

Qualitative Health Research

<http://qhr.sagepub.com>

Heartful Autoethnography

Carolyn Ellis

Qual Health Res 1999; 9; 669

DOI: 10.1177/104973299129122153

The online version of this article can be found at:
<http://qhr.sagepub.com/cgi/content/abstract/9/5/669>

Published by:

 SAGE Publications

<http://www.sagepublications.com>

Additional services and information for *Qualitative Health Research* can be found at:

Email Alerts: <http://qhr.sagepub.com/cgi/alerts>

Subscriptions: <http://qhr.sagepub.com/subscriptions>

Reprints: <http://www.sagepub.com/journalsReprints.nav>

Permissions: <http://www.sagepub.com/journalsPermissions.nav>

Citations (this article cites 8 articles hosted on the SAGE Journals Online and HighWire Press platforms):
<http://qhr.sagepub.com/cgi/content/refs/9/5/669>

KEYNOTE ADDRESSES FROM THE FIRST ANNUAL ADVANCES IN QUALITATIVE METHODS CONFERENCE

Heartful Autoethnography

Carolyn Ellis

The author seeks to develop an ethnography that includes researchers' vulnerable selves, emotions, bodies, and spirits; produces evocative stories that create the effect of reality; celebrates concrete experience and intimate detail; examines how human experience is endowed with meaning; is concerned with moral, ethical, and political consequences; encourages compassion and empathy; helps us know how to live and cope; features multiple voices and repositions readers and "subjects" as coparticipants in dialogue; seeks a fusion between social science and literature in which, as Gregory Bateson says, "you are partly blown by the winds of reality and partly an artist creating a composite out of the inner and outer events"; and connects the practices of social science with the living of life. In short, her goal is to extend ethnography to include the heart, the autobiographical, and the artistic text. This article provides a conversation with a student researching breast cancer that introduces issues in heartful autoethnography.

Awoman in her mid-40s opens the door to my office and hesitates in the entryway. A large-brimmed, floppy straw hat covered with purple bangles hides her face. A matching scarf hangs loosely around her neck. "Professor Ellis?"

"Yes, that's me," I respond.

"My name is Sylvia Smith. I'm a Ph.D. student in psychology. I'm planning to do my dissertation on breast cancer, and your name was given to me as someone

AUTHOR'S NOTE: This article is an edited version of a portion of a longer chapter that will appear as "Autoethnography, Personal Narrative, Reflexivity: Researcher as Subject" in *The Handbook of Qualitative Research* (2nd ed.), edited by Norman Denzin and Yvonna Lincoln, to be published by Sage in 2000. I acknowledge Arthur P. Bochner, who is the coauthor of that chapter. I thank Norman Denzin and Yvonna Lincoln for permission to publish this shortened version in *Qualitative Health Research* and Janice Morse for her assistance in publishing this article. Arthur Bochner, Norman Denzin, Rosanna Hertz, Yvonna Lincoln, Laurel Richardson, and William Tierney commented on several drafts of this work. An earlier version of this article was presented as a keynote address at The International Advances in Qualitative Methods Conference held in Edmonton, Alberta, Canada, February 1999.



QUALITATIVE HEALTH RESEARCH, Vol. 9 No. 5, September 1999 669-683
© 1999 Sage Publications, Inc.

interested in illness. I'd like you to be on my dissertation committee. Three members of my committee are from the Psychology Department, and the fourth is a research oncologist."

"Hold it," I say, my hands extended in front of me to slow down her monologue. "Back up. Have a seat and let's talk about your project."

Sylvia removes her scarf and hat with a sweeping crisscross motion of both hands and continues speaking as rapidly as before. "I want to interview breast cancer survivors to understand how they're adjusting after cancer. I hope to combine qualitative and quantitative approaches. Send out a survey and then interview . . . oh, maybe 30 women and include African Americans and lesbians, older and young women, professional and working class. That way I can generalize. . ."

"How'd you get interested in this topic?" I interrupt.

"Well, uh," she begins, now slowing down and looking at me quizzically, "I've had breast cancer." Then, going back to her rapid fire, assertive style, "But I won't let that bias my research. You can count on that."

"Of course you will," I say. Sylvia immediately assumes a downcast, defeated posture before I add, "as you should."

"What do you mean?" she asks, looking straight at me with penetrating eyes. "I thought I had to keep my personal experience out of my research. If I want my study to be valid, I can't mention to my participants that I've had cancer, can I?"

"Hold that question for a minute," I say again and move my chair closer to hers. "Would you be willing to tell me a little about your breast cancer first? It'll help me understand more about your academic interest in the topic. Are you okay talking about your own experience?"

"Of course," she responds, "but nobody at the university has ever asked me about that before." She breathes deeply and slowly begins her story about the lump she discovered 7 years before, her mastectomy, and follow-up chemotherapy. Then, "And it's had a big impact on my family, especially my relationship with my daughter, and how I see myself . . .," she says, her voice trailing off.

"How has it impacted your relationship with your daughter?" I ask quietly.

"She has to worry about getting cancer as well now. You know, the genetic link, and we seem to have trouble talking openly about the risks and about our feelings."

Sylvia continues to talk about her daughter, and after a while, I ask, "And your self-image?"

