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Family Perspectives on Developmental Monitoring: A Qualitative Study

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Abstract

Developmental monitoring, an ongoing process to identify children at risk for developmental delays, is an essential component to the identification of a developmental disability in young children. In collaboration with families, medical professionals are expected to monitor the development of a child; however, current research focuses on screening with less attention on developmental monitoring and the role of the family. Here, we show the experiences of families with medical professionals specific to developmental monitoring and how families obtain and develop knowledge on child development. We analyze qualitative data from a sample of family caregivers using semistructured interviews. With a thematic approach, we identified three themes: (1) developmental monitoring with physicians is not common, (2) families use diverse supports to learn about child development, and (3) contextual factors (e.g., maternal health, work demands, demographic components) influence and shape the child development experience within a family unit. These findings indicate variability in developmental monitoring practices in addition to unique needs of children and families.

Plain Language Summary

Accurately identifying a developmental disability is important to ensure young children and families get needed supports. Developmental monitoring is a process where medical professionals work with families to identify children at risk for developmental delays. While family members have important information about their child, many times they are left out of the process. This study sought to better understand family experiences with developmental monitoring. We interviewed family caregivers of children ages birth to 5. We found three themes. The first theme is physicians often do not use developmental monitoring. The second theme is families use many ways to learn about child development—this includes community-based programs. The third theme is that contextual factors influence family experiences. There is a need to include families in developmental monitoring. Also, it is important to consider the individual factors and needs of a child and family.

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Monitoring young children’s development is both critical to early identification of a developmental delay and/or disorder and overall well-being of children and their families (Raspa et al., 2015). Developmental monitoring (DM) is an ongoing process where healthcare professionals’ partner with parents and caregivers to learn about and record a child’s developmental progress (Duby et al., 2006). DM generally involves a pediatrician or other medical professional working with families to document and track development through parent and other caregiver reports, observations, and screenings (Lipkin & Macias, 2020). While DM is endorsed by the American Academy of Pediatrics (AAP), only about a third of children receive DM (Hirai et al., 2018) and only a small percentage of children are identified early enough to receive early intervention services (Boulet et al., 2009; Boyle et al., 2011; Rosenberg et al., 2008). Yet, research suggests that when family concerns are considered as part of the diagnostic process, professionals make more accurate diagnoses (Gaspar De Alba & Bodfish, 2011; Ozonoff et al., 2010; Young et al., 2003; Zwaigenbaum et al., 2009). This research suggests an opportunity for professionals to partner with families through DM to enhance the diagnostic process (Chödrön et al., 2020).

Developmental Monitoring

While developmental monitoring is generally led by medical professionals, active involvement from families is critical. Yet, research suggests family involvement is often undervalued (Barger et al., 2018). Insight from families informs medical professionals regarding nuances of behavior in multiple contexts, which is needed for accurately identifying developmental delays early. Evidence has shown that when families are given the opportunity to discuss their child’s development and concerns, professionals make decisions and referrals that benefit the child and family’s overall well-being (Glascoe, 2000). To improve DM practices, a better understanding of a families’ knowledge and perspectives on child development is needed.

The AAP recommends that DM, alongside the complementary practice of developmental screening, be a part of every well-child preventive care visit and addressed at routinely scheduled appointments. While developmental screening consists of the administration of a brief standardized tool to track child development and help identify children at risk of a developmental delay (Duby et al., 2006), DM is a broad practice that can take many forms (Lipkin & Macias, 2020). There are six components generally considered to be important to the DM process: (1) eliciting and attending to the parents’ concerns about their child’s development; (2) documenting and maintaining shared information; (3) reporting accurate observations of the child; (4) identifying strengths, risks, and protective factors of the child and family; (5) maintaining an accurate record of the developmental monitoring process; and (6) sharing findings with other professionals and community-based programs with whom the child and family are involved (Lipkin & Macias, 2020). This process allows for tracking of growth and development as well as the opportunity for families to speak with medical professionals about potential parental observations and concerns. Medical professionals can then educate families on effective ways to promote and encourage child physical, mental, and social health and well-being based on family observations (Lipkin & Macias, 2020).
Developmental screening has proven to be an effective practice in identifying children at risk for developmental delays (Council on Children with Disabilities et al., 2006; Earls & Shackelford Hay, 2006; Hix-Small et al., 2007; King et al., 2010; Sand et al., 2005). However, one study suggests DM and developmental screening completed individually is insufficient in the identification of delays. In analyzing families’ responses to receiving developmental screening and/or monitoring for their children aged 10 months to 3 years, researchers found that children and families who reported receiving both developmental screening and monitoring were more likely to receive early intervention services compared to children and families who received developmental screening alone, DM alone, or neither (Barger et al., 2018). Findings such as these justify the need for further research in DM to meet the current and future needs of families and children who may have a developmental delay and/or disorder.

