

# Uncertainty of parents due to having children with cancer: A concept analysis

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## Abstract

**Background:** Parents of newly diagnosed cancer children often experience significant concerns about the implications of the diagnosis. They find themselves in challenging decision-making situations, navigating through uncertain conditions following the disclosure. Uncertainty is a prevailing issue in healthcare, yet its interpretation and application within the context of health and nursing practice exhibit multiple meanings and variations.

**Objective:** This study aimed to clarify the concept of parental uncertainty arising from having children with cancer.

**Methods:** The concept analysis followed the steps outlined by Walker and Avant. A thorough literature search was conducted using the Embase, CINAHL, and MEDLINE databases to identify articles published between 1980 and 2022.

**Results:** The literature search yielded 147 articles from various disciplines, including health, nursing, medicine, psycho-oncology, and management. After analysis, 20 articles were selected for inclusion. This study identified four key attributes of parental uncertainty associated with having a child with cancer: (1) emotional disturbance, (2) unpredictability, (3) insufficient information, and (4) problems with decision-making. The antecedents of parental uncertainty encompassed the complexity of the disease, the diagnostic and treatment processes, the hospital environment, communication, and support from credible authorities. The consequences of parental uncertainty included the pursuit of new information, parental adaptability to their role, and parental distress.

**Conclusion:** Understanding the four attributes of parental uncertainty, along with their antecedents and consequences, can facilitate the future development and operational translation of the concept of uncertainty in nursing practice. This concept is valuable in the evidence-based provision of nursing care to parents of children with cancer, enabling comprehensive recognition and assessment of parental uncertainty and the implementation of appropriate interventions that are sensitive to parental experiences. Ultimately, this approach promotes the adaptation of both the child and the parent.

## Keywords

cancer; children; concept analysis; parents; uncertainty

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## Background

Cancer diagnosis in children significantly impacts parents, particularly mothers (Peek & Melnyk, 2014). It can be a source of long-term stress for sick children, their parents, and siblings (Lewandowska, 2021). Parents of newly diagnosed cancer children are frequently concerned about the implications of the diagnosis, which forces them to make difficult decision-making (Peek & Melnyk, 2014). As a result, parents are thrown into unexpected situations in which they must care for very ill children while also dealing with difficult stressors such as their fears and anxieties (Lewandowska, 2021). Distress among parents of cancer children can range from 10% to 41% (Dunn et al., 2012). Anxiety, depression, and uncertainties are all symptoms of parental distress that can affect children and last

throughout the childcare process and for years afterward (Eche & Aronowitz, 2018; Eche et al., 2019; Kazak et al., 2004; Peek & Melnyk, 2014).

The uncertainty caused by uncertain circumstances will influence parents' caring behaviors after disclosure. Uncertainty is substantially connected with mental health problems, particularly mood disorders among parents of cancer children (Taylor Piliae & Molassiotis, 2001). This might make it tough for parents to cope with their child's diagnosis. Evidence suggests that parental uncertainty influences the level of uncertainty felt by chronically ill or receiving treatment children (Page et al., 2012). This circumstance necessitates changes in future or near-term family goals, priorities, and values. Families must learn to perform their roles in new

situations, deal with challenges, control difficult emotions, and solve other problems (Lewandowska, 2021).

The concept of uncertainty has long been of interest in the social sciences, particularly in areas related to decision-making and knowledge (Wakeham, 2015). References to the problem of uncertainty – and related concepts – are dispersed throughout disciplines, including economics, psychology, anthropology, nursing, and medicine. However, in various disciplines, intra and inter-disciplinary, there are different understandings of the concept of uncertainty and different interpretations of its significance for social behavior and social sciences (Wakeham, 2015).

Uncertainty is a crucial aspect of disease experience that influences patients' and their families' adaptability and can affect health outcomes (McCormick, 2002). The concept of uncertainty in nursing is almost entirely influenced by Mishel's "uncertainty in illness model" (Tas Bora & Buldukoglu, 2020). However, despite the increasing popularity of this concept, no concept of uncertainty was published in the nursing field after the development of Mishel's Uncertainty in Illness Model and its reconceptualization from 1990 until 2002 (McCormick, 2002).

According to Han et al. (2011), uncertainty is becoming a major issue in the health sector with the rise of evidence-based practices, shared decision-making, and patient-centered care. However, understanding of the concept of uncertainty remains limited because its coherence is not yet clear. The concept of uncertainty has numerous meanings and variations, many of which are not distinguished or recognized, although each may have a distinct impact on the concept. Due to the fragmentation of the literature on health uncertainty, this concept is only partially translated into clinical practice (Han et al., 2011).

Nurses, in particular, must comprehend the concept of uncertainty well. To collaborate with other health professionals to provide appropriate interventions, nurses are expected to be able to identify the conditions of uncertainty among parents who have children with cancer, including the response, causes, and consequences. As a result, clarifying parental uncertainty through concept analysis is critical for developing a clear and comprehensive definition that can be used to advance both nursing research and practice.

## Concept Analysis of Uncertainty

Walker and Avant's eight-step concept analysis was used in this study (Walker & Avant, 2014). This concept analysis was supported by databases from Embase, CINAHL, and MEDLINE and was searched with the keywords: (uncertainty) AND (parent\*) AND (definition). In addition, the following criteria were used to select the article: 1) open access; 2) English-language writing; 3) publication between 1980; and 4) had a full text. In this analysis, the authors do not limit the definition of uncertainty to obtain more comprehensive and complete information about the concept of uncertainty. The steps in this study are outlined below.

### Selecting the Concept

According to Walker and Avant (2014), selecting the best concept is adjusted to the area of interest and how important and valuable the concept is for developing theory and practice

in that field. The authors reviewed and analyzed the concept of uncertainty in this study. The selection of this concept is expected to help nurses better recognize the conditions of uncertainty in parents of children with cancer, such as responses, causes, and consequences so that appropriate instruments and interventions can be provided. It is hoped that proper uncertainty management will support parents in adapting to new circumstances brought on by uncertain conditions following a childhood cancer diagnosis.

