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Pathways Through Care of Latinx Individuals Experiencing First-Episode Psychosis

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PATHWAYS THROUGH CARE OF LATINX INDIVIDUALS EXPERIENCING
FIRST-EPIISODE PSYCHOSIS

A Thesis
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Science
in
Clinical Counseling Psychology

by
Estevan Hernandez
August 2023

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ABSTRACT

Many individuals experiencing first-episode psychosis (FEP) are unable to work or live independently due to the debilitating nature of their illness. Many individuals experiencing FEP fail to seek mental health treatment for their symptoms. The families of these individuals are often the first to notice early signs of psychosis and seek treatment for the individual (Bridges et al., 2012). There continues to be a high percentage of disengagement from mental health services which may, in turn, contribute to poorer outcomes across various areas in one's life (Kreyenbuhl et al., 2009). There continues to be a high percentage of disengagement from mental health services which may, in turn, contribute to poorer outcomes across various areas in one's life (Kreyenbuhl et al., 2009). Given the high rates of disengagement from mental health services, understanding the pathways through care (i.e., the pathways or trajectories one may experience as they continue their mental healthcare) of individuals with FEP and their families' pathways through care may help us better understand why some people disengage from care while others remain engaged in care. The current study aimed to help address aim three of the parent study by exploring factors that affect engagement in mental health services in Latinx individuals experiencing FEP and their families using qualitative methods. The current study also explored critical socioeconomic barriers that may influence engagement in services among Latinos with FEP and their families as well as barriers for continued care that are not characterized as socioeconomic in nature. Grounded

theory methods were one approach to meeting this qualitative study's objectives. Grounded theory methodology was used to examine the influence socioeconomic barriers have on service engagement along the pathway through care for Latinx individuals experiencing FEP. For this study, individual and family cases were used to develop conceptual categories to synthesize, explain, and understand the data and to identify patterns of relationships among the conceptual categories (Charmaz, 1996). Data collection and analyses followed grounded theory methodology as well. Results described facilitators such as aiding the individual to adhere to care and caregiver advocates for the individual's care, and barriers such as caregiver and individual unable to afford continued care, along the pathways through care. Our findings suggest that the pathways through care for this population are complex and multifaceted. Further research is needed to better understand and conceptualize the experiences and underlying factors at multiple levels that may contribute to racial-ethnic mental health disparities in order to identify points along the pathways through care that may increase the likelihood of consistent engagement in mental healthcare and provide more well-informed care for this population.

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CHAPTER ONE: INTRODUCTION

First-Episode Psychosis

Many individuals experiencing first episode psychosis (FEP) are unable to work or live independently due to the debilitating nature of their illness. An individual experiencing FEP tends to gradually develop non-specific changes in cognition and perceptions (Doyle et al., 2014). Typical diagnoses for individuals experiencing psychotic symptoms include, but are not limited to, schizophrenia, schizoaffective, and psychotic disorders not otherwise specified (Giannitelli et al., 2018). Many individuals experiencing FEP fail to seek mental health treatment for their symptoms. The families of these individuals are often the first to notice early signs of psychosis and seek treatment for the individual (Bridges et al., 2012).

As many as 3 in 100 individuals will experience a psychotic episode at some point in their lives. Approximately 100,000 young people experience psychotic symptoms each year (National Alliance of Mental Illness, 2021). Mental health services aimed at minimizing the severity of symptoms common to first-episode psychosis, such as hallucinations, have demonstrated effectiveness in symptom management and service engagement (Lal & Malla, 2015; Plamadon et al; 2015). However, there continues to be a high percentage of disengagement from mental health services which may, in turn, contribute to poorer outcomes across various areas in one's life (Kreyenbuhl et al., 2009). In fact, as many as 30% of individuals receiving treatment or specialty care for FEP disengage from

treatment within the first year (Doyle et al., 2014). Individuals who are less likely to engage in proper mental health care for FEP may be at an increased risk of experiencing difficulties with securing or maintaining employment, socioeconomic status, or education (Corrigan et al., 2017; Gomez de Regil et al., 2014). Given the high rates of disengagement from mental health services, understanding the pathways through care (i.e., the pathways or trajectories one may experience as they continue their mental healthcare) of individuals with FEP and their families' pathways through care may help us better understand why some people disengage from care while others remain engaged in care. Knowledge about what leads to engagement and disengagement for this population would better position us to develop interventions to bolster engagement and increase educational advancement in this area of study.

Latinx

U.S. Latinx individuals are at high risk of disengaging from mental health services. In the United States, Latinxs are the largest ethnic/racial minority group. They comprise 18.7% (62.1 million) of the country's population and are expected to comprise 29% of the population by 2060 (Colby & Ortman, 2015; U.S. Census Bureau, 2020). Within the individuals who self-identified as Latino or Hispanic, 19.8 million (33%) were immigrants (Migration Policy Institute, 2021).

