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Authors

Thompson-Lastad, Ariana
Yen, Irene H
Fleming, Mark D
et al.

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Defining Trauma in Complex Care Management: Safety-Net Providers' Perspectives on Structural Vulnerability and Time

Ariana Thompson-Lastad, PhD(c)[a], **Irene H. Yen, PhD, MPH**[b], **Mark D. Fleming, PhD**[c], **Meredith Van Natta, PhD(c)**[a], **Sara Rubin, PhD(c)**[a], **Janet K. Shim, PhD**[a], and **Nancy Burke, PhD**[c]

[a]UC San Francisco Dept. of Social and Behavioral Sciences 3333 California St., Suite 455, San Francisco, CA 94118, USA

[b]UC San Francisco School of Medicine 513 Parnassus Ave, San Francisco, CA 94143-0410, USA

[c]UC Merced Department of Public Health School of Social Sciences, Humanities and Arts, Classroom & Office Building 5200 North Lake Road Merced, CA 95343

Abstract

In this paper, we delineate how staff of two complex care management (CCM) programs in urban safety net hospitals in the United States understand trauma. We seek to (1) describe how staff in CCM programs talk about trauma in their patients' lives; (2) discuss how trauma concepts allow staff to understand patients' symptoms, health-related behaviors, and responses to care as results of structural conditions; and (3) delineate the mismatch between long-term needs of patients with histories of trauma and the short-term interventions that CCM programs provide. Observation and interview data gathered between February 2015 and August 2016 indicate that CCM providers define trauma expansively to include individual experiences of violence such as childhood abuse and neglect or recent assault, traumatization in the course of accessing health care and structural violence. Though CCM staff implement elements of trauma-informed care, the short-term design of CCM programs puts pressure on the staff to titrate their efforts, moving patients towards graduation or discharge. Trauma concepts enable clinicians to name structural violence in clinically legitimate language. As such, trauma-informed care and structural competency approaches can complement each other.

Keywords

United States; complex care management; trauma-informed care; structural competency; trauma; chronic illness; social determinants of health

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Corresponding Author: Ariana Thompson-Lastad, UC San Francisco Dept. of Social and Behavioral Sciences, 3333 California St., Suite 455, San Francisco, CA 94118, USA, Ariana.thompson-lastad@ucsf.edu, 916-508-0502.

INTRODUCTION

> "What if we approached all care assuming that everyone has been exposed to trauma?" -Presenter at a Complex Care Management Conference

In the U.S., 1% of the population accounts for approximately 20% of health care expenditures (Cohen and Yu 2012). In an effort to improve healthcare quality and decrease costs, "super-utilizers" –patients with multiple chronic conditions and frequent hospital visits—have been identified as a population whose care is particularly costly and fragmented (Gawande 2011; Hasselmann 2013). The Centers for Medicare and Medicaid funded complex care management (CCM) demonstration projects, interdisciplinary teams of health care providers integrated into primary care who work to improve outcomes and reduce expenditures for "super utilizers." CCM programs draw on the growing body of research that shows trauma and chronic stress are strongly associated with poor physical and mental health, as well as with social and structural barriers to accessing care (Felitti MD et al. 1998; Lee, Tsenkova, and Carr 2014; Sinnott et al. 2015). More recent research shows extremely high rates of trauma among CCM patients (Haas 2014; Hong, Siegel, and Ferris 2014).

In this paper, we delineate how staff of two CCM programs in urban public hospitals use concepts of trauma. We seek to (1) describe how staff in CCM programs talk about trauma in their patients' lives; (2) discuss how trauma concepts allow staff to understand patients' symptoms, health-related behaviors, and responses to care as results of structural conditions; and (3) delineate the mismatch between long-term needs of patients with histories of trauma and the short-term interventions that CCM programs provide. We will argue that CCM staff use trauma concepts to understand patients' social histories as a relevant part of their health. CCM staff face the challenges of patients' social vulnerabilities on a daily basis, and some talk about trauma and health in ways that align with social scientific understandings of structural violence (Anglin 1998; Farmer et al. 2006) and structural vulnerability (Quesada, Hart, and Bourgois 2011). In addition to conventional notions of trauma as individual episodes of violence, some staff also define trauma to include traumatic experiences accessing health care and exposure to racial violence and homelessness that echo social scientific understandings of community trauma and structural violence. Staff describe trauma as a precipitating factor in patients' hospitalizations, and talk with patients about connections between traumatic experiences, health behaviors, and physical symptoms. Conversations and practices, we observed made clear that even in health care settings that do not officially consider themselves to provide trauma-informed care, trauma concepts can permeate the work of clinical staff, who may informally implement elements of trauma-informed care.

We first summarize recent literature on trauma, health and trauma-informed care, as well as structural understandings of health. We then delineate the three kinds of trauma that CCM staff describe, with a case of a patient whose story exemplifies each: (1) individual experiences of violence; (2) structural violence; and (3) health care as traumatizing. We examine how time acts as a barrier to trauma-informed care in these CCM programs, and conclude by pointing out potential intersections between trauma-informed care approaches and structural understandings of health.

