



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

MOMENTUM Knowledge Accelerator



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ABBREVIATIONS

EN-BIRTH	Every Newborn – Birth Indicators Research Tracking in Hospitals
GS-PEQ	Generic Short Patient Experiences Questionnaire
HHFA	Harmonized Health Facility Assessment
IMCI	Integrated Management of Childhood Illness
JSI	JSI Research and Training Institute, Inc
LMIC	Low- and middle-income country
PRB	Population Reference Bureau
PREM	Patient-reported experience measure
QoC	Quality of care
SARA	Service Availability and Readiness Assessment
SPA	Service Provision Assessment
UNICEF	United Nations Children’s Fund
USAID	United States Agency for International Development
WHO	World Health Organization

EXECUTIVE SUMMARY

Background

Preventable under-five mortality remains high in many contexts, despite progress over the last decades in reducing under-five deaths and 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—and 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 and external and health system factors that provide supportive conditions, such as the availability of clean equipment at health facilities.

Research is lacking, however, around the frameworks and measures to assess experience of care among children, their caregivers, and families and aspects that may be positive or negative in low- and middle-income countries (LMICs). Recognizing these gaps, we undertook this 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. 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 through a scoping review.
- Apply the WHO standards and suggest additional domains and subdomains for defining 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 also examined. The scoping review was designed to be 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; and then were mapped and cataloged 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 feedback in writing from consultation and interview participants as well as other relevant expert informants recommended by the participants. In addition to developing a conceptual framework to better understand drivers and consequences of positive and negative experiences of care, we created a model patient pathway that shows some illustrative interpersonal and health systems factors that influence experience of care and a proposed framework for pediatric experience of care with domains and subdomains that can broaden our understanding.

Findings

FRAMEWORKS

A number of 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. But to successfully perform their jobs, they 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.

From the scoping review, interviews, and consultations, 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 children and their families having positive or negative experiences while receiving health services.

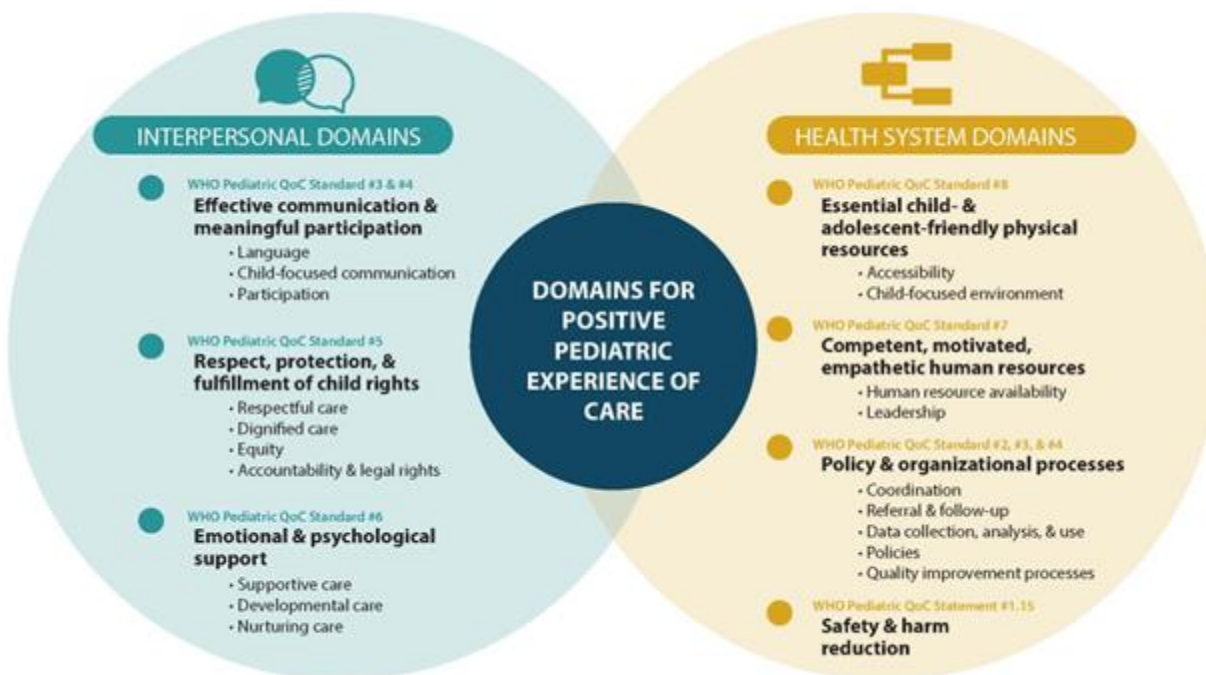
PEDIATRIC EXPERIENCE OF CARE FRAMEWORK

We developed a positive, holistic framework for optimal pediatric experience of care; the framework also identifies violations and abusive care to eliminate those occurrences. We started with many of the domains from WHO’s [*Framework for Improving the Quality of Pediatric Care*](#), including the experience of care domains related to effective communication and participation, respect, protection and fulfillment of child rights and 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). Through the review of pediatric experience of care frameworks, key informant interviews, and the consultation, 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.

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 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, 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 ensure comfort and reduce pain.

PROPOSED PEDIATRIC EXPERIENCE OF CARE FRAMEWORK



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. Available and adequate stocks of child-formulated medicine, as well as pediatric equipment, are necessary. Health workers are a critical component

of health systems, and facilities must have sufficient, competent, and motivated staff who are fairly compensated, respected, given opportunities to update their skills, and supported by strong leadership and governance in order to provide high quality and respectful care. 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, especially those related to referrals of children. Data collection, analysis, use, and sharing of information among and between care teams is essential for continuity of care for children and quality improvement, as is making performance statistics about the facility available to the community. Policies and processes facilitating the provision of positive experiences may include professional development and skill updates, emotional support to avoid burnout, and protections against abuse by patients, other staff, and supervisors for providers as well as quality improvement processes that can continually address challenges. Within the subdomain of safety and harm reduction, facilities should work to reduce and avoid unnecessary procedures and harm and should follow best practices for infection control for patients and providers.

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 parents (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. 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, with few measures on respecting the child (although there is not one definition for this).

Discussion and Recommendations

Our proposed experience of care framework draws extensively on the WHO's pediatric framework and includes both interpersonal and health systems domains, which 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 stress (an interpersonal factor) and result in more negative interactions.

There are existing tools and metrics for measuring domains related to pediatric experience of care; however, there are currently none that also address the additional aspects of pediatric experience of care identified through our review. The domains included in our proposed framework represent a starting point for developing 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, such as the updated [Service Provision Assessment](#) (SPA), will be essential for identifying gaps in service

quality and for establishing quality improvement plans that do not only address clinical outcomes. Improving measurement of pediatric experience of care is essential for researchers, policymakers, and program managers to understand baseline conditions, track progress of improvement efforts, and assess the effectiveness of interventions through rigorous assessments. Based on our review, we recommend the following:

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. Experience is inherently subjective and related to these expectations; therefore, it is difficult to measure. 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 themselves. 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.

THROUGH ADDITIONAL RESEARCH, 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. Health care providers are at the forefront of interpersonal domains but are also greatly influenced by health systems factors; however, the causal mechanisms vary across contexts and require further examination across contexts. 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.

Conclusion

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, and ultimately increasing the overall quality of pediatric care.

INTRODUCTION

Background

Over the last few decades, efforts to reduce child mortality globally have made significant progress.¹ Historically, efforts to reduce child mortality have focused on improving families' access to and use of high-impact interventions, such as increasing immunization coverage, access to safe water, and access to essential clinical and preventative care, as well as improving nutrition practices and outcomes.² These interventions have achieved substantial progress globally in recent decades, contributing to a decline from 12.6 million under-five deaths in 1990 to five million in 2020.³ Estimates suggest that about 60 percent of the global decline in mortality among children under the age of five since 1990 is due to the treatment and prevention of infectious diseases.¹ However, even with these achievements, many countries fell short of Millennium Development Goals, which aimed to reduce child mortality by two-thirds by 2015, and morbidity and mortality remain significant in this age group.⁴ In 2020, the mortality rate was 38 deaths of children under five per 1,000 live births and most were from preventable and treatable causes¹; considerably higher deaths occurred in low- and middle-income countries (LMICs).^{1,3}

As part of the global response to this important issue, the United Nations set a goal to end preventable deaths of newborns and children under the age of five by 2030 as part of the United Nations' Sustainable Development Goals.⁵ According to the 2021 report by the United Nations Inter-agency Group for Child Mortality Estimation,¹ 54 countries will most likely not meet the under-five mortality target of 25 or less child deaths per 1000 live births by 2030, and more than 60 countries will not meet the neonatal mortality target of less than 12 neonatal deaths per 1000 live births without immediate action. Reducing child mortality, particularly in LMICs, will require expanding access to essential interventions, providing high-quality care, and offering strong primary care services.^{1,5} One area that has been shown to have a significant effect on child health outcomes globally is the quality of patient care, including the experience of care that a patient receives and expects to receive across the health care continuum.⁶

Quality of Care

Quality of care (QoC) occurs across and throughout the phases of the patient's care experience and is a concept comprised of multiple components. The World Health Organization (WHO) broadly defines QoC as "...the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with evidence-based professional knowledge."⁷ QoC not only affects an individual's outcomes and experiences, it also impacts population health outcomes, especially where the costs required to access health care may be high, resources are more limited, and quality is an important factor in seeking care.⁶

About 5.7 to 8.4 million deaths per year occur due to substandard care in LMICs; poor-quality care contributes to up to 15 percent of deaths in adults and children.⁷ A large proportion of preventable maternal, childhood, and neonatal deaths occurs in areas where high-quality, essential health services are difficult to access.⁸ Substandard health services not only have a direct effect on individual health outcomes but also may deter people from seeking primary care, immunizations, maternity care, care for sick children, and other essential health services.⁹ When seeking health care, people may bypass closer health services they perceive

to be poor quality, potentially incurring higher costs and increasing travel time.⁷ They may turn to expensive or unregulated private sector services, experience delays in receiving care, or avoid seeking care completely.¹⁰ In each case, children and families may miss opportunities to receive essential and often lifesaving preventative and curative care. Poor QoC also results in significant costs in lost productivity and increases both morbidity and mortality.¹¹ The United Nations Children’s Fund (UNICEF) found that most maternal and child deaths worldwide could be averted with better quality health care.¹²

Quality of Care Concepts and Measurement

Much of the work to define and measure QoC has been developed as part of a health systems approach. Over 20 years ago, the WHO devised a strategy on measurement of health systems responsiveness that aimed to define and measure aspects of QoC as an important aspect of health system effectiveness and performance.¹³ Under this strategy, the WHO defined health systems responsiveness as the experiences of health service users in seven areas: dignity, autonomy, confidentiality, prompt attention, quality of amenities, and access to social support networks.¹³ This approach laid the groundwork for understanding aspects of QoC measured through the **experiences** of health service users.

In 2006, in a report highlighting QoC as part of the process for making choices in health systems strengthening, the WHO also integrated the concept of experience of care in the six characteristics they established as defining QoC (Box 1).¹⁴ These characteristics aim to capture a holistic picture of QoC by including aspects of clinical QoC (effective and safe), the health care system (efficient), and the population’s ability to access and receive that care (accessible and equitable). Importantly, they include **experience of care** (acceptable/ patient-centered) as an essential component of the quality of health care.

BOX 1. WHO SIX CHARACTERISTICS OF QUALITY OF CARE

1. **Effective:** Health care that is adherent to an evidence base and results in improved health outcomes for individuals and communities, based on need.
2. **Efficient:** Health care in a manner which maximizes resource use and avoids waste.
3. **Accessible:** Health care that is timely, geographically reasonable, and provided in a setting where skills and resources are appropriate to medical need.
4. **Acceptable/patient-centered:** Health care that takes into account the preferences and aspirations of individual service users and the cultures of their communities.
5. **Equitable:** Health care which does not vary in quality because of personal characteristics such as gender, race, ethnicity, geographical location, or socioeconomic status.
6. **Safe:** Health care that minimizes risks and harm to service users.