Studies on immigration status and mental health demonstrate an increased risk in developing mental health issues among foreign-born immigrants and individuals within an immigrant household (Abdel-Baki et al., 2018; Bourque

et al., 2011; Plamadon et al., 2015). Ottenson et al., 2014 suggest that Latinx immigrants are particularly vulnerable to disengaging from mental health services due to socioeconomic barriers. Despite the size of Latinx population, not enough attention is given to addressing the mental health needs of Latinxs when compared to non-Latino whites (Lopez et al., 2012). One hypothesis states this may be caused by immigrant groups or racial-ethnic minorities presenting with distinct symptom profiles and culturally based misinterpretations (Corrigan et al., 2017; Eisenberg et al., 2009).

Disengagement

Disengagement from mental health treatment by patients experiencing FEP or with a serious mental illness is of critical concern within the Latinx population. Of the individuals receiving mental health services, it has been reported that up to 50% disengage from treatment which contributes to poor outcomes (Lal & Malla, 2015). Long term treatment and adherence has demonstrated effectiveness in minimizing symptoms, improving daily functioning, and reducing the risk of relapse (Hernandez et al., 2018; Marshall et al., 2005) within Latinx individuals experiencing FEP (Heun-Johnson et al., 2020; Kline & Thomas, 2018). Therefore, disengagement from services and treatment nonadherence are of particular concern (Doyle et al., 2014). Relevant studies examining disengagement from services within the Latinx population noted dissatisfaction with services, lack of fluency in primary language, lack of trust in medical providers, associated stigma, and poor insight as potential reasons for

disengagement (Lal & Malla, 2015; Stowkowy et al., 2012). Maraj et al. (2018) suggested that Latinx individuals may possess beliefs in alternative explanatory models and health practices utilized in their countries of origin, which may relate to their lower utilization of mental health care services.

Pathways Through Care

Marquez and Ramírez García (2013) and Myers et al. (2019) argue that Latinx individuals experiencing FEP may undergo trajectories or pathways through the mental health care system that may lead to low service utilization and disengagement from care. These pathways through care may be particularly critical to attend to for immigrant Latinxs, as findings have shown immigrant Latinxs maintain lower service utilization rates (Bridges et al. 2012). In the beginning stages, a Latinx individual or a family member may initiate seeking services to resolve the problem. For this study, we operationalize family as any individual who provides caregiving and support in one's care such as a parent, a family member, or a close friend. As Latinxs engage in or travel through the mental health care system for FEP, they often receive therapy, are prescribed medications, and receive other recommendations such as follow-up appointments and maintaining contact with service providers by their psychiatrist, case manager, or primary mental health clinician. The individual or family member will then progress through a series of networks composed of family, peers, or health service providers and may encounter difficulties that threaten continued service use. The pathways through care for Latinx individuals may be

primarily shaped by family or social support, influenced by socioeconomic barriers, or governed by culture (Myers et al., 2019; Rogler & Cortes, 1993).

Lal et al. (2019) and Snowden (2007) suggest that family and social support increase the likelihood of following treatment recommendations for Latinx individuals experiencing FEP throughout the course of treatment. The family or social network of the individual may support them in creating and maintaining appointments, transporting them to appointment times, assisting the individual in taking their medication, and maintaining contact with mental health providers. In many cases, the families of individuals receiving care for FEP may disengage or lessen their involvement from treatment of the individual due to increased stress and demand of the individual's symptoms and care, which may then lead the individual to disengage or be inconsistent with their own treatment. Thus, considering the role of the family along the pathways through care is essential in considering the process of engagement for Latinxs with FEP.

Once mental health services have been accessed, Latinx individuals may encounter socioeconomic barriers that threaten continued engagement in care (Plamadon et al., 2015; Raymond-Flesch et al., 2017). Additionally, socioeconomic barriers, such as lack of services provided in one's native language, may influence a Latinx individual's decision and/or ability to continue mental health services (Raymond-Flesch et al., 2017). These prevalent barriers may be particularly impactful for immigrant Latinxs who face high rates of complexities involving mental health care utilization (Plamadon et al., 2015)

Individuals may not have ongoing access to transportation, insurance coverage, or sufficient funds to subsidize the cost of continued treatment recommendations which, in turn, leads to an increase in the disengagement of services (Bismar & Wang, 2021; Jongsma et al., 2021).

Cabassa et al. (2018) and Myers et al. (2019) state that pathways through care may be heavily influenced by the mental health care itself. Myers et al. (2019) note that cultural factors and incongruities between the treatment setting and help-seekers, such as the language in which services are provided and treatment expectations, can affect the quality and length of care. When compared to individuals who primarily spoke English, individuals who primarily spoke Spanish displayed lower utilization rates of specialty and any mental health services (Alegria et al., 2007).

