

Psychosocial Aspects of People Living with HIV/AIDS

Lenka Fabianova

*Trnava University, Faculty of Health Care and Social Work, Trnava
Slovakia*

1. Introduction

The chapter reports on psycho-social aspects of people living with HIV/AIDS and their responses. Besides identifying particular issues like fear, loss, grief, hopelessness and helplessness syndrome, guilt and self-esteem, anxiety and depression, denial, anger, aggression and suicide attempts are also identified. The objective is also to analyse the spiritual needs, discrimination and stigmatization of HIV positive people. Special remark is directed towards children, as a most vulnerable group, especially in the situation when they are orphaned and need to cope with the dead and dying.

Discussion on HIV/AIDS is in many third-world countries still accompanied by taboo, misunderstandings, shame, guilt and rejection. Culturally conditioned silence about sexuality, sexual behaviour conceals risky sexual behaviour and sexual abuse and especially sexual abuse of children. Due to cultural, religious and legal aspects of the topic is HIV/AIDS, death, sexuality, the discussion is led only by a small group of experts. Rejection or lack of awareness about HIV/AIDS significantly limits the ability of effective and decent care for HIV-positive people and their families. It is very important to speak about HIV/AIDS loudly, to speak about the feelings and reactions of people living with HIV/AIDS.

The research study rivets at psycho-social aspects of HIV/AIDS people living in Nairobi, in Kenya, who received voluntary counselling and testing services.

2. Psychosocial responses

People living with HIV/AIDS (PLWHA) feel uncertainty and they have to cope with the situation. Feelings of insecurity have its origin in the fear from the upcoming future and the people focus on their families and their job. They feel even more uncertain and are more concerned because of the quality of life and life expectancy as well the treatment's outcome and the reaction of the society. All concerns are unpredictable, and therefore they should be discussed. Above all, positive thinking and faith of is recommended.

The situation is very special for children, who have lost their family and home. The HIV positive child must react to this uncertainty and make several decisions to adapt to the current situation. Even if it seems, that the child does not react at all, it can be the very adaptation to the illness by denying it. People begin their adaptation process from the day they learnt about it. Their daily life reflects the tension between uncertainty and coping with

the situation. It is the tension, which raises a lot of *psychosocial responses* of bigger and smaller intensity.

2.1 Fear and loss

Fear of HIV/AIDS is closely associated with fear of our own death, which belongs to the most basic of fears. It is the fear which most of us are trying to fight with by constantly running away from the idea of self-termination or by inventing a series of comforting ideas. Escape and rationalization will help only to cultivate the fear of death. Above all, people have to be settled with self-extinction, with own death and thus perhaps would help those who just need help in the process of dying.

In countries with high rate of infected people are found amongst doctors and other health-care staff. PLWHVA are pushed to the margins of the society, and are isolated. They are forced to leave their job, they, lose their homes, often their family and friends. They are not given adequate health care and by the provided health care they are confronted with rejection. All of this happens because of an illness which cannot be transmitted by common contact. This attitude of professionals who are unable to overcome prejudices and refuse to provide health care is a deep misunderstanding of their mission. The reasons for this kind of handling is fear of being infected with HIV and, ultimately, fear from death itself. (Frensman, 2000)

Another aspect associated with HIV/AIDS is *a loss*. People in the developed stage of AIDS are worried because of the loss of their life, their ambitions, physical performance and potency, sexual relations, loss of their position in the society, financial stability and independence. With the increasing essential need of systematic tendency they lose their sense of privacy and control over their lives. Perhaps the most problematic issue is the loss of confidence. It may affect the future, anxiety originating from a relationship with a loved one or caregiver and negative reactions from the society.

For many people finding out about their HIV/AIDS status it is the first opportunity, to realize their mortality and psychological vulnerability. They face social isolation due to the inability to perform all daily activities which they used to do. Relationships within the family change more frequently, one loses their colleagues and the attitude of acquaintances and friends changes frequently as well. Many are afraid of the loss of memory, their concentration and ability to make decisions.

Death of a relative, who dies of a deadly disease, presents an extreme burden for each human being. He tends to surrender the pressure of the situation, which seems to be insolvable. Mental failure is accompanied by significant behaviour, changes in physiological and psychological processes in the body, which have sometimes permanent effects on health. This persistent extreme burden leads to disruption of relationships with the social environment.

2.2 Grief, hopelessness and helplessness syndrome

Grief is another strong emotion that is closely linked to the loss. The HIV/AIDS positive patients often dive into sadness because of their loss they experienced or the one they expect. Natural sadness results from unfulfilled dreams and plans and from the nearness of an inevitable end. The patient may lose the sense for relationship with parents, children, friends or life partner, as well as with other people. In connection with the impending death of a loved one there is mentioned a so called "anticipate grief", which occurs by the closest

relatives of people with long-term illness, in terms of expected death. HIV/AIDS is a fatal disease. Some people survive ten years, another few months from diagnosis. As the disease gets hold of their body, they lose control over their life. PLWHA tend not to care anymore about things which made them happy, they submit to their fate, they do not see any hope and wait for the death to come.

Hopelessness and *helplessness syndrome* includes elements of giving up and leaving. The survival mechanism includes the following:

- Painful feeling of helplessness and hopelessness face to face to the situation,
- The subjective feeling of reduced ability to deal with the situation ("it is beyond my strength"),
- Feeling of danger and decreased satisfaction from relationships with others,
- Loss of continuity of the past and future, a reduced ability to hope and trust,
- Tendency to revive and re-construct former deprivations and failures. (Simek, 1993 as cited in Bastecky, 1993)

Small children, since most of them do not know about their diagnosis, experience their state very differently. They still have a bit of life joy. In their ignorance, purity and their nativity they can spend a nice childhood, in the case, if somebody takes care of them and provides them with their basic needs as well as health care.

2.3 Guilt and self-esteem

Diagnosis of HIV/AIDS infection often brings feelings of *guilt* from the possibility of infecting the other people or from the previous way of life which led to the infection. There is also a feeling of culpability of what disease brings to people in one's own family, especially children. Previous events that caused pain or sadness of others remained unresolved; they can reoccur and cause the patient even greater feelings of wrongdoing.

People living with HIV/AIDS, who have to cope with their complicated destiny, very often lose rapidly their *self-esteem*. Rejection of colleagues, relatives and loved ones and often people can very quickly lead to loss of self-esteem and social identity, which leads to the feeling of one's own worthlessness. This condition can be enhanced by worsening of symptoms accompanying the disease, e.g. facial disfigurement, deteriorating body, loss of strength as well as loss of control over one's body.

Self-esteem is an ability to appreciate oneself and treat oneself with dignity and love. Anyone who is loved is willing to change. Human beings can grow and change throughout their life." The behaviour is the result of managing well. Coping is the expression of the level of self-evaluation. In coping the way how a person perceives oneself is reflected and one's own relationship. The problem is not the problem itself, but how one handles it. It can be deduced from that fact that the increase of one's self-esteem and self-evaluation can lead to well managing the life's situation of these children.

2.4 Anxiety disorder and depression

Feelings of anxiety in PLWHA can be detected very soon which reflects the continuous uncertainty associated with the disease. This state results from:

- short and long-term prognosis,
- risk of infection with other diseases,
- risk of infecting other people
- social, professional, familiar and sexual rejection,

- separation, isolation and physical pain,
- fear from degradation,
- fear of undignified dying and dying in pain,
- inability to change the circumstances and consequences of HIV infection
- the inability to ensure optimal health condition,
- failure of the one's close relatives to deal with the situation,
- unavailability of appropriate therapeutic procedures,
- loss of privacy and fear of disclosure of information,
- future social and sexual rejection
- sequential failure of vital functions,
- loss of physical and financial independence. (Satir, 2006)

Anxiety disorders are often accompanied by characteristic somatic, physiological, and autonomic, biochemical, endocrinal and behavioural changes. The fact is that so far there is no possibility to cure HIV infection, leading to the feeling of helplessness, loss of personal control, which may be associated with a resulting depression.

Depression can have many causes. An affected person may get the feeling that the virus takes control over his body. Just the fact that a close person died of AIDS, together with not existing the possibility of planning one owns long-term future has a negative impact on one's psychic condition.

In connection with the depressive syndrome there are several types of depression, i.e. exogenous, endogenous or neurotic depression. By the *exogenous depression* there have been reported such problems as the experience a sudden loss caused by the death of a loved one. There is expected an internal biological ability, which causes depressive psychopathology regardless of external circumstances by the so-called *endogenous depression*. By the *neurotic depression* there is an expected effect of long-term stress and frustration. This form is present in the condition of most HIV/AIDS positive orphans. The symptoms of depression are present in neurotic and anxiety disorders such as mixed anxiety depressive disorder and the disorder of adaptation. Depressive behavioural disorder is often diagnosed especially, in the childhood, within a mixed behavioural and emotional disorder. (Koutek & Kocourkova, 2003)

The prevalence of depressive disorders rates up to 40 to 55% by orphans with HIV up to the age of 10, up to 50 to 75% of adolescents who were given professional help. (Rubinstein, 2001)

Depressive syndrome in these children is associated with an extremely sad mood, slowing of psychomotor speed, sleep disturbance and suicidal thoughts. A typical symptom is presented by increased irritability, behavioural problems with elements of aggression.

2.5 Denial, anger, aggression and suicide attempts

Some people react to news about their HIV/AIDS status by denying it. For some of them, such refusal may present a constructive way to handle the shock of the diagnosis. However, if this condition persists, the denial can become unproductive, because these people refuse also the social responsibility associated with HIV positivity. This reaction is typical for children, in the case of the death on a parent.

