

Transition The Nottingham Experience

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Definition

- A purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-orientated health care systems.
- DH/Child Health and Maternity Services (2006) *Transition: getting it right for young people. Improving the transition of young people with long term conditions from children's to adult health services.* Department of Health

Transition Issues

- Psychological
 - Migration, family disease, stigma, diagnosis in adolescence
- Medical
 - Adherence, treatment experience, side effects, neuro-cognitive problems
- Relationships/ Sexual Health
 - Negotiating relationships with STI, disclosure

Why do we need to think about it?

- Predominantly adolescent cohort of HIV infected patients
- Recently transferred our first patient to adult services
- National guidance on transition processes
 - General (NSF, DH, You're Welcome etc)
 - HIV specific (CHIVA, HYPNet)
- CHIVA standards of care audit highlighted need for HIV-specific Individual Care Plan

Who's involved

- Young People
- Families
- Voluntary Agencies
- Children's HIV nurse
- Adult HIV nurse
- Paediatrician
- Adult Physicians (ID or GUM)
- Psychologist
- Social Worker

Nottingham Team

- Young People
- Families
- TH trust children's and families' practitioner
- Children's nurse – new appointment
- Adult HIV nurse
- Paediatricians
- Adult Physicians
- Psychology – on referral
- Social worker – adult team

Current Model

- Specialist Services – Handing Over
 - To either GUM or ID
- Other models:
- Family Clinics
- Specialist Services – Separate Youth Clinic

Current Practice

- Young Person seen alone – ad hoc
- Appropriate waiting facilities
- Involvement with TH trust practitioner and young people's group
- Adult nurse
 - Home, paediatric and adult clinic visits
- Generic hospital transition pack

Audit

- Describe our cohort of patients
- How well are processes of transition documented in medical notes?

Points audited

- Demographics
- Seen alone?
- Which clinic?
- Meet adult nurses
- Visit Clinic
- Sexually active?
- Contraception
- STIs
- HIV transmission
- Education

Points audited

- Psychology input
- Adherence
- Treatment experienced
- Side effects
- Co-infection

Results

- 16 patients in clinic
- Median age: 13
- Age range: 1-17 years
- Place of birth
 - UK 2
 - Poland 1
 - Thailand 1
 - Sub-Saharan Africa 12
- 6 patients over 14 years

Results – whole group

- 1 patient had psychology input
- 1 patient with neurocognitive problems, another being investigated
- 4 patients with adherence problems leading to increased viral load
- 4 patients previously had treatment changed due to failing regime
- 5 patients with side effects
 - 2x Lipodystrophy
 - Neutropaenia
 - Diarrhoea
 - 2x Raised lipids
- No co-infection

Results – transition cohort

- Seen alone 2/6
- Which clinic 1/6
- Visit clinic 1/6
- Meet adult nurses 1/6
- Transfer summary 1/6
- Sexually active
 - No 2/6
 - Not Known 4/6
- Contraception 1/6
- STIs 0/6
- HIV transmission 2/6

Discussion

- Data underestimates work being done
- Risk of duplication and omission
- Tracking progress through transition process is difficult

Moving Forward

- What do the young people want?
- MDT to discuss and map pathway
- Documentation
 - CHIVA MDT clinic proforma adapted for Nottingham
 - Trust transition paperwork (slim-line version)
- New appointment of children's HIV specialist nurse
- Identified Adult physician link

Any Questions?