BACKGROUND

Complex Care Management

Complex care management programs have been implemented with private insurance and Medicare patient populations, and more recently in settings that serve Medicaid recipients. They typically enroll patients for a limited period, provide team-based care and health coaching for symptom management, and "graduate" patients back into standard primary care when CCM providers deem them able to self-manage their health. Reviews of CCM best practices do not discuss an optimal length of the time for enrollment. Across CCM programs serving Medicaid patients, high levels of substance use, mental illness, and childhood trauma have been reported (Hasselmann 2013; Hong, Siegel, et al. 2014). In some cases, CCM programs have developed networks of medical and social service referrals to support their patients in addressing social needs (Garg, Boynton-Jarrett, and Dworkin 2016).

Trauma, health, and trauma-informed care

Diagnosis with multiple chronic illnesses (multimorbidity) in adulthood is associated with a history of Adverse Childhood Experiences (ACEs) such as abuse and parental incarceration (Sinnott et al. 2015), and multimorbidity is universal among CCM patients. ACEs are now a widely-used approach to measuring individual experiences of stress and trauma in childhood. Perhaps the most widely used definition of trauma in the US comes from the Substance Abuse and Mental Health Services Administration (SAMHSA): "Individual trauma results from an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or life threatening and that has lasting adverse effects on the individual's functioning and mental, physical, social, emotional, or spiritual well-being" (2014). Though SAMHSA acknowledges elsewhere that trauma can affect whole communities and multiple generations, its definition focuses on the individual, which some argue separates trauma from the neighborhood and structural conditions and community exposures to adversity that make it so common and damaging (Cronholm et al 2015; McKenzie-Mohr, Coates, and McLeod 2012; Pinderhughes et al 2016). In contrast, Machtinger and colleagues define trauma broadly to include experiences of structural violence (2015:193), suggesting that trauma can affect whole communities (Pinderhughes et al. 2016), over multiple generations (Brave Heart et al. 2011).

The term "trauma-informed care" originated in fields including juvenile justice and mental health, and has recently spread to medical settings. Bowen and Murshid (2016) define trauma-informed care as "an organizational change process centered on principles intended to promote healing and reduce the risk of re-traumatization for vulnerable individuals." Machtinger and colleagues (2015) provide a clinical framework for "trauma-informed primary care." It encompasses *environment* (including staff training and interdisciplinary collaboration); *screening* (including universal screening for abuse, mental health conditions, and chronic pain); *response* (including connecting patients with services such as housing as well as trauma-specific therapy); and a strong organizational *foundation* that includes community partnerships and support for clinicians. These elements draw on other frameworks organized around elements of trauma informed-care, commonly including safety, trustworthiness, collaboration, empowerment, and choice (SAMHSA 2014; Wolf et al. 2014). We use the trauma-informed primary care framework to aid in description and analysis of trauma-informed care in safety-net CCM programs.

Structural understandings of health

Structural violence, a concept widely used by social scientists, describes how inequality is made visible when "persons are socially and culturally marginalized in ways that deny them the opportunity for emotional and physical well-being, or expose them to assault or rape, or subject them to hazards that can cause sickness and death" (Anglin 1998). *Structural vulnerability* refers to the manifestation of structural violence in the social positions of individuals and communities, and subsequently, in poor health (Quesada et al. 2011). Recently, some have called for clinicians to develop *structural competency*, coupling awareness of how structural issues influence individual health with skills to address these issues in clinical practice:

> the trained ability to discern how a host of issues defined clinically as symptoms, attitudes, or diseases (e.g., depression, hypertension, obesity, smoking, medication "non-compliance," trauma, psychosis) also represent the downstream implications of a number of upstream decisions about such matters as health care and food delivery systems, zoning laws, urban and rural infrastructures, medicalization, or even about the very definitions of illness and health (Metzl and Hansen 2014: 128).

Trauma is implicitly present as both cause and symptom of disease in the structural competency framework. However, many trauma-informed care approaches define trauma as an individual phenomenon, separate from "upstream" or social determinants of health, which structural competency advocates view as necessarily connected to clinical medicine. We will examine the use of trauma concepts in CCM programs, including how staff members define trauma broadly to include patients' structural vulnerability. Neither the CCM programs nor the larger hospitals they are part of claim to be implementing trauma-informed care, yet staff consider trauma an important element of their patients' past and present health.

METHODS

This paper emerges from a longitudinal study that seeks to understand how the interactions, processes, and organizational arrangements of two CCM programs contribute to patients' use of health care services and fulfilment of their social and medical needs. We focus on two programs located within county-run health care systems in the Western U.S.

