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UBC Department
of Family Practice

CARE FOR ELDERS

Dementia with Behavioral Challenges II (late)

•Pre-reading•

Dementia with Behavioral Challenges II (late)

- Marcia Carr, RN
- Martha Donnelly, MD
- Diane Jansen, OT
- Alison Phinney, RN

Revised: January 2008

- Martha Donnelly, MD

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Welcome to the Care for Elders Modules!

The Care for Elders modules have been written for and by interdisciplinary teams. These modules are unique in that they are interactive and participatory. The goal is for you to learn about elders and also about you – exploring your role and attitudes; other disciplines; your team and how to work as part of a team caring for elders.

The Care for Elders learning experience is comprised of two parts:

1) Pre-reading - this is a general comprehensive overview of one topic

2) A 2 to 3 hour small group session with case study discussion.

- To get the most out of this module it is <u>strongly recommended</u> that you read the pre-reading package. Information in the pre-reading is reviewed during the small group discussions.

- Small groups will consist of 6-10 participants from various disciplines, and a facilitator.

- The facilitators will not 'teach'; rather your small group will discuss one fictional case using the information you possess, and the information you acquired from the pre-reading. The learning is accomplished if your team fully discusses the questions asked in the case study.

- The facilitator's role is to guide discussion and ensure that all learning points are covered during the session. Your facilitator is NOT expected to provide information!

We hope that this experience will be a rewarding one for you!

Dementia with Behavioral Challenges II (late)
Goals and Learning Objectives

At the end of the Dementia with Behavioral Challenges II (late) module, you will be able to:

☆ create an interdisciplinary, person-centered care plan for Maria Donatello through the moderate to severe stages of dementia.   This plan will include:

1. involving the person and family in planning for care, in meaningful and appropriate ways, throughout Maria's experience with dementia,

2. formulating strategies to help the Donatello family anticipate, plan and make decisions to prepare for the journey of dementia,

3. analyzing the pertinent aspects of family caregiver stresses and psychological experiences in Maria's case,

4. incorporating compensatory and enabling strategies to maintain personhood in the areas of communication, activities of daily living, and the physical environment,

5. determining the appropriate use of medications along the continuum of the illness, and

6. describing strategies that encourage effective communication between family and healthcare staff and between staff on different teams.

☆ Apply the GPEP Model to determine contributing influences on the behaviours exhibited by an older person with dementia.

Behavioral and Psychological Disturbances in Alzheimer's Disease – Assessment and Treatment

Alzheimer's is not a disease of cognition alone. A wide array of behavioral or psychological problems is associated with it. In fact, delusional jealousy, paranoia, auditory hallucinations, screaming and agitation were prominent features of the dementia described by Alzheimer in his original report.[1] Behavioral problems may be the most challenging for caregivers to deal with and often lead to a need for institutional care. The origin of the problems needs to be understood before defining patient centered management strategies.

Definitions and Origins of Behavioral Problems

"The term behavioral disturbance refers to a behavioral or psychological syndrome or a pattern associated with subjective distress, functional disability, or impaired interactions with others or the environment". [2]

Classification has typically been phenomenological, relying on a description of mental state and problematic behaviors. [3] Table 1 gives a list of major behavioral and psychological disturbances seen in dementia.

Table 1 – Major Behavioral and Psychological Disturbances in Dementia

Depression
Psychosis
Agitation
- nonaggressive
- physical (wandering)
- verbal (screaming)
- aggressive
- physical (hitting)
- verbal (cursing)
Resistance to care
Hypo/hyperphagia
Disinhibition
Diurnal rhythm disturbances
Sleep disorders

It can be argued that behavior should be recognized as a form of communication, rather than as random, unpredictable, or meaningless events**.** It is therefore essential for both family and health care team members to carefully assess the nature and timings of the behaviors to understand the communication. Once understood, modification of exacerbating factors may prevent recurrence. A simple example could be pain causing agitation. Because of cognitive problems, the patient can not verbally express discomfort and therefore ends up pacing or screaming as a means of communication.

The agitated behavior in this instance could be seen as adaptive or as a call for help instead of being random or difficult.

Behaviors can also be seen as caused by both environmental provocations and intrinsic neurobiological aspects of the disease. [4]

Measurement Tools
In office practice or institutions, the most practical way to measure behavior is to have the caregiver give a detailed description of what is observed, first, without drawing any conclusions as to the origins of the problem. Caregivers should be asked to paint a picture in words. It is helpful to have them keep a daily behavioral diary. [5] This should include: duration, frequency and severity of symptoms, the pattern of the disturbance over time, and which activity is occurring or which caregiver is in attendance when the behavior occurs.

When possible, the caregiver should complete the diary for a few days before an intervention is planned and continue after the intervention is applied, to observe effects. It is best to introduce one intervention at a time to assess the degree of success of a particular mode of therapy.

