Title

An Inquiry into Medication Meanings, Illness, Medication Use, and the Transformative Potential of Chronic Illness among African Americans with Hypertension.

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Acknowledgements

We express our gratitude to the participants of this study for sharing their perceptions regarding their medications and illness experience. The physicians and pharmacists at the community health center where this study was conducted are thanked for their cooperation during the data collection process. We acknowledge Dr. Stephanie Crawford and Dr. J. Warren Salmon for their valuable contributions during the study's development. We also acknowledge Dr. Donna Enersen and Dr. Kimberly Plake for comments on an earlier draft. Appreciation is extended to Pharmacia Corporation for providing financial support for this study.

Abstract

Background: Hypertension is a chronic illness with serious economic and clinical consequences. The asymptomatic nature of this condition contributes to the challenge of persistent medication use.

Objectives: The objectives of this qualitative study were to explore perceptions of medication meanings, illness, identity, and biographical disruption among people with hypertension and to examine how salient themes and categories relate to medication use.

Methods: In-person interviews were conducted with 20 participants. Eligibility criteria included being 18 years or older, diagnosed with hypertension, and currently taking antihypertensive drug treatment. Interviews were tape-recorded and transcribed. Data were analyzed with grounded theory methodology employing coding techniques and constant comparison.

Results: All participants were African-American and most were between 45 to 64 years. Key themes including perceptions of the medication being effective, life saving, part of life, and a reminder of the regimen were found to have a positive impact on medication use. Themes including fear of side effects, fear of dependency, forgetting to take medication, the medication being a hassle, and the experience of medication related sexual side effects were found to be negatively related to medication use. Participants were cognizant of consequences of uncontrolled hypertension and illness control was important to them. Biographical disruption was minimal. Taking medications and changing diet were the most significant changes in the lives of participants after being diagnosed with hypertension. Achievement of lifestyle modifications had a positive impact on identity.

Conclusions: Findings contribute to our understanding of medication use behavior and have implications for patient education and counseling.

INTRODUCTION

Cardiovascular disease and stroke have been identified as the first and third leading causes of death in the United States.[1] Hypertension is well recognized today as a leading risk factor responsible for coronary heart disease.[2] Results from the 1999-2000 National Health and Nutrition Examination Surveys indicate that hypertension and pre-hypertension were prevalent in approximately 60% of the adult U.S. population with evidence of a 10% increase in hypertension prevalence during the past decade.[3] However, hypertension control was reported only in 31% of individuals diagnosed with hypertension.[3] Over the last three decades, a number of effective medications have been discovered, developed, and improved for the treatment of hypertension. Medication adherence is crucial to hypertension control and has generally been defined as consumption of 80% of the prescribed antihypertensive medication.[4, 5] Only 50 percent of people with hypertension regularly follow advice concerning dietary regimens, physician appointments, and drug therapy.[6] Hypertension, termed the "silent killer," is primarily asymptomatic,[7] resulting in an absence of a compelling reason to persistently take medication. This aspect of the condition contributes further to challenges related to medication use.

During the last 30 years, sociologists, anthropologists, nurses, and other qualitatively-oriented health researchers have developed a comprehensive theory of chronic illness and the role of medication in illness management.[8-11] This theory is strongly influenced by symbolic interactionism social constructionism.[12, 13] On this account, the impact of illness is not the direct result of physiological defects or physical impairments. Instead, it is shaped by personal and cultural interpretive processes that give meaning to the lived experience of illness.[14, 15] In order to understand how and why patients follow (or choose not to follow) treatment regimens, one must understand the meanings that individual patients attach to their illnesses and their treatments.[16-21]

Meanings are described as "fundamental to people in perceiving, interpreting, and defining symptom states and in motivating them to seek care"[22] and play an important role in the formation of human behavior. According to the symbolic interactionist notion, meanings are derived from social interaction, and emerge from individual and collective interpretations.[23] These meanings, therefore, do not arise in a vacuum. Rather, as many authors have noted, the significance of an illness can be understood in relation to the sick person's unique identity, biography, and cultural background. Identity refers to "attributes, actions, performances, and appraisals of self."[24] Chronic illness can disrupt plans, performances, and meanings, which formerly contributed to valued appraisals of self resulting in loss of previously valued self-image or appraisal without reconstruction of a new, valued self-image; an experience described as "loss of self."[25]

