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## Concepts of Health in Older Urban African American Women with Chronic Health Conditions: A Focus Group Study

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# **Concepts of Health in Older Urban African American Women with Chronic Health Conditions: A Focus Group Study**

## **Project Report**

**June 30, 2012**

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## Executive Summary

The purpose of this report is to relate the findings of the study 'Concepts of Health in Older Urban African American Women with Chronic Health Conditions.' This investigation, undertaken at the request of the Indiana Minority Health Coalition, Inc. (IMHC) is collaboration between IMHC, Butler University College of Pharmacy and Health Sciences, and the community partner, the Black Nurses Association of Indianapolis, Inc. (BNA). The purpose of the study is to gain an understanding of the ways older African American women from medically underserved areas of Indianapolis characterize the various parts of the concept of health; how they understand and interpret the determinants of health status; and to understand how they assess health.

Researchers decided to hold focus groups of African American women from Indianapolis ages 50 years and older who had at least one diagnosis of a chronic illness. The Principal Investigator created a moderator's guide for the focus group. All research partners met to review and redesign the guide to make sure that it was appropriate and would be effective in stimulating discussion to address the three specific aims. The groups, one of currently employed women, two of residents of senior/disabled housing, one group of members of a community church, and one mixed-recruitment group, were held in community settings. Participants received \$25.00 gift cards for their involvement.

Major findings are that women view 'health' as a concept that includes many elements: physical health, mental/emotional health, ability to function through day-to-day activities, and spiritual health. These components work together to produce a state of wholeness or well-being. 'Health' is determined through interplay between influences that operate on many levels: the personal, the interpersonal, and the immediate and social/political environment. Specific determinates include health behaviors, state of mind, stress, relationship with God, and the aging process. Women speak at length about their relationship with institutions of healthcare. They express problems in communicating with their healthcare providers, feeling that they are not treated as unique individuals, and they often express distrust of providers. Participants assess their own health through paying attention to their own physical symptoms, their state of mind, and their energy level. Medications are named as determinants of health and markers of health status. Women assess health of their families and friends through observation, intuition, and communication. These women act as facilitators of health status and behaviors for their family members and others in the community.

Women are well aware of the importance of positive health behaviors, especially diet and exercise, and they feel strong senses of control over their health. As these women envision 'health' as involving many concepts and levels, interventions need to address issues beyond the physical, involving women actively through relationships within communities. Public health professionals need to work with these women in a respectful and collaborative manner. Issues that need further exploration are interplay between mental and physical health through the aging process, patient-provider communication, and women's understanding of medications in maintaining and improving health.

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## Purposes and Procedures

The reduction or elimination of health disparities has been a part of the U.S. national health policy since *Healthy People 2000*, the first national health agenda, was formulated in 1991. [1] In order to ameliorate health disparities, it is necessary to understand concepts of 'health' in the populations that experience them.

'Health' is a complex concept, with many elements and levels. Its meaning is embedded within a cultural context. The 1948 World Health Organization definition of health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" [2] has been criticized as being so broad and ill-defined as to leave 'health' un-measurable. Others have complained of a lack of consideration of other domains, such as spirituality. [3] It is clear that the concept of health contains many elements, especially for those at older ages. These include physical health (with the presence or absence of specific disease states), mental and emotional health, cognition, social function, physical function (including instrumental and other activities of daily living), spiritual functioning, and resilience. In general, elders cite factors such as physical activity, autonomy, and energy when describing their health. [4]

Although a small body of knowledge exists on health concepts of older African Americans [5], especially in comparison with Caucasians or other populations, [6] [7] [8] little attention has been paid to older, chronically ill, African American women. Mature and older African Americans are a fast-growing segment of the U.S. population. By 2050, African Americans will make up approximately 11% of all people ages 65 and older. [9] Eighty percent of older U.S. residents have at least one chronic condition, and half report two or more. [10] The situation is likely to be even more serious for mature and older women living in disadvantaged urban areas; thus, they represent a population whose well-being can be enhanced through primary, secondary, and tertiary prevention strategies.

Chronically ill mature and older African American women face multiple and competing needs in their lives. One source of stress is in dealing with their health issues in the context of other competing constraints on their resources. Many investigations, both qualitative and quantitative, have been undertaken to explore particular aspects of the relationship of women and the issues surrounding their health needs. Qualitative studies have been performed to investigate particular health issues, such as management of chronic illness [11], perspectives on physical activity [12], satisfaction with healthcare [13], care-seeking behaviors [14], or for a particular health condition. [15] A more fundamental and global investigation is required in order to gain insight needed to improve the health of this group of people. Chronic stress exacerbates and mimics the effects of the aging process [16]; indeed, chronic stress has been termed 'accelerated aging.' [17] In the context of African American women, this process has been termed 'weathering.' [18] For this reason, we include women ages 50-64 years. The middle years of life are the time at which racial/ethnic health disparities are the most pronounced. [19]

A previous investigation of the Principal Investigator illustrates the importance of understanding the various elements that constitute health status. The 36-Item short Form Health Survey (SF-36--a standard measure of health status and health-related quality of life) may give the same overall score to different populations, but scores for subscales may differ considerably. This previous study compared SF-36 scores from two groups of urban African American caretakers raising children at risk of neglect--mothers and custodial grandmothers. This demonstrates that, while a summary health measure may be the same, the actual components of health can vary markedly.

It is important also to understand how medically vulnerable older women assess their risks and consider the factors that determine their health. This concept has been called 'lay epidemiology,' a term that first appeared in the early 1990s in articles from the United Kingdom. According to an article by Allmark and Tod published in 2006 [20], it has two elements. "The first is empirical: lay beliefs about the causes, course and management of illness. The second is values: lay beliefs about the place of health and risks to health in a good life." Thus, insight into a community's lay epidemiology will provide understanding of perceptions of health and risk. When working cooperatively with the community, an explicit understanding of these views is needed. This proposed investigation lays the ground work for this knowledge among older, chronically ill, African American women.

An understanding of concepts is particularly important before undertaking collaborative work with a community. It is especially important when designing health education and other interventions to improve health status, since health education must be done in a way that is respectful of health beliefs of the community. Information from this investigation will be useful in designing more quantitative needs assessments and targeting community-based interventions. It provides pilot data needed to obtain funding for larger-scale projects to be implemented cooperatively with the community, in a community-based approach to improve health and well-being for this vulnerable population.

This investigation is undertaken at a fundamental 'up-stream' level in order to get at information not usually considered in other studies. In most studies, 'health' is not explicitly defined, either by investigators or participants in the studies. This investigation provides data that will be important in working with this vulnerable population. Explorations of lay epidemiology have, for the most part, taken place outside of the United States, and no investigations have involved older, chronically ill African American women.

The specific aims of this investigation are to gain an understanding of: (1) how chronically ill African American women ages 50 and older, who reside in medically underserved areas of Indianapolis, Indiana, characterize the various domains of the multi-level constructs of health; (2) how they assess their own health, as well as that of family members, friends, and others in their communities; and (3) how they understand and interpret the determinants of health.



In the tradition of community-based research, the Indiana Minority Health Coalition (IMHC) has brought together an experienced epidemiologist-gerontologist researcher from an academic setting (the College of Pharmacy and Health Sciences at Butler University) and community-based partners from the Black Nurses Association of Indianapolis and IMHC. The Principal Investigator-epidemiologist developed a protocol, and a moderator's guide for the focus groups. All research partners met to discuss study aims and methods. The protocol was reviewed, with changes in recruitment strategies, including defining groups within Indianapolis from which to draw participants. The moderator's guide was also reviewed and re-structured. The research team grouped questions according to domain and decided which questions should be asked in every group and which could be considered optional, depending on the discussion within each group. Prospective moderators, co-moderators, and scribes were trained on qualitative research techniques so that each focus group would be run consistently.

Participants were recruited by an experienced community advocate (who also acted as co-moderator for each group). She also identified and recruited community settings in which focus groups took place. Participants were recruited through flyers distributed in targeted neighborhoods, as well as through personal contacts. To be included in the study, participants had to: 1) self-identify as African American or black; 2) be at least 50 years of age; 3) report at least one diagnosis of a chronic health condition; and 4) reside in a medically-underserved area of Indianapolis.

Five focus groups were held. The first consisted primarily of women who were currently employed, often in 'professional' capacities. Participants for the second and third groups were recruited from subsidized housing for seniors and disabled people. The fourth group represented members of a single community church. The final group was more general in nature. Participants from this group responded to general community solicitations, or were people who were not able to attend another group at the scheduled time.

Each focus group included 10-12 participants, with three community researchers acting as moderator, co-moderator and scribe. Before the session began, participants filled out demographic surveys. Participants were invited to share a meal before each session and each received a \$25.00 gift card at the end of the session. Sessions were audio-recorded, and researchers debriefed on tape after each group. Tapes of the focus groups and the debriefings were transcribed for analysis.

Initial data analysis was undertaken by the principal investigator and a research assistant, who manually grouped and coded themes as they emerged from the texts. After coding individually, the two researchers conferred to resolve coding differences. Additional analysis was done with the assistance of NVIVO software (version 9), using themes determined in the first step of analysis. Preliminary analytic results were presented to community partners in order to improve accuracy and credibility of analysis. All research partners conferred on critical themes that arose from groups. Through this process, community partners provided feedback to improve the validity of the analysis.

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## Findings

Fifty-two women participated in five focus groups held between April 2 and April 14, 2012. Group 1 consisted primarily of women who were employed. Groups 2 and 3 were recruited from among residents of senior/disabled housing. Participants for Group 4 were members of a church located in a medically underserved area. Participants in Group 5 consisted of women who recruited through flyers and personal contacts in the community or those who would have participated in another group, but were not able to do so. Like Group 1, many of Group 5 participants were employed. Women from Groups 2 and 3 were older, less educated, less likely to be employed, more likely to live alone, and more likely to report being in poor health. Characteristics of participants are shown in Tables 1a (Demographics) and 1b (Health-Related Characteristics). The Moderator's Guide appears as Table 2. Answers to specific questions from the Moderator's Guide are summarized in Table 3.

### Elements of Health

While respondents feel that 'health' makes up a totality, they identify several specific elements of health: physical, mental/emotional, functional, and spiritual. These elements work together; when they are properly balanced a person is in good health, which can also be defined as well-being and is essential for high quality of life. Physical health is defined by symptoms and experiences and is the element that is best addressed through medical intervention. It is possible for a person to be 'healthy' or 'in good health' in one realm while not in others.

### Determinants of Health

Many factors can cause good or bad health. Health status is often attributed to health behaviors, particularly diet and exercise. In addition, mental factors, particularly one's state of mind and experiencing stress are important determinants of health status. It is important to remain positive and up-beat to maintain health. Stress can cause specific illnesses such as high blood pressure, and it is also a determinant of state of mind, which in turn may cause one to become unhealthy.

Balance is an important determinant of health. It is important to keep all the elements of health in equilibrium to maintain well-being. One also needs to pay attention to spiritual health; God can grant good or bad health, and one's relationship to Him, maintained through prayer and other spiritual practices, is crucial to good health. In addition, the aging process itself can cause certain conditions, or make existing conditions worse. It can be unclear whether health conditions are part of the aging process, or are disease states. The environment, with both physical and psychosocial aspects, is an important determinant of health. The physical environment, when pleasant, can promote good health by improving mood and offering opportunities for physical activity. When problematic, the physical environment threatens health through toxins in the air and

water, unsafe conditions, or institutions such as liquor stores and fast food outlets. The psychosocial environment is the realm of relationships with family members and friends. The physical and psychological environments interact to affect state of mind. The final determinant of health is access to resources. It is difficult to maintain health if one does not have enough money to buy healthy food or time to prepare it. It is necessary to visit health providers and to take prescriptions regularly to maintain good health, and these require health insurance and money. It is also necessary to have the resource of supportive friends and family members and to be positive in one's community.

Healthcare itself is a determinant of health. Doctors are often characterized as indifferent to their patients, and communication between patients and providers is problematic. While some participants report positive interactions with their doctors, others are suspicious of providers' motives in prescribing medications or other treatments. Respondents, on the other hand, claim that doctors do not offer to perform services that the respondents expect to receive. Participants do acknowledge the importance of seeking preventative services, such as mammography, in maintaining health.

Women feel that they have a great deal of control over their health, through positive health behaviors, maintaining a good attitude, avoiding stress, and upholding a close relationship with God. There are limits to their control, however. It may not be possible to avoid inherited diseases, and it may not be possible to exercise control when one's resources are limited.

## Health Appraisal

Women know whether they are healthy or unhealthy through listening to their physical selves and through intuition. They monitor their mood and energy level, and may compare their health to information received from media sources. Women assess the health of family members and friends through observation of symptoms, function, and energy level. Communication plays an important role in assessing health. Others may tell participants about health issues directly, or the women may discern problems through the amount or quality of the communication. Participants are very aware of their central role in promoting health of family members and friends.

## Summing Up

Participants enjoy the process of getting together to discuss health, appreciate that researchers are asking for input, and hope that what they say will be used to make their community healthier.

