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Quality of Life for Patients with Dementia: A Systematic Review

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Quality of Life for Patients with Dementia: A Systematic Review

By

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MSW Clinical Research Paper

Presented to the Faculty of the School of Social Work
St. Catherine University and the University of St. Thomas

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The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present the findings of the study. This project is neither a Master's degree thesis nor a dissertation.

Abstract

There is an increase in the amount of people becoming diagnosed with dementia. With that increase, a concern has been created in regards to maintaining a person's quality of life and intervention strategies to properly maintain their quality of life. The systematic review was set up using peer-reviewed articles published after 2001. The database SocINDEX was used to conduct the search for articles using the terms; "dementia and intervention strategies," "dementia and non-pharmacological interventions," "caregiver support," "dementia and medications," and "dementia and behavioral interventions." Out of these searches, 32 articles satisfied criteria for inclusion and were used in the final systematic review. Four themes emerged from the research synthesis regarding what intervention strategies can improve the quality of life for patients with dementia: 1) Validating the Patient's Sense of Self; 2) The Relationship between Caregiver and Patient 3) The Impact on Patient's Daily Routine and 4) Depression and Mental Health. The research suggests the importance of including several factors and perspectives in intervention strategies with dementia patients. Moving forward, more research is required with patients with dementia to better understand the impact of interventions with this population. Exploring potential risks of pharmacological interventions as well as the connection between dementia and mental health are also important areas for further study.

Keywords: quality of life, dementia, intervention, strategies

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Quality of Life for Patients with Dementia: A Systematic Review

Dementia is a disease that varies from person to person. “An estimated four million individuals in the United States have Dementia” (Leifer, 2003, p. 281). There is no cure for the disease and unfortunately, for people diagnosed with dementia, there are no preventative measures to ensure that someone will not develop the disease. There are currently some types of strategies used to help those with the disease and their caregivers manage the behaviors and symptoms more effectively. However, these strategies are not always successful due to the different types of dementias that are being diagnosed.

The purpose of this paper is to conduct a systematic review of articles that examine intervention strategies for patients with dementia to potentially improve their quality of life. The goal of this research is to find effective non-pharmacological interventions that have been proven successful in decreasing behaviors in patients with dementia along with understanding the need for medications to treat agitation and other negative behaviors; which can sometimes be necessary to maintain the patient’s quality of life. This research will identify medications that can be used to treat agitation and other behaviors displayed by patients with dementia. There is an understanding for medication needs; however, non-pharmacological treatments can also be more effective based on research provided in this paper. This research gives a general perspective regarding dementia and quality of life. The perspective and information in this research is not specific to a certain stage of dementia.

Definition of Dementia

The Alzheimer’s Association (2015) defines dementia as a “general term for a decline in mental ability severe enough to interfere with daily life.” Alzheimer’s disease

is considered the most common form of dementia. While the symptoms can vary greatly, at least two of the following core mental functions must be significantly impaired to be considered dementia: memory, communication and language; ability to focus and pay attention; reasoning and judgment; and visual perception (Alzheimer's Association [ALZ], 2015). A few examples of these impairments can look like but are not limited to, having trouble with their short-term memory, keeping track of a purse or wallet, paying bills, planning and preparing meals, remembering appointments or traveling out of their neighborhood (ALZ, 2015). Different types of dementia are associated with particular types of brain cell damage in particular regions of the brain at which the damage can interfere with communication, thinking, behavior and feelings which are controlled by certain regions of the brain such as the temporal lobe, parietal lobe, and frontal lobe (ALZ, 2015). Two abnormal structures called plaques and tangles are prime suspects in damaging and killing nerve cells; plaques are deposits that building up in the spaces between nerve cells and tangles are twisted fibers of another protein that build up inside of the cells (ALZ, 2015).

Stages of Dementia

Dementia typically progresses slowly in three different stages which are called, mild (early stage), moderate (middle stage), and severe (late stage) (ALZ, 2015). In the mild, or early stage, of dementia, a person may still function independently which can include driving, working, and participating in social activities; however, the person may have some memory lapses, persons could be having trouble with not being able to verbalize what they want to say out loud, or the location of everyday objects (ALZ,

2015). This is typically the stage that loved ones will notice the difficulties that a person is having with their memory or concentration which can include but are not limited to:

- Word finding
- Difficulty remembering names when introduced to new people
- Having difficulty perform tasks as work or in social settings
- Forgetting material that they just read
- Losing objects
- Increasing trouble with planning and organizing (ALZ, 2015).

Moderate stages of dementia. The moderate, or middle stage, of dementia is the longest-lasting. A person may remain in this stage for many years. Others may notice someone confusing their words, getting frustrated or angry, or acting in unexpected ways such as refusing to take a bath or shower (ALZ, 2015). Damage to the nerve cells in the brain can make it more difficult for the person to express their thoughts and perform routine tasks (ALZ, 2015). Symptoms that become significantly noticeable during this stage can include but are not limited to:

- Forgetfulness of events or about their own personal history
- Feeling moody or withdrawn, especially when it is not a part of their typical personality
- Being unable to recall their address or telephone number or other personal information that they might otherwise know
- Confusion about who they are or what day it is
- Trouble controlling their bowel or bladder in some cases

- Increased risk of wandering and becoming lost in private or public places
- Personality and behavioral changes, including delusions, compulsive and repetitive behavior, or suspiciousness (ALZ, 2015)

Severe stages of dementia. In the severe or late stage of dementia, a person may lose the ability to respond to their environment or to carry on a conversation and may also lose control of movement (ALZ, 2015). A person may still say words or phrases; however, it may become very difficult due to their memory and cognition skills worsening (ALZ, 2015). During this stage, a person may:

- Require 24-hour nursing care and supervision
- Lose awareness of recent experiences
- Require high levels of assistance with their personal cares and activities of daily living (dressing, bathing, grooming, etc.)
- Experience changes in physical abilities and may not be able to walk, sit, or eventually swallow
- Have increasing difficulty with communication
- Become vulnerable to infections (ALZ, 2015)

Assessment of Dementia

There is no one specific test to determine if someone has dementia; however, there are physical exams, laboratory tests, and characteristic changes in thinking, day to day functioning and behavior associated with each type (ALZ, 2015). A few of the cognitive exams that physicians will perform on patients are called the Mini Mental State

Exam (MMSE) and Mini-Cog Exam (ALZ, 2015). The MMSE asks patients a series of questions designed to test a range of everyday mental skills and the Mini-Cog exam instructs a person to recall three common objects after they have been told to the person as well as to draw the face of a clock showing all 12 numbers and a time specified by the examiner (ALZ, 2015). Some physicians will also perform brain imaging on the patient that includes an MRI or CT scan which can show if there is trauma to the brain in certain areas that could rule out other diagnoses that are affecting a person's memory and cognition (ALZ, 2015).

