

Social support as a right for elderly individuals with dementia

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Abstract

This research studies social support systems and the rights of the elderly with dementia through qualitative research. The research aimed to determine the support systems in use in Thailand which had the greatest efficacy. A purposive sampling method coupled with consultations with nurse practitioners was used. The nurse practitioners were based at the Pootarn Health Service Center, located in the Nongkam District of Bangkok. The participants of the study included five elderly people with dementia, living in Nongkam community, who were able to independently communicate. In-depth interviews with guided questions were conducted. All five of the elderly individuals with dementia who were part of the study were female. Their age ranged from 65 to 75 years and all suffered from hypertension. All had had dementia for more than three years and were somewhat able to care for themselves. The participants, felt that social support encompassed - support and assistance from family members when it was requested. They also explained that social support of the elderly with dementia should include being treated with dignity and respect and should be carried out without condescension.

Dementia patients require quality health care and social services support, that protects them and cares for their evolving needs. Care of elderly dementia patients includes attention to cognition, behavior, personality, and mental health. The rights of elderly dementia patients should be legally guaranteed. They should have the right to receive adequate medical and health care services as well as have access to legal professionals for the preparation of wills and protection of their rights. These rights and social supports should be classified as human rights, alongside their rights of citizenship, patient rights, and the Health Care Act.

Keywords: elderly individuals, dementia, social right, social support

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1. Introduction

Thailand is currently on a trajectory towards being classified as an “aging society,” as the population percentage of elderly individuals is rapidly increasing. A survey, conducted by the Office of National Economic and Social Development Board in 2008 found that hospitalization among the elderly was predominately caused by neurological and psychiatric conditions, with a large percentage related to dementia. In 2000, it was estimated that roughly 25 million of the world’s elderly people have dementia. This figure is expected to rise to 63 million by 2030 and 114 by 2050 [1, 2]. This growing trend of elderly individuals with dementia is mirrored within the Thai population. Each year sees an increase in the total number of elderly individuals with dementia.[3] Table 1 illustrates this growing trend in Thailand.

Table 1 illustrates that the number of elderly individuals with dementia has continued to grow each year between 2012 and 2014, with a greater percentage found in female patients. Dementia is not a one -

dimensional disease. It requires many facets of treatment and care, from a spectrum of individuals. These include physicians, nurses and family members. Moreover, complications arising from dementia related - illnesses or injuries tend to have broader deleterious effects for patients. This is due to the broad-reaching effects of the illness. These are exacerbated by lack of or insufficient healthcare treatment or lack of hospitalization when it is required. [4]

The unique conditions of dementia onset can be different from patient to patient., Signs of the initial stage of the disease can be fairly subtle. Individuals are still able to perform daily tasks, however issues often arise with short – term memory or forgetfulness, such as inability to remember familiar names and places. Repeating patterns of speech or questions is also common. Subtle changes in language and other diction can also be common. [5] Early stages of dementia can also manifest themselves through other characteristics, such as the inability to find things in one’s home, lacking creativity, being passive, self – isolation, and

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Table1 Demonstrates the numbers of patients with dementia versus general patients(1 vs. 100,000) categorized by gender.

2012			2013			2014		
Total	Male	Female	Total	Male	Female	Total	Male	Female
1,234 (1.92%)	565 (1.79%)	669 (2.05%)	1,245 (1.93%)	586 (1.84%)	659 (2.01%)	8,342 (12.84%)	3,579 (11.21%)	4,763 (14.42%)

Table 1: Number of patients with dementia in large total patient population in Thailand (1 v.100,000)

ignoring social activities. In this phase, many patients begin to recognize that they are not functioning at their normal cognitive capacity and may request to see a doctor.

