Using the Uncertainty in Illness Theory to provide care for the caregiver: A case report

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Abstract
Mishel's Theory of Uncertainty in Illness (1988-1990) explains how patients and caregivers interpret the uncertainty about the course of an illness. Additionally, it provides a framework for selecting of interventions that will improve the psychological and behavioral outcomes of uncertainty. This manuscript provides an example of the care provided to a caregiver of an individual with schizophrenia based on Mishel's Theory of Uncertainty in Illness. A caregiver referred to as GC is staying with the patient who has been hospitalized at the clinic for one and a half months and has experienced psychosocial problems. The main concepts of the Theory of Uncertainty in Illness are: antecedents of uncertainty, appraisal of uncertainty and coping with uncertainty. GC's statements such as "While we were thinking that she was almost well, now we are back to the beginning and I am confused about it" as well as reporting her lack of understanding about the course of the illness shows the uncertainty that she experienced and the antecedents of this uncertainty. The caregiver needed information about the course of the chronic illness and perceived uncertainty as a negative situation. Her crying and feelings of helplessness illustrated she had an emotion-focused coping mechanism. Having knowledge about the situations that create uncertainty in the caregiver, the researcher used the interventions to improve knowledge about the disease, cognitive reframing, problem solving and communication skills in managing uncertainty. The theory is thought to explain the uncertainties caregivers have with managing a patient with schizophrenia. This theory supports the interaction between caregivers and nurses. There are few studies based on UIT in Turkey, therefore further studies are needed to test the UIT.

Keywords: Caregiver; Mishel's Theory of Uncertainty in Illness, psychiatric nursing; schizophrenia.
and uncertainty about the course of the disease. Parents who care for adult children with schizophrenia need to receive more formal support regarding caregiver roles and have better communication with mental health professionals.

Uncertainty is defined as the inability to determine the meaning of illness-related events. Uncertainty in an illness may arise due to the severity, treatment success or failure, the effects on an individual's life, and the probability of pursuing life goals. Merle Mishel, a nursing theorist, developed the Uncertainty in Illness Theory (UIT), a middle-range theory, in 1988 within the framework of “uncertainty in illness”, considering uncertainty as a cognitive stressor imposed by the illness on patients and families. The theorist discussed continuous uncertainty in cases of a chronic disease, which is likely to recur and require continuous management, in her “Reconceptualized Uncertainty in Illness Theory (RUIT), introduced in 1990. The theory is applicable to both acute and chronic health conditions, including those of both patients and caregivers.

There are studies of the uncertainty in illness experienced by caregivers of patients with dementia, Parkinson’s disease, schizophrenia and leukemia. In UIT, Mishel (1988) argues that management of uncertainty is important for adaptation to illnesses, and explains how individuals cognitively perceive illness-related events. UIT describes the experience of uncertainty in individuals with acute or retrogressive disease. In the present case, the caregiver experienced uncertainty due to the exacerbation of the disease, therefore, the care provided to GC was based on UIT.

The basic concepts of the theory are “antecedents of uncertainty, appraisal of uncertainty, coping with uncertainty, and adaptation”. In RUIT, the concepts of “probabilistic thinking and self-organization”, which constitute “a new view of life”, were added to the previous ones. The antecedents of uncertainty are “stimuli frame”, “cognitive capacity” and “structure providers”. Each of these factors positively or negatively affect the uncertainty perceived by individuals.

The stimuli frame refers to the type, composition and structure of stimuli accompanying illness experiences. These stimuli are severe and unpredictable illness-related events with unforeseen consequences, triggering uncertainty. The stimuli frame is defined using elements such as “symptom pattern”, “event familiarity” and “event congruency”. These elements are used by patients to reduce uncertainty. The symptom pattern refers to the sufficient consistency of symptoms to establish a model/structure. It has features such as number, frequency, placement, intensity and duration. The unpredictable and inconsistent nature of symptoms in illnesses together with remissions and exacerbations such as schizophrenia may prevent the formation of a symptom pattern for individuals, causing uncertainty about the illness status. The event familiarity

![Figure 1. Mishel’s Theory of Uncertainty in Illness](image-url)

