

Preferences for Receipt of Care Among Community-Dwelling Adults

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ABSTRACT. Preferences for long-term care alternatives include both place of care and persons to provide care. In this analysis, these elements are separated for mature adults (N-1503, ages 40-70) regarding future care needs. Most adults preferred care in home/community settings by kin or non-kin, with few deeming nursing homes acceptable. Demographics and personal knowledge, experience, and expectations were marginally likely to influence preferences; males were more likely to prefer care in paid/

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professional settings. Women, who more often expressed preference for kin/home care, face demographic trends reducing available female kin who might be caregivers. [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <<http://www.HaworthPress.com>> © 2004 by The Haworth Press, Inc. All rights reserved.]

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INTRODUCTION

As the demand for supportive services to elders increases, new housing/care options are appearing within the continuum of care, such as assisted living. The growth of alternatives like assisted living and home-based care is increasing the choices that used to pit home versus nursing home. Studies suggest, however, that a gap exists between the supply of housing and services designed to meet the elderly's diverse needs and the older consumer's use of these facilities and services (Gibler & Lumpkin, 1997). Research also indicates that consumers are unaware of the various residential care options, tending to group or stereotype them negatively as "nursing homes" (Gibler & Lumpkin, 1997). As we plan for retirement housing and long-term care options to meet future need through expansion of Medicaid waivers and incentives for the purchase of long-term care insurance, it will be increasingly important to understand the preferences among mature adults. Needs for care are projected, based on health and disability data, but what do people want?

Incorporating consumer preferences into the long-term care model requires a focused effort on two fronts: social planning to ensure the availability of services to support consumer preferences and the provision of adequate information to future users about all long-term care options available to them. Inadequate effort in the first may result in a mismatch between needs/preferences for care in coming cohorts and service alternatives available; insufficient effort regarding information may result in misguided or insufficient planning by individuals and families toward their own future care. This mismatch could be costly both in terms of publicly funded programs and in poor fit between older adults and housing/care options.

In anticipating future needs for health and personal care, a sample of Maryland adults (ages 40-70 years, $N = 1503$) was interviewed about long-term care planning and preferences. Preferences for long-term care were measured along two intertwined dimensions: care location (home/community versus institution) and provider (kin versus professional/para-professional care).

BACKGROUND

Research on the preferences of the elderly for various care arrangements is scarce, since most extant research is based on the actual use of services rather than the preferences of potential users (Brennan, Moos, & Lemke, 1989; Brown, Davey, & Halladay, 1986; Soldo, Wolf, & Agree, 1990; Wielink et al., 1997). Since choices have been limited (and remain so to some extent), preferences were seldom an issue in the past. The closest bodies of research related to preferences for long-term care are studies of service use. Such studies traditionally use Andersen's three-factor model composed of predisposing, enabling, and need factors to predict health services utilization (Andersen, 1968; 1995; Andersen & Newman, 1973; Wan, 1989; Wolinsky, 1990). Wolinsky (1990) notes that need factors tend to be the strongest determinants of service use. For example, persons who remain married have a decreased risk of institutionalization (Branch & Jette, 1982; Hanley et al., 1990). The next strongest determinants tend to be predisposing factors of age and marital status, followed by enabling factors of income and living arrangements (Soldo, Agree, & Wolf, 1989). Much of the research on long-term care utilization focuses on demographic, community, physical functioning, social support, social networks, and health status factors (Keysor et al., 1999). However, studies of service use do not equate with preferences of potential users.

In a recent review, Keysor and colleagues (1999) found only a few studies on the relationship between elders' attitudes and placement (Biedenharn & Normoyle, 1991; Imamoglu & Imamoglu, 1992). Biedenharn and Normoyle (1991), for example, found that elders who had positive attitudes toward institutionalization and favorable perceptions of quality of care and life in such facilities were more likely to enter institutionalized settings than elders without positive attitudes. Other research has reported on the widely held desire of elders to remain independent and receive help in their own homes rather than move to relatives' homes or enter long-term care facilities (Butler & Lewis, 1982; Kraus et al., 1976; McAuley & Blieszner, 1985).

