Needs of children affected by HIV and AIDS: Mangaung in the Free State

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The terminal illness or death of a parent due to HIV and AIDS has a disastrous effect on the surviving children. The purpose of this study was to explore and describe the needs of HIV and AIDS orphans and pre-orphans. A qualitative method using in-depth interviews with 10 children affected by their parent's illness or death was carried out. Results indicate that there was a marked reduction in financial capital paving the way for basic physical needs such as food, clothing, fuel and shelter. Lack of school fees, uniforms and transport money together with biased teachers and rigid school policies were affecting school attendance and performance. On the psychosocial level needs expressed were for family and community support, friendship, acceptance by the group as well as love and belonging. It seems as if stigmatisation and resulting ostracism by important-others is a drawback at all levels of interaction for AIDS orphans and pre-orphans.

Abstrak

Die terminale siekte en dood van 'n ouer a.g.v. MIV en VIGS het 'n sterk negatiewe effek op die kinders wat agterbly. Die doel van die studie was om die behoeftes van MIV weeskinders en kinders wie se ouers sterwend was, te ondersoek en te beskryf. 'n Kwalitatiewe metode, waartydens in-diepte onderhoude gedoen is met 10 kinders wat beïnvloed is deur hul ouers se siekte en/of dood, is gevolg. Die resultate het getoon dat daar 'n merkbare afname in die beskikbaarheid van geld was wat gelei het tot 'n tekort aan die basiese behoeftes soos kos, klere, brandstof en beskutting. Skoolbywoning en prestasie is negatief beïnvloed deur gebrek aan skoolgeld, bevooroordeelde onderwysers en rigiede skoolbeleide. Op die psigo-sosiale vlak was daar 'n behoefte aan ondersteuning, vriendskap en aanvaarding van familie en die gemeenskap. Daar was ook die behoefte aan liefde en om te behoort. Dit blyk dat die stigmatisering en die verwerping van die belangrike-ander in die kinders se lewe, hulle op alle vlakke van die lewe strem.

Introduction

It is an accepted fact that the Human Immune virus (HIV) and the cluster of diseases it causes, Acquired Immune Deficiency Syndrome (AIDS) has devastated Sub-Saharan Africa. An estimated 80% of the millions of deaths have occurred in this region (Dorrington, Bourne, Bradshaw,. Laubscher and Timaeus, 2001:3). As shocking as these deaths may be, we have to consider the fact that the impact of HIV and AIDS on the lives of the children in this region of the world defeats description.

The disastrous effect of AIDS manifests in the vast number of children who watch as their parent(s) slowly become ill and ultimately die. In South Africa it is estimated that by the year 2015 children orphaned by AIDS will comprise 9 to 12 % of the total population of South Africa

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(Smart, 2000). With the strategic use of anti-retroviral drugs by pregnant mothers, at least 70% of children will be born without the HI virus while there is a 100% chance that they will be orphaned (Whiteside, 2000). Therefore Sub-Saharan Africa will be raising an orphaned generation in societies already weakened by social and economic problems and underdevelopment.

The AIDS epidemic has the following consequences for the children: they may become orphaned or abandoned as a result of AIDS; they may be members of an HIV infected family and at risk of becoming infected; or they may be living in an affected family but be members of a community which has suffered the socio-economic devastations brought about by HIV and AIDS (Smart, 2000).

HIV and AIDS affects children long before their parents die. It is pertaining to such a situation that the term "pre-orphan" is used to describe a child who has not yet lost a parent to HIV and AIDS, but nonetheless, who is caring for his/her terminally ill parent (World Bank and UNICEF, 2002:2, 6).

The developing child has a diverse range of needs on the physical, emotional and social level which are mostly underpinned by financial need. The needs of AIDS orphans and pre-orphans are neglected at most levels as their parent/s become ill and die.

The physical and developmental needs of the growing child are many and varied. The mother normally functions as the primary care giver and takes care that the child is clothed, warm and safe; she provides nutrition and she oversees and teaches cleanliness and hygiene; she responds to physical ailments, ensures that the child is immunised against communicable diseases such as measles, polio and tuberculoses. With little or no response to these needs children may suffer hunger, cold and general physical neglect. They may be predisposed to infectious diseases and at risk of contracting HIV and AIDS.

The psychological or emotional needs such as love and security, the need for praise and recognition and the need for new experiences and responsibility which are essential to the growing child will be unmet and may lead to psychological underdevelopment. The

social needs of the child are closely linked to the emotional needs and are manifested in varying relationship needs such as the need for friendship and the need to belong to a group. The timely fulfilment of these needs is related to the development of a healthy self esteem and an individual who grows up confidently with the psychosocial skills needed to function as a well adjusted adult. For the AIDS orphan and pre-orphan there may be many shortcomings in this process as so many of their psychosocial needs are not met.

As parents become ill or die children are left at a crossroad where their lives have the possibility of following one of the following courses. They can be taken in and cared for by the extended family such as aunts and uncles, they may be cared for by grandparents, or they may care for themselves with the eldest becoming head of the household and caring for siblings. In all of these scenarios the community may offer assistance to whoever is caring for the children. In most cases families or communities who could have taken over their care and made a difference, turn away. The reasons being that as HIV and AIDS take its relentless toll, the situation of orphanhood is fuelled by poverty, prejudice and ignorance. Accordingly the ability and/or desire of the affected families and communities to support these children is vastly reduced or non-existent.