### Determining the Purpose of the Analysis

The second step in concept analysis is to define the purpose of the analysis. This second step assists in directing attention to the intended application of the analytical concept (Walker & Avant, 2014). Concept analysis in this paper aims to clarify the concept of uncertainty, particularly in the context of parents with cancer children, so that nurses can recognize these situations or conditions and respond appropriately. Furthermore, it is expected that nurses will be able to select the appropriate instrument to measure parental uncertainty.

### Identifying all Possible Uses of the Concept

Walker and Avant (2014) state that at this step, searching for as many concepts as possible can be accomplished by using dictionaries, thesaurus, colleagues, and available literature. Concept identification is not limited to just one aspect but must consider all term uses (Walker & Avant, 2014). However, limiting the search to medical literature or imposing limitations may skew the understanding of the true nature of the concept. Incorporating implicit and explicit concept use and extensive reading from as many different sources as possible will result in a more meaningful understanding (Walker & Avant, 2014).

A literature review was conducted to identify the use of the concept of uncertainty. This approach is used to comprehensively identify the concept's application in various scientific disciplines to understand the concept of parental uncertainty. The results of a literature search using predetermined keywords in three databases (Embase, CINAHL, and Medline) obtained 147 articles. These articles are from various fields, including nursing, health, medicine, psycho-oncology, and management. The articles were then selected based on inclusion criteria, and after reading the title, abstract, and full text, appropriate articles for the concept analysis were chosen.

The literature search yielded 20 articles. Nursing (seven articles), medicine (two articles), economics (three articles), psychology (three articles), management (two articles), communication (one article), psycho-oncology (one article), and public/general (one article) were the disciplines represented. The uncertainty definition is depicted in Table 1.

### Defining Attributes

The process of identifying attributes entails grouping keywords or characteristics with similar meanings, which are then clustered and labeled based on the meaning discovered (Walker & Avant, 2014). The authors recognized the concept's definition repeatedly during this stage. The authors manually utilize a table to cluster keywords with similar meanings. The authors then decide on the names or attributes reflecting each previously identified keyword cluster (Walker & Avant, 2014). The authors obtained four key attributes from 20 sources on

the topic of uncertainty. Four attributes of uncertainty were identified: (1) emotional disturbance, (2) unpredictability, (3) insufficient information, and (4) problems with decision-making. According to the findings, parental uncertainty can be

defined as the emotional disturbance experienced by parents as a result of unpredictable circumstances and insufficient information, which causes problems in decision-making. **Table 2** shows clustering attributes.

**Table 1** The concept definition of uncertainty

No	Authors	Disciplines	Definition
1.	Sheer and Cline (1995)	Public	Lack of information for decision-making: A state of lack of confidence or uncertainty about something that is not completely decided, nor is it certain or fixed. This condition also means doubting something.
2.	Toma et al. (2012)	Economy	In unpredictable conditions, the probability of outcomes is near zero.
3.	Wakeham (2015)	Risk-economic	An epistemic state at the limits of knowledge included a subjective phenomenological experience of cognitive and emotional.
4.	Knight (2013)	Economy	A result of conventional thinking, the very fast development of the world refers to things that are not known and cannot be quantified or measured.
5.	Milliken (1987)	Management-economics	Related to the problem of perception, to the unknown effects/results of an action, the unknown response from a particular environment.
6.	Funtowicz and Ravetz (1990)	Management	The situation of inadequate information: inexactness, unreliability, and bordering ignorance.
7.	Brashers (2001)	Communication	Unpredictable situation based on individual appraisal, associated with inconsistency, and/or unavailability or lack of information, providing too many choices or alternatives to unexpected outcomes.
8.	Bar-Anan et al. (2009)	Psychology	An unavoidable feature of the unpredictable world or chaotic condition refers to psychological states or phenomenological experiences.
9.	Bammer and Smithson (2012)	Psychology	Subjective experience is motivated by personality, emotions, cognitions, and decision-making problems. The main center is a lack of understanding and bias of cognitive and heuristics.
10.	Holm et al. (2013)	Psychology	Uncertainty is documented in various settings and is closely associated with impaired physical and mental health.
11.	Kasper et al. (2008)	Psycho-Oncology	Subjective experience is a person's cognitive experience – a mental state rather than an objective world aspect. A lack of knowledge of some aspect of reality entails a subjective awareness of a lack of information, a type of "metacognition"-knowledge about knowing.
12.	Han et al. (2011)	Medicine	Subjective perceptions of ignorance, which patients and healthcare professionals experience in diverse ways and to differing degrees, inspire action and evoke psychological responses.
13.	Wright et al. (2009)	Medicine	A cognitive stressor, or a doubtful perspective of a situation, evolves and arises when disease-related consequences are unpredictable, and there is a dearth of information about the disease's severity and prognosis.
14.	Mishel (1988)	Nursing	Inability to determine the meaning of events related to disease. A cognitive condition occurs when a person does not have an adequate structure or category of an event due to insufficient cues, and the decision-maker is unable to give a definitive value to an object or event and/or accurately predict consequences.
15.	McCormick (2002)	Nursing	A major component of illness understanding that will influence psychosocial adaptation and illness outcomes
16.	Penrod (2001)	Nursing	A patient's and a family member's perceived inability to assign outcomes probability is related to the period when they are uncertain about the results of a procedure or disease process.
17.	Dolbeault et al. (2011)	Nursing	A feeling of loss of control, ambiguity, a lack of clarity of information, and a dread of the unknown, has a relationship with family stress.
18.	Mullins et al. (2012)	Nursing	The interaction of objective disease events and parent's subjective assessments of probable consequences, and associated with psychological distress in parents. A major predictor of adjustment/adaptation outcomes.
19.	Cohen (1993)	Nursing	Variations in scale, intensity, and significance range from broad existential issues of life and death to the insignificance of probabilities.
20.	Kerr and Haas (2014)	Nursing	A main source of stress that affects the entire family altering family relations and quality of life.

