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DEMENTIA CARE IN ASSISTED LIVING: NEEDS AND CHALLENGES

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Abstract

Assisted living (AL) is an increasingly popular long-term care option for older adults with dementia. Recent reports suggest that as many as 68% of AL residents have dementia, and that frequency of both behavioral symptoms and psychotropic medications are high. This pilot project explored the feasibility of research methods for use in AL facilities. Findings suggest that most AL residents with dementia have moderate to severe dementia, and the majority are taking one or more psychotropic medication. Descriptive and qualitative findings related to health records, caregiver perceptions of behavioral symptoms, and practicality of assessment methods undertaken are described and implications for psychiatric nursing practice and research are reviewed.

Assisted living (AL) has become an increasingly popular long-term care alternative for older adults over the last decade. Estimates suggest that 1 million older adults currently reside in AL facilities (Assisted Living Federation of America, 2007), a number that is close to the 1.6 million that reside in nursing homes (National Center for Health Statistics, 2007). AL has been described as “a promising new model of long-term care, one that blurs the distinction between nursing homes and community care and reduces the chasm between receiving long-term care in one’s own home and in an ‘institution’” (Hawes, Rose, & Phillips, 1999, p. 15). Common tenets of AL’s philosophical model include autonomy, dignity, and service flexibility that facilitate maximum independence and aging-in-place (Hawes et al., 1999). However, philosophical and operational definitions of AL vary widely within the industry, resulting in wide variations in environments, services offered, and policies about residents.

AL facilities are known by a long list of names, including residential care, sheltered housing, domiciliary care, intermediate care housing, adult foster care, and congregate care (Zimmerman & Sloane, 1999). As suggested by these diverse labels, facilities range from

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small “mom and pop” type care provided in personal homes to large, new-model facilities that are more commonly associated with the term AL (Watson, 2003).

Of interest to psychiatric mental health nurses, a substantial number of AL residents experience dementia and other psychiatric disturbances. The Maryland Assisted Living study, the first large scale investigation specifically designed to determine the prevalence rates of dementia among AL residents, reports that 68% of residents have dementia diagnoses, 10% have other cognitive impairment, and 26% have psychiatric disturbances such as depression or anxiety disorders (Rosenblatt et al., 2004). Additional reports indicate that behavioral symptoms affect 34% of all AL residents (Gruber-Baldini, Boustani, Sloane, & Zimmerman, 2004) and 56% of those with dementia (Boustani et al., 2005). In tandem, use of psychotropic medications among AL residents also is quite high, with 36% to 56% of AL residents estimated to be receiving these medications (Boustani et al., 2005; Gruber-Baldini et al., 2004; Lakey, Gray, Sales, Sullivan, & Hedrick, 2006).

As dementia and behavioral symptoms become increasingly common in AL settings, so do questions about the quality of dementia care in AL facilities. An early report suggested that dementia-specific AL service areas were not providing more dementia-sensitive environments, such as the minimization of aversive stimuli or the provision of pleasant or engaging activities, orientation cues, or continuity with the past, than were other care areas (Sloane, Zimmerman, & Ory, 2001). More recently, a series of research articles related to quality of dementia care in AL settings observed that the prevalence of dementia-related problems in AL were comparable to those observed in nursing homes, including depression, behavioral symptoms, reports of pain, mobility deficits, low food/fluid intake, and low activity involvement (Schulz, 2005).

In short, AL environments are increasingly selected by older adults with dementia as a long-term care alternative. However, many questions remain about both the quality of dementia care in AL facilities and the feasibility of transplanting dementia-related models of care that have shown to be effective in other settings to AL environments. Although a number of excellent models and theoretical approaches to dementia care are described in the literature, most have not been evaluated for use in AL, creating an important opportunity for psychiatric nurse consultants and investigators alike. For example, the Progressively Lowered Stress Threshold (PLST) model of dementia care, first described by Hall and Buckwalter in 1987, has been successfully adapted for use in a wide variety of residential and clinical settings (Smith, Gerdner, Hall, & Buckwalter, 2004). Although the effectiveness and applicability of this model has not been evaluated in AL, brief review of the PLST model suggests it should be helpful to AL caregivers.

Basic principles of the PLST model include the beliefs that behavioral symptoms are the manifestation of unmet needs and accumulated stress and are avoidable by training caregivers to adapt care routines and approaches. The model proposes that anxiety-related behaviors signal increasing distress for the person with dementia and are a precursor to more intense and often threatening behaviors like agitation, striking out, or elopement (Hall & Buckwalter, 1987). Thus, anxiety-recognition by caregivers provides important opportunities to institute interventions that reduce escalation, restore baseline function, and promote comfort for the person with dementia. By incorporating PLST-based approaches into daily care routines, caregivers often are able to reduce the risk of behavioral disturbances occurring and better assure that physical and psychological comfort is maintained.

