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Ethical Implications of Cultural Barriers to the Depression Diagnosis: Conversations with Primary Care Physicians.

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Ethical Implications of Cultural Barriers to the Depression Diagnosis: Conversations with Primary Care Physicians.

By

Diana Cagliero
B.S. Emory University 2017

Advisor: Kathy Kinlaw

An abstract of
Ethical Implications of Cultural Barriers to the Depression Diagnosis: Conversations with Primary Care Physicians.
submitted to the Faculty of the
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Abstract

Ethical Implications of Cultural Barriers to the Depression Diagnosis: Conversations with Primary Care Physicians.

By Diana Cagliero

The diagnosis of depression is based on Western medical definitions. It has changed over time within the medical culture, as can be seen in the changing categorizations in the various editions of the DSM. However, depression, like many mental health diagnoses, is often an illness that is not understood or accepted by all patients in the same way that a physical diagnosis may be. This project explored the experiences of Primary Care Providers caring for patients with the diagnosis of depression. Through structured interviews the challenges and reasoning in diagnosing depression in patients from different cultural backgrounds were discussed to determine how the culture of the patient affects the understanding and diagnosis of depression. Potential ethical issues that arose centered on the mental health diagnosis, the misdiagnosis of individuals related to their cultural background, problems with the Western-centric care that is being provided by US doctors, issues with cultural sensitivity training experienced by healthcare workers, and the problems associated with a shift in mental health definitions.

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Introduction

Depression is a mental illness that is highly prevalent in the United States and throughout the world. While depression is a condition that falls under the diagnostic realm of psychiatry, more patients with depression will encounter a primary care physician than a psychiatrist or mental health specialist (Beck, 2008). The lifetime prevalence of depression varies among ethnic groups in the United States as "approximately 13.5% of Hispanics, 11.4% of Native Americans, 10.8% of non-Hispanic Blacks, 17.9% of non-Hispanic Whites, and 9.1% of Asian Americans met criteria for major depressive episode" (Kalibatseva & Leong, 2014). However, depression is not an unbiased diagnosis; its definition is centered in Western medical care and has been shifted and edited throughout modern medical history (American Psychiatric Association, 1952-2013). Currently, Mayo Clinic describes the symptoms for depression as "the persistent feeling of sadness or loss of interest that characterizes major depression can lead to a range of behavioral and physical symptoms. These may include changes in sleep, appetite, energy level, concentration, daily behavior, or self-esteem. Depression can also be associated with thoughts of suicide" (Mayo Clinic, 2018). Depression, like other mental health diagnoses, is an illness that may not be understood or accepted by all patients, especially when compared to a recognized "physiological" disease.

The challenges in doctor-patient communication that result from this gap of understanding can fall along cultural lines, as not all patients and providers hold the same understanding of depression. Cultural understanding is linked to a "'highly variable systems of meanings, which are learned and shared by a people or an identified segment of a population'" (Kalibatseva & Leong, 2014). This gap in understanding may occur when physicians “medicalize personal or interpersonal problems, during the process coming to disregard the stress that provoked the complaints while focusing only on the complaints themselves,” while patients view their mental health through a different lens (Kleinman, 1988, p. 59). For example, anthropologist Arthur Kleinman has suggested that patients from non-Western cultural backgrounds may view their body as an “open system linking social relations to the self, a vital balance between interrelated elements in a holistic cosmos. Emotion and cognition are integrated into bodily processes” (Kleinman, 1988, p. 11). The ways in which cultural orientation plays a role in the doctor-patient interaction is especially meaningful when discussing a diagnosis such as depression, which as a term is highly stigmatized in both the United States and in cultures and communities around the world (Parcesepe & Cabassa, 2013). Therefore, understanding these cultural orientations, “the patterned ways that we have learned to think about and act in our life worlds and that replicate the social structure of those worlds” of both primary care physicians and of patients may help better “organize our conventional common sense about how to understand and treat illness” (Kleinman, 1988, p. 5).

This research project explores conversations about the diagnosis of depression that participating Primary Care Providers report having with patients of different cultural backgrounds. Structured interviews reveal the challenges around diagnosing depression, how the culture of the patient affects the patient’s understanding of depression, and the ethical issues that arise. These ethical challenges center on mental health stigma and how this can be affected by cultural sensitivity training, language barriers, screening tools, the ways in which depression is normalized by the provider, and the ways that patients may present somatic complaints for their mental health conditions.

> *"To fully appreciate the sick person's and the family's experience, the clinician must first piece together the illness narrative as it emerges from the patient's and the family's complaints and explanatory models; then he or she must interpret it in light of the different modes of illness meanings—symptom symbols, culturally salient illnesses, personal and social contexts" (*Kleinman, 1988, p. 49*).*

This research begins with a discussion of the experience of cultural minority groups in the context of mental health research. The analysis of the literature highlights the ethical responsibility that researchers have to include cultural and ethnic minority groups in order to increase knowledge about the ways these populations experience and describe mental health care.

Building on such evidence, a second chapter describes the ways that "culture" has historically been incorporated into psychiatric and mental health care, and how attempts to improve understanding on cultural illnesses does not necessarily translate to a reduction in stigma on mental illnesses.

Chapter Three describes mental health care in primary care settings and the advantages and risks of the ways that depression is screened within primary care clinics.

Chapter Four analyzes the current state of cultural sensitivity training for clinicians within the medical education system, especially with regard to the current professional guidelines for educating future physicians.

Chapter Five reports the methodology and results of the original research conducted for this study. It focuses on the ethical challenges of several themes that arose during conversations with primary care providers.

Chapter Six discusses two of the most salient themes that emerged during the interviews: the “Biomedical Model” and “Somatization of Symptoms.” These themes are discussed with a focus on the ethical implications of these concepts for primary care providers.

Finally, a concluding chapter summarizes the main implications of this research. An appendix includes information on the acronyms used throughout the paper, a glossary of important terms, and important documents used during the research project.

Chapter 1

Ethical Considerations in Research with Culturally Diverse Communities

Depression is a disease that has been historically diagnosed at different incidence for different population groups. In fact, "that 76 percent of whites with self-reported depression symptoms are officially diagnosed, compared to just 58.7 percent of blacks, 62.7 percent of Hispanics and 47.4 percent of Asians" (Nauert, 2015). Studies have found that "ethnic minorities traditionally receive less care for depression than do white populations" in the United States (Miranda & Cooper, 2004). An important consideration in having a discussion about the barriers to care for patients from cultural and ethnic minorities is the fact that medical research, and specifically mental health research, has primarily been conducted without minority participation. It was in 1994 that the National Institute of Health (NIH) released guidelines on the inclusion of women and minorities as subjects in biomedical and behavioral research; before this their inclusion was not a requirement.

However, even this guideline allowed for this policy to be ignored if the investigator could provide "a compelling rationale and justification" to not include women and minorities as subjects (Freedman et al., 1995). Routine exclusion of minority groups has remained an issue in research, and this has resulted in a lack of literature on patient behaviors in cross-cultural settings. Therefore, it is important to consider some of the ethical issues encountered by mental health researchers when developing recruitment strategies and research protocols in order to provide comprehensive and culturally sensitive mental health care.

Background

Minorities in the United States, including racial, ethnic, and cultural minorities, have been historically underrepresented in research. Often this problem is discussed with regard to mistrust of researchers from these communities due to famous cases in which minority groups were taken advantage of by scientists, such as the US Public Health Services Syphillis Study at Tuskegee or the case of the immortal cells taken from Henrietta Lacks. However, there have been systematic biases in recruiting minorities from research that have been significantly less publicized. In the 21st century, disengagement from research is linked to contemporary socioeconomic and political factors that disadvantage minorities from autonomously deciding to participate in research (Evans, 2017).

An important example of this would be the practice of providing financial incentives to research participants. Some minority groups may be more vulnerable to manipulation by a research team when financial incentives are offered, as participation in the study is significantly more appealing for individuals of lower socioeconomic status. Examining these situations from a perspective of research subject autonomy, free choice for individuals may be diminished when biomedical research offers them an opportunity for financial gain and may provide them with medical care they would have not otherwise received? As racial, ethnic, and cultural minorities are often disproportionately affected by poverty, their "'voluntary' participation in research must be evaluated in light of the latitude they have to pursue other options" (Williams, 2005, p. 513).

However, there is another, opposing challenge in the recruitment process as there are situations in which a minority population does not wish to participate in a study. This is what some have called "rational non-participation" of minority groups and it is evidence of how declining to participate in research can represent autonomous decision making (Williams, 2005, p. 516). In many settings, non-participation in research is linked to socioeconomic barriers such as financial worries about the termination in care by the researchers when the study is concluded, time limitations such as caregiving for children or strict hourly schedules for work, and a sense of disempowerment in their community (Williams, 2005, p. 516).

The results of minority non-engagement in research can be significant. It leads to conclusions in research studies, whether it be behavioral or mental health research or biomedical research, based on the results of a small, homogenous group of the population. However, the implications of these research studies, whether they be about therapies or in the production of a drug, are typically utilized to affect a large, heterogeneous population which often includes minority groups, which includes those not included in research. An example of this can be seen specifically in psychology studies, where the majority of the subject population is generally college students. Therefore, scientific results from these studies are based on the evidence from a population of young adults primarily coming from high socioeconomic backgrounds. It is important for researchers to strive to include a diverse, representative sample of their community in the study in order to avoid these pitfalls.

Therefore, it is important for a research study to make efforts to reduce barriers for research participation from a minority community. Lack of childcare, transportation, financial constraints, culturally inappropriate incentives, lack of time, inconvenient locations and employment status were all mentioned as barriers to research for minority groups (Waheed et al., 2015). Resolving some of these constraints would be methods researchers could consider incorporating into their research recruitment in order to encourage all potential participants in research in a non-manipulative way and to therefore produce results that are representative of the population they are studying.

Research Design & Cultural Diversity

Ethical research practices are often evaluated through bioethical principles and ethical theories such as utilitarianism and deontology. What is interesting to analyze is how using these ethical principles in research demonstrate the Western bias that dominates research decision making. There are some principles, such as beneficence and nonmaleficence, that are values about interpersonal behavior held by individuals from non-Western cultures (Hoop et al., 2008, p. 356). For example, "One of the tenets of the Eastern philosophy of Confucianism, for example, is benevolence in the treatment of others" (Hoop et al., 2008, p. 356). With regard to maintaining a diverse population sample for a research study, the principle of justice with regard to distributing benefits and burdens to the study population is important to acknowledge.

It does not seem just to burden a minority community solely with the task of participating in the research, but it is also important to include these individuals in the study to gain representative information about their community which may impact their mental health care. When discussing justice with the burden of participating in research, there are several methods through which one can define a way to distribute benefits and burdens. One can give everyone an equal share of the burden, or one can "divide up the materials based on some relevant human property, such as individual need, merit, effort, or contribution made to society" (Hoop et al., 2008, p. 367). However, what is interesting about different approaches to justice in research is the way each of these strategies is based in culture. While Western values may dictate that goods should be distributed based on individual merit, a collectivist culture might prefer distributing goods based in societal contributions (Sinha, 2014, p. 42).

Although these methods for distributing the burden of research on different members of the community may not be the ones the researcher is examining, it is important to note that the principles through which ethical research is conducted can be different based on the diverse cultural values in a community. Currently, ethical justifications for mental health research require investigators to maximize the probability of benefits of the research, minimize risks to individuals, and "demonstrate a favorable balance of benefits over harms" (Fisher et al., 2002, p. 1025). While this cost-benefit analysis of research may be a Western-centric approach to research ethics, there are other factors that researchers can consider while conducting the study that allow for a more culturally-sensitive approach in minority communities. Maintaining "thoughtful consideration of the design's scientific merit," considering "the impact of historical and contemporary discrimination on mental health outcomes" as described above, and predicting "cultural and contextual factors that may interfere with or facilitate responsiveness" are all important steps for researchers (Fisher et al., 2002, p. 1025). With regard to cultural minority communities, it would be important for a researcher to learn about the ways in which the culture they are studying may impact the ethical research principles used to produce the best study possible.

Cultural Adaptation of Assessment Measurements

When conducting mental health research, standardized assessments are often used to determine the presence of a condition within a population. Classic examples of these tools are the Beck Depression Inventory and the Generalized Anxiety Disorder 7 (GAD-7), which are lists of questions which scale the determination that the subject may have a mental health disorder. The problem of determining the cultural validity of these tests is crucial when implementing screenings. Many times, the types of questions that are asked are not familiar or logical for an individual with a different, non-Western, cultural background. Minorities may not have equal benefits and may be subject to harm in research when these assessment norms are used, especially when these assessment tools are derived from a population that is significantly different from the one being studied (Fisher et al., 2002, p. 1026). Failure to consider the minority perspective when ensuring cultural validity and measurement equivalence is extremely problematic with these assessment tools.

The risks of not using culturally-validated assessment tools are “the over- or under-identification of mental health problems,” which can compromise scientific benefits to these communities or can “lead to harmful social labeling or maladaptive self-conceptions of members of the racial or ethnic group studied” (Fisher et al., 2002, p. 1026). If researchers are working in a community with a large presence of a specific cultural group, they should look at instruments that are adapted for members of the research participants’ cultural group. If, within a specific population, the instrument does not exist or hasn’t been evaluated before, researchers should “take steps to ensure that their instruments are assessing conceptually and operationally the mental health characteristics under study" (Fisher et al., 2002, p. 1026).

One way to do this would be to examine the cultural item equivalence of the instrument used in the research for this minority population. Furthermore, if the community included individuals who spoke different languages, the investigator should aim to translate the standardized instruments and determine that the above measurements are equivalent in order for the psychological constructs to be properly measured (Fisher et al., 2002, p. 1027). There are two positive outcomes that are obtainable when culturally adapting assessment tools. First, consultation with community-based experts about the appropriateness of the research instrument and interpretation of the results promotes "inclusive equitable participation in the research process" (Williams, 2005, p. 515). Secondly, culturally validating these scales may be a way for the investigator to help remedy research in the past that has used invalid tools and may have negatively defined minority people. This work requires time and more research on behalf of the investigator. However, this is an important step in order to maintain accurate and unbiased measurements from the entirety of the community they are studying, including a cultural minority group.

Ethical Obligations

Of researchers

As to whether or not it is a duty of the researcher to incorporate a more diverse sample of participants in the study, it is important to consider both the ethical principles that are addressed in research as well as the outcomes of the decision. The researcher has an obligation to promote respect and justice among their research subjects, as well as to ensure that they are maximizing benefits and reducing harms to the community. The researcher may walk a fine line when continuing to include minority community members. On one hand, they must respect the autonomy of the minority participants who actively choose not to participate. At the same time, researchers need to recognize that not including minority participants in the study may result in problematic outcomes for that population. The results of the study may be applied later to minority groups even though there is currently no evidence to support that application (Williams, 2005, p. 518).

Therefore, it should be an imperative for a researcher to strive to recruit within a minority community. This recruitment should entail engaging with the community, and may include methods such as meeting with community staff, holding information sessions within the community, and bringing the research team together with community members who are “connected to potential beneficiaries of the research” (Williams, 2005, p. 518). A researcher should be required to connect with the community in a productive, informative way, and must do what they can to continue to build trust between themselves and the participants. It is in this way that the obstacles to comprehensive care for cultural minority groups can be dissolved in a productive, ethical manner.

Of participants

While researchers do hold an ethical obligation for including minority groups in research, it is not only researchers who are solely responsible for rectifying injustices. A statement that is sometimes made with regard to participation in research is that it is a moral duty for everyone who benefits from research to also participate in this research. As all individuals who use medication or seek therapies are using the results of a research study in which others participated, the argument goes that these same individuals are also obligated to contribute to research for the sake of helping others down the road. However, it is interesting to consider how this requirement applies to individuals from minority communities: do they also have an ethical requirement to participate in this research study?

