

# Wait Times for Paediatric Rehabilitation

## Temps d'attente pour la réadaptation pédiatrique



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## Abstract

*Background:* Early therapy intervention for children with disabilities may improve functional outcomes. Access to paediatric rehabilitation services can sometimes be difficult.

*Objectives:* To describe waiting time to receive physical therapy (PT) and occupational therapy (OT) services at rehabilitation centres for young children with physical disabilities; to examine factors associated with these waiting times.

*Design:* Prospective cohort.

*Subjects:* Two hundred and six children with physical disabilities, aged 6 to 72 months, referred in 2002–2004 from the Montreal Children's Hospital and Sainte-Justine Hospital to paediatric rehabilitation centres.

*Measures:* Data on date of referral, age, gender and diagnosis were obtained from the hospital databases. Data on date of first PT or OT appointments at the rehabilitation centre, family socio-demographics and disability severity (WeeFIM) were obtained during parental interviews.

*Results:* Half of the sample waited more than 7 and 11 months for PT and OT services, respectively. Shorter waiting time was significantly associated with younger child's age and referral to one particular rehabilitation centre.

*Conclusion:* Children with physical disabilities experience long waiting times for PT and OT rehabilitation services. Strategies to improve timely service delivery are needed.

## Résumé

*Contexte :* Une intervention thérapeutique précoce chez les enfants atteints de handicaps pourrait améliorer les résultats fonctionnels. L'accès à des services de réadaptation pédiatrique peut parfois s'avérer difficile.

*Objectifs :* Décrire les temps d'attente pour recevoir des traitements de physiothérapie et d'ergothérapie dans des centres de réadaptation pour les jeunes enfants handicapés; examiner les facteurs associés à ces temps d'attente.

*Conception :* Cohorte prospective.

*Sujets :* Deux cent six enfants âgés de 6 à 72 mois et atteints de handicaps physiques, aiguillés par l'Hôpital de Montréal pour enfants et l'Hôpital Sainte-Justine vers des

centres de réadaptation pédiatriques entre 2002 et 2004.

*Mesures* : Les données sur la date de la recommandation, l'âge, le sexe et le diagnostic ont été obtenues à partir des bases de données des hôpitaux. Les données sur la date du premier traitement de physiothérapie ou d'ergothérapie au centre de réadaptation, la composition sociodémographique de la famille et la gravité du handicap (WeeFIM) ont été obtenues dans le cadre d'entrevues avec les parents.

*Résultats* : La moitié de la cohorte a attendu plus de sept et onze mois pour obtenir des traitements de physiothérapie et d'ergothérapie respectivement. Les temps d'attente moins longs étaient associés de manière significative à des enfants plus jeunes et à un aiguillage vers un centre de réadaptation particulier.

*Conclusion* : Les enfants atteints de handicaps physiques doivent attendre plus longtemps pour obtenir des services de physiothérapie et d'ergothérapie. Des stratégies visant à améliorer la prestation des services en temps opportun doivent être élaborées.

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**H**EALTH SERVICES RESEARCH REGARDING THE NEEDS, DELIVERY AND utilization of paediatric rehabilitation is an emerging field of interest, given the increase in infant survival and subsequent growing focus on childhood disabilities (Perrin 2002; Halfon et al. 2004; Msall et al. 1998; Majnemer et al. 2002; Limperopoulos et al. 2001). Childhood disability has a substantial impact on the healthcare system, as children who have restrictions in activities are high users of healthcare services, particularly rehabilitation (Newacheck and Halfon 1998). Early identification of children with physical and developmental disabilities is crucial to ensure that appropriate interventions are provided as soon as possible to allow children to develop their full potential, maximize their level of function and prevent further disabilities (L'Office des personnes handicapées du Québec 1992; Michaud and Committee on Children with Disabilities 2004; Halfon et al. 2004; Majnemer 1998; Majnemer et al. 2002; Feldman et al. 2002; Simpson et al. 2003; American Academy of Pediatrics 1996). Conversely, barriers limiting accessibility to rehabilitation services (e.g., long waiting times) could significantly compromise a child's functional and health status.