There is growing research examining individuals' pathways to care, or the sequence of contacts with individuals and agencies initiated by the distressed individual and families in their efforts to seek treatment (Cabassa et al., 2018; Myers et al., 2019). However, there is limited research and literature examining pathways through care or how individuals make the decision to continue engaging in care beyond initial contact and move toward recovery (Myers et al., 2019; Rogler & Cortes, 1993). We need to better understand the earliest patient- and family-cited barriers to treatment especially for Latinx individuals, whose pathways through care and service use may be more likely to be negative,

complex, and impacted by socioeconomic barriers (Myers et al., 2019; Sass et al., 2009).

CHAPTER TWO: METHODS

Design

This qualitative study was conducted as part of a parent study that is designed to improve engagement in community mental health services among Latinos with FEP and their family caregivers. Study protocols have been approved by the CSUSB Institutional Review Board and the Los Angeles County Department of Mental Health Human Subjects Research Committee.

The parent study evaluates an intervention program to help people with mental health problems stay involved in mental health services, like medication management and therapy, once they have started care and better understand the reasons why people stay in care and how to help them remain involved in the care they need. The current study aimed to help address aim three of the parent study by exploring factors that affect engagement in mental health services in Latinx individuals experiencing FEP and their families using qualitative methods. The current study also explored critical socioeconomic barriers that may influence engagement in services among Latinos with FEP and their families as well as barriers for continued care that are not characterized as socioeconomic in nature.

Grounded theory methods were utilized to meet this qualitative study's objectives. Grounded theory methodology was used to examine the influence socioeconomic barriers have on service engagement along the pathway through

care for Latinx individuals experiencing FEP. For this study, individual and family cases were used to develop conceptual categories to synthesize, explain, and understand the data as well as to identify patterns of relationships among the conceptual categories (Charmaz, 1996). Data collection and analyses followed grounded theory methodology as well. For the current study, the process of developing codes and categories based on the raw interview data was adopted.

Community and Settings

Participants of the target Latino population were recruited from within the San Fernando Valley, Los Angeles County, California. Latinos are one of the two largest ethnic groups in the area (U.S. Census Bureau, 2012-2016 American Community Survey 5-Year Estimates). Participants were recruited through two mental health service sites – the San Fernando Mental Health Center (SFMHC) and Olive View-University of California, Los Angeles (UCLA) Medical Center (Olive View). The SFMHC is a community mental health center operated by the Los Angeles County Department of Mental Health (DMH) and affiliated with the UCLA Department of Psychiatry. It offers psychiatric and psychosocial outpatient mental health services to Valley residents. Olive View provides psychiatric inpatient and outpatient care to Valley residents. Both sites serve a large number of Latinos in the San Fernando Valley. In 2012, SFMHC served 695 patients, 73% of whom were Latino.

Participants and Sampling

Mental health providers who serve patients with FEP and their families, clinical supervisors of providers who offer these services, and Latinx with FEP and their caregivers were recruited for this study. Patient-caregiver dyads will be recruited at SFMHC and at a non-LACDMH site (Olive View Medical Center). Providers were recruited at SFMHC exclusively. Consent to participate was obtained prior to enrolling a participant in this study.

Snowball sampling (Palinkas, Horwitz, Green, Wisdom, Duan, & Haogwood, 2015), also known as the referral technique, was used to recruit providers from the two recruitment sites by using a process of chain referral. Supervisor/provider interest in participating in the qualitative interview was assessed to recruit initial providers. These providers were then asked to refer other supervisors/providers who may be interested in participating. An underlying assumption of snowball sampling is that members of the target population often know each other (Singleton & Straits, 1988). The final number of participants was contingent on access and availability of participants and reaching saturation, a point that occurs when the data collected no longer provide additional information (Strauss & Corbin, 1998). Interviews were completed and data collection is ongoing as saturation of themes has not been achieved. This study represents the preliminary findings to address the themes of the study.

Patient-caregiver dyads were recruited from the pool of participants recruited for the parent study's randomized controlled trial of BA for FEP vs TAU.

Latinx with FEP inclusion criteria included: a) self-identification as Latino; b) age 15 to 35; c) Diagnostic & Statistical Manual of Mental Disorders-5 diagnosis of schizophrenia, schizoaffective disorder, schizophreniform disorder, brief psychotic disorder, other specified schizophrenia spectrum, affective psychotic disorder, and other psychotic disorder criteria; d) less than 3 years after the onset of psychotic symptoms; e) ability to speak English or Spanish; f) caregiver who is willing to consent to participate in the study and participate in care; and g) ability to provide fully informed consent. Exclusion criteria included: a) diagnosis of psychotic disorder due to another medical condition or substance/medication-induced psychotic disorder, b) presence of a serious medical condition, c) 3 or more years after the onset of psychotic symptoms. Criteria are largely consistent with FEP intervention studies (Dixon et al., 2015). Regarding the operational definition of FEP, a duration of illness criteria was selected per recommendations by Breitborde, Srihari, and Woods (2009) in *Early Intervention in Psychiatry*. Given that most of the deterioration in functioning occurs within the first 2-5 years following the onset of psychotic symptoms, they suggest that the end of the first episode be demarcated at some point 2-5 years later. Using a demarcation of 4 to 5 years may lead to selecting individuals that share more commonalities with chronic patients. In the absence of strong scientific evidence to select an appropriate cut-off point, 3 years from the time of onset was selected for this study.

