The Effects of Habilitative Hospital Admission on Self-Care, Self-Esteem, and Frequency of Physical Care

Deborah J. Bolding, Lela A. Llorens

Key Words: arthritis, juvenile rheumatoid • pediatrics • spina bifida

The effects of a habilitative hospital admission for the multidisciplinary teaching of activities of daily living were investigated with 3 children with spina bifida and 1 child with juvenile arthritis. Specific evaluation tools included analysis of individualized goals, the Klein-Bell Activity of Daily Living Scale (Klein & Bell, 1979), the Physical Child Care Record (Johnson & Dietz, 1985), and the Piers-Harris Children's Self-Concept Scale (Piers & Harris, 1967). The children were evaluated on hospital admission, at discharge, and 3 months after discharge. The results show that hospital admission can be an effective means of increasing independence and decreasing frequency of physical care by parents. Some changes in self-esteem occurred in both directions, however, these changes may be attributed to variables other than hospitalization or changes in self-care status.

Children with physical disabilities receive habilitative services on an outpatient basis in a variety of settings, including child development centers, private practice, schools, and hospitals. Some settings may lack an interdisciplinary team, or staffing may preclude an intensive therapy program. Further, not all habilitative goals are appropriately addressed in some of the settings. Although a short hospital stay with intensive therapeutic intervention may be an effective means of helping children achieve habilitative goals, little research has been conducted to study the effects of habilitative hospital admission on children.

The effects of a community-based day habilitation program on self-help, use of community services, knowledge about self, and improved support systems were studied by Sherman, Berling, and Oppenheimer (1985), who rated the value of the program primarily by the participants' attendance and subjective comments. The authors concluded that the program helped with normalization by providing the subjects with socialization with nondisabled peers and typical teen activities in community facilities. A more systematic program evaluation was undertaken by Bodzioch, Roach, and Schkade (1986), who evaluated adolescents with myelodysplasia before and after a 2-week camping experience. Six campers with myelodysplasia and 6 adolescents with myelodysplasia who served as the control group completed the Piers-Harris Children's Self-Concept Scale (Piers & Harris, 1967) and an activity of daily living evaluation. Eight months after the camping experience, the campers had improved significantly more than the control subjects in activities of daily living. The campers also had higher scores on the Piers-Harris scale, but the differences were not statistically significant.

Two hospital-based independent living courses are described in the literature. A 10-day hospital stay for 5 teenagers with spina bifida included self-care, homemaking, shopping, budgeting, and recreational activities. In follow-up reports after hospitalization, the parents and teenagers alike reported greater independence (Dainty, 1978). A similar program for 10 subjects lasted only 1 week (Macredie & Bradshaw, 1984). The children and parents were interviewed before, immediately after, and 4 months after hospitalization. Assessments of self-care and mobility tasks were made at each interval. All of the subjects showed improved ability during hospitalization, although in some cases the subjects were not performing at their level of ability at the 4 month follow-up.

Although hospitalization affords the opportunity for intensive interdisciplinary teaching, evidence suggests it may also lead to behavioral disturbances or decreased self-esteem after discharge (Wilkinson, 1978). Preparation for hospitalization, a healthy parent-child relationship, frequent visiting or rooming in by the parents, and maintenance of contact with school friends appears to decrease the risk of problems (Riffee, 1981; Wilkinson,
1978). Many pediatric hospitals now follow the principles of family-centered care. For school-age children, there is evidence that when these principles are followed, there is no increased risk of negative behavioral changes after discharge (McClowry & McLeod, 1990).

The purpose of the present study was to investigate the effects of a short habilitative hospital admission for the interdisciplinary teaching of activities of daily living on children with myelodysplasia and juvenile arthritis. The hypotheses were as follows:

1. The children will become more independent in functional skills.
2. Self-esteem will change as a result of the child's becoming more independent.
3. The frequency of personal care that the parents provide to the child will decrease once the child is discharged to the home.

**Method**

**Subjects**

All children admitted to the hospital for habilitation during a 4-month period and their parents were asked to participate in the study. Of the 5 subjects admitted during the study period, 3 had spina bifida and 1 had juvenile arthritis. The fifth subject, who had cerebral palsy, was omitted from the study because of incomplete data. Each of the remaining 4 subjects is described below.

Subject 1 was a 14-year-old boy with lipomyelomeningocele at the L-3 level. He lived with his parents and sister and was in the ninth grade. Before admission, he was independent in all self-care except bowel and bladder programs. Mobility was accomplished with a lightweight wheelchair. He was active in wheelchair sports and the school band and had part-time jobs mowing lawns and babysitting. He was hospitalized for 8 days.

