

DECISION MAKING IN ADOLESCENT ONCOLOGY PATIENTS

by

Simone Stenekes

A Thesis

Submitted to the Faculty of Graduate Studies

in Partial Fulfilment of the Requirements for the Degree of

**MASTER OF NURSING**

Faculty of Nursing

The University of Manitoba

Winnipeg, Manitoba

**THE UNIVERSITY OF MANITOBA**  
**FACULTY OF GRADUATE STUDIES**  
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of Manitoba in partial fulfillment of the requirements of the degree  
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**MASTER OF NURSING**

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## ACKNOWLEDGEMENTS

I will forever be indebted to the wonderful adolescents who took time to share their experiences with me. Before undertaking my research, I had the privilege to care for some of these adolescents as in-patients during their cancer experience. Their energy, compassion, and wit never ceased to amaze me. To have the opportunity to connect with these adolescents again during the data collection process was particularly touching.

To my thesis committee, I thank you for your encouragement and perseverance. To my advisor, Dr. Lesley Degner thank you for your guidance, ideas and your global view of the whole process. Dr. Roberta Woodgate, your attention to detail and your concern for my well-being is greatly appreciated. Dr. Rochelle Yanofsky, as my external committee member, you were helpful with specific details, and eased the entire process. I appreciate the commitment and dedication each of you had towards this research project, but also for me as a student. You have each taught me many useful things for the future!

To Cathy Bourne, the pediatric oncology nurse clinician who assisted me with the recruitment of individuals for this study, I am forever thankful. Your dedication is not only appreciated by me, but was also mentioned in several interviews by the study participants, which is a testament to your fabulous work.

To the staff on CK5, I am grateful to you for always encouraging me in my studies and also being willing to listen to what was happening with my thesis. Also, I am wanting to thank the pediatric oncology team at Cancer Care Manitoba for allowing me to access their patients for this study. To Lorena McManus and Mike Harlos, my current “bosses” in the Palliative Care Program, I thank you for your support in many ways.

I would like to acknowledge the financial support I received throughout my entire graduate education from the following: The Canadian Cancer Society, The Manitoba Association of Registered Nurses Foundation, The Canadian Nurses Foundation (The Aplastic Anemia Myelodysplasia Association of Canada Scholarship), and The University of Manitoba (Graduate Fellowship, Arthur V. Mauro Senior Student Award, Dr. D. S. Winkler Memorial Award, Child Health Graduate Studentship in Nursing, Murphy Scholarship in Graduate Research in Oncology Nursing, UMSU Scholarship).

And who could make it through the process of a graduate degree without other students and special nurses encouraging you along the way. Special thanks to some important friends, colleagues and cheerleaders: Michelle, Kelly, Wanda, Genevieve, Vanessa, Megan, Suzanne, Alex, Darlene, Peggy, and Auntie Jean.

Lastly, a huge thanks to my family, who survived this experience alongside me. To my Dad, the ultimate editor. I do not know what every paper in my undergrad and graduate degree would have been like without your keen awareness of the English language! To my Mom, the encourager who said to just plod along and get this thing done - thanks! A special thanks to Andreas (aka "poopsie"), who provided much needed "nephew therapy" along the way and kept me grounded in reality, as only someone under two years old can!

This research is dedicated to my Grandmother Katherine who died of cancer. Unknown to me until after I had graduated with my undergraduate degree in nursing, she had always wanted a nurse in the family. She got her wish!

## ABSTRACT

Minimal research has been done that evaluates decision making in adolescent oncology patients. The purpose of this exploratory study was to research the decision making preferences of adolescent cancer patients. The study focused on the role that adolescents with cancer preferred when participating in treatment decision making, the relationship between family functioning and decision making preferences of adolescents with cancer, and the relationship between demographic and health information factors and decision making preferences of adolescents with cancer. The theoretical framework for the study integrated two models describing the decision making process, the Framework of Competence in Adolescent Decision Making, by Mann, Harmoni and Power (1989) and the Patterns of Control and Participation in Health Care Decision Making, by Degner and Beaton (1987).

Nineteen adolescents participated in the study. The four instruments utilized in data collection included: a Demographic and Health Information Form, the McMaster Family Assessment Device - General Functioning Scale, the Control Preferences Scale, and the Semi-structured Open-ended Interview Questions Guide.

The results of the study showed that participants desired varied roles in decision making from active to passive, with just over half of the participants choosing the collaborative role as their first preference. There was not a significant relationship between family functioning and decision making preference. When evaluating the relationships between specific demographic variables and the decision making preferences of participants the only demographic variable to show any significant relationship was the participants age at the time of interview ( $p = .096$ ). Those who were

older at the time of interview preferred a more active role in decision making.

This study will impact the health of adolescents with cancer by assisting health care professionals to develop a better understanding of adolescent decision making preferences and to provide the health care team with information regarding the decision making needs and desires of adolescent oncology patients. Recommendations for future research are also discussed.

## Table of Contents

	Page
Acknowledgements.....	i
Abstract.....	iii
Table of Contents.....	v
Chapter I: STATEMENT OF THE PROBLEM.....	1
Introduction.....	1
Background.....	1
Purpose of the Study.....	3
Research Questions.....	3
Significance of the Study.....	4
Theoretical/Conceptual Framework.....	4
Framework of competence in adolescent decision making.....	4
Patterns of control and participation in health care decision making.....	5
Integration of Models.....	5
Concept Definitions.....	6
Summary.....	8
Chapter II: LITERATURE REVIEW.....	9
Introduction.....	9
Factors Influencing Decision Making in Adult Populations.....	9
Adolescent Decision Making.....	11
Adolescent Development and Decision Making.....	11
Competence.....	12

Key Factors in Adolescent Decision Making.....	13
Family.....	13
Peers.....	15
Decision Making Studies in Oncology.....	16
Decision Making in Adult Oncology.....	16
Decision Making by Parents of Pediatric Oncology Patients.....	18
Decision Making in Pediatric Oncology.....	20
Limitations of the Current Research.....	22
Chapter III: METHODOLOGY.....	25
Introduction.....	25
Research Design.....	25
Recruitment and Sample.....	25
Setting.....	27
Data Collection Methods.....	27
Instruments.....	27
Demographic and Health Information Form.....	27
Control Preferences Scale.....	27
McMaster Family Assessment Device.....	28
Semi-structured Open-ended Interview Questions.....	29
Data Collection Procedure.....	29
Ethical Issues.....	31
Informed Consent and Confidentiality.....	31
Potential Issues.....	32



Participant and Parental Involvement.....	32
Summary.....	33
Chapter IV: FINDINGS.....	34
Introduction.....	34
Participant Description.....	34
Research Question One: Adolescents Desired Role in Treatment Decision Making.....	37
CPS Reliability and Validity.....	41
Research Question Two: Relationship Between Family Functioning and Decision Making Preferences.....	41
Research Question Three: Relationship Between Demographic and Health Information Factors and Decision Making Preferences.....	43
Semi-structured Open-ended Interview Questions Analysis.....	44
Good Decision Experience.....	44
Bad Decision Experience.....	46
Additional Decision Experiences.....	48
Health Care Professionals.....	48
Parent(s) and Family.....	49
Advice to Newly Diagnosed Adolescent with Cancer.....	50
Preferred and Actual Decision Making.....	51
Additional Interview Comments.....	54
Post Hoc Power Analysis.....	57
Summary.....	58
Chapter V: DISCUSSION.....	60

Introduction.....	60
Prominent Findings .....	60
Comparison of Study Results to Other Pediatric Oncology Studies.....	60
Relationship Between Decision Making Preferences and Demographic Variables.....	61
Preferred Decision Making Style and Suggestions to Hypothetical Newly Diagnosed Adolescent.....	63
Importance of Collaborative Decision Making in Adolescents.....	64
Theoretical Framework .....	64
Instruments .....	67
Sample Representativeness .....	69
Limitations .....	69
Future Research .....	71
Summary .....	74
REFERENCES .....	76
APPENDIXES	
A.. Conceptual Model of Theoretical/Conceptual Framework.....	89
B. Demographic and Health Information Form.....	90
C. McMaster Family Assessment Device General Functioning Scale.....	93
D. Control Preferences Scale.....	95
E. Semi-structure Open-ended Interview Questions Guide.....	98
F. Initial Contact Statement (Recruiter).....	99
G. Poster .....	100
H. Researcher Initial Contact Statement.....	101

I.	Information Sheet and Assent Form (Participant).....	102
J.	Information Sheet and Consent Form (Participant).....	105
K.	Information Sheet and Consent Form (Parent).....	108

## Tables

Table 4.1	Demographic Profile of Participants.....	34
Table 4.2	Control Preferences Scale String Variables Results - Frequency of Responses .....	38
Table 4.3	Control Preferences Scale Information - First Two Selections.....	40
Table 4.4	Family Assessment Device - General Functioning Scale Final Score....	42
Table 4.5	One-way ANOVA .....	43
Table 4.6	2 x 2 Table for CPS by Age at Time of Interview.....	44
Table 4.7	Summary of Responses to Question Regarding Good Decisions.....	46
Table 4.8	Summary of Responses to Question Regarding Bad Decisions.....	47
Table 4.9	Summary of Responses Regarding Health Care Professionals and Decisions .....	49
Table 4.10	Preferred and Actual Decision Making Roles.....	54

## Chapter I

### Statement of the Problem

This first chapter provides the background for the study by focusing on the current state of childhood cancer, the purpose, the three research questions that guided the project, the significance of the research, the theoretical framework, and the definitions of the key concepts utilized.

### *Background*

In Canada, a diagnosis of cancer occurs in approximately 17 out of every 100,00 children and adolescents under the age of 20 years of age (Health Canada). Within the province of Manitoba and the surrounding area, an average of 10.5 adolescents between the ages of 12 and 17 have been diagnosed with cancer each year in the last 10 years (Manitoba Cancer Registry, 2003). Statistically, this is a small number of adolescents within the population. But for the adolescents and children affected by cancer, it is a significant part of their lives and shapes who they are and who they become.

Mortality rates for childhood cancer have been steadily declining, resulting in an increase in childhood cancer survivors. This positive outcome is a result of increased knowledge regarding cancer treatment approaches, the large number of children involved in clinical trials, as well as biological differences in children with cancer, compared to adults who have a cancer diagnosis (National Cancer Institute of Canada, 2003). This pattern changes the public's perspective of childhood cancer. It will also impact the way in which health care professionals view pediatric oncology patients and their families. With a greater emphasis on survivorship and the issues that relate to this phenomenon, the experience that children have when diagnosed with cancer will impact the rest of

their lives. For an adolescent dealing with a diagnosis of cancer it provides an opportunity to learn and mature. The long-term outcomes, both positive and negative are only beginning to be studied within this population. It is unknown what effect involvement in decisions will have on the adolescent who has survived cancer.

The diagnosis of cancer in an adolescent or child results in a crisis that affects the entire family. This diagnosis brings with it many emotions, such as helplessness, uncertainty, fear and anger (Chesler & Barbarin, 1987; Feldstein & Rait, 1992; Heath, 1996; Martinson & Cohen, 1988; Scott-Findlay, 1998; Thorne, 1984; Tringali, 1986). It is a crisis event for the family (Moore, Kramer, & Perin, 1986). In the midst of this crisis and emotional upheaval, many decisions must be made by the patient, family and health care team. Limited research has evaluated decision making in adolescent cancer patients and it is unknown what effect this crisis will have on the decision making abilities and preferences of adolescents during their treatment experience and after their treatments have been completed.

There are many unique aspects of a cancer diagnoses in an adolescent. This transitional time from childhood to adulthood may become more difficult with the diagnosis of a severe illness (Eiser, 1996). Adolescents with cancer are faced with many challenges throughout their course of treatment. One such challenge is the degree of involvement they desire when making treatment decisions. A large amount of literature is available about decision making in the general adolescent population regarding health promotion, such as choices about sexual activity or risk taking. This literature has shown that adolescents desire to have control over their lives and the decisions they make. Minimal research has focused on the decision making involvement preferences of

adolescents who are diagnosed with medical illnesses, specifically cancer. Health care providers need to better understand decision making preferences of adolescents with cancer in order to provide appropriate care (Dunsmore & Quine, 1995). It is also unknown the impact a diagnosis of cancer has on an adolescent and if it changes their views on decision making. It is not known if adolescents who are surrounded by decisions in the health care environment develop improved patterns of decision making later in life. The effect of the health care experience exposes adolescents to serious circumstances and may actually improve their understanding of the decision making process. Understanding of the process involved in decisions could lead to a better understanding of their own desires or abilities to be involved in decisions encountered in their future. The experience of cancer could profoundly impact the adolescent in this transitional time. Therefore it is important to continue studying decision making in the adolescent population, specifically the population of adolescents who deal with complex health issues.

#### *Purpose of the Study*

The purpose of this exploratory study was to research the decision making preferences of adolescent cancer patients.

#### *Research Questions*

The study was designed to answer the following research questions:

1. What role do adolescents with cancer prefer when participating in treatment decision making?
2. What is the relationship between family functioning and decision making preferences of adolescents with cancer?

3. What is the relationship between demographic and health information factors and decision making preferences of adolescents with cancer?

### *Significance of the Study*

This study has contributed to the understanding of decision making preferences of adolescent oncology patients. Through the dissemination of the findings, health care professionals will become more aware of the decision making needs and desires of adolescents with cancer. This study will impact the way in which health care professionals interact with adolescents during their cancer experience. From the information obtained potential interventions can be developed to assist adolescents in determining the role they desire to play in decision making surrounding their illness.

### *Theoretical/Conceptual Framework*

This study incorporated two models which describe the decision making process. The model developed by Mann, Harmoni and Power (1989) has focused on adolescent decision making while Degner and Beaton (1987) developed a model for health care decision making.

### *Framework of Competence in Adolescent Decision Making*

The first model is that of Mann, Harmoni and Power (1989) who reviewed the literature available on adolescent decision making and developed a model of competence in decision making from a cognitive perspective. They highlighted nine indicators of competence: choice; comprehension; creativity; compromise; consequentiality; correctness; credibility; consistency; and commitment. Their model also discussed the following barriers to achieving competence in adolescent decision making: (a) attitudinal constraints; (b) peer group pressures to conformity; (c) breakdowns in family structure



and functioning; and (d) restricted legal rights to make important personal decisions.

### *Patterns of Control and Participation in Health Care Decision Making*

The second theoretical model that guided this study was the work of Degner and Beaton (1987). Their model focusing on the patterns of control and participation in decision making described four patterns of control and participation that patients desired when making health care decisions. The first is provider-controlled decision making which involved the health care personnel deciding the plan for treatment. The second pattern is patient-controlled decision making where the patients granted or withheld the final consent on treatment decisions. The third pattern of decision making is described as family-controlled. The family members involved themselves in decisions by controlling the treatment plan or ensuring that the health providers respected the wishes the patient had previously expressed. The fourth and final pattern of control is titled jointly-controlled decision making. This involved the sharing of control over the treatment plans, with the underlying assumption that patients and families possess the capability to engage with health care personnel in these decisions. Degner and Beaton (1987) clearly stated that the person(s) with control determine(s) the selection of treatment options. Based on the grounded theory study on decision making by Degner and Beaton (1987), an instrument using a card sorting technique was designed (Degner, Sloan & Venkatesh, 1997). This instrument was used in this study to measure the degree of control adolescents desired in their health care decisions.

### *Integration of Models*

Together, these two models provided a more comprehensive view of the decision making process, from deliberation to the style of decision making participation

desired by the individual (see Appendix A for conceptual map). The purpose of this study was to explore the decision making preferences of adolescents with cancer. The decision making process framework theorized that the demographic data and family functioning will impact the decision making process (Mann, Harmoni and Power, 1989). The control and participation in health care decision making framework sought to explain and describe the variable of decision making preference.

The theoretical framework utilized for this study suggests that family functioning has an impact on decision making competence and ultimately the decision making preferences of adolescents who are involved in making decisions. The theoretical framework utilized for this study indicates that breakdowns in family structure and functioning impact the competence of adolescent decision making and therefore would impact the amount of control the adolescent would give or keep. The theoretical framework would propose that healthy family functioning would result in competence in decision making and therefore a desire to have a more active role in health care decisions.

