

UC Merced

UC Merced Previously Published Works

Title

Patient engagement at the margins: Health care providers' assessments of engagement and the structural determinants of health in the safety-net

Permalink

<https://escholarship.org/uc/item/5qv5z44c>

Authors

Fleming, Mark D

Shim, Janet K

Yen, Irene

et al.

Publication Date

2017-06-01

DOI

10.1016/j.socscimed.2017.04.028

Peer reviewed



HHS Public Access

Author manuscript

Soc Sci Med. Author manuscript; available in PMC 2017 October 24.

Published in final edited form as:

Soc Sci Med. 2017 June ; 183: 11–18. doi:10.1016/j.socscimed.2017.04.028.

Patient Engagement at the Margins: Health Care Providers' Assessments of Engagement and the Structural Determinants of Health in the Safety-net

Mark D. Fleming^a, Janet K. Shim^b, Irene Yen^b, Ariana Thompson-Lastad^b, Sara Rubin^b, Meredith Van Natta^b, and Nancy J. Burke^a

^aPublic Health, School of Social Sciences, Humanities and Arts, University of California, Merced, 5200 North Lake Road, Merced, CA 95343

^bDepartment of Social and Behavioral Sciences, University of California, San Francisco, 3333 California Street, Suite 455, San Francisco, CA 94143-0612

Abstract

Increasing “patient engagement” has become a priority for health care organizations and policy-makers seeking to reduce cost and improve the quality of care. While concepts of patient engagement have proliferated rapidly across health care settings, little is known about how health care providers make use of these concepts in clinical practice. This paper uses 20 months of ethnographic and interview research carried out from 2015 to 2016 to explore how health care providers working at two public, urban, safety-net hospitals in the United States define, discuss, and assess patient engagement. We investigate how health care providers describe engagement for high cost patients—the “super-utilizers” of the health care system—who often face complex challenges related to socioeconomic marginalization including poverty, housing insecurity, exposure to violence and trauma, cognitive and mental health issues, and substance use. The health care providers in our study faced institutional pressure to assess patient engagement and to direct care towards engaged patients. However, providers considered such assessments to be highly challenging and oftentimes inaccurate, particularly because they understood low patient engagement to be the result of difficult socioeconomic conditions. Providers tried to navigate the demand to assess patient engagement in care by looking for explicit positive and negative indicators of engagement, while also being sensitive to more subtle and intuitive signs of engagement for marginalized patients.

Keywords

United States; Patient Engagement; Poverty; Health Inequalities; Safety-net; Super-Utilizers

Introduction

Improving patient engagement in care has become a priority for health care providers and policy-makers. Current health care reforms aim to develop and expand new forms of care delivery that place primary care as the foundation for the health care system (Rittenhouse et al. 2009). These new care delivery models, including patient-centered medical homes and accountable care organizations, are intended to tailor care to individual patients' needs, preferences, and circumstances (Dubbin et al. 2013, Ishikawa et al. 2013, Nutting et al. 2011). However, health care organizations and policy-makers recognize that these delivery models require increased patient engagement in primary care in order to be successful (Cosgrove et al. 2013, Shortell et al. 2015). These reforms thus depend upon patients being willing and able to engage in care and take actions to improve their health. Efforts to increase patient engagement and implement patient-centered care have often focused on patients with chronic illness, as high health care costs continue to be driven by the growing number of patients with chronic illness entering the health care system (Anderson and Horvath 2004, Shortell et al. 2015).

Health care organizations are implementing complex care management (CCM) programs to manage the care provided to the highest cost patients—the “super-utilizers” of health care services (Bodenheimer 2013, Hong et al. 2014). Super-utilizers typically have a combination of multiple chronic illnesses, socioeconomic challenges, fragmented care, and frequent emergency room visits and hospital admissions (Harris et al. 2016, Johnson et al. 2015, LaCalle and Rabin 2010). CCM programs work to coordinate care, improve patients' ability to self-manage their conditions, and reduce emergency room visits and hospitalizations. By reducing patients' utilization of inpatient and emergency care, CCM programs aim to make up the costs of the care management intervention and save money for the health care organization (Hong et al. 2014).

The criteria for enrollment into many CCM programs include diagnoses of “ambulatory care-sensitive conditions” (Harris et al. 2016, Lewis 2010), usually chronic illnesses that can be affected through a change in self-management. Moreover, the literature on CCM suggests that selecting for patients who are willing and able to engage in care is a crucial factor in determining whether or not a CCM program is successful in reducing hospitalizations and emergency room visits, and therefore reducing costs (Freund et al. 2012, Hong et al. 2015, Jackson and DuBard 2015, Lewis 2010). The definition of “care sensitivity” and the criteria determining eligibility for care management often include patient willingness to engage in care. In our ethnographic study of CCM programs in two safety-net hospitals, we examine how CCM providers select and retain patients based on assessments of patient engagement, and describe the challenges and dilemmas this presents for providers.

Concepts of patient engagement vary significantly, with some definitions focusing on the individual—e.g. “actions individuals must take to obtain the greatest benefit from the health care services available to them” (Center for Advancing Health 2010:2)—and other definitions pointing to contextual factors and the actions of health care providers (see Koh et al. 2013). Carman et al. (2013) propose a framework for understanding patient engagement that includes “patients, families, their representatives, and health professionals working in

active partnership at various levels across the health care system—direct care, organizational design and governance, and policy making—to improve health and health care”(224). Concepts of patient engagement generally differ from compliance or adherence, which social scientists have critiqued extensively for their emphasis on individual factors such as patient responsibility, agency, belief, and lifestyle at the expense of attention to the role of the health care system or socioeconomic conditions (Farmer 2005, Maskovsky 2005, Whitmarsh 2013). While conceptual frameworks for patient engagement purport to account for contextual factors, it is unclear how this might work in clinical practice. Despite the importance of patient engagement for health care reform and the proliferation of conceptual frameworks, little research has examined how health care providers define, discuss, and assess patient engagement as part of their practices of providing care.

