A·C·C·E·S
Alberta Continuing Care Epidemiological Studies

DESIGNATED ASSISTED LIVING (DAL) AND LONG-TERM CARE (LTC) IN ALBERTA:

SELECTED HIGHLIGHTS FROM THE ALBERTA CONTINUING CARE EPIDEMIOLOGICAL STUDIES (ACCES)

EXECUTIVE SUMMARY

May 2011

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EXECUTIVE SUMMARY

The **Alberta Continuing Care Epidemiological Studies (ACCES)** was a province-wide research program involving over 2,000 older adults residing in designated assisted/supportive living facilities (DAL) and in long-term care facilities (LTC) between 2006 and 2009, their family caregivers, and the facilities in which they lived.[1] The objectives of ACCES were:

(1) to examine the health, social needs, and quality of care of older adults living in DAL and LTC facilities in Alberta;
(2) to identify the mix of services provided to these residents, including assistance from family caregivers; and,
(3) to examine health outcomes across settings, taking resident and facility characteristics into account.

ACCES was built around a large-scale longitudinal study that relied on numerous data sources. Comprehensive baseline assessments, using the interRAI-AL and interRAI-LTCF, were conducted with 1089 residents in 59 DAL facilities and 1000 residents in 54 LTC facilities across Alberta. Baseline interviews were completed with 974 DAL family caregivers and 917 LTC family caregivers. 1-year follow-ups were attempted with all residents and caregivers. Facility surveys with an administrator, manager, or director of care who was familiar with the facility and had direct knowledge about residents were undertaken.

This report provides descriptive profiles of facilities, residents, and families first for DAL and then for LTC. A brief comparison of the two settings follows. A discussion of issues and challenges facing DAL and LTC concludes the report.

DAL and LTC Facilities

Several facility characteristics were examined, including location, ownership, type and size of the facility, admission and retention criteria, health and wellness services, hospitality services, the physical and social environment, and fees.

- 59% of DAL facilities were owned by non-profit organizations, 36% by for-profit organizations and 5% by the health region. In comparison, 44% of LTC facilities were owned by non-profit organizations, 26% by for-profit organizations, and 30% by the health region.
- The size of DAL facilities, taking all levels of care into account, ranged from 10 to 507 spaces, with an average of 108 spaces. The LTC facilities ranged in size from 20 to 502 spaces, with an average of 134 spaces.
- 59% of LTC facilities had LTC spaces only, compared to 10% of DAL facilities having DAL spaces only.

[1]At the time of the study, designated spaces in Alberta were referred to as designated supportive living (DSL), designated supportive housing (DSH), enhanced lodge (EL), designated assisted living (DAL) and enhanced designated assisted living (E-DAL). DAL is used in this study to incorporate all these types of spaces.

- 42% of DAL facilities had units devoted solely to their DAL residents while 58% mixed DAL residents with other clients in the same unit. All LTC spaces were on units designated solely for LTC.
- DAL facilities were most likely to unequivocally admit and retain individuals with limited mobility restrictions and those with bladder control that could be managed by the resident and/or staff and bowel control that could be self-managed. Relatively few DAL facilities unequivocally admitted or retained individuals who required 2-person transfers, needed mechanical lifts, required assistance with feeding or tube feeding, required assistance with bowel control, or had cognitive/behavioural issues, reflecting the availability and mix of staffing. In comparison, LTC facilities admitted and retained individuals with mobility limitations, cognitive/behavioural problems, bladder/bowel incontinence, and feeding issues.
- In terms of staffing, both DAL and LTC facilities had personal care attendants (PCAs) on site 24/7, with the exception of 5 DAL facilities. 46% of DAL facilities and 33% of LTC facilities had licensed practical nurses (LPNs) on site 24/7.
- The availability of registered nurses (RNs) differed significantly between DAL and LTC. 92% of DAL facilities had RN coverage on call only while 7% had RN coverage on site 24/7. In comparison, 98% of LTC facilities had 24/7 on site RN coverage. One-third of DAL facilities had a GP formally affiliated with the facility, compared to 98% of LTC facilities. These differences in staffing mix have important implications for the type of residents who can safely be cared for in the two settings.
- Services provided and/or arranged in both settings included assistance with personal care, meals, housekeeping/cleaning, and some type of exercise/health program. DAL facilities were less likely than LTC facilities to provide incontinence supplies, therapies in the facility, and planned recreation activities as part of base fees.
- 78% of DAL facilities and 11% of LTC facilities had private rooms only. More frequent in LTC was a mix of private and semi-private (2-person rooms) (82%). Other LTC arrangements included private/semi-private/3-person rooms (4%) and private/semi-private/4-person rooms (4%).
- Variation in base fees was evident, reflecting in part the size/design of the resident's apartment or room and the services provided. In DAL, the range was from $800 - $2650 per month while in LTC, it was $1261 - $1542.

