

# Primary Care Professional's Perspectives on Treatment Decision Making for Depression with African Americans and Latinos in Primary Care Practice

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**Abstract** Increasing interest has been shown in shared decision making (SDM) to improve mental health care communication between underserved immigrant minorities and their providers. Nonetheless, very little is known about this process. The following is a qualitative study of fifteen primary care providers at two Federally Qualified Health Centers in New York and their experience during depression treatment decision making. Respondents described a process characterized in between shared and paternalistic models of treatment decision making. Barriers to SDM included discordant models of illness, stigma, varying role expectations and decision readiness. Respondents reported

strategies used to overcome barriers including understanding illness perceptions and the role of the community in the treatment process, dispelling stigma using cultural terms, orienting patients to treatment and remaining available regarding the treatment decision. Findings from this study have implications for planning SDM interventions to guide primary care providers through treatment engagement for depression.

**Keywords** Depression · Primary care · Shared decision making

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## Introduction

Depression is highly prevalent among primary care patients, with impact comparable to the burden of major medical illness, and is associated with high morbidity and mortality, diminished quality of life, and elevated healthcare costs [1–4]. Various effective treatments exist for depression but are not frequently accessed or are discontinued especially among diverse racial and ethnic populations [5–7]. Several quality improvement programs have been developed to improve delivery of depression care in primary care [8–10]. While successful for non-Hispanic white patients, these programs have not been able to minimize depression care disparities among immigrant and minority patients [11, 12]. A report by the Institute of Medicine, *Unequal Treatment*, identified uncertainty in communication and decision making between patient and healthcare professional as a potential source of these disparities [12]. Recent research has found that minority and low-income populations are more likely than non-Hispanic whites to feel disenfranchised in the treatment decision-making process, receive less health related information, and perceive a lack of

respect for their preferences [13]. If primary care providers engaged their patients more systematically in decision-making about their care, this may allow patients to express their preferences more freely and to choose more acceptable treatments, thereby increasing the likelihood of entry into mental health care, treatment adherence, and possibly better health outcomes. As a result, the development of interventions to improve communication about treatment choices specifically targeted to these groups is necessary [14, 15].

Shared decision making (SDM) is a strategy to improve communication and is built upon the notion that there are two experts in the consultation room: the patient and the healthcare professional. Patients have the expertise derived from the lived experience of their disorder. Healthcare professionals have expertise in their knowledge and clinical training of medical diagnosis and treatment [16, 17]. SDM interventions can facilitate a dialogue between the patients, their family members and healthcare professionals about their concerns and preferences for treatment [18]. Relative to other medical illnesses that have equivalent rates of morbidity and mortality, there is a dearth of literature on patient and healthcare professional perspectives' on depression treatment decision making. Although involvement of patients in the decision making process has been cited as a key indicator of the quality of mental health care [19, 20], we know very little about what is discussed during mental health treatment decision making, how treatment decisions are made and who participates in this process between ethnic and racially diverse patients and health care professionals.

Understanding the treatment decision-making process may provide useful information for developing interventions that can foster patient involvement in decision making for depression treatment in primary care, where minorities are most often treated [21–23]. Primary care providers perspectives on depression treatment in the context of primary care have been extensively studied [24–27]. These studies have focused primary care professionals' perspectives on the recognition of depression [24], screening tools for depression [25], referral to specialty care [26] and implementation of a collaborative care model for depression treatment [27]. Hardly any attention has been paid to professionals perspectives on the depression treatment decision making process with ethnic minority immigrant patients [28]. With the goal of designing a SDM intervention for primary healthcare professionals, this article reports the results of a descriptive qualitative study of 15 primary care healthcare professionals who provide collaborative depression care for depressed ethnic minority and immigrant patients in two Federally Qualified Health Centers (FQHCs) in New York. The aims of this exploratory study were: (1) to elicit primary care professionals' perspectives of treatment decision making with depressed minorities in primary care; (2) to identify content addressed

during each stage of decision making process and characterize the model providers follow; and (3) to understand barriers faced in depression management and strategies used to engage patients in decision making and care.

