

communicate their emotions in depth verbally. Discomfort is often described as “feeling bad” or “it does not feel good”. In a peer group discussion with two senior Zulu-speaking social workers (Mrs Mahlangu & Mrs Mabena on 2005.10.14) it was explained that there are very few words in Zulu to describe emotions and that the discussion of emotions is not deemed appropriate by traditional households. Discussions about the deceased are also not seen as appropriate.

The young participants expressed the following emotions during the interviews:

TABLE 3
EMOTIONS EXPRESSED BY PARTICIPANTS

EMOTION	CONTEXT	EXPRESSION
Sadness	Remembering the parent	“... We miss her a lot. I feel sadness if I think of her.” – ZA “I cry if I am reminded of her.” – BERN
Guilt	Not being at father’s funeral Selling mother’s possessions to survive Not being able to ‘unveil the tombstone’ Feeling guilty about being a burden	“I felt very bad, because I was not able to see him for the last time.” – MZ “It felt so bad- she worked so hard for it, but we had no choice.” – ZA “There is no tombstone. It feels so bad.” – ZA “I am just trouble. My grandmother said that. Where to get food from?” – NOMV
Loneliness	At night Talking about her family Talking about feelings	“I felt so lonely that I sometimes my mother is calling me.” – NH “...so, I really have no-one left.” – GU “There is no-one to listen.” – BAWN
Humiliation	Asking for food or money About not having clothes	“They talk and talk before they give. It makes me feel not good inside.” – BAWN “It was very hurtful” – BD
Anger	Why did it happen to me?	“I am angry” – NH “I was so angry. I ran away if someone wanted to help me.” – SF
Powerlessness	Unable to cope	“I did not know what to do anymore.” – SIMP “They did not want to help me.” – MZ “I am waiting for months now (for foster care grant).” – BAWN
Pain	Thinking about parent	“I feel so much pain. I don’t want to cry, because the last time I cried was at my mother’s funeral.” – NH
Irritation	Not having a variety of food Dealing with younger cousins or siblings	“Pap and eggs- it really irritates me.” – NH “They are noisy.” – ZA “I can only do homework when they went to bed.” – NH
Fear and Worry	Looking after parents whilst ill Worry about what will happen if grandparents die	“I was so scared.” – TH “I was very worried, because he was the only person who was looking after me.” – MZ “I worried when she (grandmother) also passed away”. – GU “Things became really bad when my grandfather died. It was so terrible when my grandmother also died and we worried because we did not have anybody then.” – SIMP

Sub-theme 2.3: Poverty as a result of being orphaned

Demmer (2004:40) indicated that the South African Social Welfare system is unable to adequately meet the needs of children orphaned by HIV/AIDS, as there are still thousands of children who are waiting for services. The provision of care for orphans when their foster parent

grandparents pass away is also a worrying factor, as it appears from the study that children then depend on children's homes or child-headed families for care.

Food security is affected first when the breadwinner of the family gets sick or die. Foster (1997:15) mentioned food stinting and the selling of furniture and assets as a way in which a severely affected family attempts to cope with food shortages:

We only ate once a day for a long time- we only ate at night... maybe for two months. My granny tries to buy clothes. – BAWN

We did not have enough food at that time, because my father was not working. Sometimes we did not eat for two days. – TH

We did not have money or someone to fix the house. The roof was taken by the wind (blown away). So then we stayed outside most of the time. We only had pap to eat and sometimes maroggo. The uncles sometimes brought a chicken. – NVA

We had no food. Everything we had to ask. Sometimes we only drank water. The worst was when the small ones ask for food and I have nothing to cook. – SIMP

We had to sell the furniture of my mother. – ZA

Access to proper clothes and school clothes appears to be a constant source of worry and humiliation for the participants.

