Collaborative Research Grant Initiative: Mental Wellness in Seniors and Persons with Disabilities

Seed/Bridge Final Report

Enhancing the Quality of Life of Seniors With Dementia Who Live Within Assisted Living Settings: A Review of the Literature and Current Promising Practices

March, 2015 – Anna Litle & Suzanne Maisey
EXECUTIVE SUMMARY

Dementia care research has been conducted for decades in the nursing home context. Little published research is available focusing on those with dementia living in assisted living settings. We examined the available research and conducted a review to identify promising practices specific to dementia assisted living settings. A literature search was initiated in year one resulting in a collection of articles that became the foundation of this literature review. In addition, the collection was immediately used to support the environmental and program design of Shepherd’s Care Foundation’s newest secured dementia assisted living setting (Shepherd’s Care Vanguard), which opened in 2011. Based on year one outcomes, a modified search strategy was designed and implemented to expand the search to ensure collection of all articles relevant to the purpose of this project. The diversity of labels (and research database keywords) used for the contexts of interest made the evidence capture more complex than originally identified and the re-design resulted in a more comprehensive collection of literature to achieve the research objectives. Through the phases of the literature review, applying a progressive filter of inclusion criteria, 19 articles were selected for detailed consideration. The main points from each article were extracted to include suggestions and examples of promising practices. These “dementia care in assisted living promising practices” were then grouped into categories that included: Staffing, social aspects, safety, physical environment, cognitive training, and emotional well-being to create the final project outcomes, communicated in the local research community through a number of academic presentations. As well, in parallel with the study review process, the collected promising practices were combined with other relevant evidence (i.e., those excluded from the review by the research question and strategy but still high quality) to inform the development of the Shepherd’s Care Vanguard Dementia Care Program Pilot and from there the organization’s dementia care strategy. Beyond the dissemination and applications of knowledge already achieved, the results of this literature and practice review will be useful to inform future provincial and organizational policy and practice decisions regarding dementia care in assisted living.

RESEARCH OVERVIEW

Objective(s)
The objective of this project was to conduct a comprehensive review of the research and current practices specific to dementia assisted living settings.

The goals of this review were to:
1. Identify promising practices specifically relevant to dementia assisted living settings that will stimulate and encourage independence to support residents who have dementia and are living within these settings; and
2. Identify services, activities, and social programs based on published evidence that will increase residents’ quality of living.

Promising practices could be described as activities, programs, or services; interventions, supports or features; and/or assessment approaches to practice outcomes (i.e., measurements of care). The concept of promising best practices allows the literature review to still capture interesting but as-yet-unproven ideas, not just established proven ones (i.e., “best”).

Background
There are approximately 500,000 people living with dementia in Canada today and it is projected that will increase to over 1.2 million, 2.8% of the population, by 2038 (Alzheimer Society of Canada, 2010). Alzheimer’s disease is the most common cause of dementia, resulting in a progressive decline in cognition that impacts daily life and functioning. Eventually, affected individuals require full-time support to ensure that their safety and daily life needs are met. Long-term care (or nursing home...
care) has traditionally been the setting that was available and developed for those with Alzheimer’s disease or related dementia. However, as the diversity of availability of housing and support options increase within the community, individuals with dementia are now residing in other contexts, many of which are labelled assisted living, a general category label that has many synonyms across country and even regional areas (now formally called supportive living in Alberta). Seniors’ assisted living settings can include seniors living with a wide range and depth of support and care needs, including all levels of cognitive impairment or dementia, always within a congregate housing environment (see Appendix A). The nursing care needs of assisted living residents are typically less than the nursing care needs of long-term care residents, but the need for complex care and support is increased for those with more advanced dementia.

In Alberta, there is a recent provincial direction to expand the availability of assisted living\(^1\), focusing on supporting Albertans – including seniors with dementia – to “age in the right place” (Alberta Health and Wellness, 2008) and expanding the types of options available to make that possible. In Alberta, a study examining the health, social and quality of care needs of seniors living with assisted living and long-term care across the province found that 58% of those who live within assisted living had dementia (Strain, Maxwell, Wanless, & Gilbart, 2011). Both predictive demographics (e.g., The Rising Tide Alzheimer Society of Canada Report), research measures of dementia prevalence and community development strategies indicate that an ever increasing number of people will be living with a dementia in the new assisted living settings. There will therefore clearly be a need to accommodate the unique and complex needs of seniors with dementia who live within these assisted living settings, where the designed purpose of the setting may or may not be to provide dementia-specific care and support. However, despite the increasing need for knowledge in these settings, minimal research and collected practice information exists to identify approaches specifically designed to support seniors with dementia who live within an assisted living context (e.g., Hyde, Perez, & Forester, 2007). Of the research available, the majority is related to dementia care and support within long-term care settings. There is also a great deal of literature focused on general research conducted within assisted living settings (e.g., Kane & Mach, 2007), but there is a deficit in evidence that combines assisted living and research focused on the housing and support needs of seniors who have dementia (Smith, Buckwalter, Kang, Ellingrod, & Schultz, 2008). Even when studies combining dementia care and assisted living exist, they tend to focus more on epidemiological or healthcare issues rather than on the holistic aspects of daily living (Mitchell & Kemp, 2000; Smith et al., 2008; Zimmerman et al., 2005). With the preceding issues previously addressed, there is a need to identify and synthesize existing research related to promising practices and proposed methods of care and support for individuals with dementia residing in assisted living contexts.

**Approach and Methods**

To meet the objectives of this project, the team conducted a comprehensive review and summary of the literature. Regular team meetings were held to seek expert guidance, present evidence gathered to date, discuss the quality and applicability of what was discovered (e.g., relevance to objective, ideas to redirect the search), and discuss the impact of the findings. The review itself can be sorted into 3 main phases: Database Search, Exclusion Process, and Categorization (see Figure 1).

