Building Research Capacity for Examining The Impact of Developments on Quality of Life for Nursing Home Residents and their Families

Background Document

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1.0   Introduction

This document is intended to provide background information for participants of a workshop being held on June 18, 2009 organized by the Nova Scotia Centre on Aging, on the topic of building research capacity to examine the impact of developments on quality of life for nursing home residents and their families. It contains information on the rationale for the workshop, the objectives of the workshop, and a review of the literature on the topic.

2.0   Context for Workshop

The NS Department of Health is moving forward with its plans to increase long term care bed capacity in the province. Part of this development has included attention to physical design and staffing responsibilities for facilities approved for the new beds. One of the approved facilities is Northwoodcare Inc. in Halifax which is scheduled to open its new facility in the spring of 2010. Their 150-bed facility contains a new floor plan that features the "neighborhood design" (i.e., small self contained units of 10-12 residents) and staffing organized on resident relationships as opposed to hierarchical relationships. Each of these innovations has the potential to enhance the experiences of staff, residents and their families.

In May 2008, Northwood hosted a "research day" inviting researchers and decision makers to help build a program of research and to identify potential areas for collaboration. One of several areas of inquiry identified during that day was in what ways the new developments will impact the resident and his/her family. Dr. Janice Keefe, Director, Nova Scotia Centre on Aging, and Dr. Robin Stadnyk, School of Occupational Therapy, Dalhousie University obtained funding from MSVU to facilitate research in this area. Specifically, the immediate research funds are intended to foster and build an interdisciplinary research collaboration of academic researchers, practitioners and decision makers interested in examining resident quality of life and family involvement in long term care facilities. This will be achieved through identifying individuals with expertise and interest; synthesizing existing knowledge; identifying potential funding sources; and hosting a workshop with interested researchers, practitioners, and decision makers.

Specific objectives of the workshop are to:

- Identify potential topics/areas of interest for a funding proposal(s).
- Identify potential team for a funding proposal(s).
- Identify a framework and protocols for a funding proposal(s).

3.0 Literature Review

Over the past 15 years, long-term care facilities have altered their approaches to care, and are now acting from a resident-centred perspective (Calkins, 2002). This new approach emphasizes resident choice, autonomy and dignity, and encourages increased social interaction both among residents, and between residents and staff (Calkins, 2002; Rahman & Schnelle, 2008; Wiersma & Pedlar, 2008). Increased partnering between staff and families is also a goal (Baker & Steber, 2005). Contributing to this shift in philosophy are the changes taking place in how nursing home space is utilized and designed. This is believed to exert great influence over both resident quality of life and family involvement.

In order to develop an understanding of the existing literature, a search was conducted for both peer-reviewed and grey literature (see Appendix A for a complete list of included search terms). The included literature is both local and international, spans the last decade, and refers to individuals with varying levels of cognitive impairment. It is therefore important to note that discrepancies may exist regarding the language that is used to refer to facility (aged care home versus nursing home) and caregiver (caregiver versus carer). The primary scope of this paper, however, concerns nursing home care, and addresses how facility changes impact residents and their families. Section 3.1 discusses the latest trends in nursing home design and care approach, and provides examples. Section 3.2 introduces the various concepts that are found in the current literature, including quality of life, satisfaction, and quality of care for individuals with and without dementia (a list of the instruments used to measure the concepts is contained in Appendix D), and presents a discussion regarding the relationship between these three constructs. Section 3.3 provides a synthesis of current knowledge regarding the impact of changes in nursing home approach to care and physical design on residents and families (Appendix E). Section 3.4 highlights a few opportunities for further elaboration.

3.1   Latest Trends

Newly constructed long-term care facilities demonstrate a neighbourhood design, also known as clusters or pods (Boyd, 2003; Kane, 2001; Schwarz, Chaudhury, & Tofle, 2004). These typically serve between 20 and 40 residents, and allow individuals the privacy they desire, as they feature single rooms with private baths (Brush, Calkins, Kator, Wyatt, & Miller, 2008; Rabig, Thomas, Kane, Cutler, & McAlilly, 2006). They also often have large bay windows that bring the outdoors in for those who cannot go outside to enjoy it (Cioffi, Fleming, Wilkes, Sinfield, & Le Miere, 2007). Rooms are personalized with residents' meaningful possessions, and centrally located near nursing stations, lounges, and dining areas. In these environments, choice and interaction are of utmost importance. For example, residents have the freedom to decide when and what to eat, when to sleep and awaken, and how to fill their days (Komarek, 2004).

As previously stated, relationship formation is a key component of this new approach. Staff are being trained to work in multi-functional, empowered care teams, and perform many tasks for only a few residents (Boyd, 2003). Research comparing U.S. nursing

homes with and without such teams demonstrates that increased contact between certified nurse aide's (CNA) and a smaller number of residents occurs, which helps staff to learn and remember individuals' preferences, and to sensitively serve them. The small design also allows residents to get to know their neighbours, and they form more fulfilling friendships as a result (Kruschke, 2006; Yeatts & Cready, 2007).

3.1.1 Eden Alternative

A widely cited example of a program that has pioneered the above discussed approaches to care and changes in physical design is the Eden Alternative. Developed by Dr. William Thomas in 1992, the Eden Alternative aims to decrease resident loneliness, helplessness, and boredom (Tavormina, 1999). Since its inception, many organizations intending to improve quality of life for their residents have adopted key elements of the model. These include: relinquishing the institutional/medical approach to care; including pets, plants, and children in order to foster a more spontaneous and home-like environment; providing ample opportunity for social interaction and relationship formation; promoting resident choice and participation; and continually reassessing how residents' needs can be met (Tavormina, 1999; Thomas, 2003). The noted benefits of implementing such a model include decreases in behavioural incidents (defined as altercations between two or more residents) and use of restraints, as well as in staff absenteeism and turnover. A series of behavioural studies conducted before and after Eden implementation at Providence Mount St. Vincent, a large senior-living care facility in Seattle, also found increases in resident satisfaction and activity engagement (Boyd, 2003; Thomas, 2003). Qualitative interviews conducted at two other facilities in the United States revealed residents' beliefs that their lives had improved, and that the goals of alleviating resident loneliness, helplessness, and boredom had been achieved (Kruschke, 2006; Parsons, 2004)

3.1.2 Greenhousing

The latest illustration of Thomas' Eden Alternative is the Green House initiative (Thomas, 2003). These "small homes" feature even fewer residents, serving approximately seven to ten each. The aim is to promote individual growth and development, and foster excellent resident quality of life "under normal rather than therapeutic circumstances" (Kane, Lum, Cutler, Degenholtz, & Yu, 2007, p. 834). They feature a family-style open kitchen with a large dining table, and private rooms and baths around a central area (Rabig & Rabig, 2008). In these environments, staff, known as "shahbaz" (universal workers), are CNAs, and are responsible for cooking, cleaning, and laundry, as well as resident care (Kane et al., 2007; Rabig, Thomas, Kane, Cutler, & McAlilly, 2006).

