

IT TAKES TWO: AN ARGUMENT FOR MIXED METHODOLOGY IN
EPILEPSY HEALTH DISPARITIES RESEARCH

A Thesis
Submitted to
the Temple University Graduate Board

In Partial Fulfillment
of the Requirements for the Degree
MASTER OF ARTS

by
Petra E. Brayo
May 2017

Thesis Approvals:

Nora L. Jones, PhD, Thesis Advisor, Center for Bioethics, Urban Health, and
Policy

ABSTRACT

In recent decades, neurologists have been directing more of their research efforts to exploring the sources of health disparities in medical and surgical treatment of epilepsy. Many studies reveal that racial and ethnic minority patients continue to receive suboptimal care, which has some dire repercussions on their physical and mental health, as well as their social wellbeing because epilepsy is a chronic disease that tends to affect multiple aspects of the patient's life. Although the earliest landmark studies emphasized the importance of mixed methodology research, the studies that followed tended to rely heavily on quantitative methods to unravel patterns of disparities with sparse use of qualitative methods to give voice to the patients concerned. In this work, I present a mixed methodology framework that is particularly suitable to investigating health disparities in epilepsy care, which affirms the complementary nature of quantitative and qualitative methods. I explore some of the challenges that clinicians face to utilizing qualitative methods, and introduce some of the validity criteria and techniques of qualitative research that make it a valuable methodology to understand disparities. I highlight some of the ethical concerns with recent studies in health disparities in epilepsy care which adopt only quantitative or qualitative methodology, and contribute very little to eliminating disparities compared to the potential contribution of mixed methodology research. This will be supported by various examples from research led by clinicians, public health professionals, and social scientists.

TABLE OF CONTENTS

ABSTRACT.....	II
CHAPTER 1: INTRODUCTION.....	1
CHAPTER 2: A HISTORICAL PERSPECTIVE ON SOCIAL DETERMINANTS OF HEALTH.....	4
CHAPTER 3: THE ROLE OF SOCIAL DETERMINANTS OF HEALTH IN NEUROLOGICAL DISORDERS	7
The Role of Social Determinants of Health in Epilepsy.....	8
CHAPTER 4: A FRAMEWORK FOR RESEARCHING HEALTH DISPARITIES IN EPILEPSY	11
Challenges to Incorporating Qualitative Methodology in Health Disparities Research.....	13
What Qualitative Methods Add to Health Disparities Research	15
An Overview of Validity Criteria for Qualitative Research.....	16
An Overview of the Techniques of Qualitative Research	18
CHAPTER 5: A LANDMARK STUDY IN HEALTH DISPARITIES IN EPILEPSY ..	21
CHAPTER 6: ETHICAL CONCERNS WITH HOW HEALTH DISPARITIES HAVE BEEN STUDIED SINCE SWARZTRAUBER.....	24
CHAPTER 7: CLINICIAN LED HEALTH DISPARITIES RESEARCH.....	27

CHAPTER 8: PUBLIC HEALTH FOCUSED RESEARCH ON HEALTH DISPARITIES IN EPILEPSY	31
CHAPTER 9: SOCIOLOGICAL INQUIRIES INTO HEALTH DISPARITIES IN EPILEPSY	36
CHAPTER 10: THE FUTURE OF HEALTH DISPARITIES IN EPILEPSY	41
BIBLIOGRAPHY	47

CHAPTER 1: INTRODUCTION

More than ever before, physicians have come to realize the significant relationship between their patients' social worlds and their health outcomes. Factors that make up a social world include race and ethnicity, socioeconomic status, and access to healthcare services. Differences in social worlds often lead to the development of numerous health disparities that affect almost every aspect of the patient's experience with the healthcare system. For individuals with neurological disorders, their social worlds also include a high disability and stigma burden, which further contributes to a high degree of health disparities. As a result, over the last two decades, many neurologists have explored the sources of these disparities with the goal of establishing guidelines for health policies that bring about positive changes to their clinical practice.

Among neurological disorders, epilepsy stands to benefit the most from this approach because it affects the physical, psychological, vocational, and social aspects of a patient's life. In this work, I propose a framework for studying health disparities in epilepsy that incorporates an initial quantitative phase, followed by a second qualitative phase. This framework strives to make the most of the complementary relationship of both research methodologies to produce findings that can transcend theoretical discussions and move us into the realm of practical policy and guidelines that will enhance the health care outcomes of epilepsy patients who experience disparities. I will then present an overview of some of the challenges that block the implementation of this framework, most of which have to do with physician unfamiliarity with qualitative

methodology and over-reliance on quantitative research to answer research questions that are more suited for qualitative research.

Focusing on qualitative methodology as a fundamental component of health disparities research, I then turn the conversation to the unique aspects that such methodology offers to complement and further add to quantitative methodology. Subsequently, I direct my attention to validity—by far the most important contribution of qualitative research by adding truthfulness to research findings in rooting them in the patient’s actual beliefs, attitudes, and experience. What follows is a most needed examination of the validity criteria of qualitative methodology, namely *credibility*, *authenticity*, *criticality*, and *integrity*. Afterwards, I address some of the available techniques of qualitative research that ensure fulfilling these criteria in any qualitative inquiry. With this foundation laid, I will turn my attention to one of the earliest landmark studies in health disparities in epilepsy, the Swarztrauber study, and explore how it fits within the two-phase framework presented earlier and how it complies with the validity criteria using the illustrated techniques. With this considerable contribution to the health disparities in epilepsy literature as a reference, I review what other investigators, from medicine, public health, and the social sciences, have added to the field over this last decade and how much they have deviated from this model set by Swarztrauber and her colleagues. This includes an analysis of some of the ethical concerns brought about by this deviation. To conclude this exploration of the current practices used to study health disparities in epilepsy, I present a model for moving forward that relies on the multidisciplinary methodology for which I advocated in my proposed framework. With this model, the goal is to transcend the field of health disparities from mere intellectual

study to praxis where “knowledge gained from theory, research, personal experiences and practice inform one another”¹ and truly uproot disparities instead of adding another cosmetic patch to the long festering problem.

¹ Stephen B. Thomas and others, “Toward a Fourth Generation of Disparities Research to Achieve Health Equity,” *Annual Review of Public Health* 32 (2011): 407.

CHAPTER 2

A HISTORICAL PERSPECTIVE ON SOCIAL DETERMINANTS OF HEALTH

To start the discussion on how health disparities in epilepsy care are studied, I would like to present a brief history on how social determinants of health came into prominence in the medical field. As Rudolf Virchow, the founder of social medicine, elegantly asked in 1848, “do we not always find the diseases of the populace traceable to defects in society?”² Over the course of the following decades, these words were slowly forgotten as the medical establishment concentrated its efforts on the countless emerging technological advancements, such as immunization, molecular and genetic research, and the race to find the cure to many common illnesses. These endeavors were rewarded by the eradication of many infectious diseases (most notably smallpox,) the extension of the average life expectancy, and the reduction in all-cause mortality. They also shifted the scope of medical practice from primarily treating acute and life-threatening illnesses to managing chronic medical conditions. By the mid-twentieth century, the spotlight was once again on the interplay between patient and community. Numerous public health officials became interested in studying how the surrounding environment can shape the health outcomes of various populations. This was highlighted by the 1980 landmark *Report of the Working Group on Inequalities in Health (The Black Report)*, which demonstrated that patients of low socioeconomic status in the UK experienced a multitude of health disparities, such as higher mortality rates.³ This study sparked many

² A. Irwin and E. Scali. “Action on the Social Determinants of Health: A Historical Perspective,” *Global Public Health* 2, no.3 (2007): 236.

³ *Ibid*, 245.

similar inquiries in other nations over the next two decades, with the attempt to delineate the extent to which social forces determine various health outcomes.

Consistently, studies have shown that a health gradient exists, with people further down the social ladder experiencing more adverse health outcomes than their counterparts at the top.⁴ These differences are caused by both material and psychological causes, and they play a major part in most disease processes and causes of death. Furthermore, research helped establish the vicious cycle that exists between low socioeconomic status and poor health. Starting off with limited family resources can lead to receiving poorer education, which in turn jeopardizes the person's chances of securing good employment and safe housing. These conditions can work synergistically to affect health by limiting access to regular preventative services, health insurance, adequate nutrition, and healthy living conditions. Subsequently, poor health becomes another disadvantage in an already dire situation.⁵

It became apparent that for healthcare providers to successfully manage the chronic conditions of their patients, they needed to intervene beyond the clinical setting. As a result, there was a shift in public health initiatives to include social determinants of health paradigms, offering a more holistic picture of disease processes.⁶ It soon became

⁴ World Health Organization, *Social Determinants of Health: The Solid Facts*, 5th ed, ed Richard Wilkinson and Michael Marmot (2003), 10.