### *Concept Definitions*

The key concepts which required defining were decision making and decision making preferences. Patient decision making was rarely defined in nursing and health care literature. Decisions (made by health care providers, patients and families) were defined in a consensus statement on pediatric oncology as "choosing between alternatives" (Hinds et al., 1998, p.24). Carnevale (1997) described decision making as a "human practice - something a person does". In their concept analysis of decision making, Matteson and Hawkins (1990) have included the defining attributes of a decision

as “making a deliberate mental choice, taking action based on indication or evidence, choosing between two or more options, committing to certain actions or inactions, bringing doubt or debate to an end, and expecting to accomplish certain goals” (p. 7). They also discuss that “derivations of the word decide are used extensively in the nursing literature to refer to the activity (to decide), the process (decision making) or the outcome (decision)” (Matteson & Hawkins, 1990, p. 5). Decision making has also been defined as incorporating “the decision making preferences of the patient and is a process that involves deciding between two or more options by the exchange of information, deliberation, and weighing of the patient’s goals, beliefs, and values with the outcome being a decision that the health care team respects and implements” (Stenekes 2001, p. 12). A more recent concept analysis by Noone (2002) contained defining attributes which included: “an intentional choice between two or more discrete options, based upon recognition of stimulus for action, commits a person to a path of action, expects to accomplish a specific goal or goals”.

The definitions above all stress the choice that is involved for patients when making decisions. The definitions are similar in that they all contain options that are presented, a choice that needs to be made, and an outcome or goal that is strived for. The nursing literature is quite consistent when defining patient decision making, as these above definitions reveal.

It is the process of decision making, not the activity or the outcome, that was the focus of this study. It is within the process of decision making that decision making preference need to be considered. Decision making preferences have referred to the level of involvement subjects have desired when considering their health care treatment

options.

### *Summary*

This chapter has outlined the problem statement, purpose of the study, research questions, as well as the significance of the study for health care professionals. Also included in this discussion was the study's conceptual framework, developed utilizing two models of decision making from the literature, and definitions pertaining to key terms.

## Chapter 2

### Literature Review

A review of the literature related to decision making preferences in oncology patients has revealed a paucity of research in the area of decision making in adolescent oncology patients. However, there is a substantive amount of literature evaluating decision making preferences of adult oncology patients. The review of the literature utilized the on-line databases of MEDLINE, CINAHL, PsychINFO, and Dissertation Abstracts. A manual search of all key articles was also performed. This review of the current literature focuses on: factors influencing decision making in adult populations, adolescent development and decision making, key factors in adolescent decision making, decision making in adult oncology patients, decision making by parents of pediatric oncology patients, decision making in pediatric oncology patients, and concludes with a discussion of the limitations of the current literature.

#### *Factors Influencing Decision Making in Adult Populations*

Patient involvement in health care decisions is known to be based on a variety of factors, (a) the interactional styles of health providers, (b) the nature of the relationship with health providers, (c) the type, amount, and timing of the information given to the patient, (d) anxiety of the patient, (e) the degree of helplessness a patient feels, (f) the age of the patient, (g) previous experiences of the patient, (h) gender, (i) prognosis, and (j) demographic characteristics (Beaver et al., 1996; Bilodeau & Degner, 1996; Blanchard et al., 1988; Cassileth, Zupkis, Sutton-Smith & March, 1980; Degner & Kristhanson et al., 1997; Degner & Sloan, 1992; Hack et al., 1994; Kalisch, 1975; Roberts et al., 1994; Schain, 1980; Weeks et al., 1998). It is important to recognize these factors as potential

contributing elements to the decisions adolescent oncology patients make.

The health care literature also lacks information in the area of evaluation and description of the process of decision making for patients and families. Often the focus has been on the outcome, instead of the various attributes that have contributed to the decision. Davison and Degner (1998) included the following factors as influencing treatment decision making in patients with cancer: the uncertainty of the disease, the competency of the patient, the settings in which decisions are made, the economics of the health care environment, the presence of conflict among members of the health care team, predictors of preferred role in decision making, and lastly, the disclosure of information. In a qualitative study of HIV-infected women who were making a decision whether to have a baby or not, Sowell and Misener (1997) revealed that spiritual and religious beliefs, knowledge and beliefs about HIV, previous experiences, the attitudes of families and partners, their personal health and also their intrapersonal motivation all were themes that factored into the decision the patient made. It is these situational aspects that are involved in making decisions that need to be considered and also valued by the health care team.

Brownlea (1987) highlighted that patient participation in decision making was changing due to developments in the health arena, but that increased participation was being impeded by medical dominance, bureaucratic cultures, the political economy of health, and professional paradigms which were inhibitory for patients. Within the changing health care environment, it is important that nurses assess the decision making preferences of patients and families in order to assist them in achieving their desired level of involvement.

### *Adolescent Decision Making*

#### *Adolescent Development and Decision Making*

Adolescence is viewed as the time between childhood and adulthood, which encompasses transition and brings great changes to the individual and his/her environment (Petersen & Hamburg, 1986). Piaget (1972) and Inhelder and Piaget (1958) have stated that the time of formal reasoning is normally reached by the age of 14-15 years of age. Formal reasoning means that adolescents can think abstractly and consider various outcomes. Kohlberg (1984) theorized that by 12 years of age, moral development (which includes ethical standards and social responsibility), ultimately results in decision making. Ormond, Luszcz, Mann and Beswick (1991) and Mann, Harmoni, and Power (1989), both supported this belief, having stated that middle adolescents (15 year olds) have a knowledge of what is involved in decision making. Susman, Dorn and Fletcher (1987) also found that the older participants in their study with higher levels of cognitive function were higher on the stage of reasoning about illness, which would increase their understanding about illness.

An observational study by Runeson, Hallstrom, Elander and Hemeren (2002) supports the above view, having suggested that children should be encouraged to participate more in the decisions made during hospitalization. This study also showed that parents and health care staff were not always supportive in difficult situations, did not consistently present possible alternatives, and did not request the child's opinion when decisions are made.

Leikin (1993) stated that adolescents with cancer should have involvement in the decision concerning their cancer therapy based on the weight of the bioethical

considerations (which are affected by the clinical stage of the malignancy) and the cognitive ability of the adolescent. King and Cross (1989) offered the following four factors to consider in the assessment of the capacity children have to make decisions:

1) reasoning, 2) understanding, 3) voluntariness, and 4) the nature of the decision.

Adhering these criteria means that every case requires ongoing assessment by the health care team in order to provide an environment that meets the capabilities of each adolescent. However, difficulties may exist in adolescents achieving independence when making decisions, particularly when diagnosed with cancer, as families may become more protective. The common view in North America is that during the adolescent years, independence should be gained. However, cultural factors may impact the degree of involvement an adolescent may have in decisions. Further research needs to be done to evaluate how culture impacts decision making and the degree of comfort adolescents have with making decisions.

*Competence.* In the last few years, most of the literature regarding the health care decision making abilities of adolescents has strongly suggested that adolescents should be involved in decisions if competent to do so (Cohn, 1991; Doig & Burgess, 2000; McCabe, Rushton, Glover, Murray, & Leikin, 1996; Terry & Campbell, 2001; Weir & Peters, 1997). However, as Beidler and Dickey (2001) have stated, there are arguments for both sides, to include and exclude children from health care decisions. Defining competence is difficult and requires specific criteria that are currently not in existence (Friedman Ross, 1997). Laws around this issue of competence are also unclear and a consensus has not yet been reached (Hartman, 2002). Competence, and the assessment of competence, is therefore one of the major issues that may hinder health care



professionals from involving adolescents in decisions. The involvement of the court in complex cases is often necessary, which could lead to further reluctance on the part of the health care staff, family and the patient to address differing opinions regarding treatment choices (Cohn, 1991).

#### *Key Factors in Adolescent Decision Making*

*Family.* The family is an integral component of an adolescent's life.

Parents/caregivers have an incredible impact on the adolescent and their values, views, and ultimately their decision making process and ability (Brown & Mann, 1990; Mann et al., 1989). Family functioning is an important variable to consider in terms of how the family moves through the experience with one member who has cancer (Fobair & Zabora, 1995). Any change in one family member will affect other members of the family (Chesler & Barbarin, 1987; Wright & Leahey, 2000). Families of children with cancer experience more stressful life changes than families with physically healthy children (Thoma, Hockenberry-Eaton, & Kemp, 1993).

The extent to which family functioning will impact the ill adolescent is unknown and is a variable to consider when engaging in decision making research with adolescents. Kuczewski (1996) has suggested that families need to be more involved in decisions about the care of patients. Eiser (1996) highlighted the fact that the normal changes and challenges in adolescence may be more complex for the adolescent with cancer, as independence and autonomy from the nuclear family may be more difficult to achieve (p. 266). Woodgate (2001) found that adolescent oncology patients valued the social support received from their parents and siblings. Her study also determined that adolescents recognized that their parents, in varying degrees, were a part of the decision

making process. The adolescents' desired role in involvement in decision making varied, supporting the view that decision making preferences are individualized. The findings from this study suggest that further examination of decision making in adolescent oncology patients is necessary.

Brown and Mann (1990) have examined the relationship between the family structure and process and decision making in healthy adolescents. Their study of 585 adolescents concluded that "high family cohesion, good parent-adolescent communication and sound parental conflict resolution skills were also significantly related to adolescents' vigilant decision making, testifying to the importance of family environment in the socialization of adolescents decision making" (p. 25). These same features should influence the way in which ill adolescents make decisions or desire to be involved in the decisions about their treatment.

Angst and Deatrick (1996) have evaluated the health care decision making of parents whose children have cystic fibrosis and scoliosis in a descriptive study. Their study showed that the children with cystic fibrosis and their parents were not always aware that alternative treatments existed. The children with cystic fibrosis were not a part of the communication regarding decisions and perceived that few decisions were actually made. The families of these children also did not see themselves as playing a key role in decision making.

Woodgate (1998) evaluated the experience of chronic illness in adolescents and discovered that adolescents desired to remain actively involved in decisions about their treatments options. The adolescents desired a collaborative role, receiving information from physicians and their parents.

*Peers.* Peers are an important part of an adolescents life. Adolescents with cancer may find it difficult to interact with friends, as there is a "risk of rejection and loss of self image" (Eiser, 1996, p. 266). However, Noll, LeRoy, Bukowski, Rogosch, and Kulkarni (1991) have stated that although it has been thought that children with cancer are more isolated, in fact they found children with cancer were no different in terms of popularity, acceptance, number of friends, self-concept or loneliness. Peer support groups have been known to impact ill adolescents positively, and have often been used as a form of therapy for this age group (Bluebond-Langner, Perkel, & Goertzel, 1991; Byrne, Stockwell, & Gudelis, 1984; Heiney, Wells, Coleman, Swygert, & Ruffin, 1990; Katz & Varni, 1993). This does not mean that the opinion of their parents carries less weight, or that seeking the advice of their parents diminishes. Adolescents with cancer recognized that interacting with peers who have cancer had psychosocial benefits for them as individuals (Dunsmore & Quine, 1995).

In another study, however, Lewis' (1981) research about adolescent decision making noted no difference in peer or parent advice seeking, in the study of three groups of healthy adolescents (grades 7-8, 10 and 12). Lewis recognized this result was contrary to popular belief, but hypothesized that the study focused on significant decisions rather than minor decision making. Decisions regarding cancer treatment would be considered a significant decision. Therefore, one would anticipate that cancer patients would seek advice from parents and not just peers when making major decisions regarding their cancer treatments.

## *Decision Making Studies in Oncology*

### *Decision Making in Adult Oncology*

A wide variety of literature exists which has addressed the health care decisions of adults who have been diagnosed with cancer. Research that has evaluated adult preferences in decision making has produced varying results. Some research has shown that most oncology patients desired a passive role, meaning the patients desire that others (for example, the health care team) make decisions on the patients behalf (Beaver et al., 1996; Bilodeau & Degner, 1996; Blanchard, Labrecque, Ruckdeschel, & Blanchard, 1988; Davison & Degner, 2002; Davison, Degner, & Morgan, 1995; Degner & Sloan, 1992; Sutherland et al., 1989). However, other studies have found their subjects desired a more collaborative or active role (Brandt, 1991; Cassileth et al., 1980; Degner, Kristjanson, et al., 1997; Degner & Aquino Russell, 1988; Hack et al., 1994; Ramfelt, Languis, Bjorvell, & Nordstrom, 2000). The collaborative role would be defined as joint decision making with the health care team., making decisions together with everyone who is involved in the situation. The active role would be described as the patient desiring control over decisions regarding their health care treatments. When assessment of the subjects preferred and actual role obtained were evaluated in studies, only half or less than half of the subjects reported that they achieved the role they preferred (Bilodeau & Degner, 1996; Degner, Kristjanson, et al., 1997; Ramfelt et al., 2000). This is distressing, as patients are not taking part in decisions in the way that they desire.

Preferred involvement in cancer decision making and age and gender as variables which correlated with this preference were established in several studies. This research showed that older patients desired a more passive role, while younger adults desired a

more collaborative role (Beaver et al., 1996; Bilodeau & Degner, 1996; Blanchard, Labrecque, Ruckdeschel, & Blanchard, 1988; Davison & Degner, 2002; Degner & Sloan, 1992; Degner, Kristjanson, et al., 1997). Also, two studies that included both genders in their participant population identified that women desired a more active role than men (Blanchard et al., 1988; Degner & Sloan, 1992). However, Ramfelt et al. (2000) stated that sociodemographic data were not related to the decision making preferences of patients.

An exploratory study of breast cancer patients revealed that the treatment choice of these women was not related to the amount of information they had received at their clinic visit nor the manner in which the information was presented. However, the selection of a treatment was related to the amount of information subjects received prior to their clinic visit (Hughes, 1993). Blanchard et al. (1988), Davison et al. (1995), Juvonen and Lauri (1996), and Sutherland et al. (1989) have highlighted the fact that subjects in their studies desired more information about their cancer experience. Other studies that have considered information needs of patients have evaluated the specific type of information subjects most desired. These studies have found that patients most desired the following types of information: the stage of the disease, likelihood of cure, personal sources, and treatment options. (Bilodeau & Degner, 1996; Davison et al., 1995; Degner, Kristjanson, et al., 1997; Luker et al., 1995; Turner, Young, Young, & Hudson, 1996).

Several studies emphasized the need to include information assessments in the care of cancer patients and considered the extent to which patients desired to be involved in treatment decision making (Bilodeau & Degner, 1996; Degner & Aquino Russell,

1988; Hack, Degner, & Dyck, 1994; Harris, 1998; Neufeld, Degner, & Dick, 1993).

When evaluating the impact of information on decision making, it is evident that patients benefit from being given information. When evaluating the impact of increased information on decision making, Cassileth et al. (1989) found that subjects given information had increased participation in decision making. Other studies have shown an association between decision making and desire for information. They have found that patients who undertake an active decision making role desired more information. (Cassileth et al., 1980; Hack et al., 1994; & Sutherland et al., 1989). However, Davison et al (1995) found that the subjects in their study who preferred a collaborative or passive role desired more information.

#### *Decision Making by Parents of Pediatric Oncology Patients*

A small number of studies have been completed that have evaluated the treatment decisions making preferences of parents who have children with cancer. Pyke-Grimm, Degner, Small and Mueller (1999) evaluated the treatment decision making preferences of parents who had children (less than 13 years of age) with a diagnosis of cancer. Through retrospective interviews they found that parents preferred role in treatment decisions at the time of diagnosis were collaborative (52%), passive (34%) and then active (14%). What was not explored was if parental decision making preferences influenced the preferences of their adolescent children. This warrants further study in order to determine if the majority of adolescents would prefer a collaborative role as well.

Hinds et al. (2000) conducted an exploratory study that sought to describe parental decision making regarding treatment options for their children who were

diagnosed with cancer. Parents included in this study were selected if they met the criteria for one of four groups. These criteria depended on the point of treatment or the disease progression of their child with cancer. The researchers identified that there were differences in the responses from the various sites used for the study (Hong Kong, the United States, and Australia) and from the various decision groups. The 13 parents from group one in this study had children with cancer that had completed their first treatment protocol without disease progression four to six weeks before the interview. This group most frequently stated that the factors that impacted their decision making included “ ‘not having a real choice’ (eight parents, 62%); ‘considering likely adverse effects of treatment’ (seven parents, 54%); ‘maintaining my child’s dignity’ (four parents, 31%); and ‘knowing my child’s preference’ (four parents, 31%)” (p. 1236). It is interesting to note that 31% of the parents included their child’s preferences in their decisions, which suggests that there was collaboration within the family in less than half of those studied.

