

PROFILE OF HANDICAP SITUATIONS IN CHILDREN WITH CEREBRAL PALSY

Céline Lepage, MSc, PT¹, Luc Noreau, PhD^{1,2}, Paul-Marie Bernard, MSc³ and Patrick Fougeyrollas, PhD¹*From the ¹Rehabilitation Institute of Quebec City, ²Department of Rehabilitation, Laval University, ³Department of Social and Preventive Medicine, Laval University, Quebec City, Canada*

ABSTRACT. The purposes of this study were to establish a profile of handicap situations in children with cerebral palsy and to identify some variables associated with the occurrence of these situations. Ninety-eight children with a diagnosis of cerebral palsy (mean age \pm 1 SD, 10.5 ± 3.5 years) were recruited on a voluntary basis. The Life Habits Assessment (LIFE-H, version 1.0) was used to measure the degree of accomplishment in 12 categories of life situations (activities of daily living and social roles). Significant disruptions in the accomplishment of all life habit categories were revealed. The highest disruptions were observed in the following categories: recreation, community, personal care, education, mobility, housing and nutrition. Disruption progressed significantly with increased severity of cerebral palsy. Impairment type, severity, speech and language disorders, and comprehension difficulties explained a high percentage of the total variance (>60%) in the accomplishment of life habits. The results suggest that life habits related to school and social integration are greatly disturbed.

Key words: cerebral palsy, disability, handicap, rehabilitation, social integration.

INTRODUCTION

Cerebral palsy (CP) is the most frequent cause of severe motor disability in children (18). Defined as a permanent disorder of movement and posture, it is caused by a defect or non-progressive lesion in the immature brain (3), appearing in the early years of life. Three categories related to the type of CP are observable: quadriplegia, diplegia and hemiplegia (5), as are four patterns of disorder in muscle tone: spastic, dyskinetic, ataxic or mixed (23). The severity of cerebral palsy varies greatly. A classification of mild, moderate and severe is often used in rehabilitation settings, and is based on clinical judgment (26, 27). Likewise, associated impairments can be observed at various levels: sensory (vision, hearing,

touching), neurological (epilepsy), intellectual, speech and language (1, 21). A higher prevalence of CP (2.5 in 1,000 live births) (4, 14, 24, 30) and the increased life expectancy over the last decades have brought about an additional demand for health, education and social services (18). In children with CP, the acquisition of different skills, such as gross and fine motor function or language, is usually delayed. The most frequent disabilities are observed in mobility, activities of daily living and communication. Therefore, rehabilitation aiming primarily at attaining optimal function is essential for these children (31).

There is an obvious need to evaluate the efficiency of therapeutic interventions and to determine their impact on the social integration of persons with disabilities (12, 15, 17, 22, 31, 32). Methods have been developed to evaluate specific aspects of motor development (2, 6–9, 28, 29) and functional skills in children with CP (13, 16). However, few tools allow adequate evaluation of the degree of social integration of the person in his/her living environment. The lack of tools limits the ability to assess the impact of clinical intervention on social integration, which is the ultimate goal of rehabilitation. In children with CP, a low level of social integration is directly related to the occurrence of handicap situations, which are defined as “disruptions in the accomplishment of a person’s life habits, taking into account his age, sex and socio-cultural identity, resulting, on the one hand, from impairments or disabilities, and on the other hand, from environmental factors” (10). This definition emphasizes the interaction between the individual characteristics linked to organic and functional consequences of diseases or trauma, and the environmental factors specific to a person’s life.

To our knowledge, only one study addressed the issue of handicaps in children with CP (19). The level of handicap was evaluated by means of a questionnaire (71 items) on various aspects of daily living, such as mobility, dependence, school integration and social resources. A three-level ordinal scale was used for the

quantification of handicap. This study suggested that children with quadriplegia or diplegia are generally more handicapped than children with hemiplegia. The total handicap score correlated highly with physical disability and mobility ($r > 0.70$). The authors also mentioned that CP affects children's ability to participate in normal everyday activities (19). Therefore, the nature and significance of disturbances in the performance of activities of daily living and social roles of children with CP should be carefully assessed. Such evaluations are prerequisite to determining appropriate intervention which will foster social integration. The purposes of this study are to establish a profile of handicap situations in children with CP, and to identify some variables associated with the occurrence of handicap situations.

