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## Dementia & Caring

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### Abstract

Dementia is a degenerative disease of the brain that affects the elderly population. Dementia is caused by primary sources, such as organic brain disorder, and secondary sources, such as cerebrovascular attacks. Dementia can not be treated but is slowed down by medications such as acetylcholinesterase inhibitors, while other drugs treat the combative behaviors related to the disease. Dementia can be looked at through the pathophysiology and cognitive effects of dementia on a patient, as well as the perception of the patient with this disease. Lastly, Jean Watson's Caring Theory elaborates how nurses, as caring persons, should focus on patients with dementia, preserving and protecting their human dignity.

### Dementia: An Altered Life Process

With age come many things, such as wisdom and experience; with age also come many illnesses, such as congestive heart failure, hypertension and dementia. Carrieri-Kohlman, Lindsey & West (2003) define dementia as a loss of multiple acquired cognitive and emotional abilities sufficient to interfere with activities of daily living. It includes impairment in short and long term memory, as well as impairment of thought processes and high cognitive functioning as well as personality changes. Dementia is a gradual and debilitating degenerative disease that is very strenuous on the patient. The smallest tasks, such as getting dressed in the morning, can become most difficult and try-

ing tasks for a patient. Imagine having a sock in hand and looking at it not knowing what it is or where it goes, but knowing that you should know. Nurses can help the dementia patient, focusing on nursing as caring theory to nurture the patient and see him/her holistically as a person.

Dementia is a broad term that encompasses many forms and predisposing factors of cognitive degeneration. Today more than 4 million elderly people suffer from some form of dementia (Kolanowski, Litaker & Baumann, 2002). Dementia can also be related to primary causes such as Alzheimer's disease or Lewy body dementia; primary dementia is a dementia related to an organic brain disease and is not caused from any other illness. Dementia can be secondary when it is caused by vascular disease (such as cerebrovascular accidents), head trauma, Huntington's disease, HIV disease, substance abuse, Parkinson's disease, as well as Creutzfeldt-Jakob disease (Townsend, 2006).

Morphological changes to the brain and heredity are reasons why a person develops dementia. The three most common forms of dementia are Alzheimer's disease, vascular dementia and Lewy body dementia. Alzheimer's disease is hereditary, caused by mutations in chromosomes 21, 14 and 1. It is also a result of neuritic plaques, neurofibrillary tangles, decrease in neurons and atrophy of the brain (Boyd, 2006; Carrieri-Kohlman, et al., 2003; Cunningham & Archibald, 2006). Neuritic plaques are amyloid deposits, which are composed of axons, synaptic terminals and dendrites (Carrieri-Kohlman, 2003); these deposits build up on the brain, disrupting and ruining cholinergic neurons of the

brain. Neurofibrillary tangles, proteins in the brain, are chemically altered and destroyed, disrupting nerve functioning with cholinergic neurons (Boyd, 2001). A final cause for Alzheimer's disease is the alteration of the neurotransmitter acetylcholine and in the later stages, gamma-amino butyric acid (GABA). A reduction in acetyltransferase, the enzyme required to form acetylcholine, results in memory loss and permanent cognitive impairment (Boyd, 2001).

Vascular dementia, the second most common form, is related to cerebrovascular accidents and lack of blood flow to the brain, as evidenced by the impact on memory loss and cognitive functioning. Lewy body dementia, the third type, is characterized by episodes of confusion alternating with lucid intervals that can last for minutes or days, related to shifting levels of alertness (Cunningham & Archibald, 2006). Lewy body dementia has manifestations of hallucinations, delusions, dehydration and falls. Lewy bodies can be found in patients with Parkinson's disease but are found in higher densities in dementia patients (Cunningham & Archibald, 2006).

With dementia, patients experience memory loss, apraxia, loss of functional movement, and agnosia, an inability to recognize the surrounding environment (Carrieri-Kohlman et al., 2003). Keady (2003) describes what living with memory loss is like when he states, "I have no recall of past events except for my notes. They are my memory.... Reading books with more than three characters is out of the question as I have to go back and forth through the text to find out who's who and who did what." Keady also describes agnosia when he states that for months he wore two different black shoes, yet was unable to recognize that they were different, till one day he found the odd pair and realized what he had been doing (Keady, 2003).

