Writing The Gap: The Role Of Clinician-Authored Narratives In Building Structural Competence And Situated Knowledge In Service Of Marginalized Patient Populations

Anusha Singh

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Writing the Gap: The Role of Clinician-Author Narratives in Building Structural Competence and Situated Knowledge in Service of Marginalized Patient Populations

A Thesis Submitted to the Yale University School of Medicine in Partial Fulfillment of the Requirements for the Degree of Doctor of Medicine and the Degree of Masters of Health Science

By
Anusha Singh
2020
Abstract

This thesis analyzes clinician-authored narratives about mental illness. Through this lens, it argues that the writing and reading of medical narratives can facilitate the development of key clinical skills such as structural competence and situated knowledge – terms that this thesis will define and discuss at length. It will argue that clinicians who write about structural barriers to health do so to develop a deeper understanding about their vulnerable and marginalized patient populations. It will assert that clinicians who pursue situated knowledge can positively impact health outcomes. Ultimately, this thesis will compare what clinician-authored narratives can achieve with what patient-centered advocacy sets out to do. It will contend that writing is a tool for improving patient care that has a different but vital function from the important work of advocacy.
Acknowledgments

I would first like to thank Dr. Anna Reisman for her willingness to guide me through this project. The questions posed in this thesis motivated my decision to become a physician. Dr. Reisman’s insight was instrumental in turning these broad philosophical ideas about medicine into a thesis with specificity and purpose.

I would also like to thank the members of my thesis committee. Dr. Carolyn Mazure for providing perspective informed by her expertise in gender and psychiatry and connecting me to the Women’s Health Research network. Dean Nancy Angoff for lending her expertise in writing and the intersection of the humanities and medicine to the review of this thesis. Additionally, I would like to acknowledge Dr. Naomi Rogers from the Program in the History of Science and Medicine at Yale School of Medicine for graciously sharing her time and extensive knowledge of resources on multiple occasions.

Furthermore, this project would have remained impossible without the participation of the narrative authors. I would like to thank Dr. Christine Montross, Dr. Cassie Addai, Dr. Kamal Kainth, Dr. Sand Chang, and Dr. Kay Jamison for their time. It was a privilege to discuss my thesis with each of them. Their narrative writing and our conversations about narrative medicine were fundamental to developing the conclusions of this thesis.

Finally, I would like to thank the Office of Student Research and the James G. Hirsch, M.D., Endowed Medical Student Research Fellowship for their support of this project.
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Foreword

Learning about a patient’s illness experience is vital to the effective and ethical practice of medicine. Before arriving at medical school, I had internalized this lesson thanks to an undergraduate course called International Law and Global Health. Professor Admay, or simply Admay as she preferred, was a career advocate for health as a human right. A lawyer by training, she would argue the following: physicians, because of their privileged access to the most vulnerable patients’ experiences, are morally obliged to advocate on behalf of those patients. I remember the case study that followed this statement with clarity. Admay described a Russian prison that housed inmates in appalling, inhumane conditions in the dead of winter. The whistleblower who revealed the human rights violations endured by these prisoners was the only outsider granted access to the prison; he was their doctor.

The question compelled me. How, I wondered, should clinicians incorporate advocacy into the doctor-patient relationship? Never did I question whether advocacy belonged in medicine. It seemed irrefutable that some patients – perhaps due to their demographic or social identities or the very illnesses they were battling – were vulnerable to injustice and needed their physicians to be allies and advocates for their right to healthcare. Given this circumstance, the choice between silence and action felt untenable. I was convinced that the ethical practice of medicine required physicians who acknowledge that they bear witness to the experiences of vulnerable, voiceless patients and who recognize that this privilege comes with a responsibility to speak.

So, I decided advocacy was a natural extension of the physician’s professional role. Physician failures in this role were most apparent in the realm of research. History is
riddled with landmark studies that either exploited the most vulnerable members of our society or failed to include them in scientific and medical advancement. Notorious and horrifying examples of exploitation include the Tuskegee Study or the forced sterilization of black women in the 1980s. One contemporary example of exclusion is heart disease, the leading cause of death in women. Despite this statistic, the presentation and treatment of heart disease has been woefully understudied in gender and racial minority groups alike.

Examples such as these have led to policy changes that require physicians to design inclusive research studies. However, more than a change in policy, I wished for a change in vision. Behind these studies were physicians who did not prioritize the right to equitable healthcare. At worst, these physicians were informed by discriminatory and racist ideologies. At best, they were indoctrinated into a narrow theory of scientific inquiry that neglected the lived experience or diversity of their patients.

Arriving at medical school, however, I soon noticed that the role of advocacy in medicine was controversial. Advocacy was not part of the culture of medicine, and many physicians disagreed it needed to be. Faculty, residents, and medical students alike emphasized the need for a narrow clinical scope in medicine. They argued that physicians, in their limited time, already struggled to achieve clinical excellence. For these physicians, advocacy was a political action rather than a professional responsibility. My impression that physicians shared a belief in their professional duty to advocate for equitable healthcare disintegrated. Now immersed in the culture of medicine, I too felt the burden of competing demands on my time. It was a humbling moment of culture shock.
How, in such an environment, could physicians create the space to reflect on their patients’ experiences and discern opportunities to improve the system of clinical care? I suspected that medical education itself was the key. In the same way that medical education emphasizes the fundamentals of the physical exam or preaches the importance of randomized control trials, it could arm us with the tools to recognize and address inequities in our system of healthcare. I had hoped my training would incorporate this skillset and was disheartened to note its absence during each year of medical school.

I could not shake a burgeoning sense of guilt. Was I complicit to a narrow medical pedagogy that, among other failings, excluded the experiences and needs of gender, racial, and other social minorities? In light of this exclusion, how could I trust that my training served the best interest of all patients? The missing illness narratives of social minorities in medical education had come into sharp focus, and I could not ignore the harm caused by this pervasive disparity. This thesis has been an opportunity to shed light on such narratives and define their role and purpose within medical education.

To this end, the following narratives were included. The first narrative, *An Unquiet Mind*, is a memoir describing psychologist Kay Jamison’s personal experience with manic depressive illness. In it, she speaks movingly and eloquently from the perspective of both patient and clinician. The second narrative, *Falling Into The Fire*, is a collection of clinical cases from various stages of psychiatrist Christine Montross’ career. Montross delves into those patients’ stories that baffled, eluded, and challenged her most. The third narrative, *The Colour of Madness* (edited by Dr. Samara Linton and Rianna Walcott), is an anthology that centers the mental health experiences of Black, Asian, and ethnic minority individuals. The book represents a concerted effort to address the absence
of mental illness narratives authored by individuals who identify as racial minorities. The final narrative, *The Remedy* (edited by Zena Sharman), is another anthology; its purpose is to highlight the illness experiences of queer and trans identifying individuals.

My preoccupation with clinicians’ privileged access to patient narratives and their obligation to those narratives motivated this thesis. In researching and writing this thesis, I chose to focus on clinician-authored narratives of mental health written by individuals who identify as gender or racial minorities. This was a deliberate decision to A) examine the educational utility of illness narratives written by clinicians and social minorities, and B) center voices that had been relegated to the margins of medical education. I hoped to discover if this subset of illness narratives could promote a more inclusive approach to clinical care, one that drew attention to the connection between healthcare inequities and poor health outcomes.
**Introduction**

In considering the mental illness experiences outlined in the narratives I have chosen, I was struck not only by the essential role of trust in the provider-patient relationship, but also by the layers of complexity intrinsic to building this trust. Imagine you are speaking with your therapist, aware that the judgements and insights they offer are based on your words and their perceptions. Though the conversation is guided by years of training, it is also vulnerable to the biases of both parties. Like any dialogue between two people, each individual brings perspectives informed by the groups and value-systems in which they have developed and to which they ascribe.

Both historically and today, social minority groups struggle for fair recognition of their rights and values. Unequal power and representation of women, for example, resulted in oppressive systems of government that prioritized the societal advancement of men. The field of mental health has developed and matured within such systems of thinking. In fact, "the patriarchal nature of [psychiatry] has been documented by M. Foucault, T. Szasz, E. Goffman, and T. Scheff." [Chesler, 2005 #221]

Below, I provide some history on the disease of “hysteria.” The evolution of this diagnosis is an excellent example of the limitations of mental healthcare historically and today. Later, in the discussion section of this thesis, I will return again to this disease and how it exemplifies the arguments of this thesis.

Hysteria is an antiquated catch-all diagnosis for women who exhibited a wide range of otherwise unexplained physical and emotional symptoms. These included anxiety, shortness of breath, fainting, insomnia, irritability, loss of appetite for food or sex, sexually forward conduct, and “troublesome” behavior. I chose this
diagnosis for its notoriety in popular culture. Hysteria is a famous example of psychiatry’s failure to include the narratives of its marginalized patients in constructing a theory of disease. The consequence of this failure is hundreds of years of embarrassing conclusions that pass as clinical expertise. The greater consequence is psychiatry’s failure to serve the needs and promote the well-being of its female patients. The example of hysteria justifies the necessity of this thesis. It confirms that medical practice must be informed by a diverse set of illness experiences and narratives. The subsequent goal of this thesis will be to evaluate how writing and reading the illness narratives of marginalized individuals can improve clinicians’ structural competence and situated knowledge – two concepts that I will define and discuss later at length.

The History of Hysteria

The example of hysteria illustrates the demographic homogeneity of the physicians, psychiatrists, and psychologists who shaped the field of mental health. For the majority of history, these experts were white cisgender men, highly influenced by western cultures of health and medicine. The consequences of this lack of diversity permeated the diagnosis and treatment of mental illness for centuries and has lasting impact today.

“The two approaches toward mental disorders” in women, the “scientific” and “magic-demonological” views, become evident in the diagnosis of hysteria. Not only were women considered biologically vulnerable to mental illness, they were also weak, easily influenced by the “supernatural,” and somehow “guilty” [Tasca, 2012 #233].
Written in 1600 BC, the Egyptian Eber Papyrus is the oldest medical record of mental illness, with "symptoms of hysteria described as tonic-clonic seizures and the sense of suffocation and imminent death" [Cosmacini, 1997 #259]. Hysteria was initially an affliction of women, and the suggested therapeutic intervention at the time depended on returning a dislocated uterus to its natural position through the polar placement of acrid and sweet scented substances at the mouth and vagina [Cosmacini, 1997 #259].

Greek physicians and philosophers offered augmentations to the theory of uterine based illness in 1300 BC. The mythological healer Melampus was credited with founding the field of psychiatry when he attributed hysteria to "a lack of orgasms and 'uterine melancholy,'" [Tasca, 2012 #233] and prescribed the herb hellebore and sexual activity as the cure. Plato, Aristotle, and Hippocrates all agreed that a lack of sex and child birth made the uterus prone to retaining toxic hysteria-inducing humours. "Virgins, widows, single, [and] sterile women" [Tasca, 2012 #233] were particularly vulnerable.

In 100 AD Rome, the Greek physician Soranus penned his treatise on *Gynaecology*. In it, he contested the theory of the wandering womb, "the uterus does not issue forth like a wild animal from the lair, delighted by fragrant odors and fleeing bad odors" [Fantham, 1995 #260]. However, Soranus still felt hysteria and other women's disorders were related to the "toils of procreation," [Tasca, 2012 #233] and he suggested abstinence, hot baths, massages, and exercise as the appropriate path to recovery.

For the next several hundred years, both the theory of the wandering womb and the idea that women were vulnerable to melancholy and hysteria persisted in expert discourse. The Middle Ages were notable for the publication of *Malleus Meleficarum* (*The Hammer of Witches*), a manual that equated mental illness with sin and blamed
diseases without a known cause on the Devil [Kramer, 2009 #261]. Women were predominantly the witches in question, and until the 1700s, "thousands of innocent women were put to death on the basis of 'evidence' or 'confessions' obtained through torture" [Kramer, 2009 #261]. Even as recently as the 1900s, women were encouraged to carry smelling salts. Their odor was thought to facilitate recovery when a woman was "inclined to swoon" [Leff, 1988 #262] by forcing the uterus back to its appropriate position.

In the late nineteenth century, physicians began to establish a uniform clinical definition for hysteria. In his review of 430 cases, French physician Paul Briquet defined hysteria as a syndrome of several physical and neurological symptoms [North, 2015 #263]. Soon after, French neurologist Jean-Martin Charcot, known for his theatrical demonstrations of hypnotic cures for hysteria, wrote that "hysterical phenomena...represent neurodegenerative conditions and [should be separated] from their historical enmeshment in occult and superstitious beliefs" [Bogousslavsky, 2011 #272].

In the 1900s, Pierre Janet's dissociative theory and Sigmeund Freud's conversion theory of hysteria emerged [North, 2015 #263]. Until then, "somatization, conversion, and dissociation...were closely intertwined under the common label of hysteria for nearly four millennia" [Bowman, 2006 #271]. In 1952, hysteria and its early theories of etiology were incorporated into the first edition of the diagnostic and statistical manual of mental disorders (DSM). And in 1980, the psychoanalytic theories behind hysterical neurosis were finally discredited and the diagnosis was removed from the DSM. Despite evolving notions of hysteria, the disorder and its present-day offshoots (dissociation, conversion,
and somatic symptom disorder) remain disorders of women in the collective psychiatric conscious.

The History of the Diagnostic and Statistical Manual of Mental Disorders

To date, the DSM has undergone several revisions; each reflects foundational shifts in the field of psychiatry. The most notable revolution occurred with the DSM-III, which centered the concept of evidence-based diagnostic criteria. Rather than relying on the "psychiatrist's own possibly idiosyncratic views," [Shorter, 2015 #273] it required patients to present with defined symptoms to "qualify" for a diagnosis. The DSM-III "began a rapprochement between psychiatry and the rest of medicine" [Shorter, 2015 #273] - it valued "diagnoses that [were] clinically well defined, verified with physical findings and laboratory data, and validated with specific responses to treatment" [Fischer, 2012 #274].

Considering the historical example of hysteria, we can appreciate how "mental disorders, especially in women, were so often misunderstood and misinterpreted, generating...pseudo-scientific prejudice" [Tasca, 2012 #233]. While the DSM's adoption of the "medical model" signified a turning point for psychiatric diagnosis, the example of hysteria also helps to illustrate the work that remains. From its inception to its introduction into the first edition of the DSM, hysteria demonstrates how the language used to describe mental illness was influenced by historical and cultural power structures.

Though the current DSM attempts to minimize the impact of bias by emphasizing clinically-validated diagnosis and treatment, it is impossible to separate the document entirely from the specific social, cultural, and scientific backgrounds of the experts who
have historically informed it. Until recently, the majority of these experts have been male physicians informed largely by western European and North American approaches to mental health.

**The Biopsychosocial Model**

The present-day Diagnostic and Statistical Manual of Mental Disorders emphasizes evidence-based diagnosis. In order to receive a formal diagnosis, patients must meet the standardized criteria. As a result, the DSM is a valuable point of references for both patients and clinicians. It can assuage a patient’s feelings of uncertainty or isolation, and it can also reassure a patient that there is an effective treatment for their illness. By the same token, it can help a clinician understand a series of disparate symptoms through a unifying diagnosis. However, despite its strengths, the DSM is still a document composed by a narrow group of experts that is limited by its vulnerability to bias. A proposed solution to these limitations is the biopsychosocial model of mental health. Below I will define this model and discuss why proponents support it.

