Tying eHealth Tools to Patient-Needs:
Exploring the Use of eHealth for Patients with Complex Chronic Disease and Disability

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OBJECTIVES

Health policy makers have recently shifted attention towards examining high-users of healthcare, in particular patients with complex chronic disease and disability (CCDD) characterized as having multi-morbidities and care needs that require ongoing use of services. The adoption of eHealth technologies may be a key strategy in supporting and providing care for these patients, however, these technologies need to pay attention to the specific needs of patients with CCDD. As such a patient-centred approach to eHealth technology development is warranted.

As part of the development of new eHealth technologies to support patients with CCDD in primary care settings we sought to determine the perceived needs of these patients with respect to:
1) The kinds of health and health service issues that are important to them;
2) The information that should be collected and how it could be collected in order to help meet their needs; and,
3) Their views on the challenges/barriers to using eHealth mobile applications to collect the information.

A DESIGN EVALUATION APPROACH

We use a Design Evaluation Approach to developing our eHealth tools which involves refining designs based on prior research and ongoing evaluation that involves end-users throughout the process [1]. This approach ensures patients and providers are heavily involved in the full development process and helps to ensure we build a tool that is patient-centred. This is particularly important given the need for patient-centred approaches to care delivery for complex patients [2] liked patients with CCDD.

Our development approach involves multiple phases, beginning with focus groups with patients with CCDD and their providers. Focus group findings used to support tool development are presented here.

METHODS

Focus group participants were recruited from a Family Health Team (FHT); an inter-professional primary care delivery model [3] in Ontario Canada. The practice serves over 5,000 people in Toronto .

Sampling
- Purposive criterion sampling to identify participants
- To be included participants had to: 1) have been identified as a patient with CCDD (defined as individuals with one or more health conditions that are difficult to manage); 2) be a patient at the FHT; 3) have the ability to give informed consent; and 4) understand and speak English.
- In a few cases patients were accompanied by caregivers

Procedure
- Focus groups conducted Nov-Dec 2013; 6-9 participants assigned to each focus group and lasted between 90 and 120 minutes; audio recorded and transcribed verbatim
- Participants answered questions regarding their perceived needs are were presented with an example of an eHealth mobile application and invited to discuss usefulness of the tool
- Groups were conducted until thematic saturation was reached [4]

Analyses
- Exploratory content analysis [5] conducted concurrently with data collection.
- Transcriptions independently coded by two researchers (CSG and DM), coding compared and consensus was reached.
- Secondary analysis conducted to examine relationship between different codes
- Participants provided feedback on the analysis

Ontario

RESULTS

Needs Framework for Community-Dwelling Patients with CCDD

Patient-provider interactions
Participants identified the need for open, ongoing two-way interaction between themselves and their providers, timely feedback, and an open dialogue.

"Don't rush us out the door like we're a bloody number. We're not on the slab, you know. We're not a piece of meat. Listen to us, deal with us. Don't push us out the frigging door because you're not helping us like that." (FG 3)

Provider-provider interactions
As might be expected patients with CCDD will tend to have multiple providers. Coordinating care between these providers was identified by participants in all focus groups as an ongoing problem in their care. with regard to ensuring appropriate referrals, medication management, visits to the hospital, and overall coordination of care.

"That hospital did not notify [my primary care doctor] [...] I got out of the hospital and [my primary care doctor] said to me, "What happened?" I said, "Well, I don't know what happened but I had to have bowel surgery." [...] They did not give her any info on me." (FG 3)

Patient-centred approach
Participants described wanting to be treated as whole-persons, to be seen as experts in their own care, and desired a strong ongoing relationship with care providers.

"I had someone before who looked at me, pegging me immediately as someone like her mother [...] But you know, like no, I'm not your mother. [...] You really need to start with respect. We all deserve respect. Don't have preconceived notions. Start with respect. Look at the whole person and really listen." (FG1)

eHealth Tradeoffs

While participants were excited about the potential for eHealth to support their ongoing needs, they were also concerned about: privacy and data security, added burden for patients and over-stretched providers, entry errors, training requirements, potentially confusing interfaces, and the potential to displace necessary in-person visits, or contribute to isolation:

"Like for people who are like bedridden and can't get out, and you know, get their Meals on Wheels and stuff like that. If [eHealth monitoring is] the only contact that they're going to have, that's going to cut them off even more from society." (FG 4)

Information sharing to improve care, using eHealth tools

Patient-provider information sharing

Monitoring symptoms by provider
"…anything that can help replace another visit to the doctor or an easy way to be monitoring a person who's just come out of hospital at home, I think that it is so important." (FG 1)

Patient self-monitoring
"You could set this up to keep track of just how much you're progressing or how much you're regressing." (FG 2)

Patient accessing medical history
"But I'd want to know the results of the test." (FG 3)

Patient — Information sharing — Patient-centred — Information sharing Continuity Coordination — Primary care provider — Other care providers

Provider-provider information sharing

Continuity
"But besides that, it's in print right in front of the doctor. She can read it and know it's there, and she can recall it rather than, talking on the phone with someone for 5 minutes and only taking in half of what the person said." (FG 2)

Providers access to patient medical history
"I think the communication between each doctor would be a lot faster [using eHealth]. Like you'd have the patient file. They can each access it." (FG3)

Coordination
"…if she was let go from the hospital, [the social worker] would have had all that information on the tips of their fingers – How is she going home and all, are we going to make something accessible, is the volunteer going to take her down? … Who is going to be at your home? Who is going to feed you? Do you want Meals on Wheels?" (FG 4)

PARTICIPANTS

Four focus groups were conducted with patients with CCDD (n=10), caregivers (n=2), and those who were both caregivers and patients with CCDD (n=2). Each focus group had between two and five members.

Patients included in the focus groups reported having multiple chronic illnesses including diabetes, chronic pain, osteoarthritis, osteoporosis, anemia, cardiac conditions, glaucoma, and mental illness. The average age of participants was 64.4 years, nine participants were female, and eleven were born in Canada.

KEY FINDINGS

Many of the identified needs of patients with CCDD can be addressed using eHealth technologies. The use of Electronic Medical/Health Records (EMRs and EHRs) and telemonitoring may be of particular use, and have been shown to improve communication between patients and providers, patient self-management, and patient outcomes [6,7,8].

While participants also identified concerns with adopting eHealth tools, these concerns were often weighed against the benefits. Often the benefits would outweigh the costs. This finding is supported in the broader literature on the adoption of EHRs [9].

IMPLICATIONS

From the patient perspective, there is a significant potential for eHealth tools to support patients with CCDD in community and primary care settings. Our findings suggest the need to focus on developing telemonitoring to support ongoing patient-provider interaction and patient self-management that would be integrated into EHRs that better support provider-provider interactions. Our participants emphasis on patient-centred approaches to care supports our use of a Design Evaluation Approach to developing eHealth tools.

However, we need to be wary of the potential downfalls of adopting eHealth technologies and pay special attention to patient-identified needs and concerns. Our development approach will ensure that patient concerns are considered and addressed prior to implementation.

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