In 2018, the Lancet Global Health Commission of High-Quality Health Systems called for a “Quality Revolution,” noting that measuring individual aspects of quality was insufficient to assess overall quality.¹⁵ The Commission noted that while attention has been paid to certain elements of services, such as service coverage and affordability, elements of quality, access to quality services, and robust data systems for quality measurement were largely missing.¹⁵ The Commission recommended a paradigm shift away from considering coverage targets alone toward a deeper understanding of the needs of patients. This paradigm shift would put patients’ experience of care on equal footing with clinical care by addressing structural inequities; harmonizing the actions of governments, donors, and health care users; and committing to data collection and utilization.⁶

Box 2 highlights the definitions of concepts used in this review. The concept of “*experience of care*” can be defined as “...the sum of interactions, shaped by multiple factors, that is experienced by the patients and their families across the continuum of care.”¹⁶ Studies have linked perceived QoC and patient experiences of care to health care service utilization, health outcomes, and intended or actual health behaviors.¹⁷

Patient- or family-centered care is key to improving a pediatric patient’s and their family’s experience throughout the care continuum. ***Patient-centered care*** is care that is respectful of and responsive to individual client preferences, needs, and values, with the individual values of the client guiding all clinical decisions.¹⁸ ***Family-centered care*** is generally considered a partnership approach in which the family and health care provider work together to make health care decisions.¹⁹ This approach places the patient and their family at the center of care and makes them equal partners with providers in planning and decision-making about health care.²⁰ Family-centered care is respectful, maintaining the dignity, privacy, and confidentiality of all involved. Further, families should be able to make care decisions in an informed manner, without inducement or coercion and free from stigma, discrimination, mistreatment, and harm.^{20,21} The MOMENTUM Knowledge Accelerator team developed a working definition of ***respectful care***, stating that “Care is respectful if it maintains all individuals’ dignity, privacy, and confidentiality; ensures that interactions with individuals or carers enhance informed decision-making, without inducement or coercion; promotes continuous support (as appropriate); is compassionate and responsive to their preferences, needs, and values; and is free from stigma, discrimination, mistreatment, and harm.”²¹ Figure 1 illustrates the overlap of these important constructs within positive experience of care.

BOX 2. DEFINITIONS OF CONCEPTS USED IN THIS REVIEW

Experience of care: “...the sum of interactions, shaped by multiple factors, that is experienced by the patients and their families across the continuum of care.”¹⁶ This experience, positive or negative, includes interpersonal care factors, such as respectful and dignified interactions with health providers, and external factors, such as cleanliness and the availability of equipment at health facilities.

Patient-centered care: Care that is respectful of and responsive to individual client preferences, needs, and values, with the individual values of the client guiding all clinical decisions.¹⁸

Family-centered care: A partnership approach in which the family and health care provider work together to make health care decisions,¹⁹ placing the patient and their family at the center of care and making them equal partners with providers in planning and decision-making about health care.²⁰

Respectful care: “Care is respectful if it maintains all individuals’ dignity, privacy, and confidentiality; ensures that interactions with individuals or carers enhance informed decision-making, without inducement or coercion; promotes continuous support (as appropriate); is compassionate and responsive to their preferences, needs, and values; and is free from stigma, discrimination, mistreatment, and harm.”²¹

FIGURE 1: POSITIVE EXPERIENCE OF CARE OVERLAPPING CONSTRUCTS



Experience of Care in Maternal, Newborn, and Child Health

Much of the work on improving experience of care in maternal and child health has focused on respect and dignity within maternity services. In 2010, the USAID-funded Translating Research into Action project commissioned a landscape report on issues regarding the disrespect and abuse of women during childbirth.²² This report identified seven themes constituting disrespect and abuse: physical abuse, non-consented care, non-confidential care, non-dignified care, discrimination based on specific patient attributes, abandonment of care, and detention in facilities. The findings recognized that drivers of abuse within health care settings included national laws, facility policies, community norms, and individual provider training and behavior.²² The WHO published a statement in 2014 calling for the elimination of disrespect and abuse in childbirth, and galvanized more research and programs focused on this part of the continuum of care.²³ A systematic review in 2015 further refined these themes, adding additional subthemes, such as verbal abuse and stigma, and defining categories such as failure to meet professional standards of care, poor rapport between providers and patients, and health system constraints.²⁴ In 2018, the WHO developed standards and a framework for improving the quality of maternal and newborn health care that highlighted provision of care and experience of care as essential to maternal and newborn health outcomes.²⁵ The standards included statements that newborns and their caregivers (defined as the child’s family member, guardian, or individual responsible for the child’s health) should be treated with respect and dignity.²⁵ Respectful maternity care was defined through a human rights perspective and required that every woman, her baby, and the baby’s caregivers (defined as the baby’s parent, family member, or guardian) be treated with care, respect, and dignity; be free from harm; and maintain autonomy. These human rights include protection from disrespect, neglect, trauma, and abuse and define a positive experience of care as extending beyond the absence of abuse.²⁵

From its research into QoC concepts, the WHO has developed guidelines for maternal, newborn, and child health and survey tools for women emphasizing the importance of patient experience as part of QoC, which have been used and adapted in multiple countries.²⁶ Since then, global and country-level public health

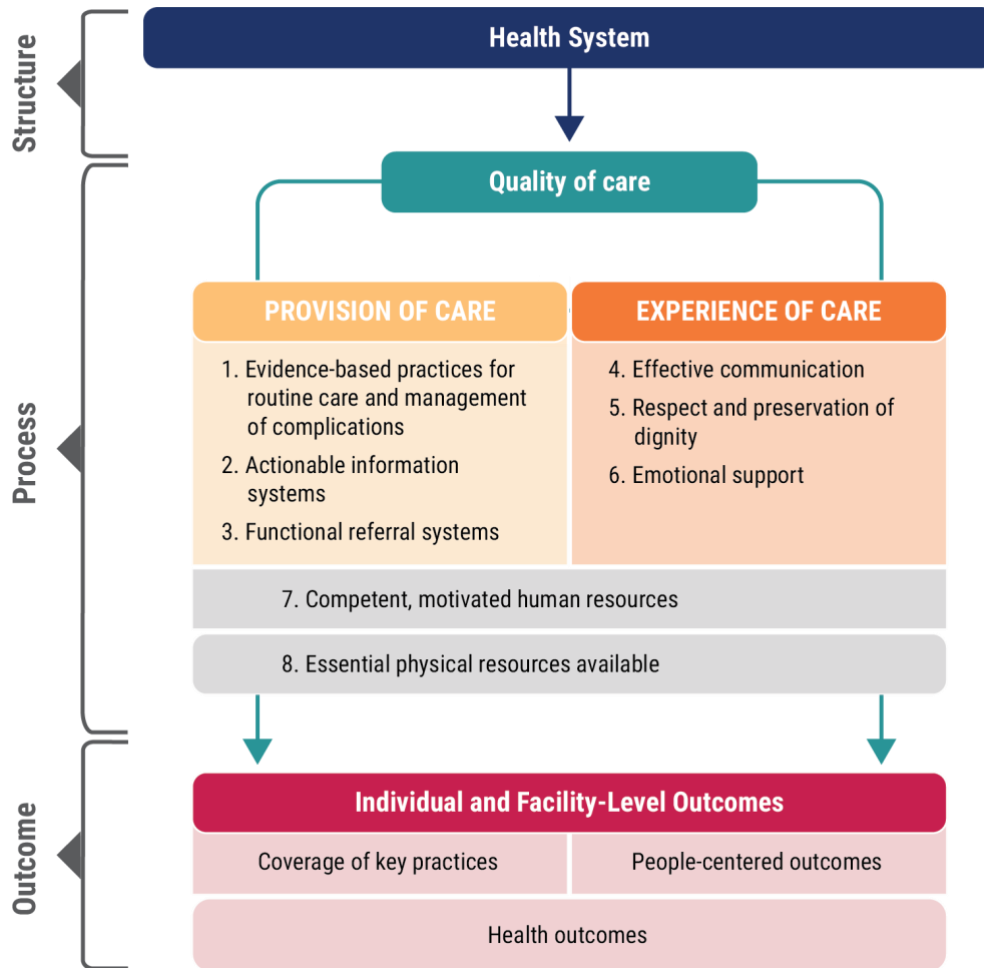
practitioners have recognized the concept of “experience of care” as a core aspect of QoC and the overall functioning of health systems. Over time, as these stakeholders established the importance of QoC and experience of care, tools have been developed to measure the prevalence of both negative and positive experiences of maternal care and to track progress at the facility and national level, including the Person-Centered Maternity Care Scales and the Mothers on Respect index.^{27,28,29,30} These tools are important in assessing and addressing issues of QoC, but their primary focus is measuring mothers’ experience of care. Some of these tools incorporate the needs of the newborn nominally or as part of the mother-newborn dyad. However, more recently, the global community has recognized newborns’ additional rights, independent from their parents and caregivers.³¹ In 2017, a literature review on global newborn QoC found that many newborns were denied high-quality medical care, the right to be with a caregiver, caregivers’ consent for their medical care, gentle handling, pain management, and receipt of birth (and death) certificates.³¹ The Respectful Maternity Care charter, first published in 2011, defines the rights related to receiving care in health facilities based on various global human rights instruments.³² In 2019, an update to this charter included infants’ rights to a birth certificate and nationality.³³ While the Convention of the Rights of the Child codifies the general rights of children, there is no similar agreed-upon set of rights for children related to care in health facilities.³⁴ In 2022, the WHO developed recommendations aimed to improve the quality of essential, routine postnatal care for women and newborns, emphasizing the role of QoC and experience of care in maternal and newborn health.³⁵

The global efforts to improve the QoC for children have included new standards for high-quality services, including the readiness of health facilities to provide high-quality services, the provision of care, and the experience of care.³⁶ Long-standing strategies for improving clinical quality of services and reducing mortality and morbidity in children under five at the primary care level exist, such as the Integrated Management of Childhood Illness (IMCI).³⁷ IMCI is a more holistic approach to addressing health services that takes into account various factors that might put newborns and children at risk of preventable morbidity or mortality.

Compared to work in maternal health, there has been much less research conducted around the frameworks and measures to assess experience of care and respectful care of children (up to 18 years) and caregivers of children, either healthy (during well-child visits, including immunization and nutrition monitoring) or sick (during acute pediatric care). There is also scant evidence of the prevalence of positive or negative experiences of care or respectful care for children in LMICs. A scoping review of experience of care of hospitalized newborns and young children in all income settings found very limited evidence on overall experiences of care or interventions to improve experiences for families and their hospitalized children aged 60 days to 24 months.³⁸ Recent qualitative work in Kenya inpatient settings among female and male caregivers of sick children 0-24 months suggest hospital infrastructure and processes, such as unhygienic and crowded conditions, long wait times, and difficulties in navigating the hospital’s physical environment and payment policies, contribute to negative experiences of care.^{39, 40} Interactions with providers were sometimes positive, with providers showing empathy and concern. However, negative experiences included discrimination, ineffective communication, harsh language, and rough or non-consented care.^{39, 40}

With the recognition of the impact of experience of care on health outcomes, the WHO framework for Improving the Quality of Pediatric Care describes elements of “experience of care” and “provision of care” as essential elements of effective care, similar to the WHO framework for the quality of maternal and newborn health care.^{24,36} In this framework, “experience of care” is comprised of effective communication and meaningful participation, respect, protections and fulfillment of child rights, and emotional and psychological support (Figure 2).³⁶

FIGURE 2. THE WHO FRAMEWORK TO IMPROVE THE QUALITY OF PEDIATRIC CARE



WHO. 2018. *Standards for Improving the Quality of Care for Children and Young Adolescents in Health Facilities*. Geneva: WHO. <https://apps.who.int/iris/bitstream/handle/10665/272346/9789241565554-eng.pdf?ua=1>

As noted above, experience of care, as part of the larger QoC agenda, encompasses principles of respectful care and patient-centered care, and interacts with health system factors, such as infrastructure and the facility environment. While some stakeholders have used respectful care and experience of care interchangeably, they are different, as illustrated in Figure 1. In the context of pediatrics, person-centered care overlaps greatly with family-centered care. Pediatric experience of care depends on both the treatment of the child and the treatment of their family members, such as the family being able to stay with the child and being involved in decision-making about medical treatments.

