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"Nobody is born with knowledge": a Qualitative Analysis of Latinx Families' Experiences in a Traditional vs. Family Centered Pediatric Health Care Model

By

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Abstract

As the Latinx population in the U.S. continues to grow, public health interventions aimed at improving health care access for Latinx individuals are increasingly vital. DULCE (Developmental Understanding and Legal Collaboration for Everyone), a pediatric health intervention built around the Family Centered Care (FCC) model, is one promising intervention for tackling Latinx health disparities beginning at infancy. Drawing on qualitative interviews from Latinx DULCE participants, the current study explored how FCC transformed Latinx families' pediatric health care experiences and how cultural barriers, such as immigration status, impacted engagement in overall services. The FCC model utilized in DULCE was able to bridge barriers to care and increase parental knowledge through the assignment of Family Specialists, who worked to assist parents in finding and enrolling in additional services outside and within the clinic. These one-on-one relationships resulted in more open and honest discussion of needs by Latinx parents and bolstered family's engagement in services, improving overall family health outcomes. Family Centered Care interventions may be a promising strategy for better assisting Latinx families and improving infant health outcomes, further mitigating Latinx health disparities across the lifespan.

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> ...what scares me is, I'm afraid of deportation, of leaving my children here with people I don't know, strangers other than the people they know, which is their mom and the family circle. That is my only fear; other than that, being a parent, you learn as you go. Because **nobody is born with knowledge.** And thank God I hope and wish the situation we are in will be solved. - *Margaret, mother of three*

In the United States, stark disparities in health across gender, race, ethnicity, and socioeconomic status remain a pervasive public health challenge (KCDC, 2020). Increasingly initiatives that tackle life-long inequalities during formative early childhood years have been proposed as one promising strategy to address health inequities across the lifespan (McCrae et al. 2021; Schor, 2003). Early childhood (age 0-8yrs) is a ripe period to set the foundation for future health and wellbeing, but the U.S. consistently lags in metrics of child health compared to other industrialized nations (Schor, 2003; Kayal, 2021). In 2020, the U.S. ranked 10th in the world for childhood poverty among 38 developed nations, one in 7 families with children relied on federal assistance, and over 4.3 million children were uninsured (FFOC, 2021). With over 34.5 million children living 200% below the poverty line, these numbers reflect the struggles many parents in the U.S. experience when raising their children (Family Interagency Forum, 2019). With so many families facing obstacles to meet basic needs, it is essential to increase our understanding of how to better assist parents to overcome such challenges and put their children on the path for a long and healthy life.

Within public health, it is ethically important to center highly vulnerable populations when designing population health interventions. By targeting at risk populations, interventions can create big impacts in the lives of those most impacted by health disparities. Specifically, Latinx children and their families have been identified as a U.S. population facing severe and unequal health disparities. Within the U.S., Latinx members have the lowest health insurance rates of any racial group, with 51% of the population lacking health coverage (U.S. Dept. Health and Human Services, 2017). It is projected that by 2050 1 in 3 children born in the U.S. will be Latinx, yet without access to pediatric health care or early childhood programming, Latinx children could face health disparities which may set them on a course for poorer health outcomes across the lifespan compared to other U.S. children (Family Interagency Forum, 2015; McCrae et al. 2021). Lack of health insurance coverage can be attributed to poverty, working without benefits, and ineligibility for Medicaid. For the Latinx population, social stigmas surrounding migrants and legal barriers to access programming which could assist immigrant families, can also pose barriers to insurance access and social service utilization (Zhang, 2021). Latinx families, whose members may hold different immigration statuses, experience unique challenges when accessing health care, facing conflicting needs of protecting undocumented family members and maintaining their physical health. This mixed family structure is most common for low-income Latinx families who would especially benefit from social support services, but who often go without for fear of family separation (Capps & Fortuny, 2006). For Latinx families who are U.S. born, negative political discourse and perpetuation of immigration stereotypes continue to foster a hostile environment, making it increasingly difficult to navigate safety net services and other healthcare resources for fear of social profiling and discrimination (Lopez et al., 2018).

As the population of Latinx members in the US continues to grow, and the importance of public health initiatives become increasingly imperative, researchers have sought to explore how innovations to pediatric health care may hold the key to mitigating the drivers of negative health outcomes such as childhood poverty and ethnic health disparities (Russ, 2014; Schor, 2003).

DULCE (Developmental Understanding and Legal Collaboration for Everyone), a pediatric health intervention for Latinx families, is an example of one-such innovation (McCrae et al, 2021). DULCE was designed to assist new mothers and their infants by meeting caregiver needs to improve parental stress and resilience. Improving parental quality of life subsequently improves the quality of life for their children, promoting positive infant and family health outcomes (Sege et al., 2015). Within the DULCE model, Latinx families were partnered with a Family Specialist (Community Health Worker) to screen for unmet needs and enroll families in various programmatic supports such as housing, employment, legal/immigration, and food assistance services. DULCE services were offered as an optional enrollment program for parents through traditional pediatric clinics, where the normative focus remains on infant rather than parental or family health. Originally, DULCE was administered in a 2017 study to an ethnically diverse sample of families (McCrae et. al. 2021). In the current qualitative analysis, we extend the original study by specifically focusing on post-enrollment interview transcripts from Latinx families who participated in DULCE. A majority (69.2%) of the DULCE families were Latinx, many of whom faced pervasive health, socioeconomic, and parenting barriers similar to national trends (McCrae et al., 2021). Understanding how Latinx families experienced family centered programming is vital to starting dialogue around the issue of pediatric health access for Latinx families, and the need for interventions better suited for Latinx needs, which cannot be provided in the traditional care model. It has been posited that the FCC care model could prove useful in scaffolding care for a variety of differing cultural and family needs (Ngui & Flores, 2006). Furthermore, barriers to the FCC model have been explored within qualitative research studies of health care professionals (Heerman & Wilson, 2000). However, there is a lack of qualitative studies on how the FCC model may be experienced by the Latinx population in practice, or if this model can overcome socioeconomic and culturally specific barriers faced by Latinx families. Therefore, the goal of the current study is to explore how Latinx families experienced the traditional pediatric health care model and DULCE's impact on these experiences, understand how immigration influenced Latinx pediatric health care experiences, and how future health interventions can be better tailored to the growing Latinx population in the United States. By understanding the history which informs the family centered care model, and the interplay between parental stress and childhood wellbeing, we can better understand if pediatric family centered care interventions, such as DULCE, can promote positive health outcomes across the lifespan for Latinx children and their families.

