Comprehensiveness of the RUG-III grouping methodology in addressing the needs of people with dementia in long-term care

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Abstract

Funding of services to residents in publicly funded long-term care (LTC) facilities has historically rested upon a list of physical needs. However, more than 60% of residents in nursing homes have dementia; a condition in which physical needs are only a part of the overall clinical picture. Since past funding formulas focused primarily on the physical characteristics of residents, the Ontario government has adopted the RUG (Resource Utilization Groups)-III (34 Group) for use in LTC facilities which follows the adoption of the Minimum Data Set (MDS) 2.0 assessment instrument. Some still question whether the newer formula adequately reflects the care needs of residents with dementia despite its validation in many countries.

The purpose of this study was to determine the comprehensiveness of the RUG-III (34 Group) in addressing the needs of residents with dementia living in LTC. First, a critical systematic review of the literature was conducted to determine the needs of residents with dementia. Numerous electronic databases were searched for articles published between January 2000 and September 2010, and later cross-referenced. Second, needs identified from the literature were matched to the items of the RUG-III which are selected variables of the MDS 2.0. Third, the priority of the items in the RUG-III was analysed in accordance with the importance of the identified needs.

The documented needs were taken from 68 studies and classified into 19 main categories. The needs most supported by the literature were the management of behavioural problems, social needs, the need for daily individualized activities/care and emotional needs/personhood. Among the needs identified, activities of daily living (ADLs), cognitive needs and general overall physical health met the most RUG-III items. These needs were found to be well represented within the system. Other needs of importance such as social needs are not thoroughly considered in the grouping methodology though matched to MDS variables. The fact that these needs are not well addressed in the RUG-III poses concerns. Future research is needed to validate the significance of these needs. Considerations should be made as to the adequacy of the funding system and the allocation of funding.

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List of Abbreviations

AD	Alzheimer's disease
ADL	Activities of daily living
AL	Assisted Living
AMSTAR	Assessment of multiple systematic reviews
ARCS	Alberta Resident Classification System
CANE	Camberwell Assessment of Need in the Elderly
CBoC	The Conference Board of Canada
CCAC	Community Care Access Centre
CCIM	Community Care Information Management
CHA	Canadian Healthcare Association
CIHI	Canadian Institute for Health Information
CMI	Case-mix index
CMS	Centers for Medicare & Medicaid Services
DLB	Dementia with Lewy Bodies
EOL	End-of-life
FTD	Fronto-temporal dementia
IADL	Instrumental activities of daily living
LTC	Long-term care
MDS	Minimum Data Set
Me SH	Medical subject headings
MMSE	Mini-Mental State Examination
MOHLTC	Ministry of Health and Long-Term Care
NH	Nursing home
NHMRC	National Health and Medical Research Council
NPC	Nursing and Personal Care
NUPGE	National Union of Public and General Employees
OA	Other Accommodation
P-O-S	Physical, occupational and speech therapy
PSS	Program and Support Services

PWD	People with dementia
QoL	Quality of life
RAI	Resident Assessment Instrument
RF	Raw Food
RC	Residential Care
RCT	Randomized controlled trial
RUG	Resource Utilization Groups
SIGN	Scottish Intercollegiate Guidelines Network
VaD	Vascular Dementia

Chapter 1 - Literature review

This chapter introduces long-term care (LTC) funding in Ontario and the Resource Utilization Groups (RUG)-III (34 Group) grouping methodology as well as some background information and details on the Minimum Data Set (MDS) 2.0 assessment instrument which constitutes the basis for the RUG-III. Dementia in long-term care is also briefly discussed. The problem formulation, the purpose and objectives of the study are outlined and a thesis outline is presented at the end of the section.

1.1 Long-term care funding

Long-term care services in Canada are considered to be extended health care services within the context of the principles of the *Canada Health Act* of 1984 (Canada Health Act, 1984). While "medically necessary" services such as hospital services, physician services and surgical-dental services are regulated across Canada under the Act, long-term care services have been free to develop differently throughout the country (Canada Health Act, 1984). As an extended health care service, no constraints and standards are placed on provincial governments for the provision of LTC within their jurisdictions. Both the provincial government and the user assume the costs of long-term care services. The portion paid by the user refers to the resident co-payment (facility charge or accommodation fee). All long-term care residents are subject to a fixed daily rate (Canadian Healthcare Association [CHA], 2009). However, the co-payment rate varies depending on the type of accommodation and province/territory of residence. In Ontario, for example, the daily rate for a private room is $71.23 whereas the rate for a basic accommodation (rooms with three or more beds) is $53.23. Subsidies are available to residents with insufficient income to cover the costs of the basic accommodation (Community Care Access Centre [CCAC], 2011).

In Ontario, the Ministry of Health and Long-Term Care (MOHLTC) allocates funding to facilities on a per diem basis through four funding envelopes. The four funding components with examples of associated expenditures and per diem are: (1) Nursing and Personal Care (NPC) (e.g. salaries for direct care staff who provide assistance with activities of daily living) ($86.05),

(2) Program and Support Services (PSS) (e.g. salaries and benefits for active staff such as physiotherapists and recreational staff who provide recreation and social activities) ($8.35), (3) Raw Food (RF) (e.g. purchase of raw food including food materials and supplementary substances ordered by a physician) ($7.46), and (4) Other Accommodation (OA) (e.g. housekeeping services and property maintenance) ($51.08) (MOHLTC, 2011a). The per diem for each component (see Appendix 1) is set and adjusted by the MOHLTC annually, and represents the base funding allocated to residents on a daily basis.

The per diem associated to the first funding component (NPC) is adjusted by a case-mix system to reflect resident acuity whereas the other components are fixed annual rates (MOHLTC, 2011a). For example, a resident with above average care needs will reflect a higher NPC per diem, than the base per diem set at $86.05. Case-mix systems represent the relative costs of caring for individuals with specific types of needs.

Case-mix systems utilized by LTC facilities hold a number of categories and subcategories. Each subcategory is associated to a specific case-mix index (CMI)[1] value which takes into consideration the care needs of the resident. For instance, a resident needing more care will be assigned to a higher ranked subcategory, hence a category with a higher CMI. If a resident meets more than one subcategory, the subcategory with the highest CMI value is selected. In the RUG-III (34 Group) grouping methodology for instance (see Appendix 2), a resident meeting subcategories 14 (CB1) and 17 (IB2), which are associated with CMI values of 1.1161 and 0.9729 respectively (see Appendix 3), will be classified in the higher ranked subcategory, thus CB1. Care provided to such a resident is more costly and thus, the facility is reimbursed at a higher rate (Hirdes, 2001). Residents' CMIs are summarized to determine the facilities' case-mix index. The CMI of the facility is subsequently multiplied by the base NPC to obtain the NPC adjusted for CMI that defines the reimbursement which that facility is entitled to receive. Each facility's adjusted NPC is calculated once a year based on the resident population for the last year (MOHLTC, 2011a). It is important to note that the facility will not be reimbursed at the exact amount determined by the case-mix system due to a set budget, but rather, at a proportionately

[1] A CMI measure represents the relative care requirements (resource use) of residents. A LTC home is also assigned a CMI numeric value which represents the average resource use of its residents (MOHLTC, 2011b). A CMI of 1.0 represents the average resource use of residents (MOHLTC, 2011a).

higher rate than facilities with an average mix of residents. In brief, facilities with higher CMIs will receive proportionally higher funding levels in comparison to facilities with lower CMIs.

1.1.1 Implementation of the Minimum Data Set 2.0 in long-term care

In June 2005, the MOHLTC initiated the implementation of the Resident Assessment Instrument (RAI) – MDS 2.0 for use in all long-term care homes. The move towards this assessment instrument was to improve the quality of care provided to residents and standardize the assessment and care planning process (Community Care Information Management [CCIM], 2011). The tool used prior to the MDS 2.0, the Alberta Resident Classification System (ARCS), was not designed to help plan resident care (MOHLTC, 2011a).

The MDS 2.0 is part of the interRAI family which is by definition "a collaborative network of researchers in over 30 countries committed to improving health care for persons who are elderly, frail, or disabled" (InterRAI, 2006, "Mission and Vision"). The network has developed a series of assessment tools with a number of applications such as quality indicators and allocation indicators. All tools have been designed for specific populations and settings, and share common measures to enable data comparison throughout the continuum of care (InterRAI, 2006).

The MDS 2.0 is a standardized tool which gathers information on resident needs, preferences and functional status (e.g. cognitive patterns, physical functioning and psychosocial well-being) over a 24-hour period. The tool contains more than 400 variables categorized within 23 sections. Each section represents an area of care. Section J (Health conditions) for example, includes a number of variables (e.g. J1c – dehydrated) targeted to "record specific problems or symptoms that affect or could affect the resident's health or functional status, and to identify risk factors for illness, accident, and functional decline" (Morris et al., 2010, p.187). This information guides staff in the development of a comprehensive and individualized care plan. The assessment is completed upon admission of each resident as well as quarterly and when significant changes in the health status occur (Morris et al., 2010). The RAI-MDS 2.0 has been in place across Ontario LTC homes since the summer of 2010 (CCIM, 2011).

Despite its many advantages and tested reliability and validity, the tool is not without a few limitations. Data quality concerns have been raised by a number of stakeholders stating that

some of the items within the system are more accurate than others. Measures that are observable (e.g. activities of daily living (ADLs)) are stronger than those which require a judgement (e.g. cognitive patterns, psychosocial well-being and activity pursuit patterns) (Poss et al., 2008; Rahman & Applebaum, 2009). As a result, inaccuracies in data collection are possible and some aspects of care tend to be overreported such as the resident's level of functional dependency (Shin & Scherer, 2009).

1.2 Resource Utilization Groups-III (34 Group)

As of April 2010, the MOHLTC adopted the Resource Utilization Groups (RUG)-III (34 Group) grouping methodology as the case-mix system for adjusting the NPC funding component in LTC facilities as a result of the adoption of the MDS 2.0 across the LTC sector (see Appendix 2). While the MDS 2.0 identifies resident characteristics, the RUG-III uses selected resident characteristics (105 MDS variables) to group residents in fundable bins that reflect their resource consumption (Canadian Institute for Health Information [CIHI], 2009a). The MDS 2.0 variables used in the RUG-III are listed in Appendix 4. The adoption of the RUG-III for funding purposes was also due to a number of limitations perceived in the ARCS. To name a few, the system as a whole (e.g. funding weights) had never undergone any adjustments from its original version developed in Alberta in 1988 (Pink, O'Brien-Pallas, & Leatt, 1994) and the system did not adequately account for the unique and changing needs of residents (MOHLTC, 2011a; National Union of Public and General Employees [NUPGE], 2007) and especially those with cognitive, emotional and behavioural problems (Ontario Health Coalition, 2008). The ARCS relied on a limited number of characteristics which are strictly physical in nature (Charles & Schalm, 1992; Hirdes, 1997, 2001).

The RUG-III was developed in the United States in the early 1990s as part of a strategy by the Multistate Nursing Home Case Mix and Quality Demonstration group to develop a single classification system for use in both Medicaid and Medicare and to respond to changes in practice patterns. The tool was developed based on the assessment of resident characteristics, using the original version of the MDS, and detailed nursing staff measurement (resource use) over a 24 hour period from a sample of 7 658 residents from 203 nursing homes (NH)s in seven US states. The type and amount of resources needed by residents (dependent variables) were

chosen to form the basis of the grouping methodology (RUG groups). All MDS variables were considered for inclusion in the RUG-III grouping methodology, but only those explaining resource utilization were selected (Fries et al., 1994). The system has been validated in a number of countries (e.g. United States, Switzerland, Iceland and Spain) and is today one of the best known case-mix classification systems of the InterRAI (Resident Assessment Instrument) organization for use in institutional LTC settings (InterRAI, 2007a).

While the 44-group version of the RUG-III appears to be the standard version of the system used in Canadian LTC settings, the MOHLTC adopted the 34-group version (CIHI, 2011; MOHLTC, 2011a). This version is said to be better adapted for the Ontario LTC setting where nursing rehabilitation needs are rare (e.g. training in dressing and communication). For example, nursing rehabilitation needs account for approximately 4% of the needs of residents in LTC facilities in comparison to 50% in complex continuing care hospitals (Poss & Hirdes, 2008). The main difference in both versions of the RUG-III relate to the nursing rehabilitation category. In the 44-group version, 14 subcategories relate to nursing rehabilitation in comparison to four subcategories in the 34-group version. The nursing rehabilitation category is also placed in first rank in the 44-group hierarchy as opposed to the 34-group version where this category appears in second after extensive services (CIHI, 2011).

The 34-group version of the RUG-III has seven main categories (ranging from highest to lowest care intensity), namely: (1) extensive services, (2) special rehabilitation, (3) special care, (4) clinically complex, (5) impaired cognition, (6) behavioural problems, and (7) reduced physical function. These seven categories are further divided in subcategories on the basis of ADL dependency (bed mobility, transfer, eating and toilet use), extensive services (e.g. parenteral feeding, IV medication, suctioning, tracheostomy care or ventilator/respirator), depression and rehabilitation (physical, occupational, and/or speech therapy) (Appendix 2). Every subcategory is ranked by cost, each having a specific CMI value. The SE3 subcategory within the extensive services category is ranked first and holds the highest CMI value. Residents classified in this subcategory require the highest resource needs which are reflected by the need for up to five extensive services (e.g. IV medication) with significant ADL dependency. The subcategory ranked last and associated to the lowest CMI is the PA1 subcategory within the reduced physical function category. Residents classified within this subcategory have the lowest resource needs

which are reflected by reduced physical functions with no significant ADL dependencies and nursing rehabilitation requirements (Centers for Medicare & Medicaid Services [CMS], 2001). When looking at the 2010-2011 CMI values released by the Canadian Institute for Health Information (CIHI) for funding nursing home residents in Ontario, SE3 has a CMI value of 1.9422 whereas PA1 has a CMI value of 0.6308 (Appendix 3) (CIHI, 2009b), suggesting that residents classified within the SE3 subcategory use about three times the resources of residents classified in the PA1 group. A resident may meet the qualification criteria for many RUG-III groups, but is only assigned to the group with the highest payment rate. Residents who do not meet the criteria of any of the first six categories are assigned to the lowest category of funding, the reduced physical functions category of the RUG-III. The classification of residents within this category depends on the support needed with ADLs and the need for nursing rehabilitation (CMS, 2001).

The RUG-III case-mix system seems promising in addressing the needs of people with dementia in LTC. In addition to the tool's complexity and validation in many countries, it contains a separate hierarchy for classifying residents with impaired cognition. The impaired cognition category was added to the RUG-III version as a result of the refinement process of the tool which examined the relationship between residents' cognitive dysfunctions (e.g. dementia) and the staff time and costs related to their care (Fries, Mehr, Schneider, Foley, & Burke, 1993). The authors found, as in other studies, that dementia was correlated with increased resource use. Caring for residents with cognitive impairment as a whole was associated with slightly higher staff time than caring for less physically-impaired residents without serious medical conditions and not receiving heavy rehabilitation (Fries et al., 1993).

While the RUG-III is expected to be better suited to meet the needs of cognitively impaired residents, it is hypothesised that the tool will not fully capture the resource needs of people with dementia. Resident characteristics considered within the impaired cognition category of the RUG-III are the level of cognitive impairment (moderate to severe) and ADL impairment as well as short-term memory, cognitive skills for daily decision making and ability for self-expression. The need for nursing rehabilitation services (e.g. communication training and toileting program) is also considered. Characteristics such as behavioral problems however are not considered in this category and thus, such problems may not be accounted for in a resident's care plan in the

event where a resident demonstrates behaviors and qualifies in the impaired cognition category. As argued by McGuire (2010), very few LTC residents, many of whom have AD and other dementias, classify within the 'Behaviour Problems' category, being relegated to other RUG groupings. Residents with dementia may not meet the criteria of this category due to other clinical conditions such as greater ADL impairment (score between 11 and 18) and symptoms of depression (McGuire, 2010). The resources necessary to manage problem behaviours, in and of themselves, may not be properly accounted for if residents are classified in other groupings not related to the behaviour problem category. Further, most LTC residents in Ontario (44.3%) meet the lowest resource intensive category of the RUG-III (reduced physical functions) even though nearly 60% of residents have dementia (Hirdes, Mitchell, Maxwell, & White, 2011) and dementia has been found to be associated with greater resource use. This is important considering, as reported above, that the MDS 2.0 system has been found to underreport items which require judgement such as items pertaining to cognitive patterns.

1.3 Dementia in long-term care

The majority of residents living in long-term care facilities have a diagnosis of dementia (Hirdes et al., 2011; Holroyd, 2004). More than 60% of residents in nursing homes have dementia (Hirdes et al., 2011), and nearly 40% of people in residential care (RC)/assisted-living(AL) facilities have moderate to severe dementia (Zimmerman et al., 2005). Dementia is "characterized by multiple cognitive deficits that include memory impairment and at least one of the following cognitive disturbances: aphasia, apraxia, agnosia, or a disturbance in executive functioning" (American Psychiatric Association, 2000, p.148). Among all types of dementia, Alzheimer's disease (AD) is the most common, representing approximately 60% of all cases. Other types include vascular dementia (VaD), Fronto-temporal dementia (FTD), dementia with Lewy Bodies (DLB) and Creutzfeldt-Jakob disease (Grealy, McMullen, & Grealy, 2005; Levine, 2006). Symptoms differ greatly in type and frequency, and vary from one person to another depending on the type and stage of the condition (Jacques & Jackson, 2000; Landreville, Rousseau, Vézina, & Voyer, 2005). However, the most important symptoms are memory loss and behavioural and psychological symptoms (Landreville et al., 2005). Over half of residents with dementia exhibit disruptive behaviours such as physical aggression and verbal outburst (Kolanowski, Buettner, Costa, & Litaker, 2001; Kovach, Kelber, Simpson, & Wells, 2006) and

more than one neuropsychiatric symptom (i.e. depression and apathy) (Kverno, Rabins, Blass, Hicks, & Black, 2008). Institutionalization is usually a result of the progression and severity of symptoms of a behavioural and/or psychological nature (Grealy et al., 2005; Holroyd, 2004; Landreville et al., 2005). Physical symptoms typically only appear at the later stages (Kovach, Kelber, et al., 2006; Kovach, Wilson & Noonan, 1996), unless the dementia is of a vascular nature. In the latter case, areas of the brain affecting motor control might be damaged thereby affecting mobility.

Dementia remains one of the most challenging conditions for health professionals (Lai, 2003). O'Brien and Caro (2001) found, based on 1995 resident data from the Massachusetts Medicaid database, that nursing home residents with dementia require on average 22% more care (or 229 additional hours of care per year) than people without cognitive impairment. In this study, the care needs of residents is reflected by a scoring system incorporating the basic nursing and caregiving activities, more specifically ADLs, as well as certain resident characteristics (e.g. continence and behavioural problems) that lead to additional care. Interestingly, this additional care includes care resulting from behavioural problems. About 70% of residents with dementia with documented behaviours moved to higher levels of care solely on account of these symptoms (O'Brien and Caro, 2001). Disruptive behaviours may require additional staff time as they can be challenging to manage. As the population ages and the number of seniors with dementia rises, the long-term care required by residents with dementia alone is expected to increase ten-fold (Alzheimer Society of Canada, 2010).

1.4 Problem formulation

According to Cohen-Mansfield and Mintzer (2005) and Orrell et al. (2008), the needs of people with dementia (PWD) are unmet in LTC. Several factors contribute to the issue, such as the improper allocation or lack of resources (Cohen-Mansfield & Mintzer, 2005). In fact, direct care workers feel most incapable of meeting residents' social, psychological and emotional needs (Bruce, Surr, Tibbs, & Downs, 2002; The Conference Board of Canada [CBoC], 2011).

Understanding and responding to the needs of PWD is of great importance as unmet needs are a source of increased disruptive behaviours (Kaplan & Hoffman, 1998; Kovach, Kelber, et al., 2006; Orrell et al., 2008). It is thought that only about 10% of residents' symptoms are caused by

the dementia itself with the other 90% resulting from the quality of care PWD receive (Nazarko, 2009). For instance, a problematic behaviour exhibited by a resident with dementia may be a means to express discomfort or a lack of social support. Hancock, Woods, Challis and Orrell (2006) found a higher score on the Challenging Behaviour Scale to be positively correlated with higher unmet needs *($r= 0.22$, $p<0.01$)* among residents with dementia in residential care homes. Unmet needs lead to greater behavioural problems which become a very challenging issue to both caregivers and residents (Buhr & White, 2006) and become associated with decreased quality of life (QoL) (Chung, 2004; Orrell et al., 2008).

Residents with dementia in long-term care have a variety of complex needs which change over time as the condition progresses. While there exists' a plethora of studies dealing with disruptive behaviours and dementia, only two cross-sectional studies address the question of need from the perspectives of residents themselves. Hancock et al. (2006) highlight the unmet needs of PWD as identified from the perspective of residents whereas Orrell et al. (2008) report on the comparison of ratings of needs as assessed by the residents, the staff and the family caregivers. Unmet needs as reported by both studies were the lack of stimulating daytime activities and social company, lack of support to help cope with psychological distress (e.g. depression and anxiety), as well as poor assistance with memory, eyesight and hearing problems. Needs that were more likely to be fulfilled were those of a basic nature such as food and appropriate accommodation (Hancock et al., 2006; Orrell et al., 2008). Reed and Tilly (2008) suggest that the care fundamentals of PWD should not only include the relief of discomfort and pain, but the need for social support, the opportunity to engage in meaningful activities as well as the basic need of consuming adequate food and fluid (Reed & Tilly, 2008). At the end-of-life, care for physical symptoms (including pain) and behavioural symptoms become the focus (Tilly, Reed, Gould, & Fok, 2007).

A number of other studies have looked at the needs of people with dementia, but have focused on community dwellers, which often include higher functioning individuals. Bossen, Specht and McKenzie (2009) conducted a literature review looking at the needs of older adults with early stage Alzheimer's disease. Some of the needs identified were the need to be heard, the need for information and knowledge, and the need for health promotion (Bossen et al., 2009). A systematic review of the literature looking at the needs of people with dementia residing in the community was also conducted. Studies selected for review included mostly residents from adult

day programs and memory or psychogeriatric clinics. Only three studies from those selected included a sample of residents with severe cognitive impairment. Identified needs included the need for adequate strategies to cope with disabilities, the need to be respected and accepted as well as the need to come to terms with the condition (Van der Roest et al., 2007). As needs of individuals with early stage dementia differ greatly from those with moderate to severe impairment, results from these reviews cannot be generalized to individuals living in LTC facilities.

Since LTC is partly funded by the healthcare system in Ontario and Canada, and since unmet needs appear to lead to disruptive behaviours and potentially a need for more resources, it is important to identify the "real" needs of this resident population as soon as possible. Additional funding cannot simply be added to address these needs but careful analysis of the healthcare system funding allocation mechanism in terms of responding to these needs may indeed be an important avenue of exploration.

1.5 Purpose of study

As a result of potentially unmet needs in LTC, there is reason to believe that case-mix systems may not capture the full spectrum of needs for a population with cognitive impairment. Care provided in LTC is largely focused on the physical needs (Bruce et al., 2002; Hancock et al., 2006). However, PWD have complex care needs and physical aspects only represent a part of their overall clinical picture, and though more so in the later stages of the condition.

The aim of the current study is to determine, using the best evidence possible, the needs of residents with dementia in long-term care and to evaluate the comprehensiveness of the current funding mechanism utilized by the Ontario provincial government to address these needs.

1.6 Objectives

The main objective of the current study is to answer the following question: Does the RUG-III adequately address the needs of PWD in long-term care? The specific objectives of this study are to:

a) Determine the needs of residents with dementia living in long-term care as identified by the best studies in the current literature, regardless of severity and type of dementia;
b) Link the identified needs with the items of the case-mix classification system; and
c) Analyze the priority of items in the grouping methodology in relation to the importance of the identified needs in the literature.

1.7 Thesis outline

In order to answer our research question, the thesis has been structured as follows.

Chapter 2 describes the methodology used in this study. The approach adopted for data collection and the data analysis process are described in detail. A three part methodology was adopted.

Chapter 3 outlines the results of the data collection phase and the analysis. The needs of people with dementia are presented with a greater emphasis on the needs that were more heavily supported by the literature. The linking of the needs with the case-mix system items and their relative importance within the system are further described.

Chapter 4 discusses the comprehensiveness of the RUG-III in relation to the identified needs in the literature. The implications of the results as well as the study limitations/methodological issues and recommendations for future research are also discussed.

Chapter 5 concludes briefly on the appropriateness of the funding system for people with dementia in long-term care.

Chapter 2 - Methodology

The objectives of the study were attained using a three part methodology. First, a systematic review of the literature was conducted to determine the documented needs of people with dementia living in long-term care facilities. The review was designed to answer the following question: **What are the (care) needs of people with dementia living in long-term care facilities as supported by the best evidence?** The method allowed for critical appraisal and synthesis of all relevant studies on this particular topic by means of a well-defined scientific strategy. In the second part of the methodology, the MDS 2.0 variables used in the calculation of the RUG-III (34 Group) grouping methodology were matched with the needs identified in the literature. Other MDS variables not considered in the calculation of the RUGs were sought for possible relevance to the unmatched needs. In the final and third part of the methodology, the significance of the items and components of the RUG-III grouping methodology were analyzed in accordance to the importance of the needs as supported by the literature.

2.1 Objective 1: Identifying the needs

2.1.1 Search strategy

Searches were conducted in various databases, namely: MEDLINE, CINAHL, HealthSTAR, EMBASE, PsycINFO and the Cochrane Library. The searches were limited to the period of January 1, 2000 to September 16, 2010 inclusively, and to English and French publications. A ten-year span was applied to obtain an appropriate breadth of information representing the latest research. Over the last decade, there has been an increasing interest in dementia care research as well. All types of studies (e.g. theses and book chapters) were considered for review. The following search strategy was used:

- (care needs OR needs assessment OR health services needs and demand OR Camberwell assessment OR quality of life)
- AND (dementia OR Alzheimer Disease OR vascular dementia OR frontotemporal dementia)

- AND (long-term care OR long term care OR longterm care OR nursing home OR geriatric nursing OR homes for the aged OR charitable home OR municipal home OR aged care home OR care home)

The above search terms were entered as Medical subject headings (Me SH) and/or keywords. Boolean operators (e.g. AND, OR, NOT), proximity operators (e.g. pre/n) and truncation symbols (e.g.*) were also used to further delineate the search strategy in each database. A list of the specific search commands are attached (Appendices 5 to 10). A subject librarian from the University of Ottawa was consulted to develop the search strategy and offered guidance throughout the search process. Additional relevant studies were searched in the reference lists of the studies that met all eligibility criteria. The full book of relevant book chapters was retrieved and searched for other chapters of interest.

Full articles were retrieved from the University of Ottawa library resources. For those not available from the library resources, including the interlibrary loan service, the authors of the study were contacted.

2.1.2 Criteria for selection of studies

Studies were selected on the basis of the following criteria. Studies needed to 1) relate to individuals with dementia and 2) offer a description of the (care) needs of individuals with dementia living in long-term care.

In order for a study to be eligible for inclusion, study participants had to have a diagnosis of dementia or suspected dementia, and reside in a LTC setting. If the majority of study participants did not have dementia or reside in LTC, results needed to be separated by setting and impairment level to meet eligibility requirements. Only the results related to dementia and LTC were of interest. The LTC setting included but was not limited to nursing homes and long-term care facilities. Geriatric nursing, homes for the aged, aged care homes, care homes with nursing and municipal homes were included as other analogous terms. The terminology varies greatly within and between countries. The initial focus of the review was to retrieve papers conducted in settings that offered 24h long-term care services to people with dementia. It was later found, after completing the database searches, that residential care and assisted living facilities are

gaining popularity over LTC (Ballard et al., 2001; Stone, 2000). More than half of residents in these facilities have Alzheimer's disease or a related dementia, and a significant proportion consists of people with moderate to severe impairment (Alzheimer's Association, 2004). Data from a sample of RC and AL facilities in four US states suggests that between 23% and 42% of residents have moderate to severe dementia, depending on the type of facility. Smaller facilities (fewer than 16 beds) have been found to house residents with more severe impairment, in comparison to facilities with a greater number of beds (Zimmerman et al., 2003). As a result, papers conducted in RC and AL facilities were considered for eligibility.

Studies were excluded if they were anecdotal, letters to the editor, expert opinions (including 'non-study' book chapters) and non-systematic literature reviews. While useful in stimulating thought processes, these types of literature were excluded as their level of evidence is considered weak by the scientific community in providing concrete results. Studies were further excluded if the setting of focus was one of the following: community, adult day center and/or acute care hospital.

2.1.3 Screening of the studies

Studies were selected based on the i) title and abstract, and ii) full-text. The selection of studies was done by two independent judges (J1 and J2)[2]. When disagreements occurred, a third judge (J3) assessed the relevance of the studies. The relevance of the articles was determined with the use of a specifically developed data abstraction form (Appendix 12). The form helped to standardize the process of selection of relevant studies for review (part 1) and extraction of appropriate information (part 2). The first section of the form incorporated the list of inclusion and exclusion criteria, as outlined in the previous section. To determine the relevance of a study, the list of criteria was analysed in the same order, from top to bottom, until the study did not fulfill a particular criterion. To ensure adequacy, the form was pilot tested by two individuals (J1 and J2) by means of five randomly selected articles. Slight modifications (i.e. separation of anecdotal exclusion criterion from other criteria) were made as a result. Only the articles meeting all inclusion criteria were kept for further analysis. Judges were asked to include the article in the next filtering round if they had any doubt. In other words, judges were told to include rather than

[2] A detailed list of the judges' part of this study is outlined in Appendix 11.

to exclude all articles for which they were unsure. All articles of potential interest that were identified in the reference lists of the selected articles were retrieved by one judge (J1) according to title and assessed for relevance by means of the full-text by two independent judges (J1 and J4). As above, when disagreements ensued, a third judge (J3) was used in the final decision as to whether to include the article or not.

2.1.4 Methodological quality of the studies

All studies meeting the inclusion criteria were critically appraised by two independent judges (J1 and J3 for qualitative studies and J1 and J5 for quantitative and mixed studies). Differences in results were discussed between the judges to obtain a consensus. Qualitative studies were assessed by means of a critical review form for qualitative studies (Letts et al., 2007) (Appendix 13). The critical review form for quantitative studies was used to assess the methodological quality of quantitative studies (Law et al., 1998) (Appendix 14). The methodological quality of mixed studies was assessed with both the quantitative and qualitative critical review forms. The quality of systematic reviews was assessed with the measurement tool for the 'assessment of multiple systematic reviews' (AMSTAR) (Shea et al., 2007) (Appendix 15). No study was excluded on the basis of methodological quality.

2.1.5 Data collection and analysis

Selected articles were rigorously evaluated to extract specific information related to the needs of people with dementia living in LTC. As mentioned above, the second part of the data abstraction form was used to extract the information from the selected studies (Appendix 12, part 2). Data extracted in this section included the study design (e.g. qualitative and/or quantitative), the purpose of the study, the setting of the study (e.g. nursing home, assisted living), the location of the study (e.g. Canada) as well as a section for listing the (care) needs of people with dementia addressed in the study.

