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"Courage Drives Us": Narrative Construction of Organizational Identity
in a Cancer-Specific Health Non-Profit Organization

by

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A thesis submitted in partial fulfillment
of the requirements for the degree of
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Abstract

Health care organization's functioning and operating within the complex and shifting landscape of the U.S. health care system develop and publicize narratives that inform audience members about the organization, such as who is being served (clients/patients), what problems the clients are facing, what the clients need, and how they should be morally evaluated. For this study, I am focusing on the research questions: (1) What kinds of images of organizational work are promoted by publicly broadcasted stories of "typical clients"? (2) What types of work do these narratives do? I employ a narrative perspective to analyze publicly broadcasted stories featured on the Austin Brody Cancer Center (pseudonym) (acronym: ABC) website. Health care organizations, like ABC, construct and publicly broadcast stories that utilize widely circulating systems of meanings, thereby producing an image of a specific type of person. From an "oppositional reading" lens, the patients' stories act in a manner that directs attention away from the institutional structures of the U.S. health care system, while the dialogues of morality (re)produce social hierarchies and systems of domination. This, of course, is not the reading ABC encourages. Within this public, virtual space, these stories are about patients evaluated as 'inspirational.' Explicitly, these patients are to be models emulated by others. Analyzing the stories that cancer-specific organizations publicly broadcast offers insights into how images of patients are constructed. This is a necessary step into understanding the expectations and obligations of patients and physicians, as well as how organizations facilitate the relationship.

Introduction

Narrative, public policy, and organizational studies literature suggests that, in order for organizations to persist, they must develop organizational narratives that justify their procedures and services (Bublitz et al 2016; Kusow and Eno 2015; Loseke 2007). For example, organizational scholars have shed light on how organizational actors create narratives that construct their organizational identity. Organizational identity refers to the organizational actors “collective perceptions and shared understandings of what characteristics are central, distinctive and enduring” (Ravasi & Schultz 2006 as quoted in Ran & Golden 2011:420) to the organization. In particular, organizations may use media, awards, rankings, and communications, board, managers, and human resource management practices to construct (and control) their identity (Dhalla 2008). Ran & Golden (2011) propose that organizational identity is intentional, temporal, relational, and external.

For this reason, this paper is focused on meaning-making, and therefore is situated within an interpretive/constructionist approach. The main objective is to explore how a cancer-specific health non-profit organization (NPO) integrates patients’ stories into their publicly broadcasted organizational narrative. Health nonprofit organizations (NPOs) play an important role in the U.S. healthcare system in research, patient care, information, and advocacy. It is important to understand the role these organizations play, not only on individual patient experiences and health outcomes, but also on the larger health care system of our nation. One potential way in which health NPOs may be shaping both is through their publicly broadcasted narratives.

For this study, I am focusing on the research questions: (1) What kinds of images of organizational work are promoted by publicly broadcasted stories of “typical clients”? (2) What types of work do these narratives do?

For the purpose of this paper, I employ a narrative perspective to analyze publicly broadcasted stories featured on the Austin Brody Cancer Center (pseudonym) website. Specifically I explore the ways in which the Austin Brody Cancer Center produces an image of a type of person, the ‘inspirational’ patient, or the ‘good’ patient, and how their organizational stories circulate dominant images of individual character and morality, while at the same time producing social hierarchies and structures of domination.

Literature Review

The Role of Narratives (with/in) Illness

Like many other contemporary societies, the United States has a heterogeneous population that varies in their understandings of what is meaningful, and in how they perceive social reality. One way in which individuals might “come to know, understand, and make sense of the social world” is through narratives (Somers 1994). A narrative is a recognizable story, which story listeners evaluate on its believability and importance (Loseke 2019). Stories, or narratives, are pervasive and persuasive tools individuals and organizations can use to make sense of the social world and their experiences.

Therefore, if, and/or when, an individual experiences illness, one way in which they attempt to make sense of their experience is through narrative. Illness narratives are focused on illnesses, illness episodes, or illness experiences, and experiences considered to be “unhealthy” (Hydén 1997). However, other socially circulating narratives influence the content, structuring, and telling of an individual’s story – specifically, individuals weave together their own stories by utilizing, modifying, and/or discarding aspects of stories heard over their life course. Sociologist Donileen Loseke (2007) contends that the world around us is comprised of intersecting levels of narratives – cultural, institutional, organizational, and personal –which are reflexive and reiterative with one other. Then, in other words, an individual’s personal illness narrative may be influenced by widely circulating cultural, institutional, and organizational stories about health and illness. My interest is in exploring how organizational stories “do work” for the organization, particularly in how stories offer images of organizational clients and organizational workers.

Organizations may use carefully curated personal stories of their clients to demonstrate and dramatize the image they wish to create in their narratives. Consequently, the publicly broadcasted stories of cancer-specific organizations, and more specifically how they are structured in terms of their content and meanings, may have consequences for the patients entering the organization and the employees who work for it. The types of stories constructed by these organizations socially circulate and are potential resources for audience members to use in order to understand the experience of cancer and the work the organization does. In particular, these organizational stories illuminate who a “typical” cancer patient is, how these individuals should act and/or feel about their cancer, the type and quality of treatments and services they should receive, the type of individuals who are treating people with cancer, and the variety and quality of types of treatment and services provided by the organization.

While many scholars highlight the psychological functions of narratives (Loseke 2012; 2007; Linde 2001; Ewick and Silbey 1995), my focus is primarily on the social and cultural aspects of narratives.

