

Introduction to special section on patient engagement

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From its inception, the field of quality of life (QOL) research has focused on bringing the patient's perspective to medical research. By creating patient-reported outcome tools, QOL investigators have helped to bring the patient's voice and experience to center stage in evaluating medical treatments and considering health trajectories. The resulting research in this growing field has led to many findings that support the validity of the patient's perspective, an important move away from a history of prevalent health-care provider chauvinism—when only the doctor's perspective was considered valid. This growing emphasis on patient-centered research has led to an even more radical concept: that patients could and *should* be involved at all stages of the research endeavor. This 'soup-to-nuts' perspective on patient engagement underlies many current funding initiatives in USA, Canada, Australia, and Europe.

In response to this promising new direction in QOL research, we offer a sampling of 12 articles addressing key topics in patient engagement research. Selected through a competitive review process, we issued a call for papers for letters of intent related to patient engagement, and invited what we thought were the best representatives of this emerging new subfield of QOL research. The resulting 12

articles represent the top 40 % of submitted letters of intent.

This special section can be divided into four types of articles: (1) theoretical or conceptual pieces that reflect the thinking and models of this new subfield; (2) methodological pieces that illustrate novel methods for engaging patients or under-represented patient groups in QOL research; (3) intervention studies that successfully recruit under-represented patient groups; and (4) applications or policy papers that illustrate why patient engagement is important.

Conceptual models for patient engagement

Good research requires a sound theoretical underpinning. Such a foundation provides important structure for generating relevant and meaningful hypotheses, and can guide different aspects of the study, including the design, procedures, measures, and statistical models tested. Frank et al. [1] offer a useful conceptual model of patient-centered outcome research. This model underlies the focus and funding priorities of the Patient-Centered Outcome Research Institute (PCORI), a nonprofit, nongovernmental organization located in Washington, D.C. Congress authorized the establishment of PCORI in the Patient Protection and Affordable Care Act of 2010. This sponsor of QOL research has provided hope and support to researchers and patients alike who are interested in making the patient's voice central to medical outcome research.

Moving away from a clinical trial setting where recruited patients represent a small sample of the patient population, patient engagement studies face a range of challenges for which an organizational framework would be helpful. Adding an important pragmatic layer to theory,

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Holden et al. [2] offer a framework for dealing with challenges of community-based participatory research. The authors offer a thoughtful enumeration and suggestions for navigating a range of challenges. These include barriers, such as relational (e.g., trust) or practical barriers (e.g., time constraints, patients' cognitive deficits), to methodological (e.g., combining data from multiple sources).

By engaging patients in an active role at each stage of research, the researcher is creating a new role that is distinct from the patient's role in the recent past. Marlett et al. [3] present a study that examines the emerging role of 'patient engagement researcher' using qualitative methods. They present a theoretical model that elucidates this new role, and describe how this role can be integrated into patient-led medical teams.

Novel methods for engaging under-represented patients

Haywood et al. [4] present results of a study of QOL investigators which suggests that many of us are at a loss as to how to effectively engage with patients throughout the research process. Accordingly, a set of articles address methods that were developed or modified to facilitate patient engagement research. These 'how to' papers can help researchers to think creatively about alternatives for recruitment and engagement that will not only enhance the generalizability of their study, but also will amplify the patient's voice. Absolom et al. [5] describe the use of a patient advocacy group in the research institution. Barello et al. [6] describe a qualitative study aimed at understanding the chronically ill patient's experience of the Italian healthcare system. They identify a process that promotes the patient's engagement in critical event responses, with an end-goal of improving the impact of QOL interventions. Starks et al. [7] describe the development of a decision support for depression management in an Alaskan native tribal health organization. This tool integrates technology (iPad) and internet-based accessibility (website) to provide a convenient, flexible tool for sharing information and preferences.

Intervention studies

Patient engagement research will necessarily seek to improve the health and well-being of hard-to-reach patient groups. This application will necessarily confront cultural and practical barriers, and two articles in this special section exemplify this line of research. Rush et al. [8] present methods for a national randomized trial for Latina cancer survivors. They describe the development and engagement process for

adapting a previously successful patient-caregiver program. Their multi-level team included researchers, clinicians, Latina cancer survivors, and caregivers.

Two other articles addressed how to integrate underserved patients into an effective and relevant disease management program. Vidyanti et al. [9] describe the use of an automated telephone assessment call as a facilitator for a diabetes–depression care management program. Their metric of success was disarmingly simple: completed call rates. The authors suggest design and implementation suggestions for future studies wishing to build on existing technology to reduce outcome disparities in low-income minority populations. Similarly, Petre et al. [10] describe a fast, multifaceted use of information and communication technologies to recruit obese subjects into epidemiological and health promotion studies. They report study recruitment that was evenly distributed across important descriptors, including body mass index, age, gender, and socioeconomic level.

Why patient engagement is important

Two articles highlight why patient engagement methods are important. Allen et al. [11] document a gap between patient' and clinicians' assessment of rehabilitation progress. Using a computer-adapted patient-reported outcome, they examined current-versus-ideal gap in movement ability from the perspective of the patient, and compared this gap to physical therapists' clinic notes. Although both patients and clinicians noted progress, their level of agreement on the amount of progress was only poor or slight. This type of documentation of the process of outcomes is an important contribution that patient engagement research can make to patient care.

Another novel article by O'Rourke et al. [12] illustrated the use of a systematic review and qualitative interview data from patients in conjunction with clinical administrative data. This work utilized the gaps between these three knowledge sources to map broad themes and variables of relevance to care for dementia patients, and to select patient-reported outcomes for subsequent quantitative research on this same target population.

As a group, this set of 12 articles demonstrates the breadth and depth that a focus on patient engagement can bring to the field of QOL research. They represent a range of theoretical, pragmatic, interventional, and motivational pieces that can help to characterize, define, and shape this emerging subfield of QOL research. By providing such definition, they can also help to shape future research priorities and goals. It is our hope that this special section will help to stimulate growth in this field.

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