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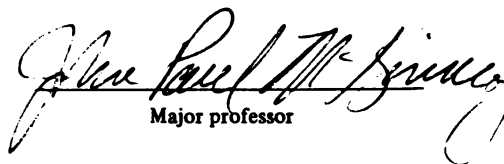
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HEALTH LOCUS OF CONTROL AND ENGAGEMENT STYLE  
IN CHILDREN AND ADOLESCENTS WITH CANCER

presented by

Dan Allen Mondoux

has been accepted towards fulfillment  
of the requirements for

M.A. degree in Psychology

  
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**HEALTH LOCUS OF CONTROL AND ENGAGEMENT STYLE  
IN CHILDREN AND ADOLESCENTS WITH CANCER**

**By**

**Dan Allen Mondoux**

**A THESIS**

**Submitted to**

**Michigan State University  
in partial fulfillment of the requirements  
for the degree of**

**MASTER OF ARTS  
Department of Psychology**

**1989**

## **ABSTRACT**

### **HEALTH LOCUS OF CONTROL AND ENGAGEMENT STYLE IN CHILDREN AND ADOLESCENTS WITH CANCER**

**By**

**Dan A. Mondoux**

This study investigated health locus of control beliefs (HLOC) and engagement style in children with cancer and matched comparison children. Participants were twenty-three pairs of children aged eight to 18 ( $n = 46$ ). Each child with cancer was matched with a child from his or her own classroom on the basis of sex, date of birth, and race. The study used McKinney's Test of Engagement Style, and Parcel and Meyer's Multidimensional Children's Health Locus of Control test. Analyses revealed that, contrary to predictions, children with cancer were more agent (perceiving themselves as doing in social situations rather than being done to) than children without cancer ( $p < .05$ ). No differences between groups on HLOC were found. Chance external HLOC was found to be negatively correlated with age for children without cancer but not for children with cancer. Theoretical implications of the findings, ramifications for children's cancer treatment and future research were discussed.

**For Mom and Dad**

## ACKNOWLEDGMENTS

I would like to express my gratitude to the members of my committee for all their efforts on my behalf. They each made a special contribution to this project:

Dr. Lauren Harris, whose counsel and insight have made all the difference.

Dr. Robert Noll, whose suggestions, knowledge, and energy made this project possible.

Dr. John Paul McKinney, whose enthusiasm has inspired me, whose perspective has changed my way of thinking about research, and whose friendship I value.

I want to thank Sarah LeRoy for the road trips, for the neighborhood walks, and for Timmy.

I thank the Psychology Department for their support during this project.

I would like to thank Cynthia Kaufman for making me remember the reason.

I want to express my thanks and admiration to all the participants in this project. Your time and effort is appreciated.

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## INTRODUCTION

The problem of childhood chronic illness and its psychological impact is becoming increasingly important. Medical advances in recent years have greatly extended the life expectancies of children with serious chronic illnesses (Hobbs, Perrin, Ireys, Moynihan, & Shayne, 1984). As a result, growing numbers of children and families are faced with the burden of long-term chronic illness (Thompson, 1986). Chronic illnesses can be categorized in a variety of ways including how serious the disease is (Hobbs et al., 1984) and whether or not it is primarily of physical origin (Thompson, 1986). Some chronic illnesses, such as cystic fibrosis and cancer, are highly life-threatening whereas others, such as asthma and various orthopedic conditions are not nearly so dangerous.

Childhood cancer is a life-threatening chronic illness. Untreated, it is often fatal. Fifteen years ago, most children who were diagnosed with one of the various cancers died within five years. The life-expectancy of children with cancer has improved greatly in recent years. Although the prognosis for some types of cancer is still very poor, for many other types, patients with proper treatment can live for years. As cancer research has made surgery, radiation, and chemotherapy more effective, it has become important to consider the long-term psychological impact that the experience of pediatric cancer has on individuals (Koocher, O'Malley, Gogan, & Foster, 1980). Although the prognosis has vastly improved in the last

decade, the hardships undergone by children with cancer are still great. The specific prognosis is dependent upon the particular type of disease and its stage of development at diagnosis. The treatments the children need to save their lives are often painful and the side effects can result in extreme discomfort and nausea. In addition, children often face more visible side effects such as hair loss from chemotherapy and the coarsening of facial features from steroid therapy. As Goldberg (1974) has found, visible side effects of chronic illness can make children feel out of place among their peers.

If one considers the extent of the difficulties faced by these children, one might expect a large amount of research to be devoted to understanding these children and their problems. Until recently, this has not been the case. It has been suggested that chronically ill children as a class have been comparatively ignored and that the vast majority of research monies are devoted to basic biomedical research, while research into psychological issues related to childhood cancer and other chronic illnesses has been less vigorously supported (Hobbs et al., 1984). A recent review of the psychosocial literature dealing with childhood cancer has suggested that this is changing and that scientific inquiry into this area is increasing (Van Dongen-Melman & Sanders-Woudstra, 1986). One task for the social scientist and the health care worker involved in such research is to attempt to discover methods of not only prolonging life but of enhancing the quality of life to the greatest possible degree.

Koocher (1986) has argued for the importance of improving psychological as well as medical treatment of pediatric cancer. An important aspect of this

treatment, according to Koocher, involves the reduction of anxiety in the child and the bolstering of the child's feelings of self-control. This can be accomplished early in treatment by encouraging the child's "engagement in the process" through discussions with the child. Such discussions would deal with topics such as the child's fears about his or her condition, apprehensions about physical changes resulting from treatment, and how peers may react to the illness.

Unpleasant life events that cause disruption in living patterns are stressful to individuals and families. Krantz, Grunberg, and Baum (1985) have described stress as the mental condition of a person who finds their physical or psychological well-being threatened. Since poor health by itself is associated with higher levels of stress (McFarlane, Norman, Streiner, & Roy 1983), it is no surprise that childhood cancer is also associated with stress (Koocher & Sallan, 1978; Lewis & LaBarbera, 1983) and with psychological problems including anxiety, depression, regression, emotional withdrawal, and sleep disturbances (Derogatis, et al., 1983; Hobbs et al., 1984, Van Dongen-Melman & Sanders-Woudstra, 1986). Koocher and Sallan (1978) assert that the relationship between staff mental health professionals and pediatric cancer patients and their families is crucial in order to help counter the stresses produced by the hardships and uncertainties of treatment. It is necessary, therefore, to improve our understanding of these children so that mental health professionals will be able to perform this important task adequately.