Rather than starting with a definition of engagement, we look to how health care providers themselves describe patient engagement for “super-utilizers,” who are patients that face complex challenges related to socioeconomic marginalization (Bourgois and Schonberg 2009, Farmer 2005, Knight et al. 2014) including poverty, housing insecurity, exposure to violence and trauma, cognitive and mental health issues, and substance use. By investigating what counts as engagement for patients at the margins, we offer insight into how medical providers in safety-net settings try to account for the effects of difficult life conditions on patients’ ability to take part in medical care. Our study considers the perspectives of the CCM teams who provide direct care to these patients.

In this paper we describe how CCM providers navigate the demand to assess patient engagement by looking for positive and negative indicators of engagement, while also being sensitive to more subtle and intuitive signs of engagement. Next we describe how CCM providers understand the socioeconomic marginalization their patients face to interfere with their ability to adhere to treatment or explicitly engage in care. We also describe how providers understand engagement to fluctuate in response to precarious life conditions, making it very difficult to predict which patients would successfully engage in care. Finally, we explore the dilemmas that providers face in trying to assess engagement for patients at the margins. Here we emphasize the conflicts created by the demand, on the one hand, to enroll and retain patients who engage more easily and, on the other hand, the desire to provide care to patients that may be more difficult to engage but have a high need for care.

Methods and Setting

We studied CCM programs located at two urban, safety-net hospitals in California. The CCM programs were established to reduce costs and improve the quality of care for the approximately 5% of patients who make up 50% of Medicaid and Medicare spending. The CCM teams we observed included nurses, community outreach workers, social workers, a medical assistant, a pharmacist, managers, and medical directors. The teams worked closely with primary care providers to design a patient-centered care plan, coordinate care, and meet the complex needs of patients who experienced fragmented healthcare, multimorbidity, and significant socioeconomic and behavioral challenges. The primary diagnoses driving repeated hospitalizations for super-utilizing patients in these safety-net hospitals were congestive heart failure (CHF), chronic obstructive pulmonary disorder (COPD), asthma,

hypertension, end stage renal disease, and diabetes. The vast majority of patients served in the two CCM clinics had four or more chronic diseases and a mean of 16 prescription medications (Yen et al. n.d.). The main factors complicating the management of these conditions included substance use disorder, mental health issues, trauma history, and socioeconomic challenges, most prominently homelessness and housing insecurity.

The two CCMs programs started in February 2012 and January 2013. Both programs began with initial enrollment criteria of a diagnosis of chronic illness and at least three hospitalizations within the previous 12 months. One program changed its enrollment criteria to include only patients determined to be at high risk for future hospitalization on the basis of a “risk assessment” tool. Both programs received referrals mainly from primary care physicians, although one program also accepted referrals from in-patient providers and used a case finding method where a community outreach worker reviewed a list of hospitalized patients to identify eligible patients. When a patient was determined to meet criteria for a CCM program, a nurse approached the patient during a medical appointment or, if the patient was hospitalized, at the bedside. If the patient agreed to enroll, a nurse and community outreach worker made a home visit where they conducted a more extensive intake assessment to determine the patient’s medical and social needs. Beginning with the initial contact, providers continually attempted to assess patient engagement through the informal strategies that we describe in this paper.

Data were collected during a 16-month period from 2015–2016 via in depth ethnographic observations and in-person interviews with CCM staff. We conducted a total of 50 in-depth, semi-structured interviews with CCM team members and affiliated medical staff (See Table 1). Interview topics included: CCM program goals and objectives, patient engagement and interaction, work practices and organization, institutional arrangements, and barriers and challenges to providing care. Interviews were conducted in the workplace of the CCM team members and associated providers. Interviews ranged from 45 minutes to one hour, and were recorded and transcribed verbatim.

Four ethnographers (two at each research site) attended CCM team meetings and case conferences, and shadowed providers as they performed their day-to-day work and interacted with patients. Observations were conducted an average of two days per week for 16 months for a total of about 1200 hours of observation. Ethnographers wrote descriptive field notes recording details of clinic visits, meeting discussions, provider/patient interactions, and the daily telephone and in-person work of the CCM staff. The Institutional Review Boards of the two CCM program institutions, as well as of the University of California, San Francisco, approved this study.

All textual data (e.g. field notes and interview transcripts) were coded and analyzed using standard anthropological methods (Bernard and Ryan 2009) and using the qualitative data management software, Atlas.ti. A team of seven researchers conducted iterative reviews of the data and agreed on a largely inductively derived coding scheme, which included but were not limited to codes that capture data related to patient/provider rapport, patient engagement and activation, patient success and failure, housing, mental health, and substance use issues.

After coding, we ran Atlas.ti “queries” to enable thematic comparisons between data tagged with different codes or those tagged with specific combinations of codes.

Looking for Signs of Engagement

That’s been the difficult piece, finding people who are appropriate and they want our help at the same time. That’s been the trickiest piece. CCM Nurse

CCM providers in our study actively looked for positive and negative indicators that patients were willing to engage in care. Providers often found these explicit signs to be inadequate for detecting patients’ desire or readiness to engage in care and therefore looked for more subtle signs and tried to make intuitive assessments.

The enrollment criteria for the CCM programs included a willingness to engage in care. Providers attempted to assess engagement in order to determine whether or not a patient was a “good fit” for the program. The programs tried to select patients who appeared willing to engage in order to maximize the impact of their limited resources. We observed a meeting where a CCM team manager explained the rationale for selecting patients who show, as she said, “readiness for engagement and making progress on some goals.” She told the team, “We are trying to tip the scales to more success for the team and more success for patients who need you, and will benefit from you.” In response to the institutional imperative to maximize the impact of limited resources, managers and medical directors often repeated the view that team members should try to enroll patients who appear willing to engage in order to direct care to patients who will benefit the most.