As in the selection of articles, two independent judges (J1 and J6) extracted the data from the selected studies with use of the data abstraction form. Disagreements were assessed by a third judge (J3). The extracted data led to the identification of a list of needs of people with dementia living in LTC. The list was agreed upon by the judges and synthesized within larger, manageable

categories. For example, the following extracted needs: need for satisfactory communication, need for conversation and need for socialization were categorized within a category named social needs. Operational definitions were developed for these main categories. Three judges (J1 and J6 - student and J7 – Degree in Occupational Therapy) completed the matching of the needs with the newly developed categories. Disagreements were judged by two other judges (J3 and J5) and a consensus was reached amongst all judges. A list of the main categories with operational definitions and matched needs is further discussed in the results section. The quality of the evidence (needs) is outlined under objective 3.

RefWorks (RefWorks, 2009) was used for managing the references and create bibliographies.

2.2 Objective 2: Matching of the needs to the grouping methodology items

In the second part of the methodology, the needs identified in the literature were matched to the MDS 2.0 variables used in the calculation of the RUG-III (34 Group). Needs that could not be matched to the MDS 2.0 variables used in the calculation of the RUG-III were kept for further analysis. Other MDS 2.0 variables/sections were sought for possible relevance to the unmatched needs.

Since many of the judges used in this study were not familiar with the MDS 2.0, an MDS coordinator (J7) independently completed the matching of the needs of residents with dementia to the appropriate MDS 2.0 variables. Judge 1 also independently completed the matching. Divergences in the matching were discussed between both judges and a consensus was reached.

2.3 Objective 3: Analysis of the priority of items in the grouping methodology in relation to the importance of the identified needs in the literature

The third part of the methodology involved linking the important needs of people with dementia as identified by the literature and supported with evidence with the weighted MDS 2.0 variables that were also a part of the grouping methodology (RUG-III). In order to determine the relative importance of the needs identified in the literature a method based on the quality and quantity of the studies associated to each need was used. In other words, needs that were supported in the literature by both higher quality and a larger number of studies were listed as being more

important than needs supported by weaker evidence and fewer studies. Where there was a conflict between quality and quantity, that is, when there were a few, high quality studies versus large numbers of poorly designed studies, the quality of the studies took precedence.

The overall quality of studies was based on the sum of two variables, namely: 1) the quality rating of studies based on selected quality criteria (Appendix 16) taken from the critical review forms and 2) the level of evidence of each study (Appendix 17). The quality rating was calculated on a scale of 1 (lowest quality) to 10 (highest quality) based on selected quality criteria taken from the assessment forms. If an article addressed a quality criteria, the criteria was marked fulfilled (+), however when an article did not address a criteria, this last was marked unmet (-). When inadequate information was provided by an article for a particular item, the quality item was marked unknown (u). The levels of evidence were ranked in multiples of 10, from 10 (lowest evidence - level 3B) to 50 (highest evidence – level 1A). Both scores were added to obtain the overall quality for each study, with possible scores ranging from 11 (a score of 1 on quality + a score of 10 on level of evidence) to 60 (a score of 10 on quality + a score of 50 on level of evidence). Studies with higher evidence levels (e.g. randomized controlled trials - level 1) and that met a greater number of quality criteria were given more weight than studies with lower evidence levels (e.g. observational studies without control groups – level 3B) that met fewer quality criteria. Levels of evidence were ranked in multiples of 10 to ensure that a higher level of evidence always surpassed a lower level of evidence regardless of the quality rating of the studies. For example, Kolanowski et al. (2001) which is a level 1 evidence has a higher overall score than Sung, Chang and Lee (2010) which is a level 2 evidence regardless of the fact that the quality rating of the study by Kolanowski et al. (quality rated 5/10) is less than the study by Sung et al. (2010) (quality rated 10/10).

Levels of evidence were only assigned to quantitative studies as such a system is non-existent for qualitative studies according to the Scottish Intercollegiate Guidelines Network (SIGN 50, 2011). As a result, only the quality criteria were used for qualitative studies. Thus, qualitative studies with a higher quality rating (e.g. 10) were deemed to have a better overall quality than those with a lower quality rating. For studies with mixed designs, a quality score was considered for both the quantitative and the qualitative aspects. For example, Lai (2003) was assigned an overall score of 50 for its quantitative strand and a score of 8 for its qualitative strand.

The relative importance of the needs as determined above was compared to the weighting given to the MDS 2.0 variables included in the RUG-III (34 Group) grouping methodology, and of relevance to the needs as identified by our own systematic analysis of the literature. The items and components (similar items) in the grouping methodology are weighted differently to permit classification of residents within the system according to their relative cost of care. For example, the ADL (e.g. assistance/supervision with toileting and eating) is one of the most important components of the grouping methodology. The matching of the needs with the MDS 2.0 variables that form a part of the RUG-III as performed under objective 2 was used to facilitate this process.

Chapter 3 - Results

In this chapter, the results will be discussed as follows. This chapter will begin with the results of the search process and will describe the characteristics and the methodological quality of the articles identified for review. The needs identified in the literature will then be outlined and their importance as defined by the count and quality of the identified studies will be presented by type of methodology. Hence, results identified from the quantitative studies will be presented separately from those identified in the qualitative studies. A greater focus will be placed on the needs that were identified as most important by the literature, meaning those needs that were supported by a greater number of studies and studies with a higher overall quality (needs classified in the first tier of the prioritization tables). The top three and four needs as supported by the quantitative and qualitative studies respectively are discussed in detail. Subsequent to the description of the identified needs, the linking of the needs with the MDS 2.0 variables which form the basis of the RUG-III grouping methodology will be analysed. The importance of the needs with the relative weighting of the RUG-III items will be further analysed.

3.1 Identifying the needs

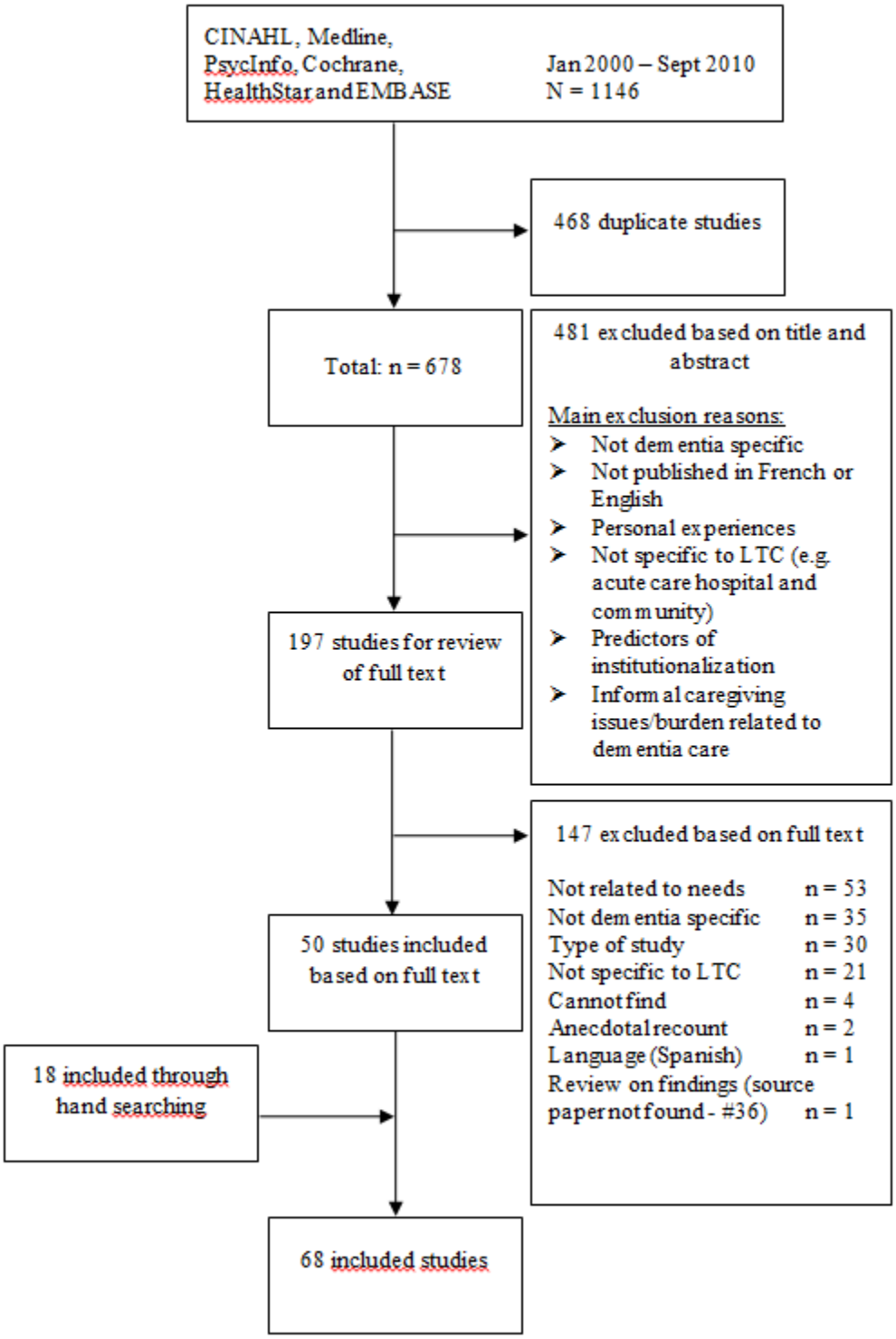
3.1.1 Search results

The breakdown of the search strategy is outlined in Figure 1. The search resulted in 1146 studies from the database searches. After excluding duplicates, 678 studies remained. Of the remaining studies, 481 were eliminated based on title and abstract, leaving 197 articles to be filtered by full-text. The two initial judges (J1 and J2) disagreed on 231 of the 678 (34%) articles to exclude or include in the next filtering round. Of the 231 articles, Judge 3 selected 152 (66%) articles to be included and filtered by full-text. Papers were eliminated due to the following main reasons: (1) not dementia specific, (2) not published in French or English, (3) discussed personal experiences/stories of people with dementia, (4) not specific to long-term care (e.g. acute care hospital and community) and (5) articles discussed predictors for institutionalization as well as (6) caregiver issues/burden related to dementia care.

Of the 197 papers resulting from this selection process, 147 were excluded based on full-text. Judges 1 and 2 disagreed on the inclusion/exclusion of 74 (38%) articles. Of these, 35 (47%)

articles were included for review by J3. Reasons for exclusion were as follows: not needs related (n=53), not dementia specific (n=35), type of study (non-systematic literature review, expert opinion and anecdotal recount) (n=30), not specific to LTC (n=21), article not found (n=4), language of study – Spanish (n=1), anecdotal (n=1) and source paper of an article reporting on findings could not be found (n=1). The main author of four articles for which the full-text was not available from the library resources were contacted but none responded to the request. In total, 50 articles met all inclusion criteria. Reference lists of the eligible studies were reviewed to identify additional relevant studies. Of the potential relevant studies, 18 met eligibility criteria. Disagreement between J1 and J4 ensued on 4 (13%) of the 30 selected articles from the reference lists, and all but one were included for review by J3. In total, 68 studies were included in the review (Appendix 18).

Figure 1 - Results of search strategy



When a paper reported on the findings of a study, the source article was retrieved and kept as the paper of relevance. The source paper could not be found for three studies (Bruce et al., 2002; Camp, 2006; Van Haitsma, 2000). Information pertaining to the methodology and results was received by the authors of one study only (Bruce et al., 2002). The article by Camp (2006) was excluded since it did not report on the methodology or present any concrete results.

3.1.2 Characteristics of the studies

The characteristics and outcomes of all studies included in the review are shown in Appendix 19. The majority of studies included in the review used a quantitative design (n=48). Only 15 relevant qualitative studies were identified. Three studies with mixed designs were included and both the qualitative and quantitative aspects of the studies were analysed separately. Of the 48 studies with quantitative designs, 15 were randomized controlled trials (RCT) (level 1), four were before and after designs (level 2), 15 were classified as level 3A (cohort with control, single case design and case-control study) and 17 as level 3B (cohort without control, case-study and cross-sectional designs). The quantitative designs used by the three mixed studies were a RCT (level 1), a retrospective cohort (level 3A) and a before and after with control (level 2).

Studies were conducted in many locations, with the majority being in the United States (n=37), the United Kingdom (n=8) and Canada (n=7). Other locations were: Australia, China, The Netherlands, Sweden, Taiwan, Japan, New Mexico and Israel. The settings in which the studies took place varied as well. In total, 33 studies were conducted in long-term care settings with 24 hour nursing care (Beck et al., 2002; Bharani & Snowden, 2005; Blass et al., 2008; Bourgeois, Dijkstra, Burgio, & Allen-Burge, 2001; Choi, 2001; Chung, 2004; Cohen-Mansfield, Golander, & Arnheim, 2000; Cohen-Mansfield & Jensen, 2006; Dröes et al., 2006; Finnema et al., 2005; Galik, Resnick, & Pretzer-Aboff, 2009; Gardiner, Furois, Tansley, & Morgan, 2000; Hicks-Moore, 2005; Hicks-Moore & Robinson, 2008; Koch, Datta, Makhdoom, & Grossberg, 2005; Kolanowski et al., 2001; Kolanowski, Litaker, & Buettner, 2005; Kovach, Kelber et al., 2006; Kverno et al., 2008; Lai, 2003; Mickus et al., 2002; Morgan, Stewart, D'Arcy, & Werenak, 2004; O'Brien & Caro, 2001; Opie, Doyle, & O'Connor, 2002; Powers, 2000; Powers & Watson, 2008; Ragneskog, Asplund, Kihlgren, & Norberg, 2001; Reid & Chappell, 2003; Smith, 2008; Sung et al., 2010; Van Haitsma, 2000; Young, Binns, & Greenwood, 2001; Zeisel et al., 2003).

The remaining studies included either a mix of participants from the residential setting (i.e. residential care/assisted living facilities) and the long-term care setting with 24 hour nursing care (i.e. NHs) or participants from the residential setting only.

All study participants had a formal or "probable" diagnosis of dementia. The majority of participants were female and had moderate to severe dementia. Only three studies included cognitively-intact participants as well as individuals with dementia. All were quantitative in nature. One study compared the intervention effect of books on agitation levels of a patient with AD in comparison to a stroke patient using a single subject design with repeated measures (Gardiner et al., 2000) and two studies compared residents with cognitive impairment to those without (O'Brien & Caro, 2001; Quinn, Johnson, Andress, & McGinnis, 2003). O'Brien and Caro (2001) compared the annual cost of caring for a nursing home resident with and without dementia based on resident assessment data from Massachusetts. Quinn et al. (2003) examined the health characteristics (psychosocial, functional health and physical health differences) between personal care home residents with dementia, possible dementia and without dementia.

3.1.3 Methodological quality

The methodological rigor, as assessed by two independent reviewers based on selected quality criteria, is summarized in Tables 1, 2 and 3. Table 1 demonstrates the rigor of the **quantitative** studies. Ten quantitative studies fulfilled all ten quality items. The majority of the studies (34 of 53) obtained a quality rating between seven and nine and only two studies were found to have a methodology with a quality rating lower than five out of a possible 10. Two studies (Innes & Surr, 2001; Van Haitsma, 2000) obtained a low quality rating primarily because the sample size was not justified, the results were not reported in statistical terms and the analyses were very general.

Table 1 - Quality rating of the quantitative studies selected for review

Quantitative studies	A	B	C	D	E	F	G	H	I	J	TOTAL
Cohen-Mansfield, Parpura-Gill, & Golander (2006)	+	+	+	+	+	+	+	+	+	+	**10**
Gerdner (2000)	+	+	+	+	+	+	+	+	+	+	**10**
Hicks-Moore (2005)	+	+	+	+	+	+	+	+	+	+	**10**
Hicks-Moore & Robinson (2008)	+	+	+	+	+	+	+	+	+	+	**10**
Kolanowski et al. (2005)	+	+	+	+	+	+	+	+	+	+	**10**
Kovach, Logan et al. (2006)	+	+	+	+	+	+	+	+	+	+	**10**
Lai (2003)	+	+	+	+	+	+	+	+	+	+	**10**
Sloane et al. (2004)	+	+	+	+	+	+	+	+	+	+	**10**
Smith (2008)	+	+	+	+	+	+	+	+	+	+	**10**
Sung et al. (2010)	+	+	+	+	+	+	+	+	+	+	**10**
Beck et al. (2002)	+	+	-	+	+	+	+	+	+	+	**9**
Choi (2001)	+	+	+	+	+	n/a	+	+	+	+	**9**
Finnema et al. (2005)	+	+	+	+	+	-	+	+	+	+	**9**
Gardiner et al. (2000)	+	+	-	+	+	+	+	+	+	+	**9**
Hoe, Hancock, Livingston, & Orrell (2006)	+	+	+	+	+	n/a	+	+	+	+	**9**
Koch et al. (2005)	+	+	+	+	+	n/a	+	+	+	+	**9**

Kverno et al. (2008)	+	+	+	+	+	n/a	+	+	+	+	**9**
O'Brien & Caro (2001)	+	+	+	+	+	n/a	+	+	+	+	**9**
Opie et al. (2002)	+	+	-	+	+	+	+	+	+	+	**9**
Reid & Chappell (2003)	+	+	+	+	+	n/a	+	+	+	+	**9**
Ruka (2003)	+	+	-	+	+	+	+	+	+	+	**9**
Sung, Chang, Lee, & Lee (2006)	+	+	-	+	+	+	+	+	+	+	**9**
Zimmerman et al. (2005)	+	+	+	+	+	n/a	+	+	+	+	**9**
Bourgeois et al. (2001)	+	+	-	+	+	+	+	+	-	+	**8**
Caserta & Lund (2002)	+	+	-	+	+	+	+	+	-	+	**8**
Dobbs et al. (2005)	+	-	+	+	+	n/a	+	+	+	+	**8**
Gill, Williams, Zimmerman, & Uman (2007)	+	+	+	-	+	n/a	+	+	+	+	**8**
Gonzalez-Salvador et al. (2000)	+	+	-	+	+	n/a	+	+	+	+	**8**
Hancock et al. (2006)	+	+	-	+	+	n/a	+	+	+	+	**8**
Kovach, Kelber et al. (2006)	+	+	-	+	+	+	+	+	u	+	**8**
Mickus et al. (2002)	+	+	-	+	+	+	+	-	+	+	**8**
Milke, Beck, & Danes et al. (2006)	+	+	-	+	+	n/a	+	+	+	+	**8**
Orrell et al. (2007)	+	+	-	+	+	-	+	+	+	+	**8**
Orrell et al.	+	+	-	+	+	n/a	+	+	+	+	**8**

(2008)											
Potkins et al. (2003)	+	+	+	+	+	n/a	+	+	-	+	**8**
Quinn et al. (2003)	+	-	+	+	+	n/a	+	+	+	+	**8**
Ballard et al. (2001)	+	+	-	+	u	n/a	+	+	+	+	**7**
Buettner & Fitzsimmons (2006)	+	+	+	+	+	n/a	-	+	u	+	**7**
Chung (2004)	+	+	+	-	u	n/a	+	+	+	+	**7**
Cohen-Mansfield & Jensen (2006)	+	+	-	-	+	+	+	+	-	+	**7**
Powers & Watson (2008)	+	+	+	+	+	n/a	-	+	-	+	**7**
Ragneskog et al. (2001)	+	+	-	+	+	+	-	-	+	+	**7**
Sloane, Zimmerman, Williams, & Hanson (2008)	+	+	-	+	+	n/a	+	+	+	-	**7**
Zeisel et al. (2003)	+	+	-	+	+	n/a	+	+	-	+	**7**
Blass et al. (2008)	+	+	-	u	u	n/a	+	+	+	+	**6**
Morgan et al. (2004)	+	-	-	+	+	n/a	+	+	-	+	**6**
Orsulic-Jeras, Judge, & Camp (2000)	+	+	-	u	u	+	+	+	+	-	**6**
Cohen-Mansfield et al. (2000)	+	+	-	u	u	n/a	+	+	-	+	**5**
Kobayashi & Yamamoto (2004)	+	+	-	u	u	n/a	-	+	+	+	**5**
Kolanowski et al. (2001)	+	+	-	u	u	+	+	-	+	u	**5**
Young et al. (2001)	+	+	-	u	u	n/a	+	+	+	-	**5**

Van Haitsma (2000)	+	+	-	u	u	+	-	-	+	-	**4**
Innes & Surr (2001)	+	-	-	+	u	n/a	-	-	u	+	**3**

Quality criteria: design appropriate for study question (A); sample described in detail (B); sample size justified (C); outcome measures reliable (D); outcome measures valid (E); intervention described in detail (F); statistical analyses reported (G); analysis method(s) appropriate (H); drop-outs reported (I); appropriate conclusions given methods and results (J). Criterion met (+); Criterion not met (-); Unknown if criterion met or not (u); not applicable (n/a). Not addressed = unknown.

Tables 2 and 3 demonstrate the rigor of the **qualitative** studies. Systematic reviews are reported in Table 3 with all other qualitative studies presented in Table 2. Only one qualitative study fulfilled all ten quality criteria (O'Connor, Ames, Gardner, & King, 2009). The majority of the studies (12 of 18) obtained a quality rating between seven and nine. Three studies (Malone & Camp, 2007; Tilly & Fok, 2008; Tilly & Reed, 2005) were given a quality rating lower than five. The most common flaws found in these studies were the lack of details (i.e. description of participants and characteristics of studies selected for review), the relevance of the results and the weakness of the conclusions.

Table 2 - Quality rating of the qualitative studies selected for review

Qualitative studies	A	B	C	D	E	F	G	H	I	J	TOTAL
Bruce et al. (2002)	+	+	+	u	+	+	+	+	+	+	**9**
Dröes et al. (2006)	+	+	+	u	+	+	+	+	+	+	**9**
Powers (2000)	+	+	+	u	+	+	+	+	+	+	**9**
Smith (2008)	+	+	+	u	+	+	+	+	+	+	**9**
Zingmark, Sandman, & Norberg (2002)	+	+	+	u	+	+	+	+	+	+	**9**
Galik et al. (2009)	+	-	+	u	+	+	+	+	+	+	**8**
Lai (2003)	+	+	+	-	+	+	+	+	-	+	**8**
MacDonald (2006)	+	-	+	u	-	+	+	+	+	+	**7**
Powers & Watson (2008)	+	+	+	-	+	+	+	+	-	+	**7**
Hernandez (2007)	+	+	-	u	-	+	+	+	+	+	**7**
Cioffi, Fleming, Wilkes, Sinfield, & Miere (2007)	+	+	+	u	+	-	+	u	-	-	**5**
Malone & Camp (2007)	+	+	+	u	-	-	-	-	-	-	**3**
Tilly & Fok (2008)	+	-	+	u	-	-	-	-	-	-	**2**

Quality criteria: design appropriate for study question (A); theoretical perspective identified (B); purposeful selection (C); sampling done until redundancy reached (D); clear and complete description of site and participants (E); data analysis were inductive (F); findings consistent and reflective of data (G); decision trail developed (H); evidence of the four components of trustworthiness (I); appropriate conclusions given methods and results (J). Criterion met (+); Criterion not met (-); Unknown if criterion met or not (u); not applicable (n/a). Not addressed = unknown.

Table 3 - Quality rating of the systematic reviews selected for review

Systematic reviews	A	B	C	D	E	F	G	H	I	J	TOTAL
O'Connor et al. (2009)	+	+	+	+	+	+	+	+	+	+	**10**
Bharani & Snowden (2005)	+	u	+	+	+	+	+	+	+	u	**8**
Pearson & Chalmers (2004)	+	+	+	+	+	-	+	+	n/a	-	**7**
Finnema et al. (2000)	+	u	+	+	+	+	+	-	u	u	**6**
Tilly & Reed (2005)	-	u	+	+	-	-	-	-	-	-	**2**

Quality criteria: 'priori' design provided (A); duplicate study selection and data extraction (B); comprehensive literature search performed (C); status of publication used as an inclusion criterion (D); list of studies provided (E); characteristics of included studies provided (F); scientific quality of included studies assessed and documented (G); scientific quality of included studies used appropriately to formulate conclusions (H); appropriate methods used to combine the findings of studies (I); likelihood of publication bias assessed (J). Criterion met (+); Criterion not met (-); Unknown if criterion met or not (u); not applicable (n/a).

The overall methodological quality of the studies is shown in Table 4. Quantitative and qualitative studies are presented separately in the table as the quality was determined differently for both types of design. The quality of the **quantitative** studies is reflected by the sum of the methodological rigor and the level of evidence of each study whereas the quality of the **qualitative** studies is based on the methodological rigor only. The quantitative and qualitative designs of mixed studies are reported in both sections of the table and are marked in bold. Results in sections 3.1.4.1 to 3.1.4.3 are reported separately as a result. The results generated by the quantitative studies report on the quality of the evidence. Results obtained from the qualitative studies served to support the quantitative findings in addition to generating new ideas and identifying future avenues for quantitative research.

Table 4 - Overall methodological quality of the quantitative and qualitative studies

QUALITY RATING (1 to 10)	QUALITATIVE METHODOLOGIES	QUALITY RATING (1 to 10)	QUANTITATIVE METHODOLOGIES LEVELS OF EVIDENCE (10 to 50) Level 3B (10)	Level 3A (20)	Level 2 (30)	Level 1 (40)	Level 1A (50)
1		1					
2	Tilly & Reed (2005); Tilly et al. (2008)	2					
3	Malone & Camp (2007)	3	Innes & Surr (2001)				
4		4	Van Haitsma (2000)				
5	Cioffi et al. (2007)	5	Cohen-Mansfield et al. (2000); Kobayashi & Yamamoto (2004); Young et al. (2001)			Kolanowski et al. (2001)	
6	Finnema et al. (2000)	6	Blass et al. (2008)	Morgan et al. (2004)	Orsulic-Jeras et al. (2000)		
7	**Powers & Watson (2008)**; Hernandez (2007); MacDonald (2006); Pearson & Chalmers (2004)	7	Ballard et al. (2001); Zeisel et al. (2003)	**Powers & Watson (2008)**; Buettner & Fitzsimmons (2006); Chung (2004); Cohen-Mansfield & Jensen (2006); Ragneskog et al. (2001); Sloane et al. (2008)			
8	**Lai (2003)**; Bharani & Snowden (2005); Galik et al. (2009)	8	Dobbs et al. (2005); Gill et al. (2007); Hancock et al. (2006); Milke et al. (2006); Orrell et al. (2008); Potkins et al. (2003)	Caserta & Lund (2002); Gonzalez-Salvador et al. (2000); Quinn et al. (2003)	Mickus et al. (2002)	Bourgeois et al. (2001); Kovach, Kelber et al. (2006); Orrell et al. (2007)	
9	**Smith (2008)**; Bruce et al. (2002); Droes et al. (2006); Powers (2000); Zingmark et al. (2002)	9	Choi (2001); Hoe et al. (2006); Zimmerman et al. (2005)	Gardiner et al. (2000); Gerdner (2000); Koch et al. (2005); Kverno et al. (2008); O'Brien & Caro (2001); Ruka (2003)	Reid & Chappell (2003)	Beck et al. (2002); Finnema et al. (2005); Opie et al. (2002); Sung et al. (2006)	
10	O'Connor et al. (2009)	10		Hicks-Moore (2005)	**Smith (2008)**; Sung et al. (2010)	**Lai (2003)**; Cohen-Mansfield et al. (2006); Hicks-Moore & Robinson (2008); Kolanowski et al. (2005); Kovach, Logan et al. (2006); Sloane et al. (2004)	

As illustrated by Table 4, the **quantitative** studies with the strongest methodological quality are situated in the lower right hand corner of the table. None of the studies obtained the highest score (60) for overall quality, as no study was classified with a highest level of evidence (1A). The highest overall quality identified was 50 (level 1 + quality rating of 10). Most quantitative studies were categorized in the lower half of the table, representing moderate to strong evidence (level 3B to level 1) and quality (7 to 9). The **qualitative** studies with the strongest quality are located in the lower left hand corner of Table 4. One study obtained the highest quality score of 10. The majority of the qualitative studies obtained a moderate to high quality (7 to 9) rating, as demonstrated by Table 4.

3.1.4 Identification of the needs of residents with dementia

Three of the selected studies for review specifically addressed the needs of people with dementia whereas others addressed the needs indirectly. Met and unmet needs of residents with dementia were assessed by Hancock et al. (2006) using the Camberwell Assessment of Need in the Elderly (CANE) on a sample of 238 participants from care homes. The most common unmet needs identified were the need for stimulating daytime activities (76%), the need for support to cope with (psychological distress) (48%) and the need for company (41%). The need for assistance with memory problems (39%) and sensory problems such as eyesight or hearing (39%) appeared as other frequent unmet needs. Results revealed that one in five participants in the study had more than seven unmet needs. The needs that were most often met related to help with household tasks (99%), appropriate accommodation (94%) and self-care (93%). Results showed that the care homes included for study were better at meeting the physical and environmental needs of residents. More specifically, the need for food, appropriate (adequate facility) accommodation, help with household tasks, access to physical health care and protection against safety risks were the needs most often satisfied. The authors also examined the relationship between needs and clinical (e.g. behavioural problems, depression and anxiety) and demographic (e.g. age) factors. A lower age, a shorter length of stay in the home as well as greater depression and anxiety levels were associated to more unmet needs. Behavioural problems were positively correlated with higher needs and more unmet needs ($p<0.01$) (Hancock et al., 2006).

Needs addressed in a study by Milke et al. (2006) were presented as statements in a questionnaire used to compare the views of families, caregivers, staff and volunteers as to the adequacy of care received by residents from assisted living facilities. The groups of respondents differed significantly on 34% of the statements directly related to needs of residents. The family group were more critical of the resident's limited opportunity for freedom of choice such as the resident's right to refuse medications, to get out of bed at night if restless, having the option to eat meals in the dining room and to decide when to get out of bed in the morning and when to be bathed. The direct care staff were critical on needs reflecting their own performance, such as skin care, calming residents when agitated, resident's opportunities for regular outings and their own knowledge and training on dementia care. The statements part of the questionnaire related to the physical layout of the facility, room personalization, physical care, meals, behaviours of daily living, problem behaviours (e.g. protection from self-injury and correction when exhibiting disruptive behaviours), medications, social activities, social and emotional support, physicians (e.g. regular doctor visits), care staff (e.g. knowledge of staff on dementia care), families (e.g. involvement in care plans of residents) and volunteers (e.g. awareness of concerns of staff and family about residents) (Milke et al., 2006).

Orrell et al. (2008) compared the ratings of needs as expressed by residents, staff and family caregivers using the CANE. Among the needs addressed, daytime activities and social company appeared as those most unmet, as rated by all respondents. Hence, care homes were found not to offer sufficient regular stimulating activities and opportunities to make social contacts for residents. Agreement between residents, staff and family caregivers was fair. Staff for example rated more met needs than unmet needs as compared to residents. Staff felt that the need for food, sensory problems, physical health, psychological distress, information, company and money were met, in comparison to users which rated these needs as unmet. High agreement for met needs was found in the areas of accommodation and food (Orrell et al., 2008).