The Middle stages of dementia are characterized by more severe symptoms. These include larger changes in personality and other mental health issues. Auditory hallucinations, illusions, delusions, affective disorder, or irritability can also present themselves during this stage. Emotional responses may be magnified with less inhibition. For instance, if an individual gets angry, they may use strong language that they might not have previously used. These symptoms are often coupled with potentially harmful behaviors to themselves or others, which can include beating and biting. During the manifestation of these symptoms, the patients may be unable to understand others' emotions, feelings and the situation surrounding them. Their critical thinking and problem solving capabilities may be impaired and they may require assistance from others.

The final stages of dementia are characterized by severe cognitive impairments. These include the loss of perception of time, place or the identity (of both themselves and others). Self – care is largely impossible at this stage. Patients will need 24 – hour care from skilled caregivers for basic daily functions as well as their medical needs. [6]

Dementia has far reaching effects for both patients and caregivers. It is not uncommon for dementia patients to suffer abuse, mistreatment or the violation of their rights. The complexities of dementia require that caregivers are properly trained to protect those with dementia, but also to treat them in such a way as to slow the progression of the disease by preventing social and physical isolation.

2. Objective

This research aimed to identify effective social support strategies in order to maximize the rights and quality of life for elderly individuals with dementia.

3. Definition of Terms

Dementia refers to a neurological disease classified by a deterioration in cognition, memory and brain

function. It can cause behavioral and emotional changes that affect the physical health and daily life of individuals that are affected.

Elderly individuals refers to patients who are 60 years and older who have been diagnosed by a physician as having dementia under the diagnosis criteria established by the American Psychiatric Association. [7]

Social support refers to care, assistance and nurturing that elderly dementia patients receive from families, peers, and caregivers.

Social rights refers to dementia through the lenses of citizenship and human rights

4. Material and Method

A qualitative research methodology was utilized to determine the meaning and classifications of social rights for elderly individuals with dementia. A purposive sampling method was used, coupled with consultations with nurse practitioners from the Pootarn Health Service Center in the Nongkam District of Thailand. Participants of the study also included five elderly individuals with dementia living in Nongkam, who were able to independently communicate with the researchers. In-depth interviews were conducted using a script of interview questions to service as a guide and to maintain consistency between interviews.

5. Findings

5.1 Demographic Information

Five elderly individuals with dementia were interviewed. All were female between the ages of 65 and 75 years. All were Thai and Buddhist. All were married. Three of the interviewees had attained a secondary education, while the remaining two had both achieved university degrees. All of the interviewees were retired and lived with their families. All of the interviewees had hypertension and had a diagnosis of dementia that dated back three or more years. All were able to care for themselves to some degree.

5.2 Perspectives on the definition of Social support

Apart of their interviews, participants were asked to define what the concept of “social support” encompassed to them. The participants largely defined “social support” as receiving support and assistance

from family members upon request in addition to being taken to the doctor, having food prepared and being taken on trips outside the house. This included taking care of them, personal company, transportation and assistance with hospital visits and meal preparation.

On March 15, 2017, one interviewee commented that “ my daughter always takes me to see a doctor whenever I have appointment.”

Another stated, “ my daughter cooking food for me every day.”

While a third participant remarked, “ my daughter always stays with me and takes me to any places I want to go such as the temple.” Daily care of individuals with dementia by family members was found to include, preparing meals, bathing assistance, dressing assistance, medicine administration, help with walking and mobility, and help with bodily functions. In the circumstances studied for this research, the majority of the care given to the patients was undertaken by family members.

In the context of the same interviews conducted on March 15, 2017, one caregiver recalled, “My grandmother wants to sleep but she isn’t sleepy and still alert, so I have to give her a sleeping pill so that she can sleep.”

Others recalled, “When my mother wants to defecate, she will be cry out... I think she may forget how to excrete so I have to give her an enema, then she stops crying out.”

Another remarked, “While having symptoms, my grandmother will throw everything away... I will let her do it until she tires, stops doing it, and sleeps. Then I take care of it. The caregivers have to be very patient; otherwise, there will be a huge argument.”

