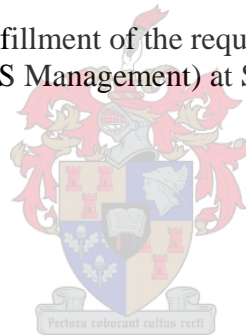


**LACK OF A SUPPORT SYSTEM FOR PEOPLE INFECTED AND AFFECTED BY
HIV AND AIDS IN THE WORKPLACE: CAN EMOTIONAL AND
PSYCHOSOCIAL SUPPORT ASSIST THEM TO COPE BETTER WITH THEIR
PROBLEMS?**

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Assignment presented in partial fulfillment of the requirements for the degree of Master of
Philosophy (HIV/AIDS Management) at Stellenbosch University



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Declaration

I, the undersigned, hereby declare that the work contained in this assignment is my own original work and that I have not previously in part submitted it at any university for a degree.

Signature:

Date:



ABSTRACT

This research paper investigates the need for emotional and psychosocial support for people infected and affected by HIV and AIDS in the workplace. Most employees infected and affected by HIV and AIDS, as well as their families, often need assistance to cope with stigma, rejection, and discrimination, as well as having to adjust to the diagnosis, to confront the fear of losing independence, and to prepare themselves for the changes that might happen to their lives. Hence, through counseling and support, they can have more knowledge about HIV and AIDS and reduced fears and misconceptions about living with HIV and AIDS.

Some research organizations, such as the Perinatal HIV Research Unit, do provide emotional and psychosocial support, and advice for people infected and affected by HIV and AIDS.

An attitude survey was conducted with about 400 employees at the Unilever Company in Boksburg, Johannesburg, in September and October 2005 to determine whether emotional and psychosocial support could play a role in motivating people infected and affected by HIV and AIDS to live positively with the virus, in eliminating related stigma and fears. Employees from this organization were chosen as the population for this survey as a prevalence study and VCT was carried out with them in August and September 2005, so they knew and trusted the counselors who were giving results to them and they had established a relationship with them.

I booked appointments for follow-up counseling sessions of 45 minutes after VCT (Voluntary Counseling and Testing) and then told them about the support group at their workplace.

The findings indicate that there is indeed a need for emotional and psychosocial support for people infected and affected by HIV and AIDS in the workplace. Among other findings, respondents, especially those infected, reported that they had learned that being HIV

positive is not the end of the world but the beginning as long as you look after yourself you can live a normal and productive life for many years, as long as you take extra care of yourself. Most of the affected respondents reported that they had never done an HIV test before due to their own fear of the prognosis. Having acquired more facts about HIV and AIDS, those that had not been tested stated that they now planned to do so. Both groups – those who tested negative and those who tested positive – reported that they also learned about the importance of disclosing your one’s status as a means of getting support.



OPSOMMING

Hierdie mini-tesis ondersoek die behoefte aan emosionele en psigologiese steun deur persone in die werksplek wat besmet is of geaffekteer is deur MIV en VIGS. Meeste van hierdie werknemers, asook hul gesinne, benodig dikwels hulp in hul ervaring van die skandvlek, verwerping en diskriminasie; asook om aan te pas na 'n negatiewe diagnose, die moontlikheid dat hulle hul onafhanklikheid verloor, en om hulself voor te berei vir veranderinge wat in hul lewens kan gebeur. Dus, deur berading en steun, kan hulle meer kennis oor MIV en VIGS bekom en dus verminderde vrese en wangegrippe oor 'n lewe met MIV of VIGS.

Sommige navorsings organisasies, soos die 'Perinatal HIV Research Unit', voorsien emosionele en psigologiese steun en raad vir persone wat besmet is of geaffekteer is deur MIV en VIGS.

'n Houdings-opname is met 400 Unilever werknemers (in Boksburg, Johannesburg) aangevoer, in September en Oktober 2005 om vas te stel of emosionele en psigologiese steun 'n rol kan speel in die motivering van persone wat besmet is of geaffekteer is deur MIV en VIGS om positief met die virus te leef, en om vrese en wangegrippe rondom hul situasie te verminder. Werknemers van hierdie maatskappy is gekies as die populasie vir hierdie aanname omdat hulle in Augustus en September 2005 betrokke was by 'n algemeenheids-studie sowel as 'VCT' (Voluntary Counseling and Testing). Hulle het dus die beraders geken en vertrou, uitslae van hulle ontvang, en 'n verhouding reeds gehad.

Ek het afsprake vir opvolg beradingssessies van 45 minute na 'VCT' gemaak en die respondente van die steun groep by hul werksplek vertel.

