

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

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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

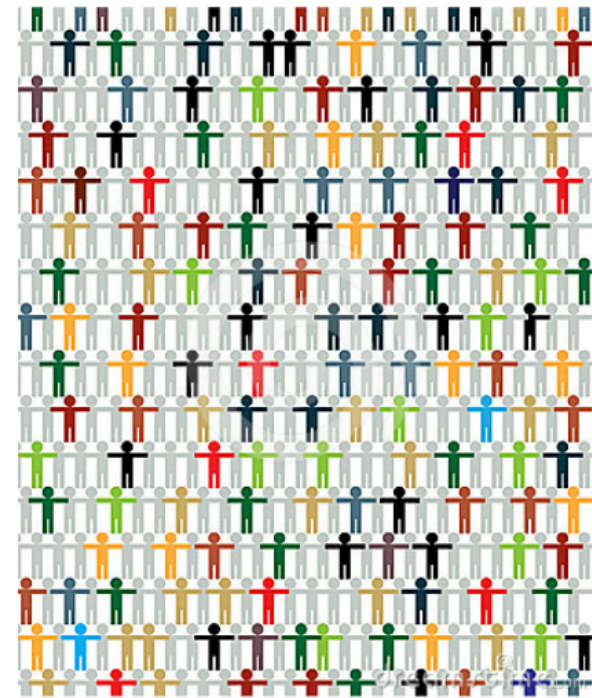
64 with two parents from African origin

25 single parent families

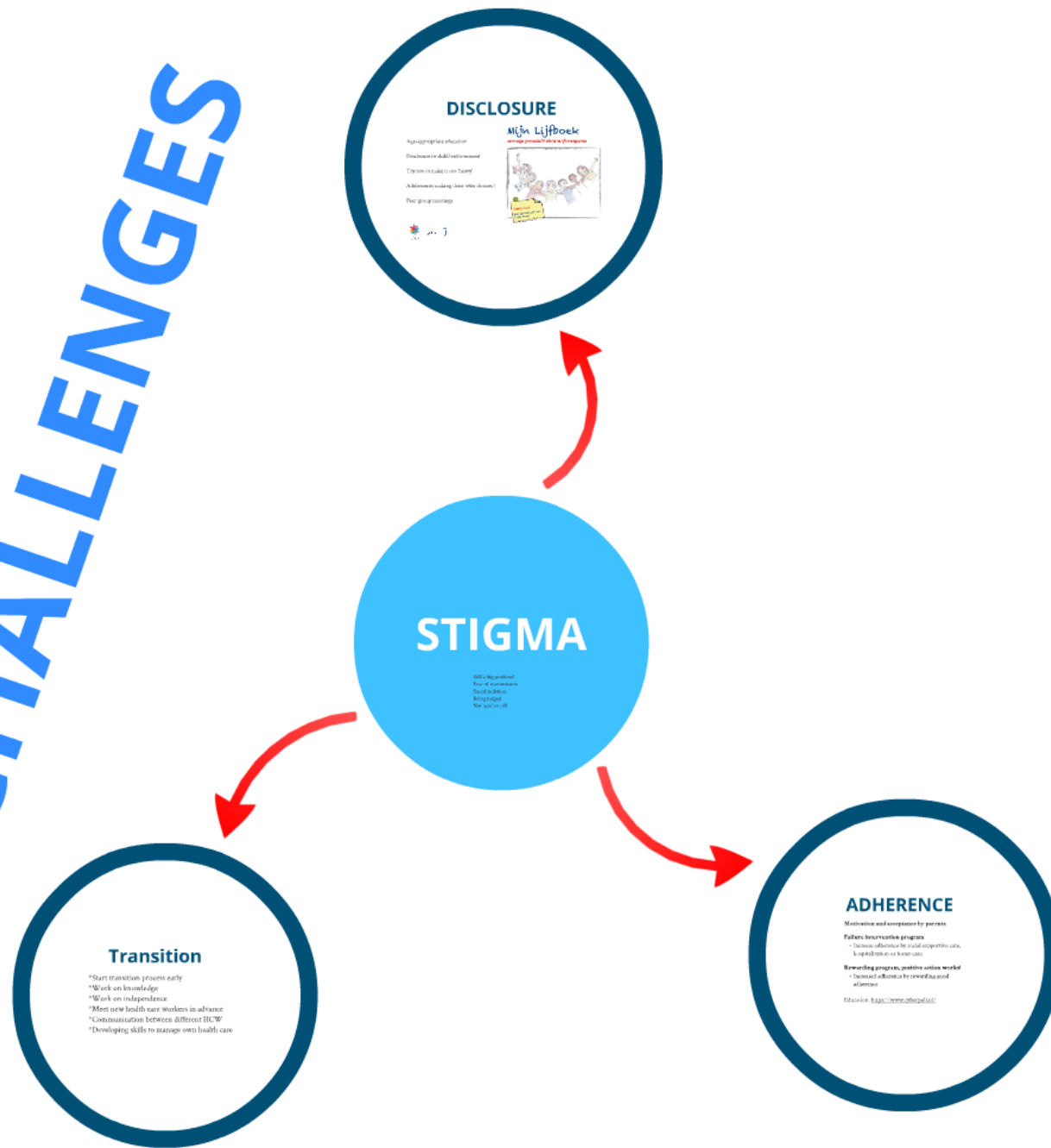
31 adoptive children

38 adolescents (12-18)

Since 1996, 78 patients transferred to adult health care
(nationwide)



CHALLENGES



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

Mijn Lijfboek

over mijn gezondheid, bloed en afweersysteem



The Young Ones



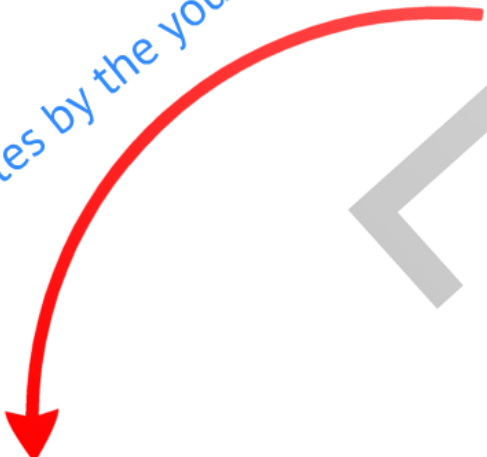
Peer group

12-20 years

2 meetings a year

Education, friendship and fun

Quotes by the young ones



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"
"That it is for others"
"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"
"I do not judge easily"
"A good friend accepted it"

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ADHERENCE

Motivation and acceptance by parents

Failure intervention program

- Increase adherence by social supportive care, hospitalization or foster care

Rewarding program, positive action works!

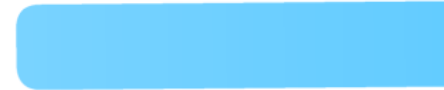
