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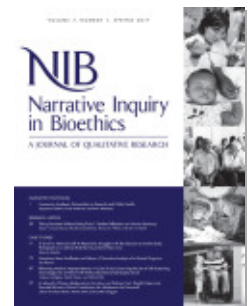
The Common Denominator

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Commentary

The Common Denominator

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Abstract: Despite the best of intentions, researchers and subjects can fall into mindsets of “Us vs. Them”, focusing on the different characteristics of their roles, skillsets and agendas. This commentary looks at the commonalities of the investigators and community members in these narratives, and the ways these shared human traits and experiences become the basis for merged social unit that moves productively toward relevant research goals.

Key Words: community-based research, partnership, collaboration, paternalism, subject empowerment, subject voice, engaged presence

“Community-Based Research” moves away from the paternalistic investigator premise that, “We have identified an issue that concerns you and we are going to come to where you live to study this problem so we can help you.” There is an upfront expectation that members of the targeted community will be partners, collaborators and even co-designers of the research, contributing study questions and shepherding research activities through the twists and turns of their daily lives. When investigators enter a social space to do community-based research, they have identified an issue, constructed a hypothesis, devised a strategy, and expect to collect and evaluate data before formulating conclusions. It is a linear mindset. It guided the formulation of their original thoughts, helped them to explain their quest to administrative bodies and secured the funding for their journey.

When at last they begin the dance of collaboration, the proclaimed goal might be “equal partners” or “local leadership” or “subject-driven”—which implies a unity of and parity between stakeholders, but the mentality and reality of “I am researcher” and “you are subject” permeates every study relationship (artificially constructed), every meeting (carefully scheduled), every response (which must be recorded) and every next action (determined by the weight and value of preceding events). I venture to say that despite the best of intentions, it is nearly impossible for researchers to become truly “one” with a community they intend to study.

As the caregiver of a cancer patient and the facilitator of support networks, I have been part of the growing trend to include patient/subject advocates and community representatives in the design and review of research. In the early days, I

saw myself as a bridge between different worlds. I wore many hats and although it seemed important to keep them separate, over time it became too difficult to compartmentalize my identities. I learned to embrace the fullness of myself as a patient–caregiver–advocate–reviewer–regulator–advisor and bring this collective with me to each assignment. I later found a way to articulate the separateness and unity of my selves in the work of John Crosby. In his book *The Selfhood of the Human Person* (1996), he describes the “communicability” of being human, which is the essence, the common denominator, of what all persons share with one another. In other words, humans—past, present and future—are alike in significant and innumerable ways (e.g. subject to physical, emotional, spiritual and intellectual impulses). At the same time, each human is “incommunicable”—that is, possessing a non-reproducible set of physical and emotional traits and temporal experiences that make us each uniquely ourselves. We long for and find comfort in our communicability—in the ways we “belong” to the group—while simultaneously asserting independence, angling for dominance and rejoicing in our incommunicability—our distinctive selves. Much of the human condition is based on the tension between these two ways in which we exist and is the basis for our interactions with the world.

It is my experience that many problems in research are the result of a similar tension. The communicability of the humans involved in research is usually taken for granted or completely disregarded. Investigators and their subject populations are first defined as separate categories of research stakeholders, easily identified by the nature of their incommunicability and traditionally evaluated by these differences in their roles, skill sets, resources and agendas. There is an “Us vs. Them” presumption that is difficult to ignore. Thinking back, my early (well-intentioned) self-labeling reinforced the notion that there *are* separate camps—and they needed to be bridged. I have come to believe that this emphasis on differences frustrates good research. The narratives in this symposium describe concerted efforts to bring investigators

and subjects together to address community-specific issues. Terminology for these efforts include Community–Academic Partnerships, Community Based Research (CBR), joint projects, collaborations, Community Based Participatory Research (CBPR), Community Advisory Boards (CABs), and Community Advisors on Research Design and Strategy (CARDS) While these words are accurate—and I realize that descriptive labels are necessary for logistical and other purposes, the emphasis on stakeholder dyads and the identification of distinguishable communities remind me of my inadvertent reinforcement of “Us vs. Them”. In this commentary, I reframe researcher and subject experiences to illustrate the communicability they share. This is evident in topic threads throughout the narratives and in a comparison of the voices of both the investigators and community partners. It is no surprise to find that when differences fade and commonalities are embraced, mutual learning and respect become the basis for the exploration of concerns by a new social unit—a merged group of researchers and community members.

