

# Uncertainty in Adolescents and Young Adults With Cancer

Carol L. Decker, PhD, MSW, Joan E. Haase, PhD, RN, and Cynthia J. Bell, BSN, MS, RN

**Purpose/Objectives:** To describe uncertainty in three groups of adolescents and young adults with cancer at specific times in their cancer experience: newly diagnosed, diagnosed one to four years, and diagnosed five or more years.

**Design:** Descriptive, cross-sectional, comparative.

**Setting:** Six pediatric oncology centers in North America.

**Sample:** 193 adolescents and young adult cancer survivors aged 11–22 years, able to read English, with no central nervous system disease.

**Methods:** A booklet of questionnaires was completed during a clinic visit or hospitalization. Uncertainty was measured using Mishel's Uncertainty in Illness Scale.

**Main Research Variables:** Uncertainty and time since diagnosis.

**Findings:** No significant differences were found in the overall level of uncertainty among the three time-since-diagnosis groups; however, analysis of variance on individual items detected significant group differences for 8 of the 33 items. Newly diagnosed survivors had significantly higher uncertainty for future pain, the unpredictable illness course, staff responsibilities, and concerns about when they would be able to care for themselves. Survivors five or more years from diagnosis had significantly higher uncertainty related to knowing what was wrong, and they had more unanswered questions and higher uncertainty compared to the two other groups about the probability of successful treatment. All of the survivors had high uncertainty about the multiple meanings of communication from doctors.

**Conclusions:** The overall level of uncertainty remained unchanged across the survivorship continuum, but differences existed in specific concerns.

**Implications for Nursing:** Uncertainty is important to consider far beyond the treatment period, particularly assessment of information needs and acknowledgment of inherent uncertainty throughout cancer survivorship.

## Key Points . . .

- Uncertainty related to cancer is an understudied but important concern for adolescent and young adult survivors of childhood cancer.
- Overall uncertainty levels did not diminish from the time of diagnosis throughout long-term survivorship for adolescents and young adults with cancer.
- Overall uncertainty levels remain high throughout the cancer experience, so healthcare providers should continue to assess the specific focus of uncertainty across the survivorship continuum.

and distress (Edwards & Clarke, 2004; Friedman, Freyer, & Levitt, 2006). Research with adults indicates that high uncertainty is linked with problems in processing new information (Gaberson, 1995; Mishel, 1990), predicting outcomes, and adapting to cancer diagnosis (Mishel, 1990). Most research in the area has been conducted in the adult population and has focused primarily on the early stages of survivorship. The current study seeks to address the gap in the understanding of uncertainty across the multiple stages of survivorship, from diagnosis through several years of treatment, in adolescent and young adult survivors.

The purpose of this cross-sectional, secondary analysis study was to describe uncertainty in three time-since-diagnosis groups of adolescents and young adults with cancer: newly diagnosed, diagnosed one to four years, and diagnosed five or more years. The time-since-diagnosis groups were chosen to reflect the different stages in the cancer experience. The term "cancer survivor" is used to describe an individual from diagnosis through the remainder of his or her life (Centers for Disease Control and Prevention, 2004). Survivorship has been divided into a series of stages: acute, extended, and permanent (Mullan, 1985). The acute stage represents the initial

Advances in the treatment of pediatric cancer have dramatically improved survival rates to 78% at the five-year point (Institute of Medicine, 2003; National Cancer Policy Board, 2003), but the outcome for individual children and adolescents remains unpredictable. Cancer now is considered a chronic illness with no definitive end point. Uncertainty throughout the cancer experience long has been identified as a significant aspect of pediatric cancer and a major concern of adolescent and young adult cancer survivors (Bearison & Pacifici, 1984; Novakovic et al., 1996; Parry, 2003; Prouty, Ward-Smith, & Hutto, 2006).

Studies of uncertainty during illness experiences such as cancer have shown that high levels of uncertainty create a stress response (Barron, 2000; Mishel, 1981), which, in turn, results in defensive coping (Haase, 2004), anxiety, fear,

*Carol L. Decker, PhD, MSW, is a postdoctoral fellow at the Walther Cancer Institute, Joan E. Haase, PhD, RN, is the Holmquist professor in pediatric oncology in the School of Nursing, and Cynthia J. Bell, BSN, MS, RN, is a predoctoral student in the School of Nursing, all at Indiana University in Indianapolis. (Submitted June 2006. Accepted for publication September 15, 2006.)*

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period after diagnosis, whereas the extended stage is the time of remission or when intense treatment has ended. During the extended stage, a survivor enters a time of periodic examinations or consolidation or intermittent therapy. The final stage, permanent, is the stage during which a patient is seen as “cured.” Although the stages do not have specific time frames, the intervals for the current study were chosen in an attempt to generally reflect the three stages of survivorship.