\(^1\) For clarity, the label “assisted living” is used throughout the report regardless of the terminology used in a specific article or regional area.
**Phase 1 Database Search:** The first phase of the review involved consultation with the research team subject experts as well as a research librarian to develop search terms and strategies. Articles were identified and retrieved through the use of both an EBSCO literature search interface and the Education Resource Center, an Alberta health care library and information resource centre ([www.educationresourcecentre.ca](http://www.educationresourcecentre.ca)). Databases searched included: Health Business Elite; Psychology and Behavioural Sciences Collection; Nursing & Allied Health Collection: Comprehensive; Biomedical Reference Collection: Comprehensive; CINAHL plus with Full Text; MEDLINE with Full Text. During Phase 1 of the literature review, keywords were used to identify the literature collection that fit the population most of interest within the study’s purpose. To focus on the more recent literature, the search included only articles published between January 1, 2000 and February 28, 2012.

When the keywords were limited to “assisted living” and “dementia” relevant terms, the search resulted in 1,927 articles. Once the keyword literature collection was identified, that collection was combined, repeatedly and systematically, with each of the other keyword collections (e.g., Administration, Staffing) to generate the study article collection. The actual words identified for use in the search strategy came from:

- A careful examination of the various database keyword and literature indexing systems,
- Known common labels and terminology, within the fields of seniors housing and dementia care,
- Keywords from “good fit” articles already collected, and
- Expert consultation with the research team and other organizational experts

This strategy (e.g., terms and combinations) is fully outlined in Appendix B.

Each article was then put into the following 6 categories (see Table 1). Duplicates were removed resulting in 1,007 articles.
Table 1: Literature Review Categories and Number of Articles

<table>
<thead>
<tr>
<th>Category</th>
<th>Number of Articles</th>
</tr>
</thead>
<tbody>
<tr>
<td>Administration</td>
<td>1228</td>
</tr>
<tr>
<td>Clinical</td>
<td>605</td>
</tr>
<tr>
<td>Education</td>
<td>873</td>
</tr>
<tr>
<td>Staffing</td>
<td>294</td>
</tr>
<tr>
<td>Recreation</td>
<td>801</td>
</tr>
<tr>
<td>Model</td>
<td>17</td>
</tr>
</tbody>
</table>

Due to the inclusive search strategy employed, a large number of irrelevant articles were also captured. As a result, a number of steps were required to eliminate articles without direct relevance in line with the study purpose.

**Phase 2 Exclusion Process:** The exclusion process consisted of two stages.

Stage 1 of the exclusion process consisted of reviewing the 1,007 articles by reading the titles, abstracts, and keywords. This process was completed to include only articles that satisfied the keywords described in the search terms. Setting, medical diagnosis/condition, age, and relevance were considered during the review.

1. Setting – articles that did not contain the phrases: residential facility, assisted living facility, homes for the aged, assisted living, housing for the elderly, continuing care, retirement community, or congregate housing were excluded.
2. Medical Diagnosis/Condition – articles that did not contain either of the words dementia or Alzheimer were excluded.
3. Age – articles that did not focus on the senior population in addition to satisfying the setting and the medical diagnosis/condition as described above were excluded.
4. Relevance – articles that discussed: lawsuits, mortgage approval/denies/requests, in-depth physiological findings, new medications, sexuality, or palliative were excluded.

This process resulted in 232 articles that could be included for final review.

Stage 2 was performed to ensure relevance of the 232 articles through a more in-depth exclusion process. This stage of exclusion was carried out by two research assistants (RAs). The RAs sorted articles independently, inter-rater agreement was initially sought (i.e., 5-10 articles were analyzed by each RA and then a measure of agreement was made). Stage 2 of the exclusion process is illustrated in Appendix C. Nineteen articles were retained in this stage.

Articles were excluded based on the following criteria:

1. Articles without an abstract: Articles without an abstract were excluded as the determination of eligibility for inclusion would be challenging and time-consuming. Articles without abstracts tended to be magazine articles and resource guide contributions. Items excluded were typically 1-2 pages in length.
2. Articles that did not include reference to a population with dementia: Articles that focused only on an aging population and/or people with mild cognitive impairment (MCI) were excluded.
3. Articles that did not include reference to assisted living settings: Articles were included from many countries as care settings were known by different names. Decisions to exclude region-specific terminology were grounded in descriptions of setting and population(s) served provided by the authors. Categorical descriptions of assisted living and not-assisted living settings can be found in Appendix A.
4. Articles deemed irrelevant for this study: These articles were excluded after RAs and team members were unable to reach a consensus about the appropriateness of the article in the project’s purpose. For example, a collection of abstracts from a conference was excluded at this level.
5. Articles in which ‘promising practices’ were not described: RAs excluded articles that focused on prevalence, current state of settings/services, or descriptive data and associations between specific characteristics of settings. Articles that described change to or effectiveness of a practice were included.
**Phase 3 Categorization:** While excluding articles, RAs simultaneously categorized retained articles into topic areas. Categorization was distinct from the exclusion process and therefore is presented separately. Of the 19 articles, seven were summarized by both RAs and high levels of agreement were reached. Any minor disagreements were mainly around the amount of detail extracted from the articles.

The investigative team and RAs developed nine categories of study focus:
1. Staffing, education, knowledge translation/exchange/transfer (n=6)
2. Social, environment, engagement, isolation, privacy, activity, recreation or culture change (n=3)
3. Safety, security, risk, technology (n=1)
4. Physical environment, context (n=1)
5. Systems, facilitating aging in place (n=0)
6. Emotional well-being, mental health, and quality of life (n=2)
7. Behaviour, behaviour management, and care practice (n=0)
8. Mixed – articles that pertained to one or more category, no matter how minimal were included as mixed (n=5)
9. Other – articles that did not fit in to any of the above categories (n=1)

**Key Findings**
A full detail of the articles reviewed can be found in Appendix D. Below is a summary of the key findings for the nine categories.

