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)

May 2011

Prepared by: Laurel A. Strain, Colleen J. Maxwell, Deanna Wanless, & Erin Gilbart
On behalf of the ACCES Research Group

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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.

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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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INTRODUCTION

Assisted/supportive living is increasingly being offered as a residential care setting for older adults who require more assistance than can be provided in their own homes but do not yet require the 24-hour unscheduled registered nursing care provided in **long-term care settings.** Despite the expansion of this setting in Canada, relatively little research attention has focused on assisted/supportive living, its residents, the services provided, the involvement of family and friends, changes over time, or comparisons to long-term care settings.

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/friend caregivers, and the facilities in which they lived. 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.

Following a brief discussion of **key definitions** and the study **methodology**, this report provides a descriptive overview of selected **study findings**. Topics addressed include:

- Characteristics of the DAL facilities[2] and LTC facilities;
- Characteristics of DAL and LTC residents, including a profile of their health status at baseline and an examination of their 1-year outcomes;
- Characteristics of the family caregivers of DAL and LTC residents, including a profile of their caregiving contributions and concerns at baseline and changes over the 1-year period; and
- Issues and challenges facing DAL and LTC.

This report serves as a catalyst for the identification of questions that may be addressed with further analyses of the ACCES data or require new data collection efforts.

[2] 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.

Defining Assisted/Supportive Living, Designated Assisted Living and Facility Living in Alberta

The Supportive Living Framework developed by Alberta Seniors and Community Supports (2007) highlights key differences between the types of facilities studied in ACCES:

- Supportive living means a philosophy and an approach for providing services within a housing environment. It provides a home-like setting where people maintain control over their lives while also receiving the support they need. The building is specifically designed with common areas and features to allow individuals to "age in place". Building features include private space and a safe, secure barrier-free environment. Supportive living promotes residents' independence and aging in place through the provision of services such as 24-hour monitoring, emergency response, security, meals, housekeeping, and life-enrichment activities. Publicly-funded personal care and health services are provided to supportive living residents based on their assessed unmet needs. (p. 7)

- Designated assisted living/designated supportive living/designated supportive housing: The term "designated" refers to spaces within a supportive living facility where there is a contract between a regional health authority and a housing operator. Under the contract the facility operator provides health and support services based on assessed need. The regional health authority, in collaboration with the operator makes decisions regarding admission and discharge. Regional health authorities differ in terms of their target populations for these spaces, type and availability of health care staff, and the services that the operator must provide as part of the contract. (p. 10)

- Facility living includes "nursing" homes under the *Nursing Homes Act* and "auxiliary hospitals" under the *Hospitals Act*. Persons with complex and chronic health needs who require support and 24-hour registered nursing care are placed within these institutional settings. (p. 10)

Compared to supportive living (including DAL), facility living (including LTC):

- Cares for residents with medical conditions that may be serious, chronic and/or unpredictable and require access to registered nursing services on a 24-hour basis. These professionals are able to respond to the need for unscheduled assessments and prescribe interventions.

- Provides 24-hour registered nursing care from nursing staff that are able to respond immediately and on a sustained and unscheduled basis.

- Has specialized physical design and infrastructure to address highly complex needs.

- Is governed by the *Nursing Home Act* or the *Hospitals Act*. (p. 4)

These definitions provide a framework to examine the characteristics of DAL and LTC facilities, residents and family caregivers involved in ACCES. It is important to recognize that assisted/supportive living is an option that continues to evolve. The findings presented here reflect the situation at the time of ACCES data collection. It is recognized that some changes in assisted/supportive living may have been implemented since that time (for a description, see the Alberta Health Services website www.albertahealthservices.ca).

ACCES Methodology

A brief overview of the ACCES methodology is presented here (see Wanless, Strain, & Maxwell, 2011 for further information). ACCES was built around a **large-scale longitudinal study** that relied on numerous data sources (Table 1). From 2006-2009, comprehensive **baseline** and **1-year follow-up assessments** were conducted with **1089 residents** in **59 DAL facilities** and **1000 residents** in **54 LTC facilities** across Alberta. Data were also collected from **family/friend caregivers** and **facility representatives**. Five former Health Regions (Calgary, Capital, Chinook, David Thompson and East Central) participated in ACCES; these regions represented a mix of urban and rural settings (see Appendix A for number of facilities, residents and family caregivers by region).

TABLE 1. ACCES STUDY COMPONENTS AND SAMPLE SIZES

	Sample Size	
Study Component	**DAL**	**LTC**
ACCES Facilities		
Facility Surveys with Administrators	59	54
ACCES Residents		
Baseline Resident Assessments	1089	1000
1-Year Follow-up Resident Assessments	892	691
Baseline Views of Residents Survey	704	N/A
1-Year Follow-up Views of Residents Survey	464	N/A
ACCES Family Caregivers		
Baseline Family Caregiver Interviews	974	917
1-Year Follow-up Family Caregiver Interviews	791	609
Discharge Interviews with Family Caregivers	199	38
Decedent Interviews with Family Caregivers	148	273

Ethical approval was obtained from the University of Calgary Conjoint Health Research Ethics Board, the University of Alberta Health Research Ethics Board, and the University of Lethbridge Human Subject Research Committee. Administrative approvals from the health regions and/or facilities were also obtained.

DAL and LTC Facilities

- ACCES began with the selection of DAL and LTC facilities. A DAL/LTC facility was **eligible** for consideration in ACCES if:
  - It had been in operation for at least 6 months;
  - There were 4 or more residents aged 65 years or older in smaller facilities and 10 or more in larger facilities; and,
  - It did not primarily serve clients with a mental illness or developmental disability.

- 60 DAL facilities across the 5 health regions met the eligibility criteria. One facility refused participation. The remaining **59 DAL facilities** were involved in ACCES.

- Given the larger number of LTC facilities in Alberta, it was not possible to include all LTC facilities that met the eligibility criteria. Within each region, facilities were divided in small versus large facilities based on the median bed size for the region. A random sample of facilities was then selected within each group for each region. 59 facilities were randomly selected and 5 refused participation. The remaining **54 LTC facilities** were involved in ACCES.

- A **facility survey** was completed in person or via telephone with a facility representative. This representative was the facility administrator, manager, or director of care who was familiar with the facility and had direct knowledge about the residents. Questions focused on location, ownership, type and size of the facility, admission and retention criteria, staffing, health and wellness services, hospitality services, the physical and social environment, fees, and issues/challenges facing DAL or LTC. Some questions were modeled on those used in a U.S. national study of assisted living (Hawes, Phillips, & Rose, 2000) while other questions were developed specifically for ACCES and the Canadian context.

DAL and LTC Residents

- A DAL or LTC resident was considered **eligible** for ACCES if s/he:
  - Was 65 years of age or older;
  - Had lived in the facility for at least 21 days;
  - Was not a short-stay/temporary resident; and
  - Was not currently palliative.

- All 1510 DAL residents who met the eligibility criteria were invited to participate in ACCES. **1089 DAL residents** were assessed at baseline (2006-2007), for a response rate of 72%. These individuals were followed over a 1-year period, with **892 DAL residents** assessed at follow-up. Residents who moved to a new setting such as LTC were assessed in that setting. If a resident died in the year following the baseline assessment and their family caregiver had been interviewed, attempts were made to briefly interview the caregiver. Decedent interviews were completed for **148 DAL residents.** There were **199 DAL residents** for whom a discharge interview was completed.

- When ACCES began, there were 5785 residents in the 54 LTC facilities. A random sample of residents within each facility was selected. Of the 1731 eligible LTC residents randomly selected, assessments were completed with **1000 LTC residents** at baseline (2007-2008), for a response rate of 58%. 1-year follow-up assessments were conducted with **691 LTC residents.** Decedent interviews were completed for **273 LTC residents**. Discharge interviews were completed for **38 LTC residents**.

- Trained study nurses (RNs) administered the **Resident Assessment Instrument for Assisted Living (interRAI-AL)** with DAL residents and the **Resident Assessment Instrument for Long-term Care Facilities (interRAI-LTCF)** with LTC residents, at baseline and at follow-up. These comprehensive, standardized assessments provide information on sociodemographic characteristics, physical and cognitive status, health conditions, behavioural problems, social relationships, and use of medications and services. The interRAI tools draw on multiple sources of information including the resident, staff, family members, and chart reviews (for further

information, see www.interrai.org). Guided by the assessment manual, the study nurses used their clinical judgement to determine the best source of information for each item. Many items are the same in the interRAI-AL and interRAI-LTCF tools although some are setting-specific. These tools are the most recent interRAI tools available; key domains are the same as those covered in the MDS 2.0 and RAI-Home Care tools.

- In conjunction with the interRAI assessment, a short **Views of Resident Survey** was conducted with the DAL residents only. This survey was a modified version of the Nursing Home Consumer Assessment of Healthcare Providers and Systems (NHCAHPS) survey developed by the Agency for Healthcare Research and Quality (AHRQ) in the United States (Sangl et al., 2007; for further information on CAHPS, see www.cahps.ahrq.gov). In consultation with an ACCES decision-maker partner, only items deemed relevant to the DAL population were retained. At baseline, **704 DAL residents** completed the survey while **464 residents** did so at follow-up.

DAL and LTC Family Caregivers

- An attempt was made to complete an interview with a family/friend caregiver of each DAL and LTC resident in ACCES (referred to as family caregivers). A family member, friend, or volunteer was considered **eligible** for ACCES if s/he:
  - Was an informal/unpaid caregiver of a DAL or LTC resident in the ACCES cohort, and,
  - Was identified as the person most involved in the care and/or most informed about the resident.

- This individual was identified by the resident and/or the facility. If the resident had no one who met these eligibility requirements or if the resident requested that their caregiver not be contacted, an interview was not completed.

- In total, interviews were completed with **974 family caregivers of DAL residents** (90% response rate) and **917 family caregivers of LTC residents** (93% response rate) at baseline.

- Follow-up interviews were completed with **791 DAL caregivers** and **609 LTC caregivers**.

- The caregiver interview focused on assistance provided to the resident, the resident's health and use of services, the effects of caregiving on employment, caregiver burden, knowledge and views about the facility's services/policies, and costs related to care. Some questions were from the Canadian/Manitoba Study of Health and Aging (C/MSHA) (MSHA Research Group, 1998) and from a U.S. national study of assisted living (Hawes, Phillips, & Rose, 2000) while other questions were selected/developed specifically for ACCES.

- As noted above, if a resident died during the 1-year period, their caregiver was asked to complete a short **decedent interview**. In addition, if a resident moved during the year, their caregivers were approached to complete a brief **discharge interview about the move**.

Organization of the Report

This report provides information about both DAL and LTC and is organized as follows:

- **DAL**
  - A profile of DAL facilities
  - A profile of DAL residents
  - A profile of DAL family caregivers
  - Residents' and caregivers' views about DAL
- **LTC**
  - A profile of LTC facilities
  - A profile of LTC residents
  - A profile of LTC family caregivers
  - Caregivers' views about LTC
- **A comparison of DAL and LTC on key characteristics** related to the facilities, residents, and family caregivers
- **Issues** and **challenges** facing DAL and LTC.

It is anticipated that some readers will be interested only in DAL or only in LTC and will focus on certain sections. As a result, the topics discussed, the format used, and much of the wording are the same when presenting findings for DAL and LTC. However, it should be noted that some information is unique to one setting and is not available for both DAL and LTC.

A PROFILE OF DAL FACILITIES

In total, **59 DAL facilities** participated in ACCES. Their characteristics are highlighted here in relation to **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.** Information was provided by the facility administrator, manager, or director of care who was familiar with the facility and had direct knowledge about the residents.[3]

Location

- The 59 DAL facilities were located in 5 former **health regions** in Alberta (see Appendix A).
  - Calgary Health Region (13 facilities) (22%)
  - Chinook Health Region (11 facilities) (19%)
  - David Thompson Health Region (12 facilities) (20%)
  - Capital Health Region (14 facilities) (24%)
  - East Central Health Region (9 facilities) (15%)

- The **size of the community** varied, with 34% of the facilities in communities with a population under 10,000, 24% in communities with a population of 10,000-100,000, and 42% in communities with a population >100,000.

Ownership

- 59% of DAL facilities were **owned/operated** by non-profit organizations, 36% by for-profit organizations, and 5% by the health region.

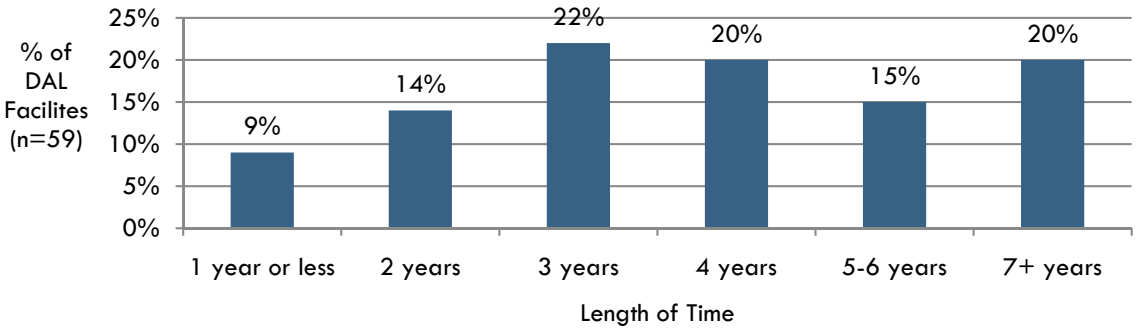
- 46% of the facilities were **part of a chain** that provided both assisted living and long-term care while 29% were part of a chain that offered assisted living only. 20% were not part of a chain while 5% were RHA owned/operated.

- The **years in operation** varied considerably from less than one year to 51 years, with 69% in operation for less than 10 years. This represented the length of time the facility had been in operation regardless of when it began to provide DAL.

- The **length of time the facility had offered DAL spaces** ranged from less than one year to 12 years, with 64% in operation for less than 5 years (Figure 1).

[3] The sample size is 59 unless otherwise noted. In some instances, respondents declined to answer the question. Percentages may not total 100% due to rounding.

FIGURE 1. LENGTH OF TIME DAL SPACES AVAILABLE IN A FACILITY



Type and Size of Facility

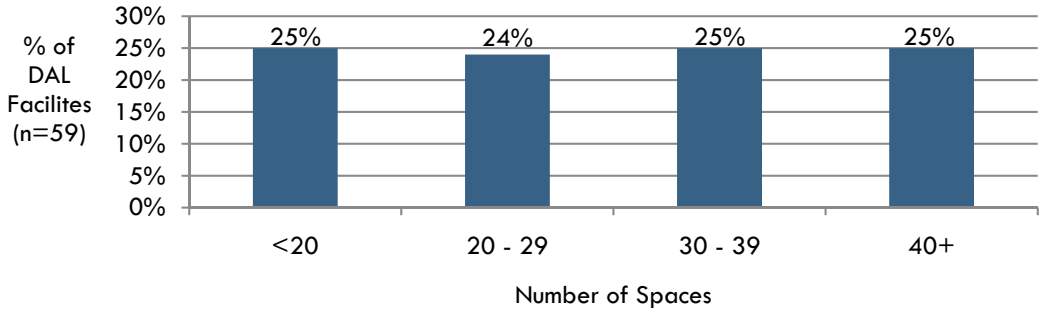
- Only 6 of the 59 facilities (10%) were DAL-only facilities. The remaining 90% were **multi-level facilities** that offered more than one level of care.
  - DAL and a lower level of care (34%)
  - DAL and an equivalent level of care (22%)
  - DAL and a higher level of care (9%)
  - DAL, equivalent and a lower level of care (15%)
  - DAL, equivalent and a higher level of care (3%)
  - DAL, a lower level of care and a higher level of care (7%)

Lower: independent, lodge, condo
Equivalent: private assisted living (PAL), residential dementia spaces, respite if no LTC in facility, Community Support Beds (CSB), and transition spaces (if no LTC in facility)
Higher: LTC (nursing home), acute care, respite if LTC in facility

- Taking **all levels of care** into account, the **size** of the facilities varied from 10 to 507 spaces, with an average of 108 spaces.

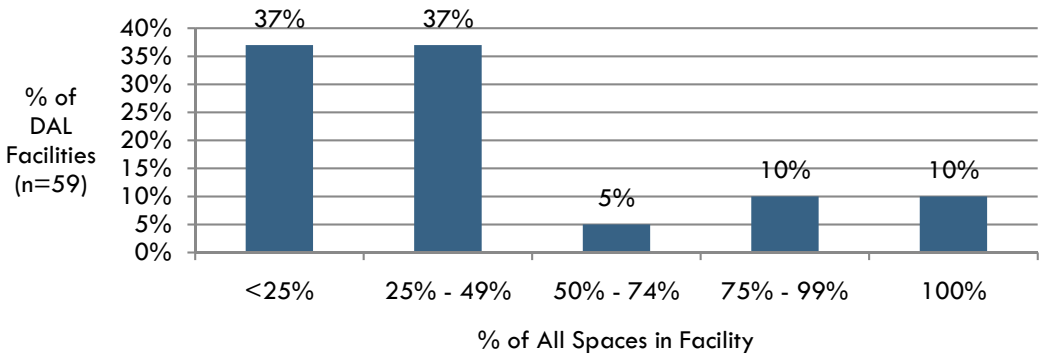
- The **number of DAL spaces** in a facility ranged from 8 to 104, with an average of 32 spaces. 25% of the facilities had less than 20 DAL spaces (Figure 2).

FIGURE 2. NUMBER OF DAL SPACES IN A FACILITY



- The **percentage of a facility's spaces allocated to DAL** varied from 6% to 100% (Figure 3).

FIGURE 3. PERCENTAGE OF FACILITY SPACES ALLOCATED TO DAL



- DAL spaces were located on **DAL-only units** in some facilities (42%) but were mixed with other types of spaces (most often private assisted living (PAL)) in other facilities (58%).
  - 27% of facilities had one unit for DAL only.
  - 15% had more than one unit for DAL only.
  - 29% had one unit with DAL and other types of spaces.
  - 29% had more than one unit with DAL and other types of spaces.

- When asked "*How many of your DAL spaces/beds are designated as Alzheimer's/dementia spaces (e.g., safe living unit, locked unit)?*", 47% of the facility representatives indicated that their facility had **dementia spaces**. These spaces accounted for 25% of the available spaces in the 59 facilities; the number of spaces ranged from 4 to 40 per facility. Among the 28 facilities with dementia spaces, 5 were serving only residents with dementia, 12 had at least one unit with dementia spaces only and 11 had dementia spaces mixed with other types of spaces. Information regarding staff training and physical design features for dementia care was not collected.

Admission and Retention Criteria

- **Admission and retention criteria** are important to consider as they affect who enters and stays in assisted living, have an impact on the ability to "age in place", and reflect where assisted living potentially fits on the continuum of care.

- The **Supportive Living Framework** prepared by Alberta Seniors and Community Supports (2007) outlines the **resident needs** that are to be met in assisted living, including DAL (Table 2).

- Facility representatives were asked if they were **"*able to admit someone*"** and **"*able to retain a resident*"** with certain characteristics. Responses were "No", "Yes" or "Depends". "Yes" indicates an unequivocal yes, while "depends" reflects a qualified criterion for admission or retention. Their responses reflect the situation at the time of data collection; it is recognized that there may have been some policy changes related to admission and retention since that time.

- Generally, facilities would **admit** the same types of residents they were willing to **retain** (Table 3).

TABLE 2. SUPPORTIVE LIVING FRAMEWORK: RESIDENT NEEDS

Assisted Living – Level 3	Enhanced Assisted Living – Level 4
Has choices but may need assistance in making some decisions about day-to-day activities.	Needs assistance in making decisions about day-to-day activities, but should still be given as many choices as possible.
Requires assistance with many daily tasks.	Requires assistance with most/all daily tasks.
Most personal assistance can be scheduled. The need for unscheduled personal assistance is infrequent.	The need for unscheduled personal assistance is frequent.
May require increased assistance to participate in social, recreational and rehabilitation programs.	Requires enhanced assistance to participate in social, recreational and rehabilitation programs.

Source: Alberta Seniors and Community Supports. (2007). Supportive Living Framework. Edmonton, AB.

TABLE 3. ADMISSION AND RETENTION CRITERIA: DAL FACILITIES

	Admit		Retain	
Criterion	**Yes**	**Dep**	**Yes**	**Dep**
Mobility Issues				
• Is bedfast	10%	10%	12%	24%
• Is chairfast	19%	17%	24%	27%
• Uses a wheelchair to get around inside	85%	5%	88%	7%
• Uses a scooter/mechanized wheelchair	59%	17%	61%	17%
• Needs 1-person assistance with transfers	86%	9%	88%	10%
• Needs 2-person transfers	14%	5%	14%	24%
• Needs mechanical lift	15%	9%	17%	9%
Cognitive/Behavioural Issues				
• Has recent history of psychiatric hospitalization (mental illness)	19%	73%	22%	71%
• Wanders	34%	46%	32%	46%
• Is an elopement risk	25%	29%	25%	29%
• Engages in verbally aggressive behaviours	15%	46%	19%	54%
• Engages in physically aggressive behaviours	7%	15%	7%	22%
• Engages in socially inappropriate behaviours	9%	27%	10%	41%
• Resists nursing care or ADL care	48%	29%	53%	36%
• Has severe memory or judgment problems	49%	24%	51%	31%
Continence Issues				
• Lacks bladder control but can manage own incontinence supplies (i.e., wears and changes own pad or adult diapers)	98%	2%	98%	2%
• Lacks bladder control and needs help managing incontinence (e.g., someone helps change pads, bed linens)	92%	7%	90%	10%
• Lacks bowel control but can manage own incontinence supplies	97%	2%	97%	2%
• Lacks bowel control and cannot manage own incontinence supplies	54%	19%	54%	24%
Feeding Issues				
• Requires assistance with feeding	22%	25%	25%	41%
• Requires tube feeding	20%	14%	24%	14%

n=59. Dep: Depends. It should be noted that admission and retention decisions are to be collaborative between the RHA and the facility operator. Information was obtained only from facility representatives. The extent to which the RHA representatives would agree with the facilities' assessments is not known.

- 75% or more of DAL facilities unequivocally admitted *(unequivocally retained)* a person who:
  - Used a wheelchair to get around inside (85%) *(88%)*.
  - Needed 1-person assistance with transfers (86%) *(88%)*.
  - Lacked bladder control but could manage own supplies (98%) *(98%)*.
  - Lacked bladder control and needed help managing (92%) *(90%)*.
  - Lacked bowel control but could manage own incontinence supplies (97%) *(97%)*.

- 25% - 74% of the facilities unequivocally admitted *(unequivocally retained)* a person who:
  - Used a scooter/mechanized wheelchair (59%) *(61%)*.
  - Wandered (34%) *(32%)*.
  - Was an elopement risk (25%) *(25%)*.
  - Resisted nursing care or ADL care (48%) *(53%)*.
  - Had severe memory or judgment problems (49%) *(51%)*.
  - Lacked bowel control and could not manage own incontinence supplies (54%) *(54%)*.

- Less than 25% of the facilities unequivocally admitted *(unequivocally retained)* a person who:
  - Was bedfast (10%) *(12%)*.
  - Was chairfast (19%) *(24%)*.
  - Needed 2-person transfers (14%) *(14%)*.
  - Needed mechanical lift (15%) *(17%)*.
  - Had recent history of psychiatric hospitalization (19%) *(22%)*.
  - Engaged in verbally aggressive behaviours (15%) *(19%)*.
  - Engaged in physically aggressive behaviours (7%) *(7%)*.
  - Engaged in socially inappropriate behaviours (9%) *(10%)*.
  - Required assistance with feeding (22%) *(25%)*.
  - Required tube feeding (20%) *(24%)*.

- Admission criteria related to **cognitive/behavioural issues** were the most likely to be reported as "it depends", reflecting stability, safety or the availability of a dementia space. For example, 73% of the facility representatives responded "it depends" when asked if they would admit a person who has a recent history of psychiatric hospitalization.

Facility Representatives

Depends on the behaviours and effect on other residents.

We'd need to know particulars – and if it was under control, not recurring.

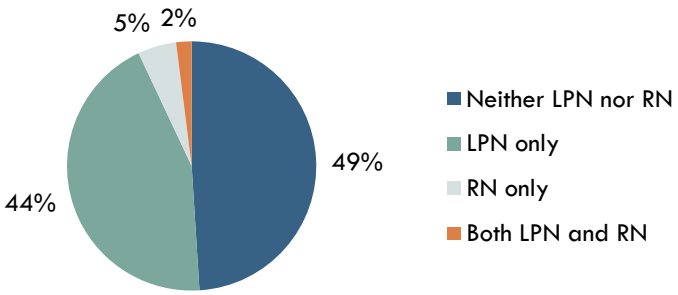
Services Provided by DAL

As outlined in the Supportive Living Framework (Alberta Seniors and Community Supports, 2007), at the time of the study, case management was to be provided by the regional health authority (RHA) and assessment for DAL services was completed by the RHA based on unmet need. Personal assistance and/or professional services may be provided by the RHA directly, the operator on contract with the RHA, the operator privately, or private pay by an alternate vendor. DAL services included both health and wellness services and hospitality services.

Health and Wellness Services

- All 59 DAL facilities had personal care aides (PCAs), licensed practical nurses (LPNs) and/or registered nurses (RNs) **on site.**
  - 93% of the facilities had **PCA** coverage on site 24/7.
  - 46% had **LPN** coverage on site 24/7.
  - 7% had **RN** coverage on site 24/7.
  - 49% had neither a LPN nor a RN on site 24/7 (Figure 4).

FIGURE 4. LPN/RN COVERAGE 24/7: DAL FACILITIES

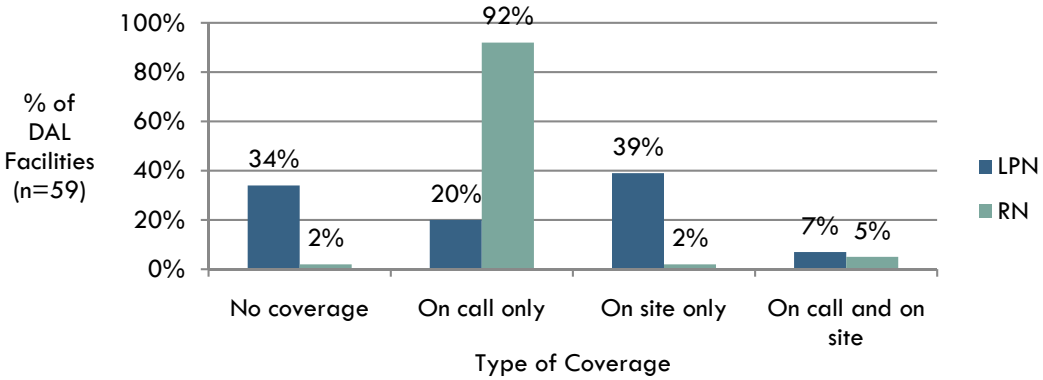


% of DAL Facilities (n=59)

- LPNs and/or RNs were available on an **on call basis.**
  - 27% of the facilities had LPNs available on call.
  - 97% of the facilities had RNs available on call.

- Considering **on site and on call coverage** together, 34% of the facilities had no LPN coverage while 20% had a LPN on call coverage only. In comparison, 92% of the facilities had RN coverage on call only (Figure 5).

FIGURE 5. LPN AND RN ON SITE AND ON CALL COVERAGE: DAL FACILITIES



- Services were **provided or arranged** by the DAL facilities as part of the **base fee** or as an **extra charge**. Facility representatives were asked if their facility regularly offered various services, if it was provided directly by facility staff as part of the basic monthly fee or for an extra charge, or if the service was arranged by the facility with an outside agency as part of the base fee or for an extra charge.

- All 59 facilities provided/arranged assistance with **dressing, locomotion,** and **toileting** as part of the base fee (Table 4). One facility reported that these services may involve an extra charge.

TABLE 4. HEALTH/WELLNESS SERVICES PROVIDED/ARRANGED: DAL FACILITIES

Service	% of DAL Facilities (n=59)			
	As Part of Base Fee	As Extra Charge	Both Base Fee and Extra Charge	Not Provided/ Arranged
Personal care				
• Assistance with bathing	95%	---	3%	2%
• Assistance with dressing	98%	---	2%	---
• Hair care (brushing/shampoo)	98%	---	2%	---
• Assistance with locomotion	98%	---	2%	---
• Assistance with toileting	98%	---	2%	---
Oral care	97%	---	---	3%
Nursing care (blood pressure, dressings)	73%	---	2%	25%
Administration of medications	88%	12%	---	---
Incontinence supplies	5%	36%	2%	58%
Physiotherapy in facility	19%	---	---	81%
Occupational therapy in facility	15%	---	---	85%
Speech/language therapy in facility	15%	---	---	85%
Foot care in facility	7%	59%	12%	22%
Mental health/psych counseling in facility	20%	---	---	80%
Social work/clergy counseling in facility	46%	2%	---	53%
Transportation to medical/dental appointments	19%	22%	---	59%

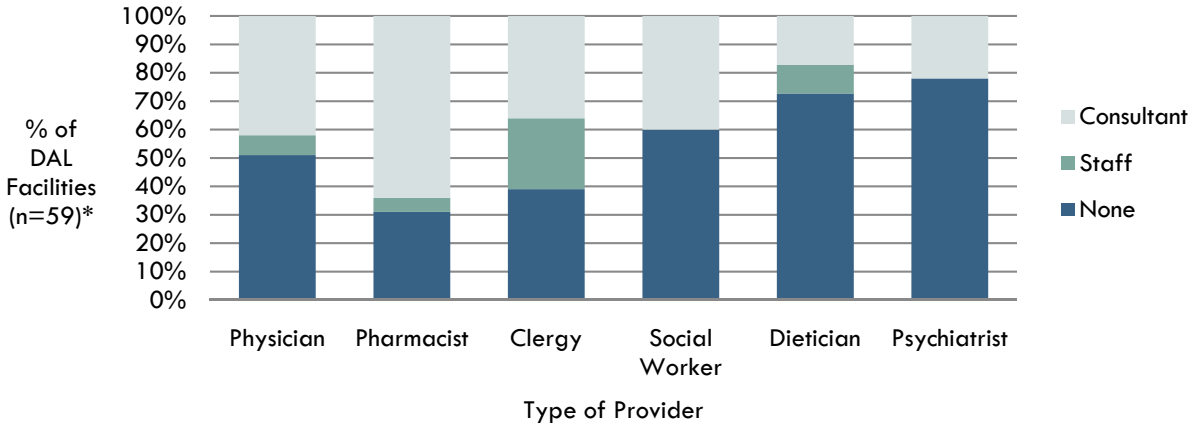
- Assistance with **bathing** was provided/arranged by 95% of the facilities as part of the base fee (Table 4). In 2 facilities, this service was covered by the base fee as well as an extra charge while one facility relied on Home Care to provide the service.

- **Administration of prescription medications** involved PCAs, LPNs, and/or RNs. More specifically, 39% of the facilities reported that only PCAs administered medications, 7% noted that only LPNs/RNs did this task, and 54% had PCAs, LPNs and RNs involved in medication administration. Over one-half (58%) of the facilities had residents who administered at least some of their own medications with the assistance of health care providers in the week prior to the survey.

- In terms of **incontinence supplies,** 36% of the facilities provided/arranged these supplies at an extra charge while 5% covered this as part of the base cost (Table 4).

- **Foot care** was provided/arranged by 78% of the facilities, as either an extra fee (59%), part of the base fee (7%), or as both part of the base fee and an extra charge (12%) (Table 4).
- **Physiotherapy (PT), occupational therapy (OT),** and **speech/language therapy (SLP)** were seldom provided/arranged by the facility (Table 4). Home Care arranged such services based on need.
- Some DAL facilities involved other **health care providers** as either staff members or consultants in the month prior to the interview (Figure 6).

FIGURE 6. INVOLVEMENT OF OTHER SERVICE PROVIDERS DURING PREVIOUS MONTH: DAL FACILITIES



* Except for social worker (n=58) and dietician (n=58)

- While 49% of the facilities indicated that they had a physician involved during the past month (Figure 6), 34% reported that at least one **Physician/GP was formally affiliated** with the facility. Only 8 of these 20 facilities had an office on site for their physicians. DAL residents were not required to change their physician to a facility-affiliated physician.

Hospitality Services

- As outlined in the Supportive Living Framework (Alberta Seniors and Community Supports, 2007), **hospitality services** included meal services; housekeeping services; personal laundry; laundry and linen services; safety and security; social, leisure and recreational opportunities; and coordination and referral services to community supports.
- All DAL facilities provided **meal service**, most frequently as part of the base fee (Table 5). Six facilities offered breakfast and lunch for an extra charge.
- All had a **common dining area** for their residents. In 12 facilities, residents were expected to **walk/wheel themselves to the dining room.**
- All facilities reported that facility **meals could be delivered to the resident's room** (Table 5). Some facilities charged extra while some restricted the service to times when a resident was ill.

TABLE 5. HOSPITALITY SERVICES PROVIDED/ARRANGED: DAL FACILITIES

Service	% of DAL Facilities (n=59)			
	As Part of Base Fee	As Extra Charge	Both Base Fee and Extra Charge	Not Provided/ Arranged
Meal services				
• Breakfast	90%	10%	---	---
• Lunch	90%	10%	---	---
• Dinner	100%	---	---	---
• Snacks	100%	---	---	---
• Escorts to meals	90%	2%	3%	5%
• Meal delivered to resident's room	75%	2%	24%	---
• Special diets	78%	2%	12%	9%
Housekeeping/cleaning	90%	2%	9%	---
Towels/bedding laundry	92%	9%	---	---
Personal laundry	27%	64%	7%	2%
Personal response system	85%	2%	3%	10%
Social, leisure, recreation				
• Planned recreational activities	73%	7%	20%	---
• Exercise/health program	92%	---	---	9%
• Transportation to social activities	27%	49%	7%	17%

- All but 5 facilities indicated that they met **special dietary requirements** of DAL residents, with a diabetic diet being the most frequent modification.
- Most facilities (86%) indicated that they met some **special dietary preferences** such as vegetarian meals and cultural choices.
- Some facilities offered the residents options to store food in their room in a **refrigerator** (88%), or to cook/prepare food in their own room using a **microwave** (56%) or a **stovetop** (20%).

Facility Representatives

As best we can, we do that [special dietary preferences] *within reasons. The menu has more than one option.*

It depends. Options are challenges. The family has to bring in ethnic dishes.

- **Housekeeping** and **laundry/linen services** generally were covered as part of the base fee (Table 5). Several facilities provided **personal laundry** services at an extra cost.
- All but 7 facilities provided a **personal response system,** most often as part of the base fee (Table 5). Two of the 7 indicated that they arranged for a personal response system.
- **Social, leisure and recreational opportunities** were provided by all facilities (Table 5). Facility representatives were not asked detailed questions about these opportunities.

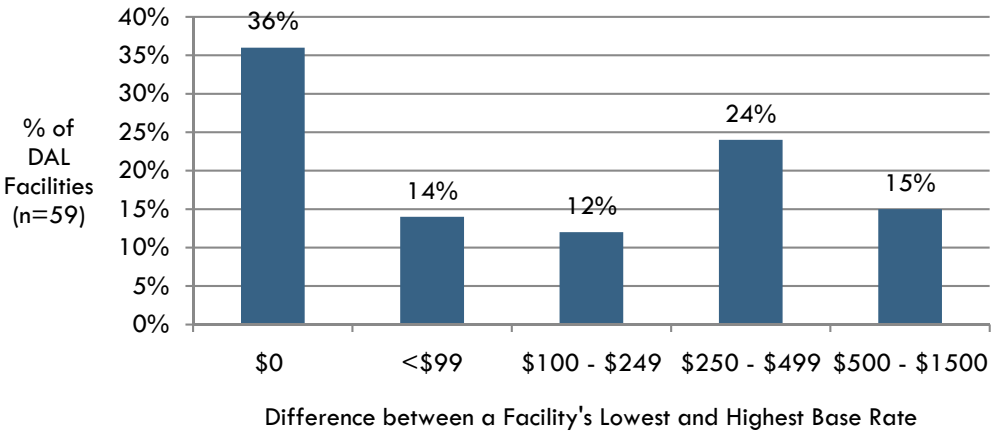
Physical and Social Environment

- 78% of the DAL facilities had **private rooms** only.
- 18 facilities (31%) had **spousal suites,** with a range from one to 10 suites per facility. At the time of the survey, 6 of these 18 facilities had no spousal suites occupied by spouses while 4 facilities reported 100% occupancy.
- All facilities reported that residents could bring their own **personal furniture** to the facility. This ranged from furnishing their entire room/apartment (93%) to bringing a few personal items such as pictures and some furniture (5%), and bringing only small personal items such as photos, bedspreads, or small lamps (2%).
- Residents could **physically change their rooms** in some facilities by painting the room (63% of facilities), wallpapering (53%), or changing the locks (14%).
- 53% of the facilities reported that the DAL residents could **bring pets** to live in their room. Some facilities had restrictions on the size or type of the pet and whether the resident had to be able to look after the pet. Eight facilities charged extra fees for pets.
- 58% of the facilities had **animals or pets that belonged to the facility**. All facilities allowed **visiting pets**.
- **Outside amenities** for DAL residents included picnic areas (86%), gardens (95%), chairs in an inner courtyard or backyard (98%), and chairs at the front door (86%).
- Fourteen facilities (24%) reported some restrictions in the **hours for visiting**. All but 3facilities had some **restrictions on how visitors could enter** the building. Several facilities locked doors in the evenings and visitors had to buzz for access. Some had a secure entrance 24/7 where visitors either had to buzz or sign in with security/reception.
- **Overnight accommodations for visitors** were available in 76% of the facilities. Among these 45 facilities, 56% provided a separate room at a cost ranging from no charge to $95/night (including three meals) while 89% allowed visitors to stay in the resident's room for anywhere from no cost to $30.

Fees

- **Monthly base fees** ranged from $800 to $2650 per month.
- About one-third (36%) of the facilities reported the same base fee for all residents. The difference between the lowest and highest monthly base rates within a facility varied from $57 to $1500 depending on room size and shared versus private occupancy (Figure 7). For example, 2 facilities charged $1050 for a studio and $1128 for a 1-bedroom. Another facility had a rate of $1585 for a studio and $1895 for a 1-bedroom.

FIGURE 7. VARIATION BETWEEN A FACILITY'S LOWEST AND HIGHEST BASE RATES: DAL FACILITIES



- Some facilities had **extra charges** that residents were given as optional fees, including cable, telephone, or personal laundry (see section on services for additional information).

Summary

This brief profile of DAL facilities has revealed a number of similarities and differences between the facilities. The size, the proportion of spaces allocated to DAL within a facility, and the availability of other levels of care on site varied greatly. Some facilities had units devoted solely to their DAL residents while others mixed DAL residents with other clients in the same unit.

Facilities were most likely to unequivocally admit and retain individuals with limited mobility restrictions, those with bladder incontinence that could be managed by the resident and/or staff, and those with bowel incontinence that could be self-managed. Few facilities unequivocally admitted or retained individuals who required 2-person transfers, needed mechanical lifts, required assistance with feeding or required tube feeding, reflecting the availability of staffing to accommodate these needs.

Virtually all facilities had PCAs on staff. Almost one-half had LPNs on site 24/7. RNs were available on call only except for 7% of the facilities that had RN coverage on site 24/7. One-third of the facilities had a GP formally affiliated with the facility. Services provided/arranged included assistance with personal care, meals, housekeeping/cleaning, and some type of exercise/health program. Less likely was the provision of incontinence supplies, therapies in the facility, and transportation to appointments. Variation in base fees was evident, reflecting in part the size of the resident's apartment or room.

Attention now turns to a profile of DAL residents. Of particular interest is the extent to which there is a match between the admission/retention criteria and the services offered by DAL, and the corresponding needs of DAL residents.

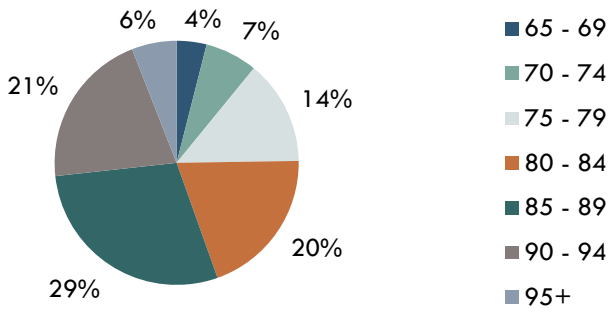
A PROFILE OF DAL RESIDENTS

In total, **1089 individuals residing in DAL facilities** participated in ACCES. Their profile is presented here in relation to **sociodemographic characteristics**, the **move to DAL, clinical issues, physical function, cognitive function and mental health, social and lifestyle characteristics, use of health services**, and **1-year outcomes**. Information is from the interRAI-AL assessments, and includes the **interRAI Clinical Assessment Protocols (CAPs)** that focus on key issues identified during the assessment process (Canadian Institute for Health Information (CIHI), 2008). Some information is from the interviews with the 974 family caregivers.[4]

Sociodemographic Characteristics

- The DAL residents ranged in **age** from 65 to 103, with an average age of 84.4 years. 55% were aged 85+ (Figure 8).

FIGURE 8. 5-YEAR AGE GROUPS: DAL RESIDENTS



% of DAL Residents (n=1089)

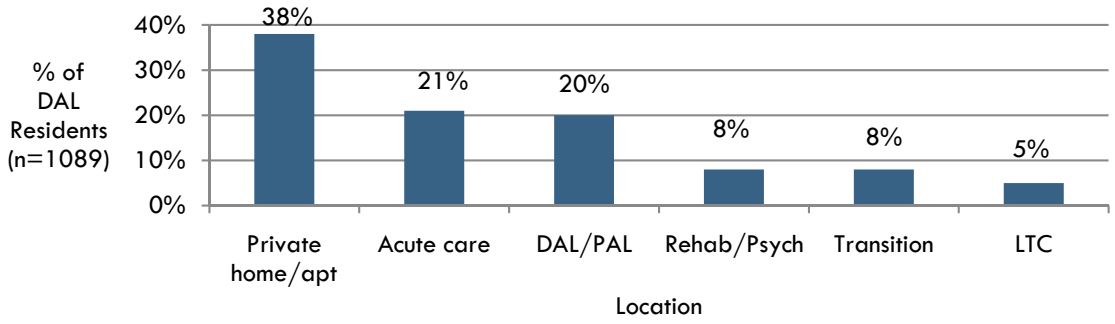
- 77% of the residents were **female.**
- In terms of **marital status,** 71% were widowed, 15% were married, 8% were divorced/ separated, and 6% were never married.
- **English** was the primary language of the vast majority of residents (96%).

Moving to DAL

- 38% of the residents moved to their current DAL facility from a **private home/apartment** while 21% moved from an **acute care hospital** (Figure 9). 5% moved from LTC to DAL.

[4] Sample sizes are 1089 for residents and 974 for family caregivers unless otherwise noted. In some instances, respondents declined to answer the question. Percentages may not total 100% due to rounding.

FIGURE 9. LOCATION PRIOR TO THE MOVE: DAL RESIDENTS



Private home/apt: private home/apartment/rented room
Acute care: acute care hospital
DAL/PAL: board and care/designated assisted living/private assisted living
Rehab/Psych: rehabilitation hospital or unit/psychiatric hospital/mental health residence
Transition: Respite/IT Bed or Community Support Bed/RCTP or Enhanced Transition Bed
LTC: long-term care facility (nursing home)

- 52% were **living alone** prior to the move, 16% were living with their spouse and 8% lived with their children. The remainder lived with other relatives (2%) or with non-relatives (22%). The majority of individuals living with non-relatives resided in congregate settings prior to their move.

- Family caregivers were asked to identify the most **important reasons** that led to the move. Their responses related to:
  - the **resident's situation** such as the resident being unsafe in the current setting;
  - the **caregiver's situation** such as the caregiver feeling burdened/overwhelmed, having their own health concerns, or having work demands;
  - **service limitations or health providers' recommendations** including the resident's needs exceeding the level of care that could be provided or a physician or other health care professional recommending the move; and,
  - **features of the facility itself** such as its geographical proximity to family members, the availability of a private room/bathroom, and knowledgeable/caring staff.

Wife of Male Resident

I couldn't handle it anymore. We were refused services by Home Care. My husband was too much to handle. It was an invasion of privacy – there was always someone there. I had no time to myself. There was constant turnover of staff – continuity was not there.

Son of Female Resident

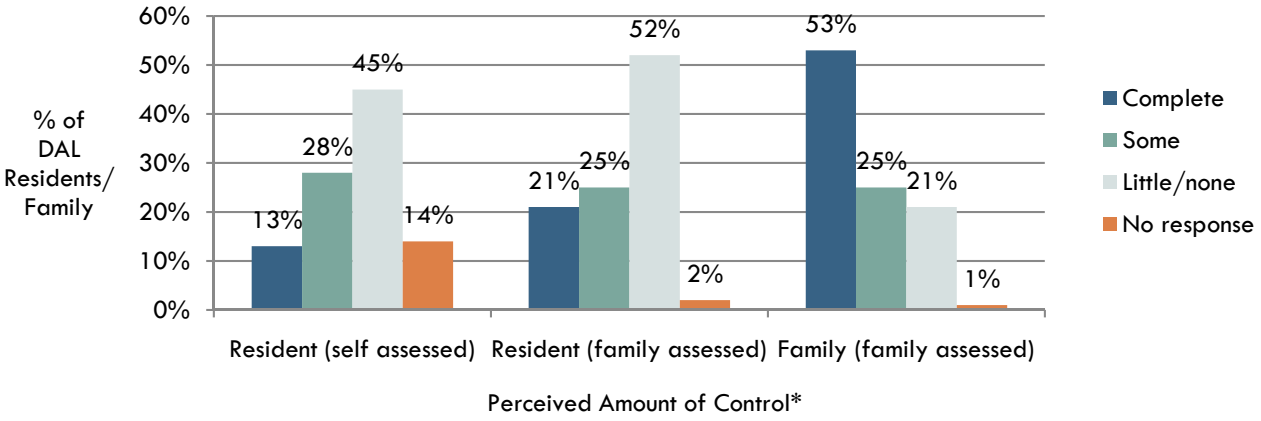
She required full-time supervision. She was dropping and mixing up medications, hot plate left on. She was unhappy in the prior place. We wanted to get her into a place with good care.

Daughter of Female Resident

Mom could no longer manage routine tasks at home due to a fall which fractured her hip. Caregiving for Mom and managing the house was becoming too much for Dad. Concern for two elderly people living alone in terms of managing meals, medications and daily tasks.

- 72% of family caregivers indicated that the facility was their **first choice**.
- Residents reported varying **levels of control over the decision** to move, with 45% indicating little or no control (Figure 10). 52% of family caregivers perceived that the resident had little or no control while 53% indicated that they themselves had complete control over the decision.