"I could write a book about that," she says, shaking her head back and forth. "You know, I'm a therapist. I thought I could deal with it all. But it's hard to feel like a whole person. I don't mean because I lost a breast. Good riddance, I say to that. They were always too big anyway. I had breast reduction on the other one when I had reconstruction. It's just . . . well . . . my life has changed so drastically, except the day-to-day; actually that's not all that different."

She becomes animated as she tells her story. Sensing that she is comfortable and desires to keep going, I continue asking questions. Her story inspires thoughts about myself. How would I feel if I had a breast removed? As she talks, I glance at her small breasts then casually glide my hands across my own large ones. I can't imagine their not being there. Without them, I'd feel incomplete, desexualized. Did she really feel "good riddance" or is that a cover?

" . . . And the hair," I hear her say through my thoughts. "Just look at my fuzz. It never really grew back like before. Shaving it was the most difficult yet exhilarating

thing I've ever done." The thin, inch-long brown and gray strands don't move as she casually tosses her head from side to side. My fingers reach for my fine textured, shoulder-length brown hair—I'd feel naked without it. I wonder why she cuts hers so short now, as if she's drawing attention to having had cancer. But what about the hat and scarf? Does she use them in case she wants to "pass," I wonder?

Sylvia and I are about the same age. This could happen to me. No, it couldn't. I get an annual mammogram.

"... I'd had a mammogram just a few months before I found the lump," her voice intrudes into my thoughts.

But I do self-examinations every month, I argue back from inside my head.

"I found it during my monthly self-exam." Sylvia shakes the false predictability of my world. I listen intently, understanding that Sylvia has a lot to teach me.

"Anyway, I'm interested in other women's experience," she says, adding hesitantly, "you know, how it compares to mine. That's not something I've admitted before, the personal part, I mean."

I nod. What do I do now? I don't want to wean another student off the science model and deal with a science-oriented committee. And I'm weary of getting involved in another study that simplifies, categorizes, slices, and dices the illness process.

"Do you have any idea what I do?" I ask.

"Just that you study illness and do qualitative research. Nobody does qualitative in my department. But I've taken qualitative methods in education, and I think I could get my committee to accept grounded theory for my dissertation."

"I don't use grounded theory much anymore," I say. "Most of what I do is autoethnography."

"Autoethnography? What's that?" she asks, writing the word on her notepad as she looks at me.

"Well, I start with my personal life. I pay attention to my physical feelings, thoughts, and emotions. I use what I call systematic sociological introspection and emotional recall to try to understand an experience I've lived through. Then I write my experience as a story. By exploring a particular life, I hope to understand a way of life, as Reed-Danahay (1997) says."

"Who?" she asks, pen poised in the air.

"Reed-Danahay, an anthropologist who wrote a book on autoethnography."

"How do I get a copy?"

"Don't worry about that yet. There's plenty of time to read about autoethnography. I want you to *experience* it first."

I ignore Sylvia's confused look as I dig through my file cabinet. "So if I understand you correctly, the goal is to use your life experience to generalize to a larger group or culture," Sylvia speaks to my back.

"Yes, but that's not all. The goal is also to enter and document the moment-to-moment, concrete details of a life. That's an important way of knowing as well."

"So, you just write about your life?" Sylvia says casually. "That doesn't sound too difficult."

I turn around, stare at her for a moment as though I'll get a sign as to whether I should promote autoethnography to Sylvia. When no sign is forthcoming, I say, "Oh, it's amazingly difficult. It's certainly not something that most people can do well. Most social scientists don't write well enough to carry it off. Or they're not

sufficiently introspective about their feelings or motives or the contradictions they experience. Ironically, many aren't observant enough of the world around them. The self-questioning autoethnography demands is extremely difficult. So is confronting things about yourself that are less than flattering. Believe me, honest autoethnographic exploration generates a lot of fears and self-doubts—and emotional pain. Just when you think you can't stand the pain anymore, well that's when the real work has only begun. Then there's the vulnerability of revealing yourself, not being able to take back what you've written or having any control over how readers interpret it. It's hard not to feel your life is being critiqued as well as your work. It can be humiliating. And the ethical issues," I warn, "just wait until you're writing about family members and loved ones who are part of your story."

Sylvia holds on to her chair, her eyes wide. I smile and let out the breath I've been holding. "I'm sorry. I get really passionate about all this," I say more gently. "Of course, there are rewards, too: For example, you come to understand yourself in deeper ways. And with understanding yourself comes understanding others. Autoethnography provides an avenue for doing something meaningful for yourself and the world."

"Ah, here they are," I interrupt myself as I pull two stapled papers from my autoethnography file. "The one on top is 'Survivors,' a paper I wrote about my brother's death. The other one's a chapter from Butler and Rosenblum's (1991) book *Cancer in Two Voices*, a coconstructed narrative about a woman with breast cancer and her lesbian lover who takes care of her."

"Coconstructed?"

"We'll talk about that later. For now, just see how you respond to these stories. I think that after you've read them what I've been saying will be clearer. If you're still interested then, leave me a note and I'll mail you some other materials. Since you didn't take my courses, I will want you to read everything on my syllabi from the narrative, autoethnography, and emotions classes." I point to the syllabi on my desk. "These are minimum requirements if I'm going to be on your committee."

"Oh, my," she says. "I don't know if I'll have time. I have to take 'Tests and Measurement' and 'Advanced Experimental Research Design' this semester."