In Quebec, services were reformed in the early 1990s to better meet the needs of families of children with disabilities. The intent was to implement comprehensive coordinated services within the community (Office des personnes handicapées du Québec 1992; Régie régionale de la santé et des services sociaux de Montréal-Centre 1998; Ordre des physiothérapeutes du Québec 1996). Paediatric outpatient rehabilitation services for children under 6 years of age were no longer provided at acute care paediatric hospitals; children requiring these services were referred to specialized paediatric rehabilitation centres. This situation created accessibility problems (Régie régionale de la santé et des services sociaux de Montréal-Centre 1998; Institut de

réadaptation en déficience physique de Québec 2002). Problems with accessibility to paediatric rehabilitation services are not limited to Quebec residents (Fox et al. 1993; Majnemer et al. 2002; Feldman et al. 2002; Simpson et al. 2003).

Some of the factors associated with accessibility to these services have been identified. Younger children typically receive rehabilitation services before older children (Majnemer et al. 2002; Bailey et al. 2004; Feldman et al. 2002; CanChild 2000). Very young children referred to rehabilitation are more likely to have an identifiable pathologic condition (e.g., genetic syndrome, seizure disorder) or risk condition such as prematurity. Older children are more likely to be referred for problems related to developmental delay (Bailey et al. 2004).

Severity of the disability may be another factor influencing accessibility. For example, children may be denied access to rehabilitation services provided by Health Maintenance Organizations (HMOs) if the child cannot improve significantly over a short period of time, which is often the case for children with severe disabilities (Fox et al. 1993). In other cases, the more severe a physician perceives a child's disability, the more likely it is that the child will be referred to physical therapy (Campbell et al. 1995). Diagnosis may also influence referral times to rehabilitation. Because paediatricians appear to be reluctant to refer children with developmental delays or less severe disabilities to early intervention services (Bailey et al. 2004), it is unclear whether severity enhances or impedes access to rehabilitation.

Socio-economic status (SES) may also influence access to rehabilitation. Parental knowledge of child development has been linked with higher parental educational level (McCune et al. 1984), implying that those who are knowledgeable may recognize problems earlier, perhaps leading to earlier rehabilitation. In addition, it is well established that lower family SES has been associated with higher incidence and severity of disability in children (Simpson et al. 2003; Msall et al. 1998; Perrin 2002).

Two studies have explored service delivery (by measuring waiting times or service utilization patterns) for paediatric rehabilitation services in Montreal. These studies used a cross-sectional design and were limited to only one of two paediatric tertiary care hospitals (Feldman et al. 2002; Majnemer et al. 2002). Feldman et al. (2002) included school-aged children using resources allocated by the school system as opposed to rehabilitation centre, while the study by Majnemer et al. (2002) included children with pervasive developmental delay (autistic spectrum disorders) receiving services at centres specialized in treating intellectual disability. Neither study measured disability in a consistent or standardized fashion.

The current study was designed to address some of the limitations of previous studies. We followed a prospective cohort of preschool-age children with physical disabilities recruited from both tertiary care paediatric hospitals in Montreal and measured their performance with a well-accepted functional measure. The objectives of this study were to describe waiting time to receive physical therapy (PT) or occupational

therapy (OT) services at rehabilitation centres for preschool-aged children with physical disabilities, and to examine the factors associated with waiting time, including the child's age and the diagnosis and severity of the physical disability. We hypothesized that access time to rehabilitation was longer for younger children within specific diagnostic groups and for those with more severe disabilities.

## Methods

### Study population

The study population included parents of preschool-aged children between 6 and 72 months, referred from the Montreal tertiary care paediatric hospitals to outpatient PT or OT at five local rehabilitation centres from September 1, 2002 to February 28, 2004. It was necessary to limit the minimum age to 6 months because our outcome measure that served as a proxy for severity of disability (Functional Independence Measure for Children, WeeFIM) was designed for children with developmental disabilities as young as 6 months (Msall et al. 1994b). Children with purely cognitive problems were excluded, as were those who resided farther than 50 kilometres from the city. Parents had to have adequate comprehension of English or French to participate. In Quebec, public rehabilitation services (including PT and OT) are covered for all residents by the provincial public health insurance plan.

