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Diabetic and Normal Children's Understanding of Illness Causality.

Randi C. Mcallister

Louisiana State University and Agricultural & Mechanical College

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Diabetic and normal children's understanding of illness causality

McAllister, Randi C., Ph.D.
The Louisiana State University and Agricultural and Mechanical Col., 1988
Diabetic and Normal Children's Understanding of Illness Causality

A Dissertation

Submitted to the Graduate Faculty of the Louisiana State University and Agricultural and Mechanical College in partial fulfillment of the requirements for the degree of Doctor of Philosophy in

The Department of Psychology

by

Randi C. McAllister
B.S., California State University, 1975
M.A., Louisiana State University, 1984
August, 1988
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Abstract
The purpose of this study was to determine developmental levels of the understanding of illness causality among diabetic children as compared to normal children. Thirty diabetic and 30 normal children were interviewed in order to measure their conceptual understanding of various illnesses and of diabetes. The subjects were also tested on a set of conservation tasks in order to determine their general level of cognitive development. The data analysis consisted of multivariate analysis of variance; analysis of variance with each of the two illness interviews as a dependent measure; analysis of covariance; a correlation of scores on the conservation tasks with scores on the two illness interviews; and a measure of interrater reliability for the two illness interviews. It was hypothesized that older children would score significantly higher than younger subjects on both illness measures; that diabetic children would score higher than normals on the Diabetes Interview; and that older diabetics would score higher than all other subjects on both illness interviews. In addition, it was expected that children who were labeled concrete operational on the tasks would score higher on the illness interviews than children labeled preoperational on the tasks. A major question in this study was whether the experience of a diabetic child with his illness would increase his level of cognitive development as compared to his normal peers. Results
indicated that older children scored higher than younger children on both illness measures. Normal children scored significantly higher than diabetic children on the general illness interview, while diabetic children scored significantly higher than normal children on the diabetes interview. However, the higher scores achieved by diabetics on the diabetes interview is more representative of their knowledge of diabetes than of their understanding of diabetes causality. Results of the interrater reliability indicated very good agreement between the two raters for both illness measures. Correlation of the conservation tasks with scores on the two illness interviews indicated that concrete operational subjects scored higher than preoperational subjects on the interviews. The water task scores were better indicators of high scores on the interviews than either the clay or number tasks.
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Diabetic and Normal Children's Understanding of Illness Causality

CHAPTER I

Introduction

Accidents and chronic illness have increasingly become a focus of pediatric medical practice. One in ten children is afflicted with a chronic illness by age 15 (Jordan & O'Grady, 1982) and almost 50% of the pediatric practice is concerned with the chronically ill child (Magrab & Calcagno, 1978).

Chronic illness is not only widespread in the pediatric population, but it also encompasses unique health care problems "because behavior rather than medical technology, is often the major factor contributing to [its] prevention, treatment and outcome" (Jordan & O'Grady, 1982, p. 58). Within the last decade, psychologists have increasingly become more involved in health care, and in addition, a developmental perspective is becoming more widely acknowledged (Maddux, Roberts, Sleddren & Wright, 1986).

A number of factors have contributed to the holistic approach to health care sometimes referred to as "behavioral medicine" or "health psychology," of which pediatric psychology is a subspecialty. These factors include research in such areas as stress (Selye, 1976) and maladaptive health behaviors (Stone, 1979). Advances in such research areas
have led to a more comprehensive "biopsychosocial" conceptualization of illness. The control of previously fatal infectious diseases by medical science, and the growing awareness of the staggering costs of health care in general have also been contributing factors (Jordan & O'Grady, 1982; Tuma, 1982). In addition, the American Psychological Association's establishment of the Task Force on Health Research in 1976, designed to analyze the potential contribution of psychology to health care settings, was, according to Tuma (1982), "the single most influential factor responsible for psychology's greater involvement in health care" (p. 2).

A potentially important variable affecting the treatment of chronically ill children is their beliefs about illness, medical procedures and hospitalization. Although it is frequently acknowledged that cognitions mediate behavioral responses, it is surprising that little empirical research exists in this area. As research with adults has demonstrated that attitudes can influence and predict behavior, this relation among children, taking into account the influence of developmental factors, is certainly worthy of investigation (Maddux et al., 1986).

Some observations of children's beliefs regarding illness causality have been made since the 1930's, and reviews of the early literature (e.g., Vernon, Foley,
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Sipowicz and Shulman, 1965) as well as reviews of more recent literature (e.g., Peters, 1978; Bibace and Walsh, 1981) indicate that children's conceptualizations regarding illness are often distorted. Although children's misconceptions regarding illness causality are well documented, many early studies are methodologically limited and lack a developmental perspective. Further, virtually no research has been conducted on the beliefs of chronically ill children (Eiser, 1985; Perrin & Gerrity, 1981).

A major purpose of the present paper is to expand the research literature on children's beliefs about illness to include chronically ill populations as recommended by Blos (1978). The literature in the area of children's beliefs about illness will be reviewed with an emphasis on the importance of research that employs a developmental perspective. In addition, literature in the area of patient-physician communication and medical compliance will be presented in order to further support the importance of research in the area of children's beliefs about illness causality.
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CHAPTER II

Review of the Literature

Illness Causality Beliefs

The literature on children's beliefs about the causality of illness can be divided into two broad groups: studies around the early 1930's and extending into the mid-1960's (the early literature) and studies conducted after that time (the later literature). The two major reviews of the early literature that will be presented here are by Vernon, et al. (1965) and Peters (1978). The review of the later literature has been accomplished by Bibace and Walsh (1981).

In a review of the early literature on children's responses to hospitalization and illness, Vernon et al. (1965) discuss a number of studies concerned with children's interpretations of being ill. For example, a study by Beverly (1936) pointed out that children believe that illness is related to "being bad." Several other studies suggest that children believe that illness is punishment for wrongdoing (e.g., Gips, 1956; Richter, 1943). Finally, the beliefs that illness means abandonment by the parents or the loss of parents' love are emphasized in studies by Chapman, et al. (1956) and Cooley (1951).
Also emphasized in the Vernon et al. (1965) review was the view that children's fantasies regarding surgical procedures affected their response to surgery more than the type of operation being performed (A. Freud, 1952).

The early literature is characterized by the authors' interest in children's fantasies regarding illness and hospitalization, and many of these studies reflect psychoanalytic theorizing about children's conceptualizations. Within the psychoanalytic framework, children's concepts about illness are often viewed as defense mechanisms that are either adaptive or maladaptive depending on the interpreted content of the fantasies.

Although some psychoanalytically-oriented authors recognized developmental factors in children's ideas about illness (e.g., they noticed that fearful fantasies were more common in younger children), their articles focus primarily on interpreting children's conceptualizations according to psychosexual theory; for example, that conflicts associated with the oedipal phase might be a source of children's beliefs about illness as punishment and medical procedures as injury or attack (e.g., Gips 1956, cited in Vernon et al., 1965).

A few early studies speculate along cognitive developmental lines. Vander Veer (1949) argued that the child has undeveloped cognitive functioning and limited
reality-testing ability, and Gellert (1961) described increasing objectivity with age regarding beliefs about the causality of illness.

More recently, Peters (1978) reviewed the literature regarding children's concepts of illness causality. The studies in this review are less observational and psychoanalytic; however, most of the studies are methodologically limited. The majority of the studies use unstructured interview formats or projective techniques, with no scoring criteria or reference to developmental theory. For example, Blos (1956) asked children to respond to pictures of ill children, Gellert (1961) asked children to look at pictures of ill children and tell a story about them, and Lynn, Glaser and Harrison, (1962) utilized an interview with a structured doll play technique.

Peters (1978) cites Nagy (1951) as one of the early researchers investigating children's beliefs about the causality of illness. In a study of 350 healthy children, ages 3 to 12, Nagy (1951 asked the question, "What makes us ill?" and identified four stages of causal belief in her sample of children:

1. Children younger than six years related cause and effect to contiguous events;

2. Children age six to seven believed that illness was caused by an unspecified infection;
3. Children age 8 to 10 blamed microorganisms as causing illness; and,

4. Children age 11 to 12 understood that different organisms could cause different illnesses, although they did not understand the concepts of virulence of organisms or body resistance to organisms.

Thus, Nagy (1951) concluded that, with increasing chronological age, children moved from single-cause explanations to multiple-cause explanations. Although Nagy's research has been criticized for methodological flaws, her work does suggest developmental changes in children's conceptualization of illness (Perrin & Gerrity, 1981).

Although the studies reviewed by Peters (1978) suffer from methodological problems, (e.g., unstructured interview formats with no reported scoring criteria, limited statistical investigation, and lack of reference to developmental theory), Peters concluded that the early literature strongly supported two prevalent themes: that illness is caused by human behavior—either the child's or someone else's behavior, and that illness results from misbehavior on the part of the ill child.

Bibace & Walsh (1981) note that in the last two decades, a number of studies have been conducted about the child's ideas of illness due to the combined effect of clinicians' awareness of the importance of children's beliefs and the
interest of the academic psychologist in children's cognitions.

Early psychoanalytic interpretations centering on children's beliefs that illness is a punishment for bad behavior was confirmed in a study conducted in 1974 by Brodie. Brodie (1974) found that this idea was more prevalent among hospitalized children than among healthy children; however, 25% of the healthy sample also believed that children who misbehaved became sick more often.

Cook (1975) cited in Bibace & Walsh (1981) found that the moral explanation of illness confirmed by Brodie (1974) only occurred when children offered spontaneous accounts, and not when they were asked in a directive interview to explain the cause of illness.

Other beliefs about the causality of illness have surfaced in the literature, indicating that children's concepts about illness are broader than originally thought. For example, Bibace & Walsh (1981) cite Perrin & Gerrity (1979) who noted the belief that germs or contact with others causes illness. Palmer & Lewis (1975) documented the belief that illness can be prevented by certain activities (e.g., getting enough rest). Children also differ in their belief about how likely it is that they will become ill (perceived vulnerability), according to studies by Gochman (1971) and Palmer & Lewis (1975). Campbell (1975) documented that
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psychological as well as physical processes may be used to explain an illness.

In addition to the increased range of children's explanations described in the later literature, Bibace & Walsh (1981) also point out that the studies of the 1970's document changes in concepts with changes in age. The older, more mature child shows evidence of increased conceptual sophistication and greater abstractness (e.g., Campbell, 1975; Perrin & Gerrity, 1979; Simeonsson, Buckley & Monson, 1979). These studies clearly indicate a relation between the child's conceptualization of illness and his or her developmental status.

However, as Bibace & Walsh (1981) point out, these studies document the existence of the general Piagetian stages of cognitive development, but fail to explain

...the novel or unique way in which Piaget and Werner's general stages of cognitive development are expressed in the particular content being investigated....these analyses provide no appreciation for the way in which a child assimilates a particular phenomenon or aspect of reality—that is, illness—to the general schemata that reflects the evolution of cognition" (p.34).

Elsewhere, Bibace and Walsh (1979) argue that the developmental theories of Piaget and Werner can be useful to
professionals in applying the general stages of cognitive development to specific content areas.