Another study by Hinds et al. (1999) focused on decisions surrounding continuation of treatments for children or adolescents with cancer. The parents “most frequently reported factors included receiving information from the healthcare team, seeing my child suffer, and remembering my child’s preferences” (p. 95) as influencing their decision making. The decisions evaluated in this study were around treatment continuation and not initiation of treatments. Treatment continuation decisions are quite different from those that are treatment focused or those decisions made after the initial diagnosis of cancer. For example, decisions made at the end-of-life involve the child’s preferences to a greater extent.

*Decision Making in Pediatric Oncology*

A study by Dunsmore and Quine (1995) took place in Australia and focused on adolescent oncology patients and their decision making. This study surveyed adolescents who previously had undergone cancer treatment or at the time of the study were receiving treatment for cancer. Their study determined that in regard to decision making about ongoing treatment, almost half of the respondents desired a collaborative approach, meaning the physician, parents, and the respondents themselves were involved. When asked who had made the actual decision about treatment, most respondents reported that they were not consulted or that they had no control over the decision. This study revealed that adolescents from the sample were not given the role in decision making which they desired. Most respondents felt that they were only partially or not well informed about what had happened to them in the hospital.

Another informative study by Ellis and Leventhal (1993) utilized surveys to discover the information needs and decision making preferences of 50 children (between ages 8 and 17) with cancer and their parents. The results regarding decision making from this study are interesting. Most patients (96%) did not want to make treatment decisions that were curative in nature. The majority of patients (89%) preferred that their physician made decisions, while 7% desired that their parents make the decisions, and 4% wanted to make the decisions on their own. However, 63% of adolescents wanted to make decisions regarding palliative therapies, whereas 28% of the younger patients desired palliative decisional control. This shift in preferred decision control when the illness is considered terminal is an interesting pattern. The results of this study have shown that most children preferred a passive role in decision making about their curative



cancer treatments. This study did not differentiate between preferred and actual decision making.

Information seeking and denial were identified as the most common coping mechanisms that children with cancer used as strategies to deal with the diagnosis of their disease (Chesler & Barbarin, 1987). Coping styles could impact the way in which adolescents desire to be involved in decisions about their care. Intuitively one would expect that those who are utilizing denial as a coping mechanism would desire a more passive role, while those who are information seeking would desire a more active role. Therefore, one would anticipate that adolescents could be at any point on the decision making continuum, from active to passive.

An older study by Levenson et al. (1982) found that patients ages 11-20 years who were newly diagnosed with cancer were less likely to want additional information about their illness and also were less likely to perceive physicians as their main source of information. These researchers also discovered that younger patients were more likely to prefer information from their parents, avoided group discussions with peers and did not want their friends to receive further information about their cancer. No relationships were found between the type cancer diagnosis or the gender of the patient and the desire to have information were found. There are some trends in this data that may have relevance for decision making research. If younger patients prefer more information from their parents instead of health care professionals they may want to have a more collaborative role in decision making, as they desire the involvement of those closest to them. Also, younger patients may not desire the direct connection with the members of

the health care team, which could impact decision making style. Levenson et al. (1982) also stated that the majority of the adolescents in their study preferred the inclusion of parents in discussions regarding their illness. If this principle of collaboration would translate into decision making, it would suggest that adolescents would prefer a more collaborative style of decision making, involving parents and health care providers in decisions.

Hinds et al. (1999) identified the following key factors as influencing the decisions around the continuation of cancer treatment for children and adolescents: making a decision based on what others think is best, ensuring that the choice will benefit others, and also remembering other patients who have died (p. 95). It is interesting to note the way in which the children and adolescents focused on the thoughts and feelings of others. These children and adolescents also valued the experiences of others. It is unknown whether this focus has also been seen in other cancer decisions, the decisions that are not focused around end-of-life treatment decisions.

Several studies describing decision making around risk behaviors in adolescent cancer survivors have been done (Hollen, 2000; Hollen & Hobbie, 1993; Hollen & Hobbie, 1996; Hollen, Hobbie, & Finley, 1997; Hollen, Hobbie, Finley, & Hiebert, 2001). These studies focused on the ability of cancer survivors to make decisions and also the quality of their decisions. They did not focus on the decision making preferences related to cancer treatments.

#### *Limitations of the Current Research*

Minimal research has focused on adolescent oncology patients as the subjects of

study regarding decision making. Nursing research regarding decision making in adolescents with any type of chronic illness is lacking. Limited knowledge exists about the preferences adolescents who are ill have regarding health care decisions. It is unknown what impact the family and health care providers have on the level of involvement adolescents actually possess, and desire to have in decision making. Adolescents are assumed to have some degree of competence and therefore should be offered a choice as to how involved in decisions they desire to be. Research to date has suggested that adolescents are not as involved in the decisions made about their care as they would like to be (Dunsmore & Quine, 1995). However, research has not concluded if adolescents desire one specific way of being involved in decisions (either active, collaborative, or passive). It is evident that there is a necessity to determine how adolescents with cancer desire to be involved in decision making and if any external factors impact upon their decision making preference.

The inconsistencies in the adult oncology literature regarding decision making is evident. Some oncology studies have shown that most adults desire a collaborative role, while other studies have shown that most participants desire a passive role. The studies evaluating decision making aids have suggested that these interventions are of benefit (O'Connor et al., 2003). It is difficult to know if adolescents respond in the same way to decisions and decision making aids as adults. Therefore, it is not advantageous to apply the results of these adult studies to the adolescent population.

The area of study that evaluates adolescent decision making lacks research. This literature review has demonstrated the lack of clarity as to what the decision making preferences of adolescents would be and supports the need to carry out further research

in the area of decision making. This study will contribute to the limited knowledge about decision making in the adolescent oncology population that currently exists.

## Chapter III

### Methodology

This chapter discusses the method and research design utilized in this study. The chapter contains information on the research design, recruitment and sample criteria, the setting for interviews, an explanation of data collection methods (including a description of the instruments utilized), data collection procedures, and also a discussion of the ethical issues considered.

#### *Research Design*

This exploratory study incorporated multiple data collection methods. The semi-structured open-ended interviews assisted in identifying issues that were not captured by the instruments. An exploratory design was utilized as there has been minimal research that has focused on the treatment decision making preferences of adolescents with cancer.

#### *Recruitment and Sample*

The sample was obtained from the pediatric oncology clinic, which provides care for pediatric oncology patients under a universal health system that does not charge user fees. The pediatric oncology clinic provides services to the province of Manitoba as well as northwestern Ontario and parts of Saskatchewan.

The pediatric oncology team at the provincial cancer treatment centre were provided with a presentation and approval was gained to pursue the research that focused on patients seen in their clinic. The Research Impact Committee at the provincial cancer centre approved the study. An intermediary (one of the pediatric oncology nurse clinicians) assisted with the recruitment of participants.

For participation in the study, subjects had to meet the following requirements: 1) between the ages of 12 and 17 and receiving active treatment for cancer (ie. not under palliative treatment, having a life expectancy of one year or longer) or were diagnosed with cancer at the age of 12-17 (meaning they are currently not receiving treatment, but have in the past); 2) were being cared for or had been cared for by the pediatric oncology team at the provincial cancer treatment facility; 3) had been diagnosed with cancer greater than 30 days ago; 4) able to speak, read and write English; 5) given approval by their parent(s)/caregiver(s) (parental/caregiver consent form signed); 6) gave approval to participate in the study (participant assent form signed); 7) had not been diagnosed with a developmental delay or a mental illness; and 8) had not been diagnosed with metastatic disease which could have affected cognitive functioning.

For this study, the age of subjects included 12-17 year olds. This age range was chosen due to the fact that children between 12 and 17 have the ability to make decisions and consider several view points. The study also included participants who were finished active treatment, but were diagnosed with cancer when they were between the ages of 12 and 17. Including individuals who were receiving treatment for cancer and also those who were completed their cancer treatments would allow an opportunity to compare the two groups. The reflection that takes place after cancer treatments are completed may enhance the range of responses.

Nineteen study participants were obtained during the data collection period from July 19 to November 11, 2002. Two eligible individuals refused to participate in the study. The reasons for refusing participation were not obtained. One person agreed to participate, however when interviewed by the researcher it was determined that the

inclusion criteria for the study were not met, as the adolescent was younger than 12 years of age at diagnosis and had completed receiving treatment at the time of the interview. This resulted in a total of 19 participants in the study.

### *Setting*

Interviews with participants took place in several locations. The choice of interview location was based on the participants preference. Four interviews took place within the hospital area where the cancer treatment facility was located. The other 15 interviews took place outside of the hospital.

### *Data Collection Methods*

The study incorporated four instruments, which included the Demographic and Health Information Form, the Control Preferences Scale, the McMaster Family Assessment Device and a Semi-structured Interview Questions Guide.

### *Instruments*

*Demographic and Health Information Form.* The Demographic and Health Information Form was developed for this study by the researcher (Appendix B). This was completed by the participant with or without the assistance of their parent/caregiver. The majority of the participants filled the form out on their own or with minimal assistance from the parent that was present.

*Control Preferences Scale.* The Control Preferences Scale (CPS) was used to measure the decision making preferences of the subjects. The CPS is based on Coomb's theory (1976).

Unfolding theory is based on the premise that an individual's preference corresponds to an ideal point on a continuum, and that this ideal point can be

derived by presenting successive paired comparisons of stimuli that fall along the continuum. In the case of the CPS, the stimuli are the cards and the ideal point is represented by the order in which the subject places the cards, from most to least preferred. (Degner, Sloan, & Venkatesh, 1997, p. 25)

The instrument uses five cards that have a statement and cartoon depicting a patient's role in treatment decision making (Appendix D). These cards focus on three levels of decision making: active; collaborative; and passive. Placing cards in a specific order determines which level of decision making the person desires. The style of presentation of cards used in this experiment was the fixed-order (D, B, C, A, E - see Appendix D for explanation of each card) presentation by hand (Degner, Sloan, & Venkatesh, 1997).

Degner, Sloan, & Venkatesh (1997) and Degner (1998) state the CPS has demonstrated construct validity, having used grounded theory to define the constructs. They also state that the reliability of the CPS is demonstrated in cancer populations through unfolding theory, if 50% plus one of the subjects tested falls on the hypothesized dimension, the scale is considered reliable. This criterion has been met in all previous studies of adult cancer patients. In addition, test-retest reliability was recently demonstrated (.93) in 54 adult cancer patients (L. Degner, personal communication, April 18, 2001).

*McMaster Family Assessment Device.* The McMaster Family Assessment Device (FAD) subscale of General Functioning (see Appendix C) was used to assess the family functioning of the adolescent participants. This self-report scale, based on the McMaster Model of Family Functioning (MMFF), contains 12 items with a choice of one of four answers for each question (strongly agree, agree, disagree, and strongly disagree). The FAD was designed as a screening tool to collect information on the family system as a



whole. (Epstein, Baldwin, & Bishop, 1983; Well-established Self-report Instruments, 1994). The FAD is divided into seven scales, which measure the following: (a) problem solving; (b) communication; (c) roles; (d) affective responsiveness; (e) affective involvement; (f) behavior control; and (g) general functioning. The General Functioning Scale (FAD-GFS) was used in this study. The FAD has a grade seven (age 12) reading level (Well, 1994, p. 12), and therefore is appropriate for the age of the participants in the study. Internal consistency for the FAD-GFS is reported as .83-.86 (Well, 1994) with test-retest estimates as .71 (Miller, Epstein, Bishop, & Keitner, 1985; Well, 1994). The FAD-GFS has also shown discriminative validity (Miller, Epstein, Bishop, & Keitner, 1985), predictive, concurrent and construct validity (Well, 1984).

*Semi-structured open ended interview questions.* The Semi-Structured Open-ended Interview Questions Guide (Appendix E) was developed by the researcher. The questions have been derived from the literature available on adolescent decision making and were reviewed by three experts in pediatric oncology. These questions were used in order to capture perspectives that could not be identified within the quantitative instruments. The purpose was to capture the general decision making experiences during the time of treatment for cancer. The analysis of the interviews involved categorizing responses according to themes or answers identified. The answers obtained were usually short with not a great deal of description. The researcher attempted to obtain more detailed answers from some individuals, but the responses remained short in most cases. Answers were grouped according to similarities of the responses.

#### *Data Collection Procedure*

Initial contact with the subjects was be made by the recruiter. The recruiter

approached eligible participants during their clinic visit or phoned eligible participants at their home. The recruiter needed to contact eligible participants by phone due to the fact that those who were eligible may not have attended the clinic during the data collection phase. The recruiter used the Initial Contact Statement (Recruiter) (Appendix F) when approaching or phoning potential participants. If the participant and parent/caregiver consented to being contacted by the researcher, the recruiter notified the researcher, and provided the researcher with the potential participant's name and phone number. The recruiter told the participant that the researcher would either phone the participant or meet the participant during a clinic visit. Posters describing the research project were displayed in the pediatric oncology clinic area (Appendix G). These posters included the recruiters contact information and were used as another way of recruitment. No adolescents or parents responded to the poster by contacting the researcher directly. All participants in the study were obtained through the recruiter.

The researcher's initial contact with the study participant was by phone (Appendix H). The researcher arranged to meet the participant and parent/caregiver at a convenient time and location. At that meeting (a) a description of the study and the assent or consent form was given to the participant (Appendix I or Appendix J) and their parent/caregiver (Appendix K), (b) the consent and assent forms were signed (if agreement to take part in the study was obtained) and (c) the Demographic and Health Information Form was completed (by the participant with or without the assistance of their parents/caregiver), (d) the FAD-GFS was completed by the participant, (e) the CPS was completed by the participant, and (f) the semi-structured open ended interview questions were answered by the participant.

### *Ethical Issues*

This study was reviewed by three committees. The first approval process was by the investigators thesis committee. The second approval process was through the University of Manitoba, Education/Nursing Research Ethics Board (ENREB). The third review was through the clinical site, the Cancer Care Manitoba Resource Impact Committee. This third review included gaining the approval and support of the Pediatric Oncology group.

#### *Informed Consent and Confidentiality*

Informed consent was gained from study participants and their parent/caregiver through the signing of consent and assent forms. The subjects and their parent/caregiver were made aware that participation in the study was voluntary and that withdrawal at any time during the study was allowed, without penalty. Participants were also made aware that confidentiality would be maintained throughout the study. They were informed that confidentiality would only be broken in one of the following two circumstances: 1) if information relating to child abuse was discovered, or 2) if the participant verbalized that they intended to harm themselves. Neither of these circumstances occurred with any of the participants during the study. All names were removed from the questionnaires and interviews and were replaced with coded numbers. All of the assent/consent forms were stored in a separate place from the coded data obtained during the study. The raw data was stored in a locked container of the researchers and was confidentially destroyed after the study was complete. The researcher is the only individual with a key to the locked data and participant information. No harmful effects were experienced by participants in this study and there were no known risks for those who participated. The researcher did

not access any health records of the participants.

### *Potential Issues*

No known risks to the participants were apparent in this study. This study elicited information regarding the participants actual role in decision making and their preferred role. These decision making roles could possibly have been in conflict. If the adolescent would have discussed issues regarding a desire to change their actual role and voiced that this may have caused tension/conflict in their relationship with their parents, or should other emotional or psychological issues have arisen that were beyond the scope of the research study, the adolescent would have been referred to the psychosocial oncology department. The researcher would have assisted the participant in gaining access to this department, if the participant desired. Should the participant have experienced undue stress during the research process, the researcher would not have continued with the project and would have informed the parents and suggested that their child be referred to psychosocial services. None of the above situations occurred during the interviews with participants.

### *Participant and Parental Involvement*

The parent and child filled out the Demographic and Health Information Form together (if the parent was present with the adolescent). After completing this instrument, the parent was asked to leave the room. If the parent of the participant desired to stay in the interview room or the adolescent requested that their parent stay, the parent was be allowed to stay in the room for the remainder of the data collection stage. However, since this research focused on the participant, the researcher asked the parent to refrain from interfering during any part of the interview. This included

interfering with the completion of the instruments used in the research or answering any questions being asked of the participant after the Demographic and Health Information Form were completed. Four interviews took place with the parent present in the same room. The parents of these four participants did not interfere with the interview process and were not able to see the answers that the participants gave to questions on the FAD-GFS. These parents also did not interfere with the CPS or the semi-structured interview questions. In two of the four cases the parent was attending to other tasks in another area of the room, which did not interfere with the interview.

