


Decolonizing Qualitative Research With Rural People With Disabilities: Lessons From a Cross-Cultural Health Systems Study

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Abstract

Decolonization of research is nowhere more pressing than in post-apartheid South Africa, where cross-cultural encounters characterize every aspect of society. The health system plays a critical role in realizing the rights of marginalized populations, particularly rural communities and people with disabilities. However, cultural divides between service users and health care workers render health care provision unexpectedly complex. Such divides likewise obscure the meanings embedded in qualitative data, rendering research interpretations challenging. A study of the engagement between rural isiXhosa-speaking people with disabilities and primary health care workers was conducted by the first author, a White English-speaking female health care worker, in partnership with the second author, a Xhosa male research implementer. Ethnographic and narrative methods were used to create an embedded case study of 11 households of people with disabilities. Lessons on conducting ethical and culturally congruent research with this population are presented, important limitations in the qualitative paradigm raised, and alternative stances explored.

Keywords

decolonization, qualitative paradigm, primary health care, disability, rural, South Africa

Introduction

The international movement for the decolonization of the academy highlights the political nature of knowledge generation and the ways in which the Western approach to research has contributed to oppression of marginalized groups (Denzin & Lincoln, 2008; Richardson, 2018). Critical indigenous methodologies draw attention to the performative dimension of research and call for processes that are collaborative and emancipatory, with power increasingly being held by indigenous participants themselves (Smith, 2012). There is a call for indigenous values to replace Western ones in informing research ethics and engagement, and for indigenous knowledge systems to be interpreted on their own terms, without the imposition of outsider theories and worldviews (Denzin & Lincoln, 2008; Owusu-Ansah & Mji, 2013). Similar concerns are raised by disability scholars, in the light of historical power relations between nondisabled researchers and people with disabilities (McKenzie et al., 2014).

Since 2015, protests on the campuses of South African universities have called for the decolonization of the academy, the deconstruction of Western ways of thinking and knowing, and the reimagining of more inclusive ways of understanding the

world (Le Grange, 2016). Researchers are increasingly acknowledging their own positionality in their work, exploring the ways in which relative “insider” or “outsider” identity influences knowledge generation (Keikelame, 2017).

The health system plays a critical role in realizing the rights of marginalized populations, particularly rural communities and people with disabilities (Ned et al., 2017). However, Western-trained health workers face significant cultural barriers in engaging with communities and their health needs, especially as most of these workers still come from urban middle-class backgrounds. In South Africa, as elsewhere, cultural competence is increasingly emphasized in health

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professional training and practice (Matthews & Van Wyk, 2018), but much must still be learned in this area.

This article presents insights into qualitative research methodology gained during a doctoral study by the first author (KS), a female White English-speaking South African occupational therapist. This gendered, racial and educationally privileged positionality was crucial to the unfolding of the research on many levels, and in keeping with the interpretive stance adopted in the study, the findings will from this point be related in the first person, from the first author's perspective. The significant roles played by the other authors in the process will however become clear.

The study emerged from my clinical experience in a remote rural district in the Eastern Cape province of South Africa. Employed at a state-run district hospital, I was responsible for establishing rehabilitation services within the primary health-care (PHC) platform for a catchment of approximately 100,000 people. This area is part of the former "homeland" designated for the amaXhosa people by the apartheid regime during the 1950s (Mbeki, 1964). Today, much of the region remains under tribal leadership, and Xhosa cultural practices and ways of life are continued by the almost exclusively isiXhosa-speaking population. Historical lack of investment in infrastructure and development has left this area with sparse access to basic services, and the majority of residents are extremely poor, relying on social grants and remittances from family members working in the city for their survival (Alfred Nzo District Municipality, 2015; Bank & Minkley, 2005).

Working at PHC level placed me constantly in the interface between the health system and the community, with the challenge of shaping services within the former to respond to the realities of the latter. I faced significant cultural and language barriers in this work, and over time I came to see how incorrect assumptions and lack of knowledge about the realities, values, and needs of this community formed further barriers to effective services.

These realizations led to a doctoral study seeking to better understand the lived experiences of patients in their daily lives and specifically in accessing health care. The study site chosen was a rural village in a neighboring district, outside my hospital's catchment. Previous work on a research project in this village (Duncan, 2016) gave me access to existing contacts and positive research relationships in context, which proved invaluable. "Kwabisi" was the pseudonym given to this village for the purposes of reporting. Ethical approval for this study was provided by the Human Research Ethics Committee of the Faculty of Health Sciences, University of Cape Town (ref no. 569/2012).

