A psychological approach, within 4 children of different ages

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Maryke GUITTARD co autor: MH BLANCHIN
Unité de Néphrologie du DR. DECRMER
Hôpital des Enfants CHU – Toulouse- FRANCE
Introduction:

The announcement of a chronic disease for a child can produce a wave of a shock on the whole family: parents, siblings and the children themselves.

- Total care of the child with chronic kidney disease: if the medical care work on the visible part, the psychologist works on the hidden side.

- The purpose of this presentation is to share with you some psychological considerations in the follow up of 4 cases: going from to youngest to the eldest child.
First case:
Boy 4 years old...

• was hospitalized at 9 month for a HUS syndrome, had a DP at the age of 1, a myocarditis at the age of 2 and underwent a transplantation at 3...

• The period from 9 months until 3 years was very hard for the family: they had a healthy little boy who was totally transformed by his disease. During several months they feared losing their only child, he was baptized for his first birthday ... finally he survived, but lost his kidneys and was fully dependant of the medical care.
“kidnapped” by his chronic disease

• The medical care: the only way to keep the child alive ....

• During this period both parents were in constant communication with the team, talking about the child but not really about themselves. From the beginning the mother could talk about her anger about the disease and the hospitalization ... the disease is like a kidnapping.
3 years later

• The little boy is going part time to “kindergarten”.
• His language is on the level of a child of 2 ½, he has no hearing loss, but is bilingual: Dutch and French.
• Most of the time he’s using short operational words from both registers: *Veux koekje*
  Globally everyone understands: follow-up without difficulties.
What about the parents:

Mostly it’s his mum who talks in her mother tongue. Daddy only listens, not really agreeing with the way she speaks: without holding back her anger about the fact that her son doesn’t want to eat something else than mixed food...and asking me if she should request a psychological follow up.

She seems to make a fixation on the food but asking ME about a psychological follow up...could be interpreted as a provocation. I prefer to interpret this as a way of expressing her suffering: her child is doing well, considering the circumstances...but she’s still ill!

And daddy suffers in silence.
The heart of the problem is else:
The chronic kidney disease has destroyed their only child, their healthy child doesn't exist anymore... they never accepted the new situation, even if they are still loving parents.

“Strangers” from the medical care adopted their child with his disease, accepting him as he is. Quite a disqualifying situation, for them as parents... Who might live with the new situation but not really accept this...

The parents have a narcissic wound, but only the mum talks. Daddy remains silent in an active participation, ready to do everything that is necessary, like a kind of resignation in front of this terrible situation, with a profound respect for his child, his wife and the medical team.

Daddy is aware of her anger, he understands it but doesn't seem to share her way of expressing her profound disgust of the chronic disease, but she doesn't speak about this terrible period, she tries to project herself in the future, with her identity of a mother, who also has the nourishing role.
Is the child really ok?

• “N is quite ok” ... in medical terms perhaps...if we consider his story, but he remains an infant without speech... Is he a symptom of his parent's suffering?

• Is it a good thing to grow up?
  Wouldn’t it be better to stay an infant, the baby the parents lost? Has he an anti-depressive function? Does he need to console his parents?

• They come twice a year on the place where they lost the child they desired, it’s quite impossible to do a therapeutic work on the “place of the crime...” It seems that the parents would benefit from psychological follow up near their home.
2 case: L. was 7 years old

... when she went to the holiday camp in OSSEJA... with the group of children with a chronic kidney disease coming all over France.

One day at the swimming pool...
Several clans…different ages…
The little ones need some special care…
Then she showed her hairy legs… and started to talk about her body before and after… transplantation… I asked her if she would like to draw this...
The next day...

• she described her feelings and the way she sees herself.
by Art therapy…
Before and after… transplantation

Our team contacted her’s… they spoke about medication…

I never saw her back since.
3 case: Quentin almost 15
Chronic disease since the age of 1 month and is preparing his transplantation.

He has 2 sisters, one proposed her kidney.

His mother has cancer, but Quentin never talked about this with me.

• He wrote especially for you his witness about his current feelings ...
His disease…

• « I don’t talk often about my disease but I’m really angry: why does this happen to me? I just would like to be a boy like any other. But since I’m a baby I’ve have had health problems, and it’s getting worse all the time.