"Despite individual differences among clinicians, most have been steeped, professionally and culturally, in patriarchal ideologies" [Chesler, 2005 #221]. One response is reemergence of the "biopsychosocial model," a "means to clarify the [connection between an] individual's mental health [and their] specific social class" [Strauss, 2019 #275]. Advocates for equitable mental healthcare look to this model to "reconstruct our psychological knowledge of [social minorities with] more inclusive...approaches to psychotherapy" [Comas-Díaz, 1994 #222].
Unfortunately, "constructing a meaningful biopsychosocial model for the mental health field has been extremely elusive...[and] especially daunting" [Strauss, 2019 #275]. Skeptics criticize the approach for being too expansive and detracting from the ability to understand illness and treatment through unifying categories. However, proponents of the biopsychosocial model encourage clinicians to develop "structural competence" [Metzl, 2014 #276]. Achieving structural competency requires going “beyond the cultural specificities of patient care to confront the larger social inequalities of place, race, and economy” [Schneider, 2012]. The term is meant to introduce into the language of medicine a concept that links social structures to health outcomes.

Metzl et al. believe structural competence is necessary to intervene on the "economic, physical, and socio-political forces [that] impact medical decisions." They suggest the following strategies to integrate structural competence into the patient encounter. First, their five-step system requires awareness that "the political economy of healthcare in the U.S. impacts [health decisions]" [Metzl, 2014 #276]. Second, the informed clinician must look beyond biomedicine, which is adept at describing the "biological impacts of lived environments" [Metzl, 2014 #276]. Instead, clinicians must engage with fields like medical anthropology, sociology, and urban planning. Such pedagogies are decades ahead of biomedicine in their analysis of the environmental determinants of illness and health disparity. Third, clinicians must eschew the term cultural competence in favor of structural competence. Evidence suggests that the former may obfuscate "the deeper ways in which complex structures produce inequalities" [Metzl, 2014 #276]. In the last two steps, physicians are encouraged to practice structural intervention and structural humility.
The Utility of Clinician-Authorized Narratives

Here I will return to the concept that diverse illness narratives can improve clinical care. In particular, clinician-authored narratives can serve to promote the biopsychosocial model of mental health by developing the skills of structural competence and situated knowledge. Situated knowledge is the idea that all forms of knowledge reflect the particular conditions in which they are produced – a concept I will elaborate on later in this thesis.

Imagine, once more, a woman speaking with her therapist. Her story and behavior are being evaluated; her therapist records data about her appearance, her attitude, her affect. The patient, the provider, both, or neither may enter the encounter aware of the history that shapes their conversation or the social contexts that separate their lived experiences. Regardless of their awareness, these certainly impact their relationship, their rapport, and the work they do related to the patient’s mental healthcare.

Through the narrative form, clinicians can create the time and space to reflect on the social determinants of health that complicate and inform their clinical encounters. They can return to these encounters and think deeply about their own and their patients’ lived experiences, and ultimately how these have influenced their evaluations.

And suppose the clinician is aware, or learns to be aware, of the complicated factors that inform their clinical evaluation. How do they grapple with them? How do they harness them to improve their patient’s experience and care? In this thesis, I will argue that the clinician-authored narrative is not only a tool that facilitates reflection on the social determinants of health, but it is also a way for clinicians to develop the
knowledge and competencies necessary to understand and intervene on these determinants of health.
Methods

The Search for Primary Sources

When I first began to think about this thesis, my intention was to focus on the narrative writing of mental health clinicians who identified as women. I was aiming to center the voices of women, and I was curious about how the lived experience of women was represented by narrative medicine. I also chose to focus on clinicians rather than patients. I made this decision because I hoped to draw conclusions about the utility of engaging with narratives as a clinician-reader or clinician-author. Specifically, I intended to identify concrete ways in which narratives improve the clinical education and practice of providers from all backgrounds. In order to accomplish these goals, I also felt it was important to have a narrow clinical scope. So, I chose to focus on mental health.

Multiple resources, including the Yale School of Medicine librarians, the Stanley Jackson Collection of ninety-seven mental illness narratives, and the NYU LitMed Database, were used to locate primary sources. I soon noticed that I was generating a list of white cisgender women authors. I wondered if the lack of authors from racial minority or gender non-conforming backgrounds was due to a flaw in my review of the literature. I set out to fill this gap by querying databases and library associations that would be most likely to curate a collection of medical narratives written by authors with these marginalized backgrounds. These included the American Indian Library Association and the Black Caucus of the American Library Association. I also enlisted the help of scholars in the History of Science and Medicine program. Unfortunately, these strategies proved unsuccessful. It became evident that book length narratives written by individuals
who were mental health clinicians with racial minority or gender non-conforming backgrounds were not easy to locate. In fact, I did not find a single narrative that fit these criteria.

I understood that it was impossible to include authors from an exhaustive range of lived experiences. For example, I recognize that this thesis does not discuss the ways in which religion, ethnicity, class, or other marginalized social identities can inform medical narratives. However, the exclusion of women authors from racial and gender minority backgrounds struck me as particularly self-defeating. Race and gender are two types of marginalized identity that have been extensively associated with poor health outcomes. I was attempting to write about the importance of centering and promoting women’s voices in the narrative medicine space, and I could not do so by discussing a series of narratives written only by white cisgender individuals. I decided to relax my criteria and hoped this would uncover authors I had overlooked. Turning to Twitter, I began looking for shorter narrative forms that still fit my author criteria. There, I discovered *The Colour of Madness* and *The Remedy*. Both books were a collection of anthologies curated to include narrative essays written by authors from marginalized backgrounds.

Ultimately, following a thorough literature review, four narratives were selected as primary sources for this thesis. The clinician-authors of these narratives were interviewed about their perspectives on and motivations for narrative writing, and the primary sources and interviews were analyzed for common themes. From these themes and the literature, arguments were constructed on the utility of clinician-authored narratives.
The Process of Interviewing Authors

I had the opportunity to interview the authors of the narratives selected for this thesis. The purpose of these interviews was to learn the authors’ perspectives on the biopsychosocial model of healthcare, structural competence, situated knowledge, and gender and race in mental illness. Over the course of the year, I located each author’s contact information or reached out through a mentor or mutual acquaintance. Dr. Reisman introduced me to Dr. Montross, and Dr. Mazure introduced me to Dr. Jamison. I was able to reach Dr. Cassie Addai, Dr. Kamal Kainth, and Dr. Sand Chang via email to set up interviews. Each of the authors were scheduled for an interview, and the interviews were conducted over the phone. I selected quotes from each author’s written narratives in order to prompt specific questions about the categories listed above. I then transcribed the interviews as I conducted them to create an accurate and quotable document of the authors’ answers. Interviews are included in the appendix.

The Qualitative Analysis of Primary Sources and Author Interviews

This evaluation of clinician-authored narratives used qualitative research methods. Specifically, primary sources and author interviews were appraised for common themes. Themes are defined as “recurrent unifying concepts or statements about the subject of inquiry” (Boyatzis 1998) or “fundamental concepts that characterize specific experiences of individual participants by the more general insights that are apparent from the whole of the data” (Ryan and Bernard 2003).

Themes that emerged from analysis of primary sources and author interviews included, the biomedical diagnosis of mental illness, developing structural competence in
clinical care, building situated knowledge through writing, and the role of gender and race in mental illness. These themes were developed and presented at the biannual research in progress meetings, and the slides are included in the appendix. Each of these themes will be defined in later sections, and they will serve as the basis for the discussion that follows in this thesis.

The specific qualitative method used for this project can be best described by the concept of phenomenological research. This refers to research that is interested in ascertaining what an experience – for example, the writing and reading of medical narratives – means to the subject, in this case the clinician. As the researcher, I was interested in the lived experience of mental health clinicians and how this experience was represented in their narratives. Ultimately, I used the phenomenological approach what purpose these narratives served for clinician-writers and clinician-readers in their practice.
## Results

### The Comprehensive List of Potential Primary Sources

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<tr>
<th>Source of Narrative</th>
<th>#</th>
<th>Title</th>
<th>Subject</th>
<th>Author</th>
<th>Author Background</th>
<th>Format</th>
<th>Introduction for Interview</th>
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<tr>
<td>Twitter</td>
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<td>The Colour of Madness: Exploring BAME mental health in the UK</td>
<td>Mental Illness &amp; Black, Asian, and Minority Ethnic Patients</td>
<td>Guilaine Kanouse, Samara Linton, Carole Addicott, Kamal Kaif</td>
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<td>Psychiatrist</td>
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<td>Psychiatrist</td>
<td>Article</td>
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<td>Left Side, Goa Regine</td>
<td>Breast Cancer</td>
<td>Uma Yous</td>
<td>Psychiatrist</td>
<td>Memoir</td>
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<td>Coexisting Women Modern and Traditional Healing on a Navajo Reservation</td>
<td>Lee Anna Averb</td>
<td>Surgeon</td>
<td>Memoir</td>
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<td>The first doctor-patient relationship</td>
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<td>The healthcare experiences and challenges of queer and trans people</td>
<td>Sand Chang</td>
<td>Psychiatrist</td>
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**Director of the Program for Humanities in Medicine: Anna Relman**

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<td>An Unquiet Mind</td>
<td>Music Depressive Illness</td>
<td>Kay Jamison</td>
<td>Psychiatrist</td>
<td>Memoir</td>
<td>Dr. Carolyn Mason and the Center for Women’s Health Research at Yale</td>
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<td>Falling Into The Fire</td>
<td>Mental Illness</td>
<td>Christine Montross</td>
<td>Psychiatrist</td>
<td>Book</td>
<td>Dr. Anna Relman</td>
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**Yale School of Medicine Librarians: Melanie Norton, Janeen Batten, Dana Haug**

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<th>Introduction for Interview</th>
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<td>Lay Her Hidden Down: Suicide and the Medieval Health Crisis among African Americans</td>
<td>Post-traumatic stress disorder</td>
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<td>Book</td>
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<td>Losing Control: Living with Bipolar Disorder</td>
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<td>Mother</td>
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**Library Associations: American Indian Library Association & Black Caucus of the American Library Association**

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**NYU Langone Medical Center**

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**YSM’s Stanley Jackson Collection: 97 narratives of mental illness written by both clinicians and patients**

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Discussion

The Biomedical Diagnosis of Mental Illness

In this section, I will discuss the role of the biomedical diagnosis in the patient’s and the provider’s understanding of mental illness, outlining the pros and cons of receiving a diagnosis. I will link this to the role of writing, describing how providers record narratives about mental illness to complement and expand the medical field’s understanding of the patient experience beyond what is gained from the diagnosis alone. Furthermore, I will argue that narrative writing not only expands this understanding, but it also illuminates the gaps in it. This is particularly true of narrative writing authored by providers who hold marginalized identities themselves, as they are more likely to put words to their patients’ experiences of oppression.

For many patients, receiving a diagnosis can be helpful. “Although research has found that individuals respond to receiving a psychiatric diagnosis in diverse ways, one common finding is the expression of relief and validation” [Proudfoot, 2009 #283]. A biomedical name for a patient’s illness can help them feel their experience is legitimate rather than unusual. It can also offer them hope that their illness, because it has been identified, could also be treated. Furthermore, “in orienting around the problems of the body (such as genetics or neurochemistry), a biomedical approach can” help the patient and the public accept the legitimacy of illness without “impos[ing] judgments of weakness, laziness, belligerence, or a simple failure to cope” [Lafrance, 2013 #368]. Ultimately, it can “transform individual distress to a shared experience, one that is understood as both credible and treatable” [Lafrance, 2013 #368].
However, not all individuals feel so positively about receiving a formal diagnosis. In fact, there are several critiques of diagnostic categorization in mental illness. I will outline a few of these critiques and subsequently argue that the narrative form serves to inject the historical and contextual nuance that is sometimes missing from formal diagnosis.

Despite its recent historical shift away from psychoanalysis and toward biomedical evidence-based diagnosis, the Diagnostic and Statistical Manual of Mental Disorders is neither a “neutral nor value-free document” [Hare-Mustin, 1997 #369]. Like any document, it is prone to the “social, moral, and religious prejudices” of those who write it. Not only are critics of the DSM skeptical of its neutrality and inclusivity, but they are also aware of the “strong market forces [that] operate to ‘incentivize’ the use of diagnostic labels” [Jensen, 1997 #370] and the pharmaceutical benefits to an ordered system of classification. One of the strongest critiques of the DSM is that it remains “acontextual and mute about the conditions in people’s lives that might understandably and predictably give rise to symptomatic behavior” [Duffy, 2002 #371]. Its “focus on the individual in isolation [is] an especially pernicious problem for those living in oppressive circumstances” [Lafrance, 2013 #368].

Therefore, diagnosis in mental healthcare is fraught with complexity and the preference for or against receiving one remains highly personal. Not only should providers be aware of this complexity, but they should also recognize that patients rely on their expertise and nuanced understanding of the DSM to guide them through their care. One way to build this awareness and appreciation for the strengths and limitations of the DSM is through the narrative form.
**Christine Montross: Writing Narratives on Behalf of Marginalized Patients**

Dr. Christine Montross, author of *Falling into the Fire*, is an Associate Professor of Psychiatry and Human Behavior at the Warren Alpert Medical School of Brown University. In her practice, she treats complicated cases of mental illness and cares for the most severely ill patients. Dr. Montross, a white woman, has authored several books and articles that center the narratives of her often marginalized patients who identify as gender, racial, or social minorities.

In our interview, Montross commented on the tension between the benefits and limitations of diagnosis in mental health:

> “The question about diagnosis is a highly individual one. Some people bristle at the diagnosis. Some people feel affirmed by receiving a diagnosis. There’s a whole range in between where people are ambivalent. Part of the art of psychiatry is understanding what each patient needs from that part of our practice.” (Montross Interview)

In the book, Dr. Montross shares the story of Lauren, a patient with countless admissions for swallowing dangerous objects often resulting in life-threatening injury. She notes that self-injurers lose the trust and support of their community - clinicians, family, and friends included. For loved ones in particular, “the act of self-harm is frequently incomprehensible and the impulsivity associated with it can be infuriating” evoking “anger and resentment” in caregivers. She describes how a DSM diagnosis has
the power to comfort patients and caregivers in such situations, illuminating a shared experience and path to recovery.

Even so, Dr. Montross is cautious not to assume mental illness can be described by a diagnosis alone. During her interview, she emphasized lived experience:

“So many experiential things contribute to the trajectory of a person’s illness - we know that psychological health is determined by adequate housing, food, social support - those are real variables that are not measurable in the same way that you can carb count them.” (Montross Interview)

Furthermore, she has observed “the urge to render madness romantic” among academics in the field. Some scholars argue “that passion is a kind of madness; [and] that it is from a crazed and not-commonly-understood state that the most vivid and intensely human art emerges” Dr. Montross criticizes the idea that an individual’s mental illness should “benefit mankind at [their own] expense.” She is aware that the DSM is not only an incomplete story, but also one that can be imprecise and biased by the viewpoints and values of the leading voices in psychiatry.

Returning to Dr. Montross’ narrative retelling of Lauren’s illness and care, it is clear her writing begins where her patient’s diagnosis reaches its limit. Lauren was described during her numerous admissions as a “well-known” patient with a long history of “non-suicidal self-injurious” behavior. Her diagnosis simultaneously assigned her to a community and obfuscated the deeper personal history that underscored her experiences.
Dr. Montross’ writing stresses these experiences, reconstructing the social contexts in which Lauren’s illness presented. “Nearly every note made mention of…a litany of seemingly insurmountable social stressors - poverty, unemployment, family discord, lack of social supports,” she writes.

