

Caring For Caregivers of Individuals With Dementia: From the Perspective of Watson's Theory of Human Caring

Watson İnsan Bakım Teorisi'nin
Perspektifinden: Demans Hastalığı Olan
Bireye Bakımverenlerin Bakımı

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ABSTRACT

The caregiving process affects caregivers at bio-psycho-socio-cultural dimensions. Therefore, nursing care that will be carried out for caregivers should be planned and implemented in a way that cares for the whole of individuals. Watson's Theory of Human Caring that defines nursing care as a scientific, ethical, esthetic and professional process during which individuals have a physical, mental, spiritual and socio-cultural interaction is a holistic caring model that requires taking the person into consideration not only physically but also socially, psychologically, culturally and spiritually. The purpose of this article is to provide a road map, create a new perspective about how to use Watson's Theory of Human Caring as a guide for caring for caregivers of individuals with dementia.

Key Words: *Caregivers, dementia, nursing care, Watson's Theory of Human Caring*

ÖZ

Bakım verme süreci bakım vereni biyo-psiko-sosyo-kültürel boyutlarda etkilemektedir. Bu nedenle bakım verenlere uygulanacak hemşirelik bakımının bireyin bütününe hizmet eden bir şekilde planlanması ve uygulaması gerekmektedir. Hemşirelik bakımını, bedensel, akılsal, ruhsal ve sosyokültürel yollarla iki kişinin karşılıklı etkileştiği bilimsel, etik, estetik, profesyonel bir süreç olarak tanımlayan Watson İnsan Bakım Teorisi, hemşirenin bakım

verdiği bireyi sadece fiziksel değil sosyal, psikolojik, kültürel ve spiritüel yönden de ele almayı sağlayan bütüncül bir bakım modelidir. Bu makalenin amacı; Watson İnsan Bakım Teorisi'nin bakım verenlerin bakımında nasıl kullanılabileceği ile ilgili bir yol haritası çizmek, bir bakış açısı geliştirmektir.

Anahtar Kelimeler: Bakımveren, demans, hemşirelik bakımı, Watson İnsan Bakım Teorisi

INTRODUCTION

Dementia is a public health problem that is increasingly becoming a serious worldwide concern¹. The World Health Organization (WHO) reported in 2012 that there had been 35.6 million individuals with dementia in the past three years. It is estimated that the number of individuals with dementia will double every 20 years. In fact, it is expected that 65.7 million and 115.4 million elderly people will have dementia in 2030 and 2050 respectively^{2,3}. According to the Alzheimer's Europe 2012 data, numbers of the people with dementia are 331,512 in Turkey⁴. Dementia impairs judgment, accommodation, communication, personality and behavior. The disease is progressive and as it progresses, caring needs of affected individuals increase and these individuals will need a caregiver^{5,6}. Responsibility for caring individuals with dementia is usually fulfilled by their family members.

Family members offering care to patients with dementia experience burden of caring, emotional stress, depression, anxiety, strain, weakened immune system, various health problems, leave from work and financial difficulties⁶⁻¹⁰.

After a member of the family is diagnosed with dementia, responsibilities of family members and the balance between their responsibilities change. During this period, the person offering care feels tired, exhausted, hopeless and annoyed^{8,10}. In one Turkey study, of all the caregivers included in the study, 64% experienced difficulties due to the caring process and of all the caregivers experienced difficulties, 40.6% could not receive support, 34.4% had psychological difficulties and 18.8% had financial difficulties. In addition, daily life activities were affected in 90% of the caregivers and 83.3% of the caregivers looking after patients with advanced dementia had difficulties in the caring process⁷.

It has been reported that caregivers of patients with dementia should have strong support systems and should be able to access people or organizations providing information about the disease so that their burnout syndrome can be reduced. Nurses play an important role in offering education to caregivers, improving knowledge and skills of the caregivers and managing patients' behavior appropriately^{11,12}.

