Importance of hip problems in daily activities for cerebral palsy patients

Elke Viehweger

Received: 19 February 2013 / Accepted: 17 June 2013 / Published online: 15 September 2013
© EPOS 2013

Cerebral palsy (CP) arises due to an injury in the immature brain, and—even in patients in whom the disorder is considered to be nonprogressive—the resulting disability is lifelong. During the growth of a child with CP, deformities may appear, get worse, and lead to decreased function and ability to perform daily life activities, depending on the orthopedic and general management scheme implemented. CP is therefore largely perceived as a childhood disease, and the need for early management is well known. Long-term therapy strategies are required, because the groundwork for the optimal performance of activities of daily living in adulthood is laid in childhood.

Many adults with CP report decreases in activity and body functions [1–7]. Pain, increasing musculoskeletal problems, fatigue, and bladder and bowel problems are common in adult patients with CP [8–11]. Nevertheless, their levels of life satisfaction are similar to those of the average population [3]. In contrast to the general opinion, they may experience a good quality of life despite their severe handicap [12].

Well-being and self-perceived health are related to pain and deteriorating function, but are not related to the level of functioning itself [6, 13]. According to the opinions of adult CP patients, the most important issues to them are communication, daily life activities, mobility, and walking [14].

Focusing more specifically on the CP hip, its pathophysiology is directly related to its severity, i.e., delayed or nonacquired weight-bearing. Hip subluxation and dislocation occur in nonwalking patients, with femoral and

acetabular dysplasia arising due to the nonphysiological constraints on the hip joint present during persistent sitting with muscle imbalance, along with persistent femoral anteversion and coxa valga, as well as posterolateral acetabular dysplasia (Fig. 1).

Therefore, in nonambulatory adult CP, hip pain is one of the main complaints—either provoked, linked to position, or spontaneous [15]—and it may also occur in reduced hips. This is one of the most important disabling disorders seen in CP adolescents or adults. It conditions the ability to stand for transfers [16] and walk, or to sit comfortably. Therefore, we need to establish the long-term consequences of unadapted treatments and hurdles for adults with CP. With increasing body age, patients face osteoarthritis, leading to seating instability or disabilities, difficulties with care, and decubital ulcers (Fig. 2). For women, there can be problems with menstruation, sexual activity, or pregnancy. Major hip pain increases muscle tone and decreases upper limb use, finally leading to communication problems and withdrawal from the outside world.

The treatment strategy must be adapted for severely involved patients with hip problems. Recent advances in seating technology (Fig. 3), adapted focal tone treatment (Fig. 4), and the integration of surgical techniques such as total hip prosthesis [16] may be proposed (Fig. 5). These surgeries must always be integrated into a general therapy program, such as regular gastrointestinal, nutritional, and respiratory checkups and treatment.

The treatment approach for the hips of a child with CP should focus on their expected activities of daily life during adulthood, and should relate to the severity of the pathology of the patient, rather than the deformity itself. It is essential to find intervention strategies that promote good health over the course of the patient's lifetime. It was recently pointed out that the most important challenge is to

E. Viehweger (✉)
Department of Pediatric Orthopaedics, Timone Children's
Hospital, Aix-Marseille University, Marseille, France
e-mail: elke.viehweger@mail.ap-hm.fr

Fig. 1 3D CT reconstruction: posterolateral dysplasia in a nonwalking GMFCS 5 CP patient due to an underlying muscle imbalance, bony dysplasia, and persistent sitting

meet the needs arising from functional problems such as body deterioration, as well as those relating to self-esteem and aspects of autonomy [17].

With regard to long-term treatment strategy planning, the International Classification of Functioning, Disability and Health (ICF) [18] can aid in the creation of an evaluation scheme for all CP patients, and when establishing therapy objectives regarding daily living. The ICF introduces the concepts of activity and participation in the context of personal and environmental factors.

In this context, activity means the execution of a task, and participation is the involvement of the patient in a life situation. These are objective concepts that depend on personal factors and each patient's environment. The patient may experience difficulties in executing certain activities that may create problems in situations encountered in daily life. There are two qualifiers for both activity and participation: capacity and performance. Capacity is

Fig. 3 Twenty-six-year-old GMFCS 5 CP patient with major dystonia, athetosis, and a painful dislocated left hip who was initially installed in a rigid seating system in a hip-abduction/external-rotation position. The pain subsided when the patient was later installed in an elastic carbon-fiber seating system with free internal hip rotation

the aptitude of the patient when executing a task, and performance is the act of executing a certain activity in daily life.

