

How to listen and give voice to First Nations children in BC, Canada, diagnosed with Autism Spectrum Disorder– ethnography in practice.

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Abstract

The purpose of this paper presentation is to discuss some of the opportunities and challenges I have met as a PhD candidate. My work has involved conducting ethnographic fieldwork regarding the meaning of music for First Nations children in British Columbia, Canada, diagnosed with Autism Spectrum Disorder, ASD. The idea and research plan looked good in theory, but the reality presented various challenges. I am a Swedish researcher, who grew up in Canada, so having a stepmother and sisters who are First Nations has provided me access to the field. One major obstacle I encountered was the scarcity of First Nations children diagnosed with ASD. The focus of this paper presentation, however, is on ethical aspects of being accepted in Indigenous communities and welcomed into people's homes. It can be challenging to interpret and portray people's life stories. My interest lies in the impact of the interaction, both on the participant and the researcher. Finally, I will examine how the researcher can listen and give voice to First Nations children with ASD and their families, thus acknowledging and honoring the unique opportunity and privilege afforded her.

1. Introduction

The researcher's background

As an ethnographer, being connected with both the Western research tradition and the Indigenous people has been beneficial in many ways. It has also forced me to open up to Indigenous research methods and ethics which meant challenging my way of thinking.¹ I moved to Vancouver, Canada, from Sweden at the age of 11 months. During the 13 years I lived there, a strong sense of connection with the ocean, mountains and wildlife in BC developed within me. My step-mother and sisters are Carrier of the Lake Babine Nation, and through them, since 1980, I have gathered an insight into Indigenous lives and lifestyles. This, together with the multi-cultural setting of Vancouver, has contributed to my research interest and the desire to learn more.

In this paper I briefly explore my prospects of both listening and giving voice to First Nations children in BC, Canada, diagnosed with ASD. This is a neuro-developmental disorder that affects every aspect of life and can have lifelong implications for the individual. The criteria

¹ In this paper I have attempted to write according to the Western tradition without compromising the integrity of Indigenous research methods and ethics.

for ASD are within the areas of social communication and interaction, and restricted and repetitive behaviors (American Psychiatric Association, 2013). ASD prevalence has risen globally but First Nations children in BC, Canada, are not represented in research publications. ASD may be under-detected within this group which can have implications on interventions, education and funding eligibility (Lindblom, 2014). Approximately a quarter of individuals diagnosed with ASD do not speak or use language meaningfully (Autism Speaks, 2014). Since these children are scarce and a quarter of them might be non-verbal, making their voices heard is a difficult but important task. My background has given me the unique opportunity to make the attempt to do so through my research.

Aim

The aim of this paper is to discuss opportunities and challenges I have met as a PhD student doing ethnographic fieldwork. I also hope to obtain views and comments from researchers, both Indigenous and non-Indigenous, on my on-going PhD project on the meaning of music for First Nations children BC, Canada, diagnosed with ASD. The impact of interaction between participant and researcher is of special interest. My aspiration is to give voice to my participants, and at the same time, raise ethical and methodological issues.

2. Fieldwork

Ethnography

Ethnography originates from anthropology and was traditionally used to describe cultures outside the West. From the 1960s ethnography was used in sociological studies within Western societies as well, and today ethnography is used in various fields such as psychology. Collecting data about the particular aspect of the participant's lives that are in focus, is done through fieldwork in an everyday context. Data can consist of interviews and observations. (Hammersley & Atkinson, 2007). Globally, Indigenous people have been subject to colonization and research that has fed Western needs and perspectives. Cultures and traditions have been interpreted through the eyes of the researcher, acknowledging exotic aspects and depicting the studied peoples as inferior or deviant, thus silencing the Indigenous voices (Louis, 2007; Wilson, 2008). First Nations, Inuit and Metis are the three Aboriginal peoples recognized by the Canadian constitution (Aboriginal Affairs and Northern Development Canada, 2012). In this paper I will use the term Indigenous as Indian, Native and Aboriginal are names that colonists gave the Indigenous people.