Setting

Both programs strive to provide coordinated medical, behavioral health, and social services, with ongoing collaboration between the CCM team (most of whom care exclusively for CCM patients), primary care providers, and other health and social service providers. They focus primarily on supporting self-management of chronic medical conditions, and were not developed to treat mental illness or substance use. CCM patients struggle with unstable housing, substance use, and food insecurity, among other challenges. The programs began in 2012 and 2013, and since then, eligibility and referral criteria have been in flux. Typically, patients are referred to the programs by physicians, and at times of lower enrollment CCM staff reach out to patients proactively. Patients can decline to enroll, either explicitly or by declining to communicate with staff.

When patients enroll in CCM, the team, including a physician, nurses, social workers, and community outreach workers, assesses medical, psychosocial, and economic needs by reviewing the patient's medical history, and making a home visit (whether to an apartment or a park bench). The CCM team considers needs such as medical devices and mental health treatment, and assesses whether a patient needs access to food, housing, or transportation, or could obtain health insurance, government ID, or disability income. The team works to establish trust, engage the patient's family or caregivers if available, and motivate the patient to engage with outpatient health services. The CCM team designs a care plan to achieve specific goals that the patient or the staff team identified as priorities, such as better medication adherence, reducing substance use, or securing housing. Patients and CCM staff work on these goals in collaboration with primary care and other service providers, periodically updating the care plan until staff and patients determine the patient is ready to "graduate," theoretically 6–18 months after enrollment.

Data Collection

This study analyzed data from ethnographic observations and in-depth participant interviews with patients and staff using a grounded theory approach.

Ethnographic Observations—Four ethnographers shadowed patients and staff, conducting approximately 1000 hours of observations between February 2015 and August 2016 in clinics, patients' homes, and other settings. We typically attended weekly CCM case conferences, and arranged to observe medical appointments, home visits, and other interactions with patients discussed in these meetings. Observations and conversations were recorded in detailed field notes and identities of individuals being observed were anonymized. Observations were conducted concurrently with the interviews described below, so that they would inform one another.

Patient interviews—During observations, ethnographers identified eligible subjects for patient interviews. Eligibility criteria included age 21 or older; fluency in English or Spanish; and willingness to participate in three 30–60 minute interviews. Patients were asked to participate in baseline and follow-up interviews at 6–12 months and 12–24 months after baseline. This design allowed the team to track patients' experiences with the program, changes in their social or medical conditions, and perspectives on their health care. Interviews were in-person and semi-structured. Baseline interviews took place in 2015 at a time and place convenient to the participant, such as their home, hospital room, or dialysis center; this paper was completed before most follow-up interviews had been conducted. Interviewees were offered a $25 gift card per interview. Interviews were audio-recorded, transcribed verbatim, and translated (if conducted in Spanish). Despite our best efforts to interview patients at times when they would be fully able to participate, the majority struggled continuously with fatigue, mental health symptoms, active substance use, and other barriers to participation, rendering it difficult to carry out extensive, in-depth interviews. Their poor health (a substantial number of patients also died during the course of data collection) also precluded participation in a process of validating our interpretation of patient interview data.

Provider and Staff interviews—All CCM program staff were invited to participate in interviews, and nearly all participated, including physicians, nurses, administrators, community health workers, and social workers [see Table 1]. Additional interviews were conducted with primary care providers, and staff at community-based organizations with whom CCM programs partner. Participants were asked to take part in one-on-one semi-structured interviews at baseline and after one year. The content and scope of provider/staff interviews were shaped by ongoing observation of clinic procedures and interactions. Baseline interviews took place in 2015 at a time and place convenient to the participant, such as a private office. Interviewees were offered a $25 gift card per interview for their time. Interviews were audio-recorded and transcribed verbatim.

Data Analysis

Transcripts were coded and analyzed using grounded theory methods (Charmaz 2006). The seven researchers developed a list of codes and sub-codes during data collection, drawing from the interview guide and initial review of the data. Each ethnographer coded their own field notes and interview transcripts using the qualitative data management software Atlas.ti. Using a combination of deductive and inductive codes, discussion, and memoing among the team, the first iteration of the codebook was developed. We then ran Atlas.ti “queries” to enable thematic comparisons between data tagged with different codes or tagged with specific combinations of codes. All study procedures were conducted with the approval of the sponsoring university’s Internal Review Board. Informed consent was obtained from all participants.

