The social science turn toward alternative forms of research representation is prompted in no small part by the reporting conventions of the academy. Usual publishing forms and outlets tend to thwart the desires that draw us to art: desires to have our senses activated, to be personally engaged, and to reach audiences beyond our academic peers (McIntyre, 2004; Richardson, 1992). Adrienne Rich (1978) describes poetry as a criticism of language, a vital sifting-through of the words we are using and that are using us, a process of rejecting and selecting and artfully forging text and images to create new relationships among words, among ideas, among people. What does this mean to us as researchers? What are the ethical consequences of criticizing familiar language, concentrating the power of words from qualitative studies, rendering them artistically, and sending them into the world?

In this chapter we explore questions of informed choice, harm, privacy, and anonymity salient to the artistic representation of research findings. We consider these questions in relation to three constituencies: the people who create the representation, audiences, and research participants. Although we rely on insights from friends and colleagues engaged in similar projects, we draw examples primarily from our

Ethics in Relation to the People Who Create the Representation

*Louisa May’s Story of Her Life* is a poem that Laurel Richardson fashioned from a transcript of a research interview in a project about unwed mothers. Over the course of innumerable revisions to the poem, says Richardson (1992), “Louisa May moved into my psychic interior in a way that no interviewee of mine ever had. She moved in the way poetry does. She’s not yet moved out” (p. 133). Louisa May’s “moving in” changed Richardson’s life. Richardson outlines how her self has been rearranged by the artful representation of qualitative research. Several of the consequences she describes resonate for us, including a sense of being better able to appreciate the situation of “the other.” This is an ethically relevant outcome for qualitative researchers.

Yet this “moving in,” this reorganization of the self that may emerge from arts-informed engagement with research findings, may have much more difficult implications.

It is our first creative meeting about the drama *Ladies in Waiting?* Ten cancer survivors, many of them long-time advocates in the cancer community, are explaining cancer survivorship to Vrenia Ivonofski, artistic director of Act II Studio. The women describe the worry that cancer will return, their powerlessness to prevent its return, and the difficulty of speaking openly about these lived realities. They offer examples of survivors who, years after a diagnosis, find themselves weeping or enraged for no apparent reason. Their words have a vaguely didactic quality. They have said this all before.

Two meetings later, the conversation is markedly different. The women speak a few words, then stop, or speak all in a rush. Certainty has given way. They are groping now, reaching for words and pulling back from them, struggling.

In response to Vrenia’s insistence that the experience of survivorship became available to her in a way she can internalize (a prerequisite, in her training, for its dramatic representation) someone has offered the word “dread.” We have focused on dread, attending slowly to it, testing its adequacy and its power. We have acted it: one woman crouching on the ground covering her ears, the rest circling around, rocking back and forth and keening, pressing in toward her.

The process is taking a toll. One woman describes nightmares in which she is trapped in a fiery maze. Another speaks of having participated in an 8-week therapeutic group dedicated to exploring survivorship; nothing about that experience generated the kind of feeling she is having now.

There is, it seems, something about the process of representing things artistically—of undoing the familiar language, of reaching for new words, of distilling the experience into an image, of embodying it—that is especially powerful, and especially disruptive.

Vulnerability in a creative process is linked to our relationship with the topic at hand. Some of the women who took part in the creation of *Handle With Care?* have had breast cancer. In focusing intently on the experience of advanced cancer and in working closely with Mary Sue and Jan (both of whom had it), these women engaged with their possible futures. This can happen in
other research settings—a series of focus groups held over time, for instance, or participatory research projects. Yet in our experience, the intense collective search for images and language that conveyed the experience of advanced disease called for something different, and something more than is required in most research endeavors. As actors, the women with breast cancer studied and performed a part. As understudies in a more symbolic (but, we would argue, linked) sense, they were asked to step into the role of “woman with metastatic disease” and to anticipate—in a particularly visceral, embodied way—the possibility that they will someday be required to live it. Anxiety and distress (recognized risks for participants in qualitative research; Richards & Schwartz, 2002) were virtually inevitable. In both of the dramas about breast cancer with which we have been involved, members of the script development team have had difficulties sleeping as a result of our work together.