Measuring pediatric experience plays a critical role in informing patient- and family-centered care. While the correlation between patient-reported experience measures (PREMs), patient- and family-centered care, and quality improvement for adults has been well established by researchers, there is not much research regarding pediatric PREMs.⁴¹ A systematic review of PREMs used in pediatrics found that, in high-income countries, the tools often are completed by proxy and used primarily for quality-improvement purposes without being tailored to the pediatric population.⁴² Another systematic review found that many instruments

used to gather feedback from children about their health care experiences were not age-appropriate or culturally accessible.⁴³ Current large-scale facility assessment tools used in LMICs have undergone recent revisions (such as the Service Provision Assessment (SPA)) or are undergoing revision (such as the Service Delivery Indicators surveys).^{44,45} Donors and project managers are integrating more measures related to QoC, including experience of care, into these assessment tools, which have historically focused more on clinical QoC provision. During discussions about how to better measure pediatric QoC through the SPA in 2021, stakeholders recognized the need to include new measures to assess a facility's readiness to provide positive experience of care and the actual experience of care among children and their caregivers within the SPA. However, there were few existing tools or experiences from which to propose valid and reliable measures of the pediatric experience of care constructs. One systematic review found that many instruments used to gather feedback from children about their health care experiences were not age-appropriate or culturally accessible.⁴³

A recent review of child health QoC facility assessment tools found that experience of care measures were mostly absent in commonly used tools.⁴⁶ To our knowledge, no comprehensive review specific to pediatric experience of care or its measurement in LMICs has been conducted. The WHO is currently undertaking a review of tools and indicators for treatment and satisfaction with care of newborns, but the review does not extend through infancy and childhood.⁴⁷ Measuring the experiences of caregivers and children—especially for younger children with more limited communication skills and less understanding of their medical needs and legal rights—poses several challenges and requires special consideration.

Understanding how to define and navigate components of pediatric experience of care is essential to improving patient outcomes and reducing child mortality as part of the global Sustainable Development Goals. A better understanding of pediatric experience of care and better measures to assess it can help governments and other stakeholders evaluate the quality of pediatric care holistically in a country or facility, identifying areas needing improvements and assisting policymakers and planners in monitoring progress over time. We anticipate that identification of feasible and sound measures of experience of care for children and their caregivers will assist governments and the global health community in benchmarking levels of positive and negative experiences of care, determining the best approaches to improve experiences of care and measuring the effects over time of any approaches implemented. Additionally, this work can feed into larger global discussions about operationalizing the WHO pediatric QoC standards into feasible and useful indicators to track countries' progress in improving QoC.⁴⁸ It also can inform ongoing work toward mapping and harmonizing the concepts of respectful care, experience of care, and patient-centered care across the life course and care continuum.

AIMS AND OBJECTIVES

The aim of this review was to explore frameworks, metrics, and tools that exist to understand and measure experience of care for children under five years of age in LMICs. The purpose of this review was exploratory: to understand existing frameworks related to pediatric experience of care in order to move towards the development of better metrics for use in LMICs. The WHO Standards for Improving the Quality of Care for Children and Young Adolescents in Health Facilities (Appendix 1) served as a guide as they provide comprehensive goals for improving QoC for children globally.³⁶

The specific objectives of this review were to:

- Identify existing frameworks for QoC and respectful care and assess their relevance to pediatric health and experience of care through a scoping review.
- Apply the WHO standards and suggest additional domains and subdomains for defining pediatric experience of care among young children in LMICs.
- Develop a pediatric experience of care framework using these additional domains.
- 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

Scoping Review

We conducted the scoping review using an iterative process to select articles that would be most relevant to the aims of the review. When we identified an informational source, we categorized each relevant result as a “framework,” as “tools or metrics development,” or both. For those that fell under both categories, we reviewed the informational source and extracted relevant information that could contribute to the “framework” or “tools and metrics development.” Table 1 describes the search term methods for the scoping review.

TABLE 1: SEARCH METHODS FOR SCOPING REVIEW

Objective	To identify and understand aspects of pediatric experience of care in health facilities and to inform measurement methods
Date Range	All dates to July 2021
Study Location	Global
Type of Studies	Frameworks, reports, qualitative and quantitative research studies
Literature Type	White, gray, and published literature
Language	Published in English
Information Sources	PubMed, Google Scholar, Google, hand searches, expert knowledge and recommendations
Subject and Search Terms	“Experience of care,” including respectful care and patient satisfaction in pediatric (facility-based) health care; other targeted searches on the various domains and sub-domains
Population	Families and children under five years of age
Outcomes Assessed	Frameworks that include children and tools or metrics that measure experience of care or respectful care in a health facility

FRAMEWORK FOR PEDIATRIC EXPERIENCE OF CARE

We used informational sources found in the scoping review together with expert discussions to identify themes, domains, and subdomains specific to pediatric experience of care beyond the domains recommended in the WHO Standards for Improving the Quality of Care for Children and Young Adolescents in Health Facilities.³⁶ We developed a pediatric experience of care framework, including both the WHO standards and these additionally identified themes, domains, and subdomains. We refined this framework in multiple iterations to include additional domains and subdomains and to contextualize this understanding, especially for LMICs. Further, we used the results of this framework to understand how concepts of pediatric experience of care are operationalized and measured.

MAPPING OF TOOLS AND METRICS

As part of the scoping review, we identified existing tools and metrics for measuring pediatric experience of care, in addition to information on existing frameworks. We entered the identified tools and metrics into an Excel file to map indicators and survey questions against existing domains (see Table 2). The research team developed a standard form to extract this information that catalogued indicators or survey questions by domain and by data collection tool. For existing measurement tools, the team reviewed the tool itself. For survey tools referenced in reviewed sources but not publicly available or appended, we contacted the authors to request copies. In some cases, when tools were under development and shared for reference, the authors requested that they not be included in the review until their results were published; thus, they are not included in the review but may inform future efforts.

Key Informant Interviews and Expert Consultation

Once we had developed the preliminary pediatric experience of care framework and compiled a preliminary list of available tools, we conducted individual interviews and a consultation of experts on the development, dissemination, and use of experience of care tools.

We conducted key informant interviews with five expert informants with experience in measuring and implementing experience of care metrics. We identified individuals through their experience and reputation in the field and through recommendations. Each interview was approximately one to two hours long and addressed challenges in measuring pediatric QoC, important gaps in current measurement approaches, feedback on the framework and conceptual model of drivers and consequences, and suggestions for further tools to be examined. We conducted interviews virtually using the Zoom or Teams videoconference platforms and reviewed interview notes for information relevant to the aims of the study. Most of the interviewees followed up by email to provide additional comments or documents.

The consultation included 20 experts from USAID, MOMENTUM, and other partners who were invited based on their interest or involvement in the development, dissemination, and use of experience of care tools. During the August 2021 virtual consultation, we gave an overall update on the project and presented the draft framework and indicator/question mapping for feedback. We provided consultation participants with a list of all references that we used to develop the framework or reviewed for the mapping; we asked participants to review the list and provide or suggest additional resources that were not already included.

We solicited feedback in writing from the consultation and interview participants and asked them to recommend other experts who may have additional important information. In addition, we encouraged consultation and interview participants to share additional resources and tools to include in the review.

We consolidated and organized the results from the scoping review as well as the interviews and consultation to inform the development of domains and subdomains of the framework and to document existing tools, metrics, and measurement considerations for pediatric experience of care constructs.

FINDINGS

The scoping review identified pediatric experience of care frameworks, tools, and metrics from 32 articles and reports in the gray and published literature and information collected from the individual key informant interviews and consultation. We organized the scoping review and interview results into two categories. The first category included frameworks and principles relevant to pediatric experience of care, which informed the revision of the domains and subdomains included in the framework for pediatric experience of care. The second category focused on existing tools and metrics for measuring pediatric experience of care.

Frameworks Related to Pediatric Experience of Care

Through our review, we identified additional concepts important for pediatric experience of care and respectful care that build on and enhance those outlined in the WHO standards.³⁶ These concepts include 1) human and child rights principles, 2) national and facility policies to support a positive pediatric experience of care, and 3) the role of the health care provider in experience of care.

HUMAN AND CHILD RIGHTS PRINCIPLES

Rights pertaining to the health and well-being of the child and newborn are essential to experience of care for children. Several documents and frameworks highlighted this principle, as do national laws and policies that enforce protection from abuse in health facilities.^{12,23,32,35} Many of the interviewees and consultation participants noted that a human rights framing was essential to moving the respectful maternity care agenda forward and may be a crucial element in raising awareness about child rights.

We located two key documents that define and discuss rights relating to the health and well-being of the child and newborn. The Convention on the Rights of the Child states that the rights of the child include the right to not be discriminated against, the right to an identity, and an obligation of the government to privilege the best interests of the child by prioritizing keeping families together and respecting caregiver guidance.³⁴ The second document, geared more specifically to the health care setting, is the Respectful Maternity Care: Universal Rights of Women and Newborns charter; it is based on widely accepted human rights instruments and reports as well as regional human rights instruments.³³ In its 2019 revision, the charter recognizes the rights of newborns, as well as the needs of the child and parents or caregiver, focusing on the connectedness between the well-being of a mother and her child.⁴⁶ One key principle states, “Everyone is their own person from the moment of birth and has the right to be treated with dignity and respect”; other statements address the rights of children and women and the basic human rights of each. Many principles included in this document highlight aspects of maternal, child, and newborn experience of care as key components of high-quality care.³³

In addition to the rights of the child, the rights of family and caregivers are essential in pediatric experience of care. In both documents named above, the role of the family and caregivers is considered central to ensuring the rights and dignity of newborns and children.^{33,34} Our assessment of these documents found that in many cases there is an alignment between the best interests of the child and the best interests of family or caregivers. There is a benefit for parents and caregivers to be given the opportunity to participate in care choices and consent to the child's medical care. However, there may be instances where the best interests of the child may conflict with the wishes of family members, in which case there should be clear policies at the national level to handle conflicts to ensure the best care and health decisions for the individual child and family. Many key informants noted that the presence of multiple family members or stakeholders adds to the complexity of the pediatric experience, in contrast to the maternal experience, where women often have autonomy.

NATIONAL AND FACILITY POLICIES TO SUPPORT A POSITIVE PEDIATRIC EXPERIENCE OF CARE

At interpersonal and health systems levels, the rights of children, newborns, their families or caregivers, and their health providers are key to ensuring a positive experience of care. However, we found that broader structural laws and policies also play a significant role in ensuring that there are official directives in place that define, protect, and inform these rights. Existing national laws and policies generally guarantee protections for patients related to respectful care in health facilities and protection from abuse. For example, in almost every country, detention (i.e., imprisonment) for lack of payment is illegal, and many countries have policies for free maternal-newborn health services.^{49, 50, 51} Some official facility policies, such as rooming-in or visitation policies, may be restricted by available space and resources at the facility; however, this infrastructure can be influenced by district or national directives and budget. Many key informants mentioned that, as important as structural laws and policies are, patients and providers might be unaware of accountability processes or options for redress when their rights are violated. Patients' and families' awareness of these policies, as well as an understanding of the processes needed to advocate for their rights, is essential to ensure accountability and enforcement of these policies. In addition, poor enforcement, resource constraints, and lack of feedback mechanisms limit the utility and effectiveness of policies and laws in some contexts.^{22,33} The implementation and enforcement of these laws and policies depends on good governance and leadership at the facility, district, national, and global levels.^{25,52}

ROLE OF HEALTH CARE PROVIDERS IN PEDIATRIC EXPERIENCE OF CARE

Health care providers not only deliver clinical care but are the main actors in communicating with and supporting children and their families. If health providers deliver the type of care that reduces fear, ensures safety, reassures the child and caregivers, uses clear communication, includes assent and consent, and forms trust and partnerships with children and their families, this contributes to positive experiences and the well-being of pediatric patients. In our review, interviews, and consultation, it was unequivocal that the rights of health care providers be respected and their needs met if they are to contribute to positive experiences of care for children and their families; despite this, health care providers' rights and experiences are not always given enough attention.