The caring process has biological, psychological, sociological and cultural effects on caregivers. Therefore, nursing care to be offered to caregivers should be based on the holistic approach. Watson defined nursing care as a scientific, ethical, esthetic and professional process during which two people have physical, mental, psychological and socio-cultural interactions¹²⁻¹⁴. Watson's Theory of Human Caring is a model based on the holistic approach which allows nurses to take care of individuals in terms of not only physical but also social, psychological, cultural and spiritual dimensions¹⁶. This article is directed towards providing guidance in and creating a point of view about how to use Watson's Theory of Human Caring in offering care to caregivers of patients with dementia.

Conceptual Framework: Watson's Theory of Human Caring

The Theory of Human Caring was developed by Jean Watson between 1975 and 1979¹⁷. Fawcett stated that this is a moderately explanatory theory. The theory is composed of four main concepts, namely, the transpersonal caring relationship, caring moment/caring occasion, caring- healing consciousness and clinical caritas processes¹⁴.

Transpersonal caring relationship: Transpersonal relationship refers to the moment when a nurse and an individual enter each other's' experiences. At that time, space and time dimensions are transcended. The unity of mind body spirit of other influences the nurse's consciousness and influences on those for whom they serve. A transpersonal caring relationship involves scientific, ethical, esthetic, creative and individualized giving and receiving behavior and reactions between individuals and nurses. During this interaction, nurses approach individuals in a sensitive, harmonious, respectful, friendly and ethical way, full of empathy to fulfill a caring relationship¹⁸⁻²⁰.

Caring moment/caring occasion: It is the moment when a nurse and an individual meet a person for caring. It also refers to the moment when interpersonal interaction is realized. During a caring moment, communications and interactions occur between an individual offering care and another receiving care^{15,21}.

Caring- healing consciousness: Underlying the core of nursing is caring and healing consciousness, which involves the concepts caring, healing and love. Watson emphasized that caring- healing consciousness can be acquired through love and that when nurses approach their patients with love, they can help to facilitate healing^{18,22}. Caring and healing can be achieved when caring is based on healing consciousness¹⁹.

Caritas processes/ Carative factors: Watson stated that caritas processes constitute the core of nursing. When caritas processes are implemented appropriately, a nurse is a carative factor and the individual is treated as a whole person; for example mentally, physically and spiritually^{18,20,23,24}. Caritas processes provide guidance for nursing. These processes make caring and carative roles of nursing become new standards of authentic patient care, rather than emphasizing the curative aspect of medicine¹⁹. Ten factors play a role in the caritas process and they are listed below^{21,22}.

Humanistic- altruistic system of values: Humanistic values result from beliefs, culture and arts. They involve kindness, empathy, concern and love for self and others. Altruistic values are made up of relationships with others, beliefs and commitments²³. The humanistic-altruistic factor is based on the adoption of humanistic-altruistic values and having love and affection for self and others. Humanistic feelings and altruistic approaches are the basic carative factor necessary to fulfill needs and to provide professional care^{23,25}. Therefore, nurses should have a positive attitude and should be cheerful, tolerant, tender and loving. Nurses should approach individuals with kindness and love from their heart²⁶.

Enabling and sustaining faith and hope: It is important to encourage, honor and respect individuals' beliefs in order to protect and promote their health. Irrespective of health status and medical regimens of individuals, nurses should provide them with support for faith and hope^{23,25}.

Sensitivity to self and other: Being a human means to feel. Although humans can talk about their opinions freely, they have a hard time expressing their feelings. The

way to improve individuals' sensitivity to themselves and others is that they should be encouraged to get to know their own feelings. Being sensitive helps individuals to become mature psychologically and to accept themselves as they are. Nurses realize and promote themselves when they are sensitive to individuals' feelings^{23,25}.

Developing helping, trusting caring relationship: During a human caring relationship, nurses become involved in individuals' experiences and vice versa. They share a space beyond the physical one. They establish a connection with each other's spiritual world and thanks to this connection, human dignity is protected and two individuals help each other. Nurses can provide helping, trusting care by playing an authentic role (natural, sincere, reliable and loving) in this interaction^{23,25}.

