

## **Shades of Silence: Doing Mental Health Research as an 'Insider'**

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### **Abstract**

This article traces my endeavours to enlist research participants in my doctoral research. I interviewed both people who, like me, hold a 'psychosis' history, as well as their direct caregivers, who were most often family members. My research is embedded in an emancipatory episteme, and focuses on understanding the barriers to recovery in the psy-medico-legal landscape prevalent in India. During my participant recruitment process, I encountered 'silence' of diverse sorts and, with this article, I attempt to deconstruct that silence. At the individual level, I was met with silence by individuals and their caregivers who were reluctant to be interviewed due to various forms of stigma, paternalism, and their hesitancy to question psychiatric authority. At the organizational level, non-governmental organizations (NGOs) were largely unsupportive of my work because my research queries psychiatry and its motives, and this undermines the powers of dominant psychiatric discourses. Central to my argument is that as a 'peer researcher,' my position destabilizes common held truths about ex-patients. Thus, being an 'insider' researcher actually hindered my access to some potential participants because I was understood as an 'exception' who should not be engaged with. I end by exploring the asymmetrical power relations between researchers and those we research, and the potential that emancipatory approaches bring to mental health social change.

**Keywords:** peer researcher, narratives, emancipatory epistemology

## Introduction

For two decades as a 'patient', I rarely disclosed my diagnosis, until I entered into mental health research. My first writing about myself (Sharma, 2011) helped me establish networks and connections with scores of people across India, many of whom in turn shared their own stories with me. Because of this, when I started my doctoral research, I thought I had a ready resource of networks to draw on to help with my research recruitment. However, my experience proved otherwise, for the arrival of an ex-patient in the garb of a researcher seems to threaten the consensus built around a psychiatry-led worldview of a patient's 'pathology' and its permanence. While my research outreach seemed to invite an array of reactions, silence dominated. This proved equally true whether I approached individuals given a diagnostic label and their caregivers, or organizations devoted to 'mental health.'

Peer engagement in mental health is mostly seen in support groups run by non-governmental organizations (NGOs) in India (Pathare et al., 2018). Apart from that, most other forms of in/formal peer engagement are uncommon<sup>1</sup>. Unlike traditional positivist research, peer research is a new form of inquiry, currently at a nascent level in India, and like any new venture faces uncertainty. What are the challenges of working in peer research in India, which remains an unrecognized research method, and where does it deviate from traditional research in terms of research roles? Further, how does being an 'insider' peer researcher affect how potential participants respond to my invitation to participate? In my research I am working with ex/patient narratives, and this paper attempts to capture some experiences I gathered while collecting them. These experiences led me to delve into methodological dilemmas and helped me arrive at a better understanding of what emancipatory research may look like as we approach it with a commitment of equalizing relationships with our study participants. In keeping with the theme of this special issue, this article explores an ex-patient's exclusion from research interactions with 'peers' at both an individual level and by various mental health groups.

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<sup>1</sup> Recently peer support workers have been employed on an experimental basis in India in certain settings, as may be seen in this film - [https://www.youtube.com/watch?time\\_continue=226&v=phd\\_PoHuL9c](https://www.youtube.com/watch?time_continue=226&v=phd_PoHuL9c)

## Personal and Research Positions

As an ex-patient, when I initially wrote about myself in research, it was as an emancipatory act: an attempt at wresting free of psychiatric self-identification, diagnosis, medication, and nomenclature. It was an act of “resistance...by way of a most personal avenue - self disclosure” (Costa et al., 2012, p.86). I do not identify as a ‘survivor,’ nor ‘Mad,’ but rather seek to understand my identity beyond any identity categories that align with psychiatry or the counter-identities that have resulted from contact with psychiatry systems. Burstow (2013) argues that when our talk is psychiatry-resistant or psychiatry-free, we do something very different, potentially even revolutionary. Simply by how we speak, we are either tacitly upholding or undermining psychiatric rule (Burstow, 2013, p.82). Thus, my politics are not determined by identifying myself as a psychiatric subject or counter-subject, but as an articulator of an emancipatory perspective. Over my years of research and analysis (Sharma, 2014; 2015), I have moved from the personal to the social domain, where others are now the area of my interest and concern. At present, I work in the twin areas of offering collaborative counseling/therapeutic support to others in addition to being a researcher. My work is political and, among other things, an attempt at demystifying the ideological structures within which power relations are located (Oliver, 1992, p. 110). Philosophically, my work is grounded in an emancipatory worldview, which is premised on redefining the structures of power in mental health and recognizing that individual ex/patients can be empowered “through the privileging of experiential accounts on mental health” (Cohen, 2016, p.301). In all my work, I foreground the individual narratives of people who have come in direct contact with mental health systems.

