

Public Health Ethics Analysis 7
Series Editor: Michael J. Selgelid

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Narrative Ethics in Public Health: The Value of Stories

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Public Health Ethics Analysis

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Series Editor

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Editors

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Preface

Overview

As the field of public health ethics is both relatively new and distinctive, there are few training resources to help practitioners and health officials address ethical challenges likely to arise in public health practice. To address this gap, in 2011, the Centers for Disease Control and Prevention (CDC) developed training geared toward informing local health officials about the field of public health ethics. This included development of student and facilitator manuals and an accompanying PowerPoint presentation that provide an overview of the field and included five case studies to generate discussion of ethical considerations of public health practice. These are “living documents” and are updated, most recently in 2019, to ensure that they contain current information. The student manual is posted on the CDC website (<https://www.cdc.gov/os/integrity/phethics/trainingmaterials.htm>); the facilitator manual and PowerPoint presentation can be requested from Phethics@cdc.gov.

In 2012, CDC spearheaded an effort to develop a public health ethics casebook. This open access book, *Public Health Ethics: Cases Spanning the Globe*, published in 2016 by Springer Press, features 40 cases written by authors from around the globe and describes a framework for analyzing ethical issues in public health. The casebook is available at <https://link.springer.com/book/10.1007/978-3-319-23847-0>. Like the training manuals, this book uses case studies as a technique for illustrating how ethics principles can be applied to public health decision-making. The case study format which describes a specific scenario based on particular facts in a realistic situation is a familiar teaching tool for health officials who are comfortable with relying on science and facts to consider how to weigh conflicting potential actions.

In 2018, Drs. Barrett, Ortmann, and Larson began exploring the role of narrative ethics as an alternative method for providing training on public health ethics issues. Narrative ethics has been successfully used to illustrate medical ethics issues but has not been used to the same degree to explore ethical issues that arise in public health practice and research. The advantage of the use of narrative is that it prompts

the reader to connect to the issues on a more personal level compared to the case study approach. Narrative raises questions about how one should (or should not) think, act, or live, usually in relation to others. Narratives, then, whether drawn from fiction or everyday experiences, help us open a reflective space to think through ethical questions.

We begin in Part I by providing an overview of public health ethics, narrative ethics, and the usefulness of applying narrative to public health. In Chap. 1, Dr. Ortmann describes various approaches for defining public health ethics based on what he terms the four Ps: problems, practice, procedure, and principles. He emphasizes the importance of listening to communities and describes how use of narrative can benefit public health practice. In Chap. 2, Dr. Larson provides an overview of the field of narrative ethics and discusses some of the challenges of applying this approach in public health.

In Parts II through VI, we present 14 narrative chapters that illustrate the use of stories to explore ethical issues in public health practice and research. You will note that the authors take different approaches to their narratives, including presenting personal stories and reflections, creating fictionalized accounts of actual events, and using existing literature to illustrate public health ethics concerns. The ideas and opinions expressed in the chapters are the authors' own. The chapters are not meant to reflect the official position, views, or policies of the editors, the editors' host institutions, or the authors' host institutions.

There were a variety of ways that we could have organized the narrative chapters (e.g., area of ethical concern, public health intervention, disease category, or narrative approach). We chose to group the chapters into five broad categories based on the predominant ethical issue addressed by the narrative. Several of the chapters address multiple issues so categorization was also guided by our desire to include a balanced number of chapters across the categories. The five categories include the following:

- Justice Concerns
- Surveillance and Stigma
- Community Values and the Value of Community
- Trust and the Value of Information
- Freedom and Responsibility

Justice Concerns

The first category, Justice Concerns, includes three chapters that focus on issues of health disparities, health equity, social justice, social determinants of health, and concerns of vulnerable and/or marginalized populations. In Chap. 3, the chapter by Lathrop and colleagues, "Empowering Communities that Experience Marginalization Through Narrative," presents the story of Marcia Mercy Rumutsiro Kasambira, a Certified Peer Specialist, who overcame struggles with depression, substance abuse,

diabetes, intimate partner violence, and racism. The narrative explores Marcia's relationship with the staff of a community health clinic who took the time to listen to her story and assist her with addressing the social factors impacting her health. In this chapter, Lathrop and colleagues illustrate the importance of narrative for understanding the health concerns of underserved and vulnerable populations and the role narrative can play in challenging providers' underlying assumptions that perpetuate stereotypes and promote persistent inequities.

Chapter 4, by Thompson, "The Boys Under My Deck: Racialized Violence and Moral Repair," is a personal narrative that explores issues of racial disparities in the United States and the health impact of structural racism and racialized violence. Thompson describes her experience with the practice of moral repair when she moved into one of Baltimore's oldest and most distressed neighborhoods. For Thompson, this involved gaining an intimate understanding of the social and economic history of her community and building caring relationships that crossed racial, income, class, and age boundaries. The story focuses on her experiences with the "boys under the deck" and how these interactions increased her understanding of the impact of racial inequities. Through this story, Thompson challenges the reader to consider their own assumptions about racism and racialized violence.

Chapter 5, by Hodge, "Voices of Our Fathers: Narrative (Care) Ethics, Trust and Trustworthiness," explores the legacy of the U.S. Public Health Service "Tuskegee Study of Untreated Syphilis in the Negro Male" and, more broadly, the impact of institutionalized racism. The author draws on historical documents to give voice to the men who were impacted by the study as represented by two study survivors, Mr. Charles Pollard and Mr. Herman Shaw. Their voices are presented in contrast to the doctors and system that supported the study as illustrated by the comments and writings of Dr. John Cutler, one of the most vocal defenders of the study. The chapter also considers how an empathic (relational) care ethics approach is useful for examining the ethical impact of the study.

Surveillance and Stigma

The second category, Surveillance and Stigma, includes two chapters that address ethical issues relating to conducting human immunodeficiency virus (HIV) surveillance. The chapters raise issues relating to respect for individuals, protection of privacy and confidentiality, and stigma. Chapter 6, by Miller and colleagues, "Disclosure of a Participant's HIV Status During a Household Community HIV Testing Project," describes issues relating to disclosure of HIV status and protection of privacy and confidentiality in the context of a community household HIV testing project. It raises lessons relating to the duties and responsibilities of project staff at all levels and the importance of appropriate training of staff. Readers are also asked to consider the respective rights of individuals and community members.

Chapter 7, by Watson and colleagues, "Stories, Stigma and Sequences: HIV Cluster Detection and Response Activities Through a Narrative Ethics Lens," raises

ethical issues relating to the use of molecular HIV cluster detection as part of public health prevention and response efforts. This chapter explores issues relating to the lack of individual consent for HIV surveillance, how HIV surveillance data are used, the importance of transparency in describing these uses, and the impact of the data on marginalized populations. The narrative also illustrates the importance of partnering with communities to establish public trust. These issues are illustrated by contrasting two different interactions about a fictional HIV outbreak. The first is an email interaction between staff members at different health departments discussing the fictional outbreak. The second involves an online exchange on a public blog post among HIV advocates. The narratives challenge the reader to apply various ethical principles, such as autonomy, confidentiality and consent, beneficence and non-maleficence, and respect for persons to consider how to best weigh the benefits and harms of public health interventions for lowering the transmission of HIV.

Community Values and the Value of Community

The third category, Community Values and the Value of Community, includes three chapters that focus on issues relating to the importance and power of community. The chapters explore ethical issues relating to cultural competence, empowering communities, community values, and individual and community resilience. Chapter 8, by Gartner and Wilbur, “Exploring Public Health’s Role in Addressing Historical Trauma among U.S. Indigenous Populations,” examines the impact of colonization on the continued experiences of health disparities by Native Americans and how public health has contributed to these disparities. The story illustrates how cultural humility and respecting community cultural values can help public health researchers begin to understand historical traumas and lead to more effective public health interventions. The narrative presents the story of a day in the life of an Indigenous woman who is a public health researcher studying historical trauma. It illustrates some of the challenges for public health when working with native populations and the importance of considering cultural values and narratives for addressing the long-standing impact of historical trauma.

Chapter 9, by McMorrow, “Ethical Considerations with the Photovoice Research Method: A Narrative Reflection,” describes the author’s experiences with using the photovoice method as a tool for empowering women who are refugees from the Democratic Republic of Congo living in the United States. The story considers the important role that empathy, cultural competence, and cultural humility play in conducting community-based participatory research (CBPR). Photovoice is a process in which community members use photography to reflect their community experiences, both positive and negative, and ultimately to open a dialogue and impact policy makers. The narrative describes the perspectives of two research team members working on a photovoice project who come from vastly different cultural and economic backgrounds to illustrate the ethical tensions that may arise from CBPR.

Chapter 10, by Sandul and Moore, “Harm Reduction: Tipping the Balance Toward Treatment and Recovery,” could easily have been grouped in several of the other categories. We chose to include it in the Community Values and Value of Community category due to its focus on considering community values when developing community-based harm reduction interventions for opioid and other substance abuse disorders. It describes tensions between community members about establishing a comprehensive harm reduction program for treatment of substance disorders, including the use of a syringe services program, and presents the perspective of a person who has benefited from these types of services. Readers are asked to consider approaches for increasing understanding of community values and concerns relating to harm reduction interventions.

Trust and the Value of Information

The fourth category, Trust and the Value of Information, includes three chapters that explore issues relating to the value of information for the successful practice of public health. The themes explored in these chapters include health education, risk communication, health literacy, transparency, and the importance of collaborations for ensuring information sharing for building public trust. Chapter 11, by Navin and Kozak, “Vaccine Refusal: Stories from the Front Lines of Immunization Education,” explores ethical considerations relating to mandatory childhood vaccination programs and the impact of mandatory education for approval of vaccine waivers on both the parents and public health professionals. The narrative is presented in the form of a fictionalized personal memoir of an immunization educator; however, the memoir reflects the experiences of actual immunization educators interviewed by the authors. The story illustrates the feelings, hopes, frustrations, and challenges of public health officials charged with ensuring parents are aware of the impact of refusing mandatory childhood vaccines.

Chapter 12, by Glässel and colleagues, “Using Narratives to Improve Health Literacy – An Ethical and Public Health Perspective,” explores the importance of clear communication of complex medical information even for patients with relatively high levels of literacy, and how the sharing of stories collected in a scientifically rigorous way can be beneficial for addressing patient concerns. The narrative describes the health experiences of a well-educated woman dealing with a difficult pregnancy who is left on her own to understand the complex medical information her health provider presents to her about her pregnancy. This chapter draws upon the authors’ work documenting and analyzing patients’ narratives as an approach for improving health communication and healthcare. Their work has resulted in a Database of Individual Patient Experiences (DIPEX), which serves as an open access tool that can be used by health professionals to improve their health communication and can be accessed by the public to better understand their health conditions.

In a timely example of a real-world event, Chap. 13, by Zinner, “A Novel Approach to Public Health Crises Using Narrative Ethics,” draws on existing fictional literature to explore ethical considerations relevant to responding to an infectious disease outbreak. Zinner presents excerpts from Steven King’s *The Stand* and Michael Crichton’s *The Andromeda Strain* to consider the important role of information sharing during a pandemic and how teamwork and collaboration can improve public health decision-making. She also considers the obligations of government officials to address harms they have caused during and after a public health crisis. The author asks the reader to consider if the novels provide any lessons for responding to the COVID-19 pandemic or future public health emergencies.

Freedom and Responsibility

The final category, Freedom and Responsibility, includes three chapters that address issues relating to personal responsibility, individual rights versus public good, and the government’s role in protecting the public good. Chapter 14, by Valentine and Bolan, “Naming the Patient: Partner Notification and Congenital Syphilis,” illustrates these issues through the experiences of a disease intervention specialist (DIS) and her efforts to prevent and control sexually transmitted diseases. The conflict between individual rights and public good arises when the DIS seeks to convince a pregnant woman who has been exposed to syphilis to come into the clinic to be screened in order to protect her unborn child from congenital syphilis. It highlights questions about a patient’s right to privacy and right to refuse treatment even when there is potential for harm. This story also illustrates issues related to the importance of partnerships between health departments, community members, and other social service providers to adequately implement public health interventions.

Chapter 15, by Farías-Trujillo, “My Mother, Obesity and Me: Our Narrative. How Obesity is Intimately Related to Biopsychosocial and Spiritual Factors,” illustrates issues relating to the role of personal responsibility versus the role of the government in addressing the public health problem of obesity. The author shares his and his mother’s personal struggle with obesity and addresses the set of factors that influenced his food behavior. In addition to illustrating the complex nature of obesity, this narrative raises questions about how personal stories can be integrated into efforts to address obesity without stigmatizing people.

Chapter 16, by Childress and Nuila, “Exploring the Human Impact of Public Health Interventions in T. C. Boyle’s ‘The Fugitive,’” is unlike the other two chapters in this category in that it uses existing literature to address the balancing of individual rights and protecting the common good. The narrative uses T. C. Boyle’s 2017 short story “The Fugitive” about a man with multi-drug-resistant tuberculosis who struggles to remain compliant with treatment. Childress and Nuila explore how narrative can assist with understanding patients’ values and beliefs and other factors and social determinants that may affect compliance with recommended treatment. Like the Farías-Trujillo chapter, this also explores issues related to stigma and the

balance between individual responsibility and the role of the government in improving public health. Childress and Nuila describe a narrative tool, mattering maps, which may be useful for helping public health practitioners explore the personal values that impact public health choices and decisions.

Uses of This Book

We view this book as a complement to our other public health ethics training resources and as an alternative to use of case studies. The primary audiences are instructors in schools of public health and other academic settings, public health students, and ethicists interested in the fields of public health and public health narrative ethics. This book may also be useful to other public health practitioners, including front-line workers, field epidemiology trainers and trainees, managers, planners, and decision-makers for raising awareness about ethical issues in public health practice and research.

Our intent is to have the narrative chapters serve as standalone tools for encouraging dialogue about public health ethics issues. To achieve this goal, each chapter provides an overview of the public health ethics issues relevant to the narrative, a discussion of contextual issues and background information, and questions to prompt discussion. There are several ways that the chapters can be used for instructional purposes. They may be reviewed and discussed separately or in combination based on the ethical issues (as we approached categorization), public health intervention, disease category, or narrative approach. We hope you will find that this book provides an additional approach for considering public health ethics issues.

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taught courses in ethics, bioethics, and research ethics and coached their Intercollegiate Ethics Bowl team. Prior to Tuskegee, he taught philosophy at several universities. He is the recipient of a Fulbright grant to conduct research on the relation of science to ethics at Ruhr University in Bochum, Germany. Dr. Ortmann holds B.A. and Ph.D. degrees in philosophy from Yale College and the Pennsylvania State University, respectively.

Stephanie A. Larson is currently a fellow in clinical ethics at the Cleveland Clinic. She is a former Laney Graduate School Fellow and Dean's Teaching Frost Fellow at the University of New Mexico, Albuquerque, where she taught courses on professional writing and ethics in the School of Public Administration. Dr. Larson received her Ph.D. in English and Bioethics from Emory University. She also holds a B.S. in psychology and a B.A. in English from Purdue University with honors and distinction. Interested in interdisciplinary scholarship, Dr. Larson studies the intersection of literature, public health, ethics, and medicine. Her dissertation project, "Hooked: Public Health, Parasites, and Twentieth-Century Literature of the US and Global South," used the case study of twentieth-century hookworm eradication campaigns to propose an exchange between the fields of public health and literature. Dr. Larson has taught courses examining the intersection of public health, ethics, and the humanities at the undergraduate, graduate, and professional level. Dr. Larson's work has been published in *Disability Studies Quarterly*, *The Journal of Clinical Ethics*, *The Journal of Humanities in Rehabilitation*, and *Literature and Medicine*.

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Part I
Introduction to Public Health
Narrative Ethics

Chapter 1

Defining Public Health Ethics for Practitioners



Leonard W. Ortmann

Abstract This chapter stresses the collective nature of public health, defines public health ethics, and relates the latter to narrative ethics. The chapter offers four ways to define public health ethics; namely, through its problems, practice, procedure, and principles. Every area of Public Health Service poses ethics problems that involves either training issues, compliance with ethical rules and standards, or a utilitarian weighing of courses of action. The practice of public health ethics not only analyzes and addresses emergent ethical problems but also integrates ethics upstream into the design of public health programs. A public health ethics procedure provides a systematic framework for analyzing ethical problems, for designing and evaluating interventions, and for justifying one's decisions. The chapter explores the core principles found in the American Public Health Association's 2019 Public Health Code of Ethics. This Code reflects public health's emphasis on health equity, inclusiveness, and engagement with marginalized communities. Accordingly, the subsequent discussion calls attention to an approach that advocates empathic listening to community members, namely, Human-centered design. The chapter closes by suggesting that narrative ethics can improve the capacity of practitioners to empathically hear the voices and stories of community members and thereby improve public health practice.

Keywords Ethical analysis · Ethical principles · Public health code of ethics · Public health ethics · Utilitarianism · Deontology · Empathic listening · Human-centered design · Equity

Disclaimer: This paper is presented for instructional purposes only. The ideas and opinions expressed are the author's own. The paper is not meant to reflect the official position, views, or policies of the editors, the editors' host institutions or the author's host institution.

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In introducing a field, abstract or essential definitions that lack a broader context often convey little meaning. To avoid that shortcoming, this introductory chapter provides a richer, multifaceted definition of public health ethics. Ethicists may find the distinctions drawn useful but miss the philosophic argumentation found in most ethics texts. That is a feature not an oversight, as this introduction primarily targets future and current public health practitioners. Its immediate aim is to practically orient practitioners to ethical considerations in public health. Its more specific aim is to encourage practitioners to learn how to empathically listen to, and learn from, members of the communities they serve. For practitioners trained in scientific methodology and justly proud of their discipline, mastering the art of empathic listening may require some retooling. Yet it is no more challenging than physicians' efforts to embrace the humbler skill of effective bedside manner. It is a skill proven to improve patient satisfaction and outcomes (Remein et al. 2020). Our hypothesis is that the capacity to empathically listen to community members will lead to better public health interventions. Hopefully, the stories in this volume will contribute to that aim.

Many definitions of public health exist, but the U.S. Institute of Medicine (IOM) offers a concise one suited to the topic of public health ethics. "Public health is what we, as a society, do collectively to assure conditions for people to be healthy" (IOM 1988, 1). Public health, then, entails concerted action to create the means or the foundation to secure the health of the entire population. This definition implies that securing the entire population's health does not depend primarily on individuals acting independently. This implication seems counterintuitive to many people. They believe that were everyone to adopt a healthy lifestyle and seek appropriate medical care, the entire society would be healthy. However, not everyone has access to affordable medical care. Moreover, healthy lifestyle and medical care account for only a fraction of the factors that impact a person's health. A far larger share of health outcome depends on social determinants of health, especially wealth, educational level, social class, and race/ethnicity (Marmot 2007). Those who stand higher on the social ladder generally enjoy better health, while those who stand lower display comparatively worse health. Health differences that reflect natural variability are ethically neutral, but others reflect underlying health inequities. According to the World Health Organization (WHO), health inequities denote "health differences which are socially produced; systematic in their distribution across the population; and unfair" (WHO 2007, 7). Being socially produced, these differences are actionable and unfair, thus summoning our sense of justice to seek redress. This brief account of IOM's definition of public health explains two central features of public health ethics. First, in contrast to the attention the individual patient receives in medical ethics, public health ethics emphasizes collective action to address population or community health. Second, this population-community focus commits public health ethics to advancing social justice, for example, by addressing health inequities in underserved communities.

Various definitions of public health ethics likewise exist, the following one from my home agency, the Centers for Disease Control and Prevention (CDC). "Public health ethics involves a systematic process to clarify, prioritize, and justify possible courses of public health action based on ethical principles, values and beliefs of

stakeholders, and scientific and other information” (CDC 2017). To elaborate, public health officials must respond in a timely fashion to ethical *problems* that arise in their daily activities. A timely, consistent, and effective response to these problems results from integrating public health ethics into *practice*. Good ethical practice in public health must begin in the planning and design stage. It entails a *procedure* to analyze ethical problems, evaluate alternative courses of action, and justify what practitioners have deemed optimal for a community. Evaluation and justification rely on ethical *principles*, weighing them in relation to scientific evidence, contextual factors, and the input of stakeholders and community members. What follows will further define public health ethics with respect to its the problems, practice, procedure and principles.

Public Health Ethics Problems

Listing and categorizing the problems that arise within a discipline provides a good, practical way to characterize it. Most ethical problems in a practical discipline arise in relation to its goals, which its activities operationalize. Public health goals relate directly or indirectly to advancing human well-being not only by promoting health, preventing disease, and protecting the public but also by improving social conditions (American Public Health Association (APHA) 2019). While performing any public health activity that advances these goals, practitioners may encounter ethical problems.

An itemization of the main public health activities appears below in the 10 Essential Public Health Services (10 Essential Public Health Services Futures Initiative Task Force 2020). To emphasize that the services form an iterative cycle of assessment, policy development and assurance, the 10 Essential Services are graphically configured within a wheel with a large hub in the center. Originally, “research” occupied the hub position to underscore its cross-cutting importance within each of the activities. In the 2020 version of the wheel, “equity” has replaced “research” at the hub (Public Health National Center for Innovation 2020). That replacement reflects both the priority public health gives to equity issues today and their cross-cutting relevance to every facet of public health activity. Following each of the 10 essential services listed below is an example (*in italicized text*) of a corresponding ethical problem or issue that could arise.

1. Assess and monitor population health status, factors that influence health, and community needs and assets (*Managing surveillance data to protect privacy*).
2. Investigate, diagnose, and address health problems and hazards affecting the population (*Fairly distributing among groups the burdens and benefits of public health actions*).
3. Communicate effectively to inform and educate people about health, factors that influence it, and how to improve it (*Avoiding stigmatizing racial/ethnic groups when messaging about diseases originating outside the country*).

4. Strengthen, support, and mobilize communities and partnerships to improve health (*Building and maintaining trust with communities*).
5. Create, champion, and implement policies, plans, and laws that impact health (*Getting community input and buy-in for policies and plans affecting a community*).
6. Utilize legal and regulatory actions designed to improve and protect the public's health (*Imposing liberty-limiting measures such as quarantine to protect the public*).
7. Assure an effective system that enables equitable access to the individual services and care needed to be healthy (*Protecting vulnerable populations and advancing health equity*).
8. Build and support a diverse and skilled public health workforce (*Ensuring that public health staff and practitioners are properly trained*).
9. Improve and innovate public health functions through ongoing evaluation, research, and continuous quality improvement (*Protecting human subjects in research*).
10. Build and maintain a strong organizational infrastructure for public health (*Allocating resources to programs efficiently and fairly*).

These 10 essential services correspond with 10 of the domains identified by Public Health Accreditation Board (PHAB 2013). In addition, PHAB has identified two additional functional domains. As with the essential services, corresponding examples of ethical issues or problems that could arise follow (*in italics*) each functional domain.

1. Maintain Administrative and Management Capacity (*Avoid conflicts of interest when accepting donations from outside entities*).
2. Maintain Capacity to Engage the Public Health Governing Entity (*Negotiating the political context*).

PHAB has linked all 12 domains to performance standards and measures that serve as a basis for accrediting health departments (PHAB 2013). More to the point, the APHA Code of Ethics provides specific ethical guidance for all 12 of these functional domains (APHA 2019). This guidance is useful for practitioners, who need to identify what ethical problems occur in their area(s) of activity and how to address them.

It is equally important for practitioners to be aware not only that ethical problems vary with the area of activity but also that there are different modes of ethical thinking. The three most common and basic ethical modes are virtue ethics, deontology, and utilitarian ethics. We can distinguish each mode with an image that represents its focus: for virtue ethics, a *compass* representing the practitioner's ethical orientation; for deontology, a *fence* representing rules that limit actions; for utilitarian ethics, a *scale* representing the weighing of competing ethical considerations. Linking a problem to an ethical mode of thinking helps to identify where one needs to focus efforts to address the problem. Some problems may implicate more than one mode, but often a specific mode offers the best strategy for addressing a problem. The next section will explore how these modes play out in practice.

Public Health Ethics Practice

A second way to define public health ethics relates to how officials integrate it into routine practice. Many practitioners view ethics as an afterthought, part of review processes that occurs after planning and development but before implementation. They show interest in ethics only in reaction to a sudden, disruptive ethical conflict. Others fail to recognize the ethical dimension in such conflicts, treating them only as difficult practical problems. This failure precludes taking advantage of readily available ethical resources to address the conflict more effectively. Proactively ensuring that ethics informs interventions before implementation can prevent some ethical problems from occurring. For public health ethics to be more useful, health departments need to integrate it into daily practice.

There are several key aspects to integrating public health ethics into daily practice. First, practitioners need to avail themselves of some of the public health ethics training tools and resources the preface mentions. Second, health departments can establish a formal process to respond to sudden and disruptive ethical dilemmas and conflicts. Tracking ethical problems and establishing a process to respond to them are now accreditation requirements for state and local health departments in the United States (PHAB 2013). Third, instead of just reacting to ethical disruptions, more proactive integration requires that public health ethics be ‘upstreamed’ by adopting a public-health-ethics-in-all-policies approach. This entails incorporating public health values and principles as well as stakeholder/community input into the design phase of practice. Fourth, integration requires practical know-how in dealing with the different types of ethical problems: virtue ethics (compass), deontology (fence), or utilitarian ethics (scales). These three modes exhibit a temporal aspect. The practice of virtue ethics prepares practitioners *ahead of time* to address ethical problems, deontology identifies problems *inherent in the actual activities* themselves, while utilitarian ethics assesses the beneficial and harmful *results of actions*.

Virtue ethics anticipates ethics problems by ensuring the availability of good people who are trained to address them. Common virtues, like honesty and reliability, are good habits acquired through practice that form the basis of good character and make us good citizens. They establish our moral compass, aka conscience, which enables us to distinguish right from wrong, esteem worthy values, and guide our decisions. We bring this moral compass with us 24/7 to ethical problem that arise in our daily lives.

Virtue ethics also plays a role in professional training. Training in the relevant knowledge, skills, and values of a discipline serves to define profession-specific duties and responsibilities. It also establishes the professional ethos and orientation that practitioners bring to the table prior to addressing ethical and practical problems. Acquiring the knowledge, skills, and ability to function competently as, say, an epidemiologist forms the core of one’s professional duties and responsibilities as an epidemiologist. When staff lack requisite trainings, holding them accountable for failure to perform professional duties becomes problematic. A basic ethical challenge for public health leadership, then, is to ensure a workforce trained and

competent in the skills and abilities needed to be a successful practitioner in the field. Problems in this area typically occur when adding staff, deploying them to unfamiliar situations, or initiating new functions and programs.

In public health, virtue ethics is useful for thinking about how to develop skills and foster a professional ethos regarding professional responsibilities. Social justice advocates have also employed the idea of virtue or functionality in the “capabilities approach” (Sen 2010). This approach holds government responsible for providing citizens with basic capabilities such as an education that allows them to maintain their health and flourish. Virtue ethics, however, does not offer a procedure for analyzing many ethical problems or dealing with the kind of specific ethical dilemmas that suddenly arise in practice and demand immediate resolution. As a result, ethical consults or deliberations that do not involve professional training seldom invoke virtue ethics. However, given the U.S. government’s current prioritizing of health equity, the capabilities approach may gain increasing attention going forward.

A second mode to address ethical problems is deontology, the study of duties, which are ethical or legal rules governing behavior. The Hippocratic Oath’s “do good” and “do no harm” illustrate two central features of deontological rules. First, these rules of duty express imperatives or commands (commandments in a religious context) we are obligated to obey. Second, they can be positive or negative. Most rules command or obligate us *not* to trespass upon some limit or parameter, which explains why the fence serves to represent this type of problem. Positive commands like “do good,” “honor thy parents” or “promote health,” however, are aspirational and enjoin us to strive toward some desirable goal in a way not bound by specific limits.

The fence image also explains why deontological problems in public health often involve professional misconduct or noncompliance: these involve transgression of rules or regulations. Determining misconduct or noncompliance is a straightforward procedure *in principle* that mainly involves two things. Determinations compare (1) an operative rule or regulation against (2) the behavior of the individual practitioner or an intended public health action. *In practice*, rules may be vague or the behavior in question may be borderline or “pushing the envelope.” For this reason, someone making determinations requires expertise in interpreting the scope of the rule and usually some familiarity with the area of activity at issue. Determinations, then, entail ascertaining the scope of a rule and assessing whether an action or behavior falls under or oversteps that scope. Organizations often hire lawyers as ‘ethicists,’ i.e., compliance officers, because they are adept at interpreting and applying rules and standards.

Ethical rules often inform the content or aims of laws and regulations but differ from them in a decisive way. Whereas ethics represents the sphere of voluntary discretionary activity, laws enacted by legitimate authorities are enforceable. However, once an ethical rule becomes enforceable under pain of punishment or penalty, it formally functions as a law, even though we still speak of ethics violations. Voluntary rules are like hedgerows, which guide us along in the right direction. Most people observe voluntary rules, but some rules need to be legally enforced. Violating, say, traffic signals would be so dangerous or disruptive that

compliance cannot be left up to individual prerogative. Laws establish order, but their rigidity allow for less discretion and often create a regulatory burden. In unusual legal cases or those involving mitigating circumstance, rigidity can make it difficult to arrive at a satisfactory ruling. Conversely, discretionary rules allow for more flexibility but could also result in greater variability in rulings, while lack of enforcement mechanisms can lead to increased noncompliance.

The rules or guidance documents governing an area of public health practice can be voluntary and discretionary, regulatory and enforceable, or lacking altogether. The status or availability of guidance, especially ethics guidance, has a bearing on how one addresses the ethical problems that arise in an area. Where available, one should consult ethics guidance documents, but they are unavailable for many specific areas of public health practice. In such cases, practitioners may need to seek or conduct an ethics consult that employs the kind of deliberative process discussed below. For emergency response activities, many ethics guidance documents are available which generally are voluntary or discretionary in nature. This gives practitioners greater latitude in making decisions in what are often chaotic circumstances. Ethical rules governing surveillance activities are generally discretionary; perhaps for that reason fewer guidance documents are available, though the WHO's surveillance guidelines are thoroughgoing (WHO 2017). The rules governing research ethics committees, designed primarily to protect human research subjects, generally follow the International Ethical Guidelines for Health-related Research Involving Humans. These guidelines, now in their 4th edition, have been published since 1982 by The Council for International Organizations of Medical Sciences (CIOMS) under the auspices of WHO (CIOMS 2016). The guidelines, though discretionary, distinguish between “must” and “should”, the former being “used to attach greater moral weight to requirement when compared to “should” (CIOMS 2016, xii). In the United States research ethics guidance is based on the Belmont ethical principles—beneficence (and nonmaleficence), autonomy, and justice (U.S. Department of Health, Education, and Welfare [USDHEW] 1979). By contrast with the CIOMS guidelines, these rules comprise an enforceable section, 45 CFR 46, of the U.S. Code of Federal Regulations (USDHEW 2018).

The U.S. regulations apply to all federally funded human subjects research, not just to biomedical research as do the CIOMS guidelines. In the social sciences, much of the research that fell under the purview of these regulations posed minimal harm to subjects, such as research that mainly involved interviews. Many researchers considered the harm posed to such subjects disproportionate to the amount of regulatory burden the regulations imposed on researchers. In response to this and other complaints, policy makers recently revised the rules to expedite the review process especially for research that posed minimal danger (USDHEW 2018).

Most decisions about research protocols, especially those posing minimal danger, amount to straightforward determinations of compliance. More high stakes research projects can pose more danger to subjects while potentially providing more valuable information. The ethics committee discussions for such projects more closely resembles the kind of deliberations discussed below that must weigh competing factors in making decisions.

An ethics violation resulting from noncompliance differs decidedly from an ethical conflict, which requires a different remedy. For the former, the remedies include punishment, changing the offending behavior to become compliant, or preventing it altogether by conducting a prior compliance determination. Such determinations basically distinguish good or acceptable behavior from bad, unacceptable behavior. By contrast, an ethical conflict does not imply wrongdoing. An ethical conflict results from competing—sometimes diametrically opposed—views of what is most important, beneficial, or effective. These varying views usually correlate with the values, beliefs, and interests of stakeholders, including public health stakeholders. Remedying a conflict, then, does not replace bad behavior with good but, rather, involves prioritizing and selecting from amongst competing views of the good. To optimally resolve a conflict in public health, practitioners need to weigh and balance competing or opposed elements. They must do so with an eye toward the optimal result in the context of a community and relevant stakeholders. In public health, the optimal result typically involves designing an intervention that will result in maximum health benefits for a population, also factoring in the harms caused.

The idea of maximizing health benefits brings us to the third basic ethical mode, namely, utilitarianism, a form of consequentialist ethics. Consequentialism judges the ethicality of an action not by its compliance with an ethical rule but according to its good or bad consequences or results. Two distinguishing features of utilitarianism that harmonize well with public health approaches are its egalitarian and population perspective. Utilitarianism does not privilege particular individuals but, rather, looks at the greatest *net* good or happiness for the greatest number of people. The net good (in public health, the net health benefit) is that which remains after bad consequences are subtracted, such as higher costs, increased morbidity, or infringements on liberty. This utilitarian procedure of quantifying results by calculating net benefits over disadvantages aligns well with epidemiological science. Public health practitioners are employing utilitarian approaches when they conduct cost-benefit or risk benefit analyses of future public health programs or assess the health impact of existing programs. Utilitarianism, then, is a maximizing approach that bases decisions on which course of action provides the optimal net benefit for a population among the available alternatives.

The utilitarian approach works best where researchers or practitioners can readily quantify impacts; for example, in terms of financial costs, reduction in the prevalence of disease, or the number of lives saved. It becomes more difficult to weigh net benefits over disadvantages where the operative terms are values that lend themselves less readily to quantification, such as liberty infringement or community trust. A utilitarian approach focused on maximizing, say, the number of lives saved or vaccines administered can also run into problems regarding an equitable distribution of benefits. For example, hard-to-reach groups or those with more comorbidities may require more resources or personnel to reach or to treat compared to the general population. If resources and personnel are limited and there are time constraints, practitioners will serve a greater number of people by focusing on the general population rather than on groups that are hard-to-reach or that have more co-morbidities. But such an approach could lead to an inequitable distribution of

services and increase health disparities in minority or underserved populations. Such problems in weighing values or achieving equity will require ethical deliberations to adjudicate.

Public Health Ethics Procedure

Having an established public health ethics procedure or framework in place allows practitioners to tackle problems consistently and methodically rather than haphazardly. Suddenly emerging ethical problems are disruptive and can cause consternation or paralysis. An ethics procedure is not a magic bullet; it cannot make tough ethical decisions easy, but it nevertheless offers advantages. It averts the likelihood practitioners will push the panic button, allowing them to arrive calmly at a resolution by following a series of procedural steps. It also allows practitioners to utilize ethics resources that others have found useful in similar situations. Finally, practitioners can make tough ethical decisions more confidently knowing they have followed standard practice in the field.

Procedures or frameworks to address public health ethics problems display large overlap but also some variation depending on the problems addressed or on which ethics principles one prioritizes (Lee 2012). The 3-step procedure we advance below has proven useful over time for addressing a wide range of ethical problems in public health (Bernheim et al. 2007). The introductory chapter of our open-source public health ethics casebook provides an extended example of applying the procedure to a concrete ethical problem (Barrett et al. 2016).

Step 1: Analyze the Problem

- Public health goals?
- Moral claims of the stakeholders?
- Risks and harms of concern?
- Is the source or scope of legal authority in question?
- Are precedent cases relevant?
- Do professional codes of ethics provide guidance?

Ethical analysis of a problem does not take place in a theoretical vacuum; relevant scientific evidence and circumstantial facts should inform it throughout. Specific public health goals will reflect broader public health objectives and values, such as promoting health, acquiring scientific evidence, or building trust with communities. Practitioners must weigh these goals in relation to the moral claims, that is, the rights, interests, or values of community members and other stakeholders. Both the public health goals and stakeholder claims will indicate the benefits or advantages that parties hope to gain from any proposed intervention. Against these

advantages, practitioners must weigh the risks and harms of concern, that is, the disadvantages of any proposed action. Analyzing the advantages and disadvantages of all relevant parties sets the stage for a utilitarian calculus that will assess the maximal net advantage that a proposed intervention might realize for a population or community.

Considering the source and scope of legal authority has several uses. It provides legal justification for proposed actions. It also can indicate what practitioners may do as well as the constraints on their action. This point in the deliberation is the time to consider any compliance issues that might constrain options. It is worth noting that other constraints, such as technical, budgetary, or political constraints can also limit action. Determining constraints in advance can clarify and simplify decision making by eliminating unfeasible alternatives. Ethics is about voluntary activity which demands that we be clear minded about the scope of our discretionary power.

Considering relevant precedents and ethics guidance, particularly professional codes of ethics, allows practitioners to utilize ethics responses or resources that others have developed. The more a current situation resembles a precedent case, the more readily it helps practitioners to make or justify a course of action. However, a precedent does not bind current or future responses. It may instead reflect an outdated prioritization of values or reveal how a current situation differs from the precedent case in some crucial respect. Noting such differences can help practitioners develop more nuanced responses that better reflect particular circumstances, community values or public health priorities.

Step 2: Design and Evaluate Alternative Courses of Public Health Action

Typically, several alternate ways to approach a problem exist. So, it is generally helpful to evaluate and compare alternative courses of action to determine the best approach in a given context. Approaches can vary not only technically and in cost, duration and intensity, and but also with respect to the goals, values, and interests an approach prioritizes. Ethical considerations add features to the many variables practitioners need to factor into planning and design, but do not fundamentally alter the process. The original title for Step 2 has been modified by adding the words, “Design and.” Design is a creative process not usually associated with ethical analysis, evaluation, or justification but also not foreign to it.

The upstreaming of ethics into design first came about in response to engineers. In their design stage, engineers frequently work with budgetary, building code, or architectural constraints, incorporating them into project design. Incorporating ethical constraints upstream during design, they argued, would be more efficient than retrofitting a project. Retrofitting is more expensive and time consuming than designing in constraints from the outset and often adversely affects the quality of the original design. Similarly, practitioners might think of stakeholder input and

community values as constraints that need to be designed into projects. Projects so designed will more likely resonate with communities and be less likely to create resistance that would result in the need for design modification.

Where possible, practitioners should evaluate different designs and alternative courses of action according to the following ethical principles.

- Utility
- Justice
- Respect for individual and community interests and values

Utility refers to the net balance of benefits or advantages over harms or disadvantages. Lower effectiveness or reach, greater costs or harms, and more liberty restrictions comprise some of the chief comparative disadvantages of different public health actions. Conflict with community values and the resultant tension or loss of community trust also count as significant disadvantages. A course of action can resonate with one community's values and be cost effective but not with another community, due to local values and conditions. Practitioners, then, cannot rely solely on cost or scientific/technical considerations in evaluating a course of action. Local conditions and community values also need to be prioritized and weighed in making decisions.

Justice has a range of meanings both in general and in public health settings. Its most basic sense is *just deserts*, namely, that persons receive what they deserve. This principle recognizes the equal and fundamental dignity of all persons, which implies equal access to public health services. It also implies reciprocity which compensates members of the public for burdens that a public health action causes. *Procedural justice* or due process requires that stakeholders have an opportunity to participate in decisions regarding public health interventions that impact them. Because *distributive justice* involves a wider nexus of individuals and groups, it has the most relevance to public health. It requires that the benefits and burdens of public health interventions be distributed fairly among impacted groups. Health equity entails a fair distribution of health resources, where everyone has equal access to health services and to the social conditions that foster health. Achieving health equity requires not only avoiding interventions that exacerbate health inequities but also designing interventions that reduce health inequity. At the behavioral level, interventions intended to benefit all sometimes exacerbate health disparities by only benefitting the already well-off who have the knowledge, time and resources to take advantage of them. Justice would demand that interventions be redesigned so that all could benefit or that outreach efforts target those with lower health literacy and fewer resources. At a social level, health equity ultimately demands that society take steps to restructure society and institutions to prevent inequities from occurring. Given the relevance of justice to public health practice at so many levels and our growing awareness of the depth and pervasiveness of health disparities, practitioners increasingly are adopting an equity lens in public health planning and practice.

Respecting individual and community interests and values means that practitioners and researchers avoid implementing community interventions and research that clash with existing civic roles or community values and wishes. Showing

respect is crucial for building and maintaining trust with individuals and communities. Respect should also extend to giving community members a voice in what happens in their community. It may ultimately require that practitioners design or redesign interventions that community input informs.

Step 3. Provide Justification for a Particular Public Health Action

- Effectiveness: Is the public health goal likely to be accomplished?
- Proportionality: Will the probable benefits of the action outweigh the infringed moral considerations?
- Necessity: Is overriding the conflicting ethical claims necessary to achieve the public health goal?
- Least infringement: Is the action the least restrictive and least intrusive?
- Public justification: Can public health agents offer public justification that citizens, and in particular those most affected, could find acceptable in principle?

To justify an action might only involve explaining the rationale behind it but it can also mean having to defend it. Whether one finds oneself explaining or defending an action depends as much on the audience as it does on the nature of the action. In the United States, individual liberty is a presumptive value in discussions of public policy. That partiality to individual liberty puts the onus on the party who infringes on liberty to vigorously defend its action. Conversely, in countries where communitarian values are presumptive, the onus would be on those who defend libertarian values. Public health's mission involves collective action for the good of the entire population or community. In a libertarian setting, this communitarian orientation of public health regularly puts it at odds with political tradition and public sentiment. Public health officials therefore should be prepared to defend their actions against libertarian objections. Whereas the first and last questions above apply equally to libertarian or communitarian settings, the middle questions are especially relevant to libertarian settings. Designing and evaluating a public health action for which affirmative answers could be given to these middle questions might obviate libertarian objections to it. If not, being able to affirmatively answer these questions could at least serve as a defense against charges of liberty infringement or paternalistic overreach.

Not all public health actions that demand justification infringe on liberty or raise the specter of government overreach. The need to justify an action can result simply from the expectation of transparency on the part of the public. Lack of transparency can create suspicion and undermine trust. Routinely explaining the rationale for important official actions, then, makes for good communication strategy that can foster trust with the community.

Controversial public health proposals may also require justification; for example, establishing a Syringe Service Program (SSP) in a community. The last bullet point

above, about public justification, applies to controversial proposals and suggests a standard public justifications must meet. Namely, public justifications must be acceptable in principle to stakeholders whom an action affects most, who often are those most adversely impacted. In the example of SSPs, the most deeply affected could be community members concerned that an SSP would increase crime and expose their children to people with opioid use disorders. Persuading community members to accept an SSP in their neighborhood would likely require more than one-way scientific messaging. It would probably require two-way dialogue that goes beyond explaining an action and answering questions. Genuine dialogue requires listening and giving voice to those impacted. Giving voice to those impacted gives them a stake in the outcome of the discussion and gets their buy-in. Buy-in does not imply they agree with the outcome or welcome it, but only that they feel ownership through their participation in the discussion. This ownership allows them to more readily accept an outcome even when it adversely affects them.

This dialogical process works best when public health practitioners make genuine efforts to incorporate alternatives, trade-offs or compromises in response to stakeholder input. For example, residents might accept the rationale for an SSP but nevertheless object to locating it in a residential neighborhood. Further discussion might elicit creative alternatives from community members. These could include locating the SSP in an area zoned for commercial use or in a moving van located at a designated place at designated times. Stakeholder suggestions are often unfeasible in whole or in part. Nevertheless, eliciting them, seriously considering them, and explaining why they cannot be incorporated can go a long way toward gaining acceptance for even a controversial public health action. Trade-offs and compromises are ways of balancing or adjudicating competing claims. This process of balancing claims more closely resembles the art of negotiation than the maximizing calculus of utilitarianism. Nevertheless, if in designing a course of action one can find the right balance or the “sweet spot” between competing claims, the intervention in question more likely will be the alternative that achieves optimal impact.

Public Health Ethics Principles

Introductory textbooks typically define a field with respect to its basic principles. Some of these it may share with allied fields, but other more specific principles distinguish it from other fields. Although public health theorists and practitioners have proposed diverse principles to guide public health ethics, there is considerable overlap in what they deem foundational (Lee 2012). Along with medical ethics, research ethics and bioethics, public health ethics shares the Belmont ethical principles of beneficence and nonmaleficence, respect for persons, and justice (USDHEW 1979). These principles focus on benefitting, not harming, individuals, respecting their privacy and autonomy, and ensuring their equal access to clinical trials and to care. Recognizing the insufficiency of an individual focus, pioneers in public health ethics oriented the emerging field around the ethical claims of

communities. Public health ethics focuses on the common good, respects community roles and values, and pursues social justice, seeking health equity for groups experiencing actionable health disparities.

The following exposition of the core principles of public health ethics is based on the 6 sets of core principles found in the APHA's Public Health Code of Ethics (APHA 2019). The pioneering work of earlier thinkers and the input of numerous current reviewers inform the revised Code, which updates a 2002 version of the Code (Public Health Leadership Society 2002). The newer Code also reflects the increasing attention paid in intervening years to the impact of social determinants on health and to efforts to address racial and health inequities. The authors of the new Code do not rank the sets of principles or present them in order of importance. Below, they are presented in a way designed to illustrate their relation to narrative ethics.

Interdependence and Solidarity

The values of interdependence and solidarity most decisively demarcate public health ethics from allied fields of health ethics, so it is appropriate to begin with them. These values reflect public health's commitment to community and population health. Uncovering statistical evidence of the health or disease of populations drives epidemiology and surveillance, but ultimately these approaches represent means rather than goals. Because the goal of collecting population data is to positively impact communities, public health cannot afford to lose sight of the nature of a community and its needs. A community is not a mere aggregate of individuals, a denominator for statistical purposes. Rather, it consists of a nexus of social relations held together by familial ties, common interests, and bonds of loyalty, friendship, and compassion. Public health practitioners therefore need to see the establishment of relations with communities and their members as integral to research and implementation activities. Solidarity demands that we recognize that we are all in it together when facing our greatest problems and that we must stand together to collectively address them. Interdependence means every community member is so linked to every other community member that individual actions can impact other community members. Interdependence underlies a key rationale for public health's legal authority to limit individual actions that can adversely impact others. The demonstrable harm of smoking to smokers, for example, generated few restrictions on smoking during the twentieth century. Conversely, the "primary purpose of smokefree laws and policies is to protect people who do not smoke from second-hand smoke" (CDC 2018). This authority to limit individual action through legal measures like quarantine, smoking bans, or vaccination mandates clearly distinguishes public health ethics from medical ethics and bioethics.

Health and Safety

Unlike clinicians, who mainly treat disease in individual patients, public health practitioners have a duty “to prevent, minimize, and mitigate health harms and to promote and protect public safety, health, and well-being” for the entire community (APHA 2019, 5). Upholding the health and safety of the community provides the justificatory basis for those situations where public health must limit individual actions that pose health or safety threats to others.

Professionalism and Trust

Public health cannot be effective without the trust of the communities it serves. The Code links gaining the public’s trust to following the highest ethical, scientific and professional standards. Conversely, the influence of secondary interests, whether personal, financial, or political, and a lack of transparency regarding them, undermines trust and public health institutions. Scientific integrity, we can say, mediates the translation of scientific evidence gained by research into interventions that can resonate with communities.

Health Justice and Equity

All major public health institutions including the WHO, the APHA, and the CDC have embraced health justice and equity as core concerns. As we have outlined in the “Procedure” section above, practitioners need to evaluate public health actions through a justice and equity lens. More challenging, health justice and equity also requires that public health practitioners promote activities that reduce not only existing health inequities but also inequalities related to “voice, power, and wealth” (APHA 2019, 5). This broader mandate is required because inequalities with respect to social determinants such as education, social status, and economic resources profoundly impact health. For this reason, public health practitioners need to collaborate with officials and practitioners in other sectors such as transportation, building, or education that may impact health. Ultimately, addressing the social determinants of health requires that public health takes steps to remediate long-stranding institutional practices and structural conditions that adversely impact health.

Recognition of the need to remediate social determinants to improve health is hardly new. However, change in this area has proven to be a long-standing challenge, and one that other developments have overshadowed. In 1848, the Prussian government sent Rudolf Virchow, to assess a typhus epidemic in Silesia. In reporting on the epidemic’s origin in 1849, Virchow, founder of “social medicine”, emphasized underlying social determinants of health, Addressing them in his report,

he proposed not medical solutions but a bold program of social reconstruction that the Prussian government rejected as too radical (Taylor and Reiger 1985). That same year 1849 also witnessed John Snow's advancement of the theory of a waterborne transmission of cholera (Thomas 1968). He famously followed up on that theory in 1854, discovering the source of a cholera outbreak in London in a contaminated well. This discovery, which led to the well's disabling, marks the founding event of the science of epidemiology. However, his waterborne theory remained a bone of contention until 1883, when *Vibrio cholerae* was isolated. Gradually, the field of public health began modelling itself after the precedent John Snow had set of implementing interventions based on epidemiologic data (CDC 2004). His model, which bases public health action on epidemiological evidence, has been enormously successful. Once it became successful and established it also has been largely uncontroversial in improving health and reducing disease for entire populations. By contrast, Rudolf Virchow's model of addressing social determinants of health has enjoyed little success or wide acceptance. Unlike Snow's model, it targets subsections of the population that lack power and demands radical restructuring of society and its institutions. Virchow's model requires not only enormous resources, but also social and political changes that face an uphill climb against the powers that dominate the status quo.

Most progress to date in addressing health inequity has been made when public health science and technology "lifts all boats," as it has in the past with improvements in sanitation or more recently with universal vaccination campaigns. Today we have far better epidemiologic measures of the range and depth of health inequities and more awareness of them. Yet relatively little progress has been made in remediating social determinants, that is, in radically restructuring social conditions and institutions. In many countries, including the United States, the real frontier for addressing health inequity does not lie in remediating the ultimate causes of health inequity. Rather, it mainly lies in mitigating their effects. For this more modest mission, even gaining universal access to affordable health care would represent an enormous step in all but the most highly industrialized countries. Although highly industrialized, the United States is an exception, because it has never officially ratified a right to health and still has not provided universal health care to its citizens. In the United States, the even steeper challenge of remediating the causes of health inequity may require as a first step the adoption, really creation, of the role of "chief health strategist" in local health departments (DeSalvo et al. 2017). The role of these chief health strategists would be to coordinate collaborative efforts with other sectors that impact health to address health issues. The success of such collaborative efforts may then serve eventually as a catalyst to bring about political consensus and transformation. If history provides a lesson, it is that eliminating health disparities will require such a transformation in order to restructure existing social structures and institutions.

Human Rights and Civil Liberties

While access to health care accounts for only part of the determinants of health, it nevertheless can have a sizable impact on health and health equity. Not surprisingly, then, public health as a profession supports the right to health, universal access to health care, and civil liberties as both professional concerns and as matters of social justice and ethical obligation. WHO's Constitution adopted in 1946 proclaimed "the highest attainable standard of health" as a fundamental human right. It defined health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO 1948, 1). Hahn and Muntaner recently have contended that this notion of the highest attainable standard of health is open-endedly vague and unattainable. They propose instead a more practically attainable right: "a right to equitable access to available resources for health (RARH), including equitable access to the social determinants of health" (Hahn and Muntaner 2020, 249). Regarding civil liberties, Hahn et al. have shown that their existence and enforcement or the lack thereof can constitute an influential social determinant of health (Hahn et al. 2018). Protecting civil rights of racial/ethnic minorities in the United States "by laws, regulations, and court decisions and redress of violations of those rights" promotes health (Hahn et al. 2018, 23). Specifically, such measures "have been associated with marked improvements in the health of covered populations and of intermediate outcomes such as education and income known to produce health benefits" (Hahn et al. 2018, 23). Both Human rights and civil liberties are grounded in the principles of autonomy, justice, and the pursuit of human well-being. Public health is committed to these values, even though in circumstances that jeopardize society's health and safety, it supports coercive measures that can limit individual behavior.

