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“The land of the sick and the land of the healthy”: Disability, bureaucracy, and stigma among people living with poverty and chronic illness in the United States

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Abstract

Disability benefits have become an increasingly prominent source of cash assistance for impoverished American citizens over the past two decades. This development coincided with cuts and market-oriented reforms to state and federal welfare programs, characteristic of the wider political-economic trends collectively referred to as neoliberalism. Recent research has argued that contemporary discourses on ‘disability fraudsters’ and ‘malingerers’ associated with this shift represent the latest manifestation of age-old stigmatization of the ‘undeserving poor’. Few studies, however, have investigated how the system of disability benefits, as well as these stigmatizing discourses, shapes the lived experience of disabling physical illness in today’s United States. Here we present qualitative data from 64 semi-structured interviews with low-income individuals living with HIV and/or type 2 diabetes mellitus to explore the experience of long-term, work-limiting disability in the San Francisco Bay Area. Interviews were conducted between April and December 2014. Participants explained how they had encountered what they perceived to be excessive, obstructive, and penalizing bureaucracy from social institutions, leading to destitution and poor mental health. They also described being stigmatized as disabled for living with chronic ill health, and simultaneously stigmatized as shirking and malingering for claiming disability benefits as a result. Notably, this latter form of stigma appeared to be exacerbated by the bureaucracy of the administering institutions. Participants also described intersections of health-related stigma with stigmas of poverty, gender, sexual orientation, and race. The data reveal a complex picture of poverty and intersectional stigma in this population, potentiated by a convoluted and inflexible bureaucracy governing the system of disability benefits. We discuss how these findings reflect the historical context of neoliberal cuts and reforms to social institutions, and add to ongoing debate

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around the future of public social provision for impoverished and chronically ill citizens under neoliberalism.

Keywords

United States; Disability; Stigma; Neoliberalism; HIV; Diabetes; Social insurance; Welfare

1. Introduction

Over the past three decades, shifts in public discourse and policy have transformed the way government assistance to individuals in need is perceived, configured, and experienced in the United States. During the 1980's, widespread political attacks began to mount against federal welfare policy (M.B. Katz, 2013). Emerging public discourses formed around accusations of overdependence and abuse aimed at welfare recipients. Racialized rhetoric concerning 'welfare dependence' among the 'underclass' found its epitome in the castigatory, stigmatizing, gendered image of the 'welfare queen' (Gustafson, 2011; M.B. Katz, 2013). These developments culminated in President Clinton's pledge to "end welfare as we know it" in 1992, and, ultimately, in the Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (M.B. Katz, 2013).

This legislation replaced the primary federal welfare program, Aid to Families with Dependent Children (AFDC), with Temporary Assistance to Needy Families (TANF). Unlike AFDC, TANF is constrained by a lifetime benefit cap of five years, stricter eligibility criteria, and requirements for workforce participation ('workfare'). Moreover, TANF case managers were compelled—using market-based work incentives often deployed by contracted private companies—to shift their approach towards disciplining clients into changing their own work-related behavior (Schram, 2015). This cost-saving divestment of responsibility from state to citizen— or 'responsibilization' (Brown, 2015)—was achieved primarily via penalizing and paternalistic techniques of governance, such as tracking and documentation of clients' work-related activities and financial sanctions for insufficient engagement (Schram, 2015). In parallel, General Assistance (GA) programs (state/local welfare for adults without families who are therefore ineligible for AFDC/ TANF) underwent substantial cutbacks. The number of states either providing statewide GA or mandating counties to provide GA fell from 38 to 26 between 1989 and 2015 (Schott and Hill, 2015). Moreover, while 25 out of 38 GA programs (66%) offered assistance to non-disabled unemployed adults in 1989, only 11 out of 26 (42%) did so in 2015 (Schott and Hill, 2015). The real value of GA benefits also decreased over this period in almost every state that continued to offer them (Schott and Hill, 2015).

These changes were part of broader, long-term political-economic shifts away from government regulation and social provision towards a more market-oriented economy and state, characterized by financial deregulation, privatization, and the retraction of government responsibility for social welfare (Brown, 2015; Harvey, 2005; M.B. Katz, 2013; Ong, 2006; Schram, 2015; Wacquant, 2009). The resultant political-economic configuration is referred to as neoliberalism. This constriction of welfare for non-disabled individuals, however, has

left federal disability benefits as the last form of substantial government cash assistance available to many indigent US adults—obtained through either Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) (Hansen et al., 2014; Knight, 2015; Wen, 2010). SSI is a welfare program administered by the Social Security Administration (SSA) that requires no work history of recipients, who must be either aged over 65 years, blind, or disabled to access cash assistance. The SSA defines disability as having a medical condition that (1) prevents the individual from doing their work, (2) prevents them from adjusting to other work, and (3) is expected to last for at least one year or result in death (SSA, 2016b). SSDI is a social insurance program for disability supported by Social Security tax deposit withdrawals from monthly paychecks, also administered by the SSA. Eligibility is dependent on having a work history of certain length, determined by the applicant's age.

