



Narrative arcs and shaping influences in long-term medication adherence

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ABSTRACT

Long-term adherence to medications is not well understood and poses a significant challenge for many chronically ill persons. Past research provides insights on adherence in short durations such as a day or several weeks, even though chronically ill patients are required to take medications for periods as long as a lifetime. To fill this important knowledge gap, we study the temporal unfolding of prolonged medication-taking experiences among thirty adults, mostly African American, with chronic hypertension in the U.S. Specifically, we take an extended, experience-centered, narrative approach to examine retrospective patient accounts of adherence efforts over spans of one year to more than four decades. Applying Gergen and Gergen's concept of narrative forms (1983), we find four distinct narrative arcs, or patterned sequences of medication consumption, that we term Out of the Gate, Existential Turn, Fits and Starts, and Slow Climb, along with individual and social elements that shape and shift practices in the context of time.

1. Introduction

Taking medications as prescribed can be difficult for many reasons ranging from high prescription costs, unwanted side effects, complex dosing regimens, lack of perceived need by patients, and demanding trial-and-error adjustments to name a few (Amin et al., 2020; Muir et al., 2001; Savola et al., 2017). Consequently, approximately 50 % of medications are taken as intended, levels which undermine treatment efficacy and health benefits (Brown and Bussell, 2011; Osterberg and Blaschke, 2005). The adherence challenge is heightened all the more for persons with chronic diseases that are managed not cured. In such cases, medications are usually prescribed for long durations, sometimes an entire lifetime. Yet the longer the requirement, the more susceptible the patient is to stopping medication-taking without medical guidance.

Numerous interventions have been developed and tested with the goal of increasing medication adherence. However, systematic literature

reviews have consistently concluded that existing “methods of improving adherence for chronic health problems are complex and not very effective,” particularly over longer periods of time (Nieuwlaet et al., 2014, 2; Conn and Ruppert, 2017). Despite this lack of success, research into medication adherence continues undeterred. As quoted from Haynes in a 2003 World Health Organization report, the belief persists that “increasing the effectiveness of adherence interventions may have a far greater impact on the health of the population than any improvement in specific medical treatments” (WHO, 2003, 11), a conclusion based on WHO's global study of long-term therapies for chronic diseases such as asthma, diabetes, hypertension, and depression.

Long-term medication adherence requires individuals to modify their lives so that medication regimens are integrated in daily activities and decisions. At the most basic level, individuals must organize their lives to allow medications to be taken at specific times of day. For some, the impact may be perceived as minor. For others, major changes in

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dietary intake, sleep patterns, and/or lifestyle are needed. Additional attention is required for filling and refilling prescriptions within specified timeframes, along with visiting healthcare providers to assess disease management, address new problems, and modify medications when needed. These activities depend on reliable transportation and incur additional costs that challenge some individuals more than others.

Importantly, these adjustments, once made, must be sustained over the life course of a chronic illness. Yet life circumstances can change, potentially affecting adherence efforts and routines. While researchers acknowledge temporality is a critical aspect of adherence (Lutfey, 2005; McCoy, 2009), and fluctuations in adherence are known to occur (Karve et al., 2009; Unni et al., 2016), few have explored adherence over extended periods of time. Medication taking has instead been investigated over several days, weeks or months, or in rare instances one to two years. Hence a critical knowledge gap exists on patients' adherence experiences during long stretches of time. Understanding these experiences may provide new insights for intervention design.

To understand chronic illness medication adherence as it retrospectively unfolds over time, we propose taking an extended, experience-centered, narrative approach to its study. This approach permits temporally tracing occurrences and changes in adherence from the perspective of patients as they recall experiences with medication (Riessman, 1990; Squire, 2013). The questions addressed are what are narrative arcs of long-term adherence, or sequences of medication taking experiences over the years? How are arcs patterned yet distinct across persons suffering from chronic illness? In what ways are arcs shaped by individual and social elements in relation to time?

To address these questions, we interviewed patients being treated for essential hypertension about their adherence efforts from diagnosis to the present, a period varying one to forty plus years. The majority of patients were African American, a group known to suffer more often from chronic hypertension and adhere less regularly to drug regimens than other populations (Lewis et al., 2010). Focusing on this racial minority permitted us to discover potentially nuanced adherence trajectories, and thereby broaden and enrich current understandings of long-term adherence. Hereafter we present the literature background for this study, the concept of narrative forms, the methods and findings, and conclude with a discussion of implications.

1.1. Medication adherence

To determine why prescribed therapies are not followed as instructed, researchers have largely sought behavioral rational explanations. Among these are the theory of planned behavior, self-regulation model, health belief model, and social cognitive theory (Ajzen and Fishbein, 1980; Bandura, 2000; DiMatteo et al., 2007; Howson, 1999). Pathways for adherence have been posited involving personal goals, attitudes, and motivations, alongside traits such as personality, gender, and age (Lutfey, 2005). Nonetheless, the complex realities of consuming, delaying, or foregoing prescriptions are not fully captured by these models as concluded in several reviews of the literature (Pound et al., 2005; Michie et al., 2018; Trostle, 1988).