Table 1a. Demographic Characteristics of Participants by Group (N=52)

<b>Variable N(%)</b>	<b>Group 1</b>	<b>Group 2</b>	<b>Group 3</b>	<b>Group 4</b>	<b>Group 5</b>	<b>TOTAL</b>
<b>Age (mean <math>\pm</math> SD)</b>	56.7 $\pm$ 4.3	60.3 $\pm$ 5.0	70.8 $\pm$ 6.1	73.8 $\pm$ 13.1	69.2 $\pm$ 8.7	65.8 $\pm$ 10.0
<b>Highest Educational Level</b>						
Did Not Graduate High School	0	4 (33.3)	8 (80.0)	2 (22.2)	2 (20.0)	16 (31.4)
High School Graduate	3 (30.0)	3 (25.0)	2 (20.0)	1 (11.1)	3 (30.0)	12 (23.5)
Trade School	2 (20.0)	1 (8.3)	0	0	2 (20.0)	5 (9.8)
Some College	3 (30.0)	4 (33.3)	0	4 (44.4)	0	11 (21.6)
Bachelor's Degree	2 (20.0)	0	0	1 (11.1)	1 (10.0)	4 (7.8)
Post-Graduate Study	0	0	0	1 (11.1)	2 (20.0)	3 (5.9)
<b>Employment</b>						
Working Full Time	5 (50.0)	0	0	3 (37.5)	6 (60.0)	14 (28.0)
Working Part Time	1 (10.0)	0	1 (10.00)	0	0	2 (4.0)
Not employed	4 (40.0)	12 (100.0)	9 (90.0)	5 (62.5)	4 (40.0)	34 (68.0)
<b>Usual Church Attendance</b>						
More Often than Weekly	5 (55.6)	0	1 (10.0)	6 (66.7)	4 (40.0)	16 (32.0)
Weekly	1 (11.1)	6 (50.0)	2 (20.0)	3 (33.3)	4 (40.0)	16 (32.0)
Few Times per Month	1 (11.1)	1 (8.3)	3 (30.0)	0	1 (10.0)	6 (12.0)
Less than Monthly	2 (22.2)	3 (25.0)	0	0	0	5 (10.0)
Does not Attend Regularly	0	2 (16.7)	4 (40.0)	0	1 (10.0)	7 (14.0)
<b>Marital Status</b>						
Currently Married	5 (50.0)	0	0	02 (22.2)	2 (20.0)	9 (17.6)
Widowed	0	1 (8.3)	5 (50.0)	2 (22.2)	4 (40.0)	12 (23.5)
Divorced or Separated	3 (30.)	6 (50.0)	3 (30.0)	3 (33.3)	4 (40.0)	19 (35.2)
Single, Never Married	2 (20.0)	5 (41.7)	2 (20.0)	2 (22.2)	0	11 (21.6)
<b>Lives Alone</b>						
	2 (20.0)	12 (100.0)	10 (100.0)	3 (50.0)	6 (66.7)	33 (70.2)

Table 1b. Health-Related Characteristics of Participants by Group (N=52)

Variable N(%)	Group 1	Group 2	Group 3	Group 4	Group 5	TOTAL
<b>Health Insurance</b>						
Medicare	3(33.3)	6 (50.0)	7 (63.6)	5 (62.5)	4 (44.4)	25 (51.0)
Medicaid	-	8 (66.7)	7 (63.6)	-	-	15 (30.6)
Veteran's Insurance	1 (11.1)	-	-	1 (12.5)	-	2 (4.1)
Other Insurance	4 (44.4)	2 (16.7)	2 (18.2)	4 (50.0)	8 (88.9)	20 (40.8)
No Insurance	1 (11.1)	-	3 (27.3)	-	-	4 (8.2)
<b>Regular Source of Healthcare</b>						
Particular Doctor	9 (90.0)	9 (75.0)	9 (81.8)	8 (100.0)	8 (88.9)	43 (89.6)
Particular Clinic	1 (10.0)	3 (25.0)	2 (18.2)	-	1 (11.1)	7 (14.6)
No Usual Source	-	2 (16.7)	1 (9.1)	-	-	3 (6.3)
<b>Prescription Medications</b>						
Takes Prescription Medication Regularly	9 (90.0)	8 (80.0)	9 (90.0)	8 (100.0)	6 (66.7)	40 (85.1)
Reports Problem Filling Prescription Because of Money*	1 (10.0)	2 (16.7)	0	1 (14.3)	1 (11.1)	5 (10.2)
Lacks Prescription Drug Coverage*		1 (9.1)	3 (27.3)			4 (9.1)
<b>Self-Rated Health</b>						
Excellent	0	0	0	0	1 (11.1)	1 (2.0)
Very Good	1 (10.0)	1 (8.3)	0	0	2 (22.2)	4 (8.0)
Good	3 (30.0)	6 (50.0)	5 (45.5)	4 (50.0)	4 (44.4)	22 (44.0)
Fair	6 (60.0)	4 (33.3)	4 (36.4)	4 (50.0)	2 (22.2)	20 (40.0)
Poor	0	1 (8.3)	2 (18.2)	0	0	3 (6.0)
<b>Reported Diagnoses</b>						
COPD (emphysema, chronic bronchitis)	-	5 (45.5)	2 (18.2)	-	2 (22.2)	9 (18.4)
Heart Disease	1 (10.0)	-	2(18.2)	4 (50.0)	-	7 (14.3)
Arthritis	6 (60.0)	7 (63.6)	6(54.5)	3 (37.5)	5 (55.5)	27 (55.1)
Hypertension	5 (50.0)	10 90.9)	8 (72.7)	7 (87.5)	5 (55.5)	35 (71.4)
Stroke	1 (10.0)	-	3 (27.2)	-	-	4 (8.2)
Kidney Disease	-	-	1 (9.1)	1 (12.5)	-	2 (4.1)
Osteoporosis	-	3 (27.2)	1 (9.1)	-	-	4 (8.2)
Diabetes	3 (30.0)	4 (36.4)	5 (45.5)	2 (25.0)	1 (11.1)	15 (30.6)
High cholesterol	3 (30.0)	4 (36.4)	5 (45.5)	6 (75.0)	4 (44.4)	22 (44.9)
Severe Headache	-	-	3 (27.2)	-	1 (11.1)	4 (8.2)
Obesity	3 (30.0)	3 (27.2)	1 (9.1)	1 (12.5)	1 (11.1)	9 (18.4)

\*Within past two years \*\*Among those with insurance

Table 2: Moderator's Guide

**When I say the word 'health,' what things come to mind?**

**How would you define the word 'health'? What are the different parts of health, like physical health, the ways you function or get around, mental health, emotional health, and spiritual health? Are there others?**

**How do you know when you are healthy? When you are unhealthy?**

**What about your family members? How do you know when they are healthy?**

How does your health compare to the health of your parents or other family members at the same age as you are now?

How have your ideas about health changed over your lifetime?

Think about your life over time. How could experiences earlier in your life affect your health now?

How does your state of mind affect your health?

**I heard a lady say that she was "in good health but not healthy." What do you think she meant by that?**

What kinds of things would cause a person to say that they were in bad health?

In your opinion, how would you describe a person who is likely to get diabetes? How about cancer? [can prompt with high blood pressure, or other conditions]

**What things in your neighborhood could make you have good health or bad health?**

[Probes: Physical things like having sidewalks, being afraid of being unsafe. Emotional or mental things like having neighbors you can trust and count on]

What do doctors and other health professionals think are the most important things to do to get healthy or stay healthy? How do you agree or disagree with that attitude or information?

Has it ever happened that you went to your doctor and they told you something that you thought didn't apply to you?

[Follow up] Have you felt like they were blaming your health conditions on things that weren't important or didn't apply to you?

**How much about your health can you personally control? What things can you control and what things can't you?**

What things do you do to stay healthy?

**What keeps you from being healthier?**

How can you tell the difference between a minor illness and a major illness?

How do you make a decision about when it's time to do something about your health?

**What are your biggest fears around your own health?**

When you are having a hard time with your health, what do you do to feel better?

[Questions in **bold** are mandatory; others are optional]



Table 3: Summary of Responses by Question

Question	Concepts Expressed
Questions Asked of Each Group	
<p>What comes to mind with the word 'health'? (Question 1)</p>	<p><u>Physical elements</u>: Pain, 'structure of body,' nutrition, breathing</p> <p><u>Well-being</u>: Quality of life, how you feel in life, happy when health is good, healing, 'in the right mind'</p> <p><u>Function</u>: Ability to walk, ability to perform daily activities (even despite minor pain), exercise, 'the things I do that keep me from being healthy'</p> <p><u>Healthcare</u>: going to the doctor, money and cost, taking medication</p>
<p>Definition of 'health' (Question 2)</p>	<p><u>Mental health</u>: Importance of staying positive and de-stressing; 'aging is not the end of life;' well-being</p> <p><u>Spiritual health</u>: Spiritual health (prayer, relation to God) is integral to health</p> <p><u>Inter-Inter-Connectedness</u>: Good physical health leads to good mental health and good attitude; 'wholeness'</p> <p><u>Function</u>: Ability to do day-to-day tasks</p> <p><u>Healthcare</u>: Regular visits, preventive care (breast exams, blood work)</p>
<p>Recognizing one's health status (Question 3)</p>	<p><u>Physical Cues</u>: 'Your body tells you;' eyes; complexion. Bad health—headaches, pain</p> <p><u>Physical Function</u>: Good health--has energy, moves well. Bad health—falling, sleeping too much, can't do usual activities</p> <p><u>Mental/Emotional Function</u>: Good health—being helpful to others, laughing and talking, getting on well with others, positive thought processes. Bad health—lack of motivation, asking for help, feeling sad and lonely, concentrating on pain, feeling stressed out, mind shuts down</p> <p><u>Healthcare</u>: Your doctor tells you if something is wrong, number of medications</p> <p><u>Uncertainty</u>: Only God knows if you are healthy; you can't always know</p>
<p>Recognizing health status of family (Question 4)</p>	<p><u>Communication</u>: 'They just tell you;' whether they complain; when they do or don't make contact; spending time together as a family.</p> <p><u>Physical symptoms</u>: Fever; coughing</p> <p><u>Observation</u>: Looking for changes in people you know well; looking at their eyes</p> <p><u>Function</u>: Sleeping too much; having energy versus being grouchy or irritable; how they move</p> <p><u>Awareness</u>: 'Instinct'; knowing conditions that 'run in families'</p>
<p>"In good health but not healthy" (Question 9)</p>	<p>Healthy outside (looking good) while having problems inside.</p> <p>Feeling fine (or having good function) despite having medical diagnoses.</p> <p>Good physical health but poor mental health OR good mental health but bad physical health.</p> <p>Feeling healthy, but not being 'where you should be'.</p>
<p>Neighborhood determinants of health (Question 12)</p>	<p><u>Safety</u>: Dogs, dangerous or threatening people, unsupervised kids, overgrown foliage; lighting at night; geese</p> <p><u>Air quality</u>: Pollution, asbestos, mold, dust, fumes, gas, allergens</p> <p><u>Opportunities affecting health behaviors</u>: Monon Trail and other safe and pleasant walking or bicycling venues versus lack of sidewalks in some neighborhoods; fast food outlets</p>

	<p><u>Quality of life issues:</u> Beneficial-- 'enjoying the scenery' and exercise opportunities [above] (pleasant surrounding lead to good mental health). Detrimental—Liquor stores and alcohol consumption, smoking, seeing some kinds of people can be depressing</p>
<p>Personal control of health (Question 15)</p>	<p><b>Can't Control</b></p> <p><u>Environment:</u> Loud music, bad neighbors, bad infrastructure (streets)</p> <p><u>Illnesses:</u> Having chronic pain, getting hereditary illnesses, having been diagnosed with a chronic illness</p> <p><u>Food and water:</u> Way foods are processed, being able to afford healthy food, water supply</p> <p><b>Can Control</b></p> <p><u>Behaviors:</u> Eating habits (amount eaten, salt, sugar; and fat content), exercise, taking medications properly, tobacco, drugs, and alcohol, regular doctor visits, avoiding dangerous situations</p> <p><u>Reactions:</u> Reaction to stressors, not losing one's temper, controlling one's thoughts, reading the Bible</p>
<p>Barriers to being healthy (Question 17)</p>	<p><u>Behaviors:</u> Eating (types of food, portions—self-control/self-discipline trouble), exercise (procrastinating, trouble making oneself do it with pain), being unable to quit smoking, not seeing doctor regularly, not taking medicine, not drinking water</p> <p><u>Caregiving and family responsibilities:</u> Interfere with exercise and time to care for oneself</p> <p><u>Financial problems</u> Interfere with ability to eat well or to go to doctor</p>
<p>Health fears (Question 20)</p>	<p><u>Aging:</u> Losing ability to function, losing one's looks</p> <p><u>Death:</u> Sudden death, falling asleep and not waking up, dying before specific event</p> <p><u>Medications:</u> Taking too many, side effects/interactions, unnecessary prescribing by doctors, not taking enough</p> <p><u>Specific health problems:</u> Not being able to breathe, panic attacks, cancer breast cancer, lung cancer, needing chemo and radiation treatments), diabetic complications, blindness, falling</p>
<p><b>Optional Questions*</b></p>	
<p>Comparing own health to previous generations (Question 5)</p>	<p><u>Parents were healthier:</u> They didn't complain; didn't go to the doctor, took fewer medications; didn't have high blood pressure; mother was fertile longer; they had better function (ability to walk); were in better spirits</p> <p><u>Parents were less healthy:</u> They died at younger ages; they didn't have good access to healthcare; they didn't know proper health behaviors; they suffered more diabetic complications (amputation)</p>
<p>Change of health over lifetime (Question 6) AND Effect of lifetime experience (Question 7)</p>	<p><u>Behaviors:</u> Have become more conscientious about health behaviors (eating, exercise); going to doctors more regularly (especially with preventive services); regrets not being more active or stopping/tapering off frequent exercise; less likely to cook full meals since living alone; tries to maintain better emotional and spiritual health; didn't take care of self when younger (didn't need to); smoking formerly considered 'cool'</p> <p><u>Awareness:</u> Formerly never worried about health; more awareness of health because of information on television and the internet; body is more sensitive to effects of weight; learning vicariously from other's experiences with bad health</p>

