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Research Article

Care Arrangements of Older Adults: What They Prefer, What They Have, and Implications for Quality of Life

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Abstract

Background and Objectives: Meeting individual preferences for long-term services and supports (LTSS) is a policy priority that has implications for quality of care. Evidence regarding preferences is sparse. In addition, little is known regarding whether preferences and care arrangements match for those receiving care, and implications for quality of life.

Research Design and Methods: A random sample (n = 1,783 in 2012) of National Health and Aging Trends Study participants were asked the best care option for someone 80+ who needs help with personal care and mobility. Analyses examine variations in care preferences, the relationship of preferences to care arrangements, and the association of matched preference and care arrangements to quality of life indicators.

Results: Care preferences vary by demographics. Equal proportions (3 in 10) of older adults chose assisted living or continuing care retirement communities (CCRC), care in own home with family help, and care in own home with paid help, as the best options. Persons in assisted living/CCRC settings were significantly more likely to choose this option as best. Only 1 in 3 older persons receiving care are in arrangements that match preferences. No association with quality of life indicators was found.

Discussion and Implications: Aging in place remains the care preference of a majority, but close to one-third chose assisted living/CCRC, suggesting preferences are evolving. Aligning care preferences and arrangements is a policy goal, but many do not achieve a match and there remain gaps in understanding trajectories in preferences and care arrangements and implications for quality of life.

Keywords: Caregiving–informal, Continuum of care, Assisted living facilities, LTSS preferences

Varied options exist for long-term services and supports (LTSS) to meet the needs of older people who are no longer independent in mobility, basic self-care or performing routine household activities. Family caregiving remains the most commonly relied upon source of assistance (National Academies of Sciences, Engineering, and Medicine, 2016), but the last two decades have seen substantial changes in the availability and use of paid long-term care services. In the realm of institutional care, there has been a steady decline in the nursing home population (Alecxih, 2006; Weiner, 2013), and a growth in other care options, primarily home and community-based services and non-nursing home residential care such as assisted living and continuing care retirement communities (CCRC). The inter-relationships among these developments are not clear. Some data suggest use of nursing homes is still greater than for other long-term care service options (Harris-Kojetin, Sengupta, Park-Lee, & Valverde, 2013), while other studies find that the growth of assisted living is likely directly tied to declines in nursing home occupancy (Stevenson & Grabowski, 2010). Home and community-based services also have expanded, most notably for lower income persons through Medicaid

Waiver programs (Watts & Musumeci, 2018) and policy initiatives, such as the on-going federal initiative (Money Follows the Person) designed to support state efforts to reduce reliance on institutional settings to provide LTSS (Mathematica Policy Research, Inc., 2018).

Individual preferences are often cited as a factor influencing the changing landscape of long-term care service options, including the growth of nursing home alternatives and increased emphasis on options that support aging in place (Harris-Kojetin et al., 2013; Stevenson & Grabowski, 2010). Concerns about the future availability of family caregivers for an aging population is driven in part by the awareness that "aging in place" is preferred by many older people. There also is evidence that expectations regarding LTSS may be changing; one state-specific study found middle-aged baby boomers when asked about places they might live in or move to as they grow older, while favoring aging in place also were more likely to consider both coresidence with a child and living in retirement communities or assisted living than their parents' generation (Robison, Shugrue, Fortinsky, & Gruman, 2014).

Kane and Kane (2001) argued that determining long-term care preferences of older adults is a necessary step in providing care that better reflects preferences, but characterized the research literature on preferences as "sparse and confusing." Lehnert, Heuchert, Hussain, and Konig (2018) in a recent review of research on long-term care preferences examined 59 studies and noted substantial methodological heterogeneity, but also concluded that a common key finding was that people prefer to age in place. Early studies of care preferences among older adults often contrasted community with nursing home care and typically documented a strong aversion to nursing home care. A survey of adults 60 or older published 30 years ago (McAuley & Blieszner, 1985) provided options for long-term care arrangements and asked for agreement or disagreement for each option "if you became sick or disabled for a long time" (p. 189). Help in the person's own home from a relative or paid caregiver had the highest levels of agreement (66% and 70%, respectively), less than one-third endorsed nursing home care. Similarly, a study of community-dwelling older adults in North Carolina published nearly 20 years ago (Keysor, Desai, & Mutran, 1999) found a greater preference for home care across multiple situations under different scenarios, with some variation by characteristics, such as marital status and severity of disability. A more recent study (Wolff, Kasper, & Shore, 2008), of older women with moderate to severe disability examined preferences for a broader range of care options (paid help at home, unpaid help at home, living with child, assisted living, nursing home) and also found help in one's home was preferred for help with activities of daily living (ADL) and instrumental activities of daily living (IADL) needs, although preferences fluctuated somewhat (e.g., between paid help and unpaid help at home) over a 1-year period for a substantial proportion of women.

