
9-1-2004

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Recommended APA Citation

Flicker, S. (2004). "Ask Me No Secrets, I'll Tell You No Lies:" What Happens When a Respondent's Story Makes No Sense. *The Qualitative Report*, 9(3), 528-537. Retrieved from <https://nsuworks.nova.edu/tqr/vol9/iss3/9>

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Abstract

In health research, we depend heavily on the goodwill of study participants. However, the whole social contract of health research is based on the premise that everyone comes to the research table with honorable intentions. What course should we take if we doubt the authenticity of our participants accounts? Through the use of an illustrative case study, this paper will explore three different ways of thinking about (and handling) implausible narratives.

Keywords

Reliability, Validity, Trustworthiness, Self-report, Lies, Qualitative, and Community-Based Participatory Research

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Acknowledgements

I want to express my gratitude to the entire Positive Youth Project team— especially the youth who shared themselves and their stories. Many thanks to Harvey Skinner and Jeffery Aguinaldo for their valuable feedback on earlier drafts of this manuscript. Funds for this research were made possible by a grant from The Ontario HIV Treatment Network.

“Ask Me No Secrets, I’ll Tell You No Lies”: What Happens When a Respondent’s Story Makes No Sense

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In health research, we depend heavily on the goodwill of study participants. However, the whole social contract of health research is based on the premise that everyone comes to the research table with honorable intentions. What course should we take if we doubt the authenticity of our participants’ accounts? Through the use of an illustrative case study, this paper will explore three different ways of thinking about (and handling) implausible narratives. Key Words: Reliability, Validity, Trustworthiness, Self-report, Lies, Qualitative, and Community-Based Participatory Research

Introduction

In health research, we depend heavily on the goodwill of study participants. As health researchers, we ask questions to better understand people’s experiences and their present state of health, illness, disease, and well-being (Nettleton, 1995). We depend on our research participants to answer our questions as honestly as possible. In turn, we attempt to treat their responses with confidentiality, care, and respect. We tell our respondents (and ourselves) that we will use the knowledge co-created in the interview interaction to better support, care for, and understand the problem(s) we are investigating. However, the whole social contract of health research is based on the premise that everyone comes to the research table with honorable intentions. What course should we take if we doubt the authenticity of our participants’ accounts?

In quantitative research, a number of measures are taken to minimize subjectivity and maximize the potential for uncovering “objective realities.” Much time and energy is spent on validating research instruments for consistency and reliability. Where possible, “objective” measurements (e.g., weight) and bio-markers (blood tests) are used to “validate” self-reports. Epidemiology, psychology and other health sciences that situate themselves in a positivist research tradition are very concerned about ensuring that data collected accurately represents reality. Quantitative and statistical methods texts go to great lengths describing how to do “reliability,” “validity,” and “consistency” checks using complex statistical methods. In addition, most quantitative research methods texts touch on approaches for dealing with “outliers” in large data sets.

By contrast, qualitative research methods texts rarely discuss or even mention what to do with data that makes little sense (Denzin & Lincoln, 2000; Miles & Huberman, 1984). While grounded theory scholars ask us to pay particular attention to

disconfirming findings, they do not go into detail about what to do if you question the authenticity of a participant's account (Charmaz, 2000; Glaser & Strauss, 1967; Strauss & Corbin, 1990). Things become even murkier in research projects where we are interested in participants' own perceptions of their experiences or feelings. Often "objective measurements" are unavailable and undesirable. Thus, qualitative health researchers, more often than not, are left in the position of trying intuitively to tease out the importance of truth in people's claims.

This paper discusses what happened when one young man volunteered for our study and told me a story about himself that was unlikely to be true. First, I will provide some background on the study and details about the case in question. Then, I will present three different ways of thinking about this narrative - offering the reader a chance to question his/her own assumptions about research. Finally, I will conclude with the implications of these different approaches for qualitative researchers and how we came to a resolution.

