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### Trust And Healthcare: A Qualitative Analysis Of Trust In Spanish And English Language Group Well-Child Care

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Trust and Healthcare: A Qualitative analysis of Trust in Spanish and English language  
Group Well-Child Care

A Thesis Submitted to the Yale University School of Medicine  
in Partial Fulfillment of the Requirements for the  
Degree of Doctor of Medicine

by

Nicolas Muñoz

2020

## ABSTRACT

Trust and healthcare: a qualitative analysis of trust in Spanish and English language  
group well-child care

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**Background:** Trust, in the healthcare setting, is defined as the optimistic belief that providers and systems serve patient's best interest. It is a multidimensional concept including competence, and value congruence, and exists due to patient vulnerability. Trust has been demonstrated to impact healthcare utilization. In pediatric patients, trust is key for strong and effective provider-patient relationships though Black and Latinx parents of children have lower trust in their physicians when compared to non-Hispanic white parents. Group well-child care (GWCC) is a model of care redesign that has been associated with increased trust among participants, and has demonstrated efficacy in serving black and Latinx as well as low socioeconomic families. This study aimed to describe themes related to trust among parents who participated in both English and Spanish language GWCC.

**Methods:** GWCC includes a 90-minute health care visit in the first year of life that takes place instead of traditional well-child care. We performed purposeful interview sampling of parents who participated in either Spanish or English Language GWCC at the Yale Primary Care Center from 2016-2017 using a semi-structured interview guide.

Directed content analysis was performed using a theoretical framework for trust in healthcare.

**Results:** Twenty interviews were performed in total with half being parents in each Spanish and English GWCC. A majority of parents participating were mothers (81%), hispanic/latinx (56%) and 39% participated with their first liveborn child. Three themes related to trust and GWCC emerged: 1) group dynamic flattens traditional hierarchies in care, 2) opportunity for cross-validation and triangulation of information, and 3) structural competency from providers and the healthcare system is associated with trust.

**Conclusions:** As healthcare is redesigned strategies to increase trust in healthcare for minority patients is important to achieve the triple aim of less per capita cost, greater population health and better patient experience. In this study we characterize how trust works in the GWCC setting, and facilitates structurally competent care for families.

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To my family: Sebastian and Tomás, for keeping me humble regardless of the accomplishments and successes that I have, to you two I am just your brother and you know all of my flaws. To my mom, Angela Duque, who left one career but found a passion in teaching bilingual second grade science to children primarily from Latin America. You carry their stories, and teach me the impact we can have on youth through the impact you've had on your students who are going on to do great things. To my dad, Rodolfo Muñoz, who's self-sacrifice and tireless work ethic pushes me every day to learn and succeed through the opportunities you've afforded me.

“People, as being ‘in a situation,’ find themselves rooted in temporal-spatial conditions which mark them and which they also mark. They will tend to reflect on their own ‘situationality’ to the extent that they are challenged by it to act upon it. Human beings *are* because they *are in* a situation. And they *will be more* the more they not only critically reflect upon their existence but critically act upon it.

Reflection upon situationality is reflection about the very condition of existence: critical thinking by means of which people discover each other to be “in a situation.” Only as this situation ceases to present itself as a dense, enveloping reality or a tormenting blind alley, and they can come to perceive it as an objective-problematic situation—only then can commitment exist. Humankind *emerge* from their *submersion* and acquire the ability to *intervene* in reality as it is unveiled. *Intervention* in reality—historical awareness itself—thus represents a step forward from *emergence*, and results from the *conscientização* of the situation. *Conscientização* is the deepening of the attitude of awareness characteristic of all emergence.”

Paulo Freire

*Pedagogy of the Oppressed*

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## **Introduction**

### **Theoretical framework for Trust in Healthcare**

The evaluation and understanding of trust and distrust in healthcare have been rooted in a sociological, theoretical framework of trust that defines dimensions key to development of trust. Within healthcare, trust in providers has been most broadly defined as the belief that the provider will act in the patient's best interest.<sup>1</sup> Hovland, Janis, and Kelly first described a paradigm of trust with two dimensions, perception of values congruence and perception of competence.<sup>2</sup> Perceived value congruence means that the patient believes that the provider shares a similar value structure to the patient that will guide decisions in care. Perceptions of competence rely on the belief that a provider has the knowledge, skill set, and credentials to deliver appropriate care. This 2-dimensional paradigm has been used to understand trust in healthcare settings, and has formed the basis for quantitative tools used to measure trust in healthcare.<sup>3,4</sup>

More specifically, a systematic review of the literature identified 32 articles that discussed trust in the healthcare field, including the development of trust scales. Methodology for development of these scales in the majority of studies used qualitative methods, pilot surveying, and validation testing.<sup>5</sup> Across these studies, the dimensions of trust identified included: honesty, confidentiality, dependability, communication, competency, fiduciary responsibility, fidelity, agency, respect, caring, privacy, and global trust.

## **Trust and Vulnerability**

Trust forms a critical component of societal interactions and is especially important in healthcare. Mark Hall, JD and Director of Health Law and Policy at Wakeforest is among the first to thoroughly explore the importance of trust in Healthcare. In their primary work, he and his team stated that, in healthcare, trust is necessary due to patients' vulnerability.<sup>6</sup> In the framework they suggest, trust in the provider-patient relationship is contingent on the unavoidable vulnerability of the patient. Illness is a source of vulnerability that requires trust in the provider's knowledge and skill-set to engage in a beneficial relationship. The greater the vulnerability and risk involved in the relationship, the greater the potential for trust.

Hall et al., in their discussion of trust and vulnerability, focus on vulnerability of the patient with regards to their illness. In this next section, we expand upon this limited view of patients' vulnerability and argue that the provider-patient relationship should also take into consideration how social, political, and environmental vulnerabilities significantly impact patients' health. This view of vulnerability and trust should consider the holistic view of the patient within their social context. Provider understanding of the structural vulnerabilities patients face when engaging with care is critical to the development of a more trusting relationship, and particularly important when serving vulnerable patient populations.

### **Structural Vulnerability and Structural Competency**

In the last decades, public health and health care professionals have put increasing emphasis on the need to address the social factors, social vulnerabilities, that affect people's health. The "social determinants of health" are recognized to have a role in the health inequities faced in the United States such as those rooted in race, ethnicity, socioeconomic status, and gender.<sup>7,8</sup> Cultural competency has been promoted as a way to address racial and ethnic disparities in care that have been attributed to difference in cultural beliefs and values, but in recent years has been critiqued for its reinforcement of stereotyping individuals from different cultural and ethnic backgrounds.<sup>9</sup> One of the main criticisms has been that focusing on cultural barriers misattributes health outcomes to cultural practice instead of understanding the multifactorial effects of social inequality stemming from political, social, and economic roots.<sup>10</sup> This evolving criticism in the social science literature reframes cultural competency under the emerging concept of structural competency.<sup>11,12,13,14,15</sup> Encompassing the social determinants of health, the concept of structural vulnerability emphasizes the effects that social context has on the individual, and recognizes the limited agency individuals have within these greater structures.

The current work on structural competency emphasizes the need to train clinicians to understand how clinical symptoms, attitudes, and diseases represent downstream effects from a system of decisions beyond the individual in areas such as "health care and food delivery systems, zoning laws, urban and rural infrastructures,

medicalization, or even the very definitions of illness and health”.<sup>11</sup> Structural competency has been operationalized to re-structure the social history, in order to provide a framework for providers to better recognize, understand, and intervene on the factors that affect patients’ health.<sup>14</sup> In 2018, *The New England Journal of Medicine* began publication of “Case Studies in Social Medicine” that highlight “the importance of social concept and context to clinical medicine.”<sup>13</sup> Further, structural competency is being embraced as an educational focus in premedical and medical school curricula, aligned with the eight competency domains for health professions as outlined by the Association of American Medical Colleges.<sup>12,16</sup> Emphasizing provider competency in understanding the language and impact structural vulnerabilities will promote better provider-patient relationships and empower advocacy for institutional and structural interventions on a system.<sup>11</sup>

### **Distrust in Healthcare**

Equally important in the healthcare setting is the idea of distrust, which is distinct from the absence of trust and is defined as a belief that providers/organization may act *against* an individual’s interest. Several theoretical frameworks of trust and distrust suggest that the two lie on opposite sides of a linear scale, with trust being in the positive direction, distrust being negative, and no trust being neutral at ‘zero’.<sup>4</sup> Among racial and ethnic minorities, concern about distrust is important given the history of structural racism, the repercussions of which have impacted generations of individuals. Historically, the U.S. Health Service Corp Syphilis Study (also known as the

Tuskegee syphilis experiments) serve as only one example of the medical mistreatment of the Black community that has been linked as a contributing factor in the increased distrust in the medical system among Black communities, and to increased health disparities.<sup>17,18</sup>

Similarly, eugenic sterilization laws in the 20<sup>th</sup> century disproportionately affected minorities, such as Latinxs.<sup>19</sup> These are two specific historical examples of how medical institutions have violated minority groups, however they are by no means unique examples. The extensive historical violation of Black Americans by medical institutions from pre-colonial times through the present has been detailed in Dr. Harriet A. Washington's book, *Medical Apartheid*.<sup>20</sup> Both Blacks and Latinxs have demonstrated lower institutional trust, and while relatively few people distrust their personal physician, there is significant distrust among Blacks with regards to shared values.<sup>21,22,23</sup> In evaluation of the significant racial disparity in cardiac disease, Black patients perceive existent racism in health care settings and have higher health care distrust.<sup>24</sup> This distrust has been justified by work that illuminates significant implicit bias of providers, who were less likely to offer black patients thrombolysis for management of infarction compared to white patients with the same clinical presentation.<sup>25</sup> Similarly, Latina women have higher medical mistrust surrounding breast cancer screening, with Spanish-interviewed participants having higher mistrust scores compared to other studied groups.<sup>26</sup> Consideration of the historical trauma of medical mistreatment and

abuse of trust by providers and the healthcare system as well as continued systematized racism and structural barriers in part explains minority distrust of healthcare.

