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Cooperation with Treatment in Adolescents with Cancer

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COOPERATION WITH TREATMENT IN ADOLESCENTS WITH CANCER

by

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VITA

The author, Joanna Kentes, is the daughter of Milton C. Kentes and Dena (Pantelis) Kentes. She was born on May 1, 1961 in St. Louis, Missouri.

Her elementary education was obtained in the public schools of St. Louis, Missouri and Palos Heights, Illinois. Her secondary education was completed in 1979 at Alan B. Shepard High School, Palos Heights, Illinois.

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CHAPTER I

PROBLEM

Introduction

The health care professions have made great strides in incorporating advanced technology and new, more effective treatments into practice over the past 20 years. What must be recognized, however, is that the efforts of health care providers cannot achieve the outcomes intended without patient cooperation. Cooperation requires that a person change his behavior in some way, either by incorporating new behaviors or by omitting unhealthy ones. Since this is often a difficult task, cooperation is a significant and widespread problem among every age group, race, and sex.

Webster defines the word "cooperate" as follows: "To act or work together with others for a common purpose" (p.312). Other words cross-referenced under "cooperation" in Roget's Thesaurus are "voluntary" and "participation". The terms "adherence", "therapeutic alliance", "conformity", and "compliance" are often used interchangeably with cooperation. "Compliance" is often used among health professionals. The definition given by the McMaster University Symposium on Compliance is "the extent to which the patient's behavior (in terms of taking medication, following diets or executing other lifestyle changes) coincides with the clinical prescription"

(Blum, 1984, p. 144). This will be the conceptual definition of cooperation used in this study. Cooperation will be the term used predominantly, due to a more positive connotation than compliance. Cooperation can be characterized in various ways. It is an act of human behavior and as such is voluntary. If cooperation were not voluntary, it would constitute coercion (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1982).

Cooperation is also a unique and unpredictable phenomenon. Researchers have not been able to predict exclusively which patients will cooperate with prescribed therapy. The circumstances associated with cooperation also allude identification. Cooperation may vary over time with certain individuals and be fairly predictable in others.

Every age, sex, race, disease, and income level has problems with cooperation. Thus, another characteristic of cooperation is its universality.

Problems associated with cooperation have been with us ever since Eve tempted Adam with the famous apple. Hippocrates also reported the existence of this issue in ancient Greece, stating, "The physician should keep aware of the fact that patients often lie when they state that they have taken certain medicines" (Haynes, Taylor, & Sackett, 1979, p. 3). Thus in transcending time, cooperation may be characterized as an omnipresent concept.

It may be said then, from the characteristics cited, that cooperation is a unique, personal, and unpredictable act of choice associated with following recommendations of health care providers. It remains a universal and everpresent health care issue (Dolgin et al., 1986).

Cooperation is a significant concern associated with the nursing care of the adolescent population, as the major developmental task during this period is to develop a strong, autonomous decision-making identity. This explains the basis for the rebellious, uncooperative behavior seen during this period, but it can not be ignored, because of the potential consequences. Jay, Litt, and DuRant (1984) state the following about adolescent behavior:

> We who care for adolescents are constantly faced with the stereotypes of adolescents as abusers of nonprescription drugs on the one hand and abusers of prescribed drugs on the other hand. These commonly held beliefs often result in a different standard of care for this age group since this problem has only recently undergone serious study and many questions remain unanswered. (p. 124)

The diagnosis of cancer was chosen as a focus for study because it is a particularly life-threatening disease and because cooperation with treatment could improve disease outcomes and the effectiveness of therapy. Tebbi, Cummings, Zevon, Smith, Richards, and Mallon (1986) state that therapy outcomes for certain malignancies such as leukemia are less favorable in adolescents than in younger children, and that

noncompliance may be an explanation for these poorer outcomes. Thus, the research study at hand is important in terms of possible future impact on the prognosis of cancer in adolescents.

Research Questions

The general question to be addressed in this study, is: "What factors are associated with cooperation in adolescents with cancer?" Specifically, the factors of age, self-concept, and perception of cancer will be examined as they relate to cooperation. Hypotheses are:

1. There will be a relationship at the $p \leq .05$ level between age and self-concept.

2. There will be a relationship at the $p \leq .05$ level between age and perception of cancer.

3. There will be a relationship at the $p \leq .05$ level between age and the patient's rating of cooperation.

4. There will be a relationship at the $p \leq .05$ level between age and the nurse's rating of cooperation.

5. There will be a relationship at the $p \leq .05$ level between self-concept and perception of cancer.

6. There will be a relationship at the $p \leq .05$ level between self-concept and the patient's rating of cooperation.

7. There will be a relationship at the $p \leq .05$ level

between self-concept and the nurse's rating of cooperation.

8. There will be a relationship at the $p \leq .05$ level between perception of cancer and the patient's rating of cooperation.

9. There will be a relationship at the $p \leq .05$ level between perception of cancer and the nurse's rating of cooperation.

10. There will be a relationship at the $p \leq .05$ level between cooperation as rated by the nurse and cooperation as rated by the patient.

11. The findings from this study will support the work of Jamison et al. (1986).

Theoretical Framework

This study through its descriptive correlational design will attempt to explicate the concept of cooperation among adolescents with cancer. It will attempt to confirm the findings of Jamison et al. (1986) and will expand their previous study to include patient perceptions of cancer. The assumption is made that the tools used by Jamison et al. (1986) are reliable and valid.

Summary

Cooperation is a unique, personal, unpredictable act of choice in following the recommendations of health care providers and is a significant concern in the adolescent population with cancer. Cooperation with treatment may improve disease outcomes and the effectiveness of therapy, and is therefore a significant subject for research.

CHAPTER II

REVIEW OF THE LITERATURE

The Jamison Study

Many factors have been associated with cooperation, and have been examined in adolescents, with conflicting results. This study will be a partial replication of a study by Jamison, Lewis, & Burish (1986), in which the variables of age, self-concept, and perception of disease (among others) were examined in 27 adolescents with various diagnoses of cancer. The authors discovered that younger adolescents appeared to be more cooperative than older adolescents (r = -.35, p < .05), that there was a significant positive relationship between cooperation and self-concept (r = -.37 to -.61, p <.05), and that patients rated high in cooperation perceived cancer to be a more life-threatening disease than patients rated low in cooperation (r = .52, p <.01). Cronbach's alpha for the Cooperation Scale = .87 (for the sum of both raters; 20 items).

Limitations of the Jamison et al. (1986) study include a relatively small sample size. Replication of the results in a different population and part of the country would strengthen the external validity of the

study. Replication of Jamison et al.'s findings will support the generalizability of the results.

Jamison et al. (1986) also compared self-image and perception of illness in 31 adolescents with cancer to 203 healthy adolescents. A one-way ANOVA indicated that there were no differences between groups in terms of self-image. They also discovered that cancer patients perceived their disease to be significantly less severe ($p < .01$), better understood by doctors ($p < .001$), and gave themselves a higher probability of recovery compared to normals ($p < .001$). No reliabilities were reported for any of the tools. The authors concluded that cancer does influence health perception among adolescents with the disease, but does not contribute to a lower self-image. Again, the study's sample size was small, and external validity is dependent on verification of the findings in future studies.