“I’ve been taking care of my husband with dementia for many years... I used to be very stressed by it but I had to let it go... I have to take care of him anyway!”

“I am stronger so it is my job to take care of a weaker person!”

5.3 Social support and Existing Legal Protections for the Elderly with Dementia

The rights and access to care for elderly individuals with dementia are classified as a basic human right, with further protections covered by existing Thai laws. Article 4 of the Constitution of the Kingdom of Thailand B.E. 2540 stipulates rights for the protection of people. It requires equal rights, equal opportunity and encourages people to live together happily with dignity for all citizens. [8] In the case of dementia patients, memory and cognitive deficits should not lead to mistreatment and loss of dignity. The protection of these rights is, essential.

For Thai citizens, Section 2 of the Constitution of the Kingdom of Thailand B.E.2560 outlines the right for

protection and assistance by the state. This includes the right of access to healthcare. [9]

The Declaration of Patient’s Rights, legislated on August 12, 2015, stipulates that, “The elderly with dementia must have the legal right to receive health care services”. [10] The Declaration of Patient Rights outlines the following:

(1) All patients have the legal right to receive health care services as stated in the Constitution BE 2540.

(2) All patients have the right to receive services from health care professionals without discrimination due to differences in status, race, nationality, religion, political belief, gender, age or the nature of their illness.

(3) Patients who request health care services have the right to stay informed so that they clearly understand the cause of their symptoms from health care professionals. Given this clear understanding, the patients can then choose whether they agree to consent or not to the treatment recommended by health care professionals. This is with the exception of emergency treatment when time may not permit this process.

(4) Patients in life-threatening emergencies, have the right to receive urgent and medically necessary assistance from health care professionals regardless of whether the patients requests help or not.

(5) The patients have the right to know the name, qualifications and licenses held by the health care service providers.

(6) The patients have the right to seek second opinions from other health care professionals and have the right to change health care service providers and agencies.

(7) The patients have the right for their information to be kept in confidence, unless they give consent or it is legally necessary.

(8) Patients have the right to receive clear and accurate information before deciding to refuse or to participate in medical research.

(9) Patients have the right to receive information about their specific medical treatment in medical records upon request. The provision of such information must not infringe on the privacy or rights of others.

(10) Parents or legal guardians may legally act on behalf of patients who are under the age of 18. This also extends to patients with mental illness who do not have the mental capacity to exercise their own rights. The Second National Elderly Plan states that “the elderly with dementia” who are able to recognize their symptoms, have the right to be informed about their symptoms and treatments.

The second National Elderly Plan (B.E.2545 – 2567) outlines the rights of the elderly with dementia to access healthcare. The law establishes strategies and legal frameworks for the improvement of health care security.

[11] The plan outlines the guidelines and legal frameworks to establish a social protection system for elderly people.

Article 15(4) of the Mental Health Act B.E.2551 stipulates universal healthcare coverage. It states that; "Patients with any disorder have equal right to be covered in health insurance, social security and other systems of the state."

Article 80(2) of the Constitution of the Kingdom of Thailand B.E.2550 promotes universal access to healthcare services and the right to annual physical exams. It states "that is required for the state to provide, promote and develop the health care system targeting health care promotion,"

The Ministerial Regulations B.E. 2552 classifies dementia as a form of mental illness. The Mental Health Act B.E.2551 therefore also applies. It stipulates that if elderly patients are diagnosed with behavioral and psychological symptoms of dementia (BPSD), physicians have the ability to treat them in hospital.

