Concept Analysis: Uncertainty in Illness

Dana L. Burns

Auburn University/Auburn University Montgomery

**Abstract**

This paper is a concept analysis of the concept of uncertainty and focuses on the area of uncertainty in illness. Uncertainty, a leading cause of distress, is a determinate of how an individual manages a disease diagnosis. The definition of uncertainty will be explored along with its use in a variety of disciplines. Antecedents such as stimuli frame, structure providers, and cognitive capacity will be examined along with critical defining attributes including probability, temporality, and perception. Consequences such as frustration, anger, vulnerability, irritability, apprehension, fear, loss of self-esteem, and an exaggerated need for information will be discussed to provide a better understanding of the effects of uncertainty. Empirical referents are tools used to measure a concept. For the purpose of uncertainty in illness, this paper will take a closer look at Mishel’s Uncertainty in Illness Scale, Parents’ Uncertainty in Illness Scale, and Children’s Uncertainty in Illness Scale. To further understand the concept of uncertainty in illness, the analysis will provide case illustrations including a model case, borderline case, and related case as well as implications for nursing practice.

Concept Analysis: Uncertainty in Illness

Uncertainty is viewed as the most significant source of psychosocial stress for people diagnosed with an illness. Uncertainty has the potential to cause frustration, anger, vulnerability, irritability, apprehension, fear, and loss of self-esteem. It may also lead to an exaggerated need for information (Halliday & Boughton, 2011, p. 135). Uncertainty can decrease quality of life and psychosocial adjustment leading to the inability to adequately cope. It can disrupt individuals’ sense of control and intensify feelings of helplessness and stress causing excessive worry (Baty, Dudley, Musters, & Kinney, 2006, p. 241). Few individuals are able to adequately manage uncertainty. However, there are those who view uncertainty as a door of hope or an opportunity. These individuals allow uncertainty to be a positive experience rather than a threat to their well-being (Halliday & Boughton, 2011, p. 138). Uncertainty is present in many aspects of an individuals’ life. Increased knowledge about what contributes to uncertainty and how it effects an individuals’ life will assist practitioners in minimizing the impact of uncertainty in illness.

# Rationale for Selection of the Concept

Theorists agree that uncertainty should not be defined as either good or bad. Like any other object or event, an individual must determine if the uncertainty being experienced is a threat or an opportunity (Checton, Greene, Magsamen-Conrad, & Venetis, 2012, p. 116). Mishel provides a theoretical framework for nurses to help increase understanding of patients’ responses to uncertainty in illness. Nurses with knowledge about the role that uncertainty plays have the opportunity to help the patient process their personal uncertainty and how it will affect their decision making. Nurses can promote social support to decrease uncertainty and help patients to cope with a new diagnosis. Providing information about the diagnosis, what to expect from treatment, advice, encouragement, and reassurance that uncertainty is normal are all important responsibilities of the nurse. This can help minimize uncertainty and assist patients in making informed decisions (Guadalupe, 2010, pp. 81-82).

# Concept Definition

Several definitions of uncertainty have evolved over time. “Mishel (2006) defined uncertainty in illness as: the inability to determine the meaning of illness-related events; this occurs in situations where the decision maker is unable to assign definite value to objects or events or is unable to accurately predict outcomes due to lack of sufficient cues” (Guadalupe, 2010, p. 78). Much of Mishel’s work was based on that of Lazarus and Folkman (1984) who defined uncertainty as confusion about the meaning of the environmental configuration, rather than illness-related. In 1992, Hilton defined uncertainty as a cognitive state that results when an event cannot be adequately defined or categorized because of a lack of information. In 1994, he described it as a cognitive perceptual state that ranges from feeling less than sure to vagueness. He pointed out that uncertainty changes over time and can include threatening and/or positive emotions. Mishel argues that uncertainty is a neutral cognitive state and should go beyond emotions. Mishel agrees that uncertainty can be positive or negative, but not simply as emotions that go along with uncertainty. His work was more focused on the danger, threat, or opportunity that could be elicited by uncertainty (McCormick, 2002, p. 128).