## Methods

### Setting

Primary care healthcare professionals (nurse practitioners, psychiatrists, primary care physicians, social workers and practice administrators) were recruited from two FQHCs in neighborhoods that have been designated as medically underserved areas of the Bronx, serving African Americans, Afro-Caribbeans, a growing number of new immigrants from Africa, US born Latinos and immigrants from Caribbean, Central and South America. Forty percent of the residents in this area earn less than \$15,000 annually and 43 % receive some form of public assistance (M. Golub, personal communication, May 11, 2011). In the area of depression and primary care, these centers implement the Improving Mood Promoting Access to Collaborative Treatment (IMPACT) evidence-based collaborative depression care management program for primary care. In this collaborative care model, the primary care physician identifies depression using a standard depression screening measure (e.g., Patient Health Questionnaire-9 for depression) and works with a care manager (nurse, social worker or psychologist) and a psychiatrist (for those who do not respond to treatment) to develop a treatment plan using a stepped care model for depression treatment [29].

### Sample Recruitment

Recruitment was conducted via a random sampling of primary care health care professionals employed at the FQHCs. Supervisors of the clinic staff provided the research team with a list of all clinic healthcare professionals to approach for participation. From this list, a random sample of sixteen primary care professionals were approached using a ward off letter and research project fact sheet to reach our recruitment goal of two types of professionals from each category (i.e. practice administrator, nurse, primary care physician, psychiatrist, and social worker). We sampled all health care professionals in each category, including practice administrators, as they all play a role in the depression care management (IMPACT) of primary care patients.

The ward-off letter, a letter informing participants of the study, specific aims, and procedures with information on how to decline contact by our research team regarding participation in the interview, decline participation, and

research project fact sheet were sent to 16 primary care professionals at their work address. Professionals who did not refuse participation within 21 days were approached by the research staff for participation. This study was approved by the FQHC and academic-research partner Institutional Review Boards. Informed consent was obtained from all providers.

### Conceptual Framework

The Charles treatment decision making framework adapted for primary care practice [30] (See Table 1) was used to guide interview development, characterize the model of treatment decision making during each stage in the process and present the key themes raised in each stage. This framework outlines each stage of treatment decision making (e.g., information exchange, deliberation and choosing a treatment), provides a dynamic view of treatment decision-making by recognizing that the approach adopted at the outset of a medical encounter may change as the interaction evolves; identifies decision-making approaches which lie between the three predominant models three predominant models of decision making (e.g., paternalistic, shared and informed decision making) and has practical applications for clinical practice and medical education [30].

### Interview

An interview guide (see Appendix) was developed with senior qualitative experts (PJG, KH) and was informed by the conceptual framework described above. The interview guide was comprised of two sections to address our study aims. The first section of the interview solicited case material from primary care healthcare professionals about: (1) a newly diagnosed patient with whom they recently discussed treatment for major depressive disorder (termed depression here forward) and (2) a depressed patient with whom they experienced difficulty during treatment decision making for depression. For each case, questions were posed about each analytical stage

treatment decision making (i.e. information exchange, deliberation and choosing a treatment). The second section presented case vignettes and follow up questions of two anonymous depressed patients who had participated in focus groups for a larger study on treatment decision making for depression in primary care. Case vignettes were staged to describe successive encountered barriers to depression treatment engagement (i.e. stigma, patient-physician trust, access to care, preferences for informal sources of treatment) [31–36] and to probe for decision making strategies.

### Analyses

All interviews were conducted by the first author (SRP) and audiotaped using a digital recorder and labeled with provider type and date. Interviews were transcribed verbatim by a research assistant and analyzed using grounded thematic analysis [37], a procedure developed from grounded theory methodology [38]. Through a series of open and axial coding, and constant comparison processes, the coders identified provider perspectives on treatment decision making. Each coder (SRP and RS) independently coded 15 transcripts, meeting at 3 points during the process to establish consensus and discuss the implications of their coding.