To address this need, they conducted a landmark study of children's beliefs about illness causality. A pilot phase intended to delineate a preliminary category system, used 180 children ages 3 to 13, and had the children respond to 12 sets of questions. The "methode clinique" of comprehensive inquiry (i.e., they followed any leads of the child and obtained the meaning of all terms used by the child in his/her explanation) adopted from Larendeau and Pinnard (1962) was employed. The responses from this pilot phase were classified into Piaget's three broad stages of preoperational, concrete operational and formal operational development. Within each Piagetian stage, the authors delineated two substages. They labeled their six stages as follows:

- Preoperational
  1. Phenomenism
  2. Contagion
- Concrete Operational
  3. Contamination
  4. Internalization
- Formal Operational
  5. Physiological
  6. Psychophysiological
The investigators then tested their illness protocol on 72 children. These children represented three different age groups (4, 7, and 11) evenly split between male and female. Following Piaget (1929) and Larendeau and Pinard (1962), Bibace and Walsh (1979) examined the responses as a whole in assigning each child's response to one of the categories. They obtained good interrater agreement (88 percent) between two independent raters who scored the verbatim protocols blindly. The findings, consistent with a developmental theory of cognitive development were as follows:

<table>
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<tr>
<th>Age Group</th>
<th>Phenomenistic explanations</th>
<th>Contagion explanations</th>
<th>Contamination explanations</th>
<th>Internalization explanations</th>
<th>Physiological explanations</th>
<th>Psychophysiological explanations</th>
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<td>4 year olds</td>
<td>12.5%</td>
<td>70.8%</td>
<td>16.7%</td>
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<td></td>
</tr>
<tr>
<td>7 year olds</td>
<td>16.7%</td>
<td>75.0%</td>
<td>8.3%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11 year olds</td>
<td>25.0%</td>
<td>70.8%</td>
<td>4.2%</td>
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Bibace and Walsh have proposed a developmental model of the changes in children's beliefs about illness based on their research. Each of the six stages in the model
represents an increase in the sophistication of the child's cognitions over the previous stage. Briefly, the model is as follows:

**Preoperational Thought. Stage 1 - Phenomenism:** child explains illness in terms of an external, concrete phenomenon which co-occurs with the illness, but is spatially or temporally remote (e.g., people get colds from the sun or from trees). **Stage 2 - Contagion:** child explains illness in terms of an object or person close to, but not touching, and transmission is magical, or "catching" without explanation (e.g., people get colds by magic or by someone being near them).

**Concrete Operational Thought. Stage 3 - Contamination:** child explains illness in terms of physical contamination (e.g., dirt, germs) or moral contamination (bad behavior). **Stage 4 - Internalization:** child explains illness in terms of internalizing an external cause, through breathing, eating, swallowing (e.g., breathing in too much air in winter).

**Formal Operational Thought. Stage 5 - Physiological:** child explains illness in terms of immediate cause (malfunctioning of internal structure or process) and external cause (e.g., overwork, pollutants). **Stage 6 - Psychophysiological:** child explains illness in terms of psychological processes (e.g., thoughts and feelings) as well
as internal and external physiological causes (e.g., a heart attack is caused by the heart not working right and too much tension and worry).

Following the rationale of Bibace & Walsh (1979), Perrin & Gerrity (1981) studied 128 healthy children, randomly selected from a public school system in upstate New York. Their sample included children from kindergarten, second, fourth, sixth and eighth grades. Using a semi-structured interview format, these authors asked the children eight questions regarding cause, treatment and prevention of illness along with 14 questions which assessed the children's general cognitive development (e.g., questions about the conservation of mass, weight and volume; questions about the interrelation between the parts of objects). The authors rated the responses and placed them in six general response categories:

1. Don't know
2. Global responses
3. Concrete rules
4. Internalization and relativity
5. Generalized principles
6. Physiologic processes and mechanisms

Significant differences were obtained between each two grade levels despite the wide variety of responses in each grade. Thus, the results showed a progression of sophistication in
responses with increase in chronological age. No consistent differences were found when the results were analyzed by sex and socioeconomic status.

Interestingly, in this sample, only one-third of the eighth graders had attained the stage of formal operations, as conceptualized by the authors based on categorization of the quality of responses. Although many of the eighth graders appeared to understand the causation and treatment of illness, very few of the eighth graders described prevention in more abstract terms than the fourth and sixth graders.

Another recent study of normal children was conducted by Millstein, Adler and Irwin (1981); however, this particular study examined the concepts of adolescents only. With a sample of 77 junior high students, age 11 to 15, the authors coded responses to interview questions according to the coding scheme developed by Campbell (1975), which included a cognitive as well as a social model in its development. The coding scheme involved 11 themes which were broadly represented by the categories: symptoms, objective signs of illness, specific diagnoses and psychosocial indicators. Interrater agreement was 93 percent on the response codes. An unexpected finding of this study was that the older adolescents gave more concrete responses than the younger adolescents; however, the authors speculate that this finding is due to a unique characteristic of this sample: younger
adolescents enrolled in the general science classes from which the sample was drawn tended to be more intellectually endowed than the older adolescents in those classes. However, despite this finding, the study did show a developmental trend indicating that adolescents tended to generate more abstract, "adult-type" themes than children, when their responses were compared to children's responses that the authors surveyed from other studies.

A recent study by Potter and Roberts (1984) approached the problem from a slightly different perspective. They studied the acceptance of chronically ill children by their peers. The subjects in this study were 56 first- and 56 third-grade, normal children from classrooms in two public schools. The authors examined the level of cognitive development, as well as the type of disease (epilepsy versus diabetes), and the amount of information provided to the children about the two chronic illnesses. Results indicated that these children's comprehension of the two illnesses was affected by the cognitive stage as well as the type of information presented about the illness.

Children in the concrete operational stage comprehended and retained more specific information, whereas children in the preoperational stage understood more global, nonspecific explanations. These results are consistent with Bibace and Walsh (1980) who described preoperational children as
thinking more globally, while concrete operational children have progressed to more logical and differentiated ideas.

The role of socioeconomic status as it affects children's perceptions of illness has been recently examined by Roberts, Johnson, and Beidleman (1984). The subjects in this study were 105 normal fifth graders from two different socioeconomic classes. In general, results indicated that SES contributes little to children's perceptions of medical and psychological disorders.

The reviews of early literature and the citation of more recent research in the area demonstrates that studies have progressed from general observations and psychoanalytic interpretations to more systematic studies within a cognitive developmental model. Two general trends appear to be prevalent in the literature as a whole: that children's perceptions are indeed, often misperceptions, and that children's conceptualizations tend to follow a cognitive developmental progression. In addition, a recent study suggests that, in general, SES differences do not affect children's perceptions of illness causality.

As Bibace and Walsh (1981) point out, developmental theory is a necessary component of meaningful research in the area of children's understanding of illness. In addition, sound methodology and a systematic approach have, until recently, been lacking in the literature. There is a need
for additional research that utilizes a developmental framework, as well as a systematic and empirical approach, in order to expand our knowledge of how children conceptualize illness causality.

In the next section, research is presented to demonstrate the problems in communication between pediatric patients and their physicians, as well as between the patients' parents and the physicians. The discussion that follows will develop the idea that health care professionals do not communicate effectively with their patients and that this lack of appropriate communication and possible resulting low medical compliance, supports the need for research on children's beliefs about illness causality. Empirical research with a developmental perspective could contribute to more effective patient-professional communication, as well as increased compliance with medical regimens.

**Physician-Patient Communication**

Despite the generally recognized importance of effective communication between health care professionals and their patients to ensure treatment compliance, a considerable amount of recent research suggests that communication between physicians and patients is less than optimal.

For example, Azarnoff (1984) indicates that in her studies of hospital settings, physicians rarely discuss with parents the nature of their child's illness or the
hospitalization experience. In one of her studies, a survey of 1,427 hospitals for children and general hospitals with pediatric units, she found that less than one-third of the hospitals prepared the parents as part of a regular, ongoing service. She further reported that the parents in her studies were unsure of the meaning of medical terms and procedures being planned for their children.

Similarly, Korsch and Negrete (1972) cited in Steward & Regalbuto, (1975) demonstrated that one-fourth of the mothers seen in an emergency walk-in clinic complained that, after talking with the doctor, they did not understand their child's illness or its cause, and further, they reported that they felt the physician had not listened to them.

A second factor noted in the literature that contributes to poor patient-physician communication is the limited exposure of physicians to developmental information. Several authors have acknowledged that health care professionals do not receive systematic exposure to contemporary developmental information during their training (MacPhee, 1984; Perrin & Perrin, 1983).

Perrin and Perrin (1983) studied the accuracy of health care professionals' knowledge of child development. Pediatricians, nurses and child development students were given a list of typical responses to five questions about illness and asked to estimate the age at which the children
made each response. The clinicians overestimated the understanding of young children and underestimated the understanding of older children. The authors concluded that "physicians and nurses make little use of the notion of developmental stages, and approach all children more or less as if they were in middle childhood, or in the Piagetian stage of concrete operations" (p. 877).

Another often overlooked component of physician-patient communication in pediatric settings is the physicians' direct communication with the pediatric patients themselves. It has been suggested that communication between a physician and an ill child is practically nonexistent, or when it occurs, is probably grossly inadequate (Perrin & Perrin, 1983). For example, Plank (1971) cited in Perrin & Gerrity, (1981), tells of a 7-year-old child who thought that when his doctor told him he had "edema in your belly" that a demon had been sent to punish him. Similarly, Azarnoff (1984) describes a number of examples of miscommunication: "A 7-year-old believed that a bone marrow aspiration was a 'bow and arrow' that would kill him. He was fearful of the procedure, but the staff had assumed he was afraid of pain. . . . A 10-year-old believed that she had no heart when her physician first applied the stethoscope and said, "I can't hear it.'" (p. 10). If these examples are representative, it appears likely that not only do physicians have limited developmental
information, but that children frequently misunderstand what they are told.

In a very recent study, Haight, Black & DiMatteo (1985) examined young children's understanding of the social roles of doctor and patient, and noted that most pediatric professionals adhere to a social role model which requires an active therapist and a passive patient. Their research findings indicate that children strive to understand what is going on in the medical setting. They note that the way in which information is provided can result in children drawing erroneous conclusions. These researchers propose that the "active therapist-passive patient" model be discontinued, and that physicians should encourage questions and provide information appropriately so that they may better alleviate children's anxiety and gain greater patient cooperation.

The beliefs of chronically ill children have implications for medical compliance, considering that successful treatment of many chronic conditions depends upon changes in the patient's behavior. A current major focus of health care, then, is compliance with therapeutic medical regimens. It has been estimated that in adult patients, compliance ranges from 30% to 70% across all medical procedures (Haynes, Taylor & Sackett, 1979, cited in Jay, Litt & Durant, 1984). However, few studies of medical compliance have reported figures on children alone (Jay, et
Nine studies of child compliance have been reviewed in the literature and the average rate of compliance has been estimated at 54% (Jay et al., 1984; Jones, 1983). Although this percentage encompasses too much diversity to be of significant value (e.g., it includes varying settings and procedures), it does indicate that, in general, compliance among pediatric patients is low.