Background

The Positive Youth Project (PYP) is a collaborative initiative of eleven youth and health-serving organizations that seek to improve the health of youth living with HIV. We conducted a province-wide needs assessment to examine what can be done to help support this marginalized group. We adopted a Community-Based Participatory Research (CBPR) approach (Minkler & Wallerstein, 2003). CBPR is not so much a set of methods, as a set of underlying beliefs and principles about the ways in which research ought to be conducted (Wallerstein & Duran, 2003). It is a philosophy that privileges collaboration, participation and emancipatory social justice agendas over positivist notions of objectivity and the idea that science is apolitical (Hall, 1993). CBPR recognizes the limitations of "value-free" science and encourages critical, reflexive research.

CBPR projects bring together partners with diverse skills, knowledge, and expertise in order to enhance the relevance and usefulness of the data collected (Israel, Schulz, Parker, & Becker, 1998). CBPR is based on the premise that working with community members as co-researchers renders research more accessible, accountable, and relevant to real people's lives.

Furthermore, the very process of meaningful participation in CBPR can be transformative: through active engagement, individuals and communities may become more empowered and better equipped to make sustainable personal and social change (Maguire, 1987; Minkler & Wallerstein, 2003). By explicitly acknowledging the link between knowledge and power, CBPR projects attempt to disrupt traditional knowledge/power distributions (Mason & Boutilier, 1996). Through community-building and capacity enhancing exercises, those traditionally considered "research subjects" become the "active researchers" and are given the opportunity to set the research agenda. CBPR involves marginalized communities to examine the impacts of marginalization and attempts to reduce or eliminate it.

In keeping with the principles of CBPR, a stakeholder working group of youth and professionals met regularly to come up with the "right" questions to ask and the best ways to ask them. The group collaboratively developed the research instruments and protocol. It was decided that the best methodological approach for answering our

questions would be to conduct thirty key informant interviews with a cross-section of HIV-positive young people in Ontario. The protocol received ethical clearance by the human subjects ethical review committee at the University of Toronto. In order to recruit young people, feelers were put out to a wide network of youth and health organizations across the province. Youth workers, health professionals, and community workers were asked to help “spread the word.” They were provided with posters and information sheets about the project. Some approached youth directly; others simply put up posters in their reception areas. Youth approached the research office directly (either by phone or email). In order to ensure that they were eligible for participation, they were asked three questions:

- (1) How old are you?
- (2) Have you lived in Ontario the past three months? and
- (3) When were you diagnosed with HIV?

Youth between the ages of 12 and 24 who had lived in Ontario the past three months and reported a positive HIV diagnosis were considered eligible for participation. Youth were never asked for “confirming evidence” of their age or HIV status. Self-report was taken at face value.

Youth were assured that interviews would be anonymous and confidential. As such, they were encouraged to come up with a pseudonym for participation and were never asked for identification of any sort. All data collection happened through anonymous face-to-face interviews. Only those youth that were interested in receiving a report about the project findings provided contact information. Youth received a \$20 honorarium for participation.

During the interviews youth were asked to fill out a brief demographic survey and then to answer a series of “open-ended” questions. Youth were asked about four major areas of inquiry: their goals for the future, treatment and self-care issues, social support, and Internet use. Generally, interviews were audio-taped and transcribed verbatim. Two youth, however, objected to being audio-taped. In one case a youth opted to write out his own answers and in another, I took copious notes while interviewing. I personally conducted all the interviews.

Given the tremendous stigma around HIV and the particular vulnerability of young positives, it was imperative that we create a safe space for young people to participate anonymously. As such, we did not ask for any contact information and so were unable to follow-up with any youth after their interview. In order to ensure data quality, a modified “member checking” system was used. HIV-positive youth (peer community members) were an integral part of the research team and provided valuable in-depth readings of transcripts that were stripped of key identifying information. In order to optimize rigor, a team of four youth and three professionals collaboratively read and coded each transcript and participated in the analysis.

The results of the interviews are being used to guide program and policy recommendations for working with young people living with HIV in Ontario.

The Case

“James” is a 19-year-old street-involved Caucasian male. He saw a poster about the study at the shelter where he stays and contacted me because he wanted to participate. James arrived clean and well-groomed. He was alert, enthusiastic, and very open about himself and his story. A cheerful young man, James seemed happy to openly share his perspectives and experiences.

