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Older Adults' Participation in Nursing Home Placement Decisions

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Abstract

African American (n = 7) and European American (n = 9) older adults newly relocated to a nursing home described the extent of their relocation decision-making participation via semistructured interviews. Additionally, the study identified whether sense of coherence, functional ability, and physical functioning were related to decision participation. Two themes emerged, "They put me in here" and "I/we made the decision (together with others)." Older adults whose decisions were in the "They" category were younger, were African American, had more children, had lower Mini Mental State Examination scores, and had less education than those in the "I/we" category. Findings suggest older adults' participation in nursing home relocation decisions may be determined more by informal support than ability to participate. No significant differences were found in sense of coherence, functional ability, or physical functioning across decision-making categories. Decision-making participation approached significance in a positive association with social support.

Keywords

older adults, discharge planning, decision-making participation, decision making, African Americans, nursing homes

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When older adults require nursing home care, the decision to relocate may be one of the most challenging events that a family can experience. Ethnic groups perceive nursing home placement differently. African American (AA) families typically rely more on informal older adult care support sources than European American (EA) families (Johnson & Tripp-Reimer, 2001). Even though EAs may use more formal support services than AAs, they also rely on family members for assistance. When either formal or informal support services are no longer sufficient, the possibility of relocating to the nursing home becomes a tangible reality for many older adults. Currently in the United States more than 1.5 million adults live in nursing homes, with this number expected to double by 2050 (Jones, Dwyer, Bercovitz, & Strahan, 2009). The extent to which older adults are active participants in the nursing home relocation decision has not been addressed in the literature. In particular, relocation to nursing homes among AA older adults has been understudied despite the increasing size of this group (Johnson, Tripp-Reimer, & Schwiebert, 2000). Understanding relocation decisions, including older adults' participation in the decision to relocate, will become vitally important as the U.S. population aged 65 years and older grows by 20% per year beginning in 2010 (Administration on Aging, 2003).

Literature Review

Decision Making

Decisions are the choices or actions from which one must choose what to or not to do and are based on beliefs about what must happen to achieve goals (Tversky & Kahneman, 1981). Decisions made by or about older adults' health care occur in family and cultural contexts defined by race, ethnicity, socioeconomic status, and geographic location (Caron & Bowers, 2003; Choi, 1999; Gaugler, Kane, Kane, Clay, & Newcomer, 2003). The degree of participation in health care decisions is influenced by a variety of elements, including severity of illness, education, ethnicity, gender, family role expectations, and prior experiences (Clark, Wray, & Ashton, 2001; Mansall, Poses, Kazis, & Duefield, 2000; Sciegaj, Capitman,& Kyriacou, 2004; Shawler, Rowles, & High, 2001).

When the decision is about relocation to nursing homes, there are distinct differences in EA and AA family structures that heavily influence the choices that are made (Johnson, Schweibert, Alvardo-Rosenmann, Pecka, & Shirk, 1997). Johnson and Tripp-Reimer (2001) reported that the actual and culturally preferred care network for both AAs and Latinos is the family. Kersting

(2001) in national study about the impact of social support, diversity, and poverty on nursing home utilization noted AAs had one half the risk of nursing utilization when compared with EAs, and those living with child or spouse had one third less of a chance of relocating to a nursing home. Nonetheless, AA older adults report higher levels of disability than EA older adults, which makes it difficult for family members to provide care, despite familial norms advocating this (Navie-Waliser et al., 2001; Timaris, 2003).

All older adults regardless of racial and ethnic background are at risk for relocation to the nursing home if they live alone, have functional limitations, dementia, or are in poor physical health (Gaugler et al., 2003; Ryan & Scullion, 2000). Many decisions to relocate to the nursing home are made after hospitalization for an acute illness, under conditions of stress, by family members who may have been dominated by members of the health care team (Lundh, Sandberg, & Nolan, 2000; Patterson, Russell, & Throne, 2001). Even when older adults are directly involved in the decision, their participation may be blocked because they are not allowed to fully communicate in a forthright way about their concerns and desires regarding their decisions (Efraimsson, Sandman, Hyden, & Rasmussen, 2006; Huby, Stewart, Tierney, & Rogers, 2004).

