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The pharmaceutical regulation of chronic disease among the U.S. urban poor: an ethnographic study of accountability

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Abstract

The Massachusetts experience of health care reform before the Affordable Care Act of 2010 reveals a moral economy of care in which expanded access was met by neoliberal demands for accountability and cost control. Publicly-subsidized health insurance programs in the U.S. are deeply concerned with managing and regulating low-income residents' access to and coverage for medications. By focusing our attention on the new forms of social relations invoked by specific techniques of governing, analyses of accountability can help us understand the ways in which subjectivities are shaped through their encounters with overarching social and economic structures. This paper presents qualitative findings from a four-year, prospective study that combined two waves of survey and chart-based data collection with four qualitative methods. Medicaid patients are made accountable to their medication regimens as they must track their supply and obtain refills promptly; regular blood tests carried out by health care providers verify their adherence. Both patients and their physicians are subject to cost savings measures such as changing lists of covered medications. Finally, patients struggle to pay ever-increasing out-of-pocket costs for their medications, expenses which may keep patients from taking their medications as prescribed. The fraught relationship between trust, accountability and verification finds emphatic expression in the moral economy of health care, where the vulnerability of the sick and their hope for a cure confront policies designed to hold down costs.

Keywords

accountability; pharmaceuticals; chronic disease; United States; medically underserved groups; health disparities; access to health care; costs of care

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People living with chronic conditions such as diabetes or hypertension frequently depend on one or more prescription medications to control their disease progression and symptoms. In liberal states in the U.S. like Massachusetts, efforts to expand coverage through publicly-funded health insurance programs must balance issues of cost and access. MassHealth, the Massachusetts Medicaid program that provides insurance coverage to low-income residents, is deeply concerned with managing low-income residents' access to and coverage for medications. The program uses a variety of techniques to limit expenditures on prescription medications, including pruning the rolls of beneficiaries and adding and subtracting brand name drugs to and from its formulary. Shifts in benefits intersect with a rich set of pharmaceutical beliefs among low-income patients to shape their experiences of chronic disease care. Part of a larger project that examines the forces and rhetorics of accountability in chronic disease management, this paper explores the experiences of patients and health care providers in Massachusetts who struggle to manage chronic illnesses under Massachusetts health care reform in the years preceding the U.S. Patient Protection and Affordable Care Act (ACA) of 2010.

Health care activists in Massachusetts had worked for decades with policy advocates and health insurance companies to increase health insurance access as a preliminary step to achieving universal coverage in the state (McDonough, Rosman, Phelps, & Shannon, 2006). The effort that culminated in the state's 2006 health care reform law, which served as a model for the ACA, took place amid ever-increasing concerns about health care costs and a general rollback of social services (Himmelstein & Woolhandler, 2007). The resulting law enacted a moral economy of care which entitled citizens to limited conceptions of health care within a larger framework of individual responsibility.

Anthropologies of accountability

Anthropologists and others have analyzed the extension of neoliberal policies into diverse sectors of social and economic life using the rubric of 'accountability.' In contrast to the norms of justice, service, or humanitarianism that previously governed the nonprofit sector (Clarke, 2007; Rose, 1996) and certain areas of health care (Rivkin-Fish, 2011), policies such as 'outcome funding' or 'return on investment' bring private sector rationalities of *transparency, choice* and *cost-effectiveness* to the governance of health, which together may be termed *practices of accountability* (W. Brown, 2015; Li, 2009). The concept of accountability was extended to domestic U.S. nonprofit domains from the private sector and from international good governance programs (Borneman, 1997; Clark, Fox, & Treakle, 2003; McDonald, 2000). In its myriad articulations, the concept of accountability has become both a concrete aim that signals new ways of 'doing business' and a symbolic value (Harvey, 2005). In studies of accountability, anthropologists and others have examined the social relations invoked by the actual technologies of accounting and audit (e.g., Strathern, 2000), as well as rhetorics of accountability in a variety of domains (e.g., Clark et al., 2003; Shore & Wright, 1999; Sloan, 2007). Accountability has also been understood as the ethical injunction to take responsibility or be held responsible for wrongdoing (e.g., Borneman, 1997; Li, 2009). In studies of chronic illness, Mol and Law (2004) describe the diverse forms of accountability experienced by people with diabetes insulin whose insulin doses are high enough to produce the risk of hypoglycemia. Diabetes is highly unpredictable and even those patients who faithfully adhere to their medications often fail to manage it, as evidenced by test results that fall outside the ideal blood sugar range (Mol & Law, 2004).