Despite repeatedly visiting the emergency room for acute medical problems, patients were oftentimes resistant to engage with medical providers and follow medical recommendations. A CCM nurse described unengaged patients: “They’re just going to the hospital to get fixed for right now, then they’re going to go back and do what they’ve been doing. It takes some sort of effort to actually go to the appointment.” Providers in our study viewed patient engagement with their own health care and with the CCM team as crucial for good health outcomes. For example, a CCM nurse stated, “Engagement is a key first step ... It’s the engagement piece that is the first big hurdle to get over.” Another CCM nurse said, “The ones that are more challenging are the ones that we’re having trouble engaging.” However, as we will describe in the sections below, the criteria that patients be willing and able to engage in care created dilemmas for providers who saw low engagement as a consequence of patients’ experiences of socioeconomic marginalization.

CCM providers looked for indicators that patients were willing to engage during initial patient encounters and enrollment, and looked for signs of successful engagement in ongoing assessments of patients’ communication and actions. When CCM providers first met patients, positive indicators that they were willing to engage included verbally agreeing to take part in the program, returning phone calls to the CCM team or answering the phone when CCM team members call, being receptive to a home visit, and showing up to an initial appointment. CCM providers continued to assess engagement over time by considering how frequently patients missed appointments, how well they adhered to medication and treatment regimes, how much progress they made towards behavioral changes such as reducing

substance use or increasing exercise, and how candidly and regularly they communicated with the CCM team. A social worker said that she considers patients likely to engage over time when “we reach out to them by phone and we make an appointment and they show up.” The indicators that patients would not engage were both direct (e.g., saying that they are not interested in the program, and refusing to communicate with CCM team) and indirect (e.g., missing too many appointments, refusing to acknowledge substance use, and not taking medications). A CCM nurse described an explicit negative indicator of engagement: “If you walk in and the patient has their back turned towards you and they’re like, ‘Get out of my room.’”

While providers looked for explicit indicators of engagement, such as medication adherence, such indicators were often absent or fluctuated over time. Providers therefore also deployed intuitive or impressionistic approaches for assessing patient engagement. In describing how the team knows when a patient is willing to engage in care, a physician said, “That is a subjective thing that the primary care provider gets from talking [with and] from knowing their patient. That is really where the gestalt comes to bear.” Providers often described such assessments as intuitive skills or gut feelings. In response to the interview question “How do you know if a patient is ready to engage?” a nurse on the CCM team stated, “I don’t know if it’s necessarily one particular thing. It’s a sense you get sometimes. I’m not very good at it. It’s definitely a skill that I’m still picking up on.” During case conferences, the CCM team discussed their intuitive sense of a patient’s engagement by referring to their own feelings about the patient, and to subtle signs such as the patient appearing attentive or interested. A CCM nurse said that she looks at “body language and the way a patient is talking to you, and stuff like that, [to assess] whether or not this patient is going to be somebody that you’re going to be able to work with, or maybe they just don’t want your assistance right now.”

During a team meeting focused on best practices for selecting appropriate patients for the CCM program, we observed a medical director instructing the team to enroll patients who appear willing to engage. He emphasized that the initial assessment of a patient’s willingness to engage should be based on an overall impression of the patient, rather than a specific set of criteria:

It is a ‘we know when a patient is ready to buy in when we see it’ kind of thing [...] After you chat with a patient by the bedside for five minutes, if you say, wow this is a complicated patient, but there is not enough evidence that they are ready to buy in, then you can say no. Everyone here has expertise in evaluating whether or not a patient is ready to engage, and can make that decision unilaterally.

Providers also reported that many patients took a long time to accept their diagnoses of chronic illness and did not initially believe the providers’ claims that medications or behavioral changes would improve their symptoms. Providers saw it as a sign of engagement when patients began to accept the medical explanation for their illness. A nurse reported in an interview that new patients “hit us at first with denial ... real loss of identity, a lot of guilt, a lot of bargaining” and described the process of accepting their diagnosis of chronic illness as central part of engagement. Another patient appeared unable to manage his medications himself and repeatedly lost them. When the patient finally admitted that the mismanagement of his medications was his own fault, the nurse saw this as a sign of engagement and that the

patient wanted to “do better” and “do the right thing.” A community outreach worker described a major “success” where a patient finally “believed” that crack cocaine use was causing her CHF exacerbations. The patient was not yet able to reduce her substance use but her agreement with the community outreach worker was a sign of engagement.

Engagement at the margins: Looking towards the socioeconomic determinants of health

CCM providers reported that more marginalized patients often have low trust of the medical system and appear unwilling to engage, necessitating a search for more subtle signs of engagement and an intuitive approach to assessment. Moreover, providers understood patient engagement to fluctuate in response to precarious life conditions and to be therefore difficult to predict for patients living in poverty.

When asked to describe their patients, nearly all of the CCM identified poverty, housing and food insecurity, histories of violence and trauma, racism, and exclusion from the medical system as key determinants of patients’ health crises as well as predominant factors shaping care relationships. A view towards the socioeconomic determinants offered CCM providers an explanation for why patients frequently did not follow-through with treatment regimes. During an interview, a community outreach worker described the patient population as follows: “Many are drug addicted, substance abuse issues, marginalized, poverty stricken, less educated and really, really lost in that void that they’ve never been able to crawl out of because of all of these other additional environmental problems that they face.” A CCM nurse told us, “most of our patients are living in poverty and are suffering the effects of that on their health including just not having sometimes very basic resources.”

