

MILESTONES ON MY RESEARCH JOURNEY: PANIC ATTACKS, EPIPHANIES, AND PARENTAL DEATH

Mary Ann Clute, M.S.W., Eastern Washington University

A doctoral student describes the early stages of her qualitative research on bereavement of adults with developmental disabilities after parental death. Methodology challenges and Institutional Review Board (IRB) anxiety as well as personal growth throughout the process are discussed. The death of the student's mother plays a pivotal role in infusing a renewed sense of commitment to her research.

Being one of those doctoral students who never has to be told to think outside the box because I can never *see the box* poses challenges to my professors as well as to my own research efforts. I am the circular thinker, the creative writer who is referenced in dissertation seminar as doomed to struggle with scientific writing. One of my coping mechanisms throughout early classes in the doctoral program was writing somewhat sarcastic poetry about Foucault, Popper, and epistemology and causal process. Much of the time I sit in class, envious of colleagues preparing to delve into secondary data sources using quantitative methods. I know I can never be like them. I know I have to take a different path. I want to go where few have gone before and where few of my colleagues plan to go. I want to do qualitative research with vulnerable subjects, individuals with developmental disabilities who have experienced the death of a parent. I want to understand how they experienced the loss of their parent. Most importantly, I want others to understand as well.

During my struggles and triumphs within the dissertation research process, I have had two major panic attacks and two epiphanies. The first panic attack was about methodology; the second was the Institutional Review Board (IRB). (I now notice that since I was studying grounded theory and theory development, I am sorting and coding my own experiences!)

My fears of methodology and IRB's co-exist, feeding off each other. They lie on the fertile ground of self-doubt that is fostered by the doctoral student experience and the dissertation process. In between the panic attacks, I had an "ah-ha" or epiphany about seeing my research as an evolving process, not a static product. The idea of my dissertation research as a dynamic process has helped me view the constant change process as "re-visions," not corrections. My second epiphany came thanks to my mother, who taught me one last lesson about the importance of honoring losses, with her death during my dissertation process.

Methodology is the first area of anxiety I will reveal and discuss. I will then describe my epiphany about process. Next, anxiety about IRB's will be fully disclosed, and finally, how my own grief has provided fuel for my convictions on the importance of my research. (Hopefully by this transition paragraph you will see that I have learned *something* about scientific writing.).

Methodology: Panic Attack Number One

I formulated my problem, decided on grounded theory, and completed a literature review of major bereavement theories for the general population. I reviewed literature on adult bereavement following parental death. I reviewed the sparse literature on

bereavement and persons with DD. I then had to work to tie all the research summaries into a document that would lead my reader to the same conclusion I reached, that not enough is known about bereavement for adults with DD. I have to lead them to the same deduction as I have, that grounded theory methodology is the path to take for uncovering more knowledge. I feel confident weaving the threads together and moving the reader along.

My next step, however, was to re-read grounded theory methodology descriptions and examples. I had to refamiliarize myself with how coding would work, how themes could be uncovered, how codes and themes would be redefined, reworked, and reanalyzed. I sat with articles, bookmarked pages, and notes and stared blankly at the computer screen when I tried to knowledgeably describe the process I would use to analyze the data I planned to collect. I finally had to draw the process as a spiral. That reaffirmed for me how my conclusions would evolve from the data after repeated analysis. It also explained my dizzy spells.

Simultaneously, I read articles about interviewing people with intellectual disabilities and learning disabilities. I added review of articles about forensic interviewing of children. I read articles about interviewing people about death and dying. I needed to respectfully ask them questions that would get them to describe their life, their emotions around the death of a parent. But *how* was I going to proceed? What were the best questions to ask to really find out the lived experience of an adult with DD whose parent had died? I sat befuddled as if I had backed my research vehicle into a huge snow drift. My wheels spun, but I got nowhere. Bottom line, for a time I was mired in the methodology chapter.

