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Waiting for care: Chronic illness and health system uncertainties in the United States

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ABSTRACT

Structures of power and inequality shape day-to-day life for individuals who are poor, imposing waiting in multiple forms and for a variety of services, including for healthcare (Andaya, 2018a; Auyero, 2012; Strathmann and Hay, 2009). Constraints, such as the age requirements for Medicare, losing employer-provided health insurance, or the bureaucracy involved in filing for disability often require people to wait to follow recommendations for medical treatments. In 2016–2017, we conducted 52 narrative interviews in St. Louis, a city with significant racial and economic health inequities and without Medicaid expansion. We interviewed people with one or more chronic illnesses for which they were prescribed medication and who identified as having difficulties affording their prescriptions. Throughout the interviews, participants frequently recounted 1) experiences of waiting for care, along with other services, and 2) the range of strategies they utilized to manage the waiting. In this article, we develop the concept of *active waiting* to describe both the lived experiences of waiting for care and the responses that people devise to navigate, shorten, or otherwise endure waiting. Waiting is structured into healthcare and other social services at various scales in ways that reinforce feelings of marginalization, and also that require work on the part of those who wait. While much medical and public health research focuses on issues of diagnostic or treatment delay, we conclude that this conceptualization of *active waiting* provides a far more productive frame for accurately understanding the emotional and physical experiences of individuals who are disproportionately poor and made to wait for their care. Only with such understanding can we hope to build more just and compassionate social systems.

1. Introduction

It is hard to comprehend how much of their lives poor people spend waiting: in the emergency room, dealing with indifferent bureaucracies that are supposed to address basic needs, in the laundromat, where people must scramble for available machines and keep a close eye on their laundry. Waiting adds yet more pressure and pain on feet that may already be swollen ... Many poor people spend years of their lives on waiting lists: for a public housing unit, a Section 8 voucher, a bed in rehab, a hearing in landlord-tenant court. They wait for erratic buses, food at a food pantry, or a bed in a shelter. Their names fill long lists of people in dire need (Williams, 2009, p. 150).

Waiting is a pervasive aspect of poverty. Just as poor people are most likely to wait for laundry machines, housing, food, so too they are most likely to wait for their healthcare, and this can have especially grave

consequences (Andaya, 2018b; Oostrom et al., 2017). The link between the timing of treatment and health outcomes is well documented. In health disparities research, it has become axiomatic that timely adherence to and receipt of medications, screenings, and follow-up health services is vital for decreasing inequities in health outcomes (Bickham and Lim, 2015; Dickman et al., 2017). As a result, much public health intervention work aims to identify and rectify the sources of protracted times to diagnosis and/or treatment (Diamant et al., 2004; Koopmanschap et al., 2005). Similarly, healthcare organizations are increasingly attentive to time elements, identifying time as a critical quality metric: shorter wait times, particularly for appointments or between diagnosis and the initiation of treatment, reflect greater efficiency and improved patient satisfaction and outcomes (Bleustein et al., 2014; Michael et al., 2013). Nevertheless, organization-level effort to reduce wait times is unevenly distributed; bureaucratic interventions disproportionately advantage wealthier and privately insured patients. The task of waiting

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in and for healthcare—in waiting rooms, for future appointments, procedures, and treatments—is performed overwhelmingly by people who are poor (Kennedy et al., 2004; Oostrom et al., 2017).

In this article, we focus on what we are calling *active waiting*, a concept that we suggest more accurately describes the lived experience of gaps in healthcare action than does the more frequently used word, *delay*. When contemporary health disparities researchers examine patient behavior and action as it relates to the timing of treatment, they often focus on patients' delaying diagnostic tests or treatments. While understanding why a person might delay a diagnostic procedure or treatment regimen can identify barriers (e.g., long wait times on phones or for follow-up procedures, a lack of transportation or money) that discourage individuals from taking more immediate actions (Diamant et al., 2004), thinking in terms of delays can also place excessive responsibility and blame on individuals for non-action and non-adherence (Hunleth et al., 2016). "Why did she delay scheduling her follow-up appointment?" is not the same as "Why did she wait to schedule her appointment?" And though waiting can lead to assumptions about passivity or non-action, social scientists have demonstrated that waiting is *not* a passive state (Auyero, 2011; Mulcahy et al., 2010).

We derive our own focus on active waiting, as opposed to delay, from narrative interviews we carried out with people who have chronic illnesses and who have difficulties affording their medications. Studies of chronic illness in the U.S. offer important insights into waiting. People living with illness and in poverty wait a lot, during the many appointments needed to manage their conditions (i.e., for/on health service and treatment providers), and for disability, insurance, and paychecks (i.e., for/on bureaucratic actors). Of key importance, active waiting, unlike delay, remains true to the linguistic preferences of the individuals with whom we have worked: participants in the study we describe below spoke of their experiences of temporality in healthcare as of waiting and not as of delaying. Further, the concept of active waiting allows us, and others working in and studying healthcare, to move beyond analyses that either locate responsibility for wait times solely with the individuals doing the waiting or perpetuate overly-deterministic views of systemic barriers that erase experience and social action. To frame our conceptualization of active waiting, we bring together two scholarships: one on the political economy of healthcare (which includes the elucidation of bureaucratic time) and the other on waiting as a feeling and an experience which gains meaning within power relations and through social interactions.

