

**FAMILY MATTERS: INCLUDING THE FAMILY IN
BRAIN INJURY REHABILITATION**

Rikke Kieffer-Kristensen (organizer)

Acquired Brain Injury (ABI) is a chronic condition that is associated with changes in the patients' physical, cognitive and behavioural functioning and may have serious consequences on patients' quality of life. Family stress following brain injury has in the recent years been well-documented and the impact of brain injury on the family is often immense. However many questions still remain open.

The aim of the symposium "Family Matters: Including the family in brain injury rehabilitation" is to give a short overview of the status of research and interventions within the various phases of brain injury rehabilitation. We address the question how acquired brain injury affect different family members in both the sub acute and post acute phase and whether it is possible to forge a link between family therapy and neurorehabilitation. Caetano address the theoretical and methodological considerations with the field of brain injury rehabilitation and the family. Norup et al. found that relatives to adult patients with ABI had significantly psychological problems and distress within the first month of injury, and address how neuropsychologists can work with relatives of patients with severe brain injury. Kieffer-Kristensen et al. presents evidence that parental ABI puts school-aged children in significant risk of developing severe stress response symptoms.

Finally From et al. recognise the need for family support that exceeds the traditional definition of relatives and presents the experiences of including not only parents and siblings, but also grandparents, friends, and others in the treatment of paediatric brain injury.

Carla Caetano, Copenhagen: Theoretical and methodological considerations: Key findings – key challenges.

Current research within the field of brain injury rehabilitation and the family will be considered, highlighting key findings and areas lacking in research. Methodological challenges in conduction research within this field will be discussed and future directions discussed.

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Lars Siert & A. Norup, Copenhagen:
Neuropsychological support to relatives of patients with severe brain injury in the sub-acute phase. We address how neuropsychologists can work with relatives of patients with severe brain injury. At our unit, we consider the work with the relatives as an important and parallel process in the treatment and rehabilitation of the patient. Thus, all relatives are offered individual neuropsychological support from day one of hospitalization until discharge from the unit and they also have the opportunity to participate in a support group led by a neuropsychologist.

Based on our clinical experiences demonstrating why working with the relatives is an important part of the rehabilitation, we conducted a study

investigating the emotional distress and quality of life in a sample of relatives of patients with severe brain injury. All relatives completed the depression and anxiety scales from SCL-90-R (Symptom Checklist) and the quality of life scales of the SF-36.

We found that the participants had significantly lower scores on all quality of life scales ($p < 0.01$) and significantly more symptoms of anxiety ($p < 0.01$) and depression ($p < 0.01$) than normal reference populations.

Correlations were found between the patients' condition and the level of anxiety and depression in relatives.

Future research should focus on developing and evaluating interventions in the acute phase.

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Rikke Kieffer-Kristensen, Copenhagen: "The forgotten children" - Stress responses and emotional functioning in children of parents with acquired brain injury

Introduction/Objectives: The effect of parental brain injury on children has been relatively little investigated. This study examines stress symptoms and psychological functioning in children with a parent with an acquired brain injury.

Participants, Materials/Methods: The participants were 35 patients with acquired brain injury, their spouses and children aged 7-14 years recruited from out-patients Brain Injury Rehabilitation Units across Denmark. Children self-reported psychological functioning and stress responses.

Emotional and behavioural problems among the children were also identified by the parents using the Achenbach's Child Behaviour Checklist (CBCL). A matched control group consisted of 20 children of parents suffering from another chronic illness, here diabetes, and were recruited from the National Danish Diabetes Register.

Results: The children in the brain injury group scores significantly higher ($p < 0.01$) on all stress scales compared to the diabetes group. The parents in the brain injury group reported significantly more psychological problems in their children when compared to published norms (CBCL).

Conclusions: When parents have acquired brain injury, their children are at a substantial risk for developing psychological and stress-related symptoms. These results indicate the need for a family-centered approach in the care for parents with brain injury with special attention to emotional well-being of their children.

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Kåte From, Copenhagen: Family counselling in paediatric brain injury rehabilitation
Children's Rehabilitation Center is a specialised neurorehabilitation clinic in the post acute phase, focusing on children and adolescents with brain injury, acquired between the age of 1 and 18. The Center has a neuropsychologically based multidisciplinary approach. The programme offers intensive specialised rehabilitation at the Center

as well as rehabilitation based in local settings depending on the specific needs of the child. The purpose of the rehabilitation is to enable the best possible return to daily living and to maximise the child's independence and the family's quality of life. Whilst it is the child in the family who has sustained the brain injury as a result of trauma or other acute clinical incident, it is the whole family that feels and lives with its effects. This is why Children's Rehabilitation Center finds it important for all members of the family as well as for the closest friends of both children and parents, to understand the nature of the brain injury. In practise this means family support that exceeds the traditional definition of relatives. In relation to this we offer individual as well as group counselling services not only to parents and siblings, but to grandparents, friends, and others as well. In addition to this all parents and siblings are invited to participate in the child's rehabilitation programme at least one day during their child's or sibling's stay at the Rehabilitation Center.

The counselling addresses a wide variety of cognitive and emotional issues that often present barriers to recovery and community reintegration and to optimal family functioning. The aims of these services are to prevent isolation for any involved person and to present a better understanding of the nature of the brain injury. This type of support tends to lead to a better adjustment and to more realistic personal expectations for all involved parties.

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