METHODOLOGY

Subjects

Ninety-eight children (mean age = 10.5 ± 3.5 years) were recruited on a voluntary basis from the CP program and the rehabilitation service of the Centre Cardinal-Villeneuve (CCV) (Quebec City, Canada). They were recruited from a potential population of 265 children with CP (from 5 to 17 years of age). First contact was initiated by mail with the parents of all potential subjects. A letter was sent describing the nature of the study and encouraging parents and children to participate. The sample was made up of those parents and children who returned the reply coupon.

Forty-four percent of participants had quadriplegia, and 20% were severely impaired. Severe impairments were found in individuals with quadriplegia (except for one participant with diplegia), while moderate and mild impairments were distributed across the three types of CP. A majority of subjects (88%) had spastic CP. A significant proportion of subjects also showed

associated impairments (visual defects, speech and language disorders). These were mostly observed in children with quadriplegia (60%). No significant difference was observed between the sample and the base population for age, gender, impairment type and understanding difficulties (Table I). However, since a smaller proportion of children in the sample lived in a foster home or a home care centre, an over-representation of children living with their parents was observed in the sample compared to the base population (97% vs 87%, $\chi^2 = 8.87$, $p < 0.05$). Moreover, a larger proportion of children of the sample lived with two parents (76% vs 66%, $\chi^2 = 8.98$, $p < 0.05$).

Methods

The following characteristics of the subjects were identified from the clinical records: impairment type (quadriplegia, diplegia or hemiplegia), muscular tone (spastic, dyskinetic, ataxia or mixed) and degree of severity (mild, moderate or severe). The general criteria used to classify the children according to impairment type are as follows (5): for quadriplegia, the whole body is affected, the upper limbs and the trunk are usually more affected than the lower limbs; head control is poor. In diplegia, the legs are more affected than the arms, which present a moderate deficit; head control is good. In hemiplegia, one side of the body shows some dysfunction. The degree of severity corresponds to impairment in muscle tone. It is evaluated by experienced physiotherapists and based on clinical judgment. All data were verified by attending physiotherapists. Associated impairments, such as auditory or visual defects, epilepsy, and speech and language disorders, were documented from a questionnaire filled out by parents. Understanding difficulties were noted simultaneously during a locomotion test. They were identified when the child was unable to understand simple instructions given during this test. Prior to data collection, a pilot test was carried out in five children in order to verify the study procedures.

The same evaluator (CL) met parents for an evaluation session of approximately 90 minutes. They signed an informed consent form, as outlined by the CCV human subject ethics

Table I. Characteristics of study subjects (n = 98) compared to base population (n = 265)

Characteristics		Sample	Population	Statistical tests
Mean age		10.5 ± 3.5 years (mean ± 1SD)	11.1 ± 3.6 years (mean ± 1SD)	$t = -1.64$ n.s.
Age distribution	5-8 years	37	31	$\chi^2 = 2.41$ n.s.
	9-12 years	37	35	
	13-17 years	26	34	
Gender	female	52	48	$\chi^2 = 0.65$ N.S.
	male	48	52	
Impairment type	hemiplegia	33	36	$\chi^2 = 0.40$ n.s.
	diplegia	23	22	
	quadriplegia	44	42	
Understanding difficulties		17	16	$\chi^2 = 0.075$ n.s.
Family	two parents	76	66	$\chi^2 = 8.98^*$
	single parent	21	21	
	others	3	13	

* $p < 0.05$.

n.s. = non-significant.

committee. During the session, socio-demographic variables (age, gender, order and number of children in the family, schooling, type of school attended, place of residence, parents' schooling and occupation, and annual family income) were collected in order to examine their potential association with the occurrence of handicap situations.

