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## Complex Care and Contradictions of Choice in the Safety Net

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### Abstract

This paper explores the complicated and often-contradictory notions of choice at play in Complex Care Management (CCM) programs in the U.S. healthcare safety net. Drawing from longitudinal data collected over two years of ethnographic fieldwork at urban safety-net clinics, our study examines the CCM goal of transforming frequent Emergency Department (ED) utilisers into ‘active’ patients who will reduce their service utilisation and thereby contribute to a more rational, cost-effective health-care system. By considering our data alongside philosopher Annemarie Mol’s (2008) conceptualisation of the competing logics of choice and care, we argue that these premises often undermine CCM teams’ efforts to support patients and provide the care they need – not only to prevent medical crises, but to overcome socio-economic barriers as well. We assert that while safety-net CCM programs are held accountable for the degree to which their patients successfully transform into self-managing, cost-effective actors, much of the care CCM staff provide in fact involves attempts to intervene on structural obstacles that impinge on patient choice. CCM programs thus struggle between an economic imperative to get patients to make better health choices and a moral imperative to provide care in the face of systemic societal neglect.

### Keywords

Chronic illness; long-term illness; Determinants of health; Health care systems; Patient centredness; Health behaviour; Inequalities/social inequalities in health status

## Introduction

Healthcare organizations in the U.S. have increasingly embraced Complex Care Management (CCM) programs that aim to reduce costs and improve health outcomes by supporting particularly vulnerable patients. These programs employ a team-based approach that combines primary care, social service coordination, and self-management techniques directed toward chronically ill patients who tend to frequent the Emergency Department (ED) and generate high healthcare costs (Hong et al. 2014). CCM programs seek to establish patient ‘self-management’ through collaborations between ‘informed, activated patients’ and ‘prepared, proactive practice teams’ (Bodenheimer et al. 2002, 1775). Such partnerships purport to embrace the patient’s role in healthcare decision-making, enable patients to apply relevant knowledge, and encourage patients to ‘[stay] the course even under stress’ (Hibbard et al. 2004, 1005). These strategies are especially appealing to ‘safety-net’ clinics and hospitals – sites that historically have served individuals who lack private health insurance – because they rely on public funds to cover costs. Compared to other healthcare institutions, safety-net clinics serve a greater share of patients who are either covered by Medicaid (public insurance for low-income individuals) or are uninsured.

Safety-net CCM programs, however, face obstacles in their attempts to support low-income patients with multiple chronic conditions. Our study illustrates these challenges with longitudinal evidence from two CCM programs at urban safety-net clinics. Like CCM programs in settings with private insurance, the basic premise is to transform so-called ‘complex’ patients into self-managing agents who engage in better healthcare decision-making and contribute to a more rational, cost-effective health-care system through decreased service utilisation. To do so, CCM programs must ‘activate’ patients such that problematic service recipients conform to the ethos of individual responsibility behind the United States’ predominantly market-based healthcare system.

In this paper, we argue that the consumerist ethos of individual choice and responsibility underlying the program model often undermines CCM teams’ efforts to support the most frequent utilisers of the safety net. By considering our data alongside philosopher Annemarie Mol’s (2008) conceptualisation of the logics of choice and care, we argue that these premises often contradict the truly *complex care* that CCM patients need – both to prevent medical crises and to overcome socio-economic barriers. We assert that while safety-net CCM programs are held accountable for the degree to which their patients successfully transform into self-managing, cost-effective actors, much of the care CCM staff provide in fact involves attempts to intervene on structural obstacles that impede patient choice. CCM programs thus struggle between an economic imperative to get patients to make better health choices and a moral imperative to provide care in the face of systemic neglect.

### Patient Choice and Complex Care

Hibbard et al.’s (2004) theory of ‘patient activation’, and its concomitant Patient Activation Measure (PAM), are gaining traction across a variety of national healthcare regimes. Despite distinct healthcare systems, for example, they are currently ‘at the heart’ of efforts to reduce hospital utilisation related to chronic illness in the U.S. and the U.K. (Hibbard & Gilbert

2014, 26). Their underlying premise is that getting patients to engage with care and embrace self-management is fundamental in ‘both the consumer driven health care approach and the chronic illness care models’ (Hibbard et al. 2004, 1006). ‘What would it take’, they ask, ‘for consumers to become effective and informed managers of their health and health care? What skills, knowledge, beliefs, and motivations do they need to become “activated” or more effectual health care actors’ (Hibbard 2004, 1006)?

These questions refer not to ‘patients’ but ‘consumers’, and they focus on the individual recipient of care – not the care team or institution – as the locus of transformation. In doing so, this premise overlooks several key issues. It does not ask whether external obstacles exist, what structural factors – such as poverty and discrimination – are at play, or what supra-individual resources may be needed to achieve said skills, knowledge, beliefs, and motivations. In this transformation from patient to consumer, the patient/consumer comes to shoulder much of the responsibility in healthcare interactions. The absence of structural considerations also minimises the role of providers and institutions that the CCM approach supposedly promotes. This deflects attention away from situational constraints and back onto the patient/consumer.