### *Emotional Disturbance*

The first attribute is an emotional disturbance that has been refined based on definitions from Bammer and Smithson (2012); Bar-Anan et al. (2009); Kasper et al. (2008); Wakeham (2015). Parents of newly diagnosed cancer children reported emotional experiences such as shock, fear, hopelessness, and feeling overwhelmed (Benedetti et al., 2014; Lewandowska, 2021). In addition, parents feel guilty for blaming their child's illness on their actions and are concerned about their child's future (Al Yateem et al., 2017). On the other

hand, uncertainty changes over time and is accompanied by negative emotions, making unpleasant events more unpleasant (Bar-Anan et al., 2009). Uncertainty increases affective reactions to adverse events (Bar-Anan et al., 2009). This happens because uncertainty increases curiosity in emotional states, causing them to become more emotionally involved (Bar-Anan et al., 2009). Uncertainty is a multifaceted concept that encompasses emotional outcomes (McCormick, 2002).

**Unpredictability**

The second attribute of uncertainty is unpredictability. Uncertainty is a set of conditions or factors that cannot be predicted (Brashers, 2001; Toma et al., 2012). Unpredictability means that the situation or condition came suddenly and was not anticipated in advance (Bar-Anan et al., 2009) or is the result of the high-speed and rapid development of a particular situation (Knight, 2013). Uncertainty occurs when the outcomes of an illness are unpredictable due to a lack of consistency in the progression of the illness, the course of treatment, and the expected results (Wright et al., 2009). Parents of cancer children are suddenly forced to care for a seriously ill child, despite having no or very little knowledge (Lewandowska, 2021). Parents are suddenly expected to take on this responsibility despite being largely untrained and lacking the necessary skills for symptom management or medication administration. Therefore this situation increases parental uncertainty (Kars et al., 2008; Kazak et al., 2004).

**Insufficient Information**

Insufficient information is the third attribute of the concept of uncertainty. There is uncertainty when information is unavailable or inconsistent (Brashers et al., 2006). Numerous studies have found that one of the challenges in caring for cancer children is that parents are frequently unsure about how to access and participate in their child’s cancer treatment. Giving parents sufficient information about their child’s diagnosis, treatment, and complications can reduce parental anxiety. Furthermore, nurses must facilitate a normal family environment and increase parental control, particularly while children are hospitalized (Motlagh et al., 2019). Adequate and clear information helps alleviate difficulties for patients and caregivers while lowering anxiety and depression (Xie et al.,

2017). When providing information to families, their needs and preferences must be considered (Brand et al., 2017). This can be accomplished by carefully examining the responsibilities, expectations, and parent and child development levels. Parents and other family members may have different preferences depending on how much information they want to hear. The majority of parents want an adequate and clear explanation of their child’s diagnosis, projections of what the child may face in the future, and recommendations for what to do next. Parents also want the opportunity to ask questions, and nurses are expected to be open and compassionate listeners (Hockenberry et al., 2017; Landier et al., 2016).

**Problems with Decision Making**

The fourth attribute of uncertainty is problems with decision-making. Uncertainty, decision-making, and difficulties or inability to make decisions are intertwined concepts (Bammer & Smithson, 2012; Wakeham, 2015). Decision-making is a basic cognitive process that happens every day (Damjanovic et al., 2019). Uncertainty can be defined as a person’s state of mind or cognitive process when making decisions without knowing the outcomes in advance (Wakeham, 2015). Parents frequently face cognitive roadblocks during decision-making, undermining their confidence in selecting the best course of action (Damjanovic et al., 2019). The complexity of the symptoms that cancer patients and their parents experience and cognitive and interpretive limitations that lead to biased understanding all contribute to decision-making difficulties (Ruland et al., 2009). Uncertainty is an interaction function involving parents’ assessments of the potential course of a disease. This assessment, closely related to cognitive ability, determines the degree of uncertainty (Stewart et al., 2010).

**Table 2** Keyword clusters of uncertainty attributes

Keywords cluster	Sources	Attributes
<ul style="list-style-type: none"> <li>▪ Emotional experience</li> <li>▪ A feeling of loss of control</li> <li>▪ The subjective phenomenological experience of emotional</li> <li>▪ Subjective perception of ignorance</li> <li>▪ Subjective experience</li> <li>▪ Psychological experience</li> </ul>	(Bammer & Smithson, 2012; Bar-Anan et al., 2009; Han et al., 2011; Kasper et al., 2008; Wakeham, 2015; Wright et al., 2009)	Emotional disturbance
<ul style="list-style-type: none"> <li>▪ Unpredictable condition</li> <li>▪ Unpredictable situation</li> <li>▪ Unpredictable world or chaotic condition</li> <li>▪ The very fast development of the world</li> <li>▪ Cannot predict outcome accurately</li> <li>▪ Unknown effects/results of an action</li> <li>▪ No clarity of results</li> <li>▪ No clarity of effect</li> <li>▪ Unsure about the outcomes of a procedure or disease process</li> </ul>	(Bar-Anan et al., 2009; Brashers et al., 2006; Knight, 2013; Milliken, 1987; Mishel, 1988; Penrod, 2001; Toma et al., 2012)	Unpredictability
<ul style="list-style-type: none"> <li>▪ Lack of information</li> <li>▪ Unavailability or inadequate information</li> <li>▪ Insufficient cues</li> <li>▪ Insufficient information about severity and prognosis</li> </ul>	(Brashers et al., 2006; Dolbeault et al., 2011; Funtowicz & Ravetz, 1990; Kasper et al., 2008; Mishel, 1988; Sheer & Cline, 1995; Wakeham, 2015; Wright et al., 2009)	Insufficient information
<ul style="list-style-type: none"> <li>▪ Problems with decision making</li> <li>▪ Not completely decided</li> <li>▪ The decision-maker cannot assign a definite value to an object or event</li> <li>▪ Doubting about something</li> <li>▪ Lack of information for decision making</li> <li>▪ The bias of appraisal for decision making</li> <li>▪ Lack of meaning</li> <li>▪ Lack of understanding</li> </ul>	(Bammer & Smithson, 2012; Brashers, 2001; Mishel, 1988; Tas Bora & Buldukoglu, 2020)	Problems with decision making