Well-being and "quality of life" are measures that reflect on the needs of residents with dementia. Hoe et al. (2006) for instance, found that residents with dementia felt that a high quality of life was strongly correlated with lower depression ($p<0.0001$) and anxiety ($p<0.001$) levels. Care staff also felt that fewer behaviour problems such as neuropsychiatric symptoms (e.g. agitation and depression) ($p<0.001$) were strongly correlated with a higher QoL, in addition

to a lower level of physical disability ($p<0.001$) (Hoe et al., 2006). End-of-life (EOL) care requirements, predictors enhancing the sense of identity of residents as well as the effect of pharmacological and/or non-pharmacological interventions as a way to address underlying needs expressed by disruptive behaviours were other foci of interest.

3.1.4.1 Categorization of the identified needs

All needs extracted from the review articles were categorized within larger, manageable categories, referred to as "codes". The classification of the needs resulted in 19 codes defined and summarized in Table 5. All needs identified were addressed by both quantitative and qualitative studies, with the exception of functional needs – instrumental activities of daily living (IADL)s and sensory needs that have been considered by quantitative studies only as well as spiritual needs that were only considered by qualitative studies. Most needs met the definition of one particular code with the exception of five needs that were classified in two separate categories. These needs were 1) the need for access to personal items and identifying materials (codes 3 and 12), 2) the need to receive preferred food and drink (codes 4 and 8), 3) the need for structured and individualized activities (codes 2 and 9), 4) the need for physical and mental health (code 3 and 4) and 5) the need for reduced physical disability (codes 5 and 6). For instance, the need to receive preferred food and drink was associated to two different needs as it can be viewed as either a need to satisfy the basic human need for food or a need to be able to choose the food to be consumed.

The most reported needs in the quantitative studies, in order of frequency, were the need to have behaviours managed (28 studies) as well as the need for individualized activities/care (20 studies) and social needs (19 studies). Money – financial issues (2 studies) was the need least represented by quantitative evidence. Conversely, emotional needs/personhood (8 studies) was the need most reported by the identified qualitative studies followed by the need for individualized activities/care and the need for independence/choice (6 studies). Money – financial issues (1 study) was also one of the needs least represented by the identified studies. Other needs represented by only one qualitative study were cognitive needs, the need for daily structured care and the need for knowledgeable staff. To note, representation of a need in the literature does not necessarily equate to importance. Although the representation of a need in the

literature is sufficient to provide evidence that this is a need, the simple fact that a need has not been studied or studied very little does not mean it is not a "real" need (e.g. knowledgeable staff) for residents with dementia. A list of the extracted needs and associated codes and references from the literature is outlined in Appendix 20.

Table 5 - Description of the needs ("codes") identified in the literature

Need	Number of studies (overall total and total by design type)	Definition	Examples	Code
Management of behavioural problems	Total: 31 Quantitative: 27 Qualitative: 3 Mixed design: 1	Need to receive support from staff in decreasing behavioural symptoms (general) and be provided with appropriate care measures (e.g. redirection) when exhibiting disruptive behaviours.	Improve behaviours; Management of behavioural symptoms; Use of daily psychoactive medications to treat behaviours; Decrease aggressive behaviour; Receive correction or direction when exhibit disruptive behaviours.	10
Need for daily individualized activities/care	Total: 26 Quantitative: 20 Qualitative: 6	Need to engage in meaningful daily activities (inside or outside the facility) tailored to the resident's interests and abilities. Activities are not limited to the individual per se; activities may be offered in a group setting. Includes need to receive individualized care (e.g. medication prescribed to meet individual symptom).	One-on-one contact; Active participation; Stimulation via activities; Need for meds tailored to individual symptoms and condition; Individualized care; Need for leisure activities.	2
Social needs	Total: 24 Quantitative: 17 Qualitative: 5 Mixed design: 2	Need for social interactions that allow the resident to connect with others on an interpersonal level; meaningful interactions and communication opportunities with staff, family members and residents.	Need for conversation; Need for interactions; Social engagement; Need to reduce social withdrawal; Opportunities to talk openly with others; Opportunities for information sharing.	1
Emotional needs/ Personhood	Total: 23 Quantitative: 15	Need to retain a good emotional balance (increase positive feelings such as pleasure) and (decrease negative feelings such as	Positive relationships; Emotional support through staff touch; Attention; Self-esteem; Recognition of individuality;	3

	Qualitative: 7 Mixed design: 1	sadness). Development of a sense of personal identity (expression of self). Feelings such as: reassurance, affection, acceptance and appreciation are of great emotional importance.	Enhancement of self-identity ('personhood'); Promote positive behaviours.	
ADLs	Total: 18 Quantitative: 14 Qualitative: 4	Receiving assistance with activities of daily living (ADLs). These include activities we normally perform for ourselves (e.g. hair care, eating/drinking, getting in and out of bed, and toileting).	Supervision and assistance with ADLs (e.g. toileting, grooming, dressing, walking); Repositioning in bed; Improve ADL function; Eating and drinking.	5
Need for independence/ Choice	Total: 12 Quantitative: 6 Qualitative: 6	Need to preserve a sense of agency by means of opportunities for decision-making and personal control (i.e. right to refuse medications and choice of activities). In the inability to make own decisions, residents' next of kin should be sought for decisions related to their care.	Familiar/preferred activities; Option for privacy; Care based on preferences; Integration of preferences into everyday care; Freedom of movement; Flexibility in timing of bath; Autonomy.	8
Cognitive needs	Total: 11 Quantitative: 10 Qualitative: 1	Need for assistance with interpretation of messages and surroundings.	Assistance with receptive language skills (impairment); Cognitive understanding (awareness of surroundings and mental clarity); Capture attention due to memory impairment; Facilitation of orientation by means of way finding cues for instance.	15
Need to be safe / secure	Total: 11 Quantitative: 8 Qualitative: 3	Need to feel safe and be protected from self-injury as well as harm from other residents. An example of a safety feature on a dementia unit would be exit control measures (Zeisel et al., 2003).	Security and safety; Safety features of the unit and outdoor area; Protection from harm; Protection from staff for self-belongings and harassment from other residents.	18
General overall physical health	Total: 10	Need to retain good physical health by means of clinical care, exercise and proper	Need for medications to treat medical conditions; Eating well; Maintain	4

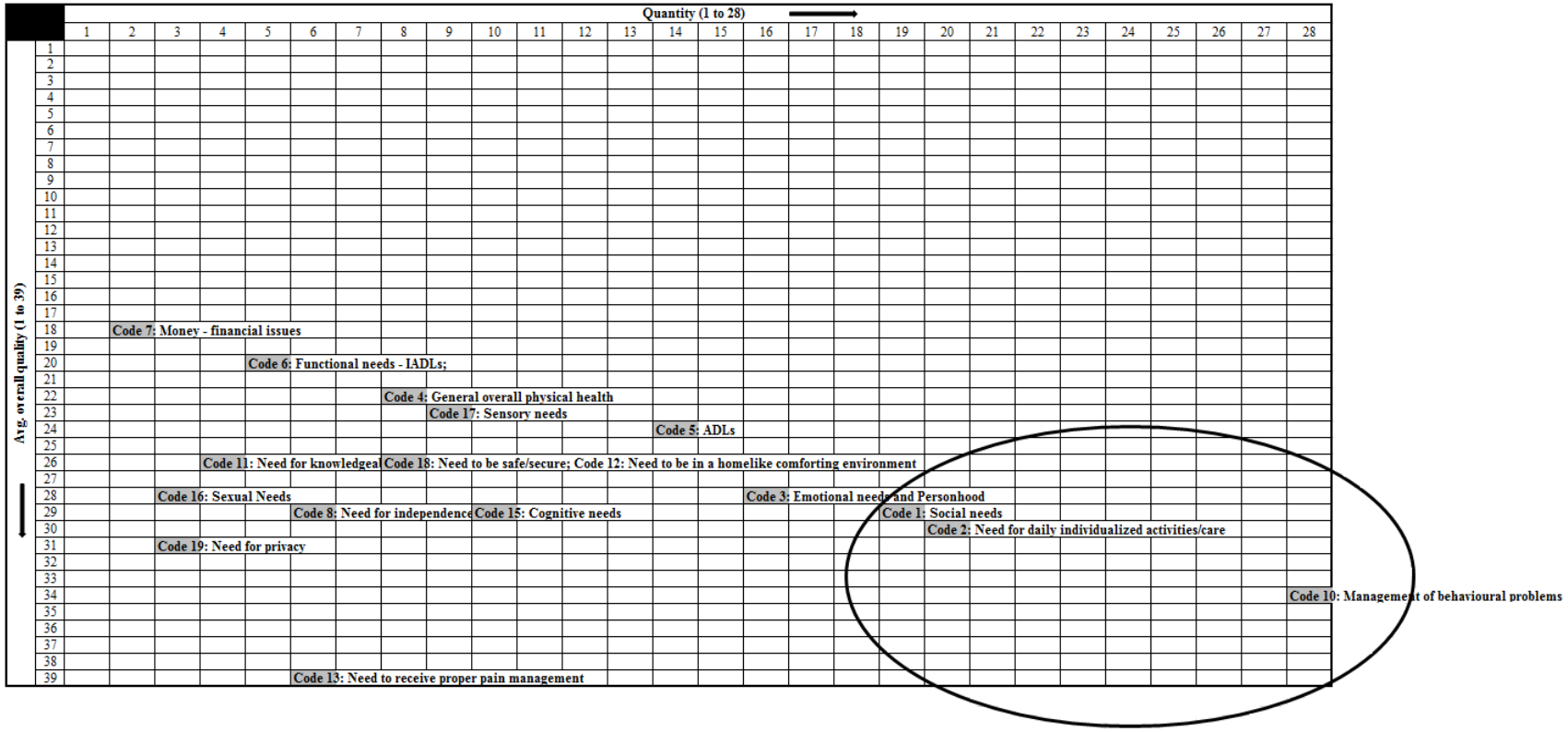
	Quantitative: 8 Qualitative: 2	nutrition.	functional abilities; Hygiene care; Physical exercise.	
Need to be in a homelike comforting environment	Total: 10 Quantitative: 8 Qualitative: 2	Need to reside in a 'homelike' environment which may include but is not limited to having a quiet space and personalized spaces. Such environment induces a sense of familiarity.	Personal belongings (item); Familiar environment (personalized spaces); Increased space (unrestricted nature of environment); Pleasant and fresh environment; Quiet space and calm environment.	12
Need to receive proper pain management	Total: 10 Quantitative: 5 Qualitative: 4 Mixed design: 1	Need to diminish the discomfort caused by physical pain.	Physical comfort; Pain relief; Symptom management.	13
Sensory needs	Total: 9 Quantitative: 9	Need for optimal sensory stimulation from the environment (e.g. proper lighting – visual stimulation). Relates to the residents five senses.	Sensory stimulation; Help with eyesight/hearing; Need for proper eye care; Understandable / controlled environment; Adequate temperature and lighting.	17
Need for daily structured care	Total: 6 Quantitative: 5 Mixed design: 1	Need for continuous, routine, predictable care based on the resident's needs.	Need for specific dressing and undressing routine; Consistency in daily activities (stability); Regular visits by physicians.	9
Functional needs – IADLs	Total: 5 Quantitative: 5	Receiving assistance in performing instrumental activities of daily living (IADLs) which include tasks that we often do to ensure our independent living (e.g. taking medication, managing money, talking on the phone and shopping).	Assistance with managing money; Assistance with household tasks.	6
Need for knowledgeable staff	Total: 5 Quantitative: 4 Qualitative: 1	Need for well trained and educated (dementia specific) staff as well as staff who have gained extensive experience in caring for people with dementia at various levels.	Professional monitoring of unpleasant effects of meds; Need for proper staff care response to behavioural symptoms as a sign of unmet need; Need for good	11

			communication with caregiver/staff; Competent, knowledgeable and experienced staff; Positive staff attitude (dementia-sensitive).	
Sexual needs	Total: 5 Quantitative: 3 Qualitative: 2	Need for intimate relationships.	Intimate relationships.	16
Need for privacy	Total: 5 Quantitative: 3 Qualitative: 2	Need for a secluded personal environment, if privacy is desired.	Privacy and freedom from unwanted physical intrusion; Distinct spaces and activities for PWD (separation).	19
Money – financial issues	Total: 3 Quantitative: 2 Qualitative: 1	Need to have a good financial situation for purchase of desired items and bill payments.	Sufficient money to do what liked; Money.	7
Spiritual needs	Total: 2 Qualitative: 2	Need for spiritual support and opportunities to exercise one's religion.	Spiritual support; Spirituality (religion).	14

3.1.4.2 Importance of the needs as supported by the quantitative evidence

Table 6 depicts the needs identified in the quantitative literature based on the quality of the evidence and the number of studies reporting each need. As previously mentioned, the quality of studies is based on a sum of the scores given for methodological rigour (quality criteria, 1 to 10) and level of evidence (10 to 50), with total possible scores ranging from 11 to 60. The level of quality of the studies addressed for each of the needs is represented by the mean quality score of the studies reporting each need. The needs most supported by quantitative studies appear in the lower right hand corner of the prioritized needs table. As indicated by the bold oval in Table 6, the need most supported by the literature is the management of behavioural problems followed by the need for daily individualized activities/care and, thirdly, social needs. The need least supported by the literature appears to be money – financial issues, situated in the top left corner of Table 6. Functional needs – IADLs is another need not heavily supported by the quantitative evidence.

Table 6 - Prioritized needs of residents with dementia as determined by the quantitative evidence



3.1.4.2.1 Management of behavioural problems

As demonstrated by Table 6, a number of studies identified in the review provide strong evidence that there is a need to manage disruptive behaviours. These articles were included in this review since the symptoms (i.e. the disruptive behaviour) is often construed as an indication of unease or unmet need in the resident. Thus, for example, the need to reduce these disruptive behaviours translates into a need to reduce the levels of agitation, aggression and so on. They are seen as a symptom of the resident not being comfortable. In a well-conducted cross-sectional study by Hoe et al. (2006), the authors found that unmet needs were associated with higher levels of distress such as anxiety in a sample of 119 participants from 24 residential care homes. Hancock et al. (2006) similarly found that more frequent challenging behaviours was positively correlated with higher unmet needs ($p<.01$).

The experimental studies reviewed are presented in Table 7. Nine randomized controlled trials relevant to behaviour management were identified. One study tested the efficacy of recreational activities tailored to individual needs as related to behavioural symptoms associated with dementia. The behavioural symptoms of thirty participants were observed by trained research assistants during each session, of which three consisted of the experimental conditions (activities matched to skills - A, activities matched to interest - B and activities matched to both - C). Significantly less agitation was found during all treatments ($p=.007$ for A, $p=.001$ for B and $p=.002$ for C) in comparison to baseline. No significant differences were found between treatment groups ($p>.940$). Passivity was significantly reduced during treatments as well, especially during treatment C (activities matched to skills and interests) (Kolanowski et al., 2005). Two randomized controlled trials revealed the importance of returning behaviours to baseline by assessing and addressing the unmet needs of residents. In one of the studies, comprehensive responses to behaviours by nurses demonstrated less recurring behaviours in residents in comparison to nurses who provided no treatment when change in behaviours were recognized (dismissive response), a same assessment or treatment over a period of time although ineffective in reducing the behaviours (static response) or a treatment provided after a general assessment of the cause of the behaviour (reactive response) (Kovach, Kelber, et al., 2006). For example, a resident is fidgeting in a wheelchair and setting off the chair alarm. In this particular situation, a comprehensive response would be one that assesses thoroughly (e.g. check blood

pressure, history of disease and ask resident of any pain) the cause for the behaviour and provides systematically treatments until the behaviour is settled. A nurse that would recognize the behaviour and provide no treatment relates to a dismissive response. A static care response relates to a nurse that makes the same assessment (e.g. incontinent of urine) and provides the same treatment (e.g. cares given) to this behaviour day after day even if the treatment is not effective. A reactive care response reflects the provision of different treatments (e.g. 1- snacks provided, 2- one-to-one communication provided) after generally assessing (e.g. 1- ask resident if he/she needs to go to the bathroom, 2- resident denies pain) the cause of the behaviour (Kovach, Kelber, et al., 2006). The data showed that the experimental group (N=114) of a double-blind randomized-controlled trial had their behaviours more frequently returned to baseline when their needs were comprehensively addressed, meaning that the resident was thoroughly assessed and provided with a set of treatments until his/her behaviours were settled (Kovach, Logan, et al., 2006).

Three other RCTs demonstrated significant results in favour of the experimental group. Hand massage, favourite music and a combination of both treatments significantly reduced agitation ($p<.001$) for 32 participants compared to participants in the control group (N=9) (Hicks-Moore & Robinson, 2008). Agitation and aggression significantly declined ($p<.001$) for residents (N=46) receiving person-centered showering and person-centered bed-bath routines (Sloane et al., 2004). In this study, person-centered bathing focused on resident comfort and preferences and utilized appropriate communication techniques, whereas person-centered showering used a variety of techniques (e.g. use of bath products recommended by the family, use of no-rinse soap and the provision of choices) with a goal to individualize the residents' experience. Agitated behaviours were also shown to reduce significantly during and following individualized music in comparison to classical relaxation music using an experimental repeated measures pretest-posttest crossover design (Gerdner, 2000). One of the randomized controlled trials involving emotion-oriented care found the treatment to be effective in decreasing anxiety in residents, but not beneficial in managing agitation (Finnema et al., 2005). Only one of the nine randomized controlled trials identified found no significant differences between the experimental and control groups in decreasing disruptive behaviours (Beck et al., 2002).

Eight other experimental studies related to behaviour management were identified, of which three used a before-after design with a control sample and five used a single case design with repeated measures. Only one of these eight studies (Cohen-Mansfield & Jensen, 2006) did not obtain significant results as to the effectiveness of the intervention. The interventions studied by the experimental studies which found positive results related mostly to individualized music (Gardiner et al., 2000; Hicks-Moore, 2005; Ragneskog et al., 2001; Sung et al., 2000). A prayer exercise (Smith, 2008), a non-pharmacological approach (PRIDE) during bathing (Mickus et al., 2002) and an individualized reminiscence intervention for promoting comfort (Ruka, 2003) were the other interventions studied that provided significant results.

Table 7 - Effects of interventions for managing disruptive behaviours in residents with dementia in long-term care: experimental studies

Behaviour	Intervention	Effect	Ref ID
Disruptive behaviours	ADL therapy (ADL), psychosocial therapy (PSA) and a combination of both therapies vs. placebo control and no intervention control.	No difference in behaviour between treatment and control groups.	2
Agitation	Interventions bringing self-care routines into greater correspondence with those practiced before the onset of dementia.	No effect on agitation.	13
Agitation, anxiety and restlessness	Integrated emotion-oriented care vs. usual care	No significant difference between groups on agitation measures. Significant effect on anxiety for the experimental group.	17
Physical and verbal aggression, agitation and wandering.	Music and book intervention	Both interventions significantly decreased behaviours for the participant with Alzheimer. Agitation of stroke participant decreased during and after the book intervention only.	20
Agitation	Individualized music vs. classical 'relaxation' music	Significant reduction in the frequency of agitated behaviours during and following the intervention as compared to control.	21
Agitation	Relaxing music	Agitated behaviours decreased during weeks music played compared to weeks when no music was played.	26
Agitation	Hand massage (HM), favourite music (FM) and a combination of both (HMFM) vs. Control	Significant difference ($p<.001$) between treatment (FM, HM and HMFM) and control in reducing agitation. No significant differences in agitation over time ($p=.17$) and across treatments ($p=.08$).	27

Agitation and passivity	Activities matched to skill level only (A), activities matched to style of interest only (B) and activities matched to both (skill level and style of interest) (C) vs. baseline.	Significantly less agitation in all three treatments ($p=.007$ for A, $p=.001$ for B and $p=.002$ for C) compared to baseline. No significant differences between treatments. Significant reduction in passivity for all treatments compared to baseline.	33
N/S	Nurses responses to behaviours part of the Serial Trial Intervention vs. basic care.	Comprehensive response received significantly more ($p<.001$) by residents in treatment group vs. control. Reactive ($p<.001$) and static ($p<.001$) responses used by significantly more nurses in control group. No significant difference between groups in the use of dismissive care ($p=.340$).	34
N/S	Serial Trial Intervention	Intervention effective in returning behaviours to baseline; significant difference between groups ($p=.002$).	35
Agitation, anxiety, apathy, disinhibition and irritability.	Psycho-educational intervention centered on acronym PRIDE (privacy, reassurance, information-giving, distraction and evaluation).	All behaviours improved after the intervention; only anxiety and irritability were significantly ($p<.016$) reduced.	40
N/S	Personalized intervention to meet the unmet needs of residents vs. usual care	Minimal change in behaviours from baseline to follow-up between groups.	46
Agitation	Individualized music	Music affected all participants, but reduction in agitation differed from one to another.	54
Resistiveness to care	Individualized reminiscence intervention	All participants experienced a change in behaviour from baseline to intervention. Only two of the four participants demonstrated a statistically significant change in resistiveness to care (participant 1: $p<.01$ and participant 4: $p<.05$).	56
Agitation and aggression	Person-centered showering and person-centered bed-bath vs. Control	Agitation and aggression declined significantly in both treatments ($p<.001$) but not in control.	57
Agitation	Prayer exercise vs. Control	No statistically significant differences found between the treatment and control groups on neuropsychiatric symptoms ($p=.161$); yet slight improvement in the mean scores for the treatment group.	59
Anxiety	Preferred music listening intervention vs. usual care	Experimental group had significantly lower anxiety post-intervention than control group ($p=.001$).	60

Overall summary: Evidence suggests that unmet needs can translate into disruptive behaviours. When responding to the behaviours of residents, a thorough assessment of the needs and the reasons for the behaviours stand as the best option in returning behaviours to baseline. The experimental studies identified demonstrate that interventions targeting needs are effective in reducing behaviours.

3.1.4.2.2 Need for daily individualized activities/care

Some of the evidence in the literature suggests that residents with dementia need individualized activities and care to improve quality of life. In a randomized controlled trial including 93 participants, the personalization of interventions based on familiar self-identity roles was explored. The intervention group (N=52) showed a significant increase ($p<.001$) in interest, pleasure and involvement in activities in comparison to controls. Fewer agitated behaviours were also observed in this group demonstrating the benefits of individualized activities (Cohen-Mansfield et al., 2006). In a pilot randomized controlled trial (N=10), significantly more time on task ($p<.04$) was found in residents when participating in activities matched to interests and skills over a period of 12 consecutive days (Kolanowski et al., 2001). The activities provided to residents were selected based on 1) their current cognitive and physical abilities and 2) their personality-specific style of interest reflected by a personality quadrant of extraversion (social contact vs. solitary pursuits) and openness (familiar interests vs. wide interests). Residents who enjoyed social contact and preferred familiar activities were engaged in group games and dancing, for instance. Quilt/cooking projects are examples of activities that were matched to residents with broader interests and who preferred solitary pursuits (Kolanowski et al., 2001). In a more recent study, using a larger sample (N=30) from four NHs, Kolanowski et al. (2005) found that participants demonstrated significantly more time on task ($p<.001$) and greater participation ($p<.001$) when involved in activities matched to interest only. Further, a randomized controlled trial of individually tailored medical, pharmacological, nursing and psychosocial interventions administered among a large sample (N=99) of NH residents support the need for individualized care plans. A team of four members with experience in aged care formulated individualized care plans targeting specific behaviours. These were presented to NH staff in the form of a structured behaviour management plan which explained the rationale of each intervention (e.g. psychotropic dose, rest periods and social interactions) as well as the timing and responsibility for the staff. These individualized plans showed a favourable impact on the frequency and severity of the behaviours of participants who were part of the experimental group (Opie et al., 2002). The effect of individualized interventions (individualized music) on behaviours is also supported by three other good quality studies, including a RCT (Gerdner,

2000) and two single case designs with repeated measures (Gardiner et al., 2000; Ragneskog et al., 2001).

A good quality observational study by Chung (2004) also suggests that the well-being of residents is better supported in facilities that encourage participation in and provide the opportunity for daily activities. Significant correlations between the state of well-being and activities were found in this study. Well-being was significantly correlated ($p<0.001$) with engagement in positive and enjoyable activities such as therapeutic/leisure activities (e.g. participating in: exercise/sport, a game and religious activity), ADLs (e.g. eating and performing self-care activities) and mobility and interaction activities (e.g. independent walking and interacting with others). Well-being was negatively correlated ($p<0.001$) with time spent in passive (e.g. sleeping and being socially withdrawn) and negative activities (e.g. talking to oneself and unattended distress) (Chung, 2004).

Four good quality cross-sectional studies found that the need for daily individualized activities is often unmet in residents with dementia (Gill et al., 2007; Hancock et al., 2006; Milke et al., 2006; Orrell et al., 2008). A group of researchers found that the most common unmet need among a sample of 238 residents with dementia from residential care homes was the need for stimulating daytime activities including leisure, social and learning activities. This need was identified as unmet in 76% of the residents (Hancock et al., 2006). Using the same sample of residents, Orrell et al. (2008) explored the views of residents themselves, staff and family carers in identifying the residents' met and unmet needs. All informants identified the need for daytime activities to be unmet for most residents. In a study conducted by Gill et al. (2007), residents (N=311) rated the quality of their care lowest for activities. The need for social activities such as opportunities to enjoy crafts and play games was also of interest in a study by Milke et al. (2006). This study compared the views of family, direct caregivers and other staff on their perceptions of how the needs of residents were being met. The respondents did not feel that the need for residents to engage in regular (e.g. shopping) outings was being adequately met. Among the respondents, direct care staff were the ones that most agreed that this need was not met in residents. Respondents also agreed that residents had few opportunities to participate in social activities (e.g. tea time and games).

Overall summary: Daily individualized activities/care appear to increase resident interest, time spent on task and participation in activities as well as reduce disruptive behaviours. Well-being of residents can also be increased when provided with the opportunity to engage in activities. Despite the suggested benefits of daily individualized activities/care, this need is often unmet in residents.

3.1.4.2.3 Social needs

The quantitative evidence also supports the importance of social needs for residents with dementia. The results of a well-conducted RCT supported the importance of communication and meaningful interactions between residents and staff (Bourgeois et al., 2001). The authors examined the effect of memory aids on conversations between nursing aides (N=66) and residents (N=66) with dementia as a means to highlight the communicative competence of residents and change the conversational interactions between residents and staff. The experimental group improved on a number of quantitative and qualitative conversational measures in comparison to the controls. Residents that were part of the experimental group significantly reduced the time they verbalized ($p<.001$) and significantly increased the number of utterances they used in post-training conversations ($p<.01$). The mean frequency of positive statements also increased over time for the treatment group by an average of 0.5 statements per conversation (Bourgeois et al., 2001). The need for residents to have opportunities to talk openly with others was also stressed in a RCT including three treatment conditions (ADL and a psychosocial activity intervention and a combination of both) and two control groups (placebo and no intervention) (Beck et al., 2002). The interventions developed in this study were designed to address the psychosocial needs of residents with dementia such as the need for communication. Results revealed increased positive affect in residents but not decreased disruptive behaviours in the experimental groups (Beck et al., 2002). The positive effects of communication and social interactions were further demonstrated by an experimental study examining the effect of group music with movement intervention. The participants who received social interventions as part of the experimental group (N=18) demonstrated a significant decrease in the number of agitated behaviours (Sung et al., 2006). Results from a well-conducted cross-sectional study by Choi (2001) highlight the need of a social network, defined as "the web of social relationships that surround a person, and the characteristics of those social ties" (Choi,

2001, p.13), for residents with dementia. A poor social network among participants with severe cognitive impairment from two nursing homes (N=54) was found to be a significant predictor of physical aggressiveness and helped predict verbal aggressiveness (Choi, 2001).

Meeting social needs not only seems to be associated with decreased behaviours, but also with a higher level of well-being, as suggested by a number of high quality observational studies. Greater interaction with others (verbally or otherwise) was found to be positively correlated with better well-being in a group of residents with severe dementia living in nursing homes (N=43) (Chung, 2004). Similarly, Zimmerman et al. (2005) found that better and more positive communication between residents and staff was associated with higher quality of life as observed and reported by care providers (mostly nurses and personal care aides) from RC/AL facilities and NHs. Despite the evident importance of social needs, a number of studies have found that the need for companionship is often unmet. This need was found to be unmet for 97 of 238 residents from residential care (40.8% of the sample) based on an assessment of needs using the Camberwell Assessment of Needs for the Elderly (Hancock et al., 2006). Using the same sample of residents, companionship was also assessed as the need most often unmet by family caregivers, staff and residents themselves (Orrell et al., 2008). Companionship was also found to be one of the lowest domains, after activities, for quality of care as rated by a large sample of residents with primarily moderate to very severe dementia (N=311) from NHs and RC/AL facilities (Gill et al., 2007).

Overall summary: Residents with dementia need to have positive communication and meaningful interactions with others. A decrease in behaviours as well as increased well-being in residents was found in the identified studies targeting this need. Despite the suggested importance of social needs, the need for companionship is often unmet in long-term care residents.

3.1.4.3 Importance of the needs as supported by the qualitative evidence

Table 8 outlines the importance of the needs identified in the qualitative literature based on the quantity and the methodological rigor of the studies reporting on each need. The qualitative evidence further supports the importance of the need for daily individualized activities/care and

social needs for residents with dementia. The qualitative literature also suggests the importance of emotional needs/personhood as well as the need for independence/choice. Studies on the need for knowledgeable staff appear to be lacking in numbers and in quality.

Table 8 - Prioritized needs of residents with dementia as determined by the qualitative evidence

Avg. overall quality (1 to 9) ⟵	Quantity (1 to 8) ⟶							
	1	2	3	4	5	6	7	8
1								
2	Code 11: Need for knowledgeable staff							
3								
4				Code 5: ADLs				
5								
6		Code 14: Spiritual needs						
7	Code 9: Need for daily structure	Code 12: Need to be in a homelike comforting environment; Code 19: Need for privacy			Code 13: Need to receive proper	Code 8: Need for independence/choice		Code 3: Emotional needs and Personhood
8		Code 4: General overall physica	Code 18: Need to be safe/secure	Code 10: Management of behavioural problems		Code 2: Need for daily individua	Code 1: Social needs	
9	Code 7: Money - financial issue	Code 16: Sexual Needs						

3.1.4.3.1 Emotional needs/Personhood

The qualitative evidence suggests that residents with dementia living in nursing homes have emotional needs and a need to be recognized as an individual (personhood). In an explorative study conducted by Dröes et al. (2006), the residents with mild to moderately severe dementia (N=37) expressed a need for attachment (feeling attached, being understood, being involved in things around you and living in the midst of your family), a need for self-esteem/self-image (being accepted for who they are and perceived continuity in their self-image) and a need for affect (being allowed to express positive feelings and being approached by others in a positive manner). The importance of self-identity in residents is also discussed by a study on well-being which observed from analyses that long-term care residents with dementia with a strong sense of identity demonstrated high well-being (Bruce et al., 2002). Zingmark et al. (2002) discussed the importance of offering respect, looking for the residents' personalities and providing residents with the chance to preserve their external appearance (e.g. do hair in usual way) as caring aspects supporting a strong sense of well-being in residents. Caring aspects were identified from phenomenological hermeneutic interpretation of interviews among ten care providers working in a selected special care unit in Sweden (Zingmark et al., 2002). Another element which may positively impact the well-being of residents is the therapeutic effect of gardens (Hernandez, 2007). Observations of resident's emotional expressions revealed that they seemed happy in the garden space and demonstrated a better attitude when returning from the garden area. It was also observed that the garden reminded the residents of their former homes and lives and kept them in touch with nature and the reality (Hernandez, 2007).

