Review

Measuring quality of life in cerebral palsy children


Objectives. – To identify and describe available health-related quality of life (HRQL) markers in walking paediatric cerebral palsy (CP) patients.

Methods. – A Medline literature review (1980–2007); content, application field, and metrologic properties of the scales were specified.

Results. – Seventeen scales were identified and classified into three categories: scales developed for cerebral palsy patients or developed for neuromotor pathologies and used mostly in cerebral palsy patients; generic scales developed for the general population; generic scales developed for chronic, non-specific diseases.

Discussion and Conclusion. – Documentation of metrologic properties in available HRQL scales is unequal. Information about “sensitivity to change” of the scales is necessary for their use in therapeutic outcome or cohort follow-up studies in CP patients. To include an analysis of the patient’s opinion is important, thus most of the questionnaires are based on the experimenter’s experience and synthesis of the literature. CP children’s auto-evaluation of their quality of life using a questionnaire developed based on the patients’ and families’ opinions, in association with a participation questionnaire, seems to be the most informative method to include in outcome studies.

Keywords: Indicators; Quality of life; Children; Cerebral palsy

1. Introduction

Cerebral palsy (CP) represents a group of pathologies due to a non-progressive lesion of the developing central nervous system in a child less than three years old that leads to neurological and neuromuscular anomalies [1]. It is the most frequent aetiology of incapacity in developed countries, with an incidence of around 1.7 to 2.5/1000 live births [2–4]. Chronic perturbation of movements and posture may lead to functional deficits and incapacities to realise daily life activities, which compromise the patient’s functional independence and quality of life (QL). Thus, studies of patient’s QL are becoming increasingly required internationally as an important component of global therapy outcome evaluation in CP children [5].

Measuring a patient’s QL has to allow for integration of both the patients’ and their families’ opinions and perceptions in the outcome evaluation of the proposed therapy program and in medical decision-making. QL measuring has to be based on the use of standardised and validated questionnaires. These questionnaires will be answered either by the patient or by a proxy of the patient (e.g., parent). Cognitive perturbations in CP that are a part of the disease limit the use of self-questionnaires, but the influence of the subjects’ cognitive functions on self-administered QL measures is poorly documented.

The term health-related quality of life (HRQL) is used to evaluate the influence of the health status (or the disease) and its treatments on the patient’s life and well-being.

HRQL is multidimensional, exploring the following aspects according to the health concept of the World Health Organisation (WHO) [6]:


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physical (autonomy, physical capacities, capacities to realise daily life activities, pain...);
- psychological (well-being, anxiety, emotion...);
- social (relation to family environment, friends, professionals...) [7–9].

Certain instruments, called specific, concern diseases or particular populations and do not allow the comparison of programs oriented to different pathologies. However, generic instruments developed for the general population allow for these kinds of comparisons. It is important to compare HRQL in CP children to healthy children and to explore the influence of their handicap and therapy. Three recent reviews concerning generic HRQL measurements for children and adolescents described around twenty published instruments during the 1990s [10–12].

In France, although interest in QL is widespread, integration of this approach in medical decision-making is still limited. The subject initiates multiple practical questions:

- which instruments are available and which to choose;
- how to use the measures in daily practice and with which objectives;
- how to interpret QL data, etc.

A major implication in allowing the use of QL measurement in our CP patients is to have sufficient information about the tools available for choosing a good QL measures that may be adapted for use in this specific context.

The purpose of our paper was to present the principal available tools to evaluate HRQL in CP children, with an analysis of content, field of application, and metrological qualities of the cited instruments.

2. Methods

A Medline literature review from 1980 to 2007 was performed (http://medline.cos.com/cgi-bin/search) using the keywords “cerebral palsy”, “quality of life”, “functional status”, “children”, “adolescents” and “outcome”. Further tools were found via the paper references. Original papers in English, French, and German concerning generic HRQL in children or adolescents, used in CP patients, were selected and the principal tools were identified.

