

# **Assisted Living Research, Practice and Policy: The Status of Translational Research**

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# Who is in assisted living

- Many residents are seriously impaired.
- In Florida in 1995, 25% had 3+ ADL impairments or serious cognitive impairment. In 2003, 87% in the Florida Medicaid waiver ALF program had no caregiver and 70% had a dementia diagnosis—both higher percentages than in the nursing home population.
- A recent study from Washington (Hedrick, et al., 2003) found residents at all impairment levels, including those with 6+ ADL impairments, though adult foster homes had a higher percentage of more impaired residents—and lower payments.
- The four-state survey of AL and nursing homes (233 facilities) by Zimmerman et al. (Eds.) (2001) found a wide range of impairments among residents, including many in small facilities, which also had higher proportions of African-American residents.
- The limits of AL in terms of resident impairment, level and care needs are far from clear.

## Outcomes: Resident assessments of assisted living and health outcomes

- Hawes & Phillips (2000), in their survey of 1,500 residents in 300 high-privacy, high-service facilities, found that most reported they were treated with dignity (80%) and respect (60%).
- They also found:
  - Concern about staffing level and turnover.
  - 26% who needed help with toilet reported unattended for assistance.
  - 90% thought they could stay in ALF as long as they wanted, but most were uninformed about policies on retention and discharge.
  - Staff appear satisfied with working conditions, but need to know more about dementia and normal aging.
  - Only 12% of those discharged over a 12-month period expressed dissatisfaction with care.

## Outcomes (cont'd)

- Hedrick, et al. (2003) found very high levels of satisfaction in AL and AFH programs—overall and with each aspect of care—92% reported that moving to AFH or AL was a good decision. They also found that:
  - ... AL residents were significantly more satisfied with respectful treatment from staff and with their apartment or room, possibly indicating the influence of the stated AL philosophy of autonomy and privacy, and the required physical layout of separate apartments with lockable doors, kitchenettes, and the like.

## Outcomes (cont'd)

- A recent study of LTC consumers in a sample of nursing homes, AL facilities and in-home programs (Salmon, 2001) found that ALF residents had higher life satisfaction scores—there were no differences for happiness, depression and satisfaction with care/staff scores.
- Rosalie Kane and her colleagues (2001) found that ALFs and nursing homes in Oregon achieve comparable outcomes in terms of activities of daily living (ADL) trajectories, pain and discomfort levels and psychological well being, after controlling for differences in baseline conditions. Although nursing home residents were substantially more impaired than those in ALFs, these findings are encouraging in terms of the capacity of ALFs to accommodate “aging in place” by providing necessary healthcare services.

# Reasons for discharge from AL

- Hawes, et al. (2002) found that:
  - On annual basis, 8% move to PHs, 4% to another ALF, and 81% remain; most moved because they needed more care. A decline in cognitive status was only resident variable that significantly affected likelihood of entering a nursing home.
  - Residents in facilities with a fulltime RN involved in direct care were half as likely to move to a nursing home. When different formulations of staff/service variables were used (any RN arranging for nursing care), the relationship between services and outcomes was not significant
  - It appears that these alternative staffing arrangements, or just better staffed facilities, are no substitute for a fulltime RN who does direct care.

## Reasons (cont'd)

- In their four-state study of 233 AL facilities (three types) and nursing homes, Zimmerman et al. (Eds.) (2001), found that, with the exception of a discharge policy related to inability to walk, facility type (small, traditional, new model) made no difference in likelihood of discharge based on resident characteristics—factors that mattered included state in which facility was located (FL vs. NC), ownership type (for-profit more likely to discharge) and age of facility (older facilities more likely to discharge).

# Significance of assisted living values (autonomy, privacy, dignity)

- In the third report of findings from the national assisted living survey, Hawes & Phillips (2000) found that:
  - The vast majority (85%) of their respondents reported that their top two priorities on entering the ALF were the availability of a private bath (#1) and private bedroom. Among those who had left an ALF (19% over 12 months) most (65%) continued to identify these same privacy-oriented priorities. The other 35% of those discharged identified the presence of an RN or staff and the quality of the staff as their top two priorities.
- Zimmerman, et al. (Eds.) (2001) found that AL facilities do more to support resident choice and autonomy than nursing homes and place fewer restrictions on activities.