Key elements to a quality end-of-life care include respect from others, expression of caring and affection from staff and one-to-one interaction with staff (Powers & Watson, 2008). Continued interaction between staff and resident apart from medical care can positively affect the end-of-life experience of residents by providing a means for staff to get to know the resident better (Tilly & Fok, 2008).

Overall summary: Residents with dementia have a need for attachment, self-esteem and affect which remains throughout the progression of the disease. The need for residents to preserve a

sense of self (personality, respect and appearance) is also of importance. Some studies have demonstrated that preserving a sense of self can support the sense of well-being.

3.1.4.3.2 Need for independence and choice

Qualitative evidence appears to support the need for independence and choice. The importance of autonomy and freedom as well as the opportunity for control have been discussed as elements adding to the QoL of residents. The importance of self-determination and freedom for residents was supported by both residents themselves and professional caregivers alike (Dröes et al., 2002). Residents expressed the need to do things as they wished and have the freedom to pick up after themselves (personal belongings) when desired. Professional caregivers acknowledged the need for autonomy and identity by offering examples such as being able to get up and eat when desired (Dröes et al., 2002). Promoting power and control in residents was further identified by care providers as a caring aspect for promoting well-being in a study conducted by Zingmark et al. (2002). These authors suggest providing options from which residents can choose yet not pushing the residents to make choices they are unable to make. The relocation of residents to a special care unit from a traditional institution provided a greater opportunity for freedom which had a positive effect on their quality of life (Cioffi et al., 2007).

A high quality study written by Powers (2000) reported on daily ethical issues affecting nursing home residents with dementia. A common theme which emerged from the in-depth interviews conducted among residents, staff members and families was resident autonomy. The ability for residents to exercise choice as much as possible, independent of their capability to communicate, was raised by the respondents. Resident autonomy was of main interest in two of the identified domains of ethical issues (learning the limits of intervention and preserving the integrity of the individual). An example of an ethical issue includes the limit to which residents can be autonomous when resisting going to bed. In this example, conflicting staff views were the acceptance of the residents' behaviour (resident rights) or the intervention with resident choice over concern of sleep deprivation in residents (Powers, 2000).

Overall summary: Autonomy and freedom are important to residents and stand as elements promoting their quality of life.

3.2 Matching of the needs to the grouping methodology items

The needs identified in the literature were 1) matched with MDS 2.0 variables used in the RUG-III, 2) matched with MDS 2.0 variables not used in the RUG-III, and/or 3) not matched with any MDS 2.0 variables (Table 9). First, needs were matched with similar MDS 2.0 variables that are a part of the RUG-III (34 Group) grouping methodology. Out of the 19 code categories, fourteen needs met one or more RUG-III items (Table 9) with cognitive needs, ADLs and general overall physical health matching the greatest number. The MDS variables used in the calculation of the RUG-III are outlined in Appendix 4 along with their description.

Table 9 - Needs identified in the literature and associated MDS 2.0 variables part of the RUG-III grouping methodology or other MDS 2.0 variables of relevance

Need	Code	MDS 2.0 section/variable part of the RUG-III[3]	Other MDS 2.0 variables[4]	Extra
Management of behavioural problems	10	E1; E4 (a)	E3, E5, F, N2, O, P2 (a,d,e), P4	
Need for daily individualized activities/care	2	Section G, P1b, P3	E4B, F1 (b), F3, N2, N3 (d), N4 (g,h,k), O, P2	
Social needs	1	C4	C3, E2, F, F1(a, e), F2, F3, N2, N4(k, l)	
Emotional needs/Personhood	3	C4, E1	A9, E3, E5, F1 (e), F2, F3 (a), N2, N4 (k, l), P1be	
ADLs	5	E1 (j, k); Section G (G1aB; G1h; G1i); H; P1b (c); P3	G1 (c, d, g, j), G5a, G2, G7, G8b, G9, J1n, L1f, P1ar	
Need for independence/ Choice	8	B4, C4	A9 f, A10, F1, F2, G8 (b, c), K4, N3, N5, P4	
Cognitive needs	15	B2(a); B4; C4; P1ba; P3j	B3, B5, C6, P2d	
Need to be safe / secure	18	E1	P1an	
General overall physical health	4	Section G; Section M; P1b (c); P3	G1j, K4, K5 (e,f,h), J2, O, N4c	
Need to be in a	12		P2d, F3c	

[3] Description of the MDS 2.0 sections/variables in Appendix 4.
[4] See Appendix 21 for a description of other MDS 2.0 variables of relevance.

homelike comforting environment				
Need to receive proper pain management	13	M5 (a, b, c); O3	J2, J5c, O (O4f)	
Sensory needs	17		C1, C2, C6, D, P1an, P2d	
Need for daily structured care	9	P7	F1(b), F3c	
Functional needs – IADLs	6	P1b, P3	P1ar	
Need for knowledgeable staff	11	C4, J1	C6, F1a, N4k, O, P1ae, P1be	
Sexual needs	16			X
Need for privacy	19	E4	F1, F2 (b,c), N2, N3	
Money – financial issues	7			X
Spiritual needs	14		F1 (e,f), P1be	

The three needs identified from the literature in this study that met the greatest number of MDS 2.0 variables used in the RUG-III, were linked to variables from more than two different sections. Cognitive needs met the definitions of variables within the cognitive (i.e. cognitive skills for daily decision making – B4) and communication/hearing pattern (i.e. ability to making self-understood – C4) sections as well as the special treatments and procedures section (i.e. training and skill practice in communication – P3j). The need for general overall physical health and ADLs were categorized within the physical functioning and structural problems (i.e. assistance with toileting) and special treatments and procedures (i.e. physical therapy – P1bc) sections. ADLs met variables from section E1 (indicators of depression, anxiety and sad mood) and H (continence in last 14 days), and the need for general overall physical health met section M (skin condition).

Second, other MDS 2.0 variables not a part of the RUG-III were sought for possible relevance to the unmatched needs. The unmatched needs relate to the needs that were not linked with any RUG-III items including 1) the need to be in a homelike comforting environment, 2) sensory needs, 3) sexual needs, 4) money – financial issues and 5) spiritual needs as well as other needs that while meeting RUG-III items also were associated with other MDS 2.0 variables. Third, all,

but two needs categories, met other MDS 2.0 variables. The needs that were not matched to any MDS 2.0 variables were sexual needs and money – financial issues.

Many of the MDS variables linked to the unmatched needs are similar to those included in the RUG-III calculation. However, a number of needs were associated with sections of the MDS 2.0 not considered by the RUG-III, namely section F (psychosocial well-being), section D (vision patterns) and section L (oral/dental status). The variables that appeared to be pertinent within these sections are: F1 (sense of initiative/involvement), F2 (unsettled relationships), F3 (past roles) and L1f (daily cleaning of teeth and dentures, or daily mouth care – by resident or staff). In total, ten of the 19 needs categories were associated with one or more variables from section F of the MDS. Section N (activity pursuit patterns), which is not thoroughly considered in the RUGs calculation, also appeared to be relevant to a number of needs identified from the literature. Eight needs (1- management of behavioural problems, 2- need for daily individualized care, 3- social needs, 4- emotional needs/personhood, 5- need for independence/choice, 6- general overall physical health, 7- need for knowledgeable staff and 8- need for privacy) met one or more variables included in this section. The variables of relevance were: N2 (average time involved in activities), N3 (d) (preferred activity settings (outside facility)), N4 (c, g, h, k, l) (general activity preferences-adapted to resident's current abilities (exercise or sports, trips or shopping, walk/wheeling outdoors, talking or conversing, helping others)) and N5 (prefers change in daily routine). A complete detailed matching of the needs with associated MDS 2.0 variables (both those that form part of the RUG-III and those that do not) is outlined in Appendix 22.

A few of the needs identified from the literature and part of 16 of the 19 code categories did not meet any section(s)/variable(s) of the MDS assessment tool. All needs related to the need to receive proper pain management, the need for privacy and spiritual needs met MDS variables. Needs left unmatched from the other needs categories were either too general to be associated with an MDS variable or viewed to be a quality indicator derived from the MDS (related to the management of behavioural problems).

3.3 Analysis of the priority of items in the grouping methodology in relation to the importance of the identified needs in the literature

The priority of items in the grouping methodology is outlined in Table 10. The table summarizes the triggers (indicators (specific groups/sequence of MDS variables) and MDS variables) for all seven RUG-III categories. The triggers are what prompt resident placement in one or more categories. To note, triggers (MDS variables) for category I hold more priority in the hierarchical classification than do the triggers for category V for instance because they represent clinical characteristics that are more resource intensive. The determinants for categorization within a category are shown as well. However, these are of lesser significance than triggers as they determine classification of residents in one of the groups within the RUG category.

Table 10 - Priority of items within the grouping methodology

Category rank	Category name	Triggers	Determinant(s) for categorization within category
I	Extensive services	ADL score between 7 and 18 AND Any extensive care clinical indicators* * K5a, P1ac, P1ai, P1aj and P1al	Number of extensive care clinical indicators (1 to 5)
II	Special rehabilitation	5+ P-O-S* therapy days in last week AND 150+ minutes of P-O-S therapy in last 7 days OR 3+ P-O-S therapy days in last week AND 45+ minutes of P-O-S therapy in last 7 days AND 2+ nursing rehab techniques** on 6 of last 7 days * physical (P1bc), occupational (P1bb), speech (P1ba) (P-O-S) ** P3a,b,c,d,e,f,g,h,i,j, H3a and H3b	ADL score (4 to 18)
III	Special care	Any extensive care clinical indicators OR Any special care clinical indicators* AND ADL score between 7 and 18 * I1s, I1t, I1y, I1bb, I2f, J1c, J1h, J1o, K3a, K5b, M2a, M4c, M4g, M5a, M5b, M5c, M5d, M5e, M5f, M5g, M5h, P1ah and P1bdA	ADL score (7 to 18)
IV	Clinically	Any extensive care clinical indicators	ADL score (4 to 18) and presence

	complex	OR Any special care clinical indicators OR Any indicators for clinically complex care* * I1a, I1w, I2f, I2h, J1c, J1j, J5c, K5b, M4b, M6b, M6c, M6f, O3, P1aa, P1ab, P1ag, P1ak, P7 and P8	of depression* or not * E1a,b,c,d,e,f,g,h,i,j,k,l,m,n,o,p
V	Impaired cognition	ADL score between 4 and 10 AND CPS score* between 3 and 6 *based on the following variables: B1, B4, B2a, C4	ADL score (4 to 10) and 2+ nursing rehabilitation techniques in last 6 of 7 days or none
VI	Behavioural problems	ADL score between 4 and 10 AND E4aA or E4bA or E4cA or E4dA or E4eA (occurred on 4 or more of last 7 days) or J1e or J1i (present in last 7 days)	ADL score (4 to 10) and 2+ nursing rehabilitation techniques in last 6 of 7 days or none
VII	Reduced physical function	No specific trigger	ADL score (4 to 18) and 2+ nursing rehabilitation techniques in last 6 of 7 days or none

Source: (CIHI, 2009a)

As demonstrated by Table 10, the ADL score represents one of the main components of the RUG-III, as it is considered in the determination of resident placement in all 34 groups of the system. The ADL score relies on late loss ADLs, more specifically, bed mobility (G1a), transfer (G1b), toilet use (G1i) and eating (G1h). Extensive services (K5a, P1ac, P1ai, P1aj and P1al), rehabilitation therapy related to the disciplines of physical (P1bc), occupational (P1bb) and speech (P1ba) therapy as well as nursing rehabilitation techniques (P3a,b,c,d,e,f,g,h,i,j, H3a and H3b) stand as other important indicators in the grouping methodology. Extensive services represent one of the triggering factors of categories I, III and IV. Rehabilitation therapy and nursing rehab techniques are triggers of category II, with nursing rehab techniques being determinants for categorization within categories V, VI and VII as well.

The need most supported by the quantitative evidence is the **need for the management of behavioural problems** (see Table 6). In the grouping methodology however, the related items associated to this need do not hold the same level of importance. Variables related to E4 (behavioural symptoms) trigger the behavioural problems category (VI) and variables related to E1 (verbal expressions of distress) influence the placement of residents within the clinically

complex category (IV). **Emotional needs/personhood** was the need most supported by the qualitative studies (see Table 8). Similarly to the need most supported by the quantitative evidence, the variables that are part of the grouping methodology and that were associated to emotional needs/personhood do not have the same level of priority. Emotional needs/personhood was associated with variables E1 (verbal expressions of distress) and C4 (making self-understood), the latter being a variable used to determine the Cognitive Performance Scale score of a resident, in other words the resident's cognitive impairment level. Additionally, the **need for independence/choice** which has been suggested of particular importance by the qualitative studies meets lower priority variables of the RUG-III. As with the above mentioned needs, most variables of relevance to this last need are not even considered by the grouping methodology.

Both the quantitative and qualitative evidence have also demonstrated the importance of social needs and the need for individualized activities/care. Only one of the MDS 2.0 variables of relevance to **social needs** is part of the RUG-III calculation. This is variable C4, a variable which is not a top priority item of the RUG-III, as previously mentioned. A few MDS 2.0 variables associated with the **need for individualized activities/care** represent important items within the grouping methodology however. Variables of relevance to this need are P1b (therapies), P3 (nursing rehabilitation/restorative care) and variables in section G (physical functioning and structural problems). The two first variables constitute triggers for category II. P3 is also considered for determining the classification of residents within categories V, VI and VII. Variables that are part of section G relate to ADLs which represent the most important component of the RUG-III.

Interestingly, two of the needs that are supported moderately by the evidence were associated with items of importance in the RUG-III. **General overall physical health** and **ADLs** are relevant to the ADL component of the grouping methodology as well as rehabilitation therapy and nursing rehab techniques, both triggers for category II. Further, a number of variables associated to **cognitive needs** are triggers of the impaired cognition category of the RUG-III. These variables are B2a (short term memory), B4 (cognitive skills for daily decision making) and C4 (making self-understood). Cognitive needs were also linked with variables used as triggers of category II. The **need to receive proper pain management** which is moderately

supported by the literature is represented by items of similar priority within the RUG-III, being associated with special care clinical indicators and an indicator for clinically complex care.

The other needs identified in the literature which were supported by both fewer and lower quality studies were not represented within the grouping methodology or were matched with a few RUG-III items. The need to be in a homelike comforting environment, sensory needs and spiritual needs do not appear to be represented within the RUG-III. The need for knowledgeable staff was linked with a few items of priority in the RUG-III, yet most variables associated with this need are not used in the grouping methodology. Functional needs – IADLs, a need that was supported by both fewer and lower quality studies, met a few items more heavily weighted in the RUG-III as well. The need to be safe/secure, the need for daily structured care and the need for privacy were all matched with one RUG-III item of moderate priority. Most of the MDS 2.0 variables relevant to these needs are not used in the calculation of the RUG-III. Sexual needs and money-financial issues are not represented in the RUG-III, nor do they relate to any MDS 2.0 variables as previously discussed.

3.4 Summary of results

In total, 68 studies were selected for review, from which 19 needs were identified. The needs suggested as most important for people with dementia by the quantitative studies were the need for the management of behavioural problems, social needs and the need for individualized activities/care. Qualitative studies also suggested the importance of these last two needs, but seemed to support more strongly emotional needs/personhood. On the other hand, quantitative studies were less numerous or had fewer strong studies supporting the need to deal with financial issues or functional needs – IADLs. On the qualitative side, the need for knowledgeable staff did not surface amongst the strongest studies or amongst the majority of studies. There were no studies indicating this was not important but rather our study may indicate that we need more evidence in this area.

Most needs identified in the literature met one or more RUG-III item with the exception of the need to be in a homelike comforting environment, sensory needs, spiritual needs, sexual needs and money – financial issues. In fact, all, but these two last needs, were associated with MDS 2.0 variables.

The needs that were most supported by the literature were not weighted in sync with the items of the RUG-III (management of behavioral problems, emotional needs/personhood and the need for independence/choice) or were not found to be thoroughly considered by the system (social needs and the need for daily individualized activities/care). The grouping methodology recognizes well ADLs, the need for general overall health and cognitive needs. The need to receive proper pain management also appears to be well captured by the grouping methodology.

Chapter 4 - Discussion

In this chapter, the comprehensiveness of the RUG-III in relation to the identified needs in the literature will be discussed in addition to the implications of the results as well as the study's limitations/methodological issues. Recommendations for future research will be further outlined.

4.1 Comprehensiveness of the RUG-III in relation to the identified needs in the literature

The needs that were identified in this study and characterized as most important by the scientific literature for people with dementia do not appear to be addressed appropriately by the RUG-III grouping methodology. Quantitative evidence highly supports the need for management of behavioural problems. The elements in the RUG-III which capture this particular need are not given much weight however. The variables of relevance to this need are listed as triggers to one of the lower ranked categories. Social needs and the need for daily individualized activities/care also appear of great importance as suggested by the quantitative and qualitative literature. Only one lower priority RUG-III item was associated with social needs. However, this need was linked to a number of other MDS variables not captured by the RUG-III. Hence, social needs are recognized in the assessment tool but this is not translated into the funding scheme. Furthermore, the need for daily individualized activities/care could be identified in variables of importance from two MDS sections. Though, many of the MDS variables associated to this need are also not considered in the grouping methodology. Qualitative studies also suggest the importance of emotional needs/personhood as well as the need for independence/choice for people with dementia. Only two RUG-III items and triggers of lower ranked categories were linked to these needs. Many other MDS 2.0 variables were found to be relevant to emotional needs/personhood and the need for independence/choice. These were also mainly relevant to the psychosocial well-being and the activity pursuit patterns sections of the MDS assessment instrument.

The resources used for ADLs appear to be fairly well captured by the RUG-III grouping methodology as well as items related to general overall health and cognitive needs which are needs that were not considered amongst the top priorities by the scientific evidence in the last 10 years. ADLs and general overall health seem to be more heavily weighted in the grouping methodology than what the literature suggests. Cognitive needs met most variables that trigger

the impaired cognition category of the grouping methodology in addition to other items of importance within the system. The other MDS variables of relevance to all three needs are similar to the associated variables part of the RUG-III. Further, the need to receive proper pain management is similarly represented in the RUG-III than that suggested by the literature. The RUG-III items that this need did relate to, reflect a moderate priority.

4.2 Implications of results

As already mentioned, the management of behaviours is one of the most important needs of people with dementia in LTC. The anxiety and aggression manifested by the residents is perceived as a signal of unease and therefore the need to deal with these anxieties becomes a source of resource consumption. The cost required to respond to these needs remains to be explored. The MDS gives us a good starting point for capturing this data. The physical environment, the presence of pain and the lack of social stimulation are examples of needs that can trigger behavioural problems (Camp, Cohen-Mansfield, & Capezuti, 2002). Despite the need to comprehensively understand the reason behind the behaviours, caregivers often do not have the resources available in terms of time and/or tools to assess the behaviour prior to administering a treatment. Reactive responses to behaviours which refer to the administration of a treatment after assessing quickly the cause of the behaviour was found to be the most prevalent type of response by nurses based on a sample of 112 participants from nursing homes (Kovach, Kelber, et al., 2006). In a prospective study examining the time used by nursing staff to manage disruptive behaviours, it was found that no nursing assessment or intervention was provided for behavioural symptoms in about 25% of the cases (Souder & O'Sullivan, 2003). This may suggest that caregivers tend to opt for an immediate solution to the behaviours as a result of their distressing nature or as a result of the lack of resources to deal with these behaviours. Tilly and Fok (2008) caution that a distinction be made between managing disruptive behaviours for the sake of residents versus for the sake of staff (Tilly & Fok, 2008). If the resources are not sufficient to allow proper management of the behavioural issues, the behaviours might worsen leading to an escalation of unmet needs that become unmanageable. For residents with dementia, the increased levels of agitation, anxiety and verbal outbursts can decrease their quality of life and have a negative impact on their health (Cohen-Mansfield & Jensen, 2006; Zimmerman et al., 2005).

The suggested importance of social needs, the need for daily individualized activities/care, emotional needs/personhood and the need for independence/choice for residents with dementia suggests that there is a need to create the notion of *home* for this population. As identified by Aminzadeh and colleagues (2010), the creation of the meaning of *home* for people with dementia is of particular importance when being transferred to a collective dwelling of care. According to the participants in this study, a *home* encompasses the following: i) familiarity, ii) a center of socialization, iii) connectedness and affiliation, iv) a place of retreat, v) a locus of autonomy, control, choice and freedom of actions, vi) a site for engagement in meaningful activities of daily living, vii) a place for the expression of personal interests, values, achievements, and status, and viii) a source of memories of life histories (Aminzadeh, Dalziel, Molnar, & Garcia, 2010). Long-term care facilities are often stigmatized as a place of "sickness" and may lack this notion of *home*. In a study by the same authors (Aminzadeh, Dalziel, Molnar, & Garcia, 2009), exploring the perspectives of 16 PWD on the meanings and experiences linked with the relocation to a residential care facility, the relocation signaled an inevitable downward trajectory to a more dependent, protected and structured lifestyle.

The RUG-III recognizes ADLs, general overall health, cognitive needs and the need to receive proper pain management which are all relevant to direct nursing care. In fact, these needs, with the exception of the need to receive proper pain management, are more heavily weighted in the funding formula than those needs that the literature would suggest are the priority needs for the residents. In brief, direct nursing care refers to care provided by active care staff (e.g. nurses) and include such activities as assistance with toileting and bathing as well as personal care (e.g. grooming). The fact that the RUG-III grouping methodology reflects these needs as a priority is not surprising since it is used to adjust the nursing and personal care funding component set by the MOHLTC. The fact that the grouping methodology does not thoroughly consider the needs most strongly evidenced in the literature flags a concern that these needs may not be properly addressed and may hinder the care received by residents with dementia. As is now widely known unmet needs can lead to greater problems in these residents. Since the results of this study suggest that the RUG-III does not properly account for these needs (management of behavioural problems, social needs, need for daily individualized activities/care, emotional needs/personhood and need for independence/choice) in this population of residents, a new strategy may need to be

developed or minor changes to the current funding formula may need to be made to address this matter.

First, the results beg us to consider whether it is appropriate for the RUG-III to allocate funding to respond to the needs identified in the literature. Is the system only intended to capture nursing and personal care requirements of residents? If so, what are the links then between responding to the quality of life needs of residents and the impact on nursing and personal care? If the funding formula is not intended to capture only the nursing and personal care requirements, why does the RUG-III not capture the needs identified most strongly in the literature, especially since the MDS seems to capture most of these elements? Is it because the needs are not well understood, viewed as optional or considered supplementary to daily care? Although the RUG-III is a generic system developed to capture the care needs of all long-term care residents, there is evidence that psychosocial needs such as meaningful activities and social contact are essential to all residents and not only specific to those with dementia or probable dementia (CHA, 2009; Tolson et al., 2010). As mentioned previously, there may be a need for a culture shift in the way we think about LTC from a "hospital" to a "home".

The need for a cultural shift in LTC has been highlighted in a recent report by The Conference Board of Canada. Today's LTC residents have different preferences (e.g. independent living and need for greater autonomy) and higher expectations. Facilities that promote socialization, choice and independence positively impact the quality of life of residents, thus suggesting a need to shift from a structured to a more flexible type of care (CBoC, 2011).

Second, if the system was designed to specifically capture the nursing and personal care requirements of residents, considerations should be made as to whether social needs, for instance, be considered as an NPC requirement. If social needs such as personal contact, positive relationships and information sharing are not met additional direct nursing care costs could result.

Third, a possible revision to the program and support services funding component could be considered. Expenditures for recreation and social activities fall mainly under this funding component. As of July 1st, 2011, the daily amount per resident for the PSS component was $8.35 compared to a total daily funding of $152.94 per resident. This represents approximately 5% of

the daily amount which is surprisingly low to address the daily activity and social needs of residents. Hence, is the PSS funding amount sufficient to provide daily meaningful and individualized activities as well as satisfactory communication with residents?

Fourth, if activities and social needs are indeed not satisfied in long-term care and if the dollars for PSS cannot be increased from a reallocation of money of the daily funding, community partnerships for the provision of meaningful activities could be considered. In this sense, incentives could be provided to homes that partner with community groups and organizations for ensuring satisfactory levels of recreational and social activities to residents. An example of a community linkage would be to partner with spiritual leaders as an opportunity for residents to receive regular spiritual care visits from a pastor, for instance. Partnerships between homes and community groups do exist. A long-term care home in Brampton Ontario, for example, has a partnership with a local garden club. The club visits the home once a month and engages residents in various stimulating activities such as working hands-on in the facility's gardens (Peel Region, n.d.). Such community partnerships would respond to the needs of residents without adding government funding significantly.

Fifth, funding schemes could include incentives to homes that keep residents in stable environments and reduce staff turnover. In a cross-sectional study conducted by Hancock et al. (2006), it was found from a sample of 238 participants with dementia that unmet needs were associated with a lower age, a shorter length of stay in the home as well as greater depression and anxiety levels. It could be argued that residents that reside in the same home longer have less unmet needs and a lower depression level because care professionals know them better and are better suited to cater to their individual needs. Professionals that care for residents for a long period of time can for example, better understand the reason for their behaviours and know how to communicate and approach them based on their preferences. Furthermore, environments based on social interaction and where behavioural sequelae are minimized makes for a more interesting workplace, further encouraging the staff to stay.

Staff retention stands as one of the most important challenges facing the LTC sector at present. The average levels of turnover are 12% and 6.5% per year for full-time Registered Nurses/Registered Practical Nurses and Personal Support Workers respectively. Staff dissatisfaction is mainly influenced by heavy workloads. Other factors influencing staff retention

include the lack of training opportunities, the lack of autonomy and the nurses feeling that their work is not as highly valued as those working in acute care (CBoC, 2011).

4.3 Study limitations and methodological issues

The interpretations of these data are not without a few limitations. First, the importance of the identified needs relies exclusively on the literature. The importance was determined based on the quality and the quantity of the identified studies. Therefore conclusions based on this method may be biased, as it relies on what researchers decided to study and what they believed made more sense in terms of research focus. What appears to be most important as supported by the literature may not reflect the "real" importance of the needs of residents with dementia in long-term care homes. Needs that were supported as low to moderate importance by the evidence may simply be due to the fact that they are considered of real importance and/or are met in long-term care, and thus not a needed area for scientific inquiry (e.g. ADLs and need for privacy) or they may reflect needs that are not particularly well understood (e.g. spiritual needs). In such case, these needs would not be reflected similarly by our results. Needs that were given a low priority (i.e. the need for knowledgeable staff) could also not reflect a real need from the residents' perspective or may be captured in another category such as the need for proper pain management, thus suggesting that this is not a need of significant importance to PWD. As the needs generated were not validated in real centers this may reflect areas of further exploration and, as discussed may have biased the literature against the surfacing of ADLs as an important need.

Second, we cannot objectively conclude on the appropriateness of the RUG-III for people with dementia as we did not associate a cost to satisfying the needs identified in the literature. What needs to be stressed is the fact that the RUG-III is concerned with the cost of fulfilling a need in comparison to the importance of a need. The needs considered in the RUG-III will not be more heavily weighted because of their importance, but rather because they are more costly to satisfy. For example, what is the cost associated with providing social needs and how does this cost translate with the weighting of the related RUG-III items? What we do know at this point is that some needs well-supported by the literature are not represented in the RUG-III and other less supported needs by the literature are better represented within the grouping methodology. The

question of what it would mean to adequately address the needs identified in this study within the funding formula should be the subject of further study.

Third, residential care and assisted living were not considered as keywords or Me SH terms in the search strategy. The setting of focus in this study was initially long-term care, and so only terms relevant to this setting were considered in the search process. However the term aged care home does encompass residential care as well as lower levels of care in addition to 24 hour nursing care. After reviewing a considerable number of articles it was found that the RC/AL setting is gaining popularity as a choice for care for people with dementia. Articles that did pertain to this setting were not excluded based on this criterion in the selection process as a result. Since residential care and assisted living were not terms considered in the searching of articles, this may have limited the thoroughness of our results. Fourth, our search strategy focused exclusively on the needs of people with dementia and not on the needs of staff or family. This might have limited the types of studies we identified.

4.4 Recommendations for future research: Next steps

This research adds to the scientific evidence by providing a basis towards understanding the overall needs of this population in relation to the funding system. Future research is needed to validate whether the list of needs identified by this study is comprehensive both in terms of content and in terms of priorities. Validation should include asking frontline staff, families and potentially residents to comment on the list of needs and how they would prioritize them. A few very high quality quantitative studies addressed the need to receive proper pain management. More evidence is needed to determine the importance of this particular need. Spiritual needs were considered by qualitative studies suggesting its importance for people with dementia. This presents an avenue for future quantitative research.

Another avenue of interest would be to look at the list of needs identified by this study for subgroups with dementia. For example, it could be interesting to see if differences exist between men and women as well as people from different ethnic backgrounds. This last should be of particular interest for study as the ethnic and linguistic diversity is expected to increase considerably in the coming years. Based on results from a 2006 Canadian census, 7.6% of people aged 75 years and over reported being a member of a visible minority in comparison to 12.7%

for those aged between 45 and 64 (CBoC, 2011). Other interesting factors of study relating to need differences are the level of income and the presence/absence of a spouse.

To ensure updated results of needs, the searches conducted in September 2010 could be performed at present in the same databases and using an identical search strategy. This would help identify additional relevant studies published after September 2010. The evidence identified in these studies could help validate our results and/or suggest other findings.

A further area of future research would be to determine the adequacy of the weighting of the RUG-III groups in relation to the identified needs in the literature. A possible future study could examine the resource requirements for meeting each need found in the literature and then determining how those resource requirements compare with other components of the grouping methodology.

Chapter 5 - Conclusion

The RUG-III grouping methodology recognizes the importance of ADLs, general overall health, cognitive needs and the need to receive proper pain management which are needs related to direct nursing care. The results of this study suggest that some important needs well supported by the literature are not thoroughly considered by the funding system. It is clear from our discussions with clinicians and administrators in LTC that there will be important challenges ahead in how we manage our LTC health system. Results from this study are expected to inform policy-makers on possible changes within the system with a goal to improving the quality of care offered to people with dementia in long-term care. In light of the aging population and the increasing rates of dementia, it is crucial that we not neglect this sector of the health care system and that we ensure that the allocation of funding and the funding system be as comprehensive as possible in meeting the needs of residents with dementia as well as other residents.