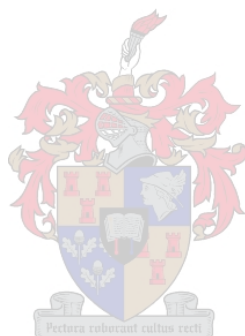
Hierdie bevindinge dui aan dat daar inderdaad 'n behoefte is vir emosionele en psigologiese steun vir persone in die werksplek wat besmet is of geaffekteer is deur MIV of VIGS. Bevindinge is, onder andere, dat respondente, veral die wat besmet is, glo dat hulle geleer het dat om HIV positief te wees nie die einde van die wêreld is nie, en dat as jy na jouself

kyk kan jy 'n normale en produktiewe lewe vir vele jare lei. Meeste van die respondente het weens vrees vir 'n negatiewe diagnose nie tevore 'n MIV-toets ondergaan nie. Met nuwe feite oor MIV en VIGS het die wat nog nie getoets is nie wel beplan om getoets te word. Beide groepe – die wat negatief en die wat positief getoets het – het gesê dat hulle ook geleer het hoe belangrik dit is om hul status openbaar te maak – as 'n manier om streun te bekom.



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1. INTRODUCTION

The HIV and AIDS epidemic in South Africa has begun to have an impact on all areas of life. The emotional, social, and economic impact of HIV and AIDS are felt by society at all levels, from individual, to family, to companies and the community. In most companies those infected with and affected by HIV or AIDS are impacted in many ways. Absenteeism will occur for various reasons, for example when a sick employee begins to take more and more time off work, because of his or her own illness, to take care of, and finally bury, infected family members and friends.

The temporary and permanent absence of staff members affects the performance and the productivity of the company. Often new staff has to be recruited and trained, at high cost to the economy, especially in the case of highly qualified people. The issue of staff morale is also important, as fear of rejection and death reduces levels of staff morale. Additionally, the need to carry more responsibilities increases for unaffected employees as others become sick and spend time away from work.

That is why today most companies are doing prevalence studies and VCT (Voluntary Counseling and Testing) to find out the percentage of people living with HIV and AIDS as well as those who are negative, or to assess the risk impact of HIV and AIDS in their companies so that they are able to plan for the future. However, most of the employees infected with and affected by HIV and AIDS as well as their families often need assistance to cope with stigma, rejection, and discrimination, to adjust to the diagnosis, to confront the fear of losing independence and to prepare themselves for the changes that they will probably experience.

There is evidence to suggest that because of these problems, most HIV-positive employees who know that they are HIV positive, have high rates of absenteeism from work as well as poor performance but do not disclose the reason for this to their employers. Some employees end up losing their jobs by being fired because of absenteeism and others resign because of depression, as they don't have anyone to talk to about these issues. That is why I

believe there is a need in the companies for emotional and psychological support for employees infected and affected by HIV and AIDS to assist them with these problems.

Many studies have suggested that good counseling assists people to make informed decisions, to cope better with their health condition, to lead more positive lives, and reduce further transmission. In the way that VCT is being done in most companies, employees who tested positive don't have emotional and psychological support in their organization as there is no Employment Assistance Programme (EAP) available. Even those companies that have an EAP, the focus is on issues other than HIV and AIDS. Some employees end up going to the public health centres to participate in support groups, which means the organization loses productivity as the employee has to be absent for the day or has to leave early.

Most of the councilors who have been doing counseling in the workplace indicated that as they have been doing pre-test and post-test counseling to these employees they felt that these employees are not able to remember everything for one day. They said they feel as if they are not providing emotional support to these employees. So they believe there is a need for follow-up sessions, where they can spend more time with them to monitor their progress, so that they can raise their concerns, and can talk openly about other issues that they might have.

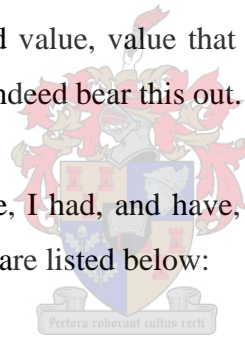
Most of the employees that we see in the workplace are in denial and they don't want to disclose their status to their partners, family, friends or bosses so they don't have anyone to talk to about their status. As a result they end up dying alone and lonely because of the burden they are carrying alone (of being HIV positive). That is why I believe there is a need for emotional and psychological support in the companies to support and care for them so that they can understand the importance of telling someone they trust about their status. It can also help in reducing discrimination and stigma that is happening in our companies as well as our communities (Neilson 2004).

It is important to note that the aim of this research study is not to argue that EAP or disease management should be replaced by emotional and psychological support programmes but to raise the growing need for the emotional and psychological support needed by people infected with and affected by HIV and AIDS. This programme can also benefit family members, as well as other infected and affected people in the entire company such as contractors as well as staff that are on contract – as most of the programmes, such as disease management, do not cover them.