A process leading to informed choice outlines risks and enables potential participants to assess and express their willingness or not to take them. We entered our first research-based drama projects with considerable naiveté (gall, say some); alerting others involved in the creative process to the risks ahead of time was out of the question. Working with an artist did not merely call for approaches or generate insights unanticipated at the outset, as is common in qualitative studies. We spent most of our time utterly baffled about what would happen next and what it would take from the group in emotional terms, and in terms of time and energy.

In subsequent research-based drama projects, we have described to potential participants the experiences we and our collaborators have had. We have acknowledged how intense the creative process was and talked about the surprising and profound ways it spoke to our experiences and worries about illness. Thus informed, everyone has the option of avoiding the project entirely. Among those who do take part, having made an informed choice does not foreclose distress; indeed, anyone paying any kind of attention suffers in some way. Our description of previous creative work does, perhaps, allow participants to gauge their levels of emotional involvement. Certainly our talk normalizes and contextualizes the suffering, which in our experience is no small thing.

Arts-informed processes offer unique ways to respond to distress when it emerges. Beyond the usual strategies (skipping a difficult interview question, treading lightly with probes, pausing the interview, etc.) we also had play and movement. Wrung out from a particularly intense discussion about family members’ responses to illness, we moved on to creating commercials and lists: an advertising the merits of a cancer diagnosis; a list of 10 things you “shouldn’t oughta” say to someone with cancer. When the drama became intense, we retreated to discussion; when the discussion became intense, we stood up and moved—opportunities paralleled in drama therapy (Mulkey, 2004).

It is true that all of the people involved in creating these artful representations struggled emotionally over the course of our work together and that these struggles matter in ethical terms. It is equally true that we laughed, often—that we delighted in the achievement of the dramas and became immensely fond of one another. After several months of traveling with Handle With Care? the ethical question had turned on its head: Where we had wondered about the ethics of proceeding with the work, we were now confronted with the ethics of ending it. Some of the people involved in creating the drama, perceiving its benefit to audiences and loyal to Mary Sue’s and Jan’s memories, felt it simply wrong to call a halt to the tour.
Ethics in Relation to Audiences

Linda Park-Fuller (2000) suggests that, insofar as audiences take the risk of witnessing artistic testimony, creators and performers of that testimony must make an effort to stand in with the audience, to anticipate their needs, concerns, and expectations. In taking up these responsibilities to "stand with" audiences, we find ourselves teetering between imperatives. We want both to recognize and to avoid exaggerating our power or the power of our art; likewise, we want both to recognize and to avoid overstating the vulnerability of people who witness our work. When people are tearful while witnessing an exhibit or reading a research-based short story, it is usually because the art has spoken to losses or yearnings in their lives. The losses and yearnings were there before they witnessed the representation, and we do not wish, with excessive warnings or interventions, to render the experience or expression of emotion problematic. We also do not want to stand between audiences and the representation. When we offer art rather than a traditionally constructed scholarly manuscript as our form of research publication, we deliberately invite audiences to craft their own meanings (Cole & McIntyre, 2004). To make the process consent-heavy up front (to ask potential audience members to sign a form that specifies exactly what they will encounter and anticipates their responses) or to imply a significant need for follow-up support is at odds with the context and purposes of the endeavor and risks foreclosing its possibilities.

That said, the artful presentation of research findings does invoke particular ethical challenges. As we have noted, art "moves in," rearranges our understandings of ourselves and the world, and goes home with us in ways that traditional social science representations rarely do. Arguably, then, artful research representations have a particular potential to do harm (Nisker, Martin, Bluhm, & Daar, 2006; Nisker & Daar, 2006). The subject of artful representations, like that of qualitative research generally, is often Hard Life Stuff. Artistic representations are commonly presented to people directly affected by the subject at hand. Such audiences are more fully in harm's way than are researchers' usual audiences. Venues are community settings that may be awkward to leave; the right to withdraw from participation may be difficult to exercise. Community settings may also carry expectations of what will (and will not) be seen and heard there. The intersection of art, audience, and venue is an ethically complex space.\(^3\)

In general terms, we encourage arts-informed researchers to anticipate ways that their representations may harm people witnessing them, especially people most affected by the subject matter. So, for instance, ethical principles around privacy suggest that our audiences may require protection from receiving unwanted information. In Handle With Care? although loathe to deny the medical realities of metastatic cancer, we realized that some women might hear the word "incurable" applied to their diagnoses for the first time. The potential of artful representations to either undermine or bolster hope is, we believe, a central ethical concern. A much crafted and agonized-over line was included in the introduction: "While metastatic disease is rarely curable, it can be treated, and many people in communities around the world are living with it today." The line attempts to speak the medical truths while also leaving space—space for hope—around those truths.