**Staffing:**
- All articles on staffing pertained to staff education and development.
- When trainers spoke using a standardized training script, like the Foundations of Dementia Care program developed by the Alzheimer Association (USA), trainees were significantly more satisfied and perceived the trainers to be more knowledgeable (Fletcher, Zimmerman, Preisser, Mitchell, Beeber, & Reed, 2010a).
- Where training message fidelity is required, standardized trainer manuals and trainer support (conference calls) helps to maintain high implementation consistency (Fletcher et al. 2010b).
- Effective communication is critical to providing good dementia care (Gould, Cox, Johnson, McGuinness Vaillancourt, & Stanley, 2010).
- An internet-based training program for Certified Nursing Assistants can achieve promising gains in dementia care knowledge and participants report increased confidence, though technology and computer literacy are barriers (Hobday, Savik, Smith, & Gaugler, 2010).
- Reaction to resident challenges significantly improved in staff who received Staff Training in Assisted Living Residences (STAR) training (Teri, Huda, Gibbons, Young, & van Leynseele, 2005).

**Social:**
- People living with mild to moderate cognitive impairment can benefit from cognitive training (Hochhalt, Stevens, & Okonkwo, 2007).
- Attitudes and behaviours of caregivers have a very powerful influence upon social environment; more attention needs to be placed upon increasingly subtle ways that residents indicate interest to engage in activity; the experience of the resident needs to be considered when establishing the meaningfulness of an activity (Teitelman, Raber, & Watts, 2010).
- Memory loss support groups can provide benefit for residents (i.e., decreased stigma and isolation, increased self-esteem and well-being, intellectual stimulation), families of those residents, as well as staff (Yale & Kaplan, 2006).

**Safety:**
- Recommended (promising) dementia care practices in assisted living include ensuring person-centred approaches, consistency in care and development of consistent relationships with care providers (Reed & Tilly, 2008). Additionally, safety-specific recommendations include:
  - Regarding wandering behaviour:
Assessing residents for wandering behaviour patterns and triggers; making the environments home-like; ensuring walking pathways free of obstruction.

- Regarding falls and fall prevention:
  - Monitor for needs that may increase the risk of falls; encourage exercise and improvement of strength; ensure furniture is sturdy; provide nonslip floors and footwear.

- Regarding restraint-free care:
  - Individualized care is the key to eliminating the use of physical restraints; use resident’s remaining abilities; properly educate and communicate with family.

**Physical:**
- Garden space was valued by staff and family members as a therapeutic tool to improve quality of life for residents (Hernandez, 2007).

**Other (Cognitive Training):**
- A combination of resident cognitive training and individual-based computer training reduced decline and may have improved cognitive and behavioural functioning in older adults with dementia (Mate-Kole et al., 2007)
- Caregivers reported improvement in participants’ behaviours and socialization (Mate-Kole et al., 2007).

**Emotional Well-Being:**
- Residents at larger sites spent more time away from common areas compared to those living within dementia-specific sites (Kuhn, Kasayka, & Lechner, 2002).
- Residents in the large sites had higher well-being ratings and higher ratings of diversity of interactions and activities contributing to positive well-being (Kuhn, Kasayka, & Lechner, 2002).
- A significant positive association was found between staff member’s level of hope and the resident’s rating of quality of life (Spector & Orrell, 2006).

**Mixed:**
- Overall, negative correlations were found between physical environmental quality and resident neuropsychological scores and fall risk (Bicket et al., 2010).
- Positive correlation was found between physical environment quality and quality of life scores for residents (Bicket et al., 2010).
- Statistically significant improvement in residents’ performance of activities of daily living following an individualized intervention program that included caregiver training in verbal cueing/reinforcement and environmental modifications (Chard, Liu, & Mulholland, 2009).
- In less creative organizational climates (for staff), residents spent more time with fellow residents and residents spent more time alone than with staff members. In creative organizational climates, residents spent more time with staff members and more time with staff than alone (Norbergh, Hellzen, Sandman, & Asplund, 2002).
- Resident and environmental characteristics, related to quality of life for those with dementia living in assisted living, included:
  - Agitation/aggression, apathy and irritability are significant predictors of lower quality of life, and
  - Homelike environment and facility size are not significant predictors of quality of life (Samus et al., 2005)

**Conclusions**
In this report, we have outlined the major findings of the literature review conducted on promising practices in assisted living environments. We discovered promising practices across several topic areas that will help lay the foundation for future research and may provide preliminary information to inform policy and practice in assisted living environments.
IMPLICATIONS FOR POLICY OR PRACTICE
Assisted living has become one of the settings of choice that is growing and diversifying to serve seniors, including people with dementia. Within Alberta there is a provincial strategy that strongly supports assisted living (supportive living) developments, however the implementation and the definitions of the care and support components that are found within these settings, have varied. Whether the variations are meaningful and impactful, or not, is a question for ongoing research and policy/practice development to assess whether these settings have been designed to be the “right place” for those with a dementia as originally envisioned in the “aging in the right place” Alberta Continuing Care Strategy (Alberta Health and Wellness, 2008). Identifying which features and components in assisted living should be included within these settings to promote the best possible quality of life and care for those with dementia, should be of high interest both at a provincial policy level as well as for the organizations that seek to develop and provide assisted living, given the existing and future-predicted prevalence of dementia within assisted living settings (e.g., Strain et al., 2011), even settings not purpose-designed for dementia support. As Alberta now develops a Dementia Care Strategy, this information may also be useful to inform that policy. As well, organizations that build and operate the assisted living buildings for those with a dementia diagnosis can use the collected promising practices as evidence to support design, practice and policy developments. Shepherd’s Care Foundation, one of the largest providers of seniors assisted living in Alberta (including three dementia-specific developments), has used this research and the promising practices identified, across the life of the project, to inform the design of its most recent dementia care assisted living building as well as core components of its organizational dementia care strategy.

DIRECTIONS FOR FURTHER RESEARCH
Research evidence of the promising practices for assisted living dementia care, like those described here, is growing and can inform the policy and practice development at all levels. Given the proliferation of these assisted living settings, especially where they support people with a dementia, future research is certainly needed and should be focused on the following issues:

- A focused definition of “promising practices” in specific practice areas should be used to guide future searches.
- More consistent definitions of assisted living should also be used to ensure that settings discussed in publications are indeed comparable.
- Interventions and outcomes should be specifically targeted to provide evidence for implementation of programs.
- Incorporating grey literature in the form of specialized dementia care practice knowledge (e.g., Alzheimer associations, dementia care standards, model-specific rather than context-specific practices like those of the Pioneer Network, Eden Alternative and Dementia Care Matters, etc.), reports, evaluations, conference proceedings and book chapters should also be highlighted in addition to peer-reviewed articles.

