

4. Health economic modelling of the costs and effectiveness of CCTH models.

Results: The international evidence base on costs and effectiveness of CCTH remains weak. Three main models of CCTH are evident, with different organisational and delivery features and costs.

Conclusions: Children with complex, long-term care needs, as well as children with acute conditions that will resolve can be and are cared for safely closer to home. However, barriers and facilitators to further development of CCTH need to be addressed before we can understand 'how far we can go'.

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ASSESSING PSYCHOLOGICAL WELL-BEING IN MOTHERS OF CHILDREN WITH DISABILITY: PREDICTING DEPRESSIVE SYMPTOMS, PARENTING STRESS, RESILIENCY, AND FAMILY FUNCTIONING

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Background/aims: In family-centred children's services, it is critical to understand how mothers are responding to the challenges that childhood disability brings to the family. Some mothers will meet these challenges with resiliency and adequate coping; others will need more support and assistance from professionals to care for their child. Currently, there are no brief, psychometrically-sound measures of psychological well-being for use during intake to childhood disability services. The aim of this study was to evaluate two new measures designed to assess the need for psychological support in mothers of children with disability.

Methods: Canadian mothers ($N = 195$) of children with serious health and developmental disabilities completed the Parenting Morale Index (PMI) and Family Impact of Childhood Disability (FICD) scale, and validation measures via computer-assisted telephone-interview. Of these, 154 completed additional validation measures 1 year later.

Results: Confirmatory factor analysis supported the factor structure of the PMI and FICD. The PMI and FICD demonstrated strong internal consistency and temporal stability, as well as convergent and discriminant validity. After 1 year, the PMI and FICD jointly predicted maternal depressive symptoms, parenting stress, family resiliency, and family

adjustment, with adjusted R^2 s of .30, .36, .29, and .22, respectively.

Conclusion: Together, these brief measures appear to capture unique, but important aspects of maternal psychological well-being, and adaptive coping in the care of their child with disability. Within the Process Model of Stress and Coping, the PMI and FICD can be recommended to complement clinical interviews at intake to childhood disability services.

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PARENTAL SATISFACTION CONCERNING THEIR CHILD'S HOSPITAL CARE: A QUESTIONNAIRE SURVEY

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Background: Nowadays, healthcare needs to be more evidence-based, patient-oriented and families' perspectives must be taken into account in the appraisal of health services.

Aim: The aim of this study was to rate parental satisfaction concerning their child care during hospitalization and the factors that determine it.

Methods: Parents of 206 children, randomly selected, hospitalized in two pediatric and two surgical units. Data collection was based on interviews using a 68 item questionnaire, the Swedish Pyramid Questionnaire. Stepwise multiple regression was used to explore the characteristics which may have affected the parents' answers.

Results: Parents showed greater satisfaction with staff attitudes and medical treatment, whereas they were less satisfied with the information concerning routines and the staff work environment. They were pleased by the nursing care ($N=180$, 87.37%), nurses' concern ($N=179$, 86.89%) and from the respect to their needs ($N=181$, 87.86%) or their child's needs ($N=186$, 90.29%). Fathers gave statistically significant higher ratings for information

about illness than mothers did ($U=2416.000$, $p=0,035$). Adequacy of care, adequate pain management, parents' involvement in care, trusting relationship and staff attitudes were the most important determinants of parental satisfaction.

Conclusions: Parental satisfaction can be used as an indicator of the quality of care experienced by parents and patients. Interventions in pediatric care should include measurements of parental and child satisfaction, along with quality of care during treatment's outcomes assessment since hospitals are obliged by the state and private sector to document quality improvement measures.

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PROBLEMS OF CHILDREN AND ADOLESCENTS WITH A MITOCHONDRIAL DISEASE, THEIR PARENTS AND SIBLINGS. THE PATIENTS' PERSPECTIVE.

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Background and aims: This study aimed to identify problems as experienced by Dutch children and adolescents with a mitochondrial disease, their parents and siblings. We chose to describe these problems from the patients' perspective as we thought this would give optimal input for care improvement.

Methods: A qualitative design using the grounded theory approach, involving single individual open interviews with 9 children/adolescents with a mitochondrial disease, 16 mothers, 11 fathers and 7 siblings.

Results: Respondents mentioned lack of energy as the most basic problem in having a mitochondrial disease, leading to multiple varied problems in all areas of daily life, intertwining the physical, psychological, social and spiritual human domain.

And where one problem often led to other problems.

For children we determined the themes: 'lack of energy', 'crossing boundaries and frustrations',

'vulnerability and social participation' and 'stress and coping'.

For parents we determined: 'parenting and caring', 'continuing stress', 'loss of social participation', 'loss of dreams and future', 'stress and coping' and 'lack of health care'.

For their family we determined: 'family stress' and 'family coping'.

Conclusions: In this first study on this theme we conclude that Dutch children/ adolescents with a mitochondrial disease experience a variety of problems in the physical, psychological, social and spiritual human domain and in the field of health care, as well as their parents and siblings. The results can be used as a challenge and guide for improving health care, education and research and might result in an improved quality of life.

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IDENTIFYING, TREATING AND PREVENTING CHILD ABUSE AND NEGLECT (CAN)

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Method used: Educating professional workers on Identifying, treating and preventing CAN by e-learning

Results obtained: At present we developed 7 e-modules: Three "two-hours lasting" e-modules ("Recognizing Signals of CAN", "Acting according protocols on CAN" and "Communication about CAN") are developed for nurses and physicians working in Emergency Rooms. Three modules are especially designed for nurses and physicians working at child-departments of hospitals. One e-module is custom made for day-care personnel. In 2010 and 2011 more e-modules will be designed for general practitioners and school teachers.

Conclusions reached: Many countries struggle with the same problem: the majority of their professionals (like teachers, day-care workers and physicians) lack knowledge on recognizing CAN. Residency programs lack a required rotation on CAN. Subsidized continuing education only reaches small percentages of these (hundreds of thousand) professionals.

Augeo Foundation, a Dutch charity organisation,