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Among the Metavivors: Social Media and Illness Narratives of Stage IV Breast Cancer Patients

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Abstract

Dominant breast cancer narratives equate early detection and screening with “cure,” advocate for “awareness,” and identify women who undergo treatment for early stage disease as “survivors.” Left out of these narratives are the “metavivors”: women and men diagnosed with “incurable” metastatic breast cancer, also known as Stage IV. This article uses case studies to profile four women living with metastatic breast cancer who turn to social media to tell their stories: Sally, a former civil rights attorney turned breast cancer activist, who uses social media platforms to organize and mobilize Stage IV patients to advocate on their own behalf; Jane, who plows through databases of dense medical research to find treatments to save her own life; Jenny, a young mother dying of metastatic breast cancer who shares her experiences on a YouTube channel; and Grace, who participates in an early-stage clinical trial that she believes “cured” her, a term eschewed by both the medical establishment and fellow metavivors.

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Dominant breast cancer narratives, found in both clinical as well as popular literatures, tend to equate early detection and screening with “cure,” advocate for “awareness,” and identify women who undergo treatment for early stage disease with the heroic language of the “survivor.” These narratives, galvanized by the public activities of organizations like Susan G. Komen for the Cure (Hill & Thompson-Hayes, 2017), are fundamental to the ubiquitous culture of pink ribbons, postage stamps, and fashion merchandising (King 2008). Frequently left out of these narratives, however, are what have often been called “metavivors”: that is, women and men who have been diagnosed with “incurable” metastatic breast cancer, also known as Stage IV.¹ The average life expectancy of Stage IV patients is 2-3 years (“Living with Metastatic Breast Cancer,” 2010), although new treatments, like Herceptin, are extending this timeline for a few (Lewis, 2011; Mukherjee, 2010).

The existence of metavivors challenge the aforementioned “pink” narratives by taking up a critical position that began among feminist intellectuals in the 1970s. These include Susan Sontag’s questioning the military metaphor of the breast cancer “battle,” which she said fostered a culture that blames the patient for the disease (1978), followed by Audre Lorde warning breast cancer patients that silence and compliance would not save them, after her own mastectomy in the 1980s (2006), Barbara Ehrenreich’s questioning the “cancer industrial complex” after her own diagnosis (2001: 52), and Judy Segal’s warning that the breast cancer narrative was designed to “evaluate and govern” its victims to the extent that “some stories have become more permissible, and more speakable, than others” (Segal 2007). Much of this criticism emerges in relation to what Donna Haraway has interrogated in her examination of the nature of institutional science itself, questioning the claim to objectivity granted to and taken by “masculinist scientists and philosophers replete with grants and laboratories.” She called for “an earth-wide network of connections, including the ability partially to translate knowledges among very different-and power-differentiated-communities” (Haraway 1988, 575).

Interestingly, Haraway's words presciently echo the ideas of the early days of social media, which, like the Internet itself, was initially theorized as facilitating access to knowledge from multiple sources and multiple perspectives (Barlow, 1996; Gillmor, 2004; Lee & So, 2001; Negroponte, 1996).

Dozens of online forums and chat rooms, Facebook groups, YouTube channels, Instagram pages, and other social media channels are dedicated to conversations among the metavivors, where they exchange information about treatment options, side effects, clinical trials and offer emotional support. Social media may provide an outlet for metastatic breast cancer patients to tell their stories, exchange information and, in a meaningful way, circumvent the traditional top-down communication of doctor-to-patient (Dray & Papen, 2004; Klawiter, 200) to potentially enable what Haraway (1998, p. 590) describes as a community of situated knowledges, where "partiality and not universality is the condition of being heard to make rational knowledge claims." In other words, metavivors articulate, share, and validate their collective experiences among each other in addition to receiving information about their illness from professionals in white coats.