Anger and aggression are typical aspects which accompany people in situations of bereavement. Some individuals become angry and aggressive. They are often very upset about their fate. They continuously have the feeling, that they are not treated decently and

tactfully enough. Anger can sometimes escalate into self-destruction: suicide. Aggression is one of the most frequently reported reactions in frustrating situations. In the frustrating situations, an individual may focus his anger, remorse, indignation, outrage, hostility on other people that are considered as suitable object. There is another possibility, presented by the concept of self-accusation, which the aggressive reaction are aimed at oneself. (Bratska, 2001)

There is an increased risk of *suicidal attempts* for HIV positive people. They may see the suicide as a way out from pain and difficult situation, out of their shame and grief for their loved ones.

Suicide may be active (e. g, causing a fatal injury) or passive (planning or preparation of such a situation, which could result in fatal complications of HIV/AIDS). (Yelding, 1990)

HIV positivity presents a risk factor, particularly amongst adolescents. There are significant complications in the development of personality in adolescence age and it can be perceived as an unacceptable problem. Suicidal behaviour is associated with a wide range of mental disorders, HIV positive children and adolescents suffer primarily from depression.

3. Spiritual aspects

A situation in which one must face loneliness, loss of control and death, can lead to *spiritual questions* and seeking assistance in the faith. Concepts such as sin, guilt, forgiveness, reconciliation and tackle, may become subjects of spiritual and religious discussions. Similar moments become topical for many HIV positive patients. The cause of many emotional and psychic problems is presented by various infections, difficult situations and difficult periods of exhaustion. Even greater impact on the HIV positive person, however, presents the rejection of one's own family or friends and one is separated from the society and pushed aside.

Many people believe that only religious people have spiritual needs. But non-believers begin to deal with questions about the meaning of one's own life exactly during their illness and when they suffer. Everybody needs to find out, that the life has had had and still have some meaning. Everybody needs to deal with things, which are hard for him and which are unchangeable.

Sometimes the suffering radically changes the actual life and it often affects moral values of people. (Dobrikova, 2005)

When talking about the spirituality of children, many may argue that children's ability of abstract thinking needed for understanding of religion is not developed and that they cannot understand the concept of God Despite the developmental perspective that generally criticizes the view of children's spirituality, we must acknowledge the fact that children are the pilgrims, who are trying to the meaning of world and the meaning of their own life.

Of course, the initial views of spiritual values and experiences children may experience in different ways, depending on whether they are raised in religious families, if they regularly experience religious rituals and to what extent are they raised in a religious way. Every child explains these events introspectively to oneself. It is perhaps not so important, at what age, the child begins to understand and express spirituality, but it is important to create room for a child's questions and to supply her or him with the answers. (Dane & Levine, 2002)

Any death, especially death of a parent brings many spiritual issues. The child asks: "Why did he / she die?" "Why is this happening to me?" "Who will take care of me?" All these

questions imply the spiritual dimension. These questions are very real for children whose parents died of AIDS but they are suppressed from fear and because of the stigma associated with HIV positivity.

The child can have trouble finding help and support from peers and adults because there is a mysterious silence about everything, no one wants to talk about the death of his close relative or what so more, to talk about HIV / AIDS. The child feels fear and shame to share his feelings with others, or it makes the situation deteriorate. If somebody belongs to the Christian faith, who perceives AIDS as a consequence of the moral bankruptcy of the individual, it does not make the situation easier. While the church preaches to love sinners, at the same time it condemns the sin. From this perspective, PLHWA are responsible for their conditions, but they deserve compassion and assistance. The child could eventually find their harbour in the church, even if it offers a very mixed or negative image of people with HIV / AIDS. This point of view complicates the child's spiritual interpretation. All life situations the child had already had to go through, such as the death of a parent, poverty, deprivation, sniffing the glue, violence, make the spiritual survival complicated and they burden his purity. HIV positivity present chaos, uncertainty, unpredictability to the child, it causes lot of problems and on-going struggle. (Shorter & Onyancha, 1998)

The spirituality and religion can present a complicated issue. It is necessary to have the child explained his own responsibility for loss, death, disease, so that the child does not perceive these as his own sins. It is necessary to give them room, time and assistance in this direction. Religious rituals, in which the child can take part, can help and be one of the most significant is at the funeral. The child itself has to make the decision, whether he wants to be part of it or nor. Memorial mass, private rituals, lightning the candles, prayer, all of that can be a part of the therapy for the child.

4. Discrimination and stigmatization

Article 1 of the Universal Declaration of Human Rights speaks of the equality of all people. Right for health, which is enshrined in the status of WHO, i.e. the highest level of physical, mental and social well-being, reminds us all that HIV-infected people have the same right for equal treatment as well as the right to protect their civil, political, economic, social and cultural rights as all other members of human society do. The issue of human rights is given a priority position in the programs of such institutions as Council of Europe, UNICEF and many others. The next evidence of this priority is presented by the creation of the United Nations Program for the Fight against HIV/AIDS (UNAIDS), by a combination of powers and funding of six institutions of UNO.

The most inexorable form of discrimination against people with HIV/AIDS is that of popular or institutionalized retribution. This can go for mere avoidance to the refusal of medical treatment, imprisonment, ostracization or even physical assault against high-risk groups, such as gay people, commercial sex-workers, and intravenous drug users. All these forms of discrimination have been recorded in different parts of the world. A frequent prejudice is that people living with HIV/AIDS should be subject to legal controls or quarantined in order to stop the spread groups should be compulsorily tested for HIV. Such beliefs have influenced the enacting of laws, especially those relating to immigration and emigration. Such laws have, in turn, helped to define public attitudes towards those living with AIDS. (Shorter & Onyancha 1998)

In the current phase of the unstoppable progress of HIV/AIDS pandemic and development of the fight against HIV/AIDS, is a systematic effort needed more than ever. Effort, which could counteract with the spreading of infection from the position of respecting human rights, in particular in these areas:

- Wide access to modern medicines and clarifying of their correct application. Treatment success depends on a motivated and diligent cooperation with the physician. As a broad and comprehensive approach a wide-spread, not-discriminating use of drug prophylaxis is understood and is indicated in cooperation with health insurance,
- Extension of expert advising, testing and other activities related to prevention,
- Informational and educational campaigns which lead to increased tolerance of the society towards the affected population and to elimination of the constant re-occurring social stigma,
- Improvement of legislation protecting privacy and preventing discrimination. (Mayer, 1999)

HIV/AIDS positive individuals have the same right to protect their rights as other members of the society. They have the right to work, have a job, right to obtain education, the right to attend a school, right for the social security and assistance, right for the protection against inhuman or degrading treatment or punishment. The most important and recognized principle is, that people or groups of people, who are at a higher risk of getting infected, in particular those, who are already infected or those who develop AIDS will not be discriminated.

Probably the most common reason for the discrimination is an irrational fear of and fear from contact with people infected by HIV/AIDS, fear from infection and from, the possible consequences of the disease, suffering and death. Based on ignorance, all of these factors cause discrimination tendency. It is also subconscious, but irrational. A significant percentage of discriminatory attitudes of the population are related to the fundamental ignorance, about HIV transmission routes. That is another reason for the necessary repetition of targeted informational and educational campaigns.

Another reason for discrimination is usually called *pre-existing discrimination*, i.e. disagreement or disapproval with the existence of certain opposition groups. Only few common people are aware that in this case, the discrimination itself presents a risk of further spreading infection. It is necessary to combat the discrimination as such, in all its forms and manifestations. Frequently, the reasons for this are certain social manifestations originating from certain professional attitudes. They usually manifest themselves in condemning people with certain lifestyle or still uncertain attitudes of some churches, based on intolerance. Daily preventive practice is therefore necessary, so that new social and other moments can be steadily implemented into plans of prevention to weaken the mentioned attitudes. (Mayer, 1999)

One group which has experienced overriding forms of discrimination is that of women. All over the world there is evidence that women have been coerced or pressured to have abortions or be sterilized because they are HIV-positive. Doctors have even exaggerated the rate of perinatal transmission of HIV to infants in order to convince women to terminate a pregnancy. Others have refused outright to offer reproductive health services to such women. In health care, there are reports of a refusal to treat HIV-positive patients and of discrimination against health workers who are HIV-positive. Health workers are also compromised because of their physical closeness to AIDS patients. Discrimination has occurred in the provision of funeral services. This includes the refusal to handle bodies of

people known or suspected to be HIV-positive, the imposition of an extra fee, etc. (Shorter & Onyancha 1998)

The most common forms of discrimination experienced by people living with HIV/AIDS, we could include:

- condemnation, isolation,
- ignoring or avoiding people with HIV/AIDS, because a person does not know how to handle an unpleasant situation during the meeting,
- refusal of care,
- unwillingness to disclose HIV status to someone other because of the fear from discrimination,
- inability to discuss the sexual behaviour, personal preferences and desires, as these topics are accompanied by unpleasant feelings of shame or guilt,
- refusal or neglecting of discussion about the guidance by the risk behaviour and HIV prevention,
- inability and unwillingness to accept a person with AIDS and their families with understanding and without prejudices,

One apparent consequence of discrimination for people living with AIDS is the break-up of families. On learning that their wives are HIV-positive, many husbands desert them and marry other women. This not only deprives women of the love and care due from their spouses, but also promotes the spread of the disease via their husbands. Another shocking phenomenon is the extent to which infants who are HIV-positive are abandoned in hospitals by their parents. Parents, who cannot face up to the dilemma which the epidemic poses for their children, often abandon their parental responsibility altogether. Various organizations have been set up to deal with the problem, but the battle is still far from being won. Most foster homes are reluctant to take HIV-positive children, claiming that they do not have the resources to care for them. In some cases, even members of extended families are reluctant to care for HIV/AIDS members for fear of being infected. In such cases, these people are left lonely and desperate. ((Shorter & Onyancha 1998)

Discrimination is closely linked with the concept of *stigma*. Stigma can be distinguished into two basic types. The first category is called *felt stigma*, which distinguishes the individual sensitivity to the potential of negative attitudes and fear of discrimination based on HIV status. Repeated or *enacted stigma* presents a real discrimination experience based on HIV status. For example, an individual may intentionally avoid a HIV test because of the fear that the community would react negatively to any disclosure of its positivity. Should his positivity be disclosed, the patient fears that he would be rejected from the community by his family as well.