Sub-theme 2.4: Coping with being an orphan

Poverty resulting from the HIV/AIDS pandemic can lead to the sale of assets or land. Orphans may even have to turn to crime or sex as a survival option (Smart, Pleaner & Dennil, 2000:93; USAID, 2002:4). Meintjes, Moses, Berry and Mampane (2007:22) explain: "Poverty exacerbates the difficulties for caregivers raising children, and heightens children's risk of neglect, abandonment and possibly abuse." The participants in the study reported the following strategies to cope with the sudden loss of parental income:

We were selling sweets and fruit. – BD

We don't have furniture anymore. It was sold for food. – BD

We had to ask food from the neighbours. – BD

I stole money...even from my grandmother to get food. I was also tempted to do housebreaking when we did not have anything to eat. That is why I am here (Secure Care Centre). – BD

Sub-theme 2.5: How it was decided where i should stay

Living with uncertainty poses a great challenge to the secure psychological base essential to a child's development of a healthy and functional personality (Geballe & Gruendel, 1998:51). It was interesting to note that all the young persons who participated in the study initially remained in their original homes after their parents' death. They were only removed or assisted by family when serious problems arose. In some cases the young persons remained in the home they knew, mostly with grandparents or maternal family (for example AY, TH, GU). Richter *et al.* (2004:16) hold that older caregivers may have difficulties responding to the economic, health and psychological needs of children and that they may suffer severe resource constraints.

The absence of a formal family decision about their future is a constant source of disappointment and humiliation for the adolescents in child-headed households:

They (family) did not decide because we stayed in our homes. After the funeral, just immediately when we came back from the graveyard...two hours and we were left all alone. That is when we made the decision to stay away from them, because they showed us

that they did not really care. – NH

They knew my sister became sick and we had to look for food in the dustbins. They just made as if they did not know us. Except my grandfather, but he is old. Other people wanted us, but just for the money. When they saw they will not get it, they chased us away. – SF
I always lived with my granny. It is my home. – AY

THEME 3: PARENT'S ILLNESS AND DEATH

Children's psychosocial distress begins with a parent's illness, and they are left emotionally and physically vulnerable by the death of one or both parents. They may suffer lingering emotional problems from attending to dying parents and seeing parents die (Hunter & Williamson, 2002:17).

Sub-theme 3.1: This is what I saw

The clinical course of HIV/AIDS is disturbing to the infected person and affected family. The participants in the study were not required to reveal the actual illness of their deceased parent or parents, but to describe the symptoms they observed.

The last week before she passed away, she was unable to eat...she could only drink mageu...she could not swallow anything. It was so terrible. – NH

He was coughing and sometimes he could not even walk. I had to make fire for him to keep him warm. He died at home, but I was not there. – MZ

It was terrible. Her face was so swollen, you could actually not see where her eyes were, cause the black thing of her eyes totally disappeared. It was so terrible – she had so much pain and she could not do anything. She was in a Pretoria hospital but they could no longer help her. – GU

She was coughing and blood and phlegm came from her mouth. She was screaming sometimes with pain. It was terrible. She died in hospital. – BD

She was so sick. She was talking no sense and she was urinating in bed. My sister ran away, she could not take it. I did not know what to do. They took her to hospital. – SF

Sub-theme 3.2: Funerals and illness of other people

According to German (2004:19), children affected by HIV/AIDS suffer multiple losses. This may result in "bereavement overload" (Richter *et al.*, 2004:32-33; Geballe & Gruendal, 1998:52). SIMP saw the death of both her primary caregivers in a period of six months. From the study it became clear that funerals and the illness of other persons are a source of secondary trauma for them, as it brings repressed memories and emotions to the fore.

I cannot handle funerals. I cannot handle it anymore, it is too painful. I don't want to remember. I don't want to cry. Even now, if you can tell me someone is sick, I would not ... even...the person could rather go. I am scared if people are really sick. – NH

It just came back when my grandmother also died. It brings back memories. You don't really cry for the person who died, but for your mother or grandmother. I prefer not to go to other people's funerals. I don't like dead people- I saw my grandmother also - now I rather stay in the car. – GU

FINDINGS ON THE EXPERIENCES OF ADOLESCENTS ORPHANED BY HIV/AIDS-RELATED CONDITIONS

The researcher is of the opinion that orphaned adolescents experience their environment both as supportive and hostile. Social workers featured seldom as a source of support, but rather as

inconsistent providers of material needs and broken promises. Friends and siblings are the most trusted sources of support, together with home-based care groups. Hurt and anger are mostly the result of being betrayed, gossiped about or rejected by family members or those in helping professions.