The number of working-age adults (aged 18–64 years) enrolled in these two programs has grown significantly in the last two decades (SSA, 2015). While this is likely driven in part by the increasing prevalence of chronic illness in the US (Bodenheimer et al., 2009), it also gives weight to recent claims that a ‘medicalization of poverty’ is occurring here, as diagnoses of disabling chronic illness represent increasingly prominent and important gateways to cash assistance for individuals in need (Hansen et al., 2014; Knight, 2015; Wen, 2010). The associated shift in visibility from welfare to disability benefits, however, has been accompanied by a rise in stigmatizing public discourses on ‘disability fraudsters’ and ‘malingerers’ (Fox News, 2014; Karlinsky et al., 2014; Kessler, 2015; The Wall Street Journal, 2014), who have replaced welfare dependents as the latest manifestation of the recurring specter of the ‘undeserving poor’ (Hansen et al., 2014). This most recent rhetoric, relatively under-researched in the US context, mirrors well-documented depictions of ‘benefit cheats’ and ‘scroungers’ in the United Kingdom (Baumberg, 2016; Garthwaite, 2011; Patrick, 2016), thereby perpetuating a stigmatizing, transatlantic preoccupation with deservingness originally imported from England that traces back to the Elizabethan Poor Law (Schram, 2015). Moreover, as with welfare in the 1990's, these discourses are reflected in how disability policy is implemented. The SSA's current anti-fraud strategy comprises eighteen separate components—including regulations and sanctions, national review committees, specialized investigation and prosecution units, and research efforts into psychological testing and symptom evaluation—to identify and discourage fraud, many of which have been enacted over the past few years (SSA, 2016a).

Few studies, however, have investigated the lived experience of receiving disability benefits in today's US, particularly among individuals living with a chronic physical health condition. Specifically, it has not been asked how the post-reform disability benefits system, as well as its associated stigmatizing discourses, shapes the lived experience of chronic, physical illness. Here we use qualitative data from individuals living with HIV and/or type 2 diabetes mellitus (T2DM) in the San Francisco Bay Area to examine these relationships within populations living with two important chronic illnesses in the US, both of which can lead to disability. Chronic HIV infection can have various systemic effects including chronic diarrhea, wasting, fatigue, and neuropathy, and also increases the risk of cardiovascular disease and other chronic diseases in the long-term. Poorly controlled T2DM can lead to neuropathy, kidney failure, retinal damage, and cardiovascular disease, and is a leading

cause of amputations in the US. Any of these sequelae may cause bodily impairment, activity limitation, or participation restriction. Work-limiting disability results when any such consequences occur *and* negatively interact with contextual factors (environmental and personal factors) to prevent the individual from carrying out their work or adjusting to other work (World Health Organization, 2002). In the US, class, race, and other social factors strongly affect the development and progression of chronic illness and disability. Both HIV and T2DM disproportionately burden poor and ethnic minority individuals—particularly African Americans—who also have worse access to healthcare, accelerating the onset of chronic disease-related disability among these populations (Pellowski et al., 2013).

1.1. Theorizing stigma

Our research draws on theoretical frameworks from the literature on stigma. Stigma is the convergent process of labeling, stereotyping, separating, and discriminating against individuals possessing a particular attribute by stigmatizers with access to social, political, and/or economic power (Mahajan et al., 2008). It takes enacted, felt/anticipated, and internalized forms (Turan et al., 2017). Enacted stigma describes acts of hostility or discrimination towards individuals possessing a stigmatized attribute. Felt/anticipated stigma is the anticipatory fear among such individuals of being subjected to enacted stigma. Internalized stigma occurs when individuals with a stigmatized attribute come to accept these attitudes as natural and valid, thereby developing negative self-perceptions and feelings of shame (Turan et al., 2017). Here we also employ the concept of structural stigma, which is defined as “societal-level conditions, cultural norms, and institutional policies that constrain the opportunities, resources, and wellbeing of the stigmatized” (Hatzenbuehler and Link, 2014, p. 2). This concept extends understanding of stigma beyond an interpersonal phenomenon, demonstrating how it is not only created and propagated within networks of individuals but also embedded in broader macro-social arrangements (Hatzenbuehler and Link, 2014; Link and Phelan, 2001). Related is the concept of intersectional stigma, which draws on intersectionality theory to reject isolated understandings of stigma. Intersectional stigma instead provides a framework for understanding how stigma interacts with other axes of social oppression to produce unique experiences among stigmatized individuals—as occurs, for example, when stigmas of disease are superimposed onto social hierarchies of gender, race, class, and sexual orientation (Collins et al., 2008; Logie et al., 2011; Wyatt et al., 2013).

HIV infection has a long, well-documented history of stigmatization in the US, beginning with its origins among the gay community, intravenous drug users, and Haitian immigrants in the early 1980's (Castro and Farmer, 2005). HIV-related stigma has persisted throughout the American epidemic, with serious negative implications for prevention and treatment efforts (Mahajan et al., 2008). In contrast, research has only recently begun to explore stigma associated with T2DM, which largely centers on the perception that it is self-inflicted through poor lifestyle choices (Schabert et al., 2013). No studies, however, have examined how shifts in government assistance policy have shaped the lived experience of disability and stigma among individuals living long-term with these conditions.