There are many different formal assessment tools for behaviors that can be used if staff is trained properly to administer them. These include:
- the Cohen-Mansfield Agitation Inventory (CMAI) [6]
- the Cornell Scale for Depression and Dementia [7]
- the Geriatric Depression Scale (GDS) [8]
- The Neuropsychiatric Inventory (NPI) [9]
- Behavioral Pathology in Alzheimer's Disease (Behave-AD) [10]

Frequency of Behavioral Problems in Alzheimer's Disease
The reported frequencies of behavioral problems in Alzheimer's disease vary widely.[4],[11] This undoubtedly "relates to the fact that there is a lack of consensus regarding the best way to assess noncognitive features of Alzheimer's disease, and selection bias in clinical samples which may lead to an overestimation of the true prevalence of disturbed behaviors and an underestimation of "deficit" symptoms". [4]

In a population based study of psychiatric phenomena in 178 patients with Alzheimer's disease in a defined area of the United Kingdom[12], the following cumulative prevalences of individual mental and behavioral disturbances were found: delusions 16%, hallucinations 17%, major depression 24%, mania 3.5%, agitation/aggression 20%, wandering 17%, and apathy 41%.

<u>Psychotic Symptoms</u>
Psychotic symptoms include: misidentification of other people or self, delusions and auditory or visual hallucinations.

Studies have found that the presence of psychotic features predicts a more rapid cognitive decline. However, psychosis occurs at all stages of Alzheimer's disease and does not accelerate mortality. [4]

Affective Symptoms
Affective symptoms range from apathy to agitation and from dysphoria to a clear syndrome of depression. Reported rates of depression in Alzheimer's disease have ranged from 0% to 86% with major affective disorder in 5% to 15%, minor depression in 25% and depressive symptoms in 50% at some stage of illness.[11, 13] Lower reports of depression as measured by an NPI, have been found in Alzheimer's disease 20% as opposed to vascular dementia 32.3%.[3] Because depression is highly treatable it may be prudent to over diagnose and give trials of antidepressants. The diagnosis of depression is easier to make in early stages of dementia when verbal skills are in tact. In severe dementia, however, behaviors like withdrawal, agitation or screaming may need to be interpreted as depressive equivalents.

Agitation/Aggression
Acts of aggression are particularly frightening for both family caregivers and staff in institutions. They also have a wide variety of causes ranging from pain to delirium to poor care approaches. Agitation is harder to define than discrete acts of aggression. Cohen-Mansfied/Deutsch[14] have argued for separating out definitions of aggressive and nonaggressive behaviors. They also suggest sub-categorizing verbal and physical symptoms of agitation. Each requires a different approach to care. In one study motor restlessness and nonverbal expression of agitation were found in up to 2/3 of patients, verbal outbursts in up to 45% and physically threatening or violent behaviors in up to 27%. [15]

Sleep Disturbances
Disruption of sleep in patients with dementia has many adverse effects including increasing the likelihood of day night reversal, increasing agitation and increasing caregiver stress. The inability of patients, being cared for at home, to stay in bed at night has been found to be strongly related to decisions for nursing home placement. [16] In a review of current management of sleep disturbances in dementia, Boeve et al[17] report that there are a few well designed studies. They describe sleep problems in four categories (insomnia, hypersomnia, excessive nocturnal motor activity and hallucinations or behavioral problems). Specific therapy depends on a precise understanding of the cause of the problem.

General Approaches to Management
There are two overall goals in treating behavioral or psychological problems in dementia. The first is to remove or significantly reduce the symptom while preserving maximum function. The second is to lighten the burden of the caregiver. The most important principle in treatment is to establish as far as possible an understanding of the origins of behaviors before developing a management strategy. In general, origins of behavior should be examined for biological, psychological, social and environmental dimensions as well as predisposing, precipitating and perpetuating factors for each

dimension. See Table 2. The second most important principle is to use medications thoughtfully and only when psychosocial/environmental approaches are not adequate on their own. The third most important principle is to continually evaluate and modify the approach, based on outcomes. It should also be understood that caregivers must be involved in care planning to ensure that these strategies are achievable and easily monitored for effectiveness.

Table 2

Analysis of Origins of Behaviorals
Dimensions

	Bio	Psycho	Social	Environmental
Predisposing				
Precipitating				
Perpetuating				

The Vancouver Coastal Health Authority Geriatric Psychiatry Education Program (GPEP) defines a simple but effective approach to assessment of behavioral problems. Diagram 1.[18] This has been used as an educational tool and check list in care facilities to help staff understand and deal with patient problems.

Tarriot[19] described an 11 point approach to behavioral disturbances:
1.   Define target symptoms
2.   Establish or revisit medical diagnoses
3.   Establish or revisit neuropsychiatric diagnoses
4.   Assess and reverse aggravating factors (sensory, environmental)
5.   Adapt to specific cognitive deficits (e.g. cues, memory books)
6.   Identify relevant psychosocial factors
7.   Educate caregivers
8.   Employ behavioral management principles when appropriate
9.   Use psychotropics for specific syndromes
10.   Use psychotropics for specific symptoms
11.   Continually evaluate effectiveness and reassess as required.

