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ORIGINAL ARTICLE

Family processes and duration of untreated psychosis among US Latinos

Mercedes Hernandez[1] | **Maria Y. Hernandez**[1] | **Daisy Lopez**[1] | **Concepción Barrio**[2] | **Diana Gamez**[1] | **Steven R. López**[1]

[1]Department of Psychology, University of Southern California, Los Angeles, California

[2]Suzanne Dworak-Peck School of Social Work, University of Southern California, Los Angeles, California

Correspondence
Mercedes Hernandez, Steve Hicks School of Social Work, University of Texas at Austin, 1925 San Jacinto Boulevard (D3500), Austin, TX 78712-1405.
Email: mercedeh@utexas.edu
Steven R. López, Department of Psychology, University of Southern California, 3620 S. McClintock Avenue, Los Angeles, CA 90089-1061.
Email: lopezs@usc.edu

Present address
Mercedes Hernandez, Steve Hicks School of Social Work, University of Texas at Austin, Austin, TX.
Maria Y. Hernandez, School of Social Work at California State University, Los Angeles, Los Angeles, CA.
Daisy Lopez, Department of Psychology, University of Miami, Coral Gables, FL.
Diana Gamez, School of Education, University of California, Irvine, Irvine, CA.

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Aim: Little is known about family processes and treatment seeking among Latinos with first-episode psychosis (FEP) living in the United States. This study examined family processes prior to treatment and their relation to duration of untreated psychosis (DUP) among Latinos with FEP and their family caregivers.

Methods: Thirty-three Latinos with FEP and their low-acculturated family caregivers (n = 33) participated in qualitative semi-structured interviews focused on treatment-seeking experience and family relationships. Transcripts were analysed using thematic analysis and themes were grouped based on short (n = 18) or long (n = 15) DUP.

Results: Findings revealed differences based on DUP length. Patients with short DUP had stronger family relationships characterized by open communication and disclosure of symptoms that facilitated awareness and direct action by family caregivers. However, patients with long DUP had more troubled family relationships that often challenged early treatment seeking.

Conclusions: Findings highlight the relevance of family context in the provision of early treatment for Latinos with FEP. Family-based services are needed that increase awareness of symptoms and provide families with support that can facilitate ongoing patient treatment during this critical period.

KEYWORDS
duration of untreated psychosis, family caregivers, first-episode psychosis, Latinos

1 | INTRODUCTION

Duration of untreated psychosis (DUP), the period between illness onset and treatment, is an important predictor of outcomes for individuals experiencing first-episode psychosis (FEP). Patients with short DUP have better clinical and functional outcomes than those with long DUP (Marshall et al., 2005; Perkins, Gu, Boteva, & Lieberman, 2005). Timely treatment is influenced by various individual and contextual factors, including the role of families, which is critical in service provision (Addington, 2007; McCann, Lubman, & Clark, 2011). Although studies have called attention to family context in pathways-to-care models, little is known about specific strategies families use to seek care for their loved ones. Learning about these family processes, especially those malleable to change, is important to reducing DUP.

Family processes, as observed in family interactions, illustrate how family systems function and may highlight strategies used to respond to a loved one with early psychosis. For example, perceptions of a positive and warm family environment among patients with FEP were associated with lower risk of patient relapse (Lee, Barrowclough, & Lobban, 2014). Similarly, studies have found that caregiver perceptions of family strengths and support were related to shorter DUP among patients with FEP (Compton, Goulding, Gordon, Weiss, & Kaslow, 2009; Goulding et al., 2008; Mo'tamedi et al., 2014). Although these studies included African American (Compton et al., 2009;

Goulding et al., 2008) and Iranian (Mo'tamedi et al., 2014) patients, their quantitative methodologies gave little consideration to social context and family processes that may have led to treatment seeking.

