The Long Term Care Ombudsman Program

Special Care Units
For Dementia:
A Survey of Connecticut Nursing Homes

SPONSORED BY THE OFFICE OF THE STATE LONG TERM CARE OMBUDSMAN
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Executive Summary

This study of Connecticut nursing homes was undertaken to provide an estimate of the prevalence of special care units or programs within these facilities that are operated for the purpose of delivering specialized dementia care services to residents. Special care units (SCUs) have become increasingly popular as vehicles for the delivery of dementia care. However, the precise meaning of the term *special care unit* has not been established in regulation or in practice – neither in Connecticut nor around the nation. The study was sponsored by the Connecticut Long Term Care Ombudsman Program.

Findings are based on a 55% response rate (n = 137) to a survey instrument administered to all licensed nursing homes in the state. Of these, nearly one third of the facilities report having either a dementia program or a special care unit for residents with dementia.

Special care units in Connecticut are predominantly characterized by an identifiable physical location within a facility; often newly constructed or renovated for the purpose of dementia care. However, about a quarter of these programs integrate the delivery of their special dementia care throughout the facility’s general population. Another distinguishing characteristic of these units is that almost universally the staff assigned to them is not rotated to other assignments within the facility. Turnover among these staff is also reported to be very low.

While some aspects of these SCUs did not appear to be “special” or distinct from programming in other areas of the facility program, nearly 90% of the respondents
identified therapeutic recreational programming – a key component of dementia care – as being different in the SCU than in the traditional LTC setting. Nearly half of the respondents also indicated the use of unique physical or architectural arrangements that were specific to the dementia care unit. Security and physical safety of residents was often enhanced through the use of locked access doors, controlled-access wander gardens, and wander guards (electronic bracelets or anklets to alert staff to a wandering resident).

Specialized training in dementia care may be the most significant hallmark of these dementia care programs. Over three-quarters of the respondents indicated that all staff assigned to work in the special care unit received dementia care training. An even larger proportion of these indicated that at least some of the staff not working in the SCU also received dementia care training. Remarkably, nearly two-thirds of these facilities indicated that all staff in the facility received dementia care training. This would appear to be a very strong commitment to training that has imbued these facilities organization-wide. In spite of this seeming commitment to training, approximately three-quarters indicated that there were no funds specifically ear-marked for training support. Instead, nursing homes appear to be relying heavily on outside resources including the Connecticut Alzheimer’s Association.

Consistent with the evolving use of special care units throughout the country, the practice in Connecticut nursing homes reflects a common thread even as it includes considerable diversity. Given the stage of evolution in which special care units currently exist, this is an appropriate balance. New procedures for effective care are developed, validated, and enter into common practice alongside new trial initiatives that serve as
experiments in cutting edge care. “Best practice” will continue to emerge from this evolution. Research must continue to document and evaluate these practices so that they might be incorporated into the standard of care for all residents experiencing a dementing illness.
While the term special care unit (SCU) is widely used in discussing programming and treatment options for nursing home residents with dementia, the term does not have a consistently defined meaning in Connecticut or in the nation. As a result, it is difficult to know precisely what is meant when the term is used by those offering services for the care of persons with dementia, or even how commonly the supposed services (SCUs) are offered. In order to begin to rectify these shortcomings, the Connecticut Long Term Care Ombudsman Program sponsored this study to document the prevalence of special care units (SCUs) as residential programs for the provision of services within Connecticut nursing homes. Beyond the enumeration of these programs, additional study objectives included 1) descriptions of both the facilities that provide special care units and the residents who are served by them, 2) specification of the range of security procedures used in special care units, 3) identification of care programming including the availability and scheduling of various therapeutic programming activities as well as specialized dementia care planning, 4) identification of training requirements and opportunities for staff training, and 5) descriptions of family support services offered and the opportunities for family involvement in caregiving. Finally, this study captured a wide range of descriptive data in order to document both the range of variability found within SCUs as well as the “typical” offering that might be found under this rubric.
Background and Literature Review

The professional literature was reviewed to identify the extant research concerning the roles and functions of SCUs for residents with dementia in contrast to programming and services for residents of traditional long-term care nursing homes. To that end, primary attention is given to research that highlights differences (or similarities) between these two placement types. No attempt is made to review the much larger literature relating to the myriad programs, interventions or treatments that are provided within these special care units as well as within nursing home programs more generally.

There is little question that the long-term care field has seen a substantial growth in the number of facilities offering special care units in the past 15 years. In 1987, 7.6% of nursing homes were estimated to have SCUs (Leon, Potter, & Cunningham, 1991). By 1991, the National Survey of Special Care Units in Nursing Homes reported that slightly less than 10% of all nursing homes offered special programs or units for dementia care (Leon, 1994). This number grew to 22% by 1996 with an annual growth rate of over 21% (Leon, Cheng, & Alvarez, 1997). Rapid growth has continued to date with expansion of the specialized care concept for dementia into the assisted living market. In spite of this remarkable growth, there is nothing approaching a standard definition of what constitutes a “special care unit” – although various typical service components can be identified (e.g., specialized staffing, environmental modifications, specialized programming, or physically distinct units) (Kovach, 1996). One effort toward standardization was identified – the state of Arkansas recently passed The Alzheimer’s Special Care Standards Act with the intention of defining these units and

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clarifying for consumers what might be expected from facilities offering SCUs for dementia care.

Comparisons Between Special Care Units in Traditional Long-Term Care Settings

Calkins (2001b) offers a review of the physical environments in special care units and reports several characteristics that have been consistently confirmed with empirical research over the past ten or 15 years. First, she notes that unit size has been determined to make a difference in quality of care. Smaller units (i.e., less than 30 residents) have been associated with more positive resident outcomes. Further, “home-like” environments appear to support positive resident attributes including less agitation, emotional well-being, and improved functioning. She also reports “modest evidence that noise has negative impacts on residents with dementia” (p 44). Yet, it seems that these environmental accommodations could be made available to residents with or without a “special care unit” designation.

At a descriptive level, a statewide study of long-term care settings in Minnesota (including 61 facilities with special care units) found that the presence of a special care unit was associated with an urban location, larger facilities, and a higher proportion of residents with moderate ADL dependencies among the residents in SCUs compared with the general nursing home population (Grant, Kane, Connor, Potthoff, & Stark, 1996). Notably, no relationship was found with the proportion of Medicaid residents or the for-profit status in the presence of an SCU. Beyond some indication that special care units exist to provide some uniquely "specialized" programming and service for residents with diagnosed dementias, there are no explicit standards that are applicable across-the-board in identifying these units. Wagner (1996) has suggested that the
primary hallmark of special care units is a "willingness to try various and individualized approaches to care." Additionally, she lists the presence of specialized staff training and programming along with a secure environment that includes adjustments to reduce confusion and frustration associated with dementia. With such a definition, there is considerable room for variation in specific practices employed in the growing number of special care units that exist.

Residents who are admitted to special care dementia units have been found to be quite similar to other residents in traditional long term care with respect to wandering, problem behaviors and Medicaid status (Riter & Fries, 1992). While Leon and Ory found differences at admission in the age and level of aggression among SCU residents, placement on the SCU had no effect on aggression when age and baseline levels of disruption were controlled (Leon & Ory, 1999). As indicated above, Grant and associates (1996) found lower ADL dependencies and higher levels of dementia among those admitted to dementia special care units. However, these differences at admission should be anticipated given the explicit admission criteria for special care units. The presence of dementia – at least in the early and moderate states – may well operate without a concomitant negative impact on ADL functioning, especially when contrasted with other traditional long-term care residents who may exhibit severe functional limitation in the absence of a diagnosed dementia (although it is well-recognized that dementia is common among all LTC residents).