Related to loss of self is the concept of biographical time. The three major dimensions of biography are conceptions of self, biographical time, and body.[26] Biography revolves around time and biographical time refers to past, present, and future time in which self conceptions are formed and embedded.[26] Chronic illness interrupts performances and biographical time resulting in what is termed "biographical disruption."[26] These two related notions: (a) that chronic illness brings about a loss of self,[21-29] and (b) that chronic illness constitutes a biographical disruption,[30-35] have become cornerstones of qualitative research on chronic health problems. Against this theoretical backdrop, the goals and motivations underlying a chronically ill person's treatment decisions become clearer. People with chronic illness are primarily motivated to slow or reverse the illness-induced loss of self and to restore continuity to their disrupted biographies.[36] Understanding the ill person's situation in these terms allows one to make predictions about treatment adherence. If a recommended treatment is perceived to assist in slowing or reversing loss of self or in restoring continuity to one's biography, then the recommended treatment will be followed. If it is perceived to obstruct goals related to identity or biography, then recommendations may be modified or ignored.[37, 38]

This general perspective on chronic illness has stimulated a large body of research and has led to important insights about the experience and management of chronic illness. However, most of the work in this tradition has focused on people with serious, often life-threatening, illnesses, injuries, and disabilities. The illnesses studied, including schizophrenia,[42] chronic fatigue syndrome,[31] major depression,[40] multiple sclerosis,[32] asthma,[41] and epilepsy,[42] among others, are often serious enough to cause unambiguous biographical disruption and loss of self. Studies of such serious illnesses illustrate important themes and demonstrate how people grapple with problems more or less successfully. But not all chronic illnesses are the same. Some illnesses, such as hypertension, are largely asymptomatic. There is a paucity of research on whether and to what extent the themes of identity damage, medication meaning, loss of self, and biographical disruption resonate among people with less obviously intrusive illnesses.

Investigating the impact of medication and illness meanings on medication use in hypertension, and the effects of identity transformation and biographical disruption is significant in increasing our understanding of how people manage this condition, its prescribed medication regimens, and the associated impact on daily life. In order to explore these questions, we chose to interview people with hypertension. The purpose of this study was to explore and describe the salient themes, patterns, and categories in participants' meaning structures related to medications, illness, biographical disruption, and medication use and to examine how these patterns can be linked with one another. In doing so, we sought to extend and elaborate on the themes of identity change, medication meaning, and biographical disruption that have been so central to the sociological analysis of chronic illness.

METHODS

Design

An exploratory qualitative study was conducted using in-depth interviews. This study was conducted using procedures of grounded theory methodology. Although grounded theory methodology is most often used to generate and develop theories, it can be applied to a study that is more descriptive in purpose.[43] The steps involved in conducting the study included (1) conducting in-person interviews using a semi-structured interview guide, (2) theoretical sampling during data collection and analysis, (3) coding and constant comparison to identify and develop categories, (4) linking categories and establishing relationships between concepts, (5) examining categories for case differences and variations.

Setting and participants

A purposive sample of persons with hypertension currently taking anti-hypertensive medication was obtained. Participants were required to be greater than eighteen years of age, English speaking, and in a position to offer written consent. All interviews were conducted at a community health center on the west side of Chicago, Illinois. The community health center serves a primarily African-American clientele and subsequently, all participants were African-American. Approval was obtained from the University Institutional Review Board and the review committee of the community health center. Physicians and pharmacists were responsible for identifying patients' eligibility to participate in the study. A physician-confirmed diagnosis of hypertension was thus obtained. Individuals who were identified as eligible were requested to participate in the study by the primary author.

Participants were interviewed in person in a private room while they were waiting to meet their physician or while they were waiting to fill their prescriptions. Information regarding the participant's age, race, and gender was obtained by way of a short demographic survey. Interviews lasted for thirty to forty-five minutes and were audio-recorded. Interviews were conducted with the help of a semi-structured interview guide consisting of a set of open-ended questions. Theoretical sampling involving sampling on the basis of concepts was employed during data collection. Therefore, as emerging themes arose from initial interviews, these themes were questioned further in subsequent interviews. Examples of open ended questions were:

1. How important is it for you personally to achieve control over your blood pressure? (probes used were why it is important or why it is not important)
2. How have your everyday activities changed since your diagnosis?