### Referral sites

There are five outpatient rehabilitation centres in the Montreal area where children with physical disabilities can receive services; place of referral is based on the location of the family's residence.

### Recruitment

Participants were identified with help from the rehabilitation discharge coordinators at the hospitals. Both hospitals have computerized databases that provided the following information for children transferred to rehabilitation centres: name of the rehabilitation centre where the child was being referred, date of referral to the centre, demographic data about the child and family and the child's diagnosis. The date of transfer request for this study was defined as the date when all necessary documentation was forwarded to the rehabilitation centre by the hospital rehabilitation discharge coordinator. At the time of referral, parents were contacted by telephone by a research assistant and asked to participate in a series of interviews. Written parental informed

consent was obtained during the initial interview. The study protocol was approved by the Research Ethics Committee of each hospital.

## Data collection

### INTERVIEWS

The initial face-to-face interview with one of the child's parents was conducted within 4 weeks of referral and took place at the family's residence or the hospital, whichever was most convenient for the family. The followup interviews were administered by telephone to the same parent and occurred at 3-month intervals following the initial interview. A final interview was conducted when the child received PT or OT services at the rehabilitation centre. The interviews were conducted by one of three trained research assistants and consisted of structured questionnaires and standardized measures. In our study, the wait time for rehabilitation services was defined as the time between referral request to rehabilitation from the tertiary care hospital and the child's first PT or OT appointment at the rehabilitation centre.

### Study questionnaire

The initial interview included a structured questionnaire that was pre-tested in a pilot study (Feldman et al. 2002). It consisted of questions regarding district of residence, mother's educational level, family income and receipt of rehabilitation services (PT, OT or both).

### Functional outcome measure

The Functional Independence Measure for Children (WeeFIM) was administered. The WeeFIM is a valid and reliable tool used to determine level of independence and need for assistance as a result of disability when performing basic daily skills (Lollar et al. 2000; Msall et al. 1994a,b; Sperle et al. 1997; Ottenbacher et al. 1996, 1997). Scoring consists of calculating quotients for the three subscales (self-care, mobility, cognition) and for the total score, with lower quotients representing higher levels of disability (WeeFIM System<sup>SM</sup> WeeFIM<sup>TM</sup> Software Manual 1999). A quotient of 75 or higher represents a mild disability, a quotient of 50–75 represents a moderate disability and one below 50 represents a severe disability (Lowen et al. 2000).

## Analysis

Descriptive statistics to summarize the characteristics of the cohort were calculated.

Cox proportional hazard regression (survival) analysis was used to determine the association between earliest time to rehabilitation (i.e., waiting times for PT or OT) and the various factors (Christensen 1987; Kleinbaum 1996). For the purpose of this study, we dichotomized maternal education into *completed high school or less* and *completed junior college or higher*. Age was classified as either above or below the median (29.6 months), and diagnosis was either global developmental delay (GDD) or non-GDD. Family income was categorized in \$20,000 intervals between \$0 and \$80,000, and then \$80,000 and above. Since one of the rehabilitation centres had significantly shorter waiting times than the others ( $p=0.0003$ ), we dichotomized rehabilitation centre as either that one centre or the other four centres grouped together. Disability severity was classified as mild, moderate or severe, according to the cut-off values for WeeFIM total score quotients as established by Lowen et al. (2000). Therefore, two design variables were created, with mild severity as the reference group. For the survival analysis, all children still waiting for services on March 31, 2005 (end of study period) were censored. SAS version 8.02 (SAS Institute, Cary, NC) was used to perform the analyses.

## Results

### Cohort

There were 282 parents who met the inclusion criteria for our study, of whom 206 agreed to participate (response rate = 72.7%). The non-participants ( $n=77$ ) were similar to the participants ( $n=206$ ) in terms of the child's age ( $34.8 \pm 17.3$  vs.  $31.6 \pm 16.4$  months), gender (64% vs. 65% male) and diagnosis (34% vs. 45% with developmental problems). Characteristics of the cohort are presented in Table 1. Of the 206 participants, 132 were referred to PT, 198 were referred to OT and 124 were referred to both PT and OT at the various rehabilitation centres.