Methodological Choices

Participatory action research (PAR) has been the preferred methodology where research intends to give voice to vulnerable and marginalized people (Bozalek, 2011). PAR aims at sharing control with participants, creating opportunities for participants to benefit by steering the research process toward their own interests and needs (Guba & Lincoln, 2008). But such processes

demand significant time, energy and resources, and we were hesitant to impose this burden on participants in a context of dire poverty and the added daily challenges of disability—particularly since the learning need was not theirs but my own. As the research aimed at improving health services for this group, I felt justified in undertaking it and sought to balance sharing decision-making and control with minimizing unnecessary demands on participants. This stance bore a weighty responsibility to conduct research relationships and activities justly and sensitively, and to hear and interpret the voices of our participants with great care. Partnerships with key community members and cultural insiders were essential to this.

A research advisory group had been formed during the previous research project, a PAR study that explored how building community-level policy literacy might facilitate better access to services for people with disabilities. The advisory group included the local chief, one person with a disability, and several male and female elders. We met with them to discuss our research plan at the outset and continued to consult with them during the study as ethical issues arose.

To facilitate the day-to-day implementation of the research, I employed a local isiXhosa-speaking man with extensive experience working with health researchers as translator, cultural broker, and fieldworker in this area (XD). Mr Dabula's role quickly expanded to that of co-researcher, guiding the conduct of our relationships with participants, sharing decision making, and engaging deeply in data analysis and interpretation. Being familiar with Western research approaches as well as strongly grounded in his own culture, he had unique insight into both worlds and the interactions between them. As a well-known local resident of good reputation, he held a position of trust and respect that gained us entry into this community and fostered an openness in our participants which I could not have hoped for without him.

As a partnership, we occupied the interface between the community and the health service: each rooted in one with some knowledge of the other and with a curiosity to understand better how the two played out in the lives of our participants. Our often-contrasting personal perspectives on the unfolding events of the research produced rich discussion and learning, even as they raised tensions and sometimes misunderstandings. As the primary investigator, I held the responsibility for maintaining rigor and satisfying institutional requirements in line with best research practice. Mr. Dabula was responsible for guiding our behavior in the light of local ethics, values, and responsibilities to the community. From the outset, we perceived the latter set of demands as our priority, and this frequently took us into unknown territory, raising ethical and pragmatic dilemmas that needed to be worked out as the research progressed.

Research Design

The focus of the study was the interface between two distinct worlds, that is, a rural village of amaXhosa people and a state health care service. While the latter was familiar to me from a

health care worker/employee perspective, the study sought to understand it from the perspective of rural people with disabilities. An ethnographic approach was therefore adopted (Kielmann, 2012), and I spent several months living in Kwabisi at the start of the project. Immersion in context is recommended to deepen background understanding and enrich interpretation in cross-cultural research (Smith, 2012). Renting a room in the chief's homestead gave me opportunities to take part in local activities, from attending funerals to catching local transport.

Sociocultural immersion created the starting point for formal data gathering, following a case study approach. Eleven households that included a member with a disability were recruited from the Kwabisi area, and their stories of interacting with the health system were followed in-depth over two years. Our units of analysis were both the experiences of these households themselves and the broader interface between villagers and local health services, comprising an embedded case study (Yin, 2009). PHC services available to our participants included a nurse-run clinic, several *nomakhayas* (community health workers), and the small district hospital in the nearest town, a two-hour drive along a rough gravel road. While villagers also used other health services, including traditional healers (Booi, 2012), the interface with PHC services was our focus.

Purposive sampling sought to reflect the broad range of physical, neurological, psychosocial and cognitive disabilities, and also sought maximum variation in age, gender and health care need. Participant households were identified by the second author from his previous work in the area, with the help of the *nomakhayas*, and sometimes by other participants themselves (snowball sampling; DePoy & Gitlin, 2011). Sample size was limited by time and resources. Given the close interdependence of household members in this setting, family members of the key informant with disability were also included in data generation.

Data generation was organized around the production of case narratives for each of our 11 participants. In the first visit to a household, participants were asked to tell the story of a recent interaction with health care services. The process of narrative interviewing (Greenhalgh, 2006) was used as a framework. Where the story narrated was a recent or current one, we then sought complementary interviews with involved health care workers and other key informants, and where possible participant observation (e.g., visiting the clinic). Verbal permission for such follow-up was first requested from the participant, and the appropriate consent procedures followed with the health facility concerned.

Interviews were audio-recorded, and field notes and reflective journaling captured experiences and observations. Daily debriefing conversations between the two researchers were also audio-recorded as additional data. While I transcribed recordings in English, the translation and transcription of interviews in isiXhosa proved more complex than expected, and the process we developed to ensure the linguistic, cultural, and conceptual accuracy of the data is discussed below.

Data generation and analysis took place in an iterative manner. Analysis began with immersion in the data and a process of data reduction, compiling each case story from all its various sources (Flick, 2013). Atlas.ti was used for thematic coding across the whole body of data, and a preliminary set of descriptive categories developed. The second (overlapping) stage took place within the translation/transcription of isiXhosa interviews, through a co-analysis and interpretation process discussed in more detail below. The third stage involved selection and construction of key narratives from the data, and the fourth a final round of thematic analysis (Flick, 2013).