Over the course of the interview however, James told me a number of “facts” that made me doubt parts of his story. He said that he was born with HIV; transmission was perinatal. Also, James stated that he and his mother are both well, although neither has ever been on medications to control their HIV. Furthermore, neither has ever been seriously ill or hospitalized. He said they were both managing on their own and that as long as they maintained a “positive outlook” they would be fine. He also mentioned six younger brothers and sisters, all of whom were HIV-free.

In a qualitative interview, it is rare that a story comes out in a linear format. The facts that I have summarized “neatly” above came out interspersed over the course of our one hour conversation. Bits and pieces emerged as the conversation twisted and wound its way around. During the interview I tried to question James about his story. I probed around his experiences of illness. I asked him to clarify points on a number of occasions. I tried to balance being confrontational with maintaining a safe space for James to feel comfortable telling his story. I knew intuitively that something did not make sense. It was only after I listened to the tape again that I understood there was something amiss.

His story is highly unlikely for several reasons. First, mortality from HIV/AIDS and related conditions in the early 1980’s (pre-HAART era)¹ was much higher than it is today. A young woman who refused access to medical treatment for herself and her child was unlikely to survive 20 years. Furthermore, it is unlikely that a woman who was diagnosed with HIV and refusing medication would then go on to have six more children that would all be free of the virus. Finally, if in fact both James and his mother did live with HIV, it is virtually impossible that in the last 20 years neither of them would have run into serious health problems (and perhaps hospitalization) at some point for HIV/AIDS related complications.

Studies that have looked at the relationship between self-report and sero-status as measured by blood samples have found that individuals are more likely to report a false negative than a false positive (Strauss, Rindskopf, Deren, & Falkin, 2001). These studies have consistently found that a small minority (1-2%) of those reporting a positive HIV diagnosis do not actually test positive for HIV in the laboratory (Latkin & Vlahov, 1998; Lima, Freidman, & Bastos, 1994; Lindan, Avins, & WJ, 1994; McCusker, Stoddard, & McCarthy, 1992; Ross, Loxley, & Wodak, 1993). While these studies have documented a “discrepancy,” none have delved into the reasons why someone would self-report as being HIV positive when they were not. Nor do these studies show any major differences between those whose self-reports accurately represent their sero-status and those who do not.

¹ HAART stands for Highly Active Anti-Retroviral Therapies, new drugs that only became available in the early 1990s that significantly improved the health outcomes for those accessing the therapy.

The Cynic

My first reaction after considering the events of the interview was that there was an excellent chance that James made the whole thing up for the \$20 honorarium. As a young man who was street-involved, James experienced severe poverty and many social, structural, and psychological barriers to paid employment. There are few opportunities for young men to “earn” \$20 in the space of an hour with minimal effort. Thus, one interpretation of the account he presented in the interview is that it was entirely fabricated. James may have been a perfectly healthy and enterprising young man who saw an opportunity to make a quick buck.

If this were indeed the case, then the best approach might be to simply not include his responses in the analysis because he did not meet the basic inclusion/exclusion criteria.

The Skeptic

Another interpretation of the events that transpired might be that only some or a part of his story was fabricated. Perhaps the assurances of anonymity and confidentiality allowed him to overcome the stigma of identifying himself as a person living with HIV, but did not make him comfortable enough to discuss how (or when) he was infected with the virus. Perhaps discussing injection drug use and/or unprotected sex was considered too taboo. James might have been willing to disclose his HIV status, but unwilling to discuss his route of transmission.

If this were indeed the case, then the situation is more difficult. There is no clear-cut way to proceed. The very act of introducing one logistical inconsistency into his story makes the researcher cast doubt on the entire narrative. If James was willing to lie/fabricate/distort one aspect of his story, how are we to know whether there was any shred of “truth” at all?

Perhaps the best approach is to treat everything he says with a “grain of salt.” Rather than outright including/excluding him for analysis, the approach might be to look at whether his comments and insights are in line with what other people are saying/experiencing, or whether they are very different and need to be thought about.