More of the older children were diagnosed with global developmental delay (GDD), whereas more of the younger children tended to have an identifiable pathologic diagnosis or risk condition. In fact, 62.1% (54/87) of children under 2 years of age had a diagnosis other than global developmental delay (non-GDD), whereas only 24.4% (10/41) of children 4 years or older had a non-GDD diagnosis (Figure 1). Univariate analysis revealed that the child's age and diagnosis were correlated. Those with a diagnosis of GDD were older (mean age =  $36.8 \pm 15.4$  months), compared to those with a diagnosis of non-GDD (mean age =  $24.3 \pm 15.0$  months;  $p<0.0001$ ).

Disability severity, as measured using the WeeFIM, indicated that 105 (51.0%) children had mild functional disabilities, 85 (41.3%) had moderate functional disabilities and 16 (7.7%) had severe functional disabilities. Figure 2 shows the distribution of functional disability severity by age group and indicates that those 4 years of age and older were referred mainly with mild disability.

TABLE 1. Frequency distribution of demographic data for children with physical disabilities (n=206)

Mean Age (SD)	31.6 (16.4) months – range of 6.8–69.4
Gender (% male)	134 (65.0%)
<b>Diagnosis</b>	
Global developmental delay	92 (44.7%)
Prematurity	25 (12.1%)
Seizures/neurological conditions	24 (11.6%)
Spinal bifida	3 (1.5%)
Trisomy 21	10 (4.9%)
Other syndromes	27 (13.1%)
Cerebral palsy/hypotonia	25 (12.1%)
<b>Educational level of mother</b>	
Completed high school or less	82 (39.8%)
Junior college diploma or higher	124 (60.2%)
<b>Family income (n= 197) (\$Canadian)</b>	
\$0–\$19,999	46 (23.4%)
\$20,000–\$39,999	45 (22.8%)
\$40,000–\$59,999	51 (25.9%)
\$60,000–\$79,999	25 (12.7%)
\$80,000 and above	30 (15.2%)
<b>Place of residence</b>	
City dweller	127 (61.7%)
Suburb	79 (38.3%)
<b>Referred to rehabilitation services</b>	
Physical therapy (PT)	132 (64.1%)
Occupational therapy (OT)	198 (96.1%)
Both PT and OT	124 (60.2%)

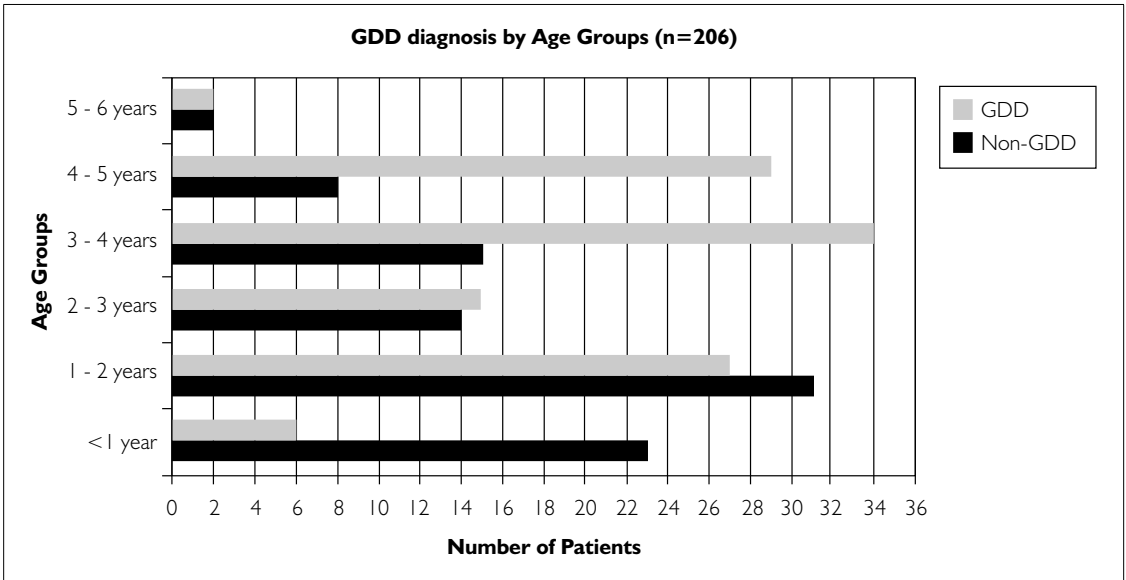
Among the 135 children who received PT or OT services or both within the study period, the mean waiting time from date of referral at the hospital to the child's first PT or OT appointment at the rehabilitation centre was  $6.6 \pm 5.1$  months (median time = 5.8 months, IQR = 4.8) and  $7.5 \pm 5.2$  months (median time = 6.0 months, IQR = 6.4), respectively.