Performing the Research: Ethicizing in Uncertainty

Continuous reflection, discussion, and ethical reasoning were necessary to deal with the complexities of such cross-cultural research. Duncan and Watson (2010) describe this process of "ethicizing in uncertainty" as being made up of three aspects: reflexivity, transparency, and representivity. Reflexivity involves considering how one's own presence impacts the research situation, and how personal worldview and perceptions shape the knowledge being created. Transparency is the requirement of openness and honesty with research participants about one's intentions and activities. Representivity refers to faithfulness in hearing and representing the voices of participants in the research product. These three concepts capture the core concerns of ethicizing as we experienced it during the study. The following sections elaborate how each concept was worked out in our research practice.

Reflexivity: Objectifying Researcher Positionality

The contrasts between my sociocultural identity and that of the participants meant that my presence had a profound impact on our research interactions. It was impossible to remove or ignore these effects, and I chose instead to interrogate them as part of the data. Practices of reflexivity therefore formed the backbone of the research process (Cousin, 2010), including daily reflective journaling, discussion with Mr. Dabula after each data collection episode, and peer debriefing with EMD and SR (my supervisors). The final stages of analysis and interpretation took place in contrasting spaces removed from the research site (Kuntz, 2010), both in my home in Cape Town and as a visiting scholar in the Netherlands.

Identity and Trust

As White, educated urban woman in Kwabisi, I was treated with respectful distrust. Interracial interactions in South Africa are strongly influenced by the history of apartheid and colonialism, although local dynamics vary. In this deep rural area, White people are seldom seen, excepting a handful who work in health centers. Distrust toward White people (for obvious historical reasons) may therefore be mixed with other kinds of

responses based on service experiences. As a White person, I was invariably perceived as powerful and wealthy, which could give rise to a range of expectations not always expressed. It was not always possible to know what perceptions people held of my activities and affiliations, despite our best attempts to explain them. In much of South Africa, less educated people (especially in rural areas) have a deep distrust of the educated, due in part to historical experiences of manipulation and exploitation by both colonial and apartheid powers (Lefko-Everett et al., 2018). My academic role therefore did not necessarily inspire trust (perhaps the reverse). Being known as a health care worker was both positive and negative, reflecting the complex dynamics between the Kwabisi community and the health system. Where I was able to provide information or assist with access to services, my position was valued. However, being identified with the attitudes and beliefs of Western health care could mean that certain subjects were avoided (e.g., use of traditional medicine), or opinions expressed to match what they felt I expected (e.g. that prescribed medication was helpful, whether or not this was believed).

Trustworthiness in this setting relies far more on who one is relationally than one's qualifications or credentials, and our acceptance by the community depended heavily on Mr. Dabula's identity and reputation in the area. We were also known to be affiliated with E.M.D. and another researcher (also occupational therapists), who had worked in this area previously and were well regarded. They were known to have assisted numerous people with disabilities to access assistive devices and start small businesses, and had built positive relationships with community leaders.

Positionality and Communication

These multiple dynamics surrounding my positionality rendered the community entry process both essential and challenging. Mr. Dabula's guidance was vital in helping me recognize and understand what was happening, especially as expression of feelings and opinions could be very subtle. In one example, he was translating an apparently simple statement made by the father of a participant, when he began to laugh. Mr. Dabula explained to me that the man was speaking to us in isiBhaca, the local dialect:

There are few who do this, they are that showing they are proud of their language. Sometimes they don't want you to understand. It's a way of showing us that he depends on this language, and he is not educated. Because when someone [from outside] is coming to your house, you change the language and use isiXhosa so that they understand you. This is showing a little bit of resistance: if you don't understand, it's unlucky for you.

While the father's words seemed straightforward in themselves, the manner in which they were expressed conveyed a different message. Paradoxically, participants' awareness that I could only partially understand their language may actually have made them more willing to speak. Some participants

(especially male) were noticeably more open when Mr. Dabula conducted follow-up interviews without me present, indicating the significance of our respective positionalities and his important role in the depth and authenticity of the data.

Positionality and the Research Partnership

At the same time, similar social and cultural dynamics were present in our research partnership itself, although to a lesser extent. It took time to build the mutual trust needed for frank discussion, especially in a culture that prioritizes harmony and deference for authority. I was often frustrated and confused by Mr. Dabula's difficulties responding to my Western directness, especially in practical matters. One example arose when he conducted visits without me, and I asked how much money he would need for transport. To me, this seemed both practical and straightforward, but he found it difficult to answer, stating: "No, I can't tell you what you should give me. You must decide." Eventually, I learnt to break down the question into others that were more acceptable to him, such as the distances to be driven and fuel consumption of his vehicle. Over time, we were able to discuss these sociocultural differences, shedding light on communication barriers between our participants and their Western-trained health care workers.

