

**Citation for this document (APA):** Flinn, J. A. (2009). Researching the personal [thesis chapter]. In J. A. Flinn, *The educational impacts of tuberous sclerosis complex* (pp. 4-13). (Master's thesis, University of Western Ontario, London)

### *Researching the Personal*

In the course of preparing and carrying out this research, I had some ethical and methodological considerations to sort out. I became interested in Tuberous Sclerosis after my first child was diagnosed with this disorder. This has led me down the path of discovering what it meant to research something I was personally invested in, and what that meant for my research and for me.

Scholarly writing and researching that involves the personal is a controversial topic that has received more attention in recent years (Bleich & Holdstein, 2001). My methodological choices, their consequences, and my own investment in the study of TSC will be explored with reference to the current literature, primarily from education, on the use of narrative, researcher-participant relationships, writing from the self, issues of voice and representation, personal history research and power issues in research relationships.

I came to research TSC after my daughter was born in 2006 with this disorder. After dealing with the initial shock, denial and other bereavement symptoms, similar to what Holland (1996) describes in other parents dealing with a TSC diagnosis have gone through, I started to wonder how I would incorporate this new reality into my life. I went to a conference, hosted by TSC Canada, a non-profit organization supporting parents and people affected by TSC. Two doctors spoke. One, a neuroscientist named Dr. Whittemore, has a child with TSC and in fact herself has TSC, and has dedicated her career to working with the TSC Alliance (Whittemore, 2007). Another doctor, Dr. Hulbert, a urologist, spoke about how he came to research TSC. He has a son, now a teenager, who was born with this disorder, and he wanted to do something to help children affected with it. He devoted his research career to researching kidney and urological issues in TSC. He suggested everyone at the conference had some sort of gift that they could use to help others with TSC (Hulbert, 2007). For some it might be ability in fundraising, or public speaking. It got me to thinking, what was I good at? What could I do to help? I realized that as a student pursuing a Master's degree in education, I was in

a unique position to contribute to the field of study in TSC. So I decided to begin this study for my thesis about the educational impacts of TSC.

In the course of planning the study, I realized I would also need to find out about the children's medical difficulties and manifestations of the disease to date, age, method of diagnosis, challenges and behavioural differences, and a whole range of other related questions. This made me reflect on my own feelings towards those questions, and how I might feel if I were the participant answering those questions instead of the researcher. Holland (1996) and Whitehead and Gosling (2003) have both found that the initial diagnosis of TSC can bring up many negative emotions, similar to grieving. De Vries et al. (2005) found that parents and caregivers of people with TSC experienced considerable stress in caring for these individuals. Thus, in conducting this research, I may have been bringing up some negative emotions.

Researching from within a community or group, in which the researcher is already a member, is a process DeLyser (2001) calls "professionalizing the personal" (p. 446). Some researchers, including myself, "find topics close to home, or close to our hearts-topics so compelling we can't leave them alone-and we try to find ways to use our "insider" status to help, not hinder, insights" (DeLyser, p. 446). In my choice to study the educational issues of children with TSC, I was very much studying from an "insider" position. Despite the possible complications of studying from within the community of parents of children with TSC that I have become a member, the hope that I could contribute something positive and help others affected by this disorder, of which I have so much personal knowledge and understanding, was quite compelling to me.

Although the most challenging aspect of the project was recruiting participants, most of the participants that I spoke to seemed happy and willing to share their experiences with me. I think TSC is a rare enough disorder that many of the parents relished the opportunity to have someone who understood the disorder listen to their experiences. Being an insider researcher helped to bridge the gap between my participants and myself. It helped my participants feel they could talk to me about their experiences, and not feel it was such an intrusion into their private world. This seemed especially true for the participants from Canada. In Canada, the organization to support families with TSC is very small, and there is only one TSC clinic, which has very

recently opened. Thus, many parents do not have the opportunity to meet with and speak to other families affected by TSC. The situation is somewhat different in the United States, as their TSC support organization (the TSC Alliance) is very large and has 26 TSC clinics across the country. Many American parents have more opportunities to meet other families with TSC and have the opportunity to see specialists in TSC. In the education field, the TSC Alliance has a full time educational advocate that parents can contact for assistance in getting appropriate services and programming for the child in school. Therefore, those parents may feel more supported in their efforts to navigate the education system.