I shrug my shoulders as I stand and open the door. Sylvia winds her scarf around her neck, throws her hat along with the papers I've given her into her large open bag, says good-bye, and quickly scurries from view.

Two days later, I arrive at school and find a faxed message from Sylvia:

Dear Professor Ellis:

This is some of the most powerful writing I've ever read. I identified with your grief over losing your brother so suddenly. You reminded me of how I felt when I found out I had cancer. So did Butler and Rosenblum. This work violates everything I've been taught about social science research, but I'm fascinated and want to know more. Will you mail some articles to help me understand autoethnography? While you're at it, do you mind including a few more autoethnographies?

I smile and pull out several stories from my autoethnography file—Ronai (1992), Tillmann-Healy (1996), Kiesinger (1998), and Kolker (1996)—that ought to do it—and a section on defining autoethnography I have just written for a chapter with Arthur Bochner for Denzin and Lincoln's (in press) second edition of *The Handbook of Qualitative Research* (Ellis & Bochner, in press). I pause to read the first few sentences of the draft, titled "What Is Autoethnography?"

Autoethnography is an autobiographical genre of writing and research that displays multiple layers of consciousness. Back and forth autoethnographers gaze, first through an ethnographic wide angle lens, focusing outward on social and cultural aspects of their personal experience; then, they look inward, exposing a vulnerable self that is moved by and may move through, refract, and resist cultural interpretations (cf. Deck, 1990; Neumann, 1996; Reed-Danahay, 1997). As they zoom backward and forward, inward and outward, distinctions between the personal and cultural become blurred, sometimes beyond distinct recognition. Usually written in first-person voice, autoethnographic texts appear in a variety of forms—short stories, poetry, fiction, novels, photographic essays, personal essays, journals, fragmented and layered writing, and social science prose. In these texts, concrete action, dialogue, emotion, embodiment, spirituality, and self-consciousness are featured, appearing as relational and institutional stories impacted by history and social structure, which themselves are dialectically revealed through actions, feelings, thoughts, and language.

Smiling at the social science prose, I skim through the rest of the text and place the copy in the package with the stories I'm sending Sylvia.

A week later, Sylvia catches me in the hall. "Okay, I read everything you sent me. Wow, those personal narratives just blew me away. Your theoretical piece was interesting but pretty hard to get through. It'll be more helpful later, I'm sure," she reassures, then continues quickly, "but now I'm very confused."

"What confuses you?"

"Well, in my methods classes I was taught that I had to protect against my own biases interfering with my observations and that my research should produce general knowledge and theory. But the articles you gave me emphasize concrete expressions over abstraction. So, I'm confused about what my goals would be if I do an autoethnography. Why would anybody want to read my story? What rules do I follow anyway? I haven't been keeping notes or anything. Where would I start?"

"Answering your questions will take a while. Let's go get a cup of coffee," I announce, motioning for her to follow me.

"There are a number of ways to go about writing autoethnography," I say as we walk. "It really depends on where along the continuum of art and science you want to locate yourself. What claims do you want to make? If you want to claim you're following traditional rules of ethnographic method, then it would be best if you had kept notes on the experience as it happened. The notes would serve as field notes and you'd write from those."

"If you didn't have notes, how would you remember what actually happened?" Sylvia asks.

"Do you think the notes would tell you what actually happened? Aren't they partial interpretations as well?"

"Well, yes, but then how would I make sure that what I said was truthful?"

"The truth is that we can never capture experience. Narrative is always a story about the past, and that's really all field notes are: one selective story about what happened written from a particular point of view at a particular point in time for a particular purpose. But if representation is your goal, it's best to have as many sources and levels of story recorded at different times as possible. Even so, realize that every story is partial and situated."

I take four quarters from my pocket and insert them into the coffee machine. "I'm buying," I say. "Creme and sugar?"

"Oh, no. Let me pay," she insists, opening her purse.

"Next time. Okay?"

"Okay. Just black for me." We take our coffees outside and sit under a tree to enjoy the perfect Florida spring day. "Is there a way other than representation to think about personal narrative?" Sylvia asks.

"Well, yes, if you viewed your project as closer to art than science, then your goal would not be so much to portray the *facts* of what happened to you accurately but instead to convey the *meanings* you attached to the experience. You'd want to tell a story that readers could enter and feel a part of. You'd write in a way to evoke readers to feel and think about your life and their lives in relation to yours. You'd want them to experience the experience you're writing about—in your case, breast cancer."

"If these were your goals," I continue, "writing notes at the time the experience occurred would have been helpful but not absolutely necessary. If you're writing about an epiphany, which you usually are in this kind of research, you may be too caught up in living it to write about it."

"But then how do you remember all the dialogue and details later?"

"When I wrote *Final Negotiations* (Ellis, 1995a), about the chronic illness and death of my first husband, I didn't actually remember everything I wrote about, certainly not the exact words we spoke anyway. I had notes for much of what I described, but I still had to construct scenes and dialogue from the partial descriptions in my notes. And I hadn't kept immediate notes for everything I wrote about, though I constructed them later. But it's amazing what you can recall, and for how long, if the event was emotionally evocative. Another story I wrote, about race relations in a small town, was constructed without notes more than 25 years after the event occurred."

"But how can that be valid?"