3. Do you believe your medication is helping you? (“yes” or “no” responses were used as probes for further questions): How can you tell that it is helping? How much is it helping you? Why do you think it is helping or why do you think that it is not helping you?
4. What problems do you have following the treatment?
5. How often in the last two weeks were you able to take the medication?

Data Analysis

All interviews were audio-taped, transcribed, and then analyzed. Analysis was aimed at bringing order to the data and was achieved by organizing the data, generating themes or patterns, relating categories, and finally searching for negative cases or alternative explanations.[44] Categories were developed in keeping with the requirement that they need to be internally consistent,[45] distinct from each other, and reflect “grounded categories of meanings” held by participants.[44] Coding was used as an analytic aid to link data fragments to form categories that have a certain common property, and facilitated organization, and integration of data.[46, 47] Analytic processes of open or substantive coding and axial coding were used to develop categories and relate them to one another as part of comparative analysis.[43] Open coding involved a line-by-line analysis to look for key themes. Either a line or paragraph of the data was examined and then coded using a particular name or label. Data were thus broken down into more manageable parts facilitating the search for commonalities across all subjects.

Theoretical sampling is defined as sampling on the basis of emerging concepts, with the aim being to explore the dimensional range or varied conditions along which the properties of concepts vary.[43] Theoretical sampling was continued in the data analysis phase by sorting through interviews, and searching for variations in situations.[43] Emerging themes and patterns found in initial interviews guided further coding. Earlier interviews were valuable in terms of discovery of patterns while later interviews helped strengthen the understanding of categories. Theoretical saturation occurs when further interviews cease to add data regarding emerging categories, categories become well developed, and relationships between categories are established.[43] The range of responses became bounded and repeated with progressive interviews, suggesting theoretical saturation. Constant comparative analysis was employed involving a search for similarities and differences to identify and develop categories.[43] Categories that were developed had relevance to each case and were examined for case differences and variations. Cases that did not fit were used to explain variation. Memos and diagrams were employed to facilitate comparative analysis and integration.

Identification of conditions, actions, and consequences, suggested by Strauss and Corbin was used to conduct axial coding, which increases understanding of categories and the linkages between them.[42] Axial coding involved the identification of *conditions* or situations which people respond to with certain *actions*, resulting in some *consequences*.[43] "Conditions," the first component of the paradigm, answered questions such as why, how come, where, and when.[43] The second component "actions or interactions" described either strategic or routine activities that were deliberately undertaken by participants in an attempt to address issues and were arrived at by asking questions such as whom and how.[43] The "consequences or outcomes" of actions undertaken constituted the last component of the paradigm and were answered by a search for the outcomes of actions or the refusal to undertake actions.[43] When studied together, these components of the paradigm gave us a more complete understanding of the phenomenon of interest.

RESULTS

Sample

Twenty persons (10 males and 10 females) were interviewed. Sixteen participants were between 45 and 64 years of age, one person was between 25 and 44 years of age, and three were over 75 years. All participants were African American. Eight individuals (four males and four females) were diagnosed with diabetes mellitus. Two female participants had arthritis and three participants had serious complications including cardiac bypass, congestive heart failure, and valve replacement. One male participant had survived a serious accident, which had resulted in the amputation of his foot.

Medication Meanings and Medication Use

Figure 1 provides an overview of major themes and linkages found between categories. All participants expressed belief that the medication prescribed to them was "effective," except one woman with arthritis. Medications were perceived as very important primarily because participants believed that the medication was helping them in their pursuit of "illness control." Illness control itself was very important to participants. Themes related to belief that the medication works or is helping were "effectiveness" of the medication, the medication being "life saving," and the perception that "no serious side effects" were associated with regular medication use.

