ISSUE FOR TRANSITIONING FROM CHILDREN TO ADULT EPILEPSY CARE

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Transition Care

Ped Neurologist

Adult Neurologist

Patient & Family

Main Stakeholders

Transitioning From Children to Adult Epilepsy Care Issue

- What pediatric neurologists want and should know?
- What adult neurologists want and should learn?
- What patients and families want and the barriers?
- Proposed Transitional Model

WHAT PEDIATRIC NEUROLOGISTS WANT & SHOULD KNOW?

What Pediatric Neurologists Want ?

- Kick the patients out of the crowded pediatric neuro clinic
- Patients will receive the same multi-disciplinary care as in pediatric care
- Patients become seizure free
- Caring of patient with intellectual disability by adult healthcare team

What Pediatric Neurologists Should Know ?

- 30-50% of children with epilepsy (CWE) become adult with epilepsy
- 70-80% of CWE have cognitive, behavioral, and psychological comorbidities
- Pediatric service usually ends at the age of 15-18 years
- CWE should be prepared for transfering into adult care

3 groups of CWE transitioning to adult epilepsy care

1) Childhood onset epilepsy, drug resistant, with comorbidities
   - ✓ Lennox-Gastaut syndrome, Dravet syndrome
   - ✓ TSC, SWS

2) Adolescent onset epilepsy with normal intellectual function
   - ✓ JME
   - ✓ Focal epilepsy

3) CWE, seizure resolved, with residual comorbidity
   - ✓ CAE, BECTS

Nabbout R and Camfield P. Bringing the transition of epilepsy care from children to adults out of the shadows. Epilepsia, 55(Suppl.3):52–53, 2014

Childhood onset epilepsy, drug resistant, with comorbidities

- Complex comorbidities: Intellectual disability, need caregiver
- Sophisticated work up – EEG, MRI, genetic, metabolic,....
- Several ASMs use – response / failed / side effect / interaction

✓ TSC – multidisciplinary team, shifting care from seizure and development to renal / chest / psychiatric problem

✓ LGS – handicap & behavioral issue, family preparation, reproductive and bone health, etc.

Thiele E et al. Transition into adulthood: TSC, SWS, and Rasmussen encephalitis. Epilepsia 2014
Camfield P et al. Strategies for transitioning to adult care for youth with LGS and related disorders. Epilepsia 2011

Adolescent onset epilepsy with normal intellectual function

- Long-term ASMs – adverse event consideration
  - ✓ JME: up to 25% can discontinue ASM and seizure free
    15% drug resistant
- Time for optimized ASMs: decreasing or changing a new one
- Reconsidering diagnosis / presurgical evaluation
- Special situation: pregnancy / driving / psychological concern
- SUDEP

Camfield C et al. Transition issues for BECTS, non-lesional focal epilepsy, CAE, and JME. Epilepsia 2014

CWE, seizure remission but residual comorbidity

- ✓ BECTS will enter terminal remission by the age of 16 years
  - ➢ Social outcome in adulthood = general population

- ✓ CAE: 65% outgrown by late adolescence
  - ➢ Psychosocial issue: lower academic performance, linguistic difficulty, ADHD, anxiety
  - ➢ Evolution to JME (5-15%)

Camfield C et al. Transition issues for BECTS, non-lesional focal epilepsy, CAE, and JME. Epilepsia 2014

WHAT ADULT NEUROLOGISTS WANT & SHOULD LEARN?

When adult neurologists receive medical transition from pediatric care

- Worry
- Stress
- Anxiety

What adult neurologist wants?

- Smooth, planned, coordinated movement of adolescents from child-oriented, family centered environment of pediatrics to adult-oriented care setting
- Both patients and physician feel comfortable
- No interruption in treatment and worsen of symptom
  Unnecessary use of emergency services and unscheduled hospitalization
- Patient and family satisfaction

Obstacle

- Adult neurologists may be uncomfortable with young adults with intellectual disability
- Lack of knowledge about complex disease of childhood epilepsy, with more specific diagnosis
- Patient and family separation anxiety
- Lack of organized system

  - Difficult to coordinate schedule and bring together physician from pediatric and adult program

  - Space for transition clinics

  - Multidisciplinary programs require extra funding for special services and coordinators

What adult neurologist should learn?

1. Learning about disease, its manifestations, outcome

2. Learning about medications, treatment issue, to manage problems to minimize effect on normal adult life esp. social issue

1. LEARNING ABOUT DISEASE, ITS MANIFESTATIONS & OUTCOME

Learning about disease, manifestation and outcome

- Childhood-onset epilepsy often changes in adulthood
- Seizures may increase or decrease depending on etiology
- Some childhood neurological disorders are only a/w epilepsy in adulthood
- Some epilepsy syndromes evolve to different syndromes in adolescence and adulthood with differing treatments (CAE → JME)
- Number of other serious medical and psychiatric disorders dominate adult lives

Adult outcome of childhood epilepsy

1. Seizure outcome

Seizures remit in about 60-70% of patients during childhood

2. Psychosocial outcome

High risk of social isolation, unplanned pregnancy, behavioral and psychiatric problems, lower education, increased financial dependency

Disorders with changing problems in adulthood

- TSC is multisystem disorder

Childhood concerns focus around seizures and cognition

Adult concerns center on kidney, lung disease, serious anxiety disorders

Dravet Syndrome: important change in adult

- Seizures tend to decrease in frequency, few pts become seizure-free
- Less sensitive to fever, but can still have fever-induced seizures
- Change in circadian rhythm of seizures, seizures occurring more in sleep with age
- Convulsive status epilepticus much less common
- Cognitive outcome is poor
- Gait disturbances mimic Parkinson's disease and may improve with levo-dopa

Decreased seizure severity in adulthood with increasing concerns about mobility

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Nabbout R. et al. Outcome of childhood-onset epilepsy from adolescence to adulthood: Transition issues. Epilepsy & Behavior 2017

Metabolic and mitochondrial diseases may have late onset epilepsy

- Epilepsy may only present in adulthood as late complication

- Problems of transition

  Rarity, severity, complexity, multidisciplinary nature of care, unusual treatments, lack of expertise in metabolic disorders and concerns about medical liability

Table 1
Inborn errors of metabolism with onset or predominance of seizures during adulthood.

- Energy metabolism disorders
  - MERRF, MELAS, GAMT, GLUT1, SLC19A3 (thiamine transporter)
- Lipid metabolism/storage disorders
  - Niemann-Pick C, Gaucher 3, NCL, LIMP2, sialidosis, Lafora
- Intoxication syndromes
  - Homocystinuria, SSADH, acute intermittent porphyria, lysinuric protein intolerance, arginase deficiency
- Others
  - HI/HA

MERRF (myoclonic epilepsy with ragged red fibers); MELAS (mitochondrial encephalomyopathy with lactic acidosis and stroke-like episodes); GAMT (guanidinoacetate methyltransferase); GLUT1 (glucose transporter 1); SLC 19A3 (solute carrier family 19A3); NCL (neuronal ceroid lipofuscinosis); LIMP 2 (lysine integral membrane protein 2); SSADH (succinic semialdehyde dehydrogenase); HI/HA (Hyperinsulinism/Hyperammonemia).