The problem of the AIDS orphan or pre-orphan should be seen against the background of stigmatisation of people suffering from HIV and AIDS and the economic crises that many communities are experiencing.

The traditional African model of surrogate parenting seems to have become dysfunctional and remains questionable. The lack of knowledge and understanding born out of stigma, discrimination and fear regarding the nature and transmission of HIV and AIDS have denied many children the option of surrogate parenting by the extended family. The families and communities that are expected to respond to the plight of the AIDS orphans and pre-orphans are also faced with the social and economic problems that prevent them from total commitment to the care of any child affected by AIDS (Kerkhoven, 1998:4-5). Grandparents might sometimes take on

the responsibility of the orphaned child, yet this situation offers its own dilemmas. Grandparents are usually very old and very poor and have to struggle to raise orphaned children on meagre government grants. According to Foster (1997) the average age of grandparents recruited into childcare is 62 years. At this age and with their economic problems one could expect the children in their care to be disadvantaged at many levels of development.

According to UNAIDS, UNICEF and BLCA (1999; 1-3) children often become heads of households at primary school age. In such cases they take care of siblings and sick or dying parents. Not only are these children deprived of parental care and nurturing but they also have to play the role of adults in taking care of younger siblings. These children are not equipped to take care of younger siblings and cannot meet their physical and psychosocial needs. Many older children leave school and jeopardise their own health and developmental needs in order to take on roles as parent, nurse and provider.

The AIDS orphan situation leave some children without shelter as they are abandoned, sent from one relative to another because their extended family already have too many children to take care of or because of the stigmatisation of AIDS orphans. These children are left living on the streets and deprived of basic needs, dignity and their human rights. Street children are easily drawn into crime and the selling of sexual favours because of hunger or a need to belong. This will predispose them to HIV, other sexually transmitted diseases and unwanted pregnancies.

Families frequently experience abandonment and social isolation once the diagnosis of HIV and AIDS have been made and is known publicly. The fear, stigmatisation and ostracism of people with HIV and AIDS is reflected on the children when they too are discriminated against or when they isolate themselves from their peers due to the shame they feel for a parent who suffers from the disease.

Many communities affected by HIV and AIDS are already disadvantaged and as the income of the HIV parent is reduced due to loss of earnings, because of repeated sick leave and high medical

costs the children are plunged into even deeper economic crisis and high insecurity levels.

Children are exposed to the HI virus in several ways. They may contract HIV and AIDS through vertical transmission, sexual exploitation and unsafe cultural practices as in the case of scarification and circumcision.

There are various ways in which children are affected by HIV and AIDS. This limits their possibility of a successful childhood, which in turn could affect their future as productive members of the community.

The purpose of the study was to explore and describe the needs of children affected by HIV and AIDS. In so doing it was hoped to understand the children's needs from the totality of their life ways bearing in mind the dynamic interplay of these life ways with their social, economic, political, religious and cultural values within historical and meaningful life events.

Method

Based on the purpose of the study, a non-experimental research design of a descriptive, exploratory and contextual nature in the qualitative paradigm was used to explore and describe the needs of children affected by HIV and AIDS. The method of in-depth unstructured interviews was used to gather data.

The study was descriptive because it sought to understand the actual state of the children affected by HIV and AIDS, as disclosed by their uninterrupted descriptions of their real-life situations. The study was exploratory because of the little theoretical knowledge of orphan- and pre-orphanhood consequential to HIV and AIDS which is a persistent phenomenon. The study was also contextual in nature as the phenomenon of "needs" of HIV and AIDS orphans and pre-orphans were studied directly from the children who experienced the needs intrinsically and within the context of their natural life settings.

Population and sampling

For the purpose of this study the population consisted of children affected by HIV and AIDS. The sample in this study consisted of 10 children in Mangaung whose parent/s was/were ill

or had died due to HIV and AIDS and had been or were currently under the Home Based Care Program of the Naledi Hospice. The children were of different age, sex and cultural background. (See Table 1.)

The sampling method that was used was a non-probability convenience sampling method. The greatest advantage of the convenience sampling method is the way it creates accessibility to respondents that may be recruited for a study. To select the children they had to fulfil certain inclusion criteria. The inclusion criteria for the study were as follows:

- Children were between the age of 11 and 18 years. At this age their cognitive development allow them to be more aware of their needs, hence it was easy for them to verbalise their needs; as at this age their operational thinking allow them to hypothesise about possible outcomes of problems and to evaluate these outcomes comparatively (Pawik & Rosenzweig, 2000).

- The children were able to speak Sesotho, IsiXhosa or Tswana, as these are the main languages of Mangaung and the researcher is fluent in them.

- The children were all residents of Mangaung, as the study concerned the children in Mangaung affected by HIV and AIDS.

- The children expressed their willingness to participate in the study.

- The children were either paternal or maternal orphans or both due to HIV and AIDS or;

- Either one or both parents were ill due to HIV and AIDS.

- The caregivers of these children gave consent for the children to participate in the study.

- Children 18 years of age gave consent themselves as they were heads of households.