Green House residents, as well as those living in two comparison sites, were interviewed in order to assess their quality of life in relation to 11 domains: physical comfort, functional competence, autonomy, dignity, privacy, individuality, meaningful activity, relationships, enjoyment, security, and spiritual well-being (Kane, 2001; Kane et al.,

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2003; Kane et al., 2007). Residents demonstrating a range of cognitive impairment[*] reported higher quality of life in seven domains (privacy, dignity, meaningful activity, relationship, autonomy, food enjoyment, and individuality) in comparison to one of the sites, and higher in four (privacy, dignity, autonomy, and food enjoyment) in relation to the other (Kane et al., 2007). Although the results differed in relation to the two comparison sites, Green House residents overall reported higher emotional well-being and were more satisfied with their living arrangements. They were also more likely to participate in organized activities on and off-site, and were less likely to be on bed rest or to be depressed.

3.2   Assessing Changes – Overview of Key Concepts

Evaluating the impact of such large-scale changes is a challenging, yet necessary task. With a shift in focus toward resident-centred care comes an increased demand for accountability. Research to date appears to contain three main constructs: quality of life, quality of care, and resident satisfaction. Research demonstrates that quality of life is largely subjective, and as a result, relates to residents' perceptions of key psychosocial domains. These may include feelings of being a meaningful contributor to one's family and community, perceptions regarding exertion of control and freedom of choice, as well as those relating to physical comfort and feelings of safety and security (Kane, 2001). Quality of care also incorporates many of the above-noted subjective components. Instruments assessing this concept, however, may uniquely include service- or facility-related domains, such as nursing and medical services, availability of help, staff-related factors, cleanliness, noise, facility milieu, and cost (Rantz et al., 1998; 1999; Sangl et al., 2007). Finally, resident satisfaction measures seem to demonstrate an equal item distribution relating to both subjective and objective components. Domains addressing room and home design, as well as those referring to social interaction and community life are included (Chou, Boldy, & Lee, 2001; 2002; 2003; Paulus & Jans, 2005) (see Appendix D for information on instruments and measures).

Although overlap exists, the way in which each construct is approached provides us with new and different information in terms of resident outcomes. Understanding which specific construct is being measured, and how, is of utmost importance if we are to learn how specific elements relating to physical design and approach to care affect individuals (Peters, 2004). It will also allow us to contextualize this knowledge within an already-existing base of literature.

3.2.1   Quality of Life

As quality of life is a subjective concept, resident self-report measures are considered to be the "gold standard" of assessment (Sangl et al., 2007, p.66). Matters are complicated however, in cases of dementia, when researchers must turn to a knowledgeable nurse or close family member for this information, which means accepting the limitations

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[*] Cognitive impairment was measured by the Minimum Data Set (MDS). Possible range of scores is 0-6, with a higher score indicating greater cognitive impairment. Mean MDS = 2.8 for participating Green House residents.

associated with using proxy sources (Kane et al., 2005; Robbins, 1999; Sangl et al., 2007). Other challenges include instrument design, sampling strategy, instrument validation, scoring and reporting, and inclusion of residents unable to self-report (Kane, 2003). The following will discuss instruments and methods used by researchers inquiring into this area.

In assessing resident quality of life, a number of approaches have been utilized. The leading researchers in this area, Rosalie and Robert Kane, have developed a measure that has been used and modified by many (Bishop et al., 2008; Degenholtz et al., 2006; Sangl et al., 2007). As they believe that quality of life is a multidimensional construct, their measure incorporates social and psychological outcomes (Kane et al., 2005). Through a literature review, seeking expert opinion, and conducting focus groups with key stakeholders, 11 domains relating to quality of life were identified (mentioned above). After testing their instrument with almost 2000 nursing home residents, the "individuality" domain was dropped, as it was found to be indistinguishable from that of "relationship." The resulting instrument is a 42-item interview that taps into ten domains of quality of life (Kane et al., 2003). Interviews are conducted with residents using Likert responses with those who are able to respond, and dichotomous answers with those who are not, as this promotes participation of residents with cognitive impairment (Degenholtz, Kane, Kane, Bershadsky, & Kling, 2006; Kane et al., 2003; 2004; 2005). Other noted strategies that improve ease of responding include using Yes," "No," or "Sometimes;" grouping items by response type; asking for ratings, as opposed to reports; and using the non-specific present (Sangl et al., 2007).

Other measures, including a General Quality of Life question (GEN-QOLQ), the Philadelphia Geriatric Center Morale Scale (PGCMS), the Positive and Negative Affect Scales (PANAS), the Depression List (DL), the Geriatric Depression Scale (GDS), the GIP-sad behaviour, and the MDS Depression Rating Scale (DRS), have been assessed in relation to residents with varying degrees of cognitive impairment (Gerritsen, Steverink, Ooms, de Vet, & Ribbe, 2007) (for a description of each, see Appendix D). Although the researchers conceptualized quality of life as relating to an individual's subjective well-being, many of the included scales were designed to assess depression. This may wrongly lead individuals to infer that those who are not depressed are experiencing a high quality of life, and appears to be a poor way of measuring a complex and multidimensional construct such as quality of life. As Kane (2001) states, "it is sadly narrow to define quality as the *absence* of negative outcomes" (p. 297).

The results from the above-discussed study demonstrated that individuals with varying levels of cognitive impairment were better suited for different scales. This has implications in terms of assessing quality of life in residents with dementia, as individuals may experience difficulty understanding questions, making comparisons, recalling events, and communicating (Ettema et al., 2007a). Some researchers have met these challenges by modifying already existing measures, or have developed their own. Questions in the Dartmouth Cooperative Functional Assessment Charts/World Organization of General Practitioners/Family Physicians (COOP/WONCA) charts were simplified, and found to be useful for 60% of people with dementia in participating

nursing homes (Ettema et al., 2007a). Later work led to the development of QUALIDEM, a dementia-specific quality of life questionnaire (Ettema, Dröes, de Lange, Mellenbergh, and Ribbe, 2007b; 2007c).

Dementia Care Mapping (DCM) has also been modified successfully. Typically in this approach, residents' well-being and activity engagement are recorded every five minutes over a period of six hours; however, this modified version involved assessing individuals in the hour before lunch. The results found the one-hour assessment to be significantly correlated with the total assessment period (Fossey, Lee, & Ballard, 2002). It has been suggested that this may facilitate a more widespread use of the tool (for a list of other measures that have been used to assess quality of life in individuals with and without dementia, see Appendix D).