It is necessary to consider different narratives surrounding cancer as they influence how organizations treating cancer are likely to make sense of their patients. These stories, in turn, shape the images and expectations that health care organizations publicly broadcast about their patients, their employees, and the larger organization. The following sections review the different narratives surrounding cancer. For the purpose of this review, I discuss the narratives as distinct, yet in practice they are socially circulating, simultaneously interacting and influencing one another. Beginning with cultural narratives, I describe the types of frames utilized to construct the socially circulating images and stories of those with cancer in the public realm. Next, I discuss organizational narratives and the larger health care system in which health care

organizations are operating. Then, I describe cultural understandings of the “sick role” and the ‘good’ patient, which are both embedded in cultural, institutional, and organizational narratives of health and illness. The literature review concludes with a review of relevant narrative elements.

Cultural Narratives of Cancer

Cultural narratives are widely socially circulating collective representations forming images of categories of people through widely socially circulating images and stories. Often these stories are formula stories (Berger 1997) and contain characters (such as heroes, victims, and villains) whose behaviors are predictable. These types of narratives are located in the public realm and utilize widely circulating systems of meanings, or cultural codes (Loseke 2019; 2012; 2007), which mirror how audience members perceive the social world. (I will discuss cultural codes more in depth later in the narrative element section.)

There are a variety of formula stories about the experiences of individuals with cancer that may both overlap and contradict each other. For example, on one hand, cancer has been characterized as one of most feared modern diseases, linked to death, long and sickening treatments, punishment, lack of cleanliness, contagion, uncertainty, and unpredictability (Clarke and Everest 2006). On the other hand, some cancer diagnoses, like breast cancer, can be linked to individual virtues like heroism (courage and bravery in the face of adversity) (Seale 2001). From either perspective though, the stories reflect and perpetuate ways of thinking and feeling, such as pity or sympathy, that contain meanings and messages about individuals with and without cancer.

Widely socially circulating stories often frame illness and disability as a personal tragedy (for the individual and their loved ones), which should be feared, and can only be resolved, or

“cured,” by biomedical intervention (Maconi 2019; Oliver & Barnes 2012). Simultaneously, there are “super crips” formula stories that cast individuals with disabilities and illnesses as “inspirational,” because they have “overcome” their “tragedy” in “incredible” ways (Maconi 2019; Kafer 2013). As an example, Kafer (2013) examines the ways in which the organization Foundation for a Better Life (FBL) utilizes billboards to reproduce images and messages that individuals with disabilities and illnesses are able to overcome their disability through personal responsibility and individual virtues such as integrity, courage, and determination. Similarly, Seale’s (2001; 2002) work on mass media portrayals of cancer also highlights how cultural expectations can influence the content and messages publicly broadcasted. Seale found that some cancer diagnoses, in particular breast cancer, are linked to heroism, desired transformation, and even positive stigmata. Clarke and Everest’s (2006) findings support this, as they indicate that sometimes just by receiving a diagnosis of cancer individuals are characterized as heroic. These types of stories function to inspire those who are able-bodied and minded by constructing disability or illness as an individual tragedy that can be “overcome” by personal efforts and characteristics.

These stories of cancer utilize cultural codes that construct those with cancer as victims and/or heroes, which encourage certain ways of thinking and feeling about individuals with cancer, and a diagnosis of cancer in general. These narratives may contain various meanings and morals that pertain to the personal responsibility an individual “should” undertake in regards to their health and how they “should” emotionally respond to such a diagnosis. This in turn may influence how individuals make sense of their cancer experience, and how physicians, health care professionals, and organizations make sense of their roles and the stories they (re)produce and publicly broadcast.

One cultural narrative that has such implications, in particular for the institutional and organizational narratives surrounding cancer, is the *restitution narrative*, first purposed by Frank as one type of illness narrative. It has a basic plot of:

“Yesterday I was healthy, today I’m sick, but tomorrow I’ll be healthy again.” The storyline is filled out with talk of tests and their interpretation, treatments and their possible outcomes, the competence of physicians, and alternative treatments (Frank 1995:77).

Throughout restitution stories, there are reminders that the story is about health, more specifically its restoration, which is framed as a “natural desire.” It relies on the contemporary cultural understandings and expectations surrounding illness – specifically, that being sick is not normal, and is something that should be fixed, or “cured.” Through analyzing a brochure from a major hospital in the Eastern Region of the U.S. and a generic television commercial, Frank (1995) demonstrates how pervasive and compelling the restitution narrative is and how it underpins cultural, institutional, and organizational stories, which then act as models for individuals to learn how to tell their own illness stories. Frank highlights how, within these stories, the focus is on the restitution, or the restoring of the status quo before the patient’s experience with illness. For example, patients in the hospital brochure are not shown to *be impacted by* or *actively going* through treatment, but rather are depicted smiling and doing their favorite pastimes. While the patients would describe their treatments within their narratives, the emphasis of the story is on how well they are doing *now* that they have been “fixed.” While serving as an educational resource by describing different types of cancers and their respective treatments, these stories reflect the institutionally and organizationally preferred narrative.

Further, the restitution narrative relies on the modernist expectation that for every puzzle there is a solution. Frank (1995) contends,

The purpose that restitution narratives aim toward is two-fold. For the individual teller, the ending is a return to just before the beginning: “good as new” or status quo ante. For the culture that prefers restitution stories, this narrative affirms that breakdowns can be fixed (90).

Some individuals will not experience a “cure” for their illness, which reflects a central issue in illness narratives that may not have “narrative closure.” Ewick and Silbey (1995:200) purport a main element of narratives is the that “[t]he temporal and structural ordering ensure both “narrative closure” and “narrative causality”: in other words, a statement about how and why the recounted events occurred.” But illness narratives may not have a “narrative closure” as some illness may not be cured or are reoccurring. On the other hand, when some individuals get sick they are able to receive treatment and *do get well again*. Frank (1995) argues that it is this fact that provides the “narrative force” of the restitution narrative, because for individuals who do not get well, many want to continue to believe they will. Thus, the restitution narrative has implications for narratives at all levels of social life --cultural, institutional, organizational, and personal (Loseke 2007).

