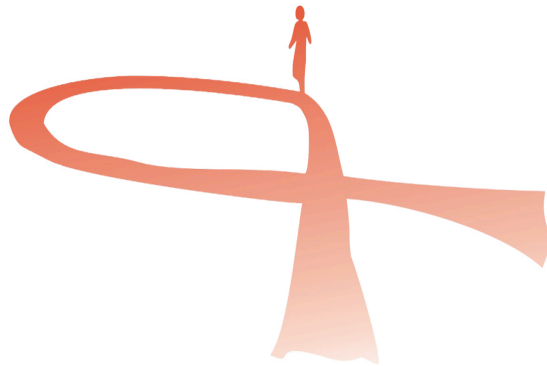


Silenced by the Academy: The Dilemma of Collaborative Doctoral Research



by
Alex Keating: keatingfamilycircus@telus.net
&
Laura Cooper: Kwantlen University College, Surrey BC
laura.cooper@kwantlen.ca

Paper presented to the Qualitative Inquiry Conference 2005, University of Illinois
May 7th 2005

© Keating & Cooper, 2005

Abstract

In 1999, two biological sisters, Alex Keating, an HIV infected woman and Laura Cooper, then a doctoral student, engaged in collaborative ethnographic narrative research. “Conversations with my sister: an HIV/AIDS counterstory”, examined marginalizing processes of those living with HIV/AIDS. Focusing on Keating’s narrative of 18 years with HIV, the dissertation chronicled her advocacy, research, lecturing, and activism. Told in her own voice, Keating’s life story was framed as a counterstory against Cooper’s analysis of the marginalizing of master narratives that deny agency to ill persons. Exploring the healing power of counterstories, the methodology gave Keating full editorial control over her own story and the opportunity to comment, unedited, on Cooper’s analysis and discussion. Keating was also forwarded all communication between the committee and Cooper, and was encouraged to comment to or question the committee whenever necessary. Crucial to the research methodology, Keating’s control over her narrative was to ensure that she was treated as a full collaborator and not an object of research. Prior to the oral examination, however, Cooper was denied the right to put Keating’s name on the title page, being told that the work would not be granted a PhD if it were coauthored. During the oral examination, two external examiners challenged the collaborative methodology as not giving Cooper a central enough role to warrant a PhD regardless that Keating’s story accounted for one third of the total page length produced. Among other concerns, one of the external examiners called into question Keating’s access to the doctoral committee, suggesting that it diminished the authority of the process. Critically examining these experiences, this paper explores the ways in which the Academy attempts to silence the voices of those who seek to challenge its authority.

Silenced by the Academy: the Dilemma of Collaborative Doctoral Research
By Alex Keating and Laura Cooper PhD

Alex:

My name is Alexandria Keating. In 1986 I was infected with HIV but I did not get diagnosed until 1989. When given my diagnosis I was not given much hope. I was told I could live up to two years and that to be a responsible person I should consider myself to be a non-sexual being. I bought into this ignorance and spent the next 4 years dying from AIDS.

Before I was diagnosed I was involved with spreading the AIDS/Safe Sex message and in supporting my friends who were living with HIV, but not in any large organized way. After my diagnosis in 1989 my external activism activities stopped as I went into myself and focused on dying. Contrary to the chaos I was experiencing in preparing for my death, in 1990 I got married to James Keating and we began a life together. Since we were both living with HIV we married sooner than we had originally talked about so we could live together as a married couple while we still had some relatively healthy time left.

Activism history, healing and counterstories

In 1993, at a retreat for women with HIV, I came face to face for the first time with other women with this same illness. This was the beginning of my journey to living with HIV not dying from AIDS. After the retreat I began to volunteer with a women and AIDS organization, initially doing peer counseling, providing support and welfare/medical advocacy for women with HIV. That same year I began doing TV news interviews, attending and sitting on panels at conferences, public presentations about AIDS 101/safe sex education/personal perspectives in high schools, colleges, and prisons and with health and welfare agencies. I also began attending international conferences and working on national projects regarding women and AIDS. I continued doing variations of this work up to present day, including coauthoring Laura's dissertation

Laura:

This project came about as a result of my witnessing the transformations in Alex as I observed my sister develop strategies for living with the biological disruption (Bury 2001) caused by HIV. Over the years I saw her reassert control over her illness experience, both privately and publicly, from the early years when social, political, medical and gender-based stigma and discrimination created barriers that forced her to live in seclusion and fear. Whether lecturing in a wide range of public settings, doing advocacy work, engaging in activism, or care giving her husband and animals, Alex was healing from that beaten down young woman who was given an HIV death sentence on her telephone answering machine in 1989.