A promising line of inquiry is patients' quotidian efforts to follow therapeutic regimens. Unlike scholarship on identity disruptions where a malady upends a life (Bury, 1982; Charmaz, 1995), this newer stream of work attends to concrete aspects of managing conditions, including following instructions on what, when, and how to take medications. Huyard and colleagues (2019) for example examine the invisible work of drug consumption and the causes of unintentional adherence, while Reichenpfader et al. (2020) reconstruct three practices of accepting, challenging, or appropriating prescriptions.

We extend this line of inquiry by conducting an experience-centered study of long-term chronic illness medication adherence. By assuming a timeframe of a disease's life course, we aim to understand how adherence evolves over the years, from an inchoate to established or nascent practice. Specifically, we trace medication-taking for hypertension from

diagnosis to the present in retrospective patient accounts. Such narratives have been used for example to determine concerns in and sources of adherence through discourse analysis of women treated for HIV (Sakar et al., 2002), and to surface themes in pain and factors in persevering with cancer therapy (Torresan et al., 2015). Studying patient stories on hypertension, which differs from HIV and cancer by its more somatically imperceptible nature that presents no less a lethal threat (per the "silent killer" label), allows us to extend narrative-based insights on adherence. In this paper, we apply Gergen and Gergen's narrative framework to identify patterns of adherence phases over time. Furthermore, we seek individual and/or social elements that affect and shift adherence periods. Together the patterns and elements illuminate patients' time-related, situational strategies in attempting to create and stay with medication routines.

1.2. Gergen and Gergen's narrative framework

Narratives have long been the subject of chronic illness studies as well as an analytical lens to understand psychological, physical, and social aspects of patients' lives (Bury, 1982). Importantly, narratives go beyond clinical descriptions of disease states by chronicling the emotions, worldviews, and occurrences that together lend meaning for storytellers. A promising framework for delineating the contours of chronic medication adherence is Gergen and Gergen's theory of narrative forms (1983). According to this theory, individuals attempt to build connections among events, producing directionality towards a goal and constructing lives that appear coherent and intelligible to themselves and others.

Gergen and Gergen (1983) specify narratives occur in three forms: progressive, regressive, and stable. Each form assumes an evaluative stance towards a personal valued goal such as adherence, and consists of discrete incidents or images linked across time. Progressive narratives indicate increments towards a goal. The presentation is positive, even if the individual is confronting difficulties. Regressive narratives are characterized by decrements relative to a goal. The presentation is negative, sometimes with the individual anticipating further distance from a desired end. In stable narratives the status remains unchanged with respect to the goal.

While researchers have used single forms for an entire personal account (see e.g. Kelly and Dickinson, 1997; Robinson, 1990), they can be combined to create hybrid narratives (Gergen and Gergen, 1983, 259). Thus, a story may have contrasting periods, such as a progressive followed by a regressive one, rather than fitting exclusively into one form. The longer a patient is asked to take a medication, the more likely changes in adherence occur. Therefore combining progressive, regressive, and/or stable forms in various sequences permits constructing more nuanced narratives that reflect critical differences in medication taking.

Importantly, Gergen and Gergen's theory underscores the individual and social natures of narratives. Although a personal account is produced by an individual storyteller, it is also a social representation to others of self and what occurred and why. An account thus reveals that an individual does not operate in isolation but in relation to others: "Others' actions contribute vitally to the events to be linked in narrative sequence" (Gergen and Gergen, 1983, 271). Given the theory's emphasis on the outside world knitted into the fabric of personal lives, we examine both social and individual influences on medication efforts in addition to the composition and structure of narrative arcs.

2. Study methods and questions

The study method is secondary analysis of a set of qualitative data, or examining already collected qualitative data to pursue new questions and/or apply a distinct theoretical perspective from the primary analysis (Heaton, 2008; Hinds et al., 1997). The data set consisted of thirty semi-structured interviews with patients in the U.S. suffering from

hypertension as detailed hereafter. The interviews focused on the chronology, practices, and dynamics of adherence to anti-hypertensive medications from diagnosis to the present time. The primary analysis explored the circumstantial impacts on adherence using a socio-cultural and -economic frame, particularly the roles of income and race, whereas in this study, we investigated distinctive patterns of narrative movements in chronic illness medication adherence over extended time periods and the roles of individual and social elements. Following guidelines on secondary analysis by Ruggiano and Perry (2019), Hinds et al. (1997), and Heaton (2008), this study was carried out by the same team of researchers using analytic techniques applied earlier, thereby ensuring sufficient familiarity with the data, context, and methods to proceed. All study activities were conducted with full ethics approval from the University Institutional Review Board.

2.1. Sample and interviews

The study was conducted at an academic medical center that serves predominantly socially disadvantaged lower income minorities (i.e., Black/African American and Hispanic/Latino). Patients were recruited within a primary care clinic as they came for a scheduled provider visit. Clinic staff identified potentially eligible patients who were screened by research staff for interest and eligibility. Criteria for participation included diagnosis and treatment for essential hypertension, ability to provide informed consent, and willingness to participate in an hour plus interview at that time. Clinic wait times were common; therefore, many patients welcomed study participation while they waited to see their provider. After obtaining informed consent, patients and research staff met in a private room within the clinic where interviews were conducted in English. A convenience sample of thirty patients participated, consisting of 12 males and 18 females, aged 39 to 77, with a majority African American. The average time on anti-hypertensive medications was 14 years.