The next section reviews the organizational context in which physicians and patients operate. In particular, I discuss the structuring of the health care system and how that influences the organizational narratives produced by health care organizations.

Organizational Narratives of Cancer

The U.S. health care system, situated within western capitalism, is constantly evolving due to changing policies, shifts in payment models, technological developments, and growing consumer pressures (Light 2010; Timmermans & Oh 2010). Recent research from organizational scholars highlights how health care in the U.S. is influenced by the competing and shifting logics of the market, the profession of medicine, and the state (Kitchener 2002; Light 2001; Scott et al.

2000). Many sociologists have illustrated the impacts of macro factors on help-seeking behavior, as well as the practice and delivery of health care in everyday life (Freidson 1970; Mechanic 1975; Parsons 1951). Scholars argue that the health-care sector has shifted to a disorganized market-oriented system comprised of various organizational forms (Fennell & Adams 2011; Caronna 2004; Light 2001; Scott et al. 2000), and some further argue this has resulted in a shift of power dynamics within health care from physicians to managers (Fennell & Adams 2011; Light 2001; Scott et al 2000).

Within this complex and shifting landscape, non-profit health care organizations create publicly broadcasted narratives for audiences across a variety of organizational fields that include referring professionals, clients and families, and potential financial donors. To attract clients/patients, referrals and donations, the stories non-profit health organizations tell about themselves must resonate with often conflicting organizational fields and institutional logics as well as with broader cultural ideas about health, illness, and the profession of medicine. Yet, Currie and colleagues (2012) call attention to how health care organizations, and correspondingly their narratives, have not been the focus of much research within medical sociology.

Through organizational narratives, health non-profit organizations (NPOs) define who their “typical” clients are (and subsequently who they are not), how clients are served, and how clients should be morally evaluated (Loseke 2007; 2019). Health NPOs must develop and maintain an organizational narrative that simultaneously validates their mission and is capable of resonating with various audiences such as private and corporate donors, government funding agencies, organizational actors, and cancer patients who will be organizational clients. One way in which health NPOs appeal to various audiences is by incorporating different organizational

actors' and clients stories in ways that legitimate and garner material and symbolic support for the organization.

Organizations construct clients' stories in ways that highlight the necessity and importance of the organization's work. Loseke (2007:671) argues,

...ongoing services must have images of their "typical" client because these images justify organizational procedures and services by offering stock answers to important practical questions: Who is our client? What are our client's problems? What does our client need? How should our client be morally evaluated?

Publicly broadcasted organizational narratives tell social actors in various organizations and institutions what the health NPO does, the kinds of people it serves, and why it and their patients are worthy of public trust and support. Focusing on how organizations construct their narratives may broaden our understandings or our perspectives on the role(s) and impact(s) of health NPOs, and their publicly broadcasted narratives, have on both the larger national health care system and individual patients experiences.

Furthermore, similar to culture, organizations are dynamic, ever-changing bodies, and while having their own goals, they also respond to the social and cultural contexts surrounding them. Through exploring the cultural understandings of the "sick role" and the 'good' patient, which are both embedded in cultural, institutional, and organizational narratives of health and illness, the relationship between cultural systems of meanings and organizational stories may be illuminated.

The Sick Role and the 'Good' Patient

The concepts of the *sick role* and the 'good' patient need to be briefly discussed as understanding their constructions, pervasiveness, and utilizations provides insight into the

publicly broadcasted messages of health and illness, and the organizational stories of health non-profit organizations.

Within medical sociology, Talcott Parsons' theory of the *sick role* has been the dominant perspective for understanding the relationship between physicians and patients (Varul 2010). Employing a functionalist perspective, Parsons describes obligatory normative expectations that regulate the relationships between patients, physicians, and society as a whole (Frank 2016, 1995; Parsons 1970, 1978). According to his theory, patients have two obligations and two rights within the relationship. The sick individual has the right to (1) not perform normal social roles and (2) not to be held accountable for their condition. Their obligations are (1) to try to get well and (2) to seek and accept medical orders (Parsons 1951). The physician's obligations are to validate the disease of the patient, but in such a way that encourages the individual to get well rather than desiring to maintain their sick role. Within Parsonian sociology, the physician is expected to view the patient as a suspicious character whose only moral expectation is to get better.

Frank (1995) delineates how the sick role in of itself is a restitution narrative, in particular, one that informs individuals and institutions about what types of behaviors and feelings are expected from sick individuals and those providing services to them. Frank (1995) articulates,

These expectations are *institutionalized* in such matters as sick leave from work and medical care; they are validated by social *norms*; they are *functional* for society as a whole; and they are *internalized*, meaning that individuals regard their expectation around sickness as normal and natural (81).

Therefore, regardless of the extent to which the sick role accurately describes the *experience* of being ill, it remains an influential and compelling narrative of what medicine *expects from* the ill individual and in return, what other social institutions expect from medicine. Frank (1997) also

highlights how Parsons' theory "reduces the ill person to the patient, and this patient's agency is limited to *compliance*; the physician becomes the active agent in the illness process" (131; emphasis added). In other words, due to the power and social dynamics between the two, the physician becomes an agent of social control and the moral agency of the patient is reduced, as the only expectation for the patient is to follow the advice of the physician and get better.

