African American elders' long-term care preferences and choices

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African-American Elders' Long-Term Care Preferences and Choices

Final Report

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PROJECT BRIEF
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Highlights of Project Outcomes

The culture of caring is strong among African-American family members of all generations, with the youngest groups expressing the highest filial expectations. There exists a cultural lag between the ideals of filial obligation, or the culture of caring, and the material conditions which make it increasingly more difficult to attain the ideal. Filial expectations have failed to keep pace with the demographic and economic realities, causing cognitive dissonnance in those who embrace the ideal but cannot attain it.

Elders and their families prefer home care from kin and/or supplemented by formal services. Nursing home placement is an option of last resort, often embraced more enthusiastically by elders than by their families. If there are changes in the long-term care use patterns of African Americans away from kin care to the formal services, such changes appear to be driven by elders' desire not to be a burden on their families.

Elders vary greatly in their availability of informal support which ranged from unwavering and total support from many children, to no support, and exploitation by children.

African-American elders are increasingly using nursing homes as an option. In Ohio, they are more likely than their white counterparts to go to a nursing home. Attitudes toward nursing home use are shaped by and vary with one's health and perception of one's frailty, fear of becoming a burden on kin, own caregiving experiences, and experience with and knowledge about nursing homes.

Nursing home care enhances delivery of kin care; provides security for care recipient and peace of mind for caregiver; re-establishes elder's sense of competence and well-being; provides refuge from inadequate or unsatisfactory kin care. Families who provided care before formal services were use continue to do so in a more focused and efficient manner.

Of the three kinds of constraints on kin-care identified (caregiver factors, care recipient factors, and circumstances), care recipient factors such as dementia, ingratitude, or eccentric behaviors were most likely to exeed caregivers' limits of support.

Lack of information about in-home services hampers families' effective and efficient search for appropriate care. Most of those who received in-home services learned about them only when a crisis situation put them in contact with the service system.

Families would greatly benefit from educational and supportive services, help with exploring all possible options, guidance in their search for appropriate care, help with planning for increasing needs, and referral to such program; outreach by and accurate information about nursing homes.

African-American Elders' Long-Term Care Preferences and Choices

Executive Summary

<u>Background</u>

African-American elders represent a special challenge to the service system for two reasons: they are the fastest-growing segment of the African-American population (Wykle and Kaskel 1991), and there is a growing recognition that they may have special needs and preferences for long-term care. African Americans have shorter life expectancies and higher levels of impairment than do whites (Gibson and Jackson 1987). These factors could be expected to propel a disproportionately large number of African-American elders into nursing homes. Yet, a body of literature contends just the opposite: African Americans are depicted as finding nursing home placement less acceptable and as using nursing homes less frequently than do whites (Murtaugh, Kemper, and Sillman 1990; National Caucus and Center on Black Aged 1987; Vallé 1989; Yeo 1990). The two most often cited but equally inconclusive explanations for African American's lower use of nursing homes are that they have a greater dislike of nursing homes, and that they have better informal support. A number of writers have attributed African Americans' different patterns of nursing home use to structural reasons such as cost and poverty (Berk and Bernstein 1985; Hanley and Wiener 1991), discrimination against poor people (Spohn, Bergthold, and Estes 1988), staffing patterns, and type of ownership (Burrack-Weiss 1985; Schafft 1980). Others point out that we really do not know the reasons for the reported differences, but that such knowledge is crucial for informed policy decisions (Murtaugh, Kemper, and Spillman 1990). The double jeopardy hypothesis, which posits a cumulative disadvantage of age and minority status, may partly explain racial differences in access

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to institutional care but raises many questions that only qualitative research can answer (Belgrave, Wykle, and Choi 1993).

<u>Project Objectives</u>

This project was designed and approved for a period of two years. Its purpose was two-fold: to enhance our understanding of how perceptions of filial obligations and patterns of intergenerational family support affect the long-term care preferences and choices of African American elders; and to identify factors that strengthen the family's role as a support network within and across generations. Specifically, we set out to do the following: (1) identify generational differences in the perception of filial obligations that may or may not lead to changing patterns of long-term care arrangements; (2) describe African Americans' long-term care preferences; (3) identify the constraints affecting their choices; (4) describe the current models of services used by African American elders and their strengths and weaknesses with regard to meeting users' needs; (5) construct, test, and disseminate a culturally appropriate quantitative instrument informed by the findings of the qualitative research to measure long-term care needs, preferences and choices. We achieved goals (1) through (4) during the first year of the project. Because of cuts in funding of Title IV projects under the Older Americans Act, we were unable to achieve goal (5).

<u>Project Approach: Data Collection</u>

We used **two qualitative data sources** for this project: eight (8) **focus groups** to explore ideas about filial obligations across generations, and sixty (60) **individual open-ended face-to-face interviews** with care recipients and caregivers, in three different care settings, about their experiences of receiving and providing care. We used **four quantitative data bases**: **US and Ohio Census data**; the **MDS+ data base for Ohio**; **PASSPORT--Ohio's Medicaid-waver in-home**

services program; and **ESP--a county-wide levy-funded in-home services program** to explore whether the findings from our qualitative research mirrored state and county-wide long-term care use patterns.

Project Approach: Data Analysis

Focus groups and individual interviews. We carried out text analysis of the transcriptions of the verbal accounts collected through focus groups and interviews. We used the method of open coding to first identify major themes, then to scrutinize themes for interconnections, consistency, contradictions, and lastly to reveal patterns in beliefs and practices. Emerging concepts such as the "culture of caring," "the limit of support," or "kin police/kin surveyors", for example, are grounded in the data. (For a succinct description of this method of text analysis, see Lincoln & Guba, 1985.)

MDS+ data set. First, we compared five quarterly assessments (June 1993, December 1993, June 1994, December 1994, and June 1995) to ascertain whether the profile of Ohio's nursing home population was consistent over time. Second, we used the MDS+ data set to construct a profile of African American nursing home residents in terms of age, gender, living arrangement before institutionalization, payment source, physical impairment, cognitive and behavioral functioning, and social support. This profile provides a backdrop against which to evaluate our qualitative research findings. We also used the MDS+ data set in combination with the PASSPORT and ESP data sets mentioned above to calculate utilization rates by race.

Findings

Generational Differences in the Perception of Filial Obligations

Our findings suggest that our youngest groups were the most vehement in their insistance on kin care and in their expressions of filial obligations. Older groups tended to temper their ideals of

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filial obligations with their observed or experienced realities of the demands of caregiving. Our care recipient groups showed the lowest level of filial expectations; they expected more in terms of interpersonal support rather than physical or instrumental assistance. Our findings suggest that if there are changes in the long-term care use patterns among African-Americans away from kin care and towards the use of formal services, these changes appear to be driven by a desire among older generations not to burden their younger family members. The culture of caring, which emerged from our focus groups and interviews, is strong among African-American family members of all generations. However, the realities of caregiving often pose problems which cause families to seek formal support services. Our findings indicate the existence of a cultural lag between the ideals of filial obligation, or the culture of caring, and the material conditions which make it ever more difficult to attain the ideal. Filial expectations have failed to keep pace with the demographic and economic realities, causing a kind of cognitive dissonnance in those who embrace the ideal but cannot attain it.

Constraints Affecting Choices

The major constraints on kin care included *Caregiver factors* (health problems, conflicting work and family demands, economic difficulties, "selfishness," and unwillingness to provide care); *Care recipient factors* (lack of gratitude, conflict created by the elder, meanness, lack of consideration, criticism of caregiver, excessive needs and demands, and eccentric behaviors); *Circumstances* (geographic distance, lack of financial resources, medical expenses, and a variety of individual situations). Constraints were also distinguishable by whether they did or did not have a solution. The only constraints thought to be without a solution were care recipient factors. The limit of informal support, one of the major concepts that emerged from the data, was most often

reached when care recipient factors such as eccentric behaviors or excessive demands could not be overcome.

Reasons for caring. We identified three major reasons for caring: (1) reciprocity either as payback for services rendered in the past, or as insurance for future adversity; (2) altruism; (3) self interest; plus a hybrid of the two which we called self-interested altruism.

All discussions were permeated by what we identified as a "culture of caring," which consists of deliberate efforts to teach children not only that taking care of elders is something one should do, but also to show them how to do it, either by example or through explicit instructions.

African Americans' Long-Term Care Preferences and Choices

African-Americans, like other older Americans, generally expressed a preference for obtaining care in their own homes, as long as this was a reasonable alternative. When care is needed, home care services are generally preferred to nursing homes, which families use as a last resort. There is little to suggest that the provision of formal services results in a reduction of kin care. Instead, formal services allow families to refocus their efforts to where they are most effective, and to shift their support from certain instrumental tasks to the affective aspects of interpersonal support most desired by elders. In-home services also allow elders without informal support to remain in their homes. The greatest obstacle to obtaining services was lack of information about them.

Strengths and Weaknesses of Models of Care

Elders receiving kin care only were less impaired and had more children than elders in the other two care settings. Most had not tested the limits of their families' support. The kin care model derives its strengths from love, gratitude, and respect--the sentiments it symbolizes and engenders at the same time; teamwork among siblings in some families; children's happiness about being able

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to repay what parents did for them in the past; and elders' deep satisfaction with their success in having raised "good children" who take care of their needs. However, need for care can rarely transform a weak relationship into a strong one, nor an uncaring family into a caring one. Brittle kin support systems may be unreliable in their delivery of care and they may place vulnerable elders in danger of victimization. Accepted wisdom, which depicts African American elders as relying heavily on the kin care only model, fails to acknowledge that kin care may leave some elders vulnerable, stressed, struggling against great odds, and unable to manage. Caregivers too may be vulnerable--to estrangement from siblings, to an inability or delay in making economic provisions for their own futures, and to feelings of stress and burden.

Formal In-Home Services. For childless elders, for those without children nearby, and for those whose families were unavailable or uninvolved, in-home services made the difference that allowed them to maintain their independence. In-home services allowed those with strong family supports to limit what they expected from family and to avoid the feeling of being a burden. Most of our interviewees found their services indispensable. They recognized that at some point they might have to go to a nursing home, but for the time being, in-home services allowed them to postpone that event. The weakness of home care services has to do with management and structural problems: High worker turnover, unreliability, mismatches in personality, dreaded cuts in funding, and burdensome co-payments in the case of ESP clients.

Nursing Home Care. Our analysis of the Ohio MDS+ in conjunction with US Census data shows that African-American elders are more likely than whites to use nursing homes. (See Appendix A.) Although perceived as the option of last resort, African Americans are increasingly using nursing home placement as a viable alternative. However, the perception of this option as the

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last resort at the end of an often laborious and painful trajectory of decline suggests that it is not a decision made lightly, nor that it is without problems. Negative stereotypes, poor publicity, and lack of any experience with a nursing home caused some elders and their families to fear a nursing home placement. However, most of them felt strongly that family members could assure high quality of nursing care by visiting, policing, and actively participating in the care of their loved one. We found overwhelming evidence for the continuation of kin care after nursing home placement of elders who had enjoyed good kin care before. In fact, we found compelling evidence that nursing home placement can and does enhance the effectiveness of kin care.

