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SHORT REPORT

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Conceptualizations of health, ability to act upon those definitions and desire for supports among families from historically marginalized communities

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Abstract

Respect for parents' values and clinician–parent collaboration is less common among families from historically marginalized communities. We investigated how parents from marginalized communities operationalize health and their preferences for paediatric primary care. We recruited families who spoke English, Haitian Creole or Spanish with at least one child younger than 6 years old. Staff queried families' values and life experiences, perspectives on health and healthcare, social supports and resources. Fourteen interviews with the parents of 26 children were thematically analysed. Interviews revealed the following four themes: (1) parents' definitions of 'health' extend beyond physical health; (2) families' ability to actuate health definitions is complicated by poverty's impact on agency; (3) parents engage in ongoing problem recognition and identify solutions, but enacting solutions can be derailed by barriers and (4) parents want support from professionals and peers who acknowledged the hard work of parenting. Eliciting parents' multidimensional conceptualizations of health can support families' goal achievement and concern identification in the context of isolation, limited agency and few resources. Efforts to improve family centred care and reduce disparities in paediatric primary care must be responsive to the strengths, challenges, resources and priorities of marginalized families.

KEYWORDS
family centred care, marginalized populations, paediatrics, primary care

1 | BACKGROUND

The American Academy of Pediatrics (AAP) (American Academy of Pediatrics, n.d.; Wallis et al., 2020) and the Institute for Patient- and Family-Centered Care (Institute for Patient- and Family-Centered Care, n.d.) define family centred care (FCC) as respect for parents' knowledge, values and beliefs and clinician–parent collaboration. FCC is especially relevant for young children, whose ability to achieve good health necessarily relies upon their parents' resources (National Academies of Sciences, Engineering, and Medicine, 2016). Despite ongoing efforts, children and families from historically marginalized communities experience less FCC and more health and healthcare-related disparities throughout the life course (Berkman, 2009; Castañeda et al., 2015; Decamp & Davis, 2011; Kline, 2020; National Academies of Sciences, Engineering, and Medicine, 2019; Phelan et al., 2010; Prather et al., 2018; Williams & Mohammed, n.d.). Emerging research shows that parents from marginalized communities report stigma related to parenting (Brodie et al., 2019; Cosgrove &

Flynn, 2005; Keller & McDade, 2000; Koschmann et al., 2021; Lynam & Cowley, 2007; Matthew et al., 2022; O'Donnell et al., 2008; Radecki et al., 2009; Romagnoli & Wall, 2012; Sobo et al., 2006; Yoder & Lopez, 2013), including being treated as incompetent and perceived as unable to properly raise their children by other parents and professionals (Cosgrove & Flynn, 2005). Despite stigma, parents desire partnerships with experts (Keller & McDade, 2000; Koschmann et al., 2021; Radecki et al., 2009; Yoder & Lopez, 2013) to, for example, assess their child's progress and address developmental milestones (Cosgrove & Flynn, 2005; Koschmann et al., 2021). Substantial literature has explored conceptualizations and definitions of health, but little of that research has focused on marginalized communities (Bircher, 2005; Gessert et al., 2015; Leonardi, 2018). Available scholarship suggests that definitions of health vary within and across marginalized groups (Boddington & Raisanen, 2009; Dodgson & Struthers, 2005; Gessert et al., 2015; Song & Kong, 2015). For example, older adults prioritize independence while spirituality is central among some aboriginal groups (Boddington & Raisanen, 2009; Dodgson & Struthers, 2005; Song & Kong, 2015). Future research is needed to better understand the perspectives of marginalized communities and build innovative models of family centred primary care.

We sought to gain insight regarding how parents and caregivers (hereafter: parents) from historically marginalized communities conceptualize and operationalize health and the types of paediatric primary care they would like to receive. Data were collected as part of a larger quality improvement project to co-design a paediatric primary care clinic responsive to the needs of a diverse group of historically marginalized families at Boston Medical Center, a safety net hospital.