5. Children as the most vulnerable group

Children infected with HIV live almost their whole life with some fear. Many of them first experience fear from loss of their parents. Many of them have to watch by, as one or both parents suffer from the AIDS, and they take care of them and spend time with them during the process of dying. After death of one of the parents many of the children must deal with other fears and concerns. In many cases the children guess, that they are sick themselves, too and this fact results in other further concerns. They are constantly confronted with the burden of evidence, which they carry with them for the rest of their life. Some of them will experience a hospitalization associated with many changes, which have to be adapted. If

they happen to realize, that their life will not last very long, they are confronted with the fear from their own death.

Children, in particular, suffer from grief after losing their parents, when confronted with the fact that one becomes an orphan. Many of them never experienced, what it means to have a family. They may also suffer from grief, which is transmitted to them from their loved ones, family members and friends. People, who take care of these children and provide them with daily support and assistance, can observe a continual comedown of these children.

Children lose their hope when they have to deal with the loss of their parents, siblings or other relatives. And these are the greatest wounds none of which are ever healed.

If their status becomes known to others e.g. peers, family members and the community it can have a very bad impact on the further development of a child. The child often gets isolated; he or she is excluded by the classmates, in many cases even by their own family members. It is therefore necessary to talk about HIV / AIDS in all its aspects and not make it a taboo topic. It has to be discussed among at all the groups of the society and HIV positive people have to be showed, how to live with this disease.

Many children blame themselves from causing the disease of their parents and dying. They feel responsible for events that occurred. They blame themselves of not being caring enough, that they were evil and that is the reason for their parents' death. They feel very guilty.

The feeling of guilt, anxiety and their fears can be so strong, which can lead to depression. It happens very seldom, but still, that a child may attempt to commit a suicide. An attempt to commit a suicide can be according to Spitz affected by several elements, such as:

- The concept of death is usually corresponds with age and mental maturity of a child. Even a seven-year old child is able to express the wish that it would rather like to be dead, since his life is meaningless,
- The perception of oneself, the consciousness of one's own value. Feelings of guilt, lack of adequate self-appreciation, excessive underestimation from the others, unfavourable comparisons with others - lead to the idea of making an end to all of it. Feelings and expressions of depression begin to appear, such as, loss of social interest, feelings of sadness and emptiness, eating and sleep disorders, decreased activity, feelings of loneliness, stubbornness.
- Familiar environment of the child has great impact on him, the idea of a complete family, the fact of experiencing the death of the parents; all of this plays a significant role,
- Form of discrimination is the child experiencing, if it is stigmatized and isolated, what are the social ties. (Spitze, 1991 as cited in Brabec, 1991)

A specific situation is on in which children living with HIV/AIDS are a most vulnerable group. There are some specific psycho-social issues, counsellors have to deal with. Most of them are experiencing fear, anxiety, lethargy and quietude. Some children are segregated by the guardians, who fear their children might also contract the virus when they will play together, sleep together or eating together by sharing the utensils. Some parents have feared to send their children to school; they don't go to school, as some schools don't allow them to play with the rest. There is also high risk, possibility of dropping from school due to ill health. They don't get well balanced food; there is poor access to medication. Some HIV/AIDS positive children already lost their parents; some older children take on the roles of the parents.

They are experiencing stigma and discrimination as well as the adults, even more. Counselling psychologists believe that the age when a child can know the HIV status varies. What is important is the amount of build-up activities related to the disclosure either of the child's status or of a very close relative. The older the child the better and easier it is thought, but this doesn't guarantee easiness with status disclosure.

The care of HIV/AIDS suffering children requires high quality synchronisation and combination of health and social services with taking account on special needs these children. The main goal is to lengthen and to improve children live and life of their families. (Botek et al., 2005)

Every child is unique in his own way and has special attributes that must be honoured, respected and used carefully. They need help to create the necessary support they need to live with the reality about disclosure of their or other significant people's status in their lives. They are encouraged through their parents/guardians to join support groups that help to reduce the impact of the shocks they receive.

5.1 Psycho-social aspect of children living in developing country, whose parents died due to HIV/AIDS

Organizations such as WHO and UNICEF had assumed that the number of orphans will double every 6 to 9 months and in many developing countries it happened. Many of them stay on the street and they become victims of discrimination. Orphans, who live on the street, so called "street-children," become often victims of sexual abuse, and in the case, they did not get infected, it can happen very quickly.

The majority of them suffer from lack of proper care and supervision. Most of them live with their relatives or grandparents, who themselves suffer from a lack of income and have a problem and take care of themselves. Some of them start to run their own household and take care of their younger siblings. For example 1996 in Kenya, up to 58% of all orphans who survive were aged from 10 to 14 years, 19% are 15 or more. Up to 58% of orphans are dependent on their relatives or on the community to be able to survive. 32% of the orphans depend on the sale of vegetables, roasted corn or collection of paper, and iron for living and 10% survive only thanks to begging. (Shorter & Onyancha, 1998)

In the research study from Nairobi in Kenya in 2008 shows, that nearly 20% of street children were complete orphans, 10% had only their fathers and 59% only their mothers alive. These survey results show that most street children have single parents, predominantly the mother. (Fabianova et.al, 2010)

Children whose parents died of AIDS are discriminated against, the society often treats them as potential carriers of HIV virus and they are expected to lead a promiscuous life following the way of life of their parents. These children live in real poverty, in an extraordinary situation including the lack of basic resources and lack of access to services, which would help them to resolve the difficult situation. The wider family usually takes care of orphans, but the rapid increase of the number of orphans needing care requires extended possibility apart from family. In many cases, the orphans are taken care of by their grandparents, sometimes elder children take care of their younger siblings, and surprisingly, their age is about 10 to 12. In some cases, children live completely outside of the family structure and very often on the street.

The death of one or of both parents, who died of AIDS triggers many sociological, economic and psychological changes for the orphaned child. Orphans are exposed to a large number of problems, such as malnutrition which is associated with a lack of food or poor position to

occupy in the familiar environment. Their educational opportunities are limited due to domestic responsibilities, or lack of funds to purchase books and uniforms. Suffer physical and psychological support and protection, as well as lack of parental attention and their absence. Orphans - girls are more vulnerable because of sexual abuse and are at greater risk of HIV transmission and continuing spreading of infection. Sometimes orphaned boys are rejected more often than their sisters because the girls are more useful in the household.

The situation gets worse, when the orphans have to live on the street and they are exposed to the danger of abuse. Street-girls in their early adolescent age were tested for a small study of Undugu association, and the outcome showed, that more than one quarter is HIV positive. Some of the tested girls suffered from syphilis, gonorrhoea or some other infections. (Guest, 2001)

The social situation of each orphaned child is always difficult and it can have long-lasting and traumatic effects. The situation of AIDS orphans presents some more specific problems which are specific only for this type of group of children, It is necessary to eliminate and to get to know, the stigma associated with AIDS which interfered with the lives of many orphans and it is necessary to satisfy the basic needs of children using the practical interventional programs. There are slight socio-economic differences amongst the orphans in Kenya, even though the majority of them live in extreme poverty. HIV/AIDS, combined with the problem of poverty presents a significant stress for the traditional structure of assistance, as well as for the complete set-up of the household. Satisfaction of all the demands of the family plays a priority role for the orphans despite of significant limitation of financial resources. It is very difficult to discuss the long-term consequences of pandemics, but it is clear, that adaptability, power and the survival of a Kenyan family is seriously threatened in the social system.

In the developing counties the services for HIV/AIDS children are often provided by professionals coming from western countries. Most of the approaches, used in Europe, are based on local traditions, religion, and mentality and so on. Using of these approaches in other parts of the world can cause problems, or, can cause their non-efficiency. There is strong necessity to adapt the European standards of care to local standards and search for appropriate range of services. An adaptation of educational and therapeutic approaches is necessary due to significant differences, in upbringing, such as the use of punishments, and so on. (Botek & Kovalcikova, 2008)

5.1.1 Psycho-social aspects of children living in developing country, who have lost their father due to HIV/AIDS

A majority of men, who are also fathers become infected and die before their wives. Along with the death of the father, who presents the male element of the family, the family loses the social and physical protection associated with male authority. A woman as a head of the family in the developing countries does not have any right of property inheritance, because the relationships to her husband's family are weakened. The mother has to manage her time to be a parent and to satisfy the needs of the family. Children usually help to run the household. In rural areas children work on family farms in order to help the family to survive.