Background

Life Course Theory & Developmental Model

As early as the 1930's, researchers have noted the importance of early childhood experiences in shaping health outcomes across the lifespan. While studying children in Poland, early psychologists discovered infant mortality rates were correlated to the health of the mother. Furthermore, their data "behaved as though the expectation of life was determined by the conditions which existed during the child's early years" (Kermack et al., 1934). These formative findings were largely neglected until the 1980's when evidence from the Fetal Origin's Hypothesis demonstrated correlation between parental health and infant health outcomes (Barker, 1990). These findings led to the development of the Life Course Theory and the Life Course Development Model, which posits that later health outcomes are determined over time due to ever evolving contexts and challenges that arise across the life span (Russ et al., 2014). This theory places high emphasis on early life experiences as a critical period for forming the foundation for later health outcomes. To date, the Life Course Development Model has been adopted by numerous federal organizations such as the World Health Organization (WHO), the National Institute of Health (NIH), and Maternal and Child Health Buero (MCHB; Russ et al., 2014).

Life Course Theory has shaped modern understandings of public health and the impact of outside factors on health outcomes and mortality. These outside factors impacting health are classified as Social Determinants of Health (SDoH); identified areas of need which can significantly impact individual quality of life and overall health outcomes. The U.S. Department of Health and Human Services has compiled their own list of SDoH categories encompassing many multilevel factors including economic stability, education access and quality, health care access and quality, neighborhood and built environment, and social and community context (n.d). Examples of specific SDoH within these categories include literacy skills, safe housing, access to healthy foods, and freedom from pollutants (U.S. Dept. Health & Human Services, n.d). Public health interventions aim to improve SDoH domains to improve physical health outcomes.

Theory of Accumulation & Toxic Stress

The acknowledgement of SDoH role in modern health disparities has altered the way public health researchers think about health care in the United States (Schor, 2003). The traditional model of health care focuses on monitoring physical health, with an emphasis on clinical care (McCrae et al., 2021). However, it is now known that without addressing the underlying SDoH which may contribute to poor health overall, such as poverty, food insecurity, or unsafe living conditions, health across the life span cannot be effectively improved (Henzie, 2015; Sege et al., 2015). Research shows that limited access to health affirming SDoH and social resources can contribute to parent’s mental health, toxic stress, and parenting behaviors. These patterns influence children’s health and wellbeing through the accumulation of adverse childhood experiences (ACE’s; Horwitz et al., 2001). The theory of accumulation posits that the more negative or positive the experiences in early life, the increased likelihood for accumulation of similar experiences across the life span (Ferraro et al., 2016). In this way, experiencing ACEs in early life elevates the likelihood of experiencing further SDoH barriers and poor health outcomes later in adulthood, such as lowered socioeconomic status, social detachment, obesity, and increased likelihood for negative health behaviors such as drinking, and smoking (Ferrero et al., 2016).

Experiencing negative SDoH can lead to stress, which can have negative effects on one’s physical and mental health outcomes (Schor, 2003). Navigating negative or stressful life situations activates a cascade of physiological responses, primarily through the release of cortisol, a stress hormone, along the hypothalamic–pituitary–adrenal (HPA) axis (Yaribeygi et al., 2017). This response triggers a series of metabolic actions to regulate the body and prepare the individual for a dire emergency. Over time, exposure to stressful experiences and the regular activation of these physiological processes leads to progressive damage to the body from the strenuous action involved with regulating cortisol release through bodily mechanisms. Specifically, these processes have been linked to elevated blood pressure, elevated risk of cardiovascular disease, poorer cognitive functioning, and overall higher mortality rates than less-stressed peers (Yaribeygi et al., 2017). Within parents, increased stress can lead to lower quality of parenting, poorer mental health, and poor physical health outcomes (Huan et al, 2014; McCrae et al., 2021). This parental stress can go on to affect children by increasing caregivers' struggle to meet their child’s needs physically, emotionally, and mentally (Huang et al, 2014 ; McCrae et. al., 2021; Schor, 2003; Yaribeygi et al, 2017). Since caregiver health has a direct impact on infant health, it is important to find ways to mitigate toxic stress and prevent accumulation of ACEs for the child, and negative SDoH for the parents,through promotion of resilience.

Resilience

Resilience can be defined as one’s ability to adapt, overcome, or persevere through times of hardship or adversity (Conner & Davidson, 2003). Levels of resilience vary from person to person and can fluctuate across the life course in response to changing biological and environmental stimuli (Conner & Davidson, 2003). High resilience has been identified as a protective factor against ACE’s and accompanying stress related health outcomes such as post-traumatic stress disorder, depression, and anxiety (Conner & Davidson, 2003; Youssef et al., 2017). Resilience can be fostered through protective factors such as access to daily needs and supportive or positive relationships with others, which can improve confidence, efficacy, positivity, control, and spiritual freedom (Conner & Davidson, 2003; McCrae et al., 2021). Bolstering resilience in parents and children is a promising approach to mitigating the effects of toxic stress and ACE’s. However, current pediatric practices lack the resources, personnel, or training to enlist parents in social assistance programming that could improve these areas (McCrae et al., 2021). To address this issue, the arena of pediatric health has begun to shift towards the Family Centered Care model.

Family Centered Care Model

Recently the American Academy of Pediatrics has underscored the importance of Family Centered Care (FCC) which highlights the central role that families and pediatric partnerships play in childhood development (Eichner, et al., 2012; Schor 2003). Within this model of care, parents are viewed as the key to promoting their child's health across the life span. In order to build parental confidence, support networks, and minimize ACEs for the child, practitioners within this model view pediatric health as not only encompassing the child, but also the parent. By making referrals to social programs such as employment, housing, or educational assistance programs, parents can overcome obstacles which may foster negative childhood experiences and create lasting impacts on personal resilience- consequentially improving the resilience, health, and quality of life for their children (Eichner et al., 2012; Schor, 2003; Sege et al., 2015).