Working under constrained human and physical resource conditions in LMICs may limit the providers' ability to accommodate the needs of every patient⁵³ and effectively communicate.⁵⁴ Especially during times of high stress, these providers risk burnout and depersonalizing their interactions with patients.⁵⁵ Health systems factors, such as the availability of sufficient human resources, support for human resources, and adequate equipment and supplies, are all vital to ensure health care providers can provide high quality care, including

effective and respectful communication and positive experiences.^{22, 56, 57, 58} Lack of these factors can contribute to non-respectful care and even violence.⁵⁹ A recent initiative across eight LMICs and the United Kingdom found that midwives' number one demand when asked what they want was "more and better supported personnel."⁵⁷ Midwives across the nine countries asked for fair and on-time compensation, job security and professional development opportunities, and job benefits, such as longer maternity leave and staff housing.⁵⁷ Almost as important as human resources to midwives' experiences were the infrastructure, equipment, and supplies available to do their job.⁵⁷ Studies have found that inadequate physical health systems resources are associated with poor provider-patient communication.^{54, 58}

Health providers also require the training and tools they need to perform their job duties and have access to professional development, both for improving clinical care as well as interpersonal interactions with patients. Clinical pre-service training often can encourage distance between health providers and patients.^{22, 59} Including ethics and communication and human rights perspectives in pre-service training is a first step in addressing disrespect and violence⁵⁹; recent work has also advocated for the inclusion of compassion into pre-service clinical training.⁶⁰ Provider pre-service and in-service training in pediatric health may not reflect the latest evidence-based research or standards and may, in fact, include practices that would now be considered harmful or even abusive, such as slapping newborns after birth or not obtaining assent from children. Access to professional development, such as in-service training, ensures that health care providers can update their skills and knowledge in light of evolving evidence and best practices. In-service training that addresses providers' subconscious methods of coping with high stress or resource-constrained settings, such as emotional detachment or distancing, as well as on recognizing burnout and depersonalization, can impact patients' and their families' experience of care.^{22, 61}

Health care providers should feel safe in their places of work, receive respect from their supervisors and the patients themselves, and feel that their general psychosocial and emotional well-being is supported. Environments where health providers do not feel respected and recognized can result in these providers disrespecting clients.^{22, 59} Health care workers who feel supported and have opportunities for connections with other staff and leadership provide compassionate, higher QoC,⁶⁰ while lack of support can contribute to poor provider-patient communication.^{54, 58} About 7 percent of midwives surveyed across eight countries expressed "respect, dignity, and non-discrimination" from the health system, supervisors and patients as their top demand and 5 percent asked for "power, autonomy and improved gender norms and policies."⁵⁷ In hierarchical and unequal gendered health systems, women, who comprise the bulk of the midwives and nurses in many settings, may be at particular risk for emotional fatigue. Health care providers dealing with high prevalence of pediatric mortality and morbidity may also be more likely to suffer emotional burnout.⁶²

Supporting health care providers in providing positive experiences of care requires understanding and addressing challenging health care environments, as well as health systems that recognize and address providers' needs.

Pediatric Experience of Care Framework Development

To understand the context within which a pediatric patient and their family experience care, we first examined relative domains and subdomains in pediatric experience of care. We considered the scoping review, the WHO Standards of Care,³⁶ and theoretical understandings of both potential **drivers** and **consequences of experience of care** and potential influences and interactions patients and their families may have as they move through a health care visit (the **patient pathway**). We used two major categories that

influence pediatric experience of care—interpersonal and health systems—identified in the WHO standards.³⁶ We built out conceptualization of these elements in an iterative process to contribute to a more holistic understanding of a patient’s experience of care and develop our proposed framework. These exercises provided a more comprehensive understanding of the themes, domains, and subdomains contained therein and inform the discussion of appropriate tools, metrics, and measures for assessing pediatric experience of care.

DRIVERS AND CONSEQUENCES OF PEDIATRIC EXPERIENCE OF CARE

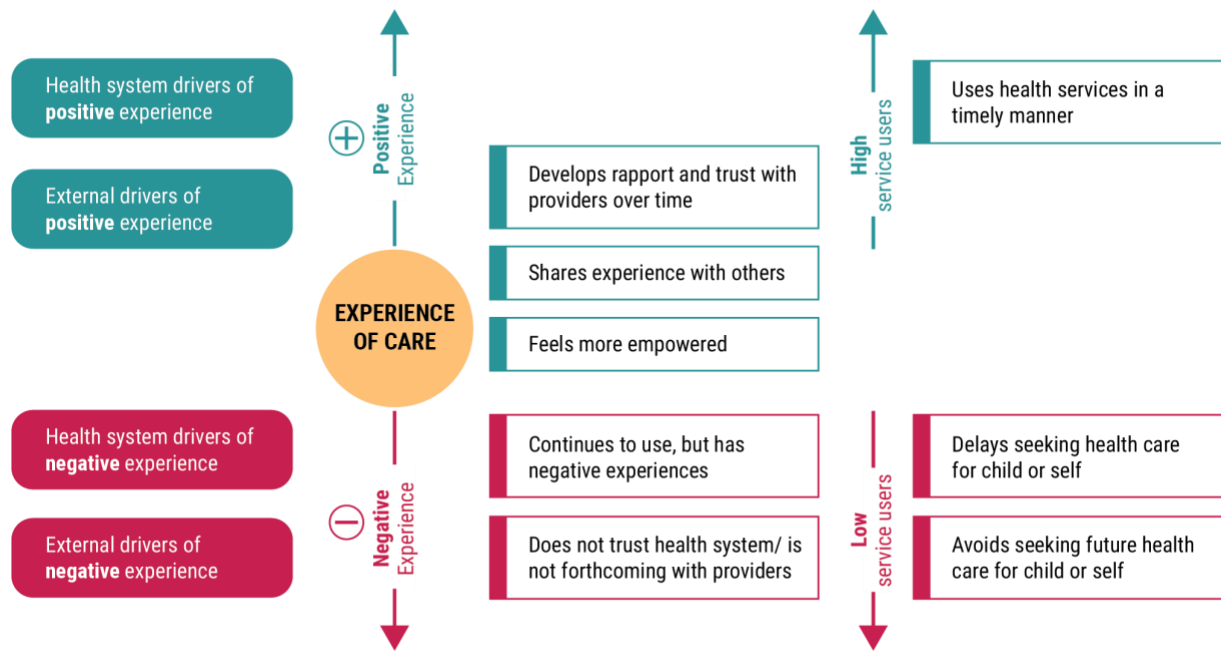
From discussions with experts, we developed a preliminary conceptual model of drivers and consequences of positive and negative pediatric experience of care, which we then revised iteratively over the course of the review. We used this preliminary model (Figure 3) to guide and organize the scoping review and in the development of the proposed framework for pediatric experience of care. We defined drivers of experience of care as any underlying factors that enable either a positive or a negative experience of care for the patient. Consequences of patients’ and families’ positive or negative experience of care are potential outcomes of these experiences. We hypothesized that these factors exist on interpersonal and external levels and interact and affect each other, all creating the environment for experience of care.

The model (Figure 3) includes both health system factors (such as patient-provider rapport, physical infrastructure, and provider training and competence) and external factors (such as community; familial, socio-cultural, and gender norms and influences; economic climate; and accessibility for ethnic and linguistic minorities)⁵⁴ that can “drive” or influence experience of care in positive or negative ways.

We hypothesized that positive experience of care can provide opportunities for patients and families to develop trust and rapport with their provider and trust in the health care system. In positive experiences, children and families will likely feel dignity, secure that their rights will be upheld, and an increased sense of autonomy and self-empowerment. Families who have positive experiences may be more likely to share their experiences with others, influencing other community members to seek care. When families consistently have a positive experience of care, these families and other community members may be more likely to seek timely services, increasing care and positive health outcomes for individuals, families, and communities.

Negative experiences can result in poor health outcomes. If families and children grow accustomed to poor service experiences, they may continue to use services that do not foster their empowerment or trust in the system or providers, especially if there are no other options available. Negative experience of care can lead to avoidance or delays in seeking preventative and/or curative health care services. For maternal-child care, this can result in avoidance or delay of pediatric care for children, avoiding antenatal care for future pregnancies, and neglecting family planning, leading to negative health outcomes.⁶³ Another potential result of normalized negative experience of care is that patients may be grateful to have any type of care or feel that poor QoC is the only type of care available to them. Families may be less likely to advocate for themselves or be critical of the system, leading to a lack of accountability for poor-quality, negative experiences, or discriminatory services or for the health care provider and the larger health care system. At the community level, once a facility develops a poor reputation, members of the community may avoid it or travel to other facilities that may be further away, more expensive, or less regulated.^{64,65}

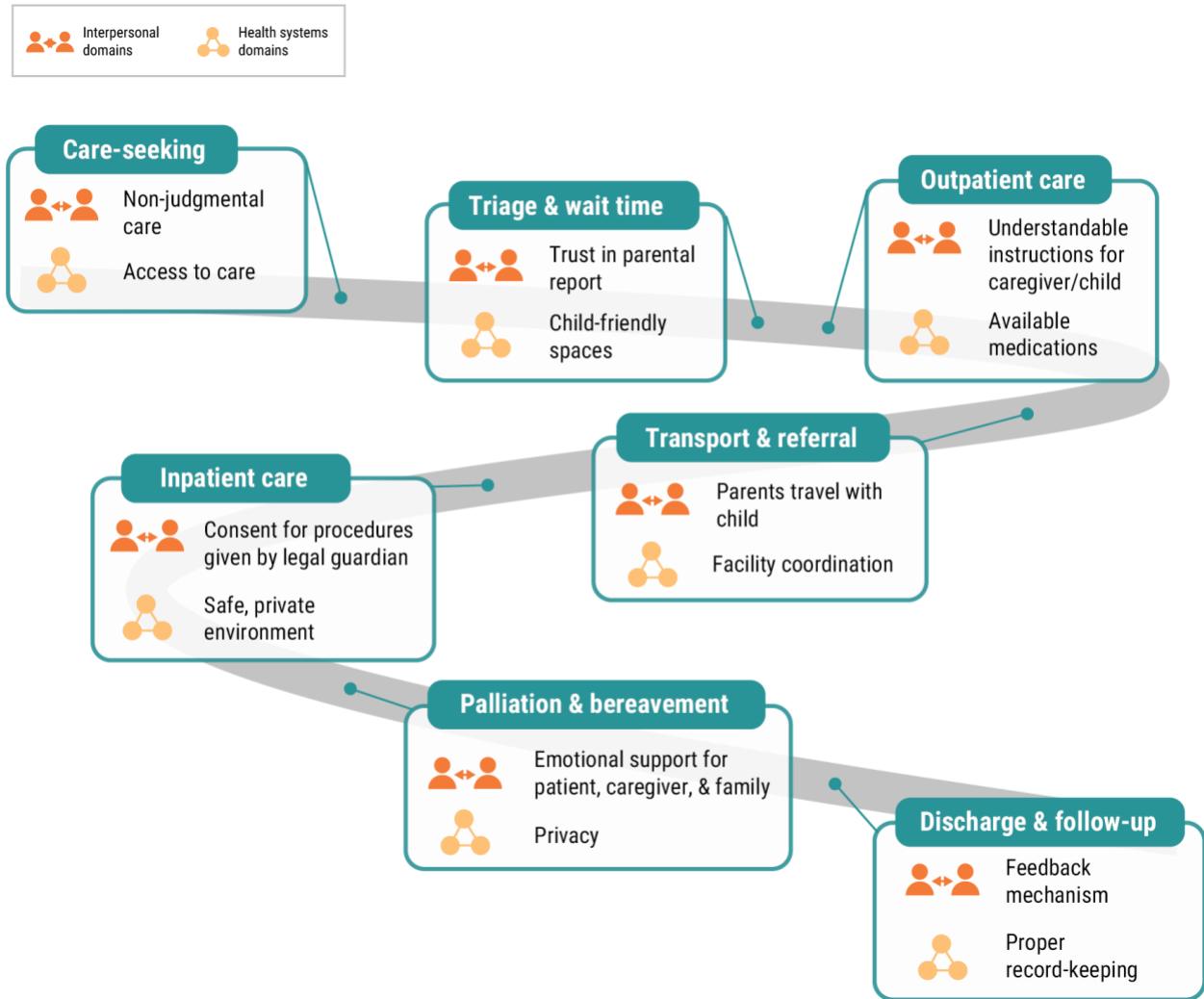
FIGURE 3. POTENTIAL DRIVERS AND CONSEQUENCES OF EXPERIENCE OF CARE FOR CHILDREN AND FAMILIES



INFLUENCES THROUGHOUT THE PATIENT PATHWAY

From the moment of first contact with the health care system until the completion of treatment, a patient will have numerous interactions, relationships, and experiences; this process is called the patient pathway. At each point in this pathway, patients and families interact with different staff members and services, as well as health systems factors, that can influence their overall experience of care, whether in a single visit or over the course of their care. Figure 4 presents a hypothetical patient pathway that provides examples of both interpersonal and health system factors that can influence experience of care as families navigate health services. This pathway is by no means exhaustive: there may be additional interactions, such as with lab technicians, pharmacists, and even other patients that influence the experience of care. Other frameworks for patient journeys, such as that for immunization, promote a comprehensive human-centered approach that includes factors and interactions between health systems, communities, families, and health providers that affect families accessing and seeking care, interactions during services, and feedback to communities after receiving services.⁶⁶ Experience of care concepts and interactions are similar between the immunization journey and the framework presented here. Even when limited to just interactions at the point of health services care, the experiences of children and their families can be dynamic, with a complex series of relationships and influences that add to the challenge of measuring experience of care.