The Seeker

Another way of thinking about the interview is asking whether it really matters if James indeed has HIV or how he got it. So long as he self-identifies, within this context he has a story to tell and therefore his accounts “count.” As someone who lives in a youth shelter that is populated with other young people living with HIV, and as a young person who engages in behaviours that put him at increased risk of transmission, perhaps his account as a person affected socially and emotionally (if not necessarily physically) is valid, important, and needs to be heard. His story may have important things to tell us, regardless of the absolute “truth” of his words. Taking this approach, one might include James’ narrative as an equally valid voice among many in the analysis.

Table 1

Three Approaches to Dealing with Uncertainty in Research

Approaches	James' Behaviour	What to do
The Cynic	He lied and can't be trusted	Exclude him for analysis
The Skeptic	He misrepresented some aspects of his story, but perhaps not others	Tentatively include him in analysis, but treat with a "grain of salt"
The Seeker	Does it matter whether he told the truth or lied?	Include him in analysis

Considering the Three Approaches

Underlying each of these three approaches to understanding and dealing with inconsistencies are different ontological and epistemological approaches to conducting research (Table 1). Ultimately, the researcher needs to ask: what is the primary purpose for doing this research and how does one understand 'truth' and the social contract of research? As Chamberlain argues, methods and methodological approaches ought to stem clearly from theoretical and epistemological choices (Chamberlain, 1999).

Constructivist and post-modern scholars argue that there is no singular universal truth (Lather, 1991). Instead they posit that qualitative researchers ought to be concerned with "describing, interpreting, and understanding the meanings which people attribute to their existence and their world" (Cutcliffe & McKenna, 1999). Nevertheless, questions of validity still come to the fore (Cresswell, 1998). Even those researchers steeped in interpretive traditions remain concerned about the *trustworthiness* and *authenticity* of their data (Lincoln & Guba, 1985).

Despite the importance of thinking about standards of data quality and verification, research methods texts tend to focus on how to ensure that data analysis happens in a stringent and ethical manner. Few deal with the problem of informants misrepresenting themselves. Berg suggests that "frauds, hoaxes, and forgeries" are not uncommon (Berg, 1989). Similarly, Van Maanen (1990) argues that there are three main reasons for informants to provide unclear stories: 1) wanting to mislead researchers, 2) lying about things they are shy about, and 3) being deluded because they may be misinformed. Gorden suggests that sometimes respondents can avoid appearing uncooperative by responding voluminously with irrelevancies or misinformation. This presents a challenge in the interview. Yet, these researchers offer little in the way of suggestions around data management.

By contrast, Taylor and Bogdan suggest that "the best way to deal with contradictions and internal inconsistencies is to raise the issue directly... what are suspected lies and deceptions often turn out to be misunderstandings or sincere changes in a person's perspective" (Taylor & Bogdan, 1984). Similarly, Lincoln and Guba (1985) suggest that prolonged engagement is essential to the enhancement of trustworthiness and credibility. However, if the inconsistencies only become clear after the fact, and the research that is conducted is done in such a way that it is impractical or impossible to try

and reconnect with an informant (as was this case in this particular study), we are left in a similar conundrum.

Aguinaldo argues that we need to shift from asking, “is this valid research?” and begin asking the question, “what is this research valid for?” (Aguinaldo, 2004). Ultimately, depending on how we imagine our role as researchers and the possibilities for our research findings, different approaches to managing data become apparent.

A Resolution

Given that this interview took place in the context of community-based participatory research project, the question of what to do with James’s story was brought back to the larger stakeholder group (of HIV positive youth and community-based organization representatives) that designed the study. The discussions lead to a lengthy debate about what it means to be the “arbitrator” of truth. Many on the team felt very strongly that we needed to include all the voices we heard, and that everybody lies sometimes and that it was OK. Others on the team were very disturbed by the inconsistencies and were eager to disregard the interview.