Common Causes of Dementia

Many diseases that can cause dementia are not curable; however, the symptoms of those underlying diseases can be improved when properly treated. The most common causes of dementia include:

- Degenerative neurological disorders such as Parkinson's disease, Huntington's disease, and some types of multiple sclerosis
- Vascular disorders, such as multi-infarct dementia which can be caused by multiple strokes in the brain
- Traumatic brain injury cause by motor vehicle accidents, falls, etc.
- Infections in the central nervous system such as meningitis, HIV, Creutzfeldt-Jakob disease
- Chronic alcohol or drug abuse
- Depression
- Certain types of hydrocephalus (ALZ, 2015).

Dementia is not a curable disease and is degenerative over time. This leads to the importance of identifying non-pharmacological interventions that can be applied to assist in improving the patient's quality of life as the disease progresses over time. To reiterate, the goal of this research is to find effective non-pharmacological interventions that have been proven successful in decreasing behaviors in patients with dementia along with understanding the use of medications to treat agitation and other negative behaviors; which can sometimes be necessary to maintain the patient's quality of life.

Literature Review

The purpose of this paper was to conduct a systematic review of articles that examine intervention strategies for patients with dementia to potentially improve their quality of life. The researcher was looking to find effective non-pharmacological interventions that have been found successful in decreasing behaviors in patients with dementia; while also reviewing medications used to treat agitation and other negative behaviors, which can sometimes be necessary to maintain the patient's quality of life.

In the following section, a broad review of the literature will be examined. While this project involves a literature search, the literature review discussed here will overlap to some extent with the more specific research (i.e., articles reviewed) that is the core of this paper. The following themes that are included which will be discussed are: a) Psychological Impact, b) Behavioral Interventions which include Non-Pharmacological Interventions, Cognitive Behavioral Stimulation and Therapy, c) Pharmacological Interventions, and d) Patients Experiences with Caregivers.

Psychological Impact

While being diagnosed with dementia can have its own impact on someone's physical and cognitive life, it can also have a psychological impact as well. Depression and anxiety symptoms can be assessed using the Cornell Scale for Depression in Dementia (CSDD) which assesses mood and related signs, behavioral disturbances, function and ideational disturbance as well as any physical signs of depression on a scale using patient and proxy interviews (Hilgeman et al., 2014). The Cornell Scale for Depression in Dementia (CSDD) is a 19-item scale scoring 0 to 2 for each item and uses the information from the interview with the patient and their caregiver (Woods et al., 2006). The CSDD is considered to be a valid and reliable source of depression testing (Woods et al., 2006). It is believed that hopefulness in chronic illness has shown association with an improved quality of life through pain management and improved tolerance as well as having improved coping and problem solving skills (Radbourne et al., 2010).

Disturbances in the circadian rhythm and restlessness has been proposed as a cause for psychological and psychiatric symptoms in patients with dementia; along with wandering behavior and lowered levels of acetylcholine, which may also be an implication for aggressive behavior (Turner, 2005).

Behavioral Interventions

Non-pharmacological interventions. Non-pharmacological interventions are interventions that do not include medications or other chemical measures to decrease agitation and other behavioral symptoms among patients diagnosed with dementia. The

American Association for Geriatric Psychiatry stresses that non-pharmacological strategies should be the preferred method as a treatment approach to managing behavioral symptoms (Kales et al., 2014). However, if a person is in imminent danger or compromising the safety of others or themselves, then pharmacological interventions may be necessary (Kales et al., 2014). Some pharmacological interventions are reported to precipitate agitation regardless of the interventions commonly used to decrease the agitation among patients diagnosed with dementia (Kong et al., 2009). There are common behaviors, especially for families, that don't respond to pharmacological treatments, such as refusal of care, repetitive vocalizations, and arguing (Gitlin et al., 2010). Other common behavioral symptoms of dementia may include aggression, screaming, restlessness, wandering, culturally inappropriate behaviors, hoarding, cursing, and sexual disinhibition (Turner, 2005). "Advancing caregiver training (ACT) conceptualized problem behaviors as a consequence of interacting factors reflecting three domains: patient based (unmet needs, discomfort or pain, incipient medical condition), caregiver based (stress, communication style), and environment based (clutter, hazards)" (Gitlin et al., 2010, p. 1466). In a systematic review completed by Kong et al (2009), the researchers reported that only sensory interventions such as aromatherapy, thermal (heated) bath, calming music and hand massage had a moderate effect in reducing agitation for those with dementia. The use of effective non-pharmacological interventions may be able to delay nursing home placement for patients currently living in the community, and also lower the use of physical restraints and decrease the use of pharmacological interventions for those who are living in the nursing home setting (Kong et al., 2009).

A study completed by Toot et al (2013) aimed to identify factors that can cause crises and identify interventions to help manage these crises for those with dementia in their own homes in the community. There are contributing factors that precipitate crises which can include psychosocial, physical problems, the environment and/or caregiver burden (Toot et al (2013). Behaviors can stem from unmet needs, environmental overload, and the interactions between themselves and their caregivers as well as environmental factors (Kales et al., 2014). Unfortunately, there are not currently proven approaches or training programs that are available for assessing and managing behavioral symptoms of dementia that will allow providers to use alternative strategies to replace antipsychotics (Kales et al., 2014).