This article uses case studies to explore metavivor communities, profiling four women living with metastatic breast cancer who use social media to tell their stories, and by doing so, expand the characteristics of what Arthur Frank (2013) has identified as "illness narratives" of restitution, chaos, and quest to include a network of readers, responders and reciprocal influencers. In the following pages, we will meet Sally, a former civil rights attorney turned breast cancer activist, who uses social media platforms to organize and mobilize Stage IV patients to advocate on their own behalf; Jane, who plows through databases of dense medical research to find treatments to save her own life; Jenny, a young mother dying of metastatic breast cancer who shares her experiences on a YouTube channel; and Grace, who participates in an early-stage clinical trial that she believes "cured" her, a term eschewed by both the medical establishment and fellow metavivors.

Illness Narratives: Restitution, Chaos and Quest

In *The Wounded Storyteller*, Frank (2013) outlines a framework of three archetypal illness narratives: the restitution narrative, the chaos narrative and the quest narrative. Restitution follows a simple narrative arc: “Yesterday I was healthy, today I am sick, but tomorrow I will be healthy again” (p. 77). Scholars have noted that the early stage breast cancer narrative is most frequently associated with the restitution narrative: women get breast cancer, undergo difficult treatments, including chemotherapy and hair loss, and then slowly get better, putting cancer behind them (e.g., Wong & King, 2008). But the Stage IV cycle of “scan-treat-repeat,”² where the metastatic patient is never done with treatment, is seemingly at odds with the story of restitution. The second narrative type is the Chaos narrative, which Frank describes as being the opposite of restitution, as “its plot imagines life never getting better” (p. 97). Chaos stories are anti-narratives, “an incessant present with no memorable past and no future worth anticipating” (p. 99), where the subject does not have the ability to engage in reflection. These are stories that cannot be told but can only be lived, Frank tells us. The third narrative is the Quest. “Quest stories meet suffering head on; they accept illness and seek to use it. Illness is the occasion of a journey that becomes a quest,” Frank writes, noting that “most published illness stories are quest stories” (p.115).

Frank is not the only scholar to investigate illness narratives. Bury (2001, p. 263) also identifies three categories of illness narratives: contingent narratives, which concern the origins of disease, the causes, and the effects on everyday life; moral narratives that account for “changes between the person, the illness and social identity;” and core narratives that “reveal connections between the lay person's experiences and deeper cultural levels of meaning attached to suffering and illness.” Kleinman (1988, p. 96) urges doctors to listen “empathetically” to patients’ stories to better understand and manage their treatment. “Each

patient brings to the practitioner a story. That story enmeshes the disease in a web of meanings that make sense only in the context of a particular life,” Kleinman writes. He encourages medical practitioners to think “beyond the languages of molecules and drugs to include the language of experience and meanings,” in order to address quality and meaning of life issues of the chronically ill (p.266). Kleinman’s approach to the chronically ill may be particularly resonant with metastatic breast cancer patients, who may live with their illness for several years before succumbing to the inevitable. Two of the stage IV breast cancer patients profiled here, for instance, adopt the quest narrative when telling their stories on social media. While Frank draws parallels between the Quest narrative and Campbell’s (1972) “hero’s Journey,” the analogy goes only so far: drop into any online discussion by metavivors and you will see disdain for the concept of cancer as a “journey,” a description that implies that the narrator takes part willingly.

Of course, metavivors are not the only patients on social media. Indeed, social media create spaces for all people diagnosed with terminal illness to become “wounded storytellers.” Nearly eighty percent of Internet users have sought health information online, and about sixty percent of Americans with chronic health conditions have sought information about their condition online (Fox & Duggan, 2013). Some, like the four women profiled in this article, are motivated to tell their story as full-throated narratives, in detail, to a public or semi-public audience. Others choose to lurk around the edges of social media spaces, posting occasional updates, sharing links to potentially useful resources and commenting on the contributions of others. About 99% of breast cancer patients are women, and research has shown that women participate more on social networking sites and that social networks are more influential among same-sex members (Hargittai, 2007; Christakis & Fowler, 2008). Internet users are no longer solely passive consumers of online health content; they are active producers as well. Social media, such as social networking sites, are increasingly being used as online venues for the exchange of health-related information and advice.

However, little is known about how participation on health-related social networking sites affects users (Hether, Murphy & Valente, 2014).