Providers understood patients’ difficult life conditions to impede their ability to take actions that would appear as explicit indicators of engagement. Providers described patients as engaged when they perceived that the patients wanted to get better, even when they were unable to adhere to treatment regimes or make lifestyle changes. A CCM nurse defined engagement by referring to the patients’ desire to get better: “Engagement is ‘I feel bad and I don’t want to feel bad.’” Another nurse said that she considered patients engaged when they showed that they want to get better, even if they have not been able to successfully manage their health: “Even if they aren’t doing a good job in managing their health conditions, they have made some attempt to show that they want to do that.” Providers reported that more marginalized patients often do not readily or explicitly engage in medical care, and therefore require a more subtle assessment of their willingness to do so. For example, we observed a team deliberating about whether or not they should enroll a new patient suffering from CHF and COPD who continually lost her medications and appeared unable to understand or manage her health conditions. A physician noted that these difficulties could be explained by the patient’s long-term homelessness, and the mental health and substance use problems associated with housing insecurity. A nurse agreed, and suggested that the patient’s willingness to answer the phone when she called could be taken as a sign that the patient might engage in the future.

CCM providers also reported that the difficulty they had engaging marginalized patients stemmed from the high rate of substance use problems within this population. Providers estimated that about half of the super-utilizer patients actively use substances and more have a history of substance use. CCM providers often connected substance use to contextual factors. A nurse described how the CCM team views substance use as a “symptom” of upstream factors:

It’s this vicious cycle of inadequate health care, exposure to violence, and substance use. But, again in our clinic, we really view substance use as a symptom... It’s not a separate issue, but it’s generally a symptom of something else. It’s like, what’s going on in your life that cocaine is making better? What is going on in your life that alcohol is making better? What is going on your life that methamphetamine is making better? Because we need to work on that before we can realistically think that you’re going just stop using substances.

Providers also understood more marginalized patients to be mistrustful of the medical system. Providers described the often pervasive mistrust to result from instances when patients were given inadequate care, incorrect medications, or discharged from the hospital without support or housing, or when patients with chronic pain did not receive adequate treatment due to ongoing substance use problems, racial discrimination on the part of primary care providers, or lack of trained medical staff. As a physician told us, “These are the patients who really have reason to have mistrust of the system.” According to a community outreach worker:

A lot of them are very hesitant ... They’ve have had very, very difficult lives and, and this [hesitancy], it stems from miseducation about health, about the healthcare system. Misinformation and all these things they don’t have access to, makes you mistrust the system, and we are the system.

As a result of marginalization and mistrust, patients often required a long period of relationship- and trust-building with CCM staff before they were willing to engage. A CCM nurse said, “It’s a longer process than I guess we initially thought. I think we’re all sort of humbled by the fact that trust building can take months.”

CCM team members represented patient engagement not as a pre-given attribute of a patient, but rather as the outcome of a process of relationship- and trust-building. A CCM nurse said in an interview, “It takes time to develop a relationship with your patient so they could develop a trust with you. Then from there, then you are able to work out the kinks or whatever is going on with your patient. Then the patient is willing to engage with you.”

Many providers took a self-described “harm reduction” approach to engaging and building trust with patients who actively used substances. Another CCM nurse said:

We let patients know we don’t care if you show up high. Show up. And we need to know if you’re high, because then that will help us make a care plan that actually is reality-based for you versus something that we might like for an ideal patient.

A social worker described her perspective that patients benefit most when providers “meet them where they are.” She said, “We don’t push him to make any decisions. [We] don’t say,

you have to quit.” Some CCM team members said that a nonjudgmental attitude towards patients enabled a trust-building relationship and engagement.

Providers also reported that more marginalized patients had highly unpredictable trajectories of engagement. Many patients were motivated and willing to engage when first approached, and then later disengaged. Other patients initially refused care management and then decided to engage at a later point in time, often after experiencing a significant health or personal crisis. Further, many patients intermittently or cyclically engaged in care, engaging when their lives were going well and disengaging when things were more difficult, or vice versa.

While providers looked for explicit as well as more intuitive signs of patients’ potential to engage in care, they also reported that engagement oftentimes could not be predicted. A CCM physician communicated her struggle to cope with patients’ often transitory willingness to engage:

I think we do a little bit better with people [who] somewhere deep down want to engage with us. I think that’s very hard. We always struggle with figuring out who that is because a lot of people don’t want to engage with us in the beginning and eventually, some people do and then do well, and then some people just never.

This physician’s description of a “deep down” desire further exemplifies the view that engagement is oftentimes not readily perceptible. A community outreach worker, when asked how she knew if a patient was ready to engage, responded:

We will never know. We just have to test it and try it out ... There are times when the patient said ‘Okay yeah I’m interested in the program.’ That’s usually when they’re in the hospital when they’re in the critical stage. They’ll be willing to reach out to accept any kind of assistance that is available. When you start enrolling the patient from time to time they’ll say ‘Oh well, I don’t need you anymore.’ Or they change their mind. It’s really hard to say whether they’ll be successful in a program or not.

Many patients initially refused care management and appeared unwilling to engage, and then engaged at a later point in time, usually after a prolonged period of outreach and trust-building on the part of the CCM providers. When asked to provide an example of a “success story,” a CCM nurse described a patient who was initially unwilling to engage:

It took us actually four months of chasing him just to get him to enroll in the program. He was not really interested. He progressed, starting with four months of him not wanting to be enrolled, to being enrolled, to weighing himself every day, to learning how to fill his own medi-set [a standard pill organizer box], because med adherence was also a really big challenge for him. Taking his meds every day, stopping meth. Those were our main goals for him, to get his symptoms of CHF under control by helping him with med-adherence and he 100% met that goal.

