Moving towards independence? Evaluation of the 'Mobility Opportunities Via Education' curriculum with children with profound intellectual and multiple disabilities
Putten, Annette Adriana Johanna van der

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Chapter 3

The effects of movement-oriented activities on joint motion and active motor function in children with profound multiple disabilities.

Annette van der Putten¹, Koop Reynders¹, Carla Vlaskamp², Han Nakken²
¹Institute of Human Movement Sciences, University of Groningen, the Netherlands
²Department of Educational Psychology, University of Groningen, the Netherlands

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Abstract

Background The Mobility Opportunities Via Education (MOVE)™ curriculum includes movement-oriented activities for children with profound multiple disabilities (PMD) and fits in the current educational view in supporting these children. The developers of MOVE claim effects at anatomical and physiological structures and functions as essential for effects at functional skills. This study analysed whether MOVE causes an increase in the passive range of joint motion and active motor function in children with PMD.

Methods A repeated measurement design with baseline measurements was used. Children with PMD were tested twice before and twice after implementation of the MOVE curriculum.

Results Results show that the passive range of motion changed during the intervention phase, however, these changes did not take the expected direction. The active motor function, on the other hand, did alter in the expected direction.

Conclusions Movement-oriented activities do not seem to have a positive effect on the passive range of motion in children with PMD. Active motor function seem to change positively after implementation of movement-oriented activities. Further research has to establish whether this effect can subsequently increase the acquisition of motor- and functional skills in children with PMD in order to enhance their independency.

Keywords Movement-oriented activities, Profound multiple disabilities, Joint motion, Active motor function, Mobility Opportunities Via Education
Introduction
The importance and positive effects of physical activity in several domains of development for children with and without disabilities are common knowledge. In children with profound multiple disabilities (PMD), the effects of physical activity should not be limited to increasing the acquisition of motor skills. Instead, training should focus at increasing functional skills to enhance independence and ‘control of their life’. In other words, training should not solely focus at body functions or structures but training must enhance acquisition of activities and participation with or without (technical) equipment. For example, training walking skills must facilitate the child to move around independently and choose where to go, or training arm or head function must lead to increased communication skills by for instance handling a mechanical communication device. However, most training programmes in children with PMD aim at development of cognitive skills instead on the development of motor domain. If they are activated in this latter domain, it is mostly by receiving physical- and occupational therapy once or twice a week (Inspectie voor de Gezondheidszorg 2000). The offered (motor) interventions usually consist of traditional treatment approaches that are theoretically based on a developmental model and mainly focus at the impairment level of functioning rather than focussing on functional skills and performance of daily life tasks. Also, the lack of ‘functional carry over’, the transfer of the learned skills into meaningful activities of daily life, can be assumed to be a fundamental shortcoming (Ketelaar et al. 1998). Research carried out by Brown, Effgen and Palisano (1998) for instance, showed that improved gross motor abilities, practiced during therapy did not consistently transfer to the home setting. Therefore, training should be integrated in the natural setting which practically includes repeated practising in the meaningful environment (Barnes & Whinnery 2002). The intensity is positively related with the acquisition of skills (Bower & McLellan 1992, Bower et al 2001).

In response to the described shortcomings and corresponding with the current viewpoint in the education of children with PMD, Bidabe and Lollar (1995) developed the ‘Mobility Opportunities Via Education’ (MOVE) curriculum. In this curriculum, functional mobility practise within typically daily activities in the natural context is provided with the ultimate goal of the acquisition of motor skills in order to increase participation and independence (Bidabe & Lollar 1995). Besides these effects, the developers also claim effects on body functions and structures. Bidabe and Lollar (1995) state that the motor activities will prevent or reduce contractures of joints and increase the function of the extensor muscles (Bidabe & Lollar 1995; Burton & Miller 1998). These positive changes on the joint motion and active motor function are supposed to be essential for the acquisition of motor- and functional skills. An increase in the motor function of the extensor muscles leads, for instance, to improved lifting up the head and increases the participation of the child in communication, according to Bidabe and Lollar (1995). These supposed effects of MOVE are endorsed by ‘direct support personnel’ (DSP) who work with the curriculum in practice (Paleg 1996; Homeijer 2000). Despite the extensive use of the curriculum all over the world, little research is carried out on the effects of the MOVE curriculum on children with PMD.