- Increased adherence by rewarding good adherence

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



Acknowledgments

AMC Amsterdam :	Michelle Mutschelknauss, Atie van der Plas, Hans-Erik Nobel, Hans van Eden, Frank Pijnappel, Aafien Henderiks Aniek Westerman, Astrid van Hes
OLVG Amsterdam:	Esmee Oude Geerdink
MC Alkmaar:	Danielle Pronk, Frieda van Truijen
Rijnstate Hospital Arnhem:	Nienke Langebeek, Petra van Bentum Gerjanne ter Beest
UMC Groningen:	Piet van der Meulen, Hanny de Jonge, Dorien de Weerd, Janneke Roukema
MC Leeuwarden:	Sandra Faber, Klaske Dijkstra
LUMC Leiden:	Willemien Dorama, Conny Moons
Radboud UMC Nijmegen:	Bert Zomer, Riet Albers, Karin Grintjes, Marjolein Bosch
Erasmus MC Rotterdam:	Laura Zonneveld, Linda van der Knaap, Eline Visser, Marion Vriesde, Nadine Bassant, Jan van Beek, Marina Miletovic
Maasstad Hospital Rotterdam:	Jannigje Smit, Esther Smit, Melanie Kastelijns
St. Elisabeth Hospital Tilburg:	Marien Kuipers, Bernadette van der Ven, Rick Santegoets, Brigitte de Kruijf
UMC Utrecht:	Joke Patist, Nike Nauta, Sigrid Vervoort, Esther van Oers, Danielle van Elst, Laura Laan.
Isala Clinic Zwolle:	Anja van den Berg, Astrid van Hulzen