Inclusivity and Engagement

Inclusivity and engagement rooted in transparency and accountability are as important to building trust as is the professionalism of public health practitioners. The slogan, "Nothing about us without us," neatly sums up the rationale behind engaging with communities and stakeholders. Namely, everyone should have a voice in matters that affect them. The antithesis of inclusivity and engagement happens when practitioners and researchers engage in "helicopter science" or "parachuting research" (Nature 2018, 274). These phrases conjure up images of commando researchers swooping down upon unsuspecting communities for "get in, get out" operations. The researchers are less than transparent about their intentions, give no voice to the community in what happens, and fail to report the research results back to the community. As public health undergoes data modernization, practitioners will need to redouble efforts to engage with communities in order to avoid the pitfalls of helicopter science. Extending Snow's legacy, data modernization holds enormous

potential to strengthen and extend public health practice, but it also raises many privacy and equity concerns. More importantly, its very success may tempt some practitioners to over rely on data and machine learning algorithms while overlooking the role of engagement. Factoring stakeholder input into the design of interventions may become even more crucial, then, precisely to the extent progress in data modernization unfolds.

Looking Forward: Human Centered Design and Narrative Ethics

Public health today is experiencing something analogous to the transitioning in the 1990s from top-down paternalistic medicine to patient-centered care. Patient-centered care emphasizes patient satisfaction, engaging with patients, and involving them in decision making (Capko 2014). Likewise, it may increasingly become unfeasible to have *evidence-based* interventions designed by public health officials simply imposed upon a community. The resistance to social distancing and lockdown measures during the COVID-19 pandemic suggests that opposition to paternalistic governmental measures, let alone mandates, is strong. That holds especially for Western libertarian societies compared to communitarian-oriented societies like China and Korea. A solution to this opposition to top-down measures may well lie in having *evidence-informed* interventions codesigned by public health officials and stakeholders. In other words, going forward, bottom-up public engagement must complement top-down evidence-based public health measures. That strategy may be crucial for mitigating health inequities in minority communities whose members feel alienated from government and public institutions.

As we look forward in public health, human centered design (HCD) presents itself as an approach especially suited to complement data modernization efforts (IDEO 2018). That is because, while HCD, too, comes out of the digital technology sector, it emphasizes the creation of user-friendly products. It no longer suffices that products incorporate the latest technology; it is equally important that they be designed with the end user in mind. Whereas traditional public health focuses on replicating evidence-based solutions, HCD is iterative and interactive. It emphasizes empathic listening to end users (stakeholders) and incorporating their input into design. An evidence-based solution might serve as a take-off point for discussion, but through the HCD process, a new idea is conceived, put into design, then iteratively tested and redesigned until it resonates with end users.

“Listening sessions” to gather input from communities has become part of the standards of good public health practice (PHAB 2013, 23). Both listening sessions and empathic listening gain information, but the latter understands the importance of establishing personal rapport with people. Empathic listening, the heart of HCD, however, is not on the radar of most public health practitioners as a skill to master. Nor was good bedside manner formerly considered a skill required to practice

medicine. But bedside manner has been shown to be important to patient outcomes, while training and exposure to narrative medicine programs can improve bedside manner (Remein et al. 2020). The presupposition of this volume is that an analogous case can be made for public health practitioners. To become more effective in working with communities, especially alienated minority communities experiencing health inequity, practitioners need to develop their empathic listening skills. Doing so will complement and enhance their scientific training, making them better practitioners. Our hope is that this volume and the stories in it can make a modest contribution to this development.

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Chapter 2

Why Stories Matter: An Introduction to Narrative Approaches to Public Health Ethics



Stephanie A. Larson

Abstract This chapter provides a brief overview of narrative public health ethics to help guide engagement with the narratives contained within this book. The first section introduces narrative medical ethics, which serves as the foundation for the public health narrative ethics we propose in this book. The second section explores the developing field of narrative public health ethics and surveys scholars who have laid the groundwork for this approach. Finally, conclusions are drawn with consideration given to major challenges and future directions for the field of narrative public health ethics.

Keywords Narrative · Stories · Public health humanities · Literary methods · Narrative ethics · Empathy

Stories Matter

In her 2009 TEDGlobal Talk, “The Danger of a Single Story,” author Chimamanda Adichie discusses the double-edged power of narratives:

Stories matter. Many stories matter. Stories have been used to dispossess and to malign, but stories can also be used to empower and to humanize. Stories can break the dignity of a people, but stories can also repair that broken dignity (Adichie 2009).

Stories which, for our purposes can span from fictionalized accounts of events to personal narratives, regularly inform public health practice. We use stories to understand and communicate the data we gather. We use stories to educate and to

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implement interventions and new measures to protect the public's health. We even use stories to understand what we have done right in our work and where we could improve.

This edited collection hopes to add yet another role for narratives in the field of public health: as a vehicle for ethical discussion, reflection, and decision-making (also known as narrative public health ethics). Narrative public health ethics operates under the same assumption made by Adichie: that stories (the plural form) matter. And it is through the existence of multiple stories that we can gather a fuller, more nuanced picture of the ethical issues.

The texts represented in this collection span the ways in which narratives and resources are available in public health settings. We might consider three types of narrative: public narratives, implicit narratives, and explicit narratives. Public narratives are understood as records of an engaged public such as social media, public media, and transcripts of public engagement. These are the words of a community filtered through a record. While not written to tell a story, wrapped within the text are the elements of narrative. Implicit narratives are those found in the qualitative and quantitative data in fields like epidemiology, history, medical sociology, medical anthropology, and bioethics. These implicit narratives do not start out as narratives (i.e. the creators are not writing with the intention of telling a story). Instead, implicit narratives must be made explicit through ways of reading and analysis as discussed later in this chapter. Finally, there are explicit narratives which are perhaps the type that first come to a reader's mind when thinking of stories. Explicit narratives may be fiction or non-fiction and contain recognizable literary elements such as characters, dialogue, conflict, and plot. In explicit public health narratives, for example, one might see a conflict in the form of an epistemological clash and characters that include humans, microbes, and the environment.

What follows is a brief overview of narrative public health ethics which can be used as a guide for engaging with the narratives contained within this book. The first section introduces narrative medical ethics, which serves as the foundation for the public health narrative ethics we propose in this book. The second section explores the newly developing field of narrative public health ethics and surveys scholars who have laid the groundwork for this approach. Finally, conclusions are drawn with consideration given to major challenges and future directions for the field of narrative public health ethics.

Introduction to Narrative Ethics

Narrative Medical Ethics

The term "narrative ethics" has become ubiquitous in both professional and academic disciplines like literature, medicine, and ethics. Despite widespread use of the term, there is no single definition or approach to narrative ethics. In his entry for

the *Encyclopedia of Global Bioethics* Clive Baldwin distinguishes two primary, but distinct, approaches that are signaled by the term narrative ethics: “narratively informed ethics” and “narrative ethics” (Baldwin 2015). Regardless of the distinction within narrative ethics, discussion and development of the field has primarily occurred within the field of medicine with most of the focus on physicians and patients.

“Narratively informed ethics,” according to Baldwin, employs both fictional stories and non-fiction personal narratives to “support ethical development or reasoning” for clinical practitioners (Baldwin 2015). In particular, the focus of narratively informed ethics is to help professionals develop empathetic listening strategies and, more recently, share their own stories to help reduce burnout and promote mental health. The narratively informed ethics approach has been developed by scholar/medical practitioner Rita Charon who has argued that “what medicine *lacks* today—in singularity, humility, accountability, empathy—can, in part, be provided through intensive narrative training” (Charon 2006, viii). For Charon, “A medicine practiced with narrative competence will more ably recognize patients and diseases, convey knowledge and regard, join humbly with colleagues, and accompany patients and their families through the ordeals of illness” (Charon 2006, vii). According to Charon, literary training can help future physicians become better listeners: “By the time a student has been coached in close reading for a period of time, he or she develops the reflexes to notice many, many aspects of a text” (Charon 2006, 113).

“Narrative ethics,” in contrast, uses narrative as an ethical framework rather than as an ancillary tool for enhancing empathy. However, narrative ethics remains largely narrative *medical* ethics and focused on patients and clinicians (especially physicians). James Phelan’s entry on Narrative Ethics in *The Living Handbook of Narratology* helpfully provides a concise definition of narrative ethics.

Narrative ethics explores the intersections between the domain of stories and storytelling and that of moral values. Narrative ethics regards moral values as an integral part of stories and storytelling because narratives themselves implicitly or explicitly ask the question, “How should one think, judge, and act—as author, narrator, character, or audience—for the greater good?” (Phelan 2013).

Unique to a narrative ethics approach is the application of literary analytic techniques to better understand the moral values and ethical dimensions of stakeholders. Although public health could benefit from both narratively informed ethics and narrative ethics, the work of this book is focused on narrative ethics.

In 2014, *The Hastings Center Report* published a special issue on narrative ethics. The focus was on narrative ethics in the clinical setting, particularly when applied to bioethics consultation services. In this special report, literary scholar and clinical ethicist Martha Montello makes the claim that narrativists (those taking a narrative ethics approach) focus on the *how* (questions like: How did stakeholders get here? How do stakeholders want to move on from this juncture?) whereas traditional medical ethics focus on the *what* (for example, What happened? What should we do next?) (Montello 2014, S3). In short, whereas traditional medical ethics is directive focused, narrative medical ethics focuses on progressions.

Montello outlines four key literary elements applied to a narrative approach to medical ethics.

Voice: “Who’s telling the tale?” and “From whose perspective are we hearing it?”

Character: “Who is at the center of the tale?” and “Whose story is it?”

Plot: How do events progress? How are details linked?

Resolution: Progression in the story rather than a solution (Montello 2014, S4–5).

The following section briefly considers how each of Montello’s narrative elements apply to narrative public health ethics.

Narrative Public Health Ethics

Narrative public health ethics can trace its roots to both narrative medical ethics as well as the larger field of the health humanities which proposes an exchange between traditionally humanistic disciplines (e.g., literature, philosophy, history) and health professionals (e.g., public health, clinical medicine, physical therapy, nursing).

Stories and narrative are not novel in the field of public health. Lise Saffran et al. (2020) has turned to empirical evaluation of storytelling and literary techniques in public health classrooms while Kate Winskell et al. (2015) has used close reading of narratives to study HIV stigma. While humanities scholars like Priscilla Wald (2008), Cristobal Silva (2011), and Rebecca Garden (2019). However, there is still a critical gap in the scholarship, pedagogy, and application of narrative public health ethics.

Although the field is still developing and there is no authoritative source for defining narrative public health ethics, one can understand narrative public health ethics as an approach that uses narrative as a framework to approach population-level ethics. Given this understanding of narrative public health ethics, it makes sense that our starting place will always be a narrative (rather than a case study or scientific report). For the purpose of this book, we have taken a broad approach to narrative that encompasses both fiction and non-fiction stories. In the remainder of this section This section will return to the four literary elements of voice, character, plot, and resolution to explore how they might be applied to narrative public health ethics. There is no standard order for applying the aforementioned elements to ethical analysis of narrative. Further, the elements will often blend into and inform one another. For example, a discussion of voice will often depend on, and even inform examination of character in a narrative. Thus, while this chapter has broken each element into discrete sections here, those teaching or applying a narrative public health ethics approach will encounter less distinction between the elements.

The literary element of voice, as Montello proposes it, requires a bit of complex analytical engagement and the development of narrative reading strategies to recognize that stories often contain multiple voices, perspectives, and, often tellers. Thus,

one has to account for both the teller (the person sharing the story) and the voices represented (often as characters) who may be distinct or an extension of the teller.

To get a sense of the complexity of voice, one need only look to any detective fiction like the kind written crime novelist Agatha Christie, where an “unreliable narrator” is the storyteller. Because the teller is crafty, they can insert themselves into the story and manipulate the voices of others in such a way that the teller’s own complicity in the so-called crime goes unnoticed by the reader.

The concept of voice in narrative public health ethics presents a unique additional challenge in that narrative has traditionally been viewed as a mode of individual expression. Stories offer us insight into the mind of individuals (storytellers, characters, writers). Thus, how do we approach narrative ethics and the question of voice when public health focuses on the community and population level? The answer, to return to Adichie’s point about the importance of multiple stories, is through recognition that there is no single story.

According to Howard Brody and Mark Clark (2014), unreliable narrators (like the detective novel example above) are telling “bad” stories. Bad stories are not bad in the sense that they aren’t entertaining or well written. Instead, “stories are bad when we need to understand something by moving on to different stories told from different perspectives but cannot because the initial story prevents us from seeing this and from seeking those alternative stories” (Brody and Clark 2014, S9). This lure is particularly appealing when thinking of narrative public health ethics. One could easily become seduced by the appeal of a single voice, telling a, single story masquerading as representation of a community.

To deal with the trap of the single story, just as Adichie suggests, the goal is to take a comparative approach to narrative public health ethics. Creating space for multiple stories (that employ different voices) helps prevent the reader from taking a single narrator at face value. Readers must be on the alert for “bad” stories; dominate narratives of the powerful that suppress or obscure the vulnerable while maintain the façade of an objective, omniscient story. We must remain skeptical of a single, omniscient voice in our narrative public health ethics practice in order to “... learn to detect stories that make it too hard for the vulnerable to hold their own. We can learn to respond to such stories with a demand for additional stories—not just any additional stories, but ones in which the point of view shifts to favor how the world looks to the characters previously marginalized” (Brody and Clark 2014, S9). Thus, for example, narrative public health ethics would rely upon gathering stories not just from researchers or students, but from communities and other stakeholders directly impacted by public health interventions.

Regardless of one’s comfort with literary analysis, almost everyone will be familiar with the element of character. In fact, character is often the first thing we learn about the texts we encounter; one need only ask a young child who their favorite movie or book character is in order to see how early we come to recognize characters. However, when we turn to a deeper analysis of narrative, character becomes easy to confuse with voice because both are represented in the story. However, voice indicates a certain level of power; it is the person who is telling the story, who is

being given agency to speak. Whereas character involves both those who have voice as well as those who are simply represented. For example, both the narrator and the person who has no lines in the narrative are characters. When we think of community, character challenges us to recognize that there is no single character, no one story, but rather a web of stories. When listening to stories, and following characters, we should not only follow the journey of those who are represented but also consider the characters on the margins and those who exist beyond the text. Understanding the stories, perspectives, and voices of characters on the margins can add to the discourse and examination of ethical concerns.

Characters exist within a plot. For Montello, stories create expectations as they go. “One thing happens because of another” (Montello 2014, S4). However, those reasons are rarely neat and orderly cause and effect. Plots, especially in the domain of life, are often complex, twisted mazes with many seeming detours, back-roads, and a few potholes. The work of narrative ethics means encountering and recognizing complex plots and disentangling and extracting meaning from them. Other times, it means resting in the uncomfortable space where there is no meaning between events. This is particularly true of public health emergencies where plots are disrupted by something unexpected like disease, a natural disaster, or scarcity of resources.

The final literary element Montello proposes to guide narrative ethics is resolution. Life narratives do not conclude until life itself has concluded. Rather than tidy final resolutions, we might imagine a network of individual stories (or individuals and communities) that build upon one another. For example, one might think of the story of meeting a research participant for the first time. While the story of that first meeting will have a beginning, middle, and end, the overall narrative of both the researcher and participant and (possibly) their shared experiences does not end with that initial meeting.

Montello positions resolution as a “progression” rather than solution; “Resolution can come when meaning and purpose and commitment deepen, when one narrative thread is lost as a new one is being found” (Montello 2014, S5). The goal of narrative public health ethics is to arrive at a resolution; that is, a progression from one step or episode to the next. By taking into account the whole of the story, we can examine the *how*: How did the stakeholders arrive at the current situation? Resolution can help us understand a second *how*: How do stakeholders wish to proceed?

Narrative public health ethics is not limited to Montello’s four elements. As the field continues to develop, new foci will emerge that are salient to public health ethics. For example, one could imagine language, mood, and tone could function as additional methods for understanding the ethics at play. What kind of language is the writer using to convey their message? Does it emerge from public health discourse, or is it steeped in shared language of the community? What might mood (i.e. the writer’s attitude to the topic of the narrative) and tone (i.e. the feeling elicited by the writing) tell us about the writer’s values?

Critiques of Narrative Ethics

Because the field is so new, to date, there are no significant critiques of narrative public health ethics. However, one may turn to critiques of use of narrative in medical ethics to anticipate some of the critiques that may be leveraged for public health applications. This section will outline four particular critiques that those interested in narrative public health ethics will need to consider going forward.

First, narrative ethics assumes everyone is comfortable with the use of narrative form or storytelling. Additionally, developments of narratives can feel intrusive. Narrative approaches to ethics, while touting the benefits of the framework, rarely consider the ethical implications of the mere act of constructing and sharing a narrative. In public health, especially, there may be situations where stakeholders either do not feel they have a duty to share their story or listeners do not have a right to engage. When faced with this issue, public health practitioners will need to remain vigilant against telling the “single story.” If only certain stakeholders feel comfortable sharing their story, is there enough representation to adequately frame and analyze the ethical issues at hand?

Second, Christine Mitchell (2014) argues that storytelling involves the act of selection, whether conscious or, more often than not, unconscious. It is impossible to incorporate every detail of a story, and the listener is limited to the details the teller includes. However, this critique may apply to any form of information shared when discussing an ethical issue (consider, for example, the work of case studies). However, this idea of narrative selection, just like attention to voice and character, challenges us to attend to the information that is missing and consider, in our ethical deliberation, if (or why) that missing information is key to our own thinking.

Finally, stories are not unvarnished, objective, value-neutral representations of events. Mitchell in particular notes that stories, especially in the hands of a skilled teller, slip naturally between representation of phenomena and ethical content thus giving “expression to what the teller thinks is right and wrong, admirable and reprehensible, worthy of telling or not” (Mitchell 2014, S14). This is why one could solicit the narratives of five people who experienced the same event and receive five vastly different stories in return. Such slippage is natural and, in fact, the mark of good storytelling that distinguishes a narrative public health approach to a report or case study. This third critique illustrates the importance of educating and developing tools for public health professionals about how to incorporate narrative ethics approaches into their work. Those untrained and unaccustomed to such a framework could understandably approach narratives as objective truth rather than as a complex comingling of values and events (i.e. phenomenon).

Hilde Lindemann suggests three steps to address critiques leveraged against narrative medical ethics:

1. Stories should be co-constructed. In other words, stories may benefit from collaborative co-authorship. In public health this might mean community members each contribute to a shared story. Ultimately, the goal of truly co-constructed stories is that they help avoid what Chimamanda Adichie warns against: the single story.

2. Stories should be critically examined by asking questions. Engaging with literary elements can help raise questions about the most relevant moral considerations that could or should be raised in the context the narrative presents.
3. Develop a narrative sophistication to recognize “when the story needs telling and when it isn’t yet ready to be told” because the real phenomena that form its content are not yet ready to be told because events either haven’t fully developed or people haven’t fully digested their meaning (Lindemann 2014, S31).

Public health narrative ethics, which is likely to face similar critiques, could benefit from Lindemann’s suggestions. In particular, the first recommendation to co-construct stories, seems well-suited for a population-based approach to ethical analysis of narratives.

The Future of Narrative Public Health Ethics

The field of narrative public health ethics faces two primary challenges as it continues to develop: programmatic and evidentiary. Because narrative public health ethics relies on certain narrative competencies, the methodology for adopting this approach is not intuitive. Public health students and professionals, especially those who do not have a background in the humanities may find the process of interpreting or even producing narratives challenging. It is the hope of this book that we may contribute to the ongoing education efforts in narrative public health ethics.

Second, to date, there is no robust evidentiary base to support the efficacy of narrative ethics (medical or otherwise) as a method for ethical analysis. While there have been a number of studies that have led to reports in the popular press that reading enhances one’s ethical and empathetic abilities.¹ Whether narrative ethics is an empirically valid source of ethical insight is still largely unknown. Research to study the role of narrative public health ethics, especially while the field is still developing, could provide not only a fruitful means of supporting its continued application in public health ethics but also provide new insights into how to improve narrative methods.

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Part II
Public Health Ethics Narrative –
Justice Concerns

Chapter 3

Empowering Communities That Experience Marginalization Through Narrative



Breanna Lathrop, Marcia Mercy R. Kasambira-Emerson, Veronica Squires, and Scott Santibañez

Abstract Resolving to share one’s narrative may empower a person to own and appreciate their personal experiences and encourage fellow marginalized community members to become empowered by owning their own narratives. Respecting people, hearing their stories, and inviting them to share their stories with people with similar lived experiences can become both a reflector of, and contributor to, community empowerment. In this paper, we present a narrative from a woman experiencing major depressive disorder and Type 2 Diabetes. Her personal reflection describes how she came to understand her lived experience and the ways in which social factors impacted her health, and how this understanding contributed to her ongoing healing process. Her work as a Certified Peer Specialist illustrates the ability of her narrative to empower other marginalized community members and inform health interventions. Rather than imposing solutions without community engagement, public health interventions should resonate with the values and voices of community members and stakeholders. When both speaker empowerment and listening are taken into account, public health can avoid harm, maximize positive out-

Disclaimer: This paper is presented for instructional purposes only. The ideas and opinions expressed are the authors’ own. The paper is not meant to reflect the official position, views, or policies of the editors, the editors’ host institutions or the authors’ host institution.

Although this chapter focuses on the narrative from a woman experiencing Type 2 diabetes and depression, we do not discuss medical or scientific aspects of diabetes or mental illness. We encourage interested readers to visit <https://www.cdc.gov/diabetes/index.html> and <https://www.cdc.gov/mentalhealth/index.htm> for the most up-to-date information on these conditions.

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comes, and treat storytellers fairly, as autonomous partners in their own health and the health of their community.

Keywords Narrative · Faith-based · Homelessness · Mental health · Social determinants of health · Community empowerment · Public health

Public Health Ethics Issue

To engage people who have been marginalized, public health practitioners are increasingly turning to authentic and truthful narratives. As a tool of both discovery and communication, narratives help public health professionals understand health issues from the perspective of the individual. Just as importantly, they promote a process that forces health professionals to identify and question the presuppositions and biases inherent in their own public health narrative. Understanding how their own narrative can drown out their capacity to listen and learn from community members can play a crucial role in the success of public health interventions.

Despite potential benefits, the use of narrative requires caution. Narratives that lack proper consent from their authors, contain inadequate framing or misleading information, or reinforce stereotypes can cancel their potential to effect social change. Employing narrative as a tool must begin with a respect for the autonomy of the narrator and an appreciation of the risk that recounting sensitive personal experiences poses. These demand the use of informed consent, privacy protections, and special protections for those who are vulnerable or have diminished autonomy. Thus, a personal narrative should never result from an intrusion upon privacy or a violation of autonomy that appropriates information from the person. Rather, consenting to share a personal narrative for the benefit of others should, we suggest, signify the narrator's active demonstration of empowerment. We cannot empower people who are marginalized without first respecting and protecting them.

Resolving to share one's narrative may empower a person to own and appreciate his or her personal experiences. That resolve to take ownership of one's life story can also empower the decision making of others. The deliberate sharing of a personal story can encourage fellow marginalized community members to become empowered by owning their own narratives. When they in turn share their stories, sharing can become a chain reaction of both individual empowerment and social solidarity. Thus, respecting people, hearing their stories, and inviting them to share their stories with people with similar lived experiences can become both a reflector of, and contributor to, community empowerment.

The World Health Organization (WHO) defines social determinants of health as the conditions in which people live that impact health (WHO 2020). Inequities in the social determinants of health have put some groups that have historically been economically or socially marginalized at increased risk of adverse health outcomes.

Addressing these social determinants of health has become a recognized ethical obligation of public health professionals who work with communities. The Public Health Leadership Society lists as a guiding principle for the ethical practice of public health: “Public health should advocate and work for the empowerment of disenfranchised community members, aiming to ensure that the basic resources and conditions necessary for health are accessible to all” (Public Health Leadership Society 2002). Similarly, the American Public Health Association Public Health Code of Ethics states that ethical policies and practices used to conduct and disseminate assessments of public health status and public health issues facing communities should, “Promote cross-disciplinary collaboration to define community problems and identify causal factors or social determinants of health” (American Public Health Association 2019).

In this paper, we present a narrative from a woman experiencing major depressive disorder and Type 2 Diabetes. Her personal reflection describes how she came to understand her lived experience and the ways in which social factors impacted her health, and how this understanding contributed to her ongoing healing process. Her experience also illustrates the ability of her narrative to empower other marginalized community members and inform health interventions.

Background Information

Mental health, including social, emotional, and psychological well-being, affects how people interact with others, cope with stress, and make health choices. Depression can increase the risk of physical health problems in type 2 diabetes (Egede et al. 2009). Conversely, chronic health conditions may increase the likelihood of mental illness (National Institutes of Health 2015). Out of fear of being stigmatized, people may conceal that they have a chronic disease or a mental health disorder. Such fear can add to stress and worsen their health condition (Centers for Disease Control and Prevention 2012). Childhood and adult financial hardship are independently important predictors of common mental health disorders such as depression and anxiety in adulthood (Morrissette and Kinderman 2020). Almost all types of mental health disorders are associated with higher rates of substance abuse disorders (Ross and Peselow 2012).

Social conditions such as poverty, housing instability, unemployment, and racism, are consistently related to poorer mental and physical health and lowered life expectancy (Braveman and Gottlieb 2014). Closing life expectancy gaps requires strategies which address social determinants of health (WHO 2020). Public health interventions that ignore the impact of social determinants of health on their population of focus will likely fall short not only of closing life expectancy gaps but also of addressing health disparities and fostering health equity.

Approach to the Narrative

As public health professionals work to promote health equity, it is important that they understand the lived experience of individuals experiencing health disparities. Narratives can include both personal stories and broader collective perspectives of how communities have experienced marginalization, bias, and adverse health outcomes. Individual and collective narratives can illuminate the impact of social determinants on health, inform public health interventions, and form an act of empowerment by the storyteller.

The narrative that follows centers around Marcia Mercy Rumutsiro Kasambira, who experiences major depressive disorder and Type 2 diabetes. Everywhere she goes, she makes a point about two things. “Firstly, I acknowledge and give all credit to my faith in the God of Abraham, Isaac, and Jacob for my life. Also, I’d like to use my full name.” To Marcia, these two epitomize her heritage and story of pain, survival and now, flourishing. The eldest of four children, she was born at the Mutambara Mission Hospital in Zimbabwe and named for Rev. Marcia Ball, a white missionary who served her people for over 60 years and whom Marcia’s family affectionately called “Auntie Marcia.”

Marcia is a Certified Peer Specialist, a health professional with lived experience of mental health illness and/or substance abuse who uses her story to assist people experiencing similar circumstances. Marcia sees owning her story as empowering. She works alongside the other authors at the Good Samaritan Health Center, a non-profit clinic founded in 1998 in metro Atlanta. The clinic offers quality medical, dental, health education, mental health, and social services in an atmosphere of dignity and respect, regardless of race, ethnicity, or religion. In addition to clinical care, Good Samaritan provides a range of public health prevention services such as health screenings and vaccinations. Good Samaritan’s mission is “Spreading Christ’s love through quality care to those in need.”

Marcia was asked to share her experience for this article based on her use of narrative in her work and desire to further impact others through her story. Prior to hearing her story, the co-authors informed Marcia that her story would be used in its entirety, not combined to form a composite narrative. Marcia joined us as an author, providing feedback with each draft. We also promised to provide Marcia with a copy of the book in which her story would appear. Giving verbal and written permission sealed what was an act of empowerment on her part to share her narrative for the benefit of others. She does not view the sharing of her narrative as an intrusion in which her personal health information was taken from her or used for purposes without her consent. Sharing Marcia’s story serves three purposes: (1) the sharing empowers and heals the teller (2) the story resonates with others and can embolden them to pursue change and (3) her lived experience informs specific and general healthcare practice decisions.

Narrative

Marcia first heard about Good Samaritan Health Center from the founder of a recovery group where she was a twelve-step program leader. As someone who had grown up in in the Republic of Zimbabwe (formerly White minority ruled Rhodesia), she was skeptical. True, it was a Christian Mission Hospital in Zimbabwe that had provided the only available health care. But getting to that hospital was difficult and, as a Black person living under apartheid, keeping a low profile was essential. As a result, trips to the Mission were reserved for truly devastating illnesses. Health care was not accessible and not a priority. Marcia recalls stepping on a stick in her backyard which punctured her skin and resulted in an infection. She was 13 at the time but did not mention the ailment to her parents, as this was not the type of illness that would warrant care in Zimbabwe. The pain and infection festered through the school year. She remembers suffering under the assumption that nothing could be done. “The experience started a narrative that I don’t matter,” she explains.

Early experiences of racism reinforced this narrative. She was among a small number of Black students accepted into a competitive school in Zimbabwe. Students socialized, sat, and studied in segregated groups, yet Marcia befriended several White girls. As a result, her peers ostracized her, which fueled the feeling that she did not belong. On one occasion, she signed up for a school trip to hear a performance by a popular South African singing group. The day of the performance, dressed in her best, she got in line to board the bus along with the other students who had registered for the event. All of the other students were White. The school nun took her out of the line, informing her that she could not attend. She could not ride the bus and attend a public event with the White students. “I cried for hours as the nun rocked me in her arms,” Marcia remembers.

Although undiagnosed until the age of 47, Marcia had been experiencing depression for as long as she can remember. When her family moved to the United States, her attitudes and beliefs about health and illness, as well as her struggle with self-worth, traveled with her. Drinking became her way of dealing with life. “Alcohol was my best friend,” Marcia describes. Her experience of racism continued in the United States as well. She married a White man and they faced opposition as a mixed-race couple raising three children. By her account, he was abusive, emotionally, verbally, financially, and physically. She continued drinking to cope. One day, he came home and started hitting her. As she turned from him, she saw her daughters were standing in the doorway watching. The thought of her girls growing up believing this is how women are to be treated finally gave her courage. The next day, after a traumatizing 16-year marriage, she left with her children to seek emergency protection at a women’s shelter.

Though crippling, her depression remained undiagnosed and untreated. Her fleeting experiences with the U.S. health care system did nothing to dissuade her belief that health care was useless to her. Front desk workers talked down to her, and providers rushed by her ignoring her concerns and shaming her for her substance abuse. She was turned away when she couldn’t pay. “When people come in broken,

all they have left is their dignity. So never take away a person's dignity." Marcia explains, quoting her mother's words. When social and health care service providers threatened her dignity, she gave up. "You don't want to come back, so you continue being sick."

A twelve-step program, with the guidance of her Sponsor, opened a path to sobriety. After Marcia's grown children had established lives of their own, she reconciled with her ex-husband who suffered from a terminal illness. He had found God and asked for her forgiveness. She cared for him during the last 6 months of his life, eventually quitting her job for the final month while his life ended in hospice. After his death, she lived with her younger sister's family, who graciously opened their home for 2 years. During this time, Marcia's brother offered spiritual support, which proved instrumental to her recovery. Through a partnership with Odyssey III, a program with a holistic approach to addressing homelessness, she entered a housing program at Zion Hill Community Development Corporation. There she began to grow out of her life-long survival mode belief system. She found community in the twelve-step recovery program noted above which was made up almost exclusively of people experiencing homelessness. The founder encouraged her to go to the local clinic that she had heard about, Good Samaritan Health Center. After watching friends jump on the van to the clinic each week, she decided to give it a try. "My initial thought was to just keep going as I had always done, but I knew I was sick," recalls Marcia. Her depression was worsening, and she was regularly experiencing suicidal thoughts. She knew she had diabetes but using insulin consistently seemed overwhelming.

Marcia's personal and cultural beliefs and traditions allowed her to connect with the health center's name, The Good Samaritan Health Center. Her mother, whose life had been taken in an accident, was a pastor and community healer who had taught Marcia the biblical story of the Good Samaritan and embodied love for neighbor in her ministry. Marcia remembers she was treated with respect and value at Good Samaritan. From the van ride to the clinic to her visit with a provider, she felt as though she was being told, "you are worth something."

The clinic supplied medication for high blood pressure, anti-depressants to address major depressive disorder, and insulin to control her blood sugar. The presence of consistent access to care and medication provided hope that maybe she could get well. The medication and mental health consults improved her health, but the space the clinic provided for her to share and reflect on her story proved equally important. Her providers spent time listening to her story and spoke about life trauma, poverty, homelessness, and the impact these factors had on her health. "I couldn't address diabetes until I got my mental stuff taken care of," she insists. For Marcia, this included counseling and medication. As she started to partner with her provider to address her diabetes, she began taking ownership of her health. She took advantage of nutrition, health education, and cooking classes. Marcia still suffers from depression but has found a new approach to life with the help of treatment. She uses insulin daily and her blood sugar has been at her goal level for almost a year now. "I'm no longer coming from a place of destitution," she says, "but walking into the promised land."

Marcia presented at Good Samaritan appearing uninterested in managing her diabetes and non-compliant with her treatment, although she was open to behavioral health services. Her ability to share her story and understand the way in which her life experiences impacted her health were the start of her path to managing mental illness and controlling her diabetes. When her providers took time to hear her story and reflect upon their own beliefs and practices, the providers' narratives were also challenged and changed. Her care plan focused increasingly on addressing her mental health in addition to her diabetes. The roots of her challenges in managing depression and diabetes became clearer in the context of the trauma she had experienced and the conceptions she held about health care.

"One of the most powerful pieces of information for me has been learning about these social determinants of health," Marcia explained. "It made my life up to now finally make sense. My poverty mentality had caused me to not see that there was any hope for me." She recalls feeling enslaved to life factors outside of her control. She describes it as, "the dark cloud that didn't allow me to take a step beyond addressing the immediate." She was stuck in a survival mindset. Her experiences of racism fueled her sense that "I don't matter" and stopped her from seeking help. Having experienced racial discrimination within the health care system, she feared rejection and mistreatment if she sought care. "Understanding this," Marcia describes, "was the starting place of healing." For Marcia, understanding the relationship between her upbringing, traumatic life experiences, and current health, allowed her to relinquish self-blame and become an active participant in her health care.

Marcia has since become a Certified Peer Specialist and now works at Good Samaritan, using her lived experience to open doors for others to tell their story. Her work as a Certified Peer Specialist centers on being empowered to use her personal story of recovery to encourage others in their own recovery journeys. "You know, I have to take medication too," Marcia says in her interactions with patients. By sharing her story, Marcia de-stigmatizes mental illness, addiction, abuse, and homelessness. Her story thus encourages health-promoting behaviors and public health prevention measures, such as screening and routine vaccinations (Fischer et al. 2019, 990). Marcia engages in empathetic listening with her peers, using storytelling as a tool for making sense out of illness and suffering (Stanley and Hurst 2011, 39). "I see it over and over again with my peers," explains Marcia. "When a person is given the opportunity to talk and know that someone is actually listening, they break down in relief." She provides a space in which they can share their own narratives and receive validation that their experiences are significant and understood. Validating their lived experience builds trust and creates opportunities to make change. "When the walls come down, I can ask them, 'Have you thought about counseling?'" She also focuses on removing shame, changing the question from, "what is wrong with you?" to "what happened to you?"

Guided by the principle of self-determination, Marcia empowers individuals to make their own decisions and achieve their goals. Most recently, this has led to a project in which Marcia is helping peers to share their stories within their communities. "This is transformational," she explains. "As they share their narratives, they

are encouraging other peers that they can accomplish their goals.” One patient, who has been receiving care at the clinic for several years, just moved into permanent supportive housing. Marcia helped her create a video in which she shares her experience of recovery and fulfilling her goal of moving inside after 15 years on the street. She is now sharing this video with her community. Her audience includes people currently experiencing homelessness as well as people who have supported her in her recovery. Marcia emphasizes that for peers who have chosen to share their story in this way, this experience has given them a purpose. “This is the most important thing,” she exclaims. “This is life-changing.”

The narratives of Marcia and peers who have chosen to share their stories have also shaped the approach taken by the health care team at Good Samaritan. Identifying themes in the narratives of patients allows the team to restructure programs in a way that addresses social needs. These needs include actions like providing breakfast in the morning, setting up an art table to decrease stress while waiting, and building partnerships with housing providers. Marcia has shared her story with the staff, helping the health care team understand social determinants, such as poverty, as traumatic experiences with health implications (Sapolsky 2005, 96–99; Squires and Lathrop 2019, 30–39). Through her narrative, Marcia is empowering her peers and equipping the health care team to better meet the needs of community members who have been marginalized.

By responding to the needs of patients and creating an atmosphere of respect and caring, the staff at Good Samaritan has maximized opportunities for public health interventions. All patients have access to mammography, Pap tests, sexually transmitted disease screening, tuberculosis (TB) screening, colon cancer screening, and smoking cessation support. Women commonly complete breast cancer screening on a mobile mammography unit that comes to Good Samaritan. This option allows them to complete screening in a trusted environment without additional travel. Based on expressed difficulties with transportation, TB screening is done through a blood test so that patients do not have to return to have a purified protein derivative (PPD) read. Routine adult vaccinations and annual flu shots are also available. There are many patients like Marcia, who are experiencing homelessness and facing barriers to treatment. However, they will consistently take advantage of public health interventions that take place in a trusted environment that gives them control over the services they receive.

Discussion

As public health strives toward health equity, it can learn from the sharing of personal and community narratives like Marcia’s. Such narratives can serve as engagement tools that promote individual healing, empower community members to promote positive change, and inform public health interventions.

Narratives can only accomplish these goals when they are used in an ethical manner which respects people’s autonomy and promotes the dignity, safety, and

well-being of the storyteller. We suggest that informed consent can provide an opportunity to reflect, and contribute to, community empowerment rather than just become an added burden. Used appropriately, informed consent empowers people to deliberately choose to share their narrative for the good of others. This aligns with The Belmont Report's ethical considerations of respect for persons, beneficence, and fairness (Department of Health, Education, and Welfare 1979). Such use contrasts with taking information from people without their knowledge or consent and using it in ways that do not benefit them. Involving narrators as authors is one of the distinct strengths of this narrative.

In crafting communication strategies, public health professionals need to listen to and understand the community's cultural and social values and health beliefs (Santibanez et al. 2017, 3). The activist slogan, "nothing about us without us," holds true in all health programs and practices (Squires and Lathrop 2019, 182). Our narrative used third-person voice, direct quotes from transcription, and multiple opportunities for all authors to review and critique the reconstructed account. This approach allowed us to demonstrate respect for a co-author's values and beliefs (e.g., "Firstly, I acknowledge and give all credit to my faith in the God of Abraham, Isaac, and Jacob for my life") while also permitting the overall narrative to remain objective. Previous authors have suggested that writing in the third-person may foster trust in a narrator who is by convention an authoritative figure and allow readers to see the protagonist from an observer position resulting in feelings of sympathy (van Lissa et al. 2016, 59).

Collecting and listening to narratives engages the affected population and informs decisions about how to best work with the community. Rather than imposing solutions without community engagement, public health interventions should resonate with the values and voices of community members and stakeholders. When both speaker empowerment and listening are taken into account, public health can avoid harm, maximize positive outcomes, and treat storytellers fairly, as autonomous partners in their own health and the health of their community.

Questions for Discussion

1. Considering examples from your reading and personal experience, how could public health practitioners have used narrative approaches to better understand the health concerns of underserved and vulnerable populations while also guarding against inadvertently perpetuating stereotypes that may undermine health goals?
2. When someone makes a conscious choice to share his or her narrative to benefit others, it can be an active demonstration of empowerment, rather than an intrusion or violation in which information is taken from the person. How might informed consent be framed in a way that is empowering?
3. Marcia owns her experience. Understanding the ways in which social factors have impacted her health formed the starting place for her personal healing as

well as that of her peers. How might other clinics and public health programs work with Certified Peer Specialists like Marcia to use trust, acceptance, and validation to empower individuals to make decisions, achieve goals, change behaviors and improve health?

4. In what ways can consideration of the social determinants of health and conditions in which people are born, grow, learn, work and live influence care plans and complement evidence-based clinical care?
5. Narrative can help to challenge providers' underlying assumptions that promote persistent inequities. As providers listen to clients' experiences of poverty, homelessness, illness, and addiction, how might their perspectives on these issues expand beyond their personal experiences? For example, how might a provider respond when clients experiencing homelessness frequently express the need for permanent housing as opposed to moving between shelters and temporary programs?

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Chapter 4

The Boys Under My Deck: Racialized Violence and Moral Repair



Lindsay J. Thompson

Abstract Data on youth violence show that youth homicide rates have increased in many parts of the world. Vigorously embracing social determinants and promoting health equity as the most effective approach to achieving health policy goals, the global public health community has nevertheless been ineffectual in saving thousands of young lives cut short violence. In the United States, the American Public Health Association has long considered violence to be a public health issue, but only recently acknowledged racism as a factor in violence. Despite a half-century of explicitly legal racial equality, the white majority in the United States have yet to create a normative critical mass of inclusive, equitable social practices to dismantle the legacy of structural racism created by their forebears. This narrative draws from Margaret Urban Walker as a response to the dilemma of white inaction by focusing on moral repair as an intentional social engagement practice to redress the legacy and practice of structural racism and racialized violence. Moral repair is especially applicable to structural racism because it acknowledges the underpinnings of wrongdoing in healing fractured societal relationships.

Keywords Youth violence · Racialized violence · Social determinants · Structural racism systemic racism · Health disparities · Moral repair

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Public Health Ethics Issue

From the moment the COVID-19 pandemic first appeared in early 2020, the whole world quickly came together with stunningly successful solutions to minimize and eradicate the threat. Meanwhile, a deadly epidemic of armed violence has raged unchecked for decades across American cities with no end in sight. Vigorously embracing social determinants and promoting health equity as the most effective approach to achieving U.S. “healthy people” policy goals, the public health community has nevertheless been ineffectual in saving the thousands of mostly Black and Brown young lives cut short by a deadly weapon. What are the social determinants approaches to mitigating violence? How do they work? Might it make a difference for Black and Brown boys to know that their neighbors care about them, listen to them, and have their back? The following narrative suggests simple neighborliness as a social determinant of health for young boys living in urban neighborhoods plagued by racialized violence.

The American Public Health Association (APHA) has long considered violence to be a public health issue, but not until November 2018 did the APHA acknowledge racism as a factor in police violence (APHA Policy Statement Database 2018). Racist law enforcement is just one aspect of racialized violence defined as “physical acts and structural processes that prove injurious or deadly to Black people *as* Black people. The structural manifestations of racialized violence include unjust laws and normative practices that constrain the fulfillment of Black people’s basic needs (like safety) and diminish their pursuit of liberation from persistent oppression” (Guerra and Thompson 2019, 587). Conceptualizing the “toxic triad” of marginalization, distorted policing, and violence, Hannah Cooper and Mindy Thompson Fullilove are the first public health scholars to examine racialized police violence as a social determinant of health with an unbroken pattern of antecedents dating back to the Norman Conquest (Cooper and Fullilove 2020).

The convergence of the COVID-19 pandemic, economic disruption, and police violence in 2020 riveted long-overdue public attention on racial disparities in the United States. The undeniable fact that people of color bear disproportionate burdens of the pandemic, economic loss, and police violence is proving to be a pivotal transformation of American civic conscience, with the majority of Americans now believing – however belatedly – that Black Lives Matter (Thompson and Horowitz 2020).¹ For the first time in U.S. history, the time is right to make good on the promise of equal protection for Black lives: Freedom from racialized violence and social trauma, elimination of health disparities, and promotion of equity in all policies. It is time for the United States to build a culture of health for all Americans.

¹ Tracking support for the Black Lives Matter movement, the Pew Research Center reported a peak level of support at 67% among adult Americans in June 2020 following the death of George Floyd. As racial justice protests intensified in following months, support for Black Lives Matter declined to 55%. During the same time period, support for the movement among Black Americans remained steady at over 85%.

We learn from history that informal social practices are equally or perhaps even more important in changing the culture than legal and policy initiatives. Despite a half-century of explicitly legal racial equality, the white majority have yet to create a normative critical mass of inclusive, equitable social practices to dismantle the legacy of structural racism created by their forebears. However well intentioned, the white majority has failed to create the social change they claim to embrace. The ordinary white person who decries racial injustice may have no idea how to begin the work of repairing centuries of structural racism. This narrative responds to the dilemma of white inaction by focusing on moral repair as an intentional social engagement practice to redress the legacy and practice of structural racism and racialized violence. Moral repair is especially applicable to structural racism because it acknowledges the underpinnings of wrongdoing in healing fractured societal relationships.

Background Information

I have woven background material into the main narrative to emphasize how the practice of moral repair involves immersing oneself in the social and economic history of a community as well as owning responsibility for that history in order to begin the process of healing relationships. This is especially important for white people, many of whom are descendants of twentieth century immigrants to the United States who feel no personal culpability for institutional racist practices such as slavery or Jim Crow or for the privileges they enjoy just by being white in a racist society. This experiential narrative is a first-hand account of how white Americans, as beneficiaries of structural racism, can begin to take responsibility for initiating moral repair in their own communities.

Narrative

In 2005, I bought a house and moved into Albemarle Square, a new mixed-income community funded by the U.S. Department of Housing and Urban Development (HUD) in Historic Jonestown, one of Baltimore's oldest and most distressed "Black Butterfly" neighborhoods of concentrated racialized poverty and neglect.² City planners designed the neighborhood to mitigate gentrification forces emanating from Baltimore's downtown and Inner Harbor revitalization. As a somewhat elderly white professor with years of experience in health policy and planning focused on the livability challenges of cities, I was eager to be part of a diverse urban

²The term "Black Butterfly" was coined by Lawrence Brown in "Two Baltimores: The white L vs. the Black butterfly". *City Paper*. 2016.

community. At the time, I was only theoretically aware of what living in the neighborhood would teach me about applying an equity lens to social determinants and health disparities in low-income majority-Black urban communities, but I welcomed the opportunity to be changed by the experience.

My new “market rate” community of 143 homes was built on the footprint of a demolished public housing complex surrounded by a patchwork of homeless shelters, public housing projects, historic sites, small museums, subsidized rental units, abandoned buildings, and vacant lots just a few blocks from Baltimore’s Inner Harbor, downtown, cultural attractions, Johns Hopkins Medical Institutions, and the Baltimore City Health Department. A midwestern transplant, I had lived in Baltimore for 30 years and thought I was familiar enough with the local culture to live comfortably and creatively in a mixed race, mixed income neighborhood. Then in 2015, Freddie Gray happened. A Black Butterfly kid who died while in police custody, Freddie became a symbol of the structural inequity and violence permeating cities like Baltimore. Scrutinizing my neighborhood, my city, and myself through the eyes of my black, brown, and poor neighbors, I realized that I had barely scratched the surface of the complex history and social dynamics of my neighborhood and the city I had lived in for so long.

In the 5 years since Freddie Gray’s death, Baltimore City residents have had time to reflect on the deep roots of structural racism, the culture of violence it fosters, and the role we all play either in perpetuating or repairing fractured race relations. As a white resident of a majority-Black, gentrifying neighborhood, I am sharing this narrative as a personal reflection on my experience of coming to understand the culture of racialized violence and learning the work of moral repair to build authentically just, caring, and neighborly relationships across boundaries of race, income, class, and age. This is a personal journey of moral repair that began by applying an equity lens to my own neighborhood – and myself – to understand racialized violence. This led to a deep interrogation of racist history and recognition that an informal “sanctuary space” of protective safety for neighborhood adolescents enmeshed in a culture of violence was a small but practical exercise in moral repair. From the outset, I knew that positive relationships with caring adults protect young people living with violence (David-Ferdon et al. 2016, 29). Reflecting on my experience in the light of history, I understood moral repair more clearly as a constructive response to racialized violence.

Racialized Violence and Moral Repair

The Health in All Policies (HiAP) framework acknowledges the frustrating irony of social determinants that rely on solutions well beyond the efficacious capacities of health policy and the healthcare system (Centers for Disease Control and Prevention 2016). Only by galvanizing the moral will and agency of people, publicly and privately, can society begin to repair and prevent the devastating damage of racialized violence to the health of people and communities of color. Based on her research

and international justice work with communities fractured by political violence, Margaret Urban Walker defines moral repair as “the process of moving from the situation of loss or damage to a situation where some degree of stability in moral relations is regained,” by which she means a collective normative confidence that shared values and principles will be observed, that wrongdoers will be held to account for their actions, and that victims of wrongdoing will be supported in reclaiming their lives (Walker 2006, 6). Walker focuses on the need for communities to establish credibility and trust by holding themselves and individual members accountable for their actions and for setting things right for people who have suffered offense, harm, and anguish from wrongdoing by the community or its members (Walker 2006, 24). Because the roots of racialized violence are so deep, it is impossible to understand it as a social determinant of health, much less “set it right,” without digging far into the past, as Cooper and Fullilove illustrate in their examination of racialized violence (Cooper and Fullilove 2020). I share some of that history in this narrative but hasten to add that the full story of racialized violence and its impact must include as primary sources the experience and perspectives of African Americans and other people of color. As a white person in a Black city, however, I can learn from the work of Black historians to own my part of the story and do the work of moral repair by setting things right in my own relational sphere.

Racialized Violence as a Health Issue

Like most U.S. cities, Baltimore embraces the U.S. national health goals of wellbeing and health in all policies in its own public health agenda.³ Established over 200 years ago in response to a yellow fever public health crisis, the Baltimore City Health Department now struggles with an equally deadly crisis of fatal overdoses and homicides that claim hundreds of lives every year. Achieving its Healthy People goals is a challenge for Baltimore where poverty, trauma, and violence top the list of health determinants for children and adolescents. In addition to its infamously high murder rate, Baltimore’s overdose fatalities rank among the highest in the country. Preventing the threat and trauma of violence has become a key public health goal for Baltimore. As in many American cities, the demographic patterns reveal that Black boys and young men bear the brunt of violence and society’s moral failure to protect, nurture, and prepare them to become fully functional, responsible adults.

The statistics are staggering. A city of 620,000 residents, Baltimore saw 761 drug and alcohol-related deaths and 342 homicides in 2017. The homicide rate of 56:100,000 far surpasses the national average of 6.2:100,000, making Baltimore one of the nation’s most violent cities (Wen 2017, 2). More than 90% of Baltimore

³See *Healthy People 2020 Framework*, U.S. Department of Health and Human Services, and *Healthy Baltimore 2020: A Blueprint for Health*, Baltimore City Health Department.

City homicide victims are Black; more than half are males between 18 and 30 years old. Most Baltimore homicides occur in Black Butterfly neighborhoods of concentrated poverty, longstanding racial segregation, and economic disinvestment exacerbated by the 2008 recession. Ninety-eight percent of Black Butterfly kids eat breakfast and lunch at school so they don't have to work on math, English, and social skills with a hunger headache.

Behind the statistics looms a systematic apparatus of legal and normative practices that constrains African Americans in fulfilling even their most basic need for safety. The whole apparatus seems designed to maintain structural racism by undermining people of color in their pursuit of liberation from persistent oppression (Guerda and Thompson 2019, 587). In learning to own and repair this injustice as a neighbor and city resident, I see how important it is to examine how everyday occurrences and ordinary interactions shape a community culture and perpetuate an ethos of racialized violence. For most of my years in Baltimore, I lived in safe, peaceful communities where exposure to violence of any kind was limited mostly to television and movies. When I moved to my Jonestown house, it was still a construction site where guys lined up every night selling knockoffs and drugs, girls practiced dance moves on the sidewalk, kids played kickball in the street. One night a body was casually dumped on the street in front of my house by a passing car. It was hard to miss the undercurrent of violence permeating the neighborhood.

Growing Up Black in a Culture of Racialized Violence

Growing up in the Baltimore Black Butterfly, African American adolescents are caught in the predatory jaws of violence – gangs and police – every time they walk out the door. For people who want to understand Baltimore's urban culture of racialized poverty and urban failure, Paul Attanasio's TV series, *Homicide: Life on the Streets* (1993–1999) and David Simon's, *The Wire* (2002–2008), offer a window into the struggles of Black Butterfly individuals caught in the web of distressed social, economic, and material conditions. In my neighborhood, older family members often work two or more part-time minimum-wage jobs to pay rent and keep food on the table, leaving kids to fend for themselves. The drug trade is more a quick hustle than a thoughtful career path. Without looking for it, trouble finds them in the unstructured hours and social spaces between school and sleep. This glaring poverty of opportunity is especially troubling given the overall wealth of the local economy; Baltimore ranks 19th among U.S. metro areas in Gross Domestic Production (GDP) and Maryland is one of the wealthiest states in the country (Bureau of Economic Analysis 2019, 2020). Baltimore boasts more than its share of upscale neighborhoods, fancy prep schools, exclusive country clubs, world-class institutions, and innovative tech ventures focusing on health and cybersecurity. In stark contrast, Black Butterfly kids live just blocks away from gleaming high-rise towers, upscale shopping, and glitzy restaurants as constant reminders of disparities and insurmountable barriers between the Black Butterfly world and the world of

wealth and opportunity within their sight but beyond their reach. It is no wonder that the death of 25-year-old Freddie Gray in 2015 sparked a protracted wave of city-wide protest and street violence. The crisis of civic conscience that erupted in the wake of Freddie Gray's death found Baltimore unprepared for restoring public order, despite its reputation as a progressive city with world class health knowledge, technology, and healthcare.