Penrod (2001, p.241) defines uncertainty as a state in which one perceives they are unable to assign probabilities for an outcome. This inability results in a discomforting, uneasy sensation that may be increased or decreased through cognitive, emotive, or behavioral reactions. The sensation may also be affected by time passing and changes in the perception of the situation. The experience of uncertainty is pervasive in human existence and is mediated by feelings of confidence and control that may be highly specific (event-focused) or more global (a world view). This definition of uncertainty is proposed to be relevant across many disciplines including psychology, medicine, nursing, anthropology and sociology.

# Analysis of the Concept

Concept analysis is a rigorous and logical method used to define concepts. They are useful in increasing knowledge and its’ application for the advance practice nurse (McDonald, 2011, p. 3). This analysis of the concept of uncertainty will focus primarily on uncertainty in illness, however, other usages of the concept will be explored. The analysis will include an abstract, introduction, rationale for selection of the concept, concept definition, aim of the analysis, identification of antecedents, identification of critical defining attributes, empirical referents, consequences, case illustrations, summary of the analysis, and implications for nursing practice.

## Aim of the Analysis

The aim of the analysis is to explore the concept of uncertainty, specifically uncertainty in illness. A better understanding of the concept of uncertainty in illness can assist the nurse in managing levels of uncertainty. This analysis will provide information that can help practitioners be more effective in decreasing the level of uncertainty that patients feel when diagnosed with an illness and assisting in informed decision making.

## Identification of Antecedents

Antecedents are known as the characteristics that precede a concept (Bonis, 2009, p. 1333). Mishel identified four forms of uncertainty that exist in the illness experience which include ambiguity concerning the state of the illness, complexity associated with treatment and system of care, lack of information about the diagnosis and seriousness of the illness, and unpredictability regarding disease progression and prognosis (Guadalupe, 2010, p. 79). Uncertainty did not spontaneously develop, but was composed of three categories of variables including stimuli frame, structure providers and cognitive capacity (Wallace, 2005, p. 863).

“The stimuli frame is the form, composition and structure of the stimuli produced as part of the illness and as a result of illness-related events” (Guadalupe, 2010, p. 79). It is made up of symptom pattern, event familiarity and event congruence (Kang, 2011, p. 1881). Symptom pattern refers to the symptoms of the illness that the patient is experiencing (Wallace, 2005, p. 864). Patients look for consistent patterns of symptoms to better understand their illness. When symptoms are vague and inconsistent a higher level of uncertainty is experienced. Unreliable patterns of symptoms prevent patients from attaching meaning to their illness and breeds ambiguity (Guadalupe, 2010, pp. 79-80). Event familiarity is the degree to which a situation is habitual, repetitive or contains recognizable cues. It is formed over time and experience in a health care environment and through dealing with an illness (Wallace, 2005, p. 864). It becomes easier to attach meaning to events when they are recorded in an individuals’ memory. Event congruence is known as consistency between an expected outcome and the actual outcome of an event related to an illness. When anticipated events do not occur, stability is disrupted and uncertainty is increased (Guadalupe, 2010, p. 80).

Structure providers add stability to a situation and reduce uncertainty both directly and indirectly (Guadalupe, 2010, p. 79). They refer to credible authority, social support and education (Kang, 2011, p. 1881). Credible authority is known as the degree of trust and confidence that the patient has in the health care provider (Wallace, 2005, p. 864). Patients depend on credible authorities to interpret situations or events (Kang, 2011, p. 1881). Social support is the degree to which a person is able to share ideas and opinions with others who have experienced the disease (Wallace, 2005, p. 864). Patients are able to obtain or share information about their experiences and establish a social network to help them deal with their uncertainty (Kang, 2011, p. 1881). Social support can function as a means of information exchange, a foundation for building relationships that promote trust, and provide stability during times of chaos (Guadalupe, 2010, p. 80). Education is measured in school years attended (Wallace, 2005, p. 864). Less educated patients may experience longer periods of uncertainty as it may take them longer to adequately process the situation. A sufficient level of education assists in constructing meaning for events (Kang, 2011, p. 1881).