3.2.2   *Quality of Care*

There are both overlapping and distinct components related to quality of life and quality of care assessment instruments. Demonstrating this point, is the work conducted by Sangl et al. (2007), in which ten domains related to nursing home care quality (nursing and medical services, safety and security, getting needed help from nursing home staff, interaction and communication with staff, food, dignity and respect, cleanliness, noise, activities, and overall ratings of care) were modified and merged with Kane et al.'s (2003) well known domains. This exercise revealed that many of the quality of care domains were in fact captured in the quality of life interview, including security, meaningful activity, relationships, and dignity.

Others interested in defining the many dimensions of nursing home care quality have found similar results. Individuals with a wide range of care provision experience (including nursing home administrators, social workers, physicians, and graduate nursing students, for a full list of participants, see *Rantz et al., 1998*) noted the following as important: including residents and their families as the *central focus* of the home; respectful *interactions* between attentive staff and residents; a calm, but active and friendly *milieu*; an *environment* that lacks odor, is personalized, clean, well-maintained, and includes good lighting and outdoor space; *individualized care*; knowledgeable and professional *staff*; and residents' feelings of *safety* and security. These domains appear to overlap with the following quality of life dimensions: relationships, physical comfort, individuality, and safety dimensions (Kane et al., 2003; Rantz et al., 1998).

Although this furthers our knowledge and understanding of what quality of care involves, the latter study did not include residents, who likely have a great deal to contribute in terms of the aspects most important to them. This was remedied in a later study in which focus groups were conducted with nursing home families *and* residents (Rantz et al., 1999). From these discussions, the following unique domains were noted as important: *family involvement*; good *communication* with residents and families; residents' feelings of being at *home*; and the quality of care reflecting the *cost* of the service. The above-cited research indicates that aside from quality of care's inclusion of facility-level domains, such as noise and cleanliness, quality of life and quality of care are perhaps not

as distinct as once thought. In further support of this view is the notion that long-term care facilities providing higher quality of care also promote higher quality of life (Kane et al., 2003). It may therefore be more beneficial to look at these constructs as interrelated and interconnected.

3.2.3   Resident Satisfaction

Resident quality of life measures incorporate items related to both quality of life and quality of care, and often equally so. This is likely a result of their equal influence on one's overall satisfaction. Common measures, such as the short-form Resident Satisfaction Questionnaire (RSQ), aptly demonstrate this. This measure is based on a six-factor resident satisfaction measurement model, and includes: room; home design and amenities; social interaction, including passing the time, social life and community connections; meals service, referring to variety, amount, and temperature; staff care, such as attitude, respect for resident privacy, and promptness; and involvement in decision making, and ability to discuss concerns (Chou et al., 2001). It can be seen that both quality of life and quality of care are represented equally. Quality of care is included in items relating to room, home design and amenities, meals service, and staff care. Quality of life is referenced in social interaction, staff care, and involvement.

Others who have investigated domains important to resident satisfaction have found similar results. Staff have been shown to emphasize the following: human contacts within the institution; relations outside the institution; accommodation of facilities, such as meals, rooms, and buildings; quality of care; activities; respect for the individual (privacy and freedom); and financial issues. Residents have similarly identified the following as important: quality meals; private, home-like rooms; quality of care; respect for privacy; and freedom. They have uniquely noted the importance of a friendly and family-oriented atmosphere; kind staff; quiet; a warm and welcome place; opportunities to be involved and helpful; and available help when necessary (Paulus & Jans, 2005). Other researchers have included the following: choice, activities, care and services, caregivers, administration, environment, laundry, and well-being or overall satisfaction (Robinson, Lucas, Castle, Lowe, & Crystal, 2004; Wheatley et al. 2007).

Research assessing the relationship between measures assessing quality of life (using Kane et al.'s (2003) measure) and those measuring overall satisfaction (four questions relating to satisfaction with facility services and programs, room and bathroom, physical setting, and likelihood of recommending facility to a friend) did find a significant correlation between the two, however in a way that indicates the two are related, but distinct. It has also been asserted that quality of care contributes to quality of life (Kane et al., 2003). This, as well as previously discussed research, indicates that although each construct is comprised of unique components, quality of life may be the overarching umbrella under which quality of care and resident satisfaction lie. It is therefore possible that researchers intending to achieve a broad understanding of quality of life, also referred to as resident well-being, should utilize or develop a measure that reflects this overlap and incorporates elements of all three concepts.

3.3   Assessing Changes

Great changes are accompanied by a need for evaluation. We must determine whether
these changes are positively affecting residents and their families, and more importantly
how. It is also important to acknowledge the difficulty associated with interpreting
evaluation study results. The changes taking place in long term care facilities are
multifaceted and interrelated. Changes in approach to care influence many facility
aspects, including staff approach, physical design, and a home's family and resident
involvement philosophy. Likewise, a change in physical design and utilization of space
can influence approach to care and resident and family experience. As such, it is difficult
to separate and determine the impact of such a wide range of influencing factors. The
nature of conducting field work further complicates this, as external, and potentially
confounding, variables cannot be controlled for. The following, however, attempts to
discuss the current literature for each of these areas of interest. Section 3.3.1 discusses
the impact of changes in approach to care on resident quality of life. Section 3.3.2
addresses how this is affected by physical design changes. The latter two sections
concern the impact of such changes on family involvement; section 3.3.3 speaks to
changes in approach to care, and 3.3.4 refers to physical changes. The following will
help to identify key gaps in the literature, and will highlight opportunities for future
research (for a list of literature relating to each topic, see Appendix E).

3.3.1   Impact of Changes in Approach to Care on Resident Quality of Life

Changes in approach to care are widespread across nursing home environments. They
may involve placing greater emphasis on resident choice, involvement, and
empowerment, and encourage resident-staff relationships. Research appears to consider
quality of life through two perspectives: the impact of staff on resident satisfaction and
quality of life, as well as the influence of family councils.

The Eden Alternative is an excellent example of how such changes are reflected in every
aspect of homes, and of the associated positive results (Kruschke, 2006; Parsons, 2004).
The New Vista Care Home in Burnaby, British Columbia is one such example. This
"Edenized" facility features five villages for residents with and without dementia, all of
whom enjoy private rooms. Residents have close contact with animals and children,
provide care for plants, animals, and each other, and offer input through a Resident
Council (New Vista Society, 2008). Results from a Client Satisfaction Survey
administered to residents, families, staff, and community partners, indicated that residents
appreciated being treated with dignity, respect, kindness, and care, and found staff to be
knowledgeable, competent, responsive, and available to talk to. They also felt that their
privacy was respected, and their independence encouraged (New Vista Society, 2005).

