

# **Young People Infected with HIV; How counseling can prepare them for a productive adult life.**

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**Young People Infected with HIV; How counseling can prepare them for a productive adult life.**

A thesis submitted in partial fulfillment of the requirement for the degree of

Master of Public health

By

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The Netherlands

**Declaration:**

Where other people's work has been used (either from printed source, internet or any other source) this has been carefully acknowledged and referenced in accordance with departmental requirements.

The thesis "How can we as Counsellors Support Adolescents living with HIV, Prepare them for a Productive Adult Life with HIV?" is my own work.

Signature.....

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## **Table of Contents**

Table of Contents	i-ii
List of table's	ii
Acknowledgement	iii
Abstract	iv
List of Abbreviations	v

## **Chapter 1: Introduction**

### **Chapter 2: Background information**

- 2.1 Counselling as part of clinical management
- 2.2 Young people
- 2.3 Counselling needs related psychosocial factors, social status and stigma
- 2.4 Counselling needs related to, social-cultural and economical factors

### **Chapter 3: Problem statement**

- 3.1 Objectives

### **Chapter 4: Methodology**

- 4.1 Limitations

### **Chapter 5: Disclosure of HIV status to the HIV infected adolescent**

- 5.1 Introduction
- 5.2 Definition of disclosure
- 5.3 Barriers to disclosure
- 5.4 When and Why to disclose
- 5.5 Earlier barriers in the disclosure process
- 5.6 The role of the counsellor
- 5.7 Discussion

### **Chapter 6: Sexual Health**

- 6.1 Introduction
- 6.2 Definitions of sexual health, reproductive health, sexual rights, sexuality and positive prevention
- 6.3 The sexual health needs of young people living with HIV
  - 6.3.1 Factors associating with sexual health of YPLHIV
    - 6.3.1.1 Personal context
    - 6.3.1.2 Proximal context
    - 6.3.1.3 Distal context
  - 6.4 Discussion

### **Chapter 7: Adherence to medical visits and medication**

- 7.1 Introduction
- 7.2 Definitions of Adherence
- 7.3 Factors associated with adherence
  - 7.3.1 Personal context
  - 7.3.2 Proximal context
  - 7.3.3 Distal context
- 7.4 Discussion

**Chapter 8: Discussion; the conceptual framework describing counseling needs of YPLHIV”.**

**Chapter 9: Conclusion and recommendations**

## **List of Figures**

Figure 1: Stages of adolescent development

Figure 2: Framework, based on Eaten (2003), for organizing the influencing factors on sexual health needs and behaviour of adolescents infected with HV.

Figure 3: Framework, for organizing the factors associated with adherence on three levels; distal context, proximal context and personal context.

Figure 4: Conceptual framework Counselling young people living with HIV (de Jong, 2008)

## **Foreword**

For the last 15 years, in different setting, both at the national and international level -hospital, clinic and community- I have been working as a specialized nurse, counselor, program officer and trainer in the field of HIV. Over the years I have gained valuable experience in the public health and HIV clinical and psycho-social healthcare aspects, which is where my passion lies. Through these experiences I have been direct involved with several HIV healthcare matters, which is how I came to realize that young people and HIV is a large neglected area in HIV care. As a result, I want to expand my knowledge and abilities in this field which is what I attend to do, writing this thesis.

I hope that this thesis provides people working in HIV care a better understanding of the broad and essential function of HIV counselors. Even more so, I hope counselors find some guidance and support from the framework layout, inspire them to review and improve their work for the benefit of the YPLHIV. Not only do the lives of YPLHIV benefit of well provided counseling, but the health of the entire community will benefit as well.

## **Abbreviations and acronyms**

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral treatment
CD4	CD4 <sup>+</sup> T cells are a sub-group of lymphocytes type of white blood cell or leukocyte that plays an important role in establishing and maximizing the capabilities of the immune system
HAART	Highly Active Antiretroviral treatment
HIV	Human Immunodeficiency Virus
Horizontal infected	Infection of HIV through sexual contact, IDU, blood contained material
MSF	Medicin Sans Frontieres
PLHIV	People Living With HIV
PMTCT	Preventive mother and child counseling and testing
STI	Sexual Transmitted Diseases
TB	Tuberculosis
UNAIDS	United Nations Organization for Aids
VCT	Voluntary counseling and testing
Vertical infected	Infection of HIV from mother to Child
Viral load	Amount of Virus, measured in the blood. Undetectable HIV viral load means fewer than 50 copies/cc.
WHO	World Health Organization
YPLHIV	Young people living with HIV

## **Abstract**

### **Introduction**

Twelve million people under the age of 25 are estimated to live with HIV. Almost two-third of these young people is living in Sub Saharan Africa. How can we as counsellors support young people living with HIV (YPLHIV), preparing them for a productive adult life?

This thesis explores and analysis the counselling needs of YPLHIV.

### **Methods**

A literature review on published and non-published secondary data from both developed and developing countries.

### **Findings**

Through proper support and communication about the HIV diagnosis, there is a possibility to reduce depression, feelings of isolation and risk behaviour, while increasing the possibility of self reliance. The counsellors contribution can be of great influence, because they have an ongoing relationship with the adolescent, in which they follow them through all stages of development. Furthermore, counsellors have a central position in de clinical management and act as an entry point for many issues, surrounding a YPLHIV needs for treatment and care.

### **Conclusion**

A conceptual framework is designed as a tool for counsellors to use and to show the relation and interaction between the main areas in the counselling needs of YPLHIV; disclosure, sexual health and adherence. Special awareness must be given to the cross cutting issues like poverty, gender inequity, stigma and violence. They have an impact on all components and are main barriers for good health care. To make the framework useful training of counsellors and increased involvement of YPLHIVs are critical in designing better services. Furthermore primary qualitative data from the adolescent perspective and more qualitative and quantitative longitudinal research about the social and epidemiological factors influencing YPLHIV behaviour is needed. In order to do so, I recommend research instruments and operational definitions should offer some uniformity and standardization, and the data presented should be disaggregated by age and sex to make finding results more specific and easier to compare.

### **Key words**

HIV /AIDS, Adolescents/ youth/ young people/ children, Africa, Counselling;, Counselling models, Psychosocial support, Sexual behaviour/ Sex education/ Sexuality Sexual health, Disclosure, Parents living with HIV, Human rights.

## 1 Introduction

**Twelve million people under the age of 25 are estimated to live with HIV (Human immunodeficiency virus). Almost two-third, 3.6 million of all young people (10-24 years) infected with HIV (YPLHIV) are living in Sub Saharan Africa (UNAIDS, 2007). How can we as counsellors support YPLHIV preparing them for a productive adult life with HIV? Are the means we provide, like: psychosocial support, life skills and education the support they need to reach this goal? In spite of the high numbers, attention towards this specific population is still insufficient for, their needs are often ignored (UNAIDS, 2007).**

For the last 15 years I have been primarily working as an HIV nurse counsellor in the Netherlands. And secondarily as consultant for Medicine sans Fronteirs (MSF) in different settings in Africa. During my work in clinical care I noticed an increase of youth living with HIV (YPLHIV) under clinical care which is expected to increase in time due to:

- 1) Long term survival of paediatric HIV infection; more young people who acquired HIV infection through the mother (vertical transmission) survive. Compared to 2001 there is an increase from 1.5 million children to 2.5 million children (<15 yr) living with HIV (UNAIDS, 2007). Exact numbers of YPLHIV, vertical infected are not available, but a slowly but consistent increase is shown in different countries. For example TASO (The Aids Support group Organisation of Uganda) recorded a growing population up to 5000 YPLHIV vertical infected (TASO, 2007).
- 2) There are a steady number of new infections of young people. 40% of all estimated 4.1 million new infections, are in young people (UNAIDS<sup>1</sup>, 2006).
- 3) Increased access to information and HIV testing services which is why they enrol into clinical care.

As a result I have been repeatedly approached by counselling staff for guidance on specific counselling actions how to respond effectively to this group of young people; how to disclose their HIV status and at what age, how to discuss sensitive issues like; safe sex, children wish, what to do with adherence problems etc.

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UNAIDS (2007) AIDS epidemic update: There has been a change in survival assumption estimation. As a result of this different calculation, HIV prevalence, mortality and incidence results have been lower compared to those published in previous reports. Current estimates therefore cannot be compared directly with estimates in previous reports.

The purpose of this thesis is to explore in a systematic way the counselling needs of young people and to develop a framework that can be used to design an effective response to their counselling needs.

## 2. Background information

### 2.1 Counselling as part of clinical management

There are several definitions for counselling and there are several professional backgrounds providing counselling, such as social worker, nurse, peer-educator, experienced volunteer, health educator, psychologist, who provide different levels of counselling for PLHIV. For the purpose of this paper I will combine all three definitions which are mentioned below and focus on the counselling as part of the HIV clinical management. "Part of the HIV clinical management", means a counsellor working inside the hospital, not at out clinic testing sites (VCT offices), providing follow-up counselling to YPLHIV and being a member of the HIV medical care and treatment team.

Counselling:

- The provision of support and strength to individuals, couples or families or groups by competent persons, **to help them cope** with the knowledge that they are infected with HIV. It is **an ongoing process** that allows the individuals to develop a sense of responsibility in meeting challenges posed by their infection (WHO, 2007).
- An integral with a **holistic model of health care**, in which psychological issues are recognized as **integral to patient management**. HIV and AIDS counselling has two general aims: (1) the **prevention of HIV** transmission and (2) **the support** of those affected directly and indirectly by HIV (Adler, 2001).
- A helping relationship to help a person help him/herself to cope with the prevailing situation/condition. Aims that **empowering** the infected and affected person to make **informed decision** that improve quality of life and facilitate the **balance between their rights and their responsibilities** (TASO, 2006).

The audience for these definitions can be different, WHO implements working definitions that apply to policy level, while Alders' definition applies more to health systems and the TASO definition applies more to a service delivery level. All three definitions have strengths I highlighted, which are essential in counselling. I prefer to use the definition of TASO, because it is most useable for individual counselling YPLHIV. Mentioning empowerment, responsibilities and rights promotes an active role of YPLHIV in their own health situation.

## 2.2 Young people

Young people are dealing with major challenges; develop their identities, experiment with different roles, form relationships and acquiring knowledge and skills enabling them to become productive adults. Of these young people, 85 percent live in developing countries (UNICEF, profiles in empowerment, 2003). Young people are vulnerable for risks like; unwanted pregnancy, sexual transmitted infections, alcohol and drug abuse etc. Often they are exposed to poverty, hunger, violence and fear on a daily basis, what denies them from crucial support they need to become competent adults. For example: no access to school because of displacement or financial reasons, absence of caring adults caused by death (WHO, adolescent friendly health services, 2003).

Because due to the wide age range, needs differ; a ten year old will have different needs than a twenty year old. In figure1; are some summarized general characteristics (ANECCA, 2006) that will help us to understand the issues in counselling YPLHIV.

AGE	General Characteristics
10-13 yrs	Is a time of physical and emotional change as the body matures. The body is growing fast and sexual maturation is getting established. The psyche becomes more questioning and independent. In this stage thinking is concrete and there is little ability to oversee long-term consequences of their actions. Adolescents can suffer from wide mood swings and intense feelings. They explore different roles and have an increasing need for privacy.
14-15 yrs;	The main body changes are completed. There is a development of a stronger sense of identity. Friends become very important including with opposite sex. Adolescents of this age are more able to reflect and understand abstract ideas, such as love, justice and truth. Risk behaviour peaks.
16-20 yrs	Period of personal development, having more settled ideas and opinions. The body matured and there is an increasing sense of vulnerability. There is an understanding of feelings of others and improved communication.
20-24 yrs	Young people are contributing members of society, acquiring rights to marry, to vote, drive etc. Increase of involvement in intimate relationships.