Studies that focus on expectations of future use of long-term services among those under age 65 (Henning-Smith & Shippee, 2015) or among older persons who have no current care needs (Abrahamson, Hass, & Sands, 2017), find that in addition to underestimating future need for LTSS, individuals commonly expect family members to provide assistance if the need arises. While these studies focus on who is providing the care, rather than place, expectations that family members will be future caregivers is consistent with a preference to age in place. Henning-Smith and Shippee (2015) found 73% of persons 45– 64 expected a family member to provide care. Among older persons who later developed ADL care needs, Abrahamson and colleagues (2017) found adult children (for 48%) and spouses (for 35%) were most often named as likely caregivers.

Alternative arrangements for LTSS are important for their potential impact on quality of life. One influential conceptual framework for explaining well-being in the context of disability is that of person-environment fit. Originally conceptualized by Lawton (1982) and Kahana (1982) with a focus on persons in institutionalized environments, this perspective hypothesized that characteristics of the person, the environment, and the fit between these were important predictors of residential satisfaction. Kahana, Lovegreen, Kahana, and Kahana (2003) extended this perspective to persons in community settings, and pointed to congruence between personal preferences or needs and the environment as influencing environmental satisfaction and psychological well-being, and a lack of congruence as a source of stress that may lead to adverse health outcomes.

Despite prior studies, and the more recent policy focus on preferences of older adults and opportunities for choice in assessing quality in LTSS (NQF, 2015), little is known about how preferences for care arrangements vary among older people by characteristics and circumstances. Evidence also is lacking regarding the extent to which people achieve congruence between their preferences and actual care arrangements, or whether and how congruence affects quality of life indicators such as well-being. This study examines, using nationally representative data for persons 65 and older, variations in care preferences and the extent to which preferences are congruent with or match current or future care arrangements. We also examine the relationship of matches and nonmatches to several indicators of quality of life: subjective well-being, satisfaction with living arrangements, and participation restrictions. We hypothesize that preferences will be associated with care arrangements for those currently receiving care, and for those who receive care prospectively. We also hypothesize that persons whose care arrangements match their preferences are more likely to experience positive and less likely to experience negative outcomes than those whose arrangements and preferences are misaligned.

Design and Methods

Data

Data are from the National Health and Aging Trends Study (NHATS), which provides a study sample that is nationally

representative of Medicare beneficiaries aged 65 and older. Since 2011, NHATS has conducted annual in-person interviews with older adults to enable research on disability trends and dynamics in the older population. Detailed information on health and functioning, environments, use of assistive devices and help with activities is collected in addition to demographic and other contextual data. Details of the NHATS conceptual framework and study design are available elsewhere (www.nhats.org; Kasper & Freedman, 2014). This analysis draws on a random sample of the 2012 NHATS respondents who were administered a set of questions asking about best care options for a scenario of a person of age 80 who needs help with personal care and mobility. Proxy respondents were not asked this set of questions (n = 161) and persons who said "don't know" (n = 49) or refused to answer (n = 14) the care preferences questions were excluded, as were a small number (n = 8) of self-responding persons in nursing homes in 2012, leaving a study sample of 1,783 self-respondents. The baseline (2011) response rate for NHATS was 71%; conditional upon responding at baseline, the Round 2 (2012) response rate was 86%.

Measures

Care preferences

Preferences for care options were ascertained in 2012 (NHATS, 2018) by asking respondents to "Imagine a person named Pat, who is 80 years old with health problems. Because of these problems, {he/she} needs someone to help with bathing, dressing and getting around inside. Please look at this card and tell me what would be best for Pat?" Five options were presented: living in their own home with help from friends and family; living in their own home with help from someone paid to come in; living with an adult child; living in an assisted living facility or continuing care residence; or living in a nursing home. The scenario used was designed to be realistic and to provide a brief standardized set of choices that all subjects could understand and respond to (only 2.9%, n = 63, said don't know or refused to answer). Persons were asked about preferences for another person, rather than themselves, to reduce social desirability bias (e.g., saying their current care arrangement was best for them) and the sensitivity surrounding a potentially difficult topic—current or future loss of their own independence.

Demographic characteristics

Sex, race, education, and annual income (coded into quartiles) are from 2011 (NHATS Round 1). Living arrangement, marital status, and age are from 2012 (Round 2). For this study, three age groups (65–74, 75–84, 85+) were used and race was categorized as white non-Hispanic, black non-Hispanic, and Hispanic ethnicity or other race. Education was collapsed into three categories: below high school, high school education, or education beyond high school (don't know/refused were included in this category). Living arrangement was classified as living alone, with a spouse, with children, with others, non-nursing home residential care, or nursing home. Marital status was defined as married or living with a partner, widowed, or other.