The argument that one should participate in research may ignore the social context in which participants find themselves. It is generally taken for granted that individuals have access to the benefits of medical research, but this is not always the case. In the United States, millions of people, particularly minorities, have little or no access to the benefits of research because of their socioeconomic status, cultural background, or residency (Melo-Martin, 2008, p. 32). Therefore, defending an ethical obligation to participate in research without taking this into account “can also further injustices against already disadvantaged groups” (Melo-Martin, 2008, p. 32). While research participants generally may have some obligation to participate in research, the argument that this obligation is based in the benefits that are given to all individuals lacks nuance with regard to the social context of ethnic or cultural minority communities.

Conclusion

Do mental health researchers have an ethical obligation to include cultural minorities in their research? The answer may be described as “yes, but with nuance and while maintaining an ethical and culturally sensitive recruitment protocol.” A researcher should try to learn about the history of minority group marginalization in research, and about how these issues are still pervasive in the 21st century. Furthermore, researchers should keep in mind that the ethical principles that guide their own mental health research are a good framework, but cultural variations for research protocols may need to be considered when working in a culturally diverse community.

It is also crucial for researchers to culturally adapt their assessment tools for the population in which they are working before continuing with the study. Overall, a researcher does have the ethical obligation to include minority communities in their study, but they must be cautious to avoid manipulation and respect subject autonomy at all times. The question of whether or not community members have an obligation to participate is less clear, but this obligation should not be assessed without a further understanding of the cultural and social context that affects minority groups. In the following chapter, the ways in which "culture" and "culture-bound illnesses" have historically been researched and incorporated into Western psychiatric care will be examined.

Chapter 2:
How Cultural Syndromes and Idioms of Distress have been incorporated into Western Psychiatric Care

While the research conducted in biomedical settings has historically excluded cultural minority groups, the field of medical anthropology has been at the forefront of discovery and building understanding of cultural syndromes and idioms of distress used by the psychiatric community. The Diagnostic and Statistical Manual IV (DSM IV) included as an appendix a section on "culture bound syndromes," which were defined as "recurrent, locality-specific patterns of aberrant behavior and troubling experience that may or may not be linked to a particular DSM-IV diagnostic category" (DSM IV, 1995). While the term "culture-bound syndromes" has come to be replaced with "cultural concepts of distress," and are now re-labeled in the updated DSM V, the way these syndromes are presented in both manuals demonstrates how "culture" as a concept has been incorporated into Western psychiatric care over time.

Ethnopsychology is the study of how individuals within a cultural group conceptualize the self, emotions, human nature, motivation, personality, and the interpretation of experience
Ethnophysiology explicates how a cultural group conceptualizes the body and its processes, how those processes might be harmed, and which therapies are most salient
(Keys et al., 2012)

Western psychiatric diagnoses are often viewed as the definitive assessments of various mental illnesses. However, as can be seen by studying the changes in diagnoses in the various editions of the DSM, these diagnoses have been created, removed, edited, and renamed since the first edition was published in 1952. Perhaps the most famous example of this shift in mental health diagnoses was creating the diagnosis of "homosexuality" as a mental disorder first under “paraphilia” and later under “sexual orientation disturbance” in editions I through III of the manual.

With regard to culture and cultural syndromes being mentioned in the DSM, it is important to note that “attempts to find words that capture both a psychiatric construct and a lay category in cross-cultural contexts repeatedly have identified complex, overlapping categories rather than fully synonymous terms” (Keys et al., 2012). This overlap has been acknowledged in the DSM V, as it states, “it is important to emphasize that there is no one-to-one correspondence at the categorical level between DSM disorders and cultural concepts” (DSM V, 2013). While Western medicine has historically been rooted in an ethnopsychology of mind-body dualism, other, non-Western ethnopsychologies are equally nuanced and complex (Keys et al., 2012). Two cultural syndromes, *Susto* which comes from Latin American cultures and is mentioned in the DSM V and IV as well as in the interviews conducted in this study, as well as *neurasthenia* which is used in Chinese culture and is the subject of anthropologist Arthur Kleinman’s study conducted in 1982 will be used here as examples of cultural illnesses and modern diagnoses.

Example 1: *Susto*

Susto, as mentioned in the “Glossary of Cultural Concepts of Distress” in the DSM V and in the “Outline for Cultural Formulation and Glossary of Culture-Bound Syndromes” in the DSM IV, is described as “chronic somatic symptoms attributed to ‘soul loss’ and induced by an episode of intense fear experienced by the individual, usually related to a supernatural perspective” (Nogueira et al., 2015). Symptoms related to *Susto* include fever, diarrhea, loss of appetite, restlessness, insomnia, mental confusion, apathy, introversion and even include depression (Nogueira et al., 2015). In a study conducted by Weller, the number of individuals who reported *Susto* with depressive symptoms was measured using different scales for depression, such as the Beck Depression Inventory, and the Zung and Center for Epidemiological Studies Depression (CES-D) scales (Nogueira et al., 2015). In this study, "individuals who reported having had *Susto*…in the past were 19 times more likely to have been affected by depression in the past compared to those who did not report having had Susto" (Nogueira et al., 2015). This finding can also account for how *Susto* is reported in the DSM V. Under the definition of the condition, it states that of "related conditions in the DSM V" the primary illness is major depressive disorder (DSM V, 2013).

Example 2: Neurasthenia

While neurasthenia can be examined within the context of mental illness in China, it is also interesting to note that it was used as early as 1829 in the United States to describe weakness in the nerves. Western physicians defined it as the "exhaustion of the nervous system" (Bellack et al., 1998). It is included in the Chinese Society of Psychiatry's medical texts, but it is no longer included in the DSM.

Neurasthenia emerged in China as a disease of fatigue, and it was related to problems with the flow of vital energy or an imbalance of *yin* and *yang*. It was not directly pathologized as a mental illness, as mental illnesses are highly stigmatized in China, and "the family with a mentally ill member is regarded as carrying a hereditary taint of moral failure" (Kleinman, 2007, p. 109). This stigma towards mental illness was increased during the Cultural Revolution, as Mao stated that mental illnesses were not diseases but rather they were "wrong political thinking" (Kleinman, 2007, p. 109).

A case example Kleinman presents in his work is that of Mrs. Lin, a woman of Chinese origin living in North America. Her American doctors assign her a diagnosis of depression based on her account of fatigue, feebleness and the somatic symptoms she presents. The patient however believes that the diagnosis is neurasthenia. This example demonstrates how when one understands the patient's case within her cultural conditions, depression only describes a part of the patient's illness. While treating a patient such as Mrs. Lin solely with antidepressants would most likely improve her symptoms, the physician would not be working to resolve the patient's illness problems, the "psychosocial accompaniment of disease including maladaptive coping and work, family and school problems," which are a major aspect of holistic, patient-centered care (Kleinman, 1982).

Ethical Challenges with Cultural Illness presented in the DSM

The DSM is created by the American Psychological Association (APA) and is the text used primarily by psychiatrists; the majority of depression diagnoses are made in primary care settings (Magellan Healthcare, 2014). Furthermore, "the majority (60%) of the general population with mental health symptoms will never see a mental health professional: they will only present to the general medical setting" (Beck, 2008). Keeping this in mind, the resources provided by the APA within the DSM V with respect to understanding the cultural context of illness are helpful—they may just not be helpful to primary care providers, but that is not necessarily within the scope of the APA.

The DSM V presents a Cultural Formulation Interview (CFI), a 16 item, open-ended questionnaire for psychiatrists to use with their patients to "enhance clinical understanding and decision-making" (DSM V, 2013). The CFI is open-ended and asks questions that could be important for a practitioner to know, such as: “are there any kinds of stresses that make your [PROBLEM] worse, such as difficulties with money, or family problems?” (DSM V, 2013). The CFI was found to take, on average, 15 to 25 minutes to complete, which would most likely be a major barrier for implementation into primary care, where physicians have shorter appointment times with their patients than in psychiatry (Aggarwal et al., 2015).

However, an even greater challenge with the CFI is the lack of instruction on how to decide which patients are to be administered it. Supposedly, this questionnaire can be used with any individual and is designed to avoid stereotyping. However, the DSM V also states that “the CFI is best used in conjunction with demographic information obtained prior to interview,” including “place of birth, age, gender, racial/ethnic origin, marital status, family composition, education, language fluencies, sexual orientation, religious or spiritual affiliation, occupation, employment, income, and migration history” (DSM V, 2013). While it is mentioned that the CFI can be used in the initial assessment of all patients regardless of background, there would need to be a greater emphasis by the APA than just a brief mention of this in order for all psychiatrists to take 15 to 25 minutes of their time to administer this questionnaire for every new patient. The challenge with using a tool like the CFI is the question that each practitioner will individually determine: “who gets it?” How a practitioner decides which patients of theirs are from cultures “different” enough to warrant this questionnaire is entirely subjective and therefore it is likely prone to bias, implicit or not, and ethical dilemmas. As the Primary Care Provider may be pushed for time, judging the need to incorporate the CFI into their interaction with the patient may result in barriers that are both administrative and bias-oriented, both of which hold problematic consequences for patients.

Another ethical challenge that pertains to the incorporation of cultural illnesses in the DSM is that of diagnosis and billing. While a select list of illnesses are found under the “Glossary of Cultural Concepts of Distress,” including *Susto*, none of these terms have a diagnostic classification for billing and insurance purposes. While the DSM V tries to emphasize that these cultural illnesses are similar, but not synonymous diagnostic categories with diagnoses like depression, there is no way for a clinician to enter these illnesses as their own diagnosis. Therefore, for a physician to prescribe treatment or to offer a referral for a patient suffering a cultural illness, they have no diagnosis to enter besides Western medical terms like “Major Depressive Disorder." In our current medical model, most insurance companies require a diagnosis from the provider in order to bill them and to request medications.

Therefore, if a patient feels as though they would benefit from antidepressant medications, the provider may be required to enter a diagnosis of “Depression,” even though this term may be highly stigmatized for that patient. Stigma about psychiatric care is pervasive in many cultures and it still exists in the United States. Some organizations that request medical histories from applicants such as the Peace Corps will not accept applicants who have any psychiatric medical history, as Major Depression is listed under “Health Conditions typically not Supported by Peace Corps programs” (Peace Corps). There are also anecdotal cases of physicians, who have been trained in holistic healthcare and about the challenges of mental health stigma, who will pay their therapists out of pocket because they do not want psychiatric care on their medical record (Morris, 2017).

Including culture-bound illnesses, many of which are considered spiritual or caused by supernatural forces, and which are highly stigmatized in their communities, in a psychiatric manual may be a way of creating stigma. When it comes to the reality of mental health stigmatization, an organization like the APA may need to be required to deeply examine the potential ethical consequences of their texts—in both what they do and do not include. Challenges associated with mental health stigmatization are also present in primary care settings, and in the different screening tools for depression that are used in primary care settings, which will be discussed in the following chapter.

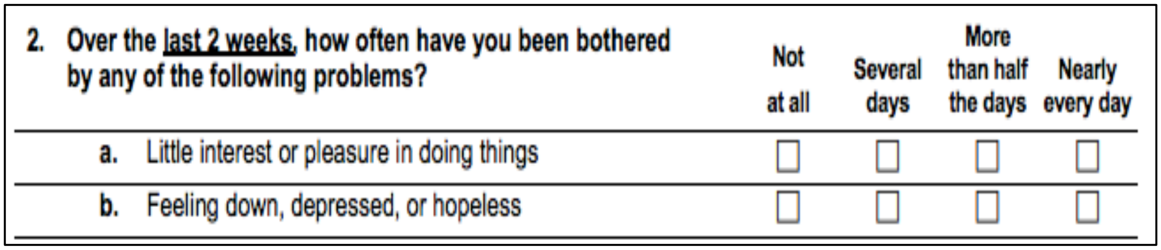
Chapter 3:

The PHQ-2 and PHQ-9:

Ethical Considerations for Depression Screening in Primary Care

Many primary care physicians screen their patients for depression upon intake. The office of the primary care physician often gives out a "systems review" form, on which there are two questions that screen for depression. These two questions, called the Patient Health Questionnaire 2 or PHQ-2 ask: "Over the last two weeks, how often have you been bothered with the following problems: 1. Little interest or pleasure in doing things and 2. Feeling down, depressed, or hopeless." If the patients answer "more than half the days" or "nearly every day" to either of these questions, they are then given the PHQ-9, a longer screening questionnaire. The Patient Health Questionnaire 9 (PHQ-9) is a nine-question instrument designed to diagnose depressive disorders based on clusters of symptoms and criteria from the Diagnostic and Statistical Manual of Mental Disorders (DSM). The use of the PHQ-9 today in primary care provides an interesting example of how medicalization in our society can be ambivalent; the way these nine questions have taken on the equivalence of a significant mental health diagnosis has both positive and negative aspects that will be analyzed below.

Image 1: The PHQ-2

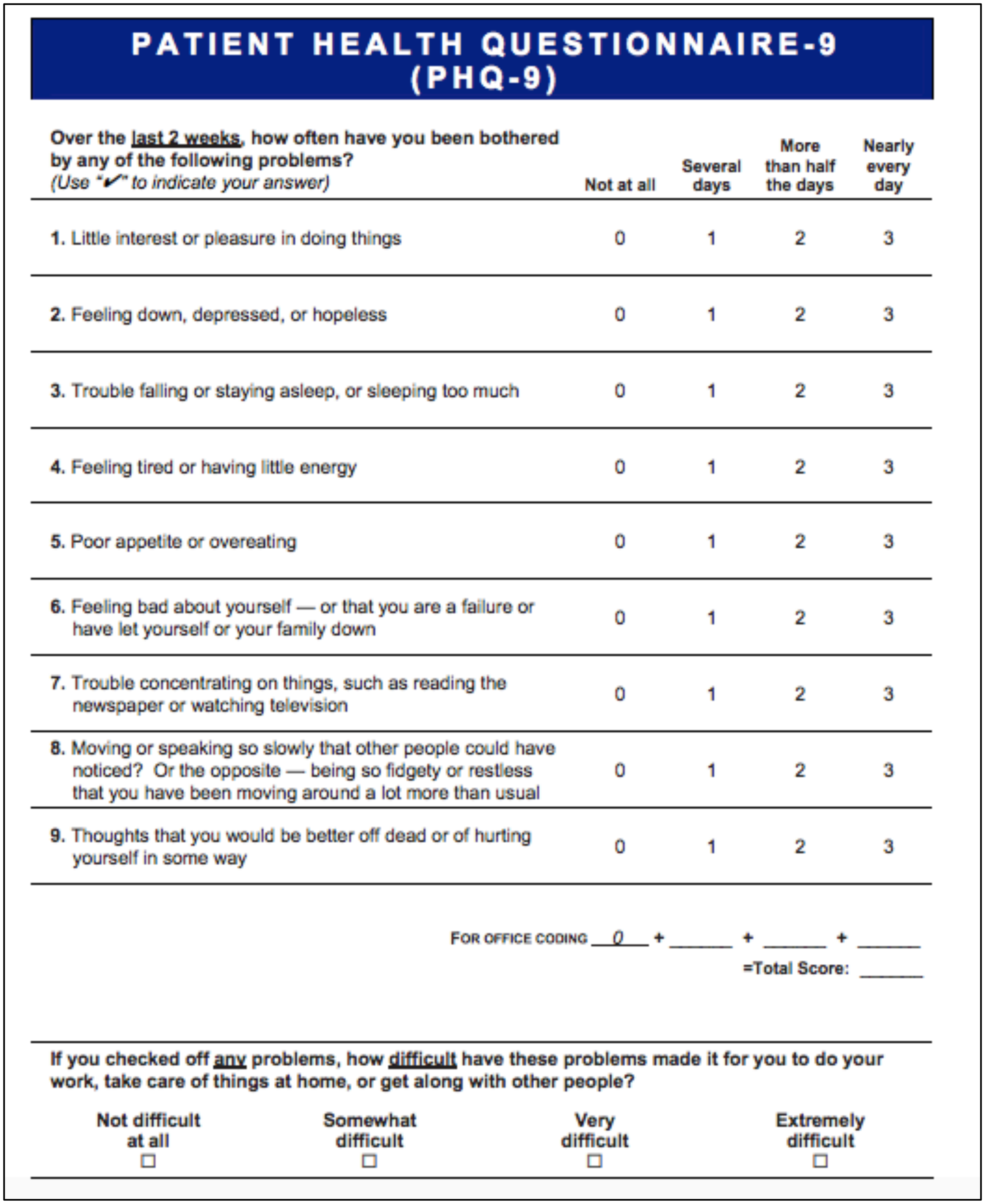


2. Over the last 2 weeks, how often have you been bothered by any of the following problems?	Not at all	Several days	More than half the days	Nearly every day
a. Little interest or pleasure in doing things	☐	☐	☐	☐
b. Feeling down, depressed, or hopeless	☐	☐	☐	☐

