Addressing Children's Needs and Evaluating Rehabilitation Outcome After Spinal Cord Injury: The Child Needs Assessment Checklist and Goal-Planning Program

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Received October 26, 2006; accepted January 8, 2007

Abstract

Background/Objective: Spinal cord injury (SCI) is a devastating event with lasting implications for children and families. The rehabilitation of children and adolescents with SCI must be developmentally based, and goal-planning programs must respond to their changing needs as they grow. The Child Needs Assessment Checklist (ChNAC) and goal-planning program provides a developmentally sensitive way to assess and address young people's needs within the context of their family and community. This preliminary study investigated the utility of the ChNAC in planning rehabilitation goals and evaluating outcomes for young people.

Methods: A retrospective review of scores on the ChNAC was conducted to assess the effectiveness of the goal-planning program in addressing pediatric patients' rehabilitation needs. The sample comprised 33 young people for whom both baseline and outcome ChNACs had been completed.

Results: Comparison of goals achieved on baseline and outcome ChNACs by median percentage score showed improvements in 9 of 10 areas. Differences in scores were compared across demographic groups.

Conclusions: The ChNAC is a practical tool for planning young people's rehabilitation after SCI and assessing rehabilitation outcome. This study is a preliminary demonstration of the pediatric goal-planning program's effectiveness in achieving positive rehabilitation outcomes. Future research should replicate these results with larger samples and include detailed studies of the ChNAC's reliability and validity.

J Spinal Cord Med. 2007;30:S140–S145

Key Words: Spinal cord injuries; Rehabilitation; Disability; Child; Adolescence; Needs assessment; Functional Independence Measure

INTRODUCTION

Spinal cord injury (SCI) is a devastating event with lasting implications for children and families. Physical and psychosocial well-being is challenged, creating a range of needs for intervention from rehabilitation services. Because these needs are dynamic, resulting from the interaction of the SCI with growth and development (1), the rehabilitation and habilitation of children and adolescents with SCI must be developmentally based and respond to these individuals' changing needs as they grow (2). This involves a process of anticipatory guidance, in which rehabilitation programs equip young

people with the skills and resources needed to manage not just their current situation but also their future adolescent and adult roles (1).

Rehabilitation programs should take into account findings on adult outcomes in pediatric-onset SCI (1). This research indicates that rehabilitation programs must focus on reducing medical complications, achieving functional independence, facilitating access to education, preparing for work, enabling and encouraging community participation (in such productive activities as hobbies, social activities, and travel within the community), and facilitating preparation for significant personal relationships with, for example, future spouses or children (3).

In a complex clinical situation, efforts at rehabilitation need to be carefully planned and organized. Goal planning is an established method of planning and delivering rehabilitation in adult SCI (4). The Adult Needs

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Assessment Checklist (NAC) was developed to provide a framework for rehabilitation after SCI and forms the basis for the goal-planning program (5). This measure provides the necessary fine level of detail to be sensitive to rehabilitation gains (5) and has been shown to have satisfactory reliability and validity (6). Goal planning has also been shown to increase adults' engagement and motivation with rehabilitation (7). This is relevant, particularly for adolescents, whose levels of motivation may fluctuate as a result of normal development, but also for children of all ages and their parents, all of whom will need to be successfully engaged in the rehabilitation process for this to be effective. The goal-planning program, instituted at the National Spinal Injuries Centre with adult patients in 1989, was adapted for use with pediatric patients to meet these key aims in delivery of rehabilitation.

Measures designed specifically for use with children and adolescents are needed to assess neurological status and outcomes of pediatric SCI; the American Spinal Injury Association (ASIA) standards and method of neurological examination and classification require adaptation for suitability with young people (1). Additionally, a measure that provides a fine-grained assessment of rehabilitation needs and outcomes for young people is required to provide details of the individual needs of the young person and family that goal planning must address, as well as an evaluation of how successful the goal-planning program has been in meeting these needs. The Functional Independence Measure (FIM and WeeFIM) has been used successfully with children and adolescents to assess rehabilitation outcomes after SCI in terms of functional status (8). However, research has underlined the importance of considering the psychosocial development and community context of children and adolescents with SCI and the interaction of these with physical development, rather than a narrow focus on functional skills and physical abilities (9). In the absence of such a measure existing for use with young people, the Child Needs Assessment Checklist (ChNAC) was developed for use with children and adolescents younger than 17 years of age. The ChNAC was developed from the Adult NAC already in use with adults undergoing rehabilitation after SCI described above, through discussion with the pediatric treatment team. It comprises 10 sections, broken down into specific microlevel skills, knowledge, and equipment needed and arrangements that must be made, covering the areas of activities of daily living, skin management, bladder and bowel management, knowledge of spine, promotion of health growth, mobility, wheelchair and equipment, community and education, discharge coordination, and psychological issues. The items were derived from evidence based on standards in clinical practice for each area of rehabilitation. The ChNAC comprises 183 behavioral indicators or quality standards; this level of detail is helpful in highlighting exactly where rehabilitation efforts need to be targeted.

