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African American elders' choices for
long-term care : an exploratory study

Lisa Groger
Miami University, commons@lib.muohio.edu

Ohio Long-Term Care Research Project

**AFRICAN AMERICAN
ELDERS' CHOICES FOR
LONG-TERM CARE:
AN EXPLORATORY
STUDY**

Lisa Groger

January 1993



Dr. Lisa Groger is an Assistant Professor in the Department of Sociology and Anthropology, a Research Fellow at the Scripps Gerontology Center, and a Faculty Affiliate in the Black World Studies Program, Miami University, Oxford, Ohio. She earned her Ph.D. in anthropology from Columbia University, and she received postdoctoral training in gerontology at the Duke Center for the Study of Aging and Human Development.

Dr. Groger has done research in rural communities in France and in North Carolina. Her major research interest is minority aging. Her most recent work has focused on differences in informal support between African American and white elders.

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**African American Elders' Choices for Long-Term Care:
An Exploratory Study**

Lisa Groger

**Scripps Gerontology Center
Miami University
Oxford, OH 45056**

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Executive Summary

The purpose of this study was to explore why, how, and under what circumstances African American elders opted either for nursing home placement or for in-home services in their search for long-term care. The research was inspired by (a) African American elders' growing demand for long-term care and (b) their alleged underutilization of nursing homes and their overutilization of in-home services. I used a qualitative approach to explore the major research question:

What are the factors leading either to nursing home placement or to in-home services?

I explored differences between nursing home residents and home care clients concerning:

- * Health, functional ability, and history of illness;
- * Informal support during declining health or health crises;
- * Decision-making about long-term care;
- * Participants in the decision;
- * Other options that were considered;
- * Satisfaction with the outcome.

The purposive, nonrepresentative sample consisted of 10 nursing home residents and 10 home care clients. Differences in functional ability alone did not explain the choice of a care setting. Nursing home residents and home care clients also differed in their progression of illness, or "health trajectory patterns." The first pattern consisted of long, in some cases lifelong, chronic illness culminating either in a slow decline or in a crisis. In the second pattern, individuals in relatively good health were toppled temporarily by a crisis from which they were able to recover. Both patterns were characteristic of home care clients. In the third pattern, characteristic of nursing home residents, elders were overwhelmed by their health crisis, which took them by surprise and from which they did not recover. The cases of the two respondents who did not fit any of these patterns are nevertheless interesting because they suggest even greater diversity in the experience leading to one or the other care setting.

The two subsamples also differed in their ability to mobilize informal support. As a group, home care clients were more likely than nursing home residents to have children, the most important source of informal support in this sample. All respondents could rally some support. At the same time, they had a clear conception of the limits of informal support, that point beyond which they would not expect or accept informal support. Unlike nursing home residents, home care clients had not yet encountered the limits of support.

The decision to receive in-home services required little more of home care clients than to accept those services. In contrast, the decision to enter a nursing home revealed itself as a complex process involving multiple decisions, phases, actors, types of interactions between the actors, and variable outcomes. Respondents who made the decision autonomously were

satisfied with the outcome, but respondents who participated only marginally or not at all were not necessarily dissatisfied.

Findings from this research suggest that policy makers and service providers should:

- * Be sensitized to the diverse needs and resources of this population;
- * Seek assurance that all elders confronted with a long-term care decision be given systematic information about all their options;
- * Work toward expansion of in-home services;
- * Institute culturally appropriate outreach methods for African American elders in need of long-term care;
- * Acknowledge the importance of non-traditional informal helpers;
- * Seek ways to reward informal caregivers;
- * Provide "natural ombudsmen" an active role in nursing homes.

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Background

African American elders contribute considerably to the growing demand for long-term care: they are the fastest-growing segment of the African American population (AARP, 1987) and of the general population age 65 and older (Manuel & Reid, 1982). As a group, they have lower life expectancies and higher levels of impairment than whites (Gibson & Jackson, 1987). They are also poorer than whites and thus are more likely to be eligible for publicly funded services (AARP, 1987).

All these factors taken together could be expected to propel a disproportionately large number of African American elders into nursing homes. Yet there is a body of literature which contends that minority elders in general, and African Americans in particular, are less likely than their white counterparts to use nursing homes and more likely to use home health care services. These reports are based on a variety of approaches: census data comparisons between African Americans and whites (AARP, 1987; Kart & Beckham, 1976; National Caucus and Center on Black Aged, 1987); National Long-Term Care Survey data comparisons of all four minority groups with whites, combined with other data (Murtaugh, Kemper, & Spillman, 1990); and on comparisons in literature reviews between or among minority groups (Vallé, 1989; Watson, 1986; Yeo, n.d.).

According to census data, 3% of African American elders are institutionalized, as compared to 5% of white elders

(AARP, 1987). When gender and age are controlled, 8.5% of African American males age 85 and over are in nursing homes, as compared to 15.8% of white males the same age. The rates of institutionalization for African American and for white females age 85 and over are 13.5% and 26.4% respectively (National Caucus and Center on Black Aged, 1987).

Structural factors such as cost, discrimination, the limited resources of nursing homes serving predominantly African Americans, and culturally insensitive staff members are cited as the major reasons for African Americans' differential use of nursing homes. Cultural factors such as greater dislike of nursing homes and preference for and availability of better informal support also have been considered responsible for minorities' alleged underuse of nursing homes (Eribes & Bradley-Rawls, 1978), although great intragroup variations exist in adherence to "traditional" and cultural values and behaviors (Harwood, 1981; Jackson, 1981; Vallé, 1989). Use of nursing homes by African Americans also has been shown to be related to type of ownership. Public institutions are more likely to serve minorities, but they constitute only 8% of all nursing homes in the United States. The majority (75%) are for-profit enterprises; the rest (17%) are nonprofit (Burack-Weiss, 1985). Outreach efforts by proprietary homes tend to be biased against members of minorities, who are assumed to be poor. Some research suggests that when proprietary homes are African American-owned and -operated, they serve a higher proportion of minority group members (Schafft, 1980).

Relatively little is known about minorities and home health services

(Johnson-Crockett, 1990). Data from the National Long Term Care Channeling Demonstration (Applebaum, Baxter, Callahan & Day, 1985) showed that 21.3% of the eligible persons identified as needing a nursing-home level of care were African American, although African Americans make up only 8.5% of the population age 65 and over. Using poverty or need as a criterion, McCaslin & Calvert (1975) and Soldo & Myllyluoma (1983) predicted greater minority participation in home health services. Factors associated with actual participation in such services include staffing, location, type of sponsorship of the service agency (Holmes, Holmes, Steinbach, Hausner, & Rocheleau, 1979), poverty (Berk & Bernstein, 1985), lack of knowledge about services (Starrett, 1986), and outright discrimination against poor people (Spohn, Bergthold, & Estes, 1988).