As noted by Wielink and colleagues (1997), research on the need for both informal and formal care suggests that age, gender, marital status, and living conditions are important determinants of preference. For example, younger married persons prefer formal home care or residential care, whereas men prefer care from relatives (McAuley & Blieszner, 1985). Characteristics such as socioeconomic status, social and psychological well-being, whether one has children or children who are supportive and/or other supportive network members are also related to preferences for formal and informal care (Branch & Jette, 1982; Huijsman & De Klerk, 1993). McAuley and Blieszner (1985) found that persons with higher socioeconomic status prefer formal home care and residential care, while those with more extensive social networks were more likely to receive care from relatives. Cause and effect may be muddled, since those with low incomes may see care by kin as better than care as a Medicaid patient in a nursing home.

Whether disability is of short or long duration has been shown to influence elders' perceptions of their resources and preferences for care location (Keysor et al., 1999; Wielink et al., 1997). In Keysor and colleagues' (1999) study of community dwelling elders' attitudes toward use of adult care homes in North Carolina, there was a preference for long-term placement for long-term disability, but not for short-term disability. Further, elders preferred long-term care placement when financial difficulty was a concern, but preferred home care if finances were not a concern (Keysor et al., 1999). Similar to findings elsewhere, married elders were more likely to prefer home care, regardless of level of disability.

Studies of ethnic differences in long-term care use show that elderly African Americans, despite evidence of greater disability, are placed in nursing homes between half and three-quarters the rate of elderly Whites (Belgrave, Wykle, & Choi, 1993; Greene & Ondrich, 1990; Hing, 1989). Few studies, however, examine the importance of both ethnicity and attitudes in the use of long-term care (Tennstedt & Chang, 1998). Sudha and Mutran (1999), in a study of attitudes toward long-term institutional care, found significant ethnic differences among elderly persons. African American elders were stronger in their desire for family care but disliked "rest homes" less than Whites. However, African American elders were less willing than Whites to consider rest-home placement. Results show that cultural preferences (beliefs and attitudes) favoring family care attributed to ethnicity are partly determined by dislike for institutional care (namely, nursing homes).

In this study, we attempted to disentangle the distribution of preferences for long-term care along two dimensions: (1) Care at home versus

a place other than home, and (2) Care provided by family versus care by others, namely, paraprofessional and professional workers. Our analysis examines the relationships between these two dimensions and a selected range of social, economic, and health characteristics shown to influence the use of long-term care services.

MEASUREMENT OF VARIABLES

Dependent Variables

Two dependent variables were constructed from five items in the survey. Items requested respondents' preferences for care provided by: (1) Your family in your home, (2) Your family in their home, (3) Paid caregivers in your home or community, or as (4) A resident of an assisted living facility, or (5) A resident of a nursing home. Respondents could find each option very agreeable, somewhat agreeable, somewhat disagreeable, or very disagreeable. Relatively few (20-40 respondents) declined to respond on each item. For purposes of this analysis, the two agreeable and two disagreeable responses were collapsed to get a positive or negative reaction to each option. Table 1 lists the frequencies of responses for each of the five housing/care options for the sample.

Embedded in these questions are two dimensions of the care situation: (1) Where the care is provided, and (2) By whom care is provided. Typically, these two factors are confounded in the choices that individuals make about their care. Two of the five options provide care in the respondent's own home; three are in places other than home. Two of these options provide care by family, while the remaining three state or

TABLE 1. Respondent Preferences on Five Care Options

	% Distribution				
	<i>Agreeable</i>		<i>Disagreeable</i>		<i>Missing</i>
	Very	Somewhat	Somewhat	Very	
Your family in your home	63.5%	20.2%	4.9%	9.4%	2.0%
Your family in their home	32.8%	31.4%	13.1%	20.1%	2.7%
Paid caregivers in your home or community	46.6%	39.0%	4.8%	8.0%	1.7%
A resident of an assisted living facility	30.1%	38.7%	13.5%	16.4%	1.3%
A resident of a nursing home	10.0%	22.4%	15.8%	50.3%	1.4%

imply care by others, primarily paraprofessional and professional workers. We coded each item twice: once indicating whether it reflected a preference for care in home (+1) or in locale other than home (-1), and once to indicate whether kin (+1) or non-kin (-1) care was preferred. Since there were five indicators of each dimension, scores could be positive, negative, or neutral. Non-responses were considered neutral on the two variables we call "home" and "kin." Scores theoretically ranged from -5 to +5 on each variable. Respondents with neutral values on the final variables were omitted for the multivariate analysis.