The participants were found through the home-based care workers from Naledi Hospice who introduced the researcher to the families that were affected by HIV and AIDS and the children that met the inclusion criteria were recruited to participate in the study. Home-based care workers had been either looking after the ill parent (pre-orphan) or had looked after the deceased parent (orphan). The home-based care workers explained the research purpose and procedures to the caregivers of the family in order that the caregiver may give informed consent for the children's participation in the study. In qualitative research the determinant of sample size is the saturation of data. This occurs when there is emergence of repeating themes or when no new information is being discovered from the interviews. In this study saturation was reached after 10 participants had been interviewed.

Research technique

In this study data collection was done by way of in-depth unstructured interviews with each of the participants until saturation of data was reached. This method is applicable for gaining information from participants who have a low literacy level. This is a face to face interview in which one person – the interviewer – attempts to elicit information or expressions of opinions, attitude, values, perceptions and experiences from another person or persons concerning his/her environment. The aim of the researcher was to discover the needs of children affected by HIV and AIDS as well as to understand the meaning attached to these needs by the children.

Pilot study

A pilot study was undertaken to test the level of understanding of the interview question. Two children were used who were not later included in the major study. One was a pre-orphan and one was an orphan. It was discovered that they could not relate to the meaning of the word "need" when asked about their needs but that they could respond when asked about their problems. It was decided that "problems" would be the operative word when interviewing the children.

The process of data collection

Before commencing the study, written

consent was obtained from the formal gatekeepers. This included the caregivers/parents of the participants.

Interviewing involves a good relationship between the interviewer and the participants and therefore the process by which the interviewer gains access to the participants and makes contact with them is crucial. The home-based care workers from Naledi Hospice introduced the researcher to the orphans and the families of the pre-orphans that met the sampling criteria. These home based care workers had a good relationship with the participants and the families of the participants. By accessing the participants via the home based care worker the researcher firstly built a relationship with the caregivers and later with the participants.

On the first visit the researcher, wearing a professional uniform was introduced to the caregivers or parents as a nurse researcher who was interested in the needs of children whose parents are ill or deceased. The concept of HIV and AIDS was only mentioned to those caregivers and participants who knew the status of the parents, or to the parents who had had their status disclosed. The researcher showed genuine concern for, and interest in the family as a whole. These social skills were used to build rapport with the caregivers. After establishing trust with the caregivers an appointment was made to meet with the participant. This would be the second visit to the family.

On the second visit the researcher met the participants individually and the purpose of the study as well as the ethical issues was explained to them. After the participant agreed to participate an appointment was made with each one for the interview. The participant's choice of location, date and time was accommodated. A third visit was made to confirm the appointment for the interview and to have an opportunity to build a good rapport with the participants before the interview took place. Eight of the interviews were done at the participants' homes and two were done at the local clinics on request of the participants. The interviews were done in quiet and relaxed settings which were free from daily disruptions. An effort was made to keep each participant in the natural environment that was contextual to his/her experience. Before the research question was asked the interviewer helped the participant to relax by engaging in ice breaking conversation concerning topics such as sports, homework and school.

For the pre-orphans the central question was:

• Will you please tell me more about all the problems that you are encountering since the illness of your mother/father

For the orphans the question was:

• Will you please tell me more about all the problems that you encountered since the death of your mother/father

The participants were given sufficient time to think about and describe their needs freely and extensively in their own words. The narrative presented an account of their perspective on experiences and the essence of meaning that they were giving to that part of their reality (Cormack, 2000; Kvale, 1996; Maxwell, 1996).

The interviewer used well established communication skills of listening, handling of silence, reflection and probing to facilitate responses of the participants. All interviews were audio taped with permission of the participants using an unobtrusive tape-recorder so as not to intimidate the participants too much.

Field notes

Besides the interviews the researcher made use of field notes to collect data as a validation of information given by the participants. The researcher kept a written account of all the things heard, seen, experienced and thought in the course of collecting and reflecting on the data. This was for the purpose of remembering, retrieving and for the analysis of data.

It is of relevance to note that the researcher felt very strained during the study because of the emotional and physical neediness of the respondents. In some cases she had to take food packages since the respondents could not function on an empty stomach. In addition she took care of an ill parent and helped with homework. The emotional bonding aided interviews but made it difficult to leave the settings.

Data presentation and literature control

The sample of the study comprised 10 children from Mangaung who were either orphans or pre-orphans and were or had been part of the Naledi Hospice Home Based care System. The following table gives a description and an analysis of the composition of the group.

TABLE 3.1:   Demographic information of the sample (N=10)

CRITERION	CHARACTERISTIC	FREQUENCY
Age	11-15 years	5
	16-18 years	5
Ethnicity	Xhosa	3
	Tswana	4
	Sotho	3
Gender	Male	6
	Female	4
Various ways of being affected	Pre-orphans	4
	Orphans	6
Years of (experience) being affected	1999-2000	6
	2001-2002	4

The caregivers of the six orphaned children comprised four grandparents, one aunt and one male child who was the caregiver of his family.