FIGURE 10. PERCEIVED CONTROL OVER DECISION TO MOVE: DAL RESIDENTS AND FAMILY CAREGIVERS



* DAL residents (n=1089) were asked about the level of control they had over the decision to move (Resident (self assessed)). Family caregivers (n=974) were asked "*All in all, how much control did you have over the decision for your family member to move to this facility? How much control did your family member have?*"

- 89% of family caregivers reported that the resident had to **wait for a space before moving to the current facility**. Among the 932 caregivers who provided information, the number of days waited varied from none to more than a year (no wait (12%), 1-29 days (23%), 30-59 days (18%), 60-89 days (14%), 90-179 days (20%), 180+ days (14%)).
- Residents had lived in their **current location** for less than one month to 149 months (median = 17 months). This may not be the length of time in DAL as the individual may have resided in the facility prior to DAL spaces being available or before the move to a DAL space.

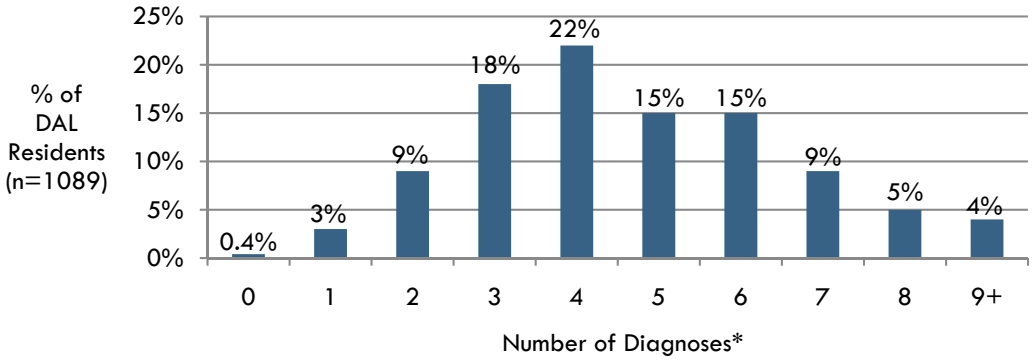
Clinical Issues

Several clinical characteristics are examined, including **disease diagnoses and symptoms, medications, balance and movement, falls, continence, skin conditions, nutritional status, tobacco and alcohol use, sleep problems, fatigue, pain, preventive health strategies**, and **CAPs for specific clinical issues**. Unless otherwise noted, the **assessment period** was the **past 3 days.**

Diseases Diagnoses and Symptoms

- DAL residents had, on average, 4.6 **disease diagnoses**, with a range from 0 to 14 (Figure 11).

FIGURE 11. NUMBER OF DISEASE DIAGNOSES: DAL RESIDENTS



* Includes diagnoses reported in Section J1 and J2 on interRAI-AL

- The **most common disease diagnoses** are reported in Table 6. 58% of DAL residents had a diagnosis of dementia, 56% had been diagnosed with hypertension and 54% had arthritis.

TABLE 6. MOST COMMON DISEASE DIAGNOSES: DAL RESIDENTS

Disease Diagnosis*	% of DAL Residents (n=1089)
Dementia (any)	58%
Hypertension	56%
Arthritis	54%
Depression	34%
Osteoporosis	32%
Coronary heart disease	29%
Stroke/CVA	24%
Diabetes	23%
Congestive heart failure	22%
Thyroid disease	20%
COPD/Emphysema	19%
Anxiety	16%
Cancer	11%

* Includes diagnoses reported in Section J1 and J2 on interRAI-AL

- **Chest pain** was reported for 11% of DAL residents.
  - 8% had chest pain present but it was not exhibited in the 3 days prior to the assessment.
  - 2% exhibited the problem 1-2 days in the 3 days prior to assessment.
  - 1% experienced chest pain daily.

- 8% of residents had difficulty **clearing airway secretions**.
  - 3% experienced this problem but not in the 3 days prior to the assessment.
  - 2% exhibited the problem 1-2 days in the 3 days prior to assessment.
  - 3% experienced the problem daily.

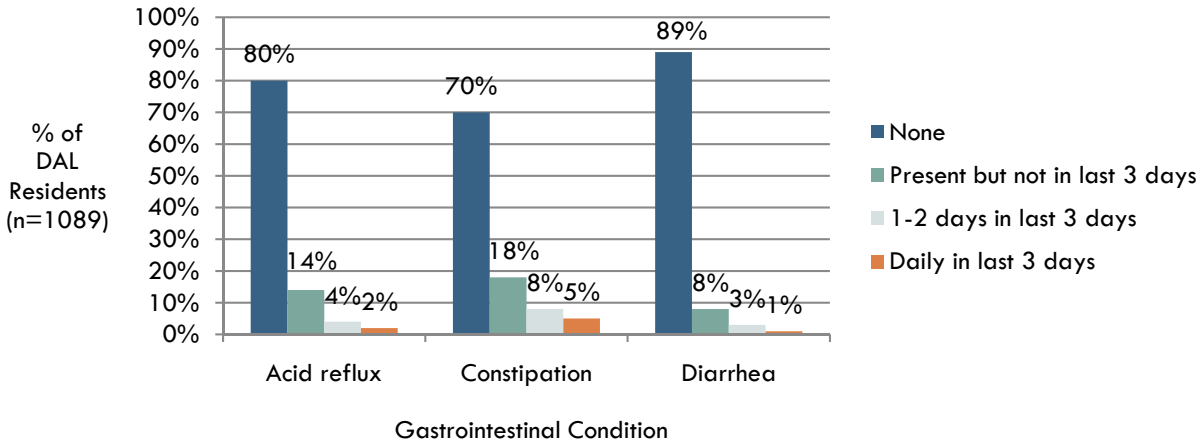
- 26% of residents were reported to have **peripheral edema** or an abnormal build up of fluid in the foot/ankle/leg tissues.
  - 4% experienced this problem but not in the 3 days prior to the assessment.
  - 2% exhibited the problem 1-2 days in the 3 days prior to assessment.
  - 20% experienced the problem daily.

- 35% of residents were reported to have **dyspnea or shortness of breath**.
  - 21% experienced dyspnea when performing moderate activities but not at rest.
  - 10% experienced it when they performed normal activities but not at rest.
  - 4% had dyspnea when at rest.

- 2% of residents were reported to have problems with **vomiting;** <1% exhibited the problem at least once in the 3 days prior to the assessment.

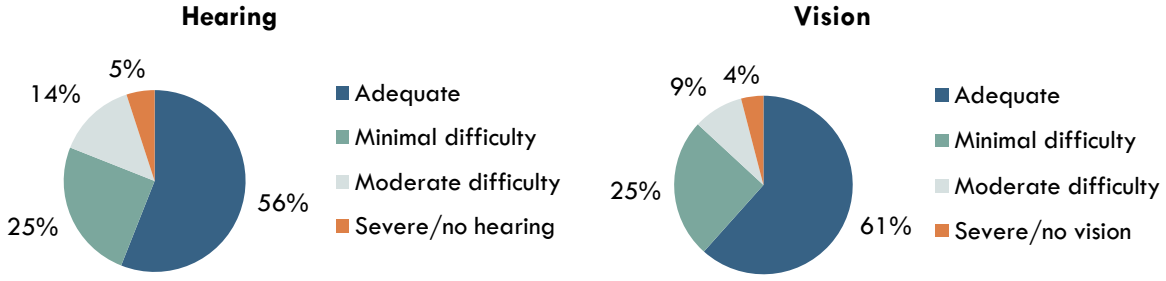
- Some residents had gastrointestinal problems such as **acid reflux** (20%), **constipation** (31%), or **diarrhea** (11%) (Figure 12).

FIGURE 12. GASTROINTESTINAL STATUS: DAL RESIDENTS



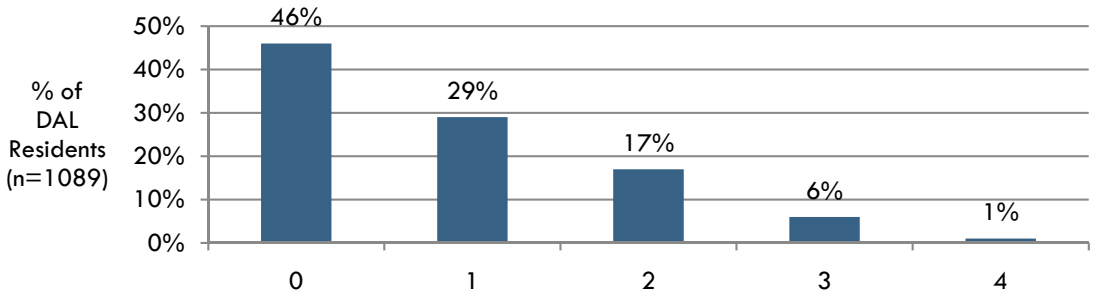
- 44% of residents experienced some **hearing** difficulty while 39% had some **vision** problems (Figure 13).

FIGURE 13. HEARING AND VISION PROBLEMS: DAL RESIDENTS



- Based on the **interRAI Changes in Health, End-stage Disease and Symptoms and Signs (CHESS)** scale (Hirdes, Krijters, & Teare, 2003), 54% of DAL residents showed **some level of instability** in terms of clinical complexity and health (Figure 14). Higher CHESS scores have been found to be associated with adverse outcomes including mortality, acute hospitalization, and pain.

FIGURE 14. interRAI CHESS SCALE: DAL RESIDENTS



Based on the following: vomiting, insufficient fluid, noticeable decline in food/fluid, weight loss, shortness of breath, edema, end-stage disease, ADL decline, and cognitive decline. Possible scores range from 0 (not at all unstable) to 5 (totally unstable). Two items (insufficient fluid and noticeable decline in food/fluid) are not on the interRAI-AL, which may result in an underestimate.

Medications

- DAL residents were taking 8.3 **regularly prescribed medications** on average, with a range from 0 to 23. Only 8 of 1089 residents were not taking any regularly prescribed medications. The **most common medication classes** were general analgesics (66% of residents) and antidepressants (45%) (Table 7).

TABLE 7. MOST COMMON MEDICATION CLASSES: DAL RESIDENTS

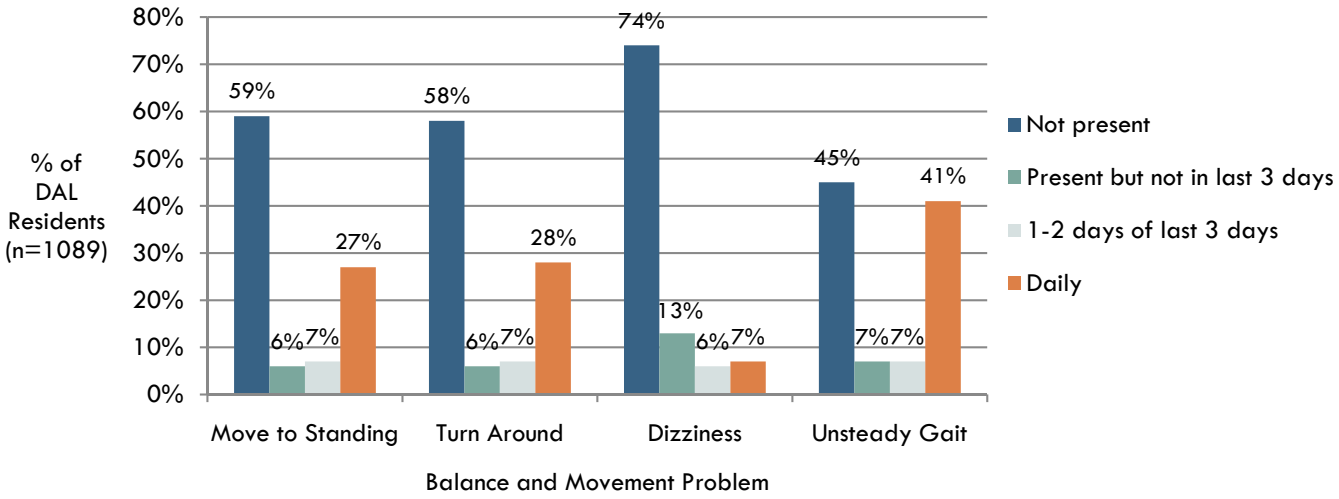
Medication Class	% of DAL Residents (n=1089)
General analgesics (including Acetaminophen and ASA)*	66%
Antidepressants (commonly SSRIs, citalopram [Celexa])	45%
ACE-Inhibitors (commonly ramipril [Altace])	38%
Proton Pump Inhibitors for peptic ulcer/gastro-esophageal reflux disease (commonly pantoprazole [Pantoloc] or omeprazole [Losec])	37%
Calcium	34%
Loop Diuretics (commonly furosemide [Lasix])	31%
Thyroid agents (commonly levothyroxine [Synthroid])	26%
Antipsychotics (commonly risperidone [Risperdal])	26%
Beta-Blockers (commonly metoprolol [Lopressor])	26%
Anti-dementia drugs (commonly donepezil [Aricept])	26%
Calcium channel blockers (commonly amlodipine [Norvasc])	25%
Vitamin D	24%
Antithrombotic agents (commonly warfarin [Coumadin])	24%
Hypnotic/sedative agents (commonly zopiclone [Imovane])	23%
Bisphosphonates for osteoporosis (commonly alendronate [Fosamax])	22%
Lipid modifying agents largely HMG CoA reductase inhibitors (statins) (commonly atorvastatin [Lipitor])	22%
Insulins & oral diabetic agents (commonly metformin [Glucophage])	20%

* Excludes opioid analgesics prevalence = 14% of DAL residents

Balance and Movement

- Some DAL residents experienced problems with **balance** and **movement** (Figure 15).
  - 41% had difficulty or were unable to move to a **standing position** unassisted.
  - 42% had difficulty or were unable to turn around and **face the opposite direction** when standing.
  - 26% experienced **dizziness**.
  - 55% had an **unsteady gait**.

FIGURE 15. PROBLEMS WITH BALANCE AND MOVEMENT: DAL RESIDENTS



Falls

- 28% had at least one **fall** in the 90 days prior to the assessment. A fall is defined as "an unintentional change in position where the person ends up on a lower level" (CIHI, 2008, p. 93).
  - 5% had 2 or more falls in the last 30 days.
  - 11% had one fall in the last 30 days.
  - 12% had at least one fall in the last 31-90 days.

Continence

- About 6 in 10 DAL residents had some difficulty with **bladder incontinence.**
  - 41% were bladder continent.
  - 2% had control with a catheter/ostomy.
  - 13% were infrequently incontinent.
  - 11% were occasionally incontinent (less than daily).
  - 26% were frequently incontinent (daily but some control present).
  - 8% were incontinent (no control present).

- 3 in 10 residents had some difficulty with **bowel incontinence.**
  - 72% were bowel continent.
  - 2% had control with an ostomy.
  - 14% were infrequently incontinent.
  - 8% were occasionally incontinent (less than daily).
  - 3% were frequently incontinent (daily but some control present).
  - 2% were incontinent (no control present).

- 18 residents had an indwelling catheter, 3 had a cystostomy/nephrostomy/ureterostomy and one used a condom catheter. 59% were reported to wear continence pads or briefs.

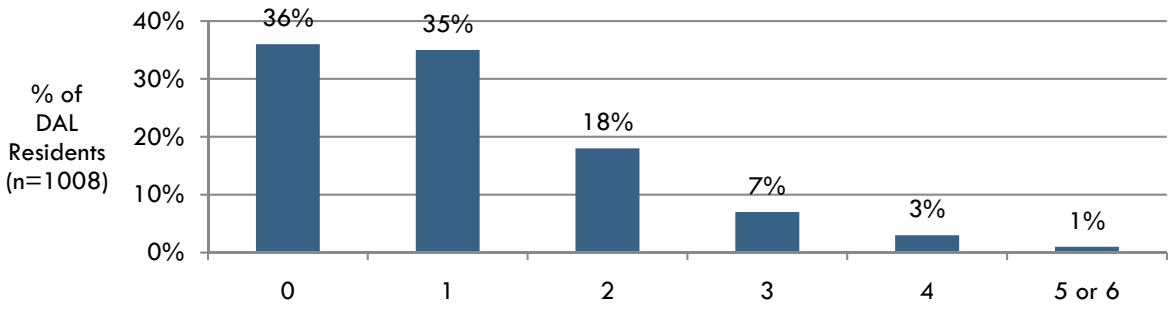
Skin Conditions

- Relatively few of the 1089 DAL residents were reported to have **pressure ulcers** at the time of the assessment.
  - 3% had an area of persistent skin redness (Stage 1).
  - 3% had partial loss of skin layers (Stage 2).
  - <1% had deep craters in skin (Stage 3).
  - <1% had breaks in the skin exposing muscle/bone (Stage 4).
  - <1% had an ulcer that could not be staged as it was covered with necrotic tissue.

- 7% of DAL residents had a documented **history of a previous pressure ulcer** that had healed.

- The **interRAI Pressure Ulcer Risk Scale (PURS)** (Poss et al., 2010) identifies individuals at risk for developing a pressure ulcer. Similar to reports for long-stay home care clients in Ontario (Poss et al., 2010), the PURS is skewed towards **lower risk for pressure ulcers,** with 71% of 1008 DAL residents who did not have a current pressure ulcer scoring 0 or 1 out of a possible 8 (Figure 16).

FIGURE 16. interRAI PRESSURE ULCER SCALE (PURS): DAL RESIDENTS



Based on the following: impaired in bed mobility, impaired in walking, bowel incontinence, weight loss, history of resolved pressure ulcers, daily pain, and shortness of breath. Possible scores range from 0 to 8: a higher score indicates higher risk. Calculated only for 1008 residents who did not have a current pressure ulcer; information was missing for 7 residents.

- 3% of the 1089 DAL residents had a **skin ulcer** other than a pressure ulcer.
- 7% had non-surgical skin tears or cuts.
- 29% had **other skin conditions** or changes in skin condition such as bruises, rashes, itching, or eczema.
- Among the 1089 DAL residents, 25% had **foot problems** such as bunions, hammer toes, overlapping toes, infections, or ulcers. Among the 274 residents with foot problems, 31% were limited from walking, 3% were prevented from walking, 54% had no limitations in their walking while the remaining 12% did not walk for other reasons.

Nutritional Status

- 7% of 1084 DAL residents were reported to have experienced a **weight loss** of 5% or more in the last 30 days or 10% or more in the last 180 days. Information was not available for 5 residents.
- Residents were asked "*In the last year, have you lost more than 10 pounds (4.5 kg) unintentionally (i.e., not due to diet or exercise)?*" 13% of the residents indicated this amount of weight loss while 11% could not/did not respond (based on 1088 residents).
- 27% had special dietary needs.

Tobacco and Alcohol Use

- **Daily tobacco use** was recorded for 5% of DAL residents.
- 9% were reported to have **consumed alcohol** in the 14 days prior to the assessment. This included 6% who had 1 drink, 2% who had 2-4 drinks, and less than 1% who had 5 or more drinks in a single sitting.

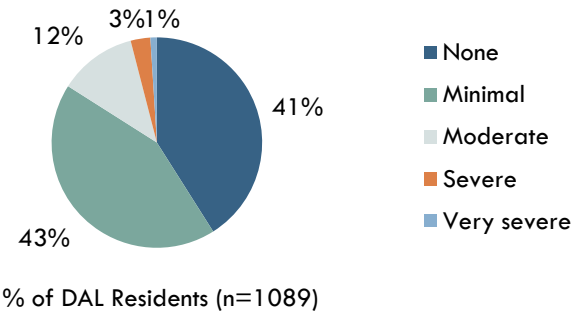
Sleep Problems

- 34% of DAL residents **experienced sleep problems,** including difficulty falling asleep or staying asleep, waking up too early, restlessness or non-restful sleep.
- 13% were assessed as getting **too much sleep** or excessive sleep that interfered with their normal functioning.

Fatigue

- 59% of residents were assessed with some level of **fatigue,** defined as diminished energy and difficulty in performing normal daily activities (e.g., ADLs and IADLs) (Figure 17).

FIGURE 17. FATIGUE: DAL RESIDENTS



% of DAL Residents (n=1089)

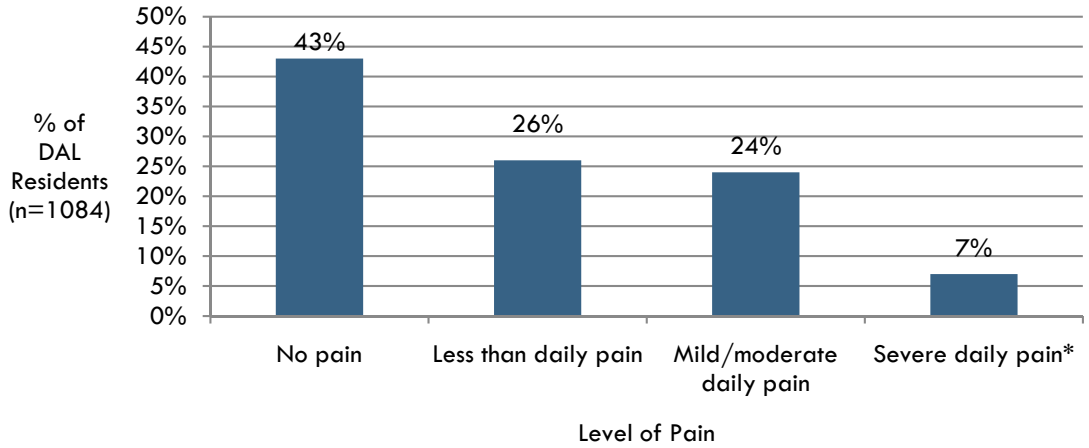
Minimal: due to diminished energy, but completes normal day-to-day activities
Moderate: due to diminished energy, unable to finish normal day-to-day activities
Severe: due to diminished energy, unable to start some normal day-to-day activities
Very severe: due to diminished energy, unable to commence any normal day-to-day activities

- DAL residents were asked "*In the past month, on average, have you been feeling unusually tired during the day? Feeling unusually weak? Feeling an unusually low energy level?*" Some individuals were unable to respond due to cognitive or communication difficulties.
  - 24% indicated feeling **unusually tired;** 14% could not/did not respond.
  - 18% indicated feeling **unusually weak;** 14% could not/did not respond.
  - 26% indicated feeling an **unusually low energy level;** 15% could/did not respond.

Pain

- Over one-half of the 1084 DAL residents experienced **some level of pain,** with 32% having daily pain, based on the **interRAI Pain Scale** (Fries, Simon, Morris, Flodstrom, & Bookstein, 2001) (Figure 18).

FIGURE 18. interRAI PAIN SCALE: DAL RESIDENTS



* Severe daily pain includes severe/excruciating pain

Preventive Health Strategies

- The likelihood of prevention strategies varied.
  - Blood pressure measured in the last year (97%)
  - Colonoscopy test in the last five years (11%, based on 1088 residents)
  - Dental exam in the last year (36%)
  - Eye exam in the last year (52%)
  - Hearing exam in the last two years (26%)
  - Influenza vaccine in the last year (87%)
  - A mammogram in the last two years (for 835 females only) (16%)
  - A pneumovax vaccine ever (67%)

Clinical Assessment Protocols (CAPs): Clinical Issues

- Information on the **interRAI Clinical Assessment Protocols (CAPs) related to clinical issues** is provided in Table 8. These CAPs are designed to focus on key common/severe issues identified during the assessment process, so that evidence-based decisions can be made to improve resident care planning. CAPs are triggered to indicate "the possibility of problem resolution, reducing the risk of decline or increasing the potential for improvement" (CIHI, 2008, p.1).

TABLE 8. interRAI CLINICAL ASSESSMENT PROTOCOLS (CAPs) FOR CLINICAL ISSUES: DAL RESIDENTS

CAP	% of DAL Residents Triggering CAP (n=1089)
Falls CAP 23% of DAL residents were at *medium risk* and 5% at *high risk* for future falls. The medium risk group had a prior report of a single fall while the high risk group had experienced multiple falls.	**28%**
Pain CAP The goal of this CAP is to identify residents in particular need of appropriate pain assessment and management strategies. 24% of DAL residents were at *medium priority* for specialized follow-up (with mild to moderate daily pain) and 8% were at *high priority* for follow-up (with horrible, excruciating pain whether it occurred daily or less frequently). *Based on 1085 residents.*	**32%**
Pressure Ulcer CAP 4% of DAL residents had Stage 2 or higher level pressure ulcers, 3% had Stage 1 ulcers and were at risk for Stage 2 or higher ulcers, and 1% had no ulcer currently but had selected risk factors. *Note: The item 'wound care' is not available on the interRAI-AL so the CAP is calculated without this item.*	**8%**

Continued…

Cardio-Respiratory CAP **51%**

This CAP identifies individuals in need of focused assessment/management and/or further referral (e.g., to a physician) for possible cardiovascular or respiratory problems. It is triggered by the presence of one or more of the following symptoms: chest pain, shortness of breath, irregular pulse, or dizziness. It may also be triggered by recorded findings of selected tests such as blood pressure, respiratory rate, heart rate, and oxygen saturation levels.

Prevention CAP **99%**

Preventive strategies are considered together in this CAP. All but 7 residents triggered the CAP, suggesting opportunities for improvement in implementing preventive strategies for DAL residents. *Note: The item 'physician visit days' is not available on the interRAI-AL tool so the CAP is calculated without this item. Based on 1087 residents.*

Appropriate Medication CAP **14%**

This CAP is based on a resident having 9 or more medications and 2 or more of the following conditions: chest pain, dizziness, edema, shortness of breath, poor health, and recent deterioration. It identifies residents who may have an increased risk of potentially inappropriate medication use and adverse drug events and require additional focused assessment and follow-up. *Note: The item 'self-sufficiency change' is not available on the interRAI-AL tool so the CAP is calculated without this item. Based on 1088 residents.*

Tobacco and Alcohol Use CAP **5%**

This CAP identifies individuals in need of targeted efforts (e.g., advice, support or treatment) to help them stop smoking or to reduce their alcohol consumption where indicated.

Urinary Incontinence CAP **50%**

The goal of this CAP is to promote improvement in bladder function in those who could improve and to prevent worsening of function in persons who may have the ability to respond to a treatment program, taking cognitive performance into account. 43% of the residents may benefit from activities such as scheduled toileting programs, and/or ongoing monitoring to *prevent decline* while such activities may *facilitate improvement* for 7% of the residents.

Bowel Conditions CAP **13%**

This CAP addresses 3 common bowel conditions: diarrhea, constipation, and fecal impaction. The goal is to facilitate improvement in bowel status whenever possible and to prevent avoidable bowel decline in others. 7% of DAL residents were at risk of *further decline* while 6% were considered to have *potential for improvement. Note: The item 'overall change in care needs' is not available on the interRAI-AL tool so the CAP is calculated without this item.*

Note: The description of CAPs is from CIHI (2008). The Under-nutrition CAP that addresses the need for nutritional support of individuals below a "medically recommended" ideal body weight, as measured by a low body mass index (BMI) was not calculated due to the lack of recorded height and weight, a decision not to have study nurses take these measurements, and a concern about the reliability and validity of the BMI calculation for this population.

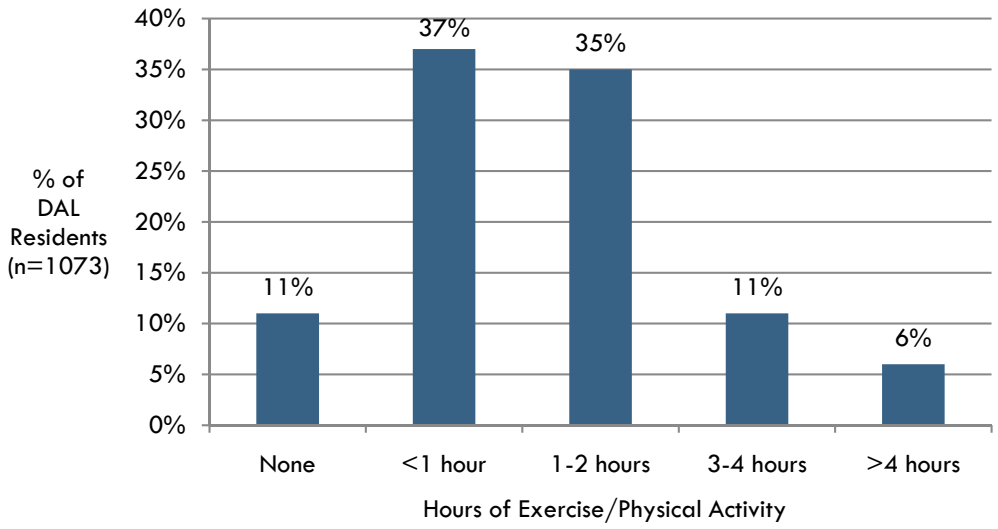
Physical Function

Information was gathered on several aspects of physical function, including **exercise/physical activity, instrumental activities of daily living (IADLs), basic activities of daily living (ADLs), mode of locomotion, use of restrictive devices,** and **CAPs for physical function.** Unless otherwise noted, the **assessment period** was the **past 3 days.**

Exercise/Physical Activity

- Residents varied in their total hours of **exercise or physical activity** in the 3 days prior to assessment, with 17% getting at least 3 hours and 11% getting none (Figure 19).

FIGURE 19. HOURS OF EXERCISE/PHYSICAL ACTIVITY IN LAST 3 DAYS: DAL RESIDENTS



- **Walking/wheeling indoors** (62%) was the only exercise/physical activity in which over one-half of the residents participated in the 3 days prior to the assessment or were regularly involved but not in these 3 days (Table 9).
- Very few residents participated in **non-preferred** activities (Table 9).
- Gardening/plants (32%) and dancing (28%) were identified for at least 25% of residents as an **activity in which they did not participate** although it was a preferred activity (Table 9). This may reflect the residents' physical/cognitive functioning, the availability of this activity in the facility, or the lack of a companion with whom to participate.

TABLE 9. EXERCISE/PHYSICAL ACTIVITIES: DAL RESIDENTS

Exercise/Physical Activity	% of DAL Residents (n=1089)			
	Participated and Preferred	Participated but Not Preferred	Did Not Participate but Preferred	Did Not Participate and Not Preferred
Walking/wheeling indoors	61%	1%	12%	25%
Walking/wheeling outdoors	42%	<1%	19%	39%
Exercise program, stretching	41%	1%	12%	46%
Trips, shopping, functions	38%	<1%	22%	40%
Household chores	22%	<1%	23%	55%
Gardening or plants	12%	<1%	32%	56%
Aquasize/swimming	1%	---	15%	84%
Bowling	6%	---	18%	76%
Shuffleboard/pool	4%	<1%	8%	87%
Dancing	3%	---	28%	69%
Floor curling/lawn bowling	3%	<1%	8%	90%
Exercise bike/treadmill	2%	---	9%	89%
Tai Chi /yoga	1%	<1%	2%	97%

Participated included involvement in the 3 days prior to assessment and regular involvement but not in these 3 days. % of residents who participated in an activity = (% Participated and Preferred) + (% Participated but Not Preferred). % of residents who preferred an activity = (% Participated and Preferred) + (% Did Not Participate but Preferred).

Instrumental Activities of Daily Living (IADLs)

- The majority of DAL residents received assistance with **meal preparation, housework,** and **managing medications** in the 3 days prior to the assessment (Table 10).

TABLE 10. IADL PERFORMANCE: DAL RESIDENTS

Activity	% of DAL Residents (n=1089)			
	Independent	Limited Assistance (includes set-up)	Extensive Assistance – Total Dependence	Activity Did Not Occur in the Last 3 Days
Meal preparation	<1%	<1%	99%	---
Ordinary housework	2%	3%	95%	---
Managing finances	8%	4%	59%	29%
Managing medications	4%	5%	91%	<1%
Phone use	54%	14%	12%	21%
Stairs	5%	2%	3%	90%
Shopping	7%	2%	12%	80%
Transportation	5%	2%	18%	75%

- Some resident's **IADL capacity** (based on assumed ability to carry out the activity as independently as possible) exceeded their performance. In other words, they were capable of performing an activity more independently than was occurring (Table 11). For activities such as meal preparation and housework, this gap reflects, in part, the services routinely provided in DAL.

TABLE 11. IADL CAPACITY AND PERFORMANCE: DAL RESIDENTS

Activity*	% of DAL Residents		
	Capacity = Performance	Capacity Exceeded Performance	Performance Exceeded Capacity
Meal preparation (n=1089)	41%	58%	<1%
Ordinary housework (n=1089)	53%	46%	<1%
Managing finances (n=771)	78%	21%	<1%
Managing medications (n=1084)	86%	13%	<1%
Phone use (n=864)	95%	2%	2%
Stairs (n=107)	92%	5%	4%
Shopping (n=217)	93%	5%	2%
Transportation (n=272)	90%	8%	2%

* The number of residents varies as the comparison of Capacity and Performance is possible only when the activity occurred in the last 3 days.

Basic Activities of Daily Living (ADLs)

- In terms of basic ADLs, almost all DAL residents required some assistance with **bathing** while over one-half needed some help with **personal hygiene, dressing their upper body** or **dressing their lower body** (Table 12).

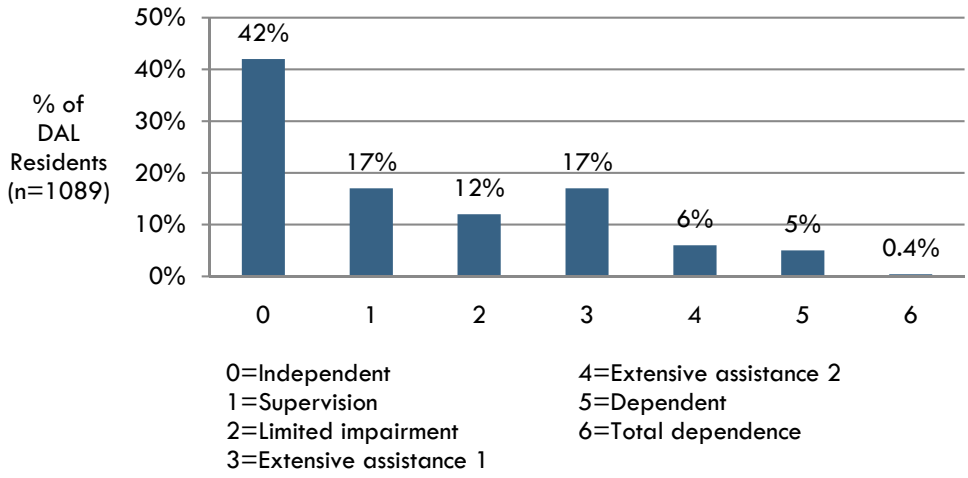
TABLE 12. ADL PERFORMANCE: DAL RESIDENTS

Activity	% of DAL Residents (n=1089)			
	Independent	Limited Assistance (includes setup)	Extensive Assistance – Total Dependence	Activity Did Not Occur in Last 3 Days
Bathing	7%	30%	56%	7%
Personal hygiene	43%	39%	18%	---
Dressing upper body	42%	38%	20%	---
Dressing lower body	37%	38%	25%	---
Walking	59%	24%	6%	11%
Locomotion	72%	17%	11%	<1%
Transfer toilet	76%	12%	11%	<1%
Toilet use	62%	19%	19%	---
Bed mobility*	85%	11%	5%	---
Eating	69%	28%	3%	---

* n=1087

- 42% of the DAL residents were assessed as independent in their activities of daily living, based on the **Activities of Daily Living Self-Performance Hierarchy Scale** (Morris, Fries, & Morris, 1999) (Figure 20). This scale measures ADL performance according to early, middle and late stages of loss using 4 ADLs (personal hygiene, toilet use, locomotion and eating). Scores range from 0 (independent) to 6 (total dependence).

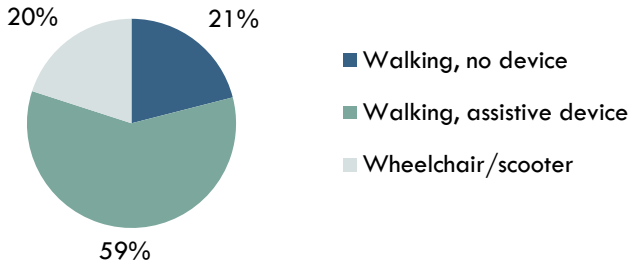
FIGURE 20. interRAI ACTIVITES OF DAILY LIVING (ADL) SELF-PERFORMANCE HIERARCHY SCALE: DAL RESIDENTS



Mode of Locomotion

- 59% of DAL residents were independent with **walking** while 72% were independent in **locomotion** (walking or wheeling).
- 20% of DAL residents used **wheelchairs/scooters** while 59% walked with an assistive device (Figure 21).

FIGURE 21. USUAL MODE OF LOCOMOTION: DAL RESIDENTS



% of DAL Residents (n=1089)

Use of Restrictive Devices

- The use of restrictive devices was relatively infrequent in DAL.
  - **Full bed rails on all open sides of bed** (3% of residents), including use daily - nights only (n=24), night and day but not constant (n=9), and constantly for the full 24 hours with possible periodic release (n=4)
  - **Trunk restraints** (2%), including use daily - nights only (n=1) and daily - days only (n=25)
  - **Chairs** to prevent rising (1%), including use daily - days only (n=8) and constantly for the full 24 hours with possible periodic release (n=1)

Clinical Assessment Protocols (CAPs): Physical Function

- Information on the **interRAI Clinical Assessment Protocols (CAPs) related to physical function** is provided in Table 13.

TABLE 13. interRAI CLINICAL ASSESSMENT PROTOCOLS (CAPs) FOR PHYSICAL FUNCTION: DAL RESIDENTS

CAP	% of DAL Residents Triggering CAP (n=1089)
Physical Activities Promotion CAP	**38%**
38% of DAL residents triggered this CAP, indicating the need for improvement in their level of physical activity including walking, planned exercise or leisure activities and performing instrumental tasks. This CAP aims to identify functionally capable older adults in need of targeted and appropriate strategies to reduce barriers to increased physical activity levels. *Based on 1073 residents*.	
Instrumental Activities of Daily Living CAP	**27%**
This CAP assesses the resident's capacity *and* interest in improving their ability to perform 4 IADLs (preparing meals, doing ordinary housework, shopping, and using transportation) while taking cognitive performance into account. The residents who trigger this CAP are considered as having the potential to improve in their IADL performance.	
Activities of Daily Living CAP	**57%**
This CAP considers a resident's ability to perform basic daily activities, including dressing, personal hygiene, walking, transferring, toileting, changing position in bed and eating, taking cognitive performance into account. 35% of DAL residents potentially required attention to *prevent decline* and 22% to *facilitate improvement*. This latter group is distinguished by having 2 or more indicators suggestive of a recent acute event or fluctuating functional status and/or condition. *Note: The item 'overall change in care needs' is not available on the interRAI-AL tool so the CAP is calculated without this item.*	
Institutional Risk CAP	**62%**
This CAP identifies individuals whose physical functioning, memory, decision-making and general health status puts them at increased risk for long-term care placement in the coming months.	
Physical Restraints CAP	**3%**
This CAP assesses whether residents are physically restrained (by any device) and are in need of focused care to permit restraint removal. The goal is to eliminate restraint use by using techniques appropriate to the resident's physical and/or cognitive abilities. Among the 32 residents who triggered this CAP, 24 had little or no ability to perform middle or early loss ADLs such as personal hygiene, dressing and walking while 8 had some ability to perform these ADLs.	

Note: The description of CAPs is from CIHI (2008).

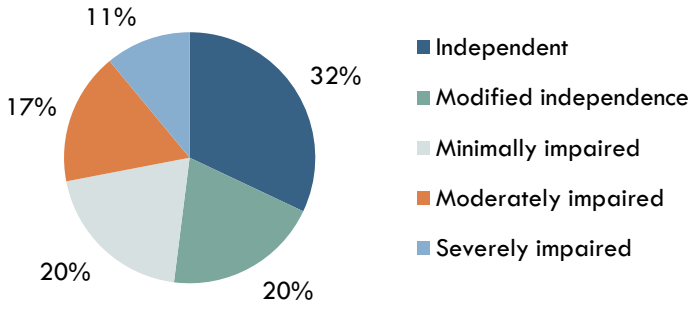
Cognitive Function and Mental Health

Several aspects of cognitive function and mental health are examined, including **cognition, communication, depression, disruptive behaviours, other mental health concerns**, and **CAPs for cognitive function and mental health.** Unless otherwise noted, the **assessment period** was the **past 3 days.**

Cognition

- As noted earlier (Table 6), 58% of DAL residents had a diagnosis of **dementia,** including Alzheimer's disease.
- Two-thirds of the residents exhibited some limitations in their **cognitive skills for daily decision-making** such as when to get up, which clothes to wear, or activities to do (Figure 22).

FIGURE 22. COGNITIVE SKILLS FOR DAILY DECISION-MAKING: DAL RESIDENTS

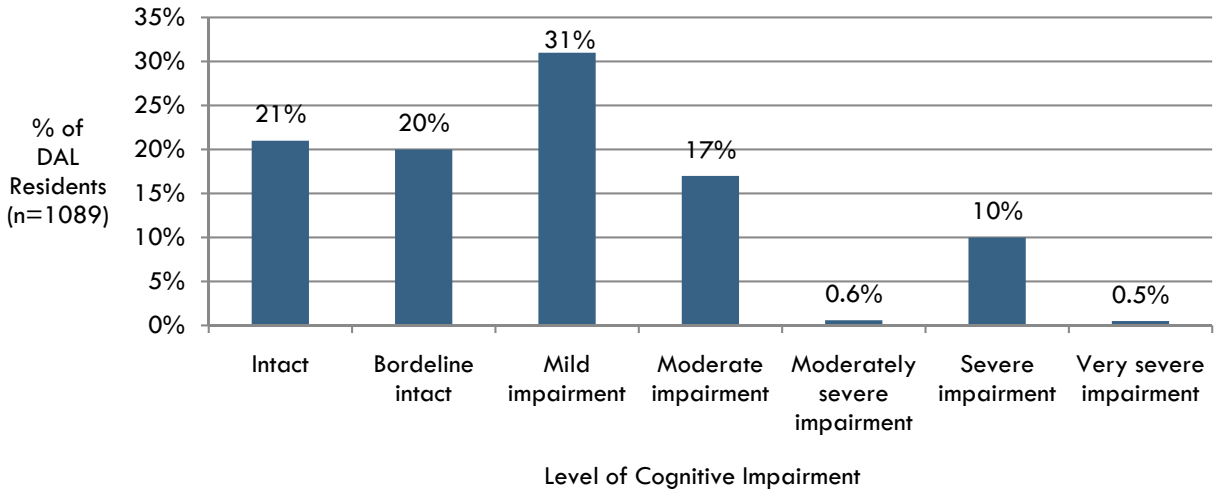


% of DAL Residents (n=1089)

Independent: decisions consistent, reasonable and safe
Modified independence: some difficulty in new situations only
Minimally impaired: in specific recurring situations, decisions become poor or unsafe; cues/supervision required at those times
Moderately impaired: decisions consistently poor or unsafe; cues/supervision required at all times
Severely impaired: never or rarely makes a decision

- In terms of memory/recall ability,
  - 66% had **short-term memory problems** (unable to recall after 5 minutes).
  - 34% had **procedural memory problems** (cannot perform all or almost all steps in a multitask sequence without cues).
  - 29% had problems with **situational memory** (not recognizing caregivers' names/faces frequently encountered and not knowing location of places regularly visited such as their bedroom or dining room).
- 59% of DAL residents had mild to very severe impairment in cognitive performance, based on the **interRAI Cognitive Performance Scale (CPS)** (Morris et al., 1994; Hartmaier et al., 1995) (Figure 23). The CPS considers skills for daily decision-making, short-term memory, making self understood, and eating impairment. Scores range from 0 (intact) to 6 (very severe impairment).

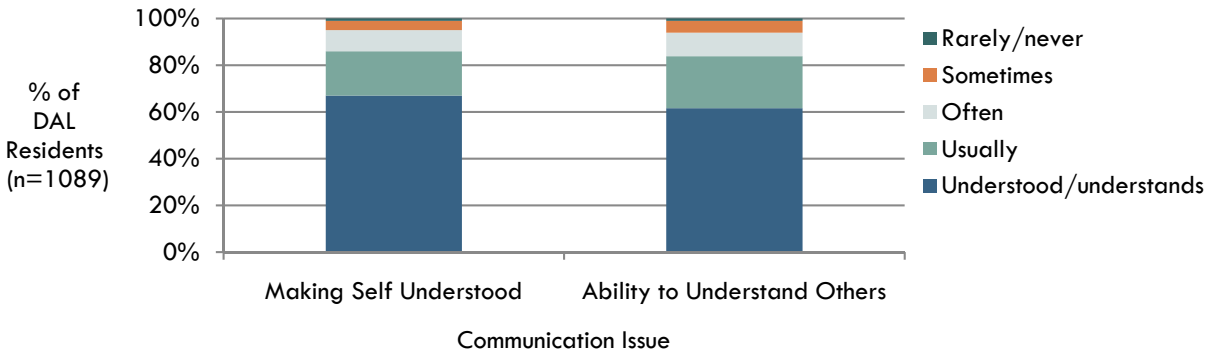
FIGURE 23. interRAI COGNITIVE PERFORMANCE SCALE (CPS): DAL RESIDENTS



Communication

- About one-third of the residents experienced difficulty **making themselves understood** (33%) or **understanding others** (39%) (Figure 24).

FIGURE 24. COMMUNICATION ISSUES: DAL RESIDENTS



Depression

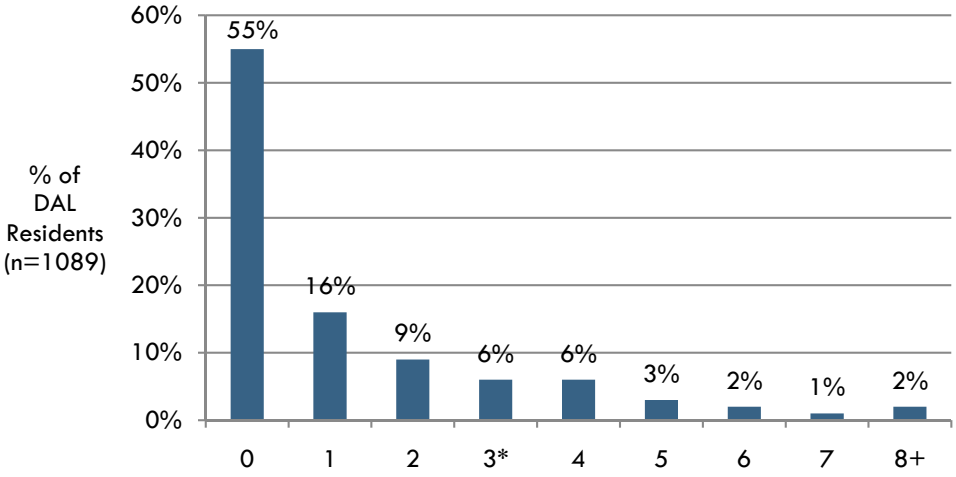
- 34% of DAL residents had a recorded **clinical diagnosis of depression.**
- Some residents showed signs of **possible depressed, anxious or sad mood** (Table 14).

