# ORIGINAL PAPER

# Barriers and Facilitators of Treatment for Depression in a Latino Community: A Focus Group Study

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Abstract We conducted focus groups with Latinos enrolled in a Medicaid health plan in order to ask about the barriers to and facilitators of depression treatment in general as well as barriers to participation in depression telephone care management. Telephone care management has been designed for and tested in primary care settings as a way of assisting physicians with caring for their depressed patients. It consists of regular brief contacts between the care manager and the patient; the care manager educates, tracks, and monitors patients with depression, coordinates care between the patient and primary care physician, and may provide short-term psychotherapy. We conducted qualitative analyses of four focus groups (n = 30 participants) composed of Latinos who endorsed having been depressed themselves or having had a close friend or family member with depression, stress, nervios, or worries. Within the area of barriers and facilitators of receiving care for depression, we identified the following themes: vulnerability, social connection and engagement, language, culture, insurance/money, stigma, disengagement, information, and family. Participants discussed attitudes toward: importance of seeking help for depression, specific types of treatments, healthcare providers, continuity and coordination of care, and phone calls. Improved understanding of barriers and facilitators of depression treatment in general and depression care management in particular for Latinos enrolled in Medicaid should lead to interventions better able to meet the needs of this particular group.

**Keywords** Telephone · Depression · Care management · Primary care

#### Introduction

Latinos represent the largest ethnic minority group in the United States. It is estimated that Latinos will constitute nearly one-quarter of US citizens by 2050 (US Bureau of

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the Census 2000). Epidemiological data indicate that depression rates in Latinos are equivalent to rates in the general population (Alegria et al. 2006, 2007), although rates vary significantly across Latino subgroups, with Puerto Ricans having depression rates almost double those of non-Latino Whites (Alegria et al. 2006, 2007). Despite rapid increases in the US Latino population, there continue to be wide healthcare disparities between Latinos and non-Latino Whites (McGuire and Miranda 2008), particularly in the area of mental health care. For example, among adults meeting criteria for mental health disorders, 38% of whites receive care whereas only 22% of Latinos receive care (Wells et al. 2001). Depressed Latinos use mental health services less frequently than non-Latino Whites, even when they have health insurance (Ojeda and McGuire 2006) and have lower rates of adherence to antidepressant medications (Ayalon et al. 2005; Miranda and Cooper 2004; Sleath et al. 2003). Once in treatment, Latinos are less likely than non-Latino Whites to receive the best available treatments for depression (Wang et al. 2000).

Approximately 50% of individuals who seek healthcare for depression seek it from a general medical provider rather than a behavioral health specialist (Wang et al. 2005). That percentage is even higher for Latinos (US Department of Health, Human Services 2001). Collaborative care programs for depression have been designed to improve depression outcomes in primary care (Bower et al. 2006). The exact nature of collaborative care varies, but it usually involves physician education about depression management as well as some type of depression care management-i.e., a depression care manager who educates, tracks, and monitors patients with depression, and coordinates care between the patient and primary care physician. Collaborative care could also include consultation with a psychiatrist or the provision of psychotherapy in the primary care setting. Two large studies have shown that collaborative care improves outcomes for Latinos (Arean et al. 2005; Miranda et al. 2003; Unutzer et al. 2002). However, these studies used many-layered interventions that involved an on-site care manager and had multiple components. Less resource-intensive interventions such as telephone care management alone, if successful, are attractive for several reasons, including lower cost, ability for one interventionist to cover a large geographic area, ability to easily match a patient to an interventionist who speaks his/her native language, and the fact that the patient does not need transportation or childcare to complete a call. In samples of mixed or unknown ethnicity, telephone depression care management is more efficacious than treatment as usual (Hunkeler et al. 2000; Simon et al. 2000; Wang et al. 2007).

Because Latinos have particular barriers to depression care, it is unknown whether telephone care management would work for them. Thus, we conducted a project designed to assess the feasibility, acceptability, and preliminary efficacy of adapting telephone depression care management for depressed Latino Medicaid health plan members. This project was a collaboration between a Medicaid health plan, a managed behavioral health care company, and an academic partner. Care management consisted of 3 months of up to eight phone calls following an antidepressant prescription from a primary care physician. Adaptations to telephone care management included the use of bilingual, bicultural depression care managers who were trained in working with depression care issues specific to this population and bilingual study research assistants who were selected for their warmth and professionalism over the telephone. Ultimately, 38 depressed primary care patients were enrolled in a pilot randomized trial of telephone depression care management + treatment as usual (TAU; i.e., treatment by their primary care physician) versus TAU. Over 1 year, research staff attempted to contact 929 potentially eligible members and ultimately enrolled 38. It was extremely difficult to reach potential participants. However, when compared to the group receiving TAU, there was a statistical trend for the intervention group to experience less depression over time. We concluded that this program could be promising; however, there was a need to investigate ways to improve recruitment rates prior to conducting a full-scale trial.

Therefore, we decided to conduct focus groups with Latinos in order to better understand the barriers to participation in telephone care management specifically as well as the barriers to and facilitators of depression treatment more generally. Previous researchers have used focus groups or individual interviews to investigate barriers to depression treatment amongst Latinos (Barrio et al. 2008; Cabassa et al. 2008; Fornos et al. 2005; Interian et al. 2007; Pincay and Guarnaccia 2007). Thus, one of the aims of the current study was to replicate previous findings in a sample of Latinos who were primarily of Puerto Rican and Dominican descent (as opposed to Mexican descent, as in Barrio et al. 2008; Cabassa et al. 2008; Fornos et al. 2005), and, unlike Interian et al. (2007), to focus on a range of treatment strategies. A second aim of this study was to better understand facilitators of treatment seeking amongst Latinos. We reasoned that it was important not only to understand what got in the way of treatment, but also what might make treatment more successful. Finally, we wanted to focus on barriers and facilitators as they related specifically to telephone depression care management.