One of the significant shortcomings in the published literature regarding special care units is that studies are most typically done in the context of a single special care unit. As a result, the unique characteristics that may exist in the selected unit will
manifest themselves in the findings with the inability to separate these distinct unit characteristics from patterns of care in special care units more generally. There have been repeated calls for multi-site and multi-state studies of special care units, but to date, these goals have been largely unrealized (Calkins, 2001b). Thus, the reader is cautioned against interpreting any individual study of special care units as offering a definitive statement on best practice. Indeed, as discussed below, a great number of conflicting findings can be found.

Outcomes in Literature

When research looks across multiple special care units, the findings tend to indicate very modest if any differences in resident outcomes between specialized care settings and traditional long-term care settings. In a study by Holmes and associates (1990), residents of the specialized care units at four facilities were found to be less alert, more likely to be unable to be aroused, unable to be fully assessed and, more generally, presenting behavioral disorders resulting in management problems. In addition, these residents appeared to be less physically frail than those in the traditional long-term care group. However, in contrast to findings reported by Grant and associates (1996), these special care unit residents had lower levels of ADL functioning – presumably as a result of their level of dementia. In spite of these differences in the resident populations, the study found neither significant negative effects nor benefits associated with placement in the special care unit (Holmes, Teresi, Weiner, Monaco, & Ronch, 1990). Similarly, Phillips and associates (Phillips et al., 1997) report finding no statistically significant relationship between residents of special care units and those in traditional long-term care settings with respect to the speed of their decline. These
findings were confirmed in a longitudinal study by Chafetz (1991) as well as in a nationally representative study of 106 SCUs (Leon & Ory, 1999).

Still, positive resident outcomes were identified by Volicer and colleagues (Volicer, Collard, Hurley, Bishop, & Kern, 1994). Their research found that residents in dementia special care units – who were similar to a comparison sample from a traditional long-term care unit on all measures at baseline – experienced lower discomfort, lower costs for medication, radiology and lab procedures, and were less often transferred to acute medical settings. However, the special care unit residents with lower severity dementia had a higher mortality rate than traditional long-term care residents. Even with these positive findings, the weight of the evidence seems to favor quite minimal resident benefits associated with placement on a special care unit.

In comparing the perceptions of family members with respect to quality of life in special care units contrasted to traditional long-term care settings, findings are mixed. Family members have been found to be significantly more positive with respect to both emotional and social functioning of their loved ones in special care units. A similar pattern among family members was found with regard to staffing ratios within special care units where more positive evaluations were associated with higher levels of staffing (Kutner, Mistretta, Barnhart, & Belodoff, 1999). In contrast to these findings, Tornatore and Grant (2004) utilized a stress process model to identify the contributors to family caregiver satisfaction. Among an extensive list of factors, the assignment of the care-receiving family member to a specialized care unit was considered. However, the results indicated that placement in a special care unit in and of itself did not influence family satisfaction.
Because special care dementia units evolve idiosyncratically, their unique qualities may operate to obscure the benefits that may exist. For instance, in studying 55 nursing homes located in five states, Gold and associates were able to identify eight distinct types of SCUs (Gold, Sloan, Mathew, Bledsoe, & Konanc, 1991). Until such variations are identified, measured and incorporated into statistical models, their presence makes it more difficult to confirm the true effects that an intervention like special care units may have. Only continued refinement in the standard of care and programming that one might expect within a special care unit along with ongoing research will help to clarify this issue.

Recognizing these existing differences among special care units, Teresi and associates (Teresi, Grant, Holmes, & Ory, 1998) reviewed the ten collaborative SCU studies funded by the National Institute on Aging in 1991. They offer several summary findings. First, as anticipated, there was a great deal of variability among the units with respect to staff and staff training. Second, many SCUs were found to have more dementia-oriented staffing practices including a higher level of training, less rotation of assignments and a higher staff ratio than non-special care units. None-the-less, their third observation was that approximately 25% of all so-called special care units provided few if any programmatic, architectural or staffing modifications. In virtually all cases, changes in specialized staff training and support were small. Finally, in spite of these disquieting findings, practices such as the permanent assignment of aides to residents were found to be beneficial for staff as well as residents.
Summary of Literature Review

While it is unquestioned that special care units have become dramatically more common on the long-term care scene and there is likely to be continued growth in the development of these units, the question has begun to be raised as to whether or not there truly is anything "special" about these units. To this end Holmes and Ramirez (2003) have proposed that rather than continued development of SCUs, it might be a more appropriate model of care for all long-term care facilities to simply emphasize quality and individualized care for all residents regardless of diagnoses. In part, the suggestion reflects the degree to which dementia has become common among all nursing home residents. Evidence suggests that over 70% of residents being admitted to long-term care facilities are demented (Berg et al., 1991).

Still in all, to the degree that a diagnosis of dementia can be used to characterize the unique care needs faced by some residents in contrast to others, the development and utilization of special care units is likely to continue for the foreseeable future. Further, these units provide the opportunity for implementing and testing a wide range of variation in dementia management. A considerable literature exists beyond the scope of the present study that evaluates a great many techniques and procedures such as the use of external memory aids (Nolan, Mathews, & Harrison, 2001), sustained activity periods (Kovach & Schlidt, 2001), grab bar placement (Sanford, 2002), intrusion and privacy (Cutler & Kane, 2002), staffing ratios (Reid & Chappell, 2003), psychosocial interventions (Van Haitsma & Ruckdeschel, 2001), and therapeutic activity (Kovach & Henschel, 1996). The value of SCUs as testing grounds for new programs and as opportunities for enhanced understanding may be especially important when one
recognizes that the basic dementia care knowledge of today was “cutting edge and radical” a decade or two ago (Calkins, 2001a). The combination of the opportunity for continued discovery, the often positive perception of SCUs by families and staff, and the potential for increased quality of care for residents with dementia all argues to support a continued effort to understand the appropriate role of special care dementia units in the long-term care continuum.

Methodology

Survey Administration

This study employed a survey methodology directed to the administrators of all licensed nursing homes (Rest Homes with Nursing Supervision and Chronic Care Nursing Homes) in Connecticut. Surveys were mailed to the entire population of 250 administrators of Connecticut’s long-term care facilities on June 8, 2004; a reminder post-card was mailed to all facilities on June 16th. On Thursday, June 24th, a final mailing was sent to all facilities from whom a response had not yet been received. Of the 250 surveys mailed, 137 were returned, representing a 54.8% response rate. Of the 137 returned surveys, 31.4% (n = 43) indicated a dementia program or special care unit; 68.6% (n = 94) indicated they had no such program. Because the purpose of this study was to describe those Connecticut LTC facilities that do offer specialized dementia care or dementia programming, the description and analysis offered here is based on the survey responses from facilities indicating such programming.

In the cover letter to administrators (See Appendix A), a provision was made that the administrator could delegate the completion of the survey to another member of the management staff. Of these 43 dementia program responses, 41 were completed by
individuals identified as Administrators or Directors (e.g., Directors of Nursing, Social Work, Admissions, Recreation, Dementia Care) within the facility and two were completed by individuals who identified themselves as “social workers” without indicating a management title.

