Applied Communication in Organizational and International Contexts
Contributions of Autobiographical Performances by Breast Cancer Survivors to Narrative Medicine

Within medical schools, the field of narrative medicine has developed as a valuable humanistic approach to educating medical students and practitioners to be more empathetic and compassionate caregivers. Conversely, survivors of illnesses and those with chronic diseases are increasingly publishing and performing their illness narratives. In performance studies, autobiographical performances dealing with disease have also grown in number and visibility. This paper begins with an overview of narrative medicine and then reviews the major findings of scholars who have studied the burgeoning field of illness narratives in general and breast cancer narratives in particular. Against this background, the paper analyzes the published scripts of two autobiographical shows by breast cancer survivors and draws on interviews with the authors to probe their varying motives and techniques, as well as their evaluations of the impact of the shows on different audiences and themselves. The paper assesses the potential contributions of autobiographical performances to narrative medicine.

Narrative Medicine

Illness narratives told by patients serve a critical role in the field of narrative medicine, which began in the early 1980s. A. Scott Pearson, a professor in Surgical Oncology at Vanderbilt, defines narrative medicine as “a patient-centered approach to the practice of medicine that rescues the patients’ stories and integrates what is important to them into decisions about their health care” (Colmenares 2004). Beginning “in such related efforts as patient-centered care and medical humanities,” “narrative medicine takes those skills that one develops as a close reader or a reflective writer and bends them toward effective clinical practice,” writes Rita Charon, from Columbia University, where narrative medicine had its start through the connections between the

Arthur Frank, author of *The Wounded Storyteller*, sheds light on the burgeoning genre of illness narratives through his concept of “the remission society,” which he defines as a postmodern and post-colonial experience (Frank 1995, 4-13). In contrast to earlier times before the great advances in biomedical tests and interventions of the latter half of the 20th century, many more people live much longer with illnesses such as cancer. In remission, but never to be fully cured, people with chronic illnesses often find them to be life changing and give voice to their new identities through writing autobiographical memoirs, or illness narratives. Contemporary illness narratives reclaim the patients’ bodies from the medical gaze and from modern medicine’s scientific, biomedical approach. As such, they are like post-colonial narratives “in their construction of self,” argues Frank (10).

Frank identifies three dominant types of illness narratives: restitution stories, chaos stories, and quest stories. He argues that the restitution narrative dominates the stories of most people and follows the basic story line, “Yesterday I was healthy, today I’m sick, but tomorrow I’ll be healthy again” (Frank 1995, 77). The restitution story, says Frank, “is the culturally preferred narrative” and functions to forestall the “intimation of mortality” brought by sickness (83-84). Unlike the upbeat tone of restitution stories, chaos stories “are sucked into the undertow of illness and the disasters that attend it,” says Frank (115). In contrast, “Quest stories meet suffering head on; they accept illness
and seek to use it,” he continues (115). Frank argues that “most published illness stories are quest stories” and follow Joseph Campbell’s three stages of the hero’s journey articulated in *The Hero With a Thousand Faces*: departure, initiation, and return. Providing the ill “their most distinctive voice” (115), quest stories fall into three types: memoir, manifesto, and automythology. While the memoir combines illness narratives with other events in a writer’s life, and the manifesto often carries demands for social action and change, the automythology “fashions the author as one who has not only survived, but has been reborn.” According to Frank, the Phoenix is “the predominant metaphor” in automythologies, “reinventing itself from the ashes of the fire of its own body” (119-122). Automythologies tend to emphasize individual change, rather than social action, argues Frank, and are typified by Oliver Sacks’ *A Leg to Stand On* and Norman Cousins, *Anatomy of an Illness* (123-126).

Other common organizing myths and metaphors in illness narratives include the journey, battle, and healthy-mindedness, according to Anne Hunsaker Hawkins (1993, 28). The latter metaphor, healthy-mindedness, is a term coined by William James in his *Varieties of Religious Experience*. James observed “in such movements as faith healing and Christian Science,” “an attitude characterized by the sense that nature is inherently and absolutely good, the relegation of evil and sin to the status of illusory constructs, a belief in the ‘conquering efficacy’ of the positive emotions, and a relentless optimism—a stance that he contrasted to that of the ‘sick soul’” (Hawkins 1993,127). Hawkins argues that today, the healthy-mindedness mythos has three basic, interrelated aspects: “a positive attitude, the body’s capacity to heal itself, and ‘active’ patienthood” (1993, 128-129).