Dr. Montross enfolds her readers in Lauren’s frustrating cycle of readmission in which clinicians are dissatisfied with her and their own futile treatments. With each presentation, surgeons exasperatedly continue to extract dangerous objects from her gastrointestinal tract and psychiatrists fruitlessly attempt to identify why her behavior persists. No therapeutic intervention proves effective. Sympathy for Lauren’s caregivers increases, and it does not help that Lauren often rudely lashes out, angrily blaming everyone involved for her unresolved illness.

From this part of the story alone, it is easy to dismiss Lauren as an unsympathetic figure. However, Dr. Montross’ forestalls this judgement. Through narrative, she explores and shares the deeper context behind Lauren’s illness. It emerges that Lauren has a profound childhood history of isolation from and insecure attachment to caregivers; she lost both her parents and her aunt by the age of six at which time she entered a series of group homes and foster homes. Rather than accepting that this is just another difficult patient, Montross must reconcile the childhood damage to Lauren’s coping mechanisms with her frustration at Lauren’s behavior.

The narrative form is an opportunity to see how Lauren’s biomedical diagnosis, in this case, does not guide effective treatment. Instead, the tools commonly available to clinicians have failed Lauren. The interventions that would help Lauren most are structural changes to her living conditions and support systems, changes beyond the
scope of emergent clinical care. Dr. Montross cites a colleague in psychiatry who summarizes feelings of inadequacy and frustration in the face of structural determinants of health. “The reasons for this state of affairs,” he writes, “includes mistrust of authority, stigma, big-stakes healthcare economics, cross-discipline rivalries, and simplistic thinking (within the mental healthcare field as well as the general public)” (Dr. Lawrence Price, NYT 2010).

Clinician-authored narratives such as this one can illuminate how biomedical diagnoses can fail marginalized patients. The clinicians who pen these narratives also have the power to identify patterns of marginalization that are unclear to the patients themselves. Furthermore, clinicians who have experienced marginalization may be more familiar with the language to describe it and can do so with greater facility than their colleagues.

**Cassie Addai: Writing Narratives Informed by Lived Experience**

In this section, I will introduce authors whose narratives center Black, Asian, and ethnic minority experiences of mental illness. I will explore how these narratives touch on the concept of a biomedical diagnosis, and I will highlight how - unlike *Falling Into the Fire* - they make explicit reference to the interplay of patient identity and marginalization in mental health.

In *On Becoming A Psychologist*, author and psychologist Cassie Addai describes her personal path to receiving treatment for mental illness. She points to two formative experiences. The first is the “hurt, anger, and loneliness” she felt from the “cumulative effects of [racist] interactions” she has as a black girl living in a majority-white city. The
second is the relief she felt on learning about her diagnosis of anxiety. In that diagnosis, she found an explanation for her response to stress and reassurance that her difficulties were common.

In speaking with Dr. Addai, I was struck by her emphasis on what she describes as “formulations, [or the ability] to create a shared understanding of [the patient’s] experience. [And] putting a name to it…the name the patient wants to give rather than the name you do, their language not yours.” Dr. Addai goes on to frame this in the context of marginalized identities:

“People who have experienced struggles throughout their life anyway - because they are moving through the world in a racialized way or with an LGBTQ identity - they may be more well versed or well practiced in thinking about that particular struggle. Not necessarily making it easier, but they already have some of that vocabulary. ‘I think what I’m experiencing is because of that racism, homophobia, microaggression.’ In some ways, they can be more articulate about what they’re experiencing because they have to move through the world with that marginalized identity.” (Addai Interview)

In her narrative, Dr. Addai is critical of colleagues she has observed “dismiss and deny black clients’ experiences of discrimination, unaware that, in doing so, they are perpetuating the very same acts of oppression that the client described.” Though Dr. Addai advocates for formal diagnosis, she believes the patient’s active participation in
diagnosis is crucial. She is cautious of leaving a patient’s feelings unacknowledged, or worse, attributing them to “paranoia” or “imagination,” as is common for black patients who wish to discuss experiences of discrimination with their therapist. Even an inadvertent dismissal of the impact of race on a patient’s mental health could send “the implicit message that therapy is not a space to talk about race.” This supports her emphasis that patients name their own illness. Her approach would allow, for example, a black patient facing discrimination to understand their feelings as a “normal response to systemic racism” rather than pathology.
Developing Structural Competence Through Narrative Writing

In this section, I will circle back to the concept of structural competence, which I defined and discussed briefly in the introduction. Focusing further on structural competence, I will describe its utility in practicing mental healthcare. I will show how both writing and reading clinician-authored narratives can be useful tools for developing structural competence and how this skill can be applied by practitioners in the clinical setting. I will demonstrate how authors who hold underrepresented or marginalized identities themselves emphasize the structural barriers to health in their narrative writing. Comparing the two concepts, I will note the difference between practicing with structural competence in medicine and advocating on behalf of patients. Ultimately, I will argue that medicine must promote the narratives of clinicians and patients who hold marginalized identities in order to effectively and equitably serve a broad range of mental health needs.

Both structural competence and advocacy have an effect on patients’ clinical outcomes. Structural competence can be incorporated into the approach to clinical care, while advocacy implies deeper engagement with community organizing and policy building endeavors. To make this distinction clearer, I will define structural competence and describe its role in the clinical setting. Structural competence describes the ability of a clinician or trainee to appreciate that symptoms, illnesses, and “attitudes toward patients, populations, and health systems” [Metzl] are influenced by social determinants of health. The idea of structural competence was born out of the now familiar concept of cultural competence, which “emerged during an era when U.S. medicine failed to acknowledge…the impact of stigma and bias in treatment decisions” [Metzl, 2014 #276].
The need to redefine and expand the term from ‘culture’ to ‘structure’ is rooted in the current politics of healthcare inequity, as demonstrated in the following quote from *Structural Competency: Theorizing A New Medical Engagement with Stigma and Inequality*.

“Increasingly, we hear that low-income African Americans are unable to comply with doctors’ orders to take their medications with food, not because they harbor cultural mistrust of the medical establishment, but because they live in food deserts with no access to grocery stores. Or, that Central American immigrants who are at risk for Type-II Diabetes refuse to exercise, not because they are uneducated about the benefits of weight reduction, but because their neighborhoods have no gyms or sidewalks or parks. Or, that small numbers of opulent white Americans pay for their healthcare out of pocket, not because they do not qualify for coverage, but because the tax breaks and advantages they receive allow them to pay cash for office visits with elite practitioners who do not accept insurance. Or even that doctors overlook “cultural” variables, not because they are insensitive, but because they work in clinics with inadequate resources, and dwindling community support” [Metzl, 2014 #276].

These examples demonstrate that cultural barriers to health should be redefined as the “sequelae of a host of financial, legal, governmental, and ultimately ethical decisions
with which [both individual clinicians and the field of medicine] must engage politically if it wishes to help its patients clinically” [Metzl, 2014 #276].

**Montross: Developing Structural Competence**

Clinician-authored narratives can be one tool through which the mental health profession builds an awareness about the broader context influencing outcomes. In my interview with Dr. Montross, she alluded to this role of the narrative form.

“"The amount of time available to think deeply about complicated cases is not built into days. Writing is a way to slow down and think more deeply about cases and consider them in a broader context [without having] to rush to action - as we so often do in medicine. There's a clinical benefit to slowing down and considering the details and the bigger picture at once, which writing really allows.

So, there’s a clinical piece to it, an intellectual piece to it, a personal and emotional piece to it. And then increasingly in my work, I also think there’s an advocacy piece. *Falling Into The Fire* came out at the time of the original debates around Obamacare. Some were arguing that providing insurance for everyone was bad for businesses and doesn’t make sense. Wow. If people could see what my patients without access to adequate care endure, they would understand. There's been a piece of my writing in recent years that is compelled to bring these aspects to light.” (Montross Interview)
In her narrative writing, we subsequently recognize that Dr. Montross commonly explores the broader structural context of difficult cases she has encountered. One example is the story of a patient she admitted in the psychiatric emergency room for ‘pseudoseizures.’ More aptly classified as psychogenic non-epileptic seizures, this somatoform disorder occurs when “psychological symptoms manifest themselves physically.” Despite the frustration they often engender in their clinicians, these patients do not intend to fool their providers. To convince of this, Montross outlines the history of this category of disorders, a discussion that is understandably sidelined in the busy clinical environment.

Historically, somatoform disorders were classified as hysteria, and even the term ‘pseudo’ points to the deep-seated belief of deception. Montross goes on to describe how “the majority of patients diagnosed with such hysterical disorders…have always been female.” With this statement, Montross embarks on an ironic and grave recounting of the treatments developed by the mostly male physicians caring for these patients. Well into the twentieth century, somatoform disorders were thought to result from a disorder of the “female reproductive organs and genitalia.”

Montross identifies the female perspective in the origin story of this clinical disorder. This disparity is evident in one particularly out-of-touch “treatment for hysteria that is highly ironic in retrospect.”

“Doctors would massage the genitals of their female patients until they responded with a ‘hysterical paroxysm,’ after which point their symptoms
would subside. The ‘paroxysmal state’ was, of course, an orgasm, and the written description that persists recounting these events render it nearly impossible to believe that the majority of clinicians over the centuries did not recognize it as such, and yet they apparently did not.” (Falling Into The Fire)

Montross goes on to describe, “how physicians, in an attempt to reduce the time spent on genital massage in their practices, led the quest to develop and market the vibrator. Medical practitioners remained utterly oblivious to the sexual nature of their treatments, a fact [attributed] to the ‘androcentric’ view of the times.”

The laughable contrast between the earnest historical belief in ‘genital massage,’ and the modern day certainty that vibrators do not treat or cure somatoform disorders is an impressive narrative tool that underscores the pitfalls of clinicians holding homogeneous identities. Further evidence is the gamut of treatments, from unpleasant and irritating chemical washes, to catastrophic gynecologic operations akin to castration where women endured female genital cutting and oophorectomies in the name of treatment for hysteria. The inevitable conclusion is that the marginalization of women from the conversation around the classification and treatment of hysterical diagnoses was dangerous and unjust.

Through navigating the historical context of somatoform disorders, Montross highlights how those clinicians failed to practice with structural competence and how this resulted in poor health outcomes for patients with somatoform disorders.
Addai: Developing Structural Competence

In this next section, I will show how author Cassie Addai illuminates the structural barriers faced by her patients through narrative. In particular, I will highlight how her identity as a marginalized individual shapes her approach to the narrative form and her choices regarding what aspects of the story to highlight and what language to include in her writing. Ultimately, I will argue that this distinction from previous authors is a particular strength of the writing contributed by marginalized clinicians and one of many reasons to promote the inclusion of diverse voices in mental health narratives.

In my conversation with her, Dr Addai notes,

“[There is] a more general responsibility [for] people who hold a minority identity to be the spokesperson. In the UK, there are very few clinician psychologists who hold racialized backgrounds. Every word or sentence that I was writing, I thought ‘how will the powers that be reading this see this.’ I don’t want to jeopardize my career, but I also have to think about what my values are and where I stand as a black woman. I think that is a very fine line. Not unique to me. I’ve spoken to colleagues who are also training, who want to avoid becoming spokespeople for the black psychologist, but who are inadvertently stepping into this role. And in identifying myself as a black clinical psychologist I AM stepping into this role; it is quite messy. I think about what I might regret not saying but also what I might regret saying because of potential career implications.” (Addai Interview)
We immediately note a difference between Dr. Addai’s approach to narrative writing and that of Dr. Montross. Addai describes the struggle to balance her obligations to patients who share her identity with her credibility among colleagues and her career aspirations. On the other hand, with regard to race and gender, Dr. Montross is not from a marginalized background. While Montross may still feel this burden, we know that she does not feel compelled to explain to her audience when and how her identity plays into her narrative choices. Addai, on the other hand, does.

Even in introducing her narrative in The Colour of Madness, she first points out how her identity as a black woman shapes her perspective on inequalities in mental health.

“I believe that psychiatry must acknowledge its own role in racism, in particular, its foundations upon a white, western and individualistic knowledge base, which does not reflect the rich diversity of society. As a profession, psychology seems to recognize that black people are less likely to access mental health support than their white peers and, in response, there are initiatives to ‘increase access’ in the hope of redressing this inequality. However, I feel uncomfortable with the prospect of merely increasing the number of black clients without true reflection on the ways in which systemic racism operates within psychology itself.” (The Colour of Madness)
In contrast to Dr. Montross, who allows her clinical stories to guide her to a variety of conclusions about the structural contexts that shape health outcomes, Dr. Addai is almost forced to start with the structural context of racism and work backwards. So present is racial identity in Dr. Addai’s experience of providing mental healthcare that she cannot discuss her patients’ stories without noting it. In her interview, Addai remembers noting this distinction between herself and many of her educators and colleagues during her training.

“A bit about my training in the UK…the academic side, I found [it] to be lacking at times. I [would] look at who the lecturers were, and it was predominantly white men promoting the western US-centric psychologic base. And when the role of gender, race, or sexuality was mentioned, it was referenced in the context of the distress. The people who are most likely to experience distress and are disproportionately marginalized by society; [people with] black ethnic backgrounds and LGBTQ backgrounds. We know this, but we still peddle ideas of medication and of short courses of therapy. There needs to be a more systemic and holistic change. That has been a frustration for me in my education and placements…the reality [is people] aren’t saying my neurotransmitters are messed up, they’re feeling depressed because they don’t know if they’ll have enough money for their families, their relationship has broken down, etc. We need to pay more attention to these aspects as clinicians.” (Addai Interview)
Addai goes on to describe the “wealth of research [that] suggests that experiences of deprivation, abuse, unemployment, homelessness, isolation, discrimination, and other forms of adversity that can negatively impact mental health.” Through writing, Addai communicates her frustration that there isn’t a more deliberate and formal effort to address these structural barriers to improved mental health. In fact, she notes that the low visibility of marginalized voices in clinician-authored narratives contributes to stagnation in the clinical practice of mental healthcare. Providers, she says, are not evolving their mental healthcare to address the structural barriers that may cause poor health outcomes. Despite the large mass of research identifying the impact of social determinants on health, many new trainees receive little exposure to it.

“For me, you’re talking about the struggle to find perspectives that are written. When I first heard about this anthology being put together, I was amazed and not really amazed. It’s 2018, there should surely be narratives like this published and they should be in the forefront of publications. Actually, it makes sense given the way that we think about mental health in both psychology and psychiatry. It’s a medicalized way of thinking and perhaps doesn’t take adequate account of the psychosocial issues and that people might be struggling with race and racism. I see this both as black women in general with less access, but also as a black clinician sitting on the other side of the table with black clients who are facing huge disparities in the services being provided.” (Addai Interview)
Dr. Addai describes a lecture that excluded nuanced discussions about the intersection of race and mental health. She remembers her frustration that the experiences of racial minorities could be overlooked in the discussion of mental health. She is particularly disappointed and frustrated that academic psychology has a Western-centric individualistic bias, thus failing to serve patients whose mental health and wellbeing is informed by a racialized experience of the world. Her narrative writing aims to create awareness about the structural context of race and its impact on mental health.

**Kainth: Developing Structural Competence**

Dr. Kamal Kainth is a clinician-author who, through narrative exploration of mental healthcare, draws the connection between being a racial minority and health outcomes. In her interview, Kainth says about her identity, “I am an Indian woman and I carry that with me, that’s who I am and I’m proud of it. I don’t see it as a burden, I want to represent myself.”