## Uncertainty

The unpredictability and unfamiliarity of the cancer experience can result in high levels of uncertainty, potentially affecting the quality of life of cancer survivors. Uncertainty is an “inability to determine the meaning of illness-related events and occurs in a situation in which the decision maker is unable to assign definite values to objects and events and is unable to accurately predict outcomes” (Mishel & Braden, 1988, p. 98). Three characteristics are central to the concept of uncertainty: probability, temporality, and perception (McCormick, 2002). Probability is the likelihood of something happening. In cancer, the unpredictability of treatment outcomes, prevention of recurrence, and course of illness contribute to what will happen in the illness experience. Temporality relates to the duration, pace, and frequency in relation to illness symptoms and treatment. The temporal unpredictability of such aspects affects a person’s ability to plan for the future. Perception is an explanation or sense based on knowledge of something. The perception of the cancer experience often involves a lack of a frame of reference to past experiences, which limits a person’s ability to form a cognitive structure of events, adequately appraise the situation, and select appropriate actions (Mishel, 1981, 1984). Event appraisal is important for selecting coping strategies to lessen stressful situations.

Uncertainty is inherent in the illness process (Atkinson, 1995) and can affect illness adaptation and outcomes (McCormick, 2002). Mishel’s (1990) *Uncertainty in Illness Theory* is based on Lazarus and Folkman’s (1984) stress and coping framework and builds on the chaos theory, in which uncertainty is defined as a part of the appraisal process. Uncertainty is the result of the inability to structure meaning. A person diagnosed with an illness attempts to construct a cognitive schema or a subjective interpretation of the illness, treatment, and hospitalization (Mishel, 1984). Uncertainty may be experienced in illness situations in four ways: (a) ambiguity regarding the state of the illness and symptoms, (b) complexity of the systems of care and treatment, (c) lack of information about the diagnosis and seriousness of the illness, and (d) unpredictability regarding the disease process and prognosis (Mishel, 1981).

### Uncertainty in Childhood Cancer Survivors

Research on illness-related uncertainty in children and adolescents is limited. Two qualitative studies described illness-related uncertainty. Haase and Rostad (1994) described the experiences of completing cancer treatment of seven children and adolescents aged 5–18 years who had completed treatment 2–12 months previously. The children and adolescents described uncertainty about the reasons for ending treatment, why certain aspects of treatment continued (e.g., blood tests), and what completion of treatment meant. They had continuous

fears about cancer returning, particularly when they returned to a clinic for scheduled follow-up appointments or when they experienced any symptoms that could indicate that cancer had returned. Weekes and Kagan (1994) used a similar sample of children completing cancer therapy to identify coping strategies used during the cancer experience. Strategies such as selective attention and distraction were used to deal with uncertainty throughout the cancer experience. Both studies found continued uncertainty beyond the treatment period and possibly for years beyond the end of treatment. Similarly, Novakovic et al. (1996) found that uncertainty about relapse and the future was one of the four negative aspects of cancer identified by adolescent survivors of Ewing sarcoma.

Neville (1998) explored relationships among uncertainty, social support, and psychological distress in 60 newly diagnosed adolescents (aged 14–22 years). Uncertainty was measured using Mishel’s (1981) *Uncertainty in Illness Scale* (MUIS). In that study, uncertainty predicted 30% of distress. The findings were similar to those of Mullins, Chaney, Pace, and Hartman (1997), who found that uncertainty predicted psychological distress in older adolescents and young adults with asthma.

Uncertainty was described as a significant theme in qualitative studies of adult survivors of childhood cancer. Parry (2003) found uncertainty to be linked most often to worry. Although Parry described uncertainty as a part of the larger framework of stress and coping linked to distress, some survivors also experienced uncertainty as a catalyst for positive change in self-identity and life outlook. Prouty et al. (2006) described survivors’ perceptions of the consequences of having cancer and receiving treatment for cancer. Uncertainty was a major theme for the survivors, those with severe late effects and those less affected by cancer and treatment; both groups had continuous thoughts of possible recurrence.

Uncertainty was found to be significantly correlated with post-traumatic stress symptoms (Lee, 2006) and to be a mediator between post-traumatic stress symptoms and health behaviors in adult survivors of childhood cancer (Santacroce & Lee, 2006). High uncertainty was associated with higher overall post-traumatic stress symptoms and with two of the three symptom clusters: avoidance and arousal (Santacroce & Lee). Uncertainty was found to mediate the relationship between symptoms and health-promotion behaviors such as physical activity, health responsibility, nutrition, and stress management (Santacroce & Lee). An understanding of the relationship of uncertainty to health promotion is vital. Evidence indicates that some late effects and second malignancies in survivors of childhood cancer can be prevented or minimized by health-promotion behaviors (Greving & Santacroce, 2005; Pagano-Therrien & Santacroce, 2005).

Uncertainty about the cancer experience clearly is an important concern for adolescent and young adult childhood cancer survivors and appears to continue beyond the initial diagnosis and treatment period. Similar to findings from studies of adults, uncertainty for adolescents and young adults also is related to distress. However, with the exception of Neville (1998), the samples in the studies were limited to a single point in survivorship. The samples also represented a wide range of ages and did not explore developmental differences. Additional knowledge about uncertainty for adolescent and young adult survivors of childhood cancer across the cancer experience is needed.

## Methods

Two Adolescent Resilience Model (ARM) studies were conducted to develop and test the ARM (Haase, 2004). The model includes five factors shown to be related to resilience in adolescents with cancer: individual protective factors, family protective factors, social protective factors, individual risk factors, and illness-related stress factors. This secondary data analysis study focused on the illness-related stress factor of uncertainty to examine the differences in uncertainty using a cross-sectional design with three time-since-diagnosis groups.

