

A PROPOSED INTERVENTION FOR MOTHERS WHO CARE FOR THEIR
HIV/AIDS OFFSPRING

By

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I want people to understand about AIDS

- *to be careful and respect AIDS*
- *you can't get AIDS if you touch, hug, kiss
hold hands with someone who is infected.*

Care for us and accept us

- *we are all human beings.*

We are normal.

We have hands.

We have feet.

We have needs just like everyone else

- *don't be afraid of us*
- *we are all the same!*

(Extract from Nkosi Johnson's speech, 13th National AIDS conference, Durban: July 2000).



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My family and friends:

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My brothers, Modikoe and Themba- thank you for being the coolest brothers



Legotla la Moemedi- "Lerato le Kopano ke maatla", lets keep on doing what we do best

Grif- "Indlela ibuzwa kwabaphambili", thank you for being a good friend and mentor

Grant- my brother in spirit, thank you for being there when I needed you

My other 11 colleagues- the struggle goes on

House no. 27 inmates- with consciousness we shall be liberated, thank you for being good friends.

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FOREWORD

1.1 Introduction

The HIV/AIDS epidemic is a serious problem, which challenges the future of our country. Its victims are usually the young sexually active members of the population. The prospects of curbing the disease are not promising at the moment; the next best thing, which can be done, is to manage the spread and the effects of the disease on the lives of those directly and indirectly affected.

There are various ways of managing the disease. They range from prevention strategies to treatment strategies. The current research study aims at impacting on the treatment level. Within this category there are various subdivisions as well. These range from providing support for the infected individuals by means of medical care, social support, psychological services, to developing social policies for such individuals. Interventions at treatment level also include support for health care workers and less often, support for informal caregivers, such as family members.

Due to the increasing costs in health care services and increasing poverty, (keeping in mind that there seems to be a strong relationship between poverty and high incidence of HIV infection), it has become a much more viable option to provide home-based care for infected individuals. The relatives of the ill individual, who are usually the mothers, usually provide such care. Caring for a dying child at home may prove to be a challenging task, as the review of literature in the next section will show.

The progressive nature of this particular disease makes the task even more challenging. The infected individuals are not the only ones adversely affected by the disease, so do those who care for them, who usually receive little or no support at all. The stigma attached to the disease makes the task of caring a secretive and isolated one.

The disease itself results in death, so the task does not culminate into triumph. This task of caregiving is thus rarely associated with positive outcomes. There are a number of challenges faced by informal caregivers of HIV/AIDS victims, these range from lack of social and emotional support or sometimes even financial support. These caregivers are also faced with the risk of burnout like any other professional, but their own needs are usually neglected as attention is usually given to the infected individuals. Government efforts and social services, focus more on helping the infected individual cope better with his or her illness while little is done in equipping the informal caregiver with necessary information pertaining to the care of infected persons.

This study thus proposes an intervention, which will address the needs of this often neglected population. The proposed intervention aims to address all the caregiver needs that are posed by the task of caregiving. The intervention is primarily aimed at the mothers who have taken the role of caregiver at home. These mothers are without formal training in health care and are all full time caregivers for their children.

1.2 Methodology and aims of the mini-dissertation

The chosen methodology for this mini-dissertation will be a literature review, reflections on the literature, conceptualization and finally an integration of the literature in a proposed intervention for mothers who take care of their offspring suffering from AIDS.

Finally, this mini-dissertation will be Chapter 3 of a doctoral dissertation to follow.

1.3 Terminology

The following terms will be used repeatedly in the discussion so it is important to give their meaning:

- **AIDS**- acquired immunodeficiency syndrome
- **Caregiver(s)/ caretakers**- people who provide care for ill individuals, in this case mothers
- **Caregiving**- the experience of giving care to the infected individuals
- **Epidemic**- an unusual marked increase in cases in a fairly short period of time
- **HIV**- human immunodeficiency virus
- **Holism**- a Gestalt-like concept that the whole is more than the sum of its parts, that a complex organism

cannot be understood by the examination of its parts. This concept is in response to the modernistic approach of reductionism.

- **Pandemic-** a global or very widespread epidemic
- **PWHIV's-** persons with HIV
- **Stigmatization-** the experience of unfair judgment and marginalisation



CHAPTER 3:**A PROPOSED INTERVENTION FOR MOTHERS WHO CARE FOR THEIR
HIV/AIDS OFFSPRING****3.1 INTRODUCTION**

HIV/AIDS is a reality that affects every living being, the disease does not discriminate, and more often than not impacts negatively on people's lives. To be able to fight and curb the spread of this epidemic, combined efforts from every discipline across the various professions should be employed. The medical field cannot fight by itself, contributions from the psychology fields may prove invaluable, so can contributions from the natural sciences and the social work fields.

Living with the Human Immunodeficiency Virus (HIV) infection or Acquired Immunodeficiency Syndrome (AIDS) is a reality for many people in South Africa. These victims face great personal difficulties, which include coping with declining health, loss of sense of control and ultimately the loss of their lives. They are however not the only ones facing coping difficulties, so do their primary caregivers, which are usually family members, such as mothers, sisters, grandmothers and sometimes even fathers (Henderson, 1998).

According to Jackson (2002), the spread of the epidemic also marks the need for other forms of health care beyond the traditional hospital context. She says that caring for patients with HIV related disease is increasingly taking place in the home and the community. With increase in health costs, she reports that people cannot afford long hospital stays, and in any case there is a shortage in hospital beds.

Patients themselves are thought to prefer to be at home rather than at hospital, provided they have access to medication, nursing care, nutrition, material support and psychological and spiritual care they need (Jackson, 2002).

In a study conducted by the government, it emerged that women incur more responsibility for the burden imposed by HIV/AIDS, both socially and culturally, since they bear the psychosocial and physical burden of AIDS care (HIVSA, 2002). In view of the literature indicating that women incur this burden, it seems important therefore that they also be considered when helping HIV infected victims in coping with their illness. A group intervention aimed at assisting such women deal with the illness would be helpful. Such an intervention should be aimed at helping such women deal with their caregiving experience by assessing and improving their coping strategies and subsequently their quality of life, improve their social support systems and prepare these caregivers for the inevitable death of their loved one.

This illness can affect the family in various negative ways; the intervention aimed at helping the caregivers should also be able to address the various areas effected upon by the disease. Hence a **group psychotherapeutic intervention** which not only focuses on psychotherapeutic issues but on various areas effected upon by the disease, e.g. societal functioning and education about the disease itself, is suggested. The proposed intervention is therefore **holistic** in nature, addressing the different aspects of human functioning.

3.2. Caring for HIV/AIDS victims

"Home care is a holistic concept that should incorporate the full needs of the patient and also address those of family carers and of children who will be orphaned"- Jackson (2002)

In a review of a study Henderson (1998) found that caring for the HIV infected individual (who in this case was a child) is challenging and affects the entire family system. This study supports findings of other studies, which showed that ongoing social support system for the victim and his or her family can determine caregiver stress and enhance coping with the illness and the caregiver experience (Henderson, 1998).

In a similar study into the coping strategies of people living with HIV or AIDS, Sikkema, Kalichman, Hoffman, Kobb, Kelly and Heckman (2000) found that AIDS influences the psychological coping not only of the person with the disease but also those close to that individual. These researchers also found that following a death from AIDS, family members and friends may experience atypical bereavement. In their recommendations following the study, they suggested that interventions for AIDS-related bereavement that reduce distress and maladaptive ways of coping are needed in order to meet the secondary prevention needs of bereaved people especially those living with AIDS themselves (Sikkema et al., 2000).