In one case, the interview started off with the mother sounding a little weary of my questions, until a comment of mine about my daughter having the same type of seizure as her daughter made her realize I had a child with the same disorder as her. Her whole demeanour seemed to change, and she seemed to relax and share more openly. My insider status seemed to make this participant feel more at ease with my questions.

Lincoln (2005) suggests that in ethnographic research it is sometimes insiders, members of the community who become researchers, who are able to more accurately represent their community from the inside than an outside researcher coming in. She is referring to research about different cultures, but I think this same logic can be applied to a researcher studying any community from the inside. The affirming questions often asked by participants during an interview, questions like ‘You know what I mean?’, might be more meaningfully answered by a member of the community. I wondered if by entering the researcher-participant relationship as an “insider”, a member of the community of parents with children who have TSC, I might be able to build a more equal relationship with participants. Although I would not be so naive as to suggest that power relationships can be equalled and that my participants and myself can be equal partners and collaborators, efforts to address the research relationship are valuable and worthwhile. The research relationship necessarily changes when the researcher is doing insider research, and having this insider status may lessen the divide between researcher and participant. By situating myself and acknowledging my own position in the research as a mother of a child with TSC, I felt I could build a more open and honest relationship with my research participants.

The interviews with parents differed in several ways from the interviews conducted with teachers and EAs. The parent interviews were much longer than the teacher/EA interviews. This is somewhat surprising, as this was an educational study, one would have expected the teachers/EAs to have more information to contribute as the experts on education. The parent interviews averaged 50 minutes, with the longest being 200 minutes and the shortest being 23 minutes, while the teacher/EA interviews averaged 23 minutes in length with the longest being 44 minutes and the shortest being 12 minutes.

There was a difference as well in the amount of times the parents sought reciprocal information and asked personal questions as compared to the teachers. Owens (2006) argues that researchers must be prepared to be asked for reciprocity in sharing, and that this sharing on the part of the researcher may help to lessen the feelings of shame on the part of the participant by evening out the power differences inherent in the relationship. This is an important point to consider in the context of my own study, as many of the participants may have felt strong emotions about having a child with a disability, recounting painful stories about how they were diagnosed and what the education system has done (or not done) to accommodate their special needs. The possibility of shame and strong emotions was very real. By building a relationship with the participants from a shared space of having a child with the same diagnosis, it was my hope that the interview space could be expanded for sharing and reciprocity, and that my participants would feel more comfortable sharing their stories with me. Almost without exception, the parents I interviewed at some point asked me reciprocal questions about my experiences with my daughter and her manifestations from TSC. By contrast, the teachers did not generally ask me many reciprocal questions. A couple of teachers asked me about my research, or about TSC, but no personal questions about me and my experiences.

I expected participants to express a need for reciprocity, but what I did not anticipate was the strength of my need for reciprocity. I felt whenever a participant was sharing their experiences, it was hard for me not to jump in with my own experiences and relate their story back to mine. Although the process was therapeutic, to have the opportunity to hear from other mothers who had endured many of the same difficulties and hardships that I had, I found it was somewhat difficult to pull myself back and

restrain from letting the relationship between myself and my participants from getting too close. It was important for me to recognize and acknowledge that these experiences and stories I was hearing, although similar to mine, were not mine and were separate from me. Otherwise, I feared I would put too much of my own experience into the data and not let it speak for itself when it came time to analyze what I had collected.

There were many times in the parent interviews when my participants asked me reciprocal questions about my own daughter, her seizures, her other physical manifestations. This was expected, but what was unexpected was that I noticed several points in the interviews when I offered up information that was not solicited by participants. While I think part of the reason for this was my own need to reciprocate and feel validated by these other mothers with children having the same rare disease, I think part of it may have also been to ameliorate their possible sense of shame in discussing such a difficult thing as having a child with a disability. It brought me back to when my daughter was first diagnosed and I felt it was somehow a secret I had to keep from the world. As if I somehow was not living up to the expected trajectory everyone's life was supposed to take; get married, have a career, have a perfect, normal child; as if I had somehow failed and needed to hide my shame. It was as though in some of my interviews I felt the need to tell my participants it was ok to let out these stories; that I had experienced similar things, almost as if I thought if I shared my story, it would lessen their shame and make it ok for them to tell their story.