# Significance (cont'd)

- Privacy may be especially important for the quality of life for cognitively impaired residents. A recent study by Zeisel, Silverstein, Hyde et al. (2003) of 427 residents in 15 Alzheimer's special care units, ranging in size from 20 to 50 residents, found that:

The environmental features associated with both reduced aggressive and agitated behavior and fewer psychological problems include (privacy) and personalization in bedrooms, residential character, and an ambient environment that residents can understand. Characteristics of the environment associated with reduced depression, social withdrawal, misidentification, and hallucinations include common areas that vary in ambiance and exit doors throughout the SCU that are camouflaged.

. . . the design features, by providing residents with greater control over their own lives, empower them and thus reduce their tendency to withdraw and even to be situationally depressed.

## Significance (cont'd)

- Salmon (2001) found that high levels of personal control and residence in an ALF generates much higher life satisfaction scores than high personal control levels in nursing homes or home care. This finding may mean that:
  - For many frail elderly persons, especially those with thin or non-existent caregiver networks, assisted living may also be the best setting in which to achieve personal control and autonomy. ALFs can offer the kinds of resources, especially staff services, transportation and social activities, necessary to make the achievement of control/autonomy a far more practical matter than may be possible in many in-home environments, where achieving the same level of opportunity to exercise personal control is beyond the financial means of most individuals or the public sector to provide, or too great a burden on the individual's informal care providers.

# Small ALFs and foster care

- Findings from research by Zimmerman et al. (2001), Morgan et al (1995), Hedrick (2003) and Kane (1991) substantiate the significance of small facilities and foster homes (mom and pop operations) in terms of affordability and quality of life and their relative vulnerability to conventional regulatory strategies—less privacy and technical healthcare availability, but more affordable homelike and informal, closer relationships among residents and staff and with the local community.

## Small ALFs (cont'd)

- The perspective on the value of small residential facilities is well expressed by Morgan et al (1995):
  - . . . As the twin pressures of cost-containment and quality control push care toward an assembly-line, rationalized state, it was encouraging to us to see the personalization of care achieved in the small board-and-care homes. Attention to individual detail in planning meals and outings can, for example, separate adequate care from a more personal ideal to which many in American society would readily subscribe. The rationalized, assembly-line care, in contrast, attends to whether caregiving tasks are completed but views workers as substitutable replacements for one another (Diamond 1992). Turnover in caregivers sharply curtails the potential for a caring, individualized relationship to evolve, reducing the gratifications to providers and permitting perfunctory treatment of clientele.

# ALFs: Summary of findings

## Summing up

- Need more research!
- AL serves residents with a wide range of physical and cognitive impairments, but a substantially smaller percentage of residents with serious impairments (4+ADLs) than nursing homes.
- A high percentage of AL residents are cognitively impaired, which is a major reason for this change.
- AL is, on average, less expensive than nursing homes (\$1,000-3,000), NH \$3,000-5,000).
- AL residents express high levels express high levels (generally) of satisfaction with their quality of life and highly value the principles of AL (autonomy, privacy, dignity).

## ALFs: Summary of findings (cont'd)

- The salience of these principles (efforts to achieve) does appear to distinguish AL from NHs, but much remains to be addressed—private rooms, negotiated risk, admission-discharge constraints, flexible living (meals, activities, bed time)
- Healthcare services are not as available in AL which restricts aging in place for the more seriously impaired—Is this a developmental issue or a definitive limit on the scope of AL?
- AL seems to have achieved a reasonably effective balance between safety and the AL principles at this point—this balance may shift as more seriously impaired persons become AL residents with major regulatory and funding implications.

# Implications of what we know for assisted living regulation

- Desire for alternatives to PHs and aging in place should not be frustrated by excessive regulation.
- The preservation/enhancement of the fundamental values of AL (autonomy, privacy, dignity) should be the first priority in the development of AL regulations. AL as the principle setting for achieving these outcomes.

# Implications (cont'd)

- Regulations should be designed to maximize the demonstrated capacity of AL to serve seriously impaired persons and allow aging in place, if specified conditions are met (i.e., clear consumer preferences, availability of necessary services). Providers, however, should be free to decide the level of care they are willing to accommodate.
- States as natural laboratories for the emergence of AL regulation that achieve an effective balance between freedom and safety, quality-of-life and quality-of-care outcomes. Avoid “rush to judgment” that could destroy what we most want to preserve.

