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# Precarity and health: Theorizing the intersection of multiple material-need insecurities, stigma, and illness among women in the United States

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## Abstract

Material-need insecurities (including insecurities in basic resources such as income, food, housing, and healthcare) are widespread in the United States (US) and may be important predictors of poor

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Author Contributions

**Henry J. Whittle:** Conceptualization, Methodology, Formal analysis, Writing – original draft. **Anna M. Leddy:** Conceptualization, Methodology, Investigation, Formal analysis, Writing – review & editing. **Jacqueline Shieh:** Investigation, Formal analysis, Writing – review & editing. **Phyllis C. Tien:** Resources, Writing – review & editing. **Ighovwerha Ofotokun:** Resources, Writing – review & editing. **Adaora A. Adimora:** Resources, Writing – review & editing. **Janet M. Turan:** Writing – review & editing. **Edward A. Frongillo:** Supervision, Writing – review & editing. **Bulent Turan:** Supervision, Writing – review & editing. **Sheri D. Weiser:** Supervision, Conceptualization, Funding acquisition, Methodology, Resources, Writing – review & editing.

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health outcomes. How material-need insecurities besides food insecurity are experienced, however, remains under-researched, including how multiple material-need insecurities might intersect and converge on the individual. Here we used qualitative methods to investigate experiences with multiple material-need insecurities among 38 food-insecure women aged over 50 years living with or at risk for HIV in the US. Our aims were: (1) to understand the co-experience of material-need insecurities beyond food insecurity; (2) to elucidate how multiple material-need insecurities might intersect; and (3) to discover how this intersection might be detrimental to health. During November 2017-July 2018, we conducted semi-structured interviews at three sites across the US (Northern California, Georgia, North Carolina) and analyzed the data using an inductive-deductive approach. We identified a common and complex picture of multiple material-need insecurities, stigma, and illness among participants across all three sites. There were five primary themes: (1) insecure income arising from a combination of precarious wage labor and federal disability benefits; (2) resultant experiences of *uncertainty*, compromised *quality*, *insufficiency*, and having to use *socially unacceptable coping strategies* across finances, food, housing, and healthcare; (3) participants' disempowerment arising from their engagement with social safety net institutions; (4) closely related experiences of intersectional stigma and discrimination; and (5) negative implications for health across a wide range of illnesses. By employing the sociological concept of precarity—a term denoting the contemporary convergence of insecure wage labor and retraction of the welfare state—we combine these themes into a unifying framework of precarity and health. This framework may prove useful for testing how the widespread intersection of multiple material-need insecurities interacts with stigma and discrimination to negatively impact physical and mental health.

### Keywords

United States; precarity; insecurity; food; housing; healthcare; health insurance; disability

## Introduction

Current indicators in the United States (US) show that a substantial proportion of the population lives in conditions either characterized by or bordering on material deprivation. During 2000–2015 the population living below 200% of the Federal Poverty Line grew by 25 million to total 106 million people, at over twice the rate of the nation's population growth (PolicyLink & USC PERE, 2018). In 2017, the US Department of Agriculture, which annually measures food insecurity (a term that denotes a spectrum of poverty-related problems with disrupted food intake and eating patterns) (Weiser, et al., 2015), counted 40 million food-insecure people in the US (12.5% of the population) (Coleman-Jensen, et al., 2018). In 2018, 38 million households paid over 30% of their income on housing costs (a standardized definition of poor affordability), representing 30% of all US households (Joint Center for Housing Studies, 2018). This percentage of households experiencing some kind of housing need rises to 35% if homeless individuals and overcrowded households are additionally taken into account, and even higher if those with poor housing/neighborhood quality or safety are included (Cox, et al., 2017). In 2018, there was not a single US state, metropolitan area, or county where a worker earning the prevailing federal or state minimum wage for a 40-hour week could afford a two-bedroom rental home at market rent (National

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Low Income Housing Coalition, 2018). Furthermore, 28.5 million people in the US (8.8% of the population) lack health insurance (Berchick, et al., 2018), and double this number report not being able to afford the healthcare or medications they or their family need (Jones & Nekvasil, 2016).

The impacts that material deprivation has on health have long been studied in the socio-medical sciences. In medical anthropology and sociology in particular, the intersection of multiple vulnerabilities has been a prominent focus of recent research, theorized under such terms as “structural vulnerability” (Quesada, et al., 2011), “precarity” (Lopez, et al., 2018), “hypermarginality” (Comfort, et al., 2015), “severe deprivation” (Desmond, 2015), and the “risk environment” (Rhodes, 2002), among others. Using primarily ethnographic research methods, these studies have illuminated the intersection of multiple harmful experiences that constrain the life-worlds of marginalized populations in the US, including extreme poverty, racism, poor access to health and social services, stigmatization, addiction, repeated incarceration, housing instability, and interpersonal violence. The strength of these studies lies in their ability to analyze, in granular detail, how complex networks of structures and institutions position groups of individuals to be at disproportionate risk for poor health and harm via these intersecting experiences.

Public health and epidemiological research has studied many of these same social phenomena using primarily quantitative methodologies. Within this literature, conditions of material deprivation including poverty, malnutrition, homelessness, and lacking health insurance—often referred to as part of the “social determinants” (Marmot, 2015) or “fundamental causes” (Phelan, et al., 2010) of poor health—are understood to drive poor health outcomes. Yet, in social epidemiological studies, the issues listed above are increasingly conceptualized as only the most extreme forms of a wider collection of related challenges. Food insecurity, for example, moves beyond malnutrition to encompass distinct but closely related experiences including inadequate quantity of food, poor diet quality, uncertainty around accessing food, and having to engage in socially unacceptable procurement of food (e.g. stealing or exchanging sex for food) (Weiser, et al., 2015). People experiencing food insecurity face any or all of these challenges at different times. Even milder forms of food insecurity (such as persistent uncertainty around food access) are associated with poor health outcomes in quantitative studies, suggesting that just the threat of hunger confers a differential disadvantage to health (Weiser, et al., 2015).

Other domains of basic need are beginning to be characterized in analogous fashion in epidemiological studies as “material-need insecurities” (Berkowitz, et al., 2015). Ongoing efforts to develop a standardized measure of housing insecurity, for example, identify seven components that might fall under its definition, including homelessness, overcrowding, living in unsafe structures, substandard quality of interiors, living in an unsafe neighborhood, and poor quality of the neighborhood environment (Cox, et al., 2017). Other housing research focuses on “energy insecurity”: the inability to adequately meet basic household energy needs (such as gas, electricity, heating, and water) (Hernandez, 2016). Employment insecurity and debt have been implicated as social determinants of health (Sweet, et al., 2013; Virtanen, et al., 2013), while other studies employ measures of

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subjective financial insecurity (Niedzwiedz, et al., 2017). Few studies, meanwhile, have examined subjective insecurities in access to health insurance.