Similar to recommendations made by Tilly & Reed (2008), there is still value to be achieved by focusing future assisted living research in a way that includes assessing those with dementia as a distinct population and identifying the needs and opportunities that may be distinct from those of the general assisted living population.

KNOWLEDGE DISSEMINATION AND TRANSLATION ACTIVITIES
The results have been formally shared, by the University of Alberta Research Assistants, within the local academic community and at a local research conference. The results have also been shared among the research partners (University of Alberta, Government of Alberta and Shepherd’s Care Foundation) and have been used within Shepherd’s Care Foundation to support program, policy and design developments (see previous report sections).

PRINCIPAL APPLICANT (TEAM LEADER)
Suzanne Maisey became the Primary Investigator in year 2 of the project, formally replacing Anna Little, the original Principal Applicant, who did not participate in the project after year 1. As well, the research team changed substantively, in people and roles, across years. To navigate some of those changes, Dr. Susan Slaughter and Dr. Tammy Hopper contributed in kind support in the final year, beyond that.
originally envisioned, through the addition of three Research Assistants who substantively enabled the final project steps.

**PROJECT PARTNERS (TEAM MEMBERS)**

<table>
<thead>
<tr>
<th>Name</th>
<th>Position Title</th>
<th>Topics of interest</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suzanne Maisey, MA</td>
<td>Director of Quality Improvement, Shepherd’s Care Foundation (Principal Investigator; Year 2 forward)</td>
<td>Seniors, Dementia, Continuing Care, Caregivers</td>
</tr>
<tr>
<td>Anna Little, BScN</td>
<td>Continuing Care Practice Leader, Shepherd’s Care Foundation (Original Principal Applicant; Year 1 only)</td>
<td>Seniors, Dementia, Continuing Care, Caregivers</td>
</tr>
</tbody>
</table>

**PUBLICATIONS AND PRESENTATIONS**


ABOUT THE ALBERTA ADDICTION AND MENTAL HEALTH RESEARCH PARTNERSHIP PROGRAM
The Alberta Addiction and Mental Health Research Partnership Program is comprised of a broad-based multi-sectoral group, representing service providers, academic researchers, policy-makers and consumer groups, working together to improve the coordination and implementation of practice-based addiction and mental health research in Alberta.

The mission of the Research Partnership Program is to improve addiction and mental health outcomes for Albertans along identified research priority themes, by generating evidence and expediting its transfer into addiction and mental health promotion, prevention of mental illness, and innovative service delivery.

The Research Partnership Program sets out to increase Alberta’s excellence and output of addiction and mental health research findings, and to better translate of these findings into practice improvements.
REFERENCES


### APPENDIX A

**Assisted Living and “Not Assisted Living” Description**

Assisted living settings are congregate housing settings that combine some collection of accommodation services (e.g., meals, housekeeping, social activities) with other supports and care (e.g., nursing care, help with activities of daily living). Some characteristics of the Assisted Living context and the “Not Assisted Living” contexts follow, to help clarify, but these are high level generalizations and will not hold true everywhere and characteristics may in fact cross the conceptual boundaries constructed (i.e., AL characteristics may additionally be true in “not AL” and vice versa) in some cases. Descriptions are not easily applied as care models vary widely across the housing and care continuums. Information found in this table is guided by clinical and expert opinion of the research team as well as locally relevant information provided by Alberta Health Services (http://www.albertahealthservices.ca/).

<table>
<thead>
<tr>
<th>Living Arrangement</th>
<th>Assisted Living (AL)</th>
<th>Not Assisted Living(^2) (Not AL)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Congregate setting</td>
<td>Congregate setting</td>
<td>Congregate setting</td>
</tr>
<tr>
<td>Newer design; more home-like environments</td>
<td>Newer design; more home-like environments</td>
<td>Older design; more hospital like environments</td>
</tr>
<tr>
<td>High degree of privacy (private rooms)</td>
<td>High degree of privacy (private rooms)</td>
<td>Lower degrees of privacy (private or semi-private rooms)</td>
</tr>
<tr>
<td>Often includes “age in place” goal</td>
<td>Often includes “age in place” goal</td>
<td>Typically a final care living setting</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Resident Population</th>
<th>Assisted Living (AL)</th>
<th>Not Assisted Living(^2) (Not AL)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Typically built specifically for, and serving, seniors</td>
<td>Typically built specifically for, and serving, seniors</td>
<td>Everyone but predominantly serving seniors</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Level of Care</th>
<th>Assisted Living (AL)</th>
<th>Not Assisted Living(^2) (Not AL)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minimal, moderate</td>
<td>Minimal to moderate assistance in personal care (i.e., activities of daily living) as well as instrumental activities of daily living</td>
<td>Minimal to moderate assistance in personal care (i.e., activities of daily living) as well as instrumental activities of daily living</td>
</tr>
<tr>
<td>Moderate to complex nursing care provision and oversight; typically where nursing/medical needs are unstable and unpredictable. Includes:</td>
<td>Moderate to complex nursing care provision and oversight; typically where nursing/medical needs are unstable and unpredictable. Includes:</td>
<td></td>
</tr>
<tr>
<td>• Moderate to complete assistance in personal care (e.g., activities of daily living) and instrumental activities daily living</td>
<td>• Moderate to complete assistance in personal care (e.g., activities of daily living) and instrumental activities daily living</td>
<td></td>
</tr>
<tr>
<td>• Complex nursing care</td>
<td>• Complex nursing care</td>
<td></td>
</tr>
<tr>
<td>• Complex end of life care needs</td>
<td>• Complex end of life care needs</td>
<td></td>
</tr>
<tr>
<td>• Complex medication management</td>
<td>• Complex medication management</td>
<td></td>
</tr>
<tr>
<td>• Inconsistent or unstable behavioral symptoms (i.e., may require every changing support or may place the resident, or others at risk)</td>
<td>• Inconsistent or unstable behavioral symptoms (i.e., may require every changing support or may place the resident, or others at risk)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Level of</th>
<th>Assisted Living (AL)</th>
<th>Not Assisted Living(^2) (Not AL)</th>
</tr>
</thead>
<tbody>
<tr>
<td>This depends on the type of AL setting.</td>
<td>Residents have moderate to severe</td>
<td></td>
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</table>