Progressive Policy and the Legacy of Slavery

Marylanders are proudly progressive, especially in health and social policy. Without acknowledging Maryland's foundation of enslaved labor and its long reach of slavery into the present, however, we cannot fully understand racialized violence. Baltimore's relentless racialized violence constantly reminds us of a living legacy of inhumanity that the achievements of a few cannot quell or silence. Racial health disparities are deeply rooted in its history as a colonial port that not only traded in enslaved Black Americans but relied on enslaved labor to build a prosperous agricultural, manufacturing, and international trading economy that spearheaded the U.S. industrial revolution. For most of its history, Baltimore normalized subservience of a sizeable Black population.

During the American Revolution, Maryland's enslaved Black population was second only to Virginia's and continued to increase until the abolition of slavery. The community of free Black Americans also expanded as moral objections to slavery took hold in the American civic conscience. As the number of free Black people in Baltimore grew – from 927 in 1790 to 17,888 in 1830 – white Marylanders viewed their presence as a problem, imposing restrictions to control and subordinate them in order to protect and justify their own social status, privileges, and human property (Millward 2016). At the dawn of the Civil War, Maryland had the largest population of free Black Americans in the country. Failing secession by a single vote in the General Assembly, Maryland emerged from the Civil War with a legacy of racist values to apply racist institutional practices to the large and growing population of emancipated Black citizens.

The subsequent century and a half of discriminatory practices such as Jim Crow laws, redlining, “zero tolerance,” “stop and frisk,” and punitive social policies continued into the present as deeply embedded structural bias designed to subordinate Black Americans and deny them opportunities for fulfilling their full human potential (Millward 2015; Gimenez 2005). Nevertheless, thousands of Black Americans from the Deep South found opportunities to thrive and prosper in racially segregated Baltimore with well-paying professions and jobs in manufacturing, steel refineries, and shipping at the height of Baltimore's industrial economy prosperity. By any measure, Frederick Douglass, Harriet Tubman, Eubie Blake, Benjamin Banneker, Vivien Thomas, Thurgood Marshall, Reginald Lewis, Elijah Cummings, Wanda Draper, and April Ryan exemplify high achievement. Although the Baltimore's Black community is one of the most prosperous and educated in the country, many

of them have never experienced the full measure of freedom and opportunity most white Americans take for granted. Instead, they have endured nearly four centuries of prejudicial treatment and systemic disadvantage. The Freddie Gray generation of kids know this in their bones and do their optimistic best to get on with a life filled with risks.

The Legacy of Jonestown

Jonestown is one of Baltimore's invisible neighborhoods with a rich, complex history. Named after Englishman David Jones who is said to have built the first European house on the shores of the Baltimore Inner Harbor, Jonestown is an eclectic hodgepodge of rowhouses, historic sites, social service agencies, small shops, vacant lots, and rundown warehouses. The busy street traffic reflects its origins as Baltimore's first commercial port in a bewildering juxtaposition of idealism and inhumanity infusing everyday existence. Within a few blocks, Quakers, Catholics, and Jews built communities, schools, and places to worship – mostly because they were forbidden to settle elsewhere in the city. Generations of sailors, traders, shopkeepers, dissidents, and immigrants from around the world also found Jonestown a welcoming place. They put down roots to build new lives as Irish, German, Italian, Polish, Greek, or Ukrainian Americans. Next to the Flag House Museum commemorating “the birth of the star-spangled banner” where Mary Young Pickersgill stitched the flag that flew over Fort McHenry as inspiration for the national anthem, a modest sidewalk plaque soberly reminds pedestrians that Baltimore's slave trading pens were located on the same street.

In the 1950s, the city tore down blocks of crumbling rowhouses in and around Jonestown to build publicly funded residential towers with easy public transportation access to schools, shopping, and jobs. The project mostly benefited lower-income whites seeking an entrée into Baltimore's working class economic and social mainstream. Twenty years later, segregation, riots, and white flight transformed Flag House Courts into one of the most distressed public housing high-rises in the entire country – a “black ghetto” of concentrated racialized poverty and violence that fragmented the surrounding neighborhood. Italians carved out Little Italy as a prosperous culinary destination; family businesses relocated to less risky locations; a sprawling concrete central post office building displaced blocks of homes and businesses; the redesigned Oldtown Market became a pedestrian island isolated from its historic social and economic context. The City met with little organized resistance as it began locating homeless shelters and social services in the neighborhood. Redesigned commuter corridors destroyed street neighborhoods and block-to-block connectivity. The only people who remained were those who could foresee no options to relocate. With an eroding tax base, civic leaders increasingly viewed funding for Baltimore inner city schools as wasteful and ineffective. Rarely expressed in explicitly racial terms, these views undermined efforts to provide Black Butterfly kids with ladders into the middle-class mainstream.

The post-industrial age dawned as Jonestown and adjacent neighborhoods were devolving into a concentrated economic geography of racialized poverty. In the 1980s, the complex racial dynamics of urban gentrification played a role in motivating James Rouse and Baltimore civic leadership to create the Baltimore Inner Harbor, a national model for revitalizing post-industrial waterfront downtown areas for investment, tourism, and affluent urban lifestyles. While 50 years of Inner Harbor gentrification have successfully positioned Baltimore for transition to the Fourth Industrial Revolution, it has also generated racial tensions that the structures and processes of conventional urban governance cannot manage. When Black neighborhoods struggling with decades of disinvestment lie adjacent to affluent white neighborhoods, race and class disparities are patently obvious. Baltimore seized upon Housing Opportunities for People Everywhere (HOPE VI), a federal program designed to foster inclusion and diversity in some of the nation's most distressed public housing communities (U.S. Department of Housing and Urban Development 2007).

A Social Experiment in Jonestown

In 2005, those of us who bought “market rate” homes in Albemarle Square (the new name for the former Flag House Courts public housing) intentionally bought into the HUD mixed-race, mixed-income neighborhood design that positioned people of different races, incomes, and social strata next to each other on the same block. Although we live side by side, the fault lines of income, class, and race are unmistakably inscribed in differentiated architectural features. Homeowners have raised decks and private garages at the back of their townhouses; renters living in publicly subsidized housing have unadorned parking pads and concrete steps at the back of their units. Property management structures also differ accordingly. Owners pool resources to manage their properties as members of independent homeowner associations, while publicly subsidized rental units feature tenant advisory councils with little power to determine the material conditions of their neighborhood. Homeowners are a racially and ethnically diverse mix of relatively affluent couples, singles, empty nesters, and a few families whose children attend private schools. Subsidized renters are mostly young African American mothers, with federally funded housing choice vouchers (Section 8)⁴ and children attending the local public charter school, and a sprinkling of senior citizens and people with disabilities. Except for occasional community-wide activities throughout the year, little mixing occurs among the children of homeowners and public subsidy renters. Children of homeowners participate in structured activities that their private schools and clubs sponsor.

⁴The Section 8 voucher HUD-sponsored program enables very low-income families, senior citizens, and disabled people to choose safe, affordable housing in the private market anywhere in the country.

See http://www.hud.gov/topics/housing_choice_voucher_program_section_8

Section 8 kids may participate in school events or community center activities, but many just hang out on local streets when school is out.

When we moved to Jonestown, all the new homeowners quickly observed the lack of green spaces and play areas for kids and families. The publicly subsidized renters understood this very well, though it disturbed them less. In 2012, after years of persistent persuasion, the city demolished a crumbling building next to my house where a group of neighborhood people pooled money and volunteer labor to build a community garden. Renters and homeowners alike enthusiastically encouraged their kids to get involved in the garden. I got to know most of the people in the neighborhood and spent many hours with the kids on days when the weather was good and everyone was outdoors. We planted, watered, weeded, and harvested while chatting about everything from weather patterns and seed catalogues to school schedules, big dreams, and neighborhood gossip. I learned that by the time the neighborhood kids are teenagers, the risks of violence and trauma are baked into their moral calculus and they become remarkably resourceful in finding ways to stay safe and upbeat in a city where dangers lurk around every corner. They don't ruminate on danger or trauma, but they are acutely aware that every venture into the street risks a potentially treacherous confrontation with gangs and the police. Yet, for 10 years, the neighborhood ambience of good will remained friendly and pleasant. Kids involved in minor disputes handled them amicably and constructively with minimal intervention. Davon and Rellvin fought over dividing up the produce of watermelons and squash they had planted, but a conversation with their mothers quickly resolved the dispute. Keisha, a neighborhood girl who hadn't been involved in gardening, outraged the other kids when she pulled all the plants in one of the beds and threw them in the compost heap. The kids retrieved the plants from the compost and replanted them successfully, threatening to "teach Keisha a lesson." A family-to-family conversation resolved the problem when Keisha came with her dad to apologize to the group, explaining that she felt ostracized by the "garden kids." A group of kids (still unidentified but thought to be from another neighborhood) found their way into the toolshed one Halloween and used the stored paint to add seasonal decoration to the walls of the shed – nothing destructive or malicious, but done without permission from adults who responded by organizing more gardening activities open to any children who showed up. These small incidents demonstrated that neighborhood disputes are normal situations that adults can help resolve peacefully.

The Boys Under My Deck

Simmering below the surface, the social and economic structures of Jonestown daily life subtly but relentlessly reinforce the message that freedom, opportunity, and prosperity are readily available – but not so much for poor people of color. How is it possible, then, for young people of color to construct prosocial identities and

behaviors? How is it possible for them believe in and commit to American ideals of freedom and opportunity when they cannot count on basic rights of safety and respect for their human dignity? How is it possible to believe in a remote and inaccessible government when a gang member offers money for food and shows up at a grandmother's funeral? How is it possible to trust a trigger-happy police force eager to arrest them for hanging out in front of a corner store? How is it possible to feel safe in a city that doesn't protect them? How is it possible to feel unsafe and devalued and also function as productive members of society?

Remarkably, despite these moral dilemmas, most of the kids in Jonestown believe in their country, their city, and in their own futures and look for ways to turn their hopes into reality. Over the years, several of the neighborhood boys – Antwon, Davon, Kevin, DaShawn, Rellvin, Travis, Dante, and their friends – started hanging out under my deck and in the garden next to my house. Through many friendly conversations, I got to know these boys – especially from the hundreds of overheard conversations they had among themselves while I was sitting on my deck alone, reading or working. I had known some of them as small boys taking care of the pumpkins and watermelons they had planted in the garden. We had ongoing conversations about what was going on in the neighborhood, how they were doing at school, what was happening with their families, girls they liked, rap songs they were creating, and whatnot. Usually they would greet me when they arrived and then go on about their business, probably forgetting that I could hear every word they are saying. The boys were (and are) well-behaved, courteous, and occasionally helpful, but sometimes there would be incidents – fights, pranks, or accidents – that prompted more pointed discussions about social rules for keeping the space safe. Charged with the responsibility for formulating and enforcing rules for good behavior, the boys would deliberate with me and among themselves about what society expects of them, what they expect of themselves, and what kind of men they were trying to be. The rules evolved to cover fighting, rowdiness, noise, tidying up, respecting property, sex (don't ask), smoking so much weed that I could smell it in my house, and looking after the younger children and senior citizens in the neighborhood. We acknowledged milestones – going off to high school, making the football team, getting a part-time job – and dreams – graduating from high school, going to college, inventing an app, getting a good job, owning a business, or buying a house.

Like most adolescents, the boys created a space for themselves where they were free from strictures of home, school, and organized activities. Unlike more affluent adolescents, however, they had few options for free space: Lack of spending money; single mothers who (perhaps wisely) did not allow teens in their homes while they are at work or entertaining guests; recreational centers and after school programs requiring signed permission slips from parents who may be too busy, distracted, or just unavailable; gangs and police patrolling the streets for loitering kids. They spoke with clear-eyed optimism about being Black in Baltimore and I shared their confidence in their ability to navigate the treacherous moral terrain of growing up to be decent, capable young men with a bright future.

The Moral Crisis of Freddie Gray

Then, in 2015, the citywide post-Freddie Gray uptick in shootings, murders, and assaults triggered a neighborhood reaction of hypervigilance among Jonestown homeowners – white and Black – and I worried about how the boys under my deck would fare and the choices they would make in a street culture that was suddenly much more risky and threatening. Freddie Gray’s death was one of the racially violent incidents across the country that evoked “Black Lives Matter.” In Baltimore, it ultimately resulted in a federal investigation of police conduct and a court injunction against racially abusive practices by the police department. Although no evidence linked the boys in our neighborhood to criminal activity, rancorous rhetoric and suspicion peppered the homeowner email chain and website bulletin board. The boys suddenly became a threat. Regular calls to the police brought a more visible police presence. A friendly corner dry cleaning shop relocated to a different area of the city, replaced by a convenience store with barred windows and a plexiglass cage for the cash register attendant. Homeowners worried in conversations and social media about “thugs” and “juvenile delinquents”⁵ hanging out in the community garden and called for stringent rules to regulate use of the garden.

At some point in late 2015 I began getting belligerent emails and text messages from homeowners about the boys under my deck. They urged me to call the police because the boys were smoking weed. They accused me of harboring criminals. They told me the space under my deck was becoming a juvenile delinquent magnet that threatened the community. They implored me to stand with the community against the threat of violence and threats from the boys under my deck. At first, I queried the veracity and motivation for the complaints: Did you actually see these kids committing illegal acts? What, specifically, were they doing? Have you seen these kids involved in illegal activities anywhere else in the neighborhood? I queried the boys: Have you been involved in anything dangerous or illegal? What about your friends? Do you know that some of the neighbors are bothered by the fact that you are hanging out under my deck? What do you think about that? What should we do about it?

These conversations were not very productive, but I did learn from the boys that doing just about anything in public “while Black” had become even more dangerous and that hanging out under my deck was a safe space. They were frustrated but unsurprised by complaints from the neighbors. They were being harassed by the police, the gangs, and even some of the more aggressively paranoid neighbors whenever they gathered in a public space. They spent several hours a day in school, at part-time jobs, hustling for jobs, or helping care for grandparents or siblings. With little money, lots of time, and no welcoming place in the neighborhood to hang out, they liked the space under my deck. I decided that, whatever my neighbors

⁵These terms reflect escalating use of racially coded language among homeowners describing young men and boys hanging out in the neighborhood.

might think or do, the boys needed the space under my deck and I needed even more to share it with them since the culture had taken such a violently racist turn.

By continuing to welcome the boys and offering them a safe space under my deck, I incurred the wrath and retaliation of some homeowners – definitely a minority, but very vocal – who blocked me from neighborhood email and text chains branding me as a danger to the neighborhood. The ensuing months of almost daily encounters with the vigilante homeowners and the boys themselves were opportunities for substantive conversations about bias, race, inequality, and the rights and responsibilities of becoming adults in a complex urban society. The boys (perhaps not surprisingly) were more resilient and adaptive than some of the adults eager to criminalize adolescents they didn't even know. A couple of the most volatile Jonestown homeowners moved away and the neighborhood has settled down, although the level of racialized street violence in the city has remained dangerously high. This has turned out to be a never-ending story that could be happening in any city neighborhood where wealth and privilege live alongside poverty and disadvantage.

Lessons Learned from the Boys Under My Deck

Five years after Freddie Gray, there are new boys under my deck and in the garden. Antwon, Davon, Kevin, DaShawn, Rellvin, Travis, Dante, and their friends are now young men who have moved on to jobs, college, girlfriends, kids, and other neighborhoods. They stop by from time to time to check in, share news, and chat. From what they tell me, despite worries about the coronavirus, they are happy and hopeful about their lives and their futures. I'm still holding my breath – their future as young Black men is risky and uncertain – but so far, they have avoided prison and death by violence or overdose.

I have learned powerful lessons about social determinants and the equity lens in building a culture of health – not only an abstraction about a world “out there” that barely touches the daily lives of professional people crafting and implementing policy, but as a practice of moral repair in rebuilding fractured relationships.⁶ Racialized violence is a structural problem in American society for which we all bear responsibility. An equity lens on health and wellbeing urges us to seek moral repair through deeper understanding of racialized violence and its health impact on people of color in our communities, but also on the privileged, affluent people who

⁶Margaret Urban Walker (2006) emphasizes the unavoidable task of repairing damaged relationships, from the most personal betrayals to systemic evils, and the crucial role of wrongdoers in making amends by acknowledging their wrongdoing and initiating reparative action to redress the wrong. Moral repair of race relations depends on white Americans, who bear responsibility for systemic racism and correlative responsibility for acknowledging and redressing the wrong, to take the initiative through their own actions, in daily life of interpersonal relationships and broad social policy, to restore Black American trust and hope in a just society.

dominate the making of policies, norms, and practices. An equity lens enables us to seek moral repair by noticing and calling out racial violence in our everyday lives, listening to the stories of people who have been wronged, repairing the damage, and building relationships that restore justice, respect, and care. Not everyone lives in a neighborhood where the social and economic inequities of health are glaringly evident, but almost all Americans – over 80% of us – live in or near metro areas where racialized injustice threatens people’s health, denies them opportunities, and obstructs their efforts to care for themselves and their families. We all can make choices to be more neighborly, to be more proactive in creating social spaces that protect and nurture people who are vulnerable, to trust and stand with people of color, and to seek justice for people whose need for safety and wellbeing is not adequately recognized or met by the society of which we are a part.

Questions for Discussion

1. What ethical values does this story highlight for you and how did it affect how you think about racism and racialized violence?
2. What role does moral distress play in trapping boys and young men in a culture of racialized violence?
3. What role does privilege and authority play in racial inequity and violence in your community?
4. What was your emotional response to this narrative of Black boys and young men? Did it cause you to think differently about racial inequities and violence in your own personal and professional communities?
5. How can public health play a more active role in addressing the needs of Black and Brown young men and boys caught up in a culture of violence?
6. How might you use the concept of moral repair in your personal and professional life to address issues relating to racial inequity and racialized violence?
7. How would you use this story to begin a community conversation of moral repair and justice for boys and young men whose futures are threatened by racialized violence?

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Chapter 5

Voices of Our Fathers: Narrative (Care) Ethics, Trust and Trustworthiness



David Augustin Hodge

Abstract The United States Public Health Service Syphilis Study at Tuskegee was the longest “medical experiment” in the United States. It was an unethical study that harmed 623 black men and their families in Macon County, Alabama. There were no protocols, no (simple) informed consent, and no end date, but there was deception. These men had no idea they were in a study. They were vulnerable to those who they thought were medical doctors of good-will, assigned to their community to help cure their “bad blood.” This chapter follows the narratives of two men who were victims of the Study, Mr. Charles Pollard and Mr. Herman Shaw, and a venereal disease expert, Dr. John Cutler, who refused to admit that he and his colleagues did anything wrong. Positive results came from the Study. Informed consent and Institutional Review Boards as requirement to medical treatment and human-subjects experiments. Additionally, the Syphilis Study and men in the Study can teach us what it means to involve empathic care in our ethics and how to understand the role of trustworthiness in our values.

Keywords Medical ethics · Public health ethics · Racism · Bioethics · Tuskegee experiment · Charles Pollard · John Cutler · Care ethics · Informed consent

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Public Health Ethics Issue

Between 1932 and 1972, 623 male residents of Macon County, Alabama were selected to participate in what has come to be known as the most pernicious human-subject experiment and public health violation to ever occur in the United States. Rather than the establishment of a protocol to prevent syphilis, the United States Public Health Service (USPHS) named their nefarious study the “Tuskegee Study of Untreated Syphilis in the Negro Male.” Later, many observers justifiably referred to it as “The Tuskegee Experiment” (Jones 1993). Post 1972, the term “experiment” gained traction as a term for unethical medical “studies.” A medical experiment requires written protocols that are consistent with the scientific method. This includes objectives, experimental design, start and end dates, a protocol for peer-review, and ethically (if not yet, legally) informed consent to educate participants on every aspect of the study. Assuredly, the title of the study—*Tuskegee Study of Untreated Syphilis in the Negro Male*—bears witness to the intended consequences: treating and preventing the disease was not essential and promoting health was not a priority. The callous indifference of the USPHS to the human rights of these men and their families resulted in a community in peril for four decades and a nation forced to again grapple with its racist past, like slavery and jim and jane crow institutionalized racism.

This narrative is a unique retrospective focusing on a few of the public health principles that were violated and, consequentially, reformed as a result of the infamous study (hereafter referred to as the USPHS Study or the Study). The USPHS Study has polarized public health conversations for decades, fostering a debate between proponents of the study (the doctors) and opponents the Study (defenders of the human rights of the men and their families). Proponents of the Study argue for its ethical justification as a positive act for the African American community. A positive action (or a positive duty) in moral philosophy is the ethical obligation to *do an act*. A positive duty is an act of beneficence; it is an act of doing good, like keeping promises and truth-telling. On this moral assertion the proponents of the Study hung their metaphorical hat. Based upon historical documents and communication, they apparently believed that their actions were right (and perhaps righteous). They were doing a good act to benefit the black community in Macon County, Alabama and beyond.

A negative action (or a negative duty) in moral philosophy is a prohibition to avoid bad behavior; it is the moral obligation or duty to *not do*; it is the act of refraining. The Ten Commandments, for example, is filled with moral prohibitions: *do not commit murder; do not steal, do not lie or deceive, etc.* With respect to medical doctors, the most prominent prohibition (negative duty) is their duty to *primum non nocere*—*above all, do no harm*. Doctors have an ethical obligation to act upon the negative duty, imbedded in their Hippocratic Oath, to *do no harm*. Assuredly, the proponents of the Study seemingly believed they were acting in accord with both positive moral duties and negative moral duties, but this paper finds that the two narratives—the doctors, represented by John Cutler, and the human-subjects,

represented by Mr. Charles Wesley “Charlie” Pollard and Mr. Herman Shaw—do not comport well ethically.

The opponents of the Study argue that it was a deceptive, unethical and racist act, serving no meritorious purpose. Although Dr. John Cutler, a senior surgeon and the acting chief of the venereal disease program in the USPHS, was not the architect of the Study, he was the head and most outspoken apologist for the Study during the 1960s until it ended in 1972 and remained so until his death in 2003. His words and actions are offered in sanguine contrast to the accepted beliefs of the men in the Study. On the one hand, Cutler unapologetically offers his course of action as a positive duty: “We were dealing with a very important study...to actually improve the quality of care for the black community” (Nova 1993). On the other hand, President William Jefferson Clinton, in his 1997 apology to the men and their families, offers a stark contrast to Cutler: “It was a time when our nation failed to live up to its ideals, when our nation broke the trust with our people that is the very foundation of our democracy” (Clinton 1997). Between the tension of these two views is the lived experiences of African American men and their families. These men witnessed, and were the recipients of, public health at its lowest ethical state.

There are plenty of public health ethics issues associated with this unethical study, but in this paper, we will consider three issues by exploring the dichotomy between Dr. Cutler’s view of the study and the voices of two outspoken men who were participants in the Study and also attended the Presidential Apology: Mr. Charles “Charlie” Pollard and Mr. Herman Shaw. We do not claim that the men in the Study were identical from a socioeconomic or educational perspective, but the story of these two men is illustrative of the Study’s impact on the participants. These three issues are as follows:

1. The failure of the USPHS to protect a very vulnerable African American population, particularly at a time when racist policies, laws and discriminatory energies were overtly practiced;
2. The ethical importance of trustworthiness in public health recommendations and actions;
3. The effect that the legacy of the Study has had on important biomedical studies and clinical trials (e.g. informed consent, institutional review boards and modern public health ethics).

There are other fundamental public health ethics issues requiring consideration: (1) the nature of public health ethics, (2) its overarching principles, and (3) the method in which it is grounded. The primary nature of public health ethics is population based. Therefore, as an applied ethical theory it is often grounded, normatively and metaethically, in utilitarianism. This grounding makes good *prima facie* sense because the strongest justification for utilitarianism is its prioritizing of the needs of the many over the needs of the one, or the few. Utilitarianism endorses sacrificial acts as a good if there are good consequences. However, as a utilitarian approach does not consider the happiness of the minority or consider how empathy and care contribute to overarching happiness, it has no purposeful value to the minority and may (at least theoretically) promote harm over beneficence.

The USPHS Study, operating from this normative public health point of departure, was deceptive because the investigators never told the men they were part of an experiment, study or “sacrifice.” As we will show in our discussion, the men in the Study were lied to. They were deceived into believing that their well-being was important, their healthcare was a priority, and their lives mattered. Inherent in all deceptions is a kind of oppressive mechanism that sways a person’s choice in a way that is often not in their best interest.

It is not presumptive to imagine how the men initially felt about the doctors who were “doctoring” on them (Nova 1993). The men felt that the doctors’ actions were grounded in empathy and care (as most people would assume about their own doctors and nurses)—that they were medical practitioners of high character who genuinely prioritized the men’s well-being. The men had no basis for believing that the vocation “doctor” wasn’t synonymous with “trustworthy caregiver.” It took 40 years before they knew there was an asymmetry between the two. Consequently, based on the initial point of view of the men, a narrative could be constructed that this was a study grounded in normative values. However, in reality, the men were subjected to a misguided utilitarian ethical framework that envisaged them as uneducated Negro “poor country boys” rather than being based on an existential and phenomenological medical value system, what is defined today as empathy and (relational) care ethics, based in virtue and character. In the discussion, we will use this ethics of care framework to contrast the ethical obligation to protect the best interest of the men and their families with the indifference that the USPHS demonstrated.

Background Information

For forty years, 623 black men in Macon, County, Alabama were unknowing participants in a study, orchestrated by the U.S. government, that failed to disclose to them they were in a race-based study to *not treat* their syphilis disease, subjected them to excruciatingly painful spinal “punctures,” surveilled their movements within the United States to ensure they did not receive treatment even when a cure for syphilis was available, and autopsied their bodies.

By the time the Study was terminated in 1972

- 74 of the test subjects were alive,
- 28 had died of syphilis,
- 100 died of related complications,
- 40 of their wives were infected,
- 19 children were born with congenital syphilis (Katz and Warren 2011, xi).

On July 24, 1973, Mr. Pollard, along with Attorney Fred Gray, brought a lawsuit against the government. Jurisdiction was invoked under the Fourth, Fifth, Eighth, Ninth, Thirteenth, and Fourteenth Amendments to the U.S. Constitution; civil rights

laws [42 USC Section 1981; Section 1985 (3); and Section 2000(D)], the Federal Torts Claims Act (28 USC 2671); federal common law; and the Constitution, statutes, and common law of Alabama (Gray 1998, 84).

As described by Attorney Gray, the purpose of the lawsuit was to “...redress grievances by damages and injunctive relief in order to secure for the plaintiffs themselves, and the class they represented, protection against continued or future deprivation of their rights by the defendants. The goal is to get the government’s full attention. Originally, \$1.8 billion in damages was sought for the surviving participants and the heirs of those who had died” (Gray 1998, 84).

In the complaint, Mr. Gray alleged the following facts:

1. *The participants were poor, southern, rural, African Americans, of limited education, who knew nothing of their roles as experimental subjects.*
2. *The Tuskegee syphilis study began in 1932 and was announced by employees of the U.S. public health service as a new health care program beginning in Macon County, Alabama. The notices were circulated throughout the county by mail, and African American schools, and African American churches. Only African Americans were given the notices, and only African American males were subsequently selected to participate in the program.*
3. *The participants were never told that they were being solicited to be used in an experiment.*
4. *The employees of the government purposely did not inform the participants when they were found to have syphilis, and intentionally withheld this information from them.*
5. *The government represented to the participants or gave the impression by words and actions that they were receiving adequate medical treatment for all of their ailments. Such representations and impressions were false and were known to be false by the government. However, each of the participants reasonably believed such representations and participated in experiment for over 40 years.*
6. *The participants were never advised that any of them had syphilis and they were never treated for syphilis.*
7. *The participants never gave the informed consent to be subjects in any such experiment.*
8. *No white persons were solicited or used in the study.*
9. *Those selected will use any program of control genocide solely because of their race and color in violation of their rights, secured by the constitution and laws of the state of Alabama.*
10. *The government exploited the participants in violation of rights guaranteed on the 5th, 9th, 13th, and 14th amendments to the constitution of the United States, and article 1, section six of the Alabama constitution of 1901. Playtest further alleged that they were injured physically and mentally. The afflicted with distress, pain, discomfort, and suffering. Some died as a result of participating in the study (Gray 1998, 87–88).*

In 1974, Attorney Gray was successful at securing a \$10,000,000 settlement which was divided into the following four categories:

1. *Living syphilitics receive \$37,500.*
2. *Heirs of deceased syphilitic’s received \$15,000.*
3. *Living controls received \$16,000.*
4. *Heirs of deceased controls received \$5000 (Gray 1998, 98).*

The Presidential Apology

On May 16, 1997, President Clinton issued a formal apology for the USPHS Syphilis Study (Clinton 1997). In addition, President Clinton made the following commitments to begin rebuilding the trust that the study had violated:

1. At Tuskegee University, a federal grant would be made available to establish a center for bioethics in research and health care;
2. A commitment to community involvement to “begin restoring lost trust;”
3. A commitment to strengthen and increase training in bioethics, nationally.

Despite their advanced age, five of the living Study participants were able to attend the Apology held in the East Room of the White House – Mr. Charles Pollard, Mr. Herman Shaw, Mr. Lester Scott, Mr. Carter Howard, and Mr. Fred Simmons. Mr. Fred Simmons reported that he was 110 years old. Mr. Shaw was less of a stereotypical “country boy” and more of an astute and singular, albeit deeply irritated, autonomous man. Hence, Attorney Fred Gray chose him to represent the men of the Study and their families at the Apology and to introduce the President of the United States.

Approach to the Narrative

In 1973, one year after the termination of the Syphilis Study, Senator Edward Kennedy and the United States Senate held hearings on human experimentation. There were four Study survivors present at the hearing, Mr. Charles Pollard, Mr. Herman Shaw, Mr. Lester Scott, and Mr. Carter Howard. There is greater documentation for Mr. Pollard (who brought the lawsuit) and Mr. Shaw (who served as spokesman for the men at the Presidential apology); therefore, we focus the narrative on these two men. Mr. Charles Pollard saw himself first as a victim, then as a survivor of an unethical force more potent than his “just a country boy” deep South stereotype. Mr. Herman Shaw saw himself as a survivor as well, but he also believed he was treated as “one of the study’s ‘Guinea hogs’” (Reverby 2009, 111).

However, Mr. Pollard’s and Mr. Shaw’s narrative is only partially clear if it is constructed independent of the doctors and system that created and maintained the study for four decades. The men’s interpretation of the Study was constrained by deception, and the doctors’ interpretation of the men was constrained by racism. So, we will first present the voice of Dr. John Cutler, the most vocal defender of the study after it was terminated. It is clear from his voice that he was convinced of the importance of the Study and its ethical congeniality with both positive and negative duties. On the other hand, Mr. Charles Pollard and Mr. Herman Shaw’s narrative resembles the lived experience of the men in the Study. Thus, their narrative is more precisely (and better understood as) a counter-narrative to the background narrative of the doctors. Behind the scenes of the lived experiences of the men of Macon

County, Alabama, the USPHS in Washington, D.C was engaged in pseudoscience and exploitation of black vulnerability.

We reviewed sources from historians, academics, journalists and attorneys who have done an admirable job documenting the Study's human tragedy. The most significant sources for this narrative compilation come from the writings of attorney Fred Gray, two historians (Susan Reverby and James H. Jones), Mr. Pollard and Mr. Shaw's testimony at the 1973 Congressional hearing, a 1993 Nova documentary about the Study (*The Deadly Deception*), and an anthology of the Study published by Reverby in 2000. Cutler's narrative is derived from the same sources.

Dr. John Cutler's Narrative

Dr. John Cutler is on record as the staunchest defender of the Study. Two decades after the Study ended, and five years before the Presidential Apology, Nova broadcast *Deadly Deception*. Obvious from the title is the fact that the producers, along with millions of Americans and others, believed that the "Study" was an act of (fatal) deception. Nevertheless, Cutler's defense of the Study was still quite formidable. The following statements by Cutler from the Nova documentary illustrate his support of the Study:

It was important that they were supposedly untreated, and it would be undesirable to go ahead and use large amounts of penicillin to treat the disease, because you'd interfere with the study (Nova 1993).

We were dealing with a very important study that was going to have the long term results of which was to actually improve the quality of care for the black community—so that these individuals were actually contributing to the work towards the improvement of health toward the black community, rather than simply serving as merely guinea pigs for the Study. And, of course, I was bitterly opposed to cutting off the Study for obvious reasons (Nova 1993).

In 1988, Dr. Cutler co-authored a paper, "Venereal Disease Controlled by Health Department in the Past: Lessons for the Present" which described what he viewed as his and his contemporaries' accomplishments relating to the control syphilis (Cutler and Arnold 1988). Interestingly, the timeline for the successful controlling of syphilis was during the same time period the syphilitic men in the Study were not given care. In fact, they were denied care. In this paper, Cutler and Arnold praise the Surgeon General of the United States, Dr. Thomas Parran, and his work in the eradication of syphilis; they even highlight the need for clear/necessary protocols if syphilis was to be controlled—but they never mention the Study. The following excerpts from the Cutler and Arnold paper describe the work of the USPHS to curtail syphilis:

By the mid-1930s the seriousness of the VD problem was beginning to come back into the medical and public consciousness, primarily because of the leadership of Dr. Thomas Parran who became Surgeon General of the USPHS in 1936, a year in which the USPHS budget for VD control was \$58,000. By then the serious problem of disability, death rates,

and cost of long-term effects of syphilis alone were again evident nationwide. A gradual, well-planned move to reestablish a full-fledged national VD control program began. It is relevant to remind ourselves that the problems Dr. Parran faced then are sharply mirrored in the current public and professional attitudes about AIDS. For instance, because of the planned use of the word "syphilis" in a radio program to be broadcasted nationally, the Surgeon General of the USPHS was denied permission to air a program. However, shortly after this episode, the Reader's Digest was concerned and farsighted enough to publish an article entitled "Why Don't We Stamp Out Syphilis?" which focused national attention on the extent of the problem. There was a highly supportive public response, matched by strong support from the medical and public health communities which were aware of the problem but had been unable to move effectively because of the lack of adequate financial and political support. It should be noted also, as is evident today, that in the period before the resurgence of public interest and availability of governmental funds for research and program implementation, the medical and public health schools and voluntary agencies have been carrying out basic and clinical research on syphilis and gonorrhea as well as public health control studies (Cutler and Arnold 1988, 373).

Cutler and Arnold describe Surgeon General Parran's efforts to revitalize the national VD control program by quoting a 1951 report on the history of the USPHS.

Thus, for the first time in the history of the United States, the Federal government entered into a partnership with the States and Territories for the protection and promotion of the health of the people. For the first time the public health service was on the legal authority cast in the role which it had so long wish to play, that of partner, advisor, practical assistance to the State's health departments, and through them to municipal and local health services to be accomplished with federal aid, and to leave the administration of these activities to the states. Consultant and technical services have been provided for the states in the planning of both general and specific programs. Personnel of the public health service frequently have been assigned to the States upon requests to administer health programs (Williams 1951 as cited in Cutler and Arnold 1988, 373).

Cutler and Arnold emphasize that Parran's VD control program was based on basic public health principles.

The program, inaugurated by Dr. Parran, was based upon the nine basic principles of public health control of syphilis which he had formulated:

- *A trained public health staff,*
- *Case finding and case holding,*
- *Premarital and prenatal serodiagnostic testing,*
- *Diagnostic services available,*
- *Treatment facilities available,*
- *Distribution of drugs for treatment,*
- *Routine serodiagnostic testing,*
- *A scientific information program,*
- *Public education.*

It should be noted that concurrent with the public health concerns about syphilis and the resulting political and public health program responses there had been a highly active and productive research program carried out both nationally through cooperative efforts with the University community and the USPHS and, internationally, through the Health Organization of the League of Nations (Cutler and Arnold 1988, 374).

Cutler and Arnold describe the treatment available for syphilis in the 1940s. However, the men in the study received no treatment.

With the beginning of World War II, the need for large scale application of the shortened, intensive or arsenical-based treatments requiring up to 10 weeks in hospitals was recognized: the increased patient mobility in civilian as well as military populations due to wartime needs cause problems in completing therapy. Starting in 1942, the so-called Rapid Treatment Centers (RTCS) were begun and by 1946 had been established in 35 States and the District of Columbia, most of them under the state health department management but with federal financial support as strong professional cooperation. By 1946 the USPHS had been given congressional responsibility for national administration of the program; \$5 million was appropriated to subsidize the centers and to pay the local general hospitals which were also important resources for treatment—usually local-government administered (Cutler and Arnold 1988, 374).

As pointed out by Dr. George A. Silver in his article “The Infamous Tuskegee Syphilis Study,” Cutler and Arnold never mention the Syphilis Study in their 1988 paper (Silver 1988, 1500). Silver objected to Cutler’s honoring Dr. Parran without honoring or even acknowledging the Study participants. Dr. Cutler’s response to Silver was quite shallow.

I understand and accept Dr. Silver’s feelings about the Tuskegee Study. However, there seem to be no reason to mention or any other study in our article; all of the studies contributed to the program developments which led to the successes of the national VD control program. I hope we can apply the knowledge gained from our past errors as well as our past successes. We need to deal with AIDS in the same nonjudgmental public health manner that made our past accomplishments in the control of gonorrhea and syphilis possible (Cutler 1988, 1500).

Mr. Charles Pollard’s Narrative

Mr. Charles Pollard was born in 1906, 26 years later he was deceived and thrust into history because he was told he had “bad blood,” which was a grab-bag term for an array of anemias, disorders or blood pathogens. The use of this term, sometimes euphemistically, was a deceptive substitute for syphilis, the contractable and potentially fatal venereal disease. Mr. Pollard was involved in the study from its inception to its termination 40 years later. He didn’t know that he was a participant in a study or an “experiment,” but when the story broke about the medical violation taking place in Macon County and Tuskegee, he was approached by journalists, governmental officials and other investigators seeking information.

In 1973, one year after the Study was exposed to the public thanks to the efforts of Bill Jenkins, then a USPHS statistician, and Peter Buxton, a venereal disease interviewer and investigator from San Francisco (Warren et al. 2019a, 643–645; Reverby 2009, 82–83), Mr. Pollard testified before the Health Subcommittee of the Committee of Labor and Public Welfare led by Senator Edward Kennedy. Excerpts of Mr. Pollard’s testimony and his statements from the Nova documentary are presented to illustrate his reflections on the Study.

Mr. Pollard: *I was born in 1906, but in 1933 they said I had bad blood and was working on it. I told the lady how they treated me every year. They treated me*

with a, with a shot—that spinal shot. I don't remember the month it was in 1933, I do remember it was 1933.

Back in 1932, I was going to school back then and they came around and said they wanted to have a clinic blood testing up there. They came around and give us the blood tests. After they give us the blood test, all up there in the community, they said we had bad blood. After then they started giving us the shots and gave us shots for a good long time. I don't remember how long it was. But after they got through those shots they give me a spinal shot. That was along in 1933.

They treat me every year. They would come down and see us every year. Of course, during that time, after I taken that spinal puncture, I wore a rubber belt around my stomach. It had a long strand around it and I would run it around, come back in front and tie it in a bowknot. They used a little ointment or salve that I rubbed on my stomach. I reckon I wore it a year or six months, something like that. After then they would see us once a year up to 25 years.

Senator Kennedy asked Mr. Pollard how he came to know that he was a part of a study.

Mr. Pollard: *The people contacted me in the stockyard...that is where I was working when they contacted me. A heavy built lady contacted me. My 17-year-old grand-boy and me were taking some cows down there for the summer. She came and asked me about Charles Pollard. I told her I didn't know a Charles Pollard, but I knew a Charles Wesley Pollard. She said she had been all over and asked about me but nobody had seen me. But I had been on the payroll bringing cows down there. She told me to get my cows unloaded because she wanted to talk to me, and that is what I did. She asked me wasn't I in a study or a clinic back 40 years ago...I had done forgot about that, but she wanted to know the story of it. So, I told her.*

Senator Kennedy then asked, “Were you a little mad that you were sort of being used in a test that you didn't know about?”

Mr. Pollard: *Well, at that time, you see, I didn't know nothing about it until well after I got back home. I had taken the Birmingham News. I had been taken it for 25 or 35 years. It was there. What I told the lady was in the Birmingham News that evening. So we read it. Got to reading it and talking about black men in Macon County. Of course, the week before then they had told me the news there about 400 or 600 men, whatever it was, the black men of Macon County, but I didn't give it even a thought, until after she told me that. That was on a Tuesday when she saw me.*

I was very busy in Macon County. I participated in many civic functions, one of them was the Macon County Democratic Club. I was a member there for many years, but I never did share with anyone what was going on with me. I just forgot about everything and put it all behind me—until that lady came to the stockyard. I went to Attorney Fred D. Gray and asked him if he read the newspaper article about “bad blood” and how they experimented on me and others for over 40 years. He asked me questions and I told him everything I knew about it.

In response to Senator's Kennedy's inquiry regarding whether the doctors' demonstrated any interest in caring for Mr. Pollard and the other men after the Study ended, Mr. Pollard's recollection was one of abandonment:

Mr. Pollard: *The Government doctors haven't come by lately. I had been visiting a doctor, some individual doctors. Of course, I had a bad case of arthritis last year, in the last week in January. I went to Montgomery to a doctor for a month. He give an X-ray on me then sent me back to the bone specialist in Tuskegee. He doctored on me for about a month and I got on crutches and stayed on them. He finally told me to go back home. If it never did get no worse, don't come back. So I am still taking medicine capsules that he gave me. That was after he gave me that shot.*

As to whether Mr. Pollard was interested in the government doctors given what he came to learn about the Study, he responded to Senator Kennedy,

I don't want no parts of it. I was fixing to say I was fixed to go to Birmingham when the penicillin came out, but the nurse told me I wasn't able to go up there. So they turned me down. I don't want no more part of it."

Twenty years after the Senate hearings, on January 26, 1993, Nova interviewed Mr. Pollard for the documentary, *Deadly Deception*. He was almost 90 years old at this point, but his cognitive and emotional recollection of the events were quite singular:

Mr. Pollard: *And when this first started up, I didn't know nothing—just a country boy, as they say. And when they got down here in Alabama, they found what they wanted—they just went to doctoring on us. And said they gon treat us. They just said 'bad blood.' I thought they were trying to treat and cure my bad blood. They would just give us the pills, and sometimes they would give us a little tablet to put under our tongues for sore throats. Then they would give us the green medicine for a tonic to take after meals.*

It was pretty bad—that spinal tap—course, I did along pretty well with it, but uh ... I stayed in the bed a week or two. After 25 years they gave me \$25—a \$20 and a \$5 bill. Then they gave me a certificate and a picture with six of us on there—“U.S. Public Health Service. This certificate is awarded in grateful recognition of 25 years of participation in the Tuskegee Medical Research Study.” I was glad to get the \$25 and I used it. We would have lunch when we went over to the Veterans Hospital. We would go to the canteen and have lunch. A lot of times I went in my own car and I would help the nurse carry the boys down there some-times, a lot of times. I would always go in my car a lot of times.

In the Nova documentary, speaking about his feelings about the Study, Mr. Pollard quietly said, “*It did make me, you know, I might have said some curse words—when I was by myself—but they ought to have been ashamed of themselves. I wouldn't have did them like that*” (Nova 1993).

Mr. Herman Shaw's Narrative

Mr. Herman Shaw was a resident of Macon County, Alabama. In 1997 when he presented President Bill Clinton to offer the Apology, he was one month shy of his 95th birthday. In 1932 he was a young man with limited education. He had a family but no healthcare, which was not irregular as the country was emerging from the Great Depression. This "Hoover Panic" (as he calls it in his testimony) was a time when families were struggling, and free healthcare was a welcome relief. In the *Deadly Deception* he explains how it was that he unwittingly became involved in the Study:

Mr. Herman Shaw: *The way I heard about it was through a rumor that the people, and this came out of Macon County, said that you can get free medicine for yourself, and things of that kind. And therefore, I went. On that Saturday afternoon when we went over there, they said we would get free medicine, that wouldn't cost us anything and the doctor... We will get free doctoring* (Nova 1993).

At the Senate Hearings, Mr. Shaw was able to very clearly articulate his experience. He was 70 at the time. He expressed his lived experience about how the surveillance program that prevented the men from receiving medical attention from other medical providers.

Mr. Howard Shaw: *For those who are living and remember, and for those who just read about it, in 1932 we began to emerge from what was known as the Hoover panic. We did not have adequate money, in other words, to care for our families. This offer was made in 1932 as free medication known as a blood test. I entered it in 1932 and I was affiliated with it ever since.*

Every four years they would take our blood. They would transport us to the Tuskegee VA hospital and give us a thorough examination. In the late 1940s—I do not remember the exact date—they sent me to Birmingham. We left about two o'clock and we got to Birmingham before dark. They saw nurse roaming through the crowd. She said she had been worried all night. She that she had been looking for a man that was not supposed to be here and his name is Herman Shaw. Naturally I stood up. She said come here. She said what are you doing up here. I said I do not know, they sent me here. They got me a bus and sent me back home. When I notified the nurse of what happened in Macon County, I did not get any response.

Senator Kennedy: *Did you feel during this period you were being cured, that they were looking after your medical needs?*

Mr. Herman Shaw: *I have never had any treatment whatever.*

Senator Kennedy: *What did they tell you when they looked at you blood? Did they tell you it looked good or it looked bad?*

Mr. Shaw: *I just got a slap on the back and they said your good for 100 years. That is all I ever had.*

Senator Kennedy: *How many years have they been slapping you on your back?*

Mr. Shaw: *Forty years. Every year they would give us a white tablet for pain and a little vial—I guess it was some type of tonic. Every year for 40 years up to now, we had two different doctors. We would never get the same doctor back each time. Slap on the back and said I was good for 100 years. I guess it was routine.*

The salience of Mr. Shaw's narrative has been broadly articulated in various spheres since the end of the Study in 1972 until his passing almost three decades later. However, as shown in the following excerpts, no articulation has been clearer than Mr. Shaw's short speech and introduction of President Clinton at the Apology in 1997.

On behalf of all the survivors who are here today, and who could not attend, and on behalf of the heirs of my fellow participants who have died, I wish to thank President Clinton for inviting us to the White House. It has been over 65 years since we entered the program. We are delighted today to close the very tragic and painful chapter in our lives.

We were treated unfairly and to some extent like guinea pigs. We were not pigs. We were not dancing boys as we were projected in the movie, Miss Evers' Boys. We were all hardworking men, not boys, and citizens of the United States. The wounds that were inflicted upon us cannot be undone. I am saddened today to think of those who did not survive and whose families will forever live with the knowledge that their death and suffering was preventable...

This ceremony is important because the damage done by the Tuskegee Study is much deeper than the wounds any of us may have suffered. It speaks to our faith in government and the ability of medical science to serve as a force for good.

In my opinion, it is never too late to work to restore faith and trust. And so, a quarter of century after the Study ended, President Clinton's decision to gather us here; to allow us to finally put this horrible nightmare behind us as a nation, is a most welcomed decision. In order for America to reach its fullest potential we must truly be one America—black, red and white together; trusting each other, caring for each other, and never allowing this kind of tragedy which happened to us in the Tuskegee Study to ever occur again (as cited in Reverby 2000, 572–573).

Discussion

Considering an empathic (relational) care ethical approach is useful for exploring the ethical implications illustrated by the narratives of Mr. Pollard, Mr. Shaw, and Dr. Cutler. Of the possible major approaches (e.g., deontology—focusing on rules and obligations or consequentialism—focusing rightness on outcomes, results), we find that care ethics, is most germane to this narrative. There are critics of care ethics who decry the notion of autonomy in care. They wonder, how can a person be autonomous if she or he is dependent on others? We suspect that Cutler and other study apologists may have relied upon this to defend their heteronomous (i.e.,

patriarchal/matriarchal) approach to ethics. A heteronomous approach fosters a hierarchical belief that another's body can be used with impunity.

Three concepts from care ethics theory are relevant to this discussion. First, as articulated by ethicist Grace Clement, "autonomy cannot be achieved individually. In fact, we learn to become autonomous, and we learn this competency not through isolation from others, but through relationships with others. An individual's autonomy is nurtured through the care of others" (Clement 1998, 24). As illustrated by the title of the Study (...Study of Untreated Syphilis...), the objective of the Study was the opposite of care. Thus, autonomy and agency were either impossible or unlikely. If the men in the Study were in a caring relationship with their "doctors" their autonomy would have been enhanced and respected.

Second, as emphasized by ethicist Michael Slote, empathy and altruism are a critical positive motivation of care (Slote 2007). Slote argues, "empathy is a crucial source and sustainer of altruistic concern or care about (the wellbeing of) others" (Slote 2007, 15). He further argues, "differences in strength or force of empathy makes a difference to how much we care about the fate of others in various different situations" (Slote 2007, 15). Empathy is always other-regarding. Like compassion, it is an emotional response to the needs of others. Correlated with care, empathy motivates an agent to feel for others. And care is an extension from an agent to seek the wellbeing of another. It does not appear that Cutler and his fellow doctors empathized with the men in the Study. By the time Cutler became involved with the study there was a cure for syphilis, but it was withheld from the men.

Third, we can care most if we find ourselves in a relationship with another person, especially if the person has relatable traits or experiences. Mr. Pollard and Mr. Shaw are now dead; nevertheless, their story remains. Empathic care relations have more value if the relationship is based on respect (i.e., they are subject/subject relationships rather than subject/object relationships). We tend to respect others who are our equals far more than those who are simply objects to us. When we listen attentively to another's voice, another's story, as an equal subject, we tend to be intentional and open, and remain committed to the relationship (this is a caring-for and caring-about relationship). Subject/subject relationships are other-regarding and emphasizes difference. Subject/object relationship are often narcissistic, egoistic, and indifferent to othering.

Each life is and has a story. Using a care ethics approach, specifically the provision of empathic care, allows us to see the world through the eyes of others, to understand others' life story. Mr. Pollard and Mr. Shaw's story is a sharing of themselves; it is offering a piece of who they were. As time rolls on Mr. Pollard, Mr. Shaw and the other study participants have become metaphors for human biomedical misappropriation of power and empathic disregard. In life they were disempowered by the powerful, but there is something empowering about the ontological and existential dimensions of these men. These dimensions are contained in their narratives. Their intimate story is offered for the purpose of empowerment rather than (re) exploitation or disempowerment. Mr. Pollard and Mr. Shaw lived their reality without expectation of positive outcomes—(e.g., millions of dollars to Tuskegee University to establish the singular, National Center for Bioethics in Research and

Health Care, public health ethics virtue theory, or public health policy). Their story is one of pain, victimization and survival in community with others who were similarly affected.

There are many themes at work in the narrative: deception, exploitation, remembrance, betrayal and abandonment are among them. Notice Mr. Pollard's statement to the woman investigator who searched him out at the stockyard, "I had done forgot about that, but she wanted to know the story of it. So, I told her." The deception and exploitation was so convincingly thorough that he *forgot* about it. This not remembering speaks to the culture of the South specifically and America more generally. It is the disposition of any oppressed person or group that sees the state as permanent—normal.

There was nothing unusual about the exploitation Mr. Pollard, Mr. Shaw and their fellows faced. For them, their experience of exploitation and apathy was normal; it wasn't strange at all. As a matter of fact, strange would have been demonstrative empathy and care, which is what they were deceived into believing they were receiving. The hard-working black men in Macon County, some of whom were share-croppers, were given less consideration than Al Capone the notorious gangster, murderer, bootlegger and tax evader. In 1942, ten years after the Study began, care ethics was adequately demonstrated on Capone's behalf as he was among the first recipients of penicillin for treatment of syphilis (Smee 2018). Mr. Pollard and Mr. Shaw, and the other Study participants were denied penicillin.