Assistance or help with self-care/mobility and household activities for health and functioning reasons

Help or assistance from others in the last month is asked in NHATS at each round for each self-care, mobility and household activity. In this analysis, persons were considered to be receiving help or assistance with self-care/mobility if they reported help from another person with any self-care—dressing, bathing, toileting, or eating—or mobility activity—getting around inside, going outside, or getting out of bed. Persons were considered to be receiving help with household activities—doing laundry, shopping, preparing meals, or keeping track of medicines—if they reported the assistance was for health or functioning reasons. These variables were constructed for each round (2012–2015) and used to identify those receiving help in 2012, as well as those not receiving help in 2012 who started receiving help within the next 3 years (2013, 2014, or 2015).

Care arrangements

Care arrangements were defined based on reports of assistance with activities (self-care/mobility, household activities for health and functioning reasons), who was providing the help (family or friends; paid helpers), living arrangements (with an adult child vs alone or with a spouse) and living in a non-nursing home residential care setting. Care arrangements were mapped to the care preference options as closely as possible. Care arrangements are from 2012 for persons who were receiving assistance at that interview. For persons not receiving assistance in 2012 who began receiving assistance within the next 3 years (2013, 2014, 2015), care arrangements are from the year assistance was first observed.

Match between care preferences and care arrangements

A dichotomous variable (yes/no) was created to indicate whether care arrangements and care preferences were congruent or matched. For those receiving help in 2012, care arrangements and care preferences from Round 2 were compared. For those receiving help subsequently, care at the round when help was first reported (2013–2015) was compared with care preferences from Round 2.

Quality of life indicators: Subjective wellbeing, living arrangement satisfaction, participation restrictions

Several indicators were created. A score from 0 to 20 using six items that reflect positive and negative emotions (how often in last month: cheerful/bored/full of life/upset; each scored from 0 for never to 4 for every day) and self-realization (my life has meaning and purpose/I feel confident and

good about myself; each scored 2 for agree a lot to 0 for not at all) was developed and persons in the highest quartile of well-being were coded as 1 versus 0 for those with lower scores. This measure has been used previously (Freedman et al., 2014) and factor analysis confirmed that the items form a single factor with loadings of .47 or higher. The single item "I like my living situation very much" was coded 1 for responses of "agree a lot" and 0 for "agree a little or not at all." Seventy-five percent of the study sample agreed a lot and only 5% agreed not at all. Experiencing a participation restriction was defined as yes if over the last month a person's health kept him/her from one or more of the following: visiting with friends or family in person, attending religious services, participating in clubs, classes, or other organized activities, going out for enjoyment, working, volunteering, or doing a favorite activity. Quality of life indicators were from 2012 for persons receiving help at that time, and from the Round when help was first reported for those receiving help in 2013–2015.

Analysis

All analyses were conducted with Stata, version 12.1. Round 2 analytic weights were used to provide nationally representative estimates and to take into account differential probabilities of selection and nonresponse. Stata's built-in svy commands were used to take the strata and clustering elements of the sample design into consideration. Bivariate relationships were examined and logistic regression and ordinary least squares models were employed to evaluate association of well-being outcomes with care arrangements and matches between preferences and care arrangements.

Results

Overall, older persons viewed the best care option for the scenario presented (person aged 80 who needs help with bathing, dressing, and getting around inside due to health problems) as being in one's own home (29.4%), closely followed by assisted living/CCRC (27.8%) and own home with paid help (27.7%; Table 1). Less than 10% selected nursing home or living with an adult child as the best choice. Care preferences varied by several demographic characteristics, although not by age. Women gave highest preference to own home paid help, while a higher percentage of men selected own home family help as the best option. Among persons who were white non-Hispanic, own home paid help and assisted living/CCRC were viewed as the preferred care options, while higher percentages of black non-Hispanic and persons of other races or Hispanic ethnicity selected own home/family help. Married persons were more likely to select own home family help relative to widowed or others, while those who were widowed favored own home paid help and others gave highest preference to assisted living/CCRC. Among persons with less than high school education, a higher percentage viewed own home family help as best, while among those with more than a high school education, about one-third chose assisted living/CCRC as the best option. Persons in the lowest education group were more likely to view nursing homes as the best option compared with those in the highest education group. A higher percentage of persons in the lowest income quartile chose own home family help as the best option in contrast to persons in the highest quartile who chose own home paid help and assisted living/CCRC as the best options.

