Confronting Cancer

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Introduction

An Anthropology of Cancer

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> I was going to die, if not sooner then later, whether or not I had ever spoken
> myself. My silences had not protected me. Your silence will not protect you.
> 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 believed, bridging our
> differences. *—Audre Lorde, The Cancer Journals*

Silences surrounding the specter of cancer have been disrupted for some but continue to manifest throughout the lives of others. *Cancer* is a global word—one that can be a metaphor for lack of control and degeneration as well as a signifier of difference, something that is part of our body and world and yet an unacceptable occurrence. In 2005 the World Health Organization (WHO) reported that there were more than seven million known deaths from cancer—12.5 percent of deaths worldwide. Each year, approximately eleven million new cases occur, and the WHO expects that by 2020 that number will have doubled. In 2001, cancer became the leading cause of death for people under the age of eighty-five in the United States (Centers for Disease Control and Prevention 2004), surpassing infectious and cardiovascular diseases. The concern over these staggering cancer rates and a desire to increase awareness prompted the World Summit against Cancer to declare February 4, 2000, as the first annual World Cancer Day.[1]

One lesson we can take away from the reports on cancer morbidity and mortality is that social inequalities and poverty expose individuals and populations to chronic infections and carcinogens at differing rates, with impoverished individuals, communities, and nations bearing the greater

burden of exposure (Stewart and Kleinhues 2003). The differences in exposure are combined with barriers that make prevention, early detection, and treatment economically and technologically prohibitive (Farmer 1999; Kogevinas et al. 1997); these ultimately lead to inequalities in cancer incidence, mortality, quality of life, survivorship, and health in general. Indeed, 70 percent of cancer deaths occur in low- and middle-income regions and countries (Parkin 2006; World Health Organization 2006). For instance, lack of access to clean water sources leads to higher rates of *helicobacter pylori* infection, which can lead to stomach cancer and is more prevalent in developing countries (Parkin 2006). Another notable trend that reveals cancer disparities related to health care access is that developed countries have higher incidence rates of cancer and lower cancer mortality rates than developing countries. In other words, while individuals in developing countries are less likely to get cancer, they are more likely to die of it (Parkin et al. 2005; Parkin and Fernández 2006).

The documentation of the unequal distribution of cancer is matched by a multitude of voices engaged in exploring and understanding cancer knowledge, experience, and resources. Cancer moves between the local and the global, the self and others, as evidenced by Winkelman's recent analysis of anthropologists' obituaries (2006)—which revealed cancer to be the leading cause of their deaths—as well as a simple Google search for *cancer* that returned 208,000,000 hits.[2] Indeed, a plethora of support groups, research and information agencies, graphic novels,[3] poems, songs, films, biographies, and fiction books exist to explain cancer. The inequalities, the inclusion of multiple voices, and the overall high rates of cancer converge to create an excess of meaning that demands attention.

The School for Advanced Research spring 2006 advanced seminar provided an opportunity for anthropologists—some of whom work in anthropology departments and some of whom work in other settings—to discuss the ways in which we answer cancer's cries. Our goals were to examine how anthropologists have contributed to an understanding of cancer and to examine how cancer gives anthropologists insights into larger social processes.

The seminar enabled participants to address anthropological concerns about the ways culture, society, and power work in the context of cancer experiences. Beyond the mass of incidence and mortality statistics and scientific and medical definitions, anthropology draws attention to the lived experiences of individuals who confront cancer. The contributors to this volume examine cancer's connections to a multitude of intertwined factors, thus exposing social orders. These authors also investigate the associated metaphors that both create and mediate the fear of cancer as a

manifestation of difference. Although medical interventions primarily attempt to rid our bodies of cancer, some contributors find that discourses about cancer are folded into the elimination, circumnavigation, or disruption of specific social groups and different ways of knowing how to be in the world. In the same vein, the authors describe increased cancer rates as an outcome of an ideology of modernity. Other contributors have found, however, that cancer and its associated metaphors provide opportunities for individuals to mediate multiple social and cultural worlds, pursuing ways to live with difference. Thus, the goal of this volume is threefold: (1) to examine the metaphors of cancer that teach us about our differences, (2) to delineate metaphors that naturalize inequalities, and (3) to contribute to the alleviation of suffering associated with cancer while exposing those perspectives that seek to homogenize diversity.

Anthropologists have spent the past few decades exploring, deciphering, and analyzing the metaphors, symbols, and social orders surrounding cancer. Many of these endeavors share the goal of representing the distinct styles and types of knowledge of individuals and groups who experience cancer (Bluebond-Langer 1990; Chavez et al. 1995; Csordas 1989; Good et al. 1990; Weiner 1999; Weiss 1997). In contributing to the documentation of human knowledge, anthropologists have also contributed to the critiques of the hegemonic characteristics of biomedical knowledge through analyzing concepts of risk and prevention (Bush 2000; Chavez et al. 2001; Hunt 1998; Martinez, Chavez, and Hubbell 1997; Mathews, Lannin, and Mitchell 1994; McMullin, Chavez, and Hubbell 1996; Press et al. 2005; Strickland 1999; Strickland et al. 1996; Wardlow and Curry 1996; Weiner 1999). More often than not, these critiques call attention to the inequities in the suffering of cancer. These works highlight the ease with which efforts to define risk and prevention become authoritative knowledge that stigmatizes and disciplines individuals and populations. Studies have also examined social inequalities in the construction of survivorship and the production of authoritative knowledge as a method for defining and framing the "correct" way to survive (Balshem 1999; Charles et al. 1998; M.-J. Good 1995; Good et al. 1990; Hunt 2000) and the coproduction of science and cancer activism (Gibbon 2007; Jain 2007a). Anthropologists have also documented experiences of cancer and survivorship (Jain 2007b; Kagawa-Singer and Wellisch 2003; Mathews, Lannin, and Mitchell 1994; Moore 1999; Saillant 1990; Stoller 2004), as well as the effects of environmental degradation and toxins on cancer incidence and treatment (Barker 2003; Brugge and Goble 2002; Erickson 2007; Karakasidou, chapter 5, this volume; Michaels 1988; Rodríguez and Silva 1988).