Many scholars have criticised the idea of patients as consumers in a supposedly free, neoliberal healthcare market (Rice 1997, Light 2003, Emanuel 2014). Even in private healthcare contexts, patients seldom have the opportunity to choose freely among treatments, personnel, and pharmaceuticals. Furthermore, patients historically defer to medical authority when making decisions for their health. Parsons’ (1951) conceptualization of the ‘sick role’ highlighted such obedience as a normative characteristic of patienthood, yet subsequent scholarship (e.g. Williamson 1992, Mol 2008) reveals growing tension between historical deference and the contemporary elevation of patient choice in global health policy rhetoric. The consumerist ethos therefore sits unsteadily astride multiple problematic decision horizons, supposing that patients can choose health care as they would any other commodity and incognisant of the real limitations to choice (Rice 1997, Emanuel 2014). The focus on consumer rationality also fails to specify what ‘choice’ means in the healthcare setting and whether it refers to choice of providers, payers, treatments, clinics, etc. The safety net context further compounds these concerns, as low-income patients have fewer options to choose from among medical providers, insurers, and services. They may choose not to seek care or not to adhere to a care plan, but they have little recourse to alternatives within the healthcare system.

Philosopher Annemarie Mol characterises this tension as a difference between the ‘logic of choice’ and a ‘logic of care’ (Mol 2008). In making a case for the latter, Mol differentiates her approach from two common critiques of the ideal of patient choice. The first states that sometimes individuals are not in a position to make their own choices, such as when they are unresponsive or cognitively impaired. The second suggests that humans in general are bad at making rational choices, particularly because (especially in healthcare settings) ‘many of us lack the material resources required to choose’ (Mol 2008, 6). In either case, ‘choice’ becomes a question of whether people – and *which* people – can and do make choices. Mol (2008) rejects the individualised focus underlying these notions of choice and suggests an alternative based on the situated-ness of ‘choice’:

Instead of focusing on the abilities of people [to make choices or not], I will talk about the practices in which people are involved. Instead of asking who should make given choices, I will take a step back and consider ‘situations of choice’... In what kinds of practices do ‘situations of choice’ arise? By shifting the focus in this way it becomes possible to show that the ideal of choice carries a whole world with it: a specific mode of organising action and interaction; of understanding bodies, people and daily lives; of dealing with knowledge and technologies, of distinguishing between good and bad, and so on. Instead of hinging on people’s limited abilities, my doubt has to do with that entire world. A world infused with what I will call the *logic of choice* (6–7).

The logic of choice, Mol argues, assumes that everyone is equally positioned to make autonomous decisions and bear their consequences as a matter of personal responsibility. It holds that actors are defined by their ability to choose, but it fails to account for how material arrangements are co-constituted with those choices. Yet these problematic assumptions then structure ‘a whole world’: they shape what kinds of actions and interactions are facilitated and allowed and how they occur, and they shape how bodies and lives are understood.

‘Situations of choice’ reflect a more dynamic conceptualisation of choice, one that focuses on activity over rationality. Whether or not someone makes the proper choice is not the question; rather it is what someone does in a situation characterised by a particular set of material configurations. Mol reminds us that which glucometer to choose is a less productive question than how to interact with it – and with other technologies – in one’s everyday life. Situations of choice thus wrest the logic of choice from the realm of individual decision-making and personal responsibility and permit a consideration of extra-individual conditions.

Mol acknowledges such limitations of choice and asserts the following (Mol 2008, 80):

Choice may be a great ideal, but only in situations in which people are indeed able to make their own choices. By making choices, or so the logic of choice claims, we [patients] become the masters of our own lives. This promise of mastery, however, hides what it costs to reshape the world in such a way that ‘situations of choice’ are created.

Mol’s conceptualisation of ‘situations of choice’ reflects her ethnographic observations of how the decisions of Dutch patients with type 2 diabetes were shaped by various factors that went beyond simply choosing well. One of her participants, for example, described experiencing distress when his insulin pump stopped working. After calling several providers who were unable to answer questions about his pump, he finally spoke with the manufacturer, who informed him that they no longer manufactured that model or spare parts for it (Mol 2008, 85). His attempt to manage diabetes depended not only on making ‘healthy’ choices, but also on other material arrangements over which he had no control. This realisation left him feeling neglected by the health system, a feeling Mol describes as: ‘A hole opens up, and you fear that you will fall right through it’ (Mol 2008, 85). Yet such holes in the Dutch healthcare system stand out as the exception rather than the rule. U.S.

health care, on the other hand, involves fragmented systems – including safety net care – that are more holes than system. It is the product of a health system conceptualised as a commodity market rather than a right, imbued with an even more insidious faith in the logic of choice.