Handicap situations were assessed with the Life Habits Assessment (LIFE-H, version 1.0) (11, 20, 25). This tool was developed from the model of disablement proposed by the Quebec Committee on the International Classification of Impairments, Disabilities and Handicaps (10). LIFE-H is a global tool determining disruptions in the accomplishment of life habits in persons with disabilities. "Life habits" is a key concept to the comprehension of handicap situations. They are defined as "those habits that ensure the survival and development of a person in society throughout his or her life". Specifically, they are activities of daily living and social roles recognized by the socio-cultural environment and normally attributed to the person in his/her life context (10). In the form of a questionnaire, LIFE-H measures the level of accomplishment of 248 life habits (or life situations) regrouped in 13 major categories (available from the authors on request). The level of accomplishment is based on the degree of difficulty and the type of assistance required (technical aids, adaptation and human assistance) to achieve the life habit. More than 200 items are applicable to the context of a child's life.

An accomplishment scale (Table II) was developed by the combination of two concepts: degree of difficulty and required assistance. A raw score was obtained for each life habit category by adding the accomplishment score of each applicable item. Since the children were at different stages of development, all life habits were not applicable to everyone. When a life habit is not carried out because it does not make up part of the child's daily life, it is considered non-applicable and is not factored into the raw accomplishment score. The total LIFE-H score was obtained by adding the raw scores of the 13 categories. The raw score of each category and the total score were expressed on a continuous scale from 0 to 10 in order to take into account variations in the number of applicable items for each child. A simple computer program was developed to obtain the different scores.

This is the first application of LIFE-H to children with CP. Previously, the content validity of LIFE-H was established by a group of rehabilitation experts (researchers, clinicians and consumers) in a study of children with myelodysplasia, who

showed a good level of test-retest reliability ($0.45 < \text{Intra-class coefficients} < 0.77$) for most life habit categories (11, 25). For the purpose of the study, the accomplishment scale was slightly adapted to quantify the degree of human assistance so as to increase its sensitivity (from 0.5 to 1 point on the scale). This modification allowed us to take into account the marked differences observed between children as to the level of human assistance required to accomplish life habits. Human assistance was noted on 4 levels: (i) minimal assistance, (ii) 25 to 49% assistance, (iii) 50 to 74% assistance, and (iv) maximum assistance. The percentages correspond to the helper's average degree of assistance in the accomplishment of life habits.

Statistical analyses

A profile of handicap situations was determined for each life habit category ($n = 12$) and for the total scores. The category "employment" was not considered because only 5 subjects were in a situation of gainful employment. A graphical representation (box plots) was used to illustrate the disruption levels in the accomplishment of life habits.

A multiple linear regression analysis was used to identify variables that might potentially explain variations in the life habit accomplishment score. The multiple determination coefficient (R^2) was used as an association measure. A global coefficient was presented for each model of regression, and partial coefficients were specified for each independent variable. The following variables were always entered in the regression models in the same order: (i) impairment type, (ii) severity, (iii) understanding difficulties, and (iv) speech and language disorders. Finally, potentially confounding variables such as age, gender and environment were taken into account in the model. Age was entered both as a continuous variable and as a categorical variable, according to 4 groupings: 5-7 years, 8-10 years, 11-13 years, and 14-17 years. Significance of all statistical analyses was fixed at the 0.05 alpha level.

RESULTS

Life habits

Examination of box plots (Fig. 1) of the accomplishment

Table II. Description of the modified scale of accomplishment of life habits adapted from the LIFE-H (version 1.0)

Score	Description
0	Performed without difficulty
1	Performed without difficulty (technical aid or adaptation)
2	Performed with difficulty (no help)
3	Performed with difficulty (technical aid or adaptation)
4	Performed without difficulty (minimal human assistance)*
5	Performed without difficulty (technical aid or adaptation, and minimal human assistance)*
6	Performed with difficulty (minimal human assistance)*
7	Performed with difficulty (technical aid or adaptation, and minimal human assistance)*
8	Performed by substitution (maximal human assistance)**
9	Not performed
N/A	Not applicable

* 25 to 74% human assistance increases the score of 0.5.

** "With substitution" means that the person does not actively participate in the accomplishment of the life habit. It is performed entirely through human aid.

