

Exploring the Lived Experiences of Adults with Physical Disability: Experiences of a Researcher

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ABSTRACT

More often the research in the disability domain is dominated by the quantitative approaches thus giving primacy to the biomedical lens and neglecting the experiential accounts of the individuals having disability. Of late, qualitative research methods aiming at subjective insights is gaining grounds in the disability research but conducting it with vulnerable group isn't an easy task. This article is born out of experiences of undertaking a PhD study that focuses on the voices of adults with physical disability in the age bracket 21-35 years by listening to their stories; it is assumed that listening to the voices would bring a shift in the dominant discourse of ableist society that views people with disabilities as passive beings. The study explores their experiences of living with a physical disability. The opening paragraph of the article outlines the role of qualitative research in making people with disabilities visible, followed by why the voices and stories of these individuals matter. However, the main focus of this article is to share the methodological challenges encountered while being in the field and how the researcher has navigated the process of collecting life stories of adults with physical disability. This paper relies heavily on field reflections of the Ph.D. work.

Keywords: People with disabilities, qualitative research, voices, life story, field reflections

INTRODUCTION

Documented research in the domain of disability studies worldwide is scarce (Wriz, 1996) and is traditionally governed by the quantitative approach (Mitchell, 1999). Historically, the research is underpinned by biomedical needs or on the efficacy of interventions in a quantifiable manner (Finkelflugel, 1998). Such kind of research studies have resulted in an exponential surge in the impairment studies, and neglected the cultural aspects of disability. This approach, together with the medicalization of disability, has given prominence to biased view of disability. Significantly, the voices of people living in developing spaces have been dominantly been excluded from research (Chataika et al., 2012). The conventional research paradigm has perpetuated the dominant idea of disability as an individual problem, and has done little to improve the position of disabled people, sometimes even compounding their difficulties (Oliver, 1990). Recently in India, disability issues have acquired importance and are receiving increased attention

due to the combined efforts of national government and the work of international organizations, such as United Nations Educational, Social and Cultural Organization (UNESCO) and World Bank, which have provided financial aid, expertise, and legislative foundations to enhance the social, educational and infrastructural access available to people with disabilities (Mani, 2002; Mishra & Kumar, 2009; Sharma, 2010). The Sustainable Development Goals have also brought focus on persons with disabilities and need for adopting inclusive practices (Sustainable Development Goals [SDG], 2015).

Traditionally, much of the disability research has been non-inclusive and demeaning to the research participants in terms of design, implementation, analysis and dissemination (Barnes, 1992; Beazley et al., 1997; Mercer, 2002; Oliver, 1992). The quantitative approach fails to recognize the significance of rich and 'life full' accounts (Kothari & Hulme, 2003). It lacked the capacity to deepen our comprehension of disability, and its impact on the lives of individuals and their families (Mehrotra, 2004). In contrast to this, the qualitative approach empowers the individuals by giving them a voice; and the idea of empowerment is crucial as pointed out by Swain et al. (2003) within disability research, as it proposes that without empowerment, research cannot be emancipatory. Qualitative research serves the purpose for "securing the place for socially vulnerable groups by bringing to light their voices at the centre of the inquiry" (Denzin, 2017, p. 9). Qualitative methods are deemed suitable when the target group is vulnerable, such as focusing on people with disabilities.

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Why listening to the “voices” matter?

It is a common practice that narratives are told about people with disabilities with the voice of the professionals gaining grounds, and not the voices of the individuals themselves (Biklen, 1988; Biklen & Duchan, 1994; Blatt, 1981; Bogdan & Taylor, 1994; Kliewer & Biklen, 1996). Qualitative research that depicts the voices of people with disabilities is scarce, and too often you would find the perspectives of the caregivers or professionals (Carlsson, Paterson, Scott-Findlay, Ehnfors & Ehrenberg, 2007; Lloyd, Gatherer & Kalsey, 2006). The present study laid emphasis on bringing to fore the voices of these individuals, by having their active participation in the study as they expressed and shared their life stories. This process reflects the principle of inclusion for the segment of people who are vulnerable, marginalized and whose voices have been silenced for long such as children, and people with disability (McCallum, Hargreaves & Gipps, 2000; Whyte, 2005).

