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# The Dark Side of Truth(s)

## Ethical Dilemmas in Researching the Personal

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This article explores the sometimes problematic issue of truth when conducting qualitative research on people's lives. Four ethical dilemmas are presented relating to the potentially harmful consequences of truth encountered by the authors in their own research: a promise to share the analysis of a patient's medical record containing unflattering comments by her physicians; the unintended sharing of a traumatic event, held secret since its occurrence, by a woman inmate; a disagreement with the Institutional Review Board over what constitutes ethical practice in online research; and an interview with a recently released political dissident in a totalitarian country. The authors advocate for multiple venues in which qualitative researchers can discuss ethical dilemmas such as these to learn from one another's experience and together develop a more reflexive practice.

**Keywords:** *truth in research; ethical dilemmas; reflexive practice*

As qualitative researchers, we choose to enter the lives of others—especially those in vulnerable situations and at pivotal points of time—with intentions of both giving voice to the depth and richness of individual experience and accomplishing socially relevant changes within the contexts examined. To fulfill these goals, we choose topics about which we feel passionately, seek triangulated methods, attempt to establish partnerships with those studied, and position ourselves openly in approaching the research scene and interpreting our observations and other materials collected. In engaging in this complex, rigorous process of inquiry, it is essential that we recognize that qualitative research is a deeply personal enterprise. In this article, we identify several complex ethical dilemmas that have arisen in our experiences of conducting research that probes the very personal, subjective truths of people's lives; in so doing, we expose our own frailties, concerns, and questions as interpretive researchers.

We enter into any research project with our selves, which is to say that we come to our work both with and in the fullness of our humanity. It is common to frame this positionality metaphorically, thinking of oneself, the researcher, as the instrument, a concept first put forward by Guba and Lincoln (1981) to highlight the multiple dimensionalities of the qualitative researcher, and it is a fundamental understanding in interpretivist research (Bogdan & Biklen, 2003; Merriam, 1998). To see ourselves as the research instrument suggests that it is our subjectivity that gives us access to the experience of those whom we study, but that is, of course, a limited metaphor. Our shared humanity is the ground on which we and our participants stand. It not only makes understanding possible between us, it is the basis of our relationship together, and it is that relationship that is the heart of the matter.

The practice of qualitative research, especially research on life history, social problems, and interpersonal relationships, is guided by important ethical principles and primary among these is our responsibility for our informants. These principles all stem from our bond with them, a relationship we initiate and for which we bear prime responsibility. Above all, we must do them no harm. Our intention and our hope, of course, is to do good. We choose to study what we think are important issues, things that matter to us and to others, and we want our work to make a difference in the lives of others and perhaps even to create social change in a particular arena. But our primary responsibility is always to our informants. We work hard to engage their informed consent to be part of our studies, and we're obligated to maintain an ongoing negotiation as the work unfolds. We are committed to give voice to their experience as fully and accurately as possible, and we make efforts to partner with them, in a meaningful way, in the construction of new understandings through our research. These are never easy goals to achieve, and ethical dilemmas often arise, dilemmas that often cannot be anticipated at the design stage. One we want to address in this article is the sometimes problematic perception of truth. We are not talking about epistemological issues here—our concern is not with the nature of truth itself. Simply put, we learn things through our inquiries, and there are times when what we learn can have consequences for our informants. Is the truth always beneficial? No. Can it also be harmful? Yes. Furthermore, multiple conceptions of truth or “right” may, at times, come into direct conflict. When these problems occur within one of our studies, what is the best course of action that will honor our profound commitment to the well-being of our informants? In such situations, we find ourselves confronted with an ethical dilemma, that is to say, a problem of conscience.

Quandaries of conscience are not unique to the research setting; at times, we face such situations in everyday life, and when we do, they cause us profound anguish. Consider a situation in which someone you love is seriously ill. You learn, perhaps by accident, that there is no hope—the condition is untreatable, and your loved one is facing death. She herself does not yet know this, and perhaps she isn't yet ready to receive and accept this news. But you know her time is limited. What is your obligation to her and to the truth in this case? Which is the more loving choice? Consider a less dire scenario but one that is no less painful emotionally. A member of your family has someone he loves dearly—a friend, a child, a partner, or spouse—and you learn that that person has done something that will put their relationship at risk. Though others know but have so far remained silent, this person will also be hurt once he does know. What are you to do? Which is the more loving choice here?