A key component of the new approach to care is staff organization. Staff are being
decentralized, empowered, and are working in teams in order to better meet the needs of
residents. Research also demonstrates the existing significant relationships between this
aspect of care facilities and resident quality of life and satisfaction. The first relationship
that emerges is between nursing assistants' job commitment and resident quality of life.

Across 18 Massachusetts nursing homes, residents on units with nursing assistants who had had higher levels of commitment were found to be more satisfied with their relationships with staff and demonstrate higher quality of life (Bishop et al., 2008). Nursing assistants demonstrated higher job commitment when they perceived that their supervisor showed them respect, was available to provide needed help, and worked with them to solve problems. These results exemplify how changes in care models affect individuals at all levels within a facility, including the residents. They also indicate that establishing conditions that foster job satisfaction and staff commitment will indirectly and positively influence resident quality of life (Boldy, Chou, & Lee, 2004).

Other research further highlights the important role of staff in resident well-being, as satisfaction with staff care has been found to exert a positive effect on all other dimensions of satisfaction (with room, home, social interaction, meals service, resident involvement) (Chou et al., 2002; 2003). Certified nurse aide (CNA) staffing has also been found to positively affect total resident satisfaction (Lucas et al., 2007). Other research corroborates this, as residents perceive staff as influencing environmental warmth, the equitable (or inequitable) ways in which residents are treated, place great importance on staff friendliness, and express care and concern for their professional caregivers (Campbell, 2003).

It is clear that staff are very important to residents. This is not entirely surprising as such individuals play a central role in almost every aspect of residents' nursing home experiences, and are the direct means through which changes in approach to care are delivered (Campbell, 2003; Chou et al., 2002). Other noted improvements associated with decentralization of staff include decreases in medication errors, and resident infection and falls, which likely also contribute to resident satisfaction overall, but likely more so from a facility perspective (Sudbury & Gnaedinger, 2007). It is also apparent, however, that more research is needed on the impact of other aspects involved in approach to care, as the majority of evaluative studies have focused on staff-related factors, such as their job commitment, or approach (team or individual).

Opportunities for choice and meaningful involvement have been identified by residents themselves as important to their quality of life and satisfaction, and may be facilitated through a number of avenues (Kane et al., 2003; Paulus & Jans, 2005; Train, Nurock, Manela, Kitchen, & Livingston, 2005; Wheatley et al., 2007). One such example is allowing residents to take part in discussions and to provide input regarding the care issues that affect them. Resident interviews have demonstrated that such opportunities promote residents' perceptions of self worth, and in turn, their feelings of empowerment (Campbell, 2003).

Another means through which resident involvement may be facilitated, is through family councils. These allow family members to act as correspondents and spokespersons for residents, and provide a direct way in which residents can voice their concerns and opinions, and participate in centre-level decision making. Research has demonstrated that residents in facilities with family councils are significantly more satisfied, which may be due to the fact that such homes are more likely to be resident-centred and open to

input (Lucas et al.,2007). Family councils are also appreciated by relatives, as they have been associated with higher ratings of facility satisfaction (further discussed in *3.3.3*).

Another resident-centred initiative that has been associated with positive outcomes is the Enriched Opportunities Programme, a project aimed at increasing well-being for residents with dementia in three specialist nursing homes in the United Kingdom. This project includes: specialist expertise, in which a Locksmith position is created to promote resident and staff well-being; individualized assessment and case work; resident activity and occupation; staff training in the areas of mental health awareness, person-centred approach, and communication; and management and leadership involvement (Brooker & Woolley, 2007). Evaluation through DCM, Dementia Quality of Life Instrument (D-QOL), Mini-Mental State Examination (MMSE), Cornell Scale for Depression in Dementia (CSD), Rating for Anxiety in Dementia (RAID), and the Bristol Activities of Daily Living Scale (BADLS) revealed that post-intervention, residents spent more time engaged in a wider range of activities, and that well-being improved regardless of level of dependency, diagnosis, or cognitive impairment. Significant decreases in resident depression were also observed (Brooker, Woolley, & Lee, 2007). The above-discussed studies demonstrate how crucial it is for facilities to provide adequate opportunities that facilitate and promote resident involvement.

3.3.2   *Impact of Changes in Physical Design on Resident Quality of Life*

Environment has been identified in much of the literature as one of the key domains in quality of life, quality of care, and resident satisfaction (Chou, 2001; Ettema et al., 2007b; Kane et al., 2003; Keating, 1998; Paulus & Jans, 2005; Rantz et al., 1998; 1999). It therefore comes as no surprise that changes in the physical design of nursing homes greatly influence well-being, regardless of which specific construct is being examined. It must be noted that the majority of the literature focuses on the impact of private rooms, as opposed to on the neighbourhood, or cluster, design.

Increasingly, homes are offering single rooms with bathrooms to residents, as the importance of allowing individuals to maintain their privacy and dignity while living in congregate housing, is understood. Research has found positive associations between private rooms and resident quality of life. Not only do they afford greater privacy, but individuals can make the space their own with art, pictures, and furniture, which residents appreciate and find empowering (Campbell, 2003; Keating, 1998; New Vista Society, 2008). Private rooms also appear to positively impact psychosocial factors, such as feelings of privacy and control. Literature reviews and focus groups with residents and staff regarding three types of rooms: traditional shared; enhanced shared, in which a dividing wall allows residents sharing a room to have a degree of privacy; and private, reveal that residents living in private rooms are more likely to experience better psychosocial outcomes than those sharing (Calkins & Cassella, 2007). The literature search revealed that adults prefer private rooms, as it affords them greater control over their surroundings. Related research from acute care settings also indicates patients' feelings that their visits with families are better and more frequent in single rooms (cited in Calkins & Cassella, 2007). Focus group participants came from three facilities, two of

which featured enhanced shared rooms. Results from this portion of the study further indicated residents' preference for privacy, although, it was noted that enhanced shared rooms were not seen as an invasion of this. Individuals saw this layout as a private room with a shared bathroom.

An Australian study, which investigated resident and staff perceptions following relocation from a traditional facility to a dementia-specific special care unit (SCU) reveal similar results (Cioffi et al., 2007). This unit featured private rooms and bathrooms, which could be personalized with decorations and pictures, a central kitchen and dining area, large bay windows, and an open garden. Informants overwhelmingly saw the change as positive. Three themes relating to family home, therapeutic environment, and work environment emerged from their discussions. Relatives and staff felt that the SCU had a pleasant milieu, and noted the benefits experienced by residents, including weight gain, decreased agitation, fewer disturbances, better sleep, and greater ease in activity participation. Families no longer felt guilty about leaving their relatives there, and were also more inclined to visit, as the environment was a more welcoming one. Staff also felt that they could provide better care, as accessibility to equipment in residents' rooms had been improved. Overall, it was also believed that quality of life had improved. Although this is a qualitative examination, the positive results experienced by residents, staff, and relatives demonstrate the influence of physical design changes. The influence of such a change on family factors, such as involvement, will be further discussed (see *3.3.4*). These results are not unique, and have been corroborated by others. For example, research assessing the impact of Eden implementation (which involves change in physical design, as well as in care approach) at a large American nursing home, Providence Mount St. Vincent, has been associated with improvements in resident quality of life (further discussed in 3.1.1) (Boyd, 2003). A Green House evaluation study found similar results, as residents reported higher overall emotional well-being and satisfaction with living arrangements than those in traditional facilities (further discussed in 3.1.2) (Kane et al., 2007).

