THE CURSE OF WRITING AUTOBIOGRAPHICAL GAMES

BY LIZZIE STARK

My family's story is one of epic generational tragedy. It begins with the three children in my grandmother's generation, the sisters Trudy, El, and Meg (my grandmother), in order of age. They'd suffer a combined six cases of cancer that took two lives. Trudy probably began developing breast cancer in her late 20s. She was a nurse and knew she had the disease, but feared the only treatment at the time–an extreme mastectomy that took parts of ribs and collarbone–so much that she didn't seek treatment until it was too late. By age 31, Trudy was dead. Unfortunately, she was my family's canary in a coal mine. Six years later, the middle sister, my Great Aunt El developed breast cancer after the birth of her fourth child. She was in her late thirties, and remembering her sister's tragic death, she did not delay treatment, but had a disfiguring and life-saving mastectomy. Five years later, the youngest sister, my grandmother Meg, who was then in her thirties, also developed breast cancer. She had a botched mastectomy that affected her self image for the rest of her life.

For the next decade, things were quiet for my grandmother and her surviving sister. But in 1974, the 50-something El was diagnosed with the late-stage ovarian cancer that would kill her, and my grandma, still in her 40s, was diagnosed with a second bout of breast cancer in her remaining breast. By 1976, El had died horribly of ovarian cancer after spending years in and out of comas, confined to a wheelchair after the cancer moves to her spine. Meanwhile, my grandmother survived her second bout with breast cancer. In 1981, I was born. In 1982 my grandmother developed late stage ovarian cancer, and miraculously survived. One year later, my mother was diagnosed with aggressive breast cancer at age 30. One of El's daughters later told me, "When I found out about [your mother] I thought oh, it's going into the second generation. The prophecy is being fulfilled. This horrible thing is now coming into the second generation." Within five years, every woman in my mother's generation would have her healthy breasts removed.

In 1994, the BRCA1 gene is discovered. Certain mutations on this gene dramatically raise a woman's risk of breast and ovarian cancer, along with certain other cancers, and raise a man's risk of developing breast and other cancers. My grandmother tests positive for such a mutation, and so does my mother, and at age 27, so do I. I'm given the choice of having many medical tests each year to watch for cancer or chopping off my breasts and ovaries to permanently lower risk. Now, I have the ultimate unwanted hipster cred: I had a preventive mastectomy before Angelina Jolie made it cool.

I put my family experience into a short freeform game called *The Curse* (2013) for two reasons: I wanted to prove an aesthetic point about larp to myself, and I also wanted to prove that my decision was not, as many mean internet commenters and clueless strangers had asserted, extreme and irrational. At the time, I was working on my second book, *Pandora's DNA*, a reported memoir about the history and science of the breast cancer genes. For years, I had been telling people that larp was simply a medium for storytelling. This was a chance to put my game design where my mouth was–why not adapt *Pandora's DNA* into a larp? I also felt that popular narratives about BRCA mutations had left a vital angle out–that watching multiple family members sicken and die of cancer, that this fear of cancer, has a powerful and understandable effect on the decision-making process of patients. I also wanted to show the considerable emotional cost of near-constant cancer screening.

In adapting my story to the freeform format, I had to make some adjustments. A novel is not the same as a movie, and a game is not the same format as a nonfiction book. I wanted my game to fit into the typical constraints of scenarios that run at the Danish convention Fastaval, where it eventually premiered. That meant it would require only a handful of people, a strong game master, and a nondescript room. No fancy props or costumes would be necessary.

Writing a short game is a bit like writing a short essay—you have to be selective about which points you hit, since time and space are limited. My BRCA ordeal offered several potential episodes—the process of learning about my family history, my relationship with my mother, deciding whether to take the genetic test, taking the test, making decisions about what to do, and so on. Initially, I struggled to settle on a particular topic, because I felt conflicted about what I wanted to do and what I thought I ought to do. At that point, I felt pretty bored by the "whether to test" question, but I thought it might be interesting to players. Thankfully, Fastaval assigned me a sparring partner–an experienced designer I could bounce ideas off of. Mine was Troels Ken Pedersen, who suggested I focus on what interested me most right now. I decided to concentrate on how patients decide what to do after testing positive for a BRCA mutation.