Fig. 1. Definitions of psychometric qualities of quality of life questionnaires: required qualities of measurement tools need adapted statistical procedures. Denomination of the different qualities are not entirely uniformed in the English- or French-speaking literature.
Questionnaires developed specifically for other chronic pathologies were excluded, as well as questionnaires validated only in adults.

For each tool, the related papers were analysed using a lecture support [7] which grouped the standard criteria in order to evaluate subjective health measurements.

This support explored mainly the underlying concepts of construction of the tool, its finality, its modalities of administration, the length of the questionnaire, the time to answer as well as the proposed score (index or profile), and the metrological qualities of the questionnaires (validity of internal and external structure, reliability with internal consistency, inter-observer reliability, sensitivity to change) (Fig. 1). Their principal application fields were also noted.

3. Results

Bibliographic analysis has identified 178 articles about QL analysis in CP children, including 17 pertinent QL tools.

Scales were grouped into three categories (Table 1):

- generic QL questionnaires developed for the general population, or scales developed for a chronic disease population, non-specific for neuromuscular disease, but used in CP patients (N = 12);
- QL questionnaires developed for CP or neuromuscular disease and used principally for CP patients (N = 2);
- “assimilated” QL questionnaires: questionnaires that did not document the three domains (physical, psychical and social); the authors themselves assimilated them to QL exploration, or users assimilated them for QL explorations (N = 3).

The content of the seventeen questionnaires was variable (Table 2), based specifically on different modes of development: certain questionnaires were constructed based on existing adult questionnaires (DHP-A [13]), or based on existing literature or professional expert opinion (e.g., physicians, psychologists) like the child health questionnaire (CHQ) [14,15]; others were based on interviews with children like the auto-questionnaire de l’enfant imagé (AUQUEI) [16] or the vécu et santé perçu – adolescent (VSP-A) [17,18]. Finally, other questionnaires combined the two points of view (pediatric quality of life inventory (PedsQL)) [19–25], DISABKIDS [26,27] or KIDSCREEN [28,29]). Only two questionnaires were developed specifically for children with CP (DISABKIDS CP module [26,27], CP QOL [30,31]).

Analysis of age groups showed that only three questionnaires, validated in French, are used on children and adolescents via an auto-questionnaire (AQ) or a parent questionnaire (PQ): VSP-A and KIDSCREEN as AQ and PQ from eight to 18 years, and the DISABKIDS as AQ and PQ from four to 16 years.

Detailed analysis of the explored categories (Table 3) showed that even if the three domains (physical, functional and social) are covered in all questionnaires, the dominant fields differ: EHRQL, AUQUEI, VSP-A and KIDSCREEN widely describe, for example, the social and psychological domain and less the physical domain, although the psychological domain is dominant in the KINDL. The Peds-QL covers each domain, but poorly explores the social domain without exploration of the parent-child relationship. Furthermore, not all questionnaires document ‘cognitive function’.

Results of the questionnaires’ psychometric properties are resumed in Table 2.

Results of the questionnaires are expressed either as a ‘profile’ (calculation of a score for each dimension (CHIP, CP-QOL, kidlQol, DHP-A)), an ‘index’ (production of a global QL score (EHRQL, GCQ, AUQUEI)), or both, furnishing a profile and an index (CHQ, KINDL, Peds-QL, TACQOL, KIDSCREEN, DISABKIDS, VSP-A).

Most of these questionnaires have a validated version in several languages and various countries (CHIP, CHQ, LIFE-H, KINDL, DISABKIDS, KIDSCREEN, Peds-QL, VSP-A), allowing for international comparisons.

The questionnaires CHQ, AUQUEI, VSP-A, DHP-A, KIDSCREEN, kidlQol, DISABKIDS and LIFE-H are validated in French. At the moment, only one, the DISABKIDS, proposes a CP children-specific module, including 16 items exploring two dimensions (impact and communication), and was tested on a limited number of CP children.