Her contribution to *The Colour of Madness* is a piece called “The Good Indian Nurse.” In it, she describes a childhood memory of bringing her mother to the hospital for admission to the psychiatric ward during an episode of psychosis. By fourteen years old, Dr. Kainth was familiar with her mother’s cycle of readmission and rehabilitation for psychosis and suicidal ideation. By then, Dr. Kainth had also begun to lose faith in the hospital’s ability to care for her mother. She was unimpressed and frustrated by the lack of long-term improvement. She describes the weight of responsibility: Was hospital admission good for her mother’s wellbeing? Was there another choice? In this moment,
Dr. Kainth describes the urge to take her mother home rather than leave her what she felt was the impersonal care of the psychiatric ward.

Then, as she is leaving her mother alone in the hospital once again, she notices an Indian nurse.

“She was an Indian woman and she was a nurse. I feel stupid about this now, but in some unknowable way it was a defining moment for me. I saw her and I thought, it’s okay to leave mum here. Mum’s going to be alright. Why did I believe that their brown skin would connect them? When I visited mum there as a smaller, naive infant I had somehow picked up that the white surroundings would be alien to her.” (The Colour of Madness)

Here, Kainth describes her concern even as a child that her mother should have an advocate in the hospital who understands her racial background. She is concerned about her mother’s wellbeing and sense of familiarity in a space where none of her caretakers resembled her. Before entering the field of psychiatry herself, she is already struggling with questions of representation in mental healthcare because of her mother’s experience. The picture of Kainth’s mother, the only South Asian woman on the ward in a sea of white patients and white providers is compelling. Add to this Kainth’s guilt that she cannot stay to serve as her mother’s advocate when she is most vulnerable, and it is clear why Kainth might latch onto this Indian nurse as hope. Hope that one of the caretakers on the ward will see themselves or their family in her mother and protect her when she is unable to.
In an interview, Kainth reflects on why she wrote this piece and what she wanted to communicate:

“What I wrote the story for The Colour of Madness, it was just a comment piece done very last minute. It was a memory I had as a teenager in a psychiatric hospital where my mother was admitted; she has Schizophrenia. I had very little contact with [that nurse] during my mother's stay that whole time. But I think the reason it stuck in my mind is, I am very political as a person and in my work. There was something about the hope that I felt about my mum and what this [nurse] means for her. I took that for granted what it means to have that nurse there. I look back and realize that she had her own shit going on.” (Kainth Interview)

Returning to the narrative, Kainth makes a similar statement about what she was hoping to find in this nurse. She describes hope followed by disappointment when this nurse fails to meet her, perhaps unfair, expectations.

“The official visiting window had closed hours ago: we had been permitted to stay longer, but now it was time to go. It felt okay because now mum had an ally. Right? We left mum sitting in a stained pleather chair in the common room. The Indian nurse was in there too, standing by the radiator. She didn’t look up or acknowledge us. I stood in the corridor for a few minutes and watched them. It was hard to leave, hard to leave her there. I
wanted some reassurance, however slight, that we had made the right
decision in bringing her here again. The nurse walked away, breaking my
heart.” (The Colour of Madness)

Kainth comments on her childhood memory of and perspective on this Indian
nurse. She notes the discomfort caused by leaving her mother on this ward admission
after admission without ‘an advocate.’ She describes this particular admission as a vivid
memory of hope that this time, her mother was actually not alone. And she admits now
that there is greater complexity in the concept of racial representation in mental health.
Though she still believes that patients require advocates who are aware of and willing to
intervene on the barriers to health outcomes that result from holding minority identity,
she is forgiving of providers in that nurse’s position, who might be held to unfair
expectations.

“I’m on the other side now, working in mental health services as a
psychotherapist. I have worked on wards and in the community, and I am
sure I have been the source of that same disappointment for others. Others
that I did not see. I work hard, from the heart and in an open way, but I have
overlooked people, patients, families. It would have been unintentional, but
it would be silly to pretend that it hasn’t happened…I wonder what my
brown skin means to the service users and their families who are faced with
me as a mental health professional.” (The Colour of Madness)
In addition to exploring the complexity of holding a marginalized identity in the mental health profession, Kainth also speaks to the burden of being a provider with such an identity. In contrast to her colleagues who are not racial minorities, when she meets a patient, she enters the encounter with several layers of race related presumptions and expectations already at play. The story of her own expectations of the sole Indian nurse on her mother’s psychiatric ward speaks to this. Kainth carries the burden of this responsibility in her work; she recognizes that she has inevitably been a disappointment to others who have looked to her for the support that she was looking to that nurse for. Regardless, she approaches her work believing that she still has a responsibility to serve as an advocate for minorities.

“I am very conscience of race in my own work. In a lot of the work I’ve done I’ve also been subject to racism. Some of the white clients feel “Oh, I’ve got the brown person.” And this experience is even worse for black people. At the same time, I feel this responsibility as a person of color to change the system. Almost not wanting to be that nurse. The importance of letting people know you see them. I notice a lot of racism in the system, and I’m an advocate against that.” (Kainth Interview)

Kainth’s writing is instrumental in creating awareness of how race plays into her sense of obligation toward her mother then and her patients now. Her narrative introduces a common internal dialogue that marginalized patients have when leaving their loved ones to receive care. It points out how these perspectives impact how patients and
families view their caretakers and trust them, and it serves to illuminate the burden of holding a marginalized identity, both as a patient and as a provider. Ultimately, both Kainth and Addai’s narratives help us contrast this burden with that of other mental health providers whose races do not make them the subject of patients regard and expectations in the same way.

**Chang: Developing Structural Competence**

In this section I will introduce a clinician author, Dr. Sand Chang, who views their work in the field of mental health as seamlessly integrated with their identity. I will discuss the challenges this clinician faces in balancing their loyalty to their identity as a transgender individual with their responsibilities as a clinician who participates in the system that determines who will receive what gender-affirming therapies and treatments. I will outline how this clinician navigates these competing obligations, and I will describe how writing about the system of care for gender non-conforming individuals allows Chang to reveal the structural barriers to care for transgender patients. Ultimately, I will argue that writing is a tool that allows Chang to work within an imperfect system while maintaining and supporting an agenda to change that system.

Dr. Sand Chang is a psychologist who has built their practice as a gender specialist and identifies as “Chinese American, genderqueer, gender fluid, [and] queer.” In their writing, Dr. Chang expresses discomfort with being a ‘gate-keeper,’ jokingly calling it “gate-keeper identity disorder.” Chang observes,
“…there is no way to get these aspects of my experience out of the way. They pave the roads that lead to either side of the gate. I never thought to myself, ‘When I grow up I want to be a Gender Specialist,’ but here I am. So how did I get here, you ask?” (The Remedy)

It is clear from this origin statement that the impact of marginalized identity - in both gender and race - on transgender health outcomes shaped Chang’s path in the field of psychology. In referring to their role of gate-keeper, Chang is describing the role of “evaluator of the request for hormones or surgery” when it comes to gender affirming treatments for Chang’s transgender patients. The discomfort stems from Chang’s quest to “align the gatekeeping role with [their] values and ethics.” Chang describes this balance,

“I…acknowledge my role as a gatekeeper. I am transparent about my disagreement with the necessity of diagnoses, yet willingly document Gender Dysphoria when necessary (i.e., when it will help the client achieve their goals). And I tell them that, letter aside, I am interested in supporting them in their process should they need it…This approach is by no means perfect, and I hope that I always have enough humility to consider it a work in progress.

I continually question my own motives and rationalizations. I’ve told myself that it is a reality that there are gates, and someone has to be there to open them. But why not work to destroy these gates? Am I no different from
the people who acted as gatekeepers in early gender clinics?…I may tell myself that I can change the system from within, but maybe the system is so broken that it needs to be abandoned…Are these small, incremental wins in access to [transgender and gender non-conforming] health care truly progress, or are they distractions that simply placate and thus prevent revolutionary change and true liberation?” (The Remedy)

Dr. Chang cannot compartmentalize the experience of being a gender and racial minority from their work as a psychologist and gender specialist. The most crucial questions related to the care of their transgender patients are asked through this filter of experience. One such question is that of Chang’s ‘Gatekeeper Identity Disorder.’ Today, clinicians recognize that Gender Identity Disorder is a problematic diagnosis, one that reflects the field of psychiatry’s history of delegitimizing individuals who identify with a gender different from their assigned sex at birth. While the DSM V has shifted from GID to Gender Dysphoria, focusing on the distress rather than the identity as a problem, Chang still recognizes their gatekeeping role in assigning this diagnosis. Clients are often looking for the medical label that will grant access to the transgender healthcare they seek. Chang defines Gatekeeper Identity Disorder as the experience of simultaneously belonging to the community you serve and the community of providers that have historically held power over trans health. Chang states “the remedy for this Gatekeeper Identity Disorder…is to be painfully aware of it, to never let myself think that I’m cured.”
Building Situated Knowledge Through Narrative Writing

This concluding section will define the concept of situated knowledge and describe its purpose in clinical care and clinician-authored narratives of mental health. It will argue that clinicians who write about biomedical diagnoses and structural barriers to health do so to develop situated knowledge about the illness experience of vulnerable and marginalized patient populations. It will assert that clinicians who pursue situated knowledge can positively impact health outcomes. Ultimately, this section will compare what clinician-authored narratives can achieve with what patient-centered advocacy sets out to do. It will contend that writing is a tool for improving patient care that has a different but vital function from the important work of advocacy.

The theory of situated knowledge originated as a feminist critique of scientific and medical scholarship. In *The New York Review of Books*, Rachel Pearson’s article on chronic Lyme illustrates this concept well. Pearson, a pediatrician, recounts a conversation with a three-year-old patient’s mother about a ‘target-shaped rash.’ She explains that while the rash resembles the shape of *erythema migrans*, the rash caused by Lyme disease, it does not resemble its typical size or progression. When Pearson recommends waiting to see how the rash progresses before treating with antibiotics, the patient’s mother resists. Pearson explains to the mother how Lyme disease is rare in Idaho, but the mother responds, “I got it. I got chronic Lyme here in the 1970s” [Pearson, 2018 #407]. Pearson writes,

> “Chronic Lyme is as nebulous as gender, an identity as much as a biological category. It describes a constellation of enduring symptoms—joint pain,
fatigue, muscle pain, brain fog, fevers, blurry vision, and much more—occuring in a person who attributes these symptoms to an infection with Borrelia burgdorferi, but who may have no plausible laboratory, clinical, or epidemiological evidence of exposure to the bacterium. Thousands of Australians identify as chronic Lyme patients, for example, despite the fact that Ixodes does not live in Australia and there has never been a laboratory-verified case of Lyme contracted there.” [Pearson, 2018 #407]

Chronic Lyme is not a clinically recognized stage of Lyme disease. However, just as Pearson writes, several thousand patients identify with the diagnosis. Here, Pearson contemplates why many of these patients are women.

“Lidija Haas began her review…of [author] Porochista Khakpour’s Sick, a memoir of chronic Lyme, by asking “Is Lyme disease a feminist issue?” Haas describes how disease in women is painfully under-studied and how physician bias affects women’s health. The most famous case of this is multiple sclerosis (MS), an often-debilitating autoimmune disease that is more common in women. As Haas mentions, MS was essentially chalked up to hysteria until the invention of Magnetic Resonance Imaging (MRI), which allowed doctors to see the characteristic lesions in the brains and spines of patients with MS. When doctors could see it, we designated it as real.
But MS was real before the MRI, and chronic Lyme is also real. It comprises a constellation of symptoms and a community of sufferers, too often attended to by unscrupulous providers. Insofar as the history of chronic Lyme is a history of physicians’ ignoring, downplaying, or refusing to investigate the symptoms of women, chronic Lyme is also a feminist issue.

Should women’s suffering be listened to, attended to, and investigated? Yes. Does our suffering deserve heroic efforts to develop and provide evidence-based therapies? Absolutely. But is our suffering caused by tick bites? Usually not.” [Pearson, 2018 #407]

This comparison between multiple sclerosis and chronic Lyme reveals the crux of the issue. Patients who hold marginalized identities — in this example, women — rely on a medical field in which providers “ignore, downplay, and refuse to investigate” their symptoms. These patients’ illness experiences are neglected by the existing system of medical scholarship and education. In fact, the health and well-being of individuals with marginalized identities is under-studied, and therefore under-valued, by the medical field. It is no surprise, then, that the women who share symptoms of chronic Lyme, like the women with hysteria or multiple sclerosis before them, are disinclined to believe physicians when they are told the disease is not caused by ticks. For these patients, the system of medicine is incompetent at best and untrustworthy at worst.

A critical look at the science behind medical knowledge confirms that it, like any human endeavor, is riddled with bias. Where does that leave the clinician? Clinicians are
tasked with translating a patient’s story into identifiable symptoms and cross-referencing these symptoms with the body of collective medical knowledge. They mine centuries of data and expertise in order to understand and treat patients’ illnesses, and hopefully alleviate their suffering. What happens when a clinician encounters a case where the objectivity or capacity of their medical knowledge is in question? A case where the “suffering cannot be identified with lab tests or treated reliably with specific medicines” (Pearson). One solution emerges from feminist critiques of medical scholarship — situated knowledge.

Situated knowledge is “knowledge [that] must include the experience of the patient, and…a doctor who is aware of her own biases…it must also include physical exams, lab tests, double-blind randomized trials, and the cumulative knowledge of biomedicine” (Pearson). It is meant to be a path to ‘objective’ truth in a society where “the power to influence and construct meaning is not distributed equally” (Burr, 1995) and where “those in prominent social groups…shape what is taken up as legitimate knowledge…what comes to be regarded as truth” (Burr, 1995). Accepting the utility of situated knowledge “requires a kind of epistemological gentleness from physicians, an acknowledgement that experiences we cannot pin to biological variance are nevertheless real” (Pearson).

Having defined situated knowledge and justified its clinical utility, I will now argue that writing helps clinicians develop situated knowledge and improve care. I will demonstrate that clinician-authors who understand the complexity of biomedical diagnosis and the ubiquity of structural barriers to health value their patients’ perspectives and incorporate them into their writing. I will share samples from the
narrative work of Kay Jamison, Christine Montross, Cassie Addai, Kamal Kainth, and Sand Chang that show this. Ultimately, I will illustrate how the narrative writing of clinician-authors builds situated knowledge, and I will argue that this process can improve the quality of care delivered both by the author and by readers who are clinicians.

**Jamison: Building Situated Knowledge**

I would like to first introduce Kay Jamison’s take on situated knowledge. Jamison’s memoir is the only narrative work included that explores the author’s personal experience of mental illness. To convince her readers that true comprehension of another individual’s illness or distress is not possible, she shares a story from years ago when she tutored a fellow undergraduate student who was blind.

“As the term went on I felt increasingly comfortable in asking him about what it was like to be blind; what it was like to be blind, young, and an undergraduate at the University of California; and what it was like to have to be so dependent upon others to learn and survive. After several months I had deluded myself that I had at least some notion, however small, of what life was like for him. Then one day he asked me if I would mind meeting him for his tutorial session in the blind reading room of the undergraduate library, rather than my office.
I tracked down the reading room with some difficulty and started to go in. I stopped suddenly when I realized with horror that the room was almost totally dark. It was dead silent, no lights were on, and yet there were half a dozen students bending over their books or listening intently to the audiotapes of the professors’ lectures that they had recorded. A total chill went down my spine at the eeriness of the scene. My student heard me come in, got up, walked over to the light switch, and turned on the lights for me. It was one of those still, clear moments when you realize that you haven’t understood anything at all, that you have had no real comprehension of the other person’s world.” (An Unquiet Mind)

The library room full of students unaffected by the dark shocked Jamison. Only in that moment, when she entered the unlit room and her vision became useless, did she recognize the chasm between her student's life and her own. The memory of this experience is a vivid metaphor for Jamison's own struggle with manic depressive illness and for the importance of situated knowledge.