The cover letter also provided assurances that participation in the survey was voluntary and that respondents could omit responding to any question to which they so chose. Assurances of respondent anonymity were given. A self-addressed stamped return envelope was provided for the respondent’s use. Finally, the cover letter explained that a coding number on the outside of the return envelope was used strictly for the purpose of removing the respondent’s name from the follow-up mailing list and would not be associated with the survey responses in any way.

To encourage respondent participation, a pledge of $5.00 to the Connecticut Alzheimer’s Association was made by the investigators for each completed survey returned. (A contribution of $685 has been made to the Alzheimer’s Association to fulfill this pledge.) In addition, the two Connecticut associations for nursing homes – Connecticut Association of Health Care Facilities and the Connecticut Association of Not for Profit Facilities for the Aged – also lent support to the study through distribution of an email notice encouraging their respective members to complete and return the survey instrument.

Final analysis of the data was conducted using SPSS 10.0

Qualitative Interviews

In order for a survey instrument to better reflect the current service environment in facility-based dementia care, a series of semi-structured qualitative interviews were
scheduled with both identified key informants as well as a small sample of facility administrators. Among the key informants were Meg Morelli, Executive Director of the Connecticut Association of Not-for-Profit Facilities for the Aged; Richard Brown, Director of Member Services of the Connecticut Association of Health Care Facilities; Alison King, North Central Connecticut Regional Planning Coordinator for the Connecticut Alzheimer’s Association; Gina Kastrup, director of an Alzheimer’s care unit at Riverside Health Care Center; and Nancy Leonard, Director of Social Work for Priority Care.

Beyond these key informants, nursing home representatives who were considered to be especially knowledgeable regarding facility-based dementia care were identified by the two major nursing home associations in Connecticut – Connecticut Association of Not-for-Profit Facilities for the Aged, and Connecticut Association of Health Care Facilities. Each of these associations identified two representatives who were willing to be interviewed in order to identify issue areas relevant to either the for-profit or not-for-profit service sectors. Although it was anticipated that such differences might arise, an analysis of these data did not indicate that differences were present.

A third important source for the identification of issue areas to be incorporated into the survey instrument was represented by the Connecticut Long Term Care Ombudsman Program Regional Ombudsmen. These individuals met on multiple occasions – first to offer initial input into the instrument development, and subsequently to review drafts of the instrument prior to finalization.
Data Collection Instrument

Based on the process outlined above, an instrument was developed to solicit feedback through a mailed survey. (See Appendix B) The instrument initially established whether or not the respondent represented a facility that had an identified “dementia program” or a “special care” unit for residents. If respondents indicated that they did not offer such services, they were requested to not complete further items on the instrument. If such services were offered, the respondent was requested to complete the remaining portion of the instrument. Thus, the data on which this report is made is drawn from those facility representatives who responded affirmatively to the inquiry regarding the presence of these specialized services.

The instrument included foci on a number of different aspects, or domains, of dementia care identified in the following section. Completion of the instrument took approximately 15 minutes.

Findings

Respondents were asked initially to provide very limited information about the facility including bed size, use of physical space, and room occupancy (See Survey Questions 1-4, 6). They were next questioned about several dimensions of their dementia program including the resident population, areas of specialization, safety and security, program philosophy, therapeutic programming including activities and scheduling, care planning, family support services, staffing and administration, staff training, and opportunities for professional affiliations related to dementia care. Results pertaining to each dimension are presented below.
Facility Characteristics

Bed size of each facility was broken down into numbers of beds by licensure category – Rest Home with Nursing Supervision (RHNS) and Chronic Care Nursing Home (CCNH) beds -- as well as the number of beds designated to the dementia program. Based on those reporting any RHNS beds (28%; n=12), the mean number of beds was 78 (range 2-334). Among those reporting CCNH beds (72%; n=31) the mean was 140 (range 60-345) beds. Twenty-six respondents (61%) reported a mean of 49 (range 20-120) dementia program beds. In comparing these averages to those computed from Department of Public Health data for all nursing homes, the respondents in this survey tended to have more CCNH beds (140 versus 124 beds) and substantially fewer RHNS beds (78 versus 141 beds). These differences almost certainly reflect the likelihood that specialized dementia care units (which were present in all of these respondents) are more likely to be present in the higher level of care (CCNH) facilities. Overall, 34 facilities provided information on either or both RHNS and CCNH beds. By combining the number of beds reported across these two categories, the mean bed size of facilities reporting was 155 (range 60-391).

The majority of facilities locate their dementia program within a clearly defined physical space (72%) while the remainder either integrate the program throughout the facility (26%) or, in one case, combine the two approaches (2%). Most facilities (65%) reported either new construction or renovations of the space designated for the dementia program although just over one third (n=15) indicated that an existing space within the facility was suitable for this use. Less than half (40%) indicated that unique physical or architectural arrangements were used by the facility to support dementia care. Of the
unique arrangements reported, the majority could be categorized as arrangements to 1) allow secure freedom (e.g., an enclosed patio or garden, a circular hallway or courtyard, other “wandering” spaces), 2) enhance aesthetics/reduce levels of stimulation (e.g., softened wallpaper, door murals, bright lighting, removal of clocks or public address systems from the unit), and 3) enhance overall security (e.g., installation of door locks, an alarm system, strong boxes). A smaller number of facilities identified more extensive arrangements including the installation of small activity centers throughout the facility and housing of the dining and recreation rooms on the dementia unit.

Most facilities report utilizing more than one room configuration (i.e., single, double, triple or greater occupancy) for residents. The great majority of facilities house utilize either single (77%) or double (98%) occupancy rooms; a small minority reported use of triple occupancy (12%) or larger (12%) rooms. As might be expected, triple occupancy and larger rooms are located in facilities with larger overall bed size. In over three-quarters of facilities (77%), residents also have access to solitary space in which to be alone, and this is most likely to be true in the largest facilities as well (100% in facilities with 200 or more beds).

Table 1: Facility Characteristics (based on facilities reporting RHNS or CCNH beds; n=34)

<table>
<thead>
<tr>
<th></th>
<th>Facilities with &lt; 100 beds (n=7)</th>
<th>Facilities w/ 100 – 199 beds (n=19)</th>
<th>Facilities with ≥ 200 beds (n=8)</th>
</tr>
</thead>
<tbody>
<tr>
<td>% Reporting RHNS beds</td>
<td>57</td>
<td>21</td>
<td>50</td>
</tr>
<tr>
<td>% Reporting CCNH beds</td>
<td>100</td>
<td>90</td>
<td>88</td>
</tr>
<tr>
<td>% Reporting Dementia beds</td>
<td>57</td>
<td>47</td>
<td>88</td>
</tr>
<tr>
<td>% Triple Occupancy or Larger rooms</td>
<td>0</td>
<td>18</td>
<td>12</td>
</tr>
<tr>
<td>% Access to solitary space</td>
<td>57</td>
<td>79</td>
<td>100</td>
</tr>
</tbody>
</table>
Resident Population

Information pertaining to the resident population included questions about new admissions, levels of care, and length of stay. Respondents were also asked if they either specialized in or wished to avoid the care of particular types of dementia patients. (See Survey Questions 5, 7-13, 15-16).