Patients with dementia also experience personality changes and anxiety related to not being able to identify incoming information and not being able to attach meaning to it (Carrieri-Kohlman et al., 2003). Self identity is changed and this causes frustration, fear, anger, humility, and powerlessness. Patients' perception of losing their self identity is expressed in this statement: "I feared losing my last shred of dignity and control over myself. My diagnosis exposed me to the elements . . . it rendered me helpless, stranded with my tender underbelly exposed to the vagaries of family and strangers alike" (Kolanowski, Litaker & Baumann, 2002).

Since dementia is a degenerative disease, there is no cure, but there are medications that may slow down dementia or combat such things as hallucinations or psychosis. Dementia drug therapy focuses on the disruption of neurotransmitters in the brain. A therapeutic drug approach to dementia is acetylcholinesterase inhibitors. These medications

inhibit the production of acetylcholinesterase that breaks down acetylcholine in the synaptic cleft (Blennow, de Leon & Zetterberg (2006). Donepezil (Aricept), galantamine (Reminyl), rivastigmine (Exelon) and memantine (Namenda) are the four acetylcholinesterase inhibitors used to help delay symptoms and, in patients with severe dementia, even enhance cognitive functioning. Drug therapy also delays or improves problems in behavior and activities of daily living (Boyd, 2001). Boyd (2001) states that medications should be started at the early stage of the diagnosis to make a difference in the long term maintenance of cognitive functioning and delay of cognitive decline.

Donepezil is the first line of treatment for dementia, while galantamine is the newest with a different property than the other two. Galantamine inhibits the breakdown of acetylcholine but is also a nicotine receptor modulation, which sensitizes the receptors to acetylcholine, resulting in an increased activity of the receptor at low concentrations of acetylcholine (Boyd, 2001). Side effects of these drugs include nausea and vomiting, which can be reduced if the medication is given with food.

Studies have also shown a relationship between anti-inflammatory drugs (NSAIDs), cholesterol-lowering drugs, oestrogens and antioxidants, which can reduce the chance for Alzheimer's-related dementia (Carrieri-Kohlman et al., 2003). Other medications such as anti-anxiety drugs, anti-psychotics and anti-convulsants are used for combating behavioral symptoms such as hallucinations, delusions and agitation. Atypical anti-psychotics are used the most to control behavioral problems in dementia, since they are more effective and do not have as many side effects.

## **Jean Watson's Theory of Human Caring**

One of the unique human needs that nursing responds to is the need to be recognized as a person. Nursing thus brings the best dynamic to dementia care, because nursing involves the intimate personal knowing of the person behind the disease, thus creating a relationship and environment of care that nurtures, validates and celebrates the person, showing that he/she is of value and worth (Touhy, 2004).

A nursing theory that promotes personhood and is relevant to dementia is Jean Watson's Theory of Caring. Watson (as cited in Hendry & Douglas, 2003, p. 96) said, "Humans should not be treated as objects...the ultimate goal of nurses is protection, enhancement, and preservation of human dignity and humanity." Watson's theory is based on the following 10 caregiving factors that are used during the therapeutic relationship of the client and nurse.

1. Formation of a humanistic-altruistic value system
2. Instillation of faith and hope

3. Cultivation of sensitivity to self and others
4. Development of helping-trust relationships
5. Expression of positive and negative feelings
6. Creative problem-solving, caring process
7. Promotion of transpersonal teaching and learning
8. Supportive, protective, and/or corrective mental, physical, social, and spiritual environment
9. Assistance with human needs
10. Allowance for existential-phenomenological-spiritual forces (Wolf, 2003).

These carative factors focus more on the inner healing of the patient and the world that the patient is experiencing (Bernick, 2004). This theory lets nurses utilize their unique skills of compassion by using the carative factors to balance the sterile world of medicine and doctors. The formation of a humanistic-altruistic value system means caring for patients with kindness, love and concern to all human beings. From the moment nurses start assessment, they must provide compassion and concern for their patient no matter what the diagnosis is.

