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Giving Care to the Caregiver According to the Theory of Uncertainty of Merle in Hemorrhagic Stroke: A Case Report

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Abstract

Stroke, which is accepted as an important health problem, especially in developed countries, ranks third after coronary artery diseases when the causes of death in the world are examined. Long-term care requirements are increasing due to physical and emotional losses caused by stroke. Considering the severe disability and limitations present at the time of stroke in performing activities of daily living, it has been stated that caregivers experience a high level of physical, psychological, and social burden and uncertainty. In this article, it is aimed to provide care to a patient with a diagnosis of hemorrhagic stroke within the framework of uncertainty theory, and the necessary permissions and informed consent form were obtained by the researcher before the data collection phase.

Keywords: Nurse, stroke, uncertainty

Introduction

According to the definition proposed by the World Health Organization, stroke, also known as cerebrovascular event (CVE), is a clinical condition characterized by signs indicative of loss of cerebral function lasting longer than 24 hours or resulting in death in a short time without an obvious cause other than vascular causes.[1]

When the causes of death in the world are examined, stroke is seen to rank third after coronary artery diseases, showing that it is a remarkable health concern all over the world, especially in developed countries.[2] When the causes of death in our country in 2017 were examined (39.7%), circulatory system diseases were in the first place; Among the deaths due to circulatory system diseases, cerebrovascular diseases come second (22.9%)[3,4]

The incidence of stroke increases with the advanced age. The prevalence of stroke over the age of 60 is reported as 500-600/100 000 in Western society and 900/100 000 in Asia. In the studies conducted in the last 20 years, the incidence of stroke can be seen to be 1-3/1000, with a prevalence of 6/1000. While its incidence in men aged 55-64 is 2-3 times higher than women, this difference decreases with the advancing age.[5,6]

Approximately 87% of strokes are caused by ischemic causes, while 13% by hemorrhagic causes. Three percent of hemorrhagic strokes are subarachnoid hemorrhages, and 10% are made up of intracerebral hemorrhages. In our country, according to the Turkish Multicenter Stroke Study of the Turkish Society of Cerebrovascular Diseases, 71.2% of all strokes are made up of ischemic ones and 28.8% of hemorrhagic strokes.[5,7] Hemorrhagic stroke is a non-traumatic intracranial hemorrhage that results only from a vascular event and causes damage to the central nervous system, which also has high mortality and morbidity rates.[8,9] The most important cause of hemorrhagic stroke is hypertension, and cerebral amyloid angiopathy and anticoagulant therapy can also lead to hemorrhagic stroke.[10]

Stroke results in disability and dependence on others in 1 out of 3 patients. Individuals may become dependent on others in their daily lives, requiring long-term care. The care provided by patients' family members is not confined to 1 type of assistance but includes planning the health care, medication, personal care, social services, shopping and doing housework, financial management, and financial aid in addition to sharing a

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house with the sufferer. The condition causes physical and mental fatigue as well as increased symptoms of depression in long-term caregivers. Considering the severe disability and reduced daily activities during stroke, it has been reported that caregivers experience a high level of physical, psychological, and social burden coupled with uncertainty.[11-13]

Hemorrhagic stroke, which causes many permanent or temporary problems in the individual, affects the quality of life of not only the individual but also the caregiver and requires these individuals to reorganize their lives as well. In addition to struggling with the problems caused by the condition, the caregivers who deal with many uncertainties regarding disease management and the process tend to feel helpless and inadequate.[12,13] Uncertainty in CVE is associated with a variety of such negative physical and psychological outcomes such as the impact of the disease on daily life, emotional distress, loss of abilities, and decreased quality of life.

Conceptual Framework Merle's Uncertainty Theory

The uncertainty in illness theory developed by Merle Mishel in 1988 serves to account for the uncertainty that arises in patients with acute illnesses and how patients should cope with this emerging situation. Merle Mishel's theory of uncertainty in illness focuses on the human being. The theory was coined to explain how patients "cognitively" process the unpredictable aspects of their health.[14,15]

The situation arising from the inability to control any situation in an individual's life is defined as uncertainty. Uncertainty in illness, on the other hand, arises from the conditions (diagnosis, treatment, the effect of the disease on the life of the individual, etc.) that are encountered as a result of an illness.[16,17]

Uncertainty in illness arises as the individual is unable to grasp the meaning of illness-related situations or to predict the consequences that are to arise as a result of the illness. While this uncertainty can cause negative emotional reactions such as anxiety, it can also mean opportunity and hope. Communicative actions aimed at reducing the uncertainty can be encouraged, and cognitive, emotional, and behavioral efforts can be increased to maintain or increase uncertainty.[18]

