



European  
AIDS Treatment  
Group



Ageing with HIV

*Quality of Life and Preventive Healthcare*

CONCLUSIONS

Koen Block

# The Long-Term Management of HIV and Quality of Life

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- *“It’s not a final destination but a journey”*

- **Observations**

- Clinicians detect 1/3 of patients’ problems
- Patient reported outcomes support professionals to better address patients’ needs
- No measure is appropriate for everyone
- Health and social inclusion receive insufficient attention from policy makers and HCP

- **Actions needed**

⇒ Use PROMs in routine practice (as they are used in clinical trials)

⇒ Role of PROMs & stigma

⇒ **Integrate services** for mental health

# Sexual Health

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- *“Sexual dysfunctions appear all over lifetime”*

- **Observations**

- When getting older **there are changes in our lifespan** => change of body; change of mind => thus a change of sexuality
- U=U: Lift of the fear of being a life long danger

- **Actions needed**

⇒ Sexual **rights** are essential for sexual health => become a human rights activist

⇒ Sexual rights of all persons must be respected, protected and fulfilled

⇒ Sexual health: it's up to us ... and to our doctors and therapists....and our partners

# Reproductive Health

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- *“A healthy baby needs a healthy mother” - “Children are conceived by fathers”*

- **Observations**

- Blame for bringing HIV within the family
- Institutionalised discrimination of women who use drugs, human rights abuses and discrimination
- Anxiety and concerns in the background: **variables can change throughout lifetime** (parental stress)
- Little research and not much literature on fatherhood (huge stigma)

- **Actions needed**

⇒ Making antenatal care based on what women want and need

⇒ Women to **be involved in the full life cycle of projects**: planning, development, delivery and evaluation

⇒ Need for more research about HIV and issues of reproduction in HIV positive fathers

⇒ More interventions on mental/psychological health, childcare services, stigma reduction, gender specific services, social environment

# Psychosocial well-being

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- *“Wings spread against the wind” - “Violence leaves scars”*

- **Observations**

- Lack of information leads to increased risks at many levels
- Destruction of social capital leads to social isolation of PLHIV
- Support in disclosure reduces stress
- Communication with family is a meaningful aspect
- Intimate violence is a silent epidemic: IPV increases vulnerability to HIV
- Violence is continuum during life span and experienced commonly by WLHIV

- **Actions needed**

⇒ Remove **prohibitions and restrictions**

⇒ Enhance communication and education (e.g. to parents about disclosure)

⇒ **More research** needed on men/trans

⇒ Need for multisectoral approach

⇒ Routine enquiry about violence (monitoring / reporting) and development of tools and guidelines

# Mental Health and HIV

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- *“POSITIVE, HEALTHY, FREE” – “Same issues, little progress”*

- **Observations**

- More common among PLHIV: add a layer of difficulty to many interactions
- How public disclosure made life easier: activism as coping mechanism
- Mental health has its own stigma
- High prevalence of mental health issues and depression among PLHIV: mental health is dynamic

- **Actions needed**

⇒ Consider cost of mental health support (expensive for patients)

⇒ Need for holistic approach and systemic changes

⇒ User friendly tools of mental health **screening and monitoring** (e.g. self scaling) and proper therapy treatment; education; normalisation of HIV; eradicate stigma

# Psychoactive substances and HIV

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- *“If I had money I would inject all day long ” – “Chemsex is more than sex and drugs”*

- **Observations**

- Limited number of syringes available: law barriers procurements; low cost of legal highs
- Problems due to late presentation
- Need of education on illicit drug use and treatment interactions
- Chemsex as ‘alternative social ritual’: potential harm related to chemsex

- **Actions needed**

⇒human factor is important: capacity building and sharing experience

⇒Improve access to socio-medical care and fight stigma

⇒importance of website for drug interactions (including recreational drugs)

⇒**Communication**, importance of disclosure, consider lower DDI regimens

⇒Get people **informed** about chemsex; personalise; don’t judge; talk about it