By analyzing how to mediate accumulation and toxic stress through early intervention programming, researchers posit they can lower health disparities across the lifespan and change the trajectory of the cumulatively disadvantaged youth, but what is the economic feasibility of this model? Researchers Luis-Garcia and Heckman (2020) studied the outcome of 2 early childhood intervention programs, the Carolina Abecedarian Project (ABC), and the Carolina Approach to Responsive Education (CARE), to determine rates of economic return on early childhood programming. They found through their algorithm that tax adjusted returns ranged from 8% up to 18.3%, providing compelling evidence for the economic benefit of early childhood interventions. This study also found early intervention programming created lifetime improvements in parental labor outcomes, improved health outcomes for both parents and children, and reduced crime rates. These factors created a total economic benefit of just over $600,000 per participant per life cycle- over a 6x profit from the total cost of programming per participant ($100,000; Luis-Garcia & Heckman, 2020).

Current Aims

The current study draws on qualitative data from DULCE’s Latinx sample to better understand how DULCE, an FCC intervention, impacted Latinx family health outcomes. Three aims guide the current qualitative analysis:

1. What were Latinx families' experiences within the traditional pediatric care model and how did DULCE impact these experiences?
2. How did factors related to immigration influenced Latinx pediatric health care experiences?
3. How can the Family Centered Model of Care be adapted to better fit the needs of Latinx individuals living within the U.S?

Methodology

Data

The current study is a retrospective analysis of qualitative data from the initial DULCE study Mitigating Toxic Stress, conducted from 2017-2019 (McCrae et al. 2021). Within the original study, researchers evaluated the implementation of the DULCE model across seven pediatric clinics within the U.S. and recruited families, clinic staff, and community members to participate in qualitative and quantitative data collection. The original study included 908 parents of various ethnic backgrounds, over half were of Latinx heritage (69.2%) and a majority were mothers (97.6%; McCrae et al. 2021). After the conclusion of their DULCE participation, researchers conducted multiple focus groups and individual interviews to better understand how these Latinx parents viewed their time in the program and its impact on their lives and health care experiences (McCrae et al., 2021)

Individual interviews and focus groups followed a semi- structured interview format for 60- 90 minutes. All qualitative interviews were conducted by trained field interviewers contracted by the original Mitigating Toxic Stress Study. Interviewers completed Human Subjects Training to ensure professional and thorough use of interview methods and the interview guide. Authorization to audio record interviews and focus groups was granted by all participants. Interviews and focus groups were conducted in English & Spanish based on participants needs. Interviews were audio recorded, translated, and transcribed by Data Gain INC., a third-party service. Upon completion of the interview or focus group, participants were given a $50 gift card for their participation (McCrae et al. 2021).

Interview transcriptions were de-identified to protect the identity of participants. The identity of interviewed participants remained anonymous during the current study analysis. Pseudonyms were created to mark participants within qualitative analysis. In the original study, participants' race/ethnicity was not documented as part of the list of focus group and interview participants. Therefore, context clues from within the transcripts were used to determine participant ethnicity and to select Latinx participants for the analysis. Examples of context clues utilized to determine Latinx ethnicity included discussion of Latinx culture, discussion of ICE, or immigration concerns within the transcript narratives. Focus group participants were grouped together by ethnicity, therefore identification of any Latinx contextual clues indicated that the entire focus group was of Latinx ethnicity. All transcripts identified to be from Latinx participants were selected for current analysis. Out of the total 32 transcripts archived from the original study, 15 were able to be determined to be from Latinx participants. Out of these, ten were in-person focus group interviews (averaging eight participants per focus group), one was an in-person individual interview, and four were individual telephone interviews. In total, transcripts included the perspectives of 77 individual participants.

Qualitative Strategy

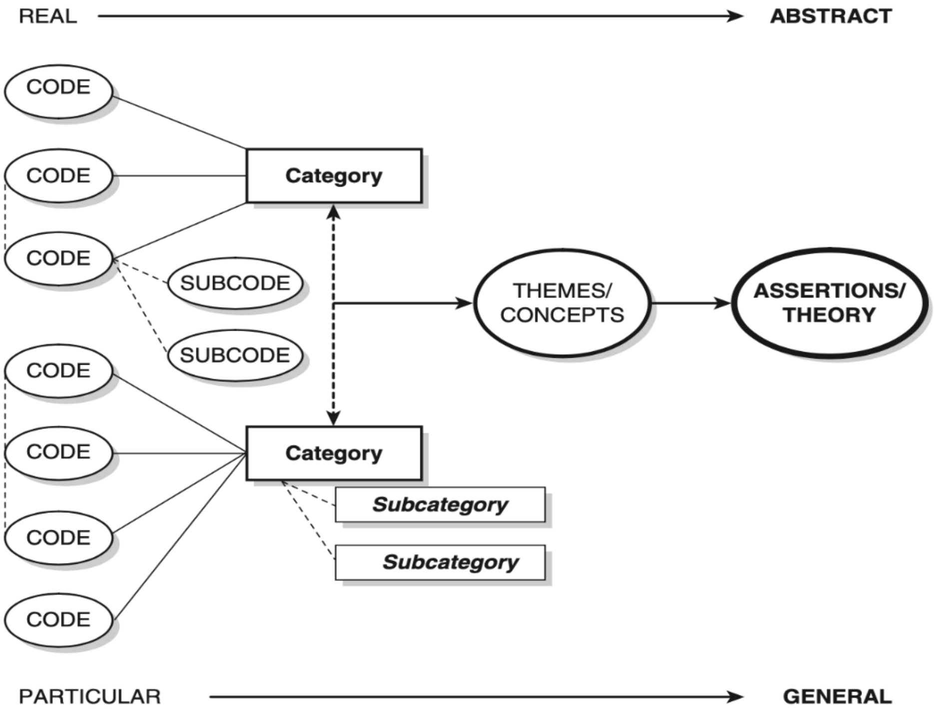

Figure 1.1 A streamlined codes-to-theory model for qualitative inquiry

(Fig 1.1., Saldaña, 13, 2013)

All qualitative methods utilized were rooted in grounded theory, the driving framework of qualitative research (Saldaña, 2013). Initial analysis by the study author began by conducting Open or Descriptive Coding of transcripts, a first cycle coding method (Saldaña, 2013). This first cycle generated a list of 37 key participant phrases and themes to begin coding. During second cycle analysis, Focused Coding was conducted through Dedoose coding software (Saldaña, 2013). In this process, codes were tracked across all Latinx transcripts to identify their prevalence within participant narratives. Codes from the first cycle were further refined by grouping based on shared meaning or context to create distinct categories for final analysis. The emergent frequency of categories and category codes informed the creation of final theoretical frameworks and assertations surrounding the research questions, as outlined by Saldaña *Fig. 1.1* (13, 2013).