Although study participants were asked about care arrangements for a standardized scenario involving someone else, their own living and care arrangements were related to care preferences (Table 2). Among those living alone, a higher proportion selected own home paid help as best, while for those living with a spouse, with a child, or with others a higher percentage chose own home family help. Half of persons living in non-nursing home residential care settings viewed assisted living/CCRC as the best option. Among persons receiving no help with personal care, mobility or household activities in 2012, about one in three selected as preferred care options: own home family help, own home paid help, and assisted living/CCRC. By contrast, persons receiving personal care/mobility help or help with household activities only (for health and functioning reasons) in 2012 were more likely to view own home family help as the best option relative to others.

Table 3 shows for persons receiving care the distribution of care arrangements and the match between preferences and care arrangements for two groups: those who were receiving help in 2012 and those who were not receiving help in 2012 but began receiving help within the next 3 years (2013–2015). The distribution of care arrangements differs for these two groups. Less than half of those receiving help in 2012 were in their own home with family help compared with two-thirds of those who began receiving help after 2012. A higher percentage of those receiving help in 2012 were living with an adult child (19.3%) or in assisted living/CCRC arrangements (13.9%) compared with those receiving help later (9.0% and 8.3%, respectively).

As might be expected current care arrangements are related to care preferences in some instances, but not all (Table 3). While receiving care in non-nursing home residential care settings was less common (13.9% of those receiving care in 2012 and 8.3% of those who started receiving care later) than other arrangements, over half of persons in these settings selected assisted living/CCRC as the preferred option and those in these settings were significantly more likely than persons in other care arrangements to select this option as best. Among those receiving self-care/mobility help and those receiving household activity help only, the preference for assisted living/CCRC among those living in these settings held. About one in five persons who in 2012 were receiving help lived with an adult child. Only about 15% of persons in this arrangement selected

Table 1. Demographic Characteristics by Preferred Care Option[a]

Demographics	Total	Preferred care option					*p* Value
		Own home family help	Own home paid help	Living with adult child	Assisted living or CCRC	Nursing home	
Total	100.0%	29.4%	27.7%	6.2%	27.8%	8.9%	
Age							.76
65–74	51.3	29.7	26.8	6.2	29.2	8.1	
75–84	36.2	29.3	28.7	6.7	26.1	9.2	
85 or older	12.5	28.6	28.5	4.7	27.2	11.0	
Gender							.00
Male	44.8	32.3	21.6	6.8	29.0	10.3	
Female	55.2	27.1	32.7	5.6	26.9	7.7	
Marital status							.05
Married	57.6	31.2	28.2	5.6	28.1	6.9	
Widowed	27.3	25.6	29.8	6.8	26.0	11.8	
Other	15.1	29.5	22.1	7.2	30.3	10.9	
Education							.00
Below HS	19.6	36.0	21.1	8.4	18.7	15.8	
HS	29.2	29.4	27.9	6.4	26.2	10.1	
More than HS	51.2	26.9	30.2	5.2	32.2	5.5	
Race							.00
White non-Hispanic	81.8	27.8	29.5	6.0	29.3	7.4	
Black non-Hispanic	8.1	36.1	22.8	7.1	20.2	13.8	
Hispanic/other	10.1	36.9	16.7	7.2	22.3	16.9	
Income quartiles							
1st (lowest)	21.6	31.7	25.0	7.3	23.1	12.9	.01
2nd	24.2	30.5	25.0	7.5	26.3	10.7	
3rd	26.0	30.8	27.2	5.5	29.0	7.5	
4th (highest)	28.2	25.5	32.5	4.9	31.7	5.4	

Note: NHATS 2012; persons aged 65 or older who were self-respondents (n = 1,783), excluding those who answered don't know (n = 49) or refused (n = 14) to questions about care preferences and nursing home residents (n = 8). CCRC = continuing care retirement communities; HS = high school.

[a]Best care option for a person aged 80 years old with health problems who needs someone to help with bathing, dressing, and getting around inside.

Table 2. Living Arrangements and Receipt of Help by Preferred Care Option[a]

Characteristics	Total	Preferred care option					*p* Value
		Own home family help	Own home paid help	Living with adult child	Assisted living or CCRC	Nursing home	
Total	100.0%	29.4%	27.7%	6.2%	27.8%	8.9%	
Living arrangements[b]							
Alone	25.8	24.5	31.8	3.6	28.6	11.5	.00
With spouse	55.3	31.8	28.5	5.6	27.3	6.7	
With child (no spouse)	9.9	32.4	21.2	15.0	18.3	13.2	
With others	4.2	37.3	19.3	9.0	25.1	9.3	
Residential care[c]	4.8	15.4	17.2	6.2	51.6	9.6	
Receiving help[b]							
Self-care or mobility	12.1	30.3	24.5	10.8	22.0	12.4	.00
Household activities only for health/functioning reasons	12.2	33.5	23.3	6.4	24.2	12.6	
None	75.7	28.6	28.9	5.4	29.3	7.7	

Note: NHATS 2012; persons aged 65 or older who were self-respondents (n = 1,783), excluding those who answered don't know (n = 49) or refused (n = 14) to questions about care preferences and nursing home residents (n = 8). CCRC = continuing care retirement communities.