The aim of this research project was to determine whether there is a need for psychological support by those infected with or affected by HIV and AIDS, and whether such psychological support can indeed add value to services already offered.

My hypothesis was that such support was indeed both required, for a variety of reasons, stated above, and that it would add value, value that is essential. The research conducted (see Chapter 3, Methodology) did indeed bear this out.

Besides the main goal stated above, I had, and have, indirect objectives, to which I hope this research will contribute. These are listed below:



- To help employees living with HIV and AIDS to see that being HIV positive is not the end of the world, that they are not alone, and that there are other employees living with this virus which is like other chronic illnesses.
- To create a caring community which accepts, supports and cares for HIV-infected people.
- To help employees receive ongoing psychosocial counseling, receive lifestyle education and knowledge, and to share their experiences of living with HIV and AIDS.
- To change attitudes, practices and knowledge level of these employees on HIV/AIDS.
- To reduce the number of employees who are having unprotected sex.
- To increase condom carrying for those who are at risk of re-infection.
- To increase the number of employees who disclose their status to partners, friends and employers.

- Decrease rate of absenteeism, as the programme will encourage employees to live actively and productive despite the fact that they are HIV positive.

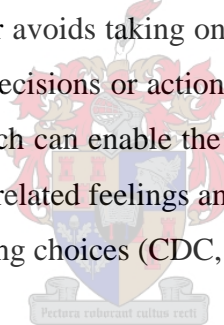


2. LITERATURE REVIEW

2.1 Counseling

Counseling is communication, both verbal and non-verbal, made in response to and in the presence of feelings. It is the work of supporting someone in making decisions when their willingness or ability to act is affected by their feelings. Effective counseling can help a client (and for the purposes of this report, a respondent) to explore, express, understand, and accept feelings so that she or he can make decisions. Counseling is different from education, although education can be a component of counseling. Good counseling is 'client centered', that is it is tailored to the behaviors, circumstances, and special needs of the person being served.

However, counseling is not solving the client's problem for him or her or giving advice. In the counseling process the counselor avoids taking on clients' problems or telling the client how to solve the problem or what decisions or actions to take. Instead the counselor brings a set of skills to the interaction which can enable the client to reach a better understanding of the problem, deal with his or her related feelings and concerns, and assume responsibility for evaluating alternatives and making choices (CDC, 2002).



2.1.1 Voluntary counseling and testing

Voluntary counseling and testing (VCT) is where the whole process starts. VCT is the voluntary presentation of an employee of him or herself for counseling and HIV testing. During this process the clients should receive information about HIV transmission and prevention and the meaning of HIV results which can be negative or positive.

VCT has 2 main objectives. Firstly, to prevent new infections. This is done by identifying people who are negative and to reinforce change in risk behavior, and reduce the risk of being infected by HIV. Also, to identify those who are HIV negative, to modify their risk behavior, to reduce transmission of HIV, and to treat sexually transmitted infections. Secondly, to identify HIV positive employees for the purpose of referring them to the next

stage of wellness programme so that they can be able to cope better with their problems. It is important for the councilor to assure client about confidentiality.

2.1.2 Ongoing counseling or follow-up sessions for people infected and affected by HIV/AIDS

Most people diagnosed with HIV go through reaction stages during their diagnosis. They go through shock, anxiety or fear, denial, anger or blame, depression and acceptance – even if they have a support system. But if they don't have any support system they die because of depression and the burden that they are carrying alone. Having a good councilor allows a client to make good decisions and to confidently put their decisions into practice (Hubley, 2002).

However, because of the above-mentioned feelings after diagnosis, people infected and affected by HIV may not absorb necessary information during VCT; thus, there is a need for ongoing counseling. They need reassurance that whereas they are HIV positive, they don't have AIDS and may expect many years of normal life before the possible onset of AIDS and some of them might not even develop AIDS if they take good care of themselves. The same applies to people who do have AIDS. In follow-up sessions where most of their questions are answered, old information is discussed again, such as changing lifestyle and sexual behavior and living positively with the virus (Hubley, 2002).

Ongoing counseling sessions can provide a valuable opportunity for the client to address related psychosocial issues. Biebel & Zylstra argue that persons with AIDS do better when they know what to expect on the journey (Biebel & Zylstra, 1996). It is commonly believed that people who disclose their status to their loved ones or friends, or publicly live with the virus for many years, live longer than people who have not. For instance, in Khayelitsha in Cape Town most of the people living with HIV or AIDS live openly, and others note that life goes on, productively and, to a large extent, normally. While working in Mowbray Maternity Hospital in Cape Town on clinical trials as a councilor, I observed that mothers who discovered that they are HIV positive, and who are also from Khayelitsha, were not as

traumatized and devastated about their results as mothers from communities where people are not living openly with the virus.

