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Qual Health Res 2014 24: 1745 originally published online 11 September 2014

DOI: 10.1177/1049732314549027

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Qualitative Health Research
2014, Vol. 24(12) 1745–1756
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DOI: 10.1177/1049732314549027
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Charles Senteio¹ and Tiffany Veinot¹

Abstract

Adherence to treatment recommendations for chronic diseases is notoriously low across all patient populations. But African American patients, who are more likely to live in low-income neighborhoods and to have multiple chronic conditions, are even less likely to follow medical recommendations. Yet we know little about their contextually embedded, adherence-related experiences. We interviewed individuals ($n = 37$) with at least two of the following conditions: hypertension, diabetes, and chronic kidney disease. Using an “invisible work” theoretical framework, we outline the adherence work that arose in patients’ common life circumstances. We found five types: constantly searching for better care, stretching medications, eating what I know, keeping myself alive, and trying to make it right. Adherence work was effortful, challenging, and addressed external contingencies present in high-poverty African American neighborhoods. This work was invisible within the health care system because participants lacked ongoing, trusting relationships with providers and rarely discussed challenges with them.

Keywords

adherence; African Americans; communication; emotions / emotion work; grounded theory; health and well-being; health behavior; illness and disease, chronic; illness and disease, experiences; motivation; poverty; psychosocial issues; relationships, patient–provider; self-care; urban issues

Treatment adherence is a significant issue among people with chronic diseases such as diabetes, hypertension, and chronic kidney disease (CKD). Adherence barriers can also be exacerbated by having more than one of these conditions simultaneously. Adherence is defined as the “active, voluntary, and collaborative involvement of the patient in a mutually acceptable course of behavior to produce a therapeutic result” (Delamater, 2006, p. 72). Adherence for these diseases remains markedly low despite potential health benefits, including reduced risk of cardiovascular disease (Prado-Aguilar, Martinez, Segovia-Bernal, Reyes-Martinez, & Arias-Ulloa, 2009) and prolonged survival (Best et al., 2011).

Adherence for these conditions is also marked by racial disparities, with African Americans adhering to treatment significantly less (e.g., M. C. Marshall, 2005) and experiencing worse health outcomes more quickly than Whites (e.g., Ogedosu, Schoenthaler, Vieira, Agyemang, & Ogedegbe, 2012). To understand the lived realities underlying this disparity, we examine adherence from the perspectives of African Americans, who often experience adherence-related challenges: those living in high-poverty neighborhoods or having more than one chronic condition.

For diabetes, hypertension, and CKD, adherence typically includes taking treatments and medications as prescribed and following diet and exercise guidelines. Low adherence is the primary reason blood pressure is uncontrolled among two thirds of people with hypertension; patients intentionally do not adhere to their medication regimen because of time constraints and fear of addiction (Marshall, Wolfe, & McKeivitt, 2012). Similarly, fewer than half of the diabetes patients maintain recommended blood sugar levels (Cheung et al., 2009), and diabetes medication adherence can be as low as 62% (Cramer, 2004). Furthermore, 20% to 30% of hemodialysis patients shorten or skip dialysis sessions (Kutner, Zhang, McClellan, & Cole, 2002), and 30% to 50% do not follow fluid restrictions (Cvengros, Christensen, & Lawton, 2004).

Such adherence rates are even lower among African Americans. For example, medication nonadherence is a

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factor in the association between poor blood pressure control and race (Bosworth et al., 2006). African Americans are also significantly less likely to adhere to diabetes medication regimens, with one study showing medication adherence rates of 76.5% for African Americans versus 82% for Whites (Schectman, Nadkarni, & Voss, 2002). Moreover, African Americans are significantly less likely to take kidney disease–related medications as recommended; in one study, 59.4% of the African American patients exhibited medication noncompliance, in contrast to 27% of Whites (Curtin, Svarstad, Keller, & Murray, 1999).

There have been many attempts to investigate the factors underlying adherence disparities between African Americans and Whites. Identified factors include knowledge, beliefs, attitudes, self-efficacy, depression, negative health care experiences, and poor doctor–patient communication (Elder et al., 2012; Ford, Kim, & Dancy, 2009; Lewis, 2012). Higher poverty rates might also contribute, through disruptions in health insurance coverage and unstable housing (Hall, Choi, Chertow, & Bindman, 2010). Health sciences researchers have also examined potential mismatches between African American cultural beliefs and biomedical concepts of disease and treatment (Schlomann & Schmitke, 2007).