⁵ Michael G. Marmot and Ruth Bell, "Action on Health Disparities in the United States: Commission on Social Determinants of Health," *Journal of the American Medical Association (JAMA)* 301, no. 11 (2009): 1170.

⁶ Steven H. Woolf, "Social Policy as Health Policy," *Journal of the American Medical Association (JAMA)* 301, no. 11 (2009): 1167.

clear from such initiatives like Healthy People 2010 (and its current successor Healthy People 2020) that research in causes of health disparities and inequities is integral to guiding any meaningful health policy. As was previously illustrated in the decades of research leading to this point, socioeconomic health disparities were found to permeate every aspect of healthcare. Equally dramatic health disparities were also identified in minority populations, particularly African Americans and Hispanics, who regardless of socioeconomic status endure worse health and die younger than non-Hispanic whites.⁷ Consequently, to fully grasp the complexity of managing chronic diseases, healthcare providers turned their attention to delving deeper into examining clinical practices for possible factors underlying these disparities to bring about changes to their practice that positively influence the health of their patients. While many disciplines were following this shift in attention, practitioners in the field of neurology felt a heightened sense of this importance.

⁷ Ibid.

CHAPTER 3

THE ROLE OF SOCIAL DETERMINANTS OF HEALTH IN NEUROLOGICAL DISORDERS

Amongst the number of medical specialties that benefit from this approach to healthcare, neurology has a high vested interest in exploring the impact of social determinants and health disparities on patients' health outcomes. Many neurological disorders result in considerable morbidity and mortality, can afflict the patient for long courses of time, often spanning the entire lifetime, with a great effect on quality of life, and carry social stigma that further derails treatment and restricts social support. These factors represent social determinants that strongly shape the disease course, and understanding them is a necessity for healthcare providers to best address diagnosis, prognosis, and treatment. Many neurological conditions, ranging from strokes to movement disorders, have a tremendous effect on the patient's daily functioning and result in disabilities or otherwise limit activities. This, in turn, may restrict participation in education and employment. Making matters worse, sometimes successful treatment of the neurological condition itself can cause disability.⁸ Similar to other medical fields, efforts to integrate multi-disciplinary teams, which work closely with the patient early on in the course of the disease to provide rehabilitation services, psychological counseling, patient education, and other social services within the community that enhance the

⁸ World Health Organization, *Neurological Disorders: Public Health Challenges* (2006): 16.

patient's quality of life have emerged as a positive policy change from emerging research into social determinants of neurological disorders. Moreover, this shift in research interests helped address the issue of societal stigma placed on having neurological disorders, which is particular to the specialty. For example, patients with epilepsy or history of brain trauma are often negatively stereotyped as being a danger to others, and frequently subjected to deprecatory labeling.⁹ This stigma threatens the patient's psychological and physical well-being by preventing the patient and their family from coming forward for diagnosis and treatment. Furthermore, the stigmatization sometimes extends to research efforts designed to find solutions to these disorders by limiting patient participation and researcher funding. Thus, in addition to determining the health outcomes of a patient, the stigma of dealing with a neurological disorder adds a component of health disparity to the patient because it leads to suboptimum healthcare. Consequently, one of the primary goals of health disparities focused research within neurology is to investigate the pervasive effect of stigma to forcefully counteract the damage it causes to the patient's health. Epilepsy is the quitesential neurological disease through which to address the impact of social determinants of health, and it is to that literature that I now turn.

The Role of Social Determinants of Health in Epilepsy

Compared to other neurological disorders, epilepsy carries one of the highest burdens of disability and stigma. Even before medicine, in general, directed its focus to social determinants of health, there was always an interest in the interplay between

⁹ Ibid, 20-1.

having seizures and how this reflected on the patient socially.¹⁰ The result is a long history of misconceptions, myths, and stereotypes related to a medical illness, which spread to every aspect of the patient's life. In a number of communities, children with uncontrolled seizures are often deemed too dangerous to others and themselves and are removed from schools. Without a basic education, they grow into adults who are unable to support themselves, and depending on the degree of their disability, might have to rely on their families for help with every facet of daily life.¹¹ To make matters worse, misconceptions about epilepsy are abundant, which presents yet another hurdle, even for patients with the most controlled seizures. From erroneous beliefs that seizures can be contagious and transferred through bodily fluids to cultural beliefs that seizures are the result of evil spirits, patients with epilepsy are often ostracized by their community. As a result, they suffer from high rates of depression and other mental health comorbidities, as well as higher rates of mortality as they are often left alone and unprotected, which can be fatal in cases of falls, fires, and exposure to bodies of water. Because of these extraneous factors that are strongly tied to how well a patient can manage their disease, epileptologists need to be extremely attuned to the social determinants of health in their patient population as they heavily contribute to access to specialty services, medication adherence, and surgical treatment of epilepsy. Furthermore, with the increasing diversity

¹⁰ Ibid, 60.

¹¹ Jorge G. Burneo et al for the Task Force on Disparities in Epilepsy Care, on behalf of the North American Commission of the International League Against Epilepsy, "Disparities in Epilepsy: Report of a Systematic Review by the North American Commission of the International League against Epilepsy," *Epilepsia* 50, no. 10 (2009): 2290.

in the US population, there is an emerging demand on epileptologists to understand the specific health disparities that affect their patients so that they can properly target healthcare resources and develop effective intervention programs and campaigns. This need has culminated in research efforts over the last decade which have identified disparities in access to medical and surgical care, knowledge and attitudes, disability in employment and education, epidemiology of epilepsy, and outcomes following medical and surgical treatment.¹²

¹² Ibid, 2293.

CHAPTER 4

A FRAMEWORK FOR RESEARCHING HEALTH DISPARITIES IN EPILEPSY

What we know is intimately related to ‘how’ we approach the search for new knowledge. Some of the most meaningful knowledge about health disparities, writ large, comes from research that incorporates multiple types of research methodology. Here I present this framework with an eye towards its applicability for understanding and addressing disparities in epilepsy. This framework consists of an initial quantitative phase followed by a second qualitative phase. With the goal of creating meaningful changes to epilepsy care, research into health disparities must undergo both of these two critical phases, effectively becoming mixed methodology research, which has been repeatedly proven to be successful in social determinants of health focused research.¹³ The first phase includes a comprehensive analysis of current practices to establish patterns of health disparities. This phase heavily relies on systematic reviews of healthcare records using established quantitative methods. The various areas of disparities previously identified are investigated in relation to variables, such as socioeconomic status, race and ethnicity, age, education and employment status, and psychiatric and physical comorbidities among others. Furthermore, studies should also contain internal comparisons between subgroups of people with epilepsy; for example, between people with different epilepsy disorders, or between people with active epilepsy and people with a history of epilepsy. Comparison studies should also be conducted between people with

¹³ Suzanne Moffat et al, “Using Quantitative and Qualitative Data in Health Services Research – What Happens When Mixed Method Findings Conflict?” *BMC Health Services Research* 6, no. 28 (2006)

epilepsy and people with other chronic illnesses. This thorough analysis helps in teasing apart significant associations between certain variables and the presence of a health disparity, and successfully eliminates confounding variables. Once a pattern of disparity is identified, the next step is to propose frameworks that can help explain it from the perspective of the patient and the family, the physician and the healthcare system, and the community in which the patient lives. There is often an overemphasis on the factors that relate to the patient and the family that are partially responsible for the existence of these health disparities. However, it is of utter importance to consider other factors, such as subconscious physician bias and the healthcare systems structures that add to these disparities. In addition, structural factors within the community, such as limited public transportation and lack of public policies that aid persons with disabilities can further increase the disparities that certain patient populations experience.