For me, the most crucial component of my BRCA experience was being forced to choose a path from a series of unappealing options. Would you prefer to eat the gristle soufflé or the snot soup? Unfortunately, for BRCA patients, choosing another restaurant is not an option. The emotions around making a terrible decision in uncertain circumstances would sit at the center of the game experience. This design choice, in turn, suggested others, and meant I had to sacrifice fidelity to my personal biography in the service of producing the emotions I was interested in. If I wanted the players to feel the struggle and weight of these decisions, then within the frame of the game, the decisions had to be unfettered and and have meaningful consequences. Players had to be free to choose differently than I had chosen. *The Curse* quickly became an experiment of whether, given similar starting conditions, strangers would make the same choices I did. Were my own choices the product of an over-determined backstory, or of my individual personality?

The Curse has four characters, the sisters Rita and Elle, and their partners, Jared and Peter. Rita and Elle represent different facets of me. Rita was a writer in her mid-thirties ruled by emotion, who had a mastectomy a few years back and was now facing decisions about whether to have children and whether to have her ovaries removed. She represents where I am now in my life. Her younger sister, Elle, is a logical businesswoman in her late twenties, who has just tested positive for a BRCA mutation and has to decide what to do—situationally, she's me as I was in my late twenties. Rita's husband Jared is a methodical scientist, and Elle's boyfriend Peter is an unreliable artist. Each couple has one partner who relates to emotion and the body, and another who venerates science and intellect. This difference propels the dramatic energy within each couple. As much as this game is a story of women making decisions, it also belongs to the men and their feelings of being pushed aside. The men's story asks them what they would do if they were forced to be supportive—it is also a story about how it feels to be powerless bystanders, reflecting some of my husband's experience of my diagnosis.[1]

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1. I feel that it is important for Peter and Jared to be male characters (though they need not be

The sisters Rita and Elle are not mere translations of my own experience. I also tried to use these characters to represent experiences of other BRCA patients I interviewed for *Pandora's DNA*, and of other women in my family. For example, I interviewed many women who felt strongly about their bodily integrity and really questioned the necessity of the surgeries, so I wanted it to be possible for the characters to choose something other than surgery.

Likewise, I've heard numerous stories of boyfriends and husbands who can't deal with a partner's BRCA diagnosis. My Great Aunt El's two daughters both had unsupportive husbands at the time they were making decisions around their inherited risk, and in both cases, the decision to have a mastectomy ended up being a flashpoint in their marriages that pushed the already unstable relationships over the brink into divorce. I chose to reflect some of this in the relationship of Elle and Peter, which begins the game on somewhat shaky ground. I think I succeeded: during one play test, Peter's player was wearing a shirt with his girlfriend's name on it. He changed out of it during a break because he wanted his real-life relationship nowhere near this fictional and somewhat dysfunctional one.

The starting conditions for the characters in the game were identical to my own. My extreme family history of cancer made me terrified of the disease, and this fear played a vital role in my own medical decisions. After altering names and professions, I provided a version of my family tree to players, along with a timeline of cancer diagnoses in my family, and some medically accurate details about inherited BRCA mutations. Presenting so much context for the scenario made for a long workshop before

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played by men) because I think it is difficult for men to understand the cultural context of breasts and ovaries that women wear under their skins every day, further upping the tension between the couples. It's true to my own experience with my very loving and supportive husband, as well as to the experience of many other BRCA carriers I spoke with during my reporting.

the game, but hopefully one that heightened the experience for players.

