

Reconceptualizing Care Transitions Research From the Patient Perspective

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Transitions of care refer to the movement of patients between health care practitioners, settings, and home as their condition and care needs change.¹ Despite best intentions, transitional care can be compromised and poor continuity of care may contribute to unnecessary visits, increased patient and family distress, poor functional and clinical outcomes, and potentially avoidable costly readmissions for hospitals and health systems.^{2,3} Care transitions research has witnessed an evolution over the past 2 decades. While studies focused on care transitions conducted in the early 2000's initially demonstrated pronounced reductions in readmission rates, results from the past decade suggest more variable outcomes.⁴ Despite early progress in the field, questions remain regarding the best intervention strategies to optimize outcomes for specific patient groups, and it is unclear which intervention components or combinations of components are best suited to specific populations and/or circumstances.⁵ Moreover, even when intervention efficacy is clear, experience has demonstrated that model implementation often varies (or is incomplete) in real-world settings, complicating interpretation of effectiveness. Improvement of transitional care remains a complex endeavor requiring research that employs nuanced modeling, employment of novel design and methodological approaches, attention to social context, and most importantly, measurement of and attention to the perspectives of the multiple stakeholders engaged in transitional care.

As noted in the accompanying commentaries and the introductory paper to this Special Issue, the Patient-Centered Outcomes Research Institute (PCORI) has made inroads in exploring key threads in the complex knot of transitional care. PCORI's approach to transitional care research integrates pragmatic, real-world comparative effectiveness research studies using patient-centered outcomes (PCOs) and a Patient-Centered Outcomes Research framework in a field marked by heterogeneity in models, populations, and outcomes. As of April 2021, PCORI had funded over \$132M in care transitions research. This investment leverages standards for complex interventions to integrate implementation science approaches into study design to better understand model fidelity; fosters patient and stakeholder engagement to enhance the relevance and quality of the science and support sustainability; and includes a full range of clinical and nonclinical stakeholder-driven outcomes.

Deploying patient-centered (and patient-reported) outcomes alongside utilization outcomes provides an opportunity to understand the role of patient and family experiences in transitional care. The aim is to understand which transitional care strategies optimize outcomes around patient needs and preferences, as defined by them. PCORI further amplified the transitional care portfolio by nurturing a learning community, the Transitional Care Evidence to Action Network, which engages PCORI-funded care transitions investigators and allied stakeholders to inform the science. The Network is intended to accelerate the research process by facilitating collaborative learning and dissemination of research findings and to shift the evidence conversation from individual studies to a portfolio level.

PCORI's foundational investment had yielded 29 studies at the time this Special Issue was conceived. While many studies are still in progress, important lessons arise from both completed studies and studies in progress. Results to date signal the importance of including

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PCOs in research, while also suggesting PCOs may not always improve with reduced readmission rates. These results raise important questions for further exploration. The papers composing this special issue highlight challenges and innovative approaches in research design and methods, patient and stakeholder engagement, implementation, measurement, and modeling of PCOs, as well as the need for a more nuanced understanding of transitional care that encompasses contextual factors, such as social determinants of health. Transitional care continues to be a critical area for ongoing research. While much has been learned, many evidence gaps in knowledge remain. Key opportunities to address these evidence gaps include: (1) integration of social determinants of health and social needs in tailored interventions; (2) identifying the relationship between PCO and patient-reported outcomes with clinical and utilization measures; and (3) using expanded models and metrics to reconceptualize care transitions based on the patient experience.

INTEGRATING SOCIAL DETERMINANTS OF HEALTH AND SOCIAL NEEDS

Limited experimental evidence on transitional care interventions extends to vulnerable populations. Specific to a patient-centered approach to care transitions is the need for tailored approaches that address social determinants of health in the pursuit of health equity. One third of patients discharged from hospitals in the United States are from traditionally underserved populations, where challenges of access and differential health outcomes pre-exist and compound the significant vulnerability of the postdischarge period to excess adverse events.⁶ Achieving the next level of quality transitional care requires that we build upon the growing work in this field, explore the tailoring of interventions to underserved populations, and incorporate components that target specific social needs. It is imperative to understand these approaches better through qualitative and pilot studies, as well as explicitly incorporate these considerations into comparative effectiveness research studies.^{6–8} It is then that we drive toward equity—when everyone has the opportunity to be as healthy as possible and no one is disadvantaged from achieving this potential because of socially determined circumstances.^{9,10}