4. Discussion

It is well established that QL evaluation represents a substantial factor in therapeutic outcome evaluation in CP patients.

The decision to include HRQL measurement in an outcome evaluation set has to be considered with the same
<table>
<thead>
<tr>
<th>Instrument</th>
<th>Year</th>
<th>Reference</th>
<th>Country of origin/language</th>
<th>Administration mode</th>
<th>Concerned age</th>
<th>Number of questions</th>
<th>Explored domains</th>
<th>Time to fill in (minutes)</th>
<th>PMV</th>
<th>Validated french version</th>
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<tbody>
<tr>
<td>Generic scales of QL in children used in CP</td>
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<td></td>
<td>AQ: CHIP-AE</td>
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<td>PQ: CHIP-PE</td>
<td>6–11</td>
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<td>VES</td>
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<tr>
<td>CHQ</td>
<td>1996</td>
<td>[14,15]</td>
<td>US/English French</td>
<td>AQ: CF87</td>
<td>10–18</td>
<td>87</td>
<td>Physical, physical functioning, body pain, physical social role, emotional social role, general health perception, mental health, general comportment, self-esteem, parental impact on emotion, parental impact on time, familiar impact</td>
<td>20</td>
<td>VIS</td>
<td>Yes</td>
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<td>PQ: PF28, PF50, PF87</td>
<td>5–18</td>
<td>87/50/28</td>
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<td></td>
<td>VES</td>
<td></td>
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<tr>
<td>AUQUEI</td>
<td>1997</td>
<td>[16,61]</td>
<td>France</td>
<td>AQ</td>
<td>4–12</td>
<td>26</td>
<td>Physical functioning, physical (sport), positive emotions, self image, cognitive functioning, relation with friends, interaction with family</td>
<td>NR</td>
<td>VIS</td>
<td>Yes</td>
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<tr>
<td>GCQ</td>
<td>1997</td>
<td>[54,62]</td>
<td>UK</td>
<td>AQ</td>
<td>6–16</td>
<td>25 × 2 (50)</td>
<td>Physical well being, emotional well being, self esteem, family, friends, daily functioning (school or kindergarden)</td>
<td>NR</td>
<td>VIS</td>
<td>No</td>
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<tr>
<td>KINDL</td>
<td>1998</td>
<td>[56]</td>
<td>Germany</td>
<td>AQ: Kiddy</td>
<td>4–7</td>
<td>19</td>
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<td>10</td>
<td>VIS</td>
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<td>AQ: Kid</td>
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<td>AQ: Kiddo</td>
<td>12–16</td>
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<td>CV</td>
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<td>PQ: 4–7</td>
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<td>clinV</td>
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<td></td>
<td>PQ: 8–16</td>
<td>31</td>
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<td>VES</td>
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<td>TACQOL</td>
<td>1998</td>
<td>[52]</td>
<td>Netherlands</td>
<td>AQ</td>
<td>8–15</td>
<td>53</td>
<td>Pain and symptoms</td>
<td>10</td>
<td>VIS</td>
<td>No</td>
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<td>PQ</td>
<td>6–15</td>
<td>55</td>
<td>Basic motor functioning</td>
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<td>CV</td>
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<td>ClinV</td>
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<td>Social functioning</td>
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<td>Global positive emotional functioning</td>
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<td></td>
<td>Physical functioning, emotional, social, scholar</td>
<td>5–10</td>
<td>VIS</td>
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<tr>