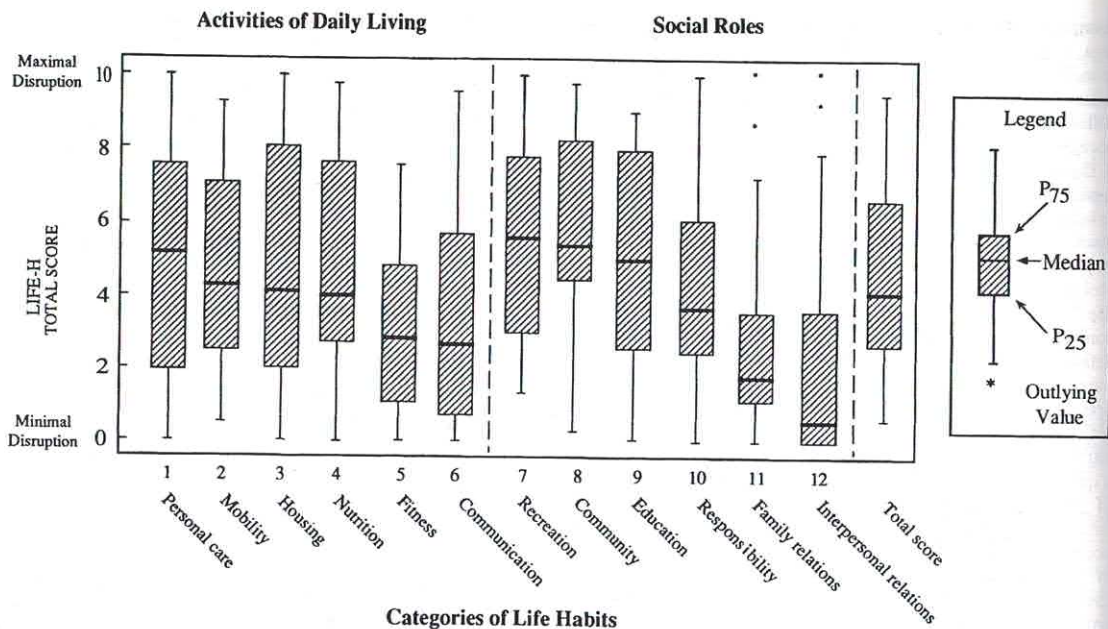


Fig. 1. Disruption in accomplishment of life habits according to activities of daily living (1–6) and social roles (7–12).

scores (LIFE-H total and categories, $n = 12$) indicated a large variability in the achievement of life habits. Performance in three categories related to social roles (recreation, community, education) were particularly disrupted, and were directly linked with school and social integration. Impairment type and severity were significantly associated with the accomplishment of life habits (Figs. 2a, b). The disturbance in LIFE-H total score increased progressively with impairment type and

severity. Children with quadriplegia demonstrated a higher degree of disruption than children with diplegia or hemiplegia. Likewise, disturbance progressed according to severity.

A significant increase in disruption for all life habit categories has also been seen when impairment type and severity are linked. Children with hemiplegia were less disturbed in their life habits (Figs. 3 and 4) than children with moderate or severe quadriplegia, who showed great

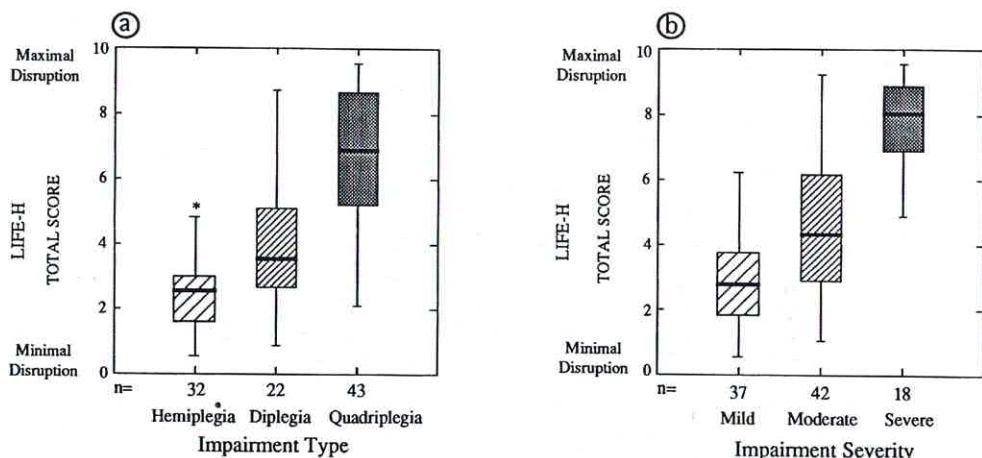


Fig. 2. Total score of disruption in accomplishment of life habits according to impairment type (a) and severity (b).

