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# Measuring experience, including mistreatment, and satisfaction with newborn care: a scoping review of tools and indicators

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## ABSTRACT

Every woman and newborn has the right to high-quality health care, with evidence-based practices delivered in a humane, supportive environment. This quality of care should encompass clinical care as well as the experience of care of women, newborns, parents and their families, such as the rights to privacy, confidentiality, dignity, and consent. With increasing evidence showing the impact that the experience of care has on health outcomes and future care-seeking behaviors, it is necessary to understand, measure, and address the experience of care as a key driver of adverse health outcomes and a component of the right to health, equity and dignity. Building on ongoing work measuring experience of care and satisfaction of women with maternity care<sup>7</sup>, we seek to identify tools and indicators that have been developed and used to measure various domains of experience of care as related to newborns. We will conduct a scoping review to identify all available research literature on the measurements of experience of newborn care and satisfaction with newborn care and extract a comprehensive list tools and indicators used to assess experience of newborn care and satisfaction with newborn care during the postnatal period.

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## KEYWORDS

newborn care, experience of care, quality of care, health systems, mistreatment, postnatal care, childbirth

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## 1 BACKGROUND

Every woman and newborn has the right to high-quality health care, with evidence-based practices delivered in a humane, supportive environment. This quality of care should encompass clinical care as well as the experience of care of women, newborns, parents and their families, such as the rights to privacy, confidentiality, dignity, and consent.<sup>1</sup> The WHO's *Standards for improving quality of maternal and newborn care in facilities* highlights eight standards of quality of care that should be guaranteed to ensure a good experience of care during childbirth and the early postnatal period including communication and participation (standard 4), rights and dignity (standard 5) and family-centered and developmental care including emotional and psychological support (standard 6).<sup>6</sup>

While efforts have been placed towards improving women and newborns' experience of care and, in particular, to ensuring respectful person-centered care during childbirth, there is still no agreement on measurement tools and indicators to guide research, action, and allow comparability and accountability. In Larson and colleagues recently published review of tools to measure maternal and newborn experience of care, they highlight the lack of a single, comprehensive, and validated instrument, with one of the biggest gaps in measurement of newborn care experience.<sup>7</sup> However, this review only looked at tools and indicators of newborn care experience as it relates to women/parents' experience.

Despite the clear overlap of the type of (mis)treatment received by women and newborns, a literature review on mistreatment of newborns found that the core domains differ.<sup>2</sup> For example, the typologies developed for women during childbirth tend to focus on events of direct abuse,<sup>3</sup> whereas early evidence about disrespectful care of newborns suggests that mistreatment primarily focuses on issues regarding neglect, separation from the mother/family, inappropriate feeding practices<sup>4</sup> and absence of gentle, compassionate or supportive environment.<sup>2,5</sup> This emphasizes the need for placing more attention into understanding and measuring newborns' experience as a separate event from that of the mother.

With increasing evidence showing the impact that the experience of care has on health outcomes and future care-seeking behaviors, it is necessary to understand, measure, and address the experience of care as a key driver of adverse health outcomes and a component of the right to health, equity and dignity. Building on ongoing work measuring experience of care and satisfaction of women with maternity care<sup>7</sup>, we seek to identify tools and indicators that have been developed and used to measure various domains of experience of care as related to newborns.

## 2 WHY IS THIS SCOPING REVIEW NEEDED?

Building on Larson and colleague's (2020) scoping review<sup>7</sup>, we consider it important to conduct an additional review for several reasons. First, we will ensure that newborn care is adequately captured in the search, as it may be missed in the search terms that exclusively or mainly focus on maternity care. Also, there is a lack of standardised and operational definition of "experience" of newborn care. Newborns capacity to communicate their experience with care depends on health providers or carers' ability to interpret non-verbal cues. Unlike women, newborns lack the autonomy to make choices about their body or medical procedures. This adds an extra consideration when defining the concept of experience of newborn care as it becomes necessary to identify who advocates on behalf of newborns, and whether they discern between their own experience and that of the newborn.

This scoping review therefore seeks to cover two main concepts within the realm of quality of care. The first concept is the experience of newborn care which includes (1) the experience of the baby for which the mother/parent/carer or family act as a proxy voice such as the management of pain during invasive procedures (direct experience); (2) the experience of the newborns through biological indicators such as cortisol levels, sleep or cry patterns (observed experience); and (3) the experience of the mother/parents/carers and families with the care the newborn receives such as being informed about the procedures performed to the newborn (indirect experience). The second concept relates to the overall satisfaction of mother/parents/carers and families with the care the newborn received, which is understood as an outcome measure influenced by experience of care. Although there is an overlap between these concepts, as experiences may be shared by a newborn and the mother/parents/carers and families, there is a conceptual difference which should be accounted for when operationalizing and developing tools to measure them.

