

The role of parents in global pediatric kidney care



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Introduction



- In pediatrics the physician-patient co-operation is based on the co-operation with the child and his family, so it is necessary to create a good constructive relationship.
- The effectiveness of pediatric therapy is a function of good communication of the physician with the child and his or her parents with regard to the child's age and the understanding of the provided recommendations (this should be verified).
- Non-adherence to recommendations is a major obstacle in achieving therapeutic goals.

Parents role in children care

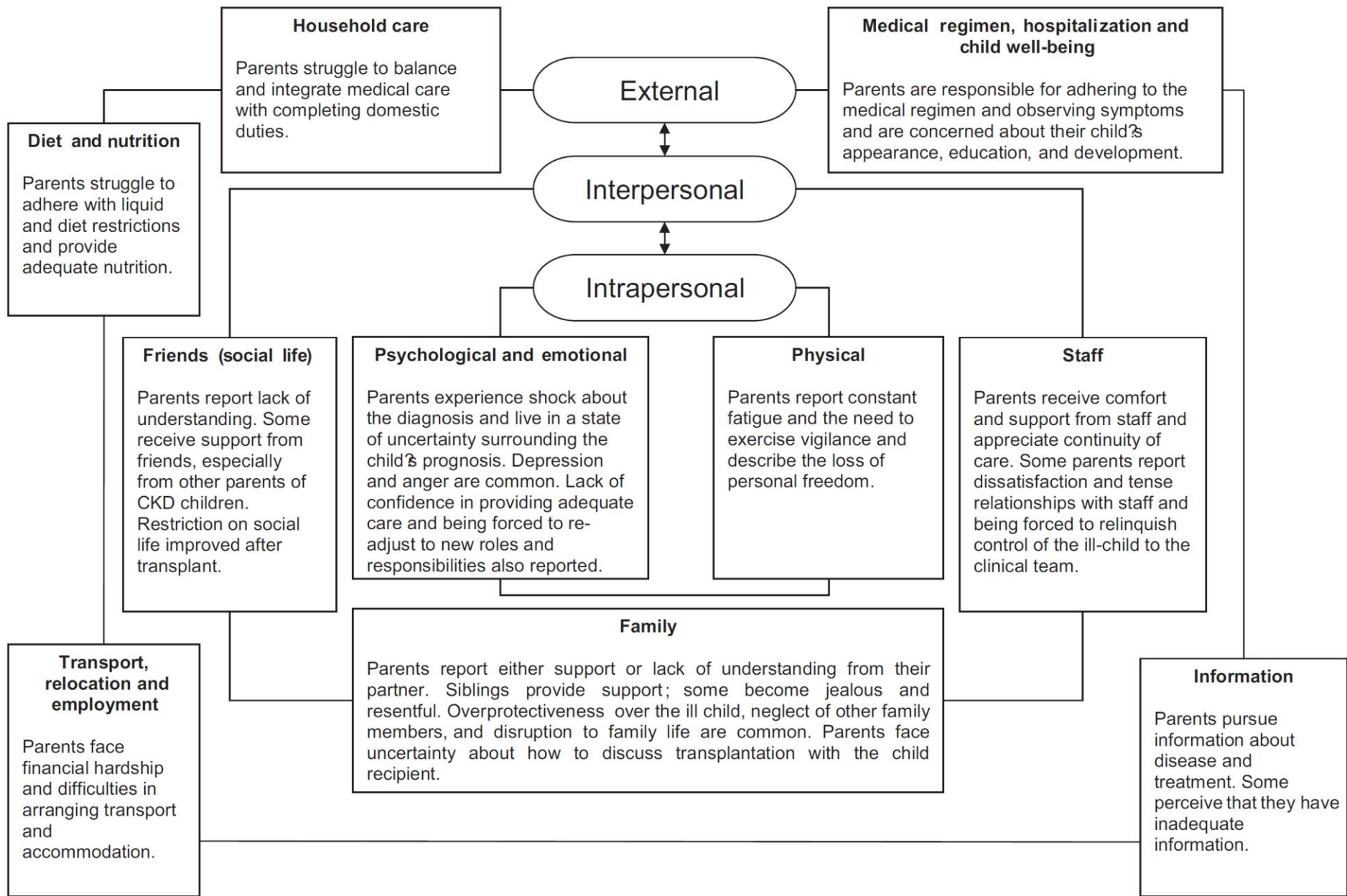
Parents play a central role in the care of children with chronic kidney disease.