	<p><u>Current health problems consequences of prior behaviors:</u> Breathing problems from drug abuse, ulcers from drinking; health problems may arise more from the motivation for the behavior than the behavior itself; If I had lived a better life would I have these problems now? ; arthritis from hard field work/not keeping knees covered/working in refrigerated rooms; foot problems from high heels; stomach problems from eating hot sauce</p>
<p>State of mind as determinant (Question 8)</p>	<p><u>Maintaining a positive attitude:</u> Be accepting and grateful; notice other people who are worse off; think about optimistic song; importance of making resolutions (living longer than mother); recognizing reasons for health states helps with coping</p> <p><u>Importance of relationships:</u> Help others in trouble; surround yourself with positive people; feeling bad causes you to isolate yourself; people who are feeling down need help from other peoples</p> <p><u>Depression:</u> Worrying causes depression that causes bad health; depression sends signals to the brain to cause bad health; makes you forget to take medicine</p>
<p>Type of person who will get a chronic illness (Question 11)</p>	<p><u>Poor health behaviors:</u> Eats badly (craves sweets, starchy foods, greasy foods); doesn't exercise</p> <p><u>Other:</u> Drinks too much water, has a bad state of mind, experiences stress, heredity, has another chronic condition</p>
<p>Providers views of determinants of health/discordance with doctors (Question 13)</p>	<p><u>Doctors are impersonal:</u> Doctors don't listen to you; don't treat you as an individual; don't know who you are; they tell you what you feel without listening to you; don't prescribe the proper medication for the individual; don't offer to perform necessary or expected services; would rather prescribe medications than discuss alternate treatments; doctor requires weight loss when you are at comfortable weight</p> <p><u>Distrust of Doctors:</u> Doctors over-treat; are in collusion with pharmaceutical companies to make higher profits; are greedy; don't do enough tests to determine diagnosis/treatment ; it's better to talk to the nurse; services was better in former times with black doctors</p> <p><u>Positives:</u> Doctors have more knowledge now; doctors discuss health behaviors in addition to medications</p>
<p>Making decision to take action on health (Question 19)</p>	<p><u>For self:</u> When you aren't feeling right you need to go to the doctor; you will regret waiting too long (could have avoided outcome by seeking treatment or eating right).</p> <p><u>For others:</u> It is important to be observant/vigilant regarding the health of others. You need to make them take action even if they are reluctant.</p>

\*Questions not noted were not asked due to time constraints and overlapping information

## Discussion

### Elements of Health

'Health' is multifaceted, with many elements working together to produce one's health status, which could also be termed 'general well-being.' Respondents take a view of health that is similar in some ways to the World Health Organization's definition of health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity", with the inclusion of a critical spiritual component. "Health' is relative to one's expectations and experiences; therefore it is possible to be healthy and not healthy simultaneously.

When asked to define 'health' many participants gave global answers.

MODERATOR: When I say the word health what things come to your mind?

MISS D: Pain for myself.

MISS J: Breathing.

FEMALE: Quality of life.

MISS O: General well being.

**Physical Health.** Physical health is reflected in symptoms of illnesses and conditions. Physical health is about the body, which is mechanistic in nature ("The body is a machine that has to be worked. I can control how much activities that I do with my body. Those things I can control.") Physical appearance of the body can be an indicator of health ("[k]ind of acidic yellow teeth. She can have poor health.")

Physical health is the realm of the doctor. It is important to visit doctors regularly to maintain health and have access to the medications one needs to control symptoms. Although doctors can diagnose and treat specific illnesses, they may not understand the totality of health.

You don't know all the time, but I feel that the majority of the time we go by our feelings and we go about - - well, our feelings, mainly. We really don't know, because in some cases we have gone to the doctor and the doctor has said you have such-and-so, and we had no signs and symptoms about it. So really, being healthy - - the health, that's the question. So we really don't know.

**Mental/Emotional Health.** Mental health—feelings, mood, attitude, and perception of stress—is a critical aspect of the totality of 'health.'

Well, I feel like your physical health is important, but also your mental health is important. And I like to think positive, even if something is going wrong. And then I like to have a positive attitude. And I think for me, my spirituality is there. It's always a part of my life. From the time that I wake up in the morning it's just so much thanksgiving. And then when I go to bed at night, I'm still thankful because - - I mean I wake up in the morning and this is my thoughts. I like to be around positive people, but I realize that you can't always be around positive people, because we're all different. And so I think the physical and the mental works together.

Mental health is closely related to energy level.

Oh well for me when I feel healthy I have a lot of energy and all that. When I'm feeling like I'm not healthy I feel like I'm shut down and my mood changes and all that.

Poor mental health can be a cause or a symptom of poor physical health; improvements in mental health through interacting with others can help restore one's 'true', healthy self.

I guess that when I get – the days that I feel bad I stay to myself. I stay in my apartment. I won't come down. If I do come down and somebody say something to me I say I'm not myself today like that. Because I get so wound up in how I'm feeling for that day I'm very short with people and when I'm trying to talk them and stuff so I stay away from them. Then I get a friend say well you're up here by yourself and your sick. Why don't you go down at least somebody might make you smile? I don't like to stay by myself. I just stay away from people. I don't nobody worrying about.

## Functional Health

How a person functions is a critical aspect of health. When someone can fulfill her roles (day-to-day tasks, etc.), then she is 'healthy' even if she has been diagnosed with illnesses or is taking medications.

When I think of health, it makes me think about how well I'm able to do my daily activities without having any discomfort, and being able to eat properly, and just be able to go about my daily routine, when I speak of health.

FEMALE: I would define the word health as how I feel in my everyday activity. My daily ideal, how do I feel when I get up on a daily basis, when I go about my activities: how am I feeling?

Functional health is closely related to mental health.

Well, my mom, when she was my age she was taking care of my dad and doing everything. And she even would work one day a week. And she was just real bouncy, just like I am. I'd work and I'd take care of the house and everything, and I help everybody I can. And she was just in good spirits.

## Spiritual Health.

A healthy spirit is an essential part of health.

MISS T: Spiritual health you know – I'm talking about myself. In spiritualize I look at the Lord first. I pray after. I go to church often and I talk to people – we all have somebody that we can talk to at the church that are having a problem with something. So I think it's you know, okay, God is good. I love the spiritual. . .

MODERATOR: So would you say then health involves your spirituality.

MISS T: Yes

Spiritual health is mediated through one's relationship with God, primarily through prayer.

FEMALE: The reason I say that about prayer is because I was on my deathbed. I shouldn't be sitting here right now. So my prayer changes things.

MODERATOR: Prayer is powerful, right.

GROUP: Yes it is.

MODERATOR: And would you agree then that prayers are an important part of keeping healthy.

GROUP: Yes.

## 'Wholeness' and the Inter-Connectedness of Health

All the elements of health together comprise wholeness, which is the essence of being healthy. The various elements of health are interrelated, acting in a synergistic manner, together producing quality of life.

I think define it [health] as being whole. Wholeness. Having a wholeness that includes everything that you're saying: the spiritual part, the physical, everything.

I see it as a state of being that allows you to carry out your daily responsibilities, or your quality of life, and ensure you have a good quality of life.

When you have good health you have good mental health. You have good mental health you have a good well being and a good outlook on life.

I agree with everything they're saying as far as health is concerned. We can be healthy in all those ways that you've spoken of. Spiritual health is just as important as the rest of

the movement and your daily feelings. And it takes all of that to be, I'll say, comfortable or to live or to function or to carry out whatever activity we're going to be doing.

Conversely, compromising one element of health can cause a downward spiral into bad health.

When I'm unhealthy everything is falling apart physically. I think about just the other night how many pills I'm taking and it makes me irritable. It's like if something increases I have to take another pill for something. So taking all medication makes me know that I'm not healthy or I'm not managing my health.

### 'Health' versus 'Healthy'

Since health is complex and has many layers, it is possible to have good health in some areas but not in others. Sometimes, when 'health' is considered as purely physical in nature, one can be simultaneously healthy yet not healthy. For instance, it is possible to have multiple illnesses or diagnoses, even with symptoms, yet consider oneself to be in good health. As participants, by definition, have at least one chronic conditions (and are therefore not physically in entirely good health), this is often the case. More participants described their health as 'good' than by any other category.

I'm sixty-four years old, soon to be sixty-five. Got my Medicare card in the mail [Laughter]. I'm a mother of four daughters, and twenty-three grandchildren and four great-grand sons. And I'm married. I work full-time. I love the Lord with all my heart. I'm in fair health. I've got some issues. I've got high blood pressure. I have what they call degenerative disc disease with spondylosis and a whole bunch of other stuff going on there. But other than that I think I'm pretty good for the road that I've traveled and everything.

Women acknowledge the existence on one or more chronic conditions that may, to some degree, impair their health, but express satisfaction at being able to function well; thus implying that ability to function has primacy over physical health.

Well, I think when she said that, that she wasn't happy. Because she probably had certain issues but there wasn't enough to bring her down; she could still function. You know, when you got other things wrong with you can still move and do things, you're healthy; but then you're not because there's other issues.

Alternately, one may be comparing one's subjective health status with a more idealized state.

I think if I heard someone say that ['I'm in good health but I'm not healthy'] I would think they were saying they were glad for where they are but they're not where they're not where they would like to be.

Another duality can exist between outer appearance and inner health status.

I agree with JJ and Miss ET that looks are deceiving and that if you look good that don't mean you feel good.

This ambivalence can result in being 'healthy' while at the same time not being 'in good health;' thus, in general, the dichotomy is between the physical aspects of health and the more subjective ones of mood and spirit.

I agree with Miss R, because the way I look at it I'm in very good health. But I have high blood pressure. They say my cholesterol is high. I have high cholesterol. And so I have those issues, and I take medication. And I take my medicine. So other than that I think I'm in very good health. But I'm not healthy because of that.



## Determinants of Health

Many specific factors were named as affecting health status. Good health and bad health have many sources. Many of these factors are under the control of the individual, while others are not. Health behaviors, psychosocial factors (such as attitude or stress level), access to resources, and interactions with the healthcare system are all important determinants of health status. Relationships with friends, family, and God can make health better or worse. Determinants were often invoked early in the focus group, when discussing the 'health' as a concept.

MODERATOR: How would you define the word health?

MISS E: Taking care of yourself.

MISS F: I think of eating healthy coincides with helping yourself. Eat the right kinds of foods.

FEMALE: Your hygiene.

MISS J: Walking a lot.

FEMALE: Exercising.

MISS S: Seeing the doctor more or regularly.

MODERATOR: Anyone else? The next question – how do you know when you're healthy or unhealthy? How do you know when you're healthy or unhealthy? Yes Miss J.

MISS J: I think that when you're feeling good you're thinking that you're healthy.

MODERATOR: What about unhealthy?

MISS J: Feeling sick and sad or lonely.

FEMALE: Stressed out.

MODERATOR: So that would be unhealthy.

FEMALE: Headaches.

MISS J: Maintaining regular checkups from your doctor.

FEMALE: Make sure you take your medications, which help you feel better.

## Specific Determinants of Health

### Health Behaviors.

'Lifestyle' factors, especially nutrition and exercise, are often named as determinants.

What I found out in my lifetime is your diet. What you're eating has a lot to do with your health. And your hair and your skin's messed up because you're not eating right. And a lot of other problems you have is because you don't eat right. When you get older, especially when you live by yourself, you don't feel like cooking a good, decent meal, you just take shortcuts. You might eat a sandwich and you got no vegetables or nothing. And that just messes up your health. So the main thing is your diet; to eat right.

Often, women spoke about the effects of health behaviors from their own experiences.

And I found out, since I've gotten older, in my late-sixties and early-seventies, I found out if you take exercise, you'll feel better. I know I do.