Ultimately, we decided to “compromise” and took the “skeptical” approach. We included James’ narrative in analyses but were very attentive to which “pieces of data” came from his interview. However, the whole experience gave us an important opportunity to check our underlying theoretical and epistemological choices. The chance to discuss, clarify, and re-evaluate the purpose of our approach to research was welcome and allowed for a deeper, richer, and more honest dialogue around analysis and interpretation of the data we collected.

Conclusion

Because of the stigma around HIV, our team had spent a great deal of time and energy brainstorming around how we could reduce barriers to participation for young people. The protocol was designed to make it as easy as possible for youth to participate. In our efforts to minimize intrusiveness and maximize privacy, we inadvertently left ourselves open to this complicated scenario. It never occurred to any of us that anyone would *want* to participate in a study about HIV if they were not in fact “positive” themselves. In retrospect, it seems difficult to imagine how we could have prevented this unlikely scenario. Given the nature of the study, and the invasiveness of HIV testing (e.g., drawing blood), relying on self-report made the most sense. While strict biomarkers (blood samples), may have resolved some of the issues (e.g., whether James in fact had HIV), it would not have necessarily helped us make sense of other inconsistencies (e.g., perinatal transmission). Furthermore, given our budgetary constraints and the challenges of recruitment, asking for biomarkers was simply unfeasible.

Alternative interviewing strategies might have helped. Interviews are a negotiation between two people (the researcher and the participant). The relationship that is formed in the interaction can have significant impacts on the types of stories that people tell (Fontana & Frey, 2000). Perhaps if I had been quicker to spot the inconsistencies in James’s story, I might have been more assertive about challenging him. Certainly, upon reviewing the transcripts, I am struck by how cautious I was to point out

these irregularities at the time. My discomfort with confrontation and emphasis on creating a safe and welcoming space for him to participate may have ultimately proved to be a poor strategy. In the future, I might be more assertive about surfacing my discomfort.

A third strategy for minimizing the likelihood of this happening might have been to ask all participants to provide some kind of follow-up contact information. While, it would certainly have helped in this case, I am quite certain that it would have made our recruitment job virtually impossible. As it was, youth that approached the research office were extremely hesitant about study participation. It was only through ensuring absolute confidentiality and anonymity that some of our participants agreed to participate. Given the transient nature of many of these young people's lives (more than half of those interviewed were street-involved), asking youth to come to in for a follow-up interview may also have proved an insurmountable barrier to participation.

Nevertheless, in the future, more attention needs to be paid up front to the possibilities of dishonesty. Had our team negotiated earlier what to do with stories that made little sense, we might have been able to imagine creative possibilities for addressing these concerns. Furthermore, I may have been more attentive to the possibilities "in the moment." Other researchers may want to take some time to reflect on the pros and cons of these (and other) strategies as they plan new and evolving research protocols.

This experience certainly challenged my understanding of the roles of researchers and participants. As a young researcher new to the field of HIV research, I was quite surprised to find myself in a situation where I doubted the narrative a respondent presented. I was extremely grateful that my first encounter with this kind of difficulty happened in the context of a community-based research project. As such, I did not have to face these difficult dilemmas alone. There was a team of active, engaged, and knowledgeable co-researchers who were there to challenge (and re-challenge) our collective assumptions. Ultimately, the process of collaborative consensus was extremely enriching. Having a diverse group of individuals from a wide variety of academic and life-experience backgrounds grapple with these difficult issues and contemplate the meaning(s) of "truth" in research only serves to enrich our process.

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I want to express my gratitude to the entire Positive Youth Project team – especially the youth who shared themselves and their stories. Many thanks to Harvey Skinner and Jeffery Aguinaldo for their valuable feedback on earlier drafts of this manuscript. Funds for this research were made possible by a grant from The Ontario HIV Treatment Network.

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Author's Citation

Flicker, S. (2004). "Ask me no secrets, I'll tell you no lies": What happens when a respondent's story makes no sense. *The Qualitative Report*, 9(3), 528-537. Retrieved [Insert date], from <http://www.nova.edu/ssss/QR/QR9-3/flicker.pdf>