*Figure 1. Stages of adolescent development.*

## **2.3 Counselling needs related psychosocial factors, social status and stigma**

Adolescents are challenged by a lot of changes in their transition to adulthood, which is accompanied with impulsive behaviour, intense feelings including depression and risk behaviour. These behavioural factors make them more vulnerable for risk behaviour towards their health. Counsellors should assess the psychological needs and make interventions, like strategies that include increased self-esteem and confidence (Wild, 2004). Some examples:

Depression is a major problem with YPLHIV which can lead to poor health, non-adherence, unsafe sex etc. Depression can be developed or reinforced due to trauma and the amount of stress YPLHIV are dealing with. YPLHIV who are aware of their HIV status often have to cope with ill health and social stigma that is non-supportive, social disapproving attitude from their community. In some cases, YPLHIV experience the "double trauma" of coping with their own HIV status and the loss of their parents, brothers and sisters (Atwine, 2005 & Hosegood 2007).

Social stigma causes the risk that many young people cannot openly express their feelings losing family members, this complicates the mourning process. (Siegel, 1994) Such lack of open grief can lead to alienations and isolation associated with behaviour problems such as anger, guilt and depression (Doka, 1995).

This risk of developing behaviour problems like; aggression, depression, alcohol & drug abuse, due to stigma and lack of social support in YPLHIV is underlined by the study of Battles et al. (2002) They concluded that; "when social support increases, problem behaviour decreases". What leads to better health outcomes; less morbidity and increase life expectancy. Identifying counselling as part of social support, counselling can be constructed as a protective or preventive measure versus morbidity and mortality. These goals can be achieved through guidance for healthy life such as talking about emotions, making future plans and training life skills etc. (D'Angelo, 2006).

For YPLHIV infected during adolescence, disclosure of the HIV-positive test result is often the first contact with the counsellor. When adolescents are informed that they have an HIV infection, they may suffer great psychosocial and psychological stress through a fear of rejection, social stigma, disease progression, and the uncertainties associated with their future (WHO, 2003). Good clinical management requires that such issues are being managed with consistency and professionalism, characterized by trained and experienced counsellors. Individual counselling in the clinical setting can contribute to prevention and support. For example; the spread of HIV can be prevented by YPLHIV practicing safe sex. This behaviour will

be encouraged through for example: having access to knowledge, negotiating skills, high self-esteem, access to condoms and family planning methods. Counselling enables open discussion of sensitive issues where YPLHIV are confronted with such as; relationships, death, shame, stigma, guilt, disclosure etc. Such discussion which may be hampered in other settings by concern for confidentiality or fear for a judgmental response from family, peers or others in their community.

## **2.4 Counselling needs related to, social-cultural and economical factors.**

Young people are not one standard group; they live in very different circumstances what consequently has an impact on their needs. War, forced migration, orphaned, poverty, insecurity, gender, cultural norms and level of stigma are all contextual risk factors that make many YPLHIV vulnerable.

In rural South Sudan, more often than not a girl has her first child when she reaches the age of 16 and she does not go to school. For them there is no such thing as youth, as they shift quickly from child to adult (own observation, 2005). There are differences in the circumstances in which young people live that demands different counselling approaches (Dehne, 2005). For instance: the needs of this sixteen year old girl in rural Sudan, married, pregnant differs from a 16 year old living in the city with her parents, attending school and very different than a orphaned girl heading a household, caring for little brothers and sisters living in a slum.

Circumstances can give sometimes more information about the needs of young people than age. A counsellor should be aware of the social-cultural context, therefore Mkandawire (1994) suggested organizing young people in such as; those who are out-of- school, those who are refugees, those who are teenage mothers, those who live on the streets, those who are orphaned etc.

Young people working in the cities are often badly paid and work in environments that are dangerous for their health. Images have been published by UNICEF (1996) of economic exploitation such as forced labour (employed against their will by the threat of destitution, detention or violence; ILO, 2008) like; fishing industry, mining, military and commercial sex exploitation (sex tourism involving adolescents, pornography and trafficking of children for sexual purposes. Early marriage is also considered a form of sexual exploitation)

Many young people in Africa are affected by war, causing insecurity, violence, rape, forced army recruitment, civil unrest and migration; movements of refugees and internally displaced people (those displaced by conflicts as well as people displaced by natural or environmental disasters; FMO, 2008).

Gender imbalance has a major impact on girls vulnerabilities; girls are younger involved in sexual contact (often before the age of 15) and are in some countries up to 6X more likely to become infected with HIV (WHO/UNICEF, adolescents: profiles in empowerment, 2003) due to:

- Biological susceptibility of women is even stronger caused by immaturity of the genitalia, sex with older men (risk partners), asymptomatic untreated STI's. (ANNECA,2006)
- Social-cultural factors; In some countries 40% of the girls are married with an much older man, before the age of 18 without their consent due to less education, lack of power and status. Girls lack ability to insist on safer sex.
- Socio-economical changes, such as increasing urbanization, breakdown of families and decline in the importance of the family changes trends. Peers become more influential and there is less parental guidance (Dehne, 2005). There is a growing gap between age at sexual maturity and age at sexual activity among young people. This increases the risk of getting HIV due to biological susceptibility. Young women are often earlier involved in sex: Fifty percent of all abortion are done by adolescents, One-third of all first born babies are born from teenage mothers. (WHO, 2007) Maputo, Mozambique mean age was 15 of young girls first sexual intercourse (Machel, 2001), Senegal one fifth of the girls is married before 15 yrs old (UNICEF, 2003) and economically more vulnerable than men. This can be expressed in transactional sex; for school fees, food or presents (Mbugua, 2007)

Cross cutting through these issues is the violence against women. Rape, forced sex and coerced sex are an important factor in the transmission of HIV. Including abuse and exploitation (WHO, gender violence, 2006).

### **3. Problem statement**

These days it is in the main acknowledged among public health decisions makers (policy makers, researchers and health professionals) that young people do not only have health needs, need for information or need for care and medication. Young people also have rights which include the right for a healthy life. The right to health is defined by UN expert Paul Hunt as: The enjoyment of the highest attainable standard of physical, mental- and social well-being and the right to a satisfying and safe sexuality. And the right to an effective and integrated health system, encompassing health care and the underlying determinants of health, which is responsive to national and local priorities, and accessible for all. Young people have an important role in the future productivity of any country, but they are living now, at this moment. Therefore programs for youth should connect to their life and understanding of today and intend to prepare them for tomorrow (WHO, 2002).

An estimated 33.2 million people are currently living with HIV. In 2007, 40 percent of the estimated 4 million new infections were among young people. This translates into approximately 6.000 young people becoming infected with HIV every day. In this figure females account for 57 percent while males account for 43 percent. Almost two-third of all youth infected with HIV lives in Sub Saharan Africa, 3.28 million. (UNAIDS, 2007)

Regardless of the high numbers of YPLHIV, there are still insufficient resources, programs, awareness, professional knowledge, and skills towards this specific population. Consequently their needs are often overlooked. Absent or inadequate data, 24 out of the 35 countries did not have data or had insufficient data about HIV prevalence and sexual behaviour trends of young people in their country, are major constraints in responding effectively to young people's needs for clinical care and counselling services. (UNAIDS, 2007). In five African countries; Botswana, Kenya, Malawi, Zimbabwe and Cote D'Ivoire there was a decrease noticed in HIV prevalence among young people (UNAIDS, 2007). However, data was collected mainly from pregnant young women and VCT centres, this may not be representative for all young people due to the fact that pregnant young women, may have less partners or have more steady relationships than not pregnant women and we do not know enough about the young men. In other African countries like Mozambique, South Africa and Zambia there was no evidence of decrease in HIV infection levels among young people.

### **3.1 Objectives**

- Exploring in a systematic way the counselling needs of YPLHIV
- Review current responses on these needs
- Develop a framework that can be used to design an effective response to their counselling needs

## 4. Methodology

This thesis is based on findings from published as well non-published literature. It also includes information from personal experience and discussions with colleagues.

In the studies reviewed I focused on African studies as much as possible. Sometimes I included data from developed countries, when there was limited data available of African cases.

Literature was collected from

- libraries; Royal Tropical Institute (KIT) and Free University of Amsterdam (VU).
- Internet searches, using search electronic databases of: Pub med, Science direct, Medscape, and Google.
- Websites dealing with HIV/AIDS like: WHO, UNFPA, UNAIDS, UNICEF, AIDS ALLIANCE, TASO, Global Found, MSF.
- Reference lists recommended from colleagues and from obtained literature.

Key words used are: HIV /AIDS, Adolescents/ youth/ young people/ children, Africa, Counselling; Counselling models, Psychosocial support, Sexual behaviour/ Sex education/ Sexuality Sexual health, Disclosure, Parents living with HIV, Human rights.

Different agencies and literature use the terms adolescents, young people, youth, and young adults to describe different age groups 10-19, 10-24, 15-24. However they do not use the same terms to describe the same age groups consistently. For example: Orphans: 0-17 yrs (UNICEF), youth in Eaton's article is 14-35 yrs, young people described by Birungi, 10-19 yrs, UNAIDS ; adolescents 10-19 yrs, youth 15-25. Besides a lot of data do not give breakdowns by different age groups, which makes it difficult to identify adolescents separately. For example in a lot of statistic data (UNAIDS, 2007) adolescents are part of the children (< 15yrs) and part of adult study population group (>15). One of the reasons is the different markers they use in their studies (which can also change in time); biological (full grown can be at 14), legal (Zambia; adult is 21 yrs), socio-historical, behavioural and demographic (a young person in rural S. Sudan is seen as an adult at the age of 15, compare to urban city Dar-es-Salaam a girl cannot officially get married before 21).

For the purpose of my thesis, I focus on young people at large, to incorporate the age group 10-24 years old. This includes the length of period of transition from childhood to adulthood (McCauley, 1995); associated with psychical, emotional, congenital and social changes as well as awareness of sexuality and an age-specific drive to experiment with sex. (ANECCA, 2007). As early as 10 years, this is the earliest age of transition, when a child becomes an adult. And as late as 24 years, before

this age young person went through all key elements of transition and is responsible for his/her own life. This broad scope allows me to incorporate data from as many sources which is relevant since there is little data specifically targeting adolescents. I will use the term young people, youth and adolescents alternated to refer to the group 10-24 years old.

After a first glance of the reviewed papers, I came to three main areas of interest in the counselling needs of YPLHIV :

- **Disclosure of HIV status from parents to the young person**
- **Sexual health**
- **Adherence to treatment and care**

Cross cutting issues which were reported to influence all three components were: poverty, stigma, depression, gender, and violence. In the next chapters, I will describe the review I conducted on these three components.

In the analysing stage I developed a conceptual framework, what covers all three components and shows that they are interlinked. Most studies I reviewed are focusing on one of the tree components alone and models are made for these components independently. Examples of these models are; the social- behavioural model developed by Eaten (2003) for organizing factors influencing sexual health and the models of Hammami's (2004) & Icovics & Meisler (1997) organizing factors influencing adherence. As far as I know there is no integrated framework developed covering the three components disclosure, sexual health and adherence.

#### **4.1 Limitations**

Insufficient data is a major constrain to get a clear picture about HIV prevalence, sexual behaviour trends of young people in their country. Little scientific information has been published on counselling related issues.

Studies methods and tools used in the literature reviewed varied; target population cohorts (YPLHIV, parents, teachers, care givers), surveys, literature reviews.

