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Autoethnography as an Accessible Method of Research

ABSTRACT: Reflecting on my own experiences as a researcher with a disability who lives and works in Poland, I examine methodological issues critical to conducting qualitative research. I argue that autoethnography is a viable method for researchers who must overcome physical and/or cultural obstacles associated with a disability. I also maintain that autoethnography as well as its usefulness as a research method is inherently situated within the sociocultural conditions in which research is being conducted. Concluding, I imply that further studies are necessary for people with disabilities to re-gain voice and articulate their experiences.

KEYWORDS: autoethnography, disability, Poland, research methods

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In this article, I will reflect on my own experiences as a researcher and a person with a disability in order to address methodological issues critical to conducting qualitative research. While my example is grounded in conditions specific to my disability and the cultural setting in which I live and work, my hope is that my experience the findings may empower other researchers who face various obstacles in their own research practice. I will argue through the lens of my own experience that autoethnography is a viable method for carrying out qualitative research and overcoming serious limitations that would otherwise impede sociocultural investigations. I will also maintain that autoethnography and its methodological usefulness must be understood as a socially and culturally embedded endeavor.

I am a person with a serious physical disability who depends on the assistance of others to be mobile. I use a manual wheelchair, which I cannot maneuver by myself. I do not have a power chair due to both financial and practical conditions. I live with my parents in an old block-of-flats in a small town in the Polish mountains, in a two-bedroom apartment on the first floor. My father pulls me up and down the flight of stairs in my wheelchair - if he is not at home, this task is performed by two or three other family members. There is no lift or ramp in the apartment building - the cooperative rejected my request to install a stair lift. Under these conditions, a powerchair weighing from 80 kg to over 150 kg would prevent me from getting out of my house. And even if I did somehow get out of my house, I would encounter other insurmountable obstacles such as curbs, potholes, inaccessible public buildings and inaccessible public transportation. If I used a power chair, I could not use the only means of transportation available to me now - my parents' car that my father and my mother transport me in. Lacking physical strength, I need help with most daily duties, including eating, dressing, hygiene and preparatory tasks related to work. However, once my workspace is established, I work independently, using my small laptop, tablet and a cell phone with a wireless headset. I hold a full-time job as a home-based office assistant to a transportation company, performing my tasks using computer technology.

In addition to this job which „pays the bills,” I hold degrees in philosophy and cultural anthropology and I am passionate about qualitative research. As a researcher, I am interested in disability studies, more specifically, in the experiences of people with physical disabilities in Poland. In my past research I have focused on such issues as disability tourism and travel as well as access to public services and information (Polczyk, 2008, 2009). Autoethnography was not my method of choice in the research I conducted. I thought that I could use the same ethnographic methods as my colleagues - students and teachers - relying on direct contact with respondents (interviews, participant observation of others) and scholarly literature. However, it was early in my research that I realized that traditional methods would not suffice. At first, due to my own limited mobility, I could not readily get to my potential respondents. This required transportation, which in my case means getting my family fully involved in transporting me and waiting for me while I conduct interviews. Moreover, most of the people I sought to interview themselves live in inaccessible places - I could not

get to them and they could not get to me. In addition to these logistical constraints, I found that the Polish people with disabilities that I contacted by phone and email were hesitant and occasionally hostile to my questions regarding their experiences and life situations. The responses that I frequently heard were, „What's in it for me?” and „Why should I answer your questions if it won't change anything in my life?” This sociocultural phenomenon of „muteness” of Polish people with disabilities has been my leading preoccupation in my previous work (Polczyk, 2008).

Additionally, the available literature on disability studies is mostly written from an „expert” vantage point in which non-disabled researchers share their findings about people with disabilities. I could not find studies that would help me understand the cultural phenomena and methodological challenges I was encountering. As Couser suggests, this problem may be more general - people with disabilities have been largely ignored by ethnography and approaches have tended to generalize the experience of disability, which in actuality varies depending on multiple factors such as the type of disability (physical, mental, sensory, etc.), gender, age, ethnicity or class:

“Indeed, like indigenous people, disabled people have sometimes been treated as colonial populations, and disability ethnography faces some of the same ethical challenges as ethnography involving populations subjected to classic Western imperialism. (...) More broadly, many disabled groups consider themselves subject to well-meaning but patronizing domination by medical experts and charitable organizations that control the terms of their integration into society as a whole. According to Lennard J. Davis, ‘people with disabilities have been isolated, incarcerated, observed, written about, operated on, instructed, implanted, regulated, treated, institutionalized, and controlled to a degree probably unequal to that experienced by any other minority group.’ (Davis, 1997, p. 1, as quoted in Couser, 2005)

But while there are English language works on disability, I have not found a compelling disability ethnography in Poland. There are, of course, similarities between the experiences of people with disabilities in the United States, Canada or Germany, but we do not have information on the specific sociocultural conditions and lived realities of people with disabilities in Poland.