<td>EHRQL</td>
<td>1999</td>
<td>[53]</td>
<td>UK</td>
<td>AQ</td>
<td>2–18</td>
<td>16 pictures</td>
<td>Activity limitation, physical symptoms (headache), negative feelings, self image, relation with friends, scholar functioning, interaction with family</td>
<td>20</td>
<td>VIS</td>
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<td>PQ</td>
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<td>Evaluation two times: &quot;like me&quot;</td>
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<td>&quot;I would most like to be&quot;</td>
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<tr>
<th>Instrument</th>
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<th>Explored domains</th>
<th>Time to fill in (minutes)</th>
<th>PMV*</th>
<th>Validated French version</th>
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<td>VSP-A</td>
<td>2000</td>
<td>[17,18]</td>
<td>France</td>
<td>AQ</td>
<td>11–17</td>
<td>39</td>
<td>Psychological well being, self esteem, energy, physical well being, school, leisure activities, relations with friends, parents, teachers, sentimental life</td>
<td>&lt; 15</td>
<td>CV VIS VES TrT</td>
<td>Yes</td>
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<td>DHP-A</td>
<td>2005</td>
<td>[13]</td>
<td>UK</td>
<td>AQ</td>
<td>AQ: 13–18</td>
<td>17</td>
<td>Health: physical, mental, social, general, appearance, self esteem, anxiety, depression, pain, incapacity</td>
<td>NR</td>
<td>VIS VES TrT</td>
<td>Yes</td>
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<tr>
<td>KIDSCREEN</td>
<td>2005</td>
<td>[28,29]</td>
<td>Europe</td>
<td>AQ, PQ</td>
<td>AQ: 8–18, PQ: 8–18</td>
<td>52/27/10</td>
<td>Physical well being, positive and negative psychological feeling, self esteem, autonomy, family life, financial resources, relations with friends, school, social integration</td>
<td>NR</td>
<td>VIS VES culV</td>
<td>Yes</td>
</tr>
<tr>
<td>kidQol</td>
<td>2005</td>
<td>[55]</td>
<td>France</td>
<td>AQ</td>
<td>AQ: 6–12</td>
<td>44</td>
<td>Physical, psychological, social</td>
<td>NR</td>
<td>VES culV NR</td>
<td>Yes</td>
</tr>
<tr>
<td>CP-QOL</td>
<td>2005</td>
<td>[30,31]</td>
<td>Australia</td>
<td>Q, PQ, AQ</td>
<td>PQ: 4–12, AQ: 9–12</td>
<td>66</td>
<td>Friends and family, participation, communication, health, special equipment, pain and border, (+ for PQ: access to treatment, parental health</td>
<td>NR</td>
<td>TrT VIS No</td>
<td></td>
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<tr>
<td>DISABKIDS</td>
<td>2006</td>
<td>[26,27]</td>
<td>Europe</td>
<td>AQ, PQ</td>
<td>AQ: 8–16, AQ: 4–7</td>
<td>37/12, Module IMC: 7</td>
<td>Independence, emotions, social integration, social exclusion, physical limitations, treatment</td>
<td>NR</td>
<td>VIS culV TrT</td>
<td>Yes</td>
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<tr>
<td>LSIA</td>
<td>1994</td>
<td>[60]</td>
<td>Canada</td>
<td>AQ</td>
<td>AQ: 12–19</td>
<td>45</td>
<td>General well-being, relations with others, personal development, personal accomplishment, leisure activities</td>
<td>NR</td>
<td>VIS VES No</td>
<td></td>
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<tr>
<td>FMH</td>
<td>1996</td>
<td>[57]</td>
<td>Germany</td>
<td>PQ</td>
<td>PQ: 0–18</td>
<td>56</td>
<td>Mobility, eating/drinking, corporal health, general independence, communication, writing/reading/calculation</td>
<td>NR</td>
<td>TrT clinV No</td>
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<tr>
<td>LIFE-H</td>
<td>1998</td>
<td>[58,59]</td>
<td>Canada</td>
<td>PQ</td>
<td>PQ: 5–18</td>
<td>62 (short version), 248 (long version)</td>
<td>Nutrition, fitness, personal care, communication, housing, mobility, responsibility, familial relations, relations with others, community, education, employment, leisure activities</td>
<td>NR</td>
<td>TrT VIS Yes</td>
<td></td>
</tr>
</tbody>
</table>