Proponents of accountability measures in health care emphasize the need to rationalize the distribution of care through transparent eligibility policies and strict cost control measures (Boehm 2005, Lopez 2005). These goals reflect what Maryon McDonald calls the 'new managerialism' of the nonprofit sector, where 'Discipline and accountancy, financial and human accountability, were merged' (McDonald, 2000, pp. 109–110). An accountability framework highlights the practices through which neoliberal policies are implemented as well as the organizational actors who carry out such policies (Boehm, 2005; Lamphere, 2005). Analyses of accountability can help us understand how our illness experiences are shaped by our encounters with overarching social and economic structures. As the rhetorics and technologies of accountability refashion our encounters with each other, health care and other service providers must enact and understand their work in new ways, while the subjects of government experience increased burdens of documentation and verification as they shoulder a greater portion of the costs of care (López, 2005; Power, 1997).

Chapter 58: Massachusetts health care reform

Despite already high levels of insurance coverage in the state (93% prior to 2006), Chapter 58 of the state's Acts of 2006 aimed to expand access to health insurance while controlling costs to the state. Chapter 58 mandated individual health insurance coverage and imposed a substantial fine on those who failed to demonstrate 'minimally creditable coverage' (Himmelstein & Woolhandler, 2007). It required employers to offer health insurance benefits or pay a 'free-rider' surcharge, and it expanded Medicaid eligibility for children whose families earn up to 300% of the federal poverty level (FPL). Like the ACA, Chapter 58 created publicly-subsidized plans provided by private insurers for adults with incomes up to 300% FPL (Himmelstein & Woolhandler, 2007; Long, 2008).

Policymakers and advocates heralded the subsequent increase of the state's insured rates to 97% after Chapter 58 (Long, 2008). Expanded access led to expanded costs, however, and by mid-2008, the costs of Chapter 58 had exceeded estimates by $150 million due to the number of new enrollees, the costs of their care, and other factors (Blendon, Buhr, Sussman, & Benson, 2008; Steinbrook, 2008). These higher-than-anticipated costs fueled efforts to limit public expenditures while maintaining expanded access. In a 2009 article in *Health Affairs,* Jon Kingsdale, director of the Massachusetts Health Insurance Connector, made the case for increased cost control measures through ethical appeals to distributive justice:

> Massachusetts took the ethical high ground and chose to begin [its cost control battle] with near-universal coverage. To the standard arguments that we must reduce waste in order to control government spending and remain internationally competitive, we have added this imperative: only by controlling costs can Massachusetts sustain near-universal coverage. Everyone acknowledges this argument. It might not suffice to tip the balance against entrenched resistance, but it does give moral weight to the dry, abstract argument for cost containment (Kingsdale, 2009, p. w589).

Here, accountability stands as both a social and economic ideal that strives to yoke together ethical claims with economic justifications. This echoes yet differs from Wendy Brown's diagnosis of neoliberal reason, in which the only justification for social policy can be economic aims of profit and competition (W. Brown, 2015). In Kingsdale's formulation, the ethical value of distributive justice undergirds arguments for cost control. The cost control measures implemented in response brought recipients under closer state scrutiny and sought to intervene in the management of their chronic illness by limiting coverage of their medications.

Cost control measures included periodic eligibility-recertifications for recipients. At least once a year, and sometimes more frequently, MassHealth recipients would be required to provide updated copies of all the information they submitted with their initial application for benefits. Eligibility re-certifications are just one of the ‘rituals of verification’ (Power, 1997) inherent in accountability measures that enact the deterrent function of bureaucracy. These policies deter would-be beneficiaries from gaining coverage when problems completing, submitting or processing the recertification forms lead to coverage termination. If this happens patients must re-apply for coverage, starting the whole process over again. Since this can take months, poor people who are sick can have significant gaps in care produced by this ‘churning of the rolls’ even while they are theoretically ‘covered’ by expanded access programs (see also López, 2005). Indeed, one year after the implementation of Chapter 58, 10% of adults with incomes under 100% federal poverty level, who were eligible for fully-subsidized health insurance, were uninsured as a result of these and other measures (Long, 2008, p. w274).