Promoting and accepting the expression of positive and negative feelings and emotions: It is necessary to take account of and explain feelings and emotions in the human caring process as well as thoughts, behaviors and experiences. By using this carative factor, nurses can establish a more in-depth, honest and authentic caring relationship. It is important to listen to others' feelings and value their stories so that they can heal and find things in their lives meaningful. Only by listening to individuals' feelings and emotions can nurses contribute to their healing^{23,25}.

Engaging in creative, individualized, problem-solving caring process: Professional nurses use creative problem solving methods in the nursing process so that they can decide nursing care. They form and implement these creative approaches in the clinical care. They make use of their own and others' knowledge, intuitions, instincts, esthetics, technological facilities, skills and experimental, ethical and personal characteristics. All pieces of knowledge are valuable and important to clinical caring. The caring process requires being creative, systematic and reasonable^{23,25}.

Transpersonal teaching and learning: This factor emphasizes that an authentic relationship between nurses and individuals will facilitate learning while nurses fulfill their roles of teaching and learning. All learning and teaching processes occur during the authentic relationship established between nurses and individuals. Nurses prepare their caring plans based on information they have received from individuals and offer education in an authentic teaching and learning environment^{23,25}.

Provision of supportive, protective, and corrective mental, physical, societal, and spiritual environment: This factor refers to creation of comfortable, esthetic and peaceful environment in the context of physical, emotional and spiritual field. The purpose of creating such an environment is to offer high quality care and achieve healing as a whole. The environment created should be comfortable, secret, safe, clean and esthetic. Nurses should rearrange the environment so that it becomes a healing and harmonious environment in which there is imagery, visualization, music-sound, intentional touch and art^{23,25}.

Assisting gratification of basic human needs, while preserving human dignity and wholeness: This carative factor includes assisting to satisfy basic physical, emotional and spiritual human needs. Individuals allow nurses to easily access themselves when they have physical needs. When nurses help these individuals, they do not only fulfill their physical needs but also touch their spirit and heal them^{23,25}.

Allowing for being open to, existential-phenomenological and spiritual dimensions of caring and healing: Some phenomenological situations, which cannot be explained

scientifically, exist. Although it is not known how they are realized, their effects on individual humans differ. This carative factor refers to human experiences, spiritual meanings, miracles, cultural beliefs and internal subjective worlds of nurses and families of individuals^{23,25}.

Implementation of Watson's Human Caring Theory of Caring for Caregivers of Individuals with Dementia

Caregivers confront many problems which can be difficult to cope with. These problems lead caregivers to experience many negative feelings. Physical and emotional burdens created by the caring process challenge individuals' strength against events and reduce the quality of their lives. This is especially true for caregivers of individuals with dementia. During the caring process, individuals should be supported, their strength should be enhanced and they should be enabled to have a positive perception of the caring process. During this difficult process, nurses protect and promote biological, psychological and social health.

Nurses should turn each moment when they meet individuals into an opportunity. So that an interaction in which sharing between caregivers and individuals with dementia occurs can be generated, nurses listen to the caregivers' experiences carefully and with interest while they provide support for caring. In this interaction environment, nurses are influenced by caregivers' experiences, feelings, lives and culture when they provide care for caregivers, that is, they learn during the caring process.

Watson noted that love between an individual and a nurse is of great importance during the caring- healing process²⁰. So that caring- healing consciousness emerges, nurses should show love and affection for caregivers of individuals with dementia. In fact, this is the way they can make use of to convey the caring- healing consciousness¹⁸. During this process, both the nurse and the individual provided care become mature. Nurses continue to provide care for caregivers with caring- healing consciousness, love, affection, forgiveness and respect appear in the integrity of a family. Thus, caring-healing consciousness is conveyed to both caregivers and individuals with dementia. Nurses can increase caregivers' self-esteem by showing love and affection. As caregivers' self-esteem increases, so does their caring performance, which leads caregivers to feel satisfied and safe²⁷.

