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Doors of Reception: Invitation to a Narrative

By Deborah L. Jones

E: [Breathes a sigh of relief] *OK…*
D: *Thank you.*
E: *You're welcome.* [Pause] *Don't dare ask me another question.*
D: *I won't. Ever again….*
[Both laugh heartily!]

And with that, the door swung to and caught with a gentle but final click. That is not to say we stopped talking. It is to say we were done with our roles–she as storyteller and I as witness. We were both clearly relieved to walk away from the metaphorical rooms behind that portal back to the concreteness of a red and white kitchen in Florida. Elle (as I will call her) is a wonderful cook, and we had finally settled down in the kitchen after runs to her favorite fresh fruit, vegetable, fish, and poultry markets. She was preparing a plump stewing chicken to be rendered into stock for soup. Our interview was punctuated by various chops, sizzles, sloshes, and conversational asides about food as the aroma filled the townhouse. She was in her element, which would turn out to be an important feature of our conversation.

In preparing for this assignment, our graduate-level narratives class was explicitly instructed to interview someone with an illness or disability, or someone who cared for such a person. So, I went into it thinking I was going to emerge with Elle's narrative, heavily weighted with a story of illness. After all, she was being treated for cancer for the fourth time in 23 years. Instead, the products from two hours of conversation were these: an interview about a rich life, an illness narrative in proper proportion to its presence in that life, a transcription – itself a narrative as much mine as hers, and, finally, an analytical paper co-authored in the narrator/listener sense by Elle and me.

I was in Florida because she had asked me to accompany her to a breakfast in Palm Beach, at which clinicians from the Dana-Farber Cancer Institute in Boston would be discussing advances in cancer treatment. They would be taking questions from invited guests, and it was her opportunity to ask specifically about uterine cancer. I had not seen her in a while, she wanted the company of an advocate, and I could–if she consented–interview her for the assignment. That is how my cousin, age 63, originally from upstate New York, became my interviewee.

What would have been different if she had initiated the conversation–if she had come to me with her story? That is a point of conjecture. She would have had her reasons, both implicit and explicit. But I am the one who knocked on her door, an unexpected solicitor whom she invited in by virtue of our relationship.

It is worth noting that she asked me if it would be easier to do the interview if I sent her the questions in advance. Elle was signaling that she wished to control the exchange. When I said no, that we would wait until I got there, she was unruffled, saying that she always reserved the right not to answer. On that we agreed.

A Rich Life–Round One

D: *All right, tell me about your life. Tell me about, for instance, what kind of expectations you had of what your life would be like from the adolescent point, you know, when we're starting to think about college, or in high school, thinking about college… What did you expect would be the course of your life?*

E: *One of my expectations or thoughts was that I wasn't going to live past 33. And I'm not sure why that date or why that number was something that occurred, but I remember there was a group of friends, and we'd talk about some of our expectations and that did come up.* [Pause] *Ummm… I didn't really have particular expectations and I don't because then you are surprised by what happens versus being disappointed maybe or being* [gurgling as water goes down the drain] *in a situation where you expected something and something else happened and maybe reacting to it negatively. So I know when I take trips, I don't necessarily say this is what I expect to happen or this is what I expect a place to look like or be like; I just go completely open…which might not be the best thing, but that's* [pause] *what I do.*

I am an old-school journalist from an era when we did not enter into the story in the interest of fairness and presenting as many sides of the story as possible without judgment. In "Autobiography, Biography and Narrative Ethics," John Hardwig says there is value in *trying* to be objective. But once we accept that objectivity is impossible,

> …we also need to learn another, rather different discipline–that of coming to recognize our own motivations, biases, agendas, and then of stating them quite explicitly. This kind of self-knowledge is required of a *narrator* [emphasis added]–and thus of a health care professional–if her account is to be maximally reliable and morally trustworthy (62).