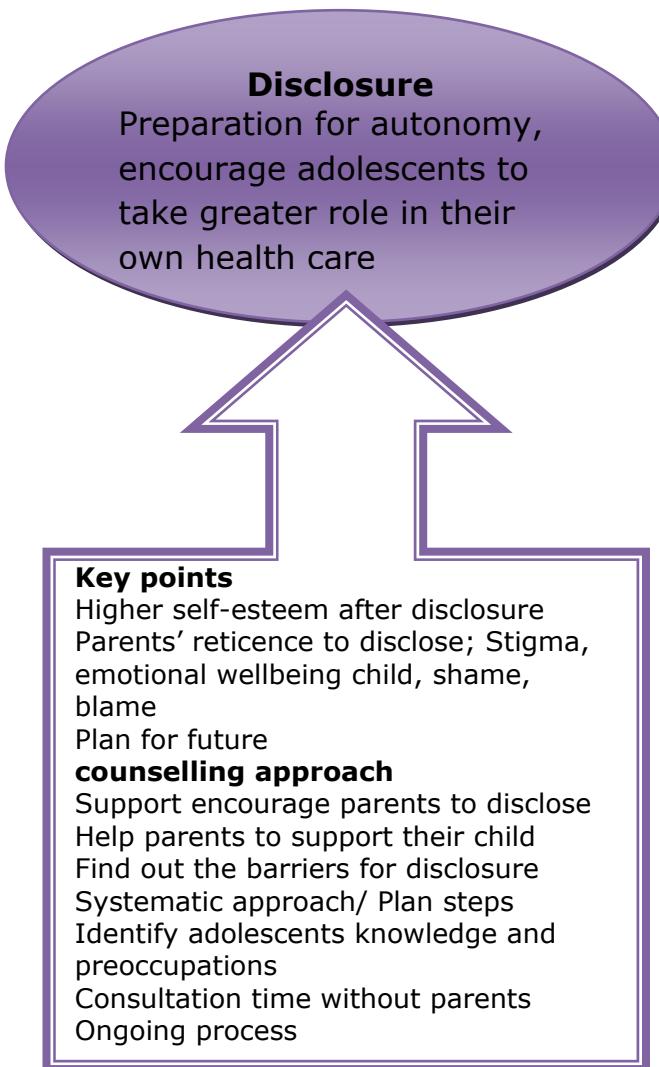
Tools used are: focus group discussions (FGD), observation, self-report interviews, literature analyses, clinical studies, audits and project evaluations.

There was a gap in methodology as I noticed that most studies are done in small cohorts of young people, certain age groups, and for a short length of time. The primary focus was on the provision of care, hardly any studies were dealing with the opinion of adolescents of the meaning of HIV/AIDS in their lives, what can be very different in many countries even

differences between urban and rural area, gender and change of perception of HIV in time.

It was hard to analyse and generalize data due to different breakdowns of age groups, inconsistent use of definitions, various measurement methods and different context variables. On the other hand it was surprising to find out that many issues and findings were similar in different contexts. For example results of behaviour studies on adherence done in cohorts from developed and developing countries had similar outcomes.

## 5. Disclosure of HIV status to the HIV infected adolescent



### 5.1 Introduction

**Encouraging self efficiency, preparing the adolescent for an independent adult life with HIV cannot be done without full disclosure. According to Claude Mellins co-director at New York-Presbyterian/Columbia hospital in New York (New York Times, 2005) about 70 percent of her young patients with HIV do not know their status by the time they are 10 or 11. These findings are raising questions like: Why do they not know? What is the benefit of telling the young person their HIV status? How? And at what age? Program managers and directors confirmed the lack of procedure, guidelines and training on this matter and counsellors reported; avoiding the questions, improvising and giving inconsistent and advice on disclosing concerns of parents (Own observation, 2007 & Rwemisisi, 2007).**

In this chapter I will describe the psychosocial complexity of disclosure; disclosure of the HIV status from parent/caretaker to the adolescent.

For this matter we can divide the YPLHIV in two categories, because transmission history may have an impact on how HIV affects a young person (WHO, 2005). For example: family situation (other family members infected), their HIV care and management (progression of HIV disease, treatment) knowledge and disclosure.

The first category is the young persons who got recently tested for HIV and received a positive HIV result (horizontal transmission). Unprotected sex or injected drug use (IDU), are in this case generally the transmission routes. Infection of young people due to IDU (10%) is a growing problem in many countries. In some countries IDU accounts for 30-80% of all reported infections (WHO, 2006). In most countries in Africa, sexual transmission is the main risk factor.

Although in some cases it is not always clear how someone became infected.

The second category is the young people who got infected through the mother and may have been under HIV care since birth; long term survival of paediatric HIV infection, who roll into their adolescence infection (vertical transmission). This counts for the majority of young adolescents. The focus in this chapter will be mainly on the second group; adolescents infected through the mother, because from my own experience and from the literature I reviewed, disclosure of HIV status to this group is a major issue parents and counsellors are struggling with.

*I turned 14 yesterday, when I found out I had HIV, now this broke my heart....the first thing that entered my head was DEATH. Till yesterday I thought the only way of receiving HIV was sexually.....but I was wrong. I received HIV through breastfeeding from my mum. From the age of 9 I was told all the medication and hospital visits were because of my weight and e...*

(Anon, 14; personal stories of YPLIH)

## 5.2 Definition of disclosure

The definition of disclosure is used in law and journalism meaning;

- to make something known what was hidden (Cambridge dictionary, 2007). Or else: giving information about vulnerabilities or discovery of information (Wikipedia, 2008). Both definitions express withholding vulnerable information on purpose.

- Chazal (2005) gives a clear explanation of HIV disclosure to children\*, by explaining disclosure she divides two types: partial and complete disclosure. Both are depending on the psychological and cognitive developmental stage and age of the children, as well by the parents' reserve to speak about HIV/AIDS.

Partial disclosure is defined as fragmented information, without speaking about the diagnose HIV/AIDS. This has been used as a concession between the obligation to give the child answers on questions and explanation about the medication, the hospital visits, what is happening in his body, and the parents' unwillingness to name the disease early.

Complete disclosure means sharing all information. This includes much more than telling the adolescent his HIV status because the child will ask many questions about transmission and disease progression, like; "How did I get It, can I still have children, will I die early?"

Although disclosure seems like a onetime moment, it should be a continuing process. Providing appropriate information about HIV/AIDS is suppose to match the age and reduces emotional distress.

### **5.3 Barriers to disclosure**

For parents the moment of disclosure is an emotional issue. Research shows that parents avoid disclosure of the HIV status for a very long time. And sometimes never tell their children. Reasons for parents reticence to disclose can be various or a combination of the following factors, summarized from different studies (Ostrom, 2006; Salter-Goldie, 2008; Kouyoumdjian, 2005; Hosegood, 2007):

- Fear their child is not ready to handle it. (fear that their child gets depressed, angry)
- Fear that their child gets stigmatized (and the rest of the family)
- Fear for rejection of their own children
- Too much to cope with; parents feel overburdened by many problems; poverty, illness of other family members, spitted families, mental illness, migration, violence etc.
- Maternal guilt
- Fear of public disclosure; child may not keep the diagnose secret, what may causes stigmatizing and discriminating attitude towards the already vulnerable family.
- Emotional burden for their child when they are asked to keep the diagnose a secret.

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\* In this chapter I will use the term child referring to the Young person in relationship with the parent (still focusing on the age group 10-24).

- Parents may not be able to deal with their own status
- They are unable to see the benefit of disclosure

## **5.4 When and Why to disclose**

The majority of the studies reviewed do not give a particular age but they all agree HIV-infected children should be informed of their status before reaching adolescence, before they become sexual active. (American Academy of Paediatrics, 1999; Instone, 2000). Besides prevention of HIV there are other reasons for disclosure around that age: adolescents will have more questions, they are ready to understand and are able to keep a secret (Leddlie, 1999).

Disclosure has psychosocial benefits as evidence shows: It is found to be positively related to, self competence, trust and decrease in problem behaviour (American Academy of Paediatrics, 1999; Haven, 2002). There is also evidence of the negative outcomes of non-disclosure. For example findings from a study in Brazil (Cesar, 2006) shows that lack of communication about HIV/AIDS creates a context of confusion about the meaning of sickness. The YPLHIV in this case did not understand the importance of medication, what resulted in increasing rebellion behaviour towards the parents and healthcare workers, refusing medication. The adolescents showed in their interview mistrust towards their parents, self stigma, and low self esteem. In comparison with the control group (children who got full disclosure of their HIV status) they scored significantly higher on risk behaviour; like unsafe sex, non-compliance and alcohol abuse. These findings underline the positive influence of full disclosure on self esteem which results in increased healthy behaviour; adherence to treatment and practising safe sex.

## **5.5 Earlier barriers in the disclosure process**

Most research about disclosure issues comes from low prevalence countries in Europe and North America done in clinical populations of infected youth. The issue been raised is how and when to disclose test results to an already diagnosed young person. Below an example of earlier barriers in the disclosing process.

Before disclosure of the HIV status, the young person must be tested. Rwemisisi (2007), talks about this issue in Uganda. In this context parents were infected with HIV but the children have not been tested (yet). Half of the 10 infected parents interviewed choose not to disclose their own status to their children (total of 51 children, ranging from 4-36 years old with a median age of 13). Four of the five parents who did disclose their own HIV status to their children, tested one child on HIV on varies ages; 1 (+), 15 (-), 27 (+), 10 (-). Parents worried that their children may be

infected, but all preferred waiting for emergence of symptoms before considering testing. Reasons given for not testing were: fear of children's emotional reaction, fear for own emotions, fear of abandonment by partner, and lack of perceived benefits from knowing their status.

This study shows the psychological burden for HIV infected parents to disclose their own status and test their children. From the interviews of the parents who choose to test their child on HIV, all reported a sense of relief and even pride despite the test result. Although all parents were afraid of shocking or shaming their children, four out of the five parents who disclosed their own status to the children reported supportive reactions from their children.

This finding underlines the importance of counselling support for HIV infected parents. Accurate information, emotional support, faith in the efficacy of treatment and services could encourage parents to test their children.

## 5.6 The role of the counsellor

The role of the counsellor should be supportive and encouraging to parents, guiding them in the disclosure process. In a study done among HIV positive mothers, Ostrom (2008) finds that mothers are interested in taking the front position in disclosing the HIV diagnose to their children for they wanted their child to hear the information from themselves. Ninety-five percentage did not regret telling their children. The results of this study, about parents' emotions and concerns around disclosure, done in America, do not much differ from the study results about parents' concerns and emotions in Uganda.

*The most difficult time for me is to understand Why & HOW & Why ME & Why MY FAMILY*

(Maria, 16; personal stories of YPLIH)

In an article written by Salter-Goldy and her team (2007), they write about their experiences with developed strategies for balancing the needs of the parents and the YPLIH by using three major stages of disclosure:

- 1) Pre-disclosure - preparation; which includes general education about HIV to the YPLHIV and building a trust bound with the parents by discussing their concerns (secrecy, stigma). This pre-disclosure preparation could also be adapted for counselling parents with HIV who didn't yet tested their children.
- 2) The disclosure itself and direct support (Being available, on the background if parents disclose to the child. or plan to do it together)

3) post disclosure (ongoing assessment, support and information and encourage the YPLHIV to take a greater responsibility regarding their own health).

Because of the stigma and secrecy associated with HIV the young people may not ask questions themselves, therefore the counsellor should be pro-active, offer information and motivate the YPLHIV to talk about their feelings. Disclosure is more than dealing with the disease and the treatment it also interlinks with other issues like; relationships, death, being orphaned, peer interactions and stigma.

Cesar E. et al. (2006) claims that disclosure is appropriate in case of new diagnosis but a wrong approach for adolescents infected through their mothers. For the reason that by waiting with disclosing of the HIV status during adolescence, the child already became aware of many aspects of the disease, and experience serious emotional suffering, disturbed self-esteem, and social separation. This has a negative influence on the psychosocial development; creates confusion, mistrust, shame, anger, growing self-stigma and increase vulnerability for risk behaviour and adherence problems to medication.