Perhaps if letting these men go untreated for a greater societal good, a clever act-utilitarian could persuade some like Dr. Cutler as to the Study's merit, but with respect to empathy and relational care ethics, there is no version of this tragedy that demonstrates ethical behavior. Experimenting on humans without letting them know, and without their consent, is unethical. The men thought they were patients. Caring about the autonomy and agency of another human being is not negotiable. Receiving and providing empathy and care is what it means to be human. Deception and exploitation are inhumane actions.; they are what it means to be inhumane.

Regarding remembering, Mr. Pollard and Mr. Shaw's memory remained quite singular; they never forgot. A motivating factor in their remembrance was that the deception and exploitation were foundational to betrayal and abandonment. This was evident in two major ways: surveillance of the men to ensure compliance with the USPHS objectives and abandonment of the men when the Study ceased. The government doctors did not offer these men 40 years of "care" for altruistic reasons. They came around for egoistic reasons—their moral compass bent to their own self-interest. This action and attitude were violations of every major normative ethical theory, including deontology, utilitarianism and virtue ethics. When it was no longer in their best interest to offer even minimum care to the men, they abandoned them to find their own medical practitioners. But this abandonment wasn't always the case. For forty years the USPHS paid attention to the men. They established a surveillance system to ensure the men would not receive medical attention from other providers. No empathy was offered to these men as care was denied. The Hippocratic injunction to "do no harm" was an abstract thought for these doctors.

Mr. Pollard and Mr. Shaw's story is an obvious contrast to Dr. John Cutler and other apologists for the study. They failed to see anything wrong with what they were doing. Even the spinal tap was not sufficiently painful to deter its usage, even though it granted no significant positive ends. Cutler is not at all ambivalent about the Syphilis Study. He quite clearly states that the results of the study will improve the quality of care for the black community. He believed that the men were contributing to the improvement of health in the black community and was bitterly opposed to terminating the Study.

On November 6, 1951, Sidney Olansky, Chief of the Division of Venereal Disease Research Laboratory, wrote to Cutler, "Dear John, We agree wholeheartedly with your premises for the validity of the study, your arguments for the importance of this follow-up, and your recommendations for the clinical examination" (Reverby 2000, 99). Cutler's argument that it would be "undesirable" to use "large amounts of penicillin to treat the disease" is in itself a violation of the Hippocratic Oath he vowed to uphold, particularly the stanza, "I will abstain from all intentional wrong-doing and harm, especially from abusing the bodies of man or woman, bond or free." Do no harm is the common phrasing. But in the minds of Cutler and his colleagues, they were not committing harm. For Cutler and his colleagues, "the validity of the study" (i.e., the argument that the Study should be prioritized over all other interpretations) or the cost-benefit calculus of the Study was sacrosanct—it was an investment in something noble, regardless of other interpretations. Olansky continues, "We have an investment of almost 20 years of Division interest, funds and personnel; a responsibility to the survivors both their care and really to prove their willingness to serve, even at the risk of shortening life, as experimental subjects. And finally, a responsibility to add what further we can to the natural history of Syphilis" (Reverby 2000, 100). The proponents of the Study were very clear: the Study was a noble act; there was no ambiguity with respect to their interpretation, even when it meant the direct infliction of pain for no curative end, which is fully in view with Olansky's words to Cutler, "Careful studies of spinal fluid and neuromuscular system are advised."

The Study has had some unintended consequences that continues to reverberate and compromise the health and healthcare of African Americans. One consequence is the distrust the overwhelming majority of African Americans (and other people of color) with the medical and research community. In 2015 less than 5% of African Americans participated in clinical trials (the numbers have increased to 9% in 2019) versus 72% participation of their non-Hispanic white counterpart (Woodcock et al. 2019), even when it is for their positive benefit (Warren et al. 2019b; Hodge 2018). The institutional memory of the USPHS study has been passed down through the black community for decades, leading to distrust for generations and future generations to come. Very few African Americans have taken the time to investigate what really took place, but the power of folklore, anecdotes, and manifest distrust, have resulted in the belief that there is a "site of memory" (Katz and Warren 2011, 29–40). Other historical evidence of medical malpractice and bad faith research has been enough for African Americans to be reluctant to participate in clinical trials. The effect of the Study has had negative public health ramifications far beyond what was anticipated.

No scholarly consensus exists about whether information derived from unethical research practices should be used for positive ends. However, positive effects clearly have resulted from the public revelation that exposed the Study and its aftermath. These positive effects include the establishment of the IRB process in the United States for all human subject research receiving government funding and the enactment of federal regulations governing such research. They also include the establishment of the Tuskegee National Center for Bioethics in Research and Health Care, and the raising of awareness of African Americans of bioethical issues. These regulations and the attention the exposure of the study gave to ethical issues in research shaped public policies and the outlook first of bioethics and subsequently of public health ethics. These positive developments, it should be stressed, were unintended positive consequences of the Study but in no way retroactively justify it.

Certainly, these policies have achieved positive social justice ends; no doubt lives are safer and better off now—but are the safeguards that resulted from the Study sufficient? It is never, I think, wise to believe that, once established, safeguards alone can suffice. New occasions may always arise that tempt researcher to pursue their own agenda in ways that jeopardize the safety and autonomy of research subjects. Therefore, public health ethics needs to remain vigilant and continue to play a role in the regular updating and revision of public health policies.

Questions for Discussion

1. In this narrative, Mr. Charles Pollard and Mr. Herman Shaw are metaphors for other men in the Study. What did Mr. Pollard and Mr. Shaw reveal in this narrative that shows they were not alone in their story?
2. Care ethics is relational, but can it work to undergird public health ethics? How does care factor into what is revealed about the doctors' attitudes?
3. If Mr. Pollard and Mr. Shaw's testimonies are persuasive, what do they persuade you to consider about public health ethics that you've not previously considered?
4. Name the public health violations you identify in Mr. Pollard and Mr. Shaw's narrative; then explain how they are ethical violations.
5. What are some of the modern public health policies derived from Mr. Pollard and Mr. Shaw's testimony and the Syphilis Study?
6. Imagine you had access to the public health ethics policies of the twenty-first century, but you were living in the early twentieth century, how would things have been different?
7. How is care ethics present in this narrative? At what juncture is care present or absent?

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Part III
Public Health Ethics Narratives –
Surveillance and Stigma

Chapter 6

Disclosure of a Participant's HIV Status During a Household Community HIV Testing Project



Leigh Ann Miller, Carin Molchan, Daniel B. Williams, Michael Grasso, Hilma Nangombe, Andrea Low, Adam Wolkon, Jessica Justman, and Ndapewa Hamunime

Abstract The narrative is framed within the context of ways that public health interventions balance the rights of individuals and community when related to infectious diseases. This central example is from a community-based HIV testing program in an area with high HIV prevalence. We describe a breach of confidentiality resulting from an involuntary disclosure of a participant's HIV status. This breach of confidentiality occurs within a family. The narrative considers the respective rights of individuals and community members related to disclosure of HIV status and pays attention to how roles (e.g., health care worker, sexual partner) influence decisions regarding disclosure of someone's HIV status. There were clear testing program guidelines for how, when, and where to disclose HIV status of household members. Standard operating procedures and careful training were meant to protect data confidentiality and privacy of patients. In practice, things were messier and less clear. The narrative describes how this confidentiality breach occurred, what was

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done to ensure the participant was safe after the fact and ways to amend the breach on a systems level.

Keywords HIV disclosure · Confidentiality breach · HIV testing · Stigma · Discrimination · Informed consent

Public Health Ethics Issue

The ethical issues underlying our narrative relate to disclosure of human immunodeficiency virus (HIV) status and protection of privacy and confidentiality in public health programs. Public health officials have duties both to protect privacy and confidentiality and to safeguard the public's health by making efforts to prevent diseases. Our narrative portrays the challenge of these ethical issues in the context of a community household HIV testing project that employed a variety of staff members. One of the lessons learned from this narrative involves appropriate training for staff to ensure they understand their duties and responsibilities.

Background Information

HIV disclosure refers to the process of revealing a person's HIV status, either positive or negative. Persons are free to disclose their HIV status voluntarily, but involuntary disclosure occurs when a person discloses another person's HIV status without that person's permission. HIV disclosure involves peoples' attitudes, emotions and behaviors, which can impact disease spread. It plays a presumed role in preventing transmission on the assumption that people aware of their HIV-positive status will not intentionally infect others. At the same time, disclosure of their status puts individuals at potential risk for stigma and discrimination (Obermeyer et al. 2011, 1011; Bott and Obermeyer 2013, S11). This risk may discourage individuals from voluntarily disclosing their status, while the fear of involuntary disclosure may discourage them from seeking testing or treatment.

In a 2011 review from 231 sources globally, Obermeyer, et al. found most persons living with HIV disclose their HIV positive status (Obermeyer et al. 2011, 1011). Women more likely will share their HIV status than men. Both men and women are more likely to disclose their HIV status to a woman than to a man. In sub-Saharan Africa, 26 studies show 65% of men and 73% of women disclosed their status. Disclosure closely correlates with expectations of emotional, social or financial support. It occurs more commonly with relatives than with friends, and partner disclosure is higher with steady partners than with casual partners (Obermeyer et al. 2011, 1014). Involuntary disclosure can take many forms. Health care workers may disclose a patient's status inadvertently due to circumstances (e.g. lack of private spaces). Conversely, it may be intentional when related to a desire to protect another

person (e.g. sexual partner) from becoming infected. Involuntary disclosure may also be malicious, when someone has access to HIV test results and uses this information to hurt, threaten or punish a person.

Gender differences matter in HIV disclosure, notably in the sub-Saharan Africa setting for our narrative. Women there more often undergo testing for HIV than men, largely because routine testing for HIV occurs during antenatal care. They also suffer more negative consequences after testing HIV-positive due to their vulnerable status (Bott and Obermeyer 2013, S10). In much of sub-Saharan Africa, “women’s economic and social vulnerability relative to men, fear of rejection, abandonment or violence by partners remain a major barrier to both testing and disclosure” (Bott and Obermeyer 2013, S10). Further findings in the United States show that rural women especially dread having their community learn of their HIV status (Sowell et al. 2003, 32). The triple burden of being female, living in a rural area, and having low socio-economic status create impediments to HIV disclosure. Despite this, women still more often disclose their HIV status than men (Obermeyer et al. 2011, 1012).

The complex and fraught issues surrounding disclosure raise many potential conflicts between competing values such as individual and community values (Obermeyer et al. 2011, 1014–1015; Bott and Obermeyer 2013, S11–S13). For example, persons who use drugs and share injecting equipment arguably have as much right to be informed and protected from contracting HIV as people living with HIV have a right to privacy protection (UNAIDS 2013, 23). Both the right to be informed and the right to privacy derive from the principles of autonomy and respect for persons, which both apply equally to individuals. Public health practitioners often must confront tensions between their duty to protect the community, including sexual partners and others, and the claims of individuals to privacy. These tensions can come to a head in situations where non-disclosure of an individual’s HIV status could contribute to disease spread. Laws have been enacted that criminalize non-disclosure of HIV status due to its potential to seriously harm others. As of 2018, 26 U.S. states had laws that criminalize HIV exposure, 19 that require persons aware of their HIV status to disclose it to sexual partners, and 12 that require disclosure to needle-sharing partners (Centers for Disease Control and Prevention 2019). UNAIDS (2013) has expressed “serious concerns about the nature and impact of criminalization of HIV non-disclosure, exposure and transmission.” They point to three main concerns: (1) science and medical knowledge do not support them, (2) they disregard standard criminal law principles and (3) their resultant disproportionately harsh sentences are counterproductive (UNAIDS 2013, 7).

In countries with high HIV prevalence where control of the epidemic has almost been attained, multiple public health efforts are often underway to identify new positive cases of HIV infection (Kim et al. 2019, 2–3; UNAIDS 2020). These include case-based surveillance, HIV recency testing, and index partner testing. HIV recency testing uses a lab algorithm to detect if the infection is new (acquired within past 6 months). These strategies use of a series of detailed questions or lab tests to learn more about how people newly diagnosed with HIV became infected. In implementing these strategies, public health officials must balance privacy protections for individuals with a larger goal of community health. For instance, with

index partner testing, people living with HIV disclose names of their sexual partner(s) to healthcare workers. Those workers then attempt to contact the partner(s) and offer an HIV test. Collecting such personally identifying information serves dual purposes: preventing HIV spread among sexual partners and ending HIV transmission in the larger community. These dual purposes, however, generate some level of conflict between an individual's right to privacy and the greater goal of stopping the spread of HIV (APHA 2019, 8). That is because revealing HIV status contains some risk of inappropriate disclosure and stigmatization.

Several considerations for ethical analysis from the *Public Health Code of Ethics* are especially relevant to our narrative (APHA 2019, 9). The first two considerations, accountability and transparency, are important preconditions for successful public health intervention. These create the support, cooperation and trust required from individuals and communities to implement public health interventions. That applies to the context of our narrative, a community household HIV testing project. Our narrative also indirectly suggests how ethical breaches left uncorrected could easily undermine trust and the ability of public health to conduct future projects collaboratively with communities.

The third consideration, permissibility, asks us to consider whether an action would be "ethically wrong, even if it were to have a good outcome" (APHA 2019, 7). This consideration applies, for example, to index partner testing, which aims at the desirable outcome of reducing HIV transmission. The question is whether doing such testing would violate some other value, right, or rule that would make it impermissible. Disclosing the names of sexual partners intrudes on these partners' privacy, something people generally value and try to protect. Strict protocols, however, limit how practitioners can use this information, so that it remains confidential. Ethical analysis suggests that under these protocols, index partner testing results in a permissible trade off. In this case, the benefits both to the sexual partners and society at large presumably outweigh the potential harm to these partners. However, our narrative raises the more ethically fraught issue of permissibility via an event that occurs in the context of a public health program. The event occurred despite protocol and program guidance intended to protect participants.

That same event, which involves a project staff member's involuntary disclosure of a woman's HIV status, also implicates a fourth consideration, respect. This demands that we consider whether a proposed action would be "demeaning or disrespectful to individuals and communities even if it benefited their health" (APHA 2019, 8). In an ethical sense, respect should apply equally to everyone regardless of status, though respecting everyone's rights equally can prove challenging. This holds true especially where privilege, power, or patriarchy override respect for the rights of women, the underprivileged, or community members who are subject to stigma. As with permissibility, ethical assessment becomes more difficult when an ethically suspect action benefits others, especially a person who is disrespected.

The *Public Health Code of Ethics* also gives guidance for specific functional domains of action in policy and practice, three of which are especially relevant to our narrative (APHA 2019, 11). Domain 1 refers to conducting and disseminating assessments focused on population health status and public health issues facing the

community (APHA 2019, 11). A duty to protect community health and prevent the spread of disease where HIV is common entails conducting community assessments of the prevalence of disease. The guidance recommends that safeguards be in place so that information gathered does not harm individuals or communities. In the small, rural community setting of our narrative, protecting the privacy and confidentiality of individuals when gathering data is especially important.

Domain 8 calls for maintaining a competent public health workforce, which entails providing ongoing training in all relevant areas (APHA 2019, 24). The main event of our narrative involves a staff member of the logistics team whose lack of training results in a breach of protocol. Finally, domain 9 calls for evaluation and continuous improvement of processes, programs, and interventions (APHA 2019, 25). Especially when breaches occur, it is crucial to engage a wide variety of stakeholders in the improvement process. It is helpful to develop a strategy involving measurable goals for improvement and regular reviews of processes to ensure continuous improvement and minimize lapses. Such breaches and the response to them also raise issues of responsibility and accountability.

Approach to the Narrative

In this narrative we describe a breach of confidentiality resulting from an involuntary disclosure of HIV status. The breach loosely follows similar events that have occurred during implementation of household HIV testing and counseling efforts by field teams who received cadre-specific training. Countries where community-based household HIV testing has been performed usually have generalized HIV epidemics where up to one out of every four people live with HIV (WHO 2016). Staff training generally includes clear guidelines regarding disclosing HIV status and information on how to protect data confidentiality and client privacy. In some instances, not all team members receive this training, notably non-technical staff (e.g., drivers, logistics managers). As this story is a composite informed by the types of challenges occurring in various situations and settings, the details are fictional, including names. As you read this narrative, we suggest that you consider the respective rights of individuals and community members as they relate to disclosure of HIV status and pay attention to how roles (e.g. health care worker, sexual partner) influence decisions regarding disclosure of someone's HIV status.

Narrative

What Maria enjoyed most while driving was the hospitality of people in an otherwise inhospitable land. As she drove the long, empty stretches separating towns, she felt strongly connected to the people of her country and deeply satisfied with this position. Maria drove a large van for HIV testing and counseling team members that

promised to reach many households with HIV testing and referrals to medical or other services for those who needed them. She took her responsibilities seriously to convey the team (counselors, nurses, etc.) and to unload carefully the equipment needed for each household. The job also gave the naturally social Maria an excuse to travel, something she liked nearly as much as she enjoyed chatting with colleagues, local shopkeepers, and even the household members. Within weeks of joining the team, Maria started to become an expert on the local weather's effect on crops, restaurants with the tastiest food, and shops with the most reasonably priced yet exotic items. Her ability to blend in like a local, no matter the town, filled her with pride.

On this day, on the second stop of the afternoon, Maria was just shy of dozing off in the van. A household member who had completed testing wandered out for some fresh air, while the remainder of the team stayed inside. She stretched out her hand and greeted "I'm Aunt Pauline." Maria didn't say anything but wondered why the woman referred to herself as Aunt Pauline. She soon learned, the household members were Uncle Elijah, his wife Aunt Pauline, their 23-year-old niece, Kandy, and her infant. Everyone now referred to her as Aunt Pauline because family life revolved around Kandy and her baby. Aunt Pauline, tall and welcoming with an engaging disposition had firmly shaken Maria's hand. Maria, welcoming the distraction, stepped out of the van and said, "Pleased to meet you, I'm Maria, the team's driver."

"Say Maria, those are some shoes you've got on," remarked Aunt Pauline. "Yes, they are. They're custom-made leather shoes I just picked up last week, not far from here." Her shoes were becoming a great source of pride as they drew attention from everyone. "Well, I expect you won't be holding out on me. Was the shop expensive?" "Truth be told, it's a real find. Every pair is hand-made, and the man who runs the place has been in business nearly 8 years. Pays real attention to detail, but he struggles to compete with retail prices. I actually wondered if he was selling these at a loss." Aunt Pauline insisted Maria give her details about the shoemaker. Honestly, Maria could not remember so they exchanged phone numbers so she could relay the shoemaker's contact information once she returned home.

Meanwhile, Werner, a counselor with the team, was talking with Uncle Elijah and his niece. Werner first sat Uncle Elijah and later Kandy down on a chair in the most private corner of the kitchen, opposite the open doorway that led from that room into the next. After being counseled, Uncle Elijah and then Kandy placed her copy of the informed consent form on the counter within easy reach. The two alternated being interviewed by Werner and caring for the baby in the other room. It was long, yet the counseling process didn't seem to bother the family. There was a nice rhythm to the whole affair.

After the counseling was complete, Werner mentioned it was time for the HIV testing portion of the visit. He introduced Festus, the nurse. Festus indicated that if Kandy were interested and willing, the baby could also receive an HIV test. Kandy eagerly agreed. It meant she could avoid the inconvenience of getting to the noisy, crowded and somewhat remote health clinic. Next, Festus returned with Aunt Pauline to the kitchen corner to review the consent process, provide pre-test

counseling, and explain how a HIV rapid test is conducted. He then described what the results would mean, clarifying how a positive test result for HIV would lead to a referral for treatment at a nearby health clinic.

By the time Kandy's turn came to be tested, her confidence had drained. She peppered the nurse Festus with questions. "Will Aunt Pauline and Uncle Elijah know our results? Is there any chance the test is wrong? Are you going to use a needle on the baby?" Festus, used to such questions, reassuringly answered, "Your results, and your baby's results, will not be shared with anyone else in the household. The test is very accurate, but there is a small chance that it could be wrong, or inconclusive. The laboratory performs quality control on its specimens, and we will ensure that you are notified of your result, if it is different from what you are told today." Lastly, Festus pulled out a small lancet and assured Kandy that the collection procedure was quick, and although her daughter would feel a prick in her foot, it was hardly anything she'd remember.

Festus, carefully followed the standard procedures and handed each household member their individual result. Uncle Elijah, Aunt Pauline, and the baby all tested HIV-negative, but Kandy tested HIV-positive. Festus privately shared with Kandy information about her diagnosis, where treatment was available, and how to prevent transmission of HIV to her baby.

Since it was time to go, the team piled into the van after saying good-bye to the family. Werner and Festus had to be dropped off at another household where their work conducting counseling and testing would continue, but Maria went for a meal. She had asked where to get good food at a reasonable price. The food was just arriving when Maria's phone rang so she stepped away from the table and answered "Hello, this is Maria."

"Maria! This is Aunt Pauline, how's it going?" she asked rhetorically. "Good, good," Maria replied, "but I haven't returned home yet. I can't get the shoe shop details until then. I'll be at least another five days on the road doing testing." "I'm not calling about that, actually. I'm calling to let you know that your team didn't provide my niece a copy of her result. When I went through her papers, she's only got a copy of her consent form. She insists that it's not a big deal, but I feel otherwise. I don't want her test results floating around in your van. That wouldn't be professional." This seemed an understandable concern to Maria, who wanted to support the team. "Listen, Pauline, I'm sorry to hear that. I'm sure it's just a misunderstanding. Why don't you give me a chance to chat with the team?"

Maria dialed Werner but got no answer. Likely, he was conducting another counseling session. Her next move was to contact Festus. It was he, after all, who had conducted the tests. "I did the consent and the counseling appropriately," Festus retorted defensively, "and I definitely gave Kandy her results. I surely remember that because she was the only one in the household that tested HIV positive. That's probably why she's not sharing them with her Aunt," she speculated. "Yeah," agreed Maria with some sympathy, "that's tough news to take." Maria generally didn't imagine what it's like to learn that kind of news. "Devastating," he said. Festus added "I just felt happy that the baby is OK. I worry for the baby whenever the mother tests positive. It's a good thing this project includes HIV testing for all

family members. We can prevent the spread when more people know their status and get onto treatment.”

Later, Aunt Pauline called again. “Pauline, how’s your evening finding you?” Maria began. “It’s good, but I’m still feeling quite uneasy. I was hoping you could tell me if you found out any information? I’m wondering if the team can provide my niece with her result. It seems that we should have that in-hand before you move on to your next place. I don’t want you leaving and forgetting to come back with it.”

“Yeah, so about that. I called the nurse to find out what had gone on. He told me that Kandy should have the paper in hand. It’s some tough news, Auntie. The baby is good, but Kandy is not OK. That might be why she doesn’t want to share the news. She needs to go to the clinic and start taking treatment for HIV.” “I cannot believe this!” interrupted Kandy, sputtering through closed teeth and a clenched jaw. Only then did it become apparent to Maria that the phone had been on speaker. “Festus promised to keep my status a secret! He told me that no one else would know, but you betrayed my privacy.” Maria could hear Kandy’s voice soften, then break into tears. At that moment, Maria wasn’t sure what to say. Her apology fell short, even as it was leaving her mouth. She hung up the phone and dialed Werner to let him know what had happened.

Soon after, Festus returned to the household to apologize to Kandy. Festus asked whether Kandy felt safe staying in the home and whether there was anything the team could do at this time. “I feel safe enough to stay here. It’s my home. I just wish I could have had a chance to break the news in my own time” is all Kandy said.

Festus, Werner and Maria notified their supervisor about what happened and how Kandy responded. The supervisor suspended Maria and Festus from further work and alerted the project leads about the breach of confidentiality. Festus subsequently resigned from the project because he had violated the country’s nursing code by disclosing a client’s HIV status. Maria requested an official hearing on the matter, as allowed under the policies of her organization.

In response to this incident, the project management sent a memo to all teams to remind them of the importance of adhering to confidentiality and privacy guidelines and not to discuss clients’ HIV status or test results with anyone outside the relevant counseling and testing staff. Additionally, they reminded drivers that directly engaging with clients was outside the scope of their work. This restriction included the exchanging of personal information, such as phone numbers, with household members. Project management also distributed a data confidentiality agreement that each driver was asked to review. The agreement stipulated that drivers were not to access or share any private information about clients while performing their jobs. All drivers were required to sign the data confidentiality agreement as a condition of continued employment. Other professional staff already had signed such agreements previously during their initial training for the project.

A week after the disclosure of Kandy’s HIV status, the project leadership arranged a meeting with heads of their organization. They discussed the incident and the need to communicate it to the project oversight committee. They also planned a joint visit to offer support to Kandy.

On the day planned, they drove together to Kandy's home and apologized to her again. They provided her with an update on the disciplinary measures applied, including Maria's suspension and the resignation of the nurse, Festus. Kandy let the team know that her relationships with Uncle Elijah and Aunt Pauline were unaffected, and that she had sought HIV treatment the day after the incident using the referral form that project staff provided. It seemed unlikely that Kandy would forgive the project team's actions anytime soon. The project staff resolved to learn from this mistake and to help educate others, hopefully preventing future incidents like this one.

The project oversight committee convened a hearing for Maria led by a neutral party and attended by representatives from partner organizations. During the hearing, the team supervisor described how the breach of confidentiality happened and how it negatively impacted a client. Maria described her actions and informed the committee how she had learned about a client's HIV status from the nurse, Festus. Maria argued that she could not have shared the information with another family member if someone on the team had not told her the client's HIV test result. Maria further testified how she had not been asked to sign a data confidentiality agreement until *after* the disclosure occurred. The outcome of the review was that Maria received an official warning. She was permitted to return to work with the clear understanding that she never exchanges personal information (e.g. phone numbers) with clients nor discloses confidential information about any clients. For the broader cohort of drivers, they received an additional training module on privacy, confidentiality and other ethics topics.

In summary, during such a household community project addressing a sensitive topic like HIV, ethical issues are bound to arise. This narrative portrays how a serious breach of confidentiality arose from a series of lapses and innocent actions that occurred during project implementation. The driver and a client struck up a friendship and exchanged personal phone numbers because of shared interest in a pair of shoes. This allowed the client to contact the driver, whereas ordinarily clients would only have contact details for staff listed on official materials (e.g. informed consent form). Because they all rode in the same vehicle and spent many hours together while implementing the project, they slipped into conversation about their shared experience. Festus did not weigh the consequences when he disclosed a clients' HIV status to his teammate. Disclosing a clients' HIV status seriously violated the country's nursing code.

During the training period, drivers were considered non-technical staff and did not receive the same level of training in ethical protections as other staff, nor were they required to sign data confidentiality agreements. The supervisor might have anticipated that non-technical staff, such as drivers, can become deeply involved in these projects just by virtue of the time they spend with community members. Drivers may not hold the same status as skilled health workers yet during their work they may have similar access to personally identifiable information. More foresight on the part of the supervisor could have mitigated the risk with appropriate training and the signing of confidentiality agreements for all levels of technical and non-technical staff.

Discussion

There were clear project guidelines for how, when, and where to disclose HIV status of household members. Standard operating procedures and careful training were meant to protect data confidentiality and privacy of patients. In actual practice, things were messier and less clear. Project staff and participants shared spaces for multiple hours with household life going on around them. There was not always a private room with a closed door where project activities could occur. A community member, such as Kandy, with pained emotion or cries after learning her positive HIV result may have been seen or heard by family or other community members who then suspected or learned about the HIV positive status. Because of the project design, it was clear to household members that everyone was being tested for HIV if they gave informed consent. Even though results were only disclosed to the person tested (or in the case of children to the persons who consented on behalf of the child), household members commonly asked one another to share test results. In this way, the benefits of convenience in providing HIV testing services at the household are in tension with returning results privately due to a setting where family members are present.

Questions for Discussion

1. Was the breach of confidentiality something that was likely to happen or easily foreseeable? Should the project supervisors have foreseen this breach could happen?
2. How might the supervisors have prevented the breach, and were their efforts to correct the problem appropriate and sufficient?
3. Why do you think Maria felt compelled to tell Aunt Pauline about her niece's HIV status, along with that of her child?
4. What motives may have led Kandy not to disclose her HIV status to Uncle Elijah and Aunt Pauline? How might her gender have influenced her decision to disclose her HIV status?
5. How might each of the project staff have contributed to the breach in confidentiality and why?
6. There is increased danger of breaches in confidentiality in small communities with high HIV prevalence because community members are more likely to know each other. In a small community setting, how should the dangers and advantages of testing be balanced?
7. How could the project design be improved to provide additional privacy protections for community members?
8. What principles, strategies, or values would you consider in weighing the benefits versus the costs of implementing such improvements?

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Chapter 7

Stories, Stigma and Sequences: HIV Cluster Detection and Response Activities Through a Narrative Ethics Lens



Meg Watson, Emily Michels, Andrew Spieldenner, Leonard W. Ortmann, and Drue H. Barrett

Abstract Viral genetic sequences are generated as part of clinical care to treat people with HIV. Public health practitioners analyze these sequences, reported routinely through surveillance systems as part of disease reporting, to identify and respond to clusters of rapid HIV transmission. The ethical, social, and legal implications of this work have arisen against the backdrop of HIV stigma and amidst efforts to build trust with the HIV community. HIV disproportionately affects persons marginalized because of racism, homophobia, transphobia, or other socially stigmatized behaviors. The compounded effects of HIV and other stigmas result in barriers to care. This narrative explores several issues related to HIV cluster detection and response, including lack of individual consent for HIV surveillance, the collection of HIV genotype data, and the use of these data for public health purposes. Moreover, the potential use of these data for non-public health purposes which are likely to disproportionately impact marginalized populations also underscores the need for

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transparency. The characters in the narrative – public health agency staff and people with HIV – portray these issues from various perspectives. The narrative also illustrates ethical considerations related to public health activities, including a focus on population-level interventions, partnering with communities, and establishing trusting relationships.

Keywords HIV · Genetic sequencing · Emergent technology · Stigma · Informed consent · Data privacy · Surveillance · Population-level intervention · Community trust · Marginalized communities

Public Health Ethics Issue

Emergent technologies create innovative techniques and new insights that hold great potential for improving human life but also can disrupt the status quo. ELSI refers to the ethical, legal, and social implications that can attend these disruptions (Gannett 2019; Greenbaum 2013). One such emergent technology is molecular HIV epidemiology, which medical researchers and epidemiologists have framed in terms of ELSI challenges (Coltart et al. 2018; Mehta et al. 2019). The use of HIV molecular sequences has emerged as an approach to identify clusters of rapid HIV transmission. The use of this technology has raised concerns among HIV advocacy groups and has ethical implications for HIV practitioners.

Viral genetic sequences are generated as part of clinical care to identify potential drug resistance and determine the appropriate drug regimen to treat people with HIV. Public health practitioners analyze these sequences, reported routinely through surveillance systems as part of disease reporting, to identify and respond to clusters of rapid HIV transmission. The ethical, social, and legal implications of this work have arisen against the backdrop of HIV stigma and amidst efforts to build trust with the HIV community.

HIV stigma follows an historic pattern of “othering” people or groups in marginalizing ways that create or increase inequalities (Powell and Menendian 2016). HIV disproportionately affects persons marginalized because of racism, homophobia, transphobia, or other socially stigmatized behaviors, including some deemed criminal (e.g. injecting drugs or engaging in sex work) (Whetten et al. 2006; Arias et al. 2015; Bogart et al. 2019). Many groups disproportionately affected by HIV have experienced historical harms and negative personal experiences when engaging with government programs and medical systems, posing challenges to building and maintaining trust. (Whetten et al. 2006; Arias et al. 2015; Bogart et al. 2019). These compounded effects of HIV and other stigmas result in barriers to care, potentially increase mental and general health issues, and further the feeling of being “less-than” or outside of regular society (Brinkley-Rubinstein 2015).

Additionally, funding for HIV programs indirectly depends on the good will of the larger public, which initially ignored HIV (Padamsee 2020). Several years of

work by advocates and public health agencies – including social marketing campaigns and activism with news media – changed the narrative around HIV and led to increased public understanding that anyone could acquire HIV and consequent increases in funding and resources (Brier 2009). Public support for funding relied, then, on enlightened self-interest, the idea that treating people with HIV also protected the broader public, a strategy that also aligns with a public health perspective. However, addressing ongoing HIV disparities will require a focus on the needs of people with HIV and the social, structural and contextual factors that disproportionately affect their communities (McCree et al. 2016). To people with HIV, a focus on protecting the general public from HIV can seem to downplay the recognition that people with HIV are already experiencing harms; it is akin to telling a Black Lives Matter advocate that “all lives matter” (McClelland et al. 2020; Nelson 2020). Suggesting that society needs to be protected from HIV (and by extension, people with HIV) can seem more like a subtle form of othering than a strategy to build trust (Center for HIV Law and Policy 2019; Kempner 2019). Instead, public health practitioners and clinical practitioners can extend dignity and respect to people with HIV as autonomous persons, to ensure that people feel they are within the “circle of human concern,” thereby fostering collaboration and building trust (Powell and Menendian 2016).

Another challenge to building trust relates to the use of emergent technologies, which alter our activities and environment in ways that foster progress but also disrupt the status quo, including its ethical and legal landscape (Greenbaum 2013). Concerns about the use of HIV sequences have arisen amid the broader context of increasing data collection by public health and national efforts to improve data quality information technology. Big data, artificial intelligence, algorithms created by machine learning, and the use of social media are transforming the potential of data collection both to promote health and to encroach on privacy (Zuboff 2019). This new era of technology necessitates that public health agencies empathically consider how the communities they serve will react to such disruptions and more specifically to privacy concerns. Mouldrem and Smith (2020) have called for a framework of “HIV data justice” through which to consider HIV cluster detection and response. Although the number of individuals potentially adversely impacted by the release of public health data may be small in relation to the benefits of cluster detection in HIV prevention and control efforts, community concerns about expanded data collection, together with lack of control over the collection of personal health data and perceived lack of communication about it, risk undermining trust and reinforce the belief that government and medical systems are putting them in harm’s way.

The sensitivity of HIV data, specifically HIV molecular sequences, raises ethical concerns related to autonomy, specifically to the confidentiality of one’s medical information. HIV sequence data is often considered more sensitive than many other types of viral sequences, for several reasons. First, in the human body, HIV viral sequences are converted from RNA to DNA and become integrated into the genome of people with HIV, leading to challenges finding a cure (though it can be well-controlled) and raising concerns that do not arise with more transient viral

infections (Maldarelli et al. 2014). HIV has historically been more stigmatized than other viral infections, such as influenza, leading to a range of discriminatory actions. In addition, concerns about non-public health uses of HIV data (i.e. as evidence in criminal proceedings) are rooted in the fact that people with HIV can be prosecuted for, or face steeper charges because of, their HIV status. Many states have laws that criminalize or control behaviors that can potentially expose another person to HIV, often including behaviors with effectively no risk of transmitting HIV, like spitting and having sex without disclosing HIV status while virally suppressed (Centers for Disease Control and Prevention 2020a). Other states that do not have specific HIV laws prosecute people with HIV on similar grounds under more general charges, such as assault, or under more general infectious disease laws. In many states, law enforcement officers or prosecutors can request and often obtain – via a court order or subpoena – data on diagnosis, viral load, and other private information (Galletly et al. 2014, 2019; Lazzarini et al. 2013). The degree to which people with HIV are prosecuted under these types of statutes varies widely by state and local jurisdiction, and health department policies play an important role in protecting data (NASTAD 2018).

Several high-profile HIV criminalization cases have raised concerns about these laws among advocates for persons with HIV (Young 2012; Tien 2019). In the same timeframe, the collection and use of molecular HIV data in health departments has expanded, amplifying concerns about the potential use of these data as evidence in HIV transmission cases. The convergence of these issues has galvanized advocates to push back against both HIV criminalization and collection of HIV sequence data. Advocates for people with HIV have called for better data safeguards and greater transparency about the implications of drug resistance testing (Ryan 2018; Center for HIV Law and Policy 2019; Kempner 2019). Advocates are concerned about the potential for criminal and immigration systems to obtain such data from health departments and use it as evidence in criminal justice proceedings or as a basis to disallow immigration (Chung et al. 2019; Ayala et al. 2019; Spieldenner 2020; The Legacy Project 2019; Ryan 2018). Concerns about the potential for these non-public health uses of data held in health departments could have adverse public health implications. For instance, individuals concerned about lack of privacy might avoid seeking testing or follow-up care or might not disclose HIV status to medical providers.

To understand how molecular HIV cluster detection has exacerbated existing ethical and legal challenges, we need to explain how and why molecular HIV sequences have been generated as part of medical care. We also describe the evolution of the use of the sequences from clinical care to their use as a new public health tool.

Background Information

Surveillance, the process of continuously and systematically collecting health-related data, is a core component of public health (World Health Organization 2020; Centers for Disease Control and Prevention 2018). Public health relies on these data to set policymaking priorities, to alert agencies to emerging threats, and to plan, implement, and evaluate programs. Careful consideration of the ethics of public health surveillance helps agencies responsibly implement programs and activities, maintain trust with communities, and balance individual and community perspectives and concerns (World Health Organization 2017).

In the United States, public health agencies have the legal authority and duty to collect and report HIV data for public health purposes from medical and laboratory records. These data are collected without informed consent for the greater societal good to address public health needs, in accordance with the Common Rule (World Health Organization 2017; Lee et al. 2012). Nevertheless, collecting individual-level public health surveillance data frequently raises concerns regarding individual privacy and consent. These concerns are heightened regarding HIV surveillance, because of the stigma and discrimination persons with HIV often face (Fairchild et al. 2007).

CDC, state, and local health departments began collecting data on the syndrome that would later be called AIDS in 1981, and later, on HIV diagnoses and treatment (Centers for Disease Control and Prevention 2019). Many states delayed adoption of reporting of HIV diagnoses because of public concerns around confidentiality and privacy, especially with regard to name-based reporting. Because few effective treatments were available early in the epidemic and the risks of stigma and harm were great, the potential harms of collecting this information outweighed the benefits. Once effective anti-retroviral treatment (ART) became available, the balance began shifting in favor of the benefits of collecting more individual-level information, including names.¹ As state and federal HIV surveillance systems have evolved in scope and technical sophistication, CDC has periodically considered the ethical implications of these developments, including recently for molecular HIV cluster detection and response (Sweeney et al. 2013; Lee et al. 2012; Centers for Disease Control and Prevention 2020b).

Molecular HIV cluster detection and response activities use HIV genotype sequences routinely collected as part of clinical care and public health surveillance to detect very similar HIV sequences. Because HIV evolves over time, changes in the genetic sequence of HIV produce different strains which can sometimes develop drug resistance. To identify appropriate medications for people with HIV and to monitor drug efficacy, clinicians order drug resistance tests, which generate viral genetic sequences (Gunthard et al. 2019). By collecting and analyzing these sequences, public health agencies can identify groups of very similar HIV strains,

¹Names are collected and used for public health response in state and local areas but are not sent to CDC.

which alert the agency to possible rapid transmission and provide opportunities to highlight and address gaps in public health programs. However, cluster analysis also includes highly sensitive information about modes and patterns of transmission, risk behaviors, and the demographics of partners. Detection of a cluster neither implies that persons involved have transmitted HIV directly nor provides conclusive information on the direction of transmission, but suggests common transmission links, whether direct or indirect (e.g. a third person transmitted to both or was the intermediary). Perhaps more importantly, these clusters shed light on much higher HIV transmission rates compared to baseline rates (Oster et al. 2018). Public health practitioners can use this information to identify and address gaps in public health prevention programs.

Approach to the Narrative

This narrative explores several issues related to HIV cluster detection and response. These include the lack of individual consent for HIV surveillance, the collection of HIV genotype data, and the use of these data for beneficial public health purposes. Moreover, the potential use of these data for non-public health purposes also underscores the need for transparency. These potential uses, and concerns about these uses, are likely to disproportionately impact marginalized populations. The characters in the narrative – public health agency staff and people with HIV – portray these issues from various, sometimes opposed, perspectives. The narrative also illustrates how common ground can exist between groups in relation to ethical concerns that arise within the context of traditional public health activities. These activities include public health focusing on population-level interventions rather than on individuals, partnering with communities, and establishing trusting relationships with them.

The following fictionalized narratives² portray a response to an HIV outbreak, first through an email interaction between staff members at two different health departments (Chris and Maria), and then through an online exchange on a public blog post between people with HIV and HIV advocates (Alex and Perry). The choice of the email and blog formats is twofold: one, to demonstrate the existence of narratives in the daily interactions of public health workers and activists that can be sources of ethical insight; two, to highlight the fact that these methods of communication can be ways for both groups to actively incorporate different perspectives into their own rhetoric surrounding the issue. The agency perspective prioritizes preventing HIV transmission and reflects a utilitarian focus on the balance of benefit and harm. The community perspective reflects an ethics of care that focuses on the client's community, an HIV-support network, and the potential harms associated with public health interventions. We have attempted to express the language in the

²All persons and situations described in these narratives are fictional.

vernacular that persons in these roles might use on these communication platforms. It should be noted that not all of the discussion in the narrative aligns with CDC or health department science or terminology, but rather is presented with an intention to convey how these conversations might unfold under informal circumstances.

Both conversations discuss a cluster of rapid HIV transmission among men who have sex with men (MSM) in a small midwestern town. The health department has identified a group of men who share similar HIV genotypes, suggesting rapid transmission. CDC and the state are working with local health departments to respond to the situation as quickly as possible, to prevent continued transmission that might result in an eventual outbreak. This robust public health response does not go unnoticed in the small community, and people start to talk; a local news station even airs a story about the “outbreak”. Many in the community are learning about HIV prevention and surveillance systems for the first time, and some are alarmed. These fictionalized accounts derive in part from previous discussions and online conversations, such as the HIV/AIDS Network Coordination webinar series on HIV Genetic Sequencing,³ CDC’s virtual meeting series on Responsible Use of HIV Cluster Data for Public Health Action,⁴ and the Center for HIV Law and Policy’s webinar⁵ and documents⁶ on the topic. The reader is encouraged, while absorbing these pieces, to call upon examples from their own professional and personal careers that could benefit from the recognition of alternate perspectives and narratives.

Narrative

Emails Between Chris and Maria: Staff Members at Different Health Departments

Hi Maria,

Did you hear about the MSM HIV cluster over here? Very challenging; it’s been keeping us real busy. We need to get the transmission rates under control, fast. It’s starting to create some panic and the governor’s office keeps wanting to know how many new cases have been diagnosed. I’d love to walk you through what we’re already doing and pick your brain for some advice on how to address it.

³HIV/AIDS Network Coordination webinar series on HIV Genetic Sequencing: <https://www.hanc.info/resources/webinars-and-presentations.html>.

⁴Meeting summary: Responsible Use of HIV Cluster Data for Public Health Action: Amplifying Benefits, Minimizing Harms <https://www.cdc.gov/hiv/programresources/guidance/cluster-outbreak/responsible-use.html>.

⁵Center for HIV Law and Policy’s webinar: <https://www.hivlawandpolicy.org/news/webinar-hiv-molecular-surveillance-worth-risk>.

⁶Center for HIV Law and Policy’s documents: <https://www.hivlawandpolicy.org/resources/hiv-molecular-surveillance-worth-risk-center-hiv-law-and-policy-september-2019>.

We're setting up testing sites in neighborhoods where men hook up. That'll help identify the positives, and then we're referring people to treatment or to PrEP⁷ depending on their test results. We're also trying to get local CBOs⁸ to set up testing and education on their end. My boss is meeting with folks at the hospital to push their emergency unit to start routine testing. That's about it. I'm hoping our weekly case counts start leveling off soon, but with the big increase in testing, that might not happen. We just don't know how many cases are out there.

What's driving me crazy and prompting me to write to you is the pushback we're getting from the community. They're suddenly upset we're collecting their personal data – we've been doing it for years! At some of the meetings we've had with community groups, we've been getting wild comments, like “you're collecting our names and blood samples without our permission,” “you're tracking us behind our back,” “next you'll be quarantining us!” Consent for research is on everyone's radar now, so they don't get it that we don't need their consent to collect data to monitor disease. I'm sure they'd be complaining just as loudly if we weren't collecting data and some outbreak caught us by surprise. Then they'd all be screaming if we actually made them come in to sign off on including their data for surveillance.

But now I'm just grumbling. I mean, sure, I agree that people have the right to control what goes on with their personal data (that's why I don't use social media), but we're in the middle of trying to contain this disease. We can't just give veto power on everything we do to the few people who don't want the government to have their lab results. We're open to any solution that everyone can live with, but right now nothing we say or do seems to pacify some of these folks. Meanwhile we have our work cut out for us dealing with the disease and that's our priority.

How have you handled these types of sticky situations before?

Looking forward to your response,

Chris

~

Chris,

Hello. Looks like you have quite the situation. Glad you reached out and am assuming you know I've had similar experiences working with communities toward win-win solutions for all involved. Getting them to understand the why and how of HIV sequences is a real challenge! Literally every term involved sounds stigmatizing or triggers some scary thought... “molecular,” “surveillance,” “cluster,” etc. – we're even doing focus groups now to try and figure out the best way to explain all this!

To address HIV, we need input from people involved, so we can understand what's going on when people are acquiring HIV really quickly. I think that's just it – we have to work *with* communities instead of just on their behalf. Everything you've said is from a public health agency perspective, which is fair, because it's where we sit. Every. Single. Day. (By the way, did you ever get that window office?

⁷Pre-exposure prophylaxis

⁸Community-based organizations

I did not... 😞) Our work comes from a place of desire to help others, which is extremely important. But we have to *also* realize that you and I will never be able to really understand the fear and stigma associated with having HIV. For example, some of your language (“identify all the positives” or “stop the spread of disease”) sounds stigmatizing for many people with HIV. I sincerely hope you don’t speak like that at community meetings. I know we want what’s best for the community’s health, but sometimes our language sounds like we only care about stopping transmission.

I’ve been around long enough to remember the early days, when we didn’t have good treatment available, so we funded community support groups. We don’t do that anymore because we just expect people to take their meds. While our biomedical advances are wonderful, focusing on HIV without a focus on *people* with HIV is part of our problem. Yes, medical advances have made HIV a manageable condition nowadays, but there are still a LOT of issues – lots of people have never heard of PrEP, or don’t believe HIV medications are effective or affordable, for example. General practitioners aren’t always comfortable prescribing PrEP, but people need PrEP *before* they get HIV, so they can’t just go to the infectious disease doc. I’ve heard recent stories of teenagers who have been kicked out of their houses when their parents found out they were diagnosed, not just because of HIV, but because they were gay. Not to mention the side effects of the medications people have to take, and the cost of meds and visits for lab work, check-ups, time off work, etc. Remember when you came back from your mission trip with malaria? Can you imagine having to deal with something like that for the rest of your life?

We want to make sure that as many people as possible understand *why* we’re doing what we’re doing, and if we’re talking down to them, they probably won’t listen. We also need to reassure them about how well-protected their data are, so that they continue to seek medical care and aren’t so afraid of being “tracked” that they forego treatment and testing. As you said, our number one goal is to “stop HIV” but where are the “people” in that goal? For people who already have HIV, we need to stop it from progressing, which helps them and *also* helps stop transmission. We don’t want to scare people away from getting tested or treated. Besides, we really need the community’s input to help us figure out what is going on. Let’s face it... some people are never going to want to come to the health department. We need to be working with folks in the community to help us figure out how to reach people in the way that is right for them.

I think we both know that molecular cluster detection and response can be incredibly useful, but to be honest, we got off to a rocky start here with our community groups because we didn’t introduce it early on or involve them in how we rolled it out. Listening to their concerns and criticisms takes longer up front, for sure, but it’s really important because it will help us create a better and more effective public health program in the long run. And yeah, you might never see perfectly eye-to-eye with some folks, but it’s still *really* important to hear them out and try and understand where they’re coming from.

I encourage you to think about the issue from another viewpoint other than the one with which you're comfortable. We can all benefit from multiple perspectives.

Thanks for reaching out and for being open to new thinking on the issue. I hope you all are able to figure out a solution quickly. Happy to talk more.

Sincerely,
Maria

Blog Posting Between Alex and Perry: Advocates for People with HIV

Blog Post #44 – Consent Concerns and Sneaky Surveillance: Alex

Hi, new and old readers, and friends! As most of you know, I started blogging a few years ago to talk about my diagnosis with friends and family, and my readership grew exponentially (not sure if that's a good thing or a bad thing!!). You've been following my dating escapades, my struggles with doctors and insurance, and my journey from scared, ashamed kid in the HIV clinic to proud and empowered advocate. I think of myself as being pretty well informed about HIV, so I was stunned when the health department had a press conference about an HIV outbreak here. While I was saddened for all the gay men finding out they're now HIV-positive, I was also shocked that there was a new surveillance system that uses my blood from lab tests⁹ without my consent. Just last year, we had an activist speak at our World AIDS Day event about HIV criminalization. He had been put in prison for close to two years because his ex claimed he did not disclose his HIV status. With this new system, could any of the people I've met online use this against me? What if a relationship doesn't work out, and someone decides to get revenge by saying I didn't disclose my status? Could this happen to me or my friends? I didn't know what else to do but blog about it.

I pride myself on being involved. Ever since I was diagnosed, I have shared my journey, my hopes and fears. You read about my first date with Coffeehouse Bear – how scared I was to tell him I had HIV, and how awesome he was about it when I finally worked up the courage. Then, I told you about how crushed I was when we broke up. But thanks to your support and advice, I got back out there. Now I'm on the apps and meeting new guys ... So, what if I don't tell them about my HIV? I mean – I do, but... I'm undetectable, so do I really have to say anything? Don't they have some responsibility to protect themselves? There's PrEP, and condoms, and all sorts of other ways of reducing risk... In this state, if I don't disclose, I've committed a felony. But how do they prove it? They don't. The legal burden is on *me* to

⁹HIV surveillance systems are not new, and do not contain blood specimens. Language here is intended to reflect actual discussions with HIV advocates concerned about HIV molecular detection.

prove I disclosed (maybe I should text them my blog? Or screenshot our Grindr chats?? 😊).

Since I learned about this law, I've gotten a little more nervous meeting new guys. Imagine my surprise to find out that on top of that, our health department has a new way of tracking us, one they've been using for over a year *without informing us*. I've seen it called Molecular HIV Surveillance,¹⁰ although now I think they're using a new name, and it's how they figured out the recent HIV outbreak here is all related.

Now when blood is drawn for HIV testing or treatment, the labs that process the samples report genetic information about my HIV to health departments and the CDC. They say it's for clinical reasons, to find out if I am developing resistance to my meds. But with so many people prosecuted for HIV, even when they didn't transmit, do we really want states collecting this type of information and risking more legal repercussions? Do the police get access to this data? What about the FBI or ICE? We should all think twice before letting our doctors run these tests.

The health department has implemented this new system without consulting us, the people living with HIV most affected by it. Haven't we learned from the early years of ACT UP that the voice of people living with HIV *must* be central to HIV services? Don't they remember, "nothing about us, without us"?? I DEMAND that the health department get feedback from all of us before continuing this potentially damaging and invasive surveillance system, ESPECIALLY in this state where people are in prison for (supposedly) exposing others to HIV (even for things like spitting at a cop, not even sex or drugs).

And, while I'm uncomfortable with the amount of data that's being collected, as a "gainfully employed" white gay guy, I can't imagine what this is doing to other folks with less privilege than me. Case in point: I recently heard news of an HIV outbreak among people who inject drugs in the town where I went to college. Most of the folks involved are experiencing homelessness or unstable housing, and the community there is, shall we say ... less than understanding (in the middle of this outbreak, there's a woman posting live feeds of people coming out of the needle exchange on a local Facebook group...). I'm worried for myself but I'm really talking about this because I fear what this additional surveillance will do to people who are more stigmatized, and less resourced, than me.

~

Blog response: Perry

Hi Alex! I appreciate the work that you do. I've followed your blog for a long time – for my friends who are newly diagnosed, it has been a real life saver. Thank you!!

¹⁰Molecular HIV surveillance refers to collection of HIV sequences. To reflect the response and prevention aspects of this work, CDC currently refers to it as "cluster and outbreak detection and response". However, many advocates still use the MHS terminology.

I do have to say, when I read *this* piece, I couldn't help but think that you might be presenting a "worst-case scenario" that could alarm people. I would hate for people to stop seeing their doctor and getting the medical care they need to thrive with HIV. You and I are undetectable,¹¹ so, for us, the healthcare system is working. And part of that system are our longtime allies at the health department, annoying and imperfect though they may be!!