Non-pharmacological treatment goals should be for the use of prevention, symptom relief, and reduction of patient and caregiver distress (Gitlin et al., 2012). There are studies that have been found successful in treating the symptoms and behaviors of patients with dementia. Listed here are a few examples of those studies. Kong et al (2009) completed a study that targeted female patients with dementia over a four week period. In this study, the aromatherapy with the oil titled “Melissa Essential Oil and Sunflower Oil” was used. There was a significant improvement in agitation of 35% reduction with aromatherapy using the Melissa Essential Oil and 11% reduction using the Sunflower Oil (Kong et al., 2009).

A study was completed that targeted female patients with dementia over the course of eight weeks with four consecutive sessions in each of the two methods with them being a thermal (heated) bath in a spa bath tub and conventional tub bath (Kong et

al., 2009). The frequency of the agitated behaviors was less for the thermal (heated) bath than the conventional tub bath (Kong et al., 2009).

Remington (2002) completed a study that targeted the female population with dementia that were exposed to 10 minutes of calming music, hand massage, and both combined (Kong et al., 2009). The results of the study represented that each three interventions had a greater reduction in agitation than having no intervention (Kong et al., 2009).

Sensory interventions such as aromatherapy, thermal (heated) bath, calming music, and hand massage have a moderate effect in the reduction of agitation in patients diagnosed with dementia (Kong et al., 2009). Sensory interventions for agitation are an important and practical intervention in regards to significant effect, the ease of use, low cost, and safer strategies (Kong et al., 2009). The use of effective non-pharmacological interventions may delay nursing home placement for patients with agitation along with the lower need for medications and/or physical restraints in the nursing home setting (Kong et al., 2009).

Another form of behavioral interventions that do not require administering medications is using music. "Music therapy treatment demands a qualified music therapist and can be defined as the professional use of music experiences and the relationships that develop through them with the aim to promote health" (Ridder et al., 2013, p. 668). While it is required to have a music therapist in a nursing home setting, patients still living in their home in the community can receive music therapy services as well (Ridder et al., 2013). Patients with dementia can experience impairments that can influence their perception, attention, memory and social engagement; interactions that

involve music could be ways of bypassing those impairments and lead to decreases in agitation (Ridder et al., 2013). Music played during personal care situations can lead to a reduction in agitation, aggression and less resistance (Ridder et al., 2013).

Cognitive behavioral stimulation and therapy. A non-pharmacological intervention technique that is currently being studied and applied in the field of dementia care is cognitive behavioral stimulation and therapy.

Quality of life (QOL) is seen as a key outcome in dementia care and in a recent trial of cognitive stimulation therapy (CST), there were significant improvements from patients that self-reported changes in their cognitive functioning (Woods et al., 2006). Some researchers will argue that dementia and quality of life should be assessed because it is more likely that changes will occur following interventions, but also because the domains of QOL can be similar between people with dementia and without dementia (Woods et al., 2006).

CST can lead to significant improvements in cognitive function and QOL and in a study, the researchers investigated whether cognitive improvements were found in clinical trials by people with dementia and their caregivers in everyday life (Spector et al., 2011). During this study, there were 14 sessions of themed activities that drew on several principles including person-centered care (Spector et al., 2011). “CST is the only non-drug intervention recommended by government guidelines for the treatment of cognitive symptoms in dementia” (Spector et al., 2011, p. 945).

Cognitive stimulation therapy (CST) and Cognitive behavior therapy (CBT) are effective for a range of anxiety disorders that includes treatment of anxiety in those that

are diagnosed with dementia (Robinson et al., 2011). A manualized approach called Peaceful Mind has been developed to do so (Robinson et al., 2011).

“The Peaceful Mind manual has demonstrated positive outcomes in an open trial. Treatment includes modified presentations of core CBT skills, including diaphragmatic breathing, coping statements, self-monitoring and behavioral activation. These skills are taught across 10-12 home based session over three months, along with between sessions over telephone calls” (Robinson et al., 2011, p. 291). An important modification for CBT within the dementia population, is the inclusion of the caregiver to assist the patient in comprehending and practicing the skills both within and in between therapy sessions (Robinson et al., 2011). “Psycho-education of caregivers has been associated with a decrease in anxiety among patients, and the skill training and symptom recognition involved in the treatment may also have served a psycho-educational function in the Peaceful Mind intervention” (Robinson et al., 2011, p. 295).

It can be easy to shift the focus from the patient to the families or couples therapy which can be beneficial, however the Peaceful Mind interventions focuses on treating anxiety in patients diagnosed with dementia (Robinson et al., 2011). The therapist should be prepared to assess the family and its impact on the patient’s symptoms and offer referrals to address those family focused concerns (Robinson et al., 2011). The inclusion of multiple collaterals can create a promising option to maximize treatment gains as well as the family’s investment in therapy.

Dementia is considered to be one of the strongest risk factors for delirium which occurs in over half of older adults with dementia (Kolanowski et al., 2010). “The intervention, in the form of cognitively stimulating activities, is designed to rescue

remaining cognitive reserve: (1) by delirium and (2) by maximizing activity-dependent plasticity” (Kolanowski, 2010, p. 232).

Pharmacological interventions. This research will identify medications that can be used to treat agitation and other behaviors displayed by patients with dementia. There is an understanding for medication needs; however, non-pharmacological treatments can also be more effective based on the review of articles provided in this paper. Intervention strategies that are identified in the pharmacological category can come with increased risk factors for the patient’s health as well as mental health; while, it is the preferred method to use non-pharmacological interventions, it can be deemed necessary to use prescription drugs to treat or suppress behavioral symptoms that the patient may be experiencing.

Interventions whether pharmacological or non-pharmacological do not completely eliminate the behavioral symptoms but can decrease the severity of them (Snowden et al., 2003). While a specific type of treatment may be well intended in helping to manage problem behaviors with pharmacological treatments, there can be mild to no benefits and cause further risks and harm to the patient’s physical health (Gitlin et al., 2010).