Cognitive capacity is the ability to process information and any physiological malfunction that may impair this ability. Cognitive capacity can decrease due to physical illness, symptoms and perceived danger. Cognitive capacity is difficult to measure and therefore often not tested (Wallace, 2005, p. 864).

## Identification of Critical Defining Attributes

Attributes are unique elements that help to distinguish a concept (Bonis, 2009, p. 1330). Attributes are similar to signs and symptoms and are critical to clarifying the meaning of a concept and separating one concept from another (Brush, Kirk, Gultekin, & Baiardi, 2011, pp. 161-162). Many attributes contribute to the situation of uncertainty but they must be present in every case to be considered an example of the concept. The three defining attributes of uncertainty have been identified as probability, temporality and perception (McCormick, 2002, p. 129).

Probability is the chance that something will occur. How to avoid a negative situation can be known, but probabilities make it unpredictable (McCormick, 2002, p. 129). When confronted with multiple alternatives, the variation in positive versus negative outcomes must be assessed (Schiebener, Zamarian, Delazer, & Brand, 2011, p. 1025). Probabilities are a vital part of all uncertain situations in illness because patients weigh the odds of potential outcomes. Probability is what prompts many of the questions that patients have about their diagnosis (McCormick, 2002, p. 129).

Uncertainty has a temporal element because its intensity and nature vary over time and related to other life events (Wiles, Cott, & Gibson, 2008, p. 565). Temporality is the duration, pace and frequency of a disease process. Temporality can make it difficult to know how long, how fast and how often. Not knowing what the future holds makes it difficult to plan. This adds to the unpredictability of an illness (McCormick, 2002, pp. 129-130).

Perception uses sensory and cognitive processes to determine how one sees the world. Information is understood based on individualized experience, processing information, and forming mental models (McDonald, 2011, p. 5). It is the interpretation of how an individual perceives a situation. Uncertainty increases when an individual is unable to link an experience to an existing memory. Unfamiliar perception initiates the search for predictability and stability (McCormick, 2002, p. 130). The evidence indicates that patients’ perception of their illness predicts health behaviors and activity limitations (Siemonsma, et al., 2013, p. 436).

Uncertainty can be found in sports, marriage, weather forecasting, gambling, pregnancy, travel and many other aspects of life. This concept analysis focuses on uncertainty in illness, however, uncertainty and its’ defining attributes can also be found in other disciplines such as education and war. Uncertainty in students participating in distance education is of importance because it can affect attention, motivation, memorization, and information processing (Jraidi & Frasson, 2013, p. 219). Probability is illustrated by students weighing the outcomes of their educational experience. Temporality is illustrated by students wondering how long will it take for them to comprehend the material being taught. Perception is illustrated when students encounter unfamiliar situations and information. Uncertainty in war is often related to the distribution of power among the countries involved in conflict (Fey & Ramsay, 2011, p. 157). Probability is illustrated through the odds that one country will be victorious over the other. Temporality is illustrated by individuals asking how long will the war last and how many battles will be encountered. Perception is illustrated when those involved in the war encounter unpredictable, unstable experiences. Uncertainty and its’ consequences are unique to each discipline. Uncertainty is a common occurrence and individuals are likely to experience some degree of uncertainty each day.

## Empirical Referents

Empirical referents are a way to measure and exhibit the occurrence of a concept (Brush et al., 2011, p. 163). Instead, empirical referents are directly related to the attributes and assist in recognizing the defining characteristics of the concept (Walker & Avant , 2011, p. 168). Multiple scales are available to measure characteristics such as stigma in mental illness, depression, quality of life, earthquakes, pain and physical or mental disability. Tools used to measure uncertainty in illness include Mishel’s Uncertainty in Illness Scale (MUIS), Parents’ Uncertainty in Illness Scale (PUIS), and Children’s Uncertainty in Illness Scale (CUIS).

