

Beliefs Regarding Development and Early Intervention Among Low-Income African American and Hispanic Mothers

Dawn M. Magnusson, PT, PhD,^{a,b,c} Cynthia S. Minkovitz, MD, MPP,^{c,d} Karen A. Kuhlthau, PhD,^{e,f} Tania M. Caballero, MD, MHS,^c Kamila B. Mistry, PhD, MPH^{c,g}

abstract

OBJECTIVES: Understand the role of health beliefs in shaping maternal decisions regarding help-seeking for children with developmental delay (DD) and explore differences between African American and Hispanic mothers.

METHODS: Open-ended, semistructured interviews were conducted with African American and Hispanic mothers of children aged 0 to 36 months with DD. Interviews were recorded, transcribed, and analyzed by using inductive content analysis.

RESULTS: Mothers ($n = 22$) were African American (36%) or Hispanic (64%), 25 to 34 years old (64%), had less than a high school education (59%), and had children receiving public insurance (95%). Five major themes emerged describing the role of maternal health beliefs in shaping key stages of the help-seeking pathway for children with DD: (1) “I can see” (observing other children and making comparisons); (2) “Children are different and develop in their own time” (perceiving that their child might be different, but not necessarily delayed); (3) “It’s not that I don’t trust the doctor” (relying on social networks rather than pediatricians to inform the help-seeking pathway); (4) “I got so much going on” (difficulty prioritizing early intervention [EI] because of competing stressors); and (5) limited and conflicting information (delaying or forgoing EI because of limited or conflicting information). Differences between African American and Hispanic mothers are also described.

CONCLUSIONS: Understanding maternal health beliefs and expectations regarding DD and EI, acknowledging the influence of social networks on help-seeking, and addressing social and financial stressors are critical to ensuring that children with DD are identified and supported at an early age.

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Departments of ^aPediatrics and ^bPhysical Medicine and Rehabilitation, University of Colorado Anschutz Medical Campus, Aurora, Colorado; ^cDepartment of Pediatrics, Johns Hopkins School of Medicine, Baltimore, Maryland; ^dDepartment of Population, Family, and Reproductive Health, Bloomberg School of Public Health, Johns Hopkins University, Baltimore, Maryland; ^eDepartment of Pediatrics, Harvard Medical School, Harvard University, Boston, Massachusetts; ^fDivision of General Academic Pediatrics, Massachusetts General Hospital, Boston, Massachusetts; and ^gOffice of Extramural Research, Education, and Priority Populations, Agency for Healthcare Research and Quality, Rockville, Maryland

Dr Magnusson conceptualized and designed the study, conducted semistructured interviews, conducted the analyses, drafted the initial manuscript, and reviewed and revised the manuscript; Drs Minkovitz and Kuhlthau helped to conceptualize and design the study, interpreted results, and critically reviewed and revised the manuscript; Dr Caballero conducted the analyses, interpreted

WHAT’S KNOWN ON THIS SUBJECT: Fewer than 25% of children eligible for early intervention (EI) services use them. African American and Hispanic children are less likely than white children to use EI. Pediatricians play an important role in linking children to EI services.

WHAT THIS STUDY ADDS: This study explores the role of health beliefs in shaping the identification of children with developmental delay, appraisals of EI, and use of EI. Understanding these beliefs is critical for ensuring early identification and intervention for children with developmental delay.

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In the United States, 1 in 4 children under the age of 5 years is at moderate to high risk of developmental delay (DD),¹ a condition in which children do not achieve timely motor, language, cognitive, social, behavioral, or adaptive skills. Early identification of DD during well-child visits and use of early intervention (EI) services are essential for optimizing the health and well-being of children and are a priority of US federal programs and professional organizations.²⁻⁴ However, only 30% of caregivers recall their child being screened for DD by using a standardized tool,⁵ and fewer than 25% of children eligible for EI services use them.⁶ Possible reasons for low use include unrecognized service need⁷ and receipt of services outside of the EI system.⁶ Evidence further suggests that the odds of having delays identified⁷ and using EI services⁸ are 44% and 78% lower for African American and Hispanic children with DD, respectively, than for white children with DD.