The women selected for this study are high-profile participants in the breast cancer social media realm, who engage on multiple intertwining platforms, and engage in “produsage,” or the production and consumption of user-generated content (Bruns, 2008). As Postill and Pink outline (2012, pp. 124-125), while the two main methods used to analyze social media are web content analysis of large data sets (Agichtein et al., 2008; Honeycutt and Herring, 2009; Oulasvirta et al., 2010) and social network analysis (Gilbert and Karahalios, 2009; Java et al., 2007; Prieur et al., 2009), these methods are “less suited to responding to research questions ... that seek to understand how, why and with what consequences” subjects like Stage IV breast cancer patients use social media. Methods associated with conventional ethnographic practice, such as interviews or participant observation (Cox et al., 2008; Humphreys, 2007; Komito, 2011; Miller, 2011) provide greater freedom to answer these questions, and “allow us to refigure social media as a fieldwork environment that is social, experiential and mobile” (Postill & Pink, 2012, p. 125).

By taking an ethnographic approach to the social media activities of four terminal breast cancer patients, this article aims to help fill the gap in knowledge about the potential impact of social networking sites on Stage IV breast cancer patients. The goal is to help illuminate the less frequently told narrative of metastatic breast cancer in an effort to better understand how social media may affect the way metastatic breast cancer patients live with their illness, and to what extent, if any, the expression of their stories in social media may shift the edges of illness narratives. The four women profiled here use social media to publicly share their experience living with metastatic breast cancer. Their motivations vary but include: helping other metavivors cope with their illness; advocating for breast cancer research (and against “awareness”); and furthering their own understanding and response to a terminal diagnosis. Using critical ethnography as method and example,³ the goal

of this work is to “challenge institutions, regimes of knowledge, and social practices that limit choices, constrain meaning, and denigrate identities and communities. ... to make accessible ... the voices and experiences of subjects whose stories are otherwise restrained and out of reach” (Madison, 2011).

Among the Metavivors

This section summarizes the illness narratives of the four subjects: Sally, Jane, Jenny, and Grace. Frank (2013) acknowledges that everyone’s illness narrative has elements from each of the three archetypal stories. This is also true of the four stories recounted here, but each woman’s experience has an overall trajectory that fits best within one of the three categories of quest, chaos and restitution. I reviewed the public and “friends-only” social media postings of the three women who graciously gave consent to use their material, but was unable to get a signed consent form from Jenny before she passed away. The material in this article is based on Jenny’s public YouTube video archive.⁴

I am a metastatic breast cancer patient who became aware of all four women in social media fora dedicated to discussions among metastatic breast cancer patients. Each of these women was like a beacon of light in the fog when I was newly diagnosed with metastatic breast cancer. I had never really been sick before, I knew absolutely nothing about cancer, and I had no idea what “metastatic” meant, except that it was bad (a clue I picked up from the tone of my oncologist). As a single, 50-year-old college professor from the East Coast of the US, I believed that I had little in common with Jenny, a 32-year-old housewife and mother from central Texas. And yet the honesty with which she spoke of her disease and its relentless progression (she died less than 3 years after diagnosis) gave me hope: If she can carry on despite these terrible things, then perhaps so can I. I met Grace at a breast cancer conference, and we struck up a friendship. She has shared her miraculous story on several online communities – she may have been

“cured” of metastatic breast cancer. Sally inspired me with her sharp wit and her drive to Do Something, compelling me to become involved in breast cancer patient advocacy. Jane and I share a similar diagnosis of HER2-positive metastatic breast cancer, although she has had progression in her brain while I continue to be NED (“no evidence of disease,” a temporary state that indicates neither PET-CT nor tumor marker blood tests can detect any cancer in my body, but does not mean that it won’t come back, and it is not the same thing as “cured”). We found ourselves comparing notes in the same online communities.