Other cost-control measures include cost-sharing—requiring higher copays for health care procedures and medications. In the general U.S. population, cost-sharing is associated with lower adherence rates (Goldman, Joyce, & Zheng, 2007). In Massachusetts, McCormick et al. (2012) report that access to health care, including medications, improved less than access to insurance following Chapter 58. Others have found that unsubsidized and even subsidized health insurance plans remained unaffordable for many (e.g., Galbraith et al., 2013), and that Chapter 58 failed to narrow racial and ethnic disparities in insurance coverage and access to health care providers (MDPH, 2010; Zhu, Brawarsky, Lipsitz, Huskamp, & Haas, 2010). These contradictions of access and cost control are lived by low-income patients with chronic illness at a safety-net community health center.

Methods

The health center where I have conducted research since 1998 is a Section 330 federally-qualified health center that provides primary care and other services to predominantly low-income and minority patients. It is located in a western Massachusetts city where almost one-third (29%) of residents live below the federal poverty level. The burdens of poverty are not equally distributed, however: over three times as many Latinos (42%) and twice as many African-Americans (26.2%) as whites (13.5%) lived in poverty in 2008 (US Census Bureau, 2014).

This paper presents qualitative findings from a four-year, prospective study that combined two waves of survey and chart-based data collection with four qualitative methods (see Shaw, Armin, Torres, Orzech, & Vivian, 2012, p. for a longer discussion of data collection methods). The quantitative survey sample included 64 African-American, 100 Latino, 93 Vietnamese and 40 white patients at the Health Center who were diagnosed with diabetes and/or hypertension. A subsample of 71 survey participants also completed one or more qualitative data collection activity. We conducted 35 in-depth interviews, 13 focus groups with a total of 47 participants, 15 chronic disease diaries, and 12 home visits. Our research team included bilingual, bicultural interviewers (who were African-American, Puerto Rican, and Vietnamese), as well as a project coordinator. I conducted most of the ethnographic interviews, often with the assistance of an interviewer who also served as translator. We conducted two focus groups with health care providers at the clinic, one with medical assistants, medical interpreters and front desk staff, and one with physicians, nurse practitioners and physician's assistants. Interviews were audio-recorded, transcribed, and entered into the qualitative database for coding. For interviews not conducted in English, on-the-spot translation was provided by bilingual interviewers. Recordings were then transcribed and all sections in Spanish or Vietnamese were re-translated into English to add any information not captured by the on-the-spot oral translation. Transcripts were coded following an open-coding method (Strauss & Corbin, 1990). We used Atlas.ti, a qualitative data management program, to analyze qualitative data for this paper by searching for all occurrences of talk about medication use and reviewing these for discussions of adherence and, especially, barriers to adherence. In addition, between 2008 and 2010 I occasionally attended and took fieldnotes on monthly meetings of western Massachusetts outreach workers. Sponsored by a Boston-based advocacy organization, these meetings updated outreach workers on constantly changing enrollment policies and procedures and served as a critical site for the exchange of information, tips and experiences negotiating the state's enrollment bureaucracy.

Our sample reflects the clinic's general population, which tends to be publicly insured and to have relatively low income and education levels. One-third of our study participants had an 8th grade education or less, and 74% estimated their household income to be less than $1,200 a month. Ten percent of our participants experienced a gap in insurance coverage in the past 12 months. Participants' median age was 56 years old with a range of 25 to 85. Our sample was nearly evenly divided between men and women (148 and 143, respectively).

Experiences of accountability

Patients and physicians we interviewed experience accountability in chronic disease care in at least three ways. First, patients are accountable to their medication regimens, which may include a dozen or more different drugs. Patients must take the prescribed dosage at assigned intervals and keep track of their supply, obtaining refills promptly so as to not interrupt doses. Patients with chronic illness face a lifetime of these challenges; years of experience may produce habits that are integrated into daily routines which may be disrupted by changes in insurance coverage. Second, patients and their physicians are subject to MassHealth and other insurers' cost savings measures such as changing formularies (the list of covered medications for a given insurance plan). (Massachusetts has Medicaid managed care, which means that MassHealth recipients are insured by private health management organizations (HMOs) under contract with the state.) Third, many patients we spoke with struggled to pay the out-of-pocket costs for their medications. If patients are uninsured or a medication is not covered by their formulary, a patient is responsible for the drug's full cost. These policies extend accountability and cost control to the level of individual bodies; patients with chronic illnesses that are controlled with medication are especially vulnerable to these costs.