These are certainly not situations that arise every day—more normally, we can assume that it is best to know the truth—but when that is not clear, we are faced with a profound dilemma, one that is salient precisely because of our relationship with the other person. When this dilemma occurs within a research context, it is equally difficult and troubling, all the more so when the research is highly personal. When these ethical dilemmas are discussed in the methodological literature, the issues are framed in various ways. The meaning of “to do no harm” is anything but straightforward.<sup>1</sup> An issue that has generated significant discussion is the impact that what we write about them has on those we study (Brettell, 1993; Josselson, 1996; Lieblich, 1996; Mauthner, 2000; Plummer, 2001). Sometimes, this means not including material that might be harmful to the informant when read. Bar-On (1996) describes the case of a woman who implied that she was the victim of incest but who would not be more explicit when given the opportunity. Given her ambivalence, he chose not to include this information in his write-up, despite the fact that omitting it weakened his interpretation. What is written about informants is particularly salient when families or other bounded groups are studied. In her study of a kibbutz, Lieblich (1996) discovered that a major issue for some participants was how they were represented in other people's stories. Especially painful was the experience of one woman who, on reading her daughters' stories, saw herself portrayed as a neglectful mother because she had dedicated so much of her time to the leadership of the kibbutz when they were young. Mauthner (2000) experienced similar tensions in her study of sistering whenever one participant would disclose sensitive information about her sister, though that individual herself had not shared that information in her interview. To protect the sisters' relationships, Mauthner chose not

to use any material not given by the person involved, but this also made it difficult for her when she wrote up her findings to fully represent the power relations at work in these sibling relationships. Also at play in these studies is the problem of maintaining confidentiality. Mauthner devised various strategies to disguise the identities of her informants in her findings, but given the intimacy of their relationships, it's questionable how successful she could have been. Lieblich quickly realized that no disguise could work in her study because the members of the kibbutz had been together for so many years and therefore knew one another so well that they immediately recognized who was who in her account. Even her effort to protect the identity of the kibbutz itself was unsuccessful because it was historically significant and therefore quickly recognizable to the public.

Another example of the problematic nature of truth is when informants provide sensitive information that the researcher neither expects nor wants. Guillemin and Gillam (2004) provide a scenario in which a woman, participating in a study on the impact of heart disease, suddenly discloses that she's just learned about her husband's ongoing sexual abuse of their daughter. Josselson (1996) describes an equally painful moment when one of her informants, after reading Josselson's favorable portrayal of her in her book, tells her about something shameful she has done because she is uncomfortable with what she sees as a depiction of a false self. Kirsch (1999) argues that this level of personal disclosure is a function of the interview process itself: "Feeling the warmth, undivided attention, and sincere interest shown by skillful interviewers (something we rarely experience in daily life), participants can easily reveal intimate details about their lives which they may later regret having said" (p. 29). What remains unclear and deeply problematic, however, is exactly how the researcher should respond in these situations.

Another source of conflict around issues of truth centers around debates with Institutional Review Boards (IRBs) over what is ethical. There is a growing literature on this topic, and this journal has recently (2004) devoted two special issues [*10*(1) and *10*(2)] on conflicts between qualitative researchers and the IRB. Nelson (2004) argues that "IRBs, which operate without their own system of checks and balances, often without secure mechanisms of appeal, are equally subject to individual and group self-deception" (p. 209) and that this can create serious ethical problems for researchers. Oakes (2002) is one of many who advocate for the education of IRBs to address these injustices. Meanwhile, however, individual researchers are left to struggle with these issues at the local level.