These households often bear an additional burden, the commitment to pay for the treatment and care of the dead father; the family must deal with the loss of income, which was supplied by him. Children usually stop going to school and are forced to look for a job, which is depressing for them. They are exposed to abuse as workers, who work for the

minimum wage and it does not cover their basic need at all. This fact strengthens the difficult situation and the family sinks into poverty.

In the developing countries in the majority of families, in which the father dies, the widow after the funeral rites returns from the countryside, where he was buried, to the city. These Kenyan widows, if not previously employed, often begin with to sell smuggled good, such as illegal alcohol to keep their household supplied with needed stuff. The children usually help or try to help in other ways to replace the father. In some cases they are forced to sell their body, because the income of the mother is insufficient. In such cases children stay with their grandparents from the mother's side in the country, while she tries to make some money in the city. Women leave their children primarily because of economic reasons. If the mother comes from a monogamous relationship, children usually stay with their grandparents from her husband's side. If a widow comes from a polygamous relationship, children are often taken care of by the first wife, who usually becomes head of the family after the death of her husband. In Kenya children living with grandparents from the father's side suffer from lack of care, and so they tend to find the grandparents of the mother's side. It is still difficult for the children to live with the uncle, because they are often perceived by their relatives as a potential candidate for the property inheritance and they are abused mainly for work. But reality shows that orphans are traditionally excluded from old-parental inheritance.

The impact of negative living conditions is significant and influences the child's mental state. We can talk of *psychological deprivation* if the child does not have sufficient amount of stimuli and such living conditions, which are necessary for its satisfaction of basic needs and healthy emotional development.

We can thus conclude that a child who has lost his father experiences this situation to its full extent. The amount of stressful situations increases and they often overlap. Death of a parent is a frustrating situation for each child and threatens its existence. It becomes a long-term stress factor in his life. The loss of the mother is equally stressing for the child.

5.1.2 Psycho-social aspect of children living in developing country, who have lost their mother due to HIV/AIDS

Men, who have lost their wives get, married as soon as possible which is reasoned by wanting the best for their children. Most children, however, do not perceive this fact as favourable, on the contrary, father's protection and support decreases with the arrival of a step-mother. These new circumstances cause a tense situation and relationships at home, the children miss the attention they used to get from their mother. It happens sometimes, that the step-mother is the same age as the children and is unable to take care of them, which makes the family situation even worse.

Children are rarely able to re-create the same emotional connection to the new mother. It is often an unsecure, uncertain and chaotic relationship of the child to its step-mother and it is filled with ambivalent feelings. With the arrival of the step - mother many children experience regular physical attacks and unbearable punishment. Many of them must follow strict rules regarding the access to food; they are discriminated in comparison to her children, who are preferred by her for the food supply. The children do not get enough of protection from their father and they are forced to seek shelter at their dead mother's family. Men, widowers who have not had the chance to marry after the death of the wife yet, are trying in the majority of cases to do so as quickly as possible. Only in few cases, stays the father with his children alone. Spreading epidemics may cause problems for a widower to

find a partner in many third-world countries. They sometimes must handle the fact that they have to raise their children alone, which presents a new created phenomenon and is a significant deviation from a traditional family life for the majority of men.

Children are social beings since the early stages of development. The tendency of social handling is not learnt, but it is probably a part of the biological equipment of a man. A strong primary motivation to be as close to the mother as possible for the child is natural. The mother presents a fundamental source of security for a child and she is a source of future relations to peers and partners, as demonstrated in recent years in long-term studies. Mother - child relationship are characterized by a strong emotional relationship, trying to be each other as much close as possible in the intimate contact. This condition it is not static, but it is a constant interaction of mother and child, it is performed repeatedly many times a day, it constantly changes, improves and strengthens weakens, depending on the proper/improper approach, which means life security and safety for the child. It is the basis for individual orientation and in the environment and getting to know the surroundings approximately from the second year of age of a child.

The close relationship of mother and child develops instantly after the birth and has a wide variety of forms. It is initiated by the mother - intimate contact, smile, voice signals and some games and by an overall positive and joyful relationship. Sensitivity to the needs of the child is expected. Interaction dynamics between mother and child has several phases for a small child:

- feeling of security in the presence of the mother,
- child leaves the mother to play or to get to know the environment,
- there is a growing sense of insecurity in the absence of mother,
- the child looks for its mother and also the safety and security,
- reunion with the mother is associated with satisfaction. (Dunovsky, 1999)

The whole cycle repeats constantly, the child goes on to discover the environment, comes back again and so on.

A number of studies showed, that children, who develop a strong attachment to their mother, develops much better emotionally, socially and in the cognitive area. This is obvious in the early years, but also in the age of 6 years and more. It is the same relationship, when the child is stressed when the mother leaves, but it calms down, when she returns and makes lively contact with her. There is a clear difference in response to the mother and foreign persons. Relationship created in such a way is beneficial for the child and in most cases it is associated with the next development of other positive stages in its development. (Dunovsky, 1999)

A number of situations and life circumstances undermine and weaken the bonding process. We distinguish two basic situations:

- Privacy: meaning living conditions in which no bonding could be created, because after the birth the child and the mother were separated, or the mother is unable to take care of the child. The damage of the development is usually significant which mostly causing irreparable changes in the development.
- Deprivation meaning the conditions in which the relationship was being built, but they were interrupted by a negative interference. It can be primarily a disease of a mother, or child's long-term hospitalization.

The impact of similar situations might not be so critical if a solution were found, which is good for the life of a child.

Other negative moments and deviations from normal development ("turning points" as they are called in evolutionary psychology) can be:

- *Long-term or repeated hospitalization of a child* without a mother (during this period of time an anxiety connection or substitution connection to some other person is often created, for example a sensitive nurse),
- *Changes in the child's environment:* mother's long-term illness, change of environment, loss of a loved one, death of someone in the family, associated with a strong child's grief and so on.

Bratska states that the worst impact is caused by a long-term hospitalization of children within 7-12 months of age. In the case, that during this period the child lacks an emotional contact with his mother, the proper relationship to his mother cannot be created, which gives basis for the social relationships of the child. (Bratska, 2001)

In a later child's and also of adults' development, significant turning points appear which are watched by the developmental psychology, focused on the length of life (life history). They can be presented by a series of events for the child, which modifies his life. These include: experience with violence, an accident, illness, serious moments associated with the maturity process of the child in various stages of its development, experience with the start of puberty and first sexual partner or relationship.

5.1.3 Children who lost both parents due to HIV/AIDS

Most of the children whose parents died of AIDS find their new place in their wider family network. But even if someone gives them a shelter, they usually do not have the feeling that they had a real home. The decision of someone from their wider family to take care of the orphan is not just an economic issue. It usually happens that the richer family is very rarely in contact with the orphans; on the contrary, the orphans are taken care of by the family, which lives in poverty.

The new family that decides to take care of those children has to deal with many reactions and their own emotions. Many family members show and feel compassion; they show the children their sympathy and understanding. But for many of them it is also a shock situation, which is filled with fear. Some families tend to blame the deceased parents, blame them for irresponsibility and children have to listen to wide variety of remorse. In such households, these children are often excluded from equal distribution of family resources. The substitute family expects and counts on the fact, that the orphans will work themselves for their living. Many of these children state that they do not have the same rights in the foster family; they have limited food supply, because they may eat after the other family members have finished their meals.

Most of the orphans prefer therefore to stay at their own home, even without an adult member. In these cases, the oldest child tends to adopt the role of head of the family, regardless of the gender. Girls take over the role of mother, trying to provide food for other children. When there is not enough food, they are the ones that eat as the last, if their mother did so. They are responsible for the household with all the things that are associated with it.

These young girls grow up without parental assistance and they gain knowledge about the world, the family, about sex from their peers, who are also low educated and are discovering the world only by them. Most of them have minimal education, they are starting too early with the intimate life and soon after that they usually have to take care of their own child. They miss the premature loss of parental love and they seek emotional support; they are an easy victim of sexual abuse. They would like to be married, but younger siblings

are often an obstacle for a potential husband. In a situation, when a brother takes care of younger siblings, his role is of the man in the family. This role is associated with the enforcement of the authority and leading positions often by the use of physical violence. He tries to provide an income and to keep the household running. Usually he avoids doing the so-called "female" work, such as preparation of food; such activities are to be done by younger sisters.

Perhaps the children of prostitutes find themselves in the most difficult situation. After the death of their mother, they are left alone, with a huge psychological trauma. Most of these orphans stay temporarily with their grandparents, who live often in extreme poverty; those children do not usually have any possibility to attend school. What happens to children after the death of grandparents is questionable, but it is clear that they are exposed to many risks. Most of them are neglected and face hostility from all people. The girls are sometimes taken care of by other family members with the intent to have somebody for house work or marry the girl to anybody, who would bring them some profit. Some of the girls make the same mistake as their mother did and they sell their body almost for nothing, which provides them some income for their living. Many of them are from 12 to 16 years of the age, presuming that they are not HIV positive.

5.2 When a child survives the death of his parents

The death of a parent means in particular a relational loss. It means the end of all opportunities to be in contact, to communicate, to have common experiences, to love, or have in some way the emotional and physical presence of the mother or father. The fact that this is a permanent loss is particularly difficult.

The death is probably the most significant loss, which may affect a person's life. It is therefore normal that the child feels profound grief, the child feels abandoned, desperate and helpless. This is a real and deep crisis for them. Mourning after the death of a parent in many aspects resembles some kind of an illness; it is in fact not an illness, but a natural way of processing a loss. It presents a complex of psychological, social and somatic reactions to the loss.