### Sample

ARM 1 was conducted in 1995 and used a convenience sample of adolescent cancer survivors. The survivors, aged 11–22 years, were seen at four pediatric oncology centers in North America. ARM 2, conducted from 1999–2003, also used a convenience sample of adolescents, aged 11–19 years and newly diagnosed with cancer at four pediatric oncology clinics and hospital units in the United States. The participants in the studies represented a wide range of cancer diagnoses. The combined sample ( $N = 193$ ) consisted of 106 males and 87 females, grouped into three time-since-diagnosis groups: newly diagnosed, one to four years from diagnosis, and five or more years from diagnosis.

### Procedures

Institutional review board (IRB) approval for the protection of human subjects was obtained at all sites for both studies, with additional IRB approval obtained for the secondary data analysis study described in this article. Similar procedures were used to enroll participants in ARM 1 and ARM 2. Potential participants were identified by a clinical nurse specialist or social worker in each outpatient clinic or inpatient unit. A staff member or study coordinator gave an explanation of the study to potential participants. After having an opportunity to ask questions about the study, adolescents provided written consent and received a booklet of questionnaire instruments. Participants were asked to complete the booklet while they were in the hospital or clinic. Completion of the booklet took approximately one hour, and participants were encouraged to take breaks. If a participant was unable to finish the instruments during a clinic visit or hospital stay, he or she took the booklet home and returned it by mail, using a study-provided stamped and addressed envelope.

The booklet consisted of multiple survey instruments to measure the various factors in the ARM, as well as a demographics section. The data from the MUIS from the two ARM studies were used to conduct the statistical analysis for the current study.

### Instrument

The MUIS was selected for the ARM studies based on consistency of the items with the earlier qualitative studies of adolescents, scale psychometric properties, and clinical appropriateness (Haase, Heiney, Ruccione, & Stutzer, 1999). The MUIS, a Likert-type scale with 33 items, initially was designed to measure uncertainty and stress associated with hospitalization but has been used extensively with people who have cancer. The MUIS has been used in several studies with children as young as seven years (Neville, 1998; Yarcheski,

1988). Although the scale items can be combined to represent two or four factors, the two-factor interpretation was used in the current study because it has demonstrated a more consistent reliability (Neville). The first subscale, ambiguity, contains 16 items related to illness, such as “I can predict how long my illness will last.” The second factor, complexity, contains 12 items about the perception of treatment and the medical care system, such as “The purpose of each treatment is clear to me” and “There are so many different types of staff, it’s unclear who is responsible for what.” The MUIS is completed by responding to the items using the response choices 1 (strongly agree) to 5 (strongly disagree). Some of the items were reverse coded so that high scores on all of the items indicated high uncertainty. The total uncertainty score is a summation of all of the items.

For this study, total scale reliability using Cronbach  $\alpha$  was 0.91 for ARM 1 and ARM 2. For the ambiguity subscale, the Cronbach  $\alpha$  was 0.77 for ARM 1 and 0.81 for ARM 2. For the complexity subscale, Cronbach  $\alpha$  was 0.87 for ARM 1 and 0.85 for ARM 2. These are consistent with the reliabilities for the MUIS reported in other studies.

### Data Analysis

Prior to analysis, the data were examined for outliers, normality, missing data, linearity, and homoscedasticity. Univariate descriptive statistics were inspected for accuracy of data input, out-of-range values, credible means and standard deviations, and univariate outliers; all were acceptable. Because the study used a combined sample from the two ARM studies, the two samples were examined for significant differences in gender, age, and ethnicity, with none detected. Additional analyses found no significant age or gender differences for the three time-since-diagnosis groups, although the group diagnosed for five or more years had significantly more Hispanics. Analysis of variance (ANOVA) was used to determine any significant differences for uncertainty and the two uncertainty dimensions based on ethnicity; none was found. ANOVA was conducted to determine any significant differences in levels of total uncertainty and the two uncertainty dimensions (ambiguity and complexity) for the three time-since-diagnosis groups. Additional analyses were conducted to identify item differences based on time since diagnosis.

## Results

Data from 193 adolescents and young adults with cancer were used to examine time-since-diagnosis differences for uncertainty measured with the MUIS. Table 1 presents the demographics of the sample.

No significant differences were detected for total uncertainty or for ambiguity or complexity among the three time-since-diagnosis groups. However, ANOVA to compare the three time-since-diagnosis groups on the individual items detected significant time-since-diagnosis group differences for 8 of the 33 items (see Table 2). Although a summed score of the items on a scale traditionally is used to best reflect the concept of interest, the analysis of individual items sometimes can provide important information for clinical settings (Hinds, Schum, & Srivastava, 2002).