TABLE 14. INDICATORS OF POSSIBLE DEPRESSED, ANXIOUS OR SAD MOOD: DAL RESIDENTS

Indicator	% of DAL Residents (n=1089)			
	Daily in Last 3 Days	1-2 Days of Last 3 Days	Present but Not in Last 3 Days	Not Present
Made negative statements	3%	4%	6%	88%
Persistent anger with self or others	5%	6%	8%	82%
Expressions of what appear to be unrealistic fears (verbal/non-verbal) (n=1088)	2%	2%	4%	92%
Repetitive health complaints	5%	3%	4%	88%
Repetitive anxious complaints/concerns (non-health)	6%	3%	6%	86%
Sad, pained, worried facial expressions	9%	5%	4%	82%
Crying, tearfulness	1%	5%	7%	87%
Recurrent statements that something terrible is about to happen	<1%	1%	2%	97%
Withdrawal from activities of interest	18%	7%	9%	67%
Reduced social interactions	26%	10%	10%	54%
Expressions of a lack of pleasure in life (verbal/non-verbal)	4%	4%	3%	90%

- 19% of DAL residents were assessed with clinically important depressive symptoms as measured by the **interRAI Depression Rating Scale (DRS)** (Burrows, Morris, Simon, Hirdes, & Phillips, 2000) (Figure 25). The DRS is based on a summary of the first 7 items in Table 14 and may be used as a clinical screen for depression. Scores range from 0 to 14, with higher values indicating a greater number and/or frequency of symptoms. A score of 3 or higher indicates clinically important depressive symptoms.

FIGURE 25. interRAI DEPRESSION RATING SCALE: DAL RESIDENTS



* Score of 3+ indicates clinically important depressive symptoms

- In addition to the nurse assessments, residents' self-assessments of mood were obtained. Residents were asked "*In the last 3 days, how often have you felt little interest or pleasure in things you normally enjoy? Anxious, restless, or uneasy? Sad, depressed, or hopeless?*"
    - 18% reported feeling **little interest or pleasure** in the last 3 days or often but not in those 3 days; 18% could not/did not respond.
    - 23% reported feeling **anxious, restless, or uneasy** in the last 3 days or often but not in those 3 days; 16% could not/did not respond.
    - 25% reported feeling **sad, depressed or hopeless** in the last 3 days or often but not in those 3 days; 15% could not/did not respond.

- 30% of residents were reported to have said or indicated that s/he felt **lonely** (based on 1086 residents).

- 17% expressed **sadness over recent loss** (based on 1084 residents).

- 16% of residents were reported to have experienced a **major life stress** in the 90 days prior to the assessment, such as episodes of severe personal illness or the death or severe illness of a close family member.

- 75% were assessed as having a **consistent positive outlook** (based on 1084 residents) while 78% were reported as **finding meaning in day-to-day life** (based on 1083 residents).

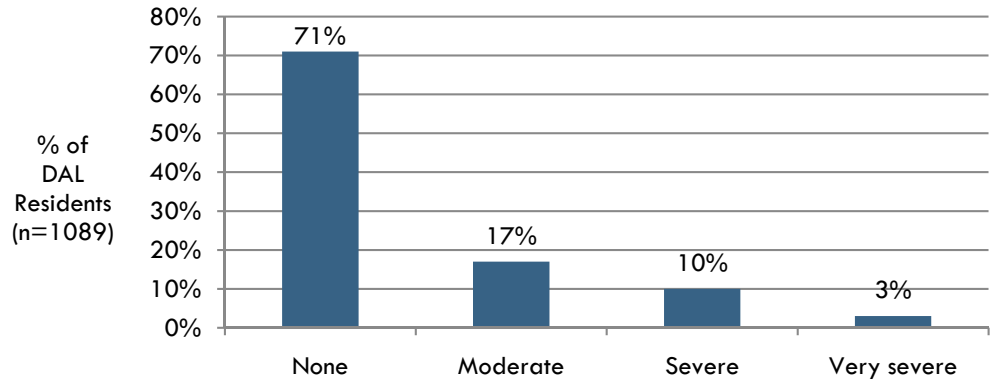
Disruptive Behaviours

- Some DAL residents exhibited **disruptive behaviours** in the 3 days prior to the assessment or usually but not in the previous 3 days.
    - Wandering (11%)
    - Verbal abuse (15%)
    - Physical abuse (5%)
    - Socially inappropriate or disruptive behaviour (6%)
    - Inappropriate public sexual behaviour or public disrobing (2%)
    - Resisting care (23%)
    - Intimidation of others or threatened violence (6%)

- 29% of residents scored in the moderate to very severe range on the **interRAI Aggressive Behavior Scale** (Perlman & Hirdes, 2008) that takes 4 behaviours (verbal abuse, physical abuse, socially inappropriate or disruptive behaviour, and resists care) into account (Figure 26).

- 6% of residents had **elopement attempts or threats** in the past 12 months while 1% displayed **dangerous, non-violent behaviour**.

FIGURE 26. interRAI AGGRESSIVE BEHAVIOR SCALE: DAL RESIDENTS



Other Mental Health Concerns

- Some residents had **other psychiatric disease diagnoses.**
  - 16% had a diagnosis of **anxiety.**
  - 4% had reported **substance abuse problems.**
  - 2% had been diagnosed with **schizophrenia.**
  - 1% had been diagnosed with **bipolar disease.**

- 8% of residents had **delusions,** 6% had **abnormal thought processes,** and 4% were reported to have **hallucinations** in the 3 days prior to the assessment or usually had such concerns although they were not exhibited in the assessment period.

- 15% of residents had a documented **history** of mental illness or intellectual disability. The number of **lifetime psychiatric admissions** varied, with 8% having 1- 3 admissions and 1% having 4 or more admissions.

- Within the previous 5-year period, 2 residents had resided in a **setting for persons with intellectual disability,** 36 residents had lived in a **psychiatric hospital or unit,** and 3 had resided in a **mental health residence such as a psychiatric group home.**

Clinical Assessment Protocols (CAPs): Cognitive Function and Mental Health

- Information on the five **interRAI Clinical Assessment Protocols (CAPs) related to cognitive function and mental health** is provided in Table 15.

TABLE 15. interRAI CLINICAL ASSESSMENT PROTOCOLS (CAPs) FOR COGNITIVE FUNCTION AND MENTAL HEALTH: DAL RESIDENTS

CAP	% of DAL Residents Triggering CAP (n=1089)
Cognitive Loss CAP This CAP focuses on helping those with reasonable cognitive skills (Cognitive Performance Scale (CPS) score of 2 or lower) to retain their independence for as long as possible. 62% of DAL residents would potentially benefit from monitoring for risk factors predictive of future decline and 9% need specialized attention to prevent decline. *Note: The item 'overall change in care needs' is not available on the interRAI-AL tool so the CAP was calculated without this item.*	**71%**
Delirium CAP This CAP indicates the presence of one or more active symptoms of delirium (e.g., acute onset, fluctuating cognitive status different from usual functioning). The goal is to identify and treat underlying causes of delirium and prevent associated complications.	**6%**
Mood CAP This CAP focuses on identifying those with depressive symptoms to permit appropriate management and follow-up. 26% of DAL residents were at *medium risk* (based on a Depression Rating Scale (DRS) score of 1 or 2) and 19% were at *high risk* (based on a DRS score of 3 or greater).	**45%**
Communication CAP This CAP considers communication status and cognitive skills for daily decision-making. The goal is to implement specialized follow-up to facilitate improvements in communication ability where possible and to prevent communication decline. Actions could be taken with 30% of the DAL residents to *prevent* decline and with 6% who have *potential for improvement*.	**36%**
Behaviour CAP This CAP considers the following behavioural issues: wandering, verbally abusive behaviour, physically abusive behaviour, socially inappropriate behaviour, resisting care, and inappropriate public sexual behaviour. Actions could be taken with 6% to *prevent* almost daily behaviours and with 11% to *reduce* daily behaviour.	**17%**

Note: The description of CAPs is from CIHI (2008).

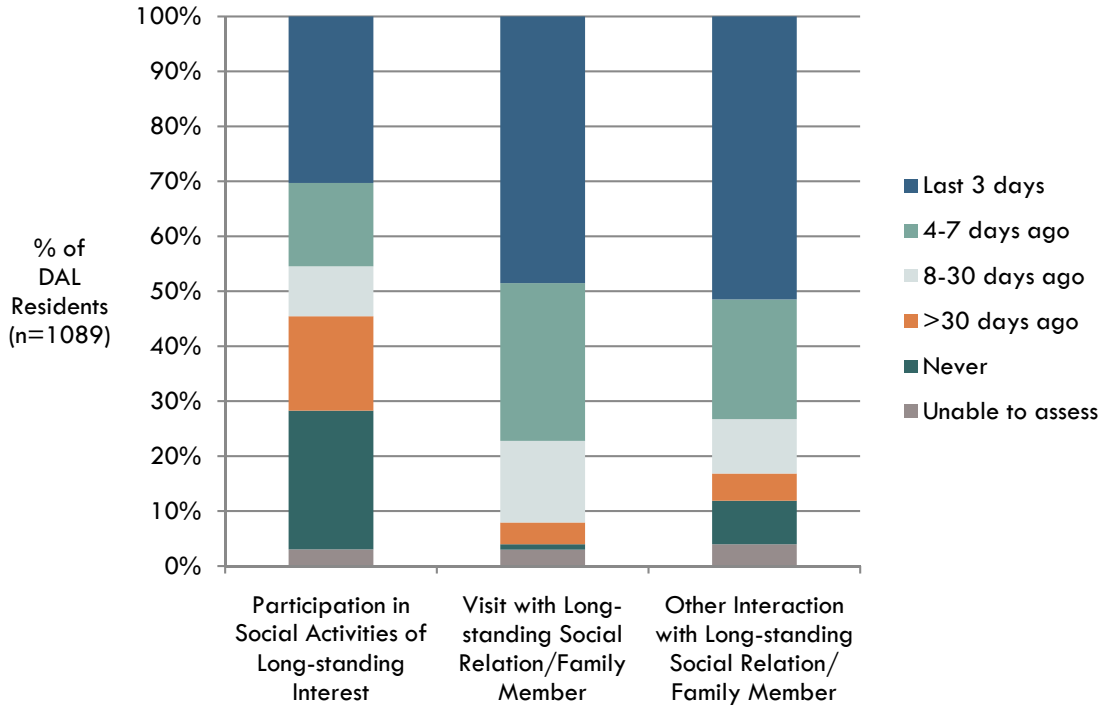
Social and Lifestyle Characteristics

Turning to social and lifestyle characteristics, information was gathered on **social functioning, social/recreational activities, initiative and involvement,** and the **CAPs for social life.** Again, unless otherwise noted, the **assessment period** was the **past 3 days.**

Social Functioning

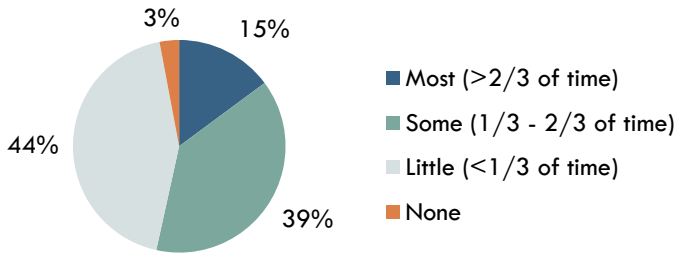
- 52% of DAL residents had not participated in a **social activity of long-standing** interest during the week prior to the assessment while 20% had not **visited with a long-standing social relation or family member** (Figure 27).

FIGURE 27. SOCIAL RELATIONSHIPS AND INTERACTIONS: DAL RESIDENTS



- Almost one-half of DAL residents were assessed as spending, on average, little (44%) or no (3%) **time involved in activities** (when awake and not receiving treatments/ADL care) (Figure 28).

FIGURE 28. AVERAGE AMOUNT OF ACTIVITY INVOLVEMENT: DAL RESIDENTS



% of DAL Residents (n=1089)

Social/Recreational Activities

- **Watching television/listening to the radio** and **music/singing** were the top two social/ recreational activities in which DAL residents were involved (Table 16).

TABLE 16. SOCIAL/RECREATIONAL ACTIVITIES: DAL RESIDENTS

Activity	% of DAL Residents (n=1089)			
	Participated and Preferred	Participated but Not Preferred	Not Participated but Preferred	Not Participated and Not Preferred
Watching TV or listening to radio	87%	<1%	5%	7%
Music or singing	71%	<1%	14%	14%
Conversation or talking on the phone	63%	<1%	7%	29%
Reading, writing or crossword puzzles	57%	<1%	14%	29%
Spiritual or religious activities	47%	<1%	15%	38%
Cards, games, puzzles, bingo	42%	<1%	20%	38%
Discussing/reminiscing about life	26%	<1%	15%	59%
Crafts or arts	21%	<1%	24%	54%
Pets	15%	<1%	25%	60%
Helping others	14%	<1%	22%	64%
Feeding or watching birds	15%	<1%	13%	72%
Volunteering (n=1088)	5%	---	16%	79%
Educational courses/meetings	4%	<1%	13%	83%
Collecting	4%	---	9%	87%
Genealogy	3%	---	8%	90%
Computer activity	3%	---	3%	95%

Participated included involvement in the 3 days prior to assessment and regular involvement but not in these 3 days. % of residents who participated in an activity = (% Participated and Preferred) + (% Participated but Not Preferred). % of residents who preferred an activity = (% Participated and Preferred) + (% Did Not Participate but Preferred).

- Very few residents were involved in **activities that they did not prefer** (Table 16).
- Some residents were **not involved in an activity that they preferred** (Table 16). Pets (25%), crafts or arts (24%), helping others (22%), and cards/games/puzzles/bingo (20%) were the activities most likely to be in this category. As discussed with regards to exercise/physical activity, this lack of involvement in preferred activities may reflect the resident's physical/cognitive functioning, the activity not being available in the DAL facility or at a time convenient for the resident to participate, or the lack of a partner with whom to participate.
- **Preferred activity locations** included their own room/apartment (82%, based on 1088 residents), the day/activity room (67%, based on 1086 residents), outdoors (54%, based on 1087 residents) or away from the facility (53%, based on 1087 residents). Only 4% would prefer a **change in location** of activities (based on 1084 residents).
- Only 5% would like the **time of activities** changed (based on 1084 residents).

Initiative and Involvement

- DAL residents exhibited varying levels of **initiative and involvement** in social relations (Table 17). Relatively few did not react positively to interactions initiated by others while 47% did not pursue involvement in the life of the facility.

TABLE 17. INITIATIVE AND INVOLVEMENT: DAL RESIDENTS

Action	% of DAL Residents (n=1089)			
	Daily in Last 3 Days	1-2 Days of Last 3 Days	Present but Not in Last 3 Days	Not Present
Reacts positively to interactions initiated by others	64%	22%	8%	7%
At ease interacting with others	66%	14%	6%	14%
Initiates interaction(s) with others	38%	15%	13%	34%
At ease doing planned or structured activities	32%	18%	20%	30%
Accepts invitation(s) into most group activities	28%	21%	19%	31%
Pursues involvement in life of facility	25%	14%	14%	47%
Adjusts easily to change in routine	20%	6%	33%	41%

- Only 6% of residents were assessed as not having a **strong and supportive relationship with their family**. 11% had openly expressed conflict/anger with their family; this could not be determined for 4% of the residents.

- Considering **relationships with staff and other residents,** 45% were assessed as not being close to someone in the facility (resident or staff). Some residents experienced **conflict** with staff or other residents.
  - 12% had a conflict with or repeated criticism of staff (based on 1088 residents).
  - 3% had a conflict with or repeated criticism of a roommate.
  - 10% had a conflict with or repeated criticism of a person other than a roommate (based on 1088 residents).
  - 15% were reported by staff to be a persistent frustration when dealing with them.

- 18% of DAL residents were determined to have **low to no social engagement,** when considering the ease of interacting with others, pursuit of involvement in life of the facility, participation in social activities of long-standing interests, and visits or other interactions with a long-standing social relation or family member.

Clinical Assessment Protocols (CAPs): Social Life

- Information on the two **interRAI Clinical Assessment Protocols (CAPs) related to social life** is provided in Table 18.

TABLE 18. interRAI CLINICAL ASSESSMENT PROTOCOLS (CAPs) FOR SOCIAL LIFE: DAL RESIDENTS

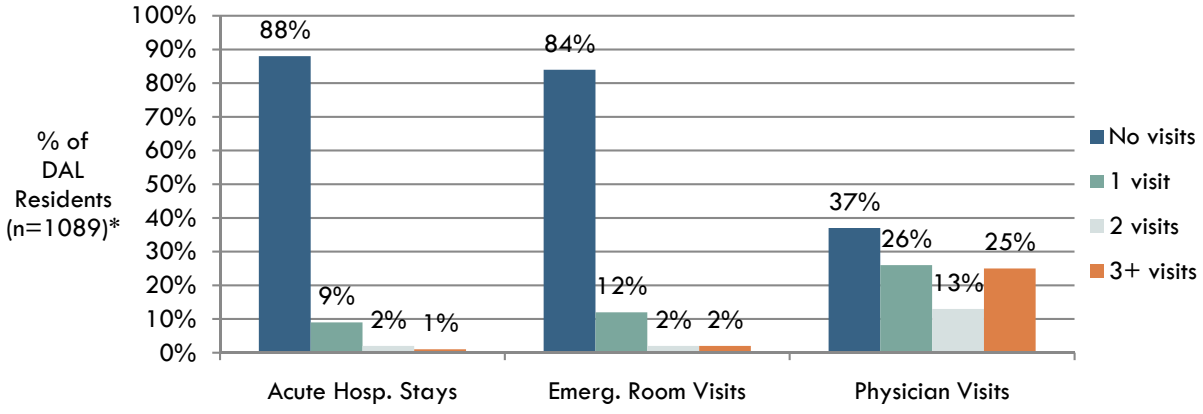
CAP	% of DAL Residents Triggering CAP (n=1089)
Activities CAP This CAP targets residents who have some cognitive reserve and have either withdrawn from or appear uneasy entering into activities and social relationships. The goal of specialized follow-up is to identify barriers and potential interventions for enhanced social activities, taking the residents' preferences into consideration.	**36%**
Social Relationship CAP This CAP identifies individuals with characteristics indicative of or associated with reduced social relationships for whom an intervention may facilitate social engagement.	**27%**

Note: The description of CAPs is from CIHI (2008).

Health Service Utilization

- 12% of DAL residents had at least one **inpatient acute care hospital visit** with an overnight stay in the 90 days prior to the assessment (Figure 29).

FIGURE 29. HEALTH SERVICE USE IN 90 DAYS PRIOR TO ASSESSMENT: DAL RESIDENTS



* Except for physician visits (n=1088)

- 16% of DAL residents had at least one **emergency room visit** (not counting overnight stays) in the 90 days prior to the assessment, with a range from 0 to 10 visits (Figure 29).
- 63% of DAL residents had at least one **physician visit** in the 90 days prior to the assessment, with a range from 0 to 36 visits (based on 1088 residents) (Figure 29).

- Few residents had received **physiotherapy** (3%), **occupational therapy** (1%), **psychological therapy** by a licensed mental health professional (1%), or **speech-language pathology and audiology** (<1%) in the 7 days prior to the assessment.

- 21% of DAL residents were reported to have received **care from a RN or a LPN** in the 7 days prior to the assessment.

1-Year Outcomes

Attention now turns to the situation of the DAL residents 1-year following their baseline assessment. Of interest is their **status at 1-year, changes in health/functioning,** and **characteristics associated with a move to long-term care.**

Status at 1-Year

- 63% of the residents were **living in the same DAL** facility at the 1-year follow-up while 3% had moved to another location where they received an equivalent or lower level of care (Table 19).

TABLE 19. STATUS AT 1-YEAR FOLLOW-UP: DAL RESIDENTS

Status	Number of DAL Residents	% of DAL Residents
Remained in DAL/equivalent	716	66%
• Same DAL	(685)	(63%)
• Different DAL	(24)	(2%)
• Lodge/residential care	(4)	(<1%)
• Private AL	(3)	(<1%)
Living in LTC Facility	176	16%
Deceased	175	16%
Other*	22	2%

Note: By 1-year, 175 residents had died, including 34 residents who died after a move to LTC. The total number of individuals who had moved to LTC during the 1-year period was 210 residents (34 residents who died after a move to LTC + 176 alive in LTC at time of 1-year follow-up).
* Other includes: withdrawn from study and location unknown (n=2), moved to a health region outside the study area and location type unknown (n=1), in a rehabilitation facility (n=1), in transition space/sub-acute setting (n=1), in hospice/palliative care (n=2), in acute care hospital (n=8), in private home/apartment (n=6), and unknown/missed at follow-up (n=1).

- At the 1-year follow-up, 16% of residents were in **long-term care** as they required a higher level of care (Table 19).

- 16% **died** during the 1-year period. This includes 3% who moved to long-term care prior to their death.

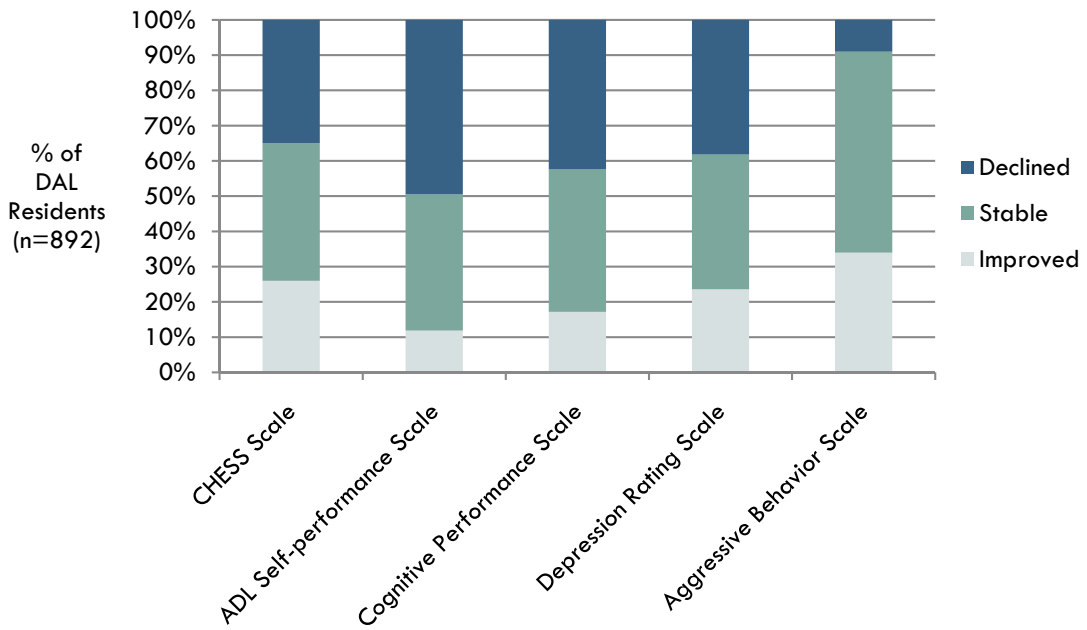
Changes in Health/Functioning

- **Changes in clinical issues as well as physical and cognitive/mental health functioning** at the 1-year follow-up were examined for the 892 residents who were assessed at baseline and follow-up, regardless of their location.

- It is important to recognize the **complexity of measuring change** with this population. Attention here focuses on changes in scores on the key interRAI summary scales only. These scales are scored such that a higher score indicates poorer functioning. Three situations are considered: stable (score at baseline = score at follow-up), decline/poorer functioning (score at baseline lower than score at follow-up), and improvement/better functioning (score at baseline higher than score at follow-up). The magnitude of the change is not taken into account and a 1-point change on the scale is considered as change. For example, a resident whose CHESS score was 1 at baseline and 2 at follow-up would be categorized as experiencing a decline. Resident and facility characteristics that may explain and/or contribute to the change have not been taken into account.

- Considering first scores on the **interRAI Changes in Health, End-stage Disease and Symptoms and Signs (CHESS)** scale (Hirdes et al., 2003), 39% of the 892 DAL residents had the same score on this measure of clinical complexity and health at baseline and follow-up, 35% had higher levels of instability (i.e., declined) at follow-up while 26% had lower levels (i.e., improved) (Figure 30).

FIGURE 30. CHANGES IN HEALTH STATUS: DAL RESIDENTS



- In terms of **physical functioning** as measured by the **interRAI Activities of Daily Living (ADL) Self-Performance Hierarchy Scale** (Morris et al., 1999), 50% of the 892 residents showed a decline in their ability to independently perform ADLs, while 12% appeared more independent (Figure 30). The remaining 39% had no change in their scores.

- Turning to **cognitive functioning**, 42% showed a decline in cognitive function as measured by the **interRAI Cognitive Performance Scale** (Morris et al., 1994; Hartmaier et al., 1995) while 17% exhibited an improvement and 40% scored the same at both time points (Figure 30).

- In terms of **depression** as measured by the **interRAI Depression Rating Scale** (Burrows et al., 2000), 34% were stable, 21% showed improvement, and 45% exhibited more symptoms (Figure 30). In addition, 25% of residents showed signs of clinically important depressive symptoms at follow-up (score of 3+ on DRS) but not at baseline, while 9% did so at baseline but not at follow-up. 57% of residents did not have a score of 3+ at either time point, while 9% did so at both time points.

- **Aggressive behaviours** increased for 34% of the residents and declined for 9%, as measured by the **interRAI Aggressive Behavior Scale** (Perlman & Hirdes, 2008) (Figure 30). The remaining 57% showed stability in their scores.

- Overall, **both stability and change** in health/functioning as measured here was evident among these DAL residents.

Moving to a Long-term Care Facility

- In total, 210 DAL residents (19%) were **admitted to a long-term care facility** in the year after their baseline assessment. This included 176 residents who were still alive at the 1-year follow-up and 34 residents who had died.

- An in-depth analysis of the **resident and facility characteristics at baseline associated with a long-term care admission** by the 1-year follow-up was conducted. The comparison was between the 210 residents who moved and the other 889 residents who were assessed at baseline but had not moved to long-term care during the year (details available upon request).[5]

- Some **resident characteristics** were significantly associated with LTC admission while other characteristics did not emerge as significant. Several of these characteristics such as cognitive and ADL impairment, and aggressive behaviours were consistent with the retention criteria discussed earlier.

[5] The model was adjusted for age, gender, and facility clustering. Results did not vary after adjusting for the competing risk of death.

- **Resident characteristics at baseline <u>significantly associated</u> with LTC admission:**
  - Mild or moderate-severe **cognitive impairment** (compared to intact)
  - Mild or moderate-severe **ADL impairment** (compared to independent)
  - Impairment in the primary mode of **locomotion** (walks with assistive device/uses wheelchair/scooter compared to walks independently)
  - **Health instability** (score on CHESS 3+ compared to 0)
  - **Aggressive behaviour** (score on ABS 6+ compared to 0)
  - **Bladder incontinence** (frequently incontinent – incontinent compared to continent)
  - **Acute care hospital/ER visit** in 90 days prior to assessment (1+ compared to 0)
  - **Falls in the 90 days** prior to assessment (1+ compared to 0)
  - Little <1/3 of time to no **time involved in activities** (compared to most >2/3)
  - Low to no **social engagement** (compared to moderate - high)

- **Resident characteristics at baseline <u>not associated</u> with LTC admission:**
  - Marital status
  - # of hours of informal care
  - Depression (score of 3+ on DRS compared to <3)
  - Bowel incontinence (frequently incontinent – incontinent compared to continent)
  - Number of co-morbid conditions
  - Length of residence in the facility

- **Facility characteristics** were also taken into account, with some characteristics emerging as significantly associated with a move to LTC. Residents in DAL facilities that did not have professional nursing staff on site 24/7 were more likely to move to long-term care, reflecting in part increased, unscheduled care needs of residents.

  - **Facility characteristics <u>significantly associated</u> with LTC admission:**
    - <24/7 LPN/RN on site coverage (compared to LPN/RN on site 24/7)
    - Health region
    - Number of DAL spaces (smaller facility, higher risk of LTC admission)

  - **Facility characteristics <u>not associated</u> with LTC admission:**
    - Owner/operator status (for-profit, not-for-profit, RHA)
    - Being part of a chain
    - Facility type (DAL/EDAL versus DSL, DSH, EL)
    - Total number of spaces/beds in facility
    - Percent of spaces allocated to DAL
    - Year DAL spaces opened and years in operation
    - Level of care available (e.g., DAL and a higher level of care, DAL and lower level)
    - Community size

Summary

This profile has highlighted the situation of DAL residents, in terms of clinical issues, physical function, cognitive function and mental health, social and lifestyle characteristics, health service use, and 1-year outcomes. The complexity and diversity among residents is readily apparent.

On average, DAL residents had 4.6 disease diagnoses, with dementia, hypertension, arthritis, and depression being the most prevalent. The average number of regularly prescribed medications was 8.3. Generally, the residents received assistance with IADLs such as meal preparation, housework, and medication management. While some required help with ADLs such as bathing, dressing and toilet use, others were independent or required limited assistance.

Several residents exhibited some limitation in their cognitive skills for decision-making and some level of impairment in the cognitive performance. About one-third had a documented diagnosis of depression. Residents exhibited varying levels of social involvement, with social isolation being a concern for some residents.

At the 1-year follow-up, stability and change in clinical issues, physical function, and cognitive function/mental health among residents who were assessed at both time points were evident. At 1-year, 16% were residing in LTC facilities and 16% had died (including 3% who moved to LTC prior to death). Several characteristics associated with a move were consistent with the retention criteria such as cognitive and ADL impairment and aggressive behaviours as well as resources such as staffing mix.

Attention now turns to the family caregivers who were assisting the DAL residents. Of particular interest is the nature and extent of their involvement and the impact of caregiving on the lives of these individuals.

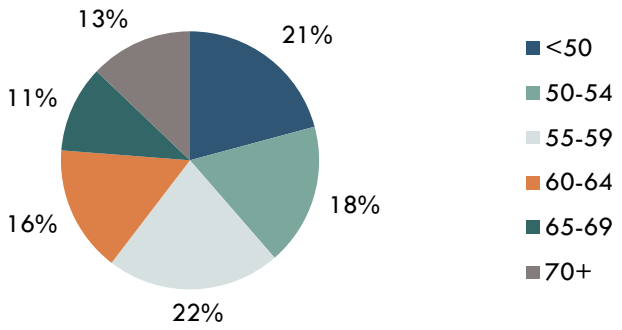
A PROFILE OF DAL FAMILY CAREGIVERS

In total, **974 individuals** were interviewed in their capacity as an informal caregiver of a DAL resident.[6] These individuals were identified as "the family member/friend who is the most involved and/or has the most information about the resident's experience in the assisted living facility". This profile focuses on **sociodemographic characteristics, visiting patterns, caregiving tasks,** the **effect of caregiving on employment, caregiver burden,** the **financial costs** to caregivers and residents, and **experiences at the time of the 1-year follow-up.**

Sociodemographic Characteristics

- The DAL family caregivers ranged in **age** from 22 to 91, with an average age of 57.7 years (Figure 31).

FIGURE 31. 5-YEAR AGE GROUPS: DAL FAMILY CAREGIVERS



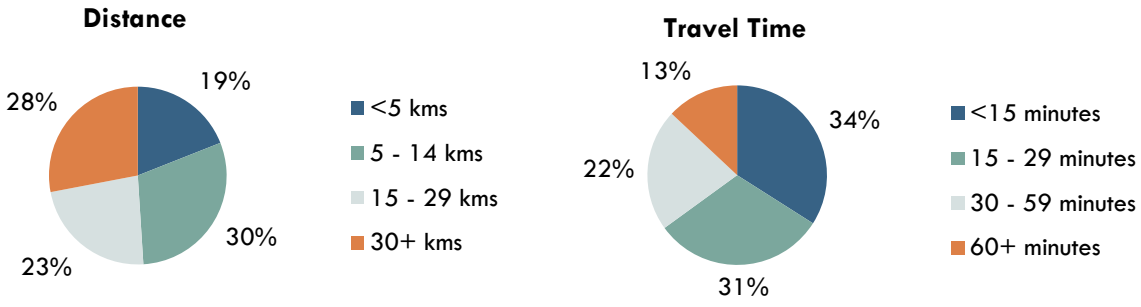
% of DAL Family Caregivers (n=967)

- 70% of the family caregivers were **female.**
- In terms of **marital status,** 82% were married, 10% were divorced/separated, 4% were widowed and 4% were never married (based on 973 caregivers).
- Caregivers were most likely to be **daughters** (51%) and **sons** (23%). Other caregivers included wives (4%), daughters-in-law (4%), nieces (3%) husbands (2%), sisters (2%), brothers (2%), granddaughters (2%), nephews (1%) and other family members (3%). Only 3% of these caregivers were friends/volunteers.

[6] Two caregivers completed a shortened interview as their family member died after the resident assessment was completed but before the caregiver interview was conducted. As a result, the total sample size varies from 972 to 974 depending on the specific question, unless otherwise noted. In some instances, respondents declined to answer the question. Percentages may not total 100% due to rounding.

- When asked "*Does the resident have any other helpers who are not paid (e.g., other family members)?*", 34% of the caregivers reported that there were no other **unpaid helpers**, 29% indicated one other helper, 19% identified two other individuals, and the remaining 18% reported three or more other helpers. The range was from 0 to 20.
- 6% of the caregivers indicated that there was no family member/friend who would **take over** their role of caring for the resident if they were not available, while 5% stated that they did not know who would do this (based on 971 caregivers).
- 59% of the family caregivers were **employed**. Among the employed, 32% worked less than 35 hours per week.
- Family caregivers resided varying **distances from the resident** (Figure 32). **Travel times** ranged from one minute to 48 hours (Figure 32). Four caregivers lived in the same facility as the resident.

FIGURE 32. DISTANCE AND TRAVEL TIME TO RESIDENT: DAL FAMILY CAREGIVERS



% of DAL Family Caregivers (n=962)*

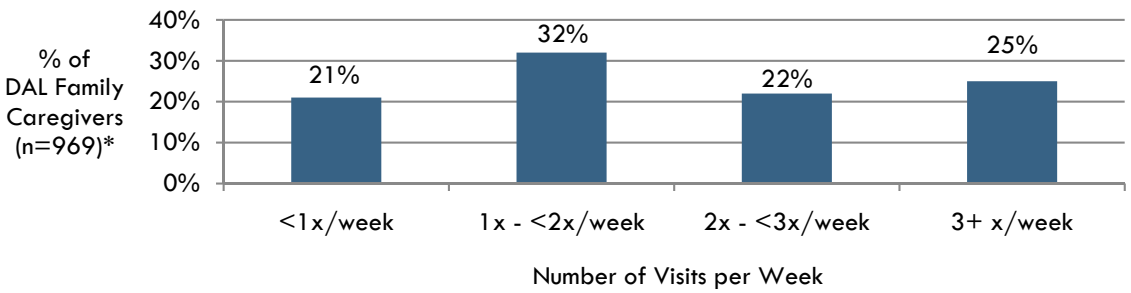
% of DAL Family Caregivers (n=966)*

* Excludes 4 caregivers who lived in the same facility as the resident

Visiting DAL Residents

- 21% of the family caregivers reported **visiting the resident** less than once a week, while 25% visited at least 3 times per week (Figure 33). Caregivers who lived further away were more likely to have fewer visits than those who lived nearby.

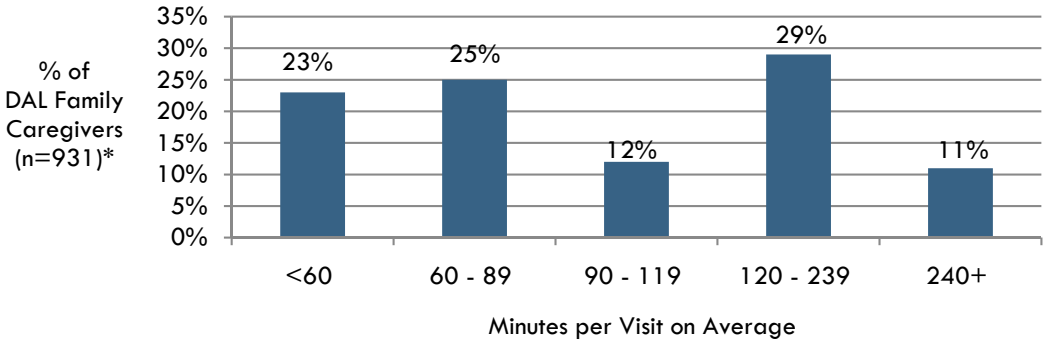
FIGURE 33. FREQUENCY OF VISITING: DAL FAMILY CAREGIVERS



* Excludes 4 caregivers who lived in the same facility as the resident

- The **length of the visits** varied from 5 minutes to 12 hours. Almost half (48%) visited for less than 90 minutes (Figure 34).

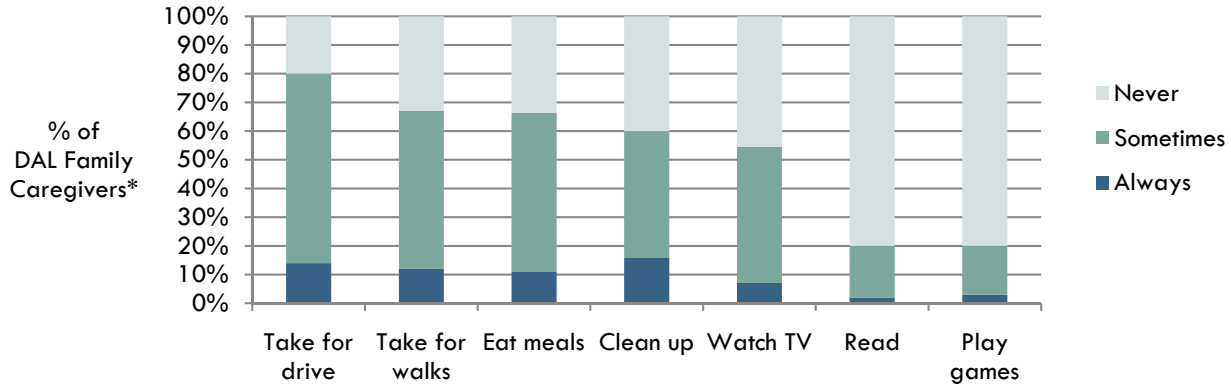
FIGURE 34. LENGTH OF VISIT: DAL FAMILY CAREGIVERS



* Excludes 4 caregivers who lived in the same facility as the resident, 3 who indicated the length of their visits varied by activity, 2 who reported that the length varied by the day of the week, 27 who indicated long-stay visits as they had travelled a long distance, and 7 who did not know/respond

- Family caregivers were asked if they always, sometimes or never engaged in various **activities when visiting** (Figure 35). The percentage of caregivers who responded always or sometimes varied by activity.
  - 80% took the resident for drives (based on 972 caregivers).
  - 67% took the resident for walks around the facility (based on 973 caregivers).
  - 66% ate meals with the resident (based on 971 caregivers).
  - 60% cleaned up the resident's room (based on 974 caregivers).
  - 55% watched TV with the resident (based on 972 caregivers).
  - 20% read to the resident (based on 971 caregivers).
  - 20% played games with the resident (based on 972 caregivers).

FIGURE 35. ACTIVITIES WHILE VISITING: DAL FAMILY CAREGIVERS



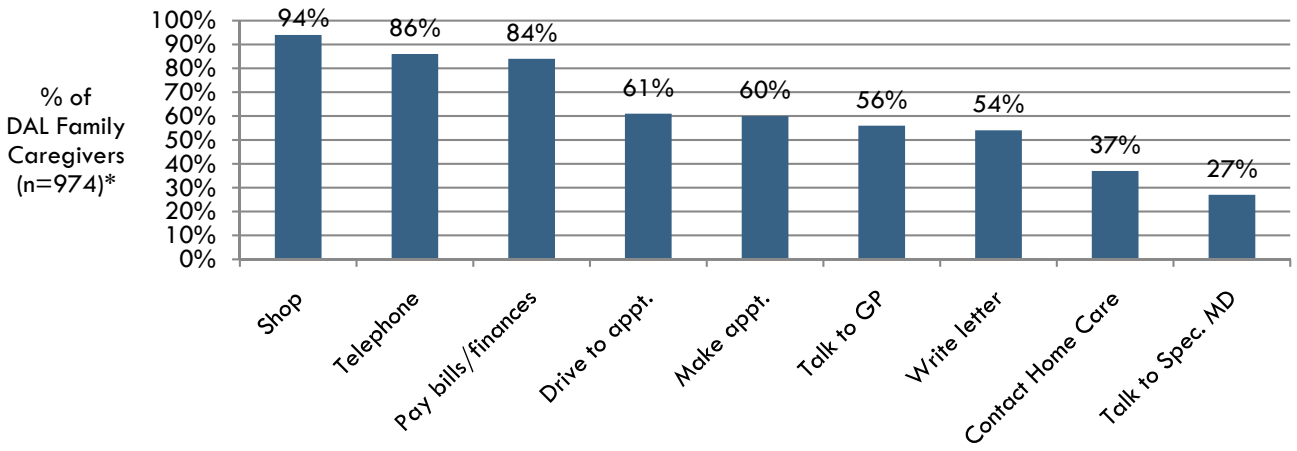
* n varies from 971 to 974 depending on the activity

- Family caregivers were given the opportunity to identify any **other activities** that they did with the resident; however, the frequency of the activity was not recorded. Activities mentioned included taking the resident out to a restaurant for meals/coffee (14%), taking the resident home or to another family member's home (12%), taking the resident shopping or running errands with the resident (11%), and taking the resident to family events/gatherings or to other events outside the facility (5%).

Caregiving Tasks

- In the 3 months prior to the interview, the majority of family caregivers **shopped for the resident** (94%) or **paid bills/managed finances** (84%) (Figure 36).

FIGURE 36. CAREGIVING TASKS IN PAST 3 MONTHS: DAL FAMILY CAREGIVERS



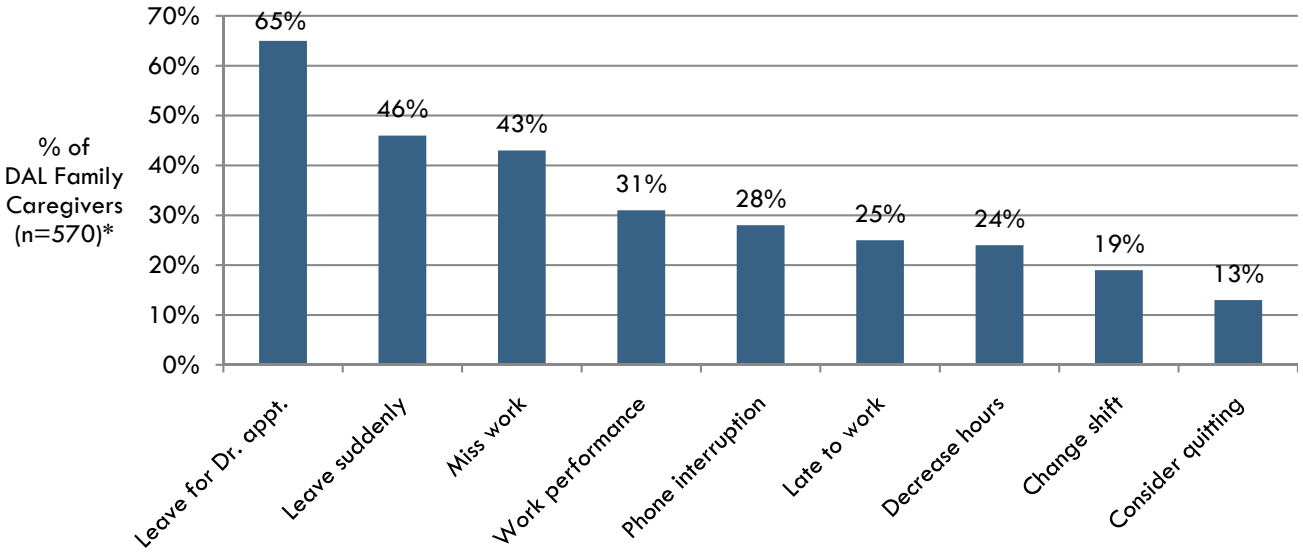
* Except for home care (n=973)

- Over one-half of the family caregivers had **made appointments** for the resident (60%) or had **driven the resident to appointments** (61%) (Figure 36).
- Some family caregivers acted as a link to health care professionals, with 56% **talking to a family physician** about the resident, 37% **contacting Home Care** or other similar agencies for the resident, and 27% **talking to a specialist** about the resident (Figure 36).
- Most caregivers (86%) had **telephoned** to see how the resident was doing while 54% had **written letters or called family or friends for the resident** (Figure 36).

Effects of Caregiving on Employment

- Employed family caregivers were asked whether their work had ever been affected in various ways because of caring for the resident (Figure 37).
- 65% of these employed caregivers indicated that they had to **leave work for the resident's appointments with doctors** (Figure 37).

FIGURE 37. EFFECTS OF CAREGIVING ON EMPLOYMENT: DAL FAMILY CAREGIVERS



* Except for leaves for doctor appointment (n=569) and consider quitting (n=569). Note: Less than 10% of employed caregivers reported the following: decline job advancement (8%), change jobs or employers (6%), increase hours worked (6%), or quit job (3%).

- 46% needed to **leave work suddenly** because of caring for the resident (Figure 37). 43% had **missed work** due to caregiving responsibilities while 25% had **come late to work**.
- Some caregivers indicated a **change in their work hours or shifts** (Figure 37).
  - 24% decreased the hours they worked.
  - 19% changed the shift they worked.
  - 6% increased the hours they worked.
- 31% felt that their **performance at work** was affected (Figure 37). Only 6% reported a **change in jobs or employers** because of caring for the resident; 8% had **declined job advancement**.
- While 13% had **considered quitting their job** due to caregiving responsibilities, only 3% reported that they had **quit a job** because of caring for the resident (Figure 37).
- 28% reported **frequent interruptions by phone calls** from or pertaining to the resident (Figure 37).

Caregiver Burden

- Caregiver burden was assessed by using the **Caregiver Reaction Assessment Scale (CRA)** (Given et al., 1992) (Table 20). The CRA examines 5 **domains** of the caregivers' lives, namely **disrupted schedules, financial problems, lack of family support, health problems,** and **the impact of caregiving on the caregiver's self-esteem**. Caregivers were read 24 statements and asked to indicate their level of agreement with the statement from strongly disagree (1) to strongly agree (5).