When I decided what I wanted to ask, I had to struggle with *how* to ask it. I had to get beyond "yes/no" responses, get a story without influencing the story itself. With persons with DD, a truly open-ended question

often draws a blank response (Biklen & Moseley, 1988). I read Davidson's (2003) *Living Outside Mental Illness* for tips on how to phrase questions. I searched for interviewing protocols for adults with developmental disabilities. I searched for interviewing protocols for children. A colleague forwarded me forensic children's interviewing literature and protocols. I read qualitative research for clues on how to unearth a person's story without my feeding the story teller any clues about what I wanted.

Concern about acquiescence (Milne, Clare, & Bull, 2002; Sigelman, Budd, Winder, Shoenrock, & Martin, 1982; Sigelman et al., 1980; Sigelman, Winer, & Shoenrock, 1982) reared its head. Acquiescence was a term that I thought I could forget after my quantitative research and statistics classes. I didn't want to cue the participants to tell me what they thought I wanted to hear. To cut down on the potential of leading questions, one of my colleagues recommended having the participant bring a picture of the parent. Maybe, I thought, a whole photo album, if possible. Then, what content did my questions need to cover? My chair wisely said to be comprehensive so I did not have to go back to the IRB's and ask to revise or expand my questions. I thought of the need to include the layers of loss. Preceding parental death may be the losses of friends, staff, and moves to other jobs or residences. I thought of potential activity increases or decreases after parental death. I read an article about how use of public and private space changes for bereaved spouses (Hockey, Penhale, & Sibley, 2001) which led me to believe I should find out about activity and space changes since the death, since often the death of parent may mean a move or loss of a key person in the social network of an adult with DD (MacHale & Carey, 2002). Krauss, Seltzer and Goodman (as cited in Seltzer and Krauss, 2001) found "...on average, half of the members of the support networks of an adult with mental

retardation were also members of the mother's support network" (p. 108). Due to this finding, I decided it is important to assess social network changes after parental death to see if the parent's death creates further losses in the social network.

Most importantly, I needed to assess emotional states. How would I get at the emotions about the loss, the depths of those emotions without putting words into their mouths? I am working on the 'who, what, when, where and how' type of questions about the death notification, the funeral, the activities before and after the parent's death. I am working on the timing of the questions, what precedes and follows each question, to ease into the intensity of emotional questions and to ease back out to less emotionally charged issues. Here I know my counseling experience is helping me. Although I have no valid and reliable measure for evidence, I have my own lived experience for evidence: the more I read and the more I play with the questions and get input from others, the fewer panic attacks I have about methodology. With my colleagues behind my research vehicle pushing and guiding me, my wheels finally took hold and I moved forward.

The Process Epiphany

Suggestions for wording, questions about my meanings or intentions, advice about grouping questions into categories have all been valuable, yet each conversation affects the process and the product. My first epiphany was that talking with or reading comments from each person who reviews and critiques my ideas, questions, or methods has caused the process and the product to change. *Webster's New World Dictionary* (1988) defines epiphany as "...a moment of sudden intuitive understanding; flash of insight" (p. 457). My "flash" hit while I was straddling both the revision process of my prospectus and the writing of this article. I sat somewhat awed when I reread discussions of positivist

and non-positivist research. I had gravitated to non-positivist research and its view of reality as an open system (House, 1991). Human experience does not hold still for a detached analysis. Human experience is dynamic. It dawned on me that so is my research process! Each time I discuss my ideas or methods with someone, I see it through their eyes and it changes subtly. Interestingly, I realized that watching my research project morph with each interaction was parallel to my non-positivist belief that when others tell their story, we, the researchers, by virtue of our interactions, are impacting their story (Devers & Robinson, 2002). The "story" of my research project changed each time it was seen or heard by another. I could not hold my research process static; therefore, my written drafts had to change as well. Luckily so far, I still view change as good. I now see the changes as "re-visions" of my work, not dreaded red-penned corrections. The doctoral student process has at least helped me (on my good days) take the comments and suggestions less personally and accept them as part of the evolving process.