Qualitative data analysis is a process of systematically organizing interview transcripts and field notes until they are understood in such a way that the research question is addressed (Minichiello, Aron, Timewell & Alexander, 1992:285). The data analyses method of Tesch (1990) was followed in this study. After following this process it was possible to group the data into four main categories and sub-categories of needs. These were the following:

- Physical needs (food, clothes, shelter, and fuel).
- Economic needs (financial capital, physical capital).
- Psychological needs (relationships, love and belonging, self-esteem, information, counselling).
- Control need (independence, family unity).

Physical needs

The study indicates that there is a high frequency of the expression of physical needs such as food, drink, clothes, shelter, warmth and safety.

The need for food was evident from most of the respondents. Eight respondents reported tat they go to school without breakfast, while seven go to school without lunchboxes. Nine of the respondents reported that they sometimes go to sleep without meals. These findings are in accordance with literature which indicates that access to food for HIV and AIDS pre-orphans as well as orphans is very limited (Gilborn, Nyonyintono , Kabumbuli & Jagwe-Wadda, 2001:19; Richter, 2001:32).

"There are times when we sleep without food and my sister would cry. But I am always comforting her saying God is watching over us"

"Sometimes I do come home to come and eat, but in most cases there is nothing to eat, and I always go back to school."

It is obvious that the lack of nutrition influences respondents' school performance since healthy nutrition is essential for energy, concentration, memory function and cognition. As could be expected the respondents reported

weakness and inability to concentrate and listen during classes.

"It becomes difficult for me to listen if I had nothing to eat, and if we have to write something like a class test, I would get things wrong because I didn't listen."

Maslow (1970: 36-38) has indicated that the need for food is pre-potent at all age levels: If a person is dominated by hunger, his/her whole philosophy of life tends to change, as the person's whole existence revolves around obtaining food. This was evident in the study as 50% of the respondents indicated how they deal with hunger:

"Sometimes we have to go from house to house asking for food."

"There is no food most of the time, and this makes me worry a lot. I sometimes feel like leaving schools that I may be able to look for work."

The findings of this study are similar to the findings of Mtiri, Mazibuko, Ncama and Nzimande (2003: 40-45) about child labour. All the children in their study pointed to the lack of food as their motivator for their decision to leave school and find work. Such children diminish their already meagre opportunities for education to become family breadwinners, and their escape hatch from poverty is firmly shut.

During the interviews the respondents reflected on the need for clothes for the purpose of comfort and protection. Much emphasis was placed on school attire for winter.

"I do get cold in the mornings because I don't have a school jersey. We get suspended from school if we wear private jersey."

This study had similar results to what was reported by Cullinan (2001: 15) who stated that children affected by HIV and AIDS may sometimes have school clothes but in most cases these were very old. He indicated that some children tramp a two-hour journey to school bare-footed.

Clothes do not only fulfil the need for comfort, warmth and protection but fulfil the psycho-social need for conformity to the group, recognition by others and building of the self-esteem as well.

"At least I must have a pair of certain

clothes, so that I too can feel I am part of and be recognized among my friends."

According to the responses in the study the need for clothing was thus related to the perception of the inner self, improvement of self esteem, recognition by others as well as a statement of individuality, just as indicated by Foster (1990:43-57).

A Shelter is a place that offers protection, safety and warmth. Respondents in the study reported different types of needs with regard to shelter. These ranged from the desire to have their own house when they grow up to having a safe house where no one can steal. Apart from safety and shelter children sometimes have to cope with the problem of asset-stripping where family, friends or neighbours claim the childrens' household assets for themselves (Loewenson, 2001: 10-21; Richter, 2001:32-33; Ayiko: 1998: 11-12). "After funeral, our stepfather came back to ask for his furniture, claiming that he also paid his money when it was bought"

"This house is not safe, because now and then people just break in and steal. Most people around here are not happy that children like us can have this kind of furniture that my mother has left for us."

Studies have shown that terminal illness or death of parents due to HIV and AIDS have unpleasant consequences for surviving children. In most incidences children have to narrate in their mind how to live alone, while at times there will be relocation to another place such as grandparents (Ayieko, 1998: 11-21). Being left to live alone as well as relocation causes uncertainty and insecurity. The need for fuel such as coal, gas or oil that can burn to produce heat or power was another physical need identified during the interviews. This finding was similar to that of Eyeington's (2002:10-11) study in Swaziland where fuel was identified as a need among people affected by HIV and AIDS.

"Sometimes you will find our home dark, because there is no electricity. And when is dark during the night I cannot do anything, not even study for test or do my homework. We have to save the paraffin to warm water for bathing before going to school."

Economic needs

Economic needs include both financial

capital as well as physical capital. Financial capital is money which is used as a medium of exchange to buy things. Physical capital relates to the acquisition of knowledge such as in education or the owning of a pen or computer. Children who are affected by HIV and AIDS have a need for both of these commodities. They lack money to buy food, school uniforms, church clothes, pay school fees and school or church trips. They have no money for the medical expenditures of an ill parent.

