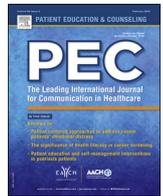




Contents lists available at ScienceDirect

Patient Education and Counseling

journal homepage: www.elsevier.com/locate/pateducou



Research Paper

Contingent engagement: What we learn from patients with complex health problems and low socioeconomic status

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ARTICLE INFO

Article history:

Received 12 April 2017

Received in revised form 6 August 2017

Accepted 30 August 2017

Keywords:

Patient engagement

Contingent engagement

Complex care

Primary healthcare

Medicaid

Traditionally underserved

Socioeconomic status

Team based care

ECHO model

Hospitalization

ABSTRACT

Objective: Elicit patients' perceptions of factors that facilitate their engagement in care

Methods: In-depth interviews with 20 adult Medicaid patients who had complex health problems, frequent hospitalizations/emergency department use, and who were enrolled in an intensive, team-based care program designed to address medical, behavioral, and social needs.

Results: Prior to engaging in the program, participants described weak relationships with primary care providers, frequent hospitalizations and emergency visits, poor adherence to medications and severe social barriers to care. After participating in the program, participants identified key factors that enabled them to develop trust and engage with care including: availability for extended intensive interactions, a non-judgmental approach, addressing patients' material needs, and providing social contact for isolated patients. After developing relationships with their care team, participants described changes such as sustained interactions with their primary care team and incremental improvements in health behaviors.

Conclusion: These findings illuminate factors promoting "contingent engagement" for low socioeconomic status patients with complex health problems, which allow them to become proactive in ways commensurate with their circumstances, and offers insights for designing interventions to improve patient outcomes.

Practice implications: For these patients, engagement is contingent on healthcare providers' efforts to develop trust and address patients' material needs.

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1. Introduction

Individuals with complex health conditions, including physical, mental, and substance use problems, often lack primary care that meets their healthcare needs [1]. When they do not receive this care, they frequently (and repeatedly) end up in emergency departments (EDs) and experience avoidable hospitalizations [2,3]. Their chronic medical problems progress, and they experience earlier deaths compared to individuals with access to adequate care [4]. Patients with complex health problems account

for substantial healthcare spending [5]. Many of these patients also experience adverse social conditions, such as poverty, low-literacy, and homelessness that make it difficult to access and benefit from care [6]. Because of these barriers and high rates of behavioral health disorders, these patients are less likely to engage in health-promoting actions, including establishing ties to the primary healthcare system, than are other patients.

Juxtapose this situation to the mounting body of research demonstrating the importance of patient engagement for improving health outcomes and healthcare experiences [7–9]. There are different definitions of patient engagement, but the construct generally includes behaviors and cognitive-emotional states reflective of patients' pro-active stance vis-à-vis their health and healthcare [10–12]. These include "understanding and acting on health information (health literacy), working together with

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clinicians to select appropriate treatments or management options (shared decision making), and providing feedback on healthcare processes and outcomes (quality improvement)" [13]. Patient activation, defined as "having the knowledge, skill, and confidence to manage one's health and healthcare" [9], is a prevailing framework of patient engagement. The self-reported Patient Activation Measure (PAM) quantifies aspects of patient engagement. Patients with high PAM scores adhere to medications, are hospitalized or use EDs less, and generate lower healthcare costs [14].

There are reasons to believe existing conceptualizations and measurements of patient engagement in general, and patient activation as one aspect of patient engagement in particular [15], are more salient for some patient groups than for others [16,17]. For example, on average patients with low SES have lower PAM scores [14]. This is unsurprising given some PAM items, such as "I am confident that I can follow through on recommendations my healthcare provider makes, such as changing my diet or doing regular exercise." Complying with provider recommendations requires resources that are unequally distributed by SES. This and other indicators of patient engagement and activation may also be less salient to individuals facing multiple, complex health problems, including behavioral disorders, which can collectively constrain proactivity. Moreover, there is evidence that low-SES patients are disinclined to participate in shared medical decision-making; and yet doing so is considered demonstrative of patient engagement [18,19].