Accountability to medication regimens

These forms of accountability are not as readily separable as this itemization appears, of course. Two patients I interviewed combined the first and third senses of accountability in their responses to my questions regarding how they were able to pay for their prescriptions. A Vietnamese woman whose medications were also covered by Medicare described the anxiety she experienced when she faced a possible interruption in her medicine as a result of insurers' cost control measures:

Hoa[1] There was one time that I was unable to get all my medications on time because [while] I have Medicare part D, they also enrolled me into the wellness program and that became AARP. And so supposedly I was eligible for both programs. But I needed to cancel one and I didn't know that, so they ended up canceling both. It was very close to the deadline, so... I had to go to the pharmacy to show my ID and everything to get my medication back, but it was like a couple days short.

Susan In the meantime you're actually, right now-

Hoa Yeah, right now, okay. There wasn't an actual time that I was without medication, it's just so worrisome for me that I knew that it was about the day for me to go refill it and I was realizing this, so I stayed on the phone from 5 p.m. to 9 p.m. calling Medicare. But that was solved. Anyway, I never ran out of medication.

Similarly, a middle-aged, married Puerto Rican woman on MassHealth described the 16 drugs her husband consumed daily. She first affirmed their mutual vigilance in maintaining a constant supply of each medication before explaining their costs, saying, 'Yes, he always has his medicines so he always… we always keep an eye on our medicines. And he pays three dollars ten for some of his medicines, and for the rest he pays two dollars. And the rest they [the insurance] pay[s].' Shifting costs to low-income patients such as these only exacerbates their challenges obtaining and paying for medications (Balkrishnan, 1998); in this case, these co-pays would add up to at least $32 month, a not-insignificant cost for families living on public assistance. MassHealth-eligible patients experience these reductions in coverage as part and parcel of broader state interventions in their lives, in which frequent 're-certs' (re-certifications) are required not only for health insurance but food stamps, public housing, and other forms of public assistance.

Patients experience this sense of accountability to their medication regimens in large and small ways, as they must remember to take their daily medications up to several times a day. Mol and Law (2004) discuss how patients in the Netherlands and the U.K. engage in continual self-surveillance as they seek to manage their diabetes by titrating their insulin dose and food intake in response to changing internal and external circumstances. Participants we interviewed frequently faced limited access to food, despite receiving some government assistance in the form of food stamps. For example, Victor, a Hispanic participant who described himself as a 'high-low glycemic' diabetic patient, described how he modified his insulin and food intake in a complex balancing act, weighing blood sugar

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[1] A pseudonym, as are all proper names of participants used herein.

levels, insulin doses, and access to adequate food. Victor explained that his food stamps allotment isn't sufficient to meet his needs as well as those of his family, which led him to stop injecting his insulin for up to several months at a time. In an in-depth interview he explained his financial straits to me this way:

> See, right now I got a problem, see. My ex-wife lost her job, right? And I got kids by her, right? So I've been trying to stretch my money buying groceries over there, helping her out, and buying groceries for me, but I, I ain't got enough for myself, you know. … So, so's what I do is buy one big *compra* [a shopping trip], and I bring it to her house if I could eat it over there while she cooks. But my kids, they eat, they eat, and they eat. And the groceries go quick, you know. …Like, last month, I had to borrow her, her car insurance money, right? To buy groceries for that month and then pay it back so she can pay for her car insurance, you know … sometimes I'm don't take my insulin, because I'm scared I might get a insulin stroke, when it, when [my blood sugar] gets too low... but that's between you and me. I won't shoot my insulin, you know, when I'm scared-- if I take it I might go into insulin shock and maybe die, you know? And my kids don't see that, you know? I try to do the best I can. [*voicing his kids' concern*] 'Oh, you didn't take your insulin today.' They fight with me you know? [But they don't understand that] there's a reason I don't take it sometimes.

Victor actively manages his health by controlling that which is within his ability—his insulin dosage—in response to severe constraints on his access to food. The extent of his sense of accountability, to both his family members and his physician, can be seen in his quasi-joking request that we not tell his doctor about his medication practices because 'I don't want to get in trouble.' So while from his physician's perspective he is noncompliant with his insulin, Victor's accounting includes not only his blood sugar numbers and his food stamp allocation but also his recently unemployed ex-wife and their children's needs as well.