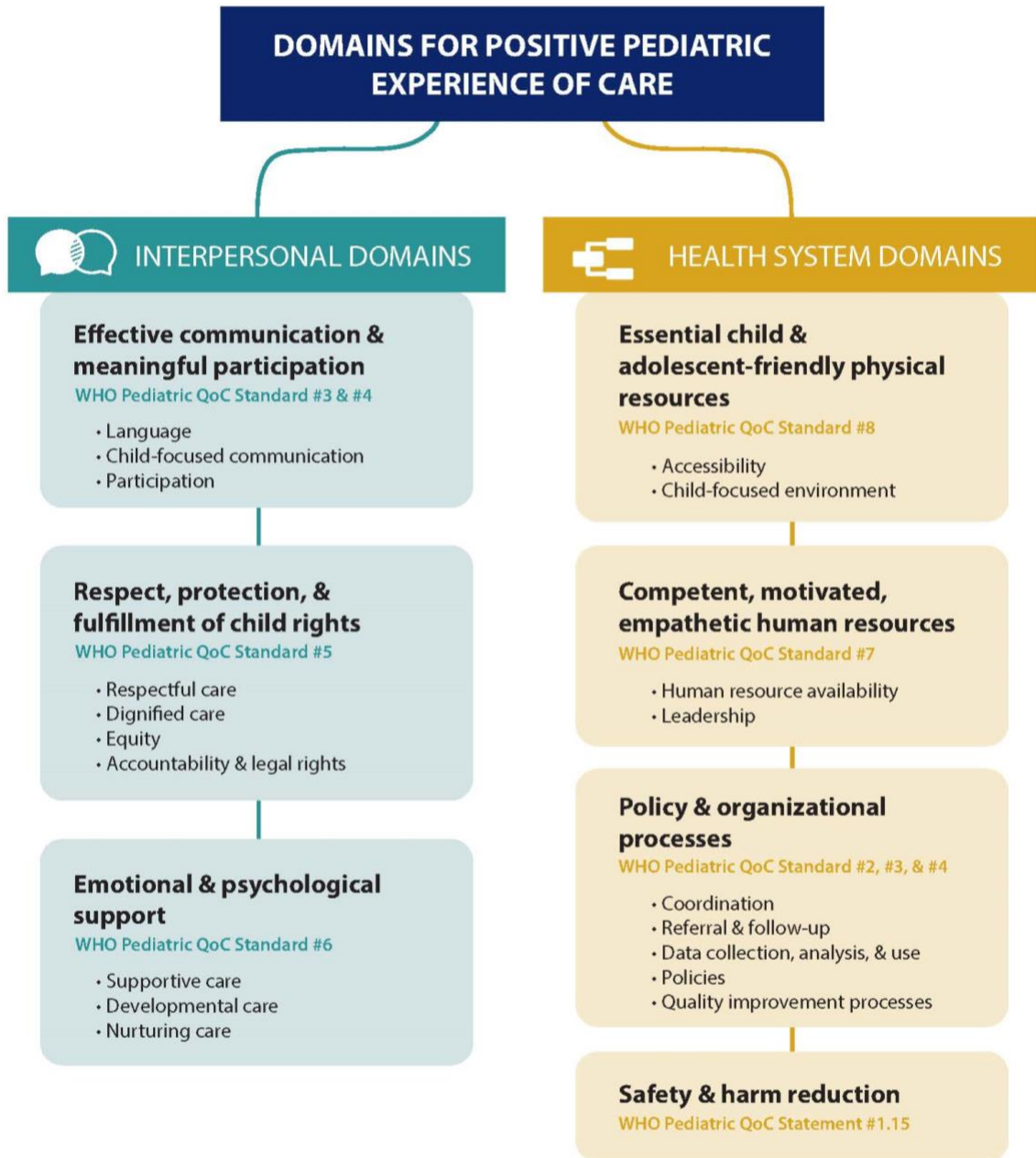
FIGURE 4. INTERPERSONAL AND HEALTH SYSTEM FACTORS THAT AFFECT EXPERIENCE OF CARE ON THE PATIENT PATHWAY



DOMAINS AND SUBDOMAINS IN PEDIATRIC EXPERIENCE OF CARE

Figure 5 presents our proposed pediatric experience of care framework. It uses the WHO Standards of Care framework³⁶ and expands some domains within the two major categories that influence pediatric experience of care—interpersonal and health systems factors. Under each of these major categories, we identified domains that influence pediatric experience of care. Interpersonal domains include 1) effective communication and meaningful participation; 2) respect, protection, and fulfillment of child rights; and 3) emotional and psychological support. Health systems require physical and human resources and adequate processes to function; health system domains specifically influencing the experiences of children and their families include: 1) essential child- and adolescent-friendly physical resources; 2) competent, motivated, and empathetic human resources; 3) policy and organizational processes that foster positive pediatric experiences of care; and 4) safety and harm reduction. The 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 postulate is an important factor in children’s and their families experience of care.

FIGURE 5. POSITIVE PEDIATRIC EXPERIENCE OF CARE FRAMEWORK



While we describe the proposed framework below, we anticipate revisions and iterations to this framework as it is operationalized. MOMENTUM Knowledge Accelerator is currently seeking feedback from child health program managers and policymakers in Africa and Asia about the framework and important domains and sub-domains to consider when measuring pediatric experience of care.*

INTERPERSONAL DOMAINS

EFFECTIVE COMMUNICATION AND MEANINGFUL PARTICIPATION

Effective communication and meaningful participation are key aspects of positive experience of care outlined in the WHO Standard #4: ***Communication with children and their families is effective, with meaningful participation, and responds to their needs and preferences.***³⁶ Communication and participation are also important within the WHO Standard #3, which relates to referral and continuity of care. Families and their children may feel mistreated if health providers speak to them in a language or manner they do not understand, do not consult them about the care of their child, do not clearly explain the child’s illness and care, do not appropriately counsel on follow-up needs, and/or do not coordinate care with other staff.^{36, 67} Child-focused communication appropriate for the child’s age and development stage is vital, and providers should strive to engage and reassure children and work in partnership with families to create a safe and comfortable environment for all. Effective communication is even more important when patients or family members have disabilities or complex medical cases with multiple treatment options, including palliative care. Meaningful participation is dependent on transparent communication when explaining health and medical plans and procedures, consent, as well as decision-making that includes children, caregivers, and their families. A review of studies found that parents felt discriminated against when health workers “talked down” to them and that lay language and open and honest communication encouraged participation.⁶⁷ In cases where referral of the child is required, effective communication between health providers and with families, as well as the participation of the family in decisions, are essential to ensure the child, caregiver, and families experience timely, seamless, and coordinated continuity of care.³⁶

RESPECT, PROTECTION, AND FULFILLMENT OF CHILD RIGHTS

WHO Standard #5 states: ***Every child’s rights are respected, protected, and fulfilled at all times during care, without discrimination.***³⁶ Respectful and dignified care requires effective communication, and thus overlaps somewhat with that domain. If health providers deny patients privacy or autonomy, make prejudicial assumptions, or humiliate or blame families, they jeopardize patients’ and their families’ respect and dignity to the detriment of positive experience of care. All children deserve protection from physical and emotional mistreatment and harm, a caregiver present during their health care visit, and supportive, nurturing care, regardless of their age, health status or demographic group.³⁴ Additionally, children should be treated as sentient beings with rights, with providers engaging with them as well as with their caregivers and providing opportunities for the child to give their assent to treatment. All families and their children have the right to access health care and family involvement with the goal of emphasizing comfort and pain reduction for the child. Countries may have codified these rights—such as respectful and dignified care, caregivers or families staying with children, and lack of discrimination—into policies. Patients’ caregivers and families should know

* MOMENTUM Knowledge Accelerator anticipates the findings from this work will be available in spring of 2023. For more information, please contact Nancy Volmer (nancy_volmer@jsi.com), Soumya Alva (soumya_alva@jsi.com), and/or Kate Gilroy (kate_gilroy@jsi.com).

and understand the accountability mechanisms and legal protections available to them if these rights are violated.

EMOTIONAL AND PSYCHOLOGICAL SUPPORT

Emotional and psychological support are included in the WHO Standard #6: **All children and their families are provided with educational, emotional, and psychological support that is sensitive to their needs and strengthens their capacity.**³⁶ Emotional and psychological support for children and their families can play a large role in positive experience of care^{39, 40} and is especially vital for those dealing with painful symptoms, unknown illnesses, distressing diagnoses, or prolonged illnesses. For children, this support generally comes from their parents and family members or caregivers, who may know the best ways to soothe or comfort them. This support must be age-appropriate and should allow the family to be present as much as possible during medical procedures and between contact with providers, which is also the child's right, as mentioned above. Care should also strive to promote the development of children in ways that are age-appropriate. Research has demonstrated the need for developmental care of preterm newborns and more recently, the need to encourage social, emotional, and educational development in young children, which may be especially relevant for those who have frequent or chronic illnesses.^{68, 69, 70, 71} Nurturing care will look different depending on the child's age and health conditions; thus, facilities will need to provide both quiet, dimly lit, calm spaces for newborns and children who need rest, as well as stimulating and physically safe play spaces for children who need exercise or have behavioral challenges.

HEALTH SYSTEMS DOMAINS

ESSENTIAL CHILD- AND CAREGIVER-FRIENDLY PHYSICAL RESOURCES

Positive experience of care for children, their caregivers, and families is influenced by the facility's physical infrastructure and resources and the accessibility of those resources, per WHO Standard #8: **The health facility has an appropriate, child-friendly physical environment, with adequate water, sanitation, waste management, energy supply, medicines, medical supplies and equipment for routine care and management of common childhood illnesses.**³⁶ For example, health facilities should have safe and well-maintained environments designed for safe and easy use by children and caregivers and adequate stocks of child-appropriate medicine and supplies. Environments for children at health facilities should be welcoming and calming, have waiting areas with stimulating colors and lights, and provide educational or intellectually stimulating materials and safe places to play. Studies have found that the physical environment, such as adequate waiting rooms, sanitation facilities, and child-friendly decor, are essential to families' reported experiences of respect and dignity.⁶⁷ In patient rooms or specialized wards, age-appropriate and tailored developmental care and stimulation should be available, recognizing their importance alongside clinical care. In critical care units, appropriate temperature and hygiene standards should be maintained, efforts should be made to create calming spaces without bright lights, and appropriate nutritious meals should be provided. Facilities should accommodate the care of children and caregivers with various types of physical, congenital, and developmental disabilities. There should be areas where caregivers are able to stay with their children who have been admitted to the hospital.

