PATTERNS OF CONCERN IN HOSPITALIZED CHRONICALLY-ILL YOUNG CHILDREN: A PRELIMINARY REPORT

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INTRODUCTION

Advances in the medical management of chronic illness have resulted in a longer life expectancy for many children, but often necessitate frequent and prolonged periods of hospitalization for increasing numbers of these children.

While very few studies have examined the young child's response during these long term hospitalizations, the authors' own experiences with young children subjected to long stays in acute care hospitals confirm staff nurses' observations that these children do develop negative behavior patterns. Lack of information about response to long-term hospitalization makes it difficult for nurses to plan care which will prevent such behaviors.

This paper is a preliminary report of a study using play interviews to determine the dominant concerns of chronically ill two to five year old children in hospital and to compare their concerns with those of healthy children and children undergoing short-stay hospitalization. The study is the initial stage of a project to develop a means of examining the coping patterns of young chronically ill children in hospital and to measure the effect of nursing intervention designed to foster these children's adaptive capacity.

The study questions are:

1. What concerns consistently recur over a six week time period?
2. What changes in patterns occur over the same period?
3. Are there differences in the concerns of healthy children and those undergoing long-stay hospitalizations (more than 28 days), or short-stay hospitalizations (under 21 days)?
4. Do the concerns vary according to age, previous hospitalization, previous painful procedures, or parental visiting patterns?

REVIEW OF THE LITERATURE

References to chronic illness in this study are based upon Pless and Pinkerton's (1975) definiton:

> A physical, usually non-fatal condition which lasted longer than three months in a given year, or necessitated a period of continuous hospitalization of more than one month. (p. 90)

Surveys conducted in the United States and Great Britain indicate that 5 to 10% of children have a chronic physical illness (Pless & Pinkerton, 1975; Rutter, Tizard & Whitmore, 1970). The effects of chronic childhood disorders have been found to place the affected child at a higher risk of psychological maladjustment than healthy children of the same age (Mattsson, 1972; Pless, Roghmann & Haggerty, 1972). Higher incidences of psychiatric disturbances, reading difficulties, and problems in functioning socially have been reported in three populations of chronically ill children (Pless & Pinkerton, 1975).

It is also apparent from the literature that the difficulty the young child has in adapting to chronic illness, extends into later life. Pless, et al. (1972) determined that school-age children with chronic physical disorders had a 10 to 15% greater incidence of psychological maladjustment than their healthy controls and that the relative risk of maladjustment increased over time. Korsch, Fine, Grushkin & Negrete (1971) reported severe damage to self-esteem and poor scores on social adjustment in children surviving renal transplant for at least one year. However, Korsch also reported in a later report that most of these children and their families had "returned to pre-illness adaptation and family equilibrium". (Korsch, 1978, p. 347).

While the effects of short-term illness and hospitalization have been shown to vary with the child's developmental stage (with resultant differences in the child's interpretations), fears and reactions, and the effects of chronic illness have potential for interfering with the child's normal development and socialization across all developmental stages (Battle, 1974; Hughes, 1975; Pless & Pinkerton, 1975; Talbot & Howell, 1971). For chronically ill toddlers, the establishment of a sense of autonomy and progress through the stages of separation-individuation are made difficult if chronic illness results in maternal or familial over-control, limitation in self-expression and feelings of anxiety, helplessness and passivity (Maddison & Raphael, 1971; Magrab & Caleagno, 1978). In pre-schoolers, chronic illness threatens intellectual and social development by decreasing opportunities to explore

the environment, establish peer relationships and develop independence (Battle, 1974; Freeman, 1967; Hughes, 1975; Travis, 1976). Restrictions on mobility and play mechanisms for mastery of tension may result in increased anxiety and fantasy activity (Freeman, 1967; Maddison & Raphael, 1971; Mattsson & Gross, 1966).

A variety of emotional responses to chronic illness has been described. Stubblefield (1974), has noted that the child's reactions are seen in the psychological responses of anxiety, depression, somatic symptoms or antisocial behavior such as addiction and running away. While specific responses have been reported in particular types of illnesses, there are similarities in these reported reactions, namely exaggerated guilt, fantasies, anxiety about functioning and dissatisfaction with body image (Belfer, Harrison & Murray, 1979; Kagen-Goodheart, 1977; Korsch, et al., 1971; Korsch, 1978; Mattsson, 1975).

Few studies have described the adaptive mechanisms used by chronically ill children. Mattsson's experience with hemophilic children has convinced him that children and their parents are able to adapt so as to function within the limits of the disease (Mattsson, 1972). Such adaptation is reported to be accomplished through coping behaviors which include cognitive functioning (Geist, 1979; Korsch, 1978; Mattsson & Gross, 1966; Mattsson, 1972, 1975); motor activities (Mattsson, 1972, 1975); appropriate emotional expression of angry, sad and then hopeful feelings (Mattsson & Gross, 1966; Mattsson, 1972, 1975); the use of psychic defenses such as identification with the medical staff (Geist, 1979); and denial of an uncertain future (Geist, 1979; Mattsson, 1972, 1975).

The literature reveals findings on long-term adjustment to chronic illness and the impact of chronic illness on development. Most of the literature presents discussions from clinical practice. Few of these discussions examine young children and no studies were found on the adaptation of chronically ill young children to hospitalization.

METHODOLOGY

Setting

The study was conducted in a university teaching children's hospital and a large multi-setting day care centre, situated in the same metropolitan area. The research was ethically assessed and sanctioned by the Ethics Committee of the Faculty of Health Professions, by the hospital's Research Committee and by the Board of Directors of the day care centre.

Consent

Written consent was obtained from all parents whose child was to become a subject in the research.

A written proxy consent was obtained from the charge nurse or the head teacher before each play interview.

Sample

The sample reported in this paper consisted of 35 subjects: 10 healthy children and 25 hospitalized children. The healthy children were chosen at random from one unit of the preschool centre. They were judged by the teacher to be of normal cognitive development and had no history of severe emotional disturbance. The hospitalized children were chosen by a convenience sample based on the following criteria:

- normal cognitive development
- no history of severe emotional problems
- anticipated hospital stay of at least 8 to 10 days
- physical condition permitted an initial play interview within five days of admission
- physical condition could be expected to permit next play interviews within five to seven days of the first interview
- child not admitted to an isolation unit requiring sterilization of the toys following the interview.

There were three groups of hospitalized children; five children in a long-stay chronic illness group who were hospitalized a minimum of 28 days; 10 children in a short-stay illness group; and 10 children in a short-stay acute illness group. Both of the short-stay groups remained in hospital less than 21 days.

Description of Subjects

The subjects ranged in age from two to five years: 21 were four years and over, and 14 were under four years. The hospitalized children had a variety of medical and surgical conditions.

Counting the present hospital stay, 17 of the 35 subjects had more than one hospital experience. Twelve of the 15 subjects with a chronic illness had been in hospital more than once.

Twenty-four of the 25 hospitalized children had one parent living in or visiting most of the day. The high parental visiting pattern may be in part related to our data sample as it would have been difficult to discuss the study with them and get their written consent.

Twenty of the 25 hospitalized children had more than three experiences with needles, including intravenous and immunization, prior to commencing the play interviews.

Fifteen of the 35 subjects had experienced surgical procedures. Eleven of these 15 subjects were children with a chronic illness.

Data Collection

Information about variables identified in the research questions was obtained through a questionnaire sent to parents of the healthy children, or a structured interview with parents of the hospitalized children. The data was collected by the researchers using the play interview procedure developed by Erickson (1958) and a suitcase containing both familiar toys and hospital equipment (Table 1).

Table 1
Contents of the Play Kit

Familiar Toys	Hospital Equipment
Bathtub	Adhesive tape
Car	Bandaids (4)
Chest of drawers	Cotton balls (4)
Crayons	Dropper bottle
Doll's bed and linen	Disposable enema bottle
Gun	Feeding tube
Kitchen sink	Gauze bandage
Nursing bottle	Gauze squares (2 - 4×4)
Refrigerator	Medicine bottle with 4 small candies
Spoon	Medicine cup
Stove	Nightshirts (2)
Tablet of paper	Plastic tape
Toilet	Rectal tube - red catheter
Family dolls: baby	Test tube
girl	Thermometer and holder
boy	Syringe and needle
mother	Venous catheter
father	Hospital dolls: doctor
	nurse

The initial interview with each child began with the researcher picking up and naming each object in the suitcase. The child was then told that he could play with the toys of his choice and the researcher "would do some writing". Questions were answered with minimal direction. For example, if a child asked, "What's this?", the researcher responded, "It can be whatever you want it to be". Any request to participate in the play was declined except on a few occasions when, at the insistence of the child, the researcher became more involved in the play. In such instances, the child indicated a need to perform certain actions on a live person rather than a doll. The researcher was a passive participant and took direction from the child. Play interviews lasted up to 45 minutes and the child was free to refuse to play or terminate the interview at any time.

The play interviews were done every 5-7 days up to a maximum of six interviews for the long-stay chronic illness and healthy groups. The interviews were held in a private room. When this was not possible in the hospital setting, the curtains were pulled around the hospital bed. At times, parents of hospitalized children were present during the play interview.

The child's verbal and non-verbal activities were recorded in writing by the researchers. To provide interobserver reliability in the recorded play interviews, the researchers were trained in observing and recording, using videotaped play interviews. An interobserver agreement of 86% was achieved by the three researchers.

A total of 100 play interviews were done. In the short-stay acute illness group, there were one to two play interviews with most subjects. In the short-stay chronic illness group, two to three play interviews were done with each subject. All long-stay subjects had five play interviews. The healthy subjects had between two and six play interviews.

Analysis of Data

The narrative recordings of the interviews were subjected to content analysis. The data was divided into units of behavior. Units of behavior were any acts of the subject which were in the form of vocalization or verbal or non-verbal behavior. The units of behavior were then categorized according to the type of object the child handled in the play activity and the type of concern expressed in the play. A unit of behavior was categorized as one of four type of objects, and as one of ten major concerns (Table 2). All behaviors were considered meaningful and reflective of a concern. A concern was defined as a matter in which a child invests some interest or energy in the course of development or in particular situations. The categories of concerns

were based on the published reports of concerns of this age group in relation to hospitalization and normal developmental concerns. To assure an exhaustive system of categories, the final decisions in the development of the categories were derived from actual content analysis of the narrative recordings. This content analysis of the narrative recordings yielded frequency counts of numbers of behaviors in each of the categories.

To assure uniformity in coding units of behavior and categorizing the units, the researchers underwent extensive training in the content analysis procedure prior to the actual coding of data. Coding was not begun until the three researchers achieved a minimum percentage of agreement of 70%. The interjudge percentage of agreement achieved in each area of coding was:

Units of behavior	88.4%
Types of objects played with	87.5%
Categories of concerns	71.8%

The preliminary analysis of the data was designed to examine differences in the proportion of concerns expressed between groups and over time. The average proportions of play behaviors classified as particular concerns were calculated for each of the four groups on each interview. This calculation demonstrated which concerns dominated the children's play. The frequency counts of classified play behaviors for each individual interview also comprised the raw data for statistical analysis. The differences in proportions of concerns expressed were analysed using the statistical package GLIM (Royal Statistical Society, 1977).

Table 2
Categories for Analysis of Data

Types of Objects	Types of Concerns Expressed
Hospital	Autonomy
Familiar	Body Integrity
Both	Caretaking
Neither	Exploration
	Interpersonal Communication
	Intrusion
	Mobility
	Punishment
	Separation
	Violence

FINDINGS

Descriptive Analysis of Concerns Expressed

Play behaviors classified as Autonomy or Exploration consistently occurred in high proportions in all groups but dominated the interviews with healthy children and the short-stay acute illness group. These behaviors always occurred in the highest proportion and ranked first or second in all interviews with the healthy and short-stay acute illness groups. However, in the long-stay chronic illness group, expressions of concerns about Intrusion challenged the dominant position of Autonomy and Exploration. For the long-stay chronic illness group, behaviors classified as Intrusion occurred in either the highest or second highest proportion in four of the five interviews.

Play behaviors classified as mobility, interpersonal communication, punishment, and separation each accounted for 5%, or considerably less, of the play behaviors in all interviews in all groups. Only those concerns accounting for a higher proportion of behavior will be presented here.

Autonomy and Exploration. Play behaviors which demonstrated concern with independent function or pride in ability to accomplish a task (Autonomy) or which demonstrated efforts to identify or describe an object (Exploration) occurred most frequently in the interviews with both the healthy children and the short-stay acute illness group. Tables 3 and 4 demonstrate that Autonomy and Exploration combined, accounted for 70 - 80% of the play in each interview with the healthy children. In contrast, Autonomy and Exploration combined, accounted for only 41 - 48% of the play on the long-stay chronic illness group on all interviews except the fourth.

Table 3
Percentage of Behaviors Expressing
Concerns About Autonomy

	GROUP			
WEEK	Short Stay Acute	Short Stay Chronic	Long Stay Chronic	Healthy
1	34.7	22.7	17.6	30.6
2	23.6	18.4	22.5	37.9
3		35.4	22.3	26.4
4			33.3	36.8
5			16.6	36.8
6				39.9

Table 4
Percentage of Behaviors Expressing
Concerns About Exploration

	GROUP			
WEEK	Short Stay Acute	Short Stay Chronic	Long Stay Chronic	Healthy
1	33.1	31.6	30.3	45.5
2	43.8	36.7	18.6	31.6
3		29.3	24.3	47.4
4			25.9	39.9
5			29.7	35.5
6				40.2

Table 5
Percentage of Behaviors Expressing
Concerns About Intrusion

	GROUP			
WEEK	Short Stay Acute	Short Stay Chronic	Long Stay Chronic	Healthy
1	6.5	7.2	21.0	2.9
2	7.2	16.7	30.9	6.4
3		18.6	32.9	3.6
4			23.4	1.2
5			27.1	9.7
6				2.8

Intrusion. Play behaviors which demonstrated concerns about any entry into the body boundaries, including injections, tests, treatments, etc., occurred in the highest proportion in both groups of chronically ill children. In the long-stay chronic illness group, Intrusion accounted for 21 - 33% of the play and occurred in either the highest or second highest proportion on all but one interview. In the short-stay chronic illness group, Intrusion accounted for 16.7% and 18.6% of the play in the second and third interviews. In contrast, Table 5 shows that Intrusion always accounted for considerably less than 10% of play behaviors of children in the healthy and short-stay acute illness groups.

Body Integrity. Behaviors which demonstrated concerns about intactness or mutilation, health, illness, or reason for hospitalization, etc., occurred least frequently in the short-stay acute illness and short-stay chronic illness groups. Body Integrity comprised 5.6% - 11.5% of the play of healthy children and consistently ranked third or fourth on all of their interviews. Body Integrity concerns accounted for 2.8% -8% of the play behaviors of the long-stay chronic illness group on all interviews except the fifth interview when the proportion rose to 15.1%.

Caretaking. Behaviors which demonstrated activities of daily living which involve providing for another person, usually occurred in fairly small proportions and ranked fourth, fifth or sixth except in the short-stay acute illness group. In that group, Caretaking accounted for nearly 10% of the play and ranked third in each of the first two interviews. Only in the long-stay chronic illness group did the proportion of Caretaking concerns reach similar levels, accounting for 11.1% of play in the second interview and 9.3% of play in the fifth interview.

Violence. Play behaviors demonstrating aggressive acts or concerns about such acts occurred most often in the first interviews with all groups. However, violence accounted for 24.5% of the play of the short-stay chronic illness group and 11.95% of the play of the long-stay chronic illness group in the first interview. In contrast, in the short-stay acute illness and healthy children groups, Violence accounted for 6.0% and 7.9% of the behaviors on the first interview.

Statistical Analysis of Concerns Expressed

The preliminary statistical analysis used a logistic linear model to examine differences in the proportion of concerns expressed over time, and to determine whether there was a group x time interaction. For each of the ten categories of concern, there was a highly significant interaction of group x time with chi-square values, ranging from 17.5 -115.1 for eight degrees of freedom. Because of the group x time interaction, it is not possible to test statistically for differences between groups. Therefore, the statistical analysis of the full data set will test whether the differences in proportion of concerns expressed are explained by age, previous hospital experience, or experience with painful procedures.

DISCUSSION

It is impossible at this stage of analysis to draw conclusions about differing patterns of concerns in the four groups of children. There are, however, important overall patterns revealed in this preliminary analysis which have implications for nursing practice.

The expression of concerns related to Autonomy and Exploration accounted for a large number of the play behaviors in all interviews with the lowest rate of occurrence being 41% and the highest, 80.1%. This consistency across groups of high proportions of behaviors which demonstrate the child's efforts to do things for himself, pride in accomplishing tasks, or exploration of the nature and function of objects seems to indicate that such activities are important developmental concerns and remain a primary element in the lives of hospitalized children. However, the somewhat lower proportion of these concerns in the chronically ill children (41 - 48%) may reflect decreased curiosity and less push toward independence in these children because of obstacles created by their illness or the hospital environment. If these children are to achieve their developmental tasks (Erikson, 1963), nursing personnel must create situations which permit extensive assertion of autonomy and the exploration of a safe environment.

The preliminary analysis also makes clear that healthy children have fewer concerns related to Intrusion than chronically-ill children. However, the healthy children's relatively high ranking of concerns related to Body Integrity seems to reflect that such concerns about intactness of the body are, in reality, a developmental rather than a hospital-related concern. In contrast, Intrusion is at least as dominant a concern as Autonomy and Exploration for the long-stay chronic illness group. This pattern reflects the multitude of diagnostic and therapeutic procedures to which these children are subjected. Their play demonstrated dramatic re-enactments of these events and of the behavior expected of patients during these events. Nurses caring for these children should provide opportunities for such play and recognize that experience does not appear to decrease the chronically-ill child's concern about Intrusion.

The patterns of concerns relating to Caretaking and Violence are more difficult to interpret. The higher proportion of behaviors relating to Caretaking in the acute illness group may be a failure of this group's lack of experience with illness and hospitalization and resulting concerns about who will meet their needs. In contrast, the high proportion of concerns relating to Violence in both chronic illness groups may reflect these children's previous experience in hospital and resulting anger at re-admission.

If the patterns demonstrated in the preliminary analysis are also demonstrated in the analysis of the full data set, the study to examine the young child's coping pattern during long hospital stays must include observations during situations of normal developmental concern; that is, those stimulating efforts to explore or assert autonomy, as well as situations which evoke concern about body integrity and intrusion.

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RÉSUMÉ

Soucis des jeunes enfants hospitalisés atteints d'une maladie chronique

Cet article tient lieu de compte rendu préliminaire à une étude basée sur des entrevues visant à déterminer les soucis principaux d'enfants âgés de deux à cinq ans atteints d'une maladie chronique et hospitalisés et à les comparer aux soucis d'enfants sains de corps et d'enfants hospitalisés à court terme. Cette étude constitue la première étape d'un projet dont le but est de trouver des moyens d'examiner les façons dont s'y prennent les jeunes enfants atteints d'une maladie chronique et de mesurer l'effet des interventions d'infirmiers et infirmières visant à renforcer la capacité d'adaptation de ces enfants. Trente-cinq enfants (dix enfants sains de corps; dix enfants atteints d'une maladie très grave; dix enfants atteints d'une maladie chronique et hospitalisés à court terme; et cinq enfants atteints d'une maladie chronique et hospitalisés à long terme) ont été interviewés toutes les semaines pendant un maximum de six semaines. Les observations notées au cours de 100 entrevues ont été analysées selon le type de soucis manifesté. Les comportements de jeu classifiés comme souci d'autonomie ou d'exploration se sont produits avec une grande régularité mais ont néanmoins dominé les entrevues d'enfants sains de corps et d'enfants atteints d'une maladie très grave et hospitalisés à court terme. Dans le groupe d'enfants hospitalisés à long terme et atteints d'une maladie chronique, les soucis d'intrusion ont occupé la première place et prévalu sur les soucis d'autonomie et d'exploration. Les conséquences de cette analyse préliminaire sont ensuite discutées.