Patients reported diverse approaches to keeping track of their chronic illnesses in ways that shape their daily routines. For example, in an in-depth interview, a Vietnamese participant showed me the notebook where he recorded his daily blood sugar numbers. Pulling out a small spiralbound notebook, he flipped to a page showing two columns of numbers, one in red ink and the other in black ink. The day of the month was listed on the left hand side of the page, and the red and black numbers show the morning and night measures for each day. He explained that he would bring this journal to each clinic appointment and said that his doctor will use it to determine his insulin levels; several participants reported similar recording techniques. Another Vietnamese participant, Tuan, described how he carried out blood sugar tests several times a day:

> In the morning when I get up, when done brushing my teeth and washing my face, I check the blood sugar. Then I take out my medication for the morning and put it there... Each morning I have...let's see...two kinds, three kinds of medication, with one pill for diabetes also, but it's the twelve hours, take one pill deal. I pick that one pill out and put it aside there. I take the other three and then I take that 12-hour pill. Then I go downstairs. There I give myself the shot, then eat breakfast. Then at noon, same thing. At noontime I check my blood sugar before eating lunch, then

> give myself the shot. In the evening I do the same thing. When you are stuck with the disease and the doctors tell you what to do, and when you do it constantly, it becomes a habit.

Tuan is made accountable to his diabetes through his own active monitoring of his blood sugar, and describes the sense of habituation that can develop over months and years of maintaining a medication regimen and tracking his glucose levels.

Other patients may be less disciplined in their self-care routines, but are made accountable by the blood tests that take place in the doctor's office. Carol, an African-American focus group participant, described the sense of accountability inculcated by the regular blood tests conducted at the clinic. She said, 'The doctor can tell if you miss from taking your blood test. I tried in New York, [when I didn't take my medicine for a weekend. The doctor] said, 'you been taking your medicine?' I said, 'yeah.' So I lied! She said, 'no, you haven't been taking your medicine. Next time you come in, we're gonna tie you to the bed and you stay there. You gotta put that stuff in your arm every morning.'' Carol laughed as she imitated the physician's mock threats, but she concluded her story by voicing her intention to follow her doctor's instructions: 'I'm gonna do the right thing!' Pressures towards medication adherence create a web of expectations for patients with chronic illness that sharpen their experiences of constraints imposed by the kinds of cost control measures described next.

Experiences of formulary changes

U.S. health insurance companies control the costs of providing coverage by adding and subtracting brand name and generic drugs to and from their formularies (the list of covered drugs). Insurance companies increasingly rely on tiered formularies with higher co-pays for 'non-preferred' drugs (Hodgkin, Parks Thomas, Simoni-Wastila, Ritter, & Lee, 2008, p. 67). Shifting a drug to a higher-cost tier is associated with decreased adherence among patients with chronic illness (Morgan, Hanley, & Greyson, 2009). These policies affect both health care providers and patients as they each become subject to new forms of accountability aimed at limiting costs. As they described in a focus group, providers were all too aware of the effects of these changes on their patients' ability to stick to their medications.

Provider 2 One barrier … is health insurance. Because, you see, insurances, some of them have specific medications they will pay for, like HMOBlue or MassHealth. MassHealth doesn't cover this particular diabetic med, so sometimes the providers have to switch around to see which medication will work for that patient because the insurance doesn't cover the one [that works best]. Sometimes this one is working for the patient, but insurance doesn't cover it, and they have to switch to something else, which doesn't work as well.

Provider 3 That's why they lose control. That's when they lose track.

Provider 2 And then the patients are frustrated because they think, well, that one used to work so well but they don't pay for it.

Susan And that's when they lose control of their blood sugar?

Provider 3 The blood sugar, everything! The tracking, everything! Because they change so much their medication so often they may be taking their meds twice a day instead of once. They lose control. They get tired. They don't want to do it anymore.

One way physicians at the clinic managed these changes, particularly when a patient's preferred drug would be dropped from the MassHealth formulary, was by using medication samples provided by pharmaceutical companies. At the time the use of drug samples was not subject to the same kind of scrutiny it later received, and health care providers seemed to regard them as a useful but clearly stopgap measure in helping low-income patients obtain needed medications. Even this measure had its drawbacks, however, because the supplies in the 'medication closet' were constantly shifting, as Provider 3 explained.