Yet it is the fear and suffering of the physical effects of cancer that also motivate many anthropologists to pursue investigation of the multiple dimensions of cancer. Anthropologists have also taken an active role in applied research interventions (Erwin et al. 1996; Kagawa-Singer et al. 2006; Ritenbaugh 1995; Teufel-Shone et al. 2006; Weiner 1999) and advocacy (see Weiner et al. 2005; Woodell and Hess 1998) that seek to make changes at the ground level for those individuals and families swept into the "village of the sick" (Stoller 2004; Frank 1997).

The practice of focusing on the medical and public health character-istics of a single condition or disease, however, has led to concern about the ability of medical anthropologists to maintain a critical position. The authors herein are concerned by what Browner (1999) calls the "medical-ization of medical anthropology." Anthropologists may become overly specialized in the same ways that medical practitioners specialize, so our thinking may become reductionistic and decontextualized. As a conse-quence, our thinking may thus become the same as that of medicine and public health rather than contribute to new approaches and theories or unravel taken-for-granted processes and knowledges. Examples can include the tendency by anthropologists to label cancer as a disease, not an illness or sickness (see Chrisman 1977; Fabrega 1978; Kleinman 1988). This view may reflect the fact that medical anthropologists often have posi-tions in schools of medicine, nursing, and public health or sometimes work for health research centers and government agencies—in both cases, anthropologists are often surrounded by colleagues in other disciplines. Medical anthropologists may also obtain funds from private and govern-ment agencies that seek to address cancer prevention, detection, and edu-cation. In our effort to contribute to the alleviation of cancer through early detection, we may become narrowly focused on the cultural dimensions that are "problematic" to seeking preventive care (DiGiacomo 1999). An anthropological focus on the cultural dimensions of belief and behaviors among populations that are underserved and that often have higher rates of cancer and associated mortality also has the possibility of making culture the problem rather than targeting larger issues of health, such as access. While anthropologists teach biomedicine about the "other," there is a potential for being led down a path of becoming handmaidens to bio-medicine and public health (B. Good 1994; Scheper-Hughes and Lock 1989). Ultimately, by contributing to the documentation of "beliefs" and practices, our work may end up contributing to the ever-increasing sur-veillance and control of people and populations by government and insti-tutions (Foucault 1977a). In the same way that physicians specialize in one

segment of the body so that a decontextualization of the illness experience is facilitated, anthropological understandings of the social relationships and contexts in which bodies with cancer are framed can also become obscured. All these ways of thinking about cancer and contributing to knowledge have the potential to weaken the great strength of anthropology and its ability to contribute to understandings of difference.

The authors herein prefer not to permit our knowledge to be used in the service of homogenizing discourse within a specific medical system and associated worldview. The play between maintaining difference and avoiding homogenization serves as an organizing lens through which to understand cancer. Cancer is marked by its physical, social, emotional, and metaphysical insistence on crossing boundaries of self and society and by its defiance of efforts to control its proliferation at the cellular and global level. In doing so, it is a disease that evokes dread and fear of difference that we continually confront through our individual and anthropological encounters.

DREAD AND DIFFERENCE

The video *Journey of Man* (2005) documents an event that the National Geographic Society and Dr. Spencer Wells of the Genographic Project had expected to be a triumph in communicating the science of human genome mapping to the lay population. As it turned out, the experience spoke of the global dread of cancer. Wells gathers a Central Asian man named Niasov, his family and friends, cameras, and a crew into Niasov's home near Kazakhstan. Wells, who had analyzed a DNA sample from Niasov, prepares him for a great revelation about his ancestry and blood. Wells begins by telling Niasov about DNA and how it is transmitted through the generations. At this point in the conversation, Niasov points to photographs of his father and grandfather that hang on the wall. Agreeing with the sentiment alluded to in the photographs, Wells tells Niasov that Wells has traced his genealogy through his father and grandfather back to one man who lived in Central Asia more than 40,000 years ago. This is a very important man because his descendants went on to populate parts of Europe and Asia; he was even the ancestor of some American Indians. With joy, Niasov thanks Dr. Wells, saying, "Thank you. That means my blood is pure."[4] Dr. Wells responds, "So, congratulations. You have very interesting blood." Niasov speaks again, exhibiting a great sense of relief. In the voice-over, Dr. Wells states, "Turns out the poor guy thought a doctor had come to tell him he has cancer. No wonder he looks so relieved." Indeed, from the perspective of these individuals, what other occurrence in the life of this man on the plains of Central Asia would warrant such a spectacle?

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Niasov's story of ancestors, bloodlines, and suspected cancer calls attention to the ways in which cancer registers on the levels of dread and difference. Cancer signifies difference, as suggested by Niasov's comment about the purity of his blood. It also registers as dread; Niasov's original thought was that he had cancer in his blood. This point is further illustrated in Niasov's relief that Dr. Wells had not come to tell him that he had cancer. For Niasov, cancer was the most available, encompassing framework that could explain the arrival of so many foreigners and scientists on his doorstep.

Herein lies the tension in anthropological work on cancer. Cancer causes us to move our attention between the micro and macro processes that create and manage diverse conditions. Cancer attacks the physical, spiritual, emotional, and social body. Cancer may homogenize bodies such that all individuals with cancer, or a particular cancer, may be placed in a similar statistical, social, or political category. Concurrently, cancer illuminates differences between and among individuals.

Viewed as a disease, cancer calls our attention to the cells that are growing out of control, differentiating themselves from the whole. Individuals with cancer are often distinguished from family and community as the carriers or bearers of a potentially deadly malady. Populations who have higher rates of cancer may be differentiated by health professionals, policy makers, administrators, and the like, as either genetically predisposed or not achieving the expectations of society that would have made them less susceptible to the disease. In this manner, cancer may be thought of as socially or biologically contagious—an entity, usually deemed dangerous or polluted, that passes between and within groups of individuals (see chapters by Weiner, McMullin, Chavez, Lee, and Heurtin-Roberts in this volume). Contagions are unique because they are potentially prevented or circumvented by avoiding exposures, objects, or thoughts that initiate illness (Green 1999:17).

Seen as a disease, a contagion, or an illness, cancer is frequently described as "uncontrollable" by health professionals and laypeople alike. Bodies, spirits, and psyches are damaged and changed by this out-of-control force, much as cities are damaged by hurricanes or earthquakes. A participant in a meeting stated, "I'd much rather have diabetes or heart disease than cancer. At least there is a possibility I can control those problems."