Living under conditions of constant uncertainty due to an illness or condition has become a part of families' daily life, changing their perceived world. According to Merle Mishel, uncertainty is a cognitive state that occurs as a result of ineffective attempts in case of an event or situation.[19] Merle Mishel's scale was initially used to appraise the uncertainty experienced in individuals with chronic diseases who were not hospitalized or did not receive active medical care, to appraise the uncertainty experienced by parents who experienced the disease in their children, and also to appraise the uncertainty experienced by other family members in case of any acute illness in the family.[20] Merle Mishel thinks that uncertainty management is of critical importance in adapting to the disease.[15,20]

Antecedents of Uncertainty

According to Mishel, antecedents of uncertainty include the stimulus ***framework*** (pattern of symptom, event familiarity, and event congruence), ***cognitive capacities***, and ***constructors*** (information from caregivers and other credible authorities, social support, and education). New disease-related stimuli create uncertainty when patients are unfamiliar with the experience (e.g., symptoms, health environment, and treatment activities) or when their expectations are inconsistent with their experience. The interpretation of disease-related stimuli is controlled by the individual's cognitive capacity and structure providers. Cognitive capacity not only affects how individuals interpret disease-related stimuli to form a cognitive structure but also indirectly affects the creation of the uncertainty.[15,20]

Cognitive Perception

This is a person's subjective view on illness, treatment, and hospitalization process. The stimulus frame is the combination of the stimuli perceived by the person that are structured by cognitive/perceptual schemas. In formulating her original theory, Merle Mishel defined a person's response to environmental stimuli as a reducing factor in terms of uncertainty in illness.[20] Cognitive capacity refers to the ability to recognize both innate abilities and limiting situations as well as the capacity for knowledge. Stronger cognitive capacity makes it easier for the patient and caregiver to understand the stimuli, which reduces the uncertainty inherent in the disease. Structure providers refer to how the patient and caregiver interpret the stimuli around them. According to Mishel, appropriate education and social support will reduce the uncertainty that exists in the case of illness.[21]

Appraisal of Uncertainty

Appraisal is a cognitive process which is employed to determine if there is a given danger (threat) or opportunity (challenge) for a stressor and also to appraise the availability of coping resources to respond to stressor. If the stress of uncertainty is appraised as a danger, the patient and caregiver will try to use coping strategies to reduce their level of uncertainty. However, in the cases where uncertainty is appraised as an opportunity, the patient and caregiver will try to use coping strategies that preserve uncertainty.[20-22]

Coping with Uncertainty

Coping is the mental and physical effort employed by the individual to manage the stress of uncertainty. Mishel postulates that different coping strategies are employed in line with the individual's evaluation of uncertainty. When uncertainty is appraised as a danger, the patient or caregiver will use strategies to eliminate the source of uncertainty and/or use effective control strategies to minimize uncertainty-related emotional distress. On the other hand, when uncertainty is appraised as an opportunity, the patient or caregiver will attempt to use buffering strategies (e.g., avoidance, selective ignoring, and neutralization of threatening information) to preserve the situation and maintain uncertainty. These buffering strategies serve to block the input of new stimuli, which can turn an individual's appraisal of uncertainty from a danger into an opportunity. The theory does not suggest that 1 type of coping way leads to better outcomes than the other but focuses on an appropriate matching of effective coping strategies with an individual's appraisal of uncertainty instead. According to Mishel, if coping strategies are effective, adaptation to the illness is achieved.[22]

Nursing Intervention Within the Framework of Uncertainty Theory

Nurses encounter different types of patient populations and uncertainties in nursing care. The role of nurses is to consider and develop possibilities and eliminate potential risks. In order to increase the adaptation to the changing nature of the illness, nurses should be aware of the fact that the response to a given illness is affected by

numerous factors and also they should be able to identify the factors that cause the uncertainty.

