

National
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Speaking Out on Health: Reflections of Midlife and Older Members of the National Black Women's Health Project

Acknowledgments

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Byllye Avery and Julia Scott of the National Black Women's Health Project would like to thank the golden ladies of the Fabulous Fifties Group for participating in their survey. "Your continued efforts and support on behalf of the National Black Women's Health Project is the reason we exist. Here's to you ladies; in wellness keep on shining!"

This publication is brought to you by the National Policy and Resource Center on Women and Aging.

Established in 1995, the National Policy and Resource Center on Women and Aging (NPRCWA) works to improve the quality of women's lives as they age, through policy analysis, research, and the production of educational materials for women across the country.

The Center's work focuses on the needs of midlife and older women in the areas of health, economic security, caregiving, housing, and the prevention of crime and violence.

The Center would like to thank Judith Apt Bernstein, Ph.D., RNC, for her contributions to this report. Dr. Bernstein is an adjunct assistant professor in the Department of Maternal and Child Health at the Boston University School of Public Health.

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Introduction

In 1981, a pilot project of the National Women's Health Project was launched to address the specific health needs of Black women. By 1984, the fledgling group had grown and become incorporated. Today, the National Black Women's Health Project (NBWHP) has 3800 members across the nation in 16 chapters and 150 self-help groups.

Early in 1996, the NBWHP's California State Office selected members to participate in a collaborative research project with the National Policy and Resource Center on Women and Aging, which was established under a grant from the Administration on Aging the year before. Focus groups were held and surveys conducted to learn about the experience of NBWHP members in finding and using health care. The following report summarizes the major findings of this study.

The Project and Participants

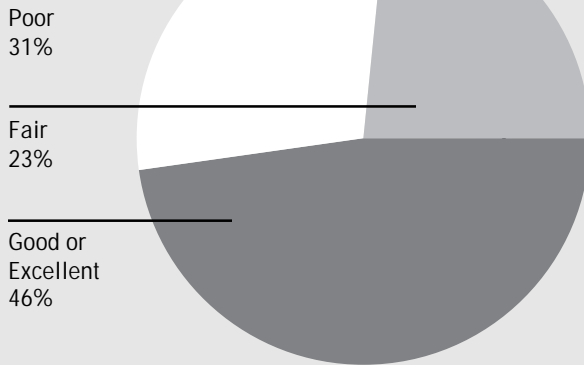
In two focus groups, women described their health problems, their needs, and their experiences with the health care delivery system; they also completed a health survey. The survey and the group discussions raised six types of questions:

- (1) What health problems are you experiencing?
- (2) What do you do to keep healthy?
- (3) Who is your health care provider, and what *do* you like and what do you *not* like about your interaction with him/her?
- (4) What are your health care needs and how do you prioritize those needs?
- (5) What kind of health insurance do you have, and are you satisfied with your coverage?
- (6) What changes would you like to see in the health care delivery system?

Fourteen women participated. Their age ranged from 52 to 82 years, and the average age was 60. Over half of them were high school graduates, and five women had attended or graduated from college, but six of the 14 women had only an eighth grade education. All described themselves as African American. Three of the women lived with a spouse, and six had adult children and/or grandchildren living with them. All but four of the women had worked outside the home—an average of 22 years of paid work—but only half had ever had employer sponsored health insurance, and even fewer had ever received sick leave (43 percent) or vacation (35 percent). Four of the women were currently retired, and five were working either full time or part time. Most of the women lived in rented apartments (71 percent).

Over half of the women said they were in fair or poor health (see Figure 1.). Half of the women reported arthritis. High blood pressure and diabetes were each mentioned by four women. Anemia, heart disease, digestive problems, and depression were listed less frequently. Interestingly, eight women—more than half—reported current medical symptoms that they thought were related to their prior or current jobs.

Figure 1.
Health Status



The Importance of Health

The women in the focus groups said that health is important to them—they talk about it all the time: to sisters, friends, and daughters, on the bus, on the phone, in stores, in regular conversation. Health is most important, they said, when they are in pain or when there is a crisis.

Although the women agreed that health is a very important issue, they thought it wasn't taken seriously enough by their communities. Food and shelter, by necessity, receive more attention, so some health services are lacking or located too far away. In particular, there is an insensitivity to Black women with chronic pain.