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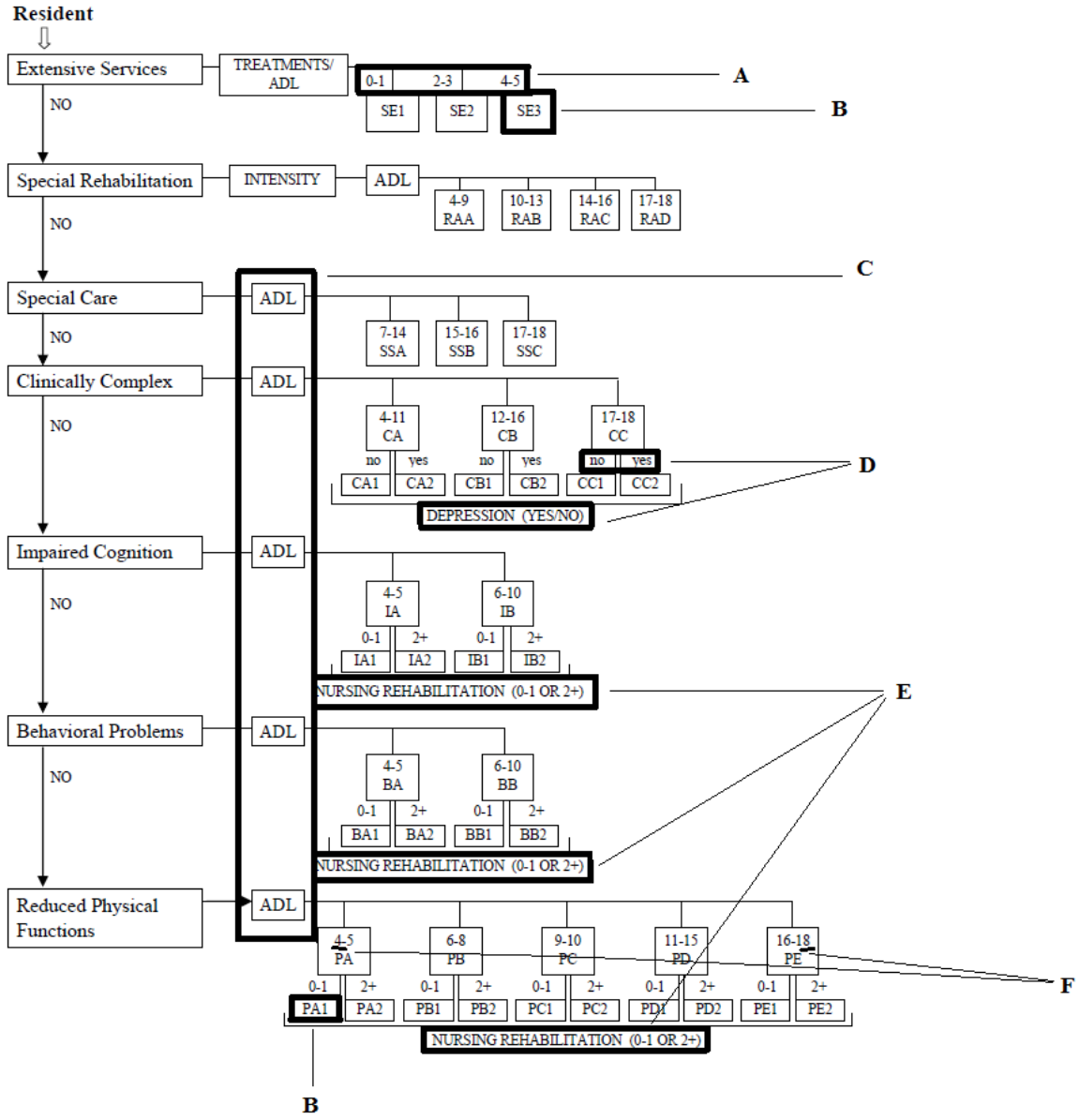
Appendices

Appendix 1: Current base level-of-care per diem funding as of July 1, 2011

Envelope	Funding Amount
Nursing and Personal Care	$86.05
Program and Support Services	$8.35
Raw Food	$7.46
Other Accommodations	$51.08
Total	**$152.94**

Source: (MOHLTC, 2011c)

Appendix 2: RUG-III (34 Group) grouping methodology



Source: (InterRAI, 2007b; MOHLTC, 2011a)

- 34 groups of RUG-III ranked from highest to lowest resource use, hence **SE3** to **PA1** *(refer to letter B)*.
- The secondary splits of the RUG-III (34-group) grouping methodology are based on an **ADL score** *(refer to letter C)*. The ADL score ranges from **4** (resident independent in all functions) to **18** (resident dependent in all functions) *(refer to letter F)*, and is based on the sum of the scores of four ADL variables (bed mobility, transfer, eating and toilet use).
- The tertiary splits of the RUG-III (34-group) grouping methodology are based on the count of **extensive services** (Extensive category) *(refer to letter A)*, **depression** (Clinically Complex category) *(refer to letter D)* and **nursing rehabilitation** (Impaired Cognition, Behavioural Problems and Reduced Physical functions categories) *(refer to letter E)*.

Appendix 3: RUG-III (34 Group) grouping methodology, 2010-2011 CMI values

RUG-III (34 Group) Category	RUG-III (34 Group) Rank	RUG-III (34 Group) Name	Fiscal Year 2009-2010
1 – Extensive Care	1	SE3 [i]	1.9422
	2	SE2	1.5910
	3	SE1	1.4460
2 – Special Rehabilitation	4	RAD	1.6125
	5	RAC	1.3492
	6	RAB	1.1973
	7	RAA	1.0167
3 – Special Care	8	SSC	1.4020
	9	SSB	1.3189
	10	SSA	1.2135
4 – Clinically Complex Care	11	CC2	1.3794
	12	CC1	1.2770
	13	CB2	1.1905
	14	CB1	1.1161
	15	CA2	1.0683
	16	CA1	0.9413
5 – Impaired Cognition	17	IB2	0.9729
	18	IB1	0.9469
	19	IA2	0.7561
	20	IA1	0.7177
6 – Behavioural Problems	21	BB2	0.9388
	22	BB1	0.8917
	23	BA2	0.7036
	24	BA1	0.6327
7 – Reduced Physical Functions	25	PE2	1.1291
	26	PE1	1.1063
	27	PD2	0.9959
	28	PD1	0.9718
	29	PC2	0.9095
	30	PC1	0.8429
	31	PB2	0.7116
	32	PB1	0.7016
	33	PA2	0.6452
	34	PA1 [ii]	0.6308

Source: (CIHI, 2009b)

Note: CMI values same for the period of 2009-2010 and 2010-2011.

[i] highest resource intensive group
[ii] lowest resource intensive group

Appendix 4: MDS 2.0 variables used in RUG-III (34 Group) grouping methodology

Section A – Identification information		
A3	(valid date)	Assessment of reference date (used for assignment of year-specific CMI values)
Section B - Cognitive Patterns		
Comatose		
B1[i, ii]	(0, 1)[iii]	Persistent vegetative state or no discernible consciousness[iv]
Memory		
B2a	(0, 1, 8)	Short term memory OK – seems or appears to recall after 5 minutes
Cognitive skills for daily decision making		
B4	(0, 1, 2, 3, 8)	Made decisions regarding tasks of daily life
Section C - Communication / Hearing Patterns		
C4	(0, 1, 2, 3, 8)	Making self-understood
Section E - Mood and Behaviour Patterns		
Indicators of depression (observed within LAST 30 DAYS)		
Verbal expressions of distress		
E1a	(0, 1, 2, 8)	Resident made negative statements
E1b	(0, 1, 2, 8)	Repetitive questions
E1c	(0, 1, 2, 8)	Repetitive verbalizations
E1d	(0, 1, 2, 8)	Persistent anger with self or others
E1e	(0, 1, 2, 8)	Self-deprecation
E1f	(0, 1, 2, 8)	Expressions of what appear to be unrealistic fears
E1g	(0, 1, 2, 8)	Recurrent statements that something terrible is about to happen
E1h	(0, 1, 2, 8)	Repetitive health complaints
E1i	(0, 1, 2, 8)	Repetitive anxious complaints or concerns - non health
Sleep-cycle issues		
E1j	(0, 1, 2, 8)	Unpleasant mood in morning
E1k	(0, 1, 2, 8)	Insomnia or change in usual sleep patterns
Sad, apathetic, anxious appearance		
E1l	(0, 1, 2, 8)	Sad, pained, worried facial expressions
E1m	(0, 1, 2, 8)	Crying, tearfulness
E1n	(0, 1, 2, 8)	Repetitive physical movements
Loss of interest		
E1o	(0, 1, 2, 8)	Withdrawal from activities of interest
E1p	(0, 1, 2, 8)	Reduced social interaction
Behavioural Symptoms (frequency within LAST 7 DAYS)		
E4aA	(0,1,2,3,8)	Wandering
E4bA	(0,1,2,3,8)	Verbally abusive behavioural symptoms
E4cA	(0,1,2,3,8)	Physically abusive behavioural symptoms
E4dA	(0,1,2,3,8)	Socially inappropriate or disruptive behavioural symptoms
E4eA	(0,1,2,3,8)	Resists care
Section G - Physical Functioning & Structural Problems		
ADL Self-Performance and ADL Support Provided		
G1aA	(0,1,2,3,4,8)	Bed Mobility - ADL Self-Performance
G1aB	(0,1,2,3,8)	Bed Mobility - ADL Support Provided
G1bA	(0,1,2,3,4,8)	Transfer - ADL Self-Performance
G1bB	(0,1,2,3,8)	Transfer - ADL Support Provided

G1hA	(0,1,2,3,4,8)	Eating - ADL Self-Performance
G1iA	(0,1,2,3,4,8)	Toilet Use - ADL Self-Performance
G1iB	(0,1,2,3,8)	Toilet Use - ADL Support Provided
Section H - Continence in last 14 days		
Appliances and programs		
H3a	(0,1)	Any scheduled toileting plan
H3b	(0,1)	Bladder retraining program
Section I - Disease Diagnoses		
Diseases		
I1a	(Missing,0,1)	Diabetes mellitus
I1s	(0,1)	Aphasia
I1t	(0,1)	Cerebral palsy
I1w	(0,1)	Hemiplegia / Hemiparesis
I1y	(0,1)	Multiple sclerosis
I1bb	(0,1)	Quadriplegia
Infections		
I2f	(0,1)	Pneumonia
I2h	(0,1)	Septicemia
Section J - Health Conditions		
Problem conditions		
J1c	(0,1)	Dehydrated
J1e	(0,1)	Delusions
J1h	(0,1)	Fever
J1i	(0,1)	Hallucinations
J1j	(0,1)	Internal bleeding
J1o	(0,1)	Vomiting
Stability of conditions		
J5c	(0,1)	End-stage disease (6 months or less to live)
Section K - Oral / Nutritional Status		
Weight change		
K3a	(0,1,9)	Weight loss of 5% or more in last 30 days or 10% or more in last 180 days
Nutritional approaches		
K5a	(0,1)	Parenteral / IV
K5b	(0,1)	Feeding tube
Parenteral or Enteral Intake		
K6a	(Missing,0,1,2,3,4,8)	Proportion of total calories the resident received through parenteral or tube feedings in the LAST 7 DAYS
K6b	(Missing,0,1,2,3,4,5,8)	Average fluid intake per day by IV or tube in the LAST 7 DAYS
Section M - Skin Condition		
Ulcers		
M1a	(0 - 9)	Stage 1 ulcers – A persistent area of skin redness (without a break in skin) that does not disappear when pressure relieved
M1b	(0 - 9)	Stage 2 ulcers – A partial thickness loss of skin layers that presents clinically as an abrasion, blister or shallow crater
M1c	(0 - 9)	Stage 3 ulcers – A full thickness of skin is lost, exposing subcutaneous tissues - presents as deep crater with or without undermining adjacent tissue
M1d	(0 - 9)	Stage 4 ulcers – A full thickness of skin and subcutaneous tissue is

		lost, exposing muscle or bone
Type of ulcer		
M2a	(0,1,2,3,4)	Pressure ulcer – any lesion caused by pressure resulting in damage of underlying tissue
Other skin problems or lesions present		
M4b	(0,1)	Burns (2nd or 3rd degree)
M4c	(0,1)	Open lesions other than ulcers, rashes or cuts
M4g	(0,1)	Surgical wounds
Skin treatments		
M5a	(0,1)	Pressure relieving device(s) for chair
M5b	(0,1)	Pressure relieving device(s) for bed
M5c	(0,1)	Turning or repositioning program
M5d	(0,1)	Nutrition or hydration intervention to manage skin problems
M5e	(0,1)	Ulcer care
M5f	(0,1)	Surgical wound care
M5g	(0,1)	Application of dressings (with or without topical medications) other than to feet
M5h	(0,1)	Application of ointments or medications (except to feet)
Foot problems and care		
M6b	(0,1)	Infection of the foot
M6c	(0,1)	Open lesions on the foot
M6f	(0,1)	Application of dressings (with or without topical meds)
Section N - Activity pursuit patterns		
Time awake		
N1a	(0,1)	Morning - Naps no more than one hour per time period
N1b	(0,1)	Afternoon - Naps no more than one hour per time period
N1c	(0,1)	Evening - Naps no more than one hour per time period
Section O - Medications		
Injections		
O3	(0 to 7)	Injections (NUMBER OF DAYS injections of any type were received during LAST 7 DAYS)
Section P - Special Treatments and procedures		
Special care (within LAST 14 DAYS)		
P1aa	(0,1)	Chemotherapy
P1ab	(0,1)	Dialysis
P1ac	(0,1)	IV medication
P1ag	(0,1)	Oxygen therapy
P1ah	(0,1)	Radiation
P1ai	(0,1)	Suctioning
P1aj	(0,1)	Tracheostomy care
P1ak	(0,1)	Transfusions
P1al	(0,1)	Ventilator or respirator
Therapies (within LAST 7 DAYS)		
P1baA	(0 to 7)	Speech - language pathology, audiology service Number of days administered for 15 minutes or more in last 7 days
P1baB	(0 and higher)	Speech - language pathology, audiology service Total number of minutes provided in last 7 days
P1bbA	(0 to 7)	Occupational therapy - number of days administered for 15 minutes or more in last 7 days

P1bbB	(0 and higher)	Occupational therapy - total number of minutes provided in last 7 days
P1bcA	(0 to 7)	Physical therapy - number of days administered for 15 minutes or more in last 7 days
P1bcB	(0 and higher)	Physical therapy - total number of minutes provided in last 7 days
P1bdA	(0 to 7)	Respiratory therapy - number of days administered for 15 minutes or more in last 7 days
Nursing rehabilitation / restorative care (within LAST 7 DAYS)		
P3a	(0 to 7)	Range of motion (passive)
P3b	(0 to 7)	Range of motion (active)
P3c	(0 to 7)	Splint or brace assistance
P3d	(0 to 7)	Training and skill practice in bed mobility
P3e	(0 to 7)	Training and skill practice in transfer
P3f	(0 to 7)	Training and skill practice in walking
P3g	(0 to 7)	Training and skill practice in dressing or grooming
P3h	(0 to 7)	Training and skill practice in eating or swallowing
P3i	(0 to 7)	Training and skill practice in amputation or prosthesis care
P3j	(0 to 7)	Training and skill practice in communication
Physician visits (within LAST 14 DAYS)		
P7	(0 to 14)	Physician visits Number of days physician (or authorized assistant or practitioner) examined resident within LAST 14 DAYS (or since admission if less than 14 days)
Physician orders (within LAST 14 DAYS)		
P8	(0 to 14)	Physician orders Number of days physician (or authorized assistant or practitioner) changed the resident's orders within LAST 14 DAYS (or since admission if less than 14 days). (Renewals without change are excluded).

Source: (CIHI, 2009a)

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[i] Variable name
[ii] One of the 105 MDS variables part of the RUG-III (34 Group) system
[iii] Valid codes
[iv] Description

Appendix 5: Detailed search strategy in Medline

1 Needs Assessment/
2 "Health Services Needs and Demand"/
3 (care adj2 needs).ab,kw,ti.
4 Long-Term Care/
5 Nursing Homes/
6 Geriatric Nursing/
7 Homes for the Aged/
8 nursing home$.ab,kw,ti.
9 (long-term adj3 care).ab,kw,ti.
10 camberwell assessment.ab,kw,ti.
11 dementia/ or alzheimer disease/ or dementia, vascular/ or frontotemporal dementia/ or lewy body disease/
12 dementia$.ab,kw,ti.
13 charitable home$.ab,kw,ti.
14 municipal home$.ab,kw,ti.
15 aged care home$.ab,kw,ti.
16 care home$.ab,kw,ti.
17 long-term care.ab,kw,ti.
18 long term care.ab,kw,ti.
19 longterm care.ab,kw,ti.
20 (longterm adj3 care).ab,kw,ti.
21 limit 16 to "all aged (65 and over)"
22 "Quality of Life"/
23 quality of life.ab,kw,ti.
24 4 or 5 or 6 or 7 or 8 or 9 or 13 or 14 or 15 or 17 or 18 or 19 or 20 or 21
25 1 or 2 or 3 or 10
26 23 not 22
27 25 or 26
28 (lewy bod$ adj3 dementia).ab,kw,ti.
29 vascular dementia.ab,kw,ti.
30 frontotemporal dementia.ab,kw,ti.
31 alzheimer$ disease.ab,kw,ti.
32 11 or 12 or 28 or 29 or 30 or 31
33 24 and 27 and 32
34 limit 33 to yr="2000 -Current"

Appendix 6: Detailed search strategy in PsychInfo

1 "quality of life"/ or life satisfaction/ or well being/
2 Needs/ or Health Service Needs/ or Psychological Needs/ or Needs Assessment/
3 quality of life.ab,id,ti.
4 (care adj2 needs).ab,id,ti.
5 dementia/ or dementia with lewy bodies/ or vascular dementia/ or alzheimer's disease/
6 frontotemporal dementia.ab,id,ti.
7 dementia$.ab,id,ti.
8 long term care/
9 Nursing Homes/
10 geriatric nursing.ab,id,ti.
11 homes for the aged.ab,id,ti.
12 nursing home$.ab,id,ti.
13 (longterm adj3 care).ab,id,ti.
14 (long-term adj3 care).ab,id,ti.
15 charitable home$.ab,id,ti.
16 municipal home$.ab,id,ti.
17 aged care home$.ab,id,ti.
18 care home$.ab,id,ti.
19 limit 18 to "380 aged <age 65 yrs and older>"
20 long term care.ab,id,ti.
21 longterm care.ab,id,ti.
22 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 19 or 20 or 21
23 2 or 4
24 3 not 1
25 vascular dementia.ab,id,ti.
26 alzheimer$ disease.ab,id,ti.
27 (lewy bod$ adj3 dementia).ab,id,ti.
28 camberwell assesment.af.
29 23 or 24 or 28
30 5 or 6 or 7 or 25 or 26 or 27
31 22 and 29 and 30
32 limit 31 to yr="2000 -Current"

Appendix 7: Detailed search strategy in EMBASE

1 NEEDS ASSESSMENT/
2 (care adj2 needs).ti,ab,kw.
3 camberwell assesment.ti,ab,kw.
4 "quality of life"/
5 quality of life.ti,ab,kw.
6 vascular dementia.ti,ab,kw.
7 dementia$.ti,ab,kw.
8 care home$.ti,ab,kw.
9 limit 8 to aged <65+ years>
10 nursing home/
11 long term care/
12 geriatric nursing/
13 home for the aged/
14 nursing home$.ti,ab,kw.
15 (longterm adj3 care).ti,ab,kw.
16 (long-term adj3 care).ti,ab,kw.
17 charitable home$.ti,ab,kw.
18 municipal home$.ti,ab,kw.
19 aged care home$.ti,ab,kw.
20 long-term care.ti,ab,kw.
21 long term care.ti,ab,kw.
22 longterm care.ti,ab,kw.
23 5 not 4
24 health care need/
25 dementia/ or alzheimer disease/ or frontotemporal dementia/
26 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22
27 (lewy bod$ adj3 dementia).ti,ab,kw.
28 frontotemporal dementia.ti,ab,kw.
29 alzheimer$ disease.ti,ab,kw.
30 6 or 7 or 25 or 27 or 28 or 29
31 1 or 2 or 3 or 23 or 24
32 26 and 30 and 31
33 limit 32 to yr="2000 -Current"

Appendix 8: Detailed search strategy in HealthStar

1 "Health Services Needs and Demand"/
2 (care adj2 needs).ti,kw,ab.
3 Geriatric Nursing/
4 Homes for the Aged/
5 nursing home$.ti,kw,ab.
6 (long-term adj3 care).ti,kw,ab.
7 charitable home$.ti,kw,ab.
8 municipal home$.ti,kw,ab.
9 aged care home$.ti,kw,ab.
10 care home$.ti,kw,ab.
11 long term care.ti,kw,ab.
12 longterm care.ti,kw,ab.
13 (longterm adj3 care).ti,kw,ab.
14 quality of life.ti,kw,ab.
15 "Quality of Life"/
16 14 not 15
17 frontotemporal dementia.ti,kw,ab.
18 dementia$.ti,kw,ab.
19 limit 10 to "all aged (65 and over)"
20 Nursing Homes/
21 Long-Term Care/
22 dementia/ or alzheimer disease/ or dementia, vascular/ or lewy body disease/
23 1 or 2
24 16 or 23
25 3 or 4 or 5 or 6 or 7 or 8 or 9 or 11 or 12 or 13 or 19 or 20 or 21
26 vascular dementia.ti,kw,ab.
27 (lewy bod$ adj3 dementia).ti,kw,ab.
28 alzheimer$ disease.ti,kw,ab.
29 17 or 18 or 22 or 26 or 27 or 28
30 24 and 25 and 29
31 limit 30 to yr="2000 -Current"

Appendix 9: Detailed search strategy in Cochrane

#1 MeSH descriptor **Nursing Homes**, this term only
#2 MeSH descriptor **Geriatric Nursing**, this term only
#3 MeSH descriptor **Homes for the Aged**, this term only
#4 MeSH descriptor **Long-Term Care**, this term only
#5 (nursing home*):ti,ab,kw in Cochrane Reviews, Other Reviews and Cochrane Groups
#6 (long-term NEAR/3 care):ti,ab,kw in Cochrane Reviews, Other Reviews and Cochrane Groups
#7 (charitable home*):ti,ab,kw in Cochrane Reviews, Other Reviews and Cochrane Groups
#8 (aged care home*):ti,ab,kw in Cochrane Reviews, Other Reviews and Cochrane Groups
#9 (care home*):ti,ab,kw in Cochrane Reviews, Other Reviews and Cochrane Groups
#10 (long term care):ti,ab,kw in Cochrane Reviews, Other Reviews and Cochrane Groups
#11 (municipal home*) in Cochrane Reviews, Other Reviews and Cochrane Groups
#12 (longterm NEAR/3 care) in Cochrane Reviews, Other Reviews and Cochrane Groups
#13 (longterm care) in Cochrane Reviews, Other Reviews and Cochrane Groups
#14 MeSH descriptor **Dementia** explode all trees
#15 (dementia*):ti,ab,kw in Cochrane Reviews, Other Reviews and Cochrane Groups
#16 (frontotemporal dementia):ti,ab,kw in Cochrane Reviews, Other Reviews and Cochrane Groups
#17 (vascular dementia):ti,ab,kw in Cochrane Reviews, Other Reviews and Cochrane Groups
#18 (lewy bod* NEAR/3 dementia):ti,ab,kw in Cochrane Reviews, Other Reviews and Cochrane Groups
#19 MeSH descriptor **Quality of Life** explode tree
#20 (quality of life):ti,ab,kw in Cochrane Reviews, Other Reviews and Cochrane Groups
#21 (care NEAR/2 needs):ti,ab,kw in Cochrane Reviews, Other Reviews and Cochrane Groups
#22 (needs assesment) in Cochrane Reviews, Other Reviews and Cochrane Groups
#23 (health services needs and demand):ti,ab,kw in Cochrane Reviews, Other Reviews and Cochrane Groups
#24 (#20 AND NOT #19)
#25 (alzheimer* disease):ti,ab,kw in Cochrane Reviews, Other Reviews and Cochrane Groups
#26 MeSH descriptor **Aged** explode all trees
#27 (#9 AND #26)
#28 (#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #10 OR #11 OR #12 OR #13 OR #27)
#29 (#14 OR #15 OR #16 OR #17 OR #18 OR #25)
#30 (#24 OR #21 OR #22 OR #23)
#31 (#28 AND #29 AND #30), from 2000 to 2010

Appendix 10: Detailed search strategy in CINAHL

#	Query	Limiters/Expanders
S31	S27 and S28 and S29	Limiters - Published Date from: 20000101-20100931; Exclude MEDLINE records Expanders - Apply related words Search modes - Boolean/Phrase
S30	S27 and S28 and S29	Expanders - Apply related words Search modes - Boolean/Phrase
S29	S3 or S4 or S5 or S6 or S9 or S10 or S11 or S12 or S13 or S14 or S15 or S17 or S18	Expanders - Apply related words Search modes - Boolean/Phrase
S28	S16 or S20 or S21 or S22 or S23 or S25	Expanders - Apply related words Search modes - Boolean/Phrase
S27	S2 or S7 or S8 or S19 or S26	Expanders - Apply related words Search modes - Boolean/Phrase
S26	S24 NOT S1	Expanders - Apply related words Search modes - SmartText Searching
S25	alzheimer* disease	Expanders - Apply related words Search modes - Boolean/Phrase
S24	quality of life	Expanders - Apply related words Search modes - Boolean/Phrase
S23	(lewy bod* N3 dementia)	Expanders - Apply related words Search modes - Boolean/Phrase
S22	frontotemporal dementia	Expanders - Apply related words Search modes - Boolean/Phrase
S21	vascular dementia	Expanders - Apply related words Search modes - Boolean/Phrase
S20	(MH "Dementia")	Expanders - Apply related words Search modes - Boolean/Phrase
S19	(MH "Health Services Needs and Demand") OR (MH "Human Needs (Physiology)") OR (MH "Human Needs (Psychology)") OR (MH "Needs Assessment") OR (MH "Maslow's Hierarchy of Needs")	Expanders - Apply related words Search modes - Boolean/Phrase
S18	(MH "Long Term Care")	Expanders - Apply related words Search modes - Boolean/Phrase
S17	(MH "Nursing Homes")	Expanders - Apply related words Search modes - Boolean/Phrase

S16	dementia*	Expanders - Apply related words Search modes - Boolean/Phrase
S15	(long-term N3 care)	Expanders - Apply related words Search modes - Boolean/Phrase
S14	(longterm N3 care)	Expanders - Apply related words Search modes - Boolean/Phrase
S13	longterm care	Expanders - Apply related words Search modes - Boolean/Phrase
S12	long term care	Expanders - Apply related words Search modes - Boolean/Phrase
S11	care home*	Limiters - Age Groups: Aged: 65+ years Expanders - Apply related words Search modes - Boolean/Phrase
S10	aged care home*	Expanders - Apply related words Search modes - Boolean/Phrase
S9	charitable home*	Expanders - Apply related words Search modes - Boolean/Phrase
S8	camberwell assesment	Expanders - Apply related words Search modes - SmartText Searching
S7	camberwell assesment	Expanders - Apply related words Search modes - Boolean/Phrase
S6	nursing home*	Expanders - Apply related words Search modes - Boolean/Phrase
S5	homes for the aged	Expanders - Apply related words Search modes - Boolean/Phrase
S4	municipal home*	Expanders - Apply related words Search modes - Boolean/Phrase
S3	geriatric nursing	Expanders - Apply related words Search modes - Boolean/Phrase
S2	(care N2 needs)	Expanders - Apply related words Search modes - Boolean/Phrase
S1	(MH "Quality of Life") OR quality of life OR (MH "Quality of Life (Iowa NOC)") OR (MH "Health and Life Quality (Iowa NOC) (Non-Cinahl)") OR (MH "Attitude to Life")	Expanders - Apply related words Search modes - Boolean/Phrase

Appendix 11: List of judges

Judge 1	Marie-Andrée Cadieux
Judge 2	Farwa Malik
Judge 3	Linda Garcia
Judge 4	Emilie Meyers
Judge 5	Jonathan Patrick
Judge 6	Madura Sundareswaran
Judge 7	Rachel Blais

Appendix 12: Data Abstraction Form

Name of reviewer: Date: Author: Year: Title: Reference ID:

Study type:

☐ Published article ☐ Dissertation/thesis

☐ Unpublished article ☐ Book/book chapter

☐ Expert opinion paper ☐ Other *Specify:*

Part 1 - Inclusion/exclusion criteria

Stop if the following is 'YES'

- Article is an anecdotal recount (excluding case reports).

  ☐ Yes ☐ No *Specify:*

Stop if any of the following is 'NO'

- Article is written in English or French.

  ☐ Yes ☐ No *Specify:*
- Article has been published between the years of 2000 and 2010.

  ☐ Yes ☐ No *Specify:*
- Has used either or both quantitative and qualitative methodology (excludes expert opinion papers, anecdotal, editor's notes and literature reviews).

  ☐ Yes ☐ No *Specify:*
- Article relates to individuals with dementia only.

  ☐ Yes ☐ No *Specify:*
- Offer a description of the (care) needs of individuals living in LTC with dementia.

  ☐ Yes ☐ No *Specify:*

**Note: If an article does not meet an inclusion criteria, specify the reason and collect no further data.*

Part 2 - Data Collection

A. What type of methodology (qualitative, quantitative or mixed methods)* is used in the study?

_____

B. What is the purpose of the study?

_____

C. In what setting(s) is the study conducted or what are the setting(s) of interest?

Note: Select all applicable settings.

☐ Nursing home (long-term care)

☐ Assisted living (residential care)

☐ Other *Specify:*

D. Location where the study was conducted (country and/or city)

_____

E. List all (care) needs relevant to people with dementia discussed in the paper? Note: Needs must be specific to people with dementia living in institutional care (long-term care and/or assisted-living).

a. (Care) needs:

_____

_____

_____

_____

_____

F. Other Note: Make notes on anything else you think is pertinent.

_____

**Fill applicable quality assessment form, and attach to data abstraction form. For mixed studies, use a combination of the qualitative and quantitative forms for quality assessment.*

Appendix 13: Critical Review Form – Qualitative Studies (4 pages)

Critical Review Form - Qualitative Studies (Version 2.0)

McMaster University

CITATION:

	Comments
STUDY PURPOSE: Was the purpose and/or research question stated clearly? O yes O no	Outline the purpose of the study and/or research question.
LITERATURE: Was relevant background literature reviewed? O yes O no	Describe the justification of the need for this study. Was it clear and compelling?
	How does the study apply to your practice and/or to your research question? Is it worth continuing this review?[1]
STUDY DESIGN: What was the design? O phenomenology O ethnography O grounded theory O participatory action research O other _____	Was the design appropriate for the study question? (i.e., rationale) Explain.

1 When doing critical reviews, there are strategic points in the process at which you may decide the research is not applicable to your practice and question. You may decide then that it is not worthwhile to continue with the review.

Was a theoretical perspective identified? O yes O no	Describe the theoretical or philosophical perspective for this study e.g., researcher's perspective.
Method(s) used: O participant observation O interviews O document review O focus groups O other _____	Describe the method(s) used to answer the research question. Are the methods congruent with the philosophical underpinnings and purpose?
SAMPLING: Was the process of purposeful selection described? O yes O no	Describe sampling methods used. Was the sampling method appropriate to the study purpose or research question?
Was sampling done until redundancy in data was reached?[2] O yes O no O not addressed	Are the participants described in adequate detail? How is the sample applicable to your practice or research question? Is it worth continuing?
Was informed consent obtained? O yes O no O not addressed	
DATA COLLECTION: **Descriptive Clarity** Clear & complete description of site: O yes O no participants: O yes O no Role of researcher & relationship with participants: O yes O no Identification of assumptions and biases of researcher: O yes O no	Describe the context of the study. Was it sufficient for understanding of the "whole" picture? What was missing and how does that influence your understanding of the research?