The distinction created by cancer is both real and metaphorical in that it ultimately resounds at the core of anthropological work as this work encounters an increasingly globalized world. As Geertz states,

> The next necessary thing…is neither the construction of a universal Esperanto-like culture…nor the invention of some vast

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> technology of human management. It is to enlarge the possibility
> of intelligible discourse between people quite different from one
> another in interest, outlook, wealth, and power, and yet contained
> in a world where tumbled as they are into endless connection, it is
> increasingly difficult to get out of each other's way." [1988:147]

An examination of anthropological work on cancer provides an opportunity to elucidate differences and dread created by the occurrence of cancer at the individual, sociocultural, political, economic, and historical levels.

METAPHORS THAT BATTLE DREAD AND DIFFERENCE

The encounter between Niasov and Wells exemplifies the hopes and concerns of anthropologists examining cancer's impact on and meaning in individual and social lives. As so poignantly discussed by Sontag (1978a), the excess of meaning associated with cancer takes, more often than not, the form of metaphors that shape our concerns with variance into the registers of dread and fear—and, ultimately, a battle with that dread. From "the war on cancer" and "poverty as a cancerous blight on a community" to the "triumph" over cancer through science and genetics, cancer has a past and a present steeped in metaphors that reveal inequality, stigmatization, and struggles to control the uncontrollable.

For decades a concerted effort has been made to reduce the incidence of and mortality from cancer. On the heels of the first man landing on the moon and the splitting of the atom—and perhaps with the "war on poverty" in the back of his mind—in 1971, US president Richard Nixon signed the National Cancer Act and shifted the fight to a full-fledged "war on cancer." Surely, if America could sit a man on top of a rocket and send him into space or could split an atom, then with "concentrated effort," we could achieve the goal of "conquering this dread disease."[5] Patterson (1987) suggests that these events followed a pattern of progress that is endemic to US linear thinking.

The fight against cancer (and other diseases, such as AIDS and diabetes) often gains visibility when the government takes notice. The United States' National Cancer Institute (NCI) was created in 1937, a full decade before the National Heart, Lung, and Blood Institute (NHLBI). The latter focused research efforts on cardiovascular disease, which from the time of the creation of the NCI until 2005 was the leading cause of death in the United States. Patterson notes that Senator Homer Bone's 1937 congressional statement linking the "dread disease" to American loss of life in all the previous foreign wars was instrumental in the creation of the NCI. Senator Bone stated, "If 140,000 persons in this country were burned over

slow fires every year…it would stagger the moral conscience of the world" (Patterson 1987:114). It was not just that people were dying of cancer, but also that their deaths were slow and agonizingly painful. Bone's comparisons of cancer to war and being burned contributed to the creation of an institute with an aim to rid the world of cancer. Since its establishment, the NCI has received annual budgets larger than the NHLBI's.

The images of fire and war also serve as key organizing categories for cancer: the incoherent or chaotic is represented in a concrete or ordered manner (Fernandez 1986; van der Geest and Whyte 1989).[6] As Ricouer notes (1979:154), metaphors have a wonderful ability to represent something that concurrently "is not" and "is like," both explaining and creating experiences. For instance, in the United States, men and women "battling" testicular and breast cancer become "survivors," "warriors," and "thrivers" —not merely patients—who will hopefully win their fights with the aid of their new identities and state-of-the-art technological weapons of care (see also Erwin 1987; Martin 1994; Nail 2001). In chapter 2 of this volume, Paul Stoller illustrates how pamphlets and advice describing cancer treatment become guides for the battlefield. These instruments of battle are created to allow a patient to take personal control of his or her situation. Moreover, as Jain (2007a) notes, weapons of war—nitrogen mustard in World War I and atomic radiation in World War II—were not only causes of cancer but also, later, some of the first treatments for it. Thus, Jain argues that cancer is very much a part of the military complex. Metaphors of war reference partial truths in the history of the disease.

Contrast the individualized and embattled stance with the stance— provided by communities in the United States (see Burhansstipanov et al. 2001; Engelberg 2006; Lackey, Gates, and Brown 2001; Mathews 2000; Mathews, Lannin, and Mitchell 1994; Weiner 2001a; Wong-Kim et al. 2005; this volume, Mathews, Chapter 3, and Erwin, chapter 7) and elsewhere (Kagawa-Singer and Maxwell 1999; Lam and Fielding 2003; Makabe and Hull 2000)—that emphasizes social interdependence, respect, humor, and spirituality as keys to survivorship and a sense of control. These alternative experiences give us room to reinterpret war metaphors as well. Perhaps the collective "Livestrong Army," the political advocacy branch of the Lance Armstrong Foundation, partially bridges the distinct perspectives. In all likelihood, individuals flexibly embrace different metaphors and descriptors as they move through cancer experiences (see Erickson 2007; Stansbury, Mathewson-Chapman, and Grant 2003).

Understanding metaphors as both explanation and creation of experience has led Ben-Amos to suggest that "it may be possible to explicate but

not to undo metaphors because they are intrinsic to language" (2000:153). As such, metaphors may be shaped and understood cross-culturally or solely among people of a particular society and may, in general, have both relative and universal qualities (Kirmayer 1992; Quinn 1991). Recall that during the encounter between Niasov and Wells, the meaning of the metaphor of "purity" of blood and of doctors coming from afar about blood was not shared; however, Niasov's fear of cancer and his relief at finding out that he did not have the disease were immediately understood by Wells.

Because cancer differentiates self from other on both cellular and social levels, metaphors for cancer can easily play in the interstices of relative and universal. For example, Weiss (1997:456) persuasively argues that cancer is often metamorphosed "beyond culture" such that Western popular and biomedical metaphors combine to represent cancer as a universal symbolic concept. This universalizing, however, also works to characterize difference as problematic. Moreover, because the metaphors are linked to biomedicine, they take on the authority of medical science to make the social processes embodied in the distribution of diseases like cancer appear as if they are natural processes to the individuals and groups disproportionately affected. As Weiss (1997:470) notes, metaphors of cancer tend to have postmodern pandemic or global conventions of uncontrolled place, status, and body.