They discuss that developmental illness experience models; evidence based models used in youth suffering from long-term diseases like cancer and diabetics, seem more promising. These models focus on the intervention supporting the children and families from the beginning of the diagnose to build up an essential understanding of the changing meanings in regard of HIV/AIDS like: discussions about stigma, death of parents, importance of medication etc.

Open communication at all ages about the interrelated meanings of sickness, medication, death of parents and having HIV/AIDS eliminate the need for disclosure, and increases adherence to medication, better preparation for safer sex, less behaviour problems and more self confidence compare to adolescents (Lipson, 1994; American Academy of Paediatrics, 1999; Mellins, 2004; Wiener, 2004; Battles, 2002).

I agree with this statement. It supports my ideas for the framework which should highlight the interaction between the continuously changing medical and psychosocial issues. Also it approaches disclosure as an ongoing continues process, not a one moment event. However, stigma is a major barrier implementing this model, which makes HIV different from other diseases.

## **5.7 Discussion**

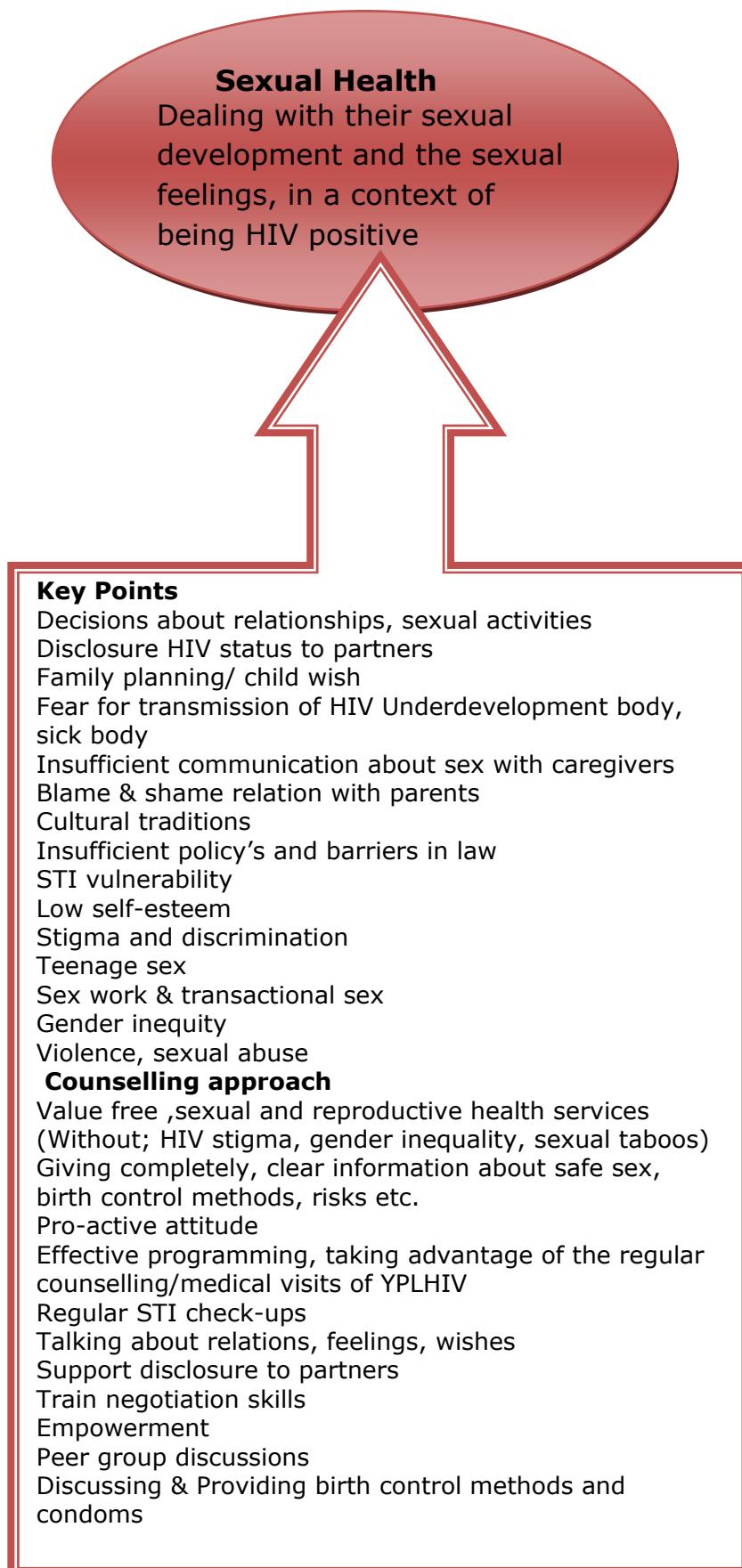
Though constrained for time, based on my literature review, I was unable to find any studies conducted from the perspective of adolescents. To me, this represents an important gap of valuable information, which is of

utmost importance for the development of counselling tools. In particular, the knowledge captured on how adolescents perceive disclosure, especially, their opinions about who is the right person to disclose their HIV status and the right time or age to hear their diagnosis, is vital for a proper counselling relationship. Many studies I found primarily focused on the parents' point of view – how they deal with disclosure, what are the reasons behind disclosing their child's HIV status, and what are the effects of disclosure on their children. While these studies from the parent's perspective provide valuable insight into the family dynamics surrounding YPLHIVs, they are not enough to provide a complete picture of the disclosure component.

From this review, I can conclude that disclosure is often a psycho-social burden for HIV positive parents. The lack of clarity and guidance for YPLHIVs' counsellors on how to balance the needs of parents and young people may jeopardize the counsellors' relationship with their patient. Counsellors need to encourage parents to prepare YPLHIVs for an independent and healthy life with HIV. In some instances, this may place the counsellor in a difficult position to not only fulfill the duties of his or her public health profession, which includes the ethical obligation to protect the rights of the young persons' right to know their status, and how to maintain familial HIV confidentiality.

During the transition to adulthood, disclosure may be the first step towards an autonomous and healthy life. As a result, open communication between counsellors and YPLHIVs and parents and YPLHIVs is indispensable. What counsellors can do is combine the knowledge of HIV as a disease, its treatment with the interrelated meanings of the disease in YPLHIVs lives. As well, we can provide relevant information of what is needed for health living, which includes adherence to medication and sexual health. Therefore, clear counselling policies and guidelines are needed for when and how to support parents to disclose the HIV status to their children, and how counsellors themselves can disclose the HIV status to young people.

## 6. Sexual health



## 6.1 Introduction

**Adolescents have sexual and reproductive health needs and concerns, of which some are related to having HIV, such as; sero-discordant relationships (one is HIV positive and the partner is not), HIV disclosure to new partners, but most are very similar to their not infected peers. (Lusti-Narasimhan, 2007).**

In this chapter I review literature to describe what the current situation is and what is known about the specific sexual and reproductive health needs of adolescents. Secondly I will organise my review findings on factors influencing sexual health by using a framework based on Badura's (1997) social learning theory.

## 6.2 Definitions of sexual health, reproductive health, sexual rights, sexuality and positive prevention.

Literature dealing with sexual health uses many different sex-related definitions. Often they are interlinked. Therefore I will start this chapter by clarifying the definitions.

**Sexual health:** "a state of physical, emotional, mental and social well-being in relation to sexuality and not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence" (international technical consultation on sexual health, 2002).

Reading this definition we should not forget that sexual health for adolescents is challenged by many factors (Shapiro K., 2007) For example; Social; boys suffer from peer pressure to have sex. Unequal power relations; girls' lack of power to negotiate about condoms. Cultural; parents do not talk about sex with their (grown-up) children; therefore there is a gap in knowledge about sexual practice and risks. Tension between individual rights (HIV status is confidential) and the rights of partners for safe sex. Economical factors; poverty can lead to transactional sex (sex for goods; food or school fees), sex work, or unsafe sex due to lack of money for condoms.

**Reproductive health:** " Within the framework of WHO's definition of health as a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity, reproductive health addresses the reproductive processes, functions and system at all stages of life. Reproductive health, therefore, implies that people are able to have

a responsible, satisfying and safe sex life and that they have the capability to reproduce and the freedom to decide if, when and how often to do so. Implicit in this are the rights of men and women to be informed of and to have access to safe, effective, affordable and acceptable methods of fertility regulation of their choice, and the right of access to appropriate health care services that will enable women to go safely through pregnancy and childbirth and provide couples with the best chance of having a healthy infant" (international technical consultation on sexual health, 2002).

**Sexual rights:** "The right of all persons, free of coercion, discrimination and violence to the highest attainable standard of sexual health, and to have access to sexual and reproductive health care services" (international technical consultation on sexual health, 2002).

**Sexuality:** "A central aspect of being human throughout life in compasses sex, gender identities and roles, sexual orientation, eroticism, intimacy and reproduction. Sexuality is experiences and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economical, political, cultural, legal, historical, religious and spiritual factors" (international technical consultation on sexual health, 2002).

**Positive prevention:** Interventions, including strategies that increase self-esteem and confidence of YPLHIV, that combine protection of personal health with avoiding HIV/STI transmission to partners. Positive prevention recognizing the right and needs of YPLHIV having sexual relationships by means of providing strategies to protect their own sexual health through prevention and treatment of STI and maintain good health through HIV treatment and care and encourage them to take responsibility to avoiding transmission of HIV to others (Burnell, 2006).

The terms sexual health and reproductive health are used frequently in many documents. For the title of this chapter, I have chosen to use sexual health because it implies a broader context than reproductive health; it also includes sexual activity not associated with reproduction.

Carrying out sexual health we have to respect the sexual rights. To start working from a sexual rights standpoint we put YPLHIV in control of their own sexual health. Which means that we are responsible that adolescents receive education and skills to practise a healthy sexual life, including protecting themselves and others when they begin to express their sexuality (UN. General Commitment No3, 2003).

## **6.3 The sexual health needs of young people living with HIV**

With the expansion of access to VCT, HIV care and treatment there is an increase need for an integrated health system that can provide both HIV and sexual and reproductive health services (Richey, 2003). YPLHIV are often living in an environment in which HIV infection is a secret and therefore impossible to talk about with their peers. Additional they are often been excluded from traditional rituals celebrating the transition to adulthood (Dago-Akribi, 2004). Therefore YPLHIV need support to cope with their sexual feelings and sexual maturity along with the medical care, because medication, disease and sexual health are often interlinked.

A study done through interviews and FGD with YPLHIV in Ivory Coast (Dago-Akribi, 2004) confirms this urgent need for information and support. The majority of the YPLHIV in this study see themselves as not being that different from their non infected peers. They are not that worried of being HIV positive (70%); they have been so, in many cases, all of their life. They are more concerned about their bodily development (shorter and lighter), because this is where the stigma was felt most, and finding a date. Worries about having sex, infecting another person with HIV or becoming pregnant were expressed by 50 percent. Generally YPLHIV desire to get married and raise a family in the future (Buringi, 2007). My colleague from Sophia Children's Hospital in Rotterdam told me during an interview that they are organizing special adolescents weekends to practice life skills; Such like make future dream lists, role plays; negotiating for condom use, disclosure and role plays putting them in the doctors or parents shoes. Besides they discussed with peers the pros and cons of disclosure and shared experience about intimate relationships. Knowledge and skills are necessary to enable them to balance rights and responsibilities, make informed decisions about their lives.

### **6.3.1 Factors associated with sexual health of YPLHIV**

Reading the study of Eaten (2003), a study done in South Africa youth, I became inspired by their model based on Bandura's (1977) Social learning theory to organize the factors influencing sexual health, influenced by factors at three levels:

- 1) Within the personal context
- 2) Within the proximal context (near environment) relationships between people and organizational environment
- 3) Within the distal context (the environment at large) culture and structural factors.

Bandura's social learning theory assumes that behaviour can be explained by the interaction of environmental and psychological factors. I will simplify this framework, and use it for organizing my review on factors influencing sexual health needs and behaviour of adolescents living with HIV and support these factors with medical information.