The children react to death and to the loss of a loved one with strong emotions, which often remain hidden. Around the age of 7 to 9 years appears more realistic understanding of the death and reaction of children may appear as those of the adults. Around the age of 10 a child starts to understand the death in its social and biological context. In the first years of life the loss of a parent has the biggest potential impact on the pathological personality development, but can serve as the basis of psychiatric problems in the later years. For children in the age from 3 to 4 years of age, his death of a parent of the same gender is the most critical. The overall behaviour of younger children may seem incomprehensible and unbounded to the tragic event. It is definitely necessary to know, that the child at this time in its life will have a new surge of emotions. (Vizinova & Preiss, 1999)

The following outlines the most common demonstrations of emotion in children losing their parents:

- Sadness, grief and sorrow,
- Concerns that may be caused by insecurity. The child asks questions like ("What is going to happen to me? What am I supposed to do all alone?"), but also questions about the meaning of life, they are confronted with the own mortality, especially with the fear of its own death,

- Anger, wrath and aggression, these negative emotions can be addressed to all the other, e.g. the medical staff (“Why could the doctors not help my parent somehow? Why couldn’t he be saved?”) Or these emotions can be addressed to the deceased (“How could he/she do that to me? Why did he/she leave me here alone?”), but also to themselves (“Why didn’t I do something? Why was I so bad?”), and so on.
- Feelings of guilt, arising from the own survival (“Why didn’t I die instead?”)
- Feeling of loneliness the children experience, when they are left by the other parent and they are left all alone or with their siblings.
- Feeling of relief especially if the child watched the parent suffer, the idea that the parent does not suffer anymore is comforting for the child
- Somatic problems of children are demonstrated in particular, by exhaustion, fatigue, anorexia and by an overall weakness of the organism.
- Disorganization of daily life and daily routines, the child is excluded from activities that he or she used to do and life of the child has stopped to run as it usually did.
- Impulsive, chaotic handling. These are common symptoms caused by stress and fear that the child is experiencing.
- The child is having imaginings/fantasies about the deceased parent, the child may imagine, they see, hear and feel the deceased parent.
- The child identifies himself or herself with the deceased parent. The children may take over certain behavioural models and patterns of deceased parent, they use his/her words, gestures, and ways of speaking and so on.
- Avoidance of social contact, the child has the feeling that nobody understands him. It can often cause irritability and hostility, especially in the presence of strangers.

It is perfectly natural and normal that a child experiences such a combination of emotions and reactions. It is important for the child to have the opportunity to express and to talk about what the child is going through and it is also very important that the child has someone, who would help him to overcome this difficult and traumatic situation.

5.2.1 The process of mourning of children: The stages of handling the death of a parent

Mourning is a consequence of the loss, which the individual realizes. It is considered a natural, normal and necessary mechanism for handling the loss in life. To what extent is this process successful depends on how one handles the tasks of mourning.

Between the mourning steps we can include: acceptance of loss of life, acute mourning, adaptation to the environment without the lost object, redirecting power to the second object, overcoming fear of change, finding new and the meaning of life. Signs of mourning can be seen in the following areas:

- Emotional (grief, anger, feelings of guilt, anxiety, helplessness, indifference).
- Vegetative (tension, sensitivity to noise and light, shortness of breath, dry mouth, asthenia).
- Cognitive (mistrust, confusion, obsessive deal with memories of lost object, forgetfulness, disorders in new memory, hallucinations, difficulty in concentrating attention).
- Lifestyle and behaviour disorders (sleep disorder, loss of appetite, secretiveness, keep oneself to oneself, out from society, scary dreams).

Even if all the processing of grief and death is unique and individual, it is possible to distinguish several phases that are not always in the same order but they stand side by side and often can be repeated.

The process of mourning is described by different authors, for example. Kubler-Ross divided the period of 5 phases:

1. Stage of shock, denial and negation of death,
2. Stage of anger and aggression,
3. Stage of negotiations
4. Stage of depression
5. Stage of acceptance and reconciliation with death. (Kubler-Ross, 2003)

These phases often overlap; they can last a different period of time and can happen parallel or do not exist at all. There is some specificity identified for children's experience when handling this situation.

Kubickova talks about 4 phases experienced by children: (Kubickova 2001)

1. **Phase of shock, denial and isolation.** Immediately after the loss of a parent, the child, responds by feeling confused numb, stunned and shocked. He usually denies the whole situation, does not want to believe that it had happened. ("No, it cannot be true! I don't believe it!") Children convince themselves, that it is not possible. They reject and deny the reality, which is actually a psychological defensive reaction. They attenuate the effects of negative news. They try not to face the fact. At the same time, they show that they still do not handle their own pain and the child seems emotionally overloaded. Some children tend to play various games, e.g. they are being cruel to animals to express the sadness and pain.
2. **Self-control phase**, which is a pretence that lasts until the evening of the funeral day. Preparation and organization of the burial ceremony makes it impossible for the surviving family to fully succumb to the grief. After the mourners have left, the surviving family are able to surrender and feel the pain of their loss to its full extent. This process may be experienced in some other way by the children, since they usually are not involved in organizing of the funeral, the shock phase may be extended to a longer period of time. Some children idealize the deceased parent at this phase of the mourning process. For some children everything that reminds them of the death parent becomes important. Objects reminding children of the dead mother or father reminds them of having a nice time that they had together. The younger children sometimes show strong desire to amalgamate with the deceased parent. Some children might to wear clothes of the deceased parent or to have the same job. At this stage of the process, children without stable identity are in danger, that the development of their own „self“ will be negatively influenced.
3. **Regression phase**, which may take from one to three months. The lamentation and mourning phase takes often the most extended period of time. The mourning child often cries, elements of regression can be found in his behaviour, these children are apathetic, closed up into his own inner world, they are anxious and desperate. The disorganizing of behaviour is obvious; the surviving family is not able to function normally in everyday life. They are unable to get their life back and they retreat from their social contacts. Many children may suffer from sleeping disorders and lack of appetite. The children sometimes switch from their idealizing of the deceased parent to his/her disparaging. Their pain is mixed with anger and rage that they have been left alone. Negative evaluation of the deceased parent is an attempt of child to let go. If the idealization of the deceased partner happens too soon, there is a danger for the child not to be able to let go. Only a realistic

picture of the deceased, accepting of all sides of his/her personality can become basis for the child to converge to his deceased partner on other level.

4. Adaptation phase. It usually takes up to one year, depending on the next development of the situation after the death of a parent. This is a period of reconciliation with past events, the child does not forget, but starts getting used to the absence of the parent. We must not overlook, that the process of handling grief is a long, painful process and it needs a lot of energy. Therefore a child needs time without sadness and when it rejects the sadness, when it wishes the deceased parent to be alive again. The last period of mourning is called a phase of a new relationship to children themselves and to the world, which reflects the fact that something new starts, something totally different from what the child has been accustomed to.

The time course of the mourning process cannot be predicted. At its end stands rapprochement to the deceased parent on a qualitatively new level. Mourning ends, but is not completed yet. The child is usually able to find a more mature relationship to the deceased parent. The deceased father or deceased mother are not physically present, but tend to be very clearly present "spiritually". The children may still feel sorrow and pain. The scars remain. The loss cannot be erased. The adult can show the children, how to treat these wounds and how to live with them.

It would be ideal if we could provide each child, whose the parent died with the following:

- Relevant information adequate their age,
- Open communication about the death,
- Supported expressing of their feelings,
- Provision of basic needs,
- As stable and safe environment as possible,
- Support and relief in the pleasant memories of the deceased parent,
- Involvement of the child in the preparations of the funeral rites,
- Respect for the needs of the child to maintain the connection to the deceased parent (Dane & Levine, 2002)

There are various different types of care for orphaned and abandoned children, which differ from country to country. In many third-world countries the concept of "adoption" does not exist in the same sense as in Europe. Orphans are taken care of by some relatives in order to avoid a total disappearance of a father's household.

In Kenya, for example, each household belonging to the given tribe is valuable and therefore it should be protected by the tribe. Although the desire to survive as a family is very strong, poor economic and social circumstances lead to the separation of some orphans. Four categories of households with orphaned children can be distinguished according to practice:

- Foster families: children are taken care of by some relative from the father's family, mostly an aunt or uncle.
- Caretakers of the third generation: presented by the grandparents
- Orphans leading their own household: when there is nobody, who could take care of those children, they usually stay alone. This forces immature children to start an adult life with full responsibility for their lives and lives of their younger siblings. Many orphans - girls become mothers in their teenage years.
- Households employing orphans: some families employ children - orphans as cheap hand in the household.

6. Forms of defence and adaptation mechanisms

In stressful situations, each person reacts differently. Each has his own defence mechanisms which help to reduce tension and anxiety. These mechanisms function on the subconscious level and they deny or distort the reality. The most common defence mechanisms occurring in different types of situations, which are stressful for the child, such as HIV / AIDS thus frustrating in situations, include the following: (Bratska, 2001)

- **Repression** - according to S. Freud repression is one of the most important defence mechanisms. During displacement memories or impulses are causing stress (pain, anxiety, guilt) and thus pushed out of consciousness.
- **Suppression** - is presented by purposeful self-control, during which a person controls his impulses and desires or temporarily removes all painful memories, especially when he needs to concentrate the effort on a particular activity.
- **Projection** - requires looking for causes of their own failures in other people, accrediting their own unacceptable impulses to another person.
- **Reactive creation** - presents acquiring attitudes and behaviour that are the very opposite of the actual thoughts and feelings.
- **Fixation** - is presented by persistence and focus on areas, which are typical for certain period of development for long time after the person should move to the next level or phase.
- **Regression** - a return to the ways of behaviour, that were adequate to an earlier developmental stages.
- **Inversion** - shows a sort of "reverse behaviour. The person in crisis reacts exactly in the opposite way one would expect. "
- **The types of rationalization** - a person reasons and apologizes for the motives for original handling by rational argument to keep self-confidence and good judgement of him. In these mechanisms can be included: is one of belittlement, which reduces and disparages the value, the aim one did not reach and the next mechanism is relativization, which rationalizes the worries comparing them to previous worries one was able to solve successfully. Another form of relativisation is the acquisition of overview; comparison with the future ("what is this in comparison with what is ahead").
- **Substitution and compensation**- the original object, who satisfied one's needs is replaced for an analogic one by substitution and substitution by compensation.
- **Identification** - when a person agrees with the behaviour of others.