#### Methods

# **Participants**

We recruited focus group participants with the assistance of a local Latino community organization, Progreso Latino. Inclusion criteria were: (1) being a member of the Medicaid health plan; (2) self-identifying as Latino/Hispanic; and (3) having had personal experience or having had a close friend or family member with depression, stress, nervios, or worries. Thirty participants were part of four focus groups. Twenty-six women and three men participated (one person did not complete gender item on his/ her form). Ethnicity was: Puerto Rican (n = 14), Dominican (n = 11), Central American (n = 1), South American (n = 2), Spanish (n = 1), and other (n = 1). Ten participants had an 8th grade education or less, 8 completed high school, and 11 had had some college education or a bachelor's degree. Six were employed full time, 2 parttime, 1 was a student and employed full-time, 10 were students, 3 unemployed, 5 on disability, and 2 were fulltime parents. In terms of nativity, 3 had been born in the US mainland, 4 had been in the US mainland for <5 years, 19 for >5 years, and 3 preferred not to respond. Twentytwo participants reported a history of experiencing depression themselves.

#### **Procedures**

Four focus groups were conducted between 7/30/08 and 9/10/08. The focus groups were conducted entirely in Spanish. There were two bilingual facilitators, both of whom were fluent Spanish speakers. One was a study team member and the other was a community facilitator. Focus groups began with the informed consent process; all participants provided written informed consent. The interviewers used a semi-structured set of questions (see "Appendix") with some scripted probes, but the interviewers were also given the latitude to explore unanticipated topics brought up by the group. Authors developed these questions collaboratively based on: (1) our own experiences with a depression care management study with Latinos and the difficulties we experienced in recruiting participants and providing the intervention; and (2) a review of the extant literature and concern that there was insufficient focus on facilitators of treatment and little focus on whether or how telephone-based treatment could work. Therefore, these questions focused on barriers and facilitators of receiving treatment for depression in general and, specifically, of being part of a telephone depression care management program. At the end of the group, all participants completed a brief demographic questionnaire.

Each focus group session was audio-taped in its entirety. The audio-tapes were transcribed completely. The transcriptions were translated into English and reviewed, and discrepancies were corrected.

This study was approved by the requisite Institutional Review Board. The authors have no conflicts of interest to disclose. All authors certify responsibility for this manuscript.

# Data Analysis

The analysis was performed using grounded theory as described by Crabtree and Miller (1999). The team did not have a priori hypotheses as to the participants' responses to the question set. The team applied a process in which codes are sorted into categories, the categories into concepts, and the concepts into themes.

## Coding

Four study team members independently coded the four focus group transcripts. Two, both fluent in Spanish, coded the Spanish transcripts, and two, who did not speak Spanish, coded the English transcripts. All four team members used in vivo coding, wherein original quotations themselves were considered to be codes. After completing coding, the team met serially to discuss the coding of these transcripts. The team discussed discrepancies and, using consensus, developed a master list of codes. Next, we triangulated the coding. One investigator who did not do the coding reviewed the clean copies of the transcripts in English. She then reviewed the set of coded transcripts and provided the analysis team with feedback. The analysis team discussed the feedback, and changes were incorporated into a final set of coded transcripts. Ultimately, there were 824 codes to be sorted.

# Categories, Concepts, and Themes

After completing the consensus coding, the team printed the codes on cards which they sorted into categories. As necessary, the team checked contexts of codes in the transcripts to be certain the proper meaning was being considered. The team used a similar process to sorting the categories into concepts, then concepts into themes. We then triangulated the categories, concepts, and themes with an investigator who was not involved in the sorting process. The investigator requested clarifications regarding naming or meaning and suggested shifts in organization within the themes and concepts when the rationale of the sorting was unclear. These were then reviewed and either incorporated or rejected by the analysis team.



#### Results

We will discuss two sets of themes that arose from the focus groups. The first set of themes reflects issues that may be considered to be "Barriers and Facilitators of Receiving Care for Depression." (Please see Table 1 for a list of these themes, along with concepts and categories.) The second set of themes is related, but deals more directly with "Attitudes Toward Care For Depression." (Please see Table 2 for a summary). To assist with identifying the level of information provided, we use bold to denote **themes**, underlining for *concepts*, and italics for <u>categories</u>. In some cases, a concept has only one category, in which case they have the same name and are both *underlined and italicized*.

Barriers and Facilitators of Receiving Care for Depression

Within this area, we identified nine themes. The first five, namely, vulnerability, social connection and engagement, language, culture, and insurance/money related primarily to barriers and facilitators of healthcare generally that also apply to mental health care. The second four, labeled as stigma, disengagement, information, and family related more specifically to care for depression. Participants drew on experiences of family and friends, and, in some cases, their own experiences, when discussing these themes.