2. Methods

2.1. Research collaboration and setting

Our study was part of a research collaboration between the University of California, San Francisco (UCSF) and Project Open Hand (POH), a community-based non-profit organization in the Bay Area. POH provides food assistance to low-income residents of San Francisco and Alameda County (which includes Oakland, Berkeley, and several other cities) suffering from chronic illnesses, including HIV and T2DM. All POH clients have a physician-certified diagnosis. Most either have Medicaid and/or access healthcare free at the point-of-care via Bay Area safety net institutions (e.g. Ward 86 at San Francisco General Hospital) or payers of last resort such as Ryan White and the AIDS Drug Assistance Program (ADAP). Many receive SSI and/or SSDI, and also support from other components of the social safety net. These include public institutions such as GA (if ineligible for or awaiting a decision on SSI/SSDI), TANF ('CalWORKs' in California), public housing assistance initiatives (e.g. Section Eight and public housing authority low-income housing), and the Supplemental Nutrition Assistance Program (SNAP; 'CalFresh' in California, known as 'food stamps'). Provision of GA is the prerogative of the county in California. San Francisco (both a city and a county) previously had one of the most financially generous GA programs nationwide, providing \$320–395/month to recipients. The 'Care Not Cash' reforms of 2004, however, cut financial assistance by 85% to \$57/month for all except the street homeless (closer to Alameda County's GA of \$27/month), channeling funds into supportive housing and mental health services instead (Gowan, 2010). In California, SSI includes a payment in lieu of SNAP benefits. Therefore SSI recipients may not additionally apply for Cal-Fresh. Individuals receiving SSDI alone, conversely, remain eligible for CalFresh. In addition, most POH clients receive support from various local private institutions, including non-profit organizations providing financial, housing, and food assistance.

2.2. Study population

In June 2014, POH initiated a new food assistance pilot program named Food = Medicine for selected clients living with HIV and/or T2DM. While POH has a long-standing history of serving HIV-positive individuals, the Food = Medicine program was extended to people with T2DM because of the known associations between food insecurity and worse T2DM health outcomes (Weiser et al., 2015). Our study population was drawn from individuals recruited into this new program. Individuals enrolled in the Food = Medicine program had been selected by POH from their existing client base with the criteria of having HIV and/or T2DM, and being an adult (>18 years old), English- or Spanish-speaking, and low-income (<300% of the Federal Poverty Line). For individuals who had been a POH client for >6 months, POH added a criterion of >75% service adherence (percentage of weekly meal packages picked up) to maximize intervention fidelity. POH also aimed to maximize diversity of race/ethnicity, illness severity, and geographical location in the program population, recruiting on a rolling basis during April–October 2014.

2.3. Recruitment strategy

All POH clients enrolled in the Food = Medicine program who had given permission to be approached for inclusion in our study were invited to participate via phone. The only inclusion criterion was being enrolled in the Food = Medicine program. There were no exclusion criteria. We recruited on a rolling basis throughout data collection until we reached saturation of ideas.

2.4. Data collection

Semi-structured in-depth interviews were conducted with 64 study participants during April–December 2014. Demographic information was collected prior to the interviews on gender, sex, race/ ethnicity, education, housing, and marital status. Interviews were then conducted in English by either a medical/graduate student (HJW) or a Master's-level research assistant (NAR), both trained in qualitative methods by UCSF faculty members experienced in qualitative research (KP, SDW). A graduate-level research assistant was also present to take fieldnotes during 18 of the interviews, which were conducted either at POH's offices in San Francisco and Oakland or at participants' homes. Aside from the researcher(s) and respondent, no one else was present during the interviews. Prior to each interview it was made clear to participants that the researchers were separate from and independent of POH. Participants knew none of the researchers previously.

Interviews followed an interview guide built around pre-identified domains of interest including financial and living situation, food security, physical and mental health, sexual behavior, health behavior, engagement in care, and perceptions of POH among participants. Questions related to interactions with social institutions explored sources and adequacy of finances, housing, access to rent subsidies, and experiences with food assistance, with the interviewers probing for perceptions of the institutions involved. Questions related to the lived experience of chronic illness explored perceptions of living with HIV and/or T2DM, experiences with adherence to medications and care, times of stress, anxiety, and depression, experiences with food insecurity, and perceptions of the neighborhood and community. In addition to pre-identified domains, interviews also allowed room to follow unanticipated directions of inquiry. Six researchers (including HJW, KP, NAR, SDW) developed the guide iteratively, fine-tuning it until consensus. Interviews lasted between 45 and 165 min (average 90 min) and were audio-recorded with permission from participants. Recordings were later transcribed verbatim. Participants were provided with \$20 cash at the end of their interview.

2.5. Data analysis

The methodology underpinning data analysis was thematic content analysis (Weber, 1990), following an integrative inductive-deductive approach (Bradley et al., 2007). Six researchers (including HJW, KP, NAR, SDW) developed a list of codes during data collection, drawing from both the literature and the data as it was being gathered. This approach permitted us to organize our codes around previous empirical data on the relationship between food insecurity and chronic illness (the original focus of the overall study) (Weiser et al., 2015), while also leaving room for new codes to emerge from the interview transcripts, which were read and discussed by the research team as the interviews were conducted. This process produced a list of codes that was subsequently discussed and refined into a codebook

consisting of primary codes and one level of sub-codes. The researchers then coded the interview transcripts using the qualitative text management software Dedoose. Independent double-coding was conducted at predetermined intervals such that approximately one-third of the interviews were double-coded. Discrepancies were discussed until consensus to validate the codebook and maximize coding reliability. Finally, excerpts were reviewed in their original context by the researchers, who discussed the data until consensus to identify salient themes. Selected quotations were chosen to illustrate key themes and sub-themes, and are presented here with pseudonyms.