[a]Best care option for a person aged 80 years old with health problems who needs someone to help with bathing, dressing, and getting around inside.

[b]Living arrangements and receiving help with self-care/mobility activities, household activities only for health/functioning reasons in 2012.

[c]Persons in non-nursing home residential care settings.

Table 3. Distribution of Care Arrangements and Proportion in Care Arrangement Who View It as the Preferred Option[a] Among Persons Receiving Care in 2012 and Those Who Began Receiving Care Within 3 Years (2013–2015)

	Preferred care option				
Care arrangements and preferences	Own home family help	Own home paid help	Living with adult child	Assisted living or CCRC	Nursing home
Any help in 2012[b]					
Care arrangement	47.7	19.3	19.1	13.9	—
In arrangement and prefer it	32.9	31.5[c]	14.9[c]	58.6[c]	—
Not in arrangement and prefer it	30.9	22.1	7.1	17.4	12.5
Self-care/mobility help in 2012					
Care arrangement	44.7	22.8	21.2	11.3	—
In arrangement and prefer it	33.2	33.5	17.5	54.6[c]	—
Not in arrangement and prefer it	27.9	21.8	9.0	17.8	12.4
Household activities help only in 2012					
Care arrangement	50.6	16.0	17.1	16.3	—
In arrangement and prefer it	33.1	28.6	11.7	61.3[c]	—
Not in arrangement and prefer it	34.3	22.2	5.3	17.0	12.6
No help in 2012 started receiving help 2013–2015[d]					
Care arrangement[e]	67.5	13.8	9.0	8.3	1.3
In arrangement and prefer it	25.0	26.7	10.3	54.2[c]	—
Not in arrangement and prefer it	24.8	28.9	6.7	27.0	10.2

Note: — represents persons in nursing homes in 2012 were excluded (n = 8). CCRC = continuing care retirement communities.

[a]Best care option for a person aged 80 years old with health problems who needs someone to help with bathing, dressing, and getting around inside.

[b]Persons aged 65 or older who were receiving help in 2012 (n = 524 receiving help; n = 259 receiving self-care/mobility help; n = 265 receiving help with household activities only for health and functioning reasons). Preferred care options are from 2012.

[c]Proportion in care arrangement who prefer that option is different from proportion not in that care arrangement who prefer it at $p < .05$.

[d]Persons aged 65 or older not receiving help in 2012 who started receiving help in 2013–2015 (n = 276). A small percentage was in nursing homes when receipt of help was first observed in 2013–2015, but was too few to examine preferences by this arrangement. Preferred care options are from 2012.

[e]Distribution of care arrangements for those not receiving help in 2012 who started receiving help later is different from distribution for those receiving help in 2012 at $p < .01$.

it as the preferred option, however—although still significantly higher than for persons in other care arrangements (7.1% of persons in other arrangements said living with an adult child was the best option). Almost half of persons receiving care in 2012 were in their own home with family help and one in five were receiving paid help in their home. Equal proportions (about one in three) of those receiving care selected own home family help and own home paid help as the preferred care options, however, only those receiving paid help in their home were significantly more likely to prefer this arrangement compared with persons in other arrangements.

Table 4 presents results from examining bivariate relationships between personal characteristics and whether care arrangements matched preferences for persons receiving care in 2012, after 2012, and overall. About one in three older persons receiving help with self-care, mobility or household activities for health or functioning reasons were in a care arrangement that matched the care option they viewed as best. Differences in likelihood of a match between those receiving care in 2012 and those receiving care later were not statistically significant. Persons who were 85 or older were more likely to be in care arrangements that matched their preferences than younger persons those ages 65–74. Among those receiving care in 2012 when preferences were obtained, those with a high school education were less likely than more educated persons to be in care arrangements that matched preferences; black non-Hispanic persons were less likely than white non-Hispanic persons to be in care arrangements that matched preferences (odds ratio [OR] = 0.61 and 0.52, respectively). Differences by living arrangement were evident among both those receiving care in 2012 and those who began receiving care after 2012, in both instances, persons who lived with a child were significantly less likely to be in a care arrangement that matched their preference (OR = 0.36 and 0.29, respectively) relative to those living with a spouse. For those receiving care in 2012 and overall, persons in assisted living/CCRC were more than twice as likely to be in a care arrangement that matched their care preferences (OR = 2.93 and 2.80, respectively) relative to persons living with a spouse.