**Breast Cancer Narratives**

Breast cancer narratives comprise a large subset of illness narratives, due to the growth in the numbers suffering from the disease from one in 20 to one in eight over a 25-year period. According to Couser, “breast cancer kills more women aged forty to forty-nine than any other cause.” Breast cancer narratives as an autobiographical or
autopathographical subgenre developed in the 1970s and 1980s, "when various forces—especially the women's movement—transformed breast cancer from a private, even shameful ordeal into a publicly narratable personal crisis." Celebrities such as Gloria Steinem, Betty Ford, and Nancy Reagan, acknowledged having breast cancer and "at least two dozen book-length narratives have been published since the mid-1970s." Couser says that it is significant that most breast cancer narratives are autobiographical (1997, 36-39).

Couser identifies six characteristics of the breast cancer narratives genre. First, most are written by survivors, and although some of them later die from the cancer, the narratives tend to have a comic master plot that ends "with recovery of some tentative assurance of health and vitality. Thus, they are also restitution narratives. Second, they are often published "about five years after initial diagnosis," a "milestone of survival." Third, because one must be always on the lookout for recurrences, "the retrospective closed-end autobiographical narrative is always somehow false to the experience." Fourth, common plot elements include "discovery by the author of a suspicious lump in her breast; diagnosis of cancer; the assessment of treatment options; some form of surgical treatment, lumpectomy or mastectomy; some form of adjuvant treatment—radiation, chemotherapy, hormone therapy, or a combination of these; recovery and resolution in the form of favorable reports and restoration of (relative) peace of mind." Fifth, some of the recurring topics and motifs of those with mastectomies include "whether to undergo reconstructive surgery, wear a prosthesis, or neither. Shopping for a prosthesis and/or a wig to hide chemotherapy-induced baldness is a common scene." Simply through the act of publishing their stories, Couser argues that the autobiographers he studied "chose not to try to pass as 'full-bodied'." Another common theme is the seeking of "alternative supplemental therapies" and evaluating their worth. Sixth, writers change autopathography into autobiography through the processes of integrating the illness into "distinctive ongoing life narratives" and enriching the genre by defying, complicating, or refining its conventions (Couser 1997, 39-44).
Analysis of Two Performances on Surviving Breast Cancer

To what extent do Linda Park-Fuller's show, "A Clean Breast of It" and Mercilee Jenkins' show, "Menopause & Desire Or 452 Positions On Love" confirm or challenge the insights of the critics of illness narratives? Both works have been published. Park-Fuller's performance was composed first, in 1993; Jenkins' was composed in 2002. Both performers had mastectomies. Both works were composed by scholars in performance-studies who are about the same age and are members of the Performance Studies Division of the National Communication Association. Further, both know each other and attend many of the same conferences. Both were inspired to compose their illness narratives after attending a conference in 1993 at Arizona State University on HIV Education and the Performance of Personal Narratives. Neither were influenced by other breast cancer narratives, but Park-Fuller says that seeing Bernie Downs' performance about his false positive diagnosis with HIV, "An Unsolicited Gift," at the HIV conference was "so affecting" that "she felt like she should do something" (Park-Fuller 2006). That fall she received an invitation to perform at the Petit Jean Performance Festival in Arkansas, so she decided to compose a performance of her own breast cancer story" (Park-Fuller 2003, 216). Both performers had read Dr. Bernie Siegle's book, *Love, Medicine, and Miracles*, which contains short vignettes by patients. Jenkins, however, hated the book, while Park-Fuller said that "it was very important to her at the time of diagnosis" because she "had no experience with positive endings with cancer" (Park-Fuller 2006). A rhetorical analysis of the two works, enriched by data from interviews with the authors follows.