The experiences of parents of children with CKD could be grouped into 3 clusters:

- **intrapersonal issues** (involving psychological, emotional, and physical impact of the child's illness);
- **interpersonal issues** (involving parents' interaction within the family and relationships with staff and friends);
- **external issues** (eg, household care, diet and nutrition, transport, employment, medical regimen and hospitalization, information)





The International Pediatric PD Network



Registered patients:
3287

Registry participants:
122 centers in 43 countries

Content of PD Training



Theory (> 15 hours)

Functions of the kidney, pathophysiology of renal failure, osmosis, diffusion, fluid balance

Practical/Technical (> 15 hours)

Aseptic technique, blood pressure monitoring, exit-site care, performance of PD exchanges, set up and function ofycler, problem solving alarms, NG/gastrostomy tube feeding (infants/small children)

Peritonitis and Exit-site/Tunnel Infection

Recognition of signs and symptoms, initiating treatment, medicating bags for ongoing treatment

Non-Infectious Complications

Hypotension/hypertension, catheter flow problems, hernias

www.pedpd.org


Training

ISPD Recommendations 2006



Who should be a PD trainer?

- **a nurse, whenever possible;**
- the ratio of patient to nurse is, ideally, 1:1;

- 
- good communicator;
 - excellent teacher;
 - flexible;
 - knowledgeable about PD;
 - experienced in general medical and surgical nursing;
 - committed to PD and patient independency.

Effectiveness of home visits to the pediatric peritoneal dialysis patients



- Home visits by a trained dialysis nurse often uncover aspects of the environment that may affect the clinical care of patient (room configuration, dialysis supply storage, required cleaning)
- Follow-up visits every 12 months, after episodes of peritonitis
- Dialysis nurse evaluate the CCPD set-up during home visit

Effectiveness of home visits to pediatric peritoneal dialysis patients



A home visit program for pediatric patients on peritoneal dialysis:

- may increase adherence with the prescribed dialysis regime and medications;
- may lower the incidence of peritonitis;
- may improve overall clinical care.

– Ellis E, Perit Dial Int 2012; 32: 419 - 423

EWOPA - European Working Group on Psychosocial Aspects of Children with Chronic Renal Failure www.ewopa-renalchild.com



- A multidisciplinary group interested in the psychosocial welfare of children with chronic renal failure and organ transplanted children.
- Every child has a right to play and learn and to have social activities in spite of illness and hospitalisation. We can make that happen.
- Annual meetings with topics focusing on the patient, the family, the carers, interaction, social problems, care and treatment, ethics and politics, activities.
- The aims of the ewopa-renalchild project are to share with each other the best of everyones experiences so that all of us and all our patients can benefit from them.

Family education programs



Some centers developed multidisciplinary family education programs for children with chronic kidney disease and their families.

Improvement of medical, psychological and social outcomes are the main aims.



e-Powered Parents

Online support program for parents of children with a chronic kidney disease

Jacqueline Knoll, nurse practitioner paediatric nephrology

Wyske Geense, PhD student



Welcome

[Meer informatie >>](#)



Communication

[Meer informatie >>](#)



Setting limits

[Meer informatie >>](#)



Coping

[Meer informatie >>](#)



Stress
management

[Meer informatie >>](#)

USB Drives for Communication of Medical Information in a Pediatric Dialysis Unit



Table. Information stored on the USB drive medical template

Patient's name
Patient's date of birth
Patient's contact information
Date information on USB was last updated
Health insurance information
Emergency contact(s)
Nephrology physician contact information
Primary care physician contact information
Specialty physician contact information
Medical diagnoses
Past medical history
Hospitalizations (reason for admission, dates, treatment)
Past surgical history
Allergies
Current medications
Dialysis prescription
Most recent laboratory studies
Social history
Family history
Review of body systems

Barriers in adherence to medications

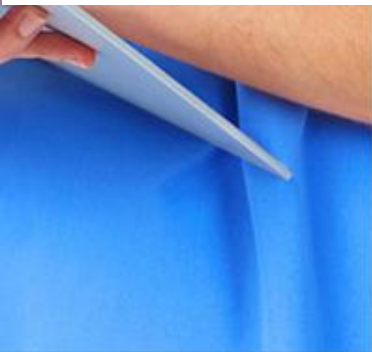


Forgot/distracted: The adolescent/family simply does not remember to take or order more of the medication on time or are in some way not cognizant of the need to take it at the appropriate time, whether due to a diversion, no cue, or merely forgetting (e.g., forgets, watching TV, nothing specific to link it to). If the word 'forget' is in the statement, use this code.