## Implications (cont'd)

- Serious consideration, however, should be given to Hawes et al. findings concerning the negative impact of cognitive decline in assisted living residents and the apparent positive impact of RN care on preventing movement to a nursing home or facilitating aging in place.
- The provision of sound dementia care and skilled nursing care are essential components of any efforts to maximize the aging-in-place potential of assisted living.

# Regulation-related approaches

Given these research findings and their policy implication, we would suggest the following regulation-related approaches:

- For the most part, we should continue to take a wait-and-see approach to assisted living regulation. We need to learn more about the effects of the different regulatory schemes across the states, the impact of Medicaid waiver funding on the demographics of assisted living, etc.
- There are some areas, however, where initiatives are needed and some where we should be prepared to stand our ground.

# Public disclosure

- Assisted Living Federation of America (ALFA) and other organizations have already moved to develop model programs for fully informing (potential) residents and their families about what facilities offer, how much they cost and how costs change in response to changes in resident need and other issues identified by the GAO as full disclosure problems in assisted living.
- This is an issue that probably needs to be clarified by state regulators, especially in the area of dementia care. Residents and their families should not be surprised by provider decisions.

# Admission/retention criteria

- In order to maximize consumer choice, admission and retention criteria should be as inclusive and flexible as possible and staffing should be sufficient to meet the needs of individual residents.
- Restrictive criteria would keep many frail elderly out of assisted living and the quality-of-life conditions they want and force them into nursing homes as could uniform staffing standards by making assisted living less affordable.
- Staffing should be based on assessed resident needs.
- Providers should be free to determine the level of care they are willing to provide, hence the level of resident impairment/need they can accommodate (the fulltime RN issue).

# Negotiated risk

- Negotiated risk contracts, if clear, non-coercive conditions are met, should be permitted on an expansive basis in assisted living.
- Risk contracts will probably continue to evolve through law and regulation over the next ten years and become an increasingly important vehicle for consumer choice and direction and aging in place.

# Dementia care

- The industry should develop a set of model guidelines for dementia care which could be used by states to develop regulatory standards designed to ensure an acceptable level of care for residents with dementia. Initially, these standards should be applied only to providers who claim to provide specialty services.
- There are a number of unresolved controversies (separation of resident, locked units, etc.) in this area and standards should be developed and implemented very carefully and in close collaboration with the industry.

# Privacy/single residency

- Physical plant/environmental designing regulations should be designed to create as homelike a living environment as possible, to provide privacy and enhance autonomy.
- We know from research by Kane, Hawes and others and from our own experience that assisted living residents and potential residents place a *very* high priority on privacy as a quality-of-life value. Most fundamentally, this means a strong preference for private rooms and bathrooms and, to a lesser but still very significant extent, kitchenettes.
- The assisted living experience in Oregon and Washington, which require these privacy provisions and where costs are within the industry norm, would seem to indicate that privacy is affordable.

# Employee training

- The industry tendency to have employees play multiple roles is generally positive in that it can help dilute the stifling effects of hierarchy and avoid the alienation and detachment of command and control structures and help maintain staff morale, creativity and commitment.
- This tendency toward “universal worker” roles can also help contain staff costs.
- It also creates a greater need for cross-training, both pre-and-in-services training, especially for workers in facilities serving more physically and cognitively impaired residents.

# Nurse delegation

- Nurse delegation, especially as it related to medication management, should be implemented in order to promote affordability—experience of states with nurse delegation.

# Quality-of-life outcomes

- Advocates, providers and policymakers should press for resident-oriented quality-of-life outcomes measures based on the fundamental values of assisted living—autonomy, privacy, dignity and the experience of a fuller life, however impaired one may be.
- This approach to performance accountability would prioritize systematic consumer feedback on such variables as enjoyment, meaningful activity, quality of relationships, spiritual well-being, autonomy, privacy and dignity as well as the resident's sense of security and physical comfort (Kane, 2001).

# Resident assessment

- We are not ready for a standard uniform resident assessment and case planning instrument in assisted living á la MDS.
- State initiatives in this area are interesting and will prove helpful in the future. But, we need more research and development and debate about the tradeoffs before requiring a single instrument.
- This is another area where states are a natural laboratory and we need to learn much more about the comparative results and give time for the emergence of a consensus.