In another study into HIV/AIDS family caregiving experiences Stajduhar (1997) found the following challenges to be common

amongst the caregivers: reconciling that a loved one would die, making life and death decisions, and letting go. The nature of support to face these challenges was highlighted in the study, with attention to its influence on HIV/AIDS caregiver bereavement. The findings from this study provide some insights into the HIV/AIDS family caregiving experience and reveal a significant need for interventions designed to support caregivers in establishing the mechanisms required for bereavement resolution. Indications from Stajduhar's (1997) study were that the need for the creation of supportive networks for HIV/AIDS caregivers can help them deal with their loss (Stajduhar, 1997).

Researchers, Gerwartz and Gossart-Walker (2000), have recommended home-based treatment over institutions for children and families affected by HIV/AIDS in dealing with stigma, secrecy, disclosure and loss. In their study of the needs of HIV-affected children and families, they found that an ongoing relationship with a clinical team who can understand and respond to the changes due the illness and provide psychotherapeutic and case management services can aid both children and parents in the painful task that AIDS presents. In their recommendations these researchers suggest that home based services can be the key to health care and treatment compliance for those affected by HIV/AIDS, the emphasis being on the principle that these home based services be integrated within the community context with regular communication with other health care providers, e.g. Aids clinics (Gerwitz & Gossart-Walker, 2000).

Ian Stulberg (in Aronstein & Thompson, 1998), a former clinical social worker and now projects manager and lecturer has worked professionally with HIV/AIDS patients for more than ten years. He has the following to say about his experiences. He found that **persons with HIV** (PWHIVs) and their families are confronted with clinical issues particular to HIV/AIDS, that result from the unique biopsychosocial environment of the AIDS epidemic. In addition to clinical issues of grief and loss associated with losing a loved one to a terminal illness, the families of PWHIVs may present with a variety of other concerns, which may require mental health interventions. Among these issues are the following:

- ❖ The young age of the vast majority of HIV/AIDS victims causes a disruption to our traditional view of developmental stages and tasks, resulting in the caretaking by families of members who would otherwise be in the most independent and productive stages of their lives. This disruption may also contribute to a more complicated kind of bereavement for parents as they outlive their children.
- ❖ Perhaps most significantly, just as with PWHIVs, the stigma and accompanying discrimination that permeate the HIV environment will often result in feelings of shame and guilt for family members and a consequent isolation from sources of social support traditionally available to families with terminally ill members (Aronstein & Thompson, 1998).

Taking the above literature into consideration, it seems that HIV/AIDS presents the family system with challenging issues, core beliefs may be questioned, traditional values

of the family system are challenged resulting in affected individuals being thrown into turmoil. Support, both socially and psychologically may be the family's best option. In his work with families of PWHIVs, Stulberg (in Aronstein & Thompson, 1998) found that the degree to which family members (who usually become primary caregivers), are affected by the societal stigmatization of HIV is yet another factor in determining how they may present for psychological assistance.

Individuals who feel that HIV/AIDS has a pejorative connotation and implies something negative about those whom it infects are likely to be much more secretive with the information and to isolate themselves from usual sources of support. This is prevalent in highly religious communities who see the disease as some form of punishment for immoral behavior (Aronstein & Thompson, 1998).

When taking the literature and the lack of interventions into consideration, it seems that a therapeutic group intervention may provide a safe space in which to ask for the support these caregivers need. In working with family members of PWHIVs, the following issues were identified by Stulberg (in Aronstein & Thompson, 1998) as presented in therapy:

- ❖ Family members may need to clarify their expectations of one another and renegotiate existing familial roles, which may have been disrupted by the chronic, terminal illness of the PWHIV.
- ❖ When PWHIVs are also parents of young children, their families may present with the need to resolve guardianship issues.

- ❖ Conflicts may arise concerning how the victim wants to die, the disposition of remains, who is to be designated as power of attorney for health care, or who will be the executor of the PWHIV's will, etc.
- ❖ Family members often need assistance in identifying ways in which they can take better care of themselves, which may require learning how to establish boundaries and set limits with the PWHIV (Aronstein & Thompson, 1998).

It may be concluded that the needs of family members who are usually faced with the task of caregiving are complex and range from basic psychotherapeutic needs, to lack of support and include practical issues such as custody and health care decisions.

In another study into the experiences of informal caregivers for people living with HIV and AIDS, Carlisle (2000) found that caregivers find meaning in their experiences of caregiving. From these findings it may be concluded that according to this researcher, caregivers felt that it was important to have control over the challenge HIV presented in their lives and they developed an attitude that put the virus into perspective and make sense out of their experience.

It may also be concluded from the above study that meaning making in the caregiving experience is a powerful way to achieve a balance between the costs of caregiving and personal reward, in other words it appears that being able to maintain positive mental health despite illness can make the caregiving experience a valuable one. With this deduction in mind and taking into account all the other

needs of families affected by HIV/AIDS, a group intervention grounded in positive psychology theory -which advocates maximising client's strengths and promotes optimal functioning- may prove invaluable for the caregiver's coping.

3.3. HIV/AIDS in the South African context

"While the headlines continue to scream of a 'Global Pandemic,' the developments of recent years actually suggest something rather different. Yes, HIV has reached every corner of the globe. Yes, it continues to spread disproportionately fast in marginalized populations in most countries. But the 'global pandemic' is -in public health terms in any rate- looking more and more like two distinct epidemics, one global and one regional" -Pisani (in Jackson, 2002).

It is true, the AIDS pandemic has over the past two decades shifted our opinions of the nature of disease. Its infection rate is unrivalled by any other disease hence despite fulfilling the criteria of a pandemic it is now considered as an epidemic for it has continued to spread at an uncontrollable rate, and seems to be much more rife in certain regions, e.g. the African continent.

A report by Abt Associates (South Africa) Inc. (2001) for the loveLife foundation indicated that during the period of 1994-2001 there has been an exponential growth of HIV infections in South Africa. This growth accompanied by the large number of deaths related to HIV/AIDS presents a picture of an alarming situation. Experts now agree that

South Africa faces one of the world's most severe HIV/AIDS epidemics {Abt Associates (South Africa) Inc., 2001}.

The HIV/AIDS epidemic has reached alarming proportions in South Africa. According to statistical reports on the prevalence of the disease in 1997, it was projected that 5.2 million South Africans would be HIV positive by the year 2000, with about 667 000 people having died of AIDS. These predictions further added that the demographic nature of South Africa could change drastically over the next 20-40 years, with the disease killing mainly the relatively young, sexually active part of the population (Jackson, 2002; Togni, 1999).

In the mid-nineties HIV/AIDS was addressed as a pandemic and the projected future effects of this disease were not being exaggerated, as recent statistics are now showing. At the end of 2001 estimates were that 4.74 million people would be infected with HIV in South Africa (Soul City Institute, 2002; Jackson, 2002). Current statistics show that approximately 4,2 million South Africans are already infected with the virus, with 1 500 new infections everyday (Tshabalala-Msimang, 2002).

According to the organisation HIVSA (2002), Africa continues to be the continent most affected by AIDS, with 71% of the estimated global people with HIV/AIDS living in the sub-Saharan Africa region. South Africa is said to be currently accounting for about 10% of the global HIV infection with a total of between 3.5 and 4.2 million cases of infection. This is considered to be the highest number of people living with HIV in the world. It is further estimated that South

Africa contributed more than 50% to the global cases of HIV infection in 1998 (HIVSA, 2002).

The annual antenatal surveillance project by the Department of Health, which has been measuring HIV infection since 1990, shows that South Africa has one of the fastest growing epidemics in the world. Results from this project show that 1700 people are infected with HIV daily. These results also reveal that approximately 13% of all South African adults aged between 20 and 64 are currently infected and these levels could rise to 20-23% by the year 2005 (HIVSA, 2002).