"It depends on your definition of validity. I start from the position that language is not transparent, and there's no single standard of truth. To me, validity means that our work seeks verisimilitude; it evokes in readers a feeling that the experience described is lifelike, believable, and possible. You might also judge validity by whether it helps readers communicate with others different from themselves or offers a way to improve the lives of participants and readers or even your own."

Sylvia looks up from her note taking and grimaces, "What about reliability?"

"Since we always create our personal narrative from a situated location, trying to make our present, imagined future, and remembered past cohere, there's no such thing as orthodox reliability in autoethnographic research. However, we can do reliability checks. When other people are involved, you might take your work back to them and give them a chance to comment, add materials, change their minds, even offer their interpretations."

"Generalizability? Is that a concern?"

"Oh yes, though again not in the usual sense. Our lives are particular, but they also are typical and generalizable since we all participate in a limited number of cultures and institutions. We want to convey both in our stories. A story's generalizability is constantly being tested by readers as they ask if it speaks to them about their experience or about the lives of others they know. Likewise, does it tell them about unfamiliar people or lives and, as Stake (1994) queries, provide opportunities for the reader to have a vicarious experience of the things told?"

"That's sure different from what I've learned, but I think I understand. Still, I don't know where to start my own project."

"Why don't you start by writing a draft of your story. Think of it as making retrospective field notes on your life. Include every detail you can recall. I find it helpful to organize my writing chronologically first, using the main events to structure the tale. I try to write daily, rereading what I wrote the day before, then filling in new memories. Remember, you are creating this story; it is not there waiting to be found. Your final story will be crafted from these notes."

"But how will I know when I'm writing from my perspective then and when my current perspective is clouding my memory of what happened?"

"Well, you won't really. Memory doesn't work in a linear way, nor does life either, for that matter. Instead, thoughts and feelings circle around us; flash back, then forward; the topical is interwoven with the chronological; thoughts and feelings merge, drop from our grasp, then reappear in another context. In real life, we don't always know when we know something. Events in the past are always interpreted from our current position. Yet, that doesn't mean there's no value in trying to disentangle now from then, as long as you realize it's not a project you'll ever complete or 'get right'; instead, you strive, as Richardson (1994) says, to get it contoured and nuanced in a meaningful way."

"What do you mean? How do you do that?"

"I use a process of emotional recall in which I imagine being back in the scene emotionally and physically. If you can revisit the scene emotionally, then you remember other details. The advantage of writing close to the time of the event is that it doesn't take much effort to access lived emotions—they're often there whether you want them to be or not. The disadvantage is that being so involved in the scene emotionally means that it's difficult to get outside it to analyze from a cultural perspective. Yet, both of these processes, moving in and moving out, are necessary to produce an effective autoethnography. That's why it's good to write about an event while your feelings are still intense and then to go back to it when you're emotionally distant. I've had students who were great at getting inside emotional experience, but they had tunnel vision. They couldn't move around in the experience. They were unable to see it as it might appear to others. They had trouble analyzing their thoughts and feelings as socially constructed processes."

"But Dr. Ellis . . ."

"Call me Carolyn, ok?"

"Ah, Carolyn, I'm not really sure I'd want to feel all those emotions again. And some of the feelings I've had and still have about my cancer I wouldn't want to share. I'd feel so vulnerable."

"Well, that's your call. But if you're not willing to become a vulnerable observer, then maybe you ought to reconsider doing autoethnography. If you let yourself be vulnerable, then your readers are more likely to respond vulnerably, and that's what you want, vulnerable readers. I agree with Ruth Behar, who wrote in *The Vulnerable Observer* (1996), that social science 'that doesn't break your heart just isn't worth doing.' My goal is the same as Dorothy Allison's (1994)—'to take the reader by the throat, break her heart, and heal it again.' "

Sylvia stares at me a moment, as though she's trying to process what I'm saying. "So," she starts slowly, "suppose I am willing to be vulnerable. How do I get from field notes to writing in a way that opens up myself and readers to being vulnerable?"

"Do you ever read fiction?" When she nods, I continue, "Well, think about how a good novel makes you feel. It does make you feel, right?" She nods again, waiting for what I will say next. "What provokes these feelings?"

"Sometimes I identify with the characters. I feel for them. Or I think about being in the situations they're in, doing what they're doing, or imagine what I'd do in the same situation. And sometimes I stop reading to think about how my life is different or similar."

"Exactly. Good fiction writers make you feel the feelings of the characters, smell the smells, see the sights, hear the sounds, as though you were there. They do this with devices of fictional writing such as internal monologue, dialogue among the characters, dramatic recall, strong imagery, things like scene setting, character development, flashbacks, suspense, and action. You enter the reality of the novel through a dramatic plot line, which is developed through the particular actions of particular characters with particular bodies doing particular things."

"Then how is what you do different from writing fiction?"

"It's more similar than different. But, of course, writing and publishing conventions are different. You're a social scientist, so that probably will affect what you look at and how you see. And among social scientists, autoethnography often has more of an overt analytic purpose and an analytic frame. Remember how Carol Ronai (1992) in the piece I gave you layers analysis through her personal narrative. But in *Final Negotiations* (Ellis, 1995a), I emphasized that analysis can come through story and dialogue, too. Arthur Frank says in *The Wounded Storyteller* (1995) that it is important to think with a story, not just about a story. Thinking with a story means to allow yourself to resonate with the story, reflect on it, become a part of it."