Defence mechanisms are often used by adults, but almost by all children. An acceptable level of use is considered normal. Only when it becomes the predominant way of response, when the child uses this mechanism electively, it signalizes a bad adaptation. The reason for that is because: they prevent the child in dealing with the world in a realistic way. They waste energy that could be used more efficiently. When they fail, the resulting anxiety can present for the child serious difficulties.

Coping with difficult life situations, describes various coping strategies. Unlike defence mechanisms, which falsify the reality, coping strategies - respect the reality. We can define "coping" as behavioural, cognitive or social response of an individual whose aim is to control internal or external pressures stemming from the individual interactions with the environment. We can distinguish two basic coping strategies:

- *Focus on self-development* - reflects the natural self-centeredness. Individual focuses on his or her own person and on their own emotions. He tries to reduce uncomfortable tension by using of the escape mechanisms - escape into fantasy, to the memories and the like.
- *Focus on your problem* - involves efforts to influence the environment and to change it. An individual seeks adequate information, to reformulate and redefine the problem and find other alternative ways of coping with the situation.

Choice of coping strategy depends on the previous experience and subjective evaluations of the event. Optimal coping strategies include an estimation of the significance of the critical events and consideration of the risks of the subsequent acts or, conversely, the risk of interruption of activity. In some emergency situations it is necessary to respond immediately, while in others it is better to stop the activity. It is a very difficult period for children and it is necessary for them to get help, whether from close relatives, friends, acquaintances or institutions in the form of emotional support, practical help, advice and information. Social support has a direct impact on reducing stress; or rather it acts as a buffer or blocking in dampening the impact of a crisis. It is also an important determinant of mental health and subjective well-being. When a system of social support is lacking, it leads to a reduction in the child's mental endurance and the possibility to deal with the crisis.

7. Process of counselling

Counselling in HIV/AIDS is a core element of the holistic approach to health care. During the process of counselling psychological aspects are recognised. Counselling enables frank discussion of sensitive issues in the client's life. People may suffer from great psychosocial and psychological stresses through a fear of rejection, disease progression, social stigma and the uncertainties associated with future.

Laboratory diagnosis of HIV infection for evidence of the specific antibody or HIV is a serious step in the life of an individual; it should be accompanied by an interview/counselling session before and after the examination. And this is especially important by diagnose of children.

In Kenya, VTC (Voluntary Counselling and Testing Centres) were created for free diagnosis and advice across the whole country. They provide services for all residents by professionally trained counsellors. The counsellors discuss a lot of psychosocial issues which people diagnosed with HIV/AIDS face in their everyday life.

Probably the most important service being offered to people living with AIDS is counselling. This is carried out by individuals and by groups. The common objectives of counselling are firstly to win the confidence of people with AIDS, so that they return for continued help. Then, people have to be helped to grow and develop, so that they can decide what they want and live valuable lives regardless of their HIV status. People who have been tested must be helped to get through the initial period of crisis. Infected people must be shown how to keep from spreading AIDS and how to take preventive steps. They must be encouraged to talk with their family members. (Shorter & Onyancha, 1998)

Because we have no cure for HIV/AIDS, we have to focus our interventions on caring for the physical as well as the psychological welfare of the HIV positive individual and his or her significant others. The aims of counselling should always be based on the needs of the client. The purpose of counselling could be as follows:

- to assist clients manage their problems more effectively and develop unused opportunities to cope more fully,
- to empower clients to become more effective self-helpers in the future

Counselling should be about constructive change and about making a substantive difference in the life of the client. However only the client can make that difference, the counsellor is merely an instrument to facilitate that process of change.

7.1 Counselling before and after testing HIV/AIDS

The counselling before and after testing HIV/AIDS has phenomenal emotional, practical, psychological and social implications for each client. This type of counselling has some specifications:

- HIV testing never is done without thorough pre-test counselling.
- Pre-test counselling that is done in a proper and comprehensive way prepares the client and counsellor for more effective post-test counselling.
- Clients are often too relieved or shocked to take much information in during post-test counselling. The counsellor should make use of the educational opportunities offered by pre-test counselling.
- Counsellors are trained to do pre- and post-test counselling in a professional way and to keep all information confidential. It is also a right of client to stay anonymous.
- Nobody may be tested for HIV without informed consent and without proper pre-HIV test counselling.

The counselling before the examination is focused on providing information regarding the technical side of screening, but also the possible personal, medical, social, psychological and legal implications of diagnosis, whether it is positive or negative. Information should be given in an appropriate form and must be based on actual information. The process of child counselling has specific differences. It is necessary to explain to them every act of procedure that will reduce the initial fear.

Interview before the inquiry should focus on two main areas:

- Personal history of the client and risks that they were or are exposed to,
- Consideration of whether the client understands the HIV / AIDS issue, as well as his previous experience in crisis management.

The initial interview should include discussion and assessment of the client's attitude, appraisal of psycho-social factors and knowledge about HIV/AIDS issues.

People who have been confirmed as being infected with HIV must be informed about it as soon as possible. The first interview should be confidential and the client should get some time to deal with this report. After that, he should be very clearly and factually informed about the importance of the diagnosis. At this time, devoid of different speculations about the forecast or consideration of how much time remains the affected person has to live. It is a time period, when a person has to deal with the new reality and overcome the *shock*. It's also time to provide security support and assistance. It is a time of hope for resolving personal and practical problems that may arise. If there are real possibilities of such support, it is appropriate to talk about possible ways of therapy in case of some HIV / AIDS symptoms, as well as the effectiveness of treatment.

Whether the client will or will not accept the diagnosis is usually determined by the following factors: (Bar, 2000)

- Current state of health. Persons, who are already sick, may have a prolonged reaction time. Their actual response occurs, only when they are physically stronger.

- Readiness to accept the situation. People, who are not ready, may respond differently than those who expect such a result. Unexpected reactions may appear even if the individual is prepared for the situation.
- Real or potential support of the environment. Factors such as satisfaction at work, harmonic family cohesion, as well as opportunities for recreation and sexual relations, may act as very positive support mechanisms. Conversely, those, who are socially isolated, have little money, scant employment perspective, poor family support and inadequate housing, react much worse. HIV positive parent, who learns that his child is infected, usually accepts the news very badly. An HIV positive parent knows his own situation and knows about the chances the child may wait.
- Personality of tested before testing and the psychological health. If there was any mental stress before the test, the response may be more or less complicated and require a different strategy compared with those who did not have such problems. Management after such information should take into account personal psychological or psychiatric problems of clients. The stress of possible HIV positivity may cause a recurrence of previous conditions. In some cases, information about HIV positivity may unearth some unresolved issues and concerns. These often complicate the process of coping with the diagnosis. Therefore, this situation is to be handled very sensitively and carefully as soon as possible.
- Cultural and spiritual values related to disease and death. In many cultures people believe in an afterlife or fatality, so they receive the report of their HIV infection in a much calmer way. On the other hand, there may be a region where AIDS is seen as a punishment for antisocial and immoral behaviour, and therefore it is associated with feelings of guilt and resistance. Counselling and support are very important when reporting the news about the disease. Some reactions can be initially very turbulent. One has to realize, however, that this is a normal reaction to the report, which for the individual represents life threatening condition and that they often do not want to admit it.
- Although the post-HIV test counselling interview is separate from the pre-test counselling interview, both are inextricably linked. The pre-test counselling interview should have given the client a glimpse of what to expect in post-test counselling.

Pre- and post-test counselling should preferably be done by the same person because the established relationship between the client and counsellor provides a sense of continuity for the client. The counsellor will also have a better idea of how to approach the post-test counselling because of what he or she experienced in the pre-test counselling. The counsellor should always ask the client if he or she is prepared to receive the results. In the case of the rapid HIV antibody test - where the results are available within minutes - the client should be asked if he/she is ready to receive the results immediately. Some clients need time to prepare for the results. For both the client and the counsellor, a negative HIV result is a tremendous relief. A negative test result could however give someone, who is frequently involved in high-risk behaviour, a false sense of security. It is therefore extremely important for the counsellor to counsel HIV-negative clients in order to reduce the chances of future infection. Advice about risk reduction and safer sex must therefore be emphasised. The possibility that the client is in the "window period" or that the negative test result may be a false negative should also be pointed out. If there is concern about the HIV status of the person, he or she should return for a repeat test after about three months and ensure that appropriate precautions are taken in the meanwhile. To communicate a positive test result to a client is a huge responsibility. The

way people react to test results depends to a large extent on how thoroughly the counsellor has educated and prepared them both before and after the test.