"A Clean Breast of It"

Park-Fuller's script, which runs around 55 minutes in performance, reflects the three impulses that shaped its formation: "an educational impulse, a sociopolitical impulse, and a performative impulse." She composed it to intervene against "the silence surrounding the disease," "the dominant medical discourse that privileges abstract knowledge over individual stories about cancer," and "the power of the disease
(or of cultural mythologies about the disease) to desubjectify my experiential identity—to force me into a passive life-role of “cancer victim.” She says that “the piece functions performatively to recompose my subjective identity and to influence society” (Park-Fuller 2003, 215).

Her show opens with a dedication to “all those who have struggled with breast cancer—those who have survived and those who have not (Park-Fuller 2003, 222). This dedication serves two functions: “First, it provides an opportunity to establish a stage relationship with the audience that is not as formal as a ‘fourth wall’ theatrical aesthetic but not as informal as a discussion . . . . Second, the dedication allows me to offer a disclaimer . . . . I make it a point to indicate that my story is not meant to ‘stand in’ for stories of other cancer survivor” (218).

Told in the form of a conversation with the audience in which Linda relates her discovery and subsequent treatment for breast cancer, Park-Fuller structures the script around six direct questions to the audience, identified by the word “Question” and followed by the word “Answer,” which enable her to educate about breast cancer, its impact on relationships, and critique its treatment. These questions range from the statistical, such as the number diagnosed (185,000) and the number who die (44,000) yearly in the U.S., to the relational (How do you make love to a woman with one breast? With no breasts?), to the political (“Why is it that in Canada and other countries sixty tablets of the cancer drug, tamoxifen, sell for $12.80, whereas in the United States, those same sixty tablets of the same tamoxifen drug sell for $156.42?”) (223-234). She adds the rhetorical question “Is anybody paying attention?” following two of these questions to confront the audience with not only society’s responsibility to take action, but their own. A number of other asides to the audience and rhetorical questions allow her to reflect on her own experiences and critique the sociocultural forces affecting the disease and its treatment.

Park-Fuller performs excerpts of the song “It’ll Come to Me” near the start of the show, in the middle, and at the end, “for aesthetic purposes.” She says that the lyrics “function rhythmically to break up the narrative; . . . establish and reinforce the theme of improvisation; and their repetition provides unity to the piece.” She also quotes from a
poem called “Faith” by Patrick Overton. She says that the poem “en-
capsulates the theme and provides a new form to balance those of sto-
ry, song, and public address” (Park-Fuller 2003, 218).

Attempting to transcend and critique her own personal experience
as a survivor, Park-Fuller introduces contingency into the show
through an electronic timer set to go off every thirteen minutes, “sym-
bolizing the death rate of breast cancer in the United States.” She sees
three purposes in using the timer. First, “it sharpens our comprehen-
sion of how many people die from disease and how little progress has
been made against it.” Second, “aesthetically, it symbolizes the the-
mes of life’s interruptions and improvisation, since I, as performer,
cannot predict exactly when the timer will go off. Like the cancer that
occurred so unexpectedly forcing me to stop, reevaluate and revise my
life, so the sounding of the timer forces me to stop and revise my per-
formance.” And third, “ethically, the timer evokes awareness of oth-
ers whose stories do not end as fortunately as mine” and helps her “to transcend the ‘merely personal’ in personal narrative—to stand with,
not to stand in for, others’ stories” (Park-Fuller 2003, 218-219).

“Menopause & Desire or 452 Positions on Love”

While Park-Fuller’s script is focused on her breast cancer story,
Jenkins’ script focuses on menopause and desire, with only four of the
10 poems comprising it dealing with breast cancer: “What to Do
When You Find Out You Have Breast Cancer,” “Show Us Your Tits,”
“The Dyke March 2002-2003,” and “Cleaning the Refrigerator.” But
since the show ends with Jenkins pulling off her shirt to reveal her
breasts before the final black out, Jenkins’ breast cancer narrative be-
comes the most memorable story in the script.