Implications

Lack of information about in-home services as well as negative stereotypes and misconceptions about nursing homes prevent many families from making effective and efficient use of these services. Educational and supportive services for families could help them reconcile their often unrealistic filial expectations with the realities of caregiving. While all caregiving families could benefit from such education and support, it would be particularly beneficial for African Americans whose special history of prolonged and systematic oppression predisposed them to developing strong familial support systems and high levels of filial expectations. In-home services would be particularly useful in easing the burden of kin caregivers and alleviate some of the tensions in less-than-perfect kin care situations if there were more effective information and dissemination pathways leading potential beneficiaries to these services.

Our study revealed no evidence for a "wood work effect," or the unwarranted use of services feared by some policy-makers. Although some elders who had family support would have been forced to solicit more assistance from family in the absence of formal services, our study shows that

formal services helped stretch informal care, allowing families to postpone reaching the limits of their support. Most importantly, our research shows that African-American elders and their families consider nursing home placement an appropriate and viable option when other options have been exhausted. The assumption that African Americans reject nursing homes is inaccurate and counterproductive to families' search for appropriate care settings for elders whose care needs could best be met in a nursing home.

Those participants who were most vehemently opposed to nursing homes were also the least informed about nursing homes. Accurate knowledge about, and positive experiences with, nursing homes greatly facilitated both acceptance of this option and adjustment to life in the nursing home. African-American families need not be reminded of their filial obligations; they need not be told that, as a group, they seem to reject nursing homes. What they need is permission for and assistance with exploring all possible options, guidance in anticipating scenarios that are likely to require nursing home placement, help with planning for increasing care needs, and referral to such programs.

Improving the image of nursing homes in the African-American community would go a long way toward easing this difficult transition for families and their elders. As younger generations have more positive experiences with today's nursing homes, the negative images of the past may fade and pave the pay to African Americans' broader and more guilt-free acceptance of nursing homes as a viable and legitimate option when they reach their limit of support. Commmunity outreach on the part of nursing homes should target African-American churches, service and youth organizations. The culture of caring we discovered in our study has a great potential for being expanded to include institutional care as an appropriate option rather than as an indicator of inadequate family caring.

<center>**Dissemination Synopsis**</center>

The following papers and presentations were prepared (or are forthcoming) for dissemination of results of the African-American Elders' Long-Term Care Preferences and Choices project, supported by the Administration on Aging grant #90-AR-2034.

Papers

A Black-White Comparison of Demographic, Physical, and Behavioral Characteristics of Ohio's Older Nursing Home Population. Lisa Groger (Miami University) & Shahla Mehdizadeh, Scripps Gerontology Center.

> Examines black-white differences in nursing home utilization, demographic characteristics, physical and cognitive functioning, and social support of all of Ohio's nursing home residents occupying Medicaid certified beds. Challenges the assertion that African Americans are less likely than whites to use nursing homes, and argues that the question of racial utilization rates must be examined on a state-wide level and for the total nursing home population rather than on representative samples. (Included as Appendix A.)

Presentations

Generational Differences in the Perception of Filial Obligations: Caregiving of African-American Families.
> Lisa Groger & Pamela S. Mayberry, Scripps Gerontology Center.
> Presentation at the Gerontological Society of America 50th Annual Meeting,
> November, 1998

A Comparison of Service Needs and Utilization by Afro-American and Caucasian Residents in Ohio.
> Lisa Groger & Shahla Mehdizadeh, Scripps Gerontology Center.
> Presentation at the 1997 National Case Mix, Reimbursement, and Quality Assurance Conference, September 1997

What We Didn't Learn Because of Who Wouldn't Talk With Us.
> Lisa Groger, Pamela S. Mayberry, & Jane K. Straker, Scripps Gerontology Center.
> Presentation at the Fourth International Multidisciplinary Qualitative Research Conference, February 1998

Cultural Lag: African Americans' Perceptions of Filial Responsibilities.
> Lisa Groger, Pamela S. Mayberry, & Jane K. Straker, Scripps Gerontology Center.
> Presentation at the 14th International Congress of Anthropological and Ethnological Sciences, July 1998.

Report

African-American Elders' Long-Term Care Preferences and Choices.
> Lisa Groger, Pamela S. Mayberry, Jane K. Straker, & Shahla Mehdizadeh, Scripps Gerontology Center. Report disseminated by the Scripps Gerontology Center to legislators, researchers, and practitioners in the field of long-term care.

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CHAPTER 1

INTRODUCTION & METHODOLOGY

<u>Background</u>

African-American elders represent a special challenge to the service system for two reasons: they are the fastest-growing segment of the African-American population (Wykle and Kaskel 1991), and there is a growing recognition that they may have special needs and preferences for long-term care. African Americans have shorter life expectancies and higher levels of impairment than do whites (Gibson and Jackson 1987). These factors could be expected to propel a disproportionately large number of African-American elders into nursing homes. Yet, a body of literature contends just the opposite: African Americans are depicted as finding nursing home placement less acceptable and as using nursing homes less frequently than do whites (Murtaugh, Kemper, and Sillman 1990; National Caucus and Center on Black Aged 1987; Vallé 1989; Yeo 1990). Relatively little is known about minorities and home-health services (Johnson-Crockett 1990), although data on users of publicly funded in-home services show that African Americans' use of such services contrasts sharply with their use of nursing homes: they use these services out of proportion to their numbers in the population (Applebaum, Baxter, Callahan, and Day 1985; Miner 1995).

The two most often cited but equally inconclusive explanations for African Americans' lower use of nursing homes are that they have a greater dislike of nursing homes, and that they have better informal support. It can be argued that dislike of nursing homes in itself is probably not sufficient to avoid institutionalization. Furthermore, it is important to separate analytically **actual use or choice of**, and **preferences for,** a given long-term care arrangement. Differences in utilization do not necessarily reflect differences in preferences (McAuley and Blieszner 1985). A number of

writers have attributed African Americans' different patterns of nursing home use to structural reasons such as cost and poverty (Berk and Bernstein 1985; Hanley and Wiener 1991), discrimination against poor people (Spohn, Bergthold, and Estes 1988), staffing patterns, and type of ownership (Burrack-Weiss 1985; Schafft 1980). Others point out that we really do not know the reasons for the reported differences, but that such knowledge is crucial for informed policy decisions (Murtaugh, Kemper, and Spillman 1990). The double jeopardy hypothesis, which posits a cumulative disadvantage of age and minority status, may partly explain racial differences in access to institutional care but raises many questions that only qualitative research can answer (Belgrave, Wykle, and Choi 1993).

It has also been suggested that comparing rates of nursing home utilization for African Americans and whites is "fraught with difficulty, resulting in potentially unstable estimates," because many of these comparisons use very different data sources (Belgrave, Wykle, and Choi 1993: 379). Based on a review of research studies, Wan (1989) found that race had little effect on long-term care service use. One reason for such contradictory findings about racial differences in the use of long-term care arrangements may be the fact that some of these comparisons are based on nationally representative samples and others are based on localized community samples.

Informal support. The extensive body of literature on African Americans' informal support has also yielded mostly contradictory and inconclusive findings. A number of comparative studies on social support found that African Americans had larger support networks and relied more heavily on informal support than did whites (Johnson & Barer 1990; Mitchell and Register 1984; Mutran 1985). In contrast, Miner (1995) found race to be an insignificant predictor of informal support. Compared to whites, African Americans' norms of filial obligations and expectations were reported

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in one study to be stronger (Frisby-Farmer, 1991), in another weaker (Hanson, Sauer, and Seelbach 1983).

Whatever African Americans' expectations of filial obligations may be, clearly the ideal cannot always be achieved, as witnessed by the considerable intragroup differences in informal support. Studies that examined only elderly African Americans found considerable variation in the kind and extent of informal support, depending on a complex interplay of demographic and familial variables (Chatters, Taylor, and Jackson 1986; Groger 1992; Jackson 1970; Taylor 1985; Taylor and Chatters 1986). By exploring more explicitly the different kinds of informal support provided to elders — by whom, under what circumstances, and how frequently — these studies have painted a more complex picture which shows great variation in African-American elders' availability of informal support.

Living arrangements and family structure. According to the 1990 census, 31.2% of African-American elders lived alone, 36.7% lived with a spouse, and 32.1% lived with others, compared to white elders among whom 32.0% lived alone, 55.3 lived with a spouse, and 12.7% lived with others (Angel and Hogan 1991). The almost identical likelihood for African-American elders to be living alone is surprising in the light of their allegedly superior informal support. Although living alone is not necessarily an indication of the lack of informal support, it is an indication of a certain vulnerability. African American elders' lesser likelihood of being married and their greater likelihood of living with others can be seen as adaptations to poverty (Stack 1974). Often, African-American elders take children, grandchildren or unrelated persons into their households to care for them rather than to be taken care of by them (Burton 1992). These adaptations may be more related to social class than to race. Willie (1978) has identified three types of African-American families

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whose norms and values differ along the lines of middle, working, and lower class status. This is not to deny the existence of specifically African-American family patterns. Staples (1978) argues that the institution of the family has changed drastically since the early 1960s with regard to sexual mores, role expectations, fertility rates, and prevalence of marriage and divorce. African-American families have undergone some of these same changes, but because of their status as a minority group, some differences continue to exist.

Project Purpose and Goals

This project was designed and approved for a period of two years. Its purpose was two-fold: to enhance our understanding of how perceptions of filial obligations and patterns of intergenerational family support affect the long-term care preferences and choices of African American elders; and to identify factors that strengthen the family's role as a support network within and across generations. Specifically, we set out to do the following: (1) identify generational differences in the perception of filial obligations that may or may not lead to changing patterns of long-term care arrangements; (2) describe African Americans' long-term care preferences; (3) identify the constraints affecting their choices; (4) describe the current models of services used by African-American elders and their strengths and weaknesses with regard to meeting users' needs; (5) construct, test, and disseminate a culturally appropriate quantitative instrument informed by the findings of the qualitative research to measure long-term care needs, preferences and choices. We achieved goals (1) through (4) during the first year of the project. Because of cuts in funding of Title IV projects under the Older Americans Act, we were unable to meet goal (5).

<u>Study Approach</u>

Clearly, large-scale quantitative studies have failed to provide an understanding of both the range of variations in long-term care preferences and choices and of their cultural meanings. Quantitative researchers themselves have suggested that intragroup variations may be more qualitative than quantitative (Gibson and Jackson 1987) and that "the content and force of cultural norms [which] remain largely understudied" are essential to understanding intragroup variations (Miller, McFall, and Campbell 1994: S23). We deemed a qualitative approach as most appropriate for exploring the wide range of intragroup variations regarding long-term care preferences and choices as well as caregiving behaviors, the circumstances under which they occur, and how care recipients and caregivers interpreted these in light of their own experiences.

We used **two qualitative data sources** for this project: eight (8) **focus groups** to explore ideas about filial obligations across generations, and sixty (60) **individual open-ended face-to-face interviews** with care recipients and caregivers, in three different care settings, about their experiences of receiving and providing care. We used **four quantitative data bases**: **US and Ohio Census data**; the **MDS+ data base for Ohio**; **PASSPORT--Ohio's Medicaid-waver in-home services program;** and **ESP--a county-wide levy-funded in-home services program** to explore whether the findings from our qualitative research mirrored state and county-wide long-term care use patterns.