The findings of this study were consistent with the findings of Richter (2001:32) who indicated that the average income falls drastically when one family member has AIDS. The study of Sliep, Poggenpoel and Gneimer (2001: 63) found that HIV and AIDS bring financial burden and crisis to the affected household. Related to the fall in income are the problems of medical costs, funeral costs and the long term consequences of borrowing money. The issue of declining household income was also highlighted by Booysen, Van Rensburg, Bachmann, Engelbrecht and Steyn (2002: 11-12) who indicated that because of reduced income and unemployment in these households, borrowing followed by no inheritance of any lump-sum payment from insurance policies or savings further drives the family from poverty to destitution: Apart from medical expenses the income of families are reduced due to funeral expenses when a parent dies (Smart, 2000:22; Wekesa, 1999: 12-14; Foster, 1997:4-5).

We had no money to bury her, as there was no money for the coffin. Then I had to borrow money just to get a coffin, but luckily from whom I lend money later said I must not repay back his money."

The absence of physical capital which relates to absence of further education for children affected by HIV and AIDS and impinges on the economic and social future of orphans and pre-orphans. Respondents were of the opinion that lack of education would affect their future since they felt that education could have safeguarded their future economic stability:

"I like being at school...but my fee has not been paid. I really feel bad because I am going to be far behind with most subjects and at the end I won't be able to pass and be what I want. Because I

want something better out of my life at the end."

Gilborn, et al. (2001:18) indicated the eagerness for education of AIDS pre-orphans and orphans who reported being in school, and that missing school and doing poorly in school was associated with feelings of sadness and social isolation. Being concerned about their education, the respondents indicated that they sometimes have to do piece-jobs in order to pay for their own education as well as their siblings ' education as well as to pay for other school requirements. As reported by Gilborn et al. (2001:19) and Ayieko (1998:27-28) AIDS orphans and pre-orphans find ways of generating money although the projects they embark on are not successful long-term because of a lack of skills. Efforts are made to wash cars, clean gardens and plait hair for cash. Wild (2001:9) indicates that the efforts of orphans and pre-orphans to generate money can put them at risk of abuse, exploitation and engaging in dangerous lifestyles

The findings in this study are supported by other studies indicating that HIV and AIDS have a disproportionate impact on poor communities. As the illness is likely to be prolonged, the families are likely to be destitute by the time parent/s die. In most cases children are left without any inheritance and they may be forced to leave school because their families cannot afford school fees or uniforms (Wild, 2001:8-9).

Psychosocial needs
HIV and AIDS is associated with complex psychosocial problems such as stigmatisation, rejection, fear of the unknown, social isolation as well as impaired quality of life and the absence of the motivation to make necessary lifestyle changes. These problems are not only felt by the suffering parent but by their children as well: just as the rights of the children are inextricably linked to their parents, so are their sufferings and happiness linked to those of the parents (John & Ndebbio, 2002:59).

AIDS orphans and pre-orphans have a need for relationship with relatives. Wild (2001:11) identified that children have a common reaction to the death of a parent and this reaction ranges from hopelessness, loneliness, confusion, anxiety and fear of being alone. The

respondents in this study confirmed Wild's findings and looked for their extended family's support.

In African culture the family is not a limited nuclear unit but extends to various other family members according to the needs arising among family members. The extended family is one of the valued structures within the African family system (Munodawafa, 2002: 7-8). If there is illness or death in the nuclear family the whole family is affected. In this study however the expectations of the children from the extended family were not met. All the participants felt that they were deserted by their families especially in the time of crises. Some participants reported that they made some advancement to these kin groups but were rejected:

"My aunts have changed. The time my father was alive, they used to be happy when we visited, because he used to help them a lot. But nowadays, they insult me, if I come to their house. And I have stopped visiting them."

Sliep, Poggenpoel and Gneimer (2001:63) support these findings and are of the opinion that even though relatives formerly formed a valuable support systems in times of difficulty, the HIV and AIDS pandemic has changed this system. Ayieko (1998: 15-17) found that there was a lack of support with regard to relatives visiting the children affected by HIV and AIDS. In John and Ndebbio's study (2002: 61) it was asserted that once the diagnosis of HIV and AIDS became known the social support of family was likely to be reduced. In this study the participants reported some degree of alienation which was similar in the current study.

The participant's interaction with members of their communities was negative as well. When one is a member of a community one aught to develop a sense of belonging through interaction with other people. The community should satisfy the person's psychological need for social intercourse and friendship. The respondents in this study whose parents were known to be deceased or dying due to AIDS were ostracised by neighbours and relatives. Children in the neighbourhood were not allowed to play with any AIDS orphans and pre-orphans. The findings in this study support Raufu's (2002:9) findings that when

parents are known to be dying of HIV and AIDS, the affected children become ostracised by the neighbours and relatives and at the same time children of the neighbourhood are not allowed to play with them. According to Raufu (2002:9) the reason for ostracism is based on the myth that AIDS will pass on to their children.

They say I too, have that disease she is suffering from. Sometimes even other children avoid me. If I start playing with them, they would walk away saying that I might infect them with my mother's disease."

With this point of view the potential caregivers in the community disappear and traditional ways of coping diminish.

Zerwekh (2000: 47-60) states that the embarrassment and humiliation that parents with HIV and AIDS feel might be projected onto their children who then isolate themselves from the community :

"I feel bad and my mother also feels bad about her face, especially when people have started to dislike her and say that she has got AIDS"

"The people around here talk about my father. And I become hurt when they say he was suffering from such a disease."