Few studies actually have asked elderly African American care recipients why and how they made certain long-term care decisions that seem to result in avoidance of nursing homes and preference for home health services.

Although any or all of the above factors may explain the apparent use patterns of African Americans as a group, they tell us little about intragroup differences in choices, decisions, and preferences. Few studies actually have asked elderly African American care recipients why and how they made certain long-term care decisions that seem to result in avoidance of nursing homes and preference for home health services.

Because this study is based on interviews with only African American elders, it cannot directly address the question of African Americans' under- or overutilization of these long-term care options. The proposed processual model of decision making, however, could be used to explore African American-white differences in the decision process.

Methods

Data Collection

I interviewed 20 African American elders between November 1991 and March 1992. I used a qualitative approach to explore respondents' history of declining health and to learn how and under what circumstances their long-term care choices and decisions were made. Interviews were audiorecorded and lasted from 45 minutes to 2 hours. The major instrument used in this research, the long interview, allows one to achieve the ethnographic objective of "getting inside the respondent's head" without the more time-consuming and sometimes inappropriate or impractical requirements of participant observation. The instrument used here, the long interview questionnaire, allows for open-endedness and contingencies but keeps the investigator on the track of the main discourse (McCracken, 1988).

Data Analysis

The verbatim transcriptions of the interviews constitute the data that I submitted to a line-by-line analysis. This

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process yielded themes and patterns that led to the identification of different health trajectories resulting in different long-term care choices, and of multiple scenarios for nursing home placement. It also led to the emergence of a processual model of decision making, a conceptual construct that is grounded in the data (Strauss & Corbin 1990).

Sample

The purposive, nonrepresentative sample consisted of 10 nursing home residents (six females, four males) in three different facilities and 10 home care clients (nine females, one male) receiving services provided under PASSPORT in Cincinnati, Ohio. The PASSPORT program screens and assesses applicants for Medicaid-eligible long-term care and refers them either to a nursing home or to in-home services. I contacted the Area Agency on Aging that administers PASSPORT, as well as several nursing homes. Participants were recruited by nursing home administrators and agency personnel, who also provided documentation on the participants' health assessment, diagnoses, and demographic background data. All nursing home residents had been admitted under Medicaid coverage. All respondents were cognitively competent and able to give informed consent. I ascertained cognitive competence in casual conversation with the prospective participants before the actual interview. I rejected the use of a more formal measure of mental competence because such measures might be culturally inappropriate for populations from which they were not derived originally.

Differences and Similarities between Sub-samples

These two subsamples seemed particularly well suited for exploring the pathways to different long-term care arrangements because their members could be assumed to be of comparable functional ability. However, nursing home residents were somewhat more impaired in their activities of daily living (ADLs).¹ Five nursing home residents could not walk and needed assistance with dressing and/or feeding; one was ambulatory but needed some help with dressing; four were completely ambulatory and needed no help with ADLs. Of the three home care clients who could not walk, two were recovering from foot or leg injuries. Three home care clients were completely ambulatory, and four had some problems with ambulation. All needed some assistance with ADLs. The nursing home sample, on the average, was 5 years older than the community sample (see Table 1). Differences in long-term care choices were unrelated to planning for sickness and old age. With the exception of one home care client, who stated that his employer had done the planning for him, all the participants confessed to never having given it a thought. The major differences between the two subsamples occurred in two areas: (a) their progression of illness, or health trajectory, and their reaction to it, and (b) their ability to mobilize informal support for their care in general and for their instrumental activities of daily living (IADLs)² in particular.

¹Activities of daily living (ADLs) include bathing and showering, dressing, eating, toileting, getting in and out of bed, walking, getting outside.

²Instrumental activities of daily living (IADLs) include meal preparation, shopping, money management, using the phone, doing housework.

Findings

Although participants differed in eloquence, personal history, and perception of their current situation, the same central themes emerged from all the interviews. These concerned the progression of illness (subsumed under the analytical category of health trajectories), the informal support available at the time of crisis, and the respondents' reaction to the crisis. All respondents had a clear conception of the limits of informal support, regardless of how much informal support they actually received. Although all were able to rally some informal support, they encountered or anticipated the limits of support at different points in their trajectories of declining health. All could pinpoint the day when they either were institutionalized or started to receive in-home services. Yet the beginning of these arrangements represents only one point in a lengthy process. This turning point is the culmination of a complex series of interrelated steps involving a person's experience with nursing homes, perceived options, and perceived competence.

All but two of the participants followed one of three types of health trajectory: the first pattern consisted of long, in some cases lifelong, chronic illness culminating either in a slow decline or in a crisis. In the second pattern, individuals in relatively good health

were toppled temporarily by a crisis from which they were able to recover. Both patterns were characteristic of home care clients. In the third pattern, characteristic of nursing home residents, elders were overwhelmed by their health crisis, which took them by surprise and from which they did not recover.

Health Trajectories

All health trajectories were punctuated by multiple movements from home to acute-care hospital and back home. For nursing home residents, intermittent hospitalizations became less frequent after nursing home placement because the condition that resulted in the placement was brought under control after a period of adjustment. For home care clients, intermittent acute-care hospitalizations continued as part of a strategy to reestablish functioning after recurring crises. Their ADL and IADL scores remained relatively stable over several assessment periods, including periods of hospitalization. All but one of the nursing home residents were aware of in-home services as a long-term care option, and three at some point had returned home with services after a stay in the hospital. All but two of the participants followed one of three types of health trajectory: the first pattern consisted of long, in some cases lifelong, chronic illness culminating either in a slow decline or in a crisis. In the second pattern, individuals in relatively good health were toppled temporarily by a crisis from which they were able to recover. Both patterns were characteristic of home care clients. In the

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third pattern, characteristic of nursing home residents, elders were overwhelmed by their health crisis, which took them by surprise and from which they did not recover.

Long history of illness: what else is new? This pattern produced elders experienced in coping with illness as part of normal life. They continued this practice by refusing the sick role even in a health crisis, which made them more likely candidates for in-home services. Eight home care clients fell into this category and spoke as follows about the nature and history of their illness:

The doctor said I have a murmur. I've had heart trouble since I was eight years old, I can remember. So I've learned to live with it. I go to a doctor, and he has been my doctor about 30 years.

I don't know when I first got sick. I'll tell you it's been so long, oh, I can't tell, I don't know, it's been years I have been ill.

This is rheumatoid arthritis. I had it so long, it don't worry me. I had arthritis all the time I was tryin' raise my kids.

I have sugar diabetes. I've had it about 28, 29 years. And I've had one of my feet just came open. I went to the hospital with it, and they opened it more.

I had a stroke about ten years go. The oven cleaner fumes went down the wrong way and I got sick. Knocked me completely out. At first they didn't know what happened. It happened about five times... First I had a limp. I could walk and

everything, but I had a limp. And each time it got a little worse. Now I can't walk at all. You see I got arthritis real bad. I've been sick ten years. Been in this chair about five years.

