



# **Brain injury as a family matter**

**– the patient and family together on a path  
from hospital to everyday life in Finland**

**Study day**  
**European examples of families supports**  
**Bordeaux – France**  
**Friday, May 20th, 2016**



# Greetings from Finland!

## - My background

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- Clinical neuropsychologist, PhD
- Käpylä Rehabilitation Centre
  - 30 years
  - Patients with TBI or stroke + family members
- The Finnish Brain Injury Society
- University of Helsinki 2013 -



# To be discussed in my presentation...

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- The Finnish perspective – Finnish studies
- Brain injuries
  - TBI
  - Stroke
  - Children after accidents
- Finnish answers to the "key questions"
  - Unfortunately, no systematic paths or systems
  - Adaptation training
  - Associations (TATU ry)
  - Peer support
  - Interdisciplinary outpatient rehabilitation



# TBI



# Finnish studies / First steps... (Koskinen 1998)

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
BRAIN INJURY, 1998, VOL. 12, NO. 8, 631–648

Quality of life 10 years after a very severe  
traumatic brain injury (TBI): the perspective of  
the injured and the closest relative

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*(Received 8 January 1998; accepted 28 March 1998)*

This study is a further follow-up of a group of 15 very severely injured TBI patients who have earlier been followed-up 5 years after the injury, and their closest relatives. The aim of this study was to evaluate the factors related to the quality of life of the injured and the strain felt by the relatives. The information was gathered by questionnaires for the injured and the relative and clinical ratings based on the observations of a clinician. The self-reported quality of life of both the injured and their closest relatives was rather high in spite of the various physical, cognitive and emotional/behavioural disturbances. However, the strain felt by many of the relatives was still high 10 years after the injury although  had decreased over the years. The neurobehavioural and emotional disturbances had the most



# Quality of life of the closest relatives (Koskinen 1998)

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- The most obvious decline in the quality of life of the closest relatives had taken place during the first year after the injury.
- After that the life satisfaction had increased but had not reached the imagined level assuming that the injury had not happened at all.
- The strain felt by the relatives was highest during the first year after the injury and had decreased by 5 years after the injury but continued to be moderate or heavy for many of the relatives still 10 years after the injury.



# Discussion & acknowledgements

## (Koskinen 1998)

Education +  
support to family  
members



development has been presented [44]. Our team in the Käpylä Rehabilitation Centre has during the last years aimed at developing specialized neuropsychological rehabilitation programmes for different subgroups of TBI patients. In these programmes special attention is paid to the problems of awareness of the injured and education and support for the family members. Special attention is paid also to the productivity of the lives of the injured; different kinds of supported work or work-trials are arranged. Furthermore, the Finnish Brain Injury Association was founded in the early 1990s on the initiative of our clinic, to give support and information for both the injured and their relatives. Much work and enthusiasm is needed to help the injured and their relatives to reach as far as possible, a harmonious and productive life.



Finnish Brain  
Injury Association

### Acknowledgements

This study was supported by the People's Culturefound/Aimo Aaltonen Found and the Finnish Konkordia Association. I am most grateful to Dr Neil Brooks for his helpful advice and support during different stages in preparing this paper.

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**Thank you Prof  
Neil Brooks!!!**





# Experiences of the family members after TBI (Markkanen 2015)

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1. How does the injury affect the family members' life?
  - Pesonal crisis
  - Effect on the health of family members
  - Effect on the roles and everyday life
  - Social relationships, friendships
2. What kind of social support was needed/available?
  - Need of information
  - Need of psychological support
3. What other support would have been needed?
  - Social support, financial support, help at home



# Stroke



# Depression and its assessment among stroke patients and their caregivers

(Berg, 2005)

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- Of the caregivers, 30-33% were depressed.
- At the acute phase, caregiver depression was associated with the severity of the stroke and the older age of the patient.
- The best predictor of caregiver depression at later follow-up was caregiver depression at the acute phase.
- The assessment of well-being of the caregivers of stroke patients should be included as a part of a rehabilitation plan for stroke patients.