Researching the personal always presents major challenges, and it is "a delicate kind of research," as Bar-On (1996) says, because "we hold the

meaning of people's lives in our hands" (p. 20). And as Josselson (1996) argues, "it is work we must do in anguish" (p. 70). The ethical struggles around what we are calling the dark side of truth(s), by which we mean its relativity and sometimes conflictual nature, is part of that anguish, but we believe it must be a shared struggle. We need to have discussions around these issues if we are to learn from them, so in this article we want to begin that process by describing four dilemmas that we have confronted. These are cases drawn from our respective research histories that illustrate a range of such problems. They include (a) a promise to share an analysis of a patient's medical record in which the practitioners' comments portrayed that individual in a very unflattering light; (b) a life history interview with an incarcerated woman who, because of the dynamics of a caring interview within the dehumanizing context of the prison, shared deeply personal information that had heretofore been secret; (c) an IRB mandate to prohibit investigators' self-identification during an online ethnography of a drug addiction chat room; and (d) a political dissident within a totalitarian country who wants his story told, but a telling of the tale, even with disguising identities of all involved, could place him at considerable risk. Although we will share how we made decisions about our ethical dilemmas, we continue to reflect on the problematic questions and feelings that persist long after these works have been completed and written as scholarly contributions. We'll describe each one and discuss how we dealt with it, along with what lingering questions remain. We'll conclude with some suggestions about how we as qualitative researchers could address such issues together.

### **When the Truth Hurts (BFS)**

Research investigators and participants, in this case a patient and her physicians, each have their own truth or construction of reality. This is to be expected. What is not so anticipated is for the doctors' "truth" to be potentially hurtful to the patient.

Our research team, consisting of scholars in health communication, literature, and medicine and a pediatrician was interested in comparing text and performance in the context of a clinical case (Sharf, Stanford, Montgomery, & Kahler, 2004). At the time we were designing the study, I had already seen an interesting videotape of a patient-doctor encounter in which a disagreement about the patient's treatment had taken place. This tape of an actual clinical encounter had been made for the purpose of training medical residents and students at a clinic affiliated with the medical school at which I worked as a faculty member. With the help of the behavioral science

coordinator who had supervised the taping, I contacted both the patient and the medical resident who had consulted with her to seek permission to use both the tape and the patient's chart for our study. At first, we intended to look only at the resident's chart entry for that day's visit, the 69th and final note in a thick patient record, but to our amazement and good fortune, the patient (as well as the clinic) granted us access to her entire chart, reflecting 6 years of consultations with more than a dozen physicians for an increasingly painful succession of joint pains that the patient had been experiencing. In exchange for the participants' consent to use these materials, we offered to share an initial draft of our analysis with each of them. This invitation not only was a gesture of gratitude but also stemmed from a sincere desire to incorporate the perceptions and reactions of those being studied within the analysis as full-fledged participants.

The taped interview that we had already seen showed the fourth-year resident, who was filling in for the patient's designated physician and had been expecting to do a routine prescription renewal for blood pressure medication, attempt to avoid the patient's insistence to change her arthritis medications. There ensued a lively debate about the intensity and contributing factors of this patient's joint problems. By the middle of this lengthy encounter, the patient had succeeded in forcing this physician into a more engaged posture that included active listening and an attempt at collaborative problem solving.

With that depiction in mind, we then delved into the substantial contents of this patient's chart, reading the entries of various physicians from diverse specialties who had assessed her; some had also tried to treat her. According to the patient's narrative in the videotape, all such treatment efforts had failed to resolve her symptoms, including intractable pain. Indeed, the written record revealed a depressing succession of varied diagnoses, medications, secondary problems (such as the high blood pressure) that were side effects of the medications, and referrals to more doctors. A consistent pattern throughout the 6 years is increasing pain and disability in terms of work functions. What was surprising to us were numerous implicitly unflattering comments about the patient herself. The moderately overweight woman was labeled as obese. Several entries hinted that perhaps the patients' reports were imaginary or that she was a malingerer:

The patient's symptom descriptions are strongly suggestive of carpal tunnel syndrome. However, electrical data tests are completely normal. . . . (The patient) seems to be in a significant amount of pain, at least subjectively.

. . . evaluation with a Minnesota Multiphasic Personality Inventory test might be helpful.

Still another physician wrote that if no “objective” evidence is found for her “damage,” they would refer her to “some type of clinic” to help her “adjust. . . .” A later note accused her of being noncompliant in taking her prescribed medications.