Data Collection

Qualitative data collection occurred via use of in-depth interviews (Strauss & Corbin, 1998). Interview guides were developed for supervisors/providers, Latinxs with FEP, and caregivers. Interview guides were semi-structured and contained open ended questions. Probing was utilized as needed during qualitative interviews to expand further into participant responses. Interviews lasted an average of one hour. Interviews were recorded and later transcribed. Interviews occurred via virtual platform (HIPAA-protected Zoom) or in-person depending on participant preference. For in person interviews, supervisors/clinicians were interviewed at SFMHC. Latinxs with FEP and caregivers were interviewed at SFMHC, Olive View, or at participants' homes. Interviews were conducted by the parent project Principal Investigator (PI: Santos) or other project researchers.

Data Analysis

After transcribing interview recordings, transcripts were read and analyzed using the line-by-line method, called microanalysis (Strauss & Corbin, 1998). An open coding process was adopted in which coding was conducted in an iterative process to identify reoccurring themes. Codes were developed to identify themes that are relevant to the research questions. Codes were used in analyzing transcripts from subsequent interviews. Given the low prevalence of said themes, additional analyses were conducted to better understand the prominent facilitators and barriers to involvement of care among this population.

CHAPTER THREE: RESULTS

Demographic Information

Table 1 presents demographic information. Individuals with FEP reported obtaining a high school education or attending some college. Qualitative interviews for individuals with FEP were all conducted in English. All caregivers who participated identified as parents and mothers. No fathers, siblings, or close friends of individuals with FEP were identified as caregivers in this study. The majority of qualitative interviews for caregivers were conducted in Spanish.

Experiences Along the Pathway Through Care

Similar pathways through care were found among individuals with FEP and their families. The following sections, caregiver increased awareness of symptoms and learning to navigate the mental healthcare system and locating resources, are included to further describe the pathways through care. The two themes describe pathways through care after first contact with mental health providers and emergency care physicians had occurred and as the individuals with FEP and their caregivers traversed through the mental healthcare system.

Caregiver Increased Awareness of Symptoms

After first contact with mental health providers and emergency care physicians, caregivers reported noticing an increased awareness of the

symptoms experienced by individuals with FEP. For most caregivers, this increased awareness of symptoms led to increased involvement in the care of the individual with FEP. This increased awareness of symptoms was a central factor in caregivers navigating through the mental healthcare system and locating additional resources for individuals with FEP.

“I was not moving, my mom would feed me and I was talking to the voices...uhhh she’s seen me...before she would notice but she didn’t even know but now at that time where I was not moving, listening to the voices, she noticed that I needed help but at that time I would say no to [medication], that I was ok...the voices agreed with me to say no.” PT 004

Learning to Navigate the Mental Healthcare System and Locating Resources

Several caregivers and individuals with FEP reported initially seeking help from emergency and primary care physicians to manage the FEP symptoms, but no participants stated initially seeking help from mental health providers. Multiple caregivers mentioned being frustrated with the mental healthcare system after care had been initiated because they were unable to locate the proper services for individuals with FEP and because of the lack of clarity and information regarding the symptoms experienced by individuals with FEP and next steps in continuing care. This led to a distrust in medical and mental healthcare providers.

“[Después de la primera hospitalización] no me dieron [los proveedores medicos] información para donde ir, no sabía donde ir...no reconocía las

síntomas no reconocía los problemas que él tenía, no me dijeron nada, no me dijeron sigue esos pasos... nomas le dieron un papel y ya.” CG 002

“[After first hospitalization] They [medical providers] did not give me information on where to go, I did not know where to go...I did not recognize the symptoms, I did not recognize the problems he had, they did not tell me anything, they did not tell me to follow these steps... they just gave him a paper and that's it.” CG 002

Facilitators Along the Pathways Through Care

The following themes were found to facilitate continued engagement in care for individuals with FEP and their caregivers.

Aiding the Individual to Adhere to Care

Caregivers and individuals with FEP described the importance of aiding the individual in adhering to their care, including attending mental health or medical follow-up appointments or locating additional resources for the individual with FEP. Experiences with aiding or supporting the individual involved in care typically occurred once care was initiated and the caregiver had consistent contact with medical and mental health service providers.