Nonpharmacological Management
Cohen-Mansfield [20] defines three theoretical models as origins of behavior which will support certain types of nonpharmacological approaches:
1.   The unmet needs model. This relates to sensory deprivation, boredom and loneliness. Sensory stimulation, activities and social contact would be appropriate therapeutic approaches.
2.   A behavioral learning model. This is a relationship between antecedents of behaviors, behaviors and the consequences. The consequences may be reinforcing. A behavioral modification approach would be called for.
3.   The environmental vulnerability/reduced stress threshold model. Patients with dementia lose their coping skills. There is a greater vulnerability to the

environment and a lower threshold at which stimuli have effects on behavior. An environment with reduced stimulation, relaxation therapy or massage may be considered.

Cohen-Mansfield[20] concludes that the literature on efficacy of nonpharmacological behaviors is problematic. Most studies occur in institutions and look at inappropriate behaviors as a whole, not specific behaviors. Assessment measures and duration of treatment vary. Very few control groups are used. Nonetheless, there is evidence that many therapies improve quality of life beyond just reducing inappropriate behaviors. The author describes seven categories of nonpharmacological approaches. See Table 3.

Table 3

Categories of Nonpharmacological Therapy
Sensory Intervention
-music
- massage/touch
- white noise
Social Contact
- one-to-one
- pet visits
- simulated presence therapy or videos
Behavioral Therapies
- cognitive
- stimulus control
Activities
- structured activities
- organized outdoor walks
- physical activities
Environmental Interventions
- wandering corridors
- natural or enhanced environments
- reduced stimulation environments
Medical/Nursing Care Interventions
- pain management
- hearing aids
- removal of restraints
Combination Therapies

Drance[21] writes about the importance of modifying not only the physical environment, but the interpersonal environment. This may involve making sure caregivers: have the knowledge to give best practice care, have good communication skills, and follow a care approach in which patient abilities are supported. In a facility, all of this requires strong

support from administration to recognize that the provision of a culture of caring is just as important as the provision of the actual care tasks.

Caregiver Support

The degree of behavioral problems in patients with dementia correlates to caregiver burden.[22]   When patients with dementia have depression, their caregivers report higher levels of burden.[23]   Studies suggest that caregivers who are firm and directive in managing behavioral problems tend to have less depression.[24] Brodaty[25] conducted a meta-analysis of psychosocial interventions for caregivers and found that structured programs that involved the patient in addition to the caregiver, such as teaching the caregiver problem solving skills in care, were more effective in reducing caregiver stress. The flexible provision of a consistent professional to give long term support was important. Less successful programs were short, support groups alone, or educational courses with no long term follow-up.

It is clear that caregivers need ongoing long term support when dealing with loved ones with dementia and behavioral problems. They also need to be involved as partners in the health care team to learn to problem solve and evaluate the effectiveness of individual interventions. Family caregivers are often patients' most important assets and must be cared for just as carefully as the patients themselves.

Pharmacological Management

The first and perhaps the most important pharmacological management should be to rationalize the use of all medications in this population and to simplify the drug regime wherever possible.

Psychotropic agents can be used to treat specific syndromes like major affective disorder depression or symptoms such as apathy, irritability, agitation or psychosis. Careful attention needs to be paid to potential side effects or drug interactions to prevent substituting one problem for another.

Once psychotropic medications are ordered, a plan for monitoring their effects and ongoing need must be implemented.

Cholinesterase Inhibitors

Anecdotal reports suggest that these drugs may be helpful with a number of behavioral disturbances including apathy, agitation and psychosis. Few trials have reported their effects on behavior and some have contradicted others. [26] Cummings[27] reports reductions in apathy and also suggests that the cholinesterase inhibitors may have positive emotional effects in those who do not respond cognitively. He also concludes that they may reduce neuropsychiatric symptoms in late stages of the disease.

Antipsychotics

Placebo controlled trials examining the role of antipsychotics in managing Alzheimer's disease psychosis and disruptive behaviors have demonstrated the effectiveness of Haloperidol, Risperidone, and Olanzapine. [5, 28]   Katz et al demonstrated the

effectiveness of Risperidone in managing aggression and psychosis.[29]   Tarriot[30] concludes that Quetiapine can be helpful with psychosis in dementia and that its side effect profile may be particularly advantageous with respect to tolerability.

Given the difficulties with extra pyramidal side effects, the old neuroleptics are best avoided except for Loxapine, if used judiciously.

Table 4 shows appropriate doses for atypical neuroleptics in this population.

Table 4
Atypical Neuroleptic Doses

	Starting Dose	Total Dose
Risperidone	0.25 mg. od or bid	1 to 2 mg.
Olanzapine	2.5 mg. qhs or bid	5 to 10 mg.
Quetiapine	25 mg. qhs or bid	150 to 200 mg.