1.1. Bureaucratic time and the agency of waiting

Though healthcare bureaucracy in the U.S. requires most people to wait for care, how long people wait, how waiting is structured, and the consequences of waiting vary. People who do not have access to insurance or other resources must endure state and federal evaluations of their low-income statuses, abilities to work, severities of illness, citizenship, and more to qualify for assistance (Tickamyer et al., 2000). As funding for social programs like Medicaid, food stamps, and disability are rolled back and work requirements become stricter, demonstrating qualifications to obtain support is increasingly difficult and time consuming (Whittle et al., 2017). While social welfare programs offer access to health services, they often require long waits in waiting or exam rooms at facilities that accept Medicaid or offer services on a sliding fee scale (Becker, 2004; Oostrom et al., 2017).

Researchers have identified how people deal with the bureaucratic schedules that shape the course of their treatment. Mulcahy et al. (2010) described how some people with cancer resisted the assumptions that they must be 'patient' patients by seeking information and resources to shorten their waiting periods. Still other researchers have shown that long wait-times for healthcare personnel in clinics and waiting rooms can lead to other forms of action. Waiting can push individuals out of the healthcare system or lead them to delay care (Becker, 2004), and it can induce feelings of pervasive uncertainty and powerlessness among

patients who then comply with bureaucratic state demands (Auyero, 2012). Waiting may be imposed, but these researchers show that it always entails a response.

Understanding the experience of waiting in the U.S. requires recognizing that the actions people take while waiting are interpreted using neoliberal ideologies that privilege, among other things, individual responsibility (Mulligan, 2017; Rylko-Bauer and Farmer, 2002). This focus on individual responsibility can lead to the blaming and shaming of people who time healthcare inappropriately or do not act appropriately within others' expected timeframes (Holmes, 2012). Scholars have shown that this privileging of individual responsibility reinforces racialized and classed hierarchies of deservingness (Horton, 2004). Notions of individual responsibility (and thus of individual failure) place pressure on patients to *do*, and in doing, they avoid or mitigate the likelihood of blame and shame while they wait. As we have previously shown, the focus on individual responsibility can lead people to blame themselves and their loved ones for waiting too long to seek care (Hunleth et al., 2016).

Sociologist Andreas Göttlich suggests that waiting is an interaction that depends on "the mutual interpretations of the actors"—those who wait and who are waited upon—as well as others who behold the scenes of waiting (Göttlich, 2015, p. 60). That is, people wait in relationship to and with others. Researchers who center the interpretive acts and emotions of 'waiters' in healthcare settings, such as waiting rooms, offer several insights into what we refer to as active waiting. In a study of interactions in a waiting room, Strathman and Hay suggested that: "When patients are told that they cannot get an appointment within the desired—even physician recommended—timeframe, it is like being told that their health, and by extension, they as persons, are less important than bureaucratic schedules" (Strathmann and Hay, 2009, p. 220). That is, waiting can add to a sense of being devalued or neglected (Andaya, 2019; Sjöling et al., 2005), and it can negatively influence peoples' perceptions of their quality of care and confidence in their care provider (Bleustein et al., 2014).

Given the above work, we understand active waiting to be the experiences and responses that people devise to navigate, shorten, or otherwise survive waiting, and also to anticipate and craft possible futures *within* the relationality and power dynamics of bureaucratic time. Resisting wait times by seeking information and other resources is part of active waiting, as is delaying and complying. Active waiting is composed of such discrete actions that people might take as patients in one place or time, but is irreducible to those actions and must be situated in how people manage multiple wait times at various scales. Further, we include not only action, but also how waiting on bureaucratic time feels. Carr, Teucher, and Casson (2014) have used the phrase "lived wait time" to communicate the fact that feelings of time differ by circumstances. Researchers have shown that chronic illness lends itself to particular feelings of time and of life, including those of time as suspended (e.g., feelings that life is "on hold") (Brown et al., 2006; Mulcahy et al., 2010; Sjöling et al., 2005). We expand this by focusing on how chronic illness feels while waiting on powerful others to make life or death decisions.