Stress Associated With Relocation

Stress associated with decisions to relocate is perceived differently by each individual involved. Antonovsky (1988) used the term *sense of coherence* (SOC) to describe a stable personality trait enabling persons to tolerate stressful events and see them relatively positively. Persons with a strong SOC clarify the nature of a stressor, choose resources to cope with it, and are open to modifying their decisions to deal with the stressor. In contrast, persons with a weak SOC have difficulty confronting problems, identifying resources to solve problems, or are unwilling to change an ineffective course of action that will not resolve or improve the stressor (Antonovsky, 1988). Relatively little is known about how older adults participate in nursing home relocation decisions, and much less is known about how SOC may be associated with this participation. It may be inferred that those with stronger SOC may be more equipped to manage stress and thus are more likely to engage in participation about relocation decisions.

Another concept that may influence stress is self-efficacy. Self-efficacy is influenced by a person's belief in his or her capability to accomplish goals (Resnick, 2002). Similar to SOC, persons with high self-efficacy believe they can succeed in attaining their goals. Self-efficacy may be problematic for

older adults. Easom (2003) noted that poorer self-efficacy found in older adults may be related to a misappraisal of one's capability. Misappraisal in either direction (over- or underestimating ability) may present difficulties for older adults in an impending relocation situation. Particularly problematic is the overestimation of their ability to care for themselves at home. If others (e.g., family members, neighbors, health care professionals) perceive a misalignment between what the older adults believe they can do and what they are doing, relocation may be more likely. This may make adjustment to relocation more challenging because the older adult may not perceive the need for the move and may be less likely to engage and participate.

Relocation Adjustment

Data suggest that for relocation to be successful those relocating must have a sense of control over the move, perceptions that the new home is an improvement over the prior one, have a well-organized plan for the move, and access to a supportive advocate throughout (Armer, 1996; Jackson, Swanson, Hicks, Prokop, & Laughlin, 2000; Mallick & Whipple, 2000; Talerico, 2004). Little is known about the variability of this phenomenon across ethnic groups. Walker, Curry, and Hogstel (2007) found that older adults viewed relocation positively, as another life transition to be accommodated. Nonetheless, relocation also has been identified as a stressful process, accompanied by depression, decreased social support, decreased SOC, and poorer self-perceived health (Johnson, 2006). Iwasiw, Goldenberg, Bol, and MacMaster (2003) found that residents viewed the move to the nursing home move negatively because of feelings of powerlessness, vulnerability, and isolation. Other investigators have found short-term declines in older adults' basic and instrumental activities of daily living after relocation (Chen & Wilmoth, 2004).

The decision to relocate to the nursing home is made for numerous reasons. The literature clearly identified that there are older adults who are at risk for being relocated to nursing homes. How many of those older adults participated in the decision to relocate is not clearly identified. The results of this study will offer more information about older adults' participation in the decision to relocate.

Purpose, Design, and Method

The purpose of the study was two-fold: (a) to identify the extent of older adults' participation in the nursing home relocation decision and (b) to identify the extent that SOC, functional ability, and physical functioning were

related to decision-making participation. A mixed-methods, descriptive design was used to study 16 EAs and AAs (9 females and 7 males), randomly selected by computer-chosen identification numbers from the sample of a larger study. In an effort to study a widely representative subset of the larger study, 24 participants were randomly selected for the subset study (12 per ethnic group). The larger study aimed specifically to describe, across ethnic groups, the participants' roles in the relocation decision-making process of 93 older adults who newly relocated to a nursing home (42 Caucasians and 49 African Americans and 2 Latinos) who completed instruments to describe their SOC, social support, functional ability, and exercise self-efficacy. Sixteen residents were selected to participate in qualitative interviews describing the residents' experiences of their relocation transition. For that part of the study, we wanted a small number of participants from whom we could obtain an in-depth picture of their experiences.

Data are reported here for participants who responded to the complete set of open-ended questions in the Interview Guide, so that we could make complete comparisons. The subset (reported here) participated in a 30-minute semistructured interview within 2 weeks of relocation to a nursing home to delineate support sources used, factors promoting and preventing relocation to a nursing home, and the relocation decision-making process. Members of the subset participated in semistructured, audio tape recorded interviews, conducted either in their rooms or in a quiet location in one of two large, Midwestern inner-city nursing homes where they lived.