In ethnographic research, fieldwork is essential in generating data. In all ethnographic studies negotiating access to the field presents challenges both initially, and also throughout the whole research process. Even if gatekeepers, people with the opportunity to arrange access (such as personnel), can facilitate access, that does not guarantee that the intended participants will be interested in being a part of the research (Hammersley & Atkinson, 2007).

Historically, Indigenous people have been subject to various types of research by Western researchers. According to Louis (2007) distrust and resistance is rising and she predicts that the doors to Indigenous populations will soon be shut. Sometimes the selected focus for

research is not reasonable and the research design or research questions must be altered. Ethnography is demanding and the researcher must have a variety of skills and be prepared to tackle uncertainty (Hammersley & Atkinson, 2007).

Access to the field

During a preparatory trip, I discovered that finding participants for my research would be very difficult. Local researchers discouraged me and said that, even if I found participants, I would not gain access to the field. Members of my Indigenous family connected me with important gatekeepers in First Nations communities and settings that covered an area of over 1000 kilometers in BC. Finally I found 5 participants who along with parents, family members, school staff and others contributed to my research. It took four trips from Sweden to Canada to accomplish proper fieldwork. The purpose of the first trip in spring 2012 was to connect with researchers and, gatekeepers, and to explore the field. The second was aimed at further networking at the First Nations Education Steering Committee (FNESC) conference in Vancouver in November 2012. I had one participant when I left for my first data collection in 2013, but found four more during my six-week stay. The many meetings and driving to remote areas was time consuming, and the collected material consisted mainly of recorded interviews. This spring (2014) I revisited my participants and had follow-up interviews with all but one. I also did some observing and filming. Obtaining access to the field was difficult but through gatekeepers I found enough participants for the project.

3. Impact on researcher and participant

Emotions

Traditionally, emotions and research do not go together and Blackman (2007) discusses the 'hidden ethnography' in sociological research. This is highly applicable in my case, even though my research is in the field of psychology. By hidden ethnography, Blackman (2007) means data from fieldwork that is too controversial or sensitive, often involving feelings, and therefore is not published. It can be, for instance, dangerous situations or emotions between researcher and participant. Hammersley and Atkinson (2007) emphasize the fieldwork journal as essential in recording feelings and responses so they can be analyzed and reflected on, because they influence the research process.

Although I believed myself to be well prepared for ethnographic fieldwork in terms of both experience and education, reality proved me wrong. I barely made any field notes at all during my first field studies due to the stress and anxiety I experienced. I was constantly terrified that someone would steal my notes or material from my car or motel room, or that I would misplace or even delete them. Some of my thoughts and feelings were so strong that I did not even want to acknowledge them. It was as if by not writing them, they did not exist. Furthermore, long hours driving to participants and meetings in different locations and staying with different people, in different places, gave me little time alone for the actual writing of notes or to reflect on what I was experiencing. The process of transcribing interviews resulted in more anguish and tears. To cope with these emotions, I have adopted different strategies;

from professional therapeutic sessions, to dog-walking in the woods surrounding my home. Nevertheless, the feelings remain very powerful and overwhelming as soon as I approach my research topic and material.

The Highway of Tears

In the course of my fieldwork I have met many strong First Nations women dealing with the everyday challenges of having a child, or working with a child, diagnosed with ASD. In contrast, of all the experiences leading to troubling emotions, the one I find most unsettling is the vulnerability of First Nations women. I will use the Highway of Tears to exemplify this. The Highway of Tears refers to the stretch of the Yellowhead Highway 16 between Prince George and Prince Rupert. When I first heard the expression, I thought it was just a nickname for the road. In 2012, while driving with my grandson Chris, we saw posters about a missing woman. That and the vastness of the British Columbian countryside caused me to start wondering what I was exposing us to. A number of Indigenous women have disappeared or been found murdered on this 724 kilometer section of highway (Wikipedia, 2014; Highway of Tears – Preventing violence against women, 2014). Moreover, Carrier territory lies along parts of the Highway of Tears. Traveling there, reading facts about the crimes committed to Indigenous women and seeing their photos are all very frightening. Implications can be seen at many levels.