Pertinent to this research, there are few studies of children's and adolescents' compliance with diabetic regimens. Simonds (1979) cites a study he did in 1975 in which he determined that 10 of 23 diabetic children who attended a diabetic summer camp admitted to sometimes misusing their treatment program. For example, they admitted to false positive urine reports to get attention and false negative urine reports to please parents or avoid angry interactions. In another sample, 9 of 27 children admitted to falsifying reports in order to get sweets, avoid punishment or increase activity (Simonds, 1975, cited in Simonds, 1979).

It is not difficult to understand, then, that given the communication problems between physicians, children, and their parents, that compliance among ambulatory pediatric patients has been found to be low (Mattar & Yaffe, 1974). In fact, Mattar and Yaffe (1974) believe that the patient's perception regarding the illness, as well as the patient's
mother's perception of the disorder are more critical to compliance than the physician's opinion.

One of the variables that may influence ill childrens' perceptions is their developmental level of conceptualization of the particular illness itself. However, although some studies have attempted to research such variables as self-concept and its relation to perception and compliance (e.g., Saucier, 1984), to date, research systematically examining the developmental levels of illness conceptualization as it relates to compliance is practically nonexistent.

A prerequisite to that type of research is the establishment of developmental levels of illness conceptualization in specific illness groups. Although some studies have examined the beliefs of hospitalized children with various illnesses, including both acute and chronic illnesses (e.g., Brewster, 1982; Simeonsson, Buckley and Monson, 1979), nonhospitalized children with chronic illnesses have not been systematically studied (Perrin & Gerrity, 1981; Eiser, 1985). Thus, there is a need to examine the beliefs of chronically ill children, not only because this issue is of developmental interest, but also because it has implications for improved communication between patients and professionals, as well as improved medical compliance.
Therefore, the purpose of this research is to provide a well-controlled effort toward establishing chronically ill children's conceptualizations of illness. The most common chronic illnesses that afflict children of all ages are asthma, epilepsy, cardiac conditions, cerebral palsy, orthopedic conditions, and diabetes mellitus. The systematic investigation of the illness beliefs of non-hospitalized chronically ill children, as pointed out earlier, has not been carried out. This research project concentrates on children with diabetes who are, by and large, non-hospitalized.

**Diabetes Mellitus**

Diabetes mellitus occurs in about 1 in 1,000 children with a peak incidence in early adolescence (Smith, 1977). Children with diabetes represent 4 to 5 percent of all diabetics (Garner & Thompson, 1978). Diabetes is a lifelong chronic illness and the most common endocrine disorder of childhood (Johnson, 1980). According to Laufer and Kadison (1976), diabetes mellitus is a disease of unknown cause with a very important genetic element in it etiology. A major feature appears to be an inability to metabolize carbohydrates normally, due either to an impaired production of insulin or to a defect somewhere in the normal process of insulin activity. The
carbohydrates, in the form of glucose, accumulate in the blood and, because of their high concentration, overflow into the urine. (p. 36). According to Garner and Thompson (1978), the development of diabetes depends on a complex interaction between genetic patterns and environmental influence.

The most acute form of the disease is called "juvenile onset" or "insulin-dependent." It is the type most often found in young people, although it can occur at any age. Untreated, the disease can rapidly progress to an unbalanced metabolic condition known as "ketoacidosis" which can lead to coma and death. The other major form of diabetes is known as "adult onset" or "insulin-independent" (Garner & Thompson, 1978; Laufer & Kadison, 1976).

Insulin deficiency may be present in a child for a long period before symptoms appear. The onset is typically abrupt and includes such manifestations as excessive thirst (polydipsia), excessive eating (polyphagia), frequent urination (polyuria), weight loss, and general fatigue (Garner & Thompson, 1978).

Management of this disease includes proper diet, exercise and daily insulin injections. It has been pointed out that the management of diabetes in children is often a focus of family conflict or a source of stress (Allen, Tenne, McGrade, Affleck & Ratzan, 1983), and that successful
treatment depends upon self-management by children with the support of their parents (Eastman, Johnson, Silverstein, Spillar & McCallum, 1983).

According to Eastman et al. (1983), studies assessing patients' knowledge of diabetes and treatment principles have shown deficits in these areas. Recently, in their own study of 159 diabetic patients (age 9 to 22) and their parents, Eastman et al. (1983) demonstrated that, in general, there was a marked discrepancy between the proportion of patients and parents who believed they could recognize hypoglycemia and hyperglycemia and the proportion who utilized physician-selected symptoms as the basis of their judgment. The majority of the sample believed that they could recognize hypo- and hyperglycemia; however, the symptoms they selected were not congruent with symptomatology described in patient instructional materials. Thus, this study suggests a lack of understanding of certain symptomatology in both patients and parents.

In a study by Allen et al. (1983) parents of diabetic children defined metabolic control differently from physicians and, in fact, parents used two measures (gross symptoms and home urine tests) that the physicians considered unreliable. These parents had been informed of other measures used by physicians.
In a review of psychosocial factors related to juvenile diabetes, Johnson (1980) concludes that very little is known about factors that are associated with healthy adjustment to diabetes and "what the child should be taught about his disease at what point in his development" (p. 110). As Johnson (1980) points out, some data suggest that children increase their understanding of diabetes as they grow older; however, other data suggest that adolescents have misconceptions about diabetes.

In summary, there are a number of studies in the literature that suggest that both patients and their parents demonstrate misconceptions or a lack of knowledge about diabetes.

An additional problem that impacts patients' misconceptions and poor management of their illness is a tendency in certain types of settings (e.g., the teaching hospital) for physicians to treat emergency diabetic problems as isolated events rather than focusing attention on the patients' overall pattern of health care (Flexner, Weiner, Saudek & Dans, 1984). These authors suggest that improving the patient's understanding of the disease and treatment rationale, as well as improving follow-up care, may lower the rate of repeated hospitalizations for diabetic emergencies such as ketoacidosis. Again, it appears from a look at the literature, that proper education via appropriate
communication is suggested as an important variable in the treatment of chronic illness.

In conclusion, diabetes is an endocrine disorder in the pediatric population that requires both drugs and behavioral management for successful treatment. The "ownership issue," that is, who should be responsible for the management of the illness is a common battle ground between parents and their diabetic children. The fact that both diabetic children and their parents have misunderstood vital information that is crucial to the proper management of the disease argues strongly for improved communication between patients and professionals.

How these children understand their illness and issues related to it is the focus of this research. If developmental trends can be observed in children's conceptualizations of their illness, and in addition, if the type of illness impacts the level of their understanding, this information can be extremely helpful in devising appropriate medical education which will improve the management of diabetic children.

Therefore, this research study was designed to ascertain how diabetic children conceptualize their illness according to developmental theory, by comparing the responses of diabetic children with responses of non-ill children on general questions about illness (Bibace & Walsh, 1979) and on
specific questions regarding diabetes designed by the investigator.

All subjects were interviewed and Piaget's "clinical method" of inquiry was used in order to ascertain the subject's reasoning on each question. Protocol scoring followed procedures developed by Bibace and Walsh (1979) to yield developmental levels of children's illness reasoning. In addition, independent measures of cognitive level were also obtained.

This developmental interview approach has been used extensively in the literature in ascertaining children's conceptualizations in other areas: friendship expectations (Bigelow, 1977); death and personal mortality (Koocher, 1973; Reilly, Hasazi & Bond, 1983); social role taking (Selman & Byrne, 1974); smoking (Meltzer, Bibace & Walsh, 1984); birth and sexuality (Bernstein & Cowan, 1975); medical procedures (Steward & Steward, 1981); the body interior (Crider, 1981); and adoption (Brodzinsky, Singer & Braff, 1984).

A major question in this study was whether or not a child's experience with a chronic condition, in this case, diabetes, would affect his cognitive developmental level. In other words, would experience with diabetes actually increase a child's general cognitive developmental level? It was expected, as the literature has indicated, that, in general, older children would score higher on both illness measures
Illness Causality

and that those children labeled as concrete operational on the tasks would demonstrate higher scores on the measures as well. Further, it was expected that diabetic children would score higher on diabetes questions as compared to the normal subjects.

Specific Hypotheses of Study

Hypotheses for Bibace & Walsh Protocol. It was hypothesized that the following effects would be obtained by analysis of variance:

1. Diagnosis Effect - the mean score on the Bibace and Walsh measure will not be significantly different between the diabetic and normal groups.

2. Age Effect - older subjects will score significantly higher on the Bibace and Walsh measure than younger subjects; specifically, the mean scores for the two age groups will be significantly different.

3. Interaction Effect (Diagnosis by Age) - older diabetic subjects are expected to score higher on the Bibace and Walsh measure than all other subjects.

Hypotheses for Diabetes Questionnaire. It was hypothesized that the following effects would be obtained by analysis of variance:

1. Diagnosis Effect - the mean score on the Diabetes measure will be significantly higher for diabetic subjects than for normal subjects.
2. Age Effect - older subjects will score significantly higher on the Diabetes measure than younger subjects; specifically, the mean scores for the two age groups will be significantly different.

3. Interaction Effect (Diagnosis by Age) - older diabetic subjects are expected to score higher on the Diabetes measure than all other subjects.
CHAPTER III

Method

Subjects

The study sample consisted of an experimental group of 30 diabetic children and a control group of 30 normal children. The diabetic children volunteered to participate in the study through the investigator's contact with the American Diabetes Association and several endocrinologists. The normal subjects were volunteers from an on-site parochial school day care center which provides day care for the elementary age students of that school. All children were from the Los Angeles and Orange County areas of southern California. See Appendix I for a detailed profile of the diabetic sample.

The diabetic children had a diagnosis of insulin dependent diabetes from a physician and the normal children did not have diabetes, nor did any member of the immediate family (i.e., parents and siblings). In the diabetic sample, only two subjects had a diabetic family member (i.e., father, sister).

The subjects ranged in age from 5 to 12 years, with the mean age of 8.2 years (standard deviation = 1.8 years). The age group breakdown for the total sample was as follows: 9 subjects were in the 5 to 6 year age group; 42 subjects were
in the 7 to 10 year age group and 9 subjects were in the 11 to 12 age group. It was more difficult than anticipated to obtain an even distribution of children within the discrete age groups as initially planned. Therefore, for purposes of statistical analysis, the total sample of 60 subjects was divided into two groups. The "Young Group" consisted of 27 subjects ranging in age from 5 to 7, and the "Older Group" consisted of 33 subjects, ranging in age from 8 to 12. Sixteen children were in the "Young Normal" group, and 14 children were in the "Old Normal" group. Eleven diabetics were in the "Young Group" and 19 diabetics were in the "Older Group."

Measures

Measure of General Cognitive Development - Conservation. Questions were asked of each subject in order to ascertain a level of general cognitive development, either preoperational or concrete operational. The type of questions used were taken from standard questions utilized in the developmental literature, which are based upon the work of Piaget and described in Sigel and Hooper (1968).

Each subject was given three conservation tasks, conservation of number, liquid, and solid. In order to be labeled at the concrete operational stage of cognitive development, a subject had to conserve on two of the three tasks. A correct response was defined as a correct response
Illness Causality

plus a correct justification for the response. Each task consisted of three trials. A passing score on the task was defined as answering correctly on two out of three trials.

