

Quality of life and subjective burden of the informal caregivers in cerebral palsy.

A Belgian observational study

C. Lombardo MD^{1,2*}, A. Aeby MD², A. Gierasimowicz-Fontana MD¹, E. Durand MD PHD³

1. Physical and rehabilitation medicine, ULB, Brugmann University Hospital, Brussels, Belgium

2. Paediatric neurology, ULB, Queen Fabiola Children University hospital, Brussels, Belgium

3. Physical and rehabilitation medicine, ULB, Erasme University Hospital, Brussels, Belgium

Purpose

Cerebral palsy (CP) affects 2 to 3 over 1000 people worldwide. Adults with CP often experience difficulties accessing to appropriate medico-social structures, resulting in a significant involvement of informal caregivers. The purpose of this study was to analyse, through specific questionnaires, the quality of life (qol) and anxiety and/or depressive symptoms related to the burden of caregivers of children and adults with CP, taking into account socio-economic and environmental data.

Methods

1) Systematic literature search

2) Caregivers Interviews

Observational multicenter study (CHUB and HUDERF)

Inclusion criteria: caregivers, aged 18-75, good comprehension of French language, no history of psychiatric diseases

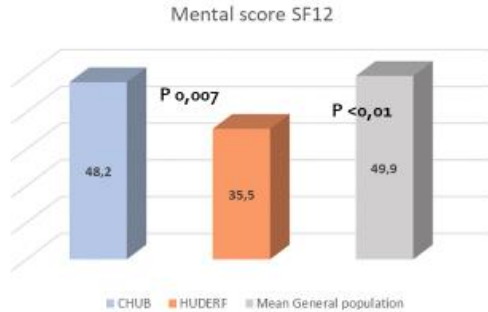
Interview guide:

- Patient's information: age, CP classification, functional levels of impairment (GMFCS, MACS, CFCS, EDACS), life setting and social interactions
- Caregiver's information: type of relationship, participation of others in caregiving, work, social and State financial aids
- Questionnaires: Short Form 12, Nottingham Health Profile, Zarit Burden Interview, Hospital Anxiety and Depression Scale

Results

Quality of life- Short Form 12

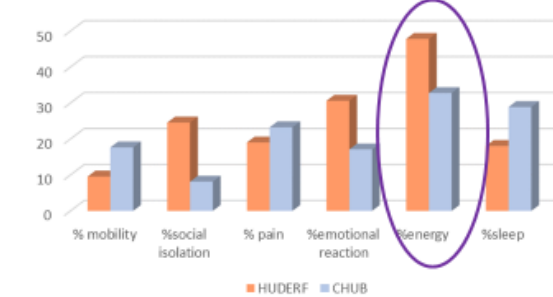
Mean Mental Score : 40,9 (p < 0,01 compared to general population)
 Mean physical score : 47,9 (p 0,4 > not significant)



Quality of life - Nottingham Health Profile

Mean values for the percentages of the impact on the 6 dimensions of qol for all participants:
 13,14% for mobility, 17,24% for social isolation, 20,9% for pain, 24,6% for emotional reactions and 22,7% for sleep disorders, **42.2% for energy**

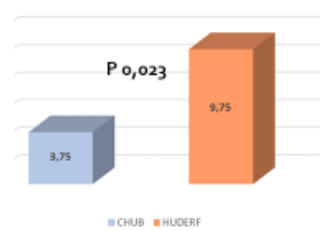
No statistically significant differences between the 2 groups



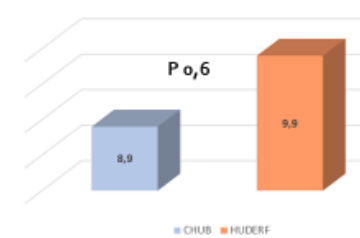
Depression and anxiety - HAD

Both populations of caregivers showed doubtful symptoms of anxiety
 No symptoms of depression in adults 'caregivers

Mean scores of depression - HAD



Mean scores of anxiety - HAD



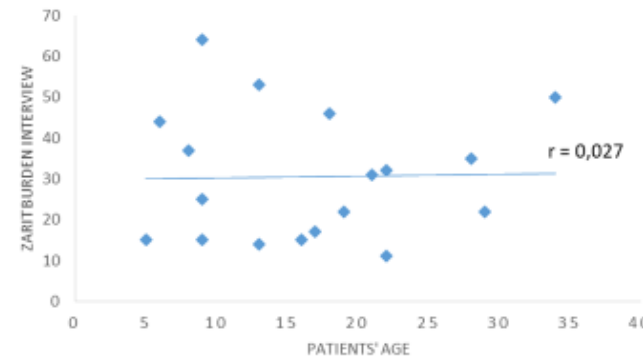
Conclusion

Feeling “burdened” or “distressed” by the demands of the patient is the most frequently reported outcome associated with caregiving. Although this phenomena is well known in literature, little is done in terms of social health to support caregivers in lifelong conditions. Interventions for early detections of anxio-depressive symptoms and regular assessments of perceived quality of life among caregivers could play a role for improving both health of the patients and their families.

Burden - Zarit Burden Interview

Mean score ZBI : 30,4 > mild to moderate burden in all caregivers

Mean score: 31,13 (CHUB) and 29,9 (HUDERF) (p = 0,6)



Are you afraid what the future holds for your relative? YES

Do you wish you could leave the care of your relative to someone else? NO