TYING eHEALTH TOOLS TO PATIENT NEEDS:
EXPLORING THE USE OF EHEALTH FOR COMMUNITY-DWELLING
PATIENTS WITH COMPLEX CHRONIC DISEASE AND DISABILITY
(PUBLICATION)



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CONTEXT

Health policy makers have recently shifted attention towards examining high users of health care, in particular patients with complex chronic disease and disability (CCDD) characterized as having multimorbidities 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 address the specific needs of patients with CCDD. This paper describes the first phase of a multiphased patient-centered research project aimed at developing eHealth technology for patients with CCDD.

OBJECTIVES

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 apps to collect the information.

METHODS

Focus groups were conducted with community-dwelling patients with CCDD and caregivers. An interpretive description research design was used to identify the perceived needs of participants and the information sharing and eHealth technologies that could support those needs. Analysis was conducted concurrently with data collection. Coding of transcripts from four focus groups was conducted by 3 authors. QSR NVivo 10 software was used to manage coding.

FINDINGS

There were 14 total participants in the focus groups. The average age of participants was 64.4 years; 9 participants were female, and 11 were born in Canada. Participants identified a need for open two-way communication and dialogue between themselves and their providers, and better information sharing between providers in order to support continuity and coordination of care. Access issues were mainly around wait times for appointments, challenges with transportation, and costs. A visual depiction of these perceived needs and their relation to each other is included as part of the discussion, which will be used to guide development of our eHealth technologies. Participants recognized the potential for eHealth technologies to support and improve their care but also expressed common concerns regarding their adoption. Specifically, they mentioned privacy and data security, accessibility, the loss of necessary visits, increased social isolation, provider burden, downloading responsibility onto patients for care management, entry errors, training requirements, and potentially confusing interfaces.

CONCLUSIONS

From the perspective of our participants, there is a significant potential for eHealth tools to support patients with CCDD in community and primary care settings, but we need to be wary of the potential downfalls of adopting eHealth technologies and pay special attention to patient-identified needs and concerns. eHealth tools that support ongoing patient-provider interaction, patient self-management (such as telemonitoring), and provider-provider interactions (through electronic health record integration) could be of most benefit to patients similar to those in our study.

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