Transitioning Residents from Nursing Facilities to Community Living: Who Wants to Leave?

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(See editorial comments by Dr. Rosalie Kane, pp 163–165).

**OBJECTIVES:** To examine nursing facility residents’ or their legal proxies’ perspectives on transitioning out of nursing facilities by assessing residents’ perceptions of their ability to live more independently, their preferences regarding leaving the facility, and the feasibility of transitioning with community support.

**DESIGN:** Analysis of survey findings from the California Nursing Facility Transition Screen (CNFTS).

**SETTING:** Eight nursing facilities in southern California.

**PARTICIPANTS:** All chronic maintenance, long-stay residents receiving Medi-Cal (California’s Medicaid program) were eligible for the study (n = 218). Of these, 121 (56%) self-consenting residents or legal proxies were interviewed. No presumptions were made as to which residents were appropriate candidates for transition based on health or functional capacity.

**MEASUREMENTS:** CNFTS contains 27 open- and closed-ended questions on preference, ability, and feasibility of transitioning.

**RESULTS:** Twenty-three percent of residents and proxies believed that the resident had the ability to transition; 46% indicated a preference to transition; and after discussing potential living arrangements and services, 33% thought that transitioning would be feasible. Of those who consented to allow access to their Minimum Data Set 2.0 (MDS) information (n = 41; 34% of the sample), agreement in the assessment of preference was found in 39% of cases.

**CONCLUSION:** Transition decisions are complex and include preference, as well as perceptions of the resident’s ability to live in a more independent setting and the feasibility of transitioning. Compared with the MDS, the screen identified a higher proportion of residents who want to transition, suggesting that a systematic approach to assessing the complex decision to transition is needed. J Am Geriatr Soc 56:1–7, 2008.

Key words: custodial care; nursing facility residents; living arrangements; relocation

For more than 2 decades, long-term care policy efforts focused on home- and community-based alternatives to institutionalization. In 1999, these efforts became a federal imperative with the Olmstead Decision, in which the Supreme Court determined that unnecessary institutionalization violates the Americans with Disabilities Act of 1990 (ADA). To assist states in promoting community-based alternatives, the Centers for Medicare and Medicaid Services (CMS) provided Nursing Home Transition Grants starting in 1998, which tended to target persons younger than 65. In 2003, under the New Freedom Initiative, CMS offered Money Follows the Person Grants as part of rebalancing initiatives to transition persons out of nursing facilities and promote flexible financing systems that follow the individual to the most appropriate setting. The Deficit Reduction Act of 2005 awarded further demonstration grants for rebalancing and increased federal Medicaid matching funds for home- and community-based services for transitioned individuals. A first step in rebalancing is to identify institutional residents who wish to transition, but research is lacking.

Although it is clear that most community-dwelling older adults want to remain in their own homes, little is known about the extent to which long-stay nursing facility residents of any age would prefer to transition to community settings. This study used a comprehensive instrument to explore three interrelated dimensions inherent in long-stay residents’ decisions to transition out of the facility: the resident’s perceived ability to leave, their preference, and the feasibility of transitioning based on community-based supports.

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UNDERSTANDING THE PREFERENCES OF NURSING FACILITY RESIDENTS

Admission and annual assessments of the Minimum Data Set 2.0 (MDS), completed for all residents in state and federally certified nursing facilities, include one question about preference to return to the community, but this single question is not uniformly asked of every resident and instructs assessors to use indirect questions with long-stay residents to avoid creating unrealistic expectations: “It’s been about 1 year that we’ve known each other. How are things going for you here at (facility)?”

The indirect approach is defensible if residents are clear and spontaneous in expressing preferences, but long-stay residents may not consider transitioning to be an option because of a loss of prior housing or an unquestioning acceptance of facility life. A study of residents in three nursing facilities with light care needs found that 70% (n = 20) did not want to remain in the facility, but all but one believed that no other option existed. Furthermore, availability of home- and community-based services to support transitioning long-stay residents varies widely according to state.6 Even if community options exist, residents, family, and legal proxies may be unable to identify and access community-based resources (e.g., accessible housing and transportation). The authors are not aware of other instruments that systematically assess long-stay residents receiving chronic maintenance care or gather comprehensive information on various dimensions of the transition decision using standardized protocols. Instruments such as the MDS allow interviewers wide flexibility in how or even whether preference questions are asked. Apart from the MDS, it is unclear whether other studies have included residents with dementia in transition interviews and, if so, how many residents could not respond or had proxies for healthcare decisions. A clear description of when proxies are used is an important issue in research with long-stay residents.