1. The antecedents of uncertainty revealing uncertainty are stimuli frame, cognitive capacity and structure providers. Structure providers and cognitive capacity positively affect stimuli frame; and structure providers and stimuli frame can also reduce uncertainty by providing information to be processed by the patient.
2. Uncertainty may be regarded as a danger indicating damage/harm or as an opportunity showing a positive outcome.
3. Coping strategies are used to maintain the uncertainty considered positive or to reduce the uncertainty considered threatening. Adaptation occurs if coping strategies are effective in managing uncertainty in the desired direction.
describes the degree to which an event involves repetitive, customary or familiar clues.\textsuperscript{10} It explains the cognizable clues about the course of an illness, treatment options, and organization of health care institutions.\textsuperscript{12} In cases requiring clinical hospitalization, unfamiliar procedures and healthcare team members may cause patients to perceive uncertainty.\textsuperscript{13} The event familiarity develops through experiences acquired over time in an environment.\textsuperscript{14} The event congruency explains the coherence between illness-related real situations and expectations. If there is a difference between what the caregiver expects and actually experiences in caregiving, then this leads to stress and uncertainty because they no longer know what the future brings.\textsuperscript{15}

Cognitive capacity is defined as an individual's ability to process information that allows understanding conditions in which an illness occurs, and to recognize or assess uncertainty in illness.\textsuperscript{11} Cognitive capacity can be impaired by medications, side effects, pain and fatigue. The concerns and fears related to diagnosis, treatment, consequences and prognosis of an illness can hinder individuals' ability to process information.\textsuperscript{15}

The structure providers are useful resources that directly or indirectly affect stimuli causing uncertainty, and help individuals to interpret these stimuli. These resources are credible authority and social support and education, which reduce uncertainty. The credible authority refers to the trust and belief of patients and caregivers in healthcare professionals. As structure providers, nurses and nursing care can change the stimuli frame through interpretation, explanation and clarification.\textsuperscript{10} As a credible authority, nurses as experts have power to minimize uncertainty in illness and facilitate individuals' ability to cope and adapt. Nurses obtain this power through individualized training, consultancy and support services.\textsuperscript{12}

The social support includes the interest, information and support provided to individuals by their families and environment, which help them explain their experiences of illness. Communicating and sharing experiences with other individuals who have similar experiences provides the individual with a database to understand the treatment environment and increase the "event congruency".\textsuperscript{12} Education has a positive relationship with stimuli frame. An education received from credible authorities provides individuals with a broad repertoire of information that expands their knowledge base and improves their interpretation of symptoms and recognition of events. This is the indirect effect of education as a structure provider. However, the direct effect of education is that it affects the level of information assimilation. Less educated individuals need more time to use the information provided to them. Therefore, these individuals experience more uncertainty for a longer period of time than individuals with higher education levels.\textsuperscript{14}

The theory has two other dimensions; assessing the illness by individuals or their families as a danger or an opportunity and coping with the illness. The theory has two evaluation processes to determine the value of uncertainty; "inference" and "illusion". The inference describes the evaluation of uncertainty based on related case studies. If inferences are positive, then uncertainty is considered an "opportunity". However, if inferences are perceived as threatening, then uncertainty is considered a "danger". The illusion allows uncertainty to be considered a potential sign for a positive outcome. Due to the indefinite and flexible nature of uncertainty, events can be re-arranged as an illusion indicating a positive situation.\textsuperscript{16}

A detrimental result is expected when uncertainty is considered a "danger". This expectation triggers coping strategies to reduce uncertainty. However, when uncertainty is considered an "opportunity", a positive result is expected and coping strategies are implemented to maintain uncertainty. Assessments of danger are often accompanied by avoidance, recovery, and other incompatible coping strategies.\textsuperscript{17} Emotion-oriented and problem-oriented coping strategies are used to manage uncertainty. However, the most commonly reported strategies are passive emotion-oriented avoidance strategies. The use of these coping strategies is associated with weaker adaptation and negative consequences. In contrast, active-emotion and problem-oriented coping strategies are associated with decrease in distress and anxiety.\textsuperscript{18} Adaptable coping strategies such as acceptance and realistic assessment, and instrumental strategies such as problem solving and planning are associated with positive mental health indicators. If the coping strategies used in both cases are effective, then "adaptation" appears. Creating positive beliefs in individuals about an event has a key role in increasing adaptable responses.\textsuperscript{17}

