



PHOTO: KAREN KASMAUSKI/MCSP

■ Brief

IMPROVING METRICS AND METHODS FOR ASSESSING EXPERIENCE OF CARE AMONG CHILDREN AND CAREGIVERS IN LOW- AND MIDDLE-INCOME COUNTRIES: AN OVERVIEW

BACKGROUND

Preventable under-five mortality remains high in many contexts, despite progress over the last decades in reducing under-five mortality rates. The *Lancet's Global Health Commission on High-Quality Health Systems* has found that quality of care is a bigger contributor to mortality than access to care. An important but often overlooked aspect of quality of care is experience of care. In 2018, the World Health Organization (WHO) released *Standards for Improving the Quality of Care for Children and Young Adolescents in Health Facilities*, which includes “experience of care” alongside “provision of care” as equally important dimensions for improving quality of care and health outcomes.

Children, their caregivers, and families can have positive or negative experiences while receiving health services—it is important to consider their various perspectives when assessing and improving overall quality of services.

A positive experience of care encompasses provider-client interactions that are respectful, dignified, and patient-centered, along with external and health system factors that provide supportive conditions, such as the availability of clean equipment at health facilities. Work to date on improving the experience of care in health facilities has focused on respect and dignity within maternity services. In the context of pediatrics, person-centered care overlaps greatly with family-centered care.

Research is lacking around the frameworks and measures to assess experience of care among children, their caregivers, and families and their positive or negative aspects in low- and middle-income countries (LMICs). Measuring user satisfaction is not enough. In health facilities in many LMICs, people’s expectations of health care may differ depending on whether resources are limited or adequate. Moreover, differing cultural and socioeconomic contexts, as well as power dynamics between health providers and the children and families receiving care, can affect perceptions and therefore need to be considered when conceptualizing and measuring experience of care. It appears that no review of pediatric experience of care concepts and measurement in LMICs has been undertaken.

Recognizing these gaps, we undertook a scoping review to examine the frameworks and guidance around quality of care and respectful care, along with the metrics and tools that have been used to measure experience of care. Based on the review’s findings, in-depth discussions, and consultations with experts, we developed a comprehensive conceptual framework to provide shared language on pediatric experience of care and to inform future discussions and activities related to measuring it. Developing better measures of pediatric experience of care can help governments, managers, health providers, and other stakeholders assess the situation in a country or facility and identify areas for improvement; these measures also can help policymakers and planners monitor progress over time.

The specific objectives of this review were to:

- Identify existing frameworks for quality of care and respectful care and assess their relevance to pediatric health and experience of care.
- Apply the WHO standards and suggest additional domains and subdomains to define pediatric experience of care among young children (ages 0 to 59 months) in LMICs.
- Develop a pediatric experience of care framework using these domains and subdomains.
- Identify existing methods and metrics for assessing experience of pediatric care, including potential opportunities for future tool development and adaptation in ongoing research efforts.
- Identify evidence gaps and areas for future research.

METHODS

We undertook a scoping review of existing frameworks and guidance documents, tools, and metrics to understand aspects of pediatric experience of care in health facilities and explore current measurement methods. The focus was on facility-level care for children under five years of age in LMICs; however, due to the limited material available from LMICs, resources from other areas that could provide insight on potential domains or measurement were included. The scoping review was an exploratory step toward understanding existing knowledge and material on pediatric experience of care. We reviewed published and gray literature from various sources, which we identified through PubMed searches, expert knowledge and recommendations, and hand searches.

Results from the scoping review were categorized based on whether they related to (1) “frameworks,” (2) “tools or metrics,” or (3) both; we then mapped and cataloged them by domain and data collection type. To develop the

conceptual framework, we used an iterative process using results from the scoping review, internal discussions, five individual interviews, and feedback from 20 experts from USAID, MOMENTUM, and other partners with relevant experience. We solicited written feedback from participants through consultations and interviews and gathered additional information from experts recommended by our initial set of participants. In addition to developing a better understanding of drivers and consequences of positive and negative experiences of care, we created a model patient pathway showing illustrative interpersonal and health systems factors influencing experience of care and a proposed pediatric experience of care framework with domains and subdomains that can broaden our understanding.