When I asked whether her recovery from her breast cancer made her
feel responsible for sharing her story with others, Jenkins said, “Yes.
I think that you want to share what you learn.” Diagnosed in 1992,
when she was in her early forties, she felt like she was the first one on
her block; she only knew one other person who had it. Jenkins wanted
people at work to know what was going on so they wouldn’t whisper
behind her back, so at a faculty meeting, when people were asked to

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say whether they would consider being department head, she explained why she couldn’t do it. Jenkins said that it made her feel better to talk to others about her condition. She did not write about her disease for five years, and then for the gay church that invited her to perform during Breast Cancer Awareness Month. Her piece, “What To Do If You Find Out You Have Breast Cancer,” became “What to Do When You Find Out You Have Breast Cancer,” because the word change reflects the high numbers of women who get the disease. She didn’t have reconstruction until five years after she had the surgery (Jenkins 2006).

Jenkins delivers her first breast cancer narrative in the show, “What to Do When You Find out You Have Breast Cancer,” “as if I am making an impassioned speech to the audience, looking at individual audience members in different locations around the theatre every time I offer instructions on what you should do.” The first stanza advocates calling friends for help, as well as expressing anger and blame:

Call all your friends and ask them to help you.
Get mad as hell and rage at the medical industrial establishment
for not taking better care of you.
Blame the government for not taking better care of all women
and this planet (Jenkins 2005, 263).

The second stanza focuses on the causes of cancer and links it to social/environmental causes such as above-ground nuclear testing and polluted air and water, as well as personal causes such as “I worked too hard for the money I needed to live / and my heart has been broken because too many of my friends / have died of AIDS.” She says:

“And no, breast cancer doesn’t run in my family
but it’s running like crazy through the family of woman.
Thirty years ago it was 1 in 20,
now its 1 in 8.
But we’re told there’s no cause for concern” (Jenkins 2005, 263).

In the fourth stanza, she seems to reject the “healthy-mindedness” approach by advocating throwing the book Love, Medicine and Miracles across the room “because you don’t want to hear about / how you
are responsible for your own healing” (263-264). Yet in stanza five, she advocates doing “whatever you need to do / to make yourself feel whole again,” including walks on beaches, dancing, pruning the garden, and having “sacred ceremonies by moonlight with witchy friends,” and renting “a lot of old movies and cry as much as you can.” In stanza nine she says “don’t be afraid to pray . . .” (264).

Since she did not have to undergo chemotherapy herself, Jenkins incorporates a friend’s story into her autobiographical account, saying:

When your doctor surprises you with the news
that now you are going to have chemotherapy,
go home
and ask your partner to cut off all your hair
because you’re going to lose it anyway” (Jenkins 2006; Jenkins 2005, 264).

The last stanza advocates telling oneself that “you love yourself” so that “it will take you to / the next person you’re going to be: wiser, more beautiful, capable of kicking ass and taking prisoners.” Here, Jenkins redefines “cancer survivor” as “a whole woman inside out.” She is “a self-made woman” who blesses her own body and honors those who have died

because that’s what eventually happens to one out of three of us. So you tell that person
that it’s about so much more than surviving.
It’s about defining yourself by new rules
even if you don’t know
how it’s all going to end” (Jenkins 2005, 265).

“Show Us Your Tits,” the second breast cancer poem, reenacts the author’s walk with a friend down Bourbon Street, in New Orleans, where people chant to women, “Show Us Your Tits.” Juxtaposed to this scene, the author reflects on her own decisions about whether to have reconstructive surgery after her mastectomy. She recounts her coming of age and first growth of her breasts, her struggle with bras, and the phases she went through after her mastectomy. These phases included a “political phase,” in which she:

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“firmly believe[s] that no breast cancer survivor should have reconstructive surgery. / We should proudly display our lopsided chests so that the world won’t forget how many of us there are.”

She also considers getting a tattoo along her scar like Deena Metzger, and once she decides “I want my boobs back,” goes to “be fitted for a bra and prosthesis /or fake boob, as I like to call it.” Not satisfied “with this bra stuffer for long,” she tries “a stick-on boob” and tells a funny story of being on a date in a bar, wearing a tank top, when she notices that the boob “is no longer attached to my chest / and instead is gently resting on my arm” (Jenkins 2005, 265-270).