Development of the Child and Adult NACs was based on treatment theory (10), which describes the processes that occur in the transformation from input to outcome in health care. The problems or needs for a specific population are defined, after which the input required, important steps to produce the desired effects, mode of delivery, and expected outcome are specified (5). The ChNAC applies this method by specifying (a) the statement of need, that is, general areas that must be covered in rehabilitation (eg, mobility), (b) the goal (eg, being independent in wheelchair mobility), and (c) the behavioral target (eg, going up and down curbs using backwheel balance). The ChNAC is administered by an allocated keyworker with the patient and parents shortly after the beginning of the rehabilitation program. Assessment is based on respondents' own views of their (or their children's) skill or knowledge, reflecting the need to incorporate service users' perceptions into assessment tools for clinical use (11). Items are scored on a scale of 0 to 3, indicating no independence up to full independence. The score for each subscale is then transformed to highlight the percentage achieved in each area, and a written summary is produced detailing the areas that remain to be addressed in the goal-planning program. This shows strengths and needs relative to each other so that priorities can be established. The keyworker coordinates the goal-planning program with the patient and other members of the interdisciplinary team to work on identifying needs, establishing goals, and setting targets. The ChNAC is readministered shortly before discharge from the rehabilitation center to highlight any outstanding issues and provide an evaluation of progress.

The ChNAC incorporates the necessary flexibility to prompt goal planning to respond to the dynamic and changing needs of the developing child. This is important to prevent the delay that rehabilitation teams may otherwise contribute to in the young person's acquisition of developmentally appropriate skills (12). Items that are not yet developmentally appropriate are scored as P, indicating "not developmentally appropriate but done by parents/carers" (entered as 3, because the need is being met). When the ChNAC is next administered, if the child has developed sufficiently for a particular item to become developmentally appropriate, this item can then be scored according to the level of independence achieved. When this score is less than 3, this highlights the area that goal planning now needs to address. Another key feature of the ChNAC (and also the Adult NAC) is that it is completed in terms of physical independence for individuals who have, or will eventually have, the physical capacity and in terms of verbal independence for individuals who will require physical assistance in the longer term. Consequently the ChNAC makes it possible for everyone to achieve 100% in each area of rehabilitation regardless of their level of injury (5).

The ChNAC and goal-planning program was implemented at the center in 1991 but had not been systematically evaluated. This preliminary study investigated the utility of the ChNAC in planning rehabilitation goals and evaluating outcome for young people. It was hypothesized that the ChNAC would demonstrate significant improvements in all areas assessed after rehabilitation delivered through the goal-planning program. A second hypothesis was that there would be no differences in improvement according to age group, gender, or level of injury.

METHODS

Design

The study involved a retrospective review comparing scores on baseline and outcome ChNACs for pediatric patients at a national SCI rehabilitation center.

Participants

All 33 children and adolescents for whom both baseline and outcome ChNACs had been completed since the institution of the ChNAC and goal-planning program were included in the study. The baseline ChNAC was completed at the start of inpatient rehabilitation, and the outcome ChNAC was completed either at the end of inpatient rehabilitation or during a follow-up admission known as “kids week,” a week-long course to improve existing skills, which took place annually. The mean age of participants was 8.45 years (SD = 4.27), with a range from 2 to 16 years. The sample comprised 20 (61%) male and 13 (39%) female participants, with 23 (70%) who had paraplegia and 10 (30%) who had tetraplegia. The most common cause of injury was road traffic accidents (17 participants, 52%), followed by nontraumatic injury due to progressive medical conditions (eg, cancer [9 participants, 27%]) and treatment complications [3 participants, 9%], falls (3 participants, 9%), and sporting accidents (1 participant, 3%). The mean time delay between the baseline and outcome ChNACs was 47.46 weeks (SD = 31.35), with a range from 1 week to 2 years, 33 weeks.