The findings in this study correlate with Ayieko's (1998: 17) conclusion, that in this era of the HIV and AIDS pandemic, children are no longer the collective responsibility of communities, a legacy that has been historically associated with child rearing in Africa. According to Harber (1999:8) modernization, urbanization and poverty are factors responsible for the weakening of traditional support system of African life. Based on the observations made by the researcher during the visits to the communities where the respondents in the study reside, the factors as identified by Harber prevailed.

The study indicated that the relationship with teachers was compromised due to a lack of understanding from school teachers as well as rigid school policies. Children were suspended from school due to incomplete school uniforms and unpaid school fees. In some cases respondents had to walk long distances to school only to find to their amazement and disappointment for their effort they

would find the school gate locked for latecomers.

"I don't have money for transport to school and if I happen to arrive late, I will have to come back, because the school gates will be closed."

"In most cases I am being sent back from school, because I don't have school shoes"

Literature is not specific about teacher's lack of understanding or rigid school policies but according to a report in the Sunday Times by Cullinan (2001; 15) there are few teachers who do not send children back for unpaid school fees or incomplete uniforms.

However, these school policies do not conform to the South African School Act, No.84 of 1996 (South African Government, 1996). According to this act no pupil can be denied attendance of a public school. In spite of this act the phenomenon of suspending pupils from school was described by many respondents in this study. Lack of understanding and rigid school policies were prevalent in the five different schools that were attended by the participants of this study.

Some of the participant's claims accord with the comments made by World Bank and UNICEF (2002) about HIV and AIDS and the school attendance of affected children: "When there is illness or death in the household, the financial resources tend to be used to care for the sick or for funerals, thus reducing sources allocated for children's schooling. The outcome is either a delay in enrolment or no enrolment at all. Attendance at school also declines, especially as the children have to work and care for sick parents. Performance suffers as a result of absenteeism and a lack of parental care and support" (pp 24, 25).

The need to belong and be loved was expressed by all the respondents. Eight of the respondents indicated that they could not be with friends as they would love to be. According to the study done by Richter (2001:33) children affected or orphaned by HIV and AIDS find themselves separated from their friends due to increased workload, exhaustion, social isolation related to insecurity and stigmatisation, as it is often assumed that they too are infected with the disease.

"Sometimes other children avoid me. If I start playing with them, they would walk away, saying that I will infect them with my mother's disease."

The experience of not being loved by a friend and not being affiliated to the group runs close to the feeling of being let down by the community. The psychosocial mechanisms that cause the community, friends or family to ignore or ostracize the orphan or pre-orphan are the same.

Literature is not quite specific about the need for love and belonging in children affected by HIV and AIDS. However it is normal for people to create conjunctive emotions of love; wanting to be with other people. Therefore, effective satisfaction of psychological needs, belonging, enjoyment and freedom, result in a sense of control or becoming a fully functioning person (Corsini & Wedding, 1995:63,294). Commenting on this, Rotenberg and Hymel (1999:155-156) said that the inability to satisfy the need to belong, whether because of personal or situational constraints is likely to result in personal difficulties such as negative conclusions about the self, others or both and this was the case in the study as some respondents said:

" Every time there is a theft committed around our vicinity, I am always a suspect."

"Some of my schoolmates know that my mother is sick, and they say my mother is ill and not working. I feel bad when they talk about their parents."

This statement is also indicative of the lack of self-worth in children affected by HIV and AIDS. Allport (1961) in Meyer, Moore and Viljoen (1997:420-421) indicates that the opinion of others and one's own direct experience of oneself forms the basis of self-esteem. AIDS orphans and pre-orphans have a whole range of problems and obstacles that contribute to bad self-esteem. They experience the negative feelings that the community, peers, teachers and family have towards them. They do not possess adequate clothing or attire that make them feel part of the group and satisfy their need to belong:

"I always envy my friends, because they have beautiful clothes and they look down at me and some of them even say I cannot wear nicely like them. I always

tell my grandmother that I too would like to look like a decent person."

Pawlik and Rozenzweig (2000:269) stated that adolescents have a conception of what they would like to be - that is the ideal self- and that unfavourable self-evaluation may be associated with depression and other negative outcomes.

The need for counselling pertaining to the provision of factual knowledge as well as emotional support was identified. The findings revealed that respondents need counselling as they exhibited signs of not being able to cope with the illness and death of their parent. Guilt, resentment, exhaustion as well as disappointment were signs exhibited by the respondents. The responses of the children indicated that they needed information about HIV and AIDS that they were not coping with the many burdens placed on their shoulders nor with the constant worrying about the ill parent and in cases of deceased parents the children had incomplete grieving processes and were grieving in isolation.

Lyons (1998:4) described how the fear of discrimination, rejection or abandonment by other families or community members had lead to some families keeping the knowledge of their HIV and AIDS a secret from the children. Participants in the study reflected on their negative feelings related to their suspicion regarding the parent's diagnosis, people's gossip as well as the actual physical state of their parents:

"I don't like when people talk about my father and that disease they were talking about. It is not possible that my father had it"

"My mother is not an ugly person, but since she became ill, she has changed. I feel bad and she also feels bad about it. Especially when people started to dislike her saying she has got AIDS. Most people here are saying she has got AIDS and this makes me feel bad. Sometimes I am very scared of meeting people. I am scared, because when I am with other children, people from our neighbourhood might say my mother has got AIDS, but I know my mother does not have that thing."