## Psychological factors

Within the personal context. This includes knowledge; for example how to use a condom, ways of HIV transmission. Ability; bringing the knowledge in action, having the skills to negotiate about condom use. Motivation; feeling responsible to have sex with a condom.

## Environmental factors

Within the proximal context. This means the near (social) environment. For example; communication about sex between partners, attitude of the healthcare providers towards sex and YPLHIV.

Within the distal context; This means the environment at large, including; culture aspects like traditions, norms within a society, and structural factors of society. For example; age limitations for adolescents to have access to birth control methods without parents consent.

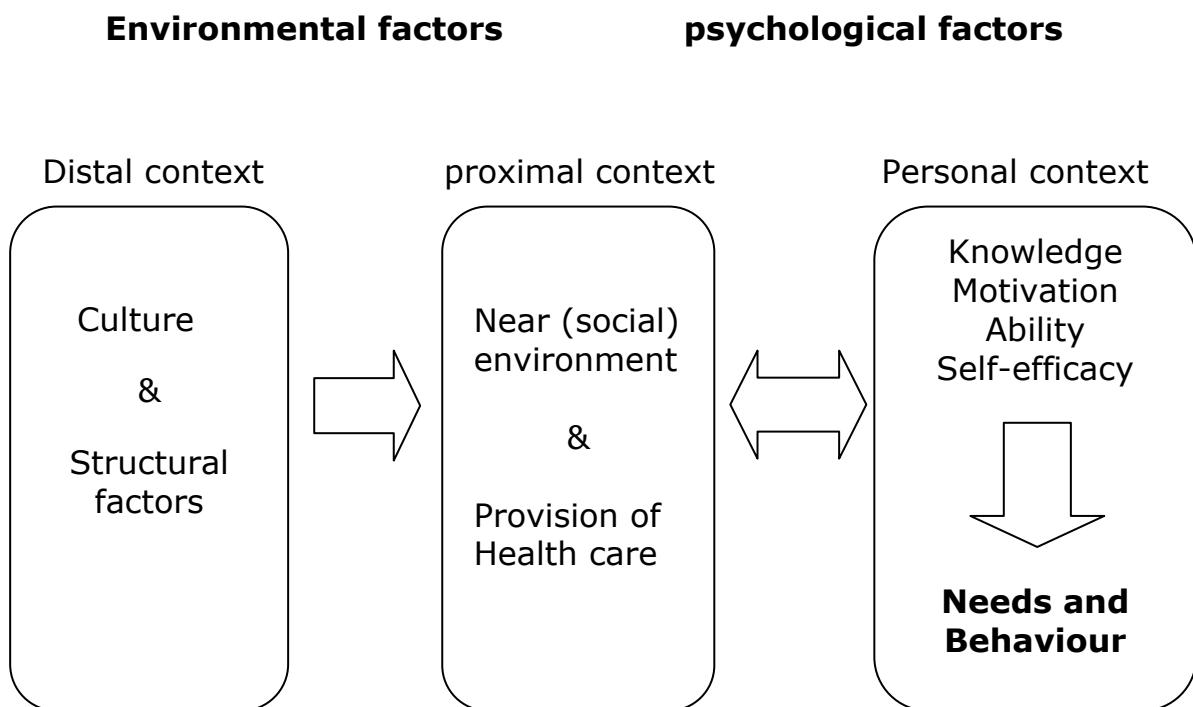


Fig.3 Framework, based on Eaten (2003), for organizing the influencing factors on sexual health needs and behaviour of Adolescents infected with HV.

### 6.3.1.1 Personal context

- Knowledge

A point raised in many articles is that for most young people in Africa sex is a taboo that cannot be discussed. Research in Burkina Faso, Senegal (Ostergard, 2004), South Africa (Rosendal Eaton, 2003), Nigeria (Moronkola, 2006) and Kenya (Mbugua, 2007) tells us that parents rarely talked with young people about sexuality and how the body function. Talking about sex is habitually limited to jokes or prohibited words. Discussing personal feelings is not usual and information about sex is hidden, fragmented in pieces within the margins of what is culturally allowed.

Because of this taboo young people are often not well informed. In many countries 30 percent of the adolescents become sexually active before the age of 15 (Exchange, 2007). Surveys in Africa showed that less than half the adolescents girls aged 15-19 knew about the ways of avoiding HIV infection. More than half the girls of this age did not know that a person who looks good could be infected with HIV (WHO, sexually transmitted infections among adolescents, 2005).

For young people with HIV this taboo is even stronger; they are expected to live without sex and when sex is discussed with parents or health providers it tends to be disapproval and on discouragement of sexual activity (Bakeera-Kitaka, 2007).

- The desire to have children

Being HIV positive and with a wish to have children is complicated due to the risk of HIV transmission to the partner, HIV transmission from mother to child and insecurity of disease progress for the PLHIV. However many YPLHIV under medical care, are in good health, feel healthy and want to have children in the nearby future for various reasons, such as:

- Childbearing in most societies plays a central role in the social life and study outcomes shows that HIV status does not press the wish to have children (Boonstra, 2006).
- The feeling to run out of time, wanting to get everything out of life as soon and much as possible, leaving something behind, has been mentioned by YPLHIV. Some studies show that YPLHIV on average are pregnant at an earlier age than their peers (Dee J, 2005).
- Wanting to be "normal" (frequently mentioned), they want the same as their peers (Cooper, 2005). In a survey done in Uganda among 732 YPLHIV, 90 percent of the boys and 87 percent of the girls expressed a strong desire to have children in the future (TASO, 2007).

Never the less, they also reported that existing HIV care programs do not seem to address these needs. YPLHIV in different countries face similar challenges; including strong pressure from family, community members and health care providers not to have children, lack of information regarding safe pregnancy and PMTCT and judgemental and unprofessional behaviour of counsellors such as pressurising PLHIV to have an abortion, not considering their own wishes. (Reis, 2005; Paiva, 2003; Bruyn, 2004; Aka Dago-Akribi, 2004; Feldman, 2002).

Concerns within a discordant couple are (if one is HIV positive and the other not): how to get pregnant safely; reducing the risk of transmitting the partner. If the man is HIV positive and the female negative, PLHIV can reduce the risk of transmission by having unprotected sex when the viral load of the men is low in combination with limiting sex to the fertile days during the woman's cycle. Other way around insemination can reduce the risk. (There is also a possibility of spermwashing; separating the sperm from the HIV virus before using for insemination, however this is very costly, especially for YPLHIV in developing countries).

Evidence (mostly from developed countries) shows that pregnancy doesn't have harmful consequence on the disease progression (Cohan D., 2003). There may be an increased risk of miscarriage and low birth weight (Abrams E.T., 2004).

Risk of mother to child transmission of HIV is less than 2% when the mother is taking ARV medication during pregnancy, safe delivery (without obstructions) and bottle milk feeding. Unfortunately, only less than 10% of pregnant PLHIV were estimated receiving PMTCT services, resulting in 1.800 children born with HIV every day! (Boonstra, 2006). Without these interventions the risk of HIV transmission ranges from 20-40% (John-Steward G., 2004).

Counsellors can have a significant impact on how YPLHIV make their choices. To make a good decision YPLHIV who are considering becoming a parent clearly need non judgmental information and counselling.

*At 13 I met my boyfriend. I told him a week after we met. He said he loved me and it didn't matter..... We want continue a normal life, kids the whole 9 yards... (Maria, personal stories YPLIH)*

- Self efficacy

Depression and poor self-esteem can lead to low self efficacy which can cause inadequacy behaviour, so also in sexual behaviour (Atwine, 2005). An example is given from a study in Uganda; where they found out that orphans whose parents died of AIDS suffer more from depression and low-self-esteem (due to stigma, poverty, lack of social support etc.) compared to adolescents who lost their parents for other reasons. These experiences of psychological distress are underlined in studies done in South Africa (Hosegood, 2007) and in Zimbabwe where 1258 AIDS orphaned young people were interviewed; a majority of these groups felt guilty (76%), worried or stressed (60), sad (63) and overwhelmed by the problems in the last month (61%) (Horizons report, 2005). These orphans are often not tested (yet) themselves for HIV, tend to have sex at an earlier age than their peers, are more vulnerable for transactional sex (sex for goods; like school fees), sex work, HIV, STI and unwanted pregnancy (Atwine, 2005).

### **6.3.1.2 Proximal context**

- Partners

YPLHIV have to deal with their sexual feelings, along with medical care, in a context where their HIV status is a secret. What makes it impossible to talk about it with friends and family. (Dago-Akribi, 2004). How does YPLHIV deal with their own needs, peer pressure, fear for stigma and avoid HIV transmission to partners?

Reasons for YPLHIV not using condoms vary from unavailability of condoms to lack of knowledge as to how to use condoms (Jones, 2006). YPLHIV may fear negotiating condom use with their partners for fear it will raise suspicion about their HIV status, causing conflict, violence or rejection by the partner.

Disclosure of HIV status; even if YPLHIV never had intercourse, they have sexual and disclosure issues; should they tell a new partner after the first date? Stigma and discrimination make the YPLHIV fearful of disclosing their status to (new) partners, being afraid of rejection or that the new partner discloses the status to others. (Nyblade, 2004).

Gender inequality; male dominated sexual relationships. Many studies report that young females are often involved in unequal power relationships. The male partner controls the sexual activity. The threat of violence or rejection prevents young girls from insisting on condom use. On the other hand in a context where male masculinity means having

unprotected sex with numerous partners young men experience peer pressure to be sexually active.

- Parents/ caregivers

Cultural and religious inhibitions hinder parents and caregivers from providing meaningful sex education. Sexual education can be even more taboo for vertically infected youth because parents infected with HIV may suffer from guilt at having acquired HIV sexually. For boys who were infected through their mothers, sex was felt as being the root of all their misfortune, they felt punished for their mothers' sexuality (Dago-Akribi, 2004). There is also a change for YPLHIV who tended to grow up overprotected, often without being told they have HIV, and many lack basic information about sexuality and reproductive health. In contrast, at the same age, those who were sexually infected suffer from stigma and discrimination at health care centre (Dago-Akribi, 2004; Ayres, 2006). Their positive HIV status has been disclosed without their consent

- Healthcare providers; organization and attitude

In many settings YPLHIV are expected not to have sexual lives. They are confronted with many barriers to access information about birth control methods.

Dual protection (condom use with another contraceptive method) is being recommended to avoid unplanned pregnancy. Even with high motives, condom use over long periods is difficult. Although data are limited about the interactions of ARV on hormonal contraceptives (such as oral contraceptives, injectables, the vaginal ring, implants) it is considered suitable (WHO 2007). Also, access to safe, legal abortions should be improved in different countries to prevent unplanned pregnancy and STI. (PLHIV are biologically more vulnerable for STI than others).

Health systems are often overcrowded and lacking competence due to shortage of healthcare workers and knowledge (often caused by the impact of AIDS itself). Besides knowledge healthcare workers need to be trained to be pro-active raising the issues and to feel comfortable talking about sex.

### **6.3.1.3. Distal context**

- Culture

The article of Rosendal Ostergaard and Samuelsen (2004) notices the gap between opinion leaders at a global level debating the importance of sexual health of adolescents and the silence around this issue at individual and relational level; adolescents, their partners and their caregivers. They describe silence of adolescents regarding sexuality and HIV towards adults and between peers as a social phenomenon; an inability and unwillingness

to talk about HIV and sexuality. We can apply this theory to YPLHIV and their counsellors; YPLHIV and counsellors are confronted with complex dilemmas, for example disclosure issues, traditional norms to get married and have children, cultural traditions, peer pressure and gender power inequity. Silence about sex might be interpreted as a form of powerless resistance characterized by: 1) uncertainty about the impact; knowing YPLHIV cannot protect themselves and others, without social and financial support. 2) repression; fear of stigma, discrimination 3) a sign of feelings of uncertainty or insecurity. 4) lack of information and training. 5) Silence of suffering; too painful to talk about. For example in case of sexual violence, shame, guilt.

