

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

Please note: This form should only be filled in if the person who suffered the head injury has been discharged from their first period in hospital (including the rehabilitation unit, if relevant).

We would like to hear about your experience as a relative during the time in hospital. We are interested to know about the experience of close relatives during different phases of the patient's time in hospital. If the patient has been hospitalized several times, please answer these questions on the basis of their first period in hospital.

		Very dis-satisfied	Dis-satisfied	Neither satisfied nor dis-satisfied	Satisfied	Very satisfied
1	Overall, how satisfied or dissatisfied are you with the care, treatment and rehabilitation the patient received at the hospital. <i>(Please take into account both the acute phase and the rehabilitation phase)</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	Overall, how satisfied or dissatisfied are you with the way you were treated as a relative?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Your experiences from the first phase, i.e. the intensive care ward, surgical ward or another ward other than a rehabilitation unit:

		Not at all	To a low extent	To a moderate extent	To a high extent	To a very large extent
3	To what extent did you experience that there was one doctor who had primary responsibility for the patient?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	To what extent did you experience that there was a fixed group of nurses who took care of you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	To what extent did you experience that the staff collaborated about the treatment and care the patient received?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	Did you perceive that the treatment, care and rehabilitation the patient received during the acute phase followed a well thought-out plan?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7	Did you receive the results of tests and examinations that you considered to be necessary during this phase?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

To what extent do you think the personnel: (only one response per question)		Not at all	To a low extent	To a moderate extent	To a high extent	To a very large extent
8	Took your family situation into account?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9	Demonstrated thoughtfulness and care for <i>the patient</i> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10	Demonstrated thoughtfulness and care for <i>you as a relative</i> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11	Were interested in hearing your opinions as a relative?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12	Gave you explanations and information that you understood?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13	Seemed professionally competent?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Complete this section if the patient was admitted to a rehabilitation ward.

What are your experiences of the rehabilitation ward / unit?

		Not at all	To a low extent	To a moderate extent	To a high extent	To a very large extent
14	To what extent did you experience that there was one doctor who had primary care of the patient?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15	To what extent did you experience that there was a fixed group of nurses who took care of you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16	To what extent did you experience that there was a fixed group of other therapists (e.g. physiotherapist, occupational therapist, social worker and speech therapist) who took care of you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17	To what extent did you experience that the staff collaborated about the treatment and care the patient received?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18	Did you perceive that the treatment, care and rehabilitation the patient received during the rehabilitation phase followed a well thought-out plan?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19	To what extent did you feel assured that the patient received the necessary treatment, care and rehabilitation?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20	To what extent was the purpose of the rehabilitative care the patient received explained to you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21	Did you perceive that the staff committed themselves to the patient's circumstances?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22	Did you experience that you had a fixed contact at the rehabilitation ward?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23	To what extent did you receive information about the patient's rights (e.g. vocational measures, social security benefits, insurance and social services)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

To what extent do you think the personnel: (only one response per question)		Not at all	To a low extent	To a moderate extent	To a high extent	To a very large extent
24	Took your family situation into account?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25	Provided assistance / help with the patient during the stay?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26	Informed you about what you as a relative could contribute with at the hospital?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27	Demonstrated thoughtfulness and care for <i>the patient</i> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28	Demonstrated thoughtfulness and care for <i>you as a relative</i> ?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29	Were interested in hearing your opinions as a relative?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30	Gave you explanations and information that you understood?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31	Seemed professionally competent?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32	Provided coordinated information about the patient?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

What did you think about the following conditions in the rehabilitation ward?

		Very poor	Moderately poor	Mixed	Moderately good	Very good
33	Cleanliness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34	Bathroom/shower/toilet facilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35	Peace and quiet in the patient's room	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36	Meals for the patient	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37	Meals for the relative(s)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38	Rest room and accommodation provisions for the relative(s)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

		Yes	Partly	No
39	Did the patient have his/her own room?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

The questions below deal with the time before the patient's discharge

		Not at all	To a low extent	To a moderate extent	To a high extent	To a very large extent
40	Did you receive the information you considered to be necessary about the period after discharge from hospital?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41	At the time of returning home, were you confident that you could manage the necessary follow-up of the patient?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42	Did you receive information about what you could do in the event of problems or unexpected events after your return home?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43	To what extent did you receive information about the short and long term consequences of head injuries?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

The questions below deal with the time in hospital as a whole

		Not at all	To a low extent	To a moderate extent	To a high extent	To a very large extent
44	Do you believe that the patient in any way received the wrong treatment (based on what you are able to judge)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
45	Were you angry, distressed or disappointed with the staff during the time at hospital?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
46	Did you experience any adverse incidents in connection with the patient's transfer from one ward to another or from one hospital to another?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
47	Were your financial needs taken care of?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
48	Were children involved? <input type="checkbox"/> Yes <input type="checkbox"/> No					
49	If yes, were the children taken care of?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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

The FECQ-TBI was developed in 2015 to assess important aspects of in-hospital care in the acute and rehabilitation phases from a family perspective. The FECQ-TBI was designed to record the quality of care experiences separately for different phases of care to be able to make relevant comparisons.

All items are scored from 1 (worst experience) to 5 (best experience), except for items 44-46 where 1 is the best experience and 5 the worst experience.

- The items 1 and 2 assess your overall experience and are scored: very dissatisfied =1, dissatisfied =2, neither satisfied nor dissatisfied = 3, satisfied = 4 and very satisfied =5.
- Items 3-32, 40-47 and 49, are scored as: not at all =1, to a low extent =2, to a moderate extent =3, to a high extent =4 and to a very large extent =5.
- Items 33-38 are scored as: very poor =1, moderately poor = 2, mixed = 3, moderately good =4 and very good = 5.

Scoring procedure of the FECQ-TBI

- Acute organization and information subscale = mean of items 4, 5, 6, 7, 8, 9, 10, 11, 12 and 13.
- Rehabilitation organization subscale= mean of items 14, 15, 16, 17, 18, 19, 20, 21, 22, 25, 27, 31 and 32.
- Rehabilitation information subscale = mean of items 23, 24, 26, 28, 29 and 30.
- Discharge period subscale = mean of items 40, 41, 42 and 43.
- Hospital facilities patient subscale= mean of items 33, 34, 35 and 36.
- Hospital facilities family member subscale = mean of items 37 and 38.
- For comparison between identical questions in the acute versus the rehabilitation phase, the following items are identical (acute/rehabilitation): 3/14, 4/15, 5/17, 6/18, 8/24, 9/27, 10/28, 11/29, 12/30 and 13/31.

References:

Anke A, Manskow US, Friberg O, Røe C, Arntzen C: *The Family Experiences of in-hospital Care Questionnaire in Severe Traumatic Brain Injury (FECQ-TBI): A validation study.* BMC Health Services Research. 2016.

Garratt AM, Bjertnaes OA, Barlinn J: *Parent experiences of paediatric care (PEPC) questionnaire: reliability and validity following a national survey.* Acta paediatrica. 2007; 96(2):246-252.