Studies so far been conducted only focused at individuals with severe multiple disabilities rather than at individuals with profound multiple disabilities. Furthermore, the studies have used small research samples, were relatively short term and did not specifically examine the effects of MOVE on the anatomic-physiological domain (Elkins 1994; Bidabe & Lollar 1995; Schomeres 1996; Barnes & Whinnery 2002). Information from these research projects can therefore not be used to decide on the effectiveness of the MOVE curriculum for children with PMD. Information about the effectiveness of MOVE contributes to the correct substantive choice of interventions available in supporting children with PMD by DSP.

The research question in this study is: ‘Do the movement-oriented activities in the MOVE curriculum have a positive effect on joint motion and active motor function for children with
PMD?’. If these changes occur, further research has to clarify if this will subsequently result in acquisition of functional skills and enhancement of participation. It is expected that as a result of the MOVE activities, the joint motion as well as the active motor function will show a significant increase in children with PMD. This increase is presupposed to be greater than the change which takes place in the period in which the children are not supported by the MOVE curriculum. Bidabe and Lollar (1995) suppose that the joint motion and active motor function will remain constant or decrease during this period.

Methods

Participants
A group of 52 children with PMD were followed for a period of 16 months. Thirty-two children from this group could not be involved in the effect measurements due to the absence of information from the actual practice or because the periods between their measurements conflicted with the research design as described below. However, the data of the first measurement of these children were used in factor analysis as described in the ‘analysis section’ of this paper.

The experimental group consisted of 20 children with PMD (11 females and 9 males, mean age 9.4 years, SD 3.7). The children were recruited from three centres of special education (CSEs) throughout the Netherlands. Before the study started, these CSE’s were planning to implement the MOVE curriculum as part of their services. From these CSE the children who met the following criteria were selected to participate in this study: 1. diagnosed as ‘profound intellectual and multiple disabled’ (Nakken & Vlaskamp, 2002) and 2. eligible for participating in the MOVE curriculum (Bidabe & Lollar, 1995). All children have an estimated intelligence quotient of 25 points or below, are non-ambulant and require extensive support to accomplish tasks in day-to-day life (Nakken & Vlaskamp, 2002). Besides the intellectual and motor disabilities they also have sensory impairments and/or other common conditional problems. The children live at home and attend the CSE at which they receive educational activities and different kinds of therapies. Between these centres, there is no significant difference in children’s ages ($\chi^2=2.2, df=2, p=.338$) nor in gender ($\chi^2=5.0, df=2, p=.084$). Informed consent was obtained by the parents for all children to participate in the study.

Design
In this exploratory study, a repeated measurement design with baseline measurements was used. The children of the experimental group were tested four times during a period of 16 months. The first two measurements were conducted before implementation of the MOVE curriculum, with two months in between. During this ‘baseline’ period, the children were treated by means of the regular program on the CSE. Two follow-up measurements were conducted after the implementation of the MOVE curriculum. Three months after the MOVE intervention had started, measurement three was conducted in order to measure the ‘short term effects’. To measure the ‘long term effects’, a fourth measurement was conducted nine months after the start of MOVE.

Instruments

Joint motion
Goniometric measurements of the passive range of joint motion (PROM) of the shoulder, elbow, knee and ankle joints were used to determine the joint motion. When conducted under standardised circumstances, goniometric measurements are a reliable and valid way of determining
the PROM for healthy individuals as well as people with a disability (Rothstein, Miller & Roettger 1983; Mayerson & Milano 1984; Pandya et al. 1985; Gogia et al. 1987; Elveru, Rothstein & Lamb 1988; Youdas, Bogard & Suman 1993; Brosseau et al. 2001). In this study, however, the measurements were conducted on a specific target group for which the reliability and validity of PROM measurements is unclear (Pandya et al. 1985). The intra-rater reliability was therefore determined in ten children with PMD. The Intra Class Correlation Coefficient (ICC) (Shrout & Fleiss 1979) was determined for several joints. The ICCs for shoulder ante flexion, elbow extension, knee extension and ankle dors flexion varied between .66 and .95, .84 being the mean for the right side as well as the left side of the body. These numbers are considered to be reliable (Streiner & Norman 1995).

