◆特 別 講 演◆

What do We Know about Uncertainly 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.

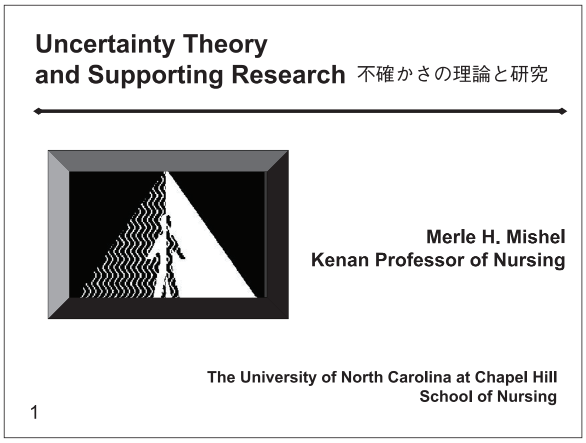
The uncertainty theory by Mishel (1988) explains how uncertainty develops in patients with an acute illness and how patients are proposed to deal with uncertainty. With the development of the Uncertainty in Illness scales, the research on uncertainty has proliferated. Most of the research has focused 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.



Uncertainty Theory and Supporting Research 不確かさの理論と研究

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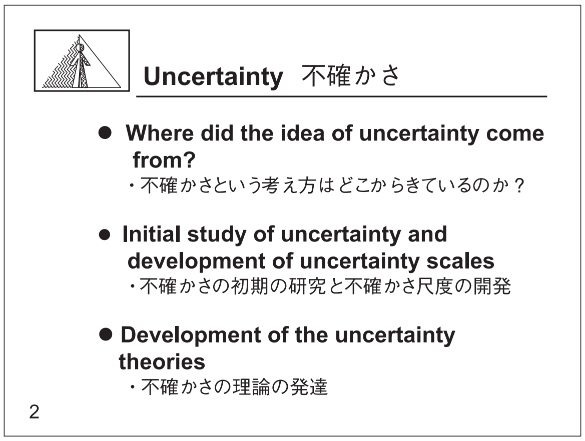

Uncertainty 不確かさ

- **Where did the idea of uncertainty come from?**
  - ・不確かさという考え方はどこからきているのか？
- **Initial study of uncertainty and development of uncertainty scales**
  - ・不確かさの初期の研究と不確かさ尺度の開発
- **Development of the uncertainty theories**
  - ・不確かさの理論の発達

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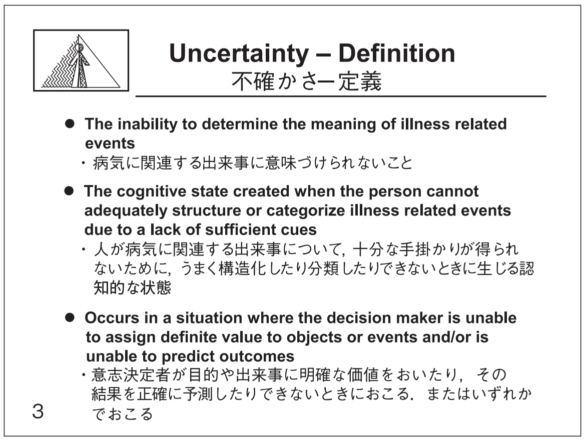

Uncertainty – Definition
不確かさー定義

- **The inability to determine the meaning of illness related events**
  - ・病気に関連する出来事に意味づけられないこと
- **The cognitive state created when the person cannot adequately structure or categorize illness related events due to a lack of sufficient cues**
  - ・人が病気に関連する出来事について，十分な手掛かりが得られないために，うまく構造化したり分類したりできないときに生じる認知的な状態
- **Occurs in a situation where the decision maker is unable to assign definite value to objects or events and/or is unable to predict outcomes**
  - ・意志決定者が目的や出来事に明確な価値をおいたり，その結果を正確に予測したりできないときにおこる．またはいずれかでおこる

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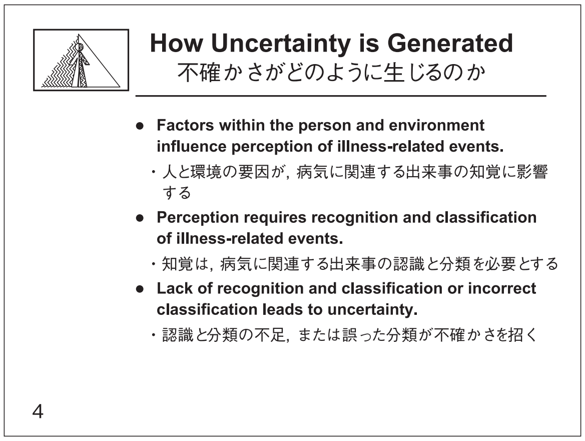