### **Association of Trust and healthcare utilization in the pediatric population**

Trust and distrust have emerged as fundamentally important elements of the interaction with healthcare, both in the interpersonal patient-physician relationship and in the healthcare system.<sup>27</sup> Trust and distrust have both been demonstrated to impact healthcare utilization, including seeking of appropriate care, and treatment adherence.<sup>28,29,30</sup> Importantly, distrust in the health care system is associated with lower self-reported health.<sup>29</sup>

In parents of pediatric patients, trust in providers has been shown to be an important factor in development of a strong and effective provider-patient relationship.<sup>31,32</sup> Parental trust in providers within a medical home has been associated with behavior change to improve newborn safety in the home, and be a factor in the decision-making process to vaccinate ones child.<sup>31,33</sup> In the United States, the proportion of children from racial minorities is growing at a rapid pace, and predicted to become a majority-minority population by the 2020s.<sup>34</sup> In the greater New Haven area, the population <18 years old is already more than 50% minority, and has been growing.<sup>35</sup> Considering the changing demographics of the pediatric population it is important to consider existing disparities related to trust that have been described among racial minorities.

Black and Latinx populations have repeatedly demonstrated lower levels of trust, and higher levels of distrust in healthcare.<sup>21,22,36,37</sup> Lack of trust in health care has been associated with prior experiences of racism and discrimination in the healthcare setting, perceptions of less supportive physician communication, and lack of continuity of care.<sup>32,38</sup> A study in the pediatric emergency department found that Hispanic and Spanish speaking parents of patients had lower trust in their physicians than did non-Hispanic and English speaking parents.<sup>39</sup> Studies that used the Pediatric Trust in Physicians Scale found that African American parents and those that self-designated race as “other” were found to have lower trust when compared to non-hispanic white parents.<sup>40</sup> The ‘other’ category in this study would likely include Latinx individuals as the study did not differentiate Hispanic ethnicity in their analysis, and studies show that people of Hispanic ethnicity often select other when self-selecting for race.<sup>41</sup> These trends suggest that differences in trust exist among parents of pediatric patients that reflect the environments and interactions experienced by these populations in approaching medical care.

### **The Study of Attitudes and Factors Effecting Infant care Practices (SAFE)**

The Study of Attitudes and Factors Effecting Infant Care Practices (SAFE), a large nationally representative study that aimed to identify mother’s decision-making related to infant care practices, reveals both the differences in trust in healthcare and a potential solution. Results from the study demonstrate that non-Hispanic Black mothers were significantly less likely to trust health care providers when compared to non-

Hispanic white mothers.<sup>42,43</sup> In a separate study, black mothers have been shown to have higher trust in providers with which they have a continuing relationship.<sup>32</sup> In comparison, Hispanic mothers in the SAFE study reported comparable levels of trust in providers when compared to non-Hispanic whites; these same Hispanic mothers had significantly higher trust of media sources for infant care practices, suggesting a possible opportunity for outreach for this population.<sup>42</sup>

In the SAFE study, mothers with higher levels of education consistently had more trust in physicians about all infant care practices. Mothers with lower levels of education had lower trust; lower education may be associated with lower health literacy and feeling a greater gap between themselves and the provider, affecting rapport.<sup>43</sup> Analysis of maternal trust in providers was also examined as a part of the same SAFE study. Characteristics associated with higher maternal trust included reporting that the doctor asked their opinion, belief in the provider's qualification, and if their child was usually seen by one provider.<sup>43</sup>

Kilbourne et. al.'s framework for advancing health disparities research suggests a three phase approach, starting with detection of disparities, moving to understanding why these disparities exist, and lastly in developing, implementing, and evaluating interventions that address these health care disparities.<sup>44</sup> With regards to trust, several studies have detected and described the disparity that exists in regards to trust in the healthcare setting for minority pediatric populations. While there is some limited understanding of factors that influence trust, understanding the reasons for differences

in trust requires continued effort, and will be addressed in part by this thesis work.

Lastly, in implementation and evaluation there is little work that has specifically looked at specific ways to improve trust in Black and Latinx patient populations specifically. One area that has been explored and will be explored in this study is the well-child visit and clinical redesign through the group well-child care model.

### **Well-child care redesign and the triple aim**

As healthcare is redesigned with the triple aim of less per capita cost, greater population health, and better patient experience, models of care redesign should consider improving trust of minority pediatric populations to improve these three aims.<sup>45</sup> Well-child care is a central component of pediatric US health care services. Guidelines on well-child care visits include recommendations on physical exam, developmental/behavioral screening, immunization, and anticipatory guidance.<sup>46</sup> Yet, evaluation of services actually received reveals a range in receipt of guideline-consistent, quality care in these areas and a majority of parents feel they have unmet needs.<sup>47,48</sup> Barriers in achieving these standards reveals structural barriers and vulnerabilities that include race/ethnicity, socioeconomic status, and English language proficiency.

For example, in the National Ambulatory Medical Care Survey data, well-child visits were 10% shorter for Latinx children than either White or Black children. Further, Black and Latinx children were, respectively, 32% and 37% less likely to receive preventive counseling.<sup>49</sup> In evaluation of parent perceptions of pediatric primary care

quality, limited English-language ability and less potential access to care are associated with lower perceived quality of care.<sup>50</sup> While one study found that half of limited-English proficient Latina mothers expressed satisfaction with their child's pediatric primary care, this same study identified that limited English skill among families and limited Spanish skills among providers and clinics results in misinformation and frustration for parents.<sup>51</sup>

Currently, over 1/5<sup>th</sup> of the United States speaks a language other than English at home, and by 2050 the US population is expected to be over 25% Hispanic.<sup>52</sup> The rapid growth of this population and the existing disparity in pediatric primary care experienced by Latino and limited English-proficient pediatric primary care patients presents a case for research and programmatic efforts for improvement in primary care practice for this population.

### **Group well-child care as a clinical redesign to serve minority populations**

Group well-child visits is a model of care redesign of caregiver-infant groups that meet at regular periods with a consistent interdisciplinary provider team, with emphasis on group discussion and facilitating caregiver social support.<sup>53</sup> When engaged in conversations about care redesign, low-income and primarily Spanish speaking parents have previously endorsed positive attitudes towards GWCC.<sup>54</sup> Additionally, the group setting may promote building of community, which has been associated with lower distrust in healthcare systems in sociologic studies.<sup>55</sup> In addition to positive attitudes around GWCC, comparisons between group and individual well-child care have shown more robust perceived benefits among GWCC participants.

In a mixed-methods study of caregiver participants in English-language individual and group well-child care in an urban setting in Philadelphia, there was no significant difference in trust between the two groups using the Trust in Physicians Scale. However, GWCC participants scored significantly higher in the domain of global trust in physicians. While the quantitative evaluation of trust in this study showed no overall difference between the individual and group visits, the group participants scored significantly higher in the domain of overall trust.<sup>56</sup> In the qualitative aspect of this study dimensions of trust were not evaluated, and as the authors of the study note, further study on trust and GWCC care is warranted. In the current study, domains of trust will be examined as they arose with empirical, qualitative interviews with parents.

In addition to participant perceptions, GWCC has been associated with lower rates of obesity, greater attendance and more timely immunizations, and has been shown to be cost-effective or cost neutral.<sup>57,58,59</sup> GWCC among low-income and Spanish speaking parents enhances collective efficacy, and discovery of inherent expertise within the group. Further, these groups may have an effect on health care utilization through peer-to-peer triage.<sup>60</sup> As such, GWCC has demonstrated efficacy as an alternative treatment model to serve minority and low socio-economic families. With increasing interest in improving patient trust and the need to improve trust among marginalized populations, there remains a need for closer evaluation of trust within the GWCC setting.

Together, these findings suggest that trust is an important component of the parent-provider relationship in pediatric care, and is an issue of equity with regard to a parent's race and ethnicity. This study of GWCC was informed by the importance of trust in the parent-provider relationship and recognition of the differences in trust among different populations, noting in particular the limited research on trust in limited English-proficient populations.<sup>61</sup> Accordingly, our specific aim and research question are as follows.

**Specific Aim:**

The aim of this study is to characterize the perceptions and experiences of trust in providers and healthcare systems among caregivers of infants who participated in either English or Spanish language concordant group well-child visits at Yale's Pediatric Primary Care Center.

**Research Question:**

Among caregivers of infants receiving group well-child that predominantly serves a low income and minority population, what are the themes of trust in providers and trust in health systems that emerge?