Independent Variables

Based on the literature, a range of items believed to influence preferences is tested. These include both demographic traits of respondents and items reflective of attitudes and beliefs pertinent to preferences. Among the demographics are self-rated health (five categories from excellent to poor); educational attainment (originally ten categories from no schooling to graduate degree, collapsed into four categories here); respondent age, self-reported race (five categories, here collapsed to three), marital status (collected in three categories, here used as married, not married), household income (collected as seven categories, employed here as three), and the respondent's sex. Table 2 summarizes distributions on these variables as utilized in this analysis.

Other variables examined here include service familiarity, prior experience of family members in long-term care, expected costs of various care options, and anticipated need by the respondent for long-term care (see Table 3). Service familiarity, a summated index of the number of "yes" responses to questions asking whether the respondent was familiar with nursing home care, adult day care, personal care services, homemaking services, supportive services in assisted living facilities, and skilled nursing services in the home. Respondents indicated high levels of familiarity with the services in question.

The remaining three measures are related to more detailed familiarity with long-term care. First, respondents were asked a yes/no question regarding whether any members of their families had received long-term care within the past 10 years. Four in ten responded in the affirmative on this item. Respondents were also asked to estimate what a month-long stay in a nursing home would cost, the hourly cost of home assistance for personal care needs, and hourly costs of skilled home care, such as that provided by nurses. It was expected that higher costs on the first

TABLE 2. Distribution of Demographic Variables

Characteristic	N	%
Self-Reported Health		
Excellent	463	30.9
Very Good	534	35.6
Good	336	22.4
Fair	119	7.9
Poor	46	3.1
Educational Attainment		
Less than High School	83	5.5
High School Graduate	353	23.5
Some College/ Tech school	403	26.8
College Graduate	305	20.3
Graduate/Prof. Study	359	23.9
Age		
40-49	604	40.1
50-59	574	38.1
60-64	174	11.5
65-70	151	10.0
Race		
White	1196	82.2
African-American	212	14.6
Other	47	3.2
Marital Status		
Married	1022	68.3
Not Married	473	31.6
Household Income		
\$0-30,000	271	20.2
\$30-60,000	499	37.2
\$61,000+	573	42.7
Sex		
Male	620	41.1
Female	888	58.9

measure and lower costs on the second and third might be predictive of attitudes more positive toward home care. High costs on all three might be expected to relate to preference for care by kin, all else being equal. Data showed wide ranges of dollar values given in response to these items, as reflected in the large standard deviations (see Table 3).

TABLE 3. Distributions on Predictor Variables

Characteristic	N	% or s.d.
Number of Services That Are Familiar		
0-3	156	10.4%
4	149	9.9%
5	312	20.7%
6	890	59.1%
Family Member Received LTC	618	41.0%
Estimated Mean Costs of		
Nursing Home/month	3,326	(s.d. = 1,799)
Personal Care at Home/hr	23	(s.d. = 18)
Skilled Care at Home/hr	39	(s.d. = 27)
Expectation of Needing LTC		
Not at all	111	7.9%
Less than average	511	33.9%
Same as average person	585	38.8%
More than average person	143	9.5%
Don't know	158	10.5%

Finally, respondents were asked to indicate whether they believed themselves likely to need long-term care in the future, compared to the average person (not at all, same, less, more likely). Only 7.4% said not at all likely, 33.9% believed their risk to be less, 38.8% indicated the same likelihood as others, and 9.5% believed it to be higher than average.

FINDINGS

The initial question addressed in analysis was whether or not there was a significant distribution on the two preference variables. Although the literature is clear that older adults prefer to remain at home, findings are somewhat more ambivalent regarding care by kin. Table 4 presents data on the distributions and the association between the two dimensions of preferences. Scores were collapsed into positive, negative, and neutral concerning care in home/community settings and care by kin versus non-kin (professionals or paraprofessionals).