“Estuve pendiente de que se tomaba su medicina, para que no se le olvidara...que viniera a su citas...pues estar allí [en citas médicas] porque en principio él estuvo... Mmm ya no tenía así como el primer día verdad como cuando estuvo en la clínica ya no tenía tanto la enfermedad, pero estaba muy como nervioso como ansioso y yo estaba allí [citas médicas] con él, a veces

siempre estaba en príncipe con él porque él me necesitaba... quería que estaba un lado de él.” CG 006

“I was making sure he took his medication, so he wouldn't forget...that he came to his medical appointments...well, to be there [at medical appointments] because in the beginning he was... mmm he didn't have it like the first day, right, like when he was in the clinic, he didn't have the sickness so much, but he was very nervous and anxious and I was there [medical appointments]with him, sometimes I was always with him because he needed me...he wanted me to be next to him.” CG 006

Caregiver Advocates for the Individual's Care

Caregivers reported advocating for the individual's care as they continue their use of medical and mental health services. Caregivers mentioned discussing the individual's care including medication support services and additional resources for care with mental health providers (e.g., family groups). This led to changes in individuals' care as they continued receiving mental health services.

“Él tomaba 10 mg, siempre como quería vomitar y yo lo miraba y miraba como que tal vez era muy fuerte esa medicina y él dijo que quería que se la bajaran. Y si la doctora se la bajo a 7.5 mg...pues yo vine, yo vengo con él y hablo con la doctora... porque él no se la toma.” CG 006

“He took 10 mg, he always wanted to vomit, and I looked at him and it looked like maybe that medicine was too strong and he said he wanted them to

lower it down. And yes, the doctor lowered it to 7.5 mg...well, I came, I come with him and talk to the doctor.” CG 006

Individual Communicates Their Symptoms and Experiences with Providers

Several individuals with FEP described being able to discuss their frustrations with their care and symptoms freely to their provider in an open therapeutic environment as a facilitator for increased engagement. One individual with FEP cited that communicating with their provider about their experiences, feelings, and symptoms aids them in continuing their care.

“To call, talk to the doctor, make an appointment, or talk to the people....just doing all the important care too...I tell the doctor everything that is going on, what I am feeling, what’s hurting, everything...be responsible taking it [medication] and I do, yes, everyday... I tell them, [providers] helps me to focus on myself, focus on the stuff I am doing, realizing what I need help on, options, situations to ask for help.” PT 005

Caregiver Obtained a Better Understanding of the Individual’s Condition

Multiple individuals with FEP mentioned communicating their symptoms and experiences in detail to their caregivers. One individual with FEP mentioned their caregiver learned more about their condition after they disclosed when they would or would not experience FEP symptoms. Many individuals with FEP stated this led to their caregivers becoming more involved in their care because their caregivers now had a better understanding of their symptoms and experiences.

“She’s more involved with me, I would tell her everything about it, if I would hear the voices or not...[why] because at first she didn’t know about it, she ignored it, my mom told me that she ignored...she learned more about my condition...I started to tell her more...[why now] because I noticed I needed help.” PT 004

“[My caregiver] knows now everything I said to her...there was a lot fighting before and different behavior and therapy helped, and everything changed, we fight less [caregiver and individual] and no fighting...she realized what’s going on with me [better understanding] ...helps think about and to take care of my care.” PT 005

Mental Health Provider Checks In and Follows Up with the Individual

Caregivers and individuals with FEP noted facilitators for increased engagement in care once services had been initiated. Consistent follow-ups and check-ins from mental health providers made several caregivers and individuals with FEP feel the provider truly cared for their well-being and their experiences which led to their increased engagement in care.

“Well...someone literally ended up going and asking for me, wondering how I was doing, it was an outpatient and from there, it made me feel that people were going slightly more than that [more than needed to]... once a week, it was a check-in for example how are you feeling, what’s going on, are you ok, simple stuff like that...they started coming back and asked what kind of medication I was

taking...it's really helpful...talking, communicating, groups...communicating what I was going through, helped me open my mind, my feelings". PT 002

Barriers Along the Pathways Through Care

The following themes were found to be barriers to continued engagement in care for individuals with FEP and their caregivers.

Caregiver and Individual Unable to Afford Continued Care

Cost of care was described as a barrier for a caregiver's continued involvement in the care of the individual with FEP. The caregiver cited being unable to afford the financial costs associated with continued care. This inability to afford continued care led to decreased involvement in care from the caregiver and the individual with FEP.

"[Después de hospitalización] Me la mandaron para a un psicólogo...pero me dijeron primero que tenía que pagar antes de eso, entonces no teníamos...y empezamos a buscar...como no teníamos medi-cal...porque no estoy pagando Kaiser para ella [en ese tiempo que no tenía medi-cal, no tenía donde llevar la]...Si y que \$250 valia la consulta [económico fue el problema]." CG 005

"[After the hospitalization] They [doctors] sent her to a psychologist...but they told me that I had to pay first, so we did not have it...and we started to search...we did not have medi-cal...because I am not paying Kaiser [Permanente] for her [in that time that you did not have medi-cal, you had nowhere to take her]...yes and that the consultation cost \$250 [the problem was economic]." CG 005

Individual's FEP Symptoms Interfere with Care

An individual with FEP described finding it difficult to maintain focus when receiving care and practicing coping skills due to the heightened and persistent FEP symptoms. This led to the individual finding it difficult to be involved in their care and effectively becoming less engaged in the recommendations given to them by providers.