All the participants reported some form of significant change in their life as a result of the death of a parent. Some experienced extreme poverty as a result of the loss of income. Deprivation and shame because of food shortages were some of the experiences related by the participants. Most of the young people reported feeling sad or depressed most of the time, struggling to understand what has happened to them.

The experiences of adolescent participants can be summarised as follows:

- They experience a lack of emotional and physical support from their extended families;
- Paternal families of unmarried parents are often not involved in the care of orphans;
- Poverty is often a result of being orphaned by HIV/AIDS-related circumstances, and leads to food stinting, inadequate clothing and shelter as well as acts of desperation like theft;
- The community and church are not perceived as supportive by adolescent orphans;
- Schools are seen as a source of support by most orphaned adolescents;
- Sadness and fear are the two most common emotions experienced by the orphaned adolescent;
- Home-based care groups are seen as the most constant source of assistance;
- The adolescent in a child-headed household has no legal protection against family members who want some of the deceased parents' possessions;
- Orphaned adolescents have insufficient opportunity to mourn their parents because of cultural norms;
- Traumatic memories are suppressed;
- Orphaned adolescents living with grandparents have a significant risk of being displaced for a second time, if grandparents become ill or pass away;
- Caregivers are not always capable or suitable to care for orphans;
- Awareness and prevention campaigns do not take cultural beliefs and practices into consideration.

RECOMMENDATIONS

Based on these findings, the following proposals are put forward for government and other social work service providers to consider.

Recommendations for the improvement of services on a micro-level

- Improved foster parent screening
The researcher is of the opinion that some family members are not suitable as foster parents and that it is not always in the interest of children to be placed with an extended family member.
- Improved awareness and prevention campaigns
Assistance of traditional leaders should be considered when prevention campaigns are planned. The distribution of condoms alone cannot create understanding and behaviour changes.

- **Establishment of support groups**
Adolescents experience their siblings and friends as most reliable sources of support, and so support groups can therefore assist them to feel less isolated. Group assistance will enhance resilience.
- **Life skills camps and programmes**
Young persons in child-headed households need training in some of the basic life skills, such as cooking, personal hygiene and household chores, to meet their own needs. Camps held during the school holidays can also address issues such as self-awareness, emotional development and grief.
- **After-school centres as respite care**
Most of the participants indicated that they have very little assistance when it comes to homework and studying. They have to look after younger siblings, cook for them and wait until they go to bed before they can study themselves. The provision of after-school centres, where younger children can eat, play and be assisted with homework, will provide more free time to the adolescent who has care-giving responsibilities.
- **Gender issues**
Female respondents experienced that their education is considered to be of less importance than that of their brothers. In most cases it was the young girls who have to take care of the sick and dying parent(s) and to look after the younger children in the family.

Recommendations for improvement of services on a macro-level

- **Strengthening of home-based care organisations**
Home-based care organisations are perceived in a positive light by adolescent orphans and therefore these organisations can be strengthened by government and civil society to become fully-fledged social welfare organisations that can provide the following services:
 - Support groups;
 - Bereavement counselling;
 - Consistent food security and economic support;
 - Nursing of ill family members;
 - After-school care;
 - Provision of fun activities;
 - Education of foster parents;
 - Foster care supervision;
 - Marketable skills training.
- **Increased children's home capacity as last resort caregiver**
Several orphaned adolescents will eventually need institutional care, even though care within the community would be the preferred option. An increase in this capacity is needed in order to provide for the escalating number of children orphaned by HIV/AIDS. This can prevent some children from living in child-headed households of falling prey to unscrupulous community members who take in children in order to obtain the foster care grant.
- **Assisted living for child-headed households**
Child-headed households appear to be a phenomenon that is here to stay. Some models of assisted living, such as the Isibindi Model, do exist but on a small scale. It is recommended that government should make provision for specific funding for this kind of project, including the employment of community childcare workers or auxiliary social workers.