Concurrently, the idea of the 'good' patient may influence how physicians and healthcare professionals interact with patients, and therefore perceive their worth (Sointu 2016; Higashi et al 2013). Sointu (2016:5) analyzes how 'good' and 'bad' patients are constructed and perceived through qualitative in-depth interviews with 27 medical school residents from the U.S.. This analysis describes major themes and subthemes such as " 'bad' patients have wrong priorities, little knowledge, and are difficult to deal with, [while] 'good' patients are active, compliant, and knowledgeable." The 'good' patient and the *sick role* responsibilities and obligations may coincide or overlap with one another, such as to listen to and trust the doctors that are trying to help. Individuals characterized as 'bad' patients "refuse the responsibilities of the 'sick role'" (Sointu 2016:2), are thought to be purposefully ill, and responsible for their illness (Jeffery 1979) as compared to 'good' patients who are understood from the perspective of the *sick role*, and therefore are morally worthy and have the right to not be held responsible for their illness. Being categorized as either social identity ('good' or 'bad') influences the type and quality of interactions within the clinical health care setting, which Sointu (2016) highlights as a way in which social and health inequalities are embodied and enforced within medical settings.

Yet, how an organization constructs their own image and story of 'good' or 'bad' patients varies as they can choose to adopt or challenge cultural systems of meanings surrounding health and illness, as well as those surrounding the patient-physician relationship. Nonetheless, these

organizational stories function to evaluate who and how the organization helps their clientele. By examining the stories cancer-specific health NPOs publicly broadcast we can gain insight into how these stories can act as models for (potential) patients on the expectations and obligations they have upon entering and receiving care from the organization.

Narrative Content

For this project, I am interested in exploring the narrative content – the scenes, events, characters, and the moral(s), or the reason for the story being told – within publicly broadcasted patient stories featured on the organizational website of a health NPO that specializes in cancer.

Stories occur within scenes, or the settings in which the story events progress. The story is highly dependent on the scenes; the meaning of story events and characters will change when the story is set in rural China during the early sixteenth century versus an urban city of Stockholm, Sweden in 2019.

The next element of narrative content is events. “The narrator selects certain events and arranges them in such a way as to form a whole – with beginning, a middle and an end – that is imbued with meaning” (Hydén 1997:60). Loseke (2019) posits events have four characteristics: (1) typically stories have events that are relevant and necessary to create the story, (2) the plot of the story prompts what events occur and coherently connects them as a whole, (3) there is a time relationship between the story events and the completed story, and (4) the meaning of the events is understood by their contextualization within the story.

Stories have characters, which can be non-human (werewolves, witches, fairies) or human (Loseke 2019). However, the most important stories typically features humans, which can be unique, named, and embodied individuals (i.e. Dr. Martin Luther King) or categorical, disembodied individuals (i.e. “Uber drivers” or “fast food workers”). And finally, stories are told

for specific reasons, or the moral of the story. Both individuals and groups tell stories for various and diverse reasons, but often there is an underlying moral message being conveyed to the audience. Sometimes, it is about the morality of vaccination, or perhaps, the morality of friendship.

Cultural Codes

Individuals are often characterized by their identity, which is based upon socially constructed categories such as race, ethnicity, gender, sexuality, religion, social class, citizenship, occupation, or political identification (Alexander 1992; Loseke 2019). Some identity categories are socially accorded more esteem and higher moral worth than others (i.e. President versus internet hacker). In this sense, identity categories can be understood as cultural codes. “Cultural codes,” Loseke argues, are “densely packed systems of meanings about anticipated appearances, personal characteristics, and behaviors, as well as expectations of rights and obligations. [These] also are social and moral evaluations” (2019: 31). Stories, then, are composed of cultural codes that audience members can use to evaluate what is expected of characters, as well as how characters should be socially and morally evaluated.

There are two sub-categories of cultural codes – symbolic and emotion codes. Symbolic codes are “systems of ideas about how the world does work, how the world should work, and about the rights and responsibilities among people in the world” (Loseke 2012:3). Socially circulating systems of meaning about things such as democracy (Alexander and Smith 1993) and good health (Edgley and Brissett 1990) act as resources to construct and evaluate story plots and morals. Other symbolic codes can be used to construct and evaluate story characters such as victim (Holstein and Miller 1990), villain (Singer 2001), and hero (Rankin and Eagley 2008). In turn, emotion codes are “systems of ideas about when and where and toward whom or what

emotions should be inwardly experienced, outwardly displayed, and morally evaluated.” (Loseke 2012:3). This category of cultural codes provides a model that informs individuals about which emotions are expected when, where, and toward whom or what.

Additionally, emotion codes indicate how individuals should inwardly experience their emotions, how they should be expressed, and how they should be morally evaluated (Loseke and Kusenbach 2008). Emotion codes such as sympathy (Clark 1997), compassion (Höijer 2004), and love (Swidler 2001) encourage or discourage certain emotional responses from the audience(s).

Summary

Health care organization’s functioning and operating within the complex and shifting landscape of the U.S. health care system develop and publicize narratives that inform audience members about the organization, such as who is being served (clients/patients), what problems the clients are facing, what they clients need, and how they should be morally evaluated (Loseke 2007). The *restitution narrative* (Frank 1995) is a pervasive and powerful cultural narrative that influences the plot, events, characters, and morals of the stories produced and publicly broadcasted by the institutions and organizations within the U.S. health care system. At the same time, cultural, institutional, and organizational understandings of the expectations and roles of patients and physicians influence the stories told. Yet, who qualifies as a ‘good’ patient, or a “morally worthy” patient, can be constructed by adapting and/or modifying these widely circulating systems of meanings for the purpose and goals of the specific health care organization.