Importance of Partnering with Families in Developmental Monitoring

With accurate knowledge of child development, families can accurately communicate observations with medical professionals to support the DM and diagnostic process (Daniel et al., 2009). Today’s families seek out information on child development and developmental milestones through a variety of sources including digital media (e.g., social media), social support systems (e.g., family, friends), print materials (e.g., books, magazines), and providers of programs that serve children and families (Carter, 2007; National Academies of Sciences, Engineering, & Medicine et al., 2016; Zero to Three, 2016). These resources can vary in terms of scientific and medical evidence accuracy, representing an opportunity for medical professionals to educate families on the science of development in family-friendly language. Knowledge on child development is important for families to be active contributors to DM.

Family participation in DM is important, and recent research suggests that family insight can lead to earlier and more accurate diagnoses (Zwaigenbaum et al., 2015). The importance of family observation can be seen clearly in the diagnosis of autism spectrum disorder (ASD), which is a condition that is generally first noticed through differences in interactions (e.g., behavior, language development) rather than physical or genetic symptoms (e.g., Cerebral Palsy or Down syndrome; American Psychiatric Association, 2013). For example, studies have shown that family concerns for their child with ASD may predict a diagnosis (Gaspar De Alba & Bodfish, 2011; Ozonoff et al., 2010; Young et al., 2003; Zwaigenbaum et al., 2009). Additionally, the concerns of families with children with ASD may differentiate children with other developmental disabilities (Little et al., 2017) highlighting the importance of DM in early detection of childhood developmental disorders. A family’s input during the DM process is critical as they offer a well-rounded perspective of their child, therefore helping to identify risk of a developmental delay. The family perspective matters in identifying children at risk of a developmental delay, and with child development knowledge, family’s input is critical to the DM process.

Study Purpose

While family observation is critical to accurate diagnosis, our review of the literature did not find any research that explores family knowledge and perspectives on development and DM.
Given the importance of the family perspective in the DM process, research is needed to understand family knowledge and perspectives on healthy child development to improve the early identification practices of DM among early childhood providers. The knowledge and perspectives families have about child development can either support or inhibit a child’s developmental trajectory. Additionally, when families are an equal partner in DM, their perspective can enhance the diagnostic process (Lipkin & Macias, 2020); therefore, we need to better understand family experiences with the DM process. To better understand DM through the lens of a family, we aim to answer the following research questions:

1. What are the experiences of families with medical professionals specific to DM?
2. How do families obtain and develop knowledge on child development?

Methods

Research Design Overview

To address our research questions, we used a phenomenological design that focuses on commonalities among a particular group and aims to describe a specific phenomenon (Creswell, 2013; Patton, 2002). We gathered data using 1-hour semistructured interviews. Next, we systematically analyzed our findings using thematic analysis, a common form of analysis within qualitative research that facilitates identification and interpretation of themes within data (Braun & Clarke, 2006). Through our analysis, themes emerged that provide insight into family’s experiences with their own child’s development and DM.

Study Team

The research team consisted of the lead author, the co-author, and students from health professions. The lead author developed and revised the interview guide with assistance from the co-author, performed all the interviews with the families, and reviewed all transcripts with the other team members. As a master’s-level social worker and doctoral student, the lead author worked many years in the field with families and children birth to 21 years of age providing support services, education, and behavioral strategies specific to ASD. These experiences led to the realization, supported by literature, that the foundational years of a young child’s life are vital to their future health and well-being. The co-author served as an expert in qualitative research methodology and supervised the project from inception. Health professions students coded transcripts after receiving training from the lead author on codes identified and defined by the lead authors. Additionally, the students completed coursework in child development but had no training in DM.

Study Participants

We used a convenience sample (Miles & Huberman, 1994), consisting of English-speaking family caregivers with at least one child under 5 years of age. Ten individuals from two Midwest states participated and each identified themselves as a mother. Across all participants, there
were a total of 20 children with a mean age of 4.39 years. The participants and lead author had no relationship prior to the interview.

Participants were given the option to complete the semistructured interview in person at their home or at a university-setting clinic. Interviews for the final five participants occurred in March of 2020, which coincided with the COVID-19 pandemic. Because of public safety measures to prevent the spread of COVID-19 put in place by the lead author’s university, face-to-face contact for research was suspended; thus, we added an option to conduct interviews remotely (via Zoom or phone). A total of 10 interviews were completed. Five interviews were completed at participant’s homes, three were over the phone, and two via Zoom.