My health began to get bad 20 years ago... The children got me to the doctor and so the doctor commenced treating me. That's when they found out that I was a diabetic and they got all that fluid, I had so much fluids. (69-year-old widow with a family history of heart disease and diabetes: a son in his late forties has disabling diabetes; a daughter died of a heart attack at age 37; another daughter, 45, has arthritis; her mother and two brothers died of massive heart attacks).

I've been sick so long... well, for a long time I didn't know how sick I really was, and this asthma, I've had it ever since I was a child, but we always thought it was just because I was a fat child. And then when I got grown up, the older, I got the worse it got.

At the time of the interview, this respondent had a sprained ankle:

I was at my daughter's house Thanksgiving Day for dinner and I spranged my ankle. I didn't tell her. I didn't want to ruin her day and she'd done fixed everything up so nice, but when I did tell her, was she mad. I didn't tell her until the doctor said it was just a bad sprang, so I had to keep it bandaged with ice pack on it for a while.... That's the

only thing making me handicap, is this ankle. (Emphasis mine)

Another home care client, age 75, lives alone in a two-room apartment in a large, littered, desolate public housing complex. Her daughter, in her forties, died of a heart attack. Her own diagnosis is epilepsy, heart condition, poor vision, color blindness, left eye cataract, obesity, and diabetes. She is obese, and her legs and feet are so swollen that she cannot wear shoes. Because she spends most of her time (waking and sleeping) in a wheelchair, she has pressure sores. This respondent greeted the interviewer with the statement that she was trying to reach Senator Metzenbaum's office, and that she was a fighter. Her great-grandsons are among those whom she has to fight off. They steal her money; they vandalize equipment, including the bath bench provided by PASSPORT; they endanger her when they take her out in the wheelchair so that she no longer allows them to take her out. She is not really afraid of them, but she keeps a meat cleaver handy just in case. Her repertory of coping mechanisms consists of an array of culturally appropriate metaphors for assistance. God and her mailman look after her. God guided her finger to dial the PASSPORT phone number, and he makes miracles happen right there in her kitchen: The medicine she needs turns up, as do people who help her. When asked how she felt on the day of the interview, she replied:

I feel wonderful. God let me live long enough to see this day [a dreary day in December]. And I walk aroun' in here. And when I git tired I just sit down in this chair.... And the food. I enjoy my food. I praise the Lord when I'm eatin' 'cause it tastes good. Um-hm. I really enjoy

my food better'n I used to... My feet and legs are swelled. But they stay swelled so much, I guess I just don't pay it no 'tention. 'Course I got sores on both sides of my butt from sittin' in this chair. But sometimes I put cushions in this chair. And sometimes I uses vaseline and powder. They do pretty good.... And when my feet swell it leak a little bit. It's bound to leak like that when it swell.

All the above speakers learned to deal with their protracted chronic illnesses by considering them almost as normal. People around them were sick; they themselves had been sick so long that they had become used to it. They were skilled in the "habit of surviving" (Scott, 1991), which they had practiced for a long time. This approach leads the woman with disabling asthma to believe seriously that her sprained ankle is her only handicap. Having coped with illness for years while they went about the business of working, raising children, managing households, and scraping by on limited incomes, these respondents did not question their ability to continue to cope. By defining themselves as competent and by not allowing the environment to define them as incompetent, they refused to enter into the "vicious cycle of induced incompetence" (Kuypers & Bengtson, 1984).

The following expressions illustrate the respondents' struggle for competence and autonomy and their determination to define themselves as competent. This struggle and this determination are embodied by the woman who, although virtually bed-bound with crippling arthritis, can say: "When I get to where I can't do for myself..." Other respondents reflect the same feelings:

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I could walk around. And I could do whatever I wanted. If I wanted to fix dinner, I could do that. I could do little things [before current acute crisis which she expects to overcome].

I learned how to manage and managed it real nice.

I could get around and could make it. I did my own breakfast and I was just trying so hard to say that I could do it... I got so I could do it myself. Anyway, I made it...

I made it like that for about three weeks. I have to walk, I don't have to, but you have to be able to do something to walk to that van, to get to that van, so I can take my walker and hold on to the banister and step down four steps and then they will help me on down the other two... If they give me a little help, you know, if they give me help down the first four steps I can make it. So I have been going pretty good and I don't feel bad.

I can get in my clothes pretty good myself. I got dressed alone today. I learned how to put them support stockings on.

And it would hurt me so bad then, I would cry. And then they took me down to therapy and train m'leg. And then they brought me a walker, so after I learned how to walk on that, now I'm pretty good.

I can git that chair up there, and I can git it down the steps.

They can't handle me. So I don't say nothin'. I sit on the toilet in there at the sink and wash myself up... I'm thinkin' 'bout washin' my hair today myself... Well I take care of my skin... I wash my laundry. I sit in there on the toilet and wash 'em in the sink... I soak them [bed sheets] in the Clorox 'n' stuff 'n' hot water 'n' stuff 'n' wash 'em.

That's why I'm so capable of doing things myself cause I had to do things then, you know, for the children.

I've been... sort of standing on my own two feet practically all my life.

The respondents' attempts to defend themselves against negative support are part of the same struggle for independence:

I made up my mind I want to be by myself.... I told my boy to leave. I just think I want to be by myself.

I had to get [a bank account] to protect my Social Security.

I'm not scared of them. I'm a lot scarer I'll hurt 'em. But if I ketch 'em doin' somethin' or other, I will hurt 'em. Now I've had that meat cleaver layin' over there for other reasons than them, but if they come in here and try somethin' or other, I'm goin' throw it at them. If God don't git 'em first... I hope God do.

The struggle for independence also can manifest itself quite positively. This story is told by the woman with disabling asthma, who administers oxygen to herself

when she is "well," and who goes to the hospital for her recurring crises:

Yeah, they laugh at me at the hospital... I get at the hospital just like I do here [at home] and they had so many needles and things in me that I couldn't reach the bathroom. So this one nurse, she would bring me a pan of hot water and I thought that was so nice. She'd say "Mary, your bath water is here," cause I would do my own bathing and I was so glad for her. By the time the other nurses got there, I was up bathing, got up and dressed and put on a clean gown, and I'd be sitting up in a chair. They couldn't get over that... And I had to clean. Cleaned out my end of the corner over there. I took and changed everything around over there just like I would be at home... just made it just like it was home, and when the housekeepers come in, they wouldn't have to do nothing to my side cause I'd be done dusting and everything. All they had to do was the floor. It made them happy.