Some researchers have examined the ways in which families of chronically ill children cope with stress. In terms of types of coping strategies used, Powers, Dill, Hauser, Noam, and Jacobson (1985) found that families with seriously ill

adolescents tended to respond to stress through the use of cognitive and affective strategies rather than by attempting to modify the stressful situation. They argue that this type of solution is probably appropriate given that the causes of the family's stress are not likely to respond to active efforts toward change (the specific illnesses examined were psychiatric disturbance and diabetes). Finally, Powers et al. found that the two types of illnesses evoked different types of responses from families. The families of children with psychiatric disorders were more passive in their response, while the families of diabetic children used more active strategies.

The results of the Powers et al. study suggest several things. In response to high levels of stress, the families of adolescents appear to expand their range of resources in order to deal with their difficulties. Also, it appears that different types of illnesses generate different types of responses from families. The specific illnesses examined do not seem to provoke active attempts at situational change from families. This is probably due to the lack of hope on the part of families that the illness will ever be "behind" them. In the case of adolescents with cancer, the life-threatening nature of the disease may result in a different constellation of coping strategies. In addition, there is a hope that the illness will be "cured" eventually. Unfortunately, because it is impossible to truly know that the disease will not recur, the concept of "cure" is problematic when one considers cancer (Mauer, 1987). In spite of this difficulty, the existence of hope may result in different strengths and different weaknesses in families of children with cancer.

As long-term mortality rates have improved, the question of the long-term psychological impact of pediatric cancer has become increasingly important. At

present, there is little information about the ways in which pediatric cancer affects long-term survivors (Mulhern, Wasserman, Friedman, & Fairclough, 1989), and few studies have been done (Van Dongen-Melman & Sanders-Woudstra, 1986). The research that has been done has reported a variety of adjustment problems including problems with social skills (Noll et al., 1988; Spirito et al., 1988), depression (Lansky, List, & Ritter-Sterr, 1986), and school-related problems and somatic complaints (Mulhern et al., 1989).

In order to enhance both the short and long-term quality of life for the chronically ill child, physicians, nurses, and mental health professionals must understand the many different factors involved in the lives of these children. One of these considerations is that of control. Some degree of uncontrollability is inevitable for any child with a chronic illness. This uncontrollability may relate to the onset or course of the illness, the treatments, the clinic visits, and/or the hospitalizations that are required (Spence, 1987).

Compared to healthy children, children with cancer find themselves much more dependent upon others for care. They are also regularly forced to undergo unpleasant and often painful treatment. Treatment and the reasons for a particular medical procedure or drug can be difficult, if not impossible, for children and even their parents to understand. This is particularly true when the child did not begin to feel ill until the treatment started, as is the case with some forms of cancer. It has been suggested that as a result of their life situation and its associated stress, pediatric cancer patients may begin to feel that they lack control over events in their

lives in both the short term (Nannis, et al., 1982), and the long term (Koocher & Sallan, 1978).

A lack of perceived control over illness can, by itself, result in a more negative evaluation of the disease. Meyerowitz, Williams, and Gessner (1984) found that among healthy university undergraduates, when cancer was perceived to be personally uncontrollable, it was seen more unfavorably than when it was believed that personal control could be exerted. The level of control that physicians were seen as having over the disease did not influence participants' attitudes toward cancer. In other words, the control that some powerful other might exert over the disease did not seem to affect the negative attitudes engendered in the undergraduates by a perceived lack of control on the part of the patient. Control must reside with the patient.

Recognizing the importance of control for children with cancer, Worchel, Copeland, and Barker (1987) examined the relationship between control-related coping strategies and emotional adjustment among these children. They examined four different types of control strategies: Behavioral, Decisional, Informational, and Cognitive. Behavioral control referred to the number of different behaviors used in assorted situations associated with medical treatments and non-medical activities. Decisional control involved the perception of control over treatment (who makes the decisions). Informational control pertained to question asking and the amount of information desired. Cognitive control was concerned with frequency of thinking about and talking about the illness and treatment.



Worchel et al. (1987) found that the best predictor of nurses' ratings of positive adjustment was low use of behavioral control. The researchers suggest that this finding indicates that individuals with a positive adjustment tend to use a few successful coping strategies rather than trying and rejecting many ineffective strategies. Worchel et al. (1987) also found that higher levels of decisional control were associated with better adjustment and fewer behavioral problems, whereas high cognitive control predicted nurses' ratings of passive non-compliance. Informational control was not related to adjustment ratings.

This study demonstrates that a better understanding of the control beliefs of chronically ill children and adolescents is needed. The work of Worchel et al. (1987) suggests that some types of control can be helpful whereas others appear to do more harm than good. These different types of control need to be differentiated and defined more clearly and examined in greater detail.

### Locus of Control

Feelings of control are generally measured through the use of some Locus of Control (LOC) scale. The concept of locus of control originated with Phares (1955) and James (1957) and was further developed by Julian Rotter (1966). Locus of control is a construct that refers to an the generalized expectancy that what happens to oneself is the result of one's own actions, or conversely is the result of external factors. People with an internal LOC tend to believe that they are in control of events in their lives, whereas those with an external LOC tend to believe that either

random chance or powerful others control outcomes. It is assumed that this expectancy is learned through repeated encounters with the social environment. The social environment is a complex one, and, as a result, issues of control can be complex as well. Rotter and his colleagues originally attempted to create a complex scale designed to measure control expectancies for several distinct domains in addition to generalized LOC (Lefcourt, 1981). This attempt was unsuccessful. Instead, Rotter developed his widely used one-dimensional I-E (Internal-External) Scale.

