

Supplementary: Parental disease specific training in pediatric hepatology

Table S1 Questionnaire for parents/guardians

Current state of knowledge

With the following questions we would like to find out your current level of knowledge regarding your child's disease/transplantation. Our intention is not to test you, but to find out whether our current advice and information to you is sufficient. Therefore, we would like you to answer the questions honestly. Please, do not try to guess or research the answers. It does not matter if you do not know the answer to some of the questions.

C1 Please, answer the following questions briefly and in bullet point form in your own words.

1. What is your child's underlying disease?

2. Please explain briefly what this disease entails.

- 3.

Which medications does your child currently take?	What are these medications for?	I do not know what this drug is given for
		<input type="checkbox"/>
		<input type="checkbox"/>
		<input type="checkbox"/>
		<input type="checkbox"/>
		<input type="checkbox"/>

Which problems does your child currently that result from his/her liver disease?

-
-
4. What other health problems may your child have in the future due to the disease?

C2 Please tick the correct answers to the following questions. One or more answers may be correct. If you cannot answer a question or are not sure, please mark "I don't know".

1. Which functions of the liver do you know?

- ☐ Production of proteins and bile
- ☐ Metabolism of e.g. medication and alcohol
- ☐ Urine production
- ☐ Storage of sugar, fat and vitamins
- ☐ I do not know

2. What is the bile's function?

- ☐ It helps in the digestion of proteins
- ☐ It helps in the digestion of fats
- ☐ It helps in the digestion of sugars (carbohydrates)
- ☐ Without bile, the stool would be colorless
- ☐ I do not know

3. What are warning signs for biliary tract infection?

- ☐ Pale stool
- ☐ Fever
- ☐ Yellowing of the skin
- ☐ Vomiting
- ☐ I do not know

4. What is abdominal dropsy?

- ☐ Accumulation of fluid in the abdominal cavity
- ☐ It is fluids secreted from wounds, which may occur for a short time after transplantation
- ☐ It occurs when blood backs up in the portal vein
- ☐ It indicates a problem in the main artery
- ☐ I do not know

5. What does the term "liver remodeling" mean?

- ☐ The liver converts damaged tissue into healthy tissue
- ☐ The liver "learns" new functions
- ☐ The liver becomes increasingly scarred
- ☐ The transplanted liver adapts to the size of the recipient
- ☐ I do not know

6. What does cholestasis mean?

- ☐ Cholestasis means that bile stasis is present
- ☐ Cholestasis means that the liver is remodeling
- ☐ Cholestasis means that water occurs in the abdomen
- ☐ Cholestasis means having gallstones
- ☐ I do not know

7. What is portal hypertension?

- ☐ The blood in the portal vein flows into the liver without problems
- ☐ Blood in the portal vein backs up in front of the liver
- ☐ The blood in the portal vein flows with higher pressure
- ☐ Portal hypertension may result from liver remodeling

☐ I do not know

8. What can happen in portal hypertension?

☐ The spleen may swell

☐ Jaundice may occur

☐ Varicose veins may occur in the esophagus and stomach

☐ Abdominal dropsy may occur

☐ I do not know

9. In case of which diseases in the immediate environment of the child (family, school, daycare center) you should report to the MHH?

☐ Chickenpox

☐ diarrhea and vomiting

☐ Measles

☐ Hand-foot-and-mouth disease

☐ I do not know

10. What are possible side of immunosuppressive drugs?

☐ Increased growth of body hair

☐ swollen gums

☐ Arterial hypertension

☐ Kidney injury

☐ I do not know

11. Which statements concerning the liver transplant waiting list are correct?

☒ The children are registered at the Central Organ Transplant Center (Eurotransplant)

☐ Laboratory values (MELD score) must be sent to the central office on a regular basis

☐ The sex of the child (male/female) influences the score on the waiting list

☐ The blood group has an influence on the suitability of grafts

☐ I do not know

C3 For the following statements, please mark whether they are true or false. If you do not know an answer or are not sure, please tick "I do not know".

	True	false	I do not know
1. My child must reach a certain age to be able to get a new liver	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Children who have been on the transplant waiting list the longest get a new liver first	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. The children who need a new liver most urgently get a new liver first	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. It is possible that a child receives an organ offer although another child has more points on the waiting list	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. My child should be as fully vaccinated as possible <u>before</u> transplantation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Any vaccination may be performed immediately <u>after</u> transplantation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Inactivated vaccines may be used from one year after transplantation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. The majority of organ donations are cadaveric donations from patients who have been diagnosed with brain death.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. There is a possibility that a relative donates a part of his/her liver	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. The immunosuppressive drugs are needed to prevent the patient's own immune system from attacking the "new liver"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. The immunosuppressive drugs must be taken for the whole life	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. The immunosuppressants should be taken during meals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Immunosuppression leads to an increased susceptibility to infections	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. The immunosuppressive drug trough level is important because it determines the dose that must be taken	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. If the drug trough level is too high, there is a risk of rejection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

16. My child is not allowed to eat before blood is drawn to determine the level of immunosuppressants	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. My child must not take his immunosuppressive drugs before blood is drawn to determine the drug trough level	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. In case of "rejection" the immune system reacts to the "new liver"	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. Rejection means that the transplanted organ is lost	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. Rejection may be related to too much immunosuppression	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. It is sufficient if my child goes for a medical checkup once a year	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. After transplantation, my child is entitled to a severely disabled person's card	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. My child must never do sports again after transplantation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

D5 How would you rate your level of knowledge on the following topics:

	Very good	Good	Sufficient	Little	Very Little
a) Illness of your child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Anatomy of the liver (portal vein, bile ducts, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Functions of the liver	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Technical terms such as liver remodeling, tarry stools, portal hypertension, etc.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Proceedings during an inpatient stay	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) Transplantation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) Proceedings before liver transplantation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) Proceedings during the in-patient stay for liver transplantation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) Proceedings after liver transplantation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) Meaning of laboratory values	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k) Medication of your child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

l) Immunosuppressants of your child	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m) Diagnostic procedures, e.g. ultrasound, MRI, X-ray	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n) Everyday life with the disease	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o) Psychological support options	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p) Possible assistance for the care of your child (e.g. care allowance, severely handicapped certificate, etc.)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
q) Importance of nutrition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Table S2 The Ulm quality of life inventory for parents of children with a chronic illness ULQUI

B7 The following is about how you assess your current life situation. Please indicate to what extent the following statements apply to your behavior and state of mind over the past 7 days.¹

During the last 7 days	Never	Rarely	Sometimes	Often	Always
a) I was active and full of energy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) I had physical complaints	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) I felt exhausted	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) I could sleep well	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) I could eat well	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f) I felt fit	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g) I had pain	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h) I could concentrate well	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i) I was worried	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j) I had trouble to get up for something	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k) I was hopeful and confident	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l) I was resilient	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
m) I was irritable and nervous	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
n) I could realize my own wishes and needs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
o) I was depressed and unhappy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
p) I had plenty of opportunity to meet friends and acquaintances	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
q) I felt comfortable in the circle of my family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
r) my relationship with my child(ren) was satisfactory	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

s) I was satisfied with my partnership	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
t) I had someone with whom I could talk in confidence.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
u) I quickly got into quarrels and arguments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
v) I was fully operational in my job/household	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
w) I was able to complete the most important tasks at hand	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
x) the care of my sick child has put a lot of strain on me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
y) I had enough free time for myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Never	Rarely	Sometimes	Often	Always
z) I had enough time for my partner	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
aa) I felt burdened by my child's illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
bb) we could support each other in the family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
cc) we could talk openly with each other in the family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>