Clinical practice in disclosure

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Disclosure of the diagnosis / Assumptions

Many of HIV infected children or adolescents somehow know about the real diagnosis, they are confused and hesitant and gradually find refuge in a separate world where the access of adults is not allowed.

However, many times they try to open doors, to facilitate parents the disclosure, but parents are not prepared and the family roles are inverted.

They don’t understand very well the dimensions of HIV infection thus they feel anxious, conflicting, helpless and tired and have no one to talk about their concerns.

The Romanian experience

- The Romanian experience related to disclosure of the HIV diagnosis is different than others countries', considering the epidemic's particularity, namely the 1988-1990 HIV cohort or the "epidemiological accident".

- The time of disclosure depends on:
  - The child's age;
  - The Romanian law that is grounded on the family's accept to deliver a diagnosis to the child until the age of 18 years.

- The age when the HIV diagnosis was disclosed to minor patients varied between 14-18 years, most patients getting to know their HIV status at 18.

Steps followed between 2002-2008:

- Establishing the team: clinician, psychologist, social worker
- Psychological counselling of the family → in a permanent adaption crisis;
- Awareness of the family's internal and external resources in view of facing the child's refusal to accept a different diagnosis than the one delivered by the family;
- Adapting to the child's or teenager's negative reactions that included, in many cases, treatment drop-out due to loss of trust in their family and friends;
- Socio-economic assistance based on special legislation (adopted in dynamics, based on the needs of HIV affected persons- Law 584/2002).

The Romanian care system addressed to the HIV/AIDS cohort has been founded, during the last two decades, on multiple social and psychological determinants, among which:

- **The patients' age at the moment of diagnosis:**
- **Living with the biological family (YES or NO);**
- **The family's level of education;**
- **Acceptance on behalf of the society/level of discrimination;**
- **Transition from the paediatric ward to the adult ward is accepted with difficulties by the young patients;**
- **Social behaviour- the same as in the uninfected young population;**
- **ART adherence that depends entirely on the time of initiation >20 years in Romania;**
- **ART treatment- difficult to individualise and adapt during the early 1990s;**
- **Counselling on self perception, on body image and acceptance of one's status;**
- **Marital status, serodiscordant couples, unplanned pregnancies;**
- **They want children and families of their own, but some of them are not prepared for this due to their health status;**
- **Specialized family planning services.**

Current practices in disclosing an HIV diagnostic to children and teenagers

<5 years

- Communication based on the level of understanding and young age;
- Simple explanations about HIV;
- Methods to stay healthy.

6-12 years

- Talking about HIV according to the patient's age and level of understanding;
- Deliver simple facts about HIV and the human body;
- Encourage the young patient to "outsmart" the virus, by taking his/her medication and staying healthy and fit.

13-18 years

- Complex age, during which the teenager is focused on his/her body image, independency, relationships, possibly- sex life;
- Proper and correct information regarding the HIV status on behalf of the medical staff (especially the psychologist) ;
- Inclusion of the young patient in the process of treatment and care;
- Encourage active participation in his/her own treatment and care;
- Proper information on HIV transmission delivered to the teenager's family so that:
  - transmission of HIV is reduced
  - stigma is eliminated.

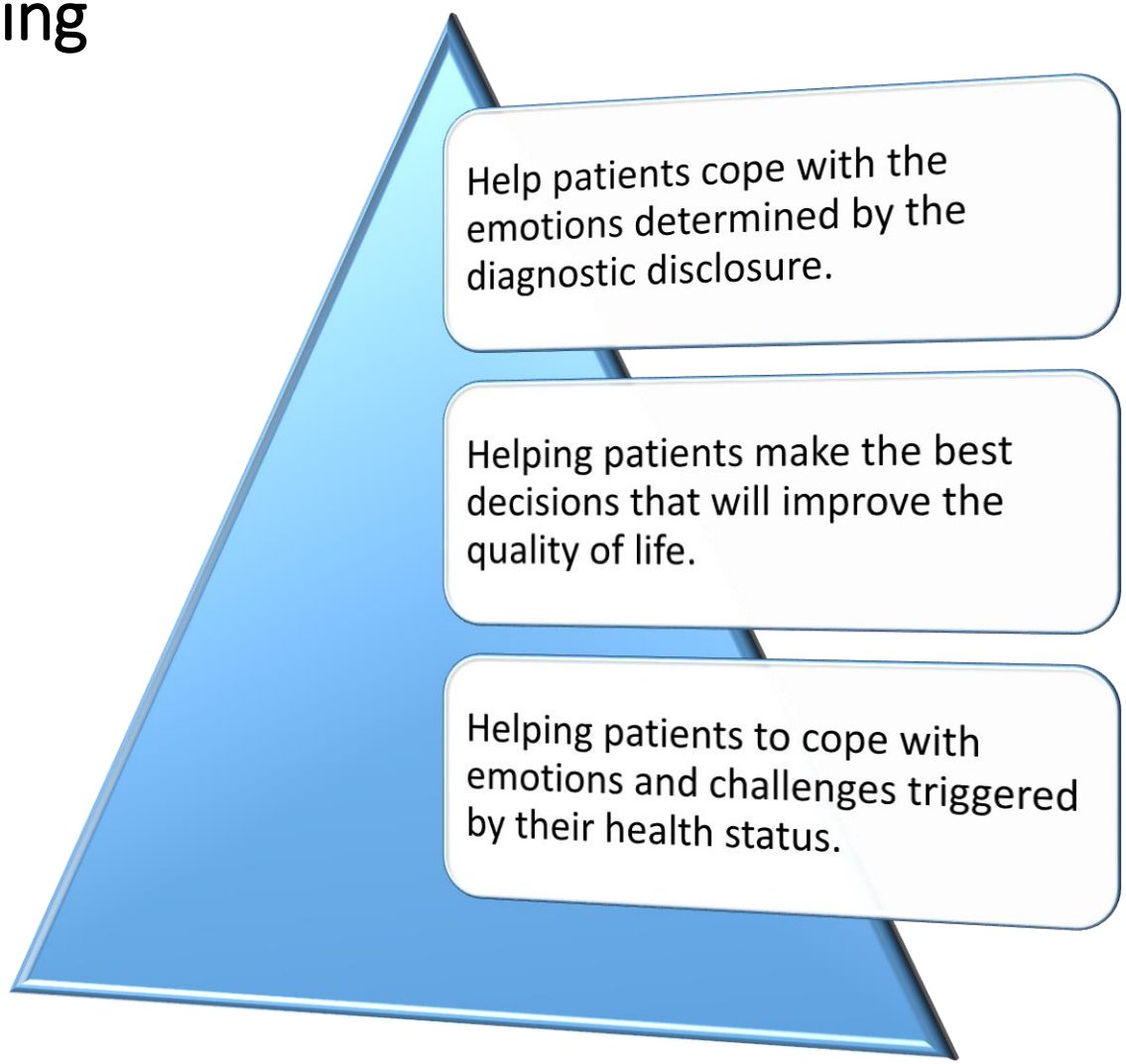
Psychological counseling of HIV positive children and teenagers entails:

- Establishing a confidence relationship with the patients in order to provide him the proper support;
- Helping children “tell their story”;
- Listening carefully to what the child says;
- Providing proper and correct data on his status;
- Assisting the child and teenager to make decisions based on complete and correct information;
- Helping the child and teenager to identify and use his skills;
- Helping the child and teenager to adopt a positive attitude towards life.

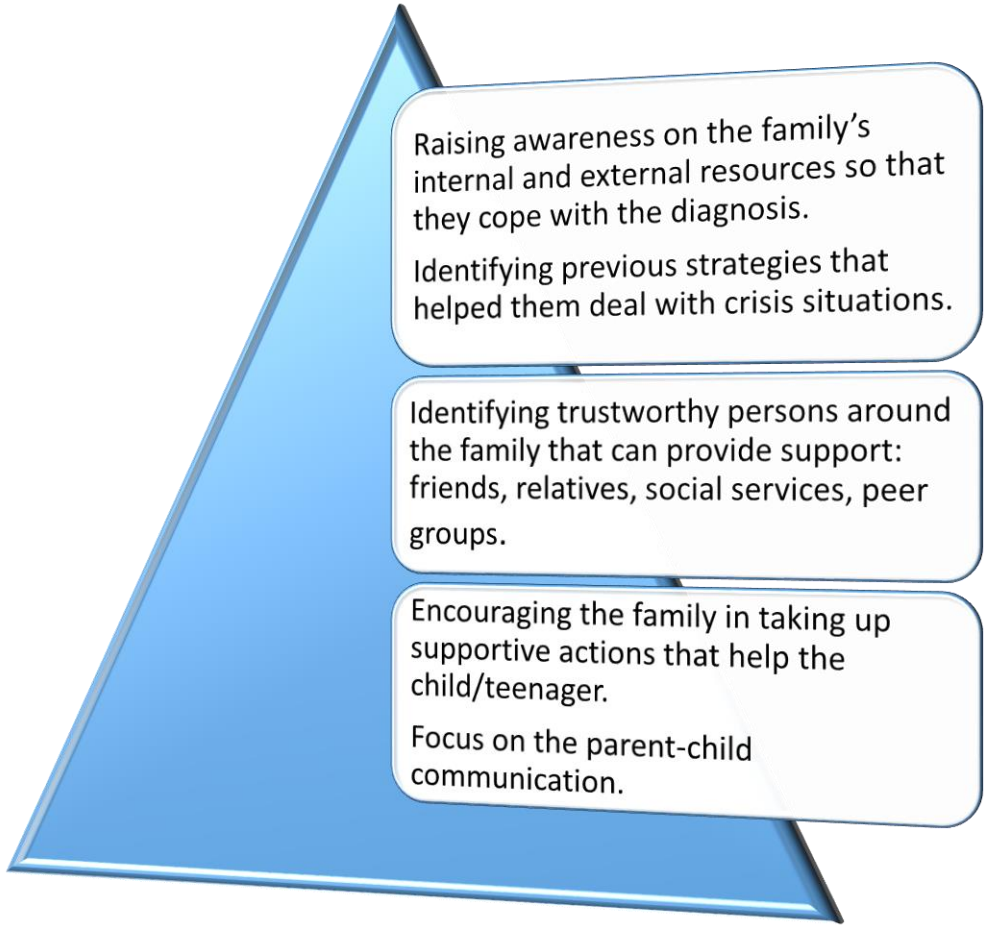
Counseling does not include:

- Taking the decisions for the child/teenager;
- Judging the child/teenager;
- Interrogating;
- Blaming;
- Making promises that can’t be kept;
- Imposing one’s own beliefs on the child/teenager;
- Contradicting the child/teenager.

Purpose of counseling



Specialized interventions in view of helping children and teenagers should include:



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