



European
AIDS Treatment
Group



Challenges of living with HIV and going through stages of development - impact on
mental health

Sanja Belak Skugor

NGO Lux Vitae – Quality of Life Improvement Center
Psychologist – University Hospital for Infectious Diseases, Croatia

Content

- Introduction: childhood and HIV
- Impact of HIV on emotional needs
- Impact of HIV on social development
- Impact of HIV on psychological development
- Adolescents developmental issues and psychosocial stressors
- Emotional and mental health considerations
 - Stigma
 - Bereavement
- Conclusion: assisting children and youth to cope

Introduction

Childhood - sensitive time of turbulent changes in emotional, social, psychological and physical development, time of learning and time of laying of foundations for life.

Psychological ramifications of HIV on children are widespread, rarely experienced singly with dramatic and long-lasting effect due to nature of illness itself and stigma around it.

Both for children infected and affected (family, social ecosystem).

HIV and emotional needs

Needs	Challenges	Impacts
Love	providers of love and affection (family), role models for future relationships can be taken away prematurely, illness, separation and institutional care all mitigate personalised warmth and love, hugs and cuddles, which are all part of child security and love.	Capacity for social adjustment, ideas of self, relationship formation Sense of security and love Disrupted patterns of love
Parenting	parenting shocks: Pregnancy, illness, treatment, job loss, stigma, death and child illness	Over close families Marital conflicts Ability to create beneficial environments for young children to flourish
Attachment and separation	Separation due to: - illness of mother & ramification on parenting, death - own hospitalization HIV stigma results in family avoidance and abandonment	Compromise security of attachment Fear arousing experience Feel neglected, ill, scared Frightened by parents absence

HIV and emotional needs

Needs	Challenges	Impacts
Unconditional relationships	Key individuals who feel and give unconditional love are separated due to HIV or those stepping into caring roles straching their resources to breaking point.	Psychosocial development and growth
Friendship and peer relationship	Stigma and discrimination Parental illness Family demands	Bulling, loneliness, soc barriers & friendship establishment and continuing them

Source: Distinct Disadvantage: A Review of Children Under 8 and the HIV/AIDS Epidemic at http://www.ecdgroup.com/pdfs/LIT_REVIEW_FINAL.pdf

Young children and HIV/AIDS: Mapping the Field at http://www.ecdgroup.com/docs/lib_003664801.pdf

Impact of HIV on social development

- **Social support is a mediator in adjustment and coping, when impeding has dramatic consequences.**
- **Stigma whether real or feared, can have dramatic influences on behaviour and happiness.**
- **Integration into a group may be affected** directly by the diagnosis, or indirectly by the lack of continuity of presence due to illness or hospitalisation, by the lack of a welcoming family environment, by poverty, by lack of time availability or even motivation because of powerful conflicting concerns.
- **Death and bereavement as well as illness and fear may limit the social opportunities and abilities of a child to seek out,** establish and maintain social relationships.

Source: http://www.aidsdatahub.org/sites/default/files/documents/Psychosocial_Aspects_of_HIVAIDS_Children_&_Adolescents.pdf.pdf, http://apps.who.int/adolescent/hiv-testing-treatment/page/Psychosocial_well_being, Distinct Disadvantage: A Review of Children Under 8 and the HIV/AIDS Epidemic at http://www.ecdgroup.com/pdfs/LIT_REVIEW_FINAL.pdf, Young children and HIV/AIDS: Mapping the Field at http://www.ecdgroup.com/docs/lib_003664801.pdf, Adolescent HIV/AIDS: Issues and challenges at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3140141/>

HIV and social development

Needs	Challenges	Impacts
Role models	Changing/substituting role models who differ for the child due to loss of a parent/s	Deprived of the strong grounding of role models for future relationship
Learning	Social environment: exposure, experience, adaptation and guidance	Learning abilities Learning opportunities Language deterioration Cognitive ability problems
Reconstituted families	Deceased parent Stigma	Adverse effects on children achievements
Integration of social roles and norms	Unsatisfied care arrangements Turnover of adult roles	Blurring of understanding Lack of clarity of role models