Positionality and Interpretation: Shifting Perspectives

My own reactions to many situations were shaped by past experiences as a health care worker. While it was vital to step outside that perspective during the research, the thoughts, interpretations, and emotions that arose were valuable data. The following extract from my journal demonstrates my reflexive process, in the context of one participant's struggle to access health care for a long-standing health problem:

The story is a familiar one to me: middle-aged woman repeatedly seeks help for a long list of "non-specific" complaints. Healthcare workers across the country have various terms for it: "GBP" (generalised body pains), [or] *umzimba wonke* ("whole body") In my clinical role, I had frequently seen how such patients were resented by busy primary care workers (including myself), and the kind of "brush-off" prescription she described was typical. A comment in my field notes after the visit demonstrated vividly why this is so: "Part of me had the usual scepticism about what was real or imagined, and how serious [her complaint] really was..."

I was better able to understand their apparently dismissive and potentially unethical professional behavior against the background of my own clinical experience:

I put myself back in the shoes of the nurses and doctors, facing the heaving outpatients' waiting area, the crowd that hardly seems to diminish as the afternoon wears away, with their sighs and tongue-clicks, reprimanding gazes when one tries to slip away for five minutes to eat something. . . . And this every day, unchanging over weeks and months and years. . . . It is unsurprising that many

people we speak to say the same thing: “There is no care there, at our hospital.”

Spending time in Kwabisi, however, challenged the notion that this woman’s illness might not be “serious” enough to warrant health workers’ attention:

Forty-plus kilometres from the hospital, and a decent walk on rough paths from the public transport to get there, I have a physical sense of the investment behind going to see a doctor, and even more so for someone who struggles to walk. She has described the time commitment (close on two days for a single consultation), and at other points mentions the cost: not only her own taxi fare, but that of a relative accompanying her. . . . Sitting in this sparsely furnished home, it is clear these repeated trips were not taken lightly.

This example demonstrates how a reflexive approach took us deeper into the ethical and social justice dimensions of the stories we encountered. It was often confusing and uncomfortable but also richly productive of new insights and further questions.

Transparency: Communication

Transparency requires the researcher not only to communicate intentions and processes to participants but to do this in ways that are intelligible and acceptable to them. Transparency in communication proved an unexpected challenge for me as a cultural “outsider.” While from my Western perspective, transparency required verbal clarity and directness, I noticed how people became uncomfortable during research explanations: more verbal information seemed subjectively to reduce rather than increase trust.

I came to understand that in this cultural setting, direct questions and answers are generally avoided, and words themselves are seldom considered to convey the full truth about anything. Understanding what someone is really saying is about extrapolating from clues. A startling example of this arose during a member-checking focus group near the end of the study. I asked participants (through Mr. Dabula’s translation) to reflect on who held power when they engaged with health care workers. I was met with complete silence. Mr. Dabula later explained that the word “power” was difficult to translate because its direct correlate in isiXhosa, *amandla*, was used by the current ruling political party (the African National Congress) as a rallying cry during the struggle against apartheid. He said, “They might think, is Kate working for the ANC?”

Much communication here is nonverbal, “heard” through what one is seen to do and how one behaves. Ethical transparency therefore meant being alert to my way of being among the community. Engelbrecht and Kasiram (2012) describe the Xhosa worldview as premised on social harmony, solidarity, and the honoring of relationships, and these are the values against which behavior is measured. For example, appearing

to be in a hurry to pursue one’s own agenda during a visit could demonstrate a lack of value on “being together.” This became clearer in the customary interactions and behavior on entering a home to visit someone. My “script” on beginning a research visit was to greet (including inquiries about the well-being of the household), then to outline the goal of our visit, remind participants about consent and confidentiality and then begin the interview. While I understood the importance of the greeting process in this culture, I completely missed the importance of *how* this was done, and I proceeded with the Westerner’s concern about “not wasting people’s time.” When Mr. Dabula took the lead during research visits, a contrast was clear. He *said* far less than I would, allowing companionable silences between remarks. I worried about following the research protocol, ensuring all the right ethical information was put into words, while he focused on the quality of relationship in each encounter, adjusting his behavior sensitively to our participants’ responses.

These realizations turned the idea of transparency on its head for me. It was no longer about what information we gave people (verbal or written), but rather how we were seen to conduct ourselves. Mr. Dabula advised me against telling people that the research was for my PhD: “They will feel you are coming here only for your own benefit, to take things from them to help yourself.” In a context where the academic world is largely alien, many probably believed the research would bring me money (I later realized that Mr. Dabula himself held this expectation: he asked me some months after submission whether I had bought a new car, “now that you are a doctor!”). Withholding information from participants seemed ethically counterintuitive, but since in this case there were no direct implications for their well-being, I followed his advice.