Focus groups are particularly useful for exploring phenomena about which little is known because they allow individuals to respond in their own words, to provide their own concepts, and to reveal their views which researchers might not be able to capture through a set of preconceived questions. We used the findings from the focus group discussions to inform our questions for the

individual interviews. In the face-to-face interviews, we explored individual trajectories of declining health, availability and use of informal and formal support, feelings about, and reactions to interviewees' careers either as caregivers or care recipients. The quantitative data bases provided a larger framework for interpreting our qualitative research findings.

Data Collection

Focus Groups. Our focus group discussions lasted between 1 ½ and 2 ½ hours. They were structured and open-ended at the same time: they were structured by the moderator who kept the group on track of the "grand tour" question; they were open-ended because participants were not only allowed but expected to take the discussion into surprising directions to reveal as much as possible of the uncharted territory that was being explored. Probing was part of the process in the course of which the significant questions for the individual interviews emerged. Our data collection with focus groups is summarized in Table 1:

Table 1: Summary of focus groups

Group	Number of Participants	
	Female	Male
University students	2	3
High school students	7	1
Young adults	1	3
Middle-aged adults	2	1
Elders attending rural senior center	6	1
Elders attending urban senior center	5	3
Nursing home residents (elders)	4	0
Adult day care center clients (elders)	4	4
Total	31	16
Grand total	47	

The focus groups were led by African-American consultants trained and hired for this project. The questions they explored with the focus groups covered the following general areas of inquiry:

(1)   Do different generations have different ideas about filial obligations in general, and caregiving in particular? If so, how do they differ?

(2)   How do ideas about filial obligations toward elders influence the level of effort families think they should muster to care for their elders?

(3)   How do material constraints (family structure, geographic distance, competing family and career demands, own health, finances) shape individuals' ideas about filial obligations in general and caregiving in particular?

(4)   How do such material constraints prevent individuals from fully meeting their ideal of filial obligations?

(5)   How and to what extent does the actual level of effort expended in caring for elders represent a compromise between the ideal and the possible?

(6)   When formal services must be used, what is the ideal, and how well do current services meet that ideal?

(For operationalization of these questions, see Appendix B.)

Qualitative interviews: To explore our overall research question from the point of view of elders in a variety of long-term care situations, we interviewed 39 elderly care recipients and 21 caregivers of elders who, at the time of the interview, were receiving one of three types of care: informal or kin care only; in-home services; or nursing home care. We used the findings from the focus groups to formulate the questions for the individual interviews. The major instrument used in this research was a one-time interview that allowed for open-endedness and contingencies while

focusing at the same time on a set of central questions asked in a nondirective manner, followed by prompts where called for. (See Appendix C for the list of questions explored in the interviews.) Table 2 provides an overview and summary of the individuals interviewed and the settings in which they either received or provided care.

Table 2: Summary and overview of individual interviews

Interviews	Care Setting			Total
	Kincare	**In-Home**	**NH Res**	
Number of interviews conducted	17	17	26	60
With caregivers	5	4	12	21
With care recipients	12	13	14	39
With matched pairs	5	3	3	11
With female caregivers	4	4	7	16
With male caregivers	1	1	4	6
With caregiving couple	0	0	1	1
With female care recipients	10	9	9	28
With male care recipients	2	4	5	11
With couple receiving care	0	2	0	2
Number of "stories" or cases (N)	12	17	23	52

The authors of this report shared equally in the recruiting and interviewing of participants. Pamela Mayberry worked through a church and a senior center and used a snowballing method for recruiting elders and their caregivers in an informal kin care setting. Jane Straker worked with rosters of clients of two in-home services agencies: Ohio's PASSPORT program which screens and assesses applicants for long term care and delivers Medicaid-funded in-home services to eligible

elders, and ESP (Elderly Services Program), a tax-levy funded home care program. Lisa Groger worked with the administrators of five nursing homes, three predominantly black, to recruit cognitively competent residents and kin caregivers. All focus group discussions and individual interviews were tape-recorded and transcribed verbatim for line-by-line text analysis.

Participants in all three categories constitute a purposive, nonrepresentative sample perfectly suited for a study intended to explore the wide variety of caregiving and receiving experiences, and to generate patterns rather than to test hypotheses. The nursing home subsample is highly biased in the sense that each of the cooperating facilities had more cognitively impaired than cognitively competent African-American residents. In fact, three nursing home residents, who had been identified by staff as cognitively competent, were borderline in the sense that they were hard pressed to tell a coherent story. Nevertheless, we made a great effort to hear their stories, hoping to complement them with interviews from their next of kin. Unfortunately, we were unable, in spite of repeated contacts, to recruit any of these three residents' caregivers to participate in our study. In addition to these three cases, we experienced general difficulties in recruiting participants, particularly caregivers. This may be due to the fact that caregivers have little discretionary time, given their caregiving activities in addition to work and family obligations. Researchers undertaking a similar study might consider offering a monetary incentive for participation.

MDS+ data set. The Scripps Gerontology Center has access to the electronic version of this extensive data set. Since December 31, 1992 and quarterly thereafter, all Medicaid-certified nursing homes in Ohio have used the state of Ohio Minimum Data Set Plus instrument to assess all residents in Medicaid-certified beds. Data are collected for each resident who is physically present in the facility on the last day of each quarter. The information collected in these quarterly assessments

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includes data on demographic characteristics and physical and mental functioning. The Ohio

Department of Human Services compiles data from all facilities in the state, generating a quarterly

database of between 80,000 and 82,000 assessments. When we compared five quarterly assessments

(June 1993, December 1993, June 1994, December 1994, and June 1995) we found that the Ohio

nursing home population profile was quite consistent over time with regard to racial composition,

age distribution, marital status, previous living arrangement, gender distribution by race, functional

(ADL total and continence), and behavioral (cognitive) characteristics. This consistency justified

our assumption that the profile at the end of each quarter represents accurately the nursing home

population on any other day during that or any other quarter. For our analysis, we selected the data

for September 1995, the most recent database available to us when we started this project. (See

Appendix A for the paper completed on the basis of this part of the project.) In connection with this

data set, we also used the 1992 Annual Survey of Long-Term Care Facilities conducted by the Ohio

Department of Health, and 1990 U.S. Census data for Ohio, to calculate nursing home utilization

rates by race.

<u>Data Analysis</u>

  <u>Focus groups and individual interviews</u>. We carried out text analysis of the transcriptions

of the verbal accounts collected through focus groups and interviews. We used the method of open

coding to first identify major themes, then to scrutinize themes for interconnections, consistency,

contradictions, and lastly to reveal patterns in beliefs and practices. Emerging concepts such as the

"culture of caring," "the limit of support," or "kin police/kin surveyors", for example, are grounded

in the data. (For a succinct description of this method of text analysis, see Lincoln & Guba, 1985.)

MDS+ data set. First, we compared five quarterly assessments (June 1993, December 1993, June 1994, December 1994, and June 1995) to ascertain whether the profile of Ohio's nursing home population was consistent over time. Second, we used the MDS+ data set to construct a profile of African American nursing home residents in terms of age, gender, living arrangement before institutionalization, payment source, physical impairment, cognitive and behavioral functioning, and social support. This profile provides a backdrop against which to evaluate our qualitative research findings. We also used the MDS+ data set in combination with the PASSPORT and ESP data sets mentioned above to calculate utilization rates by race.

CHAPTER 2

FINDINGS AND OUTCOMES FROM QUALITATIVE DATA SOURCES

Focus Groups

Perceptions of Filial Obligations Across Generations

Our findings about generational differences and similarities in the perceptions of filial obligations are primarily derived from focus group discussions with different age groups. Participants in all age groups considered nursing home placement as undesirable and to be avoided at all cost, and repeatedly referred to the nursing home as a "last resort." At the same time, each focus group had at least one participant whose family had placed one or more elders in a nursing home. While any discussion about nursing homes in general solicited negative comments, the discussion of specific cases inevitably ended with conciliatory statements to the effect that "under the circumstances," a nursing home was not only acceptable but actually the best place. Participants had no difficulty reconciling these two apparently contradictory points of view. In fact, these two points of view are not at all contradictory when one differentiates between the nursing home as an abstraction which embodies the polar opposite of home as an abstraction, and as a concrete place where people live, adjust, and may actually find possibilities for satisfaction (Groger, 1995).

All age groups expressed a strong commitment to filial obligations, although this expression varied in fervor, passion, and recognition of constraints. This variation was clearly related to cohort differences and the speakers' own experiences as caregivers or care recipients. Students were most demanding in their expression of filial expectations. They insisted that "out of respect," elders should be taken care of by family members, regardless of the quality of the relationship and the

emotional and financial cost. Although they acknowledged that their ideal might not always be achievable, they could not fully grasp the power of constraints and limitations on family members' ability to provide care. At the same time, many of them had observed their parents in sustained, arduous caregiving activities, which however seemed to have inspired rather than dispirited them. The youngest among them declared that they would be willing to give up their careers to care for their parents. Putting a person into a nursing home ranked highest among the negative examples of what one should not do, followed by limiting one's visits to days when the elders received their Social Security check.

Clearly, students' expectations exceeded by far the expectations expressed by elders themselves. **Elders** were much more measured in their expectations: they tended to ask more for ephemeral, non-instrumental, affective things like not being ignored; being looked after, visited or called. The following quotes from elders attending an urban senior center illustrate the measured nature of their expectations: "I would like for them to come and visit me and sit down and talk with me and tell me how much they love me." "Once in a while call and see how you are. That means a lot." This is how clients at an adult day care center expressed their expectations: "I think they should make the older people feel wanted. Make them feel as if they are needed." "...show them that you love them, give them a hug, give them a pat and let them know that they're somebody." Elders stressed their need for independence and described their efforts to maintain this independence. They valued their children's help but at the same time were anxious not to be a burden. They insisted that their children cared for them because they loved them, because they, the parents, had done so much for their children. At the same time, they recognized that what their children could do for them was limited by competing demands, and they were anxious not to push beyond that limit:

"Well, I would say, if they're able, take care of them as long as they can because the time is coming when you can't." Nursing home residents expressed the most modest expectations. They seemed unable to consider the conditional / hypothetical nature of the question about what people **should** do for their elders; instead they mentioned the "little things" people were doing for them.

Like students, **young adults** too rejected the idea of the nursing home and described their families' extraordinary efforts to avoid it. But their discussions also pointed to the fact that family dynamics play an important role in what happens. Listen to C, a young adult male, who described how his family dealt with his grandmother:

> The reason why we had to place my grandma in a facility was after four years of talking to her and convincing her that that was the best thing because we had tried to have [nursing] care in the home, but she always found one reason or another why they weren't sufficient. So we had to eventually put her into a nursing home. Ideally I would love for her to be at my home so that there would be someone closer who could deal with her on a daily basis.

Listen also to K, another young adult male, who is incredulous at the idea that his mother might want to go to a nursing home "when the time comes:"

> My mother's mother who passed away a couple of years ago wanted to go to a nursing home. I was two layers removed from that, of course, but I didn't understand that. And I talked about it with my mother. She said that, at that point in time, that is something that SHE might want to do. I'm like, Whoa! I don't understand why they would WANT to go. So that's another whole issue. My grandmother wanted to go. She said it'd be easier for her. I mean, our family was close enough to the home, but she felt more comfortable going in, than us pushing her.

The implication here is that K's grandmother chose the right moment for supplanting kin care with nursing home care, and by doing so, she spared herself and her family the indignity experienced by C's grandmother and family. Others in the group commented that they understood how elders might not want to be a burden on their families. The consensus of the group on this issue was more about

control and autonomy than it was about nursing homes; it was not about whether or not one should go there, but how one should go about going there.