Provider 3 The other issue is that we have to treat the non-healthcare patients with samples because they can't afford the medications. We just had a big issue with Avandia. It had a production issue. Avandia was giving us lots of samples of Avandia and Avandamet, which was great because it had the Metformin in it but when they had a production issue, that dried up. Now … you have to make sure that whatever you give them is generic and none of the TZDs are generic, like Actos and Avandia, are not generic.

Susan Generic for MassHealth?

Provider 3 Generic in general. If they have no insurance, I have several patients who are buying their Glyburide because it's generic and it's less than $12 a month. And I'm giving them samples of Actos... But if a person has no insurance, you're working out of the closet [referring to the cabinet where the samples are stored that have been donated to the clinic by the drug companies] which in some cases, you know, you never know what you're going to see when you go in there the next time, you may have to change their medication.

Provider 1 But that's another issue. If you have someone who doesn't read or write, and you put them on multiple medications, it's a potential source for confusion, errors, and I know what I'm doing in terms of trying to save the patient some money. But it could be disastrous.

Provider 3 Change the medicine and they didn't understand, they take it like the other medicine.

While health care providers struggled with these constraints on their ability to prescribe the best medication for their patients, patients have their own experiences of these formulary changes. In a single interview, Lien, a Vietnamese participant, reported no fewer than three formulary discontinuations. After over three years' successful use of Avalide by prescription for her hypertension, she had been relying on samples for six weeks since MassHealth removed Avalide from its formulary. She feared that she might soon lose access altogether. As we sat in her kitchen going over the pill bottles she produced when I began to ask her about her medications, she worried, 'But if there's no more sample[s] the doctor could give me, then I don't know what to do. I tried many other medications, [which didn't] seem to work, so the doctor had me try this and so far it's worked.' Lien reported a similar experience with a cholesterol medication, Zetia, which was also removed from the

MassHealth formulary. She explained how she's been hoarding her remaining pills: 'I'm saving it. MassHealth stopped covering that also, so this is left over, so I'm saving it for as needed.' In fact, she read the label on a bottle of glucosamine that it 'helps reduce bad LDL cholesterol,' so she now takes glucosamine 'more regularly' than her Zetia, to make it last longer. This way, she can ration her use of Zetia, which is no longer covered by insurance but which she now only takes in moments when she really feels she needs it, when she feels 'uncomfortable.' She reported the over-the-counter cost of Zetia as beyond her means at 'more than $100' for 30 pills. Finally, she had a prescription for Nexium which also went off formulary, after which she said that she would get 'the purple pill' from a friend who has the same prescription: 'When I'm done with mine and it's [my stomach is] hurting me, then I call my friend up. My friend will give me some.' Lien's repeated experiences of formulary change create a feeling of insecurity in relation to the medications she's come to rely on. Instead of being able to simply take a Nexium pill to relieve her discomfort, Lien must decide if she 'really' needs it enough to use of her few remaining pills. Her experience of her illness and its symptoms was shifted by formulary change to become one of more intensive self-monitoring and doubt.

Other participants said that the experience of arriving at a pharmacy to pick up a prescription only to be told that a drug was not covered by their health insurance led them to doubt their physician's recommendations. Edward, an African-American participant, experienced a crisis of trust in his health care provider when his insurance didn't cover a medication prescribed following a hospital discharge. He explained,

> When I had the colonoscopy done the doctors prescribed me that Prevacid. I took it to the pharmacy, and the pharmacy says the insurance won't cover it. I went back to the Health Center and spoke with the doctor there…. She had to rewrite the scrip in a certain way in order for me to get this medicine. And I said, well, you know, I had the prescription in hand but MassHealth wouldn't honor it. So she went and talked to her, and she said 'well don't worry about it.' I went back to the pharmacy, thinking that everything had been taken care of. It didn't go through. Why would they give me a prescription if you can't honor it? Either it costs too much or you're second-guessing the doctor and you're thinking I don't need it. That's counter-productive to me.