Several aspects of material-need insecurities have been associated with poor health in quantitative studies. Food insecurity has been associated with poor outcomes in cardiovascular disease (CVD) (Seligman, et al., 2010), type 2 diabetes mellitus (T2DM) (Berkowitz, et al., 2018), and HIV (Spinelli, et al., 2017), as well as substance use (Whittle, Sheira, Frongillo, et al., 2019) and mental health outcomes including depression (Nagata, et al., 2019), anxiety (Whittle, Sheira, Wolfe, et al., 2019), symptoms of post-traumatic stress disorder (Whittle, Sheira, Wolfe, et al., 2019), and suicidality (Nagata, et al., 2019). The paths through which these associations arise are multiple and complex, encompassing numerous interacting biological, psychosocial, and behavioral mechanisms that converge on the individual (Weiser, et al., 2015). Various aspects of housing need have similarly been associated with poor outcomes in CVD (Vijayaraghavan, et al., 2013), T2DM (Vijayaraghavan, et al., 2011), HIV (Clemenzi-Allen, et al., 2018), substance use (Smith, et al., 2017), depression and anxiety (Burgard, et al., 2012), and suicidality (Bossarte, et al., 2013). Subjective financial insecurity has been associated with systemic cardiometabolic risk factors (Niedzwiedz, et al., 2017), while employment insecurity predisposes to CVD (Virtanen, et al., 2013), T2DM (Ferrie, et al., 2016), and depression (Kim & von dem Knesebeck, 2016).

Epidemiological research in this topic has been limited, however, by its separation of concepts shown by social science studies to be inseparably intertwined. Material-need insecurities have largely been studied separately but are likely to be closely related and fluctuate in response to changing resource demands, financial pressures, and local provisions. Exceptions include recent studies on the role of multiple material-need insecurities in T2DM (Berkowitz, et al., 2015) and the effects of the “double precarity” of employment and housing insecurity on mental health (Bentley, et al., 2019). Previous research on food insecurity specifically has demonstrated the value of mixed methods approaches to studying material-need insecurities. Qualitative insights were used to inform the original concept (Radimer, et al., 1992) and have subsequently helped to elucidate the ways in which experiences of food insecurity are detrimental to health (Whittle, et al., 2016), contributing in both cases to the development of frameworks for quantitative testing. Few qualitative studies, however, have specifically explored the experience of other material-need insecurities in the US in this manner, or specifically focused on the intersection of multiple material-need insecurities as they are conceptualized in the public health literature. While insights from social science studies have much to contribute in this respect, the complexity of their theoretical models means that further analytic work is needed to distill and translate some of these insights into a conceptual framework of material-need insecurities that can be operationalized and tested in public health and clinical research.

## Theoretical framing

In this study, we draw on the concepts of structural vulnerability and precarity to analyze the experience of multiple material-need insecurities among women in the US, to conceptually clarify (1) our understanding of other material-need insecurities beyond food insecurity, (2)

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the ways in which multiple material-need insecurities might intersect, and (3) how the intersection of these insecurities may be detrimental to health. Structural vulnerability is a concept developed from earlier theories of "structural violence", a term that describes how historically embedded social, economic, legal, cultural, and institutional structures converge to place particular groups of individuals at elevated risk for poor health (Quesada, et al., 2011). Structural vulnerability builds on this mainly political-economic concept to additionally integrate cultural and idiosyncratic sources of physical and psychological harm, and, crucially, conceptualizes the convergence of these factors as a "positionality" that can be examined from the ground up (Quesada, et al., 2011). A key insight of structural vulnerability is that such large-scale, distal forces tend to exert more subtle and insidious everyday effects on affected individuals, slowly altering perceptions, behavior, affect, and cognition in chronically harmful ways.

Within this framework, cognitive processes of internalization, self-blame, and shame play an important role, as they tend to conceal (and therefore perpetuate) the structural causes of poor health (Holmes, 2013). Studies using structural vulnerability tend to employ concepts developed from Bourdieusian sociology—particularly "symbolic violence" (Bourdieu, 2000)—to describe these internalization dynamics. Closely related, however, is the concept of "internalized stigma," which describes how stigmatized individuals come to accept stigmatizing attitudes as natural and valid, developing negative self-perceptions and feelings of shame (Turan, et al., 2017). This is contrasted with "enacted" or "felt" stigma, which refer to actual or anticipated acts of discrimination, respectively (Turan, et al., 2017). Here we opt to employ these concepts of stigma due to their frequent use in public health research, where studies have shown that health-related stigmas (such as HIV stigma) are frequently reinforced by other marginalized social identities (e.g. pertaining to gender, race/ethnicity, socioeconomic status, or sexual orientation) to negatively impact health outcomes (Turan, et al., 2017). This process of convergence and interaction, termed "intersectional stigma," has principally been developed through insights from qualitative studies (Logie, et al., 2011; Rice, et al., 2018; Whittle, et al., 2017).

The other concept we employ, precarity, was developed in European labor activist movements before being adopted by various fields of social science (Neilson & Rossiter, 2008). We employ the term here in a sociological sense, using it to refer to contemporary social and economic insecurity in certain nations (principally in Europe and North America) driven specifically by two interlinked phenomena observed during the latter 20$^{th}$ and early 21$^{st}$ centuries: (1) the post-industrial resurgence of insecure and informal labor; and (2) the political retraction of state responsibility for social welfare (Schram, 2015; Wacquant, 2009). The ideal of combining secure wage labor with a comprehensive social safety net dominated the political economy of nations such as the US in the post-war era (Katz, 2013). The well-documented dissolution of this ideal since the 1980's, in turn, has prompted recognition of the widespread economic uncertainty, anxiety, and hardship that result when the responsible institutions are weakened (Harvey, 2005; Katz, 2013; Schram, 2015; Wacquant, 2009). Used in this sense, precarity anchors this study of US women in 2017–2018 to its specific historic and geographic context, and provides an organizing framework for conceptualizing the convergence and intersection of multiple material-need insecurities.