FINDINGS

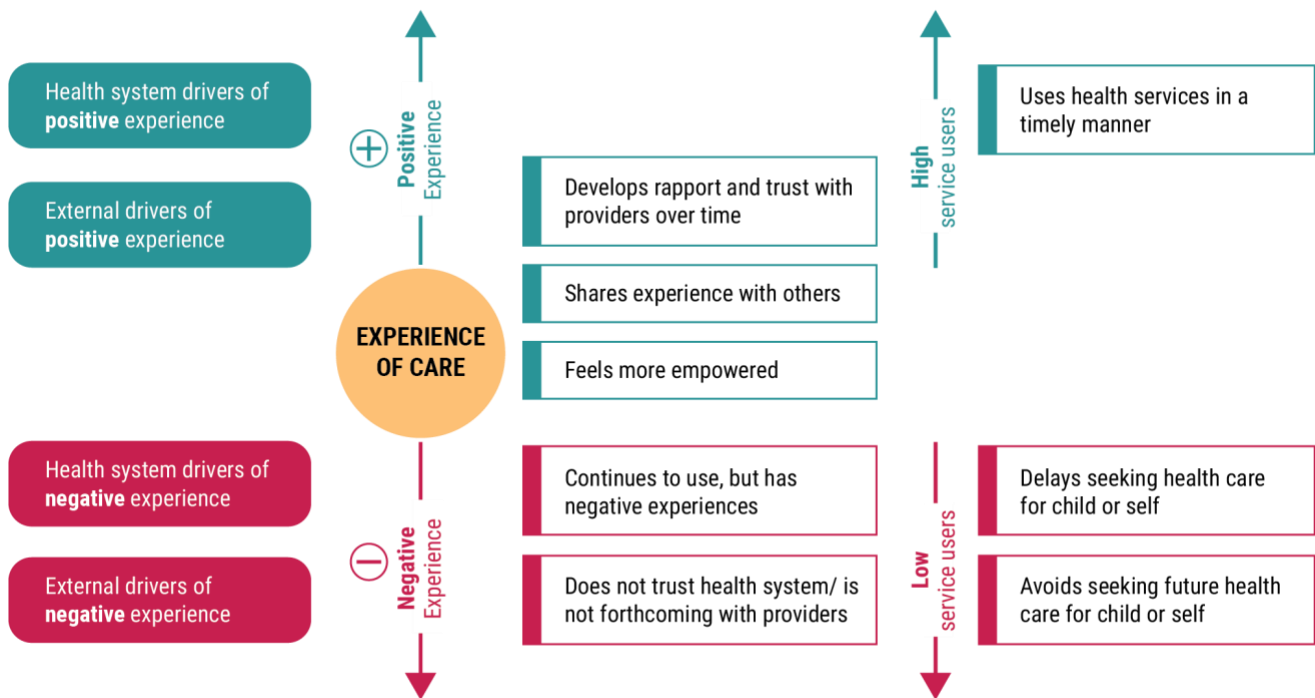
Frameworks

Several frameworks relevant to pediatric experience of care focus on rights and quality. The WHO's [*Standards for Improving the Quality of Care for Children and Young Adolescents in Health Facilities*](#) is the most comprehensive global framework for pediatric experience of care. Many sources and reports, such as the United Nations' [*Convention on the Rights of the Child*](#) and the White Ribbon Alliance's [*Respectful Maternity Care: The Universal Rights of Women and Newborns charter*](#), also highlight the importance of the rights of the patient and their families and caregivers. These rights include the mother, family, and child's right to not be discriminated against and the child's right to safety and a national identity. The frameworks also include obligations of the government to prioritize the best interests of the child, keep families together, and respect parents' decisions regarding their children's medical care.

Quality of care frameworks consistently emphasize that competent, motivated, and empathetic human resources are essential for high-quality provision and experience of care. The role of health providers in experience of care is paramount. To successfully perform their jobs, health providers require recognition and respect from supervisors and patients; fair and on-time compensation; the necessary tools, equipment, supplies, staffing, and resources; and adequate support and training. Health providers also have rights and should be assured of their safety in the workplace.