Due to the acute development of hemorrhagic stroke, it can cause permanent physical and neurological damage that can change the whole life of the individual and of the primary caregiver, and this is where uncertainty antecedents should be defined and where nurses should aid the process to be perceived as growth and opportunity, rather than regarding treatment-induced issues and side effects as irreversible losses. They should also provide support for the patients in the face of unexpected situations and facilitate areas of development and growth to help patients reach a new understanding of life.[23]

The nursing care process should begin with the identification of the individual and the caregiver. Any possible problems should be discussed with the individual or caregiver, while seeking solution for them as well. Also, solution-oriented people should be encouraged to participate in the process, while the effects of social support in reducing uncertainty should not be ignored.[23]

Healthcare professionals assume a constructive role in reducing the uncertainty in the illness. Effective communication with the patient and caregiver ensures the effective solution of the problem-causing factors. Health professionals, who can cognitively manage the events related to the illness and help them to be perceived as a less threatening situation, should support the individual to talk about the events related to the illness with the people in their close proximity, to turn their attention to the controllable areas of life, and to understand and express their reactions to the illness again.[17]

How the individual appraises the problem at this very point is of big importance. If the individual appraises the problem as an opportunity, these views and behaviors should be supported, yet if he/she appraises it as a threat, nurses should exchange ideas with these individuals about the nature of the problem and how to manage it. Problem-solving approaches should be determined in accordance with the nature of the identified problem. The individual should be supported and steered, in this respect, to the appropriate approach.[17,23]

In this article, it is aimed to provide care to a patient with a diagnosis of hemorrhagic stroke within the framework of uncertainty theory. The necessary permissions and informed consent form were obtained by the researcher prior to the data collection phase.

Case Presentation

The patient

A 48-year-old male patient named M.Ö., who was diagnosed with hypertension (HT) (uncontrolled HT for 10 years) and ulcerative colitis, is on 100 mg of acetylsalicylic acid. The patient's headache complaint started while driving around 2:00 PM on October 11, 2019, and had a traffic accident at the same time period. The blood pressure of the patient admitted to the emergency department of a university hospital was 270/150 mmHg. On physical examination, the patient was conscious, cooperative, oriented, with isochoric pupils and no gaze limitation, and no nystagmus or motor asymmetry were observed. On cranial computed tomography, a parenchymal hematoma of 18 × 29 mm localized in the left parietal area and a 22 × 24 mm of parenchymal hematoma in the left occipital region advancing to the left lateral ventricle were observed. Hemorrhage was observed in the left lateral ventricle and the third ventricle. No surgical operation was considered by the neurosurgeon, and the patient was admitted to the neurology intensive care unit due to hypertensive cortical hemorrhages. In clinical follow-up, the patient received esmolol hydrochloride infusion (100 µg/kg/min) due to high blood pressure and was fed with a nasogastric tube (NG) due to swallowing dysfunction and pulmonary aspiration risk. Since the patient had generalized tonic-clonic type seizures in the follow-up, levetiracetam 2 × 500 mg was added to the treatment.

The Caregiver

The caregiver named C.Ö is a 45-year old wife who has assumed her husband's primary care since he was admitted to the hospital. She stated that she stayed with her husband during their 1-month hospital stay and only went home to meet her personal needs. She also expressed that their life was literally "upside down" according to her own account of the event. In the clinical follow-up, it was observed that the caregiver had difficulties in adapting to the illness at the beginning. She especially stated that she did not know what to do during the seizure, and she was afraid and panicked. She also stated that the process was uncertain, and the underlying reason was unknown, and that she was worn out and was afraid that her husband would never return to his old self. In this process, the uncertainties about the process were defined in cooperation with M.Ö., and nursing care aiming at these uncertainties was provided (Table 1).[17]

Nursing Care

Situations that create uncertainty in the caregiver were defined. The acute and rapid development of the process, causing permanent damage, triggered the caregiver's feelings of *hopelessness* and *helplessness.* Despite many diagnostic procedures, the inability to explain the cause of stroke event and the inability to reach a clear and definite etiology led the caregivers to feel anxious. She explained that she had difficulty in the role she assumed as a caregiver as her patient became dependent on her care and that she was afraid to do any harm to the patient in case of a possible malpractice. In addition, the wife also stated that she could not accept that her husband could not recognize her, adding that the intense contractions frightened her during the seizures. These factors expressed by the caregiver were accepted as uncertainty-creating situations and the needs of the caregiver were taken into account while planning the care plan. In this respect, it was determined that there was a lack of information about the process in the caregiver's side, which was aimed to be eliminated at this stage. The nursing interventions to be applied were determined as providing information about the process and the illness in addition to cognitive restructuring and problem solving.