Deductions made from these findings are that HIV is a disease that mostly affects younger people with around half of all adults who acquire HIV being infected before the age of 25 years (HIVSA, 2002; loveLife, 2002). These young people eventually die of AIDS related illnesses before reaching the age of 35 years, and new infections are predicted to have adverse implications for South Africa, where 53% of the population is under the age of 25 years. Finally, deaths due to AIDS stood at 120 000 per year in 1999, this figure has climbed to 250 000 in the year 2002 and the life expectancy has decreased, with 15 years old youth having a 70% chance of dying from AIDS (HIVSA, 2002). The Department of Health antenatal statistics project shows that HIV infection among 15 to 19 years old South Africans increased by 65% in 1998 (loveLife, 2002).

According to the Medical Research Council (MRC) of South Africa, research into the socio-economic impact of HIV/AIDS on households and communities is important in guiding policies and interventions for the epidemic. This is

especially true since the burden of the disease is felt by the people affected by the illness themselves. This assessment of the socio-economic effects of the illness should thus be at the micro level or grass roots level. The impact of the illness on the quality of lives of the affected, on their economic status and on the position of their households should be investigated over a period of time. In addition to the research into the effects of HIV/AIDS, this organisation also advocates home-based care systems for HIV/AIDS victims (Booyesen, van Rensburg, Bachman, Engelbrecht & Steyn, 2002).

In 1992, when the effects of the epidemic were being addressed, a consultant to the World Health Organisation (WHO) suggested that, taking into account the fact that then (in 1992) 400 people were being infected with the HI virus everyday in South Africa, it was then necessary that all relevant players such as women's organisations, the church and others should be involved in developing suitable home-based care model for South Africa (Togni, 1999). In the late 1990's home-based care systems for HIV/AIDS victims were being suggested. It was seen as one of the ways, which can be employed in the management of the HIV, home care was seen as a practical option. Viewed as one of the ways of decentralising treatment procedures, it was suggested that the treatment and management of HIV/AIDS patients must, if at all possible, be decentralised to local level hospitals and clinics. This was seen as a way to reduce the costs of treating patients at national hospitals (Togni, 1999).

It was suggested that family members of HIV-infected individuals could be taught basic medical skills so to allow

the patient to remain at home for as long as possible, at minimal costs. Home-based care was seen as a viable alternative to expensive national hospitals. The key to this alternative however, was said to lie in the absolute necessity that medical and paramedical personnel at local level support family members. This would this day, include psychological and social services (Togni, 1999).

3.3.1 The socio-economic impact of HIV/AIDS in the South African context

Research into the socio-economic impact of HIV/AIDS individuals and their households revealed that lives of people affected by the illness are transformed, not only that of the infected individual but those around him or her as well. A study was conducted in two communities in the Free State province, in which the HIV/AIDS epidemic infection rate is considered high. The impact of the disease on individuals and their households was assessed by means of a cohort study of households affected by the disease, which was then compared with a control group of unaffected households. This impact was then determined by comparing over time, the observed trends in socio-economic variables in HIV/AIDS households and a control group using statistical methods. The results were then based on a cross-sectional analysis of the data (Booyesen et al., 2002).

Firstly, the study indicated that affected households carry greater burdens of illness and death. The study provided estimates of the frequency, nature and severity of morbidity and mortality among households known to be affected by HIV/AIDS, in comparison to their closest neighbours not known to be affected. The affected households showed

significant increased burden of illness and death attributable to HIV/AIDS. Such households predictably had a higher incidence of morbidity and death. People in these households were four times more likely to have been ill in the previous month, and to have had infectious diseases. Affected households on average included two or more ill persons than unaffected households. Ill people in affected households had more severe illness, indicated by hospital admission, not recovering and inability to perform daily tasks. Of affected households 20% had experienced a death in the previous six months, compared to 1% of unaffected households (Booyesen et al., 2002).

Secondly, the study revealed the effects of the disease on health care for the households. People who were found to be sick in the previous month were most likely to have used primary health care in the form of government clinics, followed by private doctors. A quarter of ill people were admitted to hospital during their last episode of illness related to their HIV infection. Among deaths in affected households, the most common source of health care was government hospitals (55%), followed by traditional healers (18%). The average cost of health care among ill household members and the median cost of funeral expenses appeared to be more financially crippling for the affected households. Most households with ill or dying members carried a burden of caring for the distressed member. Of ill people 75% required someone to care for them at home, while 68% required someone to accompany them during health visits. Relatively, few carers lost income as a result of these demands from the ill person. Few carers came from outside

the household (7% among cases of illness and 5% among fatal cases), (Booyesen et al., 2002).

Thirdly, the study showed heavy financial burden experienced by affected households. These affected households were reported to be on average slightly larger than unaffected households. However, the households affected by the disease had a smaller supply of labour than non-affected households, with a larger proportion of children and elderly persons. Illness and death also occurred mainly among economically active members (aged 15-49). Affected households were more dependent on non-employment sources of income than non-affected households (primarily government grants). Affected households were reported to allocate much of their finances to food, health care and rent, and less to education or personal items. Affected households also had higher levels of debt than non-affected households. Lastly, most frequent responses of households to financial crises seemed to be borrowing, followed by using of savings and sale of assets (Booyesen et al., 2002).

In view of the above study, it seems that the socio-economic costs of living with HIV/AIDS cannot be overstated. It appears that life in the face of this epidemic, changes, unfortunately for worse.

3.4. Reflections on caregiver experiences in South Africa

The above review of literature firstly looked at the experiences of caregivers in general, secondly it focused on the current state of the HIV/AIDS epidemic in the South African context. The discussion ended with the review of the socio-economic impact of the HIV/AIDS epidemic on South African households.

Henderson's (1998) report on the effects of HIV infection on the family system shows that the entire system is affected by the infection. Sikkema and his colleagues (2002) also found that living with HIV or AIDS influences psychological coping not only of the infected individual but that of people around him or her. These researchers also found that following a death from AIDS, family members and friends may experience atypical bereavement (Sikkema et al., 2000).

Other challenges were found to be associated with the experience of caregiving. These included family members having to make life and death decisions, preparing for the death of the infected individual and eventually letting go (Stajduhar, 1997). Stulberg (in Aronstein & Thompson, 1998) found that families affected by the disease also experience a lack of social support, discrimination, feelings of shame and guilt due to the stigma associated with HIV/AIDS infection.

The fact that the disease seems to target mostly the young reproductive part of the population exacerbates this experience of loss among the families and leads to complicated bereavement (Aronstein & Thompson, 1998).

The prevalent themes in caregiver experiences involve issues around the death of the infected individual. The literature indicated a specific kind of bereavement associated with HIV/AIDS. In response to this, researchers propose firstly social support for the family, specifically the caregiver and then the implementation of mechanisms aimed at helping family members reach bereavement resolution. These researchers also propose home-based treatments for the infected individual in which family caregivers are supported by clinical services. (Sikkema et al., 2000; Stajduhar, 1997).

The HIV/AIDS epidemic seems to be much more prevalent in certain regions, such as the African continent which is reportedly far more affected than other regions. This has led to the classification of this disease as an epidemic. This necessitates more focus and effort in dealing with the epidemic in those regions (Jackson, 2002).

The current number of known infected people in the South African context appears to be several million, taking into consideration the climbing HIV infection rate and the high number of deaths associated with the epidemic, indications are that many South African households are affected by the epidemic. The increase of medical costs and the stigma associated with HIV is likely to turn families to alternative treatment options. Home-based treatment seems to be the most viable option for infected families. The burden of home-based care reportedly falls on the females of the affected households. This burden is both culturally and socially constructed (HIVSA, 2002).

Research by Booyesen and his colleagues (2002) on the effects of HIV/AIDS on South African households showed the taxing impact on the families affected by the disease. Firstly, the literature reveals that affected families experience a greater incidence of illness and death. With illness as the prevailing factor in the household, the family has to rely on public health care, which is often below standards, or a fellow family member has to care for the ill individual(s), often forfeiting a working role, by so doing placing a further financial burden on the family. This financial burden places the household in more trouble. With the increasing costs in health care and little or no financial income for the family, the impact of the disease hits hard. In effect, the study highlighted the following important effects of the disease. Firstly, even though affected households are usually larger than their unaffected counterparts, they face more severe resource constraints since these resources are shared among a number of financially challenged individuals than in unaffected households (Booyesen et al., 2002).