### Model Case

V, a six-year-old boy, was referred for treatment due to fever and pallor. He was supposed to have a bone marrow puncture (BMP) test. Based on the findings of the BMP test, the doctor diagnosed him with leukemia, and he was scheduled to receive chemotherapy. With a puffy face, the patient's mother arrived at the nurse station and requested to speak with the head nurse. The head nurse took the patient's mother to her office. The patient's mother sobs and expresses sadness, shock, disbelief, and nervousness after learning that her child has leukemia and requires immediate chemotherapy. The mother stated that she had been unable to sleep for several days due to worry and confusion about her child's treatment options (attribute 1, emotional disturbance). The mother described the situation as "dream-like," with everything happening quickly, suddenly, and unexpectedly, even though her child was initially only sick with a common cold cough and did not expect to undergo chemotherapy (attribute 2, unpredictability). *"I don't know much about leukemia and why my child needs chemotherapy,"* the mother admitted. *"Yesterday, the doctor explained a little more, but I still don't understand much. I've learned a little about this disease from the parents of other patients, but I still have a lot of questions about the disease and my child's treatment"* (attribute 3, insufficient information). The mother stated that she was unsure whether or not to consent to her child receiving chemotherapy because she had not received clear information about the benefits and drawbacks of chemotherapy for her child. The mother stated that the family was still undecided about the decision to be made (attribute 4, problems with decision-making).

All definitions of the concept's attributes are displayed in the model case (Walker & Avant, 2014). The model case embodies the concept of uncertainty by incorporating all of the attributes identified in the previous stage. Patient V's mother displayed emotional disturbance by crying and expressing sadness, disbelief, anxiety, and worry. It caused the mother to be unable to sleep for several days as she considered her child's treatment options (emotional disturbance). The second attribute, unpredictability, is described in the case of a patient who was previously only mildly ill with fever and paleness, but the results of the BMP examination revealed that the child had leukemia, which the parents had not previously suspected. Furthermore, patients are advised to undergo chemotherapy, which their parents had not anticipated. The third attribute (insufficient information) is indicated by the mother's statement that there are many questions she wants to ask doctors and nurses, particularly about leukemia, the benefits of chemotherapy, and the risks of chemotherapy. The situation leaves the mother confused, unsure, and unable to decide whether or not to consent to her child receiving chemotherapy (problems with decision-making).

### Borderline Case

A six-year-old boy, V, was referred for a Bone Marrow Puncture (BPM) examination due to fever and pallor. The patient's mother came to the nurse station to talk to the head nurse. According to the mother, based on the results of the BMP, the doctor diagnosed the patient with leukemia and recommended chemotherapy. The mother cried a lot and expressed sadness, shock, and disbelief (attribute 1,

emotional disturbance) that her son had been diagnosed with cancer and required immediate chemotherapy treatment (attribute 2, unpredictability). The patient's mother stated that she and her husband had met with the doctor three times and that the doctor had thoroughly explained her child's illness, the chemotherapy procedures that the child would receive, as well as the side effects and benefits of chemotherapy. Following discussions and consultations with doctors, the patient's mother concluded that chemotherapy is currently the best option for her child, although it has numerous side effects. The mother stated that the results of discussions with doctors and other patient parents about chemotherapy convinced her and her family that the child's chemotherapy should begin immediately.

The emotional disturbance attributes are clearly stated in this borderline case, with the mother crying a lot and expressing sadness, shock, and disbelief. Furthermore, the attribute of unpredictability can be identified, as the patient's mother stated that this condition could not be predicted in advance. However, attributes 3 (insufficient information) and 4 (decision-making problems) cannot be identified because the mother states that she has received a sufficient explanation and can decide to approve the chemotherapy procedure for her child. The mother does not experience uncertainty in this borderline case because she can make clear decisions. The patient's mother's emotional disturbance could have been caused by the mother's acceptance process.

### Contrary Case

Today is a counseling appointment for the family of child patient V, who will discuss whether or not to have chemotherapy for child V. When the patient's mother appears, her husband accompanies her. The mother stated that she and her husband are now more relaxed and able to think clearly. The mother and husband said they had received adequate and clear information from doctors, nurses, parents of other patients, and reliable internet sources. The mother stated that she had predicted that chemotherapy would be the best option for her child in the end. However, after discussing and reflecting with her husband on all of the information obtained, the mother and husband concluded that chemotherapy is essential for their child at this time, so the mother and husband are certain and agree that their child will undergo the chemotherapy procedure.

The contrary case is one in which none of the identifying attributes are present. This clearly illustrates what is "not a concept" (Walker & Avant, 2014). In this case, on the other hand, the mother is not emotionally disturbed; she can adapt to the information received, think clearly, and has received enough information to make an informed decision.

### Antecedents

The concept's antecedents are events or incidents that must precede before the concept's emergence. In contrast, the concept's consequences are events or incidents that occur as a result of the concept's existence - in other words, the concept's result (Walker & Avant, 2014). Defining antecedents and consequences is critical for determining ideas, variables, or relationships that are frequently overlooked but can lead to useful new research directions in a particular field and can be very useful theoretically (Walker & Avant, 2014).