Costa et al. (2012) question the use and propagation of personal narratives, warning how our stories are increasingly being used to harness support, funding, or press coverage for the very mental health systems that we recognize as being part of the problem (p.98). I agree with them that it is unlikely for individual stories to single-handedly change deeply embedded, oppressive, and interconnected powerful social structures (Costa et al., 2012, p. 98). Yet, an attempt at challenging the hegemonic discourses of psychiatry can still effectively be mediated by narrative. Narrative analysis is not just another telling, but a tool of resistance in the hands of emancipatory researchers. Our goal is not confined to personal gain by telling individual stories, but a more political endeavour that hopes to draw others into the struggle by framing resistance in a language that the wider society can comprehend. Beresford and Wallcraft (1997) remind us that undertaking emancipatory research

has been a part of equalizing relationships between research and research subjects, and developing survivors' own collective knowledge (p.75).

Following Vernon (1997), "My research is as much about my own experiences as it is about others" (p.158). While the agenda of much research done by people with lived experiences of 'mental illness' lies in questioning psychiatric hegemony, Shaw (2016) reminds us that the purpose of such research is "often to effect social and political change" (p.277). This perspective is required because much traditional social science research is unable or unwilling to understand disability as a form of domination and oppression (Mercer, 2004, p.118). Therefore, emancipatory research rejects the positivist view of social research as the pursuit of absolute knowledge through the scientific method and also moves beyond an interpretive paradigm offered by qualitative research. Rather, emancipatory paradigms facilitate a politics of the possible by confronting social oppression at whatever level it occurs (Oliver, 1992, p.110).

### **Encounters with Silence**

My research uses emancipatory paradigms to hear peoples' narratives in their own voices, and not as reinterpreted through psychiatric expertise. I also interviewed their direct caregivers, who largely ended up being parents. To recruit potential research participants for my doctoral research, I depended on existing networks to contact people. This includes recruiting through personal, social, and work networks. I have interviewed people from different parts of the country, and have relied on the internet to connect and communicate with participants. My interviews with individuals are largely conducted over the phone or through Skype. Due to limited funding, the manner in which I approach potential research participants for recruitment is restricted. Additionally, the choice of these participants is not entirely straightforward, but a result of a struggle to enlist participants.

The first of these challenges stems from my research framework, which questions psychiatry and its motives. In India a critic of psychiatry is viewed with suspicion by most stakeholders. Here, the mental health milieu is significantly defined by representations of 'lived experiences of mental health,' and a vast majority of those who work in this field often rally for greater psychiatric resources. This is in no small measure an outcome of the Global Mental Health Movement, an expansion of psychiatry's presence and the widely spoken about 'treatment gap' in India that makes people rally for greater

psychiatric services, in response to a perceived lack of them (Prince et al., 2007; Sarin & Jain, 2012; Reddy et al., 2013; Kaur & Pathak, 2017). Those who call themselves ‘consumers’ and those more or less appeased by the mental health services they have received are the first to be chosen to sit, speak, and represent on various boards, in consultations, and on panels (Costa et al., 2012, p.90). Thus, my research threatens the foundations of dominant ideologies of mental health and illness, and people are reluctant to participate in research that threatens such long held views.

While I was able to recruit participants and complete my interviews, during this process I encountered two different types of ‘silences.’ At the time of planning my research, I thought recruiting research participants given a diagnosis of ‘psychosis’ and their caregivers would be straightforward for an ‘insider’ who knows a number of people all over the country. However, this was not the case. While a few responded positively to my outreach, a majority did not, and stemming from the responses of those that did not, I explore two different shades of silence. Firstly, silence that arose at the individual and familial levels, and the second, at the mental health organizational levels. Such silences raise a number of issues which I now turn to analyze.