Secondly, due to financial constraints resulting from the disease's impact, the use of savings and borrowing becomes the only way to survive in the affected households. Funeral costs add on to this financial burden. In general affected households appear to be poorer than unaffected households. The fact that most of these households depend on government aids, reveals that the government is faced with increasing demands as the epidemic continues to grow.

The literature above highlighted the experiences of caregivers, indicated the challenges faced by such

individuals and even made some recommendations in response to their plight. The literature however, failed to indicate viable and already implemented interventions aimed at helping the caregivers deal with their challenging experience. Most efforts aimed at dealing with the epidemic are at prevention level.

In the South African context the study by Booysen and his colleagues (2002) gives a clear indication of challenges faced by the affected households. It can be deduced from the results of their study that there is an association between HIV/AIDS and financial constraints for affected families. The study also reveals that the constraints imposed by the disease leads to the need of home-based care for the infected individuals. Social and cultural constructions place the female in the carer role, this is usually the mother or wife of the infected individual (HIVSA, 2002). Literature has shown this role to be highly demanding, but rarely recognised.

In the review of South African literature on caregiver experiences, the author also did not come across any campaigns, which were directed at making home-based care easier. By this the author refers to campaigns aimed at perhaps notifying or informing the public on services aimed available to them. The emphasis of most current campaigns is addressing the issue of . Most AIDS organisations appear to offer their services primarily to the HIV victims themselves. Services offered to the family, if any, are usually restricted to post-testing counselling following the disclosure of HIV status.

Literature also provided information on current community campaigns against the spread of HIV/AIDS, examples of such campaigns are: *The Red Ribbon Resource Centre: Small media campaign*, *Khomanani-Caring together campaign* and *The Beyond Awareness Campaigns I + II*. These community campaigns are aimed at encouraging support for AIDS orphans, reduce the stigma associated with AIDS, encourage awareness through living positively, provide information for people living with AIDS (PWA) and promote social acceptance for PWA (HIVSA, 2002). Communities are in fact encouraged to help manage the illness but these campaigns do not offer subsequent support for those caregivers who dedicate their lives to caring for their loved ones.

In view of the limited literature available on the effects of HIV/AIDS on South African households, it is clear that South African authors have a long way to go to comprehend the full impact of this epidemic. It is then in the opinion of the author that it can be concluded from the current literature that research and studies into the effects of the epidemic on the families is needed in order to get the real picture of the effects of this epidemic. Results from such studies can also be used to counter the effects on families affected by the epidemic.

There is a need for recognition of the sacrifices mothers and their families often make for their dying children and the need to provide them with support for their task. An intervention aimed at helping them with their task is thus needed. Such an intervention can be extended to other carers of terminally ill patients. It may also be utilised for the

support of carers who care for their grandchildren or spouses.

3.5. Group psychotherapy

3.5.1 A psychotherapeutic group approach

It appeared from the literature that HIV infected individuals following diagnosis, experience alienation, stigmatisation and a lack of social support. They are however not the only ones who experience such alienation, their caregivers also share in their experiences. The infected person dies in isolation, but the carer carries this burden in isolation as well (Stulberg in Aronstein & Thompson, 1998). To encourage support for the caregivers, a group context would be the best environment to encourage, initiate and facilitate the need for support (Yalom, 1975; 1995).

The choice to work on the group level also came because group psychotherapy work consists of processes, which coerce the group and aid in the formation of attachment bonds (Yalom, 1975). This is done in an environment, which ensures trust, confidentiality and support; all of which may be valuable for caregivers who face their plight alone and may think no support systems may exist for them.

A holistic therapeutic group approach will also encourage seeking aid from other support systems, such as clinics, community organisations and other support groups. Community care can help people to be more open about HIV/AIDS (Jackson, 2002).

Yalom (1975; 1995) is the main point of reference in psychotherapy for groups. He worked in this field for decades and his work has lots to offer for anyone who wishes to work with groups. In his 1985 edition of 'The theory and practice of group psychotherapy' he identified benefits of choosing a group approach. He grouped what he calls curative factors of group therapy into eleven (11) fundamental categories.

These categories are:

Installation of hope

Universality

Imparting of information

Altruism

Development of socialization techniques

Imitative behaviour

Interpersonal learning

Group cohesiveness

Catharsis

Existential factors

The corrective recapitulation of the primary family group.



In the next section benefits of group work, which are especially pertinent for the suggested intervention will be discussed. In view of the identified challenges faced by informal caregivers of HIV/AIDS it emerges that they would greatly benefit from a group based intervention. Caring for a dying child as research has supported is often a taxing task that poses a variety of challenges to the caregiver (Stulberg in Aronstein & Thompson, 1998). In addition to being a requirement for maintaining commitment to therapy, hope can also serve as a leverage to view life

beyond the death of a child for the mother's of the victims. According to Yalom (1975), any therapy group will contain people who are at different level of a coping-collapse continuum. In the group, participants have continuous contact with other group members who have improved their situation. They also come across fellow members who have had experiences similar to their own and coped with them more effectively. This encounter instils or maintains hope for other group members (Yalom, 1975; 1995).

Universality

According to Yalom (1975), many clients enter therapy believing that they are unique in their experiences; this is also true for caregivers of HIV/AIDS victims who often have to face the task of caregiving alone with little or no support. This sense of uniqueness is often aggravated by this social isolation. In the early days of the group, the disconfirmation of one's experience of exclusivity in suffering is a powerful source of relief. In hearing others reveal their experiences similar to their own, clients report a 'sigh' of relief and a new sense of belonging (Yalom, 1975; 1995).

Imparting of information

In this category, emphasis is placed on what the clients learns through participating in the group. According to Yalom (1985), at the conclusion of the group process participants have learned something about their initial problem. In the case of the caregivers, at the end of the intervention they would have learned more about the progress for the disease or better ways to cope with the caregiving task. Processes that ensure imparting are things like

participants advising each other and giving suggestions for their experiences (Yalom, 1975).

Altruism

The group affords participants the opportunity to be helpful to others in this therapeutic environment. They offer support, reassurance, suggestions, insight and share similar problems with one another. At the evaluation of the therapeutic process participants usually attribute their improvement to other group members. They value their fellow members' contributions more than anything else. Most of this is attributed to the sharing experience the members engage in (Yalom, 1975).

Development of socializing techniques

The development of relationships or social interactions is another golden thread running through most therapies and is a vital curative factor in group psychotherapies. In the case of these caregivers the isolation mentioned earlier more often than not adversely affects their relationships. The group thus allows for the new social skills to be learned and the subsequent development of new relationships.

Interpersonal learning

Interpersonal learning is facilitated by interpersonal relationships. Yalom (1985), explains the curative nature of interpersonal learning. Firstly, he explains that the therapy group is a miniature version of the participant's external world. The participants' interaction in the group is reflective of his external social interactions. According to Yalom (1975; 1995) interpersonal interactions in the

therapy sessions give way to other important therapeutic processes such as corrective emotional experience.

Group cohesiveness

Cohesiveness is described as the attraction that members have for their group and for fellow group members. Members of a group high in cohesiveness are said to be accepting of one other, more supportive towards each other and much more motivated to form meaningful relationships. Cohesiveness appears to be a significant factor in successful group therapy outcomes. Conditions created by acceptance of one another, understanding and mutual respect, participants are much more likely to explore their feelings, express them and relate more freely with others. A highly cohesive group also allows for improvement of one's self-esteem and an improvement in socialization skills. Lastly a highly cohesive group also increases the chances of successful therapy (Yalom, 1975).



