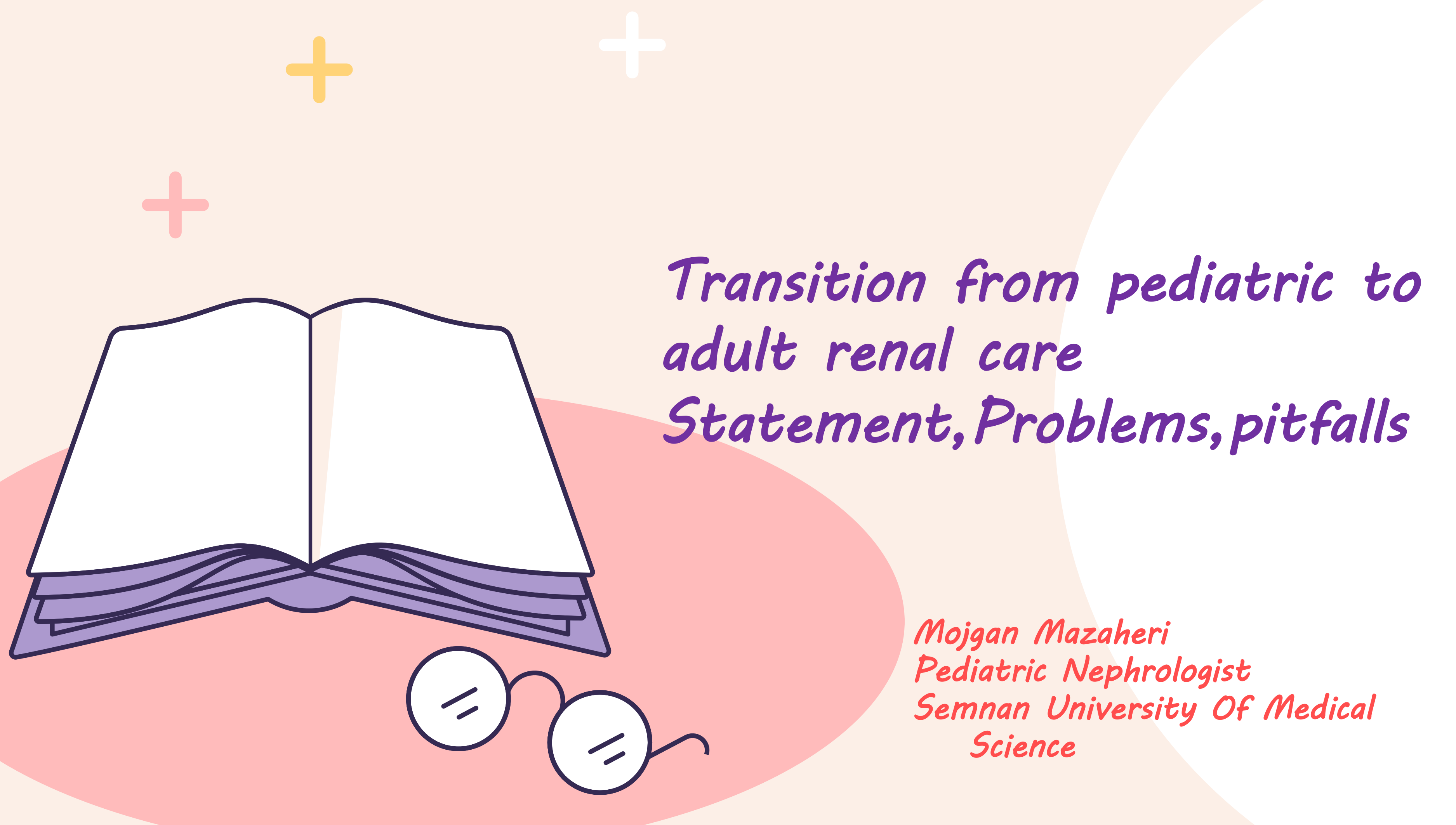

Transition from pediatric to adult renal care
Statement,Problems,pitfalls

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1. Number of young patients graduating from pediatric to adult renal care has increased due to improved diagnostic tools and knowledge & management.

2. Growth & development are essential for all children especially those with CKD.

3. Caretaking by multiprofessional team of clinicians,nurses,dietitions,social workers,play therapist,psychologists & educators is the most effective way of minimising disabilities and maximising their potentialities.