A number of demographic factors have been shown to influence scores on LOC measures. Using a measure of general locus of control, Stipek (1981) found that over the course of first grade, children tended to become increasingly internal. Stipek suggests that this may result from the opportunities that school provides for children to observe the outcomes of their own behavior. Stipek also argued that school teaches responsibility directly. This may also contribute to the increased internality over the course of first grade. Stipek also found that middle socioeconomic status (SES) children began first grade with a more internal LOC than children with a lower SES but that this difference disappeared by the end of first grade. Other researchers, however, have consistently reported differences between middle SES and lower SES adults (see Lefcourt, 1976). Either this SES difference is reestablished by adulthood, or as Stipek explains this discrepancy across ages is due to the type of LOC measure that was used in these studies (responsibility versus power). In other words, while there may be no difference between SES groups in the extent to which they attribute positive outcomes to their

own actions, there may be a difference in the extent to which these groups feel they can exercise influence in social situations.

### Demographic Factors

Another demographic factor that has been found to influence LOC is family size. Newhouse (1974) examined reinforcement-responsibility (a measure of LOC) and found that only-born children tended to be less internal than children with siblings. Newhouse's findings also suggest that between grades four and six, the tendency to accept responsibility for success declines. This finding seems to contradict Stipek's argument that school teaches responsibility, but it may just indicate an increasing awareness of the social acceptability of humility or an increasing belief in luck.

Sex differences have also been reported. Martin and Cowles (1983) found that boys tend to be more internal than girls (all subjects between six and eight years). They also found an interaction effect between sex, SES, and educational program.

### LOC Scales

Since Rotter's (1966) work, a number of specific LOC scales have been devised for specific areas of control, in order to handle the complexities arising from the diversity of human goals. Rather than attempting to create a single all-encompassing scale, these scales have focused on restricted domains. Strickland (1989) has remarked on the importance of the relationship between LOC beliefs and

health. For the purposes of this study, we are interested in this relationship and in L.O.C. scales related to health beliefs.

Wallston and Wallston (1981) have devised a number of health-oriented LOC scales. The first scale was the Health Locus of Control Scale (HLC) (Wallston, Wallston, Kaplan, & Maides, 1976). The HLC scale is a one dimensional scale with the upper end designated "HEALTH-EXTERNAL", and the lower end designated "HEALTH-INTERNAL". With this scale, researchers have found that chronic illness in general is related to external locus of control on HLC scales (see Wallston and Wallston, 1981). In response to criticisms by Levenson (1973; 1974; and 1975), who argued that health locus of control is not one dimensional, Wallston et al. (1978) eventually developed the Multidimensional Health Locus of Control Scales. These scales include three dimensions: INTERNALITY, CHANCE EXTERNALITY, AND POWERFUL OTHERS EXTERNALITY. This conceptualization of locus of control is consistent with Levenson's (1981) formulation of the construct. The Wallston et al. (1978) scales are reasonably reliable (alphas range from .67 to .77), and have fairly low interscale correlations. However, these scales were designed for use with adults and therefore may not be useful for research with children.

Parcel and Meyer (1978) developed the Multidimensional Children's Health Locus of Control Scale (MCHLC). This scale is designed to assess children's perceptions of control over illness and health where high scores indicate a relatively internal sense of control. Katz, Rubinstein, Hubert, and Bleu (1984) used this measure in their study of psychosocial functioning in newly diagnosed pediatric

cancer patients. They found, among other things, that internality was associated with depression. The direction of the effect is unclear, however. Either depressed children felt more responsible for their illness, or those children who felt more responsible for their illness were depressed.

Perrin and Shapiro (1985) examined health locus of control beliefs in healthy children and in children with one of four chronic illnesses. The illnesses selected were: asthma, diabetes, a seizure disorder, and an orthopedic condition. The result was that the control beliefs of asthmatic and diabetic children did not statistically differ from those of healthy children. Children with a seizure disorder or an orthopedic condition, however, had consistently lower Internality scores and higher Powerful Others and Chance External scores as compared to healthy children.

Perrin and Shapiro's findings suggest that there is something quite different about the experience of these two sets of illnesses. The nature of this difference needs further examination, but it may involve any of a variety of factors, including differences in the biological nature of the illnesses, differences in medical and/or psychological treatment, and differences in peer reactions to name but three possibilities.

### Engagement Style

A concept that on the surface may appear to be related to locus of control but that arises from very different origins is that of Engagement Style (McKinney, 1978). This construct is measured through the use of McKinney's Test of

Engagement Style (TES). The TES uses a semi-projective technique involving several sets of cards depicting scenes of social interaction. Participants are asked to describe the activity taking place, and their responses are scored as to whether the "main character" is acting (Agent) or is being acted upon (Patient). Agent responses are added with a maximum score of 24 (the number of scored cards). High scores indicate "agency", and low scores indicate "patience". It is assumed that the respondent identifies with the "main character". Where LOC depends upon expected outcomes of action, engagement style focuses on whether or not the individual perceives himself or herself as acting at all. In other words, LOC deals with cause and effect, whereas engagement style refers to the social actor without considering the social outcomes for that actor. McKinney (1981) has suggested that Agency may be necessary but not sufficient for an internal expectancy. However, no relationship between locus of control and engagement style has been established empirically.

McKinney (1978) has found that a number of variables are related to engagement style. Family size is one such variable. He predicted and found that children from large families generally have more extreme scores on the TES than do children from smaller families. In other words, large families tend to produce children who are either very agent or very patient. McKinney also has found that engagement style changes with age. For boys, agency declines between 2nd and 7th grade, then increases between 7th and 12th grade. For girls, agency declines throughout the school years (this decline being sharper before 7th grade than after 7th grade). McKinney (1980) has also found that family integration and maternal

employment influence engagement style. Girls whose mothers work outside the home are more agent than girls whose mothers are not employed outside the home.

Hotch (1979) has used the engagement style construct to explore the way in which adolescents perceive the transition from living with parents to living on their own. Hotch examined whether adolescents saw this transition as something they did themselves, as something that was forced on them, or as a mutual decision reflecting both agent and patient components. Hotch developed this domain-specific conceptualization of engagement style and used it as a criterion measure against which various predictors were compared. Hotch found that family variables including relatedness and self-sufficiency predicted the manner in which home-leaving was perceived. Adolescents who experienced a close relationship with their parents had a more agent style of separation. Hotch argued that these adolescents would regard the transition to independence as necessary but much less appealing than would adolescents with a more distant parental relationship. As a result, those individuals with a high level of relatedness saw themselves as having to be more agent in the process of leaving home, whereas those with a low level of relatedness saw the less pleasant home environment as a force pushing them out on their own.