Catharsis

Catharsis is considered as an important aspect of the therapeutic process, although sometimes regarded as not useful in some therapies due to its controversiality. The idea behind catharsis is that there is a lot to be gained from disclosing one's innermost feelings. This belief in the benefits of expression of intense emotion is supported by the idea that such disclosure enhances the group's cohesiveness, so it is in actuality vital for the therapeutic process. Caution is however given, in that this emotional expression should be guided by the group process and each group member should be considered in encouraging self disclosure (Yalom, 1985).

The above discussion has been highlighting the general benefits of group therapy, which Yalom (1975;1995) refers to as therapeutic or curative factors. In view of the above discussion the author believes that the therapy group will facilitate the needs of the mothers who are caregivers for their HIV/AIDS offspring.

3.5.2 The specialized therapy group

In Yalom's (1995) fourth edition of his book, *The theory and practice of group psychotherapy*, he indicates that the use of group therapy methods have extended to different clinical settings and that it has become outdated to speak of group psychotherapy. Instead a reference must be made to *group therapies*, as the number and variations of group therapies has increased (Yalom, 1995). An example of such a varied kind of group therapy is the group made for the population under discussion, the mothers who care for their HIV/AIDS children.

In view of the literature on caregiving experiences, the suggested intervention encompasses more than the traditional psychotherapeutic approach, it addresses other needs of the mothers. These needs of the mothers make them unique participants. They face ranging challenges in their caregiving experience. These unique challenges are particular to this population and they require an equally unique psychotherapeutic approach.

According to Yalom (1995), due to the nature of the proposed intervention, traditional psychotherapy group principles have to be modified to fit the special circumstances of the

intervention. He cites three (3) steps to be followed in the planning of a specialized therapy group:

1. assessment of the clinical situation,
2. formulation of goals,
3. and modification of technique

3.5.2.1 Assessment of the clinical situation

According to Yalom (1995) it is important to carefully examine all the clinical facts of life that might have a bearing on the therapy group. It is in the understanding of the author that these clinical facts of life can be likened to practical aspects that may impact on the therapy group. Yalom (1995) also states that these practical facts will bear upon the therapy group.

In the case of the proposed intervention some practical aspects that need to be considered include, transportation for the participants to and from the context of the intervention. Secondly, the availability of a stand-in caregiver for the mother, while she is participating in the intervention, should also be taken into consideration.

3.5.2.2 Formulation of goals for group psychotherapy

In any group work therapeutic goals should be formulated. Goals serve as a working premise for psychotherapy, they guide the process in a particular direction. With particular goals in mind, a plan of action can be devised with regards to the selection of relevant techniques and models to be used. Psychotherapeutic goals have certain characteristics that should always be taken into consideration. According to Yalom (1995) the following are pertinent for the formulation of goals for group psychotherapy:

- Clear and appropriate goals should be set for the therapy process. These goals should be clearly defined and outlined and be feasible. They should also be appropriate and relevant to the intended purpose.
- The goals should be appropriate to both the clinical and practical situation and be achievable in the available time frame. In the specialized psychotherapy group, the specified goals are equally unique and should thus relate to that specialized clinical or practical situation. These goals should also be achievable in the available time frame allocated for the psychotherapeutic process.
- The goals should be clear not only to the therapist but to the participants as well. The participants are considered as a valuable part of the therapeutic process, so they should ideally be clearly informed about the goals of the process they are part of.
- There should be a clear link between the specified goals and the techniques employed to achieve them. This point especially pertains to the repertoire of skills possessed by the group facilitator. The techniques or models of application used by the facilitator should be linked to the goals he/she intends to achieve.
- The participants as mentioned above, are an integral part of the therapeutic process, so they should also be viewed as co-facilitators who will aid in the achievement of set goals. They are in essence, active participants in the process.
- In time limited, specialized groups the goals must be limited, achievable, and tailored to the capacity and potential of the group members. The group facilitator

should through the evaluation of the group process be able to get a general idea about the capabilities of the whole group and its individual members. With this information he/she will facilitate the setting of goals that are within the capabilities or limits of the group members.

3.5.2.3 Modification of techniques

When one has a clear idea of the clinical and practical conditions and has formulated appropriate and achievable goals, the next step is to consider the implications these conditions and goals have for the therapeutic techniques. In the case of the proposed intervention traditional group psychotherapy will be modified to fit a holistic psychotherapeutic intervention. This according to Yalom (1995) is done by considering the therapeutic factors and to decide which will take precedence and play the pivotal role in the achievement of goals. This is the experimental phase in which technique and style, have to be altered to adapt to the goals of therapy (Yalom, 1995). In the case of the proposed intervention the most important therapeutic factor is to help the mothers cope in their caregiver experience. Techniques, which will be applied, will therefore be tailored to cater for this overarching therapeutic factor. This may be achieved by the use of a multifaceted holistic intervention, which will address many aspects of caregiver functioning.

According to Yalom (1995), the basic principles and therapeutic factors of group therapy should be retained, but applied techniques should be altered to adapt to the clinical situation and to achieve the specified goals.

Behavioural researchers have identified two types of therapeutic goals for groups: *process goals* and *outcome goals*. Outcome goals are explained as goals that pertain to behaviour changes to the group members' life, such as obtaining employment, improving interpersonal relationships, or feeling greater social esteem. Therapy groups that primarily focus on the concerns of the members are usually much more beneficial than group that focus primarily on the interactions among members. The term process goals, refers to the goals that are related to the group process (Jacobs, Masson & Harvill, 1998).

In view of the nature of the therapeutic goals that are pertinent to the proposed intervention, they may be considered to be outcome based since, the primary aim is to change the mothers' caregiving experience to a better and manageable one.

Group psychotherapy characteristics seem to be the appropriate vehicle for the proposed intervention in that healing is achieved through what Yalom (1975; 1995) calls the curative or therapeutic factors, most of which appear to be pertinent for the caregiving mothers. The shift from traditional group psychotherapy techniques to more specialized therapies for different and special populations also lays necessary foundation for the proposed group intervention for the particular population of mothers.

3.6 Holism

"Part of the appeal of traditional medicine to western observers is undoubtedly its holistic approach of viewing the person as more than simply a 'sum of organ systems' and neuro-physiological hydraulics"- Torrey (1986).

The quote above takes into cognisance that a human being is a complex entity comprising of different facets, viz. emotional, cognitive, physiological and behavioural functions, which interact with one another. These functions are in turn effected upon by other factors. These are developmental factors, which include the family, socio-economic factors, which include the society and other universal factors. See **Fig 1** on the next page.

According to Weinberg and van Wyk (in Stanley, 2000) Smuts introduced the term 'Holism' -which is a derivation of the Greek word *holos*, which means whole- to describe an alternative view of man, which *encompasses both man and nature* and to reintroduce the concept of man as an indivisible whole. Smuts (in Corsini, 1999) explains *holism* as a Gestalt-like concept that says that the whole is more than the sum of its parts, that a complex organism cannot be understood by the examination of its separate parts. This concept of holism is in contrast with reductionism and atomistic psychology (Pietroni, 1997). In its use the term *holism* includes both Smuts' definition and the definition developed by Gestalt theoreticians and is compared to reductionism with the position that holism must encompass reductionism if it is to study the relationship between parts and whole (Pietroni, 1997).