Nevertheless, Mol's critique of patient choice and her proposed alternative are useful for considering safety-net CCM programs. In contrast to the logic of choice, Mol proposes the 'logic of care' (Mol 2008, 7). This logic holds that people *act* – not just momentarily, but constantly. It neither rejects autonomy nor assumes an ideal rational consumer making instantaneous decisions based on the best information and arguments, but rather supposes that actors experimentally and collectively engage in practices to improve their lives. It requires that care providers acknowledge the situations in which patients' choices are imbricated, the range of practices that are possible within them, and the varying degrees to which such choices align with a biomedical and/or consumerist ethos. As Mol contends, 'The logic of care is not preoccupied with our will, and with what we may opt for, but concentrates on what we do' (Mol 2008, 7).

The logic of care takes into account how people interact with the material configurations that constitute situations of choice. It is also processual and visible in practices of everyday life, and it specifies rather than universalises. This makes it well suited to care contexts, such as clinical encounters, in which 'tinkering' may be more productive than fixed protocols (Mol 2008, 25). 'Tinkering' refers to the ways in which providers listen for, acknowledge, and respond to their patients' social context and adjust their care appropriately. It allows for adaptive, individualised practices that permit a logic of care to suture the gaps left by a logic of choice. In the Netherlands, universal health care and the notion of a right to health cohere in a fine mesh that can be reinforced by subtle 'tinkering' to support patients in their social contexts. The fragmented U.S. healthcare system, on the other hand, relies upon a thin-stretched safety net, including CCM programs, to catch those who slip through its many gaps. Unlike in the Netherlands, the programs we studied must often do so with few resources, complex social and medical challenges, and the urgent imperative to control costs through engaging with the logic of choice.

Especially relevant to the safety-net setting is Mol's emphasis that the logic of choice undermines good care by glossing over care's corollary: neglect (Mol 2008, 5). Within a logic of choice, patients' 'bad' choices result in poorer health and higher healthcare costs. This logic partially informed the CCM programs that emerged in privatised healthcare settings and is evidenced by their embrace of self-management strategies (Bodenheimer et al. 2002). Under the logic of choice, such programs assume that high-utilisers need only information and short-term support to effectively and efficiently manage their conditions. With the knowledge to choose better, patients should experience improved health and fewer costly hospitalisations. Mol, however, troubles this notion of patient choice. To her, 'bad' care happens 'when people are being neglected. [...] When physical parameters are isolated from their context; when patients' daily lives are not taken into consideration' (Mol 2008, 84).

Examining the challenges and opportunities of safety-net CCM programs, however, leads us to argue that the way Mol conceptualises the ‘logic of care’ insufficiently addresses the realities of complex care management in the U.S. safety net. Her exploration of how Dutch patients and providers negotiate type 2 diabetes leads her to observe that ‘there are too many holes’ in these interactions (Mol 2008, 85). Even in a setting where health care is universal, she finds that often ‘there is nobody there who listens to [the patient] properly and takes what they have to say into account’ (Mol 2008, 85). Our observations of CCM programs demonstrate the contrary: CCM providers and staff do listen, take into account patients’ social contexts, and try to address them. However, there are far too many holes beyond the clinic that fall to CCM teams to mend. Mol’s incitement to a logic of care that critically considers situations of choice is a productive starting point for overcoming the logic of choice, but its application in the U.S. safety net requires a more profound interrogation of what we call ‘systemic neglect’. Systemic neglect extends beyond the patient-provider interaction and its immediate material configurations to encompass sweeping forms of neglect – such as poverty, discrimination, and problematic social policies – that constitute those very interactions and material arrangements.

As our research shows, the notion of health as an individual choice is complicated for CCM programs in the safety net and the patients they serve. Our observations reveal that CCM teams attempt to address systemic neglect through daily care practices while at the same time working alongside and within a neoliberal healthcare system that emphasises self-responsibility and self-management. They also illuminate the frustrations of patients whose ‘situations of choice’ constrain them to act in ways that undermine health. The resulting contradictions lead to uncomfortable clashes among patients, care teams, and the institutions in which care takes place. The interactions presented below illustrate the trouble with framing health as a choice and reveal the real obstacles to practising a logic of care in the safety net. These empirical examples examine the tensions evinced by explicit invocations of ‘choice’ in CCM encounters and the complexities of ‘care’ in the safety net. The paper concludes with a discussion of possible implications of the logic of choice for future care in the safety net.

## Methods

This qualitative investigation draws from an ongoing multi-method study aiming to understand the processes and structures through which CCM programs at two safety-net sites address their patients’ social and medical needs. The safety-net sites in this study were located in major urban areas. Clinic 1 began in early 2012 and included an adult medicine clinic and a family health clinic at a public hospital. A nurse and health coach dyad worked in close collaboration with other providers outside the program, including primary care providers and social workers. Patients identified as at high risk for frequent hospitalisations and who did not receive intensive case management services elsewhere were eligible for enrolment. ‘High risk’ included anyone with multiple chronic co-morbidities who had at least 3 hospitalisations and/or ED admissions within the past 12 months. Initial enrolment criteria evolved and became more complicated over the course of the study. Clinic 2 launched in January 2013 at another public hospital. It was more interdisciplinary than

Clinic 1 but had similar enrolment criteria. Both programs aimed to reduce hospitalisations, improve self-management among enrollees, and graduate them once these goals were met.

