

## Chapter 29

***Psychosocial and Spiritual Care******Overview***

Although AIDS is considered the most recognized disease in the world today the disastrous impact it is having on children has not been given adequate attention. Being the weakest members of society, children infected with HIV/AIDS are crippled by having limited involvement in their care. Caregiver and health care worker (HCWs) decisions usually take precedence on what should be done to make children comfortable, which may not be in their best interest. Limited response to the psychosocial needs of children has rendered medical and clinical care inadequate. Children who are sick with HIV/AIDS often refuse to take the drugs prescribed by physicians or present with unexplained depression, anxiety, and isolation.

Caring for children affected and infected by HIV/AIDS must involve responding to their psychosocial and emotional needs. Learning how to do so can be rewarding for HCWs. To cope with the disease and adhere to the drug regimens they need knowledge about the disease and trusting attitude towards their HCWs and family carers. This calls for holistic care, which includes psychosocial care together with medical care (see Box 29.1). Palliative care for children calls for clear, simple, and honest communication between HCWs, family members, and the sick child.

Children in difficult situations need persons to trust or confide in — in the case of HCWs, they need familiar persons for continuity of care. They need support from adults who will understand them and help them cope. Sometimes this requires a lot of patience and understanding.

This chapter addresses the specific issues and strategies for meeting the psychosocial and spiritual needs of children on a one-to-one basis. Chapter 31: Family and Community Support addresses the aspects of psychosocial support that are best dealt with on a community level, including physical, social, spiritual, and educational needs.

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## Challenges Facing Children Affected by HIV/AIDS

### *Who Are Children Affected by HIV and AIDS*

AIDS is in many ways a family disease. When it enters a family, even children who are not infected with HIV are affected for many years. Children whose parents are HIV-positive pass through a series of difficult adjustments with their parent's progress through the successive stages of HIV. It is difficult to isolate children from the problem in the family. Many experience fear, confusion and stigma as they care for their dying parents.

- Children whose parents are sick with HIV/AIDS
- Children whose parents have died of AIDS
- Children whose siblings are infected with HIV/AIDS
- Children whose friends are infected with HIV/AIDS
- Children whose friends or relatives have died of HIV/AIDS
- Children who are heading their own families because their parents or relatives have died
- Children whose households are stressed by caring for children from another family

#### Box 29.1:

#### **Key Strategies to Address the Psychosocial Needs in Care and Support of Children Affected by HIV and AIDS**

**Holistic care:** First and foremost organisations providing palliative care should put in place measures to attend not only to the physical and material needs of children but also to their psycho-social needs.

**Family-centred care:** The care approaches should be family-based and offer general psychosocial support to all affected children.

**Inclusive home-based care:** Home visiting teams should attend to children in the family instead of locking them out when caring for sick and dying parents. The questions and fears of these children should be attended to rather than brushing off their questions and fears.

### *Issues of Children Affected by HIV/AIDS*

Children's problems start long before a parent dies of AIDS. With the parent's illness, family incomes fall and resources are diverted to medications and treatment. The children's physical needs may no longer be met, and there are many psychosocial problems which they face:

- Children are not always told their parents' diagnosis. They begin to be fearful and wonder about the illness.
- Children also start wondering about what will happen when their parent dies, and how they will live.
- Illness and death of parents create very traumatic feelings for children, who continue asking themselves why they are the ones who have lost their parents.
- Heading their families at a very tender age is another challenge. Usually when the parents die, the HIV/AIDS caring organisations do not have programmes to offer psychosocial support to their children.
- Most children are distributed to different relatives after their parents die, resulting in the total loss of family unity and love from even their siblings.
- Often children who lose their parents lack parental guidance, love, care, and acceptance in the new families that take them in. It takes a long time to adjust to the new environment without their own parents.
- In some instances, children fail to be taken in by relatives and they end up heading their own families. Others opt to move to town and start working as house girls or even commercial sex workers.
- At school, children affected by HIV/AIDS face a lot of stigma and discrimination when fellow children are boasting about their caring parents.
- In other instances, teachers at school and others in the community stop calling children by their names, only referring to them as orphans.

### *Issues of children infected with HIV/AIDS*

Parents and HCWs find it difficult to talk to children about the disease they are suffering from. This then compounds the depression which children with HIV/AIDS experience. When children are suffering from multiple symptoms and pains but the cause is not explained, they feel fear, anxiety, and confusion in their lives. In addition, children with HIV/AIDS experience distress associated with their symptoms and treatments, particularly invasive procedures.

The behavior of HCWs and family members in trying to keep everything a secret affects the emotions of the child being cared for. Children feel left alone, segregated, and not involved. They develop negative emotions towards life and carers in general.