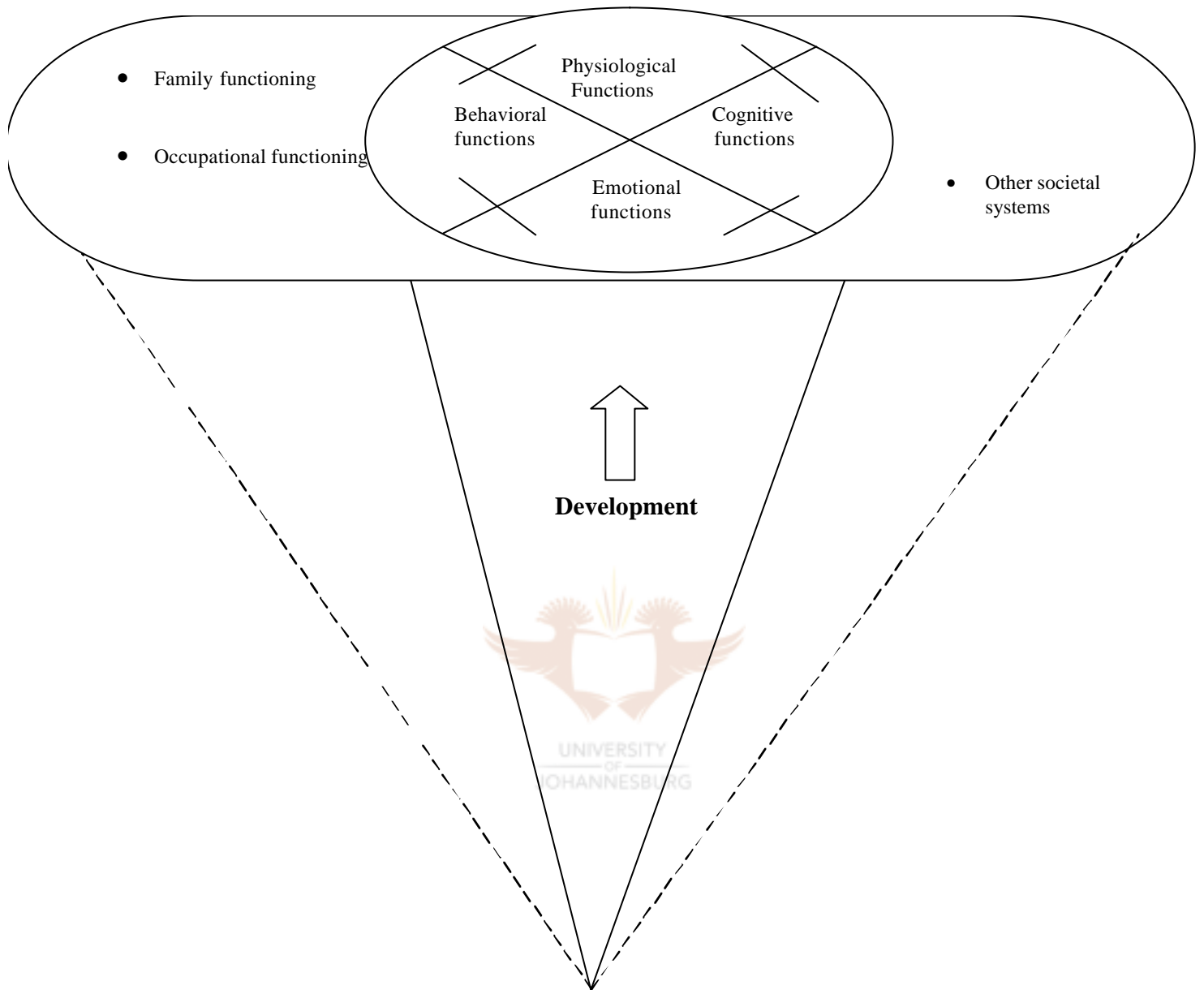


Fig 1: Diagrammatic representation of elements of client functioning. Adapted from Bush, C. (2001) and Pretorius, H.G. (2002). This diagram depicts the inter-relational nature of functioning, as well as the factors influencing such functioning.

Literature suggests that holism is considered as a response to reductionism yet in itself has to incorporate reductionism and is grounded in system's theory in psychology (Pietroni, 1997). Reduction itself has for centuries been the subject of much discussion among scientists and philosophers, and has become an integral part of modern science. The world may be viewed according to its constituents, in its reductive levels: social groups, multi-cellular living things, cells, molecules, atoms, and finally in its smallest parts the elementary particles. In contrast, holism, in the form of systems theories, builds on the idea that systemic relations arising at complicated stages of integration may produce new and unpredictable characteristics of the system (Andersen, 2001).

In the history of reductionism, particularly under the Biomedical model, the study of the human body was reduced to its components, which were thought to be representative of the entire system, and these components were also thought to be free of interaction amongst each other. Being an opposition to reductionism, holism has come as a popular anti-reductionist counter argument based on a general systems theory perspective which argues that all levels of the organism (social, psychological and biological) are linked to each other so that changes in one effect change in others. According to this view, the rules responsible for the collective order of a system cannot be understood merely by characterizing the components within each level, but need to include system characteristics as well. On this basis, social, psychological and biological approaches have to be reconciled with an integrated biopsychosocial model of disease or approach to healing (Andersen, 2001).

Reductionism, although originating in the field of mechanics, extends to the view of humans. According to Neuman (2000), many people only think in terms of individual actions and have an individualist bias, sometimes called methodological individualism. This approach especially prevalent in the United States culture, disregards units of analysis or forces beyond the individual. The error of reductionism shifts explanations to a much lower unit of analysis. One could continue to reduce from an individual's behaviour to biological processes in a person, to micro-level neurochemical activities, to the subatomic level (Neuman, 2000).

Most people live in 'social worlds' focused on local immediate settings and their interactions with a small set of others, so their everyday sense of reality encourages seeing social trends or events as individual actions or psychological processes. Often, they become blind to more abstract, micro-level entities, social forces, processes, organizations, institutions, and movements with structures. From this comes the core idea of sociology, which states that social actions cannot be reduced to the individual alone. In essence the individual acts or functions in relation to his or her social environment (Neuman, 2000).

Reductionism as mentioned earlier, was also part of the traditional Biomedical Model (BMM) in medicine. The Biomedical model's basic assumption is that disease can be attributed to cellular (organic) dysfunction. This approach excluded psychological, environmental and behavioural aspects of disease. The model also contends that disease has to be dealt with outside (independently) of social

functioning and that disordered behaviour be attributed to dysfunctional biochemical or neurophysiological functions. With this narrow approach to disease and healing, the BMM is undoubtedly reductionist in orientation (Engel, 1977). Research based on this model assumes mind-body dualism and in the past has not yielded effective health service (Bishop, 1994).

Alonzo (1985) and Engel (1977) wrote that a model to encompass the complex relationship between the individual and his social, physical and cultural environments and provide strategies for interventions has yet to be developed. These authors said that, while professionals acknowledge the importance of an ecological and holistic concept of man-environment interactions, various biases and ideologies prevent them from adequately taking this interaction into account. These researchers thus suggested a situational approach to the study of health and the adaptation of a holistic intervention for problems (Alonzo, 1985; Engel, 1977).

Alonzo (1985), believed that by stressing the socially defined situation and the social psychological actor, it may be plausible to sensitise the actor to socially situated man-environment transaction, to preserve the actor's confidence in his own health, to encourage the individual response for maintenance of health and to promote an awareness of signs and symptoms that require medical attention. In essence, the author was of the opinion that, in addition to taking into account the social environment and the effects thereof on the individual's health, the

individual then becomes the expert of his own health (Alonzo, 1985).

This orientation assumes that disease is independent of other variables and can only be explained in biochemical terms. Healing in this approach is equally narrow, with the premise of mind-body dualism, and treats human functioning mechanistically. This approach to disease and healing has since however been challenged and a new model has been proposed, the Biopsychosocial (BPS) model (Bishop 1994; Engel, 1977).