### Results

Of the professionals who were contacted, one primary care physician refused participation citing lack of interest. The sample was predominantly comprised of middle-aged ( $M = 39$  years) female (13/15) primary care healthcare professionals (5 nurse practitioners, 5 physicians, 1 psychiatrist, 2 social workers and 2 practice administrators) in their healthcare role for an average of 11 years. Nine out of 15 providers were African American, mostly non-Hispanic (12/15) and 3 were bilingual Spanish speaking.

Four key themes were coded using the three analytical stages of decision making as the organizing framework.

**Table 1** Models of treatment decision making and their analytical stages<sup>a</sup>

Analytical stages	Paternalistic	Shared	Informed
Information exchange			
Flow	One way (largely)	Two way	One way (largely)
Direction	Provider → Patient	Provider ↔ Patient	Provider → Patient
Type	Medical	Medical and personal	Medical
Amount	Minimum legally required	All relevant for decision making	All relevant for decision making
Deliberation	Provider alone or with other providers	Provider and patient (plus potential others)	Patient (plus potential others)
Deciding on treatment to implement	Provider	Provider and patient	Patient

<sup>a</sup> From Charles et al. 2006

These themes were identified solely from the data and were not predetermined. Following the framework, results based on clinical case material solicited from respondents comprised content discussed during decision making and were organized by each analytical stage of decision making and characterized by the predominant model of treatment decision making. Within each stage, we also include themes on barriers and strategies to decision making based on case vignettes presented to respondents. Quotations were selected for their representation of content discussed, barriers encountered, and strategies used to overcome them within each stage of decision making.

## Information Exchange

### *Discordant Models of Illness*

Respondents from all professional groups observed that their depressed patients attributed their symptoms to life circumstances. One participant explained,

“They don’t consider this to be a process or an ailment that is treatable or can be treated or from which they can recover.” (Primary care physician).

Respondents said the task of eliciting the patient’s understanding of his/her depression, and “speaking in common-ground terms” (Primary care physician) (i.e. when patient and provider understand each other’s perspectives), often took two to three follow-up visits. Follow-up visits involved strategies including understanding the patients’ social community and their views on depression. One respondent commented, “If they know someone who has the diagnoses, I tell them its okay to talk to them and then I discuss all different options.” (Primary care physician). Depending on the patient’s understanding of his/her depression and whether he/she was willing to accept a biomedical or psychosocial explanation of illness, providers stated that they discussed symptoms or life circumstances as a segue into a conversation about depression.

### *Stigma Surrounding Depression Diagnosis and Treatment*

All respondents, including practice administrators, described patients’ stigma associated with mental health and the view that a person is “crazy” if they need help with emotional problems. As a result, most respondents (13/15) focused consultation time on educating patients about depression and addressing concerns about diagnosis and treatment. Respondents told us that some strategies used to facilitate education involved inviting racial or language-matched nursing staff from the surrounding community to interpret or dispel concerns about depression or non-racial language-matched staff learning culturally appropriate

terms for distress within a community. Many (11/15) spoke of this strategy as an acknowledgement of their cultural differences and demonstration of respect that may help increase willingness to engage in the treatment decision making process.

I sort of learned the term, “nervios [nerves],” So if I was ever was—if I thought it was depression and they sort of weren’t hearing that word or that word wasn’t really ringing true with them, to use the term nervios like made a lot of sense to them. (Primary care physician).

With patients who believed that depression is not a treatable illness, some providers (7/15) described depression as a chronic medical condition like others commonly known in the community, such as diabetes or hypertension.

So, I try to come right up front and say this, “If you had diabetes, you would say to me, please help me fix this.” And this is no different. It’s just chemicals in your brain instead of chemicals in your liver or your kidney. (Nurse practitioner).

Primary care professionals reported a range of strategies used to address stigma including talking through misconceptions about mental illness, ensuring confidentiality, orienting patients to mental health treatment, framing treatment recommendations as if the patient were their own family member or friend, and offering reassurance about feared consequences of engaging in treatment (i.e. ACS and social work).