General Illness Measure. The subjects were interviewed using the Developmental Conceptions of Illness Protocol, (Bibace and Walsh, 1979) which consists of twelve questions. The first question is used as an introduction and the remaining eleven questions are scored. The Bibace and Walsh Protocol was used to determine the subjects' level of understanding regarding the cause of various types of illness (see Appendix A). For example, one item deals with the causality of colds. It includes four questions: (a) What is a cold? (b) How do people get colds? (c) Where do colds come from? and (d) What makes colds go away?

The investigator scored all of the protocols using the scoring criteria developed by Bibace and Walsh (1979). The scoring manual appears in Appendix D. Bibace and Walsh (1979) determined that their subjects' responses could be classified into six categories as follows:

Preoperational Responses
1. Phenomenism
2. Contagion

Concrete Operational Responses
3. Contamination
4. Internalization
Formal Operational Responses

5. Physiological

6. Psychophysiological

For each question, a subject can score anywhere from 0 (noncomprehension) to 6 (psychophysiological). In order to improve upon the quantification of the results, this investigator determined that a subject's score on the Protocol would range from 0 to 66, and each subject's score would then be a proportion of 66. For example, if a subject scored a level 2 response on all 11 questions, his score would be 22/66.

Diabetes Illness Measure. Questions regarding diabetes were constructed based upon indications in the research and from information obtained from physicians and nurses who work with diabetic children (see Appendix B). These questions were used to determine the subjects' causal understanding of diabetes. For example, one item, consisting of four questions, asks: (a) What is diabetes? (b) How do people get diabetes? (c) Can you catch diabetes from someone? How?, and (d) How do you get over diabetes?

Following the scoring model outlined above, a subject's score on the Diabetes measure can range from 0 to 48, as there are eight questions on the measure. The subject's score, for analysis purposes, is a proportion of 48. For
example, if a subject scored a level 2 response on all 8 questions, his score would be 16/48.

In order to calculate a measure of interrater reliability for each of the two measures, one-third of the total sample (ten diabetic and ten normal protocols) was randomly selected for scoring by a doctoral level psychologist who was trained in the scoring method by the investigator.

Procedure

The diabetic subjects were interviewed in their homes at a time convenient for the families. While the subject was being interviewed, the mother filled out a parent response form designed to elicit information about the subject and his family, including demographic information, medical history and daily management of the disease (see Appendix J).

The control subjects were interviewed at the day care site. The interview required approximately forty-five minutes to complete and each child was given stickers upon completion of the tasks.

Instrument Administration. First, Piagetian conservation tasks were administered to all children to determine their level of cognitive development. See Appendix C for a description of the administration of the tasks. These tasks were given first to help establish rapport with the subjects, as they have a game-like quality
Illness Causality

that appeals to children. Second, the illness interviews were administered. Piaget's "clinical method" was used to elicit meaningful responses from the subjects. That is, when the quality of the child's reasoning was not evident (e.g., vague, unclear or sparse), further probing was used until the examiner understood the nature of the child's reasoning for that particular question (Bibace and Walsh, 1979).

Design

Multivariate analysis of variance followed a 2 (age group: younger and older) by 2 (diagnosis: diabetic and normal) by 2 (evaluation: preoperational and concrete operational) design. The univariate analysis of variance followed a 2 (age group: younger and older) by 2 (diagnosis: diabetic and normal) design.
CHAPTER IV

Results

A major purpose of this study was to determine the similarities and differences in illness beliefs of children as a function of age, diagnosis, and cognitive developmental level. Subjects' responses to illness protocols were analyzed in several ways. First, a 2 (age group: younger and older) by 2 (diagnosis: diabetic and normal) by 2 (evaluation: preoperational and concrete operational) multivariate analysis of variance (MANOVA) was utilized with the two illness interviews as the dependent measures. In addition, analysis of variance (ANOVA) was utilized with each of the two illness interviews, with age and diagnosis specified as the independent variables. As the normal and diabetic subjects were not matched on age, an analysis of covariance (ANCOVA) was performed on each of the illness interviews with diagnosis as the independent variable and age as the covariate.

Interrater Reliability for Illness Interviews

Before subjecting protocol data to statistical analysis, a measure of interrater reliability was calculated. A second rater trained by the investigator and blind as to the subjects' age and diagnosis scored a random sample of one-third of the sixty protocols.
Using a Pearson r correlation coefficient, results indicated a significant correlation of .89 (p < .0001) for the Bibace and Walsh general illness measure and a significant correlation of .93 (p < .0001) for the Diabetes Interview, indicating very good agreement between the two raters.

The correlations were based on scores that were in complete agreement according to the zero to six (0-6) ratings described in Chapter III. As discussed in Chapter III, the six ratings represent three categories of cognitive development. Interestingly, although the raters disagreed on some items according to the ratings, they agreed according to category. For example, on one item, the investigator may have scored the answer as a 3, while the second rater scored that item as a 2. Although these two scores do not agree according to rating, they do agree according to category; that is, they both represent the concrete operational category. As an illustration, on Item 2 of the Bibace and Walsh Protocol, the two raters agreed that 7 out of 20 cases were in the concrete operational category by agreement on ratings. However, there were two protocols where the investigator scored a 3 and the second rater scored a 2, thus disagreeing by rating, but agreeing by category. When these two protocols are considered, the raters agreement improves from seven cases to nine cases. Perhaps one could argue for agreement by category rather than by rating; however, very
good agreement was achieved using the more conservative and fine-grained approach of agreement by rating.

**Multivariate Analysis of Variance Results**

The 2 by 2 by 2 MANOVA resulted in several significant findings. Age was significant at the $p < .0001$ level for both the Bibace and Walsh Protocol ($F = 31.09$) and the Diabetes Interview ($F = 49.33$). Diagnosis was significant for the Diabetes Interview only ($F = 193.97; p < .0001$). Level of cognitive development (evaluation) was also significant for the Diabetes Interview only ($F = 5.08; p < .028$). There were no significant interactions. Separate 2 by 2 ANOVA analyses were then conducted for each illness protocol.

**General Illness Analysis**

The 2 by 2 ANOVA analysis for the Bibace and Walsh Protocol resulted in a significant finding for age ($F = 34.58; p < .0001$). The mean score for the older subjects was 35.42, while the mean score for the younger subjects was 25.26, an approximate ten point difference (see Tables 1 and 2 for a comparison of the means). Raw scores for normal subjects on all items are presented in Appendix E. Appendix F lists the raw scores for diabetic subjects on all items. Diagnosis was not found to be a significant variable in this analysis. See Table 3 for the ANOVA procedure.
Analysis of Diabetes Interview

The 2 by 2 ANOVA analysis for the Diabetes Interview resulted in several significant findings (See Tables 1 and 4). Age was again found to be a significant variable ($F = 21.37; p < .0001$). The mean score for the older children was 19.15 as compared to the mean score of 10.52 for the younger children.

Diagnosis was also found to be a significant variable in this analysis ($F = 229.25; p < .0001$), indicating that diabetic children in general scored higher than the normal controls. The mean score for the diabetic group was 24.43 as compared to the low mean of 6.10 for the normal group.

Finally, a significant interaction was obtained between age and diagnosis ($F = 5.57; p < .02$), with the older diabetics scoring significantly higher than other subjects (see Table 2). Appendix G lists raw scores for normal subjects on the Diabetes Interview. Raw scores for diabetic subjects on the Diabetes Interview are presented in Appendix H.
Table 1

A Comparison of the Mean Scores and Standard Deviations Obtained in the ANOVA Analysis of the Two Illness Protocols

### Bibace and Walsh Protocol

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>N</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normals</td>
<td>30</td>
<td>31.37</td>
<td>10.02</td>
</tr>
<tr>
<td>Diabetics</td>
<td>30</td>
<td>30.33</td>
<td>7.27</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age Group</th>
<th>N</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Young</td>
<td>27</td>
<td>25.26</td>
<td>7.79</td>
</tr>
<tr>
<td>Old</td>
<td>33</td>
<td>35.42</td>
<td>6.49</td>
</tr>
</tbody>
</table>

### Diabetes Interview

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>N</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normals</td>
<td>30</td>
<td>6.10</td>
<td>4.00</td>
</tr>
<tr>
<td>Diabetics</td>
<td>30</td>
<td>24.43</td>
<td>6.85</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age Group</th>
<th>N</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Young</td>
<td>27</td>
<td>10.52</td>
<td>8.63</td>
</tr>
<tr>
<td>Old</td>
<td>33</td>
<td>19.15</td>
<td>10.93</td>
</tr>
</tbody>
</table>
Table 2

A Comparison of the Age By Diagnosis Group Means and Standard Deviations for the Two Illness Protocols

Bibace and Walsh Protocol

<table>
<thead>
<tr>
<th>Group</th>
<th>Normal</th>
<th>Diabetic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>Young</td>
<td>24.87</td>
<td>8.18</td>
</tr>
<tr>
<td></td>
<td>(N = 16)</td>
<td>(N = 11)</td>
</tr>
<tr>
<td>Old</td>
<td>38.79</td>
<td>5.95</td>
</tr>
<tr>
<td></td>
<td>(N = 14)</td>
<td>(N = 19)</td>
</tr>
</tbody>
</table>

Diabetes Interview

<table>
<thead>
<tr>
<th>Group</th>
<th>Normal</th>
<th>Diabetic</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>Young</td>
<td>4.75</td>
<td>3.21</td>
</tr>
<tr>
<td></td>
<td>(N = 16)</td>
<td>(N = 11)</td>
</tr>
<tr>
<td>Old</td>
<td>7.64</td>
<td>4.36</td>
</tr>
<tr>
<td></td>
<td>(N = 14)</td>
<td>(N = 19)</td>
</tr>
</tbody>
</table>
### Table 3

**Analysis of Variance Procedure for the Bibace and Walsh Protocol as the Dependent Variable**

<table>
<thead>
<tr>
<th>Source</th>
<th>DF</th>
<th>Type I SS</th>
<th>F Value</th>
<th>PR &gt; F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis</td>
<td>1</td>
<td>16.02</td>
<td>0.34</td>
<td>.56</td>
</tr>
<tr>
<td>Age</td>
<td>1</td>
<td>1633.20</td>
<td>34.58</td>
<td>.0001</td>
</tr>
<tr>
<td>Diagnosis x Age</td>
<td>1</td>
<td>165.74</td>
<td>3.51</td>
<td>.07</td>
</tr>
</tbody>
</table>
Table 4

Analysis of Variance Procedure for the Diabetes Interview as the Dependent Variable

<table>
<thead>
<tr>
<th>Source</th>
<th>DF</th>
<th>Type I SS</th>
<th>F Value</th>
<th>PR &gt; F</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis</td>
<td>1</td>
<td>5041.67</td>
<td>229.25</td>
<td>.0001</td>
</tr>
<tr>
<td>Age</td>
<td>1</td>
<td>470.04</td>
<td>21.37</td>
<td>.0001</td>
</tr>
<tr>
<td>Diagnosis x Age</td>
<td>1</td>
<td>122.48</td>
<td>5.57</td>
<td>.02</td>
</tr>
</tbody>
</table>
Analysis of Covariance Results

In order to control for the effect of age on the subjects' scores on the two illness interviews, a one-way analysis of covariance with age as the covariate was performed for each illness measure.