Participants expressed significant feelings of vulnerability. Many participants expressed worry about the security of their private information and spoke of lack of trust in other people. That is, amongst Latinos in this community, the level of trust in others was low—both with regard to others in their own community as well as with people outside the Latino community. Participants made simple statements of distrust such as: "nosotros mismos no confiamos" (we don't trust even ourselves); "es muy difícil confiar en una amiga" (it is difficult to trust a friend); and, with regard to those outside the community including health care providers, "no puede uno confiar en todo el mundo para uno contarle sus cosas íntimas" (you can't trust in everyone to hear your most intimate things). Fear about violations of privacy or confidentiality was clearly stated as a reason for keeping medical information private. Participants said that even if information about depression, health status, or immigration status was not exposed previously, this information could be exposed in the future. Participants also provided examples of breaches of confidentiality in which information was disclosed by a medical provider or via interpreters to the patient's family. Lastly, participants talked about fear about information disclosure specifically regarding immigration status: "La gente tiene miedo. Supuestamente dicen que la información es confidencial, pero en las noticias han salido que los doctores pueden llamar a Inmigración" (People are

**Table 1** Barriers and facilitators of receiving care for depression themes, categories, and concepts

#### Vulnerability

The security of private information

Lack of trust in other people

Fear about violations of privacy or confidentiality

Examples of breaches of confidentiality

Fear about information disclosure specifically regarding immigration status

#### Experiences and fear of harm

Discrimination

Victimization

#### Trust

Trust as an essential aspect of relationships with healthcare providers

## Social connection and engagement

#### Social partnership

Social partnership is highly valued

Doctors ask about family

Experiences of a connection with their doctor

#### Personal contact

Need for face to face contact and eye contact

Preferred first time contact not occur by phone

Home visits were a desirable method of contact

# Contact failures

Lack of doctor time

Lack of timely access (to care)

Sometimes healthcare providers don't pay attention to people that really need attention

Latinos may not talk about depression because they were not asked Experiences of feeling dehumanized

## Language

## Interpreters

Unmet need for interpreters

Loss of access to care because no interpreter was available

Lack of information and communication about the need for interpreters

Concerns about the accuracy of interpreter translation

## Language is a barrier to receiving medical services

Difficult when support staff or providers do not speak Spanish Useful when providers are comfortable speaking either Spanish or English

# Culture

Cultural differences can be a barrier to treatment

Sense of difference from non-Latinos

Desire for cultural concordance

Doctors' response to cultural differences

Doctors should learn about culture

#### Insurance/money

Financial troubles

Emotional statements about not having sufficient insurance Concerns for those who don't have insurance



#### Table 1 continued

#### Stigma

## Stigma as a barrier to treatment

Community stigma

Church stigma

## Normalizing depression

Need for the community to have events and education that would address depression and decrease stigma

Church as a place to address depression

#### Disengagement

## Minimize or deflect the importance or presence of depression

Minimize or deflect the importance or presence of depression

# Reasons a depressed person may not seek help

Belief that they should help themselves

Reticent to talk about the problem

Fear prevents people from seeking help

## How one might manage depression on his/her own

Exercise

Distraction

## Isolation

Choose isolation

Don't want to be bothered

Feeling isolated and unable to engage help, but not by choice

#### Information

## Lack of information

Lack of information about depression and where or how to get treatment

Little or no knowledge about what insurance covered

# Ignorance regarding depression and depression treatment

Ignorance regarding depression and depression treatment

## Need for education

Need for education

# Suggestions about outreach

Suggestions about community outreach

Suggestions for modes of outreach

Doing outreach in hospitals, schools, and churches

Suggestions for content of outreach

# **Family**

## Duty to their family

Need to take care of oneself in order to take care of one's children

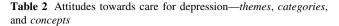
Concealing depression symptoms so as not to trouble family members

# Family members' needs and behavior

Family provides support

Family as care barrier

afraid. Supposedly, they say the information is confidential, but it has come out in the news that doctors can call immigration). There were many examples or concerns of this fear preventing community members from seeking needed care.



#### Importance of seeking help for depression

Those with depression should look for help

Go to the doctor

Talk to a counselor

## Specific types of treatments

## Pills

Positive statements

Addiction to the pills

Too many pills were being prescribed

Medication side effects

Weight gain with antidepressants

Examples of self-discontinuation of medication treatment for depression

#### Traditional treatments

Home/folk remedies

One size (treatment) does not fit all

# Addressing depression through groups

Those with depression should seek help via groups

Positive statements about groups

Why groups are desirable

#### Healthcare providers

Positive statements about doctors and mental health professionals

Negative statements about mental health professionals

# Continuity and coordination of care

Desire for care coordination

Negative experiences with lack of continuity

# Phone calls

## Arranging calls

Time of calls

Frequency of calls

# Difficulties with providing an intervention over the telephone

Phone contact is unreliable

I don't like to talk over the phone too much

The use of telephone for contact was the main reason that our previous study had difficulty contacting participants

#### Suspicion

Important to know who you are talking to

Concern about who might be calling

Written communication may be the best way to reach potential study participants

Participants spoke of experiences and fear of harm, both within and outside of the healthcare system. *Discrimination* was clearly felt; a representative quotation was: "Gente verdad se sienten discriminados, temor a ir porque le van a pedir otra clase de información como la green card, y esas cosas" (People feel really discriminated against, scared to go [to the doctor] because they might ask for another type of information like the green card and those things). Participants were afraid of *victimization*, or of being preyed



upon, especially by phone, in scams where one might, as one participant said, lose one's car to someone. Participants gave specific instances of *mistreatment*: "a mí me han tratado bien mal, más de tres veces en la clínica" (they have treated me badly more than three times at the clinic) and "Lo que pasa es que te tratan como a un número. Si yo me pongo enfermo ahí adentro me voy a morir" (What happens is they treat you as a number. If I get sick there [in the hospital], I will die).