Newly diagnosed adolescent and young adult survivors had significantly higher uncertainty (compared to one or both of the other two time-since-diagnosis groups) on items about future pain, the unpredictable course of illness, and staff



Table 1. Sample Demographics

Characteristic	Newly Diagnosed (N = 81)		Diagnosed One to Four Years (N = 54)		Diagnosed Five or More Years (N = 58)	
Age (years)						
X	15.0		16.0		16.2	
Range	11–21		12–21		12–22	
Characteristic	n	%	n	%	n	%
Gender						
Female	34	42	29	54	24	43
Male	47	58	25	46	34	57
Race						
Caucasian	48	59	26	48	29	50
African American	4	5	4	7	3	5
Asian	4	5	4	7	2	3
Hispanic	12	15	14	26	18	32
Other	8	10	3	6	3	5
Missing	5	6	3	6	3	5

responsibilities, as well as concerns about when they would be able to care for themselves. Survivors five or more years from diagnosis had significantly higher uncertainty compared to the newly diagnosed adolescents related to knowing what was wrong, and they had more unanswered questions and higher uncertainty compared to both other groups about the probability of successful treatment. Newly diagnosed survivors and those diagnosed five or more years ago had higher uncertainty about finding something else wrong with them.

Tables 3 and 4 show the five items with the highest and lowest uncertainty scores for each of the time-since-diagnosis groups. Three items were evident in all three groups for the highest uncertainty: “Because of the treatment, what I can do and cannot do keeps changing,” “The doctors say things to me that could have many meanings,” and “I can predict how long my illness will last.” Both the newly diagnosed and those diagnosed for one to four years reported high uncertainty on the item “The course of my treatment keeps changing. I have good days and bad days.” Two different items were ranked for high uncertainty by the adolescents diagnosed for five or more years: “I have a lot of questions without answers” and “My physical distress is predictable; I know when it is going to get better or worse.”

For the lowest ranked items, less consistency existed. Only the item on knowing what was wrong with them was ranked for low uncertainty for all three groups. Again, the newly diagnosed survivors and those diagnosed one to four years ago were more similar than those five or more years from diagnosis. The former group ranked the items on the dependability of nurses, the treatment having a known probability of success, and being given a specific diagnosis for lowest uncertainty. The survivors five or more years from diagnosis had low uncertainty about being able to plan for the future and being able to care for themselves.

Discussion

This study examined time-since-diagnosis differences in uncertainty for three groups of adolescent and young adult

cancer survivors. The findings indicate that, regardless of time since diagnosis, the survivors had similar levels of overall uncertainty and for the two dimensions of uncertainty, ambiguity, and complexity. This was true even for survivors many years after treatment ended. Information derived from comparison across the groups for individual items provided insights into differences in the nature of uncertainty.

Uncertainty in Long-Term Survivors

Surprisingly, for the survivors five or more years from diagnosis, uncertainty was significantly higher than for the other two groups on how illness or treatment affects their daily lives, the predictable success of treatment, predicting the length of illness, and having a lot of unanswered questions. Despite the fact that their treatments ended years earlier, the findings indicate that many adolescents and young adults continued to have uncertainty related to their cancer and long-term effects on their lives. Rolland’s (2005) Family Systems Illness Model may provide a useful framework to view the group differences. The model describes the illness process as dynamic, unfolding over time, and requiring different psychosocial developmental tasks, depending on the phase of illness: crisis, chronic, or terminal. The adolescents and young adults diagnosed for five or more years could be considered to be in the chronic phase, which requires individuals to live with anticipatory loss, uncertainty, and awareness of possible effects on current and future life cycles.

The authors are particularly concerned that the adolescents and young adults diagnosed for five or more years continued to have many unanswered questions. They no longer spent extended time in a medical center but, instead, experience sporadic reminders of their cancer experiences. They likely had less contact with others with similar experiences or medical staff, reducing the opportunity to cognitively process illness-related events by talking about the events with significant others, including healthcare providers (Lepore & Helgeson, 1998). Patient-provider communication is described as a major resource for uncertainty management (Mishel et al., 2005), and the longer-term survivors had less opportunity to ask questions and manage their uncertainty through interaction with healthcare providers.

Uncertainty in Newly Diagnosed Survivors

The uncertainty differences for the newly diagnosed adolescents and young adults compared to one or both of the other two groups make sense for those early in the cancer experience. They included the items on the unpredictability of pain, staff responsibilities, changing course of illness, and when they could resume their previous levels of self-care. Rolland (2005) described that time in the cancer experience as the crisis phase, which requires readjustment and adaptation to the diagnosis and treatment. Patients have several developmental tasks during the phase, including developing a working relationship with healthcare providers, adapting to treatments and healthcare settings, and accepting the potential permanency of illness. Newly diagnosed adolescents are thrust into the unfamiliar environment of an oncology center. They must interact with adults in new roles and have medical discussions about treatment options, survival rates, and possible side effects, both short term and long term. All of the activities are likely to underscore the uncertainty of the cancer experience. Mishel and Braden’s (1988) antecedents to uncertainty (unpredictable

**Table 2. Total Uncertainty, Complexity, and Ambiguity Subscales, and the Items With Significant Differences for Uncertainty as a Function of Time Since Diagnosis**