Source: Pfizer, Retrieved (7/9/18)

http://www.phqscreeners.com/sites/g/files/g10016261/f/201411/English_0.pdf

Image 2: The PHQ-9



PATIENT HEALTH QUESTIONNAIRE-9
(PHQ-9)

Over the last 2 weeks, how often have you been bothered by any of the following problems? *(Use "✔" to indicate your answer)*	**Not at all**	**Several days**	**More than half the days**	**Nearly every day**
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3

FOR OFFICE CODING __0__ + ______ + ______ + ______

=Total Score: ______

If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all	Somewhat difficult	Very difficult	Extremely difficult
☐	☐	☐	☐

Source: Pfizer, Retrieved (7/9/18)
http://www.phqscreeners.com/sites/g/files/g10016261/f/201411/English_0.pdf

Development of PHQ-9

The PHQ-9 and PHQ-2 were developed alongside a set of other questionnaires in a grouping called PRIME-MD, or Primary Care Evaluation of Mental Disorders, which also included other screening tools for anxiety and eating disorders. The pharmaceutical company Pfizer developed the PRIME-MD screening set in the 1990s. The development and release of the PHQ-9 tool as a public document, was described in a press release by Pfizer; "By providing unrestricted access, Pfizer is encouraging broader usage of these important patient assessment aids, which we know will help many healthcare providers and their patients" (Pfizer, 2010).

At the time, the 9 questions on the PHQ-9 were based on the diagnostic criteria of the DSM-IV. While the changes from the DSM-IV to V did not affect the nature of the PHQ-9, the DSM-V did make distinctions within the depression diagnosis for bereavement and manic episodes. Therefore, the newer version of the PHQ-9 includes in its terms of service:

> *"Diagnoses of Major Depressive Disorder or Other Depressive Disorder also require impairment of social, occupational, or other important areas of functioning... and ruling out normal bereavement, a history of a Manic Episode (Bipolar Disorder), and a physical disorder, medication, or other drug as the biological cause of the depressive symptoms" (*Terms of Use*).*

These changes correlated to the changes in the DSM, therefore maintaining the criteria for depression on the PHQ-9 to reflect those in the DSM.

The development of SSRI antidepressant medications by Pfizer was quickly followed by the grant that allowed for the development of the PHQ-9. Historically, the development and clinical use of SSRIs occurred mainly between the 1970s and 1990s, with more and more primary care providers prescribing these antidepressants as a first-line treatment.

Pfizer developed Zoloft in 1991 and afterward began the major study of the PHQ-9 in the mid 90s, leading to its publication in 2001 (Kroenke et al., 2001). It is also interesting to note that from 2013, Zoloft is the second most prescribed antidepressant in the United States, and antidepressants are more commonly prescribed as a first line treatment by providers (Grohol, 2016). The correlation between the development of Zoloft and the PHQ-9 can be captured by the "pharmaceutical public relations strategy which has been around since the 1950s, but which really picked up steam in the 1990s, is to sell a treatment by selling a disease" (Elliott, 2010, p. 96). In this case the reasoning of Pfizer behind the grant to develop the PHQ-9 could have been to bring awareness and expand the number of patients diagnosed with depression in order to sell their product.

The PHQ-9 is one of the most commonly used screening tools for depression in the United States and abroad, having been translated in over 20 languages. It is the most commonly used depression screener by Department of Defense, Veteran's Administration, Kaiser Permanente, UK NHS, and many primary care settings in US (Kroenke et al., 2010). The appeal of this simple nine-question tool can therefore be seen in many systems where efficiency is emphasized and time is a scarce commodity.

Advantages of the PHQ-9 in Primary Care

The PHQ-9 was developed for use in primary care settings but it has also been used in psychiatric and other specialist clinics. The major study conducted by Kroenke and Spitzer in the mid 90s consisted of almost 6,000 patients who were administered the PHQ-9. The study found that on average, it took physicians under 3 minutes to evaluate the results of the PHQ-9 (Kroenke et al., 2001). In the study, mental health professionals conducted psychiatric evaluations on patients and found that the PHQ-9 provided reliable and valid assessments of the patient’s mental health status.

In the United States, primary care physicians are often rushed and are allowed only a few minutes visit with a patient. By providing a quick tool for diagnosis, the physicians is able to screen everyone in an efficient way, not just people that the doctor thinks are depressed, therefore also diagnosing people that would otherwise be missed. While a psychiatrist may have up to 90 minutes to spend with their patient, primary care providers are allowed roughly 15 minutes per patient, with this time continuing to shrink as demand for healthcare increases (Kroenke et al., 2010). Furthermore, this ability to screen for depressed patients on an effective and efficient level allows for more data to be collected on prevalence of depression both nationally and on a global level. With research being done on prevalence, broader global conversations about treatment and management of mental health disorders are expanded and improved.

Problems with Simplicity of the PHQ-9

A major critique of the PHQ-9 is its simplicity. It is designed as easy to administer and easy to score, requiring no psychiatric training to do so. On the Terms of Use for the PHQ-9 on the Pfizer website, it states;

> *“Since the questionnaires rely on patient self-report, all responses should be verified by the clinician and a definitive diagnosis made on clinical grounds, taking into account how well the patient understood the questionnaire, as well as other relevant information from the patient” (*Terms of Use*).*

Regardless of this statement, the administration of the PHQ-9 is sometimes not followed-up by a visit to a psychiatrist or therapist, and risk exists that the clinician will prescribe anti-depressants to the patient before taking time to learn more about their situation.

Before the PHQ-9 was developed, the "gold standard" for psychiatric evaluations was the SCID, or Structured Clinical Interview from the DSM. The ability to conduct this interview was restricted in that it required psychiatric training to administer. A 2014 study comparing the results of the SCID as opposed to the PHQ-9 in a population of American women in a rural area, who were at a high risk for psychiatric disorders, states: "The PHQ-9 failed to detect a substantial portion of individuals with depressive disorders. The PHQ was severely limited in detecting cases other than MDD [Major Depressive Disorder]" (Eack et al., 2014). What is unique about comparing the PHQ-9 to SCID is that both techniques are based on the same body of information, the DSM, with the same diagnostic criteria. Therefore, the reductionist effect of the PHQ-9, in its easy-to-administer, nine-question simplicity, had an effect on the ability to make correct diagnoses, even when the body of reference was the same. The PHQ-9 did not have the ability to identify the nuances of many mental health diagnoses in this setting. Furthermore, while psychiatrists or psychologists generally conduct SCIDs, PHQ-9s are primarily used in primary care settings where time is an increasingly rare commodity and efficiency is prioritized, making this 9-question rating extremely popular (Eack et al., 2014).

A consideration not made in the PHQ-9 is that of normal sadness or "feeling blue." While some patients may speak to their primary care physician about an event that has passed that is causing them grief, others do not. Therefore, for some patients the PHQ-9 may show results that are interpreting grief and upsetting life events as Major Depression.

A suggestion for this may be to include a tenth question, which would ask about life changes that could include a death in the family, divorce, job loss or other illnesses. In this way, physicians interpreting the PHQ-9 would be able to differentiate between depression and grief, stress, or normal sadness.

Another commonly used assessment for depression is HADS, or Hospital Anxiety and Depression Scale. HADS screens for both anxiety and depression, and it is not based on DSM criteria. In a 2009 study comparing the effects of the two scales, "The agreement between the scales at the best suitable cut-off is moderate, although the identified prevalence was similar. This indicates that the scales do not fully identify the same cases" (Hansson et al., 2009). Therefore, while these scales identify cases with the same prevalence, some individuals are identified as depressed with one scale but not with another one.

Finally, the structure of the PHQ-9 in itself is also problematic. The questionnaire lists 9 clusters of symptoms, ranging from feeling tired to suicidal ideation, and asks how many times the individual has experienced these thoughts in the last two weeks. The "score" is calculated by adding together points, with a range of 0 to 15. Any score above a 4 is listed as a type of depression. This 9-question survey is trying to capture something very complex--a mental health diagnosis; yet the way the test is structured, every symptom gets exactly the same weight, which seems counterintuitive. Perhaps a clinician who is trained in psychiatry, rather than primary care, would be better equipped to understand the nuances of this diagnosis and to address the weight of these different symptomologies, possibly rating suicidal ideation as a more compelling measure of depression than insomnia.

The PHQ-9 and Diverse Populations

A limitation of the initial study conducted with the PHQ-9 was the original homogeneous research population of mainly white female subjects (Kroenke et al., 2001). Furthermore, the PHQ-9 was based on the DSM criteria, which were developed in the United States. It is interesting to note that the PHQ-9 is used in settings in which the DSM isn't used, such as the United Kingdom's National Health System. The manual on psychiatric illnesses in the UK and many other countries is the ICD, or the International Classification of Diseases. The range of contexts in which the PHQ-9 is used is larger than that of the DSM.

In a 2006 study, the PHQ-9 was tested within different ethnic groups in the US, in order to expand beyond the limitations of the initial study. There were four groups tested; non-Hispanic white, African American, Chinese American, and Latino. The study had promising results: "The PHQ-9 total score functions fundamentally the same in subjects from 4 of the largest racial/ethnic groups in the United States…mean PHQ-9 scores were similar amongst the different racial/ethnic groups" (Huang et al., 2006). This study demonstrated that all four ethnic groups in the US performed similarly on the PHQ-9. However, another study conducted in the US explained how studies like the one performed above may not be applicable to the entire US population, regardless of ethnic group in that:

> *"The PHQ-9 performs very well in two large studies conducted in university student populations, but poorly in several clinic populations with lower average education. We therefore recommend the PHQ-9 to screen for depressive disorders in high literacy population groups, but suggest that it may not be an appropriate tool for people with low literacy" (*Ali et al., 2016*).*

It is clear that assessing the PHQ-9 in diverse populations even within the US may be challenging.

On an international level, many studies have been conducted to assess the validity of the PHQ-9 in countries ranging from Uganda to Haiti. While many of these studies show high validity, there are also cases in which specific items in the cluster of symptoms are not captured well by local idioms of distress within the culture (Nakku et al., 2016). Kleinman explains this disconnect between local illness idioms and disease terminology available only to practitioners; "locally shared illness idioms create a common ground for patient and practitioner to understand each other in their initial encounter…. disease is what practitioners have been trained to see through the theoretical lenses of their particular form of practice" (Kleinman, 1988, p. 5). If the mechanisms for describing the illness to the patient are framed in Western disease terminology, this can lead to misunderstanding of the PHQ-9. This is problematic in that assessment tools were designed with Western populations in mind, leading to these instruments not adequately reflecting "the experience of depression at the worldwide or regional level" (Haroz et al., 2017).

The PHQ-9 and Self Diagnosis

An interesting development in the use of the PHQ-9 has been the rise of self-diagnosis. The nature of the PHQ-9 as a simple tool to administer has resulted in it being used as an online self-diagnostic tool. However, the Pfizer website states "You will only use the PHQ-9 in clinical settings (i.e., in a doctor's office or hospital as a clinical tool), for research purposes, for physician education programs, or in clinical trials" (Pearls Program, 2018). Regardless of this statement there have been various pushes for online self-diagnosis via the PHQ-9 questionnaire. The National Institute of Mental Health has partnered with Google to have the PHQ-9 result as the first link when one searches "Am I depressed?" (Duckworth et al., 2017). There are many other sites that offer similar formats and ask the same 9 questions. If one checks the marks for the highest depressed options, it states that one is severely depressed and that one should schedule an appointment with a doctor immediately. Many sites included options such as helplines or online forums (PsychCentral).

Online self-diagnosis of depression risks harming individuals who have transient psychological distress rather than a diagnosis. As clinicians are trained to look for these nuances, there is the risk of people over-diagnosing. However, self-diagnosis can also serve a positive function with individuals controlling and identifying issues with their own negative thoughts and behaviors, in the way Foucault describes noso politics (Foucault, 1984, p. 275). Through people "policing" their own behaviors to find irregularities, perhaps more individuals will seek treatment with their primary care provider.

A Pew research study found that 35% of American adults self-diagnosed themselves online with various tools. Of these people, 41% went to consult a physician who agreed with their diagnosis, 35% never sought a professional opinion, and 18% said they disagreed with the professional opinion they received (Fox & Duggan, 2013). Therefore, there are mixed results with online self-diagnosis, but many individuals do go seek clinician advice, which is a valuable outcome for patients in order for them to get help.

The answer to why people self-diagnose with depression is hard to answer. Unlike other conditions, there is no clear positive societal attitude towards the depression diagnosis, even with a large amount of people suffering from this condition. Dr. Jennifer

Sarrett of Emory University described this discrepancy: "although people often self-diagnose or identify as depressed or anxious, this type of self-diagnosis rarely results in aligning oneself with an active rights-based movement like neurodiversity" (Sarrett, 2016). The bio-certification of depression is not tied to a confirmation of social identity in the same way as other psychiatric diagnoses, such as ADHD or ASD. Rather, most benefits of self-diagnosis of depression are tied to opportunities for treatment and therapy, and perhaps the avoidance of going to seek out a diagnosis.

Conclusion

Allowing the PHQ-9 to be easily accessible is an example of ambivalent medicalization in practice. With regard to its utility as a tool, the widespread nature of it can ensure that symptoms and criteria for mental health outcomes are easy to access by the broader public, which can be beneficial and perhaps reduce stigma. However, as mental health diagnoses are made by licensed physicians, there is significance in the fact that medical school and psychiatric training require the development of skills that allow professionals to get into the nuances of these diagnoses.

While the PHQ-9 may have been developed as a result for a push to sell a novel medical treatment, it has had positive effects especially in primary care settings. Its efficiency and high validity within the United States has been noted in several studies. However, with regard to an international conversation on the prevalence of depression, there may be a need for the PHQ-9 to be culturally validated and changed to include local idioms of distress. While physicians can use the PHQ-9 as a first step in a diagnosis, perhaps more conversations with the patient are necessary before prescribing antidepressants or recommending other interventions in order to fully capture their experience of depression. In the following chapter, the training in cultural sensitivity received by physicians will be analyzed to determine how and if these nuances in the clinical interaction are being discussed when it comes to diagnosing patients with often-stigmatized mental health conditions.