Other Studies of Adolescents With Cancer

Cohen (1986) retrospectively studied the cases of 17 adolescents with cancer who refused all or part of their therapy over a six-year period. Using a chart review, the reasons given for noncompliance by these patients included religious convictions, prolonged medication therapy, busy schedules, painful procedures, interference with work, and burden to the family. This was a case

study design with a small sample. Standardized tools were not used to measure characteristics of these adolescents, and reliability data were not reported.

Dolgin, Katz, Doctors, and Siegel (1986) studied primary attending physicians' perceptions of barriers to patient cooperation and their ratings of patient cooperation in groups of adolescents with cancer in two settings: an inner city hospital with a small pediatric oncology service and a major pediatric cancer referral center. A Caregiver's Questionnaire was developed to collect information regarding the characteristics of the disease, details of the treatment regimen, and perception of patient cooperation. Interrater reliability on this scale was .90. In the first study, only 55.5% of adolescents were given a cooperation rating of "good" or "very good" by their physicians. Barriers to cooperation were identified as severe side effects and treatment related disfiguration, poor prognosis, and lengthy duration of treatment. In the major referral center setting, over 80% of adolescents were rated "good" or "very good" compliers by their physicians, and cooperation problems were attributed to treatment side effects, poor family and social supports, denial of illness severity, and lack of belief in the treatment's efficacy. Patients' ratings of their own behavior were not assessed. There is no assurance that caregivers'

evaluative comments agreed with those of patients. This is a limitation of the study. In addition, there may have been different motivating factors in the pursuit of treatments between groups in the two settings, i.e., the group at the major referral center may have been more motivated to cooperate at the outset, as evidenced by their seeking more aggressive therapy or more experienced specialists. They may also have had different types of disease processes or disease which did not require referral to a major medical center.

Tebbi et al. (1986) extensively interviewed 46 children and adolescents with cancer and their parents to determine if cooperation with home chemotherapy could be related to factors such as age, knowledge of medication, understanding of disease, complexity of the regimen, etc. Using Chi-square and one-way ANOVA analyses, they discovered that older adolescents were cooperative less often than younger adolescents (for patients on chemotherapeutic agents, $p = .05$; for patients on all medications $p = .02$). They also found no significant relationship between cooperation and stage of disease, number or type of drugs used, complexity of the regimen, understanding of the disease or treatment, belief in the medication efficacy, or degree of satisfaction with information given to the patient at the $p < .05$ level. No reliability data was reported for the questionnaire.

These results do not support the findings of Dolgin et al. (1986) previously discussed.

Studies Examining Age and Cooperation

Several studies have examined age as it relates to cooperation in adolescents with other chronic illnesses such as diabetes, asthma, and scoliosis, as well as general appointment-keeping. Those that cite a decrease in cooperation with increasing age are Gurnham (1983, among 55 adolescents with scoliosis and kyphosis, $p = .05$), and Irwin, Millstein, and Shafer (1981, among 245 adolescents, $p < .01$ using Chi-square). Studies by Hamburg and Inoff (1982, among 211 diabetic children and adolescents, $p \leq .05$ using ANOVA) and Litt and Cuskey (1984, among 38 adolescents with Juvenile Rheumatoid Arthritis, using descriptive statistics) have found increased cooperation in older adolescents. Chryssanthopoulos, Laufer, and Torphy (1983, examining the plasma theophylline levels of 33 asthmatic children and adolescents) found no significant relationship between cooperation and age at the $p < .05$ level. No correlations or reliability data were reported in any of the studies. No generalizations can be made with respect to the variable of age from recent research.

Studies Examining Self-Concept and Cooperation

Table 1 describes the findings from a number of studies related to self-concept and cooperation.

Table 1

Summary of Studies Examining Self-Concept and Cooperation

Author	Year	n	r	p	Alpha	Finding
Friedman et al.	1986	25	.39-.52	<.01-.05	.69-.82	Positive self-concept associated with better cooperation
Litt & Cuskey	1984	38	N/A	N/A	N/A	" "
Litt et al.	1982	38	N/A	<.05-.005	.71-.93	" "
Neel et al.	1985	55	N/A	<.008-.005	.79,.81	" "
Simonds et al.	1981	52	N/A	< .05	N/A	No significant relationships

Nearly all the studies associate a better self-concept with higher ratings of cooperation. Only one study found no significant relationships. No studies have associated a positive self-concept with poor cooperation. The findings from the literature suggest

Studies Examining Perceptions of Disease and Cooperation

Except for Jamison et al. (1986), only one other study (Bobrow, AvRuskin, & Siller, 1985) examined perceptions of disease in adolescents with chronic disease. In interviewing 50 female diabetic adolescents and their mothers, Bobrow and colleagues found poorer cooperation in those adolescents who had less strong beliefs that adherence to therapy would delay/avoid complications of their disease (r = .51, $p \leq .001$ with interrater reliabilities of .84 to .97). Additional research is needed to clarify what is known about perception of disease and cooperation.

Summary

In summary, there has been a minimal amount of research done to identify factors influencing cooperation with treatment in adolescents with cancer. Data from various populations need to be generated in order to be able to draw conclusions about adolescents with cancer so that their cooperation can be understood. The present study will attempt to replicate Jamison et al.'s study (1986), as support for the findings in a new population will lend credence to their generalizability. The factors selected for measurement (age, self-concept, and perception of cancer) were identified from the review of the literature.

CHAPTER III

METHODOLOGY

Sample

Subjects were a convenience sample of adolescent cancer patients between the ages of 12 and 18 years, receiving treatment as outpatients of Wyler Childrens' Hospital oncology clinic (at the University of Chicago), who had been diagnosed with various types of cancer for at least three months. This is the same criteria used for sampling as the Jamison (1986) study. Twenty-five adolescents were approached by the principal investigator in the clinic and asked to participate. None of the subjects refused. Subjects were assigned an identification number, and only grouped data were reported to maintain confidentiality. Informed consent was obtained from all adolescents, and those under 18 years of age co-signed the consent form with a parent or guardian. Adolescents who were 18 years of age signed the consents alone (see Appendix D). Subjects were informed as to the nature and purpose of the study by the principal investigator as stated on the consent forms. This was a study with negligible physical or psychological risk to its participants. Institutional

review board approval was obtained from both Loyola University of Chicago and the University of Chicago.

Measures

Several tools were used to measure cooperation, self-concept, and perception of cancer. These questionnaires were distributed to the adolescents and completed during their clinic visits. In addition, a clinical nurse specialist who was familiar with each adolescent's behavior completed the cooperation scale in order to provide a basis for comparison of perceptions between patients and caregivers.

Measures of Cooperation

The cooperation scale was devised and first used in the Jamison (1986) study. This 17-item scale was composed of factors identified by the Vanderbilt University Hospital Pediatric Oncology Team that were thought to measure cooperation in adolescent cancer patients. Six other health professionals were asked to rate which of the 17 items best measured cooperation, and the ten items which had a consensus of 50% or greater were accepted for the current scale (see Appendix F). Each item is rated on a scale from 1 (not at all) to 5 (a great deal). Interrater reliability from Jamison's study

ranged from .79 to .97 for the cooperation scale, and internal consistency was .87 (Cronbach's alpha).

