UC Berkeley

Theses

Title

The Psychology of Chronic Illness in Children and the Role of Children's Literature in Intervention

Permalink

https://escholarship.org/uc/item/2dv1812k

Author

Baumgartner, Karl M

Publication Date

1989-04-01

Copyright Information

The Psychology of Chronic Illness in Children and the Role
of Children's Literature in Intervention

By

Karl Matthew Baumgartner

B.A. (University of California at San Diego) 1985

THESIS

Submitted in partial satisfaction of the requirements for the degree of

MASTER OF SCIENCE

in

HEALTH AND MEDICAL SCIENCE

in the

GRADUATE DIVISION

of the

UNIVERSITY OF CALIFORNIA at BERKELEY

Approved: ....Carol T. Christ............................ 5/22/89
　　　　　　　　　　Chair　　　　　　　　　　　　　　　Date 5/16/89
.....Thomas C. Kishner.................................
.....William M. Runyan.................................. 5/22/89

****

Introduction

The nature of childhood illness has changed. Many once fatal conditions are now considered chronic disorders, such as leukemia, cancer and diabetes. In the not too distant past, treatment of such diseases was often simply a matter of following the doctor's orders, often without including the child itself in either the decision making process or in the specifics of the treatment(s) to be rendered. Physical disability as well has been in times past (and still is in many ways) stigmatized, and those with disabilities ostracized, ignored or treated with little concern for the psychological impact of such conditions (consider the practice, only of late being changed, of placing children with scoliosis in painful, cumbersome and unsightly braces for years). More recently it has been recognized that it will not be enough simply to treat the physical ailment of the particular child. Consideration must be taken for the psychological impact of the illness, not only on the affected individual but on his or her siblings and parents as well. Stephen Kew, author of "Handicap and Family Crisis," states: "Many siblings face enormous social and emotional problems in relation to handicap, even though they themselves are healthy and sound of limb. Most (of the problems) are related to changes which are wrought in the family as a whole as it tries to cope with and adjust to the birth and presence of a handicapped child" (Kew, 1975). The same thinking applies to the children afflicted with chronic illness. In dealing with the presence of chronic illness or disability, the approach becomes one of "the family as the patient."

As one solution to the problem of treating more than just the physcial problem, Kew goes on to discuss various means of intervention in the setting of social work, proposing "a coordinated, systematic service designed to meet the needs

of the whole family" (Kew, 1975). The idea seemed commendable, but I wondered how a thing of such scope might be implemented. As I cast about looking for "interventions" which seemed to work in terms of dealing with psychological stress in families, I became intrigued by the idea of children's books.

Children's literature has long been a means of addressing feelings, situations and problems in a manner palatable and nonthreatening to young people. The earliest folk and fairy tales captured in short, entertaining fashion the social mores and social dilemmas of the time, while current works by writers such as Sendak and Judy Blume deal with many of the turbulent feelings encountered by children as they learn to deal with the complexities of socialization. Done well, these stories hold the interest of their young readers through the use of fanciful characters and exciting plots, while at the same time deeper levels of the stories may be clarifying issues, reassuring the child that his or her strong and often frightening feelings are usually normal, or imparting new information and ideas to the children. Joanne Bernstein in her work entitled "Books to Help Children Cope with Separation and Loss" states quite clearly this notion of using literature therapeutically: "Adult guides who wish to help children come to terms with loss have a good ally in books, for books have been tools for preventing and solving psychological problems for as long as both books and problems have existed." (Bernstein, 1977). She notes that the door of the library at Thebes was inscribed "healing place of the soul," an appraisal I find most appealing, and one which is contained nicely in the term "bibliotherapy." Most simply defined bibliotherapy means helping with books. My interest became focused on children's literature and the ways in which the psychological pressures surrounding the presence of chronic illness in children's lives is explored in such literature.

2

The process of understanding how such books might be useful had to begin with a deeper understanding of the psychology of children. With that realization I began an investigation into currently held theories of child development, settling on that of the Swiss researcher Jean Piaget. The basic tenets of this theory are that the perceptions of children are not always those of adults, and that children's conceptions of reality change as they grow. Piaget's theory of general cognitive development has been extended into the areas of health and illness concepts. That is, current research looks at how children's perceptions of their bodies and of disease processes change throughout the course of childhood. This becomes applicable to understanding how the presence of chronic illness or disability in a family impacts psychologically on all of the children. Finally, such knowledge can be used to analyze the subtext present in children's books dealing with chronic illness or disability.

Chronic illness and disability are facts of life for many children. Tremendous psychological pressures can be placed on such children and their siblings, to which each child will respond differently based on the level of cognitive development attained. Children's literature may be useful in dealing with these pressures, if the child's developmental level and conceptions of health and illness are taken into account in the writing of such books. The body of this thesis illuminates these concerns, while the stories included in the appendix are intended to reflect them.

Cognitive Development & The Psychology of Chronic Illness

Several areas of child psychology are receiving interest in the literature, including the impact of illness not only on the affected child but on siblings and on families. It is clear that it is not enough simply to characterize the consequences of illness and disability in terms of the nature of the disease process itself. "In most of the literature the emphasis is on the effect of chronic illness on children and their

3

families. More recently it has been recognized that any repercussions of chronic illness are dependent on an individual's response, rather than fashioned by the disease" (Eiser, 1985). In that light, a knowledge of the child's approach to and understanding of health and illness is critical to any sort of intervention. One has to realize that the child's view of the world is fundamentally different than an adult's, and that this view changes throughout childhood. The field of developmental psychology is the starting place in correlating children's health and illness concepts to their world-view.

One of the major figures in developmental psychology is Jean Piaget, and his theory of cognitive development has been the most influential and detailed account of child development. Piaget made two crucial points about the way children interpret reality. The first was that the child was not a passive participant in the reality game. Piaget felt that children gather data and fit them to hypotheses much as a scientist would. Secondly he felt that the child builds on or discards theories about the nature of reality as necessary. For instance the very youngest child doesn't understand that objects which he cannot see still exist, yet somehow during development this concept does develop.

Central to Piaget's theory is the notion that cognitive development progresses through distinct stages, none of which can be skipped, and each of which is more advanced than its predecessor. The assumption is that development is headed toward an inevitable end stage which was predestined from the beginning, as if the early stages were like an unfinished jigsaw puzzle and only with development to full maturity is the picture complete. The flaw in this scheme is that even adults who have reached the more advanced stages operate at times in the less advanced ones; the world construct we carry with us is a fluid, dynamic thing, not a set and unchangeable one.

Piaget proposed four main stages of development. The first is the sensorimotor, from birth to approximately age one and a half (the progression of stages do not correlate exactly with chronological age, but the correlation is close enough to serve as a convenient reference. In fact, the sensorimotor stage lasts until the emergence of language). Children in this stage demonstrate "the same kind of nonsymbolic, practical intelligence as animals" (Skolnick, 1986). Piaget proposed the use of schemes by children in this stage, such as sucking, grasping, looking, etc. The notion of a scheme applies as well to the mental basis for the actual action. In that sense it is the counterpart to a concept in an adult. The sense of object permanence develops in the sensorimotor stage as well. In the earliest stages the child will not look for a hidden object at all, having no realization that it still exists even though it can't be seen. Later the child exhibits a curious behavior known as the "A, not B" phenomenon. Piaget discovered this when he hid his watch from his nine month old daughter Laurent under a blanket. Laurent promptly looked under the blanket for the watch. However, when Piaget hid his watch under a coat instead, with Laurent watching, she searched for it under the blanket! By 18 months of age children no longer go back to "A" when they see the object hidden at "B," but correctly interpret that it must exist at "B".

The next period, from around 18 months to 6 or 7 years of age, is called the pre-operational stage. This is the time the child learns to use language, and begins forming mental constructs and imagery. In addition, these mental images can be invoked during make-believe play, during which one object can stand for the image the child holds for another object (using a block as a car, or a hand for airplane). In the early part of this stage the child develops the ability to follow the successive concealment of an object in several places. Prior to this time the action of hiding an object in a box, moving the box behind a screen and then dumping the object out of the box would completely thwart the child as to the whereabouts of the object. With

the refinement of this stage comes the ability to make the logical jump necessary to solve this puzzle. Although children of this stage are beginning to use symbols and are becoming more socialized, their thought processes tend to be "centered;" that is, they tend to focus on one aspect of a situation and are unable to consider other aspects. One instance of this is that of conservation of physical properties of objects. Pour water from one glass into a taller, thinner glass and a child at this stage of development may say that there is now more water (because the glass is taller) or that there is less water (because the glass is thinner).

Recent research has challenged several of Piaget's conclusions in this matter, demonstrating with different tasks than those used by Piaget that younger children are able to perform some of the logical reasoning of older children. The feeling of some researchers is that perhaps Piaget was wrong and that the thought processes of children don't undergo a qualitative change in logical style with age. I would argue that demonstrating that children are able to perform logical tasks at a younger age than Piaget described does not negate the validity of his findings. However it might be true as well that the shift in thinking is not so massive as Piaget thought, and that one current thought that "young children's problem-solving difficulties grow out of the fact that they are 'novices'" might represent a valid modification of Piaget's theory.

The above debate notwithstanding, at around the age of seven or eight children undergo some change in their patterns of thinking that will have profound effects on their psychological functioning. This is Piaget's stage of "concrete operations," which normally lasts until approximately age 11. At this stage children are "liberated from the egocentric magic universe of early childhood." (Skolnick, 1986) Children are able to see the world through other people's eyes, not just their own, and are truly able to manipulate objects in their heads. The world becomes yet

a more permanent, solid place wherein physical properties of objects are conserved even though there appearance may change. The eight year old given the same task with the water glasses as above will be able to mentally reverse the action of pouring, and conclude that it would come out the same as before, that the amount of water has not changed. This stage is that of "concrete" operations because while the child can think about manipulating real objects such as blocks or liquids, they cannot do so with ideas or hypotheses.

Around the time of adolescence another change takes place, when children reach a stage that Piaget called "formal operations." At this time the adolescent is able to depart from reality, not in the fanciful ways of the preoperational child, but logically and systematically. Further, the adolescent is able to separate form from content. Skolnick provides a useful illustration.

> "Consider the following sentences: All cows are purple. There is a cow in my bathtub. What color is it? To a 9-year-old, the statements are likely to sound silly because cows are not purple, and it is unlikely that there is one in the bathtub. The adolescent, by contrast, is likely to recognize...that logic requires the cow in the bathtub to be purple." (Skolnick, 1986)

In other words the child at this level is able to deal with language in terms of its logical structure.

Other new aspects of the "formal operational" child's changed patterns of reasoning include the understanding not just of multiplication (which the concrete operational child has) but of proportions as well. There comes also the understanding of analogies and a more exhaustive and flexible pattern of reasoning than that of a younger child. Given a problem to solve, the adolescent is more likely to approach the solution with a plan rather than a random series of trials and errors. The idea central to this stage is that the adolescent is able to subordinate reality to possibility.

These changes in rational thought do not exist in isolation from the emotional changes, sexual urges and bodily changes of adolescence. Teenagers tend to create theories about the nature of perceived reality, and this tendency can complicate feelings of love by the construction of a romance around these feelings. Like Shakespeare's love-struck Romeo and Juliet, adolescents may be "more in love with being in love" than with the person who is the object of their emotions.

Piaget has been criticized, perhaps correctly so, for over-reliance on the ability of teenagers to use abstract logic. For instance, not everyone possesses this kind of formal operational reasoning, yet Piaget's theory implies that anyone reaching the concrete operational level should eventually go on to this level. Only 40 to 60 percent of college students can complete Piaget's tasks for this level, and the presence of formal operational thinking is difficult to ascertain in nonliterate cultures. Criticisms have been leveled as well regarding the difficult nature of Piaget's original instructions for the tasks; when the tasks are simplified they often become easier for teenagers, and even some younger children (who should be at the concrete operational level) are able to complete them. Other researchers have adopted an "information processing" approach, wherein the change in ability in not ascribed to global shifts in patterns of reasoning but to the acquisition of additional skills and an increased rate of mental processing. These researchers might be described not as anti-Piagetian but as neo-Piagetian. What is clear is that Piaget has done fundamental research into the nature of the development of our reasoning abilities. Whether the changes in thought patterns occur just as he described, or in a modified fashion at perhaps different ages or with different end-points, the basic theory serves to illustrate that there are observable differences in the ways the youngest children, older children, adolescents and adults typically think. The central aspects of the theory can be applied to studies which look at the ways children view their bodies and their health.

Children's Concepts of their Bodies and of Health and Illness

In a theory put forth by C. Crider (1981), children's knowledge of their bodies and of body parts progresses through such Piagetian stages. He used outline drawings of the human figure into which children were to place such pieces of anatomy with which they were familiar. Studies such as this, which obtain information by asking subjects to draw what is inside their bodies, have the advantage of being language free and are thus presumably unaffected by language barriers or a child's limited vocabulary. However, they have been as often criticized because the accuracy of the data obtained depend in part on the child's graphic skills. The major points of the theory are included here because as posed it does serve to relate aspects pertinent to the discussion of chronic illness to the cognitive development framework.

In the preoperational stage, the child is phenomenalistic, often imagining that what is in the body are the things the child has placed there, such as apple pie, chicken and potato chips. Most often included anatomical parts are the heart and brain, usually placed in isolation from anything else. In addition, children of this age view body parts as unrelated. The brain is not involved in walking; it is your feet which can walk for you. At the more advanced concrete operational stage, children are more likely to correctly name and place more body parts on a drawing, and see structure as different from function. For instance, muscles in the leg help it to bend, thus aiding in walking. By the formal operational stage, hypothetical transformations are possible; the brain sends the message to the muscles to move in a coordinated fashion for walking.

Eiser argues that while such a theory may be somewhat applicable, it doesn't account for how children acquire such knowledge. Further, in trying to relate the presence of illness to the development of body image the results of studies are often

at odds with each other. Some studies seem to indicate that children with disease and their non-affected siblings end up with more accurate and advanced anatomical knowledge than children in families not so affected (Auer et al, 1971) while other studies seem to contend just the opposite (Green and Levitt, 1962). These discrepancies may be attributable in part to actual developmental disadvantages experienced by children with certain types of diseases, to design studies which rely too heavily on drawings rather than an expression of functional knowledge (i.e. why we need to eat, for instance), or to the stress of hospitalization as a confounding factor.

Studies concerning children's knowledge about their bodies can be useful in that they form a starting point for the study of children's concepts about illness. Several approaches to this theme have been made. The psycho-social model as put forth by Wright (1960), Campbell (1975), Thomas (1980) and Millstein et al (1981) focuses on social interaction, learned behavior and the effect of family and culture on a child's perceptions of self and illness. According to Thomas, social psychology is "concerned with man as a social animal, how he thinks, feels and behaves in social situations" (1980). The author questions whether personality is influenced by the disability a person might have, the society's attitudes towards the disability or a combination of the two, and goes on to try to pin down personality. One approach suggested is that there is a "distinctive pattern of personality associated with medical classification" (Thomas, 1980). Without going into the details of his argument, let me just relate that he believes that the search for personality types has failed to reveal any conclusive evidence for particular "handicap personalities." Another approach is the "role theory," that of learning to act in the role of a sick person. Thomas suggests that, given several typical role relationships of the chronically ill (such as doctor-patient) "to be obliged to take a particular role (almost irrespective of the physiological cause of the handicapping condition) may

produce similar patterns of behavioural (sic) reaction." Similarly, studies by Fishler (1972) and Olch (1971) show that roles are not constant during the developmental period. Thomas also describes the aspect of self-image, saying it has both a developmental component related to biological growth and maturation and a social component based on social interactions. Most of the main points social psychology proponents make seem to be directed less towards understanding the individual with handicap or chronic illness and more towards the relation between the person with a handicap and the remainder of society.

The most well-known study of the development of children's concepts of illness by proponents of the cognitive development theory was done by Bibace and Walsh (1979). In it they argue that, after Piaget, children's concepts of illness progress through a regular sequence of developmental stages, from the magico-phenomenalistic ideas central to the pre-operational stage on through the concrete stage and finally to the more psychophysiologic ideas of the formal operational stage.

In a study done in 1980, Bibace and Walsh proposed six stages of development in children's illness concepts. The first stage is the purely phenomenalistic. Children conceive that illness and its source are external to the self. The cause is seen as a concrete phenomenon that is spatially and/or temporally remote from the child. Thus, people get colds from "the sun, from trees, from God," etc. The second stage introduces the idea of contagion. That is, the cause is still a concrete phenomenon, but now it is located in objects or people which are close to the child. People get colds "when someone else gets near them." Notice the distinction, that the association in the first stage seems arbitrary, almost random, as if the cause were attributed to one particular thing the child recalled thinking about while ill. As cognition advances, the child begins to make more

proximal, more immediately related associations. In both of these early stages, children are "overly swayed by the immediacy of some aspects of their perceptual experiences." In other words, they are not yet able to incorporate their experiences into a theoretical framework. Both of these stages can be assigned to Piaget's "preoperational" stage.

Similar studies done by other authors have revealed other characteristics of these early stages. In a study by Kister and Patterson (1980) children of this age were found to be likely to accept "immanent justice" explanations for disease, that is that mother's admonitions regarding the wearing of sweaters and the likelihood of catching one's "death of cold" really come true; "people get what they deserve." These authors also discovered that younger children are more likely to overextend the concept of contagion, assigning it to noninfectious diseases and even to injuries.