Several factors contribute to parental uncertainty. The first antecedents that cause uncertainty for parents of cancer children are the complexity of the disease, diagnosis, treatment process, and hospital environment (Malin & Johnson, 2019). Parents who have a child with cancer face a complex situation that includes the symptom of the disease, the process of diagnosing a disease that requires various laboratory tests, multimodal treatment procedures (supportive treatment, chemotherapy administration, long-term radiotherapy), and an unfamiliar hospital environment. Doctors and nurses can help parents become more familiar with their situation by describing the disease's etiology, pathogenesis, treatment procedure, and the hospital environment. In addition, providing clear information about prognosis and treatment outcomes can help parents set realistic expectations (Gyllén et al., 2019; Mishel, 1988). Furthermore, orienting parents about their surroundings, such as room ward orientation or hospital tours, can help reduce anxiety (Gyllén et al., 2019).

Communication between health practitioners, patients, and families is the second antecedent of parental uncertainty. According to Brasher's Uncertainty Management Theory, effective communication will influence one's judgment and perception of an event (Brashers et al., 2006). Effective communication can improve people's perceptions and assessments of a situation or circumstance. Fortier et al. (2013) state that increased communication between health practitioners and parents regarding their child's disease, prognosis, results, and treatment side effects will lessen parental uncertainty. Health professionals must ensure that the information conveyed to parents is well understood (Tas Bora & Buldukoglu, 2020). Health professionals can help parents reduce uncertainty by communicating effectively and ensuring that the information conveyed is not ambiguous (Tas Bora & Buldukoglu, 2020). Lastly, the third antecedent is support from a credible authority (Gyllén et al., 2019; Mishel, 1988; Wright et al., 2009). Support from resources that

patients can rely on to understand information and stimuli can give parents trust and confidence in healthcare providers. Credible health workers can increase parental trust and reduce parental uncertainty.

### Consequences

Several consequences emerge in the context of uncertainty. The first consequence is seeking out new information. Uncertainty will motivate parents to seek the necessary information (Malin & Johnson, 2019). According to Brashers (2001), uncertainty has different consequences for different people or situations. Individuals generally seek relevant information to clarify alternatives if they perceive uncertainty as dangerous. If uncertainty is viewed as a path to hope, individuals will seek information reinforcing their hope (Brashers, 2001). Parents will also seek credible authorities, in this case, trusted health workers, to help them reassess or clarify information they still have questions about (Kerr et al., 2019). Uncertain conditions affect parents' adaptability to their role as parents (Chaney et al., 2016; Mullins et al., 2016; Tackett et al., 2016). Changes in how parents fulfill their parental responsibilities are the main result of parents' uncertainty. For example, uncertain circumstances following a child's cancer diagnosis will cause parents to focus more on treating sick children, potentially neglecting siblings (Lewandowska, 2021). Parents must learn to adapt by adjusting to family goals, priorities, values, and plans soon or in the future (Lewandowska, 2021). Parents will also learn to carry out their roles in new situations, adapt to challenges, manage difficult emotions, and deal with various other conflicts when treating children with cancer (Lewandowska, 2021). Another consequence of uncertainty is parental distress. Parents' mood disorders can be exacerbated by uncertainty (Taylor Piliiae & Molassiotis, 2001). Unresolved uncertainty leads to depression, cognitive disturbances, and helplessness (Madeo et al., 2012). Figure 1 depicts the antecedents and consequences of parental uncertainty.

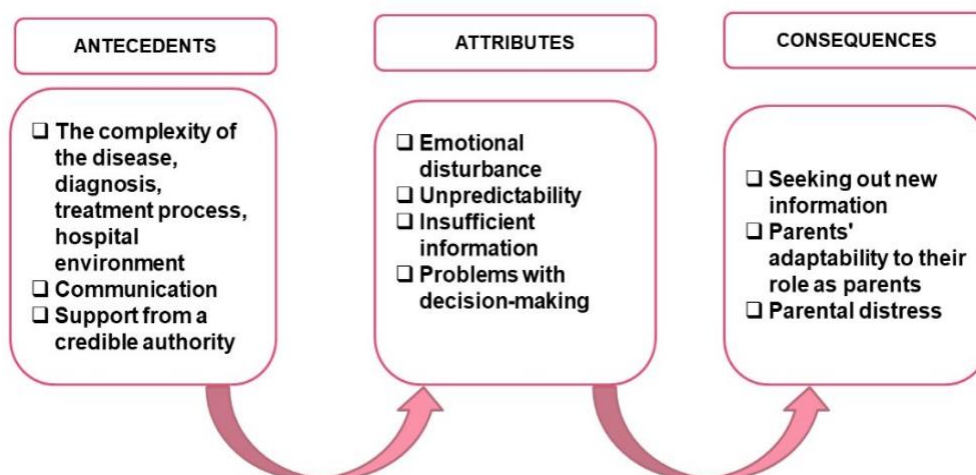


Figure 1 Uncertainty's antecedents, attributes, and consequences

### Empirical Referents

The last phase in concept analysis is to determine empirical references. Empirical references are groups or categories of actual phenomena whose presence or absence implies the

actuality of the concept itself (Walker & Avant, 2014). Empirical references are directly related to the determining attributes rather than the entire concept (Walker & Avant, 2014). In developing certain instruments, empirical references

contribute to the content and construct validity (Walker & Avanti, 2014).