Four ethnographers (two at each site) conducted observations of patients and providers in the clinic, patients' homes, and other settings. The ethnographers shadowed participants during their day-to-day interactions in order to understand clinic flows and processes. At the time of this analysis, they had conducted over 1,000 hours of observations since beginning fieldwork in January 2015. Observations of patients focused on institutional health literacy and the ways in which team-based care sought to develop effective trust and communication, self-management, and engagement strategies with patients. Observations of providers and clinic staff involved tracing interactions with patients, workflow and communication systems, and problem-solving in the CCM context. The ethnographers recorded these observations in detailed fieldnotes.

Ethnographers also conducted interviews with 108 patients and providers observed. They identified eligible interview participants, who were at least 21 years old and proficient in spoken English or Spanish, during observations and presented them with a study information sheet and verbal description of the study. In-person, semi-structured interviews probed for information on patients' experiences in the CCM program and thoughts about their past, present, and future health. Descriptive data were gathered through a brief questionnaire that included items on race/ethnicity, education, transportation, and cognitive function (via the Mini-Cog Test). The average patient was 54 years old, earned \$1000 per month or less, and had less than a college education. The sample was evenly distributed between male and female patients and between insured and uninsured. The racial/ethnic distribution of patients was: Black/African American/African (41%), Hispanic/Latino (28%), White/Caucasian (16%), Asian/Pacific Islander (7%), and other (8%). Patients were invited to participate in 3 interviews at 6–12 month intervals and received a \$25 gift card for each interview. As of May 2017, 137 patient interviews had been conducted. Audio recordings of each interview were transcribed and translated (if conducted in Spanish).

The ethnographers also conducted two waves (at an interval of one year) of semi-structured interviews with 48 CCM providers (including nurses, physicians, and social workers) and staff (including managers and clerks). The average age was 39 years, and about three quarters were female. Interviews related to providers' and staff's interactions with various departments within and beyond their respective institutions, perspectives on the goals and impacts of CCM programs, processes of patient enrolment and progress, and challenges to providing care. Baseline interviews occurred primarily in late 2015, and follow-up interviews were on-going at the time of this analysis.

Audio files from all interviews were transcribed and translated from Spanish when necessary, and all transcripts and fieldnotes were coded according to grounded theory principles using Atlas.ti software. The research team collaborated to identify emerging themes and articulate analytic codes that would enable in-depth analysis of the data. Some examples of codes that were useful for the current analysis include patient activation and engagement, workarounds, social networks, trauma, chronic pain, and substance use.



Our team has reported on providers' sense of patient engagement and the influence of socioeconomic circumstances on engagement (Fleming et al. 2017) and providers' understanding of patients' trauma (Thompson-Lastad et al. 2017). The present paper aims to reflect both patients' and providers' invocations of and reactions to choice as a mechanism for dealing with intense structural pressures. All participant information was anonymised, as were the program sites, and all study procedures were approved by the study institution's Institutional Review Board.

## Findings

Fieldwork and interviews revealed scenes in which patients and CCM staff constantly encountered challenges that, under the logic of choice, defied solution. As described below, most patients faced combinations of poverty, housing and food insecurity, substance use, mental illness, limited cognitive capacity, and inadequate social support. Many patients faced all of these simultaneously. Many also harboured deep-seated distrust of and/or lack of confidence in healthcare and other social services. Given that CCM programs targeted those who were frequently admitted to the hospital or seen in the emergency room, these patients ostensibly received the greatest ratio of healthcare services per capita. However, the lives of many patients we observed reflected a stark lack of care. This was not a lack of care by CCM teams, but rather systemic neglect at multiple levels of patients' everyday life, manifested as discrimination, limited employment and housing opportunities, insufficient mental health and drug rehabilitation support, and an absence of stable social support. In caring for chronically ill safety-net patients, CCM teams had to balance the imperative for self-management with the on-the-ground struggle to heal embodied neglect.

The logic of choice often proved counter-productive to caring for patients in situations characterised more by systemic neglect than consumer choice. The care teams therefore oscillated between the logic of choice and the logic of care as they carried out their difficult everyday work amidst rampant neglect. In one-on-one encounters, they urged patients to make 'healthy' choices whenever they could and attempted to give them the tools to do so. In meetings with colleagues, however, they often lamented their frustrated attempts to move patients along a linear path toward engaged 'self-management' while facing a lack of change in the world around them. In many ways their experience aligned with Garcia's (2010) observations of a drug treatment clinic that framed recovery in terms of patient choice and individual responsibility. While this approach suited neoliberal rational-actor theories of human behaviour, Garcia found that the biggest challenge to the clinic and its patients was not individual patients but 'life outside' the clinic (Garcia 2010, 18).