At the personal, individual level, it is very intimidating, paralyzing and almost unbearable. Thoughts racing through my mind were:

This could be my sister.

This could be my niece.

This could be me.

At the local level, it affects the daily lives of Indigenous women. The Royal Canadian Mounted Police, RCMP (2014a), in partnership with the Native Women's Association of Canada, NWAC, have a poster campaign to raise awareness about how dangerous it is to hitchhike. The Highway of Tears Symposium Recommendations Report (2006) refers to hitchhiking as poverty-related travel and points out the need for better services. Many First Nations people live on reserve which, in some cases, means in remote areas, but long distances between communities also presents challenges to travelers.

At the provincial level, there has been talk of systemic racism due to the lack of resources and or disinterest in investigating the disappearances and murders along the Highway of Tears (The Vancouver Sun, 2009-08-29). Nationally, the RCMP recently published a report (2014b) indicating that Indigenous women are over-represented among missing and murdered women in Canada and the numbers are higher than previously estimated. According to the report, 4.3% of Canadian females in 2011 were Aboriginal. The report states that, as of November 4th, 2013, 11.3% of missing females in Canada were Indigenous and 16% of all female homicide victims were Indigenous. Globally, the issue of Indigenous women's vulnerability is

fairly unknown. As an ethnographer I must put my focus of research in context (Hammersley and Atkinson, 2007). Their everyday lives are affected by their surrounding environment and events at different levels. By doing so, and raising these issues in research publications, at conferences and in my teaching, it is possible that global awareness will increase.

Sharing people's lives

Being welcomed into people's lives and homes is a privilege that comes with responsibilities. Louis (2007) suggests the term collaborators instead of participants when conducting research within the Indigenous context. Hammersley and Atkinson (2007) raise the issue of trust and conclude that people are more interested in the kind of person the ethnographer is rather than the research. In my case, the gatekeepers' trust was easily won, because Indigenous family members introduced me. This was of further aid when the gatekeepers connected me with the parents of potential First Nations children diagnosed with ASD. Had I not met their standards, however, I probably would not have been welcome to do my follow-up interviews, observations and filming. The introduction in itself was not enough. My earlier experience as a newspaper reporter and teacher in special education were very helpful, but other factors were also important, such as being European and my age. Since I come from Sweden, I am not directly connected with colonialism. Indigenous people's respect for elders was also in my favor; being mother and grandmother in my mid-fifties afforded me a degree of credibility.

Not only participants spoke with me. Relatives of participants, or even random people on reserve would talk to me and tell me personal, often shocking or terrible things about their personal lives. Acceptance in one home seemed to bring acceptance to most homes. Although I felt honored, I also was confused about what to do with the information I was given. It was not a part of my research topic, but still provided me important information on what it can be like to be First Nations, to live on reserve. Conflicting feelings within me arose concerning the expectations from these people. Was I just a person they could talk to? Were they relieving their own anxiety and counting on my ability to harbor their feelings? Did they expect me to do something? Or was listening and engaging in conversation enough? During my fieldwork it was clear that my participants and I were engaged in a reciprocal process, in which both opportunities and challenges presented themselves.