Despite these insights, researchers have not clearly connected African Americans' adherence to the communities in which they live. This is an important gap because, compared with Whites, African Americans are more likely to live in high-poverty neighborhoods (de Souza Briggs & Keys, 2009). This environmental context exerts an independent negative effect on individual health status—even after accounting for individual characteristics. “Ecological” effects on health have been shown for diabetes (Auchincloss et al., 2009), heart attack (Rose et al., 2009), and mortality (Subramanian, Chen, Rehkopf, Waterman, & Krieger, 2005).

Neighborhood disadvantage also predicts higher rates of poor diet and lower physical activity (Cerda, Diez-Roux, Tchetgen, Gordon-Larsen, & Kiefe, 2010). Neighborhood features that might contribute to such effects include poor housing conditions (Shenassa, Stubbendick, & Brown, 2004), distance from stores selling healthy foods (Beulac, Kristjansson, & Cummins, 2009), and lack of recreation facilities (Dahmann, Wolch, Joassart-Marcelli, Reynolds, & Jerrett, 2010). We do not, however, fully understand the adherence-related experiences of African Americans who live in high-poverty neighborhoods or the work required to adhere in challenging circumstances.

Another under-examined factor concerns comorbidity, having more than one chronic condition. In general, more than half of all diabetes patients have at least one additional chronic disease, and 40% have at least three (Versnel, Welschen, Baan, Nijpels, & Schellevis,

2011). Comorbidity is more common among African Americans who live in socioeconomically marginalized communities (Ford et al., 2009; Quiñones, Liang, Bennett, Xu, & Ye, 2011) and might affect adherence because of greater treatment complexity (Ho, Bryson, & Rumsfeld, 2009). Moreover, treatment complexity might be more difficult to navigate in high-poverty contexts in the United States because individuals might have inconsistent health insurance coverage or rely on safety net care.

Previous researchers have typically examined adherence only in the context of a single illness. Yet syndemic theory provides a strong rationale for the simultaneous examination of comorbidity and environmental context. A “syndemic” is the synergistic interaction of epidemics, which is in turn connected to social conditions that accord vulnerability to multiple conditions (Singer & Clair, 2003). Researchers have also sought to explain the relationship between inequality and obesity (Lee, 2011) and to describe the interaction between poverty, obesity, and diabetes (Hill, Nielsen, & Fox, 2013). We extend this prior work by examining one pathway by which disadvantaged environments might connect to health outcomes for people with multiple chronic conditions: the work of adherence to treatment regimens.

Health social scientists have made notable contributions to understanding adherence from patients' perspectives (Hunt & Arar, 2001). These researchers have challenged the assumption that low adherence is irrational or dysfunctional (e.g., Conrad, 1985) by examining the social context of medication taking. Not taking medications as prescribed might be the result of a reasoned analysis concerning the demands of one's daily life (Donovan & Blake, 1992).

Furthermore, medication holds different meanings in people's daily lives, potentially affecting behavior. Taking medications (or not) might mean “taking control” over one's illness (Conrad, 1985), or it might mean “managing symptoms” (Hunt, Jordan, Irwin, & Browner, 1989). These research findings have helped introduce a valuable, “patient centered” view of adherence that seeks to reorient power relations in medical care, beginning with Zola's (1981) seminal article—but has rarely focused on disadvantaged groups such as African Americans and issues that disproportionately affect them, such as neighborhood poverty and comorbidity. Moreover, with the exception of McCoy's (2009) recent portrait of pill taking, researchers have been largely silent regarding the “work” that individuals undertake to adhere.

Theoretical Framework: Visible and Invisible Work

We draw on Strauss and colleagues' research regarding forms of “work” in health care settings. Here, work is

understood as any exertion of effort and investment of time to produce or accomplish something (Strauss, 1993). In their attempts to illuminate the social organization of health care, Strauss, Fagerhaugh, Suczek, and Wiener (1997) identified a number of unacknowledged forms of work completed by health care providers and patients alike. One important form is “articulation work” (Strauss et al., 1997), which coordinates efforts, resources, and projects so that other forms of work can happen. Articulation work responds to internal “contingencies” that arise from illness care itself and external contingencies regarding acquisition, allocation, and use of resources.

For patients, this “work” arises from the demands of symptoms and treatments, along with the overall illness “trajectory” (Strauss et al., 1997). Much work is unrecognized by health care providers and taken for granted as “cooperation” (Strauss et al., 1997). Some might also be “invisible” because it literally cannot be seen when patients choose not to divulge it or providers are focused on other matters.

