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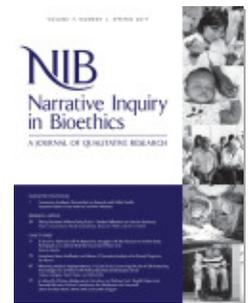
Stigma as a Facet of Community–Academic Partnership

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think about this issue seriously, but this meeting improved my materials *and* changed my attitude!”

These two practices, thoughtfully and consistently followed, enable us to harness the power of “The Personal”—breaking down barriers and building human connections that empower all stakeholders to participate in reducing health disparities and improving health outcomes for everyone.

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Stigma as a Facet of Community–Academic Partnership

Sally Mason

The Positive Families Project is a partnership between parents living with HIV, service providers, and myself, an academic at a public university. Our projects investigate the need for and develop social services with HIV-affected families. Often services focus only on the person living with HIV. Our mission is to support people living with HIV who are also parents so that families with an HIV+ member can be healthy and productive. Stigma reduction is key to our approach as

stigma can contribute to multiple risks for parents and their children.

The partnership has encompassed several projects, starting with pilot studies in 2006–2010 on the stigma experiences of non-HIV+ teens living with HIV+ parents. Parents and community-based service providers originally were research participants and the data analysis team. The team reviewed transcripts, identifying themes and making recommendations for future services. Currently parents and service providers meet monthly to develop ideas for family-focused services and review funding possibilities. Recently, we received funding to implement psychoeducational group sessions for parents with HIV. Parents and service providers recruited participants, co-facilitated groups, and reviewed evaluation data. Originally my role was researcher and a program coordinator/facilitator. Now I convene and facilitate the planning group, assist with programming when funded, and provide resources such as meeting space, writing skills, and supplies.

I was drawn to partnership and participatory methods through our pilot studies on stigma. One finding about stigma was that positive parents and their non-positive but HIV-affected children used silence as a form of protection from stigma. They identified wanting to find “safe others” who they could trust with their secret. If we, as researchers, asked them to open up, to be less vigilant for an hour or two in an interview, first, how could we reduce (and not reproduce) stigma for them during this process and, second, what was our responsibility to give them a safe place to talk in the future?

Coincidentally, I was meeting regularly with researchers committed to community collaboration and participatory methods. I became increasingly convinced that participatory methods have the potential to, at least, not reproduce stigma and, at most, reduce stigma’s impact. By leveling the power differential between researchers, service providers, and families (a difference which may be exacerbated by stigma), participation can be an antidote to stigma, by engaging families, as Paolo Freire would say, in “the struggle for their redemption.”

As a service provider, I had experienced courtesy stigma as described by Goffman or stigma-by-association with people living with HIV. Due to my status—race, class—and with support from educated family and friends, I was able to thwart efforts to label me as less than “normal” or to be silenced in my work. What I had not anticipated was how, as boundaries between academic and community members blur, parents’ stigma situations became part of the process, immersing me in their experience and confronting me with fresh personal and professional dilemmas.

A prime example occurred while convening a community group to help with the analysis of data collected during focus groups with HIV+ parents and their non-infected adolescent children. Sandy (pseudonym) was an African–American woman who had been engaged with our projects over the years. She had known her HIV status for at least 15 years and had often been a peer facilitator in our parenting groups. She called me one day saying that she had told a church member about our project. This church member was a graduate student in community psychology and was intrigued by our recent research. Sandy thought this young woman would be an asset to our process providing some assistance as we prepared the final reports and articles. Sandy was excited to involve the student and asked if she could give this young woman my number. As we always need more resources, I heartily agreed.

After hanging up the phone, I realized that I did not know if the graduate student or anyone at Sandy’s church knew Sandy’s HIV status. I called Sandy back. She said that only the minister at her church knew; she had intentionally not told anyone else in order to protect herself and her daughter. Her church was an important part of her life and she was not sure that all church members could be as trusted as her minister. She had not told the graduate student that this was a “community-based” project or how Sandy became involved so had not indirectly disclosed her HIV status.

Sandy offered to tell the graduate student but I was reluctant for her to do so. I knew enough about disclosure of stigmatized information to want Sandy to do this if and when she felt it was useful

to her and to prepare for it, rather than to have her do it on the spur of the moment for the purposes of this project alone. Sandy decided to wait. We talked about how the student’s involvement, without disclosure, might affect the group process; we would have to be careful how we presented the project to the graduate student and what other HIV+ group members might want her to know about them. We agreed that I would talk with the graduate student and then we could assess further.

The student called me the next day. As I explained the project, I felt constrained, watching every word, as I was careful not to “out” Sandy. The student was eager and, when I as part of usual business, explained confidentiality, she indicated that she understood its importance. We arranged a meeting time.

This interaction went round and round in my head for the next few days. Had I been dishonest? How did my carefulness with words affect our interaction and her perception of me? Did I seem disingenuous (I felt that way). As I reviewed it, I was struck by the knowledge that my friends and colleagues who were HIV+ dealt with this every day.

The next day Sandy called me and said she had told the graduate student about her HIV status. I expressed concern that she did this for the project rather than what was best for her. She said that she was comfortable with the decision. She asked the student to maintain confidentiality at church. I debated with myself how to handle the next communication with the student, as she would know that I had not been forthcoming in our initial phone call. I decided to be honest and, in our meeting, acknowledged that Sandy had told her and that I was concerned about how she interpreted our phone call based on this new information. She expressed understanding of the dilemma and assured me that she was still interested.

The student attended one meeting of the board and then did not return nor call. Sandy said that nothing changed at her church and she occasionally saw this young woman and everything seemed fine; Sandy did not ask her about her decision not to attend any more. We were left wondering if she was

too uncomfortable, whether with the group's status or knowing Sandy's status. I wondered if I should have handled something differently—questioning my abilities and actions in a way that made me feel tentative and ineffective.