2.6. Ethics statement

The Committee on Human Research at UCSF granted this study ethical approval in January 2014. Participation in the Food = Medicine program was not contingent on enrolment in this study, which was entirely voluntary and had no effect on the relationship between POH and the participant. We obtained informed written consent from all study participants.

3. Results

Twenty-seven participants had HIV but not T2DM; 26 had T2DM but not HIV; and 11 had both HIV and T2DM (Table 1). Roughly two-thirds were men, and roughly two-thirds lived in San Francisco. The largest racial/ethnic group was Black/African American. Most participants had some post-high school education, were living in an apartment/house, and were not partnered. These demographics are broadly representative of POH's client base. In the interviews, it emerged that the majority of participants received disability benefits, most commonly SSI, as their primary income. Many also received housing and food assistance from other public and private institutions, most commonly as rent subsidies and food provision, respectively. A substantial number were enrolled in CalFresh. Despite this, most participants had experienced long-term food insecurity. Many had previously been homeless. With regard to the lived experience of disabling physical illness, two key themes emerged: (1) challenging interactions with social institutions; and (2) experiences with stigma. We did not note any substantial differences in either theme between participants living with HIV vs. T2DM or SSI vs. SSDI.

3.1. Challenging interactions with social institutions

A major theme emerging from the interviews was the experience of bureaucracy as a complex and challenging force in participants' lives. The bureaucracy most often generating such challenges was that of the public social safety net, including government financial, housing, and food assistance institutions.

There were several subthemes. First, participants displayed misunderstandings about the type of assistance they were receiving and the eligibility criteria for disability benefits and food stamps. Many were unaware of the difference between SSI and SSDI; individuals enrolled in either program often referred to their income as "social security". Participants on SSI frequently reported not understanding why they received no CalFresh benefits. Conversely, some participants on SSDI incorrectly perceived that they were ineligible for CalFresh because they were receiving SSDI. These misunderstandings appeared to be rooted

both in the complexity of the different categories of disability benefits and in the information provided by employees of the institutions involved, which was often described as inconsistent and vague (especially from the SSA):

“I don't think anything of [the SSA]. They don't know what they're doing over there. They'll send you a letter and you'll give it to them and ask them to explain it, and they'll explain it, and then you'll take it to another worker and ask them to explain it, they'll tell you totally something different. Each person will tell you something different about that letter. They don't know what the hell they're doing. . . . It's always unclear. You never know.

” – Jose (HIV)

Second, participants articulated perceptions of certain institutions providing them with assistance as being obstructive, penalizing, and/or uncompassionate. This arose most frequently from interactions with the SSA when trying to obtain disability benefits. Such views did not, however, usually relate to the behavior of specific employees. Instead, the cumulative experience of bureaucratic delays, rejections, and having to assemble sufficient paperwork to repeatedly prove eligibility had left participants with a strong negative impression of the overarching institutions and regulations. Many individuals described the timeframe between the onset of work-limiting disability and being granted SSI or SSDI in terms of months or years, which strongly contributed to these negative perceptions. When talking about their experiences with rejection during such periods, participants were more likely to evoke deliberate or arbitrary obstruction on the part of the SSA than their own failure to meet technical criteria:

“You have to almost walk into that place with your skin falling off and stuff. I mean, we had like this much documentation; you shouldn't have to go through that many hoops for stuff like that. I mean we pay into that, you know, from working, and you should get it when you need it. If you get sick and you need it, give it to the person! It's a valid sickness and you can see it and the doctor says it—give it out! I don't understand the bureaucracy and the hoops and the stuff and the red tape and the bullshit. You should not be persecuting the sick and the poor.”

– Demarco (HIV)

Such experiences had concrete effects on the lives of participants, many of whom described periods of entrapment in destitution while various institutions processed their cases:

“The shit that Social Security puts a person through, and you can type that word ‘shit’ in there, is inhumane. The first thing, they deny you. Then you wait two-and-a-half years. The waiting period is, like, ridiculous. You know, and all these hoops you have to jump through. Well, in that period of time that you're waiting, some of us can't work. And there it went. So I went from fantastic with a totally cool income, living in my own home, and I do mean home, having everything, to that. . . . I went to \$80, \$86 a month, actually, in cash [GA], you know, and food stamps of \$127, or something like that. Those food stamps were very handy. But needless to say, I was on the street, and so on and so forth.”

– Brian (T2DM)

“I never thought I would be homeless. . . . It was a bad struggle, you know? I slept in cars. I slept in shelters. I didn't like being around different people, but I had no choice because I didn't wanna be in the rain, the cold and stuff. I was like, ‘Uh-uh. Once I get on this SSI, I am never going to be on the street ever again.’”