Subject 2 was a 9-year-old girl with spina bifida at the L-4 level. At the time of admission, she lived with her parents and sister and was in the third grade. She was independent in activities of daily living except for bowel and bladder programs. She had incoordination and weakness of her left hand, which made self-care skills, such as fastenings and catheterization, difficult. She ambulated with ankle-foot orthoses and forearm crutches. She was hospitalized for 11 days.

Subject 3 was a 10-year-old girl with spina bifida at the sacral level. She lived with her mother, stepfather, and sister. She attended a school for orthopedically disabled children because of bowel and bladder incontinence but was in a program for educationally gifted children. She ambulated independently and enjoyed cooking, roller skating, biking, and playing video games. She avoided swimming, overnight parties, and some other social activities because of incontinence. She was hospitalized for 8 days.

Subject 4 was a 14-year-old girl with juvenile arthritis. She was admitted to the hospital by the pediatrician at her first outpatient clinic visit for management of medications and intensive therapy. Her condition had first been diagnosed as arthritis when she was 4 years old. She had not received physical therapy in the year before admission and had never received occupational therapy. She had not been ambulatory in 3 years and had contractures that prevented ambulation. A powered wheelchair provided independent mobility. She was hospitalized for 2 months, with weekend passes after the first month.

**Procedure**

One aim of the research was to compare the children's functional skills before hospitalization, at discharge, and 3 months after discharge. Independence in functional activities was evaluated with the Klein–Bell Activity of Daily Living (ADL) Scale (Klein & Bell, 1979). This scale measures level of independence in dressing, elimination, mobility, bathing and hygiene, eating, and communication and provides a numerical representation of performance in these categories. In addition to this evaluation, three to four individualized functional goals were decided on by the child, parents, and health care team. Each child was reevaluated at discharge and 3 months after discharge to determine whether these goals had been met.

A second aim of this study was to compare children's self-esteem before hospitalization and 3 months after discharge. Self-esteem was measured with the Piers–Harris Children's Self-Concept Scale. This test provides cluster scores for behavior, intellectual and school status, physical appearance and attributes, anxiety, popularity, and happiness and satisfaction.

The third aim of this study was a comparison of the frequency of physical care provided by parents before hospitalization and 3 months after hospitalization. This was made possible through the use of the Physical Child Care Record (Johnson & Dietz, 1985). Subject 2's parents were trained to use the form, then asked to keep a record for 1 week before admission. The first author contacted the family by telephone during the data collection period to ensure that correct procedures were followed. Baseline data were not collected for the other 3 subjects due to an insufficient length of time before admission in which to collect information.

The subjects were referred to the program by community therapists or by the physician or nurse coordinator for the outpatient clinic. The habilitation team, which involved the physician, nurse, social worker, occupational therapist, physical therapist, dietitian, and recreation therapist, met with the child and family to make an evaluation and discuss goals. The habilitation team would recommend one of three options: increased outpatient services, no change in the program, or hospital admission. Admission might be recommended if the subject had not
progressed in a community program, if local services were limited or unavailable, or if the child required intensive individualized training.

During hospitalization, the children received individualized training in activities of daily living at a developmentally appropriate level for the following areas: bowel and bladder programs, self-medication, eating, hygiene, dressing, bathing, mobility, homemaking, nutrition, sexuality, leisure, and community skills. Family training was ongoing throughout the admission and included family conferences, individual teaching, and, sometimes, videotaped home programs. Occupational therapy was provided at least daily but usually twice daily. Goals were individualized for each child and family.

Data Analysis

The design of this study is descriptive. Baseline measurements were collected, treatment was instituted, and a second baseline was established 3 months after hospitalization. A descriptive analysis of the data was used to determine the extent to which changes occurred.

Results

Admission goals and discharge status for each subject are presented in Table 1. The three children with spina bifida met their admission goals at discharge and maintained their status at the 3-month follow-up. The child with juvenile arthritis was unable to meet her goals because of daily variations in pain, stiffness, endurance, and strength. She was referred for outpatient physical therapy and occupational therapy after discharge.