While wait time is lived, people also live during their wait times; daily lives are not easily paused (Sjöling et al., 2005). This means that the circumstances of individuals' days (and lives) often change while they wait on healthcare. Less has been said about the waiting that goes on outside of clinical settings yet is ultimately tied to health. In fact, waiting is an implicit and normalized mechanism of bureaucratic systems. In what follows, we consider how these various aspects of time and waiting combine for people experiencing illness and financial strain. We use active waiting—conceptualized as an action, orientation, relationship, and feeling that is irreducible to a singular time and place, and which shapes how individuals approach their health in particular times and places. We do so in order to best examine how various aspects of time and waiting interweave in the lives of people who are chronically ill and poor.

2. Methods

2.1. Setting

This research comes from a mixed methods study investigating cost-related issues that affect adherence to medications. Recruitment occurred in 2016 and 2017, amidst political uncertainty about changes to healthcare legislation. On the national stage, a new and controversial presidential administration was beginning its term. This administration had goals to repeal the Affordable Care Act (ACA) and introduce block-grant funding to Medicaid, which remained a possibility throughout our data collection period. For people with chronic illnesses, the ACA was significant; it mandated that pre-existing conditions be covered by insurance plans and that insurers offer at least a minimum prescription drug benefit, while also creating platforms for uninsured individuals to purchase plans. Additionally, national conversations about changes to prescription drug pricing were prominent in news coverage.

Most of our narrative interviews were conducted in St. Louis, Missouri, though a few occurred in East St. Louis, Illinois. Missouri did not expand their Medicaid program with the roll-out of the ACA; Illinois did. St. Louis is a metropolitan area with significant racial and economic health inequities. To address the health needs of those without insurance in light of not expanding Medicaid, the Gateway to Better Health program was created, which provided basic coverage to people living below the poverty line. This program was set to end in December 2017, during our study, but its extension was later approved beyond that date. Many of the people who participated in this study were using or had used this program.

2.2. Recruitment & interviews

Our research team recruited people between the ages of 35 and 80 who had one or more chronic illnesses for which they were prescribed medication and who identified as having difficulties affording their prescriptions. The study had a mixed methods design. Participants in the survey ($n = 270$) were recruited from newspaper ads, federally qualified health centers, and a multi-specialty clinic. A sub-sample of the survey participants ($n = 52$) also participated in a narrative interview focused on financial strain. While we have presented the mixed methods results elsewhere, this article focuses solely on the narrative interviews. We initially aimed to recruit 64 interview participants, stratified evenly based on prescription insurance coverage, age, and gender; however, this was adjusted based on the availability of participants. The final number of interviews was 52 (Table 1).

The interview guide was based on the McGill Illness Narrative Interview (MINI) (Groleau et al., 2006). We revised the guide and refer to it as the Modified Financial and Illness Narrative Interview. It is structured similarly to the MINI to elicit different types of narratives, but with an added focus on financial history. Two local non-profit community organizations were selected as interview locations due to their proximity to and rapport with the participant population, non-clinical

Table 1
Interview participant characteristics.

| | N (%) |
|---|-------------|
| Race/Ethnicity | |
| Non-Hispanic Black or African American | 42 (80.8) |
| Non-Hispanic White | 8 (15.4) |
| Other | 2 (3.9) |
| Gender | |
| Female | 31 (59.6) |
| Male | 21 (40.4) |
| Health Coverage | |
| Had continuous health coverage in the past year | 45 (86.5) |
| Had a gap in coverage in the past year | 12 (26.7) |
| Age (mean, range) | 58.3, 35-79 |

environments, available private interview spaces, and organizational relationships with study team members. Trained research team members conducted interviews and a note taker was present in most cases. The interviewer obtained informed consent and interviewees were compensated with a \$50 gift card. Interviews were audio-recorded and lasted about 60–90 minutes. Immediately after the interview, the interviewer and note taker wrote detailed field notes using a structured template that included their observations about body language, any conversations not recorded, a summary of the financial and illness narrative, and reflective memos.

2.3. Analysis

Interviews were professionally transcribed verbatim, de-identified, and checked for accuracy before being uploaded with their respective fieldnotes to NVivo 11. We describe the codebook development below, which was designed with the mixed methods study in mind. During that codebook development, the team identified the repetition of comments about waiting across the interviews.

The team developed a codebook using deductive and inductive codes. Deductive codes were based on questions of interest from the quantitative survey. These focused primarily on medication cost coping, access to basic needs, and related concepts. The team identified inductive codes while conducting interviews and refined and added to these codes while reviewing transcripts. During the analysis and throughout the coding process, we took note of a cross-cutting theme in the narratives: when asked to describe what it was like to deal with chronic illness, participants said that chronic illness was about waiting. We coded all discussions of waiting in the interviews, defined as any mention of waits or delays, and in the fieldnotes.