Because of feelings of vulnerability and fear of harm, <u>trust</u> was seen as *an essential aspect of relationships with healthcare providers*. Participants stressed the importance of healthcare providers actively creating trust. With regard to treatment, a participant said: "crear la confianza para poder seguir la conversación" (create trust so that the conversation will continue).

The next theme reflected the importance of social connection and engagement. Social partnership is highly valued, mostly with respect to medical care but also with respect to a telephone care management intervention: "crear el vínculo entre el paciente y la persona que te va a ayudar" (create a partnership between the patient and the person who will help you). Participants felt more of a connection when their doctors ask about family. Participants also discussed other experiences of a connection with their doctor, wherein they felt that their physician was truly interested in them as a person such as "ella te pregunta y tú te quedas mucho tiempo con ella" (she asks you and you stay a long time with her). Similarly, participants emphasized the importance of the physical aspects of personal contact as well. Specifically, participants emphasized the need for face to face contact and eye contact. This phrase was not used figuratively, but literally in the sense of having a person look one in the eye, a person who was right there in front of you. Without this, the person receiving the phone call might feel like he/she was being seen as a number rather than a person. Because of a need for face-toface connection, participants indicated that they preferred first time contact not occur by phone and home visits were a desirable method of contact.

Participants also discussed instances of <u>contact failures</u>; i.e., examples of times that connection and engagement did not happen in the health care setting and how they felt as a result. They talked about the *lack of doctor time*. Several spoke of the *lack of timely access (to care)*—i.e., not being able to get an appointment when one was needed as well as having needed appointments cancelled. Participants also discussed the idea that "algunas veces no les hacen caso a personas que de verdad lo necesitan" (*sometimes they* [healthcare providers] *don't pay attention to people that really need attention*), especially with regard to care for depression. Participants also said that *Latinos may not talk about depression* (or similar issues) *because they were not* 

asked. However, some also noted that they would not report it even if they were asked. Finally, participants described instances of being treated as a number or a paper, not as a person. Participants related experiences of feeling dehumanized: "yo he tenido doctores que he ido, you know, médicos y es como ni mirando a uno a los ojos" (I have had doctors I've gone to, you know, and it is like they don't even look you in the eyes). Participants talked about the need for this problem to be addressed: "que pongan un poco más de atención, más humanidad...como que tú importas" (they need to pay more attention, be more human...like you matter).

Language emerged as a theme, mostly due to the negative experiences with respect to interpreters. Participants discussed an unmet need for interpreters in this community. Participants discussed instances where there was loss of access to care because no interpreter was available when care was sought, such as an experience in which one participant went to the doctor and "el médico no me quiso atender porque no había un intérprete" (the doctor did not want to see me because I did not have an interpreter). There was lack of information and communication about the need for interpreters, as demonstrated in the quotation "ella no me dijo que llevara un intérprete ni nada de eso" (she [the healthcare provider] didn't tell me to bring an interpreter). When an interpreter was present, there were still *concerns* about the accuracy of interpreter translation. For example, a participant with some understanding of English said, "Porque el doctor dice que el intérprete se lo dice al contrario. Yo a veces le he dicho al intérprete: oye lo que tú estás diciendo el doctor no lo dijo" (The doctor says that the interpreter tells him the opposite. I sometimes have said to the interpreter 'Listen, what you are saying, the doctor didn't say that').

Participants described how <u>language</u> is a barrier to <u>receiving medical services</u>. It is *difficult when support staff* or providers do not speak Spanish. For example, a participant talked about it being a problem when the person who answers the telephone at a doctor's office does not speak Spanish. Participants clearly felt that it was *useful when* providers are comfortable speaking either Spanish or English.

With respect to **culture**, participants talked about the ways in which <u>cultural differences</u> can serve as a barrier to <u>treatment</u>. Participants clearly expressed their sense of difference from non-Latinos; an example quote is: "Somos culturas diferentes. Cuando tu vas a un médico anglosajón... o no anglosajón, pero que no es Hispano...son culturas muy distintas de la que estamos tratando" (We are different cultures. When you go to a White doctor, or a doctor who is not White, but is not Hispanic...they are cultures that are different from what they are treating). Participants described a desire for cultural concordance, i.e., the desire to encounter medical office staff workers



who are Latino. With respect to <u>doctors' responses to cultural differences</u>, we heard that *doctors should learn about culture*, with a representative quote being "Ellos han leído miles de libros para entender lo que tú tienes, la depresión. Entonces pueden leer uno sobre cultura Latina" (They have read thousands of books to understand what you have, depression. So they can read one about the Latino culture).

Participants discussed **insurance/money** and how it related to seeking or receiving care. Many spoke of their own or others' *financial troubles*. For example, in reference to a group that used to meet at a church, a person said: "Sí, pero no hay fondos" (Yes, but there are no funds). People made *emotional statements about not having sufficient insurance*, including quotations like: "A veces uno se trauma más pensando que se necesita un tratamiento largo y no lo puede costear" (sometimes you get more traumatized thinking that you need a long treatment and you can't pay). Although the participants were insured, they expressed *concerns for those who don't have insurance*.

The first theme that related specifically to depression was **stigma.** Participants talked about <u>stigma</u> as a <u>barrier to treatment</u>. There was *community stigma*. One participant said: "con las amistades sería qué van a decir de mí" (with my friends, it's about what they would say about me). Participants in one focus group also discussed *church stigma*: in some churches, depression was described as demonic. Participants made statements such as: "eso no se consideraba como una enfermedad, sino algo diabólico" (it is not considered a sickness, it's like something diabolical).