How Uncertainty is Generated
不確かさがどのように生じるのか

- **Factors within the person and environment influence perception of illness-related events.**
  - ・人と環境の要因が，病気に関連する出来事の知覚に影響する
- **Perception requires recognition and classification of illness-related events.**
  - ・知覚は，病気に関連する出来事の認識と分類を必要とする
- **Lack of recognition and classification or incorrect classification leads to uncertainty.**
  - ・認識と分類の不足，または誤った分類が不確かさを招く

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Significance of Uncertainty
不確かさの意義

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."
"がんサバイバーの基本的な問題は不確かさである. がんが過ぎ去ったのか，またやって来るのか？"

"It's the not knowing, it's living with uncertainty- the critical issue."
"それを知ることはできない, 不確か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
不確かさの刺激となるもの

- **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
不確かさと個人の要因

- **selective attention** （選択的注意）
- **Confusion** （混乱）
- **emotional arousal** （情動的興奮）
- **Depression** （抑うつ）
- **lack of familiarity** （不慣れさ）
- **cognitive stress** （認知的ストレス）

Uncertainty Theory 不確かさ理論
Four-Factor Scale 4一因子尺度

Uncertainty theory was developed from the literature and research on uncertainty using the Mishel Uncertainty in Illness Scale.

不確かさの理論は，Mishelの病気の不確かさ尺度を用いた文献や研究により発達した

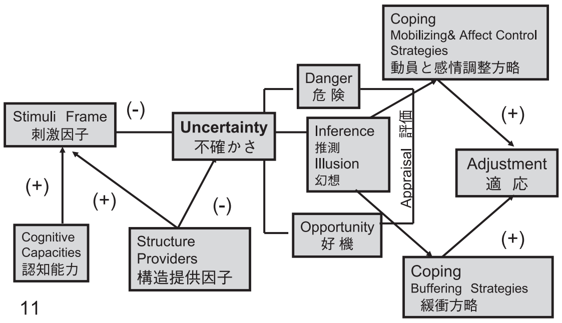
Uncertainty Theory
Four-Factor Scale

- **Ambiguity** （曖昧さ）
  - **Ambiguity Factor - 13 Items** 13項目
  - **Cues about the state of the illness are vague and indistinct and tend to blur and overlap.**
  - ・病状についての手掛かりが曖昧ではっきりせず，ぼんやりしていて，重なる傾向がある.
- **Complexity** （複雑さ）
  - **Complexity Factor - 7 Items** 7項目
  - **Cues about treatment and the system of care are multiple and varied.**
  - ・治療処置やケアシステムについての手掛かりが重なっていて多様である

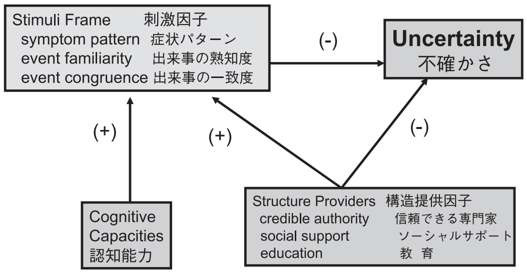
Uncertainty Theory
Four-Factor Scale

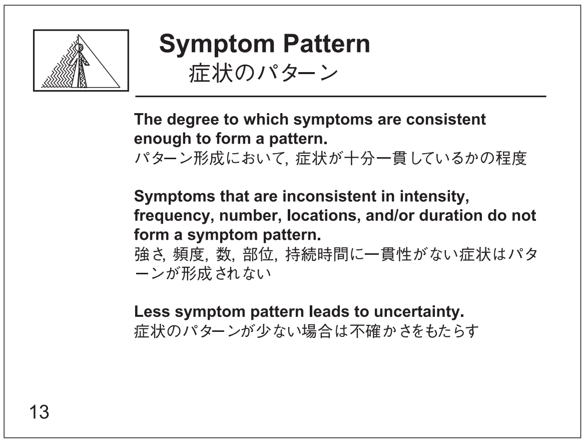
- **Inconsistency** （不一致性）
  - **Inconsistency Factor - 7 Items** 7項目
  - **Information changes frequently or is not in accord with information previously received.**
  - ・情報がたびたび変化したり，または，前に入手したものと一致しない
- **Unpredictability** （予測不可能性）
  - **Unpredictability Factor - 5 Items** 5項目
  - **Lack of contingency between illness cues and illness outcome.**
  - ・病気の手掛かりと病気の結果との間の一致を欠いている