Most interviews were completed prior to the provider visit with a few done immediately after the medical appointment. Interviews, each lasting between 60 and 90 minutes, were audio-recorded and later transcribed without identifying information. Interviews began with inquiring about hypertension and all prescriptions, followed by recall of initial reactions to the high blood pressure diagnosis, and of hypertension medication adherence efforts and considerations, including the role of others, from that time to the present. Most questions were open-ended and probing in nature, such as “Tell me more about that?” “Can you explain further about what that was like?” in order to reduce interviewer assumptions.

2.2. Analysis

The analysis was aimed at identifying patterns in retrospective informant accounts of how adherence as lived experiences altered or held steady over extended periods of time. The analysis for the secondary study began with members of the multidisciplinary research team reading transcripts and noting themes. These themes were discussed in team meetings, where quotes were shared from transcripts along with observations made during the interviews. Themes were proposed about adherence from an experiential perspective.

Thereafter the first author in collaboration with the other researchers analyzed the transcripts further by reviewing across personal accounts taken as wholes. As noted by Bury (2001) in referencing Riessman (1990, 1195), “... this approach does not fragment the text into discrete categories for coding purposes, but, instead, identifies longer stretches of talk that take the form of narrative – a discourse organized around time and consequential events in a ‘world’ created by the narrator.” The analysis required moving iteratively back and forth between the data and emerging insights per the interpretive procedures recommended in Squire (2013). Each narrative was treated as a story of human actions, including thoughts and feelings, towards resolving, clarifying or

unravelling a situation, in this case the challenge of adherence (Polkinghorne, 1995).

As the analysis evolved, the research team discussed the emergence of extended story lines, or progressions of events, in informant accounts of years-long efforts to adhere. These lines, characterized by changing actions and postures toward adherence at different points in time, became apparent by attending to the patients’ life course of managing the disease and therapies. In other words, by not truncating the adherence experience into a period as short as say a day or week, we were able to interpret medication taking as temporally discrete phases of stable, regressive, and progressive experiences. Also we allowed for complexity in informant stories by combining some or all narrative forms in varying order where evidenced. In addition we identified individual and social elements that corresponded with narrative shifts.

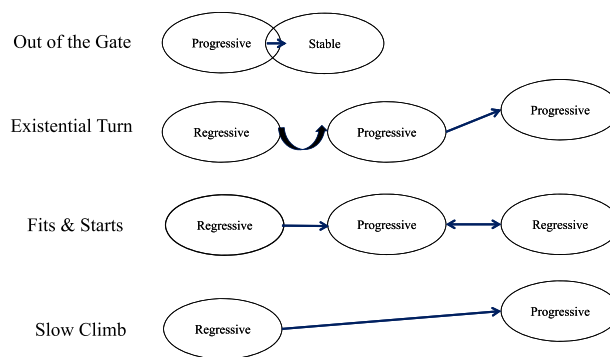
3. Findings

The analysis revealed long-term adherence experiences follow four narrative arcs that we termed Out of the Gate, Existential Turn, Fits and Starts, and Slow Climb. Each arc contained a succession of one or more narrative periods that together distinguished the nature and directionality of medication taking over several years (see Fig. 1). Consistent with Gergen and Gergen’s narrative concepts previously introduced, we refer hereafter to periods when practices and postures reflect 1) moving towards adherence as a goal as “progressive,” 2) moving away from adherence as “regressive,” and 3) not moving much if at all as “stable.” In addition, the analysis showed periods accompanied by individual and social elements impacting medication-taking.

3.1. Out of the gate

In this story arc a progressive narrative of movement toward adherence was soon followed by a stable narrative of non-movement as diagrammed in Fig. 1. The stable overlapped partially with the progressive so they were almost simultaneous, with the two together characterizing the adherence endeavor as a whole. In the progressive narrative, individuals strove to adhere from the outset, or from the moment of diagnosis, which occurred two to twenty-five years prior to the interview. During the progressive period, individuals described intensive attempts to adhere to their medications. They altered eating, sleeping, working, and other life structures to accommodate the medications. Efforts centered on formulating a regular medication routine, such as by writing out a schedule, placing bottles in plain view, and setting up alarm clocks. Practical ways of integrating medicines were tried, including keeping track of what was swallowed when. One

Figure 1. Narrative Arcs in Long-Term Chronic Illness Medication Adherence



Key: Spheres indicate narrative forms and arrows indicate directionality in adherence over time

Fig. 1. Narrative arcs in long-term chronic illness medication adherence.

patient, coded as TA, shared a simple yet useful system she had devised:

'It's just something you do. You just remember. All of the medicine I haven't taken I leave it up sitting upright. When I take it at night, when I need to take it, I turn the bottom up so that I know the next time. That's something I do.' (TA)