Results

Qualitative analysis for the current study resulted in the emergence of 4 distinct code categories: barriers in accessing care, received support types, sought support types, and common parental health concerns. These categories and their emergent codes from participant narratives, further elaborated within the results section, assisted in identifying the realities of Latinx health care experiences within the traditional pediatric health care model and the creation of our theoretical assertations surrounding the impact of DULCE, a Family Centered Care intervention.

Barriers in Accessing Care

In interviews with respondents, barriers to accessing care emerged in 94 percent of transcripts. Reported barriers included factors related to navigating services such as lack of knowledge surrounding services and how to access them, followed by previously negative clinic experiences, lack of insurance, as well as external factors such as work schedule conflicts, caring for multiple children, and transportation issues.

Lack of knowledge was often tied to dealing with insurance experiences. Many reported confusion around attaining insurance coverage and how to deal with challenges if they received it — many citing billing errors, long drawn-out complications with insurance agencies, and lack of materials in the Spanish language.

> The bill has a number, and you have to call, because they also can’t call you. I have done it, I come here [Clinic], bring the bill, and ‘look, I got this bill’, ‘We can’t help you, madam’....I was just here around 15 days ago to see a specialist, because I had problems during my pregnancy, and I came here, they did the check-up and they are charging me $1,700...And if you don’t fix it, they raise it... - *Sara, mother of two*

> [Medicaid] should at least give it in Spanish, because we don't know. It's worse for us to not know. And we don't have anyone to translate it for us, because you can't have someone all the time. And if they know we speak Spanish, why do they send it in English if we don't know how to..? They should help us too, I mean. - *Marta, mother of two*

Lack of knowledge played a large role in preventing Latinx parents from receiving or seeking out additional resources apart from the clinic that could aid them. Lucy, mother of two stated, "I think sometimes you don't request help from other places because you don't know those other places exist to get help." Interviewee Susie added, "sometimes I think we mostly don't go because we don't know about it and we don't have the transportation...then you request an Uber and they charge a lot."

Previously negative clinic experiences also created barriers for Latinx mothers. These reports included rude or dismissive staff, lack of attentive care, and long wait times. Mothers recounted how these experiences deterred them from accessing clinical care and other community resources.

> ... the doctor would treat me bad, I will explain things to him and he would always go and ask me how many kids you [have] and he would do things but he wouldn't explain why. And so I prefer not to go, and even if my daughter had something I would rather ask other people than ask him. - *Jenny, mother of three*
>
> [Medicaid] has been useful because it covers our kid's insurance. But in another way it hasn't because in certain cases when you go with Medicaid, [Clinics] treat you not kindly. - *Olivia*
>
> I spent all morning [at the clinic] a week away from a C-section, even though you feel well, it's still uncomfortable for you and the baby and secondly, the doctor took less than 5 minutes to check the girl so I thought, 'bringing [her] here again, I feel like I'll waste my time', I don't bring her because I'll leave the same as when I came in; with my head full of doubts. - *Jane*

Furthermore, traumatic, or possibly dangerous situations either experienced or heard, also contributed to further wariness among Latinx parents seeking out services.

> ...the first difficulty I had was the language. You can be dying and my husband was like...and there was no one, my baby was about to be born and there was nobody...I was so traumatized I didn't want to go back there. I got pregnant after that and went over to [Clinic] but at [Clinic] they say, over there you die because they never treat you.
> - *Marie*
>
> [Interviewer] Did any of you hear something negative and thought, I won't go because it is scary? Because there are rumors, because maybe you felt some kind of stigma?
>
> [*Sandy*] Sometimes they also say it's because of ICE.
>
> [*Katie*] They say no because of ICE.
>
> [*Carla*] Because of ICE.

Overall, exposure to these various barriers contributed to reported parental stress and deterred mothers from seeking additional resources due to their emotional and physical toll. These experiences were especially compounded for mothers facing intersecting barriers. One mother recounted how her work schedule, caring for multiple children, and dealing with family health needs impacted her ability to seek out services.

> I have three children...I don't have the other one here but he's in Guatemala, and I also have bills to pay in Guatemala...So that's very stressful and it's something I have to struggle with, because I have to work for the other boy, and also work for him, for the other baby. My partner and I are working a lot, because the other child is special, so I have lots of things to pay for there in Guatemala so I do that by working here and taking care of my other son...I have to keep an eye out for when he's about to sleep, so I sleep. If he doesn't sleep, then I don't sleep. Because I have to go to work soon. - *Mary, mother of three*

Received Support Types

Three received support types for Latinx mothers were identified by our sample population: Community, Clinical, and Relational (family & friends). Received supports were identified as resources which were able to provide emotional or physical assistance to families, and buffer some of the effects of identified barriers. The most commonly received support type was clinical, followed by community, and relational.

Discussions of clinical support differed across interview discussions. For many, support was confined to medical infant care and wellbeing such as referrals to other clinics and community supports, or chances to ask questions regarding childhood development. For those individuals, attentiveness of clinical staff during appointments and their ability to address pediatric concerns in a swift and supportive manner ultimately impacted whether clients viewed their clinic as a highly valued support resource.