**Participant Recruitment**

We recruited families through a research registry affiliated with a university research center lab. A recruitment flyer with study information was sent via email to potential participants who had consented to be notified of research studies (n = 1,591). In addition, the flyer was posted to the university research center lab’s associated social media account. Interested participants responded to researchers via email or phone. A total of 126 families responded to the recruitment flyer. Each one was contacted by the lead author with more details of the study and specific interview dates. Families who were still interested and were available on a preselected interview date were either scheduled or placed on a “wait list.”

Participants did not receive incentives or compensation for their participation. In protection of the participants, the study was approved by the Institutional Review Board (IRB) at the University of Kansas Medical Center. Participants read and signed the approved consent form before beginning the interview. As part of the consenting process, the lead researcher informed participants about the goals and procedures of the study, along with the lead author’s interests in family’s experiences with child development.

As part of the study design, the researchers continued recruiting and interviewing participants until saturation was met (Sandelowski, 2008). Saturation of data was evident within six interviews (Guest et al., 2006). A total of 15 participants were scheduled for an interview; however, five participants cancelled because of COVID-19 and increased demands of caring for their family. The final four scheduled interviews were conducted to ensure saturation.

**Data Collection**

We conducted one-time, semistructured interviews in English. A previously tested interview guide with probes explored family’s experiences and perceptions of child development. The guide was developed by the lead author and researchers with expertise in qualitative research with families. The interview guide began with family demographic information and an overview of pregnancy and birth experiences. Participants were asked open-ended questions focused on three main categories related to child development: (1) family knowledge; (2) family perceptions; and (3) family practices (see Table 1). Interview lengths varied from 15 to 116
minutes, with an average interview time of 52 minutes. Field notes were taken both during and after the interviews and provided additional context. The interviews, transcribed by an online service, were reviewed by the lead author for accuracy with the original audio recordings.

Table 1

**Interview Guide**

<table>
<thead>
<tr>
<th>Category</th>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family knowledge of child development</td>
<td>1. What does child development mean to you as a parent?</td>
</tr>
<tr>
<td></td>
<td>2. Do you feel like you have a good understanding of child developmental milestones? Explain.</td>
</tr>
<tr>
<td></td>
<td>3. Whom do you turn to when you have questions about your child’s development and/or developmental milestones?</td>
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<tr>
<td></td>
<td>4. How frequently (daily, weekly, monthly) do you monitor or track your child’s development?</td>
</tr>
<tr>
<td></td>
<td>5. If there was one resource on child development you wish you had, what would it be?</td>
</tr>
<tr>
<td>Family methods for obtaining child development information</td>
<td>6. Do you feel it is easy to find trustworthy information on child development? Explain.</td>
</tr>
<tr>
<td></td>
<td>7. What is your preferred method for receiving child development information?</td>
</tr>
<tr>
<td></td>
<td>8. Have you ever felt overloaded with information? If so, in what way (e.g., handouts, in-person, books,)?</td>
</tr>
<tr>
<td></td>
<td>9. At any point from pregnancy to now, have you felt any outside pressures regarding your child’s development? Have these influenced your parenting?</td>
</tr>
<tr>
<td>Family experiences with developmental monitoring</td>
<td>10. Do you know of or has anyone told you about resources or tools about your child’s development? Explain.</td>
</tr>
<tr>
<td></td>
<td>11. What child development information has your child’s physician given you?</td>
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<tr>
<td></td>
<td>12. What are three child development tools/resources you would recommend to a new parent?</td>
</tr>
</tbody>
</table>

**Analysis**

We used a phenomenological approach to explore the lived experiences and understand the perspectives of families of young children with respect to DM and child development (Marshall & Rossman, 2016; Patton, 2002). Consistent with a phenomenological approach, thematic analysis was used to identify, analyze, and report patterns or themes within the interview data (Braun & Clarke, 2006).

Analysis of transcripts included a rigorous coding process and interrater reliability to
ensure the saturation of the data. The lead author read and independently coded each transcript as the process occurred. For identifying codes, the lead author and health professions students independently reviewed two transcripts at a time, generating codes from the text as concepts became apparent. The initial codes were further defined and categorized through group discussion. Using the finalized codes and definitions, the lead author and one health professions student (i.e., the coding student) then re-read and coded each transcript for reliability purposes (described subsequently). Through further analysis of the category codes, patterns or themes summarizing the main ideas and experiences of the participants emerged (Creswell, 2013; Patton, 2002).

Interrater reliability was completed between the lead author and the coding student. A random sample of 11 interview snippets from each participant (representing 20% of total interview snippets) were separately coded by the lead author and coding student. Before coding the reliability sample, a threshold of 80% agreement was established for reliability. The two then met to compare their coding, classifying each interview quote as either agreement or disagreement. The percentage of agreement was then calculated as the total number of agreements divided by the total number of quotes. This resulted in an interrater reliability of 89%.