Table III. Percentage of total variance in accomplishment of life habits (dependent variables) and partial variance explained by the independent variables

Dependent variables	Independent variables					% total variance			
	Impairment type	+	Severity	+	Understanding difficulties		+	Language disorders	=
Total score	53		12		14		1*		80
Nutrition	39		17		14		1		71
Fitness	44		12		10		1		67
Personal care	52		8		7		1		68
Communication	37		6		26		2		71
Housing	46		17		6		–		69
Mobility	52		14		6		–		72
Responsibility	26		1		32		–		59
Family relations	27		7		20		–		54
Interpersonal relations	8		–		26		–		34
Community	46		12		5		2		65
Education	44		8		11		3		66
Recreation	47		11		10		1*		69

* $0.05 < p < 0.10$; otherwise $p < 0.05$.

disruptions. Differences are particularly marked between extreme groups (“mild hemiplegia” vs “severe quadriplegia”) for all habits except for those in the “interpersonal relations” categories (Fig. 4f). Although the disruption of life habits in some categories tended to vary with the impairment type and severity (personal care, mobility, recreation and education) (Figs. 3a, b, 4a–c), other life habits related to housing, nutrition and communication (Figs. 3c, d, f) showed a moderate disruption level in children with hemiplegia or diplegia, while strong disturbances were observed in children with moderate and severe quadriplegia.

Associated factors

Regression analysis allowed identification of the individual attributes potentially associated with the accomplishment of life habits. Four independent variables (impairment type, severity, speech and language disorders, and understanding difficulties) were responsible for a high percentage of the total variance (> 60%) in the accomplishment of 10 life habits (Table III). For the total score, the 4 independent variables accounted for about 80% of the total variance. As a single independent variable, “impairment type” explained more than 40% of the total variance in the disruption of 8 life habit categories. Associated impairments (speech and language disorders and understanding difficulties) also contributed to the disruption of life habits. Although they were related to the impairment type and severity, they

accounted for an additional percentage of variance (from 6 to 33%). Understanding difficulties accounted for the largest percentage of variance in two life habit categories: “responsibility” and “interpersonal relations”. Finally, none of the potentially confounding variables (age, gender, place of residence and income) were significantly associated with the disruption of life habits.

DISCUSSION

Clinical evidence suggests that many persons with disabilities experience handicap situations on a daily basis in their living milieu. In this study, handicap situations of children with CP were investigated, and their association with various characteristics of impairment and disability was analysed. To our knowledge, there is only one study that has addressed the issue of handicaps in children with CP (19). Consequently, the present study is the first to evaluate handicap situations in children with CP more thoroughly.

One of the most important findings of this study was the progressive disruption observed in the accomplishment of life habits in children with hemiplegia, diplegia and quadriplegia. This confirms the impact of impairment type on the occurrence of handicap situations. For example, motor deficits of the lower and upper limbs, trunk and neck, as observed in children with quadriplegia, induce a higher level of dysfunction than a deficit of the lower limbs (diplegia) or of one side of the body (hemiplegia). Therefore it was not surprising to