4. Ethics

Western research ethics

After my first planning trip to Vancouver, I applied for an ethical review at the University of Eastern Finland, where I am a PhD candidate. There is rigorous control of all documents and strict rules. Corrections and additions were sent several times before obtaining a positive decision. Initially, I had planned to compare the meaning of music for Swedish children and First Nations children diagnosed with autism. Discussions with a Canadian professor resulted in the planning of a screening for autism within an Indigenous community or school, on the condition of finding someone interested. Several Indigenous school officials thought it was interesting but nothing came out of it. It didn't take long for me to realize that the proposed

study was an example of a Western way of thinking and not relevant to the First Nations people at this time. It may be that this project could be realized later in the case of a school or community approaching me with interest. The meaning of music however, especially my research questions regarding the use of Indigenous music and using music as a tool for inclusion, are highly relevant. During my fieldwork I had to constantly remind myself that meetings with me might not always be first priority to my participants. During the process of the project, interacting with participants and learning about Indigenous research methodologies, I have had reason to question and alter my frame of thinking. In order to give voice to my participants I had to readjust my hearing and listen in a different manner, subsequently reshaping my researcher identity.

Indigenous ethics

According to the Indigenous ethic, everything in the world has life and spirit. As humans, we are obligated to learn how to relate to the world with respect. There are ethical obligations connected to receiving knowledge (Brant Castellano, 2004). This can be difficult for researchers, like myself, that come from another culture with a different worldview and must, in some cases, be learned (Kovach, 2009). During my fieldwork I have had several encounters with wildlife that have made me feel a reciprocal relationship with the environment. One incident, in particular, made a great impression on me, my sister Gina and her children that were with me, and subsequently, on many of my Indigenous family members. The second time I traveled the Highway of Tears, in spring 2013, I was still too afraid to go alone. Fortunately, my sister Gina and her three children came along for company. Moreover, my nephew and nieces had never been to the reserve, which lies within my fieldwork areas, so I wanted them to have that experience. My immediate First Nations family members live in Vancouver and are, to some degree, urbanized and disconnected from their traditions and heritage. During our trip, we discussed the Carrier nation and the Lake Babine Band. We talked about the four clans and how my stepmother, sisters, nieces and nephews are Caribou Clan. Driving out of Barkerville, while turning a bend, suddenly three caribou were in the middle of the road in our lane. I stopped the car and we became very excited. The children had never seen caribou before and we discussed them being of the Caribou Clan. After a few minutes we wanted to continue our journey but the caribou would not budge. They did not even react to the car horn. Finally, I started driving very slowly. The caribou started moving slowly, and soon one of them moved to the left hand side of the vehicle. We were fascinated and astounded by the experience – the actual caribou were escorting members of the Caribou Clan of the Carrier nation on their journey to their traditional territories. They escorted us for about five minutes, until a car came from the opposite direction and the caribou ran into the forest. Wilson (2008) says that relationships with our environment and with other people are sacred in equal proportion. We all felt that our encounter with the caribou was a very spiritual experience. By acknowledging such events and depicting them respectfully, the Indigenous ethics can be incorporated in my research.

5. Closing remarks

In this paper I have addressed some opportunities and challenges that my ethnographic fieldwork has offered whilst gathering material for my PhD dissertation on the meaning of music for First Nations children in BC, Canada, diagnosed with ASD. In terms of opportunities, I was able to gain access to the field, I found participants and I got data. During the process, however, I also faced challenges; I had to deal with uncertainty, emotions and face the Highway of Tears, which I was finally able to travel alone this spring (2014). A lesson learnt is that knowledge about ethnography cannot only be acquired from books or courses. It has to be lived and experienced. The method takes form during the research process. Ethical dilemmas have risen from being welcomed into people's homes. With this privilege comes responsibility. My fieldwork has made it necessary to learn about Indigenous ethics and worldviews, in order to conduct research that is ethically responsible (Kovach, 2009) from both Western and Indigenous perspectives. In doing so I aspire to give voice to my participants and also to increase the volume of Indigenous voices in BC, Canada.

In conclusion, I am sure that the people I have met have all been affected by our interaction. I know that I have been shaken, awakened and changed in every essence of my being: in my mind, my body and my spirit. I am also convinced the process has only just begun and that I will continue to evolve. Shawn Wilson (2008) says, "If research doesn't change you as a person, then you haven't done it right." (p 135). This gives me confidence that I am at least going in the right direction.

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