This paper describes findings of a pilot project that evaluated the feasibility of research methods for use (at a later time) in a clinical trial using the PLST model of care. The larger

study, Treatment Strategies for Dementia-related Anxiety in Assisted Living, was designed as a two-phase project in which recruitment strategies, scale use, and other data collection methods were evaluated in a pilot project. The Phase I pilot study was considered essential for several reasons. Although the research literature on which the study was based suggested that the strategies proposed should be practical, questions remained about how easily information would be retrieved from records, how much burden would be imposed by the array of scales proposed, and how useful the methods proposed would be in detecting various phenomena of interest. After the feasibility of methods was established in Phase I, the plan in Phase II was to test the effectiveness of a nonpharmacological, multimodal management strategy for persons with dementia-related anxiety and agitation based on the PLST model.

The results of Phase I are described here, including the extent to which participants met the study's inclusion and exclusion criteria, and qualitative findings related to health-related records in AL settings, evidence of using person-centered approaches to dementia care, and staff perceptions of behavioral and psychological symptoms. Implications for psychiatric nursing research and clinical practice are reviewed.

PHASE I: FEASIBILITY PILOT PROJECT

Four specific aims guided the pilot project, two of which are relevant to this report: (1) examine the feasibility of the proposed inclusion/exclusion criteria and data collection methods and procedures, and (2) determine the acceptability and usefulness of the proposed psychiatric, cognitive, functional, and biologic measures in AL residents. An important component of the second aim was to determine the type of information maintained in AL resident charts, including access to current medical and psychiatric diagnoses, medication use, reason for admission, and use of individualized strategies to promote function and well-being among residents.

Inclusion and Exclusion Criteria

Inclusion criteria evaluated in Phase I included the following: meets criteria for Alzheimer's disease (AD); meets specified cut-offs for anxiety, depression, and mental status scale scores; absence of sensory impairment that would prevent study participation; – presence of a decision-making representative; availability of informant who knows the subject well (e.g., has regular contact); and age over 60 years. Exclusion criteria included the presence of active psychiatric illness that predated the onset of AD; the presence of substance abuse or dependence; the use of psychotropic medications other than a cholinesterase inhibitor; a history or presence of a significant neurological condition, such as seizure, encephalitis, neoplasm; the presence of any active, unstable medical condition that impairs cognition and psychosocial function; and the presence of impairment that, in the investigator's judgment, requires immediate treatment.

The purpose of these inclusion/exclusion criteria were to identify older adults with dementia who may experience behavioral symptoms, but who had not yet been treated with psychotropic medications, and who did not have overlapping problems that might obscure outcomes in the later clinical trial. The criteria were consistent with standards successfully used in drug trials reported in the literature (e.g., Clinical Trials of Intervention Effectiveness [CATIE] Schneider et al., 2003) making their evaluation for use with a nonpharmacological intervention in AL settings a logical extension of earlier work.

Design

The Phase I pilot study used a cross-sectional, descriptive, correlational design. Facilities and participants within facilities were volunteers. Because dementia-specific facilities were

included, family members were asked to sign informed consent documents on behalf of their loved ones following protocols outlined by our Institutional Board of Review (IRB). Under our IRB rules, residence in a dementia-specific setting implied sufficient impairment to warrant securing informed consent from the resident's proxy decision-maker. To assure confidentiality, facility administrators sent standardized letters to family members designated as "responsible parties" to inform them of the study. An "agreement to be contacted" form was enclosed with the letter, asking family members for permission to be contacted by researchers so that the study could be explained, and consent provided when families were willing. Assent also was secured from all participants to assure their understanding of the interview and willingness to participate.

All data were collected by two experienced geriatric psychiatric advanced practice nurses who met weekly to compare experiences, progress, and usefulness of methods being used. Detailed notes purposefully taken during assessments (described below) were discussed during meetings to assure shared understanding of procedures and consistency in the application of assessment scales and data-gathering tools.

