing is a part of my fieldwork experience while doing Masters in Psychology at the University of Delhi. This fieldwork was being conducted at the Institute of Human Behavior and Allied Sciences (IHBAS), Delhi. Being attached to the Department of Clinical Psychology, our (i.e., field workers) job was primarily to conduct psychological testing as part of the clinical assessment of patients referred by the Department of Psychiatry. Those students (including me) who were excited by our critical learnings of the field of clinical psychology could ‘know’ the patient as a ‘person’ or as a lived reality beyond the diagnostic label assigned to him or her. So, we were the ones who meandered into the personal, social and cultural context underlying the surface presentation of illness, and thus could also see the implications of the assigned label in the very context which shaped it.

#### **Anju’s Delusion (or Normalized Patriarchal Violence?)**

Anju (name changed) happened to be my patient for clinical assessment. Anju was admitted to the private ward of the hospital and was undergoing treatment. Her hospital record file showed the label of *paranoid schizophrenia*. I was asked by one of the clinical psychologists, who was also my supervisor, to ‘talk’ to Anju. During the first session when I asked her about

her complaints she said, *“I do not eat onions. I do not eat food that is not cooked at home and I offer prayers. I get up at 4 a.m., take bath, and pray to the God”*. She reported that she has been following the Brahmakumari sect for the past six years and has been a celibate since then. As the session progressed, it unfolded that she believed her husband to be having extramarital affairs and reported having caught him red-handed and even having confronted him on a few occasions, following which she was mercilessly thrashed by him.

From a clinical perspective, everything was ‘just’ in place for me. Anju’s reporting of her husband’s illicit relations was part of her ‘delusional framework’. However, I felt the need to talk to her husband once to gain his perspective on Anju’s condition. Without an inkling of doubt, I happened to ask him if she had any doubts regarding him too. To my utter surprise, the husband very casually accepted having a relationship with a girl, which, according to him was severed by him for it interfered with his family’s health. Apart from acknowledgement of his illicit relationship, he also seemed to exaggerate Anju’s ‘symptoms’ as reported by herself. This was the moment of great ‘unease’ for me with my own understanding of Anju, in the light of the diagnostic label attached to her, and, also a new beginning of my relationship with her based on my ‘revised perspective’ of her suffering.

### **Being a Confidante of Anju in Her Severe Doldrums of Life**

Henceforward, my relationship with her changed drastically as I could empathize with her ‘relational void’ and the trauma she had been subjected to by her husband. Having sensed my willingness to give space to her suffering, Anju too expressed a desire to talk more with me. What unfolded in the following sessions was Anju’s narrative of how her husband has been torturing her both physically and mentally. He had even tried admitting her to the psychiatry ward of one of the private hospitals in Meerut and got her discharged only after one of the doctors cautioned him against it. What also unfolded were the brutal tales of domestic violence which she had been suffering at the hands of her husband and, her dilemma and helplessness

around separating from her husband. Anju also had a son whom she did not want to leave, but could not muster the courage to have a life of her own without her husband. She reported having gone to the police station once, but could not dare to file a case against him in spite of the repeated assurances from the police officer (station house officer).

In the sessions thereafter, apart from administration of psychological tests such as Bender Gestalt Test, Sentence Completion Test, and Rorschach Test, the relevance of which was as ambiguous to me as to Anju herself, I happened to hear her complaints of feelings of nausea, excessive sweating, shivering in legs, and inability to sleep at night. Besides, she also suffered a depleted sense of self-esteem as she thought of herself as not being worthy enough of her “husband’s attention”. As my relationship with Anju traversed from the clinical category of *paranoid schizophrenia* to a more contextualized, realistic and empathetic space, it gave her much more space to voice her feelings of pain, resentment and helplessness. Her narrative of herself moved from behavioral manifestations (like not eating onions, getting up early, praying to God and remaining a celibate) to her lived reality—her inner conflicts and dilemmas around separating from her husband, and conflicts regarding her own self-esteem for not being a “good wife”.

