Cincinnati Children's Hospital: Using Pre-Visit Planning and At-Home Data Collection to Strengthen the Patient-Provider Relationship

Scouting Health

Summary

Approximately 10 to 20 million children and adolescents in the United States face life with some form of chronic illness or disability.[1] The stress of caring for a child with a chronic illness can be completely overwhelming. Oftentimes, parents are asked to remember complex instructions around medication and procedures and give detailed information about the time between visits while coordinating appointments, tests, and lab results across multiple clinics and practitioners. To better manage the transfer of information between patient families and providers, and prevent the loss of vital health details that could inform the child's long-term care management, the Orchestra Project launched at Cincinnati Children's Hospital to engage patients and providers as partners in care. A partnership between the Collaborative Chronic Care Network and the ImproveCareNow network, Orchestra utilizes a mobile app and shared decision making principles to support the fluid transfer of information between patients with chronic illnesses and their providers to form a cohesive care team. Patients and providers establish more trusting relationships, and patients feel empowered to take ownership of their health journey and both patients and providers have reported feeling more prepared during visits.

[1] American Association of Pediatrics. https://www.healthychildren.org/English/health-issues/conditions/chronic/Pages/default.aspx. Accessed January 10, 2017.

Context

Families of children with chronic illnesses typically meet in-person with their specialty care teams during brief visits that occur weeks or months apart and, during these visits, both families and clinicians are expected to perform challenging tasks and remember the results for the next appointment. Families are expected to identify, remember, and communicate the important changes in their child's health since the last visit. Furthering this stressor, families and patients may also be asked to participate in decision making processes without access to or understanding of important clinical information, such as laboratory test results, that could help inform those decisions. On the other hand, clinicians are responsible for listening to the families and patients, translating that patient-reported experience into clinical terms, and then using that information to guide treatment decisions.

Given these challenges, the in-person visit is often just a snapshot of the patient's status, and information that could be used to drive long-term disease management may slip through the cracks, leading to suboptimal care. Coordinating these real-life experiences between appointments creates a new intervention to support families, caregivers, and young patients as they mature with their chronic condition.

Cincinnati Children's Hospital Medical Center (CCHMC) is a nonprofit academic medical center in Cincinnati, Ohio. The Orchestra Project was a result of a partnership between the Collaborative Chronic Care Network (or C3N Project) and the ImproveCareNow network, of which CCHMC is a member.

Description

The Orchestra Project was created to engage patients and providers as true partners in care, optimizing in-person visits and leveraging the time between clinical encounters by combining technical tools, such as a mobile application and electronic health record (EHR) modules, novel workflows, and shared decision making principles to support information sharing between providers and patients. Implementers designed the Orchestra Project to improve the quality of chronic care and health outcomes over time. Orchestra was pilot tested in the care of patients with pediatric irritable bowel disease (IBD) and cystic fibrosis (CF).

Key components of the Orchestra Project included a complex set of objectives and action steps to provide this connectivity.

- **Establishing shared patient-provider goals and data collection plans.** When a patient and family joined the Orchestra Project, they started by meeting with their care team to discuss how Orchestra could be utilized in the patient's care. Using shared decision making techniques, the provider asked the patients and family about their personal goals for treatment and worked together to identify the ways that Orchestra can be used to reach those goals. For example, a patient may have wanted to understand more about their symptoms, the frequency with which they occur, and potential triggers. The Orchestra app included an extensive library of symptoms and standardized measures that patients and clinicians could select from, based on the goal. The family and provider may have discussed reasons for using a certain

measure, the recommended frequency for tracking the data, and the ways the measure could improve care. The research team found that most of patients like to track symptoms on a daily or weekly basis. Patients, families, and providers also worked together to set expectations for their collaboration, such as how to work together between visits and when to check in with each other about symptoms or measures.

