Aging Forum: ***Until There's a Cure: How to Help Alzheimer's Patients and Families NOW"***

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Nursing homes are often perceived of as either ineffective "junior hospitals" or as poorly executed residential options. Two critical themes dominate the research literature on the U.S. nursing home industry: 1) many patients receive poor quality care; and 2) hiring and retaining a workforce that is satisfied and high performing is a major problem. Because 50% to 75% of individuals in nursing homes have dementia, the quality of nursing home care is particularly relevant for those with Alzheimer's disease and related dementias.

Nursing homes provide important skilled care, and the need for this skilled care will not abate in the near future. In my time with you this afternoon, I will briefly outline three problems and some solutions.

1. **Nursing Home Staff Do Not Adequately Understand or Treat People with Dementia Behaviors**
    a. <u>Problem</u>. The needs of nursing home residents with dementia are often left unmet because staff don't know how to interpret dementia behaviors (DBs), complete a comprehensive assessment or intervene to meet needs (White, McConnell, Bales & Kuchibhatla, 2004; Kovach, Logan, Simpson, & Reynolds, 2010). In a recent six month period, the Milwaukee Police Department was called 386 times to nursing homes. The police department reports that many of those were calls to respond to resident behavior issues (Alzheimer's Association Task Force Report, 2010). Commonly, the individual is restrained and handcuffed in order for the law enforcement official to transport him or her. The Chapter 51 petition is initiated so the person can be involuntarily committed to a psychiatric facility. The transfers,

in and of themselves, create trauma for the individual and can worsen health and behavior. In too many cases emergency detention is being used as a vehicle to involuntarily medicate and discharge nursing home residents, despite the fact that the FDA has issued "black box" warnings regarding such use (Alzheimer's Association Task Force Report, 2010).

We have tested an assessment and treatment protocol called the Serial Trial Intervention in two RCTs funded by NIH and the intervention is highly effective in decreasing dementia behaviors, discomfort and new comorbid problems (Kovach, Logan, Noonan, Schlidt, Smerz, Simpson, & Wells, 2006). However, the diffusion of this intervention into practice, particularly in poor-performing homes, will not be far-reaching without federal implementation programs. Our research and that of others shows that dementia behaviors often represent an acute delirium superimposed on dementia, which is caused by a physical problem such as pain, or a psychosocial unmet need (Kovach, Kelber, Simpson, & Wells, 2006; Beck, Baldwin, Modlin, & Lewis, 1990; Sloane et al., 1997). For example, if a person resists being moved for bathing, the problem is often arthritic pain and timing the person's arthritis medication for peak action during the scheduled bath time will prevent resistive behavior. When the behavior does have a psychosocial etiology, improved training of staff in providing anticipatory care for psychosocial and environmental needs could prevent escalation of the behavior to a crisis point.

Our research shows an astounding lack of assessment following behavior change and that nursing staff do not have knowledge of or utilize a wide array of available therapeutic interventions. We found that the most important factor in determining the speed with which a change in condition is identified is the quality of the nurse's assessment (Kovach et al., 2010). I will share one example from our study. A woman with dementia began exhibiting behavior that was deemed to be paranoia and she was treated with a psychotropic drug. If someone came close to her she would exclaim, "No, no no!" Looking back over her records there was also some indication that there were changes in her movement of her lower right extremity. Finally, on the 27th day after this behavior change was first documented, the person's hip was x-rayed and found to be fractured. Her behavior, becoming anxious and exclaiming, "no" when people approached her, was her way of communicating that something was wrong, that she would hurt if she was moved. Imagine the month of pain she endured without treatment for a fractured hip.