Methods

This research project is focused on meaning-making, and therefore is situated within an interpretive/constructionist approach. My research questions are:

1. What kinds of images of organizational clients and organizational work are promoted by publicly broadcasted stories of “typical clients” in a cancer NPO?
2. What types of work do these narratives do?

Research Site

The Austin Brody Cancer Center (ABC) – a pseudonym – is located in the Eastern United States and has been a top ranking cancer center for the past 20 years. It is a distinct type of health NPO in that its mission includes research, advocacy, information, and direct care to patients. Since its opening in the 1980s, ABC has treated individuals from every state in the United States and from all over the world. The ABC has a myriad of clinical services, such as a hospital with over 200 beds and over a dozen operating rooms, as well as research programs like Experimental Therapeutics and Cancer Epidemiology. As a research institute, ABC has received over \$46 million in research grants during 2017 and 2018 alone.

In addition to having high quality and technologically advanced facilities, the ABC offers services and resources for patients and their families. From support groups for ill individuals to an accessible art studio to yoga classes, ABC positions itself in such a way that they can meet not only the medical needs of the patient (and their families/caregivers), but their potential mental, emotional, and spiritual needs as well. By describing the size of ABC, as well as all the services

they provide, the image of who ABC is and what they do becomes clearer. This is relevant information to consider as it helps to establish the cultural and organizational context of ABC.

Data Collection

I obtained data from ABC's organizational website. Specifically, I collected the mission and value statements from the "about" tab on the website as this provides context on how the organization presents itself across a wide variety of organizational fields. However, as I am mainly interested in the stories of this organization, the main data for this project is from a specific section of the organizational website that features what are called "inspirational" stories from patients/clients, doctors, nurses, team members, executive staff, volunteers, and donors/supporters of the organization. After receiving approval from the University of Florida's Institutional Review Board (IRB), I downloaded all the stories and relevant quotes from this section and pasted them into a word document. For this project, I focused mainly on the patient/clients stories. This resulted in 37 pages of data, with a total of 48 patient/clients stories, with total word count of 20,288.

Methods of Analysis

I conducted a narrative analysis to examine characteristics of organizationally constructed stories of patients and health care providers. Initially, I used Loseke's (2012) method for the empirical analysis of formula stories to guide my data analysis process. In each story, I sought to identify the narrative elements. The audience of these stories cannot be known, but as they are featured on an organizational website we can assume the primary audiences are donors, potential donors, patients, and potential patients.

Second, I did a "literal reading" (Barthes 1982) of these stories. By "literal reading" I mean that I am analyzing and exploring the straightforward version, or "explicit reading"

supported by the ABC's editors. In this reading, stories are read as *true*: each story is meant to "inspire" individuals. The second reading of these stories is an "oppositional reading" (Hall 1980), which works to understand the narratives outside the dominant-hegemonic ideology. In particular, I consider how these stories produce social hierarchy and structures of domination.

My purpose in this analysis is not to assess the "truth" of these stories or to argue for the "superiority" of one narrative over the other, but rather, to look for generalities and patterns between these stories, which may be underscored with cultural systems of meanings about who is (un)worthy of receiving help from these organizations. During my analysis process, I frequently compared these stories to cultural narratives of health and illness, in particular, cancer narratives, which often identify the villain as the type of cancer, the victim as the person with cancer, and the heroes as the doctors and organizations that help these individuals.

Findings

In various ways, each of these stories constructs the morally good patient. This is done by dramatizing the patient's family connections, health history, current activity, feelings, and/or motivations. In this section I will do what Barthes' (1982) called a "literal reading" meaning that I will look at the explicit content of these stories without commenting on underlying meanings and/or on meaning consequences. I then move to the discussion, which will center on an "oppositional reading" (Barthes 1982) to explore what lies beyond explicit story contents and why stories matter.

Morality of Family

Although narrative characters are constructed through their age, gender, and occupations, what is most notable is the prevalence of displaying how patients are in family relationships that are important to them. For example, Larry is a 41-year-old "military man with a wife and three young kids...", while Samantha is "only 28, in good health, happily married, and working for a great company." Michelle is a 44 year old who was in the "honeymoon phase of her marriage, had a successful career, and was a proud mom of a teenage son and two new stepchildren." Logan is an "owner and operator" of a restaurant group, a "husband", a "father of two", and a "grandfather of five."

Although expectations about family have changed a great deal in recent years, it remains that a primary value within the Western world is the importance of family. Writing patients' biographies to include their family relationships is a social locator that constructs patients as good people.

Morality of Health History

One of the primary ways in which morality of ill individuals is evaluated is through answers to the question: Is this person responsible for their illness? Narratives can construct an image of a moral person by creating a biographical history for characters that is readable as that of a person for whom physical health and wellbeing is important. This can be accomplished in two ways.

First, individuals are constructed as morally worthy patients, or “good” patients, by dramatizing their health practices and behaviors, such as routine screenings and regular exercising. For example, Evelyn is “beyond fit”; Sarah is an “avid runner and yoga enthusiast” and has an “active lifestyle”; Travis is “a young man and didn’t smoke”; Harper saw her “doctor regularly and had a colonoscopy at 50”; Tanner “went in for a routine physical.” The narratives highlight and perpetuate the idea that these individuals were being responsible for their health. They were/are actively taking care of themselves, and therefore are not at fault for their illness. In particular, this works to construct patients as *victims*, or a *good* person, *greatly* harmed, through *no fault*, and for *no good* reason (Loseke 2019).

