CHALLENGES AND NEXT STEPS FOR PRIMARY CARE RESEARCH

Towards Better Health, Social, and Community-Based Services Integration for Patients With Chronic Conditions and Complex Care Needs

Individuals suffering from multiple chronic conditions may have health care needs that are more complex due to mental health comorbidities and/or social vulnerabilities, leading to frequent use of healthcare services. Individuals with such complex needs require a variety of healthcare, social, and community-based services and supports. Without well-coordinated efforts among all these partners, patients with complex needs may experience excessive or ineffective healthcare resulting in poor health outcomes, and considerable costs to the healthcare and social services system.

Organizing services to improve care and performance for these high needs patients is a priority for the healthcare system, and implies better integration of services provided by healthcare and social professionals as well as community-based services. A forum at the 2016 NAPCRG conference gathered international researchers to discuss challenges and next steps for primary care research to better inform and facilitate this integration. Below we summarize the discussion on challenges to conducting research to benefit patients with complex needs including research designs and funding.

Challenges to Conducting Research to Benefit Patients With Complex Needs

There is no clear definition for patients with complex medical and social needs and the population is heterogeneous. Therefore identifying eligible participants is often a challenge when recruiting these patients. Health care providers’ opinion, combined with objective eligibility criteria, can be helpful to properly identify the right patients for a given intervention.

Once such patients have been identified, medical or social vulnerability can make recruitment more difficult because of mistrust, travelling issues, or because data collection could seem too intensive. Retention may also be a concern during follow-up because of the increased risk of health or social problems preventing further participation in the study.

Research Designs

Interventions for these patients, such as case management, are often complex, bringing together professionals from various sectors to produce outcomes which are in turn dependent on multiple factors. Traditional randomized controlled trial studies may be harder because of the complexity of the interventions and the heterogeneity of the participants. Initial success with small, often qualitative, studies, can create a foundation for more robust pragmatic trials.

Health and social services research often starts from different paradigms, and uses different conceptual models, language, and research designs. Asking the right questions, using consensual paradigms in addressing issues that matter to patients and stakeholders, and choosing appropriate process and outcomes measures requires collaborative teamwork. It is crucial to bring together all stakeholders early on in the research process: researchers, patients with complex needs; decision makers; health and social professionals; and community-based services members. Adequate time is needed to allow productive discussions toward mutual understanding. Since capturing these process elements is essential, study designs should seek to understand as well as to measure these processes.

Engaging patients with complex needs and other stakeholders, including health authorities, in the research process could also help to identify meaningful outcomes. These may go beyond traditional measures of cost or quality indicators to include functioning and other patient reported outcomes. New designs such as realist evaluation or qualitative process evaluation, can help in identifying process points and informing about context influence. Moreover, dissemination of results should be reinforced, not only with patients and health and social professionals but also with decision makers and community partners.

Funding

In many countries, funding is specific to community, social, or health research. It is hard to get funding to cross these divides, perpetuating fragmented approaches. These silos complicate the necessary partnership among health, social, and community researchers. Having access to combined health care and social services funds would be useful to nurture relationships and integration among all partners.
An advocacy effort should aim to increase awareness of funders, decision makers, and partners concerned by metrics, about the time needed to develop productive partnerships, and meaningful process measures. Time well invested in this regard will definitely lead to interventions better answering the needs of patients and stakeholders.

**Conclusion of the Forum**

Conducting research to improve care for individuals with complex health care and social needs calls for community-based services. Taking time to develop and nurture partnerships and engage patients and other stakeholders in research allows a better understanding of each other’s reality, increasing sustainability, and identification of more relevant research designs as well as process and outcome measures. Developing a common language and having access to combined health care and social services funds would help to promote this partnership.

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