Our analysis concludes that in both the text and the face-to-face performance, there is a tendency among the physicians to try and “finalize” this case in terms of classifying it under a diagnostic category and treating the patient accordingly. When the treatments subsequently failed and the patient’s pain exacerbated, the language of the physicians vilified the patient, rather than her difficult-to-diagnose medical problem, as the troublesome agent. Although the patient had no participation in her medical record or knowledge of what had been written about her, she did have a voice in her encounter with the resident, which she used to strongly resist a clinical finalization that had in no way helped to relieve her pain.

Our ethical problem, then, was this: We had promised this patient, who had generously consented to let us use her medical record and the video of her visit with the resident in our study, that we would come back to her with the opportunity to see what we had written about her case. Having now seen the subtle and overtly negative remarks that her many physicians had written about her in her chart (several of which had been quoted in our analysis), we were very uneasy about making good on our pledge to share this information with her. Of course, it was possible that she may have been totally uninterested in seeing our work. For example, we did try a few times to reach the doctor, who never replied to the manuscript and letter we sent to him (by this time, he had relocated outside the country). Nonetheless, renegeing on our promise was a disturbing thought to us. In the end, we made our decision by consciously comparing the possible benefits (keeping our promise, offering the opportunity for the research participant to become a partner in the project, possibly empowering the patient by providing information that had been denied to her) with the possible harms (making her feel hurt and/or angry, impairing her trust in these or other physicians) of disclosing the physicians’ comments that hadn’t been intended for the patients’ eyes. We decided not to recontact this individual, and though we still felt a little guilty about the matter, on balance, we concluded that we had done the best thing having taken all the circumstances into consideration.

### **Seduced by the Caring Interview (MCC)**

For several years, I have had an interest in how women at the margins of society construct their understanding of themselves. Defining marginalization

is tricky because of its connotations of being less important or valuable, so I choose to define it as being beneath the public gaze. I began with a group of women who are not only beneath that gaze but totally outside it—those who are incarcerated. Prisons are a major industry here in Texas, and the women's units that are part of the state system are clustered in central Texas, so they were physically accessible to me. Once I gained access through the Texas Department of Criminal Justice and obtained IRB approval, two of my doctoral students and I began a year-long study of a group of 25 women inmates at one of those units. I had asked the teachers at that unit to recommend women who were reflective and articulate and who were already socialized to prison life. We had an initial meeting with the entire group to explain the purpose of the study—to work with them to develop an educational intervention that would foster personal development and self-understanding—and to ask them to participate. At that meeting, I explained the consent form, particularly stressing that their identities would be kept confidential, that their participation was totally voluntary, and that if they did agree to be part of the study, they could withdraw at any point. All the women agreed to participate. The study had two phases: individual life history interviews and then weekly meetings with the entire group.

The very first life history interview that I had scheduled turned out to be the most memorable—and the most problematic. Sabine was a quiet, reserved, African American woman in her mid-40s. As I was setting up the tape recorder, I thanked her for her willingness to be part of the study; she expressed surprise that anyone would be interested in her life, that it was all about hurt and pain. I assured her that her life experience was very valuable and that I was grateful that she was willing to share it with me. I have to say that I liked her immediately—there was a simplicity about her and a strong sense of authenticity that drew me in. The interview began slowly. She kept wanting me to ask her specific questions and was uncertain how to proceed when I told her I wanted her to tell me about her life any way she chose. Gradually, she warmed up, and the stories began to flow. Early on, she told me what her conviction was. It involved harm to a child, a crime that puts a prisoner at risk of harm from other inmates, so before she was incarcerated, she had been advised by the prison authorities not to talk about it openly and even to make up a different story about her conviction. She had taken that advice, so telling me the truth was a significant disclosure. Had she not been my first informant in this study, I think I would have realized more quickly how vulnerable she was making herself to me. In telling me the story, she also told me that she wasn't guilty of that charge, and I believed her. Liking her, believing her story and being genuinely interested



