

“Affective Economies in Crowdfunding for Cancer”
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Cancer, Crowdfunding, and Capitalism

In 2007, medical anthropologist Lochlann Jain called cancer “the perfect capitalist disease,” given that the amount of time that typically elapses between a carcinogenic exposure and a diagnosis of cancer affords the manufacturers and distributors of toxic substances enormous amounts of cover. Pointing to the ways that production contributes to cancer epidemiology, generating profits for pharmaceutical interests, insurance companies, and health care providers, and critiquing misdirection campaigns by corporations and private foundations touting breast cancer “awareness,” Jain’s critique illuminates how cancer epidemiology is entangled with economic processes.

Cancer illuminates other aspects of late capitalism – some of which Jain’s acute analysis of cancer economies only began to anticipate, because at the time of their book’s publication, these issues had not materialized. In recent years, cancer has come to generate diverse forms of value in crowdfunding economies, which I consider as an instantiation of what the sociologist Eva Illouz (2007) calls “emotional capitalism.”

As is widely known, crowdfunding is a form of alternative finance in which individuals make appeals for small donations via a third-party online platform. First used in the early 2000s as a way to support commercial ventures and creative undertakings, crowdfunding has come to serve as a source of funds for diverse types of charitable causes. Over the past decade, the sector has experienced significant growth, largely resulting from the proliferation of campaigns to

offset the costs of medical care in the U.S. Currently, one in three of all new crowdfunding campaigns is a request for assistance with medical bills or other costs associated with illness (Advisory Board 2018). Appeals for medical costs make up the largest category of crowdfunding campaigns as well as the most lucrative part of the charitable crowdfunding market in the United States, raising \$650 million annually in donations (McClanahan 2018, Zdechlik 2018).

Owing to the complexity and expense of oncological therapies and care provision, the increasing annual numbers of cancer diagnoses in the United States (CDCP 2018), and – arguably – to its strong emotional charge, cancer is the single most significant driver of the medical crowdfunding economy. Of the 250 million new medical crowdfunding campaigns launched annually in the U.S., fundraisers for cancer patients are estimated to account for almost half (Litman-Navarro 2018) – a finding that aligns with a growing research literature documenting the unique “financial toxicity” associated with cancer (c.f. Zafar et al. 2013). A recent nationally representative study found that two years after diagnosis, average losses among persons with cancer totaled over \$90,000, with over half of all patients experiencing house repossession or bankruptcy and 42% of patients having spent their entire life’s assets (Gilligan et al. 2018).

Given this background, the median ask of a crowdfunding campaign for cancer has been found to be relatively modest, just \$10,000 (Cohen et al. 2019). Though some individual campaigns are extremely lucrative, investigators found that median total fundraising is less than 25% of this target, averaging just above \$2,000 (Cohen et al. 2019). In this regard, crowdfunding functions for many as a source of “cruel optimism” (Berlant 2011), inspiring hope but ultimately also leading to disappointment. Indeed, as one medical oncologist commented to me when I

shared this data point: “Two thousand dollars would buy just a *sniff* of Herceptin (a chemotherapy drug used to treat breast cancer).”

The robust performance of medical crowdfunding campaigns in the aggregate (if not in individual cases) suggests the ability of digitally disseminated illness narratives (Kleinman 1988) to mobilize the sentiments of a broad public. Insofar as appeals generate, mobilize, and channel the affective states of prospective recipients and potential donors, crowdfunding operates as what the feminist scholar Sara Ahmed (2004) has termed an affective economy – a vehicle for circulating emotions between people as a quasi-economic system of exchanges. In this discussion, I’ll be presenting some early research findings to suggest what animates this economy, and what effects its circulations have on participants.

Literature Review

Research on the affective dimensions of crowdfunding is still in first stages. One journalist has offered the common-sense hypothesis that crowdfunding economies reward “the most heartrending stories” (Heller 2019), with funding preference shown to patients with rare or incurable diseases, for example. Empirical studies have suggested that this premise may, at times, be borne out – but have also indicated that the associations between affect and funding patterns may be complex in practice. For example, an exploratory mixed-methods study showed that crowdfunding campaign narratives explicitly foreground the social worth of ill patients as workers, family members, and community members – suggesting that those who develop crowdfunding campaigns may be aware that social perceptions of an ill individual’s apparent pathos, charisma, moral status, or worthiness will influence fundraising (Berliner and Kenworthy 2017). Kenworthy et al. (2019) also found that “marginalized race and gender groups are

associated with poorer fundraising outcomes,” suggesting that biases experienced as affects (c.f. Ahmed 2004) may inform crowdfunding economies. More concretely, a recent quantitative study has suggested that campaigns are funded most quickly when the patient is an infant girl, when campaign descriptions are easy to read, and when campaigns are begun around holidays – with the highest funding speed found for campaigns begun around the Christian holidays Easter and Christmas. The investigators attributed this latter finding to what they termed a “warm glow effect” (Proelss et al. 2018).