The concept of quality of life (QL) evaluation is not clearly integrated into the ICF. Health-related quality of

Fig. 2 Twenty-eight-year-old adult with a history of left femoral head neck resection with major pain, inability to sit, and skin problems. In this GMFCS 5 CP patient, the decision to perform this type of surgery was made based on no patient walking potential. There was no evaluation and integration of long-term general health, sitting potential, and comfort during daily life during the initial surgical decision-making process

Fig. 4 **a** Twelve-year-old non-communicating CP patient with major pain in the bilateral hips, scoliosis, loss of seating, and major general health problems who was contraindicated for surgery. **b** The patient underwent 7 years of focal objective-based tone treatment with repeated adductor and hamstring botulinum toxin injections and general health therapy. **c** The 19-year-old patient, who did not suffer any pain and showed improved general health, seating, and personal care with the aid of one care-giver

Fig. 5 **a** Loss of ability to sit due to a painful right hip in a 39-year-old CP patient before surgery. **b** The patient received a total hip prosthesis with a custom-made femoral stem and a dual mobility cup for the acetabulum

Table 1 Questionnaires employed to explore activity and participation with regard to capacity and performance

Questionnaire	Type(s)	Use in children	Concept	Behavior	Communication/ awareness	Locomotion	Manipulation/task related body us	Self care/ toilet	Situation-related incapacity
CHART (Craig Handicap Assessment and Reporting Technique) [26, 27]	1, 2	0	Roles of survival			X	X	X	X
PEDI (Pediatric Evaluation of Disability Inventory) [28, 29]	2, 3	1	Functional capacities			X	X	X	
London Handicap Scale [30]	3	0	Quantification of handicap			X	X	X	X
FMH (Fertigkeitenskala Münster-Heidelberg) [31]	2, 3	1	Performance/HRQL		X	X	X	X	X
COPM (Canadian Occupational Performance Measure) [32]	3	1	Activity/ participation			X	X	X	X
POSNA PODCI (Pediatric Outcomes Data Collection Instrument) [33]	1, 2	1	Real-life functional level			X	X		X
ASK (Activities Scale for Kids) [34, 35]	1	1	Physical activity in environment			X	X	X	X
LAQ-CP (Lifestyle Assessment Questionnaire) [36]	2	1	Activity/ participation	X	X	X	X		X
AMPS (Assessment of Motor and Process Skills) [37, 38]	3	1	Daily life activities			X	X	X	X
CAPE (Children's Assessment of Participation and Enjoyment) [39, 40]	1, 2, 3	1	Participation/ enjoyment			X	X	X	X
HSC (Handicap Scale for Children) [41]	1	1	Social participation			X	X	X	X
M-ADL (Münchener ADL-Fragebogen) [42]	2, 3	1	Daily life activities			X	X	X	X
PS-ADL (Performance and Satisfaction in Activities of Daily Living) [43]	3	0	Daily life activities			X	X	X	X
LIFE-H (Assessment of Life Habits for Children) [44–46]	1, 2	1	Activity, participation, HRQL	X	X	X	X	X	X

Type (of questionnaire): 1 = child/adolescent self-questionnaire, 2 = parent questionnaire, 3 = care-giver questionnaire

life is multidimensional, and considers the following aspects according to the concept of health proposed by the World Health Organisation (WHO) [19]: physical (autonomy, physical capacities, capacities to execute daily life activities, pain, ...); psychological (well-being, anxiety, emotion, ...); and social (relationships to family, friends, professionals, ...) [20–22].

QL is a subjective measure. It attempts to quantify the subjective feeling reported by the subject him/herself.

Considering daily life, and reviewing the literature in this field, other concepts may also be important and should therefore be evaluated, such as independence and caregiver burden/enjoyment.

It is impossible for the orthopedic surgeon to take into account all of these aspects and integrate them all into the solution of a specific orthopedic problem. However, it may be interesting to integrate some of the concepts (Table 1) into the discussions with the family and the caregiving team, who are facing the daily functional issues arising from the hip problem in the CP patient and expect a tangible treatment strategy.

For both walking and nonwalking young CP patients, from the long-term perspective of performing activities of daily living, it is important to keep the hips well centered with a level pelvis in order to achieve good sitting comfort, prevent pain, and avoid biomechanical conditions that can allow scoliosis to evolve. Surgery of a dislocated hip may not cure sitting and positioning asymmetry [23], and may even worsen it when performed unilaterally [24]. Bilateral surgery may therefore be needed to correct a pelvic imbalance that would hinder activities of daily living.