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# Methods

## Research design and setting

Our study was a qualitative study nested within the Women's Interagency HIV Study (WIHS), a multicenter prospective cohort study of HIV-seropositive women and demographically similar HIV-seronegative women at nine sites across the US. The overall aim of the qualitative study was to investigate the community- and neighborhood-level determinants of food insecurity, as well as the links between food insecurity and health, among the older population of women enrolled in the WIHS at three different study sites: San Francisco, California; Atlanta, Georgia; and Chapel Hill, North Carolina. These three sites were chosen to cover geographically distinct areas and to provide a contrast of locations with different contexts of social welfare provision. San Francisco, for example, has a historically generous public social safety net buttressed by a comprehensive network of private social institutions. Atlanta, on the other hand, resides in a state with one of the highest poverty rates in the nation yet one of the lowest proportions of the population receiving welfare benefits, indicating a high "welfare gap". North Carolina falls between California and Georgia in most indicators of poverty and social provision.

## Study population

Around 70% of women enrolled in the WIHS are confirmed HIV-seropositive as per the study design. HIV-seronegative women must meet standard risk criteria for HIV transmission at enrollment. HIV-seropositive and -seronegative women have similar demographic characteristics. The cohort is broadly representative of the HIV epidemic among US women (where about half of women living with HIV are over the age of 50) and consists of predominantly low-income women, around two-thirds of who identify as Black/African-American. Most women enrolled at the San Francisco site live either in the city or the urbanized Bay Area, whereas women enrolled at the Atlanta and Chapel Hill sites also live in surrounding peri-urban and rural areas. To better reflect this geographic diversity we hereon refer to the sites as "Northern California", "Georgia", and "North Carolina".

## Recruitment strategy

We recruited women enrolled in the WIHS at the chosen sites who met our inclusion criteria of being classified as food-insecure by the Household Food Security Survey Module (i.e., having marginal, low, or very low food security) and being 50 years of age or older. There were no exclusion criteria. Using data available from the WIHS, we used purposive sampling to identify eligible women such that approximately two-thirds were HIV-seropositive and one third were HIV-seronegative. We recruited on a rolling basis during November 2017-July 2018, aiming for an even balance across the sites. Information on age, race/ethnicity, food security, and HIV status was made available from questionnaire data collected at regular WIHS visits 43 and 44. Local WIHS staff, who recruited participants, drew upon their knowledge of the areas to ensure we recruited participants from a range of neighborhoods.

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### Data collection

A four-person research team (including HJW, AML, and SDW) developed an interview guide designed around pre-identified domains of interest. These domains included perceptions of finances, food, housing, the neighborhood, aging, relationships with community members, coping strategies, and perceived empowerment for change. The guide was developed iteratively, fine-tuned until consensus, and then piloted in two pilot interviews (conducted by AML). Feedback from the pilot interviews was incorporated into a final interview guide. Semi-structured interviews were then conducted with 38 study participants during November 2017-July 2018, following the interview guide but also allowing room to pursue unanticipated directions of enquiry. Interviews were conducted in English by three female researchers (including AML and JS) trained in qualitative interviewing, overseen by the senior author (SDW), an HIV researcher and clinician experienced in qualitative research. Interviews were conducted at the local WIHS offices, and no one besides the interviewer and respondent was present during the interviews. None of the researchers were known to any participants prior to the research. Interviews lasted 60–120 minutes and were audio-recorded with permission from participants. Recordings were later transcribed verbatim. Participants were provided with $55 cash at the end of their interview. Throughout the research process, all interviewers and analysts took detailed notes to reflect on how their experiences, values, and identity may have influenced the data collected and how they interpreted that data. Members of the research team met regularly to discuss these notes and strategize how to take them into account for future interviews and data analysis.

### Ethics statement

The study was approved by the Institutional Review Boards of UCSF (site lead for Northern California) and the University of North Carolina at Chapel Hill (site lead for North Carolina) and by the WIHS Executive Committee. Emory University (site lead for Georgia) waived approval since the Georgia data were gathered by UCSF researchers. All study participants provided informed written consent prior to their interview. The study protocol included procedures to pause or stop the interviews if participants exhibited distress. No such procedures had to be enacted during data collection. All participants were also provided with information about local mental health services and social support resources.

### Data analysis

The methodology guiding data analysis was thematic content analysis (Krippendorff, 2004) following an inductive-deductive approach (Bradley, et al., 2007). Three researchers (HJW, AML, and JS) developed an initial codebook based on the interview guide and previous research on the lived experience of food insecurity in the US (Radimer, et al., 1992). The codebook was then iteratively refined as data collection and analysis proceeded, with new inductive codes added to reflect emergent themes. This process continued with regular discussion until consensus formed around a final codebook, consisting of codes and one level of sub-codes. Transcripts were independently coded by the same team of three researchers using the qualitative text management software Dedoose. We began by double-coding transcripts from alternate sites. Discrepancies in double coding were identified and

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discussed until consensus to validate the codebook and maximize coding reliability. We double-coded until discrepancies were minimal, such that approximately one quarter of transcripts were double-coded and the remainder single-coded. After coding, extracts were reviewed by the researchers and discussed to identify salient themes. Here we present data on material-need insecurities, stigma, and health, which mostly emerged unanticipated through inductive analysis. Selected quotations were chosen to illustrate key themes and sub-themes and are presented here with pseudonyms.

## Results

Participant demographics were broadly representative of the WIHS cohort (Table 1). Collectively across the three sites, we identified five themes pertaining to material-need insecurities, stigma, and health: (1) experiences receiving income through an interlinked, dual economy of precarious wage labor and disability income; (2) multiple material-need insecurities; (3) structural disempowerment; (4) intersectional stigma; and (5) physical and mental illness (Figure 1).

### The precarious labor-disability economy

Almost all participants described receiving income through low-income wage labor, federal disability benefits (Supplemental Security Income or Social Security Disability Insurance; SSI and SSDI, respectively), or a combination of both. For those obtaining their primary income from labor, the experience was almost uniformly insecure. Women usually described working (sometimes multiple) part-time jobs, often on informal or atypical contractual arrangements (e.g. ad hoc shifts, cash payment), sometimes during odd hours (e.g. night shifts) or past retirement age against their wishes, and mostly without access to workplace benefits including health insurance. Many women supplemented their income via the social safety net where accessible (e.g. the Supplemental Nutrition Assistance Program) or, alternatively, bank loans with accruing interest and debt.

