“Transition psychiatry” across Europe – a mutual challenge

Jörg M. Fegert
It is not easy to acquire adulthood …

“The most widely-endorsed criteria for adulthood were accepting responsibility for one's self, making independent decisions, and becoming financially independent” (Arnett & Padilla-Walker 2015)
Late adolescence and emerging adulthood is a process … defined as:

The period following the onset of puberty during which a young person develops from a child into an adult (The Oxford Dictionary).

Changes (also see Remschmidt 2013; Konrad 2013):
− age of criminal responsibility, nubility, legal age, end of applicability of juvenile
− new cognitive skills (abstract reasoning)
− ability of introspection
− ethical values and norms
− internalisation of gained knowledge
− to perceive oneself as more grown-up
− to cope with developmental tasks according to age

− maturation of brain structures at a different speed („emotions vs. control“)
− increase of psychiatric disorders
Psychiatric disorders – onset age (Jones 2013)

Around 50% of all psychiatric disorders have their onset during puberty, are manifest at the age of 14 years, almost all at the age of 24.

- treatment delays (e.g. anxiety, depressive disorders)
- development steps delayed (probably)
Everybody talks about it: as transition to the adult care system is partially rather well established in (somatic) medicine, it is still the exception rather than the rule concerning psychiatry.

RESEARCH AND THEORY

"You Never Know What Happens Next" – Young Adult Service Users’ Experience with Mental Health Care and Treatment through One Year

Marian Ádnanes* and Sissel Steihaug†

Fragmented services are a well-known problem in the mental health sector. Mental health service users’ experiences of treatment and care can provide knowledge for developing more user-oriented continuity of care. We followed nine young adults with mental health illnesses and complex needs, conducting four interviews with each informant in the course of a year. The aim was to capture their experiences and views about treatment and care, focusing on (dis)continuities and episodes occurring through that year. The users’ experiences were affected by shifts and transitions between institutions, units and practitioners while their need was predictability and stability. A good and stable patient-provider relationship was considered highly useful but difficult to establish. The participants had a strong desire for explanation, adequate treatment and progress, but very different perceptions of the usefulness of diagnoses. Some felt rejected when they tried to tell the therapist about their trauma. Lack of user-involvement characterized many of the participants’ stories while they desired to become more engaged and included in important decisions concerning treatment and medication.

The participants’ experiences stand in contrast to key policy goals of coherent mental health services. The article discusses what may explain the gap between policy and reality, and how continuity of care may be improved.
Psychiatric disorders – scarce continuity of care?

Prospective population-based study in the USA (Copeland et al. 2015):

1297 participants between 13 and 16 years (1993 and 2000) and 1273 young adults (1999 and 2010) – several surveys:

- During early adulthood, only **28.9%** of the participants fulfilling DSM-IV criteria received any treatment, whereas **50.9%** of the adolescents did.

**Norditalian study** on clinical and demographic factors linked to a continuity of care (Stagi et al. 2015):

Starting from 8239 adolescents who underwent treatment in Child and Adolescent Psychiatry, 821 (**19.4%**) moved to the adult system.

- Frequent diagnoses: schizophrenia, personality disorder, pervasive developmental disorder.
- Further predictive factors: not to live in the parent’s house, psychiatric inpatient treatment, medical treatment during the last 24 months.
Consultation meeting on transition from CAMHS to AMHS: from policy to practice in all Europe
(Madrid, 12.-13.09.2014; also see Signorini et al. 2017)

• Start of an European inventory with regard to care and transition within the framework of the MILESTONE project

Posts by:
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Consultation Meeting – summary of results

• considerable – partially regional – differences in care of psychiatric patients
• transitions rarely structured or standardised
• partly different financing of care systems
• too little communication between them
Lacking continuity of care or:
Lost in transition or translation? or
“Talking a different language”

different philosophies
(systematic review, Mulvale et al. 2016)

“Findings reveal consistent differences in care philosophies between CAMHS (developmental approach, involving families and nurturing) and AMHS (clinical/diagnosis-focus, emphasis on client autonomy and individual responsibility)”.

cultural separation
(Mc Laren et al. 2013)
“A cultural divide appears to exist between CAMHS and AMHS, characterized by different beliefs, attitudes, mutual misperceptions and a lack of understanding of different service structures. This is exacerbated by working practices relating to communication and information transfer which could impact negatively on transition, relational, informational and cross boundary continuity of care”.
To understand and to improve transition for patients from CAMHS to AMHS in different health systems *

* Overall objective should be a flexible system of care, which doesn’t stick to rigid age boundaries, but rather is oriented to the individual needs of the young people.

- Is the interface between CAMHS and AMHS everywhere a problematic one?
- Europe-wide, there are different age boundaries – between 16 and 21 years – determined by capacities and limitations of care.
- public / private access
- enormous differences with regard to the quality of care

The research leading to these results has received funding from the European Community’s Seventh Framework Programme (FP7/2007–2013) under grant agreement n° 602442
The MILESTONE project

Coordination: University of Warwick, Prof. Swaran Singh

Start: February 2014

Time span: 5 years
Aims – goals (~ work packages): TRANSITION MODEL

Pre-conditions transition
- Inventory national CAMHs/AMHs
- Ethical dilemmas involving transition
- Training caregivers

Transition research
- Development of (measurement) instruments regarding transition
- Longitudinal cohort study
- Case-control study

Development of guidelines - recommendations
- Clinical recommendations
- Ethical recommendations
- Training-related recommendations
- Cost-effectiveness

This project has received funding from the European Union's Seventh Framework Programme for research, technological development and demonstration under grant agreement no 602442
Development of (measurement) instruments TRANSITION

TRAM (Transition Readiness and Appropriateness Measures)

- Evaluation of the need for transition: on the basis of different risk and protective factors the clinician can estimate the need for transition and help the young person direct to further caregiving
- Result: no further psychiatric care necessary or a low, moderate, or high care need

TROM (Transition Outcome Measures)

- Evaluation of the outcomes of transition: to measure the quality of transition and to register the evolution of the young people in this phase of life.

Risk & protective factors

- Psychiatric problems
- Suicide
- Care trajectory
- Place of living/ residence
- Hospitalisation: residential and crisis
- Risky behaviour
- Addiction problems
- Justice problems
- Autonomy of the patient
- Self-care, knowledge of disease
- Knowledge of care landscape
- Care continuity – care withdrawal
- Social embedding

Assessment among patients, parents (or informal caregivers) and clinicians.

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Longitudinal cohort study

Case-control study

Invite CAMHS from study sites to participate

Refuse

Baseline data collection CAMHS

Accept

Baseline data collection CAMHS

Invite AMHS & collect baseline data

Cluster Randomise CAMHS

Intervention (1) or Control (4)

Intervention arm

Control arm

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Due to a prolongation of the recruitment phase, reduction to 24 months

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Aims of the Study

• To validate TRAM and TROM

• To research ‘transition’ processes
  • Outcome on psychiatric level but also on the level of different life areas
  • During 27 months
  • To detect important predictive risk and protective factors

➡ Cohort of 1,000 adolescents in Europe
  – we were able to include 1146 participants!

  200 young people = « intervention » arm
  800 young people = « control » arm
Thank you very much!