Efforts to improve early identification and intervention for children with DD have largely been focused on enhancing communication among clinicians and increasing provider training regarding the importance of routinely screening for DD and referring children with concerns to EI. Less attention has been focused on understanding parent perspectives, from first learning that a child's development is delayed to understanding what services are available and how to access them. Despite growing recognition that developmentally-focused anticipatory guidance should be centered around family beliefs and expectations,⁴ most pediatric residents report being unprepared to care for families with health beliefs that differ from their own,⁹ and nearly 50% of pediatricians view cultural differences between themselves and parents as a barrier

to providing care.¹⁰ Moreover, we know little about how parental health beliefs (knowledge, attitudes, and values)¹¹ shape patterns of health care use for children with DD.

It is important that pediatricians understand the complex relationships between parental health beliefs and subsequent EI use. Several conceptual models have been developed to explain patterns of health care use and help-seeking behaviors among adults and adolescents.¹²⁻¹⁴ A common pathway underlying many of these models is: (1) recognizing that problems exist (problem identification); (2) determining whether and how to address problems (service appraisal); and (3) using available services (service use). We therefore sought to (1) understand the role of health beliefs in shaping maternal decisions regarding help-seeking for children with DD among low-income African American and Hispanic mothers and (2) explore differences between African American and Hispanic mothers.

METHODS

Setting

This study was conducted at Johns Hopkins Medicine in Baltimore, Maryland. Study sites included 2 urban pediatric primary care clinics serving predominantly low-income African American and Hispanic families. EI referrals are generated by clinic staff at both sites. In 2015, these clinics provided pediatric primary care to more than 10 000 children 0 to 21 years old. Ninety-four percent of children served by the clinic live at or below 200% of the federal poverty level.

Study Design

Given limited available evidence and the complex nature of the relationship between maternal health beliefs and help-seeking behaviors, qualitative methods were employed.

In-depth interviews were conducted to allow exploration of maternal health beliefs. Purposive sampling was used to recruit African American and Hispanic mothers who were at least 18 years old, spoke English or Spanish, and were the legal guardian of a child aged 0 to 36 months with clinician-documented DD diagnosed by administering a standardized developmental screening tool. We recruited mothers with a range of experiences with using EI services: those with no experience and those with previous or current experience. Mothers of children with significant medical complications, diagnosed congenital anomalies, or diagnosed genetic disorders were excluded. The institutional review board at the Johns Hopkins School of Medicine and the research review teams at participating clinics approved the study. Informed consent was obtained for all study participants.

Data Collection

Eligible children scheduled for well-child visits during the study period were identified through their electronic health record. Mothers attending the well-child visit were informed about the study by their child's pediatrician and were subsequently recruited by a member of the study team. For those choosing to participate, in-depth interviews took place either immediately after the well-child visit at the clinic or were scheduled for a later time in person or by phone. All recruitment and data collection took place during the summer and fall of 2015.

An open-ended, semistructured interview guide was created by using input from a multidisciplinary study team consisting of an EI provider, pediatricians, health services researchers, and the mother of a child with DD. Questions were focused on understanding maternal beliefs in shaping key stages of the help-seeking pathway: (1) identification of children with DD; (2) EI service

appraisal; and (3) EI service use. Interviews were conducted by an experienced qualitative interviewer (D.M.M.) or trained bilingual research assistant, and they lasted ~30 minutes. Each interview was audiotaped, translated into English (if needed), transcribed, and entered into ATLAS.ti (Scientific Software, Berlin, Germany). Members of the study team met weekly during data collection to ensure interview consistency and data quality and to incorporate new concepts into the interview guide as needed. Demographic data, including maternal age, education, country of origin, and length of time in the United States, were also collected during the interview. Data collection continued until thematic saturation was achieved and no new themes were identified.