In addition, developing the concept of “invisible work,” Star and Strauss (1999) discuss the contextually bound nature of “what counts” as work and how the dynamics of “visibility” often intertwine with the allocation of valued resources such as social legitimacy and financial compensation. As part of this, Star and Strauss (1999) describe several processes by which work might be rendered invisible, such as failing to recognize the full humanity of certain kinds of workers, using and manipulating abstract indicators of work that are removed from the actual work setting, and “disembedding background work,” where efforts, especially toward articulation, are taken for granted in a “background of expectation” (Star & Strauss, 1999, p. 15). Star and Strauss (1999) also link these concerns to broader economic trends such as downsizing, reengineering, outsourcing, and the erosion of the public sector.

Researchers investigating work visibility often have focused on efforts to document work that has previously been unacknowledged. Among patients, contemporary researchers have documented the “invisible work” involved in using health technologies at home (Moreira, 2008; Nicolini, 2006; Oudshoorn, 2008) and managing informational demands of one’s care (Unruh & Pratt, 2008). The goals of these researchers are often to support the (re-)design of information technologies and policies so as to improve patient experiences (e.g., Unruh & Pratt, 2008).

We build on the framework of work visibility with a novel focus on African Americans and contextual factors that affect them disproportionately, examining their lived experience as they work to adhere to prescribed regimens for at least two of the following chronic conditions (which often co-occur): hypertension, diabetes, and/or CKD.

We therefore investigate the following questions in this article: What is the “work” of adherence among African Americans who live in high-poverty communities and have comorbid chronic diseases? How “visible” is this work to health care providers?

Data and Method

In this qualitative cross-sectional study, we purposively sampled participants to represent the gender, age, and racial composition of three cities in a Midwestern U.S. state. These cities are socioeconomically disadvantaged, with large African American populations, above average unemployment and poverty rates, and below average education and literacy levels (National Institute for Literacy, 1998). In addition, they experience higher than average rates of stage four CKD, End Stage Renal Disease, and diabetes (National Minority Quality Forum, 2008; see Supplemental Table 1, available at qhr.sagepub.com/supplemental). We recruited participants through health care and service provider referrals or flyers posted in housing developments, clinics, and community centers.

We conducted in-depth semistructured interviews in private locations, typically the participant’s home. The 1- to 1.5-hour interviews included open-ended questions and follow-up probes, as well as structured questions gathering demographic data and administering an adapted measure of self-reported treatment adherence (Bandura, 2006; Morisky, Green, & Levine, 1986). Participants received US\$20 for their participation. Interviews, conducted between February 2012 and February 2013, were audio recorded and transcribed verbatim. We received ethical approval for this study from the University of Michigan’s Health Sciences and Behavioral Sciences Review Board.

We used a Straussian grounded theory systematic approach to the analysis. Our theories emerged from the data, through the constant comparative method that guided the coding process. Our interview probes were informed by early data analysis, including memos and hypotheses. An initial line-by-line coding phase preceded a focused axial coding phase and a later selective coding phase (Corbin & Strauss, 2007). We also borrowed from the Glaserian tradition by using gerunds to stay situated in the interview data and investigate processes; in addition, we used *in vivo* codes to preserve participants’ meanings and lived experiences (Glaser, 1978). We defined conditions, actions or interactions, and consequences associated with emerging categories during the axial coding phase (Corbin & Strauss, 2007). We discussed the initially generated codes and reached consensus regarding the overall framework and reviewed decisions about application of codes together after initial coding by the first author. During coding, we used memos

to capture ongoing reflections, and these were reviewed jointly by the two authors (Charmaz, 2009).

This effort was part of a larger community-based research project. There were three interviewers; one was the first author, who served various roles in the research effort that included coalition building, participant recruiting, and data analysis. Prior to finalizing the results, we presented the preliminary findings to the research project community advisory committee, comprised of various community leaders, and providers. This key validation enabled reflexivity in the process of finalizing findings.

Results

Approximately one third of the participants were drawn from each of three low-income urban areas (National Minority Quality Forum, 2008; see Supplemental Table 2, available at qhr.sagepub.com/supplemental). All of the 37 participants were African American; 27 (73.0%) were women. Ages ranged from 21 to 90 years, with a mean of 56.9 years; 56.8% had a high school education or less. A small proportion of participants (10.8%) were employed, and one (2.7%) was a student. The remainder were unemployed, retired, or on disability. All had health insurance, but most reported prior interruptions in coverage. Participants self-reported at least two of the following three chronic diseases: hypertension, diabetes (including two with prediabetes), and/or CKD, with 72.9% reporting both diabetes or prediabetes and hypertension (National Minority Quality Forum, 2008; see Supplemental Table 2), 75.7% reporting treating their conditions through a combination of medication, diet, and exercise, and 16.2% with just medication and diet. Self-reported adherence levels were moderate: 36.1% of participants self-reported high levels of treatment adherence and 33.3% reported medium high levels.