Once these medication taking methods were created, the stable narrative appeared in claims of consistently applying them, such as by not missing scheduled doses even with unpleasant side effects. Consistency was motivated by not wanting to die; not wanting to feel sick; not wanting to be hospitalized; and not wanting to suffer a stroke, blindness, paralysis or amputation. The discourse was avoidance focused, or staying away from a bad outcome (Crowe and Higgins, 1997). As noted in previous works, such efforts acted as an insurance policy against future preventable complications (Lutfey, 2005). If non-adherence was believed to invite irreparable consequences such as death, the inclination to follow physician instructions was high (Charmaz, 1997, 156). An interviewee explained the logic of adherence:

'I thought if, you know, like if I skip will I, you know, have an asthma attack? If I don't take my blood pressure medicine, will I, you know ... have a stroke or something like that? It worried me for a minute, so I just made myself a calendar and put it all down and take them [pills] like that.' (JU)

Several individual and social elements appeared along with this narrative arc. One individual element was the perspective of self-responsibility, or being disciplined enough to organize, implement, and sustain therapeutic routines. Hence the act of consuming medications—while sometimes involving others—emphasized what patients themselves could do through intentional, conscientious effort.

'But when it comes to my health, I take full responsibility. So I had to discipline myself. Some days you wake up and say, 'Take the medicine. Don't go back to sleep.' I'm very strict with myself, you know.' (KA)

The posture of self-responsibility was consistent with, and perhaps an outgrowth of, the increasing emphasis in medicine on placing patients in charge of their own health and well-being. Patients are encouraged to participate actively in therapies prescribed to them, with risk factors and related information highlighted to increase disciplined choice-making (Howson, 1999).

In addition, patients professed to educating themselves about their illness and medications, including potential interactions among drugs, expected benefits from consistent use, and effective dosing levels and times. The information helped to catalyze the progressive phase and a shift to the stable by providing impetus and guidelines for adherence. While both informal and formal information was sought, interviewees looked more to authorities, particularly physicians. Congruent with self-responsibility, the posture was not passive and unquestioning acceptance, but rather active and critical solicitation of medical expertise in order to self-initiate ways of adhering. When one patient was asked how she responded to first being told to take a drug, she replied, "Well, I always ask questions what it's for and what the side effects ... you know, what it's for." She and other individuals indicated freedom to discuss with physicians the effects of medications on their illness and body, conforming perhaps to the traditional "sick role" of patients as seeking and relying on the expertise of doctors in contrast to "bad" patients who question the legitimacy of medical institutions and are difficult in clinical encounters (Deml et al., 2020; Lumme-Sandt et al., 2000).

Along with the above individual elements, a social element that surfaced as an influence in the Out of the Gate arc was the negative model. The negative model was a personal intimate who vividly demonstrated the perils of failing to adhere. Interviewees mentioned immediate family members who ignored hypertension and other chronic conditions and then suffered grave consequences, including strokes,

heart attacks, and amputations. The events burnished frightening memories of what could happen with noncompliance, and kept individuals on the path of adherence. Such events are not uncommon in the African American community. The highest incidence of hypertension in the U.S. occurs among African Americans, who suffer a three times greater likelihood of heart-related death relative to Whites (Cuevas et al., 2017; Flack et al., 2010). One patient sadly recalled her mother was stricken with aneurysms and ended up in a nursing home with no one but her visiting. It was a fate she decided to avoid.

A second social element, also propelling the stable narrative, was the potential impact on others from refusing or forgetting to take medications. Individuals expressed how they did not want to be a burden on others by poorly managing their hypertension, forcing family members to take care of and house them. This perspective extended to concern about how infirmities, if furthered by nonadherence, would limit what they do for others. If they became disabled, interviewees noted keenly that those who relied on them would pay the price: 'That's probably another reason I'm on these pills, you know, take my medicine like because I tell myself if I can't be here to take care of myself, how am I going to take care of those kids?' (JU)

3.2. Existential turn

In the Existential Turn, the narrative arc was initially regressive in a movement away from adherence, followed by two progressive movements towards it. Distinctively, the change from regressive to progressive was triggered by an existential crisis, while the subsequent shift from the first to second progressive period was propelled by reformulation of the personal valued goal. Importantly, these movements occurred over protracted time—in one case as long as 27 years. Some individuals were diagnosed with hypertension in their teens or early twenties; yet regardless of age of diagnosis, the initial response was not to take the disease and thus treatments seriously, as relayed by one interviewee:

'I was a 22-year old kid getting out of college, partying, drinking I would get to go probably like 50 White Castles [mini hamburgers] and eat them in one sitting. When you're that age ... it feels like ... you're indestructible. So I was skipping [medications]. I would be like I'm not taking all this stuff today. This is crap. I don't have time.' (DA)

The regressive narrative emphasized how being younger meant not having to depend on pills. While sporadic adherence attempts were made, instructions were mostly ignored with the rationalization of 'I'm okay ... you know, I'm young.' (SH)

Nonetheless continual lapses in medication taking along with disease progression took a toll, leading to an existential crisis that forced recognition of the gravity of the illness. For some, the crisis was a life-or-death event, such as nearly dying from a heart attack in the middle of work, whereas for others it was a subtler, but no less vivid internal awakening followed by resolve to take care of one's health. The crisis presented a key juncture in the narrative arc where the regressive passage gave way to a progressive one, initiating a shift towards adherence. Given the intense emotional force of the existential crisis, personal meaning structures were altered (Frank, 1995; Gergen and Gergen, 1983).