Data Analysis

Inductive content analysis¹⁵ was used, whereby the primary author reviewed transcripts to identify and define an initial set of codes that were entered into a preliminary codebook. Two members of the study team, with qualitative methods training, then read and independently coded each transcript and met regularly to modify the codebook as necessary. Discrepancies were resolved through consensus. This iterative process continued until no new codes or themes emerged from the data. An audit trail documented key decisions made during data collection and analysis. Members of the multidisciplinary study team and the parent consultant further reviewed emerging concepts and themes, allowing for more rigorous interpretations of the results via triangulation.¹⁶

RESULTS

Participants

Twenty-two African American and Hispanic mothers whose children

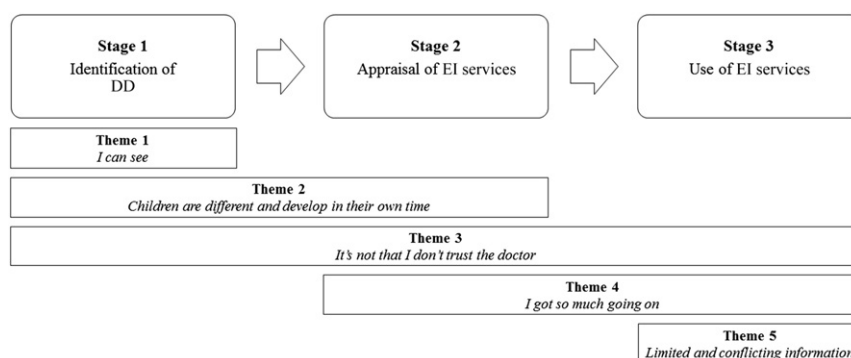


FIGURE 1

Key stages in the EI help-seeking pathway and corresponding themes.

had clinician-documented DD participated. Thirty-six percent were African American, 64% were Hispanic, 59% had less than a high school education, and 41% had study-eligible children who currently or had previously used EI services (Table 1). Details regarding children's sex, age, and developmental areas of concern are presented in Table 1.

Themes Resulting From In-Depth Interviews

The analysis revealed 5 major themes describing the role of maternal health beliefs in shaping key stages of the help-seeking pathway for children with DD (Fig 1). The 5 major themes were: (1) "I can see" (observing other children and making comparisons); (2) "Children are different and develop in their own time" (perceiving that their child might be delayed, but not being concerned); (3) "It's not that I don't trust the doctor" (relying on social networks rather than the pediatrician to inform the help-seeking pathway); (4) "I got so much going on" (difficulty prioritizing EI because of competing social or financial stressors); and (5) limited and conflicting information (delaying or forgoing EI serves because of limited and conflicting information). Key differences between African American and Hispanic mothers are also described. Representative quotations for each theme are provided in Table 2.

TABLE 1 Sample Characteristics

Characteristic	n (%)
Mothers	
Race or ethnicity	
African American	8 (36)
Hispanic	14 (64)
Age range, y	
18–24	6 (27)
25–34	14 (64)
35–44	2 (9)
Educational attainment	
Less than high school	13 (59)
High school graduate	7 (32)
Some college	2 (9)
Child publicly insured	
No	1 (5)
Child ever enrolled in EI	
No	13 (59)
Country of origin	
African American	
United States	8 (36)
Hispanic	
Mexico	11 (79)
Central America	3 (21)
Length of time in United States (Hispanic mothers), y	
0–4	3 (21)
5–9	4 (29)
10+	7 (50)
Children	
Sex	
Girl	6 (27)
Boy	16 (73)
Age range, mo	
8–11	3 (14)
12–23	7 (32)
24–35	12 (54)
Developmental area(s) of concern	
Expressive communication	13 (59)
Motor	5 (23)
Expressive communication + behavior	2 (9)
Behavior	1 (5)
Multiple	1 (5)

N = 22.