Adherence Work

In general, participants were attentive to their health status and communicated that they placed a high priority on making efforts to address their conditions. As a group, they expressed considerable concern about their health: “My health is really important. I try to keep up with [it] as much as I can.” They also largely defined “adherence” in a manner consistent with doctors’ advice; adherence included taking medications, diet, exercising, not smoking, and monitoring their health. However, some participants spoke of prioritizing directives at times: “If I don’t do anything else, I take my blood pressure medication and my diabetes medication, for sure, every day.”

Participants expended significant effort to adhere, whether or not they were always “successful.” They expended effort to address external barriers—“I’m trying

to live . . . Nothing will stand in my way as far as my health problems . . .”—as well as internal barriers—“Sometimes it’s hard to try to follow up . . . But I make myself . . .” As one explained, temporal and cognitive burdens involved were significant: “This kidney, diabetes stuff, I do it every day. I do it all the time. This is what I think about and this is what I concentrate on.”

Building on these perspectives, we identified five types of ecologically situated adherence work around which participants’ effort concentrated: (a) constantly searching for better care, (b) stretching medications, (c) eating what I know, (d) keeping myself alive, and (e) trying to make it right. These are detailed in the following.

Constantly searching for better care. Although some were satisfied with their current providers, many participants described complex, continuous searches for satisfactory health care. One described her long search for a provider: “About forty something doctors later, they found out I had diabetes.” As this suggests, frequent provider changes were integral to this ongoing search.

Instability of care relationships meant participants often lacked sustained, trusting relationships with providers. Hence, many made virtually all self-care decisions in isolation, not discussing their circumstances or decisions with providers. As one shared, “I told myself, I wasn’t gonna take these same pills for a day or two . . . I said, ‘Well, I’m gonna try it myself, the lame doctor don’t know what he’s talking about.’” This lack of satisfactory patient–doctor relationships contributed to “invisible” background adherence work for participants dealing with their circumstances in isolation from the health care system.

Switches were partly driven by changes in insurance coverage that terminated doctor–patient relationships. As this participant related, “I’m on . . . Medicaid . . . the doctors have a certain limit of how much care they’ll give you and they cut you off [suspend treatment].” Furthermore, when participants lost coverage entirely, they went to “free” clinics, where they often lacked relationships with specific providers: “Every time I would go up there [free clinic], I would see different doctors . . . I did that for . . . maybe six months.”

Some also switched doctors because of unsatisfactory experiences. Many expressed strong emotions—including resentment—about current or past care. Some expressed frustration with poor treatment, including long waits: “I go in there and I get up on the table and go to sleep before they come in to wait on me . . . I’m not going to keep [going to this clinic].” Others described disengaged providers and lack of respect: “They misdiagnosed me . . . I didn’t have a PhD. Nobody listened to me.” One questioned her doctor’s interest in treating her: “This one here that I have now he seems like he’s just going along.”

Some believed their providers were not knowledgeable enough: "I'm thinking about changing . . . because I want a doctor who really knows about [diabetes]." Others recalled poor care in other contexts, contributing to lingering distrust of health care providers: "I kind of blame [doctor] for my daughter's death."

Some participants believed their care was substandard because of physician supply problems. One dimension of this was the limited range of clinicians that accepted their insurance: "It is [a challenge to find a good physician]. Especially with the type of insurance I have." Another dimension was geographic; some believed care quality was uneven in their area: "Some [doctors] are good. Some are terrible. It's a half and half." Participants noted that some local clinics had been "shut down" because of mismanagement and that doctors were moving away without being replaced. "There's urban flight where all the doctors and the health professionals . . . moved to the suburbs . . ." Participants believed these dynamics left few good options.

As a result of continuous work to find accessible, engaged, and competent doctors, participants communicated an expectation of regularly switching providers but worked to keep their providers if they were generally satisfied with care. Some had been "dropped" by doctors for not following recommendations. One said of her doctor, "If you don't follow her instructions, she would turn you over to somebody else in a hot minute." Participants viewed being "dropped" as upsetting, but just another part of the effort required to access care.