“Antidementia medications (ADMs), including acetylcholinesterase inhibitors (donepezil, galantamine, rivastigmine) and memantine, an N-methyl-D-aspartate receptor antagonist, are commonly used to manage dementia symptoms and delay declines in cognitive, behavioral, and functional performance” (Dutcher et al., 2014, p. 1046). Individuals are often times treated with psychotropic medications to manage their behavioral and psychological symptoms of dementia which these medications can include antidepressants, antipsychotics, sedative-hypnotics, and anticonvulsants however, have

received mixed reviews on benefits in relation to the adverse effects (Dutcher et al., 2014).

Behavioral disturbances and psychiatric symptoms are common with patients diagnosed with dementia or Alzheimer's disease (Sultzer et al., 2001). "Agitated or aggressive behaviors occur in approximately 30% to 60% of patients with dementia and are a major source of morbidity, particularly in nursing homes" (Sultzer et al., 2001, p. 1294). Often times, these behaviors might be a reflection of patient distress and can be contributed to having a physical injury, caregiver distress, or potential need for institutionalization (Sultzer et al., 2001).

There is a greater rate of mortality and lower cognition associated with the use of antipsychotic medication (Dutcher et al., 2014). It is suggested that medication treatment, adjustments made to the person's environment and other behavior interventions can be effective for a person with dementia (Sultzer et al., 2001). There is also a greater risk for falls, syncope, and bone fractures with the use of antipsychotic medications at which point, patients and their caregivers should be made aware of the risks associated with antipsychotic medications (Dutcher et al., 2014). "Atypical antipsychotics, carbamazepine, valproate, trazodone, and selective serotonin reuptake inhibitors (SSRIs) have also been shown to be effective" (Sultzer et al., 2001, p. 1294). In regards to the classification of medications prescribed for patients with dementia, some are classified as antipsychotics while others are classified as antidepressants or mood stabilizers (Sultzer et al., 2001). While the federal regulations can limit the use, antipsychotic medications can be effective and remain to be the most studied medications for behavioral use and treating their symptoms (Snowden et al., 2003).

Controversy exists surrounding the use of antipsychotic medication for neuropsychiatric symptoms with the dementia population due to the higher rate of occurrence for cerebrovascular events, as well as death, even with low doses and short term use (Rhee et al., 2011). Patients with neuropsychiatric symptoms are at a greater risk for functional impairment, rapid cognitive decline, and in general a poorer quality of life than those not having symptoms (Rhee et al., 2011).

Patient Experiences with Caregivers

While it is important to be cognoscente of the patient's experience while dealing with the diagnosis of dementia, it is also important to be cognoscente of the patient's experience with their caregivers, especially those in their own home. It is important to be mindful of the interactions patients will or may have with their caregivers and to ensure that the caregivers are not only taking care of the patients but also taking care of themselves while in the caregiver role.

Caregivers are at a greater risk of distress if they manage problem behaviors with intimidation and not use effective coping strategies during times of stress and frustration (Gitlin et al., 2010). There can be decreased functional status and elimination of social roles when individuals are unaware of changes in their cognitive abilities which can be a source for significant distress in both the patient and the caregiver (Hilgeman et al., 2014). The most evidence for non-pharmacological strategies and their effects stems from caregiver interventions, which can be by enhancing communication, increasing activity, providing caregiver education and support as well as managing the environment (Kales et al., 2014).

Caregivers that are the most involved and considered “primary” in the caring role are most often involved in the activities of daily living of persons diagnosed with dementia, which can have an effect on the time and energy they devote in their own psychological functioning (Robinson et al., 2011). Having multiple family member involved can be helpful in situations where conflict arises between the patient and their primary caregiver (Robinson et al., 2011). However, it is also believed that having multiple people can have negative consequences which can change the focus from the person with dementia to the family (Robinson et al., 2011).

Safety has been identified as a critical area of risk for people with dementia and their caregivers; interventions that have been suggested include a home assessment with an occupational therapist and then completing any necessary alterations, the use of monitoring devices, and the need for eliminating access to items that can pose a danger to the patient (Black et al., 2013).

Interventions that were identified to assist the person with dementia include supportive friends or neighbors in the local area, communication equipment, prompts/cues/reminders around the home, having the presence of their family caregiver, maintaining their daily routine, and using medical home care devices for administering and monitoring medications (Toot et al., 2013). Interventions identified to assist caregivers in the home environment are having equipment that includes adapted furniture such as lift chair recliners, rails, and ramps around the home; engaging in purposeful activities in the home; communication equipment with the person with dementia; and having supportive friends and neighbors to have for support and help (Toot et al., 2013). Interventions need to be flexible and tailored specifically to the patient and caregiver’s

needs and their situation whether in a crisis or not (Toot et al., 2013). “Research evidence indicates that education and training can help to preserve family caregiver well-being and avoid crises” (Toot et al., 2013, p. 334).

Gitlin et al. (2010) completed a trial that targeted families experiencing frequent distress and behavioral issues. This trial was utilizing the Advancing Care Giving Training (ACT). An occupational therapist met with each caregiver to go over intervention goals and to review problem behaviors that were identified (Gitlin et al., 2010). “The study showed that an intervention that identifies and modifies three sources of potential triggers of problem behaviors has immediate positive effects on the most problematic behavior identified by caregivers and on caregiver upset with and confidence managing that behavior” (Gitlin et al., 2010, p. 1471).

The purpose of this paper, in contrast to the literature review, was to conduct a systematic review of articles that examine intervention strategies for patients with dementia to potentially improve their quality of life. The goal of this research was to find effective non-pharmacological interventions that have been proven successful in decreasing behaviors in patients with dementia along with understanding the need for medications to treat agitation and other negative behaviors; which can sometimes be necessary to maintain the patient’s quality of life. To answer the question of how intervention strategies can improve the quality of life for patients with dementia, only qualitative studies as well as other systematic reviews were reviewed. The researcher was specifically interested in gathering information from participants that were effected by their experiences and feelings from the patient. The qualitative studies reviewed are distinctively different than the review of the literature overall.

Conceptual Framework

The conceptual framework identified for this research project is called the Human Ecology Theory. The researcher discussed a theoretical lens, professional lens, and a personal lens in this section as well. The definition of the Human Ecology Theory was identified and how it pertains to this research project.