After her initial diagnosis, Jamison spent years resisting medication. "That I owed my life to pills was not...obvious to me for a long time; my lack of judgment about the necessity to take lithium proved to be an exceedingly costly one" (Jamison, 88). Jamison's reluctance to take lithium was rooted in a "horrible sense of loss" (Jamison, 91) for who she was.
"...if you have had stars at your feet and the rings of planets through your hands, are used to sleeping only four or five hours a night and now sleep eight, are used to staying up all night for days and weeks in a row and now cannot, it is a very real adjustment to blend into a three-piece-suit schedule, which, while comfortable to many, is new, restrictive, seemingly less productive, and maddeningly less intoxicating...When I am my present 'normal' self, I am far removed from when I have been my liveliest, most productive, most intense, most outgoing and effervescent. In short, for myself, I am a hard act to follow.

And I miss Saturn very much." (An Unquiet Mind)

Here, Jamison is describing another chasm, this time between who she was before lithium and who she will become on the medication. Though her illness caused irritability, insomnia, inability to focus, psychotic manias, and devastating suicidal depression, lithium and its debilitating side effects were not easy to accept. Jamison feared stability was not worth losing the energy and intensity of hypomania. It took her several years to choose sanity over the alternative.

“As I gradually entered into the world of more stable moods and more predictable life, I began to realize that I knew very little about it and had no real idea of what it would be like to live in such a place. In many ways, I was a stranger to the normal world.” (An Unquiet Mind)
As a clinician, author, and patient with manic-depressive illness, Jamison is able to write from a unique perspective. Not only can she share insight into the mind of manic depression, but she can also create clinical context within which to place such a mind. Moreover, her years of residence among the “normal” allow her writing to bridge the divide between the throes of madness and stability. As a result, her memoir does more than document, it contributes valuable insight to the body of situated knowledge on manic depressive illness.

**Montross: Building Situated Knowledge**

Of course, if situated knowledge is the best approximation of an ‘objective’ truth inclusive of patient input, it is apparent how a clinician-author writing about her own mental illness is well-placed to contribute to such knowledge. What recourse do other clinicians have? Does their writing also improve our collective insight into patients’ illnesses?

Christine Montross says it does. In fact, the case history, a clinician-authored document containing all information related to an individual’s illness - including the patient’s own narrative - used to be the core pedagogical tool of medical education. In this age of ‘fetishizing’ data, Montross bemoans the decline of the case history. In her article ‘Illness Is Our Human Story’ for *The Chronicle of Higher Education*, she notes that “in spite of [her] knowledge and training, there are moments in the course of any disease that do not fit neatly into data sets [or] medical literature. As a physician, I am called upon to help my patients, even so” [Montross, 2015 #408]. She cites narrative as a
means to help these patients, revealing that “[her] own writing is moored in the least certain moments of [her] medical practice” [Montross, 2015 #408].

Montross is describing what motivates her writing. She recalls moments in her practice when the “data-driven, evidence-based” [Montross, 2015 #408] foundation of her training was unable to provide her patients with answers. In contemplating these complicated cases, she turned to writing in order to “slow down and think more deeply…and consider them in a broader context” (Montross Interview). She identifies this as the ability to “[consider] details and the bigger picture at once, which writing really allows” (Montross Interview). In other words, writing favors the pursuit of situated knowledge in clinical medicine, allowing the author and reader to hold multiple perspectives together in one narrative.

Even so, the question of whether clinicians should tell the stories of their patients remains. A common critique of providers who write about their patients is that the practice is “opportunistic and exploitative” [Montross, 2015 #408]. Montross summarizes this perspective when she shares how “disability-rights advocate Tom Shakespeare…[famously] called [physician-writer Oliver Sacks] "the man who mistook his patients for a literary career" [Montross, 2015 #408]. Montross considers this defense of patient privacy and agency thoughtfully. She is a proponent of “scrupulous de-identification” [Montross, 2015 #408] or obtaining patient consent. Yet she considers the question of whose story it is to tell on a deeper level as well. She writes,

“There are, to be sure, riveting firsthand accounts. The memoirs of Kay Redfield Jamison (An Unquiet Mind), Andrew Solomon (The Noonday
Demon), and Elyn R. Saks (The Center Cannot Hold) are unsurpassed in their gorgeous, heartbreaking descriptions of bipolar disorder, major depression, and schizophrenia, respectively. But their authors are exceptional thinkers and writers: Jamison a Johns Hopkins professor of psychiatry, Solomon a National Book Award winner, Saks a professor at the University of Southern California Law School.

What of those — like most of my patients — whose psychiatric symptoms make them less apt or less able to tell their stories in a way that can be widely heard and understood? The man who is so depressed that he cannot bring himself to eat or drink or shower is unable to blog about his illness trajectory. The woman who is plagued by hallucinations and who fears that everything she says is being recorded by the CIA will face different obstacles in sharing the story of her illness than someone who undergoes a mastectomy for breast cancer. My intellectually disabled patient who is minimally verbal but who has been hospitalized repeatedly for aggression has no ability to convey that the funding of his group home has been cut, resulting in fewer workers, less programming, and a less well trained staff.

If I don’t tell my patients’ stories, then who will?” [Montross, 2015 #408]

Montross suggests that “illness is our human story, and it cannot be fully told by data, by numbers or graphs, by trends or algorithms” [Montross, 2015 #408]. She argues
that the “story is made more potent — and more real — by the individual variation of our narratives” [Montross, 2015 #408].

If the premise of situated knowledge is to be inclusive of a diversity of relevant narratives, then the notion of which clinician-authors’ narratives enjoy broad audiences and why becomes important. More specifically, what is the proportion of acclaimed and widely-read medical writers who hold marginalized racial and gender identities? The data on this topic is sparse and requires meticulous investigation.

It is a grave irony that the medical community pursues situated knowledge in the narrative form when the identities of clinicians contributing these narratives are as homogenous as ever. As I have argued, this is particularly true in the context of helping those patients whose suffering is not well-served by treatments predicated in empirical data and pattern recognition alone — patients who are marginalized by the medical system’s current approach to care. However, if the writing of clinicians who share these experiences of marginalization remains at the fringe of the medical humanities, the discussion of situated knowledge is just idealized lip service.

The remainder of this section will continue to examine the role of writing – writing by marginalized individuals - in developing situated knowledge. It will focus on the perspectives of Cassie Addai, Kamal Kainth, and Sand Chang, writers who contributed narratives to The Colour of Madness and The Remedy. These anthologies were both conceived and published to center the voices of marginalized individuals; their purpose is to combat the racial and gender disparity in whose stories are solicited and disseminated by the medical community. While an important component of this section
will be to continue the analysis of how clinician-authored narratives contribute to situated knowledge, another will be to explore themes of identity and representation.

**Addai: Building Situated Knowledge**

Cassie Addai, Kamal Kainth, and Sand Chang notably draw attention to their marginalized identities in their writing. Each describes an immense “sense of responsibility” (Guilliane) and the “heavy burden” of illuminating the inequalities and distress suffered by their communities. Addai summarizes,

“I have to think about what my values are and where I stand as a black woman. I think that is a very fine line, and not unique to me. I’ve spoken to colleagues…who want to avoid becoming spokespeople or the ‘black’ psychologist, but equally inadvertently step into this role. And identifying myself as a black clinical psychologist *I am* stepping into this role, it is quite messy. I think about what I might regret not saying but also what I might regret saying…” (Addai Interview).

Addai outlines a no-win dilemma. Either she writes against racial injustice in mental health and risks the oversimplification of her experiences and the tokenization of her minority identity, or she avoids calling attention to her race altogether and risks the opportunity to incite change for her community. That she must navigate this narrow terrain is an inevitable burden of her identity as a black female clinician. It is also in stark contrast to white clinicians who are afforded the privilege of representing only
themselves and whose identities do not cause undue scrutiny of their clinical and professional work.

Addai chooses to write about race. Like Montross and Jamison, she notes that writing leads to a more complete narrative of her patients’ experiences of illness. One notable priority in her writing, in fact, is to create space to contemplate how race intersects with her own and her patients’ clinical experiences. She observes this phenomenon below,

“…the way we think about mental health in both psychology and psychiatry, it’s in a medicalized way and perhaps doesn’t adequately account for the psychosocial issues or people’s struggles with race and racism.” (Addai Interview)

Still, race is only one component of the broad social context she incorporates into her writing. She identifies this context below as well as the frustrating lack of clinical progress on the question of social determinants of health.

“…psychology has historically held a more individualistic perspective of distress, which primarily focuses on increasing individuals’ resilience to adverse situations through changing the way that they think and behave. I am increasingly aware of the disparity between what we know about the social causes of poor mental health and the individualised interventions we
offer to those in distress. I am aware of how often this knowledge of social causes evaporates, leaving individual blame in its place.” (Addai Interview)

One shared characteristic among Addai, Kainth, and Chang, however, is they do more than simply identify social determinants of health, they also suggest intervention. Having been involuntarily immersed in the collective social conversation about race from before they chose to become clinicians, these authors appreciate how social causes of inequality and suffering are already “well-documented” (Guillaine) and how research has shown the “disproportionate rates at which people of colour continue to experience psychological distress” (Guillaine). For them, the revolution is in building a body of situated knowledge inclusive of diverse perspectives as well as identifying and effecting solutions to the disparities identified from this knowledge. Commonly, these interventions center on reevaluating pedagogies of clinical education and improving how they serve disempowered and vulnerable patients. Addai writes,

“…the academic curriculum needs to change in order to mobilize these perspectives…as it stands, it very much reflects what’s considered the norm, so whiteness, heterosexuality…There needs to be a huge overhaul of the curriculum in order to…[address] the diversity in the society that we support. Do we want to be clinicians who support people we consider the norm whoever that might be, or ones who support everyone, and support everyone productively…In addition to academic changes, the way that clinical practice works can benefit from huge changes. There is the status
quo, that you have one-to-one therapy that lasts 50 minutes, but going and meeting people out in the community or forming groups to help with socialized isolation, those ways of working are not common practice but are not so out of the box to be ridiculous. Rather than the tendency that we in the west know best, there’s a lot we can learn from other cultures and other parts of the world and use to critique practices here, develop, and learn.” (Addai Interview)

Kainth: Building Situated Knowledge

Kamal Kainth adds additional perspective. She describes herself as being “very conscious of race in her work” and “feeling responsibility as a person of color to change the system” (Kainth Interview). As a result, Kainth is a vocal advocate for policy change in support of the needs of her patients of color in her clinical practice. Even so, Kainth finds the most freedom in writing and “[feels she] can be really brave in [her] writing in a way that [she] can’t be at work…”

“For me, because my voice can only reach so far, and I can only talk about it so much in my work, I need an outlet. This gives me a method to really digest and think about things. I write so I can do that. I can’t do that at work. I have very few people around me I can do that thinking with. So it’s something I do with my writing. My feeling is it’s the only way I’m going to have an impact on services and what we’re doing. For me, it really is a form of activism. I suppose I feel so powerless that I need an avenue. Not
even to be a spokesperson, but I do want these ideas to have a little wider reach. So I feel like there’s a responsibility on those of us who have slightly different ways of practicing to try and share that. Just because all the newspapers are talking about CBT or that’s what your doctor is going to offer you, doesn’t mean that’s all there is.” (Kainth Interview)

Kainth echoes many of the perspectives Addai communicated. She notes the responsibility of being a clinician who is a person of color, and she shares the instinct to write as a means to fulfill this responsibility. It allows her to think through the barriers to mental health faced by people of color and the “ways of practicing” that can combat them.

**Chang: Building Situated Knowledge**

The final author to discuss how their own marginalized identity has an inseparable influence on both their clinical practice and writing is Sand Chang. Chang agrees with Addai and Kainth on their reflections about race, mental health, and writing. Moreover, Chang shares valuable insight on the consequences of inadequate representation of marginalized voices in clinical education and practice. They write,

“I moved to New York in 2005 to intern at a college counseling center and started facilitating trainings on gender identity. Here I began to feel the pressure of tokenization as a gender nonconforming person of color. Shortly after, I was lucky enough to secure an externship at the Gender Identity
Project (GIP) at the New York LGBT Center, where all staff members had a transgender or gender non-conforming (TGNC) identity. What was most beautiful about this experience was not that I felt affirmed in my genderqueer identity, but that I felt ordinary. It felt good to blend in, to have my gender be nothing special, to not have the lonely experience of being a token. It was powerful to see TGNC people in leadership positions, and it set me up to demand that TGNC voices be heard in health care.” (The Remedy)

Reading about Chang’s experience, I am reminded of the narrative with which this section began — Kay Jamison’s story of walking into the blind student reading room as an undergraduate tutor. The experience was a moment of clarity for Jamison. Humbled and somewhat embarrassed, she realized all at once that she understood nothing of her student’s experience. Here, Chang is describing an identical moment told from the opposite perspective. Chang writes how their identity and experience of the world was sometimes isolating, particularly in spaces where they were the only gender nonconforming individual. For Chang, working at the New York LGBT Center was a breath of freedom, freedom from the daily discomfort and “pressure of tokenization” (Chang).

Chang’s experience of the New York LGBT Center is also one of situated knowledge; it was a place where multiple relevant perspectives from the gender nonconforming community existed with shared purpose. There, Chang met examples of gender nonconforming individuals in leadership and developed a desire to “[challenge]
the dominant narratives around TGNC health and identity” (Chang). Chang is committed to increasing representation of marginalized voices in TGNC care. Like Addai and Kainth, Chang finds that a lack of representation prevents the mental health community from serving gender nonconforming individuals’ needs appropriately. Through writing, Chang identifies this disparity and suggests solutions that can be employed by mental health professionals.

Each of the clinician authors discussed here — Kay Jamison, Christine Montross, Cassie Addai, Kamal Kainth, and Sand Chang — demonstrate through published narratives and interviews a shared motivation for their writing. When these providers encounter cases where their patients’ suffering cannot be resolved with treatment alone, they turn to writing to understand the gaps between what their practice can offer and what their patient needs. Writing about these gaps contributes to a body of situated knowledge that attempts to build an objective narrative of a patient’s experience of illness. This “objective truth” serves as the foundation for improving clinical education and practice so that it is inclusive of all patients’ needs.

While these aspects of motivation remained consistent among the clinician-authors, clear distinctions emerged as well. In particular, authors who identified as marginalized themselves were more likely to highlight the impact of marginalization on health and well-being. For these authors, writing became a political tool that placed power back in the hands of these marginalized patients by creating the space to discuss race or gender and health. It allowed them to draw attention to disparity and to suggest interventions that would benefit their most vulnerable patients. Guilaine Kinouani, editor of The Colour of Madness, summarized it best.
“Writing one’s story and one’s experience is writing ourselves into being. It is asserting one’s right to exist. It is saying see me. Hear me. Hold me. And, writing is healing. Not only for authors but vicariously too for entire communities.” (Guillaine).
References


Appendix

Twitter Search for Potential Primary Sources

Anusha Singh @iamanushasingh

For a medical school thesis, I'm looking for suggestions of published nonfiction books or essays by clinician authors (either indigenous women or women of color) writing about personal or patient mental health narratives. Thank you!