Participants provided suggestions for normalizing depression in order to reduce the stigma of having depression and seeking treatment. They thought that there was a need for the community to have events and education that would address depression and decrease stigma. For example, one quote was: "Gracias a Dios que hay artistas, que hay mucha educación, y que los artistas salen en televisión. Ellos mismos dicen que sufren de depresión; entonces es más fácil para uno decir OK" (thank God there are celebrities, that there is a lot of education and that the celebrities come out on television. They themselves say that they suffer from depression and then it is much easier for you to say). In contrast to what was described above, participants also spoke of the church as a place to address depression, with quotations like "pero me sentí bien, porque me desahogué" (I felt better because I unburdened myself [to her pastor]).

**Disengagement** reflects a way in which participants, family members, or friends respond to depression, and represents a barrier to care that may be more specific to depression than other medical problems. Participants described instances of individuals trying to <u>minimize or deflect the importance or presence of depression</u>. A

representative quote is: "hay gente que no lo coge tan en serio" (there are some people that don't take it that seriously). Participants said that some family or friends might respond to a depressed person by saying, "¿Por qué estás deprimido si tú tienes todo?" (Why are you depressed when you have everything?) or "mira no parece que tiene ese problema" (look, it doesn't seem like you have this problem).

Participants discussed reasons a depressed person may not seek help. First, some might have the belief that they should help themselves rather than seek outside treatment. One participant said: "Yo mi depresión me la manejo sola" (I take care of my own depression). Participants indicated they or those they knew were reticent to talk about the problem, which was a category rich with quotations. For example, one participant stated: "no le estoy demostrando al mundo que ese problema me está afectando a mí" (I'm not demonstrating to the world that this problem is affecting me). Participants repeatedly stated that fear prevents people from seeking help. Many participants related stories of people they knew who did not seek help for themselves or their children because of their undocumented status; other types of fears included fears of having one's children removed because one was thinking about suicide as well as fear of expressing one's feelings.

Participants discussed <u>how one might manage depression on his/her own</u>, including *exercise* or *distraction*. One participant summed up this advice by saying: "Diviértete, distráete o escucha música eso te alegra, cosa así" (Have fun, distract yourself or listen to music that will cheer you up).

Lastly, participants talked about isolation as being common amongst depressed individuals and as complicating care seeking. In some cases, individuals appear to choose isolation. Representative quotations were: "lo que hacemos es que nos encerramos y lloramos, y lloramos" (what we do is we lock ourselves in and cry and cry), "Yo no salgo de la casa" (I don't go out of the house), and "muchas veces tú no quieres escuchar a nadie" (many times, you don't want to listen to anyone). Participants said that some depressed individuals don't want to be bothered to be part of depression care management or any intervention. Finally, some participants talked about feeling isolated and unable to engage help, but not by choice: "A veces me voy en carro a dar vuelta porque no tengo con quién hablar, con quién sentirme bien. Yo pienso que esto no está bien, yo sé que eso no está bien" (sometimes I drive around in my car because I don't have anyone to talk to, with whom to feel better. I think that this is not right. I know it's not right).

**Information** emerged as an important barrier or facilitator of depression treatment. Participants said that there was generally a *lack of information about depression or* 



where or how to get treatment. They also stated that community members had little or no knowledge about what insurance covered. Participants spoke of ignorance regarding depression and depression treatment in individuals and in the Hispanic community. One participant observed that "no todas las personas tenemos el mismo nivel de intelecto" (not every person has the same level of intelligence [regarding knowing one needs help for depression]). To respond to these barriers, discussants spoke of the need for education, saying, for instance, "Está la computadora; está la televisión; los folletos; busquen ayuda, edúquense" (There is the computer; there is the television, brochures; look for help, educate yourselves). Participants made suggestions about outreach with education to the Hispanic community. There were suggestions about community outreach, such as having tables with relevant information at community events. However, there were also quotations in this category expressing concern about difficulties with outreach, such as "Educar a la población sería bastante difícil, porque es que están las cuestiones migratorias" (educating the population will be really difficult because of the immigration issues). Participants made suggestions for modes of outreach to educate the Hispanic population about depression, including "debería haber anuncios en las cosas más usuales que las personas usan como son los cosméticos, los perfumes, hasta en la soda que uno se vaya a tomar" (they should have announcements in the most usual things people use like cosmetics, perfume, and even soda). People also suggested using the radio, brochures, and signs as well as doing the outreach in hospitals, schools, and churches. Finally, participants discussed suggestions for content of outreach: "Es que no hay que decir 'Depresivos vengan acá" (You don't have to say 'depressed people come here.'). Instead, "do not use negativity" (spoken in English) and say: "¿Te sientes sólo?, ¿Quieres hablar?, ¿Tienen una hora?... vamos a charlar, vamos a aprender a bailar, a cocinar" (Do you feel alone? Want to talk? Do you have an hour? ...we're going to chat, we're going to learn to dance, to cook.) This last quote illustrates a preference for classes or activities (e.g., dancing, cooking) as a way to combat depression.

Finally, participants described ways in which **family** could influence depression and care-seeking behavior. Participants reported that feeling <u>duty to their family</u> could have different types of influences. On the one hand, children might motivate a person to seek needed care—e.g., the *need to take care of oneself in order to take care of one's children*. On the other hand, participants spoke of *concealing depression symptoms so as not to trouble family members*. One participant stated "a veces uno quiere llorar y como que no puede, porque le da pena que los niños vean llorando a uno, o el esposo" (sometimes you want to cry

and it's like you can't because you are worried that the children might see you or your husband). Family members' need and behavior might have a positive or negative impact on depression. On one hand, family might be a source of either emotional or instrumental support (family provides support). On the other hand, family members might keep care from happening (family as care barrier). For example, one participant said "¿Quién se va a quedar con mis hijos especiales cuando tengo que estar metida en el hospital?" (Who will stay with my special needs kids when I have to be in the hospital?).

