Increasing Quality of Life for Parkinson's and Alzheimer's Patients

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As the older population increases there is a corresponding rise in individuals who are most vulnerable to and most affected by chronic conditions. These conditions are the major cause of illness, disability and death in the United States, and are overtaking infectious diseases such as influenza and pneumonia as the primary health problems facing America. Over 100 million Americans of all ages suffer from chronic health conditions (Hoffman, Rice and Sung 1996). In 1995 the cost of medical care for Americans with chronic conditions was $470 billion. Almost 160 million people will be affected by 2040, at a cost estimated to be as high as $864 billion (Robert Wood Johnson Foundation 1996).

Chronic conditions are those defined as illnesses or impairments that cannot be cured. Some of the most prevalent, such as sinusitis or hay fever, are not disabling. Others, such as heart disease and arthritis, can cause significant limitations in an individual's ability to perform the basic activities of daily living (ADL), and may require personal, social or rehabilitative care over a prolonged period of time. The most common chronic conditions for those age 75 and older (regardless of gender) are arthritis, hypertension, hearing impairments, heart disease and cataracts.

Added to this escalating equation are the rising demands on healthcare utilization and caregiving that result from the proportional increase in progressive neurological conditions such as Alzheimer's and Parkinson's disease, Multiple Sclerosis and Amyotrophic Lateral Sclerosis (ALS). This paper examines the impact of Parkinson's and Alzheimer's disease on the emotional and physical health of the affected population and their caregivers.

Illustration #1: In-home Care and Parkinson's Disease

According to a 1998 report from the National Institute of Neurological Disorders, an estimated 50,000 Americans are diagnosed with Parkinson's every year. Because Parkinson's disease is a chronic illness, the majority of patients are cared for in their homes by a spouse, family member or other caregiver. Thus, Parkinson's disease, like other chronic conditions, affects not only the individual, but the entire family. Family members typically have not anticipated that they will need to assume the role of spousal or parent caretaker, and are often ill-equipped to manage the emotional and physical demands that come with that role (Wallhagen & Brod 1997).

The unpredictable trajectory of Parkinson's disease challenges the perceived amount of choice and control individuals and families have over their future. The caregiver often must assume more responsibilities in caregiving duties as well as in managing the household. The success with which families or significant others cope with chronic illness may affect how the patients manage their conditions. Successful management by the caregiver is thought to lead to a decrease in the downward slope of the disease's progression.

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If, however, caregivers are unable to continue providing the needed care because of increased burden, the result is expensive care in an extended care facility (Chenier 1997). Holicky advocates that caring for caregivers should be viewed as a method of preventing a decline in their health (Edwards & Ruettiger). When caregiver health declines and requires healthcare intervention, there is an increased overall cost of care to the family. *Effective strategies for reducing healthcare costs can be achieved by (1) realizing that the caregiver is the intermediary between the patient and the healthcare system and (2) finding ways to reduce caregiver burden.*

Caregiver burden

Caregiver burden is defined by Zarit, Todd & Zarit (1986) as the extent to which caregivers perceive their health, social life and financial status to be suffering because of their caregiving experience. Caregivers often feel overwhelmed by additional tasks: At times they must carry both their own responsibilities and those that a spouse or significant other is no longer able to perform. The increasing number of commitments may have both personal and relational costs. Stressors include the physical demands of caregiving, conflict over competing roles, difficult or annoying care-receiver behaviors, loss of companionship, and a lack of support (Williams 1994).

Increased caregiver burden in Parkinson's disease families is associated with a significant decrease in management of the disease (Edward & Ruettiger). Consequences of this increase in caregiver burden may include:

- Caregivers become so involved in caregiving that they neglect their own physical and mental well-being (Chenier 1997) and may, therefore, create an "additional" patient (Parks & Pilisuk 1991; Williams 1994).

- Social support has long been regarded as a powerful mediator or buffer for stressful situations (including caregiving); a perceived lack of support from family or friends may cause caregivers to feel lonely or isolated (Borneman 1998).

- Abuse or neglect of the care recipient may result.

- Declining physical and emotional health of the caregiver can impact the care patient who must be institutionalized.

Since an increase in burden results in a decrease in management and increased institutionalization, the professional's role in decreasing caregiver burden is important to both the family and in reduced patient care expenses. Relief of this burden and, thus, more successful management of the disease may need to become the focus of nursing intervention.

The Professional's Role

The rehabilitation nursing role of counselor, educator and supporter contains these components:

- Support the family in caring for the Parkinson's patient in the home by assisting them to determine what role and what level of caregiving they may assume. Caregivers must be able to identify a realistic level of support they can give without experiencing unnecessary guilt (Kuyper 1998).