Nabbout R. et al. Outcome of childhood-onset epilepsy from adolescence to adulthood: Transition issues. Epilepsy & Behavior 2017

Children with structural etiologies for epilepsy who become seizure-free may still have emerging psychopathology in adulthood

FCD: Response to medical treatment is likely to be unfavorable in the longer term

Adolescence LGS
Tonic seizures and polyspikes often persist
Atypical absences and slow spike waves diminish and can disappear

Autoimmune encephalitis diseases vary in symptoms with age of onset and specific Ab

Anti-NMDA receptor encephalitis
In younger children, epilepsy more prominent
In youth, presenting symptom are behavioral, cognitive, , memory, speech disorder
In older adults, predominant behavioral issue

CAE: remission 85%, refractory CAE 2–9%
- 15% of children with CAE later developed JME
- Generally normal intelligence
- Adult social outcome is often poor

JME: 75% have significant adverse social complications similar to CAE

Increasing concern of children with epilepsy followed for 45–50 years that risk of stroke and dementia is increased in adulthood

Nabbout R. et al. Outcome of childhood-onset epilepsy from adolescence to adulthood: Transition issues. Epilepsy & Behavior 2017

2. MEDICATION AND TREATMENT ISSUE

2. Medication and treatment issue

- Medication used manly in pediatric age group
- Polytherapy
- Specific ASMs safety issues occur in children more than adults
- Ketogenic diet
- Rescue medication
- Psychiatric and social aspects

Nabbout R et al. Treatment issues for children with epilepsy transitioning to adult care. Epilepsy & Behavior 2017

ASMs used in pediatrics but rarely in adult

- Vigabatrin markedly restricted used due to retinal toxicity

  Specific efficacy of vigabatrin for infantile spasms, esp. in TSC

- Cannabidiol

  For pharmaco-resistant pediatric epilepsy and EE (LGS, Dravet syndrome, TSC)

  Interaction with clobazam (increased serum levels) through CYP450 inhibition

- Stiripentol as adjunctive therapy with VPA, TPM, clobazam in Dravet syndrome

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Nabbout R et al. Treatment issues for children with epilepsy transitioning to adult care. Epilepsy & Behavior 2017

ASM treatment differences in children compared with adults

- Etiology of epilepsy begins in childhood may be very different than in adult epilepsy

- Pediatric indications

  Clobazam and rufinamide for LGS

  Cannabidiol for Dravet syndrome, LGS, TSC

  Everolimus for TSC

- Specific ASM safety issues occur in children more than adults

  Increased rash from LTG

  Increased liver toxicity from VPA

  Probably increased behavioral issues from LEV, TPM, GBP, PGB

Nabbout R et al. Treatment issues for children with epilepsy transitioning to adult care. Epilepsy & Behavior 2017

Suggestions for simplifying polytherapy

1. Identify ASM that could be aggravating epilepsy such as CBZ in GGE or sodium channel inhibitors in Dravet syndrome

2. Avoid combining drugs with similar mechanisms of action e.g. CLB + clonazepam or CBZ + PHT+ LCM

3. Be cautious combinations of ASMs with competitive hepatic enz. inhibition e.g. TPM + PHT or with competitive protein binding e.g. LTG + CBZ

4. Be cautious about certain combinations such as VPA with TPM (may offset weight gain, but increased neurotoxic side effects)

5. ASMs combinations may have synergistic effects e.g. VPA + LTG

6. ASMs combination with different mechanisms of action e.g. CLB + VPA

7. Consider ASM that address both seizures and co-morbidities e.g. TPM for seizures and migraine

8. Consider retrying ASM not tolerated in the past: teenager may tolerate CLB even though caused agitation during infancy

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Nabbout R et al. Treatment issues for children with epilepsy transitioning to adult care. Epilepsy & Behavior 2017

Long-term effects of KD: How does this affect transition

- Adult neurologist is not familiar with how to manage patient on KD

- Some long-term side effects of dietary therapies

  Growth disturbance (82%)

  Kidney stones (25%)

  Bone fractures (21%)

Nabbout R et al. Treatment issues for children with epilepsy transitioning to adult care. Epilepsy & Behavior 2017

Rescue medications across age groups

Continue rescue medication into adulthood

- Rectal diazepam
- Buccal and nasal midazolam
- Oral diazepam
- Oral clobazam

- Catamenial epilepsy

Nabbout R et al. Treatment issues for children with epilepsy transitioning to adult care. Epilepsy & Behavior 2017

Could we improve compliance with ASM treatment?

- Essential step for successful transition is for adolescent to take responsibility for his/her medication
- Must accept diagnosis and need for treatment
- System for remembering to take doses: reminder cues, daily pillbox

Nabbout R et al. Treatment issues for children with epilepsy transitioning to adult care. Epilepsy & Behavior 2017

Psychiatric and social aspects related to transition

- Depression and anxiety

  Prevalence 20 and 30%, severity and duration of epilepsy being most important determinants

  Systematic screening and early identification of mental health, behavioral, cognitive problems

  Simple screening questionnaire for depression

- Hyperactivity and aggressive behavior

  Up to 40% of children and adolescent with epilepsy have intellectual disabilities, 1/3 have ADHD, 20% have ASD

  Aggressive behavior: interictal > ictal, postictal

- Identifying and intervening for social problems

  Behavioral or psychiatric diagnoses, decreased education level, unemployment or underemployment, not being married, social isolation, inadvertent pregnancy