Children with AIDS remain children foremost, and their needs are the same as those of all children. One study to identify the needs of children with AIDS showed that all the children identified adequate food as their primary need. Their second need was to play. None of their caregivers at home, mainly grandmothers, identified that the child needed to play (Marston, 1990).

If a child enjoys school, improving the quality of life may include the child going to school for as long as possible. The teacher may or may not be informed of the child's status. Children or their parents/guardians may demand confidentiality, and it should be respected. Projects to inform educators and scholars are found in many countries in Africa and many schools have policies that include education of the child with AIDS.

### *Issues of Adolescents*

As children with HIV become adolescents, the question of their own sexuality arises. Their positive HIV status suddenly becomes an issue, and if neglected has the potential of causing others to be infected. Some children born with HIV first show signs of HIV disease in their teenage years and they may not have known or even suspected HIV infection. Suddenly they have to deal with issues regarding death or come to terms with their parents' ultimately fatal illness.

Lastly many children orphaned by parents dying of AIDS are exploited sexually (e.g. rape, early marriage, defilement, prostitution), used as child labour, lose property inheritance, or experience religious proselytisation. Many of them have no access to healthcare or education. A few live in child/sibling headed households. The material, emotional, and human rights needs of adolescents infected with or affected by HIV must be addressed, including: health care, education, skills training, food, shelter, financial assistance, security, and clothing.

## Communicating With Children

### *How to Communicate with Children*

Communication is the foundation of the relationship between HCWs and children. The communication we use with child clients should be developmentally appropriate and sensitive (see Box 29.2). Communication should address the different needs of children including:

- Social needs
- Emotional needs
- Spiritual needs
- Physical needs

Communication should specifically address the concerns, fears, and questions of the child. Children should not be forced to tell their story. If a child cannot communicate verbally about something, there will be good reasons why that is the case including:

- Tradition and cultures: In Africa tradition children are 'seen but not heard'.
- Children in African cultures are not allowed to disagree with adults. They are brought up and always instructed to be quiet and humble and never to talk when adults are talking.
- Children feel embarrassed to discuss HIV/AIDS with adults because it relates to taboo subjects such as sex.
- Children might fear hurting adults. They might fear and hide their feeling in order to protect their parents, particularly if parents or guardians are unhappy.

### *Counselling Objectives*

Counselling a child may involve using any of the therapies for emotional care discussed in the following section, and the interaction can occur in many settings besides a formal counselling session. Some of the objectives might be:

- Assessing what the child already knows
- Assisting the child in making an informed decision
- Helping a child identify and strengthen his or her coping capacity
- Helping the child to develop positive attitudes towards life
- Assessing the needs of the child to determine
  - Child's needs
  - Available resources
  - Vulnerable areas
  - Established strength
- Establishing a trusting relationship
- Staying in touch with the child over time

#### **Box 29.2:**

#### *Advice for Communicating with Children*

- Insist on child-focused, not parent-focused, sessions.
- Talk with the child, rather than to or about him/her.
- Handle the likely reactions and questions during the process of counseling.
- Assure confidentiality or be honest beforehand about any one who will be told what the child confides.
- Be approachable.
- Avoid a commanding tone or judgmental attitude.
- Avoid imposing adult values on children.
- Avoid comparing the behavior of children under stress to other children.
- Don't make empty promises.

### *Involving Parents and Guardians in Children's Emotional Care*

Adults always find it difficult to talk to children who are seriously ill. When children are sick with HIV/AIDS everyone involved experiences stress, anxiety, and sometimes depression. Carers respond with a natural tendency to want to protect children from the truth. Parents and HCWs alike try their level best to shield children from the bitter truth of the disease they are suffering from. HCWs may speak with parents or guardians and give limited information to children. However, many children with HIV/AIDS have expressed the need to be involved and told what they are suffering from. In fact, children in counselling have explained that their refusal of drugs and noncompliance with treatment is based on the anger emanating from limited involvement in the decisions concerning their lives.

Although parents and HCWs feel that children do not know what is happening in their lives, children usually know the secrets adults think they are hiding. Children who know how to read get many hints when they visit clinics providing services to people with HIV/AIDS, especially if the clinic has AIDS clearly in the name. In Uganda, for example, they will figure out when they visit the programme called TASO that the letters stand for The AIDS Support Organization.

### *Educating Parents on How to Involve Children in Their Care*

A first step in working with children is for HCWs to find out how the parents have involved them in their care. Ask parents:

- What their children already know (about the diagnosis, whether of the parents or children, and about the disease process)
- What kinds of questions the children have already asked
- How the children respond if they are given incomplete or wrong information
- Whether children know how to read and write
- What parents have told the children when asked about the disease or when HCWs visit

Parents and guardians caring for sick or dying children are already overwhelmed and dealing with their own stress and depression. The best option is to assess how parents feel about talking to their children without being critical and blaming if they have tried to shield them from the truth. Then help the guardian or parent to explore the advantages and disadvantages of involving children. Help in allaying their fears, but do not advise them directly. As you talk to parents about involving children you will notice that they are battling with conflicting messages and advice from friends, neighbours, and families about what is right or wrong.