Orienting depressed patients to depression treatment involved presenting information about resources for treatment within the primary care clinic. Providers commented one of the most difficult aspects of presenting treatment options was discussing medications with patients. One respondent pointed out, “Chances are they’re likely to take the recommendations of family and friends than they are from me in terms of medications.” (Primary care physician). Four physicians in the sample reported introducing medication using the patient’s social network as a leverage point to address concerns around medications,

When I do prescribe, I always ask people, “Do you have friends that have depression that have told you about their medicines?” Because the word on the street is way more authoritative than my word. (Primary care physician).

In addition to orienting patients to medications, respondents described patients’ apprehension associated with the term “social worker” and often times used alternate terms such as case manager or counselor to mitigate feared consequences about the role of social work in mental health treatment, “Well the first thing I say is our

social worker isn't about taking your children away". I'm like, "Our social worker is about trying to get resources to help you" (Nurse practitioner). Once treatment options were presented to patients, about half of the providers said they made a recommendation for treatment and the other half of the respondents tried to elicit treatment preferences from their patients.

## Deliberation

### *Varying Role Expectations*

Some professionals (5/15) reported presenting treatment options and sharing their recommendation for treatment without asking patients about their preferences citing time constraints and competing medical problems as barriers to exploration of preferences. Some respondents (5/15) said they asked patients about their preferences and reported approaching this discussion with sensitivity by describing stepped care with counseling as a first option then medications or their combination to gauge treatment acceptability. Prescribing providers described patients' deference to their authority when discussing medications for depression. Some providers (5/15) commented on welcoming the deference while others tried to elicit patient preferences desiring more participation from patients. One PCP explained

"Well you're the doctor, I trust you." And so what I almost undeniably one hundred percent of the time say is, "Thank you -your trust is important to me and I appreciate that. However you're the patient, you're the one who is going to be taking this medication. If I prescribe you something and you're not completely comfortable taking before you take it, then you may not even start it or if you have certain side effects, but you don't want to disappoint me in terms of the treatment or don't want or disappoint yourself you might waiver on whether you continue it and delay telling me about it." (Primary care physician).

During the deliberation stage, respondents described not knowing how to empower patients to get involved in their health care.

Sometimes I just tell them, "This is your body. I can't make these decisions for you." With just the medical stuff too, like the patients with diabetes who are like, "I'll do whatever I want and you just increase my medication." It's like, "No. This is your body. You are doing this to your body." But sometimes I really don't know how to give them that power, have them create that power. I really don't know how to do that. (Primary care physician).

## Deciding on a Treatment to Implement

All respondents described a treatment decision making process that lasted two to three visits and stated that it was rare for patients to decide on a treatment for their depression in one visit, even if a recommendation was made by their provider. On occasions where a patient may not be ready to make a decision during the first two to three visits, almost all respondents (14/15) stressed the importance of being flexible and available to patients in order to keep them engaged in the treatment process. Some (6/15) considered watchful waiting a treatment decision. One provider reported,

"We can continue to talk about it," and that's part of the treatment too. You don't have to accept that you have the diagnosis. But each time you come in I'm gonna ask you, 'how are you feeling today?' and compare it with the last time. (Primary care physician).

## Discussion

This descriptive qualitative study sought to understand primary care professional's experience with depression treatment decisions in urban primary care. In this study, primary care professionals working with diverse ethnic minority immigrant patients experiencing depression described a range of experiences during the treatment decision making process comprised of negotiating discordant models of illness, addressing stigma about depression and its treatment, aligning varying role expectations, and engaging patients in care during final decision making.

Providers in this sample described more effort educating and orienting patients at the outset of decision making, during the information exchange stage. Educating patients about depression involved addressing stigma and framing depression as a treatable medical illness more than relaying information about symptoms, causes of depression and risks of benefits of treatment options. During the information exchange stage, a shared model of treatment decision making was described marked by a two-way flow of information between the patient and provider comprised of mostly personal (i.e. ideas of illness, concerns and fears) and some medical information. Respondents described discordant models of illness, stigma and concerns about diagnosis and treatment providers as barriers to shared decision making. These barriers were navigated by spending time to elicit information about the community influence, understanding of illness, and prior treatment history from patients as well as educating patients and dispelling fears of engaging in care for depression.