Table 5 examines the relationship to several indicators of quality of life of a match between care arrangements and care preferences. None of the bivariate relationships between a match (yes/no) and subjective well-being, satisfaction with one's living situation, and experiencing participation restrictions were statistically significant. When

Table 4. Match Between Preferred Option[a] and Care Arrangements by Demographic and Other Characteristics for Persons Receiving Care in 2012 and Those Who Began Receiving Care Within 3 Years (2013–2015)

	Match between preferred option and care arrangements (OR)		
Demographics and other characteristics	In 2012[b]	Within 3 years[c]	Total
Preference/arrangement match	32.8%	26.0%	30.2%
Age			
65–74	REF	REF	REF
75–84	1.70	1.08	1.45
85 or older	1.97*	1.32	1.78*
Gender			
Female vs male	1.03	0.84	0.98
Marital status			
Married	REF	REF	REF
Widowed	0.93	0.66	0.87
Other	0.72	1.09	0.85
Education			
Below HS	0.89	1.64	1.14
HS	0.61*	1.65	0.90
More than HS	REF	REF	REF
Race			
White non-Hispanic	REF	REF	REF
Black non-Hispanic	0.52*	1.28	0.73
Hispanic/other	0.89	0.38	0.78
Income quartiles			
1st (lowest)	0.98	1.31	1.09
2nd	0.86	0.94	0.89
3rd	1.34	0.90	1.13
4th (highest)	REF	REF	REF
Living arrangements			
Alone	1.06	0.61	0.83
With spouse	REF	REF	REF
With child (no spouse)	0.36**	0.29*	0.36**
With others	0.67	1.14	0.84
Residential care[b]	2.93**	1.89	2.80**

Note: HS = high school; OR = odds ratio.

[a]Best care option for a person aged 80 years old with health problems who needs someone to help with bathing, dressing, and getting around inside. [b]Persons aged 65 or older who were receiving help in 2012 when preferences for care options were asked (n = 524 receiving help). [c]Persons aged 65 or older who were not receiving help in 2012 when preferences for care options were asked and started receiving help in 2013–2015 (n = 276).

*p <.05. **p < .01.

type of assistance (self-care/mobility vs household activity only), care arrangements, and receiving care in 2012 versus later were accounted for, the relationship between a match and the quality of life indicators of interest remained non-significant. Receiving self-care/mobility help (vs household activity only) increased the odds of experiencing participation restrictions (OR = 1.51). Persons in non-nursing home residential care settings had reduced odds of participation restrictions (OR = 0.49) relative to those with care arrangements that relied on family help only.

Discussion and Implications

Preferences for care, across the spectrum from medical to LTSS, are a focus of considerable attention because they are seen as influencing decisions concerning use of services, as well as being the nexus of efforts to improve quality of care by aligning care with preferences. Attention to care preferences has been concentrated on acute care services and treatments (Street, Elwyn, & Epstein, 2012) and issues such as end-of-life care (Hanson & Winzelberg, 2013). However, the growth of home- and community-based options for LTSS has elevated interest in care preferences and indicators of individual choice and control as key elements in evaluating the quality of these services (National Quality Forum, 2015). In addition, as noted by Lehnert and colleagues (2018) because LTSS address functional losses and limitations, there is reason to view care preferences of those receiving assistance as especially relevant.

Table 5. Relationship Between Match (Preferred Care Option and Care Arrangements) and Quality of Life Indicators (Subjective Well-Being, Satisfaction With Living Situation, Participation Restrictions)

Univariate and multivariate models	Subjective well-being[a] (OR)	Satisfaction with living situation[b] (OR)	Participation restrictions[c] (OR)
Match between preferred care option and care arrangements (1 = yes)	0.92	1.08	1.05
Multivariate model:			
Match between preferred care option and care arrangements (1 = yes)	1.01	1.16	1.15
Help with self-care or mobility (=1) vs household activities only	0.71	0.78	1.51*
Care arrangements[d]			
Unpaid help family/friends	REF	REF	REF
Paid help[e]	1.52	0.78	1.13
Lives with adult child	1.47	0.91	0.94
Lives in non-nursing home residential care	0.85	0.62	0.49*
Receiving care in 2012[f]	1.19	1.13	0.90

Note: N = 800 persons receiving care in 2012 or who started receiving care in 2013–2015. OR = odds ratio.
[a]1 = in top quartile of scores from 0 to 20; 0 = scores below top quartile. Higher scores indicate greater well-being. [b]1 = a lot; 0 = a little or not satisfied.
[c]1 = yes, restriction on one or more of seven valued activities; 0 = no restrictions. [d]Excludes nursing home residents among those receiving help in 2012 or later due to sample size. [e]With or without unpaid help. [f]1 = receiving care in 2012; 0 not receiving care in 2012 but receiving care in 2013–2015. *$p < .05$.