Several tools, such as The Symptom Check List-90-Revised (SCL-90-R) and The State-Trait Anxiety Inventory Instrument, can be used to assess parents' emotional disturbance attributes (Sloan, 2015; Tas Bora & Buldukoglu, 2020). However, the two instruments generally measure emotional symptoms that are not specific to parents experiencing uncertainty, necessitating the development of new instruments that specifically measure symptoms or emotional changes that are specific to parents experiencing uncertainty. For example, Mishel's Parent's Perception of Uncertainty Scale-Family Member (PPUS-FM) Questionnaire can be used to assess the second (unpredictability) and third (lack of information) attributes (Mishel, 1988). The PPUS-FM instrument primarily reflects the attributes of uncertainty. The instrument includes a 'lack of information' subdomain (5 questions) and an 'unpredictability' subdomain (6 questions) that can be used to assess parents' perceptions of information adequacy and unpredictability. However, the PPUS-FM instrument cannot measure the attributes of decision-making problems. As a result, the attributes of decision-making problems must be measured using other tools, such as the analog for Parental Decision-making (APD) (Maduro, 2016). The instrument, however, assesses parental decision-making in general rather than decision-making for parents who have children with cancer. Respectively, a questionnaire regarding decision-making problems based on the factual situations and conditions experienced by parents of children with cancer may be necessary. Furthermore, because there is currently no specific instrument that measures all of the attributes of uncertainty, particularly those specific to parents who have children with cancer, modifications to existing instruments or the development of new instruments that can measure the four aspects of the concept of uncertainty in parents of children with cancer are required.

### Implications for Nursing

The uncertainty concept analysis has nursing implications for parents and families with cancer children. In the health domain, the concept of uncertainty has numerous meanings and variations. Hence it is only partially translated into clinical practice. The concept of parental uncertainty as a result of having cancer children has been clarified in this paper. The review includes the following attributes of uncertainty: emotional disturbance, unpredictability, insufficient information, and problems with decision-making. These attributes are necessary for nurses to develop evidence-based nursing care models for cancer patients and their families that emphasize respecting parents' experiences and being sensitive to parents' needs. Nurses should attempt to understand parents' views of uncertainty and provide intervention to help children and families adjust to their new circumstances. Parents may be surprised by their child's cancer diagnosis and treatment. Nurses must be prepared to help relieve this condition by providing the best possible care. Nursing interventions such as familiarizing with the environment, facilitating education, and effective communication allow parents to better adjust to their current situation. Parents should be informed about their child's condition and treatment process in a language that they

understand and at the right level of understanding for the parents. Parental uncertainty may be reduced by providing proven decision-making support services.

## Conclusion

This concept analysis identified four attributes of parental uncertainty in children with cancer: emotional disturbance, unpredictability, insufficient information, and problems with decision-making. In addition, this study found that parental uncertainty influenced parents to seek new knowledge, parental adaptability, and parental distress. The findings of this conceptual analysis can be used to develop nursing interventions for children with chronic diseases. This concept analysis can also be used to improve evidence-based care by making it more comprehensive, focusing on the needs of parents and children, and being more sensitive to parents' perceptions and views. Nurses and other health care providers must be able to recognize parental states of uncertainty to anticipate and provide appropriate interventions. These findings suggest that existing instruments be modified or developed to assess parental uncertainty more holistically and comprehensively.

### Declaration of Conflicting Interest

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### Authors' Contributions

All authors contributed to this article. Study concept and design: IN and NN; writing of the manuscript: IN and AA; critical revision of the manuscript: IN, DG, and YR. The revised manuscript was reviewed and approved by all authors.

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## Ethical Consideration

Not applicable.

## Data Availability

Not applicable.