Specifically, the crisis reframed what was at stake and thus spurred willingness to adhere. A patient described having two heart attacks, followed by an unexpected replacement of her pacemaker after a car accident. She said, "I was scared because I thought I was going to die. They talked to me about the medications and I just said, 'What the hell? I'll start taking them'" (ES). The crisis in this instance was a new pacemaker, not the first or second heart attack. Thus, multiple major difficulties might occur before the existential moment arrives and a turn is made towards routinizing medications.

Once tangible benefits from following prescribed therapies began appearing, such as greater energy or fewer hospitalizations, the goal of adherence was recast as a higher goal of achieving full health. The possibility came into view of being off of medications entirely upon achieving normal blood pressure and a high state of well-being. As a consequence, new health practices were pursued, including daily exercise, weight control, stress management, and a diet abundant in fruits and vegetables. The time frame was thus extended into a positive long-term future, as relayed by DA.

'I want to wake up and on my own terms. I don't know anyone who wants to take medicines all the rest of their life besides vitamins. That's got to be the goal. I'll show you a person that tears up a \$90 million lottery ticket, because no one wants that responsibility.'

Among influences for this narrative arc was the individual element of 'before and after' selves. Having undergone a life-altering event and epiphany, individuals retrospectively saw pre- and post-crisis versions of themselves as a consequence of their health struggles, even years later. Critically, the dual images formed a powerful tool to stay the progressive course towards adherence initially and medication independence subsequently. DA relayed how he compares how he is now versus prior to a massive heart attack and dramatic weight loss, using an old photo of himself to stay motivated:

'Yeah, I am proud of myself too ... It's confidence, and it's indescribable ... I mean 400 pounds [former weight]. The struggle and everything I had to do. I will never go back ... I have a picture, and I look at that picture every day, and it reminds me of the person I used to be.' (DA)

A social element pushing this narrative arc along progressive paths were trusting relations with healthcare providers. These relations went beyond mere solicitation of information found in the Out of Gate narrative; instead, patients formed motivating emotional bonds with providers while pursuing adherence and health goals. Individuals looked to these professionals to advise them on taking medications as well as managing their health to be cured eventually of their chronic disease. The openness to advice reflected a promotional focus on personal growth and change (Crowe and Higgins, 1997): 'It's just I like this hospital and they take their time, and they share the information. They'll tell you what something is for. Well, this pill is for this, and it's going to do this, and we're going to monitor this, and then let's see how you're doing with this and maybe we can wean you off of it. I tell everybody about this hospital. I love this hospital.' (MA). Such openness can also be intentionally cultivated by physicians who, through empathetic and personal connections, persuade patients to follow treatment instructions (Lutfey, 2005).

3.3. Fits and starts

Compared to the strong adherence thrusts found in the narratives of Out of the Gate and Existential Turn, the arc of Fits and Starts consisted of alternating progressive and regressive movements, as reflected in repeated cycles of striving to adhere followed by waning efforts, respectively. The Fits and Starts arc began with a regressive narrative, where prescriptions were met with disbelief that drug taking would make much of a difference, or where concerns lingered that medications could do more harm than good. NA, a 74-year old retiree, provided a glimpse of such concerns as tied to fears of broader consumption risks:

'You sit there and look at that television, and what do you see? Something is wrong with the cow. Something is wrong with the pigs. Something's wrong with everything you can put in your mouth.'

In this regressive period, which lasted for quite a while, attention to hypertension and fidelity to medications were described as 'lackadaisical.' Individuals reported thoughts about the therapies they were

asked to follow, trading off the putative benefits of adherence for the concrete experience of feeling fine—for the present moment—without them:

'I feel that I don't want to do it. I don't need it. You know, you might say I don't need it today. I mean I just don't need it. For what? You know, it's just like oh, your body is not producing something that it used to ... the medicine is helping, but you just get lax on it.' (BE)

Over sustained stretches of nonadherence, however, swelling, sweating, and headaches, along with urgent care admissions for dangerously high blood pressure, occurred. These incidents brought to fore the malady's real dangers. A patient recounted how a pleasant afternoon bike ride turned into a 'terrifying' nightmare when a nosebleed started and wouldn't stop:

'I'm feeling like I'm at the end of my rope. It's like okay, if the ER can't stop my nose from bleeding then it's either going to have to stop itself or it's never going to stop. And if it never stops, then this is the end of my life' (BA)

Unlike the personal awakening in the Existential Turn narrative, episodes of vulnerability to hypertension did not prompt a clear and lasting shift toward adherence. The episodes were ignored or quickly forgotten, maintaining a regressive narrative of nonadherence through partial or tentative efforts of medication taking that were superficially progressive. Indicative were vague descriptions of adherence practices or statements of sporadic and contradictory actions, for example of walking by a bottle but not recall having taken the pills, or being told to take pills three times a day before each meal but doing so just once a day.

Although attempts were made to take the pills out of momentary mortality fears, once the memory of a recent trauma faded, individuals reverted to a regressive mode of skipping medications. Another unexpected hospitalization or troubling somatic event could then trigger a renewed commitment to the treatment, swinging the narrative back into a progressive direction. The cycle between regressive and progressive movements would thus repeat—a vacillation suggesting sustained adherence never took deep hold.