# Attitudes Towards Care for Depression

There were five themes within this area. Participants discussed attitudes toward: the importance of seeking help for depression, specific types of treatments, healthcare providers, continuity and coordination of care, and phone calls.

Despite barriers to care, many participants talked about the importance of seeking help for depression; those with depression should look for help. More specifically, participants suggested that someone with depression should go to the doctor or talk to a counselor: For example, one person stated: "un profesional de la salud está preparado para eso, si necesitamos un medicamento, terapia, con lo que nos pueda ayudar" (a health professional is prepared for this. If we need medication, therapy, whatever, they can help us).

Regarding specific types of depression treatment, there was extensive discussion of attitudes and beliefs about pills. Positive statements described successes related to taking medication. However, participants had many different types of negative statements about pills. For example, participants said: "esa pastilla no me hace a mí nada" (that pill doesn't do anything for me) and "hay muchas personas que no creen en los medicamentos, que eso te hace daño" (there are many people who don't believe in medications; that they harm you). Participants described concerns about addiction to the pills for depression. Some indicated that too many pills were being prescribed. There were concerns about medication side effects, both about being not fully informed about such effects, such as "ese es el miedo; porque si te dan una pastilla y no te dicen los efectos secundarios" (that's the fear; because if they give you a pill and they don't tell you about the side effects) as well as about specific side effects, such as drowsiness and weight gain with antidepressants. Participants described examples of self-discontinuation of medication treatment for depression.

Participants discussed <u>traditional treatments</u>. *Home/folk remedies* were discussed in both positive and negative terms. Some participants described them as reflecting ignorance whereas others saw value in them. For example,



one participant said: "Por supuesto mi té de tilo y manzanilla, ella me dijo que no lo dejara nunca" (of course, my Linden flower and Chamomile teas, she told me never to leave them). On a related note, there were quotations stating that *one size* (treatment) does not fit all.

Participants spoke favorably of <u>addressing depression</u> through groups (e.g., support groups or groups focused on a particular activity or learning a skill). Some participants indicated that those with depression should seek help via groups and others made positive statements about groups. There was some discussion of why groups are desirable, such as "para que las personas sepan que no están solas" (so that people know that they are not alone) and "oír a otra persona hablar de lo mismo que yo siento" (hearing the other person talk about the same thing I'm feeling).

Participants also gave evaluations of **healthcare providers.** There were *positive statements about doctor and mental health professionals*, such as "me atendió bien" (she took good care of me). There were also some *negative statements about mental health professionals*, such as "Y a mí me estresó mi sicóloga" (my psychologist stressed me out) and "lo primero que hacen es darte medicamentos para relajarte; luego te mencionan al siquiatra. Ya tu dices, esta piensa que yo estoy loco" (the first thing they do is give you medicines to relax you; then they mention the psychiatrist and you think this one thinks I'm crazy).

Participants also discussed continuity and coordination of care. Participants expressed a desire for care coordination: "Tuvieran más resultados, si por ejemplo el médico general me refiere donde un siguiatra, pero que el siquiatra tenga comunicación con mi doctor" (They would have had better results if, for example, the primary care doctor referred me to a psychiatrist, but the psychiatrist communicated with my doctor) and "si trabajan juntos van a ayudar más a las personas" (if they [the primary care doctor and psychiatrist] work together, they will help people more). Negative experiences with lack of continuity were also described: "A mi se me hizo bien difícil cambiar a otro doctor con el seguro que yo tenía antes" (It was very hard for me to change my doctor with my last health plan), and, referring to the doctor, "Cada vez que te lo quiten (cambien) tu tienes que empezar de nuevo la misma vaina" (Every time they change them you have to start the same thing over again).

We were specifically interested in participants' impressions of telephone care management such as the program we had implemented. Participants had a lot to say about **phone calls.** Participants indicated the need for attention to participant preferences in <u>arranging calls</u>, including *time of calls* and *frequency of calls*. Participants want to know the person calling and to have a say in when and how often they called. Participants elaborated on <u>difficulties with</u> providing an intervention over the telephone. Focus group

participants felt that phone contact is unreliable for a variety of reasons, such as "Yo no tengo teléfono en casa" (I don't have a phone in my house) and "las personas siempre cuando uno no tiene el dinero o desconectan el teléfono o cambian" (when people don't have the money they either disconnect or change their phones). Others indicated "no me gusta mucho hablarlo por teléfono" (I don't like to talk over the phone too much). Lastly, some stated that the use of telephone for contact was the main reason that our previous study had difficulty contacting participants. Participants indicated there was a great deal of suspicion regarding being contacted by phone. Participants emphasized that it is important to know who you are talking to "porque mucha gente llama y uno no sabe a quién le está hablando...uno no ve una badge, no hay identificación" (because many people call and you don't know who you're talking to... you don't see a badge, there is no identification). Others stated concern about who might be calling—i.e., the call could be from a bill collector or telemarketer. As a result, participants indicated that written communication may be the best way to reach potential study participants.

