What do We Know about Uncertainty in Illness?

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When I began my original research on uncertainty, the concept of uncertainty had not previously been applied in the health and illness context. My original Uncertainty in Illness Theory (1988) drew from existing information processing models and personality research from the psychology discipline, which characterized uncertainty as a cognitive state resulting from insufficient cues with which to form a cognitive schema, or internal representation of a situation or event. I attribute the underlying stress/appraisal/coping/adaptation framework in the original theory to the work of Lazarus and Folkman (1984). What is unique is my structure of the theory, consideration of uncertainty as both a negative and positive cognitive state and application of this framework of uncertainty as a stressor within the context of illness. These points make the framework particularly meaningful for nursing. Currently there are two theories of Uncertainty in Illness, the original theory which I will emphasize in the presentation and the re-conceptualized theory which I will cover more generally.

The uncertainty theory by Mishel (1988) explains how uncertainty develops in patients with an acute illness and how patients are proposed to deal with uncertainty. With the development of the Uncertainty in Illness scales, the research on uncertainty has proliferated. Most of the research has focused on either the diagnosis or treatment phase of acute illness, illness survivorship and living with chronic illness. Some consistent findings have emerged. Across all illnesses studied to date, uncertainty decreases over time but returns with illness recurrence or exacerbation. Uncertainty is highest or most distressing while awaiting a diagnosis. Illness symptoms can lead to uncertainty when the symptoms change over time, are unpredictable and inconsistent. When symptoms can not be linked to a specific illness or disease, this situation results in higher levels of uncertainty. Similarly, severe illness where the outcome is unknown has been reported to lead to uncertainty. This has been found in a number of studies with varying patient samples including those with cardiovascular disease, and cancer. In studies where patients’ symptoms are not clearly distinguishable from those of other co-morbid conditions or where symptoms of recurrence can be confused with signs of aging or other natural processes, symptoms are associated with uncertainty.

Both social support and the relationship with health care provider have been studied as resources available to the patient to help manage uncertainty. A number of studies have explored the relationship between social support and uncertainty. Current evidence is strong for the role of social support in reducing uncertainty among those with an acute illness. However the type of social support needed and who is seen as supportive changes over time and by illness. The role of the health care provider in reducing uncertainty is substantiated for persons receiving treatment for cancer, yet few studies have been done to explore the role of the health care provider with other acute illness populations. Also, there is some evidence that health care providers do not function as a source of support for reducing uncertainty in parents of acutely ill children; however there is a need for further exploration since there are few studies in the area.

There is a growing body of literature on parent experience of uncertainty in caring for an ill child. There is one literature review of this work. Recently there has been support for the relationship between symptoms of post traumatic stress and uncertainty in mothers of ill children. The association of post traumatic stress and uncertainty has also been reported for other populations dealing with illness. Concerning the role of personality dispositions such as mastery or optimism in reducing uncertainty, the evidence is variable from acute illness to chronic illness. A number of personality dimensions have been identified in chronic illness as effective in managing uncertainty. In acute illness, there is some support for mastery and optimism. Studies of coping with uncertainty in acute illness have resulted in consistent findings for the relationship between uncertainty and emotion-focused coping. However, the qualitative studies offer a
greater variety of strategies to manage uncertainty.

Uncertainty functions differently in chronic illness in comparison with acute illness. Also in chronic illness we find the survivors of acute illness. The similarities and differences between survivors and those diagnosed with a chronic illness will be further clarified in the presentation. However, it is important to recognize that some of the differences can be traced to the design of the study as either qualitative or quantitative. Concerning the causes of uncertainty, the findings from qualitative data have provided a rich description of the causes of uncertainty across a variety of chronic illnesses. From the qualitative work, symptom unpredictability, an unknown future and the possibility of disease recurrence and extension have been identified as causes of uncertainty. Lack of information to make the future more predictable has also emerged from qualitative studies as an antecedent of uncertainty. The literature is rich with descriptions of these causes of uncertainty, especially the unpredictability of symptoms. The uncertainty resulting from erratic symptom display that is characteristic of some chronic illnesses has been fully described in the research done to date.

There is sufficient evidence that uncertainty has a negative impact on quality of life and psycho-social adjustment in acute and chronic illness populations. Since the evidence is consistent and strong it provides direction for interventions to target illness-specific outcomes. I have conducted six intervention studies where the focus was on teaching either breast cancer or prostate cancer patients how to manage uncertainty. These interventions are easily applicable to nursing practice and patients report that they have gained skills in managing the disease. Improvement in specific symptoms and attitudes was reported from patients in the intervention studies. Improvement in emotional state was found in another intervention study with men with recurrent and advanced prostate cancer. Even long term survivors reported gains in knowledge and in finding resources to manage enduring treatment side effects. There is evidence for the effectiveness of supportive educational interventions in modifying the adverse outcomes from uncertainty. Repeated testing of these interventions and the development of other theory and research based interventions that build on the body of existing descriptive research should be the direction of future research.
Significance of Uncertainty
不確定さの意義
New York Times June 1, 2004
（ニューヨークタイムズ 2004.6.1）
“Fundamental issue for cancer survivors is uncertainty. Is it gone or will it come back.”
“がん治療後の基本的な問題は不確定さである。願う通り去ったのか、まだやって来るのか？”
“It’s not knowing, it’s living with uncertainty—the critical issue.”
“それを知ることはできない。不確定さと共に生活することであり、重大な問題である”