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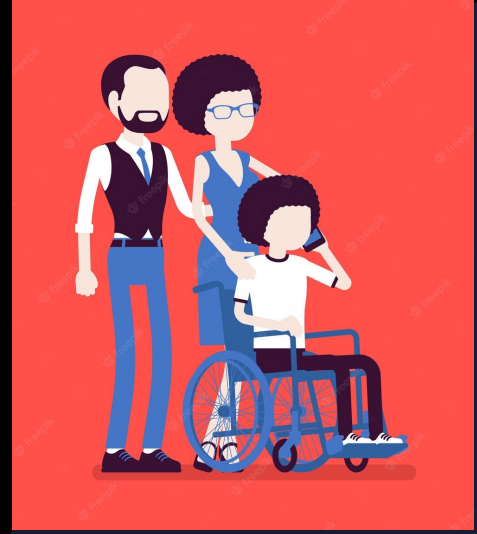
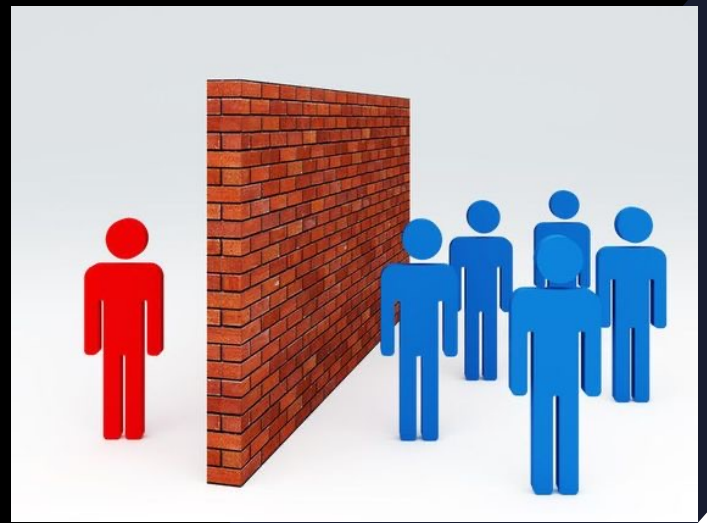
Nabbout R et al. Treatment issues for children with epilepsy transitioning to adult care. Epilepsy & Behavior 2017

WHAT PATIENTS AND FAMILIES WANT & THE BARRIERS?

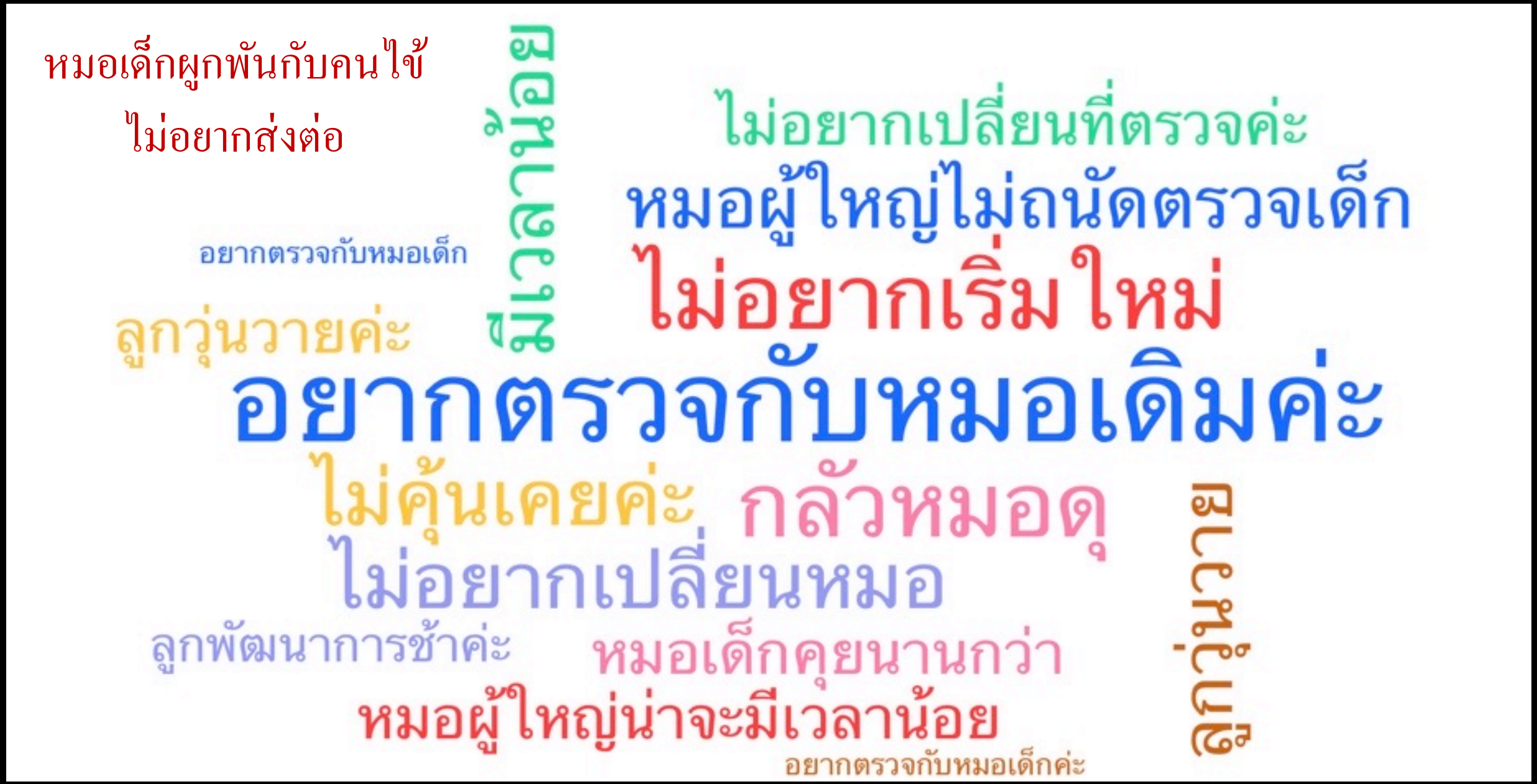




สมาคมโรคลมชักแห่งประเทศไทย
EPILEPSY SOCIETY OF THAILAND
2539 1996

Family opinion before transition to adult care

Poll - ทำไมถึงไม่อยากย้ายไปตรวจกับหมอผู้ใหญ่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หมอผู้ใหญ่ไม่ถนัดตรวจเด็ก
อยากตรวจกับหมอเด็ก
ไม่อยากเริ่มใหม่
ลูกวุ่นวายค่ะ
อยากตรวจกับหมอเดิมค่ะ
ไม่คุ้นเคยค่ะ
กลัวหมอดุ
ไม่อยากเปลี่ยนหมอ
ลูกพัฒนาการช้าค่ะ
หมอเด็กคุยนานกว่า
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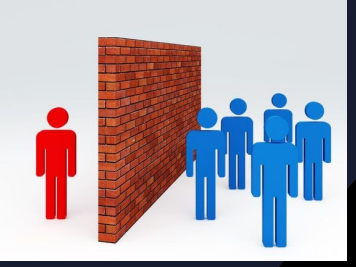
อยากตรวจกับหมอเด็กค่ะ



Barriers

- Comfort environment
- Family-pediatrician bonding (both sides)
- Intellectual disability and behavioral problem
- Time
- Experience with adult clinic

Issue of Transitioning from Children to Adult

- Age at transition = 13-19 years
- Brain change
- Puberty: hormonal change
- Sexual development
- Psychological development
- Bone health