in her life created a situation in which she felt comfortable and safe with me, a stranger about whom she knew little and with whom she had so little in common. That sense of safety is a profoundly uncommon experience for any inmate, but at that point, I didn't know that. In a real sense, both of us were entering unknown territory. The trust between us grew, her stories became more personal, until suddenly she was telling me a story she had never told anyone else before. It was a story of personal violation, horrendous and devastating in its details. Afterward, she had fallen into a serious depression, had made a suicide attempt, and had been hospitalized at her mother's insistence. She liked the psychiatrist who treated her, but she refused to tell him what had happened, and she never told either of her parents or, later on, her husband. But she told me. I am certain that when she first walked into that room for this interview that she had no intention of telling me this story. I suspect she was in the middle of the telling before she knew what she was doing. I believe that she confided in me without thinking, that in a real sense, it was a result of finding herself being listened to by a stranger who was truly interested, who expressed care and concern, and who wasn't judging her. She was seduced by the caring interview, and I was the unwitting seducer. The interview had created an intimacy that led her to reveal more than she had ever intended. How could I have let this happen? What could I do with the information she had given me?

I admit that after the interview, I was stunned and unsure how to proceed. I had structured the life history section of the study as two interviews, a structure I thought would allow both the informant and the researcher the opportunity to reflect on what had been shared initially and to clarify or further elaborate key details. In Sabine's case, the second interview gave her the chance to pull back emotionally, and she did; she was more reserved, more cautious, somewhat less forthcoming. She didn't refer to that story again, and I didn't bring it up. But she also didn't withdraw that information from the study, and I realize now that she didn't understand that she could do that. I don't think she had the sophistication to recognize that all that she had shared with me were data and that she had ownership of it. I realize now that her consent, at that point in the study, was not fully informed. But given the intensely personal nature of the sharing in that first interview, I'm unsure how I should have handled it. I certainly couldn't have turned that story away—there was some value for her in telling it. But I could and should have told her, especially in the second interview, that I would not ever use that information. I have not and will not. But the issue remains about the intimacy created in this kind of interview situation that itself can elicit truths not intended to be shared.

## Disagreeing With the IRB (BFS)

What happens when the “truth” as constructed by the IRB clashes with the “truth” as perceived by the researcher(s)? As part of a federally funded grant project on treatment of people with opiate addictions, I collaborated with colleagues from a neighboring institution. Our research team sought to investigate how addicts themselves understand addiction, how addiction affects their everyday lives, ways in which they’ve tried to stop using, how they’ve experienced withdrawal, and how various treatments compare. The original research design called for focus groups, but the difficult logistics of recruiting and talking openly with addicts impelled us to go back to the drawing board. After a preliminary exploration, we determined we could find all the kinds of information we were looking for within the discourse generated in an online discussion group for opiate addicts. Not only would we be spared the expense and complexities of conducting focus groups with a sometimes less-than-reliable population, there was the added advantage of naturally occurring discourse among people with a common problem talking with one another, raising issues of their own accord. In addition, we noted that if there were questions we had that were not addressed in the online conversation, we could post those issues online ourselves.

As the qualitative methodologist on this team, the idea of using the listserv had been mine. It was modeled on a study I had conducted a decade earlier with the newly established breast cancer listserv (Sharf, 1997). In that prior research, I’d become sensitive to issues of doing Internet investigations with a vulnerable population, with the peculiarity of using a medium that feels relatively private to the participants within the discussion group, yet at the same time it is publicly available. Even though the objectives of the breast cancer listserv explicitly invite the participation of researchers, I’d learned that many members resented people who “harvested” their words for purposes they judged to be exploitive. Struggling with matters of consent, confidentiality, and using content out of its original context, I ended up writing a follow-up essay that became one of the pioneering works on the ethics of doing Internet ethnography (Sharf, 1999). Without claiming to have definitive answers to the dilemmas emerging from this new form of investigation, I used my experience to formulate a tentative set of guidelines. A few years later, the International Association of Internet Researchers published online a more comprehensive set of ethical guidelines (Ess & Association of Internet Researchers Working Committee, 2002). While explaining that there are varying legal and ethical regulations, depending on national, international, and cultural points of

origin, researchers are ethically obligated to take into account the type of online venue, and expectations of and risks to participants being studied. Resulting research design and decisions should be accountable on the basis of this ethical assessment. With these concepts and values in mind, our research team prepared to conduct our study.

