Digital social network analysis to monitor patient participation in health care research and quality improvement

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ABSTRACT

Background

Emerging models for collaboration in learning health care systems support active participation of a broader range of stakeholders. Changes are being made to pursue formal partnerships with patients and their caregivers in research and improvement projects, but how will we know if such connections are in fact transpiring? Reliable methods are needed to detect and monitor patient-centered participation if we are to gain understanding of how such contributions can impact costs, care, and outcomes.

Objective

We share an innovative approach to tracking and evaluating participation in formal improvement and research initiatives. Digitally-enabled social network analysis affords relatively unobtrusive and objective measurement of communication and interaction behaviors of individuals and groups. This method promises insights about the extent to which the participation of patients and caregivers is authentic and comparable to that of conventional participants in health care improvement and design initiatives such as clinicians and researchers.

Methods

We used digital archives of email correspondence to model communication networks of project collaborators in a large-scale design initiative for pediatric chronic care. We generated network graphs for each month during January 2013 – July 2014 to identify collaborators and their prominence within the group network. We used Shewhart charts to compare communication behaviors and network positions of patients and parents relative to clinicians and researchers.

Results

Social network analysis based on digital traces provided concrete evidence of a qualitative trend of increased patient and parent participation in research and improvement efforts. An X-bar chart showed common cause variation amongst actor centrality measures for patients/parents alongside clinicians and researchers, evidence of similar positioning within the group network as well as comparable frequency and intensity of communication.

Conclusions

Social network analysis offers capacity to reliably and effectively detect and monitor participation of patients and caregivers in research and improvement projects. This method transcends threats to the validity of self-reported measures for participation. Future research should explore the extent to which feedback from social network analysis can enable collaborative behaviors and project structures that meaningfully involve more patients and their caregivers.