### **Analyzing Silence**

My recruitment experience as a peer researcher advances a number of important questions about the silence that came in two forms: from ‘patients’ and caregivers, and from those working in the NGO sector. The first is the reluctance of some individuals and their caregivers to partake in my research. Many individuals and their caregivers did not want to talk about mental health, or at least in the context of my research project. Is it the stigma associated with the individual who holds the diagnosis? Is it the stigma and suffering associated with being a caregiver, most often a family member? Family caregivers were reluctant to either introduce their family members to me, or participate in research themselves. This is likely due to the common patriarchal paternalism that organizes not just psychiatry, but everyday social order. Interestingly, many family members have been visible and active in public mental health advocacy – including government advocacy. Yet, their children have been invisible – few know their versions of truth about their experiences. In my research, these traditionally ‘missing actors’ take precedence over voluble caregivers, yet they are often hard to reach. That caregivers act as intermediaries between myself and those diagnosed with ‘psychosis’

posed a problem of recruitment in the field. I suspect that when I approached family members and requested that they disseminate my call for research participants to their family members, they remained 'silent' about my study and that this opportunity was not conveyed to those with direct experience of 'psychosis.'

With this silence, we encounter their children not having any voice or presence in constructing narratives of their own. This is precisely what I am trying to counteract in my own research – of giving voice to those who rarely get heard. Rather, it is mostly the parents who are heard and seen –including in public forums, working to counter 'poor mental health literacy,' and contributing, as Patel (in Mills, 2014, p.57) says, towards efforts "to make mental health for all a reality". One can see this as a reflection of "the high degree of dependency on the family in India, [and] the lesser emphasis on personal autonomy" (Jain et al., 2017, p. 48). The common dictum that 'caregivers know best' is rarely questioned. Similarly, a common dictum is that 'doctors know best.' I recognize that family caregivers carry the task of balancing delicate negotiations between their children and psychiatrists. And I suggest that they do not want to interrupt this delicate balance by allowing an ex-patient emancipatory researcher into their lives who risks of unsettling this balance. I acknowledge this suffering and the need to hold on to fragile equilibria. Meeting with an ex-patient researcher working within an emancipatory paradigm may disturb their family situations, as some children may then start looking for alternatives to psychiatry. Thus, I argue that is the direct result of my position as a peer researcher who holds emancipatory goals that I encountered 'shades of silence' from individuals and their family members.

I also sent personal emails to the heads of at least seven non-profit mental health organizations in different parts of the country. This included organizations that were headed by 'consumers' and caregivers. I reached out to them in the hopes that they would either partake in my research, or spread the word about my study by circulating my call for participation. My attempts at contact elicited negligible response. Caregivers heading organizations declined participation, either citing work commitments, that their 'patient' family members declined participation, or I received no response from them. I suspect that they did not share my request for research among their organizational networks. I also suspect that the terms of my research, that I must speak not only with them but principally with their family member with a 'diagnosis' unsettled the paternalistic control and order that they are invested in. I suspect that if I only wanted to interview them as 'family caregiver experts' that most

would have agreed to participate in my study and ‘educate’ me about what more is needed in mental health fields.

I’ve argued that some silence that accrued throughout my recruitment process can be attributed to both individual and family stigma associated with talking about ‘mental illness’, and that paternalistic control over those who have a diagnosis is entrenched in India. Now, I turn to argue that not only my stance as an emancipatory researcher, but as an ex-patient ‘peer’ researcher, influenced the response to my recruitment efforts.

### **‘Othering’ Ex-Patients**

I couldn’t understand some of the indifference that I encountered during the recruitment stage of my research. I began to wonder if this could happen to any researcher – or was it just me? Informal conversations that I had with others suggested that my particular standpoint – as a researcher, who is working and managing her life outside of psychiatric dominance – threatens the foundational principles of psychiatric power. Because of both my personal and emancipatory standpoints, many dismiss me as an ‘exceptional case,’ and as not a good role model to introduce to other ex/patients. This is because I disrupt the principal idea that those with diagnosis must stay under the remit of psychiatry in order to manage or recover from their symptoms. This has not been my experience. Beresford and Wallcraft (1997) confirm that “[s]ome disabled people do not see survivors as disabled, because they do not have an impairment or their situation may not be permanent, while others do. Some survivors do not see themselves as disabled because they associate disability with the medicalisation of their distress” (p. 66). Making an ex-patient like myself an exception is an effective way of marginalizing those like me. Dismissing us as random phenomenon or ‘exceptions’ further entrenches our status as marginal and uncommon. Cohen confirms that attempts to privilege service user/survivor voices and knowledge is difficult, as our status remains very much at the margins of mainstream thinking about mental illness (2017, p. 301). Unlike in much of the Global North (Landry, 2017; Rose, 2017), peer research in India remains unrecognized as a valid and valued standpoint for a researcher. Thus, much of the indifference, resistance, and shades of silence that I experienced during the recruitment phase of my research I link to the discomfort that my position as an ex-patient researcher poses to conventional thinking about who should be doing research.

