Emerging Platforms for Person-Centered, Community-Wide Care Coordination: Needs, Challenges, and Solutions

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Abstract

As the population ages and the burden of disease increases, there is great need for community-wide care coordination (CWCC) to help deliver triple aims of improved quality, population health and cost. This is particularly critical for underserved patients such as those in rural and low-income communities who experience health disparities. The complexity of coordinating across multiple institutions, care teams, and community services while maintaining a sharp focus on person-centeredness necessitates robust and adaptive technologies. Such systems are foundational for accountable care organizations and health home models. There is little known about technology platforms to accomplish this goal. An initial review of 20 commercially available systems marketed as fulfilling care coordination and patient engagement were assessed on 24 criteria. Most systems were lacking features for patient engagement and collaboration across multiple organizations. A diverse panel of patients, researchers, clinicians, and designers will consider and debate the needs and challenges of person-centered CWCC as well as promising technology solutions.

Introduction

In order to achieve the IHI triple aims of quality, population health and cost for those with chronic and acute illness, new models of care delivery must improve coordination across the continuum of care while engaging patients, families, and caregivers as partners in the care process. “Community-wide care coordination” (CWCC) refers to care that is coordinated across multiple institutions and community resources with individuals, family, and caregivers as active members. A handful of studies of care coordination with home telehealth have shown promise in improving quality and costs1, 2 and there are frameworks that describe information technology needs for CWCC.3, 4 While standalone applications and systems may be in use for specific chronic illness populations, there are few technology platforms for comprehensively managing integration of information, activities, and workflow. A non-systematic search of the literature, grey literature, Internet, and personal referrals to companies found 20 commercially available systems that described themselves as offering technology for “care coordination” and “patient engagement.” Analysis conducted by a multidisciplinary team using 24 a priori criteria determined that five systems fulfilled >80% necessary functions described in these frameworks and none fulfilled all. (Kim, unpublished) Of particular concern was the lack of attention to engagement that would enable patients, family members and caregivers to participate with care teams in decision-making and have shared accountability for outcomes including: patient access to comprehensive information; support for self-management of activities, care team access to patient generated data; and patient-directed access for family and caregivers. Thus, while technology solutions are emerging, there are few comprehensive technology platforms that can support CWCC and even fewer that offer effective means for meeting individuals’ needs and preferences.

Specific Aims/ Discussion Topics

Technology that supports CWCC is critical to addressing diverse users’ needs, accessing multiple data sources, incorporating various health information exchange and data sharing strategies, and remediating conflicting cultural and political influences. The panel will consider the needs, requirements, and challenges of design, development and implementation of CWCC systems that are person-centered with patients, family and caregivers as equal partners with care teams. The session will be appropriate for health professionals, managers, systems designers and developers, researchers, and patients and caregivers. Questions to be considered from diverse perspectives include:

1. What is required for a technology platform be “person-centered”?
2. What challenges do patients, family members, caregivers face in coordinating care? What are their needs and desires and how can we translate those for system designers and developers? Who is listening?
3. What challenges do care teams (clinicians, lay health workers, managers) face in coordinating care? How can we strengthen learning and sense-making and translate these for system designers and developers?
4. Are there intriguing solutions to these challenges that are being trialed currently? What results have they shown and what lessons can we learn from them?
5. How do we adapt potential solutions for publicly insured, rural and other underserved communities?
6. Is there a business case for investing in technology for CWCC? Who will pay for it?

**Contributions of Panelists**

The diverse members of the panel will provide insights and recommendations from perspectives of research, healthcare delivery, individual patient experience, and practical model design. All panelists have agreed to take part in the panel. **Katherine Kim** is a health informaticist and researcher at University of California Davis whose work involves the design of mobile and social technologies for interventions that enhance collaboration among patients, family and caregivers, and clinical teams, improve health and streamline healthcare. She has conducted multiple studies on technology-enabled care coordination in cancer and diabetes. She will serve as moderator of the panel, share learnings from current trials in this area, and speak to gaps in knowledge that research may help to fill with regard to CWCC technology. **Charles Boicey** is a nurse and Enterprise Analytics Architect for the State University of New York, Stony Brook Medicine. He leads the development of a platform for engaging patients throughout their lives in a 100-entity provider network serving 350,000 Medicare patients and 1.5M people in Suffolk County. He will share his innovative work as a clinician, informaticist, and architect in care coordination and patient engagement. **Janet Freeman-Daily** is a metastatic lung cancer patient, a writer, and a science geek. A retired aerospace engineer with MIT and Caltech degrees, she employs her skills to translate the experience and science of lung cancer treatment and research into language other patients can understand. Her days are spent tracking research and treatments, supporting others in online forums, raising awareness through writing, blogging and public speaking, and participating in a clinical trial. She is a founder and moderator of Lung Cancer Social Media (#LCMSM) tweetchats and collaborates on projects with lung cancer nonprofits. She blogs at [http://grayconnections.wordpress.com](http://grayconnections.wordpress.com) and tweets as @JFreemanDaily. She will contribute her lived patient experience and her work educating and advocating for patients. **Susan Hull** is a nursing executive and national thought leader passionate about co-creating technology-enabled innovations, transforming health and care ecosystems to dramatically improve population health and wellbeing, with national and international reach. Susan is the founder and CEO of WellSpring Consulting. She has served in a variety of roles over 30 years including designing and managing services, community partnerships, clinical informatics and technologies. She serves on the Tiger Initiative Foundation board, the NeHC Consumer e-Health Advisory Board, and ONC’s FACA Consumer Technology Standards Workgroup. She will speak from the perspective as a designer of technologies for care and implementer of these systems in healthcare organizations. **Anna McCollister-Slipp** is the co-founder of Galileo Analytics, a Visual Data Exploration and advanced data analytics company focused on democratizing access to and understanding of complex health data. Anna’s passion for improving health research is rooted in her personal experiences living with type 1 Diabetes for 28 years. She has become acutely aware of the need for increased patient involvement in health research, treatment and care. Anna was previously the director of public affairs for Radio Free Europe/Radio Liberty, director of public affairs at the Cato Institute, a Washington, DC-based think tank, and as a journalist has written for *The New York Times* and *George* Magazine. She will contribute her experience as a patient and entrepreneur. Collectively, the panel is committed to highly engaged discussion and dissemination of their dialogue as a peer-reviewed publication as well as in public media.

**References**