Standardized data on experience of care is essential to understanding the type of care women and newborns receive and to designing appropriate interventions/responses. This review will build on ongoing work in the realm of maternity care and will complement it by assessing tools and indicators to measure experience of newborn care, and satisfaction

with care during the postnatal period.

## REVIEW QUESTION AND OBJECTIVES

### 3 REVIEW QUESTION:

What are the tools and indicators used to measure experience of newborn care and satisfaction with care during the postnatal period of the newborn?

#### OBJECTIVES:

- To scope the range of available research literature on the measurements of experience of newborn care and satisfaction with newborn care during the postnatal period
- To identify the main definitions and domains of experience of newborn care and satisfaction with newborn care during the postnatal period from the identified literature
- To list tools and indicators used to assess experience of newborn care and satisfaction with newborn care during the postnatal period

To map the available domains, tools and indicators according to predefined concepts of experience of newborn care and satisfaction with newborn care during the postnatal period

## METHODS

### 4 DEFINING CONCEPTS UNDER REVIEW

The concepts being studied include (i) experience with postnatal care and (ii) satisfaction of mother/parents/carers or families with the care received by the newborn. Following Larson et al<sup>8</sup> definitions of person-centered quality measures, we consider:

**Experience of newborn care** as a *process* measure that reflects the interpersonal aspects of the quality of care received by the newborn during the postnatal period, including care sought in later weeks of the infant's life. Experience of newborn care will be divided into: 1) direct experience, if it uses participants as a proxy voice for the newborn; 2) observed experience, if it uses biological indicators such as cortisol levels, cry patterns, interruption of sleep and feeding; 3) indirect experience, if it aims at measuring mothers/parents/families or carers' experience with the care received by or sought for their newborn. The mistreatment of the newborn will be considered as a subtype of experience of care (direct, observed or indirect) that focuses on normalized or contested activities that may constitute mistreatment, or any deviations from national guidelines or international human rights standards

**Satisfaction of mothers, parents, carers or families** with the care received by the newborn defined as an *outcome* measure of a mothers/parents/carers or families' experiences of care, along with health outcomes and confidence in the health system during the postnatal and neonatal period, including care sought in later weeks of the infant's life

### 5 INCLUSION CRITERIA

#### Population of interest:

Newborns born either from home or facility-based birth who have sought or received newborn care or mothers/parents/carers or families who sought or received care for their newborn during the postnatal period (from birth until the sixth week of life).

#### Measures of interest:

We will include all tools (quantitative or qualitative, e.g. topic guides) or indicators related to experience of newborn care or satisfaction with newborn care, this will also include measures of mistreatment of the newborn by health providers during the postnatal period, including, but not limited to, neglect, denial of care, or other categories as presented in

### Type of document:

We will include primary quantitative or qualitative studies, thesis/dissertations or reports/documents focusing either on the experience of care (including mistreatment) of the newborn during the postnatal period or the experience and/or satisfaction of the mothers/parents/carers or families as it relates to the care sought or received by the newborn. We will include all resources without any restriction on country's level of development (i.e., low- middle- or high-income groups) or geographical region as long as they present information on the tools or indicators used. The review will exclude opinion pieces and editorials, policy papers, conference abstracts, and general reports that do not introduce new information. Reviews will be excluded but their reference lists will be hand searched for potentially relevant studies.

## 6 SEARCH STRATEGY

### Search on ongoing work:

Initially, we will review all included documents from the ongoing work measuring experience of care and satisfaction of women with maternity care<sup>7</sup>, to identify those that also apply to newborn experience of care, or satisfaction with newborn care

### Literature search:

After, five databases (MEDLINE [Ovid], Embase, Web of Science, CINAHL, and the WHO Global Health Library) will be searched with a pre-determined strategy. Bibliographies of those papers that match the eligibility criteria below will be searched by hand to identify any further, relevant references, which will be subject to the same screening and selection process. No language restriction will be imposed. Publication period will be limited to the past 10 years (2010-present) to ensure that the most updated and currently used indicators and methods are captured in this review.