Did I abdicate my role as an advocate by approaching the interview as a journalist, keeping as much of myself hidden as possible, even as I was thinking that Elle was hiding parts of herself? Is that a judgment for me even to make?

The key to making sense of Hardwig's statement is understanding at what point the motivations and biases should emerge. I am biased toward believing that everyone has expectations, and I could have asserted that in a follow-up question, such as, "Everyone has expectations, Elle. Think again. Didn't you expect certain things to happen?" Instead,

D: *So you like the idea of surprise?*

E: [Sighs] *I guess I don't know if I even think about it as an idea of surprise but just accepting what's there versus expecting what's there and maybe not finding what I expected there.*

I saved my statement of bias for the analytical product–this paper–in better service to Elle, the reader, and myself. She had examined her own life and opened doors as the telling of her story dictated. My biases and pre-texts, if stated at that point, could have easily cut off access to statements that she ultimately made about a career, owning property, and how to live as someone with chronic cancer.

In a way, the effort to be objective, even if it is futile, as Hardwig suggests, mirrors what is meant by narrative humility. It is allowing oneself to be receptive to what others are saying and, thereby, learning from it (Das Gupta, "Art of Medicine"). I was there in her kitchen eliciting scenes from a life-in-progress. Even though I had invited her to talk to me, she issued a reciprocal invitation. It was my responsibility to be a humble guest.

A Rich Life–Round Two

Elle's family had traveled far and wide. She went to Europe for the first time as a teenager along with her mother, who got sick, likely from a suspect meal.

E: *So we got to Madrid, and they got a doctor for Mom and gave her medicine, and she started feeling better immediately. But she didn't want me not to see things, so I took a day trip to Toledo by myself.*

D: *As a 15-year-old…*

E: *Ummm humh…*

E: *Ummm, and, I remember I even had a picture–who knows where it is now–that…there were photographers around; there were pictures of me sort of standing in front of a railing and you can see the city behind. And I went to a couple of museums–I don't remember now–and I remember…El Greco always has a picture of himself in his pictures, and you know, the tour guide pointed that out.*

D: *You've always been adventuresome and fairly fearless.*

E: *I guess so, and it's interesting because I know as an adult, sometimes when I'm nervous about something, I'm saying, "OK, hold on. If you could do some of these things when you were 15 or 16, you better be able to do it as an adult. So usually if I get nervous, I think about that.*

Alessandro Portelli writes that oral history is less about specific events than it is about their meaning.

E: *It was fascinating at that age because people would stop in the street and stare at us. And as a 15-year-old: "What's wrong? My skirt's not hanging…!" You know, blah de blah… One place, I think it was Italy so it was later – after a while I got used to it, as used as you can be–ummm, somebody walked into the side of a building. He was staring at us and not paying attention to where he was going. And of course Mother and I had to laugh. It's like, OK, that's what you get…*

D: *This was because you were black* [tourists]*?*

E: *I guess. Either that or we just looked so different. They might have been confused about Mom… I don't know if it's because we were black or we just looked so different from the tourists that they normally saw. And we were traveling on our own and not a group.*

At 15, Elle was tall with hazel eyes and a flawless golden complexion. Her mother was barely five feet, fair-skinned and curly-haired. Both were well-dressed–no shorts and white socks with sandals–and keen to experience indigenous culture. Nearly 50 years ago, they doubtless did not fit the stereotype of American tourists in Europe.

There were lessons for Elle in Spain and Italy. Portelli continues, "But what is really important is that memory is not a passive depository of facts, but an active process of creation of meanings" (52). Memory changes events or, as in the recollection of the day trip to Toledo, strips the event down to the essence. "These changes reveal the narrators' effort to make sense of the past and to give a form to their lives, and to set the interview and the narrative in their historical context" (52). Being stared at can destroy you or give you a powerful confidence. The names of the museums Elle visited are less important than the fact that she established a sense of self-reliance that she still calls on as an adult.