The discourse of **middle-aged adults**, many of whom are experiencing the strains of caregiving, was marked by the conflict between what is desirable and what is possible. This group described both the family's struggle to provide care, and the difficulty of relinquishing care. This is the generation in the middle, subject to demands from their own children as well as their elders. Cohabitation—either moving in with the elder or having the elder move in with them—was one way of satisfying the multiple demands. Such a move emerged as a process rather than an event, which begins with the elder moving closer or to a smaller apartment before actually joining a child's household. During this period, families weigh the costs and benefits of a move, which gives all parties concerned an opportunity to preadjust to the new living arrangement. Participants talked about the family's moral obligation to take in elders, and stressed that even severely diminished elders can still contribute in small ways. They also talked about the ensuing struggle to step up care for elders whose health and functional status are declining. It is during this period of accelerated decline that caregivers begin to consider other options—at first in-home services, and eventually nursing home placement, "the last resort." Statements like "we finally had to give her to a nursing facility" and "giving the responsibility to someone other than family was very difficult for us" attest to the struggle middle-aged caregivers go through before relinquishing family care.

Themes Generated by Focus Groups

Although the major purpose of the focus groups was to explore cross-generational commitments to filial obligation, these discussions yielded a number of other related themes that shed light on African Americans' preferences and choices for long-term care.

Constraints on kin care. We identified three categories of constraints that limited the amount or kind of care family members could provide.

Caregiver factors included caregivers' illnesses or own health problems; conflicting demands resulting from having to care for more than one elder, for providing child care, and from work-related demands. They also included caregivers' problems in a variety of domains, including economic stress, and "selfishness" or the unwillingness to provide care because doing so would interfere with one's life style.

Care recipient factors participants mentioned were lack of gratitude, conflict created by the elder, meanness, lack of consideration, criticism of the caregiver, excessive needs and demands, and eccentric behaviors.

Circumstances participants identified as interfering with proper caregiving included geographic distance, lack of financial resources, considerable medical expenses, and a variety of individual situations. Participants distinguished between *constraints with and without a solution*, a distinction which cut across the above categories. The only constraints thought to be without a solution were care recipient factors. For all others, a solution could be found: geographic distance could be overcome by a move; excessive demands on caregivers could be overcome by calling in back-up help, and lack of money was dealt with by pooling resources.

Limit of informal support. This concept is closely related to the effect of constraints discussed above and has to do with the maximum help available even after taking into consideration all innovative solutions to overcoming constraints. The limit was most often reached when care recipient factors such as eccentric behaviors or excessive demands could not be overcome.

Reasons for caring. We identified three major reasons for caring: (1) reciprocity either as payback for services rendered in the past, or as insurance for future adversity; (2) altruism; (3) self interest; plus a hybrid of the two which we called self-interested altruism.

Culture of caring. This concept, which emerged from the discussions, refers to deliberate efforts to teach children not only that taking care of elders is something one should do, but also to show them how to do it, either by example or through explicit instructions.

We explored some of these concepts more fully in individual interviews with elders in three different care settings.

Individual Interviews

By interviewing elders and their caregivers in three care settings, we covered the continuum of long-term care. Elders in the three settings differed in age, number of children, diagnoses of dementia and strokes, and functional status. These differences are summarized in Table 3.

Table 3: Characteristics of Care Recipients

Characteristics of Care Recipients	Kincare N=12	In-Home N=17	NH Res N=23
Average age	70.5	78.6	80.6
Age range	61-81	66-93	61-96
Childless elders	0	6 (35.3%)	6 (26.1%)
Elders with children nearby	12 (100%)	7 (41.2%)	13 (56.5%)
Average number of children	3.7	1.8	2.1
Elders with stroke(s)	1 (8.3%)	2 (11.8%)	6 (26.1%)
Elders with dementia	1 (8.3%)	0	7 (30.4%)
ADL-independent elders	11 (91.6%)	7 (41.2%)	3 (13.0%)
Elders w/2+ ADL limitations	1 (8.3%)	6 (35.3%)	15 (65.2%)
Elders w/3+ ADL limitations	1 (8.3%)	3 (17.6%)	11 (47.8%)
Elders w/3+ IADL limitations	4 (33.3%)	16 (94.1%)	N.A.

Kincare Recipients: Preferences and Perceived Choices for Long-Term Care

Elders receiving kin care only are younger, have more children, are less likely to suffer from dementia or strokes, and are much more likely to be ADL-independent than care recipients in the other two care settings. They have relatively moderate but widely varying needs for assistance. In some cases, elders received and accepted assistance for tasks such as cooking or grooming they could have done themselves but that the caregiver provided anyway as part of showing concern and affection through ongoing exchanges. This has important methodological and conceptual implications for the measurement of impairment in that receiving help with certain tasks does not automatically signal inability to carry out those tasks. Thus, the statement that 91.6% of elders receiving kincare only were ADL-independent masks the amount of informal help they receive at least intermittently for activities of daily living.

Range of giving Tasks

We identified five kinds of tasks elders in this setting received from their kin caregivers: (1) home repairs, yard work, and occasional transportation; (2) shopping, homemaking, cooking; (3) occasional and intermittent personal care; (4) daily checking, either by phone or in person, with some caregivers visiting daily; and (5) financial help, either in the form of cash, or in-kind items like clothing, food, or trips. There emerged a sexual division of care tasks, with sons doing house and yard chores, and daughters being involved with homemaking, cooking, and personal care. Sons and daughters were equally involved with daily checking and with financial help.

Reasons for Caring

Love and respect were the reasons most often mentioned by care recipients when asked why their caregivers did all the things they did. For example, when asked why her son takes care of her,

Mrs. E replies without hesitations: "Because he loves me. I know that. And I love him." In a separate interview, her son corroborates her statement:

> Basically 'cause I love her. My mom's always been there for me. You know, she's...she's the only constant, permanent thing that I've ever had in my life. So, you know, that's...I don't know how else to explain that.

Others were more explicit in their recognition of parents' sacrifices for their children. Talking about her only child, Mrs. I explained:

> I think, number one, love. He will say, "I love my mom." That's the first thing. Number two, he knows that I love him and he loves me. But sometimes I think he's thinking, "All the things that my Mama did for me. And maybe she neglected herself."

Implied in this statement, and quite openly expressed in others, is the notion of a moral obligation of children to repay their parents for the hardships they endured in raising their children.

Childhood discipline. Some elders attribute their children's willingness to care for them to the fact that they raised them properly, that they loved them well, and that they taught them what was right and wrong:

> I think it's because of the love I gave them when they was coming up. See? My children knew that they was loved, because they never was called a bad name. They never was hit all over here. They never was abused. But they also knew the rules of the house. And they know that I did not want nothing to come in contact with them that was gonna make them look bad or make me look bad.

The following statement expresses similar feelings:

> I raised my children right. If they don't do what I say, I had my switches and whupped them. And they said, tell me all the time, say, "Ma, I'm glad you whupped us and made us mind." My children ain't been in jail.

One caregiver explained that she was "laying a pattern, so when I get old, my kids will do it [take care of me]."

Need and protection. Some caregivers are motivated by more mixed feelings than love and respect. Mrs. S, primary albeit reluctant caregiver of her 79-year old mother who has Alzheimer's and is getting progressively worse, says that she finds her caregiving "a very difficult, unwelcome chore" and that she is "holding the bag because there is nobody else." She was abandoned by her mother as an infant, lived with her mother from age 11 to 18 without, however, developing either respect for or attachment to her mother. Yet this is what she does for her mother: She checks on her by phone several times during the day; she runs by in the evening and does all sorts of chores for her, ranging from financial matters to shopping for groceries, preparing food, taking her out for trips to stores, medical visits, visits with friends; she does laundry for her mother occasionally, and occasionally she provides personal care such as shampooing before a special event. She has taken care of her mother for three years, and to do so, she gave up two part-time jobs which she had taken on to save money for a house. She is angry because she gets no help and only criticism from her siblings. She is also angry when she thinks about the first eleven years of her life. So why does she do all this for a person for whom she admittedly has no feelings? She does it

> because she's still Mamma. She's still a human being. She's still Mom. She's still helpless. I'm still not going to turn her loose for the other ones to victimize her, because that's what they would do.

Mutual assistance. Elders are not just the recipients of care and assistance but are actively involved in being of service to their children: they babysit or have grandchildren for several weeks in the summer; they provide support and advice to a daughter who has a troubled teenager; they pool their resources with those of their children's to acquire housing which the children would otherwise not be able to afford; they provide emotional support by "always being there;" and occasionally, they provide financial assistance, as witnessed by Mrs. E's son, who is still in school, and who said, "I believe one of the reasons she still works is to help me."

Children as a Drain or as no Help at All

In a few situations, children who were identified as the caregiver, actually took more than they gave, or gave very little. Mrs. E's son, wife and teenage boy moved back from the Western U.S. to Ohio and into his parents' house, allegedly to help his parents. The parents found this situation more stressful than helpful because their grandson, with whom they had developed no relationship, was difficult, and they felt crowded in their own house. Eventually, the son and his family moved out. But not all elders are able to rid themselves of potentially exploitative, or to mobilize unwilling, "caregivers," as the following examples illustrate:

Mrs. B has two of her grandsons living with her. Her "caregiver," the boys' mother, speaks about this situation as though the boys are helping Mrs. B by being with her, but Mrs. B clearly assesses the situation differently when she reports that "I help too much." She works part-time as a cook in a senior center, and also helps her daughter financially.

Mr. McK had a stroke in 1995. After three days in hospital and eight weeks of having the services of a visiting nurse "it's been a downhill, uphill struggle." He takes the bus to buy groceries, but is finding it increasingly difficult to board the bus. His informal support is so slim that he has many unmet needs. He has minimal contact with a son and a daughter who live in Alabama ("very seldom I call them"), and he has to beg his daughter who lives nearby to come and do his laundry: "I'm really tired of asking. I ask her all the time. I have to start two weekends in advance to get her come get my clothes." He says he needs help with bathing, putting on his socks (he copes with this problem by not taking off his socks until the next bath), and he asks folks at the senior center to help him dress "like when my collar need turning down, or shirt fastened up." He also needs help with cooking and cleaning. When he was young, he helped the elders in his family in any way he could,

and he tried to teach his own children to be nice to old folks, but somehow he was not able to inculcate these values into his children.

Many participants also described, often in vivid terms, a community context in which caring and looking out for elders was inculcated into children. Everybody knew everybody, and community adults were not only authorized but expected to discipline misbehaving children, to show them proper behaviors, and to teach them to respect elders and help them with whatever they might need.

Strength in Large Families

Several kincare recipients had large families with 10 to 12 children as potential caregivers. These families felt they had enough people to pull together to do whatever needed to be done, a sentiment which was expressed by care recipients and caregivers alike:

> Well, I don't know who I can say do the most, you know. I don't know which one I can say do the most. They all pitch in, especially if they are needed. If I'm sick or something, and I don't feel like doin' my chores and things, they get together and do it.

> I have a sister that works over at [the hospital]. If I'm not there, she always pick [mother] up. Or my sister that works over at EPA, she can pick her up. So it kind of works out fine where if I can't, she always can call somebody. So it works out pretty good.