Item	Newly Diagnosed (N = 81)		Diagnosed One to Four Years (N = 54)		Diagnosed Five or More Years (N = 58)		F	Post Hoc <sup>a</sup>
	$\bar{X}$	SD	$\bar{X}$	SD	$\bar{X}$	SD		
Total uncertainty	2.32	0.56	2.13	0.53	2.26	0.70	1.500	–
Complexity subscale	2.22	0.59	2.13	0.54	2.26	0.71	0.670	–
Ambiguity	2.41	0.61	2.14	0.65	2.26	0.81	2.670	–
The treatment I am receiving has a known probability of success.	1.79	0.83	1.78	0.89	2.40	1.23	7.360**	2 > 0, 1
I don't know what's wrong with me.	1.44	0.73	1.54	0.87	1.97	1.08	6.240**	2 > 0
I have a lot of questions without answers.	2.09	0.98	2.42	1.35	2.95	1.43	8.160**	2 > 0
They have not given me a specific diagnosis.	1.60	0.85	1.48	0.79	2.00	1.20	4.460*	2 > 0, 1
It is unclear how bad my pain will be.	2.81	1.27	2.21	1.07	2.03	1.24	8.070**	0 > 1, 2
There are so many different types of staff; it's unclear who is responsible for what.	2.58	1.07	1.98	1.03	2.43	1.23	4.560*	0 > 1
The course of my illness keeps changing. I have good days and bad days.	3.58	1.30	2.88	1.35	2.70	1.50	7.760**	0 > 1, 2
It is difficult to determine how long it will be before I can care for myself.	2.52	1.13	2.00	0.96	1.95	1.09	5.225**	0 > 1, 2

\*  $p < 0.05$

\*\*  $p < 0.01$

<sup>a</sup> 0 = newly diagnosed, 1 = diagnosed one to four years, 2 = diagnosed five or more years

symptom patterns, unfamiliar events, and issues related to credible authority) may be most evident throughout the crisis phase of the cancer experience.

The adolescents and young adults in the study indicated low uncertainty levels for some items. Newly diagnosed survivors were optimistic about the success of treatment, knew their diagnoses, and had a good understanding of the seriousness of the illness. They also indicated that they could count on the nurses when needed. The adolescents and young adults felt well informed about their illness and treatment and believed that supportive people were there for them when needed. Studies of hope in adolescents may provide some insight into these findings. A longitudinal study of adolescents with cancer, newly diagnosed through six months later, reported consistently high levels of hope throughout that time period (Hinds et al., 1999). Other studies have shown a high correlation between high levels of hope and low uncertainty in various chronic illnesses (Wineman, Schwetz, Zeller, & Cyphert, 2003). Newly diagnosed adolescents may use hope to manage levels of uncertainty as they adjust to the life changes involved with cancer diagnosis and treatment. Consistent with the low uncertainty for support from nurses, several nursing behaviors have been reported to foster hopefulness (and, thus, low uncertainty) in adolescents, including believing in the patient's future, being supportive, and giving truthful explanations (Hinds, 1988; Hinds, Martin, & Vogel, 1987).

### Uncertainty in Survivors One to Four Years After Diagnosis

The survivors one to four years after diagnosis had the lowest uncertainty on most items compared to the other two groups. They had completed the most intensive treatment or completed treatment altogether yet still received intensive

follow-up, returning to the medical setting on a regular basis. Having moved from the crisis phase of the cancer experience, these survivors are likely to have had time to develop some type of relationship with healthcare providers, adapt to their treatments and healthcare settings, and accept the potential permanency of illness. However, they still remained uncertain about the meaning of any pain, the unpredictability of physical distress, and the changing course of illness.

### Uncertainty and Healthcare Providers' Communication

All of the survivors in the study indicated high uncertainty about the multiple meanings of communication from doctors. The researchers cannot ascertain exactly what the multiple meanings represented. They may have been the result of confusing information from the same doctor or conflicting information from different doctors. It also may be a question of what participants remembered from past discussions compared to more recent ones. Over time, additional knowledge about the long-term effects of cancer treatment became available, so the confusion may have been the result of updated knowledge. Whatever the explanation, the communication problems highlight the need for effective communication because careful and sensitive communication has been linked to increased compliance (Higginson & Costantini, 2002; Ptacek & Ptacek, 2001) and decreased distress (George & Hutton, 2003; Higginson & Costantini; Mack & Grier, 2004; Masera et al., 2003). In fact, healthcare providers' communication and support were described as having the strongest influence on uncertainty in Mishel and Braden's (1988) study of women receiving treatment for gynecologic cancer. The findings suggest the importance of providers' communication and support for cancer survivors throughout their treatment and long-term follow-up.

**Table 3. Top Five Item Rankings of Highest Uncertainty Means by Time-Since-Diagnosis Groups**

Item	Newly Diagnosed	Diagnosed One to Four Years	Diagnosed Five or More Years
The course of my illness keeps changing. I have good days and bad days.	1	2	–
Because of the treatment, what I can do and cannot do keeps changing.	2	3	5
I can generally predict the course of my illness.	3	–	–
The doctors say things to me that could have many meanings.	4	1	2
I can predict how long my illness will last.	5	3	1
My physical distress is predictable; I know when it is going to get better or worse.	–	–	4
I have a lot of questions without answers.	–	–	2
When I have pain, I know what this means about my condition.	–	5	–

An alternate explanation for the multiple meanings of provider communication was offered by Cohen (1993), who described the mechanisms used by parents of children with chronic, life-threatening illnesses to manage their uncertainty. For managing information, parents used a variety of techniques, one of which was to limit the amount and type of information they were given. The parents also managed information by discounting it, which was accomplished in three ways. One was to disbelieve information from what were perceived as unreliable sources. Another way information was discounted was having an experience with a failed medical prediction, not an uncommon situation in the course of cancer treatment. To a young person, if the doctors were wrong once, they could be wrong again. Finally, information was discounted using a very human mechanism and one common to the adolescent developmental stage: to believe in one's own uniqueness, maintaining the feeling of invulnerability. Similarly, adolescents and young adults with cancer also may limit their intake of information in various ways at different times in their cancer experiences. The needs of the group five or more years from diagnosis (needing more information and having more questions) may be explained by the uncertainty management strategies.

