PTSD in Latino Patients: Illness Beliefs, Treatment Preferences, and Implications for Care

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BACKGROUND: Little is known about how Latinos with post-traumatic stress disorder (PTSD) understand their illness and their preferences for mental health treatment.

OBJECTIVE: To understand the illness beliefs and treatment preferences of Latino immigrants with PTSD.

DESIGN: Semi-structured, face-to-face interviews.

PARTICIPANTS: Sixty foreign-born, Latino adults recruited from five primary care centers in New York and New Jersey and screened for PTSD.

APPROACH: Content analytic methods identified common themes, their range, and most frequent or typical responses.

RESULTS: Participants identified their primary feelings as sadness, anxiety, nervousness, and fear. The most common feeling was "sad" (*triste*). Other words frequently volunteered were "angry" (*enojada*), "nervous" (*nerviosa*), and "scared" (*miedo*). Participants viewed their PTSD as impairing health and functioning. They ascribed their somatic symptoms and their general medical problems to the "stress" from the trauma and its consequences on their lives. The most common reason participants volunteered for their work and school functioning being impaired was their poor concentration, often due to intrusive thoughts. Most expressed their desire to receive mental health treatment, to receive it within their primary care center, and preferred psychotherapy over psychotropic medications. Among participants who did not report wanting treatment, most said it was because the trauma was "in the past."

CONCLUSIONS: Clinicians may consider enquiring about PTSD in Latino patients who report feeling sad, anxious, nervous, or fearful. Our study suggests topics clinicians may include in the psychoeducation of patients with PTSD.

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BACKGROUND

Recent disasters,[1–3] the ongoing immigration of Latinos to the United States, and recognition of disparities in mental health care[4,5] have brought greater focus on accurate recognition and treatment of post-traumatic stress disorder (PTSD) in US Latinos. The 2004 US census estimated that 41.3 million Latinos live in the US,[6] a population larger than that of any Spanish-speaking nation except Mexico,[7] and that 40% of this population is foreign born. And while rates of PTSD range from 8% in the general population[8,9] to 10%-30% in primary care populations,[10–14] Latinos and Latino immigrants may be at higher risk for both the traumas that lead to PTSD[15–18] and PTSD itself.[3,19–21] While studies have examined depression in Latinos presenting for primary care, little is known about PTSD in this population.[22–25]

Providing primary care-based treatment for PTSD that is culturally acceptable to Latinos begins with understanding their conceptions ("illness beliefs") about their PTSD. Illness beliefs are associated with treatment seeking, adherence, and outcomes across health domains.[26–30] According to Leventhal, the main features of patients' illness beliefs include understanding its identity ("What is the illness?"), its causes, its potential and experienced consequences, how long it will last, and the degree to which (and by what means) it can be controlled or treated.[31] For instance, PTSD symptoms are frequently ambiguous (e.g., the avoidance symptoms) or somatic (e.g., the hyperarousal symptoms), and patients may have plausible alternative explanations for their origin.[32,33] Even if patients recognize their symptoms, they may not believe that their symptoms are consequential, affect functioning, or are amenable to treatment. Clinicians who are aware of their patients' beliefs about their traumatic distress may be better able to educate them about their symptoms, address cultural perspectives, and support them through the treatment processes.[34,35]

It is equally important to understand patients' treatment preferences for PTSD. Treatment preferences can influence the acceptability and utilization of mental health services.[36,37] Patients may prefer treatments that the physicians or their practice setting are not able to provide. Understanding Latino patients' treatment preferences can inform mental health service development regarding the selection of PTSD service models (e.g., on-site collaborative care vs. off-site referrals) and specific PTSD treatment services for this population.

Physicians interested in understanding their Latino patients' illness beliefs and treatment preferences regarding PTSD will find little information to guide them. To date, only one study has examined beliefs among patients with PTSD.[38] In a study of veterans receiving VA PTSD disability compensation, participants who believed that their PTSD had a greater negative impact on their lives were more likely to obtain psychotherapy treatment, though no relationship between this belief, seeking medications for PTSD, or medication compliance was identified. To our knowledge, no studies have examined treatment preferences regarding PTSD. Since illness beliefs and treatment preferences may differ between Latinos and their counterparts[39,40] and among patients with different psychiatric problems,[41] we studied the illness beliefs and treatment preferences of Latinos with PTSD.