The BPS model's basic assumption is that to understand disease and its progression, and to develop an effective health care treatment, one must take into account the patient, the environment in which he or she lives, the social and cultural systems dominant in that context. This model also shifts away from clear-cut definitions of concepts such as health and disease and views the two to be interrelated and their meanings to be socially and culturally constructed. This approach is similar to *holism* in that it is also grounded in systems theory, which holds the notion that all levels of functioning (cellular to global) are linked to each other in a hierarchical organisation and that change in one level effects change in other levels (Bishop, 1994; Engel, 1977). It is in the opinion of Bishop (1994) that a comprehensive health care approach should be based on a model that can address current problems, predict mental and physical health problems and supply a viable scientific basis for health promotion.

Taking into consideration the shortcomings of the traditional BMM approach and the suggested BPS model and holism, it seems imperative when working with a person, to consider the different components that make him or her whole and factors that influence functioning. Any intervention should thus be aimed at addressing all of the above aspects of the participants' functioning. In essence it is important to consider all aspects of functioning in a person and the context from which they come from when working with them.

3.7 The Proposed intervention for mothers of HIV/AIDS victims

"When it comes to caring for people with HIV/AIDS, the richest resource a country has is, without question, the compassion of its people." UNAIDS (in Jackson, 2002).

As previously discussed, caregivers of HIV/AIDS victims (mothers or spouses) have needs of their own as the commitment of caregiving is challenging and affects the family system. Lack of social support and the stigmatization of the family contribute to maladaptive coping (Sikkema et al., 2000).

Taking into consideration indications from the literature that caregiving is usually an experience in isolation, it seems that mothers participating in the psychotherapeutic group can be around those who understand what they go through each day and can thus share their experiences. This is especially important for this population since most caregivers experience feelings of alienation, stigmatization and declining social support systems due the sensitive and

often secretive nature of their experiences of taking care of HIV/AIDS victims (Aronstein & Thompson, 1998).

In his work with families of HIV/AIDS victims, Stulberg (in Aronstein & Thompson, 1998) discovered that a successful intervention is ensured through the ability of the professional helper to "wear many hats". With this he meant that the professional should be able to respond to a variety of needs of families impacted by HIV/AIDS. Such needs are true for primary caregivers as well. While the preference is to intervene at a psychotherapeutic level with clients, the clients may have a much stronger need for information and resources-especially directly after the revelation of the diagnosis of a loved one. According to him, one must remember that sometimes the provision of accurate information (whether in the form of clarifying erroneous conceptions about HIV/AIDS or describing the availability of much needed resources in the community-and how to access them) can be the most effective intervention for clients faced with the chaos of HIV/AIDS (Aronstein & Thompson, 1998).

The group psychotherapeutic intervention can thus include psycho-education. Giving information, which many people may consider as basic knowledge, can according to Stulberg (in Aronstein & Thompson, 1998) strengthen the therapeutic bond between client and therapist. He emphasizes that the strength of these interventions lies in working in a group context that facilitates support and that such groups are more effective when information comes from others who have "been there" rather than from a social worker or as in the author's case, a psychotherapist. Finally, it is emphasized

that education regarding the dying process may prove to be useful for family members of a loved one who is in the terminal stages of the disease (Aronstein & Thompson, 1998).

According to Theresa Kreibick (in Boyd-Franklin, Steiner & Boland, 1995), a group intervention can become a safe place for caretakers to deal with their unresolved issues such as anger and grief, and to channel the energy into productive action toward obtaining needed services for their families. These feelings are often experienced by caretakers who are angry at the unfairness of having to raise a second or even a third family because of HIV/AIDS. According to her, such emotions of anger and grief are usually difficult to resolve openly within the family. This she believes is due to the fact that caregivers often hold the anger within themselves and are fearful to express their feelings within the family for fear of making things worse (Boyd-Franklin et al., 1995).



In her work with caretakers of HIV/AIDS victims, Theresa Kreibick (in Boyd-Franklin et al., 1995), also found that a group intervention can be a place where caretakers can receive support, nurturance, and normalization of their experiences in a safe environment that buffers some of their stress. Caretakers could begin to process their emotions and grief without adding more stress to their families. In addition such a group provides the security of sharing experiences with other caretakers who have had similar or familiar difficulties. The group intervention also provides each caretaker the opportunity to begin to trust other people outside the family circle (Boyd-Franklin et al., 1995).

Through the group process, healing begins to happen when caregivers begin to realize that they are not alone, and when their experiences of social isolation and alienation is normalized and to some degree, becomes understood.

Solidarity is established among group members that replaces or compensates their missing or damaged social support systems. Lastly, for all caretakers who participate, the group intervention is of benefit because it provides a safe place for the healing process to begin in the form of self-revelation of their experiences of taking care of a dying child often in secrecy and isolation (Boyd-Franklin et al., 1995).

The aims of a group psychotherapeutic intervention are to empower the mothers to be able to cope from day to day by improving their coping strategies. The intervention will also be aimed at providing support, ranging from information on social support, health care support and government grants for these mothers by the therapist facilitating bond making amongst the mothers and providing emotional support through the creation of a platform for these individuals to openly deal with their unresolved issues and learn new ways of dealing with such feelings of anger, grief and sometimes guilt.

The group members do all this in an environment that ensures containment and is able to buffer fears of disclosure of intimate details. This holistic intervention also aims to provide the mothers and their families with knowledge of the disease by use of psycho-education. Lastly the intervention aims to prepare the mothers for the death of their child. The intervention will be conducted over a period of several weeks.

Each session, on each week will have specific goal(s), specific technique(s), and will conclude on the evaluation of the day's work. The process of each session will start off with assessment of the levels of functioning of the behaviour targeted for change, e.g. stress management. Stress management techniques will then be taught to participants. The session will then conclude with the evaluation of learned techniques.

Following is a brief outline of the different therapeutic goals accompanied by models of applications, which may be used to achieve those goals.



3.7.1 Goals and models for the proposed intervention

Goal	Models of application
<ul style="list-style-type: none"> • Provide information about the disease and its progress and the available resources • Facilitate social support 	Psycho-education Reality therapy
<ul style="list-style-type: none"> • Provide emotional support 	Gestalt therapy Client centred therapy
<ul style="list-style-type: none"> • Stress management 	Psycho-education Cognitive behavioural therapy Art therapy
<ul style="list-style-type: none"> • Prepare participants for the death of their child and the grieving process 	Logo therapy Psycho-education

3.7.2 Format of the proposed intervention

- **Week 1:** Goal- establishment of the group and the co-construction group rules
Technique- encourage self disclosure by inviting participants to briefly introduce themselves

- **Week 2:** Goal- the discussion of caregiver experiences and the identification prevalent themes
 - discuss caretakers' experiences in caregiving then distinguish facts from false beliefs
Technique- continue to encourage self disclosure

- **Week 3:** Goal- educate participants about the progress of the disease and how to safely care for an ill individual.
 - provide the mothers with information of available support systems which range from social services, health care services and government grants
Technique- psycho-education

- **Week4:** Goal- teach the mothers coping strategies and stress management techniques
Technique- psycho-education

- **Week 5:** Goal- prepare mothers for the death of their children
 - teach the mothers about the process of grieving
Technique- psycho-education
 - logo therapy