Developing a helping-trust relationship is the beginning of a nurse-client relationship and allows the client to trust the nurse, so he/she will confide in the nurse and give the nurse as much information as the client can. Expression of positive and negative feelings allows the client to feel how he/she feels, with the nurse giving the client support through therapeutic communication and care. Presencing is an intervention that encompasses this carative factor, allowing the patient to speak. Just being in the patient's presence lets him/her know that the nurse is validating but not judging the feelings that he or she is expressing, even if they are negative feelings. Supporting and protecting the mental, physical and social environment, as well as providing assistance with human needs, allows the nurse to provide a healing environment for the patient and care for the patient's basic and holistic needs.

## Patient Summary

The client that was in my care for a medical surgical rotation was an 88-year-old woman who was unable to care for herself and perform activities of daily living, related to advancing dementia. The patient was admitted to the hospital with severe weakness and was awaiting referral to an extended care facility due to her daughter's inability to care for her anymore. The patient had a history of mild renal insufficiency, hypertension, chronic atrial fibrillation, congestive heart failure, sick sinus syndrome and dementia. The patient was small, about 5'4 and about 130 pounds. Her vitals were in the normal range, with respirations at 16, blood pressure 147/64, pulse 64 and temperature 97 degrees. The client had a history of hypertension and had not yet been

administered her blood pressure medicine for the morning, which is why her blood pressure was high. The patient had irregular heart sounds related to the atrial fibrillation that she was currently being medicated for. The patient had less than three second capillary refill, no edema and was not wearing any form of antimobility accessories such as TED hose. The client had clear bilateral breath sounds with no shortness of breath or labored breathing and no sign of cough.

The client showed no signs of weakness when I cared for her, except once when she got up from the bed and stated, "I am a little dizzy." To that statement I responded by having her sit and then get up slowly, and after that she felt much better. The client was at risk for falls as evidenced by the sign over her bed; this was related to her medications, history of falls and wandering due to the dementia. The patient had bowel sounds present in all four quadrants, no evidence of skin breakdown and no pain or tenderness upon palpitation. She was on a soft food diet due to her dentures but was able to feed herself with no assistance. The patient was continent of stool and urine with a bowel movement during the shift. The patient's skin was warm and dry with no evidence of skin breakdown or shearing.

The patient was alert and oriented to herself but not to time or place. The patient was constantly asking "Where am I?" or "Why am I here?" of the people around her. If you stated that she was in the hospital because she was confused, she would get angry. She would also tell you that she didn't know why she was there because she had her own house; she would then proceed to tell us her address. The client was unable to remember my name or the names of the other nurses. She followed commands well and when asked to do something, such as get cleaned up, she would say "Ok, honey," and then ask, "Why am I here?" The client was very cooperative and pleasant to work with, only getting frustrated by my answers to why she was in the hospital. The frustrations soon subsided when I asked a different question. The client was unable to tell me the names of her daughters but was able to tell me how many she had. She also told me that she had a husband, including his name and what a wonderful man he had been. The client had a sad tone in her voice when she stated that he had passed away some time ago.

The client was able to perform tasks such as eating or washing herself up in the morning, needing no help to wash or use the toilet. The nursing staff would also give her towels to fold to prevent her from wandering the halls. The client was unable to concentrate on simple questions, such as if she liked green beans or carrots; she would say "I don't know" and then ask again why she was in the hospital. The client also wandered and I took her on walks around the unit, to reduce her risks of falls from walking by herself. On

one of our walks we met the patient's daughter. The daughter said, "Hi, Mom," and the patient stopped and looked at her for a minute, smiled and then hugged her and looped her arm through her daughter's arm, not once saying the daughter's name.

The patient seemed to be anxious as evidenced by her constant questioning about why she was there. I assessed her pain level to see if it was associated with the anxiety, but she stated that she had no pain. On top of her heart medications the patient had lorazepam (Ativan), an anti-anxiolytic, as well as donepezil (Aricept), an anti-Alzheimer's medication, that were related to her diagnosis of dementia.