Frequently changing doctors exacerbated challenges with managing multiple chronic conditions, which included needing multiple doctors with limited scopes of practice. One participant said,

I have three doctors. I had one doctor, it was for my pain. Then [another doctor] supposed to be my primary care. But he don't . . . all he do is . . . my diabetes. He don't . . . [treat my depression, hypertension, emphysema].

Consequently, participants were primarily responsible for tracking their conditions and communicating their medical history and current treatments to each new provider. They also needed to verify recommendations across multiple providers, as this woman with three doctors said, "I had a couple of different doctors that had prescribed me different medications, but I make sure my primary care doctor says it's okay for me to take [them]."

Stretching medications. Many participants struggled financially; simply meeting basic needs required effort. One Army veteran in his early 40s who was on dialysis and had hypertension shared, "Physically I'm cool, psychologically I'm not. I'm broke . . . at this point . . . at the

11th of the month and you're broke, you're not gonna be too happy about that."

"Stretching medications" involved effort to secure, allocate and use medications, scarce resources in participants' worlds. Although all had health insurance at the time of the interview and a few had comprehensive prescription drug coverage, many experienced difficulties with copayments. One recounted that her "welfare" coverage had recently changed, leaving her unable to afford diabetes medication: "My metformin and my glucophage . . . I can't afford them because like I say, they're almost like 30 dollars a pill." Because poverty haunted each financial decision, participants could not consistently afford medications. Thus, they skipped dosages ("stretched") sometimes for an entire day or a week. One said, "I used to buy half of them [medications] this week then skip a week and go with the other half." Some with multiple conditions had to choose between medications because some were cheaper or available at a discount, whereas others were not: "The diabetic medications . . . I was only on a pill . . . [t]he pharmacy used to give me a pretty good deal with that one."

Participants also used family members' medications ("borrowed") to avoid running out. This was a threat for some due to lapses in insurance coverage. One explained, "I was taking 5 milligrams and my father was taking 5 milligrams, he had [insurance plan], so I would get my meds [medications] from him."

All were aware that stretching or borrowing medications was not recommended; however, this was a financial decision they felt they had to make. Notably, participants did not discuss difficulties in paying for medications with their providers, leaving providers with the assumption that access to prescribed medications was straightforward.

Stretching medications resulted in practices with direct negative implications for participants' health. One spoke poignantly about this:

So, I got to cut back. I need to save. Stretch it out, [she has been directed by her providers that] you can't stretch it out. You got to take it until it's gone. If you take yourself off of them . . . that's when your sugar drop, it's almost like you're going into a seizure.

This practice was particularly damaging when managing multiple chronic conditions. One participant attributed her recent hospitalization to stretching her pills. "So, when I went to the hospital . . . I was trying to stretch my pills. And I said, 'Well, they cut up authorization.' And [primary doctor] didn't accept me." These practices reflect a "something is better than nothing" attitude, a pragmatic solution to one of the daily problems participants faced in getting by.

Eating what I know. Most treatment recommendations included restrictive diets, and participants worked to reconcile new restrictions with cherished memories of eating without worry. The good-tasting foods they “grew up on” and “used to eat” still defined what was “good.” Participants recalled happier times when they did not suffer consequences from eating familiar, “good” food: “I used to eat a lot of things like that and it didn’t bother me [negatively impact health] . . .” One mentioned no longer eating large, satisfying holiday meals: “You can’t eat all that nasty or that salty food no more. No great Thanksgiving dinners.” Participants struggled to make sense of the fact that the food they had enjoyed for decades actually threatened their health, a dramatic realization. Underlying this was also an issue of identity because many of these foods were associated with “soul food,” closely tied to the African American experience.

Translating awareness into new dietary habits was thus especially difficult: “I’m so used to eating fried foods . . . and that’s like the stuff that I use to eat on a daily basis.” Many continued to eat what they knew and enjoyed. “I’m still eating the wrong stuff.” They were also more likely to eat what they knew when stressed or not feeling well; then, convenience became a reason for eating foods they should avoid: “[McDonald’s] was quick and I needed to keep my blood sugar from crashing.” Such lapses were fostered by comparatively easy geographic access to unhealthy foods in their neighborhoods: “If you drive around [name of place] . . . there’s four fast food places on every intersection. You drive out to the suburbs, you see restaurants . . . and more grocery stores.”

Nevertheless, most worked to change daily eating habits. In this sense, work involved reconciling a need for comfort in the face of stress with a serious commitment to change. It took concerted effort to change one’s tastes, as this participant related:

I have this . . . big thing . . . of Dr. Pepper. It took me two years to love water. I just filled a bottle up and forced it down, but now, I can drink water and I don’t even cringe at it no more.