2 Throughout the form, "no" means the authors explicitly state reasons for not doing it; "not addressed" should be ticked if there is no mention of the issue.

Procedural Rigour Procedural rigor was used in data collection strategies? O yes O no O not addressed	Do the researchers provide adequate information about data collection procedures e.g., gaining access to the site, field notes, training data gatherers? Describe any flexibility in the design & data collection methods.
DATA ANALYSES: **Analytical Rigour** Data analyses were inductive? O yes O no O not addressed Findings were consistent with & reflective of data? O yes O no	Describe method(s) of data analysis. Were the methods appropriate? What were the findings?
Auditability Decision trail developed? O yes O no O not addressed Process of analyzing the data was described adequately? O yes O no O not addressed	Describe the decisions of the researcher re: transformation of data to codes/themes. Outline the rationale given for development of themes.
Theoretical Connections Did a meaningful picture of the phenomenon under study emerge? O yes O no	How were concepts under study clarified & refined, and relationships made clear? Describe any conceptual frameworks that emerged.

OVERALL RIGOUR Was there evidence of the four components of trustworthiness? Credibility O yes O no Transferability O yes O no Dependability O yes O no Comfirmability O yes O no	For each of the components of trustworthiness, identify what the researcher used to ensure each. What meaning and relevance does this study have for your practice or research question?
CONCLUSIONS & IMPLICATIONS Conclusions were appropriate given the study findings? O yes O no The findings contributed to theory development & future OT practice/ research? O yes O no	What did the study conclude? What were the implications of the findings for occupational therapy (practice & research)? What were the main limitations in the study?

Appendix 14: Critical Review Form – Quantitative Studies (3 pages)

Critical Review Form - Quantitative Studies

McMaster University

CITATION:

	Comments
STUDY PURPOSE: Was the purpose stated clearly? ❍ Yes ❍ No	Outline the purpose of the study. How does the study apply to occupational therapy and/or your research question?
LITERATURE: Was relevant background literature reviewed? ❍ Yes ❍ No	Describe the justification of the need for this study.
DESIGN: ❍ randomized (RCT) ❍ cohort ❍ single case design ❍ before and after ❍ case-control ❍ cross-sectional ❍ case study	Describe the study design. Was the design appropriate for the study question? (e.g., for knowledge level about this issue, outcomes, ethical issues, etc.) Specify any biases that may have been operating and the direction of their influence on the results.

	Comments
SAMPLE: N = Was the sample described in detail? ❍ Yes ❍ No Was sample size justified? ❍ Yes ❍ No ❍ N/A	Sampling (who; characteristics; how many; how was sampling done?) If more than one group, was there similarity between the groups? Describe ethics procedures. Was informed consent obtained?
OUTCOMES: Were the outcome measures reliable? ❍ Yes ❍ No ❍ Not addressed Were the outcome measures valid? ❍ Yes ❍ No ❍ Not addressed	Specify the frequency of outcome measurement (i.e., pre, post, follow-up) Outcome areas (e.g., self-care, productivity, leisure). List measures used.
INTERVENTION: Intervention was described in detail? ❍ Yes ❍ No ❍ Not addressed Contamination was avoided? ❍ Yes ❍ No ❍ Not addressed ❍ N/A Cointervention was avoided? ❍ Yes ❍ No ❍ Not addressed ❍ N/A	Provide a short description of the intervention (focus, who delivered it, how often, setting). Could the intervention be replicated in occupational therapy practice?

	Comments
RESULTS: Results were reported in terms of statistical significance? ❍ Yes ❍ No ❍ N/A ❍ Not addressed Were the analysis method(s) appropriate? ❍ Yes ❍ No ❍ Not addressed	What were the results? Were they statistically significant (i.e., $p < 0.05$)? If not statistically significant, was study big enough to show an important difference if it should occur? If there were multiple outcomes, was that taken into account for the statistical analysis?
Clinical importance was reported? ❍ Yes ❍ No ❍ Not addressed	What was the clinical importance of the results? Were differences between groups clinically meaningful? (if applicable)
Drop-outs were reported? ❍ Yes ❍ No	Did any participants drop out from the study? Why? (Were reasons given and were drop-outs handled appropriately?)
CONCLUSIONS AND CLINICAL IMPLICATIONS: Conclusions were appropriate given study methods and results ❍ Yes ❍ No	What did the study conclude? What are the implications of these results for occupational therapy practice? What were the main limitations or biases in the study?

Appendix 15: AMSTAR measurement tool

1. Was an 'a priori' design provided? The research question and inclusion criteria should be established before the conduct of the review.	☐ Yes ☐ No ☐ Can't answer ☐ Not applicable
2. Was there duplicate study selection and data extraction? There should be at least two independent data extractors and a consensus procedure for disagreements should be in place.	☐ Yes ☐ No ☐ Can't answer ☐ Not applicable
3. Was a comprehensive literature search performed? At least two electronic sources should be searched. The report must include years and databases used (e.g. Central, EMBASE, and MEDLINE). Key words and/or MESH terms must be stated and where feasible the search strategy should be provided. All searches should be supplemented by consulting current contents, reviews, textbooks, specialized registers, or experts in the particular field of study, and by reviewing the references in the studies found.	☐ Yes ☐ No ☐ Can't answer ☐ Not applicable
4. Was the status of publication (i.e. grey literature) used as an inclusion criterion? The authors should state that they searched for reports regardless of their publication type. The authors should state whether or not they excluded any reports (from the systematic review), based on their publication status, language etc.	☐ Yes ☐ No ☐ Can't answer ☐ Not applicable
5. Was a list of studies (included and excluded) provided? A list of included and excluded studies should be provided.	☐ Yes ☐ No ☐ Can't answer ☐ Not applicable
6. Were the characteristics of the included studies provided? In an aggregated form such as a table, data from the original studies should be provided on the participants, interventions and outcomes. The ranges of characteristics in all the studies analyzed e.g. age, race, sex, relevant socioeconomic data, disease status, duration, severity, or other diseases should be reported.	☐ Yes ☐ No ☐ Can't answer ☐ Not applicable
7. Was the scientific quality of the included studies assessed and documented? 'A priori' methods of assessment should be provided (e.g., for effectiveness studies if the author(s) chose to include only randomized, double-blind, placebo controlled studies, or allocation concealment as inclusion criteria); for other types of studies alternative items will be relevant.	☐ Yes ☐ No ☐ Can't answer ☐ Not applicable
8. Was the scientific quality of the included studies used appropriately in formulating conclusions? The results of the methodological rigor and scientific quality should be considered in the analysis and the conclusions of the review, and explicitly stated in formulating recommendations.	☐ Yes ☐ No ☐ Can't answer ☐ Not applicable
9. Were the methods used to combine the findings of studies appropriate? For the pooled results, a test should be done to ensure the studies were combinable, to assess their homogeneity (i.e. Chi-squared test for homogeneity, I^2). If heterogeneity exists a random effects model should be used and/or the clinical appropriateness of combining should be taken into consideration (i.e. is it sensible to combine?).	☐ Yes ☐ No ☐ Can't answer ☐ Not applicable
10. Was the likelihood of publication bias assessed? An assessment of publication bias should include a combination of graphical aids (e.g., funnel plot, other available tests) and/or statistical tests (e.g., Egger regression test).	☐ Yes ☐ No ☐ Can't answer ☐ Not applicable
11. Was the conflict of interest stated? Potential sources of support should be clearly acknowledged in both the systematic review and the included studies.	☐ Yes ☐ No ☐ Can't answer ☐ Not applicable

Appendix 16: Quality criteria

Design Type	Criteria	Source
Quantitative design	✓ Design appropriate for study question ✓ Sample described in detail ✓ Sample size justified ✓ Outcome measures reliable ✓ Outcome measures valid ✓ Intervention described in detail ✓ Statistical analyses reported ✓ Analysis method(s) appropriate ✓ Drop-outs reported ✓ Appropriate conclusions given methods and results	Law et al. (1998)
Qualitative design	✓ Design appropriate for study question ✓ Theoretical perspective identified ✓ Purposeful selection ✓ Sampling done until redundancy reached ✓ Clear and complete description of site and participants ✓ Data analysis were inductive ✓ Findings consistent and reflective of data ✓ Decision trail developed ✓ Evidence of the four components of trustworthiness ✓ Appropriate conclusions given methods and results	Letts et al. (2007)
Systematic Review	✓ 'priori' design provided ✓ Duplicate study selection and data extraction ✓ Comprehensive literature search performed ✓ Status of publication used as an inclusion criterion ✓ List of studies provided ✓ Characteristics of included studies provided ✓ Scientific quality of included studies assessed and documented ✓ Scientific quality of included studies used appropriately to formulate conclusions ✓ Appropriate methods used to combine the findings of studies ✓ Likelihood of publication bias assessed	Shea et al. (2007)

Appendix 17: Levels of Evidence

Levels of evidence

Level 1A: Systematic review of all relevant randomised controlled trials

Level 1: Randomised controlled trials (RCTs)

Level 2: Controlled Trials without randomization (quasi-experimental)

Level 3A: Observational studies with control group (single case design, retrospective cohort, case-control and cohort with control)

Level 3B: Observational studies without control group (cohort without control, cross-sectional design and case series)

Source: Levels of evidence adapted from (National Health and Medical Research Council [NHMRC], 1998, appendix B) and (Robey, 2004).

Appendix 18: Articles included in the review

Author	Study title
Ballard et al. (2001)	Quality of life for people with dementia living in residential and nursing home care: The impact of performance on activities of daily living, behavioral and psychological symptoms, language skills, and psychotropic drugs.
Beck et al. (2002)	Effects of behavioral interventions on disruptive behavior and affect in demented nursing home residents.
Bharani & Snowden (2005)	Evidence-based interventions for nursing home residents with dementia-related behavioral symptoms.
Blass et al. (2008)	Medication use in nursing home residents with advanced dementia.
Bourgeois et al. (2001)	Memory aids as an augmentative and alternative communication strategy for nursing home residents with dementia.
Bruce et al. (2002)	Moving towards a special kind of care for people with dementia living in care homes.
Buettner & Fitzsimmons (2006)	Mixed behaviors in dementia: The need for a paradigm shift.
Caserta & Lund (2002)	Video respite in an Alzheimer's care center: Group versus solitary viewing.
Choi (2001)	Predictors of physically and verbally aggressive behaviors in Korean nursing home residents with dementia.
Chung (2004)	Activity participation and well-being of people with dementia in long-term-care settings.
Cioffi et al. (2007)	The effect of environmental change on residents with dementia: The perceptions of relatives and staff.
Cohen-Mansfield et al. (2000)	Self-identity in older persons suffering from dementia: Preliminary results.
Cohen-Mansfield & Jensen (2006)	Do interventions bringing current self-care practices into greater correspondence with those performed premorbidly benefit the person with dementia? A pilot study.
Cohen-Mansfield et al. (2006)	Utilization of self-identity roles for designing interventions for persons with dementia.
Dobbs et al. (2005)	Characteristics associated with lower activity involvement in long-term care residents with dementia.
Dröes et al. (2006)	Quality of life in dementia in perspective: An explorative study of variations in opinions among people with dementia and their professional caregivers, and in literature.
Finnema et al. (2005)	The effect of integrated emotion-oriented care versus usual care on elderly persons with dementia in the nursing home and on nursing assistants: A randomized clinical trial.
Finnema et al. (2000)	The effects of emotion-oriented approaches in the care for persons suffering from dementia: A review of the literature.
Galik et al. (2009)	'Knowing what makes them tick': Motivating cognitively impaired older adults to participate in restorative care.
Gardiner et al. (2000)	Music therapy and reading as intervention strategies for disruptive behavior in dementia.
Gerdner (2000)	Effects of individualized versus classical "relaxation" music on the frequency of agitation in elderly persons with Alzheimer's disease and related disorders.
Gill et al. (2007)	Quality of long-term care as reported by residents with dementia.
Gonzalez-Salvador et al. (2000)	Quality of life in dementia patients in long-term care.
Hancock et al. (2006)	The needs of older people with dementia in residential care.
Hernandez (2007)	Effects of therapeutic gardens in special care units for people with dementia: Two case studies.
Hicks-Moore (2005)	Relaxing music at mealtime in nursing homes: Effects on agitated patients with

	dementia.
Hicks-Moore & Robinson (2008)	Favorite music and hand massage: Tow interventions to decrease agitation in residents with dementia.
Hoe et al. (2006)	Quality of life of people with dementia in residential care homes.
Innes & Surr (2001)	Measuring the well-being of people with dementia living in formal care settings: The use of dementia care mapping.
Kobayashi & Yamamoto (2004)	Impact of the stage of dementia on the time required for bathing-related care: A pilot study in a Japanese nursing home.
Koch et al. (2005)	Unmet visual needs of Alzheimer's disease patients in long-term care facilities.
Kolanowski et al. (2001)	Capturing interests: Therapeutic recreation activities for persons with dementia.
Kolanowski et al. (2005)	Efficacy of theory-based activities for behavioral symptoms of dementia.
Kovach, Kelber, et al. (2006)	Behaviors of nursing home residents with dementia: Examining nurse responses.
Kovach, Logan, et al. (2006)	Effects of the serial trial intervention on discomfort and behavior of nursing home residents with dementia.
Kverno et al. (2008)	Prevalence and treatment of neuropsychiatric symptoms in advanced dementia.
Lai (2003)	Improving the quality of life for nursing home residents with dementia: A life story approach.
MacDonald (2006)	Family and staff perceptions of the impact of the long-term care environment on leisure.
Malone & Camp (2007)	Montessori-based dementia programming: Providing tools for engagement.
Mickus et al. (2002)	Developing effective bathing strategies for reducing problematic behavior for residents with dementia: The PRIDE approach.
Milke et al. (2006)	Meeting the needs in continuing care of facility-based residents diagnosed with dementia: Comparison of ratings by families, direct care staff, and other staff.
Morgan et al. (2004)	Evaluating rural nursing home environments: Dementia special care units versus integrated facilities.
O'Brien & Caro (2001)	Alzheimer's disease and other dementia in nursing homes: Levels of management and cost.
O'Connor et al. (2009)	Psychosocial treatments of behavior symptoms in dementia: A systematic review of reports meeting quality standards.
Opie et al. (2002)	Challenging behaviours in nursing home residents with dementia: A randomized controlled trial of multidisciplinary interventions.
Orrell et al. (2007)	A cluster randomised controlled trial to reduce the unmet needs of people with dementia living in residential care.
Orrell et al. (2008)	The needs of people with dementia in care homes: The perspectives of users, staff and family caregivers.
Orsulic-Jeras et al. (2000)	Montessori-based activities for long-term care residents with advanced dementia: Effects on engagement and affect.
Pearson & Chalmers (2004)	Oral hygiene care for adults with dementia in residential aged care facilities.
Potkins et al. (2003)	Language impairment in dementia: Impact on symptoms and care needs in residential homes.
Powers (2000)	Everyday ethics of dementia care in nursing homes: A definition and taxonomy.
Powers & Watson (2008)	Meaning and practice of palliative care for nursing home residents with dementia at end of life.
Quinn et al. (2003)	Health characteristics of elderly residents in personal care homes. dementia, possible early dementia, and no dementia.
Ragneskog et al. (2001)	Individualized music played for agitated patients with dementia: Analysis of video-recorded sessions.
Reid & Chappell (2003)	Staff ratios and resident outcomes in special care units: Do activity aides make a difference?
Ruka (2003)	The effects of reminiscence on promoting a comfort zone: A single subject study of people with dementia in a nursing home.

Sloane et al. (2004)	Effect of person-centered showering and the towel bath on bathing-associated aggression, agitation, and discomfort in nursing home residents with dementia: A randomized, controlled trial.
Sloane et al. (2008)	Dying with dementia in long-term care.
Smith (2008)	Prayer as an intervention for agitation in dementia residents.
Sung et al. (2010)	A preferred music listening intervention to reduce anxiety in older adults with dementia in nursing homes.
Sung et al. (2006)	The effects of group music with movement intervention on agitated behaviours of institutionalized elders with dementia in Taiwan.
Tilly & Reed (2005)	Interventions that optimize quality dementia care: A comprehensive literature search selects the best evidence-based interventions to improve quality dementia care in LTC facilities.
Tilly & Fok (2008)	Policy barriers to quality end-of-life care for residents with dementia in assisted living residences and nursing homes.
Van Haitsma (2000)	The assessment and integration of preferences into care practices for persons with dementia residing in the nursing home.
Young et al. (2001)	Meal delivery practices do not meet needs of Alzheimer patients with increased cognitive and behavioral difficulties in a long-term care facility.
Zeisel et al. (2003)	Environmental correlates to behavioral health outcomes in Alzheimer's special care units.
Zimmerman et al. (2005)	Dementia care and quality of life in assisted living and nursing homes.
Zingmark et al. (2002)	Promoting a good life among people with Alzheimer's disease.

Appendix 19: Findings of relevant studies of needs in people with dementia living in long-term care

Ref ID	Author	Design	Setting and sample	Result	Extracted need	Main need category	Level of evidence (3B to 1A) and quality rating of study (1 to 10) Overall quality score of study
1	Ballard et al. (2001)	Cross-sectional design	United Kingdom Residents from 6 care facilities (residential home care and nursing home) (n=112)	Significant correlations between low ADL performance and reduced well-being (p‹.0001), increased social withdrawal (p‹.0001), reduced engagement in activities (p=.0001) Trend between receptive language impairment and time spent socially withdrawn	Assistance with receptive language skills; Medications tailored to individual symptoms and condition; Assistance with self-care	2; 5; 15	Level 3B Quality: 7 Overall = 17
2	Beck et al. (2002)	RCT with 3 treatment and 2 control groups	United States Residents from nursing homes; primarily females; severe cognitive impairment (n=127)	More positive affect but not reduced disruptive behaviours in treatment groups compared to control groups	Decrease problem behaviours; Privacy and freedom from unwanted physical intrusion; Opportunities to talk openly with others; Respect from others and freedom from insults; Protection from harm; control over one's life; Access to personal items and identifying material; Awareness of surroundings and mental clarity	1; 3; 8; 10; 12; 15; 18; 19	Level 1 Quality: 9 Overall = 49
3	Bharani & Snowden (2005)	Qualitative - Systematic Review	United States 89 articles reviewed of which 33 were	Pharmacological and non-pharmacological interventions are effective in reducing	Decrease behavioural symptoms (mainly agitation)	10	Level (N/A) Quality: 8

			RCT (19 in pharmacological and 14 in non-pharmacological Studies reviewed were conducted in nursing home settings	agitation • Data supports the use of conventional antipsychotics and atypical agents • Data supports activities and sensory-based interventions			Overall = 8
4	Blass et al. (2008)	Prospective Cohort	United States Residents from 3 nursing homes (n=125)	Number of meds remained pretty stable as death approached, but high Increase in palliative meds closer to death	Need for medications to treat medical conditions and symptoms; Increase in palliative medications closer to death and decrease antibiotics, anti-dementia agents, cardiovascular agents, and psychotropic agents.	4	Level 3B Quality: 6 Overall = 16
5	Bourgeois et al. (2001)	RCT with 1 control and 1 treatment groups	United States Residents from 7 nursing homes; residents mean MMSE of 11.35 for the treatment group and 13.06 for the control group. Residents (n=66) and their Nursing aides (NAs) (n=66) – equal number of each in both control and intervention groups.	Residents significantly reduced the time they verbalized ($p<0.001$), and NAs increased the time they verbalized ($p<0.01$) at post-training Residents with memory books significantly increased the number of utterances they used in post-training conversations, $p < .01$, compared with control residents Significant interactions between time and group for the use of prompts, $p < .01$; facilitators, $p < .01$; statements, $p < .001$; and unintelligibles, $p < .05$. NAs judgment of resident depressive symptoms	Need for satisfactory communication (interactions) with caregiver; Opportunities for information sharing and social closeness.	1	Level 1 Quality: 8 Overall = 48

				improved with use of memory books			
6	Bruce et al. (2002)	Qualitative – Phenomenology design	United Kingdom Residents from 10 homes (specialised and mixed residential homes) from the Methodist Homes for the Aged (MHA); primarily females; average MMSE of 9 (n=93)	Factors associated with the support of well-being: ensure appropriate levels of activity and conversation for each individual High well-being associated with strong identity and agency. A means for residents to hold on to a sense of agency is for them to find things that they can do.	Activity opportunities; Stimulation via activities; Need for conversation; Need for staff or other to facilitate conversation; Need to retain a strong and positive sense of identity, agency, hope and social confidence	1; 2; 3; 8; 15	Level (N/A) Quality: 9 Overall = 9
7	Buettner & Fitzsimmons (2006)	Retrospective Cohort	United States Residents from community (n=29) and LTC – assisted living and nursing homes (n=112); mean MMSE of 9.45 for LTC residents. (n=141)	Mixed behaviours (combination of apathy and agitation) were the most common type of disturbing behaviours in LTC (exhibited by 58.9% of residents in LTC) Analysis of the relationship between behaviour type and gender, unit type, age, MMSE score, dementia type, depression, psychotropic medications, facility activity participation, total medications, and ambulation resulted in NO significant correlations.	Decrease agitation and apathy; Decrease mixed behaviours (apathy and agitation); Use of daily psychoactive medications to treat behaviours	10	Level 3A Quality: 7 Overall = 27
8	Caserta & Lund (2002)	Single case design	United States Residents from an Alzheimer Care facility (LTC) with high levels of cognitive impairment (mean MMSE of 14.0) (n=12)	Viewer reported more verbal (p=.08) and nonverbal (p=.03) responses to VR tape when watched alone. Greater overall participation with the VR tape in a solitary setting vs. group setting	Engagement in stimulating and meaningful activities; Capture attention due to memory impairment	2; 15	Level 3A Quality: 8 Overall = 28

9	Choi (2001)	Cross-sectional design	United States Participants from 2 nursing homes with mean MMSE of 5.2 (severe cognitive impairment in 87% of residents) (n=54)	Poor cognitive function and lack of a social network are significant predictors of physical aggressiveness Poor cognitive function, lack of a social network and depression help predict verbal aggressiveness Social network as mediating role on cognitive status.	Social network; Positive relationships; Social contact with staff and visitors; Social interaction; Social support; decrease psychological distress	1; 3; 10	Level 3B Quality: 9 Overall = 19
10	Chung (2004)	Cohort design	China Participants from 2 nursing homes; mostly females; mainly moderate (35%) to severe impairment (51%) (n=43)	Significant positive correlations between state of well-being and time spent in Type 1 activities ($p<0.001$), therapeutic/leisure, ADLs, mobility and interaction activities Significant negative correlations found between state of well-being and time spent in Type II activities ($p<0.001$), passive and negative activities Engagement in interactions and eating/drinking associated with higher WIB Sleeping and dozing associated with less positive state of WIB	Positive and enjoyable engagement in daily activities; Social Interactions; Active participation in activities (potential for performance)	1; 2; 3	Level 3A Quality: 7 Overall = 27
11	Cioffi et al. (2007)	Qualitative – Naturalistic inquiry	Australia Participants from a 21-bed dementia specific SCU; 7 relatives and 12 staff members	SCU has positive impact on well-being of patients • SCU as a family home • SCU as a therapeutic environment • SCU as a work	Increased space and vision; Privacy; Need to freely engage in activities; Freedom of movement; Safety features of the unit and outdoor area; Home-like environment/setting	8; 12; 18; 19	Level (N/A) Quality: 5 Overall = 5

			comprised the sample for the focus group; staff were mostly females	environment			
12	Cohen-Mansfield et al. (2000)	Case study and Cross-sectional design	Israel Participants from 2 NHs (31 in one geriatric LTC and 7 in the other); mainly females (76.3%); mean MMSE of 8.7 (n=38)	According to family and staff caregivers family visits and going for walks were activities most likely to enhance the sense of identity of the residents Staff members felt that self-identity enhancement could contribute to the resident's quality of life in the vast majority of residents (94.1%)	Enhancement of self-identity ('personhood'); Maintenance of self	3	Level 3B Quality: 5 Overall = 15
13	Cohen-Mansfield & Jensen (2006)	Single case design (staggered control design)	United States Participants from NHs with severe cognitive impairment (n=20)	Interventions produced more positive responses (x±SD = 3.85 ±1.95) Greatest % of positive responses obtained for personal products (84%) and personal items (76%) Interventions had no effect on agitation	Promote positive behaviours (eg. Engagement); Decrease problem behaviours (eg. Agitation)	3; 10	Level 3A Quality: 7 Overall = 27
14	Cohen-Mansfield et al. (2006)	RCT with 1 control and 1 treatment groups	United States Participants from 6 adult day centers (41) and from 2 NHs (52); mostly females (71%); mean MMSE of 10.6 (n=93)	Significant interaction between the within-subject factor (baseline phase vs intervention phase) and the between-subject factor (treatment vs control group) for pleasure, interest, involvement in activities, disorientation (no significant interaction for other MOSES subscales) and awareness (all factors increased for treatment group, except for	Enhance self-identity; Need for self-perception; Maintenance of self; Individualized activities; Individualized care.	2; 3; 9	Level 1 Quality: 10 Overall = 50

				disorientation which decreased for tt).			
15	Dobbs et al. (2005)	Cross-sectional design	United States Participants from RC/AL and NH facilities in 4 states; mostly females; 64% severely impaired (n=400)	Characteristics related with lower activity involvement: • Severe and very severe cognitive impairment (NH residents) • Behavioural symptoms • ADL impairment • Depression More activity involvement associated with: • Family involvement in assessing activities • Family social involvement • Staff encouragement of activity involvement	Social engagement; Activity opportunity; Engagement in meaningful social activities	1;2	Level 3B Quality: 8 Overall = 18
16	Dröes et al. (2006)	Qualitative – Grounded theory	The Netherlands Participants from 4 NHs wards; mild to moderate impairment (n=37) Participants from meeting centers (n=106)	QoL domains: • Affect • Self-esteem/self-image • Attachment • Social contact • Enjoyment of activities • Physical and mental health • Financial situation • Security and privacy • Self-determination and freedom • Being useful/giving meaning to life • Spirituality Similarities and differences between residents, caregivers and literature related to important QoL aspects; greater similarity between staff and	Positive affect; Approached by others in a positive manner; Self-expression; Autonomy; Being accepted/appreciated; Continuity of self-image; Self-esteem; Continuation of past lifestyles; Personal belongings (item); Homelike environment; Familiar environment; Feeling attached; Recognition/being understood; Involvement; Socialization; Interpersonal relations; Need appropriate social contact; Positive relationships; Need for satisfactory communication (interactions/contact) with caregiver; One-on-one contact; Positive relationship; Friendship; Intimate relationships; Attention; Family involvement; Positive and enjoyable engagement in daily activities; Physical and mental health; Physical comfort; Eating	1;2; 3; 4; 7; 8; 12; 13; 14; 16; 18; 19	Level (N/A) Quality: 9 Overall = 9

				residents responses, yet these staff seem to view QoL partly in a dif way than residents Domain of spirituality seems to be important for a few residents, yet domain not mentionned by staff neither present in literature	well; Good financial situation; Privacy; Sense of security/ safe env; Freedom of movement; Being able to decide what to eat and when to go to bed; Spirituality; Being useful to others.		
17	Finnema et al. (2005)	RCT Pretest-posttest control group design	The Netherlands Participants from 14 NHs with great proportion of residents with moderate to severe impairment (n=146) and their nursing assistants (n=99)	Positive effects of intervention found in mild to moderately demented residents on two adaptative tasks: maintaining an emotional balance (less anxiety) and preserving a positive self-image (less dissatisfaction) Hypothesis that intervention would lead to better cognitive adaptation and social adaptation in residents was not confirmed. Intervention effect on stress reactions (fewer) only in NAs	Improve/maintain emotional balance; Decrease problem behaviour – general; Maintain positive self-image	3; 10	Level 1 Quality: 9 Overall = 49
18	Finnema et al. (2000)	Qualitative – Systematic review	23 studies reviewed of which most of them were quasi-experimental and qualitative designs; 4 RCTs found. Studies reviewed were conducted in 24-hour care settings for people with dementia.	Emotion-oriented approaches have positive effects on social behaviour problems in PWD • Validation improved ADL and cognitive functioning, and decreased aggressive and depressed behaviours • Snoezelen positively affects verbal and non-verbal interactions, interest and active watching as well as mood and memory recall.	Decrease aggressive behaviour; Decrease depression; Improve ADL function; Improve interaction – social behaviour (social contact); Improve mood; Improve emotional and social functioning; Decrease problem behaviours; Decrease psychological distress	1; 3; 5; 10	Level (N/A) Quality: 6 Overall = 6

				• Reminiscence led to comparable results as above.			
19	Galik et al. (2009)	Qualitative – Naturalistic inquiry	United States Focus group conducted with 7 geriatric nursing assistants (experts in dementia care) recruited from a 66-bed NH	Facilitators to restorative care: • Knowing what makes them tick (e.g. knowing residents past) • Teamwork and utilizing resources Barriers to restorative care (e.g. anxiety/agitation; fear of injury; family expectations)	Need to maintain functional abilities	4	Level (N/A) Quality: 8 Overall = 8
20	Gardiner et al. (2000)	Single Case design (ABACA design)	United States Both participants from a NH Participant A – stroke patient and Participant B – patient diagnosed with AD (n=2)	Part. A – Agitation decreased only during book intervention and during the week following; agitation increased with the music intervention. Part. B – Both intervention significantly effective in decreasing disruptive behaviours; Not one intervention better than the other.	Need to decrease disruptive behaviours; Need to decrease agitation; Individualized interventions	2; 10	Level 3A Quality: 9 Overall = 29
21	Gerdner (2000)	RCT Experimental repeated measures pretest-posttest crossover design (both groups received intervention)	United States Participants from 6 participating LTC facilities; mostly women (77%); mostly severe cognitive impairment (87%) (n=39)	Individualized music resulted in a significant reduction in the frequency of agitated behaviours compared to classical music (relative to baseline)	Need to decrease agitation; Individualized interventions	2; 10	Level 1 Quality: 10 Overall = 50
22	Gill et al. (2007)	Cross-sectional design	United States Participants from 4 states and 4 different types of settings (NH and	Residents rated QOC highest for environment and food (74.8 and 71.8, respectively) and lowest for activities (46.2).	Need for familiar/preferred activities; meaningful activities; Opportunity for activities outside the facility; Activity opportunity; Assistance with household task,	1; 2; 3; 4; 6; 8; 12; 17; 18	Level 3B Quality: 8 Overall = 18

			RC/AL); mostly moderate to severe impairment (82%) (n=311)	All RROC domains related to resident reported-QoL significant (p ‹ .001). Food and autonomy were the domains of RROC with best alpha coefficient; activities high as well.	when needed; Communication (interaction) with staff ; Companionship; Food; Quiet space; Adequate temperature; Appropriate lighting; Involvement; Safety and security; Clinical care; Autonomy		
23	Gonzalez-Salvador et al. (2000)	Case-control and Cross-sectional design	United States Participants were from LTC (AL (n=56) and SNF (n=64)) and had a mean MMSE of 5.8 (n=120) Direct care staff interviewed (n=32)	AL residents had significantly higher total ADRQL scores and ADRQL sub-scale scores than the SNF residents (p‹0.005), with the exception of the ADRQL-E subscale (p = 0.053) – behaviour in a person's living environment. Total score on ADRQL was significantly correlated (p‹ 0.0001) with cognitive impairment, severe impairment, physical symptoms, orientation and depression. No significant correlation was found between ADRQL and the following: resident age, caregiver age and daily or weekly care time. Multivariate regression analyses results indicate that QoL in long-term residents is associated with orientation disturbances, physical dependence and anxiolytic treatment	Decrease psychological distress; Physical care needs (ADL)	5; 10	Level 3A Quality: 8 Overall = 28