Several individual and social elements contributed to the regressive movements. While costs, side effects, dosing complexity, drug interactions, and prescription changes have been documented as reasons for medication lapses (Muir et al., 2001; Savola et al., 2017), we found the belief that adherence was a matter of personal will or strength of character to be an individual factor. Critical self-descriptions in relation to drug regimens (e.g. 'I'm a lazy bum') were tied with fatalistic outlooks on health (e.g. 'the chickens are coming home to roost'). Hence when told by doctors to stick to medications, lose weight, or eat nutritiously, some patients attributed their non-adherence to an inherent character flaw:

'So it's like, you know, okay you're 32, 33 years old. You're a little overweight. Go lose some weight and you'll be okay. Well, I never did that because I'm not very disciplined.' (BA)

Another individual element was refusal to rely on medications to conduct life, and more generally a reluctance to be told what to do, whether by physicians, friends, or family. A patient shared that she did not want to be 'a walking medicine cabinet,' while another confessed to emptying out her pill box (i.e., disassembling) before seeing the pharmacist to avoid being scolded and needled. Retaining autonomy and control was important as an act of resistance or defiance, reasserting power and competence over self, the illness, and relationships with healthcare providers (Mifsud et al., 2019).

'There has been points in life when I just said I'm not taking all these pills anymore. I'm going to strike and not take any, and you know, I'm the ring of fate. Yeah, I did that a couple of times. I've been defiant at times.' (CO)

A related social element were tense relations with medical authorities. In some cases, individuals indicated they were not empathically listened to or understood by hospital or clinic staff. They felt at times condescendingly treated. To avoid conflicts, individuals went to other health resources, including printed matter, if they wanted information on medications.

'I read instead what the pharmacist gives you on the paper, the side effects. And then the doctors ... don't know what you go through every day. They only go by what they see damn right then and there.' (FR)

'I don't like their method ... because you had to bring them (pills in monthly pill box) in, and then they want us to know what day did you miss. I just tell you what days I missed. I'm not a child.' (CO)

Turning to alternative sources of medication information was a reasonable response to difficult interactions with physicians and other clinicians. Although individuals in our study did not describe these interactions as racially based, evidence is mounting that implicit social biases in medical institutions erode minority patient trust in and communications with healthcare professionals, leading possibly to lower medication adherence. In addition, African Americans have been documented as receiving poorer quality and intensity of healthcare, including pharmacological therapies (Ben et al., 2017; Mayberry et al., 2000; Williams and Wyatt, 2015).

3.4. Slow climb

The Slow Climb narrative arc began with a regressive narrative of movement away from adherence, similar to the stories of Fits and Starts and Existential Crisis. However, the regressive phase characterized nearly the entire course of the disease, in some cases as long as ten to thirty years, before transitioning to a progressive narrative toward adherence much later in life. We refer to the arc as the Slow Climb because of the very protracted period of intentional non-adherence compared to a recent and shorter time of more regular medication consumption.

In the regressive narrative, interviewees described living with hypertension as a distant concern. While they experienced occasional breathing difficulty and other symptoms, they also had times of little to no discomfort. Asymptomatic periods occurred off and on, leading to dismissing physicians' warnings and instructions to adhere. DW, who had been diagnosed ten years prior, explained that he delayed filling prescriptions because he 'wasn't having the symptoms like everybody else, like getting dizziness' since he 'just sweated a lot.' Therefore, a personal calculus determined condition severity and drug need.

Compounding nonadherence was the nature of hypertension, which could not be entirely or predictably controlled. Like diabetes, hypertension's stochastic nature makes it difficult for sufferers to avoid the condition's ups and downs, even with disciplined efforts. Individuals shared how medications that worked at one point did not at another, requiring doctors to experiment with and change drugs and dosages. The see-saw experience went on for years, causing frustration and raising doubts about treatment efficacy:

'Sometimes medicine don't even control it. The doctor tells you I'm probably one of the people that it's hard to control my blood pressure. I've watched my salt intake, but it still doesn't work. I'm taking that medicine. It's not doing anything.' (TE)

Periodic forgetting, changes in routines, and especially side effects are well-known impediments to adherence that added to the difficulties. Side effects ranged from the inconvenient and distracting (e.g. nausea and headaches) to the intolerable and near fatal (e.g. mental fog and kidney failure). Even sexual activities were negatively impacted and dissuaded medications. Informant AM referred repeatedly to the medication 'taking my nature,' or causing erectile dysfunction, which he

would avoid by going on drug holidays.

As individuals aged and more complications from hypertension and other comorbidities materialized, a progressive narrative appeared, usually well into middle age or older. One interviewee (WI) recognized the erosion in her health over time: 'My health never came across my mind till I got older. We have to get older, then it [hypertension] would affect me. It has affected my walking. See ... my legs are swollen.' Fifty-nine-year-old TH pointed out that he had had two heart attacks and two strokes. Since the second stroke five years prior he had been diligent about watching his blood pressure: 'It took a while for me ... I had to use a cane, you know, for arthritis too. I had my good days and my bad days. I couldn't even feel on my right side. Nothing.'