Because the decision to do an analysis of online discourse was a change from the original protocol that stipulated the use of focus groups, we resubmitted an application to the collaborating institution's IRB. Despite the ambiguities of deciding what is the most correct way to proceed with Internet-based research, our stance was to assume rigorous yet feasible protection of the people we would be studying, as I had done previously with breast cancer survivors. Thus, our application stipulated that we would introduce ourselves as researchers and briefly explain our presence within this discussion group. At best, this may be a hit-or-miss endeavor because of membership changes in online interest groups, but it would be a genuine effort to negotiate the unstated privacy norms in a publicly available forum. We also stated that we planned to contact by e-mail individual posters whose words we intended to quote in our resulting analysis; in this way, we would be seeking and obtaining informed consent. Anticipating that this IRB might be unfamiliar with the issues of doing online research, we attached the above cited guidelines (Ess & Association of Internet Researchers Working Committee, 2002; Sharf, 1999) to our application. Feeling that we had done our best to honor protection of human subjects and the sensibility of agreed-on ethical standards in this relatively new and still emerging form of scholarship, our team was, therefore, shocked when the IRB refused to approve the application. Instead, it stipulated that our research design could be approved if we participated only in the form of lurking or silently reading and downloading the online interchanges, never revealing our presence and identities. This prohibition to be active participants, of course, prevented the possibility of interjecting questions to the discussion group. More problematic from my vantage point was the refusal of the IRB to let us try to seek informed consent. Its major concern appeared to be the protection of the institution and the privacy of the researchers rather than the people being studied; in other words, it was more important to the IRB to prevent the institution's name (and the names of some of its employees) appearing on an Internet site focused on drug addiction. The principal investigator talked with the IRB chair after receiving the IRB's response, but it became clear that there was no room for negotiation.

Because adhering to this condition was the only way we could proceed with the study promised to the granting agency, we resubmitted the IRB

application, promising to participate only as lurkers, never contacting posters or using the institution's name in this online context. Though we have taken care to protect the identity of any person whose posts we are quoting and feel relatively assured we are not putting any individual at risk for privacy violations, we also felt that our plans for ensuring moral rigor had been compromised by the IRB for reasons that hadn't been explained (though we could guess) and didn't seem defensible. Even after moving on with our work, the underlying ethical dilemma and this question remains: What recourse is available to an individual researcher or research team when their sense of ethics is at odds with the decisions of an IRB?

### Hearing Stifled Voices Behind the Iron Curtain (MCC)

Sometimes we were able to get our hands on smuggled tapes of music from the West and the one that spoke to me the most was the album *Evita*. My favorite song on that album was "Don't Cry for Me, Argentina." I imagine her on the balcony the night of the election, a huge crowd below; they are euphoric that Peron has won, but while the crowd voted for him, it is her that they love. I hear them chanting "Evita! Evita!" and she comes to them, arms opened wide, taking in their hearts, their hopes, their overwhelming love, taking them in and making them part of her:

Don't cry for me Argentina  
 The truth is I never left you  
 All through my wild days  
 My mad existence  
 I kept my promise  
 Don't keep your distance . . . I love you and hope you love me.

The young man seems lost in thought, transported to some other place, then he turns to me and says, "If only our leaders could understand. . . This is the bond that the people need with their government . . . love, not fear."

It was 1983. I was in the Soviet Union conducting research on the Sister City programs, particularly the grassroots partnerships that were born from a mutual desire to work for peace by fostering understanding between ordinary people of both countries. I was interviewing people involved in the program, trying to understand what impact it was having on their communities. My translator was a graduate student in modern languages. Olya was a bright young woman whom I liked a lot, and it was clear as the days passed that she was growing more comfortable with me. It was toward the end of the trip that she told me about her friend Mikhail. Two years before,

he and several other students were arrested for listening to Western music that had been smuggled in somehow by one of their professors. Someone informed on them (they never found out who), and they were denounced for their anti-Communist activity. The professor had been sent to prison for several years; the students were luckier—they were put in an asylum. Mikhail was out now, trying to put his life back together, and he was having a difficult time. Anyone convicted of a political crime had great difficulty getting work once they were released; few people were willing to risk being associated with ex-prisoners. Olya had told Mikhail about me, and he wanted to tell me his story—he wanted those in the West to know the truth of what was happening to dissidents in his country. Would I be willing to meet with him? I didn't think twice—of course I would meet with him.