### Mishel’s uncertainty in illness scale.

The MUIS was developed in 1981 to measure uncertainty. The current version consists of 34 items scored from one to five on a Likert scale with one indicating strongly disagree and five indicating strongly agree (Guadalupe, 2010, p. 78). The results are tallied to give the uncertainty score. A higher overall score indicates the presence of more uncertainty. Mishel’s scale does not include emotional outcomes, but participants are asked to rate how uncertain they are about a specific illness. The scale measures experience of illness with four key factors including ambiguity, complexity, deficient information, and unpredictability (McCormick, 2002, p. 128). Since patients’ perceptions change over time, it is suggested that the MUIS be a continual process. The scale should be repeated often and the results assessed for a better understanding of the patient’s experience. Information retrieved from the MUIS can be used to address uncertainty and decrease psychological distress (Elphee, 2008, p. 453). The advance practice nurse can find the MUIS to be a useful tool for facilitating open communication and the implementation of interventions that address uncertainty. This tool has excellent reliability with Cronbach’s alpha 0.913. The validity of the MUIS is based upon a theoretical and empirical background that directly applies to future research of uncertainty across multiple disciplines (Bailey, et al., 2011, p. 198).

### Parents’ uncertainty in illness scale.

The PUIS, also referred to as the Parents’ Perception of Uncertainty Scale (PPUS), is a variation of the MUIS. This scale was developed in 1983 and is used to measure the parents’ perception of uncertainty resulting from their child’s illness. The PPUS is made up of 31 items designed for parents to report about their child’s illness (Page, et al., 2012, p. 100). The scale can result in an uncertainty score of 31 to 155. The higher the score, the greater the level of uncertainty (Lipinski, Lipinski, Biesecker, & Biesecker, 2006, p. 234). Like the MUIS, the PPUS is composed of four dimensions of uncertainty including ambiguity, lack of clarity, lack of information, and unpredictability (Stewart, Mishel, Lynn, & Tergorst, 2010, p. 184). Of the four dimensions, the reliability coefficients are 0.87, 0.81, 0.73, and 0.72 respectively (Lipinski et al., 2006, pp. 234-235). Parents often experience an overwhelming amount of uncertainty when their child is diagnosed with an illness. The advance practice nurse can use information gathered through the PUIS to intervene early in the child’s illness to manage the parents’ uncertainty. This tool has been deemed valid because its results correlate significantly with results from the Caregiver Strain Questionnaire, Impact on Family Scale, Brief Symptom Inventory, and Impact of event scale (Bonner, et al., 2006, p. 315).

### Children’s uncertainty in illness scale.

The CUIS, like the parental version previously discussed, is a variation of the MUIS. This scale was developed in 1995 as a tool used to measure a child’s perceived uncertainty. The CUIS is a self-report measure that was adapted to be appropriate for children and adolescents and it is not illness specific (Page, et al., 2012, p. 100). The scale is a 16 item tool that addresses children’s perception about the course, prognosis, and treatment of their illness (Ryan, et al., 2011, p. 303). Children who are old enough to understand their diagnosis generally have some level of uncertainty. This level of uncertainty can be increased when children are able to sense their parents’ uncertainty as well. The CUIS can provide parents and practitioners with information regarding the factors that result in the child’s uncertainty. It can be used in conjunction with the PUIS to allow the advance practice nurse to provide more appropriate care to both the child and parent during their difficult time. This tool has good internal reliability with Cronbach’s alpha .84 (Ryan, et al., 2011, p. 303) Validity has been demonstrated by its significant association with depression among children with chronic illness (Pai, et al., 2007, p. 289).