Participants also needed to prepare food in new ways: “It’s hard . . . chicken and fish, baked or boiled.” Thus, eating what I know also became an effort to “know” new foods.

Following dietary restrictions is particularly important for treating comorbid conditions, where care for multiple conditions is affected by each choice. As one participant with diabetes and hypertension explained,

I was going through a hyperbariatric treatment for a wound on my leg, and they had to cancel the treatment because my blood pressure was like way high. They were afraid I was

going to get a stroke . . . I’m not a big salt eater but, I’ve been eating these foods all these years . . .

Apart from a few people with access to dietitians or diabetes education, such struggles with eating habits took place in isolation from health care providers. Few reported discussing their dietary choices, including setbacks or achievements, with them.

Keeping myself alive. Participants’ everyday worlds overwhelmed them with frequent, numerous sources of stress, including neighborhood crime rates. As this participant shared concerning his community, “Better have your medicine with you because it’s sure gonna shoot your blood pressure up . . . the fear of violence.” Violent crime also personally affected the mental health of some participants, such as one woman whose teenage son had recently been kidnapped, then murdered, near their home: “It was things happening and I was getting like I couldn’t be my usual self because (pause) . . . You see I had one son got killed.” Another was still haunted by her brother’s murder a decade earlier. In both cases, they experienced long periods of grief, causing considerable difficulty in managing chronic diseases.

Coping with feelings that might contribute to adherence barriers required emotional work (McCoy, 2009). Indeed, tragic experiences could even introduce new work to maintain access to care. In one example, a mother lost her health insurance days after her adolescent son was murdered because her insurance eligibility had been tied to him:

When he passed [died], I lost my Medicaid . . . the clinic [within walking distance] told me, “We’re sorry . . .” I [went] to Social Services Office . . . trying to get money to bury him.

Community crime rates, abandoned buildings, and stray dogs also interfered with self-care practices and overall health; this was rarely appreciated by providers who assumed availability of safe, walkable neighborhoods. As this participant said, “They say go take a walk. Can’t walk in this neighborhood.” This resulted in efforts to find locations to exercise, not discussed with providers. One participant said, “I’m trying to get into senior citizens nursing home and usually those places that have gyms or something like that.” Another shared how she walked in a local store with a group from her church: “I’m walking around Wal-Mart. Every morning that we go to prayer [at church], that’s what we do.” Comorbidity also sharpened their determination to exercise despite the challenges: “People who are diabetics, kidney patients need to be as physically fit as they can be.”

Participants’ social environments could be sources of stress, leading to the work of “staying away” to protect

one's well-being. One said, "I don't like being around negative people. I don't like being around people who think they can play games . . ." Another said, "When you feel . . . you're gonna go to that point [of fighting] . . . I'm like, 'I'm not gonna go there. I'll talk to you later. You have a good day. Goodbye.'"

Many participants attended local churches and called on faith to "keep themselves alive." Some found praying helpful: "Sometimes I have a load, but I just have to pray and get busy, and it helps me keep my blood pressure down." Participants also worked to pair prayer with treatments, to find an optimal balance for themselves. As one shared, "I take medication. . . . I pray a lot or read scriptures. . . . That seemed to help me." Participants also expended effort to maintain motivation and resolve in the face of setbacks. For example, the aforementioned mother who lost her son and health insurance simultaneously responded thus after she was denied Medicaid: "I cried all the way home . . . right then and there, I almost gave up . . . but I don't believe in losing my faith . . ."

Comorbidity added urgency to participants' efforts to stay alive because they were aware of the increased risk of complications associated with multiple conditions; this left many concerned about their future health. As one said, "When you're diabetic, failed kidneys, high blood pressure . . . associated things that go with these . . . all of this on one person . . ." Again, they faced this worry largely in isolation from the health care system: participants did not typically discuss stressors or efforts to manage them with their clinicians.

Trying to make it right. Most participants were familiar with chronic diseases prior to their own diagnoses because they "ran in the family." They had observed close family members with these conditions and had dramatic memories of relatives' suffering:

My mother . . . I remember what she went through with her diabetes going to kidney . . . dialysis. Gone through dialysis for a year [before she died], and it ran in . . . her mom's side of the family.