COMPETENT, MOTIVATED, AND EMPATHETIC HUMAN RESOURCES

Health care providers are a critical component of health systems, and facilities must have sufficient staff that are competent, motivated, and empathetic (WHO Standard #7)³⁶ to **contribute to positive experiences of care to children and their families.** Children and their families experience interpersonal interactions with health providers; thus, as outlined above, ensuring health providers are supported, respected, and adequately equipped is essential for positive patient experiences of care. Sufficient staffing and

infrastructure, opportunities to update skills and knowledge in provision of care and interpersonal communication, fair compensation, psychosocial support, and respect from other staff, supervisors, and the families themselves all underpin providers' ability to deliver on the interpersonal domains important for positive experiences. Sufficient human resources can also influence wait times, which have been found to be an important contributor to children's and their families' care experiences.³⁹ Providers specializing in pediatric care, including support staff, should be available and qualified to consult, depending on the level of the facility. Providers need sufficient time, as well as training and tools, to have positive interactions with pediatric patients and their families. Strong leadership and governance are required for support staff to provide care and support that is positive in all the interpersonal domains, as well as to ensure that infrastructure and policy and organization processes meet children's and family's needs.²⁵

POLICY AND ORGANIZATIONAL PROCESSES

Supportive policies and processes are needed for health providers and facilities to perform well for children and their families. This proposed domain builds on and combines aspects of the WHO Standard #2 related to **health information systems and data**; WHO Standard #3 related to **referral and continuity of care**; and WHO Standard #7 related to **managerial leadership developing, implementing and monitoring policies that foster continuous quality improvement**.³⁶ Effective coordination and continuity of care require facility- and district-level policies and processes within and between facilities, especially those related to referrals of children. Individual facilities should have strong record-keeping systems, monitoring of professional standards, and support for evidence-based care. Facilities should also coordinate with one another to provide safe transport, transfer of records, and follow-up care. Data collection, analysis, and use by providers coordinated across the continuity of care for children—within one care experience or over the course of a pediatric illness with multiple health service contacts—can make families and children's transactions with the system more respectful and efficient. This not only ensures a more streamlined and less frustrating experience for patients and their families, but also reduces the burden on health providers to coordinate logistics in patchwork ways. Processes to monitor facilities' performance and improve experience of care also require additional data collection and use. Standardized mechanisms to collect anonymous feedback from service users and the community at large and processes to use this information to improve performance are vital to ensure accountability of health care providers and the facility. In cases where health care providers are mistreated, they should also be protected and have legal recourse to ensure a positive health care environment.

For health providers and staff, policies and processes facilitating the provision of positive experiences may include paid opportunities for professional development and skill updates, psychosocial and emotional support to avoid burnout, and protections against abuse by patients, other staff, and supervisors. Where possible, interdisciplinary care teams should be formed so that trained specialists, including mental health counselors, are available to support families. Health system management should frequently review and update guidelines and policies for pediatric care, including those for offering various options and obtaining consent from patients. Facilities should have quality improvement teams (that include staff and community members) and plans to continually address challenges and improve high priority aspects within QoC.⁷² Special pediatric quality improvement teams or sessions may be needed to address the particular challenges of meeting pediatric quality care standards,⁷² including those related to experiences of care.

SAFETY AND HARM REDUCTION

Facilities should work to reduce and avoid unnecessary procedures and harm, and to follow best practices for infection control for patients and providers, in alignment with WHO quality statement 1.15: **All children are protected from unnecessary or harmful practices during their care**.³⁶ Everyone in the health facility should

also be safe from physical, verbal, and sexual abuse. Facilities must be held accountable for collection of bribes or detaining patients, and legal recourse, mediation, or other system response must be available in cases of illegal actions or malpractice. Where appropriate, facilities should serve as locations to screen children for potential harm from families or other children and adults. This may be difficult to implement for young children who may not be separated from their caregivers, but protocols should be in place and implemented if abuse is suspected.

Pediatric Experience of Care Tools, Metrics, and Measurement

The proposed Pediatric Experience of Care Framework includes domains and subdomains that are important to a contextual understanding of pediatric experience of care.³⁶ Understanding how these domains and subdomains can be measured is important to assess and address issues relating to negative or positive experiences of care in health facilities, to monitor progress in improving experience, and to evaluate interventions. To determine how these domains can be measured, we identified existing tools and metrics used to measure experience of care for children, as well as potentially relevant indicators from tools developed for other purposes, such as those used to measure general QoC, those used in high-income settings, and those used to measure care in older children. We extracted items from these identified tools and metrics as part of the scoping review and categorized them by the data collection methods used.

MEASUREMENT TOOLS BY DOMAIN AND DATA COLLECTION METHOD

Table 2 summarizes the tools, organized by category—interpersonal or health system—that we identified via the scoping review and input from experts. This table includes tools that measure some components of experience of care themes or domains, but not necessarily all of them. Even if a tool or metric source includes a domain, it does not necessarily follow that it includes all aspects of the subdomains, it only means that one or more subdomains is included in the measure. In addition to the domains identified in our proposed framework, we included tools that assess patient satisfaction. We included patient satisfaction as an outcome measure influenced by and based on, but not equivalent to, experience of care, since satisfaction is predicated on expectation. The full table of tools mapped against domains and sub-domains, including indicators, is available upon request.

Table 3 presents the tools identified in Table 2, categorized by data collection method. Types of data collection methodologies identified include exit surveys, clinical observational tools, household surveys (recall), formative, qualitative research (focus groups and interviews) and facility readiness surveys (e.g., Service Availability and Readiness Assessment [SARA] and the Harmonized Health Facility Assessment [HHFA], which builds upon the SARA). Measurements included experience of care, patient satisfaction, and validation approaches.

We found a wide range of tools available for measuring various aspects of experience of care, but no single tool or metric that encompasses every aspect defined in our proposed framework. Most tools designed to measure pediatric experience of care solicit feedback from caregivers (usually mothers) about their experience as a parent; only a few have direct observations or age-appropriate questions targeted at children. Most tools also require intensive research methods with independent, external observers or interviewers, rather than tools adapted for use within routine systems.

TABLE 2. MEASUREMENT TOOLS FOR PEDIATRIC EXPERIENCE OF CARE, BY DOMAIN

	NATIONAL SURVEY OF EARLY CHILDHOOD HEALTH, 2000 ⁷⁴	NATIONAL SURVEY OF CHILDREN'S HEALTH, 2021 ⁷⁵	CAHMI-PHDS ⁷⁶	EMPATHIC, 2009 ⁷⁷	SERVICE PROVISION ASSESSMENT (SPA), 2018 ⁴⁴	LARSON TANZANIA, 2019 ⁷⁸	FUSTINO TOOL USA, 2019 ⁷⁹	HCAHPS, 2016 ⁸⁰	HCAHPS, 2017 ⁸¹	GENERIC SHORT PATIENT EXPERIENCES QUESTIONNAIRE NORWAY (GS-PEQ) ⁸²	NATIONAL HEALTH SERVICE YOUNG PATIENT SURVEY, 2004 ⁸³	SERVICE AVAILABILITY AND READINESS ASSESSMENT (SARA), 2014 ⁸⁴	POPULATION COUNCIL BREAK-THROUGH RESEARCH KENYA, 2019 ⁸⁵
Interpersonal domains													
Communication	X	X	X	X	X		X	X	X	X			X
Non-discrimination and dignity		X	X	X	X		X			X	X		X
Accountability and legal rights				X	X				X				X
Supportive care	X	X	X	X	X				X	X		X	X
Health system domains													
Physical resources				X	X			X	X			X	
Human resources				X	X							X	X
Policy and organizational processes		X		X	X		X		X	X		X	X
Safety and harm reduction				X	X			X	X				X
Satisfaction	X			X		X	X	X	X	X			

TABLE 3. SUMMARY OF DATA COLLECTION METHODS FOR TOOLS RELATED TO PEDIATRIC EXPERIENCE OF CARE

METHODS/TOOLS	NATIONAL SURVEY OF EARLY CHILDHOOD HEALTH, 2000 ⁷⁴	NATIONAL SURVEY OF CHILDREN'S HEALTH, 2021 ⁷⁵	CAHMI-PHDS ⁷⁶	SERVICE PROVISION ASSESSMENT (SPA), 2018 ⁴⁴	LARSON TANZANIA, 2019 ⁷⁸	FUSTINO TOOL USA, 2019 ⁷⁹	HCAPHS, 2016 ⁸⁰	HCAHPS, 2017 ⁸¹	GENERIC SHORT PATIENT EXPERIENCES QUESTIONNAIRE NORWAY (GS-PEQ) ⁸²	NATIONAL HEALTH SERVICE YOUNG PATIENT SURVEY, 2004 ⁸³	SERVICE AVAILABILITY AND READINESS ASSESSMENT (SARA), 2014 ⁸⁴	POPULATION COUNCIL BR KENYA, 2019 ⁸⁵
Clinical observations				X								
Facility audit/observation				X							X	
Interview or survey after care received	X	X	X	X	X	X	X	X	X	X (AGES 0-17)*		X
Household survey					X							
Cognitive interviews or psychometric analysis							X					
Qualitative: Focus groups or in-depth interviews							X (focus group)					X (in-depth interviews)

**Indicates tools that directly gather information from children.*

Most of the tools reviewed collect data through the experiences and perception of the parent or caregiver; these tools mainly focus on the caregiver’s experience and include very few indicators focusing on the experience of the child, as indicated in Table 3. Further, most tools and literature we reviewed focus on the experience of parents with chronically ill children, those recovered from critical illness, or children and families with special needs (physical or developmental). We found few tools that assess the experience of caregivers or children during well-child and immunization visits or even routine outpatient care, except for the SPA, which focuses on outpatient care for sick children in LMICs and Every Newborn – Birth Indicators Research Tracking in Hospitals’ (EN-BIRTH) work with healthy maternal-newborn dyads after birth.⁸⁶

Essential physical resources for children in health facilities are included in indicators that use terms such as “child-friendly” to capture the notion that the physical environment is safe, clean, and suitable for children. Because more tools focus on inpatient care, particularly long-term care, few tools included questions related to the waiting area environment. Many tools addressed cleanliness, but few addressed the availability of educational or intellectually stimulating materials or play areas at facilities.

Although several very recent studies have begun to address the prevalence and impact of maternal-newborn separation, few studies address other aspects of nurturing care for newborns or children, such as sensory environment, gentle handling, and pain management.^{87, 88} Currently few tools examine support to the family, which is important for children with complex diagnoses and for bereaved families.⁶⁷

Separate tools and different processes are used to measure the quality of health care and human rights violations. We identified very few tools that capture children’s rights but did identify some that include questions to caregivers about their awareness of and inclusion in consent processes for their child’s medical care, related to accountability and legal rights. Most measures, however, did not include much detail about the consent process, type of intervention, protocols for multiple caregivers, multiple procedures, or options or knowledge about legal redress.

Similarly, there were few measures about respect focused on the child—more captured respect and the experience of the caregiver. While parents or caregivers and children may share these experiences, especially if they share characteristics, newborns and children also have independent experiences. Measurement methods and tools mask potential differences between the child’s and caregiver’s experiences. For example, questions such as “were you and your baby treated with respect?” do not separate the caregiver’s experience from that of the child. Many of the indicators included in this domain focused more on emotions, such as feelings of friendliness or kindness and overall satisfaction levels and less about the specific interactions and communication between the provider and the child and their family.

DISCUSSION

This paper explores existing pediatric experience of care frameworks, metrics, and tools and proposes a comprehensive framework to understand constructs of pediatric experience of care. Our proposed framework builds on the WHO Standards for Improving the Quality of Care for Children and Young Adolescents in Health Facilities³⁶ experience of care domains and enhances them with additional concepts from varied informational sources that affect pediatric experience of care, especially for children under five and those in LMICs. Our review of available tools and metrics for assessing pediatric experience of care reveals that there are few existing, comprehensive tools, metrics, or scales to measure important aspects across the interpersonal and health systems domains. Understanding pediatric experience of care constructs

and integrating appropriate tools and metrics for measuring these domains is essential to the assessment and improvement of pediatric care globally.