Examining first the distributions of the individual variables, we find it not surprising that most individuals expressed preferences to be cared

for in a home/community rather than an institutional setting (58%), but perhaps a surprising number of respondents expressed preferences for options such as assisted living or nursing homes (35%). Regarding care providers, again a majority (54.8%) expressed a preference for care by family members, but a significant minority (38%) said that they preferred care by or in a setting that would involve professional or para-professional caregivers. Finally, it should be noted that relatively few individuals (7.3% of the sample) were neutral on the two variables. Those who were neutral were neutral on both dimensions, perhaps indicating individuals who had not thought about the options or were, in general, non-committal. These may include many of the non-respondents to these preference items.

Turning to the cross-tabulation, we are not surprised that there are linkages between the home and kin measure, given that the places and providers of care are very much wedded in the minds of respondents. Those who preferred care in non-community settings almost exclusively reported a preference for non-kin care. Similarly, the great majority of those expressing preference for care at home also stated a preference for care by kin. A few individuals, however, deviated, preferring kin care in a non-community setting or preferring non-kin care at home overall across their preferences. The association is, not surprisingly, statistically significant ($\chi^2 = 2430$, $p = .001$).

On examination of bivariate relationships (data not shown), we found that preference for care at home was not related to current health status, educational attainment, race, marital status, or income, but was associated with gender, with males being less likely to express a preference for care in a home/community setting. This result is ironic, given that males

TABLE 4. Crosstabulation of Preference for Care by Kin, in Home/Community

	<i>Preference for Care Provider (%)</i>			<i>Total (N & %)</i>
	<i>Non-Kin</i>	<i>Neutral</i>	<i>Kin</i>	
<i>Preference for Location</i>				
Not Home	475	0	49	524 35%
Neutral	0	109	0	109 7.3%
Home/Community	98	0	777	875 58%
Totals	573 38%	109 7.2%	826 54.8%	1508

are more likely to receive care at home from their wives than are women. Examining the same bivariate associations for care by kin/non-kin caregivers, respondent gender was again the only significant relationship, with men being more likely to express preference for non-kin care than were women.

Logistic Regression

Individuals who expressed no opinion ($N = 109$) were omitted from the multivariate analyses. In addition, categorical variables were converted to dummy variables, so that the reference group in these analyses is composed of married, low-income, white men in poor health with less than high school education who believe they have no risk for nursing home placement. For each of the two binomial dependent variables (preference for home/non-home; preference for kin/non-kin care), three models were run. The first included only the demographic variables (age, health, education, race, marital status, income, and gender), the second included only the other independent variables expected to influence preferences (anticipated likelihood of needing long-term care, experience of a family member in a nursing home, estimated costs of nursing home or RN or personal care at home, and knowledge of services); the third model in each case combined the demographic and predictor variables to determine whether or not variables remain significant controlling for other factors. Results for the two dependent variables are presented in Tables 5 and 6.

Preference for Care at Home

Table 5 summarizes the findings of the three logistic models, reflecting the odds ratios for the variables and their statistical significance. Turning first to demographics, age, educational attainment, race, and marital status had no effect on the odds of selecting care at home versus care in an "institutional" setting. Those with very good health were less likely to indicate a preference for care at home, but coefficients for none of the other levels of health were significant, controlling for all other factors in the model. Females were nearly 40% more likely to express a preference for care in home/community settings.

Examining the other predictors in Model 2, expecting a risk about the same as an average person, was associated with a lowered preference for care at home (.45). Having had a family member recently in care, knowledge of services, and two of the three cost factors were not signif-

TABLE 5. Odds Ratios for Care at Home by Demographic and Predictor Variables

	Care at Home		
	Model 1	Model 2	Model 3
<i>Demographic</i>			
Age	1.0		1.02
Health			
Excellent	.48		.33
Very Good	.39*		.24*
Good	.49		.29
Fair	.40		.31
Education			
High School Grad.	.87		.49
Post High school	1.25		.69
College Graduate	.82		.61
Graduate Study	1.01		.71
Race			
African-American	.94		1.12
Other	1.20		.27
Marital Status			
Not Married	1.00		.92
Income			
\$30-60,000	.78		.76
\$60,000+	1.00		.93
Female	1.39**		1.38
<i>Predictors</i>			
Nursing home risk v. average person			
Same		.45*	.52
Less		.61	.57
More		.59	.41*
Family Member in Care		1.24	1.08
Cost of Nursing Home		1.00	1.00
Cost of Personal Care		.99*	.99
Cost of Skilled Home Care		1.01	1.01
Knowledge of Services		.91	.87

*p < .05

**p < .01

***p < .001

icant in Model 2, with only the estimated hourly cost of personal care achieving significance as a very minor influence on the odds of preferring care at home.