Model of Perceived Uncertainty in Illness
病気に関連する不確かさ認知モデル


Stimuli Frame
刺激因子
(-)
Uncertainty
不確かさ
Danger
危 険
Coping
Mobilizing& Affect Control Strategies
動員と感情調整方略
Inference
推測
Illusion
幻想
Appraisal 評価
Opportunity
好 機
(+)
Adjustment
適 応
(+)
Coping
Buffering Strategies
緩衝方略
(+)
(+)
(-)
Cognitive Capacities
認知能力
Structure Providers
構造提供因子

Antecedents of Uncertainty
不確かさの先行要件


Stimuli Frame 刺激因子
symptom pattern 症状パターン
event familiarity 出来事の熟知度
event congruence 出来事の一致度
(-)
Uncertainty
不確かさ
(+)
(+)
(-)
Cognitive Capacities
認知能力
Structure Providers 構造提供因子
credible authority 信頼できる専門家
social support ソーシャルサポート
education 教 育

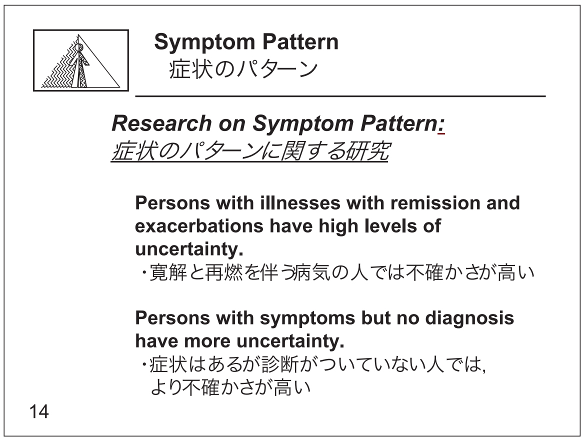


Symptom Pattern
症状のパターン

The degree to which symptoms are consistent enough to form a pattern.
パターン形成において，症状が十分一貫しているかの程度

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は不確かさをもたらす

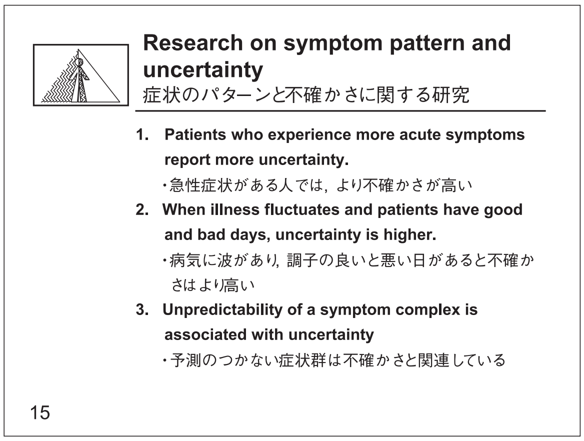


Symptom Pattern
症状のパターン

Research on Symptom Pattern:
症状のパターンに関する研究

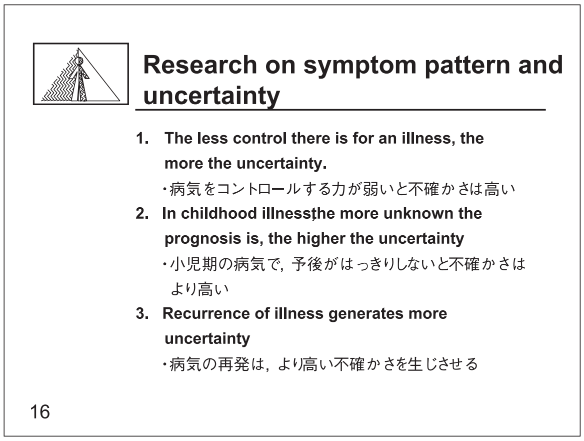
Persons with illnesses with remission and exacerbations have high levels of uncertainty.
・寛解と再燃を伴う病気の人では不確かさが高い

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では，
より不確かさが高い



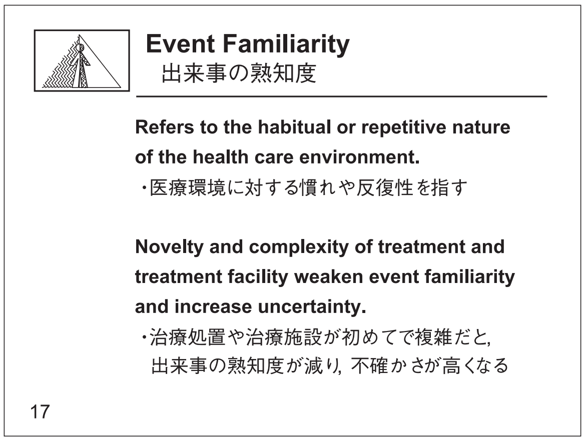
Research on symptom pattern and uncertainty
症状のパターンと不確かさに関する研究