In my own research methods, I am also cognizant of power relations. In particular, I'm concerned whether some research participants see me as trying to empower myself at their cost – by 'robbing them' of their stories and getting a degree, while they 'continue to suffer'. While it is clear how I benefit from undertaking this research, I must ensure that my research benefits those that participate in it as well. The asymmetry of research practices is something I am aware of and committed to deal with. It is this realization which inspires me to attempt a change in the social relations of research production that manifest on the ground in the relationship between researchers and those being researched.

In order to lessen the power differentials between myself and my study participants, I address questions of reciprocity in research, considering Ribbens' concern that "researchers never reveal about themselves as they expect to be revealed" (in Oliver, 1992, p.111). In my study, I continue to maintain an openness about most aspects of my life, as well as an invitation for further dialogues about the study with everyone. Most of my interviews with participants have begun with them questioning me first. I acknowledge the need for a two-way flow of information, while maintaining an emancipatory commitment to reciprocity. I offer my story not as proof of my ability, but as a testimony of their hidden potential. Throughout the interview process, I continuously attempt collaboration towards understanding our common struggles and suffering, and not simply furthering my professional growth at their expense. I offer my narrative equally as much as I have inquired into theirs. Yet, asymmetries still exist, to the extent that they may not analyze or publish on my narrative, while I would theirs. To reduce this asymmetry, I have offered to involve them at a later point in discussing my analyses of their narratives. Some have taken me up on this offer, while others have not. Further, oftentimes during the course of my interviews, participants ask me questions about alternative resources. I do not always have answers to their queries about how to look for alternatives, except for sharing what I did, but I do not hesitate to refer them to research or other resources if need be.

## **Conclusion**

At the start of my study I was unprepared to deal with silence, considering that I was connected with scores of individuals meeting my research criteria. Encountering silence has exposed me to the subtleties of stigma (even among peers), the patriarchal paternalistic management of people's mental



suffering by caregivers, and the deeply held beliefs about illness and recovery. The realization that being a 'peer' researcher may not offer an 'insider' connection and camaraderie with others is disconcerting. Indeed, my experience during the recruitment stage was that my peer research position actually created distance between myself and those whose narratives I sought to hear. Preconceived notions about the danger that I posed as an ex-patient with an emancipatory agenda, and that I was being understood as an 'exception' to the rule, created reluctance on the end of some individuals and their caregivers to speak with me.

As ex-patients, and now critical researchers, we understand the asymmetrical power relations between patients/caregivers on the one hand and psychiatric professionals on the other. Psychiatric knowledge and power is omnipresent in India, and rarely questioned. This means that psychiatrists can control what is understood as knowledge and acceptable discourse about 'mental health and illness.' Caregivers and individuals with diagnoses are unlikely to openly resist the dictums of psychiatric recommendations, or even consider it a viable possibility. This includes issues of access to knowledge about psychiatric illness and their prognosis and their ability to control what is considered acceptable discourse. The realization that often people cannot move beyond psychiatric understandings of their experience is at the heart of my struggles. I now realize that just because one knows something, does not mean we are the best sources of sharing that knowledge. I agree with Friere that further empowerment does not exist as the gift of the few who deliver it to those who do not hold such knowledge; people can only empower themselves (Freire, 1970 in Oliver 1992, p.111). Emancipatory research may begin as a personal commitment, tied to a struggle for universal emancipation and political commitment. But we cannot offer it to others, if they are not ready for it. For emancipation is also understood as a personal struggle by every individual.

No researcher or activist can fight for another: people themselves have to feel the need for it. Until that happens, we can only work with patience, respect, and look for what obstructs a fellow human from understanding what we have understood. Our agenda is social change, and our personal emancipatory struggle is only the first step in a longer journey. Emerick (1996) reminds us that as sociologists, we would expect "to find that individualistic analyses of 'psychiatric' realities would adopt and promote a conservative individual-change or therapeutic point of view, while collectivistic versions of psychiatric worlds would more likely perceive and promote a progressive social-change interpretation"(p. 139). 'Mental health' peer research carries the potential for disordering social

consensus built around psychiatric perceptions of people's mental suffering, our one transformative spark. It is also this possibility for change that creates silence: the potential our work holds that we are most feared for, which leaves some with only the power to disengage us by receding into shades of silence.