- Focus on both caregiver and patient. Educate both parties about the symptoms associated with Parkinson's and the expected trajectory of the disease. Informing both the patient and caregiver about intervention methods to control symptoms as they arise can affect the health of both.

- Promote active participation with support and exercise groups for both caregiver and patient. These groups offer continuing education and socialization opportunities, and allow for the expression of frustrations that can decrease the burdens and frustrations encountered in the caregiver/patient relationship.

- Examine the changing components of the relationship by assessing communication, workload distribution and lifestyle satisfaction, thus identifying potential problem areas that could benefit from counseling.

- Explore the advantages and disadvantages of home assistance or respite care with the caregiver and patient.

Illustration #2: Alzheimer's Disease and Nutrition

Alzheimer's disease may reach epidemic proportions by the middle of this century, increasing by 350 percent unless effective methods for prevention and treatment are developed (Medscape 2000). Approximately 4 million Americans have Alzheimer's disease (AD), affecting 1 in 10 people over 65 and nearly half of those 85 and older (Hingley & Ruggeri 1998), and it is the fourth leading cause of death. Without a cure or prevention in the foreseeable future, efforts toward improving the quality of life for AD individuals must be undertaken.

AD begins with mild cognitive deficiencies such as forgetfulness and gradually worsens, manifesting in difficulties with orientation, loss of independence, disruptive behavior and disordered eating behavior. Weight loss is common in AD patients, leading to reduced muscle mass and a loss of functional independence that typically results in an increased risk of infections, skin irritation ulcerations and falls. These factors combine to produce a decreased quality of life and an increased likelihood of hospitalization for AD patients.

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Weight loss in AD is not a new phenomenon; Alois Alzheimer first observed it in 1907. More recently, numerous studies have systematically observed lower weights for hospitalized dementia patients, particularly those with AD, than those of control subjects in good health (Morgan & Hullin 1982). Energy malnutrition, wasting and low body weight are found in approximately half of the demented older adults (Donaldson, Carpeter, Toth, Goran, Newhouse & Poehlman 1996). A two-year longitudinal study following 362 individuals with AD and 317 healthy controls found that almost twice as many AD individuals experienced a weight loss of 5 percent or more (White, Pieper & Schmader 1997).

The impact of weight loss on mortality has also been studied. White, Pieper and Schmader (1998) found that weight loss is associated with the severity and progression of disease. When controlled for age and stage of AD, weight loss is a predictor of mortality; weight gain significantly decreases mortality and slows progression. Thus, it is important to study useful clinical interventions that encourage food intake, offsetting malnutrition and weight loss.

Animal-assisted therapy

Environment is an important influence in managing difficult behaviors associated with AD. The more vulnerable the individual, the more likely it is that he or she will be influenced by environment (Lawton 1975). Although using animals to assist human therapeutic activities has a long history, its extensive, documented and organized use is relatively new (Beck 1985, 2000; Beck & Katcher 1984, 1996; Beck & Meyers 1996). Yet it has been widely observed that interactions with animals can positively influence and improve morale.

One of the first therapeutic explorations of using animals for institutionalized adults involved introducing a cat "mascot" into each ward of a nursing home (Brickel 1979). Some negative aspects, such as concerns about fleas and allergies, were reported, but the overall impression was that the cats improved patient responsiveness, offering them pleasure and enhancing the general milieu of the treatment setting. More recently, studies in different nursing homes reveal that, in general, the staff believe animal programs to be beneficial without significantly adding to the workload (Cole & Gawlinski 1995; Crowley-Robinson & Blackshaw 1998; Kranz & Schaaf 1989).

Many nursing homes today offer residential animals or animal visitation as part of their recreation programs (Beck & Katcher 1996), with most using dogs, cats and rabbits to improve patient social interaction (Beck & Katcher 1996; Bustad 1980; Draper, Gerber & Layng 1990; Fick 1993; Perelle & Graville 1993). Bird feeders in a nursing home setting improved both self-reported and nurse ratings for control, happiness and activity (Banziger & Roush 1983).

There is little indication that animal programs are particularly dangerous and, while there are risks associated with any animal contact, there are few reports of adverse effects (Shantz 1990; Walter-Toews 1993). Nevertheless, value to the patients must be demonstrated in order to justify any risk associated with animal contact; and one of the most common criticisms of animal-facilitated therapy is that they are not goal-oriented with a clear evaluation of goals (Beck 2000; Beck & Katcher 1984; Draper, Gerber & Layng 1990; Hundley 1991).

Health benefits

It is now generally accepted that natural surroundings and contact with nature is good for people (Ulrich 1993); viewing nature scenes dominated by green vegetation is less stressful than viewing urban scenes devoid of vegetation (Ulrich 1979).