Results

Participant Characteristics

Ten English-speaking caregivers were interviewed (Table 2). Participants were mothers aged 25 to 41 years ($M = 35; SD = 40.4$). Nine family members reported gender as female and one as binary, non-gender. The participants identified as White (80%), Black or African American (10%), and more than one race (10%), with the primary ethnicity being non-Hispanic (90%). Seven of the participants were married, one was separated, one was in a domestic partnership, and one was unmarried/single. All family members and their partners were employed with education levels ranging from no degree to some college without completion of a degree to professional with a degree. Two participants reported receiving Women, Infants, and Children (WIC) food supplements (Table 2).

The number of children in the home ranged from one to five with an average age of 4 years. English was the primary language spoken at home with two families indicating the occasional use of sign language and Spanish. Two participants reported that they had one child (a total of two in the study) with a developmental delay.

Themes

After initial coding using a thematic analysis approach, four categories (i.e., child development knowledge and perspective, obtainment of knowledge, DM, circumstantial experiences) were identified and defined. The four categories were then combined into three themes: (1) experiences with DM, (2) child development knowledge (encompassing codes child
<table>
<thead>
<tr>
<th>Participant</th>
<th>Characteristic</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Participant 1 was a married, White, female with two children, ages two and one. She had a master’s degree and was employed as a high school family and consumer sciences Family and Consumer Sciences (FACS) teacher. Participant 1’s children attended a daycare program and visited a pediatrician for well-child visits. Participant 1 had visited with the pediatrician about one of the child’s physical and language development; however, the pediatrician did not voice any concerns. Participant 1 confirmed no child in the family had a developmental delay or a diagnosed disability.</td>
</tr>
<tr>
<td>2</td>
<td>Participant 2 was a married, White, female with two children, ages 5 and 2. She had a bachelor’s degree and was employed as an event coordinator. Her children attended 8 hours of preschool along with 40 hours of in-home care provided by their grandparents. The children visited a family physician for well-child visits. There had not been a concern regarding the children’s development from Participant 2 or the family physician. Participant 2 confirmed no child in the family had a developmental delay or diagnosed disability.</td>
</tr>
<tr>
<td>3</td>
<td>Participant 3 was a married, White, female with two children ages 7 and 3. She had a bachelor’s degree and was a stay-at-home mother. Her child did not attend preschool but did receive services (e.g., occupational and speech-language therapy) as deemed necessary. The children visited a pediatrician for their well-child visits. Participant 3 reported the pediatrician had not voiced concern about the children’s development. However, Participant 3 did express concern for one of her children’s speech, fine motor, and feeding development. Participant 3 confirmed the oldest of her children having a delay with fine motor and social skills and the youngest of her children being diagnosed with anxiety and sensory processing disorder.</td>
</tr>
<tr>
<td>4</td>
<td>Participant 4 was a married, bi-racial, female who had a 3-year-old child. She had a master’s degree and was employed as a financial planner/wealth manager. Her child did not attend daycare, preschool, or receive therapeutic services. Her child was followed by a pediatrician who had not voiced a concern related to the child’s development. However, Participant 4 had inquired about development. Participant 4 confirmed no child within the family having a developmental delay or diagnosed disability.</td>
</tr>
<tr>
<td>5</td>
<td>Participant 5 was a married, White, female with two children. One child was 2 and another under the age of 1. Participant 5 had a bachelor’s degree and was employed as a respiratory therapist. Her children attended daycare part-time. Neither of her children received therapeutic services. The children visited a pediatrician for well-child checkups. There had not been a concern regarding the child’s development from Participant 5 or the pediatrician. Participant 5 confirmed that no children in the family had a developmental delay or diagnosed disability.</td>
</tr>
<tr>
<td>6</td>
<td>Participant 6 was a married, White, female with a 3-year-old child. She had a master’s degree and was employed as a parent educator. Her child attended daycare, which included 6 hours of in-home care and preschool for 6 hours. For well-child visits, the child visited a family physician who had not voiced a concern related to development. However, Participant 6 had requested information related to ankle pronation as she claimed her child was a late walker. Participant 6 confirmed that no child within the family had a developmental delay or diagnosed disability.</td>
</tr>
</tbody>
</table>

*(table continues)*
Participant 7 was a married, White, female who had three children ages 10, 4, and 3. She had a master’s degree and was employed as a teacher. Her children did not attend preschool or receive therapeutic services. Her children visited a pediatrician and Participant 7 voiced concern about a child’s development; however, no child in the family had a developmental delay or diagnosed disability.