Life story Approach: A suitable method to elicit life stories ‘Life story’ approach deals in personal narratives that is the unfolding history of one person’s experiences and refers to retrospective information about a life or a segment of a life that is lived by the individual (Minichiello et al., 1995). Booth and Booth (1996) depicted that life story method, underpinned in interpretivist paradigm, has contributed significantly to the understanding of the lived experiences of people with intellectual disability. The method rests heavily on the trust developed between the researcher and participant, with the voice of the participant becoming the main feature of the research. In the life story approach, the emphasis is on listening to the voices of the individuals, especially the ones who are marginalized or whose voices have been silenced for long (Atkinson, 1998). This approach as compared to other approaches, allows the individuals to share their stories and present their perspectives. Through sharing their stories people with disabilities can express their voices that have been suppressed for long (Chataika, 2005). Meininger (2006) found narration of stories to be enabling in the study of individuals with intellectual impairments. a user-friendly way.

THE RESEARCH STUDY

the present article presents the journey of a researcher undertaking doctoral research while employing the qualitative life story approach to explore the lived experiences of adults with physical disabilities. The main objective of the study was centered on listening to the voices of these individuals with an objective to capture their insights on what it means to live with a physical disability? During the conception of the research topic, discussions brought up the notion of Sustainable development Goals which came into force in the year 2015 with the theme of inclusion as an overarching one. The principle of “Nothing about us, without us” (Charlton, 2000) has been one of the core underlying philosophies of the research as the study emphasized on the voices of the participants of the study. With focus on the voices, it was assumed that the research would present the experiential accounts of the participants and in a

way would do away with the dominant ableist discourse of the society that views persons with disability (PwDs) as “passive beings”. The study acknowledged the participants as active members as they constructed their narratives along with the researcher.

Upon receiving the ethics clearance for the study from the Institutional Ethics Committee in July 2018, the process of data collection commenced with the participants and this process spanned till August 2020. The focus of the study was not on generalization, but to gain insights into the meaning of their experiences, so the sample size was of 12 participants. Purposive sampling was adopted to select the information rich cases for exploring the experiences.

The study provides a window into the experiences of the adults having physical disability, who due to the presence of the disability have faced neglect and are a hard to reach group. Their voices have been silenced for ages, and they have been deprived of their rights. In order to break their silence, the study attempted to dwell into their lived experiences in their own “voices”. The underlying assumption of the study is to explore their perspectives through listening to their stories so as to know what they think, feel and say about living a life with a physical disability. Due to the societal discriminatory attitudes the participation of these individuals is very less, and it is hoped that having their voices heard and documented will make their life stories reach a large number of people and will also improve their participation in society and also inform policy makers. Britzman (1989) writes, “A commitment to voice attests to the right of speaking and being represented.” To say it simply, voice is the medium through which one can make herself/himself heard, and present their perspectives before others and to construct their self while narrating their stories. Keeping this philosophy in mind, the participants were explained about the usefulness of the life stories. They were prepared that while sharing their life stories they would be providing retrospective information about their life and in doing this they would be able to make sense of the life events that were critical in shaping them as individuals who they have become. Also they were informed that through this research their voices would be disseminated to the society and these stories would be critical for those people with disabilities who are still in their homes and their participation is minimal. The stories have the ability to generate a feeling of communal attachment and can prove empowering to other individuals with disabilities. As already said, people with disabilities have faced stigmatized attitudes, life story approach provides them the space where someone can listen to their stories and understand their feelings (Walmsley & Johnson, 2003).

As the study involved adults having physical disabilities, the issues of co-morbidities and health issues was a peculiar nature that needed to be considered. Besides, given the research tradition where able bodied have imagined the needs of PwDs, these individuals view researchers as someone who could look down upon them. The intention of writing this reflective article is to share field experiences with future researchers planning to

work with this section of people. The following paragraphs narrate the field stories that present dilemmas, encounters and how the researcher navigated and juggled with the challenges that the qualitative research presented from time to time.