The following search strategy for Pubmed will be adapted for the other search engines:

((((((("Infant Health"[Mesh]) OR "Postnatal Care"[Mesh] OR "Newborn Care"[Mesh] OR "Newborn Health"[Mesh] OR "Neonatal Care"[Mesh] OR "Neonatal Health"[Mesh]) OR "Maternal-Child Health Services"[Mesh]) OR "Infant Care"[Mesh]) OR "Child Health Services"[Mesh]))) AND (((((experience[tiab] OR experiences[tiab] OR patient-centered[tiab] OR "woman centered"[tiab] OR "women centered"[tiab] OR "client centered"[tiab] OR satisfaction[tiab] OR "social support\*" [tiab] OR "emotional support\*" [tiab] OR "provider choice"[tiab] OR "choice of provider"[tiab] OR "wait time\*" [tiab] OR affordability[tiab] OR dignity[tiab] OR respect[tiab] OR privacy[tiab] OR confidentiality[tiab] OR discrimination[tiab] OR communication[tiab] OR disrespect[tiab] OR abuse[tiab] OR mistreatment[tiab] OR perception\* [tiab] OR "positive experience"[tiab])))

### Grey literature search:

Finally, grey literature will be scoped. ProQuest will be searched for relevant dissertations/theses. We will supplement this with a Google Scholar search using keywords relating to experience of newborn care, including mistreatment, and satisfaction with care during the postnatal period. We will also initiate a collaborative exchange with maternal and newborn health (MNH) networks and international organisations via solicitations over email list serves and social media to expand the search to unpublished studies and tools.

## 7 SCREENING AND SELECTION

For published papers, titles and/or abstracts retrieved using the search strategy will be independently screened by two reviewers according to initial inclusion criteria. For the grey literature, executive summaries and table of contents will be reviewed against the inclusion criteria. If it is unclear whether a document meets the inclusion criteria it will be carried forward to the next stage. Disagreement will be resolved by discussion or, if not possible, with reference to a third reviewer.

The full text of potentially eligible documents will be retrieved and independently reviewed by two reviewers until at least 80% of consistency is reached. After that time, the reviews will be continued by one independent reviewer. A subsample of 20% of the included and excluded documents will be reviewed against the inclusion criteria by a second reviewer to

ensure quality. Disagreement will be resolved by discussion or, if not possible, with reference to a third reviewer.

## 8 DATA EXTRACTION

An electronic data extraction form will be created and tested against five documents by two independent reviewers. The data extracted will include (i) characteristics of the document; (ii) characteristics of the tools used to measure the relevant concepts. Within the first group of extracted data, we will be including, but not limited to, study design, research question, setting, population, newborn condition at time of birth, newborn condition at time of seeking care, outcomes, data collection process, and analysis. The second extraction will include characteristics of the data collection tools, topic guide or indicators related to any of the concepts under review. In this group we will extract information of the instrument used, outcome measured, test of validity/reliability, domains, scoring system/index, population evaluated, and proportion of the measured outcomes. We will also document if the tools are designed to measure universal experience vs a subset, for example families with low birth weight infants or adolescent mothers.

If the measurement tool is not available in the document (or supplementary materials), we will contact the authors to request it. Documents will not be excluded based on the availability of tools if they contain sufficient information on indicators.

## 9 QUALITY ASSESSMENT

Quality assessment is generally not performed in scoping reviews where the purpose is to provide an overview of the existing literature regardless of quality.

## 10 STRATEGY FOR DATA SUMMARY AND SYNTHESIS

To summarize and synthesize the findings, we will follow a two-step process. First, we will describe the characteristics of the tools and indicators following the authors' description. During this step, we will present the documents' definition of the concept under study (i.e. experience of care, satisfaction or mistreatment), the domains being measured (i.e. emotional support, unnecessary medical procedures, neglect, etc), and the tools, topic guides and indicators used to measure them. This first step will provide an overview of how the different concepts are understood and operationalized within the literature, while also providing a compendium of tools and indicators that could be available for future use. In this step we will also present the tools and indicators by (i) newborn condition at birth (small and sick newborns, by complications), (ii) by place of care of the newborn (NICU, community, other facility ward) and (iii) by geographical region. Other categorizations may also be performed as relevant (maternal age, infant sex, etc).

Second, we will map each domain measured in the included documents to one of the concepts under review (direct experience of care, indirect experience of care, mistreatment and satisfaction with care) based on the definitions presented above (refer to Defining concepts under review). Because we expect a lack of consensus on how the included document define and operationalize the concepts under review, this exercise will allow us to find a common understanding of what constitute experience of newborn care, mistreatment and satisfaction with care. As an output of this step, we will allocate the domains under each concept, jointly with the tools, topic guides and indicators used to measure them.

## 11 REPORTING THE RESULTS

Reporting, write-up and any publication generated from the scoping review will follow the PRISMA-ScR (Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews) format.<sup>9</sup>

### REVIEW TEAM MEMBERS AND AFFILIATIONS

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## CONFLICT OF INTEREST

**13** We declare no conflict of interest

## TIMELINE

**14 Anticipated or actual start date**

July 2021

**Anticipated completion date**

January 2022

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