Admissions

Most new admissions into dementia programs come from either the community (27%) or from hospitals and other health centers (32%); less than one quarter are admitted from within the facility (19.5%) or as returning admissions from hospitals (2.4%). Nearly a fifth of respondents (19.5%) identified multiple sites as the primary source of dementia residents. In their assessment of new residents, a majority of facilities (73%) conduct at least some portion of the assessment process at the resident’s former living site.

The primary source of information used in making dementia program admissions decisions is the previous medical records of potential residents (91%). Assessment by an MD (77%), use of the facility’s own assessment instrument (70%), and assessment by a psychiatrist (58%) are the next most frequently cited sources of information. Just one-third of the facilities rely on the MDS (33%) and less than 10% use an MSQ (9.3%) in admissions decisions. Nurses (98%) and social workers (84%) are the staff most frequently included in the admissions assessment. Recreation (47%) and dietary (42%) staff are included in almost half of the facilities; CNAs are included in almost a third (28%). Other staff identified as involved in the assessment process
include administrators (17%), admissions personnel (17%), therapists such as PT/OT (12%), and other external or company evaluators (5%).

**Levels of Care**

Following admission to the dementia program, dementia residents are grouped by level of care needs in a majority of the facilities (61%) in this sample. In both grouped and ungrouped settings, respondents reported a broad range of physical and behavioral care levels required of their dementia program residents (see Table 2). For example, of the facilities reporting, 80% indicate that half or more of their residents require feeding assistance. However, the variance among these respondents is substantial. While 26% report less than one in ten of their residents would be described as “behaviorally heavy care,” 46% report this level of care is needed by half or more of their dementia residents. All but 3 facilities (93%) also provide end-stage care in their dementia programs, reporting that an average 10% (range 0 – 70%) of their residents were receiving end-stage care at the time of the survey.

**Table 2: Percentage of Facilities reporting Care Requirements of Dementia Residents**

<table>
<thead>
<tr>
<th>Percent of Dementia Program residents who:</th>
<th>NONE</th>
<th>&lt;10%</th>
<th>25%</th>
<th>50%</th>
<th>75%</th>
<th>100%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have Foley catheters, G-tubes, or IV’s</td>
<td>38</td>
<td>62</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Require feeding assistance</td>
<td>0</td>
<td>8</td>
<td>13</td>
<td>33</td>
<td>40</td>
<td>8</td>
</tr>
<tr>
<td>Have a mental illness diagnosis</td>
<td>18</td>
<td>44</td>
<td>21</td>
<td>13</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Would be described as medically “heavy care”</td>
<td>8</td>
<td>13</td>
<td>20</td>
<td>35</td>
<td>23</td>
<td>3</td>
</tr>
<tr>
<td>Would be described as behaviorally “heavy care”</td>
<td>3</td>
<td>23</td>
<td>28</td>
<td>8</td>
<td>231</td>
<td>8</td>
</tr>
</tbody>
</table>

* Totals may exceed 100% due to rounding
Length of Stay

Based on responses received, the average length of stay in a dementia program is 27.0 months. Responses ranged from 8 – 60 months with the most frequent response being 24 months.

Areas of Specialization

A minority of respondents indicated either an area of specialization or particular types of dementia they wished to avoid in their dementia program. Of those reporting a specialization (23%), most identified Alzheimer’s Disease or dementia secondary to a physical disorder (e.g., HIV, vascular); one facility identified “dementia with psychiatric history” as an area of specialization. A slightly larger proportion of respondents (30%) indicated a wish to avoid residents who displayed aggressive/violent behaviors (to self or others) or other disruptive behaviors, dementia secondary to alcoholism, and dementia secondary to specific physical disorders (e.g., TBI, Lewy bodies syndrome); two specified geri-psych and significant second degree psychiatric components as types of dementia that they sought to avoid.

Safety and Security

Questions related to resident safety and security focused exclusively on the ways facilities limited residents with dementia from uncontrolled wandering. (See Survey Questions 17-19.) Areas addressed included the use of locked units, use of “wander guards,” and the availability of secured outdoor areas. Of the 32 facilities that located their programs within a physically separate space, 23 reported locked units and the use of a keypad for exit and entry; 6 did not have locked units and 2 reported use of a swipe card or multiple lock types (e.g., traditional keyed lock, swipe card, key pad). Three of
the 11 facilities with “integrated” rather than separate dementia units also reported use of a key pad for security within their facilities. Use of “wander guards” was reported by 63% of all facilities and access to a secured outdoor area was reported by 67%.

Facilities without a separate unit and those with unlocked units were most likely to report use of “wander guards” – 82% and 83% respectively. Just 50% of those with a locked unit also used “wander guards.” Secured outdoor areas were most likely to be reported by facilities with no separate dementia unit (90%) as well as by facilities with locked units more generally (77%). Facilities without locked units typically tended not to have secure outdoor areas (83%).

**Program Philosophy**

Respondents were asked to indicate whether their dementia program was defined more by its physical space or by the organizational philosophy of the facility. In describing their overall approach to dementia care, respondents were asked if they followed a medical or social model (or a balance of both) and if they used either “validation therapy,” a “reality orientation” or both. (See Survey Questions 47-49). One half (56%) indicated that organizational philosophy rather than physical space defined the program; 36% indicated physical space, 8% indicated both. Seventy percent indicated they use a balance of medical and social models of care; 19% more closely follow a medical model, and 11% a social model. The most common approach to care combines the use of “validation therapy” and a “reality orientation” in 56% of the responding facilities; 28% use validation therapy alone, 3% use a “reality orientation” alone, and 13% (n=5) use neither approach. While validation therapy and a reality orientation are fundamentally at odds with one another, it is possible that programs
modify these approaches to dementia care, or use them differentially with different residents or in different situations.

**Therapeutic Programming**

Respondents were asked to provide detailed information about the variety, format, and scheduling of therapeutic recreation activities available to residents in their dementia programs (see Survey Questions 14, 20-29).

**Recreation Activities Available**

Virtually all programs provide a wide range of therapeutic recreation activities that are both different from therapeutic recreation activities offered in the rest of the facility (88%) and offered at different levels for different levels of dementia (93%). In addition to specific activities queried within the survey (See Table 3), several respondents identified a number of other programming options as well. Other recreational activities listed included pet therapy, intergenerational programming, exercise, outside entertainers, guided autobiography or reminiscing, humor therapy, skill games and a horticultural program*.

Table 3: Therapeutic Programming

<table>
<thead>
<tr>
<th>Type of program</th>
<th>Facilities that offer (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cooking</td>
<td>63</td>
</tr>
<tr>
<td>Reading</td>
<td>77</td>
</tr>
<tr>
<td>Singing/music</td>
<td>98</td>
</tr>
<tr>
<td>Craft Projects</td>
<td>95</td>
</tr>
<tr>
<td>Sensory Stimulation</td>
<td>95</td>
</tr>
<tr>
<td>Other</td>
<td>51*</td>
</tr>
<tr>
<td>Use of “memory queues”</td>
<td>68</td>
</tr>
<tr>
<td>Pets in the dementia program</td>
<td>76</td>
</tr>
</tbody>
</table>
Schedule and Format

On average, dementia care programs provide approximately 40 hours (M = 43.4 hrs; mode/median = 40 hrs) of scheduled therapeutic recreation per week. (One facility was an extreme outlier, reporting an impossible 430 hours per week; it was dropped when calculating the mean number of hours presented here.) Therapeutic recreation activities are scheduled for both groups and individuals; however, no facility reported using only individual therapeutic recreational activities. Indeed, virtually all (90%) responding facilities indicated utilizing both group and individual therapeutic activity programming and 10% indicated their use of only a group activity model.