Sample and Settings

Dementia-specific facilities in two different urban communities located in the Midwest were recruited to participate in the pilot project, which was conducted over a nine-month period of time. One facility (called ALF-A here) was part of a continuing care community that also provided apartment living, AL services for residents without cognitive impairment, and nursing home care. Nursing care in ALF-A was provided by a Licensed Practical Nurse (LPN) who served as the director of nursing (DON) and was available from 9 a.m. to 5 p.m., Monday through Friday. Direct care providers were universal workers (UWs) who provided personal care, assistance with housekeeping, and meal preparation and services, and also were certified to dispense medications. Some, but not all UWs, were certified as nursing assistants. Of the 24 older adults living in ALF-A, 13 family members agreed to allow their loved one to participate in the study.

The second facility (ALF-B) was located in a community 30 miles away from ALF-A, and was specially designed to provide AL services to older adults with dementia (e.g., dementia-specific) and to those without cognitive impairments (e.g., "regular" AL). This large campus included two dementia-specific units, one of which was included in this study. Nursing care was provided by two Registered Nurses (RNs) who served as the DON and assistant DON for the two dementia-specific units (60 residents total). Like ALF-A, the nurses were available during the day on weekdays, and daily care was provided by UWs. Of the 30 residents in ALF-B, four family members agreed to allow their loved one to participate. Possible differences for level of participation between ALF-A and ALF-B are believed to relate to change in administrative personnel at the time of recruitment and are discussed in detail elsewhere (Smith, Buckwalter, Kang, Schultz, & Ellingrod, in press).

Procedures

The Phase I pilot study included four visits with each participant. After securing informed consent, the first visit with the participant was considered a screening visit in which data were collected to determine if the older adult met inclusion and exclusion criteria. To that end, chart review was conducted and four scales were administered, including the Mini-Mental State Exam (MMSE; Folstein, Folstein, & McHugh, 1975), the Hamilton Anxiety Rating Scale (HAM-A; Hamilton, 1959), the Rating Anxiety in Dementia scale (RAID; Shankar, Walker, Frost, & Orrell, 1999), and the Cornell Scale for Depression in Dementia (CSDD; Alexopoulos, Abrams, Young, & Shamoian, 1988a, 1988b). Findings related to

each of the inclusion/exclusion criteria were recorded on a summary sheet to ensure easy review of the outcomes of this screening visit.

If the person met criteria, two additional visits were scheduled to measure behavioral and psychological symptoms and functional status, collect a saliva sample for genetic testing, and re-administer anxiety and depression scales (HAM-A, RAID, CSDD). The goal of the fourth visit was to establish that the participant and family were interested in proceeding to Phase II of the study, in which the PLST-based intervention would be tested. Because no participant met the inclusion criteria without also meeting the exclusion criteria (i.e., no participant was acceptable for this study), only methods relating to the first screening visit are described here.

Instruments

Data were collected from older adult participants using the MMSE, HAM-A, RAID, and CSDD, all of which have established psychometric properties and are widely used in geriatric psychiatric clinical practice. See Table 1 to review item categories, scoring methods, psychometric properties, and use of cut-off scores for inclusion in the study.

In addition to scoring each instrument using numeric values, comments made by older adults themselves and by staff who provided proxy reports were recorded on the scale forms. Specific words, phrases, and descriptive answers were noted in the column next to the question that precipitated the comment. Additional notes related to interesting or unusual comments or circumstances were recorded on the back of the scale form following interviews. This qualitative information was reviewed, summarized, and examined for trends related to views about anxiety.

Chart Review

Resident charts maintained by the AL residences were reviewed to collect personal, social, and health-related background information. Demographic information, including age, marital status, reason for admission, medical and psychiatric diagnoses, and number and type of medications taken were collected.

Service plans, which state-determined AL regulations require at admission with yearly updates, were reviewed for information related to personal care, use of non-pharmacological interventions related to behavioral symptoms, and other evidence of individually tailored dementia care strategies. Similarly, narrative notes were reviewed to determine the type of information routinely documented in AL care, including possible occurrence of behavioral symptoms, staff management strategies used in response to behaviors, and possible unmet needs that might be addressed in Phase II of the research. Additional information about factors occurring in the social climate during the time of research visits and interviews, both positive and negative, also were recorded.

This descriptive information was systematically recorded using specially designed forms to best assure complete information on all participants and visits. Field notes related to general experiences with facility personnel were recorded, as were anecdotal notes related to impressions of the quality of information recorded. Because state regulations have few expectations for resident-related documentation, variability within and between facilities was anticipated. Thus, the chart-related data form was designed to accommodate anecdotal notes and comments for later review.

Data Analyses

Data were analyzed using SPSS software (version 12). Frequency distributions and measures of central tendency (mean, mode, median) and dispersion (range) were used to characterize demographic and clinical variables. Descriptive information and narrative notes (e.g., reason for admission, medications, diagnoses, unsolicited comments related to scale questions) were systematically reviewed and summarized in tables using Microsoft Access. These data were examined for commonalities and themes.