More recently, Daniel, a member of our consumer advisory board, asked to speak to me privately. He had been an active member in our parenting groups and our advisory board for several years. Daniel's daughter was receiving mental health services in the outpatient clinic in our building. As part of those services, his daughter was seeing a mental health clinician for psychotherapy whose office was close to mine.

Daniel asked what the clinician knew about our relationship. I told him that I had not talked to the clinician about Daniel or his daughter. Daniel explained that when he mentioned that he knew me, he thought the clinician "made a face". Daniel expressed concern that the clinician now knew that Daniel was living with HIV and that he did not want to work with Daniel's daughter any more.

Daniel and I spent a few minutes talking about how he interpreted the clinician's reaction. I assured him that the clinician was thoughtful and caring. I suggested that the clinician could have been confused, assuming that I had worked with Daniel's daughter in our clinic but wondering why none of the chart notes reflected this. We discussed ways that Daniel might manage the situation so that he felt comfortable. Afterwards, I did not know what to say to my colleague. Did I acknowledge that I knew Daniel or not? Did I hint at how I knew Daniel based on what this colleague knew about my work in the community? I chose not to say anything. I see this colleague often and each time have a touch of doubt about what he is thinking and how I might allay my own concerns without doing a disservice to Daniel.

I was struck by how one small moment—a "face"—could trigger apprehension for Daniel and his daughter's welfare. I was reminded of Sandy, her courage, and my feelings of guilt, dishonesty, and confusion. People with HIV anticipate these situations daily. I say "anticipate" as the literature says that people living with HIV who have access to medication experience "hidden" stigma—they

do not have to let anyone know their HIV status, as they look healthy, but they anticipate the possibility of being "found out" in many encounters. Similar to people living with HIV, I had two small situations with the student and the clinician which I had to manage, internally, through my perceptions and feelings, and externally, through interpersonal interactions. What if it was multiplied with every day holding the possibility that someone would think I was "abnormal"? I felt a subtle but substantial shift in my understanding of my colleagues living with HIV. I had felt the day-to-day tension of keeping a secret, being cautious but still wanting to connect, the constraints of not being genuine.

So perhaps I have learned more about stigma through this partnership than my community-based colleagues. I hope that community members have learned about the process of research and service development. I hear their frustrations with funding changes over the years as HIV has become a lower priority. I explain that as they live longer, new social issues, such as veterans' mental health or gun violence, become more pressing. They respond that their worries are different but still substantial—concern for their children, for their chronic (rather than terminal) illness. Stigma continues but is more covert.

As in any partnership, attendance at meetings can be sporadic. Without funding, we regularly remind ourselves of our purpose and its value. Community members see me as the person with concrete resources; I see the resources as increasingly scarce, especially at a State university as I am asked to do more with the same amount of time and compensation. For community members, the majority of whom are low-income, my statement that the university lacks resources seems implausible as they see how little they have compared to the university.

I draw strength from the examples of Sandy, Daniel and others, as I consider more carefully how to use my privilege and access to contribute to our discussions and decision-making. Some days, it would be easy for me to let go of the project, especially when stretched by work responsibilities and discouraged by funding constraints. In the past, as I was frustrated or impatient, I may have allowed my opinions to take over in our meetings

or made some decisions outside the meetings and then informed the group. Now I slow down and temper my input, facilitating the process rather than directing it, knowing that they do not always have the experience of giving voice to their concerns. Before being involved in their stigma situations, I may have been silencing them, similar to those who stigmatize them. Now, I am more cognizant of giving them voice. Their fuller involvement, of course, improves the relevance and sustainability of our work. Our process also is less likely to reproduce stigma; we will not duplicate other spaces in their lives which are constrained by stigma but rather offer each other the opportunity to engage genuinely in producing change.

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The Engaged Dissertation—Conducting Community–Based Participatory Research with Rural Indigenous Communities as a Graduate Student

Jana Wilbricht

My research is equal parts academic inquiry, self-discovery, community engagement, and adventure. As a Ph.D. Candidate in Communication Studies at the University of Michigan, I study access to health information in rural,

remote communities and implications for health equity, as well as effective health message design. I am particularly interested in the role of what I call ‘emic media’ in this process. ‘Emic media’ and what we commonly refer to as community media are both locally based and community-driven. However, I see a difference in that emic media do not only present the information most interesting or relevant to a particular community, but make a conscious effort to communicate from the perspective of a cultural insider—what anthropologists call an ‘emic’ perspective—assuming a base of shared knowledge, avoiding cultural taboos, and prioritizing local indigenous norms and languages. In this way, emic media do not only serve their communities in offering a familiar voice in addition to the broader mediascape, but can function as a site of resistance to mainstream media narratives.

For my dissertation, I am engaged in community-based participatory research (CBPR) exploring the role of tribal radio stations in providing access to accurate, culturally relevant health and safety information for residents of rural American Indian and Alaska Native communities with very limited media and information infrastructures.

After working for over a year to co-design my dissertation project with my primary community partners, the general managers of two tribal radio stations, I received multiple grants, allowing me to travel to both project sites—an Indian Reservation in Northern Arizona, and a rural, mostly Indigenous community in Western Alaska—to conduct individual in-depth interviews with station employees and focus groups with listeners. I also pre-tested a survey during the focus groups which we intend to use community-wide in a future phase of the project.

There are two primary reasons why I opted to adopt a CBPR approach for my dissertation. First, tribal radio is a truly emic medium, and can only be understood to a meaningful degree with involvement from the local community, particularly those involved in its production. Second, making every effort to create equitable partnerships with the communities I work with is a matter of ethics, especially since I am an outsider to these communities. Indigenous communities in particular have long suffered