No ethical dilemmas arose during the research project. No information regarding any ethical issues needed to be resolved, and the plans in place in case an ethical situation occurred did not have to be used.

### *Summary*

This chapter has described the research methods, data collection methods and data collection procedures employed for the study. It is apparent that the guidelines for ethical research were utilized and upheld.

## Chapter IV

### Findings

The focus of this chapter is the presentation of the findings obtained from the exploratory study. The chapter will address the three research questions and the results obtained from the instruments and semi-structured interview questions. A post hoc power analysis concludes the chapter. Prior to the discussion of the findings a description of the study participants will be presented.

#### *Participant Description*

The study included 19 participants. Demographic information about the participants is contained in Table 4.1.

Table 4.1 Demographic Profile of Participants

Characteristics	Total Sample (N=19)
<b>Gender:</b>	
Female	10 (53%)
Male	9 (47%)
<b>Age at Interview:</b>	
13 years	3 (16%)
15 years	3 (16%)
16 years	2 (11%)
17 years	4 (21%)
18 years	1 (5%)
19 years	4 (21%)
20 years	2 (11%)

Characteristics	Total Sample (N=19)
<b>Grade in School (at time of interview):</b>	
Grade 8	2 (11%)
Grade 9	1 (5%)
Grade 10	4 (21%)
Grade 12	7 (37%)
University	1 (5%)
Employed	4 (21%)
<b>Age at Diagnosis:</b>	
10 years	1 (5%)
11 years	2 (11%)
12 years	4 (21%)
13 years	1 (5%)
14 years	4 (21%)
15 years	5 (26%)
16 years	1 (5%)
17 years	1 (5%)
<b>Time Since Diagnosis:</b>	
Less than one year	2 (11%)
12 - 23 months	2 (11%)
24 - 35 months	4 (21%)
36 - 47 months	6 (32%)
48 - 59 months	2 (11%)
60 - 71 months	1 (5%)
Unknown	1 (5%)
<b>Receiving Treatment for Cancer at Time of Interview:</b>	
No	13 (68%)
Yes	6 (32%)
<b>Time Since Treatment Complete</b>	
Not completed treatment	6 (32%)
Less than one year	2 (11%)
12 - 23 months	1 (5%)
24 - 35 months	7 (37%)
36 - 47 months	1 (5%)
48 - 59 months	1 (5%)
Unknown	1 (5%)

Characteristics	Total Sample (N=19)
<b>Length of Cancer Treatment</b>	
Not completed treatment	6 (32%)
Less than 6 months	3 (16%)
7 - 11 months	5 (26%)
12 - 23 months	2 (11%)
24 - 35 months	0 (0%)
36 - 47 months	2 (11%)
Unknown	1 (5%)
<b>Living Environment:</b>	
Urban	14 (74%)
Rural	5 (26%)
<b>Diagnosis:</b>	
Leukemia	8 (42%)
Hodgkin's Disease	4 (21%)
Brain/Nervous System	3 (16%)
Bone	2 (11%)
Liver	1 (5%)
Soft Tissue Sarcoma	1 (5%)
<b>Type of Cancer Treatment Received:</b>	
Chemotherapy	18 (95%)
Surgery (central line or port insertion)	12 (63%)
Radiation	9 (47%)
Surgery (removal of tumor)	4 (21%)
Bone Marrow Transplant	1 (5%)
<b>Number of Hospital Admissions:</b>	
8 or less admissions	7 (37%)
> than 8 admissions	11 (58%)
Unknown	1 (5%)
<b>Reasons for Hospital Admissions:</b>	
First diagnosed	16 (84%)
Chemotherapy	16 (84%)
Infection or fever	11 (58%)
Surgery	11 (58%)
Other (i.e. blood clot, anemia, esophagitis)	6 (32%)



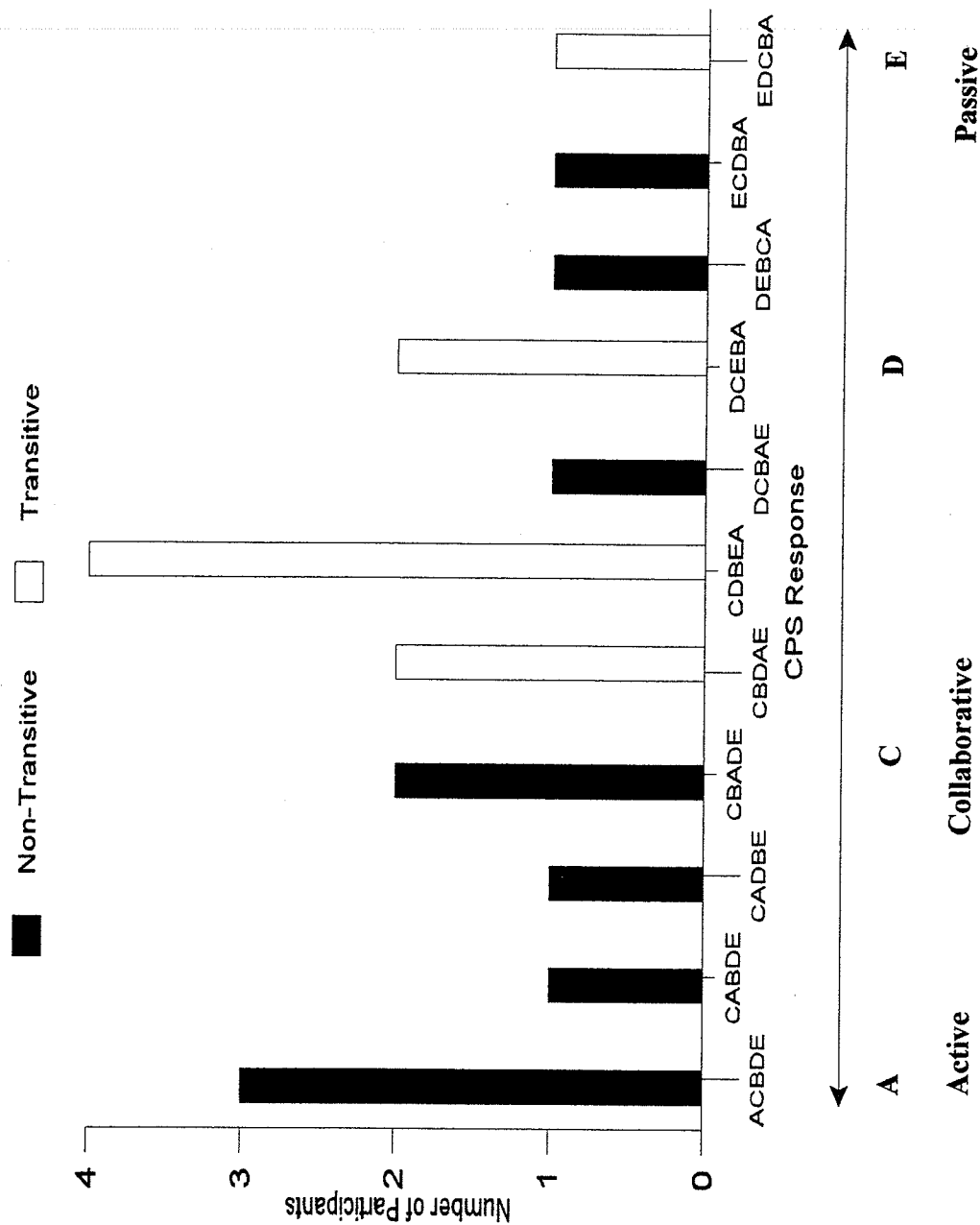
## Findings

### *Research Question One: Adolescents Desired Role in Treatment Decision Making*

To answer this first research question the CPS responses and the semi-structured open-ended interviews were analyzed. This section will highlight the CPS responses obtained from the study. Data analysis of the CPS was followed as described in the article by Degner, Sloan and Venkatesh (1997). There are a total of 120 possible preference orders, but only 11 possibilities are included on the ordinal scale. The 11 possibilities on the ordinal scale are considered valid permutations, which are known as transitive responses. These criteria are quite stringent and the preference order chosen by participants do not always fall on this ordinal scale. All preference orders were included in this study, whether they were transitive or non-transitive. The results of the CPS string variables are included in table 4.2.

Of the 11 valid permutations suggested by Degner, Sloan, and Venkatesh (1997), four of these valid permutations (a total of nine participants) are seen in the data obtained from this study. The valid permutations are also known as transitive responses and in this study the following transitive sequence orders were selected: CBDAE, CDBEA, DCEBA, EDCBA. Seven permutations (a total of 10 participants) are not on the ordinal scale, so they are considered non-transitive. In five of the non-transitive responses (ACBDE, CBADE, DCBAE, DEBCA, ECDBA) there is a switch in order of two of the letters in the string. When evaluating which two letters have been switched, in four of the five permutations the two choices that are in reverse order are the collaborative choice (C) and one of the active or passive choices (B or D). In the last permutation of the five with two letters switched, the active (A) and passive (D) choice are switched. In the

Table 4.2 - Control Preferences Scale String Variables Results - Frequency of Responses



other two permutations that are not on the ordinal scale (CABDE, CADBE), three of the letters are out of order. Both of the participants with three letters out of order were 17 years of age at the time of the interview. When accounting for age it is evident that these non-transitive permutations were not chosen by younger participants. This might be expected if it is thought that individuals who are younger may not understand the concept of decision making preferences utilized in the CPS. Therefore, one would assume that the adolescents did not have difficulty understanding the constructs and continuum on which the instrument was based.

These results highlight the fact that adolescents may not understand the specific nuances of some of the options presented in the card. Ten of the adolescents did not fall on the ordinal scale which suggests they do not recognize that there is a logical continuum (from active extreme, to passive extreme) that exists within the card choices.

The string variables were then analyzed by evaluating the first two preferences chosen by the participants, as ten participants' permutations were not on the ordinal scale. Degner, Sloan and Venkatesh (1997) stated that computer data analysis of the data obtained from the CPS can produce string variables, which are assessed for rank order in, producing ordinal scale values from one to 11. Based on the sample size for this study, and the number of results not on the ordinal scale, the first two choices were analyzed. Table 4.3 shows the answers in each category based on the first two selection preferences for the CPS card sort.

Table 4.3 - Control Preferences Scale Information - First Two Selections

<b>CPS First Two Selections</b>	<b>Number of Participants</b>	<b>Percent</b>
Active - Active	0	0
Active - Collaborative	3	15.8
Collaborative - Active	6	31.6
Collaborative - Passive	4	21.1
Passive - Collaborative	4	21.1
Passive - Passive	2	10.5

These results clearly show that there are variations within the adolescents preferred role in decision making. It is interesting to note that no participants chose the extreme of active decision making (A, B as first two preferences). The results are spread between the other categories that have one of the first two choices as a collaborative role. The category with the most responses (six participants selected this category) is the collaborative-active role. The passive-passive category has two subjects that chose this as their preferred decision making role. If dividing the CPS into active (active-active, active-collaborative, collaborative-active) and passive (collaborative-passive, passive-collaborative, passive-passive) categories based on the first two selections, nine participants (47%) would fall under the active category, while 10 participants (53%) would fall under passive. If dividing the CPS into active, passive and collaborate categories, based on the first selection chosen by participants, three participants (16%) would be under the active category, 10 participants (53%) in the collaborative category, and six participants (31%) in the passive category. Almost half of the participants would have chosen the collaborative card as their top preference in decision making.

### *CPS Reliability and Validity*

Degner, Sloan & Vankatesh (1997) have described the 11 transitive ranked orders for the CPS in their article. They state that the CPS is valid if all the transitive orders are seen in the sample (including both extremes - ABCDE, EDCBA). The CPS is reliable if 50% plus one percent of the ranked orders fall on the transitive orders. In this sample, the CPS is not valid as only 4 of the 11 transitive orders were used. Only one extreme was seen in this sample (EDCBA). The active extreme (ABCDE) was not selected by any participants. The CPS is not deemed reliable in this study, as only 9 out of the 19 participants (47.4%) chose the transitive rank orders. However, the small sample size of only 19 participants must be taken into account when evaluating the validity and reliability criteria. With such a small sample size it is almost impossible to meet the criteria to show validity and reliability. A larger sample size of adolescents is needed in order to validate the CPS in the adolescent population. No other studies of adolescents have been undertaken to validate the CPS. Therefore, it is not known whether this tool is valid for populations other than adults. Based on the above arguments, the CPS was still utilized in this study as it was difficult to achieve reliability and validity with such a small sample.

### *Research Question Two: Relationship Between Family Functioning and Decision*

#### *Making Preferences*

In order to determine the relationship between these two variables the CPS outcomes were divided into two groups (active and passive) and the FAD-GFS score was calculated. The FAD-GFS includes positive and negative statements (which require reverse scoring). The responses were then totaled and a final score obtained. Higher

scores indicate unhealthy family functioning, whereas lower scores indicate healthy family functioning (Grotevant & Carlson, 1989). The minimum score that one could obtain would be 12, with a maximum score of 48. The participants final scores for the FAD-GFS are included in Table 4.4. It is evident from the final scores, that the participants in this study rated their family functioning as quite healthy.

Table 4.4 - Family Assessment Device - General Functioning Scale Final Score

<b>FAD-GFS Final Score</b>	<b>Number of Participants</b>	<b>Percent</b>
16	2	10.5
17	2	10.5
18	0	0
19	4	21.1
20	1	5.3
21	1	5.3
22	1	5.3
23	2	10.5
24	2	10.5
25	1	5.3
26	2	10.5
27	1	5.3

Utilizing a one-way analysis of variance (ANOVA) with the CPS score as the dependent variable and the FAD-GFS as the independent variable (see Table 4.5), it was determined that there is no difference in CPS score (active versus passive) by FAD-GFS score ( $F=1.095$ , 10 df,  $p = .458$ ). Family functioning did not differ by the decision making

preferences of the participants.

Table 4.5 - One-way ANOVA

	Sum of Squares	df	Mean Square	F	Sig
Between Groups	2.737	10	.274	1.095	.458
Within Groups	2.000	8	.250		
Total	4.737	18			

*Research Question Three: Relationship Between Demographic and Health Information  
Factors and Decision Making Preferences*

To determine the answer to the final research question, the non-parametric Pearson Chi-Square test was utilized. Chi-square tests are used to evaluate the association between two variables. The CPS results were split into two groups, active (active-collaborative, and collaborative-active) and passive (collaborative-passive, passive-collaborative, passive-passive), based on the participants first two chosen cards in the CPS.

One of the chi-square tests was invalid and therefore was not used, as one of the cell sizes was too small. This test included the demographic variable describing the participants who were currently receiving treatment. There were no participants who were currently receiving treatment in the active grouping.

There were no differences in CPS outcome (active versus passive) by living environment (urban versus rural) ( $\chi^2 = .434$ ,  $df = 1$ ,  $p = .51$ ), by gender ( $\chi^2 = .059$ ,  $df = 1$ ,  $p = .809$ ), time since diagnosis (less than 3 years versus 3 years or more) ( $\chi^2 = .540$ ,  $df =$

1,  $p = .463$ ), age at interview (13-16 years versus 17-20 years) ( $\chi^2 = 2.773$ ,  $df = 1$ ,  $p = .096$ ), age at diagnosis (10-13 years versus 14-17 years) ( $\chi^2 = .038$ ,  $df = 1$ ,  $p = .845$ ), and number of admissions to hospital (8 or less admissions versus more than 8 admissions) ( $\chi^2 = 3.060$ ,  $df = 2$ ,  $p = .217$ ).

This research study is a pilot project with a small number of participants. Therefore, if evaluating these Pearson Chi-square tests with a less conservative  $p$  value ( $p = .1$ ), it is apparent from the data in the above paragraph, that age at interview would then be significant ( $p = .096$ ). The 2 x 2 table (Table 4.6) for CPS outcome by age at interview displays a trend that suggests participants who are older at the time of interview desired a more active role in treatment decision making, while those participants who were younger at the time of the interview desired a more passive role in treatment decision making.