1. **Patients who experience more acute symptoms report more uncertainty.**
   ・急性症状がある人では，より不確かさが高い
2. **When illness fluctuates and patients have good and bad days, uncertainty is higher.**
   ・病気に波があり，調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**
   ・予測のつかない症状群は不確かさと関連している



Research on symptom pattern and uncertainty

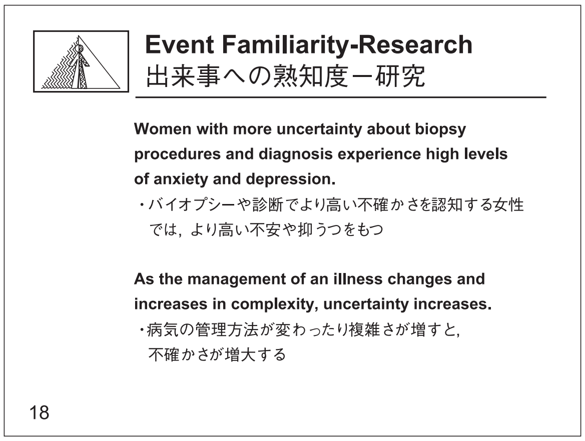
1. **The less control there is for an illness, the more the uncertainty.**
   ・病気をコントロールする力が弱いと不確かさは高い
2. **In childhood illness,the more unknown the prognosis is, the higher the uncertainty**
   ・小児期の病気で，予後がはっきりしないと不確かさはより高い
3. **Recurrence of illness generates more uncertainty**
   ・病気の再発は，より高い不確かさを生じさせる



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復性を指す

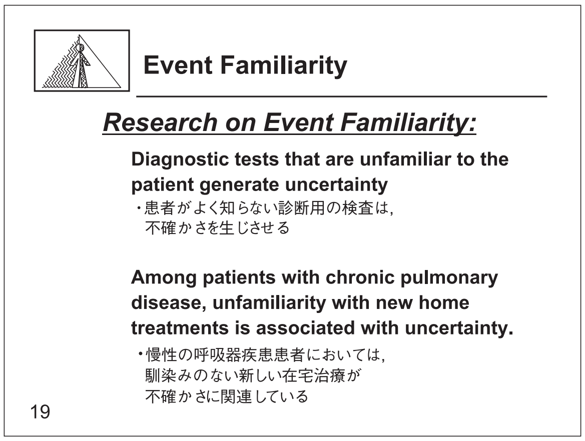
Novelty and complexity of treatment and treatment facility weaken event familiarity and increase uncertainty.
・治療処置や治療施設が初めてで複雑だと，
出来事の熟知度が減り，不確かさが高くなる



Event Familiarity-Research
出来事への熟知度－研究

Women with more uncertainty about biopsy procedures and diagnosis experience high levels of anxiety and depression.
・バイオプシーや診断でより高い不確かさを認知する女性では，より高い不安や抑うつをもつ

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

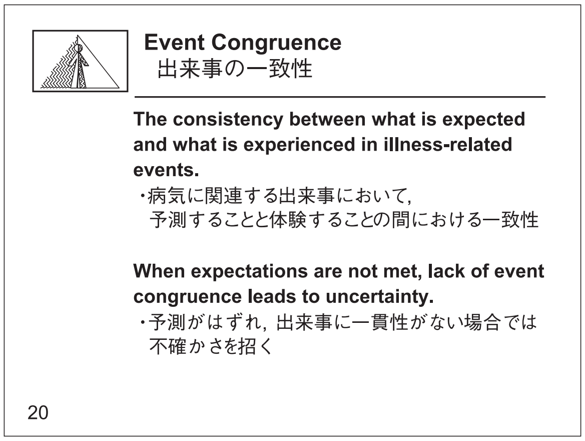


Event Familiarity

Research on Event Familiarity:

Diagnostic tests that are unfamiliar to the patient generate uncertainty
・患者がよく知らない診断用の検査は，
不確かさを生じさせる

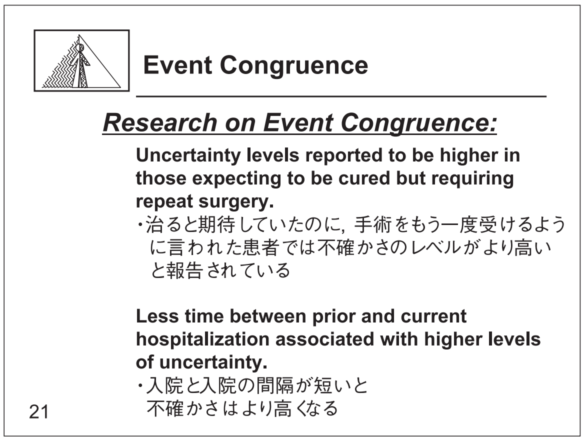
Among patients with chronic pulmonary disease, unfamiliarity with new home treatments is associated with uncertainty.
・慢性の呼吸器疾患患者においては，
馴染みのない新しい在宅治療が
不確かさに関連している