Sally: The Quest to Survive a Plague

Yet another woman with metastatic breast cancer has died. Sally publishes a video on social media, her expressive features made more prominent by her bald head. She is crying. “Every time this happens it kicks me in the gut. Her family is going through exactly what I know my family is going to go through very soon.” As Sally and every other metastatic breast cancer patient knows, the drawback of joining online communities comprised of people living with a terminal disease is that announcements of death occur with alarming frequency. In one large Facebook Group with more than 2,500 members, several people may die in a single week, a fact that is perhaps made more depressing by the introduction of the freshly diagnosed into the club, which keeps the membership numbers stable. In the Spring of 2015, Sally attended her first metastatic breast cancer conference where the participants organized an impromptu “die-in” by laying in the hallways of the hotel, pretending to be dead. After the conference was over, Sally reflected on the realities of her new-found friends: “I may never see these women again. I love them, and I don’t want them to die, but there is no cure for metastatic breast cancer. And so I know that next year, some of them won’t be back to the conference. And it won’t be because their lives are too full. It will be because their lives were too short.”

Before her diagnosis, Sally was a successful civil rights attorney

who had built a following as a “mommy blogger.” She has chronicled her life with breast cancer and as a breast cancer advocate with the same smart and direct approach that attracted the alt-mommy audience. She found a lump during a breast self-exam in the shower and was diagnosed Stage IV from the start in 2014. She often criticizes breast cancer money spent on prevention and early detection: “none of that research led to the detection of my cancer. I had to find that tumor myself. And now it would be pretty awesome if some of those research dollars that did me no good could be spent on saving my life instead.”

Sally often compares metastatic breast cancer advocacy to the AIDS movement, and encourages her audience to help “[end] this plague that has taken too many of my friends and will take too many more of them before a cure can come.” She co-founded a metastatic breast cancer advocacy organization with women she had met through social media. She saw the need for an organization similar to the AIDS activist groups that helped convert AIDS from a death sentence to a chronic illness. She writes about the similarities between metastatic breast cancer and the AIDS epidemic as depicted in movies like *And the Band Played On* and *How to Survive a Plague*: she has a lot of friends who die; their deaths are not reflected on the evening news; she worries that every ache and pain could be a symptom of cancer; researchers seem more interested in preventing metastatic breast cancer than curing people who have it; and people at risk for developing metastatic disease, particularly early stage breast cancer patients, are not warned of the possibility. “It’s not set in stone that people have to keep dying this way. What has to happen is research,” Sally writes. “Only by demanding that researchers save our lives will we have a shot at living a full lifespan.”

It is easy to see why Sally looked to AIDS as an advocacy model to save the metavivors. A movement that started in a New York apartment as the Gay Men’s Health Crisis in 1981 evolved into a worldwide campaign where the demands of patients drove scientific research in support of treatment for what was then a death sentence. Epstein (1996, p. 8) writes that AIDS drove “the first social movement in the United

States to accomplish the large-scale conversion of disease ‘victims’ into activist-experts.” The gay men who were the primary victims of AIDS in the 1980s had been schooled by the culture wars against them in the U.S. in the 1970s, and were uniquely prepared to fight social ostracism, medical bureaucracy and governmental indifference to force an agenda of scientific research and medical treatment. Lay AIDS activists, outsiders to the medical establishment, became medical researchers. They funded traditional paths of medical research, and raised money to investigate new ones. Unhappy with the long processes of drug testing and approval, the AIDS activists insisted on change, often employing noisy and even violent protests to make their point. Through these non-traditional channels, Epstein finds, AIDS activists gained enough of a voice in the scientific world to influence NIH-sponsored research.

While the AIDS movement is the most successful model for creating patient-activists, breast cancer advocacy does not face the same challenges. Led by Susan G. Komen for the Cure, which draws in more than \$250 million per year in donations (Barrett, 2017), breast cancer is the beneficiary of what is perhaps the most-successful US public health campaign ever, with the entire month of October dedicated to walks, remembrances, fund-raising and other awareness activities (Hill & Thompson-Hayes, 2017). Breast cancer receives more media coverage than any other cancer (Hurley, Riles, & Sangalang, 2014). Breast cancer research receives the largest amount of funding for any disease, \$120 million per year, from the U.S. Department of Defense’s \$1.1 billion Congressionally Directed Medical Research Program (Department of Defense, 2017). It is not a lack of awareness, lack of social support or lack of funding for breast cancer that prevents metastatic breast cancer from becoming a chronic disease, advocates like Sally would say. Rather, it is a lack of focus. The awareness campaigns of “pinktober” often overlook or exclude Stage IV patients because they fail to meet the standard restitution narrative. News organizations are also slow to cover Stage IV patients for the same reasons; celebrities with breast cancer are less willing to reveal a metastatic diagnosis. On average, less than 5% of