Another caregiver, who no longer has her mother living with her, continues to participate in caregiving if she is needed. "We all pitch in. It's twelve of us. And we all pitch in." Such large and committed families are able to respond to increasing needs for care and can more easily avoid the nursing home option.

<u>Preferences and Perceived Options for Long-Term Care</u>

When asked what would happen if they became unable to care for themselves, participants were equally divided in choosing one of three scenarios: expecting to be cared for by family; choosing a nursing home over burdening family; and considering nursing home placement with great ambivalence and as a last resort.

<u>Family care</u>. Elders and their caregivers who expressed a strong preference for family care did so at the absolute exclusion of other options, most notably nursing home placement. They agreed that their large family would provide care, and that a nursing home was not an option. Mrs. C, mother of eleven:

> 'Cause that's what it's all about. That's what the families are all about. 'Cause I tell them, I say, "Now, if something happened to me, and I get where I can't really see after myself," (I hope and pray that it don't, but it could), I say, "With all the kids that I've got, you all don't have no business putting me in no nursing home. No business." And it vexes me when I hear of a family, and it got a lots of children, and they won't see after their parents. Parents was there for them. Why can't you be there for your parents?

She reported that her children responded well to her aversion to nursing home care:

> They say, "Mama, you shouldn't, you shouldn't have to. You've got all of us, and we put all our heads together, what one can't do, it can be worked out. It can be worked out.

Two other elders, who have only one and two children, also expected to be cared for by family. Both totally rejected the nursing home option but have contingency plans for when they can no longer live alone. The woman intends to go live with her daughter if she becomes more disabled even though she admits that it would be difficult to live there because of life style differences. The man said that his sister always told him he could come to live with her in Texas, if needed. It was difficult to say how committed they are to their respective contingency plans should they ever be confronted with this choice. In the meantime, their minimal need for care enables them to perceive of several options for dealing with what they consider a remote and hypothetical event.

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Choosing a nursing home over burdening family. Four of the twelve kincare recipients insisted that they preferred a nursing home to living with their children, which they considered equivalent to being a burden. All four women had made their preferences clear to their children, although some of their children rejected or were ambivalent about their mothers' preference. Care recipients conceded that they might be willing to make interim compromises such as moving in with a child for a while, or persuading a child to accept some other kind of congregate living arrangement. Those who were most vehemently opposed to moving in with children or burdening them with responsibilities had experienced those burdens themselves and recalled them vividly. Their stories revealed striking differences in values and behaviors regarding the care they gave to their own parents, and expectations they have for receiving care from their children. Women who had previously provided round-the-clock care to family members did not expect the same from their children because they wanted to spare them the burden they had experienced. Expectations were also related to the number of children available to provide care. Mrs. I said she told her son that if ever she could not take care of herself, she wants him to put her in a nursing home

> because he's an only child, and I saw how it burdened me with my mother, and I don't want that to be on him. And he doesn't see it that way. But I do. You know, I loved my mother and everything, but it was a burden. You know. It was a burden. And I would do it over if I had to do it again. I would do the same thing for her. But it was a burden.

Similarly, Mrs. M declared:

> I want to go to a nursing home 'cause I know how hard to care is. I've already thought about it. So I myself, if I had a voice, I would say, "Put me in a nursing home, or in a care home, you know, with someone that's trained to take care of me, because it's hard work."

Or listen to Mrs. E:

> I don't want to be a burden on anybody. And I definitely wouldn't want to go stay with my son or daughter because I've been through that situation [with my mother living with me.] And I wouldn't want to... and I've seen it happen to other people. It's, it would be a hindrance with the man and the wife. And I really don't think they need anything like that. And I had

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told my son, if I get where I can't take care of myself, I'm willing to go into a nursing home, but come and see me.

Like Mrs. E, the other participants who preferred nursing home care to burdening their family stressed the importance of continued family involvement should they ever have to go to a nursing home. Such family involvement was considered to serve two important purposes: to provide love and assure the elder of not having been abandoned, and to watch over the care elders receive, a theme which was salient in interviews with nursing home residents and their caregivers, and which led us to identify such family advocates as "kin surveyors" or "kin police."

Participants who said they preferred going to a nursing home clearly recognized the appropriateness of this option under certain circumstances and they acknowledged the limits of kin care. They conceded that there were good nursing homes with good staff; and they saw nursing home care as an opportunity for a division of labor between families and staff:

> And another thing about the rest homes, most people don't realize that rest homes are for you and your condition. But it's not for love. [The staff] don't have that time. The people that work in the rest home, they are there to minister to your needs. But your love have to come from your family. So they supposed to come see you. They supposed to give you your love and your attention. And that's what this all about.

Ambivalence about the nursing home option. In four stories, care recipients or caregivers talked about the nursing home option as a possibility but stressed that they would resort to this only if absolutely no other options existed. The following statement reveals the ambivalence with which a care recipient considers this option:

> Playfully I have told my children, "If I get sick and I need help, don't fight over who's gonna stay with me. Put me in a rest home." But that was just said in fun. I don't know whether I really feel that way or not. But I think nobody really, no older person really want to be a burden to their children.

Mrs. S, the reluctant caregiver discussed above, feels that a nursing home is the only place where her mother would be completely safe. She has visited a number of nursing homes,

interviewed staff, and chosen two facilities, where her mother is on a waiting list. But her mother refuses to sign the papers; her sister disapproves of putting mother into a nursing home (presumably because that would end her being able to prey on her mother); and her aunt accuses her of taking revenge on her mother for having abandoned her as an infant. In spite of the bad family relations, Mrs. S cares about what the members of her family think. She herself is torn about the decision to place her mother in a nursing home: she has already turned down one opportunity, and she thinks that when the next bed becomes available, she may well turn it down again. In the meantime, she lives the nightmare of imagining what might happen to her mother.

In-Home Services as an Option

Participants almost never mentioned formal services spontaneously as a possibility. They appeared to lack knowledge and harbor misconceptions about formal services. When prompted to tell what they knew about in-home services, a majority of participants said they had heard about meals-on-wheels or homemaker services, and all but one thought that having someone come into their home would be good. But it was clear that they tended to view long-term care as being provided by either families or nursing homes. The only care recipient who mentioned in-home services without being prompted clearly considered them as a temporary arrangement between kincare and nursing home care.

<div align="center">In-Home Services Clients: Realization of Vulnerability</div>

Most in-home services clients we interviewed did not learn about services until they were in a crisis that brought them in contact with the service system. They often talked about the social worker or case manager who arranged for their services as their guardian angel, as the person who saved them, as a gift from God. Although they depended heavily on and appreciated greatly the

services they were receiving, they remained generally vague and unclear about how the service system worked. We interviewed elders receiving services from PASSPORT and ESP, two major in-home services agencies. **PASSPORT** (Pre-Admission Screening System Providing Options and Resources Today) is a state-wide 2176 Medicaid waiver program with the following minimal financial and functional requirement: Clients must be eligible for Medicaid, and they must need hands-on assistance with at least one of the following: 2 ADLs, 1 IADL + medication, skilled nursing or skilled rehabilitation at less than skilled care level; or 24-hour supervision to prevent harm due to a cognitive impairment. **ESP** (Elderly Services Program) is a county-wide levy-funded home care program for persons age 60 and over needing help with an unspecified number of ADLs and/or IADLs. Unlike PASSPORT, ESP has no minimal financial or functional requirements, and offers services for copayments of fees on a sliding scale.

Profile of In-Home Services Recipients

With an average age of 78.6 years, in-home service recipients were eight years older than kincare recipients and only two years younger than nursing home residents. One of the two stroke victims in this care setting could remain at home only because her husband took care of her in addition to the formal services they received. As summarized in Table 3 above, the large majority (94.1%) needed help with IADLs. None of them suffered from dementia; seven were ADL-independent; six needed help with two or more ADLs, and only three needed help with three or more ADLs.

A total of six types of services were available to these clients. They included homemaker services, meals-on-wheels, transportation, visiting nurse, personal care, and the provision of equipment such as special chairs, wheel chairs, portable commodes, or bathing benches. The most

frequently used formal services were homemaker or chore services, with 15 or 88.2% of clients receiving such services; 8 (47%) received personal care; and 5 (29%) had received equipment from the home care agency. Two clients (11.8%) received meal-on-wheels service, and 4 (23.5%) each received transportation and visiting nurse services. Ten (58.8%) received one or two services; 4 (23.5%) received three services; 2 (11.8%) received four services; one client received five services; and none received all six services.

Relationship between formal services and informal support

The two major themes that emerged from the interviews with recipients of formal services had to do with the availability or lack of informal support, and with a great concern not to expect too much of informal caregivers. Participants varied widely in their informal support. Mrs. A is at one end of the spectrum. During the interview with her, which lasted one hour and fifteen minutes, she received six visitors: the person who cuts her grass, the deliverer of Meals-on-Wheels, her nephew who is her primary caregiver, one of two male neighbors who look after her, one of the neighbor "girls" who check on her, and her PASSPORT aide. There is also Mrs. W who receives a lot of informal help from all four of her children, from grandchildren, and friends. PASSPORT fills in for what children might not be able to do in a sustained manner. Now the timing of children and grandchildren's visits is somewhat unpredictable whereas the PASSPORT aide comes at predictable times. This in turn assures the children that their mother is being taken care of, and it allows them the freedom to choose times for visiting that are convenient for them. For those who have adequate access to informal care, formal services and informal support enhance each other's effectiveness. In some cases, the formal services elders were receiving would not have sufficed if they had not been supplemented by kincare, and kincare efforts alone would not have sufficed to keep elders at home.

At the other end of the spectrum are elders whose support has "thinned out" as it has for Mr. W, who has always had thin support, or for Mr. B who outlived his wife against his expectations, and whose only kin are a stepson and siblings residing out of state. For elders like them, formal services are indispensable in allowing them to remain at home; their only alternative would be nursing home placement.

Regardless of the amount of informal support elders received, they expressed fear of imposing on their actual or potential informal helpers. They bridled their expectations because they wanted to be sure not to demand too much. They also stated that kin and friends should help, but that they should do so without having to be asked. On the whole, participants were anxious to maintain a delicate balance between needing help but not wanting to ask for it; between asking for help but not overdoing it; and between being self-sufficient and not endangering their well-being by trying to do too much.

Reliance on informal vs. formal help also affects elders' perception of themselves as either dependent or independent. Some elders referred to formal services as having given them independence because they were no longer dependent on their children, indicating that it is easier to accept services from strangers who get paid for what they do.

Reaction to Services

Clients' reaction to services ranged from superlative praise to moderate satisfaction, with the majority considering their services indispensable. Most had found it easy to accept services after returning home from hospital stays, and they continued to find them indispensable even after their condition improved. Some clients, who had no informal help, found services indispensable; others found them a most satisfactory complement to kincare because formal services kept them from

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having to make excessive demands on their informal caregivers, a concern expressed by most clients who had a good informal support system. Some clients credited the formal services with having kept them alive. The following statements summarize clients' reactions to services:

> Oh, you couldn't ask for nothin' better. To me, PASSPORT is one of the most wonderful things that I ever heard. It can't be beat. And I tell them all the time, they so good to me."

> I love it, I do. They're all very nice. I mean, they all just took me on. And I took to them. It was a help for me. I don't know that I'd be living very long [without the service]. I didn't have to worry about [cleaning the house] and I didn't have to worry about my niece and nephew coming and doing for me all the time.