"Aren't decisions social scientists make different from fiction writers?"

"Well, generally, autoethnographers limit themselves, unlike fiction writers, to what they remember actually happened. Or at least they don't tell something they know to be false. Well, even that's not so clear-cut. It depends."

"On what?"

"Well, say you want to protect the privacy of a character in your story. Then you might use composites or change some identifying information. Or you might collapse events to write a more engaging story, which might be more truthful in a narrative sense though not in a historical one."

When Sylvia looks at me questioningly, I say, "You know—the story evokes in readers the feeling that the tale is true. The story is coherent. It connects readers to writers and provides continuity in their lives."

When I see a look of recognition on Sylvia's face, I continue, "Even realist ethnographers, who claim to follow the rules for doing science, use devices such as composites or collapsing events to tell better stories and protect their participants. Yet, they worship 'accuracy' in description. They say, if it didn't happen, don't tell it. Don't put words in participants' mouths. But, of course, ethnographers do put words in participants' mouths all the time."

"Really? How can they get away with that?"

"By relying on memory, selecting and editing verbatim prose out of context, and then surrounding it with their own constructed analytic contexts. When it comes to analysis, most traditional ethnographers have no problems reaching beyond description for all kinds of interpretation."

"Give me an example."

“Oh, from limited time and access in the field, they create the ‘typical’ person or day, the ‘common’ event. And they use ambiguous descriptors like *most*, *some*, *frequent*, and *few*. And, of course, they reify concepts such as social structure and organizational climate. I did this too in my first study of two fishing villages. And let me tell you, when community members read what I wrote, well what I saw as typical was certainly not what they saw as typical. What I wrote told you more about how I organize my world than how they organized theirs” (Ellis, 1995b).

“So then it doesn’t really matter what you write?”

“Oh, it matters alright. Whatever you write has consequences. I still believe that you should try to construct the story as close to the experience as you can remember it, especially in the initial version. If you do, it will help you work through the meaning and purpose of the story. But others argue that what’s more important is the usefulness of the story. Of course, I agree that our stories should have therapeutic value.”

“Therapeutic value?” Sylvia stammers.

“Yes, I think of it as action research for the individual. Though therapy might not be the major objective in our research, it often is a useful result of good writing,” I respond.

“I thought therapy and research were separate entities. I mean, I’m a therapist, but I assumed I had to keep that role separate from my interviewer identity because if I acted as a therapist, it might bias the data. And wouldn’t it be unethical?”

“But you told me you hoped your research would provide understanding of what happened to you and help others who face similar circumstances cope. So what will you do if an interviewee breaks down or if you see a place where you could be of help?”

She looks at me, waiting for the answer, then murmurs, “I’m not sure.”

“What would you want someone in a similar situation to do for you if you were a research participant?”

“Well, I’d want them to care about me and try to understand where I was coming from,” she responds softly. “I’d want someone who listened, really listened. Someone I could cry in front of, actually who might cry with me. And who might tell me some of her story if she had been through a similar experience. Otherwise, I wouldn’t want to share my life stories with them.”

“And wouldn’t it be unethical for a researcher not to help or empathize with you if you were in need?”

“I’ve never thought of it that way before, but I know I’d want my subjects to feel that I care about them. And what good would my research be if it didn’t help others who are going through this experience, especially my subjects?”

“Participants,” I say quietly.

“Participants,” she repeats, her face turning red. “But isn’t it true that not everybody can do good therapy? I mean most academics aren’t trained therapists.”

“Being able to do therapy and being a trained therapist are not synonymous,” I respond, and Sylvia nods in agreement. “In fact, ethnographic training might be just as important for a therapist as therapeutic training. But you’re right, not everybody is comfortable or capable of dealing with emotionality. And those who aren’t probably shouldn’t be doing this kind of research in the first place, nor directing students who are.”

"Why don't you think about how this conversation provides clues for how you might want to do your own interviews," I suggest, "and let's pick up this topic next time we meet."

Two weeks later, Sylvia appears in my office. "Hi, I've written most of the story about my past now, and I waited until I was almost finished before I began reading other personal narratives of breast cancer. It's been very therapeutic," she says, "to write and to read. But I'm not sure I'm getting anywhere on my dissertation. I have so many questions."

"Like what?" I ask.

"How does my story add to what's already published? And how will my story fit with the interviews I want to do of other women?"

"Wait. Are you learning anything?"

"Oh, yes, at every turn."

"Tell me what you're learning."

"Well, that I have a lot in common with other women's breast cancer stories. For example, most women tell of their discovery of the lump—that's always a traumatic event—then the diagnosis and assessment of treatment options, then they describe waking up from the surgery, going through the follow-up treatment, and finally there's recovery and some kind of resolution at the end."

"Interesting; that's almost exactly how Couser (1997) summarized breast cancer narratives in his book on illness narratives," I respond, pleased with how much reading Sylvia has done.

"Most survivors describe making decisions about reconstructive surgery, shopping for a prosthesis—if they decide to wear one—their hair falling out, and seeking alternative treatment," she continues without skipping a beat. "And I wrote about these things as well, and . . ."

"And have you learned anything new from writing *your* story? Sorry, I didn't mean to cut you off, but I'm curious."