Using the Bibace and Walsh Protocol as the dependent measure in the first analysis, diagnosis was found to be significant ($p < .05$). The Normal group obtained a least squares mean score of 32.49 while the diabetic group obtained a least squares mean score of 29.21. This analysis demonstrates that when the effects of age were controlled, the normal group scored significantly higher than the diabetic group on questions regarding general illness. Diabetic children followed the expected pattern of cognitive development at a slower rate than their normal peers. A chronic illness may actually impede the cognitive developmental process rather than enhance it (Eiser, 1985).

In the second analysis of covariance, with the Diabetes Interview as the dependent measure, diagnosis was again found to be significant ($p < .0001$). The least squares mean for the diabetic group was 23.86 while the least squares mean for the normal group was 6.67. Differences were obtained for all items except question 3 ("What is sugar?") and question 7 "What is sensitive or 'bad' diabetes?"). Normal children and diabetic children scored very similarly on the question about
Illness Causality

sugar (3.25 and 3.22 respectively) indicating that experience with diabetes is not necessary for normal children to answer this question. Both normal and diabetic children scored very low on the question about "bad" diabetes, (.06 and .61 respectively), indicating that diabetic children have little understanding of the concept of diabetes out of control.

Correlation of Conservation Task Scores With the Two Illness Measures

In order to determine the relationship between the subjects' cognitive developmental level as demonstrated on the tasks as compared to the two illness measures, the scores on each of the two measures were separately correlated with the scores on each of the three conservation tasks (number, clay and water). For a complete description of all tasks, refer to Appendix C.

The number task was not significantly correlated with either of the two illness measures. Of the three tasks, it appeared to be the least effective in discriminating the subjects' cognitive developmental levels. Probable explanations of the low correlation include the concept of horizontal decalage, as well as the concept of the conservation of discrete versus continuous quantities (Siegler, 1981), both of which are discussed in Chapter V.

The clay task was correlated .25 (p<.05) with the Bibace and Walsh Protocol, but not correlated with the Diabetes
measure. The clay task was a somewhat better discriminator of cognitive developmental levels, at least in relation to the concepts of general illness. Again, the concepts of horizontal decalage and the conservation of discrete versus continuous quantities are possible explanations.

The water task appeared to be the best discriminator of cognitive developmental levels as related to scores on the general illness measure. Water was significantly correlated with the Bibace and Walsh Protocol (.48; p<.0001) and with the Diabetes Interview (.27; p<.04).

During the administration of the tasks, the investigator observed that it was more difficult for many subjects to conserve on the water task than on the other two tasks. The subjects who easily conserved on the water task were always older. Although most of younger subjects easily passed the number task, a number of younger subjects had difficulty with the water task. However, based upon the scoring criteria determined for this study of passing two out of three tasks in order to be labeled concrete operational, a subject could fail the water task and still be labeled concrete operational if he passed number and clay.

The final overall categorization of either preoperational or concrete operational (based upon the number of tasks passed) was also correlated with the two illness
measures, and was significantly correlated with the Bibace and Walsh Protocol only (.34; p<.009).

Overall, the significant correlations found were low, especially in relationship to the Diabetes Interview. One explanation for this is the low scores obtained by the normal control group on the Diabetes measure. Other explanations for the low correlations include the unevenness of cognitive development in general, as well as the differential responses on discrete versus continuous conservation tasks.

Preoperational Versus Concrete Operational Subjects

Several interesting findings were noted in relationship to subjects' ages and diagnostic group and their performance on the conservation tasks. Of the total sample of 60 subjects, only 10 scored in the preoperational category on the tasks. However, interestingly, 6 of these 10 subjects were older diabetics who were expected to score in the concrete operational category. The remaining four subjects were in the expected 5 to 6 year old age group. Thus, of the 24 diabetic children who were in the 7 to 10 year old age group, 25% (6 subjects) were in the preoperational category. By comparison, none of the 18 normal children in the 7 to 10 year old age group were preoperational on the tasks. Further, five of the normal subjects in the 5 to 6 year old age group were in the concrete operational stage. Thus, on the conservation tasks, the normal subjects followed the
expected Piagetian pattern better than the diabetic subjects. This observation is consistent with the results obtained on the Bibace and Walsh analysis which suggests that the cognitive development of the diabetic group is less well developed than that of the normal group.

Overall, the statistical results are consistent with other findings in the literature that as children mature, so do their conceptualizations of illness. The results also indicate that older diabetics scored higher than younger diabetics, demonstrating that despite similar knowledge and experience, conceptualizations about diabetes among diabetics follow the same progressive model of cognitive maturation.

Interestingly, when age was controlled through analysis of covariance, the results demonstrate that normal children performed better than their diabetic peers on questions about general illness. In fact, in comparing the percentage of improvement in the scores of older children versus younger children, the diabetic group showed less improvement in scores with age. The older normal children showed a 56% improvement over the scores of the younger normals, while the older diabetics showed only a 28% improvement over the scores of the younger diabetics (see Table 2).

It was expected that diabetic children would score higher than normal children on questions related to diabetes; however, this result is more reflective of the diabetic
subjects' knowledge level than of their cognitive developmental level. Normal subjects' scores were in general very low, reflecting a lack of knowledge about diabetes more than a lower cognitive developmental level. However, in examining the means for the younger normals as compared to the older normals, an increase was seen, reflecting a change in cognitive development. Even though the normals had little knowledge, the older normals scored higher than younger normals; in fact, the normal subjects obtained a 61% improvement in their scores with increased age as compared to a 46% improvement with age for the diabetics (see Table 2). Taken together, these results suggest that diabetics are not only not more advanced cognitively than their normal peers, but rather, demonstrate an impeded cognitive development pattern. This conclusion is further supported by observations made on the conservation tasks, where the normal subjects followed the expected pattern of cognitive development better than the diabetic subjects.

The finding in the MANOVA analysis that level of cognitive development on the tasks (evaluation variable) was related to the Diabetes Interview only may be a function of the low scores achieved by the normals on the Diabetes Interview as well as a function of the diabetics achieving higher scores on the Diabetes Interview. As the subjects were unevenly split on the evaluation variable (10
preoperational and 50 concrete operational subjects) it is difficult to ascertain the meaning of the relationship between task scores and Diabetes Interview scores.

Qualitative Responses

The answers given by the subjects are interesting to review because the qualitative content demonstrates what was found statistically, that indeed, children's concepts become increasingly complex as they mature. For illustration, interesting answers by children of different ages were selected from the Bibace and Walsh interview and from the Diabetes Interview.

**General Illness Responses.** When asked "What is a cold?" younger children tended to respond in terms of simple associations and gave answers that were typically in the contagion or contamination categories. For example:

Candace, age 5, control: Like a cough and you throw up. Like they playing outside or working outside. They do a lot of things. **WHERE DO COLDS COME FROM?** I don't know. **WHAT MAKES COLDS GO AWAY?** Medicine. By throwing up it sometimes goes away. One time I threwed up and it went away.

Steven, age 7, diabetic: When you're sneezing and stuff. By staying in the cold air, or going in the ice or snow skiing. Because it's cold. I don't know how it works. **WHAT MAKES COLDS GO AWAY?** Put your feet in hot water. It makes you lose the shivering. That's what my mom does.
By contrast, older children mentioned germs and gave internalization type responses; that is, they understood that some type of contaminant must enter the body. However, some of the subjects still had a sense of cold and cold weather as causal factors. For example:

Bobby, age 10, control: Certain germs get inside you and make you sick. By being in cold weather too long I guess. Colds come from everywhere cause everywhere there's germs. WHAT MAKES COLDS GO AWAY? Rest a lot. Stay in one place. Don't run around. Your body needs to heal and you can't do that when you're running around.

Carol, age 11, control: A little virus that just goes around. WHERE DO COLDS COME FROM? Breathing it in. Comes from the wind. If it's really windy and you don't have much covering on you, you can get it really easily. It's two different ways. You might get it in the wind and cough out and give it to someone else.

When asked the question "Were you ever sick; how did you get sick?" younger children tended to give answers that were in the contagion or contamination categories. For example:

Miki, age 5, control: I had a fever. I didn't keep my shoes on. I walked around barefooted. I didn't stay inside when I had a cold and it got real bad. Being outside makes you sicker. The wind makes you cold and gives you a cold and a cough.
Illness Causality

Justin, age 6, control: I had chicken pox. I got it from someone else in my class. I was walking by them a lot. HOW DID YOU GET WELL? I don't remember.

Older children tended to give internalization answers, internalizing germs or cold air. For example:

McKenzie, age 9, diabetic: I had flu. I played in cold weather without a jacket on and gloves, hat or shoes. And I was playing in the snow in Fresno. Coldness gets in your body and when you breathe it up it gets in your lungs.

Melissa, age 12, diabetic: The flu. I think I caught it from my sister because she had been sick for awhile. If she sneezes her germs get on me, then I could probably catch it. It goes into my body I guess. I'm not sure how it goes in. Mine was really bad. They took me to the hospital.

Melissa's response reflects concrete operational thinking. However, her response to a question about heart attacks reveals somewhat more advanced thinking in the physiological category. Some of the older children were able to give more physiological type responses when asked "What is a heart attack?" In addition, some subjects recognized the concept of multiple causes such as old age, general defectiveness and smoking, although their understanding was limited.

Melissa, age 12, diabetic: When your heart stops beating and you give CPR. Sometimes from old age, your heart
Isn't healthy any more. I guess someone else could have it if they weren't born with a very good heart, if their heart was weak. You might have a heart attack if you smoke too much. Smoke goes in your lungs and then can go into your heart and make it weak and then it would stop beating.

Carol, age 11, control: If your heart stops and then you can't breathe anymore. Maybe they're smokers or their heart's bad. The smoking might make a film in their lungs and it gets to their heart and something will go wrong. Maybe it surrounds the heart and the heart can't function, I don't know.

Younger children's answers regarding heart attacks were more preoperational; however, some concrete references were noted with an increase in age.

Matt, age 5, control: You die. My grandpa died cause he had a heart attack. They just get 'em. My grandpa just got one and he died.

Jennifer, age 6, control: When you get in an accident you die. WHY DO PEOPLE GET HEART ATTACKS? Cause they're not looking where they're going.

Adam, age 8, diabetic: One of your tubes gets clogged up and it stops your heart. It clogs up with food that wasn't all chopped up. When you're old, the heart goes slower and slower.
Interestingly, in this study, eleven out of sixty subjects talked about AIDS, and the awareness of this disease began at age seven. Children ages five and six did not discuss AIDS. Both AIDS and cancer were mentioned by children older than six when asked the question "What is the worst sickness to have and why?" Children ages five and six gave very simplistic answers to this question, whereas older children were concerned about illness that led to death.

Miki, age 5, control: Stuffed up nose. Cause you can't breathe and can't smell.

Jennifer, age 6, control: Diarrhea. Cause it stinks!

Kevin, age 7, control: Throwing up. Cause you throw up and get it all over your clothes. It gets all over the floor and people don't like it.

Charles, age 7: Dying. AIDS. If the doctor accidentally gets stuck by a needle from somebody who has AIDS, they die. It has the people's blood in there. AIDS is in the needle and he sticks himself and dies.