Clients' responses to the news usually vary from one person to another. Reactions may include shock, crying, agitation, stress, guilt, withdrawal, anger and outrage - some clients may even respond with relief. The counsellor should allow clients to deal with the news in their own way and give them the opportunity to express their feelings. The counsellor should show empathy, warmth and caring, maintain neutrality and respond professionally to outbursts. Because the loss of health is equated with bereavement, it manifests with all the components of denial, anger, bargaining, depression and acceptance. The counsellor must respect the personal nature of an individual's feelings.

People's needs, when they receive an HIV positive test result, vary, and the counsellor has to determine what those needs are and deal with them accordingly. Fear of pain and death are often the most serious and immediate problems and these can be dealt with in various ways. Talking to clients about their fears for the future is one of the most important therapeutic interventions that the counsellor can make. Often it is enough for the counsellor just to be "there" for the client and to listen to him or her. One of the major concerns for HIV positive people is whom to tell about their condition and how to break the news. It is often helpful to use role-play situations in which the client can practise communicating the news to others. In responding to a client's needs, an attitude of non-judgmental and empathic attentiveness is more important than doing or saying specific things. Listening is more important than talking; being with the person more important than doing some specific action.

Crisis intervention is often necessary after an HIV positive test result is given. The counsellor must be sure that the person has support after he or she leaves the office. A person in crisis should never be left alone: he or she should have somebody with whom to share the burden. If the client shows any suicidal tendencies, emergency hospitalisation should be arranged if a friend or family member cannot be with the client. Follow-up visits are therefore necessary to give clients the opportunity to ask questions, talk about their fears and the various problems that they encounter. Significant others, such as a partner, spouse or other members of the family may be included in the session. During the follow-up visits, clients should be offered a choice concerning their treatment.

If health care professionals are not in a position to do follow-up counselling, information about relevant health services should be given. If there is a concern that the person might not return for follow-up counselling, information about available medical treatments such as anti-retroviral therapy, treatment of opportunistic infections, and social services for financial and on-going emotional support should be given.

The counsellor should inform the client about support systems such as the "buddy system" that is usually available at the nearest Aids centre or from the offices of non-governmental organisations who work in the community.

It is necessary to convey information about safer sex, infection control, health care in general and measures to strengthen the immune system. It is very important also to encourage clients to go for regular medical check-ups to the health clinic. Infections and opportunistic diseases can be prevented if treated in time.

8. Research study, objectives, methodology

The *main goal* is to analyse the psycho-social aspects of people coming to the Voluntary Counselling and Testing Centre in Nairobi, Kenya. The study is realized in order to acquire

feedback information about psycho – social aspects in practices. The *main objectives* are follows:

- To discover the percentage of clients in VCT, who have certain behavioural features (anger, fear, anxiety, distress, shock and so on)
- To analyse the psycho-social factors that affect PLWHA in Nairobi,
- To identify the sources of stigmatization and discrimination of PLWHA in Nairobi,
- To analyse the most problematic social issues of PLWHA,
- To discover whether or not clients of VCT are able to speak about spiritual issues,
- To analyse the meaning of regular counselling session in order to change the behaviour of PLWHA.

The target group and place of research study.

Counsellors of VCT collected the data in the years from 2005 to 2009. They have provided counselling to 12 685 clients altogether; out of them 1165 were tested positive, which were included into the research study.

The clients were mostly from Mukuru slums, South B, South C, Nairobi West, Mugoya and from the industrial area in Nairobi. The VCT centre has a total staff included of six trained VCT counsellors, who have background trainings in public health (degree level) and psychological counselling (degree level) with vast experiences since the centre was started (2003) VCT for Mukuru slums was initiated with the aim to raise awareness about the spread of HIV/AIDS and to prevent the spread within the Mukuru population and its environment.

Being the entry point to HIV/AIDS prevention and care, the service has the specific objectives to achieve: to offer voluntary counselling and testing to the clients for HIV positivity; to provide information and education about HIV/AIDS ; to offer referral services for further management to designated referral points; to increase couple counselling and testing of VCT.

Any testing at the site must be accompanied by pre-test information and post-counselling information as prescribed in the National HIV counselling and testing guidelines. 70% of clients of VCT are coming to VCT based their own decision; this means they are not sent by doctors or nurses from any clinic or hospital.

Year	2005		2006		2007		2008		2009		Total	
	tested	positive										
Male	1079	93	1128	82	1218	94	1367	59	1672	62	6464	390
Female	1011	208	1056	162	1132	145	1264	145	1758	115	6221	775
Total	2090	301	2184	244	2350	239	2631	204	3430	177	12685	1165

Table 1. Number of clients at Mary Immaculate VCT Nairobi, Kenya by gender (Okoth & Namulanda, 2010)

Table shows clients in Voluntary Counselling and Testing Centre at Mary Immaculate Clinic in Nairobi, in Kenya. Out of 12 685 tested clients were 1165 positive. From the total number 775 were female and 390 male.

Age	15-19	20-24	25-29	30-34	34-39	40-44	45-49	50-54	55+	Total
Male	2	24	64	103	88	62	31	7	9	390
Female	27	149	216	162	118	47	39	7	10	775
Total	29	173	280	265	206	109	70	14	19	1165

Table 2. Number of HIV positive clients at Mary Immaculate VCT Nairobi, Kenya in years 2005 to 2009 by age and gender (Okoth & Namulanda, 2010)

Methodology and realization of the research study

An exploratory qualitative research study using in-depth interviews was conducted by the 6 counsellors in voluntary counselling and testing centre in Nairobi, Kenya. The interviews were carried out using semi-structured questions, open and closed questions. The counsellors collected data from their client's record for the last 5 years (2005-2009). Data were assessed using content analysis, the study of the documentation of clients, observation, comparison and interview.

8.1 Summary of results from research study

The first objective is to discover the typical reactions of clients to their HIV/AIDS positivity. Based on the research study 60% of clients felt *fear*, *anxiety*, 30% of them *anger*, 25% of them indicated *distress*, 15% *cried*. Clients spoke about *grief*, feelings of sadness of loss they experienced, or are expecting. Obviously, almost all, clients confirmed positive for HIV felt *sadness* because of their status (89%). Many clients feel this way when referring to close relatives, who had suffered and died of HIV/AIDS. Only clients who are confirmed negative of HIV feel free to continue talking of this *topic-(grief)*.

Identification of clients' way of feeling *anger and aggression* after being tested differs according to gender. We came to conclusion, that many male clients who are tested positive openly show anger, disbelief, as opposed to their female counterparts. Some became aggressive (5%) towards a counsellor and demanded a repetition of the tests. The female clients tested positive for HIV tended to cry, go into shock, swallowed big lumps of air, saliva subconsciously, shook both their hand in refusal and blame the others almost immediately.

The results, if clients were to speak with counsellors were with regard to the *loss*, loss of life, their ambition, physical performance and potency, sexual relations, position in society, financial stability and independence are still challenging area for counsellors, 89% of clients are not ready to discuss the issue of loss. What they want to hear is the assurance that there is treatment, that they will live as long as any other person, or curing miracles happen and therefore one day they will be cured and be able to lead a normal life like others. It is very evident in most sessions that the magnitude associated with this status is depends on how well prepared a client is during a pre-test session. Very few clients talk about the loss of sexual relations (2%). Most of the clients register fears relating to loss of position in the society.

Another psycho-social issue that was discovered by the clients is a *hopelessness and helplessness* syndrome. It includes elements of giving up and leaving. It is interesting, that in years 2005 to 2007, many clients felt hopeless because of the lack of immediate elaborate support structures or mechanisms.

However as time has passed, the level of awareness increased, and the level of stigma decreased. These facts were expressed in the faces of most clients, who feel hope. Information on the availability of subsequent services (comprehensive care) has boosted the morale and thus an increase in VCT service uptake. Most of the clients responded to the following question "How would you accept the fact, if you turned out to be positive for HIV" with more confidence. "There are available drugs nowadays, many people take them, and so I will be able to join the support groups, start my medication and move on with my life".

By the analysis of issues, many of these were related to *guilt*. Very few people would feel guilty about the way, in which they were infected with HIV – they got infected because of their lifestyle. The majority would blame their partners or the environment, because most of them claim to have been true to their partners. (62%). In a stable relationship (marriage) the individual will feel guilt with regard to infecting the spouse. But in instable relationships (not married), the culprit will not feel guilt, so they are both guilty.

Almost all clients seeking voluntary HIV testing services have a reason for their visit, based on some form of one's own or partner's failure, accidental happenings or poor health background and work/professional related commitments. More than half of these blame themselves subconsciously whilst up to 30% do it consciously. This is then transformed into guilt, though it is not easy to point it out openly or state it in sessions. We ask a direct question to help the client address guilt and help him accept guilt, when necessary, for example: "Do you know the direct impacts of your actions on your health when you engage yourself in unprotected sexual relationships with somebody whose state of health you do not know?"

Based on results of the research study HIV positive clients are exposed to *stigmatization* and *discrimination* which is communicated by their spouse, family members, friends, colleagues, employers, medical staff and the church. There is the complicated situation in some churches, as it is still believed, that HIV can only be spread via promiscuous way of life and they spread this message in information when preaching. The situation is really difficult, when the people living with HI/AIDS wants to get married; some religious leaders in Kenya still have a lot to say against it.

Back in 2005 to 2007 incidents of stigmatisation were higher in comparison to recent years in Kenya. 5% of women have been sent away from the husband's homestead, after his death. This was done in the belief that only women can spread HIV virus. This situation seems to be gender biased, as most of complainers were women. Some of them were helping out in houses; they were discriminated against by their employers. Mostly women from rural areas experienced discrimination from the husband's relatives.

