

PSYCHOSOCIAL DIFFICULTIES OF CHILDREN AND ADOLESCENTS WITH CHRONIC KIDNEY DISEASE AND THEIR PARENTS

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Chronic kidney disease (CKD)

CKD stage	GFR	treatment
1	>90	Mostly without problems and treatment
2	60-89	Mostly without problems, occasional check ups
3	30-59	Medicine, diet, regular check ups
4	15-29	Preparing for dialysis, adjustments at school
5	<15	Dialysis, preparing for transplantation

Psychosocial problems of children with CKD

- Restrictions in everyday life:**
special diet, taking medicine daily, regular visits at the hospital, missing out on school, hobbies, sports and time with friends
- Cognitive disabilities:**
difficulties with concentration, memory, executive functions
- Emotional difficulties:**
loss of health, dependant on health care, fear of pain, cosmetic side effects, difficulties in planning the future, coping and adjustment difficulties, isolation, depression
- Difficulties in family life:**
change of family roles (a mother as a nurse, father as a provider, siblings as caretakers), emotional difficulties and burn out of caretakers
- Impaired quality of life:**
less satisfied than healthy peers, better after TX

Aims of the study

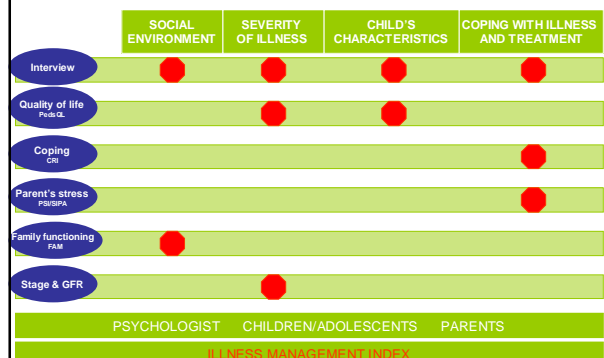
- To **evaluate psychosocial functioning** of children, adolescents and their families with CKD (3rd to 5th stage)
- Offer different **psychological and therapeutic interventions** and evaluate their success
- Prepare a **psychosocial program** for CKD children, adolescents and their families

Psychosocial difficulties are increasing with CKD stage.

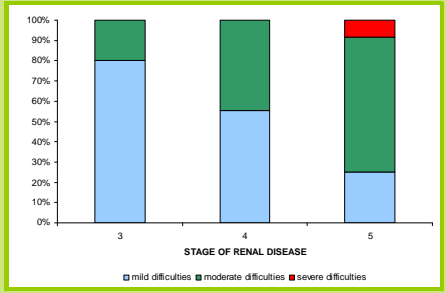
Sample

31 families	mean duration of illness (in years)	7,5 (range 0,2-18)	
	mean age at illness onset (in years)	3,9 (range 0-14,5)	
	mean age of patient (in years)	11,48 (range 0-18)	
	boys	22	
	girls	9	
	mothers	31	
	fathers	25	
	social economic status	low	15
		average	15
		high	1

Assessment

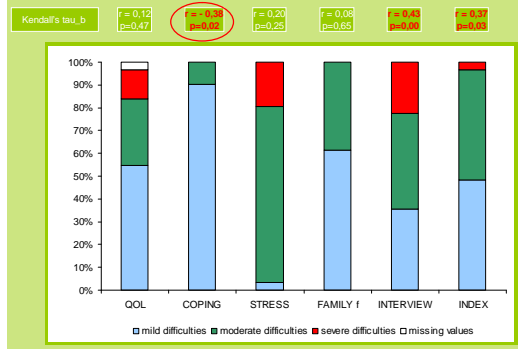


Psychosocial difficulties are increasing with CKD stage



χ^2 (STAGE & INDEXpsy_d) = 4,93; df = 1; p=0,02

Psychosocial difficulties are increasing with CKD stage



Conclusion

Psychosocial difficulties are increasing with CKD stage.

But not with duration of illness, age at onset, child's age or SES.



Psychosocial program is essential for families coping with child's CKD.

Psychosocial program for CKD families

MULTIDISCIPLINARY PARTNERSHIP IN EMPOWERING CHILDREN AND ADOLESCENTS WITH CKD

Doctors, nurses, psychologist, teachers, social worker, nutritionist, family

The main aim of this partnership is to empower child or adolescent to become independent and self-efficient, meaning that he successfully manages his own illness and treatment and most of all that all family members live a life of most possible quality.

Psychosocial program for CKD families

CHILD/ADOLESCENT	PARENTS	FAMILY
Psychological diagnostics of cognitive deficits	Educational & support group for parents	Counseling
Adjustments at school	Internet chat room	Psychological preparation for dialysis or transplantation
Team meetings with school		Family therapy
Camps for children and their siblings (once a year)		Psychological support
Support Information Stress relief		

We still have to evaluate the success of psychological and therapeutic interventions and their importance for parents.