Respondents described a shift from the two way flow of information characteristic of the shared model in the information exchange stage towards a paternalistic model during the deliberation stage when the provider was more active than the patient. Providers reported trying to elicit preferences from patients as a barrier to SDM given their observed deference to authority or apprehension to discuss treatment preferences. They described that this would result in active participation on their part by making recommendations for treatment based on their own clinical judgment despite the attempt to elicit patient preferences. Respondents did not comment on the reason for this apprehension, but reported strategies to overcome this including gauging treatment acceptability or describing their expectation of the patient's role in their treatment in an attempt to empower them to participate in treatment decision making. Although not formally reported, one possible explanation for patient's deference to authority during treatment decision making may be patient's cultural attitudes towards providers. Patient's deference to authority may be the result of low health literacy, lack of self-efficacy or a learned response influenced by cultural attitudes [39–43]. A recent study of Hispanics seeking treatment in community mental health clinics suggest that cultural (i.e. concerns about hurting physician's feelings or offending by asking questions about their views of physicians as figures of authority) and contextual (i.e. degree of familiarity with the US health care system and the potential to be perceived as intimidating) factors can influence patient participation in health care interactions [42, 43]. The notion of patients as autonomous agents implied in the shared model of decision making may not align with some culturally diverse groups who identify with a family-centered [43] or paternalistic model of decision making. Providers in this sample may have also misperceived the lack of participation as deference to authority or apprehension to express preferences for what may be patients' ambivalence towards the professional's recommendations. Furthermore, both parties may have bias or stereotyping which may result in information that is ignored by the professional or the patient's contribution to the shared decision-making process [29].

During the last stage of decision making, when providers and patients decide on a treatment to implement, providers in this sample emphasized the importance of tailoring the time period to the patient's decision making needs. A challenge to SDM faced by providers in this last stage was moving ambivalent patients towards making a treatment decision for their depression. In these cases, providers tried to support patient's decision making by keeping an open door policy so they can continue to monitor their depression and patients would feel comfortable to resume the process in the future.

Previous literature documents the effectiveness of individualized treatment designed to meet the needs and preferences of the patient in treatment of depressed ethnic minority primary care patients [44, 45]. As previously documented in studies of provider-patient communication [46, 47], our study found that patients' conceptual models of depression and preferences play a key role in the decision making process. Findings from our study further underscore the importance of providing culturally competent care for African Americans and Latinos during mental health treatment with a particular emphasis on techniques to foster SDM during each stage of the process. Specifically, during the information exchange stage, culturally relevant terms or staff may be useful during the clinical encounter to ensure that both parties understand perceptions of illness and ideas about treatment options. Respondents emphasized the importance of the patient's social community and the potential benefit of acknowledging this influence during the information exchange and involving the patient's community during the deliberation stage by inviting significant others patients wish to consult. Providers may also foster SDM by openly acknowledging cultural differences, as did some respondents with respect to the influence of the social community on decision making, and asking questions about values and ideas that may influence the effectiveness of the treatment services offered. Before SDM can take place, the professional should clarify explicitly his or her professional role and discuss with patients their preferences for participation and how they can fulfill their preferred role. In this effort, providers may want to explore the patient's views on the provider-patient relationship to identify any influence their culture may have on their willingness to be active participants (i.e. express preference or disagree with the provider's recommendations). During the deliberation stage, some respondents struggled to elicit preferences and empower patients to participate in treatment decision making. Several techniques such as motivational interviewing [48], decision coaching including questioning skills (i.e. open- and closed-ended questions about preferences for treatment options) and sending messages skills [49] may be useful for providers to help empower patients, resolve ambivalence and activate them to participate in their mental health care decisions. Lastly, ongoing access to care in the absence of a final treatment decision was also emphasized by our findings and previous literature [44].