There are many misconceptions and cultural barriers towards involving children. But parents are being asked challenging questions by children about things such as repeated visits to hospitals, stunted growth, and bad skin. These confrontations are forcing parents to seek counselling services. When they are helped to think about it, they usually understand the value of giving their children more information about the AIDS in the family.

Our role as palliative care providers is to accompany parents and other caregivers in their struggle to offer honest clear emotional care to children, offering them the support and guidance they need.

### *Disclosure to Children*

Many children with HIV/AIDS are surviving to middle childhood and many parents find it difficult to disclose to them their HIV serostatus and the name of the disease they are suffering from. Parents fear that disclosure may subject children to stigmatisation, discrimination or ostracism. Many parents feel guilt about their children's HIV infection. However, experience has shown that children who are not disclosed to are usually aware of what is going on but pretending not to know in order to protect adults.

The family is the most important partner in the disclosure process, and most of the HCW's work should be aimed at the family. Explaining the risks of non-disclosure can help convince them disclosure is better than secrecy (see Box 29.3). Providing suggestions and support can give them the courage to follow through (see Box 29.4).

Older children may be sexually active and need to know their diagnosis for their own and their partners' protection. It may be best for parents to allow HCWs to disclose to teenagers, who may be uncomfortable talking with their parents.

**Box 29.3:*****The Risks of Non-Disclosure to Children Affected and Infected by HIV/AIDS***

- Keeping secrets increases the stigma.
- Child/parent communication is depreciated and children lose confidence in parents.
- Children may receive wrong information from playmates and neighbours.
- Children who do not know their own HIV status may not receive all the support they need, participate in their own care, or be adherent to medications.
- Adolescents with HIV may become sexually active and unknowingly infect a partner.

**Box 29.4:*****Guidelines for Disclosing to Children******Young Children***

- Provide simple information in language they can understand.
- Focus on the nature of their illness.

***School-aged Children***

- Be clear about the disclosure.
- Discuss the role of treatment where available, to provide hope and encourage adherence.
- Answer all questions truthfully and honestly.

### ***Providing Spiritual Care***

Children, like adults, have spiritual needs. These include love, hope, and trust in a higher power to take control of their situation.

Palliative care should provide children with the opportunity to appreciate the meaning and purpose of life. They should have hope in future life and be able to express their contentment with life. Signs of spiritual health include:

- Feeling forgiven
- Being free from feeling guilt
- Expressing love for others through actions
- Having hope.

For more on spiritual care, see Chapter 16.

## Therapies for Emotional Care

### Play Therapy

Children have a right and need to play. Playing is an important way in which children explore their world. Through playing children share a lot; they socialize with other children, which consequently makes them feel loved, appreciated, and accepted. In addition, children's play helps caregivers to begin to understand what type of emotions they are experiencing, as their play involves imitation and acting of feeling (see Box 29.5).

By playing, children learn to:

- Coordinate hands, eyes, bodies
- Make sense of the world
- Think, plan, make choices/ decisions
- Problem solve
- Socialize, co-operate
- Relax, build up strength
- Heal, be comforted
- Deal with emotional, social issues
- Develop imagination
- Express feelings in a non-threatening way

*(Provided by the Children's Rights Centre, Durban, South Africa)*

Children sick with HIV/ADS are often denied this play. Before they are bedridden, peers and playmates deny their sick friends play because of their appearance and general weakness. When they are eventually bedridden, they usually only receive medical care, food, and drinks, but little stimulation.

Play techniques use the natural inclination of a child to engage in play to address their emotional and psychological needs and to develop the child's adaptive capacity. Play therapy can incorporate art and narrative therapy (see below) and can be used as a vehicle for encouraging and developing open and honest communication between child and caregiver.

#### Box 29.5:

#### Play Therapy in Action

Four children aged 6, 8, 9, and 14, all HIV-positive, came to the clinic for medical check ups and were told to go for free play. They started acting out a situation in which someone had died in the home. One child acted as a child wailing because her mother was dying and crying out 'whom have you left me with' (ondekede ani) in luganda. The older child among the group acted out trying to roll the body and telling others to be firm. When the HCW heard them shouting, she came close and watched what they were doing. When she asked them what they were doing, they explained what they were doing and their reasons. Their play-acting helped the children cope with their own real situations and let the HCW know what they were dealing with at home.