**Methods**

The current study was guided by the Consolidated Criteria for Reporting Qualitative Research, and used a deductive approach for qualitative methods to characterize parent perspectives on interactions within the group associated with trust

and distrust utilizing previously existent interviews from the original study.<sup>62</sup> A deductive approach was used based on a theoretical framework for trust that categorizes multiple dimensions of trust.<sup>63</sup> All members of our research team were bilingual (English and Spanish), in aggregate were multinational (of Eastern United States, Colombian, and Venezuelan descent), and included pediatricians and a pediatric social worker with experience in qualitative methods and group well-child care.<sup>60,64,65</sup> Our methods were underpinned by directed content analysis, a qualitative research strategy whose goal is to extend an existing theoretical framework (in our case, the multi-dimensional model of trust).<sup>66</sup> The Yale School of Medicine Human Investigation Committee previously approved all study procedures.

### **Setting**

GWCC is offered in the Yale Primary Care Center, an urban hospital-based clinic that is the medical home for approximately 7,500 children, serves primarily families who receive public health insurance (97%), about 45% of whom identify as Black and about 45% as Hispanic or Latinx. GWCC is offered to all families electing for infant care at the Primary Care Center for which the mother has the infant in her care and if she reports that she is able to participate in visits in English or Spanish.

This model of GWCC includes 90-minute health maintenance appointments in either English or Spanish (participants choose), in place of traditional well-child care, throughout the first year of life. For the first 30 minutes, four to eight families cycle through: anthropometric measurements by the nurse, physical exam by the resident

and pre-visit questionnaires with the child-life specialist or social worker. During the next 45 minutes, the resident, supported by a nurse, attending pediatrician, and child-life specialist or clinical social worker, facilitates a discussion about anticipatory guidance and parenting strategies. The last 15 minutes are for vaccine administration and follow-up on families' individual needs.

### **Participants**

The original study design sampled purposefully from parents electing for GWCC at the Yale Primary Care Center from 2016 through 2017, seeking to be inclusive of heterogeneity in age, language spoken (English or Spanish), number of children, and parental role (mother, father, grandparent). This included parents who had completed at least three GWCC visits to ensure a lower limit of information-richness among participants, 40 of whom existed during the study timeframe. Recruitment continued until achievement of thematic saturation: when no new themes emerged with subsequent interviews.<sup>67</sup>

### **Measures**

The authors of the initial study developed conceptually identical interview guides in English and Spanish that were agreed upon by all research team members to be culturally and structurally competent<sup>67</sup>. Open-ended questions encouraged participants to address predisposing factors, enabling factors, and needs for health services utilization according to the Andersen model of healthcare utilization (see **Text Box**).<sup>68</sup>

**Text box.** Grand tour questions from interview guide.

- Tell me about your experiences with group well child care.
- Can you describe one thing you've taught others in group well-child care? And one thing you've learned from others in group well-child care?
- What is it like to share in a group with other parents who are different from you (according to age, first child or not, having a partner or not)?
- Are there experts in the group? Who "runs" the group?
- What is your relationship like with the facilitators of the group? What is your relationship like with the other parents?
- What do you think you offer the group?

### **Procedures**

The original study used an interview strategy to optimize privacy and welcome participants to discuss their care experiences.<sup>69</sup> Depending on the participant's preference, the interview occurred in either English or Spanish, in either a private office in the clinic (not connected to a GWCC visit) or in the patient's home by Benjamin Oldfield, who did not provide GWCC. With verbal informed consent, we digitally recorded all interviews, and a professional transcriptionist transcribed the recordings. Those who agreed to participate received a \$10 gift card.

### **Bilingual analyses**

Although standards of rigor exist for the conduct of qualitative research (Tong et al., 2007), to our knowledge, no standards exist for the transformation of source to target language or the integration of multiple source languages. After consulting the literature (Santos, Black, & Sandelowski, 2015; Tong et al., 2007) and qualitative research experts, we decided to retain data in the source language to preserve participants' narratives through all steps of analysis.<sup>62,70</sup> Translation was performed only

upon dissemination of findings with the agreement of at least two analysis team members.

In the first stage of analysis, all members of the research team created conceptually identical codes in English and Spanish in consensus as concepts emerged from the data; initial code book was developed using the dimensions of trust outlined by the theoretical framework of trust, but codes were not limited to concepts the existent theoretical framework, and analyses were not conducted separately by language.<sup>69</sup> We compared coded text to identify novel themes and expand upon existing themes until no new concepts emerged in subsequent transcripts. Four transcripts were independently coded by the four member of the team (BJO, NM, PN, MR) followed by discussion to reach agreement on code definition and coding consistency within the transcripts. The first author then used the final code structure to recode all transcripts. We used qualitative analysis software (Dedoose 8.3.10, SocioCultural Research Consultants, LLC) to facilitate data organization.

The above research methods come from previous work by Benjamin Oldfield, Patricia Nogelo, and Marjorie Rosenthal. Using existing transcripts, a deductive qualitative analysis targeted to identifying discussion trust was developed in order to characterize dimensions of trust discussed. Development and refinement of the codebook, and final coding was developed performed primarily by the author of the thesis.

## RESULTS

### Participant characteristics

From March through August 2017, the authors of the original study approached 23 parental caregivers and interviewed 22; one caregiver declined to participate. Half of the interviews occurred in the home of the family and half in an office in the Primary Care Center. Half were conducted in English and half in Spanish. The mean duration of the interviews was 33 minutes. Most (81%) participants were mothers but we also interviewed fathers and grandparents who were active participants in GWCC. The age of the mother at the child's birth ranged from 18 to 44. The sample was racially and ethnically diverse and most (94%) were insured by Medicaid (**Table**).

**Table.** Interview participant characteristics ( $n = 22$ ).

Characteristic	<i>n</i> (%) or mean [range]
Interviewee relationship to child	
Mother	18 (81)
Father	2 (9)
Maternal grandmother	1 (5)
Paternal grandmother	1 (5)
Mother's age at child's birth (years)	31 [18 – 44]
Child's age at interview (months)	6 [3 – 12]
First liveborn child	7 (39)
Race/ethnicity of child	
Black/African American	6 (33)
Hispanic/Latino/a	10 (56)
White	2 (11)
Insurance of child	
Medicaid	17 (94)
Commercial	1 (6)
Participant's preferred language	
Spanish	11 (50)
English	11 (50)

### **Theme 1: Group dynamic flattens traditional hierarchies in care**

The structure of the group visits consists of a team of providers that include: a nurse, a social worker, a resident physician, and an attending physician present throughout the entire visit and consistent visit to visit throughout the year. Within the group, each provider has a role in providing care for the infants along traditional provider practices. In addition to the clinical role, they collaborate in group discussion as both facilitators and participants. Parents who participated in the group commonly described the development of familiarity in the group as providers integrate themselves into the group. As one mother in the Spanish language group describes this:

Me sorprendió que [la doctora] es muy relajada. Ella trata de integrar tanto al grupo que se sienta en el piso. Trata de que uno se sienta en familia, como si ella fuera un muchacho más. Eso me sorprendió... ella baja al nivel de uno. Ella se pone al nivel de uno.

Translated:

I was surprised that the [attending doctor] is very relaxed. She tries to integrate so much into the group that she sits on the floor. She tries to make you feel as if you are among family, as if she were one of the kids. That surprised me... she gets down to your level. She puts herself at your level”

The effect of the provider’s approach leads to flattening of hierarchies in the provider-patient relationship. In this case, the provider discussed literally brings herself to the level of the children and this creates an environment where individuals in the group feel as if they are in a family setting, rather than a healthcare visit. In other interviews, mothers discuss how the nurse, social worker, and physicians integrate into group

discussion, entertain the infants, and speak in a more casual manner with the parents.

Providers come to the level of the parents not only in their behavior, but in the way that they communicate information. One parent comments on how this compares to other providers she's interacted with:

Some doctors, if you ask a question, they'll be like, I don't know... Like, "Well, studies say this and that and that and this," and then rather than the doctors in the group, they talk... I should say they talk to you in ways you understand. I guess that's what I'm trying to say. They put it simple, right to the point, rather than some other doctors.

While development of familiarity through verbal language as well as behavior in the group contributes the flattening of hierarchies, not all parents may seek this in care. As an experienced mother and father from a Spanish language group who had older children in traditional care note:

Madre: O sea, lo que usted dice es que más hablan las mamás, que la propia doctora... Bueno, algo así, porque nosotros vinimos al grupo para que te enseñen cómo hacer con el bebé. Entonces, bueno, a veces dicen, a veces no dicen. Pero uno tiene que escuchar a las mamás porque, bueno, será para eso el grupo, digo yo... Las mamás somos las que hablamos, experiencias de cada mamá. Pero, o sea, en mi opinión y en mi costumbre con mis otros dos hijos, yo iba a una consulta y bueno, el pediatra me dice: "bueno, a su niño le va a dar esto de comer, dale así esto, esto, a la hora, a la hora, y esto...". O sea, siempre me dice qué es lo que tengo que darle yo al bebé. No, yo tengo que buscar en el Internet...Bueno, hoy cumple nueve meses, deja ver qué le puedo dar. O sea, o me dan un folleto. "Mira, dale esto al niño, esto es por cada edad, por cada peso, dale esto al bebé". Entonces...

Padre: Ella dice que faltaría en el grupo, como que le dieran más información hacia los padres...Sobre cómo debe ser el cuidado, porque no sólo debe ser la consulta de sus vacunas, de ver cómo está, pesarlo, medirlo...También debería haber como más información referente mes que pasa, qué ya debe comer, cuándo debe comer. ¿Entiende? Yo creo que faltaría un poquito más de eso.