Finally, in Model 3, when all variables were entered and simultaneously controlled, only two variables remained statistically significant. First, having very good health reduced the likelihood of expressing a prefer-

ence for home/community care settings, and, for the first time, those who thought they had a greater than average risk of nursing home placement preferred care at home less than others (.41). Several variables that had been significant in Models 1 and 2 did not remain so when all variables were combined in Model 3, including respondent sex.

Care by Kin

Table 6 outlines the resulting odds ratios for the three models examining care by kin versus professional/paraprofessional caregivers. In Model 1 age, race, marital status, and income were not significant. However, two of the four health coefficients (excellent and very good) were associated with preferences for non-kin caregivers (.47 and .41). Those with education beyond high school, but not college degrees, were much more likely to express a preference for care by kin (1.78). Again, as demonstrated in the bivariate relationships, women were much more likely than men to express a preference for family members as providers of their care (1.55).

Examining the other predictors in Model 2, once again we found that those who thought they had an average risk of needing long-term care were much less likely to express preference for care by family members (.52), and greater cost of personal care services was associated with a very slight reduction in preference for care by kin.

Turning to Model 3, which included all variables, three variables were statistically significant when all of the variables were controlled for simultaneously. The significant effect for gender persisted, as did having the same/average risk for needing long-term care. Knowledge of services, for the first time in any of the models, achieved significance, slightly reducing the preference for care by kin. Knowledge of services had almost achieved statistical significance in Model 2. Again, some variables, such as health and education that had been initially significant in Model 1, were not in Model 3, suggesting that many of these items are correlated.

DISCUSSION

Not surprisingly, the majority of individuals in this study preferred care in the home or community, provided by kin. Among those preferring care in the community, a smaller percentage desired that non-kin provide such care. Moreover, a significant number of individuals preferred

TABLE 6. Odds Ratios for Care by Kin by Demographic and Predictor Variables

	Care by Kin		
	Model 1	Model 2	Model 3
<i>Demographic</i>			
Age	1.00		.38
Health			
Excellent	.46*		.38
Very Good	.41*		.32
Good	.58		.38
Fair	.45		.38
Education			
High School Grad.	1.20		.94
Post High School	1.78*		1.32
College Graduate	1.13		1.15
Graduate Study	1.33		1.37
Race			
African-American	.83		.98
Other	1.22		.31
Marital Status			
Not Married	1.04		.95
Income			
\$30,000-60,000	.89		1.08
\$60,000+	.95		.98
Female	1.55***		1.60**
<i>Predictors</i>			
Nursing home risk v. average person			
Same		.52*	.51*
Less		.75	.68
More		.70	.49
Family Member in Care		1.05	.90
Cost of Nursing Home		1.00	1.00
Cost of Personal Care		.99*	.98
Cost of Skilled Home Care		1.01	1.01
Knowledge of Services		.88	.86*

*p < .05

**p < .01

***p < .001

care to be provided by non-kin in long-term care facilities. This may signal a shift toward greater acceptance among coming cohorts of alternatives such as Assisted Living. Nursing homes, however, were favored by few, consistent with prior research.

Unlike some other studies (e.g., McAuley & Bliezner, 1985; Wielink et al., 1997), most predisposing, demographic variables (age, educa-

tional attainment, race, marital status) were not associated with either preference on home/institutional location dimension or on the provider (kin/non-kin) dimension. McAuley and Blieszner (1985) found younger married persons preferred formal home care or residential care, whereas men preferred care from relatives—a situation reflecting the reality of spouses providing care for their husbands. In this study, however, males were more likely to express preferences for care in facilities and by non-kin providers; no differences were found based on the ages of the respondents. Moreover, variables expected to have significant effects on stated preferences, such as income/socioeconomic status, race/ethnicity, and marital status (Belgrave et al., 1993; Keysor et al., 1999; McAuley & Blieszner, 1985; Wielink et al., 1997), did not. Further examination of these findings is necessary to determine if, for example, race-related differences in preference for care are fading and/or are a result of improved access to long-term care.