The third stage described distinguishes contamination from contagion . Moving away from magical thought and towards a better differentiation between self and other, the concept of illness is now viewed as an object or person which has a harmful quality or aspect for the child. At this stage it's not enough that the child be near someone else or simply be outside. There is the beginning of an understanding of specific cause, although it remains external to the child:

> "When outside without a hat...your head would get cold--the cold would touch it--and then it would go all over your body" (Bibace and Walsh, 1981).

The fourth stage begins the process of internalization. The cause is still external but children at this stage now see the cause as having a deleterious internal effect on the body. Swallowing and inhaling are the mechanisms whereby this is achieved, and the idea of bacteria or viruses is introduced (however, all illnesses may be presumed to be caused by one "bug"). While the illness may be located within the body, the

child still demonstrates confusion regarding the internal functioning of his or her body:

> How do people get colds? "In winter, they breathe in too much air into their nose, and it blocks up the nose." How does this cause colds? "The bacteria gets in by breathing. Then the lungs get too soft [child exhales], and it goes to the nose." (Bibace and Walsh, 1981)

The third and fourth stages together Bibace and Walsh saw as comparable to Piaget's concrete operational stage. Rather than the purely descriptive outlook the younger children had, children in this stage have a more explanatory outlook. According to Kister and Patterson (1980) they are less likely to ascribe the acquisition of an illness to immanent justice and can see infectious illness as somewhat separate from noninfectious illness and injury.

There is by the fifth stage the greatestdifferentiation between self and other. Children in this stage, described as the "physiologic," view the illness as being externally triggered, while the actual source of illness is a breakdown or malfunction in internal structures, explained as a step by step sequence of events leading to the disease. Relating this to Piaget's theory, one can see that the child by this stage is able to consider more than one aspect of "reality" at a time, to perform "operations on operations" as Piaget put it. While this is a nearly mature level of understanding, it is only with the consideration of possible psychological causes for illness that the sixth stage (the "psychophysiologic") is reached. In this scheme, children understand that feelings may influence the onset or course of disease. These last two stages predictably correspond to Piaget's stage of formal operations--a child is able to consider and manipulate hypothetical situations. Children of this age know that different diseases and illnesses are caused by different germs, and that not all illnesses are caused by germs. Another interesting facet of children's understanding at these latter stages is that they view themselves as having more control over illness.

Bibace and Walsh also found the predictable correlation between age and developmental status. Among the four year olds in their study, "54 percent gave contagion explanations and 38 percent gave contamination explanations. Among seven-year-olds, 63 percent gave contamination explanations and 29 percent internalization explanations. Among the eleven-year-olds, explanations were classified as 54 percent internalization and 34 percent physiological." (Bibace and Walsh, 1981) Once again, the correlation isn't exact, but it is close enough to serve as an indicator of developmental status which is relatively content-free. That is, the authors contend that "assessment of cognitive functioning on a task whose content is distantly related to the domain of experimental interest" does not qualify as an indicator which is content-free, and that in fact form and content can never be wholly separated. That is why they prefer to use age as the indicator of cognitive level in their health related studies.

Potter and Roberts (1984) feel the literature may be inconclusive as to whether or not the conceptions of children in the earliest stages are sophisticated enough for them to benefit from information about illnesses; however, that may depend on the type of information presented and the manner in which it is presented. The authors conducted a study which considered the acceptance of chronically ill children by their peers based on the type of disease, the peer's level of cognitive development and the amount of information provided. Their hypothesis was threefold. First, that the observability of a disease would influence acceptance of the affected child by his or her peers, with the mechanism seen as a reaction to the degree of perceived similarity; "people tend to be more accepting of similar others and...acceptance decreases as dissimilarity increases." Next, that the cognitive development level of the nonaffected child would influence the reaction to the affected child as well. Kids who were at least at the concrete level would demonstrate a better level of understanding of disease than their preoperational

confreres, and their developmental level would affect the subjects' degree of perceived vulnerability, especially if given explanatory versus descriptive information. The actual results indicated that kids who received descriptive information (i.e. of symptoms) and preoperational children perceived themselves as more vulnerable to illness. There was also a marginal tendency for kids in the explanatory group to see the affected child as less attractive. Because of this result the authors question the validity of the assumption that "increasing a child's understanding of a medical disorder will also increase that child's reported acceptance of the disordered individual." However, such explanations in isolation in fact show ways in which the affected kids are dissimilar to their peers, and the authors recognize this as a factor in acceptability. Such explanations attended by other ways in which the affected peer is similar may negate this finding. The authors also question whether "brief verbal explanations alone (are) a sufficiently comprehensive method of influencing the children's understanding and...their attitudes of acceptance" (Potter and Roberts, 1984) I would contend that they are sufficiently comprehensive (or that books could be) if the above mentioned ways in which the affected peer is similar are included. The authors suggest that children at the preoperational level might "benefit most from a global nonspecific explanation while concrete operational children are more apt to comprehend detailed information." (Potter and Roberts, 1984) This is in accord with the finding by some authors that children in general and younger children in particular are more concerned with the social implications of and limitations imposed by illness than in specific physical consequences.

Several broad conclusions from these studies and others like them can be made. There in fact seems to be correlation between chronological age or cognitive development and children's illness concepts. Older children view illness in terms of specific symptoms and disease and are more likely to appreciate the psychological

and social aspects of illness than their younger and less cognitively mature peers. The older children define illness in more internal terms, while the younger children rely on external cues. Also, older and more cognitively mature children don't seem to accept the notion that illness and misbehavior are related. Further, it is understood that illness itself has an impact on cognitive development, but the studies conflict with each other as to whether ill or hospitalized children are less, equally or more mature cognitively than their non-affected peers. While the methodology can be critiqued on several levels, it is probably more important to realize that illness may hinder development by lessening the child's interaction with his or her environment. The stress of hospitalization or illness may have an influence on the course of development as well; however, stress is perceived and reacted to differently, such that some individuals may suffer for the experience while others may learn from it. Critique of the methodology does have practical import. If the studies result in inaccurate estimation of children's cognitive development as it relates to age, either from too small sample sizes, too much reliance on figure drawing or other factors then suggested guidelines for intervention may be inappropriate. These criticisms don't detract from the importance of the basic principles of the theory, however.

There are several implications for the health care field to be drawn from these works. Medical explanations for illness and for treatment usually assume some working knowledge of anatomy and physiology, when in fact young children's misconceptions and less sophisticated outlook may seriously hinder communication. A personal anecdote is illustrative, related to me by one of my clinical professors. He told us of a young patient he was treating for cellulitis of the leg. The boy was apparently completely amenable to his treatment, including the intravenous line in his arm. When the veins in his arm proved too difficult to find, the physician attempted to start an i.v. in the unaffected leg, whereupon the boy became severely

anxious and resistant. As the story unfolded, it turned out that the boy thought the i.v. in his arm was sending "healing juices" downwards, keeping the infection at bay. If placed in his leg, these juices would be unable to stop the "poison" from moving upwards, and if it reached his heart, it would kill him. An appropriate explanation of the circulatory system as a system of pipes which could carry the "healing juices" to the trouble spot allayed his fear and allowed for continuation of his care. The point is that explanations should be tailored to the cognitive level of the patient. Perhaps for the youngest children this would entail only the "more concrete, visible aspects of disease management, such as explanations of medical equipment or differentiation of the role of various medical personnel" (Eiser, 1985). Older children's explanations could be couched in metaphor, such as equating the body's immune system with a police force. Bibace and Walsh went so far as to say that explanations in purely physiological terms should be withheld until children are at the formal operational level of understanding. Another implication is that children's concepts of illness may well affect how they communicate their state of health to others. For instance a younger child operating under the burden of "immanent justice" may be reluctant to report illness if the child feels that it somehow means he or she is a bad person. For persons involved in a child's care it suggests that care should be taken in interpreting reported symptomatology.

An understanding of cognitive development allows one to understand how children view the world, and in turn how their differing conceptions of reality affect their conceptions of health and illness. One can go on to explore the psychological stresses that chronic illness and disability inflict on children, and how children and families cope with these stresses.

Children affected by chronic illness or disability

Chronic illness and disability are not conditions that affect only a small portion of our population. Conservative estimates are that 10 to 20 percent of children in America experience some long term illness. If one includes illnesses such as chronic allergies, visual and hearing impairments and so on the numbers are actually much higher. The most common conditions are asthma, epilepsy, cardiac conditions, cerebral palsy and leukemia, with asthma by far the most common, representing roughly 25% of chronic illnesses. It is estimated that 50% of children under 7 years old will be admitted to the hospital at one time or another. (Eiser, 1985)

Stubblefield (1974) reasons that children not affected by a chronic illness overcome the frustrations and setbacks of youth because they have a real expectation that with maturity will come control over these problems. Children with chronic illness on the other hand are constantly faced with the fact that mastery may never come. Setbacks are common, and the constant presence of doubt regarding the future becomes debilitating. Hughes (1976, from Eiser) describes eight emotions challenged by chronic illness. They are 1) love and affection, 2) security, 3) acceptance as an individual, 4) self-respect, 5) achievement, 6) recognition, 7) independence, and 8) authority and discipline. In a large epidemiologic study of 3294 children in Ontario, the authors concluded that "in a representative general population sample of children, those with chronic health problems including both chronic illness with disability and chronic illness without disability are at substantially higher risk for psychiatric problems than are their healthy peers." (Cadman, et al, 1987) Such behavioral disorders such as neurosis, attention deficit, hyperactivity, and school and adjustment problems were found to be twice as prevalent in chronically ill children as in non-affected children. By contrast, in a

study by Pless and Saterwhite (1975), the authors concluded that "in some instances, greater achievements were made than might have occurred in more normal circumstances." (from Eiser). Other authors have found that the presence of a chronic illness in a child may spur the child to excel in areas not affected by the illness (such as academic achievement in a child with cystic fibrosis). Obviously a variety of reactions to chronic illness or disability are possible, and while certain children may experience severe emotional and psychological repercussions, others seem to cope adequately or even seem not to be affected by the illness at all.

Generally the factors that influence how a child reacts to a chronic illness can be placed in three broad categories: those related to the disease itself and the restrictions it places on the child's life, those of the child's personality, intelligence and individual background (such as age at onset of disease, etc.), and the interpersonal environment, including the reactions of parents and peers.

One might think intuitively that children with more severe illness would stand to have more profound psychological impairments. On the one hand, the Ontario child health study (1987) concluded that this correlation exists. On the other hand two studies cited by Eiser found no such relationship. Eiser goes on to state that there are several studies which show that the least severely affected children tend to be more maladjusted. Wright (1960) feels this may be due to the fact that more severely affected children tend to acknowledge their limitations and realign their value structure accordingly, whereas the children with milder afflictions still try to compete with their non-affected peers. In another study by Garson et al (1978) the authors contend that the parents of children with milder illnesses are seen as needing less support than they might in reality require, and in receiving less support the family is more prone to psychological difficulties. Perrin and MacLean note that distinctions should be made among disease, disability and handicap.

"All chronically ill children have some disease. For some children, the disease causes disability, such as a knee that functions poorly. The disability can become a handicap, preventing the child from participating in certain ...activities... Handicap therefore usually represents an interaction between a disability and the child's physical and social environment" (Perrin and MacLean, 1988).

A more useful concept than trying to correlate severity of disease with severity of impact is to realize that certain children with severe disease will face little handicap, while others with limited disability will face severe handicap. In turn, interventions should be directed towards the individual and the family, not the disease.

The demands of the treatment regimen vary with the illness, but often the impact of these demands can become enormous. From personal communication with patients who have diabetes for instance, it is evident that the necessity to carefully monitor blood sugar levels up to several times a day (each involving jabbing oneself with a lancet), to administer insulin and to follow a selective diet becomes discouraging at best and perhaps impossible at worst. Studies have shown that noncompliance with the treatment regimen can result from such hardships.

Other effects of the disease process include the visibility of the disease, the isolation the disease might bring about (whether because of treatment requirements or, e.g., sensory impairment such as blindness), and pain involved in the disease. Several studies have shown that diseases which are more visible tend to lead to less acceptance of the affected individual by his or her peers. The level of pain engendered by the disorder is felt to correlate directly with maladjustment.

It is generally felt that the younger the child at diagnosis or onset of the illness, the greater the psychological consequences are likely to be. One study (Maddison and Raphael, 1971) suggested that the age of onset was reflected in difficulties with particular Freudian or Eriksonian stages of development (younger children had problems with control, older children with guilt and initiative, and the

oldest with establishment of role and identity, and so on), however there in fact seems to be little evidence for concluding that there is other than a rough correlation between behavioral and intellectual difficulties and age of onset (with greater problems accruing with younger age at diagnosis).

Part of the problem seems to lie with the difficulty in assessing anything like "psychological maladjustment." Most studies tend to deal with either one or a few clinical psychiatric diagnoses or with such measures as school dropout rate or "social adjustment" as defined by the researcher's own instrument. As well done as a piece such as the Ontario Child Health study might be (the authors looked at diagnostic categories for several emotional or behavioral disorders, basing their conclusions on data received from both affected children and their caretakers), even these authors admit that "first, the magnitude of psychosocial risk for such children in the general population is far from clear [and] second, the specific types of mental health problems associated with chronic illness and disability have not been well described" (Cadman et al, 1987). Further, many of the studies regarding children at risk have been based on clinical populations, and there is a vast population of children who don't receive direct psychological services or whose psychological status isn't assessed in the medical clinic setting. Cadman et al state that only 15% of their study population received specialized social or mental health care services.

How is the family likely to react to the diagnosis of a chronic illness, or the birth of a child affected by congenital disease? Only recently has any empirical research been done on the impact that the diagnosis of chronic illness has on the family structure, while considerably more has been done on the parental reactions following the birth of, for instance, a premature infant. Most of such studies have concluded that the parents of premature babies are likely to make less contact with the child, smile at it less, or talk to them less. Some mothers were found to perceive

their infants as still small and weak several months or years after birth when the child had "caught up" to its peers in terms of growth.

It seems that parents of children with chronic illness tend to adopt more restrictive, protective and dominant behaviors towards the affected child than the child's non-affected siblings, with the result that such children tend to be more passive and less directly involved in social interactions than non-affected children. The cycle continues as the parents react to this passive behavior, not with the permissiveness required to allow the child to "open-up," but with yet more restrictive behavior. One early study of twins, one of whom had cerebral palsy (Shere, 1957) found that the mothers were more directive towards the affected child, and that this child became less involved in family decisions. The challenge to strike a balance becomes considerable:

> "For the child to adjust well to an illness or handicap, it is widely recognized that the parent must still make the necessary demands upon the child for appropriate behavior toward peers and siblings, independence training, and developing the ability to tolerate the frustration that accompanies efforts towards academic achievement." (Lavigne and Burns, 1981)

The task becomes one of accepting the child's limitations and not over-reacting to them, while developing the child's other assets.

The difficulty of this task was elicited by Blotcky et al (1985) in a study of 32 pediatric cancer patients and their families. The authors concluded that parental coping strategies were more important in decreasing anxiety and hopelessness among the children than the parents' level of subjective distress. "Two specific patterns of coping for both mothers and fathers were inversely related to feelings of hopelessness in the child, namely, fostering family integration and maintaining self-stability." (Blotcky et al, 1985) They further found that seeking to understand the child's medical condition was related to a decreased level of subjective level of

distress in the parents, but not significantly related to the child's adjustment. It would seem that behaviors which are aimed at fostering family integration might be of benefit to the child, but not decrease distress in the parents, while medical information seeking might have the opposite effect. The need to move back and forth between such coping behaviors lends to the difficulty in achieving effective coping by parents.

In what ways do the children afflicted with chronic illness respond to these various pressures? Affected children often score higher on tests of anxiety than non-affected children. This is perhaps related to the level of anxiety expressed in parents and significant others. Kew (1975) has noted that young children have "limited resources for coping with frightening or threatening experiences." Children may turn to parents for guidance or protection, and it is from them that children learn what is to be feared and not feared, and what are appropriate or inappropriate reactions to such experiences. A child might react with the anxiety expressed by the parents towards the child itself and the illness; alternatively, the child may react to perceived anxiety and stress in the parents by distancing himself or herself from the parents, as if to protect them.

Spinetta, Rigler and Karon (1974) looked at how such feelings of anxiety might affect be reflected in the child's dealings with significant adults. Children were given a doll which was to represent significant others and were asked to place the doll with another doll representing the child into a model of a hospital room. Children with leukemia placed the doll farther away from the "self" doll than did children with non-fatal illnesses. They reasoned that children with fatal illnesses anticipate their own deaths by progressively placing more emotional distance between themselves and their significant others (not only parents, but doctors, nurses, siblings, etc). It seems at least intuitively obvious that younger children, who

23

are liable to believe in immanent justice or whose health and illness concepts may simply be less sophisticated, would be more apt to adopt such behaviors. However, I was not able to locate any data which addressed these issues as they relate to level of cognitive development.

A child's level of cognitive development generally and of perception of illness in particular may affect their attitude towards their disease. Matus et al (1978) found that, among children with asthma, younger children, who would tend to have magical beliefs about illness, had feelings of helplessness and passivity, whereas older children were able to associate increased levels of activity with exacerbation of the disease. If a younger patient feels that illness is a punishment for misbehavior, then it follows that the child might conclude that the way to get better is to start behaving. The child would then try to accept the treatment or "punishment" as directed by an adult authority figure, the result being a further feeling of helplessness. With similar reasoning, however, the child might conclude that the severity of the illness should be minimized in the hope of avoiding further punishment for having been "bad."