Shared experience. It can be daunting to stand in front of a group of strangers and try to convince them that they should care about your personal agenda. Many of the narratives describe dismay, fear and frustration as the investigators struggle to craft relationships and infrastructure that will further their research goals. Rosana Bravo plodded unhappily through four meetings with her *promotoras*, unable to provoke more than listless responses to her carefully designed questions. EmmaLee Pallai describes the social awkwardness of medical students unwilling to move past dispassionate objectivity in group activities with patients. Trina Ward points to “a moment of terror” as student researchers realize their hypothetical question had struck fertile ground. Jana Wilbricht is weary before her study even begins, “aware of the multitude of complications I invited into my already busy student life . . .” These sentiments are offered from the researcher’s point of view and we can imagine their effect on the health of each study. However, these are only one side of the emotional picture.

Bravo's frustration is *shared* by her community partners. It dawns on her that she had inadvertently "perpetuated the research hierarchy" by assuming "we had the 'research' skills and they had the 'community' skills." This realization forces her team to rethink their understanding of roles, skill sets and the nuances of empowerment. The resulting new paradigm becomes the turning point in the study. The academics and the *promotoras* takes turns being "the experts", eventually becoming "partners, colleagues and equals" within the context of the project.

Sally Mason's work involves the stigma surrounding families who have an HIV positive member. She describes two occasions where she finds it necessary to guard her knowledge of someone's HIV status during nuanced communication about project business. She felt "the day-to-day tension of keeping a secret," wonders "what if it was multiplied, with every day holding the possibility that someone would think I was 'abnormal'," and describes a "subtle shift in my understanding." In this instance, the researcher experiences something deeper than empathy; she has an emotional investment in her colleagues and her project and experiences the weight of stigma right along with them. Mason admits that she had not expected that "as boundaries between academic and community members blur, [. . .] stigma [. . .] became part of the process, immersing me in their experiences . . ." She suspects that she might have learned more than the community members she intended to help.

Researchers and community members share more than just emotions. Wilbricht's lament over her crowded life is not unlike the stress felt by Sakseña's refugees who juggled jobs, family responsibilities and fear of deportation. They each have a vested interest in a good research outcome but are similarly affected by the noise of real life. J. Claire Schuch and Jyotika Saksena fought against preconceived notions of their abilities, roles and the importance of their work. Schuch encountered "push-back and skepticism" when supervisors questioned her research methodology and saw her as little more than a "service-provider". Saksena was "perceived as (a) leisurely academic" and her project was not

taken seriously. Local participants face similar challenges when their skills are not appreciated, their questions are dismissed and they are expected to assume a passive role in the research. Remember, Bravo's community members not only wanted to learn "research skills", they wanted validation for the skills they had polished in their many years as promoters of local health service.

Shirazi's work with Afghan immigrant women hinged on successfully identifying, respecting and meticulously addressing default behavior that threatened meaningful progress in addressing breast cancer. This same careful evaluation and intervention could be focused in the other direction—on the norms that guide *researcher* behavior. Pallai's patients are more than willing to tell their stories and pointedly say how important it is for them to have "their doctors admit to getting sick," yet despite the intimate nature of the narrative workshops, the medical students and healthcare providers default to emotional distance. Without a targeted intervention on the *dysfunctional members of the merged group* (in this case the non-patient members), the full benefit of the opportunity is lost.