When I was first diagnosed in the 1990s, I thought my life was over. Sadly, my partner only made it 3 years after diagnosis. It was the health department staff that helped connect us to support groups, and later, to clinics when better meds were available. Through the support groups and my doctors, I have been able to live longer than I thought possible. I see the health department folks at the Pride parade every year, and they put up PrEP ads in our town last year. I don't think it's fair to paint them as total enemies to our community. Maybe if we just reached out to them, they could figure out some way for people who have legitimate fears to opt out of some of the surveillance requirements? Maybe it's naïve to think a conversation could change things, but surely, it's a start?

I'm more worried about people with HIV who aren't getting care, unlike us. I realize this is probably because of other challenges in their lives – I have a younger friend who got diagnosed, and who didn't have health insurance. I gave him rides to the HIV clinic and helped him get enrolled in Ryan White,¹² but I can't do that for everyone. I also worry about the kids who come from farm towns to the "big city" because they want to meet guys, and don't really even think about HIV until they get diagnosed. How do we make sure everybody gets the same acceptable and affordable care that we have benefitted from? If we are a community, we need to think about the ones who do not get a seat at the table, not just ourselves.

Thanks for all you do!

-Perry

Questions for Discussion

Autonomy, confidentiality and consent, beneficence and nonmaleficence, transparency, and respect for persons are key ethical issues at the heart of the divide between advocates, people with HIV, and public health agency leadership and staff. Relative importance of the balance of potential benefits and harms to the individual versus the population presents another level of complexity for the use of sensitive personal data. Advocates often strive for outcomes that center around the needs of people with HIV, from a perspective centered on an ethics of care and justice (protecting the vulnerable, just distribution of resources).

¹¹ People with HIV who are virally suppressed.

¹² Refers to the Health Resources and Services Administration's (HRSA) Ryan White HIV/AIDS Program, which provides a comprehensive system of HIV primary medical care, essential support services, and medications for low-income people with HIV. <https://hab.hrsa.gov/>.

Lastly, respect for persons is important to consider – the narrative of stopping a virus can often seemingly remove the needs of people with HIV from the story.

1. How do these two narratives illustrate similarities and differences in the ways the health officials and people with HIV or their allies consider these ethical issues?
2. Why does the involvement of viral genetic data increase community discomfort?
3. What ethical considerations should public health agencies consider when communicating about and implementing molecular HIV cluster and outbreak detection and response activities to the public?
4. How can public health agencies foster two-way communication with the communities they serve? What mechanisms would allow people with HIV to provide more input into programs that affect them?
5. How do public health officials recognize and address the authority and power dynamics presented in public health/community collaborations?
6. How can agencies and communities work together to establish and build trust? Can there ever be true partnership between agencies and community members?
7. How can this analysis provide insight into future initiatives and expansion of existing efforts?

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Part IV
Public Health Ethics Narratives –
Community Values and the Value of
Community

Chapter 8

Exploring Public Health's Role in Addressing Historical Trauma Among U.S. Indigenous Populations



Danielle R. Gartner and Rachel E. Wilbur

Abstract Despite decades of often well-intentioned work, public health interventions can fail to achieve desired outcomes within Native American communities. These failures may not be due to a lack of motivation on either side. Rather, they stem from a history of colonization which continues to impact the fundamental structure of public health as well as Native American responses to public health intervention. We purport that there are discrepancies between the tools provided in much of public health's core training and the reality and needs of work in Indian Country. These discrepancies, including a fundamental lack of knowledge about historical trauma events and the ways their impacts reverberate through communities, families, and individuals, contribute to continued experiences of health disparities by Native Americans. Using narrative, this paper offers examples of this schism and is followed by four actionable steps that individuals working in settler public health institutions can take when approaching work with Native nations and communities.

Keywords American Indian · Native American · Historical trauma · Narrative · Public health · Colonialism

Public Health Ethics Issue

Despite decades of well-intentioned work, public health interventions can fail to achieve desired outcomes among Native American communities. These failures are not due to a lack of motivation on either side. Rather, they stem from a history of

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colonization which continues to impact the fundamental structure of public health and Native American responses to public health intervention. We purport that there are discrepancies between the tools provided in much of public health's core training and the reality and needs of work in Indian Country. These discrepancies may contribute to continued experiences of health disparities by Native Americans. This paper offers an example of this schism using narrative, followed by actionable steps that individuals working in settler public health institutions can take when approaching work with Native nations and communities, particularly when addressing the impacts of historical trauma events.

Notes on Author Orientation and Terminology

We ask for cultural humility and respect of Indigenous experiences, attitudes, and perspectives both as you read this paper and as you work in Indian Country. We write from the position of Indigenous women who are trained in accordance with mainstream, settler public health. We mention our identity because it profoundly shapes our understanding of the world, including our interpretation and application of public health. In the United States, settler colonization refers to the non-Indigenous power structures and processes that, since European contact, influence how the United States historically and contemporarily functions (Wolfe 1999). While public health has recently made strides towards inclusivity and allyship, we are intentional with our choice of the settler colonial modifier to public health. Public health, as commonly practiced in the United States, is built upon a Western-centric worldview that values positivist science and objectivity, among other characteristics. These foundational values have made it possible for traditional public health to be complicit in processes of colonization, including a history of conducting research *on*, rather than *with*, Indigenous people (Reid et al. 2019; Sherwood 2013). Additionally, we recognize that Indigenous people work in public health and that there are tribal public health departments, however, the conversation around public health's role in addressing historical trauma within an intratribal context is beyond the scope of this paper.

Indigenous people have preferences regarding the terms used to describe themselves and may use terms interchangeably, depending on context. Throughout this paper we use "Native American", "Native", "Indigenous", and at times "Indian", to refer to the first peoples of what is now the United States. With a few exceptions, we cite only Indigenous authors throughout this paper to center and amplify the voice of our communities (Simpson 2017, 37).

Background Information

This section serves as an introduction to the settler colonial origins of public health and historical trauma. It is intended to provide enough background knowledge to grasp the significance and connections between theory, history, and contemporary experiences of health and disease.

Linking Colonialism and Public Health

Both historically and contemporarily, public health has been complicit in processes of colonization, contributing to the persistent adverse physical and psychological health outcomes that pervade Indian Country. This colonial legacy calls for a fundamental shift in the way that public health approaches Native nations. We suggest that, given professional obligations – respecting community values and differences in worldviews, addressing root causes of disease, and acting with transparency (Dillenberg et al. 2002) – public health professionals are responsible for addressing this legacy of colonialism, or at the very least, of seeking to understand and acknowledging the colonial context in which they work. The need for acknowledgement is particularly salient for government-associated public health professionals. Anyone who works for the State may be seen as an actor, or appendage, of the government which dispossessed Indigenous peoples of land, enacted policies of Indigenous erasure, and failed to formally apologize for the aftermath. Government-associated public health professionals, as direct representatives of the State, carry their relationship with the settler State, even if only symbolically, with them into communities.

Links between colonialism and public health have been written about elsewhere (Paradies 2016; Reid et al. 2019). We discuss five relevant links below to highlight the colonial history of public health and demonstrate the ways in which public health is entrenched in systems of oppression (Wilson 2008) and therefore cannot, we believe, be viewed as apolitical. As such, we suggest that the application of public health knowledge cannot be viewed as inherently neutral or value-free. First, early public health efforts focused on disease control in colonizers' homelands thus ensuring that colonizers could survive and settle new lands. Second, scientists helped define racialized hierarchies that identified Indigenous people as less human than those with Western European ancestry. This devaluation smoothed the way for colonial expansion while simultaneously providing justification for federally-sanctioned relocation and genocide (Simpson 2007; Dunbar-Ortiz 2014). Third, public health research stigmatizes by declaring deficits, often using Native

communities as disparity case studies (Smith 2012; Brough et al. 2004). The identification of disparity provides justification for public health intervention (O’Neil et al. 1998). Historically, public health interventions tend to overlook structural causes of disparities and instead target “problematic” behaviors or theorized genetic contributions. Such targeting unwittingly upholds assimilationist and racialist ideologies and, in turn, colonialism (Pacino 2017; Kowal and Paradies 2005; Ehlers et al. 2013) (see Wexler and Gone 2012 for more examples).

Fourth, the public health research legacy with Native peoples primarily consists of data extraction and exploitation for the benefit of Western science and academic careers over Indigenous interests. Such research frequently fails to meaningfully engage tribal communities in the identification of issues, methodology, study design, data analysis, dissemination of findings, intervention development, or appropriate follow up (LaVeaux and Christopher 2009) (for a particularly egregious example, see Pacheco et al. 2013 for a summary). Lastly, public health science values statistics and quantitative approaches over other forms of knowledge generation and dissemination such as ethnographies or oral histories. When sharing information, public health defaults to means of communication that practitioners find most comprehensible: graphs and scientific messaging. Indigenous communities may also value and not readily adopt a biomedical frame or knowledge (Ninomiya et al. 2020). Likewise, Indigenous communities have their own notions of well-being. The combination of these five factors reinforce unequal power dynamics between public health and communities, whether Indigenous or otherwise marginalized, and predispose them to mistrust public health research and interventions.

Current efforts in public health, such as community-based participatory research (CBPR), aim to address some of these concerns. Notably, CBPR places cultural humility at its center and values community expertise in pursuit of shared research goals (Wallerstein et al. 2018). These efforts, however, remain situated in settler-colonial systems of knowledge, limiting their ability to address Indigenous health (Chino and DeBruyn 2006; Simonds and Christopher 2013; LaVeaux and Christopher 2009). Well-intentioned CBPR can also produce unintended consequences that perpetuate cycles of victimization (Kowal and Paradies 2005).

Researchers interested in conducting research with tribal nations and communities would do well to make space for additional epistemologies and follow suggested guidelines laid out by Parker et al. (2019), including framing work within a Native American historical context, reflecting Indigenous moral values, linking Native American cultural considerations to ethical considerations, and providing Indigenous-based ethics tools for decision making. Relatedly, we remind readers that, as federally-recognized tribes are sovereign nations, public health professionals working for government organizations must approach work with tribes in the same way that they would work with a foreign country, and consider research, negotiations, and interventions to be government-to-government interactions. In fact, many tribal nations have their own Institutional Review Board (IRB) that must be consulted before the start of any research project (Kelley et al. 2013).

Historical Trauma as Events and Responses

The narrative we recount involves historical trauma. Though “historical,” the trauma’s impact reverberates into the present, with implications for public health research and practice with Indigenous communities. The concept of historical trauma originated in research on the enduring impacts of the Holocaust (Brave Heart et al. 2011; Weinfeld 1981). It refers to a massive negative group experience that intergenerationally impacts survivors and their families but can also exacerbate contemporary stressors and traumas (Mohatt et al. 2014, 1). In the Indigenous context, trauma specifically includes the shared violent experience of colonization (Brockie et al. 2013). Examples of traumatic events Native peoples in the United States experienced include land loss, forced relocation, and family separation, most notably through child removal policies and forced boarding school enrollment (Dunbar-Ortiz 2014). Some State-sanctioned policies were intentionally genocidal (Ostler 2019). For many, the impact of these events transmitted intergenerationally through both physiological, including epigenetic, and psychological mechanisms, as well as socially, politically, and economically (Brave Heart and DeBruyn 1998; Evans-Campbell 2008; Lajimodiere 2012; Matthews and Phillips 2010; Myhra 2011; Roy et al. 2012; Yehuda et al. 1998). Historical trauma events are associated with historical trauma responses such as increases in mortality and morbidity from heart disease, hypertension, alcohol abuse, depression, and suicidal behavior (Bombay et al. 2014; Brave Heart 1999). Not all historical trauma responses are destructive; some coping responses focus on recognizing signs of resilience and on strengthening and maintaining it (Evans-Campbell 2008).

Approach to the Narrative

This narrative, while intended to serve as an illustrative story, is neither fictional nor anecdotal. Rather, it is first person testimony drawn from the authors’ experiences (Deloria et al. 2018). The people are not characters but beings whose experiences live on and come to life through these retellings. The people in this narrative are a combination of real people, whose names have been changed for privacy, and amalgamations of conference attendees we have interacted with over the years. This narrative is an offering to all our relations. For our readers, it illuminates some of the challenges that may arise when conventional public health is applied to address historical trauma in Indian Country and how public health research in Indian Country can fall short.

Narrative

I never sleep well in hotel beds or, really, ever when traveling. But last night was particularly rough. Anxiousness and uncertainties about this project took over my dream space. They conjured forth palpable doubts about the effectiveness of public health research to serve my people. The sinking pit in my stomach was my body bracing for worlds to collide. My auntie always preached the importance of walking in two worlds: having a strong footing in my Native identity yet knowing how to navigate the mainstream, settler culture. As a white-coding Native, my privilege has allowed me to negotiate when and in what ways to walk these paths. But the unrelenting feeling of doubt has me questioning whether my feet have ever been planted firmly in either. It is tiring. This constant maneuvering exhausts the spirit. One saving thought pierces my anxious state: get coffee!

Hot, black, liquid medicine. This fancy hotel provides a single serving espresso machine. A great invention, indeed, yet so much plastic and waste. Staring at the wall, clutching my hot cup, more anxieties weigh on my mind: limit your coffee intake because cardiovascular disease runs in the family. Avoid eating that immensely carbohydrate-packed bagel on account of impending diabetes. But tomorrow's a new day and modifications can happen then. I probably need this coffee and breakfast; besides, too much thinking and self-criticism so early in what will surely be a long day can't be good for the spirit. It is a chilly morning and the steaming hotel shower helps me wake up and focus. How did my ancestors live through so many cold and dreary mornings like this? Even outside with my bougie \$400 puffy coat I'm chilled. What a chump. My ancestors were badass.

Shu'-shaa-nin--la, Miigwetch, thank you for joining me today and for providing the opportunity to speak with you. I am honored to be able to share the draft of this report with you and hope that it does justice to this topic. I've spent several months pouring over articles, books, and reports to summarize what's out there regarding historical trauma and how its impacts reverberate and persist throughout Indian Country.

Years of training have prepared me for today. With so much time spent in the academy there's a familiarity and comfort to public health research, its ins and outs. But my hands are still shaking. I've given so many presentations. Yet this feels different.

I'm excited to get your feedback. You are leaders in your communities, and I hope that this report is useful to you. If it is not, I hope that you share thoughts on how to improve it because you are the experts. I summarized what has been written in academic texts, but, as you know, these texts provide only a few perspectives and researchers don't speak for you.

Standing at the podium, the anxiety resurfaces and some familiarity also creeps in. These are my people looking back at me, weighing my words and their impact on their experiences, the lives of their family members, and their communities. There is an immense amount of love and acceptance in this room, but despite that, or maybe because of it, even more pressure to do this right. But how? The information I'm presenting is only the tip of the iceberg. It is couched in academic language, methods, and results that are a far cry from the personal experiences that each of the

conference attendees has with historical trauma, experiences that many Native people better articulate as Soul Wound.

As you all know, the removal of Native children to federal boarding schools, starting in the 1870s and continuing through the 1930s is a more recent historical trauma event. At its peak in the early 1900s, up to 25,000 Native youth per year were enrolled in more than 350 boarding schools in twenty-nine states. While the federal boarding school policy ended in the 1930s, independent states and religious organizations continued to run the schools into the 1970s. These programs removed children from their families with the intention of assimilation and eradication through cultural erasure and the disruption of family ties. This review of the research found that the boarding school era is associated with the interruption of traditional parenting techniques and familial roles leading to intergenerational abuse, loss of Indigenous language, systemic poverty, as well as a plethora of mental and physical health problems.

Behind me a slide flashes, showing a graphic on the number of children and families who were impacted by boarding schools. The slide that follows presents cold, impersonal statistics on the ways that boarding school interrupted parenting techniques and knowledge, and the abuse and neglect that sometimes resulted from this. Another slide presents a graph showing the higher incidences of drug and alcohol abuse associated with boarding school attendance, while a fourth is covered by a dizzying list of health impacts which studies have shown result from attendance: epidemics of youth suicide, depression, and anxiety. Tears form in the corners of the eyes of many elders. Breathe. I pause to acknowledge the weight in the room. These statistics are overwhelming, and this information offers nothing new to this audience. While much of this literature was published recently, and the field of historical trauma is considered new and trendy in many academic circles, for people who lived through these events, and have witnessed the impacts directly on themselves and their families, this is old news. The blur of numbers underscores the utter insufficiency of the information I'm presenting. The audience is gracious.

Many of you have personal experience with the boarding schools. Instead of standing up here telling you about them, would anyone like to share your experiences or thoughts?

A younger woman stands up and everyone shifts around to face her, forming an impromptu circle more appropriate for the sharing of stories and knowledge. "My Great Grandmother, Odetta, attended a boarding school. We don't know a lot about her experience because she didn't talk about it. My mother tells me that Odetta and her older sister ran away from the school because they were miserable. She eventually settled in a very small town and then never talked about being Indian. I think she was afraid of being found out, because life would have been harder had people in the town known she was from across the river. I get the sense that Odetta tried to cut ties with her past. My grandmother, Odetta's daughter, remembers visiting her grandparents only once. How much of this fissure was because of her boarding school experience? In some ways, three generations later, I still feel cheated by the schools and what they stole from us. A tribal community claims me, but I didn't grow up with our people's practices and language. When researchers study just one impact of historical trauma, they look at how our history impacts specific health

conditions, but no one talks about the emotional toll, the way that our history impacts every aspect of the way that I live my life each day."

Obligated by my training to adhere to my allotted speaking time, I reclaim the podium. But there is no feeling of nervousness now. I am providing a backdrop and space for the audience to talk about historical trauma. They make it real. A person stands and offers their family's experience.

The boarding schools confuse me a little. I hear about all the bad stuff that happened and I know those schools were terrible. But I remember my great uncle talking about trying to get into a boarding school. He wrote letter after letter to the social workers asking for admittance because he wanted to become a doctor. It never came to fruition, though. This experience makes me think differently. We knew how to use this system to our advantage. Also, I recently came across some of the records that the government kept. They have his letters and also the letters written in response.

Looking around the room, he continues, "They might have your family's stories too. These are ours and we deserve to have them. Come talk with me after and I'll share how I found the letters."

The presentation is no longer mine. My colleagues at the school of public health would think I'm losing the room, but I know that this is more effective than sticking to script. "Thank you for sharing that insight, and like Brenda Childs has said, we're still sorting out the legacy of boarding schools. The emotions are complex and can create tensions. It is rare for public health research to acknowledge this, but we know the boarding schools didn't erase us and that means something."

After pausing to gather some thoughts and noting that we're in Northern California, or as many refer to think of it, land currently called California, I provide a new backdrop for further testimony:

Historical trauma in what would become the United States began with European contact in the 1500s. One instance took place in California, when settlers migrated west, drawn to the southern part of the state by the potential for large cattle ranches, and to the north by newly discovered gold. These settlers were pre-conditioned to hate and fear Native Americans by generations of racist propaganda which portrayed Indians as dangerous and less than human. This perception, combined with the belief that Native Americans failed to use the land to its potential, paved the way for genocidal policies. Settler activities destroyed land and resources through logging, mining, and livestock production, leaving Native Americans to starve whether on or off of newly developed reservations. In order to address conflict between settlers and Natives, the state sanctioned the creation of volunteer militias. These paid militias slaughtered any Native people that they met on the pretext of distributing justice. Bounties, paid by the state, were between twenty-five cents and five dollars for the scalps of Native men, women, and children. Between 1848 and 1900, the Native population of California plummeted from 150,000 individuals to less than 15,000. For those who survived, slavery was a common fate, particularly in the southern part of the state where coerced labor enabled the development of large ranches. Slaves were typically taken as children, with boys sold as manual laborers and girls as domestic help.

This time it is an older woman who stands. Her silver hair curls around her face, and while her eyes are almost hidden in a lifetime of wrinkles, her clothes are immaculate. That blouse is from one of my favorite Native-owned fashion businesses. Good choice. She tells us that she was drawn to come to this conference, her first, because of her desire to understand not only how the traumas of the past may

continue to impact her family, but also how to embrace the strength and resilience of our people in order to heal. As she speaks, she turns to look at those around her, and her voice takes on the well-worn cadence of a story.

This is the story of my ancestors and relatives, as told to me by my mother, Clara Smith. My mother told me the settlers came into her Grandmother, Tom-Watt-Welsuni's, village and that Tom-Watt-Welsuni seen them kill her father, along with other male members of the tribe. One of the other settlers, Thomas Smith, took Tom-Watt-Welsuni as his wife even though she was only eleven years old and was married by Indian custom. She was only five foot tall and of slight build and spoke only Indian. She had III tattooed on her chin. They had 11 children. She always resented her husband for being in the group who killed her father and other relatives and friends. My mother said she had a very hard life.

Later, when I was an adult, I looked up Thomas Smith and found a letter that he wrote to the General of Oregon in July of 1856, the same year he attacked my Great Grandmother's village. I brought the letter here today and want to read the end of it to you. He writes, 'At the request of the citizens of Crescent City I have written to you for a commission to raise a company of good men for the purpose of clearing the trail on the coast and to Illinois Valley. There is no peace until these devils is smitten from the face of the country. I take no buck prisoners. The treaty that I make is everlasting. I have had considerable experience in fighting Indians. My manner of fighting has always been successful'. I also found his obituary, which includes a mention of Tom-Watt-Welsuni, 'Thomas Smith wooed, and, with the required wampum, won a dusky maid of the forest.'

The traumas Tom-Watt-Welsuni, or Amelia, as she was re-named by Thomas, experienced as a young girl, and throughout her life, were passed on to her children, and how could they not be? She lost her family as a child, and raised her own children, the children of a forced union, in a time when Indians could still be killed on sight. These experiences made an impact on her children, and were passed on, along with her stories, to my mother and to me. I can see the ways they have impacted my life. Some of these impacts have been negative, but some have also been positive. They have shown me the strength of our Indian women. Even though the most horrible things in the world happened to my Great Grandmother, she raised eleven healthy children. And my mother, when she was born, because she was an Indian, she wasn't a citizen of the United States, even though she had never left California. But when she was in her fifties, she walked almost a hundred miles to Crescent City to register us as U.S. citizen. I get discouraged by numbers like those you're showing up there on that screen, and I think about our old folks dying early of diabetes and heart disease, and our young people stuck in cycles of addiction. I sometimes think that is all that White people think we are. It seems like medical professionals and public health researchers come to study us, and they only see the bad things. How come university researchers never study our strength and our resilience? How come they never ask how we are still here? That is what I want to focus on when we talk about historical trauma – celebrating our strength.

Heads are vigorously nodding around the room. There are a few audible “ahos.” The young man sitting next to the elder stands to steady her, her voice beginning to shake in a way that mimics the growing unsteadiness of her stance. He adds, “*I wonder if researchers spent more time in our communities, if they'd be more able to see our strength, our survivance? I also don't understand why the focus of our interactions has to be on research output rather than on building relationships. Relationships take time and energy to build. We learn how to be in good relation as youngsters. All of us are connected to each other and to the Creator. I can't exist without you and you without me. Everything we do impacts everyone else. Listen. Be patient. Show respect. These are fundamental ideas that seem too easily to get lost.*”

The room monitor shakes the “Time is Up” sign at me in a way that signals I should have ended a while ago. Nodding and facing the older woman and younger man, I give the deepest form of thanks that I can offer, which is to say so in my people’s language. Frantically pressing buttons to scroll through the rest of my slides I arrive at the last one, which provides my contact information.

Shu'-shaa-nin~-la, Miigwetch, thank you for making space for this conversation, sharing your insights and experiences. They have enriched my spirit and I hope yours as well. I'd love to hear more about what great things you are doing in your communities to address historical trauma and nurture resilience. You know better than anybody what your community needs to live well and be healthy.

My plane leaves soon, so I dash out of the room. Class starts in 5 h. I’m cutting it too close. Why do I do this to myself?

Within 2 h, sitting at a window seat in coach cradling a cup of tea in a paper cup, I’m looking out at the expanse of clouds stretching out below me. It is so rare in my discipline to have to report findings back to community. Resentment towards my program is growing for not setting me up better, by not providing opportunity to practice accountability to communities rather than fellow public health professionals. How could my mentors have taught this?

I am reminded of a saying one of my elders shared with me, “data are just stories with the tears wiped off.” After this presentation the saying resonates strongly. The presented report is our people’s experiences of historical trauma as portrayed by numbers; stories stripped of their humanity. It is a special kind of heartbreak to know that this report does not contain the testament of today, because stories are an N of one, they aren’t generalizable, and are too embedded in personal experience to be seen as “objective”. I wonder if non-Native people that read the report will be able to fully comprehend the intergenerational and enduring impacts of historical trauma events in Indian Country. Hopefully it isn’t too easy to dismiss the impersonal statistics, the stories with their tears wiped off. In my mind I see the faces of the audience members who shared their stories, see both the traumas and the strength, the Blood Memories of both shining through.

Discussion: Towards a Solution

Many health disparities stem from the United States’ history as a colony and Native American’s position as a people who have experienced colonization. The United States government has never offered a formal apology to Native communities for past mistreatment. Individual public health practitioners cannot apologize adequately for the government; yet they carry the lack of apology with them when entering Indigenous spaces. This lack of apology fractures trust, which can adversely impact public health practice. Failure of public health to deepen its understanding of past and continued fallout from colonization has the potential to lead to the continuation or promotion of health disparities among Indigenous communities. To

begin to address these health disparities, we believe it is necessary to acknowledge this history, and for public health professionals to reflect on the ways in which the structural forces of colonialism continue to guide their practice.

The narrative highlights some of the schisms that exist between common public health training and work with Native communities and, through this, begins to identify feasible approaches to addressing some of the discrepancies. The notions brought up in the narrative are incredibly complex and intertwined, and we cannot properly unpack them in a single paper. Despite this, we name a few here. First, work to **be good stewards of Indigenous narrative** as they can make space for stories of survival, resilience, and health that are not captured by standard indicators used in public health. Narrative also offers an opportunity to retain the power, control, and ownership of information by Native people so that they can contribute to the evidence base on their own terms (Simpson 2007; Doerfler et al. 2013). Second, **focus on relationship building** as it is essential in re-defining the ways in which Native communities and public health interact to support wellness. Native communities must lead healing efforts, including cultural revitalization, and public health practitioners can demonstrate support for Indigenous-based self-determination by providing expertise and resources *when asked*. If the focus is on relationship building, practitioners can then become grounded in locally appropriate histories, culture, and protocols. There is undoubtedly immense diversity across Indian Country, however, an emphasis on relationship building will be particularly powerful if accompanied by an openness and willingness to create space for alternative approaches (Gartner et al. 2021).

Third, **understand the variation in historical trauma responses and nurture resilience** because not all communities, families, and individuals have experienced or responded to the experience of trauma in the same way (Evans-Campbell 2008; Ehlers et al. 2013; Walls and Whitbeck 2011; Whitesell et al. 2012). While many historical trauma responses include poor health outcomes, responses are not inherently negative. Some positive responses to historical trauma include dedicated re-investment into cultural revitalization efforts, a recognition of the strength and resilience of ancestors, community, and family, and a deepened commitment to community and culture (Bombay et al. 2014; Whitbeck et al. 2001, 2004; Colmant et al. 2004; Evans-Campbell 2008). Lastly, **know that historical trauma responses can permeate all aspects of daily living**. Responses to historical trauma events are not limited to a single disease at a single time point. Their very nature as a disrupting force means that their impacts reverberate across time throughout every element of daily life by impacting social structure (Grant 2008), economic stability (Gregg 2018), and cultural continuity for contemporary communities (Heart et al. 2011). Only after completing each of the four steps detailed above can public health practitioners begin to consider ways of addressing health disparities as they relate to historical trauma.

In hopes of generating further consideration and critical reflection, we offer the following discussion questions.

Questions for Discussion

1. How might public health professionals negotiate the tension of being professionally obligated to protect the public's health (including Indigenous communities' health) while also upholding Native sovereignty and self-determination?
2. Why are statistical summaries of population health privileged by the public health profession? What are alternative approaches to capturing and disseminating population-level health-related information?
3. Who benefits from the telling and re-telling of summaries of Native ill-health and disease? In what ways might they benefit?
4. In what ways can public health practitioners support Native communities to heal from historical trauma without perpetuating settler-colonial knowledge and power hierarchies?
5. How might knowledge of diversity in historical trauma responses impact the manner in which public health professionals approach work with tribal communities?
6. In what ways would centering relationship building, rather than data collection, alter the trajectory of standard public health research and practice?

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Chapter 9

Ethical Considerations with the Photovoice Research Method: A Narrative Reflection



Shannon McMorro

Abstract This paper explores ethical considerations and challenges of using the community-based participatory research method of photovoice with marginalized populations. Experiences with conducting photovoice in an urban setting in the Midwestern United States with women refugees from the Democratic Republic of Congo (DRC) are described along with reflection on ethical aspects of that experience. Two key related ethical considerations emerge: the roles that empathy, cultural competence, and cultural humility play in working with communities and the tension in research between benefits perceived by individual research participants and greater public health benefits for the groups they represent.

Keywords Photovoice · Refugees · Women · Democratic Republic of Congo · Ethical tension · Culture · Research

Public Health Ethics Issue

This paper explores ethical considerations and challenges of using the photovoice method to conduct community-based participatory research (CBPR) with marginalized populations. More specifically, I will recount my experiences in conducting photovoice in an urban setting in the Midwestern United States with women refugees from the Democratic Republic of Congo (DRC) and reflect on ethical aspects of that experience. My reflection takes as its point of departure, Principle 4 of the *Ethical Principles of the Practice of Public Health* (Public Health Leadership Society 2002, 4): “Public health should advocate and work for the empowerment of disenfranchised community members, aiming to ensure that the basic resources and

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conditions necessary for health are accessible to all.” But as my story unfolds, two related ethical considerations emerge: the roles that empathy, cultural competence, and cultural humility play in working with communities and the tension in research between benefits perceived by individual research participants and greater public health benefits for the groups they represent.

Background Information

CBPR has evolved over the past three decades with diverse roots across multiple disciplines such as social work, education, and international development. Over the past 20 years, it has emerged as a common approach to research within public health (Minkler and Wallerstein 1999). Key principles of CBPR include facilitation of collaborative partnerships throughout the research process, promotion of co-learning with participants, and empowerment of participants to redress social inequalities (Israel et al. 1998, 178–80). It may particularly appeal to public health professionals and researchers specializing in the social, cultural, and behavioral aspects of health promotion and education and has more recently been described as an opportunity for “giving underserved communities a genuine voice in research” (Wallerstein and Duran 2008, S40). CBPR offers public health researchers concerned with holistic approaches an option to interrogate the multiple social, political, economic, and cultural roots of public health problems.

One specific CBPR method is photovoice. Photovoice owes its creation to global public health researchers doing international development work with women in rural China. They adapted it to better understand economic and social determinants of reproductive health issues (Wang and Burris 1994, 1997; Wang 1999). Simply put, photovoice is, “a process by which people can identify, represent, and enhance their community through a specific photographic technique” (Wang and Burris 1997, 369). When following the original approach of Wang and Burris, three overarching goals characterize photovoice: (1) enable people to record and reflect their community’s strengths and concerns; (2) promote critical dialogue through discussion of photos; and (3) reach policymakers (Wang and Burris 1997, 370). However, as Catalani and Minkler (2010, 447) demonstrate, public health researchers who use photovoice display a wide range of adherence to those goals.

Photovoice researchers have used the method with diverse populations internationally and across disciplines for over 20 years (Breny and Lombardi 2017; Castleden et al. 2008; Keller et al. 2008; Livingood et al. 2017; Mamary et al. 2007; McMorrow and Smith 2016; McMorrow and Saksena 2017; Saksena and McMorrow 2020; Strack et al. 2004; Wang and Burris 1997; Wang et al. 1996). Researchers often employ the photovoice method with marginalized populations to amplify voices of the group and gather often-ignored perspectives. Photovoice researchers usually hold a series of meetings with a participant group to introduce them to the process. The group learns what photovoice is, how to use a camera, the plan and timelines for taking photos, and the ethical and safety considerations for taking

photos of people in their communities. Health topics and specific goals of Photovoice projects often vary widely between groups. Researchers offer broad guidelines to participants about what to photograph based on the research questions, with careful attention to avoiding social desirability bias and encouraging both positive and negative depictions of their community. After taking their photos, participants reconvene in a modified focus group to discuss their photos. The researcher guides participants in how to choose which photos they wish to share, discuss them with the group, identify common feelings and experiences related to the content of the photos, and have further discussions that build on discussion of the photos. To accompany the photos, all discussions are recorded and transcribed. The ideal outcome is for the photos and accompanying stories to reach key decision makers and policy influencers either through a public exhibition or advocacy. Examples include participants attending a local school board meeting to discuss their photos, an exhibit at a public library with a reception inviting community leaders, or direct meetings with state or federal representatives where researchers and/or participants share the photos and stories. Figure 9.1 below shows a photo and story from a woman who came to the United States as a refugee after fleeing the ongoing wars in the Democratic Republic of Congo (DRC), (McMorrow and Saksena 2017, 8). In this project, researchers asked participants to photograph things that made them feel happy, sad, or surprised about their new life in the United States.



Fig. 9.1 Photovoice example that illustrates a participant’s daily experience of health (McMorrow and Saksena 2017, 8). *Participant photo story*: “This is sad because they find they have cockroaches and other insects in my house so I have to do all this laundry and pack all of the like that so they can...spray the medication. That picture is of packing. It reminds me of war in Africa where you have to pack and keep running, keep on the run”

Sometimes participants may photograph a blank wall or a mundane set of stairs. However, the impact of photovoice ultimately depends neither on the actual photograph nor on photography skills. It depends instead on the string of stories in conjunction with the photos, which produces compelling qualitative data with the potential to inform public health practice and policy. Just as important, participation in a photovoice project often empowers participants by facilitating their acquiring the knowledge, attitudes, and skills needed to improve their health and their lives.

Approach to the Narrative

The following narrative takes as its point of departure the photovoice project that produced Fig. 9.1. The story centers around the perspectives of Harriet, a research team member whose cultural and ethnic background mirrors that of the research participants, and of Julie, one of the research team leads. Though fictional, the characters represent composites based on the author's actual experience in conducting photovoice research. The moral lesson of the story illustrates an ethical tension that may result from the use of photovoice. On the one hand, by empowering disenfranchised community members, photovoice can in the long run enhance their access to basic resources and conditions necessary for health. On the other hand, in the short term, photovoice and other participatory research methods may reveal immediate needs of individual participants that cannot be met during the course of a photovoice project. Nested within the story are enduring questions about ethical relationships with communities and the clash between service delivery and empowerment activism that can occur in public health research and practice. These are critical to reflect upon because ethical, intentional partnerships with communities are a mainstay of public health practice.

Narrative

Harriet

Here it was 2019 and Harriet was struggling yet again over whether to become a member of the photovoice research team to help follow-up on the study she had worked on back in 2016. The researchers needed her help in recruiting participants and serving as an interpreter. She was the ideal person, because the research would focus on women and she felt connected to in her local community, refugees with families who had fled the Democratic Republic of Congo (DRC). Harriet shared a strong affinity with the study participants as she too, had fled her home in Rwanda. Though her circumstances were different from the participants in that she had not

undergone the official UNHCR¹ process as a refugee, she empathized strongly with these women. This was because she had also experienced the trauma of conflict and horrific violence in her home country as well as many of the challenges of integrating and adjusting to life in the United States that the participants now faced.

In any case, the upside of working on the photovoice project again was that she needed the money and the work would thankfully only be temporary. Also, she would get a chance to re-connect with the study participants since part of her job would be to recruit the same women she had recruited to participate in the 2016 photovoice study. On the downside, she had uncomfortable memories about the challenges of working on the study back then. Harriet had continually struggled to see how sitting and talking about photos actually helped the women. After all, being a local health navigator for the refugee resettlement agency had opened her eyes to the range of ongoing adverse mental and physical health conditions the women suffered. Those were on top of the daunting social and economic barriers facing them in adjusting to life and surviving in the United States. The last time around, during the 2016 project, she had felt overwhelmed and caught in the middle. She had to answer to both the refugee resettlement agency and the researchers, and her work for the research study was on top of her normal job duties. It had certainly become more trouble than it was worth. With the new follow-up study, they would hire her as an independent contractor and pay her directly as a “research assistant.” She would work on multiple parts of the project such as helping find a community meeting space, recruitment, and interpreting.

Would the project create false hopes for the women that the researchers were going to do something direct and specific to help them? It was already clear in 2016 that the women needed a variety of support services, so would the project do more to provide those services this time? Harriet had doubts but decided to move forward despite her reservations. Julie and Ren, the project researchers, were both women who appeared well intentioned and had some understanding of the women’s cultural background. Julie who was leading the research, at least had lived in East Africa for 3 years, with some travel to the DRC, and knew more about where the women were coming from than the average American. Ren, like Harriet, also immigrated to the United States from a developing country. She could sympathize more with some of the cross-cultural barriers Harriet faced when trying to recruit and guide participation of the women in the study. However, Harriet also thought they lacked full understanding of some of the social and economic hardships faced by the participants as they were both college professors and researchers working in high status jobs with reliable incomes. That gap in status left Harriet with a solid dose of skepticism about whether the researchers truly grasped the gravity of some of the challenges the women faced. That skepticism only added to her nagging doubts about how the photovoice project could help the participants improve their health and access to healthcare.

¹United Nations High Commissioner for Refugees.

In her day job as health navigator, Harriet was a service provider, giving refugee women concrete, practical information that helped them learn the ropes in their new country. Photovoice struck her as more roundabout. Both researchers had conducted training with Harriet, detailing the steps of photovoice, highlighting the focus on empowerment of participants as opposed to service delivery, and coaching her on how being the interpreter for a research study differed from her work with the women in her health navigator role. The researchers also started out the photovoice group meetings with the participants by explaining that the immediate project goal was to gather information directly from the women, encouraging them to share about their experiences as refugees. Later, the researchers would eventually use this information to advocate for change. However, as much as Harriet tried to translate this message clearly into Kinyarwanda and Kiswahili, the languages the study participants spoke, she still could sense the women expected the researchers to do something beyond ask questions and listen to their stories. Every now and then, the women would ask Harriet a question in their preferred language that she would not translate to the researchers lest they become offended or frustrated. For example, sometimes the women wondered if the researchers were available to help transport them to doctor appointments. After all, the women were communicating this need through their photos and discussions (see Fig. 9.2), so it made sense that the next step would be for the researchers to help them with these needs.

Fig. 9.2 Photovoice example illustrating transportation barriers (Saksena and McMorro 2020, 11). *Participant photo story*: “I took a picture of this place because it is the bus stop where we stop and just leave around that bus stop early. You go take a bus for two hours and you have a car back home. It is a pain. It is a sad picture”



Even when participants were not directly asking for help, Harriet found herself looking to the researchers to see what actions they would take after participants had shared grave concerns and experiences about their health. For example, during the initial 2016 study, they learned that one of the participants, Eliza, suffered from type 1 diabetes and had trouble paying for her medication. When Eliza participated in the 2019 study, she again offered photos and narrative stories detailing financial barriers she still faced that caused her to skip taking medication, ending up hospitalized, and as she acknowledged, fearing she might die. Harriet felt a mixture of sadness and frustration that Eliza was still facing these barriers to accessing her life-saving medication. Eliza's desperate lack of access to the resources she needed to stay healthy was the most important, immediate issue at hand. What was needed was urgent action to get her the ongoing, sustainable access to healthcare services of medication and care to manage her Type 1 diabetes. How could the researchers be so concerned about Eliza's story and seemingly care so little about helping her now?

Harriet looked to the researchers to respond when Eliza shared that she sometimes missed her medication. They appeared to be listening and sympathetic, but instead of offering her advice or consolation, they proceeded to other questions for the group to discuss. The researchers even asked a question to the group about their collective ideas and suggestions for how Eliza might handle this problem of not having access to her medication. Harriet found it ridiculous that the researchers would ask the participants how to solve Eliza's problem because it seemed clear that these women were in need and unable to solve their own problems. They needed help from her and from the researchers. At that point, Harriet deviated from her role as an interpreter for the research study to talk with Eliza in Kinyarwanda. Harriet offered advice from her other role as a health navigator to let Eliza know that the medication should be covered by Eliza's insurance. Harriet clarified that it must be an issue that Eliza was facing in terms of the complexities of using the version of Medicaid in their state and assured Eliza that after the photovoice meeting was over, she would assist her with the paperwork and other case management support needed to help her navigate the challenges.

Julie

By spring of 2019, Julie had been conducting photovoice as a community-based participatory researcher in public health for 7 years. Before that, she had worked as a public health educator in community settings for 20 years. She embraced the nuanced and messy process inherent to CBPR methods and particularly, to photovoice. Still, lingering ethical questions related to this work dogged her. She often thought about her commitment to empower disenfranchised community members and wondered if she were doing enough.

At first glance, Julie's public health career seemed to follow a crooked path. Viewed as a whole, however, pivotal experiences had guided her path to CBPR, a

road less taken in public health research. Twenty years earlier, she had taken her first public health job for Planned Parenthood, delivering sex education in California's Bay Area. Despite having attended a racially, ethnically, and socioeconomically diverse public school in the Midwest, she came off to coast dwellers as a naively underexposed Midwesterner. Her sex education delivery combined wholesome enthusiasm with an utter lack of cultural humility (Tervalon and Murray-Garcia 1998). The latter went unnoticed by her equally culturally tone-deaf supervisor, but not by colleagues and community members in whom it provoked resistance and resentment. Convinced of her good intentions of empowering the disenfranchised, she failed to fathom why her educational sessions provoked such negative reactions.

Answers began to emerge during her time with Planned Parenthood once she embarked on a Master of Public Health in Community Health Education. That course of study commenced a journey of lifelong learning that deepened her cultural competence and cultural humility. Her initial fumbling and bumbling through "on the job training" in cultural competence did, however, have an upside. The practical experience generated a deep-rooted discomfort with the way public health practitioners and researchers unwittingly plied their interventions and hypotheses. Due to their lack of cultural humility and competence, they often did more harm than good in their endeavors to empower the disenfranchised.

That lingering discomfort eventually guided Julie to zero in on photovoice as a means to both work *for* and *with* disenfranchised community members. The participatory nature of photovoice and most CBPR research in public health offered some decision making and control of the research process to participants including choices related to where to share the data. One of the core underpinnings of photovoice was empowerment and consciousness raising with the goal of sustainable change for participants (Wang and Burris 1994, 1997). However, there was also the inherent power imbalance that occurs with all research that gave Julie and the research team the opportunity and responsibility to identify how and where to use the data for advocacy. That partly explained why she felt it important that Harriet had agreed to be their Research Assistant and Interpreter. Harriet already had photovoice experience and could follow up with the Congolese refugee women who had participated in their 2016 study. Julie, who had visited the DRC several times during a three-year stint in public health in Uganda, was familiar with the study population. However, her outsider familiarity paled in comparison to Harriet's insider perspective and the ethnic and linguistic background she shared with the women in the study. Even better, Harriet's professional experience as a health navigator working for the local resettlement agency added cultural depth and insight to the bare data and its analysis. During the 2016 study, participants had demonstrably trusted Harriet; the hope going forward was that this trust would help with the 2019 recruitment and implementation. That hope was not misplaced; she managed to recruit many of the early participants into the 2019 study.

Returning participants shared their experiences of what had happened to them over the 3 years since they had last interacted with the researchers. Julie listened to these experiences with a mixture of responses. Sorting out her professional response from her emotional response was always challenging. Hearing the women tell their

stories often made her feel helpless or like she should be doing something more beyond “just research” for the participants. Though the photovoice research method had participant empowerment as a core tenet, clear and pressing service delivery needs were evident during photovoice implementation. Eliza’s distressing story, recounted during a data collection session, offered a case in point. With Harriet serving as interpreter, Eliza shared her ongoing struggle to access medications for her type 1 diabetes. Missing several doses of medication shortly after being resettled in the United States had led to her hospitalization and a flirtation with death. The story clearly unsettled Julie and Ren, who become more discomfited when Harriet, pausing from interpreting, expectantly turned to them. What decisive response would the researchers have to Eliza’s story?

Julie had listened to Eliza’s story intently, but the group sat in awkward silence when Harriet stopped interpreting. She could tell that Harriet expected her to offer advice about Eliza’s case. Instead, adhering to the methods of qualitative data collection, Julie posed further probing questions based on what Eliza had shared. All these questions nudged the group to consider ways to collectively address Eliza’s predicament. For Julie, CBPR’s overarching purpose and the project’s whole point was to empower the participants, helping them find ways to solve their problems. Moreover, harnessing, capturing, and scientifically sharing the breadth and depth of these women’s experiences had a larger, public health aim. It could ultimately impact all of the refugee women’s access to health care and their health, thereby reducing the group’s health disparities. Gathering the participants’ stories and experiences formed a crucial piece of a puzzle they could widely share and use to advocate for resources that could improve the lives of Congolese refugee women in the United States and potentially, other refugee groups. The reason that it was so crucial, from Julie’s perspective, was that first-hand stories were an important complement to the quantitative evidence that public health tended to prioritize. In the case of photovoice, both stories and photos taken by the participants added depth and a more holistic picture of how to build what would ideally guide public health practice for this population.

Despite this being the “right” way to conduct research, both then and later, it troubled Julie not to focus on Eliza’s grave challenges and try to “fix” them. Harriet’s initial reaction and subsequent actions only amplified Julie’s unease. Harriet had first shot an alarming glance at the researchers, then took matters into her own hands. She ceased interpreting for the researchers and switched to Kinyarwanda for a few moments to discuss the issue with Eliza. Harriet had prioritized the immediate end of ensuring that Eliza had the resources necessary for her to stay healthy. By contrast, Julie was attempting to discover whether the photovoice method could be an effective means for ultimately empowering women. Once again, Julie would find herself struggling with how to square what her heart and what her head were telling her.

Questions for Discussion

1. How do the differing perspectives of Harriet and Julie illustrate the potential for conflict in approaches to addressing ethical obligations (in this case the obligation to empower disenfranchised community members and ensure access to basic resources and conditions necessary for health)?
2. What was the role of money and economic need in Harriet and Julie's narratives? How might that apply when working with other "disenfranchised" community members as a public health practitioner or researcher?
3. What are potential implications and consequences when a public health practitioner or researcher endeavors altruistically to adhere to Principle 4 by "advocating and working for the empowerment of disenfranchised community members ..." without a baseline of cultural humility and training specific to working with and for such "communities"?
4. Why might some public health professionals argue that training in cultural humility and competency is an ethical obligation for the public health profession? What are some approaches for acquiring these skills? Should training on these topics be required?
5. What does it mean for public health to work *with* disenfranchised communities as opposed to *for* disenfranchised communities?
6. Do public health practitioners and researchers have an ethical obligation to include team members as staff that are "insiders" of the community like Harriet? Why or why not?
7. Do public health researchers have ethical obligations beyond the requirements of an Institutional Review Board to ensure populations comprehend the nature of scientific research aiming for long term change such as photovoice? How would they actualize this?

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Chapter 10

Harm Reduction: Tipping the Balance Toward Treatment and Recovery



Amy L. Sandul and Veda B. Moore

Abstract Opioid use has risen dramatically over the past 40 years. In response, federal programs and policies aimed at decreasing supply of prescription opioids have stabilized excessive prescribing. Unintended consequences of limiting the quantity of prescription opioids in the population has resulted in increased use of illicit drugs and opened a pathway of transition from misuse of pills to injection of heroin and use of potent formulations of cheap, synthetic opioids such as fentanyl. Harm reduction interventions function at the community level to provide health benefits and avoidance of harm to persons engaging in illicit and injection drug use. The Consolidated Appropriations Act of 2016 gives states, local, tribal, and territorial health departments the opportunity to use federal money to support a comprehensive set of harm reduction services. Critics of harm reduction strategies argue that formalizing and legalizing certain activities creates the perception that communities and local authorities are sanctioning or encouraging illicit/illegal drug use. Syringe services programs that provide clean needles and syringes so people who inject drugs are not forced to share or reuse injection equipment, are often at the heart of such controversy. This story addresses tensions that exist in communities grappling with harm reduction approaches to opioid and injection drug use.

Disclaimer: This paper is presented for instructional purposes only, the story that follows does not depict an actual event and all people, places, and dialogue are fictional. The ideas and opinions expressed are the authors' own. The paper is not meant to reflect the official position, views, or policies of the editors, the editors' host institutions or the authors' host institution.

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Public Health Ethics Issue

Health and safety are essential for human survival and prosperity. From the time of Hippocrates, doing good and avoiding harm have been central to medicine and medical ethics. Harm reduction interventions and policies function at the community level to provide health benefits and avoidance of harm to persons engaging in injection drug use. Interventions protect persons who engage in illegal and potentially fatal activities by lowering the risk of such activities. Over time, they can open a window to treatment, counselling, and recovery. The goals of harm reduction, then, align with public health's core ethical responsibilities "to prevent, minimize, and mitigate health harms and to promote and protect public safety, health, and well-being" (American Public Health Association 2019, 5).

Society criminalizes some high-risk activities, such as injection drug use, that harm reduction interventions target. Moreover, society often stigmatizes people who engage in high-risk activities, people who are already more likely to be vulnerable by virtue of belonging to a marginalized subculture or population group. All community members, including people who inject drugs, are entitled to be treated with dignity and respect. Health officials at all levels of government have an obligation to promote and protect the health and safety of the entire population – not just some or most of the population. In addition, public health authorities have a special obligation to engage and protect vulnerable populations and eliminate disparities in health status. Protecting the health of those most vulnerable protects the health of the community and upholds the right to health for all.

Background Information

Opioid Crisis of the Early Twenty-First Century

Over the past 40 years, opioid use has risen dramatically. In the 1980s the opioid propoxyphene was the second-most dispensed drug in the United States for acute pain (Dasgupta et al. 2018, 182). During the 1990s, the volume of opioids prescribed to patients for chronic pain also began to grow (Dasgupta et al. 2018, 182; Levy et al. 2015, 411; Centers for Disease Control and Prevention (CDC) 2011,

1488–1489). By the early 2000s, treating the high prevalence of chronic pain had become an increasingly large proportion of the business of pharmaceutical companies (Dasgupta et al. 2018, 182; CDC 2011, 1488–1489). The high prevalence of chronic pain was attributable to increased survival after injury and cancer, musculoskeletal problems of an aging population, obesity, and more complex surgeries. A decade later, rates of opioid use disorder and overdose spiked resulting in concomitant increases in heroin use, synthetic opioid use, and overdose deaths (CDC 2014, 852; Compton et al. 2016, 155). In October 2017, the U.S. Department of Health and Human Services (DHHS) declared opioid use disorder (OUD) a federal public health emergency (Government Accountability Office 2018). Opioid overdose had become an epidemic in the United States and by early 2020 an estimated 128 people were dying each day from prescription and illicit opioid use (CDC 2020).

Over the past decade, local, state, and federal responses to the opioid crisis have produced mixed results. A variety of programs and policies aimed at decreasing the supply of prescription opioids in the population have been implemented. The measures include prescription drug monitoring programs, education of health professionals and the public about the dangers of opioid use, and regulatory and law enforcement initiatives to deter inappropriate prescribing (Burriss 2018, 29–31; Compton et al. 2016, 154). While prescribing stabilized, unintended consequences of limiting the quantity of prescription opioids in the population has resulted in increased use of illicit drugs (CDC 2017, 701, 2019, 29; Compton et al. 2016, 154–155). Increased use of illicit drugs has opened a pathway of transition for those suffering from OUD from misuse of pills to injection of heroin and use of potent formulations of cheap, synthetic opioids such as fentanyl (National Academies of Sciences, Engineering, and Medicine (NASEM) 2020, S1). Adulteration of heroin with illegally produced fentanyl began around 2013 and has complicated the opioid overdose epidemic by increasing the risk of unintentional lethal overdose (Ciccarone 2017, 109; Compton et al. 2016, 154, 161). While government measures may have lessened the risk of misuse of prescribed opioids, for those already experiencing OUD the effect has been to shift the problem from one target drug to other, more dangerous drugs.

OUD and infectious disease have been veritably interwoven for health professionals since it was determined that HIV could be transmitted through injection drug use. Today, OUD has become associated not only with HIV, but also hepatitis A, hepatitis B, and hepatitis C virus transmission, and with bacterial and fungal infections (NASEM 2020, S-1). Outbreaks of HIV and viral hepatitis occur among people infected through injection drug use or through high-risk sexual behavior associated with drug use. Public health interventions targeting OUD, therefore, need to focus on preventing both overdoses and serious bloodborne infections (NASEM 2020, S1–2).