Second, one of the strongest constructions of morality of patients through health history is current history with the theme of *being proactive and engaged in their health(care)*. This is demonstrated in the narratives by patients who are advocating for themselves, actively researching their illness, maintaining their health, and participating and engaging with their physicians and medical team(s) about medical decisions. Simultaneously, these patients are shown to trust and respect their ABC doctors and medical team as people who are there to help them on their journey with cancer. For example, when Larry noticed his lab results had not changed in a year, he “consulted with a different oncologist” and proceeded to seek care from

ABC, where he did “research on [his] own” and asked “questions along the way” in order to have a “dialogue” with his doctors. Nora was informed that her stomach cancer was beyond treatment, but she “decided” to go to ABC for a “second opinion” on her treatment options and she “believed” in her medical team. Daniel had seen three different doctors in order to receive an x-ray on a concerning cyst; he did his “homework” on other cancer facilities before “deciding” ABC was the “place to go” for treating his esophageal cancer, and was “quickly back in action” after the removal of his esophagus. Before “committing” to receive her treatment at ABC, Isis “contact[ed] several doctors” and “visited” other cancer facilities, but ultimately decided on ABC because the physician “answered all her questions” and provided her with “optimism” about her prognosis. After initially receiving treatment for her cervical cancer at ABC, Penelope was “faced with a recurrence” and the suggested treatment was a “major surgery,” but before she committed, Penelope “traveled all over the country” in search of different solution, yet found nothing, and eventually decided to have this “radical surgery” where she felt “most comfortable” – at ABC. Summer “insisted something was wrong” and “went to appointment after appointment with her primary doctor” until she was finally able to get an MRI that revealed a brain tumor was the cause of her symptoms.

Morality, then, is formed by creating an image of a ‘good’ patient as one who has a biography of health activity. This type of person is one for whom physical health and wellbeing is important and is actively demonstrated. “In addition to – or instead of – such productions, morality can be produced through present activities” (Loseke 1995:67).

Morality of Activity

A narrative theme that constructs patients as morally worthy is the theme *moving forward; giving back*. This theme reflects how good patients do not let cancer “define” who they

are, but instead utilize this experience to “better” themselves and “give” back to others. For example, Aubrey’s experience of “fighting” cancer “sparked” her desire to “give back to others,” which led her to create a non-profit organization focused on helping young adults impaired by cancer through the connection of “community” and “faith.” After his “whole” experience, Mark was “inspired” to work in conjunction with ABC to find a group that is focused on “advocate[ing] for research and education addressing cancer health disparities in the African-American community.” After “beating” cancer, Anna applied to work at ABC to be more involved with the “patient experience,” believing that as a “cancer survivor” and someone who received care and services from ABC she can “impact the treatment and care that all patients” receive at ABC. During graduate school and working on her dissertation about her experience, Isis “worked for the U.S. Senate” in areas such as public health policy. Martin’s “life changed” due to his cancer experience as he went from a “fighter, to a survivor to a caregiver.” After his wife passed away he “decided” to “volunteer” at ABC and spends his days in the “radiation center...helping people.” Harper “truly believes cancer changed her” as she recognizes she’s not the person she “used to be” – she is a “better version, because she “appreciates life” and doesn’t get “stressed out over the little things.” During Aiden’s treatment for melanoma at ABC, one of his physicians drew a symbol on Aiden’s face, which would become a symbol for “pediatric melanoma” and lead him and his mother, Madelyn, to create a foundation that raises “money” for ABC for research in order to “pay it forward.”

Morality of Feelings

"Good" patients “do not become discouraged” (Sointu 2016); they continue to move forward despite potential medical errors (i.e. misdiagnosis) and/or recurrence(s) of their illness. Narrative characters are often described as “positive,” “courageous,” and/or a “resilient” in the

face of treatments and recovery that are by no means “easy,” and the narratives offer details of patients “uphill battle.”

First, while the narratives recognize that being diagnosed with cancer can be “overwhelming,” and “shocking,” leading patients to be “fearful,” it is repeated throughout patient stories that individuals should not “live in that area.” This is the theme of *positive perseverance*. For example, Michelle participated in a clinical trial where she received a “series of six shots under her arm” at each appointment, and attributes her strength to being able to get through this “painful” treatment to her “faith,” “positive outlook,” and “support system.” The “next opponent” Luna was facing after receiving a diagnosis of pancreatic cancer was a “discouraging outlook” as her treatment required her to not only have “chemo and radiation,” but also the removal of “most of her pancreas and spleen.” Yet Luna got through it all, and believes that she is “still here” because she never gave up “hope” and trained her “whole body” to be “positive.” After being diagnosed with a brain tumor, Lewis underwent “intensive” chemotherapy, “whole head radiation,” and two surgeries, which unfortunately, did not help. Therefore, he and his mom, Autumn, were sent to ABC for a clinical trial where Lewis took an “experimental drug” and 6 weeks of radiation. His narrative credits his ability to “control his fear,” his “courage”, and his “mental approach” “helped” his results be “promising.”

Another theme that produces morality is narrative characters as *grateful patients*. These individuals are described as feeling “thankful,” “grateful,” and/or “lucky” for their experience and time at ABC with their physicians and medical team. For instance, ABC’s screening team agreed with Peter that his mole was not “normal” for him even after his primary doctor told him he should not “worry about it,” which made Peter feel “lucky” and “eternally grateful” for his treatment and the care he received at ABC. Elijah is “ever so grateful” for the fact that his

physicians and medical team prioritized his desire to return to his “outdoor activities,” which would inspire his decision to “give back” and “volunteer” for ABC. After the birth of his new son, Travis underwent a surgery that “removed his voice box,” and now uses an “electronic voice box” and his phone to communicate. Travis is “so thankful” and “appreciates” ABC for the services and treatments they provided for him.

