

Person-Centered Health Services Research: Policy Implications

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Since the origins of the field of health services research (HSR) in the 1960¹, investigators have relied on large administrative datasets or national surveys as the primary tools to inform, increase knowledge, and ultimately improve individual patient care processes and outcomes². Over the past eight decades, the field has expanded its focus, leveraging scientific inquiry to address critical questions about healthcare access, cost, and quality of care³.

While the datasets that can be used are very large and sometimes create the possibility of population-based research, these records are generally limited by the administrative nature of information collection in healthcare. The historical emphasis for the collection of information was to support the business operations of the clinical service delivery system (e.g., billing). Consequently, these records contain extensive details about care provision but far less about the specific characteristics of individuals receiving care. Typically, only basic demographic data, such as age, sex, race (in the U.S.), and clinical diagnoses, are consistently available. In contrast, a substantial amount of information is available about service use. This imbalance has led policy research to be focused less on the people served and more on what the system has done with the people served. The nonavailability of robust person-specific information has led researchers and policymakers to depend on various metrics of healthcare services (e.g., length of stay, hospital readmissions) as proxies for access to healthcare services, as well as quality and clinical outcomes obtained from the provision of healthcare services, despite their imperfect alignment with true patient needs, values and/or health status.

Survey research in health services suffers from a similar gap albeit for a different reason. Survey research relies on a single respondent, generally the health care recipient or person sampled to answer questions about their health status. This might usually be adequate for most general questions of health status; however, it would be fundamentally flawed for more clinically relevant information that are particularly relevant for questions of clinical decision-making and utilization. Relying on self-reported respondents' data in this way requires questionable assumptions about people's awareness and openness regarding their health and recall of service utilization.

Of course, it is impossible to know what you do not know so the field of HSR has continued with its existing definition of 'normal science,' often not recognizing the policy implications of the absence of meaningful data about the clinical and functional status of people seeking healthcare in the analysis of access, costs and quality. Such

a tradition will soon change. If we ensure that our latest methods of analyses to date shall continue to replicate and generalize in a big way, then the impact will be dramatic and can potentially influence healthcare decisions and/or policy.

While researchers have long engaged in evaluation projects that resulted in the collection of more person-centered data than routinely available, the only means of developing sustainable person-centered information to inform ongoing policy research is to embed these data in routine care. One of the most important justifications for the need to incorporate person-centered data in routine care arises from the fact that patients' goals in managing their condition may differ from those of professionals, nonetheless both are equally important⁴. Studies have shown that this type of collaborative approach can lead to improvements in physical and psychological health and strengthen patients' confidence and skills to manage their health⁵, hence this justifies the need to incorporate person-centered data as well as person-centered perspectives in routine care. The widespread use of electronic health records (EHR) offers an interesting opportunity to begin to address this gap in our science. Most EHRs offer the opportunity to collect and record more patient-specific information about a patient who is seeking medical attention than most of the existing administrative datasets. However, their research utility remains limited by four key barriers: (1) clinicians using EHRs may spend more time documenting information with less time for face to face patient care, which can sometimes hinder communication⁶ in the patient encounter⁷; (2) technical constraints in bulk data extraction; (3) insufficient validation of non-audited data elements; and (4) lack of standardization across systems making most research idiosyncratic to the specific EHR.

Our work offers conceptual framework for an alternative approach to address the chronic problem of insufficient information infrastructure to support person-centered policy research. Using a conceptual framework called Transformational Collaborative Outcomes Management (TCOM)⁸, we have created and implemented reliable and consistent strategies for capturing clinical and functional information about people seeking help.

Our recent study⁹ is a landmark achievement for being the first explicit application of the TCOM approach for the purpose of conducting a HSR methodology. Its implications are impressive and particularly noteworthy. In this particular study, we were able to demonstrate that no child/youth utilized more care than would be expected by their overall level of clinical and functional complexity. In other words, there were no 'over-utilizers.' Traditional HSR had identified 'high utilizers' by targeting the upper end of the service use distribution (e.g., the top 20% of the

population that utilize 80% of the services). This framework has spurred substantial healthcare investments, with tens of millions being collected annually for the purpose of spending on managed care programs aiming at reducing healthcare utilization, especially among the groups with the highest level of healthcare utilization in order to contain cost. The implicit assumption then is that among the high utilizers are children/youth who were using more than they need and these potential 'over' utilizers should be the focus of cost containment. Our research findings have suggested that such an assumption might not hold true, at least among the group of patients receiving intensive community treatment. In fact, it might not be prudent to regard high utilizers as over-utilizers because it could potentially result in a denial of appropriate healthcare, which should rightfully be rendered to children/youth. The main problem with the person-centered analysis was 'under-utilization', whereby the children/youth were being represented as a group of patients who had expended significantly fewer services than dictated by their actual needs. Taken together, such findings have suggested that the traditional managed care model will not be effective with intensive community care because it usually tends to focus on utilization management and cost.