The study targeted long-stay chronic maintenance care residents funded by Medicaid and excluded those admitted for short-stay Medicare-funded rehabilitation, which is a crucial distinction in research.7,8 Studies indicate that residents who remain in the facility are more likely to have a cognitive disorder and to be covered by Medicaid.9,10 In targeting residents for transition, it is important to differentiate chronic maintenance residents who are unnecessarily residing in institutions from those who are short-stay and will eventually return to the community without an intervention. For example, in 1998, New Jersey launched the Community Choice Counseling Program, and an evaluation indicated that 1,975 clients were transitioned, 86% of whom were satisfied with their transitional living situation,11 yet it is unclear how many long-stay chronic maintenance residents were targeted.

Using a comprehensive screen, the following research questions were asked: What proportion of long-stay residents believe that they are able to transition to a community-based setting? What proportion prefer to leave the facility? After discussing available community supports, what proportion believe that transition is feasible? Are transition decisions stable over time? How does using a comprehensive screen administered to all consenting, custodial, Medicaid-funded residents compare with transition preferences identified by the MDS?

METHODS

The Development of the California Nursing Facility Transition Screen

The California Nursing Facility Transition Screen (CNFTS) was developed from reviews of other instruments (e.g., MDS), input from key stakeholder groups representing persons with disabilities and older adults, and pilot tests in two southern California nursing facilities. Criteria for the screen were that it assessed preference from all Medi-Cal (California’s Medicaid) residents within a facility, was not taxing to complete, and did not create unrealistic expectations about transitioning opportunities. The University of California at Los Angeles institutional review board approved all facets of the project. The screen includes 27 open- and closed-ended questions on reasons for entering the nursing facility, preference to transition, and ability to return to the community. To ensure that respondents are aware of housing and community options before assessing the feasibility of transitioning, the instrument explores potential living arrangements and services.

Participants and Setting

The study targeted all English-speaking residents receiving chronic maintenance (long-term) care covered by Medi-Cal in eight nursing facilities in southern California (n = 218). Residents paying privately and those receiving Medicare-funded rehabilitation were excluded. Non-English speaking residents (n = 4) were excluded from this pilot phase. Seven skilled nursing facilities were affiliated with for-profit nursing facility chains, and one was an independent for-profit facility. Exclusion criteria included locked psychiatric facilities, rehabilitation or subacute facilities, and facilities for the developmentally disabled.

Purposive sampling was used based on inclusion and exclusion criteria. A consultant to the California Association of Health Facilities described the project at a southern California meeting. Eight homes were recruited from nine volunteer facilities that were located in the catchment areas of community agencies assisting in transition. Data retrieved from a public California Website confirmed that the facilities were not atypical of California facilities based on resident characteristics including age, dementia prevalence, and length of stay.

Procedure

With privacy safeguards in place, each nursing facility identified all residents whose stays were funded by Medi-Cal and who were expected to be long-term. Interviewers were graduate students who received 4 hours of training and conducted practice interviews with oversight from a co-investigator to maximize interrater reliability. The first page of each resident’s chart identified self-consenters and those who required a legally designated proxy for healthcare decisions. Nursing facility staff confirmed this information and that this was the same person listed on the MDS as responsible for medical decisions. Because the study did not exclude participants based on cognitive status, the majority
had a proxy, reflecting the high number of residents with impaired cognitive functioning who reside in nursing facilities. Although it is possible that some residents (e.g., with durable powers of attorneys) were cognitively alert and able to express preferences, without Health Insurance Portability and Accountability Act of 1996 (HIPAA) consent, cognitive information could not be accessed. Using a script, researchers contacted self-consenters in person (n = 44). Proxies were contacted by telephone (n = 134), because it was not known when or whether the proxy would visit the facility. The majority of proxies were family members (76%), and the remaining had durable powers of attorney or were conservators, guardians, trustees, or friends. Three attempts were made to contact the proxy by telephone during different times of the day and using all available contact numbers; a script was used to leave messages, introduce the study, and obtain consent. It made clear that all responses would be kept confidential and that participation would not affect care received at the facility.