money raised by the popular breast cancer fundraising movements goes to research that will benefit metastatic breast cancer patients (“Why We Need You,” n.d.). “Metastatic patients are just fundamentally different from early stage patients,” Sally writes. “We aren’t part of the pink party narrative, and we’re never going to be. ...Imagine if NCI had a dedicated metastasis research program, with metastatic patient advocates and doctors specializing in metastatic cancer treatment and bench researchers focused on understanding metastasis. Instead of trying to incorporate metastatic cancers into the existing organ-of-origin structures of cancer research, give us our own programs.”

Sally eventually succumbed to metastatic breast cancer, 3.5 years after being diagnosed. She continued her advocacy work until the end, sending written remarks to a gathering of metastatic breast cancer patients at a Washington, DC, die-in just 3 weeks before her death. She put her hope in scientific research to find a cure, or at least a treatment to keep her, and others, alive a little longer and a little longer more, until a cure could be found.

Jane: The Quest to Save Your Own Life

Research has proven a fruitful avenue for Jane, who, even in a photo, radiates intensity from piercing blue eyes. Narrowly escaping death by brain tumor, recovering only to be handed the grim diagnosis of leptomeningeal metastasis (“basically, cancerous meningitis”), she undertook a quest to save herself through the power of research and self-observation. “I call this my epic battle,” she writes. Two years later, she is still alive, thanks to a regimen she negotiated with her medical team, who credit her with stabilizing her disease and extending her life. Jane is the first to post dense peer-reviewed medical journal articles in the social media circles of metastatic breast cancer patients. For example, she posted a link to this article: “Dexamethasone Interferes with Trastuzumab-induced Cell Growth Inhibition Through Restoration of AKT Activity in BT-474 Breast Cancer Cells.”⁵ Fortunately, she also offered a

helpful translation: “Gals, unless you are getting chemo, there is no reason to be taking dexamethasone/decadron (steroids) with HER2 targeted therapies. ... [I]t might actually prevent Herceptin from working well.” This post generated a fair number of reactions and comments, and is an example of Jane’s role as an “explainer,” a social media participant who helps others navigate dense medical research (Jacobson & Kashian, 2018).

Like the AIDS activists before her, Jane does not trust the scientists and researchers to save her, but takes matters into her own hands. Jane was pronounced “cured” of early-stage breast cancer after undergoing chemotherapy, surgery and radiation. But she started having odd symptoms, including migraines, muscle aches and dizziness. She contacted her medical team, but none of them connected her symptoms to a potential brain tumor. Six months after finishing early stage breast cancer treatment, Jane underwent an emergency craniotomy to remove a 5cm metastatic breast cancer tumor in her brain. “Basically anyone with brain [metastasis] is dealing with an under-researched condition,” Jane writes. While recovering from brain surgery, she felt the onset of neurological symptoms. Again, her doctors told her her symptoms did not seem to be related to her condition, and, six months after her craniotomy, an MRI showed that the cancer had spread to the lining of her brain, a condition referred to as leptomeningeal disease. “An absolute worst-case scenario,” Jane writes.

She waited for a plan from her oncology team that never materialized. She took matters into her own hands. She checked herself into the ER, where she convinced her team that, based on her research, the best treatment for her would be to receive the anti-cancer drug Herceptin intrathecally, directly into her brain. At the time, this was a novel treatment for breast cancer patients that had been given to only a handful of people, but had shown promise for treating leptomeningeal disease. “[This situation] further reinforces to me that I need to be my own advocate because on their own [the medical establishment] will try to kill me with the same-old, same-old and the path is littered with corpses

to attest to that,” Jane writes.