Her mood escalates into an outright celebration of life when she describes an outing with a group of seniors:

One thing now that's good, PASSPORT again, bless their heart, has got me one of these breathing machines that runs by battery that I can take when I go out, and I went on the boat with it with the center here... I only got to use it once. I got to go on the boat with it and I had so much fun, and I said "Now when I do this, everybody is going to stare." We went by bus from

here to Louisville, Kentucky and then we had lunch on the Star Louisville, and so we got there about a half an hour early and it was the funniest thing. I had my walker and when we got ready to go on the boat, they took a picture of them that come on the boat, and they had me in the front on the walker...there was about 40 of us, like I was leading. That was so cute, and so I sat up there and I used my breathing machine and everything, and nobody stared at me or anything, and it was wonderful. I said "Now when I start using this breathing machine, everybody is going to stare." Nobody stared or anything.

Crisis strikes the resilient. This pattern was characteristic of elders who continued to define themselves as well in a health crisis because they were used to doing so. Two home care clients fell into this category. They had suffered crises, after which they returned to living alone at home, assisted by PASSPORT. These individuals had enjoyed relatively good health until the crisis, which they took in stride, and from which they were determined to recover.

After a severe heart attack at the age of 64, Mr. T had a "light stroke" five years later, and one year after his wife's death. He recalls the event:

I was upstairs in bed and somebody knocked on the door. I started down the steps to answer the door, and I had a stroke, and I fell and rolled all the way down those steps. I skinned my leg all up. I had a big sore on my leg and that wasn't very much, but I just had a stroke. It was just a

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mild stroke... it wasn't that bad. When I came back home, the nursing came back with me. A nurse came back. She checked me out to see if I was alright, still okay. I was okay.

I never was out of control. When they put me in the hospital, my brother said, "David, you can overcome, you can overcome this. You are very strong." And he assured me that I was strong enough to overcome.... Well, I felt that way, even without him telling me. I knew it. I had strength. I was always a fighter and a person with strength, and I had the Lord with me too, you see, so I knew that I was pretty well off, and I wasn't completely out of it...."

Everything seems to be back almost to normal. I soon did everything they would ask me to do. [during therapy after heart attack]. But when I first came out, I couldn't hardly walk. I had a cane. It was a very nice cane too, cost 25 dollars. I walked on this cane, and when I went in Kroger's I used to use a cart to walk around with. I didn't use a cane then. I just put the cane in the cart and walked around like that. So I went to get in the car... I started to push the cart over to where they keep the carts. I left the cane in there and walked back to the car and I left the cane. I walked away from the cane and that was it. That was the last I ever seen of the cane.... I forgot it. So I told my sister and my brother... "I'd better go back and get my cane," and they said "Well, listen, you walked away from it..." I said, "yeah," and they said, "Well,

then you don't need it," and so that's the last time I seen the cane.

Mrs. W expressed the same determination to overcome a potentially very disabling health crisis which culminated in a below-the-knee amputation when she was 80 years old:

Before I knew anything, I was diabetic. They done cut this leg off about four years ago. Oh, my goodness, that got to me. I stayed in the hospital so many days, and then I went home. I had my own home. I done pretty good, I got up and done my cooking. I didn't have too much trouble [walking]. I done pretty good to say I didn't have but a leg and a piece [prosthesis]. I had one leg and a piece, so I managed pretty well. I just kept getting better and better. I done what I wanted to do around in the house... My own doctor told me "You're in such good shape, you have to come back for three months." Well, I don't need no nursing care. I'm thankful to Jehovah God that I can sit up or can walk around. I ain't got but one leg and a piece, but I can get around, walk around.

In both cases, the environment encouraged the respondents in their efforts to define themselves as competent. All respondents discussed so far impressed the listener with their courage, their strength, their zest for life, in spite of potentially disabling illnesses. Their ability either to cope with chronic illness or to overcome a health crisis distinguishes them from those respondents who followed the third type of health trajectory.

Crisis strikes the vulnerable. Eight nursing home residents were overwhelmed by their crisis. Of course, one runs the risk of being tautological: by definition, institutionalization is a last resort option for people who are overwhelmed by the demands of independent living. Although this point is obvious, it is less clear what exactly makes a health crisis more overwhelming for some elders than for others.

In spite of differences in their adjustment to crises, nursing home residents shared certain features that might explain their institutionalization. They were more likely to define themselves as incompetent and to accept other people's definition of themselves as incompetent after the health crisis that took them by surprise. They were also more likely to consider institutionalization as their only option.

My brother called me one day, and after I didn't answer the phone he came down to see what the trouble was, and I was unconscious that day. I had this heat stroke. I don't understand it. I was in the hospital from the seventeenth of July till the twenty-sixth of July, 1983. I went home and I had been doing pretty good. Then I started feeling weak and sick, and didn't know what was wrong with me. Had diabetes and I went in the hospital on the third of December. I was in the hospital from the third of December in '84 till the twelfth of December, so that's about it... They decided I couldn't stay by myself.

I was having some kind of spells, some kind of fallout spells, and my doctor told me I couldn't stay at

home. The people in the hospital said I had a stroke, but the way it made my legs turn under, buckle up, whatever you want to call it, like a little young baby that can't stand on their legs, well I don't know what it is, whatever it is, it's got the whole alphabet in it... I couldn't be by myself.

They sent me here [from the acute-care hospital] and they took my limbs when I first got here. I'm a diabetic. And one of them had gangrene in it, and they tried to save one of them but they couldn't. They had to take both of them off in 1987... I couldn't go home. I had nobody to take care of me. And I couldn't take care of myself. In my condition I couldn't have had nobody come in to take care of me.

I had a stroke. I first had my leg amputated and then I had a stroke and I can't stand on this one leg, so I was helpless. It got to the place where I couldn't do anything but answer the telephone, you know. I couldn't help myself. I couldn't go to the bathroom by myself cause this leg I can't stand on. I'm completely helpless except for this hand. I'm a half person.

I got some acid on my foot. You know, the stuff they pour in the toilet bowl. I fell when in the bathroom and my foot went underneath the bathtub and kicked it over, and it fell on my foot. It put a hole in my foot. That's the reason why I was at the hospital at that time. And then from the hospital I come here to this home. My wife

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was in the hospital at that time too. After the hospital she come here too. She died. She passed away.

When I first found out that I had the cancer, I was able to stay at home. In fact, my husband was living then and he was sick. He had diabetes and I was able to care for him, but still I was sick. Well, I didn't know what was wrong. My daughter lives in Cleveland and she came down to visit... I'd take care of my husband and then I'd fall over on the other bed and have to rest before I could move again, and so she called my family doctor and explained how I was acting. He sent me to a specialist and he discovered that I had cancer. So I had chemotherapy and was able to stay at home. But then I had a flareup again and the chemotherapy made me so sick that they had to discontinue it. That's when they started the radium treatments and I've had two sessions of those. I've had one just here recently. That's why I'm kind of watery now.... I didn't have any choice. I couldn't go home. So I went to the nursing home.