EXCESSES AND CONTROL

Perhaps with a tip of the hat to Lévi-Strauss (1963), Balshem noted more than a decade ago that "if one is thinking about control, cancer is good to think with" (1993:89). Cancer has historically drawn on the imagery of disorderly cells or impurities moving from one portion of the body into others. Noting the long veins radiating from a lump in the breast, Hippocrates named the disease *karkinoma*, Greek for "crab" (*cancer* in Latin). This imagery served as a description of the way the disease appears in the body and the way it eats the flesh, progressively moving throughout the body. Galen, following Hippocrates and the precepts of humoral medicine, taught that cancer was caused by too much black bile, or *melan chole*. Thus cancer has been associated with depressive personalities, those who would allow their emotions to "eat them up inside" (Olson 2002; Patterson 1987; Sontag 1978a). This imagery continues in the present through a personification of cancer cells. Indeed, a current cancer textbook begins with the assertion that "cancers are produced by cells that have gone mad. Normal cells, on the other hand, are the sanest things in the world" (Panno 2005:xi). Cells that "have gone mad" appear to be a hallmark of a Western

or biomedical understanding of cancer, one in which a multitude of disorders may afflict individuals and parts of their body.[7]

Adding to the imagery of out-of-control individual cells, problems associated with treating cancer further ingrain the sense that little can be done to restrain the unruly cells. Hippocrates, Galen (Patterson 1987), and the ancient Egyptians reported diagnosing cases of cancer and being unable to rid the body permanently of the growth (Olson 2002; Proctor 1995). The historical inability to treat or cure cancer is emblazoned in our collective memories, reminding us that few people survived most cancers before the 1980s.[8] Fueling our current trepidations, the often prolonged time of remission or death of the body—accompanied by physical, emotional, social, and spiritual pain and discomfort—adds to the persistent dread (DeCourtney et al. 2003; Lam and Fielding 2003; Long and Long 1982; McGrath 2002; Moore, Chamberlain, and Khuri 2004). Most profound of all, while cancer is sometimes viewed as a foreign invader growing out of control inside the body, there is also a sense that cancer is the body turning in on itself, permitting tumors to proliferate uncontrollably.

From the uncontrolled cells that cross internal bodily boundaries, to the unequal distribution of cancer across the globe, the significance of how the knowledge and experience of cancer create difference is embedded in issues of control, boundaries, and liminality. The uncertainty surrounding the experience of cancer, combined with its ubiquity and its profound impact on individual lives, provides a field of numerous beginnings and endings immersed in metaphors and narratives. These reflect and challenge contemporary social orders. The pre-diagnosed state is distinguished by categories quite different from those of the diagnosed. For instance, once diagnosed, a body may be labeled out of control, stigmatic, or in rebellion against itself. Cells are thought to be running amok.

The work of Mary Douglas ([1966]2002) has informed thinking about the ways in which societies symbolically understand cancer as a dreaded disease that is out of control. Her work also examines attempts to control those whose lives are marked by cancer. Douglas notes responses to "matter out of place" such as renaming it, physically controlling it, or using its dangerous and sacred status to call attention to alternative ways of being in the world. Thus, the medical discourses, metaphors, and silences represent our human efforts at controlling an unruly disease.

NAMING, CONTROL, AND ALTERNATIVE WORLDS

In some cases, silence and renaming are part and parcel of the sacred danger embedded in our efforts to control cancer. Many scholars have

documented the ways in which intentions and ideas, whether spoken or silent, have the power to create and destroy worlds (see Favret-Saada 1980; Gordon and Paci 1997; Weiner 1999). In a religious context, language, whether spoken or silent, often assists in the creation or continuation of the universe. From this perspective, the idea or the word is the mother or father of the reality or the deed. For example, Adam names objects and orders them. Christians say that "Jesus is the Word." Islamic tradition reiterates the view that creation is motivated by language—this notion is exemplified by the Koran, the Word of God (see Williams 1962). These philosophical legacies pervade the ideas of Kant, idealism, and New Age thought.

Generally, North American indigenous worlds are said to be created or shaped from chaos into order by thought. Creation and transformation may also be attributed to speech (see Caduto and Bruchac 1988; Erdoes and Ortiz 1984; Hultkranz 1980; Levy 1998; Trafzer 1997). With every telling, singing, and praying, the world is re-created. When performed in a ritual context, some ceremonial songs not only repeat the cycle of creation but also enable the world to be reborn or to continue (Tedlock 1983). Evil and sickness tend to originate when one or more of the First Beings interrupts interdependent and reciprocal interactions. Because primordial time exists alongside contemporary time, perhaps current illnesses and misfortunes are linked to the thoughts and deeds of historical, current, or primordial actors.

The acts of naming, diagnosing, and disclosing cancer are thus extremely powerful. By naming an entity, the speaker obtains the power of creator, and the named entity is empowered to act. Individuals code, or describe, and classify symptoms and events associated with illnesses. They often do so through metaphoric language, perhaps to attach flexible cultural meanings and references (Fabrega 1978) to what may appear to be incomprehensible experiences. The provision of meaning through cultural categorization and metaphors facilitates the ability to share the experiences of illness and health. The construction of stories aids people in assessing and perhaps reshaping their experiences and their selves (Pelusi and Krebs 2005; Pennebaker and Seagal 1999). Importantly, not all have the ability to share their stories with others who might assist in the alleviation of their suffering (see Weiner, chapter 6, this volume). Moreover, not all people have the opportunity to listen to narratives that might impact their experiences.

By naming, classifying, and ordering chaos, people are able to reorient a situation and make it "sacred." Mircea Eliade (1959) might say this approach makes the experience productive, centered/localized, and personal, as opposed to demonic, unoccupied, and other/foreign. It also often

allows individuals to call attention to alternative states of being in the world, whether through spirituality expressed by cancer support groups, as discussed by Mathews (chapter 3), or through survivor "witnesses," as described by Erwin (chapter 7). Stoller's recent ethnography (2004) and his contribution to this volume (chapter 2) guide us through his personal cancer experience, revealing how the chaos of cancer gave him greater insight into the healing and spiritual teachings learned in his earlier years of fieldwork. The modalities created by cancer and the associated metaphors can bring about terror and anxiety but can also create worlds in which cancer becomes an avenue for coming to terms with labels and categorizations of the disease as one of difference.