Family processes operate in a larger social context (Szapocznik & Kurtines, 1993) that shapes how family systems perceive and address symptoms and behaviours (López & Guarnaccia, 2000; Rogler & Cortes, 1993). Although studies (Bergner et al., 2008; Compton et al., 2009; Compton, Kaslow, & Walker, 2004; Connor et al., 2016) have identified several family-level factors associated with treatment initiation, it remains unclear how family processes differ among racial and ethnic groups and may affect the treatment-seeking experience. The few studies involving racial and ethnic families and FEP have focused on African Americans. There is little research to date on Latinos with FEP and the role family plays in treatment seeking. Latinos and other immigrant minority groups not only may have varying perceptions regarding their role during the initial treatment-seeking process, but also may be affected by contextual factors related to English language proficiency or mental health literacy, for instance. Latinos are less likely to seek and receive adequate mental health treatment compared to other groups (Alegría et al., 2002, 2007; Barrio et al., 2003). As a result, Latinos with FEP may be especially vulnerable to long DUP that places them at risk of worse treatment outcomes. Yet Latinos with serious mental illness are more likely to live with their families compared to other groups (Barrio et al., 2003), underscoring the relevance of examining family context and treatment seeking in this vulnerable group.

Taken together, these studies suggest that family-level factors must be considered in a larger social context to develop a more nuanced understanding of unique family processes involved in DUP for racial and ethnic minority groups. This study explored family processes prior to treatment and their relationship to DUP for Latinos experiencing early psychosis. Research to understand family processes that support or delay treatment initiation may lead to improved pathways to early intervention for Latinos and other underserved groups with FEP.

2 | METHODS

The parent study seeks to reduce DUP among Latinos with early psychosis in the San Fernando Valley in Southern California through a communication campaign. Forty-three patients and 41 family caregivers were recruited during a 15-month baseline at a public outpatient mental health clinic and psychiatric hospital (Hernandez et al., 2018). For the current study, only complete dyadic qualitative baseline data were used, generating a sample of 68 participants (n = 34 patients; n = 34 family caregivers). Patients met study criteria if they (a) self-identified as Latino; (b) were 15 to 64 years old and (c) had a clinical diagnosis of a psychotic disorder, including mood disorders with psychotic features. Exclusion criteria consisted of having a diagnosis of a psychotic disorder due to a general medical condition or prior treatment for psychosis consisting of more than 1 year of continuous antipsychotic medication. This 1-year period is longer than that used in the early treatment and intervention in psychosis study (TIPS; >12 weeks or until remission of psychosis; Melle et al., 2004) and the recovery after an initial schizophrenia episode (RAISE; ≤ 6 months of lifetime antipsychotic medications; Kane et al., 2015) study. Following either of these time limits would have significantly reduced our sample size. Once patients agreed to participate, they identified a primary caregiver who could also be contacted. Written informed consent was obtained from all participants and written assent was secured from those younger than 18 years of age. The study was approved by the university's institutional review board.

Data related to DUP were obtained from patient and caregiver interviews and analysed to reach consensus. Further details on DUP in the parent study will be presented elsewhere. We defined DUP using first outreach contact for psychotic symptoms. Family processes are most relevant using this definition of DUP as family members typically decide the first contact. Specifically, weeks between illness onset and any treatment, defined as seeking treatment from a medical doctor, other professional, or non-professional, for psychosis-related symptoms was calculated for the 34 patients. Based on the variable's distribution, an outlier was removed. The median (13 weeks; range 0-809 weeks) was used to determine short, (n = 18; ≤13.00 weeks) and long (n = 15; ≥13.01 weeks) DUP groups for the remaining 33 patients. As seen in Table 1, one patient had a DUP of 18 weeks. Although this patient's DUP was above the median, it was closer to the short DUP group and therefore was assigned to this group.

Semi-structured interviews were conducted with patients and family caregivers in their preferred language. Interviews focused on

TABLE 1 Distribution of patient DUP (onset to any help) in short and long DUP groups (N = 33)

Weeks	Short DUP (n = 18)		Long DUP (n = 15)	
	n	%	n	%
0	8	24.2		
1.57	1	3.0		
1.86	1	3.0		
4.29	2	6.1		
4.86	1	3.0		
6.71	1	3.0		
7.29	1	3.0		
11.29	1	3.0		
13.00	1	3.0		
18.00	1	3.0		
34.71			1	3.0
39.00			2	6.1
54.14			1	3.0
65.29			1	3.0
97.86			1	3.0
115.14			1	3.0
119.86			1	3.0
157.14			1	3.0
185.14			1	3.0
293.57			1	3.0
339.14			1	3.0
458.57			1	3.0
678.43			1	3.0
809.29			1	3.0

Abbreviation: DUP, duration of untreated psychosis.

several areas of treatment seeking, including family relationships and patients' pathways to care. Questions exploring family relationships included: "Could you tell me about your family? What was going on in [your or your family member's] life that made you want to come to the clinic?" with follow-up probes to capture participants' views on family relationships prior to treatment. Transcripts were analysed for instances that may have also addressed family relationships prior to treatment.

