THE INSTITUTE FOR CLINICAL SOCIAL WORK

THE USE OF MAGICAL THINKING AS A MEDIATOR OF STRESS IN PARENTS OF CHILDREN WITH CANCER

A DISSERTATION SUBMITTED AS PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY FROM THE INSTITUTE FOR CLINICAL SOCIAL WORK

BY

LYNNE K. TYLKE

CHICAGO, ILLINOIS

JUNE, 1992

PROPERTY OF INSTITUTE
FOR CLINICAL SOCIAL WORK

TABLE OF CONTENTS

Page

ACKNOWLEDGMENTS ii

LIST OF TABLES vii

Chapter

I. INTRODUCTION TO THE PROBLEM 1
   Impetus for the study
   Research Questions and Methodology
   Relevance or Implications of This Study to Social Work

II. LITERATURE REVIEW 16
   Introduction
   Psychological Approaches to Stress
   The Role of Primary Appraisal in Stress
   The Role of Emotions in Primary Appraisal
   Physiological Changes in Stress
   The Role of Secondary Appraisal in the Stress Response
   Coping Efforts
   Belief in Control
   Belief in Control Versus Actual Control
   Variables That Moderate or Mediate the Stress Response or Outcome
   Parental Affective Expression in Relation to Their Child's Diagnosis of Cancer
   Magical Thinking Theory
   Magical Thinking Research
   Internalization of Structure; Representations and Functions
   Shifts in Internal Representations and Intrapsychic Functions During Mourning
   The Transitional Object and Phenomena
   Magical Thinking and Transitional Phenomena
   Relevance of the Study
   Substantive Hypothesis

III. METHODOLOGY 50
   Study Design
   Setting
   Population
   Sampling Method
   Sample
   Methods of Measurement

Table of Contents. -- Continued

Chapter Page

Objective Tests
Written and Verbal Description of Self, Child, and Physician
Clinical Interviews
Effectiveness of Data Collection Methodology
Data Management
Data Analysis

IV. FINDINGS 72
Description of the Sample
Instruments
The Interview
Attributes of Magical Thinking
The "Cause and Effect" of Magical Thinking
Elaboration of Magical Thought
Other Attributes of The Magical Thinking
Magical Thinking Attributes in Internally Oriented Parents
Magical Thinking and Negative Affect
t-Tests

V. DISCUSSION, IMPLICATIONS, AND CONCLUSIONS 123
Introduction
Magical Thought
Substantive Hypothesis
Magical Thinking as a Regulator of Affect
External and Internal Locus of Control and Depression
Magical Thinking and Depression
The Role of the Physician in the Management of Affect
Magical Thinking and it's Role as Transitional Phenomena
Problematic Mourning
Limitations of the Study
Implications
Conclusion

APPENDIXES
A. Informed Consent 151
B. Severity of Illness Scale 152
C. Information Form 154
D. Internal versus External Scale 155
E. Beck Depression Inventory 158

Chapter Page

REFERENCES 161

LIST OF TABLES

Table — Page

1. Worry Index 80
2. Beck's Depression Scale 84
3. Locus of Control 86
4. Qualities of Magical Thought 90
5. What Preceded Episodes of Magical Thinking 93
6. Aspects Preceding Magical Thought 96
7. Attributes of Magical Thinking 100
8. Time in the Child's Treatment that Magical Thinking is Developed 102
9. Form and Domain of Control in Magical Thoughts 104
10. Domain of Parents Control 107
11. History Involved in Magical Thought 108
12. Creation of Magical Thought in History 110
13. Attributes of Magical Thinking with Internal Locus of Control 112
14. Correlations: Magical Thinking to Becks, Internal, External, Affect 116
15. Correlations: Becks, Affect, Veryworry, Someworry, NegNeg, PosPos 118

Nonetheless, pediatric cancer still remains one of the leading causes of death in childhood. Accidents (7,119, or 43.9%) were responsible for the largest number of the 16,216 children between one and fourteen years of age who died in 1987. The second leading cause of childhood deaths was cancer. In 1987, ten percent, or 1,686 of all children who died under the age of fifteen had some form of cancer, including blood-related and solid tumors. Even though survival rates of children with cancer are substantially improved, the increasing incidence of cancer in children results in a national concern over finding effective medical treatment (Boring, et al., 1991).