On one hand there is compelling evidence that patient engagement improves myriad health outcomes and the quality of care. On the other hand, as it is often conceptualized and measured, patient engagement may not be fully applicable to patients who stand to benefit the most from being engaged in some capacity. Leading scholars in the area fully acknowledge these tensions. Whereas existing efforts to enhance engagement largely assume a 'one size fits all' approach, there is growing awareness that the 'next generation' of engagement promotion will require targeted interventions [20,21] customized for different

patient populations in an effort to "meet the patient where they are" [17].

In this paper we answer the question, "What do we learn about patient engagement from listening to a population of hard-to-reach patients with complex health problems?" Based on interviews, we examine the experience of engagement among low-SES patients with multiple comorbidities as they participate in an intensive team-based primary care program. We characterize engagement among this marginalized patient population and outline aspects of care enabling activation in ways commensurate with patient circumstances. We call this *contingent engagement*, which we define as actions and attitudes that are conditional on high levels of care and support that incrementally enhances health management and the benefits of healthcare. We offer insights into the mechanisms that promote contingent engagement and concomitant improvements in health and healthcare outcomes.

2. Methods

This study investigates the experiences of patients and their close personal contacts with an intensive primary care program for low-income patients with multiple diagnoses called ECHO Care. The patient experience is increasingly recognized as important in the engagement literature and thus the use of in-depth semi-structured interviews is appropriate for examining the meaning of and processes behind patient engagement [22]. This research was approved by the University of New Mexico Human Research Review Committee, HRRC #12-617.

2.1. Intervention

ECHO Care (henceforth 'the program') is an intervention designed to give individuals with complex medical, behavioral and social needs improved access to outpatient care. Patients are referred to the program by inpatient and outpatient providers, Medicaid care coordinators, and social service agencies. The program uses an outpatient intensive team (OIT) that provides

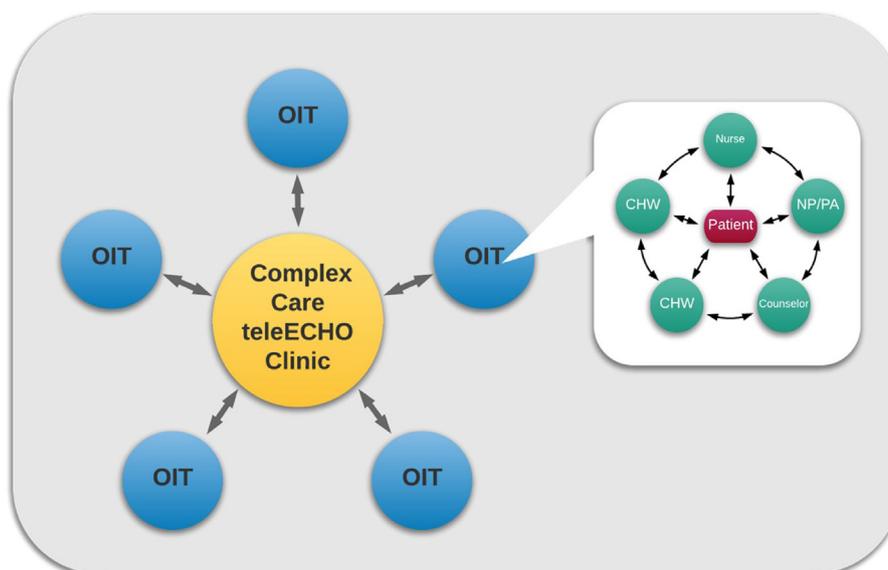


Fig. 1. The ECHO Care Model.

(ECHO: Extension for Community Healthcare Outcomes)
Outpatient Intensive Team = OIT (referred to as "care team")
CHW = Community Health Worker
NP = Nurse Practitioner
PA = Physician Assistant

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