We conducted semi-structured interviews with Latino immigrant, primary care patients with PTSD to understand: (1) how they identify and experience their PTSD and (2) the perceived knowledge and acceptability of treatment options for PTSD.

METHODS

We performed this qualitative study as part of a larger study that used mixed qualitative and quantitative methods to examine the patient, clinician, and practice-level factors associated with treatment of PTSD among Latino immigrant, primary care patients. This paper concentrates on patient factors. Subsequent papers will report on clinician and practice-level factors.

Sampling and Recruitment

We conducted in-person, semi-structured interviews with patients from five Community/Migrant Health Centers (C/MHCs) in New York and New Jersey that are members of Clinical Directors Network (CDN), a practice-based research network that works with primary care practices in medically underserved communities. These C/MHCs all serve a high proportion of Latino immigrants. These C/MHCs were purposely selected for the larger study to represent structural characteristics we initially hypothesized to be associated with PTSD care delivery. We selected four C/MHCs varying on two key structural factors (high vs. low mental health services integration and high vs. low linkage with community-based social/legal services) and a fifth site in Lower Manhattan to study differences based on exposure to the September 11th attack on the World Trade Center.

Bilingual and bicultural research assistants from CDN who were experienced in community-based research underwent a day of training in PTSD. They recruited potential participants from waiting rooms and performed the interviews. The target population was foreign-born Latino adults (Mexican, Cuban, or other Caribbean, Central and South American), age ≥18 years. Only patients of clinicians who were participating in the study were eligible.

After obtaining signed informed consent, research assistants brought the participants to a private area where they screened for PTSD in two steps—first for a traumatic experience, which is Criterion A of the DSM-IV diagnosis of PTSD, and second for symptoms of PTSD. For the first step, the research assistants administered the Stressful Life Events Screening Questionnaire (SLESQ)[42] modified to include traumas relevant to this population. Following a short discussion in which the participant chose the most "stressful experience," the research assistant administered the PTSD Checklist-Specific Version (PCL-S) as the second step in the PTSD screen. The PCL-S assesses PTSD symptoms in relation to the participant's self-identified "stressful experience." It consists of 17 items that correspond to DSM-IV symptoms of PTSD.[43,44] The PCL-S requires participants to indicate the degree of distress they have experienced for each of the PTSD symptoms ranging from 1 ("not at all") to 5 ("extremely"). Participants met criteria for PTSD symptoms if they endorsed ≥1 intrusion item, ≥3 avoidance/numbing items, and ≥2 arousal items at a severity level of 3 ("moderately") or higher. Finally, the research assistants invited all persons who screened positive for PTSD based on the SLESQ and the PCL-S to participate in an in-person, semi-structured interview. The interview took 45 min and included items inquiring about their illness beliefs and experiences, their relationship with their primary care clinician, coping and social support, barriers to PTSD care, knowledge of PTSD treatments, preferences for PTSD treatments, self-efficacy, and measures of depression, medical comorbidities, and socio-demographics. All materials, including informed consents, the SLESQ, PCL-S, and the semi-structured interview, were available in English and Spanish. Spanish-translated versions of the SLESQ and PCL-S were available from prior studies.[16,45] The semi-structured interview was translated into Spanish by study staff at CDN and reviewed for accuracy by other study staff at CDN and RAND. Interviews were audio-taped and transcribed, and Spanish interviews were translated into English. Participants were compensated $20 for their interview time. The Institutional Review Boards of RAND, Georgetown, and the Clinical Director's Network approved the study.

Sampling Frame

We approached 1,639 persons of whom 1,194 (73%) were ineligible (of these, 786 were not foreign-born Latino; 302 were not eligible patients of the C/MHC; 106 were not seeing an eligible clinician). Of the 445 eligible persons, 270 (61%) refused the trauma screen, thereby refusing the study. One hundred seventy-five (39%) agreed to the study and were screened for PTSD. Of those 175 screened, 62 (35%) screened positive for PTSD, and all were enrolled in the study. Nearly all [n=60 (97%)] persons completed the entire interview.