The results of the Klein-Bell ADL scale are presented in Table 2. All 4 subjects showed improvement in the total score. The subjects with spina bifida had deficits in the category of elimination, and all showed improvement in this area. Three-month follow-up data were not available for Subject 3. In the postdischarge period, she had surgery for implantation of a bladder stimulator, her family moved, she started a new school, and her mother had a major illness. Telephone follow-up revealed that this subject sometimes regressed in self-care and in taking medications during this period, but a formal reevaluation was not possible.

The family of Subject 2 was asked to complete the Physical Child Care Record. When they arrived at the hospital, the father had decided not to use this record and instead had written his own narrative of the week. Because the data were similar to those asked for in the Physical Child Care Record, frequency of physical care by the parent was counted. Before admission, the parents' provision of physical care averaged 8 times a day. Three months after hospitalization, their provision of physical care averaged 2 times a day, consisting of helping the child with a diaper in the morning and at night. At school, the child managed her diaper independently.

On the Piers–Harris scale, the total percentile score for Subject 1, who had spina bifida, remained the same; for Subject 2, who also had spina bifida, the total score increased. The total score for Subject 4, who had juvenile arthritis, dropped by 16 points. Follow-up scores were not available for Subject 3. Percentile scores for the subscales are presented in Table 3. The total scores on all tests, both before and after admission, were in the above-average range.

Discussion

The 3 children with spina bifida met their individual goals at discharge and maintained or improved their discharge status at the 3-month follow-up evaluation. Subject 3 showed some regression, per telephone conversations with her mother, but this might be attributed to her subsequent surgery or to her mother's diagnosis of and treatment for cancer. The subject with juvenile arthritis did not meet her admission goals, perhaps because these

### Table 1

<table>
<thead>
<tr>
<th>Subject</th>
<th>Admission Goals</th>
<th>Discharge Status</th>
<th>3-Month Follow-Up</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 (Spina bifida)</td>
<td>Independent clean catheterization</td>
<td>Independent</td>
<td>Independent</td>
</tr>
<tr>
<td>2 (Spina bifida)</td>
<td>Independent clean catheterization</td>
<td>Independent</td>
<td>Independent</td>
</tr>
<tr>
<td>3 (Spina bifida)</td>
<td>Independent clean catheterization</td>
<td>Independent</td>
<td>Independent</td>
</tr>
<tr>
<td>4 (Juvenile arthritis)</td>
<td>Moderate assist transfers</td>
<td>Maximum assist</td>
<td>Moderate assist</td>
</tr>
<tr>
<td></td>
<td>Moderate assist bathing</td>
<td>Maximum assist</td>
<td>Moderate assist</td>
</tr>
<tr>
<td></td>
<td>Prone position for 20 min</td>
<td>Achieved</td>
<td>Achieved</td>
</tr>
<tr>
<td></td>
<td>Nutrition teaching and weight control</td>
<td>Achieved</td>
<td>Achieved</td>
</tr>
</tbody>
</table>

September 1991, Volume 45, Number 9
goals were unrealistic or the results were influenced by the medical treatment of the disease (i.e., medication changes).

The improvement of scores on the Klein-Bell ADL scale at discharge indicates that hospitalization helped all 4 of the children to become more independent in self-care. At the 3-month follow-up, the 3 children for whom data were available remained at the same level or had improved. This is in contrast to the findings of Macredie and Bradshaw (1984), who found that children regressed in some cases.

Learning their personal bowel program and self-catheterization were treatment goals for the children with spina bifida. Continence of bowel and bladder were excluded as goals because continence may take a period of time to establish, and sizable numbers of children with spina bifida do not become totally continent (Okamoto et al., 1984). More realistic goals, such as learning to manage bowel and bladder programs to maintain health; developing strategies for dealing with social and environmental problems; and fostering acceptance of physical limitations will help the child feel more successful. Bowel and bladder continence is measured by the Klein-Bell ADL scale. One of the 3 subjects became continent after learning the bowel program and self-catheterization.

The inability to obtain data on physical care provided by the parents was disappointing. The Physical Child Care Record appears to be a useful tool for the study of whether the information the child learns in the clinic or hospital is used at home and the effects of treatment on the parents. Blaylock (1983), Joosten (1979), and McAndrew (1976) determined that mothers of disabled preschoolers spent 1 1/2 to 2 times as much time in physical child care activities as mothers of nondisabled children. In the present study, for Subject 2, for whom posthospitalization data were available, there was a marked decrease in the frequency of care.