It makes sense that research-based art be promoted in ways that reflect principles of informed choice. Publicity material for Sarah's Daughters, for instance, notes that the drama is "about living with the fear of hereditary breast cancer," so that people can choose with awareness whether or not to attend. Promoting Handle With Care?
made clear that the drama spoke to the experiences of women with metastatic breast cancer, and defined metastatic. In this particular case, people who had seen the drama eventually became its ambassadors, and the responsibility we felt for ensuring people understood its focus diminished. Conversely, as *Ladies in Waiting* toured, we learned that some audience members were caught off guard by its representation of cancer survivorship. We responded by letting local organizers know what we were hearing, allowing them to act as gatekeepers as they saw fit. Over time, then, researchers may continue to assess the need for more (or less) information up front about the content of the representation, or additional or different strategies to convey it.

Art, some theorists contend, lends boundaries to what is difficult to witness and endure in “real life” (Gilman, 1988). That art is avowedly constructed, and that it is contained (on the page, on the stage, in the gallery), arguably minimizes risk: Audience members have their cathartic moments and leave safe in the knowledge that it was not real and need not spill into daily life. Yet in our experience the social agreements that distinguish reality from art do not always hold. Audience members have believed that all of the actors in our dramas are cancer survivors and that relationships portrayed on stage are actual relationships, despite information to the contrary. A man attending Mienczakowski’s drama *Syncing Out Loud* walked up on stage and confronted an actor as if she were a psychiatrist. We are not suggesting that anyone was harmed in these moments (see Mienczakowski & Morgan, 1998, for thoughtful reflection on this question), merely that we cannot assume an artistic form allows all audience members distance from the subject matter.

Expectations associated with the venue operate as well and merit attention in the informed choice process. The drama *Ladies in Waiting* was usually presented in the regular meeting spaces of local cancer support groups, where the physical and emotional chronicity of cancer is often obscured by efforts to fully support people newly diagnosed with the disease (Gray, Fitch, Davis, & Phillips, 1997). The distress some audience members experienced in watching the drama may have emerged in part from its challenge to the social conventions of the setting. Similarly, audiences for *Sarah’s Daughters*, arriving at a traditional theatre venue, do not expect to receive medical information and are likely not braced for it as they might be in a clinical setting.

Of course we cannot always anticipate what will happen when art is presented. Sometimes our worries were quite off base; occasionally an audience member was unsettled or angered by an aspect of the production we found quite benign. Opportunities for audiences to debrief or “talk back” to arts-based representations can be useful in this regard. Postperformance discussions, writing spaces, notebooks, and e-mail contacts allow researchers to understand how audiences are engaging with, and affected by, the representation. Again, however, such processes are not without their own challenges. Following *Sarah’s Daughters*, audience members’ disclosures of their genetic status have sparked yet more disclosures. In at least three cases, young women learned during postperformance discussion that their mothers carry a genetic mutation that considerably increased their risk of the disease—information likely unwanted in that setting.

It may be that artful representations “end run” people’s usual defenses, leading audiences to say things they might not usually, and may later regret. In this situation we chose to have a consistent team facilitating postperformance feedback, familiar with the dynamics that can emerge and able to judge the necessity of redirecting or commenting on the discussion; as well, specialized counseling resources were on hand (see also Chapter 51 in this volume).
Although we encourage researchers to understand and anticipate potential distress for audience members, we want to caution against any easy equation between distress and harm.

Our first community showing of the video *Ladies in Waiting*? *Life After Breast Cancer* has just ended. The facilitator welcomes a woman to speak from the audience. “Can we have a show of hands to see how many people found that depressing?” the woman asks. About half the audience raises their hands. “And how many found it uplifting?” Not a single hand. And then a woman speaks from the back of the room. “It was depressing,” she says. “It hit home.”

