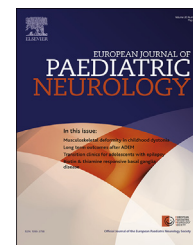




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## Original Article

# Management of drooling in children with cerebral palsy: A French survey

E. Chaléat-Valayer <sup>a,\*</sup>, M. Porte <sup>b</sup>, K. Buchet-Poyau <sup>c</sup>,  
 F. Roumenoff-Turcant <sup>a</sup>, M.C. D'Anjou <sup>e</sup>, C. Boulay <sup>f</sup>, J.C. Bernard <sup>a</sup>,  
 S. Touzet <sup>c,d</sup>

<sup>a</sup> Centre Médico-Chirurgical de Réadaptation des Massues Croix-Rouge française, 69322 Lyon Cedex 05, France

<sup>b</sup> Centre Hospitalier Universitaire de Nîmes, 30029, France

<sup>c</sup> Hospices Civils de Lyon, Pôle Information Médicale Evaluation Recherche, Lyon F-69003, France

<sup>d</sup> Université de Lyon, EA 7425 Health Services and Performance Research (HESPER), Lyon F-69008, France

<sup>e</sup> Coordination SSR Pédiatrique Hôpital Nord, Saint Etienne 42055, France

<sup>f</sup> Service de Neurologie Pédiatrique, CHU Timone Enfants, 13385 Marseille, France

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## ABSTRACT

**Aim:** To characterise children with cerebral palsy (CP) and pathological drooling in France, and to describe care pathways, assessment and treatment.

**Method:** A transversal, observational, descriptive survey of the practices and opinions of 400 health professionals potentially involved in the care of children with CP, was carried out nationally across France in 2013.

**Results:** The response rate was 36%. Seventy-five questionnaires were returned and analysed (52%). A small proportion of children were specifically treated for drooling (<25%). Assessments were carried out in 75% of cases and 91% of professionals prescribed treatments. Use of assessment tools varied widely.

The most common treatment was oro-facial rehabilitation (95% of professionals), followed by anticholinergic drugs (Scopolamine<sup>®</sup>) (94%) botulinum toxin injections (BT) (66%) and surgery (34%). Scopolamine was considered to be less effective than BT and to have more side effects.

**Conclusion:** The rate of pathological drooling in children with CP is likely underestimated and under treated in France. There is a lack of knowledge regarding assessment tools. Aside from rehabilitation, current practice is to prescribe medication as the first-line treatment, however professionals consider that BT is more effective and has less side effects.

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\* Corresponding author. CMCR des Massues Croix-Rouge française, 92, Rue Edmond Locard, 69322 Lyon Cedex 05, France.

E-mail addresses: [chaleat-valayer.e@cmcr-massues.com](mailto:chaleat-valayer.e@cmcr-massues.com) (E. Chaléat-Valayer), [melanie.porte@chu-nimes.fr](mailto:melanie.porte@chu-nimes.fr) (M. Porte), [karine.poyau@chu-lyon.fr](mailto:karine.poyau@chu-lyon.fr) (K. Buchet-Poyau), [f.roumenoff@cmcr-massues.com](mailto:f.roumenoff@cmcr-massues.com) (F. Roumenoff-Turcant), [m.charlotte.danjou@chu-st-etienne.fr](mailto:m.charlotte.danjou@chu-st-etienne.fr) (M.C. D'Anjou), [christophe.boulay@ap-hm.fr](mailto:christophe.boulay@ap-hm.fr) (C. Boulay), [bernard-mpr@cmcr-massues.com](mailto:bernard-mpr@cmcr-massues.com) (J.C. Bernard), [sandrine.touzet@chu-lyon.fr](mailto:sandrine.touzet@chu-lyon.fr) (S. Touzet).

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## 1. Introduction

Drooling, also termed sialorrhoea, hypersalivation or ptyalism, is due, in most cases, to an inability to handle oral secretions due to oro-motor problems. It is physiological before the age of 18 months, tolerated up to the age of 4, but is considered to be pathological beyond this age.