The nursing homes had both skilled and intermediate levels of nursing care. One was a not-for-profit facility with 180 certified beds. The other was a for-profit facility with 310 certified beds. Participants were aged 60 years or older, scored of a minimum 18 on the Mini Mental State Exam (to ensure sufficient cognitive functioning to enable participants to give consent, complete study instruments, give reliable information; Folstein, Folstein, & McHugh 1975), and permanently relocated to the facility within the previous 6 weeks. Those who had previously lived in a nursing home were excluded, although those with prior short-term stays were not. If a participant became fatigued during the interview, we completed the interview later the same day.

Interview Guide, Instruments, and Procedure

Qualitative interviews were guided by questions derived from the primary author's preliminary research and included the following: Why did you move to the nursing home? What things were important in your decision to move? How was the decision made for you to move to the nursing home? Who made

the decision? How did you find out about this nursing home? Where did you get information about it? How was this particular nursing home selected? Who helped you get ready to move? What did they do?

The same instruments used in the larger study were administered in an interview format: an investigator-developed Demographic Questionnaire (DQ), Iowa Self-Assessment Inventory (ISAI), Orientation to Life Questionnaire (OTLQ; Antonovsky, 1988), and Self-Efficacy for Functional Ability (SEFA; Resnick & Jenkins, 2000). The ISAI is a 56-item multidimensional instrument aiming to identify subjects' resources, statuses, and abilities. It was developed for use with older adults, and its seven-factor structure accounted for 92% of the variance in factor analytical study (Gilmer et al., 1991). The SEFA is a 9-item semantic differential scale with scores ranging from 0 (*no confidence*) to 10 (*total confidence*) in ability to perform the task described by the item. The internal consistency of the SEFA with older adults has been reported at .92 (Resnick & Jenkins, 2000). The OTLQ consists of 29 items on a 7-point analog scale testing the subscales of SOC. It showed an α coefficient ranging from .63 to .88 (Antonovsky & Sagy, 1985).

Further information about the instruments may be obtained from the authors; the instruments were selected to create a picture of the older adults' perceptions of their social support, inner resources (SOC), and ability to function. Self-efficacy for functional ability may be particularly important, because if older adults believe that they can manage themselves in their home environment, they may be more likely to participate in decisions about relocation and thus may be more apt to remain at home rather than to relocate to a nursing home.

After institutional review board approval, prospective participants were contacted by the nursing home social worker or admission coordinator, given a description of the study, and asked if they would be willing to speak with a study team member (registered nurses trained in study procedures). Those indicating interest were introduced by the social worker or a staff nurse to a study team member; consent and data collection immediately ensued. After quantitative instruments were completed, semistructured interviews were conducted in the same sitting by the primary author (RJ) or a team member.

Data Analysis

Three members of the research team analyzed the data individually and then met to establish a consensus regarding data analysis categories. During analysis, each team member identified themes that emerged from the data,

and categorized the data according to these themes. We met as a group to discuss the themes and reviewed the data during the discussion. We reached consensus on the themes making sure to retain their context in the data transcripts. Data trustworthiness was addressed during the interviews by clarifying the participants' statements. It was further ensured by the team with diligent efforts to retain the context of the participants' statements. Qualitative data addressed Study Purpose 1, which was to identify the extent of older adults' participation in the nursing home relocation decision. We independently reviewed half of the transcribed interviews to orient to the data and begin to understand participants' perceptions of their involvement in the relocation decision. Their perceived involvement in the decision varied widely. We conceptualized this participation as four points ranging from totally uninvolved to totally involved: "They made me/put me in here" (no participation), "They did it for me" (minimal participation), "We decided" (some participation), and "It was my decision" (total participation). We read and discussed all transcripts, deciding via consensus which category was most appropriate. Subsequently, we collapsed the four points into two. The groups were "They put me in here" and "I/we made the decision (together with others)." We used these two categories for comparison with quantitative data in answering Research Question 2, which was to identify the extent that SOC, functional ability, and physical functioning were related to decision-making participation.

The Wilcoxon sum rank test analyzed ordinal-level variables to test the null hypothesis for Research Question 2, "To what extent were the participants' SOC, self-reported functional ability, and physical functioning related to participation in the nursing home relocation?" Chi-square comparisons and Fisher's exact test were used with categorical demographic variables. Participation was coded dichotomously with 0 as *no participation* and 1 as *participation*. An alpha level of $p < .05$ was adopted for determining significance.