Nurses know that each caregiver is unique and that they have to accept each one as they are. While they honor caregivers' abilities and skills, they recognize their sensitive aspects. Nurses allow caregivers to select the most appropriate time to talk about the subjects related to them. They talk to caregivers calmly and focus all their attention on this talk. They should not be judgmental, but show respect and affection and have empathy so that they can understand the message given by caregivers and provide appropriate support²⁸.

Nurses should give the message that caregivers of individuals with dementia can access them whenever they like. It has been reported that counseling via telephone to caregivers provides useful care for the individual with dementia²⁹. When face to face counseling is not feasible, communication through phone calls will improve trust between nurses and caregivers. Thus, caregivers always feel that they are valued, respected and supported.

Nurses help caregivers to create meaningful and entertaining situations and to remember pleasant memories and recognize that individuals for whom they offer care are the people they have loved and respected before they become ill^{30,31}. Nurses also make caregivers believe them during the caring process. They collect information about caregivers' beliefs and enhance caregivers' hope in the direction of their beliefs. They encourage caregivers' ability to cling to life. They make an effort to show that life is a mystery to be solved rather than problems to be solved. They combine things caregivers find meaningful and important with their beliefs and hopes.

Nurses help caregivers to accept individuals with dementia as they are and the caring process. They organize occasions which allow both caregivers and individuals with dementia to have feelings of gratitude, forgiveness, mercy and submission.

Caregivers usually have ambivalent feelings associated with individuals they provide care for. They may experience such feelings as love, anger, disappointment and avoidance of responsibilities³¹. Studies performed on caregivers with dementia have revealed that although they experience negative feelings, they find some experiences meaningful in the caring process, discover or get to know themselves and become joyful and have opportunities to enhance their relationship with individuals to whom they offer care during the process and that their resilience, personal development and commitments increase^{30,32-34}. By providing a chance for caregivers to recognize their own feelings, they can be allowed to find things related to the situation they experience meaningful. As a result, they can have a harmony within their body, mind and spirit, auto-control and healing. There is a positive correlation between harmony within self and harmony with others and resilience and finding meaning in caring³¹. So that caregivers' negative experiences can be prevented and so that they can solve their problems, their psychological resilience should be increased³². Psychological resilience is an ability to overcome difficulties and to adapt to available conditions. This ability is defined as a psychological quality and contributes to psychological strength, healthy development and struggle against negative situations³⁵. It is directly associated with getting to know, respecting and healing self, self-care control, commitments, challenging and elements of resilience mentioned by Watson 1989³¹.

Nurses are aware of individuals' negative and positive feelings and try to understand how these feelings affect them²². They allow individuals to recognize positive aspects of the situation they go through and teach them how to cope with their negative feelings. Listening to music, keeping a diary, art therapy, games, humor, entertainment, breathing exercises and daydreaming can be recommended.

Caregivers of individuals with dementia should be encouraged to ask questions. Nurses search about caregivers' viewpoints of life and then share their knowledge and experiences with caregivers. They create a learning environment which allows individuals to be creative and cooperate with each other. Nurses should give the message that caregivers are always welcome to ask questions. They also teach caregivers problem solving skills.

Interviews can be held in an environment where caregivers of individuals with dementia are happy or a healing atmosphere is created by nurses. For caregivers, a quiet, calm and safe environment where the smells liked by caregivers are used and caregivers' privacy should be created and is respected. For example, touching, massage and aroma therapy

can be used to help caregivers feel relaxed. The feeling of touch is an inevitable element of human life; humans touch themselves and others with all their beings. Touching is considered as a way of communication. Physical touch does not only provide comfort but also help individuals feel better. This brings about physical, mental and spiritual wellness³⁶⁻³⁸.

Caregivers try to establish a balance between caring and their own needs (work, sleep, entertainment, nutrition and exercise). Caregivers dreams about having free time, going on holiday, taking up hobbies and spending time with their friends³¹. To help caregivers to realize their dreams, nurses respect individual needs, eliminate their worries and create a comfortable environment. They are also sensitive to caregivers' families and people they love and care about. Nurses put emphasis on the importance of receiving support for unfulfilled needs including sleep, relaxation and healing and talk to caregivers' families about offering support for them.