Ongoing information and training in communication - and negotiating skills, broad life skills activities to empower YPLHIV, training of counsellors in communication and knowledge and more understanding of the adolescents' perceptions of sexual health will help to improve the communication about sexuality and HIV.

- Politics

Some studies notice that talking about sex is taboo because of policies; many policy makers are afraid to provide sexual health service to adolescents because they believe it will increase promiscuity. The opposite has been proven; it facilitates risk behaviour. This problem is made worse by continual gender inequalities (Boonstra, 2006).

- Structures

In a study of Garvey (2003) adolescent's needs include: skills-based training on relationships, sexuality and sexual identity, assertiveness training, negotiation skills for safe sex and information on the safety of different sexual practices. These needs are not being met in most counties. Contradictive is the number of programs in many African counties promoting abstinence only, due to the funding of PEPFAR or faith based organizations (Shapiro, 2007). Programs funded by PEPFAR are not allowed to promote or distribute condoms. Two independent reviews of PEPFAR ideology, have found little evidence that by promoting abstinence alone, prevention for HIV has been effective. There is also no proof that wide-ranging sexuality education programs encourage promiscuity but there is strong evidence that it increases condom use and communication among partners (Shapiro, 2007).

Because of law, policy and social cultural norms, there are many constraints for YPLHIV to have access to reproductive and sexual health services. Examples include a parental consent, criminalizing sex-work and sex between man, restricting service only for those married and disclosure to parents. Law reform, implementation and building a broad consensus

among healthcare workers, community and policy makers is essential to strengthen the sexual health of YPLHIV (Gruskin, 2007).

#### **6.4 Discussion**

I did not find many studies about the impact of HIV on YPLHIV 's sexual lives, which includes their feelings, emotions, desires etc. What I did find was that most studies are focused around PMTCT and young people, whereby the authors did raise the issue of sex. Apart from the PMTCT literature, I could not find much data specific on YPLHIV and HIV prevention. Of this non-PMTCT literature, they mainly described prevention programs and awareness campaigns for adolescents, in general, assuming that they are not infected with HIV. The lack of literature on HIV infected adolescent possibly demonstrates the taboo nature around YPLHIV and their sexual lives.

For a more insightful approach to YPLHIV's sexual health matters, it be helpful to collect more information about the needs of the YPLHIV from their perspective. Questions like what kind of information do they need, at what age, how and given by who? Are questions that will help us to improve YPLHIV youth friendly and tailored program.

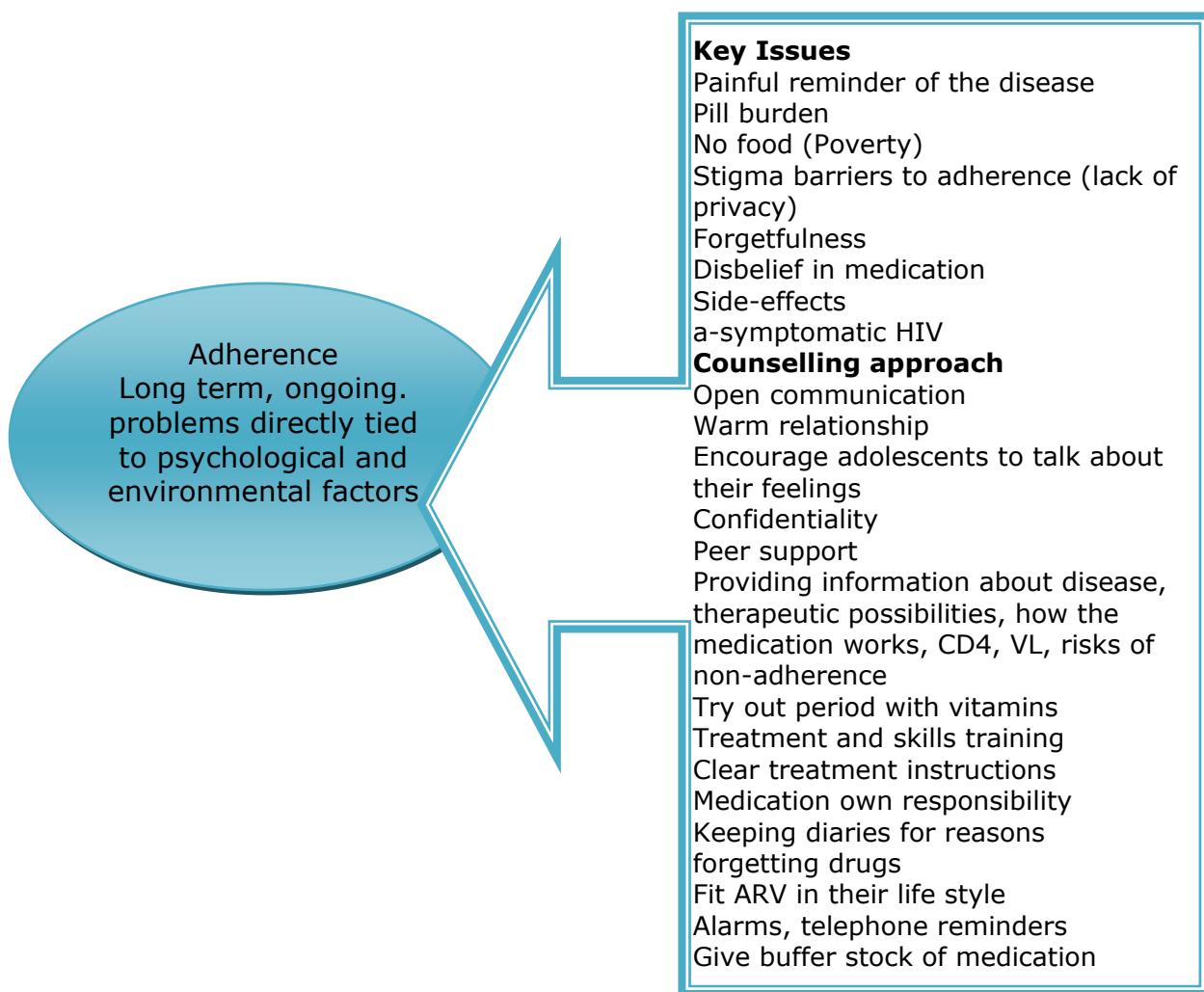
YPLHIV need psychosocial support to cope with disclose to friends and sexual partners. As well, they need support making plans for the future, including having a relationship, building a family and having children (Aka Dago-Akribi, 2004). Successful examples of programs are from Zimbabwe and Rwanda settings, which focus on the psychological and social and sexual needs of adolescents infected or affected by HIV. These programs indicate from the experience of Kids clubs (ongoing structured community based activities), kids Camps (10 days camp) and mentorship (youth-headed households receive weekly visit of an adult mentor), kids learn to talk about their feelings, relationships, life decisions regarding how to cope with grief and distress. A comparative study evaluating these interventions demonstrated that these two programs to be very successful. Attendees had greater self-confidence, a positive trend for ability to cope with difficulties in their lives, including negotiating for safe sex, disclosure issues, taking responsibilities for their treatment, in the intervention group (Horizon report, 2005).

If we want to understand sexual health needs and behaviour, we need to consider the effect of all factors described in the model. The findings illustrate an overlap in some factors, the influence they have on each other and the impact of the proximal and distal context, in particular the overwhelming effect of stigma and unequal distribution of sexual power between men and women overwhelms the personal needs and behaviour of YPLHIV. On the other hand, I can conclude that personal factors and the proximal and distal contexts interact to encourage HIV risk behaviour. In general, South African adolescents do not differ much in this matter to adolescents from other African countries.

Therefore counselors can have a significant impact on how YPLHIV determine their choices in relation to sexual and reproductive health. The knowledge and the attitudes of these counselors are very important. Several studies mentioned that healthcare workers who lack knowledge and have misconceptions about contraception may provide deter patients for taking the appropriate decisions necessary to lead a healthy, productive life. Even among counselors, who have the knowledge do not always offer it to the women who would benefit from it (Shapiro, 2007). To ensure proper treatment and care for YPLHIVs, it is vital that providers must be comfortable talking about sexual intimacy, including risky behaviours, and other sensitive issues when talking with YPLHIV. Improvements can be made by developing a counseling curriculum for adolescents to strengthen counseling training, developing life skills curriculum for YPLHIV and update providers' knowledge of sexual and reproductive health needs of ALIH by adapting counseling guidelines with family planning and sexual health counseling issues.

Meeting the sexual and reproductive health needs through integrated services for YPLHIV could make an important contribution.

## 7. Adherence to medical visits and medication



### 7.1 Introduction

**Antiretroviral therapy decreases morbidity and mortality, improves the function of the immune system and lowers the incidence of opportunistic infections (Fassinou, 2004; van Rossum, 2002). However, medication adherence is a strong predictor of therapeutic effect. Adherence level above 95% is necessary to be successful (Wiener, 2004). In practice this means that in a two times daily medication regime, from fourteen medication intake moments, 13 should be taken as prescribed.**

**Adherence of adolescents is often poor (Debra, 2005; van Dyke, 2002; Murphy, 2003) and influenced by multiple factors**

## **(forgetfulness, willingness, taste and size of medication, depression, relation with the health provider, etc.)**

It is very important for everybody involved in HIV care to understand the importance of adherence, because of the danger of drug resistance, as this is not only playing a role in the HIV control of the individual but also a larger public health problem.

ARV therapy suppresses viral replication, measured by undetectable HIV viral load (fewer than 50 copies/cc) which usually leads to improvement of the immune system (improvement of CD4 T-cell counts). The risk of developing drug resistance occur if the viral load is not reduced to these very low levels what leads to virus replication. Resistance mutations in HIV often imply cross class resistance. In other words if a patient develops resistance for a particular drug this may result in resistance for an entire class of medication, what limits future therapeutic options for the patient (APHA, 2004). Besides, second and third line medication is very expensive and often more complicated.

Transmission of drug resistant virus from patients with treatment failure is a growing problem. HIV drug resistance monitoring systems as part of the UNAIDS Drug Access Initiative have publicized the development of high levels of resistance in African countries. For example: In Uganda, resistance testing was done in patients who were receiving ART or HAART for 90 days and had a viral load of 1,000 copies/ml. 78 percentage of PLHIV treated with 3TC had evidence of resistance, 20% of those treated with AZT had resistance, and 50% of patients treated with a protease inhibitor had resistant virus; the 333 mutation, which is associated with dual AZT/3TC resistance. In Cote d'Ivoire, HIV that was resistant to AZT, was found in 43% of patients while 15% of patients were resistant to 3TC.

## **7.2 Definitions of Adherence**

- Adherence to therapy is “the extent to which a patient’s behaviour continues the agreed-upon mode of treatment under limited supervision when faced with conflicting demands, as distinguished from compliance or maintenance” (Stedman’s Medical Dictionary, 2002).
- Adherence “refers to how closely you follow a prescribed treatment regimen. It includes your willingness to start treatment and your ability to take medication exactly as directed” (The Body, 2008).

There is not one standard definition of adherence. For the purpose of this paper I summarized that adherence in this chapter refers to the behaviour of PLHIV to manage and maintain the ARV treatment as agreed upon.

To analyze the outcomes of diverse adherence studies has been difficult, given the multiple variables that have been studied, the differences in methods used (self-reporting, pill counts, biological assays) and the fact

that adherence is a continuous process involving different stages and changes (APHA, 2004). However, there is enough study material to give some examples of frequently mentioned factors associated with adherence.

### **7.3 Factors associated with adherence**

Social cognitive/-behaviour models are used in adherence studies to organize the influencing factors on adherence, for example by Hammami (2004); knowledge, ability, willingness, and by Icovics & Meisler (1997); factors related to medication, patient and healthcare provider.