Materials

The ChNAC is a behavioral checklist consisting of key indicators in the following areas of need: Activities of Daily Living (17 specific indicators), Skin Management (10 indicators), Bladder Management (7 indicators), Bowel Management (11 indicators), Knowledge of Spine and Promoting Healthy Growth (15 indicators), Mobility (11 indicators), Wheelchair and Equipment (36 indicators), Community and Education (20 indicators), Discharge Coordination (28 indicators), and Psychological Issues (26 indicators for ages 0 to 6 years and 28 indicators for ages 7 to 16 years).

Procedure

Clinical records were reviewed to gather completed ChNACs for all pediatric patients with whom both

baseline and outcome measures had been administered from 1993 through 2006. Assessment using the ChNAC had been carried out with children and adolescents admitted to the center as part of clinical intervention, as described in the Introduction. Percentage achieved scores on each of the 10 areas of need were used as the data to be compared between baseline and outcome ChNAC assessments for each patient.

Data Analysis

Because of the nonparametric nature of the data, Wilcoxon signed-ranks tests were executed to determine whether there were any significant differences between median percentage achieved scores on baseline and outcome ChNACs. Significance was taken at the $P < 0.05$ level. A Kruskal-Wallis test was carried out to assess differences in time delay between baseline and outcome ChNAC assessments according to age group.

RESULTS

Comparison of goals achieved on baseline and outcome ChNACs by median percentage score showed improvements in 9 of 10 areas of need. Differences in scores were compared across groups classified by age, gender, and level of injury. The median percentage achieved scores for baseline and outcome ChNACs are shown in Figure 1. Improvements were demonstrated in all areas except Psychological Issues, which showed a slight decrease in percentage achieved score.

The median percentage achieved scores for baseline and outcome ChNACs were compared for the age groups of younger than 5 years, 6 to 8 years, 9 to 12 years, and 13 to 16 years. Because of the small numbers in each group, results were affected by missing data in some cases. In the younger than 5 years age group, improvements were observed in Activities of Daily Living, Bladder Management, Knowledge of Spine, Mobility, Community and Education, and Discharge Coordination, but the other areas showed a decrease in scores. In the 6- to 8-year-old age group, there were improvements in the areas of Skin Management, Bowel Management, Community and Education, and Psychological Issues but a decrease in the other areas, except Wheelchair and Equipment, in which there were no differences in scores between the first and second assessments. In the 9- to 12-year-old age group, there were improvements in all areas, except Bowel Management (in which scores showed no change) and Psychological Issues and Activities of Daily Living (which decreased), and missing data prevented computation of an outcome score for Discharge Coordination scores. Figure 2 shows the results for the 13- to 16-year-old age group, in which improvements were observed in all areas.

Among the boys, there were improvements in all areas except Bladder Management and Psychological Issues. The girls' scores improved in all domains except Activities of Daily Living, which decreased, and Psycho-

Figure 1. Comparison of goals achieved on first and second child needs assessment checklist.

logical Issues, which remained the same. In terms of level of injury, individuals with paraplegia showed an increase in scores in all domains except for Bladder Management, which stayed the same, and scores among individuals with tetraplegia increased in all areas apart from Activities of Daily Living, Bladder Management, and Psychological Issues, which all demonstrated a decrease.

These comparisons were subjected to Wilcoxon signed-ranks tests to establish whether the observed differences in scores between baseline and outcome ChNACs were statistically significant. In the whole sample, statistically significant differences were observed in the areas of Knowledge of Spine ($P < 0.001$), Mobility ($P = 0.006$), Community and Education ($P = 0.031$), and Discharge Coordination ($P = 0.018$). In the younger than 5 years age group, no statistically significant differences were observed. The 6- to 8-year-old and 9- to 12-year-old

age groups were collapsed because of small N sizes, and in this group of 6- to 12-year-old children, a statistically significant difference was observed in the area of Community and Education ($P = 0.034$). In the 13- to 16-year-old age group, statistically significant differences were observed in the areas of Skin Management ($P = 0.011$), Bowel Management ($P = 0.028$), Knowledge of Spine ($P = 0.011$), Mobility ($P = 0.021$), Wheelchair and Equipment ($P = 0.028$), and Discharge Coordination ($P = 0.043$).