This diabetes hit me about three years go. I started falling around. First fall I had, I fell in the bathroom at home and I couldn't get up. I wasn't unconscious or anything, but I couldn't get up... They carried me to the hospital. They thought it was best for me to go to the hospital... I went back home and I got along alright. Maybe I fell a time or two around the house, but I didn't have no bad fall for I guess six or eight months...

And then I fell, and I fell harder than anybody could possibly fall. I just sat down like that. For the next three or four weeks I watched myself to see if I felt any change from it, and I didn't. But it was almost a year before I felt it. I was hurting all through here and couldn't hardly walk, and then my head was swimming all the time... if I'd get out, I couldn't hardly stand up. I was in bad shape when I came up here [the nursing home]... If I'd have had a wife that was able to take care of me at home I could have stayed at home. But it was just the opposite. I could take care of her, but she couldn't take care of me.

Special cases. Two of the four male nursing home residents did not fit any of the above three patterns. One man, age 77, was divorced. He has no contact with his only daughter and doesn't know where she lives. This man had taken refuge in a nursing home in his late fifties because he had no place to go:

I didn't have no health problem... I just wanted to be in a place to have protection, so that's the reason I came here. I figured it was the best place for me... I didn't want to be out in the streets.

The second man, age 71, was divorced and remarried to a woman 24 years his junior. Allegedly he sat in a stuffed armchair for ten years, refused to move, and alienated chore workers to the point where in-home services were discontinued. He has 15 children (eleven sons and four daughters) but knows the whereabouts of only one. Three years ago, when his wife no longer could take care of him, she had him

admitted to the nursing home. His story, as he told it, conflicts completely with that told by the staff. He considers himself betrayed by his wife, whereas the staff members describe him as "a hundred percent noncompliant" person who caused his present physical condition--total dependence for all ADLs--through maladaptive, if not psychotic, behavior.

The first man has found a niche and is happy. He is completely ambulatory. He is the president of the residents' council and enjoys his "position" in the facility, where he considers helping others as his main function. It is not clear whether the second man really believes his version of the story, but it is clear that he is unhappy and wants to go home. Both men's original placements may have been inappropriate. The first might have been placed more appropriately in a group home, and the second man in an institution providing mental health services in addition to nursing care. Their cases illustrate two extremes of the wide variety of reasons for nursing home placement. They also belie the stereotypical notion that African American elders invariably are embedded in large supportive networks of kin who are willing and able to provide long-term care.

Informal Support

The mere fact of having many children is no guarantee of support. Generally, respondents found female children more useful than male children; when a parent did not know the whereabouts of a child, it was more often a son than a daughter.

Girls, they're the ones stuck to me. My husband said, "I guess you love all yer kids, but them boys are some

lemons. They will not do fer you like your girls will. Now if you got anything your girls need, let 'em have it. They'll pay ye back. They might have to take care of ye one day."

My daughter was the best thing that ever happened to me. And if I had had all boys, I would have been a mess. 'Cause my boys didn't turn out so good. They...do all right. Both is good, and they good to me, and they love me so much. But I don't know whether it's just that they don't understand...and I think that's some of it... Knowin' how to raise 'em was another thing. I didn't know that, neither. When she came along, I just kinda took her in my arms and went along with it.

In one case, the lack of support from sons could be traced to the parent's shortcoming. In all other cases, the sons disappointed the parent even though the latter had "done everything for them." The disappointing behaviors usually involved drugs, dropping out of school, chronic unemployment, encounters with the police, and imprisonment--in other words, all the social ills to which young African American inner-city males are particularly vulnerable.

Even "thin" support (defined here as reliance on only one helper) is important and may be crucial in a crisis, even if it cannot be sustained indefinitely.

Differences between nursing home residents and home care clients. Nursing home residents differed from home care clients not only in their health trajectory patterns but also in their informal support. As a group, nursing home residents had thin

informal support either because of childlessness or geographic distance from children and other kin, or because of a lack of social relations altogether. The situations of two men and one woman were made particularly precarious by the sickness of their spouses. Four of the 10 nursing home residents were childless, compared to only one childless home care client. Only two nursing home residents had children who lived close enough to have taken care of the parent, compared to five home care clients who had excellent support from their children and one who had adequate support from her daughter. Three nursing home residents had no support at all; three did not know where their children were; four had only siblings nearby, who were old and impaired themselves.

In contrast, multiple helpers made up the informal support network of five home care clients, including the two most seriously impaired women. Mrs. B's case will serve as an example. She has a daughter who lives with her but who leaves for work at 6:00 a.m. and does not return until 7:00 p.m. During the day, three other daughters and one son look in on her, and another daughter comes every other week. When Mrs. B had her health crisis in 1987, her son provided the support that was crucial for recovery. Now that she is stabilized, her children have a clear division of labor for specific tasks, which include carrying out trash, cleaning, washing clothes, fixing food, and paying her bills. In addition, Mrs. B has neighbors who will check on her if her curtain remains closed in the morning. This kind of support distributes and thus considerably minimizes potential strain on caregivers; it ensures that the limits of support will not be reached for some time.

For home care clients less richly endowed with informal support, the function of in-home services assumes lifesaving proportions. The choreworker becomes the first line of defense ("she can come in here and take one look at me and tell whether I'm feeling good or not") and is often mentioned in kinship terms ("she's just like a daughter"). The case manager is viewed as a trustworthy and reliable advocate who is just one telephone call away in case of crisis. Although home care clients varied in their assessments of choreworkers, they were unanimous in their praise of their case managers. In all cases, the relationship was described in highly personal terms. ("Sometimes I swear she comes by here cause she's got a couple of other people in the building. She'll run up here and say hello to me.") For the three home care clients who had to defend themselves against their negative informal "support," the case manager took on the character of a guardian angel who never failed the respondent. Whether the choreworker did an adequate job in these cases seemed almost irrelevant in view of the respondents' daily struggle to defend themselves against a hostile environment.

For those home care clients whose informal support is either thin or negative, other services such as adult day care are extremely important. Home care clients who use that service regularly stress the importance of "getting out" and "helping others," which makes them feel good. Even though these outings are routinized, they represent a welcome break in the daily routine at home. They also provide an opportunity to see others who are worse off, which results in appreciation for one's own situation.

The limits of support. Why should a 71-year-old man with 15 children end up in a nursing home, while a never-married, childless 83-year-old woman, who followed "her lady" to the north, manages to live alone in spite of heart problems, ulcers, arthritis, and a brain tumor? And what enables a 76-year-old bedbound woman to remain at home where she is alone all day?

Differential informal support is one important factor in choices regarding long-term care. It is true that four nursing home residents and only one home care client in the sample were childless. It is also true that five of the home care clients lived alone, and three lived in constant fear of exploitative and abusive offspring. Although other kin, such as siblings and cousins, and nonkin, such as church members and friends, were part of some respondents' informal support network, children were by far the most important providers of informal care. Two home care clients would not have been able to stay at home if their children had not supplemented the formal in-home services.