Participants described an ever-present threat of income loss. One example comes from a woman who had previously been earning money as a driver for a rideshare app, but whose access to the app had been cut off when there was not enough money in her bank account to pay the car rental fee. Another example is from a nurse who feared for her ability to hold down her part-time employment looking after a private client, due to her own poor health. Her experience demonstrates the particular vulnerability of those living with chronic illnesses to income loss:

> Between, you know, the severe depression that I go through that’s further exacerbated by having HIV, that’s further exacerbated by all the pain that I have constantly [from severe osteoarthritis], the likelihood of me being able to hold down a job? Slim to none.
>
> —Christy (HIV+, North Carolina)

Across all three sites, accessing federal disability income often represented participants’ only chance of securing a steady, stable livelihood. Application for federal disability income, however, was described as an exceptionally cumbersome and complicated process. Most

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participants explained how they had either hired lawyers or grappled with bureaucratic requirements for sometimes years at a time before they were granted access. In the meantime, living conditions could border on destitute, as described by a participant on SSI for chronic obstructive pulmonary disease:

> [SSI] been taking care of me for about five years, now. I can remember when I wasn't getting disability, and I didn't have an income coming in, I stayed in the street a lot, to get what I needed. So I don't have to do that now.
>
> —Laura (HIV-, Georgia)

Similarly, some participants who had been granted access to disability income described ongoing bureaucratic challenges to keep hold of benefits, with constant administrative requirements to repeatedly prove eligibility. Even those women who had managed to obtain a certain financial stability via SSI or SSDI uniformly described the regular incomes they did receive as insufficient to meet their basic living expenses:

> It's just so aggravating 'cause $700 is nothing. When you pay $350 in rent and you pay car insurance and you put gas in the car and you buy your laundry detergent, dish detergent and toilet paper and all that, you pay lights, water, gas, $700 a month, you can't make it. You cannot make it off $700 and I don't know how the government expects you to make it off the $700.… [And] if you get a decent place to live it's gonna be $500 a month. How are you supposed to live off $200, pay the rest of your bills off $200? It's terrible. It is so hard.
>
> —Jasmine (HIV+, North Carolina)

For women in this situation, supplementing disability income with additional income through formal or informal means was often their only option. The consequences for participants who were caught earning too much extra income, however, could be severe. The SSI and SSDI programs have capacity to accommodate a small amount of extra earned income if formally declared. Participants provided numerous examples in which they unknowingly strayed over the extra income limit and were punished upon declaration by having their checks completely cut, causing them to fall into destitution. On occasion they reported that they were also obligated to repay previous benefits.

### Multiple material-need insecurities

Whether they were attempting self-sufficiency via precarious employment, accessing disability income, or some combination of both, women across the three sites described experiencing overlapping forms of multiple material-need insecurity. In addition to the income insecurity characterizing the precarious labor-disability economy, participants described experiences with food insecurity, housing insecurity, and healthcare insecurity, all of which related to insecure finances. Participants frequently talked about their worries around accessing basic needs and spoke of inevitable future struggles to put food on the table, maintain an acceptable standard of housing (with running electricity, gas, and water), and access adequate healthcare:

> If I had enough money to meet my needs, I'd still have gas, I won't be struggling to pay my light, I won't be struggling to get food, and I won't be doing none of that.

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> I'll be secure. Plus, I won't have to worry about my [health] insurance being paid on time or none of that. And, see, that takes a chunk out of your check, too, because you have to pay for your insurance and all that good stuff. So, by the time all that come out, you have bare minimum.
>
> —Helen (HIV+, Georgia)

Participants further explained how quality was frequently compromised in order to maintain at least some minimum standard across all their needs. They described responding dynamically to the most urgent need at a given moment. For example, participants often explained how they compromised their diet to save money for medications, rent, or household utility bills, and many recognized that this had negative implications for their health ("If your doctor knew what you had in your refrigerator, they'd have a heart attack." —Ruth, HIV+, Georgia).

Women most often described giving up healthy food in this manner, but also compromised on housing to afford the rent by living in poor quality or cramped conditions (most salient in Northern California), sometimes with infestations of mice or cockroaches, and/or in neighborhoods in which they did not feel safe or want to live. Likewise, participants recognized that disability benefits were usually the only route to stable income, despite the indignity, unpleasantness, and humiliation of repeatedly having to prove eligibility and being subjected to bureaucratic requirements and administrative infractions. Most participants could also only access health insurance via Medicaid or Medicare (US government health insurance programs) as they could not afford private insurance or access it through employment. They explained that government health insurance often did not cover everything they needed. One example comes from a woman who described osteoarthritis in both hips so severe that on bad days she would roll out of bed onto the floor and crawl around until she could get herself up:

> All I know is that spine clinic said I need to have both hips replaced and they done whatever they had to do to Medicaid and say this patient needs a hip replacement, and they [Medicaid] said I don't qualify. So I don't know what that means. They won't pay for it. I don't know what that means or what it's gonna get, I just ain't gonna be able to walk before they do somethin'.
>
> —Kayla (HIV+, North Carolina)

These compromises across multiple domains of need were often perceived as personally uncomfortable or unacceptable. Some participants also described having to depend on coping strategies that would almost universally be perceived as socially unacceptable:

> All together I get $690 a month [from Social Security and SSI]. $690. So, out of that, I've got to make cable, food, rent and transportation, all that for a month. Then I want to get my hair done too. So, I supplement it with prostitution. At my age, I have $100 dates or better.
>
> —Margaret (HIV-, Northern California)

Despite these significant compromises many participants experienced periodic shortages in material needs during which they would usually go without electricity, heating, or enough

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food, sometimes barely eating anything at all. Participants were most reluctant to give up medication, but several described how they had missed healthcare appointments because they were so financially insecure they could not afford the transport. Furthermore, medical emergencies and unforeseen health problems for either the participant or a close family member could be devastating, throwing the carefully balanced management of multiple different material-need insecurities into chaos. One participant, for example, described how she had lost her home, her vehicles, and "everything but the clothes [on my] back" (Kayla, HIV+, North Carolina) when her husband died from cancer. Another example comes from a participant who worked a low-income security job and had just finished paying off several loans for household bills and other basic needs when she was admitted to a hospital for an asthma attack:

> Four things [loans] I just done paid off, since this year. So, yeah. That's where all my money [goes], that's how desperate I was to really pay my stuff off. … And now Kaiser [Kaiser Permanente, a US integrated healthcare insurer/provider]. I got sick with Kaiser. I had a bronchitis asthma attack. And I needed treatments, because my nebulizer wasn't working. I needed steroids. So I went to the ER, and that was a separate payment bill for $250. And I said, "I just paid my rent!" And then Kaiser hospital itself, since the ER was inside the Kaiser hospital, whatever stuff they were using on me, too, they charged me. It was $4,000 and something.
>
> —Jennifer (HIV-, Northern California)

There were several instances where participants described experiencing insufficiencies in every domain together (i.e., destitution). The most salient mechanism for this eventuality (and a significant source of anxiety for many more stable participants) was through losing disability status upon which everything else was dependent—usually because of an inadvertent administrative infraction. One participant, for example, described how she had accidentally earned too much extra income, leading to her disability income being abruptly stopped when she declared the extra income. This rendered her penniless, homeless, unable to afford food, and without health insurance. She explained how this situation had arisen directly from the precarious labor-disability economy described in the first theme:

> I became homeless. I was up under the bridge. Because I didn't have enough money to do anything else. So when they cut the check, they took the check and they took the Medicaid. I wasn't able to see no doctor. I wasn't able to do nothing. So the government, you know what I'm saying, it's much more complacent with [people] just getting a check. Because if you try to work, [they] cut it. Especially if they don't make enough money. … It's a no-win situation. You know? Unless you just happen to get blessed, and get a job—I mean a full-time job making $15 an hour or better, and you got your benefits and everything—[only] then maybe you can kiss Medicaid and the [disability] money and the food stamps and all that goodbye.
>
> —Jessica (HIV+, Georgia)

These four subthemes (insufficiency, poor quality, uncertainty, social acceptability), cutting across all four domains of material need (income, food, housing, healthcare), form the center-point of the findings represented in Figure 1. Also represented, as determinants, are

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the market and social safety net structures and baseline health and illness that, through their interactions, form the precarious labor-disability economy.

### Structural disempowerment

A particularly salient theme was the common perception among participants that the odds were stacked against them, that the social safety net system seemed explicitly designed to keep them down:

> I wish that I had a way of just keeping food in the house. That's the main thing. It's just keeping food in the house. And it's like the system is like they keep you down. Even Social Security, it keeps you down where you have to depend on them because if you get a good enough job [you lose Social Security]. Even with the housing authorities, you have to make so much money [but] if you make too much money then your rent will go up.
>
> —Betty (HIV-, Northern California)

This perception centered around the incongruity that the disability system represented the only realistic means of obtaining stable income for many of the women, but that it also seemed, to many of them, to be "designed not to be enough money" (Jessica, HIV+, from Georgia) in order to hold them in poverty—and, moreover, punish them if they ever used it to get ahead, by cutting off their checks and plunging them into destitution. Participants explained how they perceived this system worked in tandem with the other forms of material-need insecurity described. For example, they explained that disability income was too low for them to afford high rents for housing, but that trying to earn enough through labor stripped them of the security and benefits brought by disability. Food insecurity also played a role in this structural disempowerment, forcing participants to be dependent on food stamps that could then be taken away from them, leaving them even more food-insecure. This process is demonstrated in the quote below, which illustrates the perception that the social safety net was not there to help the women but, instead, to hinder and punish them:

> Like the storm that we had, Irma and Harvey, everybody got hit with the electricity, all kinds of stuff and you know, they said that you know, if you had problems with it, you let us know and we'll make sure that you get more food stamps. So, that month, because you lost food, you know, due to electricity, I went to them and I told them. They took $30 of my food stamps away from me instead of helping me. … They won't tell you [why,] and then, because on the paper it'll say, well, if you want a hearing and all that, you call and [try to] make an appointment. You can call them all day. They never answer the phone. And see and that's not right. If they're supposed to be helping, why take from you?
>
> —Ruth (HIV+, Georgia)

Another major subtheme of this structural disempowerment related to the closely linked issues of time and control. The quality of many aspects of participants' lives seemed beyond their control and directed by the decisions of other individuals, for example charity workers, state bureaucrats, housing managers, or landlords. This, in turn, fueled the perception among

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participants that important parts of their lives ran on other people's time, not their own, and on the decisions of people who had different priorities. This subtheme is particularly evidenced by the common perception that the disability system was quick to punish and sanction, but then took several months to re-instate income after appeal. Non-profit food assistance, while mostly perceived as beneficent (in contrast to the disability bureaucracy), also sometimes produced the same sense of living on other people's time, at other people's control. Participants, for example, described queuing up in lines for food for hours only to be told when they got to the front that there was none left.

Many participants viewed these experiences through an explicitly political lens, often specifically blaming the government or politicians for a system they felt to be hostile towards already marginalized populations. Women expressed anger and frustration that what little social provision they benefitted from seemed set to be cut even further by a class of people with political power who, they explained, felt far removed from them. Furthermore, most participants, when asked whether they knew people with access to power, or people who could help them mobilize to change their situation, could not think of any acquaintances that fit that description. While some named local activists or community figures, e.g. church leaders, most were resigned to the perception that they could change little even if they tried (reflected in the inclusion of political (dis)empowerment as an overarching determinant in Figure 1).

### Intersectional stigma

Collectively, these overlapping, interlinked forms of material-need insecurity, perceived to be structurally imposed, both resulted in and were perpetuated by numerous experiences and perceptions of stigmatization. First, the perceived punitive nature of the social safety net had the effect of communicating to participants that they were marked out as a lesser class of people for accessing and depending on it:

> It's very uncomfortable applying for food stamps. Or anything that's social service related. It's very uncomfortable, it's demeaning, it's demoralizing. Nobody in their right mind would choose that.… Because there's just something about, like, when you do stuff like that, or when you go to food banks, or if you were to have to go to a soup kitchen, you got to stand out in a line, you know, everybody is watching you in the line, and then you got to go and sit down. And then if you're in a grocery store and you got a food stamp card, everybody is looking at you like you got food stamps. And God forbid you have kids. They think you just a constant welfare recipient. So there's like the stigma that's attached to some of that stuff that makes it uncomfortable.
>
> —Erica (HIV+, North Carolina)

Participants described how this stigmatization imposed by the perceptions and workings of the social safety net intersected with each of the different forms of material-need insecurity. For the above participant, for example, the stigma of food insecurity and accessing food assistance was most prominent, whereas for another participant housing insecurity and housing support via Section 8 (the flagship government housing assistance program) carried the most salient stigma:

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> I want to live in a bigger house. When I first moved out here I lived in a bigger house.… There was two home association people living on the side of me and they didn't want me there so they had me put out, because I was on Section 8.… We didn't bother nobody, whatever, but they didn't want me there because they said: How can I afford to live in a house like that being on Section 8? Because there wasn't hardly no Section 8 people living around there. Everybody around there just about owned their house, so they had me put out by the manager.
>
> —Betty (HIV-, Northern California)

Moreover, women across the three sites described how prejudices and stigmas attached to other axes of disparity, including socioeconomic status, race, gender, and illness, intersected with the stigmas around disability and material-need insecurity. Racism was most commonly described by African-American participants, some of whom explained that they felt treated as outsiders or intruders if their housing situation forced them to live in majority white neighborhoods. Similarly, the following African-American participant explained that she received dismissive and racist care at the local hospital when she had to attend:

> I don't know why I always move in racist states. I swear [*laughs*]. I will be sick as a dog, I couldn't even go upstairs and get in my bed. I couldn't even suck ice chips or nothing for weeks. And when I would tell my son … [when] I would say, you know, call the ambulance, [the Emergency Medical Services] would push me in the hospital and they would say, 'Oh, another n***** on drugs.' And I'm like, oh no, I can't—no. I just, you know, I know it [racism] is here.
>
> —Alice (HIV-, North Carolina)

Gender was also prominent in certain narratives. The following participant, who had a history of being made homeless through intimate partner violence, explained how the experience of food insecurity was made worse for women by sexual harassment:

> The lines you stand in [for food assistance], and the things that you endure while you're in the lines—especially if you're a woman. If you're a woman, and you are half-way decent, so, so many men are going to be like [*makes noise*] right to you, and just, 'Oh! Hey baby!' And this and that, and you're uncomfortable. So now you don't feel safe, and you're hungry. So what are you going to do?
>
> —Barbara (HIV-, Northern California)

Finally, women explained how certain health conditions, particularly HIV and substance dependence, were particularly stigmatized, for example via the perception that they reflected moral failings. This perception, in turn, fed into the stigmatizing narrative that women were lazy or scroungers for living off the government, sometimes discouraging them from seeking further help and driving more material-need insecurity. Such narratives illustrate how intimately linked stigma was to material-need insecurities and the social safety net in this study, hence its inclusion in Figure 1 as both a potential cause and consequence of material-need insecurities.

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### Physical and mental illness

Finally, participants provided numerous examples of how living within this mutually reinforcing milieu of material-need insecurity, structural disempowerment, and intersectional stigma could have grave consequences for their health. This theme was driven by a slow undermining of health, including chronic illnesses, by the everyday stresses and strains of life under such conditions. Access to healthcare, including medications, was a particularly pivotal mechanism through which this occurred, compromised not only by insecurities in insurance but also by competing resource demands for food and rent on the background of income insecurity, as well as hunger. The following participant, who had missed several clinic appointments due to lack of finances for public transport, described this mechanism:

> You know, the doctor up there, [their clinics are] always at the end of the month, and I'm out of money at the end of the month. You know what I'm saying? It's only $2.50 [to get there on public transportation], which doesn't seem like a big deal to other people. But I don't have it. You know, $2.50 one way and $2.50 back, I don't have it.… [The last time I did go] I'm doing all this [riding the bus] through the back door [without a ticket], hoping that I don't get caught. If you get caught, that's a $200 ticket. What? For a $2.50 ride? You know what? Take me to jail. No, I'm not taking it. [It's] police abuse.
>
> —Margaret (HIV-, Northern California)

This extended suboptimal management of health and chronic illness was then vulnerable to flashpoints of acute illness, often when new stressors were introduced. The examples provided by participants in this respect covered a wide range of medical, surgical, and psychiatric pathology. One participant, for example, described how becoming destitute and uninsured after losing her disability income had significantly compromised her clinical control of blood pressure, asthma, and other chronic conditions:

> [During that time] I didn't [access healthcare]. How am I [going to] access anything with no insurance? You know? Medicaid is the insurance for Georgia.… My blood pressure was high. And just, you know, some [other] stuff [was] going on until I got everything worked out. My asthma was bad. I could not have walked across the parking lot without gasping for air. Felt like an elephant was on my chest. I couldn't breathe.… I was just sitting in bad shape. I was in a bad place.
>
> —Jessica (HIV+, Georgia)

A participant living with HIV described how a period of severe food insecurity during which she could not afford to eat correlated with a period of immune compromise, eventually ending up in an acute surgical admission:

> Because I wasn't eating, and my immune system was down, and it wasn't fighting, I had gangrene on the inside of my thigh of my leg. Had it for a minute. Didn't know I had it because my thigh was just hurting. The pain got so bad, I went to the doctor. They took me into surgery right then. They said I had the kind of gangrene that could kill you. And said if I had waited three or four more days, I'd have been gone. But I didn't know that. And they cut my leg open. I had to stay in the

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> hospital. I ate good while I was there, too. They had some good food. Uh-huh. I ate my three meals and my snacks. I didn't want to go home because I was eating.
>
> —Helen (HIV+, Georgia)

A different example comes from a woman (Laurie, HIV-, North Carolina) discharged from hospital following a myocardial infarction who moved in with an acquaintance, providing childcare for eight children in exchange for food and lodging, to avoid moving back into a homeless shelter. She explained how her insecurities in employment, housing, and food, and her structurally imposed absence of alternatives, had forced her into this highly stressful situation that "just drained" her at a time when rest would have been clinically indicated.

Detrimental effects on health within the sample also extended to severe mental illness. A participant with a history of psychotic illness explained how her housing situation—in which a building manager had felt entitled to enter her property unannounced, leading to an argument that then caused the participant to be evicted—had combined with HIV stigmatization to exacerbate her paranoia. This had the effect of significantly destabilizing her:

> Right now, in the several communities that I have lived in, I lived in one for ten years, and I just recently had to leave. And it was because I had a smart mouth manager lady that was in the office, and she was new, and I was on low-income housing, and she and I just wasn't coming to an agreement on certain things. Because she wanted to come in the house, but like I told her, "You give me a 24-hour notice, you just don't come in here." And then, we would go back and forth. So [we] went into an argument. She turned and told me, "You the one got AIDS." Yeah. It led into a big fight. And then, she got fired and I got a 90-day notice to move. So, that was my neighborhood.…That neighborhood, I knew everybody. But [then] I [would] walk around and be like, "Do this person know [I have HIV]?" Because, again, I have psychosis. So a lot of times that haunting spirit comes back and it frightens me.
>
> —Karen (HIV+, Northern California)

Finally, another participant described how multiple material-need insecurities and stigmatization around dependence on the social safety net contributed to suicidal ideation—both among her and her friends caught in this web of precarious living:

> Sometimes you just want to go jump off the bridge. But I have always been a fighter and a survivor, and I refuse to hurt me. That's the reason my son be asking me how come my friends be doing what they're doing to theirself. Because they risks it, trying to kill theirself. He said, "Mama, why don't they talk to you? Why don't y'all sit down and talk about it?" That's because a lot of people don't like to share. They'd rather keep it bottled inside. That way they won't get pity from nobody, and they won't feel like they're worthless. And they'll feel like they're doing something if they're out there doing it theirself. They don't want to depend on nobody, and that's me.
>
> —Helen (HIV+, Georgia)

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## Discussion

Food-insecure women from three different sites in the US described a similar picture of multiple material-need insecurities, disempowerment, stigmatization, and compromised physical and mental health. Their experiences centered on a low-income dual economy of precarious wage labor and federal disability income, from which arose ubiquitous financial insecurity leading to interlinked, overlapping insecurities in food, housing, and healthcare. Together, these experiences produced a profoundly disempowering perception that the structure of the US economy and social safety net was designed to keep them insecure and impoverished, accentuating stigmas of material-need insecurity that were additionally aggravated by marginalized identities pertaining to socioeconomic status, race, gender, and illness. The women's descriptions show how deeply and intimately chronic illness was enmeshed in these experiences, both as a driver of material-need insecurity and a consequence of it. Furthermore, flashpoints of acute medical, surgical, and psychiatric pathology punctuated their narratives as the culmination of cumulative insecurities and stressors. These findings occurred among both HIV-seropositive and -seronegative women with no clear differences (which was unexpected given the additional social safety net components provided for people living with HIV, e.g. via the Ryan White HIV/AIDS Program). The salient features of these findings are represented in Figure 1, which we suggest should be a preliminary framework for further research.