* Adapted from references [7–9].
methodological exactness applied for every other clinical or technical outcome evaluation criterion. Thus, tools for these types of measurements must demonstrate the required metrological properties, and the content of the questionnaire and its application must be adapted to the patient and validated in the patient’s context.

The MOS SF 36 [32–34] for example, used in a study of adolescent CP patients [35], was excluded in our analysis because it was developed and validated in a general adult population only.

Additionally, the QUALIN questionnaire [16], which was developed and validated in children less than three years of age and was recently used in a small sample of severely involved CP patients, was also not included in our review.

Nevertheless, considering the conditions of a severely involved CP child or adolescent, autonomy restriction, vital...
dependence, and use of extra-verbal expressions to com-
municate, it may be viewed as an interesting working hypothesis.
In this context, metrological properties of the QUALIN
questionnaire could be studied in a cohort of CP children and
adolescents.

Despite the existence of different QL questionnaires in CP
children, very few questionnaires, validated in French, fulfill all
the psychometric requirements.

In addition, the expression ‘quality of life’ is often used
thoughtlessly as an umbrella term for every auto-evaluated
measurement. The concept of QL evaluation is not clearly
integrated in the International Classification of Functioning,
Disability and Health (ICF) [36], which may induce confusion
in planning patient evaluation based on the ICF principals. To
use this conceptual framework, definitions of the concepts have
to be very precise and placed within a clinical context. The ICF
introduces the concepts of ‘activity and participation’ in the
context of personal and environmental factors. These concepts
may also be explored using auto-evaluation measurement tools.
However, ‘quality of life’ and ‘activity and participation’ are
multidimensional concepts that do not explore the same
domains [37].

Activity means the execution of a task and participation
is the implication of doing something in a situation of real
life. They are objective concepts, depending on personal
factors and the environment of each patient. In contrast,
QL is a concept of subjective measure. It is the measurement
of the subjective feeling reported by the subject himself/
herself.

The patient may have difficulties in executing certain
activities that may create problems for participation in a real
situation. For both activity and participation we have two
qualification codes – capacity and performance. Capacity is the
aptitude to execute a task, and performance is the act of
executing a certain activity in daily life.

In the framework of evaluation of the concept QL, it is only
those questionnaires covering the whole of the domains of
physical, psychological and social that allows an overview of
our patient’s QL [6].

In the field of CP patient evaluation, the content (e.g.,
questions exploring significant aspects for the patient,
adapted to patient’s concerns) and the mode of application
(e.g., filled in by the patient himself/herself or by a proxy,
confidentially) are the most important difficulties in
measuring HRQL.

Questions and domains explored by most of the question-
naires used were chosen according to an expert’s opinion and
not to the patient’s point of view, and draw into question
whether the questionnaires correspond perfectly to the opinion
of the CP patients.

The experience of a chronic disease could interfere with the
value attributed to different facets of life. Are the domains
explored by the used, principally generic questionnaires
adapted to CP patients? Are the same questions pertinent for
all CP patients (diplegia, hemiplegia, quadriplegia)?

Considering the particularity of the deficiencies in CP and
the importance of their handicap on their QL, we may reflect
upon the capacity of these indicators to show specific
modifications for QL. For example, we may suppose that a
QL questionnaire that explores less of the physical domain is
less sensible in exploring the QL of a patient with a
neuromuscular deficiency.

Self-evaluation by an auto-questionnaire is, at the
moment, considered the best way to acquire a patient’s
perception. Sometimes, for example in very young children
or in certain CP patients, communication problems are
real, and because of the lack of an adapted tool, some
teams have already used the QUALIN questionnaire,
which has not been validated in a population of CP patients
[38].

Integration of the CP patient’s experience is generally
discussed because of the difficulties of appreciation related to
the severity of CP and the possible association of cognitive
deficiency. Mental retardation is present in 30 to 70% of the
cases depending on CP type [39,40], principally in quadri-
plegia. About 30% of the children have severe learning
difficulties [41,42]. Interaction of other neurodevelopmental,
non-motor and sensorial deficiencies, like epilepsy, hearing
and visual deficiencies or attention, and communication and
cognitive deficits, influence the possibility of asking the patient
himself/herself. Mental health may also be influenced by
chronic pain, social isolation and the loss of functioning and
independence associated with CP.