While waiting is a broad concept and was used to reference different processes, we chose to include in our analysis all aspects of waiting described by participants, rather than focus on just one (e.g., waiting for health insurance coverage). We did so to acknowledge that people may experience waiting that is inter-related and different from the temporal distinctions made by many healthcare practitioners. Four team members coded the interviews using the final codebook. All transcripts were coded by at least two team members and discrepancies were reconciled through consensus between the two coders. AL memoed on the waiting code throughout this process, focusing on issues such as what kinds of things people waited for, how this influenced their decisions and emotions, the outcomes of their waiting on their health and healthcare, and how waiting shaped their aspirations for the future. The team, including coders, interviewers, and investigators, compared how waiting was discussed within and across the transcripts and narrative types elicited by the guide, as well as the intersection of waiting with other codes. Interpretations and exemplar quotes were evaluated by multiple team members to guard against selective use and bias in interpretation of the data, and to encourage reflexivity.

All study activities were approved by Washington University's Institutional Review Board.

3. Results

We organize our results to make clear the meanings and experiences of active waiting. In the first section, we outline the breadth of waiting that shapes how people wait and answers the question, "waiting for what?" The second section addresses the question, "waiting for whom?", and describes how participants ascribed meaning to waiting according to their social and economic positions and in relation to those in power, what some participants referred to as the "waiting game." Finally, and building on the previous sections, we focus on waiting as an active process that people manage through a variety of tactics. In doing so, we detail the ways in which people actively wait, living their lives within structures of power that make them wait.

3.1. Waiting for what? Big and small waits

Because we cover multiple forms of waiting, we wish to be specific about what participants referred to when they talked about waiting. The list was long and it included waiting in waiting rooms, for transportation, on the phone, for surgery, for paychecks and welfare checks, for housing, and for approval for disability and insurance benefits. The things participants waited for varied according to their own unique health and social circumstances. These waits were often predictable and included: the spaces in which people wait (e.g., waiting rooms); the bureaucracies that enforce waiting (e.g., disability claims); the conditions that create waiting (e.g., strained social safety net); and the financial demands that, when unmet, lengthen wait times (e.g., a ride when one does not have transportation, a paycheck to afford a prescription). The variation in chronic illnesses and in life circumstances of participants in the study, however, meant that they discussed the structures of waiting in different ways and put emphasis on different aspects.

Within the predictability and variability, there was an overarching theme of waiting for one or a succession of big things to happen, what we term 'big waits.' Big waits were for things that had a hoped-for endpoint, ones that might change an individual's health situation. For example, many participants talked about waiting for disability assistance to come through, or for health insurance coverage to start, or for stable housing, and they often centered their discussions of waiting around this primary event. The endpoints could be a decision made by a social service agency or could be an anticipated and desired life change. One woman told us that her big wait for insurance coverage was almost over because she would soon be eligible for Medicare, which multiple others also mentioned that they were awaiting: *"The good news for me is—a year from this August—I turn 65 but, um, I always feel like it's all pending. There is nothing concrete in any of the healthcare."*

While participants talked about big waits in terms of their endpoints, they also talked about how such endpoints led to other big waits. Take Kate, for example. Kate is a Black woman in her early fifties who previously worked in home healthcare. She has osteoarthritis, Graves' disease, hepatitis C, and depression. After both her mother and husband died a few years ago, she struggled to afford housing and continue working through her arthritis pain. When we interviewed Kate, she had been homeless for several months and was recently accepted off a waiting list for transitional housing. Kate had several big waits that came in succession and were contingent upon one another. She waited for housing assistance; she waited for medical release to work after sustaining injuries in a car accident; she waited to consult with a doctor about surgeries; she waited on a disability hearing scheduled months away. Though she had been diagnosed with hepatitis C, her doctor would not begin treatment until her disability application was approved because of the high costs of the medication, which would be covered if she were on disability.

Kate worried that all of these big waits would have long-term repercussions on her health:

Until the disability [benefits are approved] or something [else comes through] and September [the date of her disability hearing] comes, they ain't going to even give me the medicine ... We will just wait and see. So, I am just in limbo until, until my hearing ... I know I ain't going to die right away, but I do want to get the medication.

Kate found herself waiting a lot on a lot. The interdependence of her waiting meant that one wait exacerbated other waits. While taking care of her sick family members, she put off her own health needs and bill payments, leading to her eventual housing instability. Her lack of a consistent mailing address delayed her ability to submit a disability application. Even after she found more stable housing and was able to see a doctor, the disability application delays led to postponed medical treatments. Without getting her health and injuries under control, she

could not work and get out of transitional housing. For Kate, each big wait led to another big wait, with worsening and compounding repercussions on her health and wellbeing. Other participants described having waited years for their disability applications to be approved, or often, denied. In the meantime, they incurred greater debt, hired lawyers, relied on family for support, postponed treatments, and endured.

These big waits – waiting for disability benefits and for other significant changes in their financial or familial situations – also created a number of smaller-scale, day-to-day situations in which study participants waited. One uninsured woman described waiting to fill her prescription and waiting to see her doctors while she searched for a full-time job to afford both: *"You wait to the extreme before you do anything about whatever the problem is. Because you don't want to go to the hospital, it costs too much."* Many participants missed appointments or went without medications while waiting for new insurance benefits, or payday, or financial assistance paperwork to go through. Holding off on care was just one way to wait actively available to those whose actions were constrained by chronic illness and financial strain.