"Yes, that cancer is more than a medical story; it's a feeling story. I learned how scared I am even though I've been a survivor now for 7 years. And that's the interesting thing—there's little about long-term survivors in stories or in social science research. Most survivors tell their stories soon after recovery from treatment, and they're usually pretty optimistic about recovery and often claim to be better off at the end than the beginning."

"I felt that, too, the optimism I mean, immediately after my treatment was over, that is," Sylvia continues passionately. "But I don't feel that way now. I try so hard to pretend that I'm an upbeat, optimistic person with no worries, a warrior who has learned from her experiences. But what I had to face as I wrote my story is that I'm scared all the time that the cancer will come back. I've had carpal tunnel syndrome and it's probably from the chemo. And now I have sweats at night, and I don't know if it's early menopause—another gift of chemo—or signs of the cancer returning. I'm sorry, but cancer has not improved my life, and I can't make it into a gift. Holding in these feelings, all these years, has been difficult, and I think it's had negative effects on my psychological and physical well-being and on my family."

Sylvia begins to cry. I touch her shoulder and hand her a Kleenex. We sit silently for a while, sadness connecting us. "Do you still want to continue this project?" I ask gently. "Or is it too painful?"

"Oh, no, I *have* to continue it," she responds forcefully though her voice shakes. "What I'm experiencing is important to me. It was hard pretending; sometimes I

thought I was going crazy. Now I realize I don't have to pretend. There are other stories to live and write. Maybe through writing and talking with other women about their experiences, I can figure out another story to live, one that might help me cope better and not take so much out of me. Maybe I can write myself as a survivor in a deeper, more meaningful way. You know, I can't help wondering how other women feel years after their treatment. That's what I want to know: how it feels to them, how they cope, or don't. Whether the experience continues to be as fresh and scary to them as it still is to me. Maybe I can both contribute to knowledge and help others—and myself—write a story we can live with. How I'm living now, denying my feelings, well, this is no way to live."

"Okay, we're getting somewhere now," I say softly. "I think you have your topic. I imagine that other women share your sense of vulnerability and loss of control over their lives. I think I would," I add, involuntarily shivering as I imagine how difficult it would be to have cancer hanging over me in such an intrusive way. "Now, how do we find out how other long-term survivors experience cancer?"

"I'd like to do intensive interviews with survivors of more than 5 years," Sylvia responds energetically. "How many participants would I need? 25?"

"Oh no," I laugh. "If you're going to do intensive interviews, you'd need only a few, maybe 5 or 6, including yourself. You'll want to interview each woman a number of times to build trust in the relationship and also so they can read and respond to each transcript before you follow up with the next interview."

"How much will I participate?"

"Given that you share aspects of their experience, the interviews should be an interactive conversation, I would think. But you have to play that by ear. Rather than overlay method onto experience, you want to relate your approach to each woman's life and think about what would help her to tell her story. In some cases, participants will feel comfortable having a conversation, if you set it up that way. But as a society, we're so accustomed to the authoritative interview situation that some women still will expect you to be the authority and ask all the questions. Some might inquire about your story; others will be too glad for an opportunity to tell their own to pay attention to yours. They'll want you to be the researcher and therapist. Perhaps a few of the women will want to write their stories. Remind me next time to give you an article on interactive interviewing that I wrote with Christine Kiesinger and Lisa Tillmann-Healy (1997), in which we had conversations over dinner about eating disorders. I'll also give you one on coconstructed narratives I wrote with Art Bochner (1996), which describes a two-part process of individually writing stories that are then shared and coconstructed by several participants."

"I guess there's no interview schedule then?" Sylvia asks, but since she's smiling, I don't respond. "How will the chapters look and where will my story be?" she asks, this time seriously.

"The form will evolve during the research process. You might start the dissertation with a short personal story, to position yourself for the reader, or tell your longer story as a chapter. Or you might integrate parts of your experience into each participant's story, each of which could form separate chapters. Perhaps you will write each chapter in a unique form to reflect the different experiences you had in each interview or to reflect something about the character of each woman's story. For example, if a participant tells her story without much input or questioning from you, you might write in the thoughts you had as you listened to her and reflected on your life. If another interview is interactive, you might write dialogue to show the

process of discovery that occurred between you. You also could pick up your story after you tell theirs and show how interacting with your participants' has changed your story."

"Or," I continue hesitantly, "you could write the whole thing in the form of a novel, which takes readers on the research journey with you. Show readers what you ask the women, how they respond, what their answers make you think about, how your stories compare. In that case, you might end by showing how your story changed as you heard their stories and interacted with them. Using that approach, you'd let the readers be privy to how the women told their stories, the role you played, and what you learned in each interaction. But you'd have to be careful that your story didn't get in the way of theirs."

"Yes, and it would probably be hard to get my committee to buy a novel." When I nod in agreement, she asks, "What about analysis? Will I do grounded theory?"

"Well, your committee will demand an analytic chapter, you can bet on that. And I think you need one."

Without waiting for a response, I continue hesitantly, "You could do a straight grounded theory analysis. Then you'd divide chapters by concepts that emerge, or types, or some kind of category. Or each chapter might represent a stage in the illness process, similar to what David Karp (1996) did in his study of depression. If you choose grounded theory, you'd need to pay a lot of attention to coding your materials and comparing and analyzing your data along the way, and you'd write in an authoritative voice about the patterns you saw."

"But what would happen then to the women's stories? And my story?"

"Well, you'd use snippets from all the stories where they applied in each chapter."