It is important to have a conceptual framework to guide a research project and to assist in articulating its relation to the topic in regards to theory. In social work practice, students are taught and guided to understanding theory which then in turn helps students understand the populations they work with and client motives.

Theoretical Lenses

The Human Ecology Theory was identified for this research project as its theoretical framework. This theory was identified as best suited for this research due to its perspective of interdependence of humans and nature as well as the blue print for cultural ecology of human development. This theory guided the research in a way that views how the person diagnosed with dementia and their caregivers are affected by the disease. It also helps guide the research in such a way that demonstrates the importance for caregivers and patients diagnosed with dementia of having an invested interest and conscious decision to help their loved one through the disease process. As well as to help care for themselves as the caregiver and attempts to avoid caregiver burnout or burden.

Professional Lenses

The researcher's experience with dementia stems from ten years of experience in healthcare. Residents living at an Intermediate Care Facility for intellectual disabilities were diagnosed with dementia and intellectual disability and were living at the facility indefinitely while receiving long term care. Throughout the ten years, the researcher has worked in a few skilled nursing facilities that care for residents with dementia. The researcher was interested in understanding more fully the behaviors and social interactions that people with dementia experience due to the progression of the disease.

The researcher chose this specific research subject due to the fact that there have been many studies completed on people with dementia. The amount of information available is overwhelming; however, can be useful in the healthcare field for professionals that work with patients with dementia. The researcher was seeking to find new strategies when working with people with dementia and how professionals can best assist in improving the patient's quality of life while living with the disease. The number of people diagnosed every day is increasing and facilities and healthcare agencies are in need of adapting to working with the many challenges that those diagnosed with the disease face every day.

Personal Lenses

The researcher has not had personal experience with the disease. There have been no relatives or friends that the researcher has personally known diagnosed with the disease. The researcher does not present as having any personal biases towards the research. The researcher had an open mind to the information that was researched and

gathered to become better informed about strategies, processes, and/or interventions available to provide more effective care to people with dementia. The researcher was more interested in learning about effective intervention strategies and studies conducted among persons with dementia. The researcher has several years of experience working with patients that are diagnosed with dementia and would like to find new innovative ways to care for patients in the future. More research is needed to learn about the different aspects of the disease and its affects, not only on the person diagnosed but also their caregivers.

Methods

Research Purpose

The purpose of this systematic literature review was to explore the question: How can intervention strategies improve the quality of life for patients with dementia?

For the purpose of this study, quality of life refers to maintaining the patient's routine, daily schedule and personal dignity as a human being as well as decreasing symptoms and behaviors associated with the disease process. Non-pharmacological and pharmacological interventions were included in different behavioral interventions for patients with dementia.

The broad literature review examined several non-pharmacological interventions such as aromatherapy, sensory therapy, cognitive behavioral stimulation and therapy, and music therapy. This study considered pharmacological interventions that looked at several medications that were classified as antipsychotics, antidepressants, and anticonvulsants. This study defined the stages of dementia and the signs and symptoms

that can occur during the disease process. This study considered the patient's experience with their caregiver(s). In the section to follow, research synthesis, the researcher will review new, differentiated articles not previously discussed (i.e. broad literature review) to answer the research question.

Types of Studies

To answer the questions of how intervention strategies can improve the quality of life for patients with dementia, only qualitative studies as well as other systematic reviews were considered. The reason for this was due to gathering information that was not defined by data from participants but instead gathering information from participants that was effected by their experiences and feelings from the patient. Case studies and focus groups were also taken into consideration. The study included the experiences of patients and their relationship with their caregivers.

Search Strategy

In a preliminary search of academic journals through the University of St. Thomas online database, SocINDEX was used as a search engine. In order to understand the scope of available literature surrounding the research question, a search both for specificity and sensitivity were conducted. A search of sensitivity allowed researchers to examine the broadest range of the research topic. This level of expansion can produce a large amount of available research with high percentage of irrelevant articles. A search of specificity allowed researchers to narrow the focus of research in order to complete a search with a high percentage of relevant articles. A specific search can cause the risk of missing out on relevant articles due to the limited scope of the search terms. Using both

sensitive as well as specific searches helped to understand the literature in order to narrow down the search terms, which then led to developing inclusion and exclusion criteria. Both sensitive and specific searches were performed as part of this study.

Review Protocol

Full text and peer reviewed articles were considered in this review. Articles that were published within the last five years were included in the systematic review of articles. Due to the topic and subject matter, newer published articles were only considered to ensure the information was up to date and current. Articles were found using the search engine SocINDEX only. With this search engine, the researcher was able to find the necessary articles and information that would suffice completing this research. Articles were searched and collected during August, September, and November 2015. These data qualifications were established as a means of addressing the issue of validity for this research.

Inclusion criteria. In the database of SocINDEX, searches were carried out using the following combination of search terms; “dementia and intervention strategies,” “dementia and non-pharmacological interventions,” “caregiver support,” “dementia and medications,” and “dementia and behavioral interventions.” All articles that were found in this database using these search terms were published after 2001. In SocINDEX, 32 peer-reviewed articles satisfied the specific search criteria. Only 5 articles were older than 2010; one was published in 2001, one was published in 2004, one was published in 2005, one was published in 2007 and one in 2009. The other 28 articles were published 2010 and after.

Exclusion criteria. Of the 176 peer-reviewed articles that met the initial search criteria, only 33 met criteria to be included in this literature review. Articles that were excluded from the research review included: studies that focused on specific cultures and ethnicities; articles that focused on specific facility type settings; articles that focused on specific locations and regions in either the United States or in international countries; and articles that focused on specific age populations. Selected articles were also limited to those that were written in English. This research was not intended to be “too” specific on a particular region or ethnicity group but rather to look at a systems issue as a whole. The researcher’s desire for this study was to conduct the study in such a way that the information could benefit anyone, not just a specific population or group.

Inclusion and exclusion decisions were made based on the title and abstract of the articles. The final review consisted of 33 peer-reviewed articles. See Table 1 for a complete list of included articles.