3:46 PM · Mar 13, 2019 · Twitter Web Client

View Tweet activity

12 Retweets 28 Likes

Anusha Singh @iamanushasingh · May 11, 2019

Replying to @iamanushasingh
Thank you all! For my thesis requirements, The Colour of Madness and The Remedy have fit wonderfully. And each of the other narratives have been really fantastic reads as well - such great suggestions!

Stephen Conn (he/him) @holympus · Mar 14, 2019

Replying to @iamanushasingh and @colleenmfarrell
The Remedy is a cool book centering pt narratives of queer/trans pts, many poc voices

Anusha Singh @iamanushasingh · May 11, 2019

The Remedy has been a wonderful read! Centering queer/trans and poc voices just as you said, I really appreciate the suggestion!

Stephen Conn (he/him) @holympus · May 11, 2019

Awesome! Glad it was helpful! I recently found the wonderful editor @zenasharman on twitter.

Zena Sharman @zenasharman · May 11, 2019

Thanks to you both for reading The Remedy! I’ll think about your question & will let you know if any books or essays come to mind.

Zena Sharman @zenasharman · May 12, 2019

I just thought of one book that might be worth checking out - it’s called Headcase (global.oup.com/academic/produ...). I haven’t read it yet (it’s high on my to-read list!) but it’s an anthology so some of the essays might align with what you’re looking for.
Quin Stevens @quinstevens · Mar 14, 2019
Replying to @iamanushasingh
The Scalpel and the Silver Bear by Dr. Lori Arviso Alvord may have elements of what you’re looking for

Laura N-M @lnm_rugby · Mar 14, 2019
Replying to @iamanushasingh
I can suggest The Colour of Madness: @MadnessColourOf

Anusha Singh @iamanushasingh · May 11, 2019
Thank you for the suggestion! The collection contained quite a few clinician authors who are women of color - it’s been a really valuable addition to my thesis.

Laura Perry, MD @LPerrytheGeriMD · Mar 14, 2019
Replying to @iamanushasingh
Check out @gradydoctor - she writes an amazing blog (gradydoctor.com), mostly focusing on interactions with patients. She is a huge inspiration to me!

Kimberly Manning, MD @gradydoctor · Mar 14, 2019
Thank you for the kind words!

Animesh Sabnis @ASabnis · Mar 13, 2019
Replying to @iamanushasingh and @eemoi
I love that you are writing a med school thesis. I’ll watch this space to fill a gap in my knowledge.

Dovid Kotkes @Dovid_Kotkes · Mar 14, 2019
Replying to @iamanushasingh
cc @lynmepthecus
The Utility of Writing: Advocating Against the Classification of Women’s Mental Illness Experiences as Hysteric

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Overview

Background
- Historical treatment of women with mental illness
- Role of the DSM
- Epidemiology of misdiagnosed illness in women

Hypothesis

Specific Aim
- The necessity of a recognized biomedical diagnosis
- The interpretive potential of biographical knowledge
- The utility of writing as advocacy

Methods / Analysis
- Close reading of texts
- Author interviews
- Literature review
- Thesis Committee Guidance

Background

Historically, psychiatric care for ‘the mad’ has been replete with mistreatment and abuse
- witch hunts
- early asylums
- penitentiary
- state run mental health institutions

“The DSM is not regarded as delineating the truth about mental illness, but it is treated viewed as a story written by the powerful that can be imposed on individuals in a way that often obscures any helpful possibilities for change” (White and Epstein, 1990)
- Origins and Evolution
- Unique link to Biomedical
- Modern Diagnoses

“Because the public rarely recognizes [social] function of the mental health profession, psychiatric regulation is an especially potent form of social control” (Naranch and Raw-Auther, 2009: 33)
- Hypochondria
- Medicine to prevent consumption
- Mentality designed
- Newt reading
- Desertion by husband
- Suppression of marriage
- Vicarious displacement
- Desire of the mother
- Imaginary sexual identity

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Methods / Analysis

- Clear Reading of Texts:
  - Falling Into the Fire – By Dr. Christine Masters
  - An Impact Meal – By Dr. Kay Balford Johnson
  - Gender Readings in American Psychology – By Dr. Gaylor Watters

- Author Interviews:
  - Develop interview questions addressing specific aims of the thesis

- Literature Review:
  - Elaborate supporting/refuting arguments drawn from texts

- Thesis Committee Guidance:
  - Anna Kuzma, MD
  - Carolyn Watson, PhD
  - Nancy Angel, MD, MPH
  - Nancy Rogers, PhD

Acknowledgments
Do clinicians’ narratives of women’s mental illness function as forms of advocacy to improve patient care?

Overview
- Hypothesis
- Specific Aims
- Methods & Analysis
- Next Steps

Hypothesis
This study investigates clinicians’ narratives as a tool to advocate for mental health improvement. It explores how clinicians might draw from their own experiences and narratives to influence and improve patient care.

Specific Aims

Methods & Analysis
- Thesis Committee & Literature Guidance:
  - Dr. Ana Rios
  - Dr. Mary Warner
  - Dr. Nancy Angel
  - Dr. Sarah Rogers
  - Dr. Roberta Robert
- Close Reading of Narratives:
  - Falling Into the Fire — Christine Montross
  - As Seen in the Mind — Kay Redfield Jamison
  - The Colour of Madness — Galliattin Loewes, Sandra Linton, Cécile Adda, Katalin Károly
  - The Anomaly — Sandra C. Chung
- Author Interviews:
  - Dr. Christine Montross 12/20/18
  - Dr. Kay Jenkins 06/18/19
- Literature Review

The Process of Narrative Selection
- Falling Into the Fire — Christine Montross
- As Seen in the Mind — Kay Redfield Jamison
- The Colour of Madness — Galliattin Loewes, Sandra Linton, Cécile Adda, Katalin Károly
- The Anomaly — Sandra C. Chung
Why do clinician authors write about their own or their patients' mental health experiences?

Kay Jamison, M.A., Ph.D.

BOOK

I feel differently about An Unquiet Mind. I have the occasional regret about having written it, certainly. But if, along with the settings and work of so many others, it has moved the understanding of mental illness a bit further into the light, then I am very glad that I made public my private experience of madness.

Sand C. Chang, Ph.D.

BOOK

My formal education as a psychologist never offered opportunities for coursework related to gender identity. I focused my studies on psychopathology, additions, eating disorders, and racial identity. Discussions concerning gender occurred exclusively in the binary system of masculine and feminine. This was the early 1980s, and while there was slight mention, things have changed inside psychology graduate training. My privilege and commitment to advocacy for people within mental health practice has more or less been thrust into分支course-based learning that does not totally concern most clinicians.

Comparison: The Narrative Form as Advocacy?

Clinic authors

- My story is important because it demonstrates the existence of a problem. I have been able to tell my story, and I have been able to become a voice for the voices of those who cannot be heard.

Clinic authors who self-identify with minority identities

- The movement is a step towards an increased awareness of inequality and how it affects people. The story of telling these stories is a message of how mental health is a critical part of our lives. It is a step towards recognizing the importance of mental health to everyone.

Christine Montross, M.D.

BOOK

"The art of writing about mental illness is to make a difference."

Gulaine Knoopani, Ph.D.

BOOK

"The power of narrative is not only to tell a story, but to change the world."
I. Biomedical Diagnosis

Question
You talk about somatoparaphrenia (delusion), asomatognosia (lack of awareness), and body integrity identity disorder (BIID) as a triad of diseases where the first two have been localized to specific parts of the parietal lobe and have thus gained legitimacy.

How does neurological underpinning lend legitimacy to diagnoses? What legitimacy might a diagnosis itself lend to a patient's experience of symptoms? Do patients suffering from symptoms of mental illness respond well to receiving a diagnosis?

Answer
There are two different questions there. The question about diagnosis is a highly individual one. Some people bristle at the diagnosis. Some people feel affirmed by receiving a diagnosis. There’s a whole range in between where people are ambivalent. Part of the art of psychiatry is understanding what each patient needs from that part of our practice. The patient response to receiving a diagnosis and talking at great length about it or emphasizing that conversation really varies widely depending on the patient.

The second question about locate-ability, this has been a long standing battle in psychiatry. There just is a way in which when you can say something like, I’m showing picture of cardiac artery that is blocked by X percent, you can lend weight to a diagnosis. There is a nebulous nature to psychiatry and diagnosis at times that can be mooring to people. I’m comfortable in that grey area but lots of people are not. So absolutely, I see people relieved by the idea that there is neurologic origin to symptoms or who view symptoms known to be related to neurochemistry and anatomy to be quote unquote real. This is a continuous ongoing battle in psychiatry that will be part of the practice. With current trends in psychiatry, there is a lot of optimism about imaging, pet scans, fMRI, different things that can be relevant. These methods can be great, but there is a little bit of a bias at their core – that once we can localize, we’ll be better off.

Because there are so many experiential things that contribute to the trajectory of a person’s illness – and how symptoms manifest, and how they are or aren’t able to adhere to their treatment plans, and how we know that psychological health is determined by adequate housing, food, social support – those kinds of things are real variables that are not measurable in the same way that you can’t carb count them. Not an ailment where you can measure how much sodium leads to hypertension and then regulate that. It’s very difficult to regulate all the factors that go into mental illness, more multifactorial and more complex in nature than a lot of non mental illness.

Question
You describe your discomfort with “mad pride,” quoting Dr. Jamison who says bipolar disorder “benefits mankind at the expense of the individual.” In An Unquiet Mind, Dr. Jamison herself says at the beginning of her illness she struggled against taking medications, medicating her “genius” away, but later realized that overall her illness had a net negative influence on her life and relationships. Can you describe your reservations with “mad pride?” Is there a connection between romanticizing madness + delegitimizing the suffering and mental illness diagnoses?

**Answer**

This is the one real rant I allowed myself. I do get very fatigued by implication that mental illness is glamorous and somehow by intervening we’re dampening the possibility of greatness. I’ve written extensively about correlation between creativity and madness. That quote of hers is so lucid and right on the money. I believe that the degree of creativity that is lost due to mental illness is far far greater. If you have depression and can’t get out of bed for 6 months, intervening is not going to prevent something great. It’s going to allow them to shower, eat, and return to their families. The pick and choose nature of what we celebrate about mental illness, that really bugs me. An intellectually and politically interesting idea is de-institutionalization, to what degree do we value individual autonomy and how much do we want to be able to allow people to refuse treatment and have their own say?

There was a great article in The New York Times recently, people with profound mental illness given autonomy over decision making were found in horribly squalid conditions, plagued by voices visions and paranoid fears. Somehow advocating for their right to be living beneath an underpass, in tents, in throws of paranoia – I find that egregious. We can’t make everyone neuronormative or be against psychiatric difference. Being really concerned with the question of suffering, means valuing autonomy without romanticizing mental illness.

**II. Role of Writing in Activism**

**Question**

You describe being compelled to write by the need to visit and revisit hard questions, your own misgivings, and the stories of patients you could not heal. Writing is what you do when patients “don’t get better.” Could you talk more about this?

**Answer**

Limited amounts of time for patient encounters, demands on time for patient care, writing orders, making lists...

The amount of time available to think deeply about complicated cases is not regularly built into days. Writing is a way to slow down and think more deeply about cases and consider them in a broader context and pause and slow down and not have to rush to action – as we so often do in medicine – but to really kind of sit in the questions of the
cases. There’s that clinical aspect of slowing down and considering details and the bigger picture at once, which writing really allows.

Also in psychiatry (and all fields of medicine) it helps me come to terms with feelings that I’m having about the encounter and my own abilities and inability. About the difficulties of the situation. Writing allows time and space for those things too.

There’s a clinical piece to it, an intellectual piece to it, a personal and emotional piece to it. And then increasingly in my work (you mentioned this earlier), I also think there’s an advocacy piece. Why that book? That book was coming out at the time that I was hearing the original debates around Obamacare. Providing insurance for everyone was bad for businesses, and doesn’t make sense. Wow. If people could see what my patients without access to adequate care endure, they would understand. There’s been a piece of my writing in recent years that is compelled to bring these aspects to light.

There isn’t a clear cut answer on this. Some patients are able to write beautifully on this front. Kay Jamison is first and foremost in this category. Another one is Ellen Saks’ *The Center Cannot Hold*. There are tons of examples of patients who write about their own experiences of illness. And in psychiatry, in particular, there are some who write beautifully about their experiences. In my practice, I work in a free standing unit, an intensive treatment unit, one with profoundly depressed patients, manic patients. Many if not all are incapacitated by their illness. So profoundly depressed they can’t get out of bed. So delusional or psychotic, they can’t care for themselves. Not in position to dash off a decree about healthcare. There is a degree of voicelessness among the profoundly ill and most vulnerable patients. Not everyone doesn’t have the capacity, but there are portions of our mentally ill populations for whom this is not a possibility. The two things aren’t mutually exclusive. There are different voices that are important in this conversation. My experience of treating does not compare to Ellen Saks’ experience of how it is to be psychotic and restrained. You can’t say that patients can’t advocate for themselves, but only relying on patient voices – because it’s purely story – would eliminate a category of narrative form from people who are able to give code to patient experiences.

**Question**

What purpose do you hope writing serves in these situations where patients have not been healed by medicine?

Why did you choose these particular cases? What about these cases? Were there other cases on the list, why did you choose the ones you did?

**Answer**

Truly these were patients that sort of confounded me. I think that makes sense when you think about more rare presentations. We are good at understanding more straightforward patients. These were unique enough encounters that I really wanted to pause and make sure that I was thinking about them in the deepest context, be sure that I was doing my best to understand what the heck is going on. They really were the cases that kept me up
and night, and I felt the need to research these themes. They tested the boundaries of our understanding of the human mind in way that I wanted to follow.

I always hope with my books that they will be interesting and accessible to a lay audience but that also if my fellow clinicians read them, that there will something that they too can glean from the books. My sense is certainly that I understand these symptoms and illnesses definitely more deeply by being able to read more and think more about them, spend more time reviewing patient charts, analyzing effective and not so effective approaches and interventions. My understanding increased and increases by writing and I hope that some of it is conveyed to people who read the book too.

III. Gender & Race in Mental Illness

**Question**
You talk about a patient with postpartum psychosis + connect it to a body of knowledge where psychiatrists are aware that intense stress increases new mother’s risk for postpartum mood disorders. And that stress has been correlated with a mother’s risk of killing her children, in the most extreme form of postpartum mental illness.

What are your thoughts on the gendered role of stress in society? Stress related to social situations / particularly domestic relationships and responsibilities are more likely to be borne by women- is this a connection you wanted to make with this example?

In your book you equate psychiatry to vet medicine to make the point that psychiatric patients are prone to being unheard. What is it about these patients / or about how society treats these patients that you believe puts them in this position? In your opinion, is there a gendered component to this treatment?

**Answer**
On gender differences between patients. The level of trauma, in particular sexual trauma, that my female patients have endured is quite striking. And that’s not to say that I don’t have male patients for whom the same thing is true. But the presence (and I don’t know the numbers about the prevalence of sexual violence) anecdotally among the patient I treat, it’s a very common part of their treatment. There are all kinds of chicken and egg questions and socioeconomic questions that rise out of that. Gender roles, when men and women desperately need money, one of the things my patients are reduced to is sexual economy. The presence of sexual violence experiences by patents is remarkable.