MEDICAL DISCOURSES, INEQUALITY, AND PHYSICAL CONTROL

David Rieff's (2005) commentary in the *New York Times* on the death of his mother (Susan Sontag) from cancer reminds us that illness is more than metaphor. Sontag fought against death using the latest biomedical technology and care. While her death was ultimately attributed to cancer, Rieff notes that Sontag's ability to access quality health care is not a privilege available to many who confront the challenges presented by their diagnosis.

Cancer metaphors—while providing a framework with which to give meaning to and rename the uncontrollable, border-crossing condition— also facilitate stigmatization of individuals and groups, a topic examined by all our contributors. Metaphors, in naming and attempting to control the experience, can shift attention away from the social inequalities that hasten the death of some and prolong the life of others. In this way, the differences already embodied in cancer metaphors are perpetuated through social inequalities, as represented in variables of economy, geography, gender, sexual preference, ethnicity, "race,"[9] class, and other social constructs and factors. These social and economic inequities also extend into the realm of knowledge—that is, what type of knowledge, biomedical or alternative, is permissible to the medical and insurance institutions that guide much of the cancer experience? Cancer inequalities speak of multiple structural, processual, and ideological inequalities that stem from biomedicine's hegemony over the definition of cancer.

A brief examination of the biomedical cancer timeline provides numerous interactions that foster the "excess of meaning" given to cancer. From a biomedical perspective, cancer is not a single disease, but rather a group of diseases that have the potential to affect all systems and organs of

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our bodies. The causes of cancer have long been debated, with seemingly minor gains in the understanding of etiologies. From the beginning, clinicians and researchers have considered the environment, poverty, diet, exercise, work habits, and even psychological disposition as potential carcinogens. The loci of responsibility may be on the individual or the collective in this construct.

While biomedicine offers standard and also promising new technologies for cancer treatment, cure rates vary. Early detection, rather than prevention, tends to remain one's best hope. The understanding of cancer has many loose ends; those who have experienced cancer firsthand—as a patient, family member, caregiver, physician, or scientist—draw these ends together based on their current understandings in order to give meaning to the illness experience.

In doing so, however, attention must be paid to the ways in which making meaning of differences turns into what Farmer (1999, 2003) calls the process of "mistaking inequality for cultural difference." For example, the view that fatalistic beliefs prevent minority populations from seeking care has been widely promoted in the public health and anthropological literature (Luquis and Villanueva Cruz 2006; Pérez-Stable et al. 1992; Powe and Finnie 2003; Spurlock and Cullins 2006); fatalism is used as a cultural explanation for high rates of cancer mortality among particular groups. However, when analyzed in a sociocultural context, the multiple inequalities that prevent early detection and ultimately lead to increased mortality explain the view that reactions to cancer diagnoses are much more than fatalistic (see Balshem 1993; Browner and Preloran 2000; DiGiacomo 1999). Indeed, people may label others whose actions they do not understand as fatalistic. Mistaking inequality for cultural difference denies a range of inequities and simultaneously shifts the focus to controlling knowledge rather than changing social conditions that produce higher incidence and mortality in specific populations. Even though cancer is one of the leading killers of humanity, cancer mortality in North America has recently dropped (American Cancer Society 2006; Canadian Cancer Society/National Cancer Institute of Canada 2007). These decreases in mortality, however, are not distributed evenly among all groups. The finding that African American men have a 38 percent higher cancer death rate than Caucasian men (Singh et al. 2003) is sufficient to raise serious questions about who is benefiting from the "war on cancer."

The calculations of cancer mortality and categorizations of ethnic and racial groups present a complicated picture of avenues that can bring greater resources to communities but may also facilitate the "mistaking of

inequality for cultural difference." For example, the use of racial/ethnic categories raises questions about diversity within communities. Concurrently, any ethnic/"racial" group as categorized by the US Census Bureau contains great diversity. For instance, the Asian/Pacific Islander designation includes people of both Japanese and Bengali descent. There is no account of class, education, language use, or other sociocultural information. Consequently, these categories become the explanatory factor for differences in cancer rates. The categories are used to signify a cultural/ethnic problem within the racial/ethnic group and not the distribution of health, economic, or other resources that contribute to differences in cancer rates. The effect is an increased call for interventions that address a "lack of knowledge" among communities rather than a call for resources that enable individuals to attend medical appointments or give them greater access to screening technologies and consistent treatment once diagnosed (see Balshem 1993 and Farmer 1999 for similar critiques). In this volume, both McMullin (chapter 4) and Chavez (chapter 8) examine the use of ethnic categories to perpetuate the structural violence that occurs when individual agency is constrained by social structures that prevent access to adequate health care.

Although there is a clear danger in conflating unequal access to resources with cultural difference, the enumeration of populations also serves as a mobilizing point—a point from which scholars and advocates alike can both critique the ways in which social inequalities produce high rates of cancer and push for better health services for the groups with higher rates of cancer. The work of Weiner, Erwin, McMullin, and Kagawa-Singer in this volume depends on their ability to show that the people with whom they work are underserved, thus providing an avenue for greater access to resources. Indeed, the ability to show that cancers are increasing highlights the fact that states and corporations, in their desire to engage in a global economy, let people die. One of many examples is Michaels' (1988) description of the failure of the US synthetic dye industry to abide by workplace health and safety rules despite knowledge of carcinogens in the dyes it produced. Only when the incidence of and mortality from bladder cancer increased was the industry made to act. The links between cancer and consumption are even more profound when we look at recent examinations of cancer activism. Increasingly, some corporations are active participants in cancer fund-raisers, using pink ribbon campaigns to sell products that often contribute to the production of carcinogens (see Ehrenreich 2001; Jain 2007a). Karakasidou's chapter 5 contributes to efforts linking global capitalism to cancer by documenting the increased use of pesticides

by Cretan farmers. The need to produce goods that have a longer shelf life and are free from insects has simultaneously exposed farmers to an increased risk of cancer and provided a more "modern" life for their families. The ability to show trends in cancer rates among groups of people allows us to elaborate on connections with policy and capital that may otherwise be obscured.