Translated:

Mother: In other words, what you are saying is that the moms talk more than the doctor... Well, something like that, because we come to the group so they can teach you what to do with the baby. So, well, sometimes they tell you, and sometimes they don't. But you need to listen to the moms, because, well, that's what the group is for, I'd say... We, the mothers, are who speaks, the experiences of each mom. But, well, in my opinion and in my experience with my other two children, I went to a visit and well, the pediatrician tells me: 'Ok, for your child you're going to give them this to eat, give them this like that, at this hour, at an hour, and this...'. In other words, they always tell me what it is I have to give to the baby. No, I have to search in the internet... OK, today they're nine months, let's see what I can give them. Or, they give me a brochure. 'Look, give this to the child, this is for each age, for each weight, give the baby this'. So...

Father: She is saying that the group is lacking, kind of that they give parents more information... on how you should take care [of them], because it should not only be that the visit is for vaccines, to see how they are doing, weigh them, measure them... There should also be more information concerning the month that passed, what they should be eating, when they should eat. Understand? I think [GWCC] lacks a little more of that

While the majority of parents speak positively about the experience of a more informal group setting, this may not be the ideal provider relationship for everyone. These parents feel that they do not always get enough specific direction on how to care for their child. They describe a previous, traditional relationship with their pediatrician in which information was given to them more directly. While this perspective is not commonly brought up among other parents interviewed, it points to the importance of establishing the goals of a provider relationship, and need to individualize and identify the relationship style desired. For some parents, the informal, flattened hierarchy of the group may engender trust in the providers and the group. For others, this may take away from traditional normative views of healthcare. These two parents may have felt

better served if they had been in a group with a more traditional approach to the delivery of information. In order to fill this perceived gap, they instead turn to the internet as a source of information on how to care for their child, a separate trusted source of information. Pursuing identification of the relationship style that works for each parent may help to identify those who may be best served with certain provider styles, or with group care versus individual care.

## **Theme 2: “The best of both worlds” Cross-validation and triangulation of information**

Within the group, providers serve as facilitators of group discussion and empower mothers to share their experiences and knowledge. Providers pose clinical questions back to the group to elicit existing parental expertise. This generates ideas about how to approach a problem and promotes discovery of expertise within the group.

We bring [a question about rashes] to the doctor, and they might ask us all, like, what do we do to treat the rash? Some of us might say, ‘Oh, we use Vaseline, or we might use the diaper rash cream.’ Or like, ‘Is there any other ideas or things that we can use to put on the rash?’ And they’ll give us any other type of creams or treatments to use for it. And they say, ‘Oh, if it gets bad, just bring her back to the doctor, and we’ll take a look at it and see what we can do.’ So if we have an issue or anything, we just bring it to the doctor. If we really don’t know what to do about it, we bring it to the doctor’s attention, and they’ll write it on the board, and they’ll talk about it. They’ll ask us what do we do. And we might tell them what we do, or we really don’t know what to do. Because we do something, and that’s not working, is there anything else that we can do to help the situation? And they’ll give us advice on it. And then they might tell us, like, ‘Okay, you could also talk to your doctor, or just take her to the doctors and see what they say.’”

Ultimately, the qualifications of the provider are used to stratify a tiered approach to addressing questions about rashes. In the groups, there is a range of mothers from different backgrounds and with different levels of experience with childrearing.

When there are mothers with different levels of experiences, there are cases in which there is doubt about the competence a first-time mother has due to their inexperience. One experienced mom comments on having learned from a first-time mom who made a recommendation dealing with cradle cap:

None of my kids had cradle cap, but my son, my newborn, he had cradle cap, so I didn't know, like, well how to -- about it, so I explained to the doctor and she brought it up in the group. And then another mother was, like, "Well, you could do this... you could Dove soap to help." She was, like, "Natural oils help get the cradle cap, so..." And the doctor was explaining, like, how to get rid of cradle cap and stuff, so I was, like, "All right." Cause I didn't know, like, none of my kids ever had it, so this would be my first child to ever have it, so... it actually felt good cause, like, even though they younger than me, like, some of the girls that's in the group is younger than me, but it's kind of cool to know, like, all right, she knows what she's talking about. And then when the doctor confirmed it, I'm like, "All right, well didn't know that, but I'm glad that you knew it... so now I know something new."

Expanding on this, the mother notes that in this process, the provider served to confirm the information given by the mother:

Mother: Like, she'll -- well the doctor -- when she was telling me about it, the doctor was, like, "I was just about to explain that to you to tell you how to get rid of it."

Interviewer: Hm-hmm.

Mother: But she took the words right out of my mouth so... she was like, "I really don't have to explain it cause she told you what you should do." So... I was like, "All right, well, now I know what to do to get rid of it."

Interviewer: Yeah, that's so neat. And that seems like that's different from a traditional... pediatric... visit cause usually it's the doctor who is giving you the advice.

Mother: Yeah, hm-hmm.

This mother shares her skepticism about the competence of the first-time mother giving her opinion due to being a younger, inexperienced mother. The provider affirms the advice that the first-time mother gave and this affirmation alters the perception the experienced mother has of the advice and expertise of first-time mothers. This demonstrates that in medical advice, trust in the competency of providers can serve to cross-validate information originating from other parents in the group in real time.

In contrast to these examples, there are also examples where there is doubt in the advice providers give. One mother describes that:

maybe the doctor will tell you to do something that you don't really want to do, but the moms would have, like, a different thing they would do that works out... or, if not, the doctor tells you, "Okay, you have to do this for your baby." And you're like, "What?" And the other moms have done it already, so they're like, "No, it works, trust me."

The mother voices the unease she feels with the advice given by the provider, and relies on her trust in the other mothers in the group. The parents in this case cross-validate the recommendation that the provider makes in real time. The reassurance from the other parents at that moment served to confirm the competency of the provider. As opposed to individual visits with a provider, the group structure promotes solidarity among mothers as back up. This same mother acknowledges that there is:

Mother: ...support and knowing there's another mom that's going to either back you up or have something to say to -- acknowledge what they're telling you... or what they have done and experienced.

Interviewer: Yeah. So, yeah, and how does that make you feel? Like, let's say you brought something up and then another mom re-acknowledges it or...

Mother: It makes me feel like I'm [not] the only one. Like, "Oh, my daughter is going through this," and they just sitting there and somebody brings it up, "Oh, yeah, my daughter went through that, too." It's like, "Oh, okay, so I'm not the only one." You know? Somebody else... has obviously been through it.

Interviewer: Yeah.

Mother: It's not just, like, a one-on-one, I'm talking to a doctor, "My daughter is going through this," and you're freaking out. You don't even know that other babies or other kids in general, are going through it.

As a part of the group, this parent feels that she is not alone in the experiences and problems she faces when taking care of her daughter, and can rely on the experience of other mothers to support her concerns. The community and shared experience with other mothers allows her to trust in the recommendations of the providers. Another mother comments on the importance of lived experience as she notes:

...some of the doctors, they even said they didn't have kids. Some of them did. That was like, if you don't have kids, how do you know everything about what they like? So it's nice to get the moms' input as well. It's like the best of both worlds. Like, the medical aspect, and then the actual parenting.

She views having the perspective from both sides as being important in helping her decision making.

The contrast of these examples reinforces the concept that trust is multidimensional. While providers are often credited with high competence based trust based upon their training and professional credentials, there are limitations. In this case,

the mother suggests limitations on believing the provider who does not have the same shared experience of parenthood. This likely falls under the values congruence dimension of trust. In the group setting, the parents are uniquely positioned to question and cross-validate information presented to them in real time. Having validation from other parents who have shared values and lived experience reassures the parent that the recommendation of the physician is valid. These examples of cross-validation occur in real-time, within the group setting. This is in contrast to traditional visits where doubts may not translate to evaluation of the claim.

Another source used for cross-validating information being used by parents is the internet. One mother describes that she learned about taking care of her baby by using the internet.

Independientemente de la intuición, uno necesita conocimiento, entonces uno tiene que buscar en Internet quiera o no quiera. Gracias Internet por existir. Gracias a YouTube, porque no sabía ni cómo bañar a mis hijas y ahí fue donde aprendí. Ahí fue donde aprendí las diferentes formas y de esas me quedé con la que me convenía, la que me gustó. Esa es la primera fuente de todo el mundo acá, yo creo. Hay otras madres que dicen, utilizan mucho YouTube.

Translation:

Independent from intuition, one needs knowledge, so one has to look on the internet, like it or not. Thanks internet for existing. Thanks to YouTube, because I did not even know how to bathe my daughters and that's where I learned. That's where I learned the different ways and from those I stuck with the one that was convenient for me, the one I liked. That [the internet] is the first source for everyone here, I think. There are other mothers that say, they use YouTube a lot.

Another mom notes that she fact-checks everything using the internet:

Mother: Like, me, I'm always like -- even though somebody give me information about something, I always Google it, so I'm, like, a Google freak.

Interviewer: Yeah.

Mother: So, I always go and Google it to make sure, but if the doctor tell me -- pretty much tell me, like, this is the best option, then I will run with that because I know that they went to school for it, they know what they...

Interviewer: Hm-hmm.

Mother: ...talking about. So I will take their opinion or their advice of what should I do as far as when it comes to my child.

The internet provides a wealth of information for parents, and is used to learn basic parenting skills such as bathing, and to confirm information received from other sources such as parents and friends. These tools appear to be used outside of the GWCC setting, and parents do not discuss the use of the internet in real time to confirm information in the same way that the interaction between maternal and provider information is discussed.