In contrast, traditional models of care for all substance use disorders (SUDs) have generally occurred in standalone settings outside of medical and public health programs. That segregation tends to align with traditional substance abuse care models that focus on terminating drug use prior to engagement in targeted counseling, treatment, or intervention. Historically, 12-step programs, substance abuse

counseling, addiction recovery centers, and inpatient rehabilitation centers have been the main providers of substance abuse care. However, these approaches are impracticable for people who inject drugs (PWID), or persons with OUD or other SUDs who continue to use drugs. Public health officials need to develop effective messaging and comprehensive evidence-based harm reduction interventions specifically for persons currently experiencing OUD or other SUDs. With a targeted approach, infectious disease transmission, outbreaks, and lethal overdoses, will be prevented and reduced.

Approach to the Narrative

This story addresses tensions that exist in communities grappling with harm reduction approaches to OUD and other SUDs. Interventions to reduce potentially severe adverse consequences of drug use do not, unfortunately, translate directly into reductions in the rate of addiction or drug overdose. Critics of harm reduction strategies argue that formalizing and legalizing certain activities creates the perception that the community and local authorities are sanctioning or encouraging illicit/illegal drug use. Syringe services programs (SSPs) that provide PWID with clean needles and syringes so they are not forced to share or reuse injection equipment, are often at the heart of such controversy. After a prolonged outbreak of HIV infections among PWID from 2011 to 2015, in Scott County, Indiana, the 1988 Congressional ban on use of federal funds for SSPs was lifted.

The Consolidated Appropriations Act of 2016 (DHHS 2016, 1) gives states, local, tribal, and territorial health departments experiencing or at risk for significant increases in hepatitis C or HIV incidence, the opportunity to use federal money to support a comprehensive set of harm reduction services. With a determination of need from the CDC, federal dollars can be used for personnel; injection supplies other than needles and syringes; testing/diagnostic kits for hepatitis C and HIV; biosafety sharps disposal containers; navigation services for linkage to care for hepatitis C and HIV prevention and treatment, including direct acting anti-viral (DAA) therapy for hepatitis C, and antiretroviral therapy (ART) for HIV, pre-exposure prophylaxis (PrEP), post exposure prophylaxis (PEP), hepatitis A and hepatitis B vaccination services; SUD treatment; recovery support services; medical and mental health services; naloxone for opioid overdose; comprehensive education materials; condoms to reduce the risk of sexual transmission of HIV, viral hepatitis, and other STDs; communication and outreach activities, and planning and evaluation activities.

Martindale, West Virginia, the setting for this story, is a fictional town, but the state of West Virginia ranked as the state with the highest rate of new hepatitis B and hepatitis C diagnoses in 2017, the last year for which surveillance data were available (West Virginia Office of Epidemiology & Prevention Services 2018). The story that follows does not depict an actual event, but it was inspired by an amazing woman and poet. She attended a workshop convened by the Board on Population

Health and Public Health Practice of the National Academies of Sciences, Engineering, and Medicine (NASEM) that explored the integration of infectious disease considerations with response to the opioid crisis. The opening session of the workshop focused on the scope of the opioid misuse problem: a subsequent panel discussion addressed the perspectives of patients and providers. That panel discussion included the personal experiences and shared journey of the poet in recovery from SUD from age 11 to age 63.

Narrative

Dr. Mikala, executive director of the Martindale Harm Reduction Center (MHRC), had just submitted her clinic funding proposal for the next fiscal year when she received a call from Lisa Ewing, the mayor. It had only been a week, and upon hearing Lisa's voice she had a sudden feeling of trepidation that it wasn't good news, "Hello Mikala, how are you?"

Mikala responded, "Relieved to have finished the MHRC grant proposal for next year, and how are you Mayor Ewing?"

"I'm well – thanks for asking. Unfortunately, I'm calling about the funding proposal – we need to determine next steps," Lisa responded.

The mayor's words caught Mikala off guard, and she began racking her brain for what might have gone wrong. She knew federal dollars couldn't be used directly to buy needles or syringes. But a big HIV outbreak in Indiana had gotten the feds to lift the ban on using federal funds for other services provided by SSPs. After that, an act of the federal government had authorized health departments to use federal money to support comprehensive services in jurisdictions experiencing, or at risk of experiencing, major increases in hepatitis C or HIV – and theirs certainly was. She had already requested and received a determination of need from the CDC.

Doctor Mike, as Mikala was called by most MHRC program participants and the community at large, went through the budget allocation checklist for services provided through the Center – it was fresh in her mind, what could be the problem?

"Next steps to address what specific problem?" responded Dr. Mike to the mayor.

Lisa Ewing cut right to the chase, "There seems to be some local opposition to the use of federal funds to support the MHRC. As you know, decisions about use of SSPs to support the health and engagement of PWID are made at the local level and the Martindale city council has decided we should have other priorities."

Given that the opioid crisis had been raging in West Virginia for years, Dr. Mike could not believe what she was hearing. "Lisa, I honestly can't believe that local government in the state with the distinction of having the highest rates of new hepatitis B and hepatitis C diagnoses over the last few years would conclude we don't need harm reduction services in our community, I am simply astounded. Can we talk some sense into them?"

"I am so glad to hear you say that," replied Lisa. "I was thinking we might host a town hall with the city council to find out where this is coming from – is it the

council members or their constituents; who exactly wants to shut down the MHRC? And why? I was thinking you could speak with them.”

Dr. Mike considered the mayor’s strategy, “I may have a better idea, let’s ask Ellie to lead the discussion – everyone in town knows and loves Miss Ellie and her children.”

Two weeks prior to the town hall, notifications about the meeting had been posted on the city government website, the local paper, and in gathering places around town. It seemed that significant controversy about the need for MHRC services had emerged from a vocal group within the local community. The group wanted to see federal dollars used primarily to fund contracts for privately run abstinence-focused recovery programs rather than services for people who continue to use drugs. Word had spread that some people wanted MHRC shut down and Dr. Mike wasn’t certain who exactly might attend the town hall to argue that.

On the scheduled day, community members came into the meeting room of Martindale City Hall in orderly fashion starting at just about 5:45 PM where the city council members were already settled into the upper dais seats. Seated in the lower dais close to the speaker podium were Mayor Ewing, executive director Dr. Mike, and MHRC’s senior prevention specialist, Ellie Phipps.

At precisely 6 PM, the chair of the city council called the meeting to order and asked the board secretary to read a brief summary of the issue slated for discussion on the agenda:

City council secretary Derek Sanders read the following statement from a letter addressed to the council:

The city council plays a critical role in determining how the city will spend money. It has come to the attention of a group of concerned citizens that federal dollars were spent in 2019 and are being spent in 2020 to fund the Martindale Harm Reduction Center (MHRC), and that the MHRC provides services to enable people who inject and abuse drugs. We are opposed for three reasons: 1) because federal funding contradicts law enforcement efforts in the “war on drugs” by signaling tacit governmental approval of illegal drug use, 2) federal funding of MHRC services and availability of clean syringes could cause a rise in injection drug abuse and weaken public health, and 3) the appearance of federal approval of MHRC services and removal of an obstacle to unsafe drug use could have a corrupting influence on children in our community.

City council president, John Smith, asked if Mayor Ewing or executive director Dr. Mikala Johnson wanted to speak to these concerns.

Dr. Mike got up and moved to the speaker’s podium,

Thank you all for coming and good evening – we are going to do our best to answer your questions and address your concerns about operating the MHRC. In 2018, Department of Public Health surveillance data for hepatitis B and hepatitis C were trending upward at an alarming rate. In response, we requested an assessment and then received permission from the federal Department of Health and Human Services to reprogram some federal dollars to syringe services programs. Not only do these programs prevent transmission of disease but they also provide opportunities to help and support persons experiencing opioid and other substance use disorder (SUD). These programs are critical to individual well-being and the long-term health of the community ...

“But giving people new syringes just encourages their illegal behavior!” a man in the first row of chairs blurted out. “And it looks like the community condones it!”

At that moment, Ellie Phipps, a local church elder beloved in her community and well-respected by everyone who worked with or had contact with MHRC, stepped to the podium. Everyone in the room either knew Ellie personally, knew her children – one of which was a legal aid attorney in a neighboring town – or knew someone who swore up and down Ellie had saved their life at some point over the past 15 years since she had come on the scene.

“I’d like to tell you about a client, it wasn’t someone from my work with MHRC – MHRC didn’t exist at the time – but this client was born in 1955 in the tenements on the southeast side of Martindale. She was sexually abused as a child, began using drugs and alcohol at the age of 11 and was snorting heroin by age 15. This girl, Sissy, had been exchanging sex for drugs in 1994 when she was diagnosed with HIV at the age of 39. On multiple occasions before and after her HIV diagnosis, she was seen in the hospital Emergency Department for various medical problems related to her drug use. She spent hours sick and in pain, waiting to be seen and suffering, only to be treated clinically and discharged as soon as possible. There was never a plan for follow up to address the root cause of her medical problems, her underlying substance use disorder. For years before her HIV diagnosis, and afterward while receiving care for HIV, Sissy was never offered counseling or treatment for her drug use. She would leave the hospital, carrying the burden of her drug issues and struggling with how to overcome it alone unassisted. All the while, she was terrified of living with HIV because she didn’t know exactly what it meant.”

Another community member stood up and asked Miss Ellie (as she was known around town), “But what does your client Sissy have to do with any of the MHRC funding concerns?”

Miss Ellie responded, “That’s a good question – so let me explain. Some years after her HIV diagnosis, Sissy had a drug dealer living with her and her children when she had to go to the hospital ED. That was the day her life was set on a different course, the day she met the Martindale Hospital’s new infectious disease doctor, Mikala Johnson.”

Dr. Mike sat lost in thought, it had been almost 20 years but she still remembered receiving a call from the triage nurse about a repeat patient in the emergency department...this was their first encounter even though the patient had been treated on previous occasions. “Do you use drugs?” She could tell the patient wanted to say no, to give the socially desirable response, however, to Mike’s surprise, she didn’t, “Yea, I use drugs.”

Mike responded, “Today is Tuesday, if I could get you a bed would you start the short-term in-patient treatment program today?” And the patient responded, “Yea”. Dr. Mike looked down at the notes from the patient’s last visit and replied, “What about your children?” And Sissy had said, “Well, they take care of me. I think they’d be okay while I go in treatment, I think they do fine.”

Dr. Mike reflected that she had left the room to call the treatment center but as she came back into the room she said, “I can’t get you anything until Friday, but if

you make it back here on Friday, I'll make sure you get up to Crestview to start treatment." She thought the chance Sissy would return was maybe 50/50.

Miss Ellie continued in a soothing tone to all those gathered in the room, "Dr. Mike made certain that Sissy had access to support services – 34 years of sustained drug use but she finally entered treatment for opioid and other substance use disorder. What made that transformation possible from drug user to patient in treatment and then recovery was outreach by Dr. Mike and her continued support. But maybe this could have happened sooner if only there had been somewhere for Sissy to go for care other than the hospital. The emergency department is intended for and focused on emergency care, maybe it didn't have to take decades – the provision of care, support, and counseling to those suffering from opioid and substance use disorder is not circumventing law enforcement – it's protecting our citizens and community" Ellie stated firmly.

Another community member moved to the microphone that had been set up between the aisles of seats, "I'm Shanice, born and raised in Martindale, and I just know that handing out needles is going to result in more people shooting up – make it easy for them, lord forbid, make it safer, and we are going to have more people doing it and kids are going to see that and you know how kids are, they'll be doing it too!"

Dr. Mike flipped the switch on her microphone to address the crowd, "Last year, West Virginia had higher rates of new hepatitis B and hepatitis C diagnoses than any other state in the nation. However, since implementation of comprehensive harm reduction services at MHRC last October, our county has flattened those epidemiological curves and we are on track to see a significant reduction in incidence for 2020 compared to last year."

Miss Ellie continued in her matter of fact way, "In accordance with public health goals, study findings indicate that the availability and use of evidence-based harm reduction programs, such as those we offer at MHRC, lead to a net reduction in opioid and other substance use over time. Such programs should not be viewed as sanctioning bad behavior but as effective interventions by which to respectfully meet people suffering addiction where they are, and provide them with care and services that reasonably offset the potential harms and losses that drug use imposes on individuals and communities."

"Our data and trend analysis thus far, appear to bear that out" Dr. Mike said as she stood up and moved to the podium next to Ellie.

Ellie turned to look at Dr. Mike, "That client, 'Sissy', that I was telling you all about – she didn't have an easy time of it. While she was waiting even that few days to go to rehab, her disability check came. She needed to return a loan to one of her neighbors but she knew if she went to the bank to get cash she would get more than she needed to repay the loan, would buy more drugs and then the cycle would begin again and she wouldn't go back to the hospital on Friday...".

"See, that Sissy woman was on welfare – using her welfare money for drugs" Mr. Butler of the local grocery piped up loudly and with resentment in his tone.

"But she didn't receive welfare because she had substance use disorder, she received disability because she was HIV positive" Miss Ellie quickly explained,

“She made it into the short term treatment program and then, with God working, after her discharge she was referred to an eight month aftercare program. After 1 year in the 8-month program, she was “put out,” as she likes to say, with instructions to attend 90 support group meetings in 90 days.”

“Is she still on welfare, are my taxpayer dollars still supporting her, Miss Ellie?” Mr. Butler wanted to know.

Ellie shifted her weight from one foot to the other as she tucked a stand of grey hair behind her ear, “You will be happy to know, she is not – Sissy went to 200 or 300 support group meetings in 90 days and then a few years later, she went to community college, and then applied the credits from her 2-year associates degree to a 4-year course of study to complete her bachelor’s degree. After graduating she reluctantly accepted a volunteer position and then once she had some experience, Sissy was hired as a paid peer mentor – that was 14 or 15 years ago – she is still employed today in a different community health position and is also a published author.”

Dr. Mike leaned forward toward the microphone, “She would tell you that things might have been different had she received a different type of care in the ED or had somewhere else to go – that maybe the existence of an intervention, even just a counselor who could have sat and talked to her, might have resulted in access to treatment and cessation of her drug use years earlier, perhaps before she contracted HIV – that there were many missed opportunities.”

“MHRC should focus on recovery and make certain people stop using drugs before they help them,” Shanice argued, popping out of her chair to get back to the microphone. “It’s not right to help them keep using by giving them medical care and testing and treatment for STDs”.

“Well,” responded Ellie, “we might consider how Sissy’s experience shows how opioid and substance use are intertwined with infectious disease transmission. It highlights the way in which harm reduction programs can overcome some of the barriers to patient-centered care and treatment faced by people who use drugs. A user who’s been treated for a disease and educated about safer sex or drug use behavior is less likely to get infected or to infect someone who does not use – your brother, your sister, your son or daughter. People take drugs to self-medicate; substance use disorder is a brain disease that requires long-term treatment and linkage to healthcare services. Some addicts never get to that place, but many take a long time before they are ready to quit.”

Jack Hanson, another community member, stepped up to the microphone as Shanice returned to her seat,

Okay, I’ll concede that having MHRC provide comprehensive care and treatment seems to make sense, I can support the use of HHS dollars to fund harm reduction locally – I really like the idea of people having somewhere to go if they are sick, need to talk to someone, or even to exchange needles – and there aren’t restrictions based on whether they have health insurance or not. MHRC is certainly cheaper than having people use the emergency department at the hospital, we pay for that with our tax dollars too. I didn’t know about the high rates of hepatitis B and hepatitis C in our community – I am glad to hear that MHRC is on top of it and impressed that it’s an issue they, and we the community, can tackle. You have my support.

“But what about our children?” Jennifer Parsons was back at the microphone. “Can you assure us that MHRC will not be a corrupting influence on our children?”

Doug and Mary Williams approached the microphone hand in hand, “Our Amanda died last year of bacterial endocarditis – infection in the lining of her heart and heart valves – as a result of injecting with dirty needles. She had been to rehab twice but couldn’t stop using... she tried so hard. If only she had access to safe injection equipment, we might have kept her alive long enough for her to get to a place where she could stop. We want MHRC to get the funding they need” declared Mary as tears streamed down her face.

“You all know me as a god fearing woman,” asserted Miss Ellie, “so trust me when I tell you that addiction is a long, arduous journey – there is physical pain, psychological pain, a deep sense of shame and feelings of stigma and discrimination – the feeling of being invisible and having nothing left but faith. Sissy wrote a poem describing her despair, I’d like to read it to you:

What Is This All About

What is this all about?

I’m dying but not yet dead,

I refuse to lay down and rest my head,

I come in many colors, races, and religions,

I’m tall, I’m short, I’m thin, I’m stout,

Do you know yet what this is all about?

I can fly just not like a pigeon,

People walk by me like they don’t have vision,

No one can hear me screaming out loud,

No one can see that I am proud,

No one knows what I’m feeling, no one can see that I’m not healing,

Up and down, up and down, all through the night, not realizing that I’m headed to the light,

Knowledge, potential, dreams, and power

Turn around now you’re heading to the end hours.

Jesus, Jesus help me please, I bow before you on my knees,

Oh God, I pray you can hear me shout,

Do you know yet what this is all about?”¹

Jack Hanson spoke from his seat, “Sounds like someone who almost died.”

“That is exactly what the poem is about,” responded Miss Ellie.

“But how would you know?” someone in the back of the room shouted.

Ellie looked out into the crowd of community members who had come to debate the value of harm reduction services and felt a small sense of redemption, “Because the author of that poem is me.”

¹Ms. Veda B. Moore attended and spoke at a 2018 workshop convened by the Board on Population Health and Public Health Practice of the National Academies of Sciences, Engineering, and Medicine (NASEM) exploring the integration of infectious disease considerations with response to the opioid crisis; she wrote the poem, *What Is This All About*, while watching and listening to other speakers and presenters at the workshop and read the poem out loud to conference attendees at the close of the conference.

Questions for Discussion

1. Why or why shouldn't people who are still using drugs have access to health services?
2. How can concerns that harm reduction programs condone or give permission for misuse of opioids or other drugs be balanced with the need to improve the health of people who use drugs?
3. Critics argue that harm reduction programs condone or enable users to misuse drugs, while health professionals tend to see substance use disorder as a disease.
 - (a) Are these positions irreconcilable and, if so, which side has the stronger argument, and why?
 - (b) Alternatively, is there a way of incorporating personal agency and responsibility within the view that substance use disorder is a disease?
4. What preconceived ideas do you have about people who experience OUD and SUD?
5. How should local, state, and federal health officials/governments work together to address the opioid use crisis?
6. Should the practice of public health require interventions to address behaviors that are illegal?
7. Are there any interventions for people who use drugs that should be beyond the scope of public health responsibility? If yes, which interventions?
8. What approaches should be used to obtain a better understanding of community values and concerns relating to harm reduction interventions?

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Part V
Public Health Ethics Narratives – Trust
and the Value of Information

Chapter 11

Vaccine Refusal: Stories from the Front Lines of Immunization Education



Mark C. Navin and Andrea T. Kozak

Abstract One way that U.S. state governments participate in immunization governance is to mandate vaccination for daycare and school enrollment. In response to rising rates of vaccine refusal, and concerns about outbreaks of previously well-controlled vaccine-preventable diseases, Michigan has chosen to require parents or guardians to attend ‘immunization counseling’ prior to receiving nonmedical exemptions to their state’s vaccine mandate. This chapter presents a brief memoir essay based on a composite of Michigan’s public health immunization educators. We constructed this composite character from interviews we conducted with 39 Michigan immunization educators. This narrative raises pressing ethics questions about the benefits and burdens of mandatory immunization education.

Keywords Education · Immunization · Nonmedical exemptions · Public health · Vaccine mandates · Vaccine refusal

Public Health Ethics Issue

In the United States, federal and state governments use diverse means to promote and govern vaccination. Federal laws, including the National Childhood Vaccine Injury Act (NCVIA) of 1986, require that persons receiving vaccines be presented

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with Vaccine Information Statements and have access to the Vaccine Adverse Event Reporting System (VAERS). The federal government also funds a majority of youth vaccines in the United States through the Vaccines for Children (VFC) program (Whitney et al. 2014). One way that U.S. state governments participate in immunization promotion and governance is by mandating vaccination for daycare and school enrollment.

Throughout the world, mandatory immunization policies take a variety of forms (Attwell and Navin 2019) and implicate a wide array of ethical values (MacDonald et al. 2018; Navin and Attwell 2019). State sponsorship of vaccination directly promotes individual health and, at high enough levels, indirectly generates community protection against outbreaks (commonly called ‘herd immunity’) (Anderson et al. 2018). Vaccine mandates can promote or undermine many other goods, depending on their structure and implementation. For example, mandates that require documentation of schoolchildren’s immunization status may promote state supervision of vulnerable children, and mandates that require immunization education as part of nonmedical exemption schemes may promote the community’s health knowledge (Leask and Danchin 2017; Luyten and Beutels 2016). In contrast, mandates that exclude unvaccinated children from daycare or school may undermine children’s education and may contribute to some parents exiting the formal workforce in order to provide in-home childcare or homeschooling. Furthermore, coercive efforts to promote vaccination can restrict parental rights, undermine trust among vaccine hesitant parents, and may cultivate anti-vaccine sentiments (Bester 2015; Omer et al. 2019).

In light of the many values implicated by vaccine mandate policies, it is essential to weigh and balance these values, and to select policies that prioritize the most important values. In particular, governments should use only as much coercion as necessary to protect communities from disease outbreaks (Nuffield Council on Bioethics 2007). This Least Restrictive Means (LRM) principle favors public health efforts that emphasize education and use liberty-preserving nudges to influence behavior (Blumenthal-Barby and Burroughs 2012; Kass 2001; Menard 2010). Accordingly, we have good reason to pursue efforts that use mandatory education as a means to increase vaccine uptake while protecting parental rights to access non-medical exemptions to daycare and school vaccine mandates, such as those in effect in Michigan and Washington (Navin and Largent 2017; Jones et al. 2018; Omer et al. 2018). However, these policies may be especially burdensome on the physicians or public health staff who the government tasks to deliver immunization education. Accordingly, further public health ethics discussions must address the efficacy of mandated education (relative to alternative policies) and the appropriate distribution of responsibility for providing immunization education. Executing public policies around these two issues will demand both respectful community engagement and effective collaboration to execute public health policies.

Background Information

There is a wide spectrum of beliefs and behaviors associated with vaccination decisions, from complete acceptance to complete refusal, with many people occupying intermediate positions, including the refusal of only some vaccines or the use of alternative immunization schedules (MacDonald and Sage Working Group 2015; Bedford et al. 2018). In response to rising rates of vaccine refusal, and concerns about outbreaks of previously well-controlled vaccine-preventable diseases, many political communities across the world have recently revised their immunization policies (Attwell et al. 2018; MacDonald et al. 2018). In the United States, vaccine mandates for children take the form of enrollment requirements for daycare or school, but *all* states waive these requirements if children have medical reasons not to be vaccinated, *most* states waive those requirements when parents object to vaccines for religious reasons, and *some* states waive requirements in response to philosophical or personal belief objections (Immunization Action Coalition 2019). Recent reforms to U.S. children's vaccine mandates have usually focused on eliminating these *nonmedical exemptions* or on making them more difficult to receive. For example, California, New York, and Maine have eliminated nonmedical exemptions (McKinley 2019; Simko-Bednarski 2019; Willon and Mason 2015); these efforts seem to have led to increased immunization rates (Delamater et al. 2019). In contrast, other U.S. states—including Michigan and Washington—have chosen to require parents or guardians to attend 'immunization counseling' prior to receiving an exemption (Lillvis 2019); those states have seen dramatic declines in nonmedical exemption rates (Jones et al. 2018; Mashinini et al. 2020). (Michigan calls its exemptions to daycare and school immunization requirements 'waivers' (Michigan Department of Health and Human Services n.d.), which is also the term that our narrative's composite character uses.) When Michigan decided to implement mandatory immunization education, it had the fourth-highest nonmedical exemption rate in the country; Michigan reduced its waiver rate by 35% after 1 year of mandatory immunization education (Navin et al. 2020).

Governments that have implemented immunization education requirements may have hoped that vaccine-refusing parents would change their minds after nurses or physicians talked with them about vaccines. Unfortunately, it is often ineffective and emotionally taxing for health professionals to try to change the minds of vaccine refusers in one-off encounters (Block 2015; Henrikson et al. 2015; Kempe et al. 2015). In addition to concerns about staff 'burnout' in the face of this difficult work, we may also worry about forms of moral distress that staff can experience if they believe it is wrong for parents to refuse vaccines or for the government to threaten to remove unvaccinated children from school. We must therefore address whether the costs imposed on public health staff who provide mandatory vaccine education are justified by the health benefits their efforts generate. In particular, there is evidence that communities can reduce nonmedical exemption rates by increasing the burdensomeness of their application processes for patents (Blank et al. 2013; Omer et al. 2012), and requiring immunization education is one way to make it more difficult to receive an exemption (Navin and Largent 2017).

Research about mandatory immunization counseling has used both qualitative and quantitative research methods to identify the core attributes and consequences of these policies (Navin et al. 2018, 2019a, b). However, a focus on the *narratives* of immunization educators can both complement existing research and provide new information about the ethics issues involved in mandatory immunization education. A narrative is an ideal format for illuminating immunization educators' frustrations, hopes, resignations, and professional commitments; and reflecting on their stories can provide a richer sense of the practical and ethical difficulties involved in public health responses to vaccine refusal.

Approach to the Narrative

This chapter presents a brief memoir essay based on a composite of Michigan's public health immunization educators. We constructed the character of Margaret from the experiences of 39 Michigan immunization educators whom we interviewed in 2017 and 2018. All of the emotions and events described in Margaret's memoir were drawn from our interview transcripts, and much of the text is direct quotation. Our interviews were part of an empirical research project, which resulted in two publications that reported our qualitative results (Navin et al. 2018; Navin et al. 2019a).¹ Our original goal for that research project did not include the telling of stories. But we were struck by the fact that our research participants frequently responded to our focused interview questions with detail-laden tales about their successes, failures, and frustrations. While we did not include these rich narratives in our earlier papers, in the character of Margaret we have pulled many narrative elements of our research participants' responses into a single story.

We imagine that Margaret has written this memoir to provide a personal, on-the-ground perspective about an exciting, frustrating, and ultimately transformative change in the work her public health department does. Her memoir's narrative arc begins with a sense of hope and optimism about the potential for immunization education to change the minds of committed vaccine refusers. It then explores a period of doubt and bitterness that she suffered through as she faced repeated failures and frustrations in her work. The narrative concludes with Margaret reconceiving the goals of immunization education after reconciling herself to the belief that the work she is doing can make a difference.

We hope Margaret's vaccine waiver education memoir will encourage more nuanced and subtle normative judgments about complicated public health interventions, including state-mandated immunization education.

¹This research was conducted with approval from the Human Subjects Institutional Review Board at Oakland University (#904562).

Narrative

Margaret's Memoir

“If I never have to talk to another person about a waiver in my life it will be too soon.” That’s what I would have told you about my immunization education work in August of 2015. I’m sure I said worse things, too. My colleagues and I were working extra hours to finish as many waiver education sessions as possible before the school year started. We wanted to make sure that as few children as possible would be excluded from school. Our work was hard, cognitively and emotionally, and it didn’t seem like we were doing much good. My original optimism was long gone by then—I no longer thought I could talk parents into vaccinating their children—and I wasn’t yet reconciled to the work. I hadn’t learned to focus on the good things we were doing.

And now?

I still think it’s foolish to try to convince committed vaccine refusers to agree to get their kids vaccinated, especially if you’ve only got 30 min to try, which is why I don’t try to do that anymore. But I’m less angry and frustrated than I used to be. I’ve even started to think that I’m doing some good: I put a positive face on public health, and I find common ground wherever I can. Most importantly, I’ve come to believe that it’s my job—that it’s public health’s job—to be a positive voice for immunization, even among members of our community who are reluctant or refusing. Because public health is what I’m all about.

This is a story about my experiences with state-mandated immunization education in Michigan. But it’s also a story about how I stretched outside my comfort zone to help my state increase its immunization rates.

I have a Bachelor of Science in Nursing (BSN), and I started my nursing career in a private provider’s office, where I ran their immunization program for 4 years. I took a few years off to stay home when my son was born. When I wanted to go back to work, there was a job in a public health department that seemed like a good fit. I’ve been here for the past 8 years. My first job was to work in our clinic, where I gave people shots 5 days a week. More recently, I have done antenatal and postnatal home visits for new mothers and babies or pregnant women. I always advocated for immunizations with the families I visited. And most people were really receptive to what I had to say. People might have had questions about vaccines, but they almost always agreed to receive the ones they were scheduled to get. My work with waivers would end up being really different. I’m going to start saying a lot about ‘waivers’, so you should know that a ‘waiver’ is what Michigan calls a nonmedical exemption to a daycare or school immunization requirement.

For decades, parents in Michigan have had to get their children vaccinated to enroll them in school or daycare. Vaccine mandates are nothing new. But it used to be the case that parents who didn’t want to vaccinate—or had just not gotten around to it—could easily avoid that requirement. The school secretary would just have them sign a form saying that they had a religious or personal belief objection to

vaccines. It didn't even have to be an official state form, and sometimes a school district would have their own form that they'd be happy to have parents sign. These waivers were way too easy to get.

I think a lot of secretaries pushed waivers on parents to make their jobs easier. If parents hadn't finished the vaccine schedule, the secretary would say "Here, sign this, and then go get the shots whenever you can," even if the parents didn't have any objections to vaccines. In 2014, I think Michigan had a higher waiver rate than almost every other state in the country. It was time to do something new.

In December of 2014, I heard that the state government changed the rules for waivers. Parents could still send their kids to school if they weren't vaccinated, but they couldn't just sign a form with the school secretary. Beginning in 2015, they would have to come to the public health department to complete an education session with a public health worker. They could only get the form if they finished the session. And our form was the only one that would let unvaccinated children get into school.

I thought this was wonderful news. Vaccines are public health. So public health professionals should be enforcing vaccine laws and trying to change people's minds. It was time to get Michigan's school secretaries out of the vaccine waiver business. Public health nurses, like me, had work to do.

Waiver education was exciting, but it was new. Public health people have always been doing vaccines, but usually it's with families and individuals who have come to us for help, or who we've been assisting out in the community. There's often been a prior relationship, and a background of trust. Some people we work with have had concerns about vaccines, and we addressed those kinds of worries as they came up. But now we were going to provide legally *mandated* waiver education to people who didn't want to see us. They *had to* come to the health department, often for the very first time.

We didn't have much time to get ready. The new waiver rule was approved in December and my first waiver education session was on January 15, 2015. I had my nursing background to rely on, and think I did ok. But I quickly realized that we were not really prepared.

In August of 2015, the state had a conference in Lansing about how to do waiver education and how to talk to hesitant parents about vaccines. Part of the conference included a live feed with Dr. Paul Offit from Children's Hospital of Philadelphia (CHOP). We also went to the Pink Book conference in 2015. The Michigan Department of Health and Human Services distributed handouts to the local health departments to guide counseling sessions or to give to parents. These were sheets that addressed different concerns parents might have about vaccines. There was one for autism, one for mercury, one for fetal tissue, etc. We had other handouts about religious objections. For example, they told us what to say if a Catholic person said their religion was against vaccines.

There are certain things the state told us we *had to* tell parents. Things like "your child will be excluded from school if there is an outbreak," and "if you go to the Emergency Room, be sure to let your medical providers know your child is not

vaccinated.” We also had to tell them about the risks of vaccine-preventable diseases and the benefits of vaccination.

But each health department got to do things in their own way. (In Michigan, the local health departments report to their local county governments; they don’t work for the state health department.) My health department put together boxes with hanging folders, and each folder had handouts to address different concerns about vaccines. We used all kinds of materials: handouts from Centers for Disease Control and Prevention (CDC), and from its Advisory Committee on Immunization Practices (ACIP); Vaccine Information Statements (VIS); materials from Michigan Department of Health and Human Services; and resources from Children’s Hospital of Philadelphia (CHOP). We also put together lists of reputable websites that parents could review if they wanted to learn more about vaccines. Some were government sources, but lots weren’t. It was not perfect. It was done quickly. But we felt good about what we had done.

We were pretty optimistic at first.

Everybody thought, “We’re going to convince them to go right over to the clinic, and they’re going to get vaccinated.” I originally had really high hopes and thought to myself, “I’m going to save the world and change all these minds.” It was a really prescriptive mindset: we were going to give people valuable information, and then they were going to do the right thing, by agreeing to get their children vaccinated. Why wouldn’t they? When my health department started offering waiver sessions, we required parents to bring their children, because we thought they would allow us to vaccinate their children *right after* the waiver session.

It didn’t take long for us to revisit our original optimism and plans. The first thing we changed was to stop telling parents they had to bring their children. That requirement just seemed to make parents mad, and leaving the kids at home didn’t make any difference, because so few parents were changing their minds.

But the biggest changes were in the attitudes of the waiver educators. After I did my first twenty or thirty sessions, I became a lot less naive. I was kind of in shock about what these parents were saying, and how they refused to see the truth. I would walk away from a session and go, “Whoa where are these people coming from?” I would provide reliable information, and they would just talk crazy to me. I mean, what do you say to people who won’t see reason? I can provide all the facts in the world, but when you get a chiropractor who says, “We believe in manipulation, we don’t give immunizations,” what do you say? I’ve had nurses and even a couple of doctors in my sessions. What do you say to them?

I thought we’d be seeing uneducated people, disadvantaged people. All they’d need was some knowledge, and they’d do the right thing. But the people who come in for waivers were not the poor or refugees—those folks have probably seen these diseases and they wanted vaccines. No, it was the well-educated: “I’m a lawyer, you can’t tell me what to do, I make my own decisions,” or “my husband’s cousin is a doctor and they believe in natural immunity,” or “your body will take care of itself,” or “people who get sick just don’t take care of themselves; they maybe have dirty houses.”

Some parents have said to me, “What’s the big deal about this? We don’t have these diseases anymore,” and then I would say, “Why do you think we don’t have them anymore? Do you realize that only 60 years ago many people were getting sick and dying from some of these diseases? Have you seen an iron lung? Do you have any sense of how afraid people were? They closed pools and schools. When the oral polio vaccine came out, and it was on a sugar cube, parents lined up around the block to get it at the school gymnasium!”

The ones that were really angry when they came in would tell me that their rights had been violated. A woman said to me, “I’d expect you to defend vaccines because you work for the government, and I don’t believe anything that the government says.” I would try to say something positive in response, like “you seem really concerned about your children,” but there’s not much moving forward with the anti-government people. The more you talk, the angrier they get. One of the anti-government parents said to me, “How dare you tell me what to do with my children!” The first year, a lot of attorneys called us because parents didn’t believe that the government had the authority to make them come to our office.

Some of the parents mention religion, but the things they say often don’t seem connected to the teachings of any organized faith. A lot of people have said “God made our bodies to fight off disease.” I used to argue with them. “Sure,” I’d say, “God made our bodies to fight disease, but He also gave us the mind and the ability to create things like the computer and cell phones *and vaccines.*” I tell them that I agree that God wants us to keep healthy, but I see Him as giving us the opportunity and the brainpower to make vaccines that keep us healthy so we can honor and praise Him. Once, a mother told me “the reason I don’t want to vaccinate my children is because Jesus didn’t get vaccinations.” I was so taken aback. And I couldn’t help myself—it just came out—I said “well, Jesus died very young.” I meant to say something like “The life expectancy in Jesus’ time was very low.”

People gave us all kinds of kooky reasons. It’s important that you get a sense that we weren’t just talking about autism or thimerosal all day. One parent told me that her family owned a plane. Her husband was a pilot, and if anyone got sick, they would fly over six thousand feet. The non-pressurized cabin would kill any infections they had, so, no need for vaccines. What do you say to that?

Sometimes the line between eccentricity and mental illness was not so clear. There was a woman who came in and sat in my office, and with a straight face and all sincerity said that she believed that she got a flu shot and somebody injected her with a tracking device, and that they were tracking her, and she knew this because of things that came up on her phone. I was looking at her like, “Oh my God.” I don’t think any of us were equipped to deal with all of the needs that these people came in with. Some of them were way out of our realm.

I used to argue with people about how important it was for their children to avoid infecting other people. Even if their children were strong enough to recover from measles, some of their neighbors or classmates might not have equally robust immune systems. Most parents would just ignore me when I said that, but some would say “I do not care about other people’s children and I don’t care about other people.” I don’t know how you respond to that.

For a while, I absolutely hated doing waiver education. My colleagues sometimes had to put up with me yelling at them because I got so frustrated and tired with the parents we talked to. I'm not kidding! Because these are people that—you know at some point, you look at them and you go, "These people believe crazy stuff, they are bringing this crazy stuff in here and yelling at me," and I can't—it's like trying to reason with a two-year-old. There's no reasoning. How do you reason with somebody who is unreasonable?

Nobody likes being yelled at all day.

I think the first year was the worst. It was literally the worst. The schools did not know what they were doing. Some were still accepting the old forms, and some were not accepting our form. It was a confusing time. And the parents did not know what they were walking into. Some of them thought we were going to yell at them, or lock in them in a room to watch a two-hour video. Many parents seemed frightened or angry or just lost. To be honest, we—on the public health side—were not always as organized as we might have liked to have been. It took a while for everyone to figure out what we were doing.

The work was emotionally draining because I wasn't just talking about statistics and facts, but I was trying to connect with these people on an emotional level, to get them to see that they really needed to vaccinate their kids. Lots of times I walked out of here just shaking my head going, "how stupid, just how stupid." I later found out that one family that came in to get waivers sends their children to my child's school. So that just angered me even more: their kids were putting my kid at risk.

It was hard, and sometimes I got overwhelmingly mad and sad at the same time.

I think the other thing for me that was emotionally wearing were the stories people would tell about how they thought vaccines injured their children. This story always went the same way: "My kid was fine until they got the shot. Something happened and I can't pinpoint it, but something happened and they were different." The first time I heard it I was like, "Yeah, ok, whatever," and then I heard it again. Then I heard it again. I had a woman pull out her phone and show me videos of her kid. It looked like a normal kid. It looked like a normal toddler just toddling around doing its thing. But the kid she brought with her to the waiver session was like a zombie. And then the mom says, "This is the same kid. This is why I don't vaccinate." How can I argue with that? I've heard it so many times now. I don't want to see any more videos.

I've worked hard to reconcile myself to doing waiver education. Things have gotten better.

I do a lot more self-care and mutual support with my colleagues. After you've had a long day of waiver appointments, we have to be able to talk to each other afterwards. We have that, even if it's just a few moments with one person to just decompress and say, "This is new that I heard today," or, "this is what this parent said and this is how I responded."

I also got more interested in learning from the parents who came in for waiver education. I study their body language, try to assess their educational level, and figure out how to get into really having a discussion. That kind of effort helps me avoid focusing on my own attitudes, feelings, and concerns. Maybe this sounds too

clinical, but I try to summon all of my best counseling skills and I sometimes find it exciting, even fun. I think that meeting all kinds of people from different backgrounds, languages, and cultures is extremely interesting.

When it goes bad now—and it still goes bad sometimes—I just remind myself that they are not really upset at me, but at the process.

I've got different goals now. I don't spend as much time talking about vaccines, but I focus on the diseases. A lot of parents come in saying, "I've done the research on the vaccine, I've done the research on the additives," and I always say to them, "But have you researched the *disease*? Do you know what the disease process looks like? Do you understand what complications can arise from getting measles? Do you understand?" A lot of them don't know as much about the diseases. So, a lot of my focus now is forward-looking. What do you need to know if your child gets a bad rash and you have to figure out whether to go to the emergency room? What should you tell the nurses and doctors once you get there? Few medical professionals have seen the diseases we vaccinate against today.

I do a lot more listening now. I always ask, "Can you give me your thoughts on vaccines?" I like to get them talking about how they feel about the vaccines first, and what they are worried about. Is it just because "it's a government issue and I don't want to be told what to do with my own children?" Or is it "I've done all the research and I don't want to put these chemicals in my kid's body?"

If they come with a stack of papers—their 'research'—I now try to diffuse things immediately. I'll say, "Did you bring some information to share with me?" And then I thank them, and I'll say, "I'll look at this later because I am on a time schedule here. I only have a half an hour for you and so we can't really get into great detail here." And I do look at what they bring. It's helpful for us to better understand where they're coming from, but it's also important to show that you respect the work the parents have already put into making vaccination decisions.

I've now got a longer-term perspective. I want parents to know that it's never too late to vaccinate. I want them to leave with a good feeling about me and about the public health department. I'm trying to open doors to the possibility of future relationships. I always tell them it's not my job to change your mind. We just really have a concern—the state does—about the number of waivers that we have.

I hope to plant a seed that they will actually take with them, and do some more research, and open their mind up to the other side of the story. That's my hope. But my bottom line is I'm always going to give them the waiver. I fill it out and sign it in the first moments of our meeting, so they know from the beginning that they're going to get what they came for. That usually drains the negative energy from the room. And it makes it easier for me to do my job, because I can educate about vaccines and diseases without being under a shadow of potential conflicts with parents.

I also hope that people will see the role of public health in a better light. Many people don't understand what public health is or they have a negative attitude about it. We're strangers to them, and for many of these people they're strangers to the health department. They never had to come here. Health departments used to be thought of as places where poor people went. There are still people that think that way. I had a mother call and say, "Am I going to get sick there? Are there a lot of

sick people in your waiting room?” If the people who get waivers leave our building feeling ok about us, then we’ve done something good for the perception of public health in our community.

Most of the people I have interacted with have appreciated what I have said to them, so they thank me. I always greet them, call them by name, and shake their hand. And then when we leave it is always on a positive note. Almost everyone goes, “Thank you so much for taking the time and being so kind and considerate.”

I don’t think as badly about these parents as I used to. I can see that they are trying to do what they think is best for their children. They’ve thought about their decisions and they’ve done some reading. I actually often say, “We all want to do the right thing. We know that you want to do the right thing for your children and keep your children safe and healthy, and so do we.” Many of them are confused and afraid, and they’ve heard so many frightening stories about vaccines. My first job now is to show compassion and to listen.

I used to think mandatory waiver education was going to change the world overnight. Then I went through a period of being angry and frustrated about it. Now I think it’s really important work for me and my colleagues to be doing.

Some of my public health colleagues say that it shouldn’t be our job to do vaccine education. But where else are parents going to hear this information? Physicians’ offices? The physicians don’t know about the vaccines. They may know a little bit, but they don’t really have the time to talk about this issue. Is there education that’s going on in pediatric clinics? Not much, I think. And nurses are the most trusted profession in America—even more than doctors—and we should use that trust when our community needs us. And my community needs me now.

Public health is my calling in life. Waiver education is now another part of how I live my vocation. It’s hard work, but I’m glad to be doing it.

Questions for Discussion

The following questions aim to promote further reflection on ethical issues in mandatory vaccination policies, including mandatory immunization education. For each of the questions, we recommend that you consider how Margaret’s story informs your responses.

1. Is mandatory vaccination ethical? In thinking about this question, consider issues relating to balancing various interests and duties and the appropriate role of government.
2. Should parents have a right to refuse vaccines for their children and if they should, what should be included among ‘parental rights’?
3. How does Margaret’s story impact how you think about parents who refuse vaccines for their children?
4. How does Margaret’s story highlight challenges and opportunities for communicating with parents who believe their child has been injured by a vaccine?

5. Immunization is both a personal medical decision and a vital tool for public health. Accordingly, who should be responsible for educating the public about immunization in the context of vaccine mandate policies?
6. How is state-mandated immunization education similar to or different from other kinds of education that public health professionals provide and how might these similarities or differences impact your consideration of the ethical issues?
7. How might state-mandated education impact trust in public health?
8. Do the potential public health benefits of mandatory immunization education outweigh the burdens (e.g. burnout, moral distress) that this work imposes on public health staff?

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Chapter 12

Using Narratives to Improve Health Literacy – An Ethical and Public Health Perspective



Andrea Glässer, Mirriam Tyebally Fang, Manya J. Hendriks, Nikola Biller-Andorno, and The Swiss DIPEX Research Group

Abstract Most people have little interaction with the health system and tend to be unfamiliar with the prevention, diagnosis, and treatment of even common health conditions. In case of illness, the medical information delivered by health professionals can be overwhelming because of its complexity, unfamiliar terminology, and use of statistical data. Understanding such information requires specific “health literacy” skills. Health literacy empowers individuals to exercise

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their autonomy and self-determination regarding health-related matters. This chapter explores how health literacy and ethical questions are interrelated as illustrated using actual patient narratives of a woman's pregnancy experiences. The narratives were collected as part of the Swiss DIPEX (Database of individual patients' experiences) database. We demonstrate that narratives of health experiences can be used to enhance health literacy. Firstly, narratives can convey complex information in an easily understandable manner. Secondly, they allow policymakers to understand, the informational needs of users of the health care system and the communication gaps they perceive can help improve the health care system and qualitative evaluate and improve medical communication efforts. The chapter ends by raising a number of ethical questions at the individual and health system level related to the use of narratives for improving health literacy for discussion.

Keywords Health Literacy · Patient experiences · Pregnancy · Database of Individual Patients' Experiences (DIPEX) · Vulnerability · Narratives

Public Health Ethics Issue

Many of us have little interaction with the health sector and are often unfamiliar with the prevention, diagnosis and treatment of even common health conditions. When we or our close contacts fall ill, the medical information we receive can be confusing and overwhelming because of its complexity, unfamiliar terminology, and use of statistical data we do not usually encounter in our everyday lives. Understanding such information requires specific skills, which health educators' term "health literacy." Health literacy refers to "people's knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgements and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain and improve quality of life during the life course" (Sørensen et al. 2012, 3). According to the World Health Organization (WHO),

health literacy implies the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions. [...] By improving people's access to health information, and their capacity to use it effectively, health literacy is critical to empowerment. [...] Poor literacy can affect people's health directly by limiting their personal, social and cultural development, as well as hindering the development of health literacy (WHO 1998, 10).

The efficacy of health literacy depends on peoples' understanding of the factors affecting health and their ability to control these factors by placing personal health, family health, and community health into context (WHO 2013, 10–40).

The consequences of limited health literacy include the improper use of medications; improper, under use, or non-use of health services; suboptimal management of chronic disease, and an inadequate response in emergency situations. These

consequences often lead to increasing morbidity and mortality rates, especially among vulnerable groups of people (McDonald and Shenkman 2018, 2–4, Vandenbosch et al. 2016, 1036–38). Patients with limited health literacy also often suffer from a lack of autonomy and low self-esteem regarding health-related decisions and are burdened by higher health-related costs (Zarcadoolas et al. 2006, 2). Additionally, discrimination and stigmatization of people who have a lower level of health literacy can often discourage people from improving their health.

Low health literacy tends to disproportionately impact people with poor functional literacy, a marker of socioeconomic disadvantage. This makes navigating the healthcare system even more difficult, thus further penalizing an already vulnerable population (Watson 2019, 193; Volk et al. 2008, 2–8). Moreover, poor health literacy negatively affects the quality of care vulnerable groups receive, thus exacerbating social inequalities (Sørensen et al. 2013, 72–82). Lower health literacy not only adversely affects individuals but can also negatively impact the entire health system. In Canada, for example, low health literacy accounts for 3–5% of health expenditure (WHO 2013, 8). It raises costs, for example, by increasing emergency room visits and hospitalizations, thus unnecessarily burdening the healthcare system.

Conversely, health literacy empowers individuals to exercise their autonomy and self-determination regarding health matters. Such empowerment contributes to the social goal of maximizing population health by helping to reduce health inequities. This entails increasing everyone's well-being, especially the health of disadvantaged populations (Schröder-Bäck 2007, 108–110; Schröder-Bäck et al. 2014, 3–4). Such efforts further align with the principle of social justice that demands a fair distribution of resources that does not unduly burden or benefit certain groups over others. Social justice efforts go hand in hand with empowering people with a lower levels of health literacy to participate in health promotion and maintenance programs. By contrast, insufficient health literacy thwarts not only society's obligation to maximize health but also efforts to achieve social justice and health equity.

Background Information

Problems with health literacy are not confined to developing countries. It is estimated that almost half of the adult population in America may have difficulties acting on health information (IOM 2004, 65, Sørensen et al. 2012, 2). The European Health Literacy Survey showed a worrisome 47% of respondents with either inadequate or problematic health literacy. Limited health literacy is therefore not just a problem confined to conventionally vulnerable populations but affects a significant majority of the European population (Sørensen et al. 2015, 1057).

In the early 1970's the concept of health literacy was first framed as a matter of social policy (Simonds 1974, 1–5). The current conceptual understanding of health literacy from the WHO Ottawa Charter has changed to, “the process of enabling people to increase control over, and to improve, their health” (WHO 1986). In order to reach a state of complete physical, mental and social well-being, an

individual or group must be able to identify and to realize aspirations, to satisfy needs, and to change or cope with the environment (WHO 1986). This recognizes health as a resource for daily living, and points to the need for political commitment to address health and equity (WHO 1986).

Health literacy continues to be identified by world leaders and global health experts as a key priority to promote health and eradicate poverty in order to achieve the ‘Sustainable Development Goals’ (Shanghai Declaration on Health Promotion, WHO 2016b, 2). Health literacy also remains the current focus of the most recent “Global Action Plan on Physical Activity, 2018–2030”, which aims to utilize health literacy to achieve a healthier world (WHO 2018a, 7).

One-way people try to understand medical information is to look to the experiences of others (Ziebland and Herxheimer 2008, 434; WHO 2016a, 33). Today’s digitally networked societies have great potential to strengthen health literacy. People make their experience more accessible by routinely sharing them and participating in discussions on digital platforms (Ziebland and Herxheimer 2008, 434; Hurwitz et al. 2008, 122).

The potential harm from accessing unverified and unregulated ‘health stories’ via digital formats can be overcome by adapting the wealth of science-based qualitative research into a format that is accessible and understandable to the lay person (Schlesinger et al. 2015, 678). An example of this is the Database of Individual Patient Experiences (DIPEX), which serves as an open access tool for health communication by systematically collecting narratives about health experiences and making them accessible via an online platform. The platform presents a collection of personal stories about health and illness experiences collected through rigorous qualitative inquiry methods, and presented in written, video and/or audio formats (depending on the consent of those sharing their stories). Short segments of these stories are arranged into relevant categories to contextualize information for other patients in similar situations. The site is run by a research team, which ensures the information is reliable. (Law et al. 2018; Ziebland and Wyke 2012, 220; Ziebland and Herxheimer 2008, 434). As an open-access platform, it is accessible to the public without the need for personal accounts or subscriptions, and can be used both on personal electronic devices or on public computers (for example those available at national libraries). The platform can also be used by healthcare staff during clinical interaction, which is also useful for those with restricted access to internet services. The sharing of these stories complements traditional forms of epidemiologic evidence and facilitates health communication, which is the cornerstone of effective public health strategies (Bernhardt 2004, 2051–52).

Including qualitative research methods based on narratives into health service research allows for a critical understanding of lived experiences, e.g. regarding information gaps and specific needs in different populations. Such methods may verify measurable aspects of quality management systems or highlight discrepancies between presumed practice and actual experiences. At the level of the individual, narratives can be shared in formats that overcome barriers of health literacy. Additionally, relatability to narratives has been shown to transcend functional literacy levels and culture (WHO 2018b, 105; WHO 2015, 13). A narrative that is

relatable is one that an individual is able to identify with. A relatable narrative provides a means of contextualizing health-related information to an individual's personal situation, thus allowing a tailored and critical reflection on health-related interventions.

Recognizing the importance of narrative methods, DIPEX has grown into a global movement that aims to reliably document narratives of patient experiences using rigorous qualitative research methods to collect health experiences. Contributors to the database are sampled across a multitude of factors to obtain what is known in qualitative research as a maximum variation sample (Glaser and Strauss 1967, 61). The intent behind this sampling is to represent as broad and comprehensive a range of experiences as possible. Broad sampling from a variety of perspectives helps contextualize information for various health-related uses that can then complement quantitative evidence-based information for public health issues (Entwistle et al. 2011, 297). The ultimate goal of DIPEX is to listen to the voices of participants and to use this information to create meaningful improvements in healthcare.