All of the survivors also indicated high uncertainty about the length of their illness. Cancer as a chronic illness differs from most other chronic illness in the absence of day-to-day reminders such as symptoms, medications, dietary needs, and other treatments (Ginsberg, Hobbie, Carlson, & Meadows, 2006; McKenzie & Crouch, 2004). However, follow-up by medical providers still is required. Thus, although being in remission for five years is considered being "cured," continued monitoring and follow-up send a different message about health status.

**Limitations**

Although the cross-sectional design in the current study provided an adequate sample to examine uncertainty for three time-since-diagnosis groups, a longitudinal study examining uncertainty would have provided a better understanding of patterns of uncertainty over time. If the sample size had been larger, additional analysis of ethnic differences also would have been useful.

Another concern regarding the study is the use of data collected during two different time periods, particularly in light of the proliferation of information available on the Internet. If high uncertainty was the result of lack of available information during the earlier studies, the time difference could be significant. However, the items of high uncertainty for those five or more years from diagnosis did not reflect a lack of information as much as the difficulties in predicting continued remission or the effects of illness or treatment on their daily lives, as well as clarifying the multiple meanings from providers.

Another concern in the study is the use of the MUIS, which originally was designed to measure uncertainty for people in the hospital or receiving medical treatment. An additional scale, the Mishel Uncertainty in Illness Scale–Community Form (MUIS-C), was adapted from the MUIS for use in alternate situations. The MUIS-C would have been more appropriate for some of the subjects in the current study but not all of them. For consistency, the MUIS was used in both ARM studies to measure uncertainty.

**Clinical Implications**

For adolescent and young adult survivors of cancer, overall levels of uncertainty did not diminish as they moved farther from diagnosis and treatment. To help survivors manage uncertainty, healthcare providers should continue to provide as clear and accurate information as possible because open communication has been found to provide comfort and reassurance. Lack of open communication was found to be an obstacle to the development of successful relationships between healthcare providers and children and adolescents with cancer or brain tumors (Young, Dixon-Woods, Windridge, & Heney, 2003). Young et al. found that some of the children and adolescents reported a preference that their parents receive medical information first without their presence; others, who were left out of discussions, believed they were not given the same information as their parents, resulting in a feeling of being marginalized. Staff may need assistance to elicit the understanding of treatment and follow-up requirements by adolescent and young adults with cancer. Using open-ended questions, such as "Tell me about (your thoughts, feelings)," rather than asking for specific knowledge, often is most helpful to facilitate discussions. To lessen the uncertainty regarding multiple meanings, healthcare providers should clarify what adolescents and young adults remember and understand from past medical discussions as well as current ones. Although healthcare providers are aware that information about treatments and late effects is updated constantly, survivors may not always realize that changes may be the result of information obtained from recent research.

Uncertainty about the responsibilities of different staff members can be reduced through repeated assessment of adolescents' and young adults' knowledge about staff responsibilities. This

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**Table 4. Lowest Five Item Rankings of Low Uncertainty Means by Time-Since-Diagnosis Groups**

Item	Newly Diagnosed	Diagnosed One to Four Years	Diagnosed Five or More Years
I can depend on the nurses to be there when I need them.	29	29	–
The treatment I am receiving has a known probability of success.	30	31	–
The seriousness of my illness has been determined.	31	–	31
They have not given me a specific diagnosis.	32	33	–
I don't know what is wrong with me.	33	32	29
I am unsure if my illness is getting better or worse.	–	30	31
Because of the unpredictability of my illness, I cannot plan for the future.	–	–	31
It is difficult to determine how long it will be before I can care for myself.	–	–	29

is especially important in large medical centers and teaching hospitals where medical teams can include medical students, residents, staff physicians, consulting specialists, nurse aides, floor nurses, clinical nurse specialists, and nurse practitioners. Other strategies include providing written descriptions of the roles of healthcare providers and using identification that clearly shows each staff member's position. Newly diagnosed adolescents and their parents may benefit from healthcare providers reminding them of their positions and roles at the beginning of each interaction. For example, an intern on the inpatient unit might say when entering the room, "I am Dr. W, an intern, and I'll be doing a physical assessment and asking you some questions so I can let the staff physician, Dr. S., know how you are doing today."

For adolescents and young adults who are several years off treatment, healthcare providers should continue to develop relationships that communicate the need for adolescents and young adults to develop self-management and advocacy skills during the long-term survivorship period. Older adolescents should begin taking responsibility for communicating health concerns and providing accurate history of their diagnoses and treatments as they approach adulthood and the transition to adult systems of care. Healthcare providers can facilitate the process by communicating directly with adolescents and young adults throughout clinic visits regardless of the presence of parents. For younger children and adolescents, parents

routinely assume the roles of advocate and information seeker; as the children and adolescents begin to move toward older adolescence, the survivors need to assume the roles. One way to facilitate this is to provide adolescents and young adults with an opportunity to ask questions and express concerns without their parents present because they may be reluctant to discuss sensitive information or take a more active role in their parents' presence.

