

Experts' Perspectives Toward a Population Health Approach for Children With Medical Complexity



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ABSTRACT

OBJECTIVE: Because children with medical complexity (CMC) display very different health trajectories, needs, and resource utilization than other children, it is unclear how well traditional conceptions of population health apply to CMC. We sought to identify key health outcome domains for CMC as a step toward determining core health metrics for this distinct population of children.

METHODS: We conducted and analyzed interviews with 23 diverse national experts on CMC to better understand population health for CMC. Interviewees included child and family advocates, health and social service providers, and research, health systems, and policy leaders. We performed thematic content analyses to identify emergent themes regarding population health for CMC.

RESULTS: Overall, interviewees conveyed that defining and measuring population health for CMC is an achievable, worthwhile goal. Qualitative themes from interviews included: 1) CMC share unifying characteristics that could serve as the basis

for population health outcomes; 2) optimal health for CMC is child specific and dynamic; 3) health of CMC is intertwined with health of families; 4) social determinants of health are especially important for CMC; and 5) measuring population health for CMC faces serious conceptual and logistical challenges.

CONCLUSIONS: Experts have taken initial steps in defining the population health of CMC. Population health for CMC involves a dynamic concept of health that is attuned to individual, health-related goals for each child. We propose a framework that can guide the identification and development of population health metrics for CMC.

KEYWORDS: children with medical complexity; children with special health care needs; complex chronic conditions; health outcomes; population health

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WHAT'S NEW

A consensus approach to population health for children with medical complexity (CMC) does not yet exist. On the basis of interviews with experts on CMC, we developed a population health framework for CMC that can help guide policies and programs for CMC.

IMPROVING THE HEALTH of populations is a national priority codified by the Triple Aim.¹ Children with medical complexity (CMC), a subset of children with special health care needs (CSHCN), are a particularly important population due to their high needs and disproportionate use of resources. Comprising less than 3% of US children, CMC generate substantial costs, including 40% of child Medicaid expenditures.^{2,3} This population of children is most commonly conceptualized as having a combination of significant family-identified service needs; chronic,

severe conditions; functional limitations; and high health care use.²

Given the outside importance of CMC to the child health system, an appropriate framework for population health is important. General definitions of population health vary, but as established by Kindig and Stoddart,⁴ typically involve the aggregated health outcomes of a group of individuals, with special consideration of the distribution of those outcomes and factors that contribute to variability in that distribution.⁵ Because CMC are generally on one extreme end of the health distribution for all children, more general conceptions of population health—such as the Healthy People 2020 framework,⁶ the Institute for Healthcare Improvement model for population health,⁷ the Institute of Medicine Framework for Indicator Development,⁸ and even the 6 Core Outcomes for Children With Special Health Care Needs⁹—and the metrics that serve them may fail to adequately capture important health differences among CMC themselves.

Furthermore, important domains relevant primarily to CMC may be missing from existing frameworks. For example, the recognized impact of caregiving for CMC on the physical and mental health of families,^{10,11} which may in turn affect the health of CMC, is largely absent from existing models of population health.

Previous efforts have explored what population health might mean more broadly for CSHCN,^{9,12} but consensus outcomes for CMC, whose problems are simultaneously more severe and more heterogeneous than those of other CSHCN, remain elusive.^{12,13} Although aspects of the outcomes applied to CSHCN are likely relevant to CMC, such as access to a medical home and adequate health insurance, they likely do not fully capture the nuances of the CMC population. Numerous outcomes have been included in research among CMC¹⁴; however, the validity of these measures and their applicability to the population are often unknown.

Qualitative research with CMC experts around the United States could supplement the current literature to fill these gaps and provide a more comprehensive conceptualization of population health for CMC. Although the importance of family members,^{15–17} providers,¹⁷ and systems leaders in comprehending and shaping outcomes related to CMC is readily acknowledged, previous work has not synthesized these experts' perspectives on population health for CMC. The purpose of this study was to interview a diverse national stakeholder group to identify key population health outcome domains for CMC as a step toward determining core health metrics for this distinct population of children.

METHODS

We performed an in-depth qualitative analysis of interview data collected from a diverse group of experts on CMC to better understand population health for CMC. This study was conducted as phase 2 of a larger project that combines systematic literature review (phase 1)¹⁴ and group concept mapping¹⁸ (phase 3) to propose candidate population health outcomes for CMC.

PARTICIPANTS

We used purposive sampling to create a sample of key stakeholders that was diverse in terms of geography, gender, race/ethnicity, and expertise related to CMC. Initially, the research team generated a list of potential nominees for interviews on the basis of personal knowledge of individuals and organizations involved in the care of CMC, subsequent snowball sampling, and our previous literature review. That list was supplemented and refined during a 4-month process; e-mailed invitations for interview participation were then sent to 28 individuals. Our goal was to interview a broad array of prominent stakeholders within each of 3 main categories of expertise (child and family advocate; provider; and systems, research, or policy leader). Twenty-three invitees (82%) agreed to be interviewed. Their primary categorization, as determined by our research team and interviewee responses to a question

asking about their role with CMC, was: 5 child and family advocates; 6 child health care and social service providers; and 12 health care systems, research, or policy leaders. Several of the 23 participants spanned multiple categories of stakeholders. All participants granted their permission to report their names and titles ([Online Appendix 1](#)).

DATA COLLECTION

We developed a semistructured interview guide that was informed by our preceding systematic literature review¹⁴ and refined after pilot testing. Interviews queried participants about their perspectives on population health for CMC, including unifying features of CMC, definitions of health for CMC, and challenges in measuring the population health of CMC. (Sample interview questions are provided in [Online Appendix 2](#).) Approximately 1 day before interviews, interview participants were e-mailed the interview guide. Qualitative methods using one-on-one, semistructured confidential interviews were used. Interviews took place by telephone and lasted 30 to 60 minutes. Interviews were conducted by 3 team members trained in qualitative methods.

DATA ANALYSIS

We used 6-step thematic content analysis to identify themes representative of participants' views on population health of CMC.¹⁹ Interviews were audio-recorded and transcribed by a transcription service. Using ATLAS.ti software (ATLAS.ti Scientific Software Development, Berlin, Germany), 3 coders independently reviewed the transcripts to discuss codes. These initial codes were discussed with our entire research team at a research meeting. After a subsequent round of independent coding, the entire research team met again to compare initial themes and reach consensus. Two coders then independently coded the interview transcripts. A third coder resolved any disagreements between coders. Kappa statistics were calculated to measure consistency between the 2 main coders on the basis of examination of a random sample of transcripts. We continued interviews until we reached saturation of themes, as assessed during discussions during weekly research team meetings. In total, we conducted 23 interviews, which passed and then confirmed saturation of themes.²⁰

RESULTS

Overall, participants across all the stakeholder groups expressed that defining and measuring population health for CMC is an achievable, worthwhile goal. The experts' perspectives on population health for CMC were categorized into the following 5 themes: 1) CMC share unifying characteristics that could serve as the basis for population health outcomes; 2) optimal health for CMC is child specific and dynamic; 3) health of CMC is intertwined with health of families; 4) social determinants of health are especially important for CMC; and 5) measuring population health for CMC faces serious conceptual and logistical challenges. Kappa ranged from 0.52 (moderate agreement)

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