HIV and social development

Needs	Challenges	Impacts
Self-esteem	death, stigma, social uncertainty, fear and the constant battle for physical survival	Damaged self-esteem Negative sense of self worth Achievement, confidence, coping
Identity	HIV infection, family disruption, quality of parenting, experience of love, hurt, rejection challenges experience and interaction with the world and influence the meaning of self and development of identity.	Affects ability to sustain & maintain close relationships
Schooling (educational opportunity and access)	Long hospitalisation of a child Dropping out of the school to earn money for household Parental illness Poverty Lack of financial/learning support within family	Less schooling - literacy, numeracy and socialisation Problems with school integration, enrolment, attendance, performance, competition Access to learning, future achievement, social exposure

Source: Evidence of impact: health, psychological and social effects of adult HIV on children at <https://www.ncbi.nlm.nih.gov/pubmed/24991898>, http://www.aidsdatahub.org/sites/default/files/documents/Psychosocial_Aspects_of_HIVAIDS_Children_&_Adolescents.pdf, Young children and HIV/AIDS: Mapping the Field at http://www.ecdgroup.com/docs/lib_003664801.pdf,

HIV and psychological development

Needs	Challenges	Impacts
Psychological adjustment	maternal HIV associated stressors maternal emotional distress social support for the child child's own coping ability and style quality of the parent-child relationship Silence about the illness	Poor psychosocial adjustment
Behavioral problems	Environmental factors: drug using parents stresses of illness stigma separation and death Discrimination by other children due to HIV	exacerbate behavioural problems - rule breaking behaviours
Sexual development	Sexuality education availability Stigma and secrecy Disclosure delayed emotional maturity resulting from reduced expectations of survival and independent functioning and therefore greater dependence on their families	dramatic influence on sexual first intercourse, sexual risk taking and negotiating safer sex, decision making,

HIV and psychological development

Needs	Challenges	Impacts
Death and bereavement	Family overwhelmed Disbelief “children too young to understand” Caretakers lacking and avoiding communicating to children about their loss and prognosis, death Coping with mortality of loved ones and their own	Anxieties associated with separation from parents and dying Regression in behaviour and acting-out behaviour (lacking sense of security)
Mental health problems	Higher depression among mothers living with HIV Poorer cohesion in the family Poorer family sociability Increased household responsibilities Life events related to HIV Complexity of HIV and treatment Poverty Alcohol and other substance use common among adolescence Trauma – rape, abuse or other form of violence	anxiety attention deficit and hyperactivity depression panic, feelings of isolation conduct disorder oppositional defiant disorder mood disorder

Source: http://www.aidsdatahub.org/sites/default/files/documents/Psychosocial_Aspects_of_HIVAIDS_Children_&_Adolescents.pdf, http://apps.who.int/adolescent/hiv-testing-treatment/page/Psychosocial_well_being, Distinct Disadvantage: A Review of Children Under 8 and the HIV/AIDS Epidemic at http://www.ecdgroup.com/pdfs/LIT_REVIEW_FINAL.pdf, Young children and HIV/AIDS: Mapping the Field at http://www.ecdgroup.com/docs/lib_003664801.pdf, Adolescent HIV/AIDS: Issues and challenges at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3140141/>

Adolescents developmental issues and psychosocial stressors

Developmental issues adolescents need to cope with:

- ➔ Taking more responsibility for themselves
- ➔ Wanting to be accepted and to fit in with peers
- ➔ Learning to navigate their emerging sexuality and new intimate relationships

Adolescents living with HIV experience numerous **psychosocial stressors** over an extended period of time.

