HIV care for adolescents; supportive care and challenges

A view from the Emma Children's Hospital Amsterdam

Presentation Outline

HIV Team
Population
Challenges in HIV care for adolescents
Research activities

Annouschka Weijsenfeld, Pediatric HIV nurse consultant
Presentation Outline

HIV Team
Population
Challenges in HIV care for adolescents
Research activities
Paediatric HIV care team

2 Paediatricians
2 Nurse consultants
1 Child psychologist
1 Social worker
1 PhD student
Population

72 HIV + children in Amsterdam
100% perinatally infected
   64 with two parents from African origin

25 single parent families
31 adoptive children
38 adolescents (12-18)

Since 1996, 78 patients transferred to adult health care (nationwide)
Still a big problem!
Fear of transmission
Social isolation
Being judged
Not ‘safe’ to tell
DISCLOSURE

Age-appropriate education

Disclosure to child/environment

Try not to make it too ‘heavy’

Adolescents making their own choices!

Peer group meetings
Peer group
12-20 years
2 meetings a year
Education, friendship and fun
What good did HIV bring me

"I am open minded"
"I am self supportive"
"I feel strong"
"I am open to other people"
"I do not judge easily"
"A good friend accepted it"

What I hate about HIV

"That I can not talk about it"
"The secret"
"That it exists, and we can not tell"
"Ignorance of others"
"Judgement of others"
"Medication"
"That I sometimes have to lie"
What I hate about HIV

"That I can not talk about it"
"The secret"
"That it exists, and we can not tell"
"That it is forever"
"Ignorance of others"
"Judgement of others"
"Medication"
"That I sometimes have to lie"
What good did HIV bring me

"I am open minded"
"I am self supportive"
"I feel strong"
"I am open to other people"
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"A good friend accepted it"
ADHERENCE

Motivation and acceptance by parents

Failure intervention program
  • Increase adherence by social supportive care, hospitalization or foster care

Rewarding program, positive action works!
  • Increased adherence by rewarding good adherence

Education: https://www.cyberpoli.nl/
Transition

* Start transition process early
* Work on knowledge
* Work on independence
* Meet new health care workers in advance
* Communication between different HCW
* Developing skills to manage own health care
Are we on the right track...?
CLIVIA Study

Clinical, Immunological, Virological and Social Outcomes of HIV Infected Adolescents before and after transition to adult health care services (a retrospective cohort study)

- National research
- 4 Paediatric and 13 adult treatment centres
- 69 of 78 patients included
- First outcome: 8 lost to follow up, 2 moved outside NL
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