### Purpose

In order to treat pediatric cancer patients in the most effective manner, we must understand how they view the world. The purpose of this research was to begin to explore the way children with cancer view their social environment. Of

particular interest was whether children perceived themselves as acting or being acted upon, and whether they see their health as being internally or externally controlled.

### Hypotheses and Predictions

The first hypothesis was that as a result of the treatment that they undergo, pediatric cancer patients would tend to believe that their health depended on factors beyond their control (see Wallston & Wallston, 1981). Therefore, it was predicted that children with cancer will have higher externality scores on the MCHLOC scale than will children who do not have cancer. As noted earlier, this effect has been found by Perrin and Shapiro (1985) in children with seizure disorders and orthopedic conditions.

The second hypothesis was that pediatric cancer patients would feel that they were acted upon by the world more than they were actors in the world because they are acted upon so frequently during their treatment. Further, this perception of their social environment would be generalized to other types of social situations. Therefore, it was predicted that children with cancer will have a lower agency score on the TES than will children who do not have cancer.

Finally, because of the stresses, cognitive growth, and emotional changes associated with adolescence (for example puberty, and the greater need for peer acceptance), it was predicted that the effect of the experience of cancer would be different for adolescents than for pre-adolescents. Some studies have found that



children diagnosed and treated at younger ages are less likely to have adjustment problems later in life than older children and adolescents (Koocher et al., 1980; Lansky, List, & Ritter-Sterr, 1986). On the other hand, Allen and Zigler (1986) report that the harmful effects of cancer on verbal intelligence scores were greater for younger than for older children. Their argument as to why this is not surprising involves issues of increasing autonomy and control. They suggest that older children are more likely to work on their problems on their own and that they are more capable of doing so. It follows, that the effect of pediatric cancer might be different for adolescents than for pre-adolescents. No prediction was made, however, about the specific nature of this difference.

## METHOD

### Research Participants

The participants were twenty-three matched pairs of children (n= 46). Fifteen of the pairs were boys, 8 of the pairs were girls. The difference in the numbers of each sex was due to random variation. Cancer patient participants in this study were contacted through the pediatric oncology clinics of two large American midwestern universities (Michigan State University and the University of Michigan). Seventeen of the children were recruited from the clinic at Michigan State and 6 from the University of Michigan. Children with cancer involving the central nervous system were excluded from the study because such children have been found to have significant psychological problems of physiological origin associated with the location of the tumor (Aram & Ekelman, 1986; Kun, Mulhern, & Crisco, 1983; Sollee & Kindlon, 1987), the magnitude of the lesion (Danoff, Cowchock, Marquette, Mulgrew, & Kramer, 1982), and the use of cranial radiation (Duffner, Cohen, Thomas, & Lansky, 1985; Duffner, Cohen, & Parker, 1988; Ellenberg, McComb, Siegel, & Stowe, 1987; Kun et al. 1983). Clinic children between the ages of 8 and 18 years who were attending school regularly and either were receiving chemotherapy or had stopped treatment within the past 12 months were contacted and asked to participate in the study. These children were selected because their disease and treatment had stabilized enough for them to attend school on a regular basis. This also meant that they were past the family upheaval and

trauma associated with diagnosis and the rigorous initial regime of treatment and were in the maintenance phase of treatment. Of these children, 10 had sustained relapses, and 12 had been treated with cranial radiation. Of the families contacted, 92% (23 out of 25) agreed to participate.

As part of a larger study examining these children's peer relationships (Noll, Bukowski, Rogosch, LeRoy, & Kulkarni, in press), the children and their families were asked for permission to contact the child's school. With this permission, the school principal was approached and the peer study was discussed. With the principal's permission, the teachers of each of the children in the study were contacted and their aid was enlisted in conducting the peer study in their classrooms. Consent forms were sent home with each of the children ( $n=575$ ). These consent forms made no mention of cancer. The children's parents were asked for permission to include their children in a study of children's friendships. Ninety percent of the parents agreed to permit their children to take part in the study resulting in the participation of 515 children. This included all of the original clinic children. The children with cancer were matched from among the other participants with a child from their own classroom on the basis of sex, closest date of birth, and race (racial match was based on observation). The parents of potential comparison subjects were contacted by telephone and asked to participate in a study examining the effect of chronic illness on children. In the case of one child with cancer, the school declined to participate. The control for this child was found by canvassing in the general neighborhood of the participant family to find an appropriate match. Families were told that it was important to have information from families with

healthy children as well as those with chronically ill children in order to understand how chronic illness affects children and families. The comparison children and their parents were asked about the health of the child at this point to confirm that they did not have a chronic illness before they were included in the study. Of comparison families 82% of those contacted (23 out of 28) agreed to participate.

### Instruments

It was thought to be important that the measures to be used in the study have validity across the entire participant age range in order to simplify comparisons between ages. The LOC instrument that was used was the Multidimensional Children's Health Locus of Control (MCHLC) scale (Parcel & Meyer, 1978) (See Appendix A). Because this scale was designed for use with children, it was thought to be a better measure for the purposes of the current research than health locus of control scales designed for use solely with adults.

Since the Test of Engagement Style (McKinney, 1978) can be used over a wide range of ages, it was well suited to the needs of the current study. McKinney (1981) reports that normative means on the TES range between 10.46 for 5th graders and 11.5 for 12th graders.

### Procedure

All data from the participants were collected in their homes by a researcher from either Michigan State University or Wayne State University. Prior to data

Table 1

Characteristics of the sample: Cancer and Comparison groups

|                                   | <u>Children with Cancer</u><br>(15 boys, 8 girls) | <u>Comparison Children</u><br>(15 boys, 8 girls) |
|-----------------------------------|---------------------------------------------------|--------------------------------------------------|
|                                   | 16 Leukemia (ALL)*                                | No Severe Chronic                                |
|                                   | 4 Solid tumor                                     | Illness                                          |
|                                   | 3 Lymphoma                                        |                                                  |
|                                   | 18 On therapy at data collection                  |                                                  |
|                                   | 5 Off therapy at data collection                  |                                                  |
| <u>Age of the Sample</u>          |                                                   |                                                  |
| Range:                            | 8-18 years                                        | 8-17 years                                       |
| M:                                | 12.3 years                                        | 12.5 years                                       |
| <u>Race</u>                       |                                                   |                                                  |
|                                   | 22 Caucasian                                      | 2 Caucasian                                      |
|                                   | 1 Black                                           | 1 Black                                          |
| <u>Marital Status of Parents</u>  |                                                   |                                                  |
| % married                         | 70%                                               | 78%                                              |
| % divorced/single                 | 30%                                               | 22%                                              |
| <u>Duncan Socioeconomic Index</u> |                                                   |                                                  |
| M:                                | 39.00                                             | 42.57                                            |
| SD:                               | 24.89                                             | 21.60                                            |