Table 4.6 - 2 x 2 Table for CPS by Age at Time of Interview

	13-16 years at time of interview	17-20 years at time of interview	Total
CPS - Active	2	7	9
CPS - Passive	6	4	10
Total	8	11	19

### *Semi Structured Open-ended Interview Questions Analysis*

#### *Good Decision Experience*

When answering the semi-structured interview question regarding good treatment



decisions five of the participants did not have an answer or could not recall any good decisions at the time of the interview. Five of the participants discussed decisions around specific treatment choices. These treatment choices included: starting treatment right away, using another anti-emetic, being placed in the experimental group for a treatment protocol, being allowed to decide between radiation or surgery as the method of treatment, and having surgery that did not require removal of their limb. Three participants described good decisions as action taken regarding their treatments and responded to the question by stating "That they could do something about it , I guess" , "Well, I guess I got better, so....That's probably the best part of it" , and "I think everything was done pretty well". Two participants commented about the health care staff being supportive by listening and explaining what would happen. Two other participants discussed the surgical procedure of getting a central line as a good decision. Of the remaining two participants, one stated that having the opportunity to give the final consent regarding taking part in a treatment study was a good decision, while the other participant stated that having their treatment close to home was a good decision that was prominent in their mind. A summary of these responses is included below in Table 4.7.

Table 4.7 - Summary of Responses to Question Regarding Good Decisions

Response	Number of Participants (N=19)
Decision about specific treatment choices	5 (26%)
Actions taken regarding treatment	3 (16%)
Health care staff supportive and provided explanations	2 (11%)
Surgical insertion of central line	2 (11%)
Opportunity to give final consent for participation in a study	1 (5%)
Having treatment close to home	1 (5%)
No answer or could not recall any good decisions	5 (26%)

### *Bad Decision Experience*

Participants had various answers regarding a bad experience when a decision was made about their cancer. Eight participants stated that they could not think of a decision that was bad or that they regret took place. Of these eight, one commented that she had no time to think during the diagnosis period, which contributed to her lack of involvement in the decision making process. Five participants recalled specific treatments when asked about a bad experience about a decision. These treatments included: an operation to remove fluid off the lungs (the participant stated he was “awake” during the procedure, which was the specific “bad” experience), a spinal tap, vaccination for exposure to chicken pox (which turned out to be unnecessary, as no exposure had taken place), nasogastric tube insertion, and a bone marrow aspiration (where the participant was not anaesthetised for the first one, but was for the all the others following the first aspiration). Two participants viewed the whole treatment

experience as a bad experience, while one discussed hospital admissions as particularly bad experiences. Two other participants discussed specific decisions as being bad. One of these participants stated that her bad experience was having a methotrexate level that was too high, so she could not be discharged from hospital, while the other stated he got his test results and then was admitted directly to the hospital and did not have time to go home and get the personal belongings that he desired. One participant discussed hospital admissions as being bad experiences. The final participant discussed that she felt she was not fully informed about the outcomes that would happen with the surgical procedure she was offered as one of the options of her treatment (the option she had chosen to pursue). The results obtained from this questions are included in Table 4.8.

Table 4.8 - Summary of Responses to Question Regarding Bad Decisions

<b>Response</b>	<b>Number of Participants (N=19)</b>
Could not think of a bad decision making experience	8 (42%)
Specific treatments /tests	5 (26%)
The entire cancer treatment experience and all decisions	2 (11%)
Methotrexate level too high and not able to be discharged from hospital	1 (5%)
Admitted directly to hospital after initial diagnosis with no time to go home and collect personal belongings	1 (5%)
Hospital admissions	1 (5%)
Not being fully informed of surgical outcomes when treatment options presented	1 (5%)

### *Additional Decision Experiences*

When participants were questioned about any other decisions and wanting to make these decisions in a different way, 14 of the participants stated there were no other decisions made or that they would not change any of the decisions. Four participants mentioned specific decisions that included: bone marrow aspiration being performed in the operating room (this decision the participant stated was a particularly good decision), being admitted to the intensive care unit (the participant stated that she was not involved in the decision, as she was not capable, due to her ill state), having radiation treatments, and the desire to be more informed about the kind of medications used and the action and purpose of the medications. One participant was not asked this question as there was a disruption in the interview and this question was unintentionally omitted from the recording of the interview.

### *Health Care Professionals*

When asked about what they would like to tell doctors and nurses about the decisions made about their cancer 14 participants stated that they would not change the way the health care professionals were involved, which suggested they were satisfied with the way in which decisions were made. Of these 14 participants, two highlighted specific qualities they appreciated such as the health care staff's ability to listen and explain procedures, while another two participants valued the health care staff making the decisions for them, and two enjoyed the opportunity to be involved in the decisions that were made about their care. It is interesting to note that of the two participants who appreciated the health care team making decisions for them, one participant chose the passive and collaborative cards of the CPS as her first two choices, while the other

participant chose the collaborative and active cards of the CPS as her first two choices. Of the five remaining participants, two participants stated that they desired more involvement in the decisions made about their care (both chose active-collaborative as first two choices), one participant discussed being upset about being told that she would have hair loss, which did not occur (chose passive-collaborative), and the other participant discussed desiring more information (collaborative-active were first two choices). Table 4.9 summarizes the results for this question.

Table 4.9 - Summary of Responses Regarding Health Care Professionals and Decisions

<b>Response</b>	<b>Number of Participants (N=19)</b>
No changes in health care professionals involvement	14 (74%)
Participants wanted to be more involved with the health care team	2 (11%)
Participant upset about information regarding hair loss given, information was not accurate for her case	1 (5%)
Participant desired more information from the health care team	1 (5%)

### *Parent(s) and Family*

More than half (13) of the participants responded to the question about parental and family involvement in decisions by stating that their parent(s) was/were involved and supportive. These participants appeared to be satisfied with the role their parent(s) played in the decisions surrounding their cancer. One of these 13 participants highlighted the fact that discussions took place in front of him, and that he appreciated

explanations and the open dialogue. Out of the six remaining participants one answered the question stating that her mother made the decisions as she was “out of it” or too sick to make the decisions herself. One participant felt that her parents were “not really” involved. Another participant stated that his parents wanted him to make a lot of the decisions and that he liked being in control of what was happening to him. One participant stated that her parents were not involved in the decisions about her care and that she would “rather them not even’ve been there”. The remaining participant who answered this question stated that her parents were very involved and took control, specifically her father. She did not mind that they made decisions with her oncologist, as she was initially too shocked to participate in any type of decisions made about her care. One participant did not fully answer the question, but did state that her parents asked questions and tried to provide explanations to her. However, she did state that she felt health care professionals talked to her parents instead of her.

#### *Advice to Newly Diagnosed Adolescent With Cancer*

The question about what advice the participant would give to other adolescents diagnosed with cancer elicited several responses. The response that was most widely used (by 10 participants) was the suggestion to be actively involved. Participants statements included being involved by taking control. One participant said “you should push for it...be pleasantly pushy”. Another stated:

Think things through very, very, very carefully. Like talk about it a lot with your doctor; if you’re not sure about something, make sure you clarify what’s going on and what they want to do and why they want to do it, ’cause otherwise, you’re gonna be freaked out. (20 year old female, completed cancer treatment for

leukemia)

It is interesting to note that the participants who suggested this active involvement had themselves preferred to be involved in decision making in several different ways. This group of 10 participants ranked their first two preferences on the CPS in the following way: three in the active-collaborative group, three were in the collaborative-active group, three in the collaborative-passive group and one from the passive-collaborative group. The three participants that responded to the open-ended question with a statement about letting the physician make the decision were from two of the CPS groups. Two participants were from the collaborative-active group, while the other was from the passive-collaborative group. Two participants did not answer this question appropriately, as one focused on the use of an anti-emetic and stated "If you don't like the med-, medicine you can ask for a different kind". The other stated "Well, I just kinda, thought that it's gotta be done, so if it hurts or whatever, just, you have to do it, so...". Of those who stated they did not have an answer to this question (four participants), one was from the collaborative-active group, one from the collaborative-passive group, and the other two were the passive-passive group.

#### *Preferred and Actual Decision Making*

The question regarding preferred decision making style and if this was the actual way in which the participant was involved in decision making was added half way through the study. Therefore only 11 participants had a chance to respond to this question. The information from this question is included in the study as the value of the answers obtained is apparent. The first choice that the participant had chosen in the CPS card sort was verbally stated to the individual by the researcher and then the participant

was asked if this was the actual way that the decisions regarding their cancer treatment had happened. One participant had their first choice in the CPS card sort as active, and stated the following about their actual role:

Actually, I didn't have a choice. They just -, they pretty much just said this is the one round, it's the treatment that we're going to give you. The only choice I really had was with the surgery: um, I could have went with the amputation or with th-, different things. And that was my final decision. I, I got to choose that. (19 year old male, completed treatment for bone cancer)

Eight of the 11 participants who were asked this question had their first choice in the CPS card sort as collaborative. Of these eight, four felt that the way in which decisions were made was collaborative. One of these four stated:

Another one of these four participants highlighted that fact that she desired more collaboration with the physician directly, without parental involvement.

I think Dr. \_\_\_\_\_ tried her hardest to make me involved in decisions, but I mean, a lot of it had to do with my parents. It was more doctor-parent type relationship. Like a lot of stuff was dealt with between the two of them, rather than just myself and her, like myself and Dr. \_\_\_\_\_. So, I would have liked to see more, like , the way it is now, where I just, I go and see her myself, is probably how I would have wanted to be treated while I was being treated, like where my Mom wasn't so involved. 'Cause I couldn't ask certain things that I wanted to ask, or I couldn't express certain things that I wanted to, and I think it would have changed my decisions in some aspects, like. (20 year old female, completed cancer treatment for Hodgkin's Disease)



Two of the eight participants with the collaborative card as their first choice did not feel this was what was actually achieved. They attributed this to the set protocols and having no choices or possible alternatives. One of these two did state that if they would have wanted to change something that the health care team would have listened. One participant had mixed comments about whether their preferred role of collaboration actually happened. She stated the following when answering the question:

Um, yes and no, I guess. For a lot of things it was. But like I said, I was 15. Had it been now, I'm 20, it would probably be a little difference because I'd be an adult, you know, I'd be a little more mature. But as it was there, my doctor and I – my parents had a lot de–, decisions in there, too, of course – but my doctor, like, wouldn't do something I was against other than stuff I had to have. Right? She wouldn't – My doctor was like, if I was, if I said no, or whatever, about doing something, they were pretty cool about it. Like taking an ambulance to hospital and stuff: they wanted me to take an ambulance...they let me get away with a lot. But for the most part, we made decisions about stuff, about should I get a new central line, should I take my central line out, should I do this, should I do that. You know? \_\_\_\_\_, she suggested to me to sit up during my spinal taps, rather than lying down. And, so that worked. We ended up doing that and that worked perfectly. So, like, we, we made that decision – I guess, I guess, we both did, yeah. (20 year old female, completed cancer treatment for leukemia)

The two participants who had one of the passive cards as their first choice both stated that their actual decision making role was congruent with their preferred decision making role. The remaining participant did not know if the collaborative way of decision making

that they desired actually occurred.

When evaluating the participants preferred and actual decision making roles it is evident that the preferred role was not obtained for all participants (see Table 4.10). Of the 11 participants who answered this question six (54.5%) of them stated that they had achieved their preferred role, 3 (27.3%) had not achieved their preferred role and 2 (18.2%) were undecided as to whether they had achieved the collaborative role that they desired.

Table 4.10 - Preferred and Actual Decision Making Roles (n=11)

PREFERRED ROLE		ACTUAL ROLE		
	Total	Achieved	Not Achieved	Undecided
Active	1		1	
Collaborative	8	4	2	2
Passive	2	2		

#### *Additional Interview Comments*

There were some comments from the adolescent's during the recorded interview that did not fit into the questions asked, but that deserve to be highlighted and included in this discussion of findings. One participant talked about a distinct point in time when she desired to be more involved in her cancer decisions, which occurred when she lost her hair. She had also stated that her parents, particularly her father, had been very

involved in decision making upon diagnosis and that she liked the control her parents took at that point.

Well, I think why reality set in - the most part- wasn't necessarily 'cause my hair fell out, but - the more I think of it - it was the fact that I was away on my own visiting family. And then my hair started falling out and I made this decision to shave my head. And, and then I was fine with everything. But, the, like, thinking about things and wondering when this is going to happen and, is a lot more difficult because I wasn't involved in my own cancer more than I wanted to be, until then....I don't know if it's that way for most people but I think, yeah, for myself, uh, I really wanted to be involved in it, but half of me was scared to be involved in it. So, that's why I think having the doctor involved along with you is much more pleasant and comfortable, because you still have the-, like I still trust my doctor and I know what she suggests probably is the right way to go, but I still would like her to suggest it to me rather than suggest it to my parents. (20 year old female, completed cancer treatment for Hodgkin's Disease)

The event of losing her hair precipitated her desire to be more involved in the decisions that were being made about her cancer. This was a unique statement made by one participant, but it would be interesting to explore if other adolescents may undergo a similar experience in terms of changing their preference for involvement during the course of their treatment.

Another participant discussed a particular encounter with an oncologist who has not been trained in pediatrics. It is interesting to note that this meeting is discussed, as it obviously stands out in the participant's mind.

Participant 12: Yeah, I think, I think the people that told me were more just telling my parents...uh, rather than me.

Researcher: They didn't really speak to you, kind of?

Participant 12: Yeah, I don-, I don't think Dr. \_\_\_\_\_ could though. 'Cause he has a young daughter, too, and like, he couldn't even look at me. Even the other day when I went to see him and he mentioned something and I started crying and he was, like, 'Oh-h-h-h-h-h', Like I, I think it really bothered him, that he had to go through this with me, because I'm so young, you know, like, just like his daughter. Like, he always talked about his daughter. So... (19 year old female, completed cancer treatment for bone cancer)

This participant must have felt that her interactions with an adult oncologist were different than those with the pediatric oncologists, as she thought it was something important to mention. This phenomenon would also be interesting to explore, as interactions with physicians not trained in pediatrics (who are not the adolescents primary physician or primary specialist) may cause the adolescent to change their preferred choices in decision making. It would be interesting to investigate if a level of comfort with a physician or the development of trust would impact the decision making preferences of adolescents. If changes in decision making would occur with increased trust, then this would suggest that decision making preferences could in fact change if an adolescent was placed in a different circumstance with different health care professionals.

When asking the semi-structured interview questions, it was interesting to note that the younger participants had a more difficult time recalling specific decisions made

about their cancer care. The interviews that were the most informative, the longest in length and included the most examples were those of the older adolescents. Some of the older adolescents recognized the impact of cancer on the rest of their life and saw the decisions that impacted their cancer treatments in more of a broad perspective. The impact of communication, specific treatment decisions and specific individuals were often included in their interview. Some individuals in this study had completed their treatments two to four years previous to the interview. When these individuals were interviewed, this did not impact their ability to recall decisions, as many examples were included in their answers.

When re-examining the quantitative data based on the answers obtained from the semi-structured interview questions it is interesting to note the degree of involvement of the participants parents. Most parents were quite involved, which is what the majority of participants stated they preferred. It was apparent that most participants appreciated the involvement of their parents. It would be natural for adolescents to demonstrate similar decision making characteristics as their parents. It is unknown what the decision making styles and preferences of the parents were. In the future it would be interesting to study if there would be a correlation between the parents decision making preferences and the decision making preferences of their adolescent children who have been diagnosed with cancer.

#### Post Hoc Power Analysis

The sample size for this study was quite small. To evaluate what sample size would be necessary for the statistical tests utilized, power analyses were done. Information by Cohen (1977) was utilized to obtain these each power analyses. To

determine the power analysis for the second study question which utilized a one-way ANOVA a medium effect size ( $F=0.25$ ) was utilized. As two groups were utilized  $u=1$ . With a power of .80 the number necessary in each group would be 64, resulting in a required total sample size of 128 participants.

The third research question was answered using Chi-square analysis. When utilizing a medium effect size ( $u=30$ ), with a power of .80 and  $\alpha=.05$ , the appropriate sample size necessary in order to detect a type II error would be 87 participants. If  $\alpha$  was changed to 0.1 to be more lenient in rejection of the null hypothesis, the sample size necessary would be 69 participants. Evaluating these calculations it is apparent that the sample size utilized in this study was very small.