RESULTS AND DISCUSSION

This paper draws primarily on observational data (including of staff meetings and medical appointments), supplemented by interviews with staff (N=50) and patients (N=61). We focus on interviews and observations related to the three patients whose cases are described in detail below. Tables 1 and 2 provide additional information on the demographics of both patients and providers. Though trauma-informed care is not a formalized part of these programs’ agenda, it is part of the national discourse on complex care management, and safety-net CCM patients live with both chronic physical illness and structural vulnerability. We found that CCM providers defined trauma expansively to include three broad categories, as illustrated in the three cases below: (1) individual experiences of violence such as childhood abuse and neglect or recent assault; (2) structural violence; and (3) traumatization in the course of accessing health care. These categories are in line with Machtinger and colleagues (2015), but distinct from many discussions of trauma which focus primarily on individual experience (Cronholm et al. 2015; SAMHSA’s 2014). These expansive definitions of trauma enabled CCM staff to care for patients in particular ways that differ from standard primary care. While these programs did not measure trauma prevalence in a standardized way, one program asked patients about particular kinds of trauma, typically during intake with a social worker. As the medical director said, “We’re not formally screening for [trauma], but the team is very attuned to it and definitely works with patients on it…We’re not a program where that’s front and center to what we do, and maybe it should be.” In case conferences, we observed providers discuss trauma as a cause of substance use, unhealthy behaviors, and physical symptoms. On other occasions, CCM staff listed trauma alongside a list of other mental health diagnoses and addictions as if it were entirely separate.

We argue that CCM staff understood their patients’ symptoms, health-related behaviors, and responses to care as embedded within structural conditions, and used available resources to provide care that at times went beyond treating mental and physical symptoms to addressing patients’ social position and circumstances. When asked to describe their patients, nearly all CCM providers emphasized social and structural determinants of health. For example, a community outreach worker explained that many CCM patients “are drug addicted, [have] substance abuse issues, [they’re] 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.” In addition, CCM staff identified poverty, racism, and violence as traumatic experiences and key contributors to health crises and relationships with providers. Trauma provided CCM staff with a flexible language that could move between individual and structural levels, and was leveraged in different ways depending on the person and situation. Trauma gave providers an explanation for patients’ challenging behavior and an imperative to modulate their reactions to that behavior. When staff saw someone as too traumatized to engage with their services, they could invoke structure to explain why their efforts were not enough to help someone change. At times, patients referenced their experiences of trauma as a way to self-advocate for treatment, and staff used a trauma framework to justify continuing efforts to engage patients whether or not they were making the kind of measurable decrease in hospitalizations that CCM programs are mandated to demonstrate. What follows are three cases we present to illustrate the kinds of experiences that CCM staff described as traumatic, and their approaches to work with patients living with trauma.

Case 1: Sabrina

Individual violence as trauma—Sabrina (all names are pseudonyms), a young African-American woman, was a CCM patient with a long history of abuse. While she disclosed her trauma history to CCM staff early in her participation in the program, they felt she remained distrustful of them. Her story demonstrates how challenging it can be for CCM staff to address a patient’s long-term needs within a short-term program. CCM staff used Sabrina’s trauma history as an explanation for her non-adherence to treatment and continued frequent hospital stays (despite the CCM goal to reduce hospitalizations), and as justification for ongoing outreach. Yet faced with her ongoing lack of measurable progress after nearly two years, staff decided to withdraw from further attempts at outreach. She died soon afterwards.

When Sabrina first enrolled in CCM in 2014, she had been diagnosed with multiple chronic conditions and told the social worker that she felt depressed, had a history of abuse and wanted to stop using cocaine. She was socially isolated; though a roommate gave her free room and board, she told CCM staff she was afraid of him. Her initial CCM care plan included applying for disability benefits, assessing readiness for substance abuse treatment and arranging transportation to appointments. Over the next year, she interacted with CCM staff only intermittently, during and between frequent hospitalizations. As a physician connected to CCM pointed out, many patients miss appointments and stop engaging in care after disclosing histories of trauma; it is unclear whether this was part of what drove Sabrina's inconsistent engagement.

A year after enrollment, Sabrina's health had declined and she was hospitalized on a weekly basis for acute problems. She was now receiving outpatient dialysis, legally blind and taking opioid medications for chronic pain. At one case conference, CCM staff discussed the importance of doing urine drug tests when Sabrina was hospitalized, though they didn't think she was ready for substance abuse treatment. Her nurse case manager asked worriedly, "What is her true prognosis? What role can we legitimately play in her life?" The CCM doctor replied, "She has some biomedically complicated stuff….and some degree of self-management that she could alter." The social worker helped Sabrina apply for disability benefits and food stamps, while the nurse and community health worker visited her regularly in the hospital, worked to coordinate her medications and accompanied her to social services appointments.