By contrast, CCM providers mentioned a common “pattern” where patients initially appeared willing to engage when hospitalized or at a crisis point but then quickly disengaged. According to a CCM nurse:

When you meet with them on the floor [in-patient unit], it's really hard to tell. Because especially when they're in the hospital, a lot of people are feeling vulnerable and feeling like they want help ... I've definitely had people in the hospital look at me straight on and be like, 'Oh my God! I need help! Things I'm doing are not right. I realize that. I can really use some extra support.' Then they don't even follow-up afterwards.

Many patients reached a crisis point as the result of exacerbations of unmanaged chronic disease. A CCM medical director said: "It is when they have had their near death experience from their combined COPD and CHF that they are like, 'Okay. I have got to do this.' Or some patients realize earlier." Substance use was the other major factor bringing about crises for patients. In response to an interview question about what contributes to success in the CCM program, a nurse emphasized the importance of crisis and timing: "When they hit rock bottom ... they ultimately are the ones that drag themselves out, but they need guidance. I think it's really about timing for them." Providers tried to strategically engage patients after crises to get patients into treatment programs or make other changes in their lives. In describing her struggle to engage a patient, a nurse pointed to what she saw as the potential benefit of crises by stating, "He was doing well for a while ... Sometimes I think that maybe I shouldn't be there, so he can maybe hit rock bottom."

Engagement and Dilemmas of Care at the Margins

If we decide, well they're not engaged, so we're not going to be engaged, I don't think that's a very good approach, because we're suppose to be above and beyond that. We're the health care providers.

-Community Outreach Worker

The CCM programs we observed aimed to enroll patients who appeared willing to engage in order to maximize the benefit of the CCM resources. The practice of directing care toward engaged patients was based on the rationale that CCM is a limited resource and therefore ought to be given to patients who have a high need and are likely to benefit. As we have demonstrated, providers continually discussed and assessed patient engagement in care, yet found such assessments difficult to make based on explicit indicators and instead relied on intuitive evaluations, sometimes based on subtle signs. Furthermore, because engagement fluctuates in response to precarious life conditions, most providers did not believe they could, during an initial assessment, accurately predict which patients would engage in care and eventually be successful in the CCM program. While providers continually tried to assess engagement in order to direct resources to patients who appear willing to engage, they also sometimes questioned and resisted this practice.

As a way of selecting more engaged patients, one of the CCM programs changed its enrollment criteria to include only patients who have a history of successfully going to primary care appointments. In an interview, a physician explained the reasoning for this change:

We take a lot of patients who [...] haven't necessarily seen a primary care doc in 30 years, if ever. Some of these patients we are successful on, but with the vast majority we are not. These are the patients that we are spinning our wheels on.

While most of the providers reported that the new criteria did result in more engaged patients being enrolled in the program, some providers expressed concern that the new criteria could further marginalize patients who have been excluded from the medical system. In an interview, a nurse contested the proposal by suggesting that prior lack of engagement could be the result of barriers to care:

[This] is not necessarily something that I agree with because there are a lot of people who are not connected [to primary care] at all. It doesn't mean that they don't need the help or they don't want the help or are not ready for the help. It's just our system is so bogged down that we cannot serve all the people that are trying to get access to our system.

Providers reported that marginalized patients faced systematic exclusion from the medical system and could not be expected to show immediate engagement with primary care. A nurse reported that the practice of selecting for engaged patients "does leave a group of people out that might need a lot of assistance ... I don't know what to do with that."

Moreover, providers attempted to make ongoing assessments of engagement for enrolled patients in order to increase or decrease the intensity of the care management intervention. When the CCM team discerned that patients were, for example, just beginning to participate in substance use treatment, their positive assessment of increased engagement motivated them to increase their contact with and support for the patient. We also observed that when a difficult patient began to soften her stance towards the staff's efforts to contact her, staff increased their involvement in order to build trust and get the patient to a point of engagement.

Conversely, when the CCM team determined that enrolled patients continued to demonstrate a lack of interest in care or showed a lack of motivation to meet their goals, CCM staff would scale back their involvement with the patient. This usually involved ceasing to reach out by phone or via home visits and instead waiting for the patient to initiate contact. Some patients began with regular primary care and chronic disease management appointments, but then went back to accessing the emergency room. Other patients would miss their appointments, not return phone calls, or not take medications causing providers to question whether or not the patients were benefiting from CCM care. For example, a patient with renal failure, liver disease, CHF, and a degenerative vision disorder relied on the CCM team to fill her medi-set, arrange her many specialist appointments and transportation, and to provide her with psychosocial support through regular home visits. The patient, however, frequently missed primary care and dialysis appointments and her in-patient utilization remained high. After two years of working with the patient, we observed a nurse approach her at her hospital bedside and say, "this is not working out" because "nothing has changed," and explain that she would no longer call the patient or make home visits. Other patients were dis-enrolled from the CCM program for "failure to engage." A nurse reported that when a patient is "hard to engage" and after investing significant time and energy "it's just

not clicking,” then the team will decide “it’s not worth all that effort and time consuming and we can give our time to someone else.”

CCM providers in our study faced a persistent dilemma about how long to continue outreach to patients who appeared unengaged. The uncertainty about how long to try to engage a patient was exemplified in the following exchange we observed between a medical director and a community outreach worker during a team meeting:

CCM medical director: We are spending a lot of time trying to engage patients who don’t want to be engaged. Doing a lot of outreach and this is not the best use of people’s time, in my opinion.

Community outreach worker: This is relevant to something we [the team] were talking about. We had a dilemma about what to do with patients who are not engaging. How long do we keep engaging with them? Because with some patients it has paid off. After a lot of outreach, sometimes at the last minute, they completely turn around and it pays off.