A parallel scale was created by this investigator to allow the adolescents to rate themselves, as this measurement was not made in Jamison's study (see Appendix E). Support for the validity of adolescents' self-assessment of their cooperation may be found in research by Litt (1985), who stated that 75% of adolescents who described themselves as cooperative were accurate in terms of their behavior six months later. This may have important implications for predicting adolescents at risk for uncooperative behavior. Initial estimates of reliability indicated that item # 8 ("Asks questions about his or her illness and/or treatment") appeared to be measuring a different domain than the other items. Thus, it was deleted from the scale. Internal consistency for the nine-item scale using Cronbach's alpha was .71 for the nurse-rated cooperation scale and .43 for the patient-rated cooperation scale. Reliabilities for Jamison et al.'s logical categories of task and emotive items were also computed. The task-item group (# 1, 2, 5, 6, and 10) showed reliabilities of .81 for the nurse-rated scale and .58 for the patient-rated scale. The reliability of the emotive items (#3, 4, 7, 8, and 9) was lower than the total scale (.14 for the nurse-rated scale and .09 for the patient-rated scale).

The cooperation scale appears to be measuring more than one domain of cooperation. Only the task items warrant consideration as a reliable scale. Interrater reliability was not assessed since only one nurse rated all the adolescents in the present study.

Measure of Perception of Cancer

The perception of cancer scale is a questionnaire designed to measure beliefs and attitudes toward cancer (see Appendix H). It was first developed by Michielutte and Diseker in 1982 and tested on 295 normal seventh graders. Perceptions of cancer are measured in a manner similar to the original Semantic Differential for Health developed by Jenkins (1966). It is a seven-point scale which asks the adolescents to rate the intensities of their beliefs for each of six items. No reliability data are discussed in Jamison's (1986) or in Michielutte & Diseker's (1982) studies. Internal consistency was evaluated on this tool in the present study, again, by the use of Cronbach's alpha. Initial analysis suggested item # 4 (which assessed the perception of the powerfulness of cancer) was measuring another domain. The reliability of the scale without this item was .40. Subsequent analyses were performed on the five item scale. This scale is determined to be of questionable reliability. Estimates of reliability of five-item

scales in a sample of this size are often misleading. Further evidence of reliability and validity will require testing in other samples.

Measure of Self-Concept

Self-concept was measured by use of the Piers-Harris Children's Self-Concept Scale (1969), a dichotomous, 80-item questionnaire which is less lengthy than the Offer Self-Image Questionnaire used in the Jamison (1986) study. It was originally standardized in the 1960's on 1,183 children in grades 4-12 from one school district in Pennsylvania (see Appendix G). Test-retest reliabilities from recent studies have ranged from .42 to .96, with a mean of .73. Internal consistency has ranged from .88 to .93 on the total scale. Thus, the instrument appears to be highly reliable with respect to stability and internal consistency. Estimates of content, criterion-related, and construct validity from many empirical studies have generally been acceptable. The reliability and validity of the Piers-Harris Children's Self-Concept Scale was assumed for this study. More studies like the present one will lend further support to its reliability and validity.

Procedures

The study design was descriptive correlational, and the data collection procedures used were as follows:

1. Parents and their adolescents were approached by the principal investigator when they came for their clinic appointments.

2. Parents and adolescents were informed about the study and asked to participate. Questions were answered as they arose.

3. Written consent was obtained from all adolescents, and from parents whose adolescents were younger than 18 years old, who consented to participate (see Appendix D).

4. Age was recorded and a number assigned to each subject to maintain confidentiality.

5. The adolescents were given a copy of the Cooperation Scale, the Piers-Harris Children's Self-Concept Scale, and the Perception of Cancer scale to complete confidentially while at the clinic. They were told to answer each question honestly and were reassured that no names would be used in the study.

6. A clinical nurse specialist who was familiar with the adolescent's behavior and with the study completed another copy of the Cooperation scale for later comparison.

7. Subjects and their families were thanked for their participation in the study after the tools were collected.

Limitations

Limitations of the present study include a small sample size, convenience sampling, non-randomization, and a non-experimental design. The questionable reliability and validity of the Cooperation and Perception of Cancer scales and the validity of one nurse making judgments about patient cooperation are also issues to be considered. A further limitation of the sample is that the subjects may have been more motivated than other populations due to the nature of therapy given and the esteemed reputation of the medical center. There was also a lack of homogeneity within the sample, i.e., various diagnoses of cancer, sex, ages, developmental stages, and stages of illness existed which could impact on cooperation.

Summary

Subjects were a convenience sample of adolescent cancer patients between the ages of 12 and 18 years, receiving treatment as outpatients of Wyler Childrens' Hospital oncology clinic (at the University of Chicago), who had been diagnosed with various types of cancer for

at least three months. Twenty-five adolescents participated; none refused. Questionnaires were used to measure cooperation, self-concept, and perception of cancer, and were completed by the adolescents during clinic visits. Patient cooperation was also assessed by a clinical nurse specialist who was familiar with the adolescents' behavior. One item was deleted from both the Cooperation and Perception of Cancer scales to improve their reliabilities, as they were found to be questionable on this criterion. The reliability and validity of the Piers-Harris Children's Self-Concept Scale was assumed for this study, as it is a standardized tool. Limitations of the study included sample size, sampling procedure, non-randomization, non-experimental design, reliability and validity of the Cooperation and Perception of Cancer tools, validity of one nurse making assessments of patient cooperation, and heterogeneity of the sample.

CHAPTER IV

RESULTS

Sample Characteristics

Twenty-five adolescents with cancer between the ages of 12 and 18 years (mean age 14.7 years) were studied. All patients were receiving treatment at the Pediatric Outpatient Oncology Clinic at the University of Chicago Hospital, Chicago, Illinois. The sample (11 females and 14 males) included 11 patients with acute lymphoblastic leukemia, 5 with osteogenic sarcoma, 2 each with Wilm's tumor and Hodgkin's disease, and one each with Burkitt's lymphoma, rhabdomyosarcoma, neuroblastoma, non-Hodgkin's lymphoma, and a cranial tumor. There were 18 caucasians and 7 negroes in the sample. All patients were being followed as outpatients, all had undergone chemotherapy, and all had experienced painful procedures such as spinal taps, bone marrow biopsies, and venipunctures. All adolescents in the study had been diagnosed with cancer for at least three months.

Data Analysis

Descriptive statistics were used to identify the characteristics of the sample. The research questions

were used as the framework for the statistical data analysis.

Pearson Product Moment Correlations were used to determine relationships between the variables of age, patient-rated cooperation, nurse-rated cooperation, perception of cancer, and self-concept, as these variables yield interval data. A significance level of $p \leq .05$ was established because of the small sample size (Polit & Hungler, 1983). In addition, t-tests were used to determine significant difference in nurse-rated cooperation scores by sex, and in patient-rated cooperation scores by sex. T-tests were also used to determine a significant difference (at $p \leq .05$) between nurse-rated and patient-rated cooperation scores for the two age ranges, 12 to 15 year olds (younger adolescents) and 16-18 year olds (older adolescents.) A two-way ANOVA was employed to assess significant interactions between nurse-rated cooperation, patient-rated cooperation, perception of cancer, and total self-concept by sex and grouped age.