– Alondra (HIV)

Moreover, participants explained how such experiences with destitution could erect barriers to returning to work. One individual, Scott, described waiting for three years for SSI and housing claims to come to fruition after his health deteriorated and he lost his job. This delay period, during which he received only GA, rendered him homeless. With no social or financial support, he considered trying to re-enter the labor market. Doing this while destitute, however, proved too difficult:

“If you don't have a place to live and you don't have food to eat, you can't do anything. I mean like even if like you're trying to apply for a job or interview, if you don't have a place to get ready or a place—you have to eat breakfast and you can't do it. You cannot do it. It's not, it's not feasible. I mean it's not doable.”

— Scott (HIV)

Finally, these bureaucratic challenges did not always end once applications were approved. Participants who had successfully applied for and were receiving disability benefits described bureaucratic run-arounds and instances of being erroneously cut off from their cash assistance or asked to re-certify their cases, which, again, took time. A typical example involves a participant with HIV and T2DM, Jermaine, who described having his benefits cut off after the SSA misclassified receipt of a county direct-to-landlord rent subsidy program as undeclared private income. Jermaine was told he owed the SSA \$5,200, and had to hire a lawyer to have the debt cancelled. Following this, the SSA asked him to file a new application in order to get his disability benefits reinstated. He refused to, asserting that this would prevent him from receiving the erroneously cancelled payments in arrears. At the time of our interview, Jermaine had had his benefits reinstated but was still awaiting retroactive reimbursement for the error.

Similar to the lengthy application process, losing benefits as a result of re-certification requirements or bureaucratic errors could have serious negative consequences for the wellbeing of participants:

“It's hard to just be stable-minded knowing that I don't have no job. You know, I got a lot of kind of crazy shit been happening to me. Like, Social Security had me deceased ever since 2002 until I just got it settled. . . . But, they still, like, kind of owe me back-time, and they're still giving me a problem with that. That's one problem that I have and stuff, and that's the only thing I'm trying to work on to try to keep my mind on what they're going to do with me. . . . My life wasn't no great life. It's just I was trying my best to make it a great life. It's just when this here happened to me with my foot [amputation] and everything, and the pain, and knowing that I was ‘deceased’, and all of that hit me at one time, I didn't know how to control the situation. So I've been working on it. Just been working on it. I don't know how to, you know, end this, but I just try my best. Talking to my lawyer and

everything. Hoping that I can wake up the next day without any bad emotion coming to me because I don't know what's going to happen when I talk to people and stuff, and they ask me something and then it just get me too emotional where I just physically cry. I just can't take it.”

– Izaak (T2DM)

3.2. Experiences with stigma

In the second major theme, participants described in detail how living with physical disability had led to them experiencing different forms of stigma. Again, several sub-themes emerged. First, participants described interpersonal experiences of enacted and felt/anticipated stigma associated with living with disabling chronic illness. Participants explained how the long-term experience of living with ongoing health problems marked them out as different from healthy individuals:

“[When you have a disability] you get put in the leper colony. Okay? You get put in a caste of people that's below everything. Okay? And that's why most people, once they become disabled, they become very, very secretive about their disability, because they know if somebody found out about it, they would lose everything. . . . And a lot of times people don't even want to stay in the same room with somebody that has a disability. And that becomes a problem. And I've experienced that many times. You know, as soon as they find out a person in the room has a disability they turn around and half the people made an excuse about why they were going to do this, that, and the other and they never come back. And you know it's because they don't want to be around a disabled person.”

– Carlton (HIV)

However, juxtaposed with this interpersonal stigma of disability was another form of stigma related to the social institutions described above. This second form of stigma was rooted in the perception among participants that others viewed them as lazy or immoral for living on government payments:

“You know, when I go online or whatever, you know, there's this sort of . . . feeling—I call it the land of the sick and the land of the healthy. In the land of the healthy, they think if you're sick and you're not getting better and you're not actually dying to a certain timetable, you're somehow shirking. You know, you're winning one over. I actually dated a guy for a while, and I was telling him about, you know, like Social Security and all this stuff, and he was like, ‘[Sighs], you don't even have to work.’ And I remember saying to him, ‘I will gladly trade you HIV for having to work.’”

– Gustavo (HIV + T2DM)

Participants therefore explained how they were, on the one hand, stigmatized as disabled because they were incapacitated by chronic illness and, on the other, stigmatized as shirkers and malingerers for claiming government support as a result. Some participants internalized this stigma of shirking, describing feelings of inadequacy, dishonesty, and shame at not being able to support themselves financially:

“It's heartbreaking, you feel like a failure. You feel like you can't take care of yourself. It can kind of take away your esteem, you know? It kind of belittles you. You know, one step could push you to begging on the street. You think about all that. It's not easy.

” — Curtis (HIV)

Participants also explained how this internalized stigma could have serious consequences, leading to refusals to seek help in times of need:

“I just didn't want to go [to POH for food] because now I'm actually publicly getting help from some entity, and people are going to know. And, you know, what does that say about me? I'm a bad person now.”

— Scott (HIV)

“It didn't bother me too much, but I saw that [shame] with other people who would actually suffer, and many died before they were supposed to die because they were just simply going to do it on their own and they didn't want to be taking any charity.”