“It hit home” was a theme reflected many times over: The representation’s distressing effect was, it seemed, part and parcel of its resonance with audience members’ experiences. Distress was evoked, yet the association of distress with negative evaluations of the production, or a desire not to have seen it, was extremely rare. Some audience members spoke, in fact, of the merits of being upset. More commonly, viewers who acknowledged they had been upset by the production affirmed, unprompted, the production’s realistic portrayal of survivorship, and expressed interest in having family members see it (Sinding, Gray, Grassau, Damianakis, & Hampson, 2006). The benefit of the production was not separate from distress; indeed, it was in a certain sense embedded in it. We suspect this holds true for many artistic research representations. This does not mean, of course, that a representation’s resonance with audiences trumps harm to them: Rather, it means that we must distinguish between efforts to minimize and mitigate harm, and efforts to eliminate distress. The latter may be inimical to the integrity and effectiveness of many artful representations.

Worries about harm and undue distress are sometimes addressed more gracefully by art than science. One woman who saw *Handle With Care* remarked on the ways its choreography drew people into difficult emotions, then carried them away as the next scene transformed the tone and the players. “You got sad,” she said, “but you didn’t stay there.” Something of the same effect is achieved in Ardra Cole and Maura McIntyre’s (2004) installation about Alzheimer’s disease. At the edge of the exhibit area a life-sized image of an aging and ill woman is affixed to a mirror; as viewers move to stand directly in front of the woman’s image, we appear in the mirror. We are directly and dramatically implicated in the illness or in caregiving or both. And yet nearby is a fridge—daily, ordinary, filled with images of a mother and daughter over time, enjoying life and each other. We get sad, unsettled, distressed—but we don’t (only) stay there.

Ethics in Relation to Research Participants

Participants in qualitative research risk being identified (by themselves and others), and they risk being misrepresented (Richards & Schwartz, 2002); they also risk witnessing their lives and struggles analyzed and objectified (Larossa, Bennett, & Gelles, 1981). Each of these risks takes on particular texture when research is represented artistically.

In a photovoice project about mothers with learning difficulties (Booth & Booth, 2003, p. 435), a “serious problem” emerged that “should perhaps have been foreseen”: Participants, alert to the surveillance of statutory authorities, were unwilling to have their photos posted on a project-mandated supportive parenting Web site. The researchers responded by severing the link between image and identity, including only photos without people in them or without any identifiable link to the women. Some artistic representations partially sidestep the risk of
identification by creating composite characters, organizing representations by theme, situation, or plot rather than the narratives of individuals.

In other projects research participants have chosen visibility. The Web site Things That Matter (www.storiesthatmatter.com), created by Nancy Viva Davis Halifax, features creative nonfiction and photographs founded on stories told by people with colorectal cancer, and participants’ faces are recognizable in several images. One woman, for instance, had searched for a photograph of a person with a stoma before her own surgery, “not a photograph that isolated a piece of the body, but that showed a whole being” (Halifax, Gray, & Jadad, 2004, p. 765). Unable to find one—and determined that others not be so alone—she chose to post on the Web site images of her daily life alongside a photo in which she is emptying her colostomy bag over the toilet. She did not, however, wished to be named.

The woman’s representational decisions emerged over several conversations—conversations to which Halifax brought her own lived understanding of the consequences of public exposure. Images of Halifax, her mastectomy, and illness narrative appear in the book My Breasts, My Choice: Journeys Through Surgery (Brown, Aslin, & Carey, 2003). She knows the sense of surprise—and vulnerability and delight—that comes with seeing herself in public spaces. One of the consequences of her visibility is her daughter’s pride; another, her daughter’s increased sense of risk for cancer. Halifax makes these experiences, in all their ambiguity and complexity, available to research participants considering the implications of “going public.”