The treatment of children with cancer has changed over the last two decades (Bleyer, 1990; Nesbitt, 1990; Vietti et al., in press). Initial forms of treatment for cancer were primarily palliative and offered temporary comfort. Untreated, the cancer resulted quickly in the child's death (Bleyer, 1990; Nesbitt, 1990). It is interesting to note that the dramatic improvement in the medical treatment of childhood cancers arose from a national effort to compile outcome statistics. Two national research study groups, Pediatric Oncology Group (POG) and Children's Cancer Study Group (CCSG), were developed to pool information about the current treatment of pediatric oncology cases and to develop protocols or "road maps" for treatment that would be used nationally. These protocols were step-by-step procedures of which chemotherapeutic agents or drugs to use, when to use them, in what dosage,

and in what sequence of the disease course. The two national study groups registered newly diagnosed patients on the various protocols to determine which protocols were the most effective with a particular constellation of medical symptoms. Patients were categorized by "staging" (how advanced their cancer was), by the type of cancerous cells that were proliferating, and by age and gender. Each piece of information about a patient, or category which he or she fit into, was used to determine the effectiveness of one treatment over others. Each protocol "opened" (began) and continued until a sufficient number of patients were registered. These patients were followed and information was gathered about how they progressed with the treatments. The resulting data provided invaluable information which helped evolve the treatment of children with cancer, effecting an improved success rate (Pediatric Oncology Group Administrative Reference Manual, 1988).

Currently there are 199 participating institutions or hospitals in the United States that register children on research protocols and provide ongoing and outcome information from open protocols (J. Smith personal communication April 4, 1990; L. Weiner personal communication April 10, 1990). The outcome information from previously closed study group protocols has been used to improve existing protocols and to develop new and more successful forms of cancer treatment. A diagnosis of cancer is no longer an assumed terminal illness.

in obtaining remission and maintaining those remissions. The parents used the statistics to calm themselves by perceptually locating their child on the "good" side, the side with a successful outcome. Parents did this to calm themselves even when the survival numbers were low, and, realistically, should not have provided comfort. They continued to deny what the actual numbers represented and seemed to use the statistics in a more concrete manner than intended. The numbers became a separate entity and were used by the parents, as a child uses a blanket, to face intense anxiety. The fact that there were "numbers" constituted the possibility of hope. A hypothetical 30% chance was better than no chance, and so the parents constructed stories as to why their child, for example, *was* in the 30% that responded to medications and *not* in the 70% that did not. Families had to believe that the numbers worked in their favor in order to submit their child to the rigors of the treatment; they had to believe that accepting pain would foster a successful outcome. "Pain now, gain later" was the mantra/motto employed to get through this difficult time. Families still had to face uncertainty, but they did so with hope. The uncertainty had to be made smaller, more manageable; the hope larger, something substantial to hold onto.

This new hope did not come without cost. Parents had to witness their children endure frightening and painful medical procedures in the belief that

the treatments would cure their children, or at least prolong their lives until a new drug or a more effective treatment was found.

For the first time, a parent was unable to protect his child from pain and fear, and instead had to encourage the child to withstand it. This fact seemed to alter the unspoken rules of parenting. Typically, a parent expects to protect her child from the ills, pains, and difficulties of life for as long as possible. These parents first had to deal with their lack of control and inability to protect their children from developing a serious illness. Next, they had to manage the fact that they were helpless to take it away or make it better. Mother was no longer was able to "kiss it and make it better." The parents had to deal with the idea that they were not all-powerful either in protecting their children or in keeping them safe. The belief in the parent's ability to fulfill the unspoken rules of parenting seemed to have been developed to help both the child and parent feel safe in an unsafe circumstance. However, it was an illusion of power and safety. When parents were confronted with the fact that their children had cancer they had to give up the illusion of being able to protect in this absolute way. In fact, the specific requirements of the medical protocol appeared to place the parent in conflict with the basic parental action of protection. Consequently, parents had to find an alternative illusion with which to manage the anxiety created by the hazardous positions in which they now found their children. The wish to

provide immediate concrete protection had to give way to a more urgent, yet long-range goal of preserving the child's life.

The protocol requirements took precedence. Parents had to witness their child being hurt during procedures and had to watch the adverse side effects over the long course of treatment. The treatment destroyed the proliferating cancer cells without knowing at what stage in the cell development they became malignant. Unfortunately, the medicines used in the treatment of cancer also inhibit the development of healthy blood cells, producing a toxic, immunologically compromised patient. The side effects of treatment created an uncertain course; dealing with uncertainty upon uncertainty became the parents' primary coping task. The previously absolute pronouncement of anticipated death was replaced by a Pandora's box of the Unknown, the Unpredictable, and the Uncertain. The illusion that loved ones can be protected from tragedy was stolen when the diagnosis of cancer was made. This illusion had to be replaced by another in order to manage the loss of control and the lost sense of safety.