— George (HIV)

Moreover, the stigma of shirking was enacted not only by members of the general population, but also via the bureaucratic procedures of the institutions themselves. That is, the perceived penalizing, obstructive, and uncompassionate nature of the institutions and their regulations, outlined in the first theme, precipitated and exacerbated this stigma:

“In the early part of the epidemic, there were a lot of people who really wanted to help and whatever, but this has now become career choices for people. So you kind of get, like, people who are involved in giving a service to the poor or to people with HIV, and they kind of don't want to deal with you. And they kind of want to make you jump through hoops. Again, even that feeling of, ‘You are screwing us over, you're cheating us,’ comes from the very people whose job it is to help you. I think it's a little bit worse in government institutions [than non-profit organizations].”

— Gustavo (HIV + T2DM)

In addition to these stigmas of disability, participants also described experiencing stigmas of poverty. Many participants' lives were characterized by long-term poverty, almost universally perpetuated by their disability. Sometimes, as discussed above, this poverty was the result of bureaucratic delays in gaining access to cash assistance or having paychecks temporarily cut off, which could result in destitution. Even when participants were routinely receiving disability benefits, however, monthly income was generally barely enough to cover basic living expenses, with most money used up paying high rent prices in the gentrifying Bay Area. A recurring theme among participants on disability benefits, therefore, was long-term poverty punctuated by periods of entrapment in more severe poverty and destitution. This material need in comparison to the general population was another source of stigma:

“You know, it has to be on [informal] credit [buying food from a local food truck] and then I feel like I'm disrespected because it's on credit. I'm not giving the money,

even though, you know, they know they'll get their money. But to me they kind of disrespect me and, like, I might buy something that requires a fork and a spoon but they'll just give me a fork. I have to eat my cottage cheese with a fork, you know? ... I feel like I'm disempowered. It's like, 'Oh, you owe me money so you're not going to get a spoon.'"

— Caroline (T2DM)

"I can't go out to eat with friends. I do my book club once a month, and it's \$10 for my share for where we go, and there were a few months where I just called and cancelled 'cause it was so embarrassing that I can't afford the \$10 plus the \$2 tip, you know?"

— Chantal (T2DM)

Finally, participants described how other stigmas and oppressive experiences superimposed on top of these experiences with disability and poverty could interact with and exacerbate them. The following participant explained how stigmas of HIV and poverty arising from his medical condition (the latter through the financial inadequacy of disability benefits) played out on a background of stigma attached to homosexuality:

"There's definitely still a stigma attached to people who are HIV-positive. And gay men my age, anyway, however we've tried to fight it or whatever, that childhood thing of, you know, gay being bad, it stays with you. So those are all things that kind of inform my depression. And although I'm doing fairly well at the moment, again, I can get very depressed. It's very weird though, the thing about having no money also. I'm acutely aware of how differently I'm treated because I don't have money. So all those things are isolating, basically."

— Gustavo (HIV + T2DM)

Other intersecting experiences related to gender inequality. A female participant with HIV-related disability who was dependent on SSDI, for example, described how a male acquaintance's view of her HIV diagnosis and its association with sexual transmission had prompted him to threaten physical violence against her. This threat had ultimately closed down a route to earning money through modeling, consolidating her dependence on social provision:

"Like I said, I did that billboard [for a pharmaceutical company associated with antiretroviral drugs]. I was on bus benches, billboards, in barbershops, beauty salons, yeah. And posters and stuff. And an old friend of mine told me, he said, 'Uh, I thought I saw you on a poster for HIV. And you could've gave that to one of my homeboys. And if I find out you got it, I'm gonna kill you.' And he was a super thug. So I was scared. I still had a year left to go on my contract with [the pharmaceutical company], and I said that I wasn't gonna do it again, do it anymore. I wasn't gonna do it, you know?"

— Marla (HIV)

A final form arose from racism. One participant gave an example from her old job, where she was denied worker's compensation after a workplace injury. The implication in the

rejection was that she was malingering. She perceived this claim was rooted in racial prejudice and racist stereotyping on the part of her former employers:

“I’m Native American. People say racist things every day. And on my job, I experienced racism. It’s just daily. These are supposedly teachers, administrators, whatever. The most ignorant people I’ve ever come across. But, you know, they just would say things. They would treat me bad. And other people were aware of this, and then one day, I got injured on the job. Some kids had gotten into a fight. And I went down the hillside and twisted my neck. And got a herniated disc. Well, of course, they were saying that I was just some lazy Indian. And they didn’t want to give me, really, any medical help, through Worker’s Comp or anything. But this had been prevalent, and gone on, and on, and on, for years.”

– Karen (T2DM)

4. Discussion

Our participants were low-income individuals living with HIV and/or T2DM, whose physical health had, in most cases, granted them access to SSI and/or SSDI for work-limiting disability. Collectively, they described salient experiences with challenging bureaucracy from social institutions, both when applying for disability benefits and in being cut off from paychecks or forced to re-certify their cases. These experiences led to widespread perceptions of the institutions involved, particularly the SSA, as incompetent, obstructive, uncompassionate, and/or penalizing—views more frequently aimed at the regulations and structures characterizing the institutions and programs rather than specific employees. Bureaucratic challenges had concrete effects on participants’ lives by trapping them in destitution (sometimes for months or years), eroding their mental health, and contributing to widespread stigmatization. To our knowledge, this study is the first to document in depth this interconnected web of poverty and stigma centered on the receipt of disability benefits among individuals with chronic, work-limiting poor physical health.