#### Discussion

Barriers to Depression Treatment and Healthcare in General

Participants discussed many barriers to depression treatment. Barriers to use of healthcare in general included fear of breach of confidentiality both with respect to healthcare data and immigration status, past experiences of mistreatment by healthcare providers, inability to schedule appointments when needed, feeling dehumanized in the healthcare system, difficulty with getting interpreters, concerns that interpreters were not accurately translating, feeling culturally different from their health care providers, and financial difficulties. Barriers specific to receiving care for depression include stigma from the community, attitudes toward depression that included ignoring or fixing the depression oneself, the tendency of depressed individuals to isolate themselves, lack of information about depression and its treatment, and family responsibilities. Participants also expressed specific concerns about antidepressants. These are consistent with other descriptions of barriers for depressed Latinos (Barrio et al. 2008; Cabassa et al. 2008; Fornos et al. 2005; Interian et al. 2007; Pincay and Guarnaccia 2007).

We focus briefly on two barriers that are not discussed as thoroughly in the previous depression literature. First, we found the comments about interpreters to be very instructive. As mentioned above, all individuals are part of



a health plan; this health plan is committed to helping to provide interpreters when needed. However, many individuals were not aware of this, and continued to have problems getting Spanish interpreters, even though Spanish is the most common non-English language spoken in the state. Concerns about accuracy of interpretation are especially troubling and have been noted in previous literature on barriers to health services use in general (Scheppers et al. 2006). It is likely that the more subtle, nuanced, and emotional a problem is, and the less visible on physical exam it is (such as depression vs. a knee injury), the more difficult it is to ensure that translation accurately reflects the patient's intended meaning. Second, we note that a sense of isolation and wanting to be left alone also may serve as a barrier to treatment; however, unlike other barriers, this may also be seen as a symptom of depression itself. The lack of motivation and energy inherent in depression also make it very difficult for an individual to face up to and find ways around other barriers to healthcare in general. A depressed person may not have the needed drive to find a healthcare provider with whom he or she feels connected or who understands the patient's culture, or may be particularly unlikely to seek out needed information about how to get interpreters or what services his/her insurance does cover.

# Facilitators

In conducting this study, we thought it important to encourage participants to brainstorm about treatment facilitators and ways around the barriers mentioned above. One key facilitator was a trusting relationship with a health professional. This relationship may be built in part by looking the patient in the eye (e.g., instead of at the electronic medical record), being interested in the person as a whole, asking about his/her family, and directly asking about problems. Providers should also be very explicit about confidentiality and its limits. Although there is clearly a desire for Spanish-speaking providers, providers who are not Spanish speaking may want to make an effort to learn about local Latino cultural groups, as demonstrated by the category Doctors should learn about culture. As documented above, rates of adherence to antidepressant medications tend to be lower amongst Latinos than whites (Ayalon et al. 2005; Miranda and Cooper 2004; Sleath et al. 2003). Future research might examine whether there are interventions or education for the provider that results in increased trust between provider and patient, and whether this, in turn, results in improved medication adherence.

In this study and in others, stigma surrounding depression and lack of information about depression and its treatment, have been identified as a barrier to treatment (Interian et al. 2007; Ojeda and McGuire 2006; Pincay and

Guarnaccia 2007). Participants provided feedback about ways to decrease stigma and increase knowledge about depression and its treatment. Community outreach, such as through a hospital or other community groups, was generally viewed favorably. Participants liked the idea of informational announcements or signs that teach about depression. Indeed, a study of Medicaid participants in California found that, amongst Latinos, there was more mental health service use in counties in which government Ethnic Services Coordinators judged outreach to be an important method of reaching minorities (Snowden et al. 2006). Participants also liked the idea of using groups such as fun group activities, classes, or support groups to treat depression. Regarding activity groups, the activities suggested (e.g., being part of a group to learn new cooking techniques) closely match some of the types of activities that a behaviorally-oriented psychotherapist may encourage a patient to engage in.

# Telephone Care Management

There are two aspects to telephone care management: the use of the telephone and the care management itself. First, we discuss the use of the telephone. Much of what Latinos may value in a relationship with a healthcare provider, such as trust, is difficult or impossible to develop without faceto-face contact. Depressed individuals with a tendency to isolate will likely be harder to connect with over the telephone, particularly if the person calling is unknown to them. Phone contact can also be unreliable. For this reason, participants clearly believed that at the very least, the initial care management contact should be face-to-face. This is important because telephone care management has been successful in some groups (Hunkeler et al. 2000; Simon et al. 2000; Wang et al. 2007); however, the use of the telephone, at least for the first contact, may not be the best strategy for low-income Latinos. Telephone care management may be more successful if the first one-two contacts are face-to-face, followed by telephone calls thereafter. In addition, it would be ideal if care managers could always call from the same telephone number, if the number were not blocked from appearing on the receiving phone, and if participants were informed about what telephone number to expect. In order to address the unreliability of telephones, particularly for low-income groups, intervention programs might experiment with low-cost ways to provide phones or provide minutes for cell phones.

Regarding care management, participants clearly seemed to view care coordination as positive. This was somewhat surprising, given concerns about confidentiality of information. However, it seems that having two healthcare providers speak to each other for the purposes of care coordination may be acceptable to at least some



members of the Latino community. We believe that it will be very important for those providers to be explicit with the patient about the types of information they will share and with whom. Therefore, a care manager might emphasize: "I am part of the treatment team. That means I will be talking with your physician regularly about how you are doing. The reason for doing this is to make sure that you get the best treatment possible."