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，
予測することと体験することの間における一致性

When expectations are not met, lack of event congruence leads to uncertainty.
・予測がはずれ，出来事に一貫性がない場合では
不確かさを招く



Event Congruence

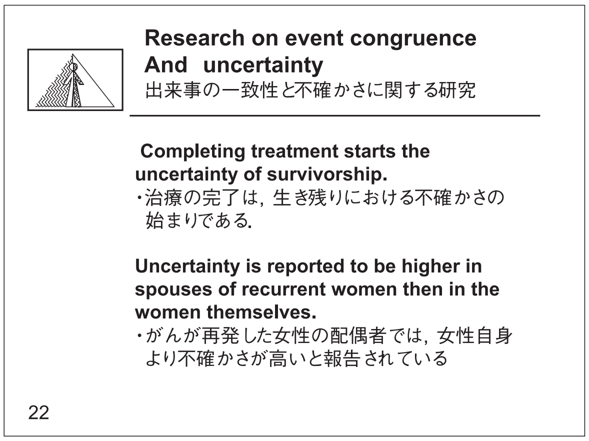
Research on Event Congruence:

Uncertainty levels reported to be higher in those expecting to be cured but requiring repeat surgery.

・治ると期待していたのに，手術をもう一度受けるように言われた患者では不確かさのレベルがより高いと報告されている

Less time between prior and current hospitalization associated with higher levels of uncertainty.

・入院と入院の間隔が短いと不確かさはより高くなる



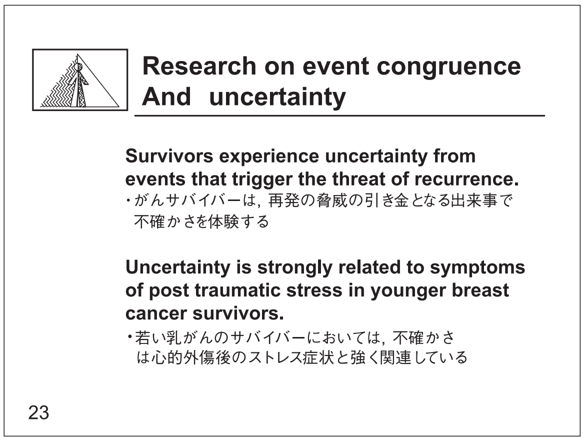
Research on event congruence And uncertainty
出来事の一致性と不確かさに関する研究

Completing treatment starts the uncertainty of survivorship.

・治療の完了は，生き残りにおける不確かさの始まりである.

Uncertainty is reported to be higher in spouses of recurrent women then in the women themselves.

・がんが再発した女性の配偶者では，女性自身より不確かさが高いと報告されている



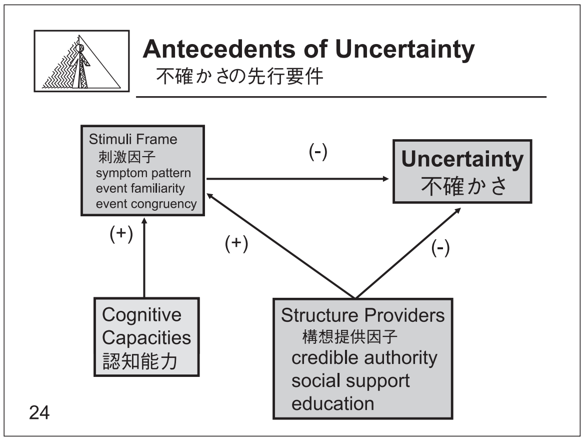
Research on event congruence And uncertainty

Survivors experience uncertainty from events that trigger the threat of recurrence.

・がんサバイバーは，再発の脅威の引き金となる出来事で不確かさを体験する

Uncertainty is strongly related to symptoms of post traumatic stress in younger breast cancer survivors.