E: *…Never expected, planned on or thought about being married. It was not one of my goals. So, again, I can't say I expected "this" to happen at a certain age. And I know some people will plan out their lives and say, "By the time I'm 30, I expect to have a husband, one and a half child* [sic]*, and a dog." I can't say I did that, but one goal I did have was that I knew I wanted to own property by the time I was 30.* [D interjects, "Hmmmmm…"] *And I think I bought my first piece when I was 30, if I'm not mistaken.*

D: *Why was that important?*

E: *Because then I owned something, and it gave me more security.*

D: *Hmm, tell me more about that–this whole idea about security.*

E: *Well, if you own something, and you have problems, you can always sell it, so it gives you financial... And I guess not thinking of always being dependent on someone else, be it my parents or a husband. I know I* [emphasizes "I"] *needed to be able to function on my own and be…be ready to support myself.*

That is how we came to be sitting in a sunny kitchen in South Florida. She functions quite well on her own. In addition to global vacation travel, Elle lived for extended periods in numerous U.S. cities as well as Nice, France; Cuernavaca, Mexico; and Mexico City. Later, her jobs and fluency in Spanish took her to Central and South America regularly, so she bought a condo in Florida as a base. Now she teaches English to adult speakers of other languages.

Cooking, a passion on par with travel, also meant that she spent much of the time facing away from me while she worked at the counter. I thought nothing of it at the time; the kitchen layout precluded our being face-to-face except toward the end of the recording when she finally sat down at the table. In hindsight, I think the positioning made it easier for her to talk and for me to listen. I could give her space to think and to fall silent during recall without the pressure of eyes awaiting an answer.

> [The listener] must listen to and hear the silence, speaking mutely both in silence and in speech, both from behind and from within the speech. He or she must recognize, acknowledge and address that silence, even if this simply means respect – and knowing how to wait (Laub 58).

As cousins just one year apart, Elle and I certainly know how to keep up a steady stream of patter–food, family gossip, clothes, our respective weight issues, and all the typical quotidian concerns. This conversation was very different. In the early minutes, it felt very much like an assignment. I fiddled a lot with the borrowed tape recorder, becoming obsessed with levels on the VU meter. If Elle found comfort in the rhythmic chopping and slicing of chicken and vegetables, I found it in tending to the mechanics of the recording process. My fussiness meant Elle also had to know how to wait.

The Illness Narrative

We switched focus to the past 25 years, during which Elle got her first breast cancer diagnosis. Events during the biopsy set a tone.

E: *You know they put you under but not with an IV. And so, I remember them talking about something, and I said, "Aren't you guys supposed to be concentrating on what you're doing?" Of course, which kinda shocked them.*

Later:

D: *Would you say that statement that you made, "Aren't you guys supposed to be paying attention to what you're doing?"–does that kind of characterize your overall attitude toward medicine and medical care and the things that are happening to you?*

E: *Well, maybe…* [Mutual laughter] *Maybe I'm conscious of what's going on and I will question…question you if I think that you're not paying attention. Probably.*

Elle had a lumpectomy, but 10 years later, developed cancer again in the same breast. She underwent a mastectomy.

E: *Went through chemo, lost my hair, but I was working from home with the software developer, so nobody particularly saw me… But I did…I was going to start traveling again, so I got a wig. And I remember somebody found someplace to get wigs. Well, that was a whole scene. People were stopping to watch me trying on all these wigs because, I mean, I tried on some blonde wigs that looked better than dark-haired*

wigs. And I probably tried on about 20 wigs, and of course it became…the guys were very flamboyant who ran the place. So, I got two wigs: one that we called my Tina Turner, and the other was a little bit longer and…so…uh…
A little later:
I do remember once, though, taking off my wig, taking off my prosthesis because I opted not to have reconstruction, and saying, "Am I less of a woman?" And then, hmmm, did whatever I had to do. But it was a weird thought because so many of the things that identify somebody as a woman…I was like, "OK" [said with a lilting tone].
D: *But it was brief…*
E: *It was brief and that was…'cause I looked at myself and said hmmph as I take off my hair, take out a boob, and said, "Am I any less of a woman?" and just kept going.*
D: *And I am assuming you answered…?*
E: *Well, I must have answered, "No," because I don't remember it even keeping me awake!"*
Arthur Frank, meet Elle.