Participant 8 identified as non-binary and White. They had twins aged 4 years and was currently separated from the children’s father. Participant 8 had a doctorate degree and was employed as a psychologist. The children attended daycare for 50 hours a week and did not receive therapeutic services. The children were followed by a pediatrician who voiced concerns related to their child’s speech, occupational therapy concerns, and sensory issues. Participant 8 reported that the pediatrician had not voiced a concern related to development but confirmed that one of the children had a developmental delay or a diagnosed disability related to speech and fine motor skills.

Participant 9 was a White, Hispanic or Latina, married female. She was in a domestic relationship and had five children ages ranging from 3 to mid-20s. She had an associate degree and was employed as a nurse. Her children did not attend childcare, preschool, or receive therapeutic services. They did see a pediatrician for well-child visits, and the pediatrician had not expressed concern about development. Participant 9 confirmed none of the children had a delay or a diagnosed disability.

Participant 10 was an African American, single, female, who had two children under the age of 3. She completed some college courses and was employed as a customer service representative. Her children did not attend daycare, preschool, or receive therapeutic services. Her children were followed by a pediatrician who had not voiced concern about their development. Participant 10 stated when choosing a pediatrician, she asked a lot of questions and had to find a good fit for her family because of her decision to not vaccinate. Participant 10 also confirmed that none of her children had a delay or a diagnosed disability.

development knowledge and perspective and obtainment of knowledge) and (3) family contextual factors (encompassing code circumstantial experiences). DM included the family’s experiences learning about child development from a physician. Three participating families actively engaged in DM (Lipkin & Macias, 2020) with their medical provider, while the other seven participated in informal monitoring (e.g., brief conversation, checklist of milestones). Child development knowledge and experiences was defined as a family’s diverse insight on child development from informational sources (e.g., courses, websites, family members and friends, medical professionals), lived experiences (e.g., previous children, work in the field), and attitudes before and after having a child (e.g., parenting practices, personal experiences). Contextual factors emerged as a theme related to risk and protective factors that can impact child development though not always covered in the DM process. For this study, contextual factors were defined as the personal, environmental, and circumstantial factors that influence and shape the child development experiences within a family unit. The authentic experiences of the participants provided information important to child development and the needs to support young children and their families (Table 3).
### Table 3

**Themes**

<table>
<thead>
<tr>
<th>Theme</th>
<th>Definition</th>
<th>Example quote for each category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Experiences with developmental monitoring</td>
<td>The experiences for learning about child development from a physician.</td>
<td>Participant 7: “They [pediatrician] just hand out a sheet on where they [children] are [developmentally], what’s typical milestones every time. And then we talk about it a little bit and she asks them questions.”</td>
</tr>
<tr>
<td>Knowledge and experiences with child development</td>
<td>A family’s diverse insight on child development from knowledge gained, lived experiences, and attitudes and beliefs before and after having a child.</td>
<td>Participant 2: “I might ask him [physician] at our checkups and appointments that we go to, but I would say I rely more on my peers [for child development information].”</td>
</tr>
<tr>
<td>Contextual influences on child development</td>
<td>The personal environmental and circumstantial factors that influence and shape the child development experience within a family unit.</td>
<td>Participant 6: “Professionally, I’ve had much experience, but then when you become parents, it is a game changer.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Participant 8: “One of the things that makes it [child development] challenging with twins is they are two people. And so, treating them as two people, sometimes it’s hard. Is this one advanced in this area? And is this one where they should be? And is this one a little bit behind in those different types of things. Even though I try not to compare them, sometimes it’s hard just to have a gauge of what is expected.”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Participant 4: “I did have postpartum [depression]. I would describe it more as anxiety than like depression. I’m just very anxious about anything that had to do with him.”</td>
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<td></td>
<td></td>
<td>Participant 7: “We live in a poverty area and because I’ve been a stay-at-home mom, we have a very low income right now. So, their (children) ability to get those things [extracurricular activities], we can’t. Coming from middle class and then being in lower class, there’s definitely a huge switch”</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Participant 8: “I do gender open parenting with the kids. I do not assign gender until they are old enough to articulate it for themselves. We did not label them as boys or girls, and we used “they/them” pronouns for them until they were old enough to tell us. We had very frequent conversations about sex and gender and body parts and lots of books.”</td>
</tr>
</tbody>
</table>
Experiences with Developmental Monitoring

Participants demonstrated diverse perspectives regarding their understanding of child development. In terms of experiences with DM, only three participants relied on their children’s primary care doctor (e.g., family physician, pediatrician) as a support and resource for child development. Of those families, they felt they had a positive relationship with their provider, were comfortable sharing child development information with their provider, and received information about child development through routine screenings and in-office handouts or pamphlets. Seven families, however, stated the primary care physician monitored development as expected (e.g., screening, handout or pamphlet with milestones, brief conversation) and expressed that they had lower expectations of their physician’s role in child development monitoring—knowing physicians could only do so much. Participant 10, who primarily obtained child development information from professional experience, family, and books, noted,

They [doctors] have so many patients that they see. They’re just going based off notes they have made previously. So that’s why you cannot rely too much on what the doctor says about development. They have the broad knowledge of what the child’s supposed to be doing at this age versus we see them in front of our face every single day and what step they’re at or what they’re doing and how they’re doing it.