We developed a conceptual framework to understand (1) the underlying factors (or drivers) that can affect experience of care and (2) the potential consequences of positive or negative experiences of children and their families while receiving health services (see Figure 1). Some factors are internal to the health system, while others are external (contextual). Internal health system factors influencing experience of care include the patient-provider relationship, the quality of physical infrastructure, the amount of user fees, the level of provider training and competence, and the availability and quality of equipment and supplies. External factors include community and sociocultural norms and structures, the level of female autonomy and empowerment, the patient's economic status and limitations, accessibility for ethnic or linguistic minorities, and the influence of family members. Some factors may overlap between health system and context, such as the normalization of inferior quality, poor patient-provider interactions in health facilities, or lack of accountability.

FIGURE 1. POTENTIAL DRIVERS AND CONSEQUENCES OF EXPERIENCE OF CARE FOR CHILDREN AND FAMILIES

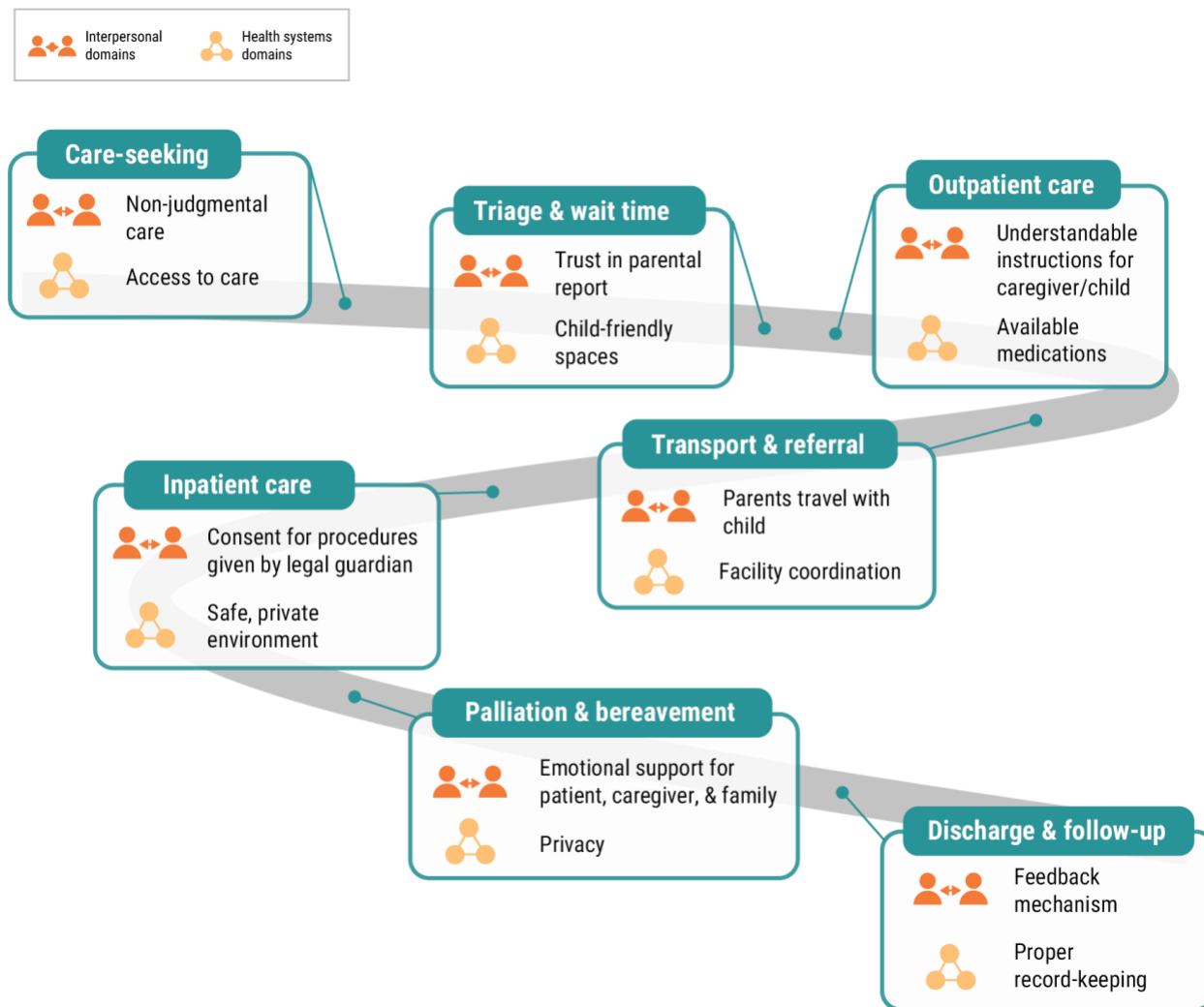


Consequences of positive experiences of care may include patients’ higher sense of dignity, assurance that their rights will be upheld, strong trust and rapport with their providers, and timely use of health services—which all may ultimately contribute to positive health outcomes. Consequences of negative experiences of care may include a loss of trust in the health system and health providers and the decision to avoid or delay accessing essential health services in the future. The consequences (positive or negative) may also spill over into the communities where the families reside.

We also considered interpersonal and health system factors that affect a patient’s experiences throughout their pathway of care at a health facility (see Figure 2). We accounted for these factors in our proposed Pediatric Experience of Care Framework (see Figure 3).



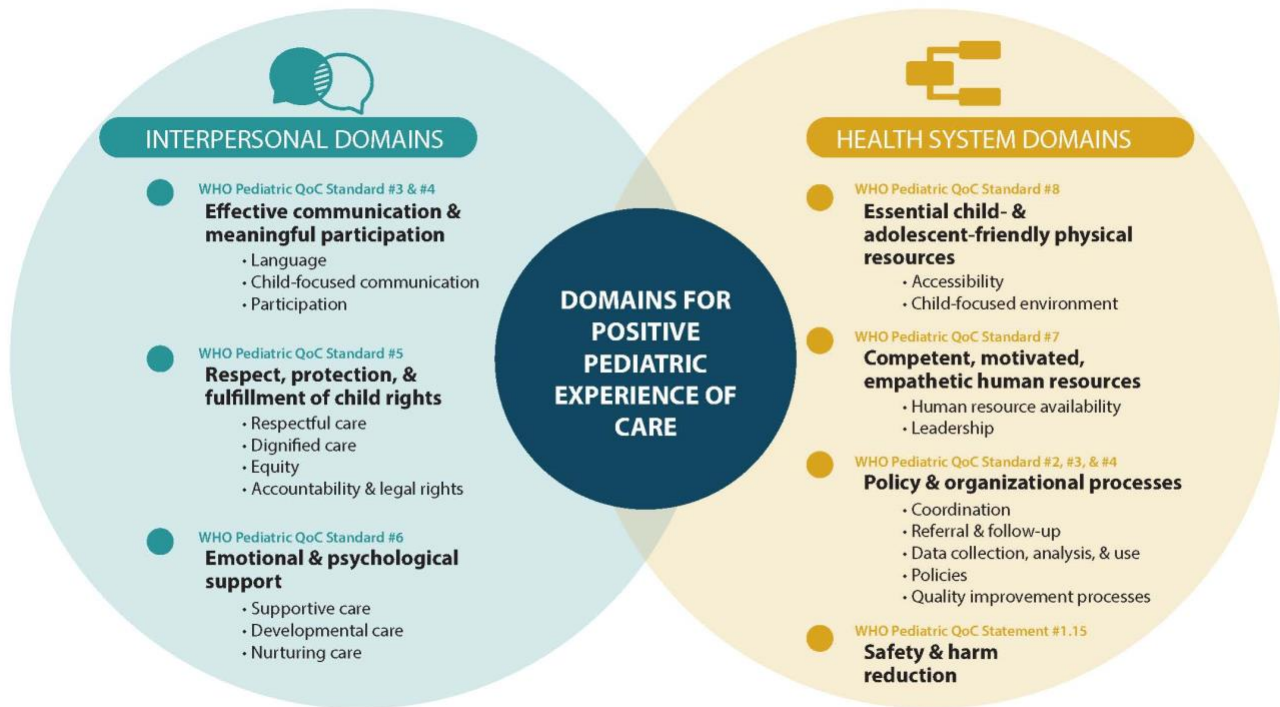
FIGURE 2. INTERPERSONAL AND HEALTH SYSTEM FACTORS THAT AFFECT EXPERIENCE OF CARE ON THE PATIENT PATHWAY



