Children's Knowledge of Illness and Treatment Experiences in Hemophilia

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The purpose of this study was to describe what children with hemophilia understand about their unique illness and treatment experiences. Subjects included 20 children with hemophilia between the ages of 6 years and 13 years who had no evidence of cognitive problems. Following the principles of grounded theory, data about children's experiences of hemophilia and their understanding of these experiences were obtained through a semistructured interview using five pictorial stimuli representing illness and treatment domains. Data analysis was conducted using the constant comparative method. Children's knowledge was described in regard to (a) the nature of hemophilia and its origin, (b) the major illness experience: bleeding, (c) the nature of treatment and its purpose, and (d) the major treatment-experience: poking. Findings indicated that although school-aged children with hemophilia were engaged actively in gaining knowledge about their disease and treatment, the overall level of understanding of children aged 6 years to 13 years did not follow a distinct path of development. Major areas of knowledge deficiency included knowledge about how one contracts hemophilia and the purpose of treatment.

HEMOPHILIA IS a congenital hereditary bleeding disorder in which the individual is deficient in the clotting factor VIII or factor IX, resulting in unpredictable recurrent bleeding episodes affecting various parts of the body, mainly the extremities and joints (Clements, 1987; Huckstadt, 1986; Kasper, 1976). The effects of hemophilia on children have been the focus of many studies in the last 30 years (Baird & Wadden, 1985; Handford, Mayers, Bagnoto, & Bixler, 1986; Mattsson & Gross, 1966a; Molleman & Knippenberg, 1987; Oremland, 1988). There is a debate in the literature as to the psychological well-being of children with hemophilia. Some researchers have suggested that school-aged children with hemophilia are less anxious and function well psychologically in comparison with a matched group of healthy children (Handford, Mayers, Bixler, & Mattison, 1986; Klein & Nimorwicz, 1982). Others have suggested that these children are at risk for developing future psychological problems (Wallender, Varni, Babani, Banis, & Thompson Wilcox, 1988).

Various factors such as maternal psychological responses, parenting style, and child's knowledge regarding illness and treatment experiences have been studied as factors influencing the child's adaptation to hemophilia. Mothers' reactions to their sons' illness have been found to vary from acceptance to severe psychological distress (Madden, Terrizzi, & Friedman, 1982; Mattsson & Gross, 1966b). Maternal guilt feelings, fear of the consequences of severe bleeding, and depression have been found to impede the adaptation of children with hemophilia (Mattsson & Gross, 1966a; Meijer, 1981; Poinsard, 1957). Maternal acceptance of the disease and minimal maternal denial predicted good child adaptation (Madden et al., 1982).

Parents' attitudes toward their children with hemophilia and the parenting styles used also were found to be related to the children's overall adaptation. Children for whom both parents were accepting of the disease had the most positive personality profiles and were well adapted (Handford, Mayers, Bagnoto, & Bixler, 1986). In contrast, the combination of an overprotective and dominant maternal behavior and rejecting parental behavior has impaired adaptation by encouraging the development of passivity and dependence in these children (Markova, McDonald, & Forbes, 1980; Meijer, 1981).

Although an important factor, the child's understanding of the experiences was only recently studied in relation to the overall adaptation process. In a pilot study of 12 families, findings indicated that there was a negative correlation between knowledge of hemophilia and extent of self-reported psychological distress for mothers and children under 15 years of age (Klein & Nimorwicz, 1982). It appears that the better informed the individual is about hemo-

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philia, the less psychological distress he or she reports. Despite these findings, there is limited information about knowledge of illness and treatment experiences among children with hemophilia and their parents.

The purpose of this study was to describe what children with hemophilia understand about their unique illness and treatment experiences. The specific aims of this study were to document children's knowledge related to (a) the nature of hemophilia and its origin, (b) the major illness experience: bleeding, (c) the nature of treatment and its purpose, and (d) the major treatment experience: poking.

METHOD

Subjects

Subjects were 20 children with hemophilia. Criteria for subject selection were the following: (a) the child was diagnosed as having a severe or moderate hemophilia: (b) the child was between 6 years and 13 years old; (c) the child showed no evidence of cognitive and major visual or hand motor problems; (d) the child understood and spoke English: and (e) both parents and child agreed to participate in the study.

Children in the sample were between the ages of 6 years and 13 years, with a mean of 7.9 years (SD = 2.11). Sixty-five percent of the children had moderate hemophilia, whereas 35% had a severe form of the disease. The severe form of hemophilia is classified by less than 1% of clotting activity; in moderate forms, there is 1% to 5% of clotting activity (Sergis-Deavenport, Miller, & Gomperts, 1983). Family social class as determined by the Hollingshead Four-Factor Index (1975) yielded a wide range of social classes: class V (n = 3), class IV (n = 7), class III (n = 5), class II (n = 4), and class I (n = 1). Yearly income ranged from less than $9,999 ($n$ = 1) to less than $29,999 ($n$ = 13) to above $30,000 ($n$ = 6).

Instruments

Data were collected from the children using a semistructured Pictorial Stimuli Questionnaire (PSQ). This instrument was used to document illness and treatment experiences of hemophilia and the understanding of these experiences by the children. Five pictorial stimuli, developed for the purpose of a larger study (Spitzer, 1990), were presented to each child. The stimuli included pictures of a child receiving an intravenous treatment (stimulus 1), a child being examined by a physician (stimulus 2), a child walking on crutches (stimulus 3), a child bleeding (stimulus 4), a child standing on the sidelines while the rest of the children are playing football (stimulus 5).

Each child was asked to tell a story about the picture, and was encouraged to describe what was happening to the character, why it happened to him, and what he could do about it. Probes had been developed to elicit maximum information. For example, to discern types of illness experiences and their meaning for school-aged children, the child was asked to describe what happens during a bleed and how it feels to have a bleed.

The face validity and content validity of the PSQ were determined by identifying the salient issues in hemophilia experience based on existing literature. Stimuli 3, 4, and 5 represented aspects of the disease as well as possible complications. Stimuli 1 and 2 represented aspects of treatment. The five stimuli were subjected to review by a panel of three expert nurses: a hemophilia clinical specialist and two experts in coping of children with chronic illness. The stimuli were judged to represent the dimensions of illness and treatment. To test and refine the instrument further, a pilot study was conducted by interviewing 15 healthy children using the PSQ. The results of this pilot study indicated that children were able to understand the stimuli presented. The language used by the children throughout the pilot interviews was incorporated into the probes and questions used in the actual study. Content validity of the PSQ was strengthened further by using each individual child's specific language throughout the interview. The interviewer used the same words as the child in probing questions.

Procedure

All 20 children were interviewed in their homes by the investigator. Informed consent was obtained from parents, and the children assented. The five stimuli were presented to the children in a random order. To insure reliable data collection and to enhance transcriptions, all interviews were tape recorded. In addition, field notes were taken during the interview. These notes were used by the investigator as a resource for filling unintelligible sections of the tape recording and to keep a record of topics that needed further exploration. During the child's interview, the parents were asked to complete a health history form and a demographic questionnaire, which took approximately 20 to 30 minutes. The interviews with the children lasted on the average 1½ hours.

The constant comparative method developed by Glaser and Strauss (Glaser, 1978; Glaser & Strauss, 1967; Strauss, 1987) was used to analyze the data from the PSQ. The tape recordings of the interview data were transcribed, entered into a computer, and formatted for use with Ethnograph (Qualis Research Associates, Littleton, CO).

In the first analysis phase, the data of 20 children with hemophilia were subjected to open coding (Strauss, 1987). The data were approached both across stimuli and across children within each stimulus. This procedure allowed the investigator to study each child's data separately across the five different stimuli, as well as to compare and contrast children's responses to the same stimulus. The initial codes identified were the result of breaking the data into small, meaningful units. In the second phase of data analysis, the codes were compared and contrasted to detect similarities and differences among them (Hutchinson, 1986). Codes that represented dimensions of an overriding category were grouped together. Following a comparison process, the initial codes were separated into categories that represented the overall treatment and illness experiences and the children's knowledge. In the third analysis phase, the relationships between categories representing illness and treatment experiences and the knowledge regarding illness and treatment were documented.

Validity checks were conducted throughout the stages of data collection and data analysis. A first-order validity check of the investigator's interpretations was performed during the data collection phase through continuous feedback from the interviewees. Often, to clarify concepts or to validate the investigator's perceptions, subjects were asked to explain or comment on other children's ideas. For example, children were asked "Other children told me about a bad bleed. Is there really something like a bad bleed?" In a second-order validity check, the importance of the various categories of experiences was validated against the standard question, "What is the child concerned about?"

The reliability of the investigator's interpretation and coding of the data was determined by subjecting a random sample of transcripts to analysis by an independent coder. The coder, an expert in qualitative research and coping of children with chronic illness, was asked to review the categories, read the transcripts, and code the data using the categories derived by the investigator from the entire data set. Eighty-three percent of agreement was reached between the two coders.

RESULTS

The Nature of Hemophilia and its Origin

Findings indicated that children with hemophilia knew very little about the disease, and especially about the way a person contracts hemophilia. In answer to the question "How do you get hemophilia?", only one 6-year-old child said, "You are born with it." Other children indicated that they did not know. One 9-year-old child gave the following explanation:

> [How do you get hemophilia?] It's not a disease like, you can't get it from me because it's not contagious. But, if like if I had a kid, my kid wouldn't have hemophilia. Their kid would have hemophilia. [Their kid would?] Yeah. Like if my daughter would be a carrier, with that my daughter's daughter wouldn't have hemophilia. [What does carrier mean?] I don't know what it means. (Subject 15: age, 9 years)

As the interviews were conducted, it became clear to the researcher that children had many misconceptions about what was happening to them. Of 13 children who responded to the question "What is hemophilia?", four children said that they did not know what it meant. Three of these children were 6 years old, and the fourth was 10 years of age. Two of the 6-year-olds could not explain what hemophilia meant, although they knew they had the disease: "I have it [hemophilia], but I don't know what it means." "I am hemophilia. [oh, you are? what is it?] I don't know."

Nine children provided an explanation as to what hemophilia is. After a close inspection of their responses, two explanatory models of hemophilia were identified: a symptom-based model and a causality-based model. Six children described hemophilia through the symptom-based model. These children explained hemophilia by the common symptoms of the disease, that is, bleeding and swelling:

> [Did you ever hear about hemophilia?] Yeah. [Do you know what it is?] Ah yeah. Um, that means somebody bleeds um, can't stop bleeding that well . . . cause they [the ones who do not have hemophilia] would stop bleeding and the hemophiliac wouldn't. (Subject 11: age, 6.5 years)

In addition, most of these children also defined hemophilia by its treatment:

> [What is hemophilia? What is the problem there?] Well, there really isn't much of a problem. It depends, you know, I used to not have the right medicine, and I couldn't get the treatment that I needed and I'd bleed all the time. You know, night and day, I couldn't go to sleep or anything. But it really isn't a problem when you have the right medicine you need. [Why do children with hemophilia bleed?] Um, I don't know that. (Subject 14: age, 12 years)

Three of the children (aged 8, 11, and 13 years) explained hemophilia by the causality-based model. These children understood the basic pathophysiology of hemophilia and based their explanation around a deficiency of factor VIII or factor IX.

> [Can you explain to me what hemophilia is?] Um, it's a disease that you're missing a factor of blood. And when you get a bleed, you can't get a bruise because your own factor is not there to make a bruise. Normally you just get a bruise, and when you have hemophilia your factor that you're missing, it won't help you make the bruise. (Subject 18; age, 11 years)
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> [What's your definition of hemophilia?] [starts out less confident, slower and softer] It's a funny disease, it's um, hemophilia is . . . is not getting and [faster and more definite] not getting enough factor into the body. Or not having enough factor VIII for your body, and so well and you need treatment if you did get a bleed or something like that. (Subject 20; age, 13 years)

A further investigation of the differences between children who used the different models showed a developmental trend related to age that could explain the use of the different models. Four of the six children (66.66%) who explained hemophilia by the symptomatic model were 6.5 years old. All the children who used the causality based model were older than 8.5 years.

The Major Illness Experience: Bleeding

Data indicated that bleeding was the dominant illness experience for children with hemophilia. A bleed was the uppermost concern of these children because it was the cause of physical pain, body mutilation, limitations in movement, and any number of complications. Reflections of the deep awareness of bleeding by the children with hemophilia were apparent through the richness of linguistic descriptions of the word *bleeding*. Whereas healthy school-aged children used the word *bleeding* only to describe an incident of blood coming out of the body, the vocabulary of children with hemophilia included terms like "outside bleed" and "inside bleed," as well as "regular bleed" and "bad bleed."

Bad Bleed

In an attempt to understand better the development of illness complications, children with hemophilia distinguished between a regular bleed and a bad bleed. A bad bleed was believed to be the source of complications and, thus, should be identified and treated as soon as possible.

These children characterized bad bleeds using four factors: visual qualities, the organ affected (location), complications, and the type of treatment needed. The factor most commonly identified by the children was visible qualities, which included the volume of the bleed, the color of the bleed, and the amount of swelling.

> The cut would be big and it will be bad, bleeding real bad. Then it will be something like dark. The blood will be dark. And if it is not so bad, the blood will be light, light red. And it wouldn't be so dark as when it's really bad. (Subject 12; age, 10 years)
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> A bad bleed probably would be like, maybe he broke an arm and it would bleed inside or if you hurt, you just got a big huge bump, and you start swelling up a whole lot. Then a regular bleed would probably be a stubbed toe and it's a little bit, it just feels a little tight and stiff, so you don't even treat it because it might not be bleeding inside, you know. (Subject 20; age, 13 years)

The second characteristic of a bad bleed was its location. Bad bleeds would be bleeds into the bones, into specific organs such as the head or the stomach, and bleeds that tended to repeat in the same place in the body.

> There are some places that can be a real bad bleed. Like the most dangerous one probably is in your head. And also a real dangerous one can be in your shoulder. It really can swell up, and sometimes it clots so you can't get enough blood throughout your arms, and it weakens your arms and stuff. (Subject 14; age, 12 years)
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> Well see, I have a place where I bleed a lot, it's in my right knee, you know. It's flat right here because when I was three years old, I fell off a swing and hurt my knee on a tree stump. And the knee cup just got in, and ever since then I have a real bad bleed. Whenever it gets a bleed, this one is really a bad bleed. (Subject 14; age, 12 years)

Bad bleeds were characterized further by the complications associated with them: mainly pain, infection, movement difficulties, and death. The children described the bad bleed as potentially catalyzing many different complications.

> Well, he could first of all bleed more and more inside. And then what happen it deteriorates. Just keep bleeding and bleeding until it just hurts him, and if he does wait on it then it just causes more problems in the future. Like he could be crippled in the knee. (Subject 20; age, 13 years)
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> It [the bad bleed] is something that bleeds real bad, like if someone got stabbed, that's called a real bad bleed. [And what would happen?] A person would be dead. (Subject 17; age, 6 years)

Pain, however, was the predominant aspect associated with bad bleeds. Children with hemophilia used this association to cast pain as a severity indicator: the more painful it is, the bigger the bleed.

> It [bad bleed] means that it hurts real bad. And usually when you first get it, you first get the bleed, it does not hurt that bad. (Subject 9; age, 8 years)
>
> It [the bad bleed] hurts so much you can't help it. And it would hurt for a long, long time. (Subject 15; age, 9 years)

The last aspect used by children with hemophilia to characterize a bad bleed was the type and amount of treatment that was needed. Bad bleeds were identified as requiring more of the regular treatment that the child usually received posttrauma, or as bleeds requiring hospitalization.

> Well if I guess, a big bleed would just be a big, maybe a stomach bleed if it gets real hit with something real hard or something. When it starts bleeding in the stomach, then what I do, I'd treat with like 12, like see about four more bags than normal. To put more cryo (coagulation factors) in my system. (Subject 20: age, 13 years)
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> A bad bleed is when you have to go to the hospital and stay in there for oh, say like two weeks. Because you have a big bump on your head, and it has to be taken off. (Subject 18: age, 11 years)

Age differences were noted in the descriptions of bad bleeds only in the category of characterizing]ed by the body organ involved. Children 6 to 11 years old described bad bleeds by the visible qualities, the characteristic complications, and the treatment needed. However, only when they reached the age of 12 years did children judge the severity of bleeds based on the relative importance of the organ affected.

These patterns of thinking are in accord with the Piagetian cognitive stages (Piaget, 1929): children aged up to 11 years tend to be very concrete in their thinking, and they described the bleed primarily in terms of the amount of blood, color, and swelling—all very concrete elements. It was only after the age of 12 years, at which time children start to conceptualize abstract concepts, that they could tie together the relative importance of an organ as well as the type of organ to the issue of severity.

These patterns of thinking also fit very well with the body of literature regarding the development of)derstanding of body organs and their functioning. Young children envision the body as similar to a hollow tube, focusing on materials entering and leaving the body (Fraiberg, 1959; Gellert, 1962). Later, they identify organs, especially those they feel. Children aged 10 to 12 years identify more organs and begin to ascribe mechanistic functions to organs; however, integration of body functions is still only appreciated after the age of 12 years.

Feeling Bad and Disgusted

In addition to describing the qualities of a bad bleed, children with hemophilia expressed their attitudes toward blood. Overall, these attitudes were very negative. It was not only in the occurrence of a bleed that these attitudes showed themselves; rather, they represented a global attitude toward blood.

> [When he saw the blood, how did he feel?] Yucky. Because he might not like what blood looks like. Sort of like me when I get poked with a needle. I really hate [emphasis on hate] what my mom does. She lets the blood run up, all the way up the tube, then she cleans it off so when the bubbie's gone it doesn't hurt. But sometimes it almost makes me barf. Because it doesn't look that good. It looks like somebody took spray paint and shoved it up in your arm. And then someone else pokes the needle, and then it rushes up as fast as it can, and so it can squirt out and paint the house. (Subject 2: age, 8 years)
>
> He doesn't like blood and he is kinda scared because he doesn't like the color of it. Because he doesn't like the color red, it kinda scares him when it is coming out of him. (Subject 6: age, 8.5 years)

Children with hemophilia had almost unanimous feelings of negativity attached to the incidence of bleeding. All of them were united in the description of their feelings as bad, sad, or mad. These feelings toward bleeding were the result of the attitudes toward blood that the children held, as well as the result of the pain, motion difficulties, and fears of what could happen as a result of the bleed.

> He feels very sad. He might have an ankle bleed, and he doesn't got any crutches, so he can't walk. (Subject 9: age, 8 years)

The Nature of Treatment and Its Purpose

Children were asked to describe how the treatment worked, that is, the process by which the child received the cryoprecipitate. Three different types of explanatory models captured the children's descriptions: a magical model; a look-a-like scientific model; and a scientifically correct, well-developed model.

The descriptions of three children fell into the magical model. These children explained the treatment either in magical terms like "super blood" or in their own created terms like "dental thing." The children had a basic understanding that the intravenous (IV) treatment was a treatment device, but beyond this, their knowledge was very limited.

> There's a kid in the hospital. And he's getting his blood pressure [an IV device] and he's watching TV. [Is he getting his blood pressure checked?] Hm, hm [yes]. (Subject 4: age, 8 years)
>
> He has a thing hooked up to his arm and he's watching TV. [What is this thing that is hooked up to his arm?] Kind of like a thing that the people walk around in hospitals with. [What's this thing doing?] It's on his arm, and like taking blood or something, like taking blood, but what makes you better is you have something inside. (Subject 5: age, 6 years)

Seven children described the treatment by a look-a-like scientific model. These children had a basic understanding that the IV apparatus was carrying a medicine and that this medicine would

treatment:

> [How will the poke help his hurt?] There's a needle they are going to hook it up to the medicine. . . . He is getting better from the needle. From the medicine. (Subject 8: age, 7 years)
>
> [Can you tell me how it works?] It [the cryo] goes in and the pain goes away. (Subject 11: age, 6.5 years)

The responses of nine children were placed in this category. These children were between the ages of 6 years and 10 years. Except for one subject who was 10 years old, all these children were 6 to 7 years old.

The second group of responses included two types of explanations. One type depicted the treatment as a literal fighting device against the bleed. Some of the children in this group described a battle field between the bleed and the cryo:

> [Now: how does the cryo know where the bleeding area is?] It goes around your body, whipping around. It just goes all the way around your body. [And what does it do to the bleed then?] It um, usually takes it right away. [How does it take it right away? What does it do?] It breaks down the bleed. [What do you mean by break down the bleed?] It's usually a tan color and I picture a tan and it goes to your vein and there's a big red spot in it and it goes in and it sort, they're all um like Indians and cowboys and the red ones are Indians and ya get a big war, inside ya. And the tan usually wins because they have more. (Subject 18: age, 11 years)

Other children talked about clotting processes but were not really sure and/or correct as to how the process took place:

> [And how does that take care of the bleed?] Well it goes into your blood and, it goes all throughout your body to get to the bleed, and work on it, you know. [What does it mean, work on it?] Well um, make it better you know. [How does it make it better?] Ah it has some chemicals or somethin' in it that will fight off the bleeding. [How does it find the bleed and doesn't go to another place?] Well it goes all over your body, and so no matter where the bleed is, no matter how many bleeds you have, it will go to it. (Subject 14: age, 12 years)

Six children were in the second group, and with the exception of one subject who was 6 years old, all of these children were older than 9 years.

Of the 20 children with hemophilia, only one subject gave a scientifically correct explanation as to how the treatment works:

> The factors just go all together and stop the bleed and put some platelet tissue were the bleed was. And just it stops bleeding. When you're a hemophiliac—you have to pick the factor and then you'll stop bleeding. But, people who don't have it, they don't have to do anything [emphasis on *anything*]. Um, it just does it all because they have the factor inside them already, and yet when they get cut it would stop automatically. (Subject 6: age, 8.5 years)

These findings suggest a trend toward age differences, such that the older the child, the more complete the understanding.

The Major Treatment Experience: Poking

To most children, a poke is an unpleasant and frightening episode in which the child is stung with a big needle. To the children with hemophilia, it is much more complex. Similar to the concept of bleeding, pokes had multiple characteristics and qualities that had their own meanings to these children. Pokes were the core of the treatment concerns of children with hemophilia. The main reason given for dreading treatment was receiving the pokes. When the threat of the actual poking was minimized (e.g., by a Hickman catheter), the concerns regarding treatment were reduced considerably.

In appreciation of the importance of pokes in their lives, children with hemophilia developed a very rich vocabulary to describe and differentiate between different types of pokes. There were good pokes and bad pokes, big pokes and small pokes, booster shots and butterfly shots. The most important differentiation, however, was between bad pokes and good pokes.

Bad Pokes

As one of the children concluded, "You don't ever want to get a bad shot." In an attempt to gain some sense of control in regard to their treatment episodes, children with hemophilia drew a line between what they called bad pokes and the ones that were good pokes. The basic idea was to avoid bad pokes as much as possible, because the good pokes were much more easy to handle. Essentially, bad pokes were associated with a lot of pain and suffering and seemed to carry many negative aspects of treatment that were difficult for the children to handle.

Children with hemophilia characterized bad pokes by several adverse elements: the size of the needle, the way in which the child was poked, the sensations that went along with different materials given to the child, and the length of time it took to receive the shot. The needle size was a common descriptor of a bad poke. Typically, children would talk about a bad poke as:

> One of those big, huge ones that they stick in your arm and stuff. The big shot is like this long with the big syringes. Those are probably the bad shots, but the little ones aren't as painful as that, or scary looking. (Subject 20: age, 13 years)

The sensations that went along with the injection of certain materials often were cited as adding to the bad qualities of a poke.

> The heparin is a bad shot because it stings and it makes you cry and stuff. It stings and you have a heparin lock in your arm. And it makes you cry. (Subject 18: age, 11 years)

It hurts only when you push on it, and the salt water goes in real fast. And when the needle starts to get cold and sting. (Subject 12: age, 10 years)

[What is the worse part of the whole thing?] Ah being so cold when it goes in. [Do you feel it in your body?] Yes . . . getting a chill. And it gets more of a bother too. Because you have to keep going to get hot rugs and putting it on there to keep it warm. And you keep getting real cold so you have to go back; back and forth and back and forth. (Subject 18; age, 11 years)

Pictorial images were used to describe the way the needle was supposed to enter the body, as well as what happened when the care provider missed the vein. When the needle did not enter in the way that they expected, or if they had to be poked several times, these elements turned pokes into bad pokes.

When my mom misses the vein, that I don't really like. It feels like, somebody has been taking rocks and shoving them in your vein, and they're trying to go up your arm. (Subject 2: age, 8 years)

The last characteristic of a bad poke described by the children was the duration of treatment. The basic idea was that if one had to get an IV drip or a continuous treatment for several days or go to the hospital to get treatment, then he was experiencing a bad poke.

He is worried if the plasma is going to stay there every day. . . . He thinks it's going to stay there for a long time. (Subject 10: age, 6.5 years)

DISCUSSION

The findings indicated that although school-aged children with hemophilia were engaged actively in gaining knowledge about their disease and treatment, the overall level of understanding of children aged 6 to 13 years did not follow a distinct path of development. Furthermore, children had different levels of understanding of various topics. For example, a child could be an expert on different types of treatment but lack an understanding of the purpose of treatment. Lack of a clear developmental trend in knowledge acquisition also was demonstrated by Klein and Nimorwicz (1982), who found that children younger than 15 years of age knew more about the disease than children who were older.

The phenomena of syncretism, juxtaposition, and declage that characterize children's thinking processes in the concrete operation stage (Piaget, 1929) provide a cognitive theory to explain findings from this study. Syncretism is defined as a tendency to connect a series of separate ideas into one, confused whole (Piaget, 1929). Juxtaposition represents an inability to express causal relations (Piaget, 1929). The phenomenon of declage represents variations in one child's understanding across different areas or content (Piaget, 1929). Children live with contradictions and do not mind them because they are a direct outcome of the syncretism and juxtaposition modes of thinking. Considering the declage phenomenon, one can understand how children can become experts on one aspect and at the same time have very little understanding on a related matter. Thus, some of the contradictions in the children's ideas and the various levels of knowledge the children held could be accounted for by the overriding cognitive limitations. However, the cognitive abilities do not explain the lack of a clear developmental path found in some of the illness and treatment concepts in this set of data, as well as in other studies (Eiser, 1985).

Previous experience was suggested as a possible explanation for variations in knowledge that are not correlated with development. Overall, findings regarding the role of experience can be classified into three groups: (a) those indicating that experience accelerates the development of the constructs of illness and treatment (e.g., Campbell, 1975; Redpath & Rogers, 1984); (b) those indicating that experience impedes the rate of development (e.g., Caradang, Folkins, Hines, & Steward, 1979); and (c) those indicating no significant experience effect (e.g., Eiser, Patterson, & Tripp, 1984; Myers-Vando, Steward, Folkins, & Hines, 1979). Eiser (1985) noted that findings about the role of experience in the development of understanding of illness and treatment aspects is inconclusive. Thus, it is still not clear as to whether experience enhances or inhibits the development of knowledge. Findings from this study did not clarify the issue. Because hemophilia is a hereditary illness, age and experience are confounded, resulting in difficulties in isolating the effects of experience on knowledge. Future studies can contribute to the understanding of this issue by identifying which aspects of experience influence the development of understanding and how.

Resources of boys with hemophilia to deal with their illness and treatment experiences were depleted as a result of knowledge deficits or distorted information. Nurses working with these boys should emphasize the importance of knowledge. Nurses cannot assume that the boys would be educated on these topics by their parents, because some parents were not sure themselves of the meaning of hemophilia or how to communicate this information to

child. Special attention needs to be given to the aspect of illness causality, as findings from this study indicated that the boys did not know how one contracts hemophilia. Similarly, teaching about the exact purpose of treatment and the way treatment stops the bleed should be given special attention to counteract misconceptions and lack of appropriate knowledge.

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