## Consequences

Consequences refer to the outcomes that result due to the occurrence of the concept (Walker & Avant , 2011, p. 167). They can be useful in developing new ideas for research as they pertain to the specific concept (Brush et al., 2011, p. 163). Uncertainty should not be considered either good or bad, but rather it should be assessed as a threat or opportunity (Checton et al., 2012, 9. 116). How a person perceives the uncertainty of their situation determines if they assess it as a harm or loss, a threat or challenge, or a combination of these (Lipinski et al., 2006, p. 233). Uncertainty can be seen by some as a door of hope or an opportunity (Halliday & Boughton, 2011, p. 138). Uncertainty affects an individual’s perception of the world around them. This can result in a new sense of confidence or control leading to a positive outlook on life. On the other hand some may experience increased threats to confidence and control leading to a negative attitude (Penrod, 2007, p. 661). Parents often experience anxiety, depression, cognitive disturbances, or feelings of helplessness when their child is diagnosed with an illness. Parents who are unable to help their sick child have increased feelings of being out of control while children diagnosed with an illness are more likely to have anxiety and post-traumatic stress disorder (Lipinski et al., 2006, pp. 233-234). Stress is often increased when one feels a loss of control due to uncertainty (Baty et al., 2006, p. 241). Uncertainty can have an effect on psychological well-being and the ability to effectively cope. This can lead to frustration, anger, vulnerability, irritability, apprehension, fear, loss of self-esteem, and an exaggerated need for information (Halliday & Boughton, 2011, p. 135). Each situation of uncertainty has different consequences. Although some view uncertainty as an opportunity for growth, uncertainty is generally associated with psychosocial distress and should be managed appropriately.

## Case Illustrations

Case illustrations are used to help paint a visual picture of a concept. Depending on the type used, they include a varying degree of the concepts’ critical defining attributes. Case illustrations are commonly used to increase the understanding of the concept itself. Three case illustrations that will be demonstrated include a model case, a borderline case, and a related case. The model case includes all defining attributes and is a pure example of the concept. The borderline case includes most of the defining attributes and assists in clarifying the concept of interest. Related cases are illustrations that are related to but fail to contain all the defining attributes of the concept (Walker & Avant , 2011, pp. 163-165).

### Model case.

JB is a 75 year-old white male due for his annual check-up. JB goes to see the nurse practitioner (NP) accompanied by his wife, MB. He reports having difficulty urinating approximately six months ago and a small amount of blood in his urine on a few occasions. MB tells the NP that his legs are swollen and he has been impotent. The NP conducts a full assessment including a digital rectal exam (DRE) and orders lab work. When the lab work results the NP tells JB and MB that his prostate-specific antigen (PSA) level is elevated at 10 nanograms per milliliter (ng/mL). She also reports that she felt an area of concern on his prostate during the DRE. She tells them he could have prostate cancer. MB cries and tells JB she should have made him go to the doctor sooner and that this is all her fault for not making him take better care of himself. JB consoles MB and asks the NP what are the chances that he has cancer versus an enlarged prostate. He also asks if he has to have treatment how long will it last and how fast can he recover.

This is a pure illustration of a model case because it includes all of the defining attributes of the concept. Perception is illustrated by MB saying it is all her fault and she should have made him take better care of himself. Probability is illustrated by JB wanting to know what are the odds that he does not have cancer. Temporality is illustrated by JB wanting to know how long will treatment last and how fast can he recover. Antecedents of JB and MB’s uncertainty include ambiguity, lack of information, complexity of treatment options, and unpredictability regarding his prognosis. Consequences JB faces include loss of control, frustration, depression, anger, vulnerability, irritability, apprehension, fear, loss of self-esteem, and an exaggerated need for information. Consequences MB faces include exaggerated need for information, anxiety, and fear. Tools useful for measuring JB and MB’s uncertainty would be the MUIS, an anxiety scale, quality of life scale and depression scale. Each of these measures would increase the NP’s knowledge of JB and MB’s experience and allow her to provide more competent care.