\* - acute lymphocytic leukemia

collection, the child and parents had an opportunity to ask questions about the study. The parents signed informed consent forms, which were also explained to and signed by the child participant. The children were then seated in a quiet place apart from the parents and were presented with the study instruments. At this time, data for this study and a related research project were collected. While this was occurring, the child's parents were seated elsewhere in the home where they completed another series of instruments including family demographic questionnaires. After the data were collected the family was again allowed to ask questions and were asked their reactions to the instruments. The entire procedure took approximately one hour.

Children were given the following instructions for the test of Engagement Style:

This is a set of pictures we're using to see if everyone can tell what's happening in them. They're all about one girl (boy) named Sally (Billy). She's the one with the bow in her hair (He's the one with the cap on). What I'd like you to do is tell me what's happening in each picture. They're all about the same girl (boy) named Sally (Billy). Okay? Let's begin.

(McKinney, 1978, p. 7-8)

Participants were then presented with two practice cards followed by six packets of test cards. Their responses were recorded verbatim by the tester onto a coding sheet. These response sentences were later scored for agency. As an example of

engagement style scoring, refer to figure 1. One child might describe the figure 1 stimulus as "Sally is giving the girl a horse-back ride." This response would be scored as agent, because the main character Sally is the active participant. Another child might respond with: "The girl is riding on Sally." Such a description would be scored patient because Sally is the object of the other child's activity. Another possible response could be: "Sally is giving the girl a ride, while the girl is sitting on Sally's back." This response incorporates both agent and patient components and would be scored 1/2 agent and 1/2 patient.

The MCHLC items were read aloud to each participant, and their responses were marked by the experimenter. This was done to make the presentation of the instrument as similar as possible for all participants across the range of ages (8 to 18 years) and the corresponding differences in reading skill. These data were likewise coded later.

### Analysis

The analysis of cross-group data was performed using a repeated measures analysis of variance. The members of each matched pair were treated as a single subject from whom data were collected on two occasions. This procedure took full advantage of the pairwise matching process used to select the comparison group and was used to reduce the random error in the scores of participants.

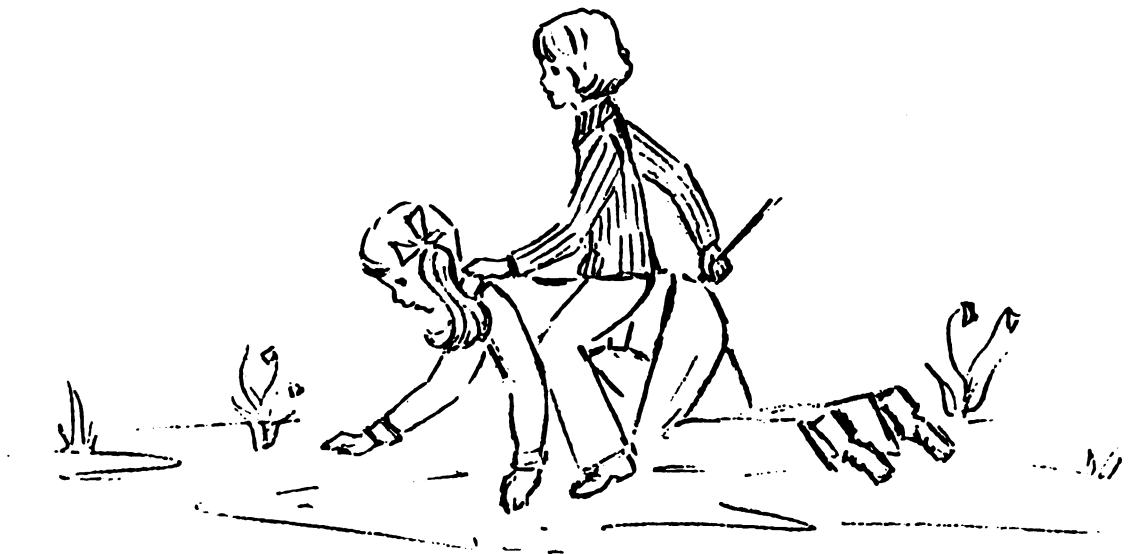


figure 1

Engagement Style sample card



## RESULTS

### Locus of Control

The locus of control data were initially examined using a multidimensional scoring system that produced three subscale scores: Internality, Powerful Others Externality, and Chance Externality. This method is consistent with Levenson's (1981) position regarding the multidimensionality of locus of control and with Parcel and Meyer's (1978) discussion of the multiple dimensions that underlie the MCHLC scale. It was thought that this procedure might reveal meaningful differences that would otherwise be hidden by the more common unidimensional internal-external scoring method.

Multidimensional methods of scoring the MCHLC have been used in previous research (Perrin & Shapiro, 1985; Green & Kolff, 1980). These studies have found low reliabilities for the subscales, however, and it has been suggested that the use of LOC subscales with children may be inappropriate (Green & Kolff, 1980). Given the short length of the MCHLC (20 items) and the correspondingly small size of the subscales (6, 7, and 8 items), reliability problems are not surprising. In the current study, the subscale reliabilities were variable. The reliability of the Internality subscale was particularly poor (coefficient alphas of .11 for children with cancer and -.031 for comparison children). The reliability of the Chance Externality subscale was somewhat better (coefficient alphas of .39 for children with cancer, and .50 for comparison children). The reliability of the Powerful Others Externality

subscale, however, was quite good (coefficient alphas of .84 for children with cancer and .88 for comparison children).

A preliminary MANOVA was carried out with the three LOC subscales to look for overall group differences. The results of this analysis were marginal ( $F(3,42) = 2.228, p < .099$ ). A closer examination of the data seemed appropriate given the exploratory nature of the study.