### Summary

From this exploratory study it has been discovered that in the population studied was representative of the age group. The participants desired varied roles in decision making from active to passive, with just over half of the participants choosing the collaborative role as their first preference. The results of the analysis also showed that there was not a significant relationship between family functioning and decision making preference. When evaluating the relationships between specific demographic variables and the decision making preferences of participants the only demographic variable to show any significant relationship was the participants age at the time of interview. Those who were older at the time of interview preferred a more active role. The semi-structured interview questions disclosed information regarding specific decisions that the adolescents could recall and also how the health care team and their parents were involved in the decisions. More than half of the participants responded to a question

about their preferred and actual decision making role and the congruence between these roles. Just over half of these respondents stated that they achieved their desired role. It is evident through the post hoc power analysis that a larger sample size would be required for further studies evaluating these research variables in the adolescent population.

## Chapter V

### Discussion

This chapter will focus on the results obtained from this study. The chapter will include a discussion of the following: the prominent findings from the current research, a comparison of the current findings to other pediatric oncology decision making studies, relationship between decision making preference and demographic variables, preferred decision making style and suggestions to hypothetical newly diagnosed adolescent, importance of collaborative decision making in adolescents, the theoretical framework, the instruments, the sample representativeness, the limitations of the study, and recommendations for future research.

#### *Prominent Findings*

There are four striking findings in this study. The first is that there was no relationship between family functioning and the decision making preferences of the participants. Secondly, there is a trend suggesting a relationship between more active involvement in decisions and higher age at interview. The third striking finding is that the advice which the participants would give to other adolescents who are newly diagnosed with cancer showed that half of the participants would tell the hypothetical newly diagnosed adolescent to have a different decision making style than what they chose as their own preference. The fourth finding is the importance of the collaborative nature of decision making for adolescents. These findings will be discussed in this chapter.

#### *Comparison of Study Results to Other Pediatric Oncology Studies*

The results of this study demand comparison with results of the two research



studies on pediatric oncology decision making included in the literature review (Dunsmore & Quine, 1995; Ellis & Levetthal, 1993). When viewing the preferences regarding involvement in decision making, Dunsmore and Quine (1995) categorized their participants preferences in a different way. However, when evaluating their categories from an active, collaborative and passive stance, it is evident that of the 51 participants in their study six (11.8%) desired active participation (decision made by themselves), 41 (80.4%) desired collaborative decision making (decision made by themselves and the physician and/or their parents), and four (7.8%) desired a passive role (physician or parents making the decision). The percentages from Dunsmore and Quine's (1995) study have similar trends with the current study where the active preference was chosen by three participants (15.8%), the collaborative chosen by 10 participants (52.7%) and the passive chosen by six participants (31.6%).

Ellis and Leventhal (1993) utilized a survey that did not allow for a response that included collaborative decision making, and therefore state that their results are not reliable (pp. 282-283). The results they obtained from the 50 patient surveys indicated that 89% of the patients desired that their doctor make treatment decisions (passive), 7% wanted their parents to make decisions (passive) and 4% wanted to make their own treatment decisions (active). Therefore, 96% want a passive role and 4% desired an active role. As the collaborative category did not exist within their study it is difficult to evaluate the similarities or differences with the present study.

#### *Relationship Between Decision Making Preference and Demographic Variables*

The results of the analysis evaluating if any relationships exist between the demographic variables and the CPS outcome show that in fact for all but one of the

demographic variables there is no relationship. There is a trend suggesting a relationship between more active involvement in decisions and higher age at interview. This is interesting to evaluate and should be further assessed with a larger sample, as it is difficult to determine differences in a sample so small. In adult populations the patients who preferred a more active or collaborative role were younger, while older patients desired a more passive role (Beaver et al., 1996; Bilodeau & Degner, 1996; Blanchard, Labrecque, Ruckdeschel, & Blanchard, 1988; Davison & Degner, 2002; Degner & Sloan, 1992; Degner, Kristjanson, et al., 1997; Rothenbacher, Lutz & Porzsolt, 1997). This is explained by the fact that those in the older generation are used to a more paternalistic or authoritarian approach to health care and therefore would not desire an active role. However, a study by Ramfelt et al. (2000) found that there was no relationship between age and patient's decision making preferences.

The adult population is quite different from the adolescent population, and there are different reasons why older adolescents would desire a more active role. Perhaps age, the extra years of maturity, increased cognitive functioning, and increased decision making skill impact the way in which older adolescents desire to be involved in decisions about their cancer treatments. Older adolescents may feel that they have the capability and intellectual ability to make decisions. Older adolescents may also have had more opportunities to make difficult life choices, which have enhanced their coping and decision making abilities. Claflin and Barbarin (1991) found that older children (9-14 years and adolescents) diagnosed with cancer were given more information about their cancer from their parents than younger children. This research points out that adolescents have had the chance to obtain more information. This may also mean that

they are involved in important decisions and their parents have given them some independence or have consulted with adolescents about decisions that may impact them, which would suggest the adolescents may feel that there is a level of confidence in their abilities. This confidence and experience would then translate into decisional competence and preference for a more active role in decision making. Younger adolescents may not know that there are varying degrees of decisional participation available to them, and so their decision abilities may be more limited.

*Preferred Decision Making Style and Suggestions to Hypothetical Newly Diagnosed Adolescent*

In the current study adolescents did not struggle with the CPS card sort and making a decision about their preferences based on predetermined responses. Some adolescents had difficulties in identifying decisions that were a part of their cancer treatments. There were also some discrepancies in the roles that the adolescents chose and then how they suggested other adolescents who were newly diagnosed should deal with decisions. Whereas only three participants chose active involvement as their first choice in the CPS, 10 participants stated in their answers to the open-ended question that other adolescents should be actively involved in decisions. This hypothetical situation of making suggestions to a newly diagnosed friend suggests that these adolescents may see others as being capable of taking an active role, but do not consider this active role as an option for themselves. This hypothesis would need to be explored in greater depth to understand the reasoning behind the discrepancy of choices for themselves and suggestions to others.

In a decision making study that utilized an intervention, there was an increased

number of participants who assumed an active role (Davison, 1997). This suggests that with effective interventions patients may be able to achieve a more active role.

Adolescents may feel they do not possess the skills or abilities to be involved in decisions, which would impact the role they chose to play. If interventions were used with adolescents these interventions may change the way adolescents desire to be involved in their health care decisions. Interventions may also make the adolescent aware of the variety of roles that they could take in decision making. This could change the desired and the actual roles they take in the process.

#### *Importance of Collaborative Decision Making in Adolescents*

From the open-ended interview question about parents and decision making it is evident that the majority of participants in this study value the input of their parents. This would suggest that they would also like the involvement of their parents in decisions made about their care. Parents/families have been identified by adolescents with cancer as being important and valued (R. Woodgate, personal communication, July 11, 2003). The theoretical framework utilized in this study would also support this statement. A study by Levenson et al. (1982) found that the majority of the adolescents in their study preferred the inclusion of parents in discussions regarding their illness. This study focused on information needs, which are reasonably similar to decisions.

#### *Theoretical Framework*

This study does not support the relationship between family functioning and decision making preference as described in the theoretical framework. There may be several reasons why this component of the theoretical framework for this study is not be supported. The first is that the portion of the theoretical framework by Mann, Harmoni,

and Power (1989) that focuses on the development of competence in adolescent decision making was developed to understand everyday decision making in adolescents and the transition that occurs in the adolescent years. The focus was on cognitive aspects of decision making. Perhaps health care decisions are not similar to other decisions made by adolescents and the process and outcomes of the decision making process may be different when more serious decisions (ie. health care decisions) need to be made. Also the cognitive aspect of decision making may not be as applicable for health care decisions. Another view may be that no matter what type of family functioning exists (if there are breakdowns in the functioning or not), families remain an important part of the decision making process. If the family is not functioning well, this may not impact the adolescents decision making ability or decision making preference in any way.

The data from this study may not have shown a relationship between family functioning (using the FAD-GFS) and decision making preferences for several reasons. The responses of the participants on the FAD-GFS showed final scores of 16-27. These scores suggested healthy family functioning for all participants in this study. The final scores were not at the extremes of the scale (final scores can be between 12-48) and therefore it was difficult to measure differences between individuals, as the responses from the participants did not span a large range. The instrument does not have a defining score that represents unhealthy family functioning, which makes it difficult to decipher if participants have healthy family functioning. Social desirability may also have played a role in how the participants responded to the questions included in the FAD-GFS. This would have lead to the participant providing responses that did not reflect their true situation.

Perhaps a prescriptive model, such as one described by Janis and Mann (1977), or an information processing model, such as a model developed by Ross (1981) would be appropriate. Pierce and Hicks (2001) support the view that a comprehensive framework of patient decision making needs to be developed. Balneaves and Long (1999) have also identified that past decisional theories have not adequately addressed health care decision making. They have developed an embedded decisional model that focuses on treatment decision making and the complexities surrounding these decisions. They state that past models have not given consideration to the social forces that influence individuals. This model links the concepts of stress and coping to decisional theory and will need to be tested and considered for decisional research in the future. This theory takes into account life-span effects that influence decision making ability, but focuses on adults, and not on children or adolescents. It seems necessary for a theory of adolescent health care decision making to be developed. This theory would have to focus on serious and chronic illness, as well as other health care decisions. Health promotion decisions are inherently different than serious health care decisions, and therefore each require a distinct theory.

The other barriers to achieving decision making competence that were included in the theoretical framework (attitudinal constraints, peer group pressure to conformity, and restricted legal rights) were not being tested in the current study. For serious decisions that are made (such as health care decisions) peer conformity or peer pressure would not be a key factor in these decisions as the peer group is not experiencing the same health difficulties. Peers would not have any idea about the severity of the decisions and would most likely not be consulted for their opinion. However, the peers

within the cancer clinic or unit may be very influential for the adolescents. Perhaps these other adolescents with cancer may influence decisions. This would be important to study in the future. Attitudinal constraints is a barrier that was not specifically evaluated in this study. However, it is apparent from the interview responses that adolescents acknowledged the severity of the decisions made concerning their health. It was anticipated that some of the participants who were to take part in this research might have reacted in an apathetic manner. However all the participants seemed to find this research interesting and were willing to share their experiences. In the future, it would be important to discover if adolescents felt that their participation in the decisions made about their cancer were any different than the decision they made about everyday life events. If adolescents would identify their cancer decisions as being different from everyday life decisions this would support the development of a decisional theory unique to health care decisions. Restricted legal rights is the last barrier included in the theoretical framework. It was not assessed in this study, but should be incorporated into future research. If adolescents would feel legally restricted their desire to actively be involved in decisions could not be jeopardized. The theoretical framework used in the study is most likely not appropriate for health care decisions. However, there are very few decisional theories that focus on the unique adolescent population. As already suggested, theoretical frameworks addressing adolescent health care decisions need to be developed and tested.

### *Instruments*

The different instruments utilized in this study were the Family Assessment Device General Functioning Scale (FAD-GFS) and the Control Preferences Scale (CPS).

The FAD-GFS was short and easily understood by the subjects in this study. The only difficulty encountered with this instrument was that two of the younger participants did not know the definition of the word "confide" used in question number six. They requested the researcher explain the meaning of the word, which was done by the researcher. The only problem with this tool was the scoring. Higher scores indicate unhealthy functioning and lower scores healthy functioning. However there was no specific scoring component that suggested at what score functioning became healthy or unhealthy. Having specific values defined as healthy and unhealthy would have assisted in deciding how to separate participants for the statistical tests utilized. For future research this instrument could be used as it is easy for the participant to complete, is short, and it has demonstrated validity and reliability.

The CPS has never been used with an adolescent population prior to this study. In this study it was easily understood by the participants and the fixed order presentation worked effectively. The participants understood the concept of paired choices and had no difficulties in their choices. However, validity and reliability for the CPS were not achieved. This is largely due to the small sample. In the future, a larger sample size would be necessary in order to determine the reliability and validity of the instrument with an adolescent population. The trend in this study showed that younger participants preferred a more passive role. It is not known if this is the a reflection of the instrument, or a true reflection of the desires of the adolescent. If this trend is due to the instrument used, the CPS would not be appropriate for younger persons. As this is the first time the instrument is was utilized, it would be necessary to further evaluate this trend. An instrument that takes into account the important parental component in decision making



may also be more suitable for the adolescent population. Therefore, an adolescent version of the CPS may possibly need to be developed and tested in the future.

### *Sample Representativeness*

When evaluating the representativeness of the sample it is evident that this study is fairly representative. When evaluating the number of new diagnoses of cancer in 12-17 year olds during the period from January 1997-September 2002, there are a total of 58 new diagnoses (Manitoba Cancer Registry, 2003). Out of these 58 diagnoses eight patients have died. Therefore, an estimate of the number of possible participants for this study would be 50. The 19 participants in this study would then represent 38% of the potential number of participants. The recruiter had only 2 refusals, meaning a total of 21 eligible patients or former patients were asked to participate in the study. The 19 participants then represent 90% of those who were eligible and approached to participate.

### *Limitations*

A small number of adolescents are diagnosed with cancer in Manitoba each year. This results in a small sample from which to draw adolescent oncology patients. To address this issue, subjects for this study included those adolescents receiving active treatment and also individuals who were diagnosed and treated for cancer when then were between the ages of 12 and 17. This increased the number of participants, but still resulted in a small sample size. Therefore, this impacts the generalizability of the research results. The difficulty in obtaining an adequate sample size is nothing new for pediatric oncology research and pediatric research in general. An article by Walker (1983) highlighted problems in pediatric oncology research which stressed the

difficulties in obtaining large enough samples and also including children of all developmental levels. Hinds and Kelly (1998) also have highlighted collaborative research as one of the objectives in researching clinical decision making in pediatric oncology. Multi-site research projects are necessary in order to continue to do research that has enough power, is relevant and can be generalized (Bossert, Evans, Van Cleve, & Savedra, 2002).

Another limitation that exists in this study includes the use of the CPS, which has never before been used to measure decision making preferences in an adolescent population. The CPS has been used with a variety of adult populations and adolescents in this study were capable of understanding the concept of choosing between various options. A limitation of the CPS is that a card which includes a collaborative decision with the family and the physician does not exist. This is a choice which adolescents may desire. The only way of addressing this issue, would be modification of the instrument, which was not attempted in this study.

Interviewing some participants retrospectively may also have influenced the results. However, when analyzed, there was no relationship between control preferences in decision making and time between diagnosis and interview.

The semi-structured interview questions did not focus on evaluating the participants thoughts about participation in decision making. These interviews could have been longer in duration and gained additional information by probing further into some of the issues surrounding decision making, such as the adolescents role. Further evaluation of the theoretical framework could have been done by incorporating additional questions to those utilized.

Another limitation is that the study desired to focus on the process of decision making, but this goal was not fully achieved. The adolescent participants did not freely discuss the process of decision making during the semi-structured interview questions. It is possible that the adolescents were not able to distinguish decision making outcomes with the process of decision making. However, further probing questions should have been utilized in order to get a more comprehensive understanding of the process of decision making in adolescent oncology patients.

#### *Future Research*

Future research needs to further investigate the role that adolescent oncology patients prefer to play in decision making process. Multi-site studies need to be done in order to obtain a large sample size and further expand on the scarce research in this area. Collaborative research in decision making in different countries and with different cultures and ethnic groups needs to be done to evaluate potential differences that may exist (Pierce & Hicks, 2001). Cultural research is just beginning, with Lee (2003) evaluating treatment decision making in adult Chinese American women and Hinds et al. (2000) evaluating differences in the treatment decision making of parents with children with cancer in the United States, Australia, and Hong Kong.

Other recommendations could be made for future studies that address some of the questions that remain to be answered. Incorporating the semi-structured interview question about preferred and actual roles earlier in the study (instead of half way through the study) would have assisted in explaining this phenomenon more in-depth and may have included the reasons behind why the preferred and actual roles were the same or if the actual role was different than the preferred. Also adding a question about the

influence of peers on health care decision making would have assisted in further testing one of the components of the theoretical framework. Further investigation into the role of parents in decision making would have been helpful in further contributing to the limited knowledge in this area. A qualitative study evaluating decision making of adolescent oncology patients, their families and health care professionals would be helpful in the development of theory and also appropriate tools to use in assessment of adolescent decision making. This type of study would be most helpful if it focused on the involvement of the adolescent and the perspective of those involved.