All who agreed to participate (n = 121) were asked to sign an HIPAA consent; 34% (26 residents, 15 proxies) did so. Participants who were interested in transitioning were more likely to consent, and those with a preference to stay were significantly more likely to decline; some were offended by the request (chi-square ($\chi^2 = 45.82, P < .001)$). Preference information from the most recent full MDS (item Q1a) was compared with the CNFTS. Analyses also compared responses to activity of daily living (ADL) questions (transferring, eating, bed mobility, toileting, personal hygiene, bathing, walking, and dressing) on the CNFTS and MDS. After collapsing the MDS scale into a dichotomy (no difficulty/difficulty) to facilitate comparison with the CNFTS, two of eight items were significantly different: bathing ($\chi^2 = 4.31, P = .04$) and transferring ($\chi^2 = 7.07, P = .008$). In both cases, participants indicated no difficulty, whereas the MDS reported difficulty. Finally, residents who believed transitioning was feasible were asked to sign a release consent to share information with community agencies.

To assess interrater reliability of the CNFTS, 12 interviews were conducted in which two interviewers coded participants’ responses. Agreement was 100% on participants’ preference to relocate and 84%, with a mean kappa of 0.77, for all numeric items. In addition, all proxy respondents were asked for consent to conduct a second interview of the resident to examine proxy reliability issues. Only 9% (8/88) permitted a second interview, and three of these residents did not consent. Of the remaining five cases, proxies and residents reported the same preference about relocation.

RESULTS

Securing Participation in the Study

As Figure 1 shows, 218 Medi-Cal residents were eligible for the study, including 44 (20%) self-consenting residents and 174 (80%) proxies. Researchers were able to contact 178 respondents: all residents and 77% of proxies. Sixty-eight percent of those contacted (n = 121) consented to the screen, resulting in a sample of 33 self-consenting residents (75% of all self-consenters) and 88 proxies (66% of proxies contacted; 51% of all proxies). Forty-one of the 57 participants who did not consent provided researchers with an explanation, including health problems that required 24-hour care (n = 27), not interested (n = 10), satisfied with the facility (n = 3), and unwilling to provide personal information (n = 1).

Ability and Preference to Leave the Nursing Facility

Participants were first asked about ability to transition: “Do you think you (your relative) would be able to leave the nursing facility and live somewhere else now?” Sixty-nine percent (n = 84) responded that the resident was not able to leave, 23% (n = 28) indicated that the resident was able, and 7% (n = 9) were unsure. Although more than twice as many proxy as resident interviews were conducted, only 25% (n = 7) of those indicating that the resident was able to leave were proxies, and 75% (n = 21) were residents ($\chi^2 = 8.72, P = .01$). When asked why the resident was unable to leave, 81% (n = 68) gave a reason, including need for facility level of care (n = 34, 50%), inability to perform basic activities such as walking or eating (n = 23, 34%), and safety concerns (e.g., falling, wandering) (n = 4, 6%).

Interviewers then addressed the second component of the decision to leave—preference: “Would you (your relative) want to live somewhere other than the nursing facility?” Fifty-six (46%) indicated that the resident wanted to leave the facility, 42 (35%) did not want to leave; and 23 (19%) did not know. A greater percentage of proxies (86%, n = 36) than residents (14%, n = 6) responded that the resident did not want to leave the facility ($\chi^2 = 16.09, P < .001$). To determine why participants did not want to transition, they were asked: “What are some reasons you (your relative) want(s) to continue living in the nursing facility?” Thirty-four of the 42 participants who did not want to leave provided responses: need for a high level of care (n = 19, 56%), like nursing facility and staff (n = 10, 29%), and nursing facility is the most appropriate placement (n = 5, 15%). About one in five (n = 24, 20%) indicated that residents were able to transition and preferred to leave.

The next section of the CNFTS provides information about community-based living arrangements and supportive services. Participants were asked whether they thought various housing and service programs were good options for the resident. For those who responded “no” or “don’t know,” the interviewer listed ADLs and instrumental ADLs (IADLs) and asked whether the response would change if the resident could get assistance with these tasks. If the participant said “yes” or “don’t know,” the interviewer proceeded with the next section. If the respondent again said “no,” the interview was stopped. For respondents who initially said “yes” to the question about living arrangements and types of support, the interviewer also listed ADLs and IADLs and asked whether assistance in these areas was important for the resident. Fifty-two respondents (43% of those interviewed) said “yes” or “don’t know” to the question of the need for or benefit of support; for these respondents, the interviewer proceeded with the next section.
Living Arrangements and Assistance

Those who continued the screen were asked to identify one or more potential living arrangements if the resident transitioned from the facility. Responses were no place to go (n = 17, 33%), live alone in an apartment or home (n = 14, 27%); live with other family members (n = 12, 23%) or with a partner or spouse (n = 3, 6%), assisted living facility (n = 4, 8%), and group home (n = 7, 13%).