Pediatric Experience of Care Framework

Our proposed framework includes the relevant experience of care and health system domains from the WHO Quality Standards,³⁶ as well as policy and organization processes and harm reduction and safety adopted from the WHO clinical care standard #1. The interpersonal and health systems factors influence each other and can each contribute to the overall care experience for the child and their family; both types of factors require attention to ensure high-level QoC. Health facilities in LMICs that have limited resources may face unique challenges and may be more likely to deal with inadequate infrastructure, limited staffing, stockouts, and other constraints. These underlying health systems issues can increase provider stress that weakens interpersonal communication—both the system’s constraints and provider interactions may contribute to negative experiences. Understanding and measuring interpersonal and health systems factors concurrently throughout the patient pathway can identify the key factors that influence a patient’s overall experience of care, the interplay between these factors, and those issues that require improvements.

Experience of Care Tools, Metrics, and Measurement

We found a wide range of tools available for measuring various aspects of experience of care, but no single tool or metric that encompasses every aspect defined in our proposed framework. Most tools designed to measure pediatric experience of care solicit the experiences and perception from caregivers (usually mothers), and very rarely ask the child age-appropriate questions directly (except for adolescents). Tools are needed to specifically ask caregivers and even very young children about developmentally appropriate assent, engagement, and comfort during visits. We found few existing tools that assess the experience of caregivers or children during well-child and immunization visits, or even routine outpatient care, with most existing metrics focusing on chronic or critical pediatric care or children with special physical or developmental needs. Less than half the tools we reviewed have been developed for and used in LMICs; tools developed for higher income settings should not be applied in LMICs without careful adaptation and inputs.⁸⁹

Some existing metrics capture essential physical resources for children, such as a facility environment that is safe, clean, and suitable for children. As part of the Global Survive and Thrive Agenda, a broad range of approaches to support nurturing care needs to be implemented and assessed.^{90, 91} Very few metrics address the educational and developmental needs of children. The potentially unnecessary separation of infants and young children from their families during facility care requires more attention as well. Supportive and developmental care is important at every age, from preterm newborns to older children. Currently, few tools examine support provided by health care providers and facilities to families, such as for children with complex diagnoses and for any bereaving families. Recent work on family-centered and nurturing care has begun addressing some of these needs.⁶⁷

PEDIATRIC QUALITY OF HEALTH CARE AND HUMAN RIGHTS

We identified very few tools that included questions about children’s rights but did identify some that include questions to caregivers about their awareness of and inclusion in consent processes for their child’s medical care, which relate to accountability and legal rights. Most measures, however, did not include much detail about the consent process, type of intervention, protocols for multiple caregivers, multiple procedures, or options or knowledge about legal redress. Further, sometimes questions around consent are asked without

first asking the caregivers or patients about language and communication (i.e., if the family understands the child’s situation). Families need to understand the details of the child’s condition to participate in care discussions.

Tools are needed to specifically ask caregivers and children about developmentally appropriate assent and engagement of children during visits. Similarly, there were few questions about respect focused on the child; there were more questions related to respect and the experience of the caregiver. Parents or caregivers and children may share these experiences, especially if they share characteristics, but newborns and children also have independent experiences. Measurement methods and tools that compound these experiences—for example, questions such as, “were you and your baby treated with respect?”—mask potential differences between the child’s and caregiver’s experiences. Many of the questions in existing tools within this domain focused on emotions, such as feelings of friendliness or kindness, and overall satisfaction levels and less about meeting the specific interpersonal and communication needs of the child and their family.

UNIQUE CHALLENGES IN MEASURING PEDIATRIC EXPERIENCE OF CARE

LIMITED COMMUNICATION CAPACITY OF YOUNG CHILDREN: Measuring pediatric experience of care comprehensively presents unique challenges because of the difficulty in eliciting and understanding responses from young children themselves, as they have limited ability to communicate their needs and preferences. Depending on their age, children may not have the words to describe their experience of care, but they might be able to communicate it in nonverbal ways. Young children also have varying abilities to understand and respond to questions; this may be based on age as well as maturity, education, and developmental opportunities. A child’s understanding of their needs and preferences depends on developmentally appropriate communication strategies. A young child’s expectations and experiences are heavily influenced by the adults around them—both caregivers and health providers. Adult caregivers and family members may act as proxies but may mediate the response and may not always know or agree with what is in the best interest of the child. Compared to maternal health experience of care domains, pediatric experience of care requires more emphasis on non-neglect, safety, and age-appropriate communication. Yet communication is complex and impacted by many individual, system, and cultural factors. Health system functions, such as allowing providers enough time to effectively communicate with patients, are crucial indirect factors that will affect patient experience. Further, culturally normative or accepted behavior of children may not foster children’s ability to assent or voice their thoughts or opinions to adults.

CONSENT AND ASSENT: Parents and guardians have the legal right and responsibility to consent to medical treatments and care of the child. Given the complexity of some cases, families may be “informed” but not fully understand the condition or procedure. However, in cases of terminal and critical illness, parents and guardians may be unable or unwilling to make final decisions about interventions versus comfort care for critically ill children and may prefer strong recommendations by care providers.⁹² For children under five, even in cases where assent is not required, informing the child may still be important, depending on the type of care or procedure needed, as supported through the child rights framework.³⁴

DIFFERING EXPECTATIONS AND EXPERIENCES AMONG THE CHILD’S FAMILY MEMBERS: Measuring experience of care will always be difficult because of the inherent subjectivity of experience. Experience is predicated on expectations and norms, and perception and recall can change over time—all of which can also differ across contexts. Families may be unaware of standards or rights and unclear about if or when there are opportunities to give input, offer feedback, or lodge formal complaints. Families may be unaware of the need for involvement in medical choices in critical care situations or options around palliation and bereavement. Multiple parents or adult caregivers may disagree or have unequal decision-making power. Primary

caregivers are often female (mothers, grandmothers, and older sisters) introducing issues of women's empowerment, including within their households, within the health system, among the hierarchy of health care providers, and within society.

Unlike adult health care, care of young children necessarily involves other family members or caregivers, who will also have their own experiences in seeking care for a child. This may be only the birth (biological) mother or father, or it may involve multiple family members (aunts and uncles, grandparents, etc.), adoptive parents, siblings, or other adult caregivers and legal guardians. The experience of each family member might be different from that of the pediatric patient and from each other, adding to the complexity around measurement. Caregivers and families may not always have the child's best interests in mind, and may put their needs or the needs of other family and community members ahead of those of the child, especially if children have chronic, stigmatized, or labor-intensive conditions. The adult accompanying the child to a visit, or even the parent interacting with care providers in the immediate postpartum period, may not be the same over multiple visits. The adult caregiver during a clinical interaction may not be the primary caregiver of the child in the household and may be one of two or more parents or family members who are responsible for care, which will influence the family's overall experience with the health system and the ability to understand and assess that experience.

DIFFERENT EXPECTATIONS IN DIFFERENT CONTEXTS: Expectations, context, and cultural norms also influence experience of care. Suboptimal experiences may meet low expectations for care, and patients therefore may report high "satisfaction" if certain objectives are met (e.g., receipt of medications or early discharge), even where there may be deficiencies in other aspects of care. In LMICs, patients may have a lower expectation for survival and recovery and may therefore rate experiences more highly even given poor outcomes, especially when assessed retrospectively.

FAMILY STAYING WITH THE CHILD DURING PROCEDURES: In the case of pediatric critical care, parents, adult caregivers, or other family members may be able to stay in the facility with the child for varying amounts of time. For newborns, there have been recent calls to promote infant- and family-centered developmental care and to support small and sick newborns in maternal-neonatal intensive care units, even when the mother does not need additional medical care.⁹³ This type of rooming-in supports breastfeeding, bonding, skin-to-skin care, and stress reduction in both the parent and infant. In cases where the mother or adult caregiver requires separate medical care, policies should support other family members in staying with the infant or child, and hospital policies should allow multiple family members or support persons when possible and desired by the family. Similar discussions are needed for inpatient care of infants and children.

HEALTH SYSTEM FACTORS UNIQUE TO PEDIATRICS: Long-term structural change of health systems may take time, but health systems can act immediately to improve experience of pediatric care. Facilities can provide proper infrastructure that not only ensures privacy and hygiene in child-friendly ways, but also encourages education and play. Facilities need to have proper pediatric equipment and medication doses; hold regular reviews of consent procedures, checklists, and posted guidelines; and ensure that health care workers receive updated training and are themselves respected. Providers' use of pictorial cards, other linguistic tools, and enhanced training can facilitate better provision and experience of care for children and families with a range of language and educational levels and for those mostly likely to be marginalized. Transparent information-sharing amongst providers and with the community is also important at the facility level, with frequent clinical audits and shared public information, as well as service processes and plans that incorporate feedback from patient surveys, community scorecards, town halls, and other forms of patient input. In the longer term, strengthening health systems should be done with attention paid to improving the environment

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

NEED FOR TRIANGULATION: Multiple data collection platforms are important to measure experience of care for children. Methods may include triangulation of multi-dimensional measures, observations to triangulate types of practices that individuals may not yet consider disrespectful or substandard, exit surveys or follow-up interviews to understand individual experiences and discrimination, and focus group discussions to understand community expectations, norms, and priorities. Those applying any of these methods must strive to create a safe environment to enable honest responses. Triangulating data from multiple data collection methods can give a more complete picture of a child's experience of care and can combine rapid assessments with in-depth investigations. Diverse methodologies are needed to understand which practices are a result of individual provider behavior and which are based on facility (or national) policy to identify specific actions needed at different levels to improve QoC. There is also a need to identify and further develop metrics and methods that program managers can use on a routine basis.

LOW PRIORITY FOR PEDIATRIC EXPERIENCE OF CARE: Physical and human resource constraints at health facilities, especially in LMICs, are common. There is a wide range of what constitutes intensive, critical, or high dependency care and how much family involvement is allowed or encouraged. In contexts of high child mortality and morbidity, experience of care has not been considered as essential but rather may be seen as a luxury.⁹⁴ Recently there has been more recognition of the importance of experience as part of QoC; however, experiential measures might still be deprioritized, especially in settings where facilities are struggling with emergencies, low survival rates, poor health indicators, or lack of funding.

Evidence Gaps and Recommendations

There is a clear and urgent need to develop and validate tools to measure pediatric experience of care for well-child, acute, and chronic care services in LMIC contexts. Methods and metrics to assess experience of care may need to be tailored to children's ages, as well as their reason for the facility visit (i.e., well child or sick child visit, chronic or acute sick child visits, inpatient or outpatient visit). Children's communication capabilities differ by age and the optimal types of communication, family participation, emotional and psychological support, and health systems structures (physical, human resources, and organization) can vary by the type and duration of the clinical encounter. Tools and their measurement domains need to consider the child rights perspective, including querying consent and assent procedures from the child's, caretaker's, and family members' perspectives. Additionally, further work on methods and metrics will need to factor in the level of health facility and care (e.g., primary versus tertiary), as well as community-level services.

FURTHER DISSEMINATE, ADAPT, AND STUDY CONCEPTS AND CONSTRUCTS IN PEDIATRIC EXPERIENCE OF CARE IN LMIC. There has been less attention to experiences of children, caregivers, and their families during pediatric care as compared to maternal and newborn care. Global, regional, and country stakeholders should elevate the notion that pediatric experience of care is an important aspect of quality services and responsive primary health care and advocate for it. The WHO Quality Standards related to pediatric experience of care and our proposed framework are starting points, but further dissemination and adaptation of both in differing LMIC contexts will be needed. The domains and sub-domains related to experiences may need to be revised or adapted based on different contexts and service areas.

UNDERTAKE FORMATIVE AND QUALITATIVE RESEARCH. Experience of care is predicated on expectations of care and its measurement is complicated by the considerations discussed above. 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. This qualitative research can enhance the conceptualization of experience of care and improve the measurement of important domains and sub-domains in different contexts.