For the consistency of this paper, I will use the model from chapter two, based on the social learning theory Bandura (1977). This groups the factors at three levels: within the person, within the proximal context (within the context of close relationships, relationships between two people and physical and organizational environment), within the distal context (the context surrounding the person; culture and structural factors). This covers most influence factors.

In the studies I reviewed I could not find any analysis about the interaction between the factors.

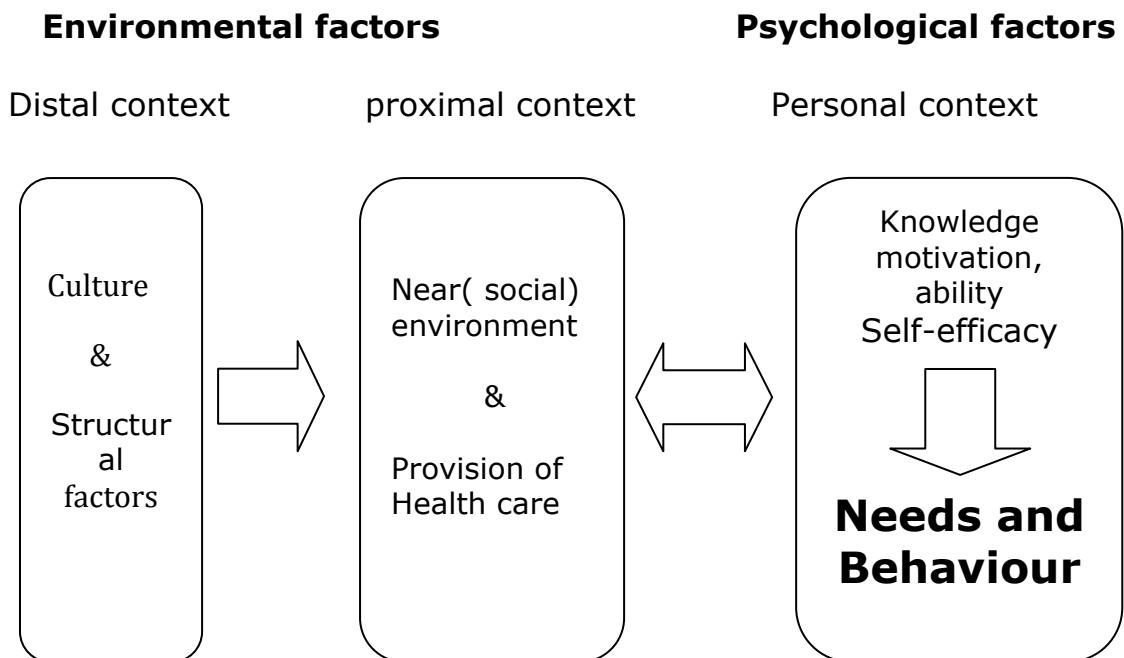
#### **Psychological factors**

Within the personal context: This includes knowledge, ability, motivation, self-efficacy beliefs; for example knowledge about disease progress and how the medication works, the ability to swallow the medication which can be influenced by taste, size and side effects of the medication.

#### **Environmental factors**

Within the proximal context. This means the near (social) environment. For example; relationship with the parents. Family disruption, attitude of the healthcare providers, but also the impact of poverty (housing, transport, availability of food )

Within the distal context; This means the environment at large, including; cultural aspects like traditions, norms within a society, and structural factors of society. For example; age limitations for adolescents to have access to treatment without parents' consent and forced migration because of war.



*Fig. 4 Framework for organizing the factors associated with adherence on three levels; distal context, proximal context and personal context.*

### 7.3.1 Personal context

- Knowledge

Education to the YPLHIV about disease progression, transmission, viral load and CD4 and knowledge about treatment; side effects (nausea, lypodystrophy, rashes), regimes (combination of tablets, time of intake, names), storage requirements is necessary for good adherence. Several studies show that education and adherence training programs has a significant improvement on ARV adherence of adolescents (Lyon, 2003; Pontali, 2005; Simoni, 2007).

Education about HIV can be challenging working in countries where most young people have had no schooling and the illiteracy rate is high. From my own experience in S. Sudan (female illiteracy 88%, WHO 2004) it took a lot of effort and time to explain, due to lack of basic anatomical knowledge, and due to the fact that pictures often were taken very literally. ("Is that army really in my body?"; picture of ARV fighting the

virus). Lack of understanding created disbelief in the diagnosis and medication.

- Motivation

Motivation be influenced negatively by different factors such as: side effects of the medication (lypodystrophy, loss of energy, neuropathy). Absence of symptoms of the HIV infection but having the burden of the medication make it, for some, hard to believe in the treatment. The amount, taste en size of the tablets, but also the regime, can influence the motivation. Therefore it is important to fit the medical regime to the life style of the young person. For example if the adolescent is in school from 9 to 5, he/she can take the medication before or after school. In another case, when it is difficult for an adolescent to remember to take the medication, it can be taken together with a meal if that was provided daily at a regular time (MSF-H; Guidance in the care of children with HIV-AIDS, 2006).

Treatment can be experienced as a painful reminder of the disease (Roberts KJ, 2000) and this will influence the motivation. Besides which, adolescents don't want to be different to their non-infected peers. Taking medication everyday reminds them of being "different". These study results support my own experience. An example; a boy P, 18 years old from Indonesia) coming for counselling had a lot of problems being adherent with his ARV medication and missed medical check-up appointments frequently. During the counselling sessions he gave as a reason for not being adherent;"I feel good, I don't want to be different than my friends or risk losing them; they are the most important thing in my life. I want to go out, dance and have a girlfriend. There is no future for me likes raising a family, getting married, why not enjoy life for this moment and die". Acceptance of the HIV diagnosis, believing that the medication is lifesaving and having future prospects will improve motivation

- Mental health

It is important to assess the mental health status of YPLHIV. Feelings of depression are common in adolescents, and this can be increased due to the impact of HIV on their lives. Their lives can be very stressful due to grief, being an orphan, poverty, hard labour, violence etc.(Debra, 2005; Lima, 2007). Depression brings down motivation for all life activities, including taking medication (Anecca, 2006). Alcohol and drug abuse are more frequent in adolescents who suffer from depression which can also result in an incorrect intake of medication and forgetfulness.

Encouraging the adolescent to talk about his feelings and treat them for depression if needed can have a positive impact on the adherence (JAMA, 2004). There are promising results from a study done in the US, randomized controlled trial in 439 adolescents, that the combination of

fluoxetine with cognitive-behavioral therapy is successful in treating adolescents with major depressive disorder.

- Forgetfulness

Although an YPLHIV can be motivated, it can be difficult to remember always to take your medication at a certain time, forgetfulness happens easily when there is a change in daily routine or a young person is playing (Bikaako-Kajura, 2006). A study done in Zimbabwe showed good results using treatment diaries, by adolescents, to find out the reasons for forgetting or not taking the medication. Strategies to improve adherence are: reminders such as alarms, telephone (mobile) and connecting medication intake to a daily activity (after breakfast/dinner, before brushing your teeth).

- Self-efficacy

For example, the belief that one is capable of taking the treatment or the belief that one is capable of having a worthwhile life with HIV. To improve self-efficacy, young people should be empowered to take responsibility for their own health. There should be clear guidelines about the steps to take making the adolescents responsible for his own drugs. Parents can support, by reminding them of medication intake and hospital appointments, but the adolescent should be responsible themselves. This is an ongoing process which takes time. Not all information can be given at once; repetition is necessary. Gradually the adolescent becomes more responsible. Include adolescents in the discussions about their health. Empower them through asking questions directly (instead of to the parent or caregiver) and obtain their full cooperation with all decisions.

### **7.3.2 Proximal context**

- Parents, caretakers

Often when there is a problem in the relationship with the parents, at whatever level, there is a problem with taking medication (Mellins, 2004). For many parents treatment is so important, therefore adolescent could use it to punish or manipulate their mothers and healthcare staff. (Akadago-Akribi, 2004; Pontali, 2005). If the adolescent is vertical infected, an opposite reaction from the parents is also possible; the parent refuse to give treatment to the child because treatment becomes a reminder of the parent's guilt. In a study done by Wrubel (2005) and Giacomet (2003) they indicated in their study that children from foster parents are more adherent than children getting treatment from their biological parents.

Fear of stigma often leads to secrecy of the HIV diagnosis. There is fear of stigma of the YPLHIV towards their peers as well as pressure from the parents for secrecy because of their fear of stigma towards the family and community. The energy spent on maintaining this secrecy can be very stressful and a barrier to taking medication (Simoni, 2006).

Family disruption, death of parents can cause poverty, grief, and loneliness, which has a negative impact on all levels. For example; poverty may result in the lack of basic needs. Loewerson (2004) mentioned in his article that many patients in need of ART have decided not to take treatment because of stigma, lack of affordable transport and time and money is needed for collecting food, clean water (Loewerson, 2004).

A study done in Uganda (Bikaako-Kajura, 2006) quoted responses from caregivers and youth considering adherence, are given. It shows increasing positive attitude (motivated, trust in medication) of adolescents towards medication if they enjoy family support, open communication and complete parental disclosure of their HIV status. Disclosure had a significant positive influence on the adherence, compared to YPLHIV who had none or partial disclosure about their HIV status. They expressed dislike, anxiety and rebelling attitude towards the medication.

- Health system factors

Services are often mentioned as being unsatisfactory; low quality, no counselling, no referral, stigmatised attitude of health workers. For example, a study on discriminatory attitude and practices in Nigeria (Reis, 2005), their finding's, interviewing 1.021 professional, was that there was a significant proportion of health workers with discriminatory behaviour and attitude towards patients with HIV/AIDS. Including denial of care (9%), breaking confidentiality to partners of patients without their consent (57%), agreed that PLHIV behaved immorally and deserved the disease (20%).

To improve the adherence of YPLHIV, services should be youth friendly, and counsellors non- judgmental and flexible. Open communication and positive question motivates, for example; "Looking at your file, I can see that when you started ARV's you improved a lot so it shows that you have been able to take them well and your CD4 increases. Now you have stopped and they have gone down but I think if you decide to start again you will be able to make them rise again. You have grown now and understand better what this is about" (MSF-H; Guidance in the care of children with HIV-AIDS, 2006). Some counsellors make a treatment contract with the adolescent to describe the responsibilities of the persons involved; patient, caretaker, counsellor so there can be no misunderstanding of who is responsible for what.

Suggestions for youth friendly services are: flexible hours, including evenings and weekends to lessen conflicts with school or work; walk in appointments, to encourage use of services; location near public transport, travel expenses being covered; assistance provided with disclosure and partner notification; active involvement of YPLHIV in program planning, operation and evaluation, culturally competent staff, appropriate information material, youthful and welcoming décor, materials and atmosphere.

### **7.3.3 Distal context**

Poverty and stigma were mentioned before in the proximal context but also in the distal context these are the most important structural prominent barriers to adherence.

- Stigma, discrimination and laws

Laws criminalizing sex-work and sex between man and age regulation to access health care without parental consent, limit young people's access to health care. For example; in most African countries a parental consent/legally appointed guardian is required before medical treatment can be given. Genrntoholtz (2004) writes in her article about South Africa that there has been no anticipation on the fact that HIV/AIDS epidemic causes large numbers of youth without parents or legal guardians, and that sexual violence (including rape of children, due to the myth that sex with a virgin will cure HIV) would impact on the life of so many young people. She gives an example of a public clinic in Soweto where four out of ten youngsters with HIV/AIDS needing treatment were orphans all below the age of fourteen; all lived in informal settings, and none had been placed in legal custody. ARV treatment but also testing is therefore almost inaccessible for those young people. In the article she is arguing for a change in the law that a caregiver (not necessary official) or a medical professional should be legally permitted to make decisions about treatment and examination, and that young people can be tested for HIV at 12 years without parental consent and even below 12 when he/she understand the implication of the test.