TABLE 20. CAREGIVER REACTION ASSESSMENT SCALE: DAL FAMILY CAREGIVERS

Item	Mean	SD	D	N	A	SA
Disrupted Schedule (n=964)	**2.58**					
My activities are centered around caring for (__). (n=969)	2.91	5%	40%	20%	27%	7%
I have to stop in the middle of work. (n=966)	2.61	18%	38%	14%	27%	4%
I visit family and friends less since I have been caring for (__). (n=970)	2.40	22%	46%	9%	18%	6%
I have eliminated things from my schedule since caring for (__). (n=970)	2.67	13%	47%	8%	27%	6%
The constant interruption makes it difficult to find time for relaxation. (n=969)	2.31	18%	53%	13%	13%	4%
Financial Problems (n=961)	**2.11**					
My financial resources are adequate to pay for things that are required for caregiving.* (n=962)	3.62	6%	9%	20%	47%	18%
Caring for (__) puts a financial strain on the family. (n=969)	1.94	29%	56%	7%	6%	1%
It is difficult to pay for (__)'s health needs and services. (n=967)	2.01	28%	55%	9%	7%	2%
Lack of Family Support (n=962)	**2.54**					
Others have dumped caring for (__) onto me. (n=968)	2.74	21%	31%	15%	19%	14%
It is very hard to get help from my family in taking care of (__). (n=966)	2.80	17%	33%	15%	24%	12%
My family works together at caring for (__).* (n=968)	3.34	9%	21%	13%	42%	16%
Since caring for (__), I feel my family has abandoned me. (n=969)	1.93	33%	51%	9%	6%	2%
My family (brothers, sisters, and children) left me alone to care for (__). (n=966)	2.53	19%	38%	19%	17%	7%
Health Problems (n=966)	**2.62**					
Since caring for (__), it seems like I'm tired all of the time. (n=968)	2.45	17%	49%	12%	16%	6%
My health has gotten worse since I have been caring for (__). (n=969)	2.22	27%	47%	9%	13%	5%
I have enough physical strength to care for (__).* (n=968)	3.81	3%	11%	6%	63%	18%
I am healthy enough to care for (__).* (n=969)	4.01	2%	5%	6%	66%	21%
Positive Self-Esteem (n=968)	**3.98**					
I feel privileged to care for (__). (n=970)	4.15	2%	3%	13%	42%	40%
I resent having to take care of (__).* (n=969)	1.76	45%	43%	7%	4%	2%
I really want to care for (__). (n=969)	4.14	<1%	3%	11%	51%	34%
I will never be able to do enough caregiving to repay (__). (n=970)	3.05	6%	30%	28%	22%	13%
Caring for (__) makes me feel good. (n=970)	4.05	<1%	3%	12%	61%	24%
Caring for (__) is important to me. (n=968)	4.30	<1%	<1%	4%	61%	35%
I enjoy caring for (__). (n=969)	4.01	<1%	4%	14%	57%	24%

Note: Scores are 1 = Strongly disagree (SD), 2 = Disagree (D), 3 = Neither (N), 4 = Agree (A), 5 = Strongly agree (SA).
* indicates reverse coding is required when computing the scale score. High scores on all subscales except Positive Self-Esteem indicate negative reactions to caregiving; a high score on Positive Self-Esteem indicates a positive reaction to caregiving.

- In terms of a **disrupted schedule** due to caregiving, over 30% of the caregivers agreed or strongly agreed that their activities were centered around caring for the resident (34%), they had eliminated things from their schedule since caring for the resident (33%), or they have had to stop in the middle of work (31%) (Table 20).

- Related to **financial problems,** less than 10% of the caregivers agreed or strongly agreed that caring for the resident puts a financial strain on the family (7%) or it was difficult to pay for the resident's health needs and services (9%) (Table 20). 15% responded that their financial resources were not adequate to pay for the things required for caregiving.

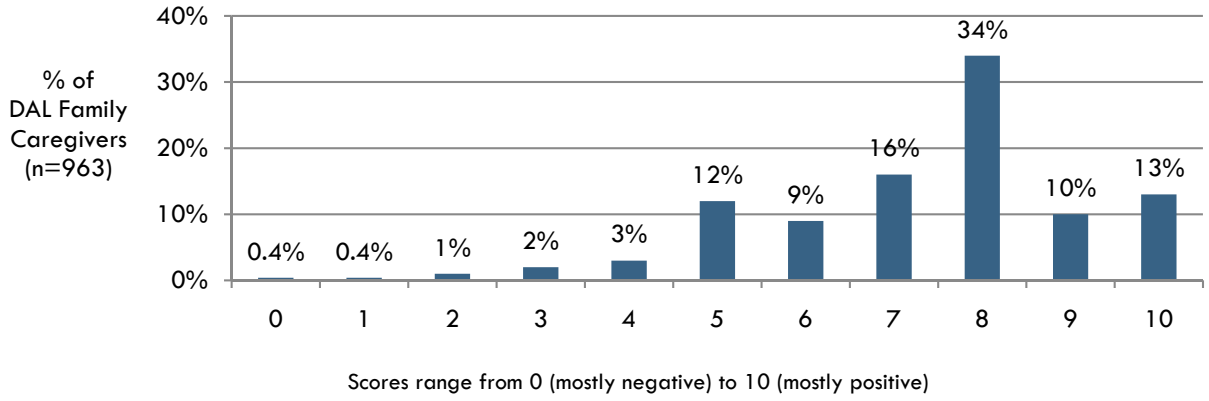
- Considering the **lack of family support,** some caregivers agreed or strongly agreed that others had dumped caring for the resident on them (33%), it was very hard to get help from family (36%), their family did not work together in caring for the resident (30%), or their family (brothers, sisters, children) had left them alone to care for the resident (24%) (Table 20). At the same time, only 8% agreed or strongly agreed that since caring for the resident, they felt their family had abandoned them.

- Turning to **health problems,** about one-fifth of the caregivers agreed or strongly agreed that since caring for the resident, it seemed they were tired all the time (22%) or their health had worsened since they had been caring for the resident (18%) (Table 20). Only 7% perceived themselves as not healthy enough to care for the resident.

- In terms of the effect of caregiving on **self-esteem,** 82% of the caregivers indicated that they felt privileged to care for the resident while 85% agreed or strongly agreed with the statement "*I really want to care for the resident.*" (Table 20). Caring for the resident often made caregivers feel good (85%) or was viewed as important to the caregiver (96%). Only 6% resented having to take care of the resident while 4% indicated that they did not enjoy caring for the resident.

- 13% of the caregivers rated their caregiving **experience** as a 10 while 18% gave a rating of 5 or less, when asked "*On a scale of 0 to 10, how would you rate your experience as a caregiver to (__), with 0 being mostly negative and 10 being mostly positive?*" (Figure 38). The mean score was 7.4 while the median was 8.

FIGURE 38. RATING OF CAREGIVER EXPERIENCES: DAL FAMILY CAREGIVERS



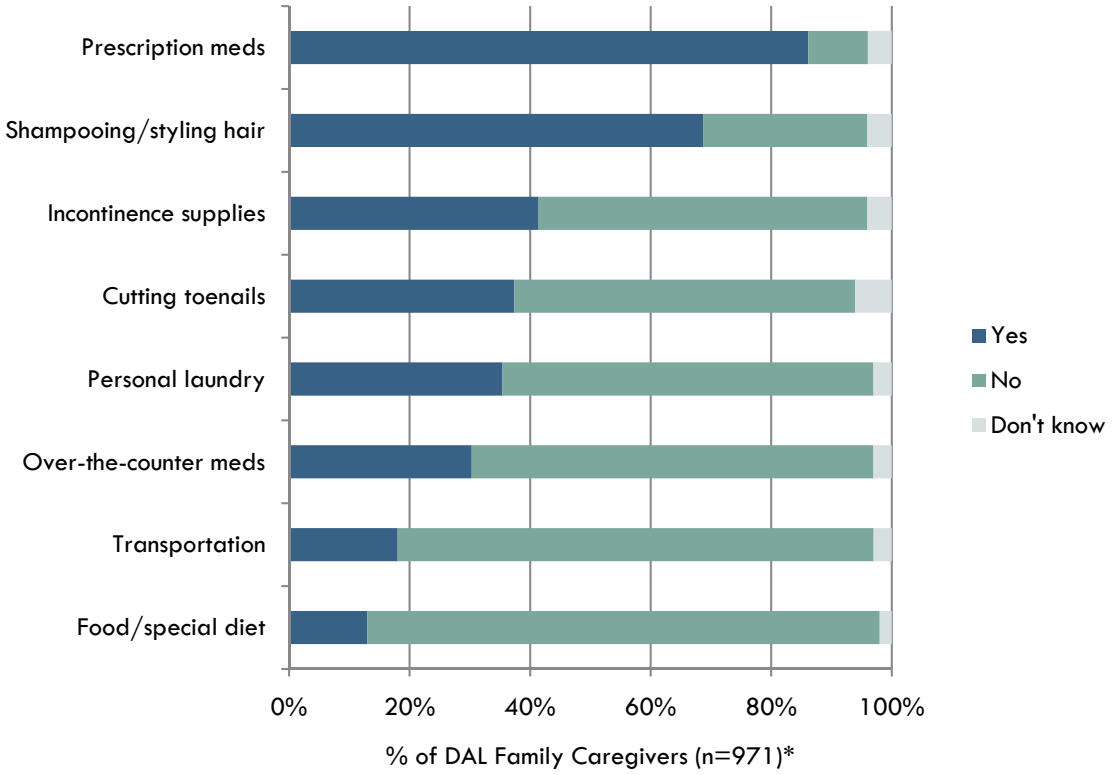
Financial Costs to Caregivers and Residents

- 86% of DAL family caregivers indicated that they handled the **payment to the facility** or were aware of the monthly charges. Responses to a question regarding the amount of the current monthly base rate ranged from $700 to $2800 per month. This is comparable to the range of $800 to $2650 per month for base fees reported by facility representatives.

- 75% of the 790 DAL caregivers indicated that the **current monthly charges,** including any extras, were about what they expected when the resident moved to the facility. 16% reported that the fees were higher than they expected while 10% indicated lower fees than expected.

- Family caregivers were asked "*During the last month, have you, the resident, or other family members purchased any of the following services or supplies for which there is an additional charge or cost (that is, over and above the regularly monthly rate charged by the facility)*?" Some caregivers did not know if these costs were incurred (Figure 39). Other caregivers were unable to provide a dollar figure but knew purchases had been made.

FIGURE 39. ADDITIONAL MONTHLY CHARGES: DAL FAMILY CAREGIVERS



* Except for prescription medications (n=970)

- 87% of DAL family caregivers indicated that there were additional costs incurred for **prescription medications** (Figure 39).
- Extra costs for **shampooing/styling hair** were identified by 68% of the caregivers (Figure 39).
- Between 30% and 50% of the caregivers reported costs related to **incontinence supplies** (41%), **cutting toenails** (37%), **personal laundry** (35%), and **over-the-counter medications** (30%) (Figure 39).
- 18% reported additional costs for **transportation** while 13% indicated that **extra food** was purchased for the resident (Figure 39).
- Less than 10% of the family caregivers reported costs for medication assistance (7%), assistance with personal care (3%), private duty attendant/sitter (3%), meals delivered to the resident's room (2%), incontinence service (1%), nursing services provided by an agency (1%), and nursing services provided by facility staff (<1%).
- 20% of the caregivers indicated that, in the past year, there had been 1-time only costs for **personal aids** such as walkers or wheelchairs.

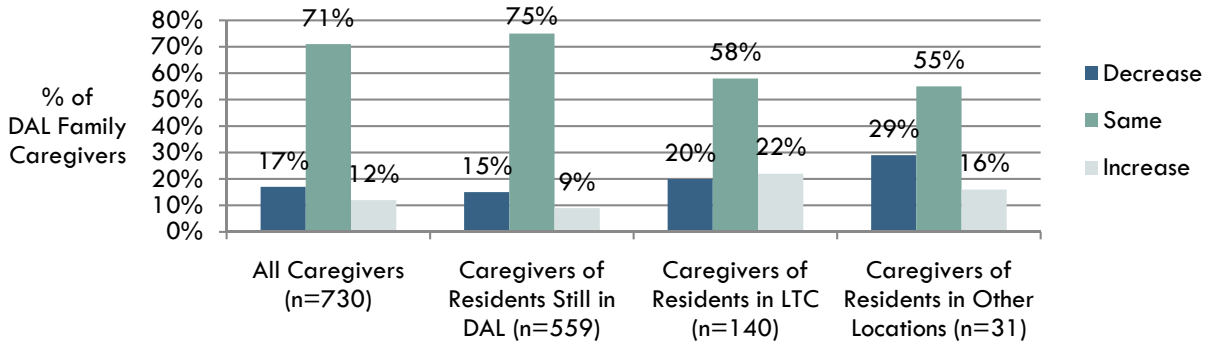
Experiences at 1-Year Follow-up with Residents

- At the time of the 1-year follow-up, 16% of the 974 caregivers had experienced the death of the resident.
- Of the 819 caregivers involved with a resident who was still alive, 736 agreed to a follow-up interview (see Wanless et al., 2011 for further details).
    - 77% of caregivers were caring for a resident who lived in the same DAL facility.
    - 19% were involved with individuals who had moved to a LTC facility.
    - 4% were caring for residents who had moved to other locations (new DAL (n=22), private home/apartment (n=3), lodge (n=3), PAL (n=1), independent living setting (n=1), private LTC (n=1), and geriatric psychiatric facility (n=1)).

Visiting

- Caregivers were asked "*During the last year, would you say that there has been an increase, decrease, or the same amount of visits?*" Among 730 caregivers, 71% reported **no change**, 12% indicated that there had been an **increase in the amount of visits**, while 17% perceived that there had been a **decrease** (Figure 40).
- Family caregivers of residents who had moved to long-term care (22%) were significantly more likely to report an **increase in their visits**, compared to those caring for residents who remained in the same DAL facility (9%).

FIGURE 40. SELF-REPORTED CHANGES IN AMOUNT OF VISITING IN LAST YEAR: DAL FAMILY CAREGIVERS



- Some caregivers explained that increased **care needs** of the residents necessitated an increase in visits while, for others, the resident's declining health and lack of recognition had resulted in decreased visits. Some caregivers discussed their own **declining health** or the **work/family demands** that they had.
- For some caregivers of residents who had moved to LTC, the new facility was closer and allowed for more visits while others faced greater **distances**.

Family Caregivers

She doesn't know me anymore and I find it difficult and upsetting to visit with her.

His needs have increased. He's quieter and needs us more.

I have been very busy with a sick son.

I'm retired now so I have more time to visit and care for Mom.

She has moved 45 minutes away and I can't just drop in.

It's a shorter distance to visit.

Caregiver Burden

- At follow-up, family caregivers again completed the **Caregiver Reaction Assessment Scale (CRA)** (Given et al., 1992). Baseline and follow-up scores on the 5 sub-scales were compared first for all caregivers and then separately for caregivers of residents who remained in the same DAL and those caring for those residents who moved to long-term care (Table 21). Separate comparisons for caregivers of residents who moved to other locations were not possible, given the small number of caregivers in this group.
- Among **all caregivers**, the ratings on **disrupted schedules** were slightly lower at follow-up than they were at baseline, suggesting less disruption at follow-up (Table 21). The ratings for **financial problems** increased significantly, indicating a more negative reaction to financial costs of caring at follow-up than at baseline. This suggests that, over time, caregivers may feel increased financial pressure due to caregiving. Assessments regarding the lack of family support, health problems, and positive self-esteem did not vary over time.

TABLE 21. CAREGIVER REACTION ASSESSMENT AT BASELINE AND FOLLOW-UP: DAL FAMILY CAREGIVERS

	All Caregivers		Caregivers of Residents Still in Same DAL		Caregivers of Residents Moved to LTC	
Sub-scale	Mean (Base)	Mean (FU)	Mean (Base)	Mean (FU)	Mean (Base)	Mean (FU)
Disrupted Schedule	2.60*	2.54*	2.60*	2.51*	2.59	2.60
Financial Problems	2.10*	2.18*	2.11*	2.19*	2.06*	2.18*
Lack of Family Support	2.58	2.60	2.59	2.59	2.55	2.65
Health Problems	2.62	2.61	2.62	2.59	2.59	2.63
Positive Self-Esteem	3.97	3.98	3.95	3.95	4.01	4.05

Note: FU=Follow-up. * denotes statistically significant differences at $p<.05$ based on paired t-tests. n varies from 727 to 731 for all caregivers, from 556 to 561 for caregivers of residents who were still in same DAL, and from 139 to 140 for caregivers of residents who moved to LTC. Scores range from 1 = Strongly disagree to 5 = Strongly agree. High scores on all subscales except Positive Self-Esteem indicate negative reactions to caregiving; a high score on Positive Self-Esteem indicates a positive reaction to caregiving.

- Significant differences in the ratings for **disrupted schedules** and **financial problems** emerged when examining the responses of the caregivers of residents who were in the same DAL facility at both time points (Table 21). For caregivers of residents who had moved to long-term care, only the rating of financial problems increased over time.

- Overall a **mixed pattern** of changes in the reaction to caregiving appears to exist. The extent to which these changes, or lack thereof, relate to changes in various aspects of the residents' and the caregivers' lives, such as health and work/family demands, needs to be explored.

Summary

This profile of DAL family caregivers has highlighted the involvement of these individuals in the lives of many DAL residents. The majority of caregivers visited at least once a week, shopped for the resident, paid bills/managed finances, and telephoned to check how the resident was doing. Several made appointments for the resident and took him/her to these appointments. In addition, some caregivers reported that they or the resident incurred costs for items such as prescription medications, hair care, incontinence supplies, foot care, and personal laundry. At the same time, there were caregivers who visited relatively infrequently and provided limited assistance to the resident.

As a result of caregiving, some employed caregivers reported leaving work for doctor's appointments, missing work, or leaving suddenly. While some caregivers reported negative reactions to caregiving such as disrupted schedules, financial problems, a lack of family support, or health problems, most indicated a positive effect on their self-esteem and rated the caregiving experience positively.

At the 1-year follow-up, the majority reported there had been no change in the amount they visited, although some felt their visits had increased while others indicated a decrease. This change was more evident among caregivers whose family member had moved to LTC. No single pattern of change in the reaction to caregiving was evident, highlighting the diversity of caregiving experiences.

Attention now turns to the residents' and family caregivers' views about DAL. Of interest is their assessment of DAL staff, services and the environment, and policy.

RESIDENTS' AND CAREGIVERS' VIEWS ABOUT DAL

DAL residents and family caregivers were asked to assess the DAL facility and the care/support provided. Attention here focuses on their views regarding **staff, services and the environment,** and **policy** as well as their **overall rating** of the facility and **recommendation to others.** Only 704 of the 1089 DAL residents were able to respond to these questions (see Wanless et al., 2011 for additional information on the Views of Residents Survey) while 974 family caregivers were asked their views about DAL facilities. [7] Several questions are from the NHCAHPS survey (Sangl et al., 2007). In some instances, residents and family caregivers were asked to rate the facility on a scale of 0 (worst possible) to 10 (best possible). Three groupings of scores are examined: 0-7, 8-9, and 10, following CAHPS guidelines (see www.cahps.ahrq.gov for further information).

Views about Staff

- DAL residents and DAL family caregivers were generally positive in their assessment of staff although room for improvement was evident.

- From the perspective of family caregivers, **staff considerations** were important to them at the time of the move to the facility (Table 22). In particular, the **availability of monitoring,** for example if the resident fell or needed help with medications (98%) and the **quality of the direct care staff** (knowledge, training, attitudes, staffing levels) (97%) were identified as important by virtually all family caregivers.

TABLE 22. STAFFING CHARACTERISTICS IMPORTANT AT TIME OF MOVE: DAL FAMILY CAREGIVERS

Amenity	% of DAL Caregivers	
	Important	Not Important
The availability of monitoring, for example if the resident fell or needed help with medications (n=969)	98%	2%
The quality of the direct care staff (knowledge, training, attitudes, staffing levels) (n=965)	97%	3%
Whether the facility had a Registered Nurse on staff (n=963)	77%	23%
The ability of the facility to provide more or different services if your relative's needs changed (n=958)	86%	14%
The availability of a nursing home on the same site (n=946)	51%	50%

Family caregivers were asked *"Thinking back to when (__) moved in to [name of facility], which of the following were important to you?"* Responses were to reflect preferences, not whether the facility had the amenity.

- Residents assessed the **gentleness of staff** (if they received assistance with dressing or bathing), the **respect** from staff, how **well staff listen,** and how **well staff explain things** (Table 23). The scores on gentleness and respect were higher than those for how well staff listen or explain.

[7] Sample sizes are 704 for residents and 974 for family caregivers unless otherwise noted. In some instances, respondents declined to answer the question. Percentages may not total 100% due to rounding.

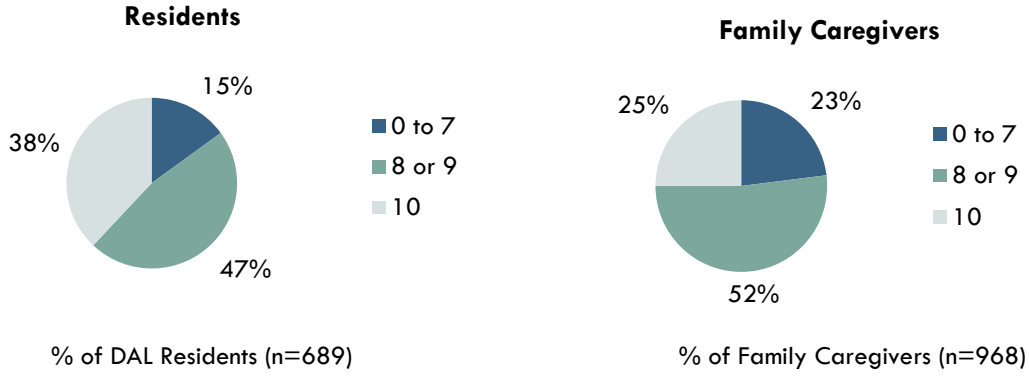
TABLE 23. ASSESSMENT OF STAFF INTERACTIONS: DAL RESIDENTS

Assessment of Staff Interactions	% of DAL Residents			Mean
	0 - 7	8 - 9	10	
How gentle staff are when they are helping you (n=539)	15%	48%	37%	8.7
How respectful the staff are to you (n=700)	13%	44%	43%	8.8
How well the staff listen to you (n=694)	22%	46%	32%	8.3
How quickly staff come when you call them for help (n=666)	28%	47%	25%	8.0

Scores range from 0 (worst possible) to 10 (best possible).

- When asked "*Overall, what number would you use to rate the care you get from staff?*", 38% of 689 residents who answered the question gave the facility a 10 out of 10 (mean=8.7). In comparison, 25% of 968 family caregivers scored the facility as a 10 (mean=8.3) (Figure 41).

FIGURE 41. OVERALL RATING OF CARE: DAL RESIDENTS AND FAMILY CAREGIVERS



Scores range from 0 (worst possible) to 10 (best possible)

- Concern about **staff shortages and staff turnover** was a recurrent theme in the interviews with family caregivers. This emerged in response to questions about the disadvantages of the facility and explanations about satisfaction with various services. When asked at follow-up about changes in staffing over the past year, several caregivers mentioned staff turnover/shortage. There were differing views with respect to the impact of quality of care.

> Family Caregivers
>
> *There has been constant staff turnovers and new faces, inconsistency and poorer quality of care. The new staff treat it as a job and not because they enjoy looking after seniors. They do bare bones and not little extras. The new staff don't know the problems and therefore don't want to deal with the problems either.*
>
> *There has been a change in individual caregivers* [staff members] *but not in the type or quantity of staff.*

Views about Services and the Environment

- DAL family caregivers expressed several **concerns regarding facility living.** The concerns generally fell under the following themes:
  - Concerns regarding **care in general**
  - Concerns about the **resident's emotional well-being**
  - Concerns about **opportunities for social interaction and activities** for the resident
  - Concerns about **diet and food choices**
  - Concerns about the **physical environment**
  - **Lack of support** from the facility and/or **poor communication**
  - **Costs**

Family Caregivers

She's become more reclusive and very shy. There's no one to volunteer to get her out of her room more. She's becoming more confused – and just sits in her room all day with no stimulation.

She's lonely. Some of it is her own doing. When she's made friends, they like to sit in the common area outside the dining room – but they have either died, moved away, or a recent friend moved to a locked area because she was wandering.

They're understaffed. I don't think they are very client friendly. They don't take the necessary time needed to care for mother – they seem annoyed if she is slow – they're impatient. She almost feels abandoned and there is no effort to get them to socialize or interact. I am not racist but there is a group of care aides who talk in their own language and exclude the residents.

- Opportunities for **social/recreational activities** emerged as an area requiring attention, from the perspective of both family caregivers and residents. In terms of **recreational activities,** 93% of the 692 residents who answered the question indicated they can **choose the activities** they do in the facility. An additional 4% reported that they sometimes could choose while 3% answered they had no choice.

- 60% of 675 residents who responded felt that there were enough **organized activities** on the **weekend,** 13% indicated there were sometimes enough, and 27% stated there were not enough. For activities during the **week,** 81% of 681 residents felt there were enough activities, 10% responded sometimes, and 9% indicated that there were not enough.

- Family caregivers' **satisfaction ratings with services** highlight several areas for improvement. While some caregivers were very satisfied, many were mostly satisfied, not satisfied or quite dissatisfied (Table 24). Of particular note were concerns regarding **housekeeping/cleaning, meals/food, personal laundry, bathing, oral care** and **toileting.**

TABLE 24. SATISFACTION WITH SERVICES RECEIVED/USED BY RESIDENTS: DAL FAMILY CAREGIVERS

Service Received/Used as Reported by Family Caregiver	% of DAL Caregivers			
	Very Satisfied	Mostly Satisfied	Not Satisfied	Quite Dissatisfied
Services received/used by >50% of residents				
Assistance with medications (n=887)	70%	24%	5%	1%
Nursing care (blood pressure, dressings) (n=779)	60%	35%	4%	1%
Foot care/podiatry in facility (n=572)	57%	35%	5%	2%
Hair care (brushing, shampooing, etc.) (n=629)	56%	36%	6%	2%
Dressing (n=585)	54%	42%	4%	1%
Bathing (n=883)	50%	40%	8%	2%
Personal laundry (n=766)	49%	41%	9%	1%
Meals/food (n=951)	49%	37%	11%	3%
Housekeeping/cleaning (n=959)	42%	46%	9%	2%
Services received/used by 10% - 50% of residents				
Oral care (n=287)	49%	39%	10%	2%
Toileting (n=374)	45%	45%	5%	4%

Family caregivers were asked *"Many services are available to help residents in the facility. My questions are about some of those services. Has (__) received/used this service in the last month? If received/used, how satisfied are you with the quantity and quality?"* The n varies as responses are based only on family caregivers caring for residents who received/used that specific service. Satisfaction ratings are not provided on services for which <10% of the caregivers reported that the resident received/used in the facility including physiotherapy, occupational therapy, speech/language therapy, mental health/psychological counseling, and counseling from social work/clergy.

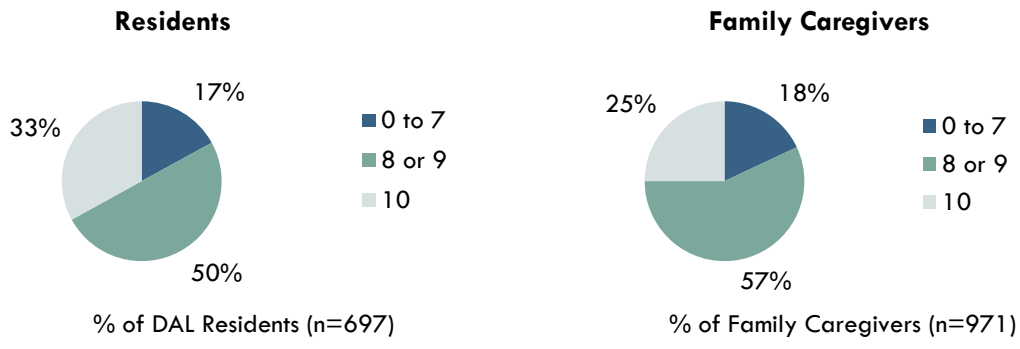
- With regards to **housekeeping/cleaning,**
  - 33% of 697 residents rated the cleanliness of the facility a 10 out of 10 (mean=8.6) (Figure 42).
  - 25% of 971 family caregivers gave a 10 out of 10 (mean=8.4) (Figure 42).
  - 42% of 959 caregivers were very satisfied, 46% were mostly satisfied, 9% were not satisfied and 2% were quite dissatisfied (Table 24).

Family Caregivers

[The resident's] room is seldom dusted. The carpet and bathroom are not clean. Housekeeping staff are very cranky when I have concerns.

Housekeeping is the last thing done when staff is short staffed.

FIGURE 42. RATING OF CLEANLINESS: DAL RESIDENTS AND FAMILY CAREGIVERS



Scores range from 0 (worst possible) to 10 (best possible)

- **Meals/food** emerged as a concern for both residents and caregivers.
  - 19% of the 703 residents rated the **food** 10 out of 10 (Figure 43). The mean (7.3) was the lowest obtained for all dimensions examined using this rating scale.
  - 19% of the 698 residents gave 10 in response to the question "*When you eat in the dining room, what number would you use to rate how much you enjoy mealtimes*?" (mean=7.5) (Figure 43).
  - 49% of 951 caregivers were very satisfied, 37% were mostly satisfied, 11% were not satisfied, and 3% were quite dissatisfied with **meals/food** (Table 24).

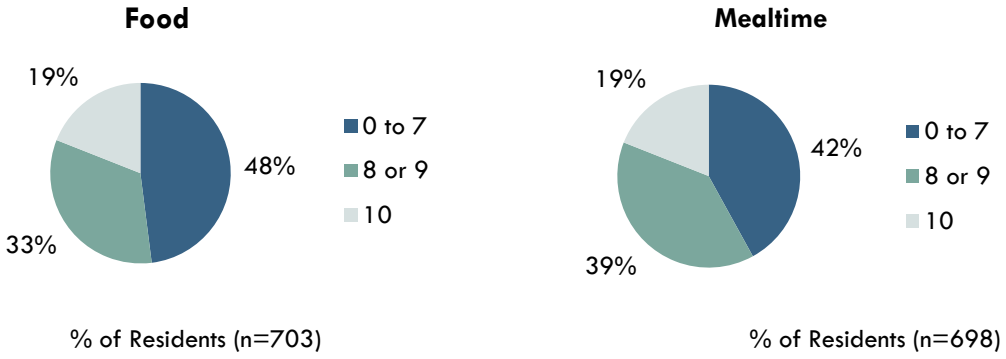
Family Caregivers

Meals are adequate. No fresh fruit.

Most of the time she goes without food. Little variety – only one choice usually. Can't eat beef – sometimes she's given a substitute.

My mother dislikes the food. People are afraid to say anything. Poor repetitive menu and no cook on the weekends.

FIGURE 43. RATING OF FOOD AND MEALTIMES: DAL RESIDENTS



Scores range from 0 (worst possible) to 10 (best possible)

- 49% of 766 caregivers were very satisfied with **personal laundry**, 41% were mostly satisfied, 9% were not satisfied, and 1% were quite dissatisfied (Table 24).
- **Noise** and **privacy** did not appear to be problematic in the DAL facilities (Table 25).

Family Caregivers

It's done but things don't always come back.

Sometimes things are shrunk. They wash everything together.

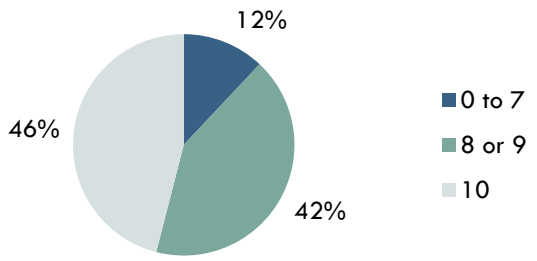
Clothes aren't being washed often enough. [The resident] is often wearing dirty clothes.

TABLE 25. ASSESSMENT OF NOISE AND PRIVACY: DAL RESIDENTS

Assessment of Noise and Privacy	% of DAL Residents		
	No	Sometimes	Yes
Is the area around your room quiet at night? (n=701)	2%	6%	92%
Are you bothered by noise in the facility during the day? (n=701)	82%	8%	10%
If you have a visitor, can you find a place to visit in private? (n=701)	2%	2%	96%
Does the staff make sure you have enough personal privacy when you dress, take a shower, or bath? (n=687)	3%	5%	92%

- In response to the question "*What number would you use to describe how safe and secure you feel here?*", 46% of the residents gave their facility a 10 out of 10 (mean=8.9) (Figure 44).

FIGURE 44. RATING OF FEELINGS OF SAFETY AND SECURITY: DAL RESIDENTS



% of Residents (n=699)

Scores range from 0 (worst possible) to 10 (best possible)

Views about Policy

- Family members were often unclear or unaware that policies existed about the situations under which a resident would no longer be able to stay in the facility. They were asked "*Does the facility have **policies about the conditions under which residents will be asked to leave the facility** or what care needs it will not be able to accommodate?*" and "*How clear do you think those policies are?*" Among the 967 caregivers who responded,
  - 15% **did not know** if a **policy about when a move would be necessary** existed.
  - 7% stated that there was **no policy**.
  - 7% indicated that the policy was **very unclear** (no policies were specified or they vary from resident to resident).
  - 17% reported that the policy was **somewhat unclear** (I know they have policies but the conditions are vague).
  - 26% indicated that the policy was **fairly clear** (I have a general idea of when the facility discharges a resident).
  - 27% indicated that the policy was **very clear** (the policies are written and were clearly explained to me and other family members).

- This lack of clarity is an issue, given the likelihood of increased needs of the DAL residents necessitating a move to a higher level of care. It may be that explanations were provided at admission but over time the existence and clarity of such policies become less apparent. Alternatively, facilities may not provide sufficient and clear information at the time of admission.

- Family caregivers who handled payment to the facility or were aware of the monthly charge, were asked about the clarity of the facility's **policies about the fees** (what is covered in the basic monthly rate and what is extra or what level of care is covered and what is not). Among the 812 caregivers who answered this question,
  - 2% indicated that they **did not know** about a policy regarding fees.
  - 4% reported that the policy was **very unclear**.
  - 6% felt that the policy was **somewhat unclear**.
  - 24% reported that the policy was **fairly clear**.
  - 65% indicated that the policy was **very clear**.

- When asked "*How comfortable would you be* ***expressing concerns or dissatisfaction with some aspect of the facility to the administrator****?*",
  - 67% of caregivers indicated that they would be very comfortable.
  - 17% would be fairly comfortable.
  - 7% would be somewhat uncomfortable.
  - 9% would be very uncomfortable.
  - <1% indicated that they did not know.

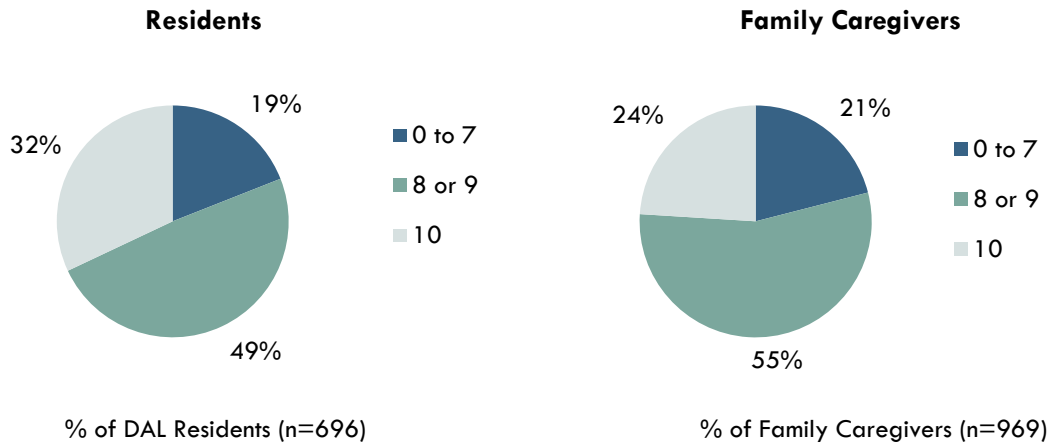
Perceived Advantages and Overall Ratings

- Despite concerns about the care of their family member, the DAL family caregivers often identified **advantages** for the resident and/or themselves including:
  - The supervision/security/safety and/or care provided by staff;
  - The companionship that their family member has with other residents;
  - Their feeling of peace of mind and/or less stress; and,
  - Personal freedom or increased time for themselves.

> Family Caregiver
>
> *Peace of mind – she's in a safe environment. We have a little freedom. Before it was like being on call 24/7.*

- When asked "*Overall, what number would you use to rate this facility*?", with 0 being the worst possible and 10 being the best possible,
  - 32% of 696 residents who answered this question gave their facility 10 out of 10 (mean=8.4) (Figure 45).
  - 24% of 969 DAL family caregivers scored the facility as a 10 (mean=8.3) (Figure 45).

FIGURE 45. OVERALL RATING OF FACILITY: DAL RESIDENTS AND FAMILY CAREGIVERS



Scores range from 0 (worst possible) to 10 (best possible)

- In response to the question "*Would you recommend this facility to others*?", 70% of the 695 residents and 76% of the 972 family caregivers answered "definitely yes" (Table 26).

TABLE 26. RECOMMENDATION OF FACILITY: DAL RESIDENTS AND FAMILY CAREGIVERS

Recommendation of Facility to Others	% of DAL Residents (n=695)	% of DAL Family Caregivers (n=972)
Definitely yes	70%	76%
Probably yes	26%	20%
Probably no	3%	3%
Definitely no	2%	1%

Summary

While many residents and family caregivers would recommend their facility to others, they had mixed views on the DAL facilities, indicating areas for improvement. Some of these concerns are explored further in the *Issues and Challenges facing DAL and LTC* section of the report.

Attention now turns to long-term care, including profiles of the facilities, residents, and family caregivers as well as their views about LTC.

A PROFILE OF LTC FACILITIES

In total, **54 long-term care (LTC) facilities** participated in ACCES. Their characteristics are highlighted here in relation to **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**. Information was provided by the facility administrator, manager, or director of care who was familiar with the facility and had direct knowledge about the residents.[8] As noted earlier, for ease of comparison, the topics, format and wording are similar to that used when presenting findings for DAL. However, some information is setting-specific and thus is presented for only DAL or LTC.

Location

- The 54 LTC facilities were located in 5 former **health regions** in Alberta (see Appendix A).
  - Calgary Health Region (14 facilities) (26%)
  - Chinook Health Region (8 facilities) (15%)
  - David Thompson Health Region (10 facilities) (19%)
  - Capital Health Region (14 facilities) (26%)
  - East Central Health Region (8 facilities) (15%)

- The **size of the community** varied, with 39% of the facilities in communities with a population under 10,000, 19% in communities with a population of 10,000-100,000, and 43% in communities with a population of >100,000.

Ownership

- 44% of the LTC facilities were **owned/operated** by non-profit organizations, 26% by for-profit organizations, and 30% by the health region.

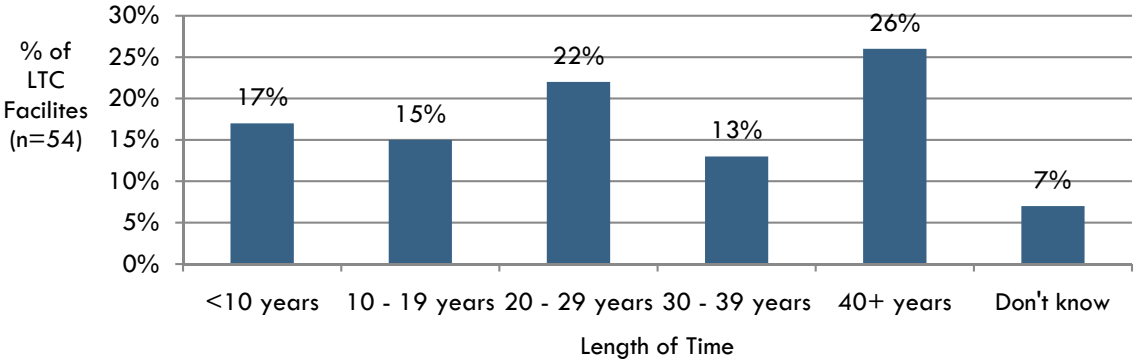
- 33% of the facilities were **part of a chain** that provided both long-term care and assisted living while 28% were part of a chain that offered long-term care only. Only 9% were not part of chain while 30% were RHA owned/operated.

- The **years in operation** varied considerably from 4 to 80 years, with only 14% in operation for less than 10 years. This represented the length of time the facility had been in operation regardless of when it began to provide LTC.

- The **length of time the facility had offered LTC spaces** ranged from one year to 60 years, with 17% in operation for less than 10 years (Figure 46).

[8] The sample size is 54 unless otherwise noted. In some instances, respondents declined to answer a question. Percentages may not total 100% due to rounding.

FIGURE 46. LENGTH OF TIME LTC SPACES AVAILABLE IN A FACILITY



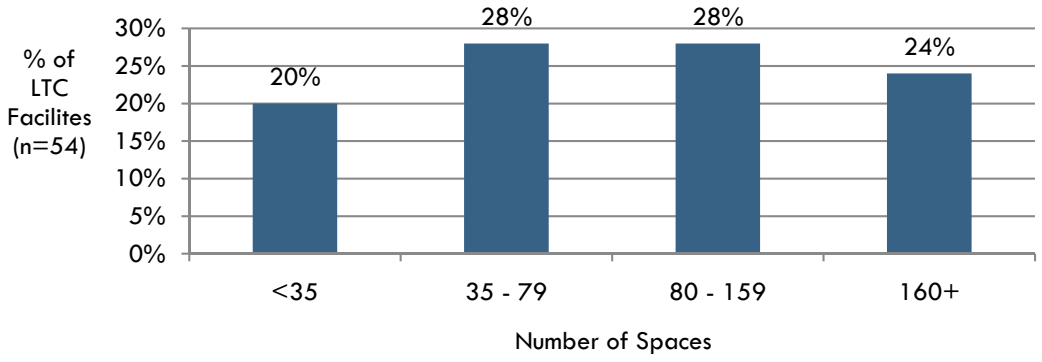
Type and Size of Facility

- 59% of the 54 facilities were LTC-only facilities. The other 41% were **multi-level facilities** that offered more than one level of care, including:
  - LTC and a lower level of care (19%)
  - LTC and a higher level of care (19%)
  - LTC, lower and higher levels of care (4%)

Lower: independent, lodge, enhanced lodge (EL), private assisted living (PAL), designated assisted living (DAL), condo, Choice Beds
Higher: acute care, rehabilitation, transition

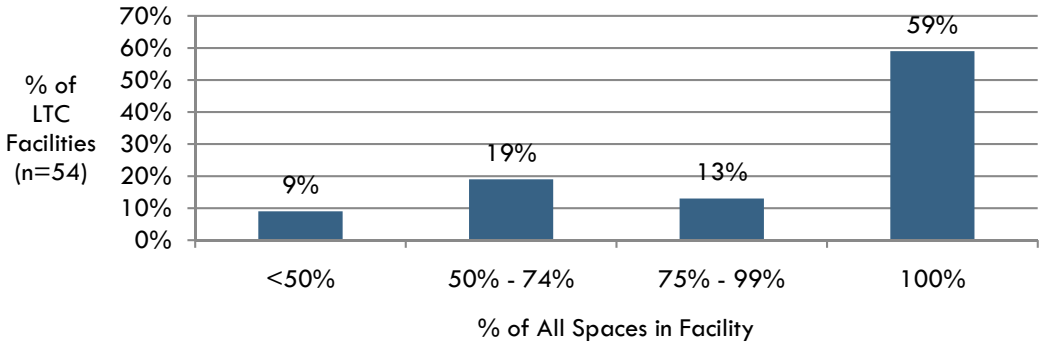
- Taking **all levels of care** into account, the **size** of the facilities varied from 20 to 502 spaces, with an average of 134 spaces.
- The **number of LTC spaces** in a facility ranged from 15 to 502, with an average of 111 spaces. 20% of facilities had less than 35 LTC spaces (Figure 47).

FIGURE 47. NUMBER OF LTC SPACES IN A FACILITY



- The **percentage of a facility's spaces allocated to LTC** varied from 10% to 100% (Figure 48).

FIGURE 48. PERCENTAGE OF FACILITY SPACES ALLOCATED TO LTC



- All LTC spaces were located on **LTC-only units.**
  - 26% of facilities had one unit for LTC only.
  - 74% had more than one unit for LTC only.

- When asked "*How many of your LTC spaces/beds are designated as Alzheimer's/dementia spaces/special care units (e.g., safe living unit, locked unit)?*", 50% of the facility representatives indicated that their facility had **dementia spaces.** These spaces accounted for 18% of the available spaces in the 54 facilities; the number of spaces ranged from 11 to 156 per facility. Two facilities had dementia spaces only. Information regarding staff training and physical design features for dementia care was not collected.

Admission and Retention Criteria

- In ACCES, facility representatives were asked if they were **"*able to admit someone*"** and **"*able to retain a resident*"** with certain characteristics. Responses were "No", "Yes" or "Depends". "Yes" indicates an unequivocal yes, while "depends" reflects a qualified criterion for admission or retention. Their responses reflect the situation at the time of data collection; it is recognized that there may have been some policy changes related to admission and retention since that time.

- Generally, facilities would **admit** the same types of residents they were willing to **retain** (Table 27).

TABLE 27. ADMISSION AND RETENTION CRITERIA: LTC FACILITIES

Criterion	Admit		Retain	
	Yes	Dep	Yes	Dep
Mobility Issues				
• Is bedfast	96%	4%	98%	2%
• Is chairfast	98%	2%	100%	---
• Uses a wheelchair to get around inside	100%	---	100%	---
• Uses a scooter/mechanized wheelchair	59%	30%	63%	28%
• Needs 1-person assistance with transfers	100%	---	100%	---
• Needs 2-person transfers	100%	---	100%	---
• Needs mechanical lift	100%	---	100%	---
Cognitive/Behavioural Issues				
• Has recent history of psychiatric hospitalization (mental illness)	72%	28%	72%	28%
• Wanders	89%	11%	89%	11%
• Is an elopement risk	74%	17%	72%	17%
• Engages in verbally aggressive behaviours	89%	9%	93%	7%
• Engages in physically aggressive behaviours	37%	54%	41%	52%
• Engages in socially inappropriate behaviours	85%	15%	85%	15%
• Resists nursing care or ADL care	96%	4%	98%	2%
• Has severe memory or judgment problems	98%	2%	98%	2%
Continence Issues				
• Lacks bladder control but can manage own incontinence supplies (i.e. wears and changes own pad or adult diapers)	100%	---	100%	---
• Lacks bladder control and needs help managing incontinence (e.g. someone helps change pads, bed linens)	100%	---	100%	---
• Lacks bowel control but can manage own incontinence supplies	100%	---	100%	---
• Lacks bowel control and cannot manage own incontinence supplies	100%	---	100%	---
Feeding Issues				
• Requires assistance with feeding	100%	---	100%	---
• Requires tube feeding	96%	4%	98%	2%

n=54. Dep: Depends. It should be noted that admission and retention decisions are to be collaborative between the RHA and the facility operator. Information was obtained only from facility representatives. The extent to which the RHA representatives would agree with the facilities' assessments is not known.