Activities of Daily Living

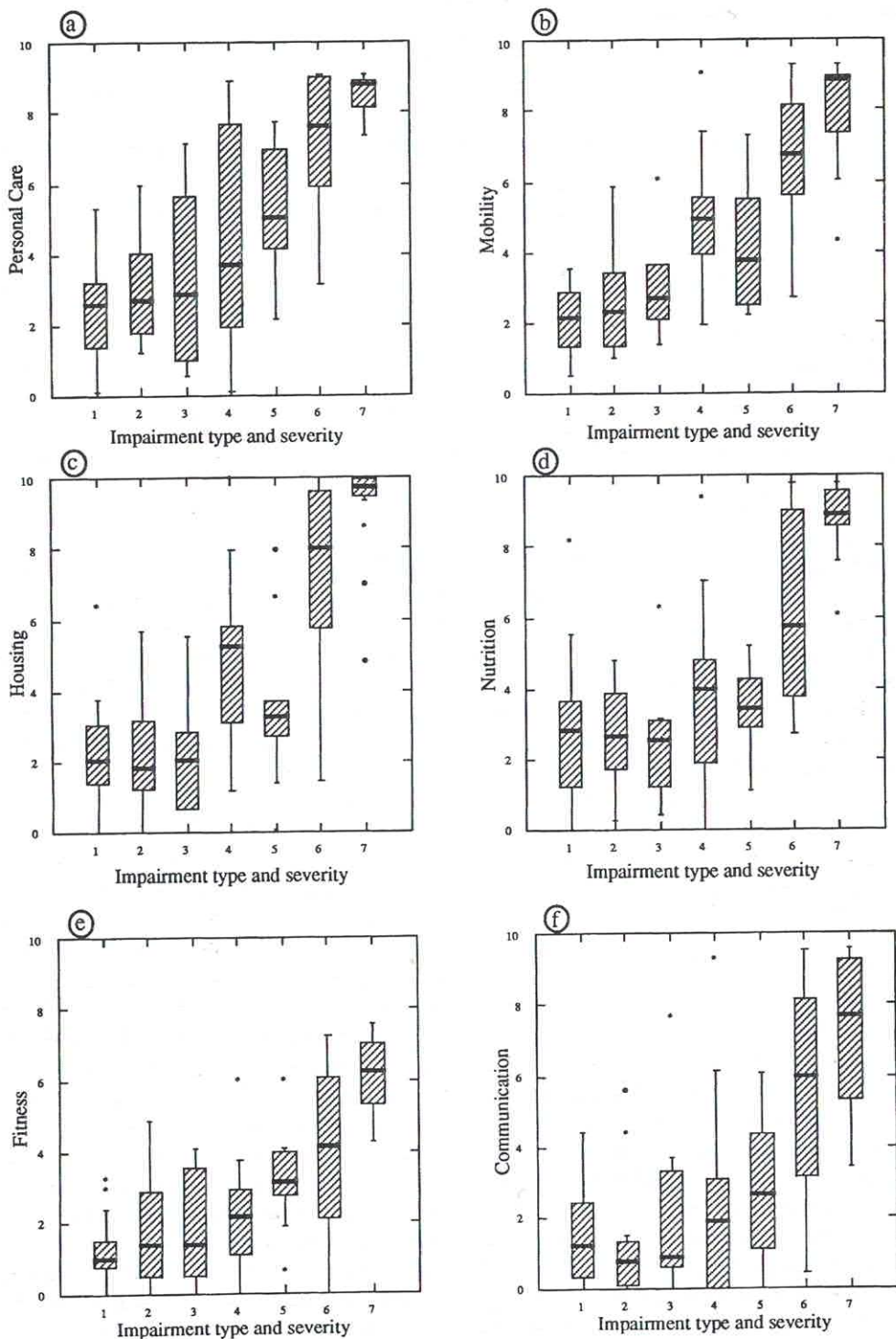


Fig. 3a-f. Disruption in accomplishment of life habits (activities of daily living), in decreasing order, according to impairment type and severity. Hemiplegia: 1: mild, $n = 20$; 2: moderate, $n = 12$. Diplegia: 3: mild, $n = 8$; 4: moderate, $n = 14$. Quadriplegia: 5: mild, $n = 9$; 6: moderate, $n = 16$; 7: severe, $n = 18$.