In many companies, employees are far away from their families, the latter often remaining in rural areas. Lacking this support system, the organization or company's ongoing support system for employees is crucial. So emotional and psychosocial support has to be in place as it is designed for client's needs that are tailored to the behaviors, circumstances, and special needs of the person being served.

Hubley argues that counseling of people living with HIV or AIDS ought to be followed by counseling of the family (Hubley, 2002:85). I think this is essential, and include issues such as how HIV is spread, and precautions that ought to be taken. In this way, shame can be addressed, and families given the tools to be supportive.

2.2 Support group

A support group is a group of people who focus helping each other cope better with stressful situations they share, by empowering each other with the necessary skills to manage their present situation. Personal experiences are shared in a safe and welcoming space. Participants can express their thoughts and fears, learn new ways of thinking, and find fresh solutions to their problems. Because of the stigma attached to HIV, this is often the only place where they can safely discuss freely their status and fears, its home away from home to them (Perinatal HIV Research Unit, 2002).

Support groups additionally help participants overcome a sense of isolation (Hubley, 2002). If such a support groups operate within companies, employees, and the company can experience these and additional benefits.

In the support group, knowledge can be acquired by participants about what to expect in their journey from other people participants living with HIV or AIDS, things they might find difficult to discuss with their families.

However, family members, especially parents, also need to attend groups offering emotional and psychosocial support, especially where parents consider associated lifestyles immoral or irresponsible. In this way, further alienation can be reduced. According to findings regarding emotional and psychosocial support that is done by PHRU, such participation has been an opportunity for many families to renew their relationships (Perinatal HIV Research Unit, 2002).

Support groups are also valuable in educating people affected by HIV and AIDS about fears about infecting themselves when they take care of their loved ones.

Another value of support groups in companies is that they are able to fund groups that have wider ripple effects. Some of the big companies and organizations also roll out antiretroviral drugs within their organization, coupled to the operation of support groups.

2.3 Employment assistance programme (EAP)

EAP is the support system available at the moment for people infected and affected by HIV/AIDS in most large companies and organizations in South Africa. It is done most of the time by social workers, or in some organizations, by nurses. It can be done face to face or by telephone. Some organizations conduct them through call centres, and employees infected and affected by HIV/AIDS will speak to different case managers. In some cases employees complain that they can't say everything they want to say because they are not sure whether the call is confidential.

2.4 Findings on results of similar programmes

Emotional and psychological support programmes for individuals infected and affected by HIV and AIDS has been done successfully in Baragwaneth Hospital by the Perinatal HIV Research Unit on their participants who are on antiretroviral drugs. They have a lot of clients who are on ongoing counseling as well as part of support groups. According to their findings, support groups are valuable in empowering and educating people infected and affected by HIV and AIDS. The members of support groups revealed that this support is

essential to them and their families; it is a very important part of their lives (Perinatal HIV Research Unit, 2002).



3. METHODOLOGY

3.1 The Research Problem

The problem that this research addresses is whether individuals infected and affected by HIV or AIDS can be motivated to disclose their status to people that they trust or believe they have to know, live positively with the virus, accept their status and live a normal and productive life. The research question is therefore: Can emotional and psychological support for individuals infected and affected by HIV or AIDS assist them to cope better with their problems?

3.2 Hypothesis

My hypothesis at the start of the research process was that an emotional and psychological counseling (independent variables) can positively influence employees infected and affected by HIV and AIDS (the dependent variable) to cope better with their problems and issues related to HIV and AIDS.

3.3 Research design

An attitude survey was at Unilever (Boksburg, Johannesburg, South Africa) in September and October 2005 to determine if emotional and psychosocial support could play a role in motivating people infected and affected by HIV/AIDS to live positive with the virus, in eliminating stigma and fears around HIV/AIDS. Four hundred (400) employees from this organization were chosen as the population for the survey because they had been part of a prevalence study and VCT in August and September 2005. They thus knew and trusted councilors who were giving results to them. And they had established a relationship.

Employees who tested HIV-positive and those who tested negative but are affected by HIV or AIDS were booked for follow-up sessions. Councilors assured clients about confidentiality, told them that coming for follow-up sessions was voluntary, and also about the advantages of follow-up sessions. Follow-up sessions are conducted immediately after, or few days after, diagnosis.

From this population, 380 adult employees who are living with HIV/AIDS were recruited to join the program. They were asked to come for follow-up sessions, one-on one, for between 45 minutes and one hour. There a counselor reflected on clients' feelings, assured clients of confidentiality, talk about clients' fears and worries.

The councilors reflected on how the client remembered information at the pre and post-test sessions, such as living positively with HIV, the differences between HIV and AIDS, infection control, the rights of the employee in an organization, and why it is important to tell someone. Towards the end of the sessions employees were asked they were sure that they were ready to join the group This was part of the baseline questionnaire, in order to be able to see the results at the end of the study, whether the experiment had an impact or not. They were asked to sign a consent form to join the study and given the date of the support group.