Boys showed statistically significant differences in the areas of Knowledge of Spine ($P = 0.015$) and Discharge Coordination ($P = 0.043$). Girls showed statistically significant differences in Bowel Management ($P = 0.043$), Knowledge of Spine ($P = 0.013$), and Mobility ($P = 0.019$). Paraplegics showed significant differences in the areas of Knowledge of Spine ($P = 0.001$) and Mobility

Figure 2. Comparison of goals achieved on first and second child needs assessment checklist (age 13–16 years).

($P = 0.001$). No significant differences were observed among tetraplegics in any of the areas.

The Kruskal-Wallis test indicated that there was a difference in time delay between baseline and outcome assessments according to age, which just reached significance ($P = 0.05$). Mann-Whitney U tests were performed to analyze further the differences among the 3 age groups (≤ 5 years, 6–12 years, and 13–16 years). The result showed that the youngest age group had significantly longer time delays between baseline and outcome ChNAC assessment compared with the 13- to 16-year-old age group ($P = 0.030$).

DISCUSSION

The results from this review of 33 young people using the ChNAC indicate that the checklist is useful in identifying areas to be addressed through rehabilitation and habilitation, the goal-planning program is effective in addressing these areas in order to produce rehabilitation gains for individual patients, and the checklist can be used to assess the effectiveness of this in terms of rehabilitation outcome. These findings are encouraging but must be treated cautiously. Because the study included no control group, the improvements noted in ChNAC scores can only be assumed to be attributable to the goal-planning program.

Analysis of the changes in median percentage achieved scores between baseline and outcome ChNAC assessments for different demographic groups of the sample showed no major differences between boys and girls or between paraplegics and tetraplegics. This is reassuring given the emphasis of the ChNAC on promoting equal opportunities for achieving maximum rehabilitation potential, regardless of level of injury and other variables (eg, gender). Contrary to expectations, however, the results showed greater improvements for adolescents compared with younger children.

This is clearly a preliminary study with a small sample size, limiting the possibility of drawing more general conclusions from the results. The sample size partly reflects the relatively low incidence of pediatric SCI and low throughput of patients in a 6-bed inpatient facility, which is to date the only dedicated pediatric SCI center in the country. It is possible that the ChNAC is a less sensitive measure for younger vs older children. However, it may also be that the scoring system for the ChNAC introduces a confound when items scored as P (tasks that are not yet developmentally appropriate and are carried out by parents/carers) are entered as 3 (the maximum score). This creates a situation in which the child who is younger at administration of baseline ChNAC and requires more parental assistance achieves an artificially inflated score in certain areas. However, when the outcome ChNAC is administered, the child is now developmentally ready to gain these skills but has not yet completed the necessary rehabilitation to do this, so the score is lower. This occurs more often when there are

longer delays between administration of baseline and outcome ChNACs (as was the case with the youngest age group in this sample) and makes it difficult to assess rehabilitation gains. This may have resulted in fewer significant differences between baseline and outcome scores in the data, in cases with a longer delay between the two, because the goal posts had moved by the time outcome was assessed. The scoring system could be adapted to avoid this problem, for instance by keeping P scores separate from percentage achieved scores.

The reliability and validity of the ChNAC as a needs assessment and clinical outcome measure have not been established and remain to be addressed. Since the data used in this study were collected, the ChNAC has been modified to include sections on autonomic dysreflexia and respiratory needs, because these areas had been identified clinically as requiring inclusion in the assessment of rehabilitation needs. Trials of reliability and validity need to incorporate these changes. Furthermore, research has not yet investigated the acceptability of the ChNAC and goal-planning program for young people and their families. Although anecdotally there is a high level of ownership of and satisfaction with the program among the spinal pediatric staff, this has not been assessed systematically.

CONCLUSIONS

The ChNAC is a practical tool for planning young people's rehabilitation after SCI and assessing rehabilitation outcome, with high face validity and clinical utility. This study is a preliminary demonstration of the pediatric goal-planning program's effectiveness in achieving positive rehabilitation outcomes. Future research should update the ChNAC items and scoring system, replicate these results with larger samples, investigate user satisfaction with the measure, and conduct detailed studies of the ChNAC's reliability and validity.

ACKNOWLEDGMENTS

The authors thank the patients, families, and staff of the pediatric ward for their participation in the Child Needs Assessment and goal-planning program, as well as Silvia Lucchi, Navtej Sandhu, and Sarah Wooderson for their assistance with data analysis.

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