In multivariate models, relatively few variables achieved statistical significance. In the full model for the location dimension (community vs. institutional setting), having good health and having a greater than average anticipated risk for nursing home placement reduced the preference for care in home/community care settings. Gender, however, lost statistical significance when other variables were included in the model, indicating a spurious relationship with preference for home care. In the all-inclusive, multivariate model addressing preferences for care provided by kin versus non-kin, those indicating an average risk of needing long-term care were less likely to prefer care provided by kin. This finding may reflect the relatively young age of the respondents; 80% were 40-59, fairly young to have thought much about their long-term care plans. The multivariate model also shows that greater knowledge of formal services is related to slightly reduced preference for care by kin, suggesting that increased knowledge or experience with LTC contributes to a more positive attitude toward such setting (Biedenharn & Normoyle, 1991). Other factors not included in the model may also have impacts on preferences for care such as knowledge of long-term care payers and financial planning behavior.

Perhaps the most troubling finding in this study was the continuing preference among these predominantly baby boomer respondents for care by kin in the home/community setting, and the especially strong preference among women for such care in the face of demographic realities. For this group, demographic data portend more limited availability of informal care in old age. Unlike the present cohorts of elderly, the baby boomers have married less, divorced more, and had fewer children. As a

consequence, Easterlin, Schaeffer, and Macunovich (1993) predict that 30 to 40% of the boomers are likely to lack a spouse on reaching retirement; and the number of surviving children is likely to be the lowest of any cohort—less than two per every married woman (Easterlin, 1996). For the leading-edge boomers, over a third of the cohort is projected to live alone at ages 65-74 (Macunovich, Easterlin, Crimmins, & Macdonald, 1993). Unfortunately, this describes an impending mismatch between the preferences for later life care of these middle age cohorts; being cared for by kin at home will be more elusive than ever. If preference for care by kin results in limited planning or preparation (via saving or purchase of long-term care insurance, for example), large numbers of older adults may need to receive care in undesired locations, from non-preferred caregivers, and at public expense.

In addressing consumer long-term care preferences, policymakers have attempted to develop long-term care policy using a consumer-oriented approach. Several programs intended to enhance access to community-based long-term care services have been developed (Miller, 1997). The Cash and Counseling Demonstration program is a consumer-oriented model of long-term care offering consumers flexibility by providing the necessary resources to purchase long-term care services that meet individual needs (Stone, 2000). Consumers decide the best use of their cash benefits in terms of who provides needed services as well as when and how services are provided.

Professionally managed service packages, such as publicly funded home- and community-based care programs, also offer the opportunity for consumer involvement in long-term care decisionmaking. Consumers provide input to professional care managers at all stages of the care plan, from development to implementation and service delivery (Stone, 2000).

Many consumers, including those studied here, are unaware of these types of consumer-oriented models of long-term care and other long-term care options in general. This lack of knowledge may contribute to the strong consumer preference towards in-home long-term care provided by kin. Insufficient information is a major constraint on long-term care preparation and decisionmaking. Findings from the current study indicate that knowledge of formal care reduces the preference for care provided by kin. As information on and experience with alternative options, such as Assisted Living and consumer-directed home care, become ubiquitous, it may be that the preferences toward these options, and a corresponding demand for affordable and public financing, may grow. Since dislike for nursing homes appears strong, high demand for alternatives could strain either private or public resources without adequate plan-

ning. In this sample over one-third preferred non-kin, non-home care, suggesting that consideration of new alternatives may shift care preferences by the time the baby boomers in large numbers require housing/care options. Together, these findings emphasize the importance of sufficient and correct information for individuals to plan and prepare in advance of need, and continued attention to testing and evaluation of care alternatives that provide alternatives to nursing homes and parallel consumer preferences.

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