> I believe that this is about the best set-up that anyone actually want. I think these services has prolonged my life because I'm more disciplined, see. And I know my medicines. And I know about all the reactions and everything of medicines.

Only one participant said she found it difficult to accept services. She tries to do as much of the work as possible before the homemaker arrives, yet she admitted that the services have made her life easier. Even the few clients who mentioned problems like staff turnover or imperfectly matched aides said they were grateful for the help.

Attitudes Towards Nursing Homes

Being older and frailer than elders who received kincare only, the recipients of formal services expressed a keener sense of their vulnerability. For them, the consideration of nursing home placement is less hypothetical and more real than it was for their younger and less frail counterparts in kincare settings. They have a clearer idea about the limits of informal support -- either because theirs is slim or non-existent, or because they do not want to become burdensome to their children.

They also know the limits and fear the tenuousness of formal services which might disappear because of cuts in funding, or which might become insufficient because of increasing needs for care.

All expressed a desire to stay at home as long as possible; some expressed a preference for assisted living or other congregate arrangements rather than a nursing home; and most struggled to do as much as possible to prevent further deterioration and thus delay the day when nursing home placement would be the only acceptable option or the most appropriate choice.

Participants' attitudes toward nursing home placement were shaped by a number of factors, and most participants expressed more than one reason for their feelings. Those elders who had positive personal experiences with nursing homes were more willing than all others to consider this as an option for themselves. For example, Mr. J and his wife were temporarily in a nursing home which they describe as "really, really nice quality." They had no complaints and liked being there because people waited on them. While they have not considered a nursing home as a permanent option for themselves, they thought they'd be welcome because they would not cause the staff too much trouble, implying that appropriate behavior by residents elicits proper treatment in a nursing home. For Mrs. L, nursing home care is a reality. Her mother and aunt are in one now, and she reported that her mother's functioning improved after she had moved into the nursing home. Mrs. C took care of her husband as long as she could, but then

> He got to where he couldn't walk or anything. He couldn't take care of hisself at all... It was too hard. Finally I had to give in, and I went [to the nursing home] every day, long as he lived. I felt better.

She felt better because she was relieved of the burden of taking care of him at home, but also because she continued to look after his well-being in the nursing home. Contemplating her own future care needs, she does not rule out going to a nursing home:

> Well, I've said a lot of times, I may have to go to a nursing home at any time. 'Cause when you get the shape like I got where I couldn't help myself completely, I don't think they could apply somebody to come in and take care of me because I would be too heavy for a woman to handle. So I know I would have to go in if I lost the use of myself. I know I would. There couldn't be any other way.

Elders whose knowledge of nursing homes was based solely on hearsay and negative media images had the hardest time considering this as an option for themselves. Listen to Mr. W:

> I'd be a stubborn old man to keep from goin' there. To keep from goin' to a nursing home. Because it's not that all of 'em are bad, but the stories that come out o' those nursing homes, there's no way in the world I would wanna go to one. But might come a day that I'll have to if I live that long. I got doubts, I got doubts as to whether I'll live that long or not.

Mr. W seems to be saying that he hopes not to live long enough for this contingency to occur, although he is not quite as explicit as Mr. R who said:

> No. I think I'd just rather go on to the happy hunting grounds. I mean, rather than go into one o' them homes.

His negative opinion is also shaped by hearsay. He says he has lots of friends who had to go and get their father back out of a nursing because they could not stand it. Since he has no kin who could get him out or look after him in a nursing home, he does not consider this as an option for him at all.

Like kin care recipients, some recipients of in-home services stated more or less ambivalently that they preferred nursing home care over kin care because they did not want to be a burden. Sometimes it was the kin caregivers who opposed this idea. Mrs. E told her granddaughter that "when I get to the place I can't make it, I'll go in the nursing home," to which the granddaughter

replied that she would not allow this to happen but instead have her grandmother move in with her. Mrs. E: "No, I would never live with any of you all." Granddaughter: "That's perfectly all right, then I'll move in with you," to which Mrs. E added laughingly, "And she would too. She's that kind." This reported exchange illustrates both the caregiver's and the care recipient's ambivalence and the complexity of family dynamics in the context of which decisions about long-term care are made. Mrs. E does not want to be a burden but seems pleased that her granddaughter "is that kind" (of caring person who would not let her go into a nursing home). Her granddaughter clearly sees nursing home placement as a metaphor for despicable failure to meet kin obligations. Furthermore, we cannot be sure how sincere Mrs. E's statement is because she is not at this moment in time confronted with having to make the decision.

Mrs. I's utterance conveys more clearly the uncertainty and ambivalence surrounding this question. She says she would go to a nursing home, but only reluctantly:

> I guess you have to push me. I don't know. I really don't know... I think you have to pull me, pull me in there, hahaha... if it becomes necessary... I wouldn't wanna mess up their lives, and things like that. And then I would have to go in a nursing home. But I'm goin' to pick my nursing home. I wouldn't want 'em to throw me into any ol' thing, you see.

She actually visited a nursing home with her grandson to inspect it: "It was nice, it was nice. Well, I wasn't quite ready for it." She and her son are in agreement about this option. He solicits his mother's participation in the process of planning for a crisis and has paved the way toward his mother's acceptance. For him, it is just a matter of time.

The complexity of kin relations and family dynamics is also conveyed by Mrs. B and her caregiver. Mrs. B is certain that she would have to go to a nursing home if for some reason she lost her in-home services.

Not that I would like to go to a nursing home. But if I get a burden on 'em, they'll stick me in there.

Her niece, who is her primary caregiver, replied with an emphatic "No" to the question whether she would consider nursing home placement for her aunt. But after some reflection she sounded less sure:

...unless she needs more care than I can give her. Like if she needs more care, like medicine, medications, and other stuff like that... 24-hour nursing.

Most participants made similar allusions to the limits of care and conceded that there might come a time when they found themselves "in that place" where nursing home placement is the only viable option or the last resort. What exactly they meant by that included "losing the use of oneself," "being completely helpless," being cognitively incompetent, or being bowel incontinent. Such limits of care were more often mentioned by elders contemplating their options than by caregivers when asked whether there were any tasks they thought they could not bring themselves to perform. For example, Mrs. M said that if she were to become bowel incontinent she would prefer to go to a nursing home. She took care of her bowel-incontinent grandmother and is glad that she did, but would prefer to go to a nursing home.

I don't want to do that to them because I don't feel like they deserve that. 'Cause I feel like they have a life of they own. And I don't think I should be the one to take it away from them.

For elders receiving in-home services as a group, the possibility of nursing home placement was much more real than it was for the younger, less frail kincare clients. All would prefer to stay at home "as long as possible," conceding that there might be a time when it will no longer be possible. The overwhelming desire of not wanting to burden their children with excessive needs for

care has led many to contemplate nursing home placement as an option. They may not embrace this option enthusiastically but they see it as appropriate "when that time comes" or when they "get to a certain place."

The Last Resort: Move to a Nursing Home

Cultural preferences notwithstanding, the nursing home residents in our study had reached "that place" where their needs exceeded the capacity of kin care and/or in-home services. In contrast to kin care recipients and in-home clients in our study, nursing home residents' realistic choices had narrowed to a point where preferences had become irrelevant or inoperable. Although nursing home residents as a group were older, more impaired, and had thinner informal support than elders in the other two care settings, and in that sense resembled each other, they differed in their reasons and pathways for reaching "that place" and in their reaction to living in a nursing home. Initially, most residents we interviewed did not like being where they were, but eventually they accepted and adapted to institutional living and conceded that under the circumstances, this was the best possible place for them to be.

Trajectories to Nursing Homes

We identified **five types of trajectories** to the nursing home which were the result of different precipitating health events.

Catastrophic event. Four nursing home residents were in this category. Typically, the elder suffered a serious stroke, was taken to the hospital, from there went to a rehabilitation center or a nursing home, where efforts for rehabilitation may or may not have been continued. This happened regardless of whether the elder had children or other caregivers who could have provided help. The

occurrence of the stroke required such rapid response that there was no time to test the limit of informal support because the effect of the stroke by far exceeded the capabilities of informal support. Nor did time permit the research required for a careful and deliberate choice of a facility. Sometimes family members sought transfer to another facility later if they were not satisfied with the home to which the elder was admitted. Typically, reaction to this precipitating health event was shock, surprise, and a sense of helplessness.

Dementia. The typical trajectory of the five nursing home residents afflicted with dementia followed a different path: During the early stage of the illness, the elder lived alone, with support from kin. Both the elder and the caregiver struggled to manage the illness and maintain the living arrangement status quo by a number of strategies, including denial. When this became too difficult, the elder moved in with kin or had kin move in with them. Over time, the struggle to manage the disease and provide care became ever more arduous, with the caregiver finding it increasingly more challenging to juggle competing demands. Finally, an escalation of behavioral problems, usually total incontinence or violence, or both, forced the caregiver to acknowledge the limit of support and seek nursing home placement. In addition to the physical struggle of providing supervision and care, the caregiver also struggled with the moral aspects of the decision, wondering whether they were doing the right thing; whether they were abandoning their charge; whether they could have done anything else, anything at all to avoid "the nursing home thing."

Spouse's failing health. Four elders we interviewed were in this category. They followed one of two scenarios. In the first scenario, the wife becomes ill and can no longer carry out her regular household chores which her husband, though not otherwise impaired, is unable to do. The husband follows his wife to a nursing home because, as one husband explained, "I can eat but I can't cook."

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He has five daughters who took turns in looking after him, but his demands for twice-daily trips to the nursing home to see his wife were too time consuming and labor intensive even for five daughters taking turns. He moved into the assisted living section of the nursing home to be close to his wife who lives in the dementia wing and whom he now can visit several times a day. In the second scenario, a wife cares for her ailing husband over a number of years during which her own health fails. During one of her own health crises, she is admitted to a hospital. Because they have no children or other kin who could look after the husband, he joins his wife in the nursing home.

Slow physical decline. Six nursing home residents experienced a slow physical decline during which they received kincare for between two and twenty years. We identified three scenarios that eventually led to a nursing home for one of the following reasons:

(1)   The elder decided to move to a nursing home rather than move in with a child and acted on this preference with the child's consent.

(2)   The caregiver became responsible for more than one care recipient, each with increasing demands, which eventually surpassed the limit of informal care.

(3)   There was no middle generation to care for the elder, a circumstance which delegated kin care either to an older person such as "the kids' other grandmother," an aged cousin or niece, or to grandchildren in their early child bearing years who were busy raising their young families.

Mental confusion / mystery cases. Three nursing home residents were very unclear on the timing of events that marked their trajectories of declining health. They were confused about what happened, when it happened, and why exactly they were in the nursing home. We carried out the

interviews anyway because we felt that in spite of the confusion about the sequence of events, these elders did have a story to tell.

Mrs. F has no children. She could not live with her sister because of crowding. She is ADL independent but, according to the MDS+ assessment of June 30, 1996, she suffers from mental confusion, depression, anxiety disorders, cataracts, and arthritis. Trying to recall how she came to be in the nursing home, she said: "I was in that state of mind that I didn't know exactly where I was, or what I was doin', and kinda depressed. And I don't know. I just felt like I was in the world all by myself."