3.4 Sampling

During the follow-up session employees living with HIV or AIDS were asked if they wanted to join the support group. However, some of the employees would probably be on ARV, others might be known to be HIV-positive, others might be hearing their status for the first time, and others might know but still be in denial. As the survey was to be optional, each employee in the sample of n=380 had the same probability of being in the study. The information was collected over the period of 6 weeks.

Regarding eligibility, participants had to be older than 18 years, and had to be either infected or affected by HIV and or AIDS.

3.5 Participation

The response at the follow-up sessions were good – a response of about 98% of people infected and affected by HIV who were booked come back for their appointments. The councilor did the follow up session reflecting back on what they said the previous day, the importance of living positive with the virus, of using condom to prevent re-infection, of telling someone they trusted about their status for those who tested positive; and for those

affected, the importance of supporting a person who is positive as well as how do they feel about the fact that they have friends and family members that are positive.

After participants finished with the counseling they were told about the study and all of them agreed to participate, and were assured that the survey is confidential and voluntarily. They were told the date of the support group. They were assigned to two groups: those infected to their own group, and those affected to their group – because of confidentiality issues. They were given consent form to sign for participating in the study. The questionnaire did not have any names but bar codes that linked a client from his/her test results, research questionnaire as well as the support group information. The bar codes appeared on the field notes, the envelopes containing HIV finger prick results, and cards giving information about ongoing emotional and psychosocial support.

3.6 The Research Questionnaire

The first question was about demographic data: age, gender, level of education and marital status. The second question was about HIV/AIDS information – in the past 12 months.

2.1 In the past 12 months which of the following activities have you participated in? (Answer each question below)		
Meeting on HIV and AIDS in the workplace	Yes	No
Volunteered for HIV and AIDS activities in the workplace	Yes	No
Given advice to others about HIV and AIDS	Yes	No
Cared for a person who is sick with HIV and AIDS	Yes	No
Attended HIV and AIDS rally in the workplace or community	Yes	No
Attended HIV and AIDS play or educational event in the workplace	Yes	No
Spoken to a peer educator	Yes	No

2.2 In the past 12 months has a friend or a relative told you that they are HIV positive?	Yes	No
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2.3 In the past 12 months have you attended a funeral of a person who is said to have died of AIDS?	Yes	No
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2.4 Answer each question below:			
A person with HIV can look healthy	Yes	No	Don't know
Antiretroviral drugs can help people with HIV live longer			
If you and you partner are HIV positive you have to use condoms to prevent re-infection.			
If you discovered that you are HIV positive, do you think it is important to tell your partner, friend or boss			
There are people living with HIV/AIDS for more than 20 years			

2.5 Do you agree or disagree with the following statements?	Agree	Disagree	Why
I am comfortable talking at least to one of my colleagues about HIV/AIDS.			
I would be embarrassed to be seen with somebody who everyone knows has HIV/AIDS			
If I ever told my work colleagues I had HIV, most of them would still support me			
If a friend told that s/he has HIV I would remain friends with him/her			
HIV infected mothers should not be allowed to have babies			

2.6 In the past 12 most how many different people have you had sex with?	0	1	2	More than 2
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2.7 Did you use condoms the last time you have sex?	Yes	No
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2.8 in the past 12 months, have you been forced by physical violence to have sex against your will by someone who works in this organization	Yes	No
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2.9 Other than being tested as part of this research survey, when last did you have an HIV test? (Mark only one)	
I have not had an HIV test before	1
Less than a year ago	2
Between 1 and 2 years ago	3
Between 2 and 3 years ago	4
3 or more years ago	5

2.10 What was your main reason for doing the test? (Mark only one)	
I had not had an HIV test before	1
I wanted to know my HIV status	2
I wanted to start a new sexual relationship	3
I applied for an insurance policy or loan	4
My employer requested it	5
I was feeling sick	6
I was pregnant	7
Me and my partner wanted to take our relationship on the next level	8
Other	9

Question 3 is about Job information:

3.1 What is your job category	
Senior manager or Executive	1
Professional or manager	2

Technical or Clerical	3
Skilled production worker	4
Labourer	5

3.2 How many years have you worked for this organization	Less than 1	1	2	More than 3
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3.3 What is your monthly salary? (gross salary before tax and other deductions)	
Less than R1000	1
R1 001 to R3 000	2
R3 001 to R5 000	3
R5 001 to R8 000	4
R8 001 to R10 000	5
R10 001 to R15 000	6
R15 001 to R20 000	7
More than R 20 000	8