2.1 | Analysis

Transcripts were analysed using thematic analysis (Boyatzis, 1998) by four bilingual and bicultural team members familiar with the literature on pathways to care. Team members were blinded to participants' DUP length during coding. Codes were derived through open coding by line-by-line reading of transcripts focusing on participant responses to questions on family relationships and treatment seeking. After independent coding of a subset of interviews, results were compared to reach consensus. Once consensus was reached, a codebook was developed, and the team coded the remaining interviews, further synthesizing codes as needed. Codes were then grouped based on DUP length. Analysis included comparing codes across and within patient and caregiver transcripts. Memo writing was used throughout the analysis to document decisions regarding theme development. Dedoose analytic software was used to organize and code the data.

3 | RESULTS

Table 2 presents demographic information. Most caregivers were parents and had higher Spanish (*M* = 3.66, SD = 0.70) proficiency compared to English (*M* = 2.56, SD = 1.08), $t(31) = -4.35$, $P < 0.001$. Although more patients with short DUP (n = 15, 65%) lived with caregivers prior to treatment compared to patients with long DUP (n = 8, 35%), there were no significant differences ($P = 0.13$; Fisher's exact test). Patients with short DUP (*M* = 23, SD = 5.85) were younger compared to those with long DUP (*M* = 30, SD = 10.75), $t(31) = -2.43$, $P = 0.02$. Patients who lived with caregivers (*M* = 24, SD = 7.36) prior to treatment were not significantly younger than patients who did not live (*M* = 30, SD = 11.33) with caregivers, $t(31) = 1.90$, $P = 0.07$.

Several themes (Table 3) depicted family processes that facilitated or challenged patient treatment initiation, with noted differences between short and long DUP. Representative quotes are featured in Table 4. Specifically, three main themes emerged: (a) relationships, (b) awareness and (c) treatment seeking.

3.1 | Relationships

3.1.1 | Short DUP

Affectionate, engaged. Patients with short DUP had family relationships with more emotionally supportive and affectionate interactions prior to treatment initiation compared to those with long DUP. These patients and families had an interest in engaging with each other and sought opportunities to spend time together.

TABLE 2 Patient and family caregiver characteristics

	Patient (N = 33)		Caregiver (N = 33)	
	n (%) or *M* (SD)	Range	n (%) or *M* (SD)	Range
Gender (male)	23 (70)		6 (18)	
Age (y)[a]	26 (9.05)	15-55	42 (10.48)	25-62
Education (y)[a]	10 (2.99)	0-16	11 (4.16)	2-17
Relationship with caregiver				
Parent			19 (58)	
Sibling			7 (21)	
Spouse/partner			5 (15)	
Other family[b]			2 (6)	
Place of birth[c]				
United States	18 (56)		8 (25)	
Mexico	5 (16)		14 (44)	
Central America	8 (25)		9 (28)	
South America	1 (3)		1 (3)	
Years in United States[d]	18 (9.21)	2-34	25 (9.86)	6-41
Interview language				
English	22 (67)		12 (36)	
Spanish	11 (33)		21 (64)	
English proficiency[a,e]	3.33 (0.85)	1-4	2.56 (1.08)	1-4
Spanish proficiency[a,e]	3.36 (0.96)	1-4	3.66 (0.70)	1-4

[a] Data missing for one caregiver.
[b] Daughter, sister-in-law.
[c] Data missing for one patient and one caregiver.
[d] Data presented for foreign-born participants only.
[e] Language skills were assessed based on one question regarding how well the participant speaks each language based on a 4-point Likert scale. Higher value indicates higher self-perceived proficiency.