When I think back on it now, I realize that my quick “yes” was driven by a number of things. Certainly, I was curious about the fate of political dissidents in the Soviet Union, and this was a totally unexpected and a priceless opportunity to learn what was happening. On an intellectual level, I saw a connection between this and my research interest in the narrative construction of identity, particularly the role agency plays in that construction. And then there was the personal level. I liked Olya and I was moved by her trust in me in this situation. She was putting herself at risk for her friend Mikhail, and I felt that I couldn't let her down.

Two days later, I met Mikhail and interviewed him for more than 2 hr. He talked about his early years, growing up in what we would consider a middle-class family. His father was a doctor and his mother a professor; both were members of the Communist Party, more out of necessity than belief. He read a lot as a child, and he did well in school. He also developed a deep love of music at an early age. Politics weren't often discussed at home, but when they were, it was done cautiously; he knew what ideas had to be kept private. He did well in school and went on to university. When he heard about the tapes of Western music that were circulating among some of the students, he didn't think about the risk; he thought only about how thrilling and exciting this music was. His favorite was the score to *Evita*. It moved him deeply and appealed to his political idealism. For Mikhail, this music represented the soul of the Soviet people and their need for a leader who was passionately devoted to them. When the group was discovered by the authorities and he and the other members sent to prison, he was shocked at first; he didn't see how what they had done threatened the State. Even now, after 2 years in the asylum, he remains idealistic and somewhat naïve. He views his period of incarceration as a senseless mistake, a sign that the Party simply didn't understand what it was doing. The years in the asylum were extremely difficult for

him, and he was finally released only after renouncing the activities he had engaged in and pledging his total loyalty to the State. But it was clear to me that he still didn't see a contradiction here. He wanted me to tell his story, not just so that people in the West would know what was happening to political dissidents but also to show the Soviet government that it was wrong to view these ideas as a threat.

The ethical dilemmas here are multiple. How can research on sensitive topics be conducted inside a totalitarian country? IRB protections are neither possible nor helpful in such a context; fundamental concerns such as confidentiality and protection from harm cannot be assured. Even the issue of negotiating consent is problematic. Mikhail sought me out, so consent was present at that level, but how informed was it? I don't believe he ever fully understood the risk he was taking in talking with me; the same naïveté that got him in such serious trouble to begin with was driving him now. By agreeing to hear his story, was I a partner in that rash decision? I also knew that he didn't have a realistic grasp of the benefits that might accrue from his story being told. This, too, was a function of his idealism, and I was at a loss to know how to explain how limited these benefits in any political sense would surely be.

Finally, there is the troubling question of what is to be done with this story. Given the risk to Mikhail (and to Olya), I cannot simply publish this story; even changing identifying details would not protect them, as my own movements on that trip were certainly known to the authorities. I could choose fiction, as I in fact have done here, creating a story of my own that holds enough but not too much (I hope) of the truth yet carrying sufficient moral purpose of the original to make it worth the telling. But that falls short, too. How can a cause that's masked be served? I don't have those answers. I remain unsure what to do, and this dilemma remains unresolved.

## Discussion

Plummer (2001) describes ethical debates in qualitative research as being a process marked by ambivalence, situated within actual experiences, and understood as a "struggling with the self" but a struggle that must be shared publicly because "we need stories and narratives of research ethics to help fashion our own research lives" (p. 229). It is our hope that we have done that here. Following Guillemin and Gillam (2004), we see our four cases as "ethically important moments" (p. 262) that call for a reflexive practice, and it is our aim to foster that.

