Learning from Social Media Patient Platforms: A Framework for Exploring Mechanisms Used to Engage Patients

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Abstract

Despite the growing interest in engaging patient in their health care process, particularly with technology, it is not clear how best to do so. Based on a narrative literature review and pilot analysis, we propose a preliminary framework to explore mechanisms used by social media platforms to engage users in health and information sharing processes, which can contribute valuable insights to support the future design of healthcare information systems.

Introduction

Patient engagement is now considered a pillar of the ideal patient centered care model, with a growing view that engaged and empowered patients are essential to improve health and decrease healthcare costs. However, despite the strong political interest in patient engagement, particularly with technology, it is not clear how best to do so. A novel approach to seek ways for better engaging and supporting patients with technology is to explore social media platforms designed for those who wish to become more involved in their health and health care decisions. Social media platforms offer rich applications, services and tools to engage users to learn how to better address their health issues. These platforms can achieve high levels of user participation outside the realm of the health care system. Thus, the objective was to develop a framework for analyzing health related social media platforms for the purpose of exploring mechanisms they use to engage patients in their health care process.

Methods

A review of the literature on patient engagement (in particular patient engagement frameworks) and patient roles in treatment decision-making was conducted to inform a preliminary framework to guide data collection and analysis. Qualitative methods were used to analyze textual and visual data (e.g., platform policies, terms of use, about us, frequently asked questions, registration process, tools, and clients) collected from a convenience sample of social media platforms.

Results

A preliminary framework was developed based on the literature review and pilot analysis. This framework draws from 1) the National eHealth Consortium patient engagement framework that attempts to align to meaningful use policies (inform me, engage me, empower me, partner with me, and support my eCommunity), 2) the Health Council of Canada’s spectrum of engagement that encourages patients to participate and influence health care reform policies to improve the effectiveness of the health care system (inform, consult, involve, collaborate, empower), and 3) concepts identified by Deber et al. on preferred patient roles in treatment decisions (passive, shared and, autonomous).

Discussion:

We propose a framework that can be used to analyze social media platforms that engage users who wish to be more involved in decisions relating to their health. We plan to employ this framework in a larger study of purposely selected social media platforms (e.g. sites with many registered users stratified by various characteristics representing different ownership types, funding sources and target users), and further refine it based on the findings. This novel approach to explore mechanisms to engage users in health and information sharing processes can contribute valuable insights to inform future policies and support the future design of health information systems to better engage and support patients within health care organizations.

References