While big waits figured strongly into participants' imaginations of their futures, small waits were not insignificant. Allen's diabetes had damaged his kidneys so severely prior to getting Medicaid coverage that he needed dialysis. He described the cycle of waiting while on dialysis. Allen – whose big wait had been, first, getting Medicaid coverage and then, once covered, getting on a kidney transplant list – did not have a car or a steady way to get to his weekly dialysis appointments. A few times a week, he waited to be picked up by a Medicaid-covered transportation company. He had little control over when they would arrive, and their arrival was often sporadic. When they arrived early, he had to wait at the clinic. When they were late, he either had to pay for his own cab or push back his dialysis appointment to later in the day and wait even more. Optimistic, Allen expressed gratitude that he was able to use Medicaid and live with his brother while waiting for a kidney transplant, his own big wait within multiple small waits. While enduring the small waits, he imagined a better future after the transplant, describing to us what he would write in a book about his experiences: *"Kidney transplant got him back to a better life. Now, he's back in the work force. He hasn't looked back to the sickness yet ... That's my story."* The day-to-day waiting was frustrating, but the promise of this story, along with having family able and willing to assist him (an unmarried man without children), shaped how he waited and his feelings while waiting. Big and small waits contribute to the dynamic aspect of active waiting, where social ties and financial resources regulate how one is able to navigate and survive waiting.

Waiting was drawn out for those without the economic resources to avoid institutions such as sliding-scale clinics, welfare agencies, and financial assistance programs. Throughout the interviews, participants described waiting as chronic, but they also held onto a sense that, once a waiting period passed, then their future goals of health and financial stability would be that much closer. For Kate, waiting was incremental and each waiting period required different tactics. The big waits participants described both promised and suspended the future; people grappled with the present while anticipating what might happen when and if the waiting ended. Some people imagined a time when they could afford healthcare, holding off certain appointments until that time, while others imagined a future *"in the work force,"* and attended appointments diligently, even in the face of smaller or shorter-term waits. Such small waits, too, structured participants' responses in how they waited based on what they were waiting for.

3.2. Waiting for whom? The "waiting game"

Many participants identified feeling like the systems in place to assist chronically ill and financially strained people were *"playing games"* with their lives by making them wait. They were made to wait by social service programs, appointment schedules, hospital and clinic waiting rooms, insurance company call centers. The waiting punctuated their

day-to-day lives and left them guessing about the reasons behind their extensive, chronic waiting. They guessed at answering, “why me?”—why *they* had to wait. They also guessed at a course of action to shorten or otherwise deal with waiting. The “*waiting game*” they described was one in which the odds were stacked against them, the rules were opaque, and endurance was necessary to win. Some study participants searched for ways to get around the game, or to play it to their advantage. How they played the waiting game – which we recognize as active waiting – depended on both their interpretations of the meaning of waiting and on the resources to which they had access.

In our interviews, some people brought up suspicions about being forced to wait for appointments and in waiting rooms due to their economic status, age, race, and other discriminatory factors. One participant talked about how, once in the examining room, she felt as if her time waiting was not reciprocated by providers: “*They do not want to spend a lot of time with you, you know, they-they’ve got to make a living too, so they move on.*” Some speculated that doctors reserved time for people of a higher economic status. These patient-provider dynamics that waiting exemplified left people feeling slighted by the medical system: “*Ah, I sat there in that waiting room for 2 hours and, and they still wasn’t ready to see me ... No one had the respect, ah, even the courtesy to come out and say, ‘Well, the doctor is running a little bit behind’.*” People felt that their lives were undervalued and unimportant when their time was not acknowledged or respected. That bureaucratic systems seemed to withhold resources by imposing waiting suggested to some a denial of their belonging and deservingness as patients, and as humans worthy of care.

Experiences of medical racism and sexism frequently underpinned participants’ feelings that their time was being wasted. Rachel, a Black woman, told us that she had been working and paying taxes since she was a kid and, still, the welfare system did not support her when she needed it:

They kept turning me down for disability, and they kept saying I was too young to have problems I had. You know, but my body was breaking down and the doctors would never [help with the application], which was really so unfair. And now, that’s the part that really makes me feel a little sad, like there is so much – I hate to say racism – but just unfair treatment. Because I’m a woman, because of my age, and then because of my race. And so, we’re talking like years [voice breaking] ... It made me be really poor.

Rachel’s doctors held the power to demonstrate that she qualified for disability but, as she recounted, they were unwilling to fill out the documentation she needed to apply for disability. She felt that the U.S. had enough resources to provide care to people who were suffering, but that people with money and power were “*more concerned about being rich.*” As a young Black woman, she described feeling unheard and mistreated by her doctors and her country, leading to increased financial strain and delayed care for her fibromyalgia, arthritis, and other illnesses.