Social Roles

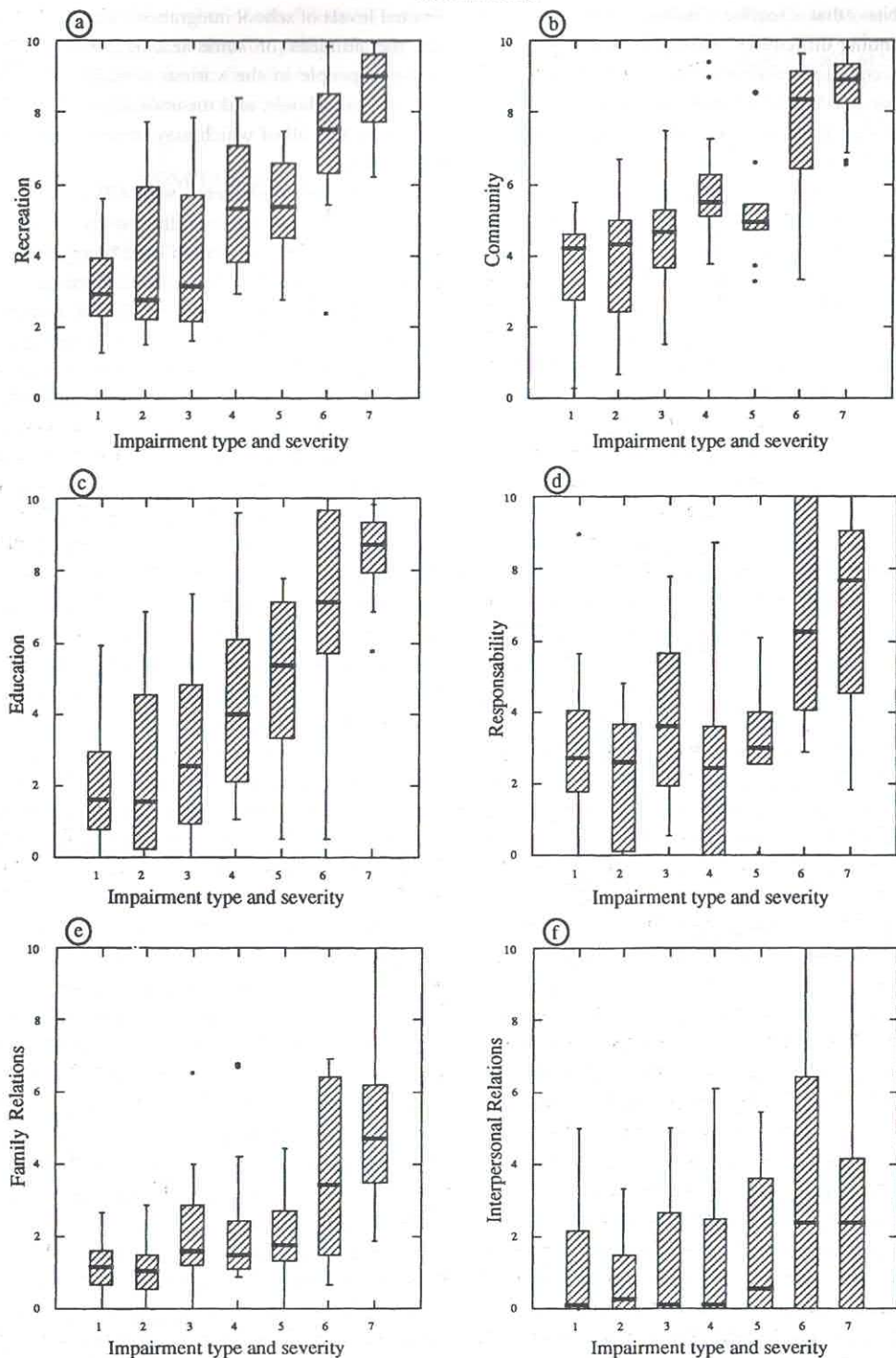


Fig. 4a-f. Disruption in accomplishment of life habits (social roles), in decreasing order, according to impairment type and severity. Hemiplegia: 1: mild, $n = 20$; 2: moderate, $n = 12$. Diplegia: 3: mild, $n = 8$; 4: moderate, $n = 14$. Quadriplegia: 5: mild, $n = 9$; 6: moderate, $n = 16$; 7: severe, $n = 18$.

observe that "impairment type" has a greater impact on life habits that require motor abilities, while "understanding difficulties" mostly influence life habits requiring cognitive abilities. For example, it is well known that quadriplegia limits the accomplishment of motor tasks such as dressing, eating, and entering and exiting the home.