### Social-structural interpretations

We interpret the findings as precarity in the US insofar as they appear to be driven by the concurrent absence of both secure employment opportunities (with workplace benefits, job security, and a living wage) and a comprehensive social safety net. Consistent with previous studies (Hansen, et al., 2014; Knight, 2015; Whittle, et al., 2017), most participants who described accessing government income received disability benefits. The emaciation of US welfare for non-disabled adults since the welfare reforms of 1996 is well documented (Katz, 2013; Schram, 2015; Wacquant, 2009), and has left the SSI and SSDI programs as among the last forms of substantial income available to many adults struggling to make ends meets (Hansen, et al., 2014; Knight, 2015; Whittle, et al., 2017). This is particularly true for women of the participants' demographic, whose age means they are unlikely to have children under the age of 18, excluding them from the flagship welfare program, Temporary Assistance to Needy Families. Previous studies have shown that accessing SSI and SSDI, however, may compound and worsen some vulnerabilities to physical and mental illness (Lopez, et al., 2018; Whittle, et al., 2017). This critical structural dependence on the disability safety net among low-income Americans has also been shown to have important transforming effects on diagnostic categories, illness perceptions, and health behaviors (Hansen, et al., 2014), and has nurtured an entire grassroots infrastructure for accessing SSI and SSDI (Knight, 2015).

Our findings add to previous studies that have illuminated the structural vulnerability produced within this web of precarity (Lopez, et al., 2018). Our participants specifically described facing multiple insecurities in finances, food, housing, and healthcare, which exacerbated their chronic illnesses and therefore made it even more difficult to hold down

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employment, obtain food, maintain adequate housing, and access or engage with comprehensive healthcare. This self-propagating pattern of multiple material-need insecurities, closely intertwined with health, was broadly reproduced across three geographically distinct sites in the US. Its effects on the participants, furthermore, moved beyond purely economic and physical health concerns: their own time and futures felt beyond their control as they became disempowered, stigmatized, and alienated. The internalization of some of these experiences was evident, particularly in narratives describing depression and suicidal ideation.

## Precarity and health: Towards a translational framework

Analyzing the experiences of these women through the lens of structural vulnerability shows (1) how multiple material-need insecurities arise from the confluence of labor and social welfare institutions in the contemporary US, (2) how these experiences foster stigma through a subjective perception of disempowerment, and (3) how physical and mental illness are related to these intersecting experiences. While ethnographies of similar US populations have described comparable convergences of multiple vulnerabilities (Knight, 2015; Lopez, et al., 2018), few have specifically unpacked the constructs of financial, food, housing, and healthcare insecurities to show they share common dimensions of insufficient quantity, poor quality, uncertainty, and compromised social acceptability. These four dimensions of material-need insecurity, which reflect the conceptualization of food insecurity derived from empirical work over the past two decades (Weiser, et al., 2015) and recent working definitions of housing insecurity (Cox, et al., 2017), can therefore be combined into a unifying framework of precarity that warrants empirical testing in quantitative studies (Figure 1).

Drawing on the qualitative results, we propose that the dynamics and perceptions of disempowerment, stigmatization, alienation, and internalization identified in our data should be incorporated into this conceptual framework. At present, research on stigma provides the best opportunity for translating between mixed methodological approaches as it can facilitate both in-depth qualitative insights and quantitative testing through validated scales (Turan, et al., 2017). Stigma research has also pioneered the use of various quantitative methods to modeling intersectionality in health disparities, such as latent class analysis and structural equation modeling, which may prove useful in modeling the intersection of different material-need insecurities (Turan, et al., 2019). In line with our qualitative data, we therefore include stigma as both a determinant and consequence of these intersecting material-need insecurities that form the mainstay of the framework.

Several other determinants (represented by the arrows at the top of Figure 1) may drive differential forms of this common pattern at different locations and among different populations in the US. In addition to flexible employment regulations that permit insecure labor (Harvey, 2005) and social safety net institutions that de-prioritize the security of recipients (Whittle, et al., 2017), local housing, job, and food markets will affect how insecurities are patterned (Brown & Brewster, 2015; Whittle, et al., 2015). Baseline health likely plays an important role in driving material-need insecurities, and demographic factors (as well as the social structures that imbue them with meaning) are also significant. The

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unique history of slavery, segregation, deindustrialization, migration, and poverty management in the US, for example, has positioned ethnic minorities, particularly African-Americans, to be disproportionately affected by forms of social insecurity (Katz, 2013; Wacquant, 2009). The different instruments of the state that take responsibility for managing that insecurity have traditionally taken on a marked gender asymmetry: welfare and social security institutions for women and the criminal justice system for men (Wacquant, 2009). That we identified this pattern of findings among a predominantly African-American sample of women, therefore, is unsurprising.

At the bottom of the framework, we propose three paths through which this precarity may negatively impact health, based on our previously published conceptual framework for the links between food insecurity and health (Weiser, et al., 2015). First, putative biological mechanisms may be either common across all insecurities (e.g. physiologic dysregulation through chronic stress (McEwen, 1998)) or specific to individual forms of insecurity (e.g. malnutrition or respiratory disease from household mould). Second, the detrimental effects of multiple material-need insecurities on health behaviors, especially engagement in health care, were particularly salient in our data. This path is intimately related to healthcare insecurity, but, as our findings and previous studies attest, is also driven by competing resource demands and insecurity-specific paths including hunger (Whittle, et al., 2016). Third, psychosocial mechanisms include the stress and symptoms of common mental illness (depressive symptoms and anxiety) salient in our data, as well as intersectional stigma. Together these phenomena may capture the sense of disempowerment, defeat, alienation, isolation, and stigmatization permeating many of our participants' narratives within constructs that can be translated across methodologies.