In addition to the productions of past and/or present activities, attributing emotions to individuals works to construct an image and/or stories of morally worthy patients particularly from an outside perspective. Yet, these narratives can construct characters from the *inside* in terms of their motivations (Loseke 1995). Narrative characters are active in their life and their health, because they “want” to be and this “want” is not for selfish reasons.

Morality of Motivations

That these individuals *want* to get better is reflected in the narrative theme of *courageous determination*. When Martha was told she had cancer she told herself she was going to “beat it” and was “determined” to follow her medical teams advice, because giving up is “never an option,” which is “courage” to her. At 18, Amanda was diagnosed with a rare and incurable cancer, and was faced with “scary odds” yet she was “determined to fight” and has turned her experience into a “life defining” event and is currently working to become a social worker to “help future cancer patients” while at the same time being involved in ABC’s “family advisory committee.”

Being courageously determined is not for selfish reasons, but rather “good” patients are active and engaged in their health for the *good of family members*. It is for their mothers, fathers, partners, children, and friends who have supported them during their cancer journey. They continue to live despite their illness; they are dedicated to family members and friends. Didi was

“overwhelmed with fear” after she did her “research” and found the “survival rate statistics” of her particular type of cancer, “all she could think about was her daughters,” and resolved “[i]t was not [her] time to go.” It “never occurred” to Summer that she would be “somebody who would get cancer,” but after she received her prognosis, she “got ready for the fight of [her] life,” because she “wasn’t ready to say goodbye” to her partner, her “grandbaby,” and her “wide network of friends.” For Tracy, “the support of her husband, kids, and grandkids” plus her “five friends” who “prayed for her” and “bonded as teachers” is what “keeps her going in life.” Martha “had so much to live for” – her family of 17 in particular, which meant that “giving up was never an option,” and credits her husband for “giving her that little push.” Even though Joe was an “eternal optimist,” he “found strength” in his conversations with his “wife, his “two children,” and “siblings,” all of whom were living in a different state while he received his treatment, and emphasizes that one has to “believe” that they are going to “beat this.”

In summary, when the patient stories are read as the “literal truth” (Barthes 1982), they produce a model of the ‘good’ or morally worthy, patient. This type of person does not “deserve” to have a diagnosis of cancer interrupt their lives; it is a person who “deserves” to receive help, because in biography, activity, feelings, and/or in motivation, they are an exemplar of the health proactive and family-centered subject.

Discussion: The Moral Production of the ‘Good’ Patient

From an “oppositional reading” (Hall 1980), these patient stories can be interpreted as an anticipated result of the ever changing landscape and the general fragmentation of our health care system, which is located within the larger social, cultural, economic, and political structures in the United States. In this section, I will be focusing on how the production of morality within these patient stories does more than publicly broadcast images of what is good and what is not.

These patient stories can be viewed as constructing morality as a virtue of individuals, who are explicitly called “inspirational patients.” While these stories produce a morality for the specific health care organization (ABC), there is no morality produced for the larger institution of health care in the U.S.. However, patient stories can regularly be read as implicitly constructing the immorality of this institution because stories contain evidence of the fragmentation of the health care system. The narratives involve explicit constructions of people who must navigate this splintered system by researching their illness and facilities where they can receive care (quality and affordable), and advocating for themselves. The narrative characters positively persevered even when they needed to go to doctor after doctor to even get tested for their health concerns; travel the country in search of a cancer facility that meets their needs; when they receive a prognosis of less than two years of remaining life; move away from their families and friends; lost their hair, go through rounds of chemotherapy, radiation, (radical) surgeries, and/or clinical trials. Throughout the story, the ABC’s characters are an instrument to convey how morally worthy patients are emotionally positive and responsible, and therefore are

deserving of support and relief on their cancer journey. Simultaneously, these stories release the health care system of responsibility for multiple hardships these heroic characters experienced.

In addition to producing morality as a characteristic of individuals, the patient stories can be read as (re)producing social hierarchies and structures of domination, particularly within a health care context. At first reading, these stories apparently reduce social hierarchies because categories such as race or socioeconomic status are not in these stories. Yet, these stories nonetheless categorize individuals into moral (worthy/not worthy) categories with accompanying expected evaluations (positive/negative). A moral, or ‘good’ patient should be accorded high moral status, which, conversely, means a not-moral, or ‘bad’, patient can be negatively evaluated. Such evaluations, of course, support particular behavioral responses: Good patients should be helped; bad patients need not be helped. As organizational stories, the patient narratives model individual expectations and obligations of those who have been diagnosed with cancer, particularly those seeking care and services from ABC. Through these stories, ABC is able to construct the image of the organizations ‘good’ patient, and correspondingly answer important questions about ABC, such as who their clients are, what their client’s problems are, what the clients need, and how they should be morally evaluated. All of which seeks to justify the existence and purpose of the organization.

Moreover, these stories form structures of domination. Over time, the health care system has developed within capitalistic ideologies and interests, which are important in shaping the expectations and obligations of both patients and physicians. For example, due to various social movements in the 1970s, ’80, and ’90s, patients’ rights and autonomy are now viewed as a fundamental aspect of contemporary Western health care, which at times may place more responsibility on patients. Yet, during this same period, health care was being commodified –

increasing health disparities among and between populations in quality, cost, and access to health care services. Combined with the ideology of ‘positive thinking,’ the focus of these stories is on individual responsibility (for health, for success), which makes invisible the importance of larger entities such as corporations and political economy (Willig 2011; Ehrenreich 2009). Specifically, the patient narratives, which can be used as templates for how individuals might tell their own story, and/or how they should feel about their health and their selves, offers little space for the expression of anger, sadness, or hopelessness and instead explicitly guides people to stay out of the mindset. Patient stories reiterate that a positive mindset is a necessary component on one’s cancer journey, and that ‘good’ patients overcome the negativity. This directs individuals to focus on the self, and does not incite any political or social action to address public and/or social health issues, such as environmental factors, that play a role in the cause of increasing rates of cancer in the USA.