Jennifer, age 8 diabetic: I wouldn't like AIDS or cancer cause you can die. When you get it, it's shocking and you hope you'll live longer.

Jimmy, age 9, diabetic: Chicken pox. You stay in bed and stay home, that's boring. It's really contagious. Maybe someone else in your family could get it and everyone would stay home because of one person.
Illness Causality

Julianna, age 11, control: Cancer. Because I've heard that your body just gets eaten away little by little and then you die.

Danielle, age 12, control: AIDS. It's killing a lot of people. You can't cure it.

**Diabetic Responses.** When asked "What is diabetes?" the youngest diabetic (age 5) did not know. Other young diabetics, older than age five, tended to conceptualize diabetes in a contamination framework. By age eight, some of the children referred to the pancreas. However, most of the subjects did not really understand what the pancreas is or what it does. Some of the children knew that insulin is produced by the pancreas and is somehow related to blood sugar, but the process remained uncertain. Several older children still referred to the ingestion of too much sugar as the cause of diabetes, even though they might mention heredity or malfunction of the pancreas as well.

The following responses were chosen in order to demonstrate the types of responses from simple to more advanced, as well as illustrate that even older diabetics had limited understanding, or combined lower level responses with higher level responses.

Keith, age 5: It means people are sick. I don't know what's wrong. I don't know how I got it. I can't get well cause I don't know how.
LeeAnn, age 7: It's something where you can't have sugar. You can't catch it from anybody else. You get it from a germ, I don't know how. It might go away; I don't know how.

Stephen, age 7: People get it cause they're not too careful what they're doing. I got it from my daddy. I was too close to him and I kissed him. I caught it from him. You can't get over it unless they make a cure. I don't know what it is.

Michelle, age 7: Ingestion of sugar. I don't know exactly what it is. You can't get it from anybody else. You get it from eating a lot of sugars. You can't get over it. I don't know why.

Scott, age 7: Something where you have to take blood out. Getting holes in you. It's some kind of a disease. It's from an IV shot I had in my arm. You can't get over it cause it stays with you.

Stacey, age 7: I don't know what's wrong. God makes you one and when you grow up you're diabetic and you have to take shots. You can't catch it. I think you can get over it by eating diabetic food like diabetic candy.

Jennifer, age 8: When your pancreas breaks down and you don't have any more insulin in you. Pancreas is something in your stomach and it performs mostly insulin. You can't get
over it. When something stops in your body it usually
doesn't work again.

Ben, age 8: It's a disease. The pancreas stops
working. It's in your belly but I don't know what it is.
It's a thing that gives you insulin. You can't catch it.

McKenzie, age 9: When I got diabetes I was peeing a lot
every night and day. Some kind of germ that's the worst
germ. You can't catch it; I don't know where it comes from.
You can't get over it. You have to live with it all your
life. I don't know why you can't get well.

Sean, age 9: Diabetes is when my insulin doesn't work.
My pancreas stopped working. The pancreas is kind of like a
heart. It has all the insulin in it so people can live.
It's in the stomach area. You can't catch it. It's one of
those diseases that needs a cure. The pancreas doesn't work
because it's filled up with too much sugar. I ate a lot of
candy.

Jimmy, age 9: It's a disease. You don't catch it. You
have to keep a good diet, you have to test your blood and
give yourself shots. Bad germs got in my body and the good
things that were going to fight the bad germs killed off the
insulin, like somebody on their own team. You can't get over
it unless scientists find a cure.

Jason, age 10: Your body fought off some kind of cell
in it instead of a sickness. I saw it on Channel 58. You
have to take shots because the insulin is replacing the cells your body fought off. You can't catch it. Some people get over it and some don't. I don't know why.

Valerie, age 10: Something where your blood sugar goes high and low. The insulin in your body isn't traveling right. I'm eating too much sugar and it goes into my blood system and blocks the insulin passage. I got it from my dad's side of the family. You can't catch it.

Renee, age 11: Your pancreas can't produce enough insulin to control your blood sugar. Your pancreas might have stopped working or you might eat too many sweets. You can't catch it. They don't have a cure for it.

Cal, age 11: You can't have sugar. I got it from my uncle. He's in my mom's family. You can't get over it. You can't catch it. You have it for your whole life. Your pancreas doesn't work. It's a thing in your stomach that digests your sugar.

Melissa, age 12: Your body makes insulin. If you have diabetes your body doesn't make insulin and you have to take shots. Cause your pancreas or something stops working. You can't catch it and you can't get rid of it. There's no cure yet.

The general illness and diabetes examples clearly illustrate that children understand more complex relationships as they grow older. The examples also
demonstrate that it is possible for a child to retain some of his thinking from an earlier stage even while he is able to begin thinking in a higher stage, a phenomenon that has been addressed in Piagetian theory regarding the development of conservation. The theory explains that children go through three stages of conservation, including a middle stage in which they sometimes conserve and sometimes do not. This explanation argues that the "stages" are not discrete but important points on a continuum of development, and that cognitive development is a gradual process (Ginsburg and Opper, 1978).

The responses of the diabetic children are particularly of interest as they illustrate the need for communication with diabetic patients that takes into account a developmental perspective. As pointed out in the literature review, health care professionals at best tend to communicate with all children as if they were in the concrete operational stage of cognitive development. These results suggest that not only do younger diabetic children think differently than older diabetic children, but that diabetic children in general are not as advanced as their normal peers in their overall cognitive development. These findings have implications for communication with and education of diabetic children, as will be addressed in Chapter V.
CHAPTER V

Discussion

This study examined diabetic and normal children's conceptualizations of illness causality from a cognitive-developmental theoretical framework. As the study of the beliefs of non-hospitalized, chronically ill children has not been accomplished in the literature (Perrin and Gerrity, 1981; Eiser, 1985), a major purpose of this project was to contribute to the literature on the beliefs of chronically ill children by studying one specific group, diabetic children. Research into children's ideas about illness have, almost without exception, examined healthy children's concepts. Blos (1978) has stressed the need for examining ill children's conceptualizations of both health and illness.

Children's perceptions about their chronic illness may be an important influential variable in their compliance with medical regimens. In the area of diabetes, both parents and patients have been shown to have insufficient knowledge (Eastman, et al., 1983; Allen, et al., 1983). Thus, this study attempted to integrate an interest in the topic from both a theoretical and a practical perspective.

It was expected that the findings of this study would replicate those of Bibace and Walsh (1979); that is, that as children mature, they demonstrate more advanced levels of
cognitive thinking regarding illness causality. Specifically, it was expected that older children in both the diabetic and normal groups would score higher than younger children on the Bibace and Walsh Protocol, a measure of general illness causality. In addition, within the group of interest, the diabetics, it was expected that older diabetics would score higher than younger diabetics on the Diabetes Interview demonstrating that a group of chronically ill, non-hospitalized children follow the same Piagetian progression of cognitive thinking regarding the causality of their own disease, diabetes.

Following Perrin and Gerrity's (1981) attempt to improve upon earlier studies, this study included a manipulation check of cognitive developmental level via performance on standard Piagetian conservation tasks. It was expected that children who were labeled as concrete operational on these tasks would score higher on the two illness measures than children labeled as preoperational on these tasks.

A final question of interest in this study was whether or not a child's experience with diabetes would affect his cognitive developmental level, as compared to his same-age normal peers. Since other cognitive accomplishments (e.g., conservation) can be acquired through certain experiences (Gelman & Baillargeon, 1983), it was hypothesized that perhaps younger diabetics would demonstrate more advanced
cognitive development than their same-age normal peers because of their experience with their disease. Indeed, as hypothesized by Bibace and Walsh (1981), based on a purely cognitive theory of development, it could be predicted that familiarity with illness would accelerate children's understanding.

This chapter discusses the empirical findings of this study and their significance in light of several developmental concepts, as well as recent developmental theory. In addition, the study's limitations and implications for future research are discussed.

**Discussion of Empirical Findings**

**Discussion of MANOVA and ANOVA Analyses.** The finding that older subjects scored significantly higher than younger subjects on both illness measures was expected and consistent with the view that children's conceptualizations about illness causality grow more sophisticated as they mature. This viewpoint was suggested as early as 1951 by Nagy, and has been demonstrated in several other more recent studies (e.g., Bibace & Walsh, 1979; and Perrin & Gerrity, 1981). In addition, studies regarding other areas of conceptualization such as medical procedures (Steward & Steward, 1981) and smoking (Meltzer, Bibace & Walsh, 1984) have also demonstrated more advanced cognitive thinking with increasing age.
In 1979, Bibace and Walsh provided a stagelike analysis of children's conceptualizations of illness causality utilizing Piaget's three stages of cognitive development. Their landmark study delineated two substages within each of the three stages of cognitive development, resulting in six scorable categories. Each of the six categories represents an increase in cognitive sophistication over the previous category.

In this study, although a wide variety of responses were obtained among the two age groups, (cf. Perrin & Gerrity, 1981), in general, both normal and diabetic subjects demonstrated progressively more advanced concepts with age. Older diabetic children demonstrated more advanced thinking not only about different illnesses in general but also about their own specific illness.

Younger diabetic children tended to offer limited concepts regarding their disease, (e.g., diabetes comes from God, comes from eating too much sugar and comes from kissing someone with diabetes), while older diabetics offered more mature explanations (e.g., diabetes is a disorder of the pancreas, the pancreas stops producing insulin). Two older diabetic children mentioned the concept of autoimmunity in relation to diabetes, and although it appeared that these children heard the explanation from TV or other sources, they were able to remember and state it in their own words.
The fact that diabetics scored lower than normals on the Bibace and Walsh Protocol, a measure of the understanding of different illnesses, is of interest in two respects. First, it indicates that experience with a complex disease does not offer an advantage in answering questions about other types of illnesses. Secondly, according to this study's findings, diabetics do not demonstrate more advanced cognitive development than their normal peers, despite their daily exposure to experience with a chronic illness. This finding is consistent with hypotheses that ill children are more regressed in their cognitive development (Bibace & Walsh, 1981; Eiser, 1985).

These findings illustrate the importance of a minimal knowledge base in answering questions. In order for a response to be meaningful, some familiarity with the topic is necessary; thus, as expected, many normal children scored poorly on the Diabetes Interview as compared to their same-age diabetic peers, because they have little or no exposure to diabetes. The normal group's scores on the Diabetes Interview reflect it's lack of a minimal knowledge base, whereas the diabetic group's scores indicate a knowledge base plus a progressive understanding with age. This finding is consistent with Chi's (1978) work which suggests that knowledge base plays a role in cognitive performance. Chi (1978) found that children experienced in chess performed
better than adult novices in a memory task regarding chess pieces.

**Discussion of Conservation Tasks.** More recently, level of cognitive development has been examined in studies of illness causality (e.g., Perrin & Gerrity, 1981; Potter & Roberts, 1984). Following the example of these studies, this study also employed a measure of general cognitive development, utilizing Piagetian conservation tasks. The inclusion of these tasks, scored conservatively over trials, was intended as a manipulation check in order to compare cognitive development as measured by the tasks with cognitive development as measured by the two illness interviews. Water was the only task that was significantly correlated with both illness measures. The correlation found was moderate in relation to the general illness measure and low in relation to the diabetes measure. Of the other two tasks, clay obtained a low correlation with the general illness measure and number was not correlated with either illness measure.