Results and Discussion of Research Questions

All adolescents were rated by themselves and by the nurse as being at least moderately cooperative, i.e., the median scores were 38 (patient-rated) and 40 (nurse-rated) with a score of 45 possible. The mean nurse-rated

cooperation score was 38.9 (range 26-45) and the mean patient-rated cooperation score was 37.3 (range 27-45). Similar scores were reported by Jamison et al. (1986), who stated that their sample of adolescents were at least moderately cooperative when rated by nurses. Patient-rated cooperation was not assessed in Jamison's study.

No significant relationships were found at the $p < .05$ level between:

1. Age and self-concept.
2. Age and perception of cancer.
3. Age and patient's rating of cooperation.
4. Age and nurse's rating of cooperation.
5. Self-concept and perception of cancer.
6. Self-concept and patient's rating of cooperation.
7. Self-concept and nurse's rating of cooperation.
8. Perception of cancer and patient's rating of cooperation.
9. Cooperation as rated by the nurse and cooperation as rated by the patient.

A significant positive relationship was found between the perception of cancer and the nurse's rating of patient cooperation ($r = .55$, $p = .005$). However, the reliability of the perception of cancer scale was .40. This makes the relationship identified quite tentative. Jamison et al. (1986) did not identify this relationship.

Results of correlations computed for all variables are found in Table 2.

Table 2

Correlation Matrix of All Variables

	AGE	NTOT	PTOT	NTASK	PTASK	PCPT	SCR	SCP
AGE	----	----	----	----	----	----	----	----
NTOT	.14	----	----	----	----	----	----	----
PTOT	-.18	.31	----	----	----	----	----	----
NTASK	.32	.83	.02	----	----	----	----	----
PTASK	-.17	.25	.74	.10	----	----	----	----
PCPT	-.06	.34	.03	.55*	.01	----	----	----
SCR	-.26	.22	.36	.15	.21	.22	----	----
SCP	-.27	.21	.35	.15	.20	.23	.99	----

Note. NTOT = Nurse-rated cooperation (all items)

PTOT = Pt.-rated cooperation (all items)

NTASK = Nurse-rated coooperation (task items)

PTASK = Pt.-rated cooperation (task items)

PCPT = Perception of Cancer

SCR = Self-concept (raw score)

SCP = Self-concept (percentile score)

*p = .005

These findings do not support those of Jamison et al. (1986), who found: (a) a negative correlation between age and (nurse-rated) cooperation, (b) a positive correlation between age and self-image (self-concept), and (c) a positive correlation between (nurse-rated) cooperation and self-image (self-concept) at the $p \leq .05$ level in a similar sample.

Results of Post-Hoc Analyses

Using *t*-tests, patient-rated cooperation scores when differentiated by sex approached significance at $p = .058$. Thus, cooperation scores for males were arithmatically higher than those of females. Although significance was not achieved in this study, this factor should be given attention in future studies as significance may be found in a more substantial sample. No other significant differences were found using either *t*-tests or two-way ANOVA.

Discussion

Several things must be noted in regards to this sample's performance on the cooperation scale, the perception of cancer scale, and the Piers-Harris Children's Self-Concept Scale.

On the nurse-rated cooperation scale, 76% of the sample had an average item score of 4 or above (1 = "not

at all", 5 = "a great deal"). On the patient-rated cooperation scale, 68% of the sample had an average item score of 4 or above. This suggests that adolescents and the nurse perceive the adolescents as cooperative. Further refinement of the scale to differentiate between levels of cooperation may be useful. Additional items need to be generated in the task-oriented and emotion-oriented groups to increase the internal consistency of the scale. This might be done by interviewing groups of adolescents to discover concepts, ideas, behaviors, etc. which they perceive as being relevant or not relevant to cooperation with treatment, and obtaining consensus on items among several groups of adolescents.

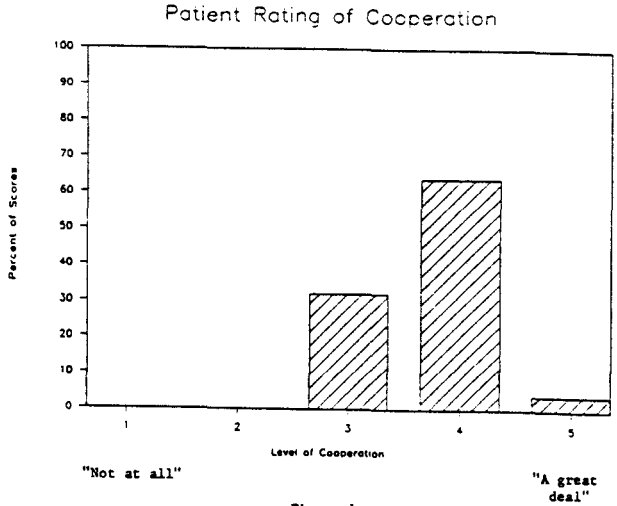

Figure 1

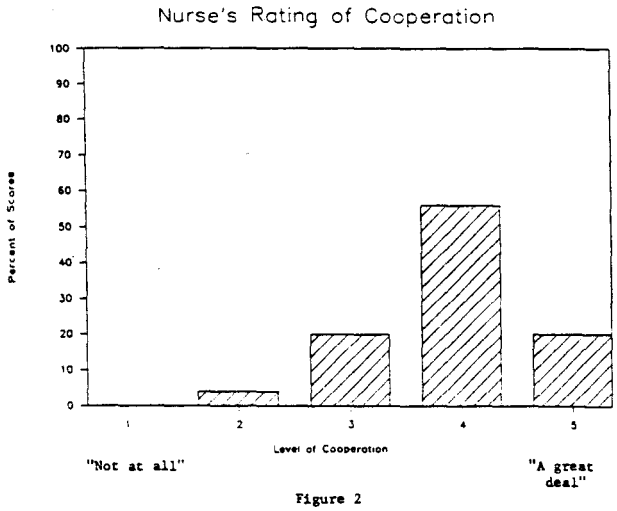

Figure 2

On the perception of cancer scale, there was a high variance (SD $\pm$ 4.67) between scores with a median score of 18 (score of 35 possible). Thus, no generalizations can be made regarding the intensity of this sample's perceptions of cancer. One might expect that after having had such strong personal experiences with cancer that these adolescents might perceive cancer as being more powerful, more severe, etc., and therefore might tend to mark lower response options than would a healthy sample. This did not occur, however, and may indicate a poor ability to discriminate among perceptions of cancer using this tool. Denial may have also been a factor here, with the adolescents being overly optimistic about the course of their illnesses, or the scores may have resulted from a problem with the tool. The reliability of the scale in this study was .40, which impacts on the tool's validity. (No reliability and validity data for this scale were reported in Jamison et al., 1986.)

Again, the perception of cancer scale needs further refinement and testing in both healthy and non-healthy populations.