## Future Research Directions

Additional research is needed to provide information on how and when to provide appropriate information to adolescents and young adults with cancer to reduce illness-related uncertainty. For example, if adolescents and young adults receive orientation to a hospital or clinic at diagnosis, when should it be provided? How often should additional information be given? What is the best way to provide this information?

Future research on illness-related uncertainty for adolescents and young adult survivors of childhood cancer is needed to obtain additional information on how they manage uncertainty. Such information would assist healthcare providers in designing intervention studies to facilitate uncertainty management. Validation of the Uncertainty in Illness Theory for this population requires additional research because findings from adult studies may not apply to this population. Additional research is needed to explore the relationship of uncertainty to outcomes such as distress, resiliency, responsibility for self-care, and other factors. Understanding uncertainty in adolescents and young adults who are five or more years from diagnosis is particularly important because survivors of childhood cancer must continue to obtain appropriate follow-up in their adult years, to enhance knowledge of late effects from cancer treatment and to monitor health risks.

Management of uncertainty is important, but some level of uncertainty always will exist for cancer survivors. Mishel (1990) described the importance of significant others (including healthcare providers) in supporting the acceptance of uncertainty as a part of reality as opposed to something that can and should be eliminated. For adolescents and young adults newly diagnosed with cancer, reducing uncertainty about the unpredictability of illness (including how they will feel day to day, when they will have pain, and when they will assume more self-care responsibilities) may not be possible. Providing appropriate information and support and discussions of other patients' experiences may serve to reduce uncertainty, but uncertainty will remain an inherent part of survivors' experiences despite the best efforts of healthcare providers.

**Author Contact:** Carol L. Decker, PhD, MSW, can be reached at [carol.decker@iupui.edu](mailto:carol.decker@iupui.edu), with copy to editor at [ONFEditor@ons.org](mailto:ONFEditor@ons.org).

## References

- Atkinson, P. (1995). *Medical talk and medical work*. London: Sage.
- Barron, C.R. (2000). Stress, uncertainty, and health. In V.H. Rice (Ed.), *Handbook of stress, coping, and health: Implications for nursing research, theory, and practice* (pp. 517–539). Thousand Oaks, CA: Sage.
- Bearison, D.J., & Pacifici, C. (1984). Psychological studies of children who have cancer. *Journal of Applied Developmental Psychology*, 5, 263–280.
- Centers for Disease Control and Prevention. (2004). *A national action plan for cancer survivorship: Advancing public health policy*. Retrieved July 9, 2004, from <http://www.cdc.gov/cancer/survivorship/survivorpdf/plan.pdf>
- Cohen, M.H. (1993). The unknown and the unknowable: Managing sustained uncertainty. *Western Journal of Nursing Research*, 16(1), 77–96.
- Edwards, B., & Clarke, V. (2004). The psychological impact of a cancer