## References

- Al Yateem, N., Docherty, C., Altawil, H., Al-Tamimi, M., & Ahmad, A. (2017). The quality of information received by parents of children with chronic ill health attending hospitals as indicated by measures of illness uncertainty. *Scandinavian Journal of Caring Sciences*, 31(4), 839-849. <https://doi.org/10.1111/scs.12405>
- Bammer, G., & Smithson, M. (2012). *Uncertainty and risk: Multidisciplinary perspectives*. London: Earthscan.
- Bar-Anan, Y., Wilson, T. D., & Gilbert, D. T. (2009). The feeling of uncertainty intensifies affective reactions. *Emotion*, 9(1), 123-127. <https://doi.org/10.1037/a0014607>
- Benedetti, G. M. d. S., Garanhani, M. L., & Sales, C. A. (2014). The treatment of childhood cancer: Unveiling the experience of parents. *Revista Latino-Americana de Enfermagem*, 22, 425-431. <https://doi.org/10.1590/0104-1169.3264.2433>
- Brand, S., Wolfe, J., & Samsel, C. (2017). The impact of cancer and its treatment on the growth and development of the pediatric patient. *Current Pediatric Reviews*, 13(1), 24-33. <https://doi.org/10.2174/1573396313666161116094916>
- Brashers, D. E. (2001). Communication and uncertainty management. *Journal of Communication*, 51(3), 477-497. <https://doi.org/10.1111/j.1460-2466.2001.tb02892.x>
- Brashers, D. E., Hsieh, E., Neidig, J. L., & Reynolds, N. R. (2006). Managing uncertainty about illness: Health care providers as credible authorities. In R. M. Dailey & B. A. L. Poire (Eds.), *Applied interpersonal communication matters: Family, health, and community relations* (pp. 219-240). Peter Lang.
- Chaney, J. M., Gamwell, K. L., Baraldi, A. N., Ramsey, R. R., Cushing, C. C., Mullins, A. J., Gillaspay, S. R., Jarvis, J. N., & Mullins, L. L. (2016). Parent perceptions of illness uncertainty and child depressive symptoms in juvenile rheumatic diseases: Examining caregiver demand and parent distress as mediators. *Journal of Pediatric Psychology*, 41(9), 941-951. <https://doi.org/10.1093/jpepsy/jsw004>
- Cohen, M. H. (1993). The unknown and the unknowable-managing sustained uncertainty. *Western Journal of Nursing Research*, 15(1), 77-96. <https://doi.org/10.1177/019394599301500106>
- Damjanovic, K., Ilic, S., Pavlovic, I., & Novkovic, V. (2019). Refinement of outcome bias measurement in the parental decision-making context. *Europe's Journal of Psychology*, 15(1), 41-58. <https://doi.org/10.5964/ejop.v15i1.1698>
- Dolbeault, S., Boistard, B., Meuric, J., Copel, L., & Brédart, A. (2011). Screening for distress and supportive care needs during the initial phase of the care process: A qualitative description of a clinical pilot experiment in a French cancer center. *Psycho-Oncology*, 20(6), 585-593. <https://doi.org/10.1002/pon.1946>
- Dunn, L. B., Aouizerat, B. E., Cooper, B. A., Dodd, M., Lee, K., West, C., Paul, S. M., Wara, W., Swift, P., & Miaskowski, C. (2012). Trajectories of anxiety in oncology patients and family caregivers during and after radiation therapy. *European Journal of Oncology Nursing*, 16(1), 1-9. <https://doi.org/10.1016/j.ejon.2011.01.003>
- Eche, I. J., & Aronowitz, T. (2018). Factors that influence parental uncertainty and health-related quality of life in children with cancer: A framework. *Nursing Science Quarterly*, 31(4), 362-368. <https://doi.org/10.1177/089431841879289>
- Eche, I. J., Aronowitz, T., Shi, L., & McCabe, M. A. (2019). Parental uncertainty: Parents' perceptions of health-related quality of life in newly diagnosed children with cancer. *Clinical Journal of Oncology Nursing*, 23(6), 609-618. <https://doi.org/10.1188/19.CJON.609-618>
- Fortier, M. A., Batista, M. L., Wahi, A., Kain, A., Strom, S., & Sender, L. S. (2013). Illness uncertainty and quality of life in children with cancer. *Journal of Pediatric Hematology/Oncology*, 35(5), 366-370. <https://doi.org/10.1097/MPH.0b013e318290cfdb>
- Funtowicz, S. O., & Ravetz, J. R. (1990). *Uncertainty and quality in science for policy*. Netherlands: Kluwer Academic Publisher.
- Gyllén, J., Magnusson, G., & Forsberg, A. (2019). Uncertainty and self-efficacy in parents of a child with congenital cataract—New implications for clinical practice. *Nursing Open*, 6(3), 799-807. <https://doi.org/10.1002/nop.2.256>
- Han, P. K. J., Klein, W. M. P., & Arora, N. K. (2011). Varieties of uncertainty in health care: A conceptual taxonomy. *Medical Decision Making*, 31(6), 828-838. <https://doi.org/10.1177/0272989X10393976>
- Hockenberry, M. J., Wilson, D., & Rodgers, C. C. (2017). *Wong's essentials of pediatric nursing* (10th ed.). St. Louis, Missouri: Elsevier Health Sciences.
- Holm, H. J., Opper, S., & Nee, V. (2013). Entrepreneurs under uncertainty: An economic experiment in China. *Management Science*, 59(7), 1671-1687. <https://doi.org/10.1287/mnsc.1120.1670>
- Kars, M. C., Duijnste, M. S. H., Pool, A., Van Delden, J. J. M., & Grypdonck, M. H. F. (2008). Being there: Parenting the child with acute lymphoblastic leukaemia. *Journal of Clinical Nursing*, 17(12), 1553-1562. <https://doi.org/10.1111/j.1365-2702.2007.02235.x>
- Kasper, J., Geiger, F., Freiberger, S., & Schmidt, A. (2008). Decision-related uncertainties perceived by people with cancer—modelling the subject of shared decision making. *Psycho-Oncology*, 17(1), 42-48. <https://doi.org/10.1002/pon.1190>
- Kazak, A. E., Alderfer, M., Rourke, M. T., Simms, S., Streisand, R., & Grossman, J. R. (2004). Posttraumatic stress disorder (PTSD) and posttraumatic stress symptoms (PTSS) in families of adolescent childhood cancer survivors. *Journal of Pediatric Psychology*, 29(3), 211-219. <https://doi.org/10.1093/jpepsy/jsh022>
- Kerr, A. M., & Haas, S. M. (2014). Parental uncertainty in illness: Managing uncertainty surrounding an "orphan" illness. *Journal of Pediatric Nursing*, 29(5), 393-400. <https://doi.org/10.1016/j.pedn.2014.01.008>
- Kerr, A. M., Harrington, N. G., & Scott, A. M. (2019). Communication and the appraisal of uncertainty: Exploring parents' communication with credible authorities in the context of chronic childhood illness. *Health Communication*, 34(2), 201-211. <https://doi.org/10.1080/10410236.2017.1399508>
- Knight, F. H. (2013). *The economic organization*. New Jersey: Transaction Publishers.
- Landier, W., Ahern, J., Barakat, L. P., Bhatia, S., Bingen, K. M., Bondurant, P. G., Cohn, S. L., Dobrozsi, S. K., Haugen, M., & Herring, R. A. (2016). Patient/family education for newly diagnosed pediatric oncology patients: Consensus recommendations from a Children's Oncology Group expert panel. *Journal of Pediatric Oncology Nursing*, 33(6), 422-431. <https://doi.org/10.1177/1043454216655983>
- Lewandowska, A. (2021). Influence of a child's cancer on the functioning of their family. *Children*, 8(7), 592. <https://doi.org/10.3390/children8070592>
- Madeo, A. C., O'Brien, K. E., Bernhardt, B. A., & Biesecker, B. B. (2012). Factors associated with perceived uncertainty among parents of children with undiagnosed medical conditions. *American Journal of Medical Genetics Part A*, 158(8), 1877-1884. <https://doi.org/10.1002/ajmg.a.35425>
- Maduro, R. S. (2016). *Understanding the determinants of parental decision-making and harsh parenting behavior* [Dissertation, Old Dominion University]. Virginia.
- Malin, K. J., & Johnson, T. S. (2019). A concept analysis of parental uncertainty in illness of an infant. *MCN: The American Journal of Maternal/Child Nursing*, 44(4), 206-211. <https://doi.org/10.1097/NMC.0000000000000535>
- McCormick, K. M. (2002). A concept analysis of uncertainty in illness. *Journal of Nursing Scholarship*, 34(2), 127-131. <https://doi.org/10.1111/j.1547-5069.2002.00127.x>
- Milliken, F. J. (1987). Three types of perceived uncertainty about the environment: State, effect, and response uncertainty. *Academy of Management Review*, 12(1), 133-143. <https://doi.org/10.5465/amr.1987.4306502>



