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# Educating the Dementia Caregiver

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## Introduction

With the continued growth of the aging population, there continues to be global concern about efficient care and support for people diagnosed with dementia. Effective interventions have been developed to care for dementia clients and their families, but there is still lack of care practice integration. Most of the work involves the need for higher education including dementia studies, that can provide key role of specialized knowledge, and skills, that are needed in dementia care. The goal is to inform the reader that higher education is a significant player in supplying proficient practitioners, and health care professionals, the necessary skills to administer care to dementia clients.

## Demographics of Alzheimer's Disease

Alzheimer's disease, the most common dementia, is a progressive, terminal, brain disorder with no known cause or cure [1]. One in nine Americans over the age of 65 has Alzheimer's disease [2]. Alzheimer's disease should not be thought of as a disease, but as a group of symptoms to manage.

Alzheimer's disease is a serious health problem throughout the world. Researchers estimate that more than 5.4 million Americans have the disease; Alzheimer's disease is the 6th leading cause of death in America [3]. "By 2050, the number of people age 65 and older with Alzheimer's disease could triple, from 5.2 million to a projected 13.8 million, barring the development of medical breakthroughs to prevent or cure the disease" Alzheimer's disease is one of the world's greatest health concerns, impacting the lives of a significant number of people. This has generated great concern about the quality of care. Thus, higher education and dementia studies are playing significant roles in providing specialist appropriate knowledge, and skills, for dementia care [4].

## Educating the Health Care Work Force

All agree that healthcare workforces must possess specialized skills to help dementia clients. Training of the dementia workforce is a huge challenge primarily, because of the increasing number of people with dementia [5]. "Having a healthcare workforce skilled in providing high quality care to people with dementia is of international concern; and high-quality dementia education is naturally being attached to this ambition".

Higher Education institutions are of extreme importance since they prepare students to serve as proficient health professionals. Research literature constantly examines the curriculum, development, and resources targeted to students getting ready to provide healthcare. Where dementia is included in the curricula is the result of the availability of staff members with knowledge, experience and a passionate interest, in dementia education [6].

A primary goal is to generate interest related to international efforts in higher education of dementia care services. Research has proven that learning outcomes, curricula, approach to teaching, and assessments required to manage dementia Behavioral symptomology. Unfortunately, there a shortage of gerontology programs working with older adults which might lead to higher psychoactive drug use that too often produce poor outcomes.

## A Theoretical Framework for Dementia: Person-Centered Care

Person-centered care models, regarding dementia care, have demonstrated positive outcomes for behavioural disturbances. The leadership, guidance and training in promoting this model into practice is weak in our healthcare system. There is an urgent and growing need for educators, clinicians and researchers to increase awareness of the requirements of the dementia population.

Older people with dementia, not surprisingly, have complex needs, that often require specialized treatment and care. For example: cognitive and functional impairment often coexists with additional neuropsychiatric symptoms such as psychosis, aggression, agitation and depression. Our outcome investigations stress the unmet needs of this population "and are likely to

 

contribute to an increase in neuropsychiatric symptoms and unfortunately the widespread prescribing of antipsychotic drugs" [7].

There has been increasing concentration on the care of the dementia client in long term care facilities. The health care work force is constantly trained to provide "task driven" care, with emphasis on meeting basic physical needs of the patient through nutrition, hygiene and medication management (consumerreports.org/patient-centered-care-helps-dementia). Research points out that task oriented approach to care leads to inconsistent routines, inability to meet the individual's social and emotional needs which lead to increased behavioural symptoms. Achieving person-centered care consistently requires specific knowledge, skills and methods of work, a shared philosophy that utilized the nursing team, and effective culture and organizational support [8].

Research has provided outcome studies from a conceptual framework, indicating that person-centered training interventions "conferred significant benefit in improving agitation and reducing the use of antipsychotics".

## Understanding the Dementia Clients View of Reality

When author first began the work with dementia care, the philosophy of care centered on "Reality Orientation". Fortunately, today, we not only have a better understanding of the disease process; but have become better acquainted with interpreting moods and Behavioral interventions to respond better to our clients. The philosophies of "Habilitation" and Validation" therapies have done tremendous service for the dementia client, particularly regarding the individual's need to preserve "personhood". Family and professional caregivers must continue to understand that dementia clients have little or no control over verbal and or physical behaviours. However, with the philosophies of "person centered care" we can keep symptoms to the minimum.

