Integrating Depression, Dementia, and Delirium in the Older Adult

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Introduction

It is the intention of this paper to integrate the concepts of dementia, delirium, and depression in the older adult, and to relate these concepts to the individual's need for palliative care. This paper will identify caregiver issues in caring for persons with these conditions and will explore ethical issues when caring for these individuals.

Discussion of Concepts

Although cognitive impairment is a significant problem for the elderly, the literature agrees that it is not synonymous with aging. Depression, dementia, and delirium are not a normal part of aging (Foreman et al, 1992; Drance, 1990; Mangino &Middlemiss, 1997).

The etiology of depressive symptoms in an older adult is complex and may arise from several intersecting situations and conditions. Depression in the aged definitely differs in several ways from that of younger adults. One of the major differences is the insidious manner in which it develops and the concurrency with other events, which results in depression frequently going unrecognized and untreated (Ebersole & Hess, 1994). Often times this individual cannot look after themselves as well, and they lose their independence (Drance, 1990). Successful treatment of depression must include considerations of the individual's premorbid personality, determination of reactive origins, symptom relief, social support manipulation, and the importance of a positive relationship with health care providers (Ebersole & Hess, 1994).

Dementia, on the other hand, does not go unrecognized, but it may be misdiagnosed. This would be tragic since some causes of dementia are fully reversible. Dementia is a group of symptoms that signify there is mental deterioration to the point where there is a disturbance in everyday behaviors (Tuokko, et al, 1993). The brain function is disturbed because brain cells are no longer working properly. It is imperative that we, as nurses are available to assist the physician in diagnosis; after all, we are usually the front–line caregivers who are able to evaluate symptoms. Golden (1995) maintains that evaluating symptoms is the first step in distinguishing between Alzheimer disease and vascular dementia.

Defining delirium is a dilemma because of its fluctuating nature, widely varying and subtle clinical manifestations, and multiple etiologies. The literature agrees that delirium is transient in nature and manifests itself as an acute impairment in cognition and attention (Mentes, 1995; Tueth et al, 1993; Morency et al, 1994). Drance (1990) maintains that with delirium, the individual may have a sudden onset of confusion and should be treated as a medical emergency. For example, urinary tract infection is the most common factor associated with the diagnosis of delirium in older hospitalized patients (Tueth et al, 1993). We, as nurses, are in an optimal position to observe and note changes in the behavior of the older adult that might be markers for the onset of delirium. Once the underlying cause of delirium is resolved, the individual may return to their previous physical and mental state (Ebersole & Hess, 1994).

1. ***intersecting conditions in practice***

   In my clinical experience, I find many similarities between these conditions. Foreman et al (1992) compares and contrasts the clinical features of delirium, dementia and depression in the elderly. The ONSET of delirium is acute, as compared with dementia's chronic, insidious onset, and depression may often be abrupt. The COURSE of delirium is short (if correctly diagnosed), dementia takes a long course, and depression fluctuates. The PROGRESSION of delirium is abrupt, dementia is slow but even, and depression may vary. The DURATION of delirium may be less than one month, dementia may last for years, and depression can be several months to years. AWARENESS in delirium is reduced, remains clear in dementia, and clear in depression. The individual's ALERTNESS and ATTENTION fluctuates in delirium, is generally normal in dementia, and may be minimally impaired in depression. ORIENTATION is generally impaired in delirium, may be impaired in dementia, and the depressed individual has selective disorientation. In delirium recent and immediate MEMORY is impaired, in dementia recent and remote memory is impaired, and in depression there may be selective impairment. THINKING is disorganized and fragmented in delirium, the dementing individual has difficulty with thoughts and finding words, and the depressed person may have intact thinking, but with themes of hopelessness and helplessness. PERCEPTION is distorted in delirium; this individual may be prone to delusional thinking and hallucinations; in dementia, misperceptions are often absent, and in depression perception remains intact (Foreman et al, 1992).

2. ***which etiologies are the easiest to diagnose and treat and which are the hardest and why?***

   Unfortunately, in my clinical practice the individual does not always present with such a clear picture as Foreman has illustrated. If delirium and/or depression superimpose the individual's dementia, then the symptoms present in such a similar fashion, that it is extremely difficult to differentiate.

Depression is the problem of greatest frequency and magnitude in the aged population; fortunately it is also one of the most manageable and remedial of psychogeriatric problems (Ebersole & Hess, 1994; Katz et al, 1994). Many depressed elderly that I work with respond extremely well to a supportive environment, that restores their sense of control and autonomy.