Sabrina continued to relate ambivalently to CCM staff. They reached out to her frequently even as they became increasingly frustrated with her periodic disengagement. The team discussed waiting for Sabrina to contact them rather than continuing frequent outreach. The nurse reported, "I spent all day on the phone…trying to convince her to go to the emergency room and she just wanted to lie in bed…she hadn't been to dialysis for six days and she was going to die. I couldn't live with myself if I didn't [call her]." After CCM staff referred Sabrina to inpatient palliative care, she shared more of her trauma history. This made staff feel she was more engaged in care, and they attempted to arrange additional support including physical therapy, ongoing mental health care, and supportive housing. Soon afterwards, Sabrina again began to "disappear" intermittently, missing dialysis sessions, losing medications, and testing positive for cocaine. She declined substance abuse and mental health treatment, saying they had been overwhelming and she could quit on her own again. Continued trauma screening and response did not successfully keep Sabrina engaged in care. When we interviewed Sabrina, she told us that before she got Medicaid and started dialysis, she lived for many years without insurance and visited the hospital where the CCM program was based only when she was "attacked or robbed or something." Recently Sabrina had started visiting another nearby hospital instead because "sometimes [the ER staff] treat me really bad, I don't know why." In contrast, she said the CCM nurse was "a very beautiful person", and that she saw the program staff as friends who she could talk comfortably with not only about medications, but "a lot of things…like depression, anxiety…and problems that I might be going through at home." She mentioned her roommate, who continued providing free housing but also drank daily and made fun of her for going to the hospital.

Eventually the CCM staff concluded that despite their extensive efforts, there had been no improvement in Sabrina's health or hospitalization frequency. In May 2016, she declined a medical procedure that providers thought would improve her chronic pain, and the CCM team decided to withdraw and wait for her to contact them. The nurse and community outreach worker explained this to Sabrina in her hospital room, saying it seemed like she did not need help anymore because nothing had changed in the time they worked with her. “I know you have a lot going on,” the nurse said. “We are not abandoning you, but…it seems like we are not helping you, so we are not going to call you anymore.” She told Sabrina she was welcome to call them any time, and Sabrina responded, barely audibly, “I will have to think about that.” Soon after, a CCM manager suggested that “That is the type of patient for whom being in the hospital is such a source of comfort and safety. I almost feel like, let her be in the hospital. It’s really PTSD, and needing to be somewhere safe.” A month later, we called Sabrina’s dialysis center in an effort to reach her for a follow-up interview. The person who answered the phone said Sabrina had died. The CCM nurse confirmed that she had learned this via voicemail from a hospice agency, but did not know anything more. There was no note of Sabrina’s death in the electronic health record at the safety-net hospital.

Like many CCM patients, Sabrina was wary of institutions and their agents that had not served her well. CCM staff screened Sabrina for trauma, and tried to provide mental health care and other support in response. They saw her frequent cessation of contact and lack of self-management practices as a trauma reaction, and made extensive outreach efforts which in themselves acted as a kind of care. This is one of multiple cases in which we observed that when staff understood patients’ behavior as a trauma response, they committed to the patient rather than discharging them from the program, even if repeated attempts at contact were the only care they are able to provide. Yet this approach was temporary; eventually, team members determined that Sabrina was not appropriately engaging in care, and after much ambivalence discontinued their work with her. Sabrina’s case demonstrates that despite resources and flexibility unavailable to most health care providers, CCM teams are not always able to stabilize patients with extensive trauma histories. It is unclear whether the CCM team could have helped prolong Sabrina’s short life if they had chosen to provide longer-term support, or whether their decision to withdraw services was a response to institutional pressures, or one of frustration with Sabrina’s continued lack of engagement.

Case 2: Bruce

Structural violence as trauma—Bruce was a CCM patient who experienced great improvements in physical and mental health after enrollment in the program, followed by a rapid decline and unexpected death. His case illustrates the poor fit between short-term programs and long-term needs, while demonstrating how CCM staff incorporated understandings of structural violence as trauma into the care they provided. We first met Bruce, an African-American man in his 50s, in March 2015 at an appointment with the CCM social worker. She had had been working with Bruce for a year, and he had recently enrolled in community college, was addressing some legal issues, and had started walking regularly. He was also attending a support group for CCM patients, which he later told us was “inspiring. Keeps you going.”

Soon after, CCM staff updated their care plan for Bruce. The nurse case manager explained that Bruce had recently been hospitalized, and was discharged with many medication changes. Bruce was confident that he should continue the medications prescribed by his CCM and primary care doctor, yet feared the consequences of not following ER doctors' orders. The nurse, a young white woman, said, "He made the conscious decision to take all the ER prescriptions, go to the pharmacy, get the meds, and then bring them into the CCM clinic and say, 'They changed all my meds.' … [We said] Why didn't you just throw the prescriptions away? You know you don't need them!" The social worker, who was African-American, responded: He does not want to be perceived as not doing what he was told to do. He said, 'I knew I didn't need them.' [but] he is afraid of what might happen to him if he doesn't do it… He waited until he got somewhere safe before he said, "I don't want to do this."

Nurse: "He doesn't trust medical providers. He has a lack of empowerment. [The social worker] and I can do some coaching about seeing providers, bringing his meds… [We can coordinate] with the ER staff when he comes in to the emergency room." She read off the care plan*:* "Mental health risk, stress and anxiety lead him to have miscommunication with providers."

Social Worker: "Actually it's cultural mistrust of the healthcare system based on his experience as a black man growing up in the South."