4.1. Bureaucracy and stigma in the American neoliberal state

This lived experience of convoluted, inflexible, and obstructive bureaucracy in social institutions, perceived to be deliberately penalizing, is consistent with previously described neoliberal trends in US policy-making and statecraft enacted over the past three decades (M.B. Katz, 2013; Schram, 2015; Wacquant, 2009). As cuts and restrictive reforms to social institutions rolled forward, including those to the old welfare and GA programs, remaining social institutions have realigned to adopt more penalizing and restrictive techniques of governance (Schram, 2015; Wacquant, 2012). This has led to the paradoxical state of affairs whereby for those impoverished American citizens dependent on government social institutions, life in the neoliberal state becomes, rather than *laissez-faire* and free from government interference, punitively paternalistic and overregulated (Schram, 2015; Wacquant, 2012). While this phenomenon has been under-researched in the context of disability benefits, it emerged here clearly in the narratives of our participants, who described struggling for months or years to assemble sufficient paperwork so that they could

prove eligibility for disability benefits—often while they fell into destitution—sometimes only to be faced with further contestations or requirements for re-certification.

Our findings further extend the previous literature by demonstrating how this intense bureaucratic oversight adds to the complex landscape of stigmatization navigated by chronically ill individuals. Participants explained how, on the one hand, they were stigmatized for having to cope long-term with disabling chronic illness, which isolated them from healthier individuals. Yet on the other hand, their attempts to seek financial stability in this condition, by applying for government disability benefits, resulted in a stigma of shirking and malingering. This latter stigma was rooted in the perception, sometimes internalized, that others viewed them as lazy or immoral for living off the state. Notably, the administering institutions exacerbated this stigmatization through their complex and inflexible bureaucratic procedures. These findings echo previous data on stigma among SSI claimants for mental illness (Hansen et al., 2014), as well as prominent public discourses on disability fraud and malingering that have arisen over the past two decades (Fox News, 2014; Karlinsky et al., 2014; Kessler, 2015; The Wall Street Journal, 2014).

These two themes characterizing the lived experience of work-limiting physical illness here—intrusive, obstructive bureaucracy and structural stigmatization—therefore emerge as the collateral damage arising from two key logics anchoring the American neoliberal state: (1) the historical retraction of protective welfare for re-deployment as disciplinary workfare; and (2) responsabilization as a key cultural trope of neoliberal governance (Brown, 2015; Schram, 2015; Wacquant, 2012). Under these logics, limited social programs representing some of the last bastions of protective government cash assistance (i.e. SSI and SSDI) can be extended only to the most in need and deserving. This restriction, paradoxically, prompts complex bureaucratic efforts to identify such individuals among ‘less deserving’ applicants, feeding stigmatization of recipients (and would-be recipients) as fraudsters, shirkers, and malingerers in the process.

Finally, the insights garnered from taking an intersectional approach further nuance this picture. Previous studies attest to the intersectional stigma faced by many people living with HIV, whose stigmatization on the basis of their illness is also shaped by poverty, race, gender, sexual orientation, and other social factors (Collins et al., 2008; Logie et al., 2011; Wyatt et al., 2013). Research is starting to explore similar questions among people with T2DM (Schabert et al., 2013). Structural staples of American neoliberal policymaking—including widespread service privatization, public sector cuts, financial deregulation, welfare retraction, and hyper-incarceration of African American males—have also been charged with exacerbating inequalities along many of these lines (Harvey, 2005; Knight, 2015; Wacquant, 2009). In accordance, social hierarchies of wealth, race, gender, and sexual orientation were all salient in our data. These enduring axes of inequality and oppression that permeate American society—and which were historically embedded in and integral to previous embodiments of the undeserving poor such as the ‘welfare queen’ (Gustafson, 2011; M.B. Katz, 2013)—are thereby revealed as equally key constituents of this most recent stigmatizing categorization.

4.2. The future of US social provision?

All bureaucracies, in order to operate, impose more rigid schemata and finite categorizations onto complex lived experiences. Our findings, however, illuminate the profound collateral damage wrought by this process in the context of work-limiting disability in today's US. Destitution, stigmatization, and aggravated mental illness emerged here as direct consequences of a neoliberal bureaucracy seemingly more concerned with fraud prevention than the distribution of disability benefits. These effects may be compounded by decreased medication adherence, poor self-care, and worsened health outcomes, all of which are associated with stigma in both HIV (I.T. Katz et al., 2013; Mahajan et al., 2008) and T2DM (Kato et al., 2016; Schabert et al., 2013).