・若い乳がんのサバイバーにおいては，不確かさは心的外傷後のストレス症状と強く関連している



Antecedents of Uncertainty
不確かさの先行要件

Stimuli Frame
刺激因子
symptom pattern
event familiarity
event congruency

(-)

Uncertainty
不確かさ

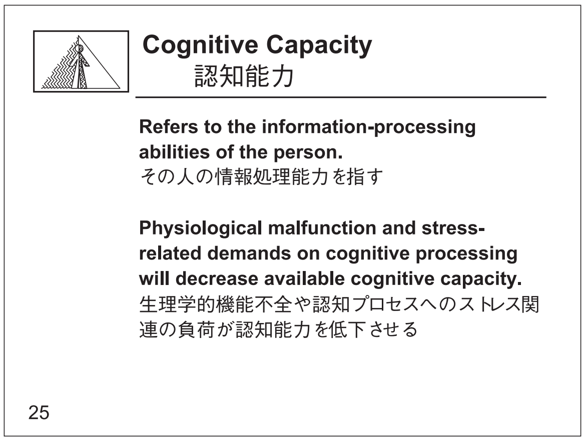
(+)

(+)

(-)

Cognitive
Capacities
認知能力

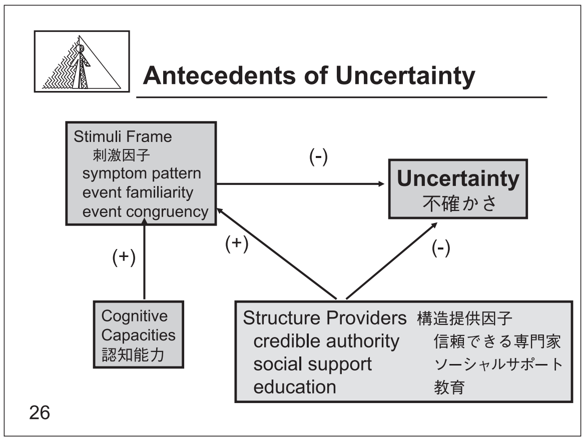
Structure Providers
構想提供因子
credible authority
social support
education



Cognitive Capacity
認知能力

Refers to the information-processing abilities of the person.
その人の情報処理能力を指す

Physiological malfunction and stress-related demands on cognitive processing will decrease available cognitive capacity.
生理学的機能不全や認知プロセスへのストレス関連の負荷が認知能力を低下させる



Antecedents of Uncertainty

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symptom pattern
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(+)

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Cognitive
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Structure Providers 構造提供因子
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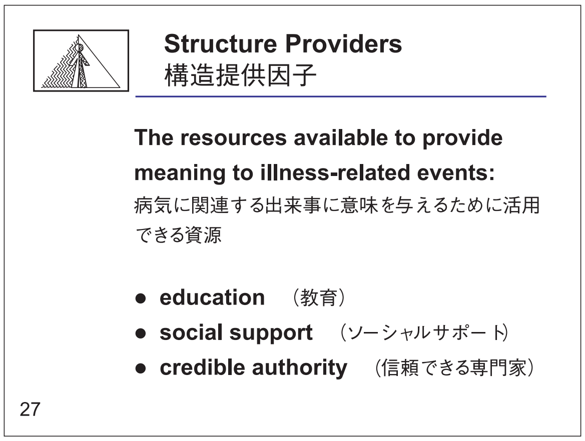
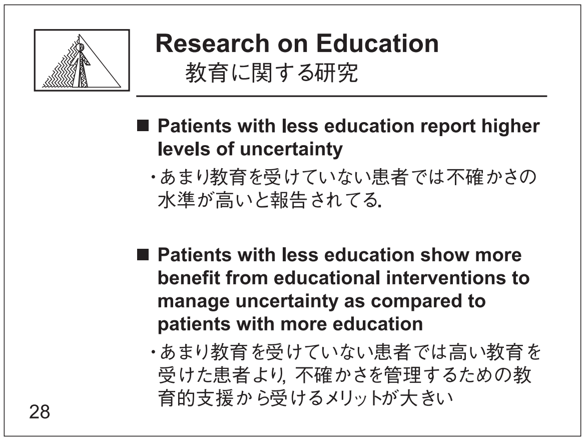
social support ソーシャルサポート
education 教育



Structure Providers
構造提供因子

The resources available to provide meaning to illness-related events:
病気に関連する出来事に意味を与えるために活用できる資源

- **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
教育に関する研究

- **Patients with less education report higher levels of uncertainty**
  ・あまり教育を受けていない患者では不確かさの水準が高いと報告されてる.
- **Patients with less education show more benefit from educational interventions to manage uncertainty as compared to patients with more education**
  ・あまり教育を受けていない患者では高い教育を受けた患者より，不確かさを管理するための教育的支援から受けるメリットが大きい

Social Support
ソーシャルサポート

Research on Social Support:

- **Use of the support network during recovery from illness is related to less uncertainty.**
  ・病気からの回復の間に，サポートネットワークを利用した人では不確かさが少ない
- **The type of social support needed to reduce uncertainty changes during diagnosis, treatment, and recovery.**
  ・不確かさを減らすために，どのようなソーシャルサポートが必要かは診断，治療，回復の期間に変化する
- **Social support reduces uncertainty by explaining symptoms.**
  ・ソーシャルサポートは症状について説明することで不確かさを減らす