Perceptions regarding effectiveness of the medication were found to be based on reduction in symptoms, the most common being headaches and dizziness as well as the actual blood pressure reading. As one participant said, "I believe it (the medication) is important….I feel better when I take it. It does work. I don't have any headaches and things like that." Another participant mentioned, "I think it is my medication that is helping me with my high blood pressure. It keeps the pressure down." Subjective and objective signs and symptoms were influential in perceiving the medication as being "effective."

The awareness that inadequate control of hypertension can lead to life-threatening consequences was evident in every interview. It is therefore not surprising that participants perceived the medication to be "life saving." As one participant said, "If I don't take these medicines, I probably won't be around much longer." People with comorbidities and complications were more inclined to endorse this view and used words such as "mandatory" or "imperative" to describe their medication:

> He (the doctor) said if you don't take it, you will die. He said, 'Are you ready to go?' I said, 'No, not really.' It is mandatory that I take my medicine.

Participants who believed that the medication was "effective" in controlling hypertension and believed that it was "life saving" also stated that they were taking the medication as prescribed during the prior two week period. However, there were some instances where individuals stated that they were not taking the medication regularly in spite of believing in the effectiveness of the medication and the fact that serious consequences can be avoided as a result of taking medications as prescribed. Further questioning and analysis revealed that "fear of side effects," "fear of becoming dependent," the perception that taking medication was a "hassle," and experience of "sexual side effects" were related to not taking the medication regularly. Although some participants said that they had taken medication as prescribed in the prior two week period, they also mentioned that they occasionally "forgot" to take their medication. One woman with arthritis who did not have belief in the effectiveness of the medication stated that she did not take her diuretic as prescribed, confirming the link we found between belief in the effectiveness and life saving nature of the medication, and regular medication use. This person expressed distress that the pain she suffered in her hands due to arthritis was unbearable and that her prescribed medications were not effective in controlling pain. In this case, her individual experience with pain medications appeared to have influenced her perceptions of antihypertensive medications, resulting in a lack of belief that the medication is "effective."

Most participants stated that they experienced "no serious side effects" associated with their *current* antihypertensive medications. However, some instances of side effects were mentioned by participants with respect to medications they had been prescribed in the past. In these cases, participants had been switched to another medication regimen by their attending physician. Direct experience of side effects appears to have influenced them to seek care, state their complaint to physicians, and eventually switch regimens until a suitable medication was found. Thus, it did not appear to result in irregular medication use but rather a change in the prescribed regimen. However, the fear of a side effect was influential in not taking the prescribed medication, as described by one woman:

> I am wondering if the medication is doing something else to another part of my body. Taking a blood pressure pill means that when I'm not having my blood pressure checked, my blood pressure could be low or it could be just doing something else to another part of my body.

Experiencing "sexual side effects" as a result of the medication, specifically *Procardia*® was identified as being negatively associated with medication use for some male participants. Although belief in the "effectiveness" of the medication and the "life saving" nature of the medication were apparent, the concern related to sexual functioning reportedly affected medication use behavior adversely, as described by one male participant:

> The *Procardia*® - I understand the pill can affect my sexual function, and I heard a lot of men say that…I don't forget to take it, I just don't take it. I guess that's the risk I take. I know - but one pill I don't think is going to hurt, not to me. I just take one pill a day and missing one pill is not going to hurt anything. I take them every day till I get back on track again.

Male participants who explained that they took their medications regularly in spite of experiencing sexual side effects due to *Procardia*® reported having other complications - one had a valve replacement, and the other had three bypasses. Thus, in their case, medication use decisions appeared to be more influenced by concerns about serious consequences that may arise due to not taking the medication than concerns about sexual functioning. Both these participants expressed belief in the "effectiveness" of the medication and the medication being "life saving," and not being associated with any serious side effects.

Acceptance of the medication and the perception that medication was "part of life" was identified as another medication-related theme. Over time, some participants were able to relate how they had been able to accommodate medication use in their lives, by recognizing the importance of it and being able to deal with it in their own way:

> Right, just like eating. It's a part of my existence. I know it's important so it's just a part of my living. I don't feel bad and I know it's a part of living just like eating gives me more energy.