Camfield P et al. The transition from pediatric to adult care for youth with epilepsy: Basic biological, sociological, psychological issues. Epilepsy Behav 2016

Transitioning Brain

- Grey matter: lose density from occipital to frontal
- White matter: increase connectivity to frontal cortex
- Increase brain dopamine: esp. in reward pathway
- Emotion and pleasure seeking are less inhibited
  → risky behavior

Camfield P et al. The transition from pediatric to adult care for youth with epilepsy: Basic biological, sociological, psychological issues. Epilepsy Behav 2016

Transitioning Hormone

- Hypothalamic–pituitary–gonadal axis
  - ➢ gonadarche (activation of the gonads)
- Hypothalamic–pituitary– adrenal axis
  - ➢ adrenarche (activation of adrenal androgen production)
- Activation of the growth hormone-insulin like growth factor axis (GH-IGF)
- Estradiol → pubertal peak of bone mineralization

Camfield P et al. The transition from pediatric to adult care for youth with epilepsy: Basic biological, sociological, psychological issues. Epilepsy Behav 2016

Sexual Development

- sexual debut overlaps with the time of transition from pediatric to adult care
- By age 18 years, 10–40% remain virgins (USA, Canada, Europe)
- adult with an intellectual disability desires a sexual interaction, whereas their guardian opposes it
- Caregivers have a dual responsibility to empower and protect persons with intellectual disability

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Camfield P et al. The transition from pediatric to adult care for youth with epilepsy: Basic biological, sociological, psychological issues. Epilepsy Behav 2016

Psychological development

- Normal development of autonomy and identity (Erikson)
  - Early (ages 10–13 years) with concrete thinking
  - Middle (ages 14–17) with more analytic and abstract thinking
  - Late (ages 18–21) with the beginning of adult reasoning
- Epilepsy can interfere with the achievement of independence, with important behavioral and emotional consequences
- Severe behavioral problems e.g. aggression, agitation, tantrums, and self-injury disruption

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Camfield P et al. The transition from pediatric to adult care for youth with epilepsy: Basic biological, sociological, psychological issues. Epilepsy Behav 2016

Bone Health

Table 2
Antiepileptic drugs and effects on bone: fracture, bone mineral density, bone quality, and biochemical abnormalities.

AED	Fracture	BMD	Bone quality	Biochemical abnormalities
Carbamazepine	Increased (OR 1.18, 1.10–1.26)[45] (OR 1.81, 1.46–2.23)[47]	Mixed results in adults Limited decrease in controlled pediatric studies	No data	↓Calcium; ↓Phosphate; ↓25(OH)D; ↑PTH; ↑BTMs
Oxcarbazepine	Increased (OR 1.14, 1.03–1.26)[45]	Mixed results in adults No decrease in single controlled pediatric study	No data	↓25 (OH)D; ↑PTH; ↑BTMs
Phenytoin	Increased (OR 1.91, 1.58–2.30)[2]	Reduced in adults No decrease in single controlled pediatric study	No data	↓Calcium; ↓Phosphate; ↓25(OH)D; ↑PTH; ↑BTMs
Phenobarbital	Increased (OR 1.60, 1.16–2.19)[2]	Reduced in adults and children	Osteomalacia and rickets in early studies	↓Calcium; ↓Phosphate; ↓25(OH)D; ↑PTH; ↑BTMs
Topiramate	No data	No decrease in single controlled pediatric study	No data	↓Calcium; ↓PTH;↓bicarbonate; ↑BTMs
Valproate	Increased (OR 1.15,1.05–1.26)[45] (OR 1.10, 0.70–1.72)[47]	Mixed results Limited decrease in controlled pediatric studies	No data	↑Calcium, ↓25(OH)D, ↑BTMs
Gabapentin	Increased (OR 1.49, 1.10–2.02)[47]	Reduced in older men	No data	No reported abnormalities
Lamotrigine	No data	No reduction No decrease in single controlled pediatric study	No data	No reported abnormalities
Levetiracetam	No data	Mixed results No decrease in single controlled pediatric study	Rat study with evidence of reduced bone strength and bone formation	No reported abnormalities
Ketogenic diet	No data	Reduced in children	No data	↓25(OH)D

Camfield P et al. The transition from pediatric to adult care for youth with epilepsy: Basic biological, sociological, psychological issues. Epilepsy Behav 2016

Issue of Transitioning from Children to Adult

- Brain change: impulsive pleasure seeking and risky behavior from imbalance between frontal and limbic maturation
  → impact on ability to deal with responsibility for their health

- Puberty: major effect on development, personality, and behavior
  ++ stigma, dependency, self-esteem from epilepsy

- Sexual: long-term sexual experiences are often unsatisfactory
- Psychological: need family support
- Bone health: supplemental vitamin D and follow up level

Camfield P et al. The transition from pediatric to adult care for youth with epilepsy: Basic biological, sociological, psychological issues. Epilepsy Behav 2016

Pediatric

Transition: How?

Adult

Pediatric

Transition: How?

Adult

Joint Ped-Adult Transition Clinic Model

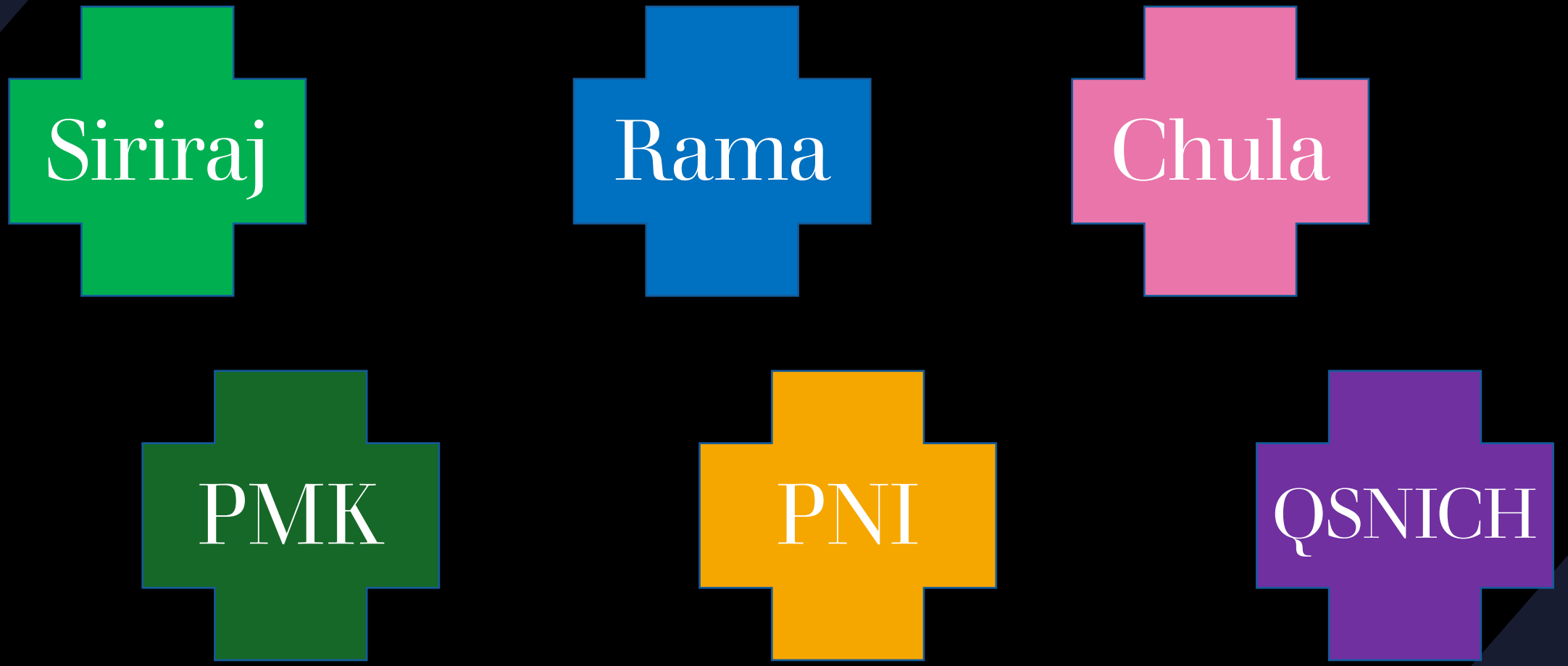
- Both Pediatric and adult neurologist at joint clinic
- May be > 1 visit
- Temporary before permanently move to adult clinic

