DRK Kliniken Berlin

Transition from childhood to adulthood in chronic diseases

Budapest 18.-19.04.2013

Arpad v. Moers, DRK-Kliniken-Berlin | Westend

Einrichtungen der
DRK-
Schwesternschaft
Berlin e.V.

Definition

Transition describes the change of health care in adolescents with chronic diseases from family-centered to patient-focused health care in adults

The transition process adresses medical as well as psychosocial, educational and vocational needs

Transition

15% of adolescents have special health care needs

90% of children with conditions that were previously fatal in childhood are surviving into adulthood

- Transplantation
- Home ventilation
- Enzyme replacement therapy
- Gene therapy
- Standards of medical care↑
- Nutrition↑

Noninvasive ventilation in DMD

38 yrs
Ventilation via nasal mask since 18 yrs
PEG tube
working part-time

Where do you/does your son mostly live?[a]

		Häufigkeit	Prozent	Gültige Prozente	Kumulierte Prozente
Gültig	With parents or with other relatives or friends	129	72,9	72,9	72,9
	In an institution	9	5,1	5,1	78,0
	On his own (with support as necessary)	36	20,3	20,3	98,3
	With a partner	3	1,7	1,7	100,0
	Gesamt	177	100,0	100,0	

a. age group pediatric or adult = >18 yrs

Transition

40% - (50%) (temporarily) drop out of specialized medical care

Unsuccessful transition results in suboptimal use of healthcare such as
failure to attend out patient appointments and negative health outcomes such as
- increased rates of emergency presentations to hospital
- dísease complications and
- long-term health and social problems

Statements

- Royal Australian College of Physicians
  2000
- American Academy of Pediatrics together with American Academy of Family Physicians, American College of Physicians,
  American Society of Internal Medicine
  2002
  American Academy of Pediatrics und verschiedene Kooperationspartner z.B. Selbsthilfeorganisationen, soziale Hilfs-organisationen) im Rahmen des US amerikanischen Regierungs-
  projektes „Healthy People 2010“ „Medical home“
  2005
- Canadian Pediatric Society
  2007

Statements

Expertise für das BMG (Versorgungssituation chronisch kranker Jugendlicher beim Übergang in das Erwachsenenalter)

1997

- Expert panel recommendation BMG 2009: Koordination und Integration. Gesundheitsversorgung in einer Gesellschaft des längeren Lebens

  2009

- American Academy of Pediatrics, American Academy of Family Physicians & American College of Physicians, Transitions Clinical Report Authoring Group

  2011

Transition programmes

Transition principles

Provide care appropriate to individual development
Support patient‘s autonomy
Ensure collaboration between healthcare providers
Teach negotiation skills
Gradiation of responsibility to the adolescent
Provide community resources
Designated professional who takes responsibility for transition
Provide patient a portable summary of their health care needs
Have current transition plan documented.

(Grant, Pan 2007)

Transition programmes

Transition processes needs

- To identify one person as a continuous contact/co-ordinator for patients and specialists
- An up to date, mobile and accessible health documentation regarding the patient
- An annual up to date written transition plan starting at the age of 14 years
- the ususal preventive healthcare measures which must be equally available for adolescents with special needs

Availability of healthcare funding for the complex coordination necessary for the transitional planning

(de Camargo 2011)

Transition programmes

Transition processes need

- Transition processes need to be individualized (personal factors)
- They should be inclusive (participation)
- They should reduce the existing barriers in society to access employment (enviromental factors)
- People with disabilities need to be empowered to make their own choices and be able to live as independently as they want to

(de Camargo 2011)

Transition programmes

Common characteristics

Case management

Patient empowerment

careful documentation

individualized process of transition

Information/teaching

Transition

but …

2011: …most of the goals established in 2002 have not been achieved (American Academy of Pediatrics)

Barriers in adolescents

- Close relation to pediatric care givers and institutions
- Refusal of unfamiliar medical attendance
- Lack of experts (rare diseases)
- Revolt against parents/adults; quest for self-determination

Barriers in pediatricians

- Improper knowledge about transition
- Uncertainty of the appropriate point in time of transfer
- lack of time
- lack of financial compensation
- long lasting, close relation to patients (over protection)
- skepticism about the expertise of adult health care

Barriers in care givers for adults

- Improper knowledge about transition
- lack of time
- lack of financial compensation
- limited expert knowledge
- Ambivalent attitude concerning the own competence

“no interest“ ?