Jenkins discusses in detail the three surgical choices available in reconstructive surgery and her search for a female surgeon who will understand her “need to leave the other breast intact.” After her three reconstructive operations, she says “I now have a new left breast which I like very much / although it’s not quite the same as the old one.” In the next to the last stanza, she realizes that this might be her last chance to “Show us your tits” on Bourbon Street, and asks, “has any woman with a mastectomy been so brave / as to show her scar, her tattoo, a rebuilt boob? Would jewelry or despair rain down on me?” She says, “maybe tomorrow, I think as we saunter down the street / arm in arm. Maybe tomorrow this sinner won’t be saved / and I’ll do it.” The last stanza ends describing her making love to her partner, who says her breasts “are just right / a champagne glass full” (Jenkins 2005, 271-272).

While “Show Us Your Tits” certainly builds suspense in the audience and leads them to expect that Jenkins might indeed reveal her bare breasts in the show, the next poem, “Bureau of Appropriate Self-Disclosure,” breaks the tension and introduces a comic self-critique, as Jenkins impersonates a “straight-laced” bureaucrat, clipboard in hands, who tells her:

you’ve got to stop talking about yourself. It’s too much for most people to take. You only get one more warning before you have to go to conversation camp, so please bear with me.”
The bureaucrat gives her a list of appropriate topics, such as the weather, as well as a "list of topics to avoid," include "your illnesses, especially as you get older and they become chronic/and less interesting" (272-273).

In "The Dyke March 2002-2003," Jenkins reflects on her gay identity and juxtaposes the toplessness of young women "marching arm in arm, / while others on fire escapes flash their breasts / in solidarity" with the Bourbon Street scene: "Men shower Mardi-Gras beads down on us all/or stand on the sidelines drinking beer, / but no man shouts "Show us your tits."/ They know this is not about them." She says,

I wanted my sisters and I, who started this revolution
to bare our breasts, proudly showing our lifetimes lived.
But we didn’t, not that night.
And this night I am no braver” (274-277).

The “The Dyke March” also reflects on the non-survivors of breast cancer by particularizing one of them, June Jordan:
On my way home, I think of the young woman
I saw last year wearing a sign on her back:
“In memory of June Jordon, 1937-2002.”
She was diagnosed with breast cancer
at the same time I was ten years ago.
Only difference
now she is the one in three who dies.
I know she would have liked that tribute.
I wrap her words around me
as I move among the women celebrating
and making ourselves whole again (277).

The final poem, “Cleaning the Refrigerator,” is a bitter-sweet and sometimes comic reflection on her life and her past relationships, some of which have gone as bad as the remnants of spoiled food and the “Tupperware Science Projects,” and her friends who have died, and “me with all my little deaths. / One breast already sacrificed to science.” The last stanza, before she pulls her top over her head with a “grand gesture to reveal breasts” reads:

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Reading “A Clean Breast of It” and “Menopause and Desire” in the Context of Illness Narratives Genre

Park-Fuller’s narrative has characteristics of the restitution, chaos, and quest narratives, in that the author reveals her trauma at the initial discovery, describes her quest for healing, including the mastectomy, chemotherapy, and her “cure,” having passed her 13th year of remission. Jenkins’ treatment of breast cancer also expresses some of the chaos, quest, and restitution characteristics. Her admonition to first throw the book *Love, Medicine and Miracles* across the room and then “pick it up and read it” shows some of the chaos caused by this life-threatening disease. She sends the audience on a quest for causes, cures, and the feeling of wholeness.

Park-Fuller’s narrative also partakes of the healthy-mindedness metaphor, but only after critiquing the “blaming the victim” approach of asking whether her own use of tobacco and alcohol, as well as stress and lack of exercise might have caused her cancer. She says, “It’s bad enough to get cancer; you don’t want to think that you caused it. And I know how dangerous that kind of thinking is because if we make everyone personally responsible for all their problems then it lets us—as a society—off the hook.” But after critiquing the Food and Drug Administration for approving “bovine growth hormone” to increase milk production, she concludes that she would truly be victimizing herself if she relied on social activism or the government to
find out what caused cancer and how to cure it, so she “resolved to make some lifestyle changes” that might help her survive:

no more tobacco, no more alcohol. Spend more time in daily meditation and prayer and exercise to help handle the stress, and watch what I put in my mouth. And learn a little more about living, just living life. And be kinder to myself. Because I discovered that I really love my body. . . . So I resolved, too, that I would start telling my body that I loved it instead of “bad-mouthing” it all the time . . . . It may sound silly, but you see, as a teacher, I believe that all living things respond positively to praise (Park-Fuller 2003, 228-229).