- All LTC facilities unequivocally admitted *(unequivocally retained)* a person who:
  - Used a wheelchair to get around inside (100%) *(100%)*.
  - Needed 1-person assistance with transfers (100%) *(100%)*.
  - Needed 2-person transfers (100%) *(100%)*.
  - Needed mechanical lift (100%) *(100%)*.
  - Lacked bladder control but could manage own supplies (100%) *(100%)*.
  - Lacked bladder control and needed help managing (100%) *(100%)*.
  - Lacked bowel control but could manage own incontinence supplies (100%) *(100%)*.
  - Lacked bowel control and could not manage own incontinence supplies (100%) *(100%)*.
  - Required assistance with feeding (100%) *(100%)*.

- 85% - 99% of the facilities unequivocally admitted *(unequivocally retained)* a person who:
  - Was bedfast (96%) *(98%)*.
  - Was chairfast (98%) *(100%)*.
  - Wandered (89%) *(89%)*.
  - Engaged in verbally aggressive behaviours (89%) *(93%)*.
  - Engaged in socially inappropriate behaviours (85%) *(85%)*.
  - Resisted nursing care or ADL care (96%) *(98%)*.
  - Had severe memory or judgment problems (98%) *(98%)*.
  - Required tube feeding (96%) *(98%)*.

- 50% - 84% of the facilities unequivocally admitted *(unequivocally retained)* a person who:
  - Used a scooter/mechanized wheelchair (59%) *(63%)*.
  - Had recent history of psychiatric hospitalization (72%) *(72%)*.
  - Was an elopement risk (74%) *(72%)*.

- Less than 50% of the facilities unequivocally admitted *(unequivocally retained)* a person who:
  - Engaged in physically aggressive behaviours (37%) *(41%)*.

- Facilities that did not admit individuals who used **scooters/mechanized wheelchairs** generally had limitations in their physical environment that prohibited use of this type of equipment.

- Admission criteria related to **cognitive/behavioural issues** generally were the most likely to be reported as "it depends". The qualifiers often related to stability, safety or the availability of a space designated for dementia. For example, 28% of the facility representatives responded "it depends" when asked if they would admit a person who has a recent history of psychiatric hospitalization.

Facility Representatives

Depends on the behaviours.

If they are safe and not a danger to themselves and others.

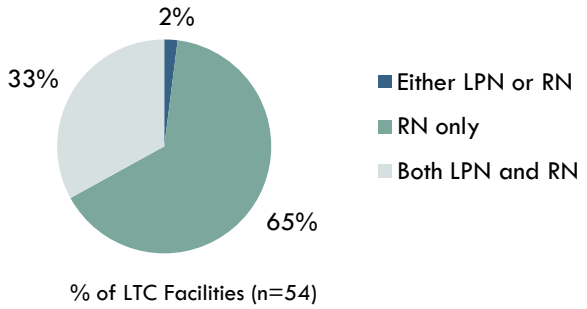
Services Provided by LTC

Both health and wellness services and hospitality services are provided in LTC, including 24-hour registered nursing care from nursing staff able to respond immediately and on a sustained and unscheduled basis (Alberta Seniors and Community Supports, 2007).

Health and Wellness Services

- All 54 LTC facilities had personal care aides (PCAs), licensed practical nurses (LPNs) and/or registered nurses (RNs) **on site**.
  - 100% of the facilities had **PCA** coverage on site 24/7.
  - 33% had **LPN** coverage on site 24/7; 3 facilities had no LPN coverage at all.
  - 98% had **RN** coverage on site 24/7.
  - All facilities had professional nursing services (either or both an LPN or RN) on site 24/7 (Figure 49).

FIGURE 49. LPN/RN COVERAGE 24/7: LTC FACILITIES



% of LTC Facilities (n=54)

- Services were **provided or arranged** by the LTC facilities as part of the **base fee** or as an **extra charge.** Facility representatives were asked if their facility regularly offered various services, if it was provided directly by facility staff as part of the basic monthly fee or for an extra charge, or if the service is arranged by the facility with an outside agency as part of the base fee or for an extra charge.

- All 54 facilities provided/arranged assistance with **personal care, oral care,** and **nursing care** as part of the base fee (Table 28).

TABLE 28. HEALTH/WELLNESS SERVICES PROVIDED/ARRANGED: LTC FACILITIES

Service	% of LTC Facilities (n=54)			
	As Part of Base Fee	As Extra Charge	Both Base Fee and Extra Charge	Not Provided/ Arranged
Personal care				
• Assistance with bathing	100%	---	---	---
• Assistance with dressing	100%	---	---	---
• Hair care (brushing/shampoo)	100%	---	---	---
• Assistance with locomotion	100%	---	---	---
• Assistance with toileting	100%	---	---	---
Oral care	100%	---	---	---
Nursing care (blood pressure, dressings)	100%	---	---	---
Administration of medications	100%	---	---	---
Incontinence supplies	82%	---	19%	---
Physiotherapy in facility	98%	2%	---	---
Occupational therapy in facility	98%	2%	---	---
Speech/language therapy in facility	82%	4%	---	15%
Foot care in facility	41%	46%	6%	7%
Mental health/psych counseling in facility	96%	---	---	4%
Social work/clergy counseling in facility	100%	---	---	---
Transportation to medical/dental appointments	43%	35%	17%	6%

- **Administration of prescription medications** involved PCAs, LPNs, and/or RNs. More specifically, 7% of the facilities reported that RNs and PCAs administered medications, 13% noted that only LPNs/RNs did this task, and 80% had PCAs, LPNs and RNs involved in medication administration. Only 4 facilities reported that at least some of their residents were administered at least some of their own medications with the assistance of health care providers in the week prior to the survey. One facility had arranged for Home Care RNs from the health region to administer prescription medications.

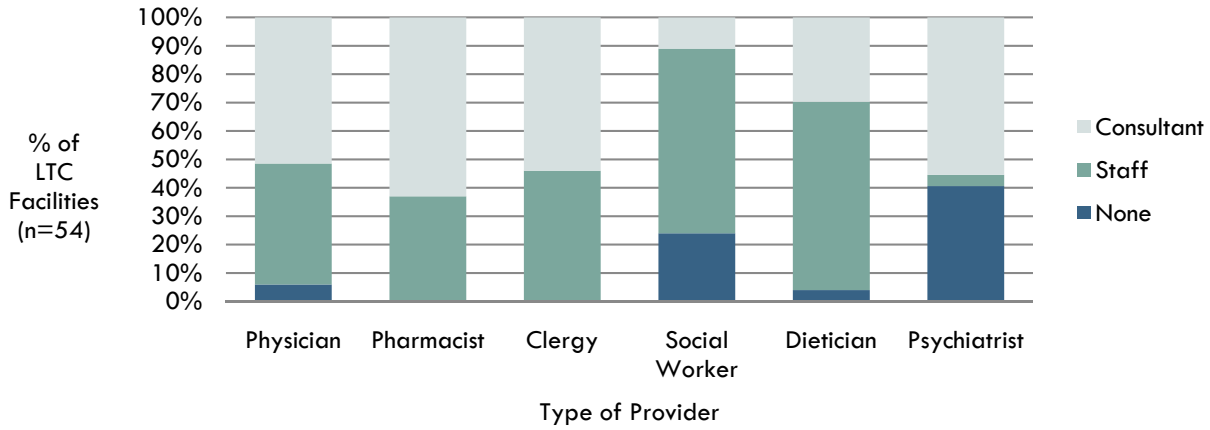
- In terms of **incontinence supplies**, 82% of the facilities provided these supplies at no additional cost to the residents while 19% covered this as part of the base fee and as an extra charge due to the use of special products (Table 28).

- **Foot care** was provided/arranged by 93% of the facilities, as an extra fee (46%), as part of base fee (41%), or by both the base fee and an extra charge (6%) (Table 28).

- **Physiotherapy (PT)** and **occupational therapy (OT)** were provided/arranged by all facilities while 86% provided/arranged **speech/language therapy (SLP)** (Table 28).

- Some LTC facilities involved other **health care providers** as either staff members or consultants in the month prior to the interview (Figure 50).

FIGURE 50. INVOLVEMENT OF OTHER SERVICE PROVIDERS DURING PREVIOUS MONTH: LTC FACILITIES



- All but one LTC facility had at least one **Physician/GP who was formally affiliated** with the facility. 16 of the 53 facilities (30%) had an office on site for their physicians. Over one-half of the 54 facilities (54%) required residents to change to a facility-affiliated physician.

Hospitality Services

- As outlined in the Supportive Living Framework (Alberta Seniors and Community Supports, 2007), **hospitality services** included meal services; housekeeping services; personal laundry; laundry and linen services; safety and security; and social, leisure and recreational opportunities.

- With the exception of **personal laundry** and **transportation to social activities,** all LTC facilities provided these types of services as part of the base fee (Table 29). **Personal laundry** was provided/arranged at an extra charge in all facilities. Transportation was an extra charge in 48% of the facilities while 35% covered this as part of the base fee.
- All facilities had a **common dining area** for their residents. All facilities assisted residents in **walking/wheeling to the dining room.**
- All facilities reported that facility **meals could be delivered to the resident's room** (Table 29).

TABLE 29. HOSPITALITY SERVICES PROVIDED/ARRANGED: LTC FACILITIES

Service	% of LTC Facilities (n=54)			
	As Part of Base Fee	As Extra Charge	Both Base Fee and Extra Charge	Not Provided/ Arranged
Meal services				
• Breakfast	100%	---	---	---
• Lunch	100%	---	---	---
• Dinner	100%	---	---	---
• Snacks	100%	---	---	---
• Escorts to meals	100%	---	---	---
• Meal delivered to resident's room	100%	---	---	---
• Special diets	100%	---	---	---
Housekeeping/cleaning	100%	---	---	---
Towels/bedding laundry	100%	---	---	---
Personal laundry	---	100%	---	---
Personal response system	100%	---	---	---
Social, leisure, recreation				
• Planned recreational activities	98%	---	2%	---
• Exercise/health program	100%	---	---	---
• Transportation to social activities	35%	48%	7%	9%

- All facilities indicated that they met **special dietary requirements** including diabetic diets, low salt and texture modification as well as some of the residents' **special dietary preferences** such vegetarian meals and cultural choices.

Facility Representatives

The cook or dietary supervisor meets with the resident or family on admission and does an interview to get preferences. The nursing staff also pass this on.

There is an alternate and we try to accommodate likes/dislikes but it can be hard making everyone happy.

We try to feed people according to religious/cultural preferences and according to likes/dislikes – vegetarian, no pork. Snacks are available on each unit.

- Most facilities (80%) offered the residents options to store food in their room in a **refrigerator**. A microwave in a resident's room was possible in only 5 facilities.
- All facilities provided a **personal response system**.
- **Social, leisure and recreational opportunities** were provided by all facilities (Table 29). Facility representatives were not asked detailed questions about these opportunities.

Physical and Social Environment

- 11% of the LTC facilities had only **private rooms**. More frequent were facilities with a mix of private and semi-private (2-person) rooms (82%). The remainder had either private, semi-private and 3-person rooms (4%) or private, semi-private and 4-person rooms (4%).
- Only one facility had **spousal suites**, with 8 units available. Both partners had to be assessed as requiring long-term care. At the time of the survey, no suites were occupied by spouses.
- All facilities reported that residents could bring their own **personal furniture** to the facility. This ranged from furnishing their entire room/apartment (32%) to bringing a few personal items such as pictures and some furniture (69%).
- Residents could **physically change their rooms** in some facilities by painting the room (57% of facilities), wallpapering (50%), or changing the locks (7%).
- 28% of the facilities reported that the LTC residents could **bring pets** to live in their room. Some facilities had restrictions on the size or type of the pet and whether the resident had to be able to look after the pet. One facility charged extra fees for pets.
- 74% of the facilities had **animals or pets that belonged to the facility**. All facilities allowed **visiting pets**.
- **Outside amenities** available to LTC residents included picnic areas (91%), gardens (96%), chairs in an inner courtyard or backyard (94%), and chairs at the front door (94%).
- Five facilities (9%) reported some restrictions in the **hours for visiting**. All but one facility had some **restrictions on how visitors could enter** the building. Several facilities locked doors in the evenings and visitors had to buzz for access. Some had a secure entrance 24/7 where visitors either had to buzz or sign in with security/reception.
- **Overnight accommodations for visitors** were available in 19% of the facilities. Eight of these 10 facilities provided a separate room at a cost ranging from no charge to $60/night, while 2 of the 10 allowed visitors to stay in the resident's room at no cost.

Fees

- The **per diem rate** ranged from $41.50 to $50.75 at the time of the study. Based on 30.4 days/month, this yields **monthly base fees** ranging from $1261 to $1542 per month (prior to November 1, 2008).
- The difference between the lowest and highest monthly base rates within a facility varied from $0 to $281 depending on shared versus private rooms. 85% of the facilities reported a difference of $205.20.
- Some facilities had **extra charges** that residents were given as optional fees, including cable, telephone, or personal laundry (see section on services for additional information).

Summary

This brief profile of LTC facilities has revealed a number of similarities and relatively few differences between the facilities. The size, the proportion of spaces allocated to LTC within a facility, and the availability of other levels of care on site varied. All facilities had units devoted solely to their LTC residents.

All facilities admitted and retained individuals with mobility restrictions, continence issues and a need for assistance with feeding. There was some variation in the likelihood of admitting individuals with certain behavioural issues; however, this variation was most often between an "unequivocal yes" and "it depends", reflecting concern for the safety of the individual and other residents as well as the availability of staff.

These facilities were most likely to be staffed by PCAs and RNs, with some facilities employing LPNs. All facilities had professional nursing services on site 24/7. All but one facility had at least one GP formally affiliated with the facility. All facilities provided assistance with personal care, oral care, nursing care, administration of medication, incontinence supplies, physical or occupational therapies in the facility, and social work/clergy counseling in the facility. Variation in base fees reflected whether the resident had a private or shared room.

Attention now turns to a profile of LTC residents. Of particular interest is the extent to which there is a match between the admission/retention criteria and the services offered by LTC, and the corresponding needs of the LTC residents.

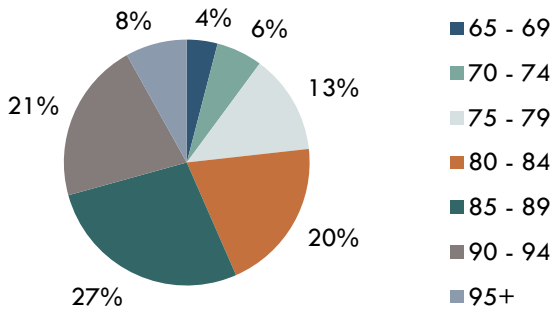
A PROFILE OF LTC RESIDENTS

In total, **1000 individuals residing in LTC facilities** participated in ACCES. Their profile is presented here in relation to **sociodemographic characteristics**, the **move to LTC, clinical issues, physical function, cognitive function and mental health, social and lifestyle characteristics, use of health services**, and **1-year outcomes**. Information is from the interRAI-LTCF assessments and the interviews with 917 of their family caregivers. [9] As discussed earlier, for ease of comparison, the topics, format and wording parallel the previous section *A Profile of DAL Residents*. Many of the key items on the interRAI-LTCF and interRAI-AL tools are the same; however, there is some information that was not collected in both LTC and DAL, given the differences in the settings.

Sociodemographic Characteristics

- The LTC residents ranged in **age** from 65 to 104, with an average age of 84.9 years. 56% were aged 85+ (Figure 51).

FIGURE 51. 5-YEAR AGE GROUPS: LTC RESIDENTS



% of LTC Residents (n=1000)

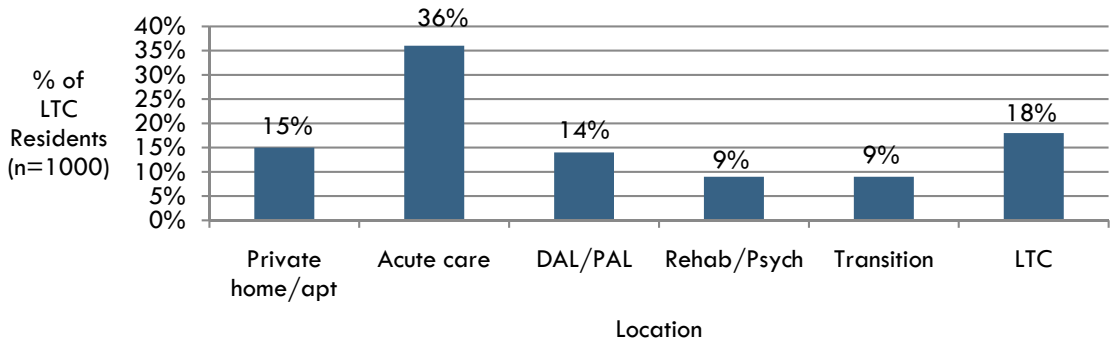
- 66% of the residents were **female**.
- In terms of **marital status**, 59% were widowed, 25% were married, 7% were divorced/ separated, and 8% were never married.
- **English** was the primary language of the vast majority of residents (93%).

Moving to LTC

- 15% of the residents moved to their current LTC facility from a **private home/apartment** while 36% moved from an **acute care hospital** (Figure 52).

[9] Sample sizes are 1000 residents and 917 for family caregivers unless otherwise noted. In some instances, respondents declined to answer the question. Percentages may not total 100% due to rounding.

FIGURE 52. LOCATION PRIOR TO THE MOVE: LTC RESIDENTS



Private home/apt: private home/apartment/rented room
Acute care: acute care hospital
DAL/PAL: board and care/designated assisted living/private assisted living
Rehab/Psych: rehabilitation hospital or unit/psychiatric hospital/mental health residence
Transition: respite/IT Bed or Community Support Bed/RCTP or Enhanced Transition Bed
LTC: long-term care facility (nursing home)

- 23% were **living alone** prior to the move, 23% were living with their spouse and 7% lived with their children. The remainder lived with other relatives (2%) or with non-relatives (45%). The majority of individuals living with non-relatives resided in congregate settings prior to their move.

- Family caregivers were asked to identify the most **important reasons** that led to the move. Similar to the reasons offered by DAL family caregivers, these related to:
  - the **resident's situation** such as the resident being unsafe in the current setting;
  - the **caregiver's situation** such as the caregiver feeling burdened/overwhelmed, having their own health concerns, or having work demands;
  - **service limitations or health providers' recommendations** including the resident's needs exceeding the level of care that could be provided or a physician or other health care professional recommending the move; and,
  - **features of the facility itself** such as its geographical proximity to family members and knowledgeable/caring staff.

Step-daughter of Male Resident

He had diabetes and my Mom was helping with his needs, his meds, and his care. Then she died and he could not take care of himself. He had to go to a Lodge but he wasn't remembering to do his insulin injections and ran into problems with his diabetes. He ended up in ER at least 7 times because of fluctuating blood sugars and finally it was evident that he needed a 24-hour care environment. His cognitive abilities were declining as well.

Daughter of Female Resident

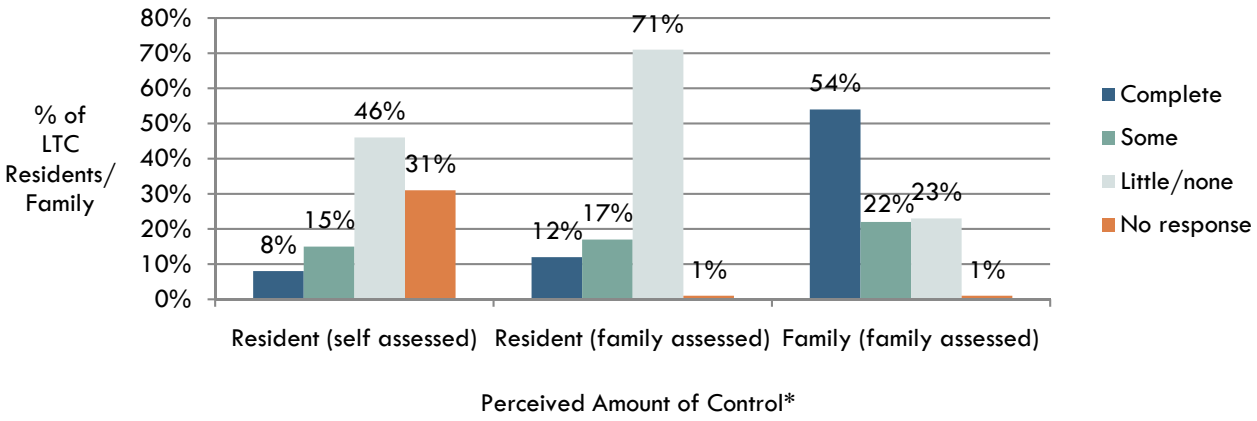
The doctor said she had to come here. She was not managing at home – falls, needing more and more help from Home Care. I was burned out.

Husband of Female Resident

She wouldn't bath, clean herself. She wouldn't change her clothes. It was a fight everyday. She was incontinent. I couldn't handle it anymore.

- 69% of the family caregivers indicated that the facility was their **first choice.**
- Residents reported varying **levels of control over the decision** to move to LTC, with 46% indicating little or no control (Figure 53). 71% of the family caregivers felt the resident had little or no control, while 54% indicated that they themselves had complete control over the decision.

FIGURE 53. PERCEIVED CONTROL OVER DECISION TO MOVE: LTC RESIDENTS AND FAMILY CAREGIVERS



* LTC residents (n=997) were asked about the level of control they had over the decision to move (Resident (self assessed)). Family caregivers (n=917) were asked "*All in all, how much control did you have over the decision for your family member to move to this facility? How much control did your family member have?*"

- 96% of family caregivers reported that the resident had to **wait for a space before moving to the current facility.** Among the 897 caregivers who provided information on the wait, the number of days waited varied from none to more than a year (no wait (4%), 1-29 days (30%), 30-59 days (22%), 60-89 days (13%), 90-179 days (15%), 180+ days (15%)).
- Residents had lived in their **current location** for varying lengths of time, with a range from less than one month to 467 months (median = 25 months). This cannot be interpreted as the length of time the individual had been in LTC as some resided in other LTC facilities prior to the move to the current facility.

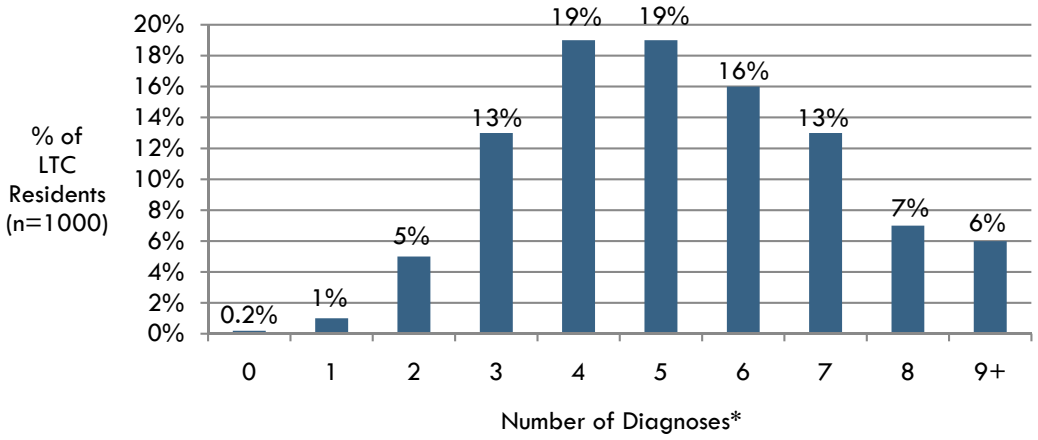
Clinical Issues

Several clinical characteristics are examined, including **disease diagnoses and symptoms, medications, balance and movement, falls, continence, skin conditions, oral health, nutritional status, tobacco and alcohol use, sleep problems, fatigue, pain, preventive health strategies,** and **CAPs for specific clinical issues.** Unless otherwise noted, the **assessment period** was the **past 3 days.**

Diseases Diagnoses and Symptoms

- LTC residents had, on average, 5.2 **disease diagnoses,** with a range from 0 to 12. (Figure 54).

FIGURE 54. NUMBER OF DISEASE DIAGNOSES: LTC RESIDENTS



* Includes diagnoses reported in Section J1 and J2 on interRAI-LTCF

- The **most common disease diagnoses** are reported in Table 30. 71% of LTC residents had a diagnosis of dementia, 59% had been diagnosed with hypertension and 52% had arthritis.

TABLE 30. MOST COMMON DISEASE DIAGNOSES: LTC RESIDENTS

Disease Diagnosis*	% of LTC Residents (n=1000)
Dementia (any)	71%
Hypertension	59%
Arthritis	52%
Depression	44%
Osteoporosis	35%
Coronary heart disease	31%
Stroke/CVA	31%
Diabetes	24%
Congestive heart failure	21%
Thyroid disease	20%
Anxiety	20%
COPD/Emphysema	19%
Cancer	13%

* Includes diagnoses reported in Section J1 and J2 on interRAI-LTCF

- **Chest pain** was reported for 10% of LTC residents.
  - 8% had chest pain present but it was not exhibited in the 3 days prior to the assessment.
  - 2% exhibited the problem 1-2 days in the 3 days prior to assessment.
  - <1% experienced chest pain daily.

- 14% of residents had difficulty **clearing airway secretions.**
  - 6% experienced this problem but not in the 3 days prior to the assessment.
  - 5% exhibited the problem 1-2 days in the 3 days prior to assessment.
  - 3% experienced the problem daily.

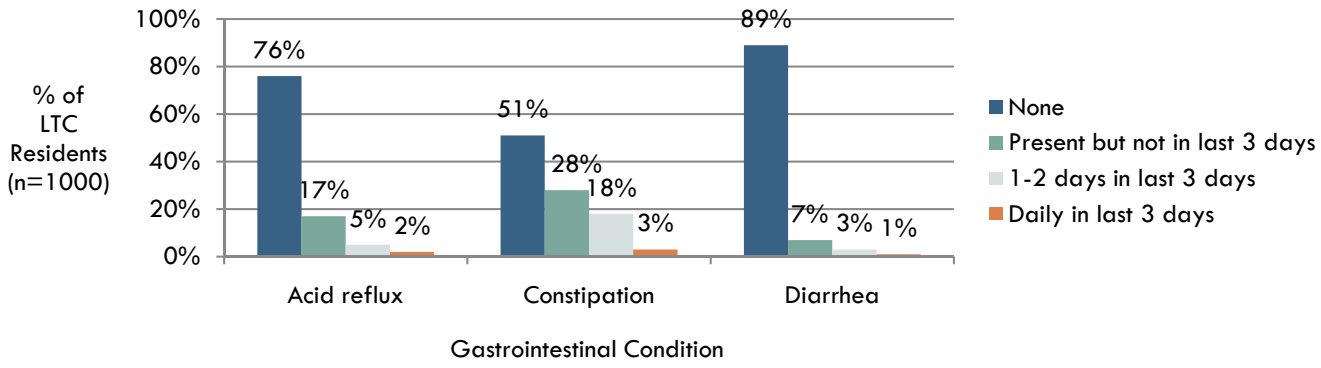
- 40% of residents were reported to have **peripheral edema** or an abnormal build up of fluid in the foot/ankle/leg tissues.
  - 5% experienced this problem but not in the 3 days prior to the assessment.
  - 6% exhibited the problem 1-2 days in the 3 days prior to assessment.
  - 29% experienced the problem daily.

- 32% of residents were reported to have **dyspnea or shortness of breath**.
  - 20% experienced dyspnea when performing moderate activities but not at rest.
  - 7% experienced it when they performed normal activities but not at rest.
  - 5% had dyspnea when at rest.

- 4% of residents were reported to have problems with **vomiting;** <1% exhibited the problem daily in the 3 days prior to the assessment.

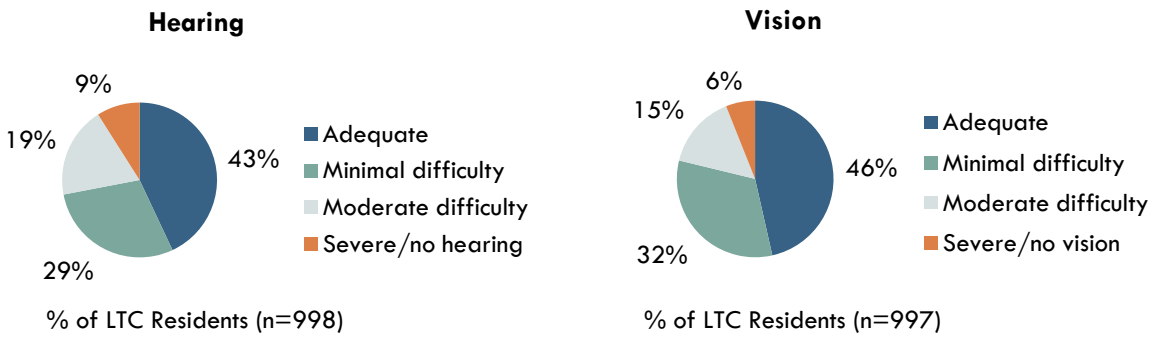
- Some residents had gastrointestinal problems such as **acid reflux** (24%), **constipation** (49%) or **diarrhea** (11%) (Figure 55).

FIGURE 55. GASTROINTESTINAL STATUS: LTC RESIDENTS



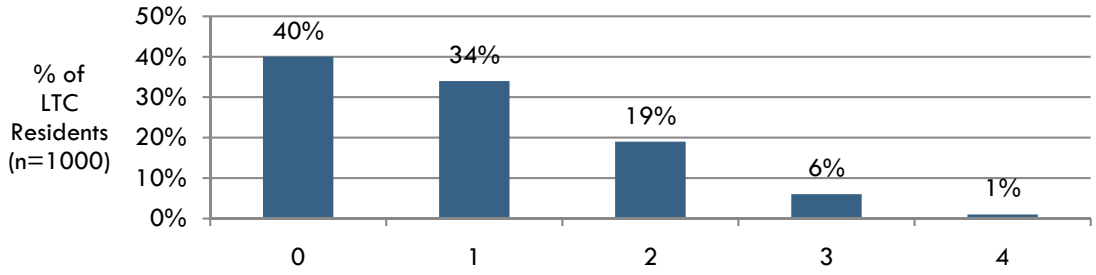
- 57% of residents experienced some **hearing difficulty** while 54% had some **vision problems** (Figure 56).

FIGURE 56. HEARING AND VISION PROBLEMS: LTC RESIDENTS



- Based on the **interRAI Changes in Health, End-stage Disease and Symptoms and Signs (CHESS)** scale (Hirdes et al., 2003), 60% of LTC residents showed **some level of instability** in terms of clinical complexity and health (Figure 57). Higher CHESS scores have been found to be associated with adverse outcomes including mortality, acute hospitalization, and pain.

FIGURE 57. interRAI CHESS SCALE: LTC RESIDENTS



Based on the following: vomiting, insufficient fluid, noticeable decline in food/fluid, weight loss, shortness of breath, edema, end-stage disease, ADL decline, and cognitive decline. Possible scores range from 0 (not at all unstable) to 5 (totally unstable). Two items (insufficient fluid and noticeable decline in food/fluid) are not on the interRAI-LTCF, which may result in an underestimate.

Medications

- LTC residents were taking 7.9 **regularly prescribed medications** on average, with a range from 0 to 21. Only 6 of 1000 residents were not taking any regularly prescribed medications. The **most common medication classes** were general analgesics (71% of residents) and antidepressants (48%) (Table 31).

TABLE 31. MOST COMMON MEDICATION CLASSES: LTC RESIDENTS

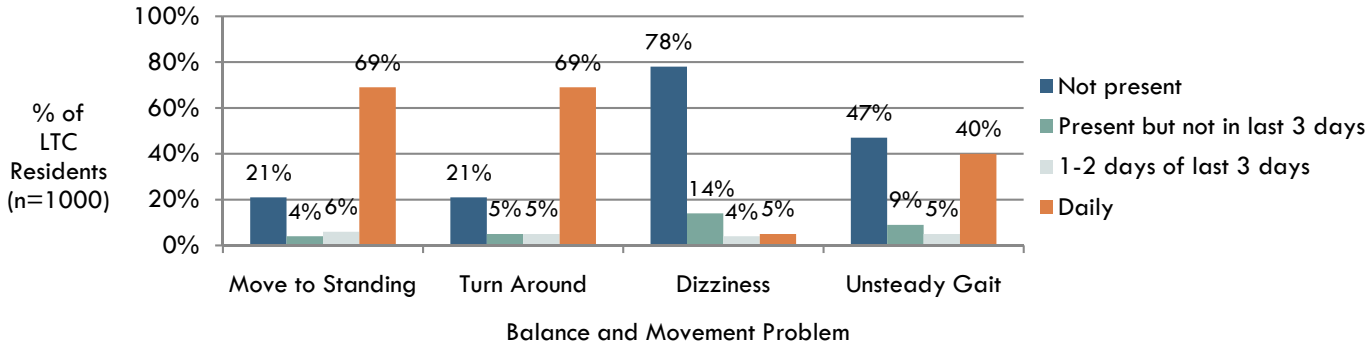
Medication Class	% of LTC Residents (n=1000)
General analgesics (including Acetaminophen and ASA)*	71%
Antidepressants (commonly SSRIs, citalopram [Celexa])	48%
Calcium	44%
Vitamin D	38%
Proton Pump Inhibitors for peptic ulcer/gastro-esophageal reflux disease (commonly pantoprazole [Pantoloc] or lansoprazole [Prevacid])	35%
ACE-Inhibitors (commonly ramipril [Altace])	33%
Antipsychotics (commonly risperidone [Risperdal])	32%
Loop Diuretics (commonly furosemide [Lasix])	29%
Beta-Blockers (commonly metoprolol [Lopressor])	24%
Antithrombotic agents (commonly warfarin [Coumadin])	23%
Thyroid agents (commonly levothyroxine [Synthroid])	23%
Insulins & oral diabetic agents (commonly metformin [Glucophage])	21%
Hypnotic/Sedative agents (commonly zopiclone [Imovane])	20%
Calcium channel blockers (commonly amlodipine [Norvasc])	17%
Bisphosphonates for osteoporosis (commonly alendronate [Fosamax])	16%
Lipid modifying agents largely HMG CoA reductase inhibitors (statins) (commonly atorvastatin [Lipitor])	16%
Anti-dementia drugs (commonly donepezil [Aricept])	16%
Anti-epileptic drugs	15%

* Excludes opioid analgesics prevalence = 19% of LTC residents

Balance and Movement

- Some LTC residents experienced problems with **balance** and **movement** (Figure 58).
  - 79% had difficulty or were unable to move to a **standing position** unassisted.
  - 79% had difficulty or were unable to turn around and **face the opposite direction** when standing.
  - 22% experienced **dizziness**.
  - 53% had an **unsteady gait**.

FIGURE 58. PROBLEMS WITH BALANCE AND MOVEMENT: LTC RESIDENTS



Falls

- 27% had at least one **fall** in the 90 days prior to the assessment. A fall is defined as "an unintentional change in position where the person ends up on a lower level" (CIHI, 2008, p. 93).
  - 4% had 2 or more falls in the last 30 days.
  - 11% had one fall in the last 30 days.
  - 12% had at least one fall in the last 31-90 days.

Continence

- About 9 in 10 LTC residents had some difficulty with **bladder incontinence.**
  - 9% were bladder continent.
  - 4% had control with catheter/ostomy.
  - 7% were infrequently incontinent.
  - 10% were occasionally incontinent (less than daily).
  - 26% were frequently incontinent (daily but some control present).
  - 44% were incontinent (no control present).

- 7 in 10 residents had some difficulty with **bowel incontinence**.
  - 31% were bowel continent.
  - 2% had control with ostomy.
  - 15% were infrequently incontinent.
  - 15% were occasionally incontinent (less than daily).
  - 9% were frequently incontinent (daily but some control present).
  - 29% were incontinent (no control present).

- 48 residents (5%) had an indwelling catheter, 2 had a cystostomy/nephrostomy/ureterostomy and 2 used a condom catheter. 90% were reported to wear continence pads or briefs.

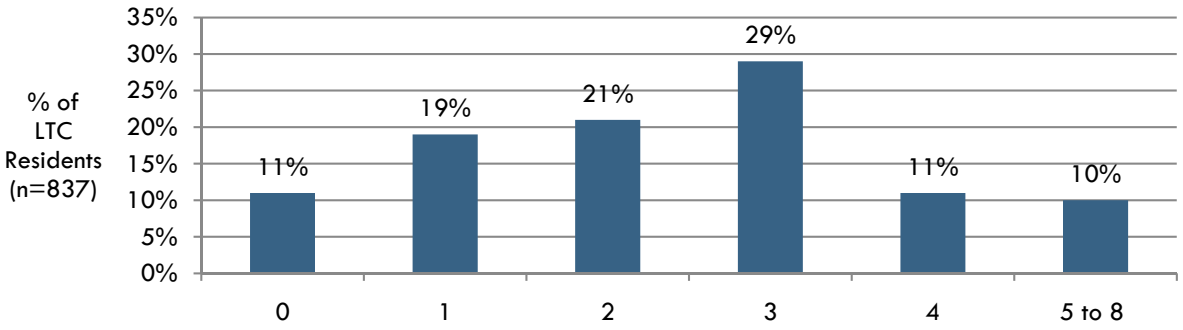
Skin Conditions

- 16% of LTC residents were reported to have **pressure ulcers** at the time of the assessment.
  - 6% had an area of persistent skin redness (Stage 1).
  - 8% had partial loss of skin layers (Stage 2).
  - 2% had deep craters in skin (Stage 3).
  - <1% had breaks in the skin exposing muscle/bone (Stage 4).
  - <1% had an ulcer that could not be staged as it was covered with necrotic tissue.

- 17% of LTC residents had a documented **history of a previous pressure ulcer** that had healed.

- The **interRAI Pressure Ulcer Risk Scale (PURS)** (Poss et al., 2010) identifies individuals at risk for developing a pressure ulcer. Similar to reports for long-term care clients in Ontario (Poss et al., 2010), the PURS is slightly skewed towards **lower risk for pressure ulcers,** with 30% of 837 LTC residents who did not have a current pressure ulcer scoring 0 or 1 out of a possible 8 (Figure 59).

FIGURE 59. interRAI PRESSURE ULCER SCALE (PURS): LTC RESIDENTS



Based on the following: impaired in bed mobility, impaired in walking, bowel incontinence, weight loss, history of resolved pressure ulcers, daily pain, and shortness of breath. Possible scores range from 0 to 8; a higher score indicates higher risk. Calculated only for 837 residents who did not have a current pressure ulcer.

- 4% of the 1000 LTC residents had a **skin ulcer** other than a pressure ulcer.

- 10% had non-surgical skin tears or cuts.

- 45% had **other skin conditions** or changes in skin condition such as bruises, rashes, itching, or eczema.

- Among the 1000 LTC residents, 27% had **foot problems** such as bunions, hammer toes, overlapping toes, infections, or ulcers. Among the 266 residents with foot problems, 9% were limited from walking, 4% were prevented from walking, 42% had no limitations in their walking while the remaining 45% did not walk for other reasons.

Oral Health

- 68% of LTC residents wore **dentures**.
- Some residents experienced **oral health problems**.
  - 26% had a dry mouth.
  - 19% had broken, fragmented, loose or otherwise non-intact natural teeth.
  - 17% had difficulty chewing.
  - 7% had gum inflammation or bleeding.
  - 5% had mouth or facial pain/discomfort.

Nutritional Status

- 10% of LTC residents were reported to have experienced a **weight loss** of 5% or more in the last 30 days or 10% or more in the last 180 days.
- 63% had special dietary needs.
- 8% were reported to be **dehydrated**.
- In terms of the mode of nutritional intake,
  - 54% of the residents were able to swallow all types of food.
  - 5% were able to sip liquids and take limited solid food.
  - 31% required diet modification to swallow solid food (e.g., mechanical diet (pureed, minced, etc.) or were only able to ingest specific foods.
  - 2% needed modifications to swallow liquids (e.g., thickened liquids).
  - 7% could only swallow pureed solids and thickened liquids.
  - 1% received combined oral and parenteral or tube feeding.
  - 1% used an abdominal feeding tube such as a PEG tube.

Tobacco and Alcohol Use

- **Daily tobacco use** was recorded for 4% of LTC residents.
- 5% were reported to have **consumed alcohol** in the 14 days prior to the assessment. This included 4% who had 1 drink, 1% who had 2-4 drinks, and less than 1% who had 5 or more drinks in a single sitting.

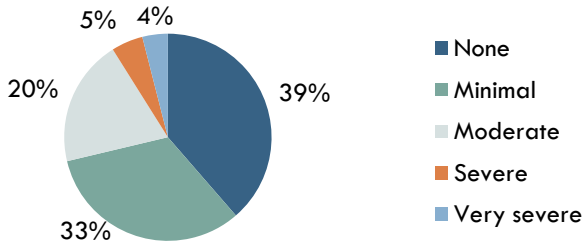
Sleep Problems

- 37% of LTC residents **experienced sleep problems**, including difficulty falling asleep or staying asleep, waking up too early, restlessness or non-restful sleep.
- 19% were assessed as getting **too much sleep** or excessive sleep that interfered with their normal functioning.

Fatigue

- 61% of residents were assessed with some level of **fatigue,** defined as diminished energy and difficulty in performing normal daily activities (e.g., ADLs and IADLs) (Figure 60).

FIGURE 60. FATIGUE: LTC RESIDENTS



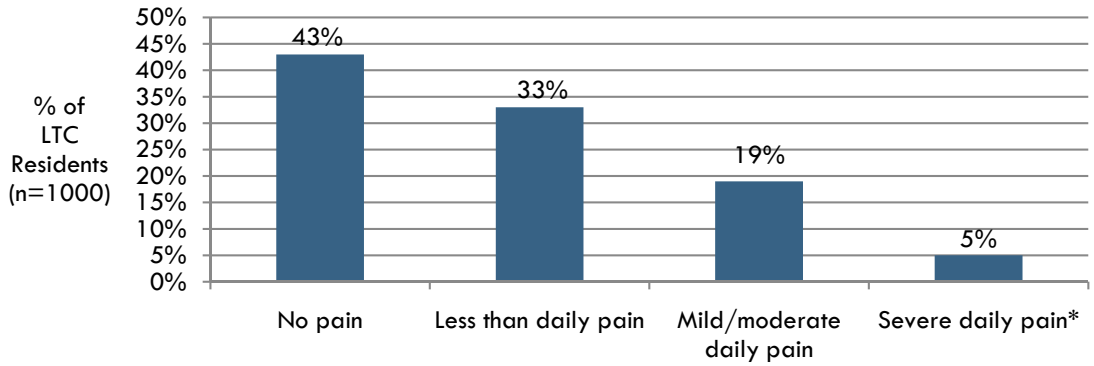
% of LTC Residents (n=1000)

Minimal: due to diminished energy, but completes normal day-to-day activities
Moderate: due to diminished energy, unable to finish normal day-to-day activities
Severe: due to diminished energy, unable to start some normal day-to-day activities
Very severe: due to diminished energy, unable to commence any normal day-to-day activities

Pain

- Over one-half of the 1000 LTC residents experienced **some level of pain,** with 24% having daily pain, based on the **interRAI Pain Scale** (Fries et al., 2001) (Figure 61).

FIGURE 61. interRAI PAIN SCALE: LTC RESIDENTS



* Severe daily pain includes severe/excruciating pain

Preventive Health Strategies

- The likelihood of prevention strategies varied.
  - Blood pressure measured in the last year (99%)
  - Colonoscopy test in the last five years (7%)
  - Dental exam in the last year (32%)
  - Eye exam in the last year (27%)
  - Hearing exam in the last two years (12%)
  - Influenza vaccine in the last year (92%)
  - A mammogram in the last two years (for 657 females only) (12%)
  - A pneumovax vaccine ever (86%)

Clinical Assessment Protocols (CAPs): Clinical Issues

- Information on the **interRAI Clinical Assessment Protocols (CAPs) related to clinical issues** is provided in Table 32. As noted earlier, these CAPs are designed to focus on key common/severe issues identified during the assessment process to guide appropriate care planning (CIHI, 2008, p.1).

TABLE 32. interRAI CLINICAL ASSESSMENT PROTOCOLS (CAPs) FOR CLINICAL ISSUES: LTC RESIDENTS

CAP	% of LTC Residents Triggering CAP (n=1000)
Falls CAP 23% of LTC residents were at *medium risk* and 4% at *high risk* for future falls. The medium risk group had a prior report of a single fall while the high risk group had experienced multiple falls.	**27%**
Pain CAP The goal of this CAP is to identify residents in particular need of appropriate pain assessment and management strategies. 19% of LTC residents were at *medium priority* for specialized follow-up (with mild to moderate daily pain) and 7% were at *high priority* for follow-up (with horrible, excruciating pain whether it occured daily or less frequently).	**26%**
Pressure Ulcer CAP 10% of LTC residents had Stage 2 or higher level pressure ulcers, 6% had Stage 1 ulcers and were at risk for Stage 2 or higher ulcers, and 7% had no ulcer currently but had selected risk factors. *Note: The item 'wound care' is not available on the interRAI-LTCF so the CAP is calculated without this item.*	**23%**
Cardio-Respiratory CAP This CAP identifies individuals in need of focused assessment/management and/or further referral (e.g., to a physician) for possible cardiovascular or respiratory problems. It is triggered by the presence of one or more of the following symptoms: chest pain, shortness of breath, irregular pulse, or dizziness. It may also be triggered by recorded findings on selected tests such as blood pressure, respiratory rate, heart rate, and oxygen saturation levels.	**44%**

Continued…

Prevention CAP **99%**
Preventive strategies are considered together in this CAP. All but two residents triggered the CAP, suggesting opportunities for improvement in implementing preventive strategies for LTC residents. *Note: The item 'physician visit days' is not available on the interRAI-LTCF so the CAP is calculated without this item. Based on 999 residents.*

Appropriate Medication CAP **15%**
This CAP is based on a resident having 9 or more medications and 2 or more of the following conditions: chest pain, dizziness, edema, shortness of breath, poor health, and recent deterioration. It identifies residents who may have an increased risk of potentially inappropriate medication use and adverse drug events and require additional focused assessment and follow-up. *Note: The item 'self-sufficiency change' is not available on the interRAI-LTCF so the CAP is calculated without this item. Based on 995 residents.*

Tobacco and Alcohol Use CAP **4%**
This CAP identifies individuals in need of targeted efforts (e.g., advice, support or treatment) to help them stop smoking or to reduce their alcohol consumption where indicated.

Urinary Incontinence CAP **58%**
The goal of this CAP is to promote improvement in bladder function in those who could improve and to prevent worsening of function in persons who may have the ability to respond to a treatment program, taking cognitive performance into account. 57% of the residents may benefit from activities such as scheduled toileting programs, and/or ongoing monitoring to *prevent decline* while such activities may *facilitate improvement* for1% of the residents.