2 | METHODS

We present the *inspiration* stage of a human-centred design (HCD) process to design a transformative paediatric primary care clinic at Boston Medical Center. HCD is a multiphase process that proceeds from *inspiration* to defining, ideation, prototyping and testing. The first phase focuses on gaining a deep understanding of families' experiences, motivations and needs (Adam et al., 2020; Termglinchan et al., 2022). HCD is both a research design and an ethnographically rooted methodological orientation (Rose, 2016).

Boston Medical Center's patient population is largely composed of Black, Indigenous and People of Color (70%), who are publicly insured (85%), and live at or below the federal poverty line (50%). Paediatric primary care is provided to approximately 14 000 patients per year by approximately 30 primary care providers. Boston University Medical Campus' Institutional Review Board approved this project.

2.1 | Eligibility and Recruitment

Eligible families included parents who spoke English, Haitian Creole or Spanish and had at least one child under 6 years old. Research assistants (RAs) fluent in each of these languages identified and recruited families at scheduled primary care visits (e.g., well-child visits) and served as interpreters during interviews with Agncy, a consulting organization specializing in HCD. One strength of HCD processes are the focus on persons whose experiences are among the most difficult (Chen et al., 2020). We purposefully identified and recruited families with complex situations, including those related to immigration, poverty and housing insecurity, to create a robust care model able to address the needs of all potential patients and families.

Key messages

- Black, Indigenous, and People of Color (BIPOC) families use multifaceted definitions of health that include social and emotional health, but their ability to act on those definitions is limited by poverty's impact on agency.
- Families engage in ongoing problem recognition and identify solutions, but these solutions can be derailed by barriers, including parents' own health.
- Parents want support and acknowledgement of their hard work parenting from professionals and peers.

2.2 | Interviews

The interview guide was piloted and refined by Agncy following beta testing with a BIPOC parent with two children. Interviews occurred during February and March 2019. Interviews were conducted by Agncy staff with extensive experience in interviewing and HCD; CB has a Master's degree in HCD. Agncy staff and RA interpreters interviewed families where they felt the most comfortable, typically families' homes. RAs fluent in the applicable languages provided in-the-moment translation during the interviews; data were analysed based on those English translations. Interviewers had substantial workplace training and experience with this mode of interviewing and HCD processes and training in trauma-informed interview approaches. Semi-structured interviews queried families' values and life experiences (i.e., household members, typical day); health perspectives (i.e., defining a thriving and healthy family life); supports (i.e., social and instrumental supports) and health care resources (i.e., connection between personal and family health concerns), values and experiences. To enhance trustworthiness and methodological rigour, interviewers invited parents to elaborate or provide additional details to avoid assumptions about parents' responses and maintained neutrality during interviews. Staff also took photographs of family living spaces with permission. Families received a $65 gift card for participating.

2.3 | Analysis

Interviews were audio-recorded and transcribed verbatim. Handwritten field notes were included in the analysis. Staff from Agncy debriefed following each interview, using abductive reasoning to identify themes, areas of agreement and resolve differences in their interpretation of the interview. Agncy staff also periodically presented their findings to the project's Family Advisory Board, which included parents of paediatric patients at Boston Medical Center, for feedback. Some interviewees also volunteered to provide feedback on the findings throughout the analysis process. Due to the sensitive nature of the information that families shared with us, we present limited sociodemographic information to protect families' anonymity and confidentiality. We also use 'they' pronouns for singular parents to reduce the likelihood of identifying parents based on gender/sex.

3 | RESULTS

Fourteen interviews with 15 parents (14 mothers and one father) of 26 children (18 males, eight females, ranging in age from 2 weeks to 14 years old) participated in interviews. Ten parents were immigrants, eight were single parents and 11 resided in Boston, Massachusetts. Five additional parents who were present for interviews but who did not participate identified as fathers. Nine interviews were conducted in English, three in Haitian Creole and two in Spanish; interviews lasted 90–120 minutes. Interviews revealed four themes (see quotes in Table 1).