> [Clinical provider] was very detailed; that's what I like. And you can see she does it like...Like a mom... you are focused on your baby. And you don't want anything to happen to them. And I see this Doctor and she does it the way I do it. - *Carla*
>
> ..My son was born at 8 months, that means he was premature so I had to take him over every week to get his weight checked out, they gave me a lot of orientations...So like she says, they always paid attention when he had his appointments and his vaccinations and everything was great. They even teach you how to carry them, how to breastfeed them, everything, and this is very important. - *Laura, first time mother*

However, some mothers had especially supportive clinical experiences which aided in additional life sectors outside of infant medical assistance such as legal, transportation, housing, or maternal medical care.

> Every time I go to [Clinic] they always ask me, do you feel safe at home? My doctor mainly tells me, you still have stress, are you sleeping well, are you having a good time with your wife, do you stress out with the girl, does she stress you out or any of them? She always asks me. 'Hey, this is going on, this hurts, okay, I'll refer you for a massage or something like that.' The response is right away. For me, it's been great. - *John, father of two*

Many of these experiences identifying support outside of just pediatric medical guidance specifically mentioned the clinic's additional programming efforts such as DULCE or other services which fall under Family Centered Care. These effects on the scope of clinic support will be further discussed within the *Impact of FCC* section in Results.

Community supports were able to provide many parents with physical and mental resources. The community support type includes government and local institutions. Government support was classified as national or state government funded programming, created to assist new parents including WIC (Special Supplemental Nutrition Program for Women, Infants, and Children), Medicaid, SNAP (Supplemental Nutrition Assistance Program or Food Stamps), and the Department of Healthy Families. Local support included localized services and agencies offered separately from the government, such as regional schools/daycares, local parenting programs, religious institutions, and other local food/resource banks. Many community support services provided links to other community supports for Latinx families, by sharing knowledge of local program options, offering referrals to additional local or government agencies, and providing positive assistance experiences, their support promoted the engagement of Latinx families in services and improved overall family health.

> [Local support]. They go there to do the application in case you need anything, like court, or Medicaid, all that. You can go with them; they will do everything and you don't have to pay anything. They provide that help. Or if we need a job, we are looking for a job, we can go there and send a fax, receive an email. They help us.....I met a friend who told me that the person in charge here at the [Church] paid for her rent, and she [couldn't] afford the expenses of her children, because her husband had a problem with the police. So she went to the [Church] and they helped her; she went to [Local support] and they helped her, and with the food from WIC, she was fine. - *Ruby, mother of three*

These linkages were especially vital for first time mothers or immigrant participants who had little knowledge on resources available in their area.

> With my first daughter...it was a bit more complicated and difficult to me because I didn't have any kind of help; I didn't have information about these programs that exist now. But with the second baby...I went to the clinic to find out if I was pregnant, they transferred me to [Local program]...and from there they transferred me here [Clinic]. - *Cecilia, mother of two*

> I’ve been here in the US for 17 years. Well is it difficult to be a mom? Yes, it is difficult. The first baby you have no knowledge, you don’t know how to take out the diaper, to breastfeed; it’s a little bit too difficult, I had a hard time. - *Sara*

Many Latinx parents identified their relational supports (family and friends) often assisted in various domains including child supervision and care, financial support, and emotional support. These supports were able to buffer the effects of some of the previously discussed barriers which prevented or deterred mothers from seeking care.

> [My family] came over to help me hold the baby so that he wouldn’t cry. I stopped working, because I was going to get back to work but then I couldn’t go back because I was breastfeeding the baby... I was going to change formula, but since I didn’t want him to cry, because his hernia could burst...I couldn’t go back to work. And my family supported me in that aspect, and they came over to help me... - *Lucy, mother of two*

These experiences were important to Latinx parents; those who identified inability to access supportive relational ties, contributed to added resource strain and parental stress.

> My mom was always there. But sometimes I can feel alone because my husband wasn’t there with me. He was still in Mexico. I was just waiting for him to come. And I was going through a lot emotionally, financially...but yeah, I did have support with my mom. - *Suzanne, first time mother*

Sought Support Types

Latinx parents within our sample were asked what resources they initially consulted when seeking information for their needs. This was different from received support which indicated where individuals received actualized support (ie. Physical medical care, childcare, clothing, diapers, etc.). The sought support type is meant to identify where respondents first turn to when encountering challenges or seeking information. Sought supports allows us to identify which sources can be targeted to ensure information flow through Latinx social networks and increase the reach of programming knowledge which was shown in our sample to be a lead barrier in accessing care. Within conversations surrounding sought support types, five were identified: Relationships (family & friends), Media (Books/Web/TV), Health Care Professionals, Community, and Earlier Experiences.

Latinx parents most often reached out to members of their social network, such as family and friends, as the first point of contact for providing information on local supports and informed advice on medical care. Interviewee Marisol stated, “I learned about [the clinic] because my husband's father was passing by and he said, ‘I notice a lot of people going there, you should go there.” Another participant, Amy, stated, “I have a sister who has a son, he is older, so she has experience. She tells me, look, this is what’s going to happen. Like, it’s normal.” Interviewee Rose also shared a similar experience, “Since my cousins all have kids now, they gave me a book, I don’t remember the name of it but I have followed it a lot. And since my husband already has kids I almost always ask him.” This sharing of knowledge appeared to be vital for Latinx members attempting to navigate services. When Vanessa, mother of five, was questioned as to why she identified other families as a primary source of information, she responded:

> ..sometimes since you trust people more, your neighbor or your friends tell you. ‘I went there, my friend went there, my sister went there’, so you go there feeling more assured than if they just gave you a brochure, and there are all kinds of brochures everywhere.

Latinx individuals also relied heavily on media sources for initial information on clinics, programming, and general infant health questions. This includes online content & apps, written media such as books or articles, as well as television shows & ads. Phone apps specifically were discussed numerous times as sources of accessible and educational information for Latinx mothers to bolster parental knowledge. These information sources were able to provide a larger wealth of information than asking relationship contacts alone. “I have a book called Baby 411.

It’s really thick and it has almost every question you can think of and the answer. So it's like my little dictionary,” stated Jenny.