Anju got discharged from the hospital with the final impression, “No active psychopathology could be discerned but some underlying psychopathology is quite evident.” My last session with her revolved around her suffering, around the pain inflicted by her husband, and her acute sense of helplessness about being able to separate from her husband anticipating absolute resistance for such a step even from her maternal family and her own son.

## Discussion and Conclusion

Through the reflections on our qualitative studies on varied topics related to health and illness experiences, we have attempted to provide insights into the ways critical reflexivity had facilitated the process of carrying out the deconstructive as well as reconstructive aspects of QHR. In particular, we focused on motivational and academic preparations, unravelling hierarchies within researcher-participant relationship, and the process of building empathy- and trust-based researcher-participant relationship, associated with the practice of critical reflexivity within QHR.

As our first three research reflections illustrated, the *deeply personal interest* in the phenomenon (caregiving experience of ASD parents, TGT among survivors of political violence, and disability experience) laid the motivational as well as academic foundation for the research journeys. Further, it was the *strong theoretical as well as ideological inclination* towards addressing some critical issues of vulnerable populations (neglected 'personal' recovery among SMI persons, silenced voices of HMI, and institutionalized care of mentally ill persons) that oriented the other three researchers to sincerely engage with their participants.

Our personal interest or theoretical and ideological inclinations allowed us to be sensitive towards the experiences, identities as well as questions of the participants. In all our reflections, one can note our sustained engagement with the challenges or questions that arose in the field that brought us closer to the hierarchies surrounding their lives as well as the researcher-participant relationship. The instances of "gendered' nature of parents' experiences', 'normalized victimhood of the survivors of anti-Sikh riots', 'researcher's unlimited and PwDs' limited freedom to exercise agency', 'meeting everyday violence faced by Sukanya', "No' as a symbol of fight against structural violence by Ms. R', and 'normalized patriarchal violence of

Anju diagnosed as delusion’, illustrated the cultural, socio-political or institution-based hierarchies in the lives of participants in the six research reflections respectively. Similarly, instances of ‘whether to align with the institutional care for ASD’, ‘negotiating survivors’ suspicion over my motives’, ‘being an ‘insider’ as well as an ‘outsider’ in the field’, ‘being puzzled by meeting everyday violence faced by Sukanya instead of her illness narratives’, ‘receiving a blunt ‘no’ to an entry into Ms. R’s world’, and ‘the epistemic view of patient as ‘person’’, brought us closer to the differences in or the hierarchies of standpoints within the researcher-participant relationship in the six narratives respectively.

Besides the insights about the above-mentioned deconstructive features of QHR, being critically reflexive also paved the way for building empathy- and trust-based researcher-participant relationship. In the first three research reflections where one can notice that an experience of the researchers—‘engaging with a close friend who is an ASD parent’, ‘personal experience of ‘loss’’, and ‘father’s accident’—similar to that of the research participants facilitated our empathic connection with the participants. In the last three research reflections, one can notice that it is the experience of ‘outgrowing the typical clinician’s role’, ‘shock over rejection as an interviewer and then connecting with Ms. R’s sense of autonomy’, and ‘critical understanding of the gulf between the lived realities of a ‘person’ and diagnosed ‘patient’ that made us question our role as a researcher, and realize that we are also fellow human beings who need to listen to the spoken and unspoken voices of the participants. This also helped forming an emotional or empathic connect with the participants.

By presenting systematic and illustrative research reflections, we have elaborated on the pivotal role of critical reflexivity in QHR as we delved deeper into addressing the issues of motivational and academic preparations, critical awareness of the hierarchies shaping participants’ experiences, and developing empathic understanding. In doing so, we have extended the concerns of Gemignani (2017) and Gergen (2015) about getting close to the

experiences of participants (through the use of critical reflexivity) from being a meaningful academic debate to its possible implementation in ethnographic or qualitative research in the field of health sciences. Indeed, in case of exploring ill or distressed persons' experiences, such concerns become pivotal as these are linked with the possibilities of healing through the empathy-based research relationship (Frank, 2000; Kleinman, 1988b; Priya, 2010, 2012).

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