\(^2\) By definition, Non AL includes both ends of the continuum – those settings where people live in an independent housing setting (e.g., in their own houses, apartments, etc.) that do not provide AL type supports as well as those where people live in settings that provide additional care/supports beyond those found in AL. Characteristics of independent Not AL living are excluded; characteristics of “beyond AL” are included.
<table>
<thead>
<tr>
<th>Assisted Living (AL)</th>
<th>Not Assisted Living(^2) (Not AL)</th>
</tr>
</thead>
</table>
| **Dementia Progression** | 1. General AL setting: Residents have mild-moderate dementia and/or do not frequently exhibit severe or challenging behavioral symptoms (i.e., no known risk of wandering)  
2. Dementia-specific AL setting: Residents have mild – severe dementia. May include residents with severe and/or complex behavioural symptoms, if designed to provide enough skilled support, oversight and/or environmental security.  
dementia combined with the above medical/care needs. They may frequently exhibit severe or challenging behavioral symptoms. |

<table>
<thead>
<tr>
<th><strong>Examples of terminology</strong></th>
</tr>
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<tbody>
<tr>
<td><strong>North America</strong></td>
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<tr>
<td>Supportive living</td>
</tr>
<tr>
<td>Supportive housing</td>
</tr>
<tr>
<td>Residential care</td>
</tr>
<tr>
<td>Continuing Care Retirement Community</td>
</tr>
<tr>
<td><strong>UK</strong></td>
</tr>
<tr>
<td><strong>Scandinavian Countries</strong></td>
</tr>
<tr>
<td><strong>Australia</strong></td>
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APPENDIX B
Search Methodology and Outcomes

The following collection, of keywords and keyword combinations, was used to execute the literature search. The “focused population” keywords were used to identify the literature collection that fit the population most of interest within the study research question: Research articles dealing with, in some way, "assisted living" settings and people with "dementia" (limited to the various acquired disease disorders, not impairments present from birth). The actual words identified for use in the search strategy came from:

- A careful examination of the various database keyword and literature indexing systems,
- Known common labels and terminology, within the fields of seniors housing and dementia care,
- Keywords from “good fit” articles already collected, and
- Expert consultation with the research team and other organizational experts.

Once the “Focused Population” literature collection was identified, that collection was combined, repeatedly and systematically, with each of the other keyword collections (e.g., Administration, Staffing), to generate the study article collection.

### Focused Population

| Residential Facilit* OR Assisted Living Facilit* OR Homes for the aged OR Assisted Living OR Housing for the Elderly OR Continuing Care Retirement Community OR Congregate Housing AND Dementia OR Alzheimer NOT Mental Retardation NOT Intermediate care facilities OR Long-Term Care OR Nursing Homes OR Skilled nursing facilities OR Primary Care |

### Other Keyword Combinations, by Group

**Administration** (Focused Population AND...)
- Facility Design and Construction
- Food Service OR Dining OR Meal
- Organization* Culture OR Organization* Innovation
- Regulation OR Standard
- Patient-Centered Care OR Resident-centered care OR Person-centered care OR Patient Centered Care OR Resident centered care OR Person centered care OR Patient-Centred Care OR Resident-Centred care OR Person- Centred care OR Patient Centred Care OR Resident Centred care OR Person Centred care
- Quality of Health Care
- Safety
- Philosophy
- Spiritual
- Meaning OR Engagement
- Age in place OR Age-in place OR Aging-in place OR Aging in place
- Knowledge transfer OR Research transfer OR Knowledge broker OR Diffusion of innovation OR Knowledge translation

**Staffing** (Focused Population AND...)
- Attitude of health personnel
- Decision making
- Delivery of health care
- Evidence-based practice OR Evidence based practice OR Evidence-based OR Evidence based OR Promising practice
- Practic* guideline OR Professional Practice OR Professional Competence
- Personnel Management

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3 Each line of keywords in a sub-set is added to the “focused population” literature collection, on its own.
### Clinical (Focused Population AND…)
- Accidental fall
- Behavior OR Social behavior
- Hypnotic OR Sedative
- Mood Disorder OR Sleep disorder
- Signs and Symptoms
- Care planning OR Care plan OR Careplan
- Privacy

### Recreation (Focused Population AND…)
- Activities of daily living
- Leisure OR Recreation
- Quality of life OR Meaning OR Engagement

### Education (Focused Population AND…)
- Education OR Training OR Learning
- Assisted Technology device OR Technology

### Model (Focused Population AND…)
- "Culture change" OR Greenhouse OR Eden OR Montessori

<table>
<thead>
<tr>
<th>Limiters:</th>
<th>Date: January 01, 2000 – February 28, 2012</th>
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<tbody>
<tr>
<td></td>
<td>Interface: EBSCOhost</td>
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<tr>
<td></td>
<td>Databases: Health Business Elite; Psychology and Behavioral Sciences Collection; Nursing &amp; Allied Health Collection: Comprehensive; Biomedical Reference Collection: Comprehensive; CINAHL plus with Full Text; MEDLINE with Full Text</td>
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<tr>
<td></td>
<td>Language: English</td>
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<tr>
<th>Expanders (Not applied to the “NOT” exclusions in “focused population”)</th>
<th>Apply related words</th>
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<tbody>
<tr>
<td></td>
<td>Also search within the full text of the article</td>
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<tr>
<th>Search Mode:</th>
<th>Boolean/Phrase</th>
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### Outcomes
Figure B1 depicts the literature collection generated through the application of the various keyword combinations within the “focused population”. Outcomes included:
1. Keywords identifying articles about the assisted living context (red, outer circle) generated 40,340 articles
2. When combined to trim the collection down to only articles dealing with people with a dementia (green, middle circle), the article collection was reduced to 10,830 articles,
3. Finally, with the elimination of "not assisted living" type contexts (purple, inner circle) a final “focused population” collection of 1,927 articles was generated.
Figures B1 and B2: Focused Population Search Results