Once a comprehensive framework of the causes of health disparities is introduced, the second phase of health disparities research begins. Using qualitative research methodology, different questions are raised to interrogate the various aspects of the data that established the frameworks, which adds multiple complex layers of interpretation, producing a greater research yield. Qualitative methods, such as surveys, focus groups, and one-on-one interviews, also offer different data than what could be drawn from quantitative methods alone. One unique aspect to this phase of health disparities research is that it not only focuses on the outcome, which is the presence of a certain disparity in this case, it sheds some light on the process that gave rise to this disparity in the first place. Moreover, it can bring attention to certain outcomes that can be essential to the healthcare of patients that might not be measurable using quantitative methods, such as

sense of security and satisfaction with the treatment process. The discovery of these outcomes helps refine the proposed frameworks, and often propels quantitative research to create operational definitions which will assist in detecting them in future studies. The ultimate goal of this phase of research is to validate some of the proposed frameworks and to spark the brainstorming process for interventions to counteract these disparities. Because this phase involves working directly with the parties concerned, it allows health disparities research to be transported from the arena of theoretical hypotheses about the nature of disparities to that of practical changes and actions. This two phase framework using mixed research methodology advocates for treating both quantitative and qualitative methods as complementary, rather than the traditional view of competitiveness that strives to mark one method as superior to the other. This way, health disparities research can benefit from the strengths of each method and at the same time counter the limitations of each, enabling researchers to take account of the complexity inherent in social interventions.

Challenges to Incorporating Qualitative Methodology in Health Disparities Research

To best take advantage of the potential benefits of this framework, it is necessary to be aware of and prepared for the obstacles that prevent the widespread implementation of this framework. For healthcare professionals, conducting this sort of research comes with its own challenges. The first challenge is rooted in the fact that the qualitative methods appropriate for the second phase of health disparities research are very different from and less familiar than the quantitative methods employed in the first phase. While healthcare training curricula generally put a strong emphasis on the quantitative methods most often used in clinical and biomedical research, with emphasis on the superiority of

randomized control trials, the same curricula are usually void of any training in the equally essential qualitative methods. Consequently, healthcare professionals find qualitative research alien and approach it with trepidation and mistrust in its ability to provide any significant information. This approach produces healthcare professionals who are immensely lacking in skills to assess the numerous areas that are not amenable to basic quantitative research, such as patient beliefs and experiences of illness. Moreover, without qualitative research skills, healthcare professionals often lack the ability to produce good operational definitions and descriptions, which are a prerequisite to high-value quantitative research.¹⁴ This vacuum in research is often filled by social scientists, who are well trained in qualitative methodology. Although the research produced can be extremely insightful into the nuances of a patient experience with healthcare, it usually lacks clinical correlation, and therefore, applicability to healthcare practices and providing direct benefits to patients. This continuous separation is exacerbated by the misconception that both research methodologies are part of an irreconcilable dichotomy, and that a single research question cannot be adequately investigated using both methods.¹⁵ This reductionist view is the byproduct of years of indoctrination in the superiority of the randomized clinical trial as the ultimate research tool, and failure to consider any qualitative tools as potentially useful in answering a different aspect of the same research question.

¹⁴ Catherine Pope and Nick Mays, "Reaching the Parts Other Methods Cannot Reach: an Introduction to Qualitative Methods in Health and Health Services Research," *British Medical Journal (BMJ)* 311 (1995): 42.

¹⁵ *Ibid*, 43-44.

What Qualitative Methods Add to Health Disparities Research

Given the challenges that face the application of the proposed two phase framework in health disparities research, with the majority of which relating to clinicians' limited knowledge and apprehension of qualitative methodology, it is important to highlight what qualitative research can bring to the table. To successfully bridge this gap between quantitative and qualitative methods in health disparities research, familiarity with what qualitative methods specifically seek to answer is of utmost importance. By emphasizing the experiences and the views of the research participants, qualitative methods aim to understand the social phenomena examined in their natural setting, which cannot be provided by the experimental setting of quantitative methods.¹⁶ Attempting to reduce the complexity of the interactions between patient, physician, and the healthcare system to questions that can be solely quantifiable is a fool's errand with adverse repercussions for patients whose health might be affected by policies that stem from such improper use of research methodology. Consequently, the relation between quantitative and qualitative methods needs to be viewed as complementary instead of contradictory. As mentioned before, observational studies, in-depth interviews, and focus groups can be used in the preliminary stages of a research question to provide comprehensive definitions of quantifiable targets that later stages aim to measure. This approach adds validity to the research question because it ensures that what is actually measured

¹⁶ Ibid, 43

corresponds to how patients behave and act, and what they mean when they describe their experiences and attitudes toward the healthcare system.¹⁷ Essentially, qualitative methods supplement quantitative ones by serving as a checkpoint when researchers compare the results of both for convergence. Additionally, both methods can be used to answer the same research question on a multilevel approach. The most valuable aspect that qualitative methods add to health disparities research is the access to the implicit forces and private beliefs that shape the attitudes and policies that are at the core of these disparities. No matter how strong the evidence quantitative methods can possibly present, they are simply incapable of revealing subconscious biases and motives behind healthcare decisions, which are constructed by decades of historical precedence and other societal forces.

An Overview of Validity Criteria for Qualitative Research

Now that I have established that qualitative methodology serve a complementary, and not a contradictory role to quantitative research, I turn the discussion to the validity criteria essential to qualitative research. Striving for the truthfulness of research findings—or validity—qualitative methods employ a set of standards which demonstrate the rigor demanded and expected of any research methodology.¹⁸ In 1985, Lincoln and Guba proposed the first formal model of validity criteria for qualitative research.¹⁹ They

¹⁷ Ibid, 44

¹⁸ Robin Whittemore, Susan K. Chase, and Carol Lynn Mandle, “Validity in Qualitative Research,” *Qualitative Health Research* 11, no. 4 (2001): 523.

¹⁹ Yvonna S. Lincoln and Egon G. Guba, *Naturalistic Inquiry* (Newbury Park: Sage, 1985).

identified *Credibility* as an ultimate goal of any qualitative inquiry, which can be achieved through conscious efforts to establish confidence in the accurate interpretation of the meaning of the data without it being affected by the investigators' experience.²⁰ This criterion is constantly employed when exploring health disparities by ensuring that the results of the proposed research question only reflect the experience of the participants in a believable way, and that the proposed explanations for the existence of the disparities fit the description provided by the participant without any external interference from the investigators. Lincoln and Guba also recognized *Authenticity*, which is closely linked to *Credibility*, as another integral criterion for quality. For qualitative research to be *authentic*, it has to reflect the meanings and experiences that are lived and perceived by the participants. This requires the investigators to have a high sense of awareness of the subtle differences in the voices of the participants, and to be attuned to the influence that they have on the participants to speak *authentically*.²¹ This is crucial when probing for health disparities as multiple, socially constructed, and sometimes conflicting realities of the participants need to be exposed without being influenced by the investigators hypotheses.

Following in the footsteps of Lincoln and Guba, the 1990s saw additional criteria of validity introduced. In 1990, Marshall emphasized the need to be *Critical* when exploring alternative hypotheses and examining biases.²² She advocated that when

²⁰ Whittemore, 530.

²¹ Ibid.

²² Catherine Marshall, "Goodness Criteria: Are They Objective or Judgement Calls?," in *The Paradigm Dialog*, ed. Egon G. Guba (Newbury Park: Sage, 1990), 188-97.

ambiguities arise, they should be thoroughly analyzed and recognized. This was pushed further by Maxwell in 1992 when he declared that evidence should corroborate the investigators' interpretations of the participants' experience to guard against any distortion or conjecture.²³ This criterion of *Criticality* becomes essential to any qualitative inquiry as more investigators with their infinitely varying interpretations, assumptions, and knowledge background start collaborating. *Criticality* ensures a systematic research design that focuses on the subject matter without getting potentially diverted in a direction that suits the investigators' attitudes.²⁴ This brings about the last major criterion of qualitative research, *Integrity*. Because of the subjective nature of the interpretation of qualitative research, the burden of creating a process to assure that the interpretation is valid and grounded in data falls on the *Integrity* of the investigators.²⁵ In health disparities research, this is achieved through repetitive checks of the interpretations, and always being open to alternative understandings, as well as being attuned of the threat of subconscious biases.

An Overview of the Techniques of Qualitative Research

As much as an understanding of the validity criteria of qualitative research is necessary for conducting health disparities inquiries, it is not sufficient without the multitude of strategic choices needed to assure each specific validity criterion. These techniques of qualitative research are designed to optimally reflect the criteria most

²³ Joseph A. Maxwell, "Understanding and Validity in Qualitative Research," *Harvard Educational Review* 62, no. 3 (1992).

²⁴ Whittemore, 531.