The Constitution of the Kingdom of Thailand B.E. 2550 defines and protects the rights of the elderly to have access to public health services. Article 11(1) of the Elderly Act, B.E. 2556 states that "medical authorities of the state must provide special channels for elderly patients in the outpatient department to reduce unnecessary procedures, duration of services and waiting times,"

Wills and living Wills of Elderly Patients with Dementia;

The legal process of drafting wills of inheritance can be a complex process. It is made further so by dementia. In order for wills of inheritance to be legally binding, the elderly must be conscious and of sound mind. [11] An indication of consciousness includes the ability to answer questions about dates, times, places and people without confusion. Additionally, they must also be able to communicate the history of the properties they own. They must also be able to communicate the value of properties, the reason for transferring the ownership of properties, and they must fully understand the consequences of transferring their property to others. The elderly must demonstrate a knowledge of their relationship with the beneficiary of the will and justify reasons for the inheritance.

In instances of living wills, Thai laws requires that the testator of the will, the elderly person with dementia, be - conscious and of sound mind. It is also essential for the elderly individual with dementia to appoint a power of attorney or executor of their estate, to act on their behalf in court and other legal capacities when required. In living wills, the testator must state what types of treatment are allowed for themselves. This includes, resuscitation requirements, use of ventilators for breathing and use of feedings tubes. It also includes the

nature and extent of extraordinary measures that may be used to preserve the life of the testator.

6. Discussion

The right of social support for elderly individuals with dementia has become a multifaceted social issue that is often given insufficient attention. This is thought to be due to the cognitive decline of those suffering from this disease. Dementia typically presents itself in the form of memory loss, loss of familiarity with family, auditory hallucinations, paranoia, illusions, isolation and depression. Presently, the increase in the elderly population, both globally and in Thailand, has coincided with a rise in the number of cases of elderly patients with dementia. Studies have shown that the care of these individuals usually falls to close relatives such as children or spouses. This is considered "compassionate care," and is considered the norm in Thai society. This care structure also recognizes the foundation of family-oriented care in morality, support and sympathy. [12] The nature of the care given to an elderly individual with dementia can be a significant determining factor in the speed of the disease's progress and the quality of life of the individual affected. The relationship between caregivers and dementia patients can often combine emotions and responsibilities, as emotional attachment is blended into the care. Education on the disease is vital, as this can help to prevent deleterious behaviors and habits of those close to the dementia patient. This can include the avoidance of laughter when seeing an undesirable behavior, not trying to force the elderly individual with dementia to memorize things, or not forcing them to do something unfamiliar as this can be particularly jarring. Caregivers should also treat individuals with dementia with respect, honoring their decisions, including them in dialogues about their care and needs. They should also be asking them simple questions and be participating in recreational activities together. Caregivers of elderly individuals with dementia need to seek medical attention when physical or cognitive issues arise. Patients should be made aware of their treatment plans and medication. Elderly patients with dementia need to be treated with the same rights and dignity as other patients and be given the same access to care. Loss of cognitive function and memory should not lead to loss of humanity in care.

Caregivers and the manner in which they provide care are essential for adequate care of elderly individuals with dementia. [13] Caregivers need to maintain awareness of cognition, behavior, personality and mental health. [14] Care and attention must be provided to elderly patients with dementia 24 hours a day. The living environment must be safe and clean in order to minimize the likelihood of trips and falls. Furthermore, the use of soft lighting and calming colors

can also contribute to the quality of life of the elderly individual with dementia. A schedule should be followed in order to provide regularity in eating, resting, recreation and socializing. When initiating communication with an elderly dementia patient, it is best to use a soft voice, repeating words and information in order to aid understanding. [15]

7. Conclusion

Elderly individuals with dementia in Thailand should have social support and access to adequate care. These rights are guaranteed under the auspices of existing human rights laws and policies, as well as Thailand's Citizenship Rights. The rights for elderly individuals with dementia are, the right to receive medical and health care services, the right to be protected by Health Care Act, rights of patients and the right to produce wills and living wills. Caregivers must recognize the social rights and legal rights of elderly individuals with dementia to both protect the patients and to follow them. This requires a close collaboration between elderly individuals with dementia, their healthcare service providers and their caregivers.

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