Bringing Assisted Living Services Into Congregate Housing: Residents' Perspectives

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Purpose: Bringing state-subsidized assisted living services (ALS) into congregate housing (CH) is a strategy for reducing rates of nursing home placement. This article discusses CH residents’ reactions as a new ALS program was introduced in their housing, and it provides recommendations for others who are considering the implementation of similar programs.

Design and Methods: Focus groups and face-to-face interviews with residents in a CH facility explored their experiences over time with the new ALS program. Residents were interviewed before the program was initiated and 6 months later as a way to better understand their knowledge of and feelings about the program.

Results: A qualitative analysis of the interview data revealed several patterns of complex attitudes and emotions linked to the program. Although the overwhelming majority of residents endorsed the program as a way to avoid nursing home placement, few understood the features of the program (e.g., cost and eligibility requirements). ALS participants’ accounts of services suggested the presence of a highly “medicalized” approach.

Implications: When new community-based models are implemented for elders, policy makers need to evaluate how these programs affect quality of life. Further, program guidelines for bringing ALS into existing housing have to address how the program complements the home-like nature of the housing.

Key Words: Policy, Long-term care, Quality of life

Connecticut has authorized a program to offer affordable assisted living services (ALS) in state-funded congregate housing (CH) as part of its effort to develop a comprehensive long-term care plan. The goal of the program is to reduce expenditures for publicly funded long-term care while expanding the range of community-based and home-based care options available to frail elders. Connecticut, similar to other states, has developed plans to provide affordable assisted living to its residents (Namazi, Begen, Jackson, & Chafetz, 2002). This article highlights an innovative approach to ALS delivery within the context of CH. Similar to assisted living models in other states (e.g., Minnesota), the program uses existing housing to deliver ALS (Mollica, 2002).

There are several distinctive features of this program. First, using multiple funding streams to pay for ALS, the program brings ALS into state-funded CH, which enables residents to age in place as their needs change, rather than requiring them to move to assisted living facilities or a nursing home. Second, ALS may be provided to residents who meet a range of medical and functional requirements as determined by different funding sources. Third, the services are targeted to the residents most in need to preserve the home-like nature of the setting.

In response to concerns raised by a CH task force, a pilot program to bring ALS into congregate housing was implemented. Based on the success of this pilot program (Sheehan, 1999), the state legislature authorized the provision of ALS in all state-funded CH. Under this program, any CH had the option to link with a licensed ALS agency (ALSA) to offer ALS to its residents. Three state agencies were charged with implementing the program statewide. Each agency represented a different component of the program: (a) CH was represented by the Department of Economic and Community Development; (b) Public Health and Addiction Services covered licensure and oversight of the ALSA; and (c) the Department of Social Services determined funding and eligibility for some participants. It took quite some time for these agencies to coordinate how the program would be implemented (e.g., financial eligibility, cost, and staffing). Consequently, even as the program was introduced to the Directors of CH, many of the details of the program had yet to be established.

Given the complexity of the program guidelines, a detailed description is beyond the scope of this article; however, a brief overview is provided. Minimum health and functional eligibility criteria
specify that program participants must have chronic but stable health conditions, and they must require assistance with at least three activities of daily living. For most ALS recipients, a comprehensive assessment is conducted by an access agency. This assessment places residents into one of three levels of need on the basis of current risk of nursing home placement, which determines the maximum allowable monthly rate for ALS. An initial financial screening is conducted by the CH staff. An applied income formula is used to determine the appropriate funding stream for ALS, based on the resident’s income and assets. Funding may come from the state home care program (Connecticut Home Care Program for Elders), or a special subsidy from the Department of Economic and Community Development. A small group of participants above certain income caps may be required to pay for some services.

Under ALSA regulations, a nurse supervisor works 20 hr per week on site and 24-hr emergency coverage is available. The nurse supervisor provides limited nursing services and oversees the aides who provide direct care. For each participant, the ALSA nurse develops an individualized service plan. The State of Connecticut licenses the ALSA rather than the residential facility. However, regulations specify that ALS must be provided in a residential setting that offers the following core services: three meals a day, housekeeping and laundry services, transportation, social programming, and 24-hr security. (For CH, the requirement that the residential community providing the ALS offer three meals per day was modified to allow aides to prepare meals when needed.)

Purpose

The purpose of this research was to elicit residents’ reactions, concerns, and appraisal of the ALS program as it was introduced into their housing. Using an in-depth, qualitative approach, we sought to capture how residents experienced the introduction of ALS into a congregate facility. By listening to the concerns of residents in response to this intervention, we hoped to gain insight into possible ways of enhancing residents’ quality of life when similar interventions are replicated elsewhere.