Having watched many of her lectures and seeing first hand the life changing influence her narrative has had on many who have heard her speak, I realized that her life was lived as a counterstory to many of the dominant stereotypes that typically surround one living with HIV (Nelson, 2001). Nelson (2001) writes that the extent to which a person's "moral agency is free or constrained is determined by our own – and others'—conception of who we are" (xi). Alex's ability to advocate, lecture, and educate was a counterstory that served to free her moral agency. Evidence of this was in watching others willingly listen to her narrative and thus, treat her respect and dignity.

In the late 1990's I approached Alex with the request that we collaborate in getting her story on paper for my doctoral thesis. The resulting dissertation examined the mechanics and ethics of decolonizing Alex's illness narrative by consciously negotiating power, voice, and representation. If the restoration of Alex's agency was to continue through collaborative doctoral work then we really had to address above mentioned issues, not only between Alex and myself, but also the supervisory committee and the university bureaucracy.

Decolonizing narrative and methodology

Maori academic, Linda Tuhiwai Smith (1999) suggests that the politics of contested stories and multiple discourses about the past are closely linked to the politics of everyday life of indigenous communities (33). In relating this to the politics of stigmatized chronic illness, I was able to draw comparisons between the oppressive master narratives about people with HIV and the contested realities that are voiced by those infected. Often infected persons' stories are located in places not identified by master narratives, requiring the researcher to be willing to work outside of traditional research frameworks and to be willing to relinquish power over the research process. Both Alex and I had to identify, as Smith has done, "struggle between the interests and ways of knowing by Western trained academics in positions of power and the interests and ways of knowing by those perceived of as the other" (ibid, 2). While meeting academic demands for scholarship and innovative research we created a method whereby Alex retained editorial control over her own story, could comment unedited on my analysis and discussion, and have unrestricted access and communication with the supervisory committee. Aiming at a democratic methodology meant that Alex and I were in "similar positions to control the process of knowledge production and its interpretation and meanings", as identified by Denis and Lomas (2003, S2:2). To decolonize traditional academic power relations, Alex was, ultimately, in control of the timelines for this work. Also, with Alex writing her own story, and having the opportunity to comment unedited on my work, she was given recourse to my interpretations of her life that did not "fit into the categories of understanding" she herself had developed (Manke, 1996, in Dunpath, 2000, 549). Because Alex is self reflexive, she and I were able to engage in critical analytical

discourse and work our way through the times of resistance without compromising each other's agency. Having said this, the journey was not free from difficulty.

Accompanying the written narrative, we also chose to tell her story using other mediums that helped to present a multidimensional background to her life. Using photos and poetry, Alex created scrapbook sections that reflected those elements of her life that she chose. The photos of her 21st birthday party boat cruise are especially poignant...the photos show a celebratory party atmosphere which one can be juxtaposed against this being the background within which she became infected. In this case, the photos helped to unfreeze the memory of the event and to evoke a visual narrative (Bach, 2001). Her poetry also enabled another dimension to emerge, especially when it was being drawn from her personal journals dating back to the early days of her infection. The poetic word pictures that come forward bring the reader to that exact place when the fear and frustration of a young terminally ill woman gain expression through journal writings. The reawakening of Alex's memory and the building of collective memory through the pictures, art pieces, and poems helped us develop the complexity of multi-vocality inherent in this collaborative work.

The Supervisory Committee

We also created a research team with the doctoral committee rather than rely on the traditional Apprentice Master Model common in many doctoral processes (Burnett, 1999). Both committee members stayed in touch with the research in a myriad of ways and often hired Alex to lecture in their classrooms, thereby communicating with Alex as an expert in her own area. The professional collegiality between Alex and the committee, without my presence, altered power relations at the supervisory level as well. I believe that collaborative doctoral research requires effective supervision that understands the complexities of power

sharing among all involved to produce emancipating knowledge (Denis and Lomas, 2003).