RESULTS

Demographic Information

A total of 17 AL residents were recruited to participate in the pilot project: 13 women (76%) and 4 men (24%). The average age of participants was 83.2 years ($SD = 8.9$, range = 62–91 years). Most lived alone in the AL residence, and were widowed (76.5%), divorced (5.9%) or never married (5.9%). Only two participants (husband and wife) were married and living together. Length of residence in the facility at the time of evaluation ranged from 9 months to 4 years, with an average of 1.9 years ($SD = .99$). Most listed adult children as their contact person (82%), followed by other family members (12%), and friends (6%). All participants met criteria for age, absence of sensory impairment that would interfere with participation in the study, and availability of an informant who knew them well.

Reasons for admission were recorded as written in clinical notes. Most admissions (64.7%) referred to increasing confusion and/or cognitive impairment as the primary reasons, and included additional references to the participant lacking family, living alone, having functional problems, needing supervision and support, the participant's family being unable to cope with demands. Other reasons included physician referral to the facility (11.7%), unclear reasons (11.7%), and behavioral symptoms such as paranoia and aggression (5.9%). Of the 13 participants that lived in ALF-A, 8 lived in the continuing care community prior to transferring to the dementia-specific AL unit.

Medical Diagnoses and Medications

The number of medical diagnoses per participant ranged from 1 to 11, resulting in a total of 90 medical diagnoses for the group, or an average of 5.3 per person. No participants were excluded on the basis of having specified neurological problems, active unstable health conditions that impaired cognition or function, or impairments that required immediate treatment. Medical diagnoses included many common health problems of late life—hypertension, coronary artery disease, osteoporosis, hypothyroidism, respiratory disease, sensory impairments, and degenerative joint disease, among others.

Participants were prescribed a total of 107 scheduled medications (average of 6.3 per person, range of 2–11 medications per person) and a total of 34 as needed (prn) medications (average of 2.0, range of 0–6) for these health conditions. Psychiatric medications and cognitive enhancing drugs were counted separately, as described next.

Psychiatric Diagnoses and Medications

All 17 participants had 1–5 psychiatric diagnoses on record, including 14 participants (82%) with diagnoses of dementia, including four with Alzheimer's disease noted in their record and seven (50%) with diagnoses of depression. Other psychiatric diagnoses included anxiety ($n = 3$), paranoia/delusions ($n = 3$), and anxious depression ($n = 1$). No evidence of alcohol or substance use among participants was found, either current or past. However, the lack of sequentially organized health information in charts made it difficult to establish whether depression and anxiety diagnoses were "active" and predated diagnoses of dementia.

All but two participants (88%) were prescribed one to three psychotropic medications on a scheduled ($n = 26$ medications) or as needed ($n = 5$ medications) basis. Medications included antipsychotics ($n = 11$; 65%), antidepressants ($n = 9$; 53%), anxiolytics ($n = 9$; 53%), and mood stabilizers ($n = 1$; 5.9%). In addition, the majority ($n = 11$; 65%) also took cognitive enhancing medications. Thus, only two participants met criteria for being psychotropic naïve at the time of screening visit.

Dementia-Specific Care Approaches

The content of service plans and narrative notes in the chart did not provide evidence of individually tailored dementia care approaches. Service plans addressed services used, such as frequency of meals or transportation needs, rather than care-related strategies. Similarly, narrative notes describing events in day-to-day care were infrequent overall, rarely included any reference to behavioral symptoms, and did not address use of either nonpharmacological interventions or decision-making processes related to the use of psychotropic medications.

Orders for psychotropic medications written by a single psychiatric consultant who evaluated 7 of 13 participants in ALF-A were located in the chart and noted in medication administration records. However, these orders were not supplemented with clinical notes in the resident chart describing the nature of the behavioral symptoms being treated. Similarly, psychotropic medication orders written by primary care providers in both facilities were not supplemented with written notes relating to the perceived problem, its treatment, or the effectiveness of the medication intervention.

Cognition, Depression, and Anxiety

No problems or concerns were encountered while administering scales with participants or staff members who knew the resident well. All scales took a matter of minutes to review and score, and were well-tolerated by participants. Eight ($n = 8$) participants were within the study's target range for mild to moderate cognitive impairment (MMSE = 15–23), 15 met criteria for absence of depression (CSDD < 8), two met criteria for presence of anxiety on the RAID (≥ 12), and none met criteria for presence of anxiety on the HAM-A (≥ 18). None of these individuals simultaneously met criteria for cognitive impairment, absence of depression, and presence of anxiety.