➢ Very difficult – need availability from both services

Table 1. Comparison of models discussed in this article

	Canada joint pediatric-adult	Canada adult neurologist in pediatric hospital	Canada nurse specialist	France referral center for rare epilepsies	Colombia proposed checklist	Germany ModuS program	United Kingdom joint pediatric- adult
Manpower	Child neurologist Adult neurologist Adult nurse coordinator	Adult neurologist Pediatric nurse coordinator	Pediatric epilepsy nurse Adult epilepsy nurse	Adult neurologist	Pediatric neurologist	Patient and neurologist learning modules	Child neurologist Adult neurologist Adult epilepsy nurse coordinator
Setting	Adult epilepsy clinic	Pediatric hospital	Adult hospital	Adult neurology office	Pediatric neurology office	Home and pediatric neurology office	Adult epilepsy clinic
Usual number of visits	2 or 3	1	2 or 3	Continuing care	Completion of checklist over several years		2–4
Who provides further care?	Adult neurologist who works in the transition clinic	Adult neurologist in adult office setting	Adult epilepsy program including the adult nurse involved in transition	Adult neurologist who works in the transition clinic	Adult neurologist	Adult neurologist in large specialty hospital center	Adult epilepsy clinic or other neurology setting
Formal evaluation	No	No	Yes[3]	Yes[4]	No	Yes[6]	No
Possible problems	Manpower	Single adult neurologist may become overwhelmed		Single adult neurologist may become overwhelmed	Depends on vigilance of pediatric neurologist over years	Unclear if applicable to small center	Ongoing funding

Carrizosa J et al. Models for transition clinics. Epilepsia 2014


Siriraj
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PROPOSED TRANSITIONAL MODEL

TRANSITION MODEL

Pediatric
Model of care

Adult
Model of care

Lifelong care

Transition model

- Transition is a process to prepare youth to adult health care
  - *Child centered → adult oriented health care system*
  - *Addresses medical, psychosocial, educational/vocational needs*

- Models of care for transition and transfer vary around the world, with no objective way to indicate which approach is most effective
  - *Depends upon nation's cultural background and financial resources*

Variables to Consider When Establishing Model of Transition Care

- Complexity of youth's condition
- Comorbidities including behavioral issues, autism, sleep disturbance, intellectual disabilities, feeding issues
- Availability of subspecialty services, nursing or social work services
- Location and availability of adult subspecialists—rural vs urban
- Insurance coverage

Basic concept for successful transition

- Identify adult neurologists and epileptologists who are willing to care for special patients
- Close communication between pediatric and adult health care providers
- Careful summary “transfer” note, copy of relevant pediatric medical records, well-organized system for exchange of medical information
- Joint pediatric/adult transition clinics may be most effective system

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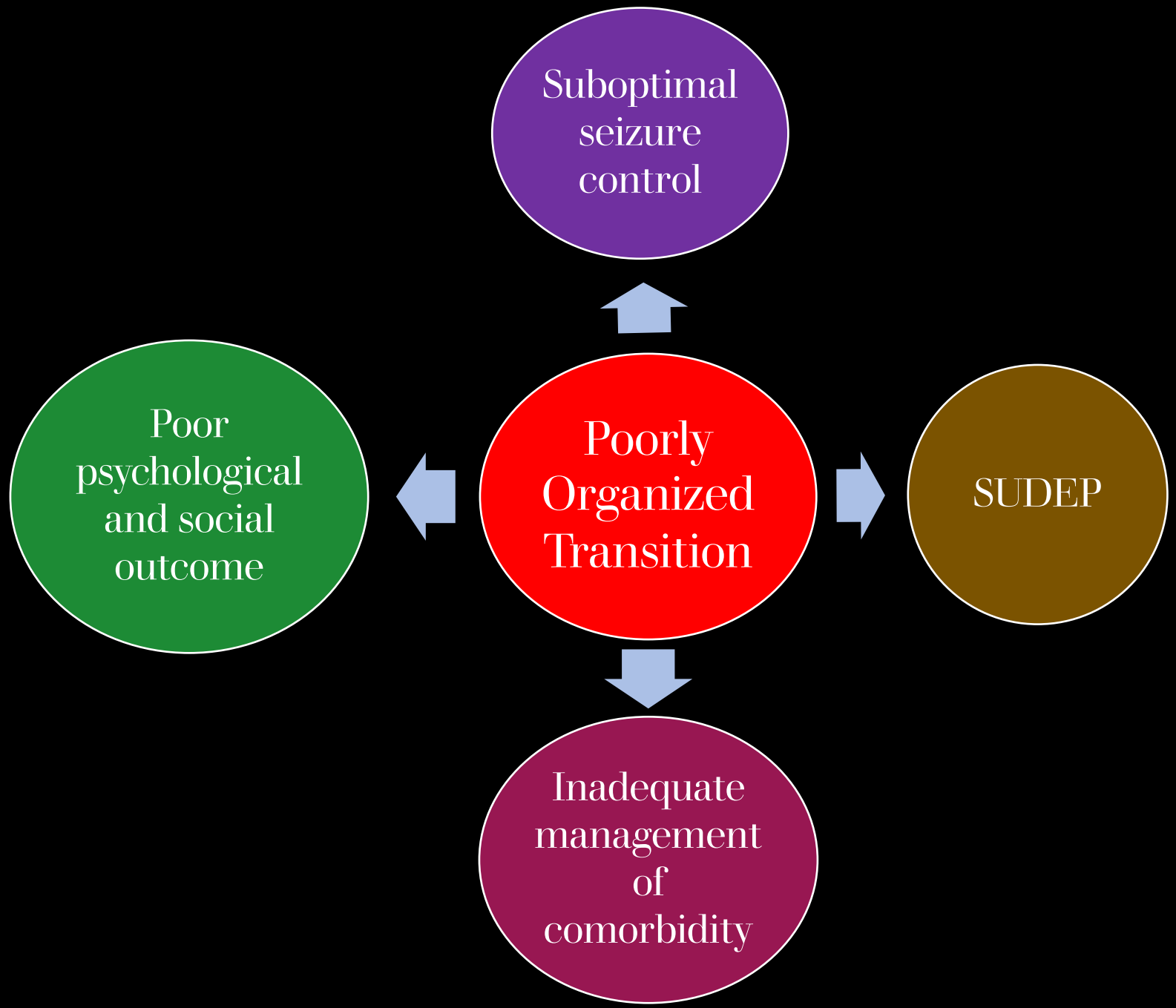
Nabbout R et al. Bringing the transition of epilepsy care form children to adults out of the shadows. Epilepsia 2014