An ANOVA revealed no significant sex differences in either the cancer or comparison groups, and a repeated measures ANOVA disclosed no significant subscale differences between groups, although differences on the Internality subscale approached significance ( $F(1,22) = 3.43, p < .077$ ). The unreliability of this subscale makes interpretation of this finding problematic, but it appeared that children with cancer ( $M = 6.7, SD = 0.82$ ) might be more internal in locus of control than children without cancer ( $M = 6.2, SD = 0.85$ ). The three locus of control subscale scores were then correlated with the age of the participants. This correlation was carried out separately for the cancer and comparison groups to assess the influence of age within each group. It revealed important differences between the groups

Although scores on both the Internality and the Powerful-Others External subscales had similar age correlations for both groups, this was not the case for the Chance-External subscale. Internality scores were not significantly correlated with age for either group of participants (Pearson correlations of -0.18 for children with cancer and -0.15 for comparison children). These correlations were not significantly different from one another (z score comparison).

Table 2

Pearson Correlations between age and the Locus of Control Subscales,  
and Subscale Intercorrelations.

---

|                         |            |                 |                            |                            |
|-------------------------|------------|-----------------|----------------------------|----------------------------|
| Children with cancer    |            |                 |                            |                            |
|                         | <u>AGE</u> | <u>INTERNAL</u> | <u>CHANCE<br/>EXTERNAL</u> | <u>POWERFUL<br/>OTHERS</u> |
| AGE                     | ---        |                 |                            |                            |
| INTERNAL                | -.18       | ---             |                            |                            |
| CHANCE<br>EXTERNAL      | -.23       | .12             | ---                        |                            |
| POWERFUL<br>OTHERS      | -.58*      | .26             | .29                        | ---                        |
| Children without cancer |            |                 |                            |                            |
|                         | <u>AGE</u> | <u>INTERNAL</u> | <u>CHANCE<br/>EXTERNAL</u> | <u>POWERFUL<br/>OTHERS</u> |
| AGE                     | ---        |                 |                            |                            |
| INTERNAL                | -.15       | ---             |                            |                            |
| CHANCE<br>EXTERNAL      | -.66*      | .39             | ---                        |                            |
| POWERFUL<br>OTHERS      | -.77*      | .18             | .65*                       | ---                        |

---

\*  $p < .05$ , two-tailed

Powerful-Others scores, on the other hand, were negatively correlated with age for both groups (Pearson correlations of  $-.58$  for children with cancer and  $-.77$  for comparison children). Older subjects were less external. That is, they were less likely to attribute health outcomes to powerful others. The correlations for the two groups were, again, not significantly different from one another (z score comparison).

Scores on Chance-Externality were negatively correlated with age for the comparison group (Pearson correlation of  $-.66$ ) but were not significantly correlated with age for children with cancer (Pearson correlation of  $-.23$ ). For the comparison group, older children were less likely than younger children to attribute health outcomes to chance factors. Among children with cancer, however, the likelihood of crediting health outcomes to chance was unrelated to the individual's age. The age correlations for the chance external subscale were significantly different between the groups,  $z = 1.77$ ,  $p < .05$ .

As can be seen from Table 2, Chance External and Powerful Others scores were significantly correlated with one another for the comparison group but not for the children with cancer. This is consistent with the finding of varying age correlations for these scores between groups.

Given the variable reliability of subscale scores, the data were further analyzed using the more common unidimensional method, which produces a single total score for each participant. Because the external items were reverse scored, high scores indicated greater internality. This technique was found to be substantially more reliable (coefficient alphas of  $0.64$  for children with cancer and  $0.75$  for comparison

children). These scores were then analyzed in the same fashion as the subscale scores; an ANOVA was carried out to check for cross-group differences, and a correlation with age was made for each group. This analysis again revealed no significant differences in overall locus of control between groups. Locus of control scores for both groups were significantly correlated with age. The Pearson correlation for children with cancer was 0.50, whereas for the comparison children it was 0.87. For both groups, older children were more Internal. Interestingly, these correlations were significantly different from one another,  $z = 2.48$ ,  $p < .01$ . This difference may be due to the differences in age correlations found between groups for Chance-External scores.

#### Test of Engagement Style

The Test of Engagement Style proved to be a highly reliable instrument for the current sample (coefficient alphas of .89 for children with cancer and .76 for comparison children). Contrary to predictions, however, the analysis of agency scores revealed that children with cancer ( $M = 11.24$ ,  $SD = 5.69$ ) showed significantly higher levels of agency than did their matched controls ( $M = 7.98$ ,  $SD = 3.62$ ),  $F(1, 23) = 4.76$ ,  $p < .05$ . Engagement Style scores were not significantly correlated with age for either group (Pearson correlations of -0.21 for children with cancer and 0.05 for comparison children). Likewise, ANOVAs revealed no sex differences in engagement style for either group.

## DISCUSSION

The results reveal a number of interesting differences between children with cancer and children without cancer. Contrary to expectations, children with cancer had a more Agent view of social relations than did comparison children. Crucial questions are raised by this finding: Does Agency influence the individual's chances of overcoming illness? If so, how does it affect survival? Based on a review of the LOC literature, Lefcourt (1982) has suggested that patients with an internal LOC may tend to avoid behaviors that make their conditions worse. If we can generalize this suggestion to individuals with an agent engagement style, this would imply that higher agency is a positive, adaptive reaction for children with cancer. One possible reason for the finding lies in the way that pediatric cancer patients are encouraged by treatment team members to take an active, responsible role in the management of their disease. The trend in recent decades of actively involving patients in their own health care (MacIntyre, 1977) may have produced higher levels of Agency with respect to health as a result. This encouragement has perhaps made these children more Agent in many aspects of their lives.

One of the two institutions involved in this research has a particular commitment to encouraging the children to participate actively in their treatment. From the point of diagnosis on, the family has access to and frequent contact with a clinical psychologist and a clinical social worker who are integral members of the

oncology team. The children as well as their families are kept informed about all relevant aspects of their treatment. This arrangement is highly unusual and places this institution at the forefront of the movement to encourage patient participation. Since this is the case, it raises the question: To what extent are these increased agency findings due to the particular circumstances of the research sample? In order to address this question, a post hoc analysis was conducted comparing clinic participants from the two treatment institutions. The analysis revealed no significant differences between the clinic samples.