Because when I think about when I was in my twenties, I didn't have to do all that I do now. But my highest weight is kind of what brings it home to me, was almost two hundred pounds. I had gotten up to almost two hundred pounds this past year. And knowing when I walked up the steps I could feel it in my knees, I could feel it in my breathing; I could feel all that change. And when I got it back down - - I started getting it back down - - and I feel so much better. I can go upstairs, I can do other things and it don't bother me. And that kind of lets me see that I have to do some exercises. And the eating right, try to eat right. [Laughter] And exercise, that kind of brings it home for me that I have to do that.

They also demonstrate that they had internalized health promotion messages from outside sources.

My diet. The way you eat if you're not eating properly. Getting the nutrition and stuff that you did. Recently, I don't have diabetes, but I took a diabetes class and in that class we learned how to read the label for sodium and different things like that. I think when you have high blood pressure and different things like that you really need to know how to eat right. So I think diet is a lot in there.

Women speak from their observations of others as well as themselves, classifying people who eat the 'wrong' foods as candidates for poor health.

My son he loved pizza and that smoked picnic hams and stuff and he's 51 and he's had open-heart surgery. Triple bypass surgery and the grease in the food and you can just tell - we use to go IHOP and he would eat the six egg omelet and you can tell that people eat like that clog those arteries. I would get after him. He's a truck driver. He won't exercise. You can look at the way they eat.

Although diet and exercise are the most frequently endorsed, other behaviors, such as smoking, drinking, and drug use are also named as determinants.

Well things that I learned, as I look back, smoking wasn't anything that would destroy your health when I was growing up. It was an attitude of being cool. It didn't have anything, or said anything bad about it. And as a result of that I had some issues with my health. I haven't smoked in double-digit years. But just learning about the things that are hazardous to your health and being informed about that gives you an opportunity to make better choices for how you want to live your life. Ignorance is not bliss.

Sometimes, skepticism is expressed about the 'conventional wisdom' of health determinants.

They always tell me about the only habit I have is smoking and I wonder sometimes if I had of stopped smoking would I have had cancer. But now that I've had it and everything he's still on me about smoking. I still smoke. He's still on me about smoking and I feel that some other people have had cancer and they've never smoked a cigarette in their life. And I wonder if you know he says it's the cause of it – especially the medicine doctor he says that nine times out of ten it's the cause of it but we don't agree on that.

### **Outlook**

Outlook is an important determinant of health, acting in part through mental control of physical health status.

Your state of mind affects your whole being, because your mind controls your whole body. That's what I think.

I agree with that. I think your mind greatly affects how you feel - - because when you speak things forth it sends sensors to your brain when you think that. And sometimes you may not really have it, but when you think that you have something, sometimes you will feel like it, because you kind of sent that signal to your brain. So I think that the way you think has a great effect on overall how you feel.

Optimism can help a person recover from a health setback. Positive attitude can be a result of conscious choice (emphasizing the positive instead of the negative, perhaps through mindful gratitude), a response to the environment, or come about through a relationship with God.

I think your state of mind greatly affects your health because if you constantly focus on my hurts, my pain, I can't do this - - you know, the negative, I think it brings you down. Even though you have health issues you gotta learn to - - in some cases accept and be grateful for where you're at. I think my greatest realization came when I had to start going to rehab, and I would go to the rehab hospital, and even though I was in pain and hurting, I saw other people walk in there much younger than me who couldn't move, you know, it brought back to me how good God is to you. And so I try to, each day, when I

get up in the morning - - yeah, something's hurting every day, but I be thinking, well that's not hurtin' today, I got something done. And just keep pushing. I really believe, mentally, that how you deal with it has a whole lot to do with how you are able to function on a daily basis.

Optimism can be maintained through conscious mindfulness with prayer or through reinforcing attitude with cues.

I definitely agree with what Miss KW said, because your mind can affect your whole body. And I have this little song, I forget who wrote it, but: *"Don't worry about a thing. Because every little thing is gonna be all right."* [Laughter] And I tell myself this whenever I think I'm really getting upset about something, maybe my family or something. So I sing: *"Don't worry about a thing..."* [Laughter]

Older women have perspectives arising from lifetime experiences. They have learned from their own pasts, as well as indirectly through observing the experiences of those around them. Putting their individual attitude together with expectations of others can result in positive attitude to bring about better health status.

I think your state of mind affects your health because if you get it to that I'm not going to get to this age. I'm not going to overcome this. Then you stop wanted to do but – me wanting to live longer than my mother lived makes me manage my diabetes better but I have to start in the morning – end my morning with prayer to get my mind in a state that I want to save Him. I want to see my Savior. I want to see Him regardless of what baggage I have. I want to see Him so I want to live and serve Him. I can't serve Him if I'm always at the point where this or that hurt. I will serve Him. I will just take an Advil when I need to go down to the basement and stand on the concrete. Let me take an Advil, put on the right shoes, I'm gonna serve Him in whatever capacity. So my state of mind says I want to stand before Him, when He says, "Well done my servant." Not look at Him, you let that arthritis keep you from serving from me. So I'm like press on, press on. I don't want to just make it in. I want to be all up in there.

Optimism may be a learned response to counteract life stressors.

And Miss L and Miss M was commenting on the sleeping and I was - - I don't want no [C-PAP] machine . I have a girlfriend on a machine and she uses it every night. But I kind of contribute it to being busy. Sometime I work long hours. Sometimes I work from seven o'clock in the morning to ten o'clock at night, and I do that two days in a row or three days in a row; and then eight hours after that. And then when I get home, my mind is going so. And then I have church stuff and doing all this stuff. And I always just contributed it to my mind just won't shut down, and is not ready to shut down yet. And I go home and it'll be twelve o'clock and I'll be looking at the clock, and I gotta get back up at five-thirty in the morning. And I do that every day. And that's what I kind of attribute to that: my mind don't want to shut down, 'cause I got so much stuff going on.

## Stress

Stress is a significant threat to health. Worrying about health problems can cause general health to decline.

My problem – I'm healthy but not healthy. Is that what you're saying? For the simple fact of the mental stress because of hereditary cancer and different cancers in my family it's stress to me because on both sides of my family there are heart attacks and all that. But I'm healthy but not healthy.

Stress can occur because of internal or external cues. Stress works through its effects on mood and attitude so that it may become necessary to intervene on a physical level. One source of stress is through the detrimental experiences of oneself or those one cherishes.

MISS D: Yeah I feel family affects your health a great deal. Speaking for myself I have a son doing 16 years federal time so that has affected my health real bad. I have grandsons that are incarcerated. That stress makes your health deteriorate. The problems that I have going on with my own personal health and that all this combined together makes me have to get on an anti-depressant. So I think stress has a great deal to do with

MISS J: Worry, Cause you know worry about your family, yourself, your health.

Perception of stress can increase as one ages.

My biggest problem is stress and worrying about every little thing. Sometimes I'll be afraid when the phone rings if somebody lost somebody. Ever since I lost my parents it's just like the older I get the more worried I get about everything.

Some chronic conditions can occur as a direct result of stress, while others are caused by more conventional health behaviors

I think eating a lot of starchy foods that's one of the main ingredients of diabetes and for high blood pressure is stress. A lot of stress cause high blood pressure.

## Balance

'Health' is at once wholeness and a synergy between each element; thus, it is necessary to maintain a balanced relationship between each domain to be in good health. It is important that all health domains (physical, mental, spiritual) remain in equilibrium: otherwise, health will suffer.

When I think about health and well-being, I just think about the overall function of the body and anything that's out of disorder that causes you to be unhealthy.

Imbalance, physical or psychic, can cause ill health.

When I'm healthy I'm happy and when – I guess I think about how I have more balance I think when I'm healthy – mental and physical. When I'm unhealthy everything is falling apart physically. I think about just the other night how many pills I'm taking and it makes me irritable. It's like if something increases I have to take another pill for something. So taking all medication makes me know that I'm not healthy or I'm not managing my health.

### *Relationship with the Divine*

God, and one's relationship with Him, are important determinants of health. On one level, God grants good health directly.

Now I've exercised all through school and all that, and I still exercise four days a week. I go to the Gardens Tuesdays and Thursdays, and Riverside, Monday and Wednesday. And even that your body's telling you to slow down, I guess, when you get sore. Just like this past week, nothing hurt me, but I didn't have mobility. I had to steady myself. And I went to the doctor and he couldn't find anything, blood pressure was good. So what do you do? I feel like, well you get up and go and do what you're supposed to do. But you still have something to lean on, and you thank God every day you can get up, 'cause He didn't have to let you get up.

God also works through His healing power.

Praying for me. I pray anyway but I do pray also for healing from my higher power and that has – I feel that has a lot to do with my physical well-being is praying for healing.

Women are able to do the things they need to do in order to maintain health because God grants them that ability. It is important to be grateful for God's gifts.

I compare my at my age now and my mother's age - - well, she never lived to get ninety, and I'm ninety. My father, I compare my health with my father when he was ninety. My father was an outgoing man, and he could do anything. And that's the way I feel, like I can do anything at ninety. And you know what? I can. [Laughter] I feel that way. And so a lot of time I know I push myself, but God gives me strength to do this. And I'm thankful.

Health comes directly from God, and also from the effects of spiritual practice, such as prayer and reading the Bible, on the spirit and in the mental arena. Participants express that their relationship with God may be more important at this later stage of their lives than it was in previous years.

MODERATOR: So would you say then health involves your spirituality.

MISS T: Yes.

MODERATOR: And your relationship with a higher being? Anything else you want to say about that?

MISS D: I think the older you get you being raised in the church. Sometime in the middle around the 20s and 30s you tend to forget but then the Lord makes his way back around to you and you just realize you took most things he gave you nothing about. You have to give it your best shot and it still winds up wrong. So all you can do is sit and wait and sometimes it takes a while, especially with children and co-workers and things like that. It's like, when is this ever going to end? It has a lot to do with it, by yourself and if there is nothing else to do, you can always pray.

MISS J: [Moderator], for the record we're going to take Miss D and B. [Laughter] My spiritual beliefs and my spiritual health and my spiritual well being not praying once a day but five times a day I need.

MODERATOR: So does prayer help you stay in good health?

MISS J: Yes it keeps a mental mind. Keeps you heart open. Keeps [pause], keeps everything in a clear view so you can just focus – stay focused. Don't forget the deterrents. Just stay focused and breathe. I don't care where I'm at – if I'm on the bus – if I'm walking I'm always praying - always praying.

I believe -- that's the first thing of mine that I do every day. Regardless of what I'm thinking when I open my eyes I ask God to bless me for waking me up every morning, to lead me and guide me. And without God you ain't got nobody, you ain't got no friends. I truly believe that saying my prayers to God goes a long way. . . For ten years I've been a widow. I think that's what helped my beliefs.

### *Aging and Lifecourse Issues*

As noted previously, concepts of health are dynamic and may differ at various times of life. Participants express the thought that they have come to stages in life in which it is imperative to work hard to maintain health.

My health up until I was fifty, no problem. I felt good. No complaints when I went to the doctor. But from fifty up until now, I don't know, I got my questions about the health. In other words, about how you feel and how you eat; you change everything is changing. I used to eat anything. I could just eat and go to bed. I can't do that. And then gradually a number of things is occurring that I can't figure it out from younger up until fifty, because I didn't have any problems. No problems, no anything. And I was more energetic. So I'm questioning it right now.

The aging body requires more effort to maintain health, and health behaviors are very important.

My life has changed a lot because I know the closer I get to 60 and I will turn 60 in November. About three years ago I started menopause during that time I started reading a whole lot and I didn't want to take any pills. But they kept saying that you should exercise so I kind of use – I exercise a lot and it really helps me. I watch what I eat. I'm just trying right now I'm trying to get ready for when I hit the 60s it's different. I look at it like this – if you don't do anything now by the time you get 60 it may be too late.

So I'm trying to prepare myself and I started years ago preparing myself for that. If I can I want to set precedence for it.

Aging, to some degree, comes with a sense of peace and acceptance for some participants.

This is sad but when I was 14 or so I never I thought I would live to be 16. Then when I made 16 worked to death. I knew I'd never make 18. Then I – it just hit you I'll never be 21. But then after I made 25 it left me. It worried me so bad that I cried everyday thinking I'm not going to be 18, not going to be 21. But once I reached 25 the feeling left me.

Participants also speculate on whether current health problems might be the result of past behaviors.

I think my earlier lifestyle affected my health now at an earlier time I was drug abuser and that had a lot to do with being an intravenous drug user. Being a smoker of drugs and then those young years all that was fine and dandy then a lot of me getting high then has fell back on me in my older days.

I still think, growing up you didn't even think about how, you know, you didn't have no aches, you didn't have no pains or anything like that. So you just lived your life. Now as you get older and things begin to change, you wonder if I had lived a better life then, then I live now, maybe I wouldn't have these. But who knows? I think it's a part of growing up ignoring what you could have done better in your younger days. But we don't look back at those things. We think, well He brought us through, so go on from here.

Mine was—I was very active in school sports wise and stuff like that. Maybe if I had kept running or walking more or doing something maybe I wouldn't stiff up like I do now.