### Art Therapy

Art is a potential for opening 'hidden cupboards' in a child's life. Making art (drawing, painting, creating things) enables children to express their emotional state without having to put it into words. Most children enjoy drawing, and it is a useful practical tool for counselling. Children can use art as a medium of expressing messages of hope to other children, or have 'art attacks' by using junk such as old boxes and used photocopied paper to create memories that are cost-effective and accessible at the grassroots level.

When a child has drawn something, it is good to follow up by asking the child to describe what is happening in his or her drawing. For example, Jane, aged 10, drew a picture of a man who used to do 'bad things'. When she was questioned, she told a story of how she used to be defiled by a maternal uncle who ended up infecting her with HIV/AIDS. This was important for her to share with a trusted adult.

### ***Memory Work and Life Stories***

Memory books contain records of families, where children came from, what their parents' interests were, and a family tree to show the other members of the family. Parents are also encouraged to write of their dreams for the child's future, and remember any special things that the child did, or how the parent felt when the child was born. Memory boxes are similarly a way for children to keep precious items from their parent(s) and from early childhood. Memory books may also contain a place for the birth certificate and any other legal documentation. They can also contain photographs, baby hand- and foot-prints, letters to be read at special stages of the child's life, and video recordings.

The role of memory in the bereavement process is widely acknowledged and relevant in all cultural contexts (Denis, 2003). Memory Work is a child-friendly approach to counselling that includes aspects of play, narrative, and art therapy, as well as music and dance. Memory work has its roots in Life Story Work. It is widely recognised as one of the most cost effective ways of addressing the psychosocial needs of children and families given the vast numbers of bereaved and dying people in Africa. The focus is on:

- Preparatory bereavement work
- Planning for the future care of children
- Dealing with past, present, and future issues

Memory boxes/books ensure that:

- Family origins and traditions are passed on.
- Children have a sense of history and belonging.
- Dying parents have values, beliefs, and aspirations for children's future lives documented.
- Communication channels in family are opened up.
- Plans for future care of children occur in a timely manner.
- Children are prepared to cope with losses and changes that lie ahead.
- Each child's sense of identity is built up.

Memory Work can be used in group or individual settings, with or without traditional counselling.

### ***Music Therapy***

Music therapy enables children to reflect and meditate on their own situations. Music gives hope and encouragement to children who view their lives as hopeless and rejuvenates their coping capacity. Music can be a source of pleasure and hope for bedridden children.

### ***Narrative Therapy***

Narrative therapy is the 'restorying and reauthoring' of life stories, in which the individual is involved in the identification and performance of empowering and liberating plots (Morgan, 2003; Soskolne, 2003). In this counselling approach, the child or adult uses story telling as a means of dealing with past and unresolved issues. People tell their own stories and recreate their pasts. They can, for instance, construct stories in which they overcome an obstacle. Narrative therapy opens a space for thinking about alternative stories that can be told, suggesting a way forward for those whose stories have had to be suppressed. It provides an opportunity for creating positive memories.

### ***Drama***

Drama or role-play is an excellent way for children to raise issues they want to communicate with others but find difficult to discuss directly. Children who are neglected, stigmatized, and abused at home find it easy to demonstrate their situations through drama.

## Rights of Children

Children living in poverty and an unsafe environment, without protection and with inadequate care, have their rights violated daily. Agencies and HCWs have an ethical obligation to act on their behalf because they are vulnerable and cannot defend their own interests. The UN *Convention on the Rights of the Child* (UN, 1989) and the *African Charter on the Rights and Welfare of the Child* (OAU, 1990) should be the main guiding principles of psycho-social care for children. These documents specify that a child has a right to:

- A name, nationality, and sense of identity
- Affection, love, and understanding
- Opportunities for play and recreation
- Opportunities to learn to be a useful member of society and to develop individual ability

All the care and support should centre on the best interests of the child.

**Nondiscrimination between children:** Hence children sick with a terminal illness should not be discriminated against. An inclusive approach should be used while dealing with sick children.

**Openness and truth:** Most children prefer to know the truth and view disclosure of their sickness positively. Openness and truth prepare children and parents for impending death. Secrecy and denial can have effects on children's long-term psycho-social health.

**Preparing children and parents for impending death:** Discussing children's illness helps to overcome their fears and worries. Understanding and addressing the fears facilitate children's capacity to cope with grief.

**Recognizing the individuality of children:** The way that illness and death are explained should be appropriate to the needs of each child. Children will respond differently to situations and will have their own psycho-social needs

**Participation and involvement of children:**

Children should be included when HCWs and parents are making decisions about their health care.

**Spiritual care in children:** Children receiving palliative care should also receive spiritual guidance and support based on their respective religious or spiritual backgrounds.

See Chapter 31 (Family and Community Support), Chapter 22 (Ethical and Human Rights Issues) and Chapter 24 (Financial and Legal Issues) for more information.

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