3.4 Are you on medical Aid?	Yes	No
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Open-ended questions

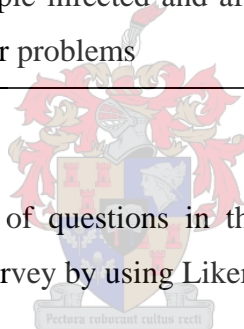
4. How do you feel about having ongoing emotional and psychosocial support in your company?	
Those who believe that ongoing counseling will help them deal with the reality of HIV.	Why
Those who believe that emotional and psychosocial support is not going to help them	Why
Those who are not sure whether it can help them or not	Why

5. If you have to choose between the two, which one would you choose?	
Those who prefer to go to the EAP specialist	Why
Those who prefer to go to the councilor who gave them results	Why
Those who don't care whether she goes to EAP specialist or councilor	Why
6. Where can a person go for HIV and AIDS emotional and psychosocial support in you company?	

7. Have you ever used these services before?	Yes	No
(If yes) what did you like or dislike about these services.		
Notes!		
(If no) what If ever you don't want this type of service, where would you go and why?		
Notes!		
8. What services do you think people infected and affected by HIV/AIDS need in your organization to help them solve their problems		

3.7 Data Collection

The survey was made up mostly of questions in the form of attitude statements, and completed by participants via the survey by using Likert scale format.



3.8 Guidelines for support group

For the experimental group, the support group was formal, with a facilitator, and participants received information on the topics below:

First session – getting to know each other: participants to get to know each other, the employee's name, where they live, what they do for living, what to do when they see each other on the streets, whether to greet each other or not and rules of the group.

Second session – discovering yourself: give each employee a booklet that s/he is going to carry in all sessions. In this session s/he draws or writes down things that she likes and discusses them in a group.

Third session – support system at home: each employee has to draw people that are close to him/her whether friends or family, people that are important in his or her life, and explain the relationship with that person, how close they are in that particular person.

Fourth and fifth sessions – positive living: invite someone who has been living positive with HIV/AIDS for years, on advice what makes him/her to live longer with the virus so that she or he can bring hope to the group. Discuss experiences of that person.

Sixth session – disclosure: why it is important to disclose to someone that you can trust that will support you. How disclosure helps in eliminating stigma and discrimination that is happening in our communities. Why it is important to disclose to your supervisor or line manager.

Seventh session – the importance of preventing infections and re-infections: Why it is important for the client to treat infections, to go to the doctor when they are not feeling well, why it is important for them to use condoms.

Eighth session – empowerment and skills building: discuss the fact that employees with HIV can be productive for many years; encourage them to be responsible for their own actions. Affirm the employees on issues of rights, working conditions and reasonable accommodation. Assist the employees to make realistic decision in relation to his or her condition.

Ninth session – planning for the future: who is going to take care of the child/children if parents happen to die; the support group is more about support, care as well as giving hope to those living with HIV and AIDS. But we need to face the facts and deal with this issue as many children who are orphans are left alone by their parents without anyone to take care of them.

Tenth session – closure: employees decide themselves whether to continue with the group or not. If they decide to continue, they will decide on what to do, maybe they can

be trained and used as educators in the company. So that other employees can see the reality of HIV and AIDS, can also reduce stigma, employees will be able to see faces of HIV for those who are will to disclose their status in their organizations. In each session they can discuss any other topics or issues that they want to discuss.

In the second group the participants can discuss anything they want to discuss whether is HIV related or not (general issues).

Many employees who were booked for the second session came back for follow-up and having the opportunity of getting more facts about HIV/AIDS. Many of them agreed to come for more sessions in the support groups in which they gain strategies on how to disclose to your partner, friend, boss, and the public and most of them are peer educators in the same company. The 2% who were not ready to participate in the survey, at least did get some information during the second session.

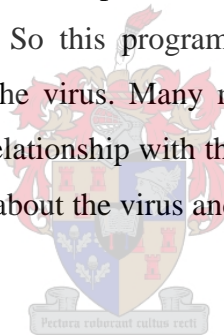


4. RESULTS

4.1 What the participants learned from the survey:

4.1.1 Affected

Participants said they will be more supportive to people living with the virus after the survey. Most of them mentioned the fact that they had never done an HIV test before as they were afraid that when they heard that they are HIV positive they would start to get sick and eventually die. But now that they have more facts about HIV and AIDS they are going to do the test so that if they are negative they will change their behavior and make sure they stay that way. If positive they are going to take extra care of themselves by eating healthily, exercising, disclosing their status to people that they trust so that they get support, use condoms to prevent re-infection and to protect the other partner that might be negative so that they can live more years. So this programme can also be used as prevention programme for those affected by the virus. Many members mentioned the fact that the programme helped them to renew relationship with their partners or to be closer to them as now they have more understanding about the virus and did learn from the other members of the group.