In older CP patients with femoral head deformity, as long as the femoral physis is open, reduction can result in a painless, functional hip provided that it is taken care of properly [16].

Reconstructive hip surgery in severely dysplastic hips or in the presence of osteoarthritis should be first weighed against its potential complications and the need for a complete preoperative work-up in the severely involved CP patient to decrease complications. Considering daily life activities, reducing spasticity using focal hip objective-based toxin injections to improve comfort and maintain symmetric motion for daily care may be more useful than having a located hip as documented on an X-ray [25].

For reliable orthopedic management of hip problems in CP patients, it is most important to be aware of long-term issues of daily living. It's essential to ask the “good” questions to be able to propose a daily living objective based therapy program.

Daily living has to be the basis for long-term decision-making regarding CP hip problems.

References

- Andersson C, Mattsson E (2001) Adults with cerebral palsy: a survey describing problems, needs, and resources, with special emphasis on locomotion. *Dev Med Child Neurol* 43:76–82
- Ando N, Ueda S (2000) Functional deterioration in adults with cerebral palsy. *Clin Rehab* 14:300–306
- Andren E, Grimby G (2004) Dependence in daily activities and life satisfaction in adult subjects with cerebral palsy or spina bifida: a follow-up study. *Disab Rehab* 26:528–536
- Bottos M, Felicangeli A, Sciuto L, Gericke C, Vianello A (2001) Functional status of adults with cerebral palsy and implications for treatment of children. *Dev Med Child Neurol* 43:516–528
- Jahnsen R, Villien L, Egeland T, Stanghelle JK, Holm I (2004) Locomotion skills in adults with cerebral palsy. *Clin Rehab* 18:309–316
- Sandstrom K, Alinder J, Oberg B (2004) Descriptions of functioning and health and relations to a gross motor classification in adults with cerebral palsy. *Disab Rehab* 26:1023–1031
- Strauss D, Ojdana K, Shavelle R, Rosenbloom L (2004) Decline in function and life expectancy of older persons with cerebral palsy. *Neuro Rehab* 19:69–78
- Jahnsen R, Villien L, Stanghelle JK, Holm I (2003) Fatigue in adults with cerebral palsy in Norway compared with the general population. *Dev Med Child Neurol* 45:296–303
- Murphy KP, Molnar GE, Lankasky K (1995) Medical and functional status of adults with cerebral palsy. *Dev Med Child Neurol* 37:1075–1084
- Schwartz L, Engel JM, Jensen MP (1999) Pain in persons with cerebral palsy. *Arch Phys Med Rehab* 80:1243–1246
- Turk MA, Geremski CA, Rosenbaum PF, Weber RJ (1997) The health status of women with cerebral palsy. *Arch Phys Med Rehab* 78:S10–S17
- Albrecht GL, Devlieger PJ (1999) The disability paradox: high quality of life against all odds. *Soc Sci Med* 48(8):977–988
- Furukawa AIH, Nshiyama M, Nii E, Ushida A (2001) A study on the subjective well-being of adult patients with cerebral palsy. *J Phys Ther Sci* 13:31–35
- Bleck EE (1987) Orthopaedic management in cerebral palsy. *Clinics in developmental medicine*, nos. 99/100. Mac Keith, London
- Hodgkinson I, Jindrich ML, Duhaut P, Vadot JP, Metton G, Bérard C (2007) Hip pain in 234 non-ambulatory adolescents and young adults with cerebral palsy: a cross-sectional multi centre study. *Dev Med Child Neurol* 43(12):806–808
- Root L (2009) Surgical treatment for hip pain in the adult cerebral palsy patient. *Dev Med Child Neuro* 51(Suppl 4):84–91
- Sandström K (2007) The lived body—experiences from adults with cerebral palsy. *Clin Rehab* 21:432–441
- WHO (2001) International Classification of Functioning, Disability and Health (ICF). World Health Organisation, Geneva
- WHO (1948) Constitution of the World Health Organization. In: Basic documents. World Health Organisation, Geneva
- Viehweger E, Robitail S, Rohon MA et al (2008) Measuring quality of life in cerebral palsy children. *Ann Readapt Med Phy* 51(2):119–137
- Simeoni MC, Auquier P, Gentile S (1999) Conceptualisation et validation d'instruments de qualité de vie liée à la santé. Enseignements d'une revue critique de la littérature. *J Econ Med* 17:17–28
- Amarenco G, Bayle B, Lagauche E, Sheikh Ismael S (2000) Construction et validation des échelles de qualité de vie. *Ann Readapt Med Phy* 43:263–269
- Feldkamp M, Treppenhauer M (1985) Prospects of success in hip operations in severely handicapped children with cerebral palsy (in German). *Z Orthop Ihre Grenzgeb* 123:189–192