b. <u>Solutions</u>. Competence of staff needs to be improved through training, through requiring that more registered nurses provide care in nursing homes, and through the wide-scale transfer of empirically validated interventions such as the Serial Trial Intervention to clinical care provided in the nursing home. The goal is to reduce out-of-facility placement in acute general or psychiatric hospitals and to keep people comfortable in the nursing home. The costs of treating many acute illnesses of nursing home residents are directly related to illness severity (Kruse, Mehr, Van Der Steen, et al. 2005). The Serial Trial Intervention is a clear and straightforward protocol that is initiated when a person with dementia exhibits a change in behavior and the person's need or the reason for the behavior change is not clear cut. It involves assessing to identify the person's physical, psychosocial or environmental need and intervening to treat that need when appropriate or consistent with the goals of care for that resident. If an etiology for the behavior change is not found, we utilize nonpharmacological comfort measures to try to ease the person's troubled state. If that is not effective we administer a low dose analgesic, to determine if the person may be in pain. We know this population is tremendously undertreated for their musculoskeletal and neuropathic pain, so a trial of analgesics is used. I'll share one case: A gentleman was living at home and highly agitated on a daily basis. He was highly restless and obsessively complained about burning in his leg and deep itch. The family caregivers could no longer cope and transferred him to the nursing home. He continued to be very restless and agitated. He was entered into our clinical trial and he complained about his legs, saying "I could go down there and pull my skin off." Many of you may recognize that this symptom is pretty typical of neuropathic pain. But because he was a person with dementia who had agitation, none of the care providers thought of that until the nurse got to Step 4 of the Serial Trial Intervention. The nurse administered a dose of prescribed Tylenol, saw an improvement, realized the pain was probably neuropathic in origin, called the physician and got the person started on medication indicated for neuropathic pain.

The staff described his behavior following treatment as "a day and night difference in which he was now 100% relaxed. We have to wonder if earlier detection and treatment of his pain could have prevented or delayed his transfer to the nursing home. I want to emphasize that the majority of people assessed and treated with the Serial Trial Intervention are treated with non-pharmacologiocal interventions. It is common for us to find that the person has too many environmental stressors, is not receiving enough exercise, is bored or is not receiving enough meaningful human interaction. These needs are easily met with inexpensive nonpharmacological interventions that have no side effects. My recommendation is that the Serial Trial Intervention be used to transform nursing home dementia care across the United States. This intervention is not costly, is replicable and effective and has been associated with no serious side effects.

2. **Palliative Care is Poorly Executed**.
    a. <u>Problem</u>: Nursing homes are where a lot of people die. Approximately 22% of all deaths in the Unites States occur in nursing homes (Centers for Disease Control, 2006). And this number would be considerably higher if not for the common practice of transferring nursing home residents to the hospital immediately prior to death (Mezey et al, 2002). Professionals working in long-term care should be experts in the holistic model of palliative care, which calls for comfort care and treatment of the whole person and family rather than futile attempts at curative care. And yet, this model has not been embraced. Research findings from nursing

    homes reveals poor symptom management (Teno, Weitzen, Wetle, & Mor, 2001) and low use of hospice care (Happe et al., 2002). When hospice services are used, nursing home staff then think the responsibility for management of symptoms lies with the hospice staff. Hospice staff, while great at cancer symptom management, often have limited understanding of end-stage dementia care, come into the facility from outside agencies, and do not know the resident or family well.

    b. <u>Solutions</u>: The competence of nursing home and hospice staff needs to be improved. Nursing home staff need increased education and need to be held more responsible for symptom management and family counseling. Building a trusting relationship with family members over time through regular family counseling can prepare the family for shifting medical goals to symptom management and comfort rather than futile attempts at cure. There is a need for increased use of hospice services in nursing homes, but many hospice staff need increased skills regarding end-stage dementia care.

3. **Nursing home culture and environmental design contribute to physical and psychosocial problems**.

    a. <u>Problem</u>. It has been said regarding nursing homes, "There are few nurses and it is not a home." Many nursing homes were initially designed based on a medical model for care delivery with long corridors, an institutional scale, and rigid schedules for activities. This creates a host of problems. For example, bodies are meant to move. They break down in all sorts of ways when movement is limited. When there are decreased opportunities for remaining safely mobile, muscle atrophy, increased falls, use of wheelchairs, and resulting pressure sores and other problems associated with immobility occur.

A psychosocial process of becoming "institutionalized" has been described in multiple reports regarding nursing home care (Krause & Shaw, 2000). In this process people give up having preferences and control over their daily activities. These changes are accompanied by increased depression and anxiety as well as decreased perception of quality of life. Nursing home staff can provide all of the skilled care needed within more homelike settings and with less rigid schedules that allow for residents to retain more control over their daily lives.

b. Solutions. We need to begin the process of expecting dining rooms in nursing homes to be small and homelike, for there to be living rooms, and for there to be space and opportunity for participating in quality-of-life activities and maximum mobility in the immediate environment. The preferences of residents, even if provided by family proxy, need to take more precedence.

There are things that can be done right now to significantly improve quality of care and quality of life for those with dementia in the nursing home. Thank you for your attention and your interest in improving the lives of those with Alzheimer's disease and related dementias.

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