Findings

Degree of Decision Participation

I/We made the decision. The category of "I/We made the decision" was a participatory form of decision making ($n = 7$). Participants described strong involvement, even ownership in the relocation decision. In this category, words such as "we," "I," or "mine" were used, and it included varying degrees of participants' perceived involvement. Those extreme examples of

the "I/We made the decision" category were similar to the "They made the decision" category and described being involved, but others such as nieces, daughters, wives, and friends had assisted them. The participant explained,

> [How was this particular nursing home selected?] . . . My niece decided to get someplace to take us . . . she said "let's do this one for now." But . . . we won't be here long, because . . . we're going to a Lutheran home. . . . We were interested in that home, they were building it . . . and we've been over to see it, it's very nice.

Although this participant relied on his niece to assist him and his wife in their temporary move, he is clear that he had a voice in the move being temporary and was involved in choosing the new residence. The situation described depicts decisions in this category where older adults were consultants about when and into which nursing home to move. Some participants were even more descriptive and assertive. One explained,

> Basically my wife looked over several possibilities such as live-in house help and things like that. . . . And we decided that (nursing home's name) provided the most for what we wanted, such as being able to care for yourself primarily, but being able to get help from (nursing home's name) whenever I needed it.

He further described how the decision was made involving other family members,

> Well, my wife and I and our daughter sat down and, my wife's sister . . . wanted to be involved too . . . so . . . I wasn't involved in the conversation about this, but they . . . put their heads together, looked over all the options . . . and picked (nursing home's name).

This represents decisions in this category where older adults partnered cooperatively with family members or friends in choosing to move to a nursing home and which nursing home to choose.

The following participant used a total "I" approach to her decision, she said,

> I told him [doctor] . . . that if I got disabled . . . I would come . . . to the nursing home. Cause I'd been here and it's the cleanest one I've been in . . . so I just made up [my] mind and put an end to the worrying and

> I put myself in here. No one put me in here . . . I made up my mind that I was going and I went.

They made the decision. The category of "They made the decision" comprises statements reflecting less perceived participation. In this category, participants stated they were not involved or minimally involved in the decision ($n = 9$). Statements reflecting that decisions were "done for" them rather than language reflecting cooperation with others indicated the perception of lack of involvement. This category also contained variations of perceived involvement. Those examples of the "They made the decision" category were similar to the "I/We made the decision" category and described providing input with little or no decisional authority. Participants' descriptions categorized as no/minimal participation described others making the decision, with a range of participation. One participant stated,

> My daughter brought me here. . . . I had nowhere to go because of health and property cost me money at the time and I couldn't afford any place else. I didn't have no decision to move here, I never wanted to be here.

Another said, "I came to see my brother and they kept me here . . . they brought me here and they left me here. Nobody helped me, they just told me—you all gonna come by here." Another voiced a similar process saying, "I didn't decide. I didn't pick. They just moved me right on in here . . . a social worker. The clothes I have on . . . are what they brought me away in . . ." Social workers and nurses were sometimes mentioned as deciding without participants' input, for example, "I guess I had to move like she (a nurse) said. The nurse selected it (nursing home) for me." An example of minimal participation is the statement by this participant, who said,

> Why I moved here—that was the best thing we could do was move into this home. Be safer in this home than we are by ourself. I thought they was gonna' take us back home. They brought us here, well I thought we was gonna' check the place out and look at it and take us back home but he didn't.

Being safer in the nursing home than in their own home helped the participants acknowledge this option as "the best thing"; however, the decision process was not as the participant had envisioned.

Table 1. Participants' Demographic Information ($N = 16$)

	No/Minimal Part ($n = 9$), "They Decided," *Mean* (Range)	Total/Some Part ($n = 7$), "I or We Decided," *Mean* (Range)
Age (Years)	74.56 (60-88)	87 (68-97)
Gender		
Female	3 (33%)	6 (86%)
Male	6 (67%)	1 (14%)
Race		
European American	2 (22%)	7 (100%)
African American	7 (78%)	0
Number of children	2.875 (0-9)	2.14 (0-8)
MMSE scores	23.33 (20-28)*	25.71 (23-29)*
Education		
Less than high school	5 (55%)	2 (28.5%)
High school diploma	3 (33%)	3 (33%)
Baccalaureate Degree	1 (11%)	2 (28.5%)

Note. MMSE = Mini Mental State Examination.
*$p < .05$.