I could vomit my disease and even the whole medical team! »

• « No not the doctors and the nurses, they are nice to me, but in fact that they are a mirror of my disease! I hate my disease !! ». 

co-autor QUENTIN
Stress…

« I’m so incredible stressed before coming to hospital, just feel my wet hands… »

« the medical terms employed by the doctors are too complicated, only ONE Dr. really helped me to relativise by explaining that transplantation is just a moment in my life and that I could live a long time after…

Thanks to him I lost some fears, tensions and an enormous stress»

co-author QUENTIN
The positive points...of being ill

« My friends do help me a lot, my girlfriend always knew about it and accepts me like this...

« I realize that if I did not have this disease I would be a different person, since a short time I start to live with it, thanks to my family and my friends »

« And now I have you...you make me laugh! »

« I make you laugh? One might think that's not professional for a psychologist to make you laugh ». 

« Don't worry I'll defend you, and I'll tell them what I think about it! »

co-author QUENTIN
Psychological help

« You say things which change my way of considering my disease, sometimes you really make me laugh...remember when you asked to play-act about my disease...I was complaining all the time...and then with the acting I realized that when I’m saying ‘why me’, it would be unfair to desire that someone else would be a victim of this disease.

You listen to me and answer me when I need it...I always thought that psychologists were in a world of their own, difficult to reach , and you are ...it’s important to talk in confidence with someone. And...I can talk just about ME , my doubts, my feelings without feeling guilty , just free of my sorrows.”

co-autor QUENTIN
Case 4: ROMANO almost 20
• born with an evolutive deafness, transplanted 2 times, a first time with the kidney of his mother, the second time thanks to a donor.

• He is a young adult now, has a nice job, but has several questions about life, friends and his future. He worked with me on this paper.

co-author ROMANO
Reality not as easy as imagined...

Deafness: still progressing... worse and worse ...

Communication: limited, even if he speaks fluently, he doesn’t hear or understand everything, especially in noisy conditions.

Schooling: became a mechanic for AIRBUS 320 and 350...

Appreciated at his work, but he has a poor social life nevertheless.

co-autor ROMANO
Social life

• **Lonesome**: no girl friend, or his twinsister is dating ...

• **No real friends**...some acquaintances go out every week-end for binge drinking...and where some « friends » appreciate him because of his money...

• Would like to know young people to travel around, but has **no deaf nor hearing friends** to share this Project...

co-autor ROMANO
PERSPECTIVES

• Soon he’ll have to leave the children hospital to go to the adults... with a lot of questions and fears because of the change in the location and in the medical team. He feels secure in the paediatric care, which is like a familial cocoon.

• Ready to change: age, punctual for his appointments, mature: able to take the initiative for a meeting with the psychologist as soon as his has a personal difficulty. Accepting to share with her and his medical referent his questions about his health and his difficulties about his social life.

co-autor ROMANO
Fragile equilibrium

• Afraid of any change like all deaf person, a change means a loss of security, the perspective to go to the hospital for adults is a real stress for him.

It would be necessary for him to have psychological help at the adults because he is still fragile…

co-autor ROMANO
CONCLUSION: each child is different

• **N. 4 y.**: how can he grow up, if he becomes the syndrome of his parents...it's time for them to have psychological help outside hospital,

• **L 7 y.**: even for a little girl the self esteem is important to face difficulties in life, doctors can help by listening to the complaints of the child and adjust the medication?

• **Q 15**: his mother's cancer is known to everyone, but we need to concentrate our consultation on him...

• **R 19**: what is his biggest handicap, his disease, his deafness, his solitude, his lack of self esteem?
Hospital and child

If medical care is the first condition, listening to what the patient tells about himself is vital for a team, to a family but first of all to the child.

Listening to him means that you don’t only take care of his body, but also of his personality, his fears, his desires.

How can we be sure to give a special time to listen, in a team where the care means often: stress, tension, lack of time? Being near to the body is not always the best condition to be near to the person…
Mot de la fin

Dr. François BOUISSOU     team of TOULOUSE:

« In each team it’s necessary to structure the possibility to listen.

One of the frustrations of the medical care is that we are there to care, but we can’t heal.

All those children show us everyday that they want to continue, we have to help them with our limits.

We all do really care about these children who stay our motor in this speciality, we work with humans not with a disease. »
Thank you for your attention.

Special thought for all the children we’re working for...
Merci à mon équipe pour son soutien.