The final format of the game is this—after some brief discussions about players' personal interaction with cancer and a guided meditation imagining what it feels like to be a cancer patient, the game master assigns roles to the players. Working from the family timeline and family tree, they improvise some scenes from the family history focused around cancer. This prologue is aimed at making players feel the pathos of coming from a cancer family. Next comes a series of five pre-set scenes, played in parallel for each couple and designed to highlight certain parts of the BRCA experience. After an initial discussion about what to do next, each couple plays out the anxiety and tension of medical monitoring, as the women begin bringing home ambiguous screening results. By the end of the piece, the siblings must both make their decisions about what to do about their genetic mutation right now. Rita and Jared must decide whether to have children. If they do want kids, they must decide whether to do so by natural means, or through an IVF procedure that could screen out her BRCA mutation. Elle must decide whether to pursue screening in the long term, whether or when to choose mastectomy, or if she wants to take no action. Peter must choose whether to stay and whether/how to support her. Both couples have to decide what missing breasts and ovaries might mean to their relationships. The game ends with a brief flash forward imagining the effects of whatever the sisters have chosen. If Elle keeps her breasts, is she in the hospital ten years later? If Rita has children, are she and Jared explaining the family curse to them? After the game, players and game master debrief about the experience.

Overall, the reception of the game has been positive, earning mentions in *The Guardian* as part of Jenn Frank's Boob Jam, a collection of games presenting non straight-male views of breasts. It's been played in Denmark, Norway, Sweden, the

United Kingdom, New Jersey, and New York by a mixture of seasoned freeformers, medical students, and artists. Many players arrive with the expectation that this will be a Very Serious Game About Very Sad Feelings, and later express surprise that though the choices are difficult, *The Curse* is more a game about living and deciding than mourning the dead. Typically, players find the workshop—which asks them to work through some of their own personal feelings about cancer—more affecting and sad than the game on its own. The Fastaval judges critiqued the game for not offering more happy slice-of-life scenes to lighten the mood of scenes focused on cancer and BRCA. I understand the concerns about thematic heaviness, but that focus was true to my experience with BRCA. I know it sounds dramatic, but between my diagnosis and the completion of my mastectomy, I basically lost the capacity for joy. I couldn't bear to be around carefree people and withdrew from social life. If I wasn't forcibly occupied with another activity, my mind lasered in on cancer, my family history, and my future. I wept almost daily. It was the worst ten months of my life.

The response to the game by players and facilitators, and their judgments of the characters have also intrigued me. After one run, the facilitator contacted me to assure me that Rita had made the "right" decision to have a baby through in vitro fertilization (IVF) to avoid passing on the BRCA gene to her children. I found this fascinating because I do not view the question of whether or how to have children as a choice with a "right" answer, and IVF is not the choice I am making for myself. Responses like this make me feel that I succeeded in not unduly prejudicing the game materials in one direction or the other. They also unsettle me, because I wanted to work against the idea that there is a universally correct decision in the context of BRCA. With BRCA, there are no absolutes, only "right for me, right now." Perhaps my favorite feedback came from a group of medical students, facilitated by a friend in a narrative medicine program, who said stuff like, “intense, but good,” and “I learned a lot.” This feedback pleased me, because the attitudes of medical professionals shape patient experience. I’ve seen both sides–doctors with great bedside manner make the experience less traumatic. Insensitive doctors, nurses and receptionists who did not understand my situation had the power to make a difficult situation much worse. Knowing that medical students got something out of the game made me feel like it had real-world impact that could benefit future patients.

On a personal level, releasing *The Curse* to the world felt frightening but liberating to me. It did what I most want my games to do—open me to personal connection with other people. After the game debuted at Fastaval, friends talked to me about how cancer had touched the lives of their families, friends and lovers, or the way in which other chronic inherited illness shaped their existence. It also gave them the opportunity to ask questions about my own experience, and offered me to show them my soft inner parts, my trauma and my fear, and to be seen for my artistry as well as the pathos that makes me me.