The close examination of theoretical explanations and experimental data reported by Mishel has led to the identification of areas that could be expanded and re-conceptualized theoretically. When a person learns how to manage uncertainty in illness, they should be considered to have reached a higher level of functionality than their pre-disease functionality level. In this context, the theory emphasizes that uncertainty is a continuous experience over many years and changes over time.\textsuperscript{9} Two new dimensions, namely "self-organization" and "probabilistic thinking", were introduced with the re-conceptualization of the theory. If appraisals and coping responses are oriented towards adaptation, these two dimensions, which represent a new view of life, appear.\textsuperscript{7} The self-organization refers to the creation of a new understanding of organization by integrating the state of continuous uncertainty, which is accepted as normal, with the existence of the individual, and accepting it within the natural rhythm of life.\textsuperscript{19} For example, caregivers state that when they associate negative behaviors of their relatives with the illness, they have a more positive caregiving experience, compared to their experience when they associate these behaviors with their relatives' personality traits.\textsuperscript{7} The probabilistic thinking refers to the belief that we cannot always be sure of everything in life and cannot foresee the results. Which means developing faith in a conditional world. The nature of uncertainty must be regarded as a natural rhythm of life in order to develop probabilistic
thinking. Adapting to uncertainty and accepting that every day brings new events are an example of probable thinking. Uncertainty is used by individuals as a basis for achieving self-organization in which they rearrange their views on life. This new organization status is not the same as the illusions described in the original theory. 

Management of Uncertainty As a Nursing Intervention

Practices to manage uncertainty are defined by Mishel as helping individuals gain knowledge, solve problems and perceive health issues as manageable. This leads to improving communication between patients and caregivers, and developing self-care skills such as management of side effects. Nurses can help individuals manage uncertainty in illness with nursing interventions such as linking the expectations and experiences of patients and their relatives, helping them understand the rationale of treatment, creating a familiar therapeutic environment, raising their knowledge level, and strengthening their sense of autonomy and self-control.

The interventions aimed at managing uncertainty are based on understanding the individual's view about the situation and defining the characteristics of uncertainty. Discovering the antecedents of uncertainty provides the nurse with important clues about the patient's uncertainty. In assessing uncertainty, the nurses should ask whether the outcomes are in line with the expectations, whether the patient believes they can control the outcomes, whether the patient is adequately informed about the situation, and whether the patient needs more information. Interventions that reduce uncertainty include communication between patients and health professionals, cognitive reframing, and problem solving. The main purpose of managing uncertainty in chronic illnesses is to provide a new view of life in which the uncertainty is normalized and becomes a part of life. The development of this new view of life emerges as a result of living in uncertainty and cannot be achieved immediately.

Healthcare professionals serve as structure providers to reduce uncertainty in illness experienced by the patient. Patients and caregivers who have open communication with healthcare professionals can obtain necessary information that will allow them to solve problems effectively and make further plans. Teaching individuals' assertiveness skills in communication to encourage self-advocacy will increase their participation in their own care. Helping individuals cognitively re-frame their concerns about the illness to problem solve is another way of managing uncertainty in illness. In cognitive reframing, illness-related events can be managed cognitively, helping individuals to perceive these events as less threatening. This component of the intervention encourages individuals to talk about illness-related events, focus on controllable areas of life, and re-evaluate and express their reactions to the illness. If individuals consider their problems as manageable, their views and behaviors are supported and reinforced. Such interventions help them to strengthen their existing cognitive orientation. However, if they perceive the situation as threatening, interventions of providing information about the nature of the problem and how to manage it are used. The problem-solving approach, another intervention proposed by the theory, allows individuals to identify the problem, produce alternative solutions, find the best solution, and plan and implement the solution. This process includes encouraging individuals to report solutions and results, and if the solutions are successful, to consider other problems where the same solutions can be applied.

Nurses use these interventions to help patients and caregivers manage uncertainty in illness. In this context, the theory can make significant contributions to understanding the experiences of patients and caregivers and improving the care provided. The present case report aims to discuss the uncertainty experienced by the caregiver of an individual with schizophrenia and the nursing care provided to this person, within the context of the Uncertainty in Illness Theory.