### Borderline case.

JB is a 75 year-old white male due for his annual check-up. JB goes to see the NP accompanied by his wife, MB. He reports having difficulty urinating approximately six months ago and a small amount of blood in his urine on a few occasions. MB tells the NP that his legs are swollen and he has been impotent. The NP conducts a full assessment including a DRE and orders lab work. When the lab work results the nurse practitioner tells JB and MB that his PSA level is elevated at 10 ng/mL. She also reports that she felt an area of concern on his prostate during the DRE. The NP tells them that he could have prostate cancer. MB cries and tells JB she should have made him go to the doctor sooner and that this is all her fault for not making him take better care of himself. JB consoles mb and asks the NP what are the chances that he has cancer versus an enlarged prostate.

This is an illustration of a borderline case because it includes most of the defining attributes of the concept of uncertainty. Perception and probability are illustrated, but temporality is not. Perception is illustrated by MB saying it is all her fault and she should have made him take better care of himself. Probability is illustrated by JB wanting to know what are the odds that he does not have cancer. Antecedents of JB and MB’s uncertainty include ambiguity, lack of information, and unpredictability regarding his prognosis. Consequences JB faces include loss of control, apprehension, fear, loss of self-esteem, and an exaggerated need for information. Consequences MB faces include an exaggerated need for information, anxiety, and fear. Tools useful for measuring JB and MB’s uncertainty would be the MUIS and anxiety scale. Each tool would provide the NP with information related to JB and MB’s uncertainty so it could be managed appropriately.

### Related case.

JB is a 75 year-old white male due for his annual check-up. JB goes to see the NP accompanied by his wife, MB. He reports having difficulty urinating approximately six months ago and a small amount of blood in his urine on a few occasions. MB tells the NP that his legs are swollen and he has been impotent. The NP conducts a full assessment including a DRE and orders lab work. When the lab work results the NP tells JB and MB that his PSA level is elevated at 10 ng/mL. She also reports that she felt an area of concern on his prostate during the DRE. The NP tells them he could have prostate cancer. They immediately start asking questions related to how did this happen, what could they have done to prevent it, what signs and symptoms did they miss, and what are their treatment options.

JB and MB are exhibiting an exaggerated need for information which results when an individual is unable to assign definite value to events or is unable to accurately predict outcomes (Guadalupe, 2010, p. 78). This is an illustration of a related case because an exaggerated need for information is similar to the uncertainty experienced in illness, but is not a defining attribute of the concept. Antecedents of JB and MB’s uncertainty include ambiguity and lack of information. Consequences JB faces include loss of control, apprehension, and fear. Consequences MB faces include an exaggerated need for information, anxiety, and fear. Tools useful for measuring JB and MB’s uncertainty would be the MUIS and anxiety scale. The NP could use information retrieved through these scales to help provide the desired information which should in turn decrease the level of uncertainty.

## Summary of the Analysis

This concept analysis explored uncertainty in education and war, but primarily in illness. It was found that uncertainty is common, is found in a variety of disciplines, and may be experienced to some degree each day. Antecedents include stimuli frame, structure providers, and cognitive capacity. They are generally expressed as ambiguity, lack of information, unpredictability, and complexity. Defining attributes include probability, temporality, and perception. Empirical referents, or tools used to measure the defining attributes, include MUIS, PUIS, CUIS, anxiety scale, and depression scale. Common consequences of uncertainty include but are not limited to frustration, anger, vulnerability, irritability, apprehension, fear, loss of self-esteem, and an exaggerated need for information. Case illustrations were given to provide a better understanding of the concept of uncertainty as it pertains to illness.

# Implications for Nursing Practice

Implications for nursing practice are expressed throughout this concept analysis. Few individuals are able to adequately manage uncertainty. Therefore, it is crucial that nurse practitioners be able to identify uncertainty early and reevaluate it often to increase their understanding of their patient’s experience. Nurse practitioners can increase the likelihood that in individual views their situation as a positive experience rather than a threat to their wellbeing. Open communication is vital to the identification and management of uncertainty. It allows the nurse practitioner to provide information and increase confidence in their clinical expertise. By doing so it is likely that uncertainty will be decreased achieving a level of trust between the patient and nurse practitioner.

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