The individuals who participated in the interviews also shared that they monitor their child’s development using photos and videos, indicating the importance of family narrative to the DM process. Photos and videos were organized in a variety of ways including photo books and online services (e.g., Google Photos, Shutterfly, Facebook). Participant 8 shared,

When I take them [children] in for developmental screenings and they ask when they started talking, I can scroll back through my photos and find out because I posted most of them or I sent messages to my family through Facebook and Instagram.

Knowledge and Experiences with Child Development

Rather than during medical visits, participants stated that they gleaned much of their child development education from their schooling, their own professional careers, social support, and a variety of other resources, including online sources and books. Eight participants had close relationships with family (e.g., grandparents, siblings, aunts, uncles, cousins) and friends, including neighbors, who were valued sources of child development information. When describing knowledge gained from other family members, Participant 4, who moved closer to her family after having children noted, “It’s one of the reasons we moved out here. My parents live probably 10 minutes away and my three younger brothers go to college nearby.” Two participants shared their closest friends happened to be physicians (e.g., pediatrician, obstetrician-gynecologist) whom they could consult with on child development and family-related health.
Community-based organizations were highly utilized and valued as sources of child development knowledge. *Parents as Teachers* was the most common program of which the families spoke highly of and recommended to other families. For example, Participant 3 shared, “*Parents as Teachers* helped a lot because they [the educators] would say what was normal and above normal.” Participant 3, a stay-at-home mother, also found value in a support system. She said,

*I definitely recommend a moms group of some kind. I prefer when I can be with other moms [learning] because it’s so crucial for my children and their brain development.*

For those involved with childcare, in-home childcare, or preschool, participants mentioned the programs as systems they are involved in but not necessarily as a resource for child development. Participant 7, whose children attended a childcare program observed,

*When they [children] were in the younger classrooms, they [teachers] would send home screening information and pamphlets, but not as much as the kids have gotten older.*

When asked about attitudes and what child development means, Participant 5, who received most of her child development information from the pediatrician and friends responded broadly that, “Child development is the process of growing up and how they figure out the world.” Several were more concrete, describing child development as the promotion of skills specific to physical, mental, emotional, social, and cognitive development. Across all the participants, it was clear that each family played a significant role in laying the foundation for their child’s development. Participant 8, whose children were 4 years old, shared her insight on being a parent.

*As a parent I think it’s incredibly important to realize what they are capable of and then how to support them. I take a scaffolding perspective. So, helping provide the framework and then as they [children] become more capable of doing things, taking away some of that support. I’m still there, but as they can become more of a master in things, my support walking them through the steps becomes less and less. I’m there for emotional support.*

**Contextual Influences on Child Development**

We did not ask specific questions about how family contextual factors affected the way families supported their child or children’s development; however, this theme emerged from participant responses. Recommended by the AAP (Lipkin & Macias, 2020) as a component of DM, the identification of family strengths, risks, and protective factors, all contextual factors, can impact the well-being of the family and the development of a child. Contextual factors that influenced the extent to which families supported development included: (1) maternal health, (2) work demands, and (3) demographic components. Across the participants, many shared experiences related to maternal health that impacted their support for child development. Some
participants shared detailed events of the birth of their children. Seven families in our study faced unforeseen circumstances during pregnancy. For example, Participant 5 described a traumatic post-delivery event as “I almost died. I hemorrhaged and lost a lot of blood. It was very scary.” This event led to Participant 5 realizing the value of taking care of herself through work and time to herself, which made her more present when at home to care for her family and support her children’s development. Two participants shared their experiences in the Neonatal Intensive Care Unit (NICU), which provided a source of encouragement and confidence to support her child’s health and development. Participant 1 shared,

*You’re like a vessel at that point [in the NICU] and you do what they [nurses and doctors] tell you to do. But it was a great experience, and the people were wonderful.*

Several shared unplanned health complications (e.g., gestational diabetes, high-risk) and experiences with post-partum depression (PPD) during the postnatal period or 4th trimester, which challenged their ability to care for their child. Despite the challenges, participants shared that the support they received from partners, family, friends, and healthcare professionals was critical for them to take care of themselves and prepare to care for their child. Participant 9, a stay-at-home mother, shared

*My parents live about five houses down from us and my mom is basically here, like almost every day. And I have an aunt that is three houses down and a cousin that lives the same distance pretty much across the street from my aunt.*

In general, the experiences at birth and shortly after, and the support the families received, impacted the families in a way that built resilience and confidence to care for themselves and their children, physically and developmentally.