Through my work I have been trying to fill this void. Faced with difficulties of access described above, I have been driven to autoethnography as an effective methodology for me as a researcher with a disability and limited mobility. Autoethnography is my way of overcoming an overwhelming feeling of „being stuck” - not being able to travel to talk to respondents, not being able to find literature dealing with the experience of disability in the Polish context and finally, being rejected by other people with disabilities who refuse to talk to me. Autoethnography is my way of voicing the experience of disability in Poland.

Ellis, Adams and Bochner state,

“Autoethnography is an approach to research and writing that seeks to describe and systematically analyze (graphy) personal experience (auto) in order to understand cultural experience (ethno) (Ellis, 2004; Holman Jones, 2005). This approach challenges canonical ways of doing research and representing others (Spry, 2001) and treats research as a political, socially-just and socially-conscious act (Adams & Holman Jones, 2008). A researcher uses tenets of autobiography and ethnography to do and write autoethnography. Thus, as a method, autoethnography is both process and product.” (Ellis, Adams & Bochner, 2010)

Autoethnography is not a widely popular and accepted method, but by explicitly bringing the researcher's own experiences and emotions into the ethnographic process, it points to the sociocultural embeddedness of all human and social research, helping to show that researchers do not live outside of social reality. When a researcher, like me, decides to use autoethnography as her method, we need to be aware that the effects of her research might – and should – change both the researcher and the reader. The effects of such research should be easy to understand in order to reach a wider public, not only scholars who are familiar with anthropology. Autoethnography should have impact and should be able to transform reality. Autoethnography is an encouraging idea, providing „an avenue for doing something meaningful for yourself and the world” (Ellis, 1999).

Reed-Danahay identifies three variations of autoethnography: (1) “native anthropology” produced by native anthropologists from the groups of people who were formerly studied by outsiders; (2) “ethnic autobiography” written by members of ethnic minority groups; and (3) “autobiographical ethnography” in which anthropologists interject personal experience into ethnographic writing (Reed-Danahay, 1997). I position my own research between version one and three. People with disabilities have been studied by outsiders, and not necessarily anthropologists (at least not in Poland). I am definitely “native” amongst people with disabilities. Still, I must admit that, based on my observations of the Polish disabled, I often feel very different from them. The people I have encountered seem to have a sense of entitlement and assume they should be given things just because they are disabled. I have never shared this point of view. Yet, I am a disabled person living in Poland and I am also an anthropologist interested in disability studies. I write through my personal experience in my ethnographic writing because it is my only way of describing the social reality I observe and experience. My goal is not to write my story; I want to avoid the narcissism of overly reflexive and personal narratives by reaching for anthropological and comparative perspective (Holt, 2003).

When I first started researching, I was excited and optimistic, looking forward to meeting various people and expecting that everyone would be happy to tell me their story. Unfortunately, I was wrong and I have been wondering since about the underlying reason for the resistance people with disabilities have to talking about their situation. Couser comments on this situation, saying: „[A]lthough disability communities are ripe for ethnographic investigation, disabled people, long subjected

both to marginalization and objectifying examination, may resent and resist such attention” (Couser, 2005). This seems like a logical explanation of the problem I have encountered. In Polish reality, disabled persons are treated as Others, as those who are stigmatized by their disability, even if it is not visible.

“Doctor’s diagnosis is not only convenient classification of given biopathological phenomenon. It may also be a label, which can cause serious social effects. For example, telling a patient that he has anemia probably won’t make him happy, but information that he has epilepsy, might cause serious changes in his life, as a result of social meaning brought by medical diagnosis. Those changes might have bigger impact on a patient’s life, than the initially diagnosed biological dysfunction.” (Sokołowska, 1986, p. 211)

Even though the situation of people with disabilities is improving, I am afraid we will never be fully accepted and treated equally. Both Murphy (1990) and Barnes and Mercer (2008) say that a person who is once labeled as disabled, even if temporarily, will never shed the disability label. He or she will always be seen as someone who was disabled or sick. He or she will always remain stigmatized in some way. People will always ask, “How are you doing?” and will inquire if there’s any change to one’s condition for better or worse. Even if nothing changes, questions will remain. Disability is a source of shame for many people and therefore, I should not be surprised that people with disabilities do not want to cooperate with ethnographers or other researchers. They are afraid that the researcher, by focusing on their disability will dehumanize and objectify them (Couser, 2005).

Ellis, Adams and Bochner (2010) advise autoethnographers to

“look at experience analytically. Otherwise [you’re] telling [your] story—and that’s nice—but people do that on Oprah [a U.S.-based television program] every day. Why is your story more valid than anyone else’s? What makes your story more valid is that you are a researcher. You have a set of theoretical and methodological tools and a research literature to use. That’s your advantage. If you can’t frame it around these tools and literature and just frame it as ‘my story,’ then why or how should I privilege your story over anyone else’s I see 25 times a day on tv?”