Bowel Conditions CAP **24%**
This CAP addresses 3 common bowel conditions: diarrhea, constipation, and fecal impaction. The goal is to facilitate improvement in bowel status whenever possible and to prevent avoidable bowel decline in others. 21% of the LTC residents were at risk of *further decline* while 3% were considered to have *potential for improvement. Note: The item 'overall change in care needs' is not available on the interRAI-LTCF so the CAP is calculated without this item.*

Note: The description of CAPs is from CIHI (2008). The Under-nutrition CAP that addresses the need for nutritional support of individuals below a "medically recommended" ideal body weight, as measured by a low body mass index (BMI) was not calculated due to a decision not to have study nurses take these measurements and a concern about the reliability and validity of the BMI calculation for this population.

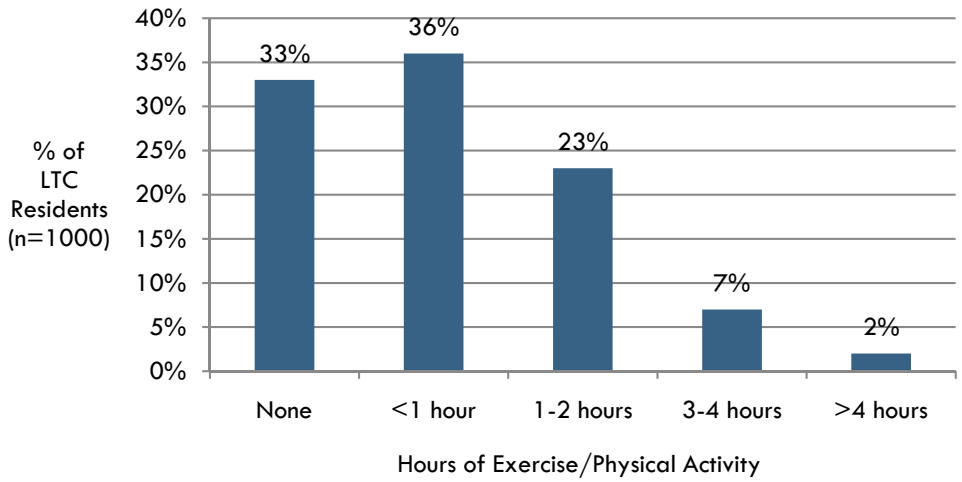
Physical Function

Information was gathered on several aspects of physical function, including **exercise/physical activity, instrumental activities of daily living (IADLs), basic activities of daily living (ADLs), mode of locomotion, use of restrictive devices**, and **CAPs for physical function.** Unless otherwise noted, the **assessment period** was the **past 3 days.**

Exercise/Physical Activity

- Residents varied in the total hours of **exercise or physical activity** in the 3 days prior to the assessment, with 9% getting at least 3 hours and 33% getting no exercise (Figure 62).

FIGURE 62. HOURS OF EXERCISE/PHYSICAL ACTIVITY IN LAST 3 DAYS: LTC RESIDENTS



- **Walking/wheeling indoors** (57%) was the only exercise/physical activity in which over one-half of the residents participated in the 3 days prior to the assessment or were regularly involved but not in these 3 days (Table 33). This was followed by **exercise programs** (42%), **walking/ wheeling outdoors** (37%), and **trips/shopping/functions** (30%).

TABLE 33. EXERCISE/PHYSICAL ACTIVITIES: LTC RESIDENTS

Exercise/Physical Activity	% of LTC Residents (n=999)			
	Participated and Preferred	Participated but Not Preferred	Did Not Participate but Preferred	Did Not Participate and Not Preferred
Walking/wheeling indoors	54%	3%	17%	26%
Walking/wheeling outdoors*	37%	<1%	26%	36%
Exercise program, stretching	38%	4%	8%	50%
Trips, shopping, functions*	30%	<1%	28%	42%
Household chores*	3%	---	30%	67%
Gardening or plants*	10%	<1%	37%	53%
Aquasize/swimming*	<1%	---	13%	87%
Bowling*	5%	<1%	15%	80%
Shuffleboard/pool*	2%	<1%	10%	88%
Dancing*	3%	---	29%	68%
Floor curling/lawn bowling*	3%	<1%	7%	90%
Exercise bike/treadmill*	2%	---	7%	92%
Tai Chi /yoga*	<1%	---	1%	99%

* n=998. Participated included involvement in the 3 days prior to the assessment and regular involvement but not in these 3 days. % of residents who participated in an activity = (% Participated and Preferred) + (% Participated but Not Preferred). % of residents who preferred an activity = (% Participated and Preferred) + (% Did Not Participate but Preferred).

- Very few residents participated in **non-preferred activities** (Table 33).
- Gardening/plants (37%), household chores (30%), dancing (29%), trips, shopping, functions (28%), and walking/wheeling outdoors (26%) were identified for at least one-quarter of the residents as an **activity in which they did not participate** although it was a preferred activity (Table 33). As discussed with regards to DAL residents, this may reflect the resident's physical/cognitive functioning, the availability of the activity in the facility, or the lack of a companion with whom to participate.

Basic Activities of Daily Living (ADLs)

- Almost all LTC residents required some **assistance with their ADLs** (Table 34).

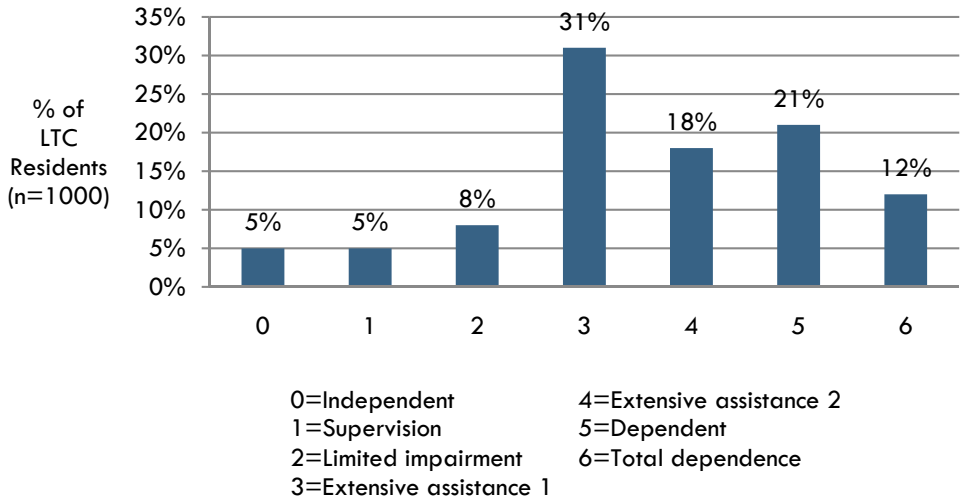
TABLE 34. ADL PERFORMANCE: LTC RESIDENTS

	% of LTC Residents (n=1000)				
Activity	**Independent**	**Limited Assistance (includes setup)**	**Extensive Assistance – Dependence**	**Total Dependence**	**Activity Did Not Occur in Last 3 Days**
Bathing	<1%	7%	38%	51%	4%
Personal hygiene	6%	25%	33%	36%	---
Dressing upper body	5%	21%	30%	44%	<1%
Dressing lower body	4%	16%	32%	47%	<1%
Walking	15%	15%	16%	<1%	53%
Locomotion*	27%	25%	17%	30%	1%
Transfer toilet	16%	16%	34%	26%	9%
Toilet use	9%	14%	32%	43%	2%
Bed mobility*	28%	21%	28%	23%	---
Eating	16%	57%	12%	15%	<1%

* n=999

- 82% of the LTC residents required at minimum extensive assistance in their activities of daily living, based on the **Activities of Daily Living Self-Performance Hierarchy Scale** (Morris et al., 1999) (Figure 63). This scale measures ADL performance according to early, middle and late stages of loss using 4 ADLs (personal hygiene, toilet use, locomotion and eating). Scores range from 0 (independent) to 6 (total dependence).

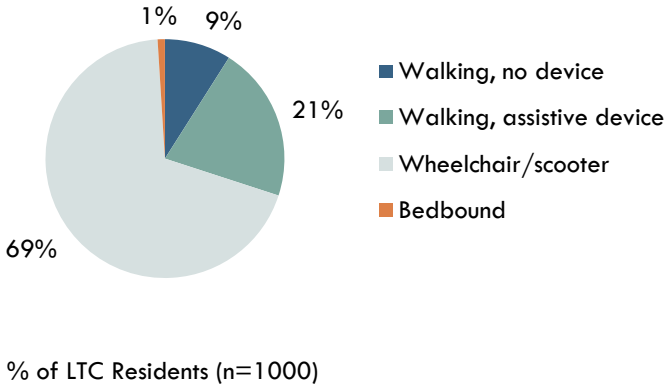
FIGURE 63. interRAI ACTIVITIES OF DAILY LIVING (ADL) SELF-PERFORMANCE HIERARCHY SCALE: LTC RESIDENTS



Mode of Locomotion

- 15% of LTC residents were independent with **walking** while 27% were independent in **locomotion** (walking or wheeling).
- 69% of LTC residents used **wheelchairs/scooters** while 21% walked with an assistive device (Figure 64). One resident was bedbound during the assessment period.

FIGURE 64. USUAL MODE OF LOCOMOTION: LTC RESIDENTS



Use of Restrictive Devices

- The use of restrictive devices varied in LTC.
  - **Full bed rails on all open sides of bed** (67% of residents), including use less than daily (2%), daily - nights only (29%), daily - days only (1%), night and day but not constant (29%), and constantly for the full 24 hours with possible periodic release (6%)
  - **Trunk restraints** (33% of residents), including use less than daily (1%), daily - days only (29%), night and day but not constant (3%), and constantly for the full 24 hours with possible periodic release (<1%)
  - **Chairs** to prevent rising (20% of residents), including use less than daily (<1%), daily - nights only (<1%), daily - days only (16%), night and day but not constant (2%), and constantly for the full 24 hours with possible periodic release (<1%)

Clinical Assessment Protocols (CAPs): Physical Function

- Information on the **interRAI Clinical Assessment Protocols (CAPs) related to physical function** is provided in Table 35.

TABLE 35. interRAI CLINICAL ASSESSMENT PROTOCOLS (CAPs) FOR PHYSICAL FUNCTION: LTC RESIDENTS

CAP	% of LTC Residents Triggering CAP (n=1000)
Physical Activities Promotion CAP	**24%**
24% of LTC residents triggered this CAP, indicating the need for improvement in their level of physical activity including walking, planned exercise, or leisure activities and performing instrumental tasks. This CAP aims to identify functionally capable older adults in need of targeted and appropriate strategies to help reduce barriers to increased physical activity levels.	
Activities of Daily Living CAP	**82%**
This CAP considers a resident's ability to perform basic daily activities, including dressing, personal hygiene, walking, transferring, toileting, changing position in bed and eating, taking cognitive performance into account. 58% of LTC residents potentially required attention to *prevent decline* and 24% to *facilitate improvement*. This latter group is distinguished by having 2 or more indicators suggestive of a recent acute event or fluctuating functional status and/or condition. *Note: The item 'overall change in care needs' is not available on the interRAI-LTCF tool so the CAP is calculated without this item. Based on 999 residents.*	
Physical Restraints CAP	**40%**
This CAP assesses whether residents are physically restrained (by any device) and are in need of focused care to permit restraint removal. The goal is to eliminate restraint use by using techniques appropriate to the resident's physical and/or cognitive abilities. 32% had little or no ability to perform middle or early loss ADLs such as personal hygiene, dressing and walking while 9% had some ability to perform these ADLs.	

Continued…

Feeding Tube CAP **1%**
Only 1% of LTC residents triggered this CAP, indicating the potential for improvement. Six residents were at low risk and 8 were at high risk.

Dehydration CAP **8%**
8% of LTC residents triggered this CAP, indicating the potential for improvement. 18 residents were at low risk while 57 were considered as high risk. *Note: The item 'fluid intake <1000 cc/day' is not available on the interRAI-LTCF tool so the CAP is calculated without this item.*

Note: The description of CAPs is from CIHI (2008).

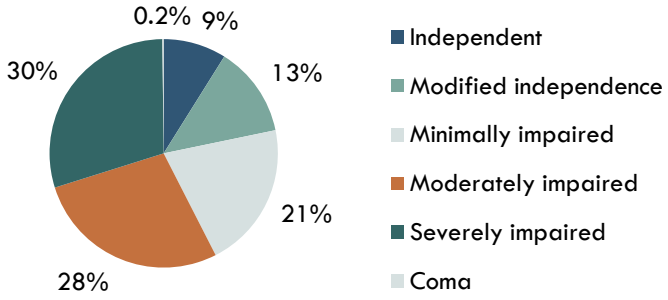
Cognitive Function and Mental Health

Several aspects of cognitive function and mental health are examined, including **cognition, communication, depression, disruptive behaviours, other mental health concerns**, and **CAPs for cognitive function and mental health**. Unless otherwise noted, the **assessment period** was the **past 3 days.**

Cognition

- As noted earlier (Table 30), 71% of LTC residents had a recorded diagnosis of **dementia,** including Alzheimer's disease.
- 91% of residents exhibited some limitations in their **cognitive skills for daily decision-making** such as when to get up, which clothes to wear, or activities to do (Figure 65).

FIGURE 65. COGNITIVE SKILLS FOR DAILY DECISION-MAKING: LTC RESIDENTS



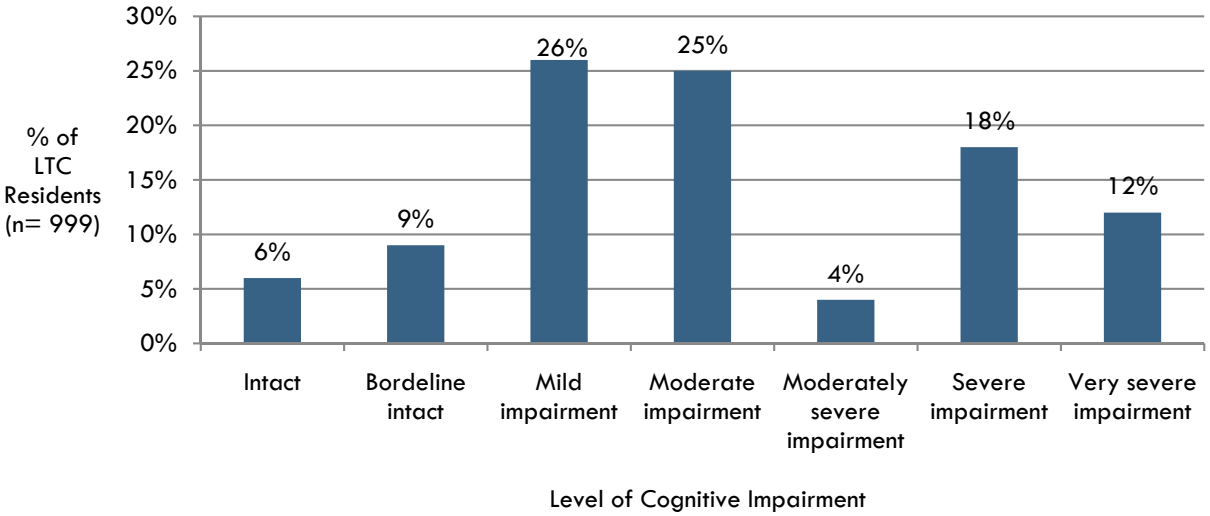
% of LTC Residents (n=1000)

Independent: decisions consistent, reasonable and safe
Modified independence: some difficulty in new situations only
Minimally impaired: in specific recurring situations, decisions become poor or unsafe; cues/supervision required at those times
Moderately impaired: decisions consistently poor or unsafe; cues/supervision required at all times
Severely impaired: never or rarely makes a decision

- In terms of memory/recall ability (based on 997 residents),
  - 83% had **short-term memory problems** (unable to recall after 5 minutes).
  - 61% had **procedural memory problems** (cannot perform all or almost all steps in a multitask sequence without cues).
  - 48% had problems with **situational memory** (not recognizing caregivers' names/faces frequently encountered and not knowing location of places regularly visited such as their bedroom or dining room).

- 85% of LTC residents showed **some level of impairment in cognitive performance**, based on the **interRAI Cognitive Performance Scale (CPS)** (Morris et al., 1994; Hartmaier et al., 1995) (Figure 66). The CPS considers skills for daily decision-making, short-term memory, making self understood and eating impairment. Scores range from 0 (intact) to 6 (very severe impairment).

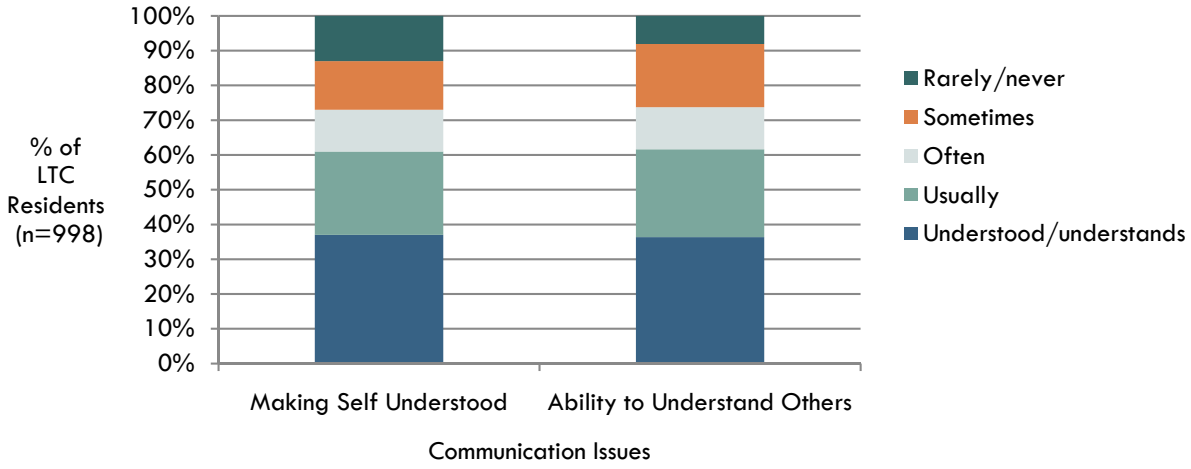
FIGURE 66. interRAI COGNITIVE PERFORMANCE SCALE (CPS): LTC RESIDENTS



Communication

- About two-thirds of the residents experienced difficulty **making themselves understood** (63%) or **understanding others** (64%) (Figure 67).

FIGURE 67. COMMUNICATION ISSUES: LTC RESIDENTS



Depression

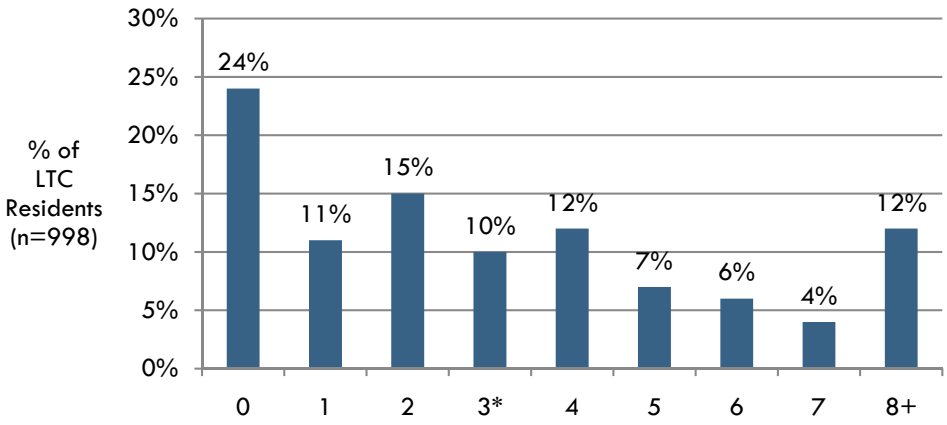
- 44% of LTC residents had a recorded **clinical diagnosis of depression.**
- Some residents showed signs of **possible depressed, anxious or sad mood** (Table 36).

TABLE 36. INDICATORS OF POSSIBLE DEPRESSED, ANXIOUS OR SAD MOOD: LTC RESIDENTS

Indicator	% of LTC Residents (n=1000)			
	Daily in Last 3 Days	1-2 Days of Last 3 Days	Present but Not in Last 3 Days	Not Present
Made negative statements	4%	4%	10%	83%
Persistent anger with self or others	22%	10%	13%	55%
Expressions of what appear to be unrealistic fears (verbal/non-verbal)	13%	4%	6%	77%
Repetitive health complaints	12%	6%	5%	77%
Repetitive anxious complaints/concerns (non-health)	24%	8%	6%	62%
Sad, pained, worried facial expressions	28%	12%	11%	49%
Crying, tearfulness	4%	6%	13%	78%
Recurrent statements that something terrible is about to happen	2%	1%	2%	95%
Withdrawal from activities of interest	35%	15%	9%	41%
Reduced social interactions	38%	19%	9%	34%
Expressions of a lack of pleasure in life (verbal/non-verbal)	4%	5%	6%	86%

- 51% of LTC residents were assessed with clinically important depressive symptoms as measured by the **interRAI Depression Rating Scale (DRS)** (Burrows et al., 2000) (Figure 68). The DRS is based on a summary of the first 7 items in Table 36 and may be used as a clinical screen for depression. Scores range from 0 to 14, with higher values indicating a greater number and/or frequency of symptoms. A score of 3 or higher indicates clinically important depressive symptoms.

FIGURE 68. interRAI DEPRESSION RATING SCALE: LTC RESIDENTS



* Score of 3+ indicates clinically important depressive symptoms

- In addition to nurse assessments, residents' self-assessments of mood were obtained. Residents were asked "*In the last 3 days, how often have you felt little interest or pleasure in things you normally enjoy? Anxious, restless, or uneasy? Sad, depressed, or hopeless?*"
  - 18% reported feeling **little interest or pleasure** in the last 3 days or often but not in those 3 days; 38% could not/did not respond.
  - 23% reported feeling **anxious, restless, or uneasy** in the last 3 days or often but not in those 3 days; 36% could not/did not respond.
  - 30% reported feeling **sad, depressed or hopeless** in the last 3 days or often but not in those 3 days; 32% could not/did not respond.

- 38% of residents were reported to have said or indicated that s/he felt **lonely** (based on 980 residents).

- 11% expressed **sadness over recent loss** (based on 999 residents).

- 12% of residents were reported to have experienced a **major life stress** in the 90 days prior to the assessment, such as episodes of severe personal illness or the death or severe illness of a close family member (based on 999 residents).

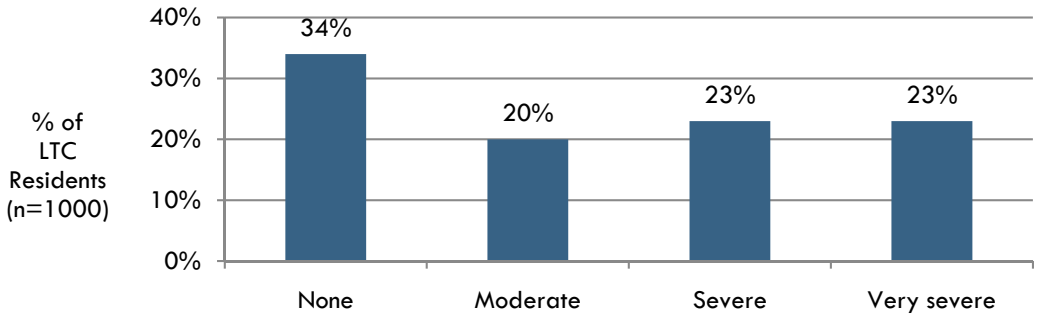
- 68% were assessed as having a **consistent positive outlook** (based on 994 residents) while 73% were reported as **finding meaning in day-to-day life** (based on 993 residents).

Disruptive Behaviours

- Some LTC residents exhibited **disruptive behaviours** in the 3 days prior to the assessment or usually but not in the previous 3 days.
  - Wandering (23%)
  - Verbal abuse (34%)
  - Physical abuse (22%)
  - Socially inappropriate or disruptive behaviour (28%)
  - Inappropriate public sexual behaviour or public disrobing (9%)
  - Resisting care (57%)
  - Intimidation of others or threatened violence (14%)

- 66% of residents scored in the moderate to very severe range on the **interRAI Aggressive Behavior Scale** (Perlman & Hirdes, 2008) that takes 4 behaviours (verbal abuse, physical abuse, socially inappropriate or disruptive behaviour, and resists care) into account (Figure 69).

FIGURE 69. interRAI AGGRESSIVE BEHAVIOR SCALE: LTC RESIDENTS



- 17% of residents had **elopement attempts or threats** in the past 12 months while 16% displayed **dangerous, non-violent behaviour**.

Other Mental Health Concerns

- Some residents had **other psychiatric disease diagnoses.**
  - 20% had a diagnosis of **anxiety.**
  - 5% had reported **substance abuse problems.**
  - 3% had been diagnosed with **schizophrenia.**
  - 1% had been diagnosed with **bipolar disease.**

- 13% of residents had **delusions,** 9% had **abnormal thought processes,** and 7% were reported to have **hallucinations** in the 3 days prior to the assessment or usually had such concerns although they were not exhibited in the assessment period.

- 14% of residents had a documented **history** of mental illness or intellectual disability. The number of **lifetime psychiatric admissions** varied, with 6% having 1-3 admissions and 1% having 4 or more admissions.

- Within the previous 5 year period, one resident had resided in a **setting for persons with intellectual disability,** 29 residents (3%) had lived in a **psychiatric hospital or unit,** and 2 had resided in a **mental health residence** such as a psychiatric group home.

Clinical Assessment Protocols (CAPs): Cognitive Function and Mental Health

- Information on the five **interRAI Clinical Assessment Protocols (CAPs) related to cognitive function and mental health** is provided in Table 37.

TABLE 37. interRAI CLINICAL ASSESSMENT PROTOCOLS (CAPs) FOR COGNITIVE FUNCTION AND MENTAL HEALTH: LTC RESIDENTS

CAP	% of LTC Residents Triggering CAP (n=1000)
Cognitive Loss CAP This CAP focuses on helping those with reasonable cognitive skills (Cognitive Performance Scale (CPS) score of 2 or lower) to retain their independence for as long as possible. 30% of LTC residents would potentially benefit from monitoring for risk factors predictive of future decline and 11% needed specialized attention to prevent decline. *Note: The item 'overall change in care needs' is not available on the interRAI-LTCF so the CAP is calculated without this item. Based on 997 residents.*	**41%**
Delirium CAP This CAP indicates the presence of one or more active symptoms of delirium (e.g., acute onset, fluctuating cognitive status different from usual functioning). The goal is to identify and treat underlying causes of delirium and prevent associated complications.	**6%**
Mood CAP This CAP focuses on identifying those with depressive symptoms to permit appropriate management and follow-up. 25% of LTC residents were at *medium risk* (based on a Depression Rating Scale (DRS) score of 1 or 2) and 51% were at *high risk* (based on a DRS score of 3 or greater). *Based on 998 residents.*	**76%**
Communication CAP This CAP considers communication status and cognitive skills for daily decision-making. The goal is to implement specialized follow-up to facilitate improvement in communication ability where possible and to prevent communication decline. Actions could be taken with 31% of LTC residents to *prevent* decline and with 6% who have *potential for improvement.*	**36%**
Behaviour CAP This CAP considers the following behavioural issues: wandering, verbally abusive behaviour, physically abusive behaviour, socially inappropriate behaviour, resisting care, and inappropriate public sexual behaviour. Actions could be taken with 11% to *prevent* almost daily behaviours and with 41% to *reduce* daily behaviour.	**52%**

Note: The description of CAPs is from CIHI (2008).

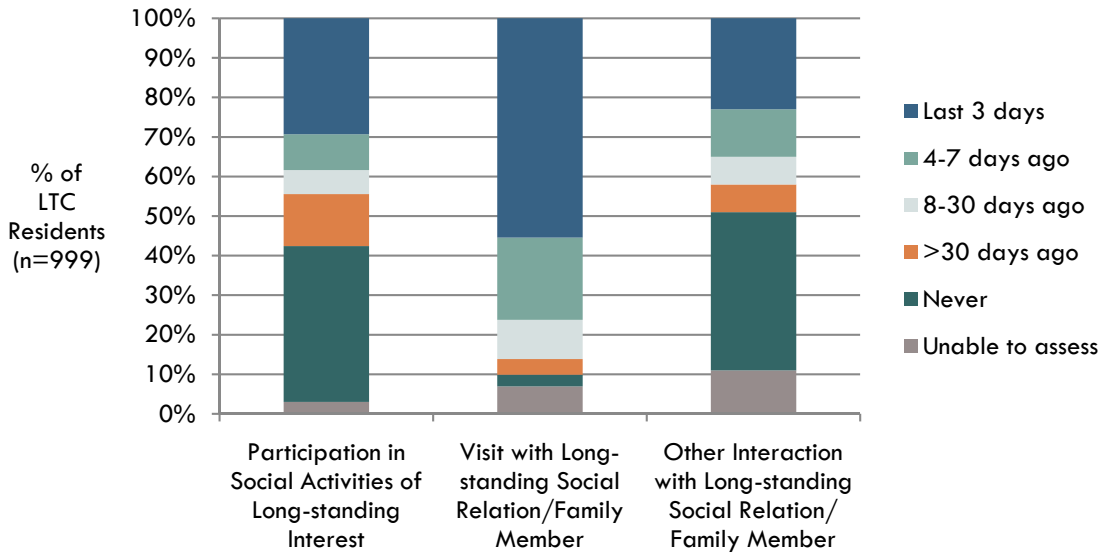
Social and Lifestyle Characteristics

Turning to social and lifestyle characteristics, information was gathered on **social functioning, social/recreational activities, initiative and involvement,** and the **CAPs for social life.** Again, unless otherwise noted, the **assessment period** was the **past 3 days.**

Social Functioning

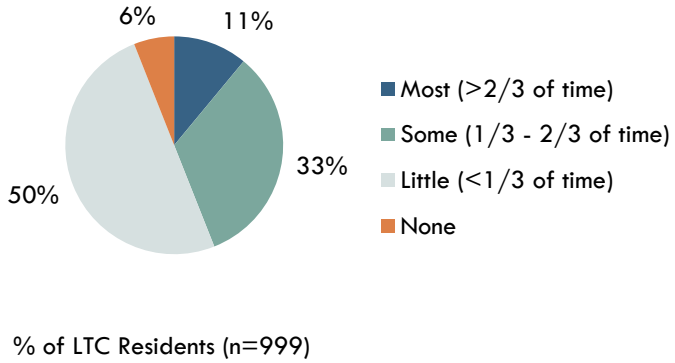
- 58% of LTC residents had <u>not</u> participated in a **social activity of long-standing** interest during the week prior to the assessment while 16% had <u>not</u> **visited with a long-standing social relation or family member** (Figure 70).

FIGURE 70. SOCIAL RELATIONSHIPS AND INTERACTIONS: LTC RESIDENTS



- Over one-half of the residents were assessed as spending, on average, little (50%) or no (6%) **time involved in activities** (when awake and not receiving treatments or ADL care) (Figure 71).

FIGURE 71. AVERAGE AMOUNT OF ACTIVITY INVOLVEMENT: LTC RESIDENTS



% of LTC Residents (n=999)

Social/Recreational Activities

- **Watching television/listening to the radio** and **music/singing** were the top two social/ recreational activities in which LTC residents were involved (Table 38).

TABLE 38. SOCIAL/RECREATIONAL ACTIVITIES: LTC RESIDENTS

Activity	% of LTC Residents (n=999)			
	Participated and Preferred	Participated but Not Preferred	Not Participated but Preferred	Not Participated and Not Preferred
Watching TV or listening to radio*	74%	1%	10%	15%
Music or singing	80%	1%	8%	11%
Conversation or talking on the phone	39%	<1%	20%	41%
Reading, writing or crossword puzzles*	38%	<1%	26%	36%
Spiritual or religious activities	48%	<1%	13%	39%
Cards, games, puzzles, bingo*	33%	<1%	23%	43%
Discussing/reminiscing about life	40%	<1%	17%	43%
Crafts or arts*	20%	<1%	25%	54%
Pets*	18%	<1%	25%	56%
Helping others*	8%	<1%	27%	65%
Feeding or watching birds*	12%	1%	14%	74%
Volunteering*	2%	<1%	22%	76%
Educational courses/meetings*	2%	<1%	15%	83%
Collecting*	1%	---	9%	90%
Genealogy*	2%	---	6%	92%
Computer activity*	1%	<1%	3%	96%

* n=998. Participated included involvement in the 3 days prior to the assessment and regular involvement but not in these 3 days. % of residents who participated in an activity = (% Participated and Preferred) + (% Participated but Not Preferred). % of residents who preferred an activity = (% Participated and Preferred) + (% Did Not Participate but Preferred).

- Very few residents were involved in **activities that they did not prefer** (Table 38).
- Some residents were **not involved in an activity that they preferred** (Table 38). Helping others (27%), reading, writing or crossword puzzles (26%), crafts or arts (25%), and pets (25%) were the activities most likely to be in this category. As discussed with regards to exercise/physical activity, this lack of involvement in preferred activities may reflect the resident's physical/cognitive functioning, the activity not being available in the LTC facility or at a time convenient for the resident to participate, or the lack of a partner with whom to participate.
- **Preferred activity locations** included their own room/apartment (79%), the day/activity room (80%), outdoors (57%) or away from the facility (44%) (all based on 999 residents). Only 2% would prefer a **change in location** of activities (based on 998 residents).
- Only 2% would like the **time of activities** changed (based on 998 residents).

Initiative and Involvement

- LTC residents exhibited varying levels of **initiative and involvement** in social relations (Table 39). Relatively few did not react positively to interactions initiated by others while 59% did not pursue involvement in the life of the facility.

TABLE 39. INITIATIVE AND INVOLVEMENT: LTC RESIDENTS

Action	% of LTC Residents (n=999)			
	Daily in Last 3 Days	1-2 Days of Last 3 Days	Present but Not in Last 3 Days	Not Present
Reacts positively to interactions initiated by others	50%	29%	7%	14%
At ease interacting with others	47%	24%	6%	23%
Initiates interaction(s) with others	24%	16%	8%	52%
At ease doing planned or structured activities	22%	28%	16%	33%
Accepts invitation(s) into most group activities	20%	28%	17%	35%
Pursues involvement in life of facility	15%	17%	9%	59%
Adjusts easily to change in routine	18%	3%	22%	57%

- Only 10% of residents were assessed as not having a **strong and supportive relationship with their family**. 10% had openly expressed conflict or anger with their family; this could not be determined for 8% of the residents (based on 999 residents).

- Considering **relationships with staff and other residents,** 56% were assessed as not being close to someone in the facility (resident or staff). Some residents experienced **conflict** with staff or other residents (based on 999 residents).
  - 26% had a conflict with or repeated criticism of staff.
  - 8% had a conflict with or repeated criticism of a roommate.
  - 17% had a conflict with or repeated criticism of a person other than a roommate.
  - 30% were reported by staff to be a persistent frustration when dealing with them.

- 34% of LTC residents were determined to have **low to no social engagement,** when considering the ease of interacting with others, pursuit of involvement in 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.

Clinical Assessment Protocols (CAPs): Social Life

- Information on the two **interRAI Clinical Assessment Protocols (CAPs) related to social life** is provided in Table 40.

TABLE 40. interRAI CLINICAL ASSESSMENT PROTOCOLS (CAPs) FOR SOCIAL LIFE: LTC RESIDENTS

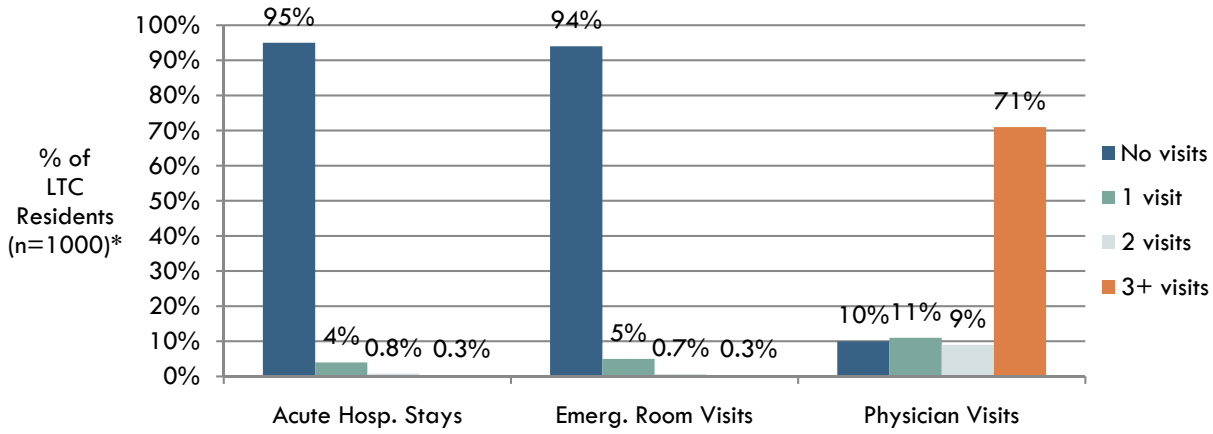
CAP	% of LTC Residents Triggering CAP (n=1000)
Activities CAP This CAP targets residents who have some cognitive reserve and have either withdrawn from or appear uneasy entering into activities and social relationships. The goal of specialized follow-up is to identify barriers and potential interventions for enhanced social activities, taking the residents' preferences into consideration. *Based on 998 residents.*	**40%**
Social Relationship CAP This CAP identifies individuals with characteristics indicative of or associated with reduced social relationships for whom an intervention may facilitate social engagement. *Based on 998 residents.*	**29%**

Note: The description of CAPs is from CIHI (2008).

Health Service Utilization

- 5% of LTC residents had at least one inpatient **acute care hospital visit** with an overnight stay in the 90 days prior to the assessment (Figure 72).

FIGURE 72. HEALTH SERVICE USE IN 90 DAYS PRIOR TO ASSESSMENT: LTC RESIDENTS



* Except for physician visits (n=999)

- 6% of LTC residents had at least one **emergency room visit** (not counting overnight stays) in the 90 days prior to the assessment, with a range from 0 to 4 visits (Figure 72).
- 90% of LTC residents had at least one **physician visit** in the 90 days prior to the assessment, with a range from 0 to 42 visits (Figure 72).

- 28% of residents had received **physiotherapy** in the 7 days prior to the assessment while 9% of residents had **occupational therapy**. Only 1% had **psychological therapy** by a licensed mental health professional or **speech-language pathology and audiology** in this time period.

- Other health services received by 10% or more of the residents at least once in the 3 days prior to the assessment included a scheduled toileting program (58%), turning/repositioning program (37%), wound care (18%), and oxygen therapy (10%).

1-Year Outcomes

Attention now turns to the situation of the LTC residents 1-year following their baseline assessment. Of interest is their **status at 1-year** and **changes in health and functioning**.

Status at 1-Year

- 69% of residents were still in LTC at the 1-year follow-up, with most remaining in the same LTC facility as at baseline (Table 41).

TABLE 41. STATUS AT 1-YEAR FOLLOW-UP: LTC RESIDENTS

Status	Number of LTC Residents	% of LTC Residents
Remained in LTC/equivalent	688	69%
• Same LTC	(656)	(66%)
• Different LTC	(32)	(3%)
Moved to a lower level of care		
• DAL	2	<1%
• PAL	1	<1%
• Lodge	1	<1%
Deceased	305	31%
Other*	2	<1%

* Other includes: moved out of province (n=1) and moved out of the country (n=1).

- Four residents **moved** to a setting where they received less care than that provided in LTC (Table 41).

- 31% of LTC residents **died** during the 1-year period.

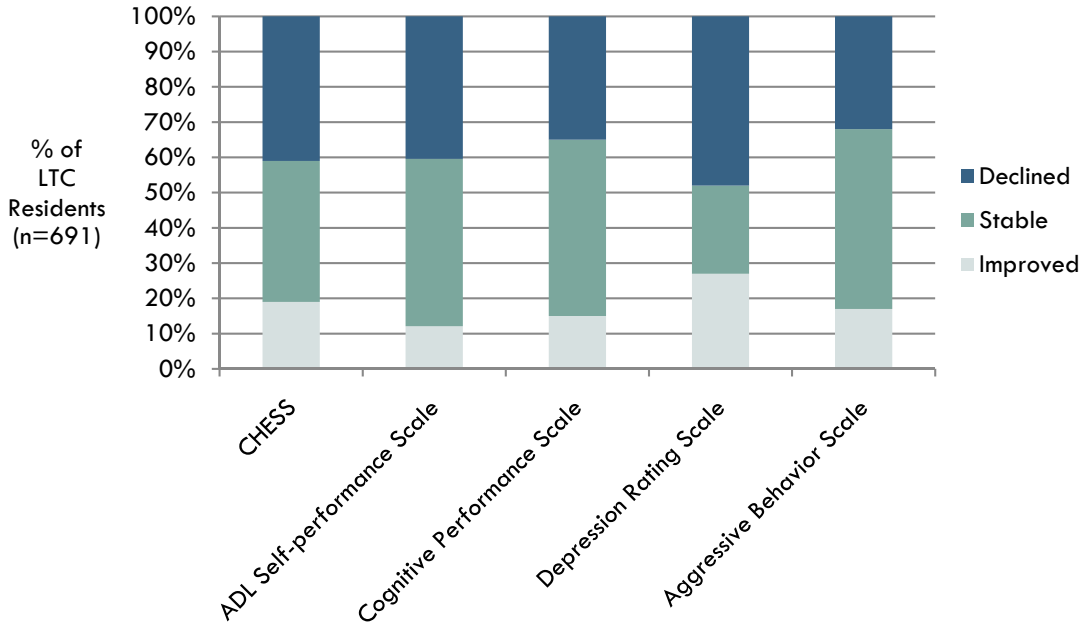
Changes in Health and Functioning

- **Changes in clinical issues as well as physical and cognitive/mental health functioning** at the 1-year follow-up were examined for the 691 residents who were assessed at baseline and follow-up, regardless of their location.

- As discussed earlier, **measuring change in this population is complex.** Attention here focuses on changes in scores on the key interRAI summary scales only. These scales are scored such that a higher score indicates poorer functioning. Three situations are considered: stable (score at baseline = score at follow-up), decline/poorer functioning (score at baseline lower than score at follow-up), and improvement/better functioning (score at baseline higher than score at follow-up). The magnitude of the change is not taken into account and a 1-point change on the scale is considered as change. For example, a resident whose CHESS score was 1 at baseline and 2 at follow-up would be categorized as experiencing a decline. Resident and facility characteristics that may explain and/or contribute to the change have not been taken into account.

- Considering first scores on the **interRAI Changes in Health, End-stage Disease and Symptoms and Signs (CHESS)** scale (Hirdes et al., 2003), 40% of the 691 LTC residents had the same score on this measure of clinical complexity and health at baseline and follow-up, 41% had higher levels of instability (i.e., decline) at follow-up, while 19% had lower levels of instability (i.e., improvement) (Figure 73).

FIGURE 73. CHANGES IN HEALTH STATUS: LTC RESIDENTS



- In terms of **physical functioning** as measured by the **interRAI Activities of Daily Living (ADL) Self-Performance Hierarchy Scale** (Morris et al., 1999), 40% of the residents showed a decline in their ability to independently perform ADLs, while 12% appeared more independent (Figure 73). The remaining 47% had no change in their scores.

- Turning to **cognitive functioning**, 35% showed a decline in cognitive function as measured by the **interRAI Cognitive Performance Scale (CPS)** (Morris et al., 1994; Hartmaier et al., 1995), while 15% exhibited an improvement (Figure 73). 50% scored the same at both time points.

- In terms of **depression** as measured by the **interRAI Depression Rating Scale** (Burrows et al., 2000), 25% were stable, 27% showed improvement, and 48% exhibited more depressive symptoms (Figure 73). In addition, 19% of residents showed signs of clinically important depressive symptoms at follow-up (score of 3+ on DRS) but not at baseline, while 8% did so at baseline but not at follow-up. 32% of the residents did not have a score of 3+ at either time point, while 41% did so at both time points.

- **Aggressive behaviours** increased for 32% of the residents and declined for 17%, as measured by the **interRAI Aggressive Behavior Scale** (Perlman & Hirdes, 2008) (Figure 73). The remaining 51% showed stability in their scores.

Summary

This profile has highlighted the situation of LTC residents, in terms of clinical issues, physical function, cognitive function and mental health, social and lifestyle characteristics, health service use, and 1-year outcomes. The complexity and diversity among residents is readily apparent.

On average, LTC residents had 5.2 disease diagnoses, with dementia, hypertension, arthritis, and depression being the most prevalent. The average number of regularly prescribed medications was 7.9 per resident. Generally, the residents received extensive assistance or were dependent with ADLs such as bathing, dressing, and toilet use.

Nine of 10 LTC residents exhibited some limitation in their cognitive skills for decision-making and 85% had some level of impairment in cognitive performance. Four of 10 residents had a documented clinical diagnosis of depression. Residents exhibited varying levels of social involvement, with social isolation being a concern for some residents.

At the 1-year follow-up, stability and change in clinical issues, physical function, and cognitive function/mental health among residents who were assessed at both time points were evident. During the year, 31% of LTC residents had died.

Attention now turns to the family caregivers who were assisting these LTC residents. Of particular interest is the nature and extent of their involvement and the impact of caregiving on the lives of these individuals.

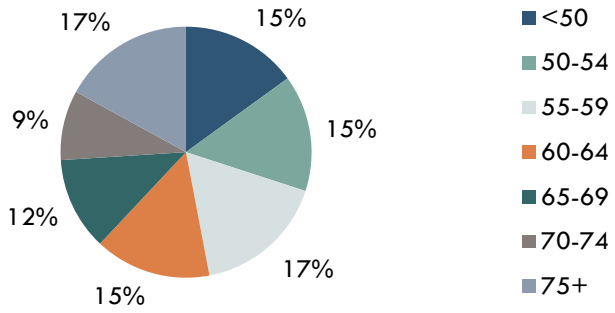
A PROFILE OF LTC FAMILY CAREGIVERS

In total, **917 individuals** were interviewed in their capacity as an informal caregiver of a LTC resident.[10] These individuals were identified as "the family member/friend who is the most involved and/or has the most information about the resident's experience in the long-term care facility". This profile focuses on **sociodemographic characteristics, visiting patterns, caregiving tasks,** the **effect of caregiving on employment, caregiver burden,** the **financial costs** to caregivers and residents, and **experiences at the time of the 1-year follow-up.** The topics discussed, format, and wording parallel those used when discussing the DAL family caregivers.

Sociodemographic Characteristics

- The LTC family caregivers ranged in **age** from 24 to 95, with an average age of 61.7 years (Figure 74).