Antidepressants

Trazodone 25 to 50 mg. hs has been used as a sedative hypnotic.[5]   It can also be used in small doses (12.5 to 25 mg) during the day to decrease agitation.

The SSRIs are the first line drug for depression in dementia. In particular, sertraline (100 to 200 mg) and celexa (20 to 40 mg.) have the best side effect profiles. Start low, go slow, and watch for increases in INR or hyponatremia.

Tricyclics should be avoided because of potential anticholinergic side effects.

Benzodiazepines

In general, benzodiazepines should be avoided because of side effects. One situation where they might be helpful, as an anxiolytic, is the use of 0.5 mg. sublingual lorazepam before medical tests or difficult care procedures like wound dressings, to calm the patient and prevent agitation or struggling behavior.

A small dose of zopiclone (5 mg.) can be recommended as a hypnotic for short transitional periods such as major moves or recovery from a medical illness, but should not be used long-term.

Anticonvulsants

Carbamazepine has been reported to decrease agitation in Alzheimer's disease but its' side effects are significant (ataxia, drowsiness, disorientation, rash). [31]   It is not appropriate as a first line drug.

Anecdotally, gabapentine has been felt to be helpful for agitation but controlled studies do not exist.

Conclusions

In order to understand behavioral problems in patients with dementia, health care professionals must be biopsychosocial/environmental detectives. Treatment should be individualized to the patient/caregiver dyad. Using evidence or best practices would be ideal. Unfortunately much more research is necessary in both pharmacological and nonpharmacological modes of therapy as well as combinations of approaches. In the meantime, carefully observing patients, listening to caregivers, removing precipitants, and trialing therapies is our best approach.

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Palliative Care in Dementia

Norman Samaroo and Martha Donnelly

The Functional Assessment Staging Tool (which is very similar to the Global Deterioration Scale) is widely used to assess degree of impairment in dementia, and is highly correlated with the Folstein Mini-Mental Status Exam.[1,2,3] In the United States there is controversy over use of the FAST as a criterion for admittance into palliative care hospice programs, where a 6-month prediction of mortality, and Stage 7c on the FAST scale, is the standard for hospice admittance.[4] The guidelines are limiting, and while it is recognized that many patients with severe dementia do not move uniformly through the scale, and often live well beyond the 6-month criterion, there is consensus that earlier palliative intervention may be the best approach to deal with the numerous and diverse difficulties faced by dementia patients and their caregiversr[4,3]. Clearly, in Canada we are not restricted by the stringent guidelines of hospice admittance. Nevertheless, information derived from the FAST can be useful in generating questions regarding the appropriateness of care, guiding care decisions, and formulating plans. The FAST is recommended as only one piece of information that should be used to decide on the best course of care. Indicators of general debility, such as ability to perform ADL's, and nutritional status are of added importance[3].

Dementia is one of several conditions that often lead to decisions by patients and their families to use palliative care services. The evidence indicates that when possible, the majority of professional and family caregivers prefer some degree of palliative care over more aggressive care plans[5]. A specific challenge faced in providing appropriate end-of-life care to demented elders is determining to what degree palliative practices should become part of the overall care plan. Prognostic estimates are important in making sound decisions regarding end-of-life-care[6,3]. Determining the stage of dementia in terms of cognitive and functional status has a host of clinical implications, and is important for two main reasons: (1) in determining the extent to which palliative care will become part of the overall care plan, and (2) to help reach the understanding that palliative care principles should be applied to all patients approaching the end stages of illness, when cure is no longer an option or prolonged survival can be achieved only with significant burden[3]. Unfortunately, healthcare professionals have traditionally been reluctant to talk about death with their patients, and there is a tendency to err on the side of optimism about prognosis and impending mortality, regardless of diagnosis[6,3]. As patient quality of life progressively declines, such an optimistic outlook and miscommunication provides a disservice to patients and caregivers by delaying the time in which meaningful palliation can be implemented[7].

Sudbury[8] explains that typically little thought is given to palliative care in the early stages of dementia, but that good palliative care begins early on with (1) accurate diagnosis and disclosure, (2) patient and family education and support, and (3) planning for future incapacity by identifying a substitute decision maker who will respect and honor the wishes of the person who can no longer speak for him/herself. Phinney[9] echoes that the main concern for people with early dementia is how they can diminish the impact of the disease so as to lead a relatively normal life, and Wenger and Rosenfeld[10] stress that open communication about diagnosis, elicitation of preferences, documentation of preferences, and ultimately clear translation of those preferences into

direct care are fundamental components of quality end-of-life care. Research indicates that individuals with mild dementia retain a fairly high degree of independence and are often relieved to know a diagnosis versus the uncertainty of not knowing [9]. When ready, discussions regarding care plans and advance directives should be guided by an individual's values and beliefs about autonomy and moral agency. The importance of appropriate and frank communication between healthcare providers, patients, and family, conveyed in a time-sensitive and empathetic fashion, and respecting the remaining independence a demented individual possesses, cannot be underestimated.