Children at a concrete operational level have begun to develop a slightly more sophisticated picture of illness and its cause. However, they tend to view all illness as being contagious, and run the risk of becoming social isolates as a result. Children at this stage are beginning to develop a sense of control over their own health, and may thus question aspects of the care which do not make sense with regard to their as yet limited understanding of bodily processes. This was the case with the child who had cellulitis about whom I reported earlier.

At the formal operational level, one might expect that the child is fully cognizant of all of the factors relating to disease treatment and would consequently be an ideal patient in terms of adherence to treatment regimens. In fact, these are

among the most difficult patients, because having just learned the concept of self-determination and illness prevention, the child is forced to face the fact that who gets ill is quite often a random occurrence. It is at this stage that individual differences in level of understanding and other variables become especially relevant to treatment. One such factor is the perceived locus of control over the disease.

Health Locus of Control (HLOC) is defined by Carraccio, McCormick and Weller (1987) as "an individual's belief system, from external to internal control, reflecting the degree to which the individual believes that his or her health is determined by fate and powerful other persons or by his or her own actions, respectively." It has been argued that those with an internal locus of control (who perceive themselves as having control over the course of their illness and the state of their health) would be more receptive to communication regarding their illness, would have better knowledge regarding their health condition, would be motivated to improve their health and "might even, through their own efforts, be less susceptible to physical and psychological dysfunction" (Strickland, 1978). Does the fact of having a chronic illness influence a child's locus of control? If so, does that have implications for how the child will cope with, or fail to cope with the illness? Several early studies seem to provide evidence that chronic illness or handicap is associated with a more external HLOC, however the results tend to be inconclusive, and conflicting results have been obtained. Carraccio et al, assessing HLOC in 85 healthy and 81 children with chronic illness found that the data "did not support an experiential effect of chronic illness on HLOC" (1987). Part of the controversy may be explained by considering the differences in diseases and the amount of dependency on others which a given illness may require. Some diseases allow for much more individual control by the patient than others. Carraccio et al looked at children with spina bifida and other children from a rheumatology clinic. Generally, children with such diseases will not have a great deal of control over the course of

their illness in any case. By contrast, Moffat and Pless (1983) found that, among children with diabetes attending a three-week diabetic "camp" that the camp experience shifted the HLOC in the direction of more internal control. With diabetes in particular, self-management and good biological control is important in preventing diabetic complications, and it is felt that such behaviors are likely to be enhanced if the patient believes he or she has some control over the course of the disease. For the teenage patient just coming to grips with the arbitrary nature of diseases and the loss of control this new fact implies, being able to develop or strengthen an internal locus of control may be critical in disease management.

Non-affected Siblings

Just as the individual with a handicap, disability or chronic illness is faced with numerous challenges to his or her psychological well-being, so too are the affected child's non-affected siblings unusually challenged. Among the feelings common to these children are those of embarrassment, identification, fear, guilt, loneliness, sorrow, frustration, rage and confusion, experienced for reasons that will be explored shortly. One might be tempted to say that a child in such a position would have a greater chance of experiencing certain types of psychological maladjustment, due to such things as the disproportionate attention paid to the affected sibling, than would a child from a family not so affected. In fact the literature is not so clear on this point. An early study by Keller (1953) looked at children divided into two groups depending on whether they were making "satisfactory" or "unsatisfactory" progress. In the latter group numbers of children with asthma, hay fever, heart disease and so on were significantly greater than in the former group (from Eiser). The demands of caring for the affected child in as normal a psychological atmosphere as possible may place tremendous strain on

sibling relationships (Willis, Elliott and Jay, 1983) and in turn on the child with the affliction.

One thing which becomes evident is that non-affected siblings from special families are, in effect, living in a world of two cultures--that of the family and that of their peers outside of the family. Within the family, special attention is paid to the sick child and extra duties may be required of all family members. The healthy child may willingly take part in the extra tasks, and in the care of his or her sibling. The child may feel a special responsibility towards the affected sibling, or may resent the special position of this child and the demands imposed upon the family.

In any case, the healthy child recognizes that his or her sibling is a part of the family and at least nominally comes to terms with this new family status. Other children outside of the family will likely not see things in the same way. "Guilt by association" is sometimes ascribed to by young children, leading to ostracism of a child whose sibling has a disability or handicap. This is how Victoria Hayden related her experience with such attitudes: (from "A Difference in the Family"):

> Mindy's "differentness" rubbed off on me in the eyes of my playmates. I was the sister of "that deaf kid." I was often excluded from neighborhood games because of my sidekick.

Such reactions from one's friends could conceivably set up strongly conflicting emotions in a child such as Victoria. At once feeling protective and resentful towards her sibling, she had this to say:

> They often did mock her, of course, and we would leave-- except for one time which to this day gives my conscience no rest, when I joined in.

These children, then, have conflicting loyalties regarding their siblings. This may result in anger at the sibling for being who they are, at themselves for their own

perceived disloyalties, and generally at the whole world for being put in what is for them such an unendurable situation.

Another closely related area is the amount of responsibility towards their affected sibling these children are expected to assume. In some families they are expected to assume much more adult roles than their peers, and to demonstrate a much more mature level of understanding and tolerance as well. In a study from 1959, Farber reported that younger siblings of retarded children often assumed the role of an older sibling, and that female siblings were at times obliged to assume the role of surrogate mother. It appears that female siblings often assume a greater portion of such "surrogate parent" duties. Stoneman et al (1987) observed mentally retarded children and their older same-sex siblings and evaluated the types of interactions which were present. the authors concluded that there was accentuation of the role asymmetries often seen between siblings. More managing type behavior by the older siblings was demonstrated (while the affected child was less compliant withthe managing thanwere control children). The authors then went on to say that "older sisters in both sibling groups were more likely to assume managing/guidance and teacher/helper roles than were older brothers," with older sisters or retarded children being "almost four times as likely to assume teacher/helper roles as older comparison sisters." Once again this has the potential for setting up conflicting emotions. While it might please the child to be treated as an adult, or to be privilege to adult information and discussions, such responsibility may also weigh heavily. Fortunately, one response open to children and not to their parents is to briefly shed this responsibility and return to the child's world.

One aspect of the child's world which is actually more of an encumbrance is that of the child's view of handicap or disability from the standpoint of their level of cognitive development. As mentioned previously young children often see illness in

terms of immanent justice and contagion. In practical terms, this means that they may wonder if they will catch the particular illness or handicap of their sibling, or may wonder if their own good health has been bought at the expense of that of their sibling. Such confusing feelings may not be easy for the child to discuss openly, even in a family with fairly good communication. For instance, Helen Featherstone has said: "A mild or ambiguous handicap may go unlabeled or even unacknowledged. The sense that an important subject is taboo--and the anger that comes with such a realization--cuts children off from their parents..." In a family not conversant with the theories of cognitive development (and I would hazard to say that most will not be) explanations of a child's illness or disability may be couched in terminology too sophisticated for a sibling to understand. A child working from the reference point of contagion may not be easily convinced that the illness of the sibling will not physically affect him or her. Furthermore, parents who are focused on the needs and treatment of the affected child may not recognize when they are not attending to the psychological needs of their other children.

There are other ways in which children are cut off from their parents as well. At the same time the child may be experiencing confusing emotions of anger, embarrassment and repulsion towards his or her sibling, the child is witness to strangers who express these feelings, and to the parents' often negative reaction towards such people. The child is thus doubly inhibited; he or she hesitates to express inner feelings for fear of parental reproach, and also to "shield" parents from perceived vulnerability and sensitivity regarding such feelings.

One of the stages common to childhood which has an enhanced impact for siblings of children with a difference is that of conformity. Children become acutely aware of any differences between themselves and others, and actively eschew them. Even in a home not encumbered by a child with chronic illness, evidence of

differences between the child's own family and that of others is likely to engender intense feelings of embarrassment. In a family where the difference is the relatively more consequential one of handicap or chronic illness, the feelings in turn may be all the more powerful. It seems, as Featherstone suggests, that there is an element of identification in such feelings. She cites a study by Grossman (1972) wherein college students with a retarded sibling of the same sex reported more embarrassment than those with siblings of the opposite sex. Featherstone says: "This makes sense, and it reminds us that children resemble the handicapped child more than parents do--and identify with him (sic) in a special way." I would also note that children resemble the handicapped child more than they resemble their parents, another setup for embarrassment. Society reinforces the identification, by generalizing from the particular child to the general family. "Carol Michaelis bitterly recalls the woman who refused to believe that her son the Little League star could have a retarded brother" (From Featherstone, p. 148, quoting Michaelis, 1974).

Kids have many of same feelings as adults, but because of their different status in the family, problems may loom larger. For instance, children don't have the same perspective as their parents, or the same coping strategies (such as recognition of a confused state, the ability to seek help and information, a more mature initial level of understanding, etc [note here the developmental and cognitive levels, body image, and how they tie in!]). The following passage from "A Difference.." is telling, in which Elizabeth Pieper whose son cannot walk recalls an incident with her daughter:

> "I hate him," she announced with deep anger. "Who?" I asked. "I hate him. I can't help it...I hate God. He made my brother crippled." As I fumbled to clarify our theology, I fervently regretted having sent her to Sunday School where she learned that human sin caused imperfection, and that imperfection is a symbol of sin.

If it took great effort for the daughter to confess these feelings, imagine the emotional baggage she carries around of which she is unable to unburden herself. In addition, much of the information which reaches the unaffected children may be second hand, or filtered through their parents' censorship. Most of these confusions might be cleared up with the deeper understanding available to an adult.

Coping with Chronic Illness

Clearly the presence of a chronic childhood illness will have significant psychological impact. Whether such an occurrence will be debilitating to the family structure and to the psychological health of the other children may depend in part on the ways in which such families are able to cope with psychological stress. Several studies at which I've looked have come to the conclusion that, in general, although children with chronic illness and their families are at increased risk psychologically, most families tend to cope reasonably well with the illness and its impact on the family (kupst et al, 1984; Perrin et al, 1987; Morrow, Carpenter and Hoagland, 1984). Featherstone points out that "a handicap inevitably changes the experience of each child in the family, but exceptional families offer normalchildren unusual opportunities as well as unusual problems" (1980). Some of the "opportunities" include an increased tolerance for people who are different, a less casual acceptance of one's own good health and perhaps an increased sense of the family bond. What is it that makes a similar situation a liability for one family and an asset for another?

Cassel (1982) came up with four working principles for the family of an ill child. 1) The family needs to retain or regain a sense of control. This can be accomplished in part with the sharing by professionals of information regarding treatment, prognosis, management programs and so forth of children with similar illnesses. 2) The parents need to understand that their affected child is in many

31

ways more similar to his or her peers than dissimilar, and that their role as parents is still paramount. 3) Having a particular diagnosis is very helpful in defining the scope of the problem. Other studies have shown that maladjustment in siblings can be more common in families in which an actual diagnosis was never made. The roles, status and expectations of all of the children are left in doubt in such situations. In addition, having a diagnosis allows forming a specific plan of. treatment and discussion of the impact of the particular disease as it applies to a articular family. 4) The family must have access to hope. Without hope, whether it be for a cure or simply an end to suffering, there is no future.

The Daniels article cited earlier had several conclusions regarding which factors seemed to decrease the risk of psychological disturbance in both children with disease and their healthy siblings. The authors found that better parental functioning in general, decreased family stressors (as measured by the Health and Daily Living form, Moos et al, 1984), and increased family resources (measures of cohesion, expressiveness and conflict) were all important in this regard. However, these conclusions were based on a population of children with rheumatic disease; the authors note from a study by Steinhausen et al (1983) that "variation in family function may be more important in less severe diseases."

Kupst et al (1984) in a follow-up study of leukemia patients and their families noted a wide variety of coping mechanisms. They found that the child's age was not related to coping, nor were the previous course of the illness or the current medical status. Somewhat surprisingly perhaps, they found "no significant differences in coping...between families whose children were alive and well, those who were not well, and those who had died" (Kupst et al, 1984). Among factors significantly related to positive coping by the family were a solid marital/family relationship,

open communication within the family, the absence of additional stresses, and an adequate support mechanism.

Social support from spouses, friends, and relatives can be a key factor for positive psychological adjustment (Morrow, Carpenter, Hoagland, 1984). It appears to be the quality of the support which is of importance, not the absolute quantity. The problem appears to be that, while most friends, relatives, etc. are capable of and willing to be supportive in the initial period following the birth of an ill child or the diagnosis of one, many will find it difficult or impossible to maintain that level of commitment for the many years a child may be ill.

There seem to be a number of more addressable factors that influence how well siblings cope with the presence of chronic illness. For instance, Grossman (1972) found that socio-economic status (SES) affected children and families differently. Children from families of higher SES tended to focus on the emotional impact of the illness, while those from working class families were more frequently constricted in their concerns to such practical considerations as the increased responsibility for care of the affected child. Among college students, males from higher SES seemed to be functioning better if their sibling had a more severe and visible illness, while females from the working class were functioning less well. The thinking is that the more severe illness made a specific diagnosis more likely. As discussed previously, having a diagnosis may reduce the psychological stress of the illness by clarifying roles and allowing formulation of realistic objectives. Moreover the author felt that traditional sex roles were placing an increased share of the responsibility for care on the working class female siblings and less on the upper class males.

Each particular child is apt to view himself or herself against the backdrop of the families expectations, and learn to live with them. One family may value

emotional insight and support of one another; the children learn to find the strengths in their sibling's condition and to turn to each other for support. Another family may hold religious tenets quite highly, and the children simply accept the affected child. Yet another family may place importance on the practical aspects of responsibility for care, so that the children are able to feel pride in accomplishment as their affected sibling makes gains in development.

It is clear that the possibility of psychological maladjustment for children with chronic illness and their siblings and families exists. Whether it is desirable to caution all parents in this regard is less clear. Doing so may only serve to increase anxiety, and as it has been pointed out, most families seem to cope well in any case. As it is not possible ahead of time to identify families or children who will incur the greatest maladjustment, it does not seem appropriate to burden all families with the possibility that their children may suffer difficulties beyond the physical ones of the disease or disability. Perhaps what is required is an increased awareness on the part of caretakers of such risks. By making themselves informed of the far-reaching consequences of chronic illness, members of the health care team may be better able to disseminate needed information in an age and developmentally appropriate fashion.

Part of a child's strength comes from the ability of children to change. Many of the problems of understanding discussed previously will tend to dissipate as the child grows psychologically. Properly guided by their parents, a child will abandon the notion of immanent justice. The confusion of the younger child regarding biological functioning is overcome with continued cognitive development. The self-centeredness of the pre-operational child gives way to the increased sensitivity of more advanced stages. The process may continue on into adulthood, where a more mature understanding of their childhood situation may allow some children to

overcome long held angers and jealousies. One possible means of helping to effect these changes entails the use of reading materials to allow children to explore in a non-threatening way some of the strong feelings arising in the presence of chronic illness.

Bibliotherapy

The use of books to bring about changes in emotional thought, attitudes and even behavior dates to the creation of literature itself. In thinking of the great oral traditions of literature, one can readily imagine the stories, legends and myths created in small communities and passed on to others as the heritage of a culture. Information, mores, customs and taboos were all expressed in stories and later in books. The ancient Greeks structured their tragedies specifically to induce catharsis in their audiences and viewed their libraries as storehouses for "medicine for the soul." By 1272 readings from The Koran were prescribed as part of the medical treatment for patients in Cairo's Al-Mansur hospital.

Through much of this time the literature provided in hospitals or mental institutions was largely religious in nature. By the eighteenth century in France reforms were beginning to take place in the treatment of the mentally ill. By the first decade of the nineteenth century such reforms were being put into practice in America. Dr. Benjamin Rush was at this time recommending novels and other fiction as well as religious material to sick and mentally ill patients.

The Red Cross during World War I helped to build libraries in Army hospitals. Many of these hospitals later came under the jurisdiction of the Veterans Administration, and much of the literature on bibliotherapy during the 1930's and 40's came from librarians at VA hospitals. One such article was entitled "Book Therapy in Veteran's Hospitals" by Elizabeth Pomeroy. At the time the view was

that the hospital librarian's function was to assist the physician in the healing process, to "use her equipment to aid the physician in the recovery of his patient." (Sourcebook, p.6). Sexual stereotypes aside, Pomeroy was at least on the right track. At the time, however less attention was paid to the content of books than to the actual process of reading. The author talks of arousing the patient's interest, and that having done so the patient "is going to be a more contented patient and therefore more amenable to treatment than he was before." (p.7)

The field of bibliotherapy got its largest impetus in the 1930's. Over 60 articles were written about the subject in this decade, 63% of which were written outside the field of library science (Using Bibliotherapy, p 14). One of the classic articles was written by William Menninger responding to what he saw as a "widespread demand by the laity for books dealing with personality formation, structure, and adjustment" (Bibliotherapy, p264). William's brother Karl had written one of the more popular books, a presentation of the field of psychiatry, and had received in turn several hundred letters which ran roughly eight to one in favor of the book.

W. Menninger saw the purpose of bibliotherapy as being threefold. The first purpose was education, primarily of psychiatric patients, "to establish or to assist the patient in maintaining contacts with external reality, and to gain insight into the nature of his problem. Recreation and reading as a from of gratification was the second purpose of bibliotherapy, and the third was "to help the individual identify himself with the social group. Menninger hit on what seems to be a central tenet of bibliotherapy, that "the most common therapeutic benefit...is derived by "identification of the patient with some particular character or experience in the book with a subsequent {release of a repressed} emotion." (p 269) The thought is that the person reading the material gains relief from realizing that one is not alone

or unique in the types of problems or feelings one has. The person is also felt to "project" his or her own traits (usually negative) onto a character in the story, again gaining a level of "relief" from the vicarious expression of the emotion or attitude.

Therapeutic benefit could also be obtained (Menninger felt) when the patient made comparisons between the author's inclinations and his or her own; adopting such ideas then allowed the patient to gain beneficial results. Fantasy expression obtained especially from works of fiction could also give the patient "narcissistic gratification," as could attempts at maintaining a sense of reality seen inindividual

who read newspapers or magazines.

Menninger went on to describe several other benefits he felt accrued from the simple act of reading. Interestingly enough, he felt that religious material tended to be more detrimental than beneficial, which represented a marked departure from the relatively recent practice of having on hand only religious materials. .

The actual term "bibliotherapy" was coined by Samuel Crothers in an article in the Atlantic Monthly in 1916, and comes simply from the Greek words for book and attending or treating. According to Webster's Third International Dictionary, bibliotherapy is defined in terms of medicine and psychiatry, seeing it as a "therapeutic adjuvant" to those fields much as Menninger must have. I would take a broader view, allowing that anyone may select and use books in this fashion. The Dictionary of Education takes this view as well, defining bibliotherapy as the "use of books to influence total development, a process of interaction between the reader and literature which is used for personality assessment, adjustment, growth, clinical and mental hygiene purposes." Murphy (1972) sees books as a means of

"establishing rapport, as an aid for emotional growth, as a source of security and credibility, as recreation, and as and aid to problem solving." In "Reading Therapy" Clark and Bostle explain the two common views of bibliotherapy, the clinical and the developmental. They cite the definitions of each given by Clara Lack, Librarian at St Elizabeth's Hospital in Washington D.C.: clinical reading therapy is "a mode of intervention in aiding persons severely troubled with emotional or behavioural problems" and developmental reading therapy is "the personalisation (sic) of literature for the purpose of meeting normal ongoing life tasks." I think an intermediate view is possible, wherein bibliotherapy is used to navigate the rough emotional waters associated with the presence of chronic illness so that such "normal ongoing life tasks" can be realized. These conceptions of the uses of literature seem more unrestricted than Webster's, the premise being that every time one picks and reads a book one is engaging in a form of bibliotherapy, whether purposeful or accidental.

Caroline Shrodes' doctoral dissertation, written in 1949, remains today one of the fundamental theoretical works in bibliotherapy. She felt that reading, "like all other human behavior, is a function of the total personality." To the extent that a reader participates emotionally in the situations presented in the reading material those experiences become a part of the reader's psychological makeup. Just how much the reader gained from the reading is a product of several factors including the persons needs and goals, the coping mechanisms of the person and, according to Shrodes, "the neural processes in the brain."

Shrodes had a unique view regarding the nature of the interactive process between reader and reading material. She related the human organism to a system of energy rather than a machine, and thought that as such it was reactive with its environment; in this way "energy may be displaced on a character by means of which

his traits may be incorporated by the reader." This process applied as well to situations, experiences, portrayals of friendships, reflections of moods and so on. The change effected may be adaptive, allowing for further pursuit of goals or creation of new goals for the reader. Shrodes saw the process of encountering literature as one of symbolization "whereby the symbol becomes interchanged with actual experience by means of a transfer of affect from the total situation to the symbol of it." (Shrodes, 1949) Insofar as one is limited in how successfully one can evoke the affective response of the actual experience since memory seems to function "largely in terms of recalling stereotyped and conventional schemata of experiences," this substitution of a symbolic literary representation may by virtue of its directness allow the reader to reclaim something of the actual experience. This would then allow "a reorganization of the perceptual field...preparing the way for a change in the self concept." (Shrodes, 1949) Furthermore, the reader is able to enter this symbolic realm and move about there more easily than he or she might be able to in similar real life situations. This concept fits well with the developmental psychology model, in which, to sum up again, "people respond to the environment by first forming some sort of image or interpretation which becomes the first step in the chain of events leading from the stimulus to the response" (Skolnick, 1986). Shrodes felt that people tend to become so enmeshed in their own problems and "membership groups" that they are unable to view them objectively or perceive the meaning such things hold for them. By the use of literature, where there is no immediate compulsion to act, "man's evaluative and critical faculties may be exercised under the impact of strong emotion detached from personal involvement."

One could label this process as "improving the capacity to respond." Arleen McCarty Hynes and Mary Hynes-Berry, in their book entitled "Bibliotherapy--The Interactive Process" (1986), feel that when morale is low, the "range of interests outside the worry cycle is low." They authors go on to say that bibliotherapy can

help by stimulating thoughts and imagination and engaging the reader in something outside of the self. It is the response that is important, for it is in this way that the reader is able to recognize and understand his or her own feelings. For some readers, the authors feel, "the expression of ordinary feelings will be an achievement" which can become the first step in coping with a previously unacknowledged aspect of the reader's life. This would have practical application for the child affected either directly or indirectly by chronic illness if the child has been repressing any of the strong emotions which he or she might be experiencing.

Using books in this manner for children has some obvious constraints. First, their fluency and attraction to books will vary. This is especially significant for children who are developmentally disabled or who have a physical disability which disallows the use of reading materials. However, for those not so hindered, and for siblings in particular, books which explore some aspects of health and illness and the attendant feelings may be just what it takes to generate an interest in reading. Secondly, "the children's stage of conceptual development and experience affects understanding of what is read by or to them" (Clark and Bostle, 1988). For this reason the choice or the creation of literature for children must take into account their developmental level. Once again, detailed explanations of physiological processes and "psychophysiological" mechansims of disease may not be appropriate for younger children, nor conversely would the use of fantasy be necessarily appropriate for children at the concrete operational level.

In this discussion of bibliotherapy, I have envisioned the use of reading material in a casual or accidental setting such as would be found in the home setting, rather than a more structured "group therapy" session. Some treatises on bibliotherapy assume the latter to be the typical approach, however I am proceeding on the premise that most children, especially the siblings of affected children, will

not be so disturbed psychologically as to end up in an institutional environment. Rather these children are likely to cope reasonably well without any intervention, but the accidental selection of books dealing with chronic illness and disability may make the passage less traumatic. Alternatively, parents concerned with the emotional well being of their children may acquaint themselves with the available literature and gently guide the reading choices of the children appropriately.

Review of Current Literature and Author's Works

Such sentiment as expressed by Caroline Shrodes regarding the use of one's "critical and evaluative faculties" resonates strongly with my own feelings regarding the use of creative literature for children. It is useful first to look at some popular children' literature which deal with issues of general importance to young people before concentrating on books which deal with health specifically. With notable exceptions such as "Huckleberry Finn" or "The Tale of Peter Rabbit," many books for children "are still populated by children who eat everything on their plates, go dutifully to bed at the proper hour, and learn all sorts of useful facts or moral lessons" (Hentoff, 1966). A quick recall of the main characters in the books mentioned above and a number of others of which the reader is likely to know reveals that these characters are not homogenized and dull. They have strong feelings, and may be angry, frightened, confused or even somewhat rebellious. More recently books for children have begun to reflect the realization that children are not without such emotions. A growing number of works can be found in which the author has taken this into account. One of the most well known and successful among these authors is Maurice Sendak.

Sendak's "dream series" stories portray a child's strong feelings regarding parental authority, childhood fears of abandonment and similar issues in a manner at once accessible and deeply moving for children. This is seen most clearly in

41

"Where the Wild Things Are," the first written and probably best known of this group of stories. Sendak does not believe that childhood is a time of absolute innocence, and the children who populate his books are often troubled, lonely, unruly, stubborn and liable at times to move into and out of fantasy realms easily. In "Wild Things" the child protagonist Max dons a wolf suit and defies his mother's authority. He is sent to bed without supper and "That very night in Max's room a forest grew." The adult reader will understand this to be a dream sequence, while the child reader will be more likely to simply accept the transition to fantasy without comment. This fluidity of reality is quite acceptable to young children who, if the reader will recall, have a less clear distinction in their own minds between reality and fantasy.

One of the main themes of "Wild Things" regards the testing of parental authority, and the anger that children are wont to feel towards parents at times. The wild things in the book are meant to represent adults, and in fact some adults have been troubled by the illustrations, feeling that children may be frightened by them. Sendak says of this reaction: "adults who are troubled by [the book] forget that Max is having a fine time. He's in control. And by getting his anger at his mother discharged against the wild things he's able to come back to the real world at peace with himself" (Hentoff, 1966). Sendak says as well that he has never heard of a child who was frightened by the book. This clear illustration of the way in which a piece of children's literature can be used to defuse the strong emotions of a healthy child lead me to think that a similar work which addresses the feelings attending a chronic illness or disability might be equally effective.

While there are a number of books for children which address the topics of death and dying, separation due to divorce, learning to deal with new siblings, new schools, new parents (as with foster children or stepchildren) and even desertion,

42

there are in fact few as yet written which have as their main theme chronic illness or disability. Many which do address health and illness concepts do so from the "medical model" standpoint. They may be written by physicians and tend to lean heavily on scientific explanations of disease processes without acknowledging the possible psychological impact of illness. One such book is "Germs make me sick!" (Donahue and Capellaro, 1975), which at times reads like a junior medical text: "Measles begins like a cold, with a high temperature, red eyes, and a cough. By the fourth or fifth day of the disease..." There is a liberal sprinkling of ponderous Latin medical terms: glomerulonephritis, Lactobacillus acidophilus and antispasmodic are a few examples. The book is interesting from a purely informative angle, but its dry style and textbook format lead me to question how well such a book could hold a child's interest, even a child afflicted with one of the several dozen maladies covered. Absolutely no account is taken of the cognitive level of the child reader and it is conceivable that the descriptions of, for example, the invasiveness of bacteria and viruses would be at best meaningless to a young child and at worst somewhat frightening.

There are a smattering of books for children which deal with the emotional and psychological issues surrounding health and illness. In her comprehensive review entitled "Books to Help Children Cope with Separation and Loss" Joanne Bernstein describes over one hundred books related to the topic of death, but only 13 under the heading of "serious illness." Of these, seven are about the hospitalization of a parent or grandparent. However, two books she cites are of particular interest.

"Hang Tough, Paul Mather" (Slote, 1973) is about a twelve-year-old boy who has leukemia. The boy actually explores the feelings of his own impending death, but in doing so he encounters a number of the intense feelings I have described

earlier, including fear, anger, confusion and loneliness. These are seen in the setting of his relationship to other children as the boy at first tries to function in as normal a fashion as possible and then has to gain permission to pitch at a baseball game as he becomes sicker. The book is thus useful not only for those who might be encountering similar feelings in themselves but for siblings and peers of a child with an illness such as leukemia.

"Ben and Annie" (Tate, 1974) takes a somewhat different tack, focusing more on the isolation of children with chronic illness. Annie is a young girl confined to a wheelchair because of a degenerative muscle disease. When her friend Ben takes her out of the house for some much needed diversion, the two engage in antics which a passerby feels are improper for Annie (he thinks the children's daring exploits with her wheelchair are torturing Annie). The friendship is ended and Annie is returned to the seclusion of her house. The strength of the book lies in the way it illustrates how easily a child's feelings can be misinterpreted by adults not cognizant of a child's point of view. Parents' well-intentioned but misguided efforts to protect a child afflicted with an illness often overlook the fact that an illness which weakens a child's limbs does not mean by default that the child's spirit is similarly dampened. This book illustrates that parents need to be aware of and cultivate the remaining assets of a child so affected and not make the mistake of defining the whole child by the disease.

Suzanna Gretz has written a number of books about a group of teddy bears, with titles such as "Teddy Bears' Moving Day" and "Teddy Bears Go Shopping." These books take a light-hearted look at the process of becoming a social animal. "Teddy Bears Cure a Cold" examines what it's like to be a child with a short-term illness. When one of the bears gets sick, the others are very solicitous and attentive to the sick one's needs. However when the requests change from honey-and-lemon

drinks to banana milkshakes, the other bears realize the illness has run its course and plot to entice the newly recovered bear out of his sick-bed. The story is rather placid and non-threatening, and does a fair job of addressing concerns of illness beyond the physical symptoms. I was pleased to note that, although the author takes pains to suggest that the sick bear has strep throat, the course of action taken was to treat the illness supportively at home rather than rushing off to the hospital to demand antibiotics. The focus was again more on the feelings surrounding the presence of illness in the self or in another. This could conceivably give a child some insight into what he or she might be imposing emotionally on those who are rendering care, or the sibling of such a child a more tolerant and understanding attitude towards the affected child.

The first story I have written, "There Are No Ears on Tom's Teddy Bear," is centered around the idea of the sibling of a child with a hearing impairment. Zack has no ears (he cannot hear), and gets more attention than Tom does as Tom notes that people always comment on Zack's missing ears, but nobody makes similar comment about an aspect of Tom which is different from Zack. Tom is infuriated, ostensibly by Zack's perceived lack of attention. The actual case is that Zack isn't hearing what's going on and Tom is rejecting Zack for this difference. As Tom dreams of Here-N-There, he assumes the role of the different one (he identifies with Zack in a sense) as the creatures of this planet reject him outright, even though at times he demonstrates himself capable of functioning in their world. He becomes frightened and confused by one of the creatures which he cannot understand. When Tom realizes his confusion and the fact that being rejected is worse than anything, he discovers that the creature he did not understand was in fact Zack. Tom has at once been made to feel what it is like to be in Zack's position and what the effect of his rejection of Zack has been. With this realization he "returns" home and now the fact that Zack doesn't say a word is not troublesome to Tom.

I tried in this story to incorporate several of the concepts I have been discussing. Tom's world view and easy acceptance of fantasy are targeted to the child at a preoperational or early concrete operational level, as is the picture book format. Rather than focus on the physical aspects of deafness, I concentrated on the emotional impact of such an affliction. Although children at a preoperational level are supposedly not able to take the other person's point of view, I feel that first this may not be so clear cut as Piaget envisioned and secondly that these stages are fluid enough that even a child at the concrete operational level could appreciate the fantasy aspects. Finally, I tried to write the story in such a way that both children who are deaf and their non-affected siblings could find value in reading the story.

In "The Golden Dragon" I was aiming at a somewhat older audience. (I am not nearly so pleased with this story, but creativity doesn't acknowledge deadlines. It should serve to illustrate similar themes as the previous story, however.) The use of realistic setting and the focus on some of the practical aspects of the disease process are appropriate for an older child, as is the writing style. Children at the concrete operational level are able to manipulate objects in their heads, so I think it is appropriate that Terry is able to use language well enough to write a story. Further, children at this stage have a grasp of the conservation of the physical properties of objects. Beyond being able to judge volumes of water, this ability implies to me that the child reader will be able to grasp the parallels between the real life struggles of Terry and the imagined ones of the island child. This story is also intended to be of use not only to a child with AIDS but to children not so affected, with the thought that insight might be gained by such children into how their unreasoning prejudices affects children with AIDS (actually I'm hoping that such a story will get the parents to thinking about their attitudes, in that it is often the parents who institute such prejudices in the first place).

Summary

The understanding of health and illness by children undergoes change during childhood. Although the cognitive development framework established by Piaget has limitations, it serves to underpin any study of the emotional impact of chronic illness on children. By understanding how a child of a particular age is likely to view the world, one is able to gain insight into the meaning chronic illness in the self or in a sibling may hold for that child. Should the unfortunate circumstance of psychological problems arise, such insight and understanding may help illuminate for an adult caring for the child the genesis of such troubles.

Chronic illness and disability undoubtedly have significant influences on families. In treating such illness it will not be enough to simply treat the physical symptoms. Care must be taken to promote the psychological health of all persons involved. Insuring a truly successful outcome depends on treating the family as the patient. In doing so, the importance of understanding a child's particular level of development becomes evident. One cannot approach the emotionally distraught four-year-old with sophisticated physiological or medical explanations, nor is it appropriate when giving such explanations to the older child to overlook the psychological or emotional component of the illness explanation. Finally, these explanations alone will not insure the avoidance of psychological maladjustments in either child patients or their siblings. The meaning that illness has, and the way such meaning is colored by the developmental level of the child is clearly as important as the simple understanding by the child of the disease process. It is in this final area that bibliotherapy may be most useful.

Bibliotherapy can be thought of in its most simple form as any positive emotional or psychological change occurring in a person upon the reading of virtually any material. In its most clinical form, bibliotherapy can be used in a

therapeutic setting such as guided group discussions. My own focus is on the use of books by children either spontaneously or with slight direction by concerned parents familiar with specific books. In this situation I am not envisioning overnight cures for severely emotionally disturbed children, nor am I supposing that reading alone will insure that children's attitudes will always be the socially desirable ones, whatever they may be. It is my contention that if, as Murphy contends (1972), books can be seen as aids for emotional growth and problem solving, then there is a need in today's rapidly changing medical environment for books which address the potential problems associated with chronic illness and disability. If these books are to be of use, then in addition to their subject matter they must be appropriately targeted to the developmental age of the child audience. My final hope is that the stories which follow accurately reflect some of these criteria.

References

Abramovitch, R., Stanhope, L., Pepler, D., Corter, C. The Influence of Down's Syndrome on Sibling Interaction. Journal of Child Psychology and Psychiatry, 1987; Vol 28, No 6, pp 865-79.

Anthony, E. The Impact of Mental and Physical Illness of Family Life. American Journal of Psychiatry, 1970; Vol 127, pp 138-45.

Auer, E., Senturia, A., Shopper, M. Congenital Heart Disease and Childhood Adjustment. International Journal of Psychiatry in Medicine, 1971; Vol 2, pp 23-30.

Bennett, K. Aids: A Generation of Children at Risk. Journal of Psychosocial Nursing, 1987; Vol 25, No 12, pp 32-34.

Bernstein, J. Books to Help Children Cope with Separation and Loss. R.R. Bowker Company, New York, 1977.

Bibace, R., Walsh, M. Children's Conceptions of Illness. New Directions for Child Development, 1981; No. 14, pp 31-48.

Bibace, R., Walsh, M. Development of Children's Concepts of Illness. Pediatrics, 1980; Vol 66, pp 912-917.

Bibace, R., Walsh, M. "Developmental Stages in Children's Conceptions of Illness." In Stone, G.C., Cohen, F., Adler, N.E., Health Psychology, pp 285-301, Jossey-Bass, 1979.

Binger, C., Ablin, A., Feuerstein, R., Kushner, J., Zoger, S., Mikkelsen, C. Childhood Leukemia: Emotional Impact on Patient and Family. New England Journal of Medicine, 1969; Vol 280, pp 414-18.

Blotcky, A., Raczynske, J., Gurwitch, R., Smith, K. Family Influences on Hoplessness Among Children Early in the Cancer Experience. Journal of Pediatric Psychology, 1985; Vol 10, No 4, pp 479-93.

Breslau, N. Psychiatric Disorder in Children with Disabilities. American Academy of Child Psychiatry, 1985; Vol 24, pp 87-94.

Breslau, N., Weitzman, M, Messenger, K. Psychologic Functioning of Siblings of Disabled Children. Pediatrics, 1981; Vol 67, No 3, pp 344-353.

Burns, W., Lavigne, J., Ed. Progress in Pediatric Psychology. Grune and Stratton, Inc., Harcourt, Brace, Jovanovich, Orlando, 1984.

Burton, L. The Family Life of Sick Children. Routledge & Kegan Paul, 1975.

Cadman, D., Boyle, M., Szatmari, P., Offord, D. Chronic Illness, Disability, and Mental and Social Well-Being: Findings of the Ontario Child Health Study. Pediatrics, 1987; Vol 79 No 5, pp 805-13.

Cairns, N., Clark, G., Smith, S., Lansky, S. Adaptations of Siblings to Childhood Malignancy. Journal of Pediatrics, 1979; Vol 95, pp 484-87.

Campbell, John. Illness is a Point of View: The Development of Children's Concepts of Illness. Child Development, 1975; 46, 92-100.

Carraccio, C., McCormick, M., Weller, S. Chronic Disease: Effect on Health Cognition and Health Locus of Control. The Journal of Pediatrics, 1987; Vol 110, No 6, pp 982-987.

Cassel, E. The Nature of Suffering and the Goals of Medicine. New England Journal of Medicine, 1982; Vol 306, pp 639-45.

Chesler, M., Paris, J., Barbarin, O. "Telling" the Child with Cancer: Parental Choices to Share Information with Ill Children. Journal of Pediatric Psychology, 1986; Vol 11, No 4, pp 497-516.

Cohen, L. Bibliotherapy: Using Literature to Help Children Deal with Difficult Problems. Journal of Psychosocial Nursing, 1987; Vol 25, No 10, pp 20-24.

Crider, C. Children's
Conceptions of the Body Interior. New Directions for Child Development, 1981; No. 14, pp 49-66. Jossey- Bass, San Francisco.

Daniels, D., Moos, R., Billings, A., Miller, J. Psychosocial Risk and Resistance Factors Among Children with Chronic Illness, Healthy Siblings, and Helathy Controls. Journal of Abnormal child Psychology, 1987; Vol 15, No 2, pp 295-308.

Donahue, P., Cappellaro, H. Germs Make Me Sick: A Health Handbook for Kids. Alfred A. Knopf, New York, 1975.

Drotar, Dennis. Psychological Perspectives in Chronic Childhood Illness. Journal of Pediatric Psychology, 1981; Vol 6 No 3, pp 211-228.

Eiser, Christine. The Psychology of Childhood Illness. Springer-Verlag, New York, 1985.

Featherstone, H. A Difference in the Family: Life with a Disabled Child. Basic Books, New York, 1980.

Gates, S. Children's Literature: It Can Help Children Cope with Sibling Rivalry. American Journal of Maternal/Child Nursing, 1980; Vol 5, pp 351-2.

Gayton, W., Friedman, S., Tavormina, J., Tucker, F. Children with Cystic Fibrosis: Psychological Test Findings of Patients, Siblings and Parents. Pediatrics, 1977; Vol 59, pp 888-94.

Gortmaker, L, Sappenfield, W. Chronic Childhood Disorders: Prevalence and Impact. Pediatric Clinics of North America, 1984; Vol 31, pp 3-18.

Green, K., Bird, J. The Structure of Children's Beliefs about Health and Illness. Journal of School Health, 1986; Vol 56, No 8, pp 325-328.

Green, M., Levitt, E. Constriction of Body Image in Children with Congenital Heart Disease. Pediatrics, 1962; Vol 29, pp 438-41.

Gretz, S. Teddy Bears Cure a Cold. Four Winds Press, New York, 1984.

Haight, W., Black, J., DiMatteo, M. Young Children's Understanding of the Social Roles of Physician and Patient. Journal of Pediatric Psychology, 1985; Vol 10, No 1, pp 31-43.

Hentoff, N. "Among the Wild Things," in Only Connect: Readings on Children's Literature. Egoff, S., Ed. Oxford, 1969, pp 323-46.

Kalnins, I., Churchhill, M., Terry, G. Concurrent Stresses in Families with a Leukemic Child. Journal of Pediatric Psychology, 1980; Vol 5, No 1, pp 81-92.

Kew, Stephen. Handicap and Family Crisis. Pitman Publishing, London, 1975.

Kister, M., Patterson, C. Children's Conceptions of the Causes of Illness: Understanding of Contagion and Use of Immanent Justice. Child Development, 1980; Vol 51, pp 839-46.

Kubler-Ross, E., On Death and Dying. New York: MacMillan, 1969.

Kupst, M, et al. Coping with Pediatric Leukemia: A Two-Year Follow-Up. Journal of Pediatric Psychology, 1984; Vol 9, No 2, pp 149-163.

Lask, B. Psychosocial factors in Childhood Diabetes and Seizure Disorders. Pediatrician, 1988; Vol 15, pp 95-101.

Livingston, S. The Physician's Role in Guiding the Epileptic Child and His Parents. American Journal of diseases in Children, 1970; 119, 99-102.

Mattsson, A. Long-term Physical Illness in Childhood: A Challenge to Psychosocial Adaptation. Pediatrics, 1972; Vol 50, 801-11.

Melamed, B. et al, Ed. Child Health Psychology. Lawrence Erlbaum Associates, New Jersey, 1988.

Morrow, G., Carpenter, P., Hoagland, A. The Role of Social Support in Parental Adjustment to Pediatric Cancer. Journal of Pediatric Psychology, 1984; Vol 9, No 3, pp 317-329.

Murphy, D.C. The Therapeutic Value of Children's Literature. Nursing Forum, 1972; Vol 11, pp 141-164.

Murray, Joseph N., McLoughlin, Caven S. Childhood Disorders. Charles C Thomas, Springfield, Ill, 1983.

National Cancer Institute. Coping with Cancer. DHHS publication #80-2080, Washington, D.C., (1980).

Perrin, E. Ramsey, B., Sandler, H. Competent Kids: Children and Adolescents with a Chronic Illness. Child: Care, Health and Development, 1987; Vol 13, pp 13-32.

Perrin, E., Gerrity, P. There's a Demon in Your Belly: Children's Understanding of llness. Pediatrics, 1981; Vol 67 No 6, pp 841-849.

Perrin, James M., MacLean, William E. Children with Chronic Illness. The Pediatric Clinics of North America, 1988; Vol 35, No 6, pp 1325-37.

Pless, I, Roughmann, K. Chronic Illness and its Consequences: Observations Based on Three Epidemiologic Surveys. Journal of Pediatrics, 1979; Vol 79, pp 351-9.

Potter, Patricia C., Roberts, Michael C. Children's Perceptions of Chronic Illness: The Roles of Disease Symptoms, Cognitive Development, and Information. Journal of Pediatric Psychology, 1984; Vol 9, No 1, pp 13-27.

Powell, Thomas H., Ogle, Peggy A. Brothers & Sisters, A Special Part... Paul H. Brookes, Baltimore, London, 1985.

Redpath, C., Rogers, C. Healthy Young Children's Concepts of Hospitals, Medical Personnel, Operations, and Illness. Journal of Pediatric Psychology, 1984; Vol 9 No 1, pp 29-40.

Reynolds, J., Garralda, M., Jameson, R., Postlethwaite, R. How Parents and Families Cope With Chronic Renal Failure. Archives of Disease in Childhood, 1988; Vol 63, pp 821-26.

Rosenbaum, Peter. Prevention of Psychological Problems in Children with Chronic Illness. CMAJ, 1988; Vol 139, pp 293-295.

Rubin, R, ed. Bibliotherapy Sourcebook. Oryx Press, Phoenix, AZ, 1978.

Rubin, R, ed. Using Bibliotherapy: A Guide to Theory and Practice. Oryx Press, Phoenix, AZ, 1978.

Satterwhite, B. Impact of Chronic Illness on Child and Family: An Overview Based on Five Surveys. International Journal of Rehabilitation Resources.

Seligman, Milton. Adaptation of Children to a Chronically Ill or Mentally Handicapped Sibling. CMAJ, 1987; Vol 136, pp 1249-1252.

Sendak, M. Where the Wild Things Are. Harper and Row, 1963.

Showalter, J. "The Child's Reaction to his Own Terminal Illness." Loss and Grief: Psychological Management in Medical Practice. Schoenberg, A. et al, Ed., New York: Columbia University Press, 1970.

Shrodes, C. Bibliotherapy: A Theoretical and Clinical-Experimental Study. Dissertation, U.C. Berkeley, 1950.

Skolnick, A. The Psychology of Human Development. Harcourt Brace Jovanovich, San Diego, 1986.

Slavin, L., O'Malley, J., Koocher, G., Foster, D., Communication of the Cancer Diagnosis to Pediatric Patients: Impact on Long-term Adjustment. American Journal of Psychiatry, 1982; Vol 39, No 2, pp 179-83.

Spinetta, J. Adjustment in Children with Cancer. Journal of Pediatric Psychology, 1974; Vol 2, pp49-51.

Spinetta, J. "Communication Patterns in Families Dealing with Life-threatening Illness." The Child and Death. Sahler, O., Ed, C.V. Mosby, St. Louis, 1978.

Stein, R, Jessop, D. Relationship Between Health Status and Psychological Adjustment among Children with Chronic Conditions. Pediatrics, 1984; Vol 73, pp 169-74.

Steinhausen, H., Schindler, H., Stephan, H. Correlates of Psychopathology in Sick Children: An Empirical Model. Journal of the American Academy of Child Psychiatry, 1983; Vol 22, pp 559-64.

Stoneman, Z., Brody, G., Davis, C., Crapps, J. Childcare Responsibilities, Peer Relations, and Sibling Conflict: Older Siblings of Mentally Retarded Children. American Journal on Mental Retardation, 1988; Vol 93, No 2, pp 174-183.

Stoneman, Z., Brody, G., Davis, C., Crapps, J. Mentally Retarded Children and Their Older Same-Sex Siblings: Naturalistic In-Home Observations. American Journal of Mental Retardation, 1987; Vol 92, No 3, pp 290-298.

Strickland, B. Internal-external expectancies and health-related behaviors. Journal of Consulting and Clinical Psychology, 1978; Vol 46, pp 1192-1211.

Susman, E. et al. Conceptions of Cancer: The Perspectives of Child and Adolescent Patients and Their Families. Journal of Pediatric Psychology, 1982; Vol 7 No 3, pp 253-262.

Thomas, David. The Social Psychology of Childhood Disability. Schocken Books, New York, 1980.

Waechter, E. Children's Awareness of Fatal Illness. American Jounal of Nursing, 1972; Vol 71, pp 1168-72.

Waters, B., Ziegler, J., Hampson, R., McPherson, A. The Psychosocial Consequences of Childhood Infection with Human Immunodeficiency Virus. The Medical Journal of Australia, 1988. Vol 149, pp 198-202.

Westervelt, V., Brantley, J., Ware, W. Changing Children's Attitudes Toward Physically Handicapped Peers: Effects of a Film and Teacher-Led Discussion. Journal of Pediatric Psychology, 1983; Vol 8, No 4, pp 327-343.

Whitt, J., Dykstra, W., Taylor, C. Children's Conceptions of Illness and Cognitive Development. Clinical Pediatrics, 1979; Vol 18 No 6, pp 327-339.

Willis, D.J., Elliott, C.H., & Jay, S.M. Psychological Effects of Physical Illness and its Concomitants. Handbook for the Practice of Pediatric Psychology. Tuma, J.M. Ed., New York: Wiley, 1983.

Appendix 1

The following is the text and rough illustrations for the story "There were no ears on Tom's teddy bear." The formatting is only approximate, and the illustrations are intended to be in color. A discussion of the story is found in the body of the thesis.

There were no ears on Tom's teddy bear
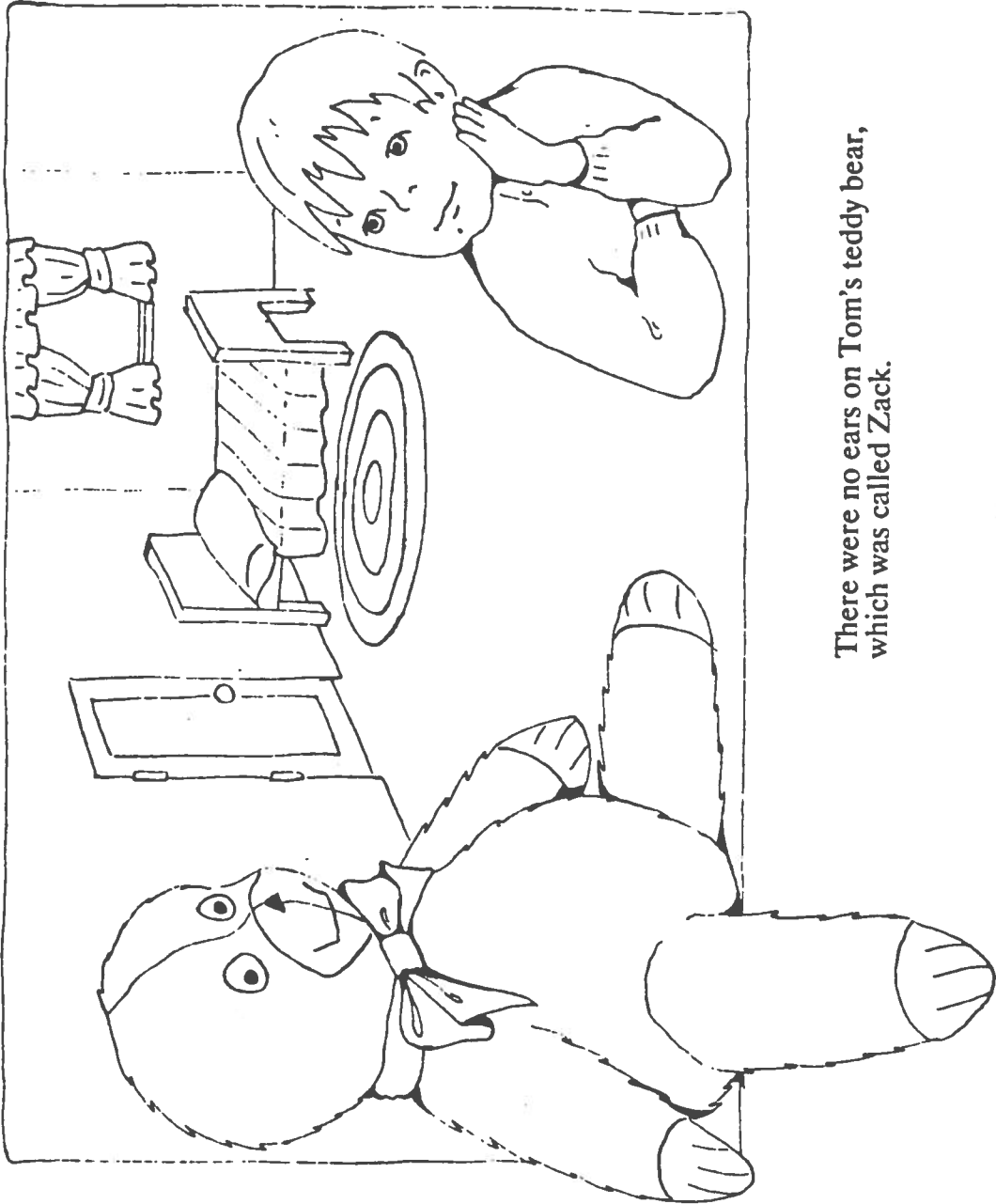
There were no ears on Tom's teddy bear,
which was called Zack.
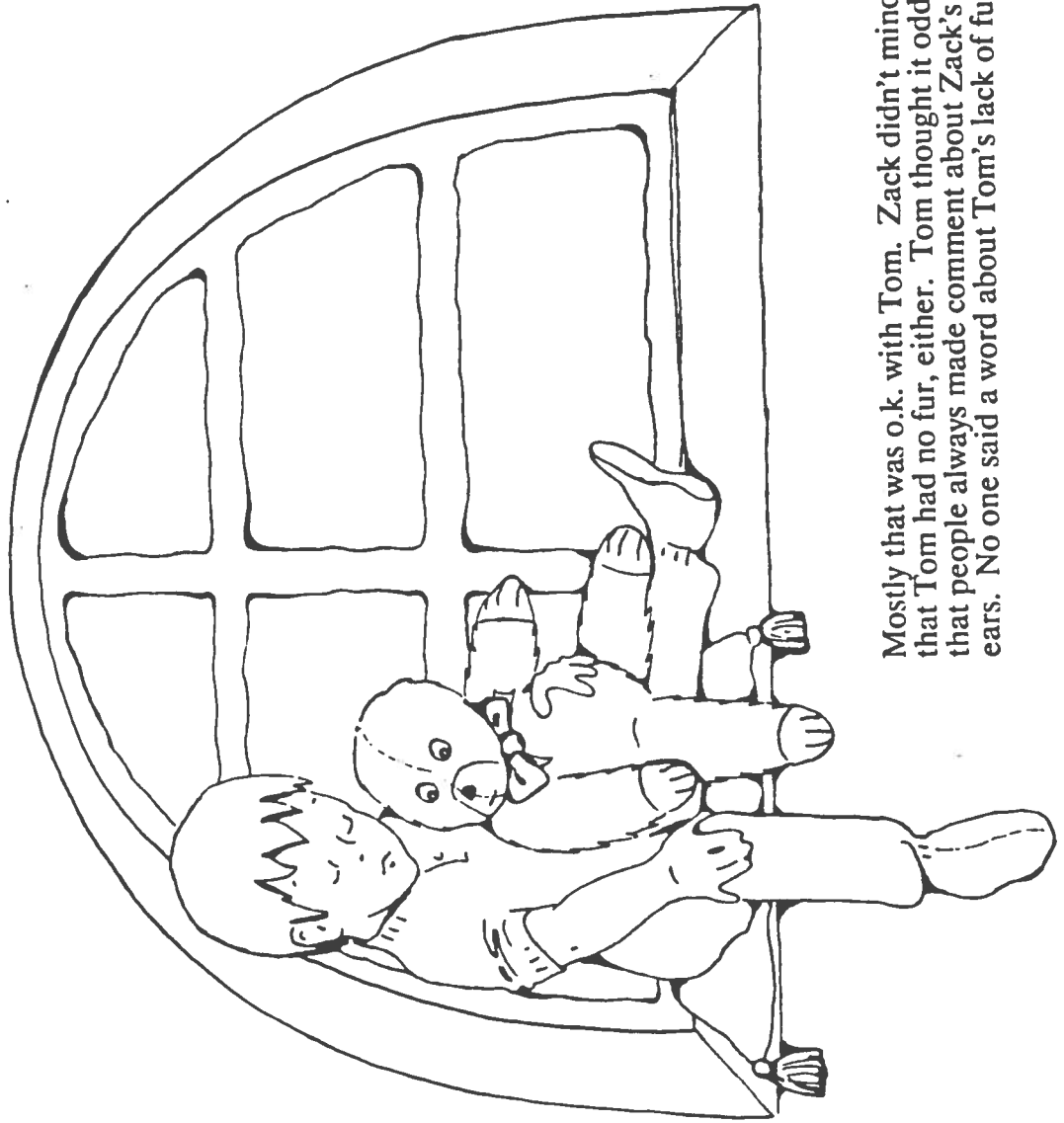
Mostly that was o.k. with Tom. Zack didn't mind that Tom had no fur, either. Tom thought it odd, though, that people always made comment about Zack's missing ears. No one said a word about Tom's lack of fur.

One evening Tom set out all of his animals. He sat them in a circle with Zack, where they all tried to play.
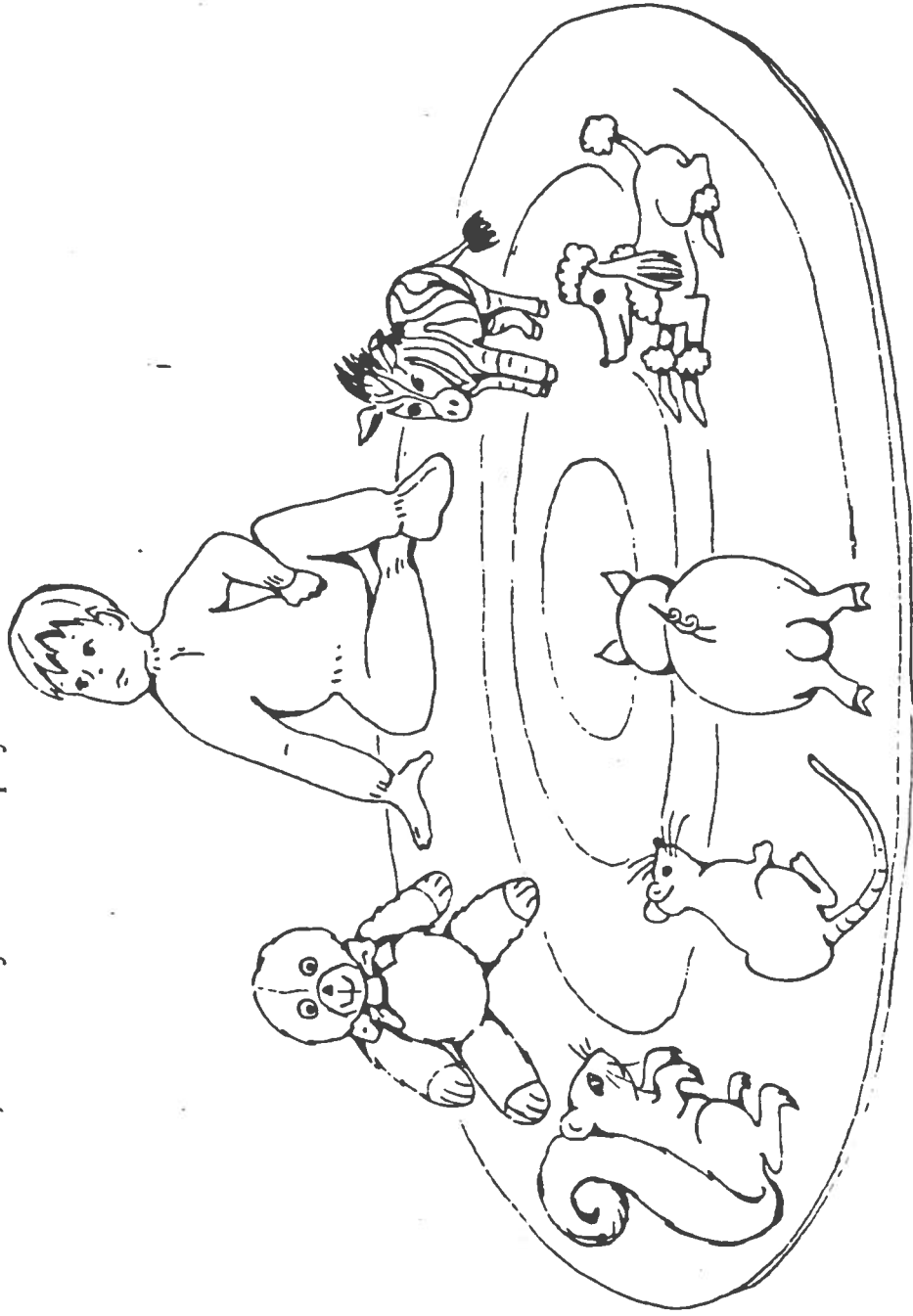
It didn't work out very well. Tom, thought Zack wasn't paying much attention.

v
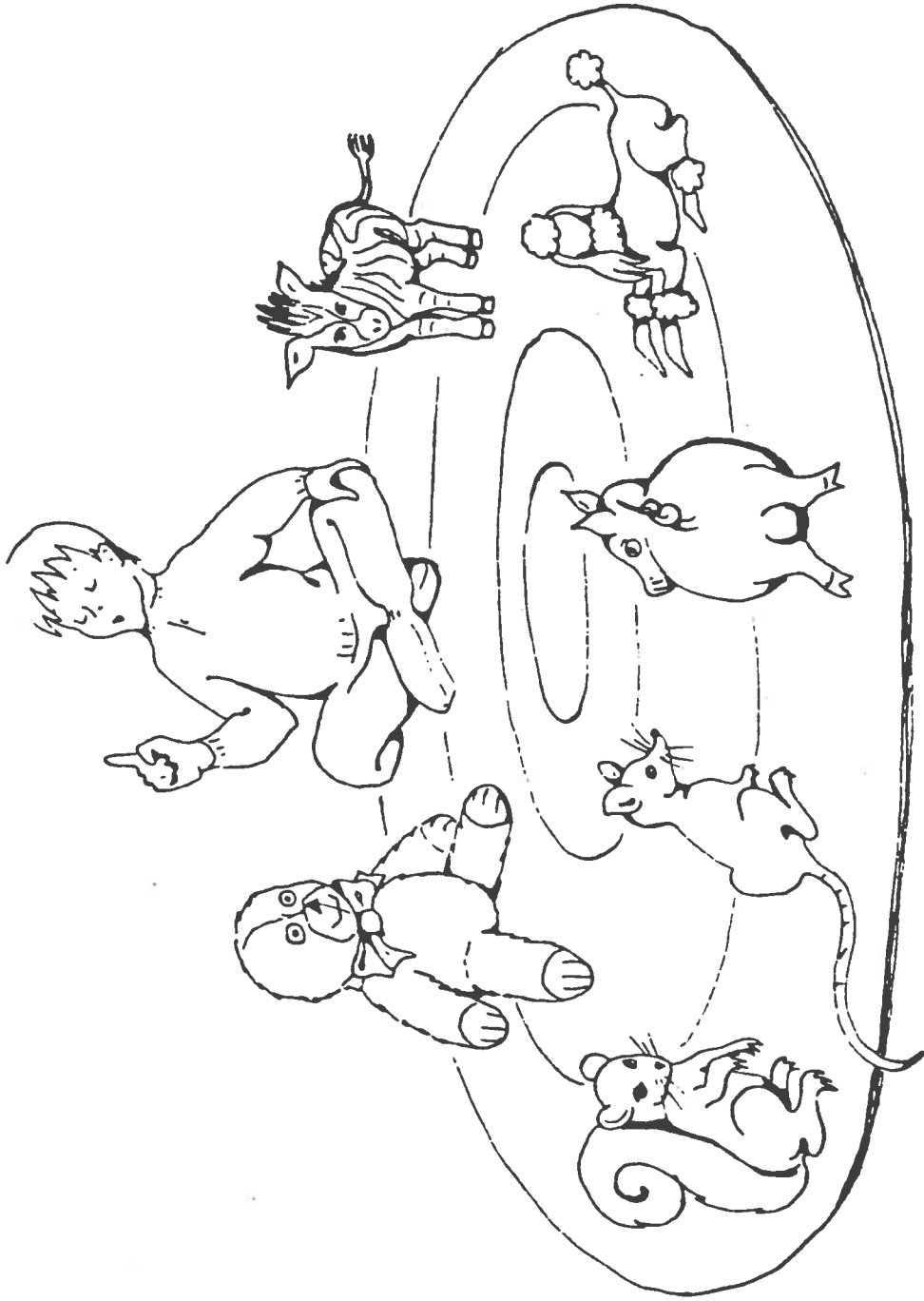
"Zack, what's three times four?" Tom asked his bear.
Zack just sat there, not saying a word.

Tom cried "stupid bear!" and hurled Zack into the corner, where he lay on his head with his feet poking the air.
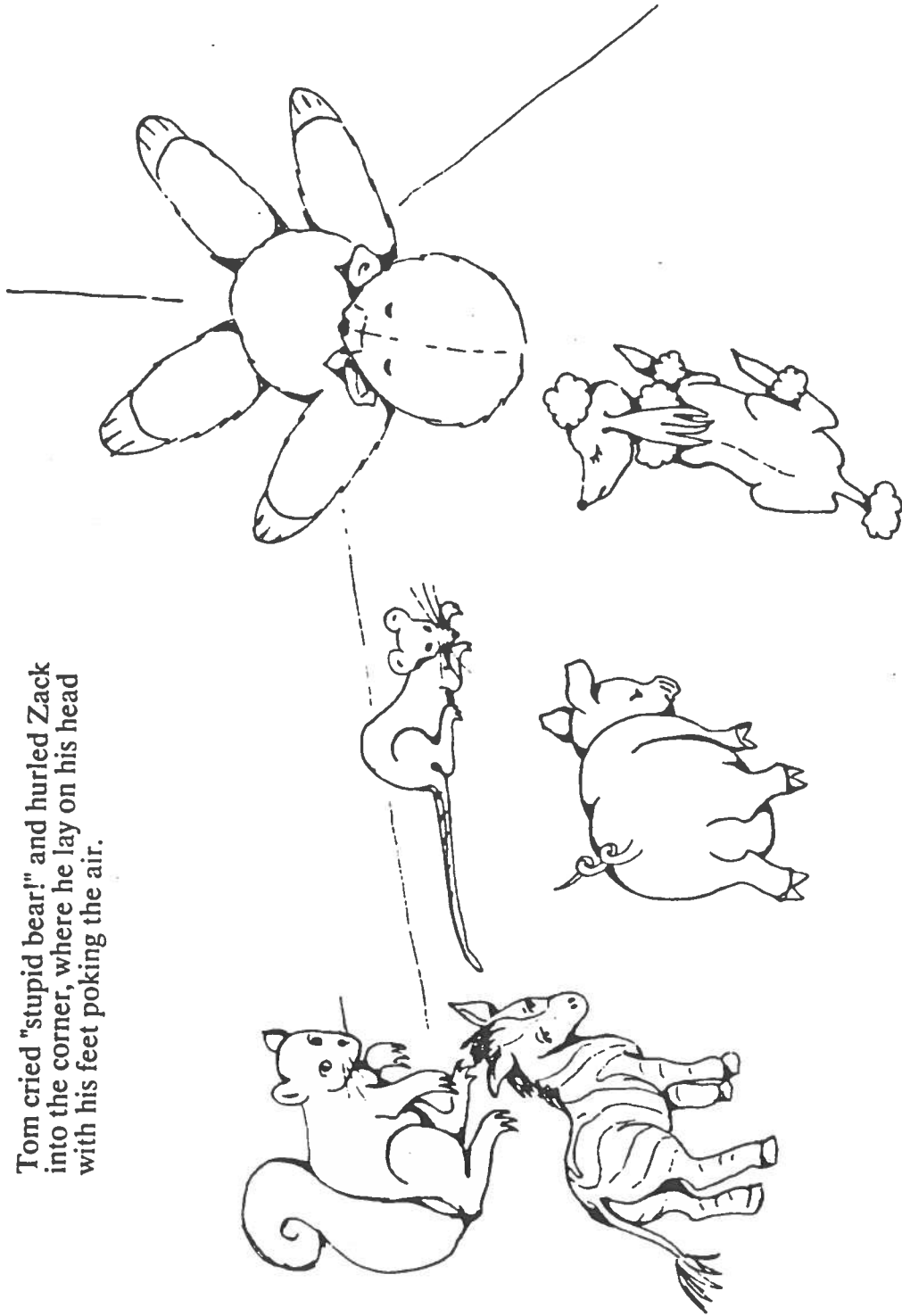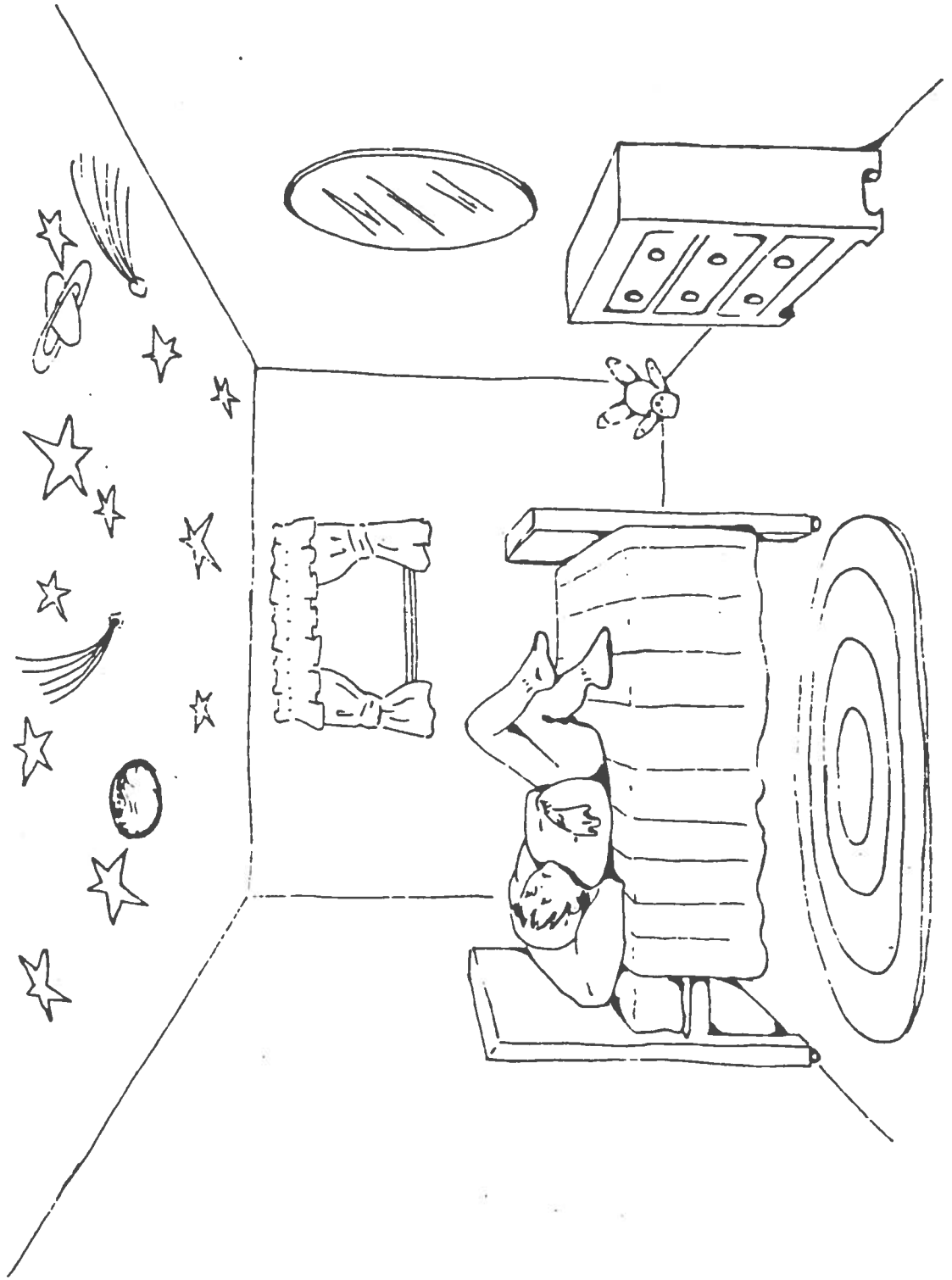
Tom lay on his back with his arms crossed on his chest and looked at the stars painted on his ceiling.

Near one of the stars was a small planet. Tom called it Here-n-there.

When his mother said "Tom, where are you going?" he replied "Here-n-there."

He heard things with loud squeaky voices
and he tried to follow but the things moved away.

When he got there it was nighttime.
Tom couldn't see a thing.

x

When he sat still the things came back close. They said
"Tom go away, you do not belong here."
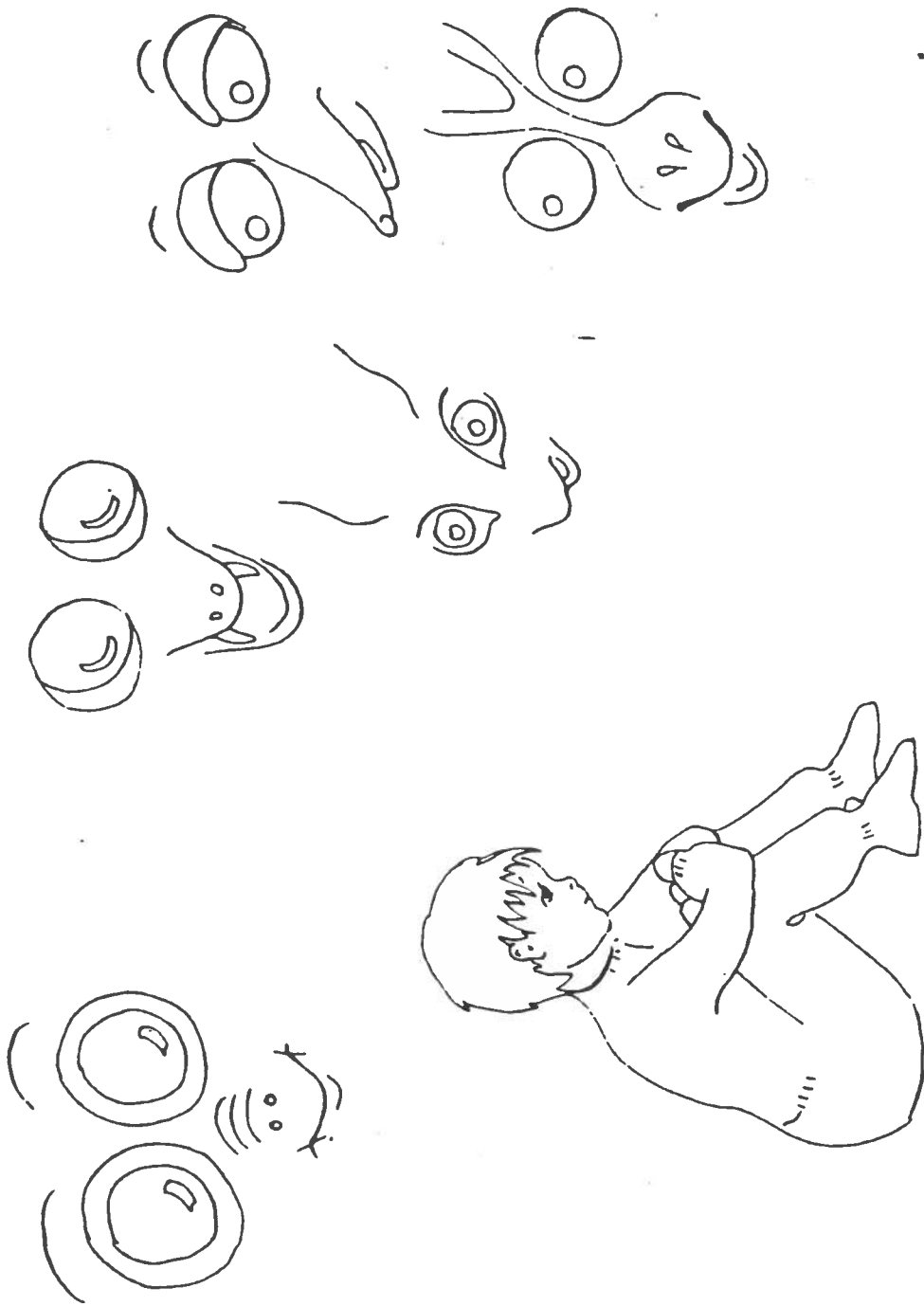
So Tom said "Hmph!" and he pushed with his hands and he pushed with his feet until he was flying high above the things with loud squeaky voices.

Tom flew to the other side of Here-n-there, where it was day and not night. There were other flying things in the bright daytime sky, but they were very far away.
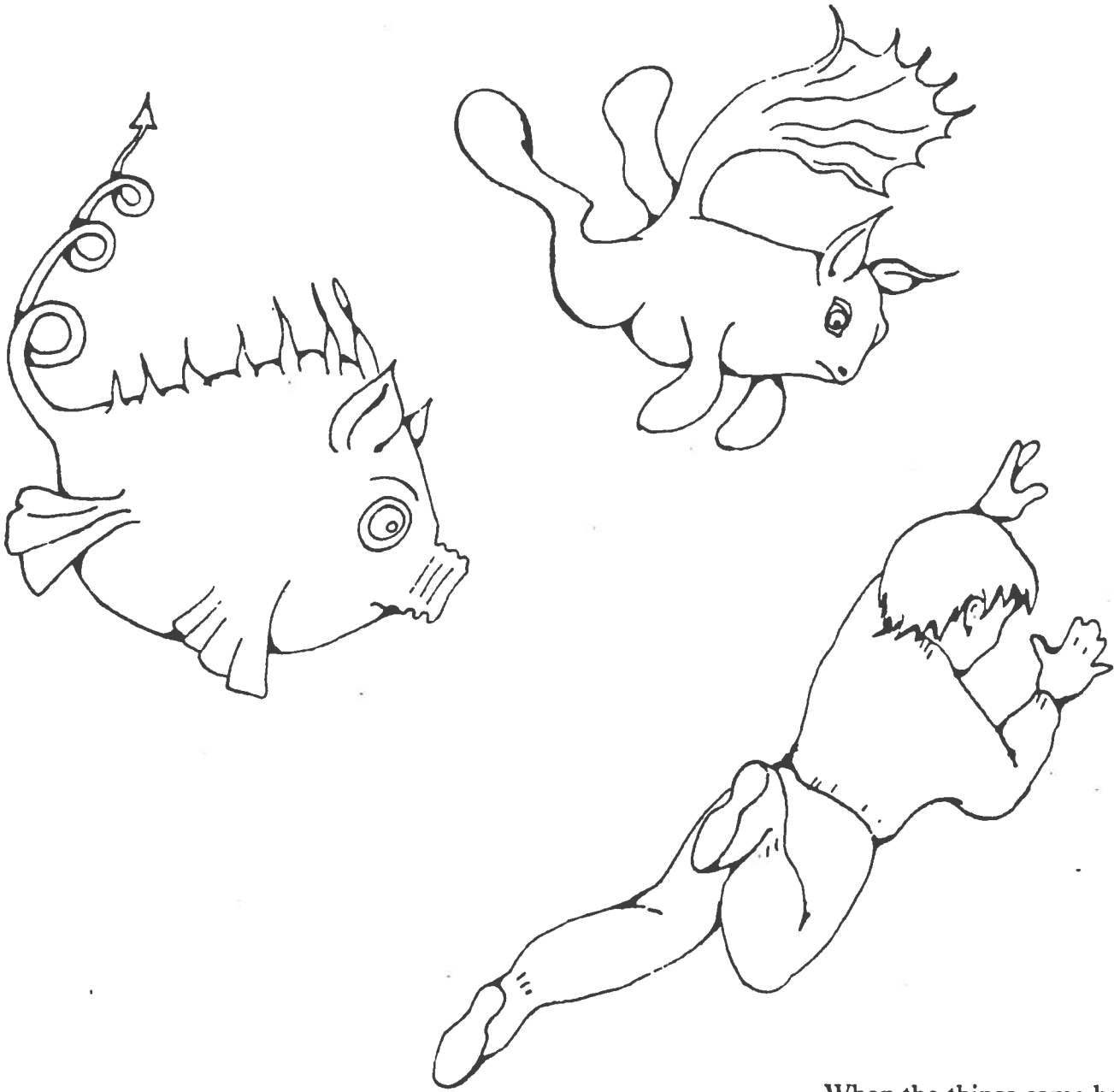
When the things came back close...

...they said "Tom go away. You do not belong here with us. You cannot fly."
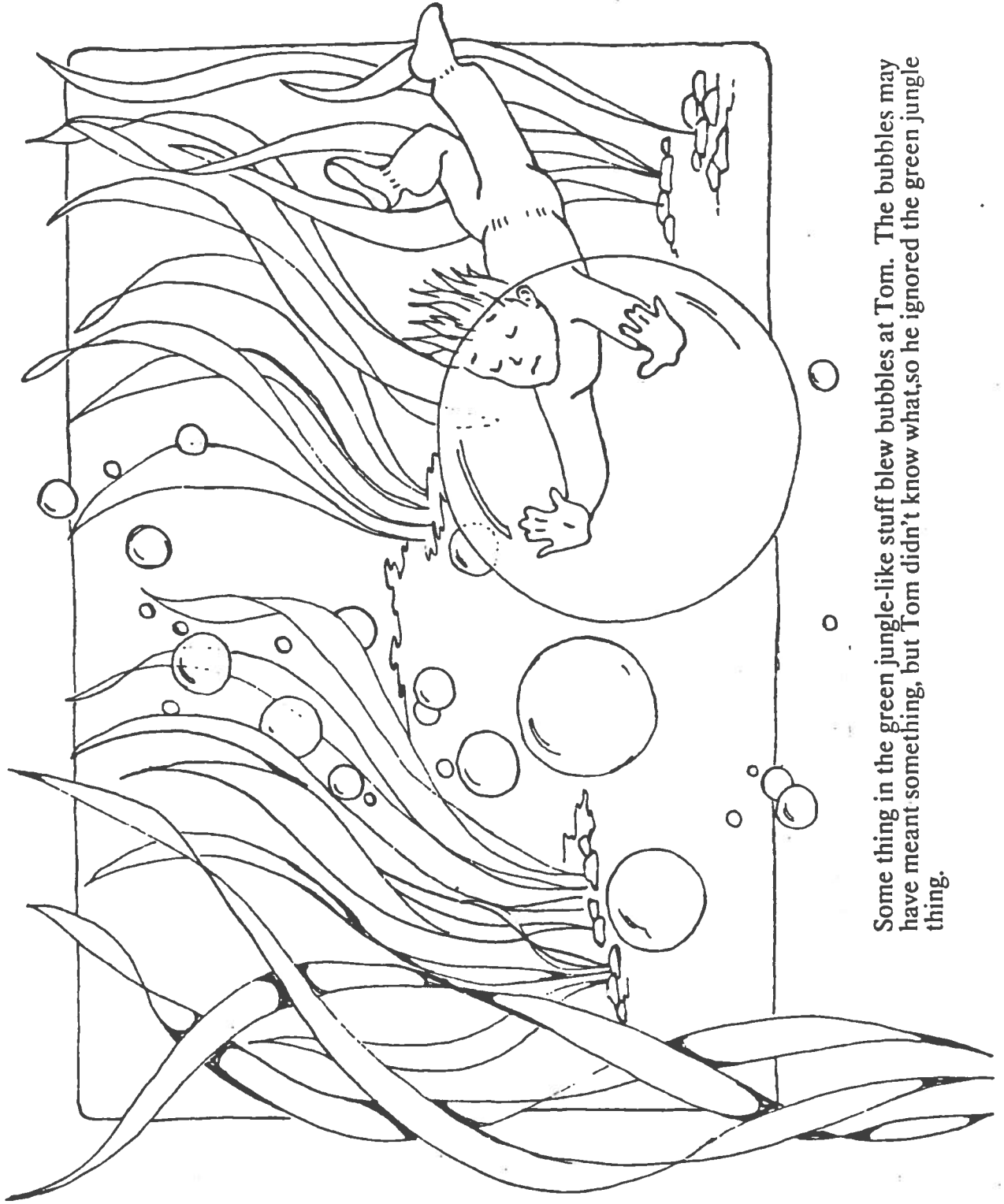
All at once Tom forgot how to fly.
PLOP! he went, into the sea.

Tom said "Hmph! Maybe I belong here and maybe I don't."

He pulled with his hands and kicked with his feet and swam down to the green jungle-like stuff at the bottom of the blue Here-n-there sea.
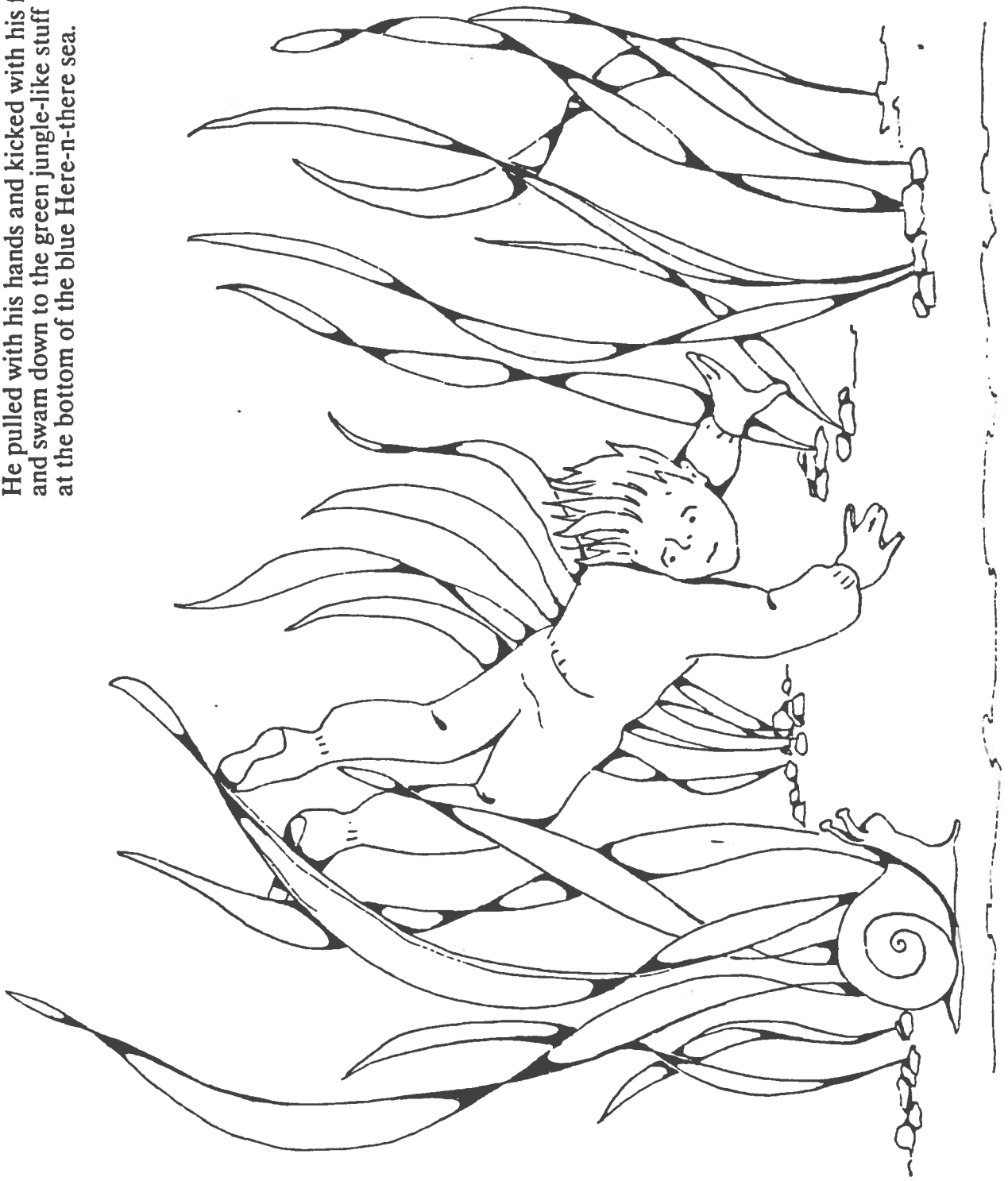
Some thing in the green jungle-like stuff blew bubbles at Tom. The bubbles may have meant something, but Tom didn't know what, so he ignored the green jungle thing.
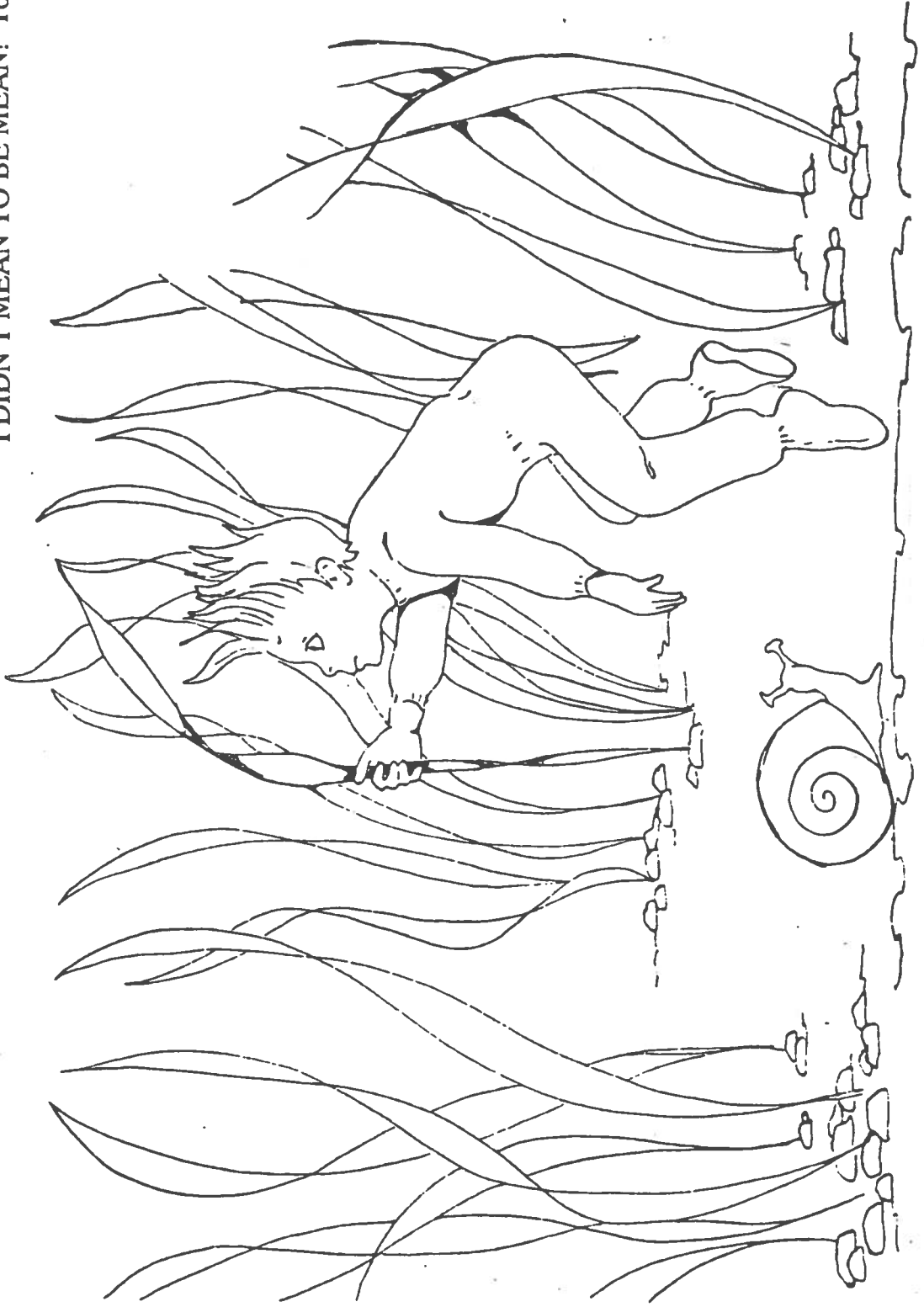
The green jungle thing blew more bubbles Tom's way.
Tom was afraid.

"Go away! I don't want you here. I don't know what you're like!"

No bubbles came up from the thing in the stuff.

"Did it do what I said? Did it just go away? COME BACK! I DIDN'T MEAN TO BE MEAN!" Tom cried.

The next thing Tom did was to snap shut his mouth. "I'm not so sure I want that thing back" Tom thought to himself.

Then tom sat and thought a little bit more. "But being alone at the bottom of the Here-n-there sea isn't much fun, I'll admit. I'm lonely, I'm frightened, I'm completely confused.

Tom put his chin in his hand. A few little bubbles arose from Tom's mouth. "Hmph," he said.
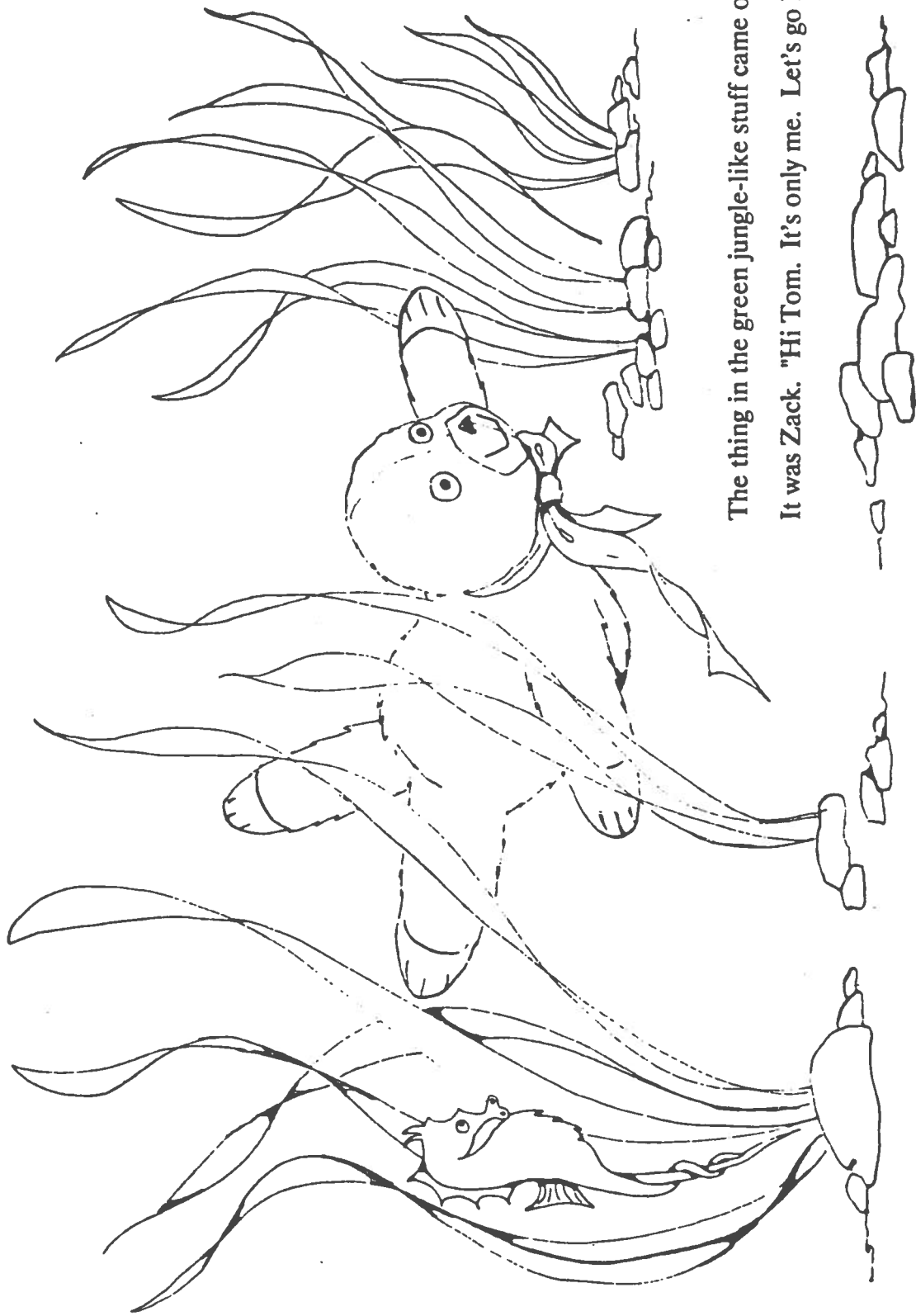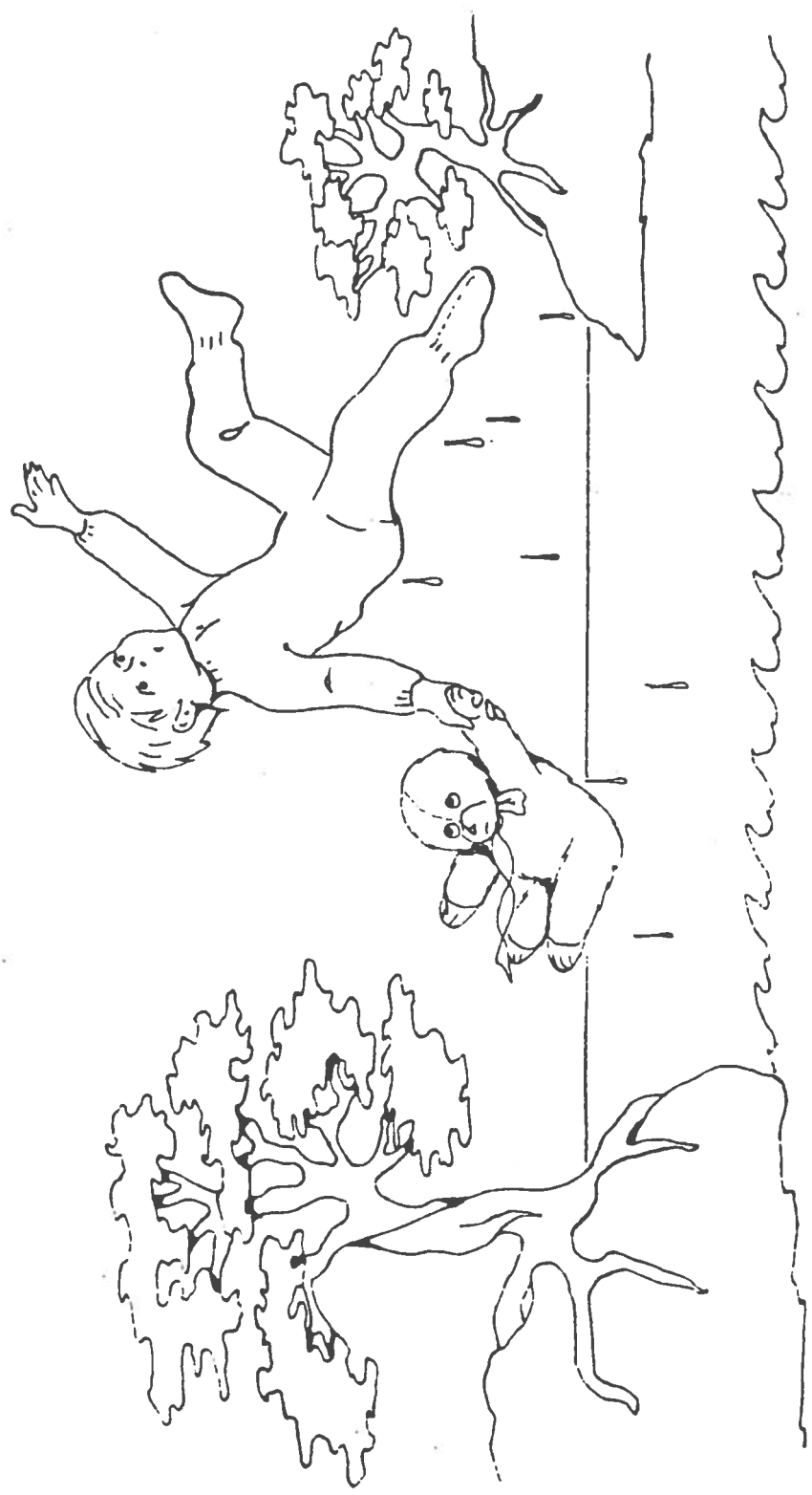
The thing in the green jungle-like stuff came out then.

It was Zack. "Hi Tom. It's only me. Let's go home."

Tom held Zack's paw and they swam up through the green stuff.

They floated out of the sea and flew into the sky. They left Here-n-there the way Tom had come.

In the morning Tom woke in his own comfortable bed. Zack was with him, of course, there under the covers with Tom. Zack didn't say a thing.

That was o.k. with Tom.

Appendix 2

The following is the rough text for the story "The Golden Dragon. Although the format is different from the previous story, it is intended to have several pictures accompanying it, however they were not available. In addition, the story is not polished, but it serves to reflect some of the issues discussed in the body of the thesis.

Once there was a time, Terry wrote. Terry never understood how "once" could be "upon a time," so the stories Terry wrote always started with "once there was a time." This was Terry's story about a very special child and a certain kind of dragon.

Once there was a time when a fierce golden dragon lived on an island not far from the mainland and the village where almost everyone lived.

For more years than anyone knew, and even a few years beyond that, no one from the village even suspected there was a dragon on the island, for no one ever went there.

Terry stopped there and put the notebook with the story in it away for the night. Terry was tired. Terry had been ill with leukemia, and had been in the hospital many times for that. Terry's mother said that the leukemia was probably cured, but Terry was still getting sick a few years later. Terry was pretty sure something else was going on but wasn't saying anything. As sleep closed in Terry's last thought was of parents who had enough to worry about.

Terry didn't work on the story about the golden dragon for several weeks. There was a busy time at school, which Terry enjoyed, and after that Terry was out of school for a week or so with pneumonia, which was much less fun. Eventually Terry continued with the story.

Lately there had been a change in the village. For several years, a short enough time that some actually knew when it had started, people had been seeing smoke rising over the island. 'It's a dragon' someone said. 'A fierce and deadly dragon that eats people.' Nobody listened closely to such talk. Even if it were true, that was on the island and the people were on the mainland. Surely the island was to far away for even a dragon to fly across the ocean in between.

Terry paused. Terry was thinking about what mother and father had said that day. The thing that was keeping Terry sick had a name now. It was AIDS. Terry had been in and out of hospitals and through the "death thing" before with the leukemia, and figured that whatever was going to happen would happen. Gazing quietly over a back yard dim in a hazy fall afternoon, Terry continued to think about how AIDS was changing everything. For Terry's parents things were already different. They had always been able to talk about the leukemia before, but now it was as if they had drawn a curtain between themselves and the rest of the world. On top of that, there was nobody else Terry could talk to. None of the other kids at school could even know about it, for Terry's mother had said that other people wouldn't understand. Terry sighed and turned back to the story.

Several years went by. People were seeing flames rising over the island now. There was a child from the village school who listened to the talk of the village adults with interest. Of late the talk was growing more alarmed. 'The dragon is killing everyone on the island, and it's getting bigger' someone said. 'Soon it will be strong enough to fly across the ocean, and then where will we be?'

The child listened very closely. For though the child went to the village school, the adults were talking about the island from which the child came. The child knew of the dragon, of course. It was dangerous and frightening not to know of it. While gathering herbs the child's own mother had strayed too near where the dragon lived.

Many others had done the same before the island people had learned to walk a wide path around the dragon's lair. The child from the island listened to the adults from the village and wondered what they would do if they knew.

The weeks that followed for Terry were difficult. The hard thing to understand about AIDS was that the virus that had infected Terry was only part of the problem. The real trouble for Terry was the weakening of the immune system by the virus, so that Terry was always at risk for other infections. Most people could shrug off these infections with the help of a healthy immune system. the same infections were likely to land Terry in the hospital. Terry also suspected that there was trouble at school, for even after returning from the hospital and feeling pretty good, terry wasn't allowed to go back to school. Whether that was mother's doing or the school's, Terry wasn't sure. With pajama clad legs dangling over the edge of the bed in Terry's room at home, Terry picked up the small notebook which held the story of the golden dragon. There might not be too many more chances to work on the story, so Terry started to write again.

One day the child from the island wandered too close to the village adults as they stood around the well in the center of the village arguing again about the dragon. Most all of them now seemed to be afraid for their very lives. As the child drew near, one of the adults who was complaining the most turned and stared angrily at the child.

Who are you and what do you want?' He was a large red-faced man with dark curly hair on his head and more hair curling out of his shirt collar. 'You don't look like anybody's kid I know. Where might you be from, anyway?'

The child was very scared. 'I'm from the island,' the child replied in a voice that shook.

'WHAT? The island! Where the dragon lives?! What're you doing here? You want to get us all killed, brining that dragon around here where decent folks live?' he bellowed.

Terrified by the big man, the child ran from the village square. Voices were being raised behind, and the child was afraid the man was telling people to go after the child.

Once again Terry was forced by tiredness to put down the story. The next day Terry found out there was a big fight going on as to whether Terry would be allowed back in school. Terry very much hoped so. School was one of the things Terry liked best. By now the story was almost finished. That night Terry picked it up for the last time.

The child ran hard for a very long time. Although it was hard to tell if the villagers were still chasing, the child thought they might be man enough not to give up. With the villagers coming from behind and the golden dragon waiting ahead the child continued running, not knowing what to do.

Terry's mother found Terry later that night with the pen still clutched in one hand. She took the pen and the notebook, and quietly turned to go.