Using nationally representative data on persons aged 65 and older, we examined preferences using a scenario for a person aged 80 or older with health problems who needs help with bathing, dressing, and getting around inside. We find that equal proportions (about 3 in 10 older people), see assisted living/CCRC, care in own home with family help, and care in own home with paid help, as the best care options. Earlier studies on long-term care preferences that predated the increase in assisted living/CCRC settings in the United States (Keysor et al., 1999; McAuley & Blieszner, 1985) often did not include this option, although Robison and colleagues (2014) found about half of middle-aged people (Baby Boomers) thought it very or somewhat likely they would live in assisted living or a CCRC in the future. Wolff and colleagues (2008) found in a 1990s cohort of older women with moderate to severe disability that only 9.7% viewed assisted living as the best care option for someone who needed help with personal care in a scenario similar to the one used here. Results from this study using nationally representative data confirm the growing visibility and acceptance among older people of residential care settings that offer services and varying levels of independence to residents. Persons with more education, higher incomes, and who were white non-Hispanic were most likely to select assisted living/CCRC as the best care option. Overall, as many prior studies have documented, aging in place, either with family help or paid help, remains the preferred option, and as many earlier studies documented, nursing home care remains least favored.

Not surprisingly, persons who do not receive help differ in care preferences from those who do, and prefer assisted/living CCRC settings and own home with paid help over other options. Care preferences also varied by current living arrangements. Most striking was that although the percentage of older adults living in non-nursing home residential care settings was low, nearly 6 in 10 persons living in these settings viewed assisted living/CCRC as the best option. By contrast, persons who lived with an adult child mostly viewed options other than living with an adult child as the preferred arrangement. This study, like most, is unable to assess motivation for choices, but a recent review of research on end-of-life care preferences among older adults with advanced illness noted one of many influences on preferences was concerns about being a burden to family members (Etkind et al., 2018). There also may be greater opportunities for disagreement concerning care provision in coresident family care arrangements. Research on this point is scarce, although family conflict has been examined in the context of specific care decisions such as nursing home placement (Gaugler, Zarit, & Pearlin, 1999).

The extent to which older persons' care arrangements match their preferences has not been examined previously to our knowledge. Persons receiving care in 2012 were examined separately from those who began receiving help later (within the next 3 years), since the first group had experience with a care arrangement when preferences were obtained, while the second group did not. In both groups, persons receiving care in non-nursing home residential care settings were more likely than persons in other care arrangements to choose assisted living/CCRC as the best option for care—over half did so. Only a small percentage (15%) of older persons living with a child (and receiving care in 2012) endorsed this option as best; significantly more than for those in other care arrangements (7%) but still quite low. Interestingly, persons in their own home with family help, still the most common care arrangement

for older people receiving help with routine activities, were no more likely than persons in other care arrangements to view this as the best care option. These findings suggest older persons do not necessarily view the care arrangement they have as the preferred option.

The distribution of care arrangements among those receiving help in 2012 and those who began receiving help later differed, reflecting the dynamic nature of care needs and care arrangements. Two out of three persons who started receiving care after 2012 were in own home with family help, in contrast to less than half of those receiving help in 2012. In the latter group, higher proportions were living with an adult child or in non-nursing home residential care settings. These differences reflect the dynamic nature of caregiving arrangements, in response to changes in care needs and other factors, and that early on individuals are more likely to receive family help at home and over time some transition to living with an adult child or moving to an assisted living/CCRC. We were not able to observe among those receiving help in 2012, how long assistance had been provided, but those who began receiving help after 2012 represent persons in their earliest care arrangements. These patterns raise interesting questions about caregiving trajectories that could be investigated further with additional longitudinal data.

Only one in three older persons receiving care was found to be in an arrangement that matched their care preferences. Few demographic characteristics were associated with matches, although older persons, and those who were white non-Hispanic or more educated were more likely to have a care arrangement that matched preferences among those receiving help when preferences were obtained in 2012. Odds of a match were over twice as high for those living in non-nursing home residential care, and substantially reduced for persons living with an adult child.

Contrary to our hypothesis, no relationship was observed among persons receiving care between subjective well-being, satisfaction with one's living situation, or participation restrictions and whether care arrangements were a match with preferred care options. As Kahana and colleagues (2003) noted, empirical results regarding the effect of congruence between environment and persons' needs or preferences on measures of well-being have been mixed or produced limited predictive power. Residential satisfaction has been suggested as a more proximal outcome that would be influenced by person–environment congruence (Kahana et al., 2003), but we found no relationship between whether care arrangements and preferences matched and satisfaction with living situation.

