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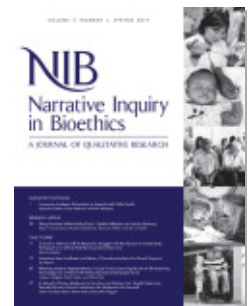
The Power of The Personal: Breaking Down Stereotypes and Building Human Connections

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saw an opportunity to help shape the learning of two budding researchers while also addressing an important issue in the Milwaukee community. YWCA leadership appreciated the ability to help shape the study design and questions, and believed the research was much more meaningful because of the value placed on the agency’s experience with the community. YWCA leadership encouraged the students to not only identify opportunities to share research results in their academic circles, but also with local community partners to ensure a strong impact in our community.

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The Power of The Personal: Breaking Down Stereotypes and Building Human Connections

Gay R. Thomas, Betty L. Kaiser,
and Kaitlin Svabek

On a weekday night, every month, twelve people meet around a table at a community center in Madison, Wisconsin. The group includes people who are homeless, previously-incarcerated, unemployed, handling chronic mental or physical challenges and several health science researchers. Someone walking by the room might notice the intense energy, lively debate, engaged participation, reams of flip chart paper, and wonder, “What’s going on??”

This has been our reality every month for over six years. The people *giving* advice are the

Community Advisors on Research Design and Strategies (CARDS)[®], community members from diverse racial, socioeconomic, and educational backgrounds. The people *getting* advice are researchers who want candid feedback about how to make their materials more engaging, easier to understand and more actionable from people often labelled “hard-to-reach.” And the people planning the meetings are our staff with the Wisconsin Network for Research Support (WINRS), a patient and community engagement resource.

We started the CARDS[®] in 2010 as a partnership between the University of Wisconsin–Madison School of Nursing, Lussier Community Education Center, and Goodman Community Center. With initial funding from a 3-year National Institutes of Health grant, our project was a response to the painful reality of persistent health disparities in our country and to the fact that health sciences research has not successfully engaged the full breadth of our country’s wonderful diversity. What’s the connection, we wondered? How can research appeal to a broader group of people? If all Americans did participate equally in health sciences research, would this move the needle on health inequality? With our community partners, we deliberately recruited CARDS[®] from groups of people most affected by health disparities and least represented in research projects. We provide an interactive orientation for all CARDS[®] and pay members for each meeting they attend. We also compensate the community centers for staff time and meeting space.

In the process of bringing unheard voices into the research enterprise, we have learned a lot about how to revise research activities and materials to engage a broader audience. We’ve also learned some interesting things about the stereotypes and assumptions that researchers make about “hard to reach” people, the assumptions that lay people make about researchers, and how to overcome prejudices that make it hard to connect with each other.

What are some common researcher assumptions? “I’ve spent my whole professional life researching this disease, what can I learn from people who don’t really know anything about this topic?” “I know what I will get—people telling me to ‘dumb down’ my materials.” “The feedback I

get from colleagues is sufficient.” And community members have their own pre-conceptions: “I think research projects are a scam. Researchers have a hidden agenda and just are trying to help themselves.” “Lots of researchers are white—they don’t want to hear my ideas.” “Research? Nope, I don’t want to be a guinea pig!” “Most researchers are uppity and just talk down to us.” And these are just the comments conveyed to our WINRS team directly. Obviously, other prejudices and stereotypes also divide us—based on how we dress, talk, our skin color, the condition of our teeth, etc.

Imagine trying to communicate in a room where these two worlds collide. On one side: I see you as less educated, less smart, and not able to offer me anything useful. On the other: I see you as sneaky, self-interested, arrogant and out to take advantage of me. How do we find common ground? How can researchers get the advice they need to make their projects more accessible, appropriate and engaging? How can we create a space where lay people feel free to share important feedback?

Two specific practices we use to break down divisive assumptions and stereotypes demonstrate the power of “The Personal.” The first practice is to start each CARDS® meeting with an opening question that everyone at the meeting answers. This may seem straightforward, but learning what makes an effective opening question has been an experience of considerable trial and error.

At one meeting, the guest was a young researcher who appeared very stiff and ill at ease at the outset. Our opening question was: “Think about a time when you took care of someone else—a child, relative or friend. Tell us what made you good at taking care of that person?” As we went around the room, we heard from a woman caring for her grandma, who described the patience (and humor!) required to deal with increasing forgetfulness. We heard about stepping up to be on call 24/7 for an ailing friend and making the decision to move in with aging parents. When it was the researcher’s turn, she started by simply holding up her hands. People shifted uncomfortably in their seats, wondering if she was giving up on the meeting before it had even started. Then she spoke: “I have 3 young children,”

she said gently. “I’ve always felt like human touch is one of the most caring gifts we can give each other. Every time I bathe my kids, wipe their noses or their tears, wash a scrape . . . touching them in a tender, loving way seems like one thing that makes me good at taking care of them.” By the time she finished this very short statement, there were plenty of damp eyes and warm smiles around the table, and we were all looking at each other with a very different perspective. The power of “The Personal.”