An older Black woman, Sherry, explained the power dynamics that shaped the waiting game and how larger-scale injustices played out in the waiting room. She expressed her anger over spending time in the waiting room for an appointment after waking up early, walking three blocks, and taking several busses to arrive on time for her appointment:

I have timed myself and I got the bus schedule in my phone. It’s an app, so I am always there on time, always. I never miss the bus. When I am on time, I expect you to be on – I am telling you what I told the doctor ... I am angry when you make me sit there and wait. I am angry and I say so. Sometimes I be cursing, I ain’t kidding. I’m really angry.

She explained that her blood pressure was elevated because she was so upset about this interaction with the clinic after she put a lot of effort into making her appointment on time. That effort, to her, was disregarded or unimportant to the medical staff. At the same time, she

recognized that high blood pressure was “*Black peoples’ number one killer,*” and explained that her waiting also stressed her body, contributing to her anger. These indignities played out in the clinic, adding to the daily stresses she said she already felt as a Black woman and grandmother living near the Ferguson neighborhood where an officer murdered Michael Brown in 2014, and was not indicted for that murder.

Participants also talked about waiting as a game that required endurance, not just because of a lengthy office wait or the months or years it could take to get a disability application approved or denied, but because of the opacity of the process. They questioned application processes, wondering if the wait to hear back about welfare and assistance services was a test of endurance: “*It is just a waiting game [for disability]. Until they get tired, tired of you being in front of them and they decide to give it to you. That is what they hope for is [you] giving up on it, but if you keep with it, sooner or later you will get it.*” While a number of participants expressed optimism for a better future once a big wait was over, waiting out bureaucratic processes wore down that optimism. “*I don’t believe I can keep going through this too much longer,*” Erica said. She was exhausted from the strain of balancing utility payments with medical costs while waiting for her new insurance plan to begin, and while coping with illness. Unexplained waiting on bureaucratic systems, whether for an application to be approved or for insurance to kick in or to be seen by a busy doctor in a sliding-scale clinic, felt like an unfair game designed to keep them from receiving necessary medical care.

By framing waiting as a game, the participants explained that there were rules that shaped the length and types of waiting, and that they did not write them. The rules were far from transparent, and enforced differently based on race and social status. As Sherry made evident in her frustration with being made to wait, waiting is not a passive state that happens without mental and physical consequences. When people responded with patience and endurance through the game, just like when they responded with anger and confrontation, their waiting was active. Put differently, participants described fashioning tactics, in part, based on their perceptions of the intentions of those for whom they waited.

3.3. Managing the wait

Participants described waiting as something uncertain, imposed on them by systems and individuals in ways that were out of their control, and yet they also understood waiting to be something to manage. Their efforts were diverse and included actions as varied as moving in with family members or devising daily strategies – such as splitting doses or ordering medication refills early in anticipation of pharmacy delays – to ensure that they had timely access to their medications. While the forms that their methods of active waiting took differed, there were several cross-cutting themes: learning how to spend time or “*toughing it out,*” attempting to change time, and making trade-offs to manage the time.

Waiting was seen as something to be endured, a learned skill that required an ability to “*tough it out.*” It necessitated that people change their behavior to meet the demands of a system that might never yield to them. Jeff explained that when he was younger and struggling harder with finances and drug addiction, he did not want to seek care because of all of the waiting it entailed:

I had no money. No insurance. Every time you go to the doctor, they made you go in the emergency room ... Make you sit over there for 9 hours, call everybody else in before you, you know ... And I went, sit there all night long. That made me not want to go to the doctor ... It is different now. I used to not have no patience to sit there in no clinics. Now, I take a book with me, take a newspaper with me. I know how to spend my time waiting.

Jeff framed endurance in moralizing terms, clarifying that he had learned to wait patiently. He and others talked about tricks for spending time while waiting, such as bringing something to distract themselves or focusing on potential positive health outcomes, to shift their experience

of and feelings about the time that they had to wait. Complying with institutional demands may not have remade the waiting process, but it was a tactic and one response to waiting.

The participants gave detailed accounts of the lengths to which they had to go to reduce the time they spent waiting. Their tactics were often learned through prior experiences and trial and error. For example, a man who had HIV discussed how he dealt with the long waits to see his caseworker: *“I learned my lesson about that. Don’t go in the middle of the day. You want to try to get a nudge up there, be the first one in line. Again, that’s another whole wasted day out of your life because you’re just sitting there all day.”* In some cases, they petitioned their doctors or their doctors’ staff, urging them to give them earlier appointments, or they showed up to the office without an appointment in hopes of being squeezed in. It was often difficult for the participants to know how successful their efforts were, but they had to keep trying as another participant, Anne, demonstrated. Anne had attempted to get disability benefits for years: *“I have been trying for the last seven-six to seven years. Fighting them every inch and nail. Now I’m waiting on a decision now and hopefully this time they will give it to me.”* Her “fight” included hiring a lawyer to push her application through and finally end her waiting.