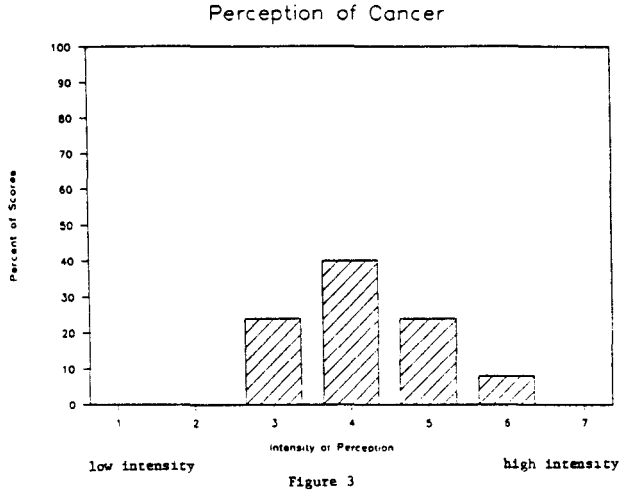

Figure 3

On the Piers-Harris Children's Self-Concept Scale, a widely used and validated tool, scores were classified according to parameters in the Piers-Harris manual (1984, p.37). Table 3 below describes the parameters used.

Table 3

Classification of Scores on the Piers-Harris

Classification	Score by Percentile
"well below average"	0 - 16
"slightly below average"	17 - 30
"average"	31 - 70
"slightly above average"	71 - 83
"well above average"	84 - 100

All adolescents rated themselves as having a generally good self-concept. Two-thirds of the sample scored in the "average" range and one-third scored in the "well above average" range.

Using a confidence level of 95%, all of the subjects in this sample were found to have scored within two standard deviations of the standardized mean for the Piers-Harris scale. This indicates that the sample in this study can be considered representative of the general population to which this tool applies.

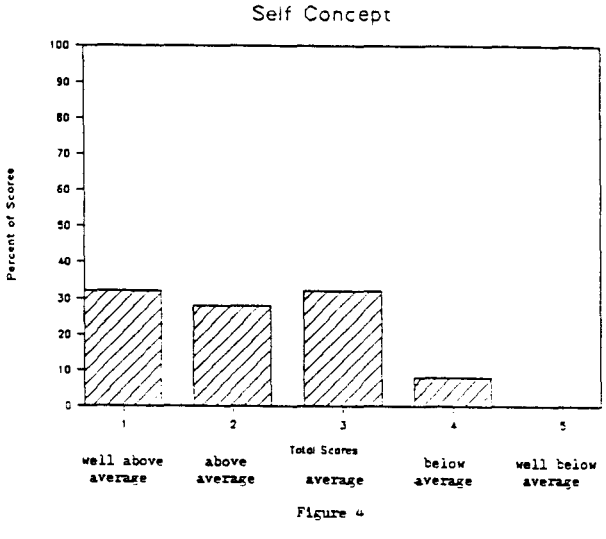

Figure 4

This scale also includes six subscales which bear discussion, in order to more adequately describe the sample under study.

Results and Discussion of Self-Concept Subscales

On the Behavior subscale, which measures overall cooperation in the adolescent's life, 72% scored "well

above average", 24% were in the "average" or "slightly above average" categories, and 4% scored "well below average." There is agreement with the cooperation scale in the high percentage of "well above average" scores, but it is interesting that the cooperation scale showed no "below average" scores at all. It may be presumed that an adolescent who behaves poorly in general would also likely be uncooperative with his or her treatment. This is further indication that the cooperation scale may require some adjustment if it is to more accurately discriminate between levels of cooperation.

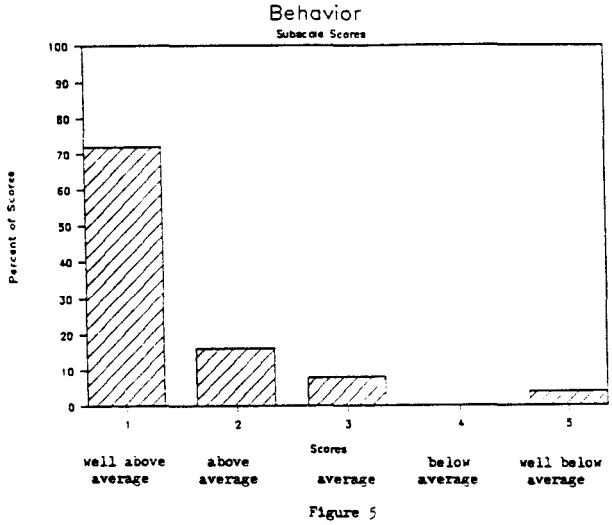

Figure 5

On the Intellectual and School Status subscale, which measures general satisfaction with school and future expectations, 48% scored "well above average", 48% were "slightly above", "average", or "slightly below" average, and only 4% rated themselves "well below

average." Again, this indicates a sample with a generally positive self-concept.

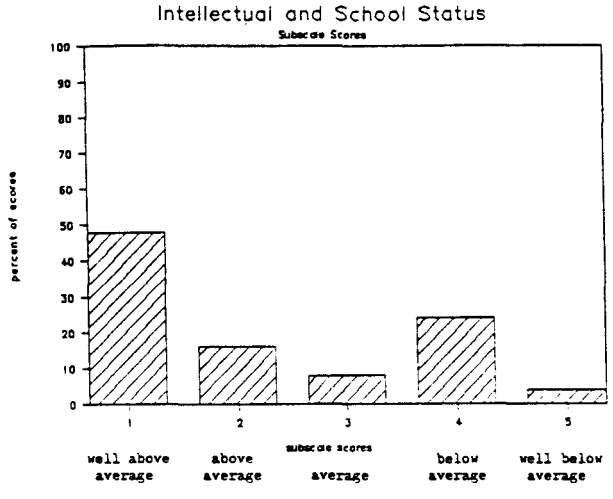

Figure 6

On the Physical Appearance and Attributes subscale, which reflects the adolescent's attitudes toward his/her physical characteristics and body image, 52% scored in the "average" range (including slightly above and slightly below), with 32% being "well above average" and 16% being "well below average." It is surprising that nearly a third of this sample scored "well above average" on this subscale, considering that cancer treatment produces some very unattractive physical characteristics (alopecia, weight loss, amputations, etc.) This is consistent with the Perception of Cancer scale findings, i.e., that the adolescents had generally positive outlooks about their disease.

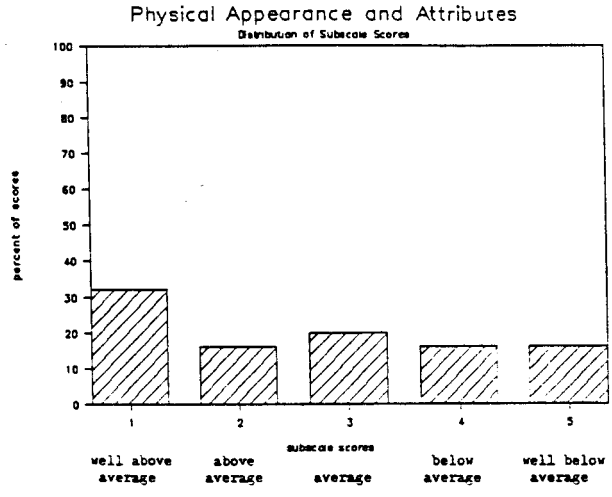

Figure 7

With respect to Anxiety, which measures a variety of feelings including worry, shyness, sadness, and fear, a full 40% of the sample scored "well below average", another 40% scored in the "average" range, and only 20% scored "well above average." Among this sample of relatively stable outpatients, it is notable that so many admit to emotional disturbances. Repeated findings in the literature indicate that cancer patients deny and repress their emotions to a greater degree than do other people (McHugh, 1985).