Of course, this is one study in a single state and requires independent replication and extension. However, the policy implication of such a move is that the traditional approaches to managed care may not work and it can result in a waste of money. Instead, our research suggests that this investment perhaps should be refocused on helping find strategies to better engage children and youth in intervention approaches to help them address their needs and build their strengths.

Similar TCOM applications are in progress elsewhere. We have used person-centered assessment to establish case management rates and to refer into service packages. We are currently collaborating with a large Western state to help them redesign their foster care system in order for the money to follow the child rather than the placement. If this initiative is successful, the implications are potentially profound.

The TCOM approach requires us to utilize a specific measurement framework [called the Child and Adolescent Needs and Strengths (CANS)] to collect a sufficient range of indicators to fully represent the healthcare needs of each and every individual in the person-centered analyses. However, such an approach is not without controversy. In fact, it necessitated the development of an alternative measurement theory: 'communimetrics'¹⁰. Evolving from 'clinimetrics'¹¹ rather than 'psychometrics'¹², this approach enables the creation of functional and clinical status profiles with individually reliable and valid indicators. This feature is essential, as it ensures a holistic understanding of an

individual's needs and strengths. Yet, measurement alone is not enough. To fully understand patterns in needs and strengths, such as trends, clusters, and outliers, we must adopt innovative analytical and visualization methods beyond those traditionally used in health services research. Emerging approaches from genomics, gene-expression analysis, and flow cytometry, particularly dimensionality reduction¹³⁻¹⁵ and latent variable modeling^{16,17}, show promise in identifying subgroups with similar functional needs. These methods offer the potential to reveal critical pathways to improvement, offering a more nuanced and actionable understanding of individual and population-level outcomes.

Still, regardless of the measurement framework or analytical approach, we believe that there are a number of important considerations for our system to achieve a true person-centered reform. Elsewhere we have described our work to accomplish such an infrastructure build in order to support a trauma-informed system of care¹⁸. An important requirement is that we must develop an information infrastructure that reliability documents the clinical and functional status of people seeking help -- with individual needs, wishes, and resources based on their lived experiences^{19,20}, -- enabling this information to be used for system design and management.

Fortunately, a paradigm shift toward person-centered care is gaining momentum in quality measurement²¹, care redesign²² and implementation of health services research findings into practice²³. For example, since 2009, the Consolidated Framework for Implementation Research (CFIR)²³ has served as a practical determinant framework, synthesizing and refining previous models to provide operationally defined constructs. The CFIR is organized into five domains encompassing 39 constructs, each designed to identify factors that influence implementation efforts. These five domains can be instrumental in exploring stakeholders', such as healthcare professionals, policymakers, and academics, perceptions of person-centered care within their respective contexts. By applying the CFIR lens, each stakeholder can assess and prioritize of person-centered care implementation efforts based on their unique understanding of it and its relevance to their healthcare delivery environment.

However, several factors initially hindered this transition, most notably the absence of a standardized, empirically validated framework for implementing person-centered approaches (including person-centered, patient-centered, and people-centered care models). The WHO Global Strategy on People-Centered and Integrated Health Services emphasizes that there is no single universal model for person-centered care²⁴. Rather, implementation should be context-specific, with each country developing its own evidence base to establish appropriate, acceptable, and

feasible practices. In the United States, while the traditional profession-centric healthcare system was well-intentioned, it has consistently fallen short of delivering truly person-centered care. Similarly, value-based contracting initiatives have largely underdelivered, primarily because they frequently fail to incorporate the clinical and functional outcome data that should define the true 'value' of healthcare interventions.

TCOM approach represents one promising pathway to accelerate this shift and be an alternative approach to address the chronic problem of insufficient information infrastructure to support person-centered policy research. Its focus on consensus-based measurement and reliability at the indicator level, as seen in tools like the CANS, addresses some of the major challenges posed by traditional behavioral health status measures²⁵. We have already had experiences of using this framework to support the redesign of a foster care rate system, the shift from a program-based eligibility model to one based on need, and providing evidence for support of sustained funding of a discretionary program after change in state governance among other examples.

The ultimate goal of a person-centered approach to systems level research is to allow the characteristics of the whole patient, not just the patient's problem, to help inform practice and policy. The incorporation of contextual data (information about patients' beliefs, behavior, or environment into clinical care) and patient-generated (e.g., behavior tracking via output from wearable devices or patient-reported goals, values, and preferences) into the EHR records of each patient is critical to supporting this goal²⁶⁻³¹. Such a fundamental reorientation of EHR documentation and the delivery of healthcare services will necessitate that the business of healthcare must also incorporate what truly matters to patients. No business is successful that does not manage the objectives of that business. The primary objective of behavioral health should be personal change. Since we cannot manage what we do not, it requires a commitment to embrace the measurement of clinical and functional status in routine care and learn to use these data in our practice and policy research.

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