Poor planning/scheduling issues: The adolescent/family is away from home and is not prepared with the adolescent's medications when it is time to take it (e.g., not at home and did not bring, at a friend's). The adolescent/family is involved with a specific scheduled activity (e.g., softball game, medical appointment, school) that gets in the way of medication taking. Also code this category if the adolescent/family reports a derivation in the normal daily routine (e.g., wake-up late, get home late, busy, weekend, school break) that interferes with the scheduled medication dose.

Physical barriers/medication issues: The physical state or health status of the adolescent prevents medication taking and/or an unpleasant property of the actual medication prevents taking it (e.g., too ill to take it, hard to swallow pills, tastes bad). If the barrier is physical or medical in nature, but implies voluntary resistance, code it as 'Voluntary Resistance/Attempts to be Normal' (e.g., tired of taking pills).

Voluntary resistance/attempts to be normal: The adolescent is deterred from medication taking because of wanting to fit in with peers or exhibits behaviors that imply more voluntary resistance to medication taking (e.g., teenage lifestyle, tired of taking pills).



Simons LE, McCormick ML, Mee LL, Blount RL. Parent and patient perspectives on barriers to medication adherence in adolescent transplant recipients.

Pediatr Transplantation 2009; 13: 338–347. © 2008 John Wiley & Sons A/S.

Strategies to improve medication adherence

Specific barriers	Potential intervention strategies
Forgot/distracted: <i>Incorporate salient cues to take medication into the daily routine.</i>	
Morning/evening dose	Reminder placed at the front door; medication next to breakfast, toothbrush, or nightstand (19).
School time dose	Reminder from teacher or nurse; schedule doses at a specific event during the day (mealtime) (19).
General forgetfulness	Digital watch with alarm set for dosing time; automatic reminders on computer, phone, etc. (16); Schedule doses at specific event times, if possible; schedule dose during an activity where mom or dad are present to provide an additional prompt (e.g., dinner, breakfast); organizational system for medications (e.g., pill box) (1).
Forgot to refill prescription	Automatic refill system established with pharmacy; put reminder to order medications on electronic (e.g., cell phone, computer), or wall calendar (19).
Poor planning/scheduling problems: <i>Plan ahead for expected or potential schedule changes by having extra doses of medication available in accessible locations (e.g., school, car). Have cues in place when the routine is disrupted.</i>	
Rushed in the morning/sleep late	Extra medication dose in the car; set alarm when sleeping late on weekends to wake up and take medication at prescribed time (20).
At a friend's house	Extra dose at friend/family's house where likely to spend the night; have a medication travel bag prepared at all times as regular item to pack.
Out to dinner	Parents carry an extra medication dose (e.g., purse, briefcase, backpack) (20); schedule dinner around dosing schedule.
Changes in schedule	Change times of doses to fit schedule; check expected vs. actual medication intake at end of day; have an 'away from home' storage container medications (e.g., small bag, hip pack).

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Physical barriers/medication issues: *Increased medical team-patient communication and potentially employ circumscribed treatments to overcome aversions to medication.*

Hard to swallow	Seek out alternative medications (e.g., liquid form, smaller pills) (16); behavioral treatment for pill swallowing fear (21).
Doesn't like the taste	Use a favorite beverage or strongly flavored food to disguise the taste; use rewards or incentives for quickly taking medication (7).
Side-effects; not feeling well	Physician and patient discuss ways to alleviate/ameliorate side-effects that are impacting quality of life (12); increase communication about the influence of current state of health on medication taking behavior (e.g., nausea, current illness) (1).

Attempts to be normal: *Identify what is important to a teenage patient (e.g., hanging out with friends) and link appropriate medication taking to being able to enjoy those valued activities (e.g., staying out of the hospital).*

Don't want friends to see	Encourage child to share with and enlist support of close friends (22).
Defiance	Offer positive reinforcement and incentives (8); individual or family counseling to address issues surrounding resistance to medication taking; use motivational interviewing techniques (23).

Summary



Parents play a central role in the care of children with chronic kidney disease, deliver home-based and technically demanding interventions.

Parents of children with CKD have reported lower quality of life, difficulties in managing the child's care, higher levels of anxiety and maladaptive behavior.

Sufficient support for parents may prevent or ameliorate these problems and lead indirectly to better outcomes for children.

Thank you