In June, the staff began planning to graduate Bruce from the CCM program because his physical and mental health had improved dramatically. Yet before they could do so, his health declined rapidly and he was in a newly unstable housing situation. He had lost 40 pounds and was again frequently visiting the ER, not taking most medications regularly, and overusing opiates for acute pain. The social worker had left the CCM program, and Bruce was no longer receiving counseling, but staff agreed that he seemed depressed and the doctor prescribed an anti-depressant. In September, Bruce was hospitalized for several weeks and died there without a clear cause of death. The first author briefly interviewed him a few days before he died and asked what he had expected from CCM when he enrolled. He said he had hoped for "A new life. A new generation. A new start. Maybe somebody could see something that, you know [my previous doctor] didn't see…That's what I got." Leading up to his death, CCM nurses were concerned that doctors were not adequately responding to how ill he seemed. After his death, one nurse told us he died in the ICU because "his heart gave out." She said the inpatient physicians weren't too surprised, and there wasn't going to be an autopsy but she, some CCM colleagues, and Bruce's family felt that more could have been done to understand why his health declined so rapidly. The program's medical director, a white man, told us that Bruce

> "felt a lot of distrust and he would just not take his meds and…[would] come to a point where he was really pissed off or really passive. And our social worker eventually was able to find out that…. he grew up in rural Arkansas and experienced the Jim Crow South. And that really shaped his view of the medical profession…white guys in authority in big institutions. And that counts as a past history of trauma as far as I'm concerned."

Though the medical director did not know the specifics of Bruce's experiences of Jim Crow, he framed this history as traumatic and viewed the counseling sessions where Bruce shared his history as an important part of his medical care. He described Bruce as a person struggling with individual effects of the historic, multigenerational trauma of racism, and drew connections between racial violence, distrust of health care providers, not taking medication consistently, and an unexpected death. By highlighting Bruce's experiences of discrimination and growing up amidst conditions of violence, this physician pointed to structural violence as an element of his history that needed to be understood in his care.

CCM staff frequently linked patients' histories of trauma to substance use, mental health conditions, and cognitive issues. They were attentive to patients' traumatic experiences and their ongoing impact, adjusting care to patients' changing health statuses. In Bruce's case, they saw his trust in the CCM team — made possible through their understanding of his life experiences as trauma, and his willingness to share those experiences with CCM providers—as connected to his improving health. Bruce's health declined rapidly in the months after the departure from CCM of the African-American social worker with whom he had shared this history most directly. Remaining staff in the program understood his worsening health as attributable in part to long-term sequelae of his trauma history, and some were concerned about treatment that they felt did not acknowledge the depth of his distrust of medical authority. While the team was not able to "graduate" Bruce from CCM as planned, they attempted to coordinate his end-of-life care and continue communication with his family. His story demonstrates how trauma-informed approaches may facilitate both improvements to physical health and caring relationships through poor health and at the end of life. However, his death also points to the need for ongoing attention to how experiences of racial discrimination shape patients' interactions with clinicians throughout the life course.

Case 3: Kumar

Health care as traumatizing—CCM staff members viewed many patients as being traumatized or re-traumatized by experiences accessing care. Health care experiences that staff described as traumatic for patients included a CT scan; a patient who didn't speak English getting lost in a clinic; and a patient being burned on the face when her oxygen caught fire. The case of a patient named Kumar serves as an example of how CCM providers drew connections between past trauma and responses to care for physical and mental health issues. The first time we heard about Kumar, CCM staff were talking about how he experienced childhood trauma during war in his country of origin and related this to his frequent hospitalizations. Kumar was a 54-year-old undocumented immigrant from a country with a long history of military rule. He was referred to CCM for congestive heart failure, which staff understood as a consequence of his past methamphetamine use. They viewed his meth use, in turn, as a way of coping with his trauma history; he had been diagnosed with PTSD, anxiety, depression, and agoraphobia. "He described the violence," the nurse said, cringing. "Tremendous." She explained that Kumar was going to drop-in therapy near his home in the city's poorest neighborhood. "He was labeled as agoraphobic, but that's just a protective mechanism so that he doesn't use." She viewed Kumar's actions as self-protective, helping him avoid neighborhood violence that would trigger memories of trauma and meth use.

A few months later, the same nurse said visiting the primary care clinic was re-traumatizing Kumar, even though he was willingly meeting with her weekly in the same building. She continued, “Kumar doesn’t like to come [to primary care] because it makes him suicidal. He has to participate in a lot of immigration appointments [at government agencies], and they aren’t…as kind. They ask about his mother, and basically, every time he gets asked about his mother, he gets re-traumatized.” The CCM social worker suggested that the nurse explain how CCM, which Kumar felt comfortable with, was part of primary care, unrelated to the immigration office. The staff decided that reconnecting him with more intensive mental health care was their top priority.