As these findings suggest, patterns of economic transfer in crowdfunding may relate not to the objective medical or financial needs of ill patients. Instead, these exchanges are evidently informed by subjective, non-cognized responses that are culturally and socially shaped – e.g. the “warm glow” of the Christmas season, the pathos inspired by a young child’s illness, or the sense of identification sparked by the narrative of a sick person who resembles oneself demographically. However, on the recipient side, as my research suggests, the affective circulations are potentially more complex. Crowdfunding exchanges raise discomfiting questions about a subject’s worth, deservingness, ability to reciprocate, and relative position in a hierarchy of suffering and need. They raise both practical and existential questions regarding the conflicted position that crowdfunding subjects occupy, posed between an ideal moral economy (c.f. Thompson 1971), in which ill individuals can be perceived as normatively deserving, and an “attention economy” in which even very serious illness may be perceived as quotidian, unremarkable, and unmoving.

Methods

To say a brief word about methods, these findings come from a set of open-ended interviews that I began conducting with cancer patients and survivors in the Bay Area this past

Fall. The individuals I quote responded to recruitment announcements posted to listservs for cancer survivors or to posters at a large hospital dedicated to cancer care. A sample of eight respondents, all female, aged 32 to 49, provided informed consent to be interviewed and their commentary was tape-recorded, transcribed, and analyzed for thematic content using the qualitative analysis software ATLAS.ti. Six respondents were cancer survivors and two were close supporters of survivors. I was given permission to review the crowdfunding pages of all respondents and retained these for qualitative analysis. Data collection is currently in a pilot phase and will be enrolling additional respondents and adding a participant observation component in the coming months.

Findings

At the outset of conversations, the individuals I interviewed described crowdfunding as playing a positive, even affirming role in their lives. They described an experience of humbling gestures of compassion from a community of family, friends, and sometimes also strangers: an affective economy of solidarity, generosity, and recognition. These endorsements concurred in ways with the paradoxically effervescent, even festive optimism of so-called “pink ribbon culture” (c.f. King 2006, Sulik 2012) which has in recent decades reshaped the cultural profile of breast cancer in particular; beyond this, some suggested how crowdfunding had become an important part of their existential “journey” of diagnosis and treatment. Shereen, a 35-year-old San Franciscan who had been diagnosed with metastatic cancer, described her crowdfunding campaign in optimistic terms:

...the Kickstarter was a super cool way for people to be like, “I see you, I’m with you. It’s this way that I can help.” (...) My mom's best friend, who had gone through breast cancer and was also very wealthy, gave me a thousand dollars –

which was amazing, really. (...) I joked about how since I'm never gonna get married, this is like my registry. (...) I had so many people be like, "(...) I want to help fund the *fun* parts of your life, not just the PET scans. We'll get the PET scans covered. But this is for fun. This is for joy." (25 September 2019)

Emotional labor and impression management

This enthusiastic endorsement notwithstanding, respondents' commentary about the experience of crowdfunding made me aware that these exchanges can prompt ambivalent feelings for cancer patients. Notably, while respondents sometimes described crowdfunding pages as having a therapeutic or cathartic aspect, it also appeared from comparing their interview commentary to their pages that having a successful campaign precluded the acknowledgment of certain kinds of negative experiences. Survivors were often willing to recount quite traumatic experiences in our interviews – particularly, it seemed, when they were aware that I was also a cancer survivor – telling me that their cancer “journey” had included abandonment by friends, family members, and partners, inadequate or inappropriate medical care, and negative outcomes like surgical failures or dependency on prescription painkillers. They also experienced what cultural critic Sianne Ngai (2005) terms “ugly feelings” – ignoble, unvalorized, and non-cathartic sentiments, “in which action is blocked or suspended” such as guilt, anxiety, and trauma. Overwhelmingly, these feelings and experiences were not acknowledged in crowdfunding campaigns, which instead typically emphasized patient biographies, information about diagnosis and treatment plans, and justifications of the financial “ask” that was presented.

Catherine, 49, struggled with her diagnosis of stage 0 breast cancer, in part because it conflicted with her professional image as a detox coach and a specialist in naturopathic cancer

prevention, and in part because her mother had died of breast cancer at 45. After being diagnosed, she explained, “I just would go to work. And then I would cry all the way home, driving crying, come home, have some dinner and then just cry all night. (...) It was terrible making decisions. My friends would ask, Well, do you want to do this or this? What do you think if people bring meals and *blah, blah, blah, blah*. I was just paralyzed.” But by contrast, Catherine’s crowdfunding page, which her friends had helped her write, emphasized how fun and outgoing Catherine was, pointed up her good chances of recovery, and updated followers about Catherine’s course of treatment in optimistic terms – showing Catherine to be the respectable, relatable “real-life superhero” that Paulus and Roberts (2017) have identified as a common trope in the texts of medical crowdfunding campaigns.