Residential Facility OR Assisted Living Facility OR Homes for the Aged OR Assisted Living OR Housing for the Elderly OR Continuing Care Retirement Community OR Congregate Housing
n = 40,340

AND Dementia OR Alzheimer NOT Mental Retardation
n = 10,830

NOT Intermediate care facilities OR Long-Term Care OR Nursing Homes OR Skilled nursing facilities OR Primary Care
n = 1,927
Administration

(Focused Population AND...) n = 1,984. Duplicates = 755. n = 1228

• Facility Design and Construction n = 25
• Food Service OR Dining OR Meal n = 261
• Organization* Culture OR Organization* Innovation n = 10
• Regulation OR Standard n = 910
• Patient-Centered Care OR Resident-centered care OR Person-centered care OR Patient Centered Care OR Resident centered care OR Person centered care OR Patient-Centred Care OR Resident-Centred care OR Person-Centred care OR Person Centred care n = 47

• Quality of Health Care n = 31
  • Safety n = 304
  • Philosophy n = 67
  • Spiritual n = 50
  • Meaning OR Engagement n = 245
  • Age in place OR Age-in place OR Aging-in place OR Aging in place n = 30
  • Knowledge transfer OR Research transfer OR Knowledge broker OR Diffusion of innovation OR Knowledge translation n=4

Staffing

(Focused Population AND...) n = 314. Duplicates = 20. n = 294

• Attitude of health personnel n = 24
• Decision making n = 114
• Delivery of health care n = 8
• Evidence-based practice OR Evidence based practice OR Evidence-based OR Evidence based OR Promising practice n = 103
• Practice guideline OR Professional Practice OR Professional Competence n = 48
• Personnel Management n = 17

Clinical

(Focused Population AND...) n = 882. Duplicates = 227. n = 605

• Accidental fall n = 20
• Behavior OR Social behavior n = 555
• Hypnotic OR Sedative n = 25
• Mood Disorder OR Sleep disorder n = 43
• Signs and Symptoms n = 88
• Care planning OR Care plan OR Careplan n = 80
• Privacy n = 71

Recreation

(Focused Population AND...) n = 1,265. Duplicates = 464. n = 801

• Activities of daily living n = 305
• Leisure OR Recreation n = 103
• Quality of life OR Meaning OR Engagement n = 857

Education

(Focused Population AND...) n = 1,346. Duplicates = 473. n = 873

• Education OR Training OR Learning n = 1,017
• Assisted Technology device OR Technology n = 329

Model

(Focused Population AND...) n = 17. Duplicates = 0. n = 17

• "Culture change" OR Greenhouse ™ OR Eden ™ OR Montessori n = 17
Figure B3: Total Number of Articles Extracted = 1,007

Combined n = 3,818
Duplicates n = 2,811
n = 1,007
APPENDIX C
Stage 2 of Exclusion Process

Phase 1 (n = 1007)

Phase 2 (n = 232)

No Abstract (n = 74)

Abstract (n = 158)

Neither Dementia or Assisted Living (n=6)

At least 1 of Dementia or Assisted Living (n = 152)

Not dementia (n = 17)

Dementia (n = 135)

Not Assisted Living (n = 90)

Assisted Living (n = 45)

Irrelevant (n =3)

Relevant to project (n = 42)

Not promising practice (n =23)