- initial diagnosis and disclosure of their HIV status; the emotional and financial strain of long-term care and adherence to treatment
- coping with stigma and discrimination; distrust of health care providers
- fear and experience of legal consequences and abuse/violence (in the case of many key populations)
- bereavement related to the death of loved ones or apprehension about their own possible death
- concerns around emerging sexuality and desire for relationships and families of their own

Source: Psychosocial Issues of Children Infected with HIV/AIDS at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3701354/>,
http://www.aidsdatahub.org/sites/default/files/documents/Psychosocial_Aspects_of_HIVAIDS_Children_&_Adolescents.pdf.pdf

Emotional and mental health considerations

Stigma

- Affects interaction with the world - less likely to seek social support out of fear of rejection or isolation
- When affects families, we can see they become withdrawn, socially isolated and emotionally cut off from traditional support systems
 - Individually affects how a person thinks and feels about him- or herself

Internalized stigma (person is aware of a social stigma and accepts, or internalizes, society's negative views as their own):

- Damages the person's self-esteem and a negative sense of self-worth
- Adolescents more likely depressed and engage in denial of their HIV status and may have fear disclosing their status to others and feel shameful of being HIV+
- Parents or caregivers delay disclosure to children due to social consequences and personal confrontation with their responsibility, guilt

Source: Psychosocial Issues of Children Infected with HIV/AIDS at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3701354/>,
http://www.aidsdatahub.org/sites/default/files/documents/Psychosocial_Aspects_of_HIVAIDS_Children_&_Adolescents.pdf.pdf

Emotional and mental health considerations

Stigma management is a way of coping with stigma by being aware of possible negative reactions and finding ways to minimize them.

- choosing and limiting disclosure to avoid neg reaction and rejection
- testing understanding and personal opinion before disclosure

“Labeling the diagnosis a secret that must not be discussed only serves to increase the stigma”

Source: http://www.aidsdatahub.org/sites/default/files/documents/Psychosocial_Aspects_of_HIVAIDS_Children_&_Adolescents.pdf.pdf

Emotional and mental health considerations

● Death and bereavement

Harsh realities for children and adolescents living with HIV and thus they **may have more experience** with death and bereavement than peers due to loss of their significant people.

Challenges arise from the need to cope with mortality of their loved ones and at the same time facing and understanding their own possible death.

Additional challenge is improper support to children in their mourning and recognition of their loss due to overwhelmed family, disbelief children cannot understand what is happening or are better off not dwelling on their loss.

Grieving adolescents and children must be able to discuss and **acknowledge their loss** and must have an **opportunity to release their grief** otherwise they could experience long term, into adult, psychological ramification and never recover from their loss.

They should also be encouraged to verbalize their fears, and their feelings should be **validated and discussed, not dismissed or minimized.**

Source: http://www.aidsdatahub.org/sites/default/files/documents/Psychosocial_Aspects_of_HIVAIDS_Children_&_Adolescents.pdf.pdf http://apps.who.int/adolescent/hiv-testing-treatment/page/Psychosocial_well_being,

Psychosocial support benefits

- patients and caregivers **gain confidence** in themselves and their **coping skills**
- increase patients' **understanding and acceptance** of comprehensive **HIV care** and support services
- **encourage adherence** to HIV treatment
- equip adolescents with **skills** to make informed **secondary prevention decisions**
- help **prevent** adolescents living with HIV adopting **risk-associated behaviours** or from developing more severe mental health problems

- **caregivers** also benefit from support that acknowledges the stress they are under and validates their concerns about their children or charges, while enabling them to learn how to cope with the adolescent's developmental and health needs

Source: http://apps.who.int/adolescent/hiv-testing-treatment/page/Psychosocial_well_being

Youth involvement

It is useful to understand the importance of youth participation in terms of three main relationships between services, programmes, policy-makers and adolescents.