Transparency: Consent

The negotiation of consent for our work was an ongoing, multi-layered, and complex process, extending far beyond the consent procedures prescribed by a research ethics board (Posel & Ross, 2015). Most residents of Kwabisi have little more than primary education, and without a general understanding of academia, truly informed consent to participate in the study was challenging to achieve. The guidelines of the ethics committee that approved the study are designed primarily with clinical trials in mind and emphasize written information and consent obtained prior to any data collection (World Medical Association, 2013). In this context however, signing forms is associated primarily with government activities and could lead both to distrust and to expectations of service provision, so the use of written documents needed careful handling. More than one household was hesitant to give consent before they could see what we were going to do and would only sign after our first interview was complete (this meant collecting data during the interview and potentially destroying it if consent were refused). While the ethics committee guidelines address the use of local languages, interpreters, and ensuring understanding for people of low literacy, they do not address these deeper issues of

cultural and social acceptability. We needed to fulfill the requirements of the ethics committee while also working out what authentic consent, respect for autonomy, and protection from harm meant in this setting. Over time, we identified four levels at which consent needed to be negotiated: community, household, neighborhood, and situational. Negotiation itself involved both overt and tacit levels of communication.

Community-Level Consent

In this collectivist cultural context, the right to consent to research participation is not held solely by individuals (Duncan & Watson, 2010). Negotiating consent with tribal authorities was a critical first step. Our actions were highly visible from the first, so being seen to follow the correct procedures and show respect for social structures was essential to our acceptance by all concerned. With the support of the chief, we were given an opportunity to address the local *imbizo* (regular community meeting) to explain the project and formally ask permission from the community leadership, which was granted. Attending headmen were requested to share information about us in their locations. Local social structures render each household accountable to the leadership, and it is unlikely that any would have agreed to speak to us without this assurance. At the same time, once leadership consent was granted, it may have been difficult for households to refuse.

Household Consent

At household level, permission needed to be sought first from the head of the household. The formal consent procedure included a summary of the research translated into isiXhosa, which Mr. Dabula would read through with the family before consent was signed. Where the person with a disability was unable to participate directly themselves (e.g., due to active mental illness), the caregiver and/or head of household would be approached as primary participant instead.

We made allowance for ongoing conversations about the study throughout our engagement with each household, although this was often ambiguous and time-consuming. We needed to address expectations as they arose, for example by clarifying the limits of the help we could provide. Questions and concerns were not always expressed openly, and Mr. Dabula played a vital role in anticipating and inferring where these might arise.

Ethical guidelines emphasize maintaining participants' confidentiality during data collection, which is usually taken to mean interviewing people in private. It is assumed that this practice protects the individual, but it proved highly problematic in context. Given the physical structure of most homesteads (large round huts used communally for living, sleeping, and all daily activities), private conversations were difficult to arrange. More importantly, however, the African conception of personhood is not individual but inherently interwoven with family and others (Oyowe, 2013). One person's story is not theirs alone to tell, nor does each automatically have the right

to speak for themselves before an outsider. It would have been inappropriate and even suspicious for us to request private interviews with individuals. In several households, tension already existed between people with disabilities and their family members, and negative treatment was suspected in several cases. By speaking privately with participants, we could actually place them at further risk if relatives suspected they had "told stories" to us.

Without Mr. Dabula's guidance, I would have remained entirely ignorant of the sociocultural complexities of informed consent. It took a number of awkward and confusing initial interviews before I came to understand both his behavior and that of participants in the light of indigenous views on authority and personhood. My initial inclination was to press for "correct" procedure, to fulfill the requirements of the ethics committee, and for cultural and social reasons, it was difficult for either Mr. Dabula or participants to contradict me directly. In time, however, I learnt to follow my colleague's lead in the alternative and largely tacit practice of situational consent, which was culturally safer and more congruent.

Situational Consent

For cultural and social reasons, individuals and households were not always able to refuse participation overtly, whether for the entire project or on specific data gathering occasions (e.g. when neighbors or family members happened to be present). Two households gave formal consent to the study but resisted engaging to any depth during our visits. Questions were answered briefly, often repeating the same stories or statements, and certain questions seemed to be willfully misunderstood. I tried initially to push for more responses, until Mr. Dabula gently intervened, alerting me to the refusal of consent being conveyed. Respecting autonomy and building trust depended on providing space for people to choose their own levels of response and to evade questions where they so wished.

Knowing how to proceed where consent was implicitly resisted was difficult, but we chose in general to honor our relationship with the household while withdrawing probing. We continued to visit these households when in the area, and followed the same procedures for termination and thanks at the end of the research. Even with otherwise willing participants, we needed to remain sensitive to situations or topics that made them uncomfortable, allowing them to negotiate the bounds of their consent on each occasion.