- Adolecsents & young adults (14-24 years) with chronic condition need special consideration because of their

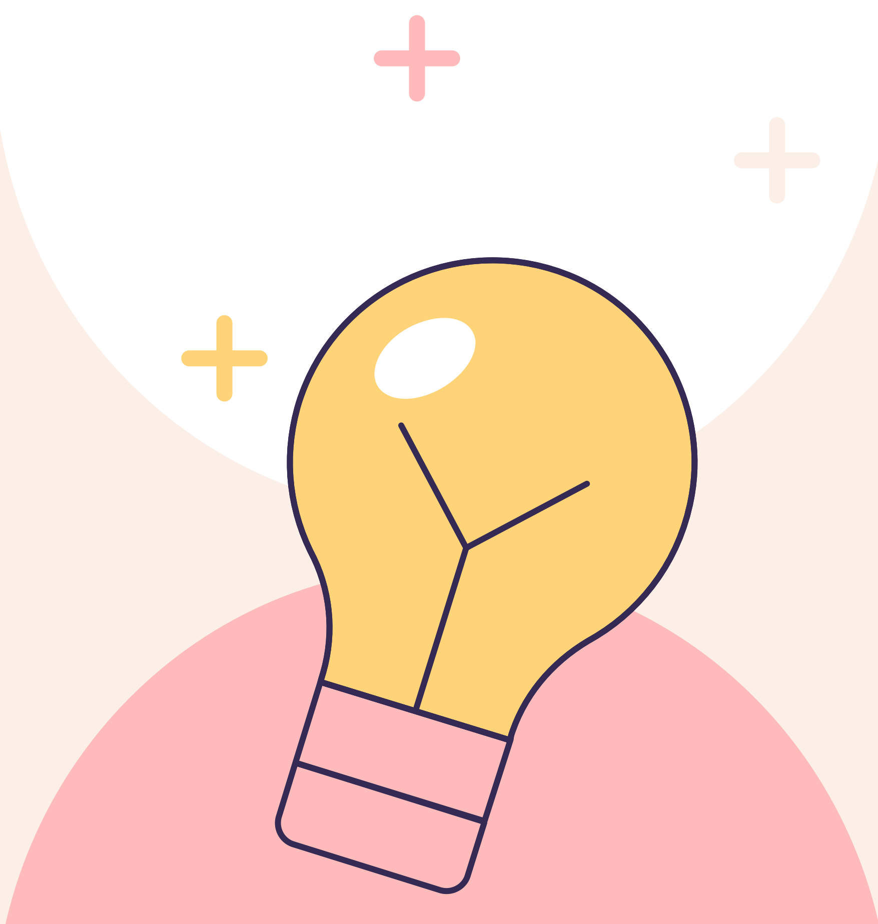
- brain development and maturation
- increased risk taking
- Impulsive behavior
- non-adherence issues

that are so common in this age .

- Transition' is a process that involves purposeful, planned efforts to prepare the pediatric patient to move from caregiver-directed care to disease self-management in the adult unit.

- \- In the most desirable format, transfer is an event that takes place at the end of a transition process and that is designed to be a more purposeful and concerted effort to prepare the young person with a chronic condition to accept responsibility for his/her disease management.

- **Consensus statement**



1- Transition to transfer

- Transfer should occur from pediatric to adult nephrology services only after efforts have been made to assess and prepare the adolescent/young adult and necessary patient-care information has been delivered to the receiving adult service

2 -Transfer from pediatric to adult nephrology should be

- individualized for each patient after he/she has completed a transition plan (It will depend upon completion of physical growth and educational, social, and psychological attainment.);
- Agreed jointly by the patient and his/her family/carers in conjunction with the pediatric and adult renal care teams
- Take place during a period without crises, especially if social support is unstable;
- Take place after completing school education;
- Take into account treatment plans by other subspecialties with particular reference to urological supervision;
- Take place with due consideration of financial

- provided with a generic transition plan, which then can be individualized for each patient
- include parents, other family members, and even boyfriends/girlfriends (if the young person agrees), as more information lessens anxiety
- be offered the opportunity of an informal visit to the nominated adult service before transfer occurs
- given the opportunity to participate in group sessions with other young people who are about to transition
- able to receive tools to aid in the acquisition of disease self-management skills, such as the transition medical passport; a self-administered transition, readiness survey, and the $TR_xANSITION$ Scale (TM) are useful adjuncts

3- The transition process

- The most effective time to transfer an adolescent/young adult from a pediatric to adult renal service is after a transition process.
- Young people should be introduced to the concept of transition in early adolescence (12–14 years);
- Given information about transition in a gradual manner that is appropriate to his/her developmental stage and intellectual ability;
- Directed by lead clinicians (‘transition champions’) in pediatric and adult units who are identified to coordinate and educate them on transition issues;
- Assigned to a nominated key worker who is responsible for coordinating transition from both pediatric and adult renal service

4- Transition or transfer clinic

- A transfer clinic in either the adult or the pediatric renal unit with both adult and pediatric nephrologists in attendance is the optimal minimum standard
- An internal medicine specialist or nephrologist in each adult service should take special interest and be trained in managing young people with CKD 4–5
- Specialist adult nurses who liaise with specialist nurses from the pediatric unit can ensure continuity of care
- Transfer to adult renal care should include a comprehensive written and verbal summary of all the multidisciplinary aspects of the young person's care. This should include medical, nursing, dietary, social, and educational information;
- The young person should be prepared through a transition pathway to assert their autonomy and to be able to provide relevant information about themselves.