Taken together, these consequences amount to what has previously been argued is a differential disenfranchisement from fully realized citizenship (Brown, 2015; Ong, 2006; Sparke, 2017). That is, our participants' narratives identify them as a population structurally excluded from (1) the benefits of economic growth and capital accumulation made possible by neoliberalism (Ong, 2006), (2) the rights of protection and security historically afforded to political subjects of liberal democracy (Brown, 2015), and (3) the capacity for active health management and expectations of health and wellbeing that are collectively referred to as 'biological citizenship' (Sparke, 2017). Moreover, the central role of government bureaucracy in the findings underlines that these exclusions occur not simply through the workings of the free market, but via sovereign political decisions made by representatives of the US state (Ong, 2006). They can therefore be understood as a *de facto* expulsion of marginalized, impoverished, chronically ill individuals, valued to possess little human capital (Brown, 2015), from the full economic, political, and biological citizenship experienced by their healthier, wealthier, more privileged counterparts (Sassen, 2014)—who increasingly surround them in the gentrifying Bay Area (Whittle et al., 2015). This was particularly clear for those participants facing multiple intersecting forces of social oppression, whose narratives show just how much they felt pushed into outcast status by poverty, homophobia, racism, and gender-based violence in addition to disabling illness.

This insight has important implications. First, the destitution, homelessness, stigma, mental illness, and poor chronic disease management associated with this conception of sub-citizenship have strong negative health consequences for the individuals concerned (Pellowski et al., 2013). Second, the health and social complications thus generated are likely to entangle the affected individuals in further bureaucratic complexities—all at additional cost to the public social safety net via Medicaid, Ryan White, SNAP, public housing assistance, legal aid, and other social programs. The neoliberal social policies outlined here are therefore likely self-defeating even by their own economizing logic. Similarly, SSI/SSDI recipients have described the stigma of disability benefits as a factor that demoralized them from returning to the workforce, along with anxiety about losing the hard-won financial stability disability benefits bring (Gomez et al., 2016). And while experiences of excessive bureaucracy among SSI/SSDI applicants may fuel greater urgency to rejoin the workforce (Gomez et al., 2016), our findings demonstrate how this bureaucracy can limit the ability to act on that very urgency if it directly leads to destitution and further ill health.

Accordingly, this study has three principal policy implications. The first is aimed at the public institutions themselves, which, at the very minimum, should build into their operations targeted staff training and clearly identifiable policies regarding minimizing stigma and avoiding unnecessary harmful delays. The second concerns vocational rehabilitation programs for people with chronic illnesses, which are an increasing focus of social policy research (Gomez et al., 2016). While these provide a critical resource for out-of-work patients, they must avoid reproducing the responsabilizing, stigmatizing logic of neoliberal governance discussed here. Only if carried out in strictly non-punitive ways that provide protection from destitution and stigmatization—e.g. by operating alongside additional advice, representation, and advocacy services for disability, as did a recently evaluated program for HIV-positive individuals (Gomez et al., 2016)—can they avoid reinforcing such collateral damage. The third implication pertains to more radical current thinking around welfare and social insurance policy. One approach soon to be tested in pilot programs in Europe and North America, for example, is to guarantee a non-means-tested, universal minimum basic income to all citizens (Henley, 2017). While a full discussion of the promises and complexities of this idea is beyond the scope of this paper, the issues examined in this study will have important implications for program design and implementation. They must be carefully considered here as well as in other avenues of exploratory future research on social provision.

4.3. Limitations

Our study has limitations. First, we recruited from a population receiving private food assistance, which may have selected for individuals with a history of difficult experiences with public institutions. Second, the Food = Medicine program selected for good historical adherence to POH services among long-term clients, and did not allow a delivery option for homebound clients. Therefore the findings may not be applicable to important populations not represented in our sample, including people with more severe disabilities and others who struggle with adherence to such programs. Third, the original focus of our overall study was the interaction between food insecurity and chronic illness. The data presented here emerged unanticipated in the interviews. While this speaks to the salience of the above themes, our interview guide was not specifically primed to explore the SSI and SSDI programs in detail, meaning we may have missed aspects of the issues discussed.

5. Conclusion

Collectively, our findings document a complex web of intersectional stigma and disenfranchisement among chronically ill individuals living with HIV and/or T2DM in the San Francisco Bay Area. Core to this web is a form of structural stigma illuminated by this study that is embedded in, and enacted through, the rigid bureaucratic procedures of social institutions, reflecting prominent public stigmatization of SSI and SSDI recipients. Maximizing the effectiveness of disability benefits while minimizing stigma and the collateral damage of eligibility criteria remains an ongoing challenge for the neoliberalized US social safety net. Considerations of stigma and potentially harmful bureaucracy should be built into current institutional frameworks, but should also inform more radical thinking around the future of public social provision.

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Table 1

Participant demographics.

	<i>n</i>	%
<i>Illness</i>		
HIV (no T2DM)	27	42
T2DM (no HIV)	26	41
HIV + T2DM	11	17
<i>Residence</i>		
San Francisco	44	69
Alameda County	20	31
<i>Age</i>		
35–49	10	16
50–64	45	70
65+	9	14
<i>Gender</i>		
Male	44	69
Female	17	27
Transwoman	1	2
Other	2	3
<i>Race/ethnicity</i>		
White/Caucasian	16	25
Black/African American	24	38
Hispanic	14	22
Native American/American Indian	4	6
Asian/Pacific Islander	2	3
Mixed/other	4	6
<i>Education</i>		
Less than high school/GED	10	16
High school/GED	15	23
More than high school/GED	39	61
<i>Housing</i>		
Apartment/house	46	72
SRO/nightly hotel	12	19
Staying with friends/relatives	3	5
Other	3	5
<i>Partnered</i>		
Not partnered	53	83
Partnered	11	17