## References

- Beresford, P., & Wallcraft, J. (1997). Psychiatric system survivors and emancipatory research: Issues, overlaps and differences. In C. Barnes & G. Mercer, G. (Eds.), *Doing disability research* (pp. 66-87). Leeds: The Disability Press. Retrieved July 10, 2013, from <http://disability-studies.leeds.ac.uk/files/library/Barnes-Chapter-5.pdf>
- Burstow, B. (2013). A rose by any other name. In B. A. LeFrançois, R. Menzies, & G. Reaume (Eds.), *Mad matters: A critical reader in Canadian Mad Studies* (pp. 79-90). Toronto: Canadian Scholars' Press Inc.
- Cohen, B.M.Z. (2016). The psychiatric hegemon and the limits of resistance. *Philosophy, Psychiatry, & Psychology*, 23(3/4), 310-313.
- Costa, L., Voronka, J., Landry, D., McFarlane, B., Reville, D., & Church, K. (2012). Recovering our stories: A small act of resistance. *Studies in Social Justice*, 6(1), 85-101.
- Emerick, R. E. (1996). Mad liberation: The sociology of knowledge and the ultimate civil rights movement. *The Journal of Mind and Behaviour*, 17(2), 135-160.
- Freire, P. (1970). *Pedagogy of the oppressed*. New York: Continuum Press.
- Jain, S., Sarin, A., van Ginneken, N., Murthy, P., Harding, C., & Chatterjee, S. (2017). Psychiatry in India: Historical roots, development as a discipline and contemporary context. In H. Minas & M. Lewis (Eds.), *Mental health in Asia and the Pacific: Historical and cultural perspectives* (pp. 39-57). Springer US. DOI: 10.1007/978-1-4899-7999-5
- Kaur, R., & Pathak, R.K. (2017). Treatment gap in mental healthcare: Reflections from policy and research. *Economic and Political Weekly*, 52(31), 34-40.

- Landry, D. (2017). Survivor research in Canada: 'Talking recovery,' resisting psychiatry, and reclaiming madness. *Disability & Society*, 32(9), 1437-1457.
- Mercer, G. (2004). From critique to practice: Emancipatory disability research. In C. Barnes & G. Mercer (Eds.), *Implementing the social model of disability: Theory and research* (pp. 118-137). Leeds: The Disability Press.
- Mills, C. (2014). *Decolonizing global mental health: The psychiatrization of the majority world*. Hove: Routledge.
- Oliver, M. (1992). Changing the social relations of research production? *Disability, Handicap & Society*, 7(2), 101-114. DOI: 10.1080/02674649266780141
- Pathare, S., Kalha, J. & Krishnamoorthy, S. (2018). Peer support for mental illness in India: An underutilized resource. *Epidemiology and Psychiatric Sciences*, 27(5), 415-419.
- Prince, M., Patel, V., Saxena, S., Maj, M., Maselko, J., Phillips, M.R., & Rahman, A. (2007). No health without mental health. *Lancet*, 370(9590), 859-877. DOI:10.1016/S0140-6736(07)61238-0
- Reddy, V.B., Gupta, A., Lohiya, A., Kharya, P. (2013). Mental health issues and challenges in India: A review. *International Journal of Scientific and Research Publications*, 3(2), 1-3.
- Rose, D. (2017). Service user/survivor-led research in mental health: Epistemological possibilities. *Disability & Society*, 32(6), 773-789.
- Sarin, A, & Jain, S. (2012). The census of India and the mentally ill. *Indian Journal of Psychiatry*, 54(1), 32-36. DOI: 10.4103/0019-5545.94642
- Sharma, P. (2011). Mending the broken frame: Self narration in a constructionist framework. *Psychological Studies*, 57(2), 189-194. DOI 10.1007/s12646-011-0126-6
- Sharma, P. (2014). Making song, making sanity: Recovery from bipolar disorder. *Canadian Journal of Music Therapy*, 20(1), 65-84.
- Sharma, P. (2015). Power to label: The social construction of madness. *Medico Friend Circle Bulletin*, 363-364, 1-4.
- Shaw, C. (2016). Telling stories. *Philosophy, Psychiatry, & Psychology*, 23(3/4), 277-279.

Vernon, A. (1997). Reflexivity: The dilemmas of researching from the inside. In C. Barnes & G. Mercer (Eds.), *Doing disability research* (pp. 158-176). Leeds: The Disability Press.

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