RELATIONSHIP OF PATIENT-CENTERED OUTCOMES WITH CLINICAL METRICS AND UTILIZATION

It is essential that transitional care research examine patients' needs, outcomes, and perspectives alongside clinical factors that drive readmission, utilization, and adverse events. Next level transitional care (and transitional care research) will require a multifaceted, multilevel, and multiperspective approach. At the system level, health systems are interested in integrating patient perspectives and patient experience to drive successful transitions, reduce readmissions, and improve outcomes. However, the relationship between patient-reported outcomes, PCOs, clinical metrics and clinical utilization outcomes is not well understood and is likely complex. One approach to addressing this complexity would be to exercise a more holistic approach that conceptualizes readmissions in the

context of other utilization outcomes (as a “family” of related outcomes) and seeks to understand the relationship between the family of utilization outcomes, patient-reported outcomes, and traditional clinical outcomes.^{7,11}

Data from a report examining the preventability of readmissions in a sample of US academic medical centers found that 27% of readmissions were potentially preventable when assessed using multiple viewpoints including perspectives of patients in addition to those of health care providers and systems.¹¹ This multistakeholder perspective yielded high-priority areas for improvement interventions that span the continuum of care including enhanced communication among health care teams and between health care professionals and patients, greater attention to patients' readiness for discharge, and enhanced disease monitoring, to name a few. How to pursue these priority areas with a patient-centered approach that measures patient experiences and outcomes they value requires further study.

Furthermore, if care delivery is centered around the patient, the patient viewpoint is not limited to a 30-day postdischarge window, the timing of outcome capture for many transitional care studies and performance measures. To date, limited experimental evidence on transitional care interventions exists beyond 30 days postdischarge. A patient-centered approach to intervention delivery and research may reshape the concept of utilization (including the timeframe for measurement), opening a new path toward research that models and explores the interaction between hospitalization/readmission, PCOs, and social contextual factors.

EXPANDED MODELS AND METRICS TO RECONCEPTUALIZE CARE TRANSITIONS FROM THE PATIENT EXPERIENCE

Expanding models and metrics to reconceptualize care transitions from a patient perspective will support identification of key issues in measurement, implementation, methods, and design. We have reached a critical juncture in the development of transitional care models, a juncture that attempts to integrate patient-reported outcomes while also revisiting and more clearly delineating what transitional care models are intended to accomplish. It is a juncture with the potential to inspire mixed methods studies, and hybrid designs inclusive of implementation and evaluation components that, when appropriate, can enhance the relevance and rapid uptake of comparative effectiveness research results. It is a juncture to consider measure validation to advance transitional care science. While a report on valid measurement tools found that no validated measures exist that assess all aspects of transitional patient safety, validated measurement tools do exist for specific aspects.¹² If indeed some of the more validated measures in transitional patient safety, as reported in this analysis, are patient-reported outcomes, much greater attention is needed to understand what is important to measure in reconceptualizing care transitions from the patient experience and outcomes they value.

With 2019 reauthorization, PCORI moves into its next phase of service to the nation, accelerating its impact on care delivery and patient health outcomes. With this next phase, PCORI can seize opportunities to stimulate rapid cycles of innovation and implementation, guided by the establishment of

PCORI's National Priorities for the future. PCORI's National Priorities serve as high-level areas of focus for the organization's work and frame PCORI's Research Agenda. The Priorities and Agenda will seek to respond to an evolving health and health care landscape. That landscape reveals prevalent health disparities and inequities, reflecting the importance of the intersection of research and clinical care within the broader public health ecosystem (eg, social determinants of health). New legislation accompanying PCORI's reauthorization introduced several new research areas of focus for PCORI: Maternal Morbidity and Mortality and Intellectual and Developmental Disabilities. Care transitions are particularly germane to these priority areas as critical transitions occur, for example, from pediatric to adult care for individuals with intellectual or developmental disabilities and across the reproductive lifecycle for women at risk for adverse pregnancy outcomes.

As PCORI continues to fulfill its mission, it is critical that transitional care research consider the patient vantage point in transitions, focusing on transitions of health as the defining construct for care transitions rather than transitions from a health system structure or care team perspective. As a community that has strived to overcome challenging issues for decades and is finding limitations to existing approaches, it is time to explore the problem of care transitions using a different lens. It is time to embrace a novel model, a model more closely aligned with patient's experiences and needs.

Note: At the time this Special Issue was conceived in 2020, PCORI had funded 29 transitional care studies, totaling \$129M, which is referenced throughout the other articles in this issue. At time of publication, Patient-centered Outcomes Research's transitional care portfolio currently includes 30 studies, with an investment totaling \$132M.

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