²⁵ *Ibid.*

relevant to the particular research question. The following is an overview of some of these techniques, emphasizing the role they play in achieving the goals of any qualitative study. Proper technique choice requires consideration of the purpose of the research and the background of the investigator. When it comes to health disparities questions, certain design considerations become highly relevant. At the core of the early stages of designing the research questions, techniques such as *giving voice* and *expressing issues of oppressed groups* must be heavily employed.²⁶ Investigators using these technique strive to dissociate their beliefs and attitudes from those of their participants and work to empower them to find their voice to share their authentic experience of disparities. This goal can be accomplished using some of the data generating techniques, such as *providing verbatim transcription*, and *demonstrating persistent observation*. This allows the investigators to be critical of their interpretation and not allow it to influence the data collection phase in one direction or the other as they are consistently interacting with the participants. It also provides a level of integrity as the data is reported verbatim from the participants to be ready for the next phase of analysis.

Moving forward, a number of analytic techniques are best suited for health disparities inquires.²⁷ *Member checking* allows the participants to be actively involved in the analysis as they provide feedback on the proposed hypotheses. *Expert checking* and *performing a literature review* are often necessary because questions of health disparities heavily rely on historical and cultural precedents as a foundation to their answers.

²⁶ Ibid., 533.

²⁷ Ibid.

Exploring rival explanations is proving to be more and more important as long held theories of why certain disparities exist are refuted. This analytical technique is becoming more essential to qualitative research as investigators are moving from eminence-based to evidence-based medical practices. These *rival explanations* can be the starting point of hypotheses that can challenge the establishment of eminence-based practices that attempt to eliminate disparities. Finally, analytical techniques, such as *performing quasistatistics, testing hypothesis in data analysis, using computer programs, and drawing data reduction tables* are the key to universalizing qualitative research findings from the studied participants to affected patients with similar demographics and settings who experience the same disparities. This universalization is the goal of any health disparities inquiry and it is the only means of affecting change on the public policy level. This relies on presentation techniques that support the research effort and makes it accessible to the decision makers. By *acknowledging the researcher perspective*, the investigators present an awareness of the limitations of their inquiry, but also allow future investigators to modify their design in a way that limits the role of the researcher perspective, thus guiding the next set of proposed research questions. Most importantly, presentation techniques need to incorporate *evidence that support interpretations*. This is the only way to change the conversation from theoretical thought exercises and policy philosophical discussions to evidence supported practice.

CHAPTER 5

A LANDMARK STUDY IN HEALTH DISPARITIES IN EPILEPSY

With this framework in mind, I turn to a landmark study that used this framework to address disparities in epilepsy. In 2003, Kari Swarztrauber et al aimed to understand patient attitudes about the treatment of medically intractable epilepsy and in particular, to explore potential barriers to epilepsy surgery. In the first quantitative phase, the study highlighted data that epileptologists at surgical epilepsy centers have observed that patients of ethnic minority groups who are qualified surgical candidates rarely undergo the surgery itself.²⁸ It also demonstrated that surgery has a higher likelihood of seizure freedom, which is in turn associated with a higher likelihood of gaining employment and scoring higher on Quality of Life (QoL) scales.²⁹ Since the investigators could not identify in quantitative data any specific reasons that African Americans and other minorities would be less likely to undergo surgery with such successful outcomes, they turned to qualitative methods. Specifically, they decided to conduct a number of focus groups for adults, adolescents, parents of adolescents, and African Americans with medically intractable epilepsy, successfully transitioning from the quantitative to the qualitative phase. To uphold the qualitative criteria of credibility, the focus groups were run by a professional moderator and study investigators were not allowed to participate. To ensure integrity, the moderator asked the participants about how they lived with epilepsy, the role of their physician, how they feel about the treatment of epilepsy in

²⁸ Kari Swarztrauber, Sandra Dewar, and Jerome Engel Jr., “Patient Attitudes about Treatments for Intractable Epilepsy,” *Epilepsy & Behavior* 4 (2003): 19.

²⁹ *Ibid*, 20.

general, and how they feel about the surgical treatment of epilepsy. To achieve criticality, the investigators read the transcripts of the audio recordings of the focus groups and summarized the content separately, and then compared their findings for each of the topics. To use the technique of giving voice, the investigators reported their findings mostly verbatim from the participants.³⁰

The study revealed that many patients believed that epilepsy surgery is “experimental” and that this misperception was reinforced by their providers’ negative attitudes towards surgery.³¹ In most of these instances, patients were receiving medical treatment under the care of a primary care physician or a general neurologist, and not epileptologists. This resulted in distrust in healthcare providers, which was most prevalent in the African American participants. The investigators attributed this finding to the limited access of African American patients to specialized epilepsy clinics and their heavy reliance on community providers who more than likely provide suboptimal epilepsy care, as well as to the historical precedent of the Tuskegee experiment, which greatly eroded the trust of African Americans in the medical community.³² In addition, the study revealed that African Americans are eager to participate in support groups and other mental health structures to help them understand and cope better with their disease. However, this desire is often left unfulfilled because they can rarely find safe spaces to share their concerns about the disease as most of these support structures are dominated

³⁰ Ibid, 20-1.

³¹ Ibid.

³² Ibid, 23.

by white patients. For their conclusions, the investigators used these findings to propose a number of possible interventions for their specific patient population that aid in building trust and changing the perception that surgical treatment of epilepsy is “experimental.” They also hoped that their findings could aid in the recruitment for a then ongoing trial that compared the outcomes of early surgical intervention to medical treatment, subsequently, showing the strong link between qualitative and quantitative research.³³ When the Swarztrauber study was first published, it was considered revolutionary as it was one of the first instances in epilepsy health disparities research where clinicians, instead of public health professionals or social scientists, were interested in learning about patient attitudes. That shift, in itself, resulted in these clinicians being able to transform their findings into practice changes. The promise of this study and for the framework underlying it has not, however, been fulfilled.

³³ Ibid, 25.

CHAPTER 6

ETHICAL CONCERNS WITH HOW HEALTH DISPARITIES HAVE BEEN STUDIED SINCE SWARZTRAUBER

In the years since Swarztrauber and colleagues published their landmark study, other researchers have attempted to follow Swarztrauber's lead. Unfortunately, unlike Swarztrauber and her co-investigators, who understood the importance of mixed methodology in their work and envisioned it as the pathway of delving deeper into the multifaceted causes of health disparities, the investigators who followed in their footsteps found it sufficient enough to merely quantitatively probe their records for instances of health disparities. As a result, the epilepsy health disparities literature is abundant with medical record reviews that show that disparities extend beyond race and ethnicity to spoken language, geographical location, socioeconomic status, immigration status, access to healthcare insurance, gender, and marital status. However, there are very few studies that attempt to explore these disparities further through patient interviews, focus groups, or any form of contact with patients. In more than one instance, investigators cite the reasons found by the Swarztrauber study, such as African American mistrust, communication problems with providers, and the perception that epilepsy surgery is experimental, to explain the findings of their record review. This reductionist view that all African American patients are expected to have the same healthcare experience is extremely problematic; furthermore, this reliance on record reviews to explore disparities in order to inform future policy is highly unethical. If beneficence is the ultimate guiding ethical principle of any healthcare inquiry, then it is the duty of investigators to scrutinize

their work to see how it can possibly derive any benefits for the studied patient population. In healthcare disparities research, the end goal is to propose interventions that will enhance the quality of life of patients by directly and indirectly addressing the various sources of disparities that the patients experience. However, it is difficult to formulate strategies to eliminate disparities when there is very little communication happening between the investigator and the patients concerned. Moreover, this obvious lack of giving voice to the patients whose lives will be affected by the proposed interventions can be harmful when such interventions only mask the disparities at the surface without dealing with their root causes. Indirectly, this practice of formulating assumptions based on previous studies and historical precedence without verifying that they are an actual reflection of the patient experience of their illness and with the healthcare establishment deprives the patient from the autonomy to be an active participant in their healthcare decision making process, as well as asserts the long-held paternalistic belief in Western medicine that doctor knows best.