For the survival analysis, 71 children were censored, 49 of whom were still waiting for services at the end of the study period. Twenty-two were censored for various other reasons: two families moved out the province, one child passed away, 10 parents dropped out of the study because they were dissatisfied with waiting times or were no longer interested in participating, and nine families could not be contacted for followup.

Graphical representation of the waiting times for children to receive PT or OT services at the rehabilitation centres is shown in Figure 3. Fifty per cent of chil-

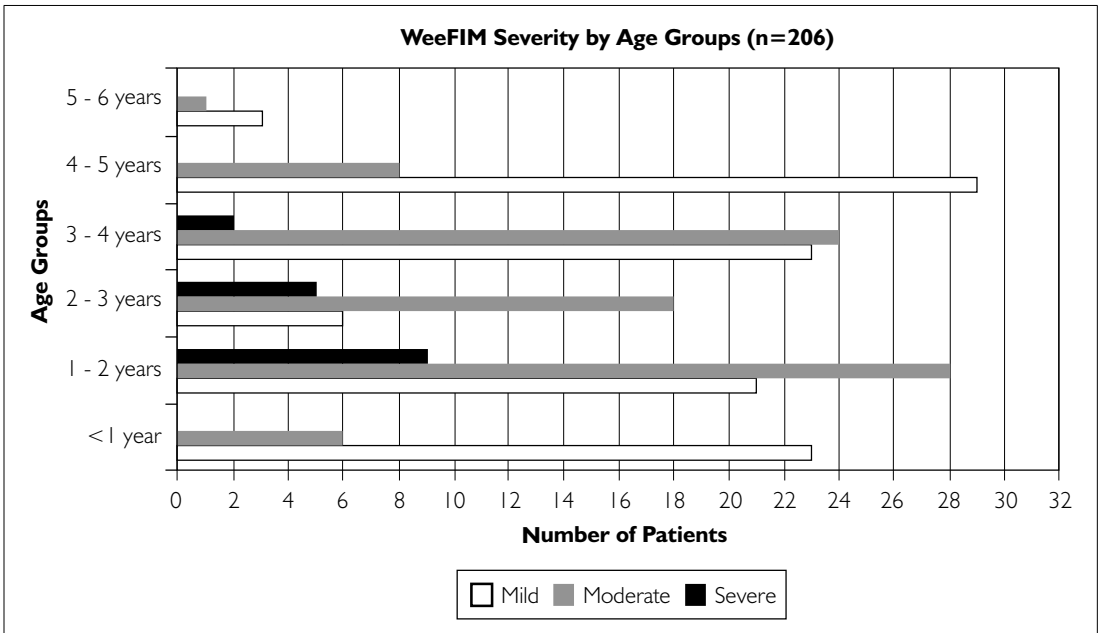


FIGURE 1. Diagnosis (GDD, non-GDD) by age group (n=206)



GDD = global developmental delay

FIGURE 2. WeeFIM severity by age group (n=206)



dren who were referred to PT (66/132) waited longer than 7 months for their first appointment at the rehabilitation centre, and 50% of the children who were referred to OT (99/198) waited longer than 11 months for their first appointment. Waiting times for receiving PT were less than for OT, throughout the study period. Only 25%–40% of children received services within 6 months of referral; among those who waited at least 9 months, only 10%–20% received services by the study's end.