Therapeutic recreation activities are most heavily scheduled from 9:00 – 11:00 a.m. and again between 1:00 and 5:00 p.m. although several facilities report activities scheduled during both earlier and later time slots (see Table 4). One facility makes available a CNA “activity closet” for use by residents who are awake during the night shift. Activities tend to be scheduled in a mix of small (5-15 minute) and large (30 + minutes) blocks of time by nearly two-thirds (63%) of the reporting facilities. However, approximately half that number (30%) scheduled all therapeutic recreation in the smaller five to 15 minute time blocks. A small proportion of the respondents (8%) scheduled all therapeutic recreation in blocks of time that were at least 30 minutes in length. Scheduling of other resident services (including dressing, eating, and bathing) is flexible in most dementia programs (88%).
Table 4: Scheduled Hours of Therapeutic Recreation

<table>
<thead>
<tr>
<th>Hours of Scheduled Therapeutic Recreation</th>
<th>Facilities with scheduled activities (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>7:00 – 9:00 a.m.</td>
<td>9</td>
</tr>
<tr>
<td>9:00 – 11:00 a.m.</td>
<td>84</td>
</tr>
<tr>
<td>11:00 – 1:00 p.m.</td>
<td>58</td>
</tr>
<tr>
<td>1:00 – 3:00 p.m.</td>
<td>81</td>
</tr>
<tr>
<td>3:00 – 5:00 p.m.</td>
<td>79</td>
</tr>
<tr>
<td>5:00 – 7:00 p.m.</td>
<td>56</td>
</tr>
<tr>
<td>7:00 – 9:00 p.m.</td>
<td>26</td>
</tr>
</tbody>
</table>

Care Planning

Two questions addressed care planning for residents with dementia (See Survey Questions 30-31). In response to whether or not the program had an explicit “progression of care” plan to parallel the progression of Alzheimer’s Disease, 28 (65%) said no, 13 (30%) said yes and 2 (5%) offered no response. When asked if care planning for dementia residents was done any differently or more frequently than for other residents, 31 (72%) indicated no, 10 (23%) said yes, and 2 (5%) did not respond. However, among those responding “no” to one or both questions, several provided written comments to indicate that care plans are modified if a change occurs and that care plans are individualized, based on the needs of the resident.

Family Support Services

A large majority of respondents (85%) indicated the availability of in-house services or support for families of residents in the dementia program. A smaller number (48%) indicated the availability of opportunities for family involvement that were unique to the dementia program (See Survey Questions 32-34). In both instances, the activities most often mentioned include family support groups, family councils, and family days; supportive counseling or liaison with a designated staff person; and
educational services such as access to a resource library, a newsletter, and various training events. Unique offerings included family involvement in bathing, dressing and feeding; family run activities or family nights; and volunteering. A slight majority (58%) of respondents indicated that someone on staff (primarily social workers, recreation directors, or program directors) in the facility had received Alzheimer’s Family Support Group training from the Connecticut Alzheimer’s Association.

**Staffing and Administration**

Just over half of the study respondents (58.5%) reported that staffing ratios in their dementia programs are different from those in other parts of the facility; (41.5%) reported no difference (See Survey Questions 35-39, 45-46, 50). Overall, the reported ratios of specific staff per 30 beds included an average of 4.7 (range 2 – 11) CNAs and 1.4 (range .5 – 4) LPN/RNs. Of the programs reporting social work and recreation staff, an average of .8 FTE social worker and 1.6 FTE recreational staff are assigned to dementia programs. In addition, some programs count among their dementia program staff (but do not include in the ratios reported above) a program director or supervisor, full-time volunteers, and a non-specific (“variable”) number of recreation staff. When comparing staffing ratios reported by those who saw the dementia program as “different from” versus “the same as” ratios in other parts of the facility, reported levels were not significantly different. Likewise, while larger facilities tended to report higher staff per bed ratios, differences across facilities of different sizes were not significant.

Typically, dementia program staff are regularly assigned to work in the dementia program (93%), rather than rotated among multiple units, and staff turnover in the dementia program is generally considered to be low (88%) or medium (10%).
Perhaps as a consequence of this stability, more than three quarters of study respondents report a limited use of pool staff in their dementia program – either never (28%) or less than weekly (48%). Fifteen percent of the respondents report using pool staff one or two shifts per week with just 10% indicating more frequent use.

In addition to inquiries about direct care staff, questions were asked about the qualifications and responsibilities of dementia program administrators. The majority of program administrators are identified as RN’s (43%) or Social Workers (29%); Recreation Therapists (14%) and LPNs (6%) are cited as well. The remaining respondents identified multiple individuals as sharing joint responsibility for program administration. Further, even when a single individual was identified as having responsibility for the dementia program, in 79% of the facilities represented in the study, the dementia program supervisor also has responsibilities other than those in the dementia program. While this may appear to dilute focused attention on dementia programming, in over three-quarters (82%) of the facilities represented there is a designated “point person” to champion the interests of the dementia care program within the organization.

*Staff training*

When asked to suggest a “best practice” tip for others seeking to provide quality dementia care, the most frequently offered advice related to the importance of staff training. Several questions within the survey addressed staff training – who received it, how much, and topics covered – as well as funding availability and training/certifications available or received from outside organizations (see Survey Questions 40-44). Overall, 77% of respondents indicated that all staff working in the
dementia program receive specialized training in dementia care for an average of 7.7 hours per year (range 1-36 hours/year). In addition, 84% reported that other staff (not assigned to the dementia program) also receives specialized training in dementia care. Somewhat surprisingly, 64% of the facilities with dementia care programming indicated that all other staff receives specialized training in dementia care.

Among those respondents who did not provide training to all staff in the dementia care unit (n = 10; 23%), training was examined further by specific staff roles only (e.g., CNA, RN, etc.) each year. The average number of training hours provided per year for facilities in which all SCU staff were trained is summarized in Table 5 along with training hours in facilities in which training was reported for specific task roles. Topics covered, and the depth of that coverage, is summarized in Table 6. Specific funding for dementia staff training is generally not available in most facilities (73%) although most facilities with dementia programs (74%) have made use of training available from outside organizations (e.g., Connecticut Alzheimer’s Association). Just over half of the facilities represented (54%) also report that a competency review related to dementia or certification in dementia care is used with staff in the facility.
Table 5: Training Hours by Staff Role

<table>
<thead>
<tr>
<th>Staff Role for which Training is Made Available:</th>
<th>Percent of Programs Reporting Availability of Specialized Training</th>
<th>Average # Hours of Training Provided per Year (Range)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Training provided to All Dementia Program Staff</td>
<td>77</td>
<td>7.7 (1 – 36 hours)</td>
</tr>
<tr>
<td>Training provided by specified staff role only:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CNA</td>
<td>50</td>
<td>10.8 (2 – 25 hours)</td>
</tr>
<tr>
<td>RN</td>
<td>50</td>
<td>9.0 (2 – 12 hours)</td>
</tr>
<tr>
<td>Recreation</td>
<td>50</td>
<td>16.0 (2 – 40 hours)</td>
</tr>
<tr>
<td>Social Work</td>
<td>40</td>
<td>7.3 (2 – 10 hours)</td>
</tr>
<tr>
<td>Dietary</td>
<td>30</td>
<td>3.0 (2 - 4 hours)</td>
</tr>
<tr>
<td>Housekeeping</td>
<td>50</td>
<td>5.8 (2 – 12 hours)</td>
</tr>
</tbody>
</table>