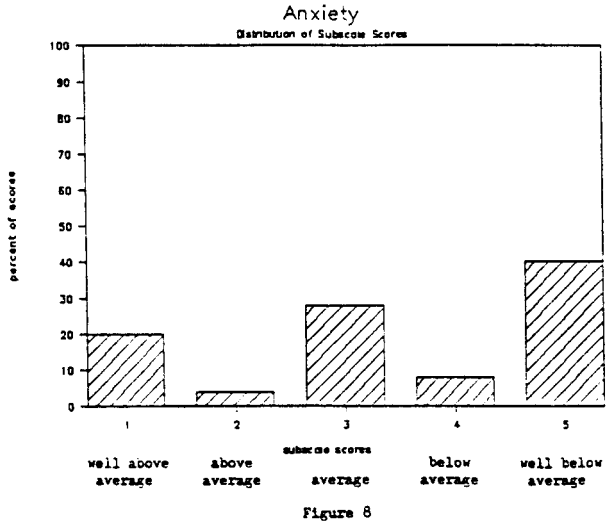

Figure 8

On the Popularity subscale, which reflects the adolescent's perceived popularity among classmates and friends, 60% scored in the "average" range, 12% scored "well above average", and 28% scored "well below average." This is a fairly normal distribution, and may suggest that most of these adolescents maintain adequate peer support.

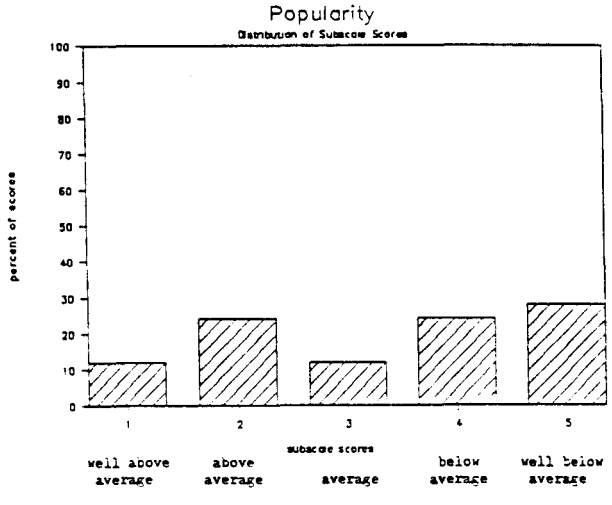

Figure 9

The final subscale, Happiness and Satisfaction, reflects the degree to which the adolescent is happy and satisfied with life. On this subscale, 44% were in the "average" range, with 24% rating themselves as "well above average" and 32% scoring "well below average." This generally positive distribution of attitudes is surprising considering the life-threatening illness which faces these adolescents. Those who rate themselves "well above average" in this area may be expressing denial, relief, strong optimism, or satisfaction.

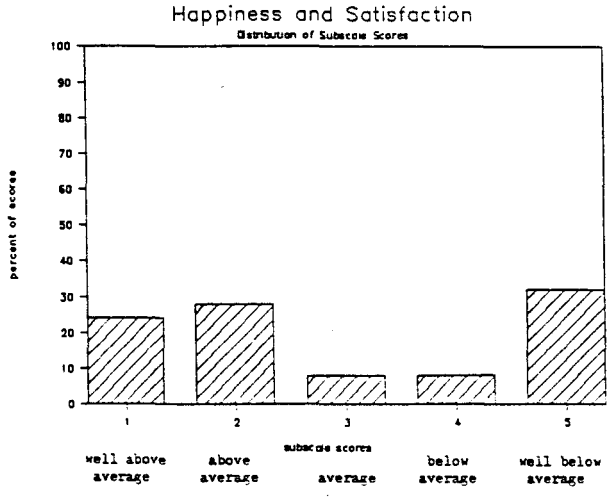

Figure 10

Summary of Self-Concept Subscales

This sample of adolescents perceives itself as being cooperative, physically attractive and intellectually capable, moderately anxious, and moderately happy/popular and satisfied with life. The subjects' self-concept and perceptions of cancer are generally positive, but denial may be a factor in these results.

CHAPTER V

CONCLUSIONS

Summary and Conclusions

The results of this study do not support the findings of Jamison et al. (1986) regarding cooperation among adolescents with cancer. A significant positive relationship was found at the $p = .005$ level ($r = .55$) between the perception of cancer and the nurse's rating of patient cooperation, which was not identified in the Jamison et al. (1986) study. However, this finding must be interpreted with caution due to the questionable reliabilities of the Perception of Cancer and Cooperation scales.

The adolescents in this study as a group rated themselves as being cooperative, physically attractive, intellectually capable, moderately anxious, and moderately popular and satisfied with life. All subjects had good self-concepts overall. No generalizations could be made regarding adolescents' perception of cancer due to the variability of scores and the questionable reliability of the Perception of Cancer tool.

Recommendations for Nursing

Of the sample characteristics cited, anxiety is the perhaps the one nurses can remedy the most when dealing with this population. Adolescence can cause enough anxiety alone, but a diagnosis of cancer can interfere with normal developmental tasks and can lead to emotional problems (Jamison et al., 1986). If this group of stable outpatients rated themselves as being moderately anxious, one might presume that acutely ill inpatients could have even higher levels of fear, nervousness, and anxiety. These adolescents may be "fragile" and emotionally dysphoric as patients, and could greatly benefit from trusting, empathetic, relationships with the nurses who care for them. These therapeutic relationships might also produce better cooperation as a consequence.

Other self-concept characteristics of this sample were related, and should be recognized by nurses who care for adolescents with cancer. This is a population which is just beginning to be described and understood.

Adolescents with more positive perceptions of cancer were rated more cooperative by the nurse, and these positive perceptions may be related to the positive attitudes some adolescents have toward themselves and their lives in general. If nurses caring for adolescents with cancer can give positive reinforcement, and support

their sense of self-esteem, cooperation may be improved as a result.

Nurses, when interpreting research findings from any study, need to pay particular attention to the reliabilities of the tools used. Nurses should be cautious of implementing interventions based on findings from small scale studies which cannot document the reliability and validity of their tools.

Recommendations for Future Research

This study failed to test the findings of Jamison et al. (1986) upon which it was based. Further studies are therefore indicated to determine and lend support to factors which may influence cooperation in adolescents with cancer.

It is suggested that larger and more homogeneous samples be used to help distribute scores more normally, and that the Cooperation and Perception of Cancer scales be further refined in order to better discriminate between degrees of the concepts being measured. The Cooperation Scale needs more items generated in both task-oriented and emotion-oriented groups to improve its internal consistency. Adolescents as well as caregivers should be used to identify characteristics of cooperation, and items which have the consensus of both groups can be used to refine the scale. The Perception

of Cancer Scale could also benefit from the input of adolescents, to generate additional items which would help to define the concept of cancer more accurately and lend better internal consistency to the scale.