DAL and LTC Residents

The profile of residents focused on sociodemographic characteristics, the move to DAL/LTC, clinical issues, physical function, cognitive function and mental health, social and lifestyle characteristics, use of health services, and 1-year outcomes.

- The average age of residents was 84.4 in DAL and 84.9 in LTC. Over one-half of the residents were aged 85+ (55% DAL, 56% LTC).
- 77% of DAL residents and 66% of LTC residents were female. 71% of DAL and 59% of LTC residents were widowed while 15% of DAL and 25% of LTC residents were married.

- The average number of disease diagnoses per resident was 4.6 in DAL (range 0-14) and 5.2 in LTC (range 0-12). Dementia, hypertension, arthritis and depression were the most prevalent diagnoses in both settings. Mental health needs were evident, with 58% of DAL and 71% of LTC residents having a diagnosis of dementia and 34% of DAL and 44% of LTC residents having a diagnosis of depression.
- The average number of regularly prescribed medications per resident was 8.3 in DAL (range 0-23) and 7.9 in LTC (range 0-21).
- 54% of DAL residents and 60% of LTC residents showed some level of instability in terms of clinical complexity and health, as indicated on the interRAI Changes in Health, End-stage Disease, and Symptoms and Signs (CHESS) Scale.
- 57% of residents in both settings experienced pain in the 3 days prior to the assessment, as measured by the interRAI Pain Scale.
- Differences emerged in the physical functioning of DAL and LTC residents, with LTC residents generally being more impaired. 42% of DAL residents and 5% of LTC residents were categorized as independent on the interRAI ADL Self-Performance Hierarchy Scale that takes personal hygiene, toilet use, locomotion and eating into account. Of interest are the 28% of DAL residents assessed as requiring extensive assistance to total dependence in ADLs and the 18% of LTC residents assessed as independent or having limited impairment. Further investigation is warranted to determine if these individuals were in settings that best meet their needs.
- DAL and LTC residents exhibited varying levels of social involvement, with social isolation being a concern for some residents. 47% of DAL and 56% of LTC residents were assessed as spending, on average, little or no time involved in activities when awake and not receiving treatment/ADL care.
- 18% of DAL residents and 34% of LTC residents were assessed as having low to no social engagement, when considering the ease of interacting with others, pursuit of involvement in the life of the facility, participation in social activities of long-standing interests, and visits or other interaction with a long-standing social relation or family member. 30% of DAL residents and 38% of LTC residents were reported to have said or indicated that they felt lonely.
- 12% of DAL residents and 5% of LTC residents were reported to have had an overnight acute care hospital stay in the 90 days prior to their assessment while 16% of DAL and 6% of LTC residents had at least one emergency room visit. DAL residents (63%) were less likely than LTC residents (90%) to have had at least one physician visit in that time period.
- Appropriate, ongoing oversight and monitoring in both settings is critical. At least 25% of both DAL and LTC residents triggered the following interRAI Clinical Assessment Protocols (CAPs): falls, pain, cardio-respiratory, prevention, urinary incontinence, physical activities promotion, activities of daily living, cognitive loss, mood, communication, activities, and social relationships. The physical restraints and behaviour CAPs were triggered by at least 25% of LTC residents but less than 25% of DAL residents. These CAPs indicate that there are clinical, physical, cognitive function/mental health, and social issues that require attention and comprehensive care planning.

- At the 1-year follow-up, 16% of DAL residents were in LTC and 16% had died (including 3% who moved to LTC prior to death), while 31% of LTC residents had died. Some characteristics associated with a move from DAL to LTC were consistent with facility retention criteria such as cognitive and ADL impairment, and aggressive behaviours as well as resources/staffing mix.

DAL and LTC Family Caregivers

The profile of family caregivers focused on sociodemographic characteristics, visiting patterns, caregiving tasks, the effect of caregiving on employment, caregiver burden, financial costs to caregivers and residents, and experiences at the time of the 1-year follow-up.