TABLE 2 Representative Quotations for Each Theme

Theme	Quotations
I can see	<p>“[My daughter] has some time with her cousin, and I can see [her development] is the same.”</p> <p>“I compare [my daughter] with many babies her age and older, and she has the behavior of a baby of almost a year old.”</p> <p>“I saw other children that could name different things, like they named their bottle, they named water and papa, and [my son] doesn’t.”</p>
Children are different and develop in their own time	<p>“Not all children are the same, and maybe he will have to struggle a little bit harder, but he will learn in the end.”</p> <p>“[My son] will do it [talk] in his own time. And that is what he has kinda showed us anyway, most of the family. There’s things he’ll do when he is ready to do it.”</p>
It’s not that I don’t trust the doctor	<p>“I hate to sound like 1 of these mothers. Like ‘oh, the doctor’s wrong,’ or whatever. I just think it’s too soon to say whether he’s on schedule or not, because he started walking early.”</p> <p>“We had a lot of family members that said their kids started walking before 1 year, and that maybe we should just wait like 2 more months [to see if our son will start walking].”</p> <p>“So like, my best friend, she has a son. So like, I will call her and ask her ‘is it normal for him to do this, is it normal for him to do that?’ And pretty much, it is. It’s just a big difference from a girl to a boy.”</p>
I got so much going on	<p>“Sometimes I don’t even bother bringing other stuff up. It’s just too much.”</p> <p>Regarding missed EI evaluations and loss of contact with the EI program “My youngest daughter [index child’s sister] was in the hospital for like 3 months.” “It might have been me. I think... I think I had [the evaluation] rescheduled and missed it or something. It was something like that. There was something that just came up.”</p>
Limited and conflicting information	<p>“There are programs for [children] to learn to speak. I don’t remember the other ones. [The doctor] might have told me about these programs but I can’t remember.”</p> <p>“I don’t know [the program] because when they call, I always speak to the translator, and they just explain things like when the appointment is going to be or if my doctor called with the referral.”</p> <p>“[EI] assessed him, but they didn’t provide any therapy until he was 24 months...they said he didn’t qualify unless his [speech delay] continued at 24 months.”</p>

Theme 1: I Can See

Observations and direct comparisons of children’s development often shaped mothers’ attitudes toward development and influenced whether mothers identified DD. Mothers either perceived their child’s development as being the same as other children, “I can see that other children are doing the same as he does,” or as being different, “I can see [other kids] utter phrases of 2 or 3 words asking for something, and my son can’t do that yet.”

Theme 2: Children Are Different and Develop in Their Own Time

The belief that children are different and develop in their own time influenced whether mothers

identified DD: “the truth is, there are some [children] that develop well and others that don’t.” Few mothers identified their child’s development as delayed. The belief that children develop in their own time also influenced EI appraisals. One mother did not perceive her son as having a DD or needing EI services because her nephew (who did not receive EI) “took a long time to walk but then started talking instead.”

Theme 3: It’s Not That I Don’t Trust the Doctor

Social networks played a much stronger role than pediatricians in influencing maternal beliefs. Regarding development and the identification of DD, 1 mother stated,

“[my friends] tell me [girls] develop quicker than, whatever, mature quicker than [boys].” When mothers recalled conversations with the pediatrician, these conversations often occurred within the context of mothers’ social networks: “it’s not that I didn’t trust what the doctor said [that her son’s development was delayed], because I did. But hearing it again from someone that I put my trust in to take care of my son, it kinda made me feel a bit more confident.” Maternal social networks also influenced EI appraisals: “I’ve heard [from friends] that those therapies are very helpful.” Few mothers recalled receiving information about accessing or using EI from their child’s pediatrician: “In the beginning, the doctor, she didn’t give me as much details. She just said, ‘there’s a program called Infants and Toddlers.’ At that point I had no idea what it entailed at all.” Unless mothers had heard of EI from a close friend or family member, they typically did not use these services.