- Mishel, M. H. (1988). Uncertainty in Illness. *Image: The Journal of Nursing Scholarship*, 20(4), 225-232. <https://doi.org/10.1111/j.1547-5069.1988.tb00082.x>
- Motlagh, M. E., Mirzaei-Alavijeh, M., & Hosseini, S. N. (2019). Information needs assessment among parents of children with cancer. *Asian Pacific Journal of Cancer Prevention: APJCP*, 20(6), 1865-1870. <https://doi.org/10.31557%2FAPJCP.2019.20.6.1865>
- Mullins, L. L., Cushing, C. C., Suorsa, K. I., Tackett, A. P., Molzon, E. S., Mayes, S., McNall-Knapp, R., Mullins, A. J., Gamwell, K. L., & Chaney, J. M. (2016). Parent illness appraisals, parent adjustment, and parent-reported child quality of life in pediatric cancer. *Pediatric Hematology and Oncology*, 33(5), 314-326. <https://doi.org/10.1080/08880018.2016.1198443>
- Mullins, L. L., Fedele, D. A., Chaffin, M., Hullmann, S. E., Kenner, C., Eddington, A. R., Phipps, S., & McNall-Knapp, R. Y. (2012). A clinic-based interdisciplinary intervention for mothers of children newly diagnosed with cancer: A pilot study. *Journal of Pediatric Psychology*, 37(10), 1104-1115. <https://doi.org/10.1093/jpepsy/jss093>
- Page, M. C., Fedele, D. A., Pai, A. L. H., Anderson, J., Wolfe-Christensen, C., Ryan, J. L., & Mullins, L. L. (2012). The relationship of maternal and child illness uncertainty to child depressive symptomatology: A mediational model. *Journal of Pediatric Psychology*, 37(1), 97-105. <https://doi.org/10.1093/jpepsy/jsr055>
- Peek, G., & Melnyk, B. M. (2014). A coping intervention for mothers of children diagnosed with cancer: Connecting theory and research. *Applied Nursing Research*, 27(3), 202-204. <https://doi.org/10.1016/j.apnr.2014.05.002>
- Penrod, J. (2001). Refinement of the concept of uncertainty. *Journal of Advanced Nursing*, 34(2), 238-245. <https://doi.org/10.1046/j.1365-2648.2001.01750.x>
- Ruland, C. M., Hamilton, G. A., & Schjødt-Osmo, B. (2009). The complexity of symptoms and problems experienced in children with cancer: A review of the literature. *Journal of Pain and Symptom Management*, 37(3), 403-418. <https://doi.org/10.1016/j.jpainsymman.2008.03.009>
- Sheer, V. C., & Cline, R. J. (1995). Testing a model of perceived information adequacy and uncertainty reduction in physician-patient interactions. *Journal of Applied Communication Research*, 23(1), 44-59. <https://doi.org/10.1080/00909889509365413>
- Sloan, C. A. (2015). *Hope, uncertainty, and coping among parents of children with cancer* [Dissertation, University of San Diego]. CA.
- Stewart, J. L., Mishel, M. H., Lynn, M. R., & Terhorst, L. (2010). Test of a conceptual model of uncertainty in children and adolescents with cancer. *Research in Nursing & Health*, 33(3), 179-191. <https://doi.org/10.1002/nur.20374>
- Tackett, A. P., Cushing, C. C., Suorsa, K. I., Mullins, A. J., Gamwell, K. L., Mayes, S., McNall-Knapp, R., Chaney, J. M., & Mullins, L. L. (2016). Illness uncertainty, global psychological distress, and posttraumatic stress in pediatric cancer: A preliminary examination using a path analysis approach. *Journal of Pediatric Psychology*, 41(3), 309-318. <https://doi.org/10.1093/jpepsy/jsv093>
- Tas Bora, S., & Buldukoglu, K. (2020). Using the Uncertainty in Illness Theory to provide care for the caregiver: A case report. *Journal of Psychiatric Nursing*, 11(1), 70-77.
- Taylor Piliae, R. E., & Molassiotis, A. (2001). An exploration of the relationships between uncertainty, psychological distress and type of coping strategy among Chinese men after cardiac catheterization. *Journal of Advanced Nursing*, 33(1), 79-88. <https://doi.org/10.1046/j.1365-2648.2001.01640.x>
- Toma, S.-V., Chiriță, M., & Șarpe, D. (2012). Risk and uncertainty. *Procedia Economics and Finance*, 3, 975-980. [https://doi.org/10.1016/S2212-5671\(12\)00260-2](https://doi.org/10.1016/S2212-5671(12)00260-2)
- Wakeham, J. (2015). Uncertainty: History of the concept. In J. D. Wright (Ed.), *International Encyclopedia of the Social & Behavioral Sciences* (2nd ed., Vol. 24, pp. 716-721). <https://doi.org/10.1016/B978-0-08-097086-8.03175-5>
- Walker, L. O., & Avant, K. C. (2014). *Strategies for theory construction in nursing* (5th ed.). Upper Saddle River, NJ: Pearson/Prentice Hall.
- Wright, L. J., Afari, N., & Zautra, A. (2009). The illness uncertainty concept: A review. *Current Pain and Headache Reports*, 13, 133-138. <https://doi.org/10.1007/s11916-009-0023-z>
- Xie, B., Su, Z., Liu, Y., Wang, M., & Zhang, M. (2017). Health information sources for different types of information used by Chinese patients with cancer and their family caregivers. *Health Expectations*, 20(4), 665-674. <https://doi.org/10.1111/hex.12498>

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