It is precisely this 'life outside' that safety net CCM patients and providers are contending with when attempting to engage in individual-level self-management strategies, and it is also what makes 'success' so difficult for such programs to measure and achieve. While they are explicitly designed to help patients manage life outside the clinic, this is a more daunting task than CCM programs likely anticipated – yet one at which they are expected to succeed. The following examples illustrate the various facets of these challenges. They explore the tensions that arise when 'choice' is explicitly articulated by patients and providers and their frustrations in negotiating structural constraints to situations of choice.

**'Nobody ever asked me.'**

A CCM nurse, Delia (all names are pseudonyms), joined a meeting during which a young patient's primary care provider intended to discuss treating her opiate dependence. The CCM team had been enlisted by the doctor to help the 26-year-old patient, Janelle, manage complications from lupus and a rare lung condition. In the span of a couple of years, Janelle transformed from a relatively healthy young woman to a chronically ill patient undergoing a variety of intense treatments and awaiting a lung transplant. Janelle reported that the only intervention that seemed to help were the pills she had been prescribed to manage her pain. Since enrolling Janelle in the CCM program, nurse Delia had also been coordinating a number of services on her behalf: dental care to address side effects of chemotherapy, aquatic physical therapy to manage chronic pain, and subsidised housing for Janelle and her young children.

When everyone was assembled in the small exam room, the doctor outlined Janelle's detox plan. She explained that Janelle must stay at a facility while she went through withdrawal from her prescribed pain medications, but that they would give her medicine to manage the symptoms. When the doctor finished describing the plan, she asked Janelle which dates would work best for her to undergo treatment. Janelle, who had not looked at her doctor since she began speaking, fixed her attention on her chipped fingernail polish and did not respond. 'You seem upset', the doctor said after a moment. 'Why are you upset?' Janelle reluctantly replied that she did not want to go through withdrawal. 'I have kids at home', she said firmly. The doctor replied that there was an outpatient treatment option, and she reiterated that Janelle would be given medications to treat her nausea and anxiety while dealing with withdrawal. 'We'll get through this together', she said confidently and then left the room.

Delia stepped out to make a copy of the plan, and when she returned, Janelle was alone in the exam room. Janelle tried to remain stoic, but tears began running down her face. Delia, seeking to comfort Janelle, attempted to praise her courage in facing detox. 'I think you're very brave', Delia said encouragingly. Janelle immediately bristled at the suggestion that she had chosen such an unappealing course of action: 'I don't have a choice', she replied coldly. 'Well you *do* have a choice', Delia countered, 'and you're making a good choice, a healthy choice'. Janelle shook her head bitterly. 'Nobody asked me', she protested. 'It's my body – somebody should have asked me'.

The doctor returned shortly after and went over the details of how detox would proceed. She urged Janelle to call while she was undergoing treatment, but Janelle countered that if her doctors did not respond to her calls in a timely manner for everyday questions, how could she count on them to answer her when she was going through withdrawal treatment? Delia encouraged Janelle to call the CCM team or the after-hours nurse line, although Janelle protested that she had never gotten through to the after-hours line. The doctor, who had finished going over the detox plan, left the contact details up to Delia and exited the room.

While Janelle dried her eyes, Delia attempted to explain what she meant when she said Janelle had a choice. Janelle could have walked out of the office at any time, Delia explained, or she could have refused to work with the doctor if she wanted. Janelle replied

that it did not feel that way: suddenly her provider informed her that this was going to happen, and now the choice was between inpatient and outpatient detox. Given her home and family situation, however, Janelle had to choose outpatient detox. One day she was told to take pain pills, and now suddenly she had a plan and a prescription to withdraw her from those same pills. Delia seemed unprepared for Janelle's reply and attempted to alleviate her anxiety over the plan by providing more information on the detox medications she had been prescribed. 'I can Google it', Janelle replied flatly, and she tuned out Delia by scrolling through videos on her cell phone. Delia attempted several more times to engage Janelle, but Janelle had clearly finished discussing the matter. Over the next few days, Delia continued to try to reach out to Janelle by phone and in person, and soon after the detox plan was suspended.

Two years later, Janelle remained disengaged from the program and still had not undergone detox treatment. Reflecting on this, Delia explained that while Janelle's lung disease went into remission and her ED utilisation decreased, her opiate use 'had created the biggest monster ever'. Janelle now exclusively attended appointments where opiates were dispensed. Janelle's care team brainstormed ways to re-engage her, but they seemed out of ideas. 'It's okay to empathise with the emotion behind it without caving', a social worker commented. The team decided their only option was to remind Janelle they were available to support her if she ever changed her mind on detox.