Most of the participants mentioned the fact that in the support group they felt included, that they lived without fear that other people would reject them or discriminate against them, and that helped them to continue functioning as ordinary members of society. They said the support group helped in empowering as well as educating them as most of them decided to do the HIV test after support group sessions.

4.1.2 Infected

Most participants said the emotional support provided valuable opportunity for them to share feelings and concerns and it helped them to overcome the sense of isolation as most of them don't have families or people that they can freely speak to where they stay. They said they learned the importance of disclosing their status to people that they could trust.

They learned that being HIV positive is not the end of the world but the beginning, and as long as one looks after oneself one can live many more years.

They said they don't feel ashamed about being HIV-positive anymore. One of the participants said that she discovered that she was HIV-positive 6 months prior to the study and that she blamed her partner, denying the fact that she was HIV positive: "...how could he do this to me, I'm only 23. My life has not even begun yet and it's already ended. I felt broken, robbed and destroyed..." She said that's how she felt before joining the support group. But now she accepted the fact that she is living with the virus and she has changed her lifestyle for the better and she knows that her life is not ending but beginning even if the journey is going to be long. She had made some important decisions in her life including forgiving a person who infected her which was difficult for her before she joined the support group.

After the support group most of the members mentioned the fact that this support group was essential to them and their families, a crucial part of their lives. Most members said in the support group they were able to express their feelings as well as fears, they had learned new ways of thinking, and they were able to find new ways of thinking and find fresh solutions to their problems from the other fellow members of the support group.

4.2 Service providers and councilors

When I was doing this survey, I also interviewed councilors who are working in the workplace as well as service providers. In most of the questions they agree with the respondents, and said that in the workplace there is no programme that focuses on emotional and psychosocial support for people infected and affected by HIV and AIDS, and stressed that there is the need for it. They said it can be a good thing if this programme can be incorporated with the disease management programme that is already implemented in most of the organization.

Councilors felt that most of the employees who are infected and affected with HIV and AIDS need emotional and psychosocial support in order to be able to cope with changes

that might happen in their lives. They said, at the time of diagnosis, most of them lose hope, the reason why you find others leaving their jobs, or being absent at work most of the time. They need someone to guide them, to assure them that as time goes by everything will be OK, that it is normal to feel the way they are feeling at that particular time. They said employees have many decisions they have to make such as when to take treatment, and advantages and disadvantages of Antiretroviral drugs, particularly the side effects, before they take the decision of being on treatment, because if they do not get proper counseling they end up not complying with the treatment, or relapsing and become resistant to the treatment.

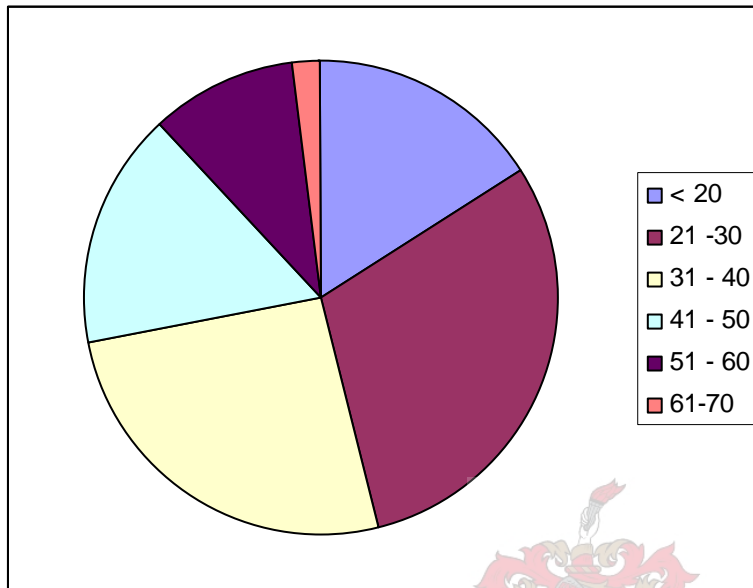
The service providers said that it is important that the companies work towards destigmatizing HIV and AIDS within their environments, before implementing a programme like this, because individuals infected and affected by HIV and AIDS won't participate in the programme like before this happens. They said in most of the companies where there is stigma around HIV and AIDS, employees don't participate even in VCT and prevalence surveys because they fear that, after the campaign they might lose their jobs.

Service providers and councilors mentioned that, as they have been doing these services in the workplace most of the employees said they appreciated it, as they believed it was convenient for them because they don't have to go to the public clinic. They agreed with this study's respondents as they also mentioned that if they can have this service on site they won't have to leave work early.