Table 6: Topical Coverage in Dementia Staff Training*

<table>
<thead>
<tr>
<th>Topic</th>
<th>Percent of Respondents Reporting Light, Moderate or Thorough Coverage of Topic in Training Provided</th>
</tr>
</thead>
<tbody>
<tr>
<td>General aging process</td>
<td>19 Lightly</td>
</tr>
<tr>
<td>Communication skills</td>
<td>6 Lightly</td>
</tr>
<tr>
<td>Understanding dementia behaviors</td>
<td>3 Lightly</td>
</tr>
<tr>
<td>Managing aggressive behavior</td>
<td>3 Lightly</td>
</tr>
<tr>
<td>Therapeutic recreation</td>
<td>19 Lightly</td>
</tr>
<tr>
<td>Dietary issues related to dementia</td>
<td>31 Lightly</td>
</tr>
<tr>
<td>Specialized care techniques</td>
<td>8 Lightly</td>
</tr>
<tr>
<td>Specialized dementia techniques</td>
<td>11 Lightly</td>
</tr>
</tbody>
</table>

* Totals may exceed 100% due to rounding

Opportunities for Professional Affiliations

Approximately 62% of these facilities with identified dementia programming indicated an affiliation with “dementia groups” such as Connecticut Alzheimer’s Association. In contrast, just 25% reported that their program had received any special certifications or accreditations related to dementia care. Those identified included
Summary: The “Typical” Dementia Program of Long-Term Care Facilities in Connecticut

Based on the responses from these 42 dementia care programs in Connecticut, a “typical” or modal program would be described as follows. The program is housed within a clearly defined physical space that has either been newly constructed or renovated for that purpose. Unique physical arrangements have been designed to both insure the safety and security of residents and to reduce undue stimulation. The unit is locked, requiring use of a keypad for exit and entry, and residents are also required to wear a “wander guard” for added security. Rooms are primarily double or single occupancy. Solitary space is available on the unit where residents can spend time alone; residents also have access to a secured area outdoors.

Prior to admission, new residents are assessed in-house and at the resident’s former living site, by a multidisciplinary team that relies primarily on previous medical records, evaluation by an MD, and the facility’s own assessment tools. Most residents will have a diagnosis of Alzheimer’s disease or dementia secondary to a physical disorder; individuals demonstrating aggressive behavior or diagnosed with a psychiatric disorder (including alcoholism) will be limited in options available for their care. A majority of residents will require feeding assistance and substantial numbers will require “heavy care” (medically and behaviorally) although few residents will require specific medical equipment (e.g., Foley catheters, G-tubes, IV’s).
In general, from these data it appears unlikely that care planning for dementia residents will differ from that available throughout the rest of the facility. Approximately 10% of residents will be receiving end-stage care at any given time. Residents will remain in the program approximately 26 months, on average.

The facility operates under a blend of both medical and social models of care and uses a combination of validation therapy and reality orientation in its approach to dementia residents. Therapeutic recreation in the dementia program differs from that in the rest of the facility and according to the different levels of dementia experienced by residents. A wide array of therapeutic recreational activities, offered in short (5-15 minute) and larger time blocks, are made available as group and individual activities, primarily between the hours of 9:00 – 11:00 a.m. and 1:00 – 5:00 p.m. Scheduling of dementia resident services - including dressing, eating and bathing – is flexible.

Services to families, particularly a family support group and access to educational materials about dementia, are provided by staff trained in the provision of Alzheimer family support groups.

Limitations

This study was based on a complete enumeration of Connecticut nursing homes. Although the response rate was very good (55%), there can never be guarantees that the facilities represented by those individuals who were willing to respond are representative of all facilities in the population. Further, it is possible that the number of respondents to the present survey who did not report having dementia care units was disproportionately higher than the number of respondents who did have special care units. This possibility is given more credence when it is recognized that the need to
complete the survey instrument (in contrast to simply indicating the lack of a special care unit and returning the survey instrument) would create some small disincentive to respond on the part of representatives of facilities offering specialized care. On the other hand, the opportunity to participate in a survey of this nature and highlight or showcase the specialized care being offered by a particular facility may create a countervailing influence. In the final analysis, as with any survey research, it cannot be said with absolute certainty that these findings are fully representative of the entire population of Connecticut nursing homes. However, utilizing a complete population (rather than a selected sample) and garnering a high response rate gives strong support to the credibility of these findings.

Conclusions

This research provides clear insights into the structure of SCUs in Connecticut nursing homes. While significant variability exists, there are also clear trends among these facilities.

Special care dementia programs in Connecticut generally appear to be offering a service package that has both differences from and similarities to the service package made available in the traditional nursing home setting. Seven out of eight (88%) of the special care programs responding to this survey indicated that they offer therapeutic recreational programming that is different from that offered in the rest of their facility. Further, over half (58%) indicated that their staffing ratios differed between the dementia program and the traditional nursing home program. However, when comparing reported staffing ratios of those who saw the dementia program as “different from” versus “the same as” ratios in other parts of the facility, reported levels were not
significantly different. Seventy-two percent of the respondents reported that care planning for residents in the dementia program was done neither more frequently nor differently than for other residents; and two-thirds reported that they did not have a “progression of care” plan that paralleled the progression of Alzheimer’s disease. Thus, while some differences do exist, other aspects of care may be equally common in both SCUs and traditional long-term care settings.

Special care units in Connecticut nursing homes also tend to be characterized by both the use of a physically defined space (in nearly three-quarters of the reporting facilities) as well as the use of new or renovated space for the dementia care program among two-thirds of the respondents. Further reflecting physical accommodations for dementia care, about 40 percent of the respondents incorporate unique physical or architectural arrangements that are specific to the special care unit. Physical security of facility grounds and residents varied widely, including at the highest level the use of locked buildings and yards coupled with the use of wander guards. Perhaps reflecting an attention to “bricks and mortar,” over one-third (36%) of the respondents indicated that their programs are more fully defined by their physical space than by any organizational philosophy. On the other hand, slightly over half reported that the organizational philosophy drives the dementia program. Of course, it is possible that there is a blending of these two dynamics with each informing the other over time.

Another point of such blending appears in the reported use of validation therapy and reality orientation. While over one in four (28%) report using validation therapy alone, over half (56%) report combining the two. Given that these two approaches are
necessarily at odds with one another, one must assume that this “blending” occurs across
different residents or otherwise distinct circumstances (e.g., dementia stage).

Specialized training in dementia care appears to be a distinguishing feature of
Connecticut special care units. When asked to provide a “best practice” tip for others
seeking to provide quality dementia care, the most frequently offered advice related to
the importance of staff training. The respondents in this survey appeared to “practice
what they preach” with regard to training. Over three-quarters reported that all staff
working in dementia care received specialized dementia care training for an average of
nearly eight hours annually. Beyond these staff, 84% of the facilities reported that at
least some other staff also received dementia care training and 64% of these programs
offering specialized dementia care indicated that all facility staff – not just those in the
dementia program – received dementia care training. Unfortunately, specific funding for
dementia training is not made available in most facilities (73%); however, outside
training opportunities were being utilized by a similar proportion of respondents. Staff
in over half of the respondent facilities had made use of the Alzheimer’s Family
Support Group training offered by the Connecticut Alzheimer’s Association. All of
these activities suggest a significant commitment to both training and resident care by
these facilities.