The phenomenon of keeping secrets from the children is also clarifies by Wild (2001:10) who says that HIV and AIDS is viewed by many people as punishment for an "immoral lifestyle" and is always viewed with an irrational fear of contamination. That is why children may be lied to or not told, ultimately causing them to be unable to understand and accept their parent's illness and death. As indicated by Smart (2000:13), Wekesa (2000:13) and Lyons (1998: 4-5) adequate information will thus enable the children to make informed decisions about activities that would increase susceptibility to infection and prevent the vicious cycle of HIV and AIDS. One respondent illustrated the need for information where fear of being infected was demonstrated:

"I am scared that I might be infected too.... Especially, because she is coughing a lot and if I think I am always close by or sitting next to her, and I might be infected. Whenever I pass by, people talk they say that my mother has such and sick illness. But even me too, I don't know if HIV can infect one just like that; staying in the same house with my mother."

The findings of this study as identified by UNAIDS (1999: 5) also indicated that children are burdened because they find themselves thrust in the role of mother, father or both – doing household chores, looking after siblings and caring for the ill or dying parent, experiencing stress that would exhaust even an adult. Added to this they live with the constant worry about the life of their parent:

"I don't concentrate well in class. I am always thinking of problems at home, as to how my mother is: Whether she is alive or not, if I am going to find her admitted to hospital. I have a lot of things going in my mind. Besides this I always have to be in hurry, for when I get home from school, I have to clean the house, cook, do my homework and go to the choir practices at church. Everything in the house has to be done by me."

The findings of this study confirmed that the illness and ultimate death of a parent is a crises for any child and as Wild (2001:8) suggests this crisis is more complicated for an AIDS orphan as there is a set of material and psychological stressors which often accompany the parent's illness and death, hence the grieving process becomes such a problem. Orphaned by AIDS the children are likely to grieve in isolation with damaging effects. Clark (1984:633-634) reported that grieving in isolation is characterised by feelings of guilt, deterioration of health as well as psychosomatic conditions.

The respondents indicated that they were not coping with the death of parents no matter how long the parent had been dead.

"I really miss her... even now when people talk about her: I miss her, even though she was doing nothing for us. I saw her when she died...I...I...I saw that she was not breathing and went out to call granny. (crying) I believe I have forgotten her..."

"I don't know what is wrong with me..I sleep a lot and I also have headache. I will start by feeling miserable and then the headache will start and I will feel like sleeping. I don't know the cause of this, but whenever I play with other children, this will start. My younger brother also has these episodes."

Need for control

The need for control is an important aspect of personality in which people hold the firm belief that they possess the potential to execute the kinds of behaviours that a given task demands. This "can do" cognition mirrors a sense of control over one's environment. The control needs of AIDS orphans and pre-orphans were expressed as the need for independence and family unity. The respondent's need for independence was mainly expressed as a desire to earn money for themselves and their families.

The respondents tried to preserve family unity by guarding the secret of their circumstances and trying to adapt to these circumstances as best they could:

"Sometimes we would wait for people coming from town with a lot of grocery. We would ask them if we can help them carry the luggage from the bus stop to their homes and they would give us R10.00."

"There are times when I think of leaving school and search for work. I wish I could do something for my sisters."

"We do not want people around to know that we are struggling... my mother wouldn't like to see us begging for food..."

These findings correlate with what Rotheram-Borus, Stein and Lin (2001:763) describe as coping skills intervention among children affected by HIV and AIDS whereby children adjust to the impact of their parent's illness and death by assuming adult-like roles.

Besides showing independence the respondents in the study seemed to have the need to build a family unit.

"I am worried as to how my brother and sisters are feeling and what is going on in their minds and how our upbringing is going to be like."

"We want to grow up together. The three of us together..."

This was similar to what was said by Vigil and Clements (2003:30-38) that as a way of coping and adaptation during the process of grief, the surviving children/ adolescents place a significant value on the maintenance of the family unit.

Discussion of findings

The findings of this study confirm that the children affected by HIV and AIDS either as orphans or as pre-orphans are extremely vulnerable facing many and diverse problems that may have a lasting affect on their lives. This finding was in accordance with the statements made by The Joint United Nations Programme on HIV/AIDS, the United Nations Children's Fund, and the National Black Leadership on AIDS (1999: 1-3). With the illness and death of parents the respondents indicated that economic needs were the most prevalent, and these formed the backdrop for most physical needs. These needs were not isolated as Wild (2001: 13) also confirms; the economic and physical problems were being further complicated by the psychosocial problems. With these needs remaining unsatisfied, children are likely to be deprived of opportunities to grow and develop successfully at the physical, emotional, social and intellectual level (Lyons, 1998:2).

Wekesa (2000: 13) confirmed that AIDS drives households into poverty as a decline in household income occur when parents stop earning their income, health care expenses increase and funeral costs deplete all current and future reserves. Booysen et al. (2002:13) indicated that it has become a common strategy to use savings or borrow money for coping with

illness thus driving the household deeper into poverty and leaving household funds totally depleted when parents die.