In most cases, the adult children who provided informal support for their parents were able to do so because they had attained a certain level of economic stability. At the same time, their commitment to jobs limited--at least theoretically--their caregiving. Respondents' statements about the limits of support were couched most often in terms of their children's responsibilities to their own families and jobs. In one case, a daughter was able to take care of her mother virtually full-time after a crisis only because she did not have a job. In fact, she had a history of living on welfare with her two sons. In view of the high poverty rate among inner-city African Americans, this arrangement may well be

more prevalent in the inner-city African American population than it was in this nonrepresentative sample.

The limit of support manifested itself in two ways: helpers already providing services could not increase their efforts, and additional helpers could not be mobilized.

Cox and Monk (1990) found that use of formal services increased as informal support declined for African American and Hispanic elders. The discourse of the participants in this study revealed the limit of informal support rather than a decline in support. The limit of support manifested itself in two ways: helpers already providing services could not increase their efforts, and additional helpers could not be mobilized. The limiting factors are related to the helpers' family, work, health, and ability, and thus seem to be related to stress on the caregiver. Actually, these factors were defined as limits by the recipients of care and can be regarded as their attempts to protect the caregivers from excessive stress.

With the exception of the two men whose wives became sick and could not fulfill the cultural expectation of caring for their husbands, nursing home residents either had reached that limit or thought they had done so. In the face of declining health, their unchanged level of informal support became insufficient. ("Then there was a point where they couldn't do enough"; "I had some help, but I didn't have enough help"; "They couldn't work and take care of me too"; "My sister always tells me how they would come to see me if they could drive themselves.") Nursing home

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residents' initial struggle to maintain competence was ultimately defeated by even a minor change in their health status.

In contrast, home care clients had not yet reached that stage. Although they discussed it hypothetically as something that might happen in the future, they did not speak of their support as giving out. Rather, they defined the limits of support themselves by stating the point to which they would allow their helpers to take care of them:

My daughter said she would never put me in a home, but before I would be a burden to anybody I would rather be in one. My daughter is very good, but she has her own family. She can't do everything.... She's an awful big help to me, but she just has so much... she works five days a week and on Saturday and Sunday she's doing her work, but she always at least comes to see me about once a week and we sit and talk.

When I get to where I can't do for myself, I would have to go in a nursin' home then. And see, them kids, they he'p me out now, but they're not able to take care of me every day. They workin'.

My niece comes in on weekends. She stays the night. She gets me up on Saturday and Sunday, makes my bed and everything. Every night she puts me to bed and wakes me up in the morning. I do pretty good. But she couldn't be staying here at night during the week. She has to work.

...they must go on with their lives. They have families and they have things to do... I tried to raise them, I wouldn't take nothing for the raising. They respects me and then whenever I ask them to do something for me they will do it. But I try not to ask them. They say, "Don't feel bad, mama, why don't you want to ask?" I say, "Well, you all have your families." "Well, the families understand that we have a mother. All you have to do is ask." And then sometimes I don't have to ask for nothing. They will just come and say, "Mama, we brought you some just now."

These respondents sounded as if they had gauged the "balancing point of care," beyond which acceptance of care would become an exploitation of their caregivers' "impulse to care" (McGrew, 1991). That is, the recipients of care acknowledged their children's desire to provide care. At the same time, they themselves decided how much help they should and would ask for or expect without endangering their caregivers' ability to meet competing work and family obligations. Thus, when helpers offered unlimited support, the recipients of care restrained themselves from making full use of such offers in an effort not to exceed the limits they had set.

Long-Term Care Decisions

It has been suggested that a relationship exists between well-being and participation in health care decisions (Clark, 1987; Harel & Noelker, 1982; Kapp, 1991; Reinardy, 1992). Findings from this study suggest the presence of a hierarchy of decisions both in complexity and in need for participation. From the patient's point of

view, the decision to enter an institution was more complex and potentially more traumatic than the decision to opt for in-home services. All home care clients viewed their in-home services as an unmitigated blessing, although their participation in the decision may have been limited to passive acceptance. For nursing home residents, some participation in the decision to enter the institution helped to minimize the potential trauma of such a momentous move.

Generally, the decision to opt for in-home services was made by service providers and hardly involved any decision by the recipients, except the decision to accept them.

Home care clients. Generally, the decision to opt for in-home services was made by service providers and hardly involved any decision by the recipients, except the decision to accept them. The recipients were not aware of the complexity of decisions and procedures leading to the outcome they appreciated so highly, and they had a poor understanding of the service system. Having had experience with the welfare system, most home care clients did not even try to understand the rationale for receiving services. The following account is typical of the respondents' level of understanding of the service system and of how they learned about PASSPORT.

I found PASSPORT through the hospital. One of the nurses said, "Would you like to talk to a social worker?" I didn't even know what a social worker was. So she sent this social worker and this social

worker asked me, "Have you ever had any kind of help?" And I said, "No more than from the welfare." So she gave me the PASSPORT number to call, but I still didn't do it... I said "Ah, that's something else you got to go through, a whole lot of old red tape...like you do these food stamps, and all I get is ten dollars a month." Well, anyway, I came home and I did pretty good for a while. Then I went back to the hospital again, and so when I went back that time, the welfare only paid for you being there so many days. So the social worker came up to my room and she said, "Why didn't you call PASSPORT?" I said, "I don't even know what I did with the phone number," and so she called PASSPORT. She must have called them cause I'd been home about two days and they sent my first worker.

Most respondents are unclear about the relationship between PASSPORT and the agency that provides the services, about how exactly Medicare and Medicaid function, and about how these differ from services provided by "the welfare." This confusion, however, does not diminish their appreciation for the services, equipment, and medication they receive. All agree that PASSPORT is the best thing that had happened to them.

Regardless of who made the decision to use a nursing home, it was a process involving three questions: whether to do so, which nursing home to choose, and how to dispose of the resident's belongings. These three discrete decisions may be made by one, two, or three actors, including or excluding the person most affected by the decision.

Nursing home residents. Regardless of who made the decision to use a nursing home, the decision involved three questions: whether to do so, which nursing home to choose, and how to dispose of the resident's belongings. These three discrete decisions may be made by one, two, or three actors, including or excluding the person most affected by the decision. How traumatic the first two decisions were depended not only on the respondents' level of participation in the decision but also on their own experience, familiarity, and knowledge regarding nursing homes. Disposal of one's belongings is potentially very traumatic; if not done to the respondent's satisfaction, it can lead to permanent anxiety, regret, and lack of a sense of closure.