To further examine the need for support and the capacity for transitioning, interviewers asked respondents about need for assistance with ADLs (transferring, eating, bed mobility, toileting, personal hygiene, bathing, walking, dressing) and IADLs (telephone, cooking, medications, housework, shopping, transportation, managing money). Residents had a mean of 3.0 ± 1.7 ADL difficulties, with most needing help with bathing or showering (n = 44, 85%) and dressing (n = 34, 63%). Residents or proxies reported a mean of 5.6 ± 1.6 IADL difficulties. Most problematic were housework (n = 49, 94%), shopping (n = 47, 90%), and transportation (n = 47, 90%).

Feasibility of Transitioning

The interview concluded by asking: “If you had help available for any of these services, would you (your relative)
be able to leave the nursing facility?” Although this question is identical to the earlier question about ability to transition, it was posed after a discussion of preferred living arrangements and services needed. Of the 52 respondents who completed the entire screen, 40 (77%) believed that transitioning was feasible, seven (13%) felt it was not feasible, and five (10%) were unsure. Of the 40 respondents who believed that leaving the nursing facility was feasible, the majority were self-consenting residents (n = 26, 65%) rather than proxies (n = 14, 35%) ($\chi^2 = 8.72, P = .01$). Therefore, of the 121 who were initially interviewed, 28 (23%) thought that the resident was able to transition; 56 (46%) indicated a preference to leave; and after learning about service and community living options, 40 (33%) believed that transitioning was feasible.

Feasibility of Transitioning: Stability over Time
To assess stability, all 40 participants who indicated that transition was feasible were re-interviewed approximately 3 weeks later. Thirty-four (85%) consented to a second interview (23 residents, 11 proxies). Overall, 27 participants (79%) responded with a stable affirmative response toward transitioning; 17 were residents (74% of the resident sample), and 10 were proxies (91% of the proxy sample). Of these 27 participants, 81% (16 residents, 6 proxies) completed release forms to enable researchers to refer their cases to a community-based agency.

Comparison with MDS Preference Question
Of the 121 residents who consented to the interview, permission was obtained to secure MDS data on 34%
Preference data from CNFTS were compared with MDS question Q1a: “Resident expresses or indicates a preference to return to the community.” Agreement with the CNFTS and MDS Q1a was found in 39% of responses (n = 16). For 46% of responses (n = 19), the screen indicated that the resident preferred to transition, and the MDS indicated that the resident did not want to leave ($\chi^2 = 4.67$, $P = .10$). In one case, the MDS indicated that the resident had a preference to leave, whereas the CNFTS found the opposite. Twelve percent (n = 5) were unsure according to the screen; the MDS was recorded as “no.”

Comparing Resident Characteristics

For those who provided HIPAA consent, Table 1 compares characteristics of subjects who believed transitioning was feasible with characteristics of those who did not want to transition. Respondents in the latter category responded “no” to at least one of the questions on ability, preference, or feasibility. One participant who provided consent was omitted from the table because he or she was unsure whether transitioning was feasible. Although the power to identify differences was reduced because only one-third of the original sample signed an HIPAA consent (26 residents, 15 proxies; 34%), it was clear that participants who thought transitioning was feasible were less cognitively impaired and younger.

DISCUSSION

Given increasing support for consumer choice and state-level policy momentum driven by the Olmstead Decision, rebalancing efforts, and Money Follows the Person grants, the goal of the study was to investigate long-stay residents’ attitudes toward leaving 24-hour facility care. Attempts to interview all Medi-Cal residents or their proxies using no health or functioning exclusion criteria resulted in a sample of 121 of 218 eligible to participate (56%). When asked about residents’ perceived ability to move, 23% (n = 28) felt that they were able, but a focus on preference rather than ability resulted in a doubling of positive responses (n = 56; 46%). Finally, after consideration of needs and options, 33% (n = 40) felt that it was feasible to transition from the facility. As these results indicate, transition is a complicated decision in which the individual weighs the capacity and the desire to relocate, as well as the community support available to meet anticipated care needs. The answer to who would like to transition depends on how the question is asked.

It can be argued that residents and proxies who believed that transition was feasible were most serious about transitioning and most likely to work closely with community agencies on the complicated tasks of securing housing and arranging for services. Respondents may want to move and believe in their ability to leave, but the discussion of available living arrangements and service needs helped to illuminate potential assistance, as well as difficulties, before determining the feasibility of transitioning.