It is well known that the department of Social Welfare gives grants to people with terminal illness as well as to orphans, including AIDS orphans (Policy Guidelines for Youth and Health, 2001:21-22). However as the respondents reported, these grants are always spent on the parent's medical expenses and nothing is left for family needs. With regard to the orphan's grants, few children reported knowledge of said grants and as for how the grants were spent, only the care givers could tell, while the needs of the orphans were unsatisfied. Some orphans reported that they could not access these grants as they did not have a birth certificate. The reason for this was that parents had not always registered the birth of the children because they had lived in rural areas at the time. On the death of the parents no one was left to start the registration process.

Another factor precipitating poverty that was discovered during this study was that of single-parenthood where the mother was the sole breadwinner and head of the family. As the mother becomes ill and dies the responsibility moves to either grand-parents or children themselves with physical circumstances exacerbated.

Most of the participants in the study indicated an absence of the expected physical and social support from extended families which has traditionally been part of the African culture. This was an expressed need and critical concern of the affected AIDS orphans and pre-orphans. The reasons for this absence of extended family structure are reportedly to be found in the stigmatisation and ostracism of AIDS sufferers and their families, prevailing westernisation and thereby loss of traditional African culture and increase of poor socio-economic conditions in urban areas (UNAIDS, 1999:5).

Adding to the problem was the fact that parents who were terminally ill did not seem to plan ahead for the care and guardianship of their children. The parents of participants in this study were well aware of the prognosis of their illness and their reluctance to plan ahead may be attributed to the concern of imposing

a burden on potential guardians as well as reluctance to face their death (Wilfert, Aronson, Beck, Fleischman, Kline, Mofenson et al., 1999:509-510). Gilborn, et al. (2001; 13-15) indicated that parents often had the intention to make arrangements for their children's guardianship but could not do it due to fear of making known their HIV status. Furthermore the findings revealed that parents did not want to discuss (in the case of orphans) or did not want to discuss (in the case of pre-orphans) their illness with the children. Probably this was done to protect the children from the fear of potential loss as well as from the stigma surrounding their illness. It is also probable that parents were embarrassed and unable to admit to the children how they had contracted AIDS.

An important finding of this study was that the children affected by HIV and AIDS have multiple problems related to their schooling. Physical problems such as lack of money for school fees, clothes, school requirements, and transport and school outings cause high absence from school. Emotional problems such as stigmatisation and ostracism by friends, family and the community, the stress of being alone and unloved, and of heading a household, taking care of siblings takes its toll in the inability to perform in school. School systems and teachers were often unsympathetic to the plight of the children and persisted in applying rigid adherence to school regulations thereby suspending children for not having school uniforms or non-payment of school fees. It was reported during the interviews that children rely on education for a better future but that their problems were exacerbated by rigid school policies regarding school fees and uniforms.

The study revealed that the social isolation of children affected by HIV and AIDS is high. Children are rejected by friends, family and the community because of parents suffering from HIV and AIDS or having died from it. Social isolation and rejection is a main contributing factor to this scenario. Other factors that play a role are the lack of time these children have for socialisation since they have added household responsibilities as well as the fact that they may be isolating themselves from others because of the shame and fear they feel for their parents' illness. The inability to cope with the illness and

death of the parents revealed the need of the children for counselling. The fact that the mention of the deceased parent's name triggered painful emotions was an indication that the grieving process had not been completed. Especially since the children admitted loneliness. These findings may be explained by the African belief system that it is inappropriate to mention or speak about the deceased. These findings reflected the findings of Van Epps, Opie and Goodwin (1997:30-31) in which youngsters were severely reprimanded for asking questions about the deceased. These findings are also confirmed by the researcher's knowledge of the cultural orientation regarding death, grief and mourning within the African belief system.

The study indicated that the respondents showed a need for information on HIV and AIDS since they could not believe that their parents had died of this disease. Their denial was attributed to the fact that their parent did not confirm their suspicion as brought about by the gossip and the actual appearance of the parent. The issue of parents failing to tell their children about their HIV status was explored by Niebuhr, Hughes and Pollard (1994: 421-425). Their findings revealed that this was related to the parents' fear of discrimination against the children and embarrassment of admitting to the children that their own behaviour had led to the HIV infection. Abrams (2000:15-16) and Hodgkinson and Stewart (1998:140-141) admit that the giving of honest information, is vitally important and sets the agenda for recovery.

The findings of this study further indicated that the respondents expressed their willingness to be an independent family unit, not to be separated but struggle together. This was in accordance with the findings of Vigil and Clements (2003:34)

Conclusion

The purpose of the study was to identify the needs of children affected by HIV and AIDS.
The findings of the study confirm that the terminal illness and ultimate death of a parent because of HIV and AIDS placed surviving children in an extremely vulnerable position, with a myriad of problems. With the breadwinner ill or deceased, children found themselves facing problems in all aspects of their

lives. The needs expressed during the ten interviews encompassed needs at the physical level such as food and shelter, needs at the economic level and needs at the psychosocial level such as the need for loving and caring relationships, self-esteem and information and counselling. The need for control as embedded in the need for independence and family unity was articulated as well. Based on the results it can be concluded that the purpose of the study has been achieved.

It is recommended that the services that render help to HIV and AIDS orphans and pre-orphans become aware of their needs and provide support with the children as active participants in the system.

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