Statements about "the decision" make it sound as if it were an event, whereas actually it is a process (see Table 2) involving multiple actors (self and others); distinct phases (assessing health status, examining attitudes about nursing homes, evaluating options and resources, gathering information, inspecting facilities, completing paperwork, selecting significant possessions, disposing of belongings, entering a facility,

giving up or selling apartment or house); multiple modes of interaction between the actors (imposition, opposition, manipulation, negotiation, agreement, delegation); and different outcomes that may change over time (dissatisfaction, coping, satisfaction). When all these factors are taken into consideration, the number of possible scenarios exceeds the number of nursing home residents in the sample. Although such a small sample does not allow us to discern definitive patterns of decision making, it indicates considerable intragroup differences in the decision-making process for an otherwise relatively homogeneous group of individuals.

All nursing home residents in this study were aware of the decisions surrounding their institutionalization. Two made the decision completely autonomously, and were satisfied with the outcome (Table 3, Cases 1 and 2); two persons on whom the decision was imposed by others were opposed to it and still are dissatisfied (Cases 3 and 4). Each of the other three nursing home residents (Cases 5, 6, and 7), whose institutionalization also was decided upon exclusively by others, followed a different scenario. So did the remaining three nursing home residents (Cases 8, 9 and 10), who had made the decision jointly with others; these others suggested rather than imposed nursing home placement.

Respondents differed also in their ability to conceive of other alternatives. The two who followed the first extreme scenario (imposition by others and dissatisfaction) could conceive of only one other option, namely being at home. All others said they had considered other options and had rejected them for various reasons, mostly concerning the limits of support. Some of the perceived options (such as

moving in with an aged sibling or with children) may have been unrealistic, or may have represented respondents' retrospective efforts to rationalize the outcome. Such retrospective rationalization can be viewed as one of the coping mechanisms that helped respondents to progress from opposition or dissatisfaction to acceptance or satisfaction. This progression was expressed most often by the statement "I made myself satisfied." The three respondents who embarked on the decision-making process jointly with others in a "negotiated consent" (Moody, 1988) reached satisfaction in the end, but so did one whose decision had been made by others (Case 7). This finding suggests that some elders indeed may be happy to be relieved of the burden of such an important decision (Kapp, 1991). The other two (Cases 5 and 6) used coping mechanisms that expressed a desire to achieve satisfaction.

One could argue that six of the 10 nursing home residents exercised their "final say" (Smerglia, Deimling & Barresi, 1988) by ultimately accepting institutionalization as the outcome of a negotiated decision. One also could argue that even the deliberate delegation of decision making is the result of a decision.

Home Care Clients' Attitudes toward Nursing Homes

This notion of delegating authority to children also emerged from several home care clients' responses when they were asked hypothetically what they would do if they could no longer remain at home. Respondents frequently referred to a child as particularly qualified to make such a decision as in this statement:

I got one daughter is a nurse. She already know about nursin' homes.

Another works out there in the hospital. She took care of the older people back there on the wards 'cause she was trained to be a nurse's aide. So they know all about it.

Only one home care client stated unambiguously that she would not mind going to a nursing home. Another voiced a similar readiness but was sure her children would not tolerate such a move. All of the other eight home care clients considered the possibility of going to a nursing home, but at the same time expressed a strong aversion. ("I didn't tell you I wouldn't go. I told you I wouldn't like to go"; "It's not that I can't go to a nursing home, I guess. I don't want to"; "I believe I would have just gone on in, but I don't want it. I pray that I don't have to stay in a nursing home"; "I feel that one day I might have to go, but I do not want it"; "If I have to go I would try to make it out, but I wouldn't feel so good about it.")

Sometimes this aversion was based on personal experience. ("I went there one time years and years ago, and they had old sick ladies there. I did not want it. I don't like it and I don't want it. I'd rather just die and suffer at home.") More often it was based on hearsay about mistreatment and neglect. ("I have heard so much about the people who are running the rest home until it turns my stomach that I don't want to go in one"; "I just hear so much about it. They say that they treat them people so nasty, they let them lay there and pay no attention"; "I have seen so many things about nursing homes. I've heard about how they're putting helpless people in the nursing homes and they halfway feed them and they put water in the oatmeal, water the oatmeal down, and they're almost skin and bones.

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It's been right on TV.") For some respondents, admission to a nursing home meant being abandoned by one's children ("Ye feel like yer kids done th'owed ye away when ye have to go to a nursin' home. Feel like they don't care nuthin' about ye when ye go into a nursin' home.")

Respondents who had visited relatives in nursing homes also had reservations, even if these relatives seemed content and well cared for. They were sure that the moment the visitor left the home, the staff resumed mistreatment. ("See, one thing about a nursing home, I can go visit a person, they do pretty good, and when I leave the nursing home they don't pay no attention. They put you in a corner and forget about you.") One respondent spoke about her sister who was in a nursing home: "Her granddaughter worked in that nursing home and she was right there, and them children, her two daughters, was right there. When one wasn't there, the other one was there all day. Plum up until she died. It was just like being at home because they was right there at that nursing home." A home care client who spent several months in a nursing home after an episode of acute illness described a similar situation: "You oughtta see what they do to them people out there. They didn't do it to me 'cause Paul wuz comin' out there. You know what? I think now I would like to go to that home. I would. 'Cau' I b'lieve Paul would see after me out there. He come an' visit me." She was the only person in the sample who said she would not mind going to a nursing home, but only because she felt sure that someone would be looking out for her.

Implications for Long-Term Care Policy

Policy and the diversity of needs.
Obviously there are considerable differences

in the subjective and objective needs in a group of individuals of similar background. All are poor, impaired African American elders who nevertheless differ considerably in their health trajectories and in their manner of confronting their health crises. Differences in lifelong reliance on certain coping strategies led similarly impaired respondents into different long-term care settings. In spite of pervasively negative attitudes toward institutional care, those who either had exhausted or could not conceive of other options, including in-home services, found themselves in nursing homes. Recipients of in-home services demonstrated a fierce determination to remain "independent" in spite of chronic and disabling ailments, whereas nursing home residents were more likely to define themselves as incompetent. Until and unless we can be sure that such a negative self-evaluation is the result rather than the cause of institutionalization, intake assessment must be sensitive to such salient personality traits in addition to functional impairment.

Policy and the decision process.
Hospital discharge planners, social workers, and case managers clearly play an important role in long-term care decisions. Often such decisions are made under duress and at a time when the person most concerned is least able to evaluate all options. Policy makers must seek assurance that all elders confronted with a long-term care decision receive systematically clear information about all their options and what they imply. Providing a telephone number without any follow-up is clearly an inefficient and inadequate referral method. In-home services are a viable and preferred option for many. Policy makers must work toward continued provision and expansion of these services.

The assumption that African Americans are cared for by their families is dangerous because it absolves service providers from addressing the needs of this population.