One voice. There is much to be learned from the voices heard in these narratives. Bravo's *promotoras* cry, "¡Díganos!" ("Tell us!"). Her community partners are literally reading her mind when they beg her to tell them what to do. With incredible insight, she restructures the hierarchy of the subject–investigator relationship so there is co-teaching and co-learning based on themes that stem organically from the partnership instead of from pre-study assumptions. Bravo's own voice reveals her relief and satisfaction with the new process, even as it retains the flavor of her expertise when she notes that "being participatory also meant being honest and transparent about the many inequities that we could not directly address or change."

The Amish tell Farrar to reflect on "Gelassenheit" ("humble, grateful actions for God.") Projecting her own agenda into their world was unsuccessful, but opening herself to their lived experience revealed a critical issue they were willing to work on. "I moved from a place of polite interaction to real humility

and gratefulness,” she says. Building a relationship with them in their space and on their terms included social activities that had nothing to do with the research question. This may seem odd, but consider that research is usually conducted according to investigator turf and terms, with actions that have no relation to the daily life of subjects. Why should *that* be the gold standard? Pallai’s subjects find confidence, respect and empowerment when the investigators interact with them outside of the clinical setting. Schuch’s participant volunteers say, “It just builds comradery to see others outside of regular work environment.” Genuine participation in the context of the subject’s space and reality seems to be crucial.

Another example of the power of voice is the repeating refrain of “my sister, my aunt, my mother, my daughter,” a rhythm set by the Afghan women in Shirazi’s community outreach. Every conversation circled unwaveringly back to the importance of family for these refugees, inviting the investigators to consider refugee storylines from countless insider perspectives. From this vantage point came the realization that the role of males, “guardians, gatekeepers and links to the outside world,” was integral to the lives of the Afghan women. Their gentle insistence that this was *their* family, *their* culture, *their* unique need—became the underpinning of long-term, effective programming that included interventions designed for the men.

The common denominator. Gay Thomas describes breaking through the divisive stereotypes that researchers and community members hold for each other: “I see you as less educated” vs. “I see you as . . . about to take advantage of me.” Using the power of “The Personal”, Thomas begins each meeting between researchers and Community Advisors by asking a question that every person answers. These snippets of personal narrative are acts of faith and by making themselves vulnerable, each person pledges loyalty to the group unit. Ronit Elk has experienced the same: “I begin by sharing aspects of my personal story that directly relate to this study.” This sets the tone for the honest engagement necessary between caregivers of the White and Black

communities who are coming together to develop a regional palliative care program. Another example is when Farrar was concerned that an honest answer to a personal question would alienate the Amish elder she depended on for her study’s success. She was willing to take a risk and her sincerity cemented the partnership.

There is more at stake here than open-mindedness, simple empathy or the use of narrative as a communication tool. Shirazi correctly notes that, “Establishing any partnership is part act of faith and part extended learning curve, but the development of a true partnership across culture, language, religion, and deep societal mistrust required more than good intentions.” Many bodies of work address the responsibilities of investigators who conduct international research. These same responsibilities should apply to “outsider” scientists who seek a productive relationship with cultural or regional communities in their own countries. In *Developing World Bioethics*, Hunt (2014) and his coauthors discuss the “ethics of engaged presence” as beginning with “recognition of the shared humanity and vulnerability that exists in health care practice . . .” (p. 51). This engaged presence is evident in the collaborative dances described in these narratives.

The key to successful community-based research lies in recognizing the communicability of the research stakeholders, understood in the context of the incommunicability inherent in each person. The pitfalls of “Us vs. Them”, paternalistic projects, and parachute research can be avoided when the shared journey unfolds in proper sequence. In the simplest of terms, it is first “Here is how we are the same.” Second, “Our differences affect our interactions, but we are, nonetheless, the same.” Third, “Now, what’s the question?” And finally, “How can *we* answer it?”

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