Descriptive notes related to staff comments and observations during the proxy interviews conducted in association with the CSDD (depression) and RAID (anxiety) scales were summarized and examined for themes. A total of 36 comments were made related to depression and anxiety symptoms. A notable theme was that questions related to anxiety resulted in description of agitated behaviors. Of the comments made, 39% described components of agitation, including pushing, grabbing, abrupt withdrawal, yelling, being argumentative, pacing, and being resistant to care.

DISCUSSION

The findings from this pilot study were largely unanticipated, as none of the participants met the inclusion and exclusion criteria previously used in community-based clinical trials related to pharmacological treatment of dementia. Although the original goal was to assess 20 participants in the pilot project, additional recruitment was aborted after 17 participants failed to proceed past the screening assessment, and trends related to cognitive impairment, psychotropic medication use, presence of anxiety, and absence of depression were reviewed by the research team.

The most pressing implication for the investigators was that a thorough review of inclusion/exclusion criteria, recruitment methods (including type of facilities, and selection of

participants within AL settings), use of cut-points for determining presence of anxiety, and other study design issues was required. Clearly, different approaches were needed to accurately identify older adults with dementia who experience behavioral symptoms, and who may benefit from nonpharmacological interventions *before* psychotropic medications are prescribed. Thus, study criteria were adapted, including participant recruitment in traditional AL residences (e.g., facilities not certified as being dementia-specific), the addition of two scales (e.g., self-report anxiety and behavioral symptom rating scale), as well as qualitative measures to better understand UWs' perceptions of anxiety, and revisions in analyses related to examination of symptom clusters compared to cut-points for scales, among other changes. After IRB approval for the modified plan was received, participant recruitment for the Phase I feasibility study was continued in three additional AL residences.

In addition to guiding modifications to the research protocol, the review of these findings raised questions related to the level of cognitive impairment among AL residents, and the frequency of both psychiatric disorders and psychotropic medications in this setting. The value of using cut-points set by scale developers, the reliability of information maintained in facility records, and the accuracy of proxy reports in assessing the presence and severity of anxiety and depression symptoms were examined and reviewed. The discussion that follows describes key findings, noting similarities and differences to earlier reports in the literature, and discusses implications for psychiatric-mental health nurse researchers, clinicians, and consultants who will likely be increasingly involved with older adults living in this important long-term care setting.

Dementia Rules in Assisted Living

An important observation about the pilot data relates to the potential influence of state-determined definitions of AL on the characteristics of older adults who live in this setting. The increasing popularity of AL care has been accompanied by rapid changes in regulations related to the type of care and services that may be provided under the umbrella of AL services. Growth in the number and type of regulations that guide AL care is illustrated by comparing issues of the *Assisted Living Regulatory Review*, an annual report of key legislative characteristics of AL in all 50 states. The 2001 *Review* was a 131-page report that included the category "Alzheimer's Unit Requirements" for reporting any requirements related to dementia-specific care. Six years later, the 2007 *Review* is a 210-page document that includes two categories related to dementia care: Alzheimer's Unit Requirements and Staff Training for Alzheimer's Care. These continued regulatory changes respond to increasing resident acuity and health-related needs among AL residents, including the provision of appropriate care for those with dementia (National Center for Assisted Living, 2001, 2007).

At the time the study was designed, the best information about the prevalence of dementia among older adults in AL suggested that 30–50% of residents had some degree of cognitive impairment and that most (58%) were mildly impaired (Sloane et al., 2001). Reports published more recently indicate that dementia is more common than previously thought (Rosenblatt et al., 2005) and that severity of impairment is greater than suggested by prior estimates. Specifically, Boustani and colleagues (2005) found that 26% of AL residents with dementia were moderately impaired (MMSE score of 11–16) and 61% were severely impaired (MMSE score of 0–10). In contrast, a report by the same research group five years earlier found that 29% were moderately impaired and 15% were severely impaired (Sloane et al., 2001). Although it is possible that earlier estimates were incorrect, a more plausible explanation is that the frequency and severity of dementia among older adults in AL is rapidly increasing.

The overall illness severity of our pilot sample, including level of cognitive impairment, frequency of comorbid psychiatric illness, and use of psychotropic medication, is consistent with characteristics of older adults in nursing homes, as recent research has suggested (Boustani et al., 2005; Gruber-Baldini et al., 2005; Maslow & Heck, 2005; Zimmerman, Sloane, Heck, Maslow, & Schulz, 2005). Although state-determined regulations are rapidly changing to better assure that dementia-related care needs are met, standards for medication use and review, staff preparation and training related to individualized approaches, and use of person-centered programs of care too often lag behind. As observed in the findings described below, many opportunities exist for psychiatric mental health nurses to improve the quality of care to AL residents.