Relating to Palliative Care

The original definition of the Latin word palliare (to palliate) means to cloak or cover (Ferris & Cummings, 1995). In hospice/ palliative care, palliation means to treat the pain, relieve the symptoms, and reduce the patient's distress. This program offers compassionate care directed at improving the quality of life of those who are dying. It offers supportive services for dying patients and their families that includes physical, psychological, social, and spiritual dimensions of care (Ross, 1994; Wilson et al, 1996). The World Health Organization states that palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death; it provides relief from suffering and pain; it integrates the psychological and spiritual aspects of the person (Mount, 1993).

The literature tends to be in agreement on the definition of palliative care; where the disagreement seems to lie is where, when, and for whom palliative care is offered. Because death is associated with old age, palliative care is often ignored in the care of people who are both older and dying (Ross, 1998). Volicer (1993), Mount (1993), Latimer (1995), and Boyd (1998) agree that a hospice approach provides optimal avenue for treatment of individuals with severe dementia. It is felt that this approach will integrate the psychological and spiritual aspects of the person. However, although Alzheimer disease has been estimated as the fourth leading cause of death, very few hospice patients have a primary diagnosis of dementia (Luchins & Hanrahan, 1993).

This may be as a result of hospice for end–stage dementia is distinctly different from the more traditional cancer–focused hospice in several important ways. Terminally ill persons with cancer differ from persons with an end–stage dementia illness because the course of the cancer is more predictable, and the type of symptom control needed is different. Problems with pain, nausea, vomiting, and breathing are common in patients with cancer, but less common in persons with end–stage dementia (Wilson et al, 1996; Volicer, 1993). I find that in working with the person with end–stage dementia, the interventions for promoting their comfort involves more psychosocial and environmental therapies. Music therapy for example is very beneficial. Also, this individual is often unable to communicate needs, therefore we may need to rely on family support to determine potential sources of discomfort. When interviewing a daughter on one particular occasion, she informed me that she only knew when her father was in pain because he would curl up in the fetal position. Her father was in the end–stages of Alzheimer disease. Because demented individuals cannot report their feelings, the psychological well–being has to be assessed by observation (Volicer, 1997).

Fainsinger (1993) reports that it is impossible to work with terminally ill patients without becoming aware of the high prevalence of delirium in this population. Some 80% – 90% of terminally ill patients can be expected to develop delirium before they die. But it is important to remember that this individual can have a prognosis from years to hours and that management varies depending on the overall assessment of the patient’s condition. One of the difficulties in understanding delirium in the terminally ill is caused by the use of different and somewhat bewildering terminology (Fainsinger et al, 1993). I find there has been very little research done in understanding the causes and management of delirium in the terminally ill.

Boyd (1998) agrees that there is a growing need for palliative care for end–stage Alzheimer patients. These individuals may also have depressive symptoms that resist the preferred environmental and psychosocial interventions of the palliative care unit. Or the depression may be a result of the dementia (Kurlowicz et al, 1997); consequently, depression is often misdiagnosed and undertreated. Diagnosis of depression in physically healthy patients depends heavily on the presence of the somatic symptoms of anorexia, fatigue, insomnia, and weight loss. These indicators are of little value as diagnostic criteria for depression in palliative care, where the diagnosis often must depend upon psychological, not somatic, symptoms (Fainsinger et al, 1993). And because the person may not be able to communicate his/her needs, I find that the depression often goes undiagnosed.

As I reflect on my own experience with these individuals, many questions arise for me. Questions that I don’t have the answer to. What more can I do for the person in end–stage dementia? How should I plan activities? How much stimulus is good for this individual? How can I maximize function and reduce disability? How can I prevent them from losing weight? Is there a way to position them to prevent contractures? Why do they scream and how to stop it? Are they in pain? I feel frustrated when I recognize that I just don’t know what to do. I find that little has been written about providing care during the terminal stage.

Even though the above is true, it does not prevent us, as nurses from providing optimal care for the person in end–stage dementia (and depression, and delirium). In fact, holistic caring should be provided throughout the trajectory of the disease process, right from the onset, not only in the terminal period. Ross (1998) maintains that the philosophy and principles of palliative care be extended to the care of older adults in all settings where they spend the final phases of their lives.

Caregiver Issues

The following case study applies to the issues and needs of families specifically dealing with the late stage of Alzheimer disease. In exploring the literature, I have been unable to discover any available research on families dealing with delirium or depression in the late stages. Although the following case study is Alzheimer disease specific, four major issues may arise for families with any of these conditions: seeking positive affirmations, wanting better staff communication, seeking permission to withdraw, and giving to others.