### Strengths and limitations

A strength of this study is its use of three distinct geographic locations, which allowed us to look for common patterns in the data that may have broader relevance across the US. Another strength is that WIHS participants are generally low-income but not widely destitute. This likely allowed some of the subtler aspects of material-need insecurities to emerge in the findings, which may be masked in destitute populations. Our study also has limitations. First, our inclusion criteria of being food-insecure may have targeted a specific population of women for who this pattern of precarity and vulnerability is particularly salient. Second, WIHS cohort interviews are conducted in either English or Spanish, whereas our interviews were only conducted in English. We are not aware of any exclusions to recruitment that occurred on the basis of language, but it is possible. Third, nesting the study within the WIHS may also mean the findings only reflect the experiences of people with or at risk for HIV, and not others living with chronic illnesses (although people living with HIV often have access to a wider range of clinical and social services than other low-income individuals in the US). This may have also under-represented some important populations, particularly undocumented migrants, who face more fundamental citizenship-related barriers to accessing labor and social support (Holmes, 2013) (hence our inclusion of citizenship at the top of the framework).

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## Conclusion

Our study presents experiences with living precariously and associated risks to health among women living across the US, who perceived that multiple material-need insecurities, stigmatization, and poor health were imposed by the structure of the nation's labor economy, the failings of its social safety net, and the distribution of its political power. We have organized their experiences into a framework that can guide further research on precarity and health, held together by theoretical insights from the social sciences and presented using constructs that can translate into social epidemiology and health disparities research. Such an approach can offer new opportunities to explore and test how precarity and intersecting insecurities affect a range of health outcomes in the 21st Century—from HIV to cardiometabolic risk to psychiatric illness and beyond.

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## Research Highlights

- Investigates the intersection of multiple material-need insecurities among US women
- Explores the experience of insecurities in finances, food, housing, and healthcare
- Shows how these insecurities are stigmatizing and widely detrimental to health
- Analyzes data through lenses of precarity and structural vulnerability
- Organizes findings into a conceptual framework for research on precarity and health

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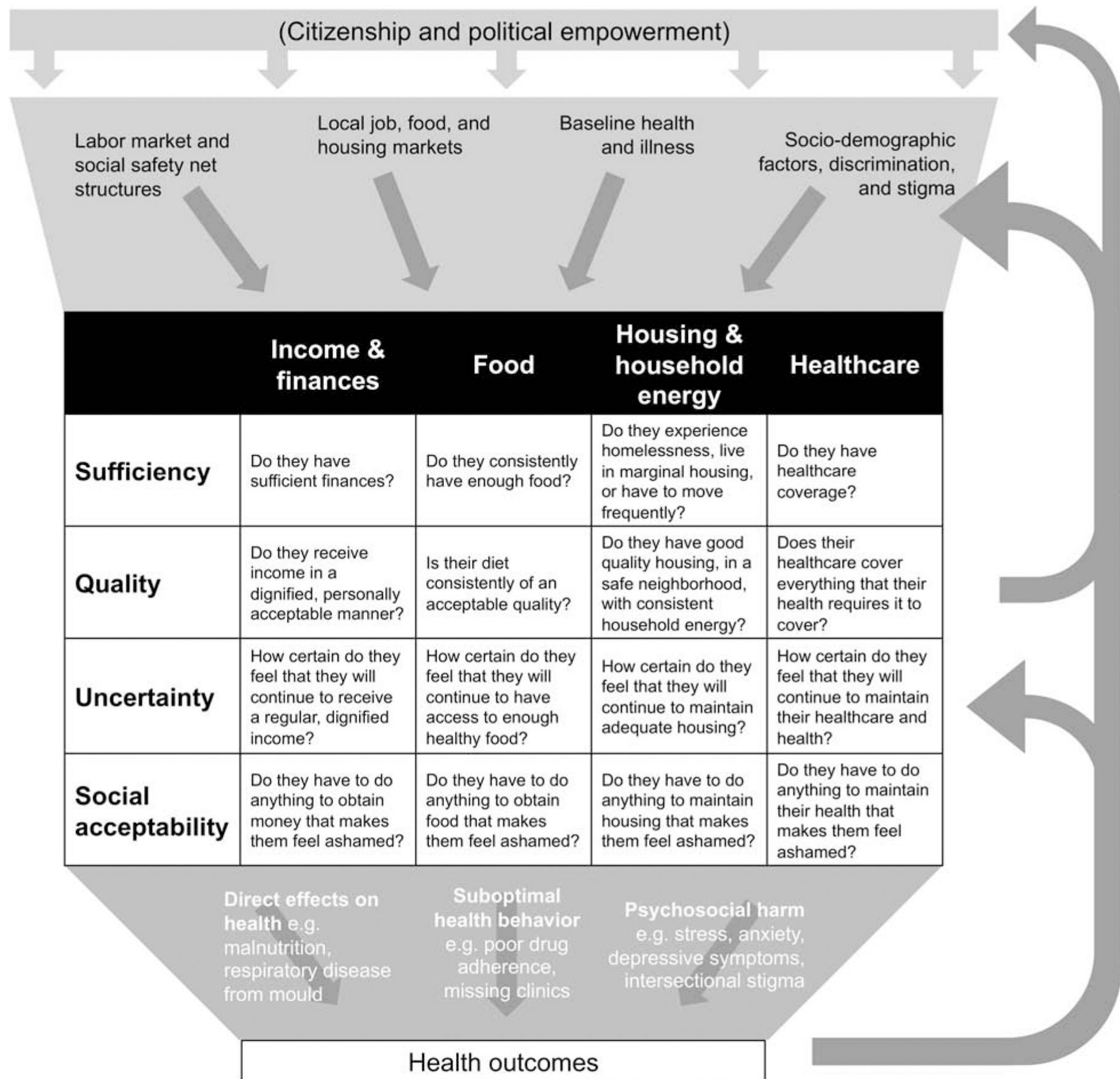


**Figure 1.**

Precarity and health: A conceptual framework

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**Table 1.**

Participant demographics

| | N (%) or Mean (Range) |
|---|---|
| **Age** | 56 (50–64) |
| **Race/Ethnicity** | |
| African-American | 25 (66) |
| Hispanic | 5 (13) |
| White | 6 (16) |
| Other | 2 (5) |
| **Food Security Status** | |
| Marginal | 5 (13) |
| Low | 14 (37) |
| Very Low | 19 (50) |
| **HIV Serostatus** | |
| Positive | 26 (68) |
| Negative | 12 (32) |
| **Location** | |
| Northern California | 14 (37) |
| Georgia | 14 (37) |
| North Carolina | 10 (26) |