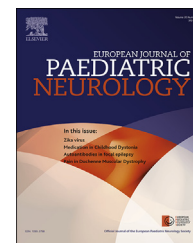




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Original article

The effect of intrathecal baclofen treatment on activities of daily life in children and young adults with cerebral palsy and progressive neurological disorders



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ABSTRACT

Introduction: Intrathecal baclofen (ITB) treatment is applied in patients with spastic cerebral palsy (SCP), dystonic cerebral palsy (DCP) and progressive neurological disease (PND). Our aim was to investigate whether ITB treatment has a different effect on activities of daily life (ADL) in these groups.

Method: A retrospective and cross-sectional survey was conducted using a questionnaire to assess the qualitative effect of ITB (Likert scale) on different domains of functioning (mobility, personal care, communication, comfort) and satisfaction with the results. Groups were compared using non-parametric statistics.

Results: Questionnaires were completed for 68 patients (39 SCP, 13 DCP, 16 PND). Satisfaction scores were relatively high in all groups (7–8) and the positive effect on personal care and communication was similar in all groups. The PND group had the shortest follow-up and scored significantly less favourably for the effect on mobility and comfort.

Discussion: This is the first study to show that ITB treatment has similar effects on personal care and communication in stable and progressive neurological disease. The decrease in mobility in the PND group is likely due to the progressive nature of the disease. The

Abbreviations: ADL, activities of daily life; CP, cerebral palsy; DCP, dystonic cerebral palsy; F, female; GMFCS, gross motor function classification system; ITB, intrathecal baclofen; M, male; N, number; PND, progressive neurological disease; SCP, spastic cerebral palsy; SD, standard deviation; VAS, visual analogue scale; yrs, years.

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different effect on comfort between groups is mainly due to the smaller effect on startles in the PND group.

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Intrathecal baclofen (ITB) treatment is a well-known and widely used treatment for individuals with severe spasticity due to stable underlying conditions. Studies describe a profound decrease of spasticity in patients with spastic cerebral palsy (SCP) during ITB treatment.^{1,2} ITB also seems to have an effect in patients with secondary dystonia.³

The effect of ITB on spasticity CP and other neurological disorders is mediated by inhibition of the GABA receptor located on the spinal interneuron. In contrast, how ITB affects dystonia is unclear.

In conjunction with the reduction of spasticity and/or dystonia, it has been shown that individual problems of daily life, such as pain, transfers, sitting and ease of care improve with ITB treatment.^{4–6} In 70% of patients with SCP or dystonic cerebral palsy (DCP), with predominantly Gross Motor Function Classification System (GMFCS) level IV and V, goals on activity and participation level are attained.⁷

Other effects of ITB treatment in patients with DCP are also comparable with the effects of ITB treatment in patients with SCP but fewer studies are available. Studies show that care is facilitated and that individual problems of daily life improve.^{7–9} Additionally, ITB treatment decreases dystonia in patients with DCP.^{8,10}

The experiences with ITB treatment in patients with progressive neurological disorders of childhood (PND) are limited. A previously published review found only six case studies which describe ITB treatment in patients with spasticity caused by PND.¹¹ The review reported a decrease of spasticity and pain and an improvement in several activities of daily care.

Caregivers of both CP and PND patients are generally satisfied with ITB treatment.^{1,5,9,12} It is, however, unknown if patients with these different conditions experience the same problems in daily life and if they benefit from ITB treatment in the same way. Therefore, the aim of this study was to compare the effect of ITB treatment on activities of daily life in patients with SCP, DCP and PND.

1. Method

1.1. Design

Combined retrospective and cross-sectional survey.

1.2. Patients

In 2007 and 2011 patients were selected from a list of patients who underwent ITB pump implantation since 2001. Patients who were using ITB treatment for less than two years at the time of the first survey in 2007 were again sent the

questionnaires in 2011. They were included if they: 1) had undergone pump implantation (Medtronic, Inc., Minneapolis, MN, USA) in the VU University Medical Center in Amsterdam or the Maastricht University Medical Center in Maastricht, the Netherlands and/or were followed up in one of these centres; 2) were using ITB treatment at the time of the survey; and 3) suffered from SCP, DCP (both with onset before the first birthday) or PND (onset before the age of 18 years). Patients were excluded if their knowledge of the Dutch language was insufficient to complete the questionnaires or if >10% of the questions were left unanswered. Patients were contacted by phone (by LB and DS) and after agreeing to participate they were sent the questionnaires by mail.

Medical charts were checked for gender, diagnosis, GMFCS level, age at pump implantation and time since pump implantation. For PND a GMFCS level was estimated on basis of chart information about functioning.

The medical ethical committee of the VU University Medical Center in Amsterdam approved the use of the current questionnaires, without the use of a formal informed consent.

1.3. Questionnaire

A questionnaire (available as additional material) was sent to caregivers of the included patients. The questionnaire consists of several items (questions), which are divided into four domains of functioning: mobility (fine and gross motor skills), personal care, communication and comfort. Each domain consists of multiple questions focussing on tasks within that domain. For example, within the domain mobility one is asked about transfer, sitting and hand use, within the domain of personal care there are questions about dressing, hygienic care and eating/feeding, for communication about the interaction with other children and the ease of being understood. For comfort there are questions about pain and wellbeing. Since we had a clinical observation that startle reactions often occur, we also included a question about startles. We defined a startle as generalized motor reaction upon auditory, tactile or visual stimulation.¹³

The caregivers were asked to compare the current situation (with ITB treatment) with the situation before pump implantation (without ITB treatment). Changes due to ITB treatment were classified using a five point Likert scale. Possible outcomes were: much better, somewhat better, no change, somewhat worse or much worse. Furthermore, satisfaction was scored on a Visual Analogue Scale (VAS), in which “0” was the worst score and “10” was the best score.

We chose not to use existing scales as the Pediatric Evaluation of Disability Inventory (PEDI) or the WeeFIM for two reasons: 1. Our study is a retrospective study looking into the effect of ITB treatment, therefore we cannot compare pre and

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