24	Hancock et al. (2006)	Cross-sectional design	United Kingdom Participants living in 24 residential care homes; mostly females (n=238)	Unmet needs: stimulating daytime activities (76%); psychological distress (48%) – untreated depression or anxiety; company (41%) – lonely; assistance with memory problems (39%); and help with hearing and eyesight (39%). Met needs: help with household tasks (99%); appropriate accommodation (94%); self-care (93%); money (91%); food (87%); access to physical health care (78%); and help with taking medications (67%). 1/5 people had seven or more unmet needs Younger residents (r= -0.16, $p<0.05$) and people who had resided in the home for a shorter period of time (r= -0.15, $p<0.05$) had more unmet needs. A higher score on the CBS (behavioural problems) was positively correlated with higher total needs identified (r = 0.19, $p<0.01$) and higher unmet needs (r= 0.22, $p<0.01$).	Stimulating daytime activities; Company; Intimate relationships; Decrease psychological distress; Assistance with memory problems; Help with eyesight or hearing; Food; Appropriate accommodation; Access to physical health care; Assistance with taking medications; Assistance with household tasks; Money; Assistance with self-care; Security and safety	1; 2; 4; 5; 6; 7; 10; 12; 15; 16; 17;18	Level 3B Quality: 8 Overall = 18
25	Hernandez (2007)	Qualitative – Grounded theory	United States High functioning residents from 2 AL SCU Staff members	3 themes emerged from discussions: • the garden as a therapeutic benefit both psychologically and	Therapeutic support	3	Level (N/A) Quality: 7 Overall = 7

			(n=28), family members (n=12) and architect/designers (n=5) interviewed.	physically • facility operations and regulations and its impact on garden use • recommendations for improving the gardens in making it a more meaningful/useful space for residents, staff and families			
26	Hicks-Moore (2005)	Single case design (ABAB design)	Canada Participants from a NH SCU; mostly women (n=30)	Incidence of agitation decreased in the week's music was played in comparison to the weeks with no music. Total agitated behaviours (incidence/day): W1 = 9.85; W2 = 4.57; W3=7.29; W4=3.43 More relaxed and harmonious atmosphere in dining room during weeks music was played; greater socialization among participants during music intervention.	Need to decrease agitation	10	Level 3A Quality: 10 Overall = 30
27	Hicks-Moore & Robinson (2008)	RCT (Experimental 3 x 3 repeated measures design)	Canada Participants from 3 SCUs in 3 NHs; mostly females (78%); mild to moderate impairment (mean MMSE of 23) Treatment group (n=32) and control group (n=9) (n=41)	No significant differences between the three treatment types, but there was a significant difference between treatment and control groups (Control group retained similarly high agitation scores across all time measurements, as expected).	Need to decrease agitation	10	Level 1 Quality: 10 Overall = 50
28	Hoe et al. (2006)	Cross-sectional design	United Kingdom Sample selected	Resident ratings of higher quality of life were	Improve mood; Decrease psychological distress; Reduce	3; 5; 6; 10	Level 3B Quality: 9

			from Hancock *et al.*(2006) study sample; mostly women (81%); mean MMSE of 8.7 (n=119)	significantly correlated with less depressed mood and less anxiety, fewer unmet needs and more cognitive impairment. Higher staff-rated QoL–AD scores were significantly associated with less physical disability, less cognitive impairment, fewer neuropsychiatric symptoms, lower levels of depression and anxiety symptoms and fewer unmet needs. Staff and individual ratings of QoL had poor agreement	behavioural problems; Reduce physical disability		Overall = 19
29	Innes & Surr (2001)	Cohort design	United Kingdom Participants from 5 residential homes with Elderly Mentally Infirm facilities and one NH; mostly females (n=76)	Around 10% of the total time observed was recorded at the +3 level of well-being (moderate). Most observations were seen at the +1 level. Less than 10% of participant's time spent in ill-being. Activities requiring staff intervention generate higher levels of well-being, e.g. intellectual activities (I) or exercises (J). Interestingly, games (G) did not enhance well-being suggesting appropriateness of activities are important.	Activities requiring staff intervention; Social contact/interactions; Appropriate activities; Stimulation via activities; Need for creative expression; Eating and drinking	1; 2; 3; 5	Level 3B Quality: 3 Overall = 13
30	Kobayashi & Yamamoto	Case study	Japan Participants from a	Stage of dementia affects time required to complete the task	Help with bathing; Proper guiding and protecting to	5; 9	Level 3B Quality: 5

	(2004)		SCU for elderly with severe dementia; 3 men and 5 women (n=8)	of guiding to the bathroom only. Time required for dressing and undressing depends on caregiver rather than stage of dementia.	complete undressing or dressing; Specific dressing and undressing routine		Overall = 15
31	Koch et al. (2005)	Retrospective Cohort	United States Participants from two NHs; mainly females; moderate to severe impairment; focused on AD patients only (n=85)	Visual impairment and decreased MMSE not significantly correlated Strong link between poor vision and ADL disability. Unaddressed visual acuity problems are very common among NH residents. Most common cause of compromised vision was uncorrected myopia.	Proper eye care	17	Level 3A Quality: 9 Overall = 29
32	Kolanowski et al. (2001)	RCT (crossover experimental design – participants served as their own control)	United States Participants from NHs (n=10)	Intervention had significant difference on time engaged in the activity and positive affect, yet no significant difference on other outcomes: mood, negative affect and participation.	Activities matched to abilities and interests (individualized)	2	Level 1 Quality: 5 Overall = 45
33	Kolanowski et al. (2005)	RCT (Crossover experimental design with repeated measures of the dependent variables)	United States Participants from four NHs; mainly females; mean MMSE of 8.6 (n=30)	Significantly more time on task, greater participation, more positive affect, and less passivity were found under NDB-derived and matched to interest only treatments compared with the matched to skill level only treatment or baseline. Agitation and negative affect improved under all treatments	Decrease behavioural symptoms; Activities tailored to individual needs (skill level and interests)	2; 10	Level 1 Quality: 10 Overall = 50

				compared with baseline. There was no significant change in mood among the treatments and none of the treatments were different from baseline.			
34	Kovach, Kelber et al. (2006)	RCT	United States Participants from 14 NHs located in one midwestern state (n=112) and their nurses (n=54); residents mostly women; mean MMSE of 7.81	Content analysis revealed that nurses responded to behaviours in four ways: • Dismissive. (no tt provided despite recognition of behaviour) • Static. (nurse uses same tt over and over again) • Reactive. (tt provided without prior thorough assessment) • Comprehensive. (assessment of 3+ domains and more than 1 tt) Reactive care responses were the most frequent responses in this sample, used with 87 residents, with an effectiveness rating of 62.66 (*SD* =31.20). As expected, residents in the treatment group received significantly more comprehensive responses than those in the control group received ($x2 = 82.40$, $p < .001$). It is noteworthy that residents in the control group received inadequate assessment 97%of the time.	Need for proper staff care response to behavioural symptoms as a sign of unmet need; Decrease problematic behaviours	10; 11	Level 1 Quality: 8 Overall = 48

				Nurses perceived comprehensive responses to be most effective with less recurring behaviours.			
35	Kovach, Logan et al. (2006)	RCT	United States Selection of participants from sample above. Participants randomized to control (n=57) and treatment (n=57); mostly females (75%); mean MMSE of 7.8 (n=114)	Statistically significant effect of STI on overall discomfort ($F = 9.64$, $P < .001$). Treatment group had significantly less discomfort at post-testing vs. control.	Comfort (decrease discomfort); Decrease behavioural symptoms	10; 13	Level 1 Quality: 10 Overall = 50
36	Kverno et al. (2008)	Retrospective Cohort	United States Participants from the CareAD study from three NHs in Maryland; severe impairment (n=123)	85.4% had one or more documented behavioural or psychiatric symptoms 78.1% of residents with documented NPS were taking at least 1 psychotropic medication Nonpharmacological tt documented for 58.1% of residents. Most frequent documented tt was safety-focused care (26.7%) 90.5% of residents with NPS received at least one pharma or non-pharmacologic treatment No significant relationship was found between receiving pharmacological and nonpharmacological treatments (x^2 [1, $N = 105$] =	Need to decrease neuropsychiatric symptoms (NPS)	10	Level 3A Quality: 9 Overall = 29

				0.03, p = 0.863).			
37	Lai (2003)	Mixed Study design RCT with parallel groups and qualitative aspect of study followed the Phenomenological framework	China Participants from 2 NHs and randomly assigned to 1 of 3 groups (treatment, control and comparison); mainly females (68%) and mean MMSE of 9.3 (n=101) and their staff (n=26)	Quantitative results: Intervention did not bring about any significant differences in outcomes for the participants over time • Repeated measures analysis failed to find any significant differences in the outcomes between the three groups in either the ITT(intention to treat) or the PP (per protocol) samples • Significant differences observed in ITT sample when comparing baseline and immediate post intervention and T2 post-int. and baseline scores of the intervention group. • Significant difference between T2 post-int. and baseline in the comparison group. Significant difference not sustained at T2 though. Qualitative results: Staff got to know the residents better, connected with them and developed an appreciation of them as individuals (attitude change).	Social engagement; Personal, meaningful and positive communication and interactions with others; Human contact	1	<u>Quantitative strand</u> Level 1 Quality: 10 Overall = 50 <u>Qualitative strand</u> Quality: 8 Overall = 8
38	MacDonald (2006)	Qualitative – Grounded theory	Canada Perceptions obtained from 5 family caregivers and 5 staff members (n=10). Study	Themes related to family voices: • lack of staff • family involvement • concerns for well-being of loved one	Leisure activities	2	Level (N/A) Quality: 7 Overall = 7

			conducted in a LTC facility with no SCU	• physical environment • opportunity for leisure was limited Themes emerging from staff members: • staff-related issues • environmental • discrimination of individual's with AD • lack of family support and education			
39	Malone & Camp (2007)	Qualitative – case study research	United States No details on study site and participants. Yet, case study conducted in a LTC facility.	Montessori principles applied to engage those with dementia by tailoring activity programming to their level of functioning. Notwithstanding the level of impairment, individuals with dementia should be provided with opportunities to engage in meaningful activity.	Engagement in meaningful and interesting activities; Activities tailored to individual needs	2	Level (N/A) Quality: 3 Overall = 3
40	Mickus et al. (2002)	Before and after design	United States Participants from a community NH; mostly females (74%); mean MMSE of 6.0 (n=23)	Pre-PRIDE – 42% had at least 3 of 5 behaviours; number reduced to 17% Post-PRIDE. Each behaviour showed improvements after intervention, yet anxiety and irritability were the only two significantly reduced.	Decrease problem behaviours/behavioural symptoms	10	Level 2 Quality: 8 Overall = 38
41	Milke et al. (2006)	Cross-sectional design	Canada (2 sites) and US (3 sites) Data collected from family and friends (n=134), direct care staff (n=93), nondirect care staff (n=25) and volunteers (n=25)	Grouped median (all 3 groups of respondents) values for 80% of the statements were favourable across all respondents Groups differed significantly across 34% of the statements (33). The family group was	Pleasant and fresh environment; Comfortable environment; Quiet space/calm environment; Appropriate lighting; Homelike environment; Secured and comfortable outdoor area; Personalization of rooms; Wayfinding cues; Physical care; Assistance with eating or	1; 2; 3; 4; 5; 8; 9; 10; 11; 12; 15; 17; 18; 19	Level 3B Quality: 8 Overall = 18

			related/caring for residents with dementia living in AL facilities. Residents mean MMSE was 13.2. (n=277 respondents)	relatively critical of 4 items: the resident's right to refuse medications, to get out of bed at night if restless, eat meals in the dining room being optional, and the flexibility in the timing of baths and getting out of bed in the morning. Direct care staff critical of: care of rashes related to incontinence, skin care, protecting residents from harassment by other residents, protection of residents' belongings, residents' opportunities for regular and special outings, calming residents when agitated or when they wanted to go home, their own knowledge of dementia, their own training for providing dementia care, their own providing of individualized care, their time available for resident care during the workday, their own asking families for guidance on matters about residents, and their own asking families for assistance	swallowing; Assistance with drinking; Food that meet diet needs; Receive preferred food and drink; Freedom to decide where to eat meals; Assistance with toileting, grooming, dressing, and walking; Physical exercise; Freedom of choice for sleep; Receive correction or direction when exhibit disruptive behaviours; Receive guidance when wandering or rummaging; Protection from harassment by other residents; Protected from self-injury; Protection for self-belongings; Help finding misplaced belongings; Assistance with taking meds; Professional monitoring of unpleasant effects of meds; Freedom to refuse meds; Opportunities to participate in social activities; Opportunities for outings; Privacy; Acceptance; Being respected; Comforted by staff touch; Being reassured by staff when needed; Being calmed when agitated or other; Attention; Regular visits and good response to residents requests by physicians; Competent, knowledgeable and experienced staff; Well-trained/educated staff; Personal attention by staff; Flexibility in timing of bath.		
42	Morgan et al. (2004)	Case-control design	Canada 8 Rural NHs with SCUs matched to 8 non-SCU NHs ('integrated	SCUs more supportive on 6 of 9 dimensions for the physical env. (stats significance): awareness and orientation; safety and security; regulation	Wayfinding cues; Safe/secure environment; Option for privacy; Support of functional abilities; Opportunities for personal preferences and choice;	1; 3; 5; 8; 9; 10; 12; 15; 17; 18; 19	Level 3A Quality: 6 Overall = 26

			facilities') based on number of beds and type of facility. Sample of residents mostly women. (Unknown sample size)	of stimulation; quality of stimulation; personal control; continuity of the self Groups differed on 2 NURS (social env.) subcales: SCUs more supportive with more separation of residents and less negative sensory stimulation.	Preservation of self; Social contact and interaction; Distinct spaces and activities; Consistency in daily activities; Homelike setting; Appropriate/Controlled level of stimulation; Limit complexity (simplicity); Control of behavioural problems by staff		
43	O'Brien & Caro (2001)	Case-control design	United States Retrospective analysis of data (care and dependency levels) from fiscal yr 1995 Massachusetts Medicaid NH Case-mix database Dementia (n= 13, 130 or 26%) vs. non-dementia residents (n=36,594) Total (n=49,724) resident data	A statistically significant ($p < .05$) shift to the higher levels of care was noted in those with dementia. Nearly three quarters (74%) of those with dementia were categorized in management levels 6 through 10. Using the median number of management minutes for each care level, a difference in care time was calculated based on this shift. Residents with some type of dementia command, on average, 229 more hours per year of care than those without dementia. This translates into 22% additional care time for those with dementia. The mean annual cost of caring for a nursing home resident with dementia of any type was $41,056. (3,865$ per patient per yr).	Assistance with ADLs – bathing, grooming, dressing, eating, toilet use	5	Level 3A Quality: 9 Overall = 29
44	O'Connor et al. (2009)	Qualitative – Systematic review	25 articles reviewed of which 10 were RCTs or nested RCTs. Studies reviewed were mainly conducted	Aromatherapy, bed baths, person-centered bathing, preferred music, one-to-one social interaction, simulated family presence and muscle relaxation therapy all reduced	Need to decrease the frequency and severity of behavioural symptoms	10	Level (N/A) Quality: 10 Overall = 10

			in nursing homes and long-stay hospital wards (n=19)	behavioural symptoms better than control conditions.			
45	Opie et al. (2002)	RCT with no control group	Australia Participants from NHs; mostly females (73%); mean MMSE of 6.4 (n=99)	Reductions in all Behavior Assessment Graphical System (BAGS) scores post-intervention. Follow-up: Staff noted decrease in frequency in at least one behavioural category for 75% of participants and severity decreased in at least one category for 60% of participants.	Individualized care	2	Level 1 Quality: 9 Overall = 49
46	Orrell et al. (2007)	RCT	United Kingdom Same sample as Hancock *et al.* (2006). Participants from 24 residential facilities (intervention: 118 patients in 12 homes) and (control: 120 patients in 12 homes) with mean MMSE of 8.7 (n=238)	Liaison service based on CANE assessments did not lead to a significant reduction in unmet needs and no evidence that liaison service led to improved QoL. • Unmet needs for PWD in the intervention homes reduced by 3.1 compared to 0.7 in the control group • QoL decreased by 1.6 points in intervention group and increased by 0.5 points in control group, as rated by residents. Staff observed a similar trend.	Assistance with memory problems*; Help with eyesight or hearing*;Mobility problems & incontinence*; Need to reduce psychological distress*; Stimulating daytime activities; Companionship; Decrease behavioural problems; Intimate relationships; Food; Appropriate accommodation; Maintenance of physical health; Help with taking medications; Assistance with Self-care; Need for information; Protection against self-harm; Need to decrease psychotic symptoms **most common needs according to results*	1; 2; 4; 5; 10; 12; 15; 16; 17; 18	Level 1 Quality: 8 Overall = 48
47	Orrell et al. (2008)	Cross-sectional design	United Kingdom Same dataset as Orrell *et al.* (2007) 238 CANE	Agreement between informants fair More unmet needs in the areas of daytime activities and social	Appropriate accommodation; Assistance with household tasks; Food; Help with self-care (grooming, dressing etc.); Stimulating daytime activities;	1; 2; 4; 5; 6; 7; 10; 11; 12; 15; 16; 17; 18	Level 3B Quality: 8 Overall = 18

			assessments of residents with dementia by care staff; Of these assessments, 149 users (residents) and 81 family members rated needs	company, as identified by the three informants Greater agreement between informants in the areas of less common needs such as caring for another, psychotic symptoms, deliberate self-harm, abuse, benefits and alcohol. High agreement in the areas of accommodation and food.	Assistance with memory problems; Help with eyesight or hearing; assistance with walking; Maintenance of physical health/ treatment of physical ailments; Help with taking medications/regular monitoring of prescribed meds; Ongoing support with psychological distress; Need for information, and assistance with its understanding; Protection from harm; companionship; social contact; supervision and treatment of behavioural problems; Intimate relationships; Money; help with managing financial affairs; Need to decrease psychotic symptoms		
48	Orsulic-Jeras et al. (2000)	Before and after and Case-control designs	United States Participants from one LTC (provides both AL and NH services); mostly females (88%); mean MMSE of 6.1 (n=16)	Sig main effect found for the treatment factor (Montessori-based programming) for CE (constructive engagement), PE (passive engagement) and pleasure. NE and SE not often seen during the activity periods Anxiety/fear showed sig main effects for both treatments Pleasure and anxiety/fear dropped from posttest 1 to posttest 2	Individualized activities meeting skill level and interests; Positive behaviours; Positive affect	2; 3; 9	Level 2 Quality: 6 Overall = 36
49	Pearson & Chalmers (2004)	Qualitative – Systematic review	306 articles reviewed of which 4 were level one studies and mainly level four studies (n=247). Reviewed articles were conducted in	Oral diseases and problems: high prevalence of coronal and root caries; more non-functioning teeth and un-restorable teeth than people without dementia; higher risk of xerostomia (dry mouth).	Maintenance of oral health/hygiene (ADL)	5	Level (N/A) Quality: 7 Overall = 7

			residential aged care facilities (analogous terms include residential care, LTC facilities and nursing homes) in Australia and overseas	All residents should have a dental assessment by a dentist upon admission to a facility and at regular intervals afterwards. Several oral hygiene care strategies to prevent oral diseases and conditions: fluoride and chlorhexidine gluconate products, dietary sugar substitutes, mouth cleaning swabs/aids, toothbrushes, etc. Dental professionals need to help carers develop skills to improve their success with oral care by means of training and education.			
50	Potkins et al. (2003)	Cohort design	United Kingdom Participants from 9 residential facilities and NHs in 2 areas of Newcastle; mainly females; mean MMSE of 9; assessment based on residents with dementia (n=298) or probable dementia (n=17) (n=315)	Irritability not associated with language impairment; Expressive language impairment strongly associated with delusion; Receptive language impairment correlated with aberrant motor behaviour; Depression shows trend with poor expressive skills (p=0.06); Level of socialization showed a weak but statistically significant correlation with language impairment.	Reduce social withdrawal; Social interactions	1	Level 3B Quality: 8 Overall = 18
51	Powers (2000)	Qualitative – Phenomenology design	United States Study conducted in a 147-bed voluntary not-for-profit NH;	Ethical implications presented in the taxonomy's following domains: • learning the limits of	Autonomy; Encouraged to exercise choice; Opportunities for personal preferences and choice; Comfort (relief of	1; 2; 3; 8; 13; 16; 18	Level (N/A) Quality: 9 Overall = 9

			experiences of 30 residents, their family and staff who cared for them were explored; residents were mostly females (67%) with moderate to severe impairment	intervention • tempering the culture of surveillance and restraint • preserving the integrity of the individual • defining community norms and values	symptoms) Safety and security; Support independence; Preserve integrity; Involvement in meaningful activities; Opportunities for socialization; Activities tailored to individual needs; Activity opportunity; Personal companionship; one-on-one contact; social interactions; intimate relationships.		
52	Powers & Watson (2008)	Mixed Study design – Retrospective Cohort and Ethnographic field study	United States Participants from 3 NHs with varying approaches to EOL care; mostly females (70%); mostly severe impairment Qualitative strand of study examined family, staff and residents points of view about EOL experiences (n=30)	Quantitative results: Symptoms increased gradually over the 12 months and jumped dramatically from 5.23 to 9.34 symptoms in last month of life. Majority (25/30) used hospice or comfort care during participation in study Emotional discomfort experiences by 70% of study participants. Qualitative results: Themes identified: difficulty in predicting prognosis, symptom management challenges, consistency of everyday life and respect and human love. EOL experience not clear cut nor absolute	Comfort and/or symptom relief; Reducing discomfort/pain; Symptom management; maintaining normalcy - Consistency of everyday life; Continuity of care; Respect and human love; Expressions of caring and affection from staff; Activities/social events	1; 3; 9; 13	<u>Quantitative strand</u> Level 3A Quality: 7 Overall = 27 <u>Qualitative strand</u> Quality: 7 Overall = 7
53	Quinn et al. (2003)	Cohort design	United States Participants from personal care homes (assisted	Several psychological or social differences were found between possible dementia and dementia group – significant	Assistance with memory problems; Assistance with receptive language skills; Connecting with others;	1; 5; 6; 15	Level 3A Quality: 8 Overall = 28

			living facilities) with dementia, possible dementia and no impairment (n=63)	differences as to decision-making abilities and communication problems. The dementia group was more impaired on most IADL variables than the other groups and showed a trend for greater help needed with toilet use (ADL) No significant differences found for physical health needs between all groups	Assistance with IADLs (medication assistance; help with shopping; help to arrange for transportation; help to manage finances and cash; assistance with preparation of snacks; help with laundry – 2 last IALDs not significant difference); Assistance with toilet use		
54	Ragneskog et al. (2001)	Single case design	Sweden Participants from NH; severe impairment, 1 women (n=4)	The music seemed to affect all participants. Participants reacted differently to music; 2 participants had apparent affect during intervention while other had marginal effects.	Manage agitation symptoms; Need for individualized care	2; 10	Level 3A Quality: 7 Overall = 27
55	Reid & Chappell (2003)	Before/After design	Canada Participants with moderate to severe impairment and newly admitted to one of 50 participating SCUs in LTC institutions; mostly females (64%) (n=162)	Residents showed significant decline in 5 of 6 outcomes (not agitation) during year following admission. Change in expressive language skills affected by: care-aide to resident ratios (greater ratio = greater decline), activity staff to resident ratios (greater ratio=less decline in expressive language skills) and number of beds (more beds= greater decline). Greater activity staff to resident ratio, the less decline in social skills.	Assistance with ADLs; Improve expressive language skills; improve social skills	1; 5; 15	Level 2 Quality: 9 Overall = 39

				Greater activity staff to resident ratio also associated to better outcome in cognitive function.			
56	Ruka (2003)	Single case design with repeated measures	United States Participants from one nursing facility (intermediate level of care); mostly females; all participants had severe cognitive impairment (n=4)	Participants demonstrated individualized patterns of resistive behaviours during bathing 2 / 4 participants demonstrated a statistically significant change with the reminiscence intervention during bathing. Evidence that the intervention had practical or clinical significance by promoting comfort and decreasing distress in both participants. 3 of the participants demonstrated a decrease in variability ranging from a 20.3% to 34% change in resistiveness to care with intro of the intervention 3 / 4 participants demonstrated increase in engagement in the intervention, other had stable engagement level	Need for comfort; Decrease distress (resistiveness); Decrease behaviours/resistiveness to care; Being understood, accepted and appreciated	3; 10; 13	Level 3A Quality: 9 Overall = 29
57	Sloane et al. (2004)	RCT (1 control and 2 treatment groups)	United States Participants from 9 SNFs (n=69) and their nursing assistants who bathed them (n=37) Most participants had moderate to severe impairment;	Reduction in behavioural symptoms (agitation and aggression) for both interventions Discomfort declined significantly in both intervention groups but not in control group	Care based on preferences; comfort; Decrease behavioural problems	8; 10; 13	Level 1 Quality: 10 Overall = 50

			mostly females	Skin conditions significantly improved and ratings of debris improved during both interventions compared to baseline.			
58	Sloane et al. (2008)	Case-control design	United States Collected interview data from staff for 581 decedents (422 with dementia and 159 without dementia) living in RC/AL and NHs in 4 states; 54% of decedents were from NHs, 73% had dementia and 69% were females. Family interviews obtained for 293 of the identified decedents. (n = 581)	Similar EOL care between dementia status and facility type. Skin ulcers more prevalent among residents with dementia in RC-AL Sedative meds and restraints more used in PWD in all facilities Residents with dementia less able to participate in decisions about their care (p>.001) Death and dying less frequently discussed with people with dementia (p=0.03)	Hygiene care; Symptom Management; Management of behavioural symptoms	4; 10; 13	Level 3A Quality: 7 Overall = 27
59	Smith (2008)	Mixed study design Before and after with control and Phenomenology designs	New Mexico Participants from a NH randomized equally to one of two groups; mostly women; mean MMSE of 7.9 (n=28)	Quantitative results: No statistical significance mean difference between control and tt group on NPI measure, yet sig results for QUALID measure (p‹.002) – QoL enhanced for residents in tt group. No findings suggesting changes in NPI behaviours, but trend towards improvement noted. Qualitative results:	Decrease stress and enhance quality of life	10	<u>Quantitative strand</u> Level 2 Quality: 10 Overall = 40 <u>Qualitative strand</u> Quality: 9 Overall = 9

				Themes emerging from qualitative analyses: gratitude, reverence, satisfaction and prayer interaction			
60	Sung et al. (2010)	Before and after design	Taiwan Participants from LTC facility randomized to treatment (n=29) and control (n=23); half the participants had severe impairment (n=52)	Mean anxiety score in the experimental group decreased from 10.93 at prettest to 8.93 at post-test = sig reduction (p‹.001). Sig lower anxiety observed when difference between groups controlled for as well. Mean anxiety score decreased in control group as well but was not significant.	Reduce/Manage anxiety	10	Level 2 Quality: 10 Overall = 40
61	Sung et al. (2006)	RCT	Taiwan Participants from a residential care facility were randomized to control (n=18) and treatment (n=18) groups; mostly male (n=36)	Significant decrease in number of agitated behaviours for experimental group vs. controls.	Positive affect; Communication and social interaction; Pain relief	1; 3; 13	Level 1 Quality: 9 Overall = 49
62	Tilly & Reed (2005)	Qualitative – Systematic review	101 articles reviewed; experimental and quasi-experimental methods. Studies reviewed were mainly conducted in LTC facilities setting	Research indicates that pleasant, noxious-free environments can lead to better performance of daily living. Pleasant environment also minimizes resident aggression and agitation. Literature suggests that environmental modifications may address basic physiological needs.	Supervision and assistance with ADLs (hygiene - bathing, dressing, grooming - and personal care); Care of resident's physiological needs (eating, drinking, toileting (incontinence) and sleeping) Care of ambulation; Maintain residents ability to walk; Psychiatric and behavioural symptoms management	5	Level (N/A) Quality: 2 Overall = 2

				Behavioural and environmental strategies may help prevent falls.			
63	Tilly & Fok (2008)	Qualitative – Grounded Theory design	United States Experts (providers and researchers from AL, NH, hospices, Veteran's Affairs medical system and academia) in the field of dementia care contacted (n=49)	Key elements of quality EOL care for residents with dementia: • communication about care* • decision making about care* • proper management of physical and behavioural symptoms • psychosocial and spiritual support • family involvement • recognition of the death of a resident and bereavement support important for the family *most important, as identidied by experts	Good communication with staff, Continued interaction with staff; Active participation in decision making if ability to do so (proxy decision maker needed otherwise); Physical symptoms and pain management; Maximise comfort; Repositioning in bed at EOL; Behavioural symptoms management; Psychosocial and spiritual support (e.g. music or religious rituals; on-site chapel); Education of disease and its trajectory.	3; 5; 8; 11; 13; 14	Level (N/A) Quality: 2 Overall = 2
64	Van Haitsma (2000)	Case study	United States Participants from NHs; mainly females (87%); mean MMSE of 13.8 (n=54)	Residents were endorsed 'liking' more activities, than disliking or having no preferences. Most preferred activity was Social interaction (74% residents liked) No clearly disliked activity *results only reported for first part of study – assessment of preferences.	Integration of preferences into everyday care; Opportunities to participate in preferred activities; Engagement in meaningful activities; Sensory stimulation	2; 8; 17	Level 3B Quality: 4 Overall = 14
65	Young et al. (2001)	Case study	Canada Participants from one LTC facility;	Significant positive association between energy consumed and delivered.	Nutritional needs (Need for increased energy (food) delivery at breakfast, Optimal (no excess)	4	Level 3B Quality: 5

			mostly women (88%) (n=25)	Energy intakes of residents with increased behavioural difficulties tended to be highly impacted by energy delivered at breakfast and the least impacted at dinner. Individuals with cognitive deterioration tended to have a stronger association between energy consumed and delivered at breakfast. Intakes of those with poor BMIs least impacted by energy delivery and contrary for those with high BMIs.	intake, and Stimulation of food intake (in residents with low BMIs))		Overall = 15
66	Zeisel et al. (2003)	Cohort design	United States Participants from 15 NHs; mostly women (72%); mostly moderate impairment (67%) (n=427)	Env features associated with reduced aggressive and agitated behaviour and fewer psychological problems are privacy-personalization in bedrooms, residential character and an ambient environment that resident can understand. Env features associated with reduced depression, social withdrawal, misidentification, and hallucinations are common area that vary in ambiance and exit doors throughout the SCU that are camouflaged. Non-environmental features (size of facility, staff ratio and AD capability) and resident	Privacy-personalization in bedroom; Increased variability among common spaces; Exit control; Residential type environment ('homelike') vs. institutional; Understandable and controlled ambient environment - sensory comprehension.	12; 17; 18	Level 3B Quality: 7 Overall = 17

				characteristics (ADL, LOS, gender) also associated with behaviours.			
67	Zimmerman et al. (2005)	Cross-sectional design	United States Participants from 35 RC/AL and 10 NHs from 4 states; mostly females (79%); mostly severe to very severe impairment (61%) (n=421)	Better QoL in facilities with specialized workers, more staff training in more areas, and that encouraged activity participation more frequently (all p ‹ .05). From resident's perspective: QoL higher for those in facilities that involved more frequently staff in care planning and where staff had more dementia-sensitive attitudes (especially hope) QoL lower in facilities that provided more treatment, including sedative and antipsychotic meds, and when residents were ungroomed No overwhelming indication that special dementia care is related to better outcomes	Specialized care; Participation in daily activities; Need to be well groomed; Positive communication with staff; need for physical contact; positive person work; Favourable staff attitudes (Dementia-sensitive; hope especially); Involvement of staff in care planning; Staff training in dementia care; Reduce/Avoid use of antipsychotic and sedative hypnotic medications	1; 2; 5; 10; 11	Level 3B Quality: 9 Overall = 19
68	Zingmark et al. (2002)	Qualitative – Phenomenological hermeneutic interpretation of interviews	Sweden Interviews with 10 staff (9 enrolled nurses and one RN) and mostly women (n=9) caring for 6 women living in a SCU located in a house built in early 20th century.	Caring aspects promoting well-being among people with AD: • viewing dignity and striving to preserve a sense of self in the resident • accepting the resident's way of being • sharing everyday life in a sense of nearness • encouraging a sense of belonging	Being respected; Maintaining a sense of self; Being accepted; Being understood; Need for close relationships; Continuation of past (familiar/preferred activities); Pain relief; Opportunity for meaningful occupation; Opportunity for autonomy; Maintain a sense of power and control	1; 2; 3; 8; 13	Level (N/A) Quality: 9 Overall = 9

				• adjusting oneself to the resident and striving for mutual understanding • offering relief • providing opportunities for occupation • promoting power and control in the resident Themes emerging from the caring aspects: Confirmation, familiarity, communion and agency considered dimensions of a good life in people with advanced AD.			