# Prevalence of depression among caregivers (Berg, 2005)

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**Table 11.** Prevalence of depression in percentages (the Beck Depression Inventory score  $\geq 10$ ) among spouses and other caregivers

	All caregivers	Spouses	Other
Acute	33	38	19
6 month	30	34	21
18 months	30	33	23





# Children with brain injury



# Child as the patient

## (Rautiainen 2015)

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- Every family member reacts in his/her own way
- The professionals become as "new members" of the family
- Need for knowledge and support
- The consequences of the injury / severity of injury
- Age
- The siblings
- Need for information is different at different stages
- The model of "Service path"



# Key questions



# 1. What is the typical/expected care path for the patient and family

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An interview among experienced professionals showed:

- ... no typical path, coincidental paths
- ... the support is rare, especially for adults
- ... the support for family members of children is also rare, especially when the recovery seems to be rapid at the first place
- ... depends of the skills of individual professionals



# The optimal path?

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- At first the family needs basic information and a sense of hope
- The patient should be followed up and rehabilitation should be planned and provided in multiprofessional settings
- The needs of the family members should be one essential focus of these interventions
- Supported work trials for adults when appropriate
- Support at school for children
- In optimal cases rehabilitation should continue as long as needed and follow-up would be frequent



# Adaptation training – an innovation of Finnish rehabilitation practices

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- The main goal of adaptation training is to help the participants realise the effect and meaning of their injury or disease on their identity, possibilities to live a good everyday life, and to find their own place in the society.
- Adaptation training is always a process, in which the individual is building a new self and identity.

(Streng 2014)



# Adaptation training

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- Started among the work of different patient associations in the 1980's
- Nowadays is based on legislation and paid by Kela (the Social Insurance Institution of Finland), other insurance companies, or Finland's Slot Machine Association
- The goal is to enhance the social wellbeing and functioning of the patient and the family members



# Adaptation training

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- Typical forms
  - intensive courses for patients and family members
  - possibilities for relaxation and pleasure while at the same time dealing with the problems caused by the injury
  - main goals:
    - to support the family in everyday life
    - to meet other people in the same life-situations
    - to share experiences



## 2. Do you have a national or local family association?

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- In Finland the associations are mostly diagnostic-specific, not purely focused on family matters.
- The best example of a family association is TATU ry



# **TATU ry**

## **Association for families with injured children (e.g. traffic accidents)**

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Focused on giving support to children and adolescents who have got an injury in an accident, and their family members

The association provides

- Individual guidance and support
- Peer support, family evenings, chat
- Adaptation training
- Information via internet and meetings





# TATU ry / basic ideas

(Rautiainen & Rönkä 17.5.2016)



1. The whole life situation taken into account
2. Pointing out the strengths
3. Activities with peers and friends
4. Peer support to the parents as well
5. Holistic approach
6. Neuropsychiatric interventions for children with TBI



# Service path by TATU ry

- provides information and peer support via internet

*Palvelupolkumalli*

Arki sujuvaksi Elämä muuttuu Järjestöt ja linkit Kysy meiltä

Palvelupolkumalli tarjoaa tietoa vammaisten, pitkäaikaissairaiden ja tapaturmaisesti vammautuneiden lasten perheille sekä heidän kanssaan työskenteleville ammattihenkilöille.



  
Sivuston ylläpidosta ja kehityksestä vastaa  
TATU ry.  
Kuvitus: Ilari Ikävalko / Pro Motius  
Toteutus: Muikkumedia Oy

  
RAY TUKEE  
HYVIÄ TEKOJA

Smooth everyday living

Life is changing

Associations and links

Ask us



### **3. Is family health routinely addressed in the typical/expected care path?**

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- Unfortunately not!
- Family-related topics are usually addressed during comprehensive rehabilitation with experienced and broad-minded therapists.



## 4. Who (if anyone) is responsible for looking after family members?

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- The social worker?
  - information considering financial benefits, rehabilitation etc.
- The members of the multiprofessional team?
  - Usually to look after the family members as well as the patient
  - However, this is not systematical and too often the family is left on its own



# Care for carers

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- ... "The carers may thus be seen as colleagues of professional carers in sharing the care for the patient, but they should also be seen as "patients" having problems and special needs themselves"...

(Care for carers of stroke patients: Evidence based practical guidelines, van Heughten et al. 2006)



# Concluding remarks

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- Brain injury always affects the whole family
- The psychological needs should be taken into account at early phases
- Different kinds of support at different stages
  - Information, sense of hope
  - Rehabilitation
  - Help in everyday life, financial security
  - Adaptation training, peer support
- New identity, new meaning in life, possibilities to live a good everyday life, and to find one's own place in the society.



# References

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# Thank you!