These pitfalls in health disparities in epilepsy care research are now so prevalent that they are the expected norm, and are rarely questioned for their clear inadequacy in advancing this field of study or contributing to any quality improvement for patients with epilepsy. A literature review of the studies that have been published concerning epilepsy disparities in the leading epilepsy journals, such as *Epilepsy & Behavior*, *Epilepsy Research*, and *Epilepsia*, over the last decade reveal that the resounding majority are based on record reviews, use proxy measurements for patient behaviors, and attempt to explain the quantitative findings using perceived assumptions and stereotypes on how the studied population is expected to behave and think. In almost all instances, the

investigators are fully aware that their methodology causes profound limitations and that their findings either need further investigation using the much needed qualitative methods or that they are not generalizable and cannot be used to guide any healthcare policy and or even practice changes on the smaller institution level. The few studies that explore patient attitudes and experience of having epilepsy are typically conducted by social scientists, and they undeniably provide a unique window into the interplay between the patient, their illness, and the multitude of societal factors that shape how the patient approaches epilepsy care. As useful as these studies are, they usually lack the necessary clinical correlates, which are much needed to bring about any feasible medical or healthcare policy changes. Studies like Swarztrauber's, which actively tried to link observed patterns in record reviews with patient interviews and define the specific patient population to which the findings pertain and can be generalized are the exception and not the rule. This is not to undermine the work done by the numerous investigators who are growing this emerging field; however, it is essential to keep in perspective the end goal of bringing about influential and positive policy changes, and not just adding to a body of literature. Clinicians should be optimally positioned to conduct such research.

CHAPTER 7

CLINICIAN LED HEALTH DISPARITIES RESEARCH

This is a small but strong tradition within the previous decade where more of the health disparities lead investigators are clinicians in the epilepsy field. One of these clinicians who has published on multiple aspects of disparities is Ramon Bautista. His research ranges from looking into issues of medication adherence to increased morbidity and mortality, and differences in coping strategies with epilepsy in the African American population. All of these issues are indispensable to getting into the roots of the disparities that the African American population experiences in epilepsy care, which is a fundamental step in formulating strategies to counteract them. Unfortunately, because most of Bautista's work relies on quantitative methodologies only, he succeeds in raising the correct questions without providing any relevant answers. In one study that looked into reasons of lower antiepileptic medication adherence in African Americans, not a single patient was interviewed or allowed to explain what led them to not take their medication as instructed.³⁴ Instead, pharmacy and clinical records were used to establish a ratio of number of days between refills to number of days in which the patient had enough pills in every prescription. This ratio revealed that African Americans took significantly longer time to refill the prescriptions, and this was used as a proxy for

³⁴ Ramon Edmundo D. Bautista, Catrina Graham, and Shahbuddin Mukardmawala, "Health Disparities in Medication Adherence between African-Americans and Caucasians with Epilepsy," *Epilepsy & Behavior* 22 (2011): 495-6.

adherence.³⁵ For the African American population in this study, which only included individuals of low socioeconomic status (at 200% of poverty level or below), issues of access to health insurance, affording the medication, or ability to pick up medication from the pharmacy are all reasonable confounding variables that can affect this calculated ratio. The study also surveyed some patients with the “Beliefs about Medicines Questionnaire” and found that African Americans experienced higher levels of hostility and resistance to use of prescription drugs. However, the investigators never attempted to explain this finding except by mentioning Swarztrauber’s finding of mistrust.³⁶ There were also no comments mentioned on the phrasing of the questions in this survey and the reading level in which it was written. In his conclusion, Bautista even acknowledges that his study design fails to comment on issues of health literacy, patient attitudes, and support systems that affect adherence.³⁷

Despite heavily relying on quantitative methodology in this previous study, Bautista is successful in employing qualitative methods properly to explore conditions that increase the morbidity and mortality related to epilepsy in the African American community in another study. In this study, patients who received their care at a tertiary epilepsy center were surveyed and some were selected for direct interviews.³⁸ Bautista

³⁵ Ibid.

³⁶ Ibid, 497.

³⁷ Ibid.

³⁸ Ramon Edmundo D. Bautista and Deepali Jain, “Detecting Health Disparities among Caucasians and African-Americans with Epilepsy,” *Epilepsy & Behavior* 20 (2011): 52-3.

points out initially the pattern that African American patients have poorer seizure control, and he proposes a possible connection to low medication adherence. Consequently, this study delved into patient beliefs about their antiepileptic drugs (AEDs) using standardized surveys, which showed that compared to Caucasian patients, African Americans tended to view their AEDs as more harmful than beneficial. In the subsequent interviews, these survey results were discussed further with the patients and revealed that the majority preferred to rely on non-traditional epilepsy therapies rather than AEDs. This stems from the belief that AEDs are addictive and can cause great disability as a result from the assumed dependence.³⁹ Bautista thus concluded that these beliefs resulted in the low adherence observed. Although this study design has many improvements over the previous one, it still falls short in multiple aspects that make it difficult to use the findings to initiate any practice changes. For example, the study did not investigate why African American patients have these beliefs in the first place. Again, Bautista chose to cite Swarztrauber's findings of mistrust as a possible explanation; however, the true explanation could have simply been obtained by asking the patient he interviewed. Finally, despite adding valuable information about patient attitudes towards AEDs, this simply served as a proxy for adherence, which is the primary goal of this study. Bautista acknowledges that there is more to adherence than a score on a standardized survey, as seizure type or financial barriers can be a strong predictor of adherence. Overall, in terms of design, this study serves as a step in the right direction for clinicians interested in using

³⁹ Ibid, 55.

mixed methodology to explore health disparities and has potential to direct patient-centered changes.

CHAPTER 8
PUBLIC HEALTH FOCUSED RESEARCH ON HEALTH DISPARITIES IN
EPILEPSY

Shifting the research perspective from that of the clinician to the public health professional, one of the lead investigators in the field is John Elliott whose studies address the different social aspects of disparities that epilepsy imposes on patients. In one interesting study, Elliott investigated the impact of marital status on epilepsy related health concerns.⁴⁰ As he explained, for patients with epilepsy, successful treatment involves beneficial effects on social, vocational, and psychological functioning. Additionally, marriage represents a strong type of social support which increases the patient's ability to cope with the disease. However, because epilepsy is a disabling factor which often results in lower income secondary to achieving a lower level of education and securing less chances of employment, patients with epilepsy are less likely to be married. Elliott surveyed epilepsy patients, noting their marital status, and focused on the following five factors: affective impact on enjoyment of life, general autonomy, fear of seizure recurrence, burden to family, and perceived lack of understanding by others.⁴¹ As Elliott discovered, marriage provides an enhanced financial situation, which leads to patients experiencing less worry about medical costs. This, in turn, allows patients to have a better sense of autonomy and increases their ability to enjoy life. Furthermore, the survey revealed that married patients experience less worry and anxiety about lack of

⁴⁰ John O. Elliott and others, "The Impact of Marital Status on Epilepsy-Related Health Concerns." *Epilepsy Research* 95 (2011): 201.

⁴¹ *Ibid*, 202.

others' understanding of their disease, which serves as an indication of a high level of surrounding societal support. Finally, compared to single patients, married ones tended to be less afraid of being injured during a seizure, further establishing the psychological role of social relationships on coping with epilepsy. Based on these findings, Elliott recommended that early social interventions should be put in place, especially in the case of childhood epilepsy, to help patients establish these types of long-term relationships.⁴² Despite the interesting findings of this study, its design of relying solely on surveys without any patient interviews leaves the conclusions somewhat lacking. For starters, there was no information provided on the length of marriage, which will help strengthen the connection between the social benefits it provides and their effect on the vocational and psychological aspects of epilepsy. Moreover, the conclusions were simply based on the marital status data collected from the patient record and did not account for common law or same sex relationships. In addition, the study did not directly measure the degree from social support that marriage adds to a patient, but assumed that a correlation between a married status and a high degree of support to be causative. This last observation is specifically troublesome because not all marriages are happy ones, which in this case can add to the social burden of the disease instead of relieving it. Besides, without exploring the actual sources of social support, such as other relationship with family members and friends, along with strong ties to the community, the study assumes a reductionist view that epilepsy patients can only receive support from a spouse. Although the study recommendation of implementing social interventions at early age is

⁴² Ibid, 203-4.

an important policy directive for epilepsy care, the incomplete identification of which areas provide true sources of social support limit the utility of such directive.

Despite his limited contribution to health disparities research from this somewhat flawed marriage study, Elliott accomplishes his goal of demonstrating the role of a public health perspective in epilepsy care in a number of studies that analyze data from national comprehensive health surveys. In one of these studies, Elliott explores the impact of poverty and its interplay with race and ethnicity on epilepsy prevalence and reported medication use.⁴³ From this wide epidemiological study, Elliott discovered that poverty plays a much greater role in explaining racial and ethnic differences in the ability to function with a chronic illness rather than explaining who has a chronic illness. As the study reveals, poor patients with epilepsy are more likely to be non-Caucasian than those with epilepsy but experience no poverty. As a result, they are also more likely to be unemployed, feel less safe, have an increased need for help with emotional support and mental health, and overall less likely to have health insurance coverage and access to epilepsy medications.⁴⁴ Consequently, compliance with anti-epileptic drugs (AEDs) is a problem with poverty that disproportionately targets racial and ethnic minorities. As a solution, Elliott proposes interventions which coordinate efforts for assistance programs within the healthcare setting that try to shift the physician focus from seizure control as a primary strategy to epilepsy treatment for these populations to addressing financial

⁴³ John O. Elliott and others, “The Impact of ‘Social Determinants of Health’ on Epilepsy Prevalence and Reported Medication Use.” *Epilepsy Research* 84 (2009): 141-2.