Stimuli Contributing to Uncertainty
不確定さの刺激となるものの
- Vague （漠然性）
- Unclear （不明確）
- Inconsistent （不一致）
- Variable （可変性）
- Complex （複雑さ）
- Unpredictable （予測不可能性）
- Novel （新奇性）

Personal Factors Contributing to Uncertainty
不確定さと個人の要因
- selective attention （選択的注意）
- Confusion （混乱）
- emotional arousal （感情的興奮）
- Depression （鬱うつ）
- lack of familiarity （不慣れさ）
- cognitive stress （認知的ストレス）

Uncertainty Theory
不確定さ理論
Four-Factor Scale
Four-Factor Scale

Uncertainty Theory
不確定さ理論
Four-Factor Scale
Uncertainty theory was developed from the literature and research on uncertainty using the Mishel Uncertainty in Illness Scale.
不確定さの理論は、Mishelの病気の不確定さ尺度を用いた文献や研究により発表した

Antecedents of Uncertainty
不確定さの先行要件

Model of Perceived Uncertainty in Illness
病気にに関する不確定さ認知モデル

Uncertainty Theory
不確定さ理論
Four-Factor Scale
Four-Factor Scale

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Symptom Pattern
症状のパターン
The degree to which symptoms are consistent enough to form a pattern.
パターン形成において、症状が十分な実在しているかの程度
Symptoms that are inconsistent in intensity, frequency, number, locations, and/or duration do not form a symptom pattern.
強さ、頻度、数、部位、持続時間に一貫性がない症状はパターンが形成されない
Less symptom pattern leads to uncertainty.
症状のパターンが少ない場合には不確かさをもたらす

Event Familiarity
出来事の熟知度
Refers to the habitual or repetitive nature of the health care environment.
・医療環境に対する慣れや反応性を指す
Novelty and complexity of treatment and treatment facility weaken event familiarity and increase uncertainty.
・治療処置や治療施設が初めてで複雑だと
出来事の熟知度が減り、不確かさが増える

Research on Symptom Pattern:
症状のパターンに関する研究
Persons with illnesses with remission and exacerbations have high levels of uncertainty.
・覚解と再燃を伴う病気の人では不確かさが高い
Persons with symptoms but no diagnosis have more uncertainty.
・症状はあるが診断がついていない人は、より不確かさが高い

Research on symptom pattern and uncertainty
症状のパターンと不確かさに関する研究
1. Patients who experience more acute symptoms report more uncertainty.
・急性症状がある人は、より不確かさが高い
2. When illness fluctuates and patients have good and bad days, uncertainty is higher.
・病気の波があり、順子の良いと悪い日があると不確かさはより高い
3. Unpredictability of a symptom complex is associated with uncertainty.
・症状のつらさない症状群は不確かさと関連している

Event Familiarity-Research
出来事への熟知度一研究
Women with more uncertainty about biopsy procedures and diagnosis experience higher levels of anxiety and depression.
・バイオプシーの手術や検査等が不確かさを高める女性では、より高い不快や不安をもつ
As the management of an illness changes and increases in complexity, uncertainty increases.
・病気の管理方法が変わったり複雑さが増すと、不確かさが増大する

Research on Event Familiarity:
出来事の熟知度に関する研究
Diagnostic tests that are unfamiliar to the patient generate uncertainty.
・患者がよく知らない医学家の検査は、不確かさを生じさせる
Among patients with chronic pulmonary disease, unfamiliarity with new home treatments is associated with uncertainty.
・慢性の呼吸器疾患患者においては、勤務のない新しい在家治療が不確かさに関連している

Event Congruence
出来事の一致性
The consistency between what is expected and what is experienced in illness-related events.
・病気に関連する出来事において、予想される事と体験される事の間の一致性
When expectations are not met, lack of event congruence leads to uncertainty.
・予想がはずれ、出来事に一貫性がない場合には不確かさを招く

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Event Congruence

Research on Event Congruence:
Uncertainty levels reported to be higher in those expecting to be cured but requiring repeat surgery.
- When expecting to be cured, patients experience higher levels of uncertainty.

Less time between prior and current hospitalization associated with higher levels of uncertainty.
- Increased uncertainty may lead to increased stress.

Research on event congruence And uncertainty

Completing treatment starts the uncertainty of survivorship.
- Completion of treatment marks the beginning of uncertainty.

Uncertainty is reported to be higher in spouses of recurrent women then in the women themselves.
- Women's uncertainty is higher due to recurrence.