These results suggest that a subject's performance on the conservation tasks was not highly related to his performance on the illness measures. This finding appears to be related to two important points. First, the generally low correlations are partly a result of the fact that the normal group scored very low on the diabetes measure. In other words, the normal group's cognitive development was not
represented by their scores on the diabetes measure because they lacked sufficient knowledge to provide meaningful answers. Second, the low correlations are partly a result of the nature of the tasks themselves. Only one of the three tasks (water) appeared to be the best discriminator of concrete operational thinking. The water task was moderately correlated with the general illness measure. This finding may be explained by the concept of horizontal decalage and by Siegler's (1981) research which describes performance differences on discrete versus continuous conservation tasks. Specifically, conservation of water is typically mastered later than number and clay. Passing of the water task would have been a necessary precondition for obtaining significant and higher correlations.

In the following sections, several developmental concepts are presented in order to discuss this study's findings in relationship to the developmental literature. In the first section, the difficulty of defining conceptual development will be discussed as an important overall consideration in this type of research. The second section discusses the stages of conservation development as defined by Piaget, as well as the concept of horizontal decalage. These two topics are important in light of the specific findings of this study as discussed previously.
The Dilemma of Defining Conceptual Development

Since his early publications, over fifty years ago, Piaget has established himself as the defining authority in the area of children's cognitive development. Piaget developed specific tasks to define children's development of various concepts, and it came to be accepted that a single concept could be defined by a child's performance on a single task. However, in the last twenty years, further research has demonstrated that children do not possess a single understanding of any concept (Siegler & Richards, 1983). The problem in defining exactly when a child has conceptual understanding is strikingly clear in the arguments of Braine (1959) and Brown (1976), both cited in Siegler and Richards (1983). As Siegler and Richards (1983) state:

Braine argued for a criterion of initial competence, Brown for a criterion of stable usage. The dilemmas that each of these proposals lead to suggest that no single standard of conceptual understanding can be adequate...it does seem arbitrary to identify understanding with anything other than the earliest form of understanding; however, it seems misleading to identify understanding with the earliest form of understanding (pp. 52-53).
This dilemma is a topic of continual debate among developmental theorists.

The Development of Conservation and the Concept of Horizontal Decalage

Since Piaget's early work, there has been an enormous amount of research devoted to the concrete operational stage of cognitive development. Further, the concept of conservation, which is only one aspect of the concrete operational stage, has received the majority of research focus.

According to Piaget's theory, the ability to conserve is the best indication that a child has passed from preoperational thought to concrete operational thought. Piaget claims that a child's capacity to conserve goes through three stages. At first, he is not able to conserve at all, then he reaches a point where he sometimes conserves and sometimes does not, and these decisions are influenced by the type of deformation he sees, and finally, the child conserves in the face of any type of deformation. The age at which most children reach this final stage of conservation is around seven or eight. In this study, there were 10 seven year olds in the diabetic group and 8 seven year olds in the normal group. Half of the diabetic seven year olds were in the preoperational stage on the conservation tasks, while all of the normal seven year olds were in the concrete
Illness Causality

operational stage. By contrast, all of the eight year olds in both groups were concrete operational. The clay task was failed by only one of the diabetic eight year olds, while the water task was failed by two of the normal eight year olds. In this study, only one nine year old (a diabetic) scored preoperational, and by age ten up through age twelve, all subjects were concrete operational. Thus, these results substantiate Piaget's observations that conservation is influenced by types of deformation and that conservation is generally achieved by age seven or eight. However, it appears that, contrary to the expectation of this study, diabetic children as a group are not as advanced as their normal same age peers in their cognitive development. The literature that is available in this area (Cook, 1975; Eiser, 1985), suggests that sick children do not have more developed concepts of illness than healthy peers. As Bibace and Walsh (1981) have hypothesized: "experience of illness has such overwhelming emotional concomitants that the level of conceptualization with respect to the illness is inhibited or regressed" (p. 45).

The principle of horizontal decalage is another interesting feature of the development of conservation. This principle states that children do not develop conservation of different quantities at the same rate; that is, they go through the three stages of conservation development at
different rates for different quantities. According to Piaget, number is easier to conserve than length, and quantity is more difficult to conserve than either number or length (Brainard, 1978). This study's results suggest that number is indeed easier to conserve than either water or clay, and that water is the most difficult of the three tasks to conserve. As pointed out earlier, some children in this study were labeled concrete operational because they passed two out of three tasks; however, they may have failed the water task, which appears to be the better discriminator. Perhaps this is one reason why it was difficult in this study to relate a child's score on the conservation tasks to his score on the illness measures.

Directions for Future Research

This study's results demonstrate a progression of cognitive thinking for both normal and diabetic children, according to the stagelike model proposed by Bibace and Walsh (1981). This finding is a step toward identifying stages of development in discrete groups of chronically ill children. In addition, the types of responses given by the diabetics can be helpful to professionals who deal with diabetic children. For example, it would be useful to a health care professional to know that a young child may think his diabetes is from God or from kissing his daddy, and that he believes this despite the education he has received to the
contrary. It would also be useful to realize that around age eight or nine, diabetic children begin to understand the simple explanation that the pancreas is a body organ necessary for health, and that improper functioning of the pancreas results in diabetes. At around age eleven, more advanced concepts can be presented such as the contribution of heredity and the concept of autoimmunity.

The fact that diabetic children are not more advanced in their cognitive thinking than their normal peers, and indeed, may be less advanced in their cognitive development (cf. Eiser, 1985), suggests that advanced concepts regarding diabetes are not useful with younger diabetics and should not be presented. However, the conservation training literature demonstrates that, in certain circumstances, the concept of conservation can be taught to younger children, suggesting that training may be helpful in advancing the cognitive thinking process in younger children (Gelman & Baillargeon, 1983). A training study with diabetic children might be a useful research direction in order to explore the possibility of strengthening the cognitive development of diabetics. However, it would seem that a simple conservation training study would not be sufficient, as it is difficult to imagine that training in conserving tangible properties would generalize to an advanced understanding of the more abstract concept of diabetes. A useful study might be modeled on
group discussion with young children exposed to a "stage plus one" reasoning paradigm, similar to that used in moral development studies (cf. Turiel, 1972, cited in Rest, 1983).

Knowledge may be an important confounding variable that needs to be controlled in future research. One consideration for improvement in this area would be the use of a measure of diabetes knowledge similar to that devised for adults by Dunn, Bryson, Hoskins, Alford, Handelson and Turtle (1984). Another approach would be to teach pertinent diabetic concepts to a diabetic group and a matched normal control group, measure their level of knowledge, and include these results as a research variable.

The low correlations obtained between the conservation tasks and scores on the illness measures suggests another direction for future research. Some considerations include altering the scoring rules so that the water task must be passed in order for a child to be labeled concrete operational and/or including some formal operational questions for comparison. A larger sample size with several discrete matched age groups would also improve the comparisons. On the other hand, this study also suggests that cognitive factors involved in illness understanding may be relatively independent of other cognitive domains, a conclusion supported by the research of Perrin and Gerrity (1981).
The indication that there were more preoperational diabetics than normals in this study suggests another avenue of research. A study with a larger sample might explore the idea that perhaps chronically ill children, due to illnesses, effects of medication and hospitalization or other factors have fewer opportunities for the type of experiences that are needed to interact with maturational processes.

A final direction for future research is the nature of the diabetic interview itself. Although an excellent interrater reliability was obtained on this measure, it could benefit from further exploration of its psychometric properties. One question that seemed to be more easily answered on the diabetic interview was the question about sugar. Children described table sugar in many answers, suggesting that the term glucose might be more appropriate. Also, the question regarding hospitalization did not appear to garner many meaningful answers, even from diabetics. The questions in this interview need to be further evaluated and perhaps revised or expanded.

Although there are, and will continue to be debates among developmental theorists of different persuasions about the nature of the development of cognitive thinking, it seems clear that children do think differently at different ages, and their conceptualizations do become more sophisticated as they mature. Although the rate of the development for
different areas of thinking appear to vary across groups and within groups, a progression from simple to complex thinking cannot be disputed. Further, this study indicates that the progression of thinking regarding illness causality is also present in a group of chronically ill children. The finding that the cognitive development of chronically ill children may be impeded has implications for communication with and education of chronically ill children.
Illness Causality

References


Illness Causality


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These consist of pages:

82-83 Appendix A

UMI
Appendix B

Diabetes Interview

1. WHAT IS DIABETES?
   How do people get diabetes?
   Can you catch it from someone? How?
   How do you get over diabetes?

2. WHAT IS INSULIN?
   What does it do?
   Why do you have to take shots, take insulin?
   What would happen if you didn't take your shots, take insulin?

3. WHAT IS SUGAR?
   What does it do?
   Why do we need it?

4. WHAT DOES HIGH BLOOD SUGAR MEAN?
   How do you tell if you have high blood sugar?
   What should you do if you have high blood sugar?

5. WHAT DOES LOW BLOOD SUGAR MEAN?
   How do you tell if you have low blood sugar?
   What should you do if you have low blood sugar?

6. WHY DO YOU TEST YOUR BLOOD?
   (For normals: Why do diabetics test their blood?)
   What does it show you?
   What does that mean?
7. **WHAT DOES IT MEAN TO HAVE "BAD" ("SENSITIVE") DIABETES?**

What happens to you when you have "bad" diabetes?

How do you stop "bad" diabetes, or how can you keep from getting "bad" diabetes?

8. **HAVE YOU EVER HAD TO GO TO THE HOSPITAL BECAUSE OF YOUR DIABETES?**

(For normals: Diabetics sometimes have to go to the hospital because of their diabetes. What might happen that would make them have to go to the hospital? How would they get better in the hospital?)

A. (If subject says "yes"): Why did you have to go to the hospital? How did you get better in the hospital?

B. (If subject says "no"): What can happen to you that might make you have to go to the hospital? How would you get better in the hospital?
1. **CONSERVATION OF NUMBER**

Two rows of 7 chips each, one blue, and the other white, are placed parallel to each other so that both rows are of the same length and the chips in one row are directly opposite those in the other. Examiner (E) will direct Subject (S) to count the number of chips in each row. Then the E will deform 1 row of chips as follows:

(a) extend one row of chips in both directions to a length of about twice as long as the other row

(b) subdivide 1 row of chips into 2 rows of 4 and 3 chips placed parallel to the other row of 7 chips

(c) E places 1 row of chips in a vertical pile in front of the other row.

After each deformation, the E will ask the standard conservation question:

"Do you think there are more blue chips in this pile, the same number of blue and white chips, or more white chips in this pile?" After S answers the question, E always asks, "Why do you think so?"

**Scoring:** 2 out of 3 deformations for credit on this item.
2. CONSERVATION OF LIQUID AMOUNT

The E will fill 2 identical, narrow glasses to the very top from a pitcher of colored water. The child will be asked whether both glasses were filled exactly to the top, and adjustments will be made if necessary. The E will ask, "Is there the same amount to drink in each glass?"