The finding (approaching statistical significance) that children with cancer scored higher on internal health locus of control than comparison children would appear to be consistent with the encouragement explanation. The findings of Nannis et al. (1982) also support this conclusion. They found that, in cancer patients between the age of 12 and 21, the cancer patient's overall sense of control and feelings of control over medical decisions are positively correlated with the patient's knowledge about their disease and treatment.

Unfortunately, the unreliability of the Internality subscale makes these findings suspect. The lack of differences in locus of control between groups on the overall measure is consistent with the findings of Perrin and Shapiro (1985). The findings of the present study suggest two possible explanations. The first is that the experiences of children with cancer are more similar to those of children with diabetes or asthma than to those of children with a seizure disorder or an orthopedic condition. This similarity could involve the children's perception of the influence they exert over their illness through treatment, daily routine, and attitude toward the

disease. The second possibility is that children with cancer belong to a distinct third category of illness. Given that cancer is a highly life-threatening illness in contrast to the illnesses studied by Perrin and Shapiro, the latter explanation seems more likely.

The current findings, albeit only approaching significance, are also consistent with the findings of Steinhausen (1982) that children with certain chronic illnesses tend to have a greater internal locus of control as assessed by generalized measures. These illnesses included cystic fibrosis, Crohn's disease, and ulcerative colitis. This increased internality was not found for children with asthma. Steinhausen suggests that a high magnitude of behavioral control is encouraged among individuals with serious illnesses as the result of severe behavioral restrictions and intensive medical treatment. If so, the higher Agency scores for children with cancer may also be a result of this encouragement.

The correlations between age and locus of control are intriguing. It is not surprising that, among children without cancer, older children are less likely than younger children to believe that their health is due to the activities of powerful others or "luck". It is commonly accepted that, in children, locus of control becomes less external with age. In fact, the Nowicki-Strickland (1973) test is specifically designed with the developmental progression from External to Internal in mind.

Among children with cancer, older children are, like the control group, less likely than younger children to attribute their health outcomes to the activities of powerful others. What is fascinating is that these older children who have



experienced cancer are just as likely as younger children to attribute their health outcomes to chance, whereas this does not appear to be the case among the healthy children. This attribution may be a defense against self-blame. It is as though the sick children are asking themselves, "What did I do to deserve this?", and answering, "Nothing, because bad luck caused it." This could be very adaptive for children with cancer and their families and would be consistent with the findings of Katz et al. (1984) that among children with cancer, a positive relationship existed between Internality and depression. This response in conjunction with an agent stance toward fighting the disease might prove a powerful force in resisting the psychological stresses associated with the disease.

This finding also provides support for the validity of the chance external LOC subscale. The scale scores indicate that adolescents with cancer consider the role of luck in health outcomes to be important. Adolescents without cancer do not seem to have as strong a belief in the influence of chance. This finding makes sense and, therefore, strengthens the face validity of the chance scale.

## CONCLUSIONS

The current research has generated a number of interesting findings. Children with cancer were found to be more agent than children without cancer and possibly to have a greater internal locus of control as well. As they grow older, children with and children without cancer seem to lose their sense that powerful others control health outcomes for them. The tendency of children without cancer to attribute their health outcomes to chance also seems to diminish with age. Children with cancer, however, do not seem to lose their belief in the influence of chance on health.

Issues of measurement have also been raised regarding the use of multidimensional approaches to the study of children's health LOC beliefs. Rather than suggesting, however, that locus of control subscales are inappropriate for the study of children, the age relationship findings provide support for the use of multidimensional approaches for the study of children's health LOC beliefs while demonstrating the need for longer and more reliable subscales for use with children. This methodological refinement is essential in order to accurately assess and understand the components that make up beliefs about locus of control. In addition to the factors of Internality, Chance, and Powerful Others, the distinction between competence and contingency must be addressed.

The findings discussed above have implications for understanding the coping strategies used by children with cancer and their families. They indicate that children and adolescents with cancer perceive themselves as acting on their environment and possibly exerting control over their health outcomes to a greater extent than do children and adolescents without cancer. They also appear to maintain a belief in the influence of random events on their health. This apparent inconsistency allows them to be active in fighting their illness, but at the same time it frees them from the guilt and increased depression that might follow if they felt that they were to blame for their illness.

The findings of this study suggest new directions for future research. It appears that different categories of chronic illnesses may influence children's locus of control in different ways. How are these categories of illnesses different from one another, and what do illnesses within these categories have in common? There are a number of possibilities: there may be characteristic family coping styles related to different kinds of illnesses; the psychological treatment that these groups receive may differ across categories; or the courses of particular types of illnesses may have unique psychosocial effects. Other questions need to be answered as well. Does perceived control affect the types of coping strategies that children use? How does this affect long-term survival? How do different psychological treatments affect coping, control beliefs, and survival? Cromwell, Butterfield, Brayfield, and Curry (1977) discovered a relationship between survival rates and treatment strategies that accommodated individual LOC beliefs among cardiac patients. The same may hold for children with cancer. A prospective study of these

relationships could provide mental health professionals with information crucial to their work. One could begin to explore these questions by collecting information about children's control beliefs at the time that families are referred to the oncology clinic and prior to diagnosis. By following up children positively diagnosed for cancer and examining their control beliefs and coping strategies, the relationships among these constructs might be better understood. Long-term survival rates of participants could then be correlated with these data. The effect of different psychological treatments could be explored either by random assignment (which is ethically problematic) or by conducting this research at different institutions with different psychological treatment approaches.

The answers to all of these questions could have an immense impact on the treatment of chronically ill children. If different psychological treatments in combination with different coping strategies and sets of control beliefs can be shown to influence family functioning, child emotional development, and/or survival rates, an important advance in clinic treatment will have been achieved.

## **APPENDIX A**

## APPENDIX A

## MULTIDIMENSIONAL CHILDREN'S HEALTH LOCUS OF CONTROL

We would like to learn about different ways children look at their health. Here are some statements about health or illness (sickness). Some of them you will think are true and so you will say YES to them. Some you will think are not true and so you will say NO. Even if it is very hard to decide, be sure to say YES or NO for every statement. Never say both YES and NO for one statement. There are no right or wrong answers. Be sure to answer the way you really feel and not the way other people might feel.