Active communication. Patients with short DUP and their caregivers tended to have more active communication. Some caregivers asked patients questions when they noticed a change in behaviour. Active communication seemed to reflect trust in patient and caregiver dyads that may have facilitated earlier detection of symptoms.

TABLE 3 Observed differences between short and long DUP and families

Themes	DUP length	
	Short	Long
Relationships	Affectionate, engaged	Rift with family, lack of engagement
	Active communication	Poor communication
Awareness	Lower threshold to behavioural change	Higher threshold to behavioural change
	Patients disclosed symptoms	Patient treatment resistance
		Accommodation
Treatment seeking	Family caregiver direct action	Lack of family caregiver direct action
	Extended support network	

Abbreviation: DUP, duration of untreated psychosis.

TABLE 4 Quotes supporting themes and subthemes for short and long DUP and families

Themes and subthemes	Quotes
Relationships	
Short DUP	
Affectionate, engaged	“Before [the illness] we would go to the movies, we liked going out to eat. … We always try to spend time together.” (Patient)
Active communication	“He was into boxing. He would go to the gym, and then one day he just said, ‘I don't want to go anymore,’ and we couldn't even get him to tell us why. … We kept trying to … we kept bugging him.” (Caregiver)
	“My mom was the one who was most aware of what was happening to me and I would try to find a refuge in her, for her to help me think … so that I could avoid all the thoughts that were hurting me.” (Patient)
Long DUP	
Rift with family, lack of engagement	“She [caregiver] does not help me, she irritates me.” (Patient)
	“I came to live alone, and there was no longer any problem. … Sometimes I feel better like this so that there is less conflict with my family.” (Patient)
	“That caused for them two [patient and brother] to fight physically and officially from there they [father and brother] just kicked him [patient] out. … That's when he just disappeared. … He was out for … maybe a year and a half.” (Caregiver)
Poor communication	“Me and her [patient] would go back and forth, but then after a while it would be that, I would just like shut down. ‘So, you can stand there and yell at me all you want, I'm going to ignore you and I'll let it be known that I'm ignoring you.’” (Caregiver)
Awareness	
Short and long DUP	
Misattributions	“She [mother] just figured he was acting up. He's a teenager, you know. Smoking weed, and she couldn't handle him.” (Caregiver)
Short DUP	
Lower threshold to behavioural change	“She started speaking more and more about God, and that God was sending her messages.” (Caregiver)
Patients disclosed symptoms	“I was hearing voices in my head. …Well my parents were scared. They were the ones that were worried.” (Patient)
	“He had already told me what the voices were telling him.” (Caregiver)
Long DUP	
Higher threshold to behavioural change	“From around 2 to 3 years until now, he has become a little more aggressive.” (Caregiver)
Patient treatment resistance	“When we were right by the car, he wouldn't get in the passenger seat. He would just step back and say, ‘You know what? Never mind.’” (Caregiver)
Accommodation	“We would ask her to calm down. … There was no other help. … We would do nothing … until she would fall asleep.” (Caregiver)
Treatment seeking	
Short DUP	
Family caregiver direct action	“We noticed for about three days, given that we work together, I noticed the change right away and [knew] something was wrong. … We did not leave him like that for long.” (Caregiver)
	“It was the first time that I saw him [with symptoms], but that was enough, it was sufficient.” (Caregiver)
	“There were many obstacles to get to where we are now. … I had to move here and there … because they were doing nothing for him.” (Caregiver)
Extended support network	“My sister, given that she has gone through similar things with her children, she was the one who told us, ‘I think this child needs help, here are some places where they can help him.’” (Caregiver)
	“My oldest son went to speak with the psychiatrist because the psychiatrist does not speak Spanish and my son speaks English…my son could explain to him all that [patient] was doing and that is how the psychiatrist was able to help us faster.” (Caregiver)
Long DUP	
Lack of family caregiver direct action	“I never went [to social service agency]; my [other] daughter went to fill out the application, but for whatever reason, it never went through.” (Caregiver)
	“Well, when she [patient] got more, and more like that, then we started talking with my wife ‘we need to seek help for her [patient]’…and I said we should do it… last five years it has already been … more about 10 years it is already bad.” (Caregiver)

Abbreviation: DUP, duration of untreated psychosis.