The mobility measurements were carried by one single independent assessor by means of a standard goniometer with a five degree calibration. The measurements were conducted under standardised circumstances and a protocol was used to guarantee their reliability (Pandya et al. 1985; Gajdosik & Bohannon 1987; Brosseau et al. 2001).

**Active motor function**

The active motor function was determined by a checklist. This checklist focussed on ‘lifting up the head’, ‘stretching the torso’, ‘stretching the hips’, stretching the knees in seated position’ and ‘stretching the knees in standing position’. A 5 point scale was used for scores. The lowest score (score 1) corresponds to ‘the child cannot carry out the activity and there is no muscle contraction at all’, whereas the highest score (score 5) corresponds to ‘the child is able to carry out the activity and is able to carry on for a considerable amount of time’.

The internal consistency, which serves as a criterion for the reliability, was determined by means of the data for 52 children with PMD. Crohnbach’s alpha was .92. The checklist can be considered to be internally consistent (Streiner & Norman 1995).

**Procedure and Intervention**

The four measurements of the PROM were carried out at the CSE, which each child visits. The tests were conducted in the same test room at the same time of the day and in the same order. All tests were conducted in supine position, the child being dressed in underwear. Each child had a DSP present at every measurement to dress and undress it to ensure that the child was as relaxed as possible. The children could only be tested on the condition that they were ‘alert’ ( state ‘3’ or ‘4’ according to Prechtl (1977)) instead of ‘drowsy’ or ‘crying’ (state 1,2 or 5 according to Prechtl (1977). This condition was met in all measurements.

The questions concerning the active motor function were completed by the physical or occupational therapist in attendance at each measurement. The therapist would judge the child on the basis of the knowledge he or she had gained from the treatments. In cases where the therapist was not sure whether an item could be scored, the child is observed in the CSE.

During the ‘baseline period’, the children received the regular educational program carried out at the CSE. This program consists of learning- and play activities that are carried out in a group. Furthermore, the children received physical or/ and occupational therapy at a individual basis. The majority of the children (n=13) received two times a week physical therapy, four children received once a week physical therapy and one child was treated three times a week. Two children did not get physical therapy. Therapy goals were formulated in general terms such as ‘prevent or reduce deformities’ (n=3), ‘normalization of muscle tone and relaxation (n=3), ‘increase or maintain skills’ (n=9), ‘facilitate symmetry’ (n=2), facilitate rotation of the torso and improve balance
(n=5), ‘facilitate head control’ (n=3), ‘to give the child movement experience’ (n=2) and ‘increase physical fitness’ (n=1). Concerning occupational therapy, nine children did not receive occupational therapy. Five children received once a week occupational therapy. For these children the following goals were set: ‘to maintain and/or facilitate motor skills (n=4), ‘to give the child different senso-motoric experience’ (n=4), ‘increase independence in activities of daily life’ (n=1), ‘facilitate arm and hand function’ (n=1) and ‘normalization of muscle tone and relaxation (n=1). Two children received occupational therapy three times a week. These two children were trained to move around independently with use of an electric wheelchair. Four children did not receive occupational during special therapy hours but their development of functional tasks and the applicability of their equipment such as their wheelchair was checked by the occupational therapist. The provided treatment approach, during physical and occupational therapy, was based on a developmental model such as Neuro Development Treatment. The activities were supported by a therapist and primarily carried out in a therapy room during special ‘therapy hours’. Each session took 30 minutes.