Defining Palliative Care in Dementia

Substantial efforts have been expended on understanding the biomedical nature of dementia, in the hopes of determining underlying causes and identifying possible treatment and cures; however, focus has slowly been directed towards finding better ways of caring for people with dementia [9]. As the patient with dementia experiences the declines associated with the illness, there must come a time when quality of life is substantially impacted such that the focus of care shifts from aggressive treatment of underlying conditions to concern for comfort. This is the cornerstone of palliative care.

As much an art as it is a science, palliative care is a multidisciplinary approach to care concerned with providing a combination of active and passive therapies to comfort and support patients and families living with life-threatening illness, while also being respectful and sensitive to personal values, traditions and beliefs[1]. Palliative care begins at the time of diagnosis with advanced disease until death, and continues through the bereavement period with support for family and caregivers[11]. Kovach and Henschel[12] verify that maintenance of quality of life and pleasure is a primary goal when caring for people with irreversible dementia. Sachs et al. [12] use the term palliative care interchangeably with 'comfort care' to refer to care directed at improving quality of life by reducing the impact of symptoms and providing support. Billings[6] defines palliative care as a comprehensive, interdisciplinary approach to the care of patients and families facing a terminal illness focusing primarily on comfort and support that includes 4 key aspects: (1) meticulous symptom control, (2) psychosocial and spiritual care, (3) personalized management plan designed to maximize patient-determined quality of life and (4) appropriate delivery and usage of coordinated services in the home, extended care facilities, day care centers, and specialized units.

Palliative care should not be misunderstood as "withholding care" or "doing nothing", but rather it should be viewed as "aggressive" comfort care that strives to maximize patient quality of life by attending to the physical and spiritual needs of patients, and by providing environments in which patients can have meaningful encounters with family and loved ones [14.]   Key players on the palliative team include nurses, nursing aides, primary care physicians, a social worker, spiritual counselors, occupational or physical therapists, an activity coordinator, and volunteers. Palliative services typically include management of patient psychosocial comfort, inpatient/nursing facilities designed for symptom control and/or respite care, education, counseling, spiritual counseling, and social services [1,15]. The success of the palliative care approach requires that patients and caregivers recognize that while death is to be expected, it is to be neither hastened nor delayed by supportive care[3].

While concern with palliative care has advanced over the years, management guidelines were originally developed for cancer patients and those with other, non-dementing illnesses. There is expressed agreement for the pressing need to develop specific palliative practices for those dying with dementia[16]. The Ethics Committee of the American Geriatrics Society [10] identifies clear areas for improving end-of-life care for vulnerable elders, including: (1) physical and emotional symptoms, (2) support of function and autonomy, (3) advance care planning, (4) aggressiveness of care near death, and (5) patient and family satisfaction. In an audit of palliative care in dementia, Lloyd-Williams[17] (1996) concluded that elderly patients with dementia did not receive adequate or appropriate palliation for their symptoms and that improved education in the principles of good symptom control is required of practitioners responsible, caring for demented elders.

General Issues in Palliative Care Planning

A key goal in any palliative approach must be to help the dying person achieve a 'good death', which as outlined by Field et al. [10] as one that is "free from avoidable distress and suffering for patients, families and caregivers, which is in general accord with patients' and families wishes, and that is reasonably consistent with cultural and ethical standards." Determining how best to accomplish this unavoidably involves making a succession of weighty care decisions that often present considerable ethical dilemmas. Decisions regarding cardiopulmonary resuscitation, use of antibiotics, tube feeding, and transfer to an acute care setting are prominent. The Alzheimer's Association[14] outlines five key steps to effective healthcare planning: (1) exploring the issues, (2) discussing preferences with loved ones, (3) creating an advance medical directive and durable power of attorney, (4) sharing the plan with others as appropriate and storing documents carefully, and (5) maintaining and updating the plan as needed. Whatever decisions are made regarding care, the fundamental right of patient autonomy and choice throughout the course of illness must be respected, and as best possible, preserved. There is an inherent obligation on behalf of the medical community to attempt to provide good advance care planning in an effort to avert the possible negative outcomes of poor planning [18].