Health-Related Information

The variability in the type and perceived accuracy of background health-related information maintained in resident charts was another important observation made during the pilot study. In our state, regulations require a service plan, defined as “the document that defines the services to meet the needs and preferences of tenant” (Iowa Administrative Code, 2004, p. 2), but do not require a “health record.” Thus, decisions related to chart maintenance are facility-based, introducing considerable variation in the type of information found in charts within facilities, as well as differences among facilities.

In this study, the categories of information found in resident charts were parallel to those found in outpatient or nursing home records. However, relevant information was often missing or outdated. For example, records describing health conditions and their treatment were collected at admission and were several years old. Medication administration records (provided by the pharmacy) systematically listed diagnoses as the rationale for medication (e.g., depression for antidepressant medications), but that information was not consistently found in the chart. Differing diagnoses were made by multiple providers (e.g., neurology, psychiatry, internists), with no clear indication of which was most current or accurate. For example, records for one participant included diagnoses of dementia, Alzheimer’s disease, and amnesic disorder, as well as delusions, anxiety, and paranoia. On interview, the participant was very hard of hearing, had mild cognitive impairment (MMSE = 18), and was somewhat anxious (RAID = 8), yet was pleasant, cooperative, and conversant.

Another notable finding was absence of evaluation reports listing a diagnosis of dementia for 3 of 17 participants who lived in the dementia-specific AL units. All three had depression and were “confused” as assessed by facility staff using the MMSE and the Global Deterioration Scale (GDS; Reisberg, Ferris, de Leon, & Crook, 1982). In one case, out-of-state family members reported the evaluation work-up was not “missing” from the facility chart. Instead, an evaluation had not been conducted. Per family report, facility staff informed them that their father was too confused for independent living and needed to be moved to the dementia unit, which they said was a “huge surprise” given recent visits. Documentation related to the transfer included a MMSE score of 24 points (above the cut-point for dementia) and a GDS score of 3, suggesting mild cognitive decline (Alzheimer Society, 2007). No additional descriptive documentation was found.

Although comparative descriptions of health-related AL documents are not found in the literature, the lack of sequential information maintained in the health record creates a number of challenges for both researchers and clinicians alike. Lack of accurate and recent information makes it difficult to identify factors that may cause or contribute to behavioral symptoms or other health-related problems. Similarly, information documenting the antecedents to, or outcomes of, treatment with psychotropic medication makes it difficult to discern if medications are currently needed and appropriate. In short, many opportunities exist to improve documentation systems within AL facilities to better assure that recent and

accurate health-related information is available for problem-solving related to care, whether in association with research, consultation related to care, or on admission to acute care settings.

Proxy Report by Staff

Additional observations were related to staffing patterns and the availability of a person who “knows the participant well” to assist in rating anxiety (RAID) and depression (CSDD). In both facilities, nurses were administrators who deferred judgments related to “behaviors over the last two weeks” to daily care providers. Although staff were compassionate and caring, their comments often suggested misinterpretation of behaviors. Discrepancies between investigators’ ratings of anxiety and depression, based on direct assessment of the participant, and staff interview data (including descriptive notes recorded during staff interviews) suggested that residents’ distress was not well understood. For example, behaviors that are consistent with agitation (e.g., pushing, grabbing, abrupt withdrawal, yelling, being argumentative or resistive to care) were commonly offered as examples of anxiety. Participants who stayed up until 11 pm were described as having sleep disturbance, and not finishing meals was considered evidence of appetite disturbance, even in the absence of weight loss. In one case, intense paranoid delusional ideas relating to the participants’ children being unsafe were considered “usual worries” and “just the way she is” by staff.

Use of scales that depend on proxy report has received mixed reviews in the literature. In pain assessment, the reports of certified nursing assistants (CNAs) were highly associated with duration and intensity of pain, and use of analgesic medication (Fisher et al., 2002), suggesting that these care providers were well aware of residents’ distress. In contrast, CNAs were not found to reliably identify behavioral symptoms among residents compared to either nurses or trained observers (Wood et al., 2000). Moreover, CNAs and nurses both over-rated anxiety, appearing to confuse anxiety with agitation (Wood et al., 2000), a pattern that also was observed in our pilot project.