DIFFERENCES AND CHANGE

While the enumeration of cancer cases enables the observation of the increases in and distribution of cancer, it also facilitates the conflation of inequality and cultural difference. Public health, epidemiology, and biomedicine, in general, view "culture" as something people have that must be changed in order to prevent the incidence of and mortality from cancer (DiGiacomo 1999; Farmer 1999; Frankenberg 1995; B. Good 1994). In contrast, as Frankenberg (1995) points out, anthropologists who seek "to act *with* others" recognize that cultural systems are not static. They argue that cultural systems are historically contingent and, though shared, not evenly distributed in any one society. Because biomedicine plays a large role in defining the dimensions of the biological and physiological processes of cancer, the contingencies of culture become obscured in the effort to change beliefs and practices. Recognizing culture as a flexible system rather than a "thing" that people have is a topic continually addressed and redressed by anthropologists and other scholars and advocates (see Culley 2006). Indeed, in chapters 5 and 6, Karakasidou and Weiner reveal how individuals from Crete and from Southern California, respectively, reassess their perspectives on cancer and health as part of changing health systems. Contributors to this volume critically examine cultural differences as these exist in current efforts to improve the cancer experiences of groups of people. In doing so, Mathews (chapter 3) and Kagawa-Singer (chapter 11), for example, address how we might use differences to work with others.

Ethnographers are well aware that biomedical models of cancer are continually constructed and negotiated. They critique the manner in which biomedical models portend fact, based partially on almost hegemonic control of cancer treatment in many health systems and countries (M.-J. Good 1995; Martinez, Chavez, and Hubbell 1997; McMullin, Chavez, and Hubbell 1996). For example, it is a biomedical construct, not a fact, that being hit in the breast does not cause breast cancer. However, most doctors communicate this message as if it were an absolute, empirically tested, and demonstrated truth. Anthropological analyses of overt and subtle health perceptions and strategies show hegemonic and social processes

that contribute to the negotiations between biomedicine's "truth" and other knowledges or perspectives that construct cancer.

Interestingly, most ethnographic studies about cancer experiences have been conducted in the West (the United States, Europe, and Canada); the few exceptions tend to illustrate the interactions between biomedicine and other health systems or cultures, such as in Japan (Fujimura 1996; Long and Long 1982), Italy (Gordon and Paci 1997), Israel (Weiss 1997), Greece (Karakasidou, chapter 5, this volume), China (Lam and Fielding 2003), Thailand (Boonmongkon, Pylyp, and Nichter 1999), and India (Trawick 1991). Yet the knowledges produced in the various modes of thinking about diagnosis, etiology, and treatment are mostly considered in terms of how they compare with biomedical standards. This power dynamic is an example of efforts to homogenize difference in knowledge through the naturalness assumed in the body, as well as the subordination of other cultural knowledges of cancer to the cultural knowledge of biomedicine.

In biomedicine, the meaning given to cancer is often decontextualized from any social arrangements, and understanding is often focused on the cells that are growing uncontrollably within the body. Whether through support groups, understandings of risk, or individual experience, multiple truths or meanings of cancer can be recognized. Clearly, cancer does not "belong" to biomedicine; however, patients and advocates of varying populations often look to biomedicine for answers regarding the "true" or "scientific" nature of the disease.

Given the multiple meanings and metaphors associated with cancer, individuals and groups looking for cancer information find biomedicine's efforts and understandings of cancer lacking. Cultural and idiosyncratic constructions of cancer etiologies; methods of prevention; associated treatments; and explanations of care, pain, and dying abound. This assertion highlights the variability with which the construct of culture is used in public health and biomedicine and how anthropologists implement its use (J. Taylor 2007). Like political and economic resources, cultural knowledge is not evenly distributed, static, or homogenous. In terms of the distribution of cancer knowledge, many North Americans may agree with the NCI guidelines suggesting that all women forty years of age and older have a mammogram every one to two years, yet some women feel that this technology may provoke or initiate cancer (see Burhansstipanov and Dresser 1994; Chavez et al. 1995). These same people may also agree with NCI perspectives that habitually used tobacco is a carcinogen. Individuals compartmentalize ideas about causation, prevention, and treatment; people may also adhere to multiple, often seemingly contrasting, views

(see Erickson 2007 and Erwin, McMullin, Weiner, and Karakasidou in this volume).

Perhaps because of the multiplicity of meanings and associations, "cancer is good to think with," not just about issues of control but also about the diversity of historical, political, and cultural ways people develop and act upon cancer knowledge. Within this framework, Lee and Heurtin-Roberts (chapters 9 and 10, respectively), critically examine biomedicine as a cultural system. They explore the ways in which the implementation of biomedical and public health agendas at times becomes an instrument through which power is exercised: the surveillance, control, and discipline of populations that do not adhere to the recommendations. More important, however, they use their critique to assist in moving biomedicine forward, into an arena where biomedicine and public health can work with anthropologists and others rather than attempt to homogenize diversity within populations and disciplines.

The integration of politics with science homogenizes the approaches taken in prevention and treatment efforts. Furthermore, focusing on the science of cancer tends to shift attention to the proliferation of cells and away from humans and human relations. As Sontag (1978a) suggested, we must not think of illness as a metaphor—or only as a metaphor. In shifting position, the ambiguities and inequalities obscured by renaming and physically controlling are clarified. A breast cancer patient and writer of fiction and nonfiction, Sontag published *On Photography*, an analysis of the worlds of recording and interpreting visual images. In this treatise, she writes:

> To photograph is to appropriate the thing photographed. It means putting oneself into a certain relation to the world that feels like knowledge—and, therefore, like power.…What is written about a person or an event is frankly an interpretation, as are handmade visual statements, like paintings and drawings. Photographed images do not seem to be statements about the world so much as pieces of it, miniatures of reality that anyone can make or acquire. [Sontag 1978b:4]

All the chapters in this volume examine pieces of the cancer experience, from the individual to the larger social fault lines that draw the lens to the inequality of suffering. At times we bear witness, as Stoller (chapter 2) argues, to the distinct expressions given to cancer and explore what it can teach us about ourselves and the accepted premises of scientific views of cancer. At other times, we place more of ourselves in the frame. We participate in the open critique of power relations and promote the understanding of

the experiences of cancer (other ways of being human in the world). This dual position—or place of liminality or ambiguity—highlights the tensions in practicing an engaged anthropology. The contributors to this volume frame cancer within the camera's lens. Instead of sitting within the boundaries created by disciplinary and experiential queries, we interrogate the borders, the places left white in the margins between the photograph and ourselves.