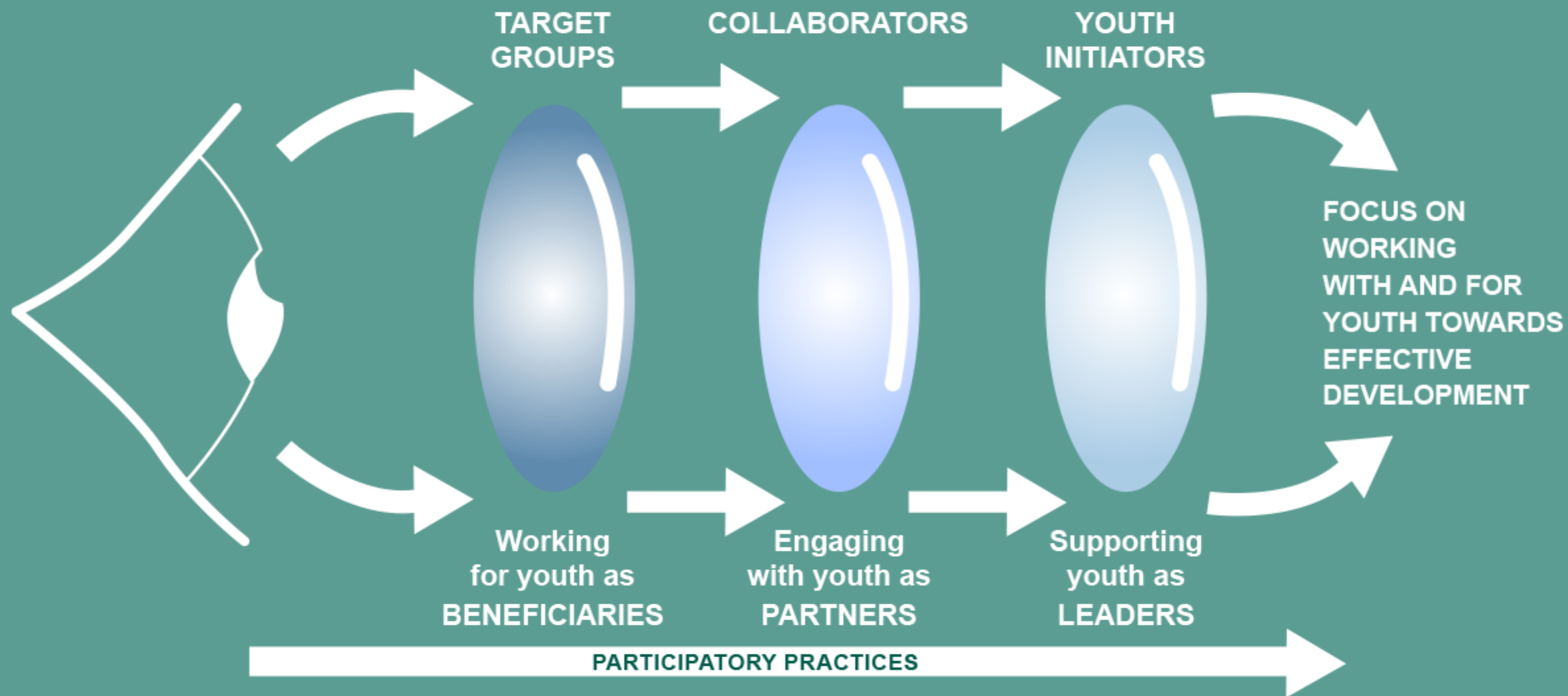
All those involved with adolescents should:

- ➔ work with and for adolescents as **beneficiaries**;
- ➔ engage with adolescents as **partners**;
- ➔ support adolescents to take initiatives and to serve as **leaders**.

This approach focuses on acknowledging and mobilizing the value, strengths, contributions and talents of adolescents rather than concentrating solely on their needs or challenges.

Source: http://apps.who.int/adolescent/hiv-testing-treatment/page/involving_adolescents

THE THREE-LENS APPROACH TO YOUTH PARTICIPATION



Conclusion

Although many effects of HIV/AIDS can be catalogued, there is no reason to doubt resilience, the enormous human capacity, the elasticity and inner resources of children and the possibility that **effects are reversible**.

"HIV is only one chapter in the book not the whole book it self"

For children and adolescent to develop fully as possible it is important to try to maintain **sence of normalicy**, child still needs rules, discipline and routine to have a sence of security and of course to play while adolescent needs to build identity and independency regardless of HIV.

The psychological aspects are often neglected.

The balance between psychological and medical needs to be redressed so that emotional health and well- being move centre stage.

Thank you for your attention!