Congregate Housing Facility

The housing site, one of 22 state-subsidized CH facilities, is a 45-unit, two-story building that is managed under the auspices of a Local Housing Authority in a suburban town. It has been in operation for 10 years. It is typical of other state-funded congregate facilities in its size and basic service package, which includes a daily meal, weekly housekeeping services, social and recreational programming, 24-hr security response, laundry facilities, and transportation services. At the time of the study, the average age of the residents was 87 years, and the residents were overwhelmingly White women.

Information about the ALS program was disseminated to residents in a variety of ways. Written information was provided to all residents. Group meetings were held for interested residents and their sponsors. Both the CH Director and a representative from the ALSA were available to answer individual questions. The program was described as a way to provide support to residents who were experiencing difficulties in carrying out activities of daily living.

Methods

Focus groups and face-to-face interviews were completed with residents in order to understand their experiences with the program as it was introduced and implemented. First, four focus groups were conducted to identify residents’ concerns. Information from these groups was used to construct an interview guide for individual interviews. The CH Director then identified 25 residents who were willing and able to participate in a 30- to 45-min individual interview. She was asked to select a diverse group of residents with a range of service needs. Residents who expressed interest were asked to provide informed consent. Participants were then interviewed at two intervals: when the program was first announced (Phase 1) and after the program had been in operation for 6 months (Phase 2). Interviews were taped, transcribed, and analyzed.

Twenty-five residents were interviewed in Phase 1. The sample was composed of 6 men and 19 women. The age range was 72–93 years (mean age: 85 years). Length of residence ranged from 2 months to 10 years.

At Phase 2, 4 of the 25 were unavailable (one moved to a nursing home, one moved in with her son, one was hospitalized, and one had died). Consequently, follow-up interviews were conducted with 22 residents (21 originals plus one additional ALS recipient who was added to maximize the number of ALS participants in the sample). Of these, 5 were ALS participants. They represented one third of the total residents who were enrolled in the program.

Results

Phase 1

As the program was introduced to residents, almost all respondents stated that it was a “good idea” to bring in services. However, most felt that other residents were more appropriate candidates for incoming services. In fact, only 4 of the 25 residents expressed any interest in receiving services, and only
Residents expressed many reasons for their reluctance to receive ALS: (a) a desire to maintain independence ("use it or lose it"), (b) the struggle to resist identity disruption, and (c) a desire to maintain an existing support network (typically a family member or long-time aide). These themes, which were not mutually exclusive, suggest that receiving ALS might disrupt the current equilibrium in their lives.

In addition, residents’ reluctance to consider services appeared to be linked to their lack of understanding about how the program would operate. Residents had questions about the cost, eligibility requirements, and the staff. There were many potential sources of confusion. Details of the program were still being finalized as information was presented to the residents, so during many question-and-answer sessions, specific concerns could not yet be addressed. Further, many residents commented that the information was presented to large groups in the facility’s dining room, where it was difficult to hear the speakers. Still other residents noted that memory deficits made it difficult to retain the information (e.g., “I don’t ask questions because I don’t remember what they are telling me”). To further complicate matters, many residents confused the ALS program with the Housing Authority’s plans to build a new, freestanding assisted living facility in the adjacent lot. The net result was that despite the Director’s concerted efforts to convey the information clearly and accurately, most residents felt they lacked adequate knowledge to make informed decisions about the program.

**Phase 2**

Six months after the program was initiated, 15 residents were receiving services. Five ALS participants were interviewed. During the interviews, a majority of respondents—both ALS participants and nonparticipants—were grateful to have the program in place. Residents expressed a sense of security with the awareness that services were available should they become necessary in the future. They saw the program as a means of preventing or delaying nursing home placement.

Because residents who were already receiving home care services had the choice of either staying with their current service provider or joining the ALS program, participation in the ALS program did not definitively distinguish frail and independent residents.

Of the five respondents who were receiving ALS, three switched care providers to join the program, whereas two were receiving services for the first time. All respondents who were participating in the ALS program expressed general satisfaction with the services. Several comments revealed concerns about the program: inconvenient scheduling of services, strict 15-min service intervals, aides hurrying to provide services, and more services than desired. One woman receiving assistance with meal preparation reported that her aide had just 15 min to prepare and clean up the meal. Another participant said, “Everyone just seems to be in a hurry. Like when giving a shower, they just want to be done.” One participant felt pressure to receive a higher level of care than he felt was necessary, which involved a considerable out-of-pocket expense. Comments such as these suggest that despite expressed “satisfaction,” the approach to delivering services involves a high degree of control with little consumer choice. This conflicts with the philosophy of assisted living in which “residents’ preferences are known; attempts are made to honor resident priorities and help them implement their preferences; and residents are, as much as their abilities allow, in control of their lives” (Kane & Wilson, 2001, p. 24).