- Support from communities
Awareness within societies must be raised to create an environment that enables support for children affected by HIV/AIDS.

Recommendations for improvement of services on a meso-level

- Legislative changes
It is recommended that legislation be improved to protect the property of children orphaned by HIV/AIDS, as the appointment of a guardian from the family often leads to the assets of the children being distributed amongst family members. Changes to the Social Assistance Act to enable orphaned children to access financial assistance without a statutory process (so-called subsidised adoption) would also increase the quality of life of thousands of South African children.
- Provision of affordable anti-retroviral medication
The improvement of the life expectancy and quality of life of HIV-positive parents is the most logical manner in which to assist their children. It is recommended that suitable, affordable medication be made available as far as possible in order to increase life expectancy.
- National Youth Service
The National Youth Service may be a possible manner in which the unemployed late adolescent can be utilised in some community development, whilst earning a stipend. This will increase their own standard of living, as unemployment was identified as a source of serious stress for the late adolescents. This will also increase the employability of these young adults, as they will be exposed to the working world.
- Address gender issues
Give attention to the role of boys and girls to address gender discrimination.
- Reduce stigma and discrimination
Provide information to reduce stigmatisation and discrimination.
- Accelerate learning opportunities
Prevent adolescents dropping out of school by setting up community-based schools and/or informal education. Interactive radio instruction programmes for out-of-school children (IRI) must be explored.
- Provision of early childhood care and education
Provision of safe care for smaller children could give adolescents the opportunity to continue their own education or home care while parents are ill.
- Assisting schools to provide psychosocial support for affected children
School social workers could address the psycho-social problems of adolescent orphans.
- Work to prevent HIV infection among adolescents
Community mobilisation and awareness programmes must be made available and implemented.

REFERENCES

- ALPASLAN, N. & MABUTHO, S.L. 2005. The experiences of elderly grandmother caregivers and AIDS orphans. *Social Work/Maatskaplike Werk*, 41(3):276-295.
- BABBIE, E. 2004. *The basics of social research* (3rd ed). Belmont: Wadsworth/Thompson.