At the same time, it is important to recognize that there is a certain tension between the ambition of providing high-quality, scientifically valid content and the intention to capture individuals' voices and to allow for a free expression of what matters to people. By setting standards on how participants are chosen, on suitable content or on how interviews are staged, DIPEX establishes a normative frame. The inherent value judgements on what is fitting, proper and important, even though mitigated by qualitative research standards such as negotiating codes and themes in a team rather than having an individual researcher determine them, in avoidably affect the presentation of patients' voices. This may lead to a perceived standard of evidence that excludes voices and perspectives that do not seem to fit – possibly even by self-censorship of interview partners. This tension can be mitigated by considering DIPEX not as an exclusive source but as part of a larger ecosystem that comprises different ways of how patients share their stories, including, for example, self-reports on social media. These freestyle self-reports can inspire additional DIPEX research. Another strategy for dealing with the issue consists of understanding DIPEX itself as a participatory research endeavor by inviting citizen feedback on DIPEX interview guides, processes, and results. This way, the bottom-up component of building health literacy can be maintained without forgoing scientific standards.

Approach to the Narrative

The following narrative about pregnancy experiences is based on an entry in the Swiss DIPEX database. It illustrates how health experiences can promote health literacy at two levels. Firstly, shared narratives can be a way of conveying information that is hard to communicate in a more abstract form (e.g. about the lived experience of a health condition). Secondly, at the level of policymaking, understanding the information needs of users of the health care system and the communication

gaps they perceive can help improve the health care system, which will in turn positively affect health literacy.

The narrative describes Kate, a 28-year-old Belgian woman who lived with her partner in Bern, Switzerland. Kate had been living in Switzerland for 2 years before she conceived. She works for a biotechnology firm, while her partner is a laboratory technician at a hospital. Kate sees herself as career-oriented but has also always wanted a child. Her pregnancy, though much-desired, coincided with a new career opportunity, so she organized her prenatal check-ups to minimize job disruption. Unfortunately, her pregnancy was not an easy one. She shared the following story with us.

Narrative

I found out I was pregnant maybe 4 weeks into my pregnancy. I am new to Switzerland, having worked very hard less than a year ago to get a job here. My gynecologist was someone I was seeing for routine gynecological care before I was pregnant, but he was not at all the person I would have chosen if I had a range of options. I chose him for convenience; he was close enough so that I could see him before work, or in between/during lunch, without disruption. He would usually ask me how I was doing, and let me speak a little, which made sense because then he would know what was on my mind, although he never really commented on what I relayed. He would just say, "Okay, let's check on the embryo." I noticed that he would always call it an embryo, not a baby, and I thought that was smart just in case someone was considering an abortion. I guess that's training, I guess doctors are trained to communicate that way.

The checkups were very standardized. I noticed him ticking things off in his mind, checking this, checking that, and in the end, he would say, "Everything's okay, get dressed." There was not much else. If I had my 'dream' gynecologist, I might have expected a little more empathy and emotional reaction, but then again, he was the one I had chosen to manage my career ambitions during my pregnancy.

I suspected I had prenatal depression and brought it up with him. I expected to be referred to a psychiatrist, but instead, he said, "Well, just chat with the midwives." I was confused, since I didn't have a midwife then, and wondered if one would indeed be able to help me with a psychological issue. I never managed to get the help I needed. If I had one piece of advice to doctors, it would be to think of the woman's emotional frame of mind. I really think a woman's emotional frame of mind is probably more important than her physical condition, and I don't think that that's recognized enough, or that doctors are equipped to handle that. It would be nice for the average doctor to broach that subject and let us know what might be going on emotionally or mentally during the pregnancy.

I had basic insurance, so I just did the prenatal tests that my doctor said were standard and normal. I did what the health insurance paid for, and I wasn't expecting a bad result. I went in that day not because it was a scheduled prenatal screen, but

because I was feeling so sick. My doctor was always very thorough, though, and did an ultrasound anyway. It was the only appointment I went to without my husband, and he has never missed one since. My doctor went, “Oh,” and then he went quiet, and he’s never quiet like this. He kept looking and I realized something was wrong. That’s when I found out what nuchal translucency means, and that her neck was too thick. I was told the risk of Down’s syndrome was one in 16.

We have a school for disabled children near our home, so we could see some children living with Down’s who were really happy. At the same time, I did think, if there was anything where the baby might not survive, or the quality of life would be really poor, it would have been an obvious decision for us to terminate the pregnancy, because I wouldn’t have wanted to just wait for it to happen. Honestly, to this day, I don’t know what we would have actually done. I wish I had the courage to accept a child with a disability, but I have so much fear. I worry about how a disabled child would survive in today’s world. I’m not thinking of how she would thrive, but how would she even survive? The world is bigger than our family, and there are so few opportunities for the disabled. I’ve read that having a mental disability makes people vulnerable to sexual assault, yet at the same time, they aren’t believed when they report a crime. Even something as basic as wheelchair access is so lacking for people with mobility impairments. Financially, it would be a huge burden. I know there is support, but I’ve heard so many stories about difficulties accessing whatever support there is. You really have to jump through hoops, find the right doctors who can diagnose the right things, and then hope it’s covered under existing plans. Even if we could afford the kind of care that is needed now, what would happen after we die? If I’m honest, I also worry about how it would reflect on me – whether people would judge me or fault me for the child I have, whether I would still be welcomed among my own friends, whether mothers would shun us from their playgroups, and whether I would still be valued at work.

I ended up in the hospital because I just couldn’t keep any water down. I expected vomiting as part of the pregnancy, I was told it was a sign of a healthy pregnancy. But I hadn’t realized how different my pregnancy was from other women. I wish I had known, and I would have sought help sooner. Once you throw up for more than 24 h and you don’t urinate, you end up being admitted and get medications and IV fluids. Later, my doctor said my vomiting wasn’t simply morning sickness, but a more serious condition called hyperemesis. When I got the poor prenatal test results, a part of me was thinking, “You know what, this means the nightmare is over.” It’s something I can only say in hindsight, I wouldn’t have dared tell anyone this then. As much as I wanted that baby, a part of me was like, “Oh, I might actually be able to be myself again.”

Someone recommended us a CVS (*chorionic villus sampling – a biopsy of the placenta*) to confirm the results. At his private practice, my doctor had given us a leaflet with all the details – what it covers, what it doesn’t. It was written at a level that I thought was almost too high for the average person. We were referred to the university hospital for the CVS. At the university hospital, I didn’t find that they were helpful in explaining the information, so that was a missing piece for me – to identify someone to follow up with afterwards. We had consent forms, but I don’t

think anyone sat down to talk us through what that really was about. Our doctor had said that they were looking for all the ‘top-line’ mutations, and if we wanted someone to go through all the results, he would send us to a geneticist. My understanding was that they would only refer us if any of the results were off, so we never got to see a genetic counselor. Not knowing beforehand what we were going through, for me was like the floor suddenly collapsing. I was young and didn’t expect to be so sick with hyperemesis. And I almost certainly didn’t expect this test result.

In hindsight, I wish there were someone besides the doctors who talks you through and explains what it is. I can only imagine someone without scientific training going through what I did, and how much more unsettling it might be for them. I tried explaining to my mother what it meant in terms of risks, and if you don’t necessarily have that scientific background and confidence dealing with numbers, it’s really hard. I found a Facebook group of moms in the same situation, and read through the different things they did, and then I found a research advisory group that also offered free advice to mothers who called in. In the end, I received the support I needed through this voluntary group. Something had stuck in my mind, “one in 16, one in 16,” – I was haunted by the number. The first thing one of the volunteers said was, “Flip it around, that’s a 95% chance that everything’s okay. I get that it’s very scary, but there’s only a 5% chance of something being wrong. So, if you were a betting woman, or this were an exam result, it would be very good. It says there’s a 95% chance, this is what it means. Do you want me to explain what your options are afterwards?” And I realized I didn’t know what the options were afterwards. I like planning, and I liked to have a mental plan. Now, whenever I have friends that go through it, when I see that, I always try and get people to turn it into a percentage, because a 95% chance, I think, is pretty good. It turned out that my child did not have Down’s syndrome after all.

In my 12th week, a blood screening test showed that my blood pressure was high (which I later learnt was part of pre-eclampsia), and I was put on daily aspirin. I had to check my blood pressure regularly and had to test my urine every 2 weeks. I was quite hesitant to take the aspirin – my father has high blood pressure and he manages by cutting down his salt and taking some blood pressure medicines. I thought aspirin was quite extreme, something that is given to people with heart attacks or strokes. I was worried about the effect it might have had on the baby. I only took it if I felt unwell, like if I had a headache. I was supposed to deliver at 36 weeks, but I ended up having an emergency Caesarean section much earlier when there were issues with the placenta. Given everything else that I was going through, I didn’t realize how serious my blood pressure issue could have been to my health and my baby, until after I delivered.

Even though the worst of the hyperemesis was over by about 17 weeks, I never really enjoyed the experience of being pregnant with my daughter. Just to be clear, I don’t think my doctor was unprofessional. I just don’t think that support resources were available. Although it would have been nice for my doctor to be more empathetic and to have more time for me, he did do his duty of making sure my pregnancy went as smoothly as possible and preventing any complications from happening to myself and my baby. He was medically competent, and objective. I do

think, however, that other resources need to be routinely available to pregnant women, like access to genetic counselling services so we can understand fully our prenatal tests and their results, or psychological support since pregnancy is such a transformative experience.

Ever since the pregnancy, I've been seeing a counsellor, to work through the things I experienced. I think it is good, because the experience can be quite traumatic. I don't think I ever switched off from that, in spite of the good outcome I eventually had with the birth of a healthy child. A part of me is jealous of some friends of mine who had fantastic pregnancies, even though I am happy for them.

Questions for Discussion

Had Kate had access to other women's experiences in a narrative format, it may have helped her in dealing with her own situation. Narratives about pre-eclampsia may even have had a preventive effect in alerting Kate to her condition. Health policymakers and communicators could benefit considerably from relations such as Kate's by better understanding current communication gaps that need to be addressed to improve health literacy and also patient satisfaction with the healthcare encounter (Britten 2011, 385; Jack 2006, 279).

Still, this narrative raises several ethical questions both at the individual and health system level relating to the use of narrative as a method for improving health literacy. The following questions are proposed to start a discussion about the topic of health narratives related to health literacy:

1. How does discrimination and stigmatization against people who have low health literacy impact health outcomes and effect efforts to address health inequities and achieve social justice?
2. Narratives have been advocated as a means of improving health literacy in vulnerable populations. What is the best way to share narratives to ensure that vulnerable populations have access to information? Are there particular formats (e.g. videos or audio clips) that are best suited for overcoming functional literacy and addressing health disparities? In what situations or with whom do you think the narrative in this chapter would be useful to share?
3. Whose responsibility is it to provide narrative information, and at what point along the health care management process, which includes health promotion, prevention and health treatment or maintenance, would the use of narratives have the biggest impact?
4. How can we ensure that vulnerable populations or minorities are represented in the collection of narratives? How can we show the spectrum of health-related situations, when diversity may not be represented by a small number of narratives? How can we avoid suppressing voices that do not fit the standards or expectations of academic research?

5. The narrator of the story believes that a woman's emotional frame of mind during pregnancy is possibly more important than her physical condition. How might a women's frame of mind affect her pregnancy, and could it also have an impact on physical outcomes?
6. The narrator of the story believes that her doctor fulfilled his professional responsibilities in spite of her unmet psychological health needs. Did her doctor adequately fulfil his professional duties towards her, if he was unable to provide care in an area she perceived as essential to her health and well-being? What barriers did he face in providing/facilitating psychological support during her pregnancy?
7. When using narratives, how would you assess the relative importance of the reliability of the information provided versus its relatability?
8. How do we ensure the emotional pull of stories does not influence patients or users to make decisions contrary to their values?
9. What is the balance between epidemiological and narrative data when presented as evidence for decision-making?
10. Even when narratives are anonymized, personal stories may have unique elements that render them identifiable to personal contacts. How can the personal identity of narrator be protected while keeping the essence of their story?

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Chapter 13

A Novel Approach to Public Health Crises Using Narrative Ethics



Susan E. Zinner

Abstract This chapter examines several public health issues using the novels *The Stand* by Stephen King and *The Andromeda Strain* by Michael Crichton. These two narratives both explore fictional U.S. events, one contained and one out of control, where microorganisms place either a community (The Andromeda Strain) or the entire country (The Stand) at risk. Both novels illustrate the significance of the roles of transparency of public health officials and distribution of accurate information to the public to minimize panic. Similarly, they also address the importance of collaboration of officials at many levels to protect individual, community and national health. When effective, these two efforts establish trust and reduce the spread of epidemics and pandemics worldwide. However, obstacles are many. They include difficult individual personalities which can hamper effective working relationships and the bureaucratic administrative structure of the U.S. public health system.

Keywords Public health · Narrative ethics · Transparency · Communication · Collaboration · Multi-level collaboration

Public Health Ethics Issue

Ethicists like Rita Charon have popularized fictional narrative as a teaching tool that offers a unique approach to exploring ethical considerations (2002). For ethical issues in public health, novels about devastating epidemics which threaten all or part of humanity exemplify the power of storytelling. By allowing readers to learn

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from and identify with fictional characters, such stories can help readers play out how they would respond in a real-life situation. The two best-selling novels discussed below illustrate how a good story and a coherent plot can explore difficult ethical choices that arise during an outbreak or epidemic. Steven King's *The Stand*, published in 1978 and Michael Crichton's *The Andromeda Strain*, published in 1969, examine the impact of life-devastating microbial outbreaks introduced as the result of government activities. *The Stand* portrays an outbreak that impacts the lives of all Americans, while *The Andromeda Strain* focuses on just the two remaining residents of a small town in Arizona. By dramatizing the difficult ethical choices which an outbreak forces upon us, both novels compel the moral imagination of readers to respond.

Mortimer (2003, 447) has argued that an outbreak, like a story, needs a coherent plot in order to ascribe meaning to a random event that creates chaos within peoples' lives. By imposing order upon the unordered, the creation of a narrative allows individuals or communities to cope with uncertainty and loss of control. Similarly, in the wake of disasters that devastate electrical power and transportation infrastructure, public health officials attempt to restore order in practical ways. Public health officials must address mass injuries and death, inadequate food and water supplies, loss of homes, disease outbreaks, and other urgent matters. Gathering useful information about a disaster to create "situational awareness" must be a priority in managing a public health crisis. Sharing this information is both a challenge and a necessity, analogous to the structural coherence a story needs to be successful. Disseminating information can calm a community threatening to unravel under extreme duress. Chaos can only be avoided, however, if citizens trust their government is working on their behalf. Transparency, trust and effective information dissemination—key components of emergency response—lay the groundwork for a coherent strategy that can keep panic at bay.

An effective way to calm the public and build trust is to establish collaborations that focus on ways to mitigate harm. Awareness that experts are working together to solve problems, both anticipated and unanticipated, can reduce panic. Sharing information and building collaborations are mutually reinforcing. Ensuring that collaborations and effective networks are in place to resolve problems can in turn encourage the collection and dissemination of appropriate information. King and Crichton highlight the importance of sharing information and building public trust, especially as the governments in their respective novels directly or indirectly have precipitated the outbreaks.

Background Information

Making key decisions depends on timely and relevant information, which is why its absence cripples decision-making. However, collecting and disseminating such information during emergencies raises several challenges, both logistical and ethical.

Disasters can destroy critical communication infrastructure yet demand a coordinated response from entities unused to communicating with each other while posing a serious logistical challenge for emergency response. The non-hierarchical character of the U.S. public health system only magnifies the challenge. Our decentralized public health system comprises a loosely organized network of about 3000 local, state and federal health agencies (Hearne 2007, 185). Accurately communicating information not only among these U.S. health agencies, but also to millions of American citizens, poses a daunting challenge during a response.

Especially daunting, although rare, are those scenarios where governments or their citizens intentionally create and expose residents to deadly microbes. While the viruses created in these two novels involve fictional events, there are only a handful of times where governments or individuals have deliberately exposed the public to a virus. These include the Sverdlosk anthrax exposure in 1970s Russia, the Raneeshee cult salmonella incident in Oregon in the 1980s and the U.S. anthrax exposure immediately after 9/11 where a few politicians and members of the media were exposed.

Collecting and disseminating public health surveillance information, while necessary during a response, raises ethical concerns. Continued surveillance reveals the extent of an epidemic and whether interventions have been effective. However, the process of screening and testing for a disease, as well as collecting and disseminating this information, poses risks to vulnerable individuals. Living in countries that lack discrimination protection could expose individuals to psychological trauma and economic harms such as loss of employment, insurance, and housing (Gostin and Berkman 2007, 82). The COVID-19 pandemic has raised issues such as the inappropriate use of contact tracing apps for purposes such as the gathering and storage of personal data not needed for health purposes (Xafis et al. 2020, 74–5).

Public health officials have an obligation to “inform and educate the public about health issues and functions” (American Public Health Association 2019, 16). However, inadequate or inaccurate dissemination of information by the media or other sources during a disaster raises distributive justice concerns. Those with few resources have less reliable access to sources of credible information and therefore lack of credible information has the greatest potential to harm them (Gostin and Powers, 2006, 1058). Historical data confirm that poorer countries fare far worse in pandemics (Faden 2007, 178). To address these justice concerns, health officials, other governmental representatives, and the media need to distribute accurate information in ways that can reach even the most disadvantaged communities.

One important set of decisions during an emergency response involves resource allocation. These decisions raise important justice considerations relating to how to best balance utility and equity. Public health officials may—at times—need to allocate resources based on equity and not equality; that is, it may be necessary to provide a greater share of resources to those especially vulnerable. Doing so, however, may not result in the greatest utility in terms of efficient use of limited resources. To be effective and sustainable, health interventions for marginalized groups facing health inequities must address the root causes of the inequities. This will often necessitate that systemic change be put in place prior to an emergency, such as law

reform or drastic changes in economic or social relationships (World Health Organization 2016; Xafis et al. 2020). In an era of global interdependence, trade, and travel, illnesses and epidemics can spread much more quickly than in the past. Health officials in each country may need to exercise their authority to limit the freedom to travel or to import products that pose health risks. Success in imposing restrictive measures depends on a community that trusts its public health officials, but trust does not develop overnight. Transparency helps to build trust, but transparency mandates that decisions be made openly and communicated to everyone impacted by a decision, that is, the stakeholders. Ensuring that stakeholders generally have a voice in decision-making will enhance the probability of compliance with short-term limits on freedoms. However, emergency response often requires expedited decisions without immediate stakeholder engagement. To build trust, then, public health officials must engage stakeholders in preparations well before an emergency event takes place.

International bioethics mandates a culturally sensitive approach. For instance, individual autonomy must often cede to the welfare of the community (Battin et al. 2009, 8–9). Practitioners from Western countries that prioritize individual rights may face challenges when working in locales where a communitarian approach is more common. These practitioners need to be prepared to place the importance of community health and welfare above individual autonomy and beneficence. It is worth adding that imposing liberty-limiting measures also invokes the primacy of the community when the exercise of individual freedom could harm the public during an emergency. However, imposing liberty limiting measures in a society that privileges liberty will be more difficult. Nevertheless, the larger point is that emergency situations underscore the need for public health officials to collaborate with communities and focus on their welfare.

Approach to the Narrative

This section contains brief excerpts from *The Andromeda Strain* and *The Stand* that deal with information collection and sharing and with collaboration. I used the 1993 version of *The Andromeda Strain* since it was readily available. I used the 1990 complete and uncut edition of *The Stand* since it is King's preferred version of the novel and contains material that was removed from the original 1978 novel. These excerpts illustrate the importance of these activities to the ethical practice of public health, especially during emergency events. Both novels address the role of information in public health decision-making and how teamwork and collaboration can better inform the decision-making process. Although fictional, these stories nevertheless raise many issues that likely would arise in real-world scenarios. I will explore how the two novels demonstrate the need for appropriate information and for collaboration, how each author addresses ethical issues, and how these issues are, or are not, resolved.

Narrative

Need for the Collection and Sharing of Appropriate Information

First, consider the need to base public health programs on appropriate information. Characters in both novels operate in a constant environment of fear. Information is a tool, perhaps the best tool available, to control fear. Public health officials use scientific information to determine which intervention is best to combat the public health crisis. Is contact tracing appropriate? Should quarantine be considered? Should travel restrictions be imposed? While there may not be enough information for public health officials, scientists and others to make informed decisions, especially early in a pandemic, they often must act, even with inadequate information. In Michael Crichton's 1969 novel, *The Andromeda Strain*, a military satellite returns to the United States and lands near a small town in Arizona. When military officers attempt to retrieve it, they find that virtually all residents of the small town have died. The town members appear to have been struck down immediately as radios and televisions are still turned on and appliances are still running. Only an elderly alcoholic man and an infant are left alive. They are taken by government scientists along with the satellite to a remote research facility in an attempt to find out why these two have survived and to investigate bacteria found on the satellite. The town is cordoned off. Scientists have a limited amount of time to save these two survivors and determine how to destroy the bacteria which appears to be the source of the epidemic. Since virtually the entire town's population has died, the operation is aptly called Wildfire, after a fire which burns out of control and threatens to destroy everything in its path. The scientists do not yet realize, however, that the population of the planet may be in jeopardy in just days. Only the judicious exercise of scientific knowledge will prevent Wildfire from destroying more lives.

A character in *The Andromeda Strain* alludes to scientific errors that follow The Rule of 48, which states simply: "All Scientists are Blind" (Crichton 1993, 125). The name of the rule refers to scientists who routinely accepted that humans possessed 48, not 46 chromosomes, despite over a decade of evidence to the contrary. Scientists, then, can collectively ignore clear evidence staring them in the face. The Wildfire team was aware that the bacteria were both mutating and reproducing at a rapid rate, but somehow the evidence did not register with them. If the team had been more attentive to the evidence and considered why these two extraordinary characteristics of the bacteria were occurring, the solution might have been revealed days earlier. "[S]pace could affect reproduction and growth. And yet no one in Wildfire paid attention to this fact, until it was too late" (Crichton 1993, 128). As it turns out, the version of the bacteria mutated by the satellite trip to space will endanger virtually every human on earth.

Later in the novel, even certain biological assumptions are called into question, including the definition of life (Crichton 1993, 194). One scientist recalls a famous seminar where a well-known researcher persuaded others present that a black cloth, a watch and a piece of granite all met the definition of life (Crichton 1993, 195–6).

He makes such compelling arguments that each of the three inanimate objects are, in fact, alive that audience members reluctantly conclude that he may be correct. Similarly, in order to resolve the conundrum presented by the bacteria from space, the researchers will need to think in new and original ways to solve the very complex problem confronting them. Leavitt, one of the key scientists on the Wildfire team, recalls this lesson and endeavors to remain flexible in his approach to the problem and not jump to conventional conclusions despite the fact that two lives and ultimately—millions—depend on a swift resolution to the problem. And yet, errors are inevitable on any path to discovery when, “despite the individual brilliance of team members, the group grossly misjudged their information at several points” (Crichton 1993, 237). Their errors, in retrospect, were inevitable, according to the scientists in the novel. “What they did not anticipate was the magnitude, the staggering dimensions of their error. They did not expect that their ultimate error would be a compound of a dozen small clues that were missed, a handful of crucial facts that were dismissed” (Crichton 1993, 237). The scientists created a chain of causal inferences; reasoning correctly but from false premises, the errors cascading as they added new false premises. Unfortunately, the correct premises, the crucial facts upon which sound reasoning must rely, are often overlooked, appearing crucial only in retrospect.

The emphasis in *The Stand* is on the information—or lack thereof—available to community members, not scientists and researchers. In Steven King’s 1990 novel, the survivors gather into one of two camps, those who dream of Mother Abigail (the good) and those following Randall Flagg (the evil). In this dystopian future, survivors soon find themselves drawn to one of the two leaders. While the camps of both Flagg and Mother Abigail offer little order, at least at the beginning, those drawn to the prior world of law and order are at home with Mother Abigail, while the false promise of technology—the source of the virus—appeals to the follows of Flagg. Only a few characters waver; most know where they belong.

King imagines that not only this virulent strain of influenza, but also human greed and suspicion, would likely undermine the cooperation survivors need in order to survive. Even some characters who survived the deadly flu cannot survive their neighbor’s selfishness. While there are many characters, the novel focuses on three. Fran is a young woman who is pregnant. Stu is her new partner and fellow survivor who becomes the reluctant leader of the new community drawn to Mother Abigail. Finally, there is Harold, who loves Fran, but ends up joining the camp of Randall Flagg when Fran chooses Stu for her partner.

An early passage in *The Stand* dramatically foreshadows the possibility of citizens seizing control of a radio station or newspaper in an effort to learn the truth or distribute the limited information they have available (King 1990, 214–30). As government officials have been withholding information, most Americans never learn about the cause of the outbreak or its impact as it spread throughout the country. Often, they first encounter the pandemic through the death of immediate family members. It should not be surprising, then, that survivors distrust the U.S. government and turn to each other in order to survive. All efforts to obtain information end badly, as the government shuts down media outlets and kills those trying to

ascertain the truth and distribute information. Even the President of the United States shares blatant lies in a misguided attempt to calm the American public (King 1990, 229). Without access to knowledge and information, the remaining survivors face a vacuum of fear and uncertainty.

After learning that Stu appears to be immune to the virus, government officials involuntarily hold him at a research facility in Vermont to take blood samples to use for development of a possible vaccine. During this time, information is withheld from him, both about the work being done at the lab and the spread of the pandemic. With nearly everyone at the facility dead, Stu must kill an official in self-defense to enable his own escape. His experience there echoes the prevailing sentiment that, with no help coming, individuals must save themselves. After his escape, Stu tells his friends that reliance on traditional social institutions is no longer an option. In the following passage, Stu shares with his friends his uncertainty about the future, while the reader learns that all the traditional social structures that we have taken for granted no longer exist. Imagine a world where science, medicine, journalism, education and everything we depend on are gone.

Assume that the age of rationalism has passed. I myself am almost positive it has.

It's come and gone before, you know; it almost left us in the 1960s, the so-called Age of Aquarius, and it took a damn near permanent vacation during the Middle Ages. And suppose...suppose that when rationalism does go, it's as if a bright dazzle has gone for a while and we could see..." He trailed off, his eyes looking inward.

"See what?" Fran asked.

He raised his eyes to hers; they were gray and strange, seeming to glow with their own inner light.

"Dark magic," he said softly (King 1990, 742).

When rational explanations fail to comfort survivors, then magic, even the appeal of black magic—or evil—offer some appeal. Randall Flagg offers empty promises, tempting each character by offering what each needs to be happy in this new and irrational world. Those who remain with Mother Abigail are realistic enough to know that their new world requires that they depend on each other to face the many challenges ahead.

Both novels raise similar issues regarding the need to base public health responses on appropriate information. The media, including social media, play a significant role in distributing information. Today, even though Americans have access to more information, that information may not be of high quality. Similarly, though it has become easier to verify information by checking reliable news sources, many people cannot determine which sources are reliable (Rampersad and Althiyabi 2020). As a result, finding appropriate information today is harder than it should be. Deliberately sowing misinformation exacerbates these difficulties and can eventually undermine confidence in the media. History teaches us that when governments hide information, it almost always harms public health efforts and contributes to the spread of disease (Markel 2007, 50). Moreover, lack of transparency and giving out misinformation destroys trust, which undermines the willingness of the public to share critical but sensitive information with all levels of government.

Developing and using good communication systems is vital in multiple ways. They are essential for transparency both at the bottom and at the top of the chain of command (Battin et al. 2009, 325). A government-initiated public health program will be less effective if it withholds information or is perceived to be sharing inaccurate or dubious information. Conversely, citizens more consistently comply with instructions when they understand their purpose. If vital information is unavailable, citizens drift along without guidance or direction and become prey to their emotions. As Reynolds has noted, the importance of consistent, timely and meaningful messages issued after a public health emergency cannot be underestimated. Exhibiting both competence and empathy—while emphasizing the likelihood that our knowledge about the health issue and instructions for the public are likely to change as public health officials and physicians learn more about the illness—is crucial to the success of policies developed by government officials’ (Reynolds 2005, 48–51).

In *The Stand*, crucial information is generally unavailable. Virtually everyone with key information about the outbreak has died; survivors must attempt to figure out the new world order on their own. Applying guesswork to the limited information available, they sometimes succeed and sometimes do not. Early in the novel, soldiers acting on government orders kill anyone attempting to provide information on the pretext that the information would incite panic. In *The Andromeda Strain*, the government deliberately withholds information until they can subdue the bacteria. This short-term gambit works without any backlash, since the scientists are able to subdue the bacteria. One can speculate, however, about potential long-term consequences of this lack of transparency and the damage to the trust in scientists it would have caused had their efforts failed and the incident became public.

The Need for Collaboration

The second public health issue addressed by both novels is that of the need to establish collaborations to build trust. *The Andromeda Strain* illustrates the point that working together to solve a common problem does not require everyone to like each other. Early in Crichton’s novel, we learn that “Manchek disliked Jagers, who was effete and precious. But Manchek knew that Jagers was good, and tonight he needed a good man” (Crichton 1993, 16). Competence would prove crucial in order to achieve the common goal of defeating the bacteria before it overwhelms the planet. Whether the task requires technical knowledge or a social skill such as communication, the team must first trust that each team member is competent to complete the assigned task. Trusting each other will lead to a more effective collaboration.

In *The Stand*, the stress of the new world order causes the lives of the non-scientists to become complicated. The characters experience the emotional toll of “the tremendous, walloping psychological shock of the empty countryside” (King 1990, 417). They all need to share their experiences (“They had stories to tell. All the stories were the same. Their friends and relatives were dead or dying.”) (King

1990, 232). Unsurprisingly, they all entertain fears about the uncertain future (“...some leader or leaders who will start the whole thing again. Maybe a fear of technology in general.”) (King 1990, 347).

In a thought-provoking exchange, Stu muses that Randall Flagg, who is drawing the evil survivors to his camp in Las Vegas, will probably collect most of the “techies,” since they are attracted to discipline and linear goals. The two new competing versions of society offered by Mother Abigail and Randall Flagg offer visions of a world which embraces different values. Flagg and his followers are choosing technology and science, ironically the source of the virus. Mother Abigail is choosing to create a democratic society that is necessarily messy and awkward at its inception. Flagg headquarters in Las Vegas, governing there with an authoritarian harshness that appeals to some, especially those seeking structure. To Harold, stung by Fran’s rejection, the dark order of Flagg and Las Vegas induces him to leave Mother Abigail and her followers. “The malignancy drew him in. It was a dark carnival—Ferris wheels with their lights out revolving over a black landscape, a never-ending sideshow filled with freaks like himself, and in the main tent the lions ate the spectators. What called to him was this discordant music of chaos” (King 1990, p. 683).

Successful collaboration demands those with multiple skills be welcomed, whether the skills be technological or not. The need for different competencies may vary depending on the nature of the crisis, during which public health officials will need to tap a wide array of individuals. In *The Stand*, this is reflected by the need, at different times, for manual labor skills, high-tech skills and other specific competencies. At other times, those with high levels of ability in multiple areas may be needed.

In both novels, government’s role in the epidemic has made collaborations more challenging. In *The Andromeda Strain*, the U.S. government failed to protect Americans living in a small Arizona town from the bacteria collected on its satellite, ultimately causing the death of most of the town residents. In *The Stand*, the U.S. government’s experimentation with flu as a bioterrorism tool has accidentally made its way to the public. In the event of such a devastating accident, public official must be prepared to face a suspicious and wary public. As Harold tells Fran:

My dear child...sorry, Fran. Fran, it was the people in authority who *did* this...Your somebody in authority got a bunch of bacteriologists, virologists, and epidemiologists together in some government installation to see how many funny bugs they could dream up. Bacteria. Viruses. Germ plasm, for all I know. And one day some well-paid toady said, ‘Look what I made. It kills almost *everybody*. Isn’t it great?’ And they gave him a medal, and a pay-raise, and a time-sharing condo, and then somebody spilled it (King 1990, 252).

This passage raises the issue of the obligations of scientists to the broader community and possibly future generations. Harold here also notes that science had an obligation to take action to protect the public from the harmful effects of an inadvertent release. Likewise, in *The Andromeda Strain* the fate of the world literally hangs in the balance due to research error. Both novels can be viewed as cautionary tales, offers a warning to the scientific community that they have an obligation to protect current and future generations from potential harms caused by their research.

Priscilla Wald, writing about outbreaks, points out that epidemics dramatize the need for regulation (Wald 2008, 17). For instance, the increase of limb deformities among pregnant women who were prescribed thalidomide to prevent morning sickness in Canada, Europe and Africa, resulted in the United States passing the 1962 Kefauver Harris Amendment and the Food and Drug Act to strengthen the regulatory environment for new drugs (Rieder and Hawcutt 2016, 1308). Similarly, food-borne outbreaks have resulted in tightened agricultural regulations. Collaborations among individuals and organizations help to achieve the goal of regulation as a tool to address the source of the epidemic. In fact, national responses to epidemics and public health crises have helped define our modern understanding of not only public health but also the notion of a population itself. (Wald 2008, 17–18, citing Rosen 2015). The two are interrelated; that is, a nation cannot develop its public health response without first understanding the population for whom the response is being readied. Wald even references the first chapter of *The Stand*, commenting that the spread of the virus through the most casual person to person contact, which will ultimately end the world as it currently exists, represents “the protagonists’ common humanity through their common susceptibility” (Wald 2008, 54). Viruses and bacteria draw humanity together paradoxically by not respecting our borders. “Rats hop ships and spread the plague, mosquitoes stow away on airplanes or infest new regions as the climate warms, and birds migrate around the globe. Infections that emerge in one corner of the earth may cause deaths far away” (Battin et al. 2009, 38). Ironically, humanity might best address vectors and their disrespect for our borders and divisions, when nations and different sectors collaborate to fight them.

Collaboration is not mere massing. The establishment of a broad consortium of individuals involved in decision-making will ensure that diverse points of views and differing values are shared and heard. As global stakeholders, it is crucial that the views of representatives from all populations likely to be impacted by decisions are heard and respected. A more diverse array of potential solutions on the table increases the chance that decision makers will be able to avail themselves of an effective solution.

In summary, basing programs on appropriate information and establishing collaborations to build trust, are essential to any public health response to an epidemic. These twin efforts will ensure that all stakeholders will be heard and respected. Improving the health of a community is a broad and challenging goal that, just like a novel with a complex plot, has a compelling story at its heart, which can be a potent teaching tool.

Questions for Discussion

1. In *The Stand*, 99% of the population has already perished and the government does not want the remaining survivors to panic. Does this circumstance justify withholding information from the public? Why or why not? If not, would any circumstance justify withholding information from the public? What value or concern might outweigh transparency?

2. Are there any circumstances where it is justifiable for the government not to seek input from stakeholders before making a decision that impacts them? If not, why not? If yes, describe the circumstances and indicate what justifies the decision to not seek input.
3. In *The Stand*, Stu says “techies” would be drawn to those working to oppose public health officials attempting to restore order in the event of a life-changing public health crisis. Whether Stu’s view characterizes or caricatures techies, it suggests an opposition between the public and experts. Today, there is a growing lack of trust in expertise. Are there steps that public health officials can take now to counter the loss of trust in expertise?
4. In times of international crises, collaboration is essential, yet different countries will make different assumptions about values and concerns to prioritize. What measures can countries take in order to effectively collaborate during crises given these differences?
5. In both novels, the U.S. government bears some or all of the responsibility for the illness that killed many people. If this were to happen in a non-fiction setting, what obligation does the government have to address the harms they have caused during and after a public health crisis? If yes, how should this obligation be fulfilled?
6. Do these novels provide any lessons for responding to current or future public health emergencies, such as the COVID-19 pandemic?

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Part VI
**Public Health Ethics Narratives – Freedom
and Responsibility**

Chapter 14

Naming the Patient: Partner Notification and Congenital Syphilis



Jo A. Valentine and Gail A. Bolan

Abstract Urgent public health problems often compel Public health professionals into situations where individual rights and population health are seemingly in conflict. Legal actions that impact an individual’s behavior may be ethically justified, but the exercise of authority alone, despite being legal, may not always be the best option. Public health interventions are more effective when practitioners have gained an individual’s trust and compliance becomes voluntary. Cooperation, not confrontation, at the individual and at the community levels, is as necessary as authority. Applying an ethical framework in the case of partner notification (PN) for sexually transmitted disease intervention supports the process of relationship-building between the practitioner and the client and leads to more successful disease intervention and prevention, promoting public health, and improving trust between local health departments and the communities they serve.

Keywords Partner notification · Congenital syphilis · Syphilis · Ethical framework

Disclaimer: This paper is presented for instructional purposes only. The ideas and opinions expressed are the authors’ own. The paper is not meant to reflect the official position, views, or policies of the editors, the editors’ host institutions or the authors’ host institution.

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Public Health Ethics Issue

Public health practitioners often encounter situations where individuals' rights and population health are in conflict. This happens more frequently in countries like the United States where greater value is placed on the principle of individual liberty. Public health practice respects personal autonomy, human rights and civil liberties, extending respect even to people who refuse medical treatment; but one relevant harm that public health is both obligated and authorized to address is the spread of communicable diseases. In other words, one's liberty rights become subject to limitation, when the exercise of that liberty threatens the health of others (Gostin and Wiley 2016, xvii). Limiting the spread of communicable disease may require coercive legal measures that impact an individual's behavior and, in some circumstances, can be ethically justified. Yet the exercise of authority alone, even when legal, is not always the best option. Exercising authority can provoke resistance, and it often fails to sustain improved health status. Public health policies, practices, and actions often are more efficacious when practitioners have gained the public's trust and compliance is voluntary. Cooperation, at the individual and at the community levels, is as necessary as authority (American Public Health Association 2019).

When the intimate act of sexual intercourse leads to the transmission of a sexually transmitted disease (STD), it can become a public health matter. Partner notification (PN) is a core public health intervention for the prevention and control of sexually transmitted diseases (Desir, Ladd and Gaydos 2016). The intervention entails contacting any person potentially exposed to an infection to notify them that they may be at risk for disease and may need treatment (Barrow et al. 2020, 9–10). Legal authority for PN rests with the states, and the service can vary among states and local jurisdictions, but adherence to basic PN program principles is common. While *patient-referral* is encouraged, most jurisdictions across the United States implement PN mainly by *provider-referral*, or more specifically *health department referral*, which involves public health workers called Disease Intervention Specialists (DIS) (Hogben 2007). Sometimes without much, if any, warning a DIS may show up at a person's residence, place of employment, or even in a street encounter to inform the person that they may have been infected with a disease that is generally considered stigmatizing (Rusch et al. 2008).

According to Centers for Disease Control and Prevention (CDC) recommendations, participation in PN should be voluntary and not coerced (CDC 2008). Individuals retain the right to refuse PN services. To be effective, health departments should ensure that the *index patient* and the *partner* voluntarily choose to: (1) provide information about themselves and others in response to questions and requests from a DIS; (2) notify others of their possible exposure to an STD; (3) accept STD testing and treatment; and (4) engage in behaviors that promote health and reduce risk for transmission or acquisition of STDs (CDC 2008). However, in some instances voluntary participation in the intervention may not be achieved. An STD index patient may be unable to or unwilling to identify his/her sex partners.

Other times, the named partner may choose to decline the notification intervention (Magaziner et al. 2018).

Despite studies that suggest that provider-referral, if used, can increase the likelihood that named partners will receive treatment (Fleming and Hogben 2017), historic patterns of injustice and indifference can leave many individuals, particularly those from disadvantaged communities, suspicious of a public health worker's concern for their welfare (Armstrong et al. 2013). Furthermore, a given partner's misgivings about PN may be exacerbated by the fact that the DIS is obligated to protect the index patient's identity and therefore cannot disclose this information to the partner (Hunter et al. 2014).

In the case of PN for STD intervention this reasonable distrust needs to be recognized, understood, and worked through, the urgency of disease transmission notwithstanding (Sankar et al. 2003) Applying an ethical framework to the PN intervention can support the process of building a relationship between the DIS and the client leading to more effective disease intervention and prevention, promoting public health, and improving trust between local health departments and the communities they serve (Cunningham et al. 2009).

Moreover, health care providers outside of the traditional public STD clinic settings increasingly are addressing sexual health care service needs. Several studies, for example, report that primary care clinics may be diagnosing up to half of reported STDs, and in 2018, 71–80% of STD cases were reported from non-STD clinics (Barrow et al. 2020, 1–2). Public health providers, i.e., health departments, will likely be more effective in their STD prevention and control efforts if they are able to establish partnerships not only with other health and social service providers but also with the communities they seek to serve (Valentine 2018).

Background Information

In the United States there are four nationally notifiable STDs: chlamydia, gonorrhea, syphilis, and chancroid. Health providers and laboratories are required by statutes and regulations to report cases or positive lab results of these conditions to state and local STD programs, who in turn provide agreed upon data without personal identifying information to CDC where national summaries are generated. The combined cases of syphilis, gonorrhea, and chlamydia reached an all-time high in the United States in 2018 (CDC 2019). In addition to individual-level risk behaviors (e.g., multiple sex partners, lack of condom use), research shows that social determinants of health also predispose populations to health threats such as sexually transmitted infections (Avey et al. 2013). To be effective, public health interventions must account for, and where applicable, address these determinants. These determinants can include income, housing, education, discrimination, and access to health care. Even transportation, or the lack thereof, can act as a determinant of health in disadvantaged communities since STD clinics can be inconveniently located from

neighborhoods experiencing higher burdens of STDs, and in many situations, public transportation may not be available (Syed, Gerber, and Sharp 2013).

According to CDC's Division of STD Prevention in their 2018 Sexually Transmitted Disease Surveillance Report, from 2017 to 2018, cases of gonorrhea in the United States increased to more than 580,000, the highest number reported since 1991; and cases of chlamydia increased to more than 1.7 million, the most ever reported to CDC (CDC 2019 3–23). There were also more than 115,000 syphilis cases in 2018. The number of primary and secondary syphilis cases, the most infectious stages of syphilis, increased 14% to more than 35,000 cases, which is the highest number reported since 1991 (CDC 2019, 24–31).

Syphilis, caused by the bacterium *Treponema pallidum*, is sexually transmitted from person to person by direct contact with infectious lesions such as a syphilitic sore, known as a chancre. The exception is pregnant women with syphilis, who can transmit the infection to their unborn child directly via the bloodstream. In the United States, as in most higher-income countries, syphilis occurs disproportionately among marginalized populations, among people who are poor with inadequate access to health care (Hook 2017). Transmission of syphilis within a sexual partnership depends on many factors, including the frequency of sex, type of sexual contact (i.e. penile-vaginal, penile-anal or penile-oral), the stage of infection in the source patient, and the susceptibility of the partner (Stoltey and Cohen 2015) Transmission of syphilis can occur during vaginal, anal, or oral sex.

The rising rate of infectious syphilis with its disturbing implications for infant mortality is a special concern. *Increases in infectious syphilis among women of reproductive age leads to increases in congenital syphilis, a disease that occurs when a mother with syphilis passes the infection on to her baby during pregnancy. Between 2014 and 2018, the syphilis rate among U.S. women increased 172.7%. More notably during this same period, the rate of infectious syphilis among reproductive-aged women (aged 15–44 years) increased 165.4%. Consequently, among newborns, syphilis cases increased 40% between 2014 and 2018 to more than 1300 cases (CDC 2019, 24–31).*

Congenital syphilis, the consequence of untreated syphilis in pregnant women, kills babies (Peeling et al. 2017). In some cases, death occurs during the pregnancy, in other cases, soon after birth. If an infected infant survives the disease, the infant can have both physical and mental developmental disabilities. In 2018 there were 78 syphilitic stillbirths and 16 infant deaths. (CDC 2019, 29–30). This is an especially tragic statistic, since most cases of congenital syphilis are preventable if women are screened for syphilis and treated early during prenatal care (Rubin 2019). Screening for syphilis at the first prenatal visit to prevent congenital syphilis is standard of care and legally mandated in most U.S. jurisdictions (Warren et al. 2018), although that assumes there is a prenatal visit and many disadvantaged women lack access to prenatal care. It is not unusual for pregnant women to be treated prophylactically, even at the risk of overtreatment, to protect the baby (Lago 2016).

Approach to the Narrative

Published in 2015, federal treatment guidelines include specific recommendations for screening and treatment of pregnant women to prevent congenital syphilis (Workowski and Bolan 2015, 69–78). However, in a world where the women at risk of transmitting syphilis to their babies are also often at risk for numerous negative determinants, what should be routine can become complicated. Nevertheless, for STD programs, getting pregnant women in for testing and treatment is a priority, particularly in the case of syphilis (Kimball et al. 2020). The narrative that follows, based on an actual PN case, describes the complex challenges one local STD clinic DIS and clinic director encountered when seeking to prevent a congenital syphilis case. Linda, an experienced DIS, learns from her syphilis index patient, Tony, that one of his sex partners, Jeanie, might be pregnant. Going with what little information Tony is able to provide, Linda launches an urgent search for Jeanie and finds her. Jeanie, however, refuses treatment.

Narrative

For Linda when it came to syphilis it was all about the babies. Fortunately, Tony was able to give Linda Jeanie’s last name and the neighborhood where Jeanie usually hung-out. Unfortunately, Tony did not have an address for Jeanie. This meant Linda was probably going to have to approach Jeanie in a public setting, on the street. Linda hated when that happened.

Before heading out to look for Jeanie, Linda huddled with Charles, her DIS supervisor, in his cramped cubicle that served as an office, to go over the details about the case.

“I asked him if he paid her for sex but he said no,” Linda reported as Charles jotted down notes. “He just helped her buy some groceries,” Linda continued. “So, I said ‘You’re friends then?’ and he said not really. But he sure wanted me to know it’s not his baby.” Linda said. “He just helps her get by.”

“But he seems to know her pretty well,” Charles observed. “You think he’ll talk to her?”

Linda shook her head doubtfully.

“Probably not. I wouldn’t chance it. Not with her being pregnant. At least I got a good description. I know who I’m looking for.”

It took her a couple of trips to the neighborhood Tony had directed her to, but Linda eventually found Jeanie, coming out of a convenience store. “Oh my God,” Linda whispered to herself that day, as she sized-up Jeanie’s skinny frame with its protruding belly. “She is pregnant!” How far along was she, Linda worried. Was the baby okay?

Frantically Linda parked her car in a no-parking zone, tossed her government *Official Business* sign onto the dashboard, jumped out of her car. Jeanie, unaware

that she was being followed, ambled along, sipping from a can of soda. When she stopped at the intersection to cross the street, Linda was able to catch up with Jeanie.

"Excuse me," Linda started. "Jeanie?"

Bristling immediately Jeanie examined Linda with a mixture of alarm and suspicion.

"How do you know me?" she demanded.

"I'm from the health department," Linda launched into her introductions and health appeal, flashing her health department badge.

"So, what do you want with me?"

"You see," Linda carefully began her explanation, "Someone you recently had sex with and who cares about your health--"

"Get lost!" Jeanie cut her off and stalked off into the street.

"Wait!" Linda called-out, hurrying after her. "Please! I need to talk to you. It's important." When she caught up to Jeanie again, Linda pleaded, "It's an important health matter."

"I said get away from me," Jeanie said sharply and kept walking.

Other people were all around, on the sidewalk, driving by. Linda noted the side-eyed glances they were getting and regretted them. If she could just get Jeanie to stop and talk, they could go back to Linda's car and thereby have some privacy.

"I just need to talk with you," she replied, mindful of her voice, even as she kept pace with Jeanie. "It could hurt your baby."

"You don't know anything about me," Jeanie shot back picking up her pace.

Linda's conservative pumps were no match for Jeanie loosely laced Nike's. The skinny pregnant woman was agile despite the basketball-size passenger pouch in her middle, and Linda was falling behind. In a breach of protocol, she reached out and caught Jeanie's arm and thankfully Jeanie stopped.

"You may have been exposed to syphilis," Linda said a bit breathlessly. "You need to come to the clinic. You need treatment."

"For what?"

"For syphilis," Linda said softly.

"Who said I have syphilis? Nothing's the matter with me." Jeanie pulled away from Linda's grasp. "How do you know. You don't know anything about me."

"I know your name. I knew where to find you."

"Just 'cause some bitch is talking bad about me don't prove nothing."

"Someone you had sex with, someone who cares about you. Who cares about your baby and wants to help you."

"Who? Who says I had sex with them?"

"I can't tell you. But please, is there somewhere we can talk privately? Do you live close by?"

"I'm not telling you where I live."

"Okay, okay," Linda hastily offered. "Let's talk in my car."

"I got nothing to say to you," Jeanie cut her off.

"Like I said I'm from the health department," said Linda again, once more offering her badge as proof. "Straight up," she pleaded. "This is serious."

“I don’t believe you,” Jeanie snapped, ignoring the badge in Linda’s outstretched hand.

“Look, you need to be treated. I can get you a free cab ride to the clinic.”

“No. Leave me alone.”

“How ‘bout this—I can take you. We’re not really supposed to, but I will. I’ll take you right now. You won’t even have to wait.”

There had been a time when DIS were regularly allowed to provide rides to the clinic in their personal cars. Driving a partner to the clinic usually guaranteed the person would be treated, and even fast-tracked for service. A high number of *brought-to-treatment* cases made for very good job performance statistics. Over time, however, as concerns about legal liabilities increased Linda’s health department program had ended the practice. But Linda was desperate. She could prevent a congenital case. Nothing was more important.

Jeanie said no to Linda’s offer. She was losing Jeanie, and really had never had her. Now Linda ratcheted up her tactics.

“I’ll have to contact the authorities if you don’t consent to testing and treatment. For the baby’s sake,” she threatened, attempting the illusion of leverage.

“I knew it!” Jeanie retorted. “You’re a cop. Well you gotta have a warrant. I’m not doing anything. You can’t just stop me. I know my rights.”

At that moment Linda wished she was a police officer. She wished for one to come along so she could enlist the aid. They could scare—force—Jeanie to come to the clinic. It would be quick. It would be dirty, but Jeanie’s baby would be protected. That was what mattered.

“What about your baby’s rights?” asked Linda desperately.

“Stay the hell away from me,” Jeanie shot back, storming off again.

This time Linda did not follow her. She could tell Jeanie was angry, maybe surprised too, and probably a little scared. It was common for people to resist treatment at first, to be in denial, but Linda believed with diligence she could bring Jeanie around and get her in for treatment. She had done it before. Jeanie just needed a little time to wrap her head around having an STD, Linda reasoned. If she pressed too hard and still got nowhere today, it might make Jeannie decide to disappear into the neighborhood and then she’d be that much harder to find again, which could spell bad news for Jeanie’s baby. Linda would give her some time and come back tomorrow.

Tomorrow came and so did Linda, but Jeanie was nowhere to be found. Linda visited the convenience store where she first saw Jeanie, and ate lunch in the neighborhood, on the lookout for Jeanie but to no avail. Had she made a mistake, Linda asked herself. All she could think about was the baby. She had to get Jeanie in for treatment. Linda was getting a little angry too; and a little scared. This could be a big fail.

During the weekly DIS *Chalk-Talk* meeting at the STD Clinic, Linda shared her frustrations. “I begged her,” Linda glumly reported to her colleagues. “It just made her mad. She kept saying I didn’t know anything about her. And who told me she had syphilis in the first place.” This was what the Chalk-Talk was for, a meeting for DIS to share and review challenging STD cases and help each other. Linda’s

possible congenital case had everyone around the table fully engaged. At one time or another all of them had had patients and partners who refused treatment, but Linda's case involved an innocent baby.

"What about the partner?" Nancy, one DIS, asked. "Maybe he can get her to come in."

Linda was shaking her head.

"He doesn't want to," she replied. "There's nothing there. I can't say as I blame him," Linda grumbled, thinking about her encounter with Jeanie. "Not sure what she'd do to him if she knew who it was."

If Tony was her only sex partner, then Jeanie would be able to figure out on her own who had named her as a partner. If she had more than one partner, then it got—complicated.

"Anybody else get her named as a partner?" Ray, another DIS, asked.

Everyone shook their heads.

"What about Tony?" Charles asked the group. "Is he a partner to any of your cases?"

Again, everyone shook their heads no.

Although Tony did have other partners. He had given Linda two additional names. Nobody else was pregnant though, at least as far as Tony knew. But maybe there were other babies at risk.