> I’ve relied a lot on platforms and YouTube and the internet, because there are channels that tell you, like this lady said, ‘my son is like that’ or they have blogs or there are specific channels where people have the same problems and you listen to experiences others have... - *John*
>
> I have an app that is called BabyCenter, and every month they send me something like ‘this is the time when your baby will smile, this is the time he will be able to crawl.’ They show you the steps that follow. - *Julia*

Healthcare professionals, community resources, and earlier experiences with children were also implicated as sources of initial information for Latinx parents. As observed in the received support category, when parents decided to initially consult health care professionals, they were often able to provide linkage to community and clinical resources with a heavy emphasis on enrolling mothers in federal community programs such as WIC. Similarly, community resources were often able to provide linkage to information on healthcare professionals in the area (social workers, family specialists, gynecologists, pediatricians, etc.), creating a cyclical flow of community and professional resource referrals.

> ...when you’re a first-time mom you don’t know what age they should be talking or crawling. So then you go to the pediatrician, and he tells you this ‘you know what? Your daughter can’t crawl, she doesn’t have any strength. And that’s when they give you information...they say, ‘we’re going to connect you over here’ or ‘we are going to refer you to [community support].’ - *Sofia, first time mother*

Earlier experiences with other children were seen to allow some Latinx parents to find initial information and services autonomously. By relying on their own previous childcare knowledge and experiences, parents were able to overcome similar barriers with their current infant.

> Generally I haven't had a bad experience with this baby because I have experiences, I have a 3 year old son and it [seemed] a bit more difficult with him because he's the first baby and everything is harder, with the second one you have experience, and you don't get scared, and you manage situations better... - *Tina, mother of two*

However, this was not the case for all families. For immigrants or parents encountering new barriers that they did not face with previous children, prior parenting experiences did not provide the same bolstering effect when attempting to navigate the complex U.S. system of care.

> I think it all starts with us, so if one has doubts, even though we might have some experience, it's always a new start, each baby is different, there are always new things, it's not the same. I feel like I'm starting from zero again. So I think it's important for them to help us a little more... - *Isabelle, mother of three*

Common Parental Health Concerns

Latinx parents identified common parental health concerns they experienced when caring for their infant. The most common concern was dealing with parental stress followed by breastfeeding and nutrition, and dealing with physical health challenges (infant and adult). These concerns were important in Latinx discussion, due to their influence on their use of services, and impact on their personal wellbeing.

Parental stress included a wide array of reports such as experiencing postpartum depression, struggles with providing financially, stress of deportation, and experiencing infant mortality. These stressors impacted parental mental health especially. Participant Sofia emotionally expressed during the interview, "The biggest challenge is...it's just being a mom, it's really hard [sobbing]. Every day. I'm sorry...Everyday there is a different challenge and you don't know what might come up tomorrow..."

> We both have full time jobs...very low paying, but full time jobs. So the biggest stressor for us has been financially. We have to be away from our kids to pay student loans and to

> pay our bills and also cover childcare. But then also that guilt of, I want to be as active as I can raising my children even through I’m away from them 80% of everyday and always the best parts of their day. - *Carmen, mother of three*
>
> ...what scares me is, I’m_afraid of deportation, of leaving my children here with people I don’t know, strangers other than the people they know, which is their mom and the family circle. That is my only fear; other than that, being a parent, you learn as you go. Because nobody is born with knowledge. And thank God I hope and wish the situation we are in will be solved. - *Margaret, mother of three*

For mothers experiencing post-partum depression (PPD), accessing services became harder. Parents described drained energy and motivation to seek out services or care. One mother described why she did not seek out supports while experiencing PPD.

> To be honest, no I didn’t, because I just wanted to be home. And I just wanted pretty much to just stay home. I think I got enough in the moment that I didn’t want to see no one, I didn’t want to see friends, I was going through a lot. I just want to be by myself. Yeah, it was really tough. - *Suzanne*

Another mother, Leanne, identified how immigration status impacted her decision to not seek help for her stress because, “after that they will be on your case. No this has not happened to me, but I imagine that for the children's welfare they must follow up on you.”

Parents were able to overcome or cope with the stressors through clinical care which offered referrals to community support groups, day care programming, and other mental health services. However, this was only possible if they were willing to come forward and acquire assistance from a support. Latinx parents identified when experiencing stress, they often were not comfortable confiding in clinic staff due to cultural differences in expectations of care and feelings that it was “inappropriate” to discuss stress in a clinical setting. This idea was reflected in multiple participant narratives.

> I understand clinics are only [to] inquire about something, to check the condition that one has and that's it. Or the condition a child has, not for personal stuff....If they asked me I would tell them; but I wouldn't just go and tell them about these things. - *Lucy*
>
> Because when your kind of shy, I think you're more shy [when] talking to the doctor and saying 'this is what's going on'...I guess because of our culture. We're not that open...I think it's just more how we are being raised. - *Suzanne*

Breastfeeding and nutrition were the second most reported concern. Breast feeding support through WIC was indicated by mothers to be especially useful in addressing these concerns; offering breastfeeding classes, free supplies, and further educational materials. Other government supports such as Medicaid were also mentioned by parents, such as first-time mother Camila, "Talking about pumps...I think it's called Medicaid, they give it to you...they give [the breast pump] to you for free." Concerns within breastfeeding and nutrition included latching difficulties, maintaining milk supply, and maintaining infant weight. While the clinic was able to provide some guidance, mothers highlighted the role breastfeeding classes or additional assistance received outside of the clinic, contributed to overcoming their breastfeeding and nutritional concerns.

Physical health concerns experienced by the parents impacted their ability to travel for care, either for themselves or the infant. Similarly, health concerns experienced by their children impacted parental stress levels by disrupting their daily living, creating additional need to make appointments, organize transportation, and follow up on infant care needs. Interviewee Ruby's statement captures the struggle of many working-class mothers in such a position,

> I think there's nothing harder than having children, and when they get sick, we have to go and take them to the hospital and so on...It's a bit difficult but you have to because when the child gets sick, you don't know if you have a job, if you are working...you have to get out of your work and sometimes people get mad, and they end up firing you. So you feel worried.

Some health concerns included preterm birth, c-section recovery, child developmental delays, and various emergency health needs which all contributed to stress and increased need for support and resource connections. For some mothers, dealing with parental stress contributed to their own experiences with physical health concerns.