Couser also mentions that there are many publications about disability; however, few of these are real autoethnographies that focus not only on the self, but also compare the writer’s experience with the lives of others (Couser, 2005). Indeed, I went through a process similar to the one described by Chang (2007):

„Autoethnography pursues the ultimate goal of cultural understanding underlying autobiographical experiences. To achieve this ethnographic intent, autoethnographers undergo the usual ethnographic research process of data

collection, data analysis/interpretation, and report writing. They collect field data by means of participation, self-observation, interview, and document review; verify data by triangulating sources and content; analyze and interpret data to decipher the cultural meanings of events, behaviors, and thoughts; and write autoethnography. Like ethnographers, autoethnographers are expected to treat their autobiographical data with critical, analytical, and interpretive eyes to detect cultural undertones of what is recalled, observed, and told to them. At the end of a thorough self-examination, within its cultural context, autoethnographers hope to gain a cultural understanding of self and others. Autobiographical narratives can add lively details to this principled understanding, but narration should not dominate autoethnography.” (p. 209)

I went through all of these steps during my research, except that my way of gathering data did not really include meeting my respondents in person. This limited my ability to perform really in-depth interviews, which allow researchers get to know his or her respondents closely (Ellis, 1999). The better a researcher knows his or her respondents, the better the effects of the research. Not having this opportunity, I gather information from the Internet and support my findings with theory and other forms of literature. While the process is fulfilling, I constantly feel that I want something more. I want to be on the move, to be able to write something that will show the lived reality, the reality in which I actively participate. Even though I cannot visit some places that would enrich my research, I work through my memories, relying partly on my diary, which, however, contains limited notes because of my disability. As Ellis, Adams and Bochner point out, “We know that memory is fallible, that it is impossible to recall or report on events in language that exactly represents how those events were lived and felt” (Ellis, Adams & Bochner 2010). Ellis further argues that having notes is unnecessary because memory is an instrument that will let us remember what is really important - that which is felt. We feel various emotions while we are experiencing things, and thanks to this we can retrace our steps (Ellis, 1999).

Autoethnography is a convenient and useful method for performing research by a researcher with a physical disability and physical mobility limitations. If Poland were more accessible and open for people with disabilities, or if Poland had a law on personal assistance, or if I had ready access to accessible transportation, there would be no problem for me to move around. And maybe in that situation I would adopt more conventional methods of conducting ethnographic research. This brings up the sociocultural aspect of autoethnography - a method that I selected due to the complexities of living and working with a disability in a particular sociocultural context, a small Polish town completely unadapted to the needs of the disabled. Many people with disabilities in Poland are dependent on their families or on institutions, and not many of them lead independent lives. Many are forced to spend their whole lives with their parents, who themselves are often emotionally and physically exhausted from taking constant care of their disabled adult children. Personal assistants would be not only useful for researchers, but also for other persons with disabilities.

In this article I have shared my own experience as a researcher and the process by which I came to adopt autoethnography as my primary mode of research. I have tried to show autoethnography as a research method is related to the complex set of personal and sociocultural conditions in which research is conducted and located. I show that my choice of autoethnography as a research method is a result of the intertwining of such factors as: my type of disability, the location of my home (1st floor of an inaccessible apartment buildings in a small Polish town), my family's financial situation, and local and national policies related to people with disabilities. However, upon reflection, autoethnography seems to be a unique tool for engaged ethnographic practice. By exposing social reality through the lens of my own experiences of encountering obstacles while conducting research in a milieu filled with barriers both physical and cultural, I feel I am getting closer to „research and writing as socially-just acts” and to filling the void in which disabled Polish people are rendered invisible (Holman Jones, 2005, p. 764, as quoted in Ellis, Adams & Bochner, 2010).

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AUTOETNOGRAFIA JAKO MOŻLIWA METODA BADAWCZA

ABSTRAKT: Artykuł ten analizuje kwestie metodologiczne kluczowe dla prowadzenie badań jakościowych, opierając się na osobistych doświadczeniach mieszkającej i pracującej w Polsce badaczki z niepełnosprawnością. Wykazuje on również, że autoetnografia jest właściwą metodą badań dla badaczy, którzy muszą obejść fizyczne i/lub kulturowe przeciwności, związane z niepełnosprawnością, aby przeprowadzić badania. Ponadto, artykuł ten udowadnia, że autoetnografia jest naturalnie osadzona w warunkach socjokulturowych praktyki badawczej i wskazuje na potrzebę dalszych badań, które pozwolą osobom niepełnosprawnym zabrać głos i opisać swoje doświadczenia.

SŁOWA KLUCZOWE: autoetnografia, metody badawcze, niepełnosprawność, Polska