"Well, we'll keep working on it," Charles said, ready to move to the next case. "Thanks, Linda. We aren't giving up."

"I wish I could get an address," Linda said. "I'd camp-out at her front door. I swear I would."

"We know you're doing your best, Linda," Charles assured her.

There were just too many Jeanies, too many Tonys for that matter. Syphilis was an easily treatable disease with one of the cheapest medications. All that was needed was penicillin.

"If she won't come in," Ray said, "We'll get a nurse to go out and treat her."

The other DIS around the conference room table agreed with Ray. Even Charles and Doris, the other supervisors, nodded their heads. They could bring the syphilis treatment to Jeanie, and maybe she would accept it. Maybe they could get a happy ending. Linda and her colleagues believed it was worth a shot.

But the STD clinic director, who frequently attended the DIS Chalk-Talks spoke up. "That's not going to happen," she said, dumping a proverbial bucket of water on the idea. "It wouldn't be safe to treat her with injectable penicillin on the street. She'd probably refuse anyway."

"But what about the baby," Linda said.

"Even if I authorized and prescribed it and there was a safe location, nurses can be hesitant to administer Bicillin outside the clinic. What if we got a severe allergic reaction? Anaphylaxis could kill her, and we'd lose the baby anyway."

"Dammit!" Ray swore under his breath.

Linda looked ready to cry.

“Is there somebody else who can talk to her,” asked April, another DIS at the table. Maybe Tony can give you a lead, you know somebody who can get to her. Somebody who can make her understand how important this is.”

Shaking her head, no, Supervisor Doris, said, “You know we can’t do that. Patient confidentiality.”

This time it was Tony’s and Jeanie’s.

“But it’s a baby!” April insisted.

“Maybe she’s not infected,” Linda finally muttered miserably.

In her head she went over the timeline she had been able to put together from Tony’s recollections. It was possible that Jeanie was not infected. So much depended on when Tony had had sex with her. Syphilis was sexually infectious to others usually only in the primary and secondary stages. Every exposure did not result in an infection. Linda could hope.

“We just have to get her to come in,” the clinic director said.

“Yes,” said Doris. “Let’s strategize on how we do that.”

Linda made several more visits to Jeanie’s neighborhood over the next 2 weeks. Ray went with her. They went to the county hospital and conducted a medical record search on Jeanie. If she had been there before, maybe they could find a doctor who could help them reach her. Maybe just maybe Jeanie was getting prenatal care. Linda and Ray’s search efforts were mainly fruitless. The hospital’s records for Jeanie revealed she had not been there for care in years, and the address they had on file was old and no longer valid. But at least the hospital staff agreed to flag Jeanie’s record to indicate that she was a named partner for infectious syphilis, if Jeanie did show up there for care.

Linda also conducted another interview with Tony, and this time Charles participated. They hoped that with another ask Tony could give them a current address for Jeanie, but he couldn’t.

“Or wouldn’t,” Charles complained to Linda afterwards. “I think he’s holding out on us. He has to know something.”

“Maybe,” Linda said. “Maybe not. They’re not like friends or something. It was just a hook-up.”

“A pregnant hook-up,” Charles said dryly.

“I guess so,” replied Linda darkly.

She was feeling defeated, convinced that a baby was going to be lost to congenital syphilis. The STD program was left with no option but to close Jeanie’s case, and hope for the best.

And on that Christmas Eve they got their chance for it. Jeanie came to the Emergency Room with a severe respiratory infection. Since her medical record was flagged for exposure to syphilis, the attending OB/GYN, following standard protocol, called the STD infectious disease *doctor-on-call* that night for a consult. The doctor-on-call happened to be the STD clinic director. Ecstatic with the good fortune the clinic director hurried to the hospital. She was sure they were going to get Jeanie treated and protect her baby after all.

A little while later in the OB/GYN's office the clinic director's optimism faded.

"She says she doesn't have syphilis," the OB/GYN informed the clinic director as soon as she sat down across the desk from her. "She's refusing treatment."

"She's a partner," the clinic director replied. "We can treat prophylactically."

That was how they did it in the STD clinic, but the dubious frown shadowing the OB/GYN's face, reminded the clinic director that a hospital setting was different from an STD clinic.

"It's fine," the clinic director tried assuring her colleague. "It won't hurt if we overtreat. It's for the good of the community, and in this case her baby. This is the public health standard of care."

"I don't know," the OB/GYN said studying Jeanie's chart. "I don't think we can just —".

"Yes," the clinic director cut her off. "Yes, you can. I'm telling you, you can. You have to."

"Let's get her to take a test. If it shows she's infected I'm sure we can persuade her to —".

"The infection could be incubating, and we could get a false negative," the clinic director interrupted the OB/GYN again. "Why don't we just treat her. Please," the clinic director begged. "Let's not risk it."

"If you don't know she's infected," the OB/GYN replied. "How do you know the baby's at risk?"

"Look," the clinic director insisted. "She could be in the infection window. You see —".

"Let me talk to the Chief," this time the OB/GYN interrupted the clinic director.

They had the patient. They had the treatment. But it was still complicated, a classic conflict between Jeanie's privacy, her individual rights and the health of her baby.

"And how long will that take?" the clinic director asked sharply.

The OB/GYN stiffened at her colleague's tone.

"I understand your concern," the OB/GYN said coolly. "But the patient does have rights."

"What about the baby's rights?" the clinic director asked.

"Our patient is the woman," replied the OB/GYN.

Questions for Discussion

1. Who are the stakeholders (s) in this situation?
2. Can Jeanie be compelled to take treatment for syphilis to protect her unborn child?
3. Does Tony's right to privacy trump Jeanie's need to know who named her as a partner for syphilis?
4. What are Jeanie's rights?
5. What is the balance between individual civil liberties and community health?
6. What could Linda have done to gain Jeanie's cooperation leading to treatment?
7. How should the clinic director proceed?

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Chapter 15

My Mother, Obesity and Me: Our Narrative. How Obesity Is Intimately Related to Biopsychosocial and Spiritual Factors



Eduardo Farías-Trujillo

Abstract The word obesity invokes multiple connotations that contain a realm of disparate descriptions ranging from disease to disdain. There are few other human conditions that cause increased morbidity and mortality and affect millions of individuals worldwide yet is viewed by many as a character fault or moral failure. This paper explores the personal experience of obesity and how it is important to face obesity not only as a biological issue, but also a philosophical one, which has its roots in a complex phenomenon. This approach allows health professionals to propose a theoretical ethic about obesity, which goes beyond mere socio-economic-religious, and leads to an applied ethics built on the firm and solid foundations of knowledge diversity. The obese human being does not live in a world of simple events, but instead faces experiences – mystical, religious, artistic, linguistic – and, from there, configures their identity, builds personality and establishes interrelations and interdependencies. While recognizing the importance of strategies to reverse the trend of increasingly sedentary lifestyles, this paper points to the need for public health obesity reduction efforts to avoid stigmatizing people who cannot lose weight.

Keywords Narrative · Obesity · Environmental influences · Obesogenic environment · Personal responsibility · Stigma

Disclaimer: This paper is presented for instructional purposes only. The ideas and opinions expressed are the author's own. The paper is not meant to reflect the official position, views, or policies of the editors, the editors' host institutions or the author's host institution.

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Public Health Ethics Issue

World-wide, obesity is a growing health problem (Fox et al. 2019, 1). The impact of this problem is clearly seen in Mexico. Over the past 20 years, obesity has increased steadily among Mexicans in conjunction with a transformation of the nutritional landscape. This transformation has involved increased availability of highly processed, inexpensive food; more advertising targeting fast food; and increased food consumption outside of the home. This has led to profound changes in the diet of a growing sector of Mexicans leading to increased consumption of food that contains high amounts of fat, sugar, and salt (Rivera et al. 2012, 119–151).

Nutrition and food behaviors are often approached as a matter of personal responsibility. This creates a challenge for health officials who need to ensure there is a comprehensive approach to obesity that focuses on creating public policy for reducing food insecurity and malnutrition (Loring and Robertson 2014), promoting public health interventions that foster better eating habits, and avoiding approaches that blame or stigmatize individuals (Puhl and Heuer 2009, 2010; Mexican Observatory of Non-communicable Diseases [OMENT] 2018).

Background Information

In Mexico, the Ministry of Health estimates that the total cost of obesity in 2017 was \$12 billion and will continue to increase until reaching \$13.6 billion by 2023, a projected increase of 13% over 6 years (Health Secretary of Mexico 2013). A study by the Mexican Institute of Competitiveness (IMCO) estimated that the total annual cost of diabetes associated with obesity amounted to \$42 billion in 2013, of which 73% represented medical expenses, 15% work-related losses due to absenteeism, and 12% income losses due to premature mortality (IMCO 2015).

To address the growing costs associated with obesity, the Health Secretary of Mexico launched the National Strategy for Prevention and Control of Overweight, Obesity and Diabetes (Health Secretary of Mexico 2013). The government promoted this as an unprecedented effort to combat two of the main challenges to the health of Mexicans: overweight that affects seven out of 10 adults and three out of every 10 children, as well as diabetes that affects almost one in ten people. This strategy has three pillars: public health, medical care and health regulation/fiscal policy. For this strategy to be successful, it must consider that food behavior is not just a matter of individual willpower and personal responsibility determined by biological needs. Rather, food behavior is also impacted by social and cultural values, (Health Secretary of Mexico 2013). Focusing solely on diet and exercise will not solve the obesity problem.

The scientific community, as well as various international organizations (i.e., the World Health Organization, the Food and Agriculture Organization of the United Nations (FAO), the World Obesity Federation (WOF) and the World Cancer

Research Fund (WCRF) have concluded that the global epidemic of overweight and obesity arises primarily from an environment that promotes obesity. (WHO 2018, 2020; World Health Assembly 2004). Such an “obesogenic environment” (Swinburn et al. 2001) results from multimillion-dollar advertising for ultra-processed foods high in sugars, fat, and sodium, and the omnipresence and affordability of these products (World Health Assembly 2004).

On international and national scales, Mexico is an obese nation. According to the Organization for Economic Co-operation and Development (OECD), which comprises 35 countries worldwide, representing each continent, Mexico ranks as one of the nations with the highest adult obesity rate (OECD 2010). In schoolchildren without program food aid, the prevalence of obesity increased 97% between 2012 and 2018 (WHO 2018). In adolescents without program food aid, the prevalence of obesity increased 60% between 2012 and 2018. In adults with moderate food insecurity, obesity increased 10% between 2012 and 2018 (Shama-Levy et al. 2019, 852).

In the face of such challenges, governments and society have not stood idly by. Massive campaigns that promote healthy eating habits, such as the consumption of fruits and vegetables, occur in almost all OECD countries. Mexico has the “5 fruits and vegetables a day” promotion, as well as regulations that seek to promote the consumption of fresh foods in season (5 x Día Verduras y Frutas, México 2006; Official Journal of the Federation [DOF] 2013). Likewise, social networks and mobile applications have encouraged users to reduce body weight and increase physical activity.

According to the National Institute of Public Health (INSP), Mexico is one of the countries with the highest incidence of obesity and diabetes (34% of the population in Mexico is obese and 9.2% have been diagnosed with diabetes) (INSP 2020). The health and economic implications are so large (Manzano 2017), that in 2016 the Health Ministry declared obesity and diabetes national public health emergencies (Rivera et al. 2018). Mexico is also a major consumer of sugary drinks, a known risk factor for obesity and diabetes. Up to 10% of all calories consumed by Mexican children and adults come from sugary drinks (National Health and Nutrition Survey [ENSANUT] 2018).

In January 2014, the Mexican government implemented a 10% tax to industrialized sugar sweetened beverages to curb the obesity and diabetes epidemic. Two years later, a first analysis by the National Institute of Public Health (NIPH) on the impact of this tax found that consumption of sugar sweetened beverages in the country had decreased by 6.1% (INSP 2020).

Obesity is not only a food problem; there are many factors that contribute to obesity, such as some genetic syndromes and endocrine disorders, (hypothyroidism, Cushing’s syndrome, tumors), medicines such as antipsychotics, antidepressants, antiepileptics, and antihyperglycemics, unhealthy lifestyle habits, age, unhealthy environments, family history and genetics, race or ethnicity and sex (Templeton 2014; Lee et al. 2019; Bolton and Gillett 2019). Educational and socioeconomic inequalities (Loring and Robertson 2014) also influence high rates of obesity. The obstacles and difficulties faced by many people in the labor market, such as lower recruitment, lower productivity and poor re-entry, reinforce these inequalities. In

Mexico, as elsewhere, it is common to find that malnutrition and obesity coexist among the inhabitants of the same community and among the members of the same household (Pedraza 2009, 108). This is because among lower socioeconomic groups, prenatal and infant nutrition is often inadequate because they receive less expensive fast or processed foods that are high in calories, fat, sugar, and salt, but poor in micronutrients (Headey and Alderman 2019, 2020–2021).

Approach to the Narrative

In the following story, I share my personal story with obesity to illustrate the complex factors that impact weight and food behavior and how focusing on individual willpower and personal responsibility will not by itself solve the challenge of obesity.

Narrative

My mother and I struggled with weight issues all our lives.

Since 1997, I have been a Catholic priest, but my priestly formation began back in 1982 at the tender age of 12. The teachings and practices of Catholicism, which emphasize individual responsibility and forgiveness, shaped my personality and approach to my and my mother's obesity.

As my story will show, my mother could not recover from obesity because the social factors that sustain it are powerful. My mother had to face obesity due to her circumstances. My father was a worker in the United States; he had to be out of the country for half a year and my mother had to take care of the family. My father did not allow my mother to work outside of the home. So, sometimes we did not have enough money to buy food. Sometimes we had to rely upon family and friends for our meals. My parents' relationship gradually deteriorated. However, my mother never wanted to permanently separate from my father. These marital conflicts and my mother's tendency to worry about her children had an impact on her physical and mental health and ultimately her obesity.

My mother and I were always very close. My father's absence because of his work, as well as the fact that I am the eldest of five siblings, led me to behave not only as her son, but as her confidant and support in the care of my brothers.

Although she was a strong, determined, tenacious woman, she could not and did not want to face her obesity. Although she wanted to have adequate weight and a good quality of life, she did not decide to fully cope with her obesity. It wasn't just about weight; it was about a different way of living. She died with obesity, although not only because of it. On one occasion she went to my room and, with tears in her eyes, she asked me: "Am I never going to be healthy?" At that time, I believed strength of will was enough to face any physical, moral, or spiritual problem. So, I

answered to her: “It is enough that you decide to do it”. I was wrong. There is no universal recipe for recovering from obesity.

In 2011, I joined a support group to address my obesity. Thanks to the internal dynamics of this group I became aware of how my physical and emotional health impacted my weight. I lost 46 pounds in 1 year. I discovered that addressing my obesity was not a matter of willpower, but of goodwill, because it is not about following crash diets or extreme exercises, but about adopting a permanent healthy lifestyle.

My father, who is now 72 years old, has been an athlete and an amateur boxer all his life. To this day he is a strong and vigorous man who takes care of his physical health. He was always trying to get me to exercise, to train, to run, to jump rope. When the movie, *Rocky*, appeared in Mexico, 2 years after it appeared in the United States, my father took me to see it. As I watched the movie, I saw my father: an athletic, handsome sportsman who took care of his body and exhorted me to imitate him. My father wanted me to be like him or like my cousins, who possessed different physical skills than me. He told me that I had to be like them—that they ran, climbed trees and were not fat like me.

In 1982, when I was 12 years old, I participated in track and field at school. My team, the Blues, lacked competitors for a 2.5-mile race. I had never run that distance and, when the coach asked me to run this race, my first reaction was to refuse. Two and a half miles are 12 and a half laps around a soccer field. After 28 min and 30 s, I finished in last place, but I earned points for my team. This experience brought about a fundamental change in my life. I realized that I had many physical abilities that were not the same as my dad’s; they were also not the same abilities as other boys’ my age. My abilities were different, but real. When the time came for the awards, some of my classmates told me, “We didn’t know you were capable of this.” I had pain in my body, but joy in my heart. When I got home, I shared with my family what I had achieved. My brothers, sisters and my parents congratulated me, when I told them that this moment had been like an epiphany, a revelation. I started participating in other sports, because, unlike my father, I was not interested in boxing. I discovered that I had ability for tennis, Tae Kwon Do, swimming, soccer, hiking, and jogging. At first, engaging in sports, caring for myself, my appearance and health, were influenced by family and social pressures. Afterwards, having a good quality of life was an issue I internalized and made mine. I learned to lead a new way of life.

I entered the Diocesan Seminary in 1985. An eleven-year stage for priestly ordination began. I was 15 years old, 5 feet, 7 inches tall, weighed 172 pounds, and my pants size was 32. My participation in sports and the intensity of my studies resulted in me losing weight and I dropped to size 28. In December 1985, when I went back home to see my father, whom I had not seen since June because of his work in United States, I thought he would be proud of my great achievement. I had lost weight, I was on the Tae Kwon Do team, I was part of the soccer team, and I was running or walking almost every day. When he saw me, my father said: “You are very skinny.” I wondered where the congratulations were, the recognition, the applause, the hug. I had thought that when my father saw that I had lost weight, he

would be happy, he would feel proud of me and congratulate me. Within me, I experienced a kind of male rivalry between father and son because of my weight and physical appearance. When he said “you are very skinny” it broke my heart. Instead of a hug and a congratulation, I felt that he saw me as a rival and that his message was: “I am better than you.” I thought he should know that I was following his example and that he should feel happy.

In the Seminary I received many awards for my academic achievements. I obtained an average of A+ during the 11 years of priestly formation. As a prize for my intellectual capacity and my responsibility, I obtained the opportunity to study in Rome. While in Rome, I swam, ran, and went to the gym. I also was careful about my diet, so I returned from Rome weighing 165 pounds. However, I was not able to maintain this healthy lifestyle when I returned from Rome.

I came back to Mexico and the bishop appointed me director of a preparatory school. These were years of intense academic work, including contact with students, parents, staff, and administration. In addition, I provided marital counseling. I worked all day long and into the evening. The daily stresses contributed to my putting on weight. I became an obese person.

I tried to exercise. I played soccer and ran, but I could not manage a healthy lifestyle. When the evening meetings were prolonged, the dinners were plentiful, and since I skipped meals during the day, I overate at dinner. These attitudes created a vicious cycle. Not eating during the day led to overindulgence at night. To compensate, the next day I would forego breakfast or lunch and just drink coffee.

While I knew that many factors impacted my obesity, including my biology, and social and emotional factors, I was still focused on personal responsibility. I felt that I, like everyone else, had to take personal responsibility for starting a recovery process. I hit rock bottom when I realized that my obesity was preventing me from having a good quality of life.

At the time I went to Rome, my mother, weighed 221 pounds, but she was 5 feet, 3 inches tall. Although obesity is not just a matter of weight, she and I realized what was happening with us. Eating more food than we needed made us tired, and our growing immobility saddened us. Things did not get better and our health became precarious. In a span of just 2 years my weight ballooned from 165 pounds to 203 pounds. What was going on inside manifested itself on the outside. I once heard someone say that the body screams what silences the soul.

A friend of mine started losing weight and I asked him how he was doing it, to which he replied that he was receiving treatment from a nutritionist and that it really worked. Although it took me a few months; I finally went to see the nutritionist. The nutritionist told me that a healthy lifestyle includes regular exercise, a balanced relationship with food, enough sleep and rest time, and not forgetting good social relationships. If I had obesity problems it was because I had stopped having a healthy lifestyle (i.e., I was not taking care of my body, my mind or my relationships). The nutritionist became an important teacher for me, because he proposed a diet of specific foods, appropriate portions, fixed schedules for eating, exercise and establishing good social relationships. I knew that I needed a new way of life that

included working to improve and maintain the health of my body; to respect, enjoy, and love my body as if it was a part of me and not my enemy.

What happened next was that I came home and talked to my mother and told her we should start together with this new lifestyle. I knew that I theory without practice is just information, because it was not just about improving our body image, but about improving our personal confidence, our psychological state and our functioning in the different areas of our lives. We had to assimilate that love for the body does not lead to creating a perfect body, but it is a condition of possibility to be happy in an imperfect, fragile body, full of challenges.

I started following the diet suggested by the nutritionist. I was walking an hour a day. In 3 weeks, I lost 13 pounds. I lost 46 pounds in a year. Deep down I was proud, because I had “willpower” and, under this premise, I asked my mother to do the same, to start this new lifestyle with me, that she should be strong, that she should eat only what was necessary and that she would soon reach good weight, but she did not, because even though she was a strong woman, determined and courageous, from my point of view, was weak in the face of obesity.

I confess I didn't consider her genetic predisposition and environmental triggers conspired against her. I did not know that in the face of these conditions, little can be done by just focusing on individual factors. My mother suffered from hypothyroidism and was 23 years older than me. Although I took this into account, my focus still was on my mother's willpower. My father, my brothers and I often blamed her for her excessive weight. We failed to understand all the pressures and circumstances that influenced her obesity. My mother had to choose the food, she had to adjust to a budget, she had to consider the different preferences of six different people and she had to cook something that everyone liked.

My main mistake was that I thought my mother should be like me, i.e., that it was enough for her to decide to change the way she ate, because I had done it that way. I wanted to lose weight because my motivation was health. I thought that everyone would react like me, that is, they would want to have a “normal” weight for health reasons. I didn't consider that each person has different motivations not only to provide food to others, but also to eat.

What did my struggle with obesity teach me? It taught me that a complex of factors that range from the individual and physiological to the social contribute to the outcome of body weight. Obesity is about biopsychosocial and spiritual factors. That is why an integrated approach makes sense and is most effective. The whole community must get involved in a sustained way and engage on all levels from individual behavior, nutrition, and physical activity up to the individual's environment, broadly conceived. The immediate social environment, the family, plays a key role in prevention by establishing healthy attitudes. Attitudes and good habits formed in the family in one generation pass on to children and can have a multigenerational effect on health. The family is a good place to start, but efforts cannot end there. Governments also play a role. Interventions that restructure the environment to make healthier choices easier and make healthy foods more available and cheaper play an important role in tackling obesity.

A holistic approach will impact the entire population down to the level of individual behaviors. The focus should be on health as the motivator and the desired outcome rather than fixating on weight. This fixation goes hand in hand with stigmatizing the person, rather than focusing on the problem and the behaviors. I know. Fixating on some ideal body type and weight I was never destined to realize was my pathway to stigmatizing myself, one that thank God I eventually learned to avoid.

Questions for Discussion

1. Are stories of personal struggles with obesity useful? If so, what makes them useful; if not, why not?
2. Some people think stigmatizing obese individuals or making them feel guilty about their condition can help them. Do you agree with this idea? Why or why not?
3. Public health professionals emphasize that obesity is a disease. What do you see as the advantages and disadvantages of this view?
4. Obesogenic environments play a role in the obesity epidemic. How great a role do you think environments play, especially compared to individual behavior?
5. Do you think it possible to address the obesity epidemic without in some way limiting or restricting peoples' lifestyle choices or access to obesogenic foods?
6. The narrative suggests that individual behavior, family life, and obesogenic environments all play a role in the obesity epidemic.
 - (a) Do you agree that a holistic approach is necessary or the best strategy to address the problem? Why or why not?
 - (b) Do you think that focusing on the family, an obesogenic environment, and the idea of obesity as a disease run the risk of giving obese individuals an excuse not to take responsibility for their condition? If so, how would you address this concern?
 - (c) What conditions do you think most influence the obesity epidemic and why?

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Chapter 16

Exploring the Human Impact of Public Health Interventions in T.C. Boyle’s “The Fugitive”



Andrew Childress and Ricardo Nuila

Abstract In T.C. Boyle’s (Boyle, *The Relive Box and Other Stories*. HarperCollins, New York, 2017) short story, “The Fugitive,” the public health practitioners treating the protagonist, Marciano, for tuberculosis (TB) override his right to decide his own treatment plan. Marciano’s struggles show an inherent conflict in public health ethics between protecting the community from infectious diseases and respecting a person’s right to autonomous decision making. Public health officials in the story failed to treat him as a human being by not eliciting his illness narrative. To avoid these failures in the future, we recommend that public health officials adopt a narrative-based approach to policymaking and training public health practitioners. Doing so will help public health officials build trust in healthcare institutions, thereby increasing compliance with public health measures. In this chapter we will explore Boyle’s story as a way to frame concerns about the effectiveness, utility, proportionality, and necessity of the public health measures taken in this case.

Keywords T.C. Boyle · Tuberculosis · Illness experience · Noncompliance · Mattering map · Stigma · Rights

Disclaimer: This paper is presented for instructional purposes only. The ideas and opinions expressed are the authors’ own. The paper is not meant to reflect the official position, views, or policies of the editors, the editors’ host institutions or the authors’ host institution.

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Public Health Ethics Issue

In T.C. Boyle's 2017 short story, "The Fugitive," the public health practitioners treating the protagonist, Marciano, for tuberculosis (TB) override his right to decide his own treatment plan.¹ Marciano's struggles show an inherent conflict in public health ethics between protecting the community from infectious disease and respecting a person's right to autonomous decision making. This conflict remains unresolved at the end of the story for two reasons. First, public health practitioners failed to elicit Marciano's illness narrative and his views on the treatment plan. They treated him merely as a case of multi-drug resistant TB due to noncompliance, rather than as a human being with goals, values, and beliefs about what makes life worth living. Second, by neglecting to elicit his perspective, public health practitioners were unaware of how social determinants of health affected his compliance with the recommended treatment. More specifically, they failed to recognize how Marciano's concerns about avoiding stigma and keeping his job affected his decision making. To avoid these failures in the future, we recommend that public health officials adopt a narrative-based approach to policymaking and training public health practitioners. Doing so will help public health officials build trust in health-care institutions, thereby increasing compliance with public health measures. In this chapter we will explore Boyle's story as a way to frame concerns about the effectiveness, utility, proportionality, and necessity of the public health measures taken in this case.

Background Information

The control of infectious diseases like TB relies on the public's cooperation. Effective clinical management of these diseases requires that patients temporarily give up some of their rights (Martini et al. 2018; Dye et al. 1998). These rights include the right to bodily freedom and integrity, privacy, and self-determination. But sometimes, patients who are infected refuse to give up these rights voluntarily. Public health officials then must resort to more coercive measures, including involuntary isolation and compulsory treatment, in order to halt the spread of the infectious disease. Many levels of government have delegated this use of police powers to public health departments, which permits them to examine, detain, and treat individuals over their objections. However, the affected individual's constitutional rights to due process and equal protection limit these powers (Matthews et al. 2007).

If caught early enough, treatment for most types of TB does not require isolation. Doctors typically prescribe four oral antibiotics for 8 weeks, followed by a two or three drug regimen to complete a total of 6–9 months of therapy (Sterling 2019).

¹A version of this story is available online in [The New Yorker](#). The version cited in this text contains minor changes that do not affect the overall story.

However, patients must take the medications according to a strict schedule, which can be challenging for them. Drug-resistant strains of TB develop when this schedule is not followed, as in Marciano's case. Treatment regimens for these mutant strains can last 1 year or longer, depending on the level of resistance, and typically require a mix of oral and intravenous antibiotics administered in a facility.

If public health practitioners understand what factors might impede the patient from receiving treatment—it could be a patient's work schedule or a side effect she feels from the medication—they may be able to adjust and treat the illness more effectively. Identifying these barriers, however, can be difficult. It's true that when patients are asked, many describe these barriers in fine detail. But this isn't always the case. The only way to ensure these obstacles are identified is through attention and listening. Unfortunately, these skills can erode during a public health career that focuses mainly on statistics and science. Literary works—stories—offer a way to heighten these listening skills.

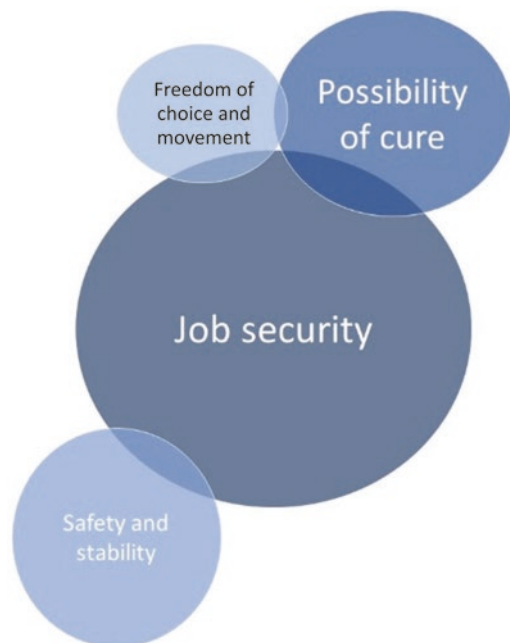
Approach to the Narrative

Brushing up on their skills of close reading can help public health practitioners thoughtfully engage with a story's thematic content and cultural context. Close reading requires "laser concentration on the formal characteristics of a text ... awareness of the complexity of the reader/text transaction...and [of] how acts of reading change the world" (Charon et al. 2017). These skills easily translate into attentive listening to patients' stories, which can help public health practitioners communicate better. For instance, T.C. Boyle's story "The Fugitive" illustrates how necessary public health interventions pit patients against public health practitioners. Attentive readers of stories like this one become attuned to their core features: plot, characters, setting, voice, and theme. They ask questions like, "Where and when is this story taking place?" As they become familiar with the characters in the story, they ask, "Who is telling this story and why are they telling it?" As the action unfolds and the story progresses, they seek to understand the characters better, as they would real people. Readers start to *see* the story unfold in their imaginations, and in doing so, develop narrative competencies, including a broader perspective and a wider moral imagination. With practice, close readers develop the ability to narratively transport themselves into a character's world. They begin to imagine themselves in the character's shoes. As they read more complex stories, they ask, "Why did that character make those choices? What might have happened if they chose differently?" Developing narrative competencies can help readers appreciate the sources of the conflicts in stories and imagine a more satisfying and ethically justifiable ending for the characters involved. This vicarious experience of decision making within a fictional world prepares them for making real-world decisions. Public health practitioners who become close readers can easily imagine the barriers and burdens that individual patients face, which helps them design ethically appropriate and effective public health interventions (Montello 1997).

As part of our close reading of “The Fugitive,” we draw from Martha Montello’s concept of a “mattering map” (Montello 2014; Goldstein 1983). A mattering map is a metaphorical means for schematizing a character’s internal and external struggles by showing how underlying personal values inform the character’s choices. Readers can identify which values conflict at different points in the story by organizing the map according to key plot points and their significance to the character. To construct a mattering map, we must identify values, beliefs, expectations, and relationships that affect a character’s motivations to pursue important goals. Taken together, these elements reveal what matters “overwhelmingly” to a character.

In key moments in the story, the values underlying Marciano’s decisions become apparent. Mapping out these plot points helps the reader understand how illness threatens his livelihood, restricts his choices, and interferes with his relationships. Below is Marciano’s map (Fig. 16.1). As the story progresses and readers complete their inventory of what matters to the character, the integrity or “wholeness within the value system” becomes apparent (Montello 2014). There is harmony or balance among the values and between the values and the other elements that constitute the character’s moral universe. However, the map itself can lose integrity when these values conflict or goods (romantic relationships, income, respect, health, etc.) that the character values cannot be obtained. When this happens, readers may temporarily or permanently “erase” some elements of the map to signify that they are not driving the character’s motivations. At those points, other values may matter more to the character and thus motivate him to make different choices. In Marciano’s case, because he desires to maintain job security above all else, he defends his right

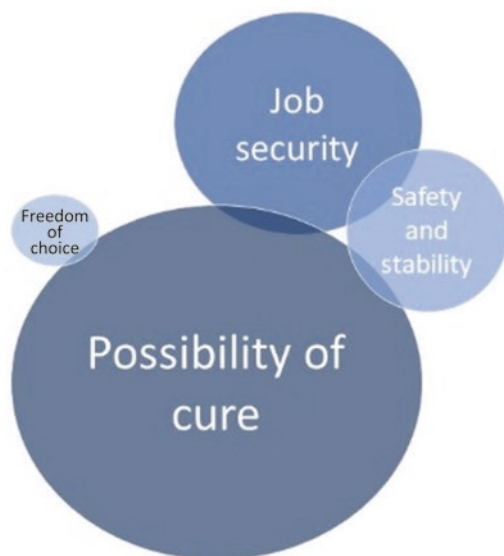
Fig. 16.1 Marciano’s mattering map before being detained for treatment. Shape and text size indicate degree of importance to Marciano



to make his own decisions about whether to accept treatment that would interfere with his livelihood. Throughout the story, this principle of autonomy coexists in harmony with other values, such as his health, personal safety, and socioeconomic stability. But the map is disrupted when Marciano is coerced into receiving TB treatment. His core value—freedom of choice—is limited by external forces, and thus, its value diminishes on his map. Successful treatment will restore that value, but at the moment, Marciano feels his autonomy doesn’t matter because he’s powerless to exercise it in a meaningful way. As the story progresses, readers construct and reconstruct parts of Marciano’s map multiple times as he responds to challenges to his value system (Fig. 16.2).

To construct his mattering map, we must look at Marciano’s story “backwards, forwards, and sideways” (Lindemann 2014). Looking backwards in time at what led to the current situation, we see how the illness experience created ruptures in his life story. In stories, as in life, it is generally the case that “one thing happens because of another,” but sometimes the unexpected happens (like catching TB), which causes a rupture or a break in the expected sequence of events that composes the “plot” of our life stories (Montello 2014). Looking sideways, we explore how TB generally affects people socially. Some patients with infectious diseases like TB may face stigma attached to the illness, social factors that heighten risk of infection and transmission to others, assumptions about the health of immigrant populations, and the conflict between preserving individual liberty rights and the health of populations. Finally, by looking forward into the future, we consider possible treatment trajectories and the consequences they will have for Marciano.

Fig. 16.2 Marciano’s mattering map after being detained for treatment



Summary of the Narrative

We meet Marciano in the opening scene of “The Fugitive,” in a clinic somewhere in California. Marciano’s doctor is giving him instructions through a public health caseworker, Rosa, who also serves as a translator. Marciano hasn’t been following the doctor’s orders and will be given one final chance to follow the treatment plan, which includes wearing a mask in public and taking oral and intravenous medications. If he doesn’t follow the plan, he will be incarcerated and forced to comply with treatment. Marciano wants to be cured but doesn’t want to bear the treatment-related burdens. He faces numerous barriers to following through with treatment. He is frustrated by the requirement to wear a mask in public because it makes him feel uncomfortable and draws unwanted attention. Moreover, it’s difficult for him to manage his clinic appointments because they interfere with his work schedule. Ultimately, these and other challenges prove to be too much for Marciano, and he fails to complete the treatment plan. In response, the public health practitioners detain him and prepare to send him to a prison colony for treatment. He attacks them and escapes. As the story concludes, his fate remains unknown. Will the authorities find Marciano and incarcerate him again? Will he infect others? The ambiguous ending forces us, the readers, to consider how things might have turned out differently had Marciano and the public health practitioners developed a therapeutic instead of an adversarial relationship.

Close Reading in Action

We need to understand how Marciano experiences his illness in order to see how public health practitioners can make better and more ethically appropriate treatment decisions. TB has ruptured his life in many ways, but the circumstances of his life before his illness made accepting treatment even more difficult for Marciano. He was born to Mexican parents in California and was subsequently deported with them before he “had a chance to learn English or go to school here or anything else” (Boyle 2017, 245). He decides to return to California, where he finds a job as a gardener and amateur exterminator. Yet, he still wrestles with his decision to trade the safety and security of being “at home” with his family in Mexico for the pursuit of a better life in the United States. Nonetheless, all seems to be going well for him until he contracts TB from an unknown source. The narrator doesn’t share too many details about Marciano’s initial illness experience with us, but it’s clear that at some point he seeks treatment. He even manages to continue working while taking his medication, at least initially. Being able to work while undergoing treatment seems to heal some of the ruptures caused by the diagnosis. This is why work matters overwhelmingly to Marciano: when he works, he isn’t Marciano the *patient* as much as he’s Marciano the *gardener*. He experiences a number of unpleasant side effects, however, which make him nauseous and itchy “as if there were something

under his skin clawing its way out" (Boyle 2017, 235). His illness also affects his ability to enjoy sexual relationships as the visible symptoms of his illness—the look of consumption—leave him feeling unattractive. Throughout the story, his constant cough, sometimes in the middle of conversations, embarrasses him. Beyond brief interactions with his co-workers and roommates, he becomes socially isolated.

Marciano's actions and thoughts show that he values social connection and avoiding embarrassment. He knows that imprisonment will only isolate and embarrass him further. Taken together, the physical symptoms and the social dysfunction he experiences create multiple ruptures in his life story.

A conflict with his case manager, Rosa, only widens these ruptures. As a day laborer with no family in the area and no close friends, Marciano is desperate for any form of social connection. He believes he's found this with Rosa. What Rosa fails to recognize is that Marciano misreads her sympathy. He takes her kindness as flirtation. His desire for a cure isn't simply a desire to avoid the public health authorities. He also wants to impress Rosa. On Marciano's mattering map, his strong desire to be cured stands only slightly above his desire to be intimate with Rosa and his yearning for social connection.

As the story progresses, we see that Marciano is indeed sexually attracted to Rosa. She notices this and encourages him to take the medications to win her affections (Boyle 2017, 243). While we don't gain insight into Rosa's mind or her thoughts about Marciano, we can imagine her incentive to entice him into treatment. For example, one could speculate that she uses his interest in her as a source of leverage to convince him to accept the treatment plan. If this is the case, then it raises a question about the use of emotional manipulation as a tool for promoting the public's best interests: should public health authorities be allowed to do this? It's also possible that she found his leering distasteful but decided not to take herself off the case because she decided their therapeutic alliance was invaluable and that she could handle his advances. Taking herself off the case would also risk wasting time and endangering the public.

Marciano's fantasies of a romantic relationship evaporate when Rosa catches him not wearing his mask. She then orders the authorities to haul him away to jail. For Marciano, cooperating with Rosa initially represents the possibility of a better life for him and the potential to heal multiple ruptures in his life story. As reflected on his mattering map, Marciano's desire for social connection, intimacy with Rosa, and a potential cure for his illness supported the choice to cooperate. Once she becomes aware that he would never meet her expectations, Rosa reveals herself as an enforcer of the state's will and a threat to his liberty. This conflict comes as a result of Rosa's failure to understand Marciano's story and to connect that story with goals that matter "overwhelmingly" to him. Rosa could have talked him through his experience of stigma. She could have made her expectations clearer. She could have communicated more clearly about the nature of their relationship. But alas, she misses multiple opportunities to do so.

What Rosa fails to understand is the significant difference between her expectations and Marciano's when it comes to the treatment plan. When he is treated initially, he feels better in a shorter time than expected. This unexpected return to

health causes him to think he is cured and impels him to stop the medication. Once he has achieved what matters to him, there seems to be no need to continue subjecting himself to the medication's harmful side effects. Were Rosa aware of Marciano's motivations, she could have explained that he had not yet reached his goal of being treated and would be risking his ability to return safely to work by ending treatment prematurely. Instead, he resorts to secretly selling the pills to make some extra money, all the while demonstrating to Rosa that he's taking them as expected. When he turns in the empty pill bottles each week, he simply claims that he took them. And so, he accomplishes two major goals at once: he continues to gain favor with Rosa, and he maintains his financial stability. However, Rosa never asks him about any of this or why he is having trouble taking his medications and wearing the mask. She fails to understand that he genuinely wants to be cured but is facing "their contempt and their antiseptic smells and their masks and their dictates and their ultimatums" in addition to the awful effects of both the treatment and the disease (Boyle 2017, 236). Beyond these challenges, he is also at the mercy of numerous psychosocial factors that are affecting his health and his decision making.

Social Determinants of Health

While researchers have attributed specific illnesses to social conditions for centuries, the idea that a person's health depends on circumstances out of his or her control—including the political, socioeconomic, and cultural environment, also known as social determinants of health—has only gained traction in the last 20 years. England's sanitary revolution in the nineteenth century made the connection between public health measures and personal health evident. New sewer systems prevented cholera outbreaks and reconfigurations of hospital spaces, as recommended by Florence Nightingale, saved patients from the germs their doctors carried (Kisacky 2017). In response to an urbanizing and industrializing world, the United States developed a decentralized public health infrastructure in the late 1800s (Starr 1982). But it would take more than 100 years for the idea that these social factors play as much of a role in a person's health as individual choices to take shape in the medical literature.

The 2010 Affordable Care and Patient Protection Act, or Obamacare, was the first piece of health care legislation to identify social determinants as major contributors to a person's health (HCERA 2010; PPACA 2010).² The law's focus on population health spurred researchers to study how psychosocial factors, like the location of a hospital or forms of payment, affect groups of people. As of yet, these studies have shown more promise than effect. While most doctors acknowledge the contribution of social determinants to healthcare, a 2016 study in the *Annals of*

²The text of the ACA can be found online at <https://www.healthcare.gov/where-can-i-read-the-affordable-care-act/>

Family Medicine showed that few have adopted these principles in their practice (Solberg 2016). Today, we are at a turning point with regard to the social determinants of health and medicine's acceptance of this idea. Given the profession's reticence to accept social determinants of health, it is at least somewhat understandable that public health guidelines, interventions, and enforcement strategies brought to bear on Marciano's case did not account for the social determinants that influenced his decision not to continue with the treatment plan. These include his lack of job security, low socioeconomic status, social isolation, poor English fluency, and stigma related to others' fear of infection. Taken together, these challenges place Marciano at a disadvantage when it comes time for him to make decisions about whether to adhere to the treatment plan. No matter which path he chooses, he will continue to face tradeoffs that could widen the ruptures already present in his illness experience.

Labeling Marciano's behavior as "noncompliance" provides public health practitioners with an excuse to dismiss his choices as mere defiance. As Poirier and Brauner note, "language not only reflects but in turn can affect" how caregivers are taught to think about patients (1988). Reframing Marciano's behavior and choices as the products of social determinants that already limited his life choices can help bridge communication gaps and identify psychosocial needs. Also at play are the values, beliefs, and desires that inform the construction of his mattering map. Although he desires to be cured, the treatment conflicts with other goods that matter most to him, namely, his independence and ability to earn a living. He "missed the job—and the money... he wanted to be back there again, under the sun, working, just that, working" (Boyle 2017, 238). Marciano's dependence on a steady source of income crucially informs his decision making. Starting work too late in the day because he had to spend the morning in the clinic may cause him to lose his job. For Marciano, losing his job, which would be reflected as a significant erasure on the mattering map, would be too great a loss to endure. It's not simply a job for him, but a way to demonstrate his value and independence. Knowing that he will have to continue to tolerate these intrusions at a stage in life when "thirty months was like a lifetime sentence, and even then, there were no guarantees," Marciano refuses to risk his job security (Boyle 2017, 238). Not only would he face daily intrusions into his work life as well as irritating and debilitating side effects, but also he would have to face these challenges with little hope for a cure if he failed to complete the regimen. For Marciano, being cured at the cost of his job and independence strikes the wrong balance between what matters and what matters overwhelmingly.

To communicate the burden of the choices Marciano faces, Boyle draws on the symbolism of a wild animal trapped in a cage moments before extermination. As he broods on the brief chapter in his life between TB flare-ups, Marciano recalls an occasion when, as part of his gardening duties, he had the distasteful job of checking and cleaning the animal traps. He comes across a live raccoon who had wandered onto the estate of one of his *patrón's* clients. His *patrón* instructs him to drown the raccoon in a garbage can. Marciano reluctantly complies. Later, with the authorities hunting him down, Marciano imagines himself in the raccoon's place. He closes his eyes and "all he could see was the glint of a metal trap, bubbles rising

in clear cold water, and the hands of the animal fighting to get out” (Boyle 2017, 252). Finding himself in a no-win situation, Marciano realizes that his illness has trapped him within an impersonal and uncaring system that provides only the illusion of autonomous choice.

Infectious Disease Management and Stigma

As Marciano’s story and our construction of his mattering map demonstrate, infectious disease management strategies that ignore stigma likely will fail to reduce disease incidence rates. Sociologist Erving Goffman defines stigma as a “dynamic process of devaluation that significantly discredits an individual in the eyes of others” (1963). Stigma related to health behaviors can exacerbate existing health inequalities. Marciano faced stigma from both external and internal sources. No matter what he did, he couldn’t hide his illness from others. As he walked around with a soiled surgical mask and halted conversations to cough violently, Marciano endured a number of negative reactions. These responses compounded his preexisting concerns about how others viewed him.

Unbeknownst to the public health authorities who detained Marciano, he deeply resented wearing the surgical mask in public because it “made him feel like he had a target painted on his back—or his face, actually, right in the middle of his face” (Boyle 2017, 233). Although an American citizen, he assumes that wearing the mask in public will likely reinforce misconceptions about non-English speakers and undocumented immigrants. As the mattering map we have constructed shows, he values the safety and security of feeling “at home,” but knows that some view him as unwanted or alien. He also embodies some of the stereotypes often attached to recent immigrants from Latin America. His appearance, native language, and field of work all mark him as someone who may have crossed the border recently. He internalizes these assumptions about how others view him, perhaps as someone to be avoided as both socially inferior and a potential threat to their health, which negatively impacts his own feelings of self-worth. In the United States during the twentieth century, persons who appeared to be “foreign-born” were associated with disease and infestation (Markel and Stern 2002; Molina 2011). Sadly, these associations have continued to frame this discourse into the twenty-first century (McCauley et al. 2013). Anti-immigrant advocates and others use this disenfranchising rhetoric of contagion to argue for restricting the flow of immigrants by labeling them as undesirable threats to public health (Alexander 2009). This larger public discourse around contagion and immigration underlies some of the stigma Marciano faces.

Ultimately, Marciano responds to perceived stigma by discarding any obvious signs of illness, thus deflecting the dehumanizing gaze of his fellow citizens. Instead of wearing the mask as instructed, he throws it away and drinks beer in a pub with other customers, thus increasing the risk of infecting those around him. This decision to remove the mask in the bar makes him appear more threatening to those who know about his condition and ultimately leads to his incarceration. Nonetheless, his

choice is justifiable according to his core values, given the importance that he attributes to both maintaining social connections and avoiding stigma.

Stigmatizing rhetoric colors Rosa's instructions to Marciano. She tells him, "You're highly contagious, and if you were to cough without the mask on, the bacteria could get into the air and infect your roommates, and you wouldn't want that, would you?" (Boyle 2017, 234). She describes *him* as "contagious," not the disease as contagious. *He* causes infection, not tuberculosis. In Rosa's view, if Marciano doesn't wear the mask, then it's *his* (and only his) fault. In her view, refusing to wear the mask or take his medicine means that he wants to sicken his roommates. The way Rosa uses "contagion" here stigmatizes Marciano and raises the question of whether shame and guilt are the best strategies for achieving compliance. What alternatives might public health practitioners have for reframing the stigmatizing rhetoric around infectious disease and the public health interventions associated with controlling its spread?

Public relations campaigns to normalize wearing masks in public may be effective at reducing stigma. Patients could be encouraged to incorporate the mask into their wardrobes as a fashionable accessory, rather than as a medical apparatus. The masks themselves could be designed to be more aesthetically pleasing while retaining their primary function. One of Marciano's chief complaints about the mask is that it is too conspicuous. Perhaps it could be redesigned to be less noticeable and more comfortable. Acknowledging that these concerns about appearance are valid and should be addressed would help reduce the stigma related to wearing the mask in public, thus preserving a value that Marciano ranks highly. As part of this campaign, public health officials could also emphasize that patients shouldn't be blamed for contracting infectious diseases like TB. Instead, they should be seen as unwilling hosts to a dangerous disease that is contagious. Reframing mask-wearing as a heroic act of compassion for others could also shift the public's view of that behavior from stigmatizing to praiseworthy. In light of the COVID-19 pandemic, this strategy may gain even more traction with the general public as awareness of the value of masks to prevent the spread of infectious diseases has grown considerably (Fisher et al. 2020).

Incarceration and Compulsory Treatment

Historically, public health authorities have restricted the liberty of both symptomatic and asymptomatic patients in very limited circumstances. The constant threat of incarceration and compulsory treatment looms over Marciano, undermining his trust in his caretakers. Trust is one of the values on Marciano's mattering map. As someone whose only consistent social contacts are public health practitioners, losing trust in them poses a significant threat to the integrity of his core values. Only after he's caught defying their orders via video and community surveillance--in a manner akin to an Orwellian regime--does Marciano attempt to assert his rights as an American citizen to due process. Unfortunately for him, he is unaware that states

also have constitutionally protected rights. In this case, they have the right to compel treatment when citizens pose a risk to public health (California Health and Safety Code; Barry et al. 2016). At the story's climax, Marciano, in an act of desperation, escapes incarceration and compulsory treatment by spitting on Rosa and everyone else in the room. It is a harsh action, as Marciano knows that he is infecting them with his "living death" (Boyle 2017, 246). As he sprays Rosa and the other shocked public health practitioners with his bloody sputum, he thinks to himself, "see how they like being condemned and ostracized and locked up without a trial or a lawyer or anything" (Boyle 2017, 246). Understanding what drove him to make this choice is important for considering the potential consequences of overzealous monitoring and pursuit of noncompliant patients.

Trust forms an essential component of the therapeutic alliance between doctors and patients. Historically, marginalized populations have had numerous reasons not to trust medical authorities. From Marciano's perspective, the public health doctor in charge of his care is callous and uncaring. As he listens to a stern warning about the consequences of not complying, the "doctor's eyes... looked at him as if he were less than human, something to step on in the street and crush, angry eyes, hateful, and what had he done to deserve this? He'd got sick, that was all—and couldn't anybody get sick?" (Boyle 2017, 235). It is clear from this interaction that Marciano feels that he is being unfairly blamed for contracting TB. He doesn't feel respected by the doctor, nor does he feel that the doctor trusts him. These suspicions are confirmed by subsequent interactions with Rosa and other public health practitioners. Towards the end of the story, he realizes that she was "part of the system and the system was against him" (Boyle 2017, 246).

Although public health practitioners commonly use surveillance methods to ensure compliance, doing so raises some concerns about privacy. These methods typically include face-to-face counseling, text reminders, monthly check-ins at home, follow up appointments at clinics, or directly observed therapy (Pradipta et al. 2020). Rosa is able to confront an unmasked Marciano at his home because she has been tracking him since he left the clinic. After his arrest, she counters his claim of innocence: "Don't even give me that. We have you on the feed from the security camera at the 7-Eleven making a purchase without your mask on—and there was testimony from the bartender at Herlihy's that you were in there without a mask, *drinking*, and on the very day you gave me your promise" (Boyle 2017, 245). Rosa's use of terms like "testimony" and video evidence suggests she is more concerned with law enforcement than Marciano's health. Her actions show that she is already convinced he will not comply with the treatment plan before he leaves the clinic. Revealing her suspicions to Marciano would have damaged their relationship even further, making future compliance even less likely. The use of these intrusive methods of monitoring to ensure adherence raises questions about whether and in which cases would resorting to measures that may infringe on patients' privacy rights be ethically supportable.

Questions for Discussion

Incarcerating Marciano and obtaining a court order to force him to take the required medication would protect the public from a potential source of multi-drug resistant TB. If the use of force is effective in curing him of TB and ensuring that he cannot spread it to others, then both society and Marciano stand to benefit. However, these benefits need to be balanced against the loss of individual liberty, especially if due process isn't followed. It is unclear whether the use of state power to place him in custody is actually warranted or simply being exercised in his case because Marciano lacks the resources needed to contest this use of power.

1. What considerations should be taken into account before public health officials exercise their police powers to confine and forcibly treat persons who are infected with TB?
2. Did Rosa exceed the boundaries of appropriate public health interventions? If so, in what way? Were her actions justified?
3. How would the principle of justice as fairness apply to this case? Is it fair to place Marciano in custody and compel him to complete an extended course of treatment?
4. How might a mattering map be useful for interviewing patients? What questions might public health practitioners ask in order to learn what matters overwhelmingly?
5. What role should public health practitioners play in addressing stigma related to infectious diseases? How responsible should they be for dispelling myths around public health interventions that may be stigmatizing or for mitigating their effects?
6. Considering the range of social determinants of health that affected his adherence in the first place, what would appropriate recompense for the restriction of Marciano's liberty look like?
7. How might public health practitioners or others help lower the barriers to adherence that Marciano faces?

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