DEVELOP, REFINE, VALIDATE, AND USE TOOLS TO MEASURE PEDIATRIC EXPERIENCE OF CARE IN LMICS. The interpersonal and health systems domains and sub-domains presented in our proposed framework should be translated into survey items to measure specific experience of care indicators and latent constructs. Items included in survey instruments will require cognitive testing in different contexts to ensure the concepts and questions are appropriate and understood by caretakers, families, and children (where applicable). MOMENTUM Knowledge Accelerator is drafting survey items on measurement of pediatric experience of care in 2023, conducting cognitive testing and collecting data through exit interviews during a health facility assessment in Laos. Psychometric analyses of experience of care survey items included in larger-scale data collection activities can reduce the survey items and identify items related to specific latent constructs. These tools and survey items may require adaptations for the types of care (e.g., acute versus preventative) and the age of child and their communication capacity—for example, taking into consideration whether a child is old enough to assent or consent to medical procedures.

The inclusion of selected experience of care measures in large facility assessments, such as the updated 2022 SPA caretaker exit interview module that includes questions about experience of care during sick child services,⁴⁴ will be essential to identify gaps in service quality and develop quality improvement plans that address more than just clinical inputs, processes, and outcomes. Implementation of the SPA in countries will also provide valuable information about the feasibility of collecting this data, as well as data pointing to the prevalence of aspects of positive and negative experiences of care during sick child visits. Use of improved metrics and methods over time will allow researchers and program implementers to understand the effects of experiences at facilities on care-seeking, future care utilization, and health outcomes, including child development.

EXAMINE THE COMPLEX ASSOCIATIONS OF INTERPERSONAL AND HEALTH SYSTEMS FACTORS PERTINENT TO PEDIATRIC EXPERIENCE OF CARE THROUGH ADDITIONAL RESEARCH. The complex relationships between interpersonal and health systems domains that are important for pediatric experience of care require further research. For example, the availability of staff and equipment may directly affect children's and their families' experiences during care, as well as their experiences through other mechanisms. In understaffed and underequipped facilities, health care providers may not feel they have enough time or organizational support to effectively communicate with children and their families, involve them in decision-making or provide them with emotional and psychological support. Health care providers are at the forefront of interpersonal domains, but greatly influenced by health systems factors; however, the causal mechanisms require further examination across contexts. 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 experience of health care providers.

COMPLEMENT PATIENT EXPERIENCE OF CARE METRICS WITH TOOLS AND METHODS THAT EXAMINE THE NEEDS AND EXPERIENCE OF HEALTH CARE PROVIDERS. Ideally, understanding health care worker experiences should be coupled with tools to measure provider competence and confidence in providing positive experience of care. Program managers can use observed scenarios to simulate patient care experience in health worker during pre- and in-service training, including role-play and guided feedback. Other methods for gathering honest feedback from health care workers should be explored.

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 at the facility, district, and sub-national levels to identify issues requiring attention and to monitor progress. Most measurement tools we reviewed require independent, external observers or interviewers to collect and analyze the data. Opportunities to incorporate experience measurements into routine systems will need to consider unique challenges, such as biased responses while patients are still under the care of the same health facility, biased health care provider responses, limitations of records and checklists that provide only cursory binary information, and the time and skills required to administer qualitative methods. Given these difficulties, streamlined measures and efficient tools that can be used in rapid exit surveys, and in combination with other data collection platforms, may be important to incorporate into routine data collection, especially to capture differences by age, ethnicity, health condition, and other characteristics that can be disaggregated to identify inequitable care. As the conceptualization and measurement of pediatric experience of care in LMICs progresses in evaluation and research settings, researchers, evaluators, and program managers should consider metrics and methods suited for routine data collection and identify opportunities for integration and testing of these metrics and methods within existing health information systems. Input or process indicators related to experience of care—beyond tracking health care providers trained—could also be incorporated into routine systems to identify and track structural changes.

CONCLUSIONS

Competent clinical care and positive experience of care must be complementary and of equal value, not separate. Even with positive clinical outcomes, if a child or their family has a poor experience, the overall outcome cannot be seen as positive. Not only are negative experiences during care intrinsically undesirable, they may also have negative impacts on health, such as increased stress, depression, and anxiety, as well as negative impacts on trust in the health system and future health care utilization.

Developing valid and feasible pediatric experience of care metrics and tools is vital and urgent to inform improvements in overall QoC. The interpersonal and health systems domains and sub-domains in our proposed framework represent a starting point for development of items into more comprehensive tools to measure pediatric experience of care constructs across different contexts, age groups, and service types. A robust health system, one that provides high QoC, must address the needs of health care providers, patients, families, and communities. Improving measurement of pediatric experience of care is essential for understanding baseline conditions, tracking progress, assessing the effectiveness of interventions, and ultimately increasing the overall quality of pediatric care.

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APPENDIX 1: WHO STANDARDS FOR IMPROVING THE QUALITY OF CARE FOR CHILDREN AND YOUNG ADOLESCENTS IN HEALTH FACILITIES

STANDARD 1: EVERY CHILD RECEIVES EVIDENCE-BASED CARE AND MANAGEMENT OF ILLNESS ACCORDING TO WHO GUIDELINES.	
Quality statement 1.1	All children are triaged and promptly assessed for emergency and priority signs to determine whether they require resuscitation and receive appropriate care according to WHO guidelines.
Quality statement 1.2	All sick infants, especially small newborns, are thoroughly assessed for serious bacterial infection and receive appropriate care according to WHO guidelines.
Quality statement 1.3	All children with cough or difficult breathing are correctly assessed, classified, and investigated and receive appropriate care and/or antibiotics for pneumonia, according to WHO guidelines.
Quality statement 1.4	All children with diarrhoea are correctly assessed and classified and receive appropriate rehydration and care, including continued feeding, according to WHO guidelines.
Quality statement 1.5	All children with fever are correctly assessed, classified, and investigated and receive appropriate care according to WHO guidelines.
Quality statement 1.6	All infants and young children are assessed for growth, breastfeeding and nutrition, and their carers receive appropriate support and counselling, according to WHO guidelines.
Quality statement 1.7	All children at risk for acute malnutrition and anaemia are correctly assessed and classified and receive appropriate care according to WHO guidelines.
Quality statement 1.8	All children at risk for tuberculosis (TB) and/or HIV infection are correctly assessed and investigated and receive appropriate management according to WHO guidelines.
Quality statement 1.9	All children are assessed and checked for immunization status and receive appropriate vaccinations according to the guidelines of the WHO expanded programme on immunization.
Quality statement 1.10	All children with chronic conditions receive appropriate care, and they and their families are sufficiently informed about their condition(s) and are supported to optimize their health, development, and quality of life.
Quality statement 1.11	All children are screened for evidence of maltreatment, including neglect and violence, and receive appropriate care.
Quality statement 1.12	All children with surgical conditions are screened for surgical emergencies and injury and receive appropriate surgical care.
Quality statement 1.13	All sick children, especially those who are most seriously ill, are adequately monitored, reassessed periodically, and receive supportive care according to WHO guidelines.
Quality statement 1.14	All children receive care with standard precautions to prevent health care associated infections.
Quality statement 1.15	All children are protected from unnecessary or harmful practices during their care.

STANDARD 2: THE HEALTH INFORMATION SYSTEM ENSURES THE COLLECTION, ANALYSIS AND USE OF DATA TO ENSURE EARLY, APPROPRIATE ACTION TO IMPROVE THE CARE OF EVERY CHILD.

Quality statement 2.1	Every child has a complete, accurate, standardized, up-to-date medical record, which is accessible throughout their care, on discharge and on follow-up.
Quality statement 2.2	Every health facility has a functional mechanism for data collection, analysis and use as part of its activities for monitoring performance and quality improvement.
Quality statement 2.3	Every health facility has a mechanism for collecting, analysing and providing feedback on the services provided and the perception of children and their families on the care received.

STANDARD 3: EVERY CHILD WITH CONDITION(S) THAT CANNOT BE MANAGED EFFECTIVELY WITH THE AVAILABLE RESOURCES RECEIVES APPROPRIATE, TIMELY REFERRAL, WITH SEAMLESS CONTINUITY OF CARE.

Quality statement 3.1	Every child who requires referral receives appropriate prereferral care, and the decision to refer is made without delay.
Quality statement 3.2	Every child who requires referral receives seamless, coordinated care and referral according to a plan that ensures timeliness.
Quality statement 3.3	For every child referred or counter-referred within or among health facilities, there is appropriate information exchange and feedback to relevant health care staff.

STANDARD 4: COMMUNICATION WITH CHILDREN AND THEIR FAMILIES IS EFFECTIVE, WITH MEANINGFUL PARTICIPATION, AND RESPONDS TO THEIR NEEDS AND PREFERENCES.

Quality statement 4.1	All children and their carers are given information about the child's illness and care effectively, so that they understand and cope with the condition and the necessary treatment.
Quality statement 4.2	All children and their carers experience coordinated care, with clear, accurate information exchange among relevant health and social care professionals and other staff.
Quality statement 4.3	All children and their carers are enabled to participate actively in the child's care, in decision-making, in exercising the right to informed consent and in making choices, in accordance with their evolving capacity.
Quality statement 4.4	All children and their carers receive appropriate counselling and health education, according to their capacity, about the current illness and promotion of the child's health and well-being.

STANDARD 5: EVERY CHILD'S RIGHTS ARE RESPECTED, PROTECTED AND FULFILLED AT ALL TIMES DURING CARE, WITHOUT DISCRIMINATION.

Quality statement 5.1	All children have the right to access health care services, with no discrimination of any kind.
Quality statement 5.2	All children and their carers are made aware of and given information about children's rights to health and health care.
Quality statement 5.3	All children and their carers are treated with respect and dignity, and their right to privacy and confidentiality is respected.

Quality statement 5.4	All children are protected from any violation of their human rights, physical or mental violence, injury, abuse, neglect, or any other form of maltreatment.
Quality statement 5.5	All children have access to safe, adequate nutrition that is appropriate for both their age and their health condition during their care in a facility.

STANDARD 6: ALL CHILDREN AND THEIR FAMILIES ARE PROVIDED WITH EDUCATIONAL, EMOTIONAL AND PSYCHOSOCIAL SUPPORT THAT IS SENSITIVE TO THEIR NEEDS AND STRENGTHENS THEIR CAPABILITY.

Quality statement 6.1	All children are allowed to be with their carers, and the role of carers is recognized and supported at all times during care, including rooming-in during the child's hospitalization.
Quality statement 6.2	All children and their families are given emotional support that is sensitive to their needs, with opportunities for play and learning that stimulate and strengthen their capability.
Quality statement 6.3	Every child is assessed routinely for pain or symptoms of distress and receives appropriate management according to WHO guidelines.

STANDARD 7: FOR EVERY CHILD, COMPETENT, MOTIVATED, EMPATHIC STAFF ARE CONSISTENTLY AVAILABLE TO PROVIDE ROUTINE CARE AND MANAGEMENT OF COMMON CHILDHOOD ILLNESSES.

Quality statement 7.1	All children and their families have access at all times to sufficient health professionals and support staff for routine care and management of childhood illnesses.
Quality statement 7.2	Health professionals and support staff have the appropriate skills to fulfil the health, psychological, developmental, communication and cultural needs of children.
Quality statement 7.3	Every health facility has managerial leadership that collectively develops, implements, and monitors appropriate policies and legal entitlements that foster an environment for continuous quality improvement.

STANDARD 8: THE HEALTH FACILITY HAS AN APPROPRIATE, CHILD-FRIENDLY PHYSICAL ENVIRONMENT, WITH ADEQUATE WATER, SANITATION, WASTE MANAGEMENT, ENERGY SUPPLY, MEDICINES, MEDICAL SUPPLIES AND EQUIPMENT FOR ROUTINE CARE AND MANAGEMENT OF COMMON CHILDHOOD ILLNESSES.

Quality statement 8.1	Children are cared for in a well-maintained, safe, secure physical environment with an adequate energy supply and which is appropriately designed, furnished, and decorated to meet their needs, preferences and developmental age.
Quality statement 8.2	Child-friendly water, sanitation, hand hygiene and waste disposal facilities are easily accessible, functional, reliable, safe, and sufficient to meet the needs of children, their carers and staff.
Quality statement 8.3	Child-friendly, age-appropriate equipment designed to meet children's needs in medical care, learning, recreation, and play are available at all times.
Quality statement 8.4	Adequate stocks of child-friendly medicines and medical supplies are available for the routine care and management of acute and chronic childhood illnesses and conditions.



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