After multiple hospitalizations and/or more physical limitations, individuals began incorporating medications into life structures. Another patient explained how she had organized her pillbox, set a time to take its contents, and arranged to have a reminder call from a friend. In the morning, she took her thyroid pill first, waited an hour and took an acid reflux tablet, ate breakfast, and took the hypertensive and other pills. At lunchtime, she swallowed a diabetes drug. If she went out, she made sure to take the lunchtime pill with her, so she did not miss it.

Among social and individual elements influencing the progressive movement were a support system and religious faith. The social element of a support system took on prominence in the progressive narrative. Interviewees mentioned spouses, siblings, in-laws, children, friends, and even grandchildren reminding them to take their medications.

'You know my grandchild would say, 'Grandma—or they call me Cee Cee—did you take your medicine Cee Cee?' I'm like 'Yeah boy, I took my medicine. Yeah, I remember. I have my grandkids over the weekend.' (RU)

Spouses played a particularly important role of medication providing, monitoring, and prompting, sometimes to the point of being irritants. Other family members were also helpful. One person claimed he had six sisters who phoned him every day to check on him about medications. These social ties were also critical in assisting individuals to learn about their conditions and therapies. A spouse read the pharmacy pamphlet accompanying a prescription that relayed the conditions of use; a son or daughter researched the drug on the Internet and passed on the warnings about side effects; or a doctor friend provided directions on dosage, encouraged regular intake, and elaborated how the medication targets the condition. Unlike in Out of the Gate, however, the learning was exclusively through personal sources and passively received, not actively sought.

Religious faith was an individual element that contributed to the progressive narrative as well. Having lived through significant health and other personal challenges, some patients shared that they would lean on God through prayer for help staying well and with medications. Others noted returning to their faith after a long absence, for example by resuming attendance at a Catholic church. Individuals who were single or had estranged family relations looked to their religious faith for support and encouragement. They expressed gratitude for being taken care of by God and for having survived thus far: 'I don't have family, sad to say. I have some cousins. The one that lives here, she doesn't keep in touch with me I won't even ask of that, but God is blessing me.' (WI)

4. Discussion

To understand chronic illness medication adherence over prolonged durations, we studied thirty retrospective accounts by adults, mostly African American, who had lived with hypertension and been prescribed medications for one to forty plus years. We applied an extended, experience-centered, narrative approach to obtain a patient-focused view anchored in life circumstances, and—by drawing on Gergen and Gergen's concept of narrative forms (1983)—to trace key health events and medication shifts in temporal order (Riessman, 1990; Squire, 2013).

Specifically, we found four distinct narrative arcs reflecting varying sequences of regressive, progressive, and stable times of adherence: Out of the Gate, Existential Turn, Fits and Starts, and Slow Climb. In addition, we identified several individual and social elements that shaped lived experiences of managing illness and medications, such as before-and-after selves and distrusting relations with medical authorities. We therefore highlight impacts on adherence over the life course, revealing nuanced ways medication practices evolve over time as conveyed in patients' stories and helping to address a knowledge gap on long-term adherence behaviors.

Several findings are worth noting. With the exception of Out of the Gate, all other arcs were characterized by a deep and long struggle with adherence. This finding is consistent with the reported rates of adherence, which remain low despite major advancements in pharmacologic therapies (Nieuwlaat et al., 2014). Even when consequences of nonadherence were life-threatening, resulting in sudden emergency room visits or repeated hospitalizations, individuals often rejected regular medication taking.

Importantly, the fact of struggle suggests how adherence was not a simple mechanical exercise of popping pills on a schedule, but an inefably complex human act reflecting intra- and extra-personal circumstances. A second observation is that durations and slopes of narrative movements were not uniform. For example, the progressive phase was quite brief for the Out of the Gate arc since it was almost concurrent with the stable period that followed; by contrast, a long, low slope characterized the progressive narrative found in the Slow Climb, corresponding with gradual encroachments from aging and disease that prodded individuals to adhere more.

Thirdly, the content or nature of a phase could differ. In the Existential Turn, the first progressive movement was focused on taking medications to stave off, say, another near-death episode. Yet the second progressive movement aimed at a higher and broader goal of full health that no longer required medications. Fourth, the fragility and difficulty of adherence was highlighted by the finding that only one of the four patterns, Out of the Gate, resolved in the stable narrative form, i.e. in some reasonable and sustained achievement of adherence. The Fits and Starts swung repeatedly between progressive and regressive modes, falling shy of a lasting and unproblematic medication regimen. Though more positive due to progressive paths, the Slow Climb and Existential Turn arcs also ended without permanence around adherence.

Next, the individual and social elements that helped spur, alter, or form narratives could be viewed as independent influences but were likely inter-related, supporting or strengthening the thrust of each distinctive arc. In the Existential Turn, the social element of deep emotional bonds with healthcare providers prodded the second progressive phase of striving to achieve full health without medications. By inducing openness to advice on stress management, weight loss, and nutritious eating, along with medication taking until full health was established, deep bonds with clinicians furthered this progressive thrust. Another impetus came from the individual element of before-and-after-crisis selves. As comparative self-images were brought to mind, they motivated implementing health recommendations and staying on a progressive course.