Theme 4: I Got So Much Going On

Competing social and financial stressors often prevented mothers from prioritizing EI services for their child: “just sometimes, I got so much going on, it’s hard keeping it all straight.” Mothers also had difficulty using EI services as a result of these stressors: “I think I had [the evaluation] rescheduled and missed it or something. There was something that just came up.”

Theme 5: Limited and Conflicting Information

Limited and conflicting information about EI referral and eligibility processes often resulted in delayed or forgone services. One mother, with limited understanding of the EI referral process, described delays in scheduling her son’s initial evaluation: “there were about 8 appointments...they cancelled them. So for about a year and a half, there was nothing.” Another mother had

her son evaluated for EI services, but did not know whether her son was eligible for or needed services: “[EI] said that we should wait a bit more [to initiate services] because it appears that, yes, he is going to walk. But the pediatrician said that she’s going to make another referral for him to be reevaluated [because he needs services].”

Differences in Help-Seeking Between African American and Hispanic Mothers

Maternal beliefs were similar across stages of the help-seeking pathway, with 1 notable exception regarding EI use. A few Hispanic mothers agreed to EI services despite not identifying their child as delayed nor being concerned about their child’s development. Although they did not necessarily agree with the pediatrician, they went along with his or her recommendation because “whatever the doctor says is fine.” In contrast, some African American mothers went along with EI services for fear of judgment and “to avoid trouble.” These mothers also reported feeling as though their opinions did not matter: “sometimes I feel like what I say don’t really matter. Like the doctor’s just gonna do whatever.”

DISCUSSION

We conducted in-depth interviews with low-income African American and Hispanic mothers to better understand the role of health beliefs in shaping maternal decisions regarding key stages of the help-seeking pathway for children with DD and to explore differences between African American and Hispanic mothers. With our findings, we highlight the important role maternal health beliefs (particularly regarding DD and EI), social networks, and external stressors play in influencing early identification and intervention for children with DD. The following discussion reveals relationships

between each theme and key stages of the help-seeking pathway and provides potential solutions for providing family-centered and developmentally-focused anticipatory guidance for children with DD.

The first theme, I can see, suggests that mothers rely on observations to compare their child with other children and to identify delays. Glascoe and MacLean speculated that the task of comparing or contrasting child development is easier and more natural than identifying, for example, the ages at which children are expected to achieve milestones.¹⁷ Mothers in our study who did not perceive their child’s development as being delayed (despite clinician-documented delays) were unlikely to value or use EI services. The use of video- or computer-assisted developmental screening tools during the well-child visit, or completion of screening tools at home, may provide parents with an opportunity to visually compare their child’s development with that of age- and culturally-appropriate peers. The Centers for Disease Control and Prevention recently published “Milestones in Action,” a free library of photos and videos of developmental milestones to supplement their “Learn the Signs. Act Early” campaign.¹⁸ Use of these pictures and videos, in conjunction with standardized developmental screening tools, may support parents in making comparisons of their child’s development, increasing understanding of developmental milestones, and improving early identification of DDs.

The second theme, children are different and develop in their own time, suggests that mothers may identify DD but may not necessarily perceive a problem or a need for EI services. These findings align with those of Jimenez et al¹⁹, suggesting that mothers who are ambivalent about DD may view the use of

community services, including EI services, as an imposition. Use of standardized screening tools and parent decision aids to elicit mothers’ developmental expectations or concerns during well-child visits, while clearly communicating one’s own expectations and concerns, may help to engage mothers as equal partners in the decision-making process.^{20,21} A recent randomized trial assessing the impact of a 3-minute video decision aid on parents’ attitudes regarding DD and appraisals of EI demonstrated favorable changes in these areas.²²

The third theme, it’s not that I don’t trust the doctor, appeared consistently across all stages of the help-seeking pathway. Mothers in our study (as with parents across cultures)^{23,24} relied on social networks for advice about their child’s care and help-seeking behaviors. Surprisingly, few mothers in our study reported having meaningful conversations with their child’s pediatrician about developmental concerns or EI services, despite such documentation in the child’s electronic health record. These findings highlight the importance of engaging mothers and influential family members or friends in the decision-making process. It might be useful for clinicians to talk with parents about their social networks, and the role networks play in shaping help-seeking behaviors. To enhance knowledge and awareness of developmental milestones and EI services in the broader community, pediatricians may consider participating in local media campaigns and outreach activities in diverse markets,²⁵ or they may consider promoting community-based parenting classes.