Pediatric Experience of Care Framework

Based on the [WHO’s Framework for Improving the Quality of Pediatric Care](#)—part of its standards document—our proposed framework includes the interpersonal domains related to effective communication and participation; respect, protection, and fulfillment of child rights; emotional and psychosocial support; and the health system domains related to physical and human resources. Our proposed domain of policy and organizational processes draws on WHO standards #2 (health information system), #3 (referral and continuity of care), and #4 (communication). Our proposed framework does not address the quality of clinical provision of care other than safety and harm reduction (WHO standard #1, statement 1.15), which we identified as important factors in children’s and their families’ experience of care in many human rights and respectful care frameworks. Through our review of pediatric experience of care frameworks, key informant interviews, and consultations with experts, we further explored concepts important for a positive pediatric experience of care and respectful care, such as 1) human and child rights principles, 2) national and facility policies to support a positive pediatric experience of care, and 3) the health care provider role in experience of care.

FIGURE 3. PROPOSED PEDIATRIC EXPERIENCE OF CARE FRAMEWORK



Our framework identifies two overarching categories that together comprise the primary aspects of a positive pediatric experience of care: interpersonal domains and health system domains. Positive experience of care involves ensuring effective, transparent, confidential, and inclusive communication between health providers and children and their families; engaging relevant caregivers in decisionmaking; and requesting consent in a language and level that is comfortable for the patients and their caregivers. Child-focused communication appropriate for the child’s age and development stage is vital, and providers should strive to engage and reassure children and to work in partnership with families to create a safe and comfortable environment. Children and their families or caregivers will likely feel respected and treated with dignity if interactions are private; confidential; and free from prejudice, humiliation, and blame; and if the adults who consent for their care have information and autonomy. All children deserve to have protection from physical and emotional mistreatment and harm while receiving health services; a caregiver present during their health care visit; and supportive, nurturing care, regardless of their age, health status, or demographic group. These rights should be enforced; they should be explained to and understood by patients and an accountability mechanism should be in place to address violations. Enabling environments and emotional and psychological support are critical, as are options for family involvement that will promote comfort and reduce pain. In patient rooms or specialized wards, developmental care and stimulation should be available according to a child’s age, recognizing its importance alongside and as a part of clinical care.

Addressing health system domains that can greatly influence experience of care—on their own or by interacting through the interpersonal domains—is equally important. Health facilities’ infrastructure and resources should be accessible to all children and their families. Clinical environments and sanitation facilities should be well-maintained and designed for safe and easy use by children and caregivers. Environments for children should be welcoming and calming and play areas should be safe and include stimulating colors and lights. Facilities should be as inclusive as possible to accommodate the care of children and families with various types of physical, congenital, and developmental disabilities. Available and adequate stocks of child-formulated medicine, as well as pediatric equipment, are necessary.

Health workers play a critical role in health systems, and facilities must have sufficient staff to provide high-quality and respectful care. But, in order to be motivated and competent and deliver on the interpersonal domains important for positive experiences, health care providers require fair and timely compensation, opportunities to update their skills and knowledge, emotional and psychosocial support, and recognition and respect from supervisors. To deliver positive care and support, providers need strong leadership and governance along with infrastructure, policies, and organizational processes that meet children's and families' needs.

Supportive policies and processes are necessary for health providers and facilities to perform well for children and their families. Effective coordination and continuity of care require facility- and district-level policies and processes within and between facilities, inclusive of referrals. Data collection, analysis, use, and sharing are essential for continuity of care and quality improvement. Processes to collect anonymous service users' feedback on their experiences and to use the information to improve performance are vital to ensure the accountability of health care providers and the facility. Policies and processes that facilitate the provision of positive experiences by health providers may include paid opportunities for professional development and skill updates; emotional support to avoid burnout; and protections against abuse by patients, other staff, and supervisors. Facilities should have teams (comprised of both staff and community members) that focus on improving quality and plans to continually address challenges and improve prioritized aspects of quality of care. Within the subdomain of safety and harm reduction, facilities should work to reduce and avoid unnecessary procedures and should follow best practices for infection control among patients and providers. Everyone in the health facility should be safe from physical, verbal, and sexual abuse.