PRACTICE: Try these statements.

- |    |                          |     |    |
|----|--------------------------|-----|----|
| a. | Children can get sick.   | YES | NO |
| b. | Children never get sick. | YES | NO |

Try one more statement for practice.

- |    |                                   |     |    |
|----|-----------------------------------|-----|----|
| c. | When I am not sick, I am healthy. | YES | NO |
|----|-----------------------------------|-----|----|

NOW DO THE REST OF THE STATEMENTS THE SAME WAY YOU PRACTICED.

- |     |                                                             |     |    |
|-----|-------------------------------------------------------------|-----|----|
| 1.  | Good health comes from being lucky.....                     | YES | NO |
| 2.  | I can do things to keep from getting sick.....              | YES | NO |
| 3.  | Bad luck makes people get sick.....                         | YES | NO |
| 4.  | I can only do what the doctor tells me to do.....           | YES | NO |
| 5.  | If I get sick, it is because getting sick just happens..... | YES | NO |
| 6.  | People who never get sick are just plain lucky.....         | YES | NO |
| 7.  | My mother must tell me how to keep from getting sick.....   | YES | NO |
| 8.  | Only a doctor or a nurse keeps me from getting sick.....    | YES | NO |
| 9.  | When I am sick, I can do things to get better.....          | YES | NO |
| 10. | If I get hurt it is because accidents just happen.....      | YES | NO |
| 11. | I can do many things to fight illness.....                  | YES | NO |

- |     |                                                                              |     |    |
|-----|------------------------------------------------------------------------------|-----|----|
| 12. | Only the dentist can take care of my teeth.....                              | YES | NO |
| 13. | Other people must tell me how to stay healthy.....                           | YES | NO |
| 14. | I always go to the nurse right away if I get hurt at school.....             | YES | NO |
| 15. | The teacher must tell me how to keep from having accidents<br>at school..... | YES | NO |
| 16. | I can make many choices about my health.....                                 | YES | NO |
| 17. | Other people must tell me what to do when I feel sick.....                   | YES | NO |
| 18. | Whenever I feel sick I go to see the school nurse right away....             | YES | NO |
| 19. | There are things I can do to have healthy teeth.....                         | YES | NO |
| 20. | I can do many things to prevent accidents.....                               | YES | NO |

**Subscale items**

Internal scale: 2, 9, 11, 14, 16, 18, 19, 20

Chance external: 1, 3, 5, 6, 10

Powerful Others: 4, 7, 8, 12, 13, 15, 17

## **APPENDIX B**



## APPENDIX B

## Clinic family contact

Hello, is this the \_\_\_\_\_ home? Good. My name is Dan Mondoux, and I'm a graduate student at Michigan State working with Bob Noll the psychologist at the MSU pediatric oncology clinic. Do you remember his asking you for your permission to release your family's name and phone number to me for possible participation in a research project? (good)

What we're trying to do is to understand some of the effects that cancer has on children and families. I'm calling now to try to find a time when I could come out to visit your home. This visit will take about 1 hour of your family's time. Since we're looking at the effect of cancer on the whole family, I would like to find a time when I could meet with you, your (husband/wife) and child's name. Also, I would like to meet child's name's brothers and sisters. Does he/she have a brother/sister over age 10?

NAME?

AGE?

GIRL OR BOY?

Okay. I do this work at your convenience in the evening or on the weekends. I'm wondering when would be a good time for me to visit with your family?

Questions?- we're trying to learn about several things. We're trying to find out about what children think about themselves, in school, with friends, in sports and games. We're also trying to figure out if all the appointments and treatments and stuff change children's feelings of control over their life. Also, we want to better understand the families of children with cancer and what they're like.

## **APPENDIX C**

## APPENDIX C

## Comparison family contact

Hello, is this the \_\_\_\_\_ house? Good. My name is \_\_\_\_\_ and I'm a graduate student at (WSU/MSU) and I'm doing some additional work on the friendship study that your child participated in at his/her school. Do you remember that project?

Good. (Explain briefly if not.)

I'm contacting you now about your possible participation in further research we're doing to learn more about children with serious/chronic illness and their families. To do this we're visiting some families with serious illness and some families with healthy children. We have visited some families with illness in the \_\_\_\_\_ area and we hoped that your family could help us learn more about families with healthy children who are in your area. Your help will take only about an hour of your family's time and would involve filling out some questionnaires. What I'd like to do now is to arrange a time that I could come to your home, meet with you, your wife/husband, and child from class to explain the study in more detail and answer any questions that you have. When would be a good time for me to come to your home?

If they ask what it involves: It will involve filling out some questionnaires.

If they say no: Ask what it was that led them to say no.

## APPENDIX D

**MSU FRIENDSHIP STUDY****RESEARCH PARTICIPATION INFORMED CONSENT FORM**

We have freely consented to take part in a research study being conducted jointly by Michigan State University and Wayne State University.

The research study has been explained to us, and we understand that the purpose of the research is to learn more about family relationships, and how parents view their children's behavior. We understand that the study is also looking at how children view themselves, their relationships, and how they view health. We understand that if we agree to participate, we and our child will be asked to fill out several questionnaires. We have been told that the procedure will take approximately one hour.

We understand that we are free to discontinue our participation in the study at any time without penalty; we are aware that lack of participation in the study will not result in any penalty for us or our child.

We understand that the results of the study will be treated in strict confidence and that we and our child will remain anonymous. Within the restrictions described previously, we understand that general results of the research may appear in professional journals and may be presented at scientific meetings. General results of the study will be made available to us at our request.

We understand that our participation and our child's participation in the study does not guarantee any beneficial results to any member of our family.

The study has been explained to my child and she/he has assented (verbally agreed) to participate in the study.

In the event of any injury resulting from the research, no reimbursement, compensation, or free medical care is offered by Wayne State University.

Any questions I have about the project will be answered. (Sarah LeRoy: phone 351-1327 or Dan Mondoux: phone 353-3933)

I understand that I will receive a copy of this consent form.

Mother's Signature

Date

Father's Signature

Date

Child's Signature

Date

Project Copy

Witness's Signature

Date

Participants Copy

## **LIST OF REFERENCES**

## LIST OF REFERENCES

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