Managing Complexity in Primary Health Care: Developing and Piloting the ePRO Tool for Patients with Complex Chronic Disease and Disability

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OBJECTIVES

High healthcare users often include people with complex chronic disease and disability (CCDD) who have multi-morbidity, experience symptoms that impact their daily lives, and face social, environmental and contextual issues that impact on health care needs [1-5].

While mHealth, and more broadly, eHealth technologies, may be important to support individuals with multiple chronic conditions and aging populations [6], the majority of applications are focused on single disease management, thereby not suiting the needs of complex patients [7].

We sought to address the mHealth technology gap facing patients with CCDD management, engaging in a multi-phased user-centred approach to develop a patient-centred mHealth solution to improve quality of care and patient experience for patients with CCDD in primary health care settings.

DEVELOPMENT APPROACH AND METHODS

- User-centred technology development emphasizes the need to incorporate user feedback as part of the design, testing and implementation process [8].
- Design evaluation approaches highlight the need for rigorous research methods and evaluations to support capturing and incorporating user input into designs [9].
- Qualitative interpretive descriptive methods [10] used to capture user feedback.
- Ethics approval obtained from Joint Bridgepoint Hospital-West Park Healthcare Centre-Toronto Central Community Care Access Centre-Toronto Grace Health Centre Research Ethics Board.

Data analysis followed interpretive descriptive approach in which findings were compared to the tool prototype. Findings were categorized into tables in relation to the tool design and function, in order directly inform modifications to the tool.

Tool Development Participants

Four **focus groups** were conducted with patients and carers (n=14).
- Average age 64 years, 9 female
- All patients reported having two or more chronic illnesses.
- Of these, 3 patients and 1 carer participated in patient/carer working group.

Interviews were conducted with **primary health care providers** (n=6) from the Bridgepoint Family Health Team.
- 2 general practitioners,1 nurse practitioner,1 registered nurse, 1 dietitian, 1 admin staff, & Executive Director

All but the executive director participated in the provider working group.

Content experts who participated in interviews (n=5) included:
- 2 experts in eHealth, 1 in complex pain, 1 in complex rehabilitation, 1 complex patient and advocate.
- All but one of the content experts participated in the expert working group, and another content expert in complex stroke rehabilitation not interviewed joined the working group.

Prototype development process

Patient Focus Groups

Four focus groups conducted with patients with CCDD and carers (n=14), recruited from Bridgepoint Family Health Team.

Patient needs were identified and linked to possible features of the tool

Requested Features:
- Symptom monitoring
- Medication management
- Educational materials

Provider & Expert Interviews

Semi-structured interviews conducted with primary care providers (n=6) and experts (n=6) .

Participants identified whether focus group findings resonated with appropriate care for patients and how these needs could be captured using mobile technology.

Requested Features:
- Symptom monitoring using validated scales
- Medication management
- Educational material
- Hospital access notification

Research Team Working Group

Findings from focus groups and interviews used to iteratively design first prototype. Lean technology development techniques like PICK analysis [11] used to identify implementable features. Literature searches conducted to identify validated measures to include.

Prototype #1 Features
- Symptom monitoring through 3 standardized tools
- Hospital access notification

Working Groups

Three working groups conducted with patients and carers (n=4), providers, (n=6) and experts (n=5) who had participated in focus groups or interview.

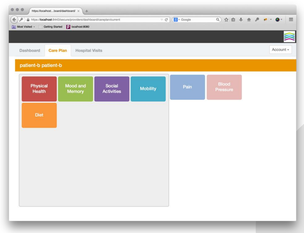
Working groups 'walked through' a live version of Prototype #1 to identify what worked and what didn't work.

Prototype #2
- Symptom monitoring connected to goal setting
- Added efficacy and confidence reporting

The Electronic Patient Reported Outcome (ePRO) Tool

Patient and provider portal

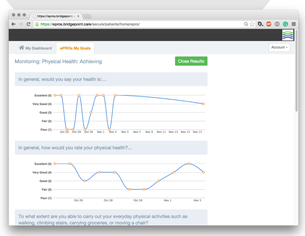
Patients and providers collaboratively identify and create care plan goals using online portal.



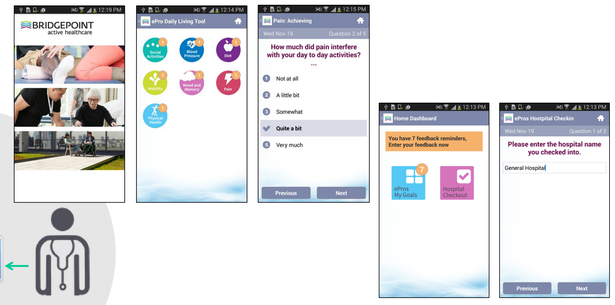
Tracking data can be viewed on the portal by the patient or provider at any time.

Patient can use information to help with self-management.

Provider can use information to see how patients are doing in relation to goals between visits, and provides a quick overview of the patient at the next visit.



Patient Mobile Device



Patients monitor goal progress using validated Patient Reported Outcome Measures including:
1) PROMIS Global Health Scale
2) PROMIS Pain Interference Scale
3) PROMIS Health Assessment Questionnaire

Included open text comments at each monitoring point to provide contextual data.

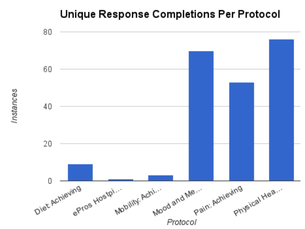
Patients can report when they have be admitted to hospital.

USABILTY PILOT

Aim: To determine utility, functionality, usability of the ePRO tool

- Study ran from November 2014 to January 2015 at the Bridgepoint FHT
- **Participants:**
  - 6 care providers: Physician, social worker, three registered nurses
  - 11 patients with two or more chronic conditions with complex care needs. Average age 58, 5 male, all reporting multiple chronic illnesses.
  - 3 drop outs.
- Providers and patients were trained on the tool prior to the start
- Patients set-up goal plans with providers, **monitored for 4-weeks,** then came in for at least one follow-up visit
- Post-intervention focus groups with patients (n=5) and interviews (n=3) and focus group with providers (n=6)

Usability pilot findings



There were 1315 responses and 212 surveys completed by 8 patients on the mobile device. It typically took 1-5 minutes to complete surveys.

The portal was used mainly by providers. Providers viewed the portal on average 10.2 times over the 4 week pilot.

Provider feedback
- Tool mainly used at the point of care
- Identified that having the tool helped to focus discussion around goals

"To be able to talk about this with her […] thank God I can help set a goal."
- Needed to better align with workflow (i.e. EMR integration)
- Potential to improve efficiency

"… maybe it saves time, especially on certain patients where you get that snapshot just before they come in. You have a whole lot of data that is very efficient."

Patient feedback
- Identified an early impact on self-management

"I knew why I felt better one week and why I didn't feel better the next week."

Identified improved patient-centredness at point-of-care

"[we] *were able to see …that* [my symptom] *was not moving really, and to try to change it better…"*
- Changes needed : individually tailored questions, getting feedback through device, and integration with other apps (i.e. FitBit)

What's Next: Four-month exploratory trial planned for July 2015

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