Kumar subsequently fell out of contact with CCM for several months. When he returned, staff continued efforts to connect him with ongoing therapy at a community mental health program, but he was hesitant. The nurse told the social worker “he’s afraid of being re-traumatized. He doesn’t wanna do therapy until he knows that the person is really qualified—what he’s got is so serious and so PTSD that he wants to feel confident about it. But again, he’s holding himself back from trying therapy again.” “Unfortunately,” the social worker said, “They use interns at Community Mental Health—so it will be hard to reassure him that that person will be experienced…tell him there’s a really lengthy training process, they take tests to make sure they’re competent; they’re receiving supervision from someone who is competent. Still, it’s very possible he could get assigned to someone who…may not be sure of what they’re doing.” CCM providers saw Kumar as triggered by his neighborhood and using substances to cope with trauma. However, because of his immigration status they were only able to help him access what he and CCM staff agreed was likely substandard care. Due to Kumar’s limited and intermittent engagement with CCM, we were unable to arrange an interview with him.

Kumar’s story illustrates how CCM clinicians saw health care as potentially traumatizing or re-traumatizing, and how they collaborated to create safer spaces within health care. Trauma concepts gave staff a deeper understanding of patients—how they communicated, why they sometimes resisted treatment and at other time sought “too much” care. However, Kumar’s case also demonstrates where concrete training and practice in trauma-informed care principles including choice and collaboration (Bowen and Murshid 2016) might have changed the CCM team’s approach to particular patients. For example, it was unclear to us whether the staff’s decision to prioritize mental health care was one Kumar agreed with. Given his stated hesitation to participate in therapy with a less experienced therapist, it is possible that the CCM team’s urging him to engage in mental health care might have been part of why he only participated intermittently in CCM services. Perhaps a more collaborative approach focused on Kumar’s priorities would have led to his more consistent participation in CCM care.

Time as a Barrier to Trauma-Informed care

The temporal reality of many CCM patients belies programmatic design and intent due to lifelong, typically degenerative chronic conditions as well as histories of trauma and structural vulnerability. This is also visible as a limitation in our methodology. We would have liked to include multiple interviews with the patients whose stories are discussed in this paper, and to review our findings with CCM patients; however, it was difficult to engage many patients in interviews due to their poor health, and would have been quite challenging to ask through them to participate in an additional element of research. CCM programs are designed as 6–18 month interventions, but in practice patients are often enrolled longer. This design follows the intent to reduce costs and utilization by increasing self-management, as well as the assumption that people will enroll, stabilize their health, then be able navigate outpatient care without frequent hospitalizations (Hong, Siegel, et al. 2014; Sweet 2012). CCM staff have more time and flexibility than primary care clinics they work with, and can offer needed care and support alongside traditional primary care. They use trauma concepts with other approaches such as motivational interviewing and harm reduction. Yet CCM patients' health ebbs and flows in ways the program design doesn't account for. As the cases above demonstrate, ongoing physical and psychological effects of trauma can change someone's health circumstances quickly and the linear model and limited timeframe of CCM does not match the cyclical nature of trauma experience.

The time horizon of CCM programs makes it challenging to provide trauma-informed care, and to see patients succeed in an ongoing way at CCM goals. CCM providers report that a high proportion of their patients will need ongoing care and support, perhaps for life. Without this, many patients are likely to experience a rapid deterioration of their health, as a doctor explained about one patient:

> "I do think that there is a need for some maintenance that's really long term. You're not taking away her poverty. You're not taking away her lack of resources, her lack of education, her depression…Even though you're doing a lot of stuff to help her, there needs to be some maintenance because we're not changing the world here."

This doctor comments on the structural limits of CCM programs. They cannot eliminate poverty and its causes and consequences, and since these fundamental causes of disease remain, CCM patients will continue to experience cyclical and fluctuating improvements in their health. Our fragmented and bureaucratic health and social services systems are difficult for well-resourced people to navigate, and almost impossibly complex for those with combinations of cognitive disability, social isolation, mental illness, substance use, and homelessness. Patients described how frequent, flexible contact with CCM staff helps them feel secure and healthier, but some noted that they did not see a time when they would "graduate" from needing this kind of support. The role of CCM, then, is to mitigate structural vulnerability; patients benefit from having providers who care, educate, and advocate for them, but are unlikely to navigate the health care system without medical and social support.