During the intervention phase, the MOVE curriculum was added to the regular program at the CSE and implemented by an internationally acknowledged ‘MOVE trainer’ by means of a protocol. For each child, goals were set in close consultation with the DSPs. All therapy goals, as described above were replaced by ‘MOVE goals’. The MOVE goals were formulated in concrete terms and all were concerned with increasing motor- and communication skills. E.g. ‘Mike can move around independently inside and outside the house with use of the gait trainer in order to go to his friends’. For each goal, a decision was made concerning the type, frequency and duration of the MOVE activities to be performed in order to reach this goal. All activities focussed on sitting down/being seated, standing up/standing or walking. The ‘MOVE activities’ were integrated in the daily life of the child and supported by all DSPs of the child. During each activity, the child is facilitate to be as active as possible and to function at their highest potential. For instance, when the child goes to the bathroom, the DSP supports the child with walking (with or without a walking aid) and gives only the support the child needs. Also, the ‘therapy sessions’ were continued with the same duration and frequency however, the therapist(s) supported the child in performing the ‘MOVE activities in the child’s daily environment. Throughout the study period, the DSP registered the length of each ‘MOVE activity’ in minutes.

Analysis
In order to analyse the PROM data, at each measurement, the scores of the left and right sides of the body were added up to produce one final score which could serve as a standard for the total PROM. To make the distinctions between the various parts of these PROM visible, a principle component analyses with varimax rotation (Stevens, 2002) was conducted with the data of the first measurement of 52 children with PMD. The variables depend on three factors, all of which have ‘Eigenvalues’ greater than one, which accounts for 84.2% of the total variance. The shoulder and elbow variants cluster on one factor together, whereas the knee and the ankle each cluster on one factor (table 1). In the analysis of the various parts of the total PROM, the final scores were determined in analogy with these three factors.
Table 1  Results of the principal component analysis with varimax rotation of the variables of the PROM

<table>
<thead>
<tr>
<th></th>
<th>Factor 1</th>
<th>Factor 2</th>
<th>Factor 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Left shoulder ante flexion</td>
<td>.855</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Right shoulder ante flexion</td>
<td>.698</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Left elbow extension</td>
<td>.903</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Right elbow extension</td>
<td>.874</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Left knee extension</td>
<td>.905</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Right knee extension</td>
<td>.942</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Left ankle dorsi flexion</td>
<td>.938</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Right ankle dorsi flexion</td>
<td>.934</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

For the analysis of the active motor function data, at each measurement, the scores of the five questions were added up. A principal component analysis with use of the data from the first measurement of 52 children with PMD, showed that all questions depend on one factor with an ‘Eigenvalue’ greater than one, which accounts for 76.3% of the total variance. Table 2 shows the results of the factor analysis of the active motor function.

Table 2  Results of the principal component analysis of the separate components of the active motor function

<table>
<thead>
<tr>
<th></th>
<th>Factor 1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lifting up the head</td>
<td>.874</td>
</tr>
<tr>
<td>Stretching the torso</td>
<td>.823</td>
</tr>
<tr>
<td>Stretching the hips</td>
<td>.908</td>
</tr>
<tr>
<td>Stretching the knees in seated position</td>
<td>.859</td>
</tr>
<tr>
<td>Stretching the knees in standing position</td>
<td>.902</td>
</tr>
</tbody>
</table>

The data of the 20 children of the experimental group were analysed by means of the general linear model for repeated measurements. The first test was to decide whether a significant change had taken place throughout the four measurements. When such a change was detected, it was determined which measurements differed significantly, the mean score on the moment of measurement being compared to the mean score of the moment of the previous measurement. A two-tailed test was used with an alpha level of .05. Mean differences can be standardized to quantify an intervention’s effect in units of standard deviation. This allows comparison of the different outcomes of one intervention, independent of the measuring units. The resulting statistical measure is known as effect size index (ES) (Middel et al. 2001). The ES was calculated in cases where significant changes were detected. Corrections were made for the correlation between the combined observations (Middel et al. 2001). An ES < .20 is judged as ‘trivial’, an ES ≥ .20 < .50 as ‘small’, an ES ≥ .50 < .80 as ‘moderate’ and an ES ≥ .80 is judged as ‘large’ (Cohen 1977; Middel et al. 2001).