3.1.2 | Long DUP

Rift with family, lack of engagement. Although caregivers of patients with long DUP demonstrated instrumental support, they tended to have more distant relationships. On several occasions, patients described a rift with their family of origin that occurred prior to treatment initiation. For some, these rifts led them to no longer live or communicate with family members.

Poor communication. Lack of communication with caregivers was more common among patients with long DUP. Poor communication was often related to disagreements, resulting in arguments. For some, arguments lead to troubled family relationships wherein patients and caregivers stopped speaking to each other.

3.2 | Awareness

3.2.1 | Short and long DUP

Misattributions. Misattribution of symptoms occurred with all caregivers, regardless of DUP length. Caregivers commonly attributed symptoms to developmentally appropriate behaviour found among adolescents, such as isolating from family and avoiding activities. In addition, some caregivers attributed behaviours to life stressors or substance use. For the most part, caregivers did not connect these early behaviour changes to a possible mental illness.

3.2.2 | Short DUP

Lower threshold to behavioural change. Differences were found in the types of behaviours and symptoms most commonly noticed by caregivers suggesting possible differences in caregivers' threshold for patients' behaviour. Caregivers of patients with short DUP were more prone to notice when patients deviated from their usual behaviour. These caregivers tended to notice odd behaviour, such as poor hygiene or speech.

Patients disclosed symptoms. For some families, patients' disclosure of their symptoms to caregivers caused awareness of a possible illness. This was common among patients with short DUP. These patients were more willing to disclose their symptoms, perhaps because they tended to have more positive relationships with caregivers who exhibited trust and caregivers were less likely to describe patients as aggressive compared to caregivers of patients with long DUP.

3.2.3 | Long DUP

Higher threshold to behavioural change. Caregivers of patients with long DUP perceived more acting out or aggressive behaviour. Caregivers said patients would become irritated easily, in some cases leading to arguments. These behaviour changes happened over time and were not seen as an immediate cause for concern.

Patient treatment resistance. Awareness of behaviour change did not always lead to treatment. Despite efforts to access services, many caregivers struggled with patients' resistance to treatment. Although resistance was found among patients regardless of DUP length, it was more common among patients with long DUP.

Accommodation. Prior to caregivers' knowledge of their loved one's illness, they accommodated the patient's behaviour by avoiding negative interactions that would aggravate the situation. Accommodation was common among families of patients with long DUP.

3.3 | Treatment seeking

3.3.1 | Short DUP

Family caregiver direct action. Treatment generally did not begin until symptoms escalated, leading to immediate action. Importantly, caregivers of patients with short DUP took direct action sooner when noticing patient behaviours. Direct action included asking health providers about the patient's behaviours, seeking emergency services or asking for support from extended family. Despite experiencing challenges in accessing care, these families demonstrated perseverance and resilience.

Extended support network. Treatment initiation was also prompted by extended family and friends who offered support. Having a social network member who had knowledge of mental health issues and treatment because of previous experience was important. Although social network support was seen across family systems regardless of DUP length, it was more common among patients who had short DUP.

3.3.2 | Long DUP

Lack of direct action. In contrast, caregivers of patients with long DUP tended to delay treatment when facing obstacles. For example, a father explained how he attempted to help his daughter access services but did not have support from providers, whom he could not communicate with due to lack of English proficiency. Therefore, time passed, and the patient did not receive treatment.

4 | DISCUSSION

Findings highlight the central role of family context in initial treatment seeking among US Latinos with FEP. Quality of relationships, as reflected in positive interactions and open communication, was related to caregivers' awareness of the illness, because patients were more open to communicating their symptoms and caregivers questioned patients and sought immediate care. Positive relationships among patients with short DUP may have facilitated the family's influence in treatment seeking by allowing more collaboration with patients. In addition, these families may have had resources that enabled coping and resilience under stressful circumstances often associated with early psychosis. Family strengths and coping have been related to shorter patient DUP in quantitative studies (Compton et al., 2009; Goulding et al., 2008; Mo'tamedi et al., 2014). Our study adds to the literature by using qualitative methods, permitting further exploration of patient and caregiver experiences for a more comprehensive perspective of family processes during this critical period.