While end-of-life decisions are typically associated with long-term care and intensive care settings, Billings[6] notes that such decisions may be appropriate within the home care setting, where issues of hydration or antibiotic treatment may arise. To help guide decisions regarding care and reduce the stress of decision-making, Volicer[15] proposes that five treatment designations, varying according to the goal of care and use of life-sustaining treatments, should be considered in any care plan, and should be made before critical situations arise: (1) Full care, (2) Do not resuscitate (DNR), (3) DNR plus do not transfer (DNT), (4) DNR plus DNT, plus do not work up fevers (DNWU), and all of the above plus do not tube feed (DNTF). Based on these designations, Volicer recommends against the initiation of CPR in most dementia patients because of the extremely limited benefits in frail elderly patients. Applebaum[19] et al. for example, found that among 115 nursing home residents in whom CPR was initiated, 102 were pronounced dead on arrival in the emergency room, and 2 more died within 24 hours of hospital admission. In the case of life-threatening infections, it is generally

recommended that dementia patients should not be transferred to an acute care center for treatment, reducing the possibility that acute care staff (who may be less familiar with common palliative practices) may opt for and implement aggressive interventions that are not well-tolerated by patients with dementia. Fried[20] et al. found that long-term care patients with pneumonia transferred to an acute care setting for treatment were associated with poorer outcomes and that baseline functional and cognitive impairment was associated with greater declines following hospitalization. Particularly in the case of dementia where impairments such as falls, incontinence and delirium are prevalent, hospitalization in an acute setting may be a particular concern[20].

Advance directives, when completed, specify patient choices for care and typically convey decisions regarding (1) the threshold for withholding or withdrawing interventions, (2) value goals and specific treatment decisions, and the (3) provision of problem-solving strategies [17]. It is imperative in the case of dementia that patient preferences be elicited prior to significant cognitive impairment, when the capacity to do so is lost, typically in the third and fourth stages of the illness[21]. Derse[22] who explores the ethical issues arising in dementia care, notes that questions regarding capacity in decision making frequently arise when a patient's choices are contrary to what family or health care professionals deem appropriate and reasonable. Importantly, Derse[22] stresses that patients who do retain at least some decision-making capacity should be able to make personal choices about treatment, and that the level of decision-making should be reasonably related to the remaining abilities of the patient. Applying these guidelines may help preserve a patient's individual privacy and dignity.

It is widely recognized, however, that relatively few patients with dementia complete an advance directive by the end-stages that clearly articulates their care wishes [21, 15]. Some estimates indicate that fewer than 20% of the adult population has completed an advance directive, and that it is likely that only a small percentage of individuals in a dementia evaluation program will have completed an advance directive [23]. Furthermore, when directives are completed, they are typically too general in scope to effectively guide specific decisions regarding medical care[15] in which cases proxy decisions are required. Volicer[15] proposes that in cases where prior treatment decisions are not clearly articulated, planning with family caregivers should occur within the forum of a 'Family Conference', where open discussions with members of the treatment team can help to explore a patient's previous wishes and philosophies of care, expressed in informal ways to help arrive at some consensus on specific care decisions. Furthermore, reaching a consensus necessarily involves ongoing education, re-evaluation, and discussion as the disease progresses and new treatment issues arise. Finally, research indicates that a patient's own care directives are more likely to be followed if a proxy caregiver is chosen versus assigned by default, and if they received direct communication about end-of-life care preferences (Emanuel & Emanuel, 1992 and Terry et al., 1999, cited in Rempusheski and Hurley[21], 2000). Whenever possible following diagnosis of dementia, family members should become active participants in developing a treatment plan.

Palliative Management - Dementia: End-Stages

Palliative care is typically associated with the end-stages of an illness. While in the earlier stages of dementia a variety of management strategies may be implemented to help maintain function and foster independence, it is in the final stages of severe impairment that the main focus shifts to providing a comfortable, pain-free existence. Caregivers of those with end-stage Alzheimer's and other progressive dementias face a host of management issues. Several management issues distinguish palliative care of patients with dementia from those with other terminal illnesses. (1) Dementia patients are more likely to be cared for in nursing facilities than in their own home (intimates the need to recognize the nursing and care staff as central units of care whose concerns and thoughts should be validated in deciding the overall management approach – in essence they become part of the patient's extended family). (2) Behavioral and psychiatric management may become the central issues in care. (3) Recurrent, remediable medical conditions (such as infection) may be treated with symptomatic care alone. And (4) issues of hydration and nutrition are frequently controversial and challenging for care staff and family. [1,8, 3]

In a recent article, Volicer[14] conceptualized management in dementia as involving three domains, each interdependent and deserving of equal attention, (1) provision of meaningful activities and sensory stimulation, (2) appropriate treatment of medical conditions, and (3) management of behavioral symptoms, with quality of life central to the paradigm. In addition to addressing these management areas, Volicer stresses that maintenance of mobility, comfort, and attending to depression are key interface issues that must correspondingly be considered in the overall management regime

Management of Medical Symptoms

Caregivers and health professionals who are tasked with managing medical symptoms in the end-stages of dementia invariably face a host of difficult decisions regarding treatment goals and outcomes, including but not limited to issues of hydration, response to infections, management of comorbidities, elimination, skin integrity, and dyspnea and other elements of the overall care plan[1]. In a descriptive study of the last year of life in both dementia and cancer patients, McCarthy[16] et al. concluded that similar symptoms were experienced in both groups, with the three most common being mental confusion (83%), urinary incontinence (72%), and pain (64%). Low mood, constipation and loss of appetite were also frequently reported in more than half of the patients in their final year.