Also discovering if there are differences in decision making preferences over time would be interesting. Changes in decision making preference may fluctuate as adolescents develop more abstract thinking and also evolve in their health care relationships. One must keep in mind that their desired level of involvement may change during the course of their illness, therefore it would be beneficial to test this hypothesis. Changing information needs and decision making is congruent with the work of Thorne and Robinson (1993). Ellis and Leventhal (1993) mention that a question in their survey might be unreliable, as three participants changed their desire for decisional control from passive to active when the survey was repeated. The change in selection by the participants may not be the survey and could actually be a change in the patients preferred decisional style. Pyke-Grimm et al. (1999) found that the preferences of parents of childhood cancer patients did not change substantially over time. However, Harris (1998) has also identified that the informational needs of oncology patients and their families change over time. It would be interesting to discover if changes in preferred decision style occur with adolescent cancer patients. One of the interviews in

this study suggested that changes in preferred role do exist. Also the results of this study that show older adolescent desiring a more active role would be congruent with this theory. Evaluating treatment decision making preferences in a longitudinal study would answer this question regarding changing preferences of adolescents over time and would be an interesting area of study to pursue in the future.

Cancer is a disease that is unique among pediatric illnesses. Most pediatric diseases are chronic, such as diabetes or cystic fibrosis. The trajectories for these diseases are fairly well-known. Since these disease trajectories are different from cancer, it would be interesting to see if the way in which adolescents with cancer and adolescents with other chronic illnesses make decisions and desire to be involved in the decisions made about their health care would differ in any way. Also, evaluating the role adolescents desire to have their family play in the decisions made about their medical treatment is an area that lacks research. Any research that is evaluating decision making in children needs to incorporate the impact of parents and family in the decision making process. The findings from a focus group exploration by O'Rourke and Germino (1998) support the need to further evaluate decision making from the family perspective.

Interventions that could be used to assess the adolescent desired role and assist the adolescent in obtaining this role should be developed and evaluated. These interventions would need to be adaptable to individual situations, by taking into account the adolescent's developmental level, their preferred role and their ability to participate in decision making with the health care team. O'Connor et al. (2001) stated in a systematic review of randomized controlled trials of decision aids (such as interactive video or computer programs, videos, pamphlets, booklets, the internet, and personal

decision analysis) in the health care environment that the use of decision aids is superior to the usual care provided to patients. Their review also suggested that there is a need for consensus regarding decision aids, standards for use of decision aids and further research to determine how decision aids affect different groups of patients.

Studies have shown that benefits exist when decision making involvement is addressed. These studies have found that cancer patients who participated more actively in decision making when diagnosed had improved psychosocial functioning. (Deadman, Leinster, Owens, Dewey, & Slade, 2001; Fallowfield, Hall, Macguire, & Baum, 1990; Hack & Degner, 2003). This would suggest that adolescents could benefit from addressing decision making when first diagnosed with cancer and could have better outcomes in the future. This is significant as survivorship is increasing. It will be important to study if the desired and actual role adolescents take in decision making is correlated to better functioning and improved outcomes later in life. Hinds and Kelly (1998) have stated that "research that focuses on the link between the process and outcomes of decision making is particularly needed". Research regarding decision making in adolescent oncology patients has just begun. There are several questions that remain unanswered and it appears that further research in this area has become a priority for pediatric health care professionals.

### *Summary*

As a part of the health care team, nurses must be aware of the decision making preferences of adolescents. Evaluation of the decision making role adolescents desire and are given needs to take place. Nurses need to assess the level of involvement that adolescents desire and be aware that adolescents have the capacity to be a part of the

health care team. Opportunities need to be identified where adolescents can learn the process of decision making and develop skills in participating in the deliberations about decisions. Options and consequences of each of these options need to be explored with adolescents throughout their illness. Also, implementation of interventions to assist adolescents in employing their desired decision making style need to be addressed. Interventions may also assist adolescents in achieving a more active role, if they desire. As part of the health care team, nurses should take the lead in the development of appropriate interventions that will improve functioning for adolescent cancer patients in the future.

This research has shown that the adolescents who participated desired various roles in decision making. The majority of the participants desired a collaborative role. The study also showed that there was not relationship between the CPS and the demographic variables obtained from the participants. There was a trend showing that the older adolescents desired a more active role in decision making.. The importance of parents in the cancer experience and the involvement of parents in decision making was welcomed by a majority of the participants.

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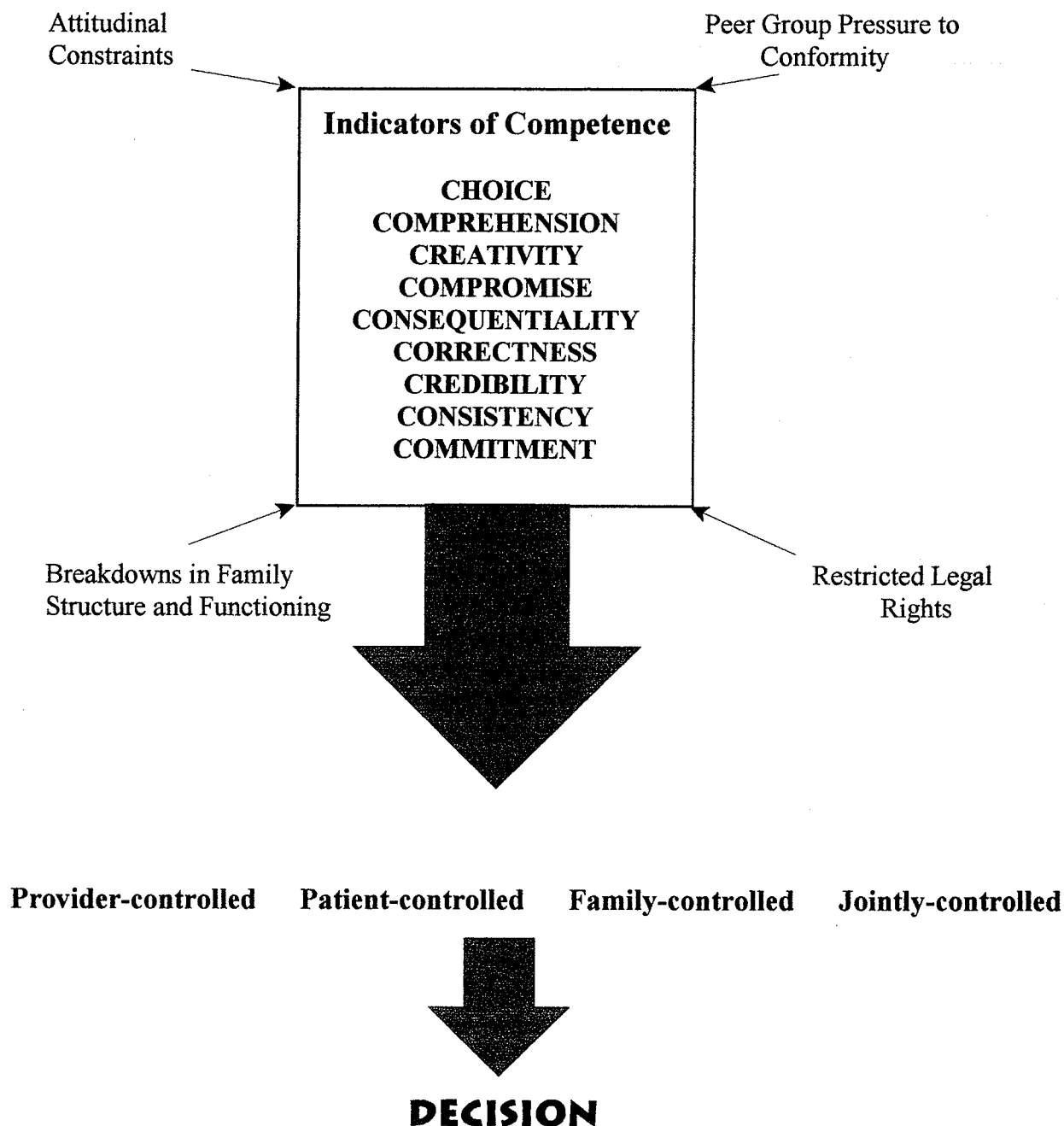
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## Appendix A

## Conceptual Model of Theoretical/Conceptual Framework



Adapted from: Degner, L. F., & Beaton, J. I. (1987). *Life-death decisions in health care*. New York: Hemisphere. and Mann, L., Harmoni, R., & Power, C. (1989). Adolescent decision-making: The development of competence. *Journal of Adolescence*, 12, 265-278.

## Appendix B

## DEMOGRAPHIC AND HEALTH INFORMATION FORM

The information shared below will be kept confidential. Please answer all of the questions below. Should you have any questions, please ask the investigator.

1) Birth date: \_\_\_\_\_  
**day / month / year**

2) Gender: **male** / **female** (circle your response)

3) What grade in school are you currently in? (circle one)

7    8    9    10    11    12    Other:

4) How frequently have you attended school since your diagnosis? (check one)

☐ have not attended  
☐ attending all the time  
☐ attending when not busy with appointments  
☐ attending about half-time  
☐ other \_\_\_\_\_ (please describe)

5) What type of cancer do you have? (please explain below)

6) When were you first diagnosed with cancer? \_\_\_\_\_  
day / month / year

7) When did you first start treatments for your cancer? (ie. surgery, chemotherapy, radiation)

day / month / year

8) Have you finished your cancer treatments? (circle one) Yes / No



If *yes*, when? \_\_\_\_\_  
                                     day / month / year

9) What type of treatment(s) are you currently receiving or have you received in the past?  
(please check as many as are appropriate)

☐ chemotherapy  
☐ radiation  
☐ other \_\_\_\_\_ (please describe)  
☐ no treatment

10) Have you required any treatments in the past, that you are **not** currently receiving?  
(please check *as many as are appropriate*)

☐ chemotherapy  
☐ radiation  
☐ surgery \_\_\_\_\_ (please describe)  
☐ other \_\_\_\_\_ (please describe)  
☐ no treatment

11) Have you been admitted to the hospital ward during your cancer experience? (circle one)

**Yes / No**

**If *YES***



proceed to *number 13*

If *NO*



proceed to *number 14*

12) How many times have you been admitted to the hospital for your cancer?

**1    2    3    4    5    6    7    8    more than 8**

13) What was/were the reason(s) for your admission? (please check as *many as are appropriate*)

- ☐ when first diagnosed
- ☐ chemotherapy
- ☐ surgery
- ☐ infection or fever
- ☐ other \_\_\_\_\_ (please describe)

14) Do you live in a rural or urban environment?

- ☐ rural (country)
- ☐ urban (city)

***Thank you for taking the time to fill out this survey***



## Appendix C

## McMaster Family Assessment Device General Functioning Scale

**Family Assessment Device**

This questionnaire contains a number of statements about families. Please read each statement carefully, and decide how well it describes your own family. You should answer according to how you see your family. For each statement, there are four (4) possible responses: Strongly Agree, Agree, Disagree, Strongly Disagree. Try not to spend too much time thinking about each statement, but respond as quickly and as honestly as you can. If you have trouble with one, answer with your first reaction. Please be sure to answer every statement and mark all answers in the space provided below each statement.

1. In times of crisis we can turn to each other for support.

\_\_\_ Strongly Agree \_\_\_ Agree \_\_\_ Disagree \_\_\_ Strongly Disagree

2. Individuals are accepted for what they are.

\_\_\_ Strongly Agree \_\_\_ Agree \_\_\_ Disagree \_\_\_ Strongly Disagree

3. We can express feelings to each other.

\_\_\_ Strongly Agree \_\_\_ Agree \_\_\_ Disagree \_\_\_ Strongly Disagree

4. We feel accepted for what we are.

\_\_\_ Strongly Agree \_\_\_ Agree \_\_\_ Disagree \_\_\_ Strongly Disagree

5. We are able to make decisions about how to solve problems.

\_\_\_ Strongly Agree \_\_\_ Agree \_\_\_ Disagree \_\_\_ Strongly Disagree

6. We confide in each other.

\_\_\_ Strongly Agree \_\_\_ Agree \_\_\_ Disagree \_\_\_ Strongly Disagree

7. Planning family activities is difficult because we misunderstand each other.

☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

8. We cannot talk to each other about the sadness we feel.

☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

9. We avoid discussing our fears and concerns.

☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

10. There are lots of bad feelings in the family.

☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

11. Making decisions is a problem for our family.

☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

12. We don't get along well together.

☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

## Appendix D

## Control Preferences Scale (A, B, C, D, E - in order)

Active Role

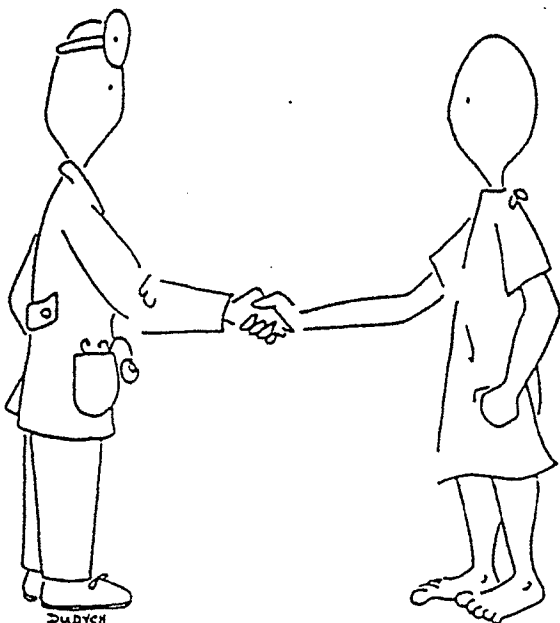


I PREFER TO MAKE THE FINAL SELECTION  
ABOUT WHICH TREATMENT I WILL RECEIVE.



I PREFER TO MAKE THE FINAL SELECTION  
OF MY TREATMENT AFTER SERIOUSLY  
CONSIDERING MY DOCTOR'S OPINION.

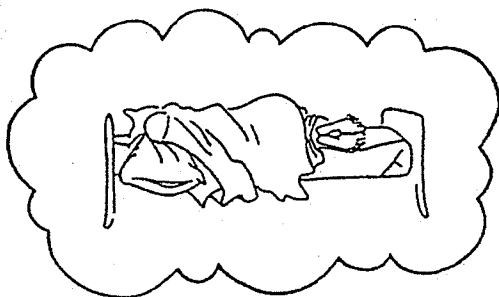
### Collaborative Role



I PREFER THAT MY DOCTOR AND I  
SHARE RESPONSIBILITY FOR DECIDING  
WHICH TREATMENT IS BEST FOR ME.



I PREFER THAT MY DOCTOR MAKES THE  
FINAL DECISION ABOUT WHICH TREATMENT  
WILL BE USED, BUT SERIOUSLY CONSIDERS  
MY OPINION.



I PREFER TO LEAVE ALL DECISIONS  
REGARDING MY TREATMENT TO MY  
DOCTOR.



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Nursing Group, St. Boniface Research Centre and  
The University of Manitoba, Faculty of Nursing

## Appendix E

**Semi-structured Open-ended Interview Questions Guide**

1. Tell me about who told you that you had cancer. Was this the way you wanted to be told, or would you have liked to been told in a different way? What would you change?
2. Tell me about a good experience when a decision had to be made about your cancer.
3. Tell me about a bad experience when a decision had to be made about your cancer.
4. Do you remember any other times when there were decisions made about your cancer? Would you have wanted these decisions made in a different way?
5. What would you like to tell the doctors and nurses about the decisions made about your cancer?
6. What would you like to tell your parents and family about the decisions made about your cancer?
7. What advice about decision making would you give other adolescents who have cancer?
8. The first card you chose as your preferred way of making decisions was \_\_\_\_\_. Was this in fact the way in which you were involved in decisions when you were first diagnosed?

## Appendix F

**Initial Contact Statement (Recruiter)**

There is an opportunity for you to participate in a research project that is looking at decision making in adolescent patients who have cancer. Simone Stenekes is a nurse who is doing a study for her Master of Nursing degree and is looking for two groups of adolescents. She is wanting participants who are 12-17 years old and receiving cancer treatment to participate. Also those who were 12-17 years old when diagnosed with cancer are also invited to participate. Simone is willing to explain her project to you, should you be interested. This does not mean that you have to participate, she will only explain the project and you can decide if it is something you would want to take part in.

**Option 1 - Contact in the Future**

Would it be okay for me to give your name and phone number to Simone so that she can set up a time to meet with you and explain her project?