Coding and Data Analysis

We used content analytic methods performed systematically in six steps. First, taking each interview question at a time, we generated initial themes using a pile-sort method.[46,47] Each response to a given interview question was cut into a separate slip of paper, and three members of the study team (DE, LM, HR) sorted the responses into piles representing similar themes. Second, we reviewed each pile, identified common themes that could be combined, and came to consensus about final themes. Third, we created summary descriptions for each theme and developed a codebook using standard procedures.[48,49] Fourth, we used text management software (e.g., Atlas/ti v5.0) to mark, or "code," instances where themes occurred in the original transcripts.[50] For this report, we present the sections of the interview pertaining to the participants' illness experience, their treatment knowledge and preferences, and their relationship with their primary care clinician. Fifth, the larger research team independently reviewed reports of the coded statements within the themes that emerged to these questions. Finally, the team met multiple times to discuss the question's themes and describe their range and most frequent or typical responses.

RESULTS

Sample Characteristics

Table 1 presents the demographic and clinical characteristics of the study population. Most participants were women, preferred to have the interview conducted in Spanish, had less than a high school education, were married or living with a partner, and were immigrants primarily from the Dominican Republic and El Salvador. The most common violent stressor endorsed was being physically attacked as a teenager or adult (33%); at least 15% of the sample reported experiencing political violence, witnessing another person killed or seriously injured, being sexually molested, or being physically abused as a child.

Table 1. Summary of Participant Characteristics (N=60)

Recruitment site	n	%*
C/MHC 1	10	17
C/MHC 2	14	23
C/MHC 3	11	18
C/MHC 4	14	23
C/MHC 5	11	18
Gender	–	–
Female	54	90
Preferred interview language	–	–
English	9	15
Spanish	51	85
Country of origin	–	–
Dominican Republic	22	36
El Salvador	13	21
Peru, Ecuador, Colombia	11	18
Guatemala, Honduras, Panama, Costa Rica	9	15
Mexico	3	5
Cuba	2	3
Health insurance	–	–
Medicaid	23	38
Medicare	2	3
Private	27	45
None	8	13
Marital status	–	–
Married/living as married	31	52
Divorced/separated/widowed	16	27
Never married	13	22
Highest degree	–	–
None, less than high school	32	53
High school diploma or equivalent	15	25
Some college or more	13	22
Reported traumas**	–	–
Physically abused as child	13	21
Physically attacked as teenager or adult	20	33
Sexual molestation	11	19
Raped, forced oral/anal sex	9	13
Witnessed death/injury of other	11	18
Family member killed/disappeared from political violence	9	15
Witnessed death/injury of many people during political violence	7	11
Personally beaten/raped during political violence	2	3
Other—not specified	3	5

**Percentages may not add to exactly 100% due to rounding error.*
***Participants could endorse multiple events so percentages do not add up to 100%*

Illness Experience

Since our screening for PTSD required a specific traumatic experience that the participant would describe as "very frightening" or that "made them feel helpless," our first questions referred directly to this trauma. To learn what participants viewed as the primary psychological sequelae of their trauma and what words they spontaneously chose to describe this, we asked "What kind of emotional distress do you feel? What do you call this distress?" Most participants used remarkably similar language to describe their emotional distress. The word most commonly chosen was "sad" (*triste*, n=38). Other words frequently volunteered were "angry" (*enojada*, n=13), "nervous" (*nerviosa*, n=12), and "scared" (*miedo*, n=10). Most participants listed several descriptors, for instance, "I get sad, nervous and I have a lot of rage inside of me." All but one person saw their distress as a consequence of their trauma, many adding emphasis with "a lot," "of course," or "everything to do with it."

When asked, "Does this experience affect your general health in any way," most subjects (n=49) answered that their traumas affected their health either directly or through the "stress" it caused in their lives (e.g., affecting their relationships and work). Only 11 patients perceived no effect of the trauma on their health. Physical symptoms were frequently reported, with the most common symptom being headaches. Other reported symptoms or illnesses precipitated or affected by trauma were poor appetite, dizziness, high blood pressure, low blood pressure, high blood sugar, asthma, stomach ulcer, gastritis, body pains, constipation, high cholesterol, arthritis, and liver and heart problems. Almost half the patients mentioned mental health symptoms, including stress, nervousness, anxiety, and sleep difficulties due to nightmares and stress.

> Yes, it affects my health a lot. When someone has gone through something as horrible as this it affects both one's mental and physical health. I can't sleep. I have nightmares and feel stressed out all the time.

We also asked participants, "How does this experience affect your life?" Most reported it affected their functioning at work, school, and relationships with friends or family. More than half said it affected work. The most common reason participants volunteered for their work and school functioning being impaired was their poor concentration, often due to intrusive thoughts.

> Yes, it affects me a lot because I can't think well. I forget everything. I used to work at a paper plate factory and I would have to count things over and over because I was constantly forgetting the number I was on.