In these ways formulary changes introduce pragmatic challenges to medication adherence by making medications more expensive and difficult to access. The emotional challenges to patients' trust in their medications and their health care providers is an equally important but perhaps less recognized consequence of formulary changes as a cost control measure. Disrupting patients' relationships with medications they have come to rely on creates a level of doubt as patients are forced to question the meaning and severity of their symptoms, diagnoses and bodily experiences.

Accountability: Paying the costs

Even for insured patients, out-of-pocket medication costs may keep participants from taking their medications as prescribed. Almost one-third (29%) of our participants reported that they were unable to afford needed medication or supplies in the past 12 months. For example, Tim, an African-American participant, described receiving a prescription for antibiotics from his physician which were not included in the formulary for his Medicaid managed care plan. When he went to pick up the medication at the pharmacy he was told his ‘insurance didn’t cover it, you got to pay for it yourself.’ When asked what happened then, Tim said, ‘I’ll put it back. I ain’t got that type of money. That was like fifty-something dollars, and I had two of them. This stuff is expensive.’

For some, insurance refusals keep patients from obtaining needed medicines. A Latino participant described caring for his diabetic mother and trying to pick up her medicines at the pharmacy. He said, ‘And that’s a mess there. She couldn’t get the medicine, every time they give ‘em a prescription she have to buy it. It’s a lot of money so... they got messed up on the medicines. Medicaid don’t want to cover the medicines that she need. And she need a lot of medicines.’ I asked how he responded to this and he replied, ‘Go back to the doctor, see if he could pass another prescription. And I been going through that for almost, since February.’ This participant struggled to care for his mother while simultaneously managing his own chronic illnesses, diabetes and high blood pressure.

Being unable to afford their prescribed medications can have serious effects for people with chronic conditions, especially those living with multiple illnesses. Julieta is a Latina in recovery who is living with depression, diabetes, panic disorder, high blood pressure, asthma, anxiety, and back pain, among other things. She takes at least six daily oral medications, with others to be taken as needed. When, in an in-depth interview, I began with a general question about her complex medication regimen, Julieta immediately volunteered that she was often unable to cover the cost of her co-pays despite having MassHealth and disability insurance.

Susan How do you manage to stay on top of all these meds?

Julieta I get more medication, it’s that, sometimes I can’t afford to take all of them out, so I take out the most important ones.

Susan How do you decide what are the most important ones?

Julieta Well, the most important ones is the ones for my diabetes, I know that’s very, because my mother had that, and she passed away, she was diabetic. She had explained a lot to me about that, cuz it runs in the family, so I know that’s the major [thing] I have to take care of. And my high blood pressure. So I do try to take out the most important ones. And then sometimes when I do can, I take all of them out.

Susan How much are you paying for your meds that sometimes you can’t afford them?

Julieta Three something each.

Susan How much is too much for you to afford?

Julieta It comes out to 20 dollars. Then I gotta take the bus too to go pick them up.

Susan So to pick up 6 bottles could be like 20 dollars a month, and that would be too much for you to afford.

Julieta Yeah, I got like 8 [meds that I take regularly].

Susan Say all 8 came due, you had to go to the drugstore for refills--

Julieta Sometimes I don't have it. Sometimes I tell them just give me the most important ones, I ask for it, and I would leave the other ones behind.

Susan So you would choose the metformin and the high blood pressure?

Julieta Yeah, the Lisinopril and the metformin. And my Doxipin to sleep and my Prozac. The other ones I leave it to the side, whenever I have the money I'll get it.

Susan What are the low priority drugs?

Julieta Well, [the one] for the worries. They gave me something for my eyes. [The strips] to check my sugar. So far I have been on top of my diet so I don't have to worry too much but it's good to check [your sugar] just to be sure. My inhaler, sometimes, I can't have it.

Susan What's the longest you've gone without an inhaler because you couldn't afford it?

Julieta Like a month.

This is quite a burden for her, since earlier in the interview Julieta reported that she uses her inhaler every day as she climbs the steps to her 4th-floor walk-up apartment. She explained that when she is without her inhaler, she is sometimes able to borrow one from her father or her brother, both of whom use the same medication. Sometimes one of them is able to get refills before his inhaler is completely empty, and he will pass the old one on to Julieta. I picture Julieta wheezing at the top of the stairs at her apartment, gratefully drawing on her borrowed inhaler, hoping to get her breath back.