## Limitations

Because this is a qualitative study, it is meant to generate ideas that can later be tested. We do not know that our results are necessarily generalizable to Latinos from different backgrounds or from different areas. Most participants were women, and all had health insurance. Further, although many participants did speak of their own experiences with what they described as depression, we did not require that individuals had been diagnosed with major depression in order to participate in this study. We also did not assess current depressive symptoms. It is possible that groups composed entirely of people with current major depression would have talked about ideas not discussed in these groups; this is limitation of this study. However, barriers mentioned by this group do reflect many of those mentioned in the literature. A final limitation of our methods is that the transcriptions of the focus groups were done in Spanish and then translated to English Two of our coders were English speaking only. These coders may not have appreciated subtle points that were literally lost in translation. We did address this problem by having two bilingual coders as well as two English language coders; coders discussed and resolved any discrepancies in their understanding.

#### Conclusion

We used rigorous qualitative methods to analyze data from four focus groups of Latinos in a northeastern state. Increased understanding of barriers and facilitators of depression treatment in general and depression care management in particular for low-income Latinos should lead to interventions better designed to meet the needs of depressed individuals in this population.

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# **Appendix: Focus Group Leader Guide**

Today we want to talk about the problem of depression, stress, *nervios*, or worries. We say someone is "depressed"

when they feel sad or down, and they do not enjoy doing things. People with depression may have trouble sleeping or sleep too much, may have trouble eating or eating too much, may have trouble thinking or concentrating, and may not have any energy. They might cry a lot, or they might not. They may have trouble getting things done around the house or at work. They might worry a lot and feel stressed a lot.

Hoy queremos hablar del problema de la depresión, estrés, nervios, y preocupaciones. Decimos que alguien está "deprimido" cuando se siente triste o decaído, y no disfruta en hacer cosas. Personas con depresión a veces tienen dificultad durmiendo o duermen demasiado, tienen dificultad comiendo o comen demasiado, les cuesta trabajo enfocarse o concentrarse, y quizás no tienen nada de energía. Pueden llorar mucho o no. Pueden tener dificultad en hacer cosas por la casa o en el trabajo. También se pueden preocupar mucho o sentir mucho estrés.

- Have you known anyone with this problem? (Don't need to tell us who). What was the experience like for them? What did you notice?
   Ha conocido a alguien con este problema? (no nos tiene que decir quién). Cómo era la experiencia para
- 2. What do you think is the best thing to do when you have this problem? Who/where do you go to first?

  Que es lo mejor que uno puede hacer si tiene este problema?

Con quién se ve/adonde va primero?

ellos? Qué notaron?

- a. What are some reasons people do not get help for this problem if they are in need? Que son unas razones porque la gente no recibe ayuda si lo necesita?
- 3. What does your family/country/culture say to do? [cultural aspects]

  Qué les dice su familia/cultura que haga?
  - a. How to overcome barriers if cultural/familial issues arise preventing treatment?
    Cómo uno supera estas cosas cuando por ejemplo (insert what has come up)?
- 4. Did they get help from a doctor or therapist? Why or why not? Recibieron tratamiento de un doctor o terapeuta? Por qué?/Por qué no?
- 5. Did they take medication for depression? Why or why not? Would you ever recommend someone take medication for their depression? Why or why not? Recibieron medicamento para la depresión? Por qué/Por qué no? Recomendarían a alguien que tomara



- medicamento para la depresión? Por qué?/Por qué no?
- 6. What would make it easier to get treatment for depression? Is there anything that doctors could do? That your health plan could do?

Qué se podria hacer para facilitar adquirir tratamiento para la depresión?

## Recent Community Events

- 1. We know that there have been several events recently, including the shopkeeper who asked two Spanish-speaking men for their social security card, and the governor's order asking state employees and police to check immigration status. What impact have these events had on your mood or your behavior? What about the people around you?
  - Sabemos que recientemente han habido varios eventos, incluyendo el dueño de una tienda quien le pidió ha dos hombres que hablaban español por sus tarjetas de seguro social (social security), y el orden del gobernador que pide que empleados del estado y policiá que tienen que verificar estado migratoria. Cómo les ha afectado su estado de ánimo o cómo se ha comportado estos eventos? Y qué tal las personas en su vida? De su comunidad?
- 2. Do these events make it less likely that you would seek treatment from a doctor or a clinic? If so, why? Estos eventos bajan la probabilidad de que vaya a un doctor o clínica? Sí, por qué?
- 3. Do these events make it harder to trust your health plan?
  - Estos eventos le hacen más difícil confiar (tener confianza) con [name of the health plan]?
  - a. What could we do? How can we implement [group members suggestions]?
    - Qué podemos hacer para aumentar la confianza?

# Telephones

- 1. We found that cell phones frequently were turned off. We had a lot of trouble reaching people. Any ideas for how to deal with this problem?
  - Encontramos que teléfonos celulares frequentemente están apagados o desconectados. Tuvimos muchos problemas localizando a la gente. Tienen ideas en cómo podemos solucionar este problema?
- We are wondering if the use of phones is a problem for members. In particular, we are concerned about:

Estamos pensando si el uso de teléfonos es un problema para miembros. En particular estamos preocupados en:

- a. Using people's minutes

  Usar los minutos de la gente
- b. People being worried about telephone scams

  La gente esta preocupada de trampas/trucos
  usados por teléfono para robar dinero.
- c. People being worried about INS

  La gente está preocupada de la migración

Are there other problems with using phones? Is there any way that we can deal with these concerns?

Hay algunos otros problemas con usar teléfonos? Hay algo que nosotros podemos hacer para arreglar estas situaciones/ideas?

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