In some instances, participants revealed a sense of being resigned to taking treatment everyday, yet holding on to the hope of getting off the medication at some point. In the following excerpt, we also see a hint of the fear of dependency: "It is something I have to deal with for the rest of my life. I'm going to try to take my medication and try to get myself better so I don't have to *lean* on that medication all the time." The hope of getting off the medication was found to play an important role in viewing the medication as "part of life," and incorporating lifestyle changes and the act of taking medication into daily life. As reflected by one participant who reported taking medication regularly, "I think and believe in my heart that if I stay on the diet and do the exercise, maybe it may be a possibility that I could go off the medication."

Anti-hypertensive medications are not habit-forming. Nevertheless, they are required to be consumed on a daily basis. The necessity and act of taking the medication everyday appeared to have created a sense of dependency for some participants. Such individuals experienced a "fear of dependency" and reluctance to taking the medication, as expressed in the following quotation: "It's okay; it's just that I don't want to be dependent on it. I guess that's why I'm not into it every day because I don't want to be dependent on anything like medicine." Most participants lived in the inner city. The word "drug" itself seemed to have a negative connotation. Even though there was a general awareness that prescribed medications are probably "good drugs," the association of the word "drug" with illicit drug use was overwhelming, thus leading to concerns about dependence that were strong enough to discourage medication use:

> I don't have any side effects; I just don't like it being habit forming whether its a drug from the store or a drug from the corner – its a drug. Some drugs are good and some drugs are bad.

In spite of believing in the effectiveness of the medication, perceiving it as life saving, or even part of life, several participants thought the medication was a "hassle." Taking medication on a daily basis involves remembering, planning, and carrying it while traveling, all of which may be perceived as "hassles." Participants voiced their displeasure at having to take medication every day of their lives. They also claimed that they would like to get off the medication at some point. Although several participants who viewed the medication as a "hassle" said that they continued to take it as prescribed, some persons who perceived the medication as a hassle stated that they had attempted to experiment with the medication in the past to verify if it actually worked:

> I just got sick of taking these pills every day. I just wanted to see if it was working or not so I stopped taking it. I came to the doctor and he said that my blood pressure was way up. I hate taking medicine every day. I really do. I just wish we could get off the blood pressure pill. I would prefer not taking the medication if I could.

Another salient medication-related theme was the medication being a "reminder of the regimen," thereby facilitating medication use. Participants who reflected this perception reported taking medication regularly. However, it appears that an individual may not be influenced by "reminder thoughts" alone if he or she chose not to take the medication for other reasons. One participant indicated a decision not to take the medication even though it was in clear sight. It was discovered that for this person, the "fear of dependency" overruled the influence of the medication being a "reminder of the regimen."

> It's hard for me to remember to take medication, and so now everyone is telling me to put it where my toothbrush is or something you do every morning in your routine, but I can look right at the medication and walk away from it. I know I'm supposed to take it. I'm not a person who takes it everyday like I'm supposed to, but I do take it four days of the week. For some reason, I can look right at it and walk right out and not take it. I think I subconsciously decide that. I don't think I really need it. I don't think I need anything everyday but water and food…. it's just that I don't want to be dependent on it. I guess that's why I'm not into it every day because I don't want to be dependent on anything like medicine.

Meanings of Illness and Medication Use

As in the case of medications, perceptions of illness also were found to play an important role in medication use behavior and in how people viewed their condition in the context of their daily existence. The underlying illness-related theme identified was "hypertension kills." All participants were aware that uncontrolled hypertension can lead to fatal situations. The most common cardiovascular problems that participants were aware of were strokes and heart attacks. The possibility of dying as a result was often acknowledged, therefore leading to the perception that "hypertension kills." One male participant said, "Living makes me feel better and if you don’t control your blood pressure, you may not be living.” Another young woman said, “I think the most scary part about it (high blood pressure) is that people like me think that high blood pressure kills, I thought that it kills. He (the physician) said that I probably had it for a while, and I haven’t died yet.”

Several participants revealed fear of becoming seriously ill or bedridden, perhaps as a consequence of a stroke, thus rendering them incapable of doing things for themselves. It is here that we see evidence of apprehension associated with potential loss of self-reliance and inability to take care of one’s self:

> If I don’t keep it under control anything can happen, stroke or heart attacks. I have seen a lot of people land up to where they can’t do a lot of stuff for themselves, and I don’t want that. I go upstairs and I get it checked, know not to drink too.