Case Study (Bonnel, 1996)

Ben cared for his wife with Alzheimer disease for 12 years; 6 years at home and 6 years at a nursing home. His wife, Mary, laid unresponsive the last two years in what he termed a vegetative state. A physician progress note and Ben's report of her status were consistent with stage seven on the Global Deterioration Scale (Reisburg, 1990). Ben was retired. He described his daughter and son, living in distant cities, as "supportive now, but it took them a long time to get there." Friends and colleagues from church and work were available, but his main support system was friends he'd made over the years through Alzheimer disease support groups. He lived by himself in the family home. He described himself as having heart problems and mild depression for which he was treated.

Ben felt his wife's physical care needs were well met at the nursing home and that he and his physician were in agreement as to treatment aggressiveness. Ben was sad and frustrated about the loss of his wife to Alzheimer disease and his caregiving experiences. "I go there and I walk down the long hall to her room....and after looking at Mary and kissing her on the forehead I usually chat with her roommate....and then I may just sit beside the bed for a little while. I sometimes lift the cover to look at her arms to see the atrophy taking place. I feel her ankles and calves again to sort of feel this atrophy...so usually I talk with the nurses, the head nurse if she's available, and leave. I think if you're a normal person, what could you feel except some depression after that?"

Ben's obituary was in the paper about 6 weeks after this case study was completed. More than a year later, his wife lives on at the nursing home.

The following categories deal with some of Ben's issues:

1. ***seeking positive affirmations***

   Ben described guilty feelings associated with care decisions and his wish for the disease to be over. In addition to his feelings of guilt, Ben felt staff was negatively judging him. He felt he received no credit for being a concerned, caring, and loving spouse for many years. He felt he'd been judged unfairly for the tough decisions he'd had to make and that he received no credit for the hard work and difficult challenges he had accepted with his spouse's illness. In dealing with family members such as Ben, one useful strategy I find, is to help them review all the ways they have been valuable in their loved one's care. I find helping them cope with difficult decisions they have made, and validating that they have done their best works really well. And most importantly, just being there to sit down with them, and listen. Often, caregivers may need assistance in understanding the relationship between their feelings of distress with caregiving tasks, their feelings of irritability, depression, or burden (Farran et al, 1993).

2. ***wanting better communication with staff***

   Ben described communication problems with staff at the nursing home. While communication in general can be challenging, there is limited knowledge about specific communication issues with late–stage caregivers. Ben believed that staff comments were often thoughtless, even painful. Nurses are rightfully proud of the good physical care they give clients and can further address how best to communicate in a supportive way with families. In my clinical experience, I find that often nursing staff is far too busy to take the time to sit with the family member and communicate in a supportive way. Also, I find that the concept of palliative care may not be comfortable for all staff. There is a need to address issues of palliative care and consider it as an interdisciplinary approach attending to both patients' and families' needs. For Ben, comments such as "she ate well" can cause conflict. Although the nurse may be trying to minimize patient complications and promote comfort, they are prolonging the patient's life even as family members may be wishing for death. Post and Whitehouse (1995) recommend staff education that clarifies that a hospice care philosophy is not the same as euthanasia or assisted suicide. Ben appreciated "having a little bit of the nurses' time, to be able to sit down and talk about feelings, including the inevitability of death."

3. ***seeking permission to gradually withdraw***

   Expectations for the course of Alzheimer disease typically cannot be predicted in weeks or even years. Because of the nature of the disease, the family must gradually withdraw emotionally from the person and find other support sources. Ben found his comfort and ability to go on coping with life more in distancing himself from the reality of the disease. Staff may be in a position to either take over the kinds of care that the spouse can no longer handle, while acknowledging and respecting the desire to provide care if so desired (Ade–Ridder & Kaplan, 1993). I encourage family members to focus more on meeting their own needs, and helping them to clarify realistic role expectations for this point in time. I find that often these caregivers need to give themselves permission to maintain other interests and take part in pleasurable activities. Also, I find it most helpful to assure the family member that their loved one is being well taken care of, and it's okay "to skip a visit."
4. ***giving to others***

   Ben described a strong commitment to making the best of his situation. He attended support groups and education groups for many years. But now it was clear that he no longer wanted to participate in these groups. He felt the need to withdraw from his previous active role as support group member. His preference at this point was to help others by being involved in research relevant to Alzheimer disease.

I find that by supporting and encouraging family members to contact the Alzheimer Society of B.C. provides for them an avenue to seek assistance. Some families choose to isolate themselves and seek their own solutions. It is important to respect individuals' choices as to how they seek help.