Mr. C's diagnosis is diabetes, hypertension, dementia; he needs supervision with eating and grooming. His physical appearance belies these conditions: handsome, ambulatory, tall, slim, and apparently in great shape, he gave the impression of being an employee rather than a resident. Asked about how he came to live in the nursing home, he said: "When I woke up in here I said, 'well, better than some of the places I been.' And I like it here. I can walk around. They treat me nice." He has three daughters whom he has not seen in years and whose whereabouts he does not know; he has a brother who, he says, visits him and brings him things he needs.

Mrs. G's diagnosis is arthritis and dizziness. She needs assistance with all ADLs. She has a son nearby who visits regularly, and a daughter who travels 540 miles round-trip once a month to see her, and together her children apparently take good care of her. When her husband died, her son brought her from Alabama to live with him. Asked why she is in the nursing home, she replied: "I started hurting. I was feeling all funny. I just wanted to get away from where I was, or something. I don't know. But I got away from 'em. I didn't wanna be like I was."

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Interviews with a family member of these three residents could have shed light on the stories they tried to tell. We contacted Mr. C's brother and Mrs. G's children, but they did not respond to our invitation to participate in this project. (In Table 3, both are counted as dementia sufferers.)

Functions of the Nursing Home

From our interviews with nursing home residents and their caregivers, we identified four major functions a nursing home may fulfill.

Enhances delivery of kin care. For some residents and their kin caregivers, the nursing home became a "partner in caring" and allowed family members to actually step up their efforts to provide care. They could do this under favorable circumstances where they were not required to be present around the clock. In such cases, the need for 24-hour supervision had made it impossible to continue to care for the elder; it had exhausted them and led them to question the efficacy of their care efforts. Once the nursing home had assumed around-the-clock supervision, family members were able to provide a series of services, including personal care, feeding, and grooming, under most favorable conditions because they could do so at their convenience.

Caregivers and nursing home residents alike insisted that residents whose family members visit regularly receive better nursing home care than residents who have no regular visitors. Such visits were described as most effective if they occur frequently and at unpredictable times. The elaborate descriptions of this aspect of kincare in nursing homes suggests that family members function as a kind of kin police or kin surveyors who watch out for their elders' welfare, who demand accountability, and who make sure that shortcomings in care are corrected.

Provides security for care recipient and peace of mind for caregiver. Kin caregivers of dementia sufferers invariably mentioned this when asked how their lives had changed since their

elder was institutionalized. But others, too, stressed this effect: elders who felt insecure living alone appreciated not having to worry about this any more; and caregivers who had been concerned about their elder's safety could channel their energies into more productive endeavors such as relatively stress-free visits to the nursing home.

Re-establishes elders' sense of competence and well-being. This was expressed by elders who described the eventual defeat of their struggle to remain in their own home. In these cases, nursing home placement re-established the fit between elders' functional ability and environmental demands, which in turn enhanced their well-being.

Nursing home as a refuge from unsatisfactory kincare. The best intentions notwithstanding, sometimes family members cannot provide the care an elder thinks he or she needs. Fear of being left alone too often and for too long, fear of not being given the proper medication, and dissatisfaction with crowded living arrangements and the resulting noise and commotion, are some of the factors that may motivate an elder to seek nursing home placement rather than "to be mistreated."

Although nursing home placement may be the last resort for a family straining to provide care, or for elders to take care of themselves, African-American elders use it when they "get to that place" where earlier preferences are no longer relevant and where the choices have diminished. From this vantage point, nursing home placement often remains the only option which elders and their families can and do embrace as the right thing "under the circumstances."

The Culture of Caring

The large majority of caregivers and care recipients in all three settings reported having been taught or having observed the giving of care to family, or of being in a family where they had to become a caregiver at an early age. Persons referred to as having had the greatest influence were always females, most often mothers, grandmothers, or an aunt who had raised the interviewee. Some participants saw their aunts and uncles pull together resources to care for their parents, and they use this model in thinking about their own caregiving responsibilities. Like the following two statements, most of these descriptions of caregiving efforts were meant to be positive examples:

> Well, I remember when I was quite young, and my mother belonged to a missionary society from her church. And any time the ladies went somewhere to do something for someone that was sick, she would always take me along. She'd say, "Come on, Mary Elizabeth, I want you to see what's happening." And I went along, and I learned a lot about taking care of elderly people through her. Yes.

> I guess maybe [I learned that] by starting off early at home, fourteen or fifteen years old. Mama took sick where she couldn't do a lot of things. And we had to start doing those kinds of things real early in life.

However, some caregiving observations and experiences when one was "coming up" could also be criticized and offered as negative examples. Mrs. S, the reluctant caregiver described above, saw her grandmother, mother, and aunt sacrifice a great deal, maybe too much, in caring for parents, and by doing so, they renounced their own life goals and happiness.

For the most part, elders said they tried to pass this culture of caring on to their children, and for the most part, they succeeded. In those cases where children were less than satisfactory providers of help, there were indications that the relationship between elders and their children were problematic for whatever reason, and talking about this subject seemed painful to interviewees.

CHAPTER 3

FINDINGS & OUTCOMES FROM QUANTITATIVE DATA SOURCES:

CURRENT LONG-TERM-CARE USE PATTERNS

Nursing Home Utilization Rates By Race

Clearly, nursing home placement is part of the repertoire of preferences and choices of African-American elders, even though a large body of literature depicts them as being less likely than their white counterparts to use nursing homes. Although the question of nursing home utilization rates by race was not the main focus of our study, we felt it was relevant to examine whether the generally accepted statement about blacks being less likely than whites to use nursing homes also holds true for Ohio. Statements about minorities' "underutilization" of nursing homes are usually based on national or nationally representative data. Given the considerable state-by-state variations in the number of nursing home beds, availability of in-home services, Medicaid reimbursement practices, and minority populations, we believe that exploration of this issue at the state level might yield a clearer picture of racial differences in utilization rates. Using the **1992 Annual Survey of Long-Term Care Facilities** by the Ohio Department of Health in combination with **1990 U.S. Census** data for Ohio, we found that 6.6% of Ohio's minorities (the majority of whom are black), but only 5.7% of whites age 65 and over were in nursing homes. Thus, in Ohio black elders appear to be more likely than whites to use nursing homes**.** This finding which contradicts accepted wisdom may well be attributable to Ohio's generous supply of nursing home beds. With one Medicaid certified bed for every 17 persons 65 and older, Ohio ranks first nationwide in the supply among the ten states that have over one million persons 65 and older.

Since December 31, 1992 and quarterly thereafter, all Medicaid-certified nursing homes in Ohio have used the state of **Ohio Minimum Data Set Plus** instrument to assess all residents in Medicaid-certified beds. The Ohio Department of Human Services makes quarterly compilations of the data from all facilities in the state, generating a quarterly database of between 80,000 and 82,000 assessments. Of the total 96,836 licensed nursing home beds in Ohio in 1995, 85,348 or 88.1% are Medicaid-certified. Our examination of this data base indicates that African Americans occupying Ohio's Medicaid nursing home beds increased from 8,148 or 10.1% in June 1993, to 8,630 or 10.6% in June 1995.

When we compared five quarterly assessments (June 1993, December 1993, June 1994, December 1994, and June 1995), we found that the Ohio nursing home population profile was quite consistent over time and justified the assumption that the profile at the end of each quarter represents accurately the nursing home population on any other day during that or any other quarter. We selected the data for September 1995, the most recent database available to us when we started this project, to construct a profile of the African American population occupying Ohio's Medicaid nursing home beds and to use it in our comparison with in-home services clients. To see whether and to what extent the findings from our non-representative sample of participants mirrored wider use patterns of in-home services and nursing home care, we examined three data bases: the state-wide MDS+ data set describing nursing home residents; the state-wide PASSPORT data set describing Medicaid-eligible in-home services clients; and a sample of the county-wide ESP data base describing non-Medicaid eligible in-home services clients.

Nursing home residents rely heavily on Medicaid for their services: According to the MDS+ data set, 86.4% had Medicaid as their payment source; 6.1% were funded by Medicare, and 7.5%

paid either though private insurance or out of pocket. PASSPORT is a state-wide Medicaid waiver program. ESP is a county-wide levy-funded home care program for elders with ADL or IADL impairments who need not be Medicaid-eligible. Although 35% of ESP clients are enrolled in Medicaid and 81.7% are enrolled in Medicare, these programs may not pay for ESP services because they may not meet Medicaid and/or Medicare eligibility requirements. Of ESP clients, 10.8% pay at least some proportion out-of-pocket for the services they receive. Tables 4 and 5 summarize our comparison of African American elders in these three care settings.

Age. On average, in-home services clients are younger and more numerous in the younger age categories than nursing home residents. As shown in Table 4, elders age 65-84 comprise 38.3% of nursing home residents, 58.7% of PASSPORT clients, and 64.9% of ESP clients. Elders age 85 and over comprise 51% of nursing home residents, 41.3% of PASSPORT clients, and 35.1% of ESP clients. These age differences are also reflected in our non-representative study sample.

Gender. Although in all three care settings males are in the minority, they make up a larger proportion of nursing home residents: 31.2%, as compared to 18.3% served by PASSPORT and 27.5% served by ESP. The relatively large proportion of males in the African American nursing home population is a function of the health status of this subgroup of the population. Compared to the nursing home population as a whole, new nursing home admissions are typically younger, more likely to be married, more likely to be male, and more likely to be black (Applebaum, Mehdizadeh, Straker, & Pepe 1995). These differences reflect the high percentages of residents who use nursing homes as a transition from hospital to home.

Marital status. The considerable differences in marital status between the three groups is partly a function of income: married couples are less likely to meet the income requirement to be eligible for PASSPORT, hence only 5% of this group are married, compared to 18.3% of ESP clients for whom no minimum income requirement exists. Being widowed, divorced, or separated increases the risk of being poor and thus qualifying for Medicaid. Hence the overwhelming majority of PASSPORT clients with this status.

Living arrangement. Our qualitative interviews indicated that temporary cohabitation with children may be a part of a person's trajectory to the nursing home. Of African-American nursing home residents statewide, 62.1% had previously lived with others, compared to 23.2% of PASSPORT clients. Nearly three-quarters of PASSPORT clients lived alone, compared to only a little over half of the ESP clients. The differences between the two in-home services populations is probably due to measure differences, with 24.4% of ESP clients in the "other" category which could include living with an adult child. Also, ESP clients as a group may be better off economically than PASSPORT clients, and thus better able to afford a separate dwelling as well as services.

Activities of daily living (ADL). As shown in Table 5, ESP clients are considerably less impaired than elders in the other two categories. Only 30% of ESP clients need help with 3 or more ADLs, compared to 70.2% of PASSPORT clients and 86% of NH residents. This is the result of minimal functional requirements for PASSPORT, as described on p.34 above.

Not all activities of daily living impairments are equally disabling. Bathing, dressing, and transfer are interrelated; one must be able to both dress and transfer in order to bathe. On the other hand, eating is usually the last ADL skill to be lost.

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CHAPTER 4

DISCUSSION & IMPLICATIONS

The following section provides a summary of our findings on each of the broad research questions, and a discussion of their implications for service and practice.