The theme that “hypertension kills” was shared by persons who reported taking their medication regularly and those who reported otherwise. However, participants who had already suffered a cardiac event were more motivated about taking their medications and reported taking medications as prescribed during the prior two week period. One male participant explained that it was only after undergoing a second heart attack that he realized the importance of taking medication:

> After I had my surgery, I didn’t take my medicine because I didn’t realize how serious it was, so then I had a second heart attack. If I continuously take my medicine, I don’t think I will have a heart attack but if I don’t I think I will…it’s a must to take it.

Personal experience involving friends or family members undergoing serious cardiovascular complications was found to have an important influence on medication use decisions:

> I’m more concerned now…my brother-in-law is on dialysis and a friend is on dialysis. They talk about high blood pressure affecting your kidneys and I don’t want that. I have enough problems. I think the medicine is helping me…I take it everyday.

While the inherent theme that “hypertension kills” did not appear to be linked directly to taking medication regularly, experiencing complications or observing friends and family members undergoing complications appeared to be linked to greater awareness of the "effectiveness" of the medication and regular medication use. In addition, the desire to control hypertension was clearly very important to participants and seemed to serve as a motivating factor to take medications as prescribed. The importance of "illness control" was related to the need to avoid serious consequences and the medication was seen as a facilitator of "illness control." In the words of a male participant with hypertension and diabetes:

> I know it's the medication (that's important). If I did more exercising that would help to. I don't do enough regularly, but the medication is the most important. My blood pressure and sugar would have gotten out of order if I wasn't on medication but since I've been on medication, it has been controlled.

Biographical Disruption

Changes in routine activities, lifestyle, and identity can be potentially useful in comprehending the effects of medication and illness in a person's day-to-day life, thereby providing insights into possible identity changes and biographical disruption. Minimal biographical disruption was noted. It is important to note that chronic conditions such as arthritis and diabetes mellitus, or temporary conditions like a fracture had much more impact on activities and performances for participants since they were found to be disabling or fraught with pain.

There were no reports of serious disruption of valued activities or performances. At least thirteen participants stated that their routine daily activities had not changed considerably. Consistent themes related to changes in routine activities and lifestyle were "taking medication," and "changing diet." Incorporating the act of taking medication into one's life was perceived as one of the key aspects of change in participants' lives as a result of living with hypertension. As one male participant said, "No (nothing changed) except that you constantly have to be on the medication for the rest of your life – that's one of the things." This is reflected in another quotation, "They (routine activities) haven't really changed - they've stayed the same. I wake up in the morning and take my medicine and I go on about my day."

Most diet changes involved reducing salt intake. In some cases, participants shared the view that although they recognized the importance of dietary control, changing their eating habits was a difficult task to accomplish. As one participant explained, “Changing the way I was eating was very hard, especially when you get up in age; it is hard to make changes in things you like. Like the salt, it is hard to go without it, but it’s a learning process, I suppose.” Two male participants attributed the difficulty in making dietary changes to the way they were brought up and the foods they were accustomed to eating since childhood. In the participant’s words, “That was how we were raised. It’s kind of hard to get off that when you have eaten like that. It’s hard to give up. I still go back ’cause that’s me. I don’t think its going to hurt me too bad.”

Exercise was seldom incorporated as a daily or weekly activity. One woman confided that she considered it unsafe to walk in her neighborhood in the words, “I love to walk but I live in the inner city and it is not always safe there to walk.” Except for one subject, walking was the only form of exercise pursued by participants. However, it often seemed as if it was based on daily chores instead of a conscious attempt to fit walking into one’s schedule as reflected by one participant who said, “I walk a little bit now taking my kids to school and back home.”

A consistent theme found was enhancement of “positive self-concept.” Changes in eating habits, weight loss, and exercise were initiated by some participants following the diagnosis. Achievement of such lifestyle modifications appeared to make some participants “feel good about themselves,” leading to a positive impact on identity:

> I feel good about myself and I’m making changes in my life and doing something with my life. I changed the way I eat and everything.