Selection of Participants

Accessing participants: Gatekeepers is an issue

Given the sensitive nature of the participants and fear in the mind of the families that their situation may be judged, the selection process was a herculean task. Gaining access to the individuals with disabilities without locating through “gatekeepers” was quite difficult. Selection of the participants is a time consuming process as there is no direct reach to the potential participants, and thus it might require lot of time and efforts than anticipated (Becker et al., 2004). The selection of participants in the present study was done by contacting the organizations or people working for people with disabilities. In this regard, emails were sent to these organizations where they expressed their willingness for helping in selection of the participants. But in some scenarios the top notch officials passed their responsibilities to the staff that appeared to be insipid for the participant selection work. This tardy process of making way to the gatekeepers was echoed by Lennox et al. (2005) who mentioned that large organizations have layers of management through which researchers must process before they could meet the concerned person who could approve recruitment. This aspect would need to be navigated by future researchers.

No faith in research process and objections by family a deterrent

Another point to be considered was of mistrust among these individuals in the research process; some of the participants expressed their dismay that the researchers only collect information from them, and nothing was being done in return to improve their plight. Given the superior position, able-bodied individuals perceived that they had and the way they have always imagined the needs of people with disabilities, these individuals view researchers as someone who could look down upon them. They clearly indicated that they viewed researchers as information gatherers, and when visited they appeared to be uninvolved. Some of them expressed disappointment over the research conducted on them in the past. Their statement of mistrust was hard hitting and kept reminding of need to build a relationship with them so as to make them feel as a part of the process. At times even after having scheduled appointment, two of the female participants dropped out from the study due to the objection posed by a husband in one of the cases, and by family in the other. In a way, it made one think that this buttressed the prevailing system of discriminatory attitudes towards women, and also the fear in the family about sharing about disability, as it stigmatized the identity of a family member.

Power relations

The disability studies are more talked about in terms of power relations that may function between the researcher and the participant (Priestley, 1999). This power dynamics continued to surface as Abberley cited in Priestley (1999)

expressed that people with disabilities were seen majorly as “passive subjects”. Not only the quantitative research studies but also the traditional interviewing processes didn’t resist the prevalent disempowerment of research participants. This ideology thus deepened the imagery of passivity and exclusion. People with disabilities have been mapped and scrutinized under the biomedical lens and the service providers decide who is ‘disabled enough’ to access support services and who would enjoy full participation rights (Magasi, 2012; Magasi & Hammel, 2009). Having been defined under the rigid biomedical lens, these individuals view researchers as someone who are just there to make profit out of their experiences.

The researcher was aware that domain of disability studies is a sensitive one, and it would depend on sensitivity and skills to traverse this path of power dynamics. Developing trusting relationships with a researcher who the participants barely knew was tough, and expecting them to reveal their stories which could be stories of discrimination and hence very personal and sensitive stories when we had only just met, was also challenging. So, research entailed a constant process of developing trusting relationships, such as having informal meetings with the participants, sitting at a place which is of same level as theirs or at times even eating with them. These all activities were a part of the routine as it enabled to steer through those power relations, and let them feel that the researcher was not an outsider, but a part of their lives. In this process, they too felt included. At the outset of the data collection or research, time estimated was to complete the data collection within six months or a year but the ground realities offered the real picture. Much of the time was invested in bridging the trust gap as only then these individuals could feel a part of the study and express themselves. Relationship building is crucial as without relationships, some people with disabilities would feel ‘mined’ by researchers (Duran et al., 2012; Kitchin, 2000) or experience discomfort in disclosing their stories to someone they do not know (Bell et al., 2008).

Ethical Considerations

Ethics in life story research involving people with disabilities is a set of responsibilities such as privacy, dignity and well-being of the participants which needs to be considered before beginning the data collection (Wang & Geale, 2015). For achieving the ethical considerations, ethics clearance was obtained from the Institutional Ethics Committee. In the initial meeting with the potential participants, the information sheet mentioning the study details, procedures of data collection, confidentiality information and informed consent form was shared with them. The information was read to them and the procedures were explained in detail thus maintaining the transparency of the research process. The participants were assured of the confidentiality and privacy of the data that they would share as they were informed that pseudonyms would be employed in the stories. The informed consent form stated that the participant is willing to be a part of the study and can withdraw at any time.