Research Synthesis

The purpose of this systematic literature review was to explore the question: How can intervention strategies improve the quality of life for patients with dementia? Using the database of SocINDEX and working within the inclusion and exclusion criteria laid out above, 33 peer-reviewed articles met criteria and were reviewed. Of the 33 articles included in this study, 7 (21.2%) were focused on behavioral symptoms and interventions. Of the articles that dealt with behavioral symptoms, the majority (85.7%; n=6) used sample populations of adult patients with dementia. Only one article included was a systematic review of interventions.

The majority of the research included in this systematic review (27.2%; n=9) focused specifically on the quality of care for patients with dementia. Included in the research from qualitative data were perspectives from both patients and their caregivers. None of the articles included in this systematic review involved research specifically focused on patient age groups or specific severity levels of their dementia. There were no dissertations included in this systematic review.

Thematic Analysis

Through analysis of the literature, four interrelated themes emerged from this systematic review regarding intervention strategies that can improve the quality of life for patients with dementia. These themes include: 1) Validating the Patient's Sense of Self; 2) The Relationship Between Caregiver and Patient; 3) Depression and Mental Health and 4) Cognitive Functioning and Awareness.

Validating the patient's sense of self. After review of the articles, the researcher identified an important theme that related to validation and patient's sense of self. There has been a recent increase in research that is being conducted on how self and identity are affected by the onset and progression of Alzheimer's disease along with other types of dementia (Caddell & Clare, 2011). It can be valuable to family, caregivers, and researchers to understand dementia patients experience themselves and their surroundings as this can be an implication for how people cope with the illness (Caddell & Clare, 2011). Some researchers have suggested that it might be important to try to preserve one's self-identity with dementia in order to improve their well-being (Caddell & Clare, 2011).

A study conducted by Caddell & Clare (2011), aimed to support self and identity in people with dementia. The study consisted of people with Alzheimer's disease participating in art therapy sessions that were held in the patient's memory care unit. Participants of the study were able to use materials such as paints, pencils, pastels, and sculpture material to create meaningful art pieces to them, however they may look. The results of the study suggested that art work can offer patients with dementia an opportunity for communication and also to allow them to cope with their environment if they are anxious or frightened. Despite the significant discussion of the impact of dementia on identity, the developing interventions that focus on changing the impact of the disease is still in the infancy stages (Hilgeman et al., 2014; Caddell & Clare, 2011).

Hope is considered to be vital and should be present in the lives of people with dementia, especially those with early stage dementia, who have the capacity to make more enriching contributions to research that can explore specific positive aspects of the patient's lived experiences (Radbourne, et al. 2010). "Key to the implementation of this construct in dementia care is an understanding of what might help a person to maintain a good quality of life, notwithstanding the real challenges associated with dementia" (Radbourne, et al., 2010, p. 450). Improving the quality of life for people living with dementia is widely accepted as an important outcome in dementia care services (Radbourne, et al., 2010).

Relationship between caregiver and patient. It is suggested that caring for someone with a cognitive impairment is more difficult than providing physical care alone (Pusey & Richards, 2001). Caregivers are often overwhelmed by the enormity of their role and find that the patient's psychotic symptoms, depression, and behavior

disturbances are the most demanding to deal with (Pusey & Richards, 2001). Historically, there has not been specialized support for people with dementia who live at home.

Pusey and Richards (2001) explains:

There are a number of other variables that should be considered that could impact the relationship between the patient and caregiver. The variables could impact the level of distress both parties are feeling and attempts to alleviate it. Examples include the quality and nature of the pre-morbid and current relationship between caregiver and patient. It has been suggested that someone who had a good relationship with the care recipient or who believes that providing assistance reciprocates for help given earlier in life, may experience less emotional distress in the care-giving role. However, adult children who feel indebted to their parents may experience guilt and frustration if the indebtedness is perceived as an obligation. Additional considerations are the social situation, socio-economic status, extent of social support or social network, and the physical and mental health of the caregiver as well as the impact of random life events (p. 116).

A study completed by Yoshioka et al (2013) found that their investigation is the first of its kind to examine whether there are differences in the presence of individual behavioral and psychological symptoms of dementia between community-dwelling dementia patients with spouse caregivers and non-spouse caregivers. There is research that supports that having a spouse or child as the patient's caregiver can cause an increased burden on the caregiver which can sometimes lead to depression in the caregiver as well. (Yoshioka et al., 2013). An estimated 90% of behavioral symptoms of

dementia affect dementia patients over the course of their illness and is associated with poor outcomes, including distress between patients and caregivers, long term hospitalizations, misuse of medication, and increased healthcare costs (Yoshioka et al., 2013). Yoshioka et al (2013) found in their study that dementia patients with non-spouse caregivers were more likely to suffer from several symptoms of behavior and psychological symptoms such as hiding and/or losing things, rummaging, crying and/or screaming, and interfering with ‘a happy home life.’

Depression and mental health. Contrary to popular belief, the ‘memory’ part of dementia and Alzheimer’s Disease, is only one symptom of many other symptoms. “Far more troubling to family and other caregivers are the behaviors that accompany cognitive changes, which can include agitation, depression, delusional beliefs, repetitive questioning, pacing, hallucinations, aggression (physical and verbal), sleep problems, wandering, and a variety of socially inappropriate behaviors” (Kales et al., 2014, p. 86). Because these behaviors are so stressful and difficult for caregivers to manage, they pose threats to caregiver health, employment income, and quality of life for both the patient and caregiver. “Behavioral and psychological symptoms of dementia also lead to many referrals to specialist mental health services which leads to the use of medications used to manage BPSD has been questioned on the grounds of appropriateness, risk of side effects (especially for patients with Lewy body dementia or additional medical problems)” (Turner, 2005, p. 93). While it can be challenging with the cognitive symptoms alone, the behavioral manifestations of dementia tend to create the most difficulties for individuals with dementia, their caregivers, and healthcare providers (Kales et al., 2014).

Because of the complexities involved in diagnosing depression in someone with Alzheimer's Disease or Dementia, it may be helpful to consult a geriatric psychiatrist who specializes in recognizing and treating depression in older adults (www.alz.org). A few ways for individuals to be diagnosed with depression in Alzheimer's Disease and Dementia is with having two or more of these symptoms lasting for two weeks or longer, social isolation or withdrawal, disruption in appetite that is not related to other conditions, change in sleep pattern, agitation or slowed behavior, irritability, fatigue or loss of energy, excessive or inappropriate guilty, feelings of hopelessness, or suicidal ideation (www.alz.org).