Sylvia pauses for a moment, jots down some notes, and then says thoughtfully, "I don't think so. It seems to me that would take away from the evocative nature of the whole stories, which is the value of my study. And besides, the women deserve to tell their own stories, though I know I'll have a strong hand in how they get told in my dissertation . . ."

"I agree," I interrupt, relieved, "given the nature of your project and your goals. But just because we decide to do analysis doesn't mean we have to do it traditionally." Sylvia's eyes open wide. "What about inviting all your participants to read each others' stories and then meet together and tape record the discussion? This could serve as the basis for your analysis: You'd 'ground' the analysis in your participants' understandings, as well as your own. You might provide your own interpretations for them to respond to."

"Okay," Sylvia says, leaning forward, speaking passionately. "I really like this idea. I'll invite my participants over for dinner one night. It'll be my way of doing something for them. Before they come, I'll send them their story and the stories I wrote about the other women as well. Then . . ."

"As long as you get permission," I caution.

"Oh, yes, I know that's important." She pauses then suddenly blurts, "What if somebody wants me to leave out something?"

"Then you might omit it or ask your participant to help you rewrite it. Or you could fictionalize a detail in a way that camouflages the actual event but still

conveys the meaning you want to get across. Or use pseudonyms or composite characters, if that helps.”

“I’d also want them to listen and respond to my interpretations. But what if they disagree with my analysis?” she asks suddenly, frowning.

“That can happen, so you have to have some understanding up front about how you’ll handle that. Perhaps you’ll put alternative interpretations, yours and theirs, in the text. Or you could listen to their interpretations without giving them yours.”

To provide an example, I say, “Susan Chase (1996), a sociologist, chose not to give her analysis to participants to read before publication, though she asked for permission to use their words and gave them an opportunity to amend their narratives. She makes a distinction between what she wanted to communicate in her analysis—how culture shapes narrative process—and what her participants wanted to communicate in their narrations—their life experiences.”

“In any case,” I continue, “you’ll need to explain in your dissertation the kinds of decisions you made and on what grounds you made them. You owe that to readers.”

“It’s a hard balance,” I continue, suddenly reminded of readers, “giving readers the information they expect without betraying the trust of participants, I mean. As Ruth Josselson (1996) says, When we get to the writing stage, we tend to take ourselves out of relationship with our participants to form a relationship with readers. How can we help then but have feelings of betraying our participants?”

“Oh, and it gets even more complicated,” I say to Sylvia, whose hand covers her open mouth as she shakes her head in disbelief. “We haven’t even talked about your family members yet. They may become central characters in your very personal story. What happens if say your husband or daughter doesn’t want you to reveal things about them or your relationship to them?”

“Oh, my, I hadn’t even thought of that,” she says. “But I’d have to talk about my family in order to penetrate the depths of my experience. How could I ask my participants to do this if I couldn’t?”

“I’d say that this is the most important ethical problem in this kind of research. Because now we’re not just talking about faceless, nameless, unidentifiable subjects—if we ever were. Your intimates are identifiable individuals with names. Don’t they deserve the same consideration as your participants who have given you permission to write about them?”

“Well, of course.”

“Are there any situations in which the ‘greater good’ outweighs individuals’ rights to privacy? In which you have a right to tell your story even if other characters in it object?”

When I see the look of defeat on Sylvia’s face, I realize that I am transferring too many of my own concerns to her too quickly. “Hey, these issues don’t all have to be resolved today. I just wanted you to know that they will come up. We’ll discuss each one as it arises and try to make good, ethical decisions.” I pick up the book I was reading when Sylvia arrived to indicate our time is up.

“I think I’m ready for those syllabi now. You know, from the courses you’ve taught.” I smile and hand Sylvia the syllabi waiting on my desk. In turn, she hands me a folded piece of paper. “It’s a poem I wrote about losing my breast. I know it isn’t research, but . . .”

“Of course it’s research. Think about including it as part of your story. Have you read any of Laurel Richardson’s (1994) ethnographic poetry?”

I'm about to get started again when Sylvia says with a twinkle in her eye, "So will you be on my committee?"

"Only if you're still planning to do that survey," I say as she chuckles, and we wave good-bye.