Objective & Goals for transition

1. Assessment of psychosocial and medical conditions
2. Provide youth with developmentally appropriate education about their epilepsy, clinical course, treatment
3. Provide information about potential lifestyle changes such as restrictions for driving, employment, use of alcohol and other substances
4. Initiate and continue ongoing relationship between patient and follow-up care providers to encourage lifelong engagement


Suboptimal seizure control
Poor psychological and social outcome
Poorly Organized Transition
SUDEP
Inadequate management of comorbidity

Transition programs specifically for epilepsy: heterogeneity in models

	Personnel and program	Comments/concerns
Edmonton, Alberta	Pediatric and adult epilepsy nurse specialists meet for several visits with patient and family	No generic transition program Little involvement of physicians Telemedicine overcomes some long distance travel problems
Hospital for Sick Children	There is a single visit with Pediatric and adult epilepsy nurse specialists Pediatric and adult social workers Adult Neurologist Adult Genetics Fellow	Strong generic program Little direct involvement of pediatric epileptologist except for case summary Relies on single adult epileptologist
Halifax, Nova Scotia	There are several visits with Adult nurse specialist Pediatric epileptologist Adult epileptologist	No generic program Discontinued when the two key pediatric epileptologists retired
Goteborg, Sweden	A conference with Adult epileptologist and pediatric neurologists is followed by continuing care with the adult epileptologist. Adult nurse specialist becomes involved after first visit with epileptologist	Good preparation before transition/transfer visit. Strong system of social supports
Great Ormond Street	12 goals for transition are reviewed one at a time in sequential visits (Table 2). There is a series of "teen talks" with epilepsy nurse specialist, There is a handoff clinic with pediatric and adult epileptologists (usually one visit)	Strong generic transition program Several subspecialty adult epilepsy clinics to receive patients with specific rare disorders
Liverpool UK	Adult nurse specialist, Pediatric and Adult epileptologists meet with patient/family for several visits	Functioning successfully for >20 years but no overall evaluation No generic program
Necker Hospital, Paris	There is a good generic program with support from a special unit "La Suite". Transfer is to a hospital within the Rare and chronic Diseases Networks	Most transfers are to a single expert adult epileptologist at the Pitié-Salpêtrière Hospital
Pitié-Salpêtrière Hospital, Paris	Adult hospital "Jump" program provides a one-day, multidisciplinary assessment to decide further care needs	A unique program with high level of family satisfaction
The MOSES Program, Bethel, Germany	A comprehensive program with multiple teaching modules delivered by trained instructors in 14 one-hour lessons longitudinally or in 2-day workshop	Randomized clinic trial has established its effectiveness. Physicians are not directly involved.
School of Medicine of the University of Antioquia, Medellin, Colombia	One-week course on transition given to medical students	
India and Egypt	Transition programs not yet developed.	Epilepsy care may be throughout life by an adult neurologist. Psychiatrists play a significant role in adult and pediatric and epilepsy care

Camfield PR et al. How can transition to adult care be best orchestrated for adolescents with epilepsy? Epilepsy & Behavior 2019.