Participants also express direct connections between past experiences and current health issues.

My arthritis in my knees affected my life growing up. I lived on a farm for seventeen years of my life, and I worked in the fields, and we picked cotton. And the cotton was so heavy, and you would get tired, so you had to crawl. And crawling on my knees, that's where my arthritis is affecting me fifty-nine years later.

Well, when I was a little girl they wore cotton stockings. And I refused to wear cotton stockings. And we'd stand on the corner to catch the bus in the summer. And an old lady came up to me and she says: "Young girl, you gonna be sorry one of these days that you don't cover up them legs." So I don't know where that's where I got arthritis or what. [Laughter] But I've often thought about that on many a day. And meanwhile, I got two knee replacements. But I just wonder if that had anything to do with it. So, I've often thought about that.



When I was young I use to eat hot sauce out of the spoon and now they say that's part of my condition that I have with my stomach.

While health problems accrue with aging, participants still feel that they have control over the manifestations, or the symptoms that come from age-related conditions. The aging process itself can't be controlled, and some health issues are caused by that alone. Others issues are attributed to other reasons, such as health behaviors. It can be difficult to distinguish the two.

I'm in the fifty age, and I'm beginning to wonder - - my body is changing and my stamina is somewhat dwindling and I'm sleeping less. So I'm trying to determine if that's part of the aging process, or do I need to bump up my exercise routine more. I exercise more now than I did when I was young. So I'm at the crossroads, trying to figure out how should I prepare my body so that it will be stronger as I get older. Because I notice after fifty, fifty-five I don't have the stamina like I used to. And I just wonder if that's just part of the aging process, or is that something I should just increase my physical activity. I notice a change.

My mom is almost ninety years old, and when she was my age - - I can remember my mother being active all her life. She doesn't have any physical problems right now. And she goes to aerobics about three times a week. She doesn't take any medicine. Well, I think she takes medicine that's kind of like a placebo. It's really not a - - it might be for high blood pressure. But she doesn't have the high blood pressure, but just because of her age. But she's in pretty good health. I think she had her last baby when she was - - because her and my sister were pregnant at the same time. So she was forty-three when she had her last baby. And now people pay to have babies at that age [Laughter].

Several participants expressed fear around aging issues, whether losing physical attractiveness or the ability to care for oneself.

My biggest fear and you're probably say I'm vain for thinking this is that I'll look in the mirror and I'll start looking my age. I just don't want to look my age. I can't stop the hands of time but I can control how it affects me and what I see in that mirror.

MODERATOR: Is that one of your fears?

MISS A: No. Well, I don't know. I really don't know. I guess just getting older and just not being able to do things on my own like JM said about being in a convalescent home. I always want to be able to do things myself. I really don't like to have people doing things for me now. So in getting older - as you get older I know you going to have to have help but to really be dependent on everything from somebody. That's a big fear.

Despite some apprehension about aging, many participants are accepting of their current health status, even if it included some degree of pain or loss of function.

I didn't realize when you get old you have many, many problems [laughter]. I'm too busy to live and too busy to be laid back. I didn't realize you have many, many problems. Wake up your finger hurt. You can't figure what's wrong and it's hurting you. And I've had five strokes getting here where I am. Five strokes – I have high blood pressure. I'm a diabetic and I wished I had lived a better life than I did. But I'm still here.

At least one participant feels optimistic about the aging process

You know a lot of seniors feel like this is the end of life. This is not it. You have a chance to reinvent yourself if you want to. You can do a lot of things you want to do that you didn't get the opportunity to do when you were younger.

### *Environment*

Both the physical and the psychosocial aspects of the environment play large roles in determining health status. Certain aspects of the physical environment affect health behaviors, which in turn contribute to health status.

Well mine is the fast food places in my neighborhood. I'm trying to get myself out of that habit. To cook and don't be running down the street and getting a hamburger or something like that.

Having a good walking path. Too many neighborhoods don't have sidewalks so it's dangerous to walk – to go for a walk. So I'm walking in the street and I have to keep looking back to see if a car is coming. So not having good sidewalks and not keeping their dogs chained or whatever makes it a safety issue.

Conversely, some features of the physical environment contribute to health-enhancing behaviors, with a pleasant environment also elevating mood.

I would have to say good health. I'm very close, two blocks away from the Monon Trail, which is around Fall Creek, and access to that: walking, riding bicycle, and just enjoying the scenery. It helps mentally, too.

Participants need to be able to reach their provider's office easily.

I think it's [health is] just everything from getting up to going to bed – the housekeeping and just everything. Nowadays it just seems like you have to be really on top of it especially the older we get for our breast cancer exams. Things like that. It's good to have your doctor's office not too far away from where you're stay. That's the main thing. Especially when you're used to going to a certain doctor.

Participants endorse the quality of their neighborhoods as a determinant of health.

One good thing about this neighborhood is you can walk anywhere and I do. Anybody in this room will tell you, you feel safe whether it's during the day or at night. Because I

have no problems with walking over to the market at 9:00 o'clock at night. We're not in a raggy neighborhood. With dogs running loose and people trying to mug you or insult you in any way. I feel like this is a wonderful location for seniors and I think everybody who lives here will say the same thing. They feel totally safer here.

The environment includes psychosocial elements, such as needing to deal with people who may be irritating. This negative interactive relationship can affect health.

My neighborhood, I really complain, is a bunch of kids in my neighborhood and they are doing things. Parents won't tell them nothing. And they got in the habit of playing out in the middle of the street and then standing on the sidewalk in front of my house on the grass. And my family get after me for, cause when I see 'em, I holler at them, you know? And they say I will make myself hollering, 'cause I jump up and holler at 'em and tell 'em to get off of it. And then they'll talk back to me: "You don't own this." I say, I don't own it, but I pay to keep it cut. And I go arguing with them. And so they get after me about it. So I just have a problem with it. I say I ain't gonna say nothing; I don't care what they do to me anymore. So that's my problem. Ow, boy, there's a bunch of them in the neighborhood, and the parents don't say nothing to 'em. So that's my problem.

Suspicious people may be a threat to safety.

I do have to watch characters walking down the street, so I cross to the other side. I don't care how they look, I just cross on the other side of the street, 'cause I don't trust them. I've got that in my neighborhood. I'm by Target. It's coming from the other apartment. I thank the Lord I got a place to stay. But I do have to watch the characters walking up and down my street.

The 'neighborhood' isn't always residential. The environment also includes the workplace, and that can also affect health.

Since I'm still in the workplace, my emotional health is how I deal with the stresses on the job. If I let it affect me physically, or if I let my attitude cause me to be pleasant or not pleasant to people. And I deal with a lot of emotional issues, since I'm still currently working. And I walk during the day to de-stress myself, so that I won't have any physical results of the emotional stress.

Regardless of location, a good psychosocial environment is important in maintaining good health.

I think staying in a positive environment, surrounding yourself around positive people, having positive activities or involving yourself in positive activities, I think it plays a great part in your health. If you are around or involve yourself in a negative environment, to me that tends to pull you down, that just depresses you. I like surrounding myself with positive people. I like surrounding myself in a positive environment. Doing positive things. I think that plays a great role in us having a good, healthy life.

A positive environment helps to maintain proper balance between elements of health, allowing one to be healthy in a holistic way.

I like to be around positive people, but I realize that you can't always be around positive people, because we're all different. And so I think the physical and the mental works together.

## Access to Resources

Participants are clear that resources, especially financial resources, are essential for achieving and maintaining good health.

When I think of health, I think of money. Money, cost.

Cost of adequate healthcare is named as a barrier to good health.

I was young when she [mother] passed away, but I do remember she had a stroke. And at that time, for us being in the South, and for us being under the doctor's care, we didn't have that; she didn't have that, they didn't have that. And she was never on any medication for it. Although, I can remember her going to a doctor, but it was not the same as like I have today. And my father - - we, of course like Miss D said, we just don't compare - - women and men health care, we just can't compare. Here I go to the doctor, and my father, he'd only go if he have to go. 'Course he's passed away now. But he passed away much later, in his sixties. And it just don't compare. When he sought help here, it was too late, almost at the end of his life. He never got into any kind of health care.

Resources other than the ability to pay for healthcare are important for maintaining health. Several participants mention costs associated with making healthy behavioral choices.

Neither one of my parents lived to get to what my age is now, because they didn't have access to, at that time, insurance, covered by insurance and was able to go to a physical fitness center and some of the things that I participate in. And neither one of my parents lived to see the age that I am now.

The thing that keeps me from being healthier is here is the expenses of food. How much food costs when you go to the grocery store. Sometimes I just can't afford to get everything I want. I had to improvise. Do what I got to. Make do with what I got. Try to do it best I know how. I try to make things from scratch and stuff like that. Add or takeaway but it's hard with the food nowadays you spend something. It's a big chunk of my pocket but I've got to eat. Either eat or I don't eat and I get sick.

## Healthcare

Participants have much to say about healthcare as a determinant of health, including relationships with healthcare providers and usage of medications.

## *Healthcare Providers' Indifference to Patients*

The issue of barriers in communicating with providers appears in all five groups. Participants complain of being treated impersonally and of not being 'heard.'

I've been to the doctor, and I'm not really sure how much they care. Maybe they care, but they're not listening. When I go in, I tell them I'm not on any medicine or medication, and then they'll turn around and say, well, maybe it's your medicine. [Laughter] So you know they're not listening. I'm not on any medication.

Sometimes participants might prefer to talk to people who they think might be better at communicating with them as individuals or to know them better.

I was thinking when she was saying the doctors don't know you. It's just like on my job. I'm around 100 or more women every day. They come and go so I'm not going to get to know them but yet still when I go to the doctor I'm telling the doctor what's wrong with me. He don't know anything. I tell him I want to talk to a nurse. The nurses are who knows what's wrong with you. The nurses are the ones that look it up. Tell the doctor what they looked up, diagnosed it from there. So I just told the doctor I don't need to talk let me talk to the nurse.

One participant alludes to a time of more segregation, when one could see a black doctor, who might be more likely to treat patients as individuals.

I have a problem nowadays because of the computer our files are on the computer and you go see this doctor at the clinic its two years and he still don't know who you are. Well I'd like to hear from you yourself. I said for two years I've been telling you the same thing and you've been pleasant, go in sweet. You know their name. How come they can't know you? And when we were kids our parents, my parents, they tried to get [into Black Medical, you know, of course, Wishard . . . had a lot of black doctors and stuff. So we were always with them and they seemed to know you. The pediatrician he saw us until we were 18 or 19 until I was out of his scope. Today I really got a thing about that and it makes me so mad and I don't want to hear I see 100 people a day

Several participants mention that doctors prescribe medications without considering the patient as an individual.

Some things I agree with but like them not giving me my medication of what I'm on when it's my body and I know how I feel when it helps me they give me trouble by giving me my prescription.

I have a question. My experience with the doctors, as she was alluding to, is a chance to prescribe medicine right off the bat without giving any type of other alternative ways that you can improve your health. Instead of something more natural or telling you, you can reduce your cholesterol by doing A, B, and C, they'll push you out a pill. And my concern is, as I get older that I keep myself healthy so that I won't get into that framework where they think to give you a pill. It's already happening. You can go to the doctor now and you might even have a little illness, but they'll give you a pill. And my

concern is that the doctors are not more individualizing their patients, and taking their patients as an individual, their history, and giving them an opportunity to maybe help correct their condition without a synthetic drug.

Participants also feel frustrated that they receive prescriptions without being told about the medication.

I agree with Sister B. You know, they give you this medication and they tell you take this or take that, and you don't know what you're taking. And then they tell you you're doing fine, see me in two months. And I ain't getting no better.

Participants are appreciative of providers who do work cooperatively with them, considering each patient as a unique individual.

I have had the same doctor for over thirty years. And I'll go and he'll check me, and if I don't need medication he won't give it to me; but if I do, he will.

Participants voice their belief that doctors may not recognize the limits of their own knowledge, and that they know their bodies best.

I agree with Miss. P because you have your appointments with your doctor and they go by your blood work and everything. And sometimes they don't even know, and they'll tell you. It's like when I go to my cardiologist and he'll say, oh you're doing fine. But I might have something that's going on in my body that's not fine. So then you go to your regular doctor and he'll say, well I think you need to see your cardiologist, or you need to see whoever. So you really don't know yourself. It's only God knows you.

I agree with both ladies, but I do get a physical so that I can be sure that I haven't developed any complications from the existing condition I have or - - then, like I say, your body's the best indicator. But a physical is what I generally get at least once a year, and a routine - - and most of these ladies probably do as well - - get the routine blood tests and all that. Then, other than that, you know your body better than the doctor.

Participants note the importance in being assertive when dealing with healthcare providers.