⁴⁴ Ibid.

matters that will enable the patient to achieve that desired seizure control.⁴⁵ Using the same dataset, Elliott studied the prevalence of comorbid conditions, access to basic health screenings and overall quality of life in patients with epilepsy.⁴⁶ The analysis showed that patients with epilepsy experience more comorbidities; however, they have the same access to basic health screenings as people without epilepsy. These findings fit the nature of the disease as “chronic with episodic attacks,” with comorbidities frequently arising with these attacks.⁴⁷ However, the chronicity of the disease ensures that the patient has multiple encounters with healthcare providers, which facilitates preventative and screening services, such as annual influenza vaccination, pap smears, colonoscopies, and mammograms. Interestingly, the analysis reveals that epilepsy often takes precedence in healthcare encounters; thus, comorbidities are often not as well managed, which further exacerbates the problem. This is especially the case with cardiovascular disease, which is a side effect of long term use of AEDs, and often goes underdiagnosed or undermanaged as seizure control takes precedence.⁴⁸ Elliott recommend further investigation of the link between epilepsy and each of the identified comorbid conditions with direct patient input. This result, then, could serve as a basis of identifying a universal pattern of epilepsy care using quantitative methods, which would then lead to the qualitative phase of health disparities research. These two studies demonstrate the critical role that public health

⁴⁵ Ibid, 142-3.

⁴⁶ John O. Elliott and others, “Comorbidity, Health Screening, and Quality of Life among Persons with a History of Epilepsy.” *Epilepsy & Behavior* 14 (2009).

⁴⁷ Ibid, 126.

⁴⁸ Ibid, 127.

professionals play to advance health disparities research in epilepsy by highlighting sources of disparities that are usually not apparent to the average clinician.

CHAPTER 9

SOCIOLOGICAL INQUIRIES INTO HEALTH DISPARITIES IN EPILEPSY

An illustrative example of sociological inquiries into epilepsy disparities is Magdalena Szaflarski's work "Social Determinants of Health in Epilepsy," which attempts to answer four key questions.⁴⁹ First, what are the social determinants of health (SDH) and their relationship to epilepsy care and outcomes? Second, what are health disparities, and what is known about disparities in epilepsy care and outcomes? Third, what are the mediating pathways through which SDH influence epilepsy care and outcomes? And finally, how do we proceed with disentangling SDH in epilepsy and eliminating epilepsy-related disparities? To undertake this mammoth endeavor, Szaflarski begins by defining several structural and social determinants of epilepsy care by identifying epilepsy as a neurological condition, which necessitates a set of regulations for diagnosis and treatment that are often affected by the established healthcare structures and the public perception of patients with epilepsy. She then moves on to define some intermediary determinants, such as access to and use of epilepsy providers, diagnostic tools and treatment modalities.⁵⁰ Both categories of SDHs are connected through the effects of social cohesion and social capital; thus, they cannot be changed at the individual level, but by how society reacts to them. With this foundation, Szaflarski tackles her proposed questions by looking into the multiple SDHs that generate health disparities and provides some suggestions on how they should be investigated on the clinical level. As regards to

⁴⁹ Magdalena Szaflarski, "Social Determinants of Health in Epilepsy," *Epilepsy & Behavior* 41 (2014): 283.

⁵⁰ *Ibid*, 284-5.

socioeconomic status, she reviews the well-established theories that it affects access to healthcare, compliance, education and employment, and associated with lower health literacy. Consequently, these patients have poor clinical outcomes with increased mortality and underutilization of proper health services. Szaflarski points out that beyond these established associations, there has been no applied work to study if strategies attuned to personalized socioeconomic status improve health outcomes and increase health literacy.⁵¹ Moving onto race and ethnicity, she observes that instead of repeating multiple studies that show that disparities cannot be explained by socioeconomic status and insurance access alone, there is a need for studies of individual populations and even communities. For example, an African American community in the Rural South has different health needs than a Senegalese immigrant community in an urban center, which translates to two different sets of health disparities, and it will be nonsensical to assume that all people with the same skin color have same healthcare experience. When it comes to gender, Szaflarski notes that there are very few studies that explore gender disparities. This is an extremely important area to study because women with epilepsy tend to have more problems, and require more services, especially with pregnancies.⁵² This lack of studies into what mitigates these health disparities plays a crucial role in the continued failure of eliminating these disparities. As Szaflarski explains, health disparities can be modified through social interventions, and society makes the decision on which interventions to enact based on the available scientific knowledge. This prompts her to

⁵¹ Ibid, 285.

⁵² Ibid.

introduce the possibility of provider bias, which itself can be a source of disparities, but also hinders research in disparities when the provider does not acknowledge their existence in the first place. Therefore, Szflarski declares that studies that explore the patient-physician relationship are urgently needed.⁵³ In this review and commentary on the current literature, Szaflarski succeeds in pointing out what aspects of health disparities research can be incredibly enhanced by adding input from patients, families, and other stakeholders. This also illustrates the importance of multidisciplinary teams to study health disparities as each area of expertise has its unique, but complementary contribution to solving the problems of health disparities.

This previous study represents an example of theoretical sociological inquiry in an attempt to navigate the numerous factors that give rise to health disparities in epilepsy. The next example shows a different significant role that social scientists play by reporting the patient's epilepsy experience with the goal of presenting as true a picture as possible of living with these health disparities. In this study Angelia Paschal and her colleagues were interested in African American female epilepsy patients' perspectives.⁵⁴ They start out by identifying a list of barriers that minority patients face, such as language and communication issues, medical practices that differ from their own beliefs and traditions, fear and mistrust of healthcare institutions, and lack of knowledge about how to navigate the healthcare system. This, in turn, results in difficulty scheduling appointments,

⁵³ Ibid, 287.

⁵⁴ Angelia M. Paschal and others, "Stigma and Safe Havens: A Medical Sociological Perspective on African-American Female Epilepsy Patients," *Epilepsy & Behavior* 7 (2005): 106-7.

misunderstandings, misdiagnoses, and lower rates of adherence. They explain their main interest of tackling these disparities by highlighting the patient perspective because “the majority of previous literature has focused on the perspectives of medical care professionals, while few have considered the voices of the patients themselves.”⁵⁵ This is especially problematic because sometimes specific motivations or barriers to care may be invisible to researchers or healthcare administrators because of educational, cultural, or socioeconomic differences between researchers and the providers or the patients. As a result, unstructured interviews provide valuable information into these barriers.⁵⁶

Although they chose a specific subset of patients with epilepsy to study, the findings are eye opening and are packed with deep insights into how to eliminate some of the ongoing disparities for these patients. For starters, financial limitations were the single most important barrier in accessing epilepsy treatment and adhering to it. Because of the inability to work or drive, patients are often unable to seek out medical care, which results in worsening their condition, thus, perpetuating the disability and poverty cycle. As one patient put it, “getting epilepsy has put me in poverty.”⁵⁷ Another issue leading to significant experienced disparities that was identified by several of the interviewed patients is the general lack of knowledge about epilepsy. This breeds misconceptions and stigma, and forces patients to spend substantial amounts of time educating family members about their disease, self-loathing, and further adding to the stigmatization.

⁵⁵ Ibid, 107.

⁵⁶ Ibid, 108.

⁵⁷ Ibid, 110.

Consequently, their help-seeking behavior is affected, and by the time the patient gets the care they need, the disease has progressed and is unamenable to medical or surgical management.⁵⁸ Because of these findings, the investigators were able to provide several social interventions that can help similar African American women manage their epilepsy based on direct input from the patients themselves. However, they agree that this study could be greatly enhanced with the addition of medical correlation, such as identifying seizure type and history, and other medical and mental comorbidities that can exacerbate the effect of the disparities on the patient. This conclusion strengthens the belief that clinicians need to partner with social scientists to reach this goal.