The crude and adjusted hazard ratios (95% confidence intervals) are described in Table 2. The hazard ratio is a ratio of the risk (or hazard) of an event (in our case, receipt of rehabilitation services) in one group (e.g., those with a specific diagnosis – non-GDD) compared to the risk in a comparison group (e.g., those with a non-specific diagnosis such as GDD). Hazard ratios are derived from survival analyses, or analyses of events occurring over time, and take into account differences in duration of followup for individual patients. Children older than 29.6 months (median age) waited approximately twice as long to receive rehabilitation services (adjusted hazard ratio [HR] = 0.55; 95% CI = 0.37–0.82) compared to children under 29.6 months.

TABLE 2. Factors associated with shorter waiting time

FACTORS	CRUDE HR (95% CI)	ADJUSTED HR (95% CI)‡
Maternal education (> high school)	1.21 (0.85–1.72)	1.10 (0.76–1.56)
Rehabilitation centre (1 vs. 3 others)	2.12 (1.49–3.01)*	2.75 (1.74–4.36)*
Age (> median)	0.62 (0.44–0.88)†	0.55 (0.37–0.82)**
Place of residence (city vs. suburb)	1.53 (1.07–2.19)††	0.98 (0.62–1.54)
Diagnosis (GDD vs. non-GDD)	0.65 (0.46–0.91)†	0.73 (0.50–1.06)
Disability severity (WeeFIM moderate vs. mild)	0.80 (0.57–1.14)	0.76 (0.53–1.10)
Disability severity (WeeFIM severe vs. mild)	1.6 (0.91–2.69)	1.12 (0.63–2.0)

‡ Adjusted for the co-variables in the table

\*  $p < 0.0001$

\*\*  $p = 0.003$

†  $p = 0.01$

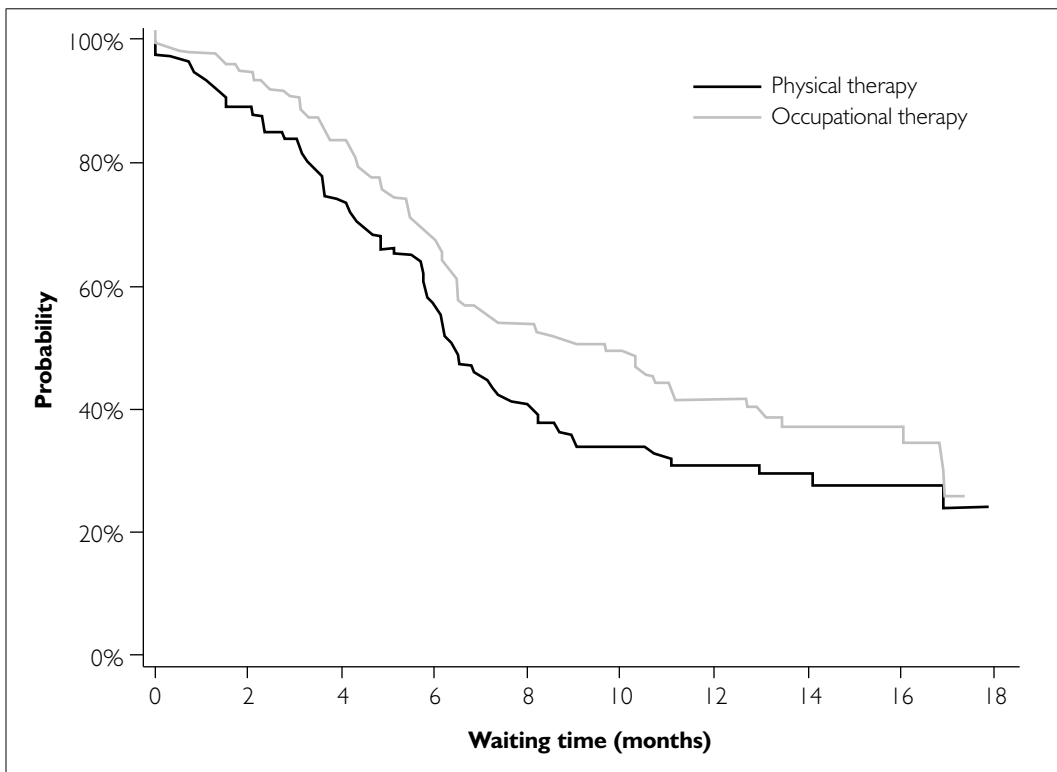
††  $p = 0.02$

HR Hazard ratio; the ratio of the measure of risk of transfer to rehabilitation at a point in time