Only a few discrimination cases are reported because it could be perceived as an offence according to some legal matters changed in Kenya and it is punishable by both jail and a fine. Clients were made redundant by an employer, who believed, that HIV positive people can become an insurance-liability issue for the company. Some companies revoked the insurance of particular employers, because they feared of overrunning of annual medical insurance costs based on misuse or on continuous illnesses treatment. It can be concluded, that stigma fades slowly away from Kenya.

The people living with HIV/AIDS themselves suffer from self-stigma, which presents an obstacle in the progress of acceptance and the consequence is low *self-esteem*.

The best way how to support PLWHA is to ask him to join *self-help support groups*. The clients who agree to join support groups and work within these groups develop internal relationships. This shows the importance of supporting one another. They have access to

up-to-date information; they can discuss issues like prevention, getting infected with HIV, how to stop spreading HIV, and where to seek appropriate medical and psychological assistance and access to appropriate home based care. The self-support groups are often the instrument within which to accept the status and accept the comprehensive care services.

It is also rare, to see the "AIDS picture" in public, thanks to the devoted involvement of ARVs, the HIV issue starts to be discussed more in families, at workplaces and in the media. A lot of PLWHA in Kenya wish to fight the stigma and to give HIV positive people hope and to encourage those who have not been tested yet to get tested and get the treatment.

As a result of self-help support groups and better edification of the public, less and less *depressive* cases seem to be recorded in VCT. In the study less than 1% of clients have tried to commit suicide. There were clients, who came get tested for HIV positivity already decided, that if confirmed positive, they would commit suicide, however with the help of counselling they changed their decision. In one case the client brought poison in VCT, just in case, he would be confirmed positive, and so he would be able to commit the suicide.

A situation in which one must face loneliness, loss of control and subsequently the inevitability of death, can lead to *spiritual questions* and seeking assistance in faith. Concepts of sin, guilt, forgiveness and reconciliation may be the subject of spiritual and religious discussions. There are a number of similar moments in life for the HIV positive patient. 35% of clients wish to discuss these spiritual issues. In their prayers they often express a wish for a so called miraculous curing. The counsellors have never seen even one client with a negative approach after so called miracle healing. The strong belief in God helps them to hope that God can heal at his own time, using his own ways and for his own reasons. In Kenya, especially in the slums, there are a great number of people living with HIV/AIDS communities seeking divine healing. This fact was of significant meaning for greedy pastors, who misuse the faith of believers and make them, in their hope for healing, to deliver offerings, tithing and to plant the seed of healing in the church. So people sell their properties, go and plant the seed of healing in the church (church business). The counsellors discourage client from dropping or even stopping the use of ARVs after "prayers" and remind them that it is not all right, when they are asked for money for a "prayer". They try politely without wanting to influence one's spirituality and make clients understand, that the love of God is the same to all people, whether positive or negative, Muslim or Christian, one tribe or another.

The issues of *grief bereavement* and issues related to *death and dying* found to be taboo issues during counselling for a large number of clients. Based on our results, only 5% felt free to speak openly about these matters. The clients, who come to be tested for HIV, do not know whether the result is going to be positive or negative. In this case should the result of the test be confirmed as negative, they state their plan to change their behaviour to reduce risk of getting infected.

If the result is confirmed to be positive, most of the clients perceive themselves as if they were already dead (walking corpses). They imagine their funeral and its realization and they visualise their grave. People regret their failures and they are not ready to discuss such an issue as the death. Most clients tend to avoid this topic. It takes a lot of encouragement and assurance from the counsellor to help them open up and to talk about these matters.

The counsellors need to encourage the clients to understand that the dying process either their own or the one of someone they know, for a HIV positive person or with some other comparable disease or sickness, is an issue that can be openly discussed.

The following outlines the *most problematic social issues* of people living with HIV/AIDS in Mukuru slums, Kenya want to discuss with counsellors in VCT:

- Financial instability,
- Lack of support and understanding from close relatives and community members,
- Follow up of adherence and compliance of drug usage in public, during working hours/in church/while travelling, and so on.
- The big challenge of disclosure and the subsequent steps,
- The issue of having a child / children. (“Will the new-born child be HIV negative?”)
- Will there be some partner of the same status to marry?
- The challenges of getting a job despite HIV positivity, (Will they be accepted as any other person?)
- In situations where the spouse is negative (the discordant couples) the positive spouse is worried if she/ he will be accepted in that relationship or will be chased away.
- Another question is, if the partner accepts him/her? Will family members of the negative partner bless that marriage?
- Relatives start to handle the property of the HIV positive person as if the was already dead.
- Recognition, HIV positive people are human beings and they should be treated with respect,
- They should be offered quality health care services.

The clients of VCT mentioned also some other issues, which they face, for example poor supplies of ARVs; how the available treatment is not available for all; corruption, which allows receiving treatment only in the case of some acquaintances and contacts with higher positioned staff in rural clinics. Clients have also financial problems. Some of them have a long way to travel from home to the treatment centres.

The service providers, who always seem to have “permanent issues” with anybody who has HIV/AIDS constantly breach confidentiality. Some clients start to drink alcohol and turn into heavy drinkers / drug users in order to avoid stress.

On the side of counsellors in VCT the challenging issues are often linked with the poor level of education of the clients and strong traditional beliefs. There is usually a high level of conflict that some clients find themselves in, for example conflict between religious beliefs and traditional African beliefs.

Another issue is the high expectation referring to the dependency syndrome, depending too much on guidance and not being able to be self-dependant or self-sufficient. There is an increase of the threshold for starting ARVs by the government from CD4 counts of below 250 to CD4 counts of below 350. This is very important and positive for a third-world country; it is not only practical but also realistic. It easily caused a shift of half a million people to be immediately put on ARVs yet the stock, stores, staff, infrastructure, expertise and counselling staff were not present and available.

9. Conclusion

The main determinants of HIV/AIDS that have a great impact on the psycho-social life of HIV positive people could be divided in four main groups: biology, behaviour, microenvironment and macro environment determinants. From the biology determinants the most affecting ones are: virus subtypes, stage of the infection, other health complications, circumstances, and so on. From the behavioural determinants the most

influential belong to issue pertaining to sexual practices, rate of partner change, prevalence of partners, condom usage and so on.

On the micro environmental level there are determinants as urbanization, mobility, access to health-care services, and status of women, violence issues, stigmatization and discrimination and so on.

The macro environment determinants influencing the daily life of people living with HIV are culture, religion, governance, income distribution as well as wealth.

All these aspects should be taken into account by analysing the psychological and social living of HIV positive people. Psychological mechanisms such as denial, avoidance, grief, discrimination, etc. are encouraged by practices and gender-dominant relationships in the African culture, which increases women's and children vulnerability to HIV infection. It is very important to create a positive environment and positive mind-set for people living with HIV/AIDS.

The stigma can be minimized through campaigning, so that people can continue to lead a life, which is productive and full-valued. For a wider outreach of actions, programs cannot be restricted to massive information diffusion but the psycho-educational strategies need to be applied on a small number of target groups. There is the need, not only to increase the medical knowledge but also to enhance the awareness about HIV/AIDS in general.

Culture, values, traditional norms and taboos are lost as a consequence of too many HIV/AIDS deaths. The support groups seem to be a very positive way in supporting people how to cope with the situation. The services provided to the families are needed very much and also the wider family should be well-informed and educated in order to provide basic emotional and psycho-social support.

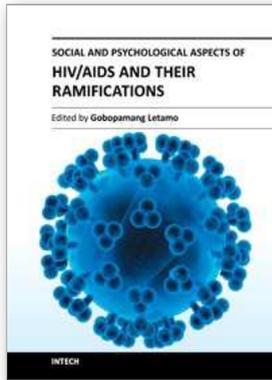
A great amount of special care must be given to HIV positive children and children, who became orphaned due to HIV/AIDS. Education and support is the most effective tool that helps people living with HIV/AIDS to live a psychologically well-balanced life. Proper support will also help people with HIV/AIDS to move through the appropriate stages and to reach the acceptance of their status and to cope with all the psycho-social issues in their lives.

HIV positive people can use the educational activities to learn the way of how in order to be in charge of their own medical care, and how to protect themselves as well as those around them. They can also disseminate this education to others and help to reduce the stigma within their communities. Through the many changes and challenges, it the support of family, friends, communities, and health care professionals which are essential to overall well-being.

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Social and Psychological Aspects of HIV/AIDS and their Ramifications

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This book has assembled an array of chapters on the social and psychosocial aspects of HIV/AIDS and their impact on HIV/AIDS and related behaviours. The book addresses key areas of HIV and AIDS, including, but not in any way limited to, care-seeking behaviour, adherence, access, psychosocial needs and support services, discrimination and the impact the epidemic has on various sectors of the economy. The book has seventeen chapters; seven chapters deal with social aspects of HIV/AIDS, four with psychosocial aspects of HIV/AIDS, and the remaining six chapters with the impact of social and psychosocial factors on HIV/AIDS and related behaviours. The book is an essential reading for academics, students and other people interested in the field of HIV and AIDS.

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Phone: +385 (51) 770 447
Fax: +385 (51) 686 166
www.intechopen.com

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Unit 405, Office Block, Hotel Equatorial Shanghai
No.65, Yan An Road (West), Shanghai, 200040, China
中国上海市延安西路65号上海国际贵都大饭店办公楼405单元
Phone: +86-21-62489820
Fax: +86-21-62489821

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