Nurses accept feelings of caregivers for individuals with dementia and respect things the caregivers find meaningful. The caregivers who question the disease in particular explain the necessity to accept some life events as they are. They believe that everything in life is full of love and goodness and occurs so that individuals improve and share this feeling with caregivers.

CONCLUSION

Using Watson's carative factors in caring for caregivers of individuals with dementia may allow the caregivers to find the caring process meaningful, enhance their psychological resilience, personal development and commitments and discover their own characteristics. Watson's caritas processes should be used as a guide to the determination of problems in the caregivers of individuals with dementia, in making care plans for them and in evaluating outcomes of these plans. Watson's Theory of Human Caring can be guidance for nurses in providing person centered, respectful, reliable, sensitive, honest and accessible care. This theory focuses on healing and love. It is thought that this caring behavior will reduce the burden on the caregivers of individuals with dementia, potentiate their power to cope with negative feelings and problems and improve the quality of their life.

SAMPLE CASE

Z.G., who is a 72 years old male-caregiver, gives care to his wife for 7 years. His wife has a middle-stage Alzheimer's disease.

Individuals who maintain the care of Alzheimer's patients cannot leave them alone if their support system is inadequate. A therapeutic environment can be established by the nurse. If proper environment is provided, interviews can be held in an environment while the caregiver is happy to be. In this sense a quiet, calm and a safe environment can be established for the caregiver, in which odors are used that the caregiver likes and privacy is respected (carative process 8 and 9). Six interviews were held with the caregiver in total. We held the interviews in the caregiver's house, while the patient was sleeping or calmed down, due to the fact that the caregiver could not leave his patient alone. During the interviews we treated the caregiver with love, respect and compassion

and we listened to the experiences of the caregiver with interest and attention (carative process 1, 2 and 4).

In the first interview the caregiver wanted to speak mostly about the care of his patient. We clearly understood that the caregiver had a lack of information about the disease and caregiving. The caregiver told that he was especially obstinate with his patient all the time, the patient was not using his medications regularly, she could not sleep at nights for fearing that his patient would wake up, he was having trouble in feeding his patient and he was giving especially liquid foods to his patient. The nursing education focused on the caregiving of the Alzheimer's disease and especially for the problems of the patient and her/his caregiver can be shared in any environment by establishing mutual learning-teaching relations (carative process 4, 6, 7 and 9). We gave suggestions about the lack of information related to caregiving within this process. In the second interview the caregiver stated that he tried to apply the new information what he learned, he had a nice week with his wife and they were not obstinate with each other anymore.

During the interviews we clearly understood that the caregiver could not accept the disease and he could not fit this condition to his patient. The caregiver was thinking that his wife acting in that way to make annoy his. The lack of information about Alzheimer's disease and the fluctuating course during the period of this disease complicates the process of accepting the disease. Even though the lack of information is fulfilled, time is required for this information to be used and to be turned into behavior. Helpful and reassuring relations should be established with the caregiver (carative process 4); the feelings and the emotions of the caregiver should be accepted and supported at this stage (carative process 5). The caregiver was feeling guilty about having negative feelings for his patient. The guilt feelings of the caregiver should not be reinforced at this stage. The stage of accepting the disease changes from person to person. During the interviews we told his that he should not feel guilty about having those feelings and that his feelings were acceptable. A discussion platform was established so that he could realize the effects of his anger on himself. We gave his time so that he could put the information he learned into practice. We asked his to record the conditions and experiences of which he did not believe that his wife was sick, until the next interview.

It is necessary to listen carefully to the experiences of the caregivers and they should be supported by the healthcare professionals and by the family members at every stage of the disease (carative process 3, 4 and 5). One should be aware of the fact that the past relations affect the experiences of the caregiver during the caregiving process. When we asked questions about their family processes he mentioned that they had a loving and respectful marriage with his wife but both his wife's family and his own family interfered a lot in their marriage in the early years and therefore he had negative communications with his wife during this period. He stated that he was feeling anger towards his wife and towards his family when he thought about the past years. He told that his wife's family was criticizing his about his caregiving all the time after the diagnosis of the disease and he thought of putting his wife to a nursing home because he was not supported by his son and his relatives but then he decided not to do so.