# The Assisted Living Workgroup

- The vast majority of the recommendations from the Assisted Living Workgroup (most supported by a majority to two-thirds) are essentially consistent with the perspective offered here—interpretation of research and application to regulatory issues. A major contingent of Workgroup participants, however, supported a substantially more stringent regulatory approach.

# Additional strategies

- In addition to quality assurance in assisted living, there are two other strategies that can be used that are more consumer (resident) oriented than conventional nursing home regulatory schemes.
  - Case management/care advocate for publicly supported residents.
  - Consumer direction—“portable” funding.
  - Room and board/housing funding issue.

# Research agenda

- The research agenda for assisted living should be as comprehensive as possible but with a focus on the following areas, most of which are related to the regulatory, practice and policy issues addressed here.
- We have suggested that assisted living may be an especially appropriate setting for the housing and care of cognitively impaired residents. It is also apparent, however, from the Hawes, Phillips et al. research that cognitive impairment is a major reason for discharge from assisted living and transfer to a nursing home. We need to know more about the kinds of assisted living settings and services that are most effective for the cognitively impaired and that have the greatest potential to allow them to age in place with an adequate quality of life. The research by Zeisel et al. on special care units represents the kinds of research (behavioral outcomes) that we need much more of on this issue.

# Research agenda (cont'd)

- We also need much more research on the capacity of assisted living to serve residents with serious healthcare needs, including end-of-life care. This area of research overlaps with the need to learn more about the utility of negotiated risk contracts and the limits (resident competence, facility capacities, etc.) within which they can be executed.
- Given the documented value of privacy to assisted living residents and the essential role it plays in the rationale for assisted living, we simply cannot accept the assumption that single occupancy is too expensive for the less affluent residents and those who are publicly supported. We need systematic research designed to determine the cost feasibility of private rooms and to identify methods that can be used to maximize their affordability.

# Research agenda (cont'd)

- Although the results to date appear to be reassuring, we need more research on the effects of nurse delegation acts, especially in the areas of medication management and care for chronic conditions (colostomy care injections, etc.) that require training and routine supervision. These are contentious issues, as demonstrated by the debates in the Assisted Living Workgroup and they are likely to become increasingly salient as the population of assisted living residents with serious healthcare needs grows and tests the capacity of facilities to allow residents to age-in-place, as many residents would like to do as long as possible.
- In what ways does size matter in assisted living and adult foster care? Does the small size of adult foster homes and five-to-ten bed assisted living facilities provide enough quality-of-life benefits (as reported by residents) to compensate for diminished economies of scale and reduced (potentially) access to more sophisticated forms of healthcare? Should regulatory distinctions be made between larger, better-capitalized facilities and small (mom and pop) facilities?

# Research agenda (cont'd)

- Quantitative quality-of-life measures, based on resident responses and extensive systematic research, need to be developed for use in assisted living and other long-term care programs. Quality of life is not likely to gain parity with quality-of-care regulatory criteria without the development of a set of widely recognized quantitative measures designed to operationalize assisted living goals/values (Kane).
- Research of case management demonstration projects should be conducted to determine the efficacy (cost-effectiveness) of case managers as a source of quality assurance (quality of care and life of residents) in assisted living. We have suggested that case managers (care advocates) can be more effective than regulatory surveys in assuring adequate quality in assisted living. This notion needs to be tested and its cost feasibility determined.

# Research agenda (cont'd)

- Assisted living should be part of comprehensive evaluations of all long-term care programs, especially those supported by public funds. This means conducting follow-up research comparing the risk adjusted (health characteristics, impairment levels, etc.) costs and outcomes (consumer satisfaction with quality of life and care, changes in health conditions and impairment levels, movement to more restrictive settings, etc.) of all home- and community-based programs, including assisted living, adult foster homes and nursing home care. This is difficult research to conduct given current data limitations, but we can begin by using Medicaid claims data for waiver-funded programs, Medicare data, consumer data collected by states and by conducting surveys.
- We also need more qualitative (observation, ethnographic) research in community-residential settings, comparable to some of the comparatively extensive qualitative research conducted in nursing homes over the last 30 years. This kind of research is especially important, given the quality of life *raison d'etre* of assisted living.