Other reasons mentioned included lack of energy and irritability that harmed relationships with co-workers. Consequences of the resulting PTSD symptoms on work were reported, such as losing a finger at work due to concentration problems and fear of working in unfamiliar neighborhoods.

> I can't stop my mind from wandering and thinking about the past. I had an accident at work and I cut off two of my fingers.

However, other (n=6) patients described work as a form of active coping.

> I work all the time, maybe I work in order to forget all those bad memories.

Patients described effects on friends/family including isolation, distrust, not feeling comfortable, and avoiding social activities that would remind them of past events.

> I am not the same ever since this happened. If they invite me out, I won't go because I'm scared to go out late at night.

Treatment Preferences and Knowledge

In response to our query, "What kind of help would you like to receive for your emotional distress," most participants (n=48) said they wanted some kind of help. Forty of these 48 participants spontaneously mentioned "counseling," "therapy," and "someone to talk to" as the type of help they want. Nine of the 12 participants who did not want to receive any help said it was because the trauma was "in the past" and therefore not amenable to treatment.

> I don't think so because it's in the past and I can't change it.

Medication was mentioned infrequently; only four persons referred to it, of whom one specifically rejected it as an acceptable treatment option.

> I would like to get psychological help but not medications. To be able to talk to someone so I can share all my problems and feelings.

Other requests were for self-help materials, social service/employment assistance, or simply "whatever the doctor recommended." Seven persons answered that they did not know what kind of help they would like to receive, for instance, "I don't know what type of help would be good for me."

When prompted with the query, "Would you get [help] from your health care clinic?" almost all agreed to receiving the service from within their primary care practice. In contrast, when prompted with the query, "Would you ask for help from your family or friends?" less than half were willing to ask for help from family or friends, citing the "personal" nature of their problems, shame or distrust, and fear of an abusive spouse.

> No, my problems are very personal. I don't like to talk to my family or friends about my problems.

Relationship to Primary Care Clinician (PCC)

Asked "Do you think your clinician would be able to help you?" over half of the participants (n=35) believed their PCC could help them. Participants spontaneously mentioned several ways their PCC could help them, including providing referrals to mental health specialists ("therapists," "psychiatrist"), providing counseling themselves, medications, and providing patient education ("giving the patient information about the problem and letting them know where the problem comes from"). A few participants stated that the PCC could not help because he would just refer them to a specialist ("No, the only thing he can do is refer me to a psychologist.")

Asked "What if the clinician asked you about your distress?" most patients (n=51) were willing to discuss it, even if they were uncomfortable doing so ("This is not something that I like to talk about, but I think that I would talk about it;" "I would answer his questions, but I don't think that I would feel comfortable talking about it.") Among those who were not willing to discuss it, the most common reported reason was that they were uncomfortable or ashamed of discussing it with their provider (n=9). However, for three of these persons the discomfort was attributed to practical obstacles, such as the presence of a translator in the room, or gender discordance with the PCC.

DISCUSSION

This is the first study to examine Latino patients' views about PTSD and its treatment. Most participants identified their primary feelings as sadness, anxiety, nervousness, and fear, and understood this distress as resulting from a trauma. They viewed their distress and PTSD as consequential in all domains, including health, social and family life, and in their occupations. They particularly ascribed their somatic symptoms, such as headache, and their general medical problems to the "stress" from the trauma and its consequences on their lives. Most desired to receive mental health treatment within their primary care center (albeit, in response to a close-ended question) and to receive psychotherapy rather than medications. This is consistent with previous findings of treatment preferences in primary care that reported 95% of Latinos viewed counseling as an acceptable treatment option for major depressive disorder, but only 59% found pharmacotherapy acceptable.[51,52] The few participants who did not want PTSD treatment said it was because the trauma was "in the past" and therefore not amenable to treatment.

Our results have implications for detecting and treating PTSD in primary care. First, participants described sadness as the primary feature of their distress. Anger and nervousness were the next most common descriptors used. The fact that participants used such similar language in this study and also in previous studies[53] indicates these words may be diagnostic clues for providers suspicious of PTSD. Clinicians may be tipped off to the possibility of PTSD in Latino patients who report feeling sad, nervous, or stressed. Most participants said they would answer clinicians' enquiries regarding their trauma and distress. Even participants who said they would not be comfortable doing so said they would feel "obligated" to answer or trusted that their providers needed to know and that it would benefit them.