Policy and the limit of support. The findings about the variations in respondents' informal support should dispel the myth that all African American elders are embedded in nurturing kin networks. They also should dispel the fear of a "woodwork effect" if services should be provided on a larger scale. Families provide a large amount of supportive care, in some cases enhancing formal services that otherwise might be inadequate. In this study, the extent of informal support ranged from excellent to adequate to minimal to negative. The assumption that African Americans are cared for by their families is dangerous because it absolves service providers from addressing the needs of this population. Providers must be educated about differences in the African American community so that they can meet the wide range of needs. They also must be trained in culturally sensitive outreach methods that include (but are not limited to) mobilizing nontraditional helpers such as mail carriers, church members, or other nonkin.

The notion of the limit of support that emerged from this study suggests that institutionalization is not always preventable even when informal support is available. Furthermore, availability of informal support alone does not predict which long-term care option will be used. Even respondents with excellent support had a clear idea of the limit of support that they

could not or would not exceed. Case managers of in-home service clients should be alerted to the limit of support when they include informal helpers in the care plan. Multiple helpers are more able to fill gaps in services than are single helpers. In addition, innovative policy makers might propose ways in which informal helpers could be rewarded for their efforts.

Respondents in this study based their negative attitudes toward nursing homes largely on hearsay of horror stories from the 1970s. Those who had first-hand knowledge of specific facilities, however, could envision themselves more readily in a nursing home. Familiarizing elders with specific nursing homes in their vicinity could go a long way toward improving the image of these institutions, and toward removing the stigma of institutionalization. The "watchdog" function of family and friends who visit nursing home residents could be formalized and incorporated into the care plan by giving these "natural ombudsmen" an active role in the provision of care.

Conclusions

All the participants in this study were poor, old African American urban dwellers. Differences in their functional ability alone did not explain why some were in nursing homes and others could manage on in-home services. Differential personal experiences with illness, conceptualized here as health trajectory, had equipped respondents with different coping strategies that made them more or less vulnerable to institutionalization in the face of similar impairments.

When the limit of support is reached, institutionalization occurs in spite of negative feelings toward nursing homes, and in apparent violation of the ideal of filial responsibility. This suggests that African American elders are subject to the same forces as are other segments of our society.

The limit of support, that is, lack of change in informal support in the face of declining health, emerged as an important parameter for respondents' expectations of help from kin. This limit represents the point of conflict between the ideal of filial responsibility and the reality that often prevents individuals from fulfilling this ideal. When this point is reached, institutionalization occurs in spite of negative feelings toward nursing homes, and in apparent violation of the ideal. This suggests that African American elders are

subject to the same forces as are other segments of our society. Institutionalization is always a last resort, a least preferred option when all others have been exhausted, and the aversion expressed by respondents in this study is hardly unique to African Americans.

The stories told by participants in this study make it clear that the choice of one long-term care setting or another is not a discrete event but a complex process involving multiple actors, phases, and aspects. Those affected most strongly by this decision may participate to varying degrees in different parts of the decision; their final say may range from a protracted negotiated decision to total delegation. Because the decision process is complex, it may be played out through many different scenarios. There is no one right way for all individuals; ideally the right way for each person will reflect his or her special needs and circumstances.

If public policy is to be effective, it must take into account the considerable range in African American elders' needs, resources, personal experiences, and coping strategies. It must make true choices available. Nursing homes are an appropriate choice for certain elders who truly have no other options: this study makes clear that home care clients embraced their choice more happily than nursing home residents embraced theirs. Although the majority of nursing home residents in this study ultimately reconciled themselves to their situation, a greater range of options along a continuum of community-based care might have enabled some of them to avoid institutionalization. The findings from this study suggest that expanding the range of community care options would be good policy from the consumer's point of view.

Appendix

Table 1
Age and Functional Ability of Nursing Home Residents (NHRs) and Home Care Clients (HCCs)

| | <u>NHRs</u> N=10 | <u>HCCs*</u> N=10 |
|--|---------------------|----------------------|
| <u>Age</u> | | |
| Range | 71-87 | 69-84 |
| Mean | 80.8 | 75.6 |
| Median | 79 | 75 |
| <u>Functional Ability</u> | | |
| Permanently nonambulatory and need help with ADLs | 5 | 1 |
| Temporarily nonambulatory and need help with ADLs | | 2 |
| Some problems with ambulation | | 4 |
| Ambulatory: | | |
| ADL independent | 4 | 3 |
| Need some help with ADLs | 1 | |

*All need help with one or more IADLs

Table 2: Decision Process for Nursing Home Placement

| Necessary | | Possible | | |
|------------|--|--|--|--|
| Aspects | Actors | Phases | Interactions | Adaptation |
| 1. Whether | 1. Self 2. Others 3. Self and others | 1. Assess health status | 1. Self decides independently/ informs others of decision | 1. Dissatisfaction 2. Coping 3. Satisfaction |
| | | 2. Examine ◦ preconceptions ◦ knowledge ◦ experience ◦ stereotypes concerning nursing homes | 2. Others impose coerce manipulate persuade intimidate | |
| 2. Where | 1. Self 2. Others 3. Self and others | 3. Evaluate options | Self opposes manipulates acquiesces succumbs | 1. Dissatisfaction 2. Coping 3. Satisfaction |
| | | 4. Assess resources | | |
| 3. How | 1. Self 2. Others 3. Self and others | 5. Gather information | 3. Self and other(s) negotiate discuss propose agree accept reconsider reassure | 1. Dissatisfaction 2. Coping 3. Satisfaction |
| | | 6. Inspect facilities | | |
| | | 7. Consult professionals | 4. Self delegates | |
| | | 8. Apply/do paperwork | | |
| | | 9. Select significant possessions | | |
| | | 10. Dispose of belongings | | |
| | | 11. Enter facility | | |
| | | 12. Give up apartment or sell house | | |

Time

Time

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Table 3
Individual Scenarios for Nursing Home Placements

| Case | Decision | Actor(s) | Interaction | Adaptation | No. of Months in NH |
|---------|-------------------------|--|---|---|---------------------|
| 1 and 2 | Whether Where How | Self | Autonomy | Satisfaction | 25 and 216 |
| 3 and 4 | Whether Where How | | Others | Imposition Opposition | |
| 5 | Whether Where How | Others | | Imposition Suggestion Acceptance | Coping |
| 6 | Whether Where How | | Others | Imposition Opposition Resignation | Coping |
| 7 | Whether Where How | Others | | Imposition Acceptance | Satisfaction |
| 8 | Whether Where How | | Self and Others | Suggestion Opposition Negotiation | Satisfaction |
| 9 | Whether Where How | Others Self Others | | Suggestion Acceptance | Satisfaction |
| 10 | Whether Where How | Self and Others Others and Self Others | Suggestion Negotiation Acceptance | Satisfaction Unhappiness | 9 |

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