Generational Differences in the Perception of Filial Obligations

The focus group portion of our study provides information which allows comparison of perceptions of filial obligations across generations. Our findings suggest that our youngest groups were the most vehement in their insistance on kin care and in their expressions of filial obligations. Older groups tended to temper their ideals of filial obligations with their observed or experienced realities of the demands of caregiving. Our care recipient groups showed the lowest level of filial expectations; they expected more in terms of interpersonal support rather than physical or instrumental assistance. Our findings suggest that if there are changes in the long-term care use patterns among African-Americans away from kin care and towards the use of formal services, these changes appear to be driven by a desire among older generations not to burden their younger family members. Both focus group participants and interviewees talked about the difficulties of juggling work and families with the demands of parent care. The pressures which are increasing African-Americans' reliance on formal services are the same ones affecting all older Americans: more women in the labor force, smaller family sizes, and geographic mobility of family members. Although many of our participants viewed nursing home placement negatively and only as an alternative of last resort, most could imagine a situation in which a nursing home might be the most appropriate setting for meeting an elder's need for care. Most of those who had already chosen the nursing home alternative felt positively about the decision and were able to recognize the advantages of this care

setting. The culture of caring, which emerged from our focus groups and interviews, is strong among African-American family members of all generations. However, the realities of caregiving often pose problems which cause families to seek formal support services.

Unfortunately, lack of information about in-home services as well as negative stereotypes and misconceptions about nursing homes prevent many families from making effective and efficient use of these services. Educational and supportive services for families could help them reconcile their often unrealistic filial expectations with the realities of caregiving. While all caregiving families could benefit from such education and support, it would be particularly beneficial for African Americans whose special history of prolonged and systematic oppression predisposed them to developing strong familial support systems and high levels of filial expectations. Our findings indicate the existence of a cultural lag between the ideals of filial obligation, or the culture of caring, and the material conditions which make it ever more difficult to attain the ideal. Expectations of filial responsiblity and values of kin obligations are far from flagging in this population. Rather, the values and expectations have failed to keep pace with the demographic and economic realities, causing a kind of cognitive dissonnance in those who embrace the ideal but cannot attain it. Instead of finding solace in what they can do, overwhelmed caregivers feel guilty and inadequate because they cannot do it all.

African Americans' Long-Term Care Preferences and Choices

African-Americans, like other older Americans, generally expressed a preference for obtaining care in their own homes, as long as this was a reasonable alternative. That is, their preferences were often tempered with realistic assessments about situations in which home care and/or family support would no longer be a feasible option. When care is needed, home care

services are generally preferred to nursing homes, which families use as a last resort. There is little to suggest that the provision of formal services results in a reduction of kin care. Instead, formal services allow families to refocus their efforts to where they are most effective, and to shift their support from certain instrumental tasks to the affective aspects of interpersonal support most desired by elders.

Participants who used formal in-home services generally viewed these arrangements positively and reported both family members' and care recipients' satisfaction. In several cases, where family members were unavailable or limited in their caregiving ability, services enabled elders to remain in their own home. In addition, some elders viewed formal services, including nursing home care, as a means to independence; that is, by relying on formal care providers, elders were able to avoid burdening family members. Thus, formal care services supplement and enhance the efficacy of kincare, provide support when kincare is limited, and allow elders to maintain independence.

If, as the literature asserts, African Americans as a group use home care services more than do whites, and out of proportion to their numbers in the population, it may be because they are more likely than whites to qualify for publicly funded services. That is, socio-economic status rather than race or culture may account for African Americans' seemingly disproportionate use of in-home services. Comparative statistics about racial differences in the use of formal services are limited to studies of publicly funded services. It is impossible to track the number of older Americans who pay individuals privately to assist them in their homes. Were these private arrangements included in the total picture of home care utilization, it is possible that African Americans would not be overrepresented. Our findings suggest that African Americans would prefer to provide kin care rather than call in "strangers" but are willing to do so when they reach the limit of informal support.

The greatest obstacle to obtaining services is lack of information about them. Most of those who received in-home services did not know about them until they came in contact with the service system, most often in a crisis situation.

<u>Constraints Affecting Choices</u>

Our participants clearly expressed an understanding of the limitations of informal support, both in terms of what and how much they could give, and what and how much they would accept. The constraints included eccentric behaviors or stressful relationships, a need for 24-hour care due to cognitive impairment, serious medical conditions, competing demands of work and children, and elders' desire not to burden families with certain types of intimate, physically difficult, and constant care. As a group, nursing home residents' needs had escalated to a point that exceeded their families' limits of support: they had more ADL impairments than those receiving home care; they were more likely to be incontinent, and also more likely to be cognitively impaired. All of these factors contributed to the decision in favor of nursing home placement. Some elders felt they were maintaining autonomy or decisional control by chosing the time to go into a nursing home. Decisions were also driven by families' and elders' anticipation of events they knew would call for nursing home placement. The time available for making an appropriate choice and exploring options was also an important constraint on the types of choices that were perceived to be available.

<u>Strengths and Weaknesses of Models of Care</u>

We explored three models of service delivery: kin care only, formal services often in conjunction with kin care, and nursing home care. Each model has strengths and weaknesses.

<u>Kin care only</u>. Of all care recipients, elders receiving kin care only were the least impaired. Typically, they also had more children than care recipients in the other two groups. Given their

better health status and their larger kin networks, most had not tested the limits of their families' support. The kin care model derives its strengths from love, gratitude, and respect—the sentiments it symbolizes and engenders simultaneously; teamwork among siblings in some families; children's happiness about being able to repay what parents did for them in the past; and elders' deep satisfaction with their success in having raised "good children" who take care of their needs.

However, need for care can rarely transform a weak relationship into a strong one, nor an uncaring family into a caring one. Siblings may be unable to agree on what is appropriate care for their parent; children may be unwilling or unable to provide more than minimal assistance; and historically weak relationships may be further weakened by the stress of caregiving. Such brittle kin support systems may be unreliable in their delivery of care and they may place vulnerable elders in danger of victimization. In-home services could ease the burden of kin caregivers and alleviate some of the tensions in less-than-perfect kin care situations if there were more effective information and dissemination pathways leading potential beneficiaries to these services.

Accepted wisdom, which depicts African American elders as relying heavily on the kin care only model, fails to acknowledge that kin care may leave some elders vulnerable, stressed, struggling against great odds, and unable to manage. Caregivers too may be vulnerable—to estrangement from siblings, to an inability or delay in making economic provisions for their own futures, and to feelings of stress and burden.

Formal In-Home Services. The strengths of in-home services were expressed repeatedly in our interviews. For childless elders, for those without children nearby, and for those whose families were unavailable or uninvolved, in-home services made the difference that allowed them to maintain their independence. In-home services allowed those with strong family supports to limit what they

expected from family and to avoid the feeling of being a burden. Most of our interviewees found their services indispensable. Because most of them had begun to receive services after a health crisis, they were more aware of their vulnerability. They were also more willing to acknowledge that at some point they might have to move to a more supportive setting such as a nursing home. For the time being, in-home services allowed them to postpone that event.

The weakness of home care services has to do with management problems. Frequent worker turnover, unreliability, or mismatches in personality caused some care recipients to express concerns about their services. Some clients of ESP, which accepts co-payments from recipients above certain income levels, felt that they needed more service than they were getting but they could not afford to increase their co-payment. Several mentioned the tenuousness of such services and their susceptibility to cuts in funding or other program changes. However, all recipients felt that the value of the services outweighed any problems they might pose.

Some policy-makers and researchers have expressed concern about the possible "woodwork effect" as a result of elders substituting formal services for informal ones if they were more readily available. Our study revealed no evidence of such behavior. Although some elders who had family support might have been able to receive more assistance from family in the absence of formal services, our study shows that formal services helped stretch informal care, allowing families to postpone reaching the limits of their support. Although African Americans may be overrepresented among poor home care users, but we found no evidence that their utilization is unjustified.

Nursing Home Care. Nursing home care grants freedom to caregivers who have reached the limit of their support. It meets those needs most families are unable to meet and does so on a sustained basis. It provides peace of mind for the caregiver, security for the care recipient, and relief

for each from having to worry about the other. Although perceived as the option of last resort, nursing home residents had adjusted to this transition. In some cases they were actually better off than before when they had struggled to maintain their independence, or were in an unpleasant living situation. As suggested by our Ohio nursing home data, African Americans are increasingly using nursing home placement as a viable option. However, the perception of this option as the last resort at the end of an often laborious and painful trajectory of decline suggests that it is not a decision made lightly, nor that it is without problems.

Some focus group participants and interviewees expressed negative feelings towards those families who opted for nursing home placement. For caregivers who placed a high value on kin care and who held high standards of filial obligations, nursing home placement may represent a failure, a lack of love or commitment, or carry other negative connotations. Elders, on the other hand, clearly preferred to go to a nursing home rather than be a burden on their families. Negative stereotypes, poor publicity, and complete lack of experience with a nursing home caused some elders and their families to be apprehensive about nursing home placement. However, most of them felt strongly that family members could assure high quality of nursing care by visiting, policing, and actively participating in the care of their loved one. We found overwhelming evidence for the continuation of kin care after nursing home placement of elders who had enjoyed good kin care before. In fact, we found compelling evidence that nursing home placement can and does enhance the effectiveness of kin care.

Our research shows that African-American elders and their families consider nursing home placement an appropriate and viable option when other options have been exhausted. The assumption that African Americans reject nursing homes is inaccurate and counterproductive to

families' search for appropriate care settings for elders whose care needs could best be met in a nursing home. It would be more honest and more useful to acknowledge that African-American elders and their families both need and accept nursing homes under the circumstances we have described.

Those participants who were most vehemently opposed to even considering the nursing home option were also the least informed about nursing homes. Accurate knowledge about, and positive experiences with, nursing homes greatly facilitated both acceptance of this option and adjustment to life in the nursing home. African-American families need not be reminded of their filial obligations; they need not be told that, as a group, they appear to reject nursing homes. What they need is assistance with exploring all possible options, guidance in anticipating scenarios that are likely to lead to nursing home placement, help with planning for increasing care needs, and referral to such programs.

Improving the image of nursing homes in the African-American community would go a long way toward easing this difficult transition for families and their elders. As younger generations have more positive experiences with today's nursing homes, the negative images of the past may fade and pave the pay to African Americans' broader acceptance of nursing homes as a viable and legitimate option when they reach their limit of support. Commmunity outreach on the part of nursing homes should target African-American churches, service and youth organizations. The culture of caring we discovered in our study has a great potential for acknowledging institutional care as an appropriate option rather than as an indicator of inadequate family caring.

Although our study focused on African Americans only, it nevertheless raises the question whether and to what extent our findings represent uniquely African-American patterns. We suspect

that a replication of this study with whites, the group they are most frequently compared to, would confirm what we suspect, namely that African Americans face the same challenges and are subject to the same pressures as are whites. We hypothesize that even if African Americans could be shown to have a more strongly developed culture of caring than a comparable group of whites, they would appear to be subject to the same demographic and economic realities which set limits to kin care, foster the use of in-home services, and make nursing home placement an appropriate and acceptable option for long-term care.

Another question our study raises is the extent to which it may have exaggerated the existence of a culture of caring. The picture we presented is based on interviews with mostly committed care givers and grateful, cognitively competent care recipients. The perspective that is missing in this picture is that of those who refused to talk with us: the over-burdened, over-committed, guilty, shy, distrustful, and the irresponsible would-be caregivers. We cannot know how access to their points of view and their realities might have altered the picture we presented. In the absence of such data, we are free to postulate that it might not have altered the picture at all. It may be that their very commitment to the culture of caring prevented them from telling us their stories because they, more than those who agreed to talk with us, fell short of attaining the ideal of the culture of caring.

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