If S says there is, the E will say, "Now watch what I do." Explaining what she is doing as she does it, the E will pour the water from 1 of the narrow glasses

(a) into a low wide glass
(b) into a tall wide glass
(c) into 2 smaller glasses

After each of the deformations, the E will ask, "Is there the same amount to drink in this glass and this/these glasses(es)?" If S say yes, E will ask, "How do you tell?" If S says no, E will ask, "Which has more?"

Scoring: 2 out of 3 deformations for credit on this item.

3. CONSERVATION OF SOLID

E will present the S with 2 balls of clay, equal in weight and volume, and tell the S that they contain the same amount of clay. If the S does not think the 2 balls look as though they contain the same amount of clay, he/she will be instructed to make them equal (by subtracting from one and/or adding to the other). After the S is satisfied that the 2
balls are equal, the E will roll one of the balls into a--- (ring, cross or sausage) form, saying, "Now I change this one into a ---" (ring, cross or sausage). After each of the 3 deformations, the standard question will be asked, "Is there the same amount of clay in the ball and in the ---?" (ring, sausage, cross). If S says yes, E will ask, "How do you tell?" If S says no, E will ask, "Which one has more clay?"

**Scoring:** 2 out of 3 deformations for credit on this item.

**Overall Scoring**

The subject must obtain credit on 2 out of the 3 tasks to be labelled in the concrete operational stage of cognitive development. If the subject obtains credit on only 1 out of the 3 tasks, he/she will be labeled in the preoperational stage of cognitive development.

**Explanations**

The explanations given by the subjects will be divided into:

(a) conserving explanations - those clearly indicating conservation

(b) nonconserving explanations - those clearly indicating nonconservation

(c) ambiguous explanations - those not clearly indicating either conservation or nonconservation. E will attempt to get subjects to elaborate ambiguous responses by
interjecting a neutral statement, such as, "Tell me more" following each ambiguous response.
PLEASE NOTE:

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These consist of pages:

90-103 Appendix D
## Appendix E

### Normal Subjects' Raw Scores on the Bibace and Walsh Items

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Appendix G

Normal Subjects Raw scores on the Diabetes Interview Items

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Appendix H

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Appendix I
Profile of the Diabetic Sample

Family Description

The subjects' mothers filled out a form designed to ascertain some demographic and medical information about the diabetic child and his family. Results indicated the father's mean age was 38 years (range 25 to 58 years) and the mother's mean age was 36 years (range 29 to 45 years). The mean number of years of education was 15 for the father and 14 for the mother with ranges of 12 to 24 years and 11 to 20 years respectively. The mean family income was in the $30,000 to $40,000 bracket, with a range from below $5,000 to above $40,000.

Age Diagnosed and Years Diabetic

Forty percent (n = 12) of the sample was diagnosed before three years of age and 33 percent (n = 10) between the ages of four to six. The remaining eight subjects (27 percent) were diagnosed between the ages of seven to nine. Thus, by age six, 73 percent of this sample had been diagnosed as diabetic.

The majority of the sample (83 percent) have had diabetes for five years or less, while 17 percent have had the disease for more than five years. Two of the subjects had been recently diagnosed, and only one subject has had diabetes for ten years.
Diabetes Camp

The majority of the sample (63 percent) had not attended Camp Chinook, a summer camp for diabetics which provides education and support within a camping environment. Eleven of the subjects (37 percent) had attended diabetes camp. Four subjects had attended camp for two years, six for one year and only one subject had attended camp for five years.

Parent Ratings

Parents were asked to rate their children on the child's understanding of diabetes, acceptance of the disease and responsibility for blood testing and injections.

In answer to the question, "Do you think your child fully understands his/her disease?," 13 parents (43 percent) responded "yes," 11 parents (37 percent) said "no" and 6 parents (20 percent) were unsure. Thus, the majority of the parents (57 percent) either were unsure or did not think their children fully understood diabetes.

Parents were asked if they felt their children had adjusted to having diabetes. Nineteen parents (63 percent) admitted that their children sometimes rebel, while 11 parents (37 percent) believed their children accepted the illness.

Parents were asked two questions regarding the child's responsibility for taking care of himself. When asked if the child tests his own blood, 16 parents (53 percent) responded in the affirmative. According to parents, 9 of the children
(30 percent) test their blood with help from parents. Only five children required an adult to take complete responsibility for blood testing.

Regarding insulin injections, 11 parents (38 percent) reported that their children were able to inject insulin by themselves, and 7 reported that their children inject with the help of parents. Eleven (38 percent) of the sample required a parent to take full responsibility for injecting the insulin. Thus, 62 percent of the sample were involved with their daily insulin injections.

When asked if having a diabetic child creates stress in their family, the overwhelming majority (87 percent) of the parents responded in the affirmative. Parents reported that eating was a major conflict area with their diabetic child. Either the child ate too much, not enough or not on schedule. Many parents felt their lives were "ruled by the clock" because of the importance of following a strict meal schedule. Other areas of stress included wives feeling that their husbands were not involved enough in the care of their diabetic child. Many wives complained that their husbands tended to deny the seriousness of the disease, and took less responsibility for the management of the disease, resulting in marital stress for many families. Parents reported that they have difficulty finding babysitters (including extended family members such as grandparents) who are comfortable taking care of a diabetic child. As a result, many of the
parents reported difficulty in spending time alone, away from
the children, even for brief periods of time.

**Chi Square Analyses**

The relationship between diabetic camp attendance and
whether or not the parent reported the child "accepting" or
"rebelling" against having the disease was examined and found
to be significant (chi square p value = .02; Fisher's exact
test p value = .05). Of the children who had attended camp,
64 percent were judged by the parent to have "accepted" the
disease. On the other hand, 79 percent of children who had
not attended camp were judged by the parent to have
"rebelled" against having the disease.

In addition, the relationship between camp attendance
and whether or not the child injects himself was also
examined. Although not statistically significant (p < .07)
there was a tendency for those who attended camp to be taking
more responsibility for their disease. The majority of
children who had attended camp either injected by themselves
(50 percent) or with help from parents (40 percent). Fifty-
three percent of children who had not attended camp were not
taking any responsibility for their injections.

The relationship between blood testing and giving
injections was examined and found to be significant
(p < .0021). Children who test their own blood tend to be
involved with their injections; 67 percent inject by
themselves and 27 percent inject with help from parents.
However, 80 percent of children who do not test their blood also do not inject themselves.

Parents rated their children as to whether or not the children used their diabetes as an excuse for their behavior. This rating was examined in relationship to whether or not the child tested his own blood and found to be significant ($p < .03$). The majority of the sample who are involved with blood testing are perceived by the parents to use diabetes as an excuse "sometimes." Fifty-six percent who test their blood by themselves and 78 percent who test their blood with help from parents were rated by parents to use their diabetes "sometimes" as an excuse for their behavior. One hundred percent of the children who do not test their blood were rated as "never" using diabetes as an excuse for their behavior. Perhaps those subjects who do not test their own blood and are not aware of the meaning of the blood sugar levels, are also less aware of opportunities to use diabetes as an excuse for their behavior.
Appendix J

Children's Understanding of Illness
Family Information Form

I. Demographic Information

Today's date ____________ Your name ____________________________

Relationship to child ____________________________

1. Child's name ____________________________

2. Child's date of birth ________ Age ________ Grade ________

3. Address ____________________________ Telephone __________

4. Father's Age ________; Father's educational level __________

5. Father's occupation ____________________________

6. Mother's age ________; Mother's educational level __________

   Mother's occupation ____________________________

7. Family Income Level (please check the choice that best describes your total combined family income):

   ____ Below $5,000 per year  ____ $20,000 - $30,000 per year
   ____ $5,000 - $10,000 per year  ____ $30,000 - $40,000 per year
   ____ $10,000 - $20,000 per year  ____ Above $40,000

8. Please circle one: Is this the child's (1) natural father
   (2) step-father, (3) adoptive father, (4) legal guardian, (5) other __________

9. Please circle one: Is this the child's (1) natural mother
   (2) step-mother, (3) adoptive mother, (4) legal guardian, (5) other __________

10. Parents' marital status - please circle one: (1) married, (2) separated, (3) divorced, (4) single-never married, (5) remarried, (6) widowed
11. Child's siblings - please list age and sex of all other children in the home:

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II. Family Health Information

1. Is child's mother diabetic?  __yes;  ____no
2. Is child's father diabetic?  __yes;  ____no
3. Are any siblings diabetic?  __yes;  ____no If yes, give age and sex of diabetic sibling: age: __________ sex: __________
4. Does the mother, father or any of the children in the family have a history of any of the following? Check those that apply and indicate which family member:

   Medical Condition:  Family Member:
   ___asthma
   ___epilepsy (seizure disorder)
   ___arthritis
   ___chronic pain problem
   ___heart disease
   ___cancer
   ___other (please describe):  

III. Information Regarding Child's Diabetes

1. How old was your child when he/she was diagnosed as diabetic?
2. What were the circumstances that led up to your child being taken to the doctor for diagnosis? (For example: child brought to emergency room in coma)

3. Who was primarily responsible for explaining diabetes to your child?
   ____mother only       ____medical personnel (doctor/nurse)
   ____father only       ____other - please describe:
   ____both parents

4. Has your child ever attended a diabetic camp?  ____yes;  ____no
   If yes, how many years has your child gone to diabetic camp?
   ____years

5. Do you think your child fully understands his/her disease?
   ____yes;  ____no;  ____unsure

6. What area of information about diabetes do you think is the hardest for your child to understand? Why?

7. How do you think your child has adjusted to diabetes?
   ____acceptance;  ____denial;
   ____accepts, but sometimes rebels;
   ____other - please describe: ______________________________________

8. Does your child test his/her own blood?
   ____yes, by him/herself  ____no
   ____yes, with help from parents

9. Does your child give him/herself insulin injections?
   ____yes, by him/herself  ____no
   ____yes, with help from parents
10. How often do you think your child uses his/her diabetes as an excuse for doing or for not doing something?

_____ never; _____ sometimes; _____ always

11. What do you worry about or fear the most in regard to your diabetic child?

12. Please describe a major area of conflict between you and your diabetic child:

13. What complaints do you have about the medical personnel you have dealt with?

14. Do you feel you need more information/understanding about diabetes?

_____ yes; _____ no

15. If yes, what type of information/understanding do you need?

16. Do you feel that having a diabetic child has created stress in your family?

_____ yes; _____ no

If yes, please describe the stress that you experience:

17. Please use this space to make any additional comments or express any additional concerns:
VITA

Born June 14, 1951, Baton Rouge, Louisiana.

September, 1979, M.A. Human Development, Pacific Oaks College, Pasadena, California.

May, 1984, M.A. Clinical Psychology, Louisiana State University, Baton Rouge, Louisiana.


September, 1982 – May, 1982, Practicum Student and Teaching Assistant, LSU Psychological Services Center.

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Presentations

DOCTORAL EXAMINATION AND DISSERTATION REPORT

Candidate: Randi C. McAllister

Major Field: Psychology (Clinical)

Title of Dissertation: Diabetic and Normal Children's Understanding of Illness Causality

Approved.

[Signatures]

Major Professor and Chairman

Dean of the Graduate School

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Date of Examination: May 1, 1988