It is recommended to explore the intellectual level of the
patients. For example, the ‘surveillance of cerebral palsy in
Europe’ (SCPE) [39] includes a description of different

To bypass the difficulties of self-evaluation, completion of
the subjective approach by information from a proxy (hetero-
evaluation), mostly the family or the patient’s caregivers, was
suggested. The collected information, however, is of a different
nature. Studies have shown that the answers of the different
responders (children and parents for example) are far from
being perfectly concordant [43].

Depending on the context, HRQL measures may allow for:

- describing HRQL in different groups of subjects, thus making
  it possible to differentiate one group from another. For example,
  it is possible to compare HRQL in a group of
  children with motor impairment to children without any
  known health problem, or to compare HRQL of children with
  different degrees of motor impairment;

- predicting future evolution in a prognostic perspective: a
good evolution in HRQL in the social field in a child with
motor impairment (like the perception to be supported by the
familiar, friend or scholar environment) could be a predictive
factor for good results of a treatment in health terms during
adolescence or adult age;

- evaluating change over time, according either to the natural
evolution of the subject’s health or response to therapy. It is
possible to evaluate the impact of different surgical strategies
on HRQL in spastic, diplegic CP children. In this evaluative
perspective, HRQL measurements are integrated in clinical
surveys.
HRQL measurements are now poorly used to evaluate the efficiency of a patient’s treatment (level of individual decision making), despite the fact that it is increasingly considered to be an essential criterion of outcome evaluation in Anglo-Saxon publications [5,44–47]. This requires, however, high quality tools of HRQL measurements (in terms of precision, validity, reliability, etc.).

Almost all available indicators were validated in the English language and mostly in the United States. Their use in European countries, particularly in France, brings about problems of transcultural validation of these kinds of indicators. A linguistic and cultural validation in the country using the questionnaire is required [7]. Sociocultural variations, particularly those pronounced in terms of treatment of handicapped patients and adaptation problems, make these tools hardly transposable.

5. Conclusion

Evaluation HRQL in CP patients has substantial implications because it allows for the evaluation and integration of the patient’s opinion and a subjective appreciation of their experience based on clinical objective criteria in order to reach a global strategy of their health and therapy evaluation.

It is essential to know the nature of the HRQL information (self- or hetero-evaluation, but also the origin of the questions and their pertinence, the studied context, etc.) and to be able to appreciate its quality (validity, reliability, sensitivity to change, etc.) in order to discuss the interests and limits of every study delivering results regarding patients’ HRQL.

The properties of the scales used in CP patients do not allow for its full and satisfying use. Therefore, continued research in terms of HRQL in CP patients is required.

Depending on its severity, CP induces a more or less significant motor deficiency and may therefore influence the domain of ‘physical functioning’ of a QL scale.

According to our literature review and based on the fact that QL, activity and participation are well differentiated concepts, we recommend a systematic QL questionnaire that:

- is generic and validated in French;
- delivers an index of global QL and profiles in different dimensions;
- is validated for children and the adolescent population (ex: KIDSCREEN, VSP-A);
- is available as a self- and hetero-questionnaire as well as a participation scale (ex: LIFE-H), until more specific tools are available.

If possible, self-evaluation is preferred, but because of the possible associated cognitive deficiencies in CP patients, association of the intellectual level seems to be essential. Parent or proxy evaluation of QL and participation may be the only solution for very young patients or for patients with severe cognitive involvement. In this case, modification of evaluation of the subjective concept of QL has to be integrated in interpreting the result.

References

[22] Varni JW, Seid M, Kurtin PS. PedsQL 4.0: reliability and validity of the Pediatric Quality of Life Inventory version 4. 0 generic core scales in healthy and patient populations. Med Care 2001;39:800–12.