“[What makes it difficult to be involved in your care] When the voices keep calling me, calling me and I try to avoid and ignore them sometimes I will still hear them a little bit...it's a little bit hard to stop hearing them [in therapy groups]...sometimes I tell them to stop, and they follow me around...[using the stay calm/meditation exercises] I would do a little bit, not that much actually, I only did it once the stay calm, the meditation, it didn't work out because I would hear the voices when I would stay calm, stay quiet, everything quiet but I would hear the voices.” PT 004

Individual's Dislike of Medication Effects

Few individuals with FEP cited a dislike of medication and its potential effects on their mood and behaviors and viewed this as a reason for their disengagement from care. One individual with FEP mentioned following recommendations from their provider and taking the prescribed medication, however, the individual disliked the medication's effect and discontinued utilizing it. This dislike of medication and its effect led to individuals with FEP decreasing

their engagement in their care and created distrust in providers who recommend medication.

“Well, I got prescribed a new one and I tried it for a couple of days, but I didn’t feel like I needed it...well, I didn’t like the effect either...well it was very subtle [the effect] I felt kind of, I guess more than anything I felt scared I might do something that I don’t want to do. Well, I don’t like what [medication] did and I feel that this one might do the same thing...um, well it made me feel very unmotivated.” PT 006

“Medications seem harsh at first, it’s about finding a balance...it’s to the point I was scared taking medication...I mean some of the medication did make me slightly suicidal...it scared me off [from continued care].” PT 002

Individual’s Difficulty in Communicating Symptoms and Experiences with Providers

Once care had been initiated, several individuals with FEP noted difficulty in communicating their symptoms and experiences with providers. One participant stated not wanting to disclose their symptoms and experiences because they felt uncomfortable with the provider whom they had met once. This difficulty led individuals with FEP to a decrease in the engagement of their care because of their unfamiliarity with the provider.

“It’s just hard to talk in general sometimes for example, for me it’s hard to talk to certain people ...anyone that would try getting close to me I would let them talk about themselves rather than myself cause I would never feel comfortable...

[provider] was probably trying to get me to open up...[provider] was always trying to engage with me but I would close...I stopped going [therapy].” PT 002

Substance Use to Cope with FEP Symptoms

Substance use, particularly marijuana, was cited as a reason for disengagement in care by an individual with FEP. This led to disengagement in their care because the individual with FEP described utilizing this substance as a way to forget or manage their FEP symptoms and experiences related to their symptoms.

“I stopped taking my medication and stuff [attending therapy sessions]...it’s not that I was dependent on marijuana, it’s just, with me smoking it, it made me just, it just felt the need of me forgetting, it made me forget my past, my future and a little present, it sort of puts a mask over my face...me normally I’m just not like this right now and when I am on it, it’s like another face in front of me but just with a smile...just a mask on my symptoms.” PT 002

Individuals with FEP and their caregivers followed similar pathways through care in which the caregivers of the individuals with FEP were the driving force in navigating through the mental healthcare system after care had been initiated. These pathways are summarized in Figure 1. In many cases, the individuals with FEP continued to experience heightened symptoms which led caregivers to become more involved in the individual’s care. Individuals with FEP and caregivers then experienced barriers along the pathways through care such as inability to afford continued care, substance use to cope with symptoms, and

dislike of medication. Caregivers then typically aided individuals with FEP in adhering to their care by accompanying them to medical appointments, speaking with doctors, or locating additional resources for their mental health issues. This led to increased involvement from both the caregivers and individuals with FEP.

CHAPTER FOUR: DISCUSSION

Understanding the earliest patient and family cited barriers of care for Latinx individuals as they traverse through the mental health system is critical to address their needs (Myers et al., 2019; Plamodon et al., 2015). This study sought to define the pathways through care for this vulnerable population and understand what factors may lead to disengagement from care once services have been initiated. Our findings suggest that the pathways through care for this population are complex and multifaceted. By utilizing data from qualitative interviews, we created hypotheses about potential factors that may affect decision-making for patients and family members. These hypotheses also suggest ways for mental health providers and services to better involve patients and families in care.

Our findings are similar to previous qualitative studies that examined the pathways through care for racial-ethnic minorities (Myers et al., 2019). Individuals with FEP and their caregivers detailed barriers that affected their ability to remain involved in care for FEP (Cabassa et al., 2018). For instance, we found individuals with FEP and caregivers followed a similar pathway through care in which caregivers felt confused and frustrated in being unable to locate the proper services and resources for the individual with FEP after initial help-seeking (Lopez et al., 2012; Plamadon et al., 2015). We also found that multiple caregivers were not given sufficient information regarding the care for the

individual with FEP and how to assist them in the continuation of their care (Myers et al., 2019). These experiences within the mental healthcare system created a distrust of mental and medical health providers and the mental healthcare system which led to some of the individuals with FEP and their caregivers disengaging from their care (Cabassa et al., 2018; Myers et al., 2019).