Chapter 4:
Culturally Sensitive Medical Training

Background

In the study discussed in the following chapters, primary care providers were found to have a wide range of experiences in cultural sensitivity training received as medical providers. Cultural competence is a phrase commonly found in US medical school curriculums or mission statements, and is defined as a set of "corresponding behaviors, knowledge, or attitudes among professionals" that enables effective work in cross-cultural situations (AAMC, 2005). While the Association of American Medical Colleges (AAMC) released a statement in 2005 expressing the importance of culturally competent medical education, the results of this statement are still being established.

For example, Emory Medical School includes mentions of a discussion on cultural competency in its foundation courses (Emory University School of Medicine, 2018). However, according to one physician interviewed in the current study, the application of the core concept of cultural sensitivity is not explicitly taught as a part of clinical practice. An elective course offered on exploring cultural humility in resource limited settings at Emory Medical School had, in the past, only five students enrolled (Dr. 3, 2018, interview). This demonstrates that despite mentioning cultural awareness, there may be an opportunity for additional teaching about cultural sensitivity for medical students. And these students are not alone. A survey of 2047 residents across a number of schools showed that in a diverse sample of clinical specialties, "trainees believed that our educational system had prepared them poorly to deliver culturally competent care" (Hobgood et al., 2006, p. 1288). Beyond basic information conveyed during medical school, this study showed also “one third to one half of respondents reported receiving little or no instruction in specific areas of cross-cultural care” (Hobgood et al., 2006, p. 1288).

Cultural sensitivity is a term that has over time come to replace cultural competency, and is preferably used, as being “competent” in a culture is unattainable, and is no longer seen as a goal for a provider. The need for deeply understanding and practicing culturally sensitive medical care will only grow, as the last US census shows that cultural diversity continues to be on the rise, and all racial and ethnic minorities are growing faster than white populations from 2015 to 2016 (Chappell, 2017).

Cultural Sensitivity: “The extent to which ethnic/cultural characteristics, experiences, norms, values, behavioral patterns and beliefs of a target population’s relevant historical, environmental and social forces are incorporated in the design, delivery, and evaluation of targeted health…programs” (American Association of Diabetes Educators, 2002, p. 923).

While the AAMC strongly recommends that medical schools implement cultural sensitivity training into their curriculum, the mechanism of action to accomplish this task is not clearly defined. However, the AAMC does include an assessment tool through which a program can evaluate how medical students have learned this aspect of the curriculum, an instrument called Tools for Assessment of Cultural Competency Training (TACCT). The provision of this evaluation metric without means for medical schools to implement this training, suggests a problematic gap in the incorporation of culturally sensitive training in different medical schools. The AAMC provides “sample content” for each TACCT criteria, including suggestions such as “Play a game of Bafa Bafa [a game designed to learn about cultural sensitivity] to introduce a session discussing the history of racism” during the “Doctoring course” (Lie et al. 2006). Therefore, there is a need to go beyond recommendations and suggestions to improve culturally sensitive medical training and to a duty for medical schools to incorporate applied culturally sensitive medical education, as this type of training can have a large impact on patient centered care.

Outlining the issue

The effect of the cultural differences in medical care are especially pronounced in psychiatric care, where a diagnosis like depression may not be understood or accepted in the same way as a purely physical diagnosis such as breast cancer. While physicians are trained with Western biomedical texts such as the Diagnostic and Statistical Manual of Mental Disorders (DSM) to diagnose a disease like depression, they still receive patients from many different cultural and ethnic backgrounds. These patients may view health, specifically mental health, in a significantly different way than that of the physician they encounter. Physicians may express mental illness as stemming from disorders or chemical imbalances in the brain, but many cultures express mental illness in alternative ways that are equally nuanced. (Keys et al., 2012). Discrepancies like these can result in gaps in doctor-patient communication that are harmful to the patients coming from different cultures because of potentially different treatment outcomes. Anthropologist Arthur Kleinman's explanatory model of doctor-patient communication describes how these gaps are due to patient's explanatory models of disease being influenced by personality and cultural factors while doctor's explanatory models are focused on a Western, biomedical perspective (Kleinman, 1983). A hypothetical example of this could be a patient from a culturally diverse background who describes symptoms to her provider such as insomnia and fatigue. While the provider believes this to be depression and wants to prescribe his patient antidepressants, the patient believes that this is a condition that stems from her heart and therefore impacts her emotions, and does not wish to take this type of medication.

Anthropological studies of clinical practice may be helpful in introducing this change in medical curriculum, as they "show how culture shapes the biomedical view of clinical reality" (Kleinman et al., 1978). It is especially useful for medical students to understand local and cultural mental health terminology and the stigma surrounding psychiatric care for a patient coming from a very different background than their own. This can demonstrate to medical students that there are multiple ways to construe sickness and treatment. By training future health professionals about both mechanisms for disease and the cultural understanding of illness, their communication during clinical interactions with patients from different backgrounds may improve. This knowledge could result in advanced management of disease, patient compliance, patient satisfaction, and treatment outcomes (Kleinman et al., 1978). The general focus in medical education on biomedical science may tend to blind health professionals to these differing interpretations of illness on behalf of their patients. Incorporating anthropology and other social sciences into the curriculum could allow professionals to gain competence with important social but not biomedical aspects of clinical practice (Kleinman et al., 1978). While medical schools may offer electives and general discussions about cultural sensitivity, fully incorporating these lessons into clinical practice would be an important development.

Implementation into curriculum

The AAMC statement on cultural competency does not outline a process through which medical schools should incorporate these important discussions into their curriculum. Rather, the TACCT assessment provides a way of evaluating graduating medical students on their knowledge of cultural competency. For example, a skill listed on the TACCT that students should demonstrate is to "Recognize and describe institutional cultural issues" (AAMC, 2005). Evaluating students and describing problems, and suggesting activities about "hot topics" such as ethics is not equivalent to a profound shift in the curriculum, which may be more challenging to carry through and implement but may provide a greater benefit to medical education (AAMC, 2005). Therefore, a proposal outlined could be to develop medical anthropology and social sciences as a clinical discipline in all medical schools.

This would mean bringing on medical anthropologists as well as physicians with anthropology training as faculty in a social sciences department, and including courses on cultural awareness in the curriculum, not only as case examples (Kleinman et al., 1978). These faculty members would teach students with clinical case examples, such as the case with the patient described above, as well as with knowledge that applies directly to patient care, and would conduct their own research (Kleinman et al., 1978). This proposal would require support from the administration as well as curriculum time and financial backing to hire teaching faculty. Furthermore, for the program to be effective it "must be integrated with departments of internal medicine and surgery as well as psychiatry," as providers in these fields may encounter noticeable challenges with patients from different cultural backgrounds (Kleinman et al., 1978). These suggestions are included because simply educating medical students on the concept of cultural sensitivity is not the same as teaching it in the context of patient care. Academic isolation of cultural sensitivity to class lectures and discussions may not benefit the medical practice of future physicians as much as it would when learned within the context of patient interaction.

Duty and Impact on Care

There is significant stigma still attached to Western mental health diagnoses, some of which may be amplified when a patient comes from a different cultural background than the provider. The ethical implications of this may be large as “in response to societal stigma, people with mental problems internalize public attitudes and become so embarrassed or ashamed that they often conceal symptoms and fail to seek treatment” (US Office of Surgeon General, 2001).

Delaying or not diagnosing patients from different cultural backgrounds because of a lack of training on culturally sensitivity may have serious impacts on care. There are consequences to lack of culturally sensitive care, especially when it results in patients not receiving treatment as “extreme distress, disability, and possibly, suicide - when people with severe mental illness do not receive appropriate treatment” (US Office of Surgeon General, 2001). The importance of understanding the nuances of cross-cultural interactions such as patient beliefs or the influence of folk medicine needs to be taught to medical professionals who will have a large impact on the health of their patients, and who may currently be underprepared for these situations.

There are currently several different models that have been developed to facilitate a clinical encounter with a patient from a different culture. These models provide a set of questions with which the provider can ask the patient about their cultural heritage and preferences when it comes to treatment options. A table of these models is included in the AAMC report on cross-cultural care, and a few of those models are described below:

Table 1: BELIEF Model
Beliefs about health: What caused your illness/problem?
Explanation: Why did it happen at this time?
Learn: Let me understand your belief/opinion
Impact: How is this illness impacting your life?
Empathy: This must be difficult for you
Feelings: How are you feeling about it?

Source: Dobbie, A.E., Medrano, M., Tysinger, J., Olney, C. (2003). The BELIEF instrument: a preclinical teaching tool to elicit patients' health beliefs. Family Medicine, 35: 316-319.

Table 2: ETHNIC Model
Explanation: How do you explain your illness?
Treatment: What treatment have you tried?
Healers: Have you sought advice from folk healers?
Negotiate: mutually acceptable options
Intervention: agreed on
Collaboration: With patient, family, healers

Source: Levin, S.J., Like, R. C., Gottlieb, J.E. (2000). ETHNIC: A framework for culturally competent ethical practice. Patient Care 34 (9), 188-189.

Table 3: Kleinman's Questions
What do you think has caused your problem?
Why do you think it started when it did?

What do you think your sickness does to you?
How severe is your sickness? Will it have a short or long course?
What kind of treatment do you think you should receive?
What are the most important results you hope to receive from this treatment?
What are the chief problems your sickness has caused you?
What do you fear most about your sickness?

Source: Kleinman, A., Eisenberg, L., Good, B. (1978). Culture, Illness, and Care: Clinical lessons from anthropologic and cross-cultural research. Annals of Internal Medicine, 88:251-258.

These models have been incorporated in several curriculums in medical schools around the world. A study conducted in Taiwan found that students who wrote anthropological ethnographies centering on the Kleinman model questions had better appreciation of different patient explanatory models and considered themselves better trained in cultural sensitivity (Hsieh et al., 2016).

While these models are a useful way for medical students to learn about how the way they ask questions can impact care in cross cultural settings, the educational boundaries to culturally sensitive care still exist. As Anne Fadiman writes in her book “The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures”;

> *Western medicine is one-sided. Doctors endure medical school and residency to acquire knowledge that their patients do not have…it would be asking a lot of them to consider, much less adopt, the notion that their view of reality is only a view, not reality itself (*Fadiman, 1997, p. 292).

Traditional medical training did not emphasize the role of the patient as having an important viewpoint with regard to their care. This was a part of the paternalistic presence of physicians in the clinical interaction. As medicine and medical training has shifted towards patient-centered care, it is essential that future physicians learn about providing this care to patients that have different belief systems and come from different cultural backgrounds.

The motivation for providing culturally sensitive care is becoming ever more important both in the US and in other countries, as well as in other professions. With the influx of refugees and immigrants both in the US as well as in other nations in Europe, understanding the differences between Western biomedical care and care practices from other cultures grows more important as providers may have increased interactions with people form these different communities. Providing culturally sensitive care training for providers in all disciplines, especially primary care, in a system that is growing in diversity is a crucial step for healthcare institutions.

The critical importance of this training will be demonstrated in the conversations with primary care providers who participated in this pilot research study. While the providers all expressed a variety of experiences in learning culturally sensitive care, ranging from none to teaching a course on this concept, they all discussed different challenges they encountered when providing mental health care to patients from diverse cultural backgrounds. These challenges will be discussed in the following chapter.

Chapter 5:
Cultural Barriers to the Depression Diagnosis: Conversations with Primary Care Physicians.

Abstract:

The diagnosis of depression is based on Western medical definitions. It has changed over time within the medical culture, as can be seen in the changing categorizations in the various editions of the DSM. However, depression, like many mental health diagnoses, is often an illness that is not understood or accepted by all patients in the same way that a physical diagnosis may be. This project explored the experiences of Primary Care Providers caring for patients with the diagnosis of depression. Through structured interviews the challenges and reasoning in diagnosing depression in patients from different cultural backgrounds were discussed to determine how the culture of the patient affects the understanding and diagnosis of depression. Potential ethical issues that arose centered on the mental health diagnosis, the misdiagnosis of individuals related to their cultural background, problems with the Western-centric care that is being provided by US doctors, issues with cultural sensitivity training experienced by healthcare workers, and the problems associated with a shift in mental health definitions.

Introduction:

If the concept of depression is socially constructed, then it will vary across cultures as different cultures do or do not medicalize personal distress in the same way the Western medical profession does (Furler et al., 2010). There are studies that explain the existence of major cross-cultural barriers to mental health treatment in the United States (Leong & Kalibatseva, 2011). In a report by the Surgeon General in 2001 titled "Mental health: Culture, race, and ethnicity," the importance of considering cultural differences when addressing the disparity in mental health outcomes of ethnic and racial minorities was stressed (Leong & Kalibatseva, 2011). A meta-analysis performed by Schouten and Meeuwesen in 2005 studying cultural differences in medical communication concluded, “findings do suggest considerable differences and difficulties in communication between doctors and patients from different cultural and ethnic backgrounds.” These gaps in doctor-patient communication are harmful to the patients coming from ethnic or cultural minorities because of potentially different treatment outcomes. Anthropologist Arthur Kleinman’s explanatory model of doctor-patient communication describes how these gaps are due to patient’s explanatory models of disease being influenced by personality and cultural factors while doctor’s explanatory models are focused on a Western, biomedical perspective (Kleinman, 1983).

When the provider is faced with different views of what is considered sickness in a cross-cultural exchange, as “cultural boundaries are a major source of discrepant views of reality,” this may lead to what is known as “provider dominance” (Putsch & Joyce, 1990). In a situation of provider dominance, the physician may take on a paternalistic professional relationship with the patient, which “may introduce an extraordinary bias, which can lead to a unilateral and ethnocentric view of ‘what's wrong’” (Putsch & Joyce, 1990). There isn’t currently a large volume of literature on patient behaviors in different cross-cultural settings, but it suggests “patient[s]…use diverse language to describe their health and ascribe meaning to their experience of illness. This language is shaped by cultural beliefs about illness and healing, by philosophies of self-actualization, and…by biomedical understandings of disease and curing. For those health conditions that are stigmatized, such as mental illness, the language can be shaped by stigma, which has long been known to be pervasive and powerful" (Tai-Seale et al., 2016). While these factors may hinder the Primary Care Physician (PCP)-patient interaction, understanding and working with these cultural designs may help the treatment of mental illness. It has been proposed that several cultural strengths such as religion, alternative healing resources, extended kinship structure, and professionals' willingness to work with families may help to mediate mental illnesses (Lefley, 1990).

Depression is a disorder that has been historically diagnosed at different levels for different population groups. Studies found that "ethnic minorities traditionally receive less care for depression than do white populations" in the United States (Miranda & Cooper, 2004). This may be connected with the ethical issues linked to the depression diagnosis, in that "depression is a disorder in which autonomy is routinely and extensively undermined" therefore, "physicians have a moral obligation to promote the autonomy of depressed patients," which can be especially challenging in cross-cultural situations (Biegler, 2011). In this project I explored the experiences of PCPs to better understand their challenges and reasoning and to examine whether the standard of care changes for patients from different cultural backgrounds.

Methods**:**

The author conducted a qualitative, pilot study on the perceptions of primary care providers regarding patients with the diagnosis of depression that came from diverse cultural backgrounds. Methods included semi-structured interviews with primary care providers from three different clinics in an urban healthcare system. All study participants provided written consent, and Emory University's Institutional Review Board approved this study.