Grappling with difficult moral dilemmas is an inherent part of life, including the sizeable portion of our scholarly careers devoted to research. That, of course, is why IRBs were created—to help us recognize and devise solutions to these problems that present unwarranted and/or hidden risks to study participants. However, the four cases discussed here show that it is not uncommon, during the process of investigating questions related to the telling of people's life story, for ethical quandaries to arise when research that has already been approved in concept runs into unforeseen circumstances as it is being conducted in the field, when the logistics of an on-site situation call for immediate decisions without opportunity for consultation, and even when the mandates of the IRB come into conflict with our own sensibilities and judgments. In three of our four examples, we, as individual investigators or members of a research team, have made an uneasy peace with our dilemmas so that we could proceed with our work. We've tried to come to resolution in ways that minimize the possibility of harm to our informants and to our own sense of conscience, though those resolutions are clearly imperfect. We hope that in presenting and publishing our work, the insights derived from interpretation and analysis of the personal data will do honor to the informants who contributed to the study, as a counterbalance to compromises that may have been made along the way. A satisfactory solution for the fourth case, in which the information provided could endanger the contributor if the source was identified by his totalitarian government, has not yet been found.

Though each situation is unique, there are transcendent, lingering questions that permeate ethical considerations in the qualitative research arena, especially in regard to eliciting personal narrative data. Among such questions are the following:

- For many nonacademic people, the concept of research is vague at best and may be visualized as people in white coats with test tubes and microscopes, an individual with a stack of books in a library, filling out a survey, or mathematical equations being worked on a blackboard or computer screen. How do we help participants to understand how the collection of narrative and discursive material constitutes research, and what it is we may do with the stories they share with us?
- What responsibilities do we, as qualitative researchers, have beyond the fulfillment of approved informed consent? How do we frame the consent process as an ongoing negotiation and do so in a way that doesn't impede the flow of the research process or put at risk the rapport between the researcher and the informant? What are boundaries in treating vulnerable self-disclosures as reportable data?<sup>2</sup>

- As the discourse generated on various Internet venues continues increasingly to be a ready and valuable source of research data, what are the ethics of lurking, and what, if any, are the responsibilities of researchers to make people who post aware that their words—even about deeply personal and heartfelt issues—are in the public domain and, therefore, are available to be studied?
- How best can we form partnerships with our informants, provide the opportunity to give them voice in our projects, and strive for egalitarian relationships? Must we be willing to take the same risks we ask of our informants? Is it in the best interests of the participants, ourselves, and our work to share our analyses? How should we view the interview process in terms of social exchange—to what degree are we obligated to reciprocate self-disclosures, and how do we maintain the balance that keeps our informant at the center of the conversation? How can we make the research experience mutually beneficial?

It's unlikely that the discomfort of dealing with the kinds of quandaries presented in this article will ever be entirely or easily settled, nor should they be. The uneasiness arising from certain aspects of relating to our informants and making unexpected decisions is a cue to be introspective and to give extra thought to exigencies and constraints, harms and benefits inherent in the research process. It should also be an impetus, after whatever has occurred, to record the specifics of the dilemma and a description of our decision-making process into some type of professional forum—conference, journal, listserv—in which other qualitative scholars can react, comment, and make suggestions about alternatives and informational resources. Within our publications, we should reflect the messiness of our methodological dilemmas and choices. Most important is that we strengthen ourselves as investigators who focus on pivotal personal experiences and struggles by learning from one another's difficult experiences.

## Notes

1. Although our focus here is on direct harm to the informants themselves, others have explored the issue of the harm research can do to groups within which the informants are positioned, such as the poor and other marginalized populations, when policy makers use research results to further disenfranchise these groups (see Fine, Weis, Weseen, & Wong, 2000, for an excellent discussion of these issues).

2. More than two decades ago, philosopher and medical ethicist Sissela Bok (1983) examined the sacred and profane implications of maintaining and breaching secrecy. She emphasized the context in which secrecy occurs and concluded that “[personal] secrecy must end when public peril begins” (Sennett, 1983, p. 3). However, we'd also argue that there are occasions when personal secrecy should begin or continue to avert public and personal peril. Bok wisely advises that the secret-bearer carefully examine his or her motives to assure that a



secret is not being upheld simply as a method of reinforcing one's power over others.

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