In *The Wounded Storyteller*, Frank breaks down elements of control. Social constructs around control demand that we are able to be the masters of our bodies. But illness disrupts the mastery. At this point Frank refers to Ervin Goffman's 1963 work regarding stigma. Frank writes about the burden placed on the bearer:

> Stigma, Goffman points out, is embarrassing, not just for the stigmatized person but for those who are confronted with the stigma and have to react to it. Thus the work of the stigmatized person is not only to avoid embarrassing himself by being out of control in situations where control is expected. The person must also avoid embarrassing others, who should be protected from the specter of lost body control (31).

E: *And I remember getting the prosthesis and, again, sort of how I look at things… There was a place not too far from here, and you know, we tried several on and I've never been very busty, so I never had a big one* [prosthesis] *anyway. And I had this thought…I said, "What a Saturday Night Live skit: somebody comes in to rob the place, and all of these boobs come flying down on him."* [Laughter] *And I was laughing, and the woman was not amused. I'm like, "Lady, I'm the one who's here because I am missing a breast…" Anyway…* [More laughter]
D: *So, do you constantly feel that people don't know how to react to your particular approach…*
E: *Oh, yeah.*
D: *Yeah, OK.*
E: *Next question.*

There are shades of writer and radical feminist Audre Lorde being chastised for not wearing a prosthetic breast because it was bad for the morale of the [doctor's] office (Lorde 60). Elle did go for her fitting, but her making light of the situation offended the fitter. She had to remind the fitter whose "story" took primacy. This happened in the 21st century. There has been progress in our ability to talk about cancer,

> [h]owever, narrative ethics is conflicted in its own terms about which value-driven stories ought to be valued. What in narrative itself distinguishes good stories from destructive ones? On what grounds precisely does narrative require fundamental changes in existing cultural and political practices? (Christians, "Primordial Issues…").

"Good" stories are still the brave ones that conform to social standards of triumph or saintly forbearance. "Destructive" ones are those told, for example, by noted author Barbara Ehrenreich in "Welcome to Cancerland"; she had the audacity to express anger about cancer and "sappy pink ribbons" on the komen.org web site right around the time Elle was imagining cascading prostheses raining down on an unsuspecting burglar.

D: *To what do you attribute, though, that…that…attitude? Kinda the, "Hey, you know, it is what it is."*

E: *Probably a lot my mother and the way I was brought up. Because there are certain things you can't change. So, you can go in a corner and emote* [with sharp enunciation on the "t"]*, or you can emote for a second if you need to and then deal with it. And I tend to emote for a second if I need to and then deal with it, because emoting in a corner with my thumb in my mouth is not going to help me.*

D: *What does help you?*

E: *Sometimes I write in my journal if I'm really sort of stressed, I will write out and through my feelings.*

The Illness Narrative–Again

About a decade after the mastectomy, Elle developed uterine cancer. After surgery and chemotherapy, she was declared free of cancer cells, but the disease returned–with cells showing up in the liver and lymph nodes of the neck. Her mother had died the year before at age 92. Elle decided to move back to New York State.