Although participants typically had background knowledge borne of family experience, many performed translational information work (Kaziunas, Ackerman, & Veinot, 2013) to learn how to avoid familiar complications and adapt information to local circumstances. As one shared, "I should try to find out anything and everything I can . . . I don't know how long I had it and then my mother, she died from it . . ." Thus, information was a resource in participants' emotional work of connecting painful memories to their own disease trajectories. This involved dealing with a sense of inevitability upon their own diagnoses, without fatalism regarding their own futures:

I try to make it right. . . . I try to eat right. . . . You are supposed to eat when taking medications . . . If I don't take my medications, I can get complications. But I try to take them.

Accordingly, participants struggled to change their futures: "In the hospital, my mom was on a renal diet . . . I don't like [it] . . . That's why I try my best to stay out of the hospital."

It also took significant emotional work to maintain adherence in the long term: "I did the same thing [participant's father] did the first year. I kept it under terrific control. But then our will powers weren't the same after a year. . . . Bad habits just returned . . ." Participants described times when they were more diligent—for example, when they were first diagnosed—as well as times when they were not "as careful." Adherence was thus a cyclical struggle that included periods of diligence and of laxity. They often felt guilty when not following recommendations and believed that they could stave off complications if they kept working to do "what they should."

Because of high community and family prevalence, participants were aware of, and wanted to avoid, complications others experienced: "There are a couple of people . . . at my church, a lady who is pre-dialysis, who is now on dialysis, I don't want this." Although many had been living with chronic diseases for some years, they rarely discussed efforts to maintain a positive attitude in the face of negative memories or the challenges of sustaining adherence with health care providers.

Discussion

We found that study participants performed significant, effortful work to "adhere" in challenging circumstances. We introduced five categories of participants' work, situating those articulation-focused activities in the contingencies and scarcities of their everyday lives: (a) constantly searching for better care, (b) stretching medications, (c) eating what I know, (d) keeping myself alive, and (e) trying to make things right. We contend that this work is largely "invisible" to health care providers because participants do not share their experiences, barriers, and efforts to adhere with their providers. Patients might be reluctant to disclose their "work" to providers if they lack ongoing, trusting relationships; as a result, providers rarely learn of patients' struggles.

In contrast to findings from prior research with more well-resourced individuals, we did not find that patients were redefining adherence or "resisting" medicine (e.g., Murdoch, Salter, Cross, Smith, & Poland, 2013) or find discordant "beliefs" between African Americans and biomedicine (e.g., Schlomann & Schmitke, 2007). Rather,

perhaps because of comorbidity, participants were worried about their health and trying hard to enact provider recommendations in the face of significant challenges. Consistent with prior research, we found that inability to pay for medications challenged adherence (Krueger, Berger, & Felkey, 2005). Like others, we also identified the challenge of cultural attachment to “unhealthy” foods (James, 2004) and the challenges of stress in high-poverty neighborhoods (e.g., Hackman, Betancourt, Brodsky, Hurt, & Farah, 2012). However, we extend this work prior by highlighting the creative efforts and agency involved in responding to such challenges. These efforts can result in sustained self-care behavior change, involving efforts that are not discussed and are largely unrecognized.

Consistent with the concept of “articulation work” (Strauss et al., 1997), adherence work was effortful, challenging, addressed external contingencies, and made the behaviors officially known as “adherence” possible. This articulation work involved resource coordination (health care and medication access, finding or making exercise-friendly environments), local tailoring or adaptation (training tastes away from dietary traditions, motivating oneself despite a fear-laden family disease history, avoiding stressful situations), and getting work back on track (praying, persisting after setbacks). This articulation work reflected the uncertainties and resource scarcities of lives spent in high-poverty neighborhoods; participants likely faced more and different challenges from their more privileged counterparts and consequently might have needed to work harder to adhere at the same level as residents of middle-class or wealthy neighborhoods. This stands in contrast to assumptions of individual control that undergird much prior adherence research findings (e.g., Cvengros et al., 2004; Elder et al., 2012).

The burden of adherence work in high-poverty African American neighborhoods might help explain why participants’ self-reported adherence was typically not “high” despite significant efforts to adhere (see Supplemental Table 2). This seemingly incongruous finding might be partly explained by research findings showing that behavioral self-control is more difficult in situations of cognitive or motivational depletion (Stroebe, 2011). Thus, we hypothesize that our participants might expend such significant psychological resources on articulation work that performing the behaviors defined as “adherence” require insurmountable effort. Accordingly, a high burden of articulation work might help explain the ecological effects of high-poverty neighborhoods on the health of people with chronic diseases. This work might also be an unacknowledged factor driving adherence disparities among African Americans. Future comparative researchers should examine this issue in depth.