We asked these older women, “Who do you think is responsible for your

Health Concerns

health?” These women felt responsible for both illness and health. One said: “As women, we bring a lot of health problems on ourselves, a result of not working from the inside out. Truth and good health comes from how we feel about ourselves.” They were quite concerned about the old cultural belief that you should follow a doctor’s advice without raising questions. They advised, “Don’t do everything the doctor tells you to do.”

The women voiced many of their own health concerns:

“Things are not told to Black women concerning health issues, and too many doctors are not listening to their patients. Doctors are biased towards groups of people who can afford health expenses and insurance—money talks.”

“We have too much of stress, fibroids, diabetes, cancer, high blood pressure, arthritis, and children being raised by grandmothers, which causes stress and tension and leads to high blood pressure, heart disease, and fatigue.”

“We have too much dependence on Medicare, and too many fixed budgets; we have too little money for preventive care.”

“Physicians give us too many psychiatric referrals when we have health problems, too many operations like hysterectomies, and too many drugs for pain.”

Transportation was a special problem: “Older people need transportation to get to medical appointments. What’s available is stressful, because seniors have to wait for 75 other people to get finished before they can go home. Cab fare is too expensive.”

The women in the group do not accept a lot of the statistics published; they said, “The surveyors never ask any of us!” Another woman said, “We do not have people who empathize with our plight.” There was a strong sense that individuals have to be advocates for their own health.

The women in the study describe a wide variety of illness prevention activities, including exercise, getting checkups, taking medicines, eating right, and getting enough rest. Each woman had a mammogram recently.

Of all the activities these women undertake to safeguard their health, there is a clear emphasis placed on maintaining spiritual health. “Peace

Prevention Activities

of mind,” says one woman, “helps to keep you healthy.” They pray, meditate, practice Yoga, and go to church. As one woman said, “I’m not an overly religious person, but I find a sense of community and a sense that I’m not alone. This helps to take away stress.” Friendships and relationships with family are important. Another woman keeps young people in her life, sits down with them, and “listens to their puppy love stories.” Yet another woman said that she has learned that “if you tell too many people, you reinforce the disease; you have to put more energy on the healthy aspect of yourself.”

The women in the focus groups felt that taking health into their own hands—deciding for themselves what is right rather than accepting, without question, physicians’ recommendations or medications—is a positive step. As one woman said, “We should live in acceptance if it’s out of our control. But if it’s somewhat in our control...”

One woman described how she “just now found the right medication. I fight for my health care. I ask a lot of questions. If they get angry, I get angry. I take medication daily, exercise, and try to stop worrying.”

One woman said, “I look at my mother’s and grandmother’s problems and wonder if their illnesses will happen to me.”

Another noted, “My parents and my grandparents may have eaten better—more fresh fruits and vegetables. They didn’t pay attention to cholesterol, but the diet may have been more nutritious in my mother’s generation.”

The women say they work on their health on a daily basis: “I stopped overeating, began walking more, and made an effort to take my medication as directed instead of stopping when I felt better.”

Future Concerns

The women expressed many concerns about their future health. Some of their worry centered around diseases for which they might be at risk: arthritis, vision problems, HIV. Some worry that their grandparenting responsibilities may leave them with too little time or energy to take good care of themselves:

“I want to be the oldest, healthiest person around....No more arthritis, high blood pressure, or anything else!”

“We want to teach our children and grandchildren not to neglect their health!”

“I want to maintain the health I have now!”

These women wonder about the aging process itself: “Is it happening naturally, or am I doing something wrong? Which body parts carry the most stress? Am I aware of the overload?” They want especially to be able to stop taking so much medication, stop overeating and eating the wrong things, and stop worrying about their grandchildren. They want to be able to afford health care when they need it, and they don’t want to have to go into a nursing home.

Health Care Providers

Half of the women would prefer to see a practitioner who is the same age or older; most of the rest had no preference about age. More than half of the women had no concerns about the gender of the practitioner; only four women preferred a female doctor.

Twelve out of 14 women have a regular doctor. For the majority, this physician is a general practitioner, a family practice doctor, or an internist.

Although gynecologists provide much primary care, only one woman listed a gynecologist as a 'regular doctor,' and none relied primarily on any other type of specialist.