Figure 1*:* Illustration of the breakdown of physicians interviewed at 3 Primary Care Clinics

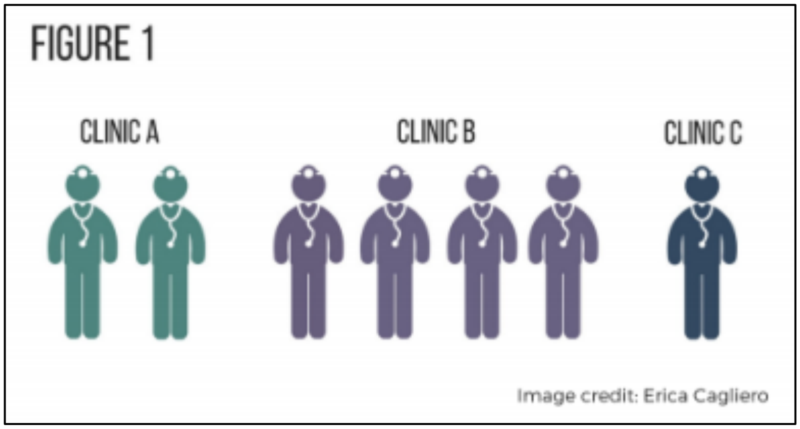


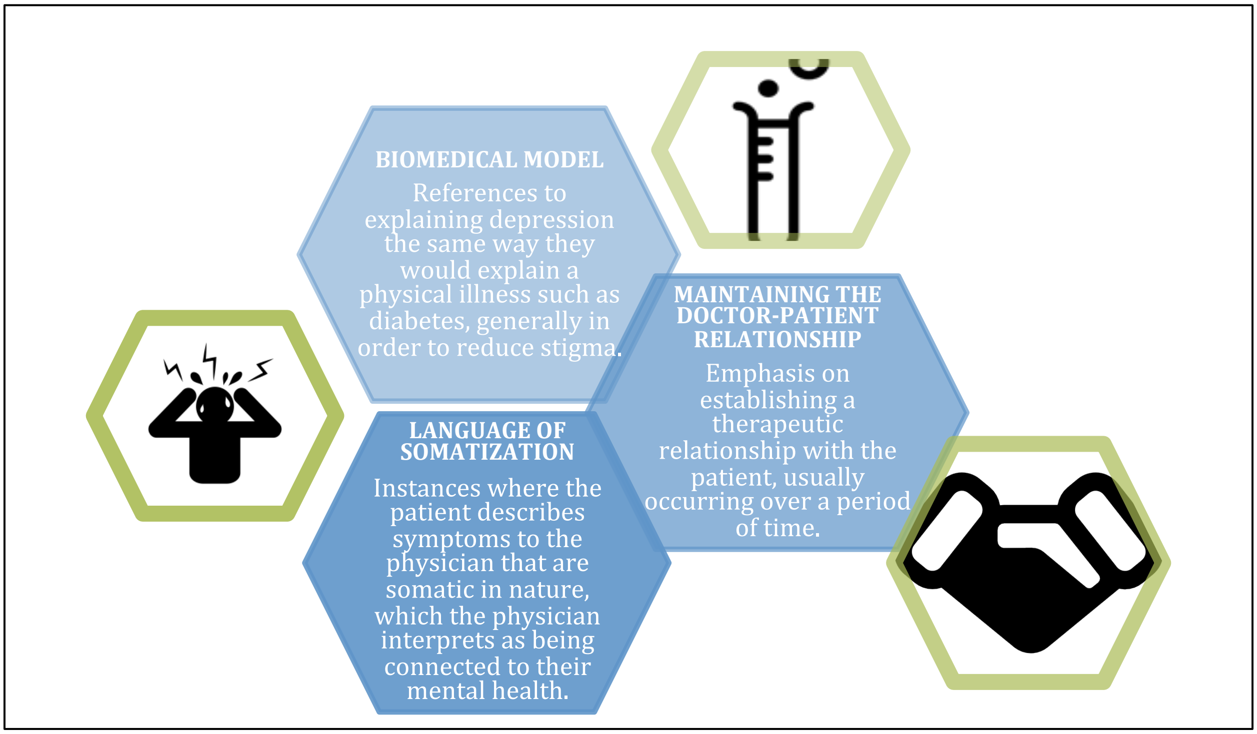
Image credit: Erica Cagliero

Qualitative Data Collection and Analysis

Seven semi-structured interviews were conducted with primary care providers from three different clinics. Physicians were recruited via email through provider lists and referrals from initial primary care contacts. Interviews ranged from 20 to 50 minutes and were audio recorded. The principal investigator conducted all interviews (Table 1). Interview questions were derived through examining literature on studies with similar research aims, such as Furler et al., with the hope of eliciting information from primary care providers that would invoke challenging experiences with patients and conversations centered on cultural sensitivity.

The principal investigator transcribed audio recordings of interviews. Through the content analysis process, themes were constructed using a combination of an inductive approach as well as an a priori approach (Ryan and Bernard 2003, p. 88). Codes were developed after the interviews were transcribed and include themes ranging from cultural sensitivity training to language translation and miscommunication issues. Codes were selected after suggested themes were brought up after the transcription of each interview separately. Once all interviews were transcribed, repeated themes with salient and relevant meanings determined that the item should then become a code. Thematic analysis and coding was facilitated using MAXQDA® software. Transcribed portions identified with each code were retrieved. Codes were retrieved for the eleven codes established for these results.

Figure 2: A sample of developed codes used for qualitative data analysis of In-Depth Interviews



BIOMEDICAL MODEL
References to explaining depression the same way they would explain a physical illness such as diabetes, generally in order to reduce stigma.

MAINTAINING THE DOCTOR-PATIENT RELATIONSHIP
Emphasis on establishing a therapeutic relationship with the patient, usually occurring over a period of time.

LANGUAGE OF SOMATIZATION
Instances where the patient describes symptoms to the physician that are somatic in nature, which the physician interprets as being connected to their mental health.

Table 4: Interview Questions
How do you screen patients for mental health disorders in your practice?
How do you approach a conversation about mental health issues with individual patients?
Did you receive any culturally sensitive training as a primary care provider? If so, what did it entail?
In your experience, how do patients typically respond to a label of depression or a mental health disorder?

Are there any culturally based discrepancies you are aware of in your clinical interactions? Are there times when your terminology is not understood, or you do not understand an idiom of distress in the community you are working with?
What actions do you take when a patient denies or does not understand their depression or mental health diagnosis?
How do you make a treatment plan or make an appropriate referral with a patient who does not accept their mental health diagnosis?
How do you follow-up with the patients in these situations?

Results:

As described, eleven codes were identified. A description of each code and examples from interview transcripts follow.

Code 1: Language Problems

Code Definition: "Any references to challenges that arose from the patient not speaking the same language as the provider as well as references to translations and translators were included in the code language problems."

This code was frequently discussed with regard to screening patients for depression when they arrive for a check-up. While most patients are given the PHQ2 as part of their intake questionnaire and review of systems, this was described as being available in only English and Spanish. Therefore, minority patients at the clinics who spoke other languages were generally not screened in the same way as English and Spanish-speaking patients were. However, providers also mentioned that even having the Spanish translation may not result in the same level of understanding as the PHQ2 questions in English:

> *"I think the problem is…[the PHQ2] works very nicely with English speaking patients, I don't know with my command of Spanish, is good enough to ask that in the right way. You know what I'm saying? And even though they have the PHQ2 questionnaires in different languages, I'm not quite sure, you know, stuff gets lost in translation." –Dr. 3*

Language and translation challenges affect all kinds of clinical conversations, both positively and negatively. Frequently when having conversations with patients who present somatic complaints, providers believe them to be related to depression or anxiety. This type of conversation was brought up frequently as being challenging in of itself, but one provider mentioned that adding language barriers to this complex clinical interaction is an entirely different challenge:

> *"Oh yeah, by tests I mean, this is a classic one "I've got this stomach issue" and I've worked up the stomach issues and I see that this is somatization, is what we say when a person is depressed or anxious and this is the way it's manifesting. And sometimes I can sit there and tell them that, "yes, you might have this and let's go ahead and do these testing because you think you have cancer but I know you don't" [laughs] "because you think you do," I try to plant the seed then and there, but I think a lot of this might be due to stress or that stress could be a contributing factor, and again how to translate this into different languages is completely different." –Dr. 3*

However, different languages were also brought up in a positive way with regard to clinical interactions. While medical terms used with English-speaking patients can sometimes be incomprehensible because of complex medical terminology, one provider mentioned that using more colloquial Spanish with her patients actually benefitted those clinical interactions:

> *"So I speak Spanish and I am completely bilingual. And I was trained in medicine in the United States. And so when I use medical terms, so I don't know the medical terms in Spanish. And I actually think that's advantageous. Because I have to speak at a much different level when I speak in Spanish. And I think that the patients actually prefer it."*

–Dr. 5

Language plays a part in patient relationships and also in patient selection of their primary care physicians, something discussed in the following code summary.

Code 2:Patients Matching Ethnicities to Providers

Code Definition: "Any reference to seeing patients of similar ethnic backgrounds or having the sense that patients prefer having providers from similar backgrounds more generally."

An extremely interesting result emerging from almost every single interview was that the physician identified that they had many patients that were of similar cultural backgrounds to themselves. This concept was sometimes outwardly expressed when describing patient demographic breakdown in their clinic; other times it was mentioned more subtly by describing that the majority of their patients came from a similar educational or socioeconomic background as the physician.

"I'm usually trying to gauge my conversation towards what I perceive to be their level of education, um, this practice, on campus, I see a lot of highly educated people," –Dr. 1

"I have issues with, just because of my practice, highly successful, highly driven, type-A people who don't accept weakness in others much less themselves. That's the most common. I also have a large percentage of patients who are perhaps the spouse of one of those successful executives, who is subjected to that." –Dr. 2

> *"I take care of lots of faculty members so in terms of culture, this is a boss, this is a giant, this is somebody with tremendous reputation who is at risk." –Dr. 2*

> *"So I will tell you that every provider's practice is different, so overall the racial breakdown of the clinic but every provider's breakdown is a little different so my practice is about 20% south Asian, you tend to attract patients like yourself, so it's about 20% south Asian and about 60-70% female, um and then the breakdown of race and ethnicity is about 20% south Asian, maybe another 30-40% is white, another 30-40% is black and other percent is Asian, other ethnicities. It's pretty diverse." –Dr. 6*

> *"I would say so yeah. I'm of Indian-origin so I may have more of an Indian or Asian population. Just because they are more attracted to similar ethnic physicians. So maybe a little bit more Asians or Indian Americans perhaps, but outside of that it's fairly typical I think." –Dr. 7*

Beyond these mentions of matching patient to provider, there were not many explanations or expressions of why this phenomenon exists, rather it was seen as something "fairly typical." A study conducted by Sweeney et al. in 2016 analyzing survey results found that while minority patients do tend to seek out providers of the same race or ethnicity, this does not result in higher patient-provider communication experiences than those with a provider from a different background, . However, there may be many positive aspects of having a patient-provider conversation in which both parties hold similar cultural understandings, as expressed by a physician above. This could decrease some of the challenges that providers experienced when discussing mental health conditions that are highly stigmatized in some cultures, whereas they may be more widely accepted in others. However, simply matching patients and providers from similar backgrounds will not be the one solution to cultural barriers to clinical conversations as there are many other variables at play, discussed below.

Code 3: Cultural Sensitivity Training

Code Definition: "Any reference to the type of training (or lack of training) they personally received or that is currently being taught with regard to cultural sensitivity."

There was an enormous variation of responses with relation to the form of cultural sensitivity training received by primary care physicians participating in the interviews. To some extent, this variation correlated with the age of the provider, as many of the older providers were trained when cultural sensitivity was not a part of the medical school or residency curriculum. However, there were some interesting results beyond just an age discrepancy. Some providers had no recollection of ever receiving training, while others had taught classes on cultural sensitivity to medical students in the past. An important shift in training that was brought up by one physician was the term "cultural sensitivity," which had been previously called "cultural competency." Furthermore, there were multiple mentions of informal ways of learning about different cultures in healthcare, such as mentions of the book "The Spirit Catches You and You Fall Down" by Anne Fadiman, which, written in 1997, was a story about the cultural clashes between a hospital in California and a Hmong family.

"I've read that book [The Spirit Catches You and You Fall Down]-I think I read it twice,

it's always stuck in my mind, to at least be aware of when I'm dealing with someone from a different culture, to have an idea that I may be need to think about if I run into some problem or have difficulty communicating that maybe I'm running into a cultural issue. If I do, then I figure out how to solve it." –Dr.1

"Interviewer: Ok, I was also wondering if you've received any culturally sensitive training as a primary care provider? And if yes what it entailed?
Participant: Not that I'm aware of.
Interviewer: Ok
Participant: If I did, I might've checked a box, I might've forgotten it, it might be one of our certifications when we do our education but if so, it obviously didn't resonate…. Yeah, all kinds of certification stuff we do, we just say "I read this" I can't tell you that I know what I read" –Dr. 2

"I have, and where did I get that kind of training? Part of that is the AFPA, the American Academy of Family Physicians has a great online module, I have certainly, because I have just gone to classes and workshops over the years enough to teach it [a course in cross cultural care], as a small introduction." –Dr.3

"The emphasis was on what you call 'cultural competence' I don't know if you've heard that but you become culturally aware, and there is a spectrum, and that was in the nineties, and I love the way it's kind of turned now, where, because now the teaching behind it is about cultural humility, where it isn't so much that you can become

competent about culture, you're never going to know everything about the patient in front of you and where they come from, even if you have pre-conceived ideas on their skin color, on the clothes they wear, on the languages they speak, their experience may be really different even compared to people in the same ethnic group….yes you should do all the reading you can about the cultural groups that you are seeing, in terms of if you see a lot of Bengali patients you should read up on it, and you kind of learn a little bit about the social working, their family structure, their health beliefs, and um, the idea of cultural humility that is used as a starting point, but you still need to get to know individual patients and in the end they can teach you as much as you can. It's a two-way street." –Dr. 3

"I've done, there was not a lot of cultural or diversity kind of training when I was going through my training which was probably before you were born [laughs]. But there was a literature that was beginning to emerge about it and there are certainly requirements as part of board certification that you at least do online training or something around diversity and cultural topics…. I've done some online things, mostly around sensitivity and being aware of different cultures and people from different countries and with different languages are not going to accept a lot of Freudian language" –Dr. 4

While cultural competency training is valued by medical schools, as discussed in Chapter Four, the implications of a physician not having this type of training is less clear. As the physicians in this study had a wide range of cultural competence training, one would expect there to be a large discrepancy in the way they discuss caring for patients from different cultures. However, all physicians interviewed were aware of the fact that they had to tailor their questions and interpretations for the patient in front of them, especially if that patient was from a culture different from their own. Therefore, while cultural sensitivity training is considered an important learning tool for medical students, it may not replace the years of experience and interactions with patients from different cultures.

> *"Not really, no. I mean other than my own reading, my own research and reading that I've done… I did a little more research and found the same was true for patients who had coronary artery disease in terms of the likelihood that they got recommendations for appropriate care were different based on ethnicity. I remember just being blown away, I just couldn't understand it." –Dr. 5*

> *"I think it's been at least mentioned in medical schools. But I'm not sure. Whenever we offer to do something around cultural competence the feedback we get from the students is 'we don't really hear this anywhere else'. Now, you take that with a grain of salt, I'm sure there's things the students think they've never heard and they really have. But there is certainly not an emphasis on it." –Dr. 5*

> *"There was an optional cultural sensitivity workshop for us I remember that we did as residents. It was optional but I think our program director made it mandatory. And then similarly in medical school there was there was this course, I think most medical schools have a version of this behavioral medicine class, and as part of that, fundamentals of doctoring, the behavioral medicine course was called I think, fundamentals of doctoring, and as a part of that there is some cultural sensitivity." –*

Dr. 6

“Certainly not medical school or in residency, we did get trained culturally as part of customer service-through [the university], [it] has some customer service skills sets, Training a few years ago…I would say that is actually 10 years ago. But in terms of training that is specifically geared towards mental health questions, mental health screening, no.