> 6 months I was doing poorly, I go to the ER and I'm there 11 hours and they say, nothing is wrong with you. They put me in the tunnel, ultrasounds, blood test, I exaggerate, 'I'm dying, it hurts, why do they say I don't have anything?' And finally the doctor sat down and told me, all your pain can be stress, the issue is that your stomach hurts, you have a lot of kids, you stress out and your stomach gets all irritated, run for a kid then after the other, the husband comes home and your stomach is all in knots. - *Marie*

Impact of DULCE (Family Centered Care Intervention)

DULCE was often brought up in response to questions surrounding supports or resources Latinx caregivers utilized to meet their needs, especially within the clinical sphere. Family specialists and legal aids incorporated by DULCE, a family centered care model, were able to assist mothers in overcoming barriers through proactive action; by enrolling them in programming, answering questions, providing translation services, and advocating on parents' behalf. Even parents who had prior experiences with children, such as interviewee Ava, found the programming beneficial, stating "it was a very good experience for me as well because I thought I knew everything because I have kids, but this program helped me a lot and it turns out I didn't know it all."

> We are a poor community and there are many needs. And honestly, from all those programs, I'd never heard of them...[Family specialist] gives you a folder with all the programs. And if you don't find something, she tries to get it. I don't even know how she does it, and there it is. I would call her at midnight...I am very grateful...and she always helped me a lot with the boy. I was actually telling her yesterday, that thanks to her, [my son] is getting therapy...Yes, she was jumping for joy and I said, oh, finally someone who jumps for joy with me. - *Bianca*

> [Family Specialist] is the best ever...If the baby was missing something, [she] had it. If the baby needed something, and she didn't have it, she would get it. She was always paying close attention to the babies. You have an appointment at the clinic and [she] was there with you. - *Elena*

By providing a knowledgeable and accessible source of contact for mothers, parents were able to learn more about relevant programming options, enroll with assistance, and overcome additional barriers they faced initially when tackling these questions alone. In one instance, a mother who had a negative clinic experience and confusion surrounding insurance coverage was deterred from contacting her clinic. However, the Family Specialist was able to advocate on her behalf to ensure proper care.

> ...I don't like the temper of that lady [clinic staff] because when you are talking she hangs up. [Family Specialist] said, let me try. And [she] insisted and insisted until she picked up and [she] told [clinic staff] 'why don't you answer the phone if you know she is about to have the baby? And when are you going to fix this? Because look, these are the bills.' And she sent them all to her. It was almost $10,000 dollars...I got Medicaid. I didn't have to pay all the bills... - *Sara*

In this way, Family Centered Care allowed for a broadened understanding of family's needs, on a level not achievable through standard clinical care. This understanding assisted Family specialists with providing proper linkage to vital resources and filling gaps in parental knowledge and referral circuits for individuals like interviewee Alba, who stated, "I heard through [Family specialist]...she told me there was WIC, I had no idea..."

> I didn't know about [local food program] and [family specialist] told me...I said, what is this about? And she started to explain to me how [local food program] works...she told me how to do the paperwork to get it. And up to this day, I'm getting [local food program]. - *Sara*

Parents' ability to utilize knowledge provided by Family Specialists and programming was able to assist parent's resilience building by strengthening parental knowledge on how to overcome barriers and meet their family's needs. Emilia, mother of three, described how her Family Specialist was able to link her to legal aid offered within the clinic to address housing concerns impacting infant and personal health.

> I had problems because my son turned out to have lead in his blood. So [Clinical Provider] told me, no you have to [look more] because it comes from the house. [The Family Specialist], and I think the social worker, went to see the house, to check it with a device...’That is affecting your son’ she said...The doctor, said you know what? Fix the house because such and such is paying for the house and [they] have to fix it. The owner of the house didn’t fix it so [Family Specialist] said, ‘we have a lawyer here’... so the owner of the house received the paper that the lawyer sent him, and he obeyed, he took everything out, he fixed it, the house was fine...they help you here.

Discussion

The current study’s research aims were to identify Latinx families' experiences within the traditional pediatric care model and how DULCE impacted these experiences, how immigration influence Latinx pediatric health care experiences, and to ascertain how the Family Centered Model of Care be adapted to better fit the needs of Latinx individuals living within the U.S. Qualitative analysis provided valuable insight into the lived experiences of Latinx families when navigating the traditional health care model for pediatric care. Many families encountered barriers such as lack of materials in the Spanish language, lack of insurance coverage for those of immigrant status, previously negative clinic experiences deterring members from seeking services, and lack of knowledge of available resources. Furthermore, conflicts such as work schedule or having to care for additional children made it difficult for many Latinx members to find availability to schedule appointments or find additional services on their own time. Latinx parents were most likely to reach out to close relational ties such as family and friends when initially seeking answers, recommendations, or support for their parental concerns and questions.

Parents found it difficult or even inappropriate to bring up concerns, family barriers, or needs to pediatric clinic staff, identifying differences in cultural expectations of health care.

In seeking to understand how Latinx families utilized the services provided in a FCC model such as DULCE, Latinx members expressed appreciation for the services offered, including the incorporation of language assistance services, legal aid, and Family Specialists. Family Specialists specifically were able to be of great assistance to Latinx families, providing translation assistance, programming knowledge, emotional support, and additional referrals to bolster family wellbeing. These services supported families and promoted infant wellbeing before and after program engagement by perpetuating continued enrollment in available programming and building trusting relationships between Latinx families and local clinics.

Immigration status impacted Latinx members ability to attain services. It was observed that Latinx immigrants may have few established local supports, little knowledge of available programming in the area, and lack of insurance coverage, making it more difficult to find assistance, overcome barriers, and address family needs. Lack of knowledge was one of the biggest barriers identified by the Latinx population while seeking supports. Furthermore, fears of deportation were expressed as another barrier contributing to Latinx hesitancy of engaging in services. It could be posited that Latinx immigrants could experience lower likelihood of seeking assistance due to lack of support or access to local programming knowledge, and fear of deportation when accepting services. Lack of materials in the Spanish language could also pose barriers for immigrant members ability to access health care services successfully.