After individuals with FEP began receiving care, some of these individuals found it difficult to locate a regular doctor for their medications and to remain consistent in their care. Cost of care was also mentioned by a caregiver as a reason for decreased engagement in the care of the individual with FEP. Individuals with FEP also described difficulty in communicating their FEP symptoms and experiences with providers they were not familiar with which also led to decreased engagement in their care (Lal & Malla, 2015). Individuals with FEP also cited substance use, dislike of medication and its effects, and persistent FEP symptoms throughout care as barriers to continued involvement in their care. These barriers are consistent with findings from qualitative studies (Myers et al., 2019; Oluwoye & Stokes, 2021)

Our study identified facilitators for continued engagement in care for individuals with FEP and their caregivers. Individuals followed a similar pathway through care in which their level of engagement in care was shaped by the support of their caregiver (Myers et al., 2019; Oluwoye & Stokes, 2021). Caregivers and individuals with FEP stated that the support of their caregiver helped individuals with FEP continue their engagement in care because

caregivers frequently advocated for the individual's care, aided in the individual's adherence to care, and helped individuals locate additional resources for their care (Marquez & Ramirez Garica, 2013; Myers et al., 2019). We also found that individuals with FEP who communicated their symptoms and experiences to their caregiver noticed an increase in their caregiver's involvement in their care due to the caregiver obtaining a better understanding of the symptoms experienced by the individuals with FEP and experiences. Individuals with FEP have reported that consistent check-ins and follow-ups from their providers led to increased involvement in their care because they believed the provider cared for their well-being and their care (Cabassa et al., 2018; Maraj et al., 2018).

It is clear that Latinx individuals and their caregivers must receive access to care prior to the occurrence of heightened FEP symptoms and crisis events. For example, classes or information sessions at hospitals can be offered, where many families initially seek help for mental health symptoms, to inform individuals of the care that is available to them before they require emergency services (Bridges et al., 2012; Doyle et al., 2014). There continues to be a lack of mental health services that involve the families of the individual, and this may be particularly critical for Latinx individuals who tend to reside more with their families when compared to their non-Hispanic white counterparts. Many caregivers also reported difficulty with finding additional resources and services for their loved one's mental health issues after care had been initiated, such as locating a regular doctor. This is emphasized across our findings and utilizing

different forms of communication, such as online classes for Latinx caregivers, may aid them in learning what they can do for their loved one to support them in their care, locating additional resources, and gaining a better understanding of FEP symptoms (Bridges et al., 2012; Maraj et al., 2018). Incorporating caregivers in the care of the individual is essential for continued engagement in care, a conclusion supported by this study's findings (Myers et al., 2019; Rogler & Cortes, 1993)

To better promote an individual's or caregiver's continued engagement in care, care ought to include consistent follow-ups and check-ins from mental health providers as individuals with FEP stated this helped continue their engagement in their care. Mental health providers should also maintain an open and judgement-free environment to allow individuals and caregivers to become more comfortable in sharing their symptoms, behaviors, experiences, and thoughts as this was shown to lead to more engagement in care for individuals with FEP and their caregivers (Lal et al., 2019; Myers et al., 2019). Additionally, therapists should develop strong therapeutic alliances and aid the individual in recognizing their symptoms, how to effectively communicate their experiences in and outside of therapy, and help the individual clarify their goals in care which is essential in the recovery process (Snowden, 2007).

Potential limitations to the present study should be noted when interpreting the findings. First, we did not meet saturation and it is possible that with a higher sample size, these themes may resurface during the data collection

phase. Future research should seek additional referral sources or contact service providers who may be connected to large mental health service networks to potentially obtain a larger sample of participants and more concrete findings (Myers et al., 2019; Plamondon et al., 2015). Second, it is important to note that the present study did not further examine the racial-ethnic heterogeneity that exists within the Latinx population (Abdel-Baki et al., 2018). Subsequent studies may benefit from including participants who identify as various ethnicities, cultures, and sub-cultures from the Latinx population (Cabassa et al., 2018). Despite these limitations, the collected qualitative interview data identified critical experiences of Latinx individuals and their caregivers after they have initiated care and continued or discontinued their engagement with mental health services, all of which represent the pathways through care.

The present study builds upon the limited research examining the pathways through care of Latinx individuals and their family members and shows that continued utilization of mental healthcare services may be dependent on a multitude of social-societal factors that persist across racial-ethnic identity. More extensively, further research is needed to better understand and conceptualize the experiences and underlying factors at multiple levels. This would allow us to better identify points along the pathways through care that may increase the likelihood of consistent engagement in mental healthcare and provide more well-informed care for this population.