The fourth theme, I got so much going on, reveals the difficulty many families experience in prioritizing or using EI services. Children in these families are likely to continue facing significant challenges in

getting their developmental needs met until families are able to achieve greater social and financial stability. Clinicians are encouraged to discuss families' socioeconomic environment and to ask about, listen to, and support families' experiences.^{4,26} For some children, the current system of primary care may not adequately address their families' complex socioeconomic needs.²⁷ Evidence-based models, such as Health Leads,^{28,29} Healthy Steps,^{30,31} or Safe Environment for Every Kid³² help pediatricians address these needs, thereby empowering families to use EI services.

The last theme, limited and conflicting information, highlights the challenge that many families face in accessing and using EI services, even when they identify their child as having a DD and perceive a need for EI services. To increase coordination between pediatric primary care and EI systems, many state and professional organizations have launched educational initiatives targeted for pediatricians and EI clinicians.^{33,34} Use of information technology (eg, shared electronic health records and patient Web portals)³⁵ or brief referral plans and checklists³⁶ further enhances communication between pediatricians and EI clinicians. Moreover, family navigators can facilitate EI use by providing families emotional support, family-centered and developmentally-focused anticipatory guidance, and logistical assistance.³⁷

Interestingly, differences between African American and Hispanic mothers emerged during conversations around service use.

Both groups of mothers reported feeling pressured into using services. African American mothers tended to go along with services to avoid trouble, whereas Hispanic mothers tended to go along with services as a result of traditional social hierarchies.²³ Regardless of the source of pressure, the end result was a process from which mothers were further disengaged. With these findings, we underscore the importance of eliciting mothers' concerns and expectations early in the help-seeking pathway and of engaging them as equal partners throughout the decision-making process.

Our study has several limitations. First, we did not capture the views of low-income African American or Hispanic mothers whose children do not receive routine well-child visits. However, it is reasonable to expect that mothers whose children do not receive pediatric primary care are at least as likely to rely on social networks for information related to development, DD, and EI and to experience challenges using EI services. Second, because this study was conducted in a single academic institution located in an urban setting, the perspectives captured may not reflect those of mothers whose children receive primary care through community-based practices or whose children are served by different EI systems. Third, we conducted interviews with low-income African American and Hispanic mothers; although we achieved thematic saturation with our sample, beliefs may differ in other racial, ethnic, and socioeconomic groups. Finally, we explored the role of maternal health

beliefs in shaping help-seeking behaviors for children with DD. Future studies should seek to obtain the views of fathers and social networks.

CONCLUSIONS

In this study, we explored the ways in which maternal health beliefs influence key stages of the help-seeking pathway for children with DD. Our findings add to a growing body of literature in which authors suggest that completion of a developmental screener and the subsequent referral of a child to EI services do not guarantee that a child with DD will use these services. Understanding maternal health beliefs and expectations regarding DD and EI, acknowledging the influence of social networks on the help-seeking pathway, and helping to address social and financial stressors are critical to ensuring that children with DD are identified and that they access needed services. Without such family-centered anticipatory guidance, disparities in early identification and intervention will likely persist.

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ABBREVIATIONS

DD: developmental delay
EI: early intervention

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Address correspondence to Dawn M. Magnusson, PT, PhD, Department of Physical Medicine and Rehabilitation, University of Colorado Anschutz Medical Campus, Physical Therapy Program, Education 2 South, 13121 East 17th Ave, Aurora, CO 80045. E-mail: dawn.magnusson@ucdenver.edu

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