Social Support

Further Research on Social Support:

- **Unsupportive interactions predict higher uncertainty.**
  ・サポートに欠ける相互作用はより高い不確かさが予測される
- **When illness is stigmatized, there is less use of social support to manage uncertainty.**
  ・偏見がもたれる病気のときは，不確かさを管理するためにソーシャルサポートを使うことが少ない
- **Family members may be unable to be supportive to the patient due to their own uncertainty.**
  ・家族メンバーは自分の不確かさから，患者をサポートできないかもしれない

Social Support

Further Research on Social Support:

1. **Often caretakers of ill patients suffer more uncertainty than the patient.**
   ・病気の患者を世話する人では，しばしば患者より高い不確かさに苦しんでいる
2. **Social uncertainty about forming relationships can develop in patients with chronic illness.**
   ・関係形成についての社会的不確かさは慢性病患の中で生まれる可能性がある
3. **Cancer patients use other patients as a support network to reduce uncertainty.**
   ・がん患者は他の患者を，不確かさを減らすひとつのサポートネットワークとして用いる

Health Care Providers
医療従事者

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

・医療従事者は一般的に信頼できる情報源であると見なされる．彼らは症状の原因と結果に関する情報を提供しながら刺激の枠組みを強化する

Health Care Providers

Research on Health Care Providers:

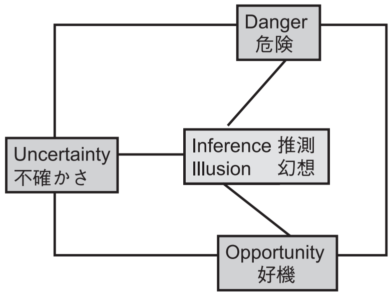
- **Four studies support that receiving relevant information from physicians/nurses leads to a decrease in uncertainty about treatment.**
  ・４つの研究は，医者／看護師からの適切な情報が治療処置に関する不確かさを減らすことを示している
- **In chronic illness, perceiving that the health care provider has control of the illness is associated with less uncertainty.**
  ・慢性疾患では，医療従事者が病気をコントロールしてくれると認識することが，不確かさの低さと関連している

Health Care Providers

Research on Health Care Providers:

- **Receiving a specific diagnosis, even with a poor prognosis, significantly reduces uncertainty.**
  ・診断されることは，それが深刻な診断であっても，不確かさを顕著に減らす
- **When patient and physician do not communicate well, physicians cannot reduce the patient's uncertainty.**
  ・患者と医者のコミュニケーションがうまくいかない場合，医者が患者の不確かさを減らすことはできない

Appraisal of Uncertainty
不確かさの評価



Illusion and Inference
幻想と推測

Illusion 幻想:

Beliefs which have a generally positive outlook.
一般的に肯定的な見方を持っているという信念

Inference 推測:

Judgments based on 以下に基づく判断

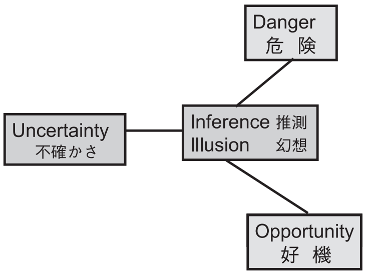
- **personality disposition** 個人の性質
- **general experience** 一般的経験
- **specific knowledge** 特定の知識
- **contextual cues** 状況から得られる手掛かり

Illusion and Inference

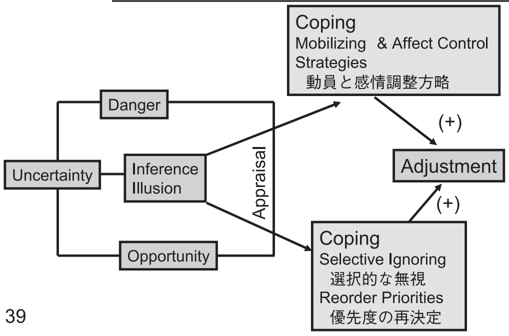
Research on Inference (Personality Factors):
推測に関する研究（性格要因）

- **Some studies report that uncertainty reduces optimism and mastery.**
  ・いくつかの研究は不確かさが楽観主義や克服力を減らすと報告している
- **Other studies indicate that hardiness, self-efficacy and spirituality decrease the impact of uncertainty on danger and other negative outcomes.**
  ・その他の研究ではストレス耐性の強さ，自己効力，スピリチュアリティが，危険やネガティブな結果についての不確かさを減らすことを示唆している