Research on event congruence And uncertainty

Survivors experience uncertainty from events that trigger the threat of recurrence.
- For survivors, uncertainty arises from the threat of recurrence.

Uncertainty is strongly related to symptoms of post traumatic stress in younger breast cancer survivors.
- Younger survivors experience higher levels of uncertainty.

Antecedents of Uncertainty

Structure Providers

The resources available to provide meaning to illness-related events:

- education (教育)
- social support (ソーシャルサポート)
- credible authority (信頼できる専門家)

Research on Education

Patients with less education report higher levels of uncertainty.
- Lower education levels are associated with higher uncertainty.

Patients with less education show more benefit from educational interventions to manage uncertainty as compared to patients with more education.
- Education interventions show greater benefit for patients with lower education levels.
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**Social Support**

**Research on Social Support:**
- Use of the support network during recovery from illness is related to less uncertainty.
  - Patients who have access to a support network are less uncertain about their illness.
- The type of social support needed to reduce uncertainty changes during diagnosis, treatment, and recovery.
  - Support that is initially helpful may become less effective as the illness progresses.
- Social support reduces uncertainty by explaining symptoms.
  - Social support helps patients understand their symptoms and reduce their uncertainty.

**Further Research on Social Support:**
- Unsupportive interactions predict higher uncertainty.
  - Unsupportive interactions can increase uncertainty.
- When illness is stigmatized, there is less use of social support to manage uncertainty.
  - Patients may avoid social support because they believe it will increase their uncertainty.
- Family members may be unable to be supportive to the patient due to their own uncertainty.
  - Family members may have their own stress and uncertainty.

**Health Care Providers**

**Research on Health Care Providers:**
- Four studies support that receiving relevant information from physicians/nurses leads to a decrease in uncertainty about treatment.
  - Patients who receive clear and understandable information are less uncertain about their illness.
- In chronic illness, perceiving that the health care provider has control of the illness is associated with less uncertainty.
  - Patients who perceive their health care providers as in control are less uncertain.

**Further Research on Health Care Providers:**
- Receiving a specific diagnosis, even with a poor prognosis, significantly reduces uncertainty.
  - Patients who receive a specific diagnosis are less uncertain.
- When patient and physician do not communicate well, physicians cannot reduce the patient's uncertainty.
  - Communication between patient and physician is crucial for reducing uncertainty.

**Appraisal of Uncertainty**

- Uncertainty can lead to irrational thoughts and behaviors.
- Different types of uncertainty can lead to different responses.

**Illusion and Inference**

- Illusion: "Beliefs which have a generally positive outlook."
  - Illusions are positive biases that can influence our thinking.
- Inference: "Judgments based on certain premises."
  - Inferences are based on assumptions and can lead to mistakes.

Health care providers are generally seen as credible sources for information. They can strengthen the stimul frame by providing information on the causes and consequences of symptoms.

- Health care providers are seen as credible sources for information. They can help reduce uncertainty and improve patient outcomes.
- Patients may have illusions about their illness, which can influence their treatment decisions.
- Inference can affect the way patients interpret information from health care providers.

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Illusion and Inference

Research on Illusion (Personality Factors):
Some studies report that uncertainty reduces optimism and mastery.
* Other studies indicate that hardness, self-efficacy and spirituality decrease the impact of uncertainty on danger and other negative outcomes.
- There other research that unresolved anxiety, self-scrutiny, and self-efficacy may increase uncertainty.

Appraisal of Uncertainty
不確から評価

Danger and Opportunity
危険と機会

Research on danger and coping
危険と共感に関する研究

Breast cancer patients who have more uncertainty about their illness use limited coping strategies because the focus of action is unclear.

Qualitative studies have reported that acceptance of uncertainty results in a new orientation to life.

Danger and Opportunity
危険と機会

Uncertainty, Danger, Coping:
Uncertainty appraised as an opportunity is associated with active coping strategies.
- 不確からを好機と見なす評価は積極的な共感が関連している。

Qualitative research shows that uncertainty as an opportunity promotes a second chance at life.

Research on uncertainty, opportunity, coping
不確から、機会、共感に関する研究

Uncertainty among breast cancer survivors has been reported to predict both psychological distress and psychological benefit.

Qualitative studies have reported that acceptance of uncertainty results in a new orientation to life.

Research on uncertainty, opportunity, coping
不確から、機会、共感に関する研究

Living with continual uncertainty during survivorship can lead to a re-evaluation of the uncertainty.

Uncertainty can be seen as the source of new opportunities.

病気からの生活の期間に限らず不確からをともに生きていくことで、不確からを再評価をすることができる

不確から新しい機会の源と見えることができる
What do We Know about Uncertainty in Illness?

Adjustment

Research on Adjustment:

- Uncertainty is related to less life satisfaction, negative attitudes toward family relationships and employment and poorer quality of life.
- 人生に対する生命観、家族関係に対するネガティブな姿勢、雇用、QOLの低下に関する、

Comprehensive Reviews of Uncertainty Theory and Research