Another contextual factor that impacted the way families supported child development was the degree to which participants and their partners worked outside of the home. Working parents expressed balancing the demands of work, caring for their children, and ensuring a safe and nurturing home environment was critical to promoting child development. Flexible and supportive employers were important and something families valued in their current jobs, along with the assurance that their children’s development was supported while working. Several relied on family members to help support children while working. For example, Participant 2, who worked as an event coordinator, expressed,

*My mom is retired and is a big part of the kids’ lives. She takes the kids to the library, other activities, and teaches them a lot.*

Other individual factors in the families’ lives (e.g., marital status, gender, socioeconomic status) also played a role in how families promoted child development. Participants reported that these individual factors posed a stress in their life. Participant 8, who was going through a divorce with her spouse, spoke to the challenges of different parenting styles on the impact of her children’s development as, “He does not have realistic expectations about what they’re [children]
capable of and would act very angrily and not talk to them in way that was appropriate.” This participant, who was a clinical psychologist, was confident that her professional knowledge on child development enabled them to support their children through the transition. Participant 7 spoke to the current change in her family’s socioeconomic status due to her spouse’s change in employment status and the resulting financial hardships as examples of changes that impacted her capacity and resources to care for her children. The financial hardships included moving to a new neighborhood, enrolling children in new schools, reduced access to healthcare providers, and access to fewer extracurricular activities. Like Participant 8, Participant 7 voiced concern about the impact of reduced finances on her children’s development but was taking initiative as a professional educator to ensure positive experiences to promote her children’s development. She shared,

The church has an amazing child program. It is phenomenal. The program is designed by preschool teachers, middle school teachers and is made for every age level. The activities are developmentally appropriate, and they send home information for parents to do with their kids that are developmentally appropriate.

A final participant shared their openness to gender diversity and identified personally as non-binary. Their spouse is transgender, and they were raising their children with no identified gender allowing them to identify according to their preference. While they spoke to the judgment received from the healthcare system, they were confident in educating others and supporting their children’s development with nonspecific gender norms embedded within their family structure.

Discussion

In this paper, we presented an exploration of the perceptions and experiences of families with young children regarding child development and DM. Key themes identified in our study included experiences with DM, knowledge and experiences with child development, and contextual influences on child development. This research provides valuable insight into parent perspectives on DM and child development, which can inform early identification efforts to fully include families in the DM process.

Experiences with Developmental Monitoring

Our study found that few family members participated in DM activities with their physician during well-child visits. Guidance by the AAP on DM state the physicians’ role is to collaborate with families to better understand children, both physically and developmentally (Lipkin & Macias, 2020); however, family-physician DM involvement was not as expected by families. A study highlighting what families want from well-child visits conducted focus groups with families and their experiences and found that families needed increased information and resources on development and behavior (Radecki et al., 2009). This study’s findings illustrate the importance of family and physician relationships and the key role families have in DM.
It is possible that physicians are engaging families in the DM process. However, if this is the case, physicians may need to clearly communicate both the steps in the early identification process and how they are engaging families in the process to ensure families recognize their involvement in the process. Previous literature suggests that physicians are not consistently using DM (Barger et al., 2018). Our research is consistent with this finding and suggests that more work is needed to educate (1) physicians on how to engage families in the DM process, and (2) families on how to partner with physicians on the DM process (Choo et al., 2019). The family needs to be a contributing partner in the child development discussion to share developmental descriptions and concerns (Glascoe & Dworkin, 1995; Trivette et al., 2010).

Families’ use of personal photos and videos emerged as a novel example of how families monitor child development. The moments captured by the family became a tool to monitor their child’s development. Research has suggested that the family’s confidence and empowerment for the care of their children increases with the convenience and accessibility of information (Madge & O’Connor, 2006). This finding places more emphasis on the need for the families and medical professionals to collaborate in the DM process.

**Knowledge and Experiences with Child Development**

While our findings indicated limited use of DM, the families relied on technology, supportive relationships, and community-based programs for information and support in the promotion of child development. Technology is a vital means for connecting families to resources, information, and support on child development. A variety of digital tools exist including web-based platforms, discussion forums, social media, and mobile applications. Families used technology to gather ideas for promoting specific child developmental milestones. For example, one family used online resources and a mobile application to learn new strategies to assist their child in walking. Previous studies have found that close to half of families surveyed use the internet and technology to obtain child development information (Hall & Bierman, 2015; Lerner et al., 2012; Walker et al., 2012). While families voiced an appreciation for information on child development from a variety of sources, families shared the need for quality resources (Yankelvich, 2000).