FIGURE 74. 5-YEAR AGE GROUPS: LTC FAMILY CAREGIVERS



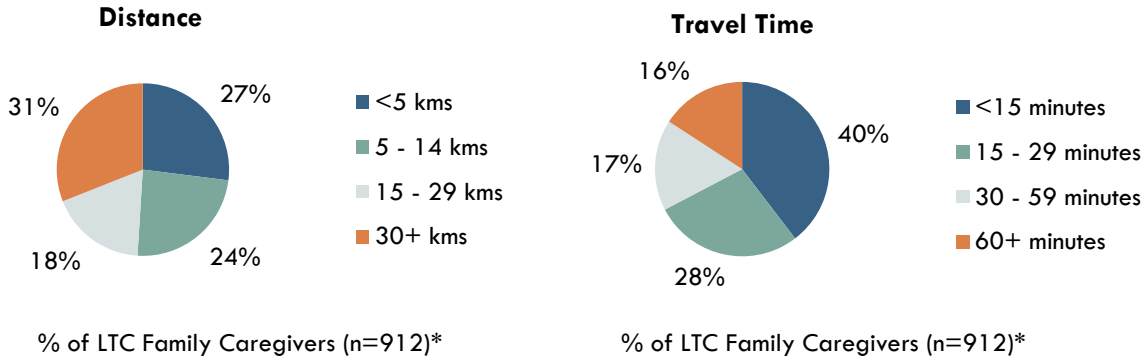
% of LTC Family Caregivers (n=911)

- 69% of the family caregivers were **female.**
- In terms of **marital status,** 78% were married, 10% were divorced/separated, 5% were widowed and 7% were never married.
- Caregivers were most likely to be **daughters** (40%) and **sons** (19%). Other caregivers included wives (12%), husbands (7%), sisters (4%), daughters-in-law (4%), nieces (2%), brothers (1%), granddaughters (1%), nephews (1%) and other family members (4%). Only 4% of the caregivers were friends/volunteers.

[10] Two caregivers completed a shortened interview as their family member died after the resident assessment was completed but before the caregiver interview was conducted. As a result, the total sample size varies from 915 to 917 depending on the specific question, unless otherwise noted. In some instances, respondents declined to answer a question. Percentages may not total 100% due to rounding.

- When asked "*Does the resident have any other helpers who are not paid (e.g., other family members)?*", 36% of the caregivers reported that there were no other **unpaid helpers**, 29% indicated one other helper, 19% identified two other individuals, and the remaining 16% reported three or more other helpers. The range was from 0 to 20.
- 8% of the caregivers indicated that there was no family member/friend who would **take over** their role of caring for the resident if they were not available while 4% stated that they did not know (based on 913 caregivers).
- 52% of the family caregivers were **employed**. Among the employed, 33% worked less than 35 hours per week.
- Family caregivers resided varying **distances from the resident** (Figure 75). **Travel time** ranged from one minute to 20 hours (Figure 75). One caregiver lived in the same facility as the resident.

FIGURE 75. DISTANCE AND TRAVEL TIME TO RESIDENT: LTC FAMILY CAREGIVERS

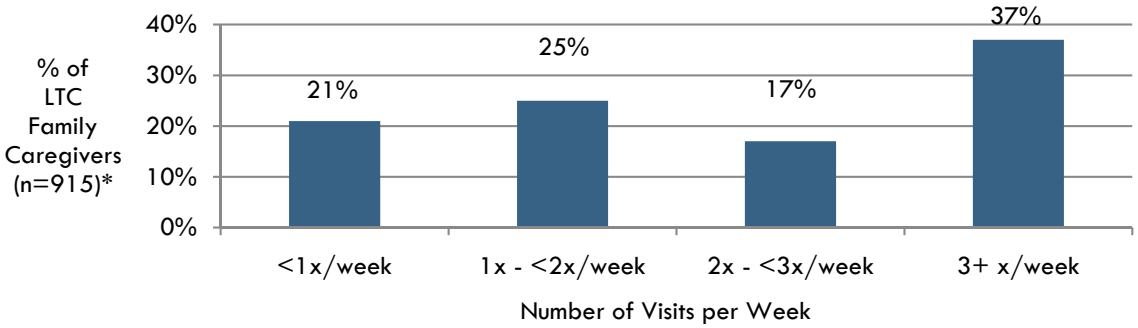


* Excludes 1 caregiver who lived in the same facility as the resident

Visiting LTC Residents

- 21% of the family caregivers reported **visiting the resident** less than once a week, while 37% visited at least 3 times per week (Figure 76). Caregivers who lived further away were more likely to have fewer visits than those who lived nearby.

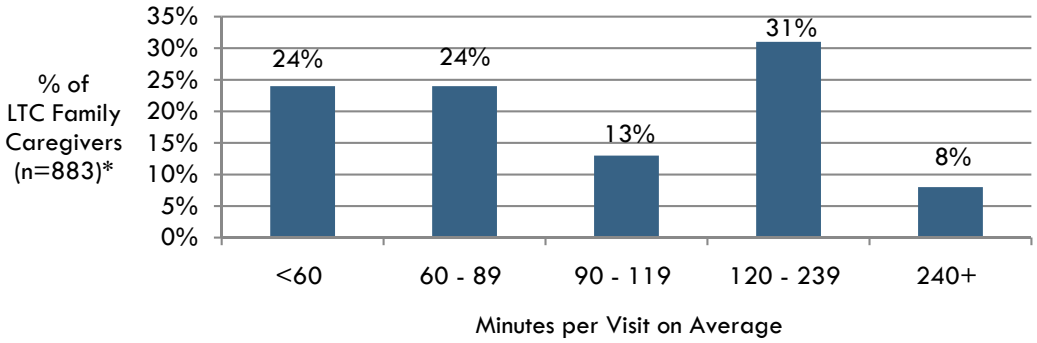
FIGURE 76. FREQUENCY OF VISITING: LTC FAMILY CAREGIVERS



* Excludes 1 caregiver who lived in the same facility as the resident

- The **length of the visits** varied from 5 minutes to 15 hours. Almost half (48%) visited for less than 90 minutes (Figure 77).

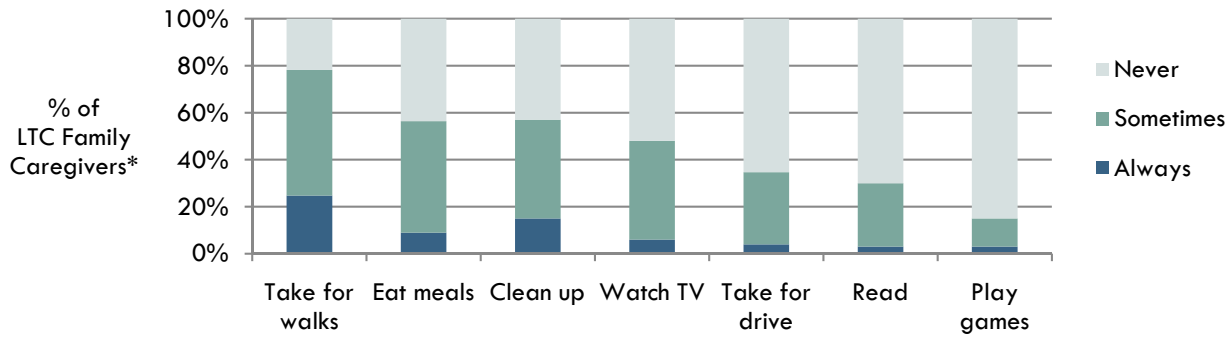
FIGURE 77. LENGTH OF VISIT: LTC FAMILY CAREGIVERS



* Excludes 1 caregiver who lived in the same facility as the resident, 1 who worked at the facility, 1 who did not visit, 1 who reported that the length varied by the day of the week, 1 who took the resident on overnight stays away from the facility, 23 who indicated long-stay visits as they had travelled a long distance, and 6 who did not know/respond

- Family caregivers were asked if they always, sometimes or never engaged in various **activities when visiting** (Figure 78). The percentage of caregivers who responded <u>always or sometimes</u> varied by activity.
  - 79% took the resident for walks around the facility (based on 916 caregivers).
  - 57% ate meals with the resident (based on 914 caregivers).
  - 57% cleaned up the resident's room (based on 913 caregivers).
  - 48% watched TV with the resident (based on 915 caregivers).
  - 35% took the resident for drives (based on 914 caregivers).
  - 30% read to the resident (based on 915 caregivers).
  - 15% played games with the resident (based on 915 caregivers).

FIGURE 78. ACTIVITIES WHILE VISITING: LTC FAMILY CAREGIVERS



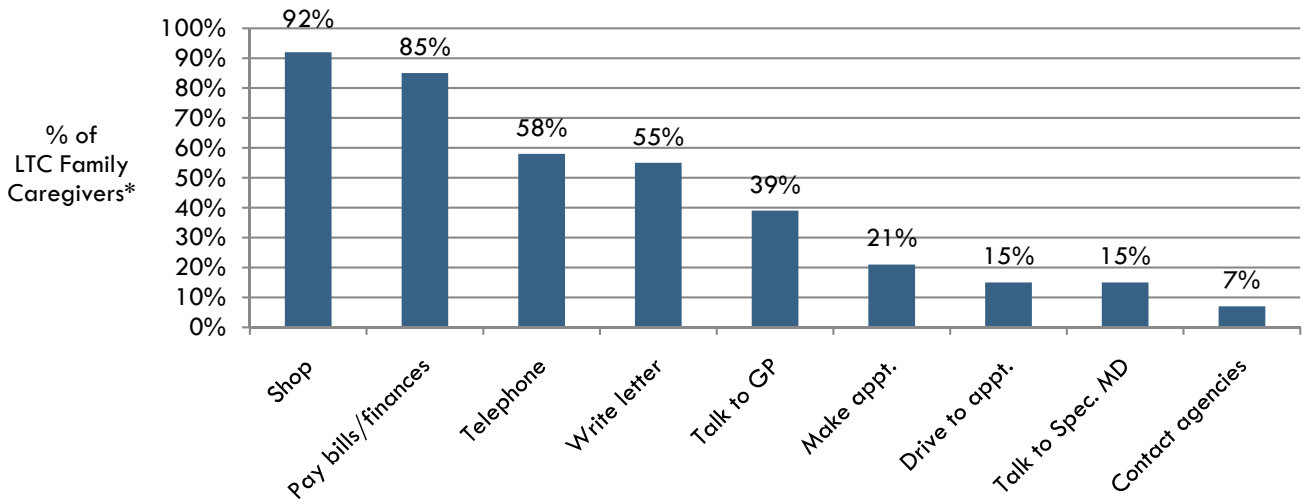
* n varies from 913 to 916 depending on the activity

- Family caregivers were given the opportunity to identify any **other activities** that they did with the resident; however, the frequency of the activity was not recorded. Activities mentioned included taking the resident out to a restaurant for meals/coffee (7%), taking the resident home or to another family member's home (6%), taking the resident to facility events/activities (6%), taking the resident shopping or running errands with the resident (4%), and taking the resident to family events/gatherings or to other events outside the facility (4%).

Caregiving Tasks

- In the 3 months prior to the interview, the majority of family caregivers **shopped for the resident** (92%) or **paid bills/managed finances** (85%) (Figure 79).

FIGURE 79. CAREGIVING TASKS IN PAST 3 MONTHS: LTC FAMILY CAREGIVERS



* n varies from 914 to 917 depending on the task

- About one-fifth of the family caregivers had **made appointments** for the resident (21%) or had **driven the resident to appointments** (15%) (Figure 79).

- Some family caregivers acted as a link to health care professionals, with 39% **talking to a family physician** about the resident, 7% **contacting another health care agency** for the resident, and 15% **talking to a specialist** about the resident (Figure 79).

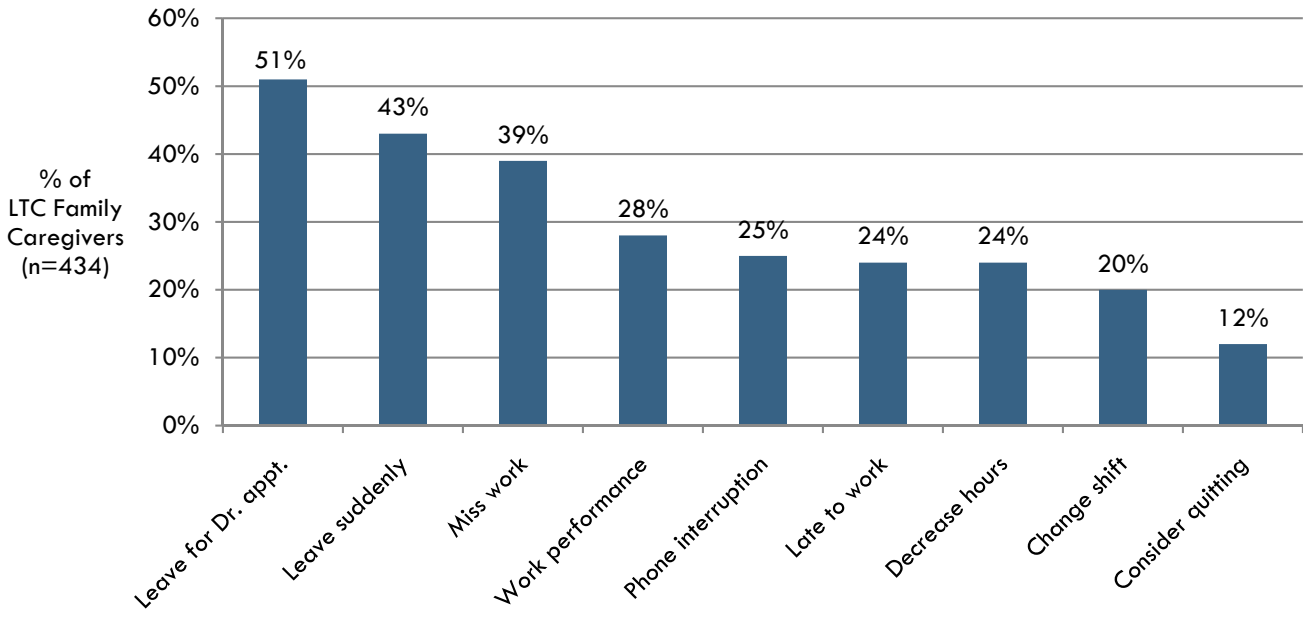
- 58% of caregivers had **telephoned** to see how the resident was doing while 55% had **written letters or called family or friends for the resident** (Figure 79).

Effects of Caregiving on Employment

- Employed family caregivers were asked whether their work had ever been affected in various ways because of caring for the resident (Figure 80).

- 51% of these employed caregivers indicated that they had to **leave work for the resident's appointments with doctors** (Figure 80).

FIGURE 80. EFFECTS OF CAREGIVING ON EMPLOYMENT: LTC FAMILY CAREGIVERS



Note: Less than 10% of employed caregivers reported the following: decline job advancement (8%), change jobs or employers (8%), increase hours worked (5%), or quit job (4%).

- 43% needed to **leave work suddenly** because of caring for the resident. 39% had **missed work** due to caregiving responsibilities and 24% had **come late to work** (Figure 80).
- Some caregivers indicated **a change in their work hours or shifts** (Figure 80).
  - 24% decreased the hours they worked.
  - 20% changed the shift they worked.
  - 5% increased the hours they worked.
- 28% felt that their **performance at work** was affected (Figure 80). Only 8% reported a **change in jobs or employers** because of caring for the resident; 8% had **declined job advancement**.
- While 12% had **considered quitting their job** due to caregiving responsibilities, only 4% reported that they had **quit a job** because of caring for the resident (Figure 80).
- 25% reported **frequent interruptions by phone calls** from/pertaining to the resident (Figure 80).

Caregiver Burden

- Caregiver burden was assessed by using the **Caregiver Reaction Assessment Scale (CRA)** (Given et al., 1992) (Table 42). The CRA examines 5 **domains** of the caregivers' lives, namely **disrupted schedules, financial problems, lack of family support, health problems,** and **the impact of caregiving on the caregiver's self-esteem**. Caregivers were read 24 statements and asked to indicate their level of agreement with the statement from strongly disagree (1) to strongly agree (5).

TABLE 42. CAREGIVER REACTION ASSESSMENT SCALE: LTC FAMILY CAREGIVERS

Item	Mean	SD	D	N	A	SA
Disrupted Schedule (n=905)	**2.49**					
My activities are centered around caring for (__). (n=913)	2.96	6%	41%	11%	33%	9%
I have to stop in the middle of work. (n=909)	2.27	22%	49%	10%	18%	1%
I visit family and friends less since I have been caring for (__). (n=914)	2.43	19%	50%	5%	22%	5%
I have eliminated things from my schedule since caring for (__). (n=913)	2.65	14%	48%	5%	28%	6%
The constant interruption makes it difficult to find time for relaxation. (n=912)	2.13	23%	58%	6%	12%	2%
Financial Problems (n=911)	**2.08**					
My financial resources are adequate to pay for things that are required for caregiving.* (n=912)	3.68	5%	12%	12%	52%	19%
Caring for (__) puts a financial strain on the family. (n=913)	1.96	25%	63%	4%	5%	2%
It is difficult to pay for (__)'s health needs and services. (n=914)	1.96	26%	62%	4%	6%	2%
Lack of Family Support (n=907)	**2.50**					
Others have dumped caring for (__) onto me. (n=914)	2.63	21%	36%	13%	19%	11%
It is very hard to get help from my family in taking care of (__). (n=911)	2.79	14%	38%	16%	21%	12%
My family works together at caring for (__).* (n=914)	3.32	8%	22%	15%	41%	14%
Since caring for (__), I feel my family has abandoned me. (n=913)	1.94	31%	52%	9%	6%	2%
My family (brothers, sisters, and children) left me alone to care for (__). (n=911)	2.49	20%	40%	18%	18%	5%
Health Problems (n=911)	**2.57**					
Since caring for (__), it seems like I'm tired all of the time. (n=913)	2.34	17%	55%	11%	14%	4%
My health has gotten worse since I have been caring for (__). (n=914)	2.18	24%	53%	6%	13%	4%
I have enough physical strength to care for (__).* (n=913)	3.70	4%	15%	4%	62%	16%
I am healthy enough to care for (__).* (n=913)	3.94	2%	8%	4%	67%	19%
Positive Self-Esteem (n=906)	**4.03**					
I feel privileged to care for (__). (n=913)	4.21	<1%	3%	12%	43%	41%
I resent having to take care of (__).* (n=913)	1.69	45%	46%	5%	4%	<1%
I really want to care for (__). (n=911)	4.22	<1%	4%	7%	52%	37%
I will never be able to do enough caregiving to repay (__). (n=912)	3.13	7%	26%	28%	27%	13%
Caring for (__) makes me feel good. (n=913)	4.15	<1%	3%	10%	55%	32%
Caring for (__) is important to me. (n=914)	4.44	<1%	<1%	2%	50%	48%
I enjoy caring for (__). (n=914)	4.02	1%	6%	12%	55%	27%

Note: Scores are 1 = Strongly disagree (SD), 2 = Disagree (D), 3 = Neither (N), 4 = Agree (A), 5 = Strongly agree (SA).
* indicates reverse coding is required when computing the scale score. High scores on all subscales except Positive Self-Esteem indicate negative reactions to caregiving; a high score on Positive Self-Esteem indicates a positive reaction to caregiving.

- In terms of a **disrupted schedule** due to caregiving, over one-third of the caregivers agreed or strongly agreed that their activities were centered around caring for the resident (42%) or they had eliminated things from their schedule since caring for the resident (34%) (Table 42).

- Related to **financial problems,** less than 10% of the caregivers agreed or strongly agreed that caring for the resident puts a financial strain on the family (7%) or it was difficult to pay for the resident's health needs and services (8%) (Table 42). 17% responded that their financial resources were not adequate to pay for the things required for caregiving.

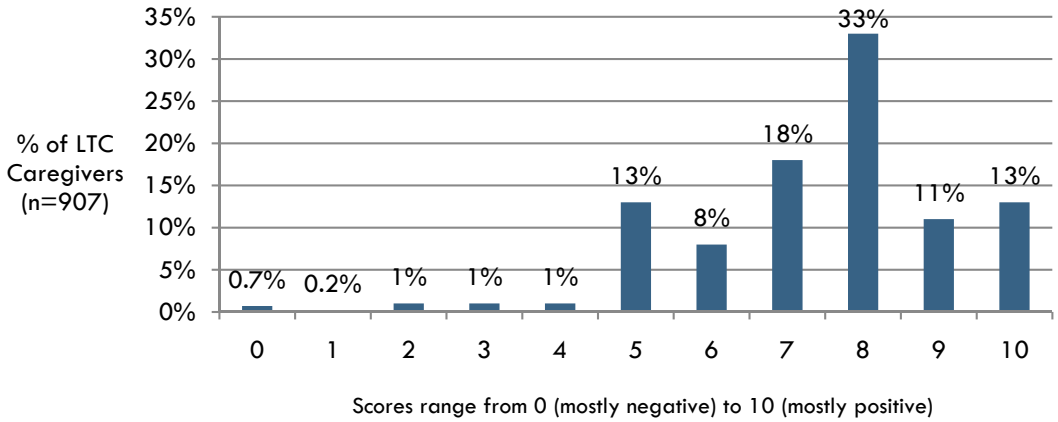
- Considering the **lack of family support**, some caregivers agreed or strongly agreed that others had dumped caring for the resident on them (30%), it was very hard to get help from family (33%), their family did not work together in caring for the resident (30%) or their family (brothers, sisters, children) had left them alone to care for the resident (23%) (Table 42). At the same time, only 8% agreed or strongly agreed that since caring for the resident, they felt their family had abandoned them.

- Turning to **health problems,** almost one-fifth of the caregivers agreed or strongly agreed that since caring for the resident, it seemed they were tired all the time (18%) or their health had worsened since they had been caring for the resident (17%) (Table 42). Only 10% perceived themselves as not healthy enough to care for the resident.

- In terms of the effect of caregiving on **self-esteem,** 84% of the caregivers indicated that they felt privileged to care for the resident while 89% agreed or strongly agreed with the statement "*I really want to care for the resident.*" (Table 42). Caring for the resident often made caregivers feel good (87%) or was viewed as important to the caregiver (98%). Only 5% resented having to take care of the resident while 7% indicated that they did not enjoy caring for the resident.

- 13% of the caregivers rated their caregiving **experience** as a 10 while 17% gave a rating of 5 or less, when asked "*On a scale of 0 to 10, how would you rate your experience as a caregiver to (__), with 0 being mostly negative and 10 being mostly positive?*" (Figure 81). The mean score was 7.4 while the median was 8.

FIGURE 81. RATING OF CAREGIVER EXPERIENCES: LTC FAMILY CAREGIVERS



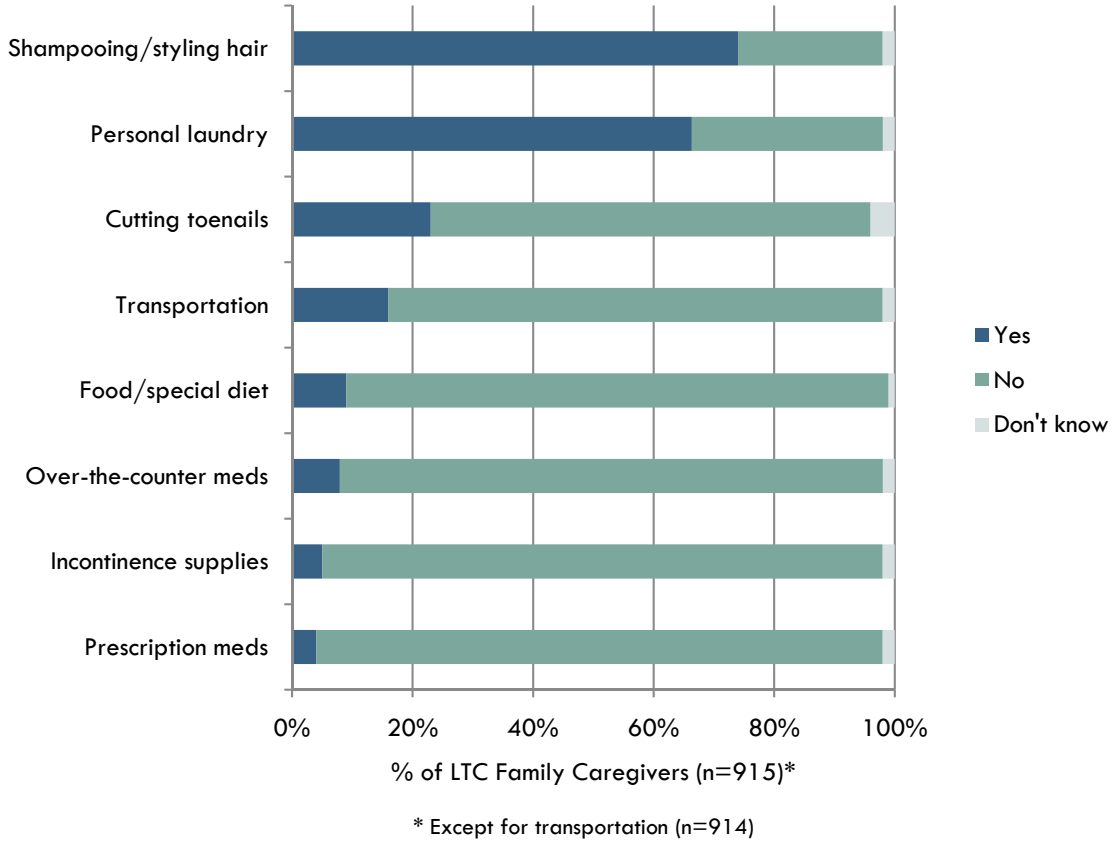
Financial Costs to Caregivers and Residents

- 90% of LTC family caregivers indicated that they handled the **payment to the facility** or were aware of the monthly charges. Responses to a question regarding the amount of the current monthly base rate ranged from $800 to $3500 per month; 4% of the 816 caregivers gave an amount of less than $1200 while 3% reported it was greater than $1600. The range reported by facility representatives was from $1261 to $1542 per month for base fees.

- 73% of the 804 LTC caregivers indicated that the **current monthly charges,** including any extras, were about what they expected when the resident moved to the facility. 21% reported that the fees were higher than they expected while 5% indicated lower fees than expected.

- Family caregivers were asked "*During the last month, have you, the resident, or other family members purchased any of the following services or supplies for which there is an additional charge or cost (that is, over and above the regularly monthly rate charged by the facility)?*" Some caregivers did not know if these costs were incurred (Figure 82). Other caregivers were unable to provide a dollar figure but knew purchases had been made.

FIGURE 82. ADDITIONAL MONTHLY CHARGES: LTC FAMILY CAREGIVERS



* Except for transportation (n=914)

- **Shampooing/styling hair** was identified as a cost by 74% of the caregivers (Figure 82).
- 67% of the caregivers indicated that there were costs for **personal laundry** (Figure 82).
- 23% reported costs for **cutting toenails** (Figure 82).
- 16% reported additional costs for **transportation** while 9% indicated that **extra food** was purchased for the resident (Figure 82).
- Only 4% of the family caregivers indicated that there were additional costs incurred for **prescription medications**, 8% reported costs for **over-the-counter medications**, and 5% had purchased **incontinence supplies** (Figure 82).
- Other costs that 10% or fewer of the caregivers reported were private duty attendant/sitter (10%) and incontinence service (<1%). In addition, when asked to identify other monthly charges, 13% of the caregivers mentioned the purchase of toiletries.
- 16% of the caregivers indicated that, in the past year, there had been 1-time only costs for **personal aids** such as walkers or wheelchairs.

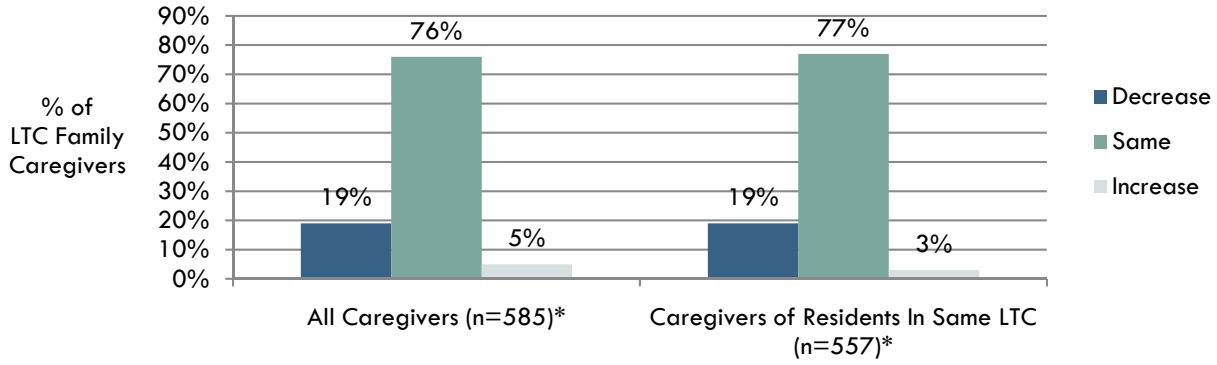
Experiences at 1-Year Follow-up with Residents

- At the time of the 1-year follow-up, 31% of 917 caregivers experienced the death of the resident.
- Of the 636 caregivers involved with a resident who was still alive, 586 agreed to a follow-up interview (see Wanless et al., 2011 for further details).
    - 95% were caring for a resident who resided in the same LTC facility.
    - 4% were involved with individuals who had moved to another LTC facility.
    - 1% were caring for residents who had moved to other locations (DAL (n=1), PAL (n=1), lodge (n=1), geriatric psychiatric facility (n=1) and out of province (n=1)).

Visiting

- Caregivers were asked "*During the last year, would you say that there has been an increase, decrease, or the same amount of visits?*" Among 585 caregivers, 76% reported **no change**, 5% indicated that there had been an **increase in the amount of visits**, while 19% perceived that there had been a **decrease** (Figure 83).
- Only 3% of caregivers of residents in the same LTC indicated that there was an **increase in their visits** (Figure 83). Among the 28 family caregivers of residents who had moved to another location, nine reported an increase in visits, while five perceived a decrease.

FIGURE 83. SELF-REPORTED CHANGES IN AMOUNT OF VISITING IN LAST YEAR: LTC FAMILY CAREGIVERS



* Excludes 1 caregiver who lived in same facility as resident

- Some caregivers explained that increased **care needs** of the residents necessitated an increase in visits while, for others, the resident's declining health and lack of recognition had resulted in decreased visits. Some discussed their own **declining health** or the **work/family demands** that they had.
- For some caregivers of residents who had moved to another location, **distance** was a factor.

Family Caregivers

I used to go 3 times a week. She doesn't need me anymore and often doesn't know it's me.

She has arthritis in her hands and can't see. I help her with meals so she doesn't have to struggle as much.

I'm too busy with a job and grandchildren.

I was getting worn out. Every other day seems okay.

She is further away. It is very hard to get there because of my other responsibilities.

He lives close now.

Caregiver Burden

- At follow-up, family caregivers again were asked to complete the **Caregiver Reaction Assessment Scale (CRA)** (Given et al., 1992). Baseline and follow-up scores on the 5 sub-scales were compared first for all caregivers and then separately for caregivers of residents who remained in the same LTC (Table 43). Separate comparisons for caregivers of residents who moved to other locations were not possible, given the small number of caregivers in this group.
- Among **all caregivers**, the only significant difference was for **health problems**, with slightly higher scores at follow-up than at baseline (Table 43). This suggests more challenges with caregiving at follow-up due to the caregivers' own health. Assessments regarding disrupted schedules, financial problems, the lack of family support, and positive self-esteem were fairly consistent over time.
- Among caregivers of residents who were in the **same LTC facility**, a significant difference in the ratings for **financial problems** emerged, suggesting that financial issues had increased over time (Table 43).

TABLE 43. CAREGIVER REACTION ASSESSMENT AT BASELINE AND FOLLOW-UP: LTC FAMILY CAREGIVERS

Sub-scale	All Caregivers		Caregivers of Residents Still in Same LTC	
	Mean (Base)	Mean (FU)	Mean (Base)	Mean (FU)
Disrupted Schedule	2.48	2.44	2.47	2.44
Financial Problems	2.11	2.16	2.10*	2.17*
Lack of Family Support	2.50	2.47	2.49	2.46
Health Problems	2.56*	2.61*	2.58	2.61
Positive Self-Esteem	4.03	4.03	4.04	4.05

Note: FU=Follow-up. * denotes statistically significant differences at p<.05 based on paired t-tests. n varies from 577 to 584 for all caregivers and from 549 to 556 for caregivers of residents still in same LTC. Possible scores range from 1 = Strongly disagree to 5= Strongly agree. High scores on all subscales except Positive Self-Esteem indicate negative reactions to caregiving; a high score on Positive Self-Esteem indicates a positive reaction to caregiving.

- The overall pattern is one of relative stability in the reaction to caregiving. Further exploration of the financial problems faced by caregivers of residents in the same LTC in particular is warranted.

Summary

This profile of LTC family caregivers has highlighted the involvement of these individuals in the lives of many residents. The majority of caregivers visited at least once a week, shopped for the resident, and paid bills/managed finances. Relatively few made appointments for the resident and took him/her to these appointments, reflecting the availability of services within LTC. Some caregivers and residents reported that additional costs were incurred for hair care and personal laundry. Costs for other items such as prescription medications, incontinence supplies, and foot care were often covered as part of the base fee. There were caregivers who visited relatively infrequently and provided limited assistance to the resident.

The impact of caregiving on the caregivers varied. For some employed caregivers, 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. While some caregivers reported negative reactions to caregiving, such as disrupted schedules, financial problems, a lack of family support, or health problems, most caregivers indicated that caring for the resident had a positive effect on their self-esteem and rated the experience positively.

At the 1-year follow-up, three-quarters reported no change in the amount they visited, 5% felt that their visits had increased while 1in 5 indicated a decrease. Increased care needs, the caregiver's own health, and distance all appeared to be related to these changes. No single pattern of change in caregiver burden was evident, highlighting the diversity of caregiving experiences.

Attention now turns to family caregivers' views about LTC. Of interest is their assessment of LTC staff, services and the environment, and policy.

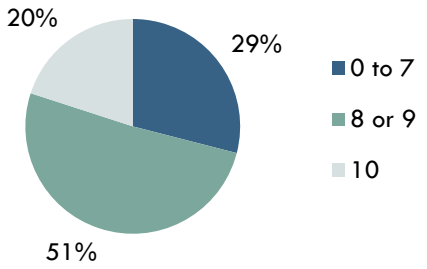
CAREGIVERS' VIEWS ABOUT LTC

LTC family caregivers were asked to assess the LTC facility and the care/support provided. Attention here focuses on their views regarding **staff, services and the environment**, and **policy** as well as their **overall rating** of the facility and **recommendation to others**. Unlike in DAL where both residents and caregivers were asked these questions, only the views of the 917 family caregivers were obtained.[11] Once again, some questions are from the NHCAHPS survey (Sangl et al., 2007). In some instances, caregivers were asked to rate the facility on a scale of 0 (worst possible) to 10 (best possible). Three groupings of scores are examined: 0-7, 8-9, and 10, following CAHPS guidelines (see www.cahps.ahrq.gov for further information). Some questions were asked only of LTC caregivers so there is no comparable information for the DAL caregivers, and vice versa.

Views about Staff

- LTC family caregivers were generally positive in their assessment of staff although room for improvement was evident.
- When asked "*Overall, what number would you use to rate the care you get from staff?*", 20% of 914 family caregivers scored the facility as a 10, on a scale from 0 (worst possible) to 10 (best possible (mean=8.1) (Figure 84).

FIGURE 84. OVERALL RATING OF CARE: LTC FAMILY CAREGIVERS



% of Family Caregivers (n=914)

Scores range from 0 (worst possible) to 10 (best possible)

- Similar to DAL family caregivers, concern about **staff shortages and staff turnover** was a recurrent theme in the interviews with LTC family caregivers. This emerged in response to questions about disadvantages of the facility and explanations about satisfaction with various services. When asked at follow-up about changes in staffing over the past year, several caregivers mentioned staff turnover/shortage. There were differing views with respect to the impact of quality of care.

[11] The sample size is 917 unless otherwise noted. In some instances, respondents declined to answer the question. Percentages may not total 100% due to rounding.

Family Caregivers

Short staffed and the staff are not well trained, not well supervised. Many staff are newcomers with accents which are difficult for seniors to understand.

There's a large staff turnover and not enough staff to take care of specific resident needs. RNs are replaced by LPNs with a lack of knowledge regarding resident care needs.

Lots of time he's in bed. If they had more nursing staff, maybe he'd be up more – if they took the time to talk him into it.

- Caregivers were asked to indicate the extent of their agreement with 8 statements reflecting different **ways that facilities involve families** in the care of the residents (Reid, Chappell, & Gish, 2007) (Table 44).

TABLE 44. PERCEIVED FAMILY INVOLVEMENT: LTC FAMILY CAREGIVERS

Involvement	% of LTC Caregivers			
	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree
I have been asked about my family member's personal history. (n=896)	12%	11%	30%	47%
I have been asked about my family member's preferences and values. (n=890)	11%	14%	32%	43%
Staff have helped me to understand how health concerns affect my family member. (n=904)	15%	14%	34%	37%
I have been asked to bring in pictures, letters, and other personal items to teach staff about my family member. (n=897)	20%	19%	24%	37%
I feel like I am involved in decision-making about my family member's care. (n=907)	10%	11%	32%	47%
I am informed about changes in my family member's care plan. (n=909)	14%	15%	27%	44%
The facility holds family information meetings. (n=895)	10%	9%	29%	52%
I trust the staff members at this facility. (n=906)	3%	6%	29%	63%

Family caregivers were asked "*I have some statements about different ways facilities involve families in the care of residents. I will read each statement and then please tell me whether you agree or disagree that this describes the facility where (__) lives.*"

- 39% of 897 family caregivers strongly or somewhat disagreed that they had been asked to **bring in pictures, letters, and other personal items** to teach staff about their family member (Table 44).
- 19% strongly or somewhat disagreed with the statement that the facility holds **family information sessions** (Table 44).
- 92% of the family caregivers strongly or somewhat agreed with the statement "*I trust the staff members at this facility*" (Table 44).

Views about Services and the Environment

- LTC family caregivers expressed similar **concerns regarding facility living** as the DAL caregivers. The concerns generally fell under the following themes:
  - Concerns regarding **care in general**
  - Concerns about the **resident's emotional well-being**
  - Concerns about **opportunities for social interaction and activities** for the resident
  - Concerns about **diet and food choices**
  - Concerns about the **physical environment**
  - **Lack of support** from the facility and/or **poor communication**
  - **Costs**

Family Caregivers

The nursing care is not consistent and it's hard to communicate with the senior nursing staff.

It's hard to see her when she is low and I am at work.

They don't have a lot of activities. They don't encourage her to do her crafts and to use her brain.

I think the building could be better equipped for people with dementia – they have no nice places to visit in the building. They have nothing for them to do.

The few activities that are offered are juvenile and I find that disturbing. The rooms are extremely small, dark and very depressing. Her oxygen is often not filled on time. It is very difficult to find staff and the call bells aren't answered immediately or even in a timely fashion.

- Family caregivers' **satisfaction ratings with services** highlight several areas for improvement. While some caregivers were very satisfied, many were mostly satisfied, not satisfied or quite dissatisfied (Table 45). Of particular note were concerns regarding **meals/food, toileting, oral care, bathing, dressing, hair care,** and **housekeeping/cleaning**.

- 40% of 897 caregivers were very satisfied with the **meals/food** while 43% were mostly satisfied, 14% were not satisfied, and 3% were quite dissatisfied (Table 45). Examples of their comments included "*no variety in the meals*" and "*lack of fresh fruits and vegetables*".

- In terms of **toileting,** 41% of 848 caregivers were very satisfied, 41% were mostly satisfied, 14% were not satisfied and 4% were quite dissatisfied (Table 45). Concerns were expressed about the **length of time the resident had to wait for assistance** and **the lingering smell of urine.**

Family Caregivers

She shouldn't go by herself but she does. She has sat on the toilet for 30 minutes before someone came after she rang.

She is often very wet and smelly. We have had to ask the staff to change her more often.

There's not enough staff. Long waits lead to incontinent episodes.

TABLE 45. SATISFACTION WITH SERVICES RECEIVED/USED BY RESIDENTS: LTC FAMILY CAREGIVERS

Service Received/Used as Reported by Family Caregivers	% of LTC Caregivers			
	Very Satisfied	Mostly Satisfied	Not Satisfied	Quite Dissatisfied
Services received/used by >50% of residents				
Assistance with medications (n=898)	65%	32%	3%	<1%
Nursing care (blood pressure, dressings) (n=890)	59%	35%	4%	2%
Foot care/podiatry in facility (n=645)	54%	40%	4%	1%
Housekeeping/cleaning (n=914)	52%	39%	8%	1%
Personal laundry (n=815)	51%	38%	9%	2%
Hair care (brushing, shampooing, etc.) (n=883)	48%	42%	9%	2%
Dressing (n=886)	47%	45%	8%	1%
Bathing (n=906)	41%	37%	18%	4%
Oral care (n=669)	41%	42%	13%	3%
Toileting (n=848)	41%	41%	14%	4%
Meals/food (n=897)	40%	43%	14%	3%
Services received/used by 10% - 50% of residents				
Counseling from social work/clergy in facility (n=175)	66%	32%	2%	---
Occupational therapy in facility (n=237)	55%	38%	6%	2%
Physiotherapy in facility (n=303)	47%	39%	12%	2%

Family caregivers were asked *"Many services are available to help residents in the facility. My questions are about some of those services. Has (__) received/used this service in the last month? If received/used, how satisfied are you with the quantity and quality?"* The n varies as responses are based only on family caregivers caring for residents who received/used that specific service. Satisfaction ratings are not provided on services for which <10% of the caregivers reported that the resident received/used in the facility including speech/language therapy and mental health/psychological counseling.

- **Bathing** was an area needing improvement, with 37% of the 906 caregivers mostly satisfied, 18% not satisfied and 4% quite dissatisfied (Table 45). The issue was primarily with regards to the resident having **only one bath a week**.
- With regards to **housekeeping/cleaning**,
  - 52% of 914 caregivers were very satisfied, 39% were mostly satisfied, 8% were not satisfied and 1% were quite dissatisfied (Table 45).
  - When asked to rate the **cleanliness** throughout the facility, 20% of 915 family caregivers gave the facility 10 out of 10 (mean=8.2) (Figure 85).

Family Caregivers

The bath and personal hygiene is not as good as it should be. Once a week is not often enough.

I wish there were more baths. She doesn't stay very fresh because of incontinence.

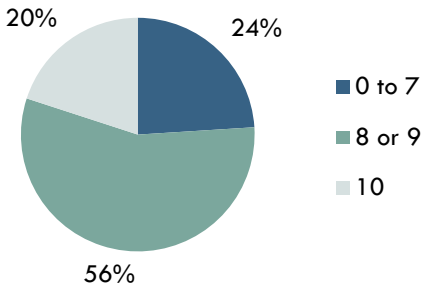
Family Caregivers

There's times when the place reeks of urine.

The bathroom could use more cleaning and tidiness of the room.

I think they are too short of staff. Basic cleaning is not done. I always have to clean his room.

FIGURE 85. RATING OF CLEANLINESS: LTC FAMILY CAREGIVERS



% of Family Caregivers (n=915)

Scores range from 0 (worst possible) to 10 (best possible)

Views about Policy

- Family caregivers were often unclear or unaware of any policy regarding moves from long-term care. They were asked "*Does the facility have policies about the **conditions under which residents will be asked to leave the facility** or be transferred elsewhere, or what care needs it will not be able to accommodate?*" and "*How clear do you think those policies are?*". Among the 912 who responded,
  - 23% **did not know** if a **policy about when a move would be necessary** existed.
  - 43% stated that there was **no policy**.
  - 6% indicated that the policy was **very unclear** (no policies were specified or they vary from resident to resident).
  - 9% reported that the policy was **somewhat unclear** (I know they have policies but the conditions are vague).
  - 12% indicated that the policy was **fairly clear** (I have a general idea of when the facility discharges a resident).
    7% indicated that the policy was **very clear** (the policies are written and were clearly explained to me and other family members).

- There tended to be greater clarity about the facility's **policies about the fees** (what is covered in the basic monthly rate and what is extra or what level of care is covered and what is not). Among the 826 caregivers who handled payment to the facility or were aware of the monthly charges and answered this question,
  - <1% indicated that they **did not know** about a policy about fees.
  - 4% reported that the policy was **very unclear**.
  - 3% reported that the policy was **somewhat unclear**.
  - 16% indicated that the policy was **fairly clear**.
  - 77% indicated that the policy was **very clear**.

- When asked "*How comfortable would you be* ***expressing concerns or dissatisfaction with some aspect of the facility to the administrator*****?",**
  - 74% indicated that they would be very comfortable.
  - 17% would be fairly comfortable.
  - 7% would be somewhat uncomfortable.
  - 2% would be very uncomfortable.
  - <1% indicated that they did not know.

Perceived Advantages and Overall Ratings

- Despite concerns about the care of their family member and similar to the DAL family caregivers, the LTC family caregivers often identified **advantages** for the resident and/or themselves including:
  - The supervision/security/safety and/or care provided by staff;
  - The companionship that their family member has with other residents;
  - Their feeling of peace of mind and/or less stress; and,
  - Personal freedom or increased time for themselves.

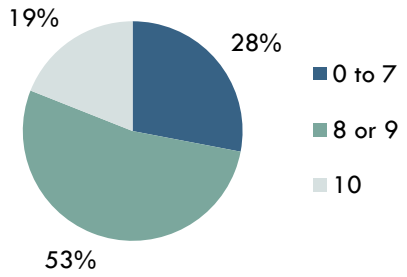
Family Caregivers

I cannot imagine how difficult it would be if the facility were not here. We would have to do 20 hours of work day in and day out. It's given us a life.

I'm happy with her care. I couldn't handle her in my home. I don't have that worry.

- When asked "*Overall, what number would you use to rate this facility*?", with 0 being the worst possible and 10 being the best possible, 19% of 911 caregivers gave the facility 10 out of 10 (mean=8.1) (Figure 86).

FIGURE 86. OVERALL RATING OF FACILITY: LTC FAMILY CAREGIVERS



% of Family Caregivers (n=911)

Scores range from 0 (worst possible) to 10 (best possible)

- In response to the question "*Would you recommend this facility to others?*", 71% of 916 family caregivers answered "definitely yes" (Table 46).

TABLE 46. RECOMMENDATION OF FACILITY: LTC FAMILY CAREGIVERS

Recommendation of Facility to Others	% of LTC Family Caregivers (n=916)
Definitely yes	71%
Probably yes	22%
Probably no	4%
Definitely no	3%

Summary

Family caregivers had mixed views on the LTC facilities, indicating areas for improvement. At the same time, many would recommend their facility to others.

Attention now turns to a comparison of DAL and LTC. Of interest is the extent to which there are similarities and differences in the characteristics of the facilities, residents and family caregivers.

A COMPARISON OF DAL AND LTC FACILITIES, RESIDENTS, AND FAMILY CAREGIVERS

This brief **comparison** of selected characteristics of DAL and LTC facilities, residents, and family caregivers is based on the descriptive information presented earlier.[12] It represents an initial examination of similarities and differences between the two settings.