In future studies, it is also suggested that other factors which might relate to cooperation, such as denial and anxiety, be measured in adolescents with cancer (using reliable and valid tools) to discover significant relationships.

More knowledge is clearly needed regarding factors associated with cooperation in this population if health professionals are to improve the outcomes of cancer therapy by improving cooperation with treatment. Reliable and valid tools are essential in this endeavor, and a greater effort must be made to include the opinions, perceptions, and beliefs of the adolescents involved to obtain accurate information regarding cooperation with treatment.

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APPENDIX A

THE UNIVERSITY OF CHICAGO HOSPITALS

Department of Nursing
The Center for Nursing Education and Nursing Research
Sharon O'Neill
Associate Director

Room L264 Box 416
5841 South Maryland Avenue
Chicago, Illinois 60637
312 702 6497

June 8, 1987

Ms. Joanna Kentes, RN
6037 W. 127th Place
Palos Heights, Il.
60463

The Nursing Research Committee of the University of Chicago Hospitals is pleased to inform you that your research application has been approved. Please note that this approval is for a period of one (1) year from study activation. If your study requires further time, you will need to complete a Continuing Review Form. Please complete the form and send it to us two (2) months prior to the end of your study approval date.

In order to recognize significant contributions of staff or hospital resources, you may be asked to include the following sentence in publications or presentations: "This research was supported in part by the Department of Nursing at the University of Chicago Medical Center."

We are looking forward with great interest to the implementation of your study and receiving the results. If we can be of further assistance to you, or if you have any questions, feel free to contact us.

We wish you success in your research endeavor.

Sincerely,

Amelia Stevens, MSN, RN
Chair
Nursing Research Committee

APPENDIX B

THE UNIVERSITY OF CHICAGO MEDICAL CENTER

Division of Pediatric
Hematology–Oncology

Room C408 Box 97
5841 South Maryland Avenue
Chicago, Illinois 60637
312 702 6808
312 702 6600
(Night Emergency)

May 28, 1987

To Whom It May Concern:

RE: Study Titled "Cooperation with Treatment In Adolescence with Cancer"

Principal Investigator: Joana Kentes

I have reviewed the proposed research which aims at studying cooperation with treatment in adolescents with cancer. This study has the full cooperation of our division and we will help as much as possible in entering patients so that information can be collected as quickly as possible.

Sincerely,

F. Leonard Johnson

F. Leonard Johnson, M.D.
Professor and Chief

FLJ/rvy

The University of Chicago Hospitals
Bernard Mitchell Hospital
Chicago Lying-in Hospital
Wyler Children's Hospital

Division of the Biological Sciences
The Pritzker School of Medicine

APPENDIX C

WPS WESTERN PSYCHOLOGICAL SERVICES
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March 26, 1987

Joanna Kentes, R.N.
6037 W. 127th Place
Palos Heights, IL 60463

Reference: Piers-Harris Children's Self-Concept Scale

Dear Researcher:

Thank you for your request to use the above-referenced material in connection with your research. WPS strongly encourages research, and no permission from us is necessary for use of our publications, in this context, with the following stipulations:

1. No reproduction of the material may be made in any format, for any purpose, without our prior written permission.

2. If you are a student, you must order and use the materials under the supervision of a qualified faculty member. Any order placed by a student must be accompanied by a letter of authorization by a supervising faculty member.

3. All materials must be used ethically and for the purposes and in the manner they were intended.

To aid researchers, WPS makes available a 20% discount on the purchase of products to be used for research approved by WPS. To qualify for this discount, submit a written description of your project to my attention, stating in your request a brief summary of the nature of the study, the estimated time frame it will take to complete, and the estimated quantities of each item you will need to purchase.

We appreciate your interest in our products, and look forward to learning the results of your research. Should you have further inquiries, please feel free to contact me.

Sincerely,

Susan Dunn Weinberg
Assistant to the President

SDW:se
Encls.

P.S. Information re validity, reliability and scoring of the PHCSCS can be found in the manual.

APPENDIX D

APPENDIX D

THE UNIVERSITY OF CHICAGO DIVISION OF BIOLOGICAL SCIENCES

CONSENT BY SUBJECT FOR PARTICIPATION IN RESEARCH PROTOCOL

PROTOCOL NUMBER: _____ PATIENT NAME: _____
RESEARCH PROTOCOL: COOPERATION WITH TREATMENT IN ADOLESCENTS WITH CANCER
DOCTOR(S) DIRECTING RESEARCH: DR. LEONARD JOHNSON PHONE: 702-6808/702-6560

You are being asked to participate in a clinical research study. The doctors at The University of Chicago Medical Center study the nature of disease and attempt to develop improved methods of diagnosis and treatment. This is called clinical research. In order to decide whether or not you should agree to be part of this research study, you should understand enough about its risks and benefits to make an informed judgment. This process is known as informed consent.

This consent form gives detailed information about the research study which will be discussed with you. Once you understand the study, you will be asked to sign this form if you wish to participate. You will have a copy to keep as a record. If you have any questions concerning this research or your rights in connection with the research, contact the doctor named above or the Clinical Investigation Committee at 312/702-1472.

I. NATURE AND DURATION OF PROCEDURE:

This is a program of research being conducted by Dr. Leonard Johnson, Joanna Kentes, R.N., and Rosanne Perez-Woods, R.N., Ed.D., CPNA titled: "Cooperation With Treatment in Adolescents With Cancer". Its purpose is to look at factors which may affect your cooperation with your recommended treatments. By discovering these factors, health professionals will have a better idea of how they can help you so that your therapies will be more effective. The procedure will involve completing three brief questionnaires, which will look at how you perceive your level of cooperation, your self-concept, and your perceptions of cancer. A nurse who knows you will also rate your cooperation to make a comparison.

II. POTENTIAL RISKS AND BENEFITS:

This study involves no physical risk of injury or discomfort. It will take approximately 15-20 minutes to complete the questionnnaires. There are no direct benefits to you except in the knowledge that you have helped us to learn more about adolescents with cancer. No names will be used in the study except as required on the consent form. All information will be reported as a group.

III. POSSIBLE ALTERNATIVES:

Not applicable.

The substance of the project and procedures associated with it have been fully explained to me and all experimental procedures have been identified. I have had the opportunity to ask questions concerning any and all aspects of the project and any procedures involved. I am aware that I may withdraw my consent at any time and such withdrawal will not restrict my access to health care services normally available at the University of Chicago Hospitals. I acknowledge that no guarantee or assurance has been given by anyone as to the results to be obtained. Confidentiality of records concerning my involvement in this project will be maintained in an appropriate manner. When required by law, the records of this research may be reviewed on an anonymous basis by applicable government agencies.

I understand that in the event of physical injury resulting from this research, The University of Chicago will provide me with free emergency care, if such care is necessary. I also understand that if I wish, the Hospital will provide non-emergency care, but that the Hospital assumes no responsibility to pay for such care or to provide me with financial compensation.

I also understand that if at any time I feel uncomfortable as the result of any questions being asked, I may choose to stop for a while or choose not to complete the research study.

I, the undersigned, hereby consent to participate as a subject in the above described research project conducted by the University of Chicago Medical Center.