A strength of this study is the ability to examine not only preferences for care arrangements among older adults, but the extent to which preferences are aligned with care arrangements among those receiving care. Use of a standard scenario for eliciting preferences has advantages in reducing social desirability bias (endorsing the care arrangement one has among those receiving care) and has the advantage of being applicable to people who are in care arrangements as well as those who are not. This study also has several limitations. The sample size was small for those who began receiving care subsequent to 2012 when preferences were elicited, limiting our ability to conduct separate analyses for this group. In analyses of care preference/arrangement matches, initial care arrangements were used for persons in this group, whereas current arrangements of unknown duration were used for persons receiving care in 2012. While most findings did not appear to differ between the two groups, inability to control for duration of care arrangement is a limitation of these analyses. Notably, the significant relationship between being in non-nursing home residential care and preferring this option held in both groups. Definitions of care arrangements among those receiving care were constructed to closely approximate the scenario options. However, because only a very small percentage of older people have paid help exclusively (5%; Freedman & Spillman, 2014), persons receiving paid help alone or with unpaid help in addition, were grouped together as being in an arrangement of own home paid help. Among persons receiving care in 2012, about one in five were receiving some paid help, and a higher percentage of those in a care arrangement that included paid help were more likely to see own home paid help as the best option compared with persons in other arrangements.

In summary, while aging in place remains the care preference of many older people, close to one-third chose assisted living/CCRC as the best option, giving support to views that preferences have changed over the last couple of decades. Nursing homes and living with an adult child are rarely the preferred care options, even among those who have this care arrangement. Care preferences vary by several characteristics, including sex, marital status, education, race, and income. However, only about one-third of those receiving care are in arrangements that match preferences, and in the overall sample, ability to match preferences and care arrangements was only related to age. Those in the oldest age group were more likely to achieve this match, which may reflect changes in care arrangements over time, or changes in preferences to match arrangements. That changes in arrangements over time occur is suggested by the differences observed between persons who started receiving care in the years after preferences were obtained and those receiving care at the time. The former group was more often in their own homes relative to other options, such as living with child or in non-nursing home residential care, which were more common in the latter group. These results underline the importance of longitudinal follow-up if we are to understand the trajectories of both care preferences and caregiving arrangements.

The absence of a relationship between quality of life indicators—well-being, satisfaction with living arrangement, participation restrictions—and a match between preferences and care arrangements merits comment. One rationale for enabling persons who receive LTSS to receive

the services they want in the form they prefer, is that there are benefits to the care recipient. We examined indicators of quality of life and while conceptually a relationship was expected with whether care arrangements and preferences matched, there are multiple other factors that may influence the indicators examined here. For example, level of assistance (self-care or mobility assistance vs help with household activities only) was related to higher odds of experiencing participation restrictions. In addition, we elicited preferences for a hypothetical care scenario to reduce social desirability bias in responses (endorsing the care arrangement one has) rather than asking preferences for one's own care (asking which arrangement is the best option for you). To the extent, preferences differ under these approaches, the relationship to quality of life indicators might differ as well. Disentangling the influence of personal, social, and environmental factors that affect quality of life indicators such as well-being or satisfaction from aspects of care arrangements and care preferences remains challenging. A second point is that little is known about stability of preferences for care arrangements over time. Wolff and Kasper (2008) found shifts in what was viewed as first versus second best care options over a 1-year period in a sample of older women. As this study and others have shown, nursing homes are rarely seen as the preferred care option, nonetheless, Zinn, Lavizzo-Mourey, and Taylor (1993) documented high levels of satisfaction among nursing home residents. Arrangements may evolve over time to better match preferences or preferences may change to align with care arrangements. As noted earlier, investigating these questions requires longitudinal follow-up of preferences and care arrangements among older people at various stages—at the start of care and in long-standing arrangements. Finally, we had available a limited set of quality of life indicators, and additional measures, including more in-depth measures of satisfaction with various aspects of living situations, for example, might yield different results.

Preferences remain a guide to what people want, even if these expectations are not always realized. The enduring preference for aging in place and the increased view of assisted living/CCRC as a preferred option signal the direction of future needs for LTSS. Understanding the preferences of older persons in this arena is increasingly seen as both policy-relevant and important for evaluating and improving quality of care. Although aligning long-term care preferences with care arrangements is complex, as noted by Kane and Kane (2001) it is an important step in providing information for better decision making by older adults and their families and an important metric in evaluating the extent to which long-term care policies and programs are evolving to meet the preferences and needs of older adults.

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Conflict of Interest

None reported.

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