One of the most important implications related to use of proxy report is the need to combine direct observation and interview with caregiver reports, as is recommended for both the RAID and CSDD. In the current study, the ability to directly observe and interact with the participant provided important balance when listening to caregiver reports of the same behaviors. On the one hand, observed inaccuracies in labeling behavior suggested that staff training may promote more accurate assessments and higher quality of care overall. However, clinician-rated observation and interview will likely still be needed to balance proxy-rated assessments.

Identifying “Distress” Among Residents

Another area of concern for the investigators was use of commonly accepted cut-off points as a means to identify clinically significant symptoms of anxiety. Although specific descriptions of dementia-related anxiety in the literature are few, most include a small cluster of significant symptoms derived from longer behavior rating scales, such as prominent anxiety, fearfulness, apprehension, and worry (Ferretti, McCurry, Logsdon, Gibbons, & Teri, 2001; Ownby, Harwood, Barker, & Duara, 2000; Teri et al., 1999). Use of the RAID and HAM-A in the pilot project was intended to capture a broader and more inclusive view of anxiety-related signs and symptoms. Putting cut-off points aside, the pilot study indicated that 15 of 17 participants experienced from 1 to 19 anxiety-related symptoms.

In both research and clinical practice, using a combination of objective and subjective data as the basis for decision-making, particularly early in the course of treatment or research, may be beneficial. For example, a more strategic approach might be to rate symptoms using designated scales and develop cut-off points that are specifically tailored to the specific project. This approach is consistent with geriatric psychiatric clinical practice that increasingly recognizes sub-threshold clinical syndromes, such as minor depression that does not meet full criteria for major depression but that causes significant distress and is considered a target of treatment.

Another important measurement consideration related to concerns and observations expressed by daily care providers while rating quantitative scales. Descriptive notes of labels, terms, and examples provided by caregivers indicated that use of qualitative methods may have elicited additional useful information. For example, 8 of 9 staff interviewed in ALF-A provided considerable detail and examples, asked the interviewer's opinion on care, and confided concerns that were not directly part of the structured interview. These insights and observations provided important procedural information that would have been useful to have audio-recorded for future reference and use in both training and research procedures.

Implications for Geropsychiatric Nursing Research and Practice

Although this study has some limitations, in terms of small sample size and use of volunteer facilities and participants that limit generalizability, the demographic characteristics of the sample (age, sex, marital status, reason for admission) are consistent with residents in AL settings in our state and across the nation (Wulf, 2006). Although findings of the pilot project must be interpreted carefully, a number of observations have implications for psychiatric mental health nurse researchers, clinicians, and consultants. The most notable concerns are high use of psychotropic medication, deficits in health-related information maintained in a facility chart, and questionable reliability of staff reports related to behavioral symptoms. Collectively, these factors present difficulties in conducting research and providing clinical care to older adults who live in AL facilities. Although much may be learned via direct observation and interview, understanding dementia-related behaviors and psychiatric disturbances relies on placing observations in the context of both background and precipitating factors that may cause or contribute to the problematic behaviors (Algase et al., 1996; Smith, Hall, Gerdner, & Buckwalter, 2006). Thus, documentation methods to promote identification and understanding of these factors are needed.

Although variability in state and facility-related policies is substantial, several general trends related to AL care are widely observed, and may come into play when interacting with AL staff related to research or clinical care of residents. First, requirements related to the provision of nursing care result in considerable variability in the presence of nurses and the roles they play (Reinhard, Young, Kane, & Quinn, 2006). As observed in our study, nursing roles are often supervisory and/or administrative, with direct "nursing" care provided by UW who may be certified to administer medications (Reinhard et al., 2006), but are not required to be trained as nursing assistants. The "9 to 5" role of nurses results in many daily care decisions being made by UWs, from overseeing nutrition and hydration needs, to encouraging participation in activities, deciding how often "as needed" psychotropic medications are used, and providing "updates" and other information to family members or professionals who telephone or visit. The range and type of responsibilities assumed by UWs is considerable, but training requirements vary widely.

Another important consideration is the level and type of documentation that may, or may not, be available to facilitate clinical or research decision-making. The view of an AL facility as a "residence with services" may reduce the likelihood that health-related records are maintained, particularly ones that guide daily care approaches or document the

occurrence and nature of behavioral symptoms. In conjunction, staff training and education may be needed to better assure recognition of behavioral symptoms and understanding of approaches to care that may improve or impede quality of care, as suggested by outcomes of the Staff Training in Assisted Living (STAR) project (Teri, Huda, Gibbons, Young, & van Leynseele, 2005).