Families in our study highlighted the importance of supportive relationships within their day-to-day lives. Participants shared the value of reliable friends and neighbors with similar-aged children as well as family members to support them. These relationships served as a source for information regarding child development that supports the DM process. For example, more than one family member reported having a close friend who was in the field of child development. Relational supports can lead to families providing a caring and healthy environment for their children (Zero to Three, 2016). Additionally, supported families have the capacity to support their children (Swanson et al., 2011).

Through collaborative efforts, community-based programs can serve as a provider in the DM process. Our findings indicated a strong appreciation for community-based programs (e.g., early intervention services, early childhood mental health consultation, public library services,
public housing and/or job assistance programs). Families shared positive experiences that included the trusting relationships with providers and knowledge gained through resources and personal interactions. Research has indicated that when programs are well implemented, they can enhance (1) emotional well-being of families, (2) broaden social networks, and (3) facilitate child development (Cochran, 1990; Kagan et al., 1987). Additionally, the AAP’s newest component to DM (sharing and obtaining opinions and findings with other professionals) encourages physicians to collaborate with community-based providers for ongoing monitoring of child development to support early identification efforts (Lipkin & Macias, 2020).

Contextual Influences on Child Development

The importance of identifying strengths, risks, and protective factors of the child and family, a recommended AAP component of DM (Lipkin & Macias, 2020), is crucial for the health and well-being of a child. The contextual influences on child development theme emerged from the data. While we were not specifically studying this phenomenon, such results indicate the importance of contextual influences in child development and DM. Our study found a variety of contextual factors that influenced family experiences with supporting their child’s development, including: (1) maternal health, (2) work demands, and (3) demographic components. These factors do not stand alone but are rather interconnected to form an ever-changing experience for the family (Trivette et al., 2010). The effects of circumstantial, day-to-day experiences can accumulate over time for families. For example, one participant described her experience with a change in socioeconomic status as a stressor for her family and reduced opportunities for play for her children. This finding echoed previous research showing that a reduction in socioeconomic status can lead to poor health behaviors (Pampel et al., 2010). Similarly, four participants shared their experiences with PPD as a new parent. The mental health challenge presented as anxiety and a new sense of worry for their child. While the participants found support through family, friends, partners, and therapists, many parents find themselves alone and may have decreased parent-child interaction (Ramchandani et al., 2005). Over time, these examples can lead to personal distress that impact family relationships and the promotion of development with a young child. Compounded stress can impact the parent-child relationship and weaken the child’s bodily system and brain architecture for health, well-being, and development (National Scientific Council on the Developing Child, 2005/2014).

Implications for Developmental Monitoring

Findings from the in-depth interviews reveal that participation in DM practices varied across families. These findings indicate an inconsistency among the awareness and utilization of DM along with the diverse and individualized needs among families with young children. The diversity of the experiences shared by participants provide insight to relevant factors that can impact a family dynamic and need to be considered as part of the DM process. Medical professionals and early childhood providers can make more informed early identification decisions by educating families and including families in the DM process. It is valuable to understand the perceptions and experiences of families of young children in addition to the importance of appropriate and individualized supports for children and families. The DM process
needs to be holistic in its approach and consider all components of child development including the physical, mental, and emotional needs of the individual child and family.

Strengths and Limitations

Our findings yield important insights that researchers and health care professionals can use to improve child development practices. The participants’ diversity in socioeconomic status and sexual orientation provided insights to the research questions and future samples. However, this study has several limitations. First, interviews were conducted in two Midwest states. It is possible that qualitative findings from other areas would have resulted in different insights and experiences. Second, all participants identified as mothers. Inclusion of other family members (e.g., fathers, grandparents) to make findings more generalizable is needed. Finally, many participants were Caucasian. A heterogenous sample would provide more knowledge to better understand the individual perspectives of the DM process and identify a holistic approach that meets the needs of families today.

Conclusion

The purpose of this study was to obtain an understanding of families’ knowledge regarding DM—an early identification practice. The results suggest there is a gap between families and their support systems and physicians in the DM process. Additionally, the emergence of circumstantial experiences provided context to the individual families and their role in promoting child development. DM is a collaborative process that is recommended in unison with families, physicians, and community providers. It is an opportunity to better understand the child from a holistic perspective and to work together to provide positive developmental outcomes for children. This study demonstrates the need for a comprehensive approach to DM with children and their families. Further research on systems and interventions specific to DM is needed.

References