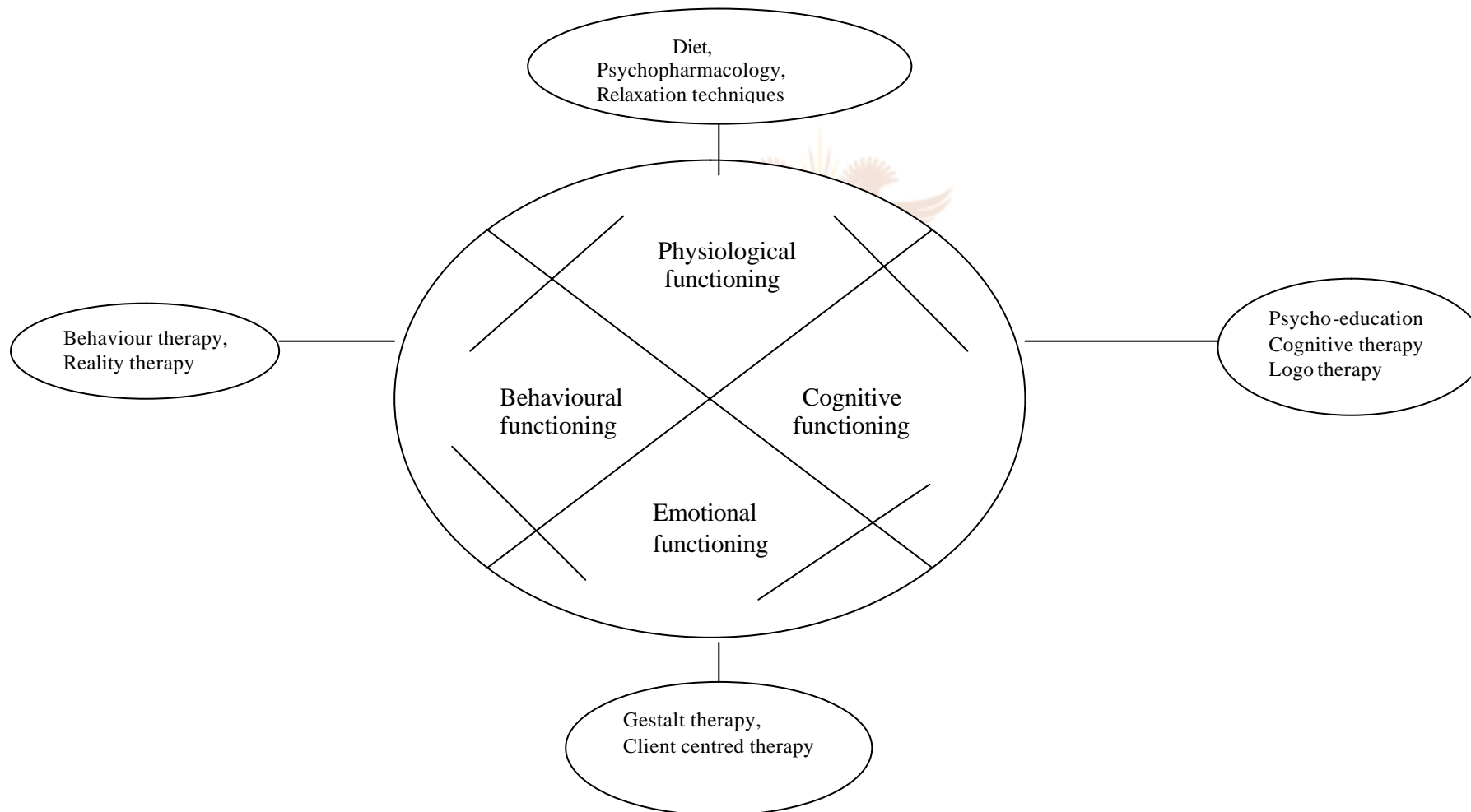
- **Week 6: Goal**- evaluate level of confidence in mother's caregiver capabilities and their confidence in social support systems

In each session of the week, the common goal will be to encourage and facilitate emotional support for the mothers and encourage peer support among themselves.



3.7.3. A conceptual framework for a holistic intervention

The previous discussion has been oriented at depicting the intricate functioning of a human being. The different yet interrelated facets of functioning have been highlighted. Parts of an integrated whole were emphasised. With this in mind, an equally multifaceted approach to therapy is required. See **Fig 2 below: A holistic intervention.**



3.8. Summary and Conclusion

Although limited, the review of literature on the impact of the HIV/AIDS epidemic shows that the disease is at alarming proportions. Research reveals that close to 4.2 million of people are infected with the HI virus. The majority of this number being the mostly sexually active and reproductive group, the teenagers and the twenties age group. This country contributes to over 50% of HIV infections in the world and a quarter of a million deaths resulting from AIDS in each year.

Rising costs in health care in the form of medicines and the funeral expenses increase the burden incurred through the disease. To try to deal with the high costs of medical care WHO in the early nineties suggested that home-based care would be the most viable option in HIV/AIDS management. Since then there has been dedicated women who spend their time caring for their infected children at home.

The effects of the high infection rates of the disease are crippling for the country in general, but are mostly felt by the affected individuals and households. Research into the effects of HIV/AIDS at the individual or household level indicates that this epidemic has both social and economic implications. Families affected by the disease experience a high incidence of illnesses and death. This high incidence has implications on the health care options for such families. They usually rely on government health care services, which are usually below satisfactory standards.

These affected families are usually larger in numbers than unaffected families and have poor financial resources due to low or absent employment of family members. This in addition to the disease places such families into higher financial burdens. To deal with such problems the family then has to rely on somebody from within the family to care for the ill individual(s). The disease eventually culminating in death, the families are usually faced with the task of funeral arrangements, which can be challenging in many ways, viz. emotionally, psychologically and economically.

The review of caregiver experiences showed that the above challenges are not the only challenges faced by carers of HIV/AIDS sufferers. Such carers, which more often than not are mothers of the victims are said to experience the same range of ups and downs experiences by the infected individual. They also face the isolation together with the infected person. They ride the same emotional roller-coaster with them. They experience the same health care challenges with the infected individuals. These mothers who usually spend their day caring for their dying child, often face this task unsupported.

Research reveals that the caregiving experience poses difficult challenge for these dedicated mothers. These challenges range from having to deal with practical day to day care for the infected child. Since most of these mothers are informal caregivers they have to worry about the possibility of secondary infection and usually have no knowledge about the progress of the disease. Due to the often secrete nature of the handling of the disease such

mothers rarely go for support services who can help in the management of the disease.

The infected individual may battle with making sense of his or her fate of being terminally ill, they are usually not the only ones trying to make sense of their situation, so do these mothers who have to understand and accept that they will outlive their children. Research has also showed that caring for a terminally ill child is a fulltime and stressful job. These mothers are usually neglectful of their own well-being and health as they are preoccupied with caring for their child. This makes coping from day to day even more difficult.

Lastly, these mothers have to reconcile with the fact that their child will die and eventually have to deal with the inevitable loss of a child.

In view of the taxing effects the experience of caregiving has on these mothers, it is more than necessary to help them deal with this challenge. An intervention is then proposed to help them deal with the task of caring for a dying child. Taking into account that most of the energy in the fight against the HIV/AIDS epidemic is exhausted at the prevention level, and that efforts at treatment level are usually focused on the infected individuals and not at the informal caregivers who live with the sufferers day to day, attempts at alleviating the carer's burden will prove invaluable.

The suggested intervention is aimed at helping the mothers deal with the experience of caregiving in many levels. The suggested intervention aims to be holistic in nature, addressing emotional, physiological, cognitive and

behavioural needs of the mothers. It aims to help them cope with the day-to-day care of their child.

The intervention is to be carried out in the form of the group with the central idea of encouraging social support, which will facilitate emotional support as well.

The suggested intervention will be carried out over a period of six (6) weeks addressing a range of needs of the mothers. The mothers will be equipped with stress management strategies, coping strategies, will be provided with information on the progress of the disease and given information on the services available at their disposal to deal with the disease. These services range from financial aid to social support services.

In conclusion, it is the belief of the author that the suggested intervention will address the needs of the mothers and help provide the best care they can for their children while taking care of themselves as well and eventually help them to prepare for the death of their children and help them deal with the loss. The author also hopes that the suggested intervention will be useful for not only the mothers who care for their HIV/AIDS infected children, but that it may be useful for other carers who care for terminally ill patients.

If the nation cannot reduce the rate of HIV/AIDS infections and the large number of deaths resulting from the disease, the next best thing to do is to manage the disease.

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