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[PL10.1] HIV+ TEENAGERS: TRANSFER TO ADULT CLINICS

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PURPOSE OF THE STUDY: Teams dealing with HIV+ infected teenagers (defined as between 12 to 19 years old) are faced with developmental issues when dealing with growing adolescent patients. HIV-infected adolescents represent both a challenge to teams caring for them, but also a fantastic opportunity to reassess common representations surrounding HIV infection through their innovative and creative approach to life. In Europe, transition from pediatrics to adult care often occurs at a very late stage, whereas in resource-limited countries, teenagers are considered as adults very early and do not benefit from specific teenager care.

The follow-up of teenagers and their transition to adult clinics compared within different settings. Two cohorts aged 12 to 19 will be analyzed: in St Pierre, a cohort of 86 patients; and in Rwanda, a cohort of 156 patients on ARV.

In the Belgian cohort (most HIV+ pediatric European cohort are now teenagers) problems include adherence issues, sexuality, high rate of psychological disturbances, including suicidal equivalent conduct, and social complications.

- Strategies to support adherence have to take into account and encourage the progressive autonomisation process adolescents go through. In opposition to common beliefs, adolescents given adequate help are able to achieve excellent adherence rates. Poor adherence during childhood is a strong predictor of adherence problems during teenage years, and this specific group requires particular attention.
- As patients mature into adult sexuality, teams are faced with issues of counseling about transmission risk and post-exposure prophylaxis, contraception, parenthood and disclosure to

partners. Pediatricians are often uncomfortable discussing sexuality issues with their patients, and might not be in the best position to do so. Timely referral to adult care settings or specialized care (gynecologists) should be encouraged and pediatric competence in dealing with sexuality should be improved.

- High rates of mental health problems are observed: low self esteem, depression, suicidal conduct through treatment disruption, eating behavior problems and body image distortion because of lipodystrophy. Early disclosure, ideally before puberty, is essential and seems to have a protective effect. It allows for optimal diagnosis integration and discussions about the future, life expectations and sexuality before patients are overwhelmed by these considerations.
- Peer group support also plays a protective role: one of the best ways adolescents engage in the individualisation process is to rely on peer relationships; of “discussion groups” can provide an opportunity for youths to identify with others who are also HIV-positive.
- Social issues are paramount: administrative problems linked to immigration, premature death of parents and school difficulties, all complicate the social implications of becoming adult. Social support is essential.
- Social workers have to prepare teenagers to do administrative procedures by themselves. Before transfer to an adult clinic, it is important to give the teenage patient all information about his medical history, including psycho-social and medical aspects. This information also has to be given to the multidisciplinary team at the adult clinic and the choice of the doctor has to be orientated to one doctor with concerns for young adults, together with meetings between the pediatric and adult teams.
- Finally, transition to adult care is a delicate step and, in fact, should be considered as a process.

In resource limited countries, taking the example of Rwanda, these specific teenager problems are even more complicated but still possible to manage by adapting teams to local situations.

- Talking about the disease, sexuality, and transmission issues can be a taboo. Early disclosure with early prevention is not always possible.
- In these countries, teenagers are considered to be adults very early (from 14 years old onwards), even though they have not reached cognitive and emotional maturity.
- Many teenagers are orphans and need special support, often access to food and education. Above all, access to ARV is difficult and not always guaranteed in these countries. Teenagers are also sometimes responsible for their siblings.
- In Kigali, we developed different support groups and noticed excellent participation of teenagers

and counselors helping to disclose, talking about taboos, the future and sexuality. We help these teenagers to deal with stigmatization of being HIV+ and with the childhood memories of genocide.

- They want to talk themselves about sexuality and prevention to other children and adults, and encourage families to test and treat their children.
- These teenagers are often orphans, living in difficult conditions, but have a very good adherence to HAART and are a good example to encourage access to treatment and counseling as early as possible.
- Therefore it is important to integrate these aspects in ARV training courses.
- WHO and international guidelines have to continue special training and supervision in decentralized ARV centers for teenagers.

CONCLUSION: Early disclosure (if possible before puberty), support groups and specific counseling should be offered to teenagers. Training and reference centers should supervise and study more deeply special needs for an effective transition between pediatric and adult clinics and between teenage and adult life in order to avoid failure to treatment and loss for follow up.

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