I: So what does that mean: customer service training?

P: So that was more for the entire staff, how to be nice to the patients that come in, how to wow them, how to make them feel comfortable. So it wasn't quite geared towards Mental Health, It was training in sensitivity towards different cultures. But that was a long time ago.” –Dr. 7

The conversations held with providers demonstrated an enormous range of experience with cultural sensitivity training, yet all of the providers interacted with patients from a range of ethnic and cultural backgrounds. It is assumed by patients that primary care providers in the United States with the same certification have similar levels of clinical knowledge when it comes to physiological conditions, which is not the case with cultural sensitivity training.

Code 4: References to specific patient ethnicities or groups

Code Definition: “Any time the provider mentions the ethnicity of a specific patient or patient group they interact with, in regard to differences among these groups.”

Every single provider, despite having very different levels of cultural sensitivity training, brought up a specific example patient ethnicity with regard to challenges with mental health diagnosis and treatment. The challenge with these retrieved sections is to interpret whether or not these statements are stereotypes, and if they are ethically permissible insofar they may improve patient care.

> *"The thing that I see the most often is anxiety, and, usually groups of middle aged women who come from places like Iran, Iraq, and South America, so. But it's not usually a challenge in diagnosing them, the challenge is managing them." –Dr. 1*

> *"Clearly there are times I have, but obviously, less socio-economically advanced African-American or perhaps Latino males who have a different work ethic and expectation of weakness, than someone who is a little more ingrained and can admit weakness and needs more than that." –Dr. 2*

> *"So the ones I've seen the most are Asian countries, among the Asian countries. And even among the Latino countries, they describe [depression] different. Health beliefs are different." –Dr. 3*

> *"The older Asians, I'm thinking of when I used to work at [hospital], like I said even though the patient population I'm seeing here, like I said they're young, I think they're less likely to come forward to admit that they have some anxiety or depression. I think that they're at least more, because they hear it and it's more accepted, than some of my older, elderly, Asians, it was not something that you could even talk about because*

it wasn't even allowed, and you know, 'I don't have that, I can't have that' you know, not a good thing, so you had to come up with terms, say things like 'stress' rather than 'depression', stress was a word I used a lot, 'life is stressful', that kind of thing." –Dr. 3

"Because for many folks from other countries, particularly from the Asian subcontinent, China, places like that, and I know this from colleagues who have had to deal with these issues with their own family members is that there is just not even a discussion of that in a lot of those cultures as part of what leads people to be sick." –Dr. 4

"The one I have the most experience with is particularly India, because I have a lot of Indian colleagues, they've been working at CDC and other places, and they'll confide in me. One person had a sister who had a major depression and there wasn't even a psychiatrist—she couldn't even find a psychiatrist. The whole idea of getting that kind of care wasn't even…and this is [medical specialty] and her sister is a [medical specialty]! Having the major depression. And you couldn't even in that country get, people just don't talk about things in those terms, even though the medical training is all based in the British system of medical training it wasn't even something people had easy access to." –Dr. 4

"in the Hispanic community [depression is] very stigmatized. And there are gender differences as well. In the south East Asian community, in the Indian community, same kind of situation." –Dr. 5

"I see a lot of south Asian women, for them in particular it's dizziness and lightheadedness. And I'm not trying to stereotype I think it's actually well documented in the literature like with Latino women it's abdominal pain, and I think the cultural background plays a big role in it. There's a lot of stigma in certain communities about mental health, some more than others, and I would say that the African-American community in particular is actually more receptive to mental health diagnoses, in my personal experience, than my south Asian community." –Dr. 6

"In all honesty I would say that African-American communities, south Asian communities, are much more receptive to taking a pill. Versus like I have an East Asian community that is probably more receptive to therapy, and my Caucasian community is probably more receptive to therapy." –Dr. 6

"Women are much more accepting than men, older people a lot less than the younger, there's certainly ethnic for sure absolutely, so as far as the cultural aspects are concerned I think Caucasians are more accepting of the diagnosis, African Americans perhaps a tad less so, and clearly in the Asian and the Hispanic community, well Hispanics I think are more easily accepting of the diagnosis, Asians are not. They are just not culturally open to talking about those kinds of things. They may not have seen those kinds of things in their family or growing up." –Dr. 7

As one physician stated, cultural background does play a large role in the way that patients express their symptoms to their physicians, and having knowledge of these different expressions of mental health is important for providers in order for them to diagnose and treat their patients in the best way possible. However, making generalizations about patient groups can risk treating a patient not as an individual, but as a stereotyped member of that group when providing care. If a provider believes that an East Asian patient is more receptive to therapy, perhaps this could risk in not having a conversation with this patient about other medication options. This may suggest a limit to "cultural sensitivity" that is not often discussed. While cultural understanding is extremely helpful, providers may need to be aware of the risk of applying generalized assumptions to a patient from a specific background instead of treating them as an individual.

Code 5: Stress

Code Definition: "Any reference to the term stress, usually with regard to using it instead of depression to avoid stigma for the patient."

Stress and depression may be linked to mental health outcomes. However, "stress" is not a diagnosis that providers can insert into a patient's chart. Stress is often considered an alternative way of speaking to patients about their mental health, as it avoids the stigma associated with the word "depression," and it is generally considered a concept with larger universal cultural translation and understanding.

> *"[Depression] was not something that you could even talk about because it wasn't even allowed, and you know, 'I don't have that, I can't have that' you know, not a good thing, so you had to come up with terms, say things like 'stress' rather than 'depression', stress was a word I used a lot, 'life is stressful', that kind of thing." –Dr. 3*

> *“Nobody likes to be labeled, but I think people, there is a lot more awareness about things like depression. I think we use the word ‘stress’ a lot, and talk about that. Because what that does is that it leads to a discussion about what people are reacting to and how are healthy ways to do that as opposed to unhealthy ways.” –Dr. 4*

> *“I have lots of patients who come in with symptoms and if I think they are mostly related to their stress levels, I ask patients all the time ‘how do you manage stress?’, ‘how are you managing stress?’, ‘what do you do for fun?’, ‘what are you doing for yourself?’ because I have patients who will say ‘I’ve got headaches and stomach pains and everything hurts and I don’t want to get out of bed and I’m not sleeping’.” –Dr. 5*

Providers reported talking about-stress to be a productive way of having conversations about mental health with their patients, especially those who may have found “depression” to be a term that was stigmatizing. To what extent is it ethical for providers to have conversations with their patients without fully discussing the medical diagnosis they believe this patient to be suffering from? As patients are autonomous agents, providers cannot hide medical information such as a diagnosis from their patient, even if they assume this would result in less stigma from the patient’s perspective. While stress may be a useful term in clinical conversations, providers need to ensure that if they are diagnosing the patient or providing treatment or a referral to psychiatric care, the patient may need to be informed of the medical condition of which they are suffering.

Code 6: The PHQ2 and PHQ9

Code Definition: “Any reference to the PHQ2 or PHQ9 exams, usually applied in the question about screening patients in the clinic.”

All but one of the physicians use the PHQ2 questionnaire in their clinic, self-administered by the patient on the intake form. This does not necessarily translate to universal screening of depression in the clinics, and some physicians mentioned that they generally recognized a diagnosis through their conversation, not through screening. Many patients never fill out the form, or simply reply “no” to every question. However, some providers expressed that screening did allow for a subset of patients who screen positive for the PHQ2 to be identified by the physician even when coming in presenting a different complaint. This was generally agreed to be a recent improvement in the screening system.

> *“I typically have not done those screening measures myself. I come into the diagnosis just through talking to the patient. Many patients of course show up with diagnosis already and I go through the validity of that diagnosis.” –Dr. 1*

> *“The answer is, we haven’t had anything too structured until extremely recently and then on the patient intake form, when patients come in they do a quick review of systems, including our interest and pleasure things, for two weeks, so there’s just two questions with a little screening, so at least we’re addressing it now. So the answer is, with the intake questionnaire, and during our history and review of systems.” –Dr. 2*

> *“I think that the bigger issue comes when they come in and we weren’t doing universal*

screening. And you would sort of uncover things that you would hear, certain things, that you would then ask, and you would go back if you had a hint that that might be an issue, then going back and asking those depression-anxiety kinds of questions." –Dr. 3

"We have them in the rooms with us, so they're on the intake form, there's a review of systems people get, in fact. And it's got 14 items on it, and one of those items is the PHQ2. So everybody gets handed that. Not everybody fills it out, [laughs] and sometimes people come in with very discrete problems, that are not related in any way, to anything depression related symptoms, and we just get them in and out, but most people will get at least the two question screening. And if they answer yes to either one of those, or if in my talking to them and they start, because a lot of people just answer no to everything, but if in my talking to them there is any suggestion that this could be complex then I'll hand them those screeners." –Dr. 4

"Um so I don't know that I comprehensively screen for mental health disorders. I do the PHQ2 which is like a 2 question depression screen, that's actually done on intake, before I actually see patients, on every visit, it's part of the review of systems is to do the two question PHQ2." –Dr. 6

"But every patient that walks in the door potentially is getting screened. They may choose to talk about it not talk about it but it depends on the urgency with other symptoms, other cough, cold. But in general the questions are there for them to be asked, obviously. Now some people come forward with those kinds of symptoms, like

> *anxiety or depression, but of course those put them as the number one symptom, or complaint is for depression. But even the others who come, they get some degree of screening questions." –Dr. 7*

Screening is a technique that has been employed fairly recently at these clinics, and the physicians interviewed presented a variety of perspectives and opinions on the screening system. While some did not adapt to the new system and continue to simply have conversations about mental health with their patients, others stated that the screening tended to save time for them by alerting them beforehand that the patient may have depressive symptoms. While screening has benefits such as saving physicians time during their clinical interaction with a patient, it may also not be universal or comprehensive, leading to different patients getting examined for mental health by their physicians at different rates. Unfortunately, this screening tends to favor patients coming from a background with less stigma attached to mental health, and may prevent cultural minorities from receiving the same level of mental health care.

Code 7: Therapy and Medication

Code Definition: "Any reference to prescribing the patient medication or offering counseling, any challenges that arise with the patient over treatment options." Physicians had a large range of opinions about therapies and medications that are available to their patients. Some physicians expressed that there are-limitations for each option such as cost, time, and stigma. While this is often expressed more in patients from different cultural backgrounds, there are also not many culturally sensitive treatment options beyond just therapy or medications available to the primary care physician.

> *"The data is very clear that for many things like anxiety and even pretty severe major depression, that counseling methods are just as good. You get outcomes that are just as good and there's data with functional MRIs and other imaging studies to show that it is actually changing the brain chemistry, there is a biological explanation for why that happened." –Dr. 4*

> *"Some people temperamentally come in and don't want to take pills for anything. Other people are very much bought into the medical model totally and men in particular, 'I think it'll be a waste of my time to sit around and talk to somebody' even though, I'll open it up for them, I'll have the discussion. … But people who are in the mild to moderate range, given the options there are some people with very clear preferences. –Dr. 4*

> *"The medical community and patient's expectations of the medical community are still really medical. Patients come in and they don't expect me to be giving them a counseling session. They expect me to be giving them a prescription, a test, a referral. Whenever any of us deviate outside of that, sometimes patients are very grateful that we attempt to treat them in a more holistic way. But sometimes patients are not. Because they don't want to go there." –Dr. 5*

> *"You have to let the patient guide you with regard to where they want to go, and where they are. Some patients are very open to pills and it just depends too on what*

the pill is for. So I'll give you an example. If I had a pill for everyone who was obese, I would be a multi-gazillionaire. So people are very open to pills for obesity, but they are not open to pills for depression. They're very concerned about addiction, about 'it's going to make me crazy', about 'what are people going to say?'. I have lots of patients who we agree to start medication as part of their treatment plan and they come back and say 'I talked to my family about it and my family said don't take it and I didn't'." – Dr. 5

"I think it's got barriers, but the barriers are not the same. I think the barriers for counseling are time, or efficacy. I think people have a hard time wrapping their brain around 'why is it going to help me to go talk to someone who doesn't know me from Adam's housecat?' or 'why is it going to help me to go to talk to someone who doesn't say anything back?'. So it's barriers but it's not the same. The concerns for medication and counseling are really different…. definitely the resistance is worse when you have someone from a different cultural background." –Dr. 5

"I will say that in general with the south Asian women, it is really really hard to convince them that it's depression. It's really really hard to convince them about thinking to go to therapy. And one of the issues is that I don't have a lot of culturally sensitive mental health options to give them. I don't know of any south Asian therapists who do CBT, and so that's one limiting factor." –Dr.6

"In all honesty I would say that African-American communities, south Asian

> *communities, are much more receptive to taking a pill. Versus like I have an East Asian community that is probably more receptive to therapy, and my Caucasian community is probably more receptive to therapy. More than ethnic background I think that the limiting factor for a lot of the communities I see is cost. A lot just can't afford therapy; it's easier and cheaper [to take a pill]. You know it's easier and cheaper to see me. It's easier to prescribe a pill than to get therapy which you know can be incredibly beneficial. I don't know. I am sure that there are some differences by ethnicity, but I feel like it comes down to will insurance pay for it or not? That often limits people." – Dr. 6*

Stigma was frequently mentioned as a limiting factor to patients when seeking medication and therapy. While some providers clearly have preferences for one or the other, many seek to find out what the patient prefers as an option, and they see these preferences as falling along cultural lines. While one provider mentioned that there was a lack of cross-cultural psychiatric care available for her patients, another provider expressed that even with a holistic care system, some patients simply want a test or a prescription from their doctor, and nothing more.

Code 8: Maintaining Patient Relationships

Code Definition: "Any reference to the importance of maintaining a relationship with a patient. Also said as "leaving the door open," usually referred to when discussing taking time for the patient to come to terms with their diagnosis. Emphasis on establishing a therapeutic relationship with the patient, usually occurring over a period of time."

A theme that stood out in the discussions with primary care physicians was their stress on the continuity of their care, and how they try to develop trust with their patients. Situations where a patient denies or doesn't accept a diagnosis are challenges to that relationship, so providers expressed to me that during those times their priority is always to maintain the therapeutic relationship rather than risk losing the patient.

> *"So it's these patients that are totally resistant to the notion, so one way to manage that is to ask if they would be willing to go see a psychiatrist, or maybe call us back in six months or eight months and if there's any progress we will reconsider, but usually we never hear from those people again." –Dr. 1*

> *"This is where everything I do has to be customized. Every single question, every single response, the spin, getting the acceptance, the when do I put labels on, when do I suggest medication, how do I follow up with that, all of that has to be really nuanced. To be successful you have to engage the trust, get agreement, get willingness to try something, you got to take somebody, if it's depression, who innately is hopeless, and give them enough hope to trust you, that whatever intervention I'm going to do, might take thirty days to even work. To get them through that barrier. I know, by the way, maybe having all the side effects up front, and the benefit comes thirty days later with the medications. So the answer is all very nuanced and that's what we do. Especially in mental health." –Dr. 2*

This is an example of how many providers expressed a large part of their role as a primary care physician. Customizing care for patients, something that is learned after years of patient interactions is a key component of trust between the provider and patient. This is also especially important in situations when a physician interacts with patients from culturally diverse backgrounds in order to prevent stereotyping.