Difficulty in making treatment decisions is complicated by the long and variable course of the illness, the patient's reduced ability to make personal decisions regarding care, caregiver stress, and the frequent underestimation of the terminal nature of the illness [4]. Volicer[15] posits that the treatment of medical conditions in advanced dementia should be guided by three general considerations: (1) the shortened life expectancy of the patient (i.e. consideration of the cost/benefits of the potential to prolong life through aggressive treatments), (2) the likelihood that the dementia patient will be unable to report treatment side-effects, and (3) the potential for behavioral symptoms and discomfort to occur in response to treatment procedures and practices not understood by the patient. While aggressive, preventive strategies may be indicated in the early

stages of a dementia, health maintenance often becomes less of a concern as the dementia progresses, at which point the concern shifts to symptom management and maintenance of comfort [1]. The goal of comfort should guide management of medical conditions in the later stages of dementia, based on which approaches will produce the fewest symptoms and side effects. This philosophy is highlighted by Lloyd-Williams[17] who stresses that all professionals dealing with demented elders should be familiar with principles of good symptom control, and Morrsion[24] et al. echo that invasive or painful procedures and prolongation of dying through the use of life-sustaining methods are major causes of discomfort and suffering experienced by patients at the end of life, particularly patients with advanced dementia. Clearly, any treatment decision is best guided when advanced directives have outlined a clear care plan, or if not in place, the family has been appropriately included in any decision regarding care.

Infection

Infections and nutritional impairments (eating difficulties) are the key medical issues faced by caregivers in end-stage dementia. Common infections acquired in the long-term care setting include urinary tract infections, respiratory infections, and skin/soft tissue infection [25] and infectious complications are a common cause of death in patients with advanced dementia. Prevalence rates of infections range from 5 to 32 per 100 residents per month, and incidence rates range from 10 to 20 per 100 residents/month (Smith & Roccaforte, 1991, cited in Yoshikawa and Norman[25], 1996). Boyd &Vernon[1] emphasize that decisions regarding preventive measures such as influenza and pneumococcal vaccines should be central components of any advanced directive discussion. The literature is clear, however, that antibiotic treatment does not extend patient survival in severely demented patients, likely because of the recurrent nature of infections in this population and the increasing resistance of pathogens, and that treatment with antibiotics is not a necessary component to maintaining comfort during peak episodes of infection (Fabiszewski et al., 1990, cited in Lloyd-Williams[17], 1996; Volicer[15], 2001).

Hanrahan et al.[2] for example, concluded that among a group of dementia patients enrolled in a hospice program, survival times were no greater for those receiving antibiotics than for those who did not receive the antibiotics. Furthermore, Hurley et al. (1992, cited in Volicer, [15] 2001) found that antibiotic treatment had no significant effects on level of discomfort among a group of patients with advanced dementia, compared to those treated with analgesics and antipyretics only. Counter intuitively, in another study examining treatment preferences for cancer patients versus those with advanced dementia within an acute care setting, Ahronheim[26] et al. found that considerably more dementia patients received antibiotics for identifiable infections, explaining that in some cases antibiotic treatment may be implemented if life-threatening infection produces significant, unbearable discomfort. It is likely in the earlier stages of dementia that antibiotic therapy may be indicated. However the decision to treat infections must be weighed by the often burdensome and discomforting diagnostic procedures involved, including the use of intravenous lines, drawing of blood, and the possibility of adverse reactions [26, 13] In keeping with the palliative philosophy, Ahronheim[26] et al. consider diagnostic tests to be inconsistent with good palliative care, furthermore that noncomatose patients who are dying should be offered sedation as an alternative to

antibiotics, and that in fact the infection itself may elicit its own coma and sedation (allowing for a peaceful death) while antibiotic therapy may prolong the dying process.

Tube Feeding

Dementia is also likely to present significant nutritional problems as those with severe impairment enter the later stages of dementia [15]. One of the most difficult decisions in the care of severely demented elders is the withholding of nutrition and hydration in response to the patient's refusal to eat or drink [1]. Refusal to eat commonly occurs in late stage dementia and is often linked to depression and medication side effects. Antidepressant therapy and medications used to improve food intake in AIDS patients (e.g. dronabinol and megestrol acetate) may be used to improve appetite in patients with severe and terminal dementia [15]. Identification of reversible secondary conditions, such as electrolyte imbalance, constipation, renal failure, and medications used to manage comorbidities that may contribute to nutritional decline should be diligently assessed and ruled out[1]. Pharmacologically, antiemetics including antihistamines, anticholinergics, corticosteroids and benzodiazepines may be used as adjuncts to nonpharmacological approaches when dealing with nausea and vomiting (Rousseau 1996, & Kaye, 1992, cited in Boyd & Vernon[1], 1996). McCann et al. (1994, cited in Billings[6], 2000) observed that among a group of chronic care patients who stopped drinking, dry mouth was the only evidence of physical suffering and that this could be treatable with simple mouth care (e.g. ice chips), concluding that dehydration is not a significant contributor to physical discomfort in later illness and does not need to be attended to with artificial hydration.