Case Report

In this case study, the caregiver of a patient with schizophrenia who had been hospitalized in the psychiatric clinic of a university hospital was provided with care based on UIT. The researcher obtained permission to stay in the hospital within the scope of a doctorate degree course. Attendents of patients with schizophrenia who were hospitalized between January 11-15, 2016 were observed in the clinical setting. After observations and an interview with one of the caregivers who contacted the researcher voluntarily to ask questions, she was observed to have an uncertainty in illness process. A verbal consent was obtained from the caregiver to understand and deal with her experience of uncertainty in illness. An informed consent was obtained from the caregiver to publish this study. The patient was 55 years old, female and single. The medical condition of the patient, who has been followed for 20 years with the diagnosis of schizophrenia, had deteriorated in the recent year. During the recent month, her rambling monologues had increased, and she stopped eating and speaking. She had aggressive and skeptical attitudes towards her relatives. She had visual hallucinations of light lines on the floor and ceiling. She began to neglect her personal care. It was noted in the examination of her mental status that she was reluctant to communicate, and had reduced self-care, alert and oriented consciousness, inappropriate speech, and visual and persecutory hallucinations.

The caregiver, coded GC, was 58 years old, a primary school graduate, and the elder sister of the patient. She has been staying in the clinic with the patient for about one and a half months. During the observations, GC frequently asked the nurses questions about the patient, had worried facial expressions, and cried while communicating with other patient relatives in the clinic. When the caregiver contacted the researcher, and asked questions related to the illness and the caregiving process, an interview was conducted with her to
identify the uncertainty she experienced. This interview was conducted for data collection, identifying the uncertainty, and planning care for her. The data from this interview shaped the interventions. According to the information received from GC; her father and other sister were diagnosed with bipolar disorder, and the father could not be persuaded to use medication for a long time, did not receive treatment, and used violence against his children. The father had been in remission as he had received antipsychotic medication for the past few years. GC stated that she had been taking care of the patient for five years in her own home with her husband and children, so there were psychosocial and domestic problems as well as child neglect.

In order to help the caregiver recognize the antecedents of uncertainty and be aware of her assessments about the uncertainty, the data obtained in the interview were tabulated on the basis of the concepts of the theory (Table 1). After defining the uncertainty in the caregiver, she was provided with a relevant nursing care in line with the interventions suggested by the theory to cope with uncertainty in illness.

**Nursing Care**

In this case study, the factors causing the caregiver to have uncertainty in illness were the exacerbating and progressive structure of the disease and the concerns whether she had sufficient knowledge to properly care for a patient with schizophrenia. The researcher used a number of interventions including information about the disease, cognitive reframing, problem solving and communication skills, taking into account uncertainty situations to manage the experience of the caregiver. The interventions included supportive caregiving approaches such as making short interviews with the care-

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**Table 1. Components of uncertainty in the caregiver**

<table>
<thead>
<tr>
<th>Antecedents of uncertainty</th>
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<tbody>
<tr>
<td><strong>Stimuli frame</strong></td>
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<tr>
<td>Symptom pattern</td>
</tr>
<tr>
<td>• The following situations were considered to increase the perceived uncertainty of the caregiver: the patient's dull mood, meaningless conversations, sometimes not answering questions, introverted personality, not knowing the caregiver by asking “Who are you?”, hallucinations suddenly appearing, and the retrogressive changes occurring in the patient's health status compared to that before hospitalization.</td>
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<tr>
<td>Event familiarity</td>
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<td>• Sharing feelings and experiences with caregivers of other people with schizophrenia in the clinic was considered to reduce the perceived uncertainty of the caregiver.</td>
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<tr>
<td>Event congruency</td>
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<td>• The caregiver stated that while she was waiting for the patient to be discharged, the delay in the discharge due to new problems caused her to be anxious with feelings of hopelessness.</td>
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<tr>
<td>Cognitive capacity</td>
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<td>• No application to measure cognitive capacity was performed. The caregiver was 58 years old and a primary school graduate. However, the caregiver’s verbalization of “What should I do, I am confused about what to do”, her unstable emotions, her self-blame and thinking about the problem constantly suggest that she had passive emotion-focused coping with the uncertainty. Consequently, fatigue and emotional problems negatively affected her problem-solving and coping skills.</td>
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<tr>
<td>Structure providers</td>
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<td>Credible authority</td>
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<td>• The caregiver stated that the workload of healthcare professionals was heavy, but when she asked them questions, they did respond to her concerns about the care and treatment of the patient.</td>
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<tr>
<td>Education</td>
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<tr>
<td>• The caregiver stated that she did not receive formal training on schizophrenia and being a caregiver.</td>
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<tr>
<td>Social support</td>
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<td>• The caregiver has been caring for the patient at home for 5 years, she is the only person caring for the patient over a long period of time and she has other family members in need of care indicates that she has poor social support.</td>
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**Appraisal of uncertainty**