Neighborhood Consent

The principle of transparency took on new significance as I came to perceive the constant gaze of neighbors and relatives, both on ourselves and on the households we visited. In Xhosa culture, identity and personhood are constituted in one's connection to others (both living and deceased) and place in the social whole (Krog et al., 2009). Social standing and relational networks are essential both spiritually and practically to one's existence, and our research activities risked upsetting these in

unforeseen ways. Our visits subjected participants to the scrutiny of their neighbors, with perceptions that as outsiders, we brought financial benefit to the household. We became aware of the potential for jealousy of our participants by their neighbors, which could expose them to harm. In the Xhosa belief system, witch doctors may be employed to curse someone who is seen as prospering unfairly (Mbiti, 1999), and conflict between neighbors could therefore have social, spiritual, and practical repercussions.

In this culture, it is very important to maintain an “open door” at one’s home, and we were often joined during interviews by curious neighbors. It was often in the best interests of our participants to allow observers, since it allowed other community members to see for themselves what we were doing. When appropriate, we would offer to reschedule the interview, but would otherwise remain alert to indications of discomfort and avoid sensitive topics. While this approach might compromise the data we hoped to gather, it was an example of placing relational values before academic ones.

These four levels of consent capture the complexities of research relationships in this setting and the many questions raised throughout on how best to act. Underpinning my struggles with knowing how to proceed was the need to learn a completely different way of hearing and understanding what people were saying—or not saying. Language aside, I had to become attuned to the silences, understatements, and cryptic allusions through which things were communicated, especially in the presence of an outsider. In order to practice ethical transparency, I also had to learn how my own behavior, actions, and words were “heard” in this community and rethink our communication in this light.

Representivity: Learning to Hear and Speak

Representivity concerns the ways in which knowledge is constructed and articulated to include the voices of groups who usually remain unheard. Dealing sensitively with language proved highly complex, and again involved the research partnership in a constant process of mutual interpretation. At a deeper level, approaches to generating and interpreting qualitative data had to be reconciled with Xhosa ways of relating, communicating, and knowing. Qualitative research depends powerfully on text, relying on participants’ words as primary data. This is appropriate in Western cultures with a matching emphasis on spoken and written language but raises serious problems in African (and other) communities such as this one, where words play only a minor role in communication.

Data Generation: Structuring Culturally Sensitive Conversations

While semistructured interviews have been used widely by qualitative researchers in different cultural contexts, it was soon evident that many of our participants were not comfortable with our questions. I was aware that in this culture, question-asking is not encouraged in children (Krog et al.,

2009; Mandela, 1995) and that question-asking in general could be experienced as suspicious or intrusive. I had experienced in the past how people resisted or had difficulty answering “why” questions, and questions about abstract constructs such as citizenship and even disability were generally challenging. It wasn’t always possible to predict what concepts might be familiar, or what implications they might have to hearers, and hidden meanings/interpretations could have unexpected responses (for instance, the response to the word “power” described above).

Narrative inquiry has been considered a culturally sensitive and safe approach in cross-cultural settings and with vulnerable populations (Neille & Penn, 2015). Inviting storytelling proved to be both simpler and more acceptable to participants than a schedule of specific questions. We eventually reduced our interview schedule to asking them to tell us a story about a time when they had sought health care, and then using probes to flesh out that story. This allowed participants to control what they shared and to convey meaning in a more culturally acceptable manner. For example, while a young woman caring for her mentally ill brother-in-law might not be willing to criticize a doctor’s behavior, she could tell the story of the encounter vividly and expressively.

Developing an appropriate and sensitive approach to interviewing was both challenged and strengthened by the issue of language. Participants generally spoke no English, and interviews were conducted in the local dialect by Mr. Dabula, which I could only partially understand. As he became familiar with the research topic, Mr. Dabula could increasingly conduct the interviews without my input. He was then able to shape them according to local patterns of social interaction, which often resulted in vastly different conversations to those planned in the interview guide. While this approach stood in contrast with the convention of standardizing questions across interviews, it tended to yield richer data and revealed a great deal about ways of communicating in this context.

Data Analysis and Interpretation: Manifest and Tacit Voices

In accordance with the original study protocol, the first round of interviews was sent for translation and transcription by a professional translator. However, on attempting to analyze the transcripts, I realized that the text alone provided extremely limited information and that without contextual insight into each interview, I could not safely make inferences from what was said.

One example of the potential for misinterpretation arose during a conversation with a hospital manager about the suggestion boxes in health facilities. Boxes are labeled “Complaints, compliments and recommendations” (translated into local language), and we asked what kinds of recommendations service users made. The manager answered with examples of praise and appreciation instead. I inferred that she was purposely avoiding discussing any criticisms of her service, until Mr. Dabula explained to me later that the isiXhosa translation for

“recommendation” is “*ukuncoma*,” which is a positive statement made about a person or organization rather than a practical suggestion (this raises interesting questions about the use of these suggestion boxes by different language groups). IsiXhosa speakers speaking English use “recommendation” in the same way, and Mr. Dabula was surprised in turn by *my* definition of the word. Without my colleague’s insight, I would have used this example to make judgments about the attitudes of hospital management to service user feedback, which were in fact unfounded. Such experiences highlighted the inadequacy of textual translation alone, however professionally done.