There existed a concern about dementia care in this country. The National Dementia Initiative (CCAL Advancing Person-Centered Living) led by national dementia experts from across the country came together "to discuss the overall lack of quality care in general and the overuse of antipsychotic medications for people who have dementia" [9]. The experts were unanimous in agreement that the fundamental problems existed in the mindset of care provision, and concluded that there is a need and understanding for:

1. Every person has his/her own meaning in life, authenticity (personality, spirit and character), history, interests, personal preferences and needs to continue to experience life at all stages of dementia.

2. Focus on the strengths of the person living with dementia rather than on what abilities and capabilities have been diminished.

3. Enter the world" of the person living with dementia to best understand, communicate with, and interpret the meaning of his/her Behavioral expressions from their perspective [10].

Author witnessed the significance of the role of physical and social environments in meeting the needs of the dementia client. Despite efforts of many to shift the trend from the medical model of care to a more holistic approach, we still struggle in this country with the medical community's inability to focus on individuality and choice of the dementia client. Author is fortunate with his work environment in that the organizational leadership embraced the philosophy of care promoting "person centered care".

As mentioned, the healthcare culture has made strides in moving away from a task oriented model of care towards a more holistic approach for dementia patients to care better, this we refer to as person centered care. To better understand this relationship to dementia care we should review it from a historical perspective such as:

1) The caregiver viewed dementia strictly from a medical perspective,
2) Care was task driven,
3) Managed the client through chemical and physical restraints,
4) Care disempowered the dementia client. In contrast, person-centered care empowers the individual through maintaining independence, empowering the individual through validation of their lifetime experiences and the freedom to promote a dignified quality of life.

To further illustrate this, person centered care promotes the principle of the individual's life time experiences, unique relationships and contributions using lifestyle assessments and appropriate treatment options. These lifetime patterns of the individual become part of the individual treatment plan. The "personhood" of the individual with dementia is able to participate in strength based programming, with a positive emotional response to care with an improved quality of life for the individual.

For instance, a client by the name of Theresa, who moved from Ireland to this country at the age of 16, and met her husband at an Irish dance in Boston raised five children while working as a nurse for the 11 pm to 7 am shift. Consequently, she was diagnosed with Dementia with Behavioral Disturbance, and admitted to the local skilled nursing facility and medicated for her disruptive behaviour during her hours of sleep.

When the facility practices "person centered care" the facility must understand Theresa's, personhood including her Irish heritage, occupation, sleep patterns and most importantly her reality. This is best describing as "…the caregiver must understand the person with dementia as having personal beliefs, remaining abilities, life experiences and relationships that are important to them and contribute to who they are as a person".

For instance, the client living within the skilled nursing facility exhibits increased pacing as if looking to go home. Understanding this client view of reality indicates that in fact the client was looking for his childhood home. To determine successful Behavioral and

redirection strategies one must utilize a good social history, and understand behaviour triggers and appropriate environmental cues. Recommended redirection approaches include:

1. Agreement: attempts to change the client's reality often resulting with increased frustration, anxieties and aggression.
2. Redirection: due to client's short attention span can be redirected to a new activity with appropriate visual cues and understanding the client's reality.
3. Environment: have an understanding that clients are sensitive to environmental stimulation such as noise, clutter and lighting.
4. Task completion: behavioural episodes may be reduced by simplifying tasks to complete, such as dressing, and utilization programming.

Before we conclude it should be mentioned how the "environment correlates to behavioural health in the Alzheimer Special Care Unit" (Gerontologist, 2011). Research has centered on creating way finding environments, and developing freedom of movement for the client. The goal is to create an environment of autonomy and support which encourages and supports residents to use their remaining faculties to carry out basic tasks and activities independently and with dignity.

Why person-centered care? There are some clinicians who believe that too much focus has been on developing person-centered care cultures, instead of valuing the physician-patient relationship. My response is that we need more education regarding the philosophy; in fact, the philosophy should be enhancing our relationships. Person centered care provides caregivers the necessary skills and resources to enable them to provide exceptional care for the client.

An attempt here was to demonstrate the limited exposure to knowledge, understanding and resources, with discussion for implication for the care and person-centered responses to staff trained in dementia services. The sample discussed was based on measuring healthcare worker knowledge of dementia, standard of care, staff training and outcome studies of psychotropic drug use among this clientele.

"Antipsychotic medications continue to be prescribed for the management of Behavioral and Psychological Symptoms of Dementia (BPSD) despite revised guidelines, tighter regulations, and evidence for associated risks including increased cognitive decline and stroke. The evidence points to the global restructuring of the Dementia Training Initiatives, and finding new ways to "enhance the quality of life for people with dementia, protect them from substandard care and promote goal-oriented, person-centered care; while the initial focus was on reducing the use of antipsychotic medications, the larger mission was to enhance and explain the non-pharmacological approaches and person-centered dementia practices" [11].

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