Contributions to ‘Cystic fibrosis‘, Annual meetings 2011

- Soc. Pediatric Pneumology 28% (23 von 83)
- Soc. Pneumology 1% (4 von 358)

Structural Barriers

- most transition programms are not implemented in regular health care
- lack of structured information transfer
- no coordinator
- no financial compensation of additional duties
- few interdisciplinary adult health care services

Initiatives for Transition

Pneumology
- *CF*

Endocrinology / Diab. mell.
- Growth Hormone Deficiency
- Turner-Syndrome
- Diabetes mellitus Type 1

Nephrology
- Chronic renal failure

Neurology
- Mental retardation
- Epilepsy
- NMD

Rheumatology
- chron. rheumatic diseases

Cardiology
- *congenital heart defects*

Oncology/Hematology
- Leukemia
- Sickle cell disease

Gastroenterology
- *CIBD*

Transplantations
- Kidney, BM-Transplantation

Das Berliner TransitionsProgramm

Ein Strukturkonzept für den Übergang in die Erwachsenenmedizin

BTP

Implementation of a structured process of transition with the following features:

- **Case management**
- **Transfer of detailed information**
- **Not restricted to certain diagnosis**
- **Independent of local infrastructure**
- **Implementing financial compensation of specific duties in the transition process**

BTP structural features

Coordination (case management)

- Contact person for the patient/family and all care givers

Instruments for structured transitionprocess

- Transition rounds
  optional: interdisciplinary case conference)
- Structured medical report
- Booklet, Flyer, Questionaires

Financing

- Financial compensation of transition specific duties covered by health insurance

Transition

Most German Medical Societies have chosen the BTP as the transition program model for Germany

BTP is part of the „Modulares Schulungssystem ModuS“

Transition in rare diseases

EU instructed all member states to develop a National concept for patients with rare diseases.

Deadline 2013 !

An essential component of the National Concept is the formation of Centers of Expertise (CE).

CE are required to establish a transition program for patients with rare diseases.

Conclusion

Transition from family-centered medical care to patient-centered medical care in adults has been identified as critical time for adolescents with chronic disease for quite a few years

Several transition programmes have been developed

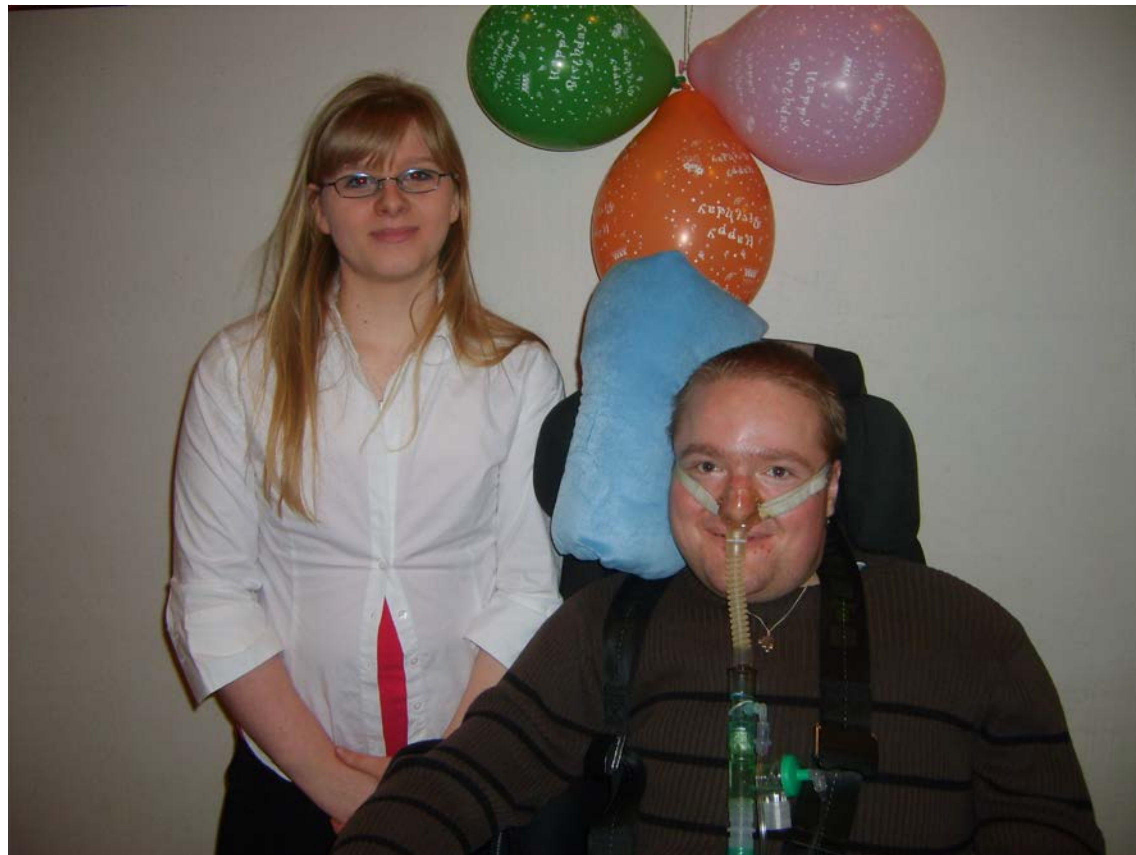
Nevertheles the Transition process is not adequately organised and still lacks sufficient financial support for the majority of adolescents

Action is needed

Conclusion

Hopefully the timeline ititiated by the EU will speed up the implementation of transition programmes into regular health care

38 yrs, Duchenne muscular dystrophy



married since 19.06.2010

Thank you !