Because of these uncertainties, CCM teams found themselves negotiating on a case-by-case basis when it was “worth it” to continue outreaching to patients who appear unengaged. During a team discussion about a patient who had been hospitalized weekly but refused to engage with the CCM team, the CCM manager told team members, “We can’t have this policy that says ‘this is how much we try’ because we also have to trust our gut about when it is worth it and when we’ve tried enough. I can’t think of a way other than just discussing the cases and feeling it out.” One of the programs established a formal policy of making three attempts to engage a patient before ceasing outreach, however providers often continued outreach for much longer. A community outreach worker said, “The goal is to reduce utilization. That’s not going to happen if we say, ‘Okay, we made 3 efforts, bye, you’re out.’”

Again, the CCM providers relied on an intuitive approach to determining who might be willing to engage in care at a later point in time. In the absence of explicit signs of engagement, as a community outreach worker said, “I think I have more of a gut feeling about that sometimes [...] about reaching out. If you do that, that person might come aboard or change their mind. That kind of feeling that, let’s give it one more try.”

The decision to stop trying to engage a patient was sometimes contentious. During a discussion about a difficult-to-engage patient, a CCM nurse said, “There’s not much there that’s impactable,” and suggested that, because “we’re a finite resource,” the team should withdraw care from the patient. A primary care provider who had referred patients to the CCM in the past responded to the discussion with frustration, clearly disappointed by the turn the conversation had taken. She said it was a “pet peeve” of hers that the CCM only seemed to want to work with patients who were “willing to engage.” Of course they would be successful, she commented, if they kicked out all the difficult patients.

Conclusion

This is, to our knowledge, the first study to explore how medical providers in safety-net settings attempt to assess patient engagement in the process of providing care. In addition to a diagnosis of chronic illness and an assessment of being at high risk for future hospitalization, CCM providers attempted to assess patient engagement in care in the process of considering who is a good patient for care management. CCM teams tried to direct care to patients who were likely to engage in order to maximize the impact of health care resources. Importantly, most providers in our study reported that patients' socioeconomic conditions shape their possibilities for engagement. From our participants' perspectives, more marginalized patients appeared to have lower engagement and fluctuating trajectories of engagement due to the continual crises related to living in poverty including housing and nutritional insecurity, substance use problems, and exposure to violence and trauma. Furthermore, in the providers' view, marginalized patients had sufficient warrant to distrust the health care system due to histories of exclusion and poor treatment. This distrust in turn manifested in behaviors or in-actions that gave the appearance of low engagement. While providers continually tried to assess engagement, they also recognized that difficult life conditions made it less likely that patients would display explicit, sustained signs of engagement.

Providers in the CCM programs we studied tried to assess engagement at the margins by attending to the social and economic determinants of health, which have generally been excluded from clinical consideration in the U.S. (Holmes 2012, Metzl and Hansen 2014). At the time of their first encounter, CCM providers reported that many patients could not yet explicitly participate in care due to factors related to socioeconomic marginalization. CCM providers in our study therefore looked for subtle signs of engagement and tried to make intuitive assessments about which patients would be willing to engage in care over time. Providers tried to select for patients who were likely to participate in care at a future point, once the CCM teams worked to meet the patients' basic needs for food, housing, and transportation.

The concept and rhetoric of patient engagement in the clinics we studied contained an ambiguity between, on the one hand, a willingness or "readiness" to engage in care at a future point in time and, on the other, current engagement in care as indicated by adherence and successful self-management. We found that patient engagement, as articulated by the providers in our study, differs from concepts of compliance or adherence. While CCM providers saw adherence to treatment as a sure sign of engagement, they also considered patients to be engaged even when they were not able to adhere to treatment. Moreover, the focus on patient willingness or desire appears suggestive of the concept of *patient activation* and its emphasis on patient agency. Hibbard and colleagues (2005) define patient activation as "patient knowledge, skill, and confidence for self-management" (1918). Similar to adherence, providers in the CCM programs saw it as a positive sign of engagement when patients worked to develop these capacities for self-management. Many patients enrolled in the CCM clinic lacked the knowledge, skill or confidence to manage their own health, and were nonetheless seen as engaged if they appeared willing to *develop* these capacities. Thus, engagement in the clinics we studied refers not to successful adherence or self-management,

but rather to the patient's generally positive orientation towards the medical providers and the patient's expressed desire to achieve better health, even if that orientation and desire were not yet manifest in present actions.

While providers continually attended to structural conditions, they also frequently deployed more proximal and behavioral explanations for low patient engagement such as choosing to refuse treatment or being uninterested in making lifestyle changes. However, rather than being strictly oppositional forms of explanation, the providers in our study represented a complex interplay between structural and individual behavioral factors, sometimes explaining detrimental behaviors as responses to structural conditions, and other times explaining behavior as the result of individual choice and will. With the growing trend toward "structurally competent" medical education and care (Metzl and Hansen 2014), our findings indicate that social scientists need to be attentive to the multiplicity of ways that structural explanations are deployed in clinical settings.

It is notable that providers in this study used a largely qualitative and intuitive style of assessing patient engagement. While some providers showed interest in adopting a more standardized approach, in general providers reported that intuitive assessments enabled a more holistic approach to patients' complex circumstances. Intuitive and gestalt-based clinical decision-making has long been understood as central to the expertise and efficacy of health care providers (Gordon 1988). The inclusion of "anecdotal" and contextual evidence may continue to be important for care that is responsive to patients' particular circumstances, even as these modalities are threatened by the demands for standardization under evidence-based medicine (Pine 2011).