Training is a recognized way of showing commitment to staff. As such, staff
training may, in part, contribute to the very low levels of staff turnover in these
programs. Nearly nine in ten facilities reported staff turnover as being low. Similarly,
over nine in ten reported that dementia program staff are regularly assigned to their
units rather than being rotated within the larger facility. This stability was logically coupled with a very low reliance on “pool” staff within the SCU.

Virtually all (93%) of these respondents report providing end-stage care for residents in their dementia care unit. While this is laudable from the perspective of avoiding relocating residents, the degree to which end-stage dementia care and end-of-life care more generally are parallel processes raises a concern that this specialized dementia care may function as substitute hospice care. Further, when residents are receiving end-stage care, their potential for taking advantage of much of the specialized programming that makes special care units special is extremely limited. Clearly, a completely different picture emerges in a facility that has one or two residents receiving end-stage care, in contrast to a situation in which a more significant number of residents are doing so.

In conclusion, special care units in Connecticut nursing homes appear to be operating similarly to the general description that is available in the national literature. As in the nation, Connecticut SCUs share many similarities even as they reflect a range of programmatic and structural differences. The conflicting findings reported in the professional literature can be found embodied in Connecticut programs as well. This should not be disturbing. While much has come to be known about dementia care in the past decade or two, the multiple disciplines that come together to provide quality care are still exploring and identifying the features of care that most consistently produce the highest quality resident results. The Connecticut SCUs that participated in this study appear to be actively engaged in this evolving process.
June 8, 2004

Dear ___________:  

We are writing to ask you to do a favor for us. We need your feedback.

We are conducting an important survey of nursing home administrators in the state of Connecticut. The purpose of this survey is to provide an accurate description of the varied forms that “dementia units” and “dementia programs” take within our state. Regardless the particular form that your program may take – or even if you do not have a specialized program within your facility – your response is important to us. Your answers, along with those of others in this sample, will enable us to better understand the many forms that dementia care may take.

In the process of developing this questionnaire, we received support from a number of people and organizations including the Connecticut Association of Health Care Facilities, the Connecticut Association of Not for Profit Facilities for the Aged, and the Connecticut Alzheimer’s Association. We are asking you to take about ten minutes to complete the enclosed survey. It is not difficult and you may find it interesting. Of course, all of your answers will be anonymous. If you feel that some other member of your management staff would be better suited to respond to the survey, please feel free to ask that person to promptly respond. When the survey is finished, please return it in the stamped return envelope that is provided. A number has been placed on the return envelope so that we can remove your name from the list for follow-up mailings after we receive your response.

All nursing home administrators in the state are being invited to participate in this survey. Your participation in this study is, of course, voluntary. However, your answers are very important to the accuracy of the study, so we hope that you will be willing to respond promptly. If you find a question that you don’t want to answer, feel free to skip it and go on with the rest of the survey.

In an effort to say “thank you” for your willingness to complete the survey, we will make a $5.00 contribution to the Connecticut Alzheimer’s Association for each survey that is returned. We appreciate your support in completing the survey and returning it to us.

Respectfully,

Waldo C. Klein, Ph.D., MSW
Principal Investigator

Cheryl Parks, Ph.D., MSW
Co-Principal Investigator
Appendix B -- Data Collection Instrument
Dementia Programming and Care
In
Connecticut Long-term Care Facilities

A study funded by the
Connecticut Long Term Care
Ombudsman Program
Teresa Cusano, M.S.W.
State Long Term Care Ombudsman

Waldo C. Klein, Ph.D.
Principle Investigator

Cheryl Parks, Ph.D.
Co-principle Investigator
Connecticut Nursing Home Dementia Programming Study

1. Do you have a “dementia program” or a “special care” unit for residents with dementia in your facility?

IF SO:
   _____ How many licensed RHNS beds are in your facility?
   _____ How many CCNH beds are in your facility?
   _____ How many beds are in your dementia program?

IF YOU DO NOT HAVE A DEMENTIA PROGRAM OR A SPECIAL CARE UNIT, YOU HAVE FINISHED THIS QUESTIONNAIRE. THANK YOU IN ADVANCE FOR RETURNING IT IN THE STAMPED ENVELOPE PROVIDED.

2. Is a clearly defined physical space set-aside for your dementia care program or is your program integrated throughout your facility?

   [ ] clearly defined physical space
   [ ] integrated throughout the facility

   If it is located in a defined physical space, is your dementia unit in space that has been:
   [ ] renovated/remodeled for this purpose?
   [ ] newly constructed?
   [ ] The existing space was appropriate for this use.

3. Have unique physical/architectural arrangements been utilized in your facility to support dementia care? (e.g., "circular" hallways, special lighting, etc.)

   [ ] no
   [ ] yes (please indicate: ________________________________________________)

4. How many residents occupy your rooms? (check all that apply)

   [ ] single occupancy
   [ ] double occupancy
   [ ] triple occupancy
   [ ] four or more residents in a room

5. Are the residents in your dementia program grouped within the program by their level of care needs?

   [ ] no
   [ ] yes

6. Do residents in your dementia program have access to solitary space to be alone?

   [ ] no
   [ ] yes

We are interested in understanding about the resident population in your dementia program.

7. Which of the following do you utilize in making an admissions decision for placement in your dementia program? [check all that apply]

   [ ] Previous medical records?
   [ ] Assessment by an M.D.?
   [ ] Assessment by a psychiatrist?
   [ ] Your own established assessment tool?
   [ ] The MDS assessment?
   [ ] a MSQ? (specify: ____________________________)

8. Is any portion of your assessment process conducted at the resident’s former living site (e.g., a community residence, a hospital, elsewhere in the facility, etc.)?

   [ ] no
   [ ] yes
Appendix B – Data Collection Instrument

9. What staff are involved in the admissions assessment? [Check all that apply.]
   - [□] CNAs.
   - [□] Dietary.
   - [□] Nurses.
   - [□] Recreation
   - [□] Social workers.
   - [□] Other (please specify _________________________________)

10. From where do the majority of residents in your dementia program come?
   - [□] New admissions from the community.
   - [□] New admissions from hospitals or other health centers.
   - [□] Returning admissions from hospitals or other health centers.
   - [□] From within your own facility.

11. Approximately what percentage of the residents in your dementia program:

<table>
<thead>
<tr>
<th>Question</th>
<th>NONE</th>
<th>&lt;10%</th>
<th>25%</th>
<th>50%</th>
<th>75%</th>
<th>100%</th>
</tr>
</thead>
<tbody>
<tr>
<td>have Foley catheters, G-tubes or IVs?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>require feeding assistance?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>have mental illness diagnoses?</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>would be described as medically &quot;heavy care?&quot;</td>
<td></td>
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<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>would be described as behaviorally &quot;heavy care?&quot;</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

12. Do you provide for end-stage care in your dementia program?
   - [□] no
   - [□] yes
   - If so, approximately what proportion of your dementia program residents are receiving end-stage care? ______% 

13. Approximately how long do residents remain in your dementia program on average? ________ MONTHS

14. Approximately what percentage of time do residents spend in their own rooms each day? ________% 

15. Do you specialize with particular types of dementia? If so, please identify them.
   __________
   __________

16. Are there particular types of dementia you would wish to avoid? If so, please identify them.
   __________
   __________
   __________

   We are interested in understanding the ways that facilities limit residents with dementia from uncontrolled wandering.