CONCLUSION

Though the CCM programs in our study did not explicitly claim to provide trauma-informed care, trauma concepts and particular elements of trauma-informed care have been disseminated into their care approaches. Staff used trauma concepts in creative and utilitarian ways that draw on both trauma-informed care and structural competency frameworks. For example, at times invoking trauma allowed CCM staff to contest inequity in the clinical setting, using available resources to provide care that at times went beyond treating mental and physical symptoms to address patients' social position and circumstances through support accessing housing or government entitlement income. However, the short-term structure of CCM programs was not in sync with their patients' long-term needs for caring relationships and coordinated health services sensitive to past and ongoing trauma. Compared to most health care providers, CCM staff had a great deal of flexibility in how they used their time, which allowed them to screen and respond to trauma alongside other patient needs. Nurses, community health workers and social workers were able and expected to have frequent, sometimes lengthy interactions with patients. They had flexibility to accommodate patients' constraints; for example, staff in one program provided transportation vouchers, and made frequent home visits. This flexibility contrasts with other services CCM patients received, where care typically included brief visits, long waits, and minimal effort to engage patients if they missed appointments or didn't return phone calls. CCM staff uses their flexibility to try to produce a safe experience for their patients, slowing down to build trust, and at times providing social support (as when Sabrina said that she thought of CCM providers as friends). Part of the CCM logic is that providing slower care that some might see as inefficient will better meet patients' needs and reduce the use of costlier medical resources. This approach echoes Victoria Sweet's idea of the "efficiency of inefficiency" (2012), viewing the patient and hospital in the context of the structural conditions (which Sweet calls ecosystems) in which they reside. However, this approach does not always align with another piece of CCM logic: reducing the cost of care by reducing hospitalizations. When slow care did not lead to reduced hospitalizations, as in Sabrina's case, CCM staff felt pressure to stop working with patients, though there were typically no other programs available to meet their needs for the long term. Some staff saw this as an acute problem: one expressed concern that the program is built to "stabilize patients, then get rid of them." Sweet offers a biting critique of extreme emphasis on health care efficiency, arguing that it can reach a point where "only death is truly efficient," and slower care that acknowledges structures and trauma cannot be justified (2012: 98).

The short-term design of CCM programs constantly put pressure on the staff to titrate their efforts, moving patients towards graduation or out of the program. CCM providers were generally aware of their patients' experiences with trauma, and had a mix of formal and informal understandings of the relationships between trauma and health. Trauma concepts allowed CCM staff to acknowledge and intervene in the medical and structural context of peoples' lives. However, they did so within the constraints of what was designed as an intensive, short-term program. In contrast, typical primary care is intended to be life-long yet generally can only provide low-intensity social and medical support. Neither model offers the intensive, lifelong support that many people need to cope with chronic health conditions caused and exacerbated by trauma. It is possible that a trauma-informed care framework could lead clinicians to view chronic stress and trauma, together with their consequences (whether social isolation or diabetes), as the conditions in need of treatment. In doing so, treating trauma can become the end goal, if staff focus exclusively on therapeutic responses without addressing structural conditions. Yet naming trauma enables clinicians to name structural violence, which has traumatic impacts on individuals and communities, in a language that is clinically legitimate; for example, viewing the stress of being homeless as a cause of poor health (McKenzie-Mohr et al. 2012). A structural competency approach would also examine the structural racism of a system that leaves many people in the area we are studying homeless with little possibility of finding affordable, permanent housing (Whittle et al. 2015). Nascent efforts to use a structural competency framework seek to address both individuals' health and the community circumstances in which individuals live, yet there are few examples of how such an approach could be used to address patients in the later stages of complex illness such as those cared for by CCM teams (Hansen and Metzl 2016). In CCM programs as in other settings, it is apparent that trauma-informed care and structural competency approaches could overlap and complement each other. Trauma-informed care has the potential to contest inequity in the care of individuals. The structural competency framework implores clinicians to understand their patients' lives in context, and to take action that will have impact on both their physical health and structural conditions.

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Highlights

- Complex care management staff define trauma expansively to include structure.
- CCM staff use trauma concepts to understand social histories as part of health.
- Trauma concepts enable staff to name structural violence in clinical language.
- Trauma-informed care and structural competency approaches complement each other.

Table 1

Demographics of Patient Sample at Baseline (N=61)

Characteristic	**n (%)**
Age, mean years (SD)	54 (10)
Gender, n (%)	
Male	32 (52)
Female	29 (48)
Race/ethnicity, n (%)	
American Indian/Native American or Alaska Native	3 (5)
Asian/Pacific Islander	4 (7)
Black/African American/African	25 (41)
Hispanic/Mexican/Mexican-American/Chicano/Latino/Spanish Heritage	17 (28)
White/Caucasian	10 (16)
Other	2 (3)
Education, n (%)	
Less than high school/GED	19 (31)
High school/GED	20 (33)
More than high school/GED	22 (36)
Homeless ever in lifetime, n (%)	38 (62)
Born outside the US, n (%)	19 (31)
Monthly income, n (%)	
Less than $500	18 (30)
$501–1000	27 (44)
$1001–2000	10 (16)
$2001–3000	3 (5)
Don’t know	3 (5)
Employed, n (%)	3 (5)
Language spoken at home, n (%)	
Only English	41 (67)
Only Spanish	9 (15)
English and another language	11 (18)
Insured, n (%)	51 (85)
Perceived health status, n (%)	
Excellent and very good	4 (7) 599
Good, fair, and poor	52 (85)
Prefer not to state	5 (8)

Table 2

Demographics of Staff Sample 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)