The thing I've realized the older I get the more health issues I face that I really have to take responsibility for my health. I have a choice to make. I don't think it's really up to my doctor you know because it used to be I would go to my doctor and whatever he said it would be status quo. Now I challenge because it's not everything you say to me that I think it's the best solution to my health problem that recently came up when I had an EKG done and they learned that I had atrial fibrillation. A-Fib they call it – an irregular heart rhythm and you know the doctor said we can shock your heart back into rhythm as an option. I'm sitting there okay – shock my heart. That's sounds real serious to me and I was like anything else that we can do and he said something else. Then he said not until after I said what if I don't want those choices. Then he said well we can put you on an aspirin and you can take a stress test and I can put on a medication that's for high

blood pressure even though I don't have high blood pressure. I can put you on that medication. So I said let's try that. He says well in meantime I want you to have this stress test done. But had I not said what if I don't want to do anything of that. You know I always felt like the choice and even challenging the physician. Even though I know he's got what he's got but it's also still my responsibility for my health. So I think as I've gotten older I've taken my mental and physical health more serious than I use to.

Its brought out a lot it's made me realize you need to start taking care of yourself. I don't like really going to the doctors because I don't get the answers that I want and you know at first so I just hang and go with the flow and I know that's bad. I'm tired of going to the doctors and here I'm paying the doctor and I still don't know what's going on.

When providers give advice about aspects of health other than medications, participants can still be skeptical when the information conflicts with their own self-knowledge.

I disagree with my doctor because they always want me to lose weight. I get a certain weight I feel good with it and it's hard for me to lose weight. When I finally lose five or ten pounds – oh they happy with it but I'm not happy with it because it makes me feel bad to lose weight. I don't know why but it do.

Participants are dissatisfied with healthcare providers who do not deliver expected services.

Well I actually – funny that you ask that question because I'm thinking about getting a new doctor just because I just sometimes don't feel – I feel like I'm just another patient. I don't feel like I get the attention that I should get especially since I've been coming to you for as long as I've been coming to you. What I mean by that is I know such things – I purposely did not ask him to check my feet for a longtime. He never checked them. I'm just thinking that something a doctor should ask. I shouldn't have to ask him to check my feet. So I am looking right now for another doctor. I think most healthcare professionals I think generally care about your health and about you. But I think there are some that are just doing it because it's a good paying job.

I'd like to get another doctor. It's hard to find certain doctor. I'm ready to have a doctor who deals with diabetes. My doctor he don't like to treat.

### ***Distrust and Suspicion of Healthcare Providers***

#### **Over-Treatment and Under-Treatment**

Participants are concerned that the treatments they receive may be inappropriate or not medically necessary.

No, I just don't - - I don't understand taking four or five different blood pressure medicines. And I just don't understand that. And I know for some people to have

hypertension that's so out of control, in some cases I can. But you cannot get out of the doctor's office without taking at least two or three blood pressure medicines.

One participant reports her pleasure in being able to improve her condition without taking the medication prescribed by her doctor.

I did that with my doctor. My cholesterol appeared high and put me on all these drugs. All these medicines just about there are, and my body wouldn't take them. And whenever I started taking the medication I could feel it in my body. And I would go back to him and tell him I couldn't take it and he'd give me another. So what I did - - I'm proud of myself - - I lowered my cholesterol by my eating. I changed my diet and I lowered my cholesterol to under two hundred myself without the medication. And he was just flabbergasted. [Laughter] He just really was. He said "you did it!"

Conversely, sometimes providers do not deliver services that participants expect to receive.

I usually agree with my doctor. However, I don't agree with any doctor that just talks to me and just prescribes me medications. I think that there should be some more testing done, because doctors like to fix it; and I'm aware of that. And I don't mind taking the medication if it's going to work. But I have the kind of relationship with my doctor that I really kind of take charge of my health. I know my body better than anybody knows my body. And so I'm just glad that I have the kind of doctor that listens to me and will do the necessary tests that need to be done. But, on the ones that can't have those tests, it's a whole different story.

### Greed as a Motivator for Providers

Participants sometimes attribute treatments offered to providers wanting to maximize their profits.

I disagree because I – from when I was coming up I believed. But right now I believe in a lot of ways they're greedy and want more money and will tell you anything. So you have to get a second opinion. A lot of them will tell you anything to get something cut off you don't need it. I mean in my opinion.

Suspicious go beyond the healthcare provider to include the pharmaceutical industry.

MISS P: Just alluding to that, when I was talking about the doctors not trying to deal with you as an individual, recently a doctor tried to get me to take some cholesterol medicine - - not recently, well a year or two ago - - and she was pressing me to take this medicine. Of course, I took a blood test, it came back; it still was slightly elevated. But what disturbed me is that what they told me ten years ago even before this medicine came on the market. That what disturbed me is that the remedy was to give me medicine, instead of telling me you need to stop eating this, this and that. My concern is - - once again, that concerns me that some of the doctors and the pharmaceutical companies are in collaboration - - and this is just my personal opinion - - to make sure that they are profiting from the medicine they're dispensing.



MODERATOR: So you're saying that, in a sense, it's Big Business?

MISS P: Yes. I believe, to a certain extent it's collaboration, and it's not really taking the individual patients and dealing with them so they can improve their health. It's more or less a market. Then, two years later, the medicines that they've been prescribing is off the market.

In addition to maximizing profits, participants are skeptical about the need for treatment offered. Similar to complaints that providers are inattentive, participants express the idea that doctors recommend treatments by assumptions made or stereotypes rather than considering each patient as an individual.

One thing about is because sometimes a doctor tell you – say for instance they prescribe you something. They try and tell you how you feel. You can't tell me how I feel. You're not in me and you don't know how I really feel. And because one prescription may work for Jane Doe it don't work for me. And then you tell me something that I don't believe so I want to have another opinion and another one and another especially when you get to talking about cutting on me. And then I've been through a situation where you said I needed surgery done and after two more opinions I didn't need no more surgeries.

### *Positive Relationships with Providers*

Participants appreciate relationships with providers who treat them as individuals and provide trustworthy information that agrees with the patient's own views of determinants of health.

I think that the doctors for the most part are really - - give people the information on foods. My doctors are always telling me: stay on your fruits and vegetables, you know, pig out on your fruits and vegetables. Which is true, you know, not a lot of red meats. Some meats, but not a lot of red meats: fish and this and that.

Patients report satisfaction with providers who treat them appropriately.

What I found out, Miss L, was that I have sleep apnea. And I didn't think I could have sleep apnea because I wasn't grossly overweight, and a lot of other things. 'Cause I was always tired during the day and I was sluggish. And so finally when I went to the doctor, she said let's just check this out and see. And so I went to a sleep study. And that's when I found out I had sleep apnea. And now I have a little machine, my husband and I both. He's got on his mask; I've got on my mask. [Laughter] The things that happen to you as you age, is just hilarious. But what happened was, when I started to use it I was reenergized. I felt so much better.

Participants do feel that it is necessary to follow their doctors' advice in order to be healthy.

But you know you try to do as he [the doctor] ask and make an effort even if it seems like whatever he recommends is the worst thing in the world especially for mental health

issues. To be social is always good to have – sometime you don't think that way but as you've come to the community more. It's like when we knew everybody on the block.

Even if participants are annoyed at having to return to providers' offices multiple times, they recognize the value of a cooperative relationship.

I really like to follow my doctor's orders, but if they prescribe some medication for me and I take that medication and my body is not feeling right, I got to make another appointment. I gotta call and go back and tell him this is not working for me, something is wrong. And then they try to work with me to try to figure out exactly what it is.

### *Preventive Services as Determinants*

Participants speak of the importance of seeing providers to get proper preventative services.

Oh, probably I'm more aware of - - even if I don't feel good, sometimes I say, well, I'm paying for this insurance, just go in and see the doctor. I'm paying for it, so it's changed like that. Because I wasn't a regular go-to-the-doctor. My mom and dad weren't. I don't ever remember my dad going to the doctor. And I'm an only child, so I don't remember her - - the only thing I remember her ever doing was she always did go see about her eyes, but other than that? When she had the aneurysm, there was a lot of questions about what medication she was on. I said none. She didn't take anything. Now I'm just more aware of - - I'll go and do the mammogram, PAP smears, and like that.

MISS J: What keeps me healthy is keeping my appointments, my yearly appointments with my doctor. What do they call it when you get your mammograms and everything yearly?

MODERATOR: Preventative health?

MISS JM Yeah, the preventative health thing. But again, I think of the women that can't do that.

### *Medication Use as a Determinant of Health*

Participants speak frequently about using medications. Prescription drugs seem to be simultaneously a determinant of health and an indicator of health status.

Participants express the thought that medications keep them in good health.

Well I think I'm in good health and I think I'm healthy, but only because I take the prescribed medication that I have to take. You know, the basics. So I never tell myself that I am unhealthy. I always say that you are healthy because you have people helping you to be healthy. [Laughter] And I know I can't miss taking medication, 'cause I think I'll be taking medication for the rest - - I had a hip replacement, I'm diabetic, and I have high blood pressure, and I have high cholesterol. So I take medicine every day. It's just

like getting up in the morning. It's the first thing I do when I wake up. I say my prayers and I go in the kitchen and get my water, get my meds: Monday, Tuesday, Wednesday, Thursday, Friday, Saturday, Sunday.

I have fibromyalgia, rheumatoid arthritis and they seem like they've raised my medicine way too high. I sit here in pain a lot of times because they got me on this 7 point something pain pill and they tell me to take one or two and most of the time they tell me to take two. Then I have to take that Lyrica tablet and it's pretty hot. Plus I take Samrota and its got something in and I get to wondering and I say I know my doctor know what she doing but it scares me that I'm taking so much. It just worries me but I take them. I take them when I wake up and maybe at noon I might not take it and I sit in pain the rest of the day until it's almost time to go to sleep and then I take it again. I don't want to get too much in me and go to sleep and not wake up

The number of medications that one takes is an indicator of health

My mother died when I was young. My father died. The only one that live now is my sister. She's in way better health than I am. She takes one pill a day and I take [inaudible] and she's 74. Yeah so she's in a lot better health than I am. She's always on the go.

Some participants worry that they aren't taking enough medication.

I always think about, because I don't take any medicine, am I supposed to take some medicine? I've been to the doctor and he says everything is fine. But what is a person my age, I'm seventy-five. You should be doing something

Just as participants are suspicious of doctors, they may distrust medications.

I think about, even with hot flashes, sometimes they can be severe. But then when you look at the side effects of the medicine, they seem more severe. Just turn the fan on at night. {Laughter}

I learned from going to seminars and stuff a lot of research with drugs is tested on white males. Well Lord knows I'm not a white male. So what is going to benefit him not going to necessarily benefit me.

## Control of Determinants of Health

Many participants express the idea that they had control over their health status. They often express nuanced ideas about when health status is under their personal control and when, due to life circumstances, they did not have control.

I can control my diabetes, my blood pressure by eating correctly and taking my medication as directed and reducing my stress. Things that I cannot control is my environment. I cannot make this person move. I cannot make the city fix the street. I

can't tell this person okay its midnight I'd like to go to sleep. Turn down that music because the repercussions but I can't control them. I can control what goes in my body and what comes out of my mouth.

Participants frequently speak of control in terms of self-discipline with health behaviors or emotional states.

MODERATOR: How much about can you personally control. So in other words what things can you control and what things can you not control.

MISS W: Taking your medicine.

MISS J: Going to the doctor.

MISS P: Losing your temper.

MISS N: The way you eat.

MOD: Anyone else? What things about your health can you control?

MISS M: I was going to say what Miss MJ said.

MOD: Anyone else. How much about your health can you personally control and what things can you not control?

FEMALE: Control your appetite when you're hungry.

MOD: Controlling overeating. Anyone else?

MISS W: Salt intake.

MISS S: Just controlling your mind. Your mental state.

MOD: Miss AR what are some of the things you think you can control?

MISS A: I control my eating.

MISS K: I think that sleeping. I think if you get a proper amount of sleep that it would help your health.

Many participants feel that personal control is paramount in determining health status.

A lot of things we do to our own bodies. We take things and do things to our own bodies so that cause all the problems. So if you take care of your body the best that you know how I think that eliminates a lot of the problems that we have when we get older.

Several participants express the idea of control of health determinants through proper health behaviors, such as proper eating and exercise, working through will power.

Well it's really important how we control our eating habits. I can control that. The body is a machine that has to be worked. I can control how much activities that I do with my body. Those things I can control.

Participants offer examples of successful control of their conditions.

I kind of right now have control a lot about my health, because even I think about my weight. When my weight went up and I know my cholesterol go up, when I know my blood sugar go up, all I have to do is exercise. And I know if I do that it's going to come down. I know that, because when I went to the doctor and they said we gotta get you back in here, your cholesterol's up and your blood sugar's up. And I'll start exercising like crazy. And when I get to them, it's down. It's gone. And I know that I can control that. It's just to get it in there. I get so busy doing stuff and I'd be so tired, and I just go home and lay down or sit down in my recliner. And just get it in here that I need to do this, that's my thing; but if I can do that. I kept my weight down now. And I know if I worked at it I can control it. I can control all of it.

Participants acknowledge how difficult exercising self-control can be, especially in eating.