The supervisory committee understood this and embraced it in practice, rather than becoming threatened by it.

Alex:

On power sharing

I believe that power was shared in the way it needed to be, with each of us taking on our area of expertise: Laura the academics and I, my life. I never felt anything less than an equal to Laura and the doctoral committee. Laura and I had discussed the ideas/stories shared in the dissertation before, during and after the writing of it. She never directed me what to write and I never directed her. On occasion I was encouraged to include facts I had not initially planned on but the way this was done did not leave me feeling exposed, I had the choice and do believe the dissertation is better for the inclusions.

We both became aware that the story Laura saw resulted from our being sisters as much or more than it did from our relationship as collaborators. Though Laura assured me that I had editorial control, she did request certain aspects of my life be included. Had she not been my sister and just a researcher, she would not have known about many of these incidents because I would not have shared them and they would not be in the dissertation. It is because of the intimate relationship we have, that this work goes to depths that it otherwise would not have ventured into.

The Research Process

The expectation of me as we saw it at the beginning of this process was not what I had anticipated it to be. At the beginning I did not have a clear understanding of this collaboration and the work it would entail. My participation ended up being considerably more than I expected as the dissertation took on a life of its own. We were able to grow with it through a lot of negotiation. At times more was wanted from or of me than I chose or was able to give. At these times we would negotiate as to what I was able or willing to give and what Laura was willing to accept or needed to get. My limitations could not have been easy

on any of the others involved in this process. Fortunately the supervisory committee was willing to work within the bounds of what I could give and Laura was able to find ways to work around my limitations to accomplish what she needed to when my illness would take me out of the picture for a while.

Though I was able to communicate directly with the committee and to comment on Laura's writing, I rarely did this. I felt that Laura's theories deserved the autonomy that my story did and therefore I kept out of it as much as I could. Although I know we did influence each others writing as we had discussed these issues so many times in the past. My story in chapters 2 & 3 were written as they needed to be to get things going. That is Laura editing transcripts from numerous lectures I had given into a coherent story, my reading and commenting on how she put it together then us doing a final edit.

My story in chapters 4 and 5 as well as prologue, epilogue and post defense epilogue were written by me without input from Laura using voice recognition software, and were then forwarded to her for a read. This process was very cathartic for me. The later chapters are more like reading one of my journals or attending one of the presentations I give. Another tool we used to accomplish this work was MSN messenger. For the last collaborative chapter we chose to have a conversation about the research process. We accomplished this by sitting together and hashing out the basic areas that we needed to address. Then we were able to have this conversation on line with the messenger program. I found the MSN messenger and voice recognition to be very effective tools.

Laura:

For me collaboration became an effective tool in assuring completion of this PhD. With Alex I had the assistance of a collaborative partner, someone to whom I was ethically bound to complete this work while she was still well. There has been much written about how collaboration in areas of doctoral research facilitates completion of one's PhD though the

level of collaboration Alex and I sought did present challenges to both the university and the external examining committee at the doctoral defense. (Witte & James, 1998; Burnett, 1999).

Before the university would accept the defense copy of the dissertation I was told to remove Alex's name from the title page, with the explanation that the university could not grant a PhD to a co-authored work. After a discussion with Alex, we agreed that we would remove her name from the title page however we created a frontispiece to the document with a picture of Alex lecturing at SFU and titled it Coauthor: Alex Keating. Of great importance here is that the dissertation was an analysis about oppressive master narratives that silence the voices of marginalized persons and the university's position on authorship was a perfect example of this. Official academic acknowledgment of our collaborative process would not have diminished the university's role as gatekeeper to my PhD nor would it have decreased the academic merit of our work. Rather, it may have gone a long way in rectifying institutional power imbalances between the academy, doctoral students, and those who give up their stories that we might gain PhDs.