17. Is your dementia unit locked or unlocked? If locked, do you open it with a keypad, a swipe card, or a traditionally keyed lock?
   - [□] unlocked
   - [□] locked with a key pad
   - [□] locked with a traditional keyed lock
   - [□] locked with a swipe card
   - [□] We do NOT have a separate physical unit.
Appendix B – Data Collection Instrument

18. Do you use "wander guard" bracelets or any similar technology?
   □ no   □ yes

19. Are residents able to access a wandering garden or some other secured outdoor area?
   □ no   □ yes

We are seeking to learn more about the different approaches to programming for residents in dementia programs.

20. Is there a flexible schedule for residents services including dressing, eating and bathing?
   □ no   □ yes

21. What kind of recreational programming is offered on your dementia program?
   □ Cooking   □ Craft projects
   □ Reading   □ Sensory stimulation
   □ Singing/music   □ Other (specify: _____________________________)

22. Does therapeutic recreation in your dementia program differ from that in the rest of the facility?
   □ no   □ yes

23. About how much therapeutic recreation is scheduled in your dementia program? _____ HOURS/WEEK

24. Are there different levels of therapeutic recreation planned for different levels of dementia?
   □ no   □ yes

25. Does therapeutic recreation in your dementia program tend to be planned for groups of residents or individual residents?
   □ groups   □ individuals   □ both

26. Does therapeutic recreation in your dementia program tend to be scheduled in larger blocks of time (i.e., 30 minutes or more) or smaller blocks of time (i.e., 5-15 minute blocks).
   □ larger blocks of time   □ smaller blocks of time   □ both

27. During what times do you have therapeutic recreation scheduled in your dementia program? [Check all that apply.]
   □ 7:00-9:00 am   □ 3:00-5:00 pm
   □ 9:00-11:00 am   □ 5:00-7:00 pm
   □ 11:00 am – 1:00 pm   □ 7:00-9:00 pm
   □ 1:00 – 3:00 pm   □ Other (specify: _____________________________)

28. Do you use memory queues and "way finding" markers in your dementia program?
   □ no   □ yes

29. Do you have pets in your dementia program?
   □ no   □ yes
We are interested in knowing about care planning for residents with dementia.

30. Does your dementia program have any explicit "progression of care" plan to parallel the progression of Alzheimer's disease?
   □ no  □ yes

31. For residents in your dementia program, is care planning done any differently or frequently than for other residents?
   □ no  □ yes

Although families are not direct service recipients for your facility, we are interested in supports that might be available for them.

32. Do you offer in-house services or support for families of residents in your dementia program?
   □ no  □ yes (specify: ________________________________________________________)

33. Are there opportunities for family involvement that are unique to the dementia program?
   □ no  □ yes (specify: ________________________________________________________)

34. Has anyone on your staff attended the Alzheimer's Family Support Group training from the Connecticut Alzheimer's Association?
   □ no  □ yes (specify position: __________________________________________________)

We are interested in knowing about the ways that dementia programs are staffed.

35. What are the approximate staffing ratios posted in your dementia program for the following positions?
   CNAs ______ per 30 beds
   LPNs/RNs ______ per 30 beds
   Social Work ______ (full time equivalents assigned to the dementia program)
   Recreation ______ (full time equivalents assigned to the dementia program)
   Other (please specify) _____________________________________________________

36. Do the staffing ratios in your dementia program differ from those in the rest of your facility?
   □ no  □ yes

37. How frequently do you use “pool” staff in your dementia program?
   □ several times a week or more
   □ one or two shifts a week
   □ less than weekly

38. Are the staff on your dementia program regularly assigned to work in that program or do they rotate among other units in the facility?
   □ regularly assigned to the dementia program
   □ rotate among multiple units
39. How would you describe the level of the staff turnover in your dementia program?
   - high
   - medium
   - low

We are interested in knowing about the training in dementia care that may be available to staff.

40. Do staff working in your dementia program receive specialized training in Alzheimer's care? If yes, which staff are involved? (Please omit if there is no specialized training.)
   - all staff are involved. Approximately ______ hours of training/year.
   - CNAs. Approximately ______ hours of training/year.
   - RNs. Approximately ______ hours of training/year.
   - Recreation. Approximately ______ hours of training/year.
   - Social Work. Approximately ______ hours of training/year.
   - Dietary. Approximately ______ hours of training/year.
   - Housekeeping. Approximately ______ hours of training/year.

If yes, please indicate how thoroughly each of the following topic areas is covered by placing a number on the line preceding each topic.

1 = lightly covered
2 = moderately covered
3 = thoroughly covered

   _____ the general aging process
   _____ communication skills with dementia
   _____ understanding dementia behaviors
   _____ managing aggressive behavior
   _____ therapeutic recreation
   _____ dietary issues related to dementia
   _____ specialized care techniques
   _____ specialized dementia techniques (e.g., validation or redirection)

41. Do other staff (not assigned to your dementia program) receive specialized training in dementia care?
   - no
   - yes If yes, which staff are involved?
       - All staff are involved.
       - CNAs
       - RNs
       - Recreation
       - Social Work
       - Dietary
       - Housekeeping
       - Other (specify: ____________________________)

42. Is there specific funding available in your budget for dementia staff training?
   - no
   - yes

43. Has anyone on the staff participated in training by the Connecticut Alzheimer's Association or other "outside" organization? (e.g., "Partners in Caring," "Activities Based Alzheimer's Care," etc.)
   - no
   - yes
44. Is any kind of regular competency review related to dementia or certification in dementia care used with staff in your facility?  
☐ no  ☐ yes

Program administration

45. What are the qualifications of your dementia program administrator?  
☐ RN  ☐ Social Worker  ☐ Other (specify: __________________)  
☐ LPN  ☐ Recreation Therapist

46. Does your dementia program administrator have responsibilities other than those in the dementia program?  
☐ no  ☐ yes

We’d like to ask a few questions about dementia care at your facility in general.

47. Would you say you more closely follow a "medical model" or a "social model" of care?  
☐ medical model  ☐ social model  ☐ balance of both

48. Do you actively employ "validation therapy" or "reality orientation" in your approach to dementia care?  
☐ validation therapy  ☐ neither of these approaches  
☐ reality orientation  ☐ both of these approaches

49. Is your dementia program defined more by its physical space or by the organizational philosophy?  
☐ by its physical space  ☐ by the organizational philosophy

50. Do you have an identified "point person" or "go to" person to champion the interests of the dementia care program within the organization? If so, what is that person’s position?  
☐ no  ☐ yes (specify: ______________________________________)

We are also interested in opportunities for professional ties related to dementia care.

51. Is your facility affiliated with any "dementia groups" like the Connecticut Alzheimer's group or other national groups?  
☐ no  ☐ yes (specify: ________________________________________________)

52. Has your program received any special certifications or accreditations related to dementia care?  
☐ no  ☐ yes (specify: ________________________________________________)

53. What is your position within the facility?  
☐ Administrator  ☐ Director of Admissionis  
☐ Director of Nursing  ☐ Other (specify: __________________________)  
☐ Director of Social Work

54. Can you suggest a single "best practice" tip for others seeking to provide quality dementia care?  
(PLEASE USE THE REVERSE OF THIS PAGE TO PROVIDE YOUR ANSWER.)

Thank you for your participation in this survey!!
References