Another reason that appeared to contribute to the positive impact on identity was that the diagnosis helped them give more attention to their personal health and motivated them to take better care of themselves, as expressed in the following excerpts: “It made me take care of myself better, watch the things I eat and I just want to be around longer,” “You know, it makes me take care of myself. Because I know I have this and I have to deal with it. I only want to get better so you have to do what you are supposed to do.” A negative impact on identity was observed for a few male participants who expressed concerns about problems related to sexual functioning due to the medication. Sexual side effects appeared to have had a negative impact on identity, and subsequently on medication use. However, in the face of personal experience of cardiovascular complications, the negative impact of sexual side effects on identity did not appear to adversely affect medication use.

DISCUSSION

This study reports on findings in African Americans with hypertension. Cultural similarities due to a common ethnicity may have played a role in shaping some perceptions among participants. The higher prevalence rate of hypertension, the higher risk of developing complications, and the earlier onset of disease in African Americans make early intervention and targeting of modifiable factors important in this population.[48] Understanding of perceptions of medications, illness, and biographical disruption among African Americans may facilitate more effective patient counseling and education in this group of patients. This study provides further insights into themes related to medication meanings, illness, biographical disruption, and medication use.

Perceptions of the medication being effective were linked to regular medication use and the need for illness control, which was judged by objective and subjective signs and symptoms such as headaches or dizziness. Beliefs in the medication's effectiveness based on signs and symptoms find support in results reported by Arluke.[49] The link found in this study between belief in the effectiveness of the medication and regular medication use is supported by Brown et al. in a study examining the effects of treatment beliefs on medication use.[50] The fear of side effects was more pronounced than side effects themselves. Findings related to actual side effects not having a major negative impact on medication use are consistent with those reported by Conrad where self-regulation of medication was attributed to more than "a reaction to annoying side effects."[51] An important finding related to medication use was that in some cases, the medication was considered to be life saving, especially if the participant had survived a major cardiovascular complication and this perception was found to motivate people to take medications regularly. It would be desirable to emphasize the life-saving feature of medications due to their positive impact on medication use.

The findings suggest that medications can serve as reminders of the regimen for some people. Strategies to help remind people of their regimen can be useful in improving medication use behavior. However, there is reason to believe that if there are more complex reasons to avoid taking medication such as the fear of dependency, a simple reminder does little in terms of improving medication use. This study brings to light the seriousness of the fear of dependency and the need for practitioners to be sensitive to this issue. Recognition that this is a real problem is needed. One way to counter this is to help people "unlearn" some facts about the nature of medications and create a conviction that anti-hypertensive drugs are required to be consumed daily but on no account pose threats of being habit-forming. Fear of dependency can be explained in the context of a microcondition related to the personal experience of knowing someone with substance abuse problems, or from the standpoint of a macrocondition involving broader social and environmental factors.

Illness related themes revolved around the seriousness of events that can arise due to uncontrolled hypertension. Awareness of the possibility of cardiovascular events such as strokes or heart attacks was found. An important finding was that the perception that "hypertension kills" did not necessarily result in improved medication use. However, personal experience of a cardiovascular event or observing friends and family undergoing complications resulting from hypertension seemed to have a greater impact on facilitating medication use. The need to control illness was able to motivate people to take medications regularly. A significant finding was that even in a primarily asymptomatic condition such as hypertension, illness control was linked to signs and symptoms. Viewing medications as facilitators of illness control is consistent with accounts of medication use among people with epilepsy,[51] and depression.[34] The connection between regular medication use and the need for illness control appears to be relevant across different illnesses. Providing information about the illness and how medications work to facilitate illness control is an important part of patient education that must be emphasized.

Disruption of valued activities and body failure was not reported except by those participants with other complications such as arthritis or diabetes. As a result, participants did not reveal any signs of being socially isolated. Findings from this study can be attributed to the unique and so-called “invisible” nature of hypertension, as observed at the lower end of the continuum and devoid of complications involving functional impairment. Biographical disruption was found to be minimal. People voiced identity concerns only in relation to the possibility of damaged identity occurring due to complications in the future, the most dreaded consequence being a stroke or heart attack.