⁵⁸ Ibid.

CHAPTER 10

THE FUTURE OF HEALTH DISPARITIES IN EPILEPSY

It is clear that research from the fields of medicine, public health, and the social sciences, each results in unique, yet complementary, answers to the health disparities in epilepsy question. Unfortunately, because of ongoing challenges, and lack of direct cooperation, the resulting studies fail to realize one of the ongoing goals of Health People 2020, which is achieving health equity, eliminating disparities, and improving the health of all groups. Thus, current approaches need to be broadened and researchers need to strive for a new model of studying health disparities.⁵⁹ Thomas et al describe three established generations of health disparities research. In the first generation, the focus is on detection, identification, and documentation of disparities, including identifying vulnerable populations.⁶⁰ The current existing body of health disparities in epilepsy literature is monopolized by such first generation studies. Although they were fundamental when this was a budding field, it is extremely problematic that this is still the case twenty years later. Over this period, some second-generation studies were able to make their way through the cracks. In this generation, research determines causal relationships that underlie health disparities.⁶¹ This usually includes an examination of the role of social determinants of health that underlie the disparities and lead to the experienced health

⁵⁹ Thomas, 401.

⁶⁰ Ibid, 402.

⁶¹ Ibid.

inequity. Most of these studies tend to be epidemiological, relying on national surveys, and the causation is usually established from statistical analysis rather than from direct communication with the patients experiencing the disparities. The previously mentioned studies by Elliott are a good example of this second generation. Rarely, this leads to third generation studies in health disparities, in which solutions for eliminating health disparities are provided.⁶² Epilepsy literature includes an extremely limited number of studies from this generation in which the effectiveness of strategies and policies to eliminate disparities were studied.

This lack of studies can be attributed to several causes relating to epileptologists, patients, and the community. For starters, epileptologists tend to have seizure and comorbidity control as their primary targets, and they dedicate scarce resources to studying efforts beyond this scope. Consequently, even though most epileptologists are aware of the existence of health disparities, their response usually is to direct more aggressive treatment toward that patient population and rarely to explore the reasons behind the higher seizure burden or number of comorbidities. The nature of epilepsy itself as a tremendously disabling disease poses another set of constraints on the third generation of research. Because epilepsy has physical, mental, and social effects on patients and their families, it is often difficult to assess the relative effectiveness of strategies to eliminate a specific health disparity when factors that give rise to it are greatly intertwined. Finally, the community itself plays a role in obstructing third generation research. Although patients with epilepsy have gained social acceptance and

⁶² Ibid.

are now more publicly open about their disease, there remains a great degree of stigma associated with epilepsy. Studies show that minority patients are more likely to face stigma in their communities, which poses a challenge to implementing any community efforts to eliminate disparities or study their effectiveness. However, even if epilepsy researchers could conduct more third generation studies, there would remain the complication of the reliance on randomized control trials (RCTs) to conduct studies in this generation. Because racial and ethnic minority populations are always underrepresented in RCTs, their conclusions produce “a color-blind evidence base, with few, if any, studies that explicitly cite evidence of effectiveness with minority communities.”⁶³

To address this urgent need for health disparities research that is capable of producing culturally appropriate interventions for minority patients, Thomas et al propose a new generation of health disparities research. This fourth generation attempts to address disparities through understanding the complex linkage between health disparities, racism, and the structural determinants of health.⁶⁴ Although various sources of disparities exist, it is essential to accept that many of them are rooted in race and racism; therefore, it is no longer sufficient to treat race as a demographic in health disparities research without “fully grappling with race and racism in contemporary society.”⁶⁵ To begin formulating this new fourth generation, Thomas et al. turn to Ford and Airhihenbuwa’s Critical Race

⁶³ Ibid, 404.

⁶⁴ Ibid.

⁶⁵ Ibid, 407.

Theory (CRT). This theory relies on the principle of race consciousness, which they define as “the explicit acknowledgement of the working of race and racism in social contexts or in one’s personal life and color blindness as positioning that nonracial factors explain racial phenomena.”⁶⁶ By being racially conscious, researchers can begin to examine the true impact of routine exposure to racism on health behaviors and health status. This translates to beginning the research process from the perspective of racial and ethnic minorities rather than from the perspectives of majority white researchers. This shift forces the researchers to examine their own lived experiences and the interaction of race, power, and class, which in turn, allows them to better reduce the impact of their own biases in their findings. Therefore, this race consciousness fueled research will be “informed by theory, qualitative data, and unlike current research, personal self-reflection.”⁶⁷

To put this theory into practice, giving voice to community members is an absolute necessity. The traditional individualistic biomedical model of health needs to be replaced by a public health model that focuses on populations in community based settings. With this, the emphasis is no longer on what the healthcare establishment can do for the patient, but on what efforts the community can take to promote the health of its members.⁶⁸ As Thomas et al point out, this requirement of community engagement is also “essential to fully understand and grapple with the impact of the ordinariness of racism

⁶⁶ Ibid.

⁶⁷ Ibid, 408.

⁶⁸ Ibid.

on community members' lives, to expand our understanding of race and racism as well as the intersectionality of other factors such as gender on their lives, and to engage community members fully as partners in action.”⁶⁹ It is, therefore, certain that this generation of research mandates a sophisticated mixed methods (quantitative and qualitative) approach that can evaluate any feasible comprehensive, multilevel interventions. Thus, it is no longer adequate for professional educational programs to continue to further the divide between quantitative and qualitative methods, and propagate the misconception of the superiority of one research methodology over the other. The future of health disparities research depends on this overhaul of research curricula if any meaningful change toward the fourth generation is to be expected. Furthermore, because the fourth generation has critical race theory at its core, education curricula also need to be more comfortable with addressing race and racism more explicitly. Finally, the medical community, as a whole, must stop turning a blind eye to the morally problematic existence of health disparities. At their core, health disparities are a violation of the social contract when specific groups are subjected to systemic racial discrimination and denied the basic benefits of society.⁷⁰ This is a frank transgression on the fundamental ethical principle of justice, and resuming the ongoing deficient ways in which health disparities are studied only perpetuates this offense. It is time to change how we approach our clinical and research practices, and adopt models, like the proposed

⁶⁹ Ibid, 410.

⁷⁰ Ibid, 412.

fourth generation of health disparities research, to fulfill the oath we took as physicians when we first put on our white coats.

BIBLIOGRAPHY

- Baum, Frances. "Researching Public Health: Behind the Qualitative-Quantitative Methodological Debate." *Social Science & Medicine* 40, no. 4 (1995): 459-68.
- Bautista, Ramon Edmundo D. and Deepali Jain. "Detecting Health Disparities among Caucasians and African-Americans with Epilepsy." *Epilepsy & Behavior* 20 (2011): 52-6.
- Bautista, Ramon Edmundo D., Valerie Rundle-Gonzalez, Rusha G. Awad, and Philip A. Erwin. "Determining the Coping Strategies of Individuals with Epilepsy." *Epilepsy & Behavior* 27 (2013): 286-91.
- Bautista, Ramon Edmundo D., Catrina Graham, and Shahbuddin Mukardmawala. "Health Disparities in Medication Adherence between African-Americans and Caucasians with Epilepsy." *Epilepsy & Behavior* 22 (2011): 495-98.
- Bautista, Ramon Edmundo D. "Racial Differences in Coping Strategies among Individuals with Epilepsy." *Epilepsy & Behavior* 29 (2013): 67-71.
- Begley, Charles E., Ross Shegog, Biebele Iyagba, Vincent Chen, Krishna Talluri, Stephanie Dubinsky, Michael Newmark, Nikki Ojukwu, and David Friedman. "Socioeconomic Status and Self-Management in Epilepsy: Comparison of Diverse Clinical Population in Houston, Texas." *Epilepsy & Behavior* 19 (2010): 232-8.
- Betjemann, John P., Atalie C. Thompson, Carlos Santos-Sanchez, Paul A. Garcia, and Susan L. Ivey. "Distinguishing Language and Race Disparities in Epilepsy Surgery." *Epilepsy & Behavior* 28 (2013): 444-9.
- Blank, Lindsay, Wendy Baird, and Markus Reuber. "Patient Perceptions of the Referral of Older Adults to an Epilepsy Clinic: Do Patients and Professionals Agree Who Should Be Referred to a Specialists?" *Epilepsy & Behavior* 34 (2014): 120-3.
- Bowman, Stephen M., Mary E. Aitken, and Gregory B. Shary. "Disparities in Injury Death Location for People with Epilepsy/Seizures." *Epilepsy & Behavior* 17 (2010): 369-72.
- Burneo, Jorge G. et al for the Task Force on Disparities in Epilepsy Care, on behalf of the North American Commission of the International League Against Epilepsy. "Disparities in Epilepsy: Report of a Systematic Review by the North American Commission of the International League against Epilepsy." *Epilepsia* 50, no. 10 (2009): 2285-95.