Given these staffing and documentation trends, psychiatric nurses may provide important assistance related to staff education, use of non-pharmacological nursing interventions, management of psychotropic medications, and use of documentation procedures to detect changes in status among older adults in AL settings. Of importance, psychiatric nurses in inpatient, outpatient, and community service settings may all advocate for the use of nonpharmacological intervention trials preceding use of psychoactive medications that are used to “control” diverse behavioral symptoms. Nonpharmacological interventions are both increasingly available, and supported by research. For example, a recent systematic review graded the quality of evidence in 1,632 studies that treated behavioral and psychological symptoms in dementia using non-pharmacological approaches (Livingston et al., 2005). Livingston and colleagues (2005) concluded that behavioral management techniques that center on individual patients’ behavior are generally successful in reducing behavioral symptoms, and that educational approaches that focus on changing caregiver behaviors (e.g., teaching caregivers how to change their interactions with persons with dementia) are particularly effective.

In summary, the increasing popularity of AL as an alternative to nursing home care suggests that psychiatric mental health nurses in all areas of practice will increasingly encounter older adult patients from this setting. Whether admitting older adults from AL settings to inpatient units, making discharge plans to AL, providing consultation services, or conducting research onsite in AL residences, psychiatric mental health nurses will likely have an ever-increasing number of encounters with older adults in AL, their family members, and staff caregivers. Increased awareness of common characteristics of AL care and the influence of state-determined regulations on staff training, services provided, and documentation procedures increases the opportunity for psychiatric nurses at all levels of practice to positively influence outcomes of care for persons with dementia in AL.

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TABLE 1

Scale Properties

Scale	Content Areas	Scoring/Psychometric Properties
Mini-Mental State Exam (MMSE)	11 items address <ul style="list-style-type: none"> • Orientation • Registration • Attention and calculation • Recall • Language 	<i>Items:</i> vary <i>Total score:</i> 0 to 30; with lower scores representing more impairment <i>Study cut-off point:</i> 15 to 23 indicating mild to moderate impairment <i>Psychometric properties:</i> ¹ Internal consistency: $\alpha = .68$ to $.77$ Test-retest reliability: $r = .80$ to $.95$ Convergent validity with other cognitive tests: $r = .70$ to $.90$
Hamilton Anxiety Rating Scale (HAM-A)	14 items address <ul style="list-style-type: none"> • Anxious mood • Tension • Fear • Insomnia • Intellectual impairment • Depressed mood • Anxiety-related physical symptoms • Behavior at interview 	<i>Items:</i> 0 to 4 <i>Total score:</i> 0 to 56 with higher scores representing greater anxiety <i>Study cut-off point:</i> ≤ 18 = clinically significant anxiety consistent with anxiety disorders <i>Psychometric Properties:</i> ² Internal consistency: $\alpha = .85$ Convergent validity with other anxiety scales: $r = .23, p < .05$ Divergent validity with depression scales: $r = .30, p < .01$
Rating Anxiety in Dementia (RAID)	20 items address <ul style="list-style-type: none"> • Worry • Apprehension, vigilance • Motor tension • Physical symptoms • Phobia • Panic attack 	<i>Items:</i> 0 to 3 <i>Total score:</i> 0 to 60 with higher scores representing greater anxiety <i>Study cut-off point:</i> ≤ 12 = clinically significant anxiety <i>Psychometric Properties:</i> ³ Internal consistency: $\alpha = .82$ Test-retest reliability: Kappa = $.53$ to 1.0 Concurrent validity with other anxiety scales: $r = .54$ to $.62$ Concurrent validity with expert ratings: $r = .73$
Cornell Scale for Depression in Dementia (CSDD)	19 items address <ul style="list-style-type: none"> • Mood • Behavioral symptoms • Physical signs • Cyclical function • Ideational disturbance 	<i>Items:</i> 0 to 2 <i>Total score:</i> 0 to 38 with higher scores representing greater depression <i>Cut-off point:</i> < 8 = absence of clinically significant depression ⁴ <i>Psychometric Properties:</i> ⁵ Internal consistency: $\alpha = .84$ to $.98$ Inter-rater reliability: Kappa = $.67$ to $.74$ Concurrent validity with research diagnostic criteria: Kruskal-Wallis $H = 37.8, df = 3, p < .0001$

¹ Tombaugh & McIntyre, 1992.² Diefenbach, Stanley, Beck, Novey, Averill, & Swann, 2001.³ Shankar, Walker, Frost, & Orrell, 1999.⁴ Watson, Garrett, Sloane, Gruber-Baldini, & Zimmerman, 2003.⁵ Alexopoulos, Abrams, Young, & Shamoian, 1988a, 1988b.