E: *Yuh. I just realized that I had to start thinking about the next years of my life, sick or not.*

D: *Do you want me to add some water?*

E: *A tad… Here…*

D: *OK….broth… You said you had to start thinking about your life…*

E: *Yes, and it…in a different way to a certain extent because of being sick but also, as I was getting older. And I never really planned on retiring in Florida, which, of course, is counter to what most people do.* [Both chuckle]

E: *Why is that surprising* [said with irony]*? Or not surprising?*

D: [Laughing loudly] *Who are we talking about here?*

E: *Yeah.* [Very long pause as chopping continues] *So the change…I don't know if it's from the disease or from…um…the disease, my mother's death, and having to make a decision about the property that I owned* [at home]. *It's a little bit of everything. Whaddya' do? So. That got me thinking.*

A little later:

E: *It was probably at that point I had…and it really hit me that I am a chronic cancer patient…'cause I had talked about it, but I don't think it had really hit me. And I had this wonderful boo-hoo* [in the oncologist's office]. *It was probably on and off for half an hour. Of course the doctor didn't really know what to do, and he said, "Obviously, it's upsetting. You are human." I'm like, well thank you. And the nurse came in; she is really nice and she wouldn't let me leave until I stopped. She said, "I'll call you tomorrow, and I said, "That's fine. If I don't answer the phone, maybe I'm still in a funky mood, but she called the next day, and she asked how I was doing, and I said, "I'm fine; I'm over it." You know I haven't cried like that probably in centuries, and it's out of my system. So… And, of course, it's good to cry, so on and so forth. I needed that 'cause it was probably a whole lot stuff that I was crying about…and… So now I'm just trying to figure out what to do because it* [chemo] *doesn't seem to be working, there's not a lot of research with endometrial cancer, and after yesterday's breakfast, I have probably as many questions as answers about what direction to go in…*

She was referring to the aforementioned Dana-Farber breakfast with the clinicians. They deferred answering her question about possible advances in treatment of uterine cancer because the lead researcher for that variant was not there. Coincidentally, the doctor they referred her to following the Q & A session was the same one from whom Elle had sought a second opinion months earlier. It was that consultation that got her name on the guest list for Dana-Farber's annual patient and benefactor breakfast.

This latest assertion of cancer took Elle into new territory where the balance of control was clearly shifting. Where would Elle's attitude fit in Arthur Frank's schema of body type, when illness or disability pose a dilemma for perceptions of self?

Control		**Desire**		**Body-relatedness**		**Other-relatedness**	
Predictable	Contingent	Lacking	Productive	Dissociated	Associated	Monadic	Dyadic

Adapted from Frank (30)

Based on our interview, she is contingent, productive, and associated. She has had to yield control to the contingency of illness, but she maintains a productive future focus; clearly, she is highly associated with her body but not imprisoned by it. I have a little more trouble pinpointing her other-relatedness. It defies a static determination because, as Frank comments, all of us are going to slide back and forth along a continuum between the introspection needed to understand our own inevitable decline (monadic) and the turning outward to others in the same circumstance (dyadic).

Elle is not likely to be a fearsome warrior like Audre Lorde, and she does not have a ready-made platform like Barbara Ehrenreich's. But, in other conversations outside this interview, she told me that she talks openly to her students about what she is going through and, in so doing, has made them comfortable with her appearance–bald or scarred, thin or swollen with ascites. In that sense, Elle is Frank's communicative body type, tending toward the dyadic as her disease progresses (30). Again, though, I would say that she keeps her audiences and platforms small–students, family, friends, health care providers–given past reactions to her attitude toward cancer and life in general.

That brings me back to Hardwig's exhortation to reveal your biases, motivations, and agendas. My bias in this analysis is an attitude not unlike Elle's, born of similar upbringings. Our mothers were sisters. Their other sister had seven daughters. I have a sister who has a daughter, and I have a daughter. All three of my brothers have daughters. That idea of acknowledging life's challenges, sitting in the corner "emoting" for a few minutes, then getting on with life is a hallmark of every one of them. No one is going to make a cottage industry out of suffering.

So, for the many people who do not share that attitude, the emotional tone of the interview would be hard to understand. There was a lot of laughter, even during discussions of disease. At one point, Elle quipped, "If I'm crying, it's because of the onions." Mostly, there was thoughtful recollection of events. Even talking about being a chronic cancer patient moved toward the practical, returning home where she has a support network, a university-affiliated hospital, and property–that one expectation of her life very much fulfilled.