Researchers assessing physical change have also utilized tools such as the Professional Environmental Assessment Protocol (PEAP), the Sheffield Care Environment Assessment Matrix (SCEAM), and Environmental checklists. Items contained with the PEAP address eight dimensions of environmental experience, including awareness and orientation; safety and security; privacy; regulation and quality of stimulation; functional abilities; opportunities for personal control; continuity of self; and facilitation of social contact. Through utilization of this measure and conducting focus groups with staff, it has been demonstrated that changes in environment, similar to those noted above, result in maximized awareness, orientation, privacy, social contact, and resident-staff interaction. The more home-like, and less institutional nature was also noted as positive (Schwarz et al., 2004).

The SCEAM assesses ten domains in three categories: universal, physical, and cognitive requirements (Parker et al., 2004). Universal requirements refer to privacy, ability to personalize surroundings, choice and control, and connection with the wider community. Physical requirements include safety and health, support for physical frailties, and

comfort. Finally, cognitive requirements involve support for cognitive frailties, awareness of the outside world, and normalness and authenticity, meaning that the environment is domestic, as opposed to institutional. This instrument has been used to assess how quality of life is related to nursing home size in England. Smaller homes were found to be related to higher quality of life in a number of areas, including choice and control, comfort, support for cognitive frailties, awareness of the outside world, and normalness and authenticity. Relationships between these particular domains and positive emotion (assessed by Affect Rating Scale ARS), well-being (assessed by DCM), and activity levels were also established. Interestingly, although larger facilities scored higher on the safety and health domains, this was determined to be related to lower scores in enjoyment of activities (assessed by Pleasant Event Schedule-AD PES-AD). Larger facilities also demonstrated low personalization, which is extremely important to residents (Campbell, 2003). These results further demonstrate the importance of embracing changes in physical design that advocate smaller, personalized, and private settings.

Although changes in nursing home physical design can positively impact resident quality of life, problems still exist. Environmental checklists (developed by Cutler, Kane, Degenholtz, Miller, & Grant, 2006) identified deficiencies in facilities, nursing units, and residents' room and bath environments in five states in the US. The following areas were noted to be problematic: lack of lounge space; overcrowded bathrooms; long distances between rooms, bathrooms, and other areas; hall clutter; and noise. Other issues included poor ventilation, low light, and inappropriate switches and storage areas. Due to the fact that such inadequacies can negatively affect the quality of life domains of dignity, privacy, comfort, security, and functional competence, it is crucial that researchers make concerted efforts to specifically assess these areas, and that recommendations for improvement are made.

Suggestions as to how such challenges can be ameliorated include using carpet to prevent falls, create a more home-like atmosphere, and reduce noise. Introducing electronic paging systems can also decrease noise, as well as installing quieter hardware, such as door latches. Light is important as many residents experience vision loss. Light allowing for high visibility, while avoiding glare is the most beneficial. Nursing home staff and visitors must also become cognizant of the negative effect perfumes and toxic fumes can have on residents (Noell, 1995).

3.3.3   *Impact of Changes in Approach to Care on Family Involvement*

Families' continued involvement in nursing homes is important to residents. Although research has shown that involvement does continue post-placement (Gaugler, 2005; Keefe & Fancey, 2000), a number of factors may influence their level of involvement and visit frequency. The impact of current approaches to care on family involvement in long-term care facilities, primarily in the form of visiting, must be investigated.

A well-cited example of a current care model that has been associated with improvements in resident quality of life is the Eden Alternative (Kruschke, 2006; Parsons, 2004).

Research has also demonstrated, however, that adopting such an approach may positively impact family involvement, as more "family-oriented" facilities are associated with greater family involvement. Relatives are observed to provide more help with activities of daily living (ADL) than in homes that are less so (Gaugler, Anderson, & Leach, 2003). Families surveyed with the Family Questionnaire (measure assesses families' perceptions regarding caregivers' skill and caring nature, quality of activities, environment, resident contentment, and their relationships with facility administration) pre- and post-Eden implementation revealed the improvements families saw. They perceived staff to be more respectful, and found the environment more conducive to visiting. Supporting these findings was the noted increase in daily visits, as well as in activity participation, such as gardening, walking home animals, and helping with special events. They also found that the presence of animals made it easier to bring children (Rosher & Robinson, 2005).

Although few studies have examined how an overall facility change impacts family involvement, many have explored associated outcomes of family involvement interventions. These initiatives allow families to provide input, learn about the facility, and establish relationships with staff. This is an area that requires attention, as an association between poor family-staff relationships and less frequent visiting has been found (Port, 2004). An intervention involving residents, relatives, and staff was implemented successfully in a dementia-specific nursing home in England. The researchers observed the home, sought staff and relative experiences through questionnaires, held off-site events where staff could discuss priorities for change, assembled a monthly action group involving relatives and various staff members, and held another off-site event in which progress was discussed. Interviews with staff and relatives revealed participants' positive perceptions of the intervention. This opportunity and others like it, allow families and staff to develop a better understanding of each other's perspective, experience improved communication, and establish trust, openness, and recognition (Aveyard & Davis, 2006; Dijkstra, 2007; Maas et al., 2004). This is particularly important as research indicates that families and staff hold different perceptions regarding each other's roles and responsibilities (Keating, 1998). Outcomes also reveal that participation in such groups allow both parties (residents and families) to feel more confident in their abilities to go forward with mutually agreed upon goals and initiatives. Residents are also indirectly positively affected, as the existence of family councils has been linked with improved resident input, and greater appreciation of their surroundings (Gaugler, 2006; Lucas et al., 2007).

Research has also demonstrated that families' participation in groups that allow them to ask questions and learn about routine procedures, as well as facilitate their understanding of residents' daily life, positively influence family involvement. Participation is related to families experiencing less guilt, finding visits more enjoyable, and being better able to relate to their relatives. It has also been noted that families find the groups to be a valuable form of social support (Peak, 2000).