There are several limitations of this study. All of the information is self-reported and we did not observe providers interacting with patients or have live conversation data to substantiate respondent reports. Given that the current study was based upon open-ended questions, a random sample of predominantly female primary care providers of varying disciplines from two community

health clinics, our findings are suggestive and tentative. Although the study did not include viewpoints of patients, family members or friends, their perspectives may differ from their providers and provide insight into their own experience during decision making, some of the barriers described by providers, decision making and treatment preferences as well as additional strategies to foster involvement in care.

The qualitative data about healthcare professional's perspectives that were documented in this research is one step towards understanding the topics and type of information discussed during depression treatment decision making with diverse groups including: content and model of decision making utilized during each stage of the process, barriers to conducting SDM and strategies suggested from providers who work with diverse immigrant groups of individuals who present for treatment in primary care. Future research from this study will present the results of audiotaped consultations involving these same providers and their patients, in which comparisons can be made between interview and observational data.

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## Appendix: Provider In-depth Interviews

Thank you for taking the time to meet with me today. The purpose of this interview is to understand how depressed African American and Latino primary care patients and their providers discuss treatment for depression. The interview will last about 30 min.

### I. Clinical Case example

Please think of a particular patient with whom you recently had a discussion with about depression? (Wait a few moments—they may need a little time to sort and select). Describe for me what took place during this discussion.

(Another approach would be to have them describe “typical” (if they can) patients in each of several classes (e.g., as above, first-timers, repeat, repeat whose meds/psychotherapy aren't working, repeaters who neglected to follow through on earlier referral suggestions, etc. What you want to solicit, I would think, are detailed descriptions about the encounters that you would then be in a position to analyze. You will have seeded this discussion with the specifics of a number of actual clinical encounters beforehand).

### II. Information Exchange

How do you give information to patients?

Can you describe to me how you lay out treatment options for patient including the pros/cons and your opinions?

What are barriers you face in informing patients?

How do you get information about patients?

How do you get their perspectives?/How do you engage patient opinions?

What do you do with that?

### III. Deliberation

What happens after you have all the information you need?

How do you use the information?

What types of treatments do patients with depression prefer?

How is this affected by their cultural, age, gender, and educational background?

What problems do people with depression encounter in seeking help and using those services?

### IV. Choosing Treatment Option

Is there a decision made?

What is easy/difficult about the treatment decision-making process with patients who are depressed?

### V. Clinical Scenarios

I am going to present two clinical scenarios and would like to know how would you deal with each one?

#### *Scenario 1*

Mrs. Lopez is a 38 year old Hispanic female, divorced, currently employed and mother of two children. She came into your office for an annual checkup. While speaking to her, she states she's been feeling sad for no reason for about 1 month now. She's been sleeping more hours than usual and finds it difficult to get out of bed some days. She is also having a hard time taking care of her children and doing chores around the house. She spoke to her sister about this and they decided to visit her local botánica for a cleansing and purchased some herbs to prepare a tea to regain her energy. She's been drinking the tea every morning for about a week now but is only feeling worse. She has now gotten several warnings at work because she is late and is in danger of losing her job.

How would you work with this patient?

She makes it clear that she does not want to take medications out of fear of depending on pills for the rest of her

life and is not sure if she would have time for therapy sessions. She also has a fear that if she has mental illness, child services will take her children away.

### Scenario 2

Mr. Jackson is a 43 year old African American male, married with 5 children, currently employed and has been your patient for 1 year. Mr. Jackson has been suffering from chronic depression most of his adult life and has been taking medication for his depression. He has been taking Paxil for 6 months and it's been working for him but he is concerned about side effects, i.e. weight gain and sexual side effects, and recent media coverage on the rates of suicide and Paxil use. As a result, he stopped taking his medication 5 days ago and is feeling much worse and his irritability caused a big fight with his wife the other night. He comes in today refusing to take any medications for his depression stating that he would prefer to wait and see if his depression improves. You give him a PHQ-9 for depression and he scores a 20, indicating severe depression.

How would you work with this patient?

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