Although the survival analysis model without co-variables showed that children with a diagnosis of GDD had a significantly longer waiting time than children with a non-GDD diagnosis, the adjusted HR was not statistically significant. Families living in the city waited less time for PT or OT services than those living in the suburbs, but this difference was no longer significant after adjustment for demographic variables, diagnosis and disability severity. Children referred to one rehabilitation centre in particular had a significantly shorter waiting time than those referred to the other centres (adjusted HR = 2.8; 95% CI = 1.74–4.36;  $p < 0.0001$ ). Neither maternal education

nor family income was related to waiting times. We report only maternal education for the Cox regression model because there were missing values for family income but not for maternal education. Severity of the child's functional disability did not appear to be associated with waiting time.

FIGURE 3. Survival analysis for first PT and OT appointment at the rehabilitation centre (in months)



## Discussion

Many parents of preschool-aged children with physical disabilities were found to experience lengthy waits (>6 months) for rehabilitation services. Half of those referred to PT waited longer than 7 months, and half waiting for OT waited more than 11 months. Of those that did receive services during the study period, the average waits for PT and OT were 6.6 months and 7.5 months, respectively – higher than the 4.3 and 5.2 months reported 5 years earlier (Feldman et al. 2002).

Lengthy waits for rehabilitation services may have a detrimental impact on the attainment of primary paediatric rehabilitation goals, including maximizing func-

tion and minimizing disabilities. Despite provincial governmental recommendations for implementation and assurance of coordinated paediatric rehabilitation programs following reports in the early 1990s of long waiting times (Office des personnes handicapées du Québec 1992; Régie régionale de la santé et des services sociaux de Montréal-Centre 1998), our findings suggest that in the past several years there has been an increase rather than a decrease in waiting times for delivery of PT and OT services in rehabilitation centres. It is thus imperative that further evaluation of service delivery at local rehabilitation centres be conducted to identify the reasons behind the long waiting times.

Our finding that younger children waited less time for services is consistent with the literature (Feldman et al. 2002; Bailey et al. 2004; Majnemer et al. 2002; CanChild 2000). These results suggest that coordinators at the rehabilitation centres may prioritize younger children to ensure the greatest benefits from early rehabilitation intervention (Office des personnes handicapées du Québec 1992; American Academy of Pediatrics 1996, 2001; Shevell et al. 2000, 2001; Halfon et al. 2004; Majnemer 1998). Perceived diagnostic certainty by physicians has been shown to influence referral of children to rehabilitation (Campbell et al. 1995; Majnemer et al. 2002; Shevell et al. 2001). One study found that the higher the certainty that a child had cerebral palsy, the higher the odds of referral to rehabilitation (Campbell et al. 1995). Physicians may recognize that children have a developmental disability, but do not refer them to rehabilitation (Office des personnes handicapées du Québec 1992; Campbell et al. 1995; Bailey et al. 2004; American Academy of Pediatrics 2001). Others may refer children with developmental difficulties for specialty evaluations for aetiologic determination and confirmation of diagnosis. These in turn can delay rehabilitation intervention, since in most cases, rehabilitation is prescribed only after medical evaluation has been completed by all specialists (Shevell et al. 2000, 2001). Once referred, waiting time may be further compounded by administrative delays, such as time for the discharge coordinators to send out the referral with the required supporting documentation. Young children with developmental delays have been known to receive services at the tertiary care hospital rather than at the rehabilitation centre as stipulated by the governmental reforms, raising concerns of overutilization of services at tertiary care facilities while awaiting services at the rehabilitation centres (Majnemer et al. 2002). This practice increases waits to receive services at the hospital, further delaying the referral process to the rehabilitation centres.