- Poverty

War, impact of HIV/AIDS on communities, natural disasters, can result in poverty; no work, no money for transport, lack of housing and secure living conditions; living on the streets, youth headed households, no food etc. Results of a study done in Uganda have concluded that families, who had financial problems, were often forced to interrupt treatment (Bikaako-Kajura, 2006). From my own experience in South Sudan, adherence

barriers in this context were major due to lack of infrastructure (especially during the rainy season; people from nearby villages could not reach the hospital), displacement, security, nomad culture etc.

## **7.4 Discussion**

Adolescents experience the same problems as adults to fit ARV into their life, such as fear for social stigma and disclosure, but unlike adults, they have less autonomy, privacy and mobility than adults (Marhefka, 2004). Unique factors influencing adherence for YPLHIV are the family involvement, depression, loneliness, and silence about their HIV diagnosis (Pugatch, 2005). A study done in Uganda concluded that the individual and environmental factors have a stronger influence on adherence than medication type (Bikaako-Kajura, 2006).

Most interventions given are not evidence-based. There are a lot of guidelines with suggestions for interventions, but hardly any comparative studies or any evaluations of interventions are done. The few evaluations found were mostly from the United States. These evaluations indicate intense education and training programs, which includes education about disease and treatment, skills training like how to swallow pills and how to overcome barriers, involvement in support groups, and the use of mobile phone reminder (Lyon, 2003) were proven effective.

From studies reviewed I can also conclude that disclosure, open communication and social support improves adherence (Battles and Wiener, 2002 & Bikaako-Kajura, 2006).

We must remember that adherence to ARV is a life-extending, and therefore an ongoing process. Studies show that the adherence is decreasing in time on treatment, a study done by Debra (2007) shows that the mean time to non-adherence was 12 months in adolescents on ARV in the US. Relationship problems, illness, change of work, loss of housing and many other factors can have an impact on the adherence. Therefore counsellors should access the adherence barriers continuously, and support the adolescent in finding solutions.

## **8. Discussion; the conceptual framework describing main counseling needs of YPLHIV”.**

How can we as counsellors support young people infected with HIV and prepare them for a productive adult Life?

On the basis of my own experience, shared experience of colleagues and literature review, I can conclude that there is a need for intensive, continuous, coordinated, comprehensive and caring case management and counselling of YPLHIV. This includes all main eras I described in the previous chapters; disclosure, sexual health and adherence. Special awareness must be given to the cross cutting issues like poverty, gender inequity, stigma and violence. They have an impact on all components and are main barriers for good health care (some level of food, housing, safety etc. needs to be met to make medical care and counselling effective).

Through proper support and communication about the HIV diagnosis, there is a possibility to reduce depression and feelings of isolation, while increasing the possibility of self reliance. During this process the counsellors contribution can be of great influence, because they have an ongoing relationship with the adolescent, in which they follow them through all stages of development. This relationship between adolescent and counsellor can be strengthened by continuous care through all stages of development. Furthermore, counsellors have a central position in de clinical management and act as an entry point for many issues, surrounding a YPLHIV needs for treatment and care

Based on my literature findings and personal experience, I developed a conceptual framework which includes all the three main areas of interest in the counselling needs (Figure 4). When this framework is used as a starting point/checklist for counselling YPLHIV , and/or as a guideline for training counsellors, this may strengthen health outcomes. Further it can be used as a starting point developing a measuring tool for evaluation on impact and quality of the counselling, as part of achieving a healthy life, that is physical, mental- and social well-being.

All the components in the framework are interlinked. For instance, the component of full disclosure is necessary to allow the adolescent to be responsible for his treatment, which is connected to behaviour changes like decisions to engage in safer modes of sex (another component). Likewise, reduce risk taking-encapsulated by the component safe sex- is connected to other positive behaviour changes such as adherence to treatment.

All though in the literature reviewed I found only a few studies that focus on integrated models, from my experience I believe it is essential for any holistic counselling approach, to utilize an integrated framework, which is

why I decided to create one. I realize this conceptual framework strengths comprehensiveness.

For practical purposes, this framework need to be adapted for specific situation to take in consideration different cultural and institutional specificities. In order to adapt this framework to local context, engagement of YPLHIV should be considered, which means involving YPLHIV in the designing, planning and evaluation of the framework.

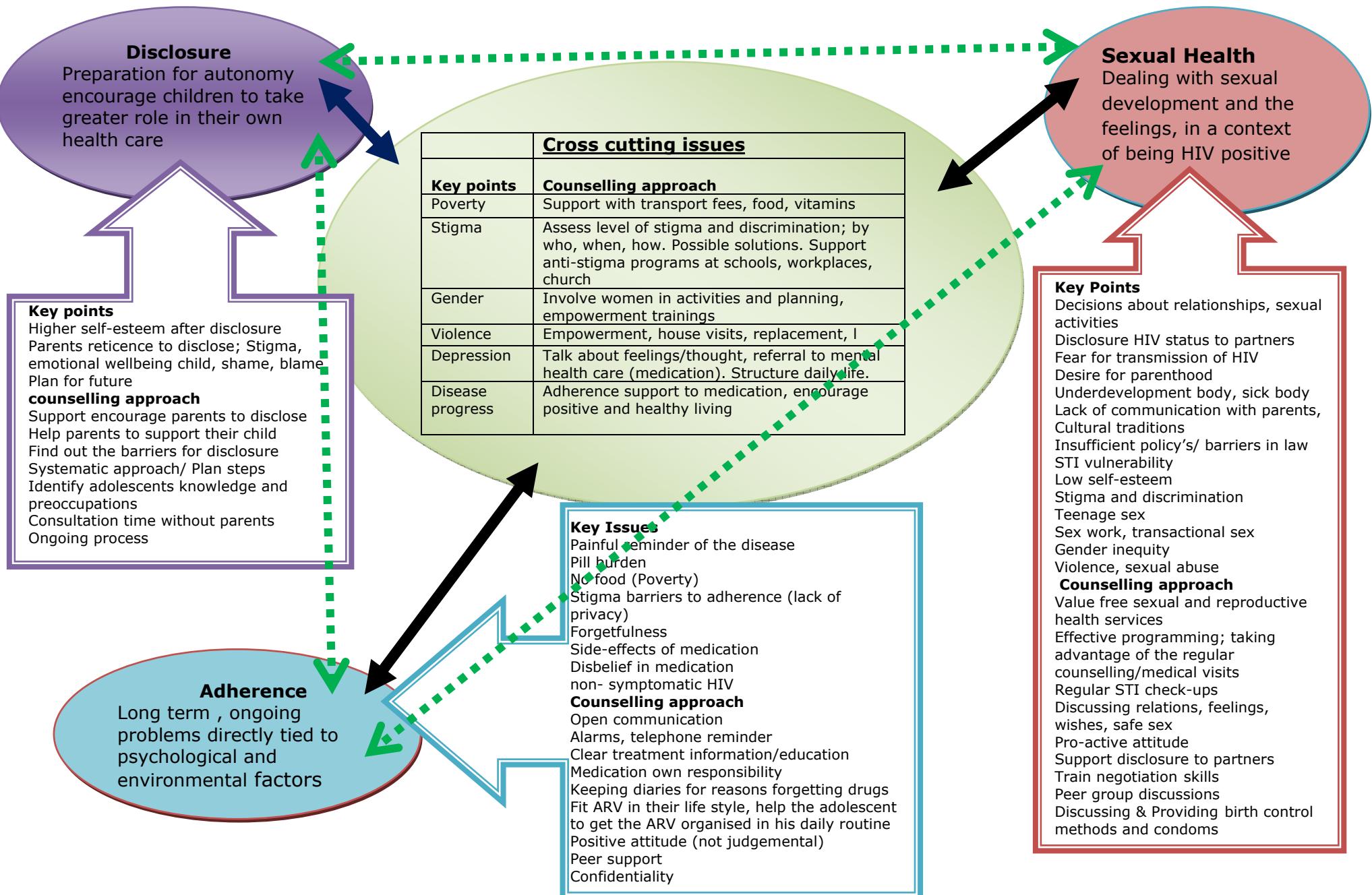


Figure 4: Conceptual framework of the main areas of interest in the counselling needs of YPLHIV (A.K. de Jong, 2008)

## **9. Conclusion and recommendations**

Writing this thesis, I discovered that my subject matter was very broad, especially since counselling as a profession covers so many issues. The broadness of subject matter and the comprehensive nature of counsellor's job, raises several important and often unaddressed questions:

What are the boundaries of a counsellor's job?

How much training and knowledge does a counsellor need to perform his or her tasks?

Within the context of a clinical management team, what are a counsellor's responsibilities?

While these answers to these questions are not the focus of my thesis, they are related to the feasibility of HIV service delivery to young people.

As a counsellor, myself, I began to doubt and reassess my findings, and wonder should I change my thesis focus? Originally, my intention was to provide some guidance and support to counsellors working with HIV and young people. These counsellors, like myself, work as part of a clinical management team, whereby, the doctor decides the medical treatment and the counsellor provides support for the patient to implement this treatment. If I were to reduce my framework components, I am convinced that I would lose an essential characteristic of my counselling job – the holistic integrated approach patient care and treatment. In my experience, this holistic integrated approach that includes disclosure, sexual health, and adherence aspects, is vital to patient care because it provides an overview of all the aspects influencing an HIV infected young person's behaviour. To neglect these aspects, would provide substandard care.

The framework covers all key components, but it can only be helpful if the counsellors have a certain level of competence. It is preferable that a counsellor has a medical background because many of the psycho-social issues are intertwined with medical care. In the Netherlands, HIV clinical counselling is primarily done by nurse specialists, nurse practitioners, or nurses with an additional degree in social science, paediatrics or mental health. These additional training is very helpful because there are challenges that come with service delivery level of HIV treatment and care, such as scaling up HIV interventions and integrating HIV services with other health care services, like family planning and tuberculosis (TB) care and management. If no such training is possible in low-income settings, provisional alternative methods need to be investigated to adequately prepare HIV counsellors to the interlinked health issues. In an overburdened health care system, it is possible that the untrained counsellor may do more harm than good. For example, without proper training, counsellors who advice young people with low empathy, coupled with a disregard for confidentiality, may end up deterring those who are in

need and want HIV counselling services. In the long run, this lack of training and professionalism may reduce the impact of HIV service delivery on HIV incidence and prevention. At the very minimum, counsellors working with adolescents infected with HIV should receive training that includes disclosure issues, child psychology, and positive HIV and STI prevention strategies for them.

A special emphasis should be given to foster skills such as empathy, sensitivity around private sexual health matters including how to ensure confidentiality of the patients. As well, consideration must be given to make counselling more youth friendly. This can be done with the active involvement of YPLHIV, to offer guidance on how to convey non-judgemental and positive attitudes, appropriate information material, when are suitable opening hours, the usefulness of walk-in appointments, and preferred location.

While training of counsellors and increased involvement of YPLHIVs are critical in designing better YPLHIV services, another crucial input is monitoring and evaluation. From my literature review, primary qualitative data from the adolescent perspective is needed to make the conceptual framework more useful. Therefore, I would recommend additional needs assessments conducted in YPLHIV populations, preferably in different settings. Furthermore, to get a better overview of the problems facing YPLHIVs and to design effective counselling interventions, there is a need for more qualitative and quantitative longitudinal research about the social and epidemiological factors influencing YPLHIV behaviour. In order to do so, I recommend research instruments and operational definitions should offer some uniformity and standardization, and the data presented should be disaggregated by age and sex to make finding results more specific and easier to compare. Without standardized research instruments and definitions, it becomes quite challenging for counsellors in different settings to make the appropriate changes to and implement holistic integrated approaches for their YPLHIV patients.

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