Results

Joint motion
Table 3 shows the mean scores and standard deviation of the PROM for the four measurements. A high score signifies an increase of the PROM. Table 3 also shows the difference scores between the measurements and the F-values, degrees of freedom and p-values of the tests, which were conducted.

The PROM changes significantly throughout the four measurements. The ES, which was calculated for the difference between O2 and O4, amounts to .54. The PROM shows an increase
between O1 and O2 and between O2 and O3. These increases, however, are not significant. The
PROM significantly decreases between O3 and O4 (see figure 1).
When looking at the separate components of the PROM, the joint motion of the shoulder and
elbow did not significant change throughout the measurements. The knee and ankle PROMs both
show a significant change over the course of time (ES = 1.05, ES = .69 respectively). For both
variables, the joint motion increases, although not significantly, between O1 and O2 and between
O2 and O3. The knee PROM as well as the ankle PROM significantly decreases between O3 and
O4.

Figure 1  Graphic representation of the mean values of PROM
throughout the four measurements (O1, O2, O3 and O4)

Active motor function
Table 3 presents the mean scores and standard deviations of the active motor function in the four
measurements. The higher the score, the better the function. This table also describes the
difference scores between the measurements and the results of the effect measurements.

The active motor function shows a significant change throughout the four measurements.
The function decreases between O1 and O2 and increases between O2 and O3 and between O3
and O4 (see figure 2). The changes between each successive measurement are not significant.
Looking at the changes between O2 and O4, however, a significant increase in active motor
function can be seen (ES=.99).
Table 3  Mean scores (M) and standard deviation (SD) of the PROM and active motor function in the four measurements, difference scores between the successive measurements and results of the repeated measures analysis of variance

<table>
<thead>
<tr>
<th>n=20</th>
<th>Measurement</th>
<th>Difference</th>
<th>Effect</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>O1</td>
<td>O2</td>
<td>O3</td>
</tr>
<tr>
<td></td>
<td>M (SD)</td>
<td>M (SD)</td>
<td>M (SD)</td>
</tr>
<tr>
<td><strong>PROM</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>1235.8</td>
<td>1251.3</td>
<td>1262.5</td>
</tr>
<tr>
<td>Shoulder/elbow</td>
<td>683.3</td>
<td>692.3</td>
<td>698.5</td>
</tr>
<tr>
<td>Knee</td>
<td>335.5</td>
<td>338.5</td>
<td>339.5</td>
</tr>
<tr>
<td>Ankle</td>
<td>217.0</td>
<td>220.5</td>
<td>224.5</td>
</tr>
<tr>
<td><strong>Active muscle function</strong></td>
<td>19.05</td>
<td>18.80</td>
<td>19.4</td>
</tr>
</tbody>
</table>

O1, O2, O3, and O4: measurements 1, 2, 3 and 4
O2-O1: difference between measurements 1 and 2, etc.
¹effect throughout measurements O1 O2 O3 O4
²effect between measurements one and two
³effect between measurements two and three
⁴effect between measurements three and four
°phericity assumed
Figure 2  Graphic representation of the mean values of the active motor function throughout the four measurements (O1, O2, O3 and O4)

Discussion
The research question was whether the movement-oriented activities of the MOVE curriculum result in an increase in passive joint motion and active motor function in children with PMD. An increase in joint motion and active motor function is seen, by the developers of MOVE, as a prerequisite for improving functional skills such as eating and drinking, communication and play which enhance participation of the child (Bidabe & Lollar 1995).

Results showed a significant change between three and nine months after the implementation of the MOVE curriculum in passive joint motion. This change however, turned out to take a direction opposite to what was expected. Also, the changes in the different components of the PROMs did not take the intended direction either. Various explanations for these unexpected results have been examined within this study. The results cannot be explained by means of the influence of outliers. Two children were considered as outliers for the total PROM, the shoulder and elbow PROM and the knee PROM. Three children were considered as outliers for the ankle PROM. They all scored 1.5 to 3 quartiles under the 25th percentile (de Vocht 2000). However, analysis without these children yielded the same results. Analyses on individual levels by means of inspecting the courses of the individual curves did not yield any explanations for the results either. Two curves run according to the expected ‘theoretical’ curves for the total PROM, shoulder and elbow PROM and knee PROM. Three curves for the ankle PROM run according to the theoretical expectations. The degree of MOVE intervention did not explain the change in the PROM either. The total duration of the MOVE activities between O2 and O3 and between O3 and O4 was calculated in order to analyse this. Regression analysis was used to determine whether there was a causal relationship between the total PROM in O3 and the duration of activities between O2 and O3, and between the PROM in O4 and the duration of activities between O3 and O4, as well as between O2 and O4.