### **Theme 3: Structural competency and Trust**

Development of a strong clinician-patient relationship is important in pediatric well child care, with trust and family-centeredness as supporting attributes for a robust medical home.<sup>31</sup> The GWCC care model aims to serve as a medical home for the patients it serves, and uses a diverse set of providers to support this aim.<sup>71</sup> In our GWCC setting, the family population served is predominantly minority with 45% self-identifying as Black and 45% identifying as Latinx, with 97% having public insurance. As such, they often face a variety of structural vulnerabilities that impact their care. In this section, we will use empirically derived qualitative data from the interviews to describe how GWCC facilitates: (1) development of a trusting and open space focused on the care of the family that (2) allows providers to elicit and identify structural concerns families face,

and (3) creates opportunities for group support as well as resources, when possible, to reduce the burden of structural barriers faced by families.

### **1: Development of trusting and open space in GWCC**

The focus of group well child care (GWCC) goes beyond the medical health of the babies. With 1.5 to 2 hours allotted to the group visit, providers have the ability to explore more topics with the parents. In contrast to individual visits, one mother comments:

Si, es diferente porque la consulta individual es una cosa dedicada al desarrollo del niño, a la enfermedad del niño. Es algo individual y local. No ve la familia, el medio [ambiente?], la cultura. Hay doctores que te llevan al cielo, te traen y estás ahí nada más en la mesa. Pero hay doctores que son más fríos...Esto es una consulta más amplia con otro punto de vista que valora más, que ve la familia, que incluso nos reparten unos papelitos para llenar de los problemas que usted tiene. Es una buena iniciativa.

Translation:

Yes, it's different because the individual visit is dedicated to the development of the child, the illness of the child. It's individual and local. They do not see the family, the environment, the culture. There are doctors that will take you to the heavens, they take you and you are just there at the table. But there are doctors who are colder... This is a visit more open with another point of view that values more, that sees the family, that even distributes papers to fill out the problems that you have. It's a good initiative.

The family-centered GWCC visit creates a space where parents feel able to discuss problems that affect their lives.

[The providers] don't judge. They're willing to not only help the kids. They're willing to help the women also. So if we have a personal problem with ourself, with us just being women or relationship problems or whatever, they're willing to either talk to us one on one or have us talk to a social worker.

The non-judgmental and open space created in the group engenders trust, and parents are able to openly discuss concerns that families are facing. Despite the often sensitive and personal nature of the topics being discussed, the parents express the security they feel with these discussions in group. This mother describes feeling trust in her providers, and knows that the other mothers in the group value the confidentiality that allows them to discuss these sensitive topics openly. She notes:

Otra cosa que la doctora nos ha dado la confianza, y el doctor, de decir "todo lo que se diga aquí, aquí se queda". O sea, confidencial. Aunque es en grupo, es confidencial. Y por ejemplo, yo sé lo que le pasa a ella, yo sé lo que le pasa a la otra, pero no es algo de que yo voy a salir: "mira, a fulanito esto y aquello"...Entonces como que...este... desde el principio que la doctora dice eso, me dio esa confianza, me dio la confianza.

Translation:

Another thing is that the doctor has given us trust, and the [other] doctor [too], of saying "everything that is said here, stays here." In other words, confidential. Even though it is in a group, it is confidential. And for example, I know what is going on with her, I know what is happening to the other one, but it isn't something where I am going to go out: "look, so-and-so did this and that"... and so like... since the beginning when the doctor said that, it gave me that trust, it gave me trust.

While many parents feel comfortable speaking with the group, providers create opportunities to elicit individual and private concerns from the parents as well:

Mom: They would do kind of like this, "Mother, do you have any questions you need to ask us? Is there anything?" And then they would ask each of the mothers. "You know, we're here for that. Ask. Tell us if there's something going on. And if you don't want to do it as a group, we'll do it as a one on one. If you didn't want to talk as a group, you let us know off to the side, and we'll do a one on one with you." Which was really good... they told them if they don't want to do it in a group, they would do it one on one with them.

Interviewer: So you sort of had the best of both worlds in a way?

Mom: So it was good, because that way, if there was something there personal that they didn't want to talk about, they could do it out of the group and get answers for it, you know? And that was good.

**2 and 3: Providers elicit social barriers faced by families, and provide support and resources when able**

With trust in the group, parents describe social barriers that impact the well-being of the family. Social factors identified by those interviewed include: social isolation, housing insecurity, domestic violence, access to care, education/literacy, transportation, food security, immigration status/policy, and limited English-proficiency (**Table 1**). In addition to developing trust and eliciting structural vulnerabilities faced by families of the children in GWCC, the group offers an opportunity for dissemination of knowledge and resources as well as direct action by providers.

Respondent: They try to steer you in the right direction of, like, if someone is having insurance problems... or if someone needs WIC, like all the material is, like, right there for you, so it's great.

Interviewer: Yeah, yeah, okay. Does that seem -- well, that's sort of advice. Does that tend to come from the other moms, or the facilitators in the group...

Respondent: Other moms...

Interviewer: ...or maybe both?

Respondent: It's both.

Interviewer: Okay.

Respondent: I like it also because everything is, like, right in that building so WIC is right there if you need it, you know, to speak to WIC. They have social workers that they could set you up with. Like, I feel like they're very supportive and they'll do anything to help you... as opposed to other places I've been to, so...

Both the providers as well as the parents have knowledge about resources that they can share. Additionally, the resources to respond to the needs of parents and families may

be immediately available for parents to access, such as the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC). The environment of GWCC elicits concerns and provides resources beyond these social services. As one parent describes, fears about the political climate and immigration policy in the U.S are talked about in the group, and providers engage with these conversations to help families:

Estamos hablando [en el grupo] del Presidente [Trump], de las nuevas reglas de la inmigración y todo eso. Entonces, todos vivimos con un temor, de una otra manera. Yo no lo había notado, pero cuando llegas al grupo y una de ellas se siente como que "yo sí tengo miedo para salir a la tienda", es como que Wow! O sea, sí también le está afectando a todos lo que está pasando, ¿no? Y cuando llegas te dan toda la información, para donde puedes buscar ayuda, recursos y todo, pues te ayuda más. Como también nos dieron información sobre dónde...sobre los números de envenenamiento, por si acaso lo necesitamos, números de la psicóloga por si necesitamos otros, o así... También nos dieron números donde podemos ir a agarrar como ropa, Pampers, todo eso para los niños...O sea que, en muy pocos lugares te dan esa información.

Translation:

We are talking [in the group] about President [Trump], of the new rules of immigration and all that. So, we all live with a fear, in another way. I had not noticed it, but when you get to group and one of [the mothers] feels like "I am scared to go to the store", it's like Wow! In other words, it is also affecting everyone, what's going on, no? And when you arrive they give you all the information, for where you can find help, resources and everything, well it helps you more. They also gave us information on... on the numbers for poison control, just in case we need it, numbers to the psychologist if you need, others, like that... they also gave us numbers for where we can go to get clothes, Pampers, everything like that for the children... in other words, in very few places do they give you that information.

Parents in the group are similarly affected by the current political climate and immigration policy. This concern shows how an upstream problem (socio-political climate and policy on immigration) has the potential for downstream effects on a

family's well-being. These families are scared to go to the store, putting them at risk for food insecurity and increased social isolation. The structural factors of political climate and immigration policy pave the way for downstream social determinants of health such as food insecurity and social isolation. Just as the providers give resources and phone numbers for poison control and mental health care, they also provide support and resources to assist families with immigration concerns.

Interviewee 1: Es así como ahorita que está eso de inmigración que están deportando... Nos ofrece ayuda la trabajadora social... Y ella dice que por cualquier cosa que la llamemos.

Interviewer: Qué bueno, okay. Okay.

Interviewee 2: Es como una protección.

Interviewer: Yeah, okay. Y, ¿hablan de eso en el grupo entero o solo con -- en llamadas con la trabajadora social?

Interviewee 1: Sí. No, ahí se habla en el grupo.

Interviewer: Ah, okay. Entonces otras en el grupo tienen esa preocupación también.

Interviewee 1: Sí.

Interviewer: ¿Cómo se siente al hablar de eso en el grupo en sí?

Interviewee 1: Bien porque si ellas dicen que nos apoyan...que por cualquier cosa nos sentimos bien.

Interviewer: Yeah.

Interviewee 2: Como con un amparo, ¿verdad? Porque uno dice que quiere alguna cosa, vamos a llamar.

Interviewer: Sí.

Interviewee 2: Y hasta le pueden ayudar a uno con la palabra que ponga, ¿verdad? Le ayudan a uno... Uno se siente como fortalecido...

Interviewer: ¿Fortalecido en qué manera?

Interviewee 2: En que le den una esperanza a uno de una ayuda, así. ¿Verdad?

Interviewer: Okay. Okay.

Interviewee 2: Porque ellos le dicen a ella que en una cosa haya que le llame.

Interviewer: Ah, okay. Y, ¿eso es la trabajadora social?

Interviewee 1: Sí... y la doctora también... Se lo dieron un papel donde está cómo se puede cuidar uno de inmigración.

Translation:

Interviewee 1: It's like this now that there is all that about immigration, that they are deporting... the Social Worker offers us help... and she says that we should call for whatever reason.

Interviewer: That's good, okay. Okay.

Interviewee 2: It's like a protection.

Interviewer: Yeah, okay. And, do you talk about that in the whole group or alone—in calls with the social worker?

Interviewee 1: Yes. No, we talk about it in the group.

Interviewer: Ah, ok. So others in the group have that worry too.

Interviewee 1: yes.