A child's functional level is considered the most important factor in clinical decision-making regarding PT service delivery in schools for children (Kaminker et al. 2004). However, we found no differences in waiting times between children who were identified as having moderate or severe functional disabilities and those who had mild disabilities. Our initial hypothesis was that children with mild disabilities would wait longer for rehabilitation services, since there may be a propensity towards providing

services sooner to children with severe disabilities (Campbell et al. 1995). Our results may reflect a phenomenon whereby those who are diagnosed at a younger age may have a more severe degree of disability.

We performed separate survival analysis for those younger than 29.6 months and those over 29.6 months, and did not find disability severity to be a predictor of waiting times in either of the age strata. There was, however, a tendency towards shorter waiting times for the younger children with moderate disabilities compared to those with mild disabilities ( $p=0.06$ ). The WeeFIM may not be sensitive enough to differentiate the levels of functional disability severity for younger children (unpublished data from the authors, presented at the Journée scientifique réseau provincial de recherche en adaptation-réadaptation (REPAR) conference, Montreal, May 15, 2004). This insensitivity may account for the lack of significant differences between waiting times for severity groups. The WeeFIM's lack of sensitivity may have been the reason that Chen et al. (2004) restricted their samples to children older than 12 months (since younger children are dependent on almost all WeeFIM items) when they studied functional outcomes in children. In addition, the lack of association between severity and waiting time may be partly explained by the fact that referrals to rehabilitation centres are made primarily with respect to the child's diagnosis, rather than the level of severity of the functional disability.

In our study, families referred to one rehabilitation centre waited one-third the time compared to those referred to any of the other centres. This result can be partly explained by differences in service delivery among the centres. The four rehabilitation centres with longer waiting times had restructured their service delivery by "thematic" programs geared to specific diagnostic groups (e.g., cerebral palsy group, spina bifida group, etc.). The one centre with significantly shorter waiting times did not have diagnostic programs, and therefore children were seen based on the therapist's availability. Although thematic programs have certain advantages, including higher level of specialization among therapists, better intervention specificity and greater opportunity for parents to find support from other parents of children with similar disabilities, they may cause longer waiting times. The availability of rehabilitation services is likely to depend on the number of children that can receive care from the program at one time.

We did not measure resources with respect to needs. Implementation of services by programs may not work for children with a diagnosis of global developmental delay, since they don't fit well into a defined diagnostic group. Interestingly, it was shown that the implementation of a prioritization process in an acute adult hospital setting resulted in more equitable service for the majority of patients, as well as more balanced caseloads for therapists, when compared to a ward-aligned process (where therapists are assigned to a certain ward and evaluate and treat patients admitted to that specific ward) (Lowe and Barber 2005). There may be a need to re-examine policies, re-organize the referral process and re-evaluate the efficacy of current service

delivery approaches to best meet the needs of children with physical disabilities and their families. Alternative models of service delivery may need to be considered. For example, intermittent intensive therapy characterized by short intensive therapy periods followed by long rest periods has been shown to have greater benefits than conventional therapy in children with cerebral palsy (Trahan and Malouin 2002). More research evaluating this and other models of service delivery in children is warranted.

## Limitations

Our study relied on parents as informants regarding receipt of rehabilitation services for their child. However, the design was prospective and families were followed at 3-month intervals, potentially minimizing problems with recall.

Also, the WeeFIM measure of functional disability may not have been sensitive enough to determine the level of disability for the younger children. This lack of sensitivity may have precluded our finding an association between severity and waiting time.

Another limitation was that additional data regarding the nature of the intake process of the rehabilitation centres was not collected, which may have explained the discrepant results at one centre.

## Conclusions

Our results demonstrate that older preschool-aged children experience long waits for rehabilitation services. The findings may support the need to increase PT and OT resources in paediatric rehabilitation centres or to develop alternative models of care delivery for children with disabilities in order to provide timely rehabilitation to maximize the children's functional abilities and well-being. The implementation of new policies in order to improve accessibility of services to physically disabled children may prevent repercussions later during the school years.

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