Data Collection

Complete flexibility: Life story interviews is all about being dynamic, innovative and free flowing.

Till the time you don't venture out in the field, you won't experience the complexities involved in data collection through qualitative research. This realization came during the third visit to the first participant (the initial two meetings went in rapport formation); she enquired if there was any questionnaire to be filled, or structured set of questions that could be answered. Adding to this she uttered that many researchers like you visit me, and get their forms filled. This is where it occurred that to date, disability research is approached from a quantitative perspective thus sidelining the voices of these individuals. Having said this, the significance of quantitative research is not being nullified, but to assert that with qualitative methodologies we could have the experiential accounts of these individuals that could strengthen the quantitative data, and thus help in informing policy and practice in a better way. Also having their voices heard would project these individuals as active agents of change, thus imbibing the philosophy of rights based approach promoted by the United Nations Convention on the Rights of Persons with Disabilities.

This also reminded the researcher that being accessible to most of the researches, the participant might have developed research fatigue. Certain people with disabilities are accessed more for research given their resources and ability to be part of the study (Bigby, Frawley, & Ramcharan, 2014). While going for life stories, many of them wanted to know from where they could begin? The standard reply was, you can begin from where you wish to, and the researcher used to put up an opening question, "what is to live with a physical disability?" Such opening questions are descriptive, as termed by Spradley (1979), and these questions when asked in the very beginning let the participants describe their daily life experiences in detail. Gradually when the relationships grew stronger, a little bit of structured questions were put up or probes were used, for example the first participant spoke about impairment experiences and said, "I used to cry, shout and break things and feel why this is happening." So in the subsequent sessions, she was questioned at this as in what made her feel like this, or a probe such as, "is it impairment related".... And then the use of probes, and structured questions led to explore finer details of the participants' experiences. And most importantly during this process, one has to be an empathetic listener and let the participant speak.

Sailing through overwhelming interview sessions is an art, as one has to be innovative, and each day one evolved as a person and as a researcher. The challenge always is how not to disrupt the flow of information. The interview process is a dynamic one, and it actually depends on an interaction with the participants, so in the field nothing goes as per pre-determined structure and is completely flexible and free flowing.

Developing trusting relationships and maintaining these is the key

When you decide to plunge in the research with people with disabilities, the formation of trusting relationships with the participants is of huge significance. In this regard, Bogdan and

Biklen (1982) argued that the researcher must establish rapport and trust if the participants are to expect involvement of the researcher in their daily lives where they would be sharing personal stories. Establishing relationship usually begins on the very first day when one meets the participants. Researcher needs to lay out clearly that she is there to listen to the insider's perspectives and to the story of their life.. A lot of time and effort is invested in forming relationships and in this particular research, maintained the same by attending events such as organization events, visiting places, and meeting in cafes for listening to their stories and free conversations or having conversations on any topic that interested them. This really helped in building rapport with them, and gradually with each meeting the relationship strengthened which was reflected in their ease of opening up to share details about their life. Llewellyn (1995) pointed out that having informal meetings with the parents in parenting study was helpful in gaining acceptance from the participants, and developing rapport and trust with the parents as they were the potential participants. The author also spoke of giving off the, "professional distance", so that the researcher-participant relationship could be maintained (Llewellyn, 1995, p. 115).

Deciding for venue: Another area that needs attention

Except for two participants who were quite comfortable in inviting the researcher to their homes, for rest of the participants searching a comfortable place which was accessible, convenient and away from noise was a task in itself. So at times settings in a garden, peaceful spaces, office of the participants or library campus (such as Indian Historical Library), or university/institute campuses (data with four participants were conducted at these spaces), and even cafes were chosen. Locating a peaceful venue where hassle free session in a fine tuned manner could happen was a challenge. This again took a lot of time, and at times due to noise in the surroundings many times, sessions were interrupted.