In terms of stability of the transition decision, 79% of participants (n = 27) who consented to a second interview continued to believe that transitioning was feasible. Instability in the remaining 21% reflects the gravity of transition decisions. This subset could be targeted for further educational or supportive efforts to better understand their concerns. Because another study that reported the stability of residents’ preferences toward transition could not be found, it was not possible to determine whether the design of the CNFTS produced a higher rate of instability than alternative methods of questioning. In practice, more than one interview may be necessary to enable residents and families to reflect on this important decision, although care must be taken not to harass those who are firm in their choice. Furthermore, 81% of participants (22/27) who completed the release form took a proactive step that demonstrated their commitment to transition. These residents, who were referred to community-based agencies to begin the transition process, can be seen as a test of the effectiveness of the screen.

A corollary goal was to compare findings from the CNFTS with those from the MDS. The MDS assesses preference with a single item based largely on the assessor’s judgment and cautions assessors against creating unrealistic expectations. By systematically interviewing all long-stay Medi-Cal–funded custodial residents and proxies regardless of residents’ health or cognitive status, the screen identified a large proportion who wanted to transition even though the MDS indicated a lack of preference to leave (n = 19; 46%). Although approximately one-third of participants allowed access to their medical records, this finding suggests that a direct questioning approach should be employed and does not create unrealistic expectations, because participants acknowledged that some residents needed a high level of care or that the nursing facility was most appropriate. At the same time, the CNFTS is not necessarily better than other screens in use, because no published data were found about whether other protocols worked with custodial residents.

This is a pilot study that explores a previously unaddressed matter in the geriatric literature—long-stay residents’ perspectives on transitioning out of the facility. Several limitations should be considered. First, the nursing homes, although similar in most characteristics to other southern California facilities, were volunteers, and a selection bias that may make their resident populations unique cannot be excluded. This type of selection bias is present in all research that cannot mandate a nursing home’s participation. Second, question wording in the screen was not identical to the MDS, because the latter contains an inadequate, vague question about preference (i.e., “How are things going for you?”). Further complicating the comparison, few people who did not want to transition permitted access to their records. Also, the MDS preference question is asked only upon admission and annually thereafter, so responses could be up to 12 months old. These factors limit the ability to determine whether the discrepancy between the MDS and the CNFTS is due to method of questioning or timing.

Third, the study did not conduct stability interviews with residents or proxies who said “no” to the move, and some of these participants may have later changed their mind. This is a significant limitation, but many proxies were definite that the resident could not move and did not want further contact. Furthermore, the majority of proxies did not permit a second interview with residents to examine
reliability. In addition, in the script for the CNFTS, a range of community-based options was listed, although it may have been more effective to provide specific examples of persons with similar needs who are successfully residing in the community. Fourth, only English-speaking residents were interviewed.

Fifth, it is important to acknowledge the substantial sample loss, because proxies could not be located or refused to participate. It is unclear how these proxies would have responded, and some could have been in favor of relocation if the protocol included an education component. Moreover, proxies may have changed their mind if educated about community supports or by observing other residents successfully transition, although it also is likely that these efforts would be unsuccessful in a group that was unwilling to complete a 10-minute interview. The percentage of people who want to transition was determined by dividing the number that expressed this preference by the number that was interviewed. If the denominator included those who refused the interview, then the percentage would be lower.

Finally, interviewing all long-stay chronic maintenance residents had two implications, which are not study limitations but rather matters that must be confronted when conducting studies with cognitively impaired residents. First, respondents who were designated proxies had to be approached first, which is necessary unless a new ethical and legal argument can be developed and accepted by internal review boards. Second, it is possible that some proxies did not consent to the interview after learning its purpose, because they strongly believed that the resident was too impaired and that the nursing facility was the best living arrangement. In addition, Medi-Cal completely covered the cost of the nursing facility stay. In the community, it is unlikely that all expenses would be covered.

Although it cannot be assumed that all self-consenting residents want to relocate, residents who were able to self-consent were more likely to express a stable preference to transition. If interviews with all long-stay residents are not feasible in practice, the findings suggest that self-consenting residents are excellent targets for transition and MDS item A9, which records the legal proxy decision-maker, could be used. Fewer interviews would need to be conducted, and a higher number of transition candidates might be identified. Future efforts could also examine the influence of proxy relationship (e.g., family, legal guardian) on transition preferences.

This study represents an important first step in an area with no previous systematic research. All long-stay, Medi-Cal–funded chronic maintenance nursing facility residents were approached and allowed to express their preferences and beliefs without presumptions as to which residents were good or bad candidates for transition. The interview identified a significant proportion of people expressing a preference to relocate, an important population according to Olmstead principles. In supporting the philosophy of consumer direction, the CNFTS presents the opportunity and the means for long-stay nursing facility residents to create a different future for themselves and receive the needed resources to meet this goal.

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REFERENCES