The key to managing behavioral symptoms of dementia is a thorough assessment of underlying causes (Kales et al., 2014). Given the poor risk-to-benefit ratio, medications like antipsychotics are used far too often to manage behaviors (Kales et al., 2014). "The recent recommendations about risperidone and olanzapine add to the continuing concerns that older people in residential care homes often have mental health problems that are undiagnosed, and receive inferior standards of medical and mental health care" (Turner, 2005, p. 101).

Cognitive functioning and awareness. "Awareness can be defined as the ability to hold a reasonable or realistic perception or appraisal of, and/or respond accordingly to, a given aspect of one's environment, situation, functioning or performance (Clare, 2010, p. 20). Awareness of deficits is a complex phenomenon. Cognitive and affective processes have several kinds of differences which are involved in response made at different levels of awareness. Clare (2010) explains that there is a large body of evidence

that indicates that people with mild to moderate dementia of various types may often show disturbances of awareness at levels involving complex cognitive operations.

Clare (2010) cites that awareness lessens as the severity of dementia increases and scores on cognitive testing declines. “At least some people with moderate to severe dementia who still communicate verbally can, for example, provide self-ratings of mood that are consistent with observation, identify when they are in pain, comment on their own quality of life and on the care they receive, demonstrate preserved self-knowledge, respond in line with familiar and preferred role identities, engage in therapeutic relationships with nursing staff, describe the nature of their subjective psychological experience, and experience ‘episodes of lucidity’ (Clare, 2010, p. 21). It may be reasonable to consider that the degree of complex awareness may sometimes be retained even where there is severe cognitive impairment. The person’s own subjective rating is the essence of their quality of life. While objective measures may be helpful in determining quality of life, it is the person’s own report of their objective circumstances which leads to the quality of life experienced (Woods et al., 2006).

Discussion

This systematic review was developed to explore the contemporary body of scholarship available on the topic of types of interventions that can improve the quality of life for patients with dementia. However, the goal of this research was not to answer this question with a simple sampling of the literature, but rather to consider a broader perspective of the different sectors that can impact a person’s life and therein, quality of life. This review was setup using inclusion and exclusion criteria, as well as both sensitivity and specificity searches, as a means of finding pertinent and current research.

What emerged from this review is how different intervention strategies can provide patients with dementia with a sense of self and more improved quality of life as the disease progresses. These findings suggest that different non-pharmacological intervention strategies can be effective if not more so, than psychotropic medications that can assist the patient as their disease progresses.

Ecological Framework

In order to understand human development, it's important to consider the entire ecological system in which growth can occur. This system is composed of five socially organized subsystems that help support and guide human growth. They range from the microsystem, which refers to the relationship between a developing person and the immediate environment, to the macrosystem, which refers to institutional patterns of culture, such as the economy, customs, and bodies of knowledge (Neal & Neal, 2013). Ecological models encompass an evolving body of theory and research concerned with the processes and conditions that govern the lifelong course of human development in the environments that people live in (Neal & Neal, 2013).

The ecological framework treats the interaction between factors at the different levels with equal importance to the influence of factors within a single level. This framework is also useful to identify and cluster intervention strategies based on the ecological level in which they act. The ecological framework helps explain that patients and their caregivers are affected by this disease not only on a personal level but also affecting their relationship, their families and support systems, as well as society, as the amount of people being diagnosed increases and

costs rise for care of those with dementia. Throughout this systematic review, the research has shown the importance for patients and their caregivers to have a caring relationship while also the importance of caregivers showing an invested interest in the patient's life and their disease process. Along with that, this framework also helps explain the importance of caregivers practicing self-care to avoid caregiver burnout as well.

From conducting this systematic review, the researcher found that it is imperative to reflect upon the fact that no two people are the same in treating their dementia and behaviors. It is also important to try to preserve the "self" of people with dementia in order to improve their well-being in some way. Facing stigma is often a primary concern of people living with dementia and their caregivers. Stigma around dementia exists, in part, due to the lack of public awareness and understanding of the disease, preventing people from: seeking medical treatment when symptoms are present, receiving an early diagnosis or any diagnosis at all, living the best quality of life possible while they are able to do so, making plans for their future, benefitting from available treatments, developing a support system, or participating in clinical trials.

The following themes in this section will be discussed: a) Validating the Person's Sense of Self, b) Relationship with the Caregiver and Patient, c) Depression and Mental Health, and d) Cognitive Functioning and Awareness.

The first theme found in the literature focused on validating the person's sense of self. This sense of self can be established through validating the person's preferences, which can include their daily routine, and hobbies and interests. It is important for those with dementia to have consistency and routine in their lives to help decrease any anxiety

they may feel as well as to decrease any other behavioral symptoms they might have as a result from feeling anxious. Self-identity is the outcome of social contact and feedback between personality, biography, physical health, neurological status and social psychology. Staff need to work with whatever view of self is put forward by a person with dementia.

Quality of life is positively linked to certain building features about choice and control, community involvement, physical and cognitive support, comfort and personal care, and creating a sense of normality and authenticity. A narrow focus on health and safety in building design may create risk-averse environments but act against people's quality of life. Little things can make the biggest difference. Well-designed physical and social environments focusing on the quality of everyday life can help people continue in relationships that uphold a sense of identity and promote self-esteem.

The second theme found in the literature explored the relationship with the caregiver and patient. This relationship is essential and crucial to the patient's well-being as they progress through the disease process. Family caregivers are encouraged to seek their own self-coping techniques or other ways to manage the stress of caring for their loved one.

In relation to caregivers that are hired whether privately in the person's home or in a residential facility, person-centered care has many benefits for staff caregivers when suitable structures and attitudes are in place. Staff can build more rewarding relationships with people with dementia and share a less stressful and more home-like environment. They have greater task variety, are more creative and feel more capable. A culture shift is needed. A home-like environment, rather than an institution based on procedures and

routines is preferred and better for residents. Old style structures are not flexible approaches to care and decision making, and often undervalue staff members' knowledge and skills.