Promising Practice (n = 19)
## APPENDIX D

**Results of Literature Review**

<table>
<thead>
<tr>
<th>Study Focus</th>
<th>Author</th>
<th>Location</th>
<th>Promising Practice</th>
<th>Sample(s)/Population(s)</th>
<th>Setting(s)</th>
<th>Method/Design</th>
<th>Major Finding(s)</th>
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</table>
| **Staff**   | Fletcher, S., Zimmermann, S., Preisser, J. S., Mitchell, C. M., Beeber, A. S. & Reed, D. (2010a) | United States | The Foundation[s] of Dementia Care (FDC) staff training program (developed by the Alzheimer’s Association) | 9 trainers from identified Alzheimer’s Association chapters; 784 staff (direct care staff and supervisory staff) | Long-term care (N=9) and assisted living (N=6) settings in 4 US states; selected from chapters of the National Office of the Alzheimer’s Association | Analysis of survey data (satisfaction forms) immediately after sessions; interviews with trainers before and after all sessions; descriptive statistics; paired sample t tests; linear mixed models | When trainers achieved higher fidelity (i.e. spoke from the script, delivering the material as intended) trainees were:  
- Significantly more satisfied  
- Perceived the trainer to be more knowledgeable  
- The more conference calls the trainers participated in the higher their fidelity |
| **Staff**   | Fletcher, S., Zimmermann, S., Preisser, J. S., Mitchell, M., Reed, D., Gould, E., Beeber, A. S. & Reed, P. (2010b) | United States | Implementation of a standardized dementia care training program, (the Alzheimer’s Association’ s Foundation[s] of Dementia Care (FDC) staff training program) across diverse settings | 9 trainers from identified Alzheimer’s Association chapters | Long-term care (N=9) and assisted living (N=6) settings throughout US; selected from chapters of the National Office of the Alzheimer’s Association | Standardized content provided to trainers; monthly conference calls with research staff; audio recordings of sessions; trainer self-report; attendance sheets; statistical comparison between observed fidelity (consistency) and perceived consistency |  
- Overall 86.7% adherence to key words across settings by numerous trainers; standardized trainer manuals and trainer support (conference calls) helps to maintain high implementation consistency |
| **Staff**   | Gould, E., Cox, T., Johnson, M. A., McGuiness Vaillanco & | United States | The Foundation[s] of Dementia Care (FDC) staff training program (developed | n/a | n/a | Response by the Alzheimer’s Association to evaluation of FDC in previous studies |  
- Effective communication and understanding are critical to providing good dementia care  
- Training may be required of administrators if the organizational climate and/or policies and procedures need to be changed to support good dementia care |
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| Staff       | Hobday, J. V., Savik, K., Smith, S. & Gaugler, J. E. (2010) | United States | Internet-based training of CARES® module: Connect with the resident, Assess behaviour, Respond appropriately, Evaluate what works, Share with the team | Certified Nursing Assistants, N=40, Mixed ethnicity, 5 male, 35 female, low mixed computer literacy | 4 nursing homes, 1 assisted living | Assessment of knowledge of dementia care before and after module; questions regarding the CARES® module | • Promising gain in knowledge of dementia care  
• Gain in confidence regarding skills, communicating with people with dementia, acquisition in common language, recognizing signs of pain  
• Barriers = technology, computer literacy |
| Staff       | Teri, L., Huda, P., Gibbons, L., Young, H. & van Leynseele, J. (2005) | United States | STAR (Staff Training in Assisted Living Residences) dementia-specific training program for direct-care Assisted Living staff, consists of a series of modules presented as lecture, discussion, role playing, videos | Feasibility study: 114 direct care staff (night shift excluded) who worked at least one full shift 2 days per week; ethnically diverse staff; 120 assisted residents living with dementia and depression or anxiety. Randomized trial: 25 direct care staff, 31 residents | Feasibility study: 15 assisted living residences  
Randomized trial: 4 assisted living residences; Washington State | Affect and behavioural distress of residents was assessed before and after education; staff skill and job satisfaction was assessed before and after education; sites were randomly assigned to receive STAR or not | Statistically significant improvement in:  
• Behavioural challenges, depression and anxiety among the residents living where staff received STAR training  
• Reaction to resident challenges among staff who received STAR training |
<p>| Staff       | Zimmerman, S., Mitchell, M. (2010) | United States | Foundation of Dementia Care (a) | 477 staff in nursing homes, 185 staff in assisted living (491 direct care) | 9 nursing homes, 7 assisted living sites; half of | Assessment of knowledge, attitudes, stress and satisfaction before intervention and 3 | • Statistically significant increase in knowledge in ‘Improving Communication’ and ‘Pain Awareness’ modules immediately |</p>
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<tbody>
<tr>
<td>Social</td>
<td>Hochhalt er, A. K., Stevens, A. B., &amp; Okonkwo, O. (2007)</td>
<td>United States</td>
<td>Structured Practice (for social and cognitive practice, and long-term information retention) consisting of practice pages, test pages, and social interaction pages</td>
<td>Residents in specialty care assisted living facilities (N=14) with documented cognitive impairment; cognitive impairment typical of mild to severe dementia as measured by an MMSE, the Hopkins Verbal Learning Test-Revised and the Dementia Rating Scale-2</td>
<td>2 specialty care assisted living facilities in one US state</td>
<td>Residents randomly assigned to practice one of two books; one-on-one sessions with research staff several times a week up to retention criterion or training limits</td>
<td>• People living with mild to moderate cognitive impairment can benefit from cognitive training delivered in the Structured Practice format • Participants who showed long-term retention were not necessarily those who scored better on the MMSE</td>
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<tr>
<td>Social</td>
<td>Teitelman, J., Raber,</td>
<td>United States</td>
<td>The power of the social environment</td>
<td>Residents in a memory support unit (N=8); seven</td>
<td>Memory support unit of an assisted</td>
<td>Based upon models: Person Centred Care, Intentional Relationship</td>
<td>• Attitudes and behaviours of caregivers have very powerful influence upon social environment</td>
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<tr>
<td>Safety</td>
<td>Reed, P. &amp; Tilly, J. (2008)</td>
<td>United States</td>
<td>Recommendations for management of wandering, falls, and physical-restraint-free care.</td>
<td>n/a</td>
<td>n/a</td>
<td>Compilation of evidence in literature and experience by national Alzheimer’s Association US; translation into specific recommendations for resident wandering, fall management, physical restraint-free care.</td>
<td>Person-centered approaches, consistency in care, development of consistent relationships with care providers; Increasing staff knowledge of individual residents. Regarding wandering: Assess for wandering patterns and triggers; make environment home-like; low-stimulus setting; walking</td>
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<tr>
<td>Social</td>
<td>Yale, R. &amp; Kaplan, D. (2006)</td>
<td>United States</td>
<td>Memory loss support groups</td>
<td>Residents identified by facility staff as likely to benefit from support group are invited to participate; having documented cognitive impairment (not necessarily a dementia diagnosis) but willing and able to communicate and discuss their feelings; Project 1 N=7 residents, average of 8 family members; Project 2 N=11 residents; Project 3 N=19</td>
<td>2 assisted living facilities in California</td>
<td>Based upon Robyn Yale’s early-stage Alzheimer’s disease support group model; Project 1=concurrent support groups for residents and families on a dementia care unit; Project 2= support group for residents in a different dementia care unit; Project 3= support group for residents in non-dementia assisted living; support group marketed as discussion group in Projects 2 and 3 due to encourage participation and overcome denial of memory issues and hesitation to discuss.</td>
<td>Benefits for residents (i.e. decreasing stigma and isolation; increasing self-esteem and well-being; intellectual stimulation); Benefits for families: (i.e. understanding of disease; skills in interacting with resident; sense of support and community); Benefits for facility and staff (i.e. staff development; reducing family dependence on staff; improved risk management; raising of standard of care; establishing leadership; decreased stigma)</td>