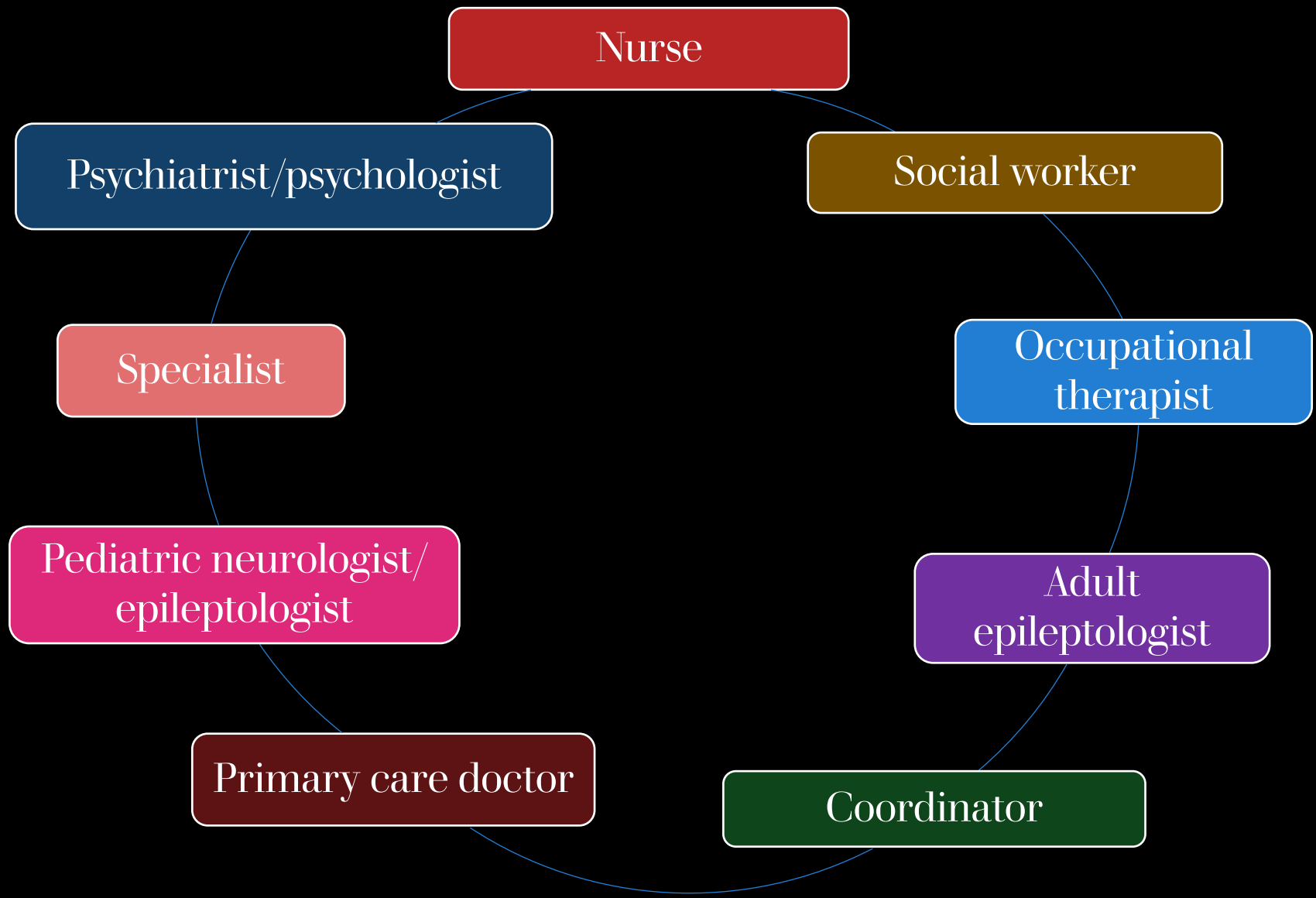
CRITICAL REVIEW AND INVITED COMMENTARY

Epilepsy: Transition from pediatric to adult care. Recommendations of the Ontario epilepsy implementation task force

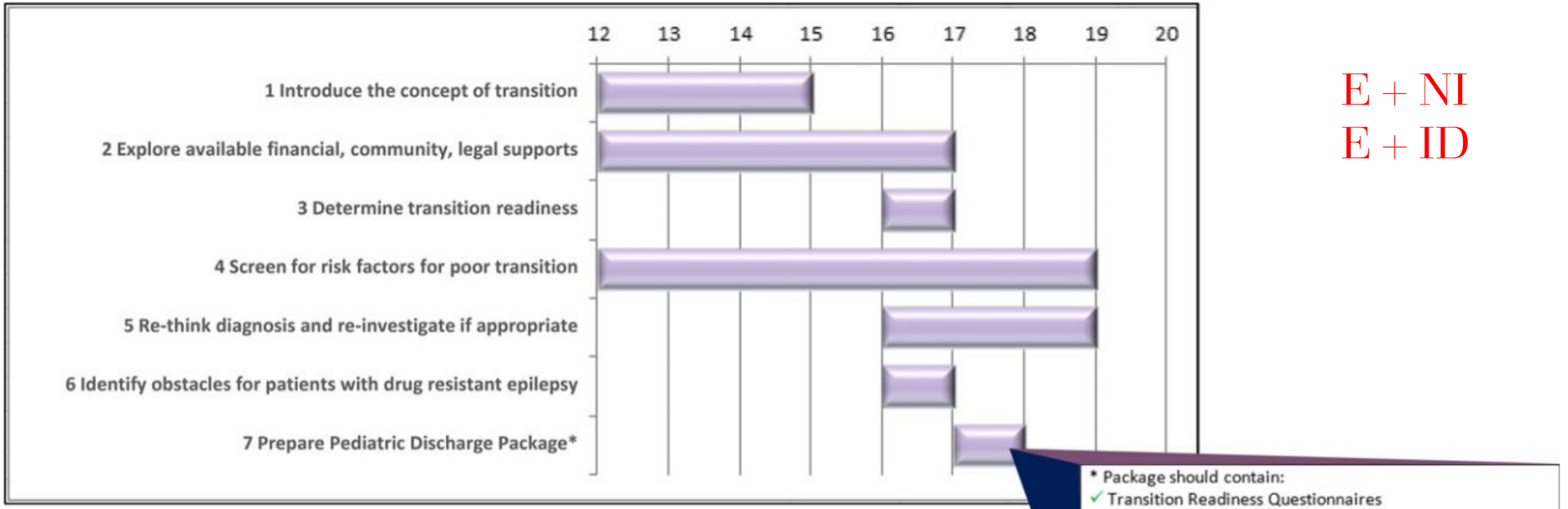
[1*]Danielle M. Andrade, [2]Anne S. Bassett, [3]Eduard Bercovici, [4]Felippe Borlot, [3]Esther Bui, [5†]Peter Camfield, [6]Guida Quaglia Clozza, [7]Eyal Cohen, [8]Timothy Gofine, [9]Lisa Graves, [10]Jon Greenaway, [11†]Beverly Guttman, [12]Maya Guttman-Slater, [13]Ayman Hassan, [14]Megan Henze, [15]Miriam Kaufman, [16]Bernard Lawless, [17]Hannah Lee, [18]Lezlee Lindzon, [19]Lysa Boissé Lomax, [20]Mary Pat McAndrews, [21]Dolly Menna-Dack, [22,23]Berge A. Minassian, [14]Janice Mulligan, [24]Rima Nabbout, [25]Tracy Nejm, [26]Mary Secco, [27]Laurene Sellers, [28]Michelle Shapiro, [29]Marie Slegr, [30]Rosie Smith, [31†]Peter Szatmari, [32]Leeping Tao, [33]Anastasia Vogt, [34]Sharon Whiting, and [35]O. Carter Snead III

Epilepsia, 58(9):1502–1517, 2017
doi: 10.1111/epi.13832

Transition: multidisciplinary team



Seven steps of epilepsy transition schedule



E + NI
E + ID

Andrade DM et al. Epilepsy: Transition from pediatric to adult care.
Recommendations of the Ontario epilepsy implementation task force. Epilepsia 2017

Step 1 (Ages 12–15 years)

- Introduce Concept of Transition

  Emphasizes gradual shift in responsibilities

  Provider → parent/family → adolescent

- Assessment of adolescent's self-management skills

Step 2 (Ages 12–17 years)

- Explore Financial, Community, and Legal Support Available

Step 3 (Ages 16–17 years)

TRANSITION READINESS OF PATIENTS AND PARENTS

- Adolescent's current medical condition
- Current medications and potential side effects
- Signs and symptoms of concern
- Genetic counseling and reproductive implications of underlying neurologic condition
- Puberty and sexuality
- Driving
- Alcohol, substance use
- Emotional/ psychological concerns and wellness