As this suggests, respondents described an awareness that the mores of social media and of cancer patienthood demanded a particular kind of warmly positive affect in order for a campaign to circulate and generate good returns – essentially, that good feelings were currency in an economy of feelings. As Lauren, a 34-year-old biologist who had been treated for early-stage breast cancer, asked rhetorically: “Who wants to give money to a negative Nancy?” Respondents also noted that the emotional labor (Hochschild 1983) required to manage a crowdfunding campaign could be significant, particularly insofar as it required that one present a coherent narrative during a time of great personal uncertainty and mandated adhering to normative cultural scripts for patienthood. Lauren commented “It’s exhausting to write [updates] and remember stuff. I feel kind of like, ‘Give the people what they want!’ – wanting to be upbeat and positive and give good news” (8 October 2019).

Along similar lines, Shereen showed me her crowdfunding campaign on her cell phone. Given the challenges of her Stage IV diagnosis and the intensive treatments she’d received, I was

impressed by the upbeat text headed by pictures of her goofing around with friends during chemotherapy. “These are so happy and positive,” I commented, and Shereen agreed: “That was my shtick, happy and positive – to get the money. (...) I never shared the negative on Facebook. Ever.”

Guilt and obligation/responsibility

Recipients particularly felt pressed by the need to thank their donors, which is one of the administrative functions permitted by the GoFundMe platform, but felt challenged by the prospect of appropriately acknowledging what they described as unrepayable gifts. Shereen said “At some point, I was like, ‘I’m going to write thank-you notes.’ But there were so many people who contributed. It was a pretty overwhelming, and then I had a lot of shame about that. I was like, ‘These people saved my life. ...What does it mean to send them a bulk email? What kind of monster am I?’”

Crowdfunding cancer patients also expressed the awareness that crowdfunding can raise questions around fraud, manipulation, and misuse of funds. The individuals I spoke to therefore felt a strong obligation to make responsible choices about their management of these monies, even though they recognized these gifts had been freely given. Catherine worried that her friends should be supporting other community members with more serious diagnoses, wondering whether they should have given her money at all. Lauren felt she should have treated her crowdfunding revenue as an investment:

...I feel guilty about spending all my GoFundMe money, even though that's what it's for. Even though like it's gone to copays and acupuncture and helping me get

by, which is what it's intended to. I feel if I was a really responsible person, I would have just put it in a health savings account and I could just continue using it – but then, how would I have helped pay rent and all of it? (30 October 2019)

Attention economies

To close, let me briefly highlight one last aspect of the emotional/economic relays in crowdfunding for cancer – specifically the issue of how patients succeed or fail in commanding “attention” – a cognitive/affective resource, transferable between subjects, which anthropologist Nick Seaver (2018) has usefully glossed as “a generic way to talk about what we value.” This came out in conversation with Regina, who had helped organize the campaign for Catherine’s breast cancer. Catherine had required two surgeries and was unable to work for a significant period of time after each procedure. Regina confirmed that donations had failed to chart the second time around, and she sensed a collective unwillingness to continue extending the generosity and recognition that accompany the “sick role” (Parsons 1951), despite the significant financial hardship that Catherine continued to face. Here, we might wonder about the temporality of electronically mediated affects – which are shaped in part by algorithmic manipulation – and consider the ways that this form of alternative finance may disrespect the time scales of cancer, chronic illness, and temporary or permanent disability:

I think also people didn't donate as much the second time because they're kind of done. Tapped out. Like, 'I gave once. I'm not going to give twice.'

Conclusion

As early research has suggested, medical crowdfunding – on its face, a prosocial charitable practice – may threaten to create a hierarchy of care in which patients who inspire

certain kinds of “public feelings” will enjoy disparate access to significant sources of financial and social support. As my early research findings suggest, we should also be concerned about the unspoken social demands for patients to leverage their experience and self-representation as currency in exchange for the mediated affirmation of a supportive public. In particular, cancer patients who experience sentiments that do not accord with the cultural image of a “cancer warrior” may encounter add burdens insofar as crowdfunding campaigns tacitly compel them to express affects of hopeful optimism and fortitude that do not accord with their lived experience. Given the low returns on crowdfunding campaigns by cancer patients, public health practitioners and advocates for health care reform can credibly point to the extractive nature of crowdfunding mechanisms, insofar as these cancer economies demand the production of affective values by vulnerable patients while offering only marginal and unpredictable forms of return.

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