Negotiating Structural Vulnerability in Cancer Control

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Edited by Julie Armin, Nancy J. Burke, and Laura Eichelberger

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The ideas and theoretical insights explored in this volume have benefited from discussion among applied and medical anthropologists: first, in a panel at the 2013 American Anthropological Association meetings; and later, in 2014, as an advanced seminar at the School for Advanced Research (SAR). The SAR seminar, titled "Structural Vulnerability in Cancer Control: Contemporary Challenges for Applied Anthropologists," was part of an exciting collaboration between SAR and the Society for Applied Anthropology (SfAA), designed to foster the production of relevant theoretical insights from engaged anthropological scholarship. The SfAA/SAR collaboration provided the funding to bring together scholars from across the United States engaged in the ethnographic study of cancer. The majority of the papers discussed are included herein. We wish to acknowledge the support Nicole Taylor provided in coordinating the initial seminar and subsequent planning for this volume. Thanks to all the contributors for their collegiality, insight, originality, and commitment to critical engagement. Others who participated and made valuable contributions to the development of the ideas in this volume include Nicolas Sheon, Lisa Tiger, and Shannon Sparks. Special thanks go to Simon Craddock Lee and the Department of Clinical Sciences at UT Southwestern Medical Center for funding the transcription of the stimulating conversations that occurred at SAR. While we all took detailed notes during our discussions, the transcripts were helpful when drafting our introduction and in weaving the themes identified in the seminar throughout the chapters. Appreciation is owed to two anonymous reviewers who offered wise and constructive comments. Many thanks to Brittney Hammons, who helped prepare and copyedit the first draft for peer review. Without her help we would possibly still be checking bibliographies. We also thank our SAR editor, Sarah Soliz, for her guidance through this process.

CHAPTER ONE

Introduction

Framing Cancer and Structural Vulnerability

NANCY J. BURKE, JULIE ARMIN, AND LAURA EICHELBERGER

In 1993, Martha Balshem published *Cancer in the Community*, an ethnography of a cancer outreach and education program in an inner-city Philadelphia neighborhood she called Tannerstown. Working as a health educator, she was tasked with delivering messages about individual cancer risk due to what are now called "lifestyle factors" (e.g., smoking and unhealthy diets) in the cancer control and public health literatures. She noted the contentious, and often resistant, response these outreach efforts generated among Tannerstown's largely working-class white community members of Polish descent. Rather than accepting the message that their cancers were attributable to smoking and unhealthy diets, community members noted that their inner-city neighborhood, an official cancer "hot spot," was surrounded by three chemical factories. They suggested that life in a heavily polluted environment was responsible for high cancer rates, not personal lifestyle choices. With this early ethnography, Balshem joined an emerging group of anthropologists studying the growing field of oncology who were challenging status-quo understandings of cancer prevention and causation by suggesting causal factors external to the individual (Del Vecchio Good et al. 1990; Gordon 1990; Lind et al. 1989; Mathews et al. 1994).

Balshem critically evaluated the processes she engaged in as a health educator in detailed field notes. Yet she waited to write about her cogent class analysis of the dynamics involved in the outreach efforts until she was safely ensconced in a tenure-track academic position. She thus spends a portion of the book drawing a distinction between "applied" and "theoretical" anthropology. We evoke Balshem's research in the introduction to this collection for several reasons. First, the dynamics and tensions she described continue to operate in the world of cancer control, and specifically cancer disparities research and

outreach today. Second, the positionality she eloquently described—that tightrope she walked between critical engagement and compensated participation—is one that resonates with many contributors to this volume. Third, the social, economic, class, and environmental contexts of Tannerstown constitute forms of structural vulnerability consonant with those described herein, albeit in different populations and in different settings. And last, the contributors to this volume collapse the divide she posited between applied and theoretical anthropology; instead, they demonstrate the profound theoretical contributions engaged anthropologists make both inside and outside the academy.

This volume stems from an applied anthropology seminar at the School for Advanced Research, which brought together anthropologists engaged in the study of cancer to discuss the ways vulnerability is understood in the social sciences and in the world of cancer control. We took as our point of departure the concept of structural vulnerability: "a positionality that imposes physical-emotional suffering on specific population groups and individuals in patterned ways" and that results from "class-based economic exploitation and cultural, gender/sexual, and racialized discrimination" (Quesada et al. 2011). Originally used to identify and name the structures that perpetuate poor health outcomes among undocumented Latino immigrants, the concept was broadened by seminar participants to address social conditions underlying cancer disparities, access to cancer-control technologies, and stigmatizing discourses. Participants also questioned the utility of this concept for thinking through the social and biological processes that form the foundation of the anthropology of cancer.

At the heart of this volume is a desire to answer two questions: What can case studies about the lived experiences of and discourses related to cancer contribute to a burgeoning interest in the concept of structural vulnerability? And can a consideration of structural vulnerability enhance applied anthropological work in cancer prevention and control? Contributors explore what it means to be structurally vulnerable; how structural vulnerabilities intersect with cancer risk, diagnosis, care seeking, caregiving, clinical-trial participation, and survivorship; and how differing local, national, and global political contexts and histories inform particular configurations of vulnerabilities. These case studies illustrate how quotidian experiences of structural vulnerability influence and are altered by a cancer diagnosis at various points in the continuum of care.

Importantly, contributors do not wholeheartedly adopt the concept of structural vulnerability, but rather utilize it as a heuristic for exploring the ways it highlights, or at times obfuscates, complex aspects of the cancer/person and social/institutional assemblage under analysis.

In the following, we review current themes in the anthropology of cancer, with a focus on how the ethnographic research included in this volume elucidates invisibilities and erasures around cancer, including causalities (e.g., occupational and environmental exposures); the hidden work of cancer prevention, treatment, and research (e.g., risk identities, gendered labor, travel, and bureaucratic management); and the shortcomings of policies that purport to increase access to treatment, among others.