Interviewer: How does it feel to talk about that in the group?

Interviewee 1: Good because if they say that they support you... for whatever thing, we feel good.

Interviewer: yeah.

Interviewee 2: It's like a protection, right? Because you say you want something, let's call.

Interviewer: Yes.

Interviewee 2: And they can even help you with their word, right? It helps you... you feel strengthened...

Interviewer: Strengthened in what way?

Interviewee 2: In that they give you the hope of some help, like that. Right?

Interviewer: Okay. Okay.

Interviewee 2: Because they tell [the mother] that if anything happens to call.

Interviewer: Ah, okay. And, is that the social worker?

Interviewee 1: Yes... and the doctor too... they gave a paper that says how to protect oneself from [Immigrations Customs Enforcement].

Providers in the group are aware of the immigration concerns of the group and demonstrate agency beyond the typical provider-patient relationship. They not only give their verbal support, but provide their phone numbers to the families as well as resources to protect yourself from immigration customs enforcement agents.

## **DISCUSSION**

### **Theme 1: Group dynamic flattens traditional hierarchies in care**

The GWCC setting cares for a predominantly low income and minority subset of parents and children. While sociodemographic characteristics of the providers participating in the group were not recorded, physicians in the workforce have higher educational attainment, incomes, tend to come from middle-upper income families, and are less racially diverse than the patients they serve.<sup>72,73</sup> The combination and sum of these socio-demographic differences and subsequent gap in group inter-relatability has been described in social theory as the “social distance” between groups. Social distance has been shown to have a number of implications within healthcare specifically, affecting patient perception of respect and time spent with a provider.<sup>74</sup> In evaluation of adults, lower perceived social status has been associated with worse interpersonal patient-provider communication, increased perception of treatment difference, and has been associated with worse health outcomes.<sup>75,76</sup>

From the interviews, caregivers described that the group setting creates a sense of familiarity as providers integrate themselves into discussion. The familiarity and perception that providers are on the same level as the parents may decrease social distance and increase trust related to values congruence. As one study noted, the perception of similarity with a provider was associated with increased belief in personal values, better satisfaction with care, stronger intention to adhere to recommendations and more trust in the provider.<sup>77</sup> Given the existing social distance present between providers and patients in the United States, communication strategies that integrate providers into the group as in GWCC may enhance trust in providers and lessen the effect of social distance on care.

While the majority of parents describe the familiarity developed in the group positively, the caregivers who felt that the group lacked enough direct information on how to care for their infants may have benefitted from a different setting or relationship style with their providers. This serves as a caution against overgeneralizing the benefits of the communication style of GWCC, and to instead understand the heterogeneity of parent needs in well-child care. The opportunity to discover if a trusting relationship based on mutual philosophies can be established is a key reason cited by advocates for prenatal visits.<sup>78</sup> Efforts to understand the individual needs of parents in well-child care may allow for optimal provider-patient relationships. GWCC provides one opportunity to develop these relationships within a framework that promotes the flattening of traditional provider-patient relationships.

**Theme 2: “The best of both worlds” Cross-validation and triangulation of information**

Providers in GWCC take a Socratic approach to facilitating sharing of knowledge within the group by asking mothers their thoughts on how to approach a clinical question. In the interviews, this was exemplified by the topic of dealing with newborn rashes. Providers asking the caregivers’ opinions has previously been shown to be associated with increased maternal trust.<sup>43</sup> In the interviews, caregivers describe being asked and learning from the experiences of other caregivers, demonstrating trust in the competence of mothers due to experience as well as the shared values associated with motherhood. Mothers feel valued by providers for their knowledge, which may mediate increased trust between those parents and the providers. Unlike informal settings where mothers share this information with one another, in the group providers are able to validate information from other mothers. This draws on trust in their educational and professional qualifications to reinforce knowledge. These findings parallel previous studies, that show mothers use various sources to confirm information, including internet, family, and friends. In using diverse resource types, pediatricians serve to give clarifying guidance, which is also supported by the interactions described in GWCC.<sup>79</sup> Unlike previous studies, our study shows how this works in real-time during the group visits.

While providers are often trusted to arbitrate knowledge in the group, parents also express doubt about provider recommendations. In traditional well-child care, these doubts may not be expressed, or there may not be an additional source available to

provide input on the recommendation. In these circumstances, traditional avenues such as family, friends or the internet may be used to investigate the recommendation. In GWCC, mothers in the group serve to give real-time cross-validation of the provider's recommendations. Reasonable doubt about the recommendation from the provider is less an indication that there is a lack of trust in the relationship, but rather supports the notion that different dimensions of trust matter in different circumstances.<sup>4</sup> In the group, social trust among the mothers develops with shared values, agency, and lived experience (a form of competence). These dimensions of trust cumulatively reassure a skeptical mother to trust the advice of the provider. Importantly, this cross-validation occurs in the moment, something that we were not able to find described in the literature.

Outside of the group, mothers describe readily using the internet as a primary source and to fact-check. This is consistent with studies that show that a majority of mothers use the internet for medical information.<sup>80</sup> Reasons for accessing the internet include convenience, as well as dissatisfaction with the information given by health professionals and not having enough time to ask health professionals.<sup>81</sup> Additionally, mothers believe that information from the internet is generally trustworthy when using reliable websites, however reliability of websites is not well defined.<sup>82</sup> As Drentea and Moren-Cross have shown, the internet serves as a platform for mothers to find social and practical information/support that strengthens the social movement of self-help in medicine.<sup>83</sup> However, while online communities may provide informal opportunities for

community building and exchange of information, there is concern about identifying reliable internet sources. With the breadth of freedom on the internet, there is also concern about the development of communities that may propagate ideas that have not been vetted.<sup>84</sup> For example, in recent years the internet has been a space for a growing anti-vaccine community in the United States and internationally. In particular, the online spread of misinformation across a variety of platforms and the insular nature of developing online communities that perpetuates this misinformation.<sup>85</sup> The presence of providers in the group may serve to address and prevent misinformation when information is elicited from group members.

GWCC provides a platform for different providers as well as parents to share information. With diverse backgrounds and experiences contributing to the knowledge in the group, there is a unique opportunity for discussion and cross-validation of the information being shared in real-time. When information is affirmed by various, diverse members of the group parents are able to assess the trustworthiness of the information being provided. Similar to their use of the internet to confirm health information, the live exchange of information in the group generates information repetition and convergence. Information repetition and convergence is the concept that suggests that information is considered more trustworthy when it comes from several different sources, and considered more trustworthy than information that is not repeated. When information from the internet, providers, or other parents is consistent, parents are more likely to believe that health information.<sup>84</sup> The presence of the different providers

and mothers in the group diversifies the sources of information in the group which allows for the repetition and convergence that enhances the overall trustworthiness of information discussed within the group.

### **Theme 3: Structural competency and Trust**

Trust has long been considered foundational in the provider-patient relationship, and the need for trust may be necessitated by the vulnerability of the patient.<sup>6</sup> As characterized here, vulnerability in the context of the provider-patient relationship should not only take into consideration vulnerability from illness, but be broadened to include the structural vulnerabilities that families face.<sup>14</sup> In serving as a medical home, GWCC promotes (1) a trusting environment that supports a family-centered approach to care.<sup>31</sup> This then (2) allows providers to contextualize structural vulnerabilities that affect the health of families. Through discussion with parents in GWCC, a broad range of social and structural barriers that they faced were elicited, and are summarized in **Table 1**. Beyond eliciting concerns, (3) providers are able to refer to social work (sometimes present in the group), immediately direct to social services such as WIC, or provide extra-institutional support through informational flyers and phone numbers for other resources. Additionally, the group itself can serve as a source of support through the shared experiences and concerns that parents face. The dimensions of trust drawn upon under the framework for structural competency include: competence, agency, and confidentiality.

Focusing on the experience of families who face concerns about immigration policy and the political climate highlights the importance of trust developed in the GWCC setting. Importantly, it shows how immigration status acts as a structural vulnerability families face, and may apply to other stigmatized immigrant families with children generally. Immigration policy focused on detention, deportation, and limiting access to resources has generated fear and toxic stress among both documented and undocumented immigrant communities of color that mirrors the effects that discrimination has on decreased healthcare utilization and worse health outcomes.<sup>86,87,88,89</sup> Establishment of a trusting relationship in GWCC, provides an opportunity for families facing stress related to immigration policy to voice their concerns and seek help. In the case of the Spanish language group, parents felt trust in the providers and the other parents which allowed them to openly discuss the fears they faced on a daily basis, due to their status as immigrants.

Fear about immigration policy and possible repercussions is an upstream, structural issue that can have concrete downstream repercussions, including social isolation, food insecurity, and increased low birth weight. As one parent in GWCC notes, they were afraid to go the store because of the political climate. The implications of this fear can lead to social isolation as well as food insecurity, which have both independently been recognized as social determinants of health and are linked to a variety of chronic diseases and worse health outcomes.<sup>90,91</sup> Empirically this has been demonstrated through research performed before and after an immigration raid in the

Midwest. That study found that after an immigration raid on a factory, Latinx families with children in that community were less able to interact with social networks, access government resources and had lower self-reported health than in the period before the study; another similar study following a separate immigration raid demonstrated a significant increase in food insecurity among Mexican non-citizen households with children.<sup>92,93</sup> Further, anthropometric effects including increased low birth weight have been documented in the period following immigration detention operations.<sup>94</sup>

Interactions between the individual and the social structures that affect the individual, as in the case of immigration and potential effect on health outcomes can be framed using Bronfenbrenner's theory on ecology of human development.<sup>95</sup> This theory describes development through three attributes, (1) the individual's perspective of the environment, (2) the environment surrounding the individual, and (3) the dynamic interaction between the individual and the environment. This framework illustrates the nested structures that affect individuals as a series of concentric circles, beginning at the macrosystem then moving inwards to the microsystem, and has been previously used in research on health disparities.<sup>96</sup> The example of parents' experience in the group exemplifies how structural layers lead to deleterious impacts on health. By applying the framework of Bronfenbrenner's ecological theory with the concept of structural vulnerability, we can visualize how the interactions of concentric structures can affect the family (**Figure 1**).