> *"And then I also think it's important to be flexible, if a patient refuses that diagnosis to be flexible in some way, but knowing that I'm going to keep going back to it and keep building, in hopes that they would be more open to hearing it." –Dr. 3*

> *"There's this whole issue about meeting people where they're at, motivational interviewing, and approaching people saying 'yeah I understand, we will do what we can using the services we have available, this is in my professional opinion what you need to be doing' and if they try to explore certain alternative therapies or alternative medicine, complementary medicine is another term that's used, some of those things have an evidence base for being helpful, some of those things are actively harmful, and so I meet the people where they're at. I explore with them what we have to offer" –Dr. 4*

> *"But if you leave an encounter with someone and they've sort of rejected what you want, all you can do is say 'we're here to help you if you change your mind and want to come back that's fine'. The only sort of place where we can take away their autonomy is if they are an imminent threat to themselves or someone else." –Dr. 4*

> *"Yeah honestly I think that most patients, in primary care they're my patients, I think most identify their visits with me as a safe place, so it's pretty rare that I get push back*

> *on not talking about it. For the most part I think people are pretty receptive, you know, they're glad you asked. As to a range of responses I think for the most part it's pretty well received, I don't see there is push back unless, you know, they are forced there by a family member, they didn't want to come in and tell me what was going on, that's a different story, and so, yeah for the most part I think it's pretty well-received." –Dr. 6*

> *"Give them some comfort level, they should feel comfortable talking about this, And I've been in practice a long time so most of my patients are known to me, Occasionally I happen to see new patients but I mainly know most of them: Their age, what their concern to talk about me, so I would know those things. In primary care and you learn how to approach those questions" –Dr. 7*

Trust was central to these physicians when discussing patient relationships, and maintaining that trust was often the most important part of their clinical interactions. However, there may be occasions where other aspects of patient care may have greater value than trust, depending on the situation.

Code 9: Patient Stories

Code Definition: "Any reference to a story regarding a specific patient encounter or their experience treating a specific patient."

Several providers recounted narratives of patient encounters they had that had left a meaningful impression on them. Below is one that resonates very well with some of the aspects of providing culturally sensitive care.

> *"So just as an anecdote I had a patient six or seven months ago, she's a woman, I don't even know what country she's from. She tells me what language she speaks I don't even know. I give the translation service her on the phone so she can tell them what language it was. I don't even recognize it. It's some subcontinent of an Asian country. And she was coming in and she was complaining that she was itching all over and she couldn't sleep and she was having belly pain and I was trying to interview her to get real specific about her symptoms and she was obviously very anxious. And the translator was getting frustrated because she was being so nonspecific about what she was complaining with. I was thinking to myself 'this is going to be a real challenge' because there will be a cultural barrier to come through this, and this is probably some sort of major….I don't know what's going on but the first thing you do is you order a whole bunch of lab tests, all this metabolic stuff and it turned out her calcium was very high. And it turned out she had a hormone-secreting tumor that was causing her calcium to get high. And that was the source of all her symptoms. I mean it was sort of a classic complaint for an underlying medical issue. So that's the other part of it, even with these cultural barriers and challenges and seeing 80, 90% of the time it pan out to be something like post-traumatic stress or an underlying anxiety disorder sometimes even active psychosis which can happen in those folks, you still need to be aware that some of these will have underlying medical issues…It's a real challenge but you can't always assume that the challenges with that person…you put it in the basket of being strictly a mental health problem." –Dr. 4*

While this patient presented with symptoms that the provider frequently associated with mental illnesses such as post-traumatic stress disorder or anxiety, during testing it was revealed that the source of her complaints was due to a physiological issue. Furthermore, the provider expressed some of the challenges he ran across when interacting with a patient who speaks a different language as well as a patient who comes from a refugee community in which there are many individuals with undiagnosed mental illnesses.

Conclusion:

The physician-patient relationship can be challenged when conversations around mental health are fraught with cultural barriers and stigma. Associating specific patient ethnicities with diagnostic groups or openness to types of treatment, using stress instead of depression in conversations with patients, varying levels of cultural sensitivity training, and the use of the PHQ2 are a few of the themes that arose in conversations that are tied to ethical considerations and individual differences. The ethical challenges focus on mental health stigma and how the patient-physician relationship affects this stigma. This can be the case when there are language barriers between the patient and their provider that may hinder their interaction, or the barriers may diminish the gap of understanding complex terminology that exists between the two parties. Patients whose ethnicities match those of their providers can allow for increased cultural understanding, but the importance of cultural sensitivity training still remains when most providers encounter patients from a diverse set of cultures. Screening tools such as the PHQ2 that are designed to facilitate clinical interactions may not benefit minority populations as much as English-speaking patients who hold less stigma attached to mental illness. Stereotypes about patient ethnicities may lead to better care for some, they risk harming patients when a stereotype results in a physician assuming different preferences towards treatment or medication, and may result in different options presented to patients. Overall, primary care providers centered their discussion on maintaining patient relationships, a value with high clinical importance, but may also clash with other ethical values presented in the next chapter. Two of the retrieved codes, the biomedical model and language of somatization, will be further analyzed with regard to their ethical implications in the following chapter.

Chapter 6:
Two Code Themes with Ethical Implications

Two final themes that emerged from the research, the Biomedical Model and Somatization of Symptoms have meaningful ethical implications for primary care providers. While other themes held ethical implications as well, these two codes were tied to deeper discussions of bioethical issues such as the concept of justice in healthcare and the barriers to doctor-patient communication. While almost all providers discussed these two themes, they offer insights into challenges that the language of patient communication as well as the organization of our medical system can have on patients from different cultural backgrounds who are affected by depression.

Use of the Biomedical Model

This code applies to references of describing depression to patients in a biomedical sense. For example, references to explaining depression in the same way they would explain a physical illness such as diabetes, generally in order to reduce stigma.

> *"[I] talk about the elephant in the room, there is a stigma to this, a bio-medical model is that I try to normalize it some. I say 'just like a person has diabetes, and they have a problem with insulin in their body', I wouldn't say 'go, get better.' I would give them insulin to treat them. For depression, for example, there are different levels of neurotransmitters in your brain, and what we do with behavioral therapy or medicine is to get those levels back up to what they should be. It just normalizes it, a little bit because I think a lot of them feel that stigma. I think that's a lot harder to do when you're working across different cultures. Some cultures just don't have that idea. A-*

sometimes there are language barriers, even with a translator there it is hard to get that concept across, especially if it's not their concept of health…If it's a balance thing, if it's the evil eye, I feel like I struggle some times." –Dr. 3

"I explain to them what the pathophysiology of the condition is. I tell them what the disease means. So I give them an example, Like high blood pressure, diabetes or low thyroid, which people can relate to, they have family members, colleagues who are taking insulin injections. If someone has low insulin and they have diabetes then they need to take an insulin injection. So like that the hormones in their brain which we didn't recognize until the late 1990s, so we now know more, CT scans, MRI you can actually see with a pet scan what the different parts of the brains are, what they mean, what they actually function, we didn't know 25 years ago and what hormones they secrete. Just like people have low insulin and they have diabetes, people have low serotonin or dopamine or epinephrine and they have depression. So I also given the physical symptoms as well like feeling tired, fatigue, loss of motivation, so not just feeling down emotionally like crying spells but also physical symptoms." –Dr. 7

"But making analogies to other disease states makes them feel comfortable. I also tell them it's a disease it's not a quote, 'mental thing' unquote., especially with older men, men from certain ethnicities, it's a question of being quote 'mentally strong' unquote, it's a question of mental weakness so I tell them it's a disease just like diabetes...I don't use the word neurochemicals or brain chemicals it's too much to throw that word, I use the word hormones because they can all understand that. Just like women have

> *estrogen people have hormones in their brain and levels go down, there is a stress in life and it's temporary very often, and just like you take an antibiotic to get rid of bacteria, or you take insulin and your diabetes gets better, you taking medication and the medication all it does is take the hormone and push it back up to normal levels." – Dr. 7*

Many providers discussed explaining depression to patients from different cultural backgrounds in a biomedical sense, or through what some called "a mind-body connection." For example, providers described the disease pathways of depression in a similar way to how they describe diseases like diabetes or high blood pressure in order to reduce stigma. This was a way to normalize depression as a diagnosis. While this technique may be useful for many patients from Western backgrounds, this mind-body dualism and connectedness might not be a familiar method for discussing mental health in many other cultures. For example, in Haitian culture, sadness may be described as *Kè fè mal*, stemming from the heart and not the mind (Keys et al., 2012).

What comes about in these conversations between patient and provider can also be interpreted as biological reductionism: when human behaviors are reduced to a biological cause (Brigandt & Love, 2017). This can be the case with many types of mental health diagnoses, as significant research is being conducted to understand the mechanisms behind these abnormal patterns of functioning. Is explaining to patients that their mental illness is simply equivalent to lower rates of neurotransmitters firing or a shift in chemicals in your brain or a different area that lights up on an fMRI scan helpful? In reality, there are many caveats to being able to make an "objective "psychiatric diagnosis such as viewing a brain scan (Makin, 2013). Attempting to bridge the gap between "mind-derived illnesses" and "true physiological illnesses" through mechanistic explanations may create validity for these mental illnesses in a problematic way.

It is not because these illnesses now metaphorically resemble physiological ones that the stigma around them should be reduced, but rather because people suffering from mental illnesses should not be shunned and shamed but taken seriously in their suffering. Furthermore, there are logistical challenges to these metaphors and analogies. Antidepressants, to a greater extent than many of the medications used in the above examples like antibiotics or insulin, aren't a guarantee to "feel better." There can be multiple behavioral reasons behind why a person is feeling depressed, many of which cannot be resolved simply by taking a pill. Finally, speaking about depression as a disease that has a physiological explanation may risk isolating individuals suffering from other mental illnesses, of which we have even less understanding of the mechanisms at play (Malla & Garcia, 2015). These patients, those suffering from psychosomatic or other illnesses with no physiological understanding are those who risk being left behind and further burdened with stigma.

While the intent of the physicians interviewed with regard to the use of a biomedical model for explaining depression was to reduce stigma and make the patient more comfortable, there may be better ways to have this conversation. Acknowledging the patient's suffering and presenting a more holistic model of mind-body connectivity may be a few ways to do so, outlined below:

> *"I try to say 'we are not just physical beings, we are physical, emotional, and spiritual beings and if any of those parts of you is not well it can affect the other part.'" –Dr. 5*

> *"The technique I often use is mind-body connection. And so I talk to my patients a lot about how the way that you're thinking up here affects how your body feels, and I try and help them get them to the place where that light bulb goes off for them, 'yeah, actually, I have been feeling down, and I have been feeling like I don't want to be doing anything, and it does make me incessantly snack or it does make me not want to get out of bed', things like that." –Dr. 6*

Or, as one physician pointed out, one can always mention:

> *"I always kind of point out there is a connection between the mind and the body, it's called the neck [laughs] and the brain is as much a part of our being as anything." –Dr. 4*

Somatization of Symptoms & Justice

Another theme that held ethical significance, especially with how it relates to the principal of justice, is that of somatization of symptoms. This code applies to instances where the patient is described as presenting symptoms to the physician that are somatic in nature, which the physician interprets as truly being connected to their mental health.

> *"[The patient is] seriously convinced they got Lyme, I'm doing the Lyme tests and in the meantime they're staying engaged and then they'll come back. Lyme's negative, thyroid's negative, you don't have chronic fatigue syndrome, you don't have whatever. 'You know what, I think if we're lucky there is a component of depression' and I'll say 'I don't think this is all of your issue, I don't know, but I do know that this part can be treated, and so if thirty percent of your problem is fixable, then let's focus on that.'" –*

Dr. 2

"This is a classic one: 'I've got this stomach issue' and I've worked up the stomach issues and I see that this is somatization, is what we say when a person is depressed or anxious and this is the way it's manifesting. And sometimes I can sit there and tell them that, 'yes, you might have this and let's go ahead and do these testing because you think you have cancer but I know you don't' [laughs] 'because you think you do.'" –Dr. 3

"The scenario that I gave you before was someone who was somaticizing, I will usually say 'let's come back when the tests are back that you were curious about, so maybe two weeks when the test results are in' and if all of them are normal, and I'd say 95% of the time it is, but not always, I mean sometimes there's something in there, but if it is normal then I feel like I have the leverage to be broach again that 'maybe this isn't what you were thinking and have you thought more about the idea of how stress may be playing into this?'" –Dr. 3

"I try to never give up on patients, I try to never to say 'you can't come back and see me', I think sometimes they've given up on me. They think that there's a physical problem here and I just can't find it, then usually they drop out and I don't know how the process turns out for them." –Dr. 3

"So that's the other part of it, even with these cultural barriers and challenges and seeing 80, 90% of the time it pans out to be something like post-traumatic stress or an underlying anxiety disorder sometimes even active psychosis which can happen in those folks, you still need to be aware that some of these will have underlying medical." –Dr. 4

"My patients would prefer to be labeled with ADHD or ADD than depression, anxiety, generalized anxiety, bipolar disorder. I have many conversations with patients who basically want me to prove to them that there is nothing else wrong with them and that their symptoms are really attributable to their mental health disorder. So there is still a very, very big stigma." –Dr. 5

"So I often have patients coming in and saying they've been down for the last few weeks, they'll come in complaining of body pain, fatigue, they're tired all the time, or just they're not motivated, or they're gaining a lot of weight, and they'll have a lot of these somatic complaints, and once you've ruled out all the organic causes of their ailment, we eliminate via process of elimination, it's likely it might be depression. And I think in those scenarios they're not really keen on the label, nor keen on thinking about the treatment option. Because for those patients who have more somatic manifestations of their depression, they truly do not believe that it's a mental health issue." –Dr. 6

"So for [these patients] it is really challenging, and they do end up getting these crazy

> *work ups of lots of testing that they don't need because they are just not as receptive to the diagnosis. I can't think of any terms that patients have used, other than again, a lot of times it's these somatic complaints, that don't have any organic cause." –Dr. 6*

Physicians indicated that a patient from a different cultural background might present only somatic symptoms to their providers. The somatization of mental health is well documented in patients from cultures that stigmatize mental illness (Kleinman, 2007). In order to maintain the trust in the doctor-patient relationship, providers indicated that they might order tests believed unnecessary for somaticizing patients. This also raises justice questions at resource-limited hospitals. However, there are cases in which a patient's symptoms are not a result of somatization but are truly physical. How are providers to account for these rare, yet serious, conditions?

The medical need for these tests is a contributing factor to this question. Beauchamp and Childress write, "need and prospect of success are value-laden concepts, and uncertainty often exists about likely outcomes and about the factors that contribute to success" (Beauchamp and Childress, 2013, p. 289). Medical need is to an extent subjective, but it is in large part decided by the physician in question. Physicians have been trained and encountered enough patients to make the determination of the medical needs of their patients, even though those require taking up resources. Therefore, in situations where the physician believes there is no true medical need, such as some outlined above, is it just for them to order unnecessary tests for the sake of maintaining the relationship with the patient? The results of these tests are unlikely to harm the patient, and the physician may catch a rare condition that they were unaware of. Testing also may be more objective than the clinical judgment of the physician. It is possible that a patient is not somaticizing, but rather has a rare parathyroid tumor such as the one described in the last chapter. Other factors physicians may need to account for are risks-what is the risk that if you simply wait and do not order these tests, something worse will happen, not to mention the legal risk of malpractice? All these considerations may lead the physician to not take the chance and to order the tests, against their personal opinion.

On the other hand, is it unethical for physicians to not use their clinical judgment when interacting with somaticizing patients and to discuss any cost considerations? When the clinician truly believes that there will be no medical value in testing the patient for Lyme disease, cancer, and thyroid problems, can they be acting ethically by providing unnecessary care? While physicians may focus on their role as patient advocates, they "tend to ignore their role as trustees for the overall pool of resources" (Lee, 2000). The allocation of medical resources, a portion of providing just healthcare, is making decisions about improving quality of care and efficiency of the system (Lee, 2000). Physicians have obligations to both their patients but also to the greater healthcare system, and their clinical judgments may need to reflect a just allocation of scarce resources.