Health and Emotional issues

Entering into the disability domain requires sensitivity and patience on part of the researcher. There were many instances where one had to return without meeting the participants. The participants often encounter health issues for which they might not be available on many occasions. Also, it might not be possible for them to continue the session at a stretch as the sessions continued for about an hour, and this they found tiring. So there had been sessions which were cut short owing to fatigue, or issues due to prolonged sitting that created trouble for the participants. Health issues such as fatigue, comorbidities and mobility challenges can pose difficulty in participation (Ellard-Gray et al., 2015).

Emotional issue might occur when people with disabilities revisit their lived experiences so as a researcher one needs to deal the situation sensitively, and if possible arrange for the counseling sessions in cases where the severe issues crop up. One of the female participants broke down in tears while narrating the school experiences of the classroom, ninth standard where she was mocked at her physicality by the

teacher and students. The pain of this experience was so heavy that even after thirteen years she felt crushed by that event. So on that day it was decided to stop for the day, and the researcher took the participant to the canteen for chit chat and snacks. So here again, the role of researcher is emphasized in building the relationship ties with the participant so that she/he could connect with the researcher and confide in, to be able to share deeply distressing experiences with her. Getting emotional was often seen in contexts where individuals share their experiences of illnesses or anything traumatic, and it was one of the reasons that two of the participants quit the study despite their voluntary consent for participation. Carey and Griffiths (2017) mentioned that the researchers need to take note of the participant's mood, feelings, and understanding as the research progressed as this would help in dealing emotional issues that might arise during the interview sessions.

Field notes journaling and transcription

Field notes refer to running record that are kept when one meets the participant. These notes capture the description of the venue, facial expressions, subtle nuances which can't be audio recorded but are critical for analysis. These are used to enhance the audio recorded transcripts. Field notes journaling, here implies that a word document or handwritten detailed description of the particular session with the descriptive details of the participant was maintained. This was basically a summarized version of how the session was and what all happened including the reflections of the researcher. All the sessions were audio recorded as per the consent of the participants, and later these were transcribed verbatim. Although audio recording assisted in gathering rich insights of the participants but despite their relaxed attitudes of using the audio recording many a times they talked something crucial which did not get recorded, as they said it after the session so that's the limitation that the audio recording poses. So in such instances, the field notes come handy and one can record such valuable information in the field notes which might not be present in the audio recorded sessions.

Bidding adieu to the field

When can you say that your data collection is over, there's no definite statement for this. In this study one participant was contacted at a time, sessions were conducted with her/him, simultaneously transcribing, doing up follow up sessions, developing life stories and following up her/him. Though one is never sure that all information has been collected and as Bulmer (1969) maintained that as per social constructionist view the understanding of social phenomena is never achieved fully as they keep on changing and understanding advances through deeper levels of understanding. So the question isn't about the completion of the data collection, but when one can decide that the interaction is no longer bringing new understanding with respect to the phenomenon in question. So this was achieved by seeing that when the participants were coming up with repeated answers during probes, and they had nothing unique to add on regarding the phenomenon, it was then felt that one could stop the data collection.

CONCLUSION

The purpose of writing this article was to get an opportunity to pause, reflect, introspect and recount the field journey and identify challenges of doing narrative life story approach with people with disabilities. Through the research the endeavor was to listen to the life stories of the participants. The study also emphasized on the fact that by employing qualitative research methods we can effectively capture the insider's views of what the essence of living a particular experience means which in this case was to live with a physical disability.

Doing qualitative life story with people with disabilities necessitates building of trusting relationships, negotiating power dynamics, and being innovative, which definitely is a taxing issue and requires patience and sensitivity on part of the researcher. Insights have been shared on navigating the field journey, which might be useful to the researchers planning for a qualitative research with people with disabilities. Finally, it is important to reiterate that there is a strong need to give thrust to qualitative research tradition in disability domain as only then we could view that the experiences of these individuals are entrenched in a cultural complexity, and these insights could inform policy in a better way.

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