- Burneo, Jorge G., Robert C. Knowlton, Roy Martin, R. Edward Faught, and Ruben I. Kuzniecky. "Race/Ethnicity: A Predictor of Temporal Lobe Epilepsy Surgery Outcome?" *Epilepsy & Behavior* 7 (2005): 486-90.
- Elliott, John O., Bo Lu, Bassel Shneker, Christine Charyton, and J. Layne Moore. "Comorbidity, Health Screening, and Quality of Life among Persons with a History of Epilepsy." *Epilepsy & Behavior* 14 (2009): 125-9.
- Elliott, John O., Christine Charyton, James W. McAuley, and Bassel F. Shneker. "The Impact of Marital Status on Epilepsy-Related Health Concerns." *Epilepsy Research* 95 (2011): 200-6.
- Elliott, John O., Bo Lu, Bassel F. Shneker, J. Layne Moore, and James W. McAuley. "The Impact of 'Social Determinants of Health' on Epilepsy Prevalence and Reported Medication Use." *Epilepsy Research* 84 (2009): 135-45.
- Halpern, Michael T., Jeanette M. Renaud, and Barbara G. Vickrey. "Impact of Insurance Status on Access to Care and Out-of-Pocket Costs for U.S. Individuals with Epilepsy." *Epilepsy & Behavior* 22 (2011): 483-9.
- Irwin, A. and E. Scali. "Action on the Social Determinants of Health: A Historical Perspective." *Global Public Health* 2, no.3 (2007): 235-56.
- Kelvin, Elizabeth A., Dale C. Hesdorffer, Emilia Bagiella, Howard Andrews, Timothy A. Pedley, Tina T. Shih, Linda Leary, David J. Thurman, and W. Allen Hauser. "Prevalence of Self-Reported Epilepsy in Multiracial and Multiethnic Community in New York City." *Epilepsy Research* 77 (2007): 141-50.
- Kharkar, Siddharth, Jyoti Pillai, Dustin Rochestie, and Zulfi Haneef. "Socio-Demographic Influences on Epilepsy Outcomes in an Inner-City Population." *Seizure* 23 (2014): 290-4.
- Konda, Kurt, Elizabeth Ablah, Kelly S. Konda, and Kore Liow. "Health Behaviors and Conditions of Persons with Epilepsy: A Bivariate Analysis of 2006 BRFSS Data." *Epilepsy & Behavior* 16 (2009): 120-7.
- Kroner, Barbara L., Mansour Fahimi, Anne Kenyon, David j. Thurman, and William D. Gaillard. "Racial and Socioeconomic Disparities in Epilepsy in the District of Columbia." *Epilepsy Research* 103 (2013): 279-87.
- Lincoln, Yvonna S. and Egon G. Guba, *Naturalistic Inquiry* (Newbury Park: Sage, 1985).
- Marmort, Michael G. and Ruth Bell, "Action on Health Disparities in the United States: Commission on Social Determinants of Health." *Journal of the American Medical Association (JAMA)* 301, no. 11 (2009): 1169-71.

- Marshall, Catherine. "Goodness Criteria: Are They Objective or Judgement Calls?." In *The Paradigm Dialog*, edited by Egon G. Guba, 188-97. Newbury Park: Sage, 1990.
- Maxwell, Joseph A. "Understanding and Validity in Qualitative Research" *Harvard Educational Review* 62, no. 3 (1992): 279-300.
- Moffat, Suzanne et al. "Using Quantitative and Qualitative Data in Health Services Research – What Happens When Mixed Method Findings Conflict?" *BMC Health Services Research* 6, no. 28 (2006).
- Myers, Lorna, Marcelo Lancman, Gonzalo Vazquez-Casals, Marcela Bonafina, Kenneth Perrine, and Jomard Sabri. "Depression and Quality of Life in Spanish-Speaking Immigrant Persons with Epilepsy Compared with Those in English-Speaking US-Born Persons with Epilepsy." *Epilepsy & Behavior* 51 (2015): 146-51.
- Nakhutina, Luba, Jeffrey S. Gonzalez, Seth A. Margolis, Ashley Spada, and Arthur Grant. "Adherence to Antiepileptic Drugs and Beliefs about Medicine among Predominantly Ethnic Minority Patients with Epilepsy." *Epilepsy & Behavior* 22 (2011): 584-6.
- Paschal, Angelia M., Elizabeth Ablah, Ruth Wetta-Hall, Craig A. Molgaard, and Kore Liow. "Stigma and Safe Havens: A Medical Sociological Perspective on African-American Female Epilepsy Patients." *Epilepsy & Behavior* 7 (2005): 106-15.
- Pope, Catherine and Nick Mays, "Reaching the Parts Other Methods Cannot Reach: an Introduction to Qualitative Methods in Health and Health Services Research." *British Medical Journal (BMJ)* 311 (1995): 42-5.
- Schiltz, Nicholas K., Siran M. Koroukian, Mendel E. Singer, Thomas E. Love, and Kitti Kaiboriboon. "Disparities in Access to Specialized Epilepsy Care." *Epilepsy Research* 107 (2013): 172-80.
- Sim, Yeeck, Brandon Nokes, Seenu Byreddy, Jenny Chong, Bruce M. Coull, and David M. Labiner. "Healthcare Utilization of Patients with Epilepsy in Yuma County, Arizona: Do Disparities Exist?" *Epilepsy & Behavior* 31 (2014): 307-11.
- Sirven, Josph I., Ricardo A. Lopez, Blanca Vazquez, and Peter Van Haverbeke. "Qué Es La Epilepsia? Attitudes and Knowledge of Epilepsy by Spanish-Speaking Adults in the United States." *Epilepsy & Behavior* 7 (2007): 259-65.
- Swarztrauber, Kari, Sandra Dewar, and Jerome Engel Jr. "Patient Attitudes about Treatments for Intractable Epilepsy." *Epilepsy & Behavior* 4 (2003): 19-25.
- Szaflarski, Magdalena, Jerzy P. Szaflarski, Michael D. Privitera, David M. Ficker, and Ronnie D. Horner. "Racial/Ethnic Disparities in the Treatment of Epilepsy: What

- Do We Know? What Do We Need to Know?" *Epilepsy & Behavior* 9 (2006): 243-64.
- Szaflarski, Magdalena. "Social Determinants of Health in Epilepsy." *Epilepsy & Behavior* 41 (2014): 283-9.
- Thomas, Stephen B., Sandra Crouse Quinn, James Butler, Craig S. Fryer, and Mary A. Garza. "Toward a Fourth Generation of Disparities Research to Achieve Health Equity." *Annual Review of Public Health* 32 (2011): 399-416.
- Thurman, David J., Rosemarie Kobau, Yao-Hua Luo, Sandra L. Helmers, and Matthew M. Zack. "Health-care Access among Adults with Epilepsy: The U.S. National Health Interview Survey, 2010 and 2013." *Epilepsy & Behavior* 55 (2016): 184-8.
- US Centers for Disease Control and Prevention Epilepsy Program. "About One-Half of Adults with Active Epilepsy and Seizures Have Annual Family Incomes Under \$25,000: The 2010 and 2013 US National Health Interview Surveys." *Epilepsy & Behavior* 58 (2016): 33-4.
- Whittemore, Robin, Susan K. Chase, and Carol Lynn Mandle. "Validity in Qualitative Research." *Qualitative Health Research* 11, no. 4 (2001): 522-37.
- Wilson, Dulaney A., Angela M. Malek, Janelle L. Wagner, Braxton B. Wannamaker, and Anbesaw W. Selassie. "Mortality in People with Epilepsy: A Statewide Retrospective Cohort Study." *Epilepsy Research* 122 (2016): 7-14.
- Woolf, Steven H. "Social Policy as Health Policy." *Journal of the American Medical Association (JAMA)* 301, no. 11 (2009): 1166-9.
- World Health Organization, *Neurological Disorders: Public Health Challenges*, 2006.
- World Health Organization, *Social Determinants of Health: The Solid Facts*, 5th ed. Edited by Richard Wilkinson and Michael Marmot, 2003.