The Transcription–My Narrative

We had covered 60-plus years in two hours. Next came the transcription. Alessandro Portelli puts it this way, "Expecting the transcript to replace the tape…is equivalent to doing art criticism on reproductions or literary criticism on translation" (47). Not only does transcription lack all the vocal/aural nuance, just about every decision I make regarding punctuation or emphasis puts my interpretive mark on Elle's words. What is a pause–how long? Is "mmm hmm" different from "uh huh"?

What makes these questions even more relevant is a strange phenomenon that occurred when I was listening to the audiotape. If I chose a random point from which to start playing, it might take me a second or two to figure out who was talking—our voices sounded that similar. Of course, the content ultimately identified the speaker, but the cadences and timbre were uncannily similar in the first few seconds. In person, we do not sound alike at all.

Perhaps that voice phenomenon signals a convergence of our individual goals for the interview. She had a story, and I had an ear. There is no narrative without an audience. Toward what would be the end of the conversation, I had stopped fiddling with the recorder, and she was across the table facing me. After letting me in the front door at my request, she showed me many rooms until we made it back around to the foyer.

E: [Breathes a sigh of relief] *OK*…

D: *Thank you.*

E: *You're welcome.* [Pause] *Don't dare ask me another question.*

D: *I won't. Ever again*….

[Both laugh heartily!]

And with that, the door swung to and caught with a gentle but final click.

Epilogue: The interview took place in February of 2014. In mid-September, Elle traveled to Ecuador and stayed for two weeks to consult with homeopaths and natural healers. It was a grueling trip from which she returned weak and exhausted. Within days of her arrival in Florida, movers showed up to pack her two-story condo. She flew to New York State on October 7. Elle died three weeks later on October 27, just shy of her 64th birthday.

Works Cited

Christians, C. "Primordial Issues in Communications Ethics." *The Handbook of Global Communications and Media Ethics*. Eds. R. S. Fortner, P. M. Fackler. West Sussex, U. K.: John Wiley & Sons, Ltd, 2011. No page. Web.

Das Gupta, S. "Art of Medicine: Narrative Humility." *Lancet* 371, 22 March 2008. 980-81. Web.

Ehrenreich, B. "Welcome to Cancerland." *Harper's* 303, November 2001. 43-53. Web.

Elle. Personal Interview. 22 February 2014.

Frank, A. *The Wounded Storyteller*. Chicago: University of Chicago Press, 2013. Print.

Hardwig, J. "Autobiography, Biography and Narrative Ethics." *Stories and Their Limits: Narrative Approaches to Bioethics*. Ed. H. Lindemann. New York: Routledge, 1997. 50-64. Web.

Laub, D. "Bearing Witness or the Vicissitudes of Listening." *Testimony: Crises of Witnessing in Literature, Psychoanalysis, and History*. Eds. S. Felman, D. M. Laub. New York: Routledge, 1992. 58-74. Web.

Lorde, A. *The Cancer Journals*. San Francisco: Aunt Lute Books, 1997 Special Edition. Print.

Portelli, A. *The Death of Luigi Trastulli and Other Stories: Form and Meaning in Oral History*. Albany: State University of New York Press, 2001. 45-58. Web.

Deborah L. Jones lives by the credo, "Stay boundlessly curious, listen actively, lead as a learner, learn as a leader, and laugh often." That explains how she came to narrative medicine after successful careers in supply chain, corporate communications, and broadcast news. Several decades separate her undergraduate degree in journalism from Syracuse University and her Master of Arts in health advocacy from Sarah Lawrence College. It was there, in a class called Illness and Disability Narratives, that the act of listening—with humility—took on new meaning. Deborah, a transplant from Chicago to southern Indiana, is currently a health advocacy consultant for Sarah Lawrence's End of Life Care program.