An example of the competencies expected of a young adult being transferred to an adult renal unit

- I understand my condition and can describe it to others
- I know my medications and what they are for
- I can make decisions for myself about my treatment
- I know what the adult clinic arrangements are and who will be reviewing me in clinic
- I know how to make my appointments
- I can make my own transport arrangements to get to the hospital for appointments

preparing for transfer

- I know who to call in a medical emergency
- I am able to talk about my worries concerning blood tests and other treatments
- I know the dietary advice that I have to follow and the importance of activity
- I have appropriate knowledge about sexual health matters
- I have discussed alcohol, smoking, and drug issues

5 - Continuity of care

- A recurring point raised by young people who have been transferred is the lack of continuity of care and build-up of trust that they experienced in the pediatric unit.

Themes relating to transition to adult care

- Preparedness
- Emotional attachment
- Adjusting to adult care
- Aadolescent self-care

Transitioning adolescents to adult nephrology care: a systematic review of the experiences of adolescents, parents, and health professionals
Kimberley Crawford, Cath Wilson, Jac Kee Low, Elizabeth Manias & Allison Williams
Pediatric Nephrology volume 35, pages555–567(2020

preparedness

- Timing of transfer
- (*The adolescents felt that the timing of transfer had been decided by a health professional , I turned 18 and they transferred me)*

- preparing for transfer
- (*Rather than basing transfer on adolescents' age, the pediatric health professionals spoke of their desire for the adolescent to be enrolled in* *professional training, be knowledgeable about their disease, competent in self-care, emotionally resilient, and medically stable)*

Emotional attachment

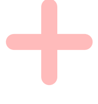
- Leaving the familiarity of the pediatric health service

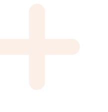
Adolescents reported that one of the most helpful aspects of the transition process was touring the adult health service and meeting the new health team prior to transfer

- Reluctance to “let go”

the patient needs some continuity, caring hands which hold him tight while everything keeps changing, and a place where he feels secure. This is why we apply for extended paediatric care until everything is settled” (Pediatric health professional)

Adjusting to adult care





- Culture shock

(It was a bit like a shearing station: long waits and not much time spent with patients" (Adolescent, transferred)

Posters of cartoon characters had been replaced by skin cancer alerts

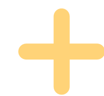
- Fear of the unknown

Adolescents who were yet to transfer to adult care were influenced by their parent's negative experiences of the adult health services

- Out of place

"Most of the other patients looked older than 60 years of age" (Adolescent, transferred)

Adolescent self-care



- Taking responsibility

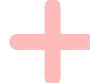
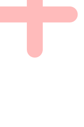
Some adolescents adjusted easily to the responsibility of managing their health care, where they saw it as a "job", "like I'm going to work… I am setting up my [dialysis] machine, take myself off and then leave" (Adolescent, transferred)

- Developing independence

- Improving the transition process

Having the contact details of a health professional in the adult health service was very important to the adolescents and a tour of the adult health service would have been very helpful .

Working with young people

Problems and pitfalls of transition from paediatric to adult renal care
Alan R. Watson
Pediatric Nephrology volume 20, pages113–117(2005)

Take time to communicate and listen in a non-judgemental way
Respect privacy and confidentiality
Understand consent requirements
Define and maintain boundaries of behaviour
Provide a safe environment
Realise the importance of family, school and peer support

Differences between paediatric and adult units

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Paediatrics	Adult
Family consultation	Individual consultation
Multidisciplinary team and psychosocial support	Limited team support (especially psychosocial)
Fewer patients	Large patient numbers
Specialist knowledge about rare genetic conditions, e.g. cystinosis	Lack of experience with rare ‘paediatric’ conditions
Shorter waiting lists	Longer waiting lists and pressure on dialysis ‘spaces’
Peer support	No ‘young adult’ clinic
Medications usually free	Payment for medications

IN SUMMARY

for a successful transfer we need

1-Preparation for a sufficient period of time before transfer

2-Reassurance of young people that their view point will be listened to

3-Empathy from the medical and nursing staff on the other side

4-Peer support from those who have already made the transition