Despite these encouraging outcomes, obstacles still exist. For example, families may be unsure of how influential their input really is. Although they participate in initiative development, they appear to lack confidence that their ideas will come to fruition. Other

challenges, such as including residents with cognitive impairments, finding time to attend meetings, and being frustrated with the lag between idea development and implementation, have also been noted (Aveyard & Davies, 2006; Dijkstra, 2007). Families may also hesitate, as they are unfamiliar with medical jargon, and may feel intimidated by medical staff (Dijkstra, 2007; Logue, 2003). Staff and family turnover may also disrupt meeting continuity, and decrease involvement (Persson, 2008). Facility-level obstacles such as staff resistance to institutional change, and inadequate availability of staff and space, may also contribute to a lack of enthusiasm surrounding family councils (Logue, 2003).

Tips that may help to ease the family council development process include clearly defining relevant issues; setting realistic goals and timelines; including those who are interested in the group's goals, as well as those who have the power to implement suggested changes; identifying obstacles; and keeping the ultimate goal of improving resident quality of life at the forefront (Persson, 2008).

The majority of research in this area has focused on the influence of family councils on their involvement. There is a need to further investigate other impacts of family involvement.

3.3.4   *Impact of Changes in Physical Design on Family Involvement*

There is a paucity of literature addressing the impact of changes in physical design on family involvement. For the most part, research has addressed family involvement in general, and may only touch on this specific aspect within a more broad overview.

Private rooms can increasingly be seen in nursing home facilities. They afford residents a more personalized and private environment, and reduce the institutional-like atmosphere that dominated facilities of the past. Although more research must be conducted in this area, preliminary results are encouraging as to the effect such designs have on not only residents, but on family involvement as well. Results from literature searches and focus groups alike have revealed that visitors also appreciate the increased privacy associated with single rooms, and both note that they help to facilitate more meaningful visits. Specifically, families have noted no longer experiencing the awkward feelings associated with being unable to avoid watching others' visits, especially during the "death or dying process" (Calkins & Cassella, 2002, p. 173). Staff also observe that more family members visit, stay longer, and use residents' private rooms more freely (Calkins & Cassella, 2002; Schwarz et al., 2004). This is likely due to the fact that residents find these environments more "home-like," and therefore more inviting (Cioffi et al., 2007). Others have noted that the presence of animals makes it easier to bring children (Rosher & Robinson, 2005). Research also demonstrates that residents and families may hold different interpretations of visiting space. Satisfaction surveys with residents and families involved with the New Vista Care Home in BC, indicate that residents are more satisfied with visitor space than families. Residents gave this aspect an A-, whereas families only gave it a B grade (New Vista Society, 2005). More research

is needed to determine how these different perspectives impact the ways in which families are involved.

3.4   Knowledge Gaps and Opportunities

This document has provided an overview of the current literature examining the impact of changes in approach to care and physical design from the perspective of residents and their families. It is clear from the literature that there are gaps in the knowledge and what does exist is primarily US based. Although there is knowledge to be gained from this review, there are important policy and practice distinctions between nursing home care in Canada and other jurisdictions that can influence quality of care and our assessment of it. With this in mind the following are a few potential areas for future work:

- Research addressing the impact of changes in approach on care on resident quality of life from the resident perspective, as much of the existing research has focused on the staff perspective.
- Research that considers the family perspective and what changes in approach to care means for them.
- Research that considers the family perspective and what changes in physical design and/or space utilization means for them.
- Research that involves a broader definition and understanding of family involvement and the changes that approach to care and physical design may have. It appears that family involvement is narrowly defined in terms of visit frequency and family council involvement.
- Research that considers changes in physical design other than through individualized rooms. It appears that while much attention is being given to different configurations of space (e.g., neighborhoods, clusters, pods, villages), there is little evidence to understand the effect of such changes on residents and their families.
- Research that includes all staff and service providers when considering changes in approach to care, not just direct personal/nursing care staff.
- Research that considers the relationship between changes in physical care and approach to care. There is likely to be an inherent change in approach to care if space is configured/utilized differently as opposed to an intentional/directed change in approach to care.

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Appendix A – Search Terms

- Physical environment and nursing home
- Physical design and nursing home
- Neighborhood and nursing home
- Neighborhood and nursing home and family
- Physical environment and nursing home and family
- Eden and nursing home and family
- Wellspring and nursing home and family
- Pod and nursing home
- Cluster and nursing home
- Cluster design and nursing home
- Physical environment and congregate living
- Physical environment and congregate housing
- Nursing home and physical environment and quality of life

- Nursing home and family presence
- Family and culture change and nursing home
- Nursing home and family participation and culture change (Limit: 1989-2009)
- Nursing home and family involvement and culture change (Limit: 1989-2009)
- Nursing home and family and culture change
- Nursing home and family participation
- Nursing home and family involvement

- Nursing home and resident-staff relationship
- Nursing home and family-staff relationship
- Nursing home and relationship and quality of life
- Nursing home and relationship and resident well being
- Nursing home and relationship and resident satisfaction

- Nursing home and quality of life and assessment
- Nursing home and quality of life and instrument
- Nursing home and quality of life and measure
- Philosophy of care and quality of life
- Philosophy of care and resident well being
- Philosophy of care and resident satisfaction and nursing home
- Person-centred and quality of life and nursing home
- Person-centred and outcomes and nursing home (Limit: 1989-2009)
- Person-centred and consequences and nursing home   (Limit: 1989-2009)
- Resident-centred and quality of life and nursing home
- Model of care and outcomes and nursing home
- Model of care and consequences and nursing home
- Model of care and quality of life and nursing home

- Organizational change and quality of life and nursing home
- Organizational change and quality of life and long-term care
- Innovations in care and nursing home and quality of life
- Culture movement and quality of life and nursing home

- Quality of care and long-term care
- Quality of care and nursing home
- Quality of care and quality of life and nursing home

- Long term care and family
- Long term care and family and physical design
- Nursing home and family and physical design
- Nursing home and relative(s) and physical design
- Nursing home and family and environment
- Nursing home and family and physical environment
- Long term care and relatives and physical environment
- Long term care and visiting and physical environment
- Long term care and visiting and physical design
- Nursing home and visiting and physical environment
- Nursing home and visiting and physical design
- Long term care and parent-child and physical design
- Nursing home and parent-child and physical design
- Nursing home and relationship and physical design
- Nursing home and interaction and physical design
- Nursing home and social and physical design
- Nursing home and social and physical environment and family
- Cooney, Teresa (AU)
- Train (AU)
- Gaugler (AU)

Google Scholar:
- Australia and aged care homes
- Australia and aged care homes and quality of life
- Australia and aged care homes and physical design and quality of life
- England and care of the aged and quality of life
- England and care of the aged and physical design and quality of life

Google:
- Gerontology Research Centre, Simon Fraser University
  - The Dr. Tong Louie Living Lab
- Centre for Healthy Aging
  - Design
  - Family
  - Quality

- Centre on Aging, University of Manitoba
  - Physical design
  - Environment
  - Family
  - Family involve
  - Family involvement
- Family involvement and nursing home
- Family involvement and nursing home and physical
- Involve families in nursing home
- Nursing home quality of life
- Alberta Centre on Aging
- Canadian Centre for Activity and Aging, University of Western Ontario
- Institute for Life Course and Aging, University of Toronto
- Centre on Aging, University of Victoria
- Centre on Aging and Health, University of Regina
- Health Studies and Gerontology, University of Waterloo
- McMaster Centre for Gerontological Studies
- National Initiative for the Care of the Elderly, University of Toronto

Appendix B - Databases

- AgeLine
- PsycArticles
- PsycInfo
- MedLine
- ProQuest

- Google Scholar
- Google

Background Information

Northwood is a private, not-for-profit long term care, homecare, independent living and community outreach organization with over 40 years of service in the Halifax Regional Municipality. 'Intouch', a personal emergency response program is offered province-wide.