Salient to the risk of misrepresentation is the intent to produce a research product that has aesthetic merit and audience appeal. Johnny Saldaña (1998) worried that his case study about a young man’s dreams of becoming an actor lacked sufficient crises and conflicts to maintain a suitable flow of tension: “As a playwright, my anxiety motivated me to include lengthy ‘monologues’ sparingly, and to interweave the participants’ voices frequently for variety” (p. 186). These choices are not misrepresentations, but Saldaña usefully alerts us to the ways misrepresentation—in the sense of overemphasizing “the juicy stuff”—may happen.

As Saldaña’s (1998) account also makes clear, however, research participants themselves (like any of us) may be less concerned about being misrepresented than about being represented unfavorably. How research reports are experienced by the communities they portray is a question little examined, in part because academics so often speak only to one another. When research results are presented as art, and public access to the work is both enabled and deliberately arranged, our recontextualizations of research participants’ stories and lives become audible, visible, felt by them, in visceral and potentially lasting ways. To the extent that we have objectified them, they will know this objectification and experience it in public. Working all of our own dramas, we have, in Denzin’s (1997) terms, “improvised on” research transcripts (see also Gray & Sinding, 2002). We can imagine the possibility that the creative transformation of participants’ stories becomes about improvising—about the artistic experimentation, with participants’ narratives mere props.

As with much in the world of artful research representation, the lines are fuzzy, the territory largely unmapped. In the most general way, we suggest, representations must respect the sensibilities of the people represented. This does not mean that we advocate for “feel-good” images devoid of edge or critique. However, we do encourage researchers to enable the people and communities represented to engage with the art before it goes public. Endorsing such a process implies not that each suggestion
or demand be taken up but rather that persistent concerns or critiques have a platform: either as changes to the representation or as a counternarrative presented alongside the researcher’s work. In this way, researchers’ representations are required (and have the opportunity) to “listen . . . very carefully for the counsel of [their] kin” (Gingrich-Philbrook cited in Park-Fuller, 2000, p. 33).

♦ Notes

1. Handle With Care? and Ladies in Waiting? emerged out of a collaboration with Act II Studio, a theatre school for adults over age 50 at Ryerson University in Toronto, Ontario. Interview transcripts and articles written from them (Gray, Fitch, et al., 1998; Gray, Greenberg, et al., 1998) inspired and grounded the dramas. Under the leadership of Artistic Director Verna Ivonoffs, cancer survivors, members of the research team, and amateur actors participated in a series of half-day meetings to explore themes in the transcripts, drawing on personal experiences and engaging in a series of improvisation exercises. Working from the images and dialogue generated in this process and the transcripts, Ivonoffs wrote the dramas (Ivonoffs, 2002; Ivonoffs & Gray, 1998).

2. The Dora Award–winning actor Liza Balkan will perform J. Nisker’s play Sarah’s Daughters, exploring the fears of a young woman whose mother and grandmother died at a young age of breast cancer, “who lives with the knowledge it will happen to her.” Sarah’s Daughters surfaces the ethical issues inherent to breast cancer (BRCA) gene testing, indeed all genetic testing, and begins the conversation toward compassionate appreciation of genetic risk and sensitive understanding of the consequences of genetic testing.

3. Handle With Care? was banned from the keynote space at a conference because the organizer felt it would be hard to watch, and because she perceived the audience as captive.

4. Alongside the knowledge about public exposure that researchers bring to such conversations, participants’ knowledge about the possible implications of visibility in their own life contexts is essential. Risks and benefits (and the balance between them) may also change over time, and unexpected consequences may emerge. Sustained conversation—an ongoing process of choice, rather than a one-time event—is required. At the same time, representations at some point slip into the public sphere; participants must be aware of the limits of the researcher’s control over images and text, and thus the limits of our capacities to respect a wish to withdraw consent late in the life of the project. Any person’s choice to “go public” has, as well, consequences for others in her or his life; Sarah’s Daughters, dealing as it does with an inheritable genetic mutation, makes this point especially clear and speaks to the value of ethics frameworks organized around communities and social networks rather than only individuals (Hoeyer, Dahlager, & Lynoe, 2005).

5. See Church (2002) for a compelling account of the tensions between celebrating, and bringing a critical analysis to, her mother’s life and work.

♦ References


Richards, H. M., & Schwartz, L. J. (2002). Ethics of qualitative research: Are there special issues for health services research? Family Practice, 19, 135–139.