The Institutional Review Board: Panic Attack Number Two

Underneath my methodological challenge has been the fear of the scrutiny of IRB's, my second panic attack. I have to go through the university and then my state's Department of Social and Health Services review process. Human Subjects Protection sounds overwhelming. I worked in the field of social work for 24 years before pursuing my Ph.D. I still work intermittently at hospice as a social worker. I always strive to 'do no harm'. I have worked with children, with individuals with DD, with families of the dying. I have built and maintained trust, going into sensitive areas with care and compassion. I have worked sensitively with children at grief camps. I had always worked with 'vulnerable'

populations. I had completed my IRB training and recertification, focusing on research with children and adolescents. Had I changed now that I was a doctoral student? Would I become bloodthirsty for answers to intrusive questions for the sake of my research? Would I trigger undue distress in my participants now that I was there, not for counseling, but for research? I was a good social worker. Wouldn't that make me a sensitive researcher?

Here I think the fear of being discovered as an imposter surfaced as I wondered if *now* at last, a panel of experts would identify my weakness and incompetence. I struggled with self doubt, envisioning the IRB scrutinizing me with magnifying glasses. Somehow the visions I conjured up of Internal Review Boards were more similar to Salem witch hunts. All I could anchor myself with was the unshakable belief that there were individuals with developmental disabilities who needed the world to pay attention to their losses and acknowledge their grief. I know I am sensitive, good at assessment, and unselfish. I could do this research and create good, not cause harm. I want adults with DD to be supported around a loss and not be forced to express their emotions through challenging behavior as MacHale and Carey (2002) have observed. I want their stories and experience honored and supported with compassion.

Personal Grief: Epiphany Number Two

As I approached agencies and families about my study, would people worry that I would make their client/son/daughter/brother/sister cry by asking these questions? On the flip side, did I think it was fair that no one asked about the death, the depth of the loss? My father had died during my undergraduate years and the loss hit me hard. Just this Christmas, my third year in doctoral studies, I experienced the death of my mother. I could not read any more bereavement literature. I had to put away the scholarly articles about parental death and live the

experience from my heart, not from my mind. No matter that the loss of my mother was expected, timely, and a release for her from a world of pain, it hurt me then and still hurts me today. As I grieve, I sometimes ask myself, what if I was a daughter with a developmental disability? Would the world around me honor my grief? Is it fair that person might never be allowed to talk about the life and death, to cry or mourn the death of a mother or father in his or her own unique way?

My past work with people with developmental disabilities and my most current work with hospice were obvious influences on my research. But I became very aware that being a hospice professional is a different experience from being a hospice patient's daughter. I felt the pain acutely. I wanted to ask my mother to hang on. As she lost her ability to swallow due to end-stage Parkinson's I struggled, irrationally questioning the decision to not place a feeding tube. I had sat as a hospice professional with many families experiencing similar qualms about the lack of food and water. Watching someone appear to 'starve to death' is much harder when you love that someone dearly. In my work, I sit with families and logically explain how the body cannot process food and fluid as it is shutting down. I was now on the receiving end of the same explanation. But, now I had *felt* the distress, the doubts, and the second thoughts. I understood it not just in my mind, but in my heart.

Thus, my second epiphany unfolded, painful as it was. My research question became less of an academic exercise based on cognitive thought and more of a research agenda based on both cognition *and* emotion. Not only do I believe in my mind that my topic is important, I care about my topic from my heart with a renewed passion. I became even more respectful of tears, of illogical emotion. I hadn't realized I needed to achieve this renewed respect for the depth of grief and the difficulty of letting go. Any callous I had

developed to death was rubbed raw by the raggedness of my own emotions. My sister and brother grieved their own ways, showing some similarities to my own process, but many differences. We respected each other's ways of getting through our shared loss.