The third theme found in the literature explored depression and mental health in patients with dementia. Depression and anxiety are common conditions that are frequently experienced by people with dementia and their caregivers. People with depression may also experience physical symptoms, such as loss of energy and appetite changes. Physical symptoms of depression are more common in older people with dementia. Many of the things that can cause people to feel depressed can also cause people to feel anxious, and vice versa. The exact causes of these conditions vary from person to person.

Depression is often diagnosed in the early stages of dementia, but it may come and go, and may be present at any stage. Depression is also common among caregivers supporting a person with dementia. People with dementia may find it even harder to remember things and may be more confused or withdrawn. Depression may also worsen behavioral changes in people with dementia, which can sometimes cause aggression, sleeping difficulties or lack of appetite. In the later stages of dementia, depression can tend to show itself in the form of depressive 'signs', such as tearfulness and weight loss.

The fourth theme found in the literature explored cognitive functioning and awareness for patients with dementia. Cognition levels can be different for everyone. As dementia is an incurable disease, the disease slowly impairs memory and thinking skills and, eventually, the ability to care for oneself. The symptoms of dementia will usually get

gradually worse. How quickly this occurs will depend on the general health of the person with dementia and on the type of dementia they have.

Quality of life is an important outcome with people with dementia and there have been important developments in the use of self-report measures. However, it can be challenging to know how accurate a person's self-report is based on whether their cognition level is intact or has decreased due to their dementia diagnosis. Awareness should be viewed within a biopsychosocial framework that acknowledges the impact of the disease process, considering the person's environment, as well as any social and psychological influences that may affect the expression of awareness. The social environment and the person's interpersonal interactions can either hinder or support their awareness of their surroundings and people involved in their lives.

While this review was designed to include all relevant contemporary research on the topic of intervention strategies for patients with dementia, there were still a number of limitations with this study. First, better prevention, assessment, and management of behavioral symptoms are critically needed. We have a far greater capability, based upon trial data, to address behaviors as compared to either current psychotropic medication approaches or the management of cognitive symptoms of dementia. "There is a growing interest in psychosocial interventions in dementia care, but few have reached the stage of rigorous evaluation and even fewer have been widely implemented" (Editorial, 2011, p. 283). "The need for a rapid and substantial increase in the quantity and quality of psychosocial research in dementia care has therefore never been more urgent" (Editorial, 2011, p. 283). "Future research is needed to understand how caregivers make decisions when dealing with crises and how these findings can be incorporated into providing

appropriate acceptable crisis interventions” (Toot et al., 2013, p. 335). The reaction of the patient with dementia to the intervention(s) is important to assess, as are any unintended side effects or consequences in regards to interventions that may or may not include psychotropic medication treatment.

Limitations

This review was limited to articles and research that were peer-reviewed and written in English. This was done to ensure the rigor of the study but may have left out less structured research focus on personal experience and less formal narrative. Focus on peer-reviewed and evidence-based research also meant that unreliable literature, or literature that has not been formally published, was excluded from this study. The focal point of this research was around working with intervention strategies for patients with dementia.

People often think of dementia as a form of memory loss. And usually it does start by affecting people's short-term memory. However, it can also affect the way people think, speak, perceive things, feel and behave. Dementia makes it harder to communicate and do everyday things, but there is a lot that can be done to help. It is possible to live with dementia. Most people may have an image in their mind as to what life with dementia looks like. Which that image can often be very bleak. So it can be very surprising to learn that many people with dementia continue to drive, socialize and hold down satisfying jobs. Of course, dementia does make it harder to do certain things, but with the right knowledge and support it is possible for someone with dementia to get the very best out of life. When someone is diagnosed, their plans for the future may change

and they may need more help and support to keep doing the things they enjoy but dementia doesn't change who they are as a person.

Further Research and Implications

It is only through research that the causes of dementia can be fully understood, allowing us to develop new treatments and potential cures and to improve the care for people with dementia. It is vital for organizations and universities to continue to fund research on dementia. People affected by dementia and their caregivers should be given a greater opportunity to be involved in the design and process of research. People with direct experience of dementia can make valuable contributions to the design and direction of dementia research projects, especially those addressing dementia care and services.

Currently, research is being conducted into how care can be delivered and organized in a range of different settings, to improve quality of life for people with dementia. More emphasis should be placed on ensuring this evidence is translated into practice. Organizations that commission and provide services for people with dementia must commit to supporting the implementation of evidence-based interventions and strengthening links between academia and health and care services delivery. Research evidence must also be made readily accessible to those who purchase and use services.

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| Articles for Dementia and Quality of Life | | |
|---|---|--|
| Database | Title | Author(s) |
| SocINDE X | What is dementia? | Alzheimer's Association. (2015) |
| | Racial and ethnic factors in dementia caregiving research in the US | Aranda, M. P. (2001) |
| | Risky and resilient life with dementia: review of and reflections on the literature | Bailey, C., Clarke, C. L., Gibb, C., Haining, S., Wilkinson, H., & Tiplady, S. (2013) |
| | Caregiver outcomes of partners in dementia care: effect of a care coordination program for veterans with dementia and their family members and friends. | Bass, D. M., et al. (2013). |
| | Unmet needs of community-residing persons with dementia and their informal caregivers: findings from the maximizing independence at home study | Black, B. S., Johnston, D., Rabins, P., Morrison, A., Lyketsos, C., & Samus, Q. M. (2013) |
| | Collaborative care management reduces disparities in dementia care quality for caregivers with less education | Brown, A. F., Vassar, S. D., Connor, K. I., & Vickery, B. G. (2013) |
| | Interventions supporting self and identity in people with dementia: a systematic review | Caddell & Clare. (2011) |
| | Awareness in people with severe dementia: Review and integration | Clare, L. (2010) |
| | Technology can enhance quality-of-life assessment in person-centered care | Edelman, P. (2013) |
| | Formal dementia care among first nations in Southwestern Ontario | Finkelstein, S., Forbes, D. A., Richmond, C. A. M. (2012) |
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