When there are difficult patients on the unit, this conjures difficult feelings in the provider. There’s a tendency among certain clinicians to pretty quickly cast women’s expressions of distress to be borderline personality based. I think that women are more apt to have the manifestations their distress be pathologized in that way. I really try to talk with my staff about guarding against this. We do a good job, but it has sexism at its roots. When clinicians are frustrated themselves about their ability to ameliorate, and somebody is self-injurious, blaming of personality can come into play.
The other thing I would say – in the last few years, I’ve done more and more work in jails and in prison. The degree to which women are incarcerated is remarkable. They are often the sole caregivers for young children, driven to desperate decisions and circumstances. In women’s versus men’s jails, the number of crimes of survival seem higher to me. This is anecdotally, not numerically based. Competency trial based evaluations are far more common. Seeing women in jail for shoplifting petty amounts or violating restraining order because they were getting something for their kids.

That’s something that I’m writing a lot about now. Self-injury within prison is almost always interpreted as manipulation and sociopathy. It’s not a defined trait of sociopathy. Gender can be a sense of how we see someone, environment can be too. People that behave that way in prison, we chalk it up to badness. We’re not recognizing how we’ve taken away every other means of expression and control.
On Becoming A Psychologist
Cassie Addai

I. Biomedical Diagnosis (excerpts from On Becoming A Psychologist)
“As a child I did not have the words to describe the cumulative effects of such interactions, but I had emotions. Hurt, anger, and loneliness.”

“As I learned about anxiety, I recall a huge sense of relief at finding an explanation for my experiences and learning just how common these difficulties are.”

Question
What legitimacy does naming the experience lend to the experience?

Answer
What you’ve said there is hugely important. That for me is a really key role in psychology. As clinicians, we call it formulations, being able to create a shared understanding of that experience. As you said, putting a name to what has happened. Something that has happened to them rather than something they have done. Not because you’re not strong enough or couldn’t cope properly, but because these are things that have happened to you. Being able to sit with someone and help them understand why their experiencing something is hugely important. And the name they want to give to that rather than the name you do, their language not ours. I might talk about depression, they may talk about loathing or the black dog.

I think that maybe people who have experienced struggles throughout their life anyway - because they are moving though the world in a racialized way or with an LGBTQ identity - they may be more well versed or well-practiced in thinking about that particular struggle. Not necessarily making it easier, but they already have some of that vocabulary. I think what I’m experiencing is because of that racism, homophobia, microaggression. In some ways, they can be more articulate about what they’re experiencing because they have to move through the world with that marginalized identity. A queer black woman from a working class background, you’ve seen the world through a background of more struggle and may be more well versed in speaking about it. That kind of discourse can make some mental health professionals feel uncomfortable.

Answer
It probably makes people feel more uncomfortable. If someone in front of me is talking about their experience as a gay man, I can’t relate to it but I still can make space and time to consider that in our work together. For some, the experience feels so dissimilar to their own experience that rather than sit with that discomfort they give cues. I don’t know what that experience is like for you because I’m not occupying that identity but I realize it’s
important to you, so I want to make space for us to think about together. So perhaps the discomfort is still there but you’re not using that to silence the person. If someone raises the issue of racism, they’re not saying you’re racist, or sexist, or homophobic, but sometimes the clinicians’ emotions get too tied into that process which makes it difficult for them to hear the person’s stories.

II. Situated Knowledge (excerpts from *On Becoming A Psychologist*)
“\[I\] believe that Psychology must acknowledge its own role in racism, in particular, its foundations upon a white, Western and individualistic knowledge base, which does not reflect the rich diversity of society.\]

“However, I feel uncomfortable with the prospect of merely increasing the number of black clients without true reflection on the ways in which systemic racism operates within Psychology itself.”

**Question**
One concept I’m thinking about in my thesis is this idea of situated knowledge, this is knowledge that includes not only physical exams, lab tests, double-blind RCTs, but also the experience of the patient and a doctor who is aware of their own biases. Could you talk more about what has motivated this understanding of the role of psychology for you and why it’s is important?

**Answer**
For me, it’s in the same way that you’re talking about the struggle to find perspectives that are written. When I first heard about this anthology being put together, I was amazed and not really amazed. It’s 2018, there should surely be narratives like this published and they should be in the forefront of publications. Actually, it makes sense that given the way that we think about mental health in both psychology and psychiatry, it’s in a medicalized way of thinking and perhaps doesn’t take adequate account of what the psychosocial issues are that people might be struggling with in race and racism. Both as black women in general who have less access, but also has a black clinician sitting on the other side of the table with black clients that are facing huge disparities in the services being provided.

**Answer**
A bit about how my training has been in the UK, when you’re training as a clinical psychologist, there are academic training lectures and assignments, and you also spend time on clinical placement. You’re being supervised in your practice, and working on your own research within a thesis project. Within the academic side, I found that to be lacking at times. I look at who the lecturers are, and it’s predominantly white men, leading into the western US centric psychologic base. And when there is mentioned the
role of gender, race, sexuality, it’s referenced in the context of the distress. The people who are most likely to experience distress and are disproportionately marginalized by society. Black ethnic backgrounds, LGBTQ backgrounds, we know that but we still peddle these ideas of medication, short courses of therapy - where there actually needs to be a more systemic and holistic change that needs to happen. That has been a frustration for me in my education and placements. Then actually talking to face to face with people dealing with race, homophobia. That’s the reality that people are living, they aren’t saying my neurotransmitters are messed up, they’re feeling depressed because they don’t know if they’ll have enough money for their families, their relationship has broken down, etc. We need to pay more attention to these aspects as clinicians.

III. Role of Writing in Activism (excerpts from On Becoming A Psychologist)
“Although I was drawn to Psychology because of my interest in hearing people’s stories, I am increasingly aware of the need for activism within my role.”

“Psychologists must also actively speak up against the systematic injustices which wear down the mental health of people of color, especially those who occupy marginalized gender, sexuality, and class identities.”

Question
How do you see clinicians incorporating activism into their practice? Do you think there is a role for writing in becoming a clinician who prioritizes activism?

Answer
I think that writing can be a huge part of the role that clinicians take and I think there are various layers to that. I wouldn’t say that it’s a common practice. Maybe because clinicians feel anxious about how it can be used, for example, when someone you’re working with is going through a benefits access to access support from the government, there’s potential to write a letter of support. And that itself can be a form of activism by supporting and advocating for the purpose if they wish. There are some quite vocal clinicians who are writing think pieces, magazine articles, so perhaps moving away from a more academic audience to something that is more accessible by a wider audience. Art is a powerful tool in this.

But there are also obviously the more traditional forms of activism, whether that’s going on marches or signing petitions. Stepping out of the therapy room and that one to one situation and trying to use your voice on multiple levels, I think that’s hugely important.

In reading diverse narratives, clinicians with minority identities used different language to write? What is your understanding of this difference? Do you believe it motivated works like The Color of Madness?
Answer
For me, that speaks to a more general responsibility that is often held by people who hold a minority identity as being the spokesperson. In the UK there are very few clinician psychologists who hold racialized backgrounds. Every kind of word or sentence that I was writing, how will the powers that be reading this see this. I don’t want to jeopardize my career, but I also have to think about what my values are and where I stand as a black woman. I think that is a very fine line. Not unique to me. I’ve spoken to colleagues who are also training, who want to avoid becoming spokesperson for the black psychologist, but equally inadvertently stepping into this role, and identifying myself as a black trainee clinical psychologist I AM stepping into this role, it is quite messy. I think about what I might regret not saying but also what I might regret saying become of potential caregiver implications.

Answer
I think that’s where perhaps each of the three areas are important – so looking at how the academic curriculum needs to change in order to more mobilize these perspectives. Because as it stands, it very much reflects against what’s considered the norm, so whiteness, heterosexuality. This is 2019, where I’m training in London, which is lauded as this multicultural population. I see that in my clinical work with who I support, but the teaching doesn’t quite reflect that because I think there needs to be a huge overhaul of the curriculum in order to even address it. It’s addressing the diversity in the society that we support. Do we want to be clinicians who support people we consider the norm whoever that might be, or ones who support everyone, and support everyone productively. Because some people don’t come to therapy because it’s not for me they don’t understand me, and that’s a shame that people are feeling disenfranchised that way. In addition to academic changes, the way that clinical practice works can benefit from huge changes as well. There is the status quo, that you have one to one therapy that lasts 50 minutes, but going and meeting people out in the communities or forming groups to help with socialized isolation that they feel, those ways of working that are not common practice but not so out of the box that might be ridiculous. Rather than the tendency of we in the west might know best, there’s a lot that we can learn from other cultures and other parts of the world that we can use to critique practices here and develop and learn.

IV. Gender & Race in Mental Illness (excerpts from On Becoming A Psychologist)
“I am increasingly aware of the disparity between what we know about the social causes of poor mental health and the individualised interventions we offer to those in distress.”

“As such, what might be understood by the black client as a normal response to the systematic discrimination they face, is pathologized by professionals as symptomatic of a mental health problem.”
Question
In my thesis, I think about the role of stress in mental health and mental illness. We know that differential social experiences play a large role in accumulated stress. Black women in American, for example, have worse outcomes in cardiovascular disease, pregnancy morbidity, etc. when all other factors are controlled. It’s reasonable to think this phenomenon would extend to mental health, yet in most fields including mental health, we don’t seem to be addressing this causative factor directly. Can you talk more about this?

Answer
The research that I’m most familiar with and most interested in around that is the research about adversity. Children with adverse life experiences - if that is poor attachment due to parents with substance use issues, trauma, bullying in school, stress adversity in childhood, adolescence, adulthood - stress and adversity has a huge impact on how we feel about the world around us that bring people into services or don’t. We know these things, we know that if you’ve been sexually assaulted, in physically or emotionally abusive relationships, all of that has an impact on your mental health. But what happens is the first call is medical, which can be hugely valuable in peoples recovery, but if that is not combined with something that looks at the psychosocial factors, that is a huge loss in terms of supporting that person. So we need to combine what we know about psychosocial distress. Not just, here’s a prescription and some sessions, because that’s not going to touch some of the real adversity that people are living.
I. Biomedical Diagnosis

**Question**
Can naming the mental health experience lend it legitimacy? In your experience, how do patients feel about receiving a diagnosis?

**Answer**
In terms of the whole diagnosis debate, I really struggle with it because I work within a system that is really based in diagnosis and the medical model. In mental health services here you have to fit a pathway. So say you have a patient who’s experienced sexual abuse in childhood, they’re struggling with mood, and there may be elements of trauma, but you may be put in the pathway of personality disorder – and they get a certain kind of treatment. The whole way these pathways work, you can lose someone completely, so for me, it just pulls me out.

A lot of the work I do is about language. Because I do get nourished in that way. I’m also training in open dialogue, it’s really linguistically based and narrative. Really encouraging everyone to have their own interpretation, really encouraging all the voices and families to inform us and staying away from depression and psychosis in order to think about the experience. I also know that for some people, it’s really comforting, they find comfort in a diagnosis. But that needs to be a journey that we go on our own. I’m really aware of the amount of power I have in my work. I remember being a trainee, in my early 20s. In the process, one of the facilitators would say something, and I would say oh my god, that’s it. So I can see how it’s useful, and I also know how powerful that is, and our job is to help people get beyond that, which is hard, to help people find their own way without putting too much responsibility on them. I really worry about diagnosis. By labeling something as a professional, I have the power to create a problem for somebody, if I define it as a problem all of a sudden it’s schizophrenia or depression. So much gets lost in translation that way, I decide I know what you’re thinking or experiencing and that person loses the power to really be in that moment.

**Answer**
That’s exactly what I believe, it’s about the story and the experience. The problem is our models don’t rely on the story, they rely on the symptoms. And as we go forward and manaulize and shorten treatment, we focus on the symptom. I disagree that diagnoses are words that sum up experiences, they’re not. They sum up symptoms. And they’re so uniform. We hear someone’s experiences and we fit it into a box. The open dialogue began with not diagnosing, not medicating. The Netherlands use it, and they have eradicated schizophrenia; they don’t diagnose it these days, because they don’t label schizophrenia. And they aren’t having repeated relapses. Where that person becomes more and more problematic because the medication is so harsh.
Answer
And I think that’s the fear, you are so powerless, you are so powerless in the face of these really extreme experiences and emotions. For me part of healing is sitting in it and having someone sit alongside you and experience the powerlessness and pain and that is not the end goal. Obviously, everyone wants it to stop and not feel bad anymore, but that’s not the focus. But people are focused on this measurement. I know in my practice, I go in these cycles of thinking “what am I doing, is this even helpful,” and really losing my belief that this is worth doing. And I’ve learned that you’re mirroring the process of what’s happening with your clients. And actually, I think that’s my strength as a therapist, really sitting with it. When I’m really feeling shit and we don’t go there because it’s frightening to really let ourselves experience it.

II. Situated Knowledge (excerpts from The Good Indian Nurse)
“She was an Indian woman and she was a nurse. I feel stupid about this now, but in some unknowable way it was a defining moment for me. I saw her and I thought, it’s okay to leave mum here. Mum’s going to be alright.”

“I wonder what my brown skin means to the service users and their families who are faced with me as a mental health professional”

Question
One concept I’m thinking about in my thesis is this idea of situated knowledge, this is knowledge that includes not only physical exams, lab tests, double-blind RCTs, but also the experience of the patient and a doctor who is aware of their own biases. Could you talk more about what has motivated this understanding of the role of psychology for you and why it’s is important?

Answer
When I wrote the story for The Colour of Madness it was just like a comment piece done very last minute, so not with a huge amount of thought but it was a memory I had as a teenager in a psychiatric hospital where my mother was admitted, she has Schizophrenia. I had very little contact with [that nurse] during my mother’s stay that whole time. But I think the reason it stuck in my mind is…I am very political as a person and in my work. There was something about the hope that I felt about my mum and what this means for her. I took that for granted what it means to have that nurse there. I look back and realize that she had her own shit going on. Now, when I look back, I see a depressed woman actually.

I am very conscience of race in my own work. In a lot of the work I’ve done and I’ve also been subject to racism. Some of the white clients feel “oh, I’ve got the brown person.” And this experience is even worse for black people. At the same time I feel this responsibility as a person of color to change the system. Almost not wanting to be that nurse. The importance of letting people know you see them. I notice a lot of racism in the system, and I’m an advocate for that. I may not name it but I report it to the service.
I’m working with a lot of young people now. When a young person of color comes in they are quickly discharged. But a young white person will be given a service. They’ll be given a chance to try something. Now they’ve noticed the role I’m playing and now they expect it from me. There have been times in my career where people have noticed. I went to my supervisor and pointed something out the other day and they said “Is that really the case,” and I said “Yes,” and they took it at face value.

Because of my experiences, I do have something to offer. I haven’t been a service user, but I’ve been a family member and caregiver. It’s also about the experience of having been a career.

III. Role of Writing in Activism

Question
How do you see clinicians incorporating activism into their practice?