The needs of the caregiver were taken into account in providing *information about the disease.* The caregiver was asked what she wanted to know and which subject she had the most difficulty giving care. She was told that this process was a temporary one which could possibly leave some permanent damage. Simple neurological examination methods were taught to her, and it was explained that health professionals should be informed in case of an abnormality in this process. The points to be considered in feeding the patient with NG were explained in an explicit and understandable way, and correct and effective oral care techniques for the wounds in the mouth of the patient were taught by demonstrating them together with the caregiver. In the interviews, it was observed that the caregiver did not know what to do during the patient's seizure and had a panic feeling. In the training made for this purpose, it was explained to her

Table 1. The Components of Uncertainty in Caregiver

Antecedents of uncertainty

Stimuli frame
Symptom pattern: The patient's not being able to recognize his/her own daughter and spouse on admission to the clinic, and his/her agitated behavior due to hemorrhagia and frequent seizures was noted to increase the perception of uncertainty in the caregiver.
Event familiarity: It is thought that communication with another patient's relative who is followed up in the clinic with the same diagnosis will reduce the caregiver's perception of uncertainty.
Event congruency/similar events: Due to successive seizures, the caregiver tends to think that M.Ö.'s condition is getting worse and this process will continue as a vicious circle.
Cognitive capacity: The caregiver is a 45-year-old woman named C.Ö., who is a high school graduate. The fact that her husband, who previously led an active life, has suddenly become a patient in need of care worries her to great extent, leading her to think that a possible mistake she will make while providing the care will cause great harm to her husband.

Structure providers
Credible authority: The caregiver states that getting support from the nurses during her caregiving practices (NG feeding, oral care, etc.) makes her feel safe.
Social support: It was determined that the social support received by C.Ö is insufficient, who stated that they have a busy daughter who can only visit them in limited times.

Appraisal of uncertainty

The change in the behavioral patterns of the patient due to the origin of bleeding and the unknown cause of bleeding and frequent seizures leads the caregiver not to know what to do. "Doctors come to us for a new reason every day. I don't know why it happened and what will happen, or I don't know whether our life will always go on like this." It has been observed that she has difficulty in her role she assumed as a caregiver and does not have enough knowledge about the process, which can be understood from her own statement: "I am afraid that I cannot take care of him as well as I should."

Coping with uncertainty and adaptation

It was determined that the caregiver did not develop effective means of coping. She stated that she did not have enough information about the process, so often read information about the illness on the internet and what she read made her feel helpless. The caregiver was aimed to be included in the care process, and in this process, she was supported in the issues where she experienced uncertainty.

Source: Bora and Buldukoğlu K. Using the Uncertainty in Illness Theory to provide care for the caregiver: A case report. J Psychiatric Nurs 2020;11(1):70-77.

that she should not try to prevent seizures but protect the patient against trauma. It was also stated that the patient should be positioned to the right side as much as possible due to the loss of vision on the left side of the patient related to the origin of bleeding. It was explained to the caregiver that this disease is a process and may have developed due to many factors within the aspect of cognitive restructuring, adding that the patient could not recognize her due to the current loss of vision and intracerebral hemorrhage and that this was due to the nature of the disease, though. For this reason, it was explained that she should sit to the side where there was no vision loss and call the patient by his name frequently and introduce herself. The importance of giving brief information about the time, place, and time during the day to the patient was expressed in order to ensure the orientation of the place, time, and person. The caregiver was given the opportunity to express their feelings, telling them that they should not perceive this process as a threat and that it was important to learn about the possible important symptoms that could be detected in the early onset in terms of taking precautions. It was ensured that the caregiver recognized this process as an opportunity and re-evaluated her caregiver role.

On the other hand, the things to be done in cooperation with the caregiver were planned for the patient to carry out his daily activities within the aspect of problem solving. The caregiver stated that her husband's condition was detected upon the first admission to the clinic as he exhibited agitated behaviors, making it impossible for him to use his arms and legs effectively and even to hold a glass without assistance. It was determined that the patient needed help due to the current *vision loss.* Hence, in-bed exercises were planned, demonstrating how to do it together with the caregiver several times. In addition, it was also explained that the patient should be encouraged to hold the water glass himself in order to exercise the upper extremities and that he could be unsuccessful at first due to loss of strength but could improve over time. She was also explained that her patient should be given support until he could mobilize independent of her help, which would prevent any possible accidents and falls.

When the patient was admitted to the clinic, an NG catheter was inserted against the risk of *pulmonary aspiration*, and the patient was fed in this way. How to care for the wounds in and around the mouth was also explained to the caregiver. The caregiver stated that she was afraid of malpractices during oral care and leaking water into his lungs. Correct and effective oral care techniques were taught ensuring the caregiver's practice. At every occasion, the caregiver expressed her concern for harming the patient in case of making any wrong applications. Thus, she was given the opportunity to openly express her feelings on this issue and she was encouraged to express her fears as well. It is believed that this sense of inadequacy in the caregiver could be overcome as the level of knowledge about the disease increases.