**Implications**

Participants’ comments about ALS highlight the importance of ensuring quality of life when new models are implemented (Spector, Shaffer, Hodlewsky, De La Mare, & Rhoades, 2002). When the State of Connecticut authorized the provision of ALS in state-funded CH, no provisions were made to evaluate the program. Concerned about the impact of the program on quality of life, we listened to residents’ experiences. Although residents appreciated the ALS, participants expressed feelings of powerlessness related to service delivery. The paradoxical nature of the findings requires greater attention. Without attention to consumer preferences, programs serving elders with disabilities may view them as passive clients who have no other alternative (Hofland, 1990). Further, the mechanism for delivering ALS may have constrained the autonomy of the residents. Because ALS were provided by home health agency staff, nurse supervisors and aides may have tended to view participants as “medical clients,” which empowered “the medical provider, not the client, to make decisions about life circumstances that may have no medical foundation whatsoever” (Raymond & Wentworth, 1993, p. 49). Notably, participants who expressed concerns about the program said that they had not shared these concerns with the nurse supervisor or with other staff members. Similarly, the ALS participant who was receiving a higher level of service than he wanted felt that he had no choice about the matter. In addition, ALS participants’ perceptions that the staff were rushed may have been the result of the pressure on staff to deliver services by using a cluster care model (serving multiple residents within a limited time frame; Feldman, Latimer, & Davidson, 1996).

2 of those appeared to have functional needs that would qualify them for the program.
Although a cluster care model offers an efficient and cost-effective approach, participants may feel disgruntled when they sense the constant time pressures on staff. This is particularly problematic when services are defined as discrete blocks of time (e.g., 15 min) rather than by task accomplishment (e.g., meal preparation). Although long-term care programs must address issues of cost and efficiency, plans of care can be developed with specific attention to strategies that enhance the delivery of services to multiple residents in a more seamless manner.

We recommend that the following steps be taken when long-term care services are added to residential settings.

First, there should be specification of an assisted living philosophy and policies that ensure residents' dignity and self-determination (Kane, 2001; Kane & Wilson, 2001). Policies must ensure that residents who receive ALS have a means of expressing their values and preferences for service delivery. Further, because the housing and ALSA staff operate within different cultural milieus characterized by differences in values, language, and problem-solving strategies, the first step is to acknowledge these differences (Sheehan, 1992). Failure to recognize these differences may create an uneasy balance between the two cultures, which may result in conflict.

Second, there should be mandated staff training. Staff members need to understand the value that residents place on independence, privacy, personalized services, and the symbolic significance of independence (Ball et al., 2000; Frank, 1999; Mitchell & Kemp, 2000). Staff training for both the housing and ALSA staff should include issues such as resident autonomy, consumer preferences, aging in place, and how to elicit residents' concerns. Changes in the behavior and attitude of the staff can go a long way toward enhancing residents' feelings of control and satisfaction with services.

Third, there should be clear information-delivery systems for residents and their families. Clear channels of communication have to be developed as programs are implemented in residential settings so that elders and their families have ready access to information about the program as it evolves. Essential information should include details about the program (e.g., choice option, cost, and level of services) and contact persons for answering questions as they develop.

Fourth, there should be mandated quality of care outcome evaluations that incorporate residents' perceptions (Frank, 1999; Schmitt, 2000). Quality of care assessments should include information “about recipients' perceptions of the quality of care being provided and the processes being used to achieve this care, so that successful models can be developed” (Schmitt, 2000, p. 177). Therefore, health outcome research must balance cost considerations with quality of care.

Although we acknowledge the methodological limitations of our research, which focused on a single CH facility, a nonrandom sample of residents, and a small number of ALS participants, our results provide some insight into the concerns of residents as a new program is introduced. Consequently, as states develop long-term care alternatives, an emphasis on cost should be balanced with quality of care issues. Although the ALS program in CH may ultimately reduce expenditures for nursing home care, elders’ rights to services that enhance their dignity, self-determination, and quality of life should not be ignored. Finally, an essential component in developing and implementing long-term care models is the articulation of a philosophy that guides the program (Kane, Kane, & Ladd, 1998). Such an operational philosophy is particularly important when housing and services are combined (housing + services models), because the resulting long-term care product is more than the sum of its parts. If personal and health care services are provided to CH residents without an accompanying philosophy that emphasizes resident autonomy, self-determination, and privacy, then the program is little more than a home care program serving frail older persons in their independent apartments. It is important for residents of CH to continue to enjoy the benefits of living in a setting that is sensitive to their preferences and needs.

References


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