- Generally, family caregivers were involved in the lives of DAL and LTC residents. At the same time, there were caregivers who visited relatively infrequently and provided limited assistance.
- Caregivers tended to be daughters (51% DAL, 40% LTC) or sons (23% DAL, 19% LTC). 19% of LTC caregivers were the resident's spouse, compared to 6% of DAL caregivers. This is consistent with the residents' marital status.
- 59% of DAL caregivers and 52% of LTC caregivers were employed.
- The majority of the caregivers visited at least once a week. 37% of LTC caregivers and 25% of DAL caregivers reported visiting at least 3 times per week. This may reflect the higher percentage of spousal caregivers for LTC residents.
- The majority of both DAL and LTC caregivers shopped and paid bills/managed finances for the resident. Compared to LTC caregivers, DAL caregivers generally were more likely to make appointments for the resident, take him/her to these appointments, talk to the family physician or a specialist, contact Home Care or another agency, and telephone to see how the resident was doing. This may be due, in part, to differences between DAL and LTC in the availability of other support, health care providers and services in the settings.
- For some employed caregivers of DAL and LTC residents, caring for the resident was perceived to have had an impact on employment, such as having to leave work for doctor's appointments, missing work, or having to leave suddenly.
- Most caregivers indicated that caring for the resident had a positive effect on their self-esteem and rated the experience positively. Some reported negative consequences, in terms of disrupted schedules, financial problems, a lack of family support, or health problems, based on the Caregiver Reaction Assessment Scale. DAL caregivers were more likely than LTC caregivers to experience disrupted schedules, financial problems and health problems related to caregiving.
- Reflecting the difference in the services provided/arranged and associated costs covered by DAL and LTC, DAL family caregivers were more likely than LTC caregivers to report that they or the resident incurred costs for items such as prescription and over-the-counter medications, incontinence supplies, and foot care. DAL caregivers were less likely to note costs associated with personal laundry; 27% of DAL facilities included personal laundry as part of the base fee while none of the LTC facilities did so.

- At the 1-year follow-up, 71% of DAL and 76% of LTC caregivers reported there had been no change in the amount they visited. 12% of DAL and 5% of LTC caregivers perceived that visits had increased, while 17% of DAL and 19% of LTC caregivers indicated a decrease. Increased care needs, the caregiver's own health, and distance appeared to be related to these changes.

Views about DAL and LTC

DAL and LTC family caregivers shared their views on staff, services and the environment, and policy as well as their overall rating of the facility and recommendation to others. DAL residents were also asked to assess various features of their care and the facility.

- DAL and LTC family caregivers were generally positive in their assessment of staff but were concerned with staff shortages and turnovers. DAL residents also tended to give their staff relatively high ratings.

- Opportunities for social/recreational activities emerged as an area requiring attention, from the perspective of DAL and LTC family caregivers and DAL residents.

- DAL and LTC family caregivers' satisfaction ratings of services highlighted several areas for improvement. While some caregivers were very satisfied, many were mostly satisfied, not satisfied or quite dissatisfied. Of particular note were concerns regarding housekeeping/cleaning, meals/food, personal laundry, bathing, oral care and toileting.

- With regard to policy, the lack of clarity surrounding the circumstances related to a move from the facility was apparent in both DAL and LTC. There was greater clarity with regards to the policy about fees.

- When asked if they would recommend the facility to others, 76% of DAL family caregivers and 71% of LTC family caregivers responded "definitely yes". On a scale of 0 (worst possible) to 10 (best possible), the average rating for the facility overall was 8.4 for DAL residents, 8.3 for DAL caregivers, and 8.1 for LTC caregivers.

Issues and Challenges Facing DAL and LTC

A wide range of priority issues and challenges were identified. Highlighted are issues regarding admission and retention of residents, meeting residents' needs, expectations regarding the involvement of family caregivers, staffing, and communication among all parties. The interrelationship of these issues is recognized. The degree of disability and the mix of residents with varying needs influence the functions that staff have to perform and the required staffing level. Appropriate policies, staffing, supervision, and communication are critical in the oversight and management of existing and emerging health concerns.