Northwood welcomes research activity as one means to enhance its knowledge in pursuit of excellence in services for older adults and those at risk in the community. A 'Research Advisory Council' has been recently established to manage and monitor all research proposals and activities in the organization. New forms have been developed along with a 'Researcher's Handbook' to guide potential researchers through the procedure for presentation and approval of proposals. Criteria have been established to assess each proposal and guidelines are in place. All information can be accessed through the Northwood website at www.nwood.ns.ca ; click on 'Research' found on the right hand side of the opening page.

The Research Advisory Council has now begun to create a proactive research agenda to address specific questions arising in the organization, particularly related to the new Northwood facility currently under construction. This facility will reflect a new design and service delivery model, in keeping with the new direction of the Department of Health, Continuing Care Branch.

Many opportunities exist for research within this new framework, and are waiting to be explored. The following description will provide a snapshot view of the philosophy behind the new design, and allow for personal refection on opportunities for research in preparation for the Workshop.

Design Description – The New Northwood Continuing Care Centre

Northwood's New Continuing Care Centre, Bedford West, NS (Under Construction)
Northwood's new 150 bed Continuing Care Centre (CCC) is the first new Long Term Care facility to be designed in accordance with the Nova Scotia Department of Health's new Long Term Care Design and Program Requirements.

A Shift from the "Old Model"
At the centre of the DoH requirements is the shift from the "old" way of Nursing Unit design prevalent among nearly all Long Term Care Facilities designed in the last 30 years. The old model is based on a <u>medical therapeutic</u> approach to aging that prioritized treating and "caring" for symptoms and disabilities. The old method had nursing stations anchoring a unit or wing of 20 to 35 residents organized along a long corridor or "racetrack". Resident dining in the old model involved long-distance treks for marginally mobile residents down long corridors - and sometimes elevators - to a central dining facility. Staff in the old model were organized along hierarchical structures relating to discipline and task as opposed to resident relationships.

A New Approach to Resident Centered Living
The new Northwood CCC reflects the state of the art in Long Term Care Design and is based on clusters or households of no more than 12 residents each. This new model is based on a Resident-Centered <u>Living</u> approach that prioritizes relationships, living life to the fullest, and overcoming obstacles rather than treating them therapeutically. In each household are Living, Kitchen, Dining, Bathing, Activity, and Personal Laundry facilities within close proximity to resident rooms. Staff are structured so that some tasks are shared across disciplines, and as a result resident interactions are with fewer staff for longer periods of time. Other aspects including access to substantial outdoor space from each household, easy "back entrance" access for family and visitors to encourage visiting, reduced travel distances, larger private rooms, and emphasis on residential atmosphere are important design features.

The Opportunity for Research

Partnerships with the academic community are embraced by Northwood, as a means to promote applied research and knowledge translation opportunities for the mutual benefit of all. The workshop is intended to explore opportunities for collaboration with the academic community and the continuing care sector. Opportunity exists for a variety of research activities related to quality of life/satisfaction for residents, staff and families related to environmental design and service delivery; cost effectiveness, policy and standards implications within the new design.

Although Northwood has identified the new design as its focus for research proposals, it also welcomes other topics related to enhancement of the quality of life for all Northwood stakeholders.

Appendix D - Instruments

Construct	Name	Description	Reference
Quality of Life (QOL)	QOL interview	42-item self-report measure assessing 11 domains: physical comfort, functional competence, autonomy, dignity, privacy, individuality, meaningful activity, relationships, enjoyment, security, and spiritual well-being. Answers are 4-pt. likert or dichotomous.	Kane et al., 2003
	QOL interview – shortened	14-item measure assessing 7 domains: meaningful activities, enjoyment, security, privacy, relationships, individuality, and spiritual well-being.	Degenholtz et al., 2006
	General quality of life question (GEN-QOLQ)	Asks: 'Overall, how would you rate the quality of your life at the moment?' 1=bad, 2=moderate, 3=good, 4-very good, 5=excellent.	Gerritsen et al., 2007
	Philadelphia Geriatric Center Morale Scale (PGCMS)	Self-report scale consisting of 17 dichotomous items measuring life satisfaction. High score indicates high quality of life.	Lawton, 1975 (cited in Gerritsen et al., 2007)
	Positive and Negative Affect Scales (PANAS)	Each scale contains 10 items relating to positive (enthusiasm, interest, determination) and negative (fear, sadness, anxiety, hostility) feelings. 2-category response scale is used, scores are summed. 0=no positive/negative affects confirmed, 10=all positive/negative affects confirmed.	Watson, Clark, & Tellegen, 1988 (cited in Gerritsen et al., 2007)
	Depression List (DL)	Dutch self-report screening measure for depression consisting of 15 key words presented on cards, accompanied by a question (ex: Do you feel down?). Scores are summed, 0=no depressive complaints, 30=many depressive complaints.	Diesfeldt, 1997 (cited in Gerritsen et al., 2007)
	Geriatric Depression Scale (GDS)	Self-report screening measure for depression consisting of 30 dichotomous items. Scores are summed, 0= no depressive complaints, 30=many depressive complaints.	Brink et al., 1982 (cited in Gerritsen et al., 2007)