Lastly, long-term adherence was partially shaped by racial minority status. Because African Americans experience higher rates of hypertension, they are more likely to have family, friends, and neighbors who are afflicted. These relationships and poor consequences from the disease spurred individuals in the Out of the Gate trajectory to avoid similar health fates by keeping to medication routines. Yet for those on the Fits and Starts arc, racialized encounters in medical settings dissuaded consulting with healthcare professionals, which in turn might have lowered following medication instructions.

4.1. Limitations

This study has limitations in that the participants were all recruited

from a single urban medical facility. Their narratives are not representative of all persons with chronic illness and all stories of adherence efforts. The strength of qualitative methods as used here is accessing informants' experiences, while gleanings about the nature and dynamics of those experiences, in this case over extended periods of time. In addition, the factual veracity of stories cannot be determined; however, this is an inherent limitation of qualitative research. Future studies are needed that examine the issue of adherence among different populations and chronic illnesses to identify other possible narrative arcs and determinants.

4.2. Implications and conclusions

By applying and connecting narrative forms, we reconstructed four narrative arcs of extended medication-taking and their shaping elements to outline how adherence is experienced differently among the chronically ill. Although the findings are specific to hypertension, they may apply to long-term medication efforts to manage other chronic conditions. Critically, we go beyond the view of adherence as a single-point-in-time decision made by all individuals, such as reflected in the health belief model, to present it as mutable periods of being nearer, further, and stationary from the medical standard over a life time. Clearly, there is no uniform experience, as years can be spent in one state—whether regressive, progressive, or stable—before moving to another.

The study raises implications for healthcare practice where providers may inaccurately assume that patients with poor adherence are unlikely to change over time. While adherence is increasingly acknowledged as complex, leading to the development of intricate interventions (Nieuwlaat et al., 2014), the underlying assumption is that the solution will be the same, such as electronic reminders or motivational interviewing, for all who suffer lapses in medications. Based on evidence from this study there are at least four subtly distinct paths of striving to adhere, pointing to the need for adherence assistance to differ by arc and phase. Furthermore, individual and social resources may be identified to propel actions toward progressive and stable phases as described further below, in recognition that adherence is not an immediately lasting state.

In addition, given the finding of narrative arcs, it may be useful in clinical settings to ask patients about their past medication taking in extended time frames to identify which consumption pattern they may follow and where in the evolution they may be. More typically, patients are queried about their present adherence, for instance by asking, "Are you taking your medications?" or "How many days did you miss taking them this past week or month?" If a more transparent and honest dialogue were to occur, acknowledging that adherence usually changes over the years, in part due to the indefiniteness and uncertainties of chronic conditions, it may be possible to determine which arc and stage a patient falls in and provide appropriate coaching and aids to encourage entering or remaining in progressive and stable periods.

Based on the above determination, individual and social influences on adherence can be pinpointed and directed towards improving medication taking as an intervention approach. For instance, a patient who seems to be following the Slow Climb can be supported towards a progressive phase with the help of a spouse or religious faith, and therefore these two forms may be discussed and incorporated as part of the larger therapy. Similarly, an individual who appears to be in the Fits and Starts path may be sustained in the progressive phase and not revert to the regressive by addressing self-expectations of adherence failure. The role of proper expectations is known to be crucial in positive health behaviors (Anderson et al., 2007).

We conclude with hope these findings will spur other narratively oriented studies on chronic illness medication adherence. We aimed to explore a significant knowledge gap on adherence, which has been studied largely through cross-sectional snapshots even though patients afflicted with a chronic illness are asked to take medications indefinitely. Our findings may be used to formulate more effective interventions to improve proper consumption of prescribed medications

and thus the quality and extension of life.

Data availability statement

The data that support the findings of this study are available from the corresponding author (CN) upon reasonable request.

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Ethics approval statement

The study was reviewed and approved by the Institutional Review Board at the University of Illinois at Chicago.

Patient consent statement

Informed consent was obtained from all study participants following the protocol approved by the Institutional Review Board at the University of Illinois at Chicago.

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Authors' contributions statement

Lisa Sharp: Conceptualization (supporting); data curation (equal); formal analysis (supporting); investigation (equal); methodology (equal); project administration (equal); writing (review & editing-supporting). **Cheryl Nakata:** Conceptualization (lead); data curation (equal); formal analysis (lead); funding acquisition (lead); investigation (equal); methodology (equal); project administration (equal); writing (original and revised manuscript-lead, review & editing-lead); visualization (lead). **Jelena Spanjol:** Conceptualization (supporting); formal analysis (supporting); funding acquisition (equal); writing (review & editing-supporting). **Anna Shaojie Cui:** Conceptualization (supporting); formal analysis (supporting); funding acquisition (supporting); investigation (supporting). **Elif Izberk-Bilgin:** Conceptualization (supporting); formal analysis (supporting); writing (review & editing-supporting). **Stephanie Crawford:** Conceptualization (supporting); formal analysis (supporting); funding acquisition (supporting); writing (review & editing-supporting); **Yazhen Xiao:** project administration (supporting); writing (review & editing-supporting)

Declaration of competing interest

There are no conflicts of interest for any authors.

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