- The caregiver stated she could not understand the course of the disease, and did not know how to behave, and that no treatment for the illness had been successful. The caregiver's statements of “she” (the patient) became a little bit better, so she would be discharged, but we (figuratively) went back to the beginning, we have fallen down the stairs again” and “Nurse, please let me know what I should do more of, I am confused what to do” indicated that she perceived the uncertainty as a danger.

- The caregiver did not express an opportunity assessment of her situation. She suffered from a lack of information about the course and outcomes of the illness and the uncertainty about the predictability. She had difficulty performing the role of caregiver, asking questions about how to provide more effective care for the patient.

**Coping with uncertainty and adaptation**

- The caregiver cried and expressed helplessness suggesting that she adapted an emotion-focused coping strategy for managing the uncertainty in illness.

- The caregiver communicated with other caregivers and nurses, and asked questions about coping with the uncertainty.

- The caregiver made efforts to include the patient in a therapeutic environment, but while doing so, she neglected her own self-care and daily activities.
the caregiver was informed about the cause, course and treat-
ment of schizophrenia and the effects on an individual's lives.
The caregiver was also reassured that chronic mental illnesses
have exacerbations and slow recovery processes and that it
may be difficult for the patient and relatives to cope with the
illness. Additionally, GC was told that the patient should not
be judged in this process.

In the dimension of cognitive re-framing, a discussion was
held with the caregiver about cognitive impairment inherent
in schizophrenia which can cause the patient not to recognize
her and to have difficulty in remembering. Additionally, she
should not take this kind of behavior emotionally and per-
sonally, otherwise it may affect both the patient and herself
negatively. Therefore, she was asked to develop a different
viewpoint in such cases. It was emphasized that the caregiver
should call the patient by her name, have frequent contact
and communicate with the patient during the day, and reori-
ent the patient from time to time. The caregiver was encour-
aged to focus on the controllable areas of her life such as the
importance of recognizing and taking early measures against
exacerbation of the symptoms of the patient. GC was encour-
aged to re-evaluate and communicate her responses to the
illness and the caregiving. She was supported in her commu-
nication of all of her positive and negative feelings. It was as-
serted that even if the uncertainty caused negative feelings in
the caregiver at first, it was an opportunity for her to seek help
and eventually have hope for a solution.

In the dimension of problem solving, a detailed assessment
was made with the caregiver about the patient's performance
of daily routines. The caregiver reported that the patient does
what she is asked to do, for instance, she is very meticulous
collecting and folding the laundry. The caregiver was told that
patients with schizophrenia may have low work motivation,
be reluctant to start and continue work, and have difficulty
focusing on work. She was informed that she should always
remind the patient what to do without getting stressed, and
direct her to do work by making simple explanations for each
step. The caregiver stated that she tried to send the patient
to a community mental health center in the district where
she lived but the patient did not want to go. Therefore, the
caregiver's effort in doing this was supported by suggesting
that the patient attending a community mental health center
would be beneficial in increasing her social participation and
making use of her spare time. This would also benefit the care-
giver in organizing her daily life.

The caregiver was encouraged to create leisure opportunities
to rest in order to prevent care-related burnout and fatigue.
GC was also told that she may need mental and physical sup-
port. As sleep and rest were considered to increase the cogni-
tive capacity of the caregiver, it was related to her that the pa-
tient is safe in the hospital receiving treatment, therefore she
can leave the clinic for rest and devote time for herself while
the patient is involved in clinical treatment activities.

In the dimension of developing communication skills; to im-
prove the communication between the patient and the care-
giver, the patient was encouraged to participate in patient ac-
tivities and the caregiver was encouraged to attend the same
activities and observe the communication between the pa-
tient and the researcher. The caregiver was observed making
an effort to include the patient in a therapeutic environment,
and was given positive feedback by reminding her that she
should continue to exert these efforts because they played an
important role in the recovery of the patient. The caregiver re-
ported that she felt much better after these practices and was
willing to take action in this respect.