Doctor/ Researcher: _____

Signature of Subject, and Parent of Subject if under 18 years old:

_____

Date: _____ Time: _____ am/ pm

APPENDIX E

SCALE OF COOPERATION WITH MEDICAL TREATMENT (PATIENT'S FORM)

Patient's number _____

Instructions: Rate your overall behavior for the past three months using the scale items of 1 (not at all) to 5 (a great deal) for the following behaviors:

		Not at all				A great deal
1.	I help with procedures by getting physically prepared, e.g. getting on the table.....	1	2	3	4	5
2.	I actively participate in venipuncture procedures, e.g. by helping to find a good vein and by holding still.....	1	2	3	4	5
3.	I let emotions interfere with procedures.....	1	2	3	4	5
4.	I try to delay procedures, e.g. by having to go to the bathroom.....	1	2	3	4	5
5.	I take my medicines as prescribed.....	1	2	3	4	5
6.	I take precautions regarding infection when instructed to do so.....	1	2	3	4	5
7.	I misuse my illness, e.g. to get out of school.....	1	2	3	4	5
8.	I ask questions about my illness and/or treatment...	1	2	3	4	5
9.	I show willingness to relate to other children with cancer.....	1	2	3	4	5
10.	I consistently keep appointments and show up on my given appointment times.....	1	2	3	4	5

APPENDIX F

APPENDIX F

SCALE OF COOPERATION WITH MEDICAL TREATMENT

Patient's Name _____ Patient's number _____

Nurse's Name _____

Instructions: Rate this child's overall behavior for the past three months using the scale items of 1 (not at all) to 5 (a great deal) for the following behaviors:

		Not at all				A great deal
1.	Helps with precedures by getting physically prepared, e.g. gets on table.....	1	2	3	4	5
2.	Actively participates in venipuncture procedures, e.g. helps find a good vein, and cooperates by holding still.....	1	2	3	4	5
3.	Lets emotions interfere with procedures.....	1	2	3	4	5
4.	Engages in delay tactics before procedures e.g. having to go to the bathroom.....	1	2	3	4	5
5.	Takes medicines as prescribed.....	1	2	3	4	5
6.	Takes precaution regarding infection when instructed to do so.....	1	2	3	4	5
7.	Blatantly misues illness, e.g. to get out of schocl...	1	2	3	4	5
8.	Asks questions abut his or her illness and/or treatment.....	1	2	3	4	5
9.	Shows willingness to relate to other children with cancer.....	1	2	3	4	5
10.	Consistently keeps appointments and shows up on given appointment times.....	1	2	3	4	5

APPENDIX G

Piers-Harris Children's Self-Concept Scale

1. My classmates make fun of me ..... yes no
2. I am a happy person ..... yes no
3. It is hard for me to make friends ..... yes no
4. I am often sad ..... yes no
5. I am smart ..... yes no
6. I am shy ..... yes no
7. I get nervous when the teacher calls on me ..... yes no
8. My looks bother me ..... yes no
9. When I grow up, I will be an important person ..... yes no
10. I get worried when we have tests in school ..... yes no
11. I am unpopular ..... yes no
12. I am well behaved in school ..... yes no
13. It is usually my fault when something goes wrong ..... yes no
14. I cause trouble to my family ..... yes no
15. I am strong ..... yes no
16. I have good ideas ..... yes no
17. I am an important member of my family ..... yes no
18. I usually want my own way ..... yes no
19. I am good at making things with my hands ..... yes no
20. I give up easily ..... yes no
21. I am good in my school work ..... yes no
22. I do many bad things ..... yes no
23. I can draw well ..... yes no
24. I am good in music ..... yes no
25. I behave badly at home ..... yes no
26. I am slow in finishing my school work ..... yes no
27. I am an important member of my class ..... yes no
28. I am nervous ..... yes no
29. I have pretty eyes ..... yes no
30. I can give a good report in front of the class ..... yes no
31. In school I am a dreamer ..... yes no
32. I pick on my brother(s) and sister(s) ..... yes no
33. My friends like my ideas ..... yes no
34. I often get into trouble ..... yes no
35. I am obedient at home ..... yes no
36. I am lucky ..... yes no
37. I worry a lot ..... yes no
38. My parents expect too much of me ..... yes no
39. I like being the way I am ..... yes no
40. I feel left out of things ..... yes no

41. I have nice hair ..... yes no
42. I often volunteer in school ..... yes no
43. I wish I were different ..... yes no
44. I sleep well at night ..... yes no
45. I hate school ..... yes no
46. I am among the last to be chosen for games ..... yes no
47. I am sick a lot ..... yes no
48. I am often mean to other people ..... yes no
49. My classmates in school think I have good ideas ..... yes no
50. I am unhappy ..... yes no
51. I have many friends ..... yes no
52. I am cheerful ..... yes no
53. I am dumb about most things ..... yes no
54. I am good-looking ..... yes no
55. I have lots of pep ..... yes no
56. I get into a lot of fights ..... yes no
57. I am popular with boys ..... yes no
58. People pick on me ..... yes no
59. My family is disappointed in me ..... yes no
60. I have a pleasant face ..... yes no
61. When I try to make something, everything seems to go wrong ..... yes no
62. I am picked on at home ..... yes no
63. I am a leader in games and sports ..... yes no
64. I am clumsy ..... yes no
65. In games and sports, I watch instead of play ..... yes no
66. I forget what I learn ..... yes no
67. I am easy to get along with ..... yes no
68. I lose my temper easily ..... yes no
69. I am popular with girls ..... yes no
70. I am a good reader ..... yes no
71. I would rather work alone than with a group ..... yes no
72. I like my brother (sister) ..... yes no
73. I have a good figure ..... yes no
74. I am often afraid ..... yes no
75. I am always dropping or breaking things ..... yes no
76. I can be trusted ..... yes no
77. I am different from other people ..... yes no
78. I think bad thoughts ..... yes no
79. I cry easily ..... yes no
80. I am a good person ..... yes no

APPENDIX H

Perception of Cancer Scale

Below you will find some statements which describe cancer. Put a circle around the number which comes the closest, in your opinion, to best describing your beliefs about cancer.

Most people never recover	1	2	3	4	5	6	7	Most people recover completely
I have a big chance of getting it	1	2	3	4	5	6	7	I have no chance of getting it
Scares most people	1	2	3	4	5	6	7	Scares hardly anybody
A very mild disease	1	2	3	4	5	6	7	A very powerful disease
Very well understood by doctors	1	2	3	4	5	6	7	Hardly anything is known about it
Many people get it	1	2	3	4	5	6	7	Almost nobody gets it

APPROVAL SHEET

The thesis submitted by Joanna Kentes has been read and approved by the following committee:

Dr. Rosanne Perez-Woods, EdD., Director
Professor and Niehoff Chair, Nursing, Loyola

Dr. Karen B. Haller, PhD.
Associate Professor, Nursing, Loyola

The final copies have been examined by the director of the thesis and the signature which appears below verifies the fact that any necessary changes have been incorporated and that the thesis is now given final approval by the Committee with reference to content and form.

The thesis is therefore accepted in partial fulfillment of the requirements for the degree of Master of Science in Nursing.

12/6/87
Date

Rosanne Perez-Woods
Director's Signature