3.1 | Parents' definitions of 'health' extend beyond physical health

Health was defined by parents as a (1) physical body that works well; (2) spiritual health and relationships with God; (3) mental health, defined by one parent as managed stress; (4) environmental health, including space to live and play and connections with nature and (5) social health and wellness, which focused on strong, supportive and loving interpersonal relationships.

3.2 | Families' ability to actuate health definitions is complicated by poverty's impact on agency

Parents discussed the importance of having *both* choice (options available to them) and agency (ability to make choices), particularly around financial well-being and health-related social needs. Nearly all families experienced barriers (i.e., immigration status, employability) to accessing money. Although social services provided a lifeline for material supports, such as housing and infant formula, programmatic stipulations limited parents' agency to allocate resources as they preferred. For example, one parent reported that their family was homeless because they were unable to shift resources from social programs to pay rent. By contrast, parents reported having more agency regarding food. Food was a key contribution to families' well-being and parents provided food they described as nutritious, culturally relevant or addressing comfort needs.

3.3 | Parents engage in ongoing problem recognition and identify solutions, but barriers can derail enacting solutions

Parents proactively identified health problems, sought solutions and successfully enacted those solutions.

Some challenges were unexpected—such as the need to monitor newborn weight gain following premature birth—while others were anticipated—such as taking professional exams or completing schooling. Parents also actively monitored progress, using observable measures, such as weight gain and how home- and school-based speech services helped children meet age-appropriate developmental milestones.

However, challenges could derail success. Problem recognition was hindered by limited knowledge of age-appropriate milestones and support systems with whom parents could share concerns. Some parents were less likely to spot potential problems because their own challenges (e.g., health) served as barriers. Identifying potential solutions was complicated due to reliance on inexpert sources and limited information gathering and assessment skills. Executing appropriate solutions was challenging due to material and non-material resource needs (i.e., time, money, emotional bandwidth).

3.4 | Parents want support from professionals and peers who acknowledge the hard work of parenting

Parents described isolation related to immigration, language barriers, public transit routes, parental health and limited employment opportunities that hindered the development of relationships with other adults. As a result, parents did not have social supports that validated their parenting efforts or buttressed their efforts to be good parents. It also left parents to celebrate successes alone. When others, including clinicians, celebrated successes with them, parents were grateful, excited and felt safe and cared for.

4 | DISCUSSION

FCC is the foundation for clinician–parent partnership. Our study is one of few providing insight into opportunities to improve FCC for families from historically marginalized communities, highlighting the need to understand each family's context and provide supports that meets people's needs and accounts for their challenges (Browne et al., 2012; Mugerauer, 2021; Sheldrick et al., 2021). One important step is eliciting parents' multidimensional conceptualizations of health; we found that parents' definitions broadly reflect flourishing, a popular concept focusing on social and cultural factors that are central to conceptualizations of well-being (de Ruyter et al., 2020). The diversity of the conceptualizations we found parallels the findings of studies among other marginalized groups (Bircher, 2005; Boddington & Raisanen, 2009; Dodgson & Struthers, 2005; Gessert et al., 2015; Leonardi, 2018; Song & Kong, 2015). These definitions can support

TABLE 1 Explanatory Quotes by Theme.

Themes	Quotes	Implications for Action
Parents' definitions of 'health' extend beyond physical health	No 'broken' parts 'God will provide … knowing God is in control of different things' 'clear mind' 'Without God we're really nothing'. 'If I'm strong and well-rested, I can be more productive'.	Ask parents about how they define health and work with them to design care plans to address those multifaceted definitions.
Families' ability to actuate health definitions is complicated by poverty's impact on agency	'If you have the money, you can buy the food'. 'I have no resources'.	Recognize that parents are doing the best that they can and that they may not be able to allocate resources to help them achieve their goals. Be compassionate and help families to identify potential solutions that are within their reach. Verbally reinforce recognition of parents' efforts so they know clinicians support them.
Parents engage in ongoing problem recognition and identify solutions, but barriers can derail enacting solutions	'Every day I'm always depressed and I'm always thinking about who I used to be, who I am now, and who I can be'.	Acknowledge the barriers that families have to addressing problems. Consider whether and how families can make incremental steps towards addressing problems that may seem less overwhelming than addressing the whole problem at once.
Parents want support from professionals and peers who acknowledge the hard work of parenting	'I wish someone would give me a high 5'. '[The pediatrician's] really good at reassuring you'. 'We're not flying solo at all!'	Partner with families by treating them as people and not only instruments of child health and development. Celebrate the large and small successes. Acknowledge their efforts to accomplish goals, even when those efforts fall short. Don't assume that parents know you support them; speak up and be specific.