The most significant changes in the lives of participants involved medication taking, and lifestyle modifications, primarily dietary changes. Strauss refers to the act of taking medication as “an illness related task” executed by people in an attempt to address illness management.[26] The act of taking medication appeared to be by far the most frequently reported change in people’s lives as far as hypertension was concerned. While the act of taking medications in some cases seemed to reflect acceptance of medications as a “part of life,” a few participants found it difficult to incorporate this action as a routine daily activity. Successful integration was sometimes facilitated by the hope that the future will offer an opportunity to be free of illness and medication. Adopting changes in diet was reported more often than incorporation of exercise. Cultural influences and upbringing were noted as strong influences on eating habits. Some were motivated to adopt lifestyle changes because of the hope that it would help them get off the medication later. A positive impact on identity was identified as a result of achievement of lifestyle modifications. This finding is unique to patients with hypertension and is in stark contrast to findings reported in qualitative studies on epilepsy,[52] multiple sclerosis,[32] and depression.[34] It seems beneficial to capitalize on this rather unique and promising feature in hypertension management.

The broader social context of the participants’ lives is of relevance in the interpretation of the findings. The lower socio-economic class of the participants can be viewed as a macro condition and a contributing factor for the development of their viewpoints. Many lived in the inner city area and some participants spoke about the level of stress associated with living in such surroundings. The community health center where the study was conducted serves individuals who are primarily covered by Medicaid or have no health insurance. In the latter case, they are financially screened and a sliding scale fee is charged. This is perhaps an explanation to why cost was not stated by participants as a major deterrent to seeking care or taking medications. The pharmacy is located in the clinic itself and is also close to where most participants reside. This may explain why access was not perceived as a problem.

This study is not without its limitations. It was conducted at a single site and this aspect of the study limits the applicability of the findings to other populations. The lack of feasibility of being able to interview participants in their own homes, due to safety issues concerning the neighborhood and the need for a confirmed diagnosis, in a sense, compromises the ideally sought "in-depth" nature of qualitative research. Social desirability bias is inherent in face-to-face interviews. Participants may have overestimated the extent to which they took medications as prescribed. However, the use of a semi-structured interview guide provided the chance to ask further questions at different points of the interview process and draw more informative accounts from participants. Our purpose was not to generate theory but rather explore and describe perceptions of participants, thereby giving voice to their concerns and thoughts. Given the limitations of time and the purpose of the study being more descriptive, development of a dense theoretical framework was not accomplished. Reaching theoretical saturation may thus have been compromised. Further development of categories identified in the present study, integration, and deeper theory generation leading to the discovery of a core category may prove useful. The study also is limited by the lack of an external reviewer assessing the development of categories. However, coding used in the actual transcripts and a draft of the manuscript were reviewed by an experienced qualitative researcher who was not internally involved in the conduct of the study. In qualitative research, the concept of replicability itself is viewed as problematic because of the observation that the world is constantly changing.[44] However, certain analytic methods can be applied to address this issue. In this study, the data were checked multiple times to ensure accuracy in the interpretation, data were compared to themes again at a later stage to check the development of themes, and negative cases were accounted for. Also, the analysis was conducted by the first author and verified by the second author, thus contributing to the consistency.

CONCLUSIONS

Key medication and illness related themes were found to be related to medication use behavior. Illness control was very important to participants. Biographical disruption was minimal and achievement of lifestyle modification was related to positive self-concept. Taking medications and changing diet were the most significant changes in the lives of participants after being diagnosed with hypertension. Educating patients about how medications work and medications' roles in illness control, along with addressing patients' fear of side effects and fear of dependency may improve medication use behavior.

The importance of the patient's perspective in health science research has increased significantly. Future studies can attempt to empirically estimate the significance of some of the themes identified in this analysis. Incorporation of critical patient education factors addressing drug dependency fears and knowledge of the way medications work need emphasis and assessment in disease management programs. Medication use behavior remains an issue that demands further research. However, insights gained by using the "insider's perspective" in hypertension may help us move toward our goals of achieving awareness and control among the many diagnosed with this condition.

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Figure1. Medication and Illness Meanings, Biographical Disruption, Identity, and Medication Use