DAL and LTC Facilities

Several characteristics of the DAL and LTC facilities are considered, including **ownership and size, admission criteria, services provided/arranged,** and **fees.**

Ownership and Size

- DAL facilities were more likely to have **non-profit** or **for-profit ownership** and less likely to be owned by the health region than the LTC facilities (Table 47).

TABLE 47. OWNERSHIP AND SIZE: DAL AND LTC FACILITIES

Characteristic	DAL Facilities	LTC Facilities
Ownership		
Non-profit	59%	44%
For-profit	36%	26%
Health region	5%	30%
Size of facility (all spaces)		
Mean (range)	108 (10-507)	134 (20-502)
Number of DAL/LTC spaces		
Mean (range)	32 (8-104)	111 (15-502)
% of facility's spaces allocated to DAL/LTC		
<50%	74%	9%
50% - 74%	5%	19%
75% - 99%	10%	13%
100%	10%	59%
Dementia spaces identified by facility representatives		
% of facilities with spaces	47%	50%
Number of spaces per facility (range)	4-40	11-156

Note: See earlier sections for sample sizes and additional information.

- The average **size of the entire facility,** taking all levels of care into account, was 108 spaces for DAL facilities and 134 for LTC facilities (Table 47). For setting-specific spaces, the average size was 32 for DAL and 111 for LTC.

[12] Total sample sizes are 59 DAL and 54 LTC facilities, 1089 DAL and 1000 LTC residents, and 974 DAL and 917 LTC family caregivers. In some instances, respondents declined to answer a question. Information on sample sizes for specific items is provided in earlier sections.

- 59% of LTC facilities had **LTC-only spaces,** compared to 10% of DAL facilities that had **DAL-only spaces** (Table 47).
- About one-half of the DAL and LTC facilities had **dementia spaces** as identified by facility representatives (Table 47). These spaces accounted for 25% of the DAL spaces in the 59 DAL facilities and 18% of the spaces in the 54 LTC facilities.

Admission Criteria

- In general, DAL and LTC facilities differed in the likelihood of **unequivocally admitting residents** with mobility issues, cognitive/behavioural issues, and feeding issues (Table 48). Only admission criteria are presented as similar patterns were evident for retention (see Tables 3 & 27).

TABLE 48. ADMISSION CRITERIA: DAL AND LTC FACILITIES

Criterion	DAL Facilities	LTC Facilities
% of facilities that unequivocally admitted a resident		
Mobility issues		
Is bedfast	10%	96%
Is chairfast	19%	98%
Uses a wheelchair to get around inside	85%	100%
Uses a scooter/mechanized wheelchair	59%	59%
Needs 1-person assistance with transfers	86%	100%
Needs 2-person transfers	14%	100%
Needs mechanical lift	15%	100%
Cognitive/behavioural issues		
Has a recent history of psychiatric hospitalization	19%	72%
Wanders	34%	89%
Is an elopement risk	25%	74%
Engages in verbally aggressive behaviours	15%	89%
Engages in physically aggressive behaviours	7%	37%
Engages in socially inappropriate behaviours	9%	85%
Resists nursing care or ADL care	48%	96%
Has severe memory of judgment problems	49%	98%
Continence issues		
Lacks bladder control, can manage supplies	98%	100%
Lacks bladder control, needs help to manage	92%	100%
Lacks bowel control, can manage supplies	97%	100%
Lacks bowel control, cannot manage	54%	100%
Feeding issues		
Requires assistance with feeding	22%	100%
Requires tube feeding	20%	96%

Note: See earlier sections for sample sizes and additional information.

- Virtually all DAL and LTC facilities would unequivocally admit individuals with **bladder incontinence** that could be self- or staff-managed or with **bowel incontinence** that could be self-managed. Only 54% of DAL facilities would unequivocally admit an individual who lacked bowel control and could not self-manage compared to all LTC facilities (Table 48).

- Few DAL facilities reported a willingness to unequivocally admit individuals with significant **mobility and cognitive/mental health care needs** while most LTC facilities did so (Table 48).

Services Provided/Arranged and Fees

- Some differences in services and fees between DAL and LTC existed (Table 49).

TABLE 49. SERVICES PROVIDED/ARRANGED AND FEES: DAL AND LTC FACILITIES

Service	DAL Facilities	LTC Facilities
LPN/RN coverage 24/7		
Neither	49%	---
LPN only	44%	---
RN only	5%	65%
Either LPN or RN	---	2%
Both LPN and RN	2%	33%
Health and wellness services offered as part of base fee (% yes)		
Assistance with bathing	95%	100%
Assistance with dressing	98%	100%
Hair care (brushing/shampooing)	98%	100%
Assistance with locomotion	98%	100%
Assistance with toileting	98%	100%
Oral care	97%	100%
Nursing care (blood pressure, dressing)	73%	100%
Administration of medications	88%	100%
Incontinence supplies	5%	82%
Physiotherapy in facility	19%	98%
Occupational therapy in facility	15%	98%
Speech/language therapy in facility	15%	82%
Foot care in facility	7%	41%
Mental health/psych counseling in facility	20%	96%
Social work/clergy counseling in facility	46%	100%
Transportation to medical/dental appointments	19%	43%
GP formally affiliated with facility (% yes)	34%	98%
Hospitality services offered as part of base fee (% yes)		
Breakfast	90%	100%
Lunch	90%	100%
Dinner	100%	100%
Snacks	100%	100%
Escorts to meals	90%	100%
Meals delivered to resident's room	75%	100%
Special diets	78%	100%
Housekeeping/cleaning	90%	100%
Towels/bedding laundry	92%	100%
Personal laundry	27%	---
Personal response system	85%	100%
Planned recreational activities	73%	98%
Exercise/health program	92%	100%
Transportation to social activities	27%	35%
Monthly base fees (range)	$800 - $2650	$1261 - $1542

Note: See earlier sections for sample sizes and additional information.

- Consistent with the policy differences regarding the availability of **professional nursing care,** LPN/RN coverage 24/7 differed between DAL and LTC (Table 49). 46% of DAL facilities and 33% of LTC facilities had licensed practical nurses (LPNs) on site 24/7. 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.

- In terms of **health and wellness services provided/arranged as part of the base fee,** DAL and LTC facilities provided assistance with personal care, locomotion, toileting, and oral care (Table 49). Differences were apparent in terms of incontinence supplies, therapies in the facility (PT, OT, SLP), counseling services, and transportation to medical/dental appointments, with DAL less likely to offer these services than LTC.

- Virtually all LTC facilities (98%) reported having **GPs formally affiliated** with the facility compared to 34% of the DAL facilities (Table 49).

- Considering **hospitality services provided/arranged as part of the base fee,** about three-quarters of the DAL facilities provided special diets and meal delivery to the resident's room, and planned recreational activities while virtually all LTC facilities did so (Table 49). 10% of the DAL facilities did not provide breakfast and lunch. No LTC facility and 27% of the DAL facilities reported that personal laundry was covered as part of the base fee.

- 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%).

- **Monthly base fees** varied and were generally higher in DAL than in LTC (Table 49).

DAL and LTC Residents

Several characteristics of the DAL and LTC residents are compared, including **sociodemographic characteristics, clinical issues, physical functioning, cognitive function and mental health, social and lifestyle characteristics, health service use,** and **1-year outcomes.**

Sociodemographic Characteristics

- There was no difference in the average **age** of DAL residents (84.4 years) compared with LTC residents (84.9 years) (Table 50).

TABLE 50. SOCIODEMOGRAPHIC CHARACTERISTICS: DAL AND LTC FACILITIES

Characteristic	DAL Residents	LTC Residents
Age		
Mean	84.4	84.9
% aged 85+	55%	56%
Gender (% female)	77%	66%
Marital status		
% Widowed	71%	59%
% Married	15%	25%

Note: See earlier sections for sample sizes and additional information.

- 77% of DAL residents were **female,** compared to 66% of LTC residents (Table 50).
- 71% of DAL and 59% of LTC residents were **widowed** while 15% of DAL and 25% of LTC residents were **married** (Table 50). This reflects, in part, the gender difference noted above.

Clinical Issues

- DAL and LTC residents had a similar average number of **disease diagnoses** (4.6 and 5.2, respectively) and a similar average number of regularly **prescribed medications** (8.3 and 7.9, respectively) (Table 51).

TABLE 51. CLINICAL ISSUES: DAL AND LTC RESIDENTS

Issue	DAL Residents	LTC Residents
Number of disease diagnoses		
Mean (range)	4.6 (0-14)	5.2 (0-12)
Number of regularly prescribed medications		
Mean (range)	8.3 (0-23)	7.9 (0-21)
% of diagnosis of dementia (any type)	58%	71%
interRAI Changes in Health, End-stage Disease and Symptoms and Signs (CHESS) Scale		
0 (not at all unstable)	46%	40%
1	29%	34%
2	17%	19%
3	6%	6%
4	1%	1%
5 (totally unstable)	---	---
Falls in last 90 days (% with 1+ falls)	28%	27%
Bladder incontinence (any difficulty)	59%	91%
Bowel incontinence (any difficulty)	28%	69%
Presence of pressure ulcer	7%	16%
interRAI Pain Scale		
No pain	43%	43%
Less than daily pain	26%	33%
Mild/moderate daily pain	24%	19%
Severe daily pain	7%	5%
Hearing (any difficulty)	44%	57%
Vision (any difficulty)	39%	54%
interRAI CAPs (% who trigger CAP)		
Falls CAP	28%	27%
Pain CAP	32%	26%
Pressure Ulcer CAP	8%	23%
Cardio-Respiratory CAP	51%	44%
Prevention CAP	99%	99%
Appropriate Medication CAP	14%	15%
Tobacco and Alcohol Use CAP	5%	4%
Urinary Incontinence CAP	50%	58%
Bowel Conditions CAP	13%	24%

Note: See earlier sections for sample sizes and additional information.

- 58% of DAL residents and 71% of LTC residents had a recorded diagnosis of **dementia** (any type) (Table 51).
- 54% of DAL residents and 60% of LTC residents showed some of level of **instability in terms of clinical complexity and health**, as indicated by the **interRAI CHESS scale** (Hirdes et al., 2003) (Table 51). Overall, the distribution of scores was similar for the two groups.
- The percentage of residents who had experienced a **fall** in the last 90 days was virtually identical (28% DAL, 27% LTC) (Table 51).
- **Bladder incontinence** and **bowel incontinence** were more likely to be exhibited by LTC residents than by DAL residents (Table 51). As indicated earlier, DAL facilities were less likely than LTC facilities to admit individuals with bowel incontinence that could not be self-managed. Similarly, DAL facilities were less likely to retain residents with this problem.
- 16% of LTC residents had a **pressure ulcer** compared to 7% of DAL residents (Table 51).
- Based on the **interRAI Pain Scale** (Fries et al., 2001), the percentages of DAL (57%) and LTC (57%) residents experiencing pain were similiar (Table 51).
- LTC residents were more likely to have both **hearing** and **vision** problems than DAL residents (Table 51).
- Compared to LTC residents, a higher percentage of DAL residents triggered the **Cardio-Respiratory CAP** while lower percentages triggered the **Pressure Ulcer CAP**, the **Urinary Incontinence CAP**, and the **Bowel Condition CAP** (Table 51). The percentages of residents who triggered the other CAPs related to clinical issues were similar in the two groups, highlighting the importance of monitoring and oversight in both DAL and LTC.

Physical Function

- Differences emerged in the **physical functioning** of DAL and LTC residents, with LTC residents tending to show more impaired functioning.
- A higher percentage of LTC residents (69%) had less than an hour or no **exercise/physical activity** in the 3 days prior to the assessment than DAL residents (48%) (Table 52).
- 42% of DAL residents were assessed as **independent** on the interRAI ADL Self-Performance Hierarchy Scale (Morris et al., 1999), compared to 5% of LTC residents (Table 52). At the other end of the scale, 6% of DAL residents and 33% of LTC residents were in the **dependent to total dependence** categories.
- LTC residents (69%) were much more likely to rely on **wheelchairs/scooters** for locomotion than DAL residents (20%) (Table 52).

TABLE 52. PHYSICAL FUNCTIONING: DAL AND LTC RESIDENTS

Characteristic	DAL Residents	LTC Residents
Hours of Exercise/Physical Activity last 3 days		
None	11%	33%
<1 hour	37%	36%
1-2 hours	35%	23%
3-4 hours	11%	7%
>4 hours	6%	2%
ADL Self-Performance Hierarchy		
Independent	42%	5%
Supervision	17%	5%
Limited impairment	12%	8%
Extensive Assistance 1	17%	31%
Extensive Assistance 2	6%	18%
Dependent	5%	21%
Total dependence	<1%	12%
Usual Mode of Locomotion		
Walking, no device	21%	9%
Walking with assistive device	59%	21%
Wheelchair/scooter	20%	69%
Bedbound	---	1%
interRAI CAPs (% who trigger CAP)		
Physical Activities Promotion CAP	38%	24%
Activities of Daily Living CAP	57%	82%
Physical Restraints CAP	3%	40%

Note: See earlier sections for sample sizes and additional information.

- DAL residents (38%) were more likely than LTC residents (24%) to trigger the **Physical Activity Promotion CAP**, suggesting that some DAL residents could benefit from physical activity interventions (Table 52).

- Of particular interest are the 28% of DAL residents who were assessed as extensive assistance to total dependence in ADLs and the 18% of LTC residents who were assessed as independent to limited impairment. Further investigation of the characteristics of both these groups is warranted. These DAL residents may be unsafe in the DAL environment given the staffing and care provided while the LTC residents may be able to safely function in an environment that provides a lower level of care. Other characteristics such as clinical complexity, cognitive functioning and mental health, social functioning and the involvement of family caregivers need to be taken into account in order to determine if individuals were in the setting that best met their needs.

Cognitive Function and Mental Health

- Differences in cognitive function and mental health were evident between the DAL and LTC residents (Table 53). As noted earlier, a higher percentage of LTC residents (71%) had a recorded diagnosis of **dementia** than DAL residents (58%) (Table 51).

TABLE 53. COGNITIVE FUNCTION AND MENTAL HEALTH: DAL AND LTC RESIDENTS

Measure	DAL Residents	LTC Residents
interRAI Cognitive Performance Scale (CPS)		
Intact	21%	6%
Borderline intact	20%	9%
Mild impairment	31%	26%
Moderate impairment	17%	25%
Moderately severe impairment	<1%	4%
Severe impairment	10%	18%
Very severe impairment	<1%	12%
interRAI Depression Rating Scale (DRS)		
Clinically important depressive symptoms (3+)	19%	51%
Documented Diagnosis of Depression	34%	44%
interRAI Aggressive Behavior Scale (ABS)		
None	71%	34%
Moderate	17%	20%
Severe	10%	23%
Very severe	3%	23%
interRAI CAPs (% who trigger CAP)		
Cognitive Loss CAP	71%	41%
Delirium CAP	6%	6%
Mood CAP	45%	76%
Communication CAP	36%	36%
Behaviour CAP	17%	52%

Note: See earlier sections for sample sizes and additional information.

- 41% of DAL residents and 15% of LTC residents were assessed as **intact/borderline intact,** based on the **interRAI Cognitive Performance Scale (CPS)** (Morris et al., 1994) (Table 53). 28% of DAL residents scored in the moderate to very severe impairment categories compared to 59% of LTC residents. A higher percentage of DAL residents triggered the **Cognitive Loss CAP** which highlights opportunity for monitoring and intervention to prevent decline.

- 19% of DAL and 51% of LTC residents exhibited signs of clinically important **depressive symptoms,** as measured by the **interRAI Depression Rating Scale** (Burrows et al., 2000) (Table 53). Similarly, a higher proportion of LTC residents had a recorded clinical diagnosis of depression (44%) than did DAL residents (34%). LTC residents were more likely than those in DAL to trigger the **Mood CAP** that identifies individuals for appropriate management and follow-up.

- Based on the **interRAI Aggressive Behavior Scale (ABS)** (Perlman & Hirdes, 2008), **aggressive behaviour** was more likely among LTC residents than DAL residents (Table 53). This may reflect differences in residents' dementia stage/severity in the two settings and is consistent with the differences in admission and retention criteria discussed earlier. It is also reflected in the higher proportion of LTC residents triggering the **Behaviour CAP**. At the same time, 13% of DAL residents were in the severe/very severe category on the ABS and 17% triggered this CAP. While recognizing that some DAL facilities had dementia spaces, the match between the needs of this group and the services provided requires further attention.

Social and Lifestyle Characteristics

- 47% of DAL residents and 56% of LTC residents were assessed as **spending little or no time involved in activities** (when awake and not receiving treatments/ADL care) (Table 54).

TABLE 54. SOCIAL AND LIFESTYLE CHARACTERISTICS: DAL AND LTC RESIDENTS

Characteristic	DAL Residents	LTC Residents
Average amount of activity involvement		
Most (> 2/3 of time)	15%	11%
Some (1/3 – 2/3 of time)	39%	33%
Little (<1/3 of time)	44%	50%
None	3%	6%
Social/recreation activities (% participated & preferred)		
Watching TV or listening to radio	87%	74%
Music or singing	71%	80%
Conversation or talking on phone	63%	39%
Reading, writing, or crossword puzzles	57%	38%
Spiritual or religious activities	47%	48%
Cards, games, puzzles, bingo	42%	33%
Discussing/reminiscing about life	26%	40%
Crafts or arts	21%	20%
Social engagement (% low to no engagement)	18%	34%
interRAI CAPs (% triggering)		
Activities CAP	36%	40%
Social Relationship CAP	27%	29%

Note: See earlier sections for sample sizes and additional information.

- At least 10% more DAL residents than LTC residents were involved in watching television or listening to the radio, conversation or talking on the phone, and reading, writing or crossword puzzles (Table 54). The reverse trend emerged for discussing/reminiscing about life.

- 18% of DAL residents and 34% of LTC residents were assessed as having low to no social engagement, reflecting a lack of social relationships and involvement (Table 54).

- A similar proportion of DAL and LTC residents triggered the **Activities CAP** and the **Social Relationship CAP** (Table 54). Given that DAL residents generally are less physically and cognitively impaired than LTC residents, this suggests the need to consider issues of activity involvement and social relationships among DAL residents in particular.

Health Service Use

- DAL residents were more likely to have had an **acute care hospital stay** and an **emergency room visit** in the 90 days prior to assessment than LTC residents, reflecting, in part, the greater availability of nursing care and other services within LTC (Table 55).

TABLE 55. HEALTH SERVICE USE: DAL AND LTC RESIDENTS

Service Use in 90 days Prior to Assessment	DAL Residents	LTC Residents
% with at least 1 acute care hospital stay	12%	5%
% with at least 1 emergency room visit	16%	6%
% with at least 1 physician visit	63%	90%
% with at least 1 physiotherapy visit	3%	28%
% with at least 1 occupational therapy visit	1%	9%
% with at least 1 speech-language pathology & audiology visit	<1%	1%

Note: See earlier sections for sample sizes and additional information.

- DAL residents were less likely than LTC residents to have had at least one **physician visit** in the 90 day period (Table 55). As noted earlier, only about one-third of DAL facilities had a GP affiliated with the facility which may account for this variation. This, along with LPN/RN staffing differences, may raise concerns about a greater risk for lack of clinical oversight in DAL.

1-Year Outcomes

- 16% of DAL residents and 31% of LTC residents died in the 1-year period (Table 56).
- Among the DAL residents, 16% moved to a higher level care, most frequently to long-term care (Table 56). An additional 3% had died by the 1-year follow-up but had moved to LTC prior to death.

TABLE 56. 1-YEAR OUTCOMES: DAL AND LTC RESIDENTS

Outcome	DAL Residents	LTC Residents
Mortality (% deceased)	16%	31%
Moved to a higher level of care (%)	16%	N/A
Remained in DAL/LTC or equivalent	66%	69%

Note: See earlier sections for sample sizes and additional information.

DAL and LTC Family Caregivers

The characteristics of DAL and LTC family caregivers examined here include **sociodemographic characteristics, visiting patterns and caregiving tasks, effects on employment, caregiver burden, financial costs,** and **1-year outcomes.**

Sociodemographic Characteristics

- The average **age** of the family caregivers was 57.7 for DAL and 61.7 for LTC (Table 57).
- 70% of DAL caregivers and 69% of LTC caregivers were **female** (Table 57).
- DAL caregivers were slightly more likely to be **daughters and sons** as compared to LTC caregivers (Table 57). 19% of LTC caregivers were the residents' spouses compared to 6% of DAL caregivers. This is consistent with the variation in the residents' marital status noted earlier.

TABLE 57. SOCIODEMOGRAPHIC CHARACTERISTICS: DAL AND LTC FAMILY CAREGIVERS

Characteristic	DAL Family Caregivers	LTC Family Caregivers
Age (mean)	57.7	61.7
Gender (% female)	70%	69%
Relationship to resident		
Daughter	51%	40%
Son	23%	19%
Wife/husband	6%	19%
Sister/brother	4%	5%
Other family (including in-laws)	13%	12%
Friend/volunteer	3%	4%
Employment status (% employed)	59%	52%
Distance from resident		
< 15 km	49%	51%
15-29 km	23%	18%
30+ km	28%	31%

Note: See earlier sections for sample sizes and additional information.

- Over one-half of DAL (59%) and LTC (52%) caregivers were **employed** (Table 57).
- The pattern of travel distance was similar for DAL and LTC caregivers (Table 57).

Visiting and Caregiving Tasks

- A higher percentage of LTC caregivers (37%) reported **visiting** 3 or more times per week than DAL caregivers (25%) (Table 58). This reflects, in part, the higher percentage of spousal caregivers for LTC residents than for DAL residents.

TABLE 58. VISITING AND CAREGIVING TASKS: DAL AND LTC FAMILY CAREGIVERS

Visiting and Task	DAL Family Caregivers	LTC Family Caregivers
Number of visits per week		
< 1x/week	21%	21%
1x - <2x/week	32%	25%
2x - <3x/week	22%	17%
3+ x/week	25%	37%
% of caregivers who:		
Shop for the resident	94%	92%
Telephone to see how the resident is doing	86%	58%
Pay bills/look after finances	84%	85%
Drive the resident to appointments	61%	15%
Make appointments for the resident	60%	21%
Talk to GP about the resident	56%	39%
Write letters or call family for the resident	54%	55%
Contact Home Care or other agencies	37%	7%
Talk to a specialist about the resident	27%	15%

Note: See earlier sections for sample sizes and additional information.

- DAL family caregivers were generally more likely to report involvement in **caregiving tasks** than LTC caregivers (Table 58). The exceptions were writing letters/calling family and paying bills/looking after finances. The differences between settings may be due to different residents' needs; the availability of other support, health care providers and services; or caregiver characteristics.

Effects on Employment

- The percentages of employed DAL and LTC family caregivers who experienced various **effects of caregiving on their employment** were generally comparable (Table 59). The only difference was that 65% of DAL caregivers left work for the resident's doctor appointments compared to 51% of LTC caregivers, reflecting the availability of a GP affiliated with LTC.

TABLE 59. EFFECTS ON EMPLOYMENT: DAL AND LTC FAMILY CAREGIVERS

Effect due to Caring for Resident	Employed DAL Family Caregivers	Employed LTC Family Caregivers
Leave for resident's Dr. appointments	65%	51%
Leave work suddenly	46%	43%
Miss work	43%	39%
Feel work performance affected	31%	28%
Frequent phone interruptions	28%	25%
Late for work	25%	24%
Decrease hours	24%	24%
Change shifts	19%	20%
Consider quitting	13%	12%

Note: See earlier sections for sample sizes and additional information.

Caregiver Burden

- Scores on the **Caregiver Reaction Assessment (CRA)** subscales (Given et al., 1992) suggest similar reactions to caregiving for the DAL and LTC caregivers (Table 60). However, the DAL family caregivers had, on average, slightly more negative reactions with regards to disrupted schedules, health problems and positive self-esteem.

- The average **rating of their experience as a caregiver** (7.4 out of 10, with 0 being mostly negative and 10 being mostly positive) was identical for both groups (Table 60).

TABLE 60. CAREGIVER BURDEN: DAL AND LTC FAMILY CAREGIVERS

Burden	DAL Family Caregivers	LTC Family Caregivers
Caregiver Reaction Assessment Sub-scales (mean out of maximum score of 5)		
Disrupted Schedule	2.58*	2.49
Financial Problems	2.11	2.08
Lack of Family Support	2.54	2.50
Health Problems	2.62*	2.57
Positive Self-Esteem	3.98*	4.03
Rating of caregiver experience (mean) (0 = mostly negative, 10 = mostly positive)	7.4	7.4

Note: See earlier sections for sample sizes and additional information. * denotes statistically significant differences in the scores of DAL and LTC family caregivers at $p<.05$.

Financial Costs

- Reflecting the differences in the services provided/arranged and associated costs covered by DAL and LTC as part of the base fee, DAL family caregivers were much more likely than LTC caregivers to report that they or the resident had incurred **costs associated with prescription medications** (87% DAL, 4% LTC), **incontinence supplies** (41% DAL, 5% LTC), and **over-the counter medications** (30% DAL, 8% LTC) (Table 61). They were also more likely to indicate costs associated with **foot care** (37% DAL, 23% LTC).

TABLE 61. FINANCIAL COSTS: DAL AND LTC FAMILY CAREGIVERS

Extra Monthly Charges (% yes)	DAL Family Caregivers	LTC Family Caregivers
Prescription medications	87%	4%
Shampooing/styling hair	68%	74%
Incontinence supplies	41%	5%
Cutting toenails	37%	23%
Personal laundry	35%	67%
Over-the-counter medications	30%	8%
Transportation	18%	16%
Food/special diet	13%	9%

Note: See earlier sections for sample sizes and additional information.

- DAL caregivers (35%) were less likely to report costs related to **personal laundry** than LTC caregivers (67%) (Table 61). As noted earlier, about one-quarter of DAL facilities provided/arranged personal laundry as part of the base fee while none of the LTC facilities did so (Table 49).

- The percentages of caregivers who indicated that costs for **shampooing/styling hair**, **transportation**, and **food/special diet** were similar for DAL and LTC (Table 61).

Experiences at 1-Year Follow-up

- 71% of DAL and 76% of LTC caregivers reported that the **amount of visiting** at follow-up was the same as it had been a year earlier (Table 62). 12% of DAL and 5% of LTC caregivers perceived that their visits had increased while 17% of DAL and 19% of LTC caregivers indicated a decrease.

- In terms of **caregiver burden**, a significant change in disrupted schedules and in financial problems emerged for DAL caregivers but not for LTC caregivers (Table 62). DAL caregivers had a less negative reaction related to the impact of caring on their schedules and a more negative impact related to financial strain at follow-up than at baseline. For LTC caregivers only, scores on health problems were slightly higher at follow-up, suggesting a more negative reaction to caregiving in terms of the caregiver's own health.

TABLE 62. EXPERIENCES AT 1-YEAR FOLLOW-UP: DAL AND LTC FAMILY CAREGIVERS

Change	DAL Family Caregivers	LTC Family Caregiver
Change in amount of visiting in last year		
Increase	12%	5%
Same	71%	76%
Decrease	17%	19%
Change in caregiver burden (Mean out of maximum score of 5, at baseline and follow-up, * p<.05 based on paired t-tests)		
Disrupted Schedule	2.60 & 2.54*	2.48 & 2.44
Financial Problems	2.10 & 2.18*	2.11 & 2.16
Lack of Family Support	2.58 & 2.60	2.50 & 2.47
Health Problems	2.62 & 2.61	2.56 & 2.61*
Positive Self-Esteem	3.97 & 3.98	4.03 & 4.03

Note: See earlier sections for sample sizes and additional information.

Views about DAL and LTC Facilities

- In general, DAL and LTC family caregivers were similar in their **assessments** of the DAL and LTC facility in which the resident resided (Table 63). Only residents in DAL were asked to rate their facility so a comparison of residents' ratings is not possible.

- Generally, the percentages of DAL and LTC family caregivers who indicated that they were **very satisfied** with particular services were similar (Table 63). However, approximately one-half of the caregivers in both settings were **mostly satisfied, not satisfied or quite dissatisfied** with assistance with dressing, bathing, meals/food, housekeeping/cleaning, oral care, and toileting, suggesting areas for improvement in service.

- When asked if they would **recommend the facility** to others, 76% of DAL family caregivers and 71% of LTC family caregivers responded "definitely yes" (Table 63).

TABLE 63. SATISFACTION RATINGS: DAL AND LTC FAMILY CAREGIVERS

Rating	DAL Family Caregivers	LTC Family Caregivers
Overall rating of care (0 worst possible to 10 best possible) (mean)	8.3	8.1
Overall rating of facility (0 worst possible to 10 best possible) (mean)	8.3	8.1
Family caregivers' satisfaction with services (% very satisfied) (based on caregivers who reported the resident received/used service)		
Assistance with medications	70%	65%
Nursing care (blood pressure, dressings)	60%	59%
Foot care/podiatry in facility	57%	54%
Hair care (brushing, shampooing, etc.)	56%	48%
Dressing	54%	47%
Bathing	50%	41%
Personal laundry	49%	51%
Meals/food	49%	40%
Housekeeping/cleaning	42%	52%
Oral care	49%	41%
Toileting	45%	41%
Recommend facility to others		
Definitely yes	76%	71%
Probably yes	20%	22%
Probably no	3%	4%
Definitely no	1%	3%

Note: See earlier sections for sample sizes and additional information.

Summary

This comparison has highlighted some key similarities and differences between DAL and LTC facilities, residents, and caregivers. Facility differences related to ownership, the likelihood of offering DAL-only or LTC-only spaces, admission and retention criteria, staffing, the provision of certain services, the availability of private rooms, and fees. DAL and LTC residents were similar in terms of the clinical issues they faced, but LTC residents were likely to have more physical limitations than DAL residents. Cognitive/mental health needs were evident among both groups. Compared to LTC caregivers, DAL family caregivers were more likely to provide assistance with tasks such as appointments and to report costs related to meeting the resident's needs. In addition, they had, on average, more negative responses to caregiving, in terms of disrupted schedules, financial problems, and health problems. More in-depth analysis using multivariate techniques is required to further differentiate between the two settings.

Attention now turns to a discussion of the issues and challenges facing DAL and LTC. Of interest are the areas of concern for residents, family caregivers and the facilities.

ISSUES AND CHALLENGES FACING DAL AND LTC

Several **priority issues and challenges** facing DAL and LTC emerged from the information collected from residents, family caregivers, and facility representatives. Highlighted here are issues and challenges 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.

Admission and Retention

Various aspects of admission and retention were challenging for both DAL and LTC. The need for **clarity in admission criteria** was particularly apparent for DAL. At the time of the study, there were no province-wide admission criteria. Facilities varied in the characteristics of individuals they would admit, reflecting in part different approaches in the health regions, the relatively early development stage of designated assisted/supportive living in the province, and/or the ability of a facility to provide a certain level of care. As noted earlier, several DAL facility representatives responded "it depends" when asked about various admission/retention criteria. Admission criteria related to cognitive/behavioural issues were most likely to be reported as "it depends", reflecting concerns about stability, safety, or the availability of a dementia space. This lack of clarity posed a challenge for some family caregivers, physicians, and other service providers as they explored options to meet clients' and family members' care needs.

The **First Available Bed Policy** that requires an individual to move into the first space available was identified by some DAL and LTC facility representatives as an issue for some families. This was particularly apparent in rural communities where care options were limited and a move to another community was necessary. For some caregivers, the travel distance and time restricted their involvement in the lives of the residents. In some instances, the policy resulted in couples being split apart.

Facility Representatives

It's a challenge getting the resident close to them – we have a 80 kilometre radius for the First Bed Policy. We get residents waiting for other facilities, maybe for just 1 week – then they are uprooted. It's a challenge [for families] to drive and visit. (LTC)

Families don't really get 1st choice right away of where to live. (DAL)

Family Caregivers

It's not convenient – I am unable to visit as often as before. Family should have a choice of location. (DAL)

He and my mom are separated. It's not good for them but particularly stressful for us as caregivers. Ideally we wanted them together but when this bed came up, we were reluctant to pass it up and go to the bottom and then we'd wait again…(DAL)

The need for increased clarity with regards to **retention** or to the circumstances under which a resident would no longer be able to stay in the facility was also evident. Almost one-half (47%) of DAL and 81% of LTC family caregivers indicated that such policies were unclear or did not exist, or that they did not know if a policy existed. In DAL, given the likelihood of increased needs of residents necessitating a move to a higher level of care, this lack of understanding is of particular concern.

Some DAL facilities faced the challenge of **caring for residents when their care needs increased**. Facilities often attempted to provide care until a LTC space was available. In rural Alberta, the lack of alternative care options such as LTC created pressure on some facilities to allow a resident to remain in their home community, despite increased needs.

Ongoing review and discussion of admission/retention criteria in DAL is warranted 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 met in these care settings.

Meeting the Residents' Needs

Meeting the **complex needs** of DAL and LTC residents represents a major challenge. Of concern is appropriate **ongoing monitoring** and **oversight** or, in other words, 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. While the residents' needs are multidimensional, attention here focuses on **mental health needs, medication administration and management, assistance with activities of daily living,** and **social engagement**.

Mental health needs require particular attention in both DAL and LTC. As noted earlier, dementia is the most prevalent disease diagnosis in both settings (58% of DAL residents, 71% of LTC residents). Depression was the 4th most prevalent disease diagnosis in both settings (34% DAL, 44% LTC). The interRAI Cognitive Loss CAP was triggered by 71% of DAL residents and 41% of LTC residents while 45% of DAL and 76% of LTC residents triggered the Mood CAP, indicating a need for monitoring and/or intervention.

Despite the relatively high rates of dementia, the availability of dementia spaces was limited. Only 25% of the available spaces in the 59 DAL facilities and 18% of the available spaces in the 54 LTC facilities were identified as spaces that were designated as Alzheimer's/dementia spaces/special care units (e.g., safe living units, locked units). The need for staff training in dementia care and physical design features to support dementia care was identified by some facility representatives in DAL and LTC.

Not surprisingly, retention when residents exhibited cognitive/behavioural problems in a setting with low staffing levels was problematic. These factors were associated with a move from DAL to LTC. Further, as noted earlier, DAL facility representatives were more likely to respond "it depends" when asked about retaining individuals with such problems. Some DALs did not have the staffing levels/mix to support individuals with increasing mental health needs. In general, there remain unanswered questions about the optimal mix and integration of mental health services and policies for appropriate placement and management of these residents. Clearly this is an area that requires increased emphasis in order to ensure the safety and security of all residents.

The **administration and management of medications** also requires ongoing review and oversight in both settings. On average, DAL and LTC residents were taking 8 regularly prescribed medications, with a range from 0 to 23. Over 10% of the residents triggered the Appropriate Medication CAP that identified residents who may have increased risk for potentially inappropriate medication use, and require additional focused assessment and follow-up (14% DAL, 15% LTC). In DAL, 39% of the facility representatives reported that only PCAs administered medications. The restrictions on the medications that PCAs can administer as well as the extent to which these staff members have the necessary training to administer and manage medications when there is no professional nursing staff on site need further investigation.

Both DAL and LTC residents required assistance with **activities of daily living**. In some instances, staff faced a challenge between allowing a resident to undertake a task on his/her own and doing the task for a resident in order to work more efficiently or to avoid safety issues associated with allowing greater independence. While there is a desire to maintain the residents' functioning, the care setting itself may create a dependency. This is reflected in the extent to which DAL residents' capacity to perform instrumental activities of daily living such as meal preparation and housework exceeded their performance.

Over one-half (57%) of DAL residents and 82% of LTC residents triggered the Activities of Daily Living CAP that identifies individuals who potentially require attention to prevent decline or to facilitate improvement, highlighting the importance of ongoing assessment and monitoring of ADLs. As noted earlier, the use of rehabilitation therapies such as physiotherapy or occupational therapy was relatively low. In addition, family caregivers' satisfaction ratings with services highlighted several areas for improvement related to ADL care. 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.

Social engagement and involvement represent another issue to address in both settings. Opportunities for social/recreational activities emerged as an area requiring attention, from the perspective of DAL and LTC family caregivers and DAL residents. About one-half (47%) of DAL residents and 56% of LTC residents were assessed as spending on average, little or no time involved in activity (when awake and not receiving treatments/ADL care). Almost one-fifth (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 longstanding interests, and visits or other interaction with a long-standing social relation or family member.

Over one-third of DAL residents (36%) and LTC residents (40%) triggered the Activities CAP that identifies individuals for whom follow-up to identify barriers and potential interventions for enhanced social activities is warranted. Furthermore, 27% of DAL and 29% of LTC residents triggered the Social Relationship CAP that targets residents who may benefit from an intervention to facilitate social engagement. This relatively low level of engagement and involvement may reflect personal preference. At the same time, it may be that increased attention to social engagement and involvement within DAL, a setting that promotes itself as a social model of care, is needed. Given the staffing levels/mix in DAL and the general lack of recreation aides/therapists in this setting, innovative approaches to providing opportunities for social activities are required.

Family Involvement

Family caregivers potentially play an important role in the lives of DAL and LTC residents. While some residents did not have such supports, the majority had at least one individual involved in some way. These caregivers were often daughters or sons who may be caring for other family members and/or may be employed. Their ability and willingness to provide support on an ongoing basis need to be taken into consideration.

DAL facility representatives often spoke about an **expectation of families** of DAL residents to be actively involved in the care of their family members, such as arranging medical/dental appointments, purchasing items, and providing social interaction. Families need to understand their own and the facility's roles at entry and as the health of the resident changes. In DAL, the role of Home Care/Supportive Living also needs to be understood.

Facility Representatives

Realizing they [family] still have responsibilities to the residents and we don't do everything like LTC. (DAL)

They feel comfortable that the resident is in the facility and they don't want to provide support and help. They don't want to take them to appointments, etc. (DAL)

Expectation to stay involved and some find that challenging. They are to take the resident to outpatient's and the doctor's as if they were in the community. Transportation is difficult in a rural community. (DAL)

If the resident's needs go beyond what we can provide, family need to pick up the slack. The expectation is that family is involved. (DAL)

Family Caregiver

It would be nice to know the facility's expectations of family. I can't be there every day. I do try to get there daily and feel guilty about not getting there more often. I'm just coming off a 6 month stress leave and some of it is related to the burden of caregiving. (DAL)

While residents should be the focus of attention in both DAL and LTC, consideration needs to be given to the support provided to family caregivers. This may include education regarding dementia, navigation of the health system, and dealing with stress, guilt and loss. The diversity of family caregivers' expectations, views, experiences, and relationships necessitates exploration of different ways to assist different types of caregivers.

Staffing

Appropriate staffing and supervisory arrangements in DAL and LTC are critical to ensure quality care is provided to the residents. **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 at length 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. The interweaving of staffing needs and meeting resident needs was readily apparent.

> Facility Representative
>
> *Staffing is critical. If you do not have staff and trained staff, residents will not get the care or the service they require to live in this environment. Resident care needs are changing and demands are greater. (DAL)*

In terms of recruitment, 83% of DAL facility representatives and 91% of LTC representatives identified the **ability to recruit** as a challenge to adequate staffing. Three-quarters of both DAL and LTC facility representatives identified PCAs as difficult to recruit (75% DAL, 76% LTC). The recruitment of LPNs and RNs was more likely to be a challenge in LTC, reflecting differences in staffing patterns (LPNs: 42% DAL, 74% LTC; RNs: 8% DAL, 78% LTC). In some facilities, it was primarily only one type of staff that was needed while in others, all types were required.

Over one-half of the facility representatives identified problems with **retaining staff** (54% DAL, 56% LTC). The type of staff difficult to retain included PCAs (46% DAL, 48% LTC), LPNs (29% DAL, 30% LTC), and RNs (5% DAL, 35% LTC), with the latter reflecting existing setting-specific staffing patterns.

Some facility representative explained the issues of recruitment and retention in relation to the lack of full-time positions, the pay rate, the workload, and the limited potential workforce within their community. These recruitment and retention challenges often led to staff shortages. As discussed earlier, family caregivers identified staff shortages and turnover as a concern. In both DAL and LTC, attempts were made to cover staffing by various means, including using the casual pool, overtime, extending shifts, shifting the workload, using agencies, and working short-staffed.

The **need for changes in staff roles** was identified by some facility representatives as posing a challenge to staffing (39% DAL, 54% LTC). This change frequently related to challenges of multi-skilling and working to the full scope of practice. In LTC, the specific challenge of the changing role of the RN, including computerized assessments, care management, leadership and training of staff, and decreased hands-on care was discussed.

> Facility Representatives
>
> *The blended role is a challenge. Residents/family often complain about PCAs doing care and housekeeping. (DAL)*
>
> *Skill level needs to be reviewed. PCAs need to work to full scope. (DAL)*
>
> *We're moving towards full scope of practice. It's just hard with the heavier load of residents and the need to do resident care. Some are not trained for the paperwork. (LTC)*

The **increasing care needs** of the residents were identified by many facility representatives as a major challenge for staffing (64% DAL, 83% LTC). Often this was linked to the need for more staff. A LTC facility representative indicated that dealing with the increased acuity was their **highest priority** as "*everything else falls under that.*" A DAL facility representative summarized the situation as "*the workload is increasing, the staff numbers don't keep up and people are wearing out.*"

Other staffing issues identified as challenges by facility representatives related to increasing the awareness and respect for different types of staff, dealing with staff whose first language is not English, keeping morale up, and providing educational opportunities and mentoring. Despite these staffing issues, both DAL and LTC representatives identified several **strengths related to staffing**. Many spoke about their staff's dedication and compassion for the care they give, the relationships they develop with residents and family, the team work, and the opportunities to learn. Family caregivers in both DAL and LTC generally recognized the demands that staff face in these settings and frequently had positive comments about staff involvement and care.

Improved Communication

Finally, improved **communication between various stakeholders** is imperative, for both DAL and LTC. These stakeholders include residents, their family caregivers, staff, program planners, policymakers, owners/operators, and other sectors of the health care system, particularly primary and acute care. A DAL facility representative summarized the communication issue as follows:

> Facility Representative
>
> *Better communication and knowledge between all the partners - resident, family, facility, region. Better knowledge about different sites and different levels. We need resources that describe what can be accommodated at different DALs and what limitations there are. (DAL)*

As noted earlier, family caregivers generally need to have a better understanding of their role and the facility's roles, and in the case of DAL, the role of Home Care/Supportive Living. At the same time, caregivers' varying desires and abilities to be involved in the residents' lives has to be recognized.

Staff need to communicate better with each other and with family members to ensure that residents receive the best care possible. Communication between shifts was noted by some family caregivers and facility representatives as an area requiring improvement. In DAL, record-keeping is kept to a minimum. In some facilities, this meant that assessments and detailed charts were in an off site Home Care/Supportive Living office which posed potential problems if communication between providers was poor. With the introduction of electronic charting, the type and nature of charting on a shift-by-shift basis needs to be reviewed on an ongoing basis.

> Facility Representatives
>
> *We have to have a better working relationship between Home Care RNs and staff LPNs. Everyone is still trying to figure out their roles. (DAL)*
>
> *Transition services and Home Care don't communicate so there are mixed messages for PAL and DAL. (DAL)*

In DAL, communication between the facility and Home Care/Supportive Living was identified by some facility representatives as an area that required improvement. Similarly there were calls for enhanced communication between the program planners/policymakers and the facilities.

Improved communication with other sectors of the health care system is also required. These sectors, particularly acute care, were perceived by some facility representative to have limited understanding of the capacity of DAL and LTC and the type of care that can be provided. Concerns were expressed about residents being "sent back" to the facility as the acute care staff assumed that the facility could provide the appropriate level of care. While these concerns were more often raised by DAL representatives, the issue was applicable to LTC as well.

Facility Representatives

More education in hospitals. They hear the person comes from a facility so they send them back right away but they don't understand that DAL can't manage what LTC can. (DAL)

We need better communication between supportive housing and acute care. They don't know the types of services that can be provided but send the residents back. (DAL)

More education about DAL – there are still a lot of people who don't know what we are, especially acute care. (DAL)

Overall, both operational issues and policy issues warrant increased discussion to allow for timely examination of issues and the identification of possible action. It is only by working together that the residents will receive the care that they require and deserve.

Conclusion

In conclusion, ACCES has provided a unique opportunity to examine DAL and LTC facilities, residents and their family caregivers across Alberta. This descriptive overview of selected study findings has highlighted several priority issues in need of further discussion, analyses and new data collection efforts. Many of the identified issues and challenges speak to the complex interplay between resident, family caregiver, facility, and health system/policy factors relevant to ensuring high quality of care and quality of life in continuing care. Increased understanding of the health, social and quality of care needs of older adults living in assisted living and long-term care facilities, the mix of services that are required, and health outcomes is critical as these care options continue to evolve.

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APPENDIX A: SAMPLE SIZES BY HEALTH REGION

Five former Regional Health Authorities (RHAs) participated in ACCES. The sample sizes of DAL and LTC facilities, residents and caregivers by health region are presented below.

TABLE A-1. SAMPLE SIZE: FACILITIES

Region	DAL Facilities Number (%)	LTC Facilities Number (%)
Calgary Health Region	13 (22%)	14 (26%)
Chinook Health Region	11 (19%)	8 (15%)
David Thompson Health Region	12 (20%)	10 (19%)
Capital Health	14 (24%)	14 (26%)
East Central Health	9 (15%)	8 (15%)
TOTAL	**59 (100%)**	**54 (101%)**

Percentages do not add to 100% due to rounding.

TABLE A-2. SAMPLE SIZE: RESIDENTS

	DAL Residents		LTC Residents	
Region	**Baseline Number (%)**	**Follow-up Number (%)**	**Baseline Number (%)**	**Follow-up Number (%)**
Calgary Health Region	311 (29%)	268 (30%)	296 (30%)	212 (31%)
Chinook Health Region	234 (21%)	173 (19%)	206 (21%)	137 (20%)
David Thompson Health Region	155 (14%)	128 (14%)	149 (15%)	95 (14%)
Capital Health	281 (26%)	240 (27%)	239 (24%)	165 (24%)
East Central Health	108 (10%)	83 (9%)	110 (11%)	82 (12%)
TOTAL	**1089 (100%)**	**892 (99%)**	**1000 (101%)**	**691 (101%)**

Percentages do not add to 100% due to rounding.

TABLE A-3. SAMPLE SIZE: FAMILY CAREGIVERS

	DAL Family Caregivers		LTC Family Caregivers	
Region	**Baseline Number (%)**	**Follow-up Number (%)**	**Baseline Number (%)**	**Follow-up Number (%)**
Calgary Health Region	274 (28%)	238 (30%)	270 (29%)	193 (32%)
Chinook Health Region	188 (19%)	144 (18%)	178 (19%)	112 (18%)
David Thompson Health Region	147 (15%)	120 (15%)	144 (16%)	87 (14%)
Capital Health	267 (27%)	212 (27%)	221 (24%)	141 (23%)
East Central Health	98 (10%)	77 (10%)	104 (11%)	76 (12%)
TOTAL	**974 (99%)**	**791 (100%)**	**917 (99%)**	**609 (99%)**

Percentages do not add to 100% due to rounding.