In addition to illustrating the layered structures that affect the family, this framework includes health care providers at the level of the group setting, and proposes how providers themselves are active in these structures. For example, throughout the interviews caregivers described that the providers in GWCC supply direct resources such as WIC referrals aimed at addressing food insecurity. They also discussed feeling trust when providers shared their phone numbers and when they received information on protecting oneself from immigration enforcement agents.

On the other hand, providers may feel that their ability to offer direct help may be limited. In a parallel study that examined the experience of pediatric residents participating in GWCC at our same institution, residents expressed feeling unprepared to deal with psychosocial matters such as a family's experiences with incarceration or substance use treatment.<sup>97</sup> Providers in GWCC may similarly feel unprepared, or under-resourced to fully support the needs of immigrant families, and feel disempowered to address the societal barriers their patients face. Provider's feeling of futility in addressing their patient's societal barriers was the original context that lead to coining of the term 'physician burnout'.<sup>98</sup>

However, as part of our proposed structural model (**Figure 1**), the provider equipped with core tools of structural competency can realize their position as healthcare providers to have an impact beyond the GWCC level.<sup>12</sup> In addition to building trust within the group, eliciting concerns of families, and providing direct resources as able, providers can operationalize their observations through organizing, activism, and

advocacy with and for their patients. As illustrated, providers can participate in structural intervention at different levels and in different ways through their own healthcare institutions, professional societies and academies, and at the level of local and national policy.

Among the first tasks for providers is to educate themselves on the facts; recognizing a need to prepare providers, organizations such as the American Academy of Pediatrics have developed and Immigrant Child Health Toolkit that provides background reading, policy facts, and legal resources for families and children, to assist providers in practice.<sup>99</sup> In addition, real world examples of individual and institutional efforts to broach the topic of immigration are occurring throughout the country. At the Boston Medical Center, employees and providers protested to promote policies that support immigrant patients.<sup>100</sup> Similarly, health professions students and providers at The Johns Hopkins University took part in sit-ins and walk outs that successfully pressured the institution to end contracts with Immigrations and Customs Enforcement (ICE) that had earned the university over \$7 million since 2008.<sup>101</sup> At Yale, Dr. Marietta Vasquez has been vocal locally in advocating for detained migrant children, in light of recent punitive policies that increased child detention as a deterrent for migrant families coming from Central America.<sup>102</sup>

Vocal and public efforts by individuals alone and through collective action leads to institutional intervention. The American Academy of Family Physicians, American Academy of Pediatrics, American College of Obstetricians and Gynecologists, American

College of Physicians, and the American Psychiatric Association were among several national professional organizations that co-signed a statement strongly objecting to new detention policy.<sup>103</sup> In response to the Trump Administration immigration policy, New York City Health and Hospitals, the largest public health care system in the United States, has promoted a campaign called “Seek care without fear” that reassures immigrants that they can get medical care within their public health institutions without fear.<sup>104</sup> In these examples, the efforts of structurally aware providers and healthcare systems can use their positionality within their own and greater structures to identify the problems patients face, such as concerns about immigration, and imagine and promote institutional intervention for structural change.

The structural framework proposed above illustrates the effect that upstream decisions in immigration policy can have downstream implications for food security and social isolation that in turn have their own downstream effects on an individual’s health. Though not discussed in detail here, this same framework can be applied to other structural vulnerabilities that were described by parents in GWCC (**Table 1**). While we argue that the GWCC created an open and trusting space that allows for discussion of structural vulnerabilities that participating families faced, competence on behalf of the providers in recognition and action to address these issues may also mediate parents’ trust in providers. Further research should attempt to quantify how structural competency acts as a dimension of trust, and should examine the effect of provider’s

collective activism on increasing the institutional trust of marginalized patient populations.

**Table 1. Social vulnerabilities identified in the group**

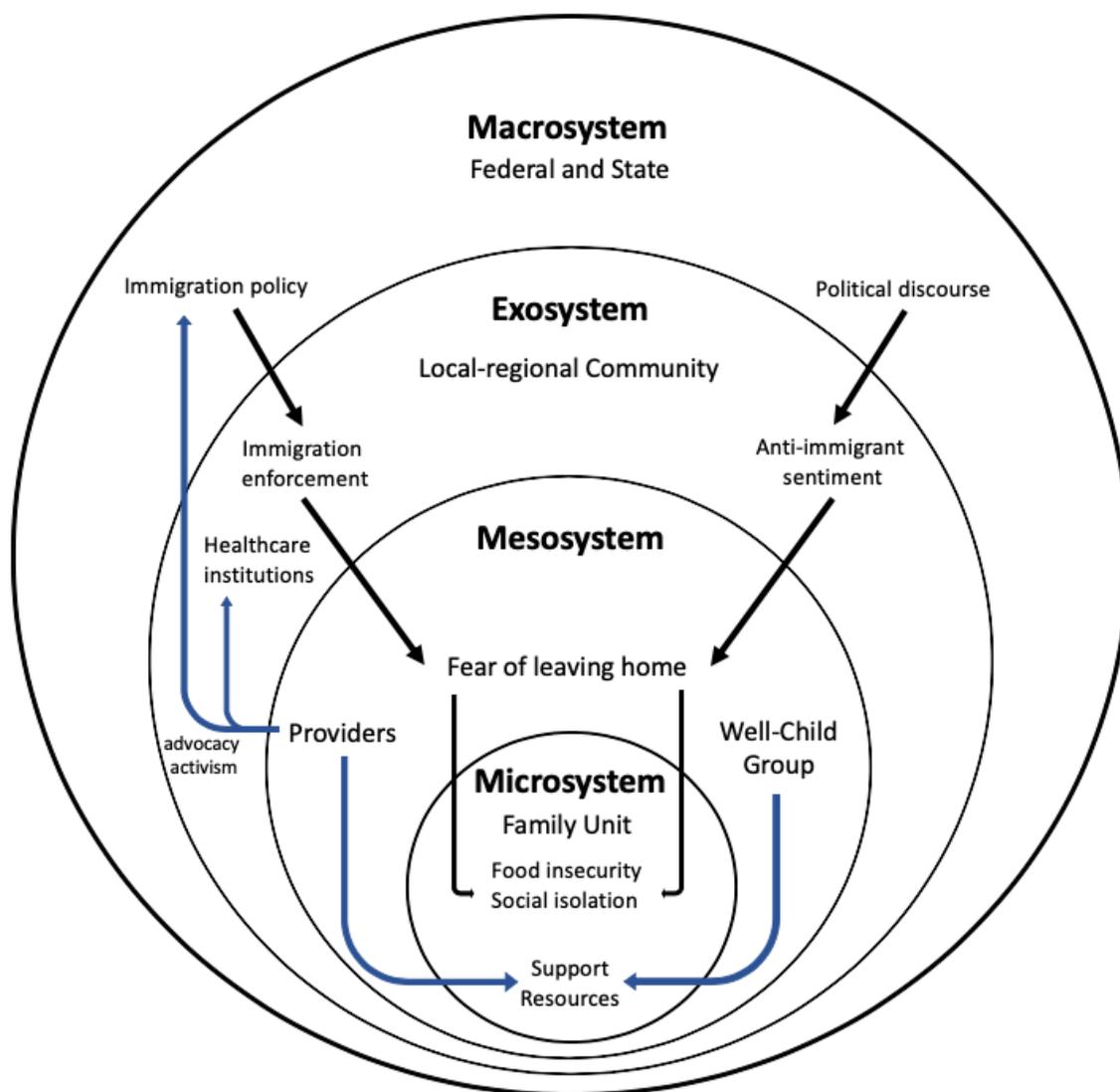
Identified Vulnerability	Quote	Description
Social isolation	<p>Interviewer: ...it does seem like it can be isolating, you know, if you're...</p> <p>Respondent: And it is at first, especially, like, you know, my mom lives, like, right down the street, and my sister, you know, they're an-hour-and-a-half away, so for them to not be here, you know, my boyfriend works and goes to school, so he was gone...fourteen hours a day and I was, like, here alone. I looked forward to going to that group a lot because it's, like, okay, now, you know, I can sit with other moms and be, like, all right... I don't know what to do, and they, like, kind of like, talk you down... To where, you know, you don't feel like you're alone in this situation and you don't feel isolated, which is nice.</p>	<p>Several mothers describe how isolating it can be to have a newborn. Whether they are isolated because other family members are at work, live in other areas, or whether they are isolated within the community and only have their partner with them. Social isolation can be viewed as a risk factor for health related issues including mental health problems.</p>
Housing insecurity	<p>Mother: Well, I stay with my aunt. Because I used to stay in a shelter before. So I ended up getting kicked out of the shelter because I had a confrontation with one of the staff workers. So my aunt ended up letting me stay here. She said I could stay here until I get my housing. So I have a [DCF] worker who's trying to help me get some type of housing. She said in order for me to get that, I have to go to therapy, because I had a DCF case with my son that was four years ago, about to be five years ago. She said I needed a little mental therapy for not just my mental health, but my substance abuse, because when I was pregnant with my daughter, I haven't really been going to most of my doctors' appointments.</p>	<p>Housing is a social determinant of health that has been linked to numerous poor health outcomes. Specifically regarding mothers and the pre- and perinatal period, housing instability has been associated with lower birth weights compared to infants of mothers with stable housing.<sup>105</sup> Low birthweight has been repeatedly linked worse health outcomes with lower birthweight.</p>