Articulation work is typically excluded from rationalized models that assume a smooth and straightforward series of work activities (Star, 1991). In this study, inconsistent health insurance coverage and overstretched, uncoordinated care often undermined the possibility of long-term, trusting provider–patient relationships. This was amplified when participants needed multiple providers to manage comorbid conditions, going beyond the coordination problems cited in extant research (e.g., Versnel et al., 2011). Lack of trusting and communicative relationships must therefore be understood in the context of under-resourcing of health care for study participants.

This context of provider–patient relationships contributed to work’s invisibility, situated in the larger reality that providers and participants did not understand one another well. Participants rarely spoke about adherence work to providers. Furthermore, suggesting its identity as “disembedded background work” (Star & Strauss, 1999), providers made inaccurate assumptions regarding resources available to patients to help them “adhere.” We thus provide new insight regarding dynamics underlying associations between a consistent, caring doctor–patient relationship and adherence among African Americans (e.g., Schoenthaler et al., 2009). Additional research is needed regarding how to build trusting, ongoing health care alliances in the context of resource scarcity.

Suchman (1995) argues that providing support for articulation work through information systems or other interventions has the potential to highlight or shift power dynamics within organizations. For example, in a legal firm, an “automation” project that was to take over document coding from human workers raised questions regarding the extent to which the work was “skilled” (Suchman, 1995). For better or worse, acknowledgment and facilitation of work confer rewards and ease burdens, and they do so for some people rather than others. For our participants, and others like them, it is therefore important to imagine new forms of support that could diminish the burdens of articulation work.

Fortunately, some efforts have already emerged, although their reach is inconsistent. For example, a growing number of educational interventions seek to adapt traditional African American foods to the demands of chronic conditions such as diabetes and hypertension (Di Noia, Furst, Park, & Byrd-Bredbenner, 2013). Programs that build “walkable” neighborhoods or address neighborhood safety concerns (e.g., Zenk et al., 2009) and efforts to promote consistent access to medications and high-quality health care also address adherence work. Emerging care coordination models such as case management aim to address the problem of aligning multiple providers for comorbid patients (Versnel et al., 2011), and patient navigator models often focus on health disparity populations (Natale-Pereira, Enard, Nevarez, & Jones,

2011). Regarding health care's "blind side" (Robert Wood Johnson Foundation, 2011), access to psychosocial support could help address stressors, family health history, and setbacks. Peer-based information systems and services can also help people imagine more hopeful futures (Veinot, 2010).

Although such interventions and programs might be individually helpful, we lack a broad, coordinated approach to their financing and provision in the United States. The concepts and findings presented here might offer a systematic framework for addressing adherence disparities among African Americans with chronic conditions.

There are several limitations to this study. We relied exclusively on participant self-reports; accordingly, responses might have been affected by social desirability and recall bias. In addition, provider perspectives were not gathered; accordingly, all assertions regarding work invisibility are based on participants' accounts of their decisions to manage their conditions without discussing their challenges and efforts with providers. Future researchers might profitably gather the perspectives of health care providers so as to better understand the relationship between the "visibility" and the "invisibility" of patient work. With a cross-sectional design, we could not rigorously assess changes in work over time. Furthermore, this study was conducted in three urban communities in the Midwestern United States, and the majority of participants were middle-aged women; generalizability to other regions, genders, and age groups awaits confirmation. Despite these limitations, this study describes important detail regarding the challenges, from the patient's perspective, of adherence work.

Conclusion

We identified five categories of adherence work among African Americans who live in high-poverty neighborhoods and have comorbid conditions. As a form of "invisible" articulation work, adherence work was effortful, addressed environmental contingencies, and was often undertaken in isolation from health care providers. An unequal burden of invisible work might contribute to adherence disparities for African Americans, suggesting a need for more systematic support. This becomes all the more critical when we realize that "the more the work is rendered deleted . . . the more suffering there is" (Star, 1991, p. 279).

Acknowledgments

We acknowledge the sustained support of key collaborative partners—the National Kidney Foundation of Michigan, the Inkster, Flint, and Detroit Public Libraries—and the Community Advisory Committees in each city. We also thank study

participants. We were privileged to hear their personal and at times difficult accounts of their illness-related experiences.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: We gratefully acknowledge funding from the Institute of Museum and Library Services (Grant LG-52-11-0212-11). Any views, findings, conclusions, or recommendations expressed in this publication do not necessarily represent those of the Institute of Museum and Library Services. This material is also based upon work supported by the National Science Foundation under Grant 0903629.

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