Appendix 20: List of needs with associated references and categories

Main categories	Needs of residents with dementia	Ref ID
Management of behavioural problems	Use of daily psychoactive medications to treat behaviours (apathy and agitation) (57.1% of LTC residents-participants)	7
Management of behavioural problems	Receive correction or direction when exhibit disruptive behaviours	41
Management of behavioural problems	Receive guidance when wandering or rummaging	41
Management of behavioural problems	Improve behaviour – general	18
Management of behavioural problems	Reduce/Avoid use of antipsychotic and sedative hypnotic medications	67
Management of behavioural problems	Calmed by staff when agitated	41
Management of behavioural problems	Decrease/treat psychological distress (depression/anxiety)	9, 18, 23, 24, 28, 46
Management of behavioural problems	Management of behavioural symptoms	58
Management of behavioural problems	Control of behavioural problems by staff	42
Management of behavioural problems	Supervision and treatment of behavioural problems	47
Management of behavioural problems	Decrease problem behaviours/behavioural symptoms – general	2, 3, 13, 17, 20, 28, 33, 34, 35, 40, 44, 46, 57
Management of behavioural problems	Decrease Neuropsychiatric symptoms (NPS) – QoL related	36
Management of behavioural problems	Decrease stress and enhance QoL	59
Management of behavioural problems	Need to decrease agitation – QoL related (manage agitation symptoms)	3, 20, 21, 26, 27, 54
Management of	Decrease aggressive behaviour	18

behavioural problems		
Management of behavioural problems	Decrease psychotic symptoms	46, 47
Management of behavioural problems	Manage / reduce anxiety	60
Management of behavioural problems	Need to decrease distress (resistiveness)	56
Management of behavioural problems	Need to decrease agitation and apathy – QoL related	7
Management of behavioural problems	Need to decrease mixed behaviours (apathy and agitation) (58.9%) of participants in LTC had these behaviours.	7
Need for daily individualized activities/care	Active participation (potential for performance)	10
Need for daily individualized activities/care	Stimulation via activities	6, 29
Need for daily individualized activities/care	One-on-one contact	16, 51
Need for daily individualized activities/care	Personal attention received when lonely by staff	41
Need for daily individualized activities/care	Opportunity for activities outside the facility	22
Need for daily individualized activities/care	Stimulating daytime activities	24, 46, 47
Need for daily individualized activities/care	Activities requiring staff interventions (use of intellect and exercices)	29
Need for daily individualized activities/care	Need for leisure activities	38
Need for daily individualized activities/care	Need for activities tailored to individual needs (skill level and interests)	32, 33, 39, 48, 51
Need for daily individualized activities/care	The need to engage in meaningful activities	51, 64, 68

Need for daily individualized activities/care	Engagement in stimulating and meaningful activities (appropriate activities)	8, 15, 22, 29, 39, 41, 64
Need for daily individualized activities/care	Social activities	41
Need for daily individualized activities/care	Participation in daily activities	67
Need for daily individualized activities/care	Need for meds tailored to individual symptoms and condition (reduction/adjustments)	1
Need for daily individualized activities/care	Specialized care	67
Need for daily individualized activities/care	Individualized care	14, 45, 54
Need for daily individualized activities/care	Individualized interventions	20, 21
Need for daily individualized activities/care	Activity based on past interests	51
Need for daily individualized activities/care	Activity opportunity	6, 15, 22, 47, 51
Need for daily individualized activities/care and daily structured care	The need for structured and individualized activities	14, 48
Social needs	Need for satisfactory communication (interactions/contact) with caregiver/ staff	5, 16, 22, 67
Social needs	Need for conversation	6
Social needs	Need for interactions	29, 37, 42
Social needs	Improve social skills	55
Social needs	Need appropriate social contact (including staff and visitors)	9, 16, 42, 47
Social needs	Improve interaction – social contact	18
Social needs	Social interactions	10, 50, 51, 61
Social needs	Opportunities for social closeness	5, 68
Social needs	Social network	9
Social needs	Connecting with others (frequency of phone calls)	53
Social needs	Companionship/company	22, 24, 46,

		47, 51
Social needs	Family involvement	16
Social needs	Interpersonal relations	16
Social needs	Social engagement	15, 37
Social needs	Socialization	16, 151
Social needs	Human contact	37, 67
Social needs	Need to reduce social withdrawal	50
Social needs	Social support	9
Social needs	Opportunities for information sharing	5
Social needs	Need for information (info-giving)	46, 47
Social needs	Activities/social events	52
Social needs	Communication (opportunities to talk openly with others)	2, 61
Social needs	Opportunities for outings	41
Social needs	Improve social functioning	18
Emotional needs/ Personhood	Need for creative expression	29
Emotional needs/ Personhood	Emotional support through staff touch	41
Emotional needs/ Personhood	Attention	16, 41
Emotional needs/ Personhood	Positive relationships	9, 16
Emotional needs/ Personhood	Friendship	16
Emotional needs/ Personhood	Self-esteem (respect from others and freedom from insults)	2, 16
Emotional needs/ Personhood	Positive and enjoyable engagement in daily activities	10, 16
Emotional needs/ Personhood	Need to retain a strong and positive sense of identity	6
Emotional needs/ Personhood	Continuity of self-image	16
Emotional needs/ Personhood	Maintenance/preservation of self	12, 14, 42, 68
Emotional needs/ Personhood	Enhancement of self-identity (‘personhood’)	12, 14
Emotional needs/ Personhood	maintain positive self-image	17
Emotional needs/ Personhood	Preserving integrity	51
Emotional needs/ Personhood	Therapeutic support	25
Emotional needs/ Personhood	Continuation of past lifestyles (recognition of individuality)	16, 68

Emotional needs/ Personhood	Need to retain hope	6
Emotional needs/ Personhood	Need to retain social confidence	6
Emotional needs/ Personhood	improve/maintain emotional balance	17
Emotional needs/ Personhood	Positive (affect) feelings and mood	16, 48, 61
Emotional needs/ Personhood	Improve mood	18, 28
Emotional needs/ Personhood	Improve emotional functioning	18
Emotional needs/ Personhood	Approached by others in a positive manner	16
Emotional needs/ Personhood	Self-expression (express feelings in own way)	16
Emotional needs/ Personhood	Expressions of caring and affection from staff	52
Emotional needs/ Personhood	Respect and human love (upholding dignity)	52
Emotional needs/ Personhood	Psychosocial support	63
Emotional needs/ Personhood	Need for proxy decision maker in the event of inability to make own decisions	63
Emotional needs/ Personhood	Being accepted/appreciated	16, 56, 68
Emotional needs/ Personhood	Being respected	41, 68
Emotional needs/ Personhood	Feeling attached	16
Emotional needs/ Personhood	Recognition/being understood	16, 56, 68
Emotional needs/ Personhood	Being reassured, when needed	41
Emotional needs/ Personhood	Involvement	16, 22
Emotional needs/ Personhood	Being useful to others	16
Emotional needs/ Personhood	Promote positive behaviours (eg. Engagement)	13, 48, 56
Emotional needs/ Personhood and Need to be in a homelike comforting environment	Personal identity (access to personal items and identifying material, e.g. clothes)	2

ADLs	Be well groomed	67
ADLs	Supervision and assistance with ADLs (hygiene - bathing, dressing, grooming - and personal care)	62
ADLs	Care of resident's physiological needs (eating, drinking, toileting (incontinence) and sleeping)	62
ADLs	Need for care of ambulation	62
ADLs	Physical care needs (ADLs)	23
ADLs	Improve ADL function	18
ADLs	Assistance with ADLs (bathing, grooming, dressing, eating, toilet use)	43, 55
ADLs	Maintenance of oral health/hygiene (ADL)	49
ADLs	Help with bathing	30
ADLs	Help/assistance with taking medications	24, 41, 46, 47
ADLs	Assistance with eating/drinking	41
ADLs	Help with toileting	41, 53
ADLs	Help with grooming	41
ADLs	Help with dressing	41
ADLs	Help with walking	41, 47
ADLs	Assistance with Self-care (grooming, dressing etc.)	1, 24, 46, 47
ADLs	Support of functional abilities (related to self-care, eating, and functional activities)	42
ADLs	Need for proper guiding and protecting to complete undressing or dressing	30
ADLs	Repositioning in bed	63
ADLs	Eating and drinking	29
ADLs and Functional needs - IADLs	Reduce physical disability (level of dependency)	28
Need for independence / choice	Support independence	51
Need for independence / choice	Freedom of movement	11, 16
Need for independence / choice	Freedom to refuse meds	41
Need for independence / choice	Opportunities for personal preferences and choice (personal control)	42, 51, 68
Need for independence / choice	Being able to decide what/where to eat and when to go to bed	16, 41
Need for	Flexibility in timing of bath	41

independence / choice		
Need for independence / choice	Need to freely engage in activities	11
Need for independence / choice	Autonomy (control over one's life)	2
Need for independence/choice	Option for privacy	42
Need for independence / choice	Autonomy	16, 22, 51, 68
Need for independence / choice	Active participation in decision-making	63
Need for independence/ choice	Care based on preferences	57
Need for independence / choice	Integration of preferences into everyday care	64
Need for independence / choice	Need to retain agency	6
Need for independence/choice	Familiar/preferred activities	22, 68
Cognitive needs	Capture attention due to memory impairment	8
Cognitive needs	Assistance with memory problems	24, 46, 47, 53
Cognitive needs	Assistance with receptive language skills (impairment)	1, 53
Cognitive needs	improve expressive language skills	55
Cognitive needs	Need for staff or other to facilitate conversation	6
Cognitive needs	Cognitive understanding (awareness of surroundings and mental clarity)	2
Cognitive needs	Help finding misplaced belongings	41
Cognitive needs	Facilitation of orientation to physical, social and temporal dimensions of the environment by means of wayfinding cues for instance	41, 42
Need to be safe / secure	Security and safety	16, 22, 24, 42, 51
Need to be safe / secure	Exit control	66
Need to be safe / secure	Safety features of the unit and outdoor area	11
Need to be safe / secure	Secured outdoor area	41
Need to be safe / secure	Security and safety	16, 22, 24, 42, 51
Need to be safe / secure	Safety and security (protection from harm)	2
Need to be safe / secure	Protection from staff for self-belongings; and harassment from other residents	41

Need to be safe / secure	Protection from staff from harassment from other residents	41
Need to be safe / secure	Protection from staff against self-injury	41, 46
Need to be safe / secure	Protection from harm	47
General overall physical health	Clinical care	22
General overall physical health	Physical care (skin care; care of rashes; hair care etc.)	41
General overall physical health	Physical exercise	41
General overall physical health	Access to physical health care	24
General overall physical health	Maintenance of physical health	46, 47
General overall physical health	Need for medications to treat medical conditions (infections, cardiovascular, gastrointestinal, and dermatological disorders) and symptoms	4
General overall physical health	Increase in palliative medications closer to death and decrease in antibiotics, anti-dementia agents, cardiovascular agents, and psychotropic agents	4
General overall physical health	Eating well	16
General overall physical health	Offered food meeting diet needs	41
General overall physical health and Need for independence / choice	Receive preferred food/drink	41
General overall physical health	Food	22, 24, 41, 46, 47
General overall physical health	Nutritional needs (Need for increased energy (food) delivery at breakfast (peak energy consumption) Need for optimal (no excess) intake Stimulation of food intake (in residents with low BMIs)	65
General overall physical health	Maintain functional abilities (physical functions)	19
General overall physical health	Hygiene care	58
General overall physical health and Emotional needs/	Physical and mental health	16

Personhood		
Need to be in a homelike comforting environment	Personal belongings (item)	16
Need to be in a homelike comforting environment	Familiar environment (personalized spaces)	16
Need to be in a homelike comforting environment	Personalization of rooms	41, 66
Need to be in a homelike comforting environment	Homelike environment/setting (continuation with past)	11, 16, 41, 42, 66
Need to be in a homelike comforting environment	Appropriate accommodation	24, 46, 47
Need to be in a homelike comforting environment	Comfortable env	41
Need to be in a homelike comforting environment	Pleasant and fresh environment	41
Need to be in a homelike comforting environment	Increased space (unrestricted nature of environment)	11
Need to be in a homelike comforting environment	Increased variability among common spaces	66
Need to be in a homelike comforting environment	Limit complexity (simplicity)	42
Need to be in a homelike comforting environment	Comfortable outdoor area	41
Need to be in a homelike comforting environment	Quiet space/calm env	22, 41
Need to receive proper pain management	Physical comfort	16
Need to receive proper pain management	Pain relief	52, 63
Need to receive proper pain management	Physical comfort at end-of-life	52, 63
Need to receive proper pain management	Symptom management	52, 58, 63
Need to receive proper	Comfort (decrease discomfort)	35, 51, 56, 57

pain management		
Need to receive proper pain management	Pain relief	61, 68
Sensory needs	Help with eyesight/hearing	24, 46, 47
Sensory needs	Visual needs (need for proper eye care)	31
Sensory needs	Adequate temperature	22
Sensory needs	Appropriate lighting	22, 41
Sensory needs	Appropriate/controlled level of stimulation	42
Sensory needs	Understandable / controlled env – sensory comprehension	66
Sensory needs	Sensory stimulation	64
Need for daily structured care	Regular visits by physicians	41
Need for daily structured care	Maintain normalcy – consistency of everyday life/familiar staff and surroundings	52
Need for daily structured care	Need for specific dressing and undressing routine	30
Need for daily structured care	Consistency in daily activities (stability)	42
Functional needs - IADLs	Assistance with household tasks, when needed	22, 24, 47
Functional needs – IADLs	Assistance with managing money	47
Functional needs - IADLs	Assistance with IADLs (functional health)	53
Need for knowledgeable staff	Need for proper staff care response to behavioural symptoms as a sign of unmet need	34
Need for knowledgeable staff	Ongoing support with psychological distress	47
Need for knowledgeable staff	Professional monitoring of unpleasant effects of meds	41
Need for knowledgeable staff	Need for good communication with caregiver/ staff	63
Need for knowledgeable staff	Competent, knowledgeable and experienced staff	41
Need for knowledgeable staff	Well trained/educated staff	41, 67
Need for knowledgeable staff	Staff involvement in care planning	67
Need for knowledgeable staff	Positive staff attitude (dementia-sensitive)	67
Need for knowledgeable staff	Positive person work	67
Need for knowledgeable staff	Good response to residents requests by physicians	41

Sexual needs	Intimate relationships	16, 24, 46, 47, 51
Need for privacy	Territoriality (privacy and freedom from unwanted physical intrusion)	2
Need for privacy	Privacy	11, 16, 41
Need for privacy	Distinct spaces and activities for PWD (separation)	42
Money	Financial situation (sufficient money to do what like)	16
Money	Money	24, 47
Spiritual needs	Spiritual support	63
Spiritual needs	Spirituality (religion)	16

Appendix 21: Other MDS 2.0 variables of relevance (with description) not a part of the RUG-III (34 Group)

A9 : Responsibility/legal guardian
A9f : Resident responsible for self
A10 : Advanced directives
B3: Memory/recall ability
B5: Indicators of delirium-periodic disordered thinking/awareness
C1 : Hearing
C2 : Communication devices/techniques
C3 : Modes of expression
C6: Ability to understand others
D : Vision patterns
E2 : Mood persistence
E3: Change in mood
E4B : Behavioural symptom alterability in last seven days
E5: Change in behavioural symptoms
F: Psychosocial well-being
F1 :Sense of initiative/involvement
F1a : At ease interacting with others
F1b : At ease doing planned or structured activities
F1e : Pursues involvement in life of facility
F1f : Accepts invitations into most group activities
F2 : Unsettled relationships
F2b : Unhappy with roommate
F2c : Unhappy with residents other than roommate
F3 : Past roles
F3a : Strong identification with past roles and life status
F3c : Resident perceives that daily life (customary routines, activities) is very different from prior pattern in the community
G1c: Support with walking in room
G1d: support with walking in corridor
G1g: support with dressing
G1j: support with personal hygiene
G2: Support with bathing
G5a: Use of a cane, walker or crutch for locomotion

G7: Task segmentation
G8b: Direct care staff believe resident is capable of increased independence in at least some ADLs
G8c : Resident is able to perform tasks/activity but is very slow
G9: Change in ADL function
J1n: Unsteady gait
J2: Pain symptoms
J5c: End-stage disease (6 months or less to live)
K4: Nutritional problems (e.g. complains about taste of food)
K5e: Therapeutic diet
K5f: Dietary supplement between meals
K5h: On a planned weight change diet
L1f: Daily cleaning of teeth or dentures, or daily mouth care – by resident or staff
N2: Average time involved in activities
N3 : Preferred activity settings
N3d : outside facility
N4c: Exercise or sports adapted to resident's current abilities
N4g : Trips or shopping
N4h : Walk/wheeling outdoor
N4k : Talking or conversing
N4l : Helping others
N5 : Prefers change in daily routine
O4f: Analgesic
P1ae : Monitoring acute medical condition
P1an: Alzheimer's/dementia special care unit
P1ar : Training in skills required to return to the community
P1be : Psychological therapy
P2a: Special behaviour symptom evaluation program
P2d: Resident specific deliberate changes in the environment to address mood or behaviour patterns
P2e: Reorientation
P4: Devices and restraints (e.g. bed rails)

Appendix 22: Matching of needs with MDS 2.0 variables

Main needs categories	Needs of resident with dementia	MDS 2.0 variables (MDS variables part of RUGs and other MDS variables of relevance)	
		MDS variables in RUGs	Other MDS variables
Management of behavioural problems	Reduce/Avoid use of antipsychotic and sedative hypnotic medications	N/A	N/A
	Improve behaviour – general		E5; P2
	Calmed by staff when agitated	E1; E4	
	Decrease/treat psychological distress (depression/anxiety)		E3; O; F; N2; P2d, P2e
	Management of behavioural symptoms		O; P2
	Control of behavioural problems by staff		O, P4
	Supervision and treatment of behavioural problems	Section E	O; P2
	Decrease problem behaviours/behavioural symptoms – general		O; P2; P4
	Decrease Neuropsychiatric symptoms (NPS) – QoL related		O; P2
	Decrease stress and enhance QoL		O
	Manage agitation symptoms		O; P2a; P4
	Decrease aggressive behaviour		O; P2
	Decrease psychotic symptoms		O
	Manage / reduce anxiety		O
	Need to decrease distress (resistiveness)	N/A	N/A
	Need to decrease agitation and apathy – QoL related	N/A	N/A
	Need to decrease mixed behaviours (apathy and agitation)	N/A	N/A
	Use of daily psychoactive medications to treat behaviours (apathy and agitation)		O
	Receive correction or direction when exhibit disruptive behaviours	E4	
	Receive guidance when wandering or rummaging	E4 a	
Need for daily individualized activities/care	One-on-one contact		F1; N4k
	Personal attention received when lonely by staff		F3
	Active participation (potential for performance)		F1
	Stimulation via activities		Section N
	Need for meds tailored to individual symptoms and condition		E4B; Section O

	(reduction/adjustments)		
	Specialized care	N/A	N/A
	Individualized care	N/A	N/A
	Individualized interventions	N/A	N/A
	Activity based on past interests		F3
	Activity opportunity		N2
	Opportunity for activities outside the facility		N3d; N4g; N4h
	Stimulating daytime activities		N2
	Activities requiring staff interventions (use of intellect and exercises)		F1
	Need for leisure activities		N2
	Need for activities tailored to individual needs (skill level and interests)		F1; N3; N4
	The need to engage in meaningful activities		N3; N4
	Engagement in stimulating and meaningful activities (appropriate activities)		N3; N4
	Social activities		F1; N4
	Participation in daily activities	Section G; P1b; P2; P3	Section F; N2
	The need for structured and individualized activities		F1 (b)
Social needs	Need for satisfactory communication (interactions/contact) with caregiver/ staff		F1a; N4k
	Need for conversation		N4k
	Need for interactions		F1a; N4k
	Improve social skills		F1
	Need appropriate social contact (including staff and visitors)		F1; N4k
	Improve interaction – social contact		F1
	Social interactions		F1; N4k
	Opportunities for social closeness		F1; N4
	Social network		F1; N4
	Connecting with others (frequency of phone calls)		F1; N4
	Companionship/company		F1; N4
	Family involvement		F2; F3
	Interpersonal relations		F1
	Social engagement		F1e
	Socialization		F1; N4
	Human contact	N/A	N/A
	Need to reduce social withdrawal		E2
	Social support		Section F
	Opportunities for information sharing		N4
	Need for information (info-giving)		N4l

	Communication (opportunities to talk openly with others)	C4	C3; F1a; N4k
	Opportunities for outings		N4
	Improve social functioning		F1
	Activities/social events		F1; N2
Emotional needs/Personhood	Physical and mental health	N/A	N/A
	Psychosocial support		P1be
	Need for proxy decision maker in the event of inability to make own decisions		A9
	Expressions of caring and affection from staff	N/A	N/A
	Respect and human love (upholding dignity)	N/A	N/A
	Involvement		F1e
	Being useful to others		N4l
	Promote positive behaviours (eg. Engagement)		F1; N2
	Being accepted/appreciated	N/A	N/A
	Being respected	N/A	N/A
	Feeling attached		F1
	Recognition/being understood	C4	
	Being reassured, when needed	E1	
	Approached by others in a positive manner	N/A	N/A
	Self-expression (express feelings in own way)	C4	
	Improve emotional functioning	Section E	F1
	Need to retain hope	N/A	N/A
	Need to retain social confidence		F1
	Improve/maintain emotional balance		E3; E5
	Positive (affect) feelings and mood		E3
	Improve mood		E3
	Need to retain a strong and positive sense of identity		F3
	Continuity of self-image		F3
	Maintenance/preservation of self		F3a
	Enhancement of self-identity (‘personhood’)		F3
	Maintain positive self-image		F1; F2; F3
	Preserving integrity		F1; F2; F3
	Positive and enjoyable engagement in daily activities		F1; N4
	Continuation of past lifestyles (recognition of individuality)		F3
	Therapeutic support	N/A	N/A
	Personal identity (access to personal items and identifying material, e.g. clothes)	N/A	N/A
	Self-esteem (respect from others	E1	F1; F2

	and freedom from insults)		
	Need for creative expression		F1; N4
	Emotional support through staff touch	N/A	N/A
	Attention (refers to social contact)		F1; N4k
	Positive relationships		F1
	Friendship		F1
ADLs	Eating and drinking	N/A	N/A
	Be well groomed		G1j
	Supervision and assistance with ADLs (hygiene - bathing, dressing, grooming - and personal care)	Section G	
	Care of resident's physiological needs (eating, drinking, toileting (incontinence) and sleeping)	E1j; E1k; G; H	
	Need for care of ambulation		G1c; G1d; G5a; J1n
	Physical care needs (ADLs)	Section G	
	Improve ADL function	P1bc	G9
	Reduce physical disability (level of dependency)	P1b; P3	G7; G8b
	Assistance with ADLs (bathing, grooming, dressing, eating, toilet use)	Section G	
	Maintenance of oral health/hygiene (ADL)		G1j; L1f
	Help with bathing		G2
	Help/assistance with taking medications	G1h	
	Assistance with eating/drinking	G1h	
	Help with toileting	G1i	
	Help with grooming		G1j
	Help with dressing		G1g
	Help with walking		G1c; G1d
	Assistance with Self-care (grooming, dressing etc.)	Section G	
	Support of functional abilities (related to self-care, eating, and functional activities)	Section G	
	Need for proper guiding and protecting to complete undressing or dressing		G1g and G7
	Repositioning in bed	G1aB	
Need for independence/choice	Receive preferred food/drink		K4
	Support independence		G8b
	Freedom of movement		G8c; P4
	Freedom to refuse meds	B4; C4	A9f; A10
	Opportunities for personal preferences and choice (personal control)	B4	
	Being able to decide what/where to eat and when to go to bed	B4; C4	
	Flexibility in timing of bath	B4; C4	
	Need to freely engage in activities		F1

	Autonomy (control over one's life)	B4	A9f
	Care based on preferences	N/A	N/A
	Familiar/preferred activities		N3
	Integration of preferences into everyday care		N5
	Autonomy	N/A	N/A
	Option for privacy		F1; F2; N3
	Active participation in decision-making	B4	
Cognitive needs	Assistance with receptive language skills (impairment)		C6
	Improve expressive language skills	C4; P3j	
	Need for staff or other to facilitate conversation	P1ba; P3j	
	Cognitive understanding (awareness of surroundings and mental clarity)	B2a; B4	B3; B5
	Capture attention due to memory impairment	B2	B5; P2d
	Assistance with memory problems	B2; B4	B3
	Help finding misplaced belongings	N/A	N/A
	Facilitation of orientation to physical, social and temporal dimensions of the environment by means of wayfinding cues for instance		P2d
Need to be safe/secure	Safety features of the unit and outdoor area		P1an
	Secured outdoor area		P1an
	Security and safety		
	Exit control		P1an
	Protection from staff for self-belongings; and harassment from other residents	N/A	N/A
	Protection from staff from harassment from other residents	N/A	N/A
	Protection from staff against self-injury	N/A	N/A
	Protection from harm	N/A	N/A
	Safety and security (protection from harm)	E1 (if person feels fear, etc.)	
General overall physical health	Clinical care	Section G	
	Physical care (skin care; care of rashes; hair care etc.)	Sections G and M	
	Physical exercise	P1bc	N4c
	Access to physical health care	N/A	N/A
	Maintenance of physical health	Section G; P1b; P3	
	Need for medications to treat medical conditions (infections, cardiovascular, gastrointestinal, and dermatological disorders) and symptoms		J2; Section O

	Increase in palliative medications closer to death and decrease in antibiotics as well as anti-dementia, cardiovascular and psychotropic agents		Section O
	Eating well	N/A	N/A
	Offered food meeting diet needs		K5e; K5f; K5h
	Receive preferred food/drink		K4
	Food	N/A	N/A
	Nutritional needs (Need for increased energy (food) delivery at breakfast (peak energy consumption) Need for optimal (no excess) intake Stimulation of food intake (in residents with low BMIs)		K4; K5e; K5f
	Maintain functional abilities (physical functions)	P1b; P3	
	Hygiene care		G1j
	Physical and mental health	N/A	N/A
Need to be in a homelike comforting environment	Personal identity (access to personal items and identifying material, e.g. clothes)	N/A	N/A
	Comfortable outdoor area	N/A	N/A
	Quiet space/calm env		P2d
	Personal belongings (item)	N/A	N/A
	Familiar environment (personalized spaces)		P2d
	Personalization of rooms		P2d
	Homelike environment/setting (continuation with past)		F3c
	Appropriate accommodation		P2d
	Comfortable environment	N/A	N/A
	Pleasant and fresh environment	N/A	N/A
	Increased space (unrestricted nature of environment)	N/A	N/A
	Increased variability among common spaces		P2d
	Limit complexity (simplicity)		P2d
Need to have pain managed	Physical comfort	O3	J2; Section O
	Pain relief	O3	J2; Section O
	Physical comfort at end-of-life	M5a; M5b; O3	J5c; Section O
	Symptom management	O3	Section O
	Comfort (decrease discomfort)	M5a; M5b; M5c; O3	Section O
	Pain relief	O3	J2; O4f
Sensory needs	Sensory stimulation	N/A	N/A
	Help with eyesight/hearing		C1; C2; C6; Section D
	Visual needs (need for proper eye care)		Section D
	Appropriate/controlled level of stimulation		P2d
	Understandable / controlled env – sensory comprehension		P1an

	Adequate temperature		P2 d
	Appropriate lighting		P2 d
Need for daily structured care	The need for structured and individualized activities		F1 (b)
	Need for specific dressing and undressing routine	N/A	N/A
	Regular visits by physicians	P7	
	Maintain normalcy – consistency of everyday life/familiar staff and surroundings		F3c
Functional needs – IADLs	Reduce physical disability (level of dependency)	P1b; P3	P1ar
	Assistance with household tasks, when needed	N/A	N/A
	Assistance with IADLs (functional health)	N/A	N/A
	Assistance with managing money	N/A	N/A
Need for knowledgeable staff	Professional monitoring of unpleasant effects of meds	J1	Section O; P1ae
	Need for proper staff care response to behavioural symptoms as a sign of unmet need	N/A	N/A
	Ongoing support with psychological distress		P1be
	Need for good communication with caregiver/ staff	C4	C6; F1a; N4k
	Competent, knowledgeable and experienced staff	N/A	N/A
	Well trained/educated staff	N/A	N/A
	Staff involvement in care planning	N/A	N/A
	Positive staff attitude (dementia-sensitive)	N/A	N/A
	Positive person work	N/A	N/A
	Good response to residents requests by physicians	N/A	N/A
Sexual needs	Intimate relationships	N/A	N/A
Need for privacy	Territoriality (privacy and freedom from unwanted physical intrusion)	E4	F2b; F2c
	Distinct spaces and activities for PWD (separation)		F1; N2; N3
	Privacy		F1; F2; N3
Money – financial issues	Financial situation (sufficient money to do what like)	N/A	N/A
	Money	N/A	N/A
Spiritual needs	Spiritual support		P1be
	Spirituality (religion)		F1e; F1f