As health care systems increasingly move towards care delivery and payment models that depend upon successful patient engagement for their financial sustainability (Shortell et al. 2015), the institutional pressure to engage patients in care will likely continue to increase. Investments in patient engagement have been argued to show promise as a means to improve quality and decrease the costs of care (Cosgrove et al. 2013). Our study suggests that the imperative of patient engagement also has the potential to exacerbate health disparities in some instances. Distributing care according to assessments of patient engagement—directing care towards engaged patients and withdrawing care from unengaged patients—holds the possibility of establishing a form of health care "deservingness" (Willen 2012) based on providers' perceptions of who legitimately desires to achieve better health. Health care providers draw from often-implicit ethical norms that define which patients are "worth" their time and effort, and tend to privilege patients who are more agreeable and have seemingly "fixable" problems (Higashi et al. 2013). Further, racial minorities and socioeconomically disadvantaged patients are more likely to be labeled as non-compliant and to be seen as refusing care (Maskovsky 2005, Rouse 2010). Our study finds that patients who are more socioeconomically marginalized or have faced sustained barriers to care appear less willing to engage in care. While the CCM providers in our study faced institutional pressure to assess willingness to engage in order to maximize the benefit of scarce resources, they also considered such assessments to be highly challenging and oftentimes inaccurate. Many of the providers believed that it was impossible to predict which patients would eventually engage in care, due largely to the fluctuations in

engagement resulting from patients' highly precarious life conditions. This study indicates that attention to socioeconomic determinants of health will be crucial to efforts by clinicians, researchers, and policy-makers to define and operationalize patient engagement in care. As health care systems seek to increase patient engagement, it will be necessary to address patients' access to basic resources such as stable housing and food as necessary preconditions for engagement. Lastly, this study compels further inquiry into how normative judgments of patient worthiness and potential to improve continue to shape distributions of vital health care resources for the most vulnerable.

Acknowledgments

We are indebted to the participants in our study for their time and attention, and for sharing their complicated work with us. We also want to thank our co-investigators Elizabeth Davis, Kathleen Dracup, David Moskowitz, and Dean Schillinger. Research reported in this publication was supported by the National Institute of Nursing Research of the National Institutes of Health under award number R01NR015233.

References

- Anderson, Gerard, Horvath, Jane. The Growing Burden of Chronic Disease in America. *Public Health Reports*. 2004; 119(3):263–70. [PubMed: 15158105]
- Bernard, H Russell, Ryan, Gery W. *Analyzing qualitative data: Systematic approaches*. Los Angeles: SAGE; 2009.
- Bodenheimer, Thomas. *Strategies to Reduce Costs and Improve Care for High-Utilizing Medicaid Patients: Reflections on Pioneering Programs*. Center for Health Care Strategies, Inc; 2013.
- Bourgois, Philippe I., Schonberg, Jeffrey. *Righteous Dopefiend*. University of California Press; 2009.
- Carman, Kristin L., Dardess, Pam, Maurer, Maureen, Sofaer, Shoshanna, Adams, Karen, Bechtel, Christine, Sweeney, Jennifer. Patient And Family Engagement: A Framework For Understanding The Elements And Developing Interventions And Policies. *Health Affairs*. 2013; 32(2):223–31. [PubMed: 23381514]
- Center for Advancing Health. [Accessed September 26] A New Definition of Patient Engagement. 2010. http://www.cfah.org/pdfs/CFAH_Engagement_Behavior_Framework_current.pdf
- Cosgrove, Delos M., Fisher, Michael, Gabow, Patricia, Gottlieb, Gary, Halvorson, George C., James, Brent C., Kaplan, Gary S., et al. Ten Strategies To Lower Costs, Improve Quality, And Engage Patients: The View From Leading Health System CEOs. *Health Affairs*. 2013; 32(2):321–27. [PubMed: 23381525]
- Dubbin, Leslie A., Chang, Jamie Suki, Shim, Janet K. Cultural Health Capital and the Interactional Dynamics of Patient-Centered Care. *Social Science & Medicine*. 2013; 93:113–20. [PubMed: 23906128]
- Farmer, Paul. *Pathologies of Power: Health, Human Rights, and the New War on the Poor*. University of California Press; 2005.
- Freund, Tobias, Wensing, Michel, Geissler, Stefan, Peters-Klimm, Frank, Mahler, Cornelia, Boyd, Cynthia M., Szecsenyi, Joachim. Primary Care Physicians' Experiences with Case Finding for Practice-Based Care Management. *The American Journal of Managed Care*. 2012; 18(4):155–161.
- Gordon, Deborah. Clinical science and clinical expertise: Changing boundaries between art and science in medicine. In: Lock, Margaret, Gordon, Deborah R., editors. *Biomedicine examined*. Netherlands: Springer; 1988. p. 257–295.
- Harris, L Jeff, Graetz, Ilana, Podila, Pradeep SB., Wan, Jim, Waters, Teresa M., Bailey, James E. Characteristics of Hospital and Emergency Care Super-Utilizers with Multiple Chronic Conditions. *The Journal of Emergency Medicine*. 2016; 50(4):203–14.
- Hibbard, Judith H., Mahoney, Eldon R., Stockard, Jean, Tusler, Martin. Development and Testing of a Short Form of the Patient Activation Measure. *Health Services Research*. 2005; 40(6 Pt 1):1918–30. [PubMed: 16336556]