After some experimentation, we developed a process of simultaneous interpretation and transcription, which incorporated an important layer of analysis. While Mr. Dabula was not trained to provide a verbatim English translation of the recorded conversation, he could add rich information about nonverbal dimensions of what had happened, as well as cultural insight into meanings and events. He also provided an invaluable sounding board for interpretations and began to contribute his own as our work proceeded. These conversations were increasingly wide-ranging and became a shared sensemaking process through which we both grappled with the research question and broader questions about our respective world-views and experiences. Notes on these discussions were recorded as part of my transcriptions of the original interviews, and the texts analyzed as additional data.

The following is taken from the co-interpretation of interviews with a young man with a mental illness (PM). At the time of data generation, he was living with his father, with whom he had a difficult relationship due to his mental illness. The translated words from the interview itself, as rendered by Mr. Dabula, are given in bold, with our co-interpretation discussion and my own notes in italics.

PM: I forgot about the medication of the clinic. Then I decided to come back to the traditional herbs, because they were helping me. So I have plans to go out.

[Note: The word “forget” in isiXhosa also means setting something aside, deciding not to do it]

KS: What does he mean, “to go out?” Where does he want to go?
XD: People say “Ndisake ndiphume ndiye emtweni”: I’m going out to a person. Ukuphuma [root verb in “ndiphume”] means to go out, but here means to go to another location or place. “Ndisaya emntweni” means “I am going to a person”—this always means someone who can give you traditional herbs. . . . It is like a code, they say it like this so that it can only be understood by people who understand this thing.

[Note: It is customary to visit a traditional healer outside one’s own community, partly because of the suspicions described below]

KS: It seems as if there are people who like traditional herbs and people who disapprove of them. Is that why there is a code word for this?

XD: It’s a private thing you can’t tell people about. It means you have a problem you don’t want to tell people about.

KS: But you don’t do the same for going to the clinic or doctor—you can say it straight?

XD: No, you can speak clearly about that . . . [Traditional medicine is different because] you can think that you have a problem because someone else is using their herbs to do something to you. . . . So you are not telling people why you are going or where you are going. . . . PM is suspecting that someone [whom he knows] is causing his problems.

XD: Since you have made this decision not to use the clinic medicine, is there any day that you are going to share this decision with your father?

PM: No, I didn’t tell him.

XD: Why?

PM: No, we didn’t have chance.

XD: Is your father sometimes coming in your room?

PM: Yes.

XD: What does he say when he sees these traditional herbs?

PM: No, he doesn’t ask anything.

[. . .]

XD: When you go out, is your father still coming to close the door of your house, since he knows you have traditional herbs in your room?

PM: Yes, because he knows about these things, he is also using the traditional herbs.

KS: What is closing the door about?

XD: His door is a two-piece. If he forgets to close the door (top half) when he goes out, his father is closing it for him.

KS: What has that got to do with the traditional herbs?

XD: When you have traditional herbs, you don’t allow others to see—we have that belief that if someone’s shadow can pass over them, your traditional herbs can’t work. I want to understand their relationship in this situation.

KS: What does it tell you, that his father will close the door?

XD: It means he is taking care of him—even though when PM is sick he doesn’t think about his father.

[Note: “Think about” in translation means to consider or care about someone]

KS: Why did you choose that question?

XD: I feel like there is a lack of sharing between them because they were both using traditional herbs, but now his father says to us he doesn’t like the traditional herbs, he wants his son to use the injection. And other thing, father was saying sometimes PM comes to the main house to cook, sometimes not—that means there is conflict.

KS: I wonder if the father told us he supports the injections because he thought we support the hospital medicine?

XD: It’s possible.

This extract illustrates the level of additional interpretation required to make sense of what our participants said during our interviews. Mr. Dabula’s oblique way of asking PM about his relationship with his father demonstrates how questions are approached in this culture. Had we asked directly about conflict

between them, PM would likely have denied it since social harmony and respect for elders are paramount here. A literal translation of the text alone (i.e., lines in bold) would have completely missed the content of these conversations, but our discussion surfaced the unspoken content, creating additional data that could be analyzed qualitatively.

The analysis of participants' stories raised further questions about the cultural underpinnings of analytical approaches. Narratives have commonly been interpreted in the light of a shared cultural repertoire of themes and plotlines (Holley & Colyar, 2010), but without sharing the cultural and linguistic background of our participants, I couldn't apply this kind of interpretation and needed to be extremely wary of assumptions that might be culturally biased (Krog et al., 2009). An example arose with a story told us by a young man with epilepsy (TL):

I was called in from another house by my mother, while I was playing with two black birds. Then when I dropped one of the birds, I started fits and I was paralyzed. I had fits from nine in the morning till midnight. And my mother took me to a *sangoma* [traditional healer], who tried everything without success.