Those with little or no participation were more likely to be younger, AA, and male more so than those with some or total participation (Table 1). Less participation was associated with lower Mini Mental State Examination (MMSE) scores, less education, and more children.

Sense of Coherence, Functional Ability, and Physical Function

There was no statistically significant relationship between decision participation and age, gender, race, or education. Table 2 shows scores on the SEFA, OTLQ, and ISAI.

Through the Wilcoxon rank sum test, the null hypothesis was partially retained; there were no significant relationships between SOC (OTLQ; $z = 0.82$, $p = .81$), functional ability (ISAI; emotional balance subscale, $z = 0.09$, $p = .32$, trusting others, $z = 0.41$, $p = .85$, cognition, $z = 0.24$, $p = .30$), self-efficacy (SEFA; $z = 0.51$, $p = .65$), and degree of participation. Social support (ISAI) approached significance ($z = 0.02$, $p = .053$); those with more social support were categorized as participating in the decision.

Table 2. Sense of Coherence, Physical Functioning, and Decision Participation ($N = 16$)

	No/Minimal Participation, "They Decided" ($n = 9$), Mean (Range)	Total/Some Participation, "I or We Decided" ($n = 7$), Mean (Range)
Self-Efficacy for Functional Ability	70 (7-90)	74 (22-90)
Orientation to Life Questionnaire	142 (90-200)	150 (110-183)
Iowa Self-Assessment Inventory		
Social	24 (17-32)*	31 (29-32)*
Emotional	18 (11-30)	24 (13-31)
Trust	23 (10-32)	29 (26-32)
Cognition	23 (11-30)	26 (11-32)

*$p = .053$.

Discussion

In this study, EAs reported total/some participation in relocation decision making, whereas AAs reported minimal to no participation. The finding that there were those who had little or no participation in the decision is not new; other investigators have also identified lack of participation as an issue, particularly in post-hospitalization relocation decisions (Nolan & Dellasega, 2000; Ryan & Scullion, 2000). A new finding is the difference in participation between AAs and EAs. Across both groups there was a tendency for more social support to be associated with greater participation. Family members were not interviewed, so we could not identify reasons for these findings. EAs described family members' role in the decision making as more facilitative than prescriptive. It may be that having more children contributed to lesser participation: children may have more readily perceived their parent as having less capacity to make decisions. In particular, participants in both groups identified nieces as instrumental. Nieces for AAs were not necessarily blood relation but were also fictive kin who facilitated the transition to the nursing home.

Another interesting finding was that problems with functional abilities were not related to participation in the relocation decision. The reason for this unclear, perhaps the issue is as Hays (2002) has identified that functional abilities, particularly in the home environment, are highly contextual. Older adults may see themselves as fully functional at home, whereas others have significant concerns for their physical safety and ability to manage chronic conditions (Popejoy, 2008). In this study there were participants who were

aware of the risk of living at home and viewed the nursing home as safer than their own homes, which helped with relocation adjustment and is consistent with previous research (Ryff & Essex 1992).

Missing in most of the participants' descriptions of relocation decision making was whether options such as community care or assisted living were considered. Taylor and Donnelly (2006) identified that availability of services was a crucial threshold for making the relocation decision. It is important to remember that the nursing home does not have to be the first step to a different, more supported living environment. Public policy and payment mechanisms that force decisions about relocation are often biased in favor of nursing homes over personal care in the community or other types of assisted living (Knickman & Snell, 2002).

When older adults live in poverty they may have few choices about alternative living arrangements once they leave their homes. For those older adults who have few options for independent living, it is vital to recognize and illuminate the feelings of powerlessness, vulnerability, and isolation that may accompany the decision to relocate. Those who were AA described nurses or social workers as being highly involved in the decision. This is also consistent with literature, which identified health care professionals as powerful others who influenced decisions (Johnson, Schewiebert, & Rosenmann, 1994; Opie, 1998; Paterson, Russell, & Thorne, 2001). It is unclear as to why SOC did not seem to influence participation in the decision to relocate. The mean SOC score for those with minimal participation was lower, and the range of scores was more variable than scores of those who had greater participation in the relocation decision. Those who participated in the decision had higher mean scores on the SEFA, and the lowest end of their range of scores was much higher than those who had less participation (although not significant). The trend in the data would suggest that physical functioning may have been more influential than SOC in determining extent of decision-making participation. For older adults who have lower physical functioning and a strong SOC, a sense of manageability, comprehensibility, and meaningfulness in their situation (the subcomponents of SOC) may not be sufficient to overcome the challenges of poor physical functioning and lack of sufficient social support to prevent relocation.