Anne’s case also exemplifies the trade-offs that people talked about making due to the big waits (e.g., a disability claim) and the day-to-day waiting (e.g., waiting rooms). Anne continued carrying out physical labor at her husband’s business, despite having severe arthritis and diabetes, in order to pay for rent while she waited on disability. This continued work was necessary to meet her everyday needs, even though it was taking a toll on her body. Participants spoke of other trade-offs: they took less than their prescribed dose of medications in order to stretch them out until they could afford to refill, tried home health remedies in hopes of reducing their medical costs, and acquired payday loans to cover utilities. Kate defended her decisions to both sell her food stamps and rely on money from a significant other to pay for her daily expenses while waiting on financial assistance: *“You got to do something to get money.”* She felt that she could not leave a current romantic relationship because she needed her partner’s financial support. Another woman revealed that she had to stop taking some of her medications while waiting for her disability back pay for costs incurred during the application process: *“Took my own self off from my depression and anxiety medicine ... I had to prioritize.”* Prioritizing some needs over others was an important step in determining what to trade off while waiting: medical copays or utility payments, time in a clinic or time with family, medicine or food.

While many participants talked about the great lengths they went to prioritize their medical care, others put off seeking medical care because the wait to be seen by a doctor added stress to their already strained schedules and bodies. Rose had multiple chronic illnesses that she needed care for, but she could not manage unpredictable wait times because she needed time for rest and family before her next night shift, so she often avoided appointments:

I can’t- I can’t sit there that long because I have to get some sleep. I have to be back so I can go to work the following night, you know. So, um, other than that, you know, I have to have it early in the day or if I can’t get it early in the day, I just won’t go. I’ll cancel it.

Other participants sometimes also avoided forms of assistance from welfare organizations because their waiting lists and unpredictability made them unreliable resources. One man decided not to apply for financial assistance with charities because the long wait to hear back made it difficult for him to predict if his bills would be paid in time or not: *“So, if I have to, uh, plead poverty, you know, to get certain help, you know, then you have to wait. I can’t do that, you know. Life is not about waiting, especially when you got to live day to day.”*

The tactics that people used while waiting had consequences. Many interviewees discussed the potential and actual repercussions they juggled in order to manage future situations. These repercussions

included increased medical debt, getting behind on bills, worsening health symptoms, inability to work, wasted time, and much more. Many fluctuated between prioritizing financial or health setbacks:

You got to go to the doctor to find out what is going on with your body. You know that is a must because if you do not, things could get worse and then you-your pay is going to cost more. You know what I am saying, when it gets worse, then the fee will go up. So, you know, I have to do what I have to do. It hurt my pocket though, believe me.

They waited for a time when they would no longer need to “trade off this for that,” but, for many people, trade-offs were vital actions they felt they needed to take. As people waited for employment opportunities, hip replacements, beds in shelters, utility assistance, and ambiguous policy changes, they learned how to structure their lives around waiting. They actively responded in ways to deal with present waiting periods that sometimes put them in worse financial and health situations later. Though they exercised agency when managing waiting, that agency was always constrained.

4. Discussion

People experiencing the combined effects of poverty and chronic illness have extensive experience waiting and they do not wait passively. The participants in our study found and created ways to respond actively, even when their resources were limited. In doing so, they attempted to reduce, avoid, or endure the waits to which they were subjected. We name this, active waiting. How the participants made sense of their waiting experiences, big and small, and then how they managed those experiences and related feelings was rooted in unequal and shifting power dynamics. Expanding our thinking in healthcare to spotlight the active waiting done by individuals moving through (or not) the healthcare system exposes the required, yet unacknowledged, work individuals invest in the systems conceived to care for them. A focus not on delays but instead on active waiting— as feeling and as action produced by overlapping and consecutive waits— allows us to examine more fully the ways that uneven power relations within slow bureaucratic time regulate how individuals navigate their health.

Active waiting provides a lens to see big and small waits as importantly interconnected. Kate, for example, had to manage waiting for housing assistance, disability hearings, and food stamps and in offices, for rides, and on phone calls. Waiting is persistent and reoccurring and layered; it is woven into the everyday lives of people who are poor and chronically ill. Sometimes, waiting on big and small things is manageable, but other times this waiting builds and becomes chronic and cyclical as people wait for application after application to be approved, surgery after surgery, appointment after appointment, phone call after phone call. As interconnected forms of waiting, we can see how big and small waits shape the timing and location of waiting and the tactics people engage to make waiting bearable.