- **Pre-visit planning.** About two weeks prior to a scheduled visit, a patient was automatically sent a pre-visit plan, which allowed the patient to review the data that they have entered, as well as any test results or other relevant health measures from the EHR. The plan included suggestions for questions or topics the patient may want to discuss with the care team based on the measures and test results. Patients could also set goals for what they wanted to accomplish during the upcoming visit. The pre-visit plan was sent to the care team so that the providers could review it and be prepared to work with the patient using this shared information during the visit.
- **Clinician alerts.** After measures were agreed upon, providers could set up alerts based on patient-reported data from the Orchestra mobile application. Providers could be alerted by the system if something has changed or crosses a threshold. For example, if a patient was tracking intestinal pain, a clinician could set an alert if the patient starts to develop moderate pain, because that could be a sign that symptoms are worsening or require a change in treatment plan.

- **Journaling and additional features.** All Orchestra users (e.g., patients, providers) could select (or design) data collection instruments and treatment plans that aligned with their goals and preferences. Patients could enter their own data and offer brief annotations by text message or directly into the web-based platform. More extensive journaling options were also available. Orchestra allowed users to design "Learning Plans," which served as individualized experiments that would help the patient-provider team to learn about the patient's unique experience with the condition. All patient-reported measures were viewable by the patient and providers in real time, and data could be displayed in longitudinal charts. Commercially-available activity trackers could be integrated into the data collection.
- **Putting it into practice.** The intervention also involved changes to clinical workflows and to patients' workflows in their daily lives to allow them to utilize the technologies.

Impact

Because of using Orchestra, providers and patients reportedly arrived at visits with a clear sense of the data, their goals, and the most important questions to address during the encounter. Orchestra helped break down power differentials between the patient and provider and supported the development of a trusting relationship, and it helped the patients have ownership of their data and their health. Implementers reported that patients gained confidence in their knowledge and Orchestra enabled patients to come to the visit in a true partnership with the provider, who needs a trusting relationship to co-produce care. As patients and providers collaborated on care,

the level of trust increased over time. In addition, researchers reported anecdotal evidence that clinical alerts on the patient-reported data helped clinical teams identify the need for intervention earlier than without Orchestra.

Lessons Learned

The Orchestra team has identified several tips and lessons learned for future innovators looking to embark on similar efforts.

- **Customizable alerts helped clinicians interpret and become comfortable with receiving large amounts of patient-reported information.** The Orchestra team reported that clinician alerts were one of the biggest implementation success stories. Initially, clinicians bought into the concept of continuous, patient-reported data collection, but they were unclear about how to effectively use and interpret the information. Key questions included: What does a slight variation in symptoms mean? What is the threshold for intervention? There was potential for the information to be overwhelming, and the clinicians did not want to miss something that may be important. The alerting system was very helpful in making clinicians feel comfortable with continuous data because it automated some of the analysis. With reliable alerts in place, the clinicians did not have to check the Orchestra Platform every day. They could trust that the platform would be there with the data when they want to see it. Alerts were also customizable based on the clinical team's and patient's preferences.
- **Engage clinical champions throughout the design and implementation process.** The Orchestra team engaged a group of

physicians, nurses, and dieticians to inform the design of the tools and workflows and to motivate other clinicians to adopt the intervention. Clinical champions helped identify relevant measures and symptoms that were pre-loaded into Orchestra's measures library. They worked collaboratively with the Orchestra team to develop algorithms for health metric reports and suggested questions included in the pre-visit plans. They also helped the Orchestra team refine the clinical workflow and process mapping to integrate the intervention into the inpatient flow and periods in between visits.

- **Teams should plan to engage in continuous quality improvement during implementation to optimize workflows and technical tools.** Although the Orchestra team devoted significant effort to prepare the intervention and train users, they also found it helpful to meet regularly with their clinical champions and quality improvement consultants throughout the implementation phase to tweak processes and iteratively improve the intervention over time.

Project Update

The Orchestra team has completed its pilot implementation and published findings from the pilot program are planned. After the pilot implementation concluded, the original Orchestra platform was discontinued due to lack of funding. However, given the promising results from the pilot, the team is developing a next generation platform based on learnings from the Orchestra work.