Fish tanks offer a way to introduce "nature" into the home or therapeutic setting. Subjects who observed fish tanks under laboratory conditions experienced significant decreases in blood pressure (Katcher, Friedmann, Beck & Lynch 1983). Other studies have shown that people who contemplated an aquarium underwent dental surgery with reduced stress (Katcher, Segal & Beck 1984). One of the first studies on the uses of fish tanks for older adults was conducted in public-subsidized housing. Residents who received aquariums were assessed to be more relaxed and to have improved overall satisfaction with their leisure than those who received services but no aquarium (Riddick 1985).

An analysis of nutritional intake

Researchers examined how fish aquariums influenced nutritional intake for AD residents in three specialized Alzheimer's units located in extended-care facilities in Indiana. The influence was analyzed by comparing the nutritional intake for the baseline period with the treatment period. All three facilities experienced a significant increase in nutritional intake when residents were exposed to aquariums.

This baseline intake was then compared to the six-week, post-treatment intake, revealing another significant increase in all three facilities. Combined data from the three facilities showed that, not only did the aquariums increase nutritional intake during the treatment period, nutritional intake for the six-week, post-treatment period was significantly higher than the treatment period.

Analyzed individually, the majority of subjects (87 percent) showed an increase in dietary intake, with only 9.7 percent having no change or a decrease in their dietary intake. Nutritional intake was also analyzed by meal, yielding a significant increase between baseline intake and treatment that remained for all meals, and for the six-week post-treatment period.

Several observations suggest why people ate more in the presence of aquariums. Individuals with a history of pacing and wandering sat during mealtimes for longer periods observing the aquarium, leading to increased nutritional intake. Lethargic individuals were more attentive and awake in the presence of aquariums, and increased their nutritional intake. These effects lasted throughout the study period.

Another positive benefit of the increased nutritional intake was an approximately 25 percent decrease in the use of supplements, yielding a significant savings in healthcare costs.

Another positive benefit of the increased nutritional intake was an approximately 25 percent decrease in the use of supplements, yielding a significant savings in healthcare costs. Typically, supplements such as Ensure, Sustacal, Glucerna or Carnation Instant Breakfast were routinely given to patients when less that 50 percent of the meal was consumed and, in many cases, wasted when only a small portion was consumed.

Nutritional problems, especially unexplained weight loss in individuals with AD, are of great concern since they are an indicator of protein-energy malnutrition in the older adult and predictive of mortality (White et al 1998). This study demonstrated a non-invasive and non-chemical intervention that resulted in increased dietary intake. Only eight subjects demonstrated no increase or a decrease in nutritional intake. Overall, the study subjects showed a 21.1 percent increase in nutrition when treatment was initiated and a 27.1 percent increase through the post-test period.

Implications for AD individuals and caregivers

Numerous, positive implications exist for increasing nutritional intake in individuals with Alzheimer's. Increased nutritional intake can delay muscle wasting which can, in turn, delay functional dependence and loss of autonomy. Additionally, the increase in intake can help prevent skin infections, decubitus ulcers, sepsis, and help decrease the incidence of falls. Quality of life improves for the Alzheimer's individual, and caregiver burden is reduced (Sandman, Adolfson, Nygren, Hallmans & Winbald 1987).

Several additional benefits accompany the reduced need for supplemental nutrition. Eating food, with its variety of textures and tastes, helps stimulate the sensory system. Facilities or home caregivers need not endure the cost of preparing and serving meals that are not eaten or substitute prepared supplements that maintain nutrition. In summary, more food consumed during mealtime brings increased nutritional value and sensory sensations, and decreases expenses attributed to wasted food and supplemented nutrition.

In the past, animal-assisted therapies with AD individuals have focused on the use of dogs, cats and rabbits but, because the AD individual can act inappropriately without warning, these programs have required direct supervision to prevent animal injuries. Specifically designed automated aquariums can be safely used and require little staff attention, but had not previously been studied with AD individuals. The tanks used in this study provided a safe environment for the animals and are still intact several years after completion of the study. This study demonstrated that the aquariums held the AD individuals' interest, increased nutritional intake at mealtimes and decreased the use of supplements, yielding these positive effects for 87 percent of the individuals studied. There may be additional positive effects not measured in this study. It did appear that the aquariums facilitated interaction between AD individuals and visitors as a focus point for communication. Furthermore, this study demonstrates that the influence of animals can be quantitatively measured, showing more than anecdotal results.

This article is based on the following:

Edwards, N. E. & A. M. Beck (2001) *The influence of animal-assisted therapy on nutritional intake in individuals with Alzheimer's Disease.* under review.

Edwards, N. E. & K. M. Ruettiger The in*fluence of caregiver burden on the extent to which individuals with Parkinson's disease manage their condition: Implications for rehabilitation nursing,* under review.

National Academy on an Aging Society newsletter (1999).

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