Appraisal of Uncertainty
不確かさの評価



Coping with Uncertainty



Danger and Opportunity
危険と好機

Uncertainty, Danger, Coping:

- **Findings are that higher uncertainty is associated with danger and poor coping strategies of wishful thinking, avoidance and fatalism.**
  ・高い不確かさは希望的観測，回避，運命論といった危険で問題のあるコーピング方略に関連することが明らかにされている
- **There are problems with the measurement of coping. Qualitative studies offer a variety of strategies for managing uncertainty.**
  ・コーピングの測定は問題がある
  ・質的研究では不確かさの管理のための様々な方略を提示する

Research on danger and coping
危険とコーピングに関する研究

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

病気についての不確かさが高い乳がん患者では，活動の焦点が不明瞭なために限られたコーピング方略を用いている

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

質的研究では不確かさを受け入れることは，人生について新しい方向性をもつことであると報告している

Danger and Opportunity
危険と好機

Uncertainty, Danger, Coping:

Uncertainty appraised as an opportunity is associated with active coping strategies.
・不確かさを好機と見なす評価は積極的なコーピング方略と関連している

Qualitative research shows that uncertainty as an opportunity promotes a second chance at life.
・不確かさを好機と見なす場合では，人生における第2のチャンスを促進することが質的研究で示されている.

Research on uncertainty, opportunity , coping
不確かさ，好機，コーピングに関する研究

Uncertainty among breast cancer survivors has been reported to predict both psychological distress and psychological benefit
・乳がんサバイバーの不確かさは心理的苦痛と心理的利得の両方を予測する

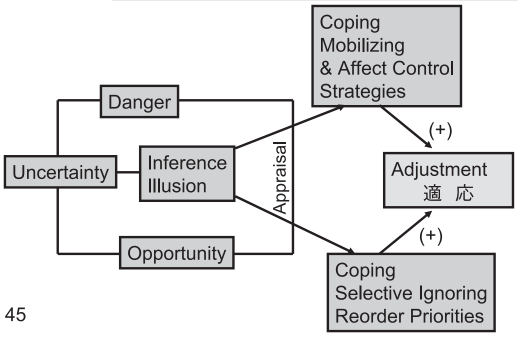
Qualitative studies have reported that acceptance of uncertainty results in a new orientation to life.
・質的研究では，不確かさを受け入れることが人生に対する新しい方向性につながることを報告している

Research on uncertainty, opportunity, coping

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

病気からの生存の期間に絶え間ない不確かさとともに生きることで，不確かさの再評価をもたらすことができる
不確かさは新しい機会の源と見なすことができる

Coping with Uncertainty



Adjustment
適　応

Refers to returning to the individual's level of pre-illness functioning.
個々人の機能が病前の状態に戻ることを指す

Most of the research has focused on emotional stability or quality of life.
ほとんどの研究では情緒的安定性やQOＬに焦点をあわせている

Adjustment

***Research on Adjustment*：**
適応に関する研究

- **Most studies ignore the model and examine the relationship between uncertainty and an outcome.**
  ・ほとんどの研究では，不確かさのモデルを無視し，不確かさとその結果の関係を検討している．
- **Findings have consistently shown positive associations between uncertainty and negative emotions of anxiety, depression, hopelessness, and emotional distress.**
  ・研究結果では，「不確かさ」と不安，抑うつ，絶望感，そして精神的苦痛というネガティブな感情との間に正の相関があることが一貫して示されている．

Adjustment　適 応

Research on Adjustment:

- **Uncertainty is related to less life satisfaction, negative attitudes toward family relationships and employment and poorer quality of life.**
  ・不確かさは人生に対する満足度の低さ，家族関係に対するネガティブな姿勢，雇用，**QOL**の低さと関連している．

Comprehensive Reviews of Uncertainty Theory and Research

4 Mast, M.E. (1985) Adult uncertainty in illness: A critical review of research. Scholarly Inquiry for Nursing Practice, 9(1), 3-24.
4 Mishel, M.H. (1993) Living with chronic illness: Living with uncertainty. In S.G. Funk, E.M. Tornquist, M.T. Champagne, R.A. Wiese (Eds). Key Aspects of Caring for the Chronically Ill: Hospital and Home (pp. 46-58). New York, N.Y.: Spring Publishing Company.
4 Mishel, M.H. (1997) Uncertainty in acute illness. Annual Review of Nursing Research, 15, 57-80.
4 Mishel, M.H. (1999) Uncertainty in chronic illness. Annual Review of Nursing Research, 17, 269-294.
4 Stewart, J.L. and Mishel, M.H. (2000) Uncertainty in childhood illness: A synthesis of the parent and child literature. Scholarly Inquiry for Nursing Practice, 17, 299-319.