This case study found that UIT was a facilitating and sup-
portive way to intervene in the uncertainty experienced by
the caregiver with psychiatric clinical nurses. This conclusion
was reached from the caregiver's feedback and the nurse's
observations of the caregiver-patient relationship. When un-
certainty in illness is experienced by caregivers and is not
identified with proper intervention, it can lead to negative
consequences in mental health without adaptation as under-
lined by the theory.

Discussion

In this study, nursing care based on Mishel's Theory of Uncer-
tainty in Illness was provided to the caregiver of an individual
with schizophrenia. In contrast to the patient-based paradigm
in other nursing theories, this theory puts the “individual” af-
fected by the illness in the center, therefore it is also applica-
table to caregivers, which constitutes one of the strengths of
the theory. This study determined that the caregiver experi-
enced anxiety, asked questions about how she could help the pa-
tient more, and had difficulties providing care for the patient.
Similarly, Baier (1995) conducted a UIT-based qualitative study
of the uncertainty experience of families of schizophrenic pa-
tients and determined that the caregivers experienced uncer-
tainty about how they could look after the patients and how
long they could postpone their own health care needs for the
patients. The study also found that some caregivers perceived
uncertainty as an opportunity for hope and others as a dan-
ger; and for all of them, their life views had changed as a result
of this experience.\(^\text{2}\)

In the present study, the caregiver stated that the clinical
nurses answered her questions about the care and treatment
of the patient. The theory emphasizes that effective commu-
nication and a reliable support from credible authorities serve
as factors reducing uncertainty in illness.\(^\text{14}\) The researcher
helped the caregiver create an illness-related symptom pat-
ttern, informed her about caregiving behaviors and a healthy
environment which facilitated the management of uncer-
tainty in illness. In a similar study, some caregivers stated they
were not respected and listened to by hospital personnel,
and had a negative relationship with them; however, did not want to upset them and remained silent because they cared for their relatives. The study also determined that the internal resources of the caregiver helped them evaluate and cope with uncertainty, rather than structure providers such as education and social support. In the present case, the caregiver stated that she received no formal training on schizophrenia and caregiving. However, as caregivers are allowed to stay in the clinic as hospital attendants, they are involved in a care environment where they can easily ask questions to healthcare professionals who are credible authorities.

GC stated she did not have a family member to help her, indicating she did not have sufficient social support, which serves as a structure provider in reducing uncertainty in illness. However, as stated in the theory, GC has communicated with the caregivers of other schizophrenic patients in the clinic which might have increased familiarity with the disease process, facilitating the management of uncertainty in illness.

The deterioration of cognitive capacity may weaken cognitive skills such as problem solving and communication skills used in coping. Cypress (2016) stated that anxiety and fears related to fatigue, treatment, outcomes and prognosis may adversely affect cognitive skills. In the present case, the fatigue and emotional burden on GC due to being the lone caregiver for a long period of time, as well as being an attendant in the inpatient clinic for a few months, were considered to affect her assessment of uncertainty, causing her to perceive the uncertainty she experienced as more threatening. As stated in the theory, the cognitive capacity of individuals can be increased by helping them gain a new perspective on the problem and develop problem-solving skills through cognitive re-framing.

In addition, an intervention can be made directly on the factor that disrupts cognitive skills. For example, as seen in this study, if the condition affecting cognitive capacity is fatigue, the caregiver should be provided with an environment and sufficient time to rest.

As suggested in the theory, the researcher also used other interventions including providing information about the illness, and developing problem-solving and communication skills, by taking into account the situations leading to uncertainty in the caregiver.

In conclusion, in the present case, although uncertainty in illness caused negative feelings in the caregiver, it was considered an opportunity for her to seek help and eventually have hope. The UIT-based care can be effective in explaining the difficult experiences of caregivers of individuals with schizophrenia and supporting them. In addition, the use of the theory in nursing education can encourage students to be aware of uncertainty in illness in routine care planning and develop a theory-based understanding of practice. As there are not many studies based on UIT in Turkey, it is recommended to develop and test theory-based interventions in different illness groups with caregivers.

Conflict of interest: There are no relevant conflicts of interest to disclose.

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References