Answer
I think we all have that responsible. I was in a role recently, I had a role in Braxton, and it’s a heavily black and Asian area. And I didn’t want to take the role, but I thought, at least I’ll have more patients of color. And I got there and everyone was white and all the patients were white and that really surprised me and it was an expensive service. And the first thing I did was point this out, and I said where are the black people? Or are they all just in prison? And people thought I was being radical. And then there was an inspection and the inspector said just that and it took that for them to take my suggestions seriously and to make changes. And that’s a real worry for me. I find it really painful to work in a system that is abusive, and I feel that mental health systems all over the world are. But mostly, I can’t be part of something that is abusive, I feel I have to be trying to do something different. Because many people don’t see the abuse in the same way. I don’t know whether it goes back to my experiences, and I think it’s part of my training as a psychiatrist and psychotherapist, but I don’t see that [advocacy] happening all around me. To the point that it’s hard to sustain it, because it’s hard to make changes in a system that isn’t ready for it. So I don’t think many people do advocate not at the level of really challenging something. The advocacy that’s happening is really on a case by case basis.

Answer
The idea of the abusive system. I think the reason it’s so difficult for clinicians to make much change within the work is because we’re sold it and people have just swallowed it. Everything is really white, and male, and western. So people are actually blinded, but a lot of clinicians think they’re doing their best. This whole theory of CBT, I’m not saying that there isn’t a time and place for it, but there’s research that says that this doesn’t work for people of color, and I see providers around me who are young, Black, Asian who really swallow it and treat it as the standard of care. So I feel like I’m fighting against something that’s becoming more grounded.

Answer
There’s always that one off lecture or one off seminar that is about race. But at school, not at all, and I was schooled in London. I think it goes back to being a really mouthy 13 and 14 year old. I grew up as a young caregiver who had to advocate for my mum, so noticing and being critical in my thinking has become natural to me. Because of the things that I’ve been exposed to, I’ve seen some really fucking mad shit. You kind of notice the disparities. For example, this concept of open dialogue. The literature I found during my schooling on open dialogue, I only found the training on it 20 years later. I was looking really actively for something different, and it was so hard to find. It was on the treatment of psychosis and what do we have if not the medical model. And it’s hard, because part of working in that way and thinking about the power of language means not having a fix. Nobody wants that. We want to be told that there’s a way to get rid of this and fix it.

**Question**
Do you think there is a role for writing in becoming a clinician who prioritizes activism?

**Answer**
I started off writing a novel. Again it’s personal, but a form of advocacy. It’s on how we understand psychosis, trauma, migration - and racism as being a part of that. Because we know psychosis is a diagnosis of people of color. For me, because my voice can only reach so far, and I can only talk about it so much in my work, I need an outlet. This gives me a method to really digest and think about things. I write so I can do that. I can’t do that at work. I have very few people around me I can do that thinking with. So it’s something I do with my writing. My feeling is it’s the only way I’m going to have an impact on services and what we’re doing. For me, it really is a form of activism. I suppose I feel so powerless that I need an avenue. Not even to be a spokesperson, but I do want these ideas to have a little wider reach. So I feel like there’s a responsibility on those of us who have slightly different ways of practicing to try and share that. Just because all the newspapers are talking about CBT or that’s what your doctor is going to offer you, doesn’t mean that’s all there is.

**Answer**
I also feel like I can be really brave in my writing in a way that I can’t be at work. So it is a way for me to express things that I can’t going forward. Because the piece that I wrote in that journal, I could lose my job over that. Which seems silly because it’s the truth.

When I write, I always write what I want to say. It’s a process, and my novel has gone through lots of different forms, and I’ve been able to train my voice and be a little open. As I’ve neared wanting to put my novel out there, I thought I’m not going to be able to use my name if I continue to work for the NHS. And it’s quite disparaging about current treatment. So when I wrote the story that I submitted to the journal, I just knew I couldn’t put that under my own name. We get a lot of complaints in our job, I work with a lot of difficult families, so any disgruntled parent could look me up. Before I put it into publication, I shared it with members of my team, and they said immediately, no you can’t put your name to that. Don’t step out of line, that’s part of the culture of the work that I do, but that’s part of keeping us in a system of abuse too.
Question
In reading diverse narratives, clinicians with minority identities used different language to write? What is your understanding of this difference? Do you believe it motivated works like The Color of Madness?

Answer
I find it a bit interesting because of thoughts that come into my head. And it’s something that I’ve noted in the younger generation and I see a difference in the politics of the younger generation who have much stronger politics. But are there 3rd and 4th generation immigrants, and actually they feel more away from the culture, and so they feel this burden of responsibility and having to represent something? Within my generation, there aren’t that many voices and there should be. This whole concept of becoming woke is quite fascinating. For me, I feel like it’s always been how I’ve viewed things and maybe didn’t have the same language, so I do wonder.

For me, I’m speaking for myself, I’m advocating for me and people like me. It’s not a burden, it’s fucking frustrating and mad that we have to do this. But at the same time, I think working in mental health is a burden. It’s not as simple as meeting one person and helping them, there’s a lot of work to do. It’s about changing society, I can do treatment work with a client or family in the room, but then they leave the room and go into a world where they are treated less than as a woman or person of color. I feel like that’s the work. I find the whole idea of the burden - I am an Indian woman and I carry that with me, that’s who I am and I’m proud of it. I don’t see it as a burden, I want to represent myself.

IV. Gender & Race in Mental Illness

Question
In my thesis, I think about the role of stress in mental health and mental illness. We know that differential social experiences play a large role in accumulated stress. Black women in American, for example, have worse outcomes in cardiovascular disease, pregnancy morbidity, etc. when all other factors are controlled. It’s reasonable to think this phenomenon would extend to mental health, yet in most fields including mental health, we don’t seem to be addressing this causative factor directly. Can you talk more about this?

Answer
Actually with my patients. And yeah, I think the more political the person in the room, the easier it is to name it. Some of the things I see most often are definitely people of color, definitely women (possibly women present more), and poverty. And it just really depends on the person. So what I’ve found is, I will let someone know that I am up for talking about these things. If someone stays away from it and struggles with it, I will try to follow them. I try to focus on what people are bringing rather than going into monologues. I do sometimes go about it differently with younger women of color.
They’re coming to me telling me about workplace bullying, experiences leading to psychosis. Women who have experienced migration, particularly from a young age and particularly for refugees. They come in and they’re not linking these things, so I will make those connections for myself, and sometimes I will say, “Oh, in my work I see this a lot.”

With young women of color, I can become more evangelistic with it, because I think, you might not meet anyone else who will have a conversation about this with you. If your parents are first generation immigrants, the whole thing about being a good immigrant and not complaining. I then do feel the burden of recognizing it and naming it and allowing my client to do with it what they want. Identity, race, politics, even religion, I’m not particularly religious, but it’s about recognizing how someone understands things and going off of that framework. But I also think part of struggling with our mental health, people take on responsibility, “it’s my fault this happened. I’m a bad Muslim, I’m a bad daughter.” I think it’s particularly important to recognize this.
I. Biomedical Diagnosis (excerpt from *Confessions of a Gender Specialist*)

“Despite my political objections to the diagnosis, I found myself documenting Gender Identity Disorder so that my clients could access services. I refused to join the World Professional Association for Transgender Health (WPATH) because I didn’t agree with the classism, racism, sexism, homophobia, and cisgender bias and privilege embedded in their excessive requirements for people seeking medical transition. The ideal candidate for hormones or surgery was typically one that resembled those with evaluative power (i.e., white, cisnormative, heteronormative) and had the ability to pay out-of-pocket. I refused to part of an organization that didn’t center the voice of TGNC people in their own health care. Still, I found myself complying with WPATH standards by writing the letters my clients were asking for.”

**Question**

In this thesis, I discuss the power of a formal biomedical diagnosis. I note that the language used to denote mental illness originates primarily from white, cisgender men who were historically the experts in the field. One consequence of this homogeneity is gender identity disorder. Today, GID is a diagnosis that informed clinicians recognize as problematic due to its history as a tool that was used to delegitimize individuals who identify with a gender different from their assigned sex at birth. With GID, the concept of a diagnosis having power takes on new and complex meaning. In your experience, what does the GID diagnosis mean for you and your clients?

**Answer**

So GID was in the DSM for many years and when I came into practice that’s basically what we had to use. However, with DSM V it changed to gender dysphoria and there’s a lot of controversy within trans communities about the intricacies of diagnosis.

The DSM changed to gender dysphoria because semantically it centers the distress as a problem rather than the identity as a problem. But what I’m finding with coding when I bill insurance, it still shows up as GID. That’s kind of a weird thing that maybe is an aside and doesn’t matter so much right now, but demonstrates there’s a difficulty moving away from GID.

People are so heated about this, I’ve seen people walk off stages after heated debates. This isn’t just about trans health but about the DSM overall. All of these things were created by cis white heteronormative men and all the research was done on populations you can access. I don’t believe in either diagnosis and my joke of what I believe is that there is one diagnosis which is complex trauma. I believe there is a diagnosis gender dysphoria and I believe there is a symptom. And I one hundred percent believe my clients when they tell me they have this symptom, or manifestation. Now, the diagnosis of gender dysphoria is really just a way to justify medical necessity, for many it’s not
accurate. They’ve trained to say the things they say in order to get medical treatment. We just had to have a diagnosis, and others think well why does there need to be a diagnosis.

II. Situated Knowledge (excerpt from Confessions of a Gender Specialist)

“There’s also the issue of what I’m calling ‘dual otherness’ – being both the gatekeeper and part of the community. How this plays out in my life and work is that among other gatekeepers (i.e., doctors, surgeons, therapists), I’m not always taken seriously because I’m perceived as having in-group bias or advocating too hard for affirming care. And with clients and sometimes other members of TGNC communities, I may be viewed as the enemy. Other TGNC folks don’t always see me as similar to them, either because my genderqueer identity/expression doesn’t qualify me for real TGNC status (whatever that means), because I have class and education privilege that affords me a position of power, because my versions of masculinity and femininity fuck with the very white and medicalized ideals and narratives that these concepts are based on, and because I will never know what it’s like to be in their shoes. That’s fair; my privilege in this dynamic is undeniable.”

Question

One concept I discuss in this thesis is situated knowledge. This is knowledge that includes not only physical exams, lab tests, and double-blind RCTs, but also the experience of the patient and a clinician who is aware of their own biases. In reading several clinician-authored narratives, I noticed that authors who shared the lived experiences of their marginalized patients were more readily able to identify those experiences and render them in narrative form. However, I argue that all clinicians can aim to develop situated knowledge about their patients’ illness experiences. What is your advice for clinicians who would like to develop this situated knowledge when they do not share their patients’ identities or lived experiences?

Answer

I think for me just the awareness and more psychological analysis. I think the tendency to belong to an identity, to classify ourselves, to fall into group think are really strong. And when you stand in like essentially a bicultural position where you have to do a lot of coasting, you have to be okay with that and not force yourself to choose one side or another. I have watched other trans clinicians who very much have to assimilate and dissociate themselves form other trans community, so they can be respected by cis heteronormative authority - there is that kind of disavowal. At the same time, you can’t claim to be just part of trans communities because you have this kind of privilege and power. So I think it’s about tolerating being in the middle and tolerating circumstance where you’re sometimes alone, and being able to be accountable to both. And ultimately to me, it is being accountable to trans comorbidities first. And the pull. I feel this every day, like I feel the pull to professionalize and deemphasize trans experiences is so strong. I would say it’s not just relevant for trans identity, I would say it’s for people of color and anyone in a marginalized group.
Also like, not playing into responsibility politics which is really actually challenging in the context of needing to survive and capitalism.

**Question**
How do you navigate the expectations placed upon you by ideas of professionalism and the priority to be an advocate for your trans patients?

**Answer**
Every day I am making very strategic choices and it’s a lot of emotional labor. Making very strategic choices and moves around how real to be basically, and I have found that in a medical setting when I’m advocating for a patient, I have to bring myself in a particular way that does play the roles and the game by the rules of a medical hierarchy. And I think a lot of my success has been the capacity to tolerate how shitty that can be and basically know how to code switch very well. Like I’ve been writing in various anthologies since 2004 or 2005, and they’re all some version of me talking about by gender experience, and *The Remedy* was one where I really brought my professional experience into the mix. That’s where I find an outlet where I can be real. And this sharing of inner experience is really intentional, and I know there are other providers who need to be validated somehow. And I know there is somewhere that I need to demystify what’s going on behind the scenes. Narrative is very powerful, and I believe in all these forums where people find a narrative that they can identify with and heal. It has been for me an outlet, a form of advocacy, and a place where I can be even more so vocal and I can speak to my - what some people might think of as - radical side, but I think of as human decency. For me, it’s very strategic. And I think that as I look at narrative and how I used it, it has mirrored the evolution of trans health over the years. When I was writing in 2005, it was about trans identity and our legitimacy. But in 2010 with insurance, and aging populations, we’ve moved into academia. I’m super fascinated with looking at not just mine but all these narrative of people I know who are academics themselves. We’re all doctors of some kind, and we started by writing about our own identities, and now our writing has matured in some ways.

Also I think that there’s something a little bit interesting about how things in print are legitimate. Like if a trans person says something, oh that’s their opinion. But if you’re able to publish it somewhere, all of a sudden it carries weight. I know that *The Remedy* piece was assigned in different graduate and social work programs. Oh that’s just me talking, it’s not publishing a research study, but it does change how people view it.

Something I will say is being someone who does write academically, it’s a completely different tone. In writing, I have to cite everything and back it up and making it neutral and even in that there’s a lot of having to switch voice.

**III. Role of Writing in Activism**
(excerpt from *Confessions of a Gender Specialist*)
“My formal education as a psychologist never offered opportunities for coursework related to gender identity. I focused my studies on psychoanalysis, addictions, eating disorders, and racial identity. Discussions concerning gender focused exclusively on the
binary options of man/male/masculine and woman/female/feminine. This was the early 2000s, and while there is now slightly more awareness, things haven’t changed much in psychology graduate training. My passion and commitment to advocacy for transgender and gender nonconforming (TGNC) people within mental health practice has more or less been viewed as some strange side interest that does not truly concern most clinicians.”

**Question**
This thesis highlights the gaps in medical education that result in physicians being poorly prepared to serve our most marginalized and vulnerable patients. My goal is to identify how writing and reading clinician-authored narratives, particularly those narratives that center the voices of clinicians with marginalized identities themselves, can help to address these gaps in our medical education and knowledge. What motivated you to write *Confessions of a Gender Specialist*?

**Answer**
Was some of what I wrote motivated by knowing there’s a gap. I think training and education is central to everything I do, part of it is yes it’s cathartic to write about my own experience. But it is also to reach someone, and that piece in particular, to reach people in gate keeping positions. Encouraging them to be self-reflective is inherent in all of my work. I’m also really motivated by people know the history of trans health, I often assign this article by Dallas Denny, “The Politics of Diagnosis.” That article is just mind blowing, it really opened my eyes about the politics of university gender clinics. So a lot of the writing I do is inspired by lets lift up the cover and look inside. A lot of people don’t know what’s happening behind the scenes, the conversations I’m having, some things have changed and some things haven’t. I believe it’s part of my work to support our clients as whole people. Sometimes it means sitting in a therapist chair and helping clients understand their feelings, sometimes it’s letter writing, sometimes it’s teaching because a lot of people don’t have adequate information about the medical side of things. And mental health professionals shouldn’t always be in this role because they’re not medical, but a lot of people have no clue. So absolutely, I would encourage advocacy to be part of our role in the same way that it’s part of our role in other ways. If there’s a child being abused, then we have the responsibility to say something. When I go to trans health conferences, the dynamic I have noticed is that you have to pledge yourself as a provider otherwise you are delegitimatized as a professional. And WPATH is stern about the fact that they are not an advocacy organization.