This story seemed bizarre to me, and I could have concluded that he was confused or intellectually impaired, which is common with poorly controlled epilepsy. As a clinician, I may have diagnosed him as such. To Mr. Dabula, however, this was perfectly intelligible: The black birds were familiar instruments of witchcraft, and a curse placed on them had been transferred to TL when he touched them, explaining the start of his epilepsy (Keikelame & Swartz, 2015).

Such examples highlighted the caution needed in interpreting stories across cultural bounds, and co-interpretation together with Mr. Dabula as a cultural "insider" was vital. The principles of reflexivity, transparency, and representivity proved a valuable guide through the many unknowns and unexpected conflicts of a research process committed to decolonizing its assumptions. One more principle emerged which went to the core of the research relationship, namely reciprocity.

Reciprocity and Researcher Roles

The primacy of relationships in the Xhosa culture has already been emphasized as well as the ways in which communitarianism influenced the research process. Reciprocity proved essential in conveying our relational commitment. The question of what we were going to give in return for people's time and information was a persistent one, whether spoken or otherwise. In accordance with ethical guidelines, participants were not paid, although we covered any transport costs and gave small gifts of groceries when data generation ended. But being perceived to have power and access to resources by virtue of my socioeconomic, professional, and racial identity, I was also expected to be able to do something about the many problems shared by participants. To them, seeking out the stories of these problems inferred a responsibility to act on them. Without sharing the cultural framework of Western academia,

participants had no reason to value research for its own sake, nor was the benefit of potentially influencing health care policy and practice (as I hoped it would) any recommendation. Participants also had no reference for the role of researcher as mere observer, and a "professional" self with confined relational responsibilities, distinct from a "personal" self, was alien.

Understanding these things, to refuse requests for help from our participants was morally and ethically unacceptable. We assisted in any way possible with their access to services: writing referral letters, sourcing support, and providing advice or information. We also sometimes accompanied people to seek health services, including driving them there (transport being a major local barrier) and assisting with obtaining the correct help. While the research might have benefitted from observing service processes without outside intervention, we deemed our first responsibility to be to our participants and chose instead to treat such experiences as incidents of participant observation.

While it was easy to assume that reciprocity demanded material or practical giving, especially in this poverty-stricken context, it was not necessarily the case. Even as participants felt themselves to be giving us something of value through their simple presence, I learnt that our intentional "being with" these households was valued in itself. To take time over greetings, to sit in companionable silence without pressing on to the business of research, and to return to visit after the research was over was to honor being together in true reciprocal exchange.

It also became clear that terminating these relationships once the research was complete would be inappropriate, demonstrating that we really had come only to take what we needed from the community. Since leaving therefore, we have attempted to maintain a presence in Kwabisi through Mr. Dabula, who visits periodically and relays news and greetings. Through the relationships built up over the series of research projects, he has become a source of information and advice regarding disability issues as well as our representative at community events.

Honoring the values and worldview of participants before those of the research meant reconsidering received notions of a researcher's responsibilities and role limitations and grappling with fundamental questions about the cultural framework and value system of academia itself. While reciprocity involved visible practices like those described above, it also became the core relational value on which all of our "ethicizing in uncertainty" was based.

Conclusion

The learning described here was far from being completed during this study and often seemed to deepen my uncertainty rather than diminish it. This may perhaps be an essential attitude for an "outsider" researcher (and health care worker) in cross-cultural settings: Feeling out of one's depth prompts questioning of received practices and greater reliance on partnerships which span the outsider-insider relationship. In ethicizing, the goal is perhaps not to reduce this uncertainty but for

researchers to develop the skills and relationships that allow them to practice reflexivity, transparency, representivity, and reciprocity in context.

This study was unusual within health systems research, in being based in the community rather than within health services. This allowed us insights into the PHC interface from the physical and social perspective of rural people with disabilities, situating their health experiences in the context of their daily lives and worldview. As a health care worker, I found this local knowledge transformed my understanding of our service users and our interactions with each other. What we learnt about communication and consent could be directly applied in my daily practice and shared with my colleagues, and a better comprehension of the depth, scope, and complexity of cross-cultural dynamics highlighted how central these are to the provision of health care. More PHC research is needed which starts outside the health system and seeks to understand health and health care engagement within their social, cultural, and relational context. This article has described some conceptual and practical approaches to the ethical challenges of such work, but more research is needed to apply them in other settings and especially among different cultural groups.

This study was, in both its topic and its execution, an exploration of the challenges and contradictions found at the interface between Western research and health care and indigenous African communities. In the project of decolonizing research methodologies and the academy, it is this interface that must be better understood and collectively renegotiated.

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