These ladies know me pretty well, and I have to agree with Miss J. Eating habits, things that you know is bad for you. Your fried foods, and highly seasoned food, that's a struggle for me. I'm doing well with it because I know how important it is now that you stick with a very good diet. And how important it is to eat, like our parents told us years ago, lots of vegetables, lots of fruit. That's what the health professionals are saying now. All red meats are bad for you. Well, all of us like red meat. I know I do. I just finished eating. I know if I had my way, I could sit right now and eat a great big grilled T-bone steak. But it's knowing now what is good for the body, what will make the body healthy. And you know it's just like our parents said, lots of fresh fruits, lots of fresh vegetables; that's what's good for us. And it is a constant struggle, especially for me, because if I'm not eating, I'm thinking about eating. [Laughter]

Participants also offer examples of what can happen when control is not exercised.

When you wait too late what happens when you do. Then you decide you going to do something about that. I know I had high blood pressure and they wanted to treat me at the clinic free. I said being stupid – it's not bothering me – I'm not going to bother and it took more than 20 years to the stroke after stroke.

In addition to self-discipline, control can come through one's relationship with God.

I can control the water amounts that I take. I take great amounts of water. And I leave coffee alone, I leave pop alone. A lot of the juices I leave alone. And when I drink juices, I add more water into them. I usually go through a gallon of water a day, and that helps me a lot. It keeps my body flushed. It keeps me flushed out. And another thing, too, that I can control is the way that I think. I like to feed myself with some type of rule. But the most important of it, reading the word of God. My thoughts I can control. And I know that I can be an over-comer by the word of God. So it's what I think.

You really have to you know when you're going through I have learned that I can't do nothing about what happened. Only Jesus can do it. When you're praying and you have a problem you turn it over to the Lord. The burden is too heavy for you and you have to turn it over the Lord. You will say Lord I give it to you and then you go and take it back. But you've got to truly give it to the Lord and that it stayed there because you know I've been through – I've lost a son and I've lost twins a son on Mother's Day could you believe it. I gave it to the Lord before I went – if you're kind of close to the Lord he will show you things to come –things that's going to happen. You may not know what going to happen but then you turn it over to the Lord and you let it stay there he's taking it away right then. We have to accept something's we bring on ourselves and we have to accept the Lord. I've learned no matter what time in my life I'm going to stay with Jesus.

While speaking in terms of control that should exist, one participant acknowledges that she has not been successful, yet she is still hopeful that she will attain control in the future, with God's assistance.

You can control if you want to be around people that are abusive towards you. Control - per say you know if you try to get control. Now if you put yourself in dangerous situations like walking the streets at 2 or 3 O'clock in the morning. Just – know people watch you and you have to change your habits a little bit. Try and develop good habits – no bad habits. I myself, I'm speaking of myself I have a bad habit with cigarettes. I'm trying to get off the cigarettes because of COPD is getting worser and worser and worser. Doctor said if I keep on smoking in two years I'm not going to be here. So it's either that or not be here. So I'm trying to make a very conscious effort to get off these cigarettes. But it's hard. I think if I keep on praying and keep my faith and I know if I keep on praying the Lord will deliver this for me.

Many participants acknowledge that they cannot control the fact that they have illnesses, but they can control the ways in which they deal with the conditions. One participant felt she can control manifestations of pain through her own actions.

On the control part, I can control my level of pain somewhat by taking my meds. Like my pain medication so I'm kind of in charge of the level of pain that I'm in. If I don't take the medicine I'm just going to be severely in pain but if I do take my pain medication then I'm able to kind of do – function and live. So I can somewhat control that.

Participants also achieve control through management of their attitudes.

I can control my blood pressure. Well I try to not stress but I can't change the pain from MS. I have cirrhosis – I had it now for 12 years. I'll just go – every day is a different day. So I just try and be happy.

Participants make distinctions between their ability to control symptoms, while not being able to control the fact that their chronic conditions exist.

I think the things that I can't control are illnesses that I already have. I can't control them being – I can control them getting better or being tolerable. But I can't control eliminating them.

Things I can't control like Miss C said is the chronic pain that I have already. But the things I can control like the stress. I don't allow stress in my spirit anymore. My attitude I can change that – control that rather. Just you now enjoy life and be happy.

Participants are aware of dangers inherent in certain environments, in which personal control is difficult or impossible; therefore, one choice is to remove oneself from the environment

Like she say, a lack of self-control. Discipline yourself. Going places that you know those things are available to you. You gotta control yourself. You can't go into certain environments and eat certain things. Just lack of self-control.

Participants also express lack of personal control over food choices that might be available to them.

But what I think too, it's not just the physicians but it's the foods that we eat. I think there's an addiction to certain foods. And I think a lot of foods is just a lot of junk foods. Eating a lot of the processed meats, a lot of the canned foods, a lot of the frozen foods. I'm noticing on the commercials that they are downsizing candies, 'cause they know that's not good. Sometimes it's more for the bang, you know, more for the money. Which is not true. And I think that they're kind of getting on the bandwagon of the amounts that they give, that they know it's creating problems there in the foods with the salts. But as far as food is now, I'm just kind of surprised.

I'm going to say, we can control our health, really by eating, like she said, eating, daily exercising, like Miss M. Those are the intakes. Those are the main two intakes as far as the food and the exercises and our body movement. We can control all that. As far as the food is concerned, we cannot control how the food is processed, how it is raised, or any of those kinds of things. Even when we read the labels and things on the cans or whatever, we cannot control that. So whatever the foods is containing, whatever the air is containing - - we can't control the air and we can't control the water. Remember the chlorine is always in the water. I don't agree with that, to what they say they using it for. I don't agree with that. Those are the things we cannot control. So were in-taking this all into our body. And everybody cannot afford to have their own water system cleaning out or control the feeding of their food products. Those are the two things that I get so angry about, is because those things are so bad. But we can control the exercise.

It may not be possible to exercise control when one lacks financial resources.

Well you can control your food if you have the money to get the proper food that you need to eat. But you can also control, well, I don't know. Our society is just so different today. There's so many stresses on women that there is not too many things that they can control. If they have the resources I say, yeah, they may be able to do that, if they

have enough knowledge of how to do it. But speaking for myself, I can control what I eat and the hours that I sleep. I can control if or not I will exercise. Those kind of things that you can do. There're so many variables I think for, especially women today, as to what they can control due to the economic status and all those other things. A lot of it's out of their control.

Control of the environment can also be exercised through asserting oneself by speaking up.

I don't know about that. The reason I think it's probably not much asbestos if there is any that was what the infrastructure was but asbestos was on the rise and the government was real aware of it when this was build. So I think it was just a dust and old system in the buildings. Now this one here this system is totally different but over there its 21 floors at night automatic turn on the heat – automatic turn on the air. The only way to control it is in the building just turned if off. But downtown I think their air quality is good compared to other parts of Indianapolis where the factories are. Especially around the river. If you – the way you can help I guess in the community is if you are aware or you know – just go in your community and see what you can get done. Closed mouths don't get fed so if you don't complain, they don't know – well they'll say they don't know. But they're aware of it but it's not on priority. Because they have a lot of problems with the water here in Indiana and of course now we've been hit with the tornadoes so that's blowing stuff everywhere. I don't know how far it goes or how far it travels because they do have dumps further out to the smaller area and of course it effects our food and the soil.

One participant expresses the idea that the physical body cannot be controlled, although feelings may be.

I think you go by your feeling. You think you're all right, but then on the other hand you really don't know because you have no control over your body. So we go by our feelings a lot of times, whether we are well or unwell or whatever you might want to call it.

While many participants feel a sense of control over chronic illnesses, others express a lack of control over the same illnesses when they are considered genetic in origin.

Sometime hereditary runs in the family. High blood pressure, diabetes. It's hereditary down from the years.

It come up through the years you know your ancestors - your grandmother, your mother.

You can't really control the hereditary illnesses. You can control the symptoms after you are diagnosed. But other than that you know you really have to follow your doctor's orders. But you know you try to do as he ask and make an effort even if it seems like whatever he recommends is the worst thing in the world especially for mental health issues. To be social is always good to have – sometime you don't think that way but as you've come to the community more. It's like when we knew everybody on the block.



## Appraisal of Health

### Self-Appraisal

Participants maintain dialogue with their physical bodies and use intuition in order to assess health status.

Your body tells you. When you healthy. Your regular routine and you wake up and you say something's wrong.

You know what? When there's something wrong you just don't even wake up right that morning.

Actually, my body tells me. I have these feelings and my body lets me know if I feel healthy or unhealthy. And then I have certain signs within myself and I know I've got to call and get some help, because - - first I say, Lord, it's something wrong. So, therefore, I say I need to really get some professional help. And so that's what I think of body and mind and spirit.

Participants pay attention to their states of mind and functional levels so they will know whether they are healthy at any given time.

You know when you're healthy when you hop out of bed. You get around. Your attitude is with you if you're healthy and you're feeling good. And if you're not feeling – myself, if I don't feel good I got attitude. I got attitude because I'm not able to do the things I use to do. You know and I hate to ask anybody to do anything for me but sometimes you have to ask somebody because you can't do it by yourself and that irritates me. So when I'm feeling good I'm a whole different person.

Participants also compare themselves and their symptoms against information received from media.

And I think that there's so much awareness. With technology being what it is, every day you're just seeing stuff just flash across the TV screen or the internet about what disease is. And sometimes you hear that and you think "do I have that?" Like Restless Leg, I never knew there was such a thing. I feel like that sometime. I wonder if I have that. I think that we're so inundated with awareness that you can't help but be aware of health issues.

## *Appraisal of Health of Others*

Participants speak of their central role in maintaining health of family members. Women are the nexus points for health in their families and communities. They appraise health through observation of symptoms and behaviors, invoking several of the elements of health—physical, functional, and mental/emotional. They also compare their own health with that of their parents' generations.

### Symptoms: The Physical

Participants sometimes assess health status by directly observing symptoms of illness.

When you see – sometimes you can see when something's wrong. They might not know but they always think [laughter]. The first thing say is are you all right? Are you?

Well, my mother, she died with cancer. And before we found out that she had cancer, I knew something was wrong with her. She was coughing all the time and spitting up blood. That's how I knew about my mother. And my father had a heart attack, but I don't remember what his symptoms were.

### The Mental/Emotional

Assessment of mood is critical in recognizing health problems.

My family members when they're feeling healthy they have a lot of energy. They spend more hours awake and active and when they're not feeling healthy they're grouchy, irritable, down, depressed and that's about it.

### Function

Participants judge health status by the ways that family members move.

Some parents if they look at their kids or if you look at their siblings. You can tell by the different way they their move their body. First thing that comes to mind is when you look somebody in the eye and can see that something is going on.

Functional health and mood are closely linked.

Usually when a person is healthy they are happy and you can tell when they're around you. You know – they're up beat. But if they come around dragging and something you know something is wrong. Sometimes you can just tell by a look a person's face. If they're looking well or no.

## Communication

Much appraisal is conducted through communication with family members, both the number of times that communication is made, or by the things that are expressed.

MISS D: Communication. I'm with my family a lot. I call them every day. I talk to them every day. I go by and check on them at least once or twice a week.

MODERATOR: So Miss D you said its by communication or talking.

MISS D: And visiting them.

MISS O: [Responding to the question "How do you know when family members are healthy"] Basically by physical and mental contact.

MODERATOR: So the way they talk to you or is it the number of times they talk to you or is it both?

MISS O: Yeah the frequency.

The 'knowing' about health of family members may come from communication.

I can tell when my family is healthy because they communicate better. They are around more I guess. You spend more time as a family together. They're always on the go doing things – getting involved – sharing what they're doing.

Participants recognize that something isn't 'right' with their children when communication changes.

I can tell when she's [daughter] sick when she's not contacting me. She use to email a lot she stopped doing that. Something's going on right about now. They contact me enough. I feel like they don't know that I should be hearing from them. I feel like I'm thrown away – the lost sheep or whatever you want to call it. And I don't have any family in this city. It hurts but you would think your only daughter would contact her mom. Then the internet – emailing – she don't call at all. That's how I know something is really wrong because a mother has an instinct and you can feel those things in your child.

Participants may rely on children communicating their symptoms.

You have young children. They're very – we go to the doctor's on a regular basis. They would tell me in a heartbeat when they don't feel well. It's not really something that I need to look at them to see but there are times when they're not eating or they're sleeping a lot I'll question to see how they feel to see if anything is wrong. But other than that they will come right out and tell me my head hurts, my stomach hurts, this hurts. I need to go see a doctor and then I do the momma analyzing and make some home remedies – drink some water, go sit on the toilet [laughter]. You know some times it is something simple that they need to do that they don't think of. But most of the times, like I said, because of the age of my children they will let me know if it's not something

like I said, just not eating or overly sleeping. Those are the two things I look out for from them.

Participants may be skeptical of the content of the communication.

I have a daughter. She had sickle cell. So I called her and asks her how she feels and most of the time she be lying.

Communication can be about relationship style. When that changes, it can be a signal of a health issue

MISS W: When they come around me and try to boss me [laughter] and once they stop something's wrong.

MODERATOR: So they're not bugging.

MISS W: Something's wrong.

### *"Momma Guidance"*

Participants relate stories of vigilance in assessing the health of family members, often recognizing health problems before the family member him- or herself.