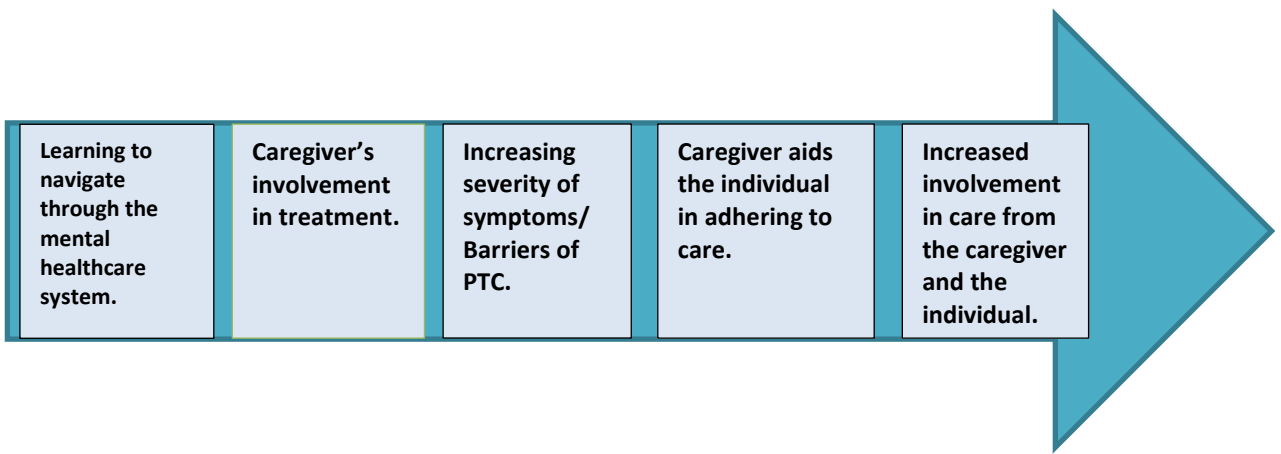
APPENDIX A

TABLE 1: LATINX INDIVIDUALS WITH FEP AND CAREGIVERS'
CHARACTERISTICS

	Individual (N=5) n (%) or M(SD)	Caregiver (N=5) n (%) or M(SD)
Gender		
Male	3 (60)	
Female	2 (40)	5 (100)
Age		
	25(1.95)	
Education		
High school	3(60)	
Some college	2(40)	
Relationship with caregiver		
Parent		5(100)
Place of birth		
United States	5(100)	
Mexico		4(80)
Central America		1(20)
Years in the U.S.		
	25(2.31)	
Interview Language		
English	5(100)	1(20)
Spanish		4(80)
English proficiency (Scale: 1-very badly, 2-not so good, 3-well, 4-very well)		
	Very well	
Spanish proficiency (Scale: 1-very badly, 2-not so good, 3-well, 4-very well)		

APPENDIX B

FIGURE 1: SUMMARY OF THE PATHWAYS THROUGH CARE FOR LATINX
INDIVIDUALS WITH FEP AND THEIR CAREGIVERS



APPENDIX C:
IRB APPROVAL LETTER

3/29/23, 11:36 AM

Mail - Maria Santos - Outlook

IRB-FY2020-167 - Modification: IRB Approval Protocol Change/Modification Letter

do-not-reply@cayuse.com <do-not-reply@cayuse.com>

Mon 3/20/2023 2:35 PM

To: herne412@coyote.csusb.edu <herne412@coyote.csusb.edu>; Maria Santos <Maria.Santos@csusb.edu>



March 20, 2023

CSUSB INSTITUTIONAL REVIEW BOARD

Protocol Change/Modification

IRB-FY2020-167

Status: Approved

Prof. Maria Santos and Estevan Hernandez
CSBS - Psychology
California State University, San Bernardino
5500 University Parkway
San Bernardino, California 92407

Dear Prof. Maria Santos and Estevan Hernandez:

The protocol change/modification to your application to use human subjects, titled "Optimizing Engagement in Services for First-Episode Psychosis (FEP) in the Community Mental Health Setting" has been reviewed and approved by the Chair of the Institutional Review Board (IRB). A change in your informed consent requires resubmission of your protocol as amended. Please ensure your CITI Human Subjects Training is kept up-to-date and current throughout the study. A lapse in your approval may result in your not being able to use the data collected during the lapse in your approval.

This approval notice does not replace any departmental or additional campus approvals which may be required including access to CSUSB campus facilities and affiliate campuses. Investigators should consider the changing COVID-19 circumstances based on current CDC, California Department of Public Health, and campus guidance and submit appropriate protocol modifications to the IRB as needed. CSUSB campus and affiliate health screenings should be completed for all campus human research related activities. Human research activities conducted at off-campus sites should follow CDC, California Department of Public Health, and local guidance. See CSUSB's [COVID-19 Prevention Plan](#) for more information regarding campus requirements.

You are required to notify the IRB of the following by submitting the appropriate form (modification, unanticipated/adverse event, renewal, study closure) through the online Cayuse IRB Submission System.

<https://outlook.office.com/mail/id/AAQkADYyMjMyY2M5LTQ2MmltNGNjMS05ZmYwLTgxZjJwZTIIzjA5ZQAQAHcj598nivFEhE4XXfbJJKl%3D>

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