Clinical guidelines and experts commonly recommend that clinicians provide patients with "psychoeducation" about the illness being diagnosed, but are less explicit about what topics PCCs should discuss.[54–56] Our study suggests topics that primary care clinicians may want to emphasize. For instance, participants associated their traumas and psychological distress to their physical health. This underscores the importance of understanding Latino patients' illness beliefs that link mental and physical health—a belief that is supported by empirical research.[57–59] Clinicians may find that educating patients to recognize and understand PTSD symptoms and talking about the link between trauma and physical health may make treatment seem more immediately useful to patients; identifying short-term treatment goals that focus on reducing the severity of these symptoms may further improve patients' acceptance of treatment and increase long-term adherence to effective therapies.[60,61] Many participants also noted the large impact that the symptoms had on their relationships and on their work functioning; one participant even reporting a serious injury due to his impaired concentration. Again, these issues make the impact of symptoms very real and offer practical and "quality of life" reasons for addressing them that the clinician may use to engage patients in a discussion about treatment. Many study participants who thought that their PTSD could not be helped said it was because the trauma was "in the past." These patients might benefit from understanding that clinical improvement does not require forgetting about the event or having no emotional distress when thinking about it. Lastly, a few participants stated that the primary clinician could not help because he or she would just refer them to a specialist. This points to the need for education on the role of PCCs in referral—PCCs might want to reframe the value of referral as not "blowing it off," but rather emphasizing their expertise in diagnosis, knowing available treatments, and continuing to educate throughout the PTSD treatment.

Our results regarding treatment preferences raise complex issues. Several studies document Latinos, African Americans, and whites reporting their depression treatment preferences for counseling over medications.[62] However, there is a mismatch between participants in our study preferring psychotherapy, preferably in the primary care setting, and the availability of counseling for low-income ethnic minorities generally, nevertheless co-located in primary care settings. While physicians may be inclined to match PTSD treatment to patient treatment preferences, the evidence supporting this appears inconclusive at least in the field of depression treatment, where matching depression treatment to patient preference may or may not improve depression outcomes.[63–65] Furthermore, treatment preferences in studies like ours may not translate into actual treatment choices, especially among minority populations who may have misconceptions about medications or limited treatment experience and knowledge.[62] In fact, education about medications can improve their acceptability to patients, as demonstrated in one randomized controlled trial of treatment for major depression in low-income ethnic-minority women.[25] In that study, participants reluctant to begin medications or psychotherapy could attend educational sessions to teach them about depression care; 96% of women in the antidepressant medication arm attended sessions before agreeing to begin medications. Psychoeducation sessions could be led by trained social workers and nurses, thereby relieving the burden from physicians.[25,62]

This study is limited by its convenience sampling methods and the high refusal rate. Ethical considerations prevented us from collecting person-level data on non-participants, hindering any comparison of non-participants and participants. However, we believe that the high refusal rate is partially attributable to the nature of our target population, foreign-born Latinos, many of whom are likely undocumented aliens who do not want to risk being identified. Moreover, the study was performed in New York and New Jersey, and the sample was predominantly female, so the findings are not necessarily representative of Latino populations across the US. In particular, our sample included mostly immigrants from the Dominican Republic or Central America with few participants of Mexican or Cuban heritage, so it remains to be seen if these results apply to Latinos from other countries. It is also unclear if the trauma this sample endured is representative of trauma that leads to PTSD in the broader Latino population. As with most qualitative studies, the objective was to gain deeper understanding from participants. These results should be validated using quantitative methods and performed in more representative Latino samples. Our study did not include a control group of Latinos without PTSD. This limits our ability to make conclusions about many of our findings. (For example, the present design makes it harder to decipher the significance of feeling "sad" when we don't really know how commonly such feelings are identified in those without PTSD.) The study contributes to the literature despite these limitations, because no studies have focused on the attitudes of US ethnic minorities toward PTSD and its treatment. Its strengths include the use of qualitative interviews allowing participants to describe their experiences, beliefs, and preferences in their own language and the study's inclusion of patients from five sites in two states.

Should future studies confirm our findings, clinicians caring for Latino immigrants may be able to improve their PTSD care by being alert to linguistic clues of traumatic stress and addressing a range of topics when providing PTSD psychoeducation. Clinicians should consider assessing preferences for PTSD treatment and educating patients on the range of treatment options as well as the active role they will have in their treatment.

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