Severity is also a significant factor explaining disruption in life habits. For example, children with severe spasticity are more likely to present a lack of coordination or balance than are children with mild ataxia. Coordination and balance are necessary to adequately perform life habits without technical aid or human assistance. When the variables "severity" or "understanding difficulties" were strongly associated with disruption of a life habit, the differences in its accomplishment were particularly noticeable between children with quadriplegia and the two other groups (hemiplegia and diplegia). We can hypothesize that children with severe quadriplegia associated with a cognitive deficit cannot compensate for their limitations by themselves, and the accomplishment of several life habits is dramatically disrupted. Conversely, children with mild or moderate diplegia can compensate more easily for some disabilities, using the upper body.

Another important finding of the study is the large variation observed in the accomplishment of life habits within each impairment type and severity level. Similar variations in handicap level have been previously observed (19). This suggests that impairment type and severity cannot totally explain the disruption. A potential explanation is that secondary disorders, such as understanding difficulties, blindness, deafness, speech and language disorders, might negatively influence the accomplishment of life habits regardless of impairment type. Generally, the disruption of life habits increases with the number of associated problems. For example, children with hemiplegia who have understanding difficulties are not able to follow regular school programmes, despite their small deficit in motor abilities. Likewise, blindness or deafness may interfere in communication with their parents or peers.

Despite efforts made to support community integration, many children still seem to have significant difficulties with school and social integration. Several factors, mostly observable in a regular school setting, might explain such difficulties. Personal attributes, such as severity and cognitive deficit, may have a negative impact on school integration. Clinical observations suggest that other factors related to the child's living

environment should also be considered in explaining limited levels of school integration. Among these factors are the attitudes of some teachers, lack of dialogue between people in the various settings (rehabilitation, family, and school), and misunderstanding of problems caused by CP, all of which may interfere with adequate integration.

Children and adolescents with CP are poorly integrated socially. Results of this study confirm these observations, since "recreation" and "community" habits showed the highest disruption level. Even children with mild hemiplegia can show significant disruption in recreational habits. Rehabilitation processes necessitate the regular presence of children with CP in clinical settings for many years. In contrast, children without disabilities rapidly develop interaction with companions that favour social integration. This lack of interaction in children with CP might be a major factor in the explanation of observed disruption. During the teenage years, the visible nature of the child's impairment makes integration in groups where uniformity and similarity are very important difficult. In addition, environmental factors such as architectural barriers or lack of transportation might cause serious integration problems for persons who might otherwise have the potential to develop social interactions.

There are some limitations in this study related to the sample and the measurement process. First, the small number of children recruited in specific sub-groups did not allow us to perform statistical analyses for the different independent variable categories. This difficulty is frequently mentioned in studies involving children with CP (6). Second, misclassification may be a factor in the measure of severity of CP. Indeed, it is difficult to obtain objective criteria of the severity of CP (19, 27). This bias could result in underestimation of disruptions despite the fact that experienced therapists performed the assessment of severity. A bias could also have been introduced into the study through the parents' responses to LIFE-H. According to Young et al. (33), however, there should be no significant difference between the responses of parents and children regarding their physical disabilities.

The present study focused mainly on the role of personal attributes in explaining disruptions in the accomplishment of life habits. Other characteristics of the children, such as their motivation levels, interest, comprehension of their own limits and involvement in the rehabilitation process, might also influence their levels of social integration. Moreover, environmental

attributes, such as the number of rehabilitation interventions, availability and quality of public services and attitudes of others toward the disabled persons can facilitate or restrain their social integration.

CONCLUSION

This study is a first step in the analysis of handicap situations in children with CP. Results show that school and social integration in these children are still greatly disrupted. Special attention should be paid to children with quadriplegia because their level of disruption in social integration is particularly high. These data should help in specifying rehabilitation objectives and in suggesting appropriate means of intervention. Although this study included the identification of some variables influencing the accomplishment of life habits, many questions remain unanswered and should be addressed in further research. It is quite important to document the relative impact of therapeutic interventions and environmental factors on the social integration of children with CP. As social integration is a major objective of rehabilitation, research on this topic should identify factors that can predict or explain the observed disruptions.

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Address for offprints:

Céline Lepage
Rehabilitation Institute of Quebec City
2975 Chemin St-Louis
Sainte-Foy (Quebec)
Canada G1W 1P9