Review

Measuring quality of life in cerebral palsy children

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Abstract

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.

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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.

![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.](image)

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 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, psychological 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 image (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, kidqol, 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, kidqol, 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>
</tr>
</thead>
<tbody>
<tr>
<td>Generic scales of QL in children used in CP</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>AQ: CHIP-AE</td>
<td>12–17</td>
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<td></td>
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<td>PQ: CHIP-PE</td>
<td>6–11</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>PQ: 5–18</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></td>
<td>PQ: PF28, PF50, PF87</td>
<td>87</td>
<td>87/50/28</td>
<td>Family and social relations, activity (play, scholarly, leisure), health, “functions” (sleeping, alimentation), separation</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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<td></td>
<td>Evaluation two times: “feel most like myself” “I would most like to be”</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>$25 \times 2 \ (50)$</td>
<td>Activity (play, scholar, leisure), health, “functions” (sleeping, alimentation), separation</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>
<td>Physical well being, emotional well being, self esteem, family, friends, daily functioning (school or kindergarten)</td>
<td>10</td>
<td>VIS</td>
<td>No</td>
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<td></td>
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<td></td>
<td></td>
<td>AQ: Kid</td>
<td>8–11</td>
<td>31</td>
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<td>AQ: Kiddo</td>
<td>12–16</td>
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<td>PQ: 4–7</td>
<td>53</td>
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<td>PQ: 8–16</td>
<td>31</td>
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<tr>
<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></td>
<td></td>
<td></td>
<td></td>
<td>PQ</td>
<td>6–15</td>
<td>55</td>
<td>Basic motor functioning</td>
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<td>Cognitive functioning</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></td>
<td>Physical functioning, emotional, social, scholar</td>
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<tr>
<td>PedsQL</td>
<td>1999</td>
<td>[19–25]</td>
<td>US</td>
<td>AQ</td>
<td>5–7</td>
<td>23</td>
<td>Activity limitation, physical symptoms (headache), negative feelings, self image, relation with friends, scholar functioning, interaction with family</td>
<td>5–10</td>
<td>VIS</td>
<td>No</td>
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<td></td>
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<td></td>
<td></td>
<td>AQ</td>
<td>8–11</td>
<td></td>
<td>Evaluation two times: “like me” “I would like to be”</td>
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<td></td>
<td></td>
<td>AQ</td>
<td>13–18</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>6–11</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>
<td>No</td>
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<td></td>
<td></td>
<td>QP</td>
<td>2–18</td>
<td>16 pictures</td>
<td>Evaluation two times: “like me” “I would like to be”</td>
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</table>

*PMV*: French version.
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<th>Instrument</th>
<th>Year</th>
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<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>VSP-A</td>
<td>2000</td>
<td>[17,18]</td>
<td>France</td>
<td>AQ QP (VSP-Ap) Vsp-Ae</td>
<td>11–17 8–10</td>
<td>39 12</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>
</tr>
<tr>
<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 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 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 cultV</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>VIS VES</td>
<td>Yes</td>
</tr>
<tr>
<td>CP-QOL</td>
<td>2005</td>
<td>[30,31]</td>
<td>Australia</td>
<td>PQ AQ QP</td>
<td>PQ: 4–12 AQ: 9–12</td>
<td>66 53</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</td>
<td>No</td>
</tr>
<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 cultV 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</td>
<td>No</td>
</tr>
<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</td>
<td>No</td>
</tr>
<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</td>
<td>Yes</td>
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</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
the importance of their handicap on their QL, we may reflect
whether the questionnaires correspond perfectly to the opinion
not to the patient’s point of view, and draw into question
questionnaires used were chosen according to an expert’s opinion and
confidentially) are the most important difficulties in
don 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
cognitive deficiencies.

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

[23] Varni JM, Limbers CA, Burwinkle TM. Parent proxy-report of their children’s health related quality of life: an analysis of 13,878 parents’
reliability and validity across age subgroups using the PedsQL 4.0 Generic Core Scale. Health Qual Life Outcomes 2007;5:3.