Like Sally, Jane believes that research is the best hope to save her. Like some of the AIDS activists, Jane works with information and treatments that are already available, making her own evaluations of therapies that her doctors would not have suggested for her, and making connections to complementary therapies, like hyperbaric oxygen therapy, which some research suggests can help improve the efficacy of radiation to the brain (Stępień, Ostrowski, & Matyja, 2016). It is perhaps because of the legacy of the AIDS movement that Jane was able to find members of the medical establishment willing to treat her based on her self-researched recommendations. Jane’s protocol has been a model for other patients with leptomeningial disease. Breast cancer patients on social media who receive a diagnosis of leptomeningial metastasis know to look for Jane for advice. She is being cared for by several major cancer hospitals in her area, “so all of these facilities are being schooled by me at the same time. As if almost dying three times wasn’t enough, this only adds to how surreal it all feels.”

Frank sees parallels between the quest narrative and Campbell’s hero’s journey. But many Stage IV patients abhor the idea that cancer is a “journey,” a description that implies that the narrator takes part willingly. Neither Jane nor Sally chose to become cancer advocates, although this turned out to be a quest that both were equipped to undertake. They might both say that the research and advocacy quests are not theirs alone (although it might help them), but rather it is one that they share with and on behalf of other metavivors. Sally founded an AIDS activism-inspired advocacy group to fight for research to effect a cure for herself and other metavivors. Her group has shaken up some of the complacency of metastatic patients and the organizations serving them to push for more money for research and a cure. Jane is known among the metavivors for her skills in researching medical and biological factors that may impact her treatment and the treatment of other patients. Both Sally and Jane have heeded Lorde’s advice about not keeping silent, sometimes coming into conflict with the established breast cancer

philanthropies or the medical establishment itself. Lorde's (2006) words are fitting here: "But for every real word spoken, for every attempt I had ever made to speak those truths for which I am still seeking, I had made contact with other women while we examined the words to fit a world in which we all believed, bridging our differences."

Chaos: A Public Death

If you watch Jenny Cooper's YouTube videos before she was diagnosed with breast cancer, you see a happy-go-lucky 32-year-old mom of two who enjoyed making goofy videos to share with her friends. In 2013 she adopted a fitness regime, changing diet, changing exercise habits, and documenting a significant weight loss that left her feeling good and optimistic about the future. Her YouTube habit was consistent, and her small audience grew from double-digits to triple-digits. Then, one year and 98 videos into her YouTube project, she recounts the familiar story of feeling a lump in her breast. Less than three years later she was dead, having reached the median survival of 2-3 years.

In her very first breast cancer video, she describes how she felt a lump, confers with her family, gets a mammogram, followed by a sonogram, then an MRI and a biopsy. In a single 14-minute take, she recounts her conversation with the diagnostician, as she struggles to keep her composure. "I don't mind getting breast cancer. I knew that I was going to get it. I just am scared of being sick, and I don't want my kids to see me sick," she says. "And I don't want to cry because I have been crying a lot all day. And my face hurts, and my eyes are all blurry, and my face burns. The tears burn my face today."

One week and two videos later, she tells us that the doctors are waiting for the pathology report to determine what kind of breast cancer it is so that they can create a plan for treatment. Fatefully, she says: "Hopefully it will come back and it will not be triple negative. Triple negative is a very, very hard cancer to fight. It does not respond well to chemotherapy. The average lifespan of a triple-negative is five years." In

the next video we learn: “It’s triple negative breast cancer.”

We follow her journey through treatment for early-stage breast cancer: Surgery for placement of a port for chemotherapy, 12 rounds of chemotherapy, a hysterectomy, surgery for mastectomy and radiation. Then, 47 videos and just over a year later, the results of a CT scan finds evidence of incurable metastatic disease in her diaphragm and lymph nodes. The mother of two says: “I will do chemotherapy until I physically, or emotionally, cannot do it anymore.”

The rapid downward spiral of Jenny’s health is reminiscent of a reality TV program edited for maximum dramatic effect. Less than one month later, she finds a bump on her head – the cancer has metastasized to her skull. Two months later they find a small lesion in her brain. One month later an MRI shows her brain tumors have quintupled size. Jenny recounts the clinical information that she has received from her doctors – size of tumors, method of radiation. “I’ve had so much chemotherapy, I’ve had my breasts cut off, I’ve had a hysterectomy. But this is the scariest thing I have to do. The reality of this is that I could lose a lot of who I am to this treatment.... It’s like you are damned if you do and you’re damned if you don’t.” She wipes away the tears. “Man, walking into this is terrifying.”