An important insight into waiting was how participants spoke of it as a game, and how the injustices of this game felt to them. The rules of the “waiting game” were opaque and unfair. The participants spoke of feeling as though they were being “tested.” When Sherry was forced to wait after taking painstaking efforts to show up to her appointment on time, she was infuriated, not just because of how her time was disrespected as a patient, but as a Black woman who felt injustices in her body, naming Michael Brown’s murder and other injustices and tying those injustices to waiting on healthcare. She had had enough, and spoke out about the waiting, even if it made little impact on her time waited. Participants expressed a range of other feelings, too – uncertainty, hope, exhaustion, neglect – cultivated within an overarching system that values individual responsibility and self-discipline, but in which social services are never sufficient and racism and inequality are built into the system. Such feelings are necessary to consider as we look to creating more just systems that support human dignity and collective

wellbeing.

By suggesting that waiting is active, we also wish to bring out the work of waiting. Managing waiting is labor. Study participants managed their own and others' emotions as they waited on phones and in waiting rooms and in the homes of family members. We have further shown the cognitive labor of waiting and the more physical work of, for example, doing things for others to make ends meet while waiting on social services. Being forced to wait pushed the participants into positions where they had to calculate their moves—from bus schedules to prioritizing certain basic needs over others, and occasionally delaying recommended medical treatments (Diamant et al., 2004). While such calculations may have been invisible to providers or seen as irrational (Tickamyer et al., 2000), we view them as work demanded by an inequitable system, work that paradoxically further threatens the health and wellbeing of individuals seeking care. Like other forms of labor, the labor of active waiting is gendered, raced, and classed, disproportionately affecting Black and Indigenous women and women of color, who are also poor (Andaya, 2019, 2018a). Rose avoided doctor's appointments due to the long and unpredictable time spent in waiting rooms that could impact other important activities, like getting rest and family time before her night shift. And while Anne waited to be accepted for disability, she continued to do work that exacerbated her arthritis symptoms in order to remain financially stable. These examples show how the work of waiting for care can lead to bodily harm.

Our research adds to the wider discussion on waiting and interactions in healthcare and social services. Several participants positioned themselves as worthy welfare recipients according to state values of deservingness (Tickamyer et al., 2000). They emphasized how long they had worked prior to becoming ill and their desire to work again and be "productive." They distanced themselves from behaviors like doing drugs or spending money on "luxuries" like cable. In hopes of shortening the wait for services, people tried to demonstrate that they were poor enough, sick enough, and desperate enough to deserve assistance. Demonstrating their deservingness of assistance was tied to a sense of societal belonging (Horton, 2004), which may inadvertently condition people not to fight back against injustices and could discourage them from seeking care at all (Becker, 2004). Responsibility, or even blame, is placed on those whose active waiting goes outside of what is expected or advised (e.g., being impatient, delaying healthcare) without acknowledging the influence of social, political, and economic factors.

Waiting is more than a byproduct of resource-scarce systems; it is a normalized type of labor that encourages compliance (e.g., the 'patient' patient (Mulcahy et al., 2010)) or avoidance, which alleviates bureaucratic structures from culpability for the harm that waiting does. As such, we advocate for greater institutional awareness of and responsibility for the repercussions of waiting. Further, as Sarah Horton (2004) points out, the "waiting game" ultimately costs money for hospitals and other agencies that must cover the cost of untreated care, especially underfunded safety-net programs (Armin, 2019). The purpose of this article is not to argue against the provision of welfare or supports, or to argue that they do not have the capability to help. Rather, we demonstrate how such services may serve as "the ground of both poor people's domination and their possibilities of survival" (Auyero, 2011, p. 25) as people wait actively on them. For those who are never able to receive services, or who receive them too late, they are given "false hope" in a system that is not able to provide enough resources within an adequate timeframe (Castañeda et al., 2010). While they wait, they work, both physically and emotionally, toward their desired futures.

4.1. Postscript

Amid the COVID-19 pandemic, so many people are waiting: for doctors' offices to reopen, for delayed unemployment checks, to visit a sick or elderly family member, to be able to resume "life." People living with poverty and chronic illness, and particularly Black and Indigenous people are bearing the brunt of the pandemic and the ensuing economic

challenges. Active waiting encourages us to understand this time, their time, not as paused or static, but as filled with everyday negotiations about how they will manage their health down the road. The structures that force certain people to wait more than others will likely intensify already grave injustices based on race, gender, and class. In light of this, active waiting becomes a crucial concept for understanding, rather than blaming and shaming, and it is a call to reimagine bureaucratic systems to be more humane and compassionate and to reduce the work of waiting.

CRedit authorship contribution statement

Amanda A. Lee: Conceptualization, Investigation, Formal analysis, Writing - original draft, Project administration. **Aimee S. James:** Conceptualization, Methodology, Formal analysis, Investigation, Writing - review & editing, Resources. **Jean M. Hunleth:** Conceptualization, Methodology, Investigation, Formal analysis, Writing - original draft, Writing - review & editing, Supervision.

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