In this example, Delia attempted to engage with the logic of choice by explicitly recognising Janelle's initiative in deciding to take action to improve her health. Janelle's reaction, however, did not align with this model. Delia's articulation of patient autonomy was at odds with the world in which Janelle, the patient, felt she could not choose. The doctor had not offered the patient a choice, but rather assumed consent. Janelle's opiate use had begun as treatment for rare, difficult to treat conditions, ones that even healthcare professionals seemed incapable of managing. Now they were informing her that she had become dependent on the treatment she had never sought in the first place, and that she would require an additional treatment – one that would compromise her ability to care for her children. The scene clashed with the consumer-based, market-oriented idea that patients must simply decide to be healthy. By focusing on the patient as the key decision-maker in their supposed partnership, Delia inadvertently illuminated these contradictions. Despite the good intention to support Janelle's healthy decision-making, the surprising revelation that this could be her 'choice' led her to question the treatment plan and the terms of its negotiation.

By explicitly invoking 'choice', Delia inadvertently revealed how constrained Janelle's 'situations of choice' really were. By focusing on Janelle's rationality in making a more or less healthy choice, Delia adhered to the logic of choice. A focus on Janelle's *situations* of choice, on the other hand, would have taken into account how Janelle's actions were caught up in a fraught material reality. In praising Janelle's 'healthy choice', Delia attempted to frame that decision as one over which Janelle had control. Yet Delia herself had coordinated services to address the structural constraints that Janelle experienced, and this should have attuned Delia to the limitations of the logic of choice. Janelle's bitter reaction reflected the frustration of an illness experience permeated by systemic neglect – by poverty, unstable

housing, and an overburdened safety-net system. While Delia intended to encourage Janelle by invoking ‘choice’, its utterance in fact became an incitement to choose otherwise – to choose to reject treatment. Janelle became an activated patient, but unlike the ‘active’ patients envisioned by Hibbard and Mol, this case revealed how in situations of choice tempered by systemic neglect, patients-as-actors may continue to undermine their health rather than improve it.

### **‘I have no choice!’**

During a clinic visit, a homeless CCM patient, Monica, and her CCM doctor disagreed over Monica’s medications for her chronic pain and drug use. The doctor intended to focus on consolidating Monica’s medications to make her a candidate for knee replacement surgery. Monica had tested positive for cocaine recently, however, and the doctor also suspected that her family member had been illicitly selling her pain medications. Monica, meanwhile, was frustrated by having to take a ‘boatload’ of medications – none of which seemed to manage her pain – while being denied the opiate-containing cough syrup that she requested. In the ensuing discussion, the provider cited Monica’s drug use as the reason he could not comply with her request.

‘You can, you just don’t want to’, Monica retorted. She added that she was being treated ‘like a child’ while the provider took away all the medications she needed without listening to her. ‘You are not the one in pain!’ she cried, ‘I have to do what you say! I have no choice. I have no control’. The provider remarked that he regretted Monica saw things this way and shortly after left the room. A CCM nurse case manager who was very familiar with Monica then entered and suggested making a plan for where she wanted to ‘go next’. ‘I’m going to go back to the shelter and throw away all my pills’, Monica replied defiantly. ‘I’m not taking them anymore. If I die, I die’. She doubled over with her head in her hands. ‘That is your choice’, the nurse responded. She then waited a moment before asking Monica whether it would be okay to visit her the following week at the homeless shelter where she lived. Monica agreed to this plan, despite her distress and anger with the clinic staff.

Such an ambiguous resolution, one that was likely unsatisfactory to all those involved, highlights the problem with the logic of choice. Monica exclaimed that she had no choice in these negotiations, yet moments later she was told that her actions — even to the hypothetical point of ceasing all medications and risking death — were her choice. And despite the nurse’s apparently severe tone, her admonition was in fact an invitation for Monica to believe she had more control over her life than she felt in the moment. As in many of our observations of CCM providers, the invocation of choice served less as declaration of patients’ personal responsibility than an attempt to cultivate a sense of choice when structural constraints made any choice seem impossible. The realities of Monica’s substance use, pain, and homelessness remained, but the possibility of continuing the care relationship endured despite both parties’ fraught articulations of choice.

### **‘How do you think we can help you?’**

In the face of such frustrations, CCM staff members often expressed ambivalence toward the premise of health as an individual choice. The tension between providing meaningful

support for patients to make rational, healthy decisions and the reality of constraints on both providers' and patients' actions appeared in numerous CCM encounters. Empirical data revealed that this tension between the explicit imperative to choose and the care team's efforts to *care* was often clear to and articulated by CCM teams. During an interview, for example, one CCM health coach described reaching out to new patients with the question, 'How do you think we can help you?' She found that patients often replied, 'I don't think you can'. She attributed this response to what she called behavioural, social, and environmental barriers: 'Barriers that we know how to overcome — and we choose not to, right? It's our choice. With our patients, sometimes it's not really a choice'. Other examples from CCM staff perspectives surfaced during observations of team meetings. For example, during one conversation regarding a diabetic patient who was binge-eating cheap food alongside donations from free meal programs for elderly and home-bound people, a health coach criticised the patient's seemingly irrational behaviour. The nurse disagreed, saying that this was actually a reflection of food insecurity. 'It's a product of our society', she explained. 'You're poor, you don't eat well. The food banks, all they have are rice and potatoes'.