During the final stages, patients may be unable to swallow, and choking and aspiration become serious concerns.[1] Perhaps the most controversial and ethically convoluted aspect of nutritional care in the terminal stages of dementia is the decision whether or not to initiate tube feeding. Unfortunately, invasive nutritional interventions with nasogastric, gastric, and jejunal tubes have historically been the rule as neurological symptoms worsen and patients become incapable of being nourished orally. Ahronheim[26]et al. found that patients with dementia were more likely to receive enteral tube feeding than cancer patients, and that while the expectation is that dying patients will eat or drink little due to poor appetite or altered consciousness, there was no indication that tube feeding would improve the situation, and that in fact it was likely to cause more discomfort. Tube feeding is also associated with several potentially undesirable side effects, including cramping, nausea, diarrhea and vomiting [15].

In a study looking at painful hospital procedures experienced by cognitively intact subjects, Morrison[24] et al. (1998) found that subjects rated nasogastric tubing as the most painful hospital procedure. While there is no reason to believe that cognitively impaired patients would experience the pain any less, this procedure would seem to be inconsistent with the goal of maintaining comfort. Implementation of a feeding tube often requires the use of physical and/or pharmacological restraints that reduce quality of life and deprive the patient of social interaction and personal meaning during mealtimes[15]. Clearly, key management goals in end-stage dementia are to ensure that patients are adequately nourished and are not at risk for aspiration. However, the literature is consistent with regards to the fact that tube feeding (nasogastric and

gastric) should be avoided, if at all possible, that it does not prevent aspiration and in some cases it may be associated with an increased risk for aspiration [26,6]. Specific feeding techniques such as altering food consistency to prevent choking (e.g. pureed foods, using thick as opposed to thin liquids thus reducing the coordination needed to swallow, gentle massaging of the cheeks, etc.) may be successful in maintaining appropriate nutrition in severely demented patients [15]. Strategies exist to appropriately nourish patients even in the latest stages of dementia, and they should become central components in the overall palliative care plan.

Dyspnea

Dyspnea is also common in late stage dementia and deserves palliative intervention. In a retrospective study of 17 terminal stage dementia patients, Lloyd-Williams[17]found that dyspnea was the most recorded symptom, occurring in 12 of the 17 cases. Underlying causes of dyspnea, including congestive heart failure, pneumonia, or positioning of bedridden patients, should be addressed and treated first [1]. The most frequent therapies for dyspnea include inhalants, oxygen, appropriate positioning, steroids and oral opioids. For most terminal patients, opioids, corticosteroids, or benzodiazepines (for anxiety) are recommended, and the use of oxygen, while beneficial for some patients, has doubtful usefulness for severely demented patients (Billings[6], 2000; Berry, 1993, & Rousseau, 1996, cited in Boyd & Vernon[1], 1996).

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"I am Maria!!!"
Part II

<div style="border:1px solid black;">

Part I.

It is now one year later. Giuseppe has used a respite bed twice for a week when he felt he could no longer cope. He has felt very proud of his abilities to care for Maria at home. His Italian friends are unfortunately inviting him and Maria out less often and Giuseppe is becoming more isolated.

Maria suddenly has a small left-sided stroke, with good physical recovery, but is exhibiting paranoid behaviour now. She hit Giuseppe when he came to visit her at the hospital. She at times may not even recognize him. He isn't sure. Antonia came home from New York and confronted the health care professionals, saying that her father couldn't cope and they had to leave Maria in hospital or find her a long term care bed.

Maria has to move to a new facility (separate from the respite bed facility that she was in) 30 miles away. The family physician says he will follow her, but a whole new health care team is now involved.

</div>

Questions:
1. How does the new care team in the facility get all the information about who Maria is and what the family needs have been?

2. What are the issues now that this new care team must address?

Care for Elders Module Evaluation

Module Title: **Date:**   **Location:**

Please rate the following statements (✓):	Strongly Disagree	Somewhat disagree	Neutral	Somewhat Agree	Strongly Agree	N/A
1. The organization, room, and timing of the session was adequate						
2. The pre-reading package covered information that was new to me						
3. The pre-reading package was well organized and easy to read						
4. Today's session DID improve my knowledge of interdisciplinary roles, responsibilities and team dynamics						
5. The facilitator was effective in keeping discussion moving forward						
6. The facilitator provided new, critical information as needed						
7. The case complexity or difficulty was appropriate for my level						
8. The discussion in my group was helpful for my learning						

1. Please name **two** changes in your own practice that you will implement as a result of what you learned today.

   1. _____

   2. _____

2. Please name **two** ways in which this session could be improved.

   1. _____

   2. _____