	Sad behavior observational scale (GIP-S)	A sub-scale of the Behavior Observation Scale for Geriatric Inpatients (GIP) used in the Netherlands. 6-item observation scale measuring behaviour of elderly people expressing sadness, unhappiness, and anxiety. Scores are summed, 0=no sad behaviour, 18=frequent sad behaviour.	Verstraten, 1988 (cited in Gerritsen et al., 2007)
	MDS Depression Rating Scale (DRS)	Based on items from Minimal Data Set (MDS). Observational scale consisting of 7 MDS items. Scores are summed, 0=no depressive behaviour, 14=frequent depressive behaviour.	Burrows et al., 2000 (cited in Gerritsen et al., 2007)
	Modified Dartmouth Cooperative Functional Assessment Charts/World Organization of General Practitioners/Family Physicians (COOP/WONCA) charts	Assesses functional status in following primary care domains: physical fitness, feelings, daily activities, social activities, pain, and overall health. Each chart consists of 1 statement printed on a separate sheet, followed by 5 response options, illustrated with drawings (ex: smiling or sad face). Higher scores indicate worse functional status.	Logsdon et al., 2002 (cited in Ettema et al., 2007a)
	QUALIDEM	37-item dementia-specific quality of life questionnaire assessing observable behaviour in following domains: care relationship, positive and negative affect, restless tense behavior, positive self image, social relations, social isolation, feeling at home, and having something to do. 4 response options: never, seldom, sometimes, often.	Ettema et al., 2007b; 2007c
	Modified Dementia Care Mapping (DCM)	Observer records behavioural indicators of well-being and activity engagement every 5 minutes of hour before lunch. Wellbeing is measured on an ordinal scale from +5 to -5 (+5=exceptional wellbeing with high levels of engagement, self expression and social interaction,+3=considerable wellbeing, interaction or initiation of social contact, +1=coping adequately with present situation, no signs of illbeing observable, -1=slight illbeing visible, for	Fossey et al., 2002

		example boredom, restlessness or frustration, -3=considerable illbeing, for example sadness, fear or sustained anger, -5=extremes of apathy, withdrawal, grief or despair). A mean well-being score, is derived from this data.	(Original measure – Kitwood & Bredin, 1992)
	Quality of Life in Dementia (QOL-D)	Assesses activity participation, and positive and negative affect. 15 items relating to activity participation. Residents rated for opportunity and engagement in the activity (frequently, occasionally, never). 6 items related to affect component (3-positive, 3-negative). Coded for frequency. 2 versions: care provider and resident.	Albert et al., 1996 (cited in Sloane et al., 2005)
	Quality of Life in Alzheimer's Disease (QOL-AD)	15-item measure assessing one's physical condition, mood, interpersonal relationships, ability to participate in meaningful activities, and financial situation. Each item is rated on a 4-point scale (1=poor, 4=excellent) and scores are summed. 2 versions: administered to care provider and person with Alzheimer's.	Logsdon et al., 2000 (cited in Sloane et al., 2005)
	Alzheimer's Disease Related Quality of Life (ADRQL)	47-time measure (completed by caregiver) assessing 5 domains: social interaction, awareness of self, feelings or mood, enjoyment of activities, response to surroundings. Scored as agree/disagree. Summary scores generated for each domain and for global quality of life.	Rabins et al., 2000 (cited in Sloane et al., 2005)
	Dementia Quality of Life (DQoL)	Self-report measure evaluating feeling states related to 5 domains: self-esteem, positive affect or humour, negative affects, feelings of belonging, and sense of aesthetics. Consists of 29 questions. Items ask how respondent has experienced the feeling, 1=never, 5=often.	Brod, Stewart, Sands, & Walton, 1999 (cited in Brooker, Woolley, & Lee, 2007; Sloane et al., 2005)

| | Resident and Staff Observation Checklist (RSOC-QoL) | Observatory measure using systematic nonparticipant observation are made every 5 minutes for 3 hours on the appearance, location, activity, behaviour, affect, restraint use, and interactions of residents. 3 measures of resident QOL are reported: agitation, physical contact, and engagement. | Sloane et al., 1991; 1998; Zimmerman et al., 2001

(cited in Sloane et al., 2005) |
|---|---|---|---|
| | Philadelphia Geriatric Center Affect Rating Scale (PGC-ARS)

(now known as Observed Emotion Rating Scale) | Observational measure assessing QOL by observing and noting facial expression, body movement, and other cues by which persons with dementia communicate. Observes 7 states every 5 minutes for 3 hours: mild pleasure, high pleasure, anger, anxiety or fear, sadness, general alertness, and sleeping or dozing. Affect states are coded. | Lawton, 1994; Lawton, Van Haitsma, & Klapper 1996

(cited in Sloane et al., 2005) |

Construct	Name	Description	Reference
Resident Satisfaction	Resident Satisfaction Questionnaire (RSQ)	Questionnaire addresses 10 dimensions of resident satisfaction: moving to home (settling in process), room, home, passing the time, social life, links with community, resident services, staff care, resident involvement, and other issues. Each item consists of either 3-point (1=no, 2=depends, 3=yes) or 4-point (1=poor, 2=fair, 3=good, 4=excellent) response.	Boldy & Grenade, 1998

(cited in Chou et al., 2001) |
| | Resident Satisfaction Questionnaire – short form (RSQ) | 24-item self-completed questionnaire addressing 6 factors of resident satisfaction: room, home, social interaction, meals service, staff care, and resident involvement. Each item consists of either 3-point (1=no, 2=depends, 3=yes) or 4-point (1=poor, 2=fair, 3=good, 4=excellent) response. | Chou et al., 2001

(cited in Chou et al., 2002; 2003) |

	Rutgers Satisfaction Assessment Tool – Nursing Home Residents (RSAT-NR20)	Consists of 18 general and 2 global items assessing five domains of nursing home care and life: environment, activities, caregiver/services, food, and personal well-being. Data collected through in-person interviews.	Lucas et al., 2002 (cited in Lucas et al., 2007)

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Appendix E - Literature Organizing Matrix

	Resident Quality of Life	**Family Involvement**
Physical Design	Boyd, 2003 Calkins & Cassella, 2007 Campbell, 2003 Cioffi et al., 2007 Cutler et al., 2006 Degenholtz et al., 2006b Kane et al., 2007 Noell, 1995 Parker et al., 2004 Schwarz, Chaudhury, & Tofle, 2004 Wiersma & Pedlar, 2008	Calkins & Cassella, 2002 Cioffi et al., 2007 Gaugler & Leach, 2003 Schwarz et al., 2004 Train, 2005
Approach to Care	Bishop et al., 2008 Boldy, Chou, & Lee, 2004 Brooker, Woolley, & Lee, 2007 Campbell, 2003 Chou, 2002; 2003 Kruschke, 2006 Lucas et al., 2007 Parsons, 2004 Paulus & Jans, 2005 Sudhury & Gnaedinger, 2007 Wheatley et al., 2007	*Aveyard & Davies, 2006 Rosher & Robinson, 2005 *Dijkstra, 2007 Vickery, 2002 Ejaz et al., 2002 Foley, 2004 Gaugler, 2003 Gaugler, Anderson, & Leach, 2003 Gaugler, 2005; 2006 Gaugler & Ewen, 2005 Keefe & Fancey, 2000 Logue, 2003 *Maas et al., 2004 *Peak, 2000 *Persson, 2008 Port, 2004 *family involvement interventions