In some ways I suppose part of my decision to research something in which I am personally involved and to include my own story in my research reflect my desire to create what Eakin (2004) calls a "counterstory". Eakin notes "telling counterstories enlists lifewriting in the service of social change, recasting the discourses of disability" (p. 12). Instead of the story of the child's helpless and devastated parent, I wanted in a way to create a counterstory of the parent of the child with a disability as powerful and able to affect change from within the community of people affected with this disorder. I had hoped that this research endeavourer might help other parents of children with TSC to create their own counterstories about their role as parents of children with disabilities. Clark/Keefe (2006) suggests a transformative process when working with participants with whom the researcher shares a background. By coming to my participants on a

somewhat equal footing, as an insider, it was my hope that the researcher-participant relationship could transcend the traditional power differences and boundaries and become a true conversational space, where participant and researcher alike are free to share their stories and meanings in a deep and personal way. This was evident in my interviews with parents. In several cases, when I finished the interview questions, the interview continued and turned into a conversation.

In my own research, I feel in order for the reader to truly appreciate the position from which I am writing, and to understand my conclusions, reporting, omissions, research relationships, and interview process, they must come to my work with the understanding that I am writing from within the community about which I speak. As a parent of a child with TSC, I am writing from a unique position within the field of research about TSC.

While it is my intention to represent the interviews and studies I conduct as accurately as possible, there is little doubt that my interpretations and even presentations of my data will be necessarily influenced by my own experiences and feelings about having a child with the disorder I am studying. For this reason, I have made the methodological choice to be upfront with both my participants and my readers about my own personal investment and involvement in the subject I am studying. Lincoln (2005) notes that there has been recent recognition of the limitations of so-called objective research. Even in positivist research, there is likely no research that is free from subjectivity. The illusive objectivity that many researchers subscribe to, although possibly a worthy goal in some circles, is likely a physical impossibility. As researchers, we play a large part in shaping our encounters with participants. “Consciously or not, we listen and make sense of what we hear according to particular theoretical, ontological, personal, and cultural frameworks and in the context of unequal power relations” (Luttrell, 2000, p. 499). Even a transcript of an interview is “already an interpretive and contextualized text; it is interpretive because it is shaped by the interpretive processes of researcher and participant and their relationship, and it is contextualized because of the particular circumstances of the interview’s origins and setting.” (Clandinin & Connelly, 2000, p. 94). Thus, there is little doubt that any research project, such as this one, will be subjective. Luttrell suggests that researchers cannot “eliminate tensions, contradictions,

or power imbalances, but I do believe we can (and should) name them” (Luttrell, p. 500). By “naming” my position upfront in my research project, I am acknowledging both its limitations, and possibly some of its strengths.

In deciding to research something that is personal to the researcher, either by researching from within a community in which the researcher is a member, or by researching something in which the researcher has personal experience, several key considerations come to the fore. Although it is unlikely that any qualitative research could really be “objective” and not influenced by many personal factors on the part of the researcher, the researcher must ask themselves, by acknowledging their subjectivities in an open way, what is lost and what is gained (see Luttrell, 2000). I suggest that what can potentially be gained is a more open research relationship, in which power differences are decreased, that can ultimately lead to more open, honest sharing of participants narratives. Owens’s (2006) conception of the “shaming” interview can be lessened when studying an emotionally laden topic when the researcher is coming to the interview experiencing many of the same feelings as the participants. This can help to form a more interactive approach to researching (as described by Chase, 2005). The researcher sharing similar narratives might satisfy the need for participants to have some form of validation and reciprocity in their experiences. Both the researcher and the participant can use the research process as a way to create a positive counterstory for themselves, and to restory their own narrative into a positive story. It is my hope that my participants were able to accomplish this by feeling that they contributed proactively to the educational experience of their child by participating in a research project aimed at improving education for children with TSC.

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