- BARNETT, T. & BLAIKIE, P. 1992. **Aids in Africa: Its presence and future impact**. London: Belhaven Press.
- BLESS, C. & HIGSON-SMITH, C. 2000. **Fundamentals of social research methods: An African perspective** (2nd ed). Cape Town: Juta.
- CASTROGIOVANNI, D. 2004. **Adolescence: Change and continuity - peer groups**. Available: <http://inside.bard.edu/academic/specialproj/darling/adpeer1.htm>. [Rev. 2004.08.06].
- DEMMER, C. 2004. Loss and grief following the death of a patient with AIDS. **Social Work/Maatskaplike Werk**, 40(3):294-315.
- DEPARTMENT OF SOCIAL SERVICES, POPULATION AND DEVELOPMENT. 2000. **The demographics of poverty in Mpumalanga**. Pretoria: Department of Social Services, Population and Development.
- DEPARTMENT OF SOCIAL DEVELOPMENT. 2003. **National guidelines for social services to children infected and affected by HIV/AIDS**. Pretoria: National Department of Social Development.
- DEPARTMENT OF HEALTH. 2007. **Training manual- operational plan for comprehensive HIV and AIDS care, management and treatment for South Africa**. Social Tract Module on HIV-related stigma. Available: <http://www.doh.gov.za/docs/misc/hiv-f.html>. [Rev. 2007.08.04].
- DWIVEDI, K.N. 1999. **Group work with children and adolescents**. London: Jessica Kingsley Publishers.
- FELDMAN, R.S. 2004. **Child development** (3rd ed). USA: Pearson/Prentice Hall.
- FOSTER, G. 1997. **Children rearing children: A study of child-headed households**. Paper presented at the Conference on the socio-demographic impact of AIDS in Africa, held 3-6 February 1997. International Union for the Scientific Study of Population: Durban.
- GEBALLE, S. & GRUENDEL, J. 1998. **Forgotten children of the AIDS epidemic**. London: Yale University Press.
- GERMAN, S. 2004. Psychosocial impact of HIV/AIDS on children. **Medical Research Council Aids Bulletin**, 13(2):18-22.
- GIESE, S., MEINTJES, H., CROKE, R. & CHAMBERLAIN, R. 2003. **Health and social services to address the needs of orphans and other vulnerable children in the context of HIV/AIDS in South Africa: Research report and recommendations**. Report directed to Department of Health, January 2003. Cape Town: Children's Institute, University of Cape Town.
- GRIESEL-ROUX, E. 2004. **A case study exploring learners' experiences of HIV/AIDS programmes**. Pretoria: University of Pretoria. (D. Phil (Psych) dissertation)
- GUBA, E.G. & LINCOLN, Y.S. 1989. **Fourth generation evaluation**. Beverley Hills: Sage.
- HUNTER, S. & WILLIAMSON, J. 2002. **Children on the Brink. Strategies to support Children Isolated by HIV/AIDS**. Arlington USA: US Agency for International Development (USAID).
- LIGHT, M. 2004. **Adolescence: Change and continuity: Cognitive transitions**. Available: <http://inside.bard.edu/academic/specialproj/darling/adpeer1.htm>. [Rev. 2004/08/06].
- LOUW, D.A., VAN EDE, D.M. & LOUW, A.E. 1998. **Menslike ontwikkeling** (3^e uitg). Kaapstad: Kagiso Tersiêr.
- MABUTHO, S. 2004. **The experience of elderly grandmother caregivers and AIDS orphans**. Port Elizabeth: University of Port Elizabeth. (MA (SW) dissertation)

- MEINTJES, H., BUDLENDER, D., GIESE, S. & JOHNSON, L. 2005. Children 'in need of care' or in 'need of cash'? Social security in the time of aids. **South African Review of Sociology**, 36(2):238-268.
- MEINTJES, H., MOSES, S., BERRY, L. & MAMPANE, R. 2007. **Home truths: The phenomenon of residential care for children in a time of aids**. Children's Institute, Centre for the study of AIDS. Pretoria: University of Pretoria.
- NELSON MANDELA CHILDREN'S FUND. 2001. **Report on: A study into the situation and special needs of children in child headed households**. Pretoria: Nelson Mandela Children's Fund.
- NEUMAN, W.L. 2000. **Social research methods: Qualitative and quantitative approaches** (4th ed). Boston: Allyn & Bacon.
- POGGENPOEL, M. 1998. Data analysis in qualitative research. In: DE VOS, A.S. (ed) **Research at grassroots: A primer for the caring professions**. Pretoria: JL van Schaik Academic.
- RICHTER, L., MANEGOLD, J. & PATHER, R. 2004. **Family and community interventions for children affected by AIDS**. Cape Town: HSRC Publishers.
- SMART, R., PLEANER, P. & DENNIL, S. 2000. **A primary HIV/AIDS capacity development course for government planners**. Pretoria: Department of Social Development.
- STRODE, A. & GRANT, K. 2001. **The role of stigma and discrimination in the vulnerability of children and youth infected with and affected by HIV/AIDS**. Report commissioned by Save the Children (UK). Pretoria: Save the Children.
- TUTTY, L.M., ROTTHERY, M. & GRINNELL, R.M. 1996. **Qualitative research for social workers**. Needham Heights: Allyn & Bacon.
- UNICEF. 2003. **Africa's orphaned generation**. New York: UNICEF.
- USAID. 2002. **Children on the brink. Strategies to support children isolated by HIV/AIDS**. Washington DC: USAID.
- VIVIERS, A. 2004. **The application of the developmental approach with respect to assessment and programmes for children and youth**. Pretoria: UNESCO.

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