Primary care physicians may feel a heavy weight with regard to the consumerism of medicine. Ads on television constantly remind watchers to "ask their doctor" if they have this condition or if the drug is right for them. If a somaticizing patient demands tests for a condition the clinician truly believes they do not have, is it the right of the patient to receive any test they might demand, against medical opinion? It is challenging decide for all cases which of the two values is right, and, like many ethical challenges in medicine, may best be decided on a case-by-case basis. It is still important for a physician to be aware that ordering multiple, rare tests is not an ethically neutral act. If a primary care physician feels strongly that their clinical judgment should come before the consumerism of the current medical model, perhaps finding ways to have conversations with their patients about mental health and about futile treatment in tactful yet resonating ways is an important next step.

Understanding the potential consequences and meanings of providing unnecessary tests to patients who are suspected to have a mental health, not a simply physiological illness, is an important role for a primary care provider.

Conclusion

Understanding and applying a culturally nuanced healthcare practice can allow for greater access to care, as well as a better patient experience and more effective healthcare delivery (Hoop et al., 2008, p. 353). Culturally sensitivity care can be a expression of the bioethical principles: respect for persons, beneficence, nonmaleficence, and justice. Ethical principles are a part of cultural norms, and the ways in which clinicians reason through challenging situations such as the ones reported and discussed in this paper may demonstrate the physician's own cultural background and bias. Beyond cultural heritage, "health professionals are also immersed in the 'health care culture,' the traditions and attitudes that pervade contemporary mental health practice. This culture also plays an important role in shaping a clinician's ethical values, and it is to some degree foreign to many patients" (Hoop et al., 2008, p. 354). Culturally sensitive care allows for physicians to become aware of their own biases and ways of thinking, and can provide an improved patient interaction.

The need for greater cultural understanding, especially with regard to mental health care, is growing. By the year 2050, it is predicted, "the majority of U.S. citizens will be of Hispanic, African, Asian, or Arabic descent, not white European" (Hoop et al., 2008, p. 354). Therefore, the development of cross-cultural care and the teaching of future physicians about culturally sensitive care can no longer be limited to "foreign" illnesses such as *Susto* and neurasthenia, but rather must expand to a more holistic approach centered on meaningful conversations with culturally diverse patients. Providers may need to remember that "diagnosing a patient with a mental disorder can be a powerful act of beneficence or maleficence, and one that carries social repercussions," due to the stigma and power held by many of these diagnoses (Hoop et al., 2008, p. 361). The drive towards diagnosis and labeling may be a part of the physician's conscious drive to do something for the patient, but it is also a part of the expectations for a physician in our current medical system (Furler et al., 2010).

While "negotiating the phenomenon" of a mental disorder rather than giving a diagnosis may be a way that physicians can "work with multiple, contested views of emotional distress," it is not likely a solution that could function with the United States health insurance model when a time constrained physician is also planning on providing medications or a referral to psychiatric care (Furler et al., 2010). However, while movements such as the anti-psychiatry movement believe it to be unethical for mental illnesses to have any sort of label, "on the grounds that doing so falsely relieves the individual and/or society from responsibility for the condition," modern psychiatry views "medical diagnoses as accurately reflecting the biological as well as social and psychological influences on mental disorders" (Hoop et al., 2008, p. 361). Creating a more holistic paradigm, including social influences on health, for having conversations with patients about their diagnosis would be a key feature of increased culturally sensitive care.

This research, based on the structured interviews of seven primary care physicians shows that there are a number of cultural barriers that exist between patients and their providers, many of which are not overtly presented as ethical problems. These issues, such as a differences in cultural sensitivity training, the risk of stereotyping treatment preferences of a specific patient ethnicity, or maintaining the relationship with the patient above other considerations such as resource allocation, are examples of challenges that clinicians in primary care settings may encounter on a daily basis. Creating awareness of these issues and starting a discussion around how learning about them may improve the care of a patient from a cultural minority is an important goal for this research project. Further recommendations for providers would include research surrounding better ways to understand the implications of over-testing somaticizing patients in resource-limited settings and examining more productive ways to have conversations with mental illnesses that expand beyond the simple reductionism that "mental illnesses function in the same way as physiological illnesses."

Primary care providers may need to learn and understand the ethical implications of not providing culturally sensitive care. With an ever-diversifying patient population, one can imagine the possibility that "Western 'psychologization' of mental illness—may one day become less prevalent than so-called somatization" (Hoop et al., 2008, p. 355). Learning about different ways patients interpret mental health diagnoses allows providers to become more aware of the assumptions they make in their own belief system, and for them to realize that these are not simply facts, but that they are varying, culturally-determined interpretations of emotional distress. Perceiving "working across cultural differences, working with biomedical and social models of depression…not as a barrier to providing high-quality depression care, but rather as a central element of that care," will be a key step in for primary care providers in addressing the ethical implications of the cultural barriers to the depression diagnosis (Furler et al., 2010).

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Appendix

Common Acronyms:

AAMC: Association of American Medical Colleges

APA: American Psychological Association

BDI: Beck Depression Inventory

CFI: Cultural Formulation Interview

DSM: Diagnostic and Statistical Manual of Mental Disorders

GAD-7: Generalized Anxiety Disorder 7-item Scale

HADS: Hospital Anxiety and Depression Scale

IRB: Institutional Review Board

NIH: National Institute of Health

PCPs: Primary Care Providers

PHQ-2 and PHQ-9: Patient Health Questionnaire 2/9

SCID: Structured Clinical Interview for DSM

SSRIs: Selective Serotonin Reuptake Inhibitors

TACCT: Tool for Assessing Cultural Competence Training

Glossary:

Culture: A "'highly variable systems of meanings, which are learned and shared by a people or an identified segment of a population'" (Kalibatseva and Leong, 2014).

Cultural Sensitivity: "The extent to which ethnic/cultural characteristics, experiences, norms, values, behavioral patters and beliefs of a target population's relevant historical, environmental and social forces are incorporated in the design, delivery, and evaluation of targeted health…programs" (American Association of Diabetes Educators, 2002, p. 923).

Ethnopsychology: "is the study of how individuals within a cultural group conceptualize the self, emotions, human nature, motivation, personality, and the interpretation of experience" (Keys et al., 2012).

Ethnophysiology: "explicates how a cultural group conceptualizes the body and its processes, how those processes might be harmed, and which therapies are most salient" (Keys et al., 2012).

Consent Form

Emory University
Consent to be a Research Subject

Title: Cultural Barriers to the Depression Diagnosis by Primary Care Physicians: Ethical Issues

Principal Investigator: Diana Cagliero

Funding Source: N/A

Introduction

You are being asked to be in a research study. This form is designed to tell you everything you need to think about before you decide to consent (agree) to be in the study or not to be in the study. **It is entirely your choice. If you decide to take part, you can change your mind later on and withdraw from the research study.**

Before making your decision:

- Please carefully read this form or have it read to you
- Please ask questions about anything that is not clear

You can take a copy of this consent form, to keep. Feel free to take your time thinking about whether you would like to participate. By signing this form you will not give up any legal rights.

Study Overview

The purpose of this study is to explore the experiences of Emory Healthcare Primary Care Providers through approximately 15 structured interviews to better understand their challenges and reasoning to determine whether, and if so, how the culture of the patient affects the understanding and diagnosis of depression.

Procedures: If you agree, you will participate in a one-time interview lasting no more than 30 minutes. The interviewer will ask open-ended questions about your challenges with diagnosing patients with depressive symptoms and how the patient's culture might impact understanding and diagnosis. The conversation will be audio recorded to so we are clear about what you said.

Risks and Discomforts: These interviews will bring up topics that may be uncomfortable for some participants. You do not have to discuss anything or answer any question that makes you uncomfortable. If you do not wish to continue participating you can stop at any time.

Benefits

This study is not designed to benefit you directly. This study is designed to learn more about issues that you may see with cross cultural mental health treatment. The study results may be used to help others in the future.

Compensation

You will not be offered payment for being in this study.

Confidentiality

Certain offices and people other than the researchers may look at study records. Government agencies and Emory employees overseeing proper study conduct may look at your study records. These offices include [the Office for Human Research Protections, the Emory Institutional Review Board, the Emory Office of Research Compliance]. Emory will keep any research records we create private to the extent we are required to do so by law. A study number rather than your name will be used on study records wherever possible. Your name and other facts that might point to you will not appear when we present this study or publish its results.

Study records can be opened by court order. They may also be produced in response to a subpoena or a request for production of documents.

Voluntary Participation and Withdrawal from the Study

You have the right to stop the interview or leave the study at any time without penalty. You may refuse to answer any questions that you do not wish to answer. Information you discuss prior to your leaving will be included in the research, unless you ask us not to use your comments.

Contact Information

Contact Diana Cagliero at 339-223-7671:

- if you have any questions about this study or your part in it,
- if you have questions, concerns or complaints about the research

Contact the Emory Institutional Review Board at 404-712-0720 or 877-503-9797 or irb@emory.edu:

- if you have questions about your rights as a research participant.
- if you have questions, concerns or complaints about the research.
- You may also let the IRB know about your experience as a research participant through our Research Participant Survey at http://www.surveymonkey.com/s/6ZDMW75.

Consent

Please, print your name and sign below if you agree to be in this study. By signing this consent form, you will not give up any of your legal rights. We will give you a copy of the signed consent, to keep.

____
Name of Subject

____ ________________
Signature of Subject Date Time

____ ________________
Signature of Person Conducting Informed Consent Discussion Date Time

Recruitment Email

(*Date*)

Dear (*Physician's name*),

I am conducting a study on the perspective of primary care providers with regard to diagnosing depression in patients from different cultural backgrounds.

This project will explore the experiences of Emory Healthcare Primary Care Providers in working with patients with the diagnosis of depression. Through a short interview I seek to understand the challenges and reasoning in diagnosing depression and to determine whether, and if so, how the culture of the patient affects the understanding and diagnosis of depression.

I am writing to ask if you would be willing to participate in my project, which would consist of a short interview no longer than 30 minutes. This study is part of a master's in bioethics thesis exploring the important ethical issues that can arise as a result of challenges in doctor-patient communication.

Please let me know if you would be interested in participating and I can set up a time around your busy schedule to conduct an interview.

Thank you for your interest and support,

Diana Cagliero
Candidate for MA in Bioethics, Emory University 2018
dcaglie@emory.edu
339-223-7671

Code List

1. The biomedical model/"the mind-body connection"

Definition: This code applies to references of describing depression to patients in a biomedical sense. For example, references to explaining depression in the same way they would explain a physical illness such as diabetes, generally in order to reduce stigma.
Example: "a bio-medical model is that I try to normalize it some, I say "just like a person has diabetes, and they have a problem with insulin in their body," I wouldn't say "go, get better," I would give them insulin to treat them. For depression, for example, there are different levels of neurotransmitters in your brain, and what we do with behavioral therapy or medicine is to get those levels back up to what they should be" (Dr. 3)

2. Language of Somatization

Definition: This code applies to instances where the patient is described as presenting symptoms to the physician that are somatic in nature, which the physician interprets as truly being connected to their mental health.
Example: "this is a classic one "I've got this stomach issue" and I've worked up the stomach issues and I see that this is somatization, is what we say when a person is depressed or anxious and this is the way it's manifesting" (Dr. 3)

3. Language Problems

Definition: Any reference to challenges that arise from the patient not speaking the same language, any references to translations or translators are included.
Example: "And even though they have the PHQ2 questionnaires in different languages, I'm not quite sure, you know, stuff gets lost in translation" (Dr. 3).

4. References to specific patient ethnicities/groups

Definition: Any time the provider mentions the ethnicity of a specific patient or patient group they interact with.
Example: "I think that they're at least more, because they hear it and it's more accepted, than some of my older, elderly, Asians, it was not something that you could even talk about because it wasn't even allowed, and you know, 'I don't have that, I can't have that'" (Dr. 3).

5. Stress

Definition: Any references to the term stress, usually in regard to using it instead of depression for the patient to feel less stigma.
Example: "so you had to come up with terms, say things like 'stress' rather than 'depression', stress was a word I used a lot, 'life is stressful', that kind of thing" (Dr. 3).

6. The PHQ2 and the PHQ9

Definition: Any reference to the PHQ2 or PHQ9 exams, usually applied in the question about screening patients in their clinic.
Example: "The standard is to use what they call the PHQ2, I guess you're talking about depression specifically what you use is called the PHQ2. So it's a two question

questionnaire asking have you been feeling down in the last two months, and the second question is…and if any of those are positive, you use another standard version of it, the PHQ9" (Dr. 3)

7. Therapy and Medications

Definition: Any reference to prescribing the patient medication or offering counseling, any challenges that arise with the patient over using these treatment options. Generally encountered after the question about treatment plans.

Example: "I don't. I'm not going to sit there and prescribe something and tell somebody it's something that it's not. Like 'this is a feel-happy pill', or I would recommend that they go to counseling or I could strongly recommend that they go but if the patient doesn't want to go, I cant force them to go" (Dr. 3).

8. Maintaining Patient Relationships

Definition: Any reference to the importance of maintaining a relationship with a patient. Also said as "leaving the door open," usually referred to when discussing taking time for the patient to come to terms with their diagnosis. Emphasis on establishing a therapeutic relationship with the patient, usually occurring over a period of time.

Example: "And it's not easily broached the first time you see someone, I feel like you need to establish a therapeutic relationship with that patient, they need to be willing to hear that" (Dr. 3).

9. Patient Stories

Definition: Any reference to a story regarding a specific patient encounter or their experience treating a specific patient. These are often very long.

Example: "earlier this week, quite by coincidence I had a woman on the schedule for a physical and then later in the day a man for a follow up and they were husband and wife. And it only took a few minutes, seconds, for me to ask some open ended questions and suddenly she was welling up with tears, and the tissue box was next to her. And we had a very long conversation about her marriage, her relationship, blah blah. And unfortunately she happens to be a good family friend, our kids grew up together so it was hard for her because she shared, and we also go to the same church and her catholic faith it was very hard for her because of the sort of obedience, and blah blah blah, so in her sense it was how she perceived her duty to be married versus the strain and stress of that. And when I saw him later, his insight was actually much better than I expected but very rigid in terms of and the discrepancy between them was he spends time reading right wing conservative stuff on the internet all night long and she's an open minded schoolteacher with young children. I'm sorry not young children now, older adult children who see things in a different, more open way, and so culturally he's fixated on his very rigid traditional right wing obedience, she's more open minded and that's causing a great deal of conflict between them mostly because of the church. And sense of duty versus happiness versus whatever. And so that's one example that's very recent" (Dr. 2).

10. Patients matching ethnicities to providers

Definition: Any reference to seeing patients of similar ethnic backgrounds or having the sense their patients prefer having providers from similar ethnic backgrounds more generally.
Example: “so my practice is about 20% south Asian, you tend to attract patients like yourself, so it’s about 20% south Asian and about 60-70% female” (Dr. 6).

11. Cultural sensitivity training
Definition: Any reference to the type of training (or lack of training) they personally received or that is currently being taught with regard to cultural sensitivity. Generally found after the question about cultural sensitivity training.
Example:
“I: If I did, I might’ve checked a box, I might’ve forgotten it, it might be one of our certifications when we do our education but if so, it obviously didn’t resonate. So I would say no but if I’m getting Emory in trouble, it may be on our standard…
I: CITI?
P: Yeah, all kinds of certification stuff we do, we just say ‘I read this’, I can’t tell you that I know what I read” (Dr. 2).