Intimate Partner Violence	<p>Mother: When I was little, my mom never been around. My grandmother was the one who raised me. My mom is in and out. And then when my grandmother passed, that made things even worse. So I really wasn't getting the help that I felt like I was getting when I met with her, when I met her father. He was there, but with him, me and him, I was in an abusive relationship with him.</p>	<p>Besides physical safety, intimate partner violence has been associated with a range of worse mental, sexual, and physical health for women as well as their children.<sup>106</sup></p>
Access to care	<p>Mother: Through [here] everything has been an amazing experience. But outside of [here], no, it hasn't.  Interviewer: Hmm.  Mother: Especially cause we have Medicaid for insurance...  Interviewer: Hm-hmm.  ...so certain places, it's like you're a number, you're not a patient, you know? It's like they want to get you in and out, it's very rushed, they don't really – not that they don't care, but I just feel like they're so overwhelmed that it's like they don't have time to, like, really care about a patient. It's just get them in, get them out, and get their insurance billed.</p>	<p>This mother describes being treated differently or having different access to care due to her health insurance status. She views having Medicaid as limiting in her healthcare interactions.</p>
Transportation	<p>Mother: And then, like, some moms don't have transportation. Maybe [the group can] provide – help with transportation... to get back and forth to the groups with the child.</p>	<p>Inadequate access to transportation is considered a determinant of health that has been called upon to be a factor taken into consideration for structural interventions aimed at improving health for minority, and poor populations.<sup>107</sup></p>
Education/literacy	<p>Interviewee: ...mi mamá, mi papá son pobres, no saben ni leer, nosotros no nos dieron estudio, a mí no me dieron estudio. A mi hijo le di pero no me alcanzó dinero también para darle más estudio... y yo no sé escribir ni leer.</p>	<p>This parent must navigate a health care system while being both less proficient in English, and being</p>

	<p>Translation</p> <p>Interviewee: ...my mom and my dad are poor, they don't know how to read even, they didn't give us schooling, they didn't give me schooling. I gave my son schooling but I didn't have to money to give him more education... and I don't know how to write or read.</p>	<p>illiterate. This dramatically affects the families ability to navigate society and this parent mentions reliance on her child to help with documents.</p>
<p>Limited-English proficiency</p>	<p>Responding about what the difference is between the group visit and individual care:</p> <p>Mother: De eso de que para la cita de ella... yo sé que voy a llegar y hablan español... Y con él [el mayor], no. Porque lo traía aquí y...</p> <p>Interviewer: Pero, tal vez no había ninguna persona que hablaba español.</p> <p>Mother: Uh-huh.</p> <p>Interviewer: ¿Es difícil?</p> <p>Mother: Sí.</p> <p style="text-align: center;">Translated:</p> <p>Mother: In that for her visits I know that I'm going to arrive and they speak Spanish...and with him [the older child], no. Because I'd bring him here and...</p> <p>Interviewer: But, maybe there was not anyone who could speak Spanish.</p> <p>Mother: Uh-huh.</p> <p>Interviewer: Is that hard?</p> <p>Mother: Yes.</p>	<p>Limited English-proficiency is a determinant of health as it affects ability to access and use care along the continuum of healthcare.<sup>108</sup> While patients are entitled to have adequate language translation by law, appropriate language services are not used or insufficient and lead to medical errors and worse care.<sup>109,110</sup> Efforts in language concordant care have shown promising results in improving care.<sup>111,112</sup></p>

### Figure 1. Bronfenbrenner's ecological model adapted for structures of Immigration and health

In the model below, we see the various levels of structures organized in concentric circles. Black arrows represent the negative, downstream effects from social structures that cross the levels of systems. Starting at the macrosystem, Federal and state powers determine immigration policy, fueled and fueling a political discourse at a national level. The exosystem is the more proximal external system to the microsystem of the family unit. At this level, families may feel the effects of immigration policy and enforcement, as well as the national political discourse and anti-immigrant sentiments in their local community. At the level of the mesosystem, we see the interaction of various microsystems, in this framework the family unit is at the center, interacting with the providers, and the well-child group. The blue arrows represent positive effects from these interactions (1) on the family unit, and (2) as it relates to providers and their ability to affect structures at higher levels through advocacy and activism.



## CONCLUSION

The existing work on trust in healthcare has emphasized the close relation between vulnerability and trust, and explored the importance of trust in health care systems. Trust has been described using a framework that highlights dimensions of trust that have been used to characterize and quantify trust in the sphere of healthcare. This allowed exploration of trust in providers and healthcare systems, and has revealed disparity in level of trust by minority patients such as Black and Latinx patients. Understanding this disparity in trust requires understanding historical and socio-political reasons that may contribute to lower trust in healthcare, and is of importance and relevance in approaching healthcare improvement for vulnerable populations in line with the triple-aim of less per capita cost, greater population health and better patient experience.<sup>5,45</sup>

Using validated qualitative methods this study explored concepts of trust in healthcare from participants in Spanish and English language pediatric group well-child visits, who are predominantly Latinx, Black, and have Medicaid insurance. Several key themes relating to trust emerged throughout the interviews. In theme one, the structure of GWCC allows providers to immerse themselves into the group and flatten traditional hierarchies in care, creating a familial environment where caregivers could openly discuss not only direct medical concerns, but concerns relating to the overall wellbeing of the family. This structure may reduce perceived social distance between

providers and caregivers, enhance trust with increased provider contact, and promote family centered care.<sup>77</sup>

In theme two, GWCC facilitated real-time cross-validation of information for caregivers in the group. Providers benefit from competence trust related to their training, however fellow caregivers had trust based on shared experience and values. This facilitated group trust where providers validate information from caregivers, and caregivers can validate the recommendations of providers.

Lastly, theme three demonstrates how GWCC can function to deliver structurally competent care. A wide range of social vulnerabilities was present in the group (**table 1**). Applying the concept of structural vulnerability and Bronnfenbrenner's Ecological model we created a model that demonstrates the impact of structural context on immigrant families (**figure 1**).<sup>12,14,95</sup> Using this conceptual framework to train providers to identify, mobilize immediate resources, and advocate for structural change may have a positive effect on trust of individual providers, as well as healthcare systems as a whole. Further studies should seek to quantify structural competence as a dimension of trust.

### **Strengths and Limitations**

While there are some robust findings from the deductive approach used to explore participant trust in healthcare, there are several notable strengths and limitations to this study, that present opportunities for future investigation. As a qualitative study with the

open-ended interviews aimed at elucidating participant experiences in GWCC, it is likely that caregivers discussed topics that they found important. However, the original interviews were aimed at overall experience, and did not focus a line of inquiry related to trust itself, and so there may be more depth to discussion of themes related to trust that may not have been reached. Despite this, the current study's focus on trust came from the initial reading of these interviews, and informed pursuing a review of literature on trust in healthcare and exploration of the theoretical framework of trust. As the results and conclusions show, using a deductive coding approach to the interviews led to identification of several themes of trust that arose when applying theoretical frameworks of trust.

Another important consideration with regards to the interviews themselves and the subsequent findings is the interviewer. Namely, the interviews were carried out by a white, male, physician on the team who speaks fluent Spanish and English. Additionally, interviewees were given information about how the interview data would be used, about deidentification processes, and were allowed to withdraw from the study at any time. While interviews were carried out in the setting of the participants choice, in the language of their preference, and in an as informal, and open environment as possible, there may be inherent limitation in the depth of conversation reached by this interaction. These may be related to race, social distance and hierarchy, or hesitancy in openness of conversation related to trust in researchers from an institution such as Yale. Lastly, while the team of researchers that read and coded the interviews was diverse in

race, gender, and professional training, the research team did not include participants from the GWCC care. Inclusion of participants in GWCC may have brought different angle to discussion of the transcripts.

### **Future work**

This work has begun to characterize the interaction of GWCC and trust for participants in English and Spanish language groups. Each of these themes was developed with a multi-dimensional framework for trust in healthcare, and comes at a time when there is renewed interest in healthcare trust, and understanding how providers and health systems can promote and improve trust.<sup>61</sup> Through this thesis work, characterizing interactions in the group with the framework of trust has given perspective on how GWCC flattens traditional hierarchies in care and reduces perceived social distance between providers and participant, and allows for cross-validation of information from various trusted sources in real-time that draws on varied dimensions of trust. Further, it has emphasized how vulnerability, and more specifically structural vulnerabilities are important factors that affect the trust and care for certain patient populations. Using the framework to advance health disparities research, this study has started to identify how trust works in a GWCC redesign model that serves lower socioeconomic and Black and Latinx families. Future study should use directed qualitative as well as quantitative trust tools to measure trust more specifically. In order to do this, we propose inclusion of structural vulnerability in the concept of the

individual's vulnerability when engaging in healthcare. This may involve inclusion of structural competency as a dimension of trust in updated trust tools.

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