

FAMILY MEMBERS EXPERIENCES WITH IN-HOSPITAL CARE AFTER SEVERE TRAUMATIC BRAIN INJURY

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Background

- Family experiences with care are vital health care indicators (Stelfox HT 2013).
- Experience and satisfaction with health care are important indicators of the quality of health care provided (Lee 2008, Pettersen K 2004, Stelfox HT 2013)
- Needs and experiences changes during different phases (Panting 1972, Rotondi AJ 2007, Norup A 2015)
- Lack of information (Smith 2000, Keenan 2010)
- Challenges related to transfers between departments or level of health care (Nalder 2012, Coco 2011)

Objectives

1. Assess family member experiences with care provided in the acute phase and during in-hospital rehabilitation
2. Investigate the relationship between family experiences with care and
 - family member characteristics
 - patient demographics, patient functioning, and
 - rehabilitation pathway (phase)

Data collection

Family members (n=122)

Structured questionnaire (1 year)

Demographics

Family Experiences of in-hospital
Care Questionnaire in severe TBI

Patients (n=122)

Injured 2009-2011

Demographics

Acute injury severity

Rehabilitation pathway

Functional independence



RESULTS VALIDATION STUDY

**Family Experiences of
Care Questionnaire in
Traumatic Brain Injury**

REGULAR ARTICLE

Parent experiences of paediatric care (PEPC) questionnaire: reliability and validity following a national survey

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New items added regarding
rehabilitation, discharge, hospital
facilities and overall single questions

RESEARCH ARTICLE

Open Access

The family experiences of in-hospital care questionnaire in severe traumatic brain injury (FECQ-TBI): a validation study



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THE FAMILY EXPERIENCES OF IN-HOSPITAL CARE QUESTIONNAIRE IN SEVERE TRAUMATIC BRAIN INJURY (FECQ-TBI)

1. Acute organization and information
2. Rehabilitation organization
3. Rehabilitation information
4. Discharge
5. Hospital facilities patient
6. Hospital facilities family member

10 questions similar wording in the acute and rehabilitation phase

10 comparable acute phase and rehabilitation items - examples

Items Acute

Organization (5)

Staff collaboration

Care and rehab well planned

Items Acute

Information/ involvement (5)

Staff gave adequate information

Staff caring for you

Items Rehab

Organization (5)

Staff collaboration

Care and rehab well planned

Items Rehab

Information/involvement (5)

Staff gave adequate information

Staff caring for you

Conclusion

- First multidimensional constructed instrument for family members after TBI that measures general satisfaction and experiences in six dimensions.
- Good psychometric properties and construct validity