Councilors mentioned that in the companies where they are doing offering services there is no one who is monitoring and evaluating what they are doing. Councilors said some individuals infected and affected by HIV and AIDS might refuse because they think or believe is not beneficial to them, and therefore they need councilors who will be able to convince them about the importance of the programme. The councilors and the service providers who are working in the community mentioned that it is very important to ensure that the client returns to the same councilor because if not they end up losing trust in the relationship between themselves and the councilor.

4.3 Survey Data

A total of 344 responses were gathered during a six week period. Of these, 320 surveys were fully completed. The demographic data for the survey questions are summarized below:



Age groups

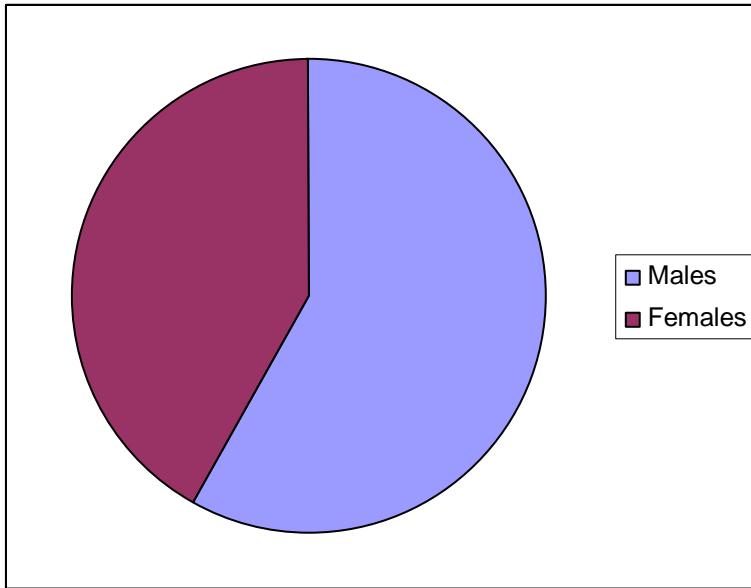
Ages of participants ranged from 18 years to 66 years. The biggest group were between the ages of 21 and 30 (about 30%) – typically, in South African statistics, the ages having a higher prevalence than any other age groups. Hence, these people are young people, are in their early years of working, most of them are educated, others are doing their internship, and they are the one's that can contribute in the growth and development of this organization as well as in the economy of our country.

Participants from ages 31 to 40 were the second largest group (about 26%). These are also young people who are educated and are having skills and know much of the work that is being done from this organization. Most of them have been working in this organization for years and they are already in management positions. Hence, now they think their careers are ending and most of them don't have any support system as they are in the cities to work. They don't have courage to disclose to their friends or bosses because as they are leaders. They felt didn't have anyone to disclose to or to talk to. They are carrying the

burden of HIV alone, which is something that can damage their health. So they felt that this programme was very beneficial for them as they believed they really need emotional and psychosocial support because they don't have any at the moment.

The third largest groups about 16% were participants who were younger than 20. These are very young people, most of them are still studying and are having a bright future ahead of them, and they don't have many facts about HIV and AIDS. Most of them believed that this programme is very beneficial to them as it give them guidance on how to live positively with the virus as well as how to disclose because they are still young their parents don't even expect them to have sex yet and now they are HIV positive.

The fourth group of participants (about 16%) were between the ages of 41 to 50 most of which have top management positions, are loyal to the organization, have been working for the organization for many years and know the everything about the organization. They have families and children. People in their communities don't expect them to be HIV positive because of their positions at work. The implications to the organization if these employees are lost are noteworthy. The fifth group was between the ages of 51 to 60 (about 10%). And the last few participants were between the ages of 61to 70 (about 2%). All participants believed that emotional and psychosocial support was very beneficial to them.



Gender distribution (Male 58%; Female 42%)

Questions 2 and 4 were about HIV and AIDS information, how do they feel about being HIV positive or to have a friend or a relative that is HIV positive, the support system at work and in their communities and their behaviors.

Most of the participants in the survey had basic about HIV. They knew how it is transmitted, that there are antiretroviral drugs available at government clinics, but they didn't know much about them, that a person can be HIV positive and look healthy. Participants don't support HIV/AIDS activities happening in the community as well as those that are happening in their organization. Whereas the company believes they have done a lot when HIV/AIDS education is concerned and have peer educators that are doing training as well as coaching, some of the employees said they never spoke to peer educators, and some of them said they don't even know what peer educators are.

Although some did care for a friend or a family member who is HIV positive, most of them mentioned the fact that in the past they did look after a family member who was sick having symptoms of HIV/AIDS who had died but never mentioned that they had AIDS. Most of them said they do give advice to each other about HIV/AIDS. However, about 50%

of the group said they had friends or relatives who told them that they are HIV positive. About 80% of them said they attended a funeral of a person who died of AIDS in the past.

Most of the participants (about 72%) said