This sense of intractable social problems extended to housing as well. Some patients informed CCM staff that they continued to live in mould-infested homes, despite awareness that this was likely harming their health. They expressed a reasonable fear of eviction if they complained to their landlords about these inadequate living conditions. Many other patients were marginally housed or living on the streets. Most of our participants (62% at Clinic 1, 80% at Clinic 2) had been homeless at some time in their life, and 30% of our sample was homeless at the time they were interviewed.

This included Liliana, an undocumented, Spanish-speaking woman in her sixties who was referred to CCM for help managing diabetes, kidney disease, cognitive impairment, and chronic infections with antibiotic-resistant bacteria. When she was not hospitalised for these issues, Liliana lived in a mini-van with her husband, who himself was recovering from a stroke. The two had a fraught relationship, but he was Liliana's only caregiver beyond CCM and other safety-net providers. Because both Liliana and her husband were undocumented immigrants, they were not eligible for housing or income assistance. The CCM team believed that Liliana's health might improve in a shelter or skilled nursing facility, but neither would accept both Liliana and her husband. For Liliana, who recounted experiencing theft and assault at shelters in the past, the choice was clear.

A case conference revealed how similarly problematic 'situations of choice' complicated attempts to care for another CCM patient. During the meeting, CCM nurse Evelyn expressed distress regarding a patient, Eduardo, who had been hospitalised several times recently in a diabetic coma. 'Now it's four times. Near death four times', Evelyn said gravely. She then expressed dismay at Eduardo's decision-making process during a recent bout of hypoglycaemia while he was at a market. 'He had a banana!' Evelyn declared, 'I asked-why didn't you just eat it? He told me that he had to wait in line to pay for it. He's been accused of shoplifting before, and he said, "I have to pay for it"'. Despite the high stakes risk of waiting in line — she had told him, 'One of these times, you're gonna die' — Eduardo opted for a possible hypoglycaemic crisis because he felt the risk for criminal accusation was

higher. He had been arrested before and was not eager to repeat the experience. From Evelyn's perspective, the likelihood of dying from low blood sugar was so real and immediate that it superseded any other considerations. For Eduardo, however, the probability of arrest and public humiliation at the market seemed at least as real and immediate given the frequent discrimination he experienced as a low-income Afro-Latino man in the U.S.

It is worth taking a moment to explore Eduardo's situations of choice in more detail. Beyond the incident in the market, what did Eduardo's choices look like on a day-to-day basis? Ethnographic observations of and interviews with Eduardo revealed a litany of crises that undermined the CCM team's attempt to improve Eduardo's health and self-management. Prior to one diabetic coma, Eduardo attempted to purchase food at a corner store when he realised his blood sugar was crashing. The store clerk informed Eduardo that the food stamp machine was not working, and as he had no cash, he left the shop and sat on the sidewalk while he tried to come up with another plan. He remembered nothing between that moment and waking up later in the hospital.

Eduardo's choices were also wrapped up in problematic socio-economic relationships. He lived with his disabled daughter in her subsidised apartment unit, but the two had a tumultuous relationship that occasionally escalated to police involvement. After her death, which traumatised Eduardo, he had to choose between waiting for his own public housing approval or moving to another county to live with his son. To stay meant hoping for a place of his own in the building where his daughter died. To leave meant abandoning his community and forfeiting his healthcare relationships at the hospital where he received CCM support. In another county, he would have to start over as an elderly, illiterate, monolingual Spanish-speaker with impaired vision and difficulty managing his blood sugar.

At another county hospital, it is hard to say whether a nurse like Evelyn would have the resources or inclination to take as much interest in Eduardo's care as the CCM team had done. What is certain is that it would take a long time to know Eduardo as well as Evelyn knew him. During one clinic encounter, Eduardo realised he had misplaced his new brand-name glucometer. This constituted a disaster because he needed to check his blood sugar four times a day. The nurse understood this and said gravely (in Spanish), 'You need the [glucometer], because you can't live without the [glucometer]'. Eduardo and Evelyn frantically searched the clinic for his device, and when they could not find it Evelyn paused in fierce concentration. She knew that Eduardo could not simply purchase a new glucometer. He did not have the money for the brand-name device, and even if he could afford an off-brand glucometer, it would be incompatible with the monitoring technology at the clinic. After some skilled manoeuvring, including a full search of the clinic's storage closets, Evelyn finally succeeded in directing an off-site pharmacist to Eduardo's Medicaid documentation, including a prior authorisation for the same device he had misplaced. Fortunately, the device was eligible for renewal, and the pharmacist agreed to have it available to Eduardo within a few hours. Given the dedication displayed by Evelyn on this occasion (and many others), it is not surprising that Eduardo chose to stay in the city he knew and with the few people, like Evelyn, who knew him.