Jenny’s story underscores the loss of control characteristic of the chaos narrative. Her Internet audience watches helplessly as the aggressive nature of her disease takes away first the hope for a cure, then hope for successful treatment, and finally the possibility of a future. The audience bears witness to Jenny bearing witness to her approaching death. She takes what control she can of the situation. Jenny never used social media to investigate complementary therapies or search for clinical trials. But she did use her platform to address her audience on topics like *Death with Dignity* and what it was like to be a parent dying of cancer.

Unlike Sally and Jane, Jenny does not believe in the power of research to save her. As Jenny herself knew, triple-negative breast cancer can be difficult to treat, and while only 10-20% of breast cancers are triple-negative, it has the poorest survival prognosis (Fallahpour, et.

al., 2017). She does not research possible existing treatment or complementary therapies as Jane does. Jenny lives the chaos narrative, but she takes control where she can, like on her YouTube channel. She recorded her last video about six weeks before her death. “[I]f you’re watching this video... I’ve passed away. I never thought that I would die at the age of 34. I certainly never thought that I would be leaving behind two children and a husband. ... The last two years have been the most intense two years of my life. When you get cancer, it is such an eye-opener as to what is important and what’s not important... If you see my kids, please tell them, always, it does not matter how often you see them or how old they get. Please tell them that I loved them oh, oh, oh so very much. And that the idea of leaving them broke my heart.”

Restitution: The “C” Word

Grace is a down-to-earth mother of two boys and a recently retired engineer. She is extremely active and healthy. Her diagnosis of Stage IV breast cancer in 2013 put a hold on her plans to pursue a second, “retirement” career as a nurse. In her soft Texas twang, she is happy to tell you how she went from being “a goner” to “I think I’m cured.” Grace participated in a clinical trial that has shown excellent results for a handful of patients. She has become a poster patient – what she calls “a prize guinea pig” – for cancer research. Her case was cited in Congressional testimony as an example of how research may lead to cures for cancer that were once thought incurable.

Grace was initially diagnosed with DCIS (ductal carcinoma in situ) in 2003. DCIS is sometimes referred to as “Stage 0,” a pre-cancerous condition. She had a modified mastectomy with no chemo or radiation. “My oncologist at the time pronounced me ‘cured,’” Grace says. “For years, I eschewed the pink ribbons because I did not consider myself a ‘survivor.’... So, while I had surgery, I did not have chemotherapy or radiation. I didn’t feel like a ‘real’ cancer patient.” Most early stage breast cancer patients are told they are “cured” when they finish treatment.

Unfortunately, about 20-30% of them, like Grace, will develop metastatic breast cancer, sometimes months, sometimes years or decades later (“Incidence and Incidence Rates,” n.d.). The restitution narrative so strongly associated with early stage breast cancer does not allow for relapses, and many metastatic breast cancer patients who were first diagnosed with “curable” early stage disease are ill-prepared to face a “terminal” diagnosis.

In 2013, the cancer came back. It spread from her breast to her lymph nodes to her chest wall and sternum. Her cancer proved to be virulent, and Grace blew through a dozen drug combinations in two years. In Summer 2015, Grace learned that her disease had progressed on her 10th drug combination. “I would probably be a little more desperate as I know that there is really nothing conventional left for me,” Grace wrote. “Fortunately, I have a plan.” Grace had attended a breast cancer advocacy meeting and met a doctor who was involved with breast cancer immunotherapy. “She thought that I would be eligible for one of their trials.”

The treatment worked. Grace has continuously posted updates of her progress. By March 2017 Grace was going on hiking expeditions and solo kayaking excursions. In Grace’s case, research does seem to have saved her.

The medical establishment is reluctant to apply the term “cure” to Stage IV cancer patients, as Stage IV is defined by contemporary medical institutions as incurable. Metavivors are also often reluctant to accept the status of “cured” for one of their own, as they fear it may further the popular misconception that all breast cancer is “curable.” Jenny, Grace and Jane were all first diagnosed with early-stage disease. If the pink restitution narrative may be applied to Stage 0-III, why not to those few Stage IV patients who beat the odds? The Metavivor experience includes the possibility of cure, even if the narrative is one of inescapable death. Surely the “restitution” story is Grace’s to tell, as today she is healthy again, but tomorrow she and, eventually, all of us, will be gone.