families' goal achievement and concern identification in the context of isolation and limited agency and resources. Efforts to provide FCC, outlined in Table 1, will likely reduce parents' experiences of stigma related to their marginalized identities (Brodie et al., 2019; Cosgrove & Flynn, 2005; Keller & McDade, 2000; Koschmann et al., 2021; Lynam & Cowley, 2007; Matthew et al., 2022; O'Donnell et al., 2008; Radecki et al., 2009; Romagnoli & Wall, 2012; Sobo et al., 2006; Yoder & Lopez, 2013).

Social (e.g., parenting validation) and instrumental (e.g., babysitting) support needs were specifically discussed by parents. Validating the work of parenting, celebrating successes and co-developing strategies to address concerns fosters clinician partnerships by centring parents' knowledge of and interest in raising healthy and well children (National Academies of Sciences, Engineering, and Medicine, 2016). Partnering to address instrumental supports, such as connecting parents to housing, food and other resources, positions the clinical team to support families' health and well-being goals. One potential benefit is that instrumental support may engender greater trust and stronger partnership between parents and providers (Hardeman et al., 2016; Smith et al., 2009; Trent et al., 2019). Our sample included mostly mothers; future research should purposefully engage fathers from marginalized communities to identify opportunities for clinicians to partner with fathers and provide FCC.

This study must be understood within the context of its limitations. Our sample of families is small, geographically limited and selected from families already engaged in paediatric primary care at a single institution. Therefore, our findings may not be representative of families outside of Boston, Massachusetts, or with other sources of paediatric primary care. Our team's capacity only allowed the inclusion of English, Spanish and Haitian Creole speakers, which are the most common languages spoken by Boston Medical Center patients. However, this limitation may bias our findings against marginalized populations who speak other languages. Additionally, five interviews were conducted with families whose preferred language was not English via multilingual RAs, which may have resulted in misinterpretations or reductions in the nuances of parent experiences (van Nes et al., 2010). We carefully reviewed our thematic findings and found no evidence of misinterpretation or reduced nuance among interviews using translators. Despite these limitations, our findings align with the National Academies of Medicine reports (National Academies of Sciences, Engineering, and Medicine, 2016; National Academies of Sciences, Engineering, and Medicine, 2020; National Academies of Sciences, Engineering, and Medicine, 2021) and provide deep insight into how paediatric primary care can support marginalized families.

Efforts to improve FCC and reduce health and healthcare disparities in paediatric primary care must acknowledge and be responsive to the strengths, challenges, resources and priorities of historically marginalized families. Our interviews reveal the extensive work done by parents to support their families' health despite limited resources. Future research should focus on larger-scale quantitative data collection to support the design of innovative primary care models and promote FCC for marginalized families. Primary care should work to partner with parents from marginalized communities to provide the supports that families need to succeed.

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CONFLICT OF INTEREST STATEMENT

Anita Morris reported that she is a member of an executive committee for which she receives remuneration. Other authors report no conflicts of interest.

DATA AVAILABILITY STATEMENT

Research data are not shared due to the small size of our sample and the sensitive nature of our data.

ETHICS STATEMENT

Boston University Medical Campus' IRB approved the use of this data.

PATIENT CONSENT

Patient consent was not elicited at the time of interviews because this project focused on quality improvement. The IRB approved our use of de-identified quality improvement data for this study.

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