Another patient, Marcus, informed his CCM nurse, Brenda, that his diuretic medication doses impeded his ability to exercise and get to food banks. He relied on transit services to get to his exercise facility and to the food banks he frequented, but the trips (with multiple stops to pick up other patients) and wait times were often long. Being on diuretics meant that he needed to use the restroom frequently, but he found that shop owners in the community refused to allow him to use their restrooms. He believed this was because they thought that he (a heavy-set African American man) was going to hurt them. This obstacle threatened to undermine the real effort Marcus was putting into adhering to his care plan and making 'healthy' choices to exercise and obtain healthy foods, and he had internalised the idea that it was his responsibility to face these challenges. 'I gotta keep moving', he said, 'I can't sit around and wait for something to happen.... I keep moving. I only got myself'. Brenda suggested informing shop owners of his medical conditions, but Marcus told her he had already tried that. She offered to write a letter on the clinic's letterhead, but he did not think this would solve the problem. He believed people would still be afraid of him. Brenda was at a loss. She could see that Marcus was making the 'right' choices, but she could do little to address the systemic neglect that stood between him and the care she believed he deserved.

## Conclusion

As health care in the United States becomes increasingly commoditised, the logic of patient choice shifts responsibility from healthcare systems onto individual patients. Safety net providers are caught in the middle and held accountable for the failure of high-needs patients to conform to cost-saving self-management strategies. As Dubbin et al. (2013) note, 'Health care providers are being asked to do more with less, while patients are being asked to shift from being seekers of health care to informed consumers of medical services' (2013, 114). This tension was particularly evident in the CCM programs we observed, where the resource-strapped safety net met the neoliberal conception of the patient as a rational consumer on the healthcare marketplace (Light 2000). It is perfectly rational for someone who is ill and who lacks private insurance to consume healthcare services at a safety-net hospital. The problem arises when that safety-net hospital must contain costs according to market-based principles while addressing the perception that their patients 1) consume an inappropriate quantity of healthcare services and 2) fail to take responsibility for their own health. We argue that the idea of patient-as-consumer is untenable even in a *privatised* healthcare context, because it seldom resembles a 'free' market; in the world of the healthcare *safety net*, then, patients could not be further away from the ideal of the rational healthcare consumer. After all, the impetus behind CCM programs is to reduce costly, uncompensated and publicly-compensated ED visits and hospitalisations among patients who frequent safety-net hospitals. Bound by the logic of patient choice and the moral imperative to provide good care to those who most need it, CCM patients and care teams struggle to meet linear, quantifiable goals.

Ultimately, the logic of choice mistreats the frequent utilisers of the safety net, patients who are deemed irrational and costly members of our ostensibly consumer-driven healthcare system. Our study reveals that patients and CCM teams struggle to reconcile the imperative for individual choice and responsibility and the realities of systemic neglect, especially in the day-to-day reality of safety-net health care. It also makes clear that truly caring for these

individuals in the U.S. safety net would require infinitely more of Mol's individualised 'tinkering' than is actually possible. The care provided in complex care management is just that: complex. This is not, however, because the patients are inherently more problematic than other patients – which the phrase 'complex patients' evokes – but because the systemic neglect in which they exist is greater. We searched for, but could not readily identify, cases in which the invocation of 'choice' did *not* create contradictions with patients' actual lives of deprivation and neglect. This suggests that CCM providers and patients alike constantly struggle to reconcile these two diametrically opposed, competing logics. Understanding how this contradiction is reconciled may be a pivot point for how programs like CCM in safety net hospitals, and health care more generally, adapt to meet (or not) the needs of their most vulnerable patients.

The CCM teams we observed went to great lengths to reframe the logic of choice into situations of choice that might remedy the systemic neglect permeating their patients' worlds and to allow patients to feel like they had a modicum of control over some small aspect of their life. Yet at the same time that they spoke to patients of healthy choices, CCM providers were acutely aware of obstacles that made a logic of patient choice irrational and untenable. In response, CCM teams tinkered, advocated, problem-solved, and made do. They constantly considered their patients' social reality and did everything they could to adjust that reality. Still, such care involved an extraordinary amount of time and energy, with outcomes that were difficult to quantify according to the criteria of the market. Patients continued to experience cyclical crises, and despite their grasp of patients' social contexts, the care teams struggled to move the needle on utilisations. This led them to frequently ask, 'Are we making a difference?'

The frustration that patients and providers encountered in relation to the ambivalent and contradictory invocation of choice illustrates the mismatch between the logic that undergirds how patients can improve and self-manage their own health and the daily realities of systemic neglect. The actions of both patients and CCM teams explicitly challenged the premises of patient activation and revealed the complex interplay of individual, institutional, and structural contexts, and yet CCM patients and providers continued to be measured against personalised parameters that judged the quality of patients' choices. As healthcare agencies and institutions evaluate and potentially attempt to scale up CCM programs to cut costs, the need to define 'success' and standardise the processes to achieve it becomes one more constraint to care in the safety net. To the extent that metrics track outcomes as if they were simply matters of patient choice, rather than the incalculable work that teams do to provide care in a world they can do little to reshape, and to conjure a sense of power over one's life where little exists, definitive CCM success will remain empirically elusive.

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