During this time of uncertainty, this researcher observed that parents verbalized stories about the cancer or theories about what caused the cancer. The parents' stories and theories sounded like an attribution of guilt and seemed to make everyone listening to them anxious. The researcher observed that the medical staff, family and friends appeared to find the stories difficult

to hear and tried to talk the parents out of these thoughts. The parents were miserable already and their theories appeared to cause them even more pain. Those close to the parents did not want to see the parents in such discomfort and needed to feel there was some way to relieve their pain. It seemed easy to try to remove the parents' discomfort as it related to the cause of the cancer, particularly when it was uncertain that there was anything else anyone would be able to do. That feeling of powerlessness in the face of the potential loss of a child's life was intolerable. The most common reaction under these circumstances was for the health care team to convince themselves that the parents would be helped by being told that the cancer was not their fault. The health care team could feel that they had power over what the parents thought and the pain associated with those thoughts. The researcher, however, questioned the merit of invalidating the parents' theories of illogical cause and effect related to their children's illness. It was unknown what would constitute a clinically helpful stance to take when, for example, a parent confessed that she thought her child developed cancer because she herself had smoked cigarettes when she was a teenager; or, when another mother saw her child's cancer as retribution for an extra-marital affair; or, when still another parent attributed the cancer to the negative magic of hearing the words of the diagnosis, believing that if he had not heard the doctor's words, he and the child would be free of the consequence.

It appeared to the researcher that parents' illusions of their ability to protect their children from the dangers in the world was shattered by the diagnosis of cancer. This illusion of absolute protection helped make them and their child feel safe. The shattering of the illusion was intolerable and families struggled to replace this need for perceived safety in the midst of danger. They tried to adopt another illusion of safety, albeit a desperate and idiosyncratic one, that would allow them to face the indefiniteness of the struggle with cancer. This cause and effect illusion of power was also shattered when the health care team urged them to relinquish the stories and theories they had developed. The team believed that if they could stop the parents from expressing this illusion of responsibility, they would have provided comfort to the distraught parents.

This study was designed to explore the development of illusions that allowed these families to submit to pain, anxiety, and uncertainty without being overwhelmed by it. The study also sought to explore what social workers, as members of a medical team involved in this kind of care, need to do to create an environment supportive of the expression of these apparently soothing illusions.

Impetus for the Study

The diagnosis of cancer is a nightmare. It does not represent anything symbolic; it isn't an unacceptable impulse which needs to be understood; it is a harsh and overwhelming reality. The parents of children with cancer do not have the luxury of looking at the difference between fantasy and reality and being reassured by this difference. The only reality is the diagnosis--a nightmare from which a parent cannot awaken. Clinically, this nightmare can not be interpreted as representing something else. To attempt to do this represents the clinician's wish to create an artificial distance from the pain. There is neither a safe space to contemplate the hypothetical, nor an intermediate space away from the painful blast of truth. How do these people create a space away from the overwhelming affect in which to contemplate their dilemma?

Clinical work with parents of children who have cancer requires special skills. A clinical social worker cannot use only a classical psychodynamic approach; nor do the descriptive superficial coping theories help us to understand the psychological complexities. Social workers need a theory that will help explain the intrapsychic and interpersonal dilemmas parents must resolve when managing their inherently overwhelming emotions and the chronic threats of loss. This research was inspired by the researcher's observation of the failure of health care providers to understand the parents'

experiences and communications about these experiences and the researcher's own struggle to discover how to be helpful to this population.

The attempt to understand these parents' experience and its intrapsychic and interpersonal significance raised many questions. What did these parents need to do intrapsychically to manage the threatened loss of their child, their child's physically assaultive medical treatment, and the uncertainty of their child's medical outcome? How could one effectively gain access to the parents' experience? How could these parents be studied during one of the most painful and intimate experiences of their lives? Why would these parents let a spectator enter their lives as they struggled to save their child's life? Since customary interpretive tools seemed not to be particularly helpful to the issue at hand, and therefore ineffectual in this new situation, what else could clinicians offer to these people to help them during this trying time? Without a plan of action or a complete theory to structure a therapeutic approach we may feel as though we approach these families only as voyeurs. More importantly, we must realize that these families will have to teach the clincian what they need. We will continue to feel horribly uncomfortable intruding on these parents' lives until it becomes clear what they need and whether we are able to offer it.

Research Questions and Methodology

Families were studied in an urban pediatric hospital. The hospital setting was chosen as it is believed that families experience greater stress in the hospital and therefore would be likely to express the forms of illusions that will be called magical thinking. Families began to participate in this study at various stages of their children's illness and treatment ranging from diagnosis to the completion of medical treatment and "cure." All children ages 0-12 with normal intelligence with some form of cancer were considered as eligible for this study. Families were identified as eligible for the study by the social worker who attended Oncology rounds on Tuesdays and every other Friday. During rounds, the social worker reviewed which families currently admitted to the hospital met the criteria (listed below). Initially, only families of children admitted for complications, relapses, or surgical treatments were considered because it was believed that these families would experience the greatest degree of stress. Children admitted for routine chemotherapy were not considered initially because it was believed that a routine, expected hospitalization would not elicit as much stress. However, when it became clear that this initial criteria would produce an inadequate number of families for the study, the criteria were extended to include all children admitted to the hospital with cancer-related problems. The social worker obtained permission from the primary physician before asking the families to participate.