PORTABLE HEALTH SUMMARY

- Obtained through web-based tools completed by patient and health care worker

- Summary of diagnosis, treatments, and concerns

Step 4: screen for risk factor for poor transition

- Step 4A (Ages 12–19 years):
  Adolescents with Normal Intelligence

  - Inconsistent medication compliance
  - Risk of unwanted pregnancy
  - Driving and seizure
  - Depression, anxiety, psychiatric disorders

- Step 4 B (Ages 12–19 Years):
  Adolescents with Intellectual Disability

  - Suboptimal engagement for EEG, imaging, blood work, other tests
  - Pediatric-onset epilepsy syndromes unfamiliar to adult neurologist (EE, genetic, cortical dysplasia, ASD)
  - Screening tools

Step 5 (Ages 16–19): Reevaluate Epilepsy Diagnosis

- Revisit epilepsy/seizure etiology, to optimize treatment
- Where? adult or pediatric center
- Careful interview, EEG, MRI, genetic, psychiatric evaluations

Reevaluation of paroxysmal events

E+NI

PNES

Interview

Home video

EEG

video EEG

E+ID

Different seizure type

VS

Abnormal behavior

Stereotyped

Autonomic change

Re-evaluation

EEG

- Not seizure free
- Change in semiology
- Question of seizure
- Epilepsy surgical candidate

MRI

- Never had MRI but still having seizures
- Previous MRIs show progressive or potentially changing lesion e.g. tumor
- Change in clinical picture
- No clear epilepsy syndrome or etiologic diagnosis
- Previous MRI studies with inappropriate protocol or low-resolution

Genetic

- Intellectual disability
- Developmental delay
- ASD
- Dysmorphism
- Multiple congenital anomalies

Step 6 (Ages 16–17): Identify Obstacles for Continuation of Treatment of Drug-Resistant Epilepsies

- Availability of neuromodulation in adult setting, health insurance coverage

- Ketogenic diet

  - Maintain diets without supervision

    # Inadequate dietary intake

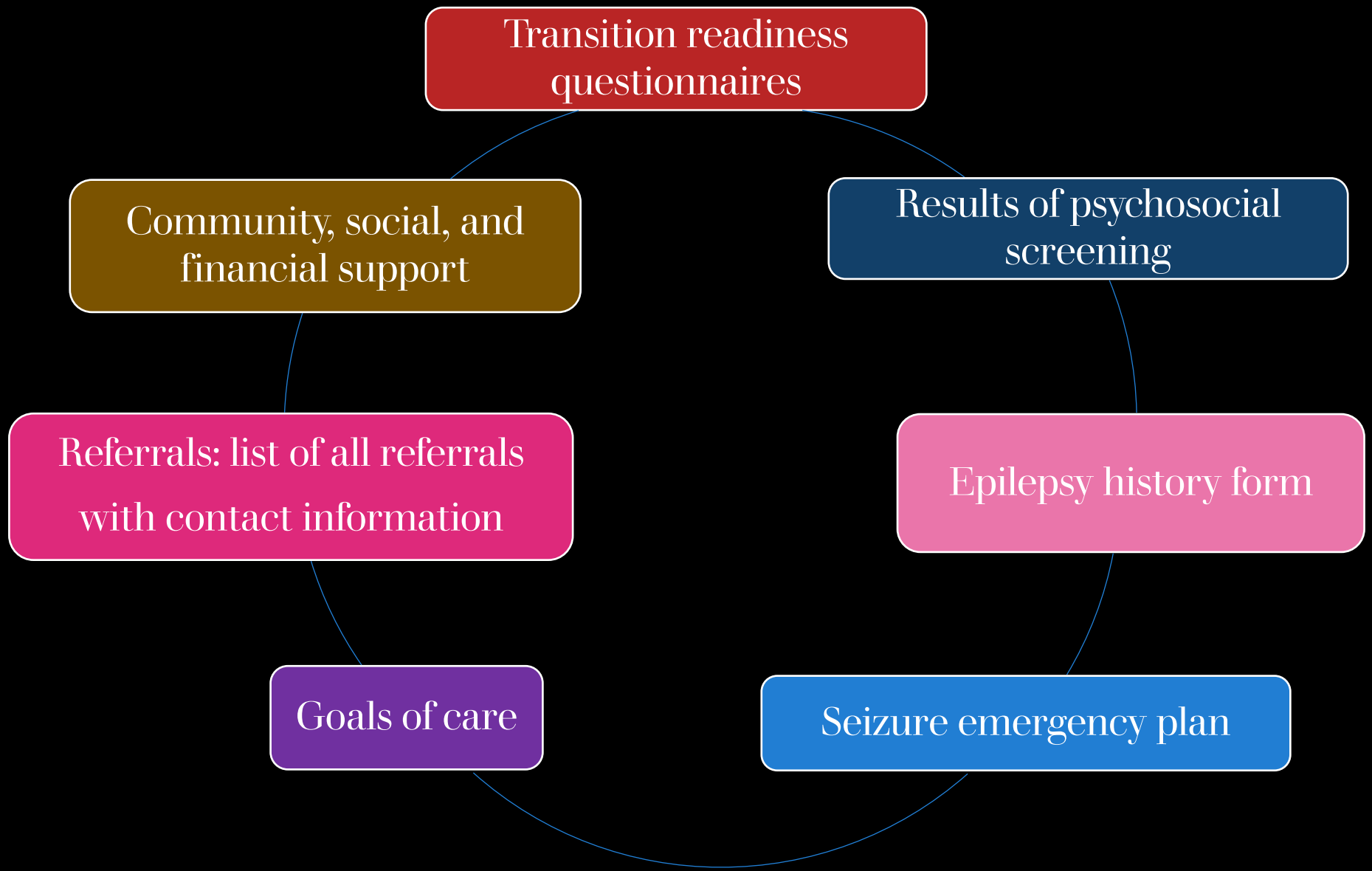
    # Loss of anticonvulsant efficacy

    # Serious side effects e.g. high cholesterol, kidney stones

Step 7 (Ages 17–18 years): Prepare Pediatric Discharge Package

- All involved receive thoroughly completed discharge package from pediatric care provider

Pediatric Discharge Package



Rare complex epilepsy syndrome

- Personalized & multidisciplinary approach
- Lifespan clinic

Summary

- Transition is a process, take time, should be started at early age
- Adolescence need to have plan for diagnostic reevaluation, updated treatment plan, screening for comorbidities
- More information pediatric team provides to adult team, better are chances of successful transition
- Successful outcomes should evaluate not only seizure control, but psychological and social outcomes and quality of life

Summary

- Healthy interaction between pediatric neurologist and adult health care team is importance
- Multidisciplinary transition programs are ideal to manage multiple issues in adolescents with epilepsy
- Joint clinic visits (pediatric and adult) are ideal, but not always possible
- Education is the key to bridge knowledge gap for caring adult with childhood onset epilepsy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THANK YOU