Measurements and Metrics

We identified existing tools in various stages of development (drafted, pretested, validated) that specifically capture pediatric experience of care, as well as other tools that produce potentially relevant information. A wide range of tools measure various aspects of experience of care, but no single tool or metric currently encompasses every aspect defined in our proposed framework. Few tools focus on routine, well-child, or outpatient child health care; instead, many are designed for chronically ill children. Most tools measure pediatric experience of care by soliciting feedback from caregivers (usually mothers), and only a few employ direct observations of children or age-appropriate questions targeted at children. Very few even approach experience from the child's point of view, regardless of who the respondent is. We found no tools designed for use within routine health information systems (although fewer of these types of tools are published at the global level), and most of the identified tools require intensive research with independent, external observers or interviewers for implementation. Many of the tools' indicators included in the interpersonal domain focus on emotions, such as feelings of friendliness or kindness, and overall satisfaction levels; only some tools focus on the specific interpersonal and communication needs of the child and their family. Few indicators or items cover details about consent, children's rights, or accountability and legal rights. Measures of respectful care most often focus on the caregiver experience, with few measures on respecting the child (although there is not one definition for this).

DISCUSSION

Our proposed experience of care framework draws extensively on the WHO's pediatric framework and includes interpersonal and health systems domains that influence each other and can contribute to the overall experiences of children, their caregivers, and families at the facility. For instance, limited resources (a health systems factor) will affect staffing, which may influence provider stress (an interpersonal factor) and result in more negative interactions. The provision of higher-level quality of care will require improvements in both direct interpersonal factors and indirect health systems factors. In the longer term, we must strengthen health systems and address interpersonal factors throughout a pediatric patient's experience of care, including by improving the environment for health care

providers, establishing standards for quality and experience of care, and recognizing the rights, views, and participation of children, their caregivers, and families.

There is an urgent need for more reliable and valid tools to measure pediatric experience of care. Improving measurement of pediatric experience of care is essential for researchers, policymakers, and program managers to understand baseline conditions, track progress, and assess the effectiveness of interventions through rigorous studies. Methods and metrics that assess experience of care should be tailored to children's ages; they should also incorporate both interpersonal and health system factors contributing to patients' and families' experiences when seeking care. Refining methods and metrics will help researchers and program implementers understand the effects of experiences at facilities on care-seeking, future care utilization, and health outcomes, including child development.

None of the tools and metrics for measuring domains related to pediatric experience of care addresses all the aspects identified through our review. Existing tools focus on the caregiver/maternal experience, especially for newborns and chronically ill children, with fewer metrics for outpatient pediatric services or interactions between the provider and child. The domains included in our proposed framework are a starting point for the development of more comprehensive tools to measure pediatric experience of care constructs across different contexts, age groups, and service types. Including experience of care measures in large facility assessments will be essential for identifying gaps in service quality and for establishing quality improvement plans that do not only address clinical outcomes. The [Service Provision Assessment \(SPA\)](#) modules were updated in 2022 to better measure quality of care; the client exit interview guide now includes questions related to a number of domains and subdomains focused on experience of care during sick child services. Implementation of the revised SPA in countries will provide valuable information about the feasibility of collecting this sort of data and on the prevalence of aspects of experiences of care during sick child visits.

Researchers and evaluators face unique challenges in measuring pediatric experience of care comprehensively because of the difficulty in eliciting and understanding responses from infants and young children. The care of young children often involves several family members or caregivers in addition to the primary caregiver or biological mother. Any family members involved in health care for the child will have their own experiences that may or may not be similar to those of other family members or to that of the children. Furthermore, any experience is inherently subjective and therefore difficult to measure. The way a person experiences any event is predicated on their specific expectations and norms, and their perceptions and recall can change over time—all of which can also differ across contexts. Families may be unaware of their rights or the health care standards and may not know if or when there will be opportunities to give input, offer feedback, or lodge a formal complaint. Multiple parents or adult caregivers may disagree or have unequal decisionmaking power in pediatric health. Caregivers are often female (mothers, grandmothers, and older sisters), compounding issues of women's empowerment within their households, within the health system, among the hierarchy of health care providers, and within society. All these complexities merit further research.