- diagnosis on families: The influence of family functioning and patients' illness characteristics on depression and anxiety. *Psycho-Oncology*, 13, 562–576.
- Friedman, D.L., Freyer, D.R., & Levitt, G.A. (2006). Models of care for survivors of childhood cancer. *Pediatric Blood and Cancer*, 46, 159–168.
- Gaberson, K.B. (1995). The effect of humorous and musical distraction on preoperative anxiety. *AORN Journal*, 62, 784–788, 790–791.
- George, R., & Hutton, S. (2003). Palliative care in adolescents. *European Journal of Cancer*, 39, 2662–2668.
- Ginsberg, J.P., Hobbie, W.L., Carlson, C.A., & Meadows, A.T. (2006). Delivering long-term follow-up care to pediatric cancer survivors: Transitional care issues. *Pediatric Blood and Cancer*, 46, 169–173.
- Greving, D.M., & Santacroce, S.J. (2005). Cardiovascular late effects. *Journal of Pediatric Oncology Nursing*, 22, 38–47.
- Haase, J.E. (2004). The Adolescent Resilience Model as a guide to interventions. *Journal of Pediatric Oncology Nursing*, 21, 289–299.
- Haase, J.E., Heiney, S.P., Ruccione, K., & Stutzer, C. (1999). Research triangulation to derive meaning-based quality-of-life theory: Adolescent resilience model and instrument development. *International Journal of Cancer*, 12, 125–131.
- Haase, J.E., & Rostad, M. (1994). Experiences of completing cancer therapy: Children's perspectives. *Oncology Nursing Forum*, 21, 1483–1492.
- Higginson, I.J., & Costantini, M. (2002). Communication in end-of-life cancer care: A comparison of team assessments in three European countries. *Journal of Clinical Oncology*, 20, 3674–3682.
- Hinds, P. (1988). The relationship of caring behaviors of nurses with hopefulness and health care outcomes of adolescents. *Archives of Psychiatric Nursing*, 2, 21–29.
- Hinds, P., Martin, J., & Vogel, R. (1987). Nursing strategies to influence adolescent hopefulness during cancer. *Journal of Pediatric Oncology Nursing*, 4, 14–22.
- Hinds, P., Schum, L., & Srivastava, D.K. (2002). Is clinical relevance sometimes lost in summative scores? *Western Journal of Nursing Research*, 24, 345–353.
- Hinds, P.S., Quargnenti, A.G., Fairclough, D.L., Bush, A.J., Betcher, D., Rissmiller, G., et al. (1999). Hopefulness and its characteristics in adolescents with cancer. *Western Journal of Nursing Research*, 21, 600–620.
- Institute of Medicine. (2003). *Childhood cancer survivorship: Improving care and quality of life*. Retrieved September 2, 2003, from <http://www.nap.edu/openbook/0309088984/html/R1.html>
- Lazarus, R.S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.
- Lee, Y.L. (2006). The relationships between uncertainty and post-traumatic stress in survivors of childhood cancer. *Journal of Nursing Research*, 14, 133–141.
- Lepore, S.J., & Helgeson, V.S. (1998). Social constraints, intrusive thoughts, and mental health after prostate cancer. *Journal of Social and Clinical Psychology*, 17, 89–106.
- Mack, J.W., & Grier, H.E. (2004). The day one talk. *Journal of Clinical Oncology*, 22, 563–566.
- Masera, G., Beltrame, F., Corbetta, A., Fraschini, D., Adamoli, L., Jankovic, M., et al. (2003). Audio taping communication of the diagnosis of childhood leukemia: Parents' evaluation. *Journal of Pediatric Hematology/Oncology*, 25, 368–371.
- McCormick, K.M. (2002). A concept analysis of uncertainty in illness. *Journal of Nursing Scholarship*, 34, 127–131.
- McKenzie, H., & Crouch, M. (2004). Discordant feelings in the lifeworld of cancer survivors. *Health*, 8, 139–157.
- Mishel, M. (1981). The measurement of uncertainty in illness. *Nursing Research*, 30, 258–263.
- Mishel, M. (1984). Perceived uncertainty and stress in illness. *Research in Nursing and Health*, 7, 163–171.
- Mishel, M. (1990). Reconceptualization of the Uncertainty in Illness Theory. *Image—Journal of Nursing Scholarship*, 22, 256–262.
- Mishel, M., & Braden, C.J. (1988). Finding meaning: Antecedents of uncertainty in illness. *Nursing Research*, 37, 98–103, 127.
- Mishel, M., Germino, B.B., Gil, K.M., Belyea, M., Laney, I.C., Stewart, J.L., et al. (2005). Benefits from an uncertainty management intervention for African American and Caucasian older long-term breast cancer survivors. *Psycho-Oncology*, 14, 962–978.
- Mullan, F. (1985). Seasons of survival: Reflections of a physician with cancer. *New England Journal of Medicine*, 313, 270–273.
- Mullins, L.L., Chaney, J.M., Pace, T.M., & Hartman, V.L. (1997). Illness uncertainty, attributional style, and psychological adjustments in older adolescents and young adults with asthma. *Journal of Pediatric Psychology*, 22, 871–880.
- National Cancer Policy Board. (2003). *Childhood cancer survivorship: Improving care and quality of life*. Washington, DC: National Academies Press.
- Neville, K. (1998). The relationships among uncertainty, social support, and psychological distress in adolescents recently diagnosed with cancer. *Journal of Pediatric Oncology Nursing*, 15, 37–46.
- Novakovic, B., Fears, T., Wexler, L., McClure, L., Wilson, D., McCalla, J., et al. (1996). Experiences of cancer in children and adolescents. *Cancer Nursing*, 19, 54–59.
- Pagano-Therrien, J., & Santacroce, S.J. (2005). Bone mineral density decrements and children diagnosed with cancer. *Journal of Pediatric Oncology Nursing*, 22, 328–338.
- Parry, C. (2003). Embracing uncertainty: An exploration of the experiences of childhood cancer survivors. *Qualitative Health Research*, 2, 227–246.
- Prouty, D., Ward-Smith, P., & Hutto, C.J. (2006). The lived experience of adult survivors of childhood cancer. *Journal of Pediatric Oncology Nursing*, 23, 143–151.
- Ptacek, J.T., & Ptacek, J.J. (2001). Patients' perceptions of receiving bad news about cancer. *Journal of Clinical Oncology*, 19, 4160–4164.
- Rolland, J.S. (2005). Cancer and the family: An integrative model. *Cancer*, 104(11, Suppl.), 2584–2595.
- Santacroce, S.J., & Lee, Y.L. (2006). Uncertainty, post-traumatic stress, and health behavior in young adult childhood cancer survivors. *Nursing Research*, 55, 259–266.
- Weekes, D.P., & Kagan, S. (1994). Adolescents completing cancer therapy: Meaning, perception, and coping. *Oncology Nursing Forum*, 21, 663–670.
- Wineman, N.M., Schwetz, K.M., Zeller, R., & Cyphert, J. (2003). Longitudinal analysis of illness uncertainty, coping, hopefulness, and mood during participation in a clinical drug trial. *Journal of Neuroscience Nursing*, 35, 100–106.
- Yarcheski, A. (1988). Uncertainty in illness and the future. *Western Journal of Nursing Research*, 10, 401–413.
- Young, B., Dixon-Woods, M., Windridge, K.C., & Heney, D. (2003). Managing communication with young people who have a potentially life threatening chronic illness: Qualitative study of patients and parents. *BMJ*, 326, 305.