When my family is healthy they are more agreeable. I can ask them things and they will follow through – the follow through is good. When they're unhealthy they avoid me. This avoidance because I work in health and they know I'm always analyzing what could possibly be wrong. So I can kind of give them some momma guidance. I just know they avoid me or don't come around.

Participants feel that it is their role in the family to get family members to take action on their health.

I told my daughter she had the little bottle with the pull up top on it and every day when I got there oh momma I got some good old cold water for you know like this. So I said when have you been to the doctor? And she said I go tomorrow. And I said have him to check you for diabetes. She said why did you say that momma? I said you're a black women right? She said right. I said you're 35 right? Right. You're overweight. Not that much but overweight, right. She said right. Next day she come in from the doctors. She tells me [crying] and I said what's wrong with you? I got diabetes. She said how did you know? I said you were drinking so much water and that's why I told her to get it checked and she had it. Now they got her on a diet and I think she done lost about 20 pounds. So she's doing good.

Participants may need to take action themselves when the family member will not.

My husband within the last five years he's had a stroke and he's had two heart attacks. And the first thing that I noticed was the changes in him, and him being a male, they don't - - they're not like we are, responsive to what our bodies are telling. And so with the last one, he was complaining about having headaches all of the time, and he was

very, very tired. And on top of that he's diabetic. So when you have that complicated stuff in there, you don't know. And I would always tell him, you need to go to the doctor. Call your doctor. Call your doctor. And when I came home from work, I found him sitting in a very confused state and I just knew. I just automatically called 9-1-1, because I knew that something was going on and it wasn't very good. But just paying attention to your family members, and if you really know them you can kind of pick up when things are not going right. Either by something that they say, the way that they act, or they're sleeping too much, they're not eating right. And I know we, as women, I think we just pay a little bit more attention to those things than some of the other men do.

After she started changing so much, I started going over there to check on her. And this particular day, I was over there talking to her and she wouldn't say nothing and trying to get her to eat and she wouldn't eat nothing and so, it got me. And I said, you got to do something. You just can't sit up here and just sit. She'll lie to the end that she [isn't sick]. And so I called her son and my sister and I told them she was sick and she need to go to the doctor and for the son can't get her to go I will call the police and she will go to the doctors.

### *Historical Health in the Family*

Participants report that their parents may not have known about their health problems, and that the 'not knowing' may have been, in some respects, positive.

My father lived till he was seventy-two, and my mother was eighty-three. Now as far as my health, the way they are, mine is basically like, I'll say, my mother's. 'Cause my father, I couldn't tell. I knew something, but I didn't know what. And so I would think mine would be on the even keel with my mother. She was active all up to the day that she went in the hospital for the test. Then, that's when she passed. She was good. In other words, she really didn't have any complaint; but I know she had one.

Many participants felt that their parents' generation was healthier than theirs.

At the age that I am now, I don't have as much energy, as much get-up-and-go, as my mother has when she was my age, 'cause she was very active. I'm active, but not as much as she was.

My dad died of cancer. And he was so healthy, he was ninety - - he died and he was ninety. But he was always healthy. And we took him to the doctor, his normal appointment, and he was coughing. So they found a mass. But he was always healthy. We didn't know. And he had a cough, but he had always had the cough. So, they didn't know.

When my mother was 71 she could walk from Speedway to East Side in a couple hours but I can't walk this building. So she was in much better shape than me.

A few participants acknowledge that their own health might be better than that of their parents.

Compared to my parents, I'm in better health. My mother died at fifty-two, my father died at fifty-four. And they both had cancer. Being an only child, that was quite a concern for me for a long time. But I'm okay with it. So I've outlived my parents. They did not have the healthcare that I have, though. So I think that makes a big difference.

I think my health is a whole lot better than my parents. My father – he retired when he was 62. It was just like he retired from life and when he just started falling apart because he stopped doing things. He just laid on the couch and looked at soap operas all day long. So he had diabetes, high blood pressure, what is that – that heart failure. He had a whole lot of stuff and I looked at him and I tried to talk to him and it didn't do any good. But I just kind of use him as an example for myself that the human body has to keep moving. So I have an exercise program and I do just 30 minutes every day for five days a week.

## Summing Up

Participants are very positive about their experiences in the focus group. Some would like to take the discussion further and to learn more about their health, in a cooperative way.

I think this was a very good forum. It did give us some opportunities to share some things, but I think in some areas we need an opportunity to go more in depth with some of the things. And especially with the issue on medicines, because there is overlapping medicines. Most of us take more medicines than we really should. Because anytime you get a prescription, and on the side of the bottle it tells you what the side-effects is, it's basically saying: take this medicine now to feel better today, but eventually it's gonna kill you. So I think that if we could get - - you know, in the future if we could get some groups that would focus more on things like medication and some of the other issues that were brought up, I think that would be very advantageous to all of us. Because I doubt if there is anyone in here that doesn't take at least one kind of medicine, even if it's an aspirin, so I would like to see that. And again, you know, I think it was good.

One participant explicitly mentioned health literacy needs.

Could I just interject? I was hoping that we would have some type of literacy information. I have a prescription book at home. Whenever they give me anything I look up what it is. That might be helpful, 'cause probably some of these ladies are taking similar medicine, and they could have looked it up in the prescription book and seen what this medicine is for and the dosage. 'Cause everybody has different body weights, that's what really gets me. They'll prescribe maybe the same medicine and your body weight could be different, so it's gonna affect you differently. So more information and literature that people could actually look at while they're here; look up your medicine while you're here.

Sometimes they take advantage of the wrap-up to offer advice to other participants.

I've enjoyed the forum and I think it's good that people got a chance to vent their concerns. But one thing I will say, it's important that you know your physician and you know why you're taking, or he's giving you the prescription he's giving you. I have a problem with that. Because I know how the body works and I understand all the medications that I'm taking and why I'm taking them. So that's vitally important. You have to be comfortable with that. I think it's good that everyone gets a chance to express their feelings about their medications and what concerned them about their medications. And wanting to know, as you grow older, how the body - - the body is an interesting machine. Your body makes cholesterol after a certain period of time, so that may be why he's giving you cholesterol medication. So you have to understand why you're being given certain medications, and be able to vent that to your doctor. Like I said, you need to know your doctor and understand why he's prescribing certain things. But for this group, I mean for this session I think it's important that one gets a chance to talk about their health concerns.

Participants like that they are heard and that they might, through the experience of the focus group, dialogue with research and the healthcare system.

MISS D: I think the focus group is much needed in the African American community because I work in the public health I know the benefit of studies and being in focus groups and it's a way to get your voice heard. By identifying yourself. Getting it out to African American men and women that this is your sounding board to get your issues heard so the researchers can now know what direction they need to go in. . . . it's a mechanism to get your voice heard without saying it's going be printed that this is what she said but to know that it's all about research. . . . So a focus group to me is a springboard to look at what is the concern of the African American women today with the chronic disease. Where can we now say studies show we need to be focused on this or that? We need to be focusing on this or high blood pressure. The silent killer. It wasn't silent for a reason that's because somebody didn't know they had it. So I look at this as an opportunity . . . . I think a focus group that we would just go back and say this was a great experience. I don't know where you're going with it but I'm okay with that because my voice was heard. It was hopefully appreciated and I think a focus group should be something ongoing all the time.

MISS H: I agree with what you were just saying but I'd like to see it a step further. Not just so you have the data. But there's an outcome that provides more opportunities for African American women and minorities to come together to dialogue. Because often times and not just the older women but the intergenerational groups because there is so much that we at our age can mentor. I think younger females need and would want to welcome that type of dialogue. So if there's way after you've done collecting research that you take it another step further to present opportunities for women to come together.



## Recommendations and Implications for Public Health Practice

This study reflects the deep and complex structure of health and its determinants in a particularly health-vulnerable population. Participants were enthusiastic about the process, suggesting that community-based group meetings that encourage women to share at a personal level may be a good strategy to make deep changes in communities. Participants represent great diversity within the community of older, chronically ill African American women in medically underserved and express a wide range of opinions. The multiplicity of responses show that 'one-size-fits- all older African-American women' strategies will not be effective.

We have uncovered several areas that require further exploration. These include the relationship between older, chronically ill African Americans and medications. Medications seem to be simultaneously an indicator of health status and a determinant of health; women worried about the number and types of medications they were prescribed while acknowledging their usefulness in maintaining good health. Learning more about medication concerns will help improve health literacy and medication adherence in this very vulnerable group.

Many women criticize their relationships with doctors. It would be beneficial to understand more about women's perceptions of their relationships with doctors. It would also be useful to understand whether the same criticisms and suspicion apply to other types of providers, such as pharmacists, dentists, or mental health professionals.

Women have many questions about the aging process, questioning which age-related conditions are controllable or preventable. Women mention the issue of menopause, in particular; this is a topic that needs more exploration.

Although we have a few preliminary answers to our research questions in this particular population, it would also be helpful to ask them of other health vulnerable groups, particularly African American men of various ages, the very old, or dual (Medicare and Medicaid) eligible people.

We have uncovered several areas that may be useful in reducing or eliminating health disparities. In working with older, chronically ill African American women for medically underserved areas in Indianapolis, we have found rich detail about their perceptions of the topic of health, as well as learning much about how they deal with health issues, particularly concerning their interactions with healthcare systems. In examining 'upstream' questions (What is health? What causes health states? How do you know about health?), several conclusions were reached.

1. **Women are aware of proper health behaviors.** In particular, our participants reiterate messages about nutrition and exercise. It may not be necessary to continue to broadcast simple messages about sugar, fat, and salt intake and the importance of regular physical activity; rather, women may need encouragement and assistance to make behavior changes they know may be necessary.

2. **Women are strongly motivated to maintain or improve their health.** Women desire better health and are committed to attaining it. They may need assistance in knowing how to take the 'next steps' for improving health. Many spoke of lack of resources, whether they were knowledge resources, financial or other concrete resources, or support services.
3. **Work from women's current sense of control.** Participants feel a strong sense of control over their health. We see little evidence of fatalism or feelings of passivity. Women seem to feel empowered; they do not require that sense from public health professionals.
4. **Women have a strong desire to be involved in health solutions.** Women spoke of their unhappiness in not being heard by outside systems, particularly in the healthcare realm. Any public health work must be undertaken in a way that actively solicits partnerships with the people it serves. Participants want to make 'a difference' in their worlds, family, churches, neighborhoods, and communities.
5. **Involving midlife and older women will affect the health of the entire community.** These women are daughters, mothers, grandmothers, and sometimes great-grandmothers. They feel responsible for and monitor the health of others close to them; they are motivators for changes in health behaviors of all those they care about.
6. **'Health' is multifaceted and should not be limited to the physical level.** Women strongly endorse the importance of the functional, mental/emotional, and spiritual aspects of health. Public health messages must include ideas of vitality and wholeness in addition to targeting specific diseases, behaviors, and conditions.
7. **Work from the level of the community, validating the importance of relationships.** Working solely on an individualistic level denies the sense of relationship and community frequently stressed by participants.
8. **Healthcare 'access' has more to do with quality of care than being able to see 'a provider.'** Typically, women have an established relationship with particular providers; however, these providers often do not provide welcoming environments. They do not build dynamic interpersonal relationships with their patients. Instead of automatically prescribing a standardized prescription for individual care, each provider should assess the patient's perception of her health and which dimension is affected (individual, family, environmental, and resource factors affecting her physical, mental, and spiritual health), what will it take to make her healthy, and what actions she can take to work towards the desired 'healthy' state.

9. **Address distrust and suspicion of the healthcare system.** Women repeatedly spoke of not being treated as individuals by their providers. Many women voiced deep-seated suspicions of the healthcare industry, including physicians. There is much room for educating doctors and other professionals on the necessity of dealing in an authentic, respectful manner that acknowledges past basis for distrust.
10. **Topics for public health intervention need to be defined by community members.** Two issues that arise repeatedly in this research are medication use and aging issues, yet these are rarely addressed in health education. The community needs to be consulted on important intervention targets; these should not be imposed from outside.
11. **Work through churches, but respect and nurture the relationship.** Older women are often highly involved with their churches; however, churches should not be used solely as a convenient venue for public health programs. 'Health' has an important spiritual component, so churches are obvious partners for health work. Working with churches requires building a strong reciprocal relationship that goes beyond a single topic or program.
12. **Involve a wide range of stakeholders.** Public health work requires broad alliances with the women public health workers are trying to reach, and also other persons important to women's lives, such as clergy members or business people. It may be useful to train key community members in health education/promotion efforts in order to achieve sustainable changes.
13. **Work with 'physician extenders' within the healthcare system.** Women may prefer to interact with nurses rather than doctors. It may also be useful for women to have access to patient advocates or navigators to improve healthcare relationships.
14. **All levels of the social-ecological model of health must be addressed in health education/promotion.** Women are aware that their health depends not only on their physical bodies, but on interpersonal relationships (family, friends, social networks), community institutions, relationships between and among institutions (e.g., churches and healthcare providers), and into the realm of policy.

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