These findings align with exiting literature on the navigation of health care by the Latinx population. Within a study conducted by Juckett (2013) identified barriers for Latinx members seeking health care included lack of Spanish language assistance, difficulty obtaining insurance, differences in cultural attitudes, and weariness or distrust due to possibility of deportation. This research identified Latinx immigrants especially face significant stress while acclimating to the U.S., culminating in negative emotional or physical symptomology. The National Standards for Culturally and Linguistically Appropriate Services (National CLAS) recommended overcoming these obstacles within the clinical sphere via language assistance materials, adoption of cultural informed care practices, and creating organizational services to assist Latinx families. Juckett (2013) identified physicians looking to support and successfully engage Latinx individuals in care should actively support their cultural values including kindness, relationship building, and respect.

Implications & Future Directions

In understanding how the Family Centered Care Model can be better adapted to fit the needs of Latinx individuals living within the U.S, study analysis identified Latinx needs including increased materials in the Spanish language across agencies, increased referrals and outreach initiatives to incorporate Latinx immigrants into supportive services, and increasing programming support aimed at reducing barriers to accessing services outside of the clinic. Within clinics, this could include weekend hours to accommodate working parents, on-site legal aid council, transportation assistance, home visitation options, incorporation of social workers or counselors into clinic staff, and active promotion of support interventions for parents who are immigrants, first time mothers, or experiencing health barriers.

> I would have liked to have a person there, like a counselor, someone to help me a little more, to know what was going to happen. Because as I said, when you are a first-time mom, you don't know anything. - *Lucy*
>
> I would ask the county to have more programs available for children who are born with a deficiency or a special need...they keep you waiting and waiting... you are fighting against the clock [for treatment]...I'm feeling this way because I don't know how to help

> her. So I am begging you to open more programs for intellectually challenged kids. - *Sophia*
>
> [The Clinicians] should also consider us as mothers not just- the baby is important, but I do think they should take us into account as mothers, asking us 'how are you feeling? Is there any situation going on at home?' - *Jane*

Latinx clients may experience hesitancy when discussing personal barriers with clinician staff. Within pediatric care, parental wellbeing is tied to infant outcomes and therefore parents should be considered an extension of pediatric care. FCC initiatives aimed at the Latinx community should work to ensure members are asked directly and honestly about their family needs. By engaging supportive roles, such as family specialists, to initiate conversations and build relationships with families, clinics are able to provide a wealth of resource information, bolster parental support, and establish positive relationships with the Latinx community. By bolstering positive Latinx community experiences with accessing care, other Latinx members may be more accepting and willing to seek out services. Clinicians can aim to build better relationships with their Latinx patients by providing verbal feedback, deeper explanations of what they are checking, acknowledging possible language barriers and respecting cultural differences for parents.

> [I would like] for them to- for you to feel like [they're] saying I'm doing it well, because [the clinician] is the professional, I mean we'll always have doubts, we make the effort, but we don't know if what we are doing is correct. - *Isabelle*
>
> I know you are not going to go to a Doctors office and usually get a lot of holistic approaches to things...but when my kids get a cold, just kind of maybe more encouragement towards, here are some popular natural things you could try, and still having the options to know here's the line, this is where medicine needs to step in... recognizing, yeah, that's part of our culture. - *Carmen*

Further studies analyzing the impact of FCC programming on parental resilience should be explored. Effects on resilience can be speculated within our research through parent's discussion of overcoming barriers with information from Family Specialists, however, understanding how resilience may be identifiably improved or reduced by FCC programming requires further analysis with field approved surveys or questionnaires. When considering the Latinx population, resilience may differ across nativity status, or length of time in FCC programming. Future studies should also seek to explore how FCC's impact on resilience may differ across ethnic communities. Similar to the Latinx community, African American's face prejudice and hesitancy in accessing health care and government services due to historic mistreatment and racial profiling, especially within areas of child welfare (Gourdine, 2019). It would be of interest to analyze how FCC may be able to support this community in similar or different ways from the Latinx community. Lastly, ensuring Latinx freedom to receive care without fear of deportation or legal ramifications is vital to increasing pediatric and health care access for Latinx families. Understanding how FCC can safely incorporate nonnative Latinx members in programming and services would be of great benefit to the Latinx community.

Limitations

Limitations to the current study include the recruitment of DULCE participants from existing clinic patient pools. This collection methods prevents participation of Latinx community members who are disenfranchised from the health care sphere; a population who would be especially useful in understanding barriers to health care for Latinx individuals. The experiences garnered from our sample population may align with common barriers for this population, but further study is needed.

Latinx population is comprised of a variety of subgroups (Puerto Rican, Cuban, etc.) Differences between these distinct subgroups were not able to be identified within the current study. Future health care research should aim to better understand potential cultural differences among the Latinx population (Tienda, 2006).

Differences in analyzed interview types (focus groups, individual phone, and individual in person) may also be considered a limitation due to lack of continuity throughout the sample population. Future studies should take this into consideration when deciding on interview collection methods.

Conclusion

Latinx families experience unique health care challenges that could be addressed through Family Centered Care (FCC) initiatives. If we seek to confront the problem of lack of Latinx access to health care and ensure infant wellbeing, future policy changes informed by research around Latinx healthcare attainment and attitudes are critical to promoting long lasting positive health outcomes. The current study identified many barriers such as language, immigration, cultural expectations, and access to insurance coverage, contributed to challenges in accessing care services. The FCC model adapted by DULCE addressed many needs unable to be met in the traditional clinical model of care for Latinx families through individualized attention and support which was highly valued by Latinx members. Furthermore, the Latinx community placed emphasis on the importance of relationship building in seeking out services and overcoming barriers to accessing care. While Latinx members were hesitant to discuss personal stressors and barriers with their clinic staff, members were more easily able to discuss these with a Family Specialist, who may have provided a more relaxed and culturally acceptable environment conducive to honest discussion of needs. The FCC model assisted parents in mitigating stress and overcoming barriers through increasing parental resource knowledge and support. By bolstering parental access to resources through assignment to a knowledgeable and culturally informed Family Specialist, potential ACE’s for Latinx children can be mitigated- promoting health across the lifespan and lowering U.S. health disparities for the Latinx community.

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