At another meeting, we asked, “Looking back on your childhood, what is one *good* memory that really sticks with you?” One of our CARDS® has struggled with drug addiction and shows many of the physical ravages of this difficult history. It would be hard for most people to look at this person and not jump to conclusions based on outward appearance. When it was his turn to answer the opening question, he said: “I grew up in New York. I had the best granny in the world. Every year, she got me all dressed up and took me to see the Christmas show with the Radio City Rockettes. Every single year! She said I would never miss a Rockettes Christmas show—and I never did.” The impact on the researcher (and the rest of us) was amazing. To see him glow with this happy memory and to unexpectedly glimpse the excited, dressed-up little boy still inside this grown man was transformative. The power of “The Personal.”

But not just any opening question works! Here are some lessons we’ve learned.

Some opening questions are simply boring, and do not help us connect with each other. When we had dementia researchers at a CARDS® meeting, we said, “Tonight we are going to talk about research on memory. What is one trick you have for remembering or keeping track of things?” Not surprisingly, the answers were all basically identical: “I write lists.” “I have a special place where I put important things, like my keys.” No one shared anything uniquely personal—so no personal connections were established and no stereotypes were really challenged.

We’ve also learned that while “The Personal” is powerful, it needs to be used thoughtfully. Some opening questions can unintentionally derail the

group with negative energy, making it harder to get on a productive track. One night we said, “We are going to talk about home care after surgery. That got us thinking about scars—we all have scars from accidents, injuries or wounds. Please tell us a story about one scar you have.” Although we prepared a staff member to model a light-hearted memory of a scar she got while playing with her beloved baby sister, the following stories took a darker turn. We heard about a stillborn baby, injuries from the Vietnam War and serious work-related accidents. Soon the group was extremely somber, with a palpable sadness around the table created by stories that led us into our own separate worlds of grief.

Lesson learned—craft a thoughtful opening question likely to draw out stories and experiences that engender positive emotions and reinforce human connections. This not only helps us to see past the stereotypes and assumptions that divide us, it also reduces our own barriers of discomfort, nervousness and feeling out of place. It’s hard to connect with a stereotype. It’s hard *not* to connect with a good personal story. As one of our CARDS® told us, “I love the opening questions. They help us accept the researcher. When we share life experiences, we see each other as human.”

The second personal practice that breaks down stereotypes is using five minutes of meeting time for guest researchers to explain their personal motivation for their research. The CARDS® have repeatedly told us how critical it is to understand why a researcher is focused on a specific topic: “Are they just doing this for the money or do they actually care about this problem?” The fundamental truth we’ve learned is “people don’t care how much you know until they know how much you care.” However, when we first started asking researchers to comment on what motivates them to do their research, they generally discussed “gaps in the literature” or the “iterative nature” of the research process. Researchers are trained to be objective and scientific—not to talk from the heart when discussing their program of research. But we have found that with some individualized coaching, researchers of all kinds can benefit from the power of “The Personal.”

Now we specifically ask researchers to reflect on why they are passionate about their research and to answer this question in a short survey before coming to a CARDS® meeting. We follow up with each researcher and together prepare a short “script” for the researcher to share at the meeting—expressing in 2–3 sentences why they have a personal stake in their research topic. Consider the difference between “I’m part of a multidisciplinary team facilitating innovative science, targeting the prevention and treatment of this disease with novel research projects . . .” versus “This research is important to me because of my own family history with this disease. I am personally committed to making a difference in the prevention and treatment of this disease.” OR “I focus on this research because scientists still don’t understand the most cost-effective way to treat this condition . . .” versus “I am a physician who treats people with this condition. I have seen my patients struggle with both the terrible symptoms of this disease and with the high costs to treat it. I hope what we learn in this project will help my patients and the many others whose lives are damaged by this condition.”

Some of the most poignant comments we have heard in evaluations with the CARDS® are about how their attitudes towards researchers have shifted as a result of the power of “The Personal.” As one of the CARDS® put it, “I get really moved when researchers tell us why they study what they do—the stories of grandparents, other family members, patients and so on. You can see that they genuinely want to make the world a better place.” Another said, “I used to think that researchers were ‘off in another universe,’ but now I see them as decent, caring human beings who are trying to do good things.”

Researchers also have shared touching comments about being able to connect with these “hard to reach” people: “The single best thing about meeting with the CARDS® was getting feedback from community members we normally wouldn’t have the opportunity to talk with.” “Getting advice from people with ‘lived experience’ is more critical than we realized. Many researchers don’t consider the perspective of participants. I really didn’t

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.”