24. Evans GA (1995) The lower limb in cerebral palsy. *Curr Orthop* 9:156–163
25. Noonan KJ, Jones J, Pierson J, Honkamp NJ, Leverson G (2004) Hip function in adults with severe cerebral palsy. *J Bone Joint Surg Am* 86:2607–2613
26. Segal ME, Schall RR (1995) Assessing handicap of stroke survivors. A validation study of the Craig Handicap Assessment and Reporting Technique. *Am J Phys Med Rehab* 74:276–286
27. Whiteneck G, Charlifue SW, Gerhart KA, Overholser JD, Richardson GN (1992) Quantifying handicap: a new measure of long-term rehabilitation outcomes. *Arch Phys Med Rehab* 73:519–526
28. Haley SM, Haliwanger JT, Andrellos PJ (1992) Paediatric evaluation of disability inventory. New England Medical Center, Boston
29. Haley S, Coster W, Faas R (1991) A content validity study of the Pediatric Evaluation of Disability Inventory. *Ped Phys Ther* 3:177–184
30. Harwood RH, Rogers A, Dickinson E, Ebrahim S (1994) Measuring handicap: the London Handicap Scale, a new outcome measure for chronic disease. *Qual Heal Res* 3:11–16
31. Wolff JEA, Däumling E, Dirksen A, Dabrock A, Hartmann M, Jürgens H (1996) Munster Heidelberg Abilities Scale—a measuring instrument for global comparison of illness sequelae. *Klin Padiatr* 208:294–298
32. Law M, Baptiste S, Carswell A, McColl M, Polatajko H, Pollock N (1998) Canadian Occupational Performance Measure. CAOT, Ottawa
33. Daltroy LH, Liang MH, Fossel AH, Goldberg MJ (1998) The POSNA Pediatric Musculoskeletal Functional Health Questionnaire: report on reliability, validity, and sensitivity to change. Paediatric outcomes development group. *Pediatric Orthopaedic Society of North America. J Paediatr Orthop* 18:561–571
34. Plint AC, Gaboury I, Owen J, Young NL (2003) Activities Scale for Kids: an analysis of normals. *J Pediatr Orthop* 6:788–790
35. Young NL, Williams JI, Yoshida KK, Wright JG (2000) Measurement properties of the Activities Scale for Kids. *J Clin Epidemiol* 53:125–137
36. Morris C, Kurinczuk JJ, Fitzpatrick R (2005) Child or family assessed measures of activity performance and participation for children with cerebral palsy: a structured review. *Child Care Heal Dev* 31:397–407
37. Van Zelst BR, Miller MD, Russo RN, Murchland S, Crotty M (2006) Activities of daily living in children with hemiplegic cerebral palsy: a cross-sectional evaluation using the assessment of motor and process skills. *Dev Med Child Neurol* 48:723–727
38. Fisher AG (2003) AMPS: assessment of motor and process skills. Volume 1: development, standardisation and administration manual. Three Star, Fort Collins
39. Law M, King G, King S et al (2006) Patterns of participation in recreational and leisure activities among children with complex physical disabilities. *Dev Med Child Neurol* 48:337–342
40. King G, Law M, King S et al (2004) Children's assessment of participation and enjoyment (CAPE) and preference of activities of children (PAC). Harcourt Assessment Inc., San Antonio
41. Detmar SB, Hosli EJ, Chorus AM et al (2005) The development and validation of a handicap questionnaire for children with a chronic illness. *Clin Rehab* 19:73–80
42. Blank R (2007) Measurement of activities in daily living in children—standardisation of a screening questionnaire. *Klin Padiatr* 219:32–36
43. Archenholtz B, Dellhag B (2007) Validity and reliability of the instrument performance and satisfaction in activities of daily living (PS-ADL) and its clinical applicability to adults with rheumatoid arthritis. *Scand J Occup Ther* 25:1–10
44. Noreau L, Lepage C, Boissiere C et al (2007) Measuring participation in children with disabilities using the Assessment of Life Habits. *Dev Med Child Neurol* 49:666–671
45. Noreau L, Fougereyrollas P, Vincent C (2002) Assessment of the quality of social participation. *Technol Disab* 14:113–118
46. Noreau L, Desrosiers J, Robichaud L, Fougereyrollas P, Rochette A (2004) Measuring social participation: reliability of the LIFE-H in older adults with disabilities. *Disab Rehab* 26:346–352