RESULTATER
PÅRØRENDES ERFARINGER MED
TJENESTETILBUDET
ETTER TRAUMATISK
HJERNESKADE

Pårørendes erfaringer –Subskalene

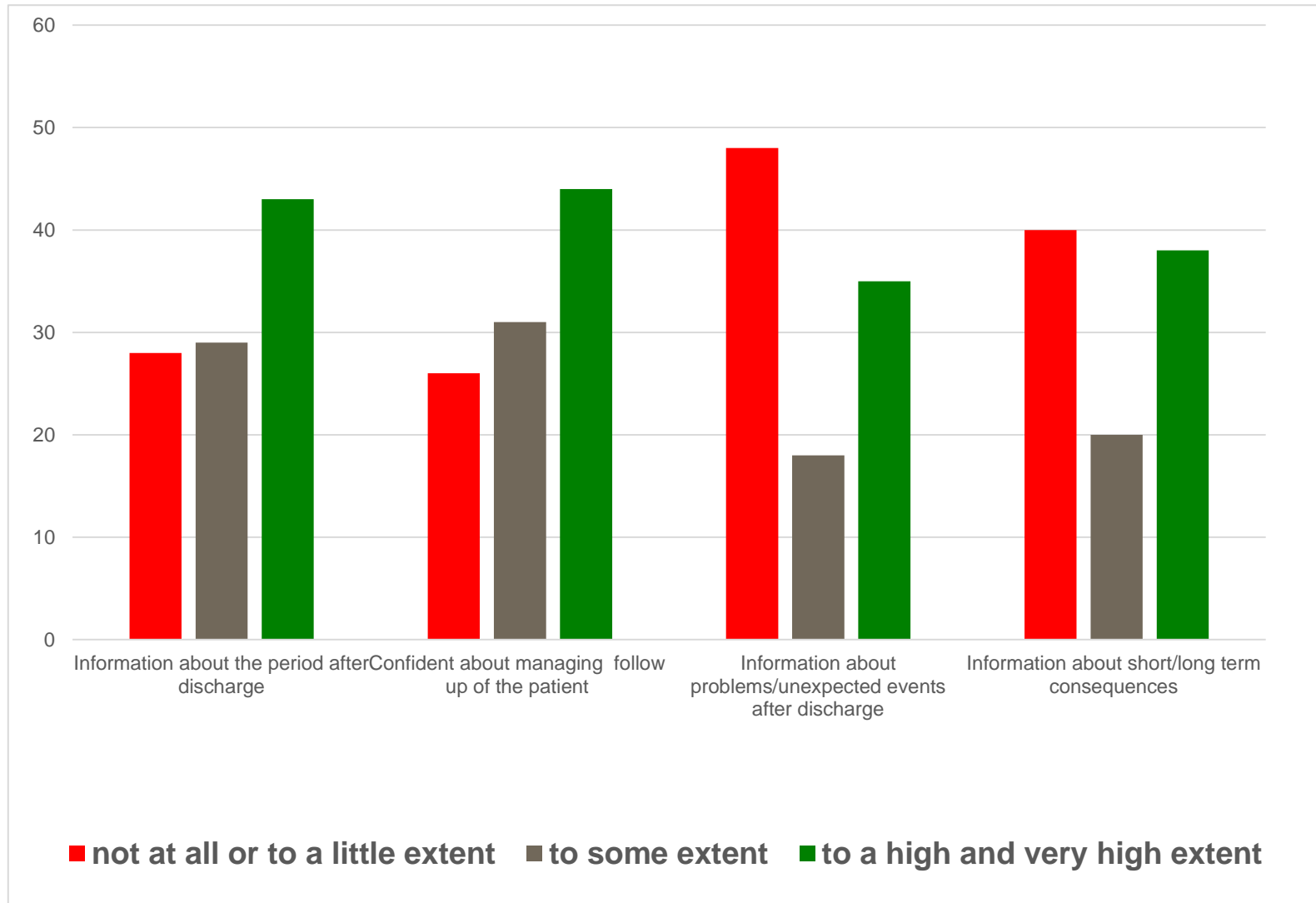
- Best erfaring med organisering og informasjon akuttfasen
- Laveste skår for erfaringer fra utskrivelses- perioden
- Generelt hadde pårørende bedre erfaringer med behandlingen i den akutte fasen enn med rehabiliteringsfasen

1. Acute organization and information
2. Rehabilitation organization
3. Rehabilitation information
4. Discharge
5. Hospital facilities patient
6. Hospital facilities family member

Erfaringer fra akutt fase bedre for:

- Samarbeid mellom de ansatte
- At behandlingen fulgte en gjennomtenkt plan
- Omtanke og omsorg for den skadde
- Omtanke og omsorg for deg som pårørende
- Interessert i å høre dine oppfatninger som pårørende
- Ga forklaringer og informasjon som du forstod

Utskrivnings-perioden



Prediktorer for lave skår

- Pårørende til skadde personer som hadde et middels funksjonsnivå hadde dårligere erfaringer ($p < 0.05$)
(Informasjon Rehabiliteringsfasen)
- Pårørende til skadde personer som ble utskrevet til ikke-spesialisert rehabiliteringstilbud hadde dårligere erfaringer ($p < 0.01$)
(Informasjon Rehabiliteringsfasen, Utskrivningsfasen)

Enkeltspørsmål med lav skår

- “Ble dine økonomiske behov ivaretatt?”
(77 % dårlig erfaring)
- Informasjon om konsekvensene av hodeskaden – på kort og lang sikt (60 % dårlig erfaring)

Konklusjon

- Pårørende har bedre erfaringer med behandlingen i den akutte fasen enn med behandlingen på en rehabiliterings-enhet
- De dårligste erfaringer er fra utskrivelses-perioden
 - Informasjon om konsekvenser av skaden
 - Hvem en skulle kontakte hvis det oppstod problemer etter utskriving
- Generelt var erfaringene bedre med organisering av tjenestene enn med informasjon
- Den skaddes funksjonsnivå og overføringer til ikke-spesialisert rehabilitering var prediktorer for dårligere erfaringer

An aerial photograph of a coastal town and harbor. The town is built on a hillside overlooking a large, deep blue harbor. A long, narrow bridge or pier extends from the town across the water. In the background, there are large, rugged mountains with patches of snow or light-colored rock. The sky is clear and blue. The text "Takk til deltakerne og multisenter prosjekt gruppen" is overlaid in white on the image.

Takk til deltakerne og multisenter
prosjekt gruppen