Williamson (1987) described increased independence in activities of daily living as a major achievement of early childhood, contributing to a sense of competence and self-esteem. Self-esteem is influenced by other factors as well, including physical appearance, familial relationships, school performance, and peer relationships. Although children with physical disabilities may be at risk for lower self-esteem (Hayden, Davenport, & Campbell, 1979; Kazak & Clark, 1986; Teplin, Howard & O'Connor, 1981), some researchers have found no significant differences between disabled and nondisabled children (Pearson, Carr, & Halliwell, 1985; Steff, Shear, & Levinson, 1989). Studies show that when the family accepts the child's disability and fosters self-responsibility and communication with the child, problems may be minimized (Matson, 1972). The scores of the children in the present study on the Piers-Harris scale were average or above-average. This may reflect high self-esteem despite physical disabilities or failure to admit problems. It may also indicate that children with higher self-esteem are more likely to seek help for their problems.

For the individual subjects in this study, it was difficult to determine if changes in self-esteem before and after hospitalization were due to treatment or to other factors. During the time between initial testing and follow-up, Subjects 1, 2, and 3 started new grade levels,

### Table 2
Children's Percentage Scores on the Klein-Bell Activity of Daily Living Scale

<table>
<thead>
<tr>
<th>Category</th>
<th>3-Month Follow-Up</th>
<th>3-Month Follow-Up</th>
<th>3-Month Follow-Up</th>
<th>3-Month Follow-Up</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Admission</td>
<td>Discharge</td>
<td>Admission</td>
<td>Discharge</td>
</tr>
<tr>
<td></td>
<td>Subject 1</td>
<td>Subject 2</td>
<td>Subject 3</td>
<td>Subject 4</td>
</tr>
<tr>
<td>Dressing</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>Elimination</td>
<td>74</td>
<td>87</td>
<td>100</td>
<td>62</td>
</tr>
<tr>
<td>Mobility</td>
<td>91</td>
<td>91</td>
<td>100</td>
<td>52</td>
</tr>
<tr>
<td>Bathing/hygiene</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>Eating</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>Mobility</td>
<td>91</td>
<td>91</td>
<td>100</td>
<td>52</td>
</tr>
<tr>
<td>Communication</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>100</td>
</tr>
</tbody>
</table>

Note: na = not available.

*(Klein & Bell, 1979)*

### Table 3
Children's Percentile Scores on the Piers-Harris Children's Self-Concept Scale

| Cluster Scores | 3-Month Follow-Up | 3-Month Follow-Up | 3-Month Follow-Up |
|               | Admission         | Admission         | Admission         |
|               | Subject 1         | Subject 2         | Subject 3         |
| Behavior      | 95                | 81                | 51               | 63               |
| Intellectual  | 90                | 70                | 70               | 90               |
| Physical      | 91                | 97                | 84               | 84               |
| Anxiety       | 58                | 81                | 37               | 48               |
| Popularity    | 38                | 86                | 52               | 52               |
| Happiness     | 90                | 72                | 20               | 20               |
| Total         | 94                | 95                | 55               | 74               |

Note: Follow-up data were not available for Subject 3; her total score on the Piers-Harris scale at admission was 94.

*(Piers & Harris, 1967)*
thus involving new teachers and classmates. This may have affected several subscores on the evaluation. Subject 2’s parents had separated. The subject with juvenile arthritis showed a large decrease in total percentile score on the Piers–Harris scale (Piers & Harris, 1967). She denied any significant family or school problems and returned to the same school and classes after hospitalization. Perhaps the hospital admission, where she achieved relatively small functional gains and which underscored the chronic nature of her disease, disrupted a coping mechanism of denial.

In conclusion, hospital admission appeared to be an effective means of meeting habilitative goals for the 4 children in this study. Self-esteem remained the same for 1 child, increased for 1, and decreased for 1 (follow-up scores were not available for 1 subject). We found it difficult to attribute changes in self-esteem to hospitalization versus other life changes in the subjects. Limitations of the study include small sample size, difficulty in obtaining data on the Physical Child Care Record, and lack of a control group. We cannot determine from this study whether the children could have been treated as effectively or more effectively in other settings. Future studies might explore these areas. A major advantage of this study is that it uses evaluation tools that are readily available to clinicians and that may already be used for the assessment of treatment efficacy. These tools are not limited to use by hospital clinicians, but may be applied in a variety of settings.

Acknowledgments
We wish to thank R. Kirklin Ashley, MD, and Dena Holbrook, SP, at the Shriner’s Hospital for Crippled Children, San Francisco, for their support of this project, and Susan Roldan, OTR, for assistance with data collection.

References