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<td></td>
<td>C., &amp; Watts, J. (2010)</td>
<td>United States</td>
<td>Engagement by residents</td>
<td>females, one male; Caucasian; aged 63-102</td>
<td>living unit; mid-western city, US.</td>
<td>Model and Model of Human Occupation; qualitative study following phenomenology; observation sessions; interviews with family and staff; engagement with individual resident by researcher</td>
<td>• Use of interactive approaches to meet the needs of the resident • More attention needs to be placed upon increasingly subtle ways that residents indicate interest to engage in activity • The experience of the resident needs to be considered when establishing the meaningfulness of an activity, not whether that activity was completed successfully.</td>
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<tr>
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<td>Physical</td>
<td>Hernandez (2007)</td>
<td>United States</td>
<td>Therapeutic garden spaces</td>
<td>Staff (n =28) Family (n =12) Architects (n=5)</td>
<td>Special care units of assisted living facilities in urban centers</td>
<td>Two case studies. Multi-method qualitative research to determine garden design on quality of life of residents with dementia (interviews, behaviour-mapping, observations using the Apparent Affect Rating Scale)</td>
<td>Staff and family members valued the garden space as a therapeutic tool to improve quality of life for residents. Residents, family and staff members engaged with the garden in a variety of ways that were categorized: Low-Level Activity (passive). E.g., viewing the garden from indoors. Mid-Level Activity (redirection and relief from stress and agitation). E.g., sitting outdoors, smoking, music therapy, and social activities. High-Level Activity (picking flowers, planting, and physically gardening)</td>
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<tr>
<td>Other (cognitive training)</td>
<td>Mate-Kole, Fellows, Said, McDougall, Catayong, Dang, &amp; Gianesini (2007)</td>
<td>United States</td>
<td>Interactive cognitive training and computer assisted programs (Mind Aerobics and Adaptive)</td>
<td>Older adults with severe dementia (n=6)</td>
<td>Secured memory impairment unit within an assisted living community</td>
<td>Single case experimental design Neuropsychological tests were administered and caregiver reports of resident behaviours and socialization were collected before and immediately after an intervention</td>
<td>Findings suggest the cognitive training interventions improved overall cognitive functions including short-term memory and cognitive failures. Caregivers reported improvement in participants’ behaviours and socialization. This combination of cognitive training and individual-based computer training reduced decline and may have even</td>
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<td>Emotion well-being</td>
<td>Kuhn, Kasayka, &amp; Lechner (2002)</td>
<td>United States</td>
<td>Residence in small dementia specific sites and large non-dementia specific sites</td>
<td>Persons with dementia (n=131)</td>
<td>10 assisted living facilities. 7 sites were exclusively for residents with dementia (10-28 residents/site); n = 97 residents 3 sites were non-dementia specific; n = 34 residents</td>
<td>Dementia Care Mapping was used to measure quality of life and interaction among residents and staff. Observations were coded (24 behaviour mapping codes) according to behaviour and person’s state of relative well-being An average of 114 observations were made per resident in the course of a day</td>
<td>• Residents’ most frequently observed behaviours: eating/drinking, being passively socially involved, and sleeping  • Second most frequent behaviours: walking and interacting verbally.  • Residents at larger, non-dementia-specific sites spent more time away from common areas compared to smaller, dementia-specific sites.  • Residents in the large sites had higher well-being ratings and higher ratings of diversity of interactions and activities contributing to positive well-being.</td>
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<tr>
<td>Emotion well-being</td>
<td>Spector &amp; Orrell (2006)</td>
<td>United Kingdom</td>
<td>Increased hope in staff related to resident quality of life (QoL)</td>
<td>Seventy-six dyads of people with dementia and care staff</td>
<td>9 residential homes</td>
<td>The Quality of Life-Alzheimer Disease (QoL-AD) was administered to each resident with dementia and completed on behalf of the resident by a staff member. Staff members were also measured on a Job Satisfaction Index and Approaches to Dementia Questionnaire that asked for ratings of agreement with statements about dementia.</td>
<td>• Persons with dementia ratings and staff ratings were significantly correlated on measures of physical health, family, and friends.  • Measures of memory, ability to do chores, marriage/closest relationship, and life as a whole revealed a clinically significant difference between staff and person with dementia ratings, but not a statistical difference.  • There was a poor person-proxy correlation in general, for QoL; care staff rate QoL differently from the person with dementia  • Positive association was found between staff member’s level of hope and the resident’s rating of quality of life.</td>
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<tr>
<td>Mixed: Emotional well-being and physical environment</td>
<td>Bicket et al. (2010)</td>
<td>United States</td>
<td>Physical factors in the environment associated with resident well-being</td>
<td>Residents in assisted living (n=326) - With dementia (n=194) - Without dementia (n=131)</td>
<td>30 Assisted living facility (13 large, 17 small)</td>
<td>Prospective cohort study</td>
<td>- Overall negative correlations found between physical environmental quality and: Resident neuropsychological scores; fall risk - Positive correlation was found between physical environment quality and quality of life scores for residents - Dignity (room autonomy, privacy, etc.) and sensory (visual/tactile) stimulation were positively associated with resident variables - Association were stronger in residents without dementia</td>
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<tr>
<td>Mixed: Staff and behaviour</td>
<td>Chard, Liu, &amp; Mulholland (2009)</td>
<td>Canada</td>
<td>Individual intervention programs that train caregivers in verbal cueing/reinforcement and environmental modifications</td>
<td>Residents with Alzheimer disease (n=5)</td>
<td>Assisted living facility</td>
<td>Prospective before and after design examined the effectiveness of caregiver training in verbal cueing and reinforcement along with environmental modifications (e.g., labelling drawers, removing distraction, etc.) on the activities of daily living (ADL) performance</td>
<td>- All 5 participants had statistically significant improvement in performance of ADL following an individualized intervention program that included caregiver training in verbal cueing/reinforcement and environmental modifications</td>
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<td>Mixed: Staff and social</td>
<td>Norbergh, G., Hellzen, Sandman, &amp; Asplund (2002)</td>
<td>Sweden</td>
<td>Creative or less creative organization climate for staff</td>
<td>Staff (n=57) - Residents with dementia (n=38) - Creative climate (n=18) - Less creative</td>
<td>4 group-dwelling units Two with a creative organizational climate; Two</td>
<td>Staff rated the organizational climate, using the Creative Climate Questionnaire, on 10 categories of work climate such as Challenge, Idea Support,</td>
<td>- In creative climates residents: Spent more time with staff members than in less creative climates; more time with staff than alone; passive activities in the presence of nursing staff were more frequent - In less creative climates, residents:</td>
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<tr>
<td>Mixed: Behaviour and staff and physical environment</td>
<td>Tilly &amp; Reed (2008)</td>
<td>United States</td>
<td>Intervention s that could improve care</td>
<td>N/A</td>
<td>Assisted Living &amp; Nursing Homes</td>
<td>Literature review for interventions that could improve care. Peer reviewed literature from 1994-2003. Included 72 studies/review articles</td>
<td>Literature review described interventions related to activities of daily living (physiological needs, hygiene and personal care); psychosocial and behavioural symptoms; alleviating psychiatric and behavioural symptoms</td>
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