If YES, please fill out information below:

Name of patient \_\_\_\_\_

Name of parent(s)/caregiver(s) \_\_\_\_\_

Phone number (        ) \_\_\_\_\_

Simone will contact you at the phone number given in the next few days.

~~~~~

**Option 2 - Contact Today**

Simone is here today, would it be okay if she would come and see you now to explain her project?

If YES, please fill out information below:

Name of patient \_\_\_\_\_

Name of parent(s)/caregiver(s) \_\_\_\_\_

Please phone Simone at \_\_\_\_\_ e-mail her at \_\_\_\_\_ to let her know  
there is another interested individual.

## Appendix G

## Poster

## **Decision Making in Adolescent Oncology Patients**

Simone Stenekes, a registered nurse, is conducting a study on decision making in adolescent oncology patients. The purpose of this study is learn more about how adolescents with cancer feel they are involved in the decisions that are made about their care. This study is part of Simone's Master of Nursing degree at The University of Manitoba.

The study involves one or two interviews. The first interview is about one hour and involves filling out two forms and doing a card sort. A card sort presents cards that a person places in the order they would like them.

The second interview is about one hour. In this interview Simone will ask you questions about decisions that have been made during your cancer experience and how you felt about these decisions. A smaller number of participants are needed for this interview, so not everyone will have to take part in the second interview.

All information from the study will be kept confidential. No information will be shared with health care providers and the care you receive will not change in any way. This study has been approved by the University of Manitoba Education/Nursing Research Ethics Board and the Cancer Care Manitoba Resource Impact Committee.

**If you are an adolescent (age 12-17) who has cancer, or if you were treated for cancer when you were 12-17 years old**

and if you are interested in receiving more information about this study contact Simone at . Please leave a message if no one is home.

Thank you for your interest!



## Appendix H

**Researcher Initial Contact Statement**

Hi, my name is Simone Stenekes. As you have already been told, I am doing a research study as part of my Master of Nursing program. I will first tell you a little bit about my project and then you can ask questions and decide if you would like to participate.

- go over information sheet
- ask if they have any questions

**Research Components for Participants**

- 1) \_\_\_\_ **Study criteria met**
- 2) \_\_\_\_ **Information Sheet** read to participant and parent
- 3) \_\_\_\_ **Parental Consent** signed (for participants under age 18)
- 4) \_\_\_\_ **Participant Assent / Consent** signed
- 5) \_\_\_\_ **Demographic and Health Information Form** completed
- 6) \_\_\_\_ **FAD-GFS** completed
- 7) \_\_\_\_ **Control Preferences Card Sort** completed
- 8) \_\_\_\_ **Interview** completed
- 9) \_\_\_\_ **Interview Transcribed**

Quantitative: parent present for step 6 and 7    **Yes / No**

Qualitative: parents present for step 8    **Yes / No**

Participant Code: \_\_\_\_\_

## Appendix I

### Information Sheet and Assent Form (Participant)

#### The Decision Making Preferences of Adolescents with Cancer

My research focuses on the decision making preferences of adolescents who have been diagnosed with cancer. When adolescents are diagnosed with cancer there are many questions they want answered. New experiences are happening, which can be overwhelming. Deciding how to deal with these questions and experiences is hard for adolescents. With this study I want to find out what role adolescents prefer to take in decision making about their health care. I am conducting this research as part of my Master of Nursing degree.

In conducting this research, I will be interviewing adolescents who have been diagnosed with cancer and are currently receiving treatment or were diagnosed with cancer when they were between the ages of 12 and 17. I got your name from one of the members of the pediatric cancer team who has talked with you about the project. Today I will let you know about the study and if you want to be a part of the study, I will get you to sign at the end of this form.

There are two parts to this study. The first part everyone will do and the second part only some people will do. The first part has participants doing three things. The first form asks personal information about you and your cancer. You will be able to complete this form with your parent/caregiver in the room. Once you have finished the form I will take ask your parent/caregiver to leave. If you wish to have your parent stay in the room, please let me know and they can stay. The second form will ask you some questions about your family. The last thing to do is put 5 cards in the order you would want them to be. This interview will take about one hour.

The second interview (which only some participants will do) involves asking you questions about your experience with cancer. This interview will be tape recorded. The reason it will be tape recorded is so that a transcriptionist (a person who types while listening to a tape) can type it out. This interview will take about 1-2 hours. If you take part in the first interview, you do not need to participate in the second interview.

All the meetings will be arranged for a time that is good for you. We can meet at your house (if you live within 200 km of Winnipeg) or at the Health Sciences Centre in a building near the cancer clinic. If you choose to come to the Health Sciences Centre to meet me, I will give you \$10.00 for parking. If you live in Winnipeg I will give you \$10.00 to pay for your car expenses. If you take public transportation (bus) or a taxi I will pay for your transportation to and from the meeting. If you live outside of Winnipeg I will give you car mileage at the University of Manitoba rate.

All information gained from the interviews will be kept confidential. This means that your name will not be included in any information. Instead of your name, there will be a code on the papers you fill out. The interview questionnaires and the answers to questions will have no information that can identify who wrote it. Also, all the information from the interviews will be locked in a filing cabinet. Within 5 years of study completion this information will be confidentially destroyed. The only people to see the transcripts will be Simone Stenekes, two of her thesis committee members from the Faculty of Nursing at The University of Manitoba, Dr. Lesley Degner and Dr. Roberta Woodgate, and a typist who will transcribe the interviews. Dr. Yanofsky (Faculty of Medicine, The University of Manitoba) will only have access to grouped data.

Being a part of this study is your choice. Nothing will happen if you do not want to do this. Signing this form means that you agree to participate in the study. But, if you want to stop being in the study at any time, just let Simone know. If you do not want to answer a certain question, you do not have to answer it. Being a part of this study is not expected to cause you any harm. While you are participating in the interview, if any information about child abuse is found out, Simone will have to report it to the police. If it is found out that you may want to hurt yourself or have plans to hurt yourself, Simone will have to tell your parents. Other than those two things, the rest of what you say in your interviews will not be told to anyone (that includes your parents).

This study has been approved by The University of Manitoba, Education/Nursing Research Ethics Board. Should you have any complaints regarding a procedure you may call the Human Ethics Secretariat at . The Resource Impact Committee of Cancer Care Manitoba and the Pediatric Oncology Team has approved this study.

*Your participation in this study is greatly appreciated. Should you wish to contact the researcher or her committee, please use the information included below.*

**Simone Stenekes - Researcher**

Tel: ---, ---

E-mail: ---

**Dr. Lesley Degner - Thesis**

**Committee Chair**

Tel: ---, ---

I, \_\_\_\_\_, agree to participate in this study about decision making of adolescent cancer patients.

I have read and understood the above information explaining this study. I understand that the study has one or two interview sessions. I understand that I have the right to refuse to answer any questions with which I feel uncomfortable and am able to withdraw at any time. I give permission to Simone Stenekes to use anonymous information from the interviews in her study, and in any presentation or publications that result from this study.

I agree to participate in the first interview    **Yes / No**

I agree to participate in the second taped interview    **Yes / No**

Printed Name \_\_\_\_\_

Signature \_\_\_\_\_ Date \_\_\_\_\_

Phone Number \_\_\_\_\_

Researcher \_\_\_\_\_ Date \_\_\_\_\_

The findings of this study will be available once the study has been completed.  
Would you like a copy of the research results mailed to you?

**Yes / No**

If *yes*, please include your address below:

Address \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## Appendix J

### Information Sheet and Consent Form (Participant)

#### The Decision Making Preferences of Adolescents with Cancer

My research focuses on the decision making preferences of adolescents who have been diagnosed with cancer. When adolescents are diagnosed with cancer there are many questions they want answered. New experiences happen, which can be overwhelming. Deciding how to deal with these questions and experiences is hard for adolescents. With this study I want to find out what role adolescents prefer to take in decision making about their health care. I am conducting this research as part of my Master of Nursing degree.

In conducting this research, I will be interviewing adolescents who have been diagnosed with cancer and are currently receiving treatment or were diagnosed with cancer when they were between the ages of 12 and 17. I got your name from one of the members of the pediatric cancer team who has talked with you about the project. Today I will let you know about the study and if you want to be a part of the study, I will get you to sign at the end of this form.

There are two parts to this study. The first part everyone will do and the second part only some people will do. The first part has participants doing three things. The first form asks personal information about you and your cancer. You will be able to complete this form with your parent/caregiver in the room, if you desire. Once you have finished the form I will take ask your parent/caregiver to leave if they are present. If you wish to have your parent stay in the room, please let me know and they can stay. The second form will ask you some questions about your family. The last thing to do is put 5 cards in the order you would want them to be. This interview will take about one hour.

The second interview (which only some participants will do) involves asking you questions about your experience with cancer. This interview will be tape recorded. The reason it will be tape recorded is so that a transcriptionist (a person who types while listening to a tape) can type it out. This interview will take about 1-2 hours. If you take part in the first interview, you do not need to participate in the second interview.

All the meetings will be arranged for a time that is good for you. We can meet at your home (if you live within 200 km of Winnipeg) or at the Health Sciences Centre in the John Buhler Building, which is near Cancer Care Manitoba. If you choose to come to the Health Sciences Centre to meet me, I will give you \$10.00 for parking. If you live in Winnipeg I will give you \$10.00 to pay for your car expenses. If you take public transportation (bus) or a taxi I will pay for your transportation to and from the meeting. If you live outside of Winnipeg I will give you car mileage at the University of Manitoba rate.

All information gained from the interviews will be kept confidential. This means that your name will not be included in any information. Instead of your name, there will be a code on the papers you fill out. The interview questionnaires and the answers to questions will have no information that can identify who wrote it. Also, all the information from the interviews will be locked in a filing cabinet. Within 5 years of study completion this information will be confidentially destroyed. The only people to see the transcripts will be Simone Stenekes, two of her thesis committee members from the Faculty of Nursing at The University of Manitoba, Dr. Lesley Degner and Dr. Roberta Woodgate, and a typist who will transcribe the interviews. Dr. Yanofsky (Faculty of Medicine, The University of Manitoba) will only have access to grouped data.

Being a part of this study is your choice. Nothing will happen if you do not want to do this. Signing this form means that you agree to participate in the study. But, if you want to stop being in the study at any time, just let Simone know. If you do not want to answer a certain question, you do not have to answer it. Being a part of this study is not expected to cause you any harm. While you are participating in the interview, if any information about child abuse is found out, Simone will have to report it to the police. If it is found out that you may want to hurt yourself or have plans to hurt yourself, Simone will have to tell the appropriate people. Other than those two things, the rest of what you say in your interviews will not be told to anyone.

This study has been approved by The University of Manitoba, Education/Nursing Research Ethics Board. Should you have any complaints regarding a procedure you may call the Human Ethics Secretariat at . The Resource Impact Committee of Cancer Care Manitoba and the Pediatric Oncology Team has approved this study.

*Your participation in this study is greatly appreciated. Should you wish to contact the researcher or her committee, please use the information included below.*

**Simone Stenekes - Researcher**

Tel: .  
E-mail: .

**Dr. Lesley Degner - Thesis  
Committee Chair**  
Tel:

I, \_\_\_\_\_, agree to participate in this study about decision making of adolescent cancer patients.

I have read and understood the above information explaining this study. I understand that the study has one or two interview sessions. I understand that I have the right to refuse to answer any questions with which I feel uncomfortable and am able to withdraw at any time. I give permission to Simone Stenekes to use anonymous information from the interviews in her study, and in any presentation or publications that

result from this study.

I agree to participate in the first interview    **Yes / No**

I agree to participate in the second taped interview    **Yes / No**

Printed Name \_\_\_\_\_

Signature \_\_\_\_\_ Date \_\_\_\_\_

Phone Number \_\_\_\_\_

Researcher \_\_\_\_\_ Date \_\_\_\_\_

The findings of this study will be available once the study has been completed.  
Would you like a copy of the research results mailed to you?

**Yes / No**

If **yes**, please include your address below:

Address \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## Appendix K

### Information Sheet and Consent Form (Parent)

#### The Decision Making Preferences of Adolescents with Cancer

My research focuses on the decision making preferences of adolescents who have been diagnosed with cancer. When adolescents are diagnosed with cancer there are many questions they want answered. New experiences are happening, which can be overwhelming. Deciding how to deal with these questions and experiences is hard for adolescents. With this study I want to find out what role adolescents prefer to take in decision making about their health care. I am conducting this research as part of my Master of Nursing degree.

In conducting this research, I will be interviewing adolescents who have been diagnosed with cancer and are currently receiving treatment or were diagnosed with cancer when they were between the ages of 12 and 17. I obtained your child's name from one of the members of the health care team who has briefly discussed the project with you. Today I will let you know about the study and if you and your child agree to participate, I will get you to sign your consent at the end of this form and your child to sign the assent form.

Participation in the study requires one or two interviews. A subset of the participants will be asked to take part in the second interview. The first interview will be about one hour in length. Together with your child you will be asked to complete a form about your child's personal information and questions about their cancer. Once you have completed this form I will ask you to leave room. Your child will then complete a questionnaire that contains questions about family. Following this, I will ask your child to put 5 cards in an order they desire.

The second interview (which only some participants will do) involves asking your child questions about their experience with cancer. This interview will be tape recorded. This interview will take about 1-2 hours. The second interview is voluntary. Taking part in the first interview does not mean that your child must participate in the second interview.

Should you wish to stay in the room during an interview, or your child desires that you remain, you can stay in the room. However, since this research is focusing on the participant, I will ask you to refrain from interfering during any part of the interview. This would include interfering with the completion of the instruments used in the research or answering any questions asked of the participant. I will ask that you sit behind your child (out of their view) so as not to influence any answers with your facial or body movements.



We can arrange for meeting at a time that is convenient for you. The meetings can take place in your home (if you live within 200 km of Winnipeg) or at the John Buhler building which is close to the Cancer Care Manitoba building at the Health Sciences Center. The choice of location for meeting is up to you and your child. Should you desire to meet at the Health Sciences Center, you will be reimbursed \$10.00 for parking and if you live in Winnipeg, will also get \$10.00 for car expenses. If you take public transportation or a taxi you will be paid for your transportation to and from the meeting. If you live outside of Winnipeg, your mileage will be paid at The University of Manitoba rate for reimbursement.

All information gained from the interviews will be kept completely confidential. The interview questionnaires and transcripts will have no identifying information and will be secured in locked files. Within 5 years of study completion this information will be destroyed. The only people to see the transcripts will be Simone Stenekes, two of her thesis committee members from the Faculty of Nursing at The University of Manitoba, Dr. Lesley Degner and Dr. Roberta Woodgate, and a typist who will transcribe the interviews. Dr. Yanofsky (Faculty of Medicine, The University of Manitoba) will only have access to grouped data.

Participation in this study is voluntary. Your child is free to refuse to answer any questions asked in the interview. You or your child is also free to withdraw from participation in this study at any time. No harm is anticipated resulting from participation in this study. If during the course of this research, circumstances relating to child abuse are discovered, the researcher is required by law to report this to the appropriate authorities. If your child states that they want to hurt themselves or have plans to hurt themselves, the researcher will report this to you and will also provide you with information regarding possible avenues to address this issue.

This study has been approved by The University of Manitoba, Education/Nursing Research Ethics Board. Should you have any complaints regarding a procedure you may call the Human Ethics Secretariat at ( ). The Resource Impact Committee of Cancer Care Manitoba and the Pediatric Oncology Team has approved this study.

*Your son's/daughter's participation in this study is greatly appreciated. Should you wish to contact the researcher or her committee, please use the information included below.*

**Simone Stenekes - Researcher**

Tel: \_\_\_\_\_  
E-mail: \_\_\_\_\_

**Dr. Lesley Degner - Thesis  
Committee Chair**

Tel: \_\_\_\_\_

I, \_\_\_\_\_, the parent/guardian of  
\_\_\_\_\_ agree to let my son/daughter participate in this study about  
decision making of adolescent cancer patients.

I have read and understood the above information explaining this study. I understand the requirements of the study. I am aware that my son/daughter will be contacted by phone to arrange or confirm any meetings necessary for this study. I understand that my sons/daughters identity will not be revealed at any time to any one. I am aware that I have the right to withdraw my son /daughter from this research project at any time. I give permission to Simone Stenekes to use anonymous information from the interviews with my son/daughter in her study, and in any presentation or publications that result from this study.

I agree to let my son/daughter participate in the first interview    **Yes / No**

I agree to let my son/daughter participate in the second taped interview    **Yes / No**

Parent Signature \_\_\_\_\_ Date \_\_\_\_\_

Printed Name \_\_\_\_\_

Researcher \_\_\_\_\_ Date \_\_\_\_\_