When I had gathered myself up enough to look again at the literature of bereavement, at the academic exercise of the dissertation process, I realized that I now come at the questions with both my mind and my heart engaged. I am more convinced than ever that the questions I want to ask are to gain information so we can better bear witness to and support the variety of bereavement experiences for adults with DD whose parents have died. I am even more committed to the belief that the benefits of my research outweigh the risks. If I didn't believe this, I couldn't go on. My mother gave me this one last reminder before leaving; *everyone's* loss needs to be acknowledged and held with tenderness and respect, for weeks, months, and even years to follow. And, it will be different for each son and daughter. And that's okay.

Conclusion

In a sense, this article is therapy for me as I write my prospectus, request meetings with the Division of Developmental Disabilities, and prepare my proposal to be scrutinized by my committee, the university, and the state IRB's. It is ironic that I do all this now while also grieving the loss of my mother. I have discovered that methodology and IRB phobias can be overcome. I don't know what my next dissertation panic attack will be about, but I think I have managed to cope with this first phase, with two epiphanies as a bonus. The most important insight I gained was that I was reminded of my own humanity, a humanity I shared with daughters and sons with DD whose own mothers or fathers have died.

My mother's picture rests on my desk

and I often look to her image and memory as I sit at the keyboard. She witnesses my work and urges me to go on. My research question needs to be answered. I am capable of witnessing stories, asking the questions, coding and developing theory from the answers. All sons and daughters need to have their bereavement witnessed and understood. Or so she whispers in my ear.

References

- Biklen, S., & Moseley, C. (1988). Are you retarded? No I'm Catholic: Qualitative methods in the study of people with severe handicaps [Electronic Version]. *Journal for the Association of People with Severe Handicaps*, 13, 155-162.
- Davidson, L. (2003). *Living outside mental illness: Qualitative studies of recovery in schizophrenia*. New York: New York University Press.
- Devers, E., & Robinson, K. (2002). The making of a grounded theory: After death communication. *Death Studies*, 26, 241-253.
- Hockey, J., Penhale, B. & Sibley, D. (2001). Landscapes of loss: Spaces of memory, times of bereavement. *Aging and Society*, 21, 739-757.
- House, E. R. (1991). Realism in research. *Educational Researcher*, 20, 2-9.
- MacHale, R., & Carey, S. (2002). An investigation of the effects of bereavement on mental health and challenging behaviour in adults with learning disability. *British Journal of Learning Disabilities*, 30, 113-117.
- Milne, R., Clare, I., & Bull, R. (2002). Interrogative suggestibility among witnesses with mild intellectual disabilities: The use of an Adaptation of the GSS. *Journal of*

Applied Research in Intellectual Disabilities, 15, 8-17.

• Neufeldt, V., & Guralnik, D. (Eds.) (1988). *Webster's New World Dictionary*. Cleveland: Webster's New World.

• Seltzer, M., & Krauss, M. (2001). Quality of life of adults with mental retardation/developmental disabilities who live with family. *Mental Retardation and Developmental Disabilities, 7*, 105-114.

• Sigelman, C., Budd, E., Winer, J., Schoenrock, C. & Martin, P. (1982). Evaluating alternative techniques of questioning mentally retarded persons. *American Journal of Mental Deficiency, 86* (5), 511-518.

• Sigelman, C., Schoenrock, C., Spanhel, C., Hromas, S., Winer, J., Budd, E., & Martin, P. (1980). Surveying mentally retarded persons: Responsiveness and response validity in three samples. *American Journal of Mental Deficiency, 84*(5), 479-486.

• Sigelman, C., Winer, J., & Schoenrock, C. (1982). The responsive of mentally retarded persons to questions. *Education and Training of the Mentally Retarded, 120-124*.

Mary Ann Clute is a Lecturer and Field Unit Coordinator at Eastern Washington University School of Social Work. Comments regarding this article can be sent to mary.clute@mail.ewu.edu.

Copyright of Reflections: Narratives of Professional Helping is the property of Cleveland State University and its content may not be copied or emailed to multiple sites or posted to a listserv without the copyright holder's express written permission. However, users may print, download, or email articles for individual use.