- Higashi, Robin T., Tillack, Allison, Steinman, Michael A., Bree Johnston, C., Michael Harper, G. The 'worthy' patient: rethinking the 'hidden curriculum' in medical education. *Anthropology & medicine*. 2013; 20(1):13–23. [PubMed: 23581400]
- Holmes, Seth M. The Clinical Gaze in the Practice of Migrant Health: Mexican Migrants in the United States. *Social Science & Medicine*. 2012; 74(6):873–81. [PubMed: 21992736]
- Hong, Clemens S., Siegel, Allison L., Ferris, Timothy G. Caring for High-Need, High-Cost Patients: What Makes for a Successful Care Management Program? The Commonwealth Fund: Issue Brief. 2014; 19:1–19.
- Hong, CS., Hwang, AS., Ferris, TG. [Accessed September 26] Finding a Match: How Successful Complex Care Programs Identify Patients. 2015. <http://www.chcf.org/publications/2015/03/finding-match-complex-care>
- Ishikawa, Hirono, Hashimoto, Hideki, Kiuchi, Takahiro. The Evolving Concept of 'Patient-Centeredness' in Patient-Physician Communication Research. *Social Science & Medicine*. 2013; 96:147–53. [PubMed: 24034962]
- Jackson, Carlos, DuBard, Annette. [Accessed September 26] It's All about Impactability! Optimizing Targeting for Care Management of Complex Patients. 2015. <https://www.communitycarenc.org/media/files/data-brief-no-4-optimizing-targeting-cm.pdf>
- Johnson, Tracy L., Rinehart, Deborah J., Durfee, Josh, Brewer, Daniel, Batal, Holly, Blum, Joshua, Oronce, Carlos I., Melinkovich, Paul, Gabow, Patricia. For many patients who use large amounts of health care services, the need is intense yet temporary. *Health Affairs*. 2015; 34(8):1312–1319. [PubMed: 26240244]
- Knight, Kelly R., Lopez, Andrea M., Comfort, Megan, Shumway, Martha, Cohen, Jennifer, Riley, Elise D. Single Room Occupancy (SRO) Hotels as Mental Health Risk Environments among Impoverished Women: The Intersection of Policy, Drug Use, Trauma, and Urban Space. *International Journal of Drug Policy*. 2014; 25(3):556–61. [PubMed: 24411945]
- Koh, Howard K., Brach, Cindy, Harris, Linda M., Parchman, Michael L. A Proposed 'Health Literate Care Model' Would Constitute a Systems Approach to Improving Patients' Engagement in Care. *Health Affairs (Project Hope)*. 2013; 32(2):357–67. [PubMed: 23381529]
- LaCalle, Eduardo, Rabin, Elaine. Frequent Users of Emergency Departments: The Myths, the Data, and the Policy Implications. *Annals of Emergency Medicine*. 2010; 56(1):42–48. [PubMed: 20346540]
- Lewis, Geraint H. 'Impactability Models': Identifying the Subgroup of High-Risk Patients Most Amenable to Hospital-Avoidance Programs. *Milbank Quarterly*. 2010; 88(2):240–55. [PubMed: 20579284]
- Maskovsky, Jeff. Do People Fail Drugs, or Do Drugs Fail People?: The Discourse of Adherence. *Transforming Anthropology*. 2005; 13(2):136–42.
- Metzl, Jonathan M., Hansen, Helena. Structural Competency: Theorizing a New Medical Engagement with Stigma and Inequality. *Social Science & Medicine*. 2014; 103:126–33. [PubMed: 24507917]
- Nutting, Paul A., Crabtree, Benjamin F., Miller, William L., Stange, Kurt C., Stewart, Elizabeth, Jaén, Carlos. Transforming Physician Practices To Patient-Centered Medical Homes: Lessons From The National Demonstration Project. *Health Affairs*. 2011; 30(3):439–45. [PubMed: 21383361]
- Pine, Adrienne. From healing to witchcraft: On ritual speech and roboticization in the hospital. *Culture, Medicine, and Psychiatry*. 2011; 35(2):262–284.
- Rittenhouse, Diane R., Shortell, Stephen M., Fisher, Elliott S. Primary Care and Accountable Care — Two Essential Elements of Delivery-System Reform. *New England Journal of Medicine*. 2009; 361(24):2301–3. [PubMed: 19864649]
- Rouse, Carolyn. Patient and practitioner noncompliance: Rationing, therapeutic uncertainty, and the missing conversation. *Anthropology and Medicine*. 2010; 17:187–200. [PubMed: 20721756]
- Shortell, Stephen M., Sehgal, Neil J., Bibi, Salma, Ramsay, Patricia P., Neuhauser, Linda, Colla, Carrie H., Lewis, Valerie A. An Early Assessment of Accountable Care Organizations' Efforts to Engage Patients and Their Families. *Medical Care Research and Review*. 2015; 72(5):580–604. [PubMed: 26038349]

- Whitmarsh, Ian. The Ascetic Subject of Compliance: The Turn to Chronic Diseases in Global Health. In: Biehl, Joao, Petryna, Adriana, editors. *When People Come First: Critical Studies in Global Health*. Princeton: Princeton University Press; 2013. p. 302-24.
- Willen, Sarah S. How is health-related “deservingness” reckoned? Perspectives from unauthorized im/migrants in Tel Aviv. *Social Science & Medicine*. 2012; 74(6):812–821. [PubMed: 21821324]
- Yen, Irene H., Robbins, Teresa C., Napoles, Tessa M., Shim, Janet K., Moskowitz, David, Burke, Nancy J. Complex care management patients in the safety-net setting: Description of medical conditions and health care utilization. Unpublished results.

Table 1

Characteristics of study participants at baseline (N=50)

Characteristic	n (%)
Age, mean years (SD)	39 (14)
Gender, n (%)	
Male	12 (24)
Female	38 (76)
Race/ethnicity, n (%)	
Asian/Pacific Islander	8 (16)
Black/African American/African	11 (22)
Hispanic/Mexican/Mexican- American/Chicano/Latino/Spanish Heritage	5 (10)
White/Caucasian	24 (48)
Other	2 (4)
Primary role, n (%)	
Clinic clerk	1 (2)
Community health outreach worker	6 (12)
Health coach	3 (6)
Manager	3 (6)
Medical assistant	2 (4)
Medical Director	3 (6)
Nurse	12 (24)
Primary care provider	13 (26)
Pharmacist	1 (2)
Project Assistant/Data Analyst	1 (2)
Social worker	5 (10)
Length of time at any CCM clinic, mean years (SD)	3.7 (4.7)