The importance of the support the caregiver should get due to that fact that he cannot fulfill his basic needs (sleep, relaxation, healing) can be emphasized and he can be asked to interview with other family members if needed about the fact that they should support

the caregiver (carative process 4 and 9). We evaluated the caregiver's way of asking for help at this stage, and we encouraged his to interview with the family members. The caregiver reached to his wife's two sisters via his nephew and told them that they could make a visit to the patient. The relatives of the patient apologized when they came to visit him and they stated that they wanted to support him more from then on. It was seen that the caregiver was very happy and relieved in the following interview.

Another negative feeling the caregiver went through during this period was that he could not forgive his wife in some matters (for expelling his mother and sister from home). In her theory, Jean Watson stated that forgiveness is an emotion that heals the person. She emphasized that individuals should be supported in terms of forgiveness. We spoke with the caregiver about this subject, we provided mutual fellowship with him and we gave suggestions to his about what he could gain if he forgave (carative process 4, 5 and 7). The Theory of Human Caring prioritizes to deal with an individual as a whole. It defines human as a being consisted of mind, body and spirit. It stated that a human cannot be evaluated only as a physical, only as a mental or only as a spiritual being. The process of giving care to Alzheimer's disease is a difficult process and the caregivers are under intensive burdens. As nurses, first of all we should accept the individuals as they are and we should have respect for what they feel (carative process 1 and 5). Sharing of emotions and experiences about caregiving and speaking of priorities in life are important in terms of therapeutic communication (carative process 4 and 5). After that we spoke about the caregiving and the meaning of life with the caregiver (carative process 2, 5 and 10). The expectation of the caregiver was for the disease not to progress any further. We observed that he could express himself more easily and he was happier.

Studies that were carried out pointed out that the caregivers not only had negative feelings and negative situations but they also had positive gains. In the fifth interview we asked whether caregiving had positive sides or not; we tried to support the faith and the hope of the caregiver with the positive sides (carative process 2, 3, 4, 5, 6 and 7). The caregiver stated that he was once a very impatient and a grumpy person but the disease thought his to be more patient. He also added that he was happy when he thought of their relationship with his wife before the disease and his wife deserved a better care. On the other hand we learned that the caregiver did not do anything to relieve himself. We spoke about the self-relieving methods (listening to music, keeping a diary, art therapy, games, humors, entertainments, breathing exercises and fantasizing etc.) the caregiver can do during this process according to his beliefs and resources and gave his suggestions (carative process 1, 3, 4, 5, 6, 7 and 9). The caregiver stated that before the disease he was interested in construction materials, he was doing small repairs at home all the time and he was happy especially when he went to the shops which were selling construction materials. He also stated that he was in the city hall choir in the past.

In the sixth interview the caregiver and his wife were looking more well-groomed compared to the previous interviews. The caregiver told that he spoke to one of his wife's sisters and left his wife's care to her sister for one day and went to a construction fair. He stated that in the past he did not have the courage to go outside but now he understood the importance of doing things for himself too. It is very important to provide the caregiver with the realization of his own power and endurance and to provide the caregiver to find meaning in caregiving (carative process 5, 9 and 10). We appreciated the caregiver

constantly from the beginning of the interviews to the end of them and tried to motivate his about the care. It is very important that he feels himself precious as an individual. It is especially important to speak about the miracles in life, and it is necessary to learn about the beliefs of the caregiver and how those beliefs affect the caregiving process (carative process 1, 2 and 10). The caregiver said that "it was a miracle that we reached to his and we showed up in front of his at a time when he needed the support a lot". He stated that previously he prayed all the time for the disease to recover and he was angry at God because his prayers were not answered. Now he accepted that the disease would not recover, and he stated that he prayed to God not to progress the disease any further and give his a healthy life so that he could give his wife a better care.

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