Understandably, because these are stories within an organization located within the traditional sphere of biomedicine, these patient narratives reify the dominance of biomedicine and rarely discuss complementary and alternative medicine (CAM), which often relies on treatments outside of standard medicine. This reinforces medical dominance; specifically, medicine is framed as the proper and favorable resolution to the dilemma of cancer. This portrayal of biomedicine as the normative process for managing cancer may be restrictive, and may result in other possible factors, such as links to the environment, culture, gender, ethnicity, and socioeconomic class, to be underestimated, and therefore, not investigated. There are only a few patient stories within the sample that mention health disparities that some minority and marginalized populations face; in particular, it is often African American or Black populations that are mentioned. However, the patient stories do not explore why these realities currently exist

for these marginalized populations, or how they may be influencing the quality, cost, and/or access to health care they receive currently within the U.S. health care system.

Furthermore, without highlighting other potential pathways for individuals to manage their cancer, the patient stories can be read as encouraging a reliance on biomedicine – as it is positioned as a necessary component to “beat” cancer. The solution to the dilemma of cancer ABC presents within these patients stories is a combination of personal characteristics (courage, determination, positivity) and biomedical intervention, which they can supply. Additionally, one moral an audience member could potentially take away is the importance of prevention – which is clearly situated within a medical context (i.e. regular and annual screenings and checks), thereby applauding biomedical intervention. These narratives encourage audience members to focus on what they can do individually to be responsible, proactive, and engaged with their personal health and well-being with the help of medicine without having to address the other potential factors that may be influential in the development of cancer.

From an oppositional reading lens, the patients’ stories act in a manner that directs attention away from the institutional structures of the U.S. health care system, while the dialogues of morality (re)produce social hierarchies and systems of domination. This, of course, is not the reading ABC encourages. Within this public, virtual space, these stories are about patients evaluated as ‘inspirational.’ Explicitly, these patients are to be models emulated by others. To the extent audiences take this advice, they may be inspired to be proactive and engaged in their health; to develop the behaviors and feelings associated with successful treatment; to applaud the work of the organization. The patient stories depict life as it *should* be: The morally worthy but ill individual deserves quality care and services that help them recover to status quo, or life before being diagnosed with cancer.

Conclusion

Cultural, organizational, and personal narratives are reflexive and reiterative, and thus are always in the process of changing, adapting, and modifying to fulfill the needs of the organization and its clients. Health care organizations, like ABC, construct and publicly broadcast stories that utilize widely circulating systems of meanings, thereby producing an image of a specific type of person. To ABC, “inspirational” patients, or “good” patients are actively engaged and responsible for their health, which means being knowledgeable, yet still compliant with the physicians recommendation; they positively persevere despite the difficulties they face due to both the fragmentation within the U.S. health care system, and the biomedical interventions and treatments; these patients feel and express their gratitude, because patients are family-centered, and have been wanting to get better specifically for their family and friends.

Analyzing the stories that cancer-specific organizations publicly broadcast offers insights into how images of patients are constructed. This is a necessary step into understanding the expectations and obligations of patients and physicians, as well as how organizations facilitate the relationship. While Austin Brody is a specific example, it illuminates the ways in which these organizations can construct their organizational stories by utilizing predominant cultural narratives and expectations about those with cancer, as well as those who provide care and services to them.

As with all research, there are limitations, the primary one being that this study is focused on only one cancer-specific health-non-profit organization. This was done intentionally to explore the depth of the stories publicly broadcasted on the organizational website. Future

research could be more comprehensive of other dimensions of the organizational website, and could examine other cancer-specific organizations that publicly broadcast stories about their patients, employees, and supporters to examine the extent to which these findings apply across organizations. Moreover, it is not uncommon within the patient stories to find constructions of how “God,” “prayer,” and/or “faith” contributed to the individuals’ restoration. Future studies could explore the relationship between cultural expectations surrounding the importance of religion and illness, specifically the role it has in individuals experience with cancer, how this may (re)produce the normative U.S. Christian ideologies and images, thereby potentially reifying its dominance and pervasiveness within a health care context.

A final limitation is that, this study examined only patient stories. Future studies could examine the relationship between patient, employees, volunteers, and donors’ stories that are also featured on organizational websites to see if there are any interconnected themes that emerge.

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Appendices

Appendix 1: USF IRB Determination Letter



NOT HUMAN SUBJECTS RESEARCH DETERMINATION

February 28, 2020

Katie Hilderbrand 5202
Pine Mill Court
Temple Terrace, FL 33617

Dear Katie Hilderbrand:

On 2/27/2020, the IRB reviewed the following protocol:

IRB ID:	STUDY000302
Title:	"Courage Drives Us": Narrative Construction of Organizational Identity in a Cancer-Specific Health Non-Profit Organization

The IRB determined that the proposed activity does not constitute research involving human subjects as defined by DHHS and FDA regulations.

IRB review and approval is not required. This determination applies only to the activities described in the IRB submission. If changes are made and there are questions about whether these activities constitute human subjects research, please submit a new application to the IRB for a determination.

While not requiring IRB approval and oversight, your project activities should be conducted in a manner that is consistent with the ethical principles of your profession. If this project is program evaluation or quality improvement, do not refer to the project as research and do not include the assigned IRB ID or IRB contact information in the consent document or any resulting publications or presentations.

Sincerely, Jennifer

Walker

IRB Research Compliance Administrator

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