Conclusion

The tropes of restitution, chaos, and quest outlined by Frank are poetic archetypes for people living through and seeking to understand the impact of illness. Metavivors occupy a liminal position between a fatal disease and one that may become a chronic condition in their lifetimes, thanks to rapid advances in medicine. But it is their willingness to share their stories on social media that enables these stories to press against the edges of the three narrative types. These stories are not told solely for the benefit of the tellers; rather they are told for the benefit of others, for the social networks, real and virtual, that make up these women's lives. In turn, the social networks send feedback to each of our metavivors, shaping their quest, providing support in the face of chaos or creating a following for a story of a potential cure with both hope and suspicion. The metavivors use social media to tell their stories to one another in real time. Their stories shape-shift as they interact with each other, as the "produsage" model of social media turns readers into responders who in turn influence the storytellers.

One shift the metavivors create in Frank's paradigm of the quest narrative is the emergence of the theme that "research will save us." This is a logical development inspired by the success of the AIDS movement, which gave patient-advocates a seat at the table where biomedical research agendas are made. However, while it is true that only new treatments will slow or reverse the course of metastatic disease, a focus on research perhaps invites an over-emphasis on "the languages of molecules and drugs," as Kleinman (1988, p. 266) has noted in the treatment of chronic illness. Sulik (2009, p. 1063) found that patients dealing with a chronic illness may develop what she calls a "technoscientific identity" for managing their illness that increases their "reliance on medical authority and technoscience," and may limit "the full range of discourses available to patients."

Metastatic breast cancer complicates the restitution narrative of early-stage disease on two fronts: first, some "survivors" of the pink

narrative go on to develop metastatic breast cancer, and a small number of Stage IV patients may die with their disease instead of it. “[I]gnorance about cancer is maintained, in part, by the rehearsal of stories that have standard plots and features, and that suppress or displace other stories,” Segal (2007, p. 3) writes. Suppressing the metavivor story does a disservice to the “survivors,” who are doubly wounded by a terminal diagnosis and the lack of information about the possibility of recurrence, and the metavivors, who find themselves outside of the pink survivor movement, armed with less readily available information and fewer resources dedicated to their disease. Social media may create spaces for these stories to be told in communities of situated knowledges, but these spaces still sit outside the mainstream. Meanwhile, treatment advances that continue to extend the lives of these patients and the proliferation of social media that make it possible for the metavivors to share their experiences with each other may yet refashion the archetypes for metastatic disease.

Notes

¹ “Metavivor” is a term coined by the advocacy group [metavivor.org](http://www.metavivor.org) to differentiate people living with metastatic breast cancer from the “survivor” rhetoric that surrounds early-stage breast cancer. The term “metavivor” is used here to differentiate Stage IV from early-stage breast cancer patients and is not used as a direct reference to [metavivor.org](http://www.metavivor.org). “Scan, Treat, Repeat” is a trademark of The Metastatic Breast Cancer Network <http://www.mbcn.org/>

² “Scan, Treat, Repeat” is a trademark of The Metastatic Breast Cancer Network <http://www.mbcn.org/>

³ The author is a breast cancer patient who has, to paraphrase Hammersley & Atkinson’s (2007, p.3) definition of ethnography, participated in the subjects’ postings on social media for an extended period of time, watching what happens, listening to what is said, asking questions and collecting documents.

⁴ You can see Jenny’s YouTube video archive at: <https://www.youtube.com/user/jparcoop>. It must be noted that Jenny’s

YouTube account name is “Coopdizzle,” a portmanteau of her name and an appropriation of language from hip-hop culture.

⁵ Sumikawa T, et al. (2008) Dexamethasone interferes with trastuzumab-induced cell growth inhibition through restoration of AKT activity in BT-474 breast cancer cells. *International Journal of Oncology*, 32(3):683-8.

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