In those with no/minimal participation, it was disturbing that several reported being tricked or lied to and brought to the nursing home unaware. It must be noted that those who perceived minimal to no participation had lower MMSE scores. These scores did not indicate cognitive impairment that would negate their ability to participate. Those with known cognitive impairment were excluded from the study by the MMSE screening cut-point of

18 points. To our knowledge, this has not been previously reported. One participant's family told him that they were taking him to an amusement park for the day. Instead he was left at the nursing home with some clothing in a plastic bag. Several were bewildered as to why they had been placed in a nursing home and with an inability to find out why. Perhaps had assistance that was tailored to support them through the process been offered, their perception of how much they participated would be quite different.

Limitations

Findings from this small sample are not generalizable to the older adult population in general or to AA and EA older adults. Similarly, it is likely that due to the small sample there was not sufficient power to detect variation among the dependent variables.

The issue of mistrust of the investigators by nursing home staff was a challenge in this study. In one nursing home with predominantly AA residents and staff, the investigators encountered deliberate undermining of recruitment. A social worker who was assigned to help with recruitment was concerned that the investigators (who were Caucasian) were taking advantage of poor, vulnerable AA older adults. She was distrustful of the financial reimbursement given to participants for their time commitment in completing instruments and being interviewed. She told family members of potential participants not to allow their loved ones to participate in the study. This was resolved through clear communication between the investigators, the social worker, and the nursing home administrator. Several participants were missed due to discouragement faced by the older adults' family members. This experience highlighted the underlying problem among the public—even among health care professionals—that research may be viewed as taking advantage of vulnerable persons, despite the many layers of review and approval that it may undergo. The study occurred in cities; family involvement and social support may differ in rural versus urban settings (Armer, 1996). Family members were not interviewed. Functional limitations were measured by self-report.

Clinical Implications

The study findings raise implications for practicing nurses who work with older adults through situations that may lead to nursing home placement. It is important for nurses to avoid making assumptions about filial piety in other ethnic groups. There may not be adequate family support for older

adults' decision-making participation, making the role of nurses even more important. In particular, there is a need to assess and counsel those in the older adults' support network (these may be family members, friends, or fictive kin) to ensure that the older adult's decision-making autonomy is respected insofar as this is possible. It may be challenged by limitations in the older adults' ability to realistically appraise their home situation and care needs. This type of extensive involvement is especially challenging during discharge planning in the current health care climate, in which lengths of stay in acute care settings are short and decisions may be made precipitously.

Conclusion

For older adults the decision to move to the nursing home means leaving their home and agreeing to live their life in a very different manner than they have heretofore experienced. This study identified two groups of older adults' decision making: those who were involved and those were not. Participation in decisions about relocation is an important area for future research. For many older adults, regardless of ethnic origin, the need to make a decision to relocate is an illness or fall away from becoming a reality. Issues of how to support older adults and their families as they make this choice are extremely important. The most pressing ethical issue related to relocation of older adults identified in this study was decision-making autonomy.

There were several key findings that are interesting. Nieces, who may or may not be blood relatives, were identified as key relocation facilitators in older adults who participated in the decision making and relocation and were decision makers for older adults who did not participate. This has not been widely reported in the literature and warrants investigation. It is also essential to understand more about how the older adult wants decision making to unfold. Not only is it important to identify who is involved but also how involved they are to be in the process. The role of SOC in decision making was not clarified by this study and warrants further investigation.

The nursing home relocation decision is emotionally difficult for many older adults. For some, the nursing home offers an opportunity to explore new friendships and community involvement. For others it means the loss of valued independence. Understanding what the move means to the older adult as well as their perception of their involvement in the decision to move can help nursing home staff assist the older adult to adjust to their new environment.

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