After a period of complete immobility followed by partial immobility, *some redness was noticed at the pressure points* in the patient, and daily care programs were established with the caregiver in order to prevent the formation of pressure sores. The importance of position change and moisturizing the skin were explained. The caregiver stated that the previously red heels of the feet regressed to the normal with the right care she provided.

When the caregiver stated that she felt *exhausted* and *tired*, she was allowed to rest and spare some time for herself, though for a short time, explaining her that her patient would be safe in the clinic, and she could rest in the meantime. Normal and abnormal situations were explained to the caregiver, so that the panic feeling could subside. It was determined that the caregiver did not have sufficient social support in this process, which was also challenging for her (Table 2). In this study, the caregiver of a patient with a diagnosis of hemorrhagic stroke was discussed, and the caregiver was included in the care in line with the theory of uncertainty in illness and the uncertainty she underwent in this process was witnessed. It is thought that determining the state of uncertainty experienced by the caregiver will facilitate the adaptation to the illness, strengthen the communication line

Table 2. Nursing Care Plan Within the Framework of Uncertainty Theory

Possible Nursing Diagnoses	Situations That Create Uncertainty	Nursing Interventions in the Framework of Uncertainty Theory	Appraisal
▪ Lack of information associated with the uncertainty of the illness process ▪ Risk of deterioration of skin integrity ▪ Fear/anxiety associated with the uncertainty of the disease process ▪ Risk of pulmonary aspiration ▪ Ineffective coping	▪ Rapid progression of the disease process ▪ Etiology cannot be determined ▪ Fear of harming the patient ▪ Thinking that you are incapable of managing the process and providing care	▪ Nursing interventions to be applied were determined as providing information about the process and the illness, cognitive restructuring, and problem solving.	▪ The caregiver was supported throughout the clinical follow-up. ▪ Information about the process and the illness was provided in a simple, plain, and understandable way, and the caregiver was given the opportunity to ask questions and express her/his feelings. ▪ When the decision to discharge the patient was made, the caregiver stated that she felt better, which she expressed saying "I know what to do now, I am not that afraid."

among the patient-caregiver-nurse, and turn the negative emotions experienced by the caregiver into positive opportunities.

Discussion and Conclusion

Mishel stated that the uncertainty theory can be utilized in the appraisal of the uncertainty experienced by other family members in any acute illness. It was determined that the uncertainty experienced due to the unexpected and acute nature of the condition gave rise to lack of information in the caregiver. In the study conducted by Mendes[24], it was revealed that the unpredictable continued uncertainty could mediate the communication with nurses in seeking and obtaining information.

In the study conducted by Rojas et al[25], uncertainty levels were found to be slightly but significantly related to the patient's condition, symptoms, length of caregiving provided by the caregiver, and perceived support from the caregiver. When the antecedents of uncertainty regarding the process were questioned, C.Ö's statements in which she expressed her fear of not being able to return to their previous normal life comply with this aforementioned study. In a study investigating the uncertainty in stroke, it was determined that the timely definition of uncertainty helps increase the survival and adaptation to the condition in case of an acute stroke. The early identification of the uncertainty that C.Ö experienced changed the caregiver's perception of the disease and enabled her to participate in care. This situation increased the adaptation of the patient and caregiver to the disease.[26]

When the literature is examined, individuals who provide care for stroke patients are suggested to plan and implement nursing services starting from clinic to home care in line with continuing education programs and effective counseling. Also, determining the factors affecting the burden of care will reduce the uncertainty and increase the quality of life of the patient and caregiver alike. In another study, it was stated that self-management could be improved, and the caregiver burden would be reduced by reducing the level of uncertainty in stroke patients.[27,28] As a result, it was determined in this case that the feeling of uncertainty affects the adaptation of the individuals to the illness and causes the caregiver to experience negative emotions. It is thought that the care planned in line with the uncertainty theory will be effective in helping individuals who care for stroke patients. A better understanding of uncertainty and its related characteristics can help nurses identify patients at higher risk who could benefit from the targeted interventions.[26] Little is known about the level of uncertainty and correlations between patients and caregivers in the acute phase of stroke. In this respect, it is recommended to develop and test theory-based interventions aiming at the caregiver.

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