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Measuring patient-centered care for specific populations: A necessity for improvement

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Abstract

The measurement of patient-centered care (PCC) is a fundamental component of assessing and improving health care quality. There are a variety of PCC measures available which have been tailored to different health care conditions and settings. These distinct measures are valuable given the diversity of health conditions and contexts encountered in the health care system. However, the type of patient has received significantly less attention when measuring PCC despite the multitude of unique patient populations that exist. Specific patient populations raise several core challenges for PCC measurement to which researchers and practitioners need to attend: identifying *what* principles to measure, *who* is the most appropriate assessor, and *how* best to measure PCC. Examples of specific patient populations include geriatric patients, refugees, migrants and dyadic patients. Dyadic patients, such as the mother-infant dyad, are two individual, independent, yet inextricably linked patients who require simultaneous care. In this commentary, we use the mother-infant dyad as one example of a specific population to illustrate the challenges and argument for why additional specific patient populations warrant dedicated measures of PCC.

Keywords

Patient-centered care, survey measurement, patient populations, dyadic care, maternal-infant dyad

Patient-centered care (PCC) is one of the core aims for health care quality and improvement identified by the Institute of Medicine (IOM).¹ In *Crossing the Quality Chasm* the IOM defined PCC as “providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions.”¹ This definition emphasizes the importance of the individual patient, their clinical needs, and their perspective. The assessment of the patient experience is a window into understanding PCC and opportunities for improvement. As such, there has been a proliferation of tools, such as the Consumer Assessment of Healthcare Providers and Systems (CAHPS) surveys, to measure patient experience for different types of health conditions (e.g., cancer care, mental health care) and care settings (e.g., nursing homes, dialysis centers, hospitals). These distinctions are valuable given the nuances within and heterogeneity between these different conditions and contexts. Surprisingly, who the patient is has received significantly less attention, despite the existence of distinct patient populations.

Utilizing appropriate measures of PCC for specific patient populations is crucial in order to improve the quality of care. Thus far, the Agency for Healthcare Research and Quality has delineated adults versus children and the American Indian population as those with specific PCC

experiences. Yet, there are other patient populations with distinctive circumstances for whom PCC may be different as well, such as geriatric patients, refugees, migrants and dyadic patients. Dyadic patients, or patient dyads, are individual, independent, yet inextricably linked patients who require simultaneous care. Examples of patient dyads include the mother-infant dyad receiving perinatal care, sexual partner dyads receiving care for sexually transmitted diseases, and partner/spousal dyads receiving relationship therapy.

Each of these specific patient populations have unique experiences and interactions with care providers and the health care system, which differ from each other and the general population. These differences imply a need for measurement specificity to capture experiences accurately. Specific populations raise several core challenges for measurement to which researchers and practitioners should attend: identifying *what* principles to measure, *who* is the most appropriate assessor, and *how* best to measure PCC. With nearly four million women hospitalized for childbirth each year,² the mother-infant dyad is a commonly encountered patient dyad in the health care system and an example population that illustrates each of these challenges.

The What. The Picker Institute identified eight principles of PCC: 1) respect for patients' preferences, 2) coordination and integration of care, 3) information and education, 4) physical comfort, 5) emotional support, 6) involvement of friends and family, 7) continuity and transition and 8) access to care.³ In the context of mother-infant care, distinguishing what principles are relevant or satisfied for each individual of the dyad, and for the dyad as a unit, is important and potentially challenging. For example, consider a healthy woman whose fetus has a high-risk condition that requires intensive care immediately after birth but that was unknown prior to birth. She delivers at a hospital close to her home, which provides timely and risk-appropriate access to care (principle #8) for her. However, the hospital does not have the capability to care for her sick infant. Thus, while the hospital does provide patient-centered access to care for the mother, it does not do so for the infant or the dyad as a whole. The combination of individual and dyadic patient needs may warrant consideration of additional or new permutations of PCC principles. The same is likely to be true for other specific patient populations. Thus, research to identify which principles are core for assessing PCC for different patient types is needed. While respect (principle #1) likely applies to all patient populations, involvement of family and friends (principle #6) may not be a core component of PCC for dyads receiving treatment for a sexually transmitted disease. Conversely, adding the principle of confidence (i.e., trust) in the assessment of migrant and refugee care⁴ or the principle of togetherness for mother-infant dyad care may be important for measuring PCC in these groups.

The Who. Assessments of patient-centeredness can be obtained from a variety of perspectives, including patients, family members, health care providers (e.g., a physician or nurse), health care staff, or third-party observers. Identifying who is the best assessor for specific patient populations is not always straightforward. Using the mother-infant dyad as an example, it is not clear whether a mother who is hospitalized concurrently with her infant can differentiate between the PCC received by her and that received by her child. Additionally, it is unclear whether differentiation is necessary if the aim is to measure PCC for the dyad. Similar challenges likely exist within the geriatric patient population as well, particularly for individuals with dementia and their caregivers. In many areas of health care, we rely on clinician or staff assessments of care, but it is unclear whether or when that is appropriate for PCC. Patient and clinician assessments of PCC can differ. In a study of adult patients with inflammatory bowel disease, coordination of care was rated lower by patients, while care accessibility was rated lower by physicians.⁵ Research that accounts for the patient's perspective, the patient's ability to individually report their experience, and differences in perception based on measurement source need to be prioritized.

The How. Dyadic patient care, for example, creates a multiplicity of providers, care teams, hospital units, or clinics, which span professional and organizational boundaries. Care that crosses boundaries raises further issues related to how to measure dyad-centered care and if previous approaches to PCC assessment can be adapted to a dyad. A significant portion of PCC research and associated measures have focused on the individual patient encounter or physician-patient relationship—the micro-organizational level of PCC. Conversely, establishment of Accountable Care Organizations and patient-centered medical homes has sparked interest in patient-centeredness at the macro-organizational level. Patient experiences during hospitalization, such as childbirth, center around the hospital unit or meso-organizational level and are often measured by surveys such as Press Ganey or Hospital CAHPS. The approach to assessing PCC for the mother-infant dyad, which crosses boundaries of time, health care disciplines, and care settings is not readily amenable to existing measures at the micro-, macro-, or meso-organizational level. This suggests a need for developing measures that span levels, in order to address the centeredness of patient care and experiences of boundary-spanning populations.

In conclusion, PCC measures for additional specific patient populations are needed. Development of such measures should balance the benefits of specificity with consistency and standardization to allow for comparison and aggregation of PCC data. Each specific population has a range of potential PCC principles as well as patient needs and values to consider (*the what*), patient and provider types involved (*the who*), and points of contact with the health care system (*the how*) that should be integrated. Given the reported benefits of PCC, such as improved treatment compliance,⁶ decreased diagnostic testing,⁷ and improved outcomes,^{8,9} optimizing the measurement of PCC for all types of patients is a key strategy for care improvement. The value of PCC measures for different health conditions and care settings has been accepted by the community. The mother-infant dyad is just one example of why specific patient populations also warrant distinct measures of PCC.

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