Medication costs keep some patients from picking up their prescriptions, with detrimental effects for their wellbeing. Even seemingly nominal copays for $1 or $3 can be prohibitive when several medications are due for refill at once. For many, these costs seemed to have direct consequences for participants' adherence.

Conclusion

In 1999 Lutfey and Wishner argued for a shift in terminology from 'compliance' to 'adherence' (1999), suggesting that the former term overemphasizes patients' agency and under-recognizes the roles played by health care providers, structural and environmental factors in promoting or inhibiting patients' adherence to medication (see also Hunt & Arar, 2001; Rouse, 2010). Cost control measures such as formulary changes are an important example of the kinds of structural factors Lutfey and Wishner mean to highlight. Patients become habituated to their medications while establishing trusted relationships with both medications and their health care providers. Yet when these patients experience changes in their insurance, withdrawing coverage for medications to which they have become accustomed, patients perceive these changes with mistrust, further undermining their faith in a health care system upon which they depend.

Techniques of accountability such as formulary changes and eligibility verification for insurance coverage alter social relations and push these changes to the level of embodied individuals, bringing MassHealth recipients under more frequent state scrutiny. Strathern points out that, in many areas of social policy, efforts to rationalize expenditures can have the paradoxical effect of *reducing* trust among parties. She notes that audit practices such as eligibility verification ‘evoke anxiety and small resistances, are held to be deleterious to certain goals, and as overdemanding if not outright damaging’ to public welfare (see also M. F. Brown, 2010, p. 748; Strathern, 2000, p. 1). The effects of these policies are felt especially acutely by the U.S. urban poor. For instance, the gaps in coverage produced by ‘churning the rolls’ illustrate what Shari Danz (2000) calls *bureaucratic disentitlement,* when citizens are denied their ‘statutory entitlements’ because representatives of the state are literally unavailable or demand long wait times for access (Danz 2000, p. 1006, cited in Lopez 2005, 28). At the monthly meetings I observed between 2008–2010, Massachusetts outreach workers cited frequent examples of such obstruction, as when the enrollment center loses a patient’s application or supporting documents, or sends out multiple notification letters on a single day, each with a different directive (see reports of similar practices in Lamphere 2005, Boehm 2005, and Lopez 2005). These measures of deferral, disinformation and delay serve the larger goal of limiting state expenditures on MassHealth benefits by shrinking the pool of insured people and limiting their number of days per year of coverage. More molecular cost control measures such as formulary changes and tiers affect patients’ access to specific medications by increasing their out of pocket costs and requiring their physicians to obtain burdensome ‘pre-authorization’ approvals.

The fraught relationship between trust, accountability and verification finds emphatic expression in the moral economy of health care, where the vulnerability of the sick and their hope for a cure, or at least treatment, confront policies designed to hold down costs. Patients we interviewed following Massachusetts’s 2006 health care reform law faced limited access to those medications no longer included on the MassHealth formulary; their coping methods included hoarding pills, skipping doses, and ‘borrowing’ medications from friends. Health care providers were not immune to the effects of such policies, as their prescribing options are narrowed by tiered formularies and formulary changes which aim to shift physician prescribing behavior in ways that lower costs to insurers (Joyce, Carrera, Goldman, & Sood, 2011). Though these policies are becoming increasingly widespread in the U.S., their implementation in safety net settings compounds patients’ experiences of inequality produced by eligibility verification procedures that harden distinctions between worthy *consumers* of care and questionable *beneficiaries* (Becker, 2004).

The Massachusetts experience of health care reform before the Affordable Care Act of 2010 reveals a moral economy of care in which expanded access was met by neoliberal demands for accountability and cost control. In Chapter 58, lawmakers heeded the ethical injunction of distributive justice and the calls of activists, advocates and policymakers to enable as many Massachusetts residents as possible to gain health insurance coverage through expanded eligibility for Medicaid and public subsidies for private insurance plans. These expansions were almost immediately followed by curtailment of benefits and churning the rolls to remove ineligible people from coverage. Low-income patients in safety-net settings experience the withdrawal of benefits and ongoing demands for verification as yet more arbitrary acts of a recalcitrant bureaucracy bent on displacing the costs of care for those deemed too expensive to cover. While demands for transparency and accountability may satisfy politicians seeking to justify public expenditures, they also transform social relations by violating patients' tenuous trust in their health care providers and limiting patients' and providers' ability to pursue health.

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