## Care Theory Related to the Patient

The most important part of care theory is recognizing the person as a person and not treating the client like an object. During care of this patient, the focus was on caring and each caring moment was focused holistically on the patient as an individual. Care provided for this client involved sensitivity, respect and high moral commitment, to provide the client with as much human dignity as possible (Bernick, 2004). This was done by talking to the patient directly about life events important to her, such as her husband and children, and additionally by answering her repetitive questions the best I could.

Answering her questions about why she was there is one of Watson's carative factors of allowing the client to express her positive and negative feelings. Another example of utilizing Watson's carative factors and theory is assisting the client to meet her basic needs. I provided the patient with socialization by talking to her, for example, sitting next to her bedside and talking about her family. I provided morning care and assisted her as much as needed to help her get ready for the day. I provided her with choices on what to do for the day and encouraged her to eat her breakfast and lunch. I implemented the humanistic-altruistic system defined earlier during the caring process for this client. I provided the care for this client with kindness and promotion of personhood through interaction, presencing and allowing the client to have as much independence as I felt was safe.

## Aesthetic Experience

The following aesthetic experience relates to my client, because during the time that I cared for her, she always had to be reoriented, but when I asked her about her husband, she was able to talk a lot about him. She had stated with a smile that he was a good man. When I asked if he was still alive, her tone of voice was sad when she talked about how he had passed away, reminding me of this song:

*Ellsworth* by Rascal Flatts

Grandma burned the biscuits  
Nearly took the house down with it.  
Now she's in assisted livin'  
We all knew that day would come.  
We knew she was too gone to drive  
The day she parked on I-65.  
Found her on the shoulder cryin'  
She didn't know where she was.  
It's like her mind just quit.  
Oh, but bring up grandpa  
It's like someone flipped a switch.  
A front porch light and a blue DeSoto,  
Couple a straws in a coca cola:  
You could see it all goin' down.  
A handsome boy in army green  
A tear on his face, down on a knee  
Shaky voice, a diamond ring  
She'll put you in that town.  
Tomorrow she won't remember what she did today,  
But just ask her about Ellsworth, Kansas, 1948.  
She takes out his medals,  
A cigar box of letters.  
Sits and scatters pictures,  
Black and whites of days gone by.  
We started losin' her when she lost him,  
But to hear her carry on you'd swear she's seventeen again  
Football games and leaves a cracklin'  
Walkin' her home in his letter jacket,  
You can see it all goin' down.  
A perfect night on a front porch glider,  
Saying goodnight for the next three hours.  
Her tired eyes grow wide and bright  
When she talks about that town.  
Tomorrow she won't remember what she did today,  
But just ask her about Ellsworth, Kansas, 1948.  
While the world is fading all around her  
Sharin' a sundae at the counter  
He's goin' on and on about her  
Bet she's right there right now  
Tomorrow she won't remember what she did today  
But just ask her about Ellsworth, Kansas, 1948.  
(Thrasher, Moldey & Rooney, 2006, Track 10)

"Ellsworth" relates to my client cognitively when the lyrics talk about how she was in assisted living, which was where my patient was being admitted after the hospital. The line "she didn't know where she was" relates to the client as evidenced by her asking "Where am I? Why am I here?" and by her inability cognitively to recognize her surroundings and to cognitively process what she was being told.

"It's like her mind just quit" can be related to her

dementia on a cellular level, as evidenced by neurotransmitter imbalances and atrophy of the brain, a reason for the development of dementia. Certain parts of this aesthetic experience can allow others to understand dementia from the perception of this client. "Tomorrow she won't remember what she did today...Oh, but bring up grandpa, it's like someone flipped a switch." Clients like mine at the stage of her dementia can not remember what was just said to them, related to impairment in short term memory, but they are able to recall past events.

Dementia is a scary and frustrating disease that robs patients of memories, knowledge and being able to care for themselves. As nurses, it is our duty to recognize these people as human beings with a disease. It is wrong to label them as the "demented," since they are still persons in spite of their disease. Using caring and compassion with Jean Watson's Caring Theory can help us to give elderly clients with dementia the dignity that they deserve.

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