Various aspects of admission and retention were challenging in both DAL and LTC. The need for clarity in admission and retention criteria was particularly apparent for DAL. At the time of the study, there were no province-wide admission criteria. The First Available Bed Policy was identified by some DAL and LTC facility representatives as an issue for some families when the resident moved to a facility that was not geographically close. This was particularly apparent in rural communities where care options may be limited and a move to another community was required. Ongoing review and discussion of

admission/retention criteria in DAL are necessary as this care option evolves and finds its place on the continuum of care. Monitoring and regular care planning/implementation are needed to ensure that residents' needs are safely being met in these care settings.

Meeting the complex needs of DAL and LTC residents represents a major challenge in both settings. Of concern is the ability of the setting to deal with existing health issues, to detect and manage emerging health issues, and to facilitate transition to other care settings, if needed. For example, as noted earlier, there were relatively high rates of dementia and depression in both settings. Addressing mental health needs and determining the optimal mix and integration of mental health services and policies for appropriate placement is critical. The administration and management of medications requires ongoing review and oversight in both settings. The extent to which staff have the necessary training to administer and manage medications needs to be further investigated. The provision of appropriate assistance with ADLs as well as ongoing and frequent assessment and monitoring is necessary as the residents' health changes. Enhancing social engagement is also a key area for improvement. In particular, given staffing levels/mix in DAL and the general lack of recreation aides/ specialists, innovative approaches to providing opportunities for social activities are required.

Family caregivers play an important role in the lives of DAL and LTC residents. Their ability and willingness to provide support needs to be taken into consideration. Expectations about their involvement need to be clearly outlined when the resident moves into the facility and reviewed on a regular basis. Providing support to these caregivers is important, as is the recognition that caregivers have varying levels of commitments, abilities, and interests in caring for the residents.

Appropriate staffing and supervisory arrangements in DAL and LTC are critical to ensure residents receive quality care. Staffing challenges such as recruitment, retention, the need for more staff, and the need for changes in staff roles were identified for both DAL and LTC. Facility representatives spoke of the staffing issues they faced and family caregivers often identified staffing as a concern and an explanation for why the resident did not always receive the services they needed.

Finally, improved communication between the various stakeholders is imperative, in both DAL and LTC. These stakeholders include residents, their family caregivers, staff, program planners, policymakers, owners/operators, and other sectors of the heath system. Ongoing discussion regarding roles and responsibilities of family, facility staff, and in the case of DAL, Home Care/Supportive Living is required. Family caregivers generally need to better understand their own as well as staff's roles. Staff need to better communicate with each other and with family members to ensure that the residents receive the best care. Increased understanding of the capacity of DAL and LTC is required by other sectors, particularly primary and acute care. Both operational issues and policy issues warrant increased discussion to allow for timely examination of issues and the identification of possible actions.

Conclusion

ACCES has provided a unique opportunity to examine DAL and LTC facilities, residents and family caregivers across Alberta. This report provides a descriptive overview of selected study findings and serves as a catalyst for the identification of questions for further analyses or new data collection efforts.

ACKNOWLEDGEMENTS

Numerous individuals have provided invaluable assistance to this research program. Residents, family caregivers, and facility staff willingly answered our many questions. The staff in the DAL and LTC facilities and Home Care/Supportive Living welcomed us and facilitated recruitment and data collection. Our study nurses collected a wealth of information in a timely manner with their thorough assessments and interviews and a number of research assistants were involved in the data entry and cleaning. Our study coordinators assisted in various aspects of the research, including the development of the data collection tools, recruitment, coordination of data collection and data entry, and interviewing participants. Our research associates have been involved in study design and data analysis. Our co-investigators and our decision-making partners provided important insight into issues related to DAL and LTC and identified important questions to be answered. Dr. Catherine Hawes and Dr. Charles Phillips who conducted a U.S. national study of assisted living generously shared their reports, tools and expertise with us and assisted in the first training session for our study nurses. The success of ACCES reflects the commitment of all these individuals to this initiative.

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Funding was provided through grants from Alberta Innovates: Health Solutions (Alberta Heritage Foundation for Medical Research #200400893) (PIs: Maxwell and Strain); the Canadian Institutes of Health Research's Institute of Aging and the Rural and Northern Health Research Initiative (HAS-63179) (PI: Strain); the Canadian Institutes of Health Research (MOP 81216) (PI: Maxwell); and Alberta Health Services and Alberta Seniors and Community Supports as part of the Collaborative Research Grant Initiative: Mental Wellness in Seniors and Persons with Disabilities (PI: Maxwell). The support of all sources is gratefully acknowledged. The results and conclusions are those of the authors and no official endorsement from the funding agencies is intended or should be inferred.


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