Jenkins too incorporates the healthy-mindedness metaphor, after rejecting Siegle’s *Love, Medicine, and Miracles* book, by advocating doing “whatever you need to do / to make yourself feel whole again” (Jenkins 2005, 264).

Both authors mitigate what Couser calls the comic plot of most restitution breast cancer narratives. Through the use of the sounding timer, Park-Fuller provides both a reminder of the unhappy endings and gives voice to those who have not survived. Despite her triumphant and unashamed display of her own reconstructed breast at the end of the play, Jenkins remembers June Jordan, the “one out of three of us” who do not survive, thereby avoiding the tendency of quest stories to romanticize the disease (Frank, 135).

The autobiographical performance allows both performers to adapt their scripts to particular audiences or situations. Park-Fuller says, “At certain places, like a church, then I may substitute some of the social activist material with poem/prayers/inspirational material.” She always keeps up to date with statistics (Park-Fuller 2006). Jenkins says that she has not modified the show as a whole, but sometimes does excerpts from it in different combinations to make a shorter program (Jenkins 2006).

Jenkins situates breast cancer almost as a rite of passage that for many women co-occurs with the passage through menopause. Although breast cancer is foregrounded in the show, it is woven throughout this memoir. The show transcends pathography. Jenkins’ reflections on the role her breasts have played throughout her life, the role of exhibiting breasts on Bourbon Street, along with her traumatic
mastectomy, when juxtaposed with her reflections on sexual desire and menopause, increase the audience’s understanding of the deep significance of women’s breasts, which symbolically embody sexual desire. Park-Fuller’s script also links breasts to sexual desire with her question of how one makes love to a woman with a mastectomy.

Jenkins’ use of the poem “The Bureau of Appropriate Self-Disclosure” functions to highlight society’s uncomfortable relationship to discussing disease and mortality. It challenges the intimate dyadic communication she is establishing with the audience, but in a way that reduces the challenge to the absurd.

Both authors found that telling their illness stories helped them to reflect on their experience. Jenkins said that, “I learned a lot about myself in constructing and performing the piece. It helps you reflect. The writing and rehearsing is a process. The first poem didn’t change very much, but the second took a lot of drafts before rehearsal, and then refinement in the rehearsal” (2006). Park-Fuller said that, “It helped her understand, just as talking always does, and putting it into a narrative structure helped her make sense of it. Putting it into as many forms as possible, allowed her to get as much meaning from it as I could.” Park-Fuller added that, “Continuing to tell it just reinforces the image of the survivor that she knows she can be” (2006).

Memorable and intense relationships with audience members have occurred as a result of their performances. At the gay church where Jenkins was first invited to perform, she was nervous that the predominantly gay male audience would not be able to relate to her breast cancer story. She got a standing ovation and was surprised, but she saw the connection between AIDS and breast cancer (Jenkins 2006). Park-Fuller reports that, “People say she has given them new courage. People need to be listened to.” In one-on-one conversations following her performances, audience members told of losing their husbands, houses, and their jobs to the disease. Through her performances, she has become closer to people who have gone through trauma (Park-Fuller, 2006).

Live autobiographical performances have many advantages over printed illness narratives. Park-Fuller frequently follows her performance with a workshop that provides more information about breast
cancer and the opportunity for others to talk—both medical professionals, other breast cancer survivors, and audience members. Both performers engage in dialogue with audience members, forming new relationships, gaining new information.

Unlike published versions, the performances can grow and reflect change in the author’s life, thus avoiding the pitfall of “the retrospective closed-end autobiographical narrative” being “always somehow false to the experience” (Couser 1997, 41). Autobiographical performances involve both audience and performer in the interrelated acts of testimony and witnessing, and witnessing carries with it the responsibility to testify further and thus keep these breast cancer stories alive (see Frank 1995, 140-145).

References: