

ADJUSTIVE AND AFFECTIVE RESPONSES OF SCHOOL-AGED CHILDREN TO A LEG AMPUTATION

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The purpose of this study was to examine the adjustive and affective responses of children undergoing a leg amputation and to determine whether the responses followed an expectable pattern. Five school-aged children undergoing leg amputation were observed and interviewed for nine to fifteen days.

METHODOLOGY

THE SUBJECTS

The subjects were four girls and one boy ranging in age from ten to fourteen years. They had had no previous serious health problem prior to the onset of the illness which necessitated the amputation. The girls had Osteogenic Sarcoma which was being treated by amputation. The boy had sustained a fractured femur and severed femoral artery when struck by an automobile. An attempt to anastomose the femoral artery was unsuccessful and amputation became necessary five days after the accident.

The five subjects underwent amputation of one lower extremity at the knee or above. One had a knee disarticulation; three had an amputation above the knee; and one had a hip disarticulation. The nature of the surgical procedure to be performed was explained to the subjects two days to two months prior to surgery.

THE SETTING

The study was carried out in a children's hospital affiliated with a large medical centre. The subjects' three or twelve-bed rooms were the areas in which most periods of data collection occurred. Treatment or diagnostic areas provided the setting for other observations and interviews.

THE INVESTIGATOR

The investigator was a registered nurse who was employed as a clinical specialist by the hospital in which the study was conducted. She gave complete nursing care to the subjects. The subjects and their parents knew the investigator as a "special nurse" from Psychi-

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atry who would care for them during their hospitalization because of the difficult nature of their surgery.

DATA COLLECTION

The data were collected through observations and interviews conducted while the investigator was giving the subjects' nursing care. Data collection occurred almost daily from the time of referral to the investigator until the day of discharge or the ninth post-operative day. Data collection sessions were timed to coincide with events which were likely to be crisis-filled such as preparation for surgery, recovery from anesthesia, X-ray examinations, cast or dressing changes, and physiotherapy treatments. Data were also collected at times when the subjects' attention was likely to be focussed on the changes in their bodies such as during the early morning bath as subjects prepared for activities of the day; during parental visiting; initial interaction between the subjects and their parents following surgery; and following full recovery from anesthesia on the operative day.

One to three sessions of data collection occurred each day for eight to thirteen days for each subject. Pre-operatively, data were collected for two to six days, including the operative day. Sessions ranged from one to seven hours a day, averaging 2.5 hours a day per subject.

Post-operatively, data were collected for six to nine days, including the operative day. Sessions ranged from one to 5.5 hours per day, averaging 3.2 hours a day per subject.

There was variation in the number of days of data collection and in the length of periods of data collection necessitated by differences in the time of referral to the investigator, the length of hospital stay before and following surgery, and the length of time required for various treatments. Further variance within days resulted from the individual subject's needs, the arrival of unexpected visitors, and by the subjects' participation in hospital activities such as craft lessons or school.

During periods of data collection, behaviours relating to the subject's view of self as an amputee were observed. Particular care was taken to observe behavior relative to the amputation, the body image, the stump, the artificial limb, the phantom limb, the future, and the social behavior in interaction with others, and in response to a specific treatment provided the data base.

Non-directive interviews were conducted in the course of conversation with the subject. The interview usually centered on topics initiated directly or indirectly by the subject related to the amputation. Questions from the investigator were usually reflective, although some direct questions were asked. Direct questions related to feelings,

pain, the stump, and the phantom limb. Any questions from the subjects were answered and explanations were given as accurately as possible.

Following the periods of data collection, descriptive and verbatim behavior of the subject in interaction with the investigator and others in the environment was recorded in narrative sequential detail. These behavior protocols comprised the raw data for analysis.

Independent observations and interviews of the subjects were conducted two or three times during the study by the child psychiatrist and by a second nurse specialist. Conferences on each subject with the child psychiatrist and the nurse specialist were held by the investigator several times to verify observations, changes in behavior, and apparent areas of the subject's concerns.

DATA ANALYSIS

Content analysis was the method used to analyze the behaviour protocols. The behavior protocols were divided into units of behavior measurement. Each unit was distributed according to a system of classification which was developed after careful and repeated scrutiny of the behavior protocols. The subjects' hospital experiences were examined in four time phases: the pre-operative phase, the early post-operative phase, the middle post-operative phase, and the later post-operative phase.

A unit of behavior was any act of the subject, a vocalization, a verbal or non-verbal behavior, which implicitly or explicitly referred to the subject's self as an amputee. One unit ended and the next began when there was a change in emotional tone, when there was a change in the subject or content matter, or when there was a change in manifest non-verbal action. If the behavior was repeated in a series of vocalizations or actions, each occurrence in the series was a new unit.

A unit of vocalization consisted of any vocal utterance which did not contain words, such as "hum," "ugh," or "oh". A unit of verbal behavior consisted of a completed statement, a question, or a phrase, such as "I don't believe the doctor will take my leg off," or "Not so good." A unit of non-verbal behavior consisted of a completed action, such as turning away, rubbing the stump, or doing exercises.

An independent coder unitized a randomly selected sample of two pages from the behavior protocols of each subject. The percentage of agreement between the independent coder and the investigator was 82%.

The units of behavior were categorized according to the dimensions of the subjects' experiences as amputees including: (1) Condition

of the self: being an amputee or being ill; (2) Physical characteristics: appearance or functional capacity; and (3) Social aspects: contact with others or reactions of others. The behavioural responses to each of the dimensions were classified as adjustive responses and affective responses.

An independent coder categorized the protocols. The percentage of agreement in coding between the independent coder and the investigator was 90% for the dimensions of the self and 74% for the behavioral responses.

The behaviors in each time phase were also analysed to determine the primary areas of concern and to determine whether there were any trends in patterns of behavior over time. The data were examined to determine whether the factors of age and sex influenced behavior patterns. Further examination of the data elicited major themes of the behavior.

FINDINGS

The children's predominant response to the aspects of the self as amputee was adjustive behavior through which they began to apprehend the reality of changes in themselves. Adjustive responses were most frequently in the form of verbal and non-verbal behaviors seeking information which identified the self as an amputee. The children limited information to manageable amounts through behaviors which restricted the amount and type of information received. Limitation behaviors decreased during the later post-operative phases. Alteration behaviors, wishes, fantasies, and dreams, which attempted to change the reality of becoming an amputee, occurred prior to the amputation and then decreased sharply. The children's adaptive responses, behaviors indicating a beginning accommodation to the changes in the self as amputee, increased with the beginning of mobility training, an event which appeared to represent a degree of restitution.

Affective responses to the self as an amputee occurred less frequently than adjustive responses. The occurrence of all affective responses except hope or pride remained constant over the four time phases. The most frequent affective response was depression through which the children expressed their sadness and grief about being an amputee. Fearful responses, occurring almost as frequently as depression responses, were expressed in relation to treatments or other threats involved in being ill, beginning mobility, and the reactions of others to them as amputees. Rejection, expressed through anger or aversion, occurred in response to being an amputee and in response to the appearance of the stump and temporary and permanent artificial limbs. Expressions of hope or pride were few in number and

were almost exclusively in relation to their functional capacity or recovery from illness.

The dimensions of the self as an amputee to which the children referred shifted in relation to the time phases of the hospital experience. The condition of the self as amputee, including being ill and being an amputee, was the major focus of the children's response throughout the study. However, the proportion of references to the condition of the self decreased with increasing mobility. The responses to the physical characteristics were mostly in relation to appearance during the early and later post-operative phases, whereas functional capacity was the focus in the pre-operative and middle post-operative phases. Reference to the social aspects of the self occurred least frequently but were observed most often in the middle and later post-operative phases when the children increased contacts in the hospital and prepared for discharge from hospital.

The children were able to begin to adapt to their amputation during the first nine post-operative days. The process of grieving the loss of a body part seemed to occur simultaneously with the striving to establish realistic information about the self as an amputee. The patterns of response to amputation seemed to represent a struggle toward mastery.

In summary, the adjustive and affective responses of five children to leg amputation revealed a theme of active coping through a reality oriented struggle to achieve mastery. This was coupled with a pattern of limitation behaviours which prevented the input of overwhelming amounts of information. In the later phases following amputation, limitation behaviors became less necessary and the children began to exhibit reality-based adaptive behaviors. The second aspect of the children's response was the effort to begin to establish an altered body image through sensations, mobility, and the social input of others.

Réactions d'adaptation et réactions affectives à une amputation de la jambe chez les enfants d'âge scolaire.

Dans cette étude, qui visait à étudier les réactions d'enfants soumis à une amputation de la jambe, le chercheur a analysé le comportement de cinq enfants âgés de dix à quatorze ans pendant deux à six jours avant et six à neuf jours après l'opération. Les données ont été recueillies à partir d'observations et d'entrevues non structurées pendant que le chercheur donnait des soins infirmiers aux malades; les séances étaient choisies en fonction des moments susceptibles d'être critiques ou d'attirer l'attention de l'enfant sur l'amputation.

En examinant par analyse de contenu, les expériences des enfants hospitalisés, les protocoles de comportement furent divisés en unités de mesure du comportement. Chaque unité était à son tour classée d'après les dimensions de l'expérience d'amputé (état de la personne, caractéristiques physiques et aspects sociaux) ainsi que d'après les réactions en termes de comportements (affectives et d'adaptation) à chaque dimension.

L'étude a révélé chez les sujets une modalité efficace et active de faire face à leur situation, associée à un schème limitatif, restreignant ainsi les informations reçues à des doses assimilables. Après l'amputation, les comportements limitatifs ont progressivement diminué, les enfants ont commencé à présenter des comportements d'adaptation fondés sur la réalité et à se faire une image différente de leur corps grâce à leur sensations, leur mobilité et aux contacts avec d'autres personnes.