OVERVIEW OF CHAPTERS

All the authors in this volume consider their contributions to the understanding of cancer as positions of advocacy: in analyzing the shifting meanings of cancer, critiquing the inequalities within the narratives, and advocating the use of metaphors that challenge the status quo. These approaches force the writer and reader to step back and recognize the excess of meaning. In doing so, we hope to highlight those metaphors, narratives, and subsequent differences that alleviate physical, psychological, and social suffering from cancer.

We begin the book with Stoller's personal narrative, which highlights the liminality experienced through diagnosis, treatment, and life with cancer. Remission, he argues, forces a person into an indeterminate state. What can one do to adjust to being continuously betwixt and between? Throughout chapter 2, Stoller argues that by embracing the indeterminacies of remission, we can better understand the complexities of our bodies and ourselves. He argues further that the metaphors associated with remission can enable anthropologists to reconfigure the discipline to bring it more in sync with the considerable indeterminacies of contemporary social life. Indeed, Stoller's cancer diagnosis and experience insist that readers confront the notion of the self–other as separate from previously experienced individual, social, and national bodies. Rather, he calls on us to imagine how we might experience the crossing of self–other boundaries as an integrated piece of life.

Deborah Erwin works closely with African American communities to increase knowledge and access to cancer prevention and screening services. Erwin's ethnography (chapter 7), like Stoller's, provides an example of the ways cancer patients mediate their new identities as "survivors." Instead of attempting to return completely to their "healthy" identities, the individuals described by Erwin find room to play with their liminal status. Like Stoller, these women locate power in the spaces between categories of healthy and unhealthy. Within the projects that Erwin discusses, communities and individuals are empowered to make decisions on their own

behalf, despite having been previously told by a variety of local, national, and international voices that these choices are not theirs to make.

Holly Mathews (chapter 3) examines another aspect of illness, suffering, and healing. Drawing on her ethnography of self-help groups, Mathews critically examines the cultural assumptions that give meaning to support and support groups. She examines both the accepted understandings associated with US middle-class individualism (which promotes support and mentorship) and the US discourses on survivorship (which implicate people who succumb to cancer as weak) in the support group narratives. She shows precisely how cancer support groups are a product of a specific segment of US society and thus do not necessarily meet the needs of the majority of cancer patients. Her work ends with cross-cultural examples of extremely successful support groups, which include anthropologists' assisting in a group's political, financial (through grantsmanship), and social production.

The historical lens informs the work of Diane Weiner (chapter 6) and Anastasia Karakasidou (chapter 5), who examine the shifting knowledge of cancer risk as it is characterized by biomedicine and new technologies as a symbol of the "modern," as well as a mediator of lived experience as revealed in increased cancer deaths. Weiner's chapter is an ethnographic account of Southern California American Indian cancer causation theories. As an example of flexible thinking about a health condition and process, knowledge of cancer etiologies provides a means to explore the changes in cancer discourse among members of neighboring tribes and communities. Based on twelve years of interviews and observations, Weiner explores the tensions between resistance to the biomedicalization of cancer causation and the simultaneous use of biomedical health systems. This examination shows how multiple knowledges can lie side by side while people experiment with efficacious systems. Through tracing these historical shifts, we can see the tensions of self/other as desires and demands to engage in different perspectives and technologies transform individual and community landscapes.

Karakasidou's long-term work in Crete offers an ethnographic example of the impact of environmental pollutants on social and physical bodies. These impacts are revealed in the shifting discourse on modernity for farmers and their families through their use of pesticides, which provides them with a way to engage in new technologies and the global economy. Drawing on the work of Giorgio Agamben, she compares the seduction of modernity and the increasing cancer rates with the choices farmers make between *zoe* ("bare life") and *bios* ("quality life"). In doing so, Karakasidou highlights

the fact that in choosing to join "civilization" through a degradation of the environment, the farmers are able to engage in the global economy and meet the needs of the state. However, in the farmers' achievement of the "quality life," the state ultimately "lets them die," in the Foucauldian sense, through the negligent promotion of pesticide use. Karakasidou's work provides a snapshot of the impact on the body politic of occupational health concerns and hazards and the role of the state.

The emphasis on creating bodies (albeit potentially diseased ones) that produce for the state is furthered in several of the authors' examinations of neoliberalism. The conversation on inequality and divergence is framed by both neoliberalism as an economic pursuit and its philosophical underpinnings, which place the onus of health and health care on individuals. Neoliberalism and institutions give interpretations to cancer that often justify inequalities. In the exercise of this knowledge/power, anthropologists meet the double-edged sword of neoliberalism. Once people are empowered to make decisions, the structural support to enact those decisions may be severely lacking. Concurrently, neoliberal policies emphasize individual responsibility. These policies, matched with Enlightenment views of equality, enhance the ability of the dominant society to place the blame for poor health on the individual. This point is clarified in Leo Chavez's chapter 8, "Wasting Away in Neoliberal-ville." He argues that neoliberal policies exclude Latinas in California from accessing health care and simultaneously blame them for their high rates of cervical cancer. The cervical cancer risks touted by public health workers and physicians emphasize the sexual responsibility of the individual. In contrast, Mexican immigrant women focus on the relational aspects of risk for cervical cancer. The tension between biomedical and scientific knowledge to categorize and stigmatize individuals and communities is further entrenched in economic policies that blame individuals for failing to progress in education and in possessions and to agree with or abide by Western views of education.