Drooling occurs frequently in children with cerebral lesions. Studies have reported a prevalence of about 40% in children with cerebral palsy (CP).<sup>3,25,18</sup> Moreover, figures of 45%<sup>21,7</sup>–58%<sup>25</sup> have been reported for institutionalised children. In France, the prevalence of CP is 2/1000 live births, with an incidence of 1500 new cases each year, thus a considerable number of children may be affected by pathological drooling.<sup>4</sup>

Drooling is often multifactorial in children with cerebral lesions.<sup>12,6,24</sup> It causes complications such as cutaneous irritation, unpleasant odour, oral and peri-oral infections, tooth decay, difficulty with hygiene and dehydration, which can all increase disability. Moreover, computers and communication aids may be damaged by saliva. Aspiration of saliva also increases the risk of lung infections. Clothes may need to be changed regularly or the child may have to wear a bib. Pathological drooling can reduce self-esteem, thus increasing social isolation. All these elements reduce quality of life for the children and their families.<sup>5,24,27,29</sup>

Treatment includes rehabilitation, medication, botulinum toxin injection and surgery.<sup>2,15,26,28,30,31</sup> Rehabilitation may consist of oro-motor therapy, biofeedback or behavioural interventions, however few studies have evaluated their effectiveness. Medication (muscarinic cholinergic receptor antagonists) may be oral, cutaneous or sublingual, however its use is limited by side effects and a lack of evidence regarding effectiveness.<sup>8</sup> Local treatment by botulinum toxin has been shown to be effective, however the most effective modalities remain to be determined.<sup>13,20</sup> With regards to surgery, the benefits of interventions may be outweighed by the risks. Further studies are thus required to define the role of each treatment. Although recommendations have been proposed for clinical practice,<sup>19</sup> there is currently no consensus regarding the assessment or timing of treatment. There is also a lack of description of the characteristics of children with CP who have pathological drooling and of care pathways for the management of this condition in France.

The aim of this observational study was thus to characterise children with CP and pathological drooling in France, and to describe care pathways, assessment tools and treatments.

## 2. Method

A transversal, observational, descriptive survey of the practices and opinions of health professionals was carried out nationally across France from March to September 2013. Data were collected via a Word-format questionnaire which could be completed electronically or by hand and returned by email or post. The questionnaire was sent by email to 421 professionals (mostly physical and rehabilitation medicine (PMR) specialists, ear nose and throat (ENT) specialists and

paediatricians and neuro-paediatricians). These professionals were located via the 2012–2013 mailing lists of the Franco-phone Society for Study and Research on Childhood Disability (SFHERE), the Rhône Alpes Pediatric Rehabilitation Network (R4P),<sup>19</sup> participants at the 4th congress of the medico-surgical French Red Cross Centre (Botulinum toxin for the treatment of the upper limb in cerebral palsy, Lyon, France 2010), a non-exhaustive list of PMR specialists in France provided by the group of experts constituted for this survey, and the list of the heads of the 32 ENT departments in France. All the professionals on these lists who potentially managed children with CP or used botulinum toxin, according to the expert group, were sent the questionnaire, except for 20 professionals whose email addresses did not function. Four hundred and one professionals received the initial questionnaire and 1 to 4 reminders were sent. If any professionals replied that they were not concerned, the reason was asked (i.e. they were only concerned by drooling in adults, or they saw children with CP but did not treat drooling).

The questionnaire was designed by the group of experts, based on data from the literature and French good practice guidelines.<sup>13,6,15</sup> It consisted of over 100 questions divided into 5 categories: 1) the professional and his/her practice, 2) description and care pathways of the children diagnosed with CP and pathological drooling, 3) assessment of drooling, 4) treatment of drooling and 5) opinion of existing treatments and potential improvements.

The questionnaire took 5–25 min to complete, depending on the responses. Questionnaires received from several professionals of the same department were treated individually since individual opinions were sought.

### 2.1. Statistical analysis

A descriptive analysis was carried out. Categorical variables were described by numbers and percentages and quantitative variables by means ( $\pm$ standard deviations) and medians (range or interquartile interval). For categorical variables regarding frequencies of events, the possible responses were never, sometimes, often and systematically.

## 3. Results

### 3.1. Characteristics of the professionals (Table 1)

The response rate to the email was 36% (143 professionals out of 401 contacted). Seventy-five questionnaires were returned and analysed (52%). The other 68 (48%) replied that they were not concerned, mainly because they did not treat children with CP and/or drooling.

### 3.2. Description of the children with CP and their care pathways, according to the professionals (Table 2)

Forty-four percent of professionals estimated that the prevalence of drooling in children with CP was less than 25%. Thirty-six percent estimated that it was between 25 and 50%. Seventy-seven percent of professionals reported that less than 25% of children were specifically treated for drooling.

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