Results show that there is no statistical causal relation between the PROM in measurements three and four and the duration of the MOVE activities (p>.05). Various researchers indicate that there is a large variability in joint motion measurements, particularly for spastic children (Harris, Smit & Krukowski 1985; Stuberg, Fuchs & Miedaner 1988; McDowell et al. 2000). Indeed, nine of the 20 children in the experimental group have a motor disability involving spasticity. This variability could provide a partial explanation although the reliability study, conducted in the current study...
yielded positive results. Furthermore, the variability does not explain the remarkable course of the PROM after the third measurement.

Active motor function increased significantly within nine months after the implementation of the MOVE curriculum. This can be said to be a large clinical relevant effect (Cohen 1977). There are, however, no significant changes between the successive measurements. The lack of statistical power to indicate the effect could be an explanation for this fact (Ottenbacher & Maas 1999).

The results of the current study can hardly be related to earlier studies since virtually no research has yet been done into the effects of physical activity on joint motion and active muscle function in children with profound multiple disabilities. Although, the results of the current study are consistent with those of studies with participants with less severe or no disabilities. Sommerfeld and co-workers (1981) investigated the effects of physical therapy on the joint mobility in subjects with severe intellectual impairments and cerebral palsy and also did not find significant changes in joint mobility (Sommerfeld et al, 1981). Research conducted by Van den Berg-Emons (et al, 1998) and Salminen (et al 1993) suggest both a positive relationship between physical activity and muscle strength. One should share in mind that these studies focussed at children with cerebral palsy (van den Berg-Emons et al, 1998) and healthy children (Salminen, et al 1993) instead of children with profound disabilities. Lancioni and O'Reilly (1998) presented an overview of the effects of physical activity on physical fitness in people with intellectual disabilities and this review generally yields positive results. Within the reviewed studies, however, activities such as jogging and fitness activities are described which suggest that the studies did not focus particularly at individuals with PMD but with less severe (motor) disabilities.

The results of the current study do not completely support the claims of Bidabe and Lollar (1995). The MOVE curriculum is supposed to have a positive effect at anatomic physiological structures and functions in order to facilitate functional skills and participation of the child as well. The positive effects of the MOVE activities on joint motion are not supported by the current research. Effects of the movement activities on active motor function seems to occur when the activities are carried out for a longer period of time. Probably, the established results are caused by a lack of functionality or purposefulness of the offered activities. However, no analysis was made of the type of MOVE activities offered to the children nor into the relationship between the offered activities and the formulated goals. Furthermore, the relation between the implementation of the activities and the abilities of the children was not subject of the study but could be one of the factors that caused the lack of results. In addition, we should ask ourselves to what extent changes in the anatomic-physiological domain help towards the acquisition of functional skills such as communication and interaction. In general, improvements on a level of impairment do not always lead to improvements on a skills level (Haley 1992; Rothstein 1994) and furthermore, improvements on a skill level do not always lead to improvement in participation, independence and ‘control of life’. Further research must be established to analyse if (part of) the theoretical basis or the way the MOVE curriculum is organised must be refined or that the implementation of the curriculum in practice failed.

In general, there is a critical need for demonstrable evidence to support the effectiveness of interventions, especially when children with PMD are concerned. Because of their profound disabilities, these children are extensively dependent on the activities offered by their DSP. These DSP can only make the correct substantive choices in supporting these children when the effects and criticality of specific components of the interventions available for children with PMD are known. The current study contributes to the understanding and development of interventions, especially the MOVE curriculum, for children with PMD.
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References


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