REFERENCES

- Allison, D. (1994). *Skin: Talking about sex, class, and literature*. Ithaca, NY: Firebrand.
- Bateson, G. (1977). Afterward. In J. Brockman (Ed.), *About Bateson* (pp. 235-247). New York: Dutton.
- Behar, R. (1996). *The vulnerable observer: Anthropology that breaks your heart*. Boston: Press.
- Bochner, A. P. (1994). Perspectives on inquiry II: Theories and stories. In M. Knapp & G. R. Miller (Eds.), *Handbook of interpersonal communication* (2nd ed., pp. 21-41). Thousand Oaks, CA: Sage.
- Bochner, A. P. (1997). It's about time: Narrative and the divided self. *Qualitative Inquiry*, 3, 418-438.
- Bochner, A. P., & Ellis, C. (1992). Personal narrative as a social approach to interpersonal communication. *Communication Theory*, 2, 165-172.
- Butler, S., & Rosenblum, B. (1991). *Cancer in two voices*. San Francisco: Spinster.
- Chase, S. (1996). Personal vulnerability and interpretive authority in narrative research. In R. Josselson (Ed.), *Ethics and process in the narrative study of lives* (Vol. 4, pp. 45-59). Thousand Oaks, CA: Sage.
- Couser, G. T. (1997). *Recovering bodies: Illness, disability, and life writing*. Madison: University of Wisconsin Press.
- Deck, A. (1990). Autoethnography: Zora Neale Hurston, Noni Jabavu, and cross-disciplinary discourse. *Black American Literature Forum*, 24, 237-256.
- Denzin, N. (1992). The many faces of emotionality: Reading persona. In C. Ellis & M. Flaherty (Eds.), *Investigating subjectivity: Research on lived experience* (pp. 17-30). Newbury Park, CA: Sage.
- Denzin, N., & Lincoln, Y. (Eds.). (in press). *The handbook of qualitative research* (2nd ed.). Thousand Oaks, CA: Sage.
- Ellis, C. (1991). Sociological introspection and emotional experience. *Symbolic Interaction*, 14, 23-50.
- Ellis, C. (1993). There are survivors: Telling a story of sudden death. *The Sociological Quarterly*, 34, 711-730.
- Ellis, C. (1995a). *Final negotiations: A story of love, loss, and chronic illness*. Philadelphia: Temple University Press.
- Ellis, C. (1995b). Emotional and ethical quagmires in returning to the field. *Journal of Contemporary Ethnography*, 24, 68-98.
- Ellis, C. (1997). Evocative autoethnography: Writing emotionally about our lives. In W. Tierney & Y. Lincoln (Eds.), *Representation and the text: Re-framing the narrative voice* (pp. 116-139). Albany: State University of New York.
- Ellis, C., & Bochner, A. P. (Eds.). (1996). *Composing ethnography: Alternative forms of qualitative writing*. Walnut Creek, CA: AltaMira.
- Ellis, C., & Bochner, A. P. (in press). Autoethnography, personal narrative, reflexivity: Researcher as subject. In N. Denzin, & Y. Lincoln (Eds.), *The handbook of qualitative research* (2nd ed.). Thousand Oaks, CA: Sage.
- Ellis, C., Kiesinger, C., & Tillmann-Healy, L. (1997). Interactive interviewing: Talking about emotional experience. In R. Hertz (Ed.), *Reflexivity and voice* (pp. 119-149). Thousand Oaks, CA: Sage.
- Frank, A. (1995). *The wounded storyteller: Body, illness, and ethics*. Chicago: University of Chicago Press.
- Josselson, R. (1996). On writing other people's lives: Self-analytic reflections of a narrative researcher. In R. Josselson (Ed.), *Ethics and process in the narrative study of lives* (Vol. 4, pp. 60-71). Thousand Oaks, CA: Sage.
- Karp, D. (1996). *Speaking of sadness*. New York: Oxford.
- Kiesinger, C. (1998). From interviewing to story: Writing Abbie's life. *Qualitative Inquiry*, 4, 71-95.
- Kolker, A. (1996). Thrown overboard: The human costs of health care rationing. In C. Ellis & A. P. Bochner (Eds.), *Composing ethnography: Alternative forms of qualitative writing* (pp. 132-159). Walnut Creek, CA: AltaMira.
- Krieger, S. (1991). *Social science and the self: Personal essays on an art form*. New Brunswick, NJ: Rutgers University Press.
- Lather, P. (1993). Fertile obsession: Validity after poststructuralism. *The Sociological Quarterly*, 34, 673-693.

- Lorde, A. (1980). *The cancer journals*. Argyle, NY: Spinsters.
- Neumann, M. (1996). Collecting ourselves at the end of the century. In C. Ellis & A. Bochner (Eds.), *Ethnographic alternatives* (pp. 172-198). Walnut Creek, CA: AltaMira.
- Reed-Danahay, D. (1997). *Auto/ethnography: Rewriting the self and the social*. Oxford, UK: Berg.
- Richardson, L. (1994). Nine poems: Marriage and the family. *Journal of Contemporary Ethnography*, 23, 3-14.
- Richardson, L. (in press). Writing: A method of inquiry. In N. Denzin & Y. Lincoln (Eds.), *The handbook of qualitative research* (2nd ed.). Thousand Oaks, CA: Sage.
- Ronai, C. R. (1992). The reflexive self through narrative: A night in the life of an erotic dancer/researcher. In C. Ellis & M. Flaherty (Eds.), *Investigating subjectivity: Research on lived experience* (pp. 102-124). Newbury Park, CA: Sage.
- Stake, R. (1994). Case studies. In N. K. Denzin & Y. S. Lincoln (Eds.), *The handbook of qualitative research* (pp. 236-247). Thousand Oaks, CA: Sage.
- Tillmann-Healy, L. (1996). A secret life in a culture of thinness: Reflections on body, food, and bulimia. In C. Ellis & A. P. Bochner (Eds.), *Composing ethnography: Alternative forms of qualitative writing* (pp. 77-109). Walnut Creek, CA: AltaMira.

Carolyn Ellis is a professor of communication and sociology and codirector of the Institute for Interpretive Human Studies at the University of South Florida. She is the author of Final Negotiations: A Story of Love, Loss, and Chronic Illness and coeditor of Composing Ethnography, Investigating Subjectivity and the AltaMira Series on Ethnographic Alternatives. Her current research focuses on illness narratives, autoethnography, and emotional sociology.