Neoliberalism and institutions also provide the knowledge and interpretations of cancer that often justify inequalities. The narratives of the people who experience a cancer diagnosis also reveal another aspect of the excess of meaning. Narratives contribute to the explication and contestation of numbers produced by epidemiology. More important, these stories also highlight the distinctions between self and other while suggesting ways to live with and maintain difference. Researchers often note that high cancer mortality rates are sometimes due to lack of insurance or economic security. This statement, while "accurate" numerically, reveals nothing about the suffering experienced by people simply trying to obtain a diagnosis or

support for the pain they experience. Recounting the diagnosis narratives of Latina cervical cancer patients, Juliet McMullin's chapter 4 examines the multiple structural barriers (prolonged waits for insurance checks, refusal of service, and searches for care at multiple clinics and hospitals) that impact bodies, lives, and memories. Their challenges are further exacerbated by medical personnel who attribute the cause of the women's cancer to sexual misconduct. These multiple obstacles to detection and care give life to the cervical cancer statistics, revealing how these women come to be "embodied as individual pathology" (Farmer 1999). The excess of meaning for cervical cancer available to medical personnel makes it easy to slide into discourses that stigmatize women, as if a woman's cancer were of her own making. McMullin's chapter contributes to our understandings of how women experience, act upon, and make sense of their diagnosis—and, in doing so, contest epidemiological and medical characterizations.

Suzanne Heurtin-Roberts (chapter 10), Simon Craddock Lee (chapter 9), and Marjorie Kagawa-Singer (chapter 11) examine the concept of cancer health disparities, which has grown in prominence at the NCI and in community-based participatory research (CBPR). Drawing on their insights at this and other institutions, these anthropologists are in a unique position to uncover the assumed ways in which the concept of "health disparities" actually perpetuates inequalities. "Health disparities" is framed in an effort to decrease the "unjust" inequality between groups that have higher rates of cancer and those that do not. As Heurtin-Roberts and Lee argue, the conceptualization of disparities is based on predetermined categorizations that primarily emphasize race and ethnicity and secondarily focus on socioeconomic status. This conflation of race/ethnicity and poor health both pathologizes communities and naturalizes the notion that they, by virtue of their race/ethnicity, carry a greater burden of disease in the United States. Similar perspectives are often upheld in other countries (see Braveman 2006). In sum, "health disparities" is frequently a replication of the self/other dynamic, in which the other is in need of fixing. Heurtin-Roberts interrogates classical liberalism to discuss the complex weaving of race, capitalism, and equality that gives rise to contemporary health inequities. Lee uses his role as an embedded anthropologist at NCI to explore the dynamics of race and health disparities in research proposals. In this role, he can make institutions talk, unraveling the often obscured values and the unintended replication of social hierarchies. Kagawa-Singer expands the argument with an examination of the ways in which health disparities programs are enacted within Southeast Asian and Pacific Islander communities in the United States. Taking a critical eye to the use of culture

in the creation of the self/other dichotomy, Kagawa-Singer highlights the ways that culture is used to reify difference and how we might overcome that reification through CBPR. These three chapters are intensely theoretical and reveal the partial connections between health disparities knowledge, institutions, and application.

Anthropological sensibilities provide a grounding within which individuals and communities can work and change those social processes and categories that are detrimental to well-being and result in higher rates of cancer. While some may consider "theoretical" and "applied" anthropology two incompatible practices, we have come to see our efforts, using cancer as the topic, as one and the same (see also Rylko-Bauer, Singer, and van Willigen 2006). We adhere to Sontag's view that words, like photos, are powerful, as are the interpreters of those words. As Stoller writes in chapter 2, we "grasp bits and pieces" of wisdom by "incorporating 'otherness' into lived experience." In doing so, we find a way to move beyond categories within and outside our discipline, breaking the silence and contributing to the hope that stems from confronting cancer.

This book includes theoretical and applied analyses of cancer. Both views enable us to peel away the layers of metaphors that make cancer seem simply a biological process. In addition to biology, the authors' "peeling away" reveals social relations and hierarchies that produce physical, spiritual, emotional, and social suffering. Our anthropological sensibilities remind us to try not to replicate power relations inherent in any one health or knowledge system. In this pursuit, we also attempt to keep people from being consumed by the "kingdom" inhabited by the monsters and chaos of cancer and suffering, for as Ben-Amos suggests, "it may be possible to explicate but not to undo metaphors because they are intrinsic to language" (2000:153). Ultimately, cancer metaphors that break stigmatizing silences may allow us to imagine and enact worlds where suffering is not a cause for blame but rather a recognition of difference that is an intimate and valuable part of life.

Notes

1. According to current epidemiological findings, one-fifth of all cancers are associated with chronic infections such as hepatitis B, human papillomavirus, *helicobacter pylori*, and HIV, and 40 percent of all cancers are associated with habitual tobacco use, dietary patterns, and exposures to known carcinogens (World Health Organization 2006). These trends illuminate the social and cultural dimensions of disease distributions.

2. The Google search for *cancer* was surpassed only by a search for *AIDS*, which resulted in 223,000,000 hits. Like HIV/AIDS, cancer evokes concern because it simultaneously attacks individuals and reveals the complexity of our social relationships.

3. See Fies 2006 and Engelberg 2006 for examples of cancer stories in graphic-novel and comic formats.

4. Niasov's quotes are via the translator present at the event.

5. The 1971 State of the Union address, available at http://stateoftheunion.onetwothree.net/texts/19710122.html, accessed January 30, 2009.

6. By "metaphors," we mean those dynamic analogies that award "the properties of one concept on another," and "all of our cognitive, affective, and somatic ways of knowing may be brought to bear to elaborate metaphoric consequences. [These ideas] may be implicit or unintentional, used without awareness or concern with the metaphoric/literal distinction" (Kirmayer 1992:332; see also Ben-Amos 2000; Henle 1958; and Richards 1965).

7. Likewise, non-Western etiologies may emphasize overindulgence of thought or action and the need to maintain balance in all things (Csordas 1989; B. Good 1994; Trawick 1991). While some theories emphasize a more holistic causation (social relations and environment) and others individualize the process (cells and genes), what is common is that these theories, in part, refer to excesses of emotion, consumption, or transgressions that allow an entity to overwhelm other bodily organs and processes.

8. In 1980 the age-adjusted mortality rate for all groups was 206.96 per 100,000, compared with 190.05 in 2003 (Surveillance, Epidemiology, and End Results Program 2006). The relatively low overall drop in mortality is often attributed to the increase in cancer incidence (417.71 per 100,000 in 1980 compared with 459.57 in 2003).

9. For a more detailed description of race as a means of categorization used in health surveillance, see Hahn and Stroup 1994.