Though I had a successful defense, it was not without a struggle between the supervisory committee and the external examining committee. Problematic areas for the external examiners revolved around Alex's unrestricted access to the supervisory committee, that she retained editorial control over her own story, and that I did not subject the "truthfulness" of Alex's narrative to an academic filter.

Alex:

My response to the defense

I was unable to attend Laura's defense due to illness, so Laura's colleague video taped it and I was able to watch it. This led to my writing the post defense epilogue as a way to address the issues brought up by the external examiners.

At the defense the external examiners challenged whether Laura had earned a PhD because I had authored my own words. I don't understand how someone could actually read this document and question whether she did enough work to merit a PhD. For goodness sake, my words consist of less than one third of the almost 300 page document and although I am reflexive and do discuss social issues and occasionally the "big picture", I mainly speak of those things which have directly impacted my life in some way. Laura was the one who took on the academic theories and the "bigger picture". The external examiners' apparent fear about Laura not filtering or editing my voice was in my opinion, a perfect finish to this project as it reinforced what we had been saying about the master narrative and how it seeks to retain power by silencing certain voices.

The criticism that I, telling my own story in my own voice/words, diminish the academic contribution of the other collaborator is, to me, not valid. Furthermore I do not believe there is one ultimate truth but that each of us sees our own truth in any given situation and that multiple truths can and do coexist. That the examiners' required an academic filter to make my story more true or credible than when told in my own voice seems to me, to be exceptionally arrogant. I think some academics work so hard to gain their position of authority that the thought of being seen as an equal with one who is not an accredited academic is very threatening.

Thus the external examiners' negative reaction to my having access to the supervisory committee reiterated to me how the sharing of power can frighten those who see themselves in positions of authority.

Throughout my life I have experienced similar reactions from health care professionals when I had the audacity to challenge their expertise with my own.

Laura:

In closing, for me this work was very emancipating as it enabled me to collaborate with Alex in an ethical research process that has multiple meaning in personal, public, academic

and non-academic spheres. By having a supportive committee in place, it also enabled me to work around and challenge colonial-based structures within Academia that attempt hang on to power at any cost while silencing dissent. In the words of Gelya Frank (1995) this work was about the “truth of telling versus telling the truth” (1995, 145).

Alex:

This dissertation has been a learning experience to say the least. I have learned much about the academic process, my familial relationships, and myself. I have watched Laura let go of years of unsaid emotion, I have watched James find his voice and I have put my story on paper, not just into the air. This experience has allowed me to revisit my past, its pain and joy, and to say things with my eyes of today. The eyes of a woman who is happy more often than she is sad; the eyes of a woman who has learned to find joy in the little things and to honor the day to day successes. A woman who is grateful for her life as it is. That doesn't mean I don't desire more. I do. I desire it all.

I desire a cure for my illness and others'. I desire equality and equitable distribution. I desire a life without stigma and marginalizing. I desire a world without war, hunger, violence, intolerance, ignorance, oppression, prejudice: all the biggies. I desire it all. But I am a realist. I know that I can desire it all but still find a way to be happy with where my world is at while working towards the rest.

References

- Bach, Hedy. (2001). The place of the photograph in visual narrative research. *Afterimage*, 29(3).
- Burnett, P. C. (1999). The supervision of doctoral dissertations using a collaborative cohort model. *Counselor Education and Supervision*, Sept. 99, vol.39/1, 46-52

- Bury, M. (2001). Illness Narratives: Fact or Fiction? *Sociology of Health and Illness*, 23(3), 263-285.
- Denis, J., & Lomas, J. (2003). Convergent evolution: the academic and policy roots of collaborative research (editorial). *Journal Health Serv Res Policy*, 8(2) October.
- Frank, G. (1995). Anthropology and individual lives: the story of life history and the history of the life story. *American Anthropologist*, 97(1), 145-148.
- Nelson, H.L. (2001). *Damaged identity, narrative repair*. Ithaca: Cornell University Press.
- Smith, L. T. (1999). *Decolonizing methodologies: research and indigenous peoples*. London: Zed Books.
- Witte, J.E., & James, W.B. (1998). Cohort partnerships: a pragmatic approach to doctoral research. *New Directions for Adult and Continuing Education*, 79, 53-62).