Findings also highlight patient and systemic barriers that persisted despite caregiver awareness of symptoms, particularly among patients with long DUP. Families of patients with long DUP tended to have more troubled relationships. It is important to note that affectionate and engaged relationships were present in some long DUP families; however, when compared to short DUP families they were less common.

Misattributions of the illness were found among caregivers, regardless of DUP length. There seemed to be a lower threshold for caregivers of patients with short DUP who noticed behavioural changes and took direct action whereas caregivers of patients with long DUP seemed to have a higher threshold for behaviour changes. Differences have been found in cross-cultural studies examining threshold for behaviour problems (Weisz, Suwanlert, Chaiyasit, &

Walter, 1987), suggesting that social context is important in how caregivers respond to early signs of the illness.

Possible differences in perceptions of behaviour change may explain why families of patients with long DUP were more prone to accommodate the illness before seeking treatment. When caregivers noticed behavioural changes in the patient, they tried to address it; when these attempts did not resolve the problem, they accommodated the behaviour by changing their patterns of interaction, restoring balance in the family system. It was not until the symptoms became severe that treatment was initiated. Latino family caregivers have been found to accommodate behavioural changes in their loved ones (Rogler & Cortes, 1993) and report low caregiver burden despite probable strain (Hernandez, Barrio, & Yamada, 2013). If early symptoms are less problematic, they may be easier to dismiss. Studies with African American families have also found they are willing to accept milder symptoms and only seek care once symptoms become problematic (Compton et al., 2004).

Attempts by families to address behaviours by accommodating the patient's needs may have prevented earlier detection of the illness. It may have been especially challenging if any attempts at addressing the problem were accompanied by the patient's refusal of treatment or other barriers such as English language proficiency. Notably, families of patients with long DUP had experienced and perhaps accommodated behavioural changes for longer, and therefore may have been exposed to more responsibilities (Compton et al., 2009) compared to those with short DUP. The combination of these factors may contribute to excessive caregiver burden and complicate interpersonal relationships.

Latinos are a heterogeneous group; as such, our sample of mostly Mexican-origin participants may not be generalizable to other US Latino groups. However, findings may be relevant for other patients with FEP and family caregivers from minority groups. Our sample contained individuals with affective psychosis, given our interest in reaching the most people with FEP. In addition, using the median to determine long and short DUP may not accurately capture DUP groupings, given more variability in the long DUP group. Participants were interviewed after their initial treatment experience and as such may not fully recollect details regarding their experience prior to treatment. Nevertheless, findings highlight family behaviour and patterns related to the initial treatment-seeking experience. Despite the non-significant results for living situation and DUP group and living situation and age, future studies should consider examining these relationships with a larger sample. Most caregivers were parents; future studies should consider possible differences based on family composition. Future studies should also examine family processes and DUP using longitudinal data to gain insight on the trajectory of family processes and long-term outcomes.

Findings have relevant implications for early intervention efforts. For instance, families of patients with short DUP demonstrated that emotionally supportive relationships and resilience are important to treatment seeking. Providers should consider treatment approaches that foster these relationships because they can be critical for continued treatment. We found that misattributions were common regardless of DUP length. To improve awareness of potential symptoms, it is important to provide Latino and other underserved family caregivers with knowledge about the illness and community resources in a manner congruent with their needs and preferences. Interventions targeting Latino family and community members' knowledge of psychotic symptoms to address possible misattributions and promote early treatment seeking have been found to improve awareness of psychotic symptoms (Calderon et al., 2015; Casas et al., 2014; Hernandez, Mejia, Mayer, & López, 2016; López et al., 2009). Family psychoeducation is beneficial for Latino patients with an established illness (Kopelowicz et al., 2012), and interventions for patients with FEP and their families also show promise (Day, Starbuck, & Petrakis, 2017). Families are a necessary component of early intervention services. As such, an important goal of treatment should be to support family functioning, which can lead to early treatment seeking and benefit patient recovery and family well-being.

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ORCID

Mercedes Hernandez https://orcid.org/0000-0001-8480-8725

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