RECOMMENDATIONS

DISSEMINATE, ADAPT, AND REVISE PEDIATRIC EXPERIENCE OF CARE CONCEPTS AND CONSTRUCTS IN LMICS.

Global, regional, and country stakeholders should elevate the notion that measuring pediatric experience of care is an important aspect of assuring high-quality services and responsive primary health care and should advocate for it. The WHO's quality standards related to pediatric experience of care and our proposed framework require further dissemination; adaptations or revisions of the domains and subdomains in differing LMIC contexts may be necessary.

UNDERTAKE FORMATIVE AND QUALITATIVE RESEARCH. More formative and qualitative research is needed to understand children's, caretakers', and families' expectations and experience of care in different clinical and cultural

contexts. Qualitative research can start to address some of the measurement challenges, which can also enhance the conceptualization of experience of care.

DEVELOP, REFINE, VALIDATE, AND USE TOOLS TO MEASURE PEDIATRIC EXPERIENCE OF CARE IN LMICS. Framework domains and subdomains should be translated into survey items to measure specific experience of care indicators and latent constructs. Cognitive testing in different contexts can ensure that the concepts and questions are appropriate and understood by caretakers, families, and children (where applicable) and psychometric analyses of survey items included in larger-scale data collection activities can reduce the number of survey items and identify items related to specific latent constructs. Tools and survey items may require adaptations for the types and levels of pediatric care and the age of child. Application of selected survey items or a more comprehensive series of items in large-scale surveys will be necessary to determine the prevalence of aspects of positive and negative pediatric experiences of care.

USE RESEARCH TO EXAMINE THE COMPLEX ASSOCIATIONS OF INTERPERSONAL AND HEALTH SYSTEMS DOMAINS PERTINENT TO PEDIATRIC EXPERIENCE OF CARE. The complex relationships between interpersonal and health systems domains that are important for pediatric experience of care require further research. There is a great need to complement pediatric experience of care metrics and methods from the children’s and families’ perspectives with tools and methods that examine the needs and experiences of health care providers.


CONSIDER PEDIATRIC EXPERIENCE OF CARE METRICS AND DATA COLLECTION METHODS THAT CAN BE INTEGRATED INTO ROUTINE, LOCAL HEALTH INFORMATION SYSTEMS. To improve experience of care at the facility and local levels, local program managers will need data to identify issues and monitor progress. As the conceptualization and measurement of pediatric experience of care in LMICs progresses, researchers, evaluators, and program managers should identify opportunities to integrate and test metrics and methods within existing health information systems.

CONCLUSIONS


Positive experience of care must be complementary to—not separate from or a lower priority than—clinical quality of care. Even with positive clinical outcomes, children and their caregivers and families can have negative experiences that, in turn, have negative impacts on their health, trust in the health system, and future health care use.


It is vital and urgent that we develop valid and feasible pediatric experience of care metrics and tools. The interpersonal and health systems domains and subdomains in our proposed framework represent a starting point. A robust health system—one that provides high quality of care—fully addresses the needs of health care providers, patients, families, and communities and includes sufficient training, infrastructure, equipment, professionalism, accountability, and leadership. Improving the measurement of pediatric experience of care is essential for understanding baseline conditions, tracking progress, and assessing the effectiveness of interventions.

MOMENTUM Knowledge Accelerator is funded by the U.S. Agency for International Development (USAID) as part of the MOMENTUM suite of awards and implemented Population Reference Bureau (PRB) with partners JSI Research and Training Institute, Inc. and Ariadne Labs under USAID cooperative agreement #7200AA20CA00003. For more about MOMENTUM, visit www.usaidmomentum.org. The contents of this brief are the sole responsibility of PRB and do not necessarily reflect the views of USAID or the United States Government.

 @USAID_MOMENTUM

 @USAIDMOMENTUM

 USAID MOMENTUM

 USAID MOMENTUM