Provider Attitudes

Focus group members were asked a number of questions about the attitudes of current providers and the quality of health care they provide. Most of the women (71 percent) thought that their doctors acted concerned, asked them how they were feeling, and listened to them. Fewer (57 percent) thought that their doctors explained tests to their satisfaction, respected their health beliefs, or were interested in their safety. Only one woman reported being asked the difficult question about risk factors for HIV exposure, but because of societal stereotypes about promiscuity among Black women, many said they would rather *not* be asked.

Satisfaction with Health Services

Seven of the 14 women reported being very satisfied with their present health care services, six were somewhat satisfied, and only one was not at all satisfied.

Access to Care

Twelve of 14 women said they were able to arrange appointments whenever they needed the attention of a health care provider. Half saw a private doctor most of the time, and more than a quarter used a hospital clinic.

Sources of Medical Advice

Who would these women turn to as the first source of medical advice? Almost half would contact a general practitioner first for health information. Others would turn first to a friend, a specialist, a nurse, or an alternative healer.

Health Care Needs and Priorities

Women also ranked the services they wanted in the order of importance on a scale of one to five, from the least important ("1") to the most important ("5"). These services are listed below (see Figure 2.), starting with those ranked most important.

Figure 2. Importance of Health Care Services

Health Care Characteristic	Mean Score
Group exercise is offered.	4.7
Prescription drugs are covered by insurance.	4.6
Free mammography is provided.	4.4
Provider explains tests/therapies clearly.	4.4
Vision exams and eyeglasses are covered by insurance.	4.3
Health care explanations are given in understandable language.	4.3
The physician provides adequate time for talking.	4.2
Home nursing is covered by insurance.	4.1
Nutritional information is available.	4.1
Links are provided to community services.	4.1
Hearing testing and hearing aids are covered by insurance.	3.9
Privacy is respected.	3.9
Screening for bone loss is provided.	3.8
Help is available to find the right M.D.	3.6
Nursing home is covered by insurance.	3.6

Along with these health care priorities, women mentioned the need for *affordable social activities* for seniors.

In general, the women in these two focus groups would like to see present services expanded, and are very concerned about their future access to health care. Eight of the women would like to see Medicare expanded, although only four are completely dependent on Medicare insurance. All are concerned about the cost of medical care, and half would have to see the doctor less often if co-payments were to be increased. Only five of the women were very satisfied with their health insurance coverage; four were somewhat satisfied, and three were not at all satisfied.

Suggestions for the Health Care Delivery System

Some women in the group felt that providers in the health care system are out of touch with their needs and concerns:

“How can a rich person tell a poor person how to live?”

“Please find out the needs of the majority of our citizens. Send out a national survey. Thank you.”

We asked, “if you were speaking with the President tonight about health issues, what would you ask him to do?” The women had excellent suggestions:

- Continue to fight for a health plan for this country, especially for women and senior citizens.
- Provide more transportation for the handicapped and seniors.
- Give quality care in the health care package.
- See what can be adopted from other countries like England and Canada, where care is free.
- Develop more volunteer programs, with incentives for young and old.
- Provide social centers and housing for seniors, and investigate rest homes and nursing homes where people are being neglected and mistreated.
- Put more money into home health care instead of nursing homes. In the long run it is less expensive and makes more jobs.

- Provide more funding for homemaker chores (in-home support services). Provide affordable, healthy living.
- Spend more money on preventive care and on Medicare. Treatment under Medicare should match that of richer patients.
- Fix the problems with insurance coverage rules and regulations (the little hardships that slip into the system).
- Continue to fund projects like the National Black Women's Health Project, Hispanic women's projects, and Family Recovery projects that promote community healing and let the citizens get in touch with their cultural heritage.
- Provide funds to train young people, and incentive programs that pay for school and encourage graduates to go back into the community to work. Continue to fund youth projects, with more staffing, and make the success stories more visible. Youth projects need to be continued and expanded.

- Encourage development of support groups that promote healthy eating habits and regular exercise.

While this group of women was relatively small, their concerns and comments must be taken seriously. Their opinions expressed in this study can serve as a springboard for future research and discussion on the health practices and concerns of midlife and older Black women in America.

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