Ethical Issues

For the past 20 years, the concept of autonomy (or personal choice) has been central in biomedical ethics and a driving force behind some significant changes in health care practices for the elderly (Rice et al, 1997). The literature agrees that people with dementia should be allowed to exercise their remaining capacities for specific tasks and choices; denying these choices challenges their independence and dignity (Post & Whitehouse, 1995; Rice et al, 1997; Day et al, 1995). Even though the individual in late–stage dementia may no longer be able to care for himself, may lose the ability to make rational decisions and understand his environment, the dignity is maintained, expressed by his remaining autonomous decisions (Volicer, 1997). It is important to realize also that emotional and relational well–being can be enhanced despite the dementia and to insist that human dignity still be respected (Post & Whitehouse, 1995). In my clinical practice, I find that even respecting the individual's choice as to when their bathing time will occur, maintains their human dignity.

One way to empower individual choice while allowing family members to deal with unforeseen situations is through an advance directive that combines the living will with the durable power of attorney for the person. The designated surrogate who holds the power of attorney for health care is usually a trusted family member. Advance directives can indicate willingness to participate in research specific to dementia (Post & Whitehouse, 1995).

Because knowledge about the terminal care preferences of decisionally impaired individuals is frequently unavailable, it is often necessary to make surrogate judgments as to the kind of terminal care the person should receive (Luchins & Hanrahan, 1993). Increasingly, the exercise of one's personal control and autonomy has extended to decision–making regarding one's own dying and death. Ethical guidelines suggest that a patient has the capability to make the treatment decisions when he or she can understand the relevant information, reflect on it in accordance with his or her own values, and can communicate with caregivers (Rice et al, 1997). The person with late–stage dementia would not be able to make these decisions.

When this is the situation and the person with late–stage dementia is unable to make their own decision, the family member may be more comfortable deciding on interventions when they ask the question: are we prolonging life or only prolonging death? (Goetschius, 1997). When we as nurses intervene with feeding tubes, antibiotics or ventilators, we must ask ourselves this question. Post & Whitehouse (1995) and Volicer (1997) are in agreement that these individuals should not be fed by tubes, because of numerous complications and the likelihood of aspiration; the effectiveness of antibiotics is decreased in individuals with advanced dementia; and the primary goal of care in advanced dementia should be similar to the goal of care in other terminal conditions: patient's comfort. In fact, there is agreement that the philosophy of hospice is highly appropriate for the care of people with advanced dementia.

Another ethical issue that often arises I find, is whether or not the individual should be resuscitated, if and when their condition deteriorates. It is an extremely difficult decision for families to make, and often requires the nurses' support and guidance. It seems to me that many physicians do not spend enough time to sit down with the family and explain what the consequences might be if their loved one is resuscitated. It is very distressing for families to see their loved one existing in a vegetative state.

I believe that our goal for the person in late–stage dementia should not only be in prolonging life, but in maintaining quality of life. Our goal should be for comfort and emotional well–being. We as nurses must continue to observe the individual carefully and provide whatever forms of comfort possible. A feeding tube will rarely be a source of comfort care; a gentle touch of the hand will. I find that spending time with the person to assess their needs, listening to the family express their concerns about their loved one, and insisting that human dignity be respected, goes a long way in maintaining quality of life.

To improve psychological well–being of the individuals with advanced dementia, we need to switch the emphasis of care from the medical to the social model and from aggressive medical interventions to palliative treatment and hospice care (Volicer, 1997). Unfortunately, many physicians are not aware of the lack of effectiveness of cardiopulmonary resuscitation, antibiotic treatment, and tube feeding in patients with advanced dementia (Volicer et al, 1993). We, as nurses must advocate for effective education to overcome this barrier.

Much of the literature deals with ethical issues for the individual with advanced dementia. What I find missing in the literature are ethical issues for the older adult with delirium and/or depression. It may very well be that the issues are similar, but this needs to be explored further, as these individuals may not be able to report their own feelings.

Summary / Closure

This paper has integrated the concepts of dementia, delirium, and depression in the older adult, and has related these concepts to the individual's need for palliative care. Some caregiver issues have been identified, and ethical needs explored when caring for these individuals.

Although I have been able to relate the person with dementia and their palliative care needs, there seems to be a dearth of literature for the individual with delirium and depression and their palliative care needs. There is implication for future research and study in this area. Also, in exploring the literature, I have been unable to discover any available research on families dealing with delirium or depression in the late stages. And as already mentioned, ethical issues dealing with persons with advanced dementia have been identified, but there is very little written that reflects ethical issues of persons with delirium and/or depression. Missing from the literature is the experience of looking after these individuals for who cure is not an issue.

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