Expansion of Research Capability to Study Comparative Effectiveness in Complex Patients – R24 Grants

Computer Assisted Quality of Life and Symptom Assessment of Complex Patients

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Infrastructure Description

This project carried out the routine collection of health-related quality-of-life and symptom-burden information using an audio computer-assisted interview (A-CASI) in patients with multiple chronic illnesses in both ambulatory clinic and inpatient settings. A-CASI data were linked with clinical data for use by health services researchers, and summary scores from the quality-of-life and symptom-burden assessments automatically populated patient electronic medical records (EMR) to inform clinicians.

Specific Aims

1. Develop modular A-CASI in English and Spanish that is adaptable to diverse clinical settings.
2. Administer health-related quality-of-life instrument (NIH PROMIS, Short Form) and a physical symptom assessment (Memorial Symptom Assessment Scale) through A-CASI.
3. Improve sustained data collection by incorporating additional assessments into A-CASI that can be activated at the discretion of clinical sites.
4. Link data collected through A-CASI to EMR.
5. Electronically populate the EMR with summary results for timely display to clinicians.

Pilot Study

This pilot compared health-related quality-of-life and symptom-burden trajectory post-hospitalization for patients with multiple chronic illnesses as they transitioned to an ambulatory care setting. Patients were randomly assigned to either usual follow up care or enhanced care through the Advanced Illness Management Clinic. All patients

Infrastructure Goal

Establish routine collection of health-related quality-of-life and symptom-burden data through audio computer-assisted interviews for patients with multiple chronic illnesses, and link these results to the electronic medical record.

Data Sources

Clinical data from Cook County Health and Hospital System’s EMR.

Quality-of-life and physical-assessment data obtained by audio computer-assisted interviews and computer-assisted telephone interviews.

Data Access

Data are publicly available through the Inter-University Consortium for Political and Social Research (ICPSR).

Strategies Addressed from the HHS Strategic Framework on Multiple Chronic Conditions

1.B. Define appropriate health care outcomes
1.D. Implement and effectively use HIT
1.F. Evaluate models of care, incentives, and other health system interventions
3.A. Identify best practices and tools
4.C. Increase clinical research
completed an A-CASI upon discharge, and then during follow-up visits. Computer-assisted telephone interviews were also administered at 1, 3, and 6 months post-discharge.

The collection of patient data using the A-CASI system shed valuable light on the reality of living with chronic conditions for patients in this population. Of the 1,436 unique respondents, we found that 2 commonly used comorbidity scores (Charlson and Chronic Disease Score) were not well correlated with a patient's quality of life. However, patients' physical symptom burden was strongly inversely correlated with quality of life. Pain and lack of energy were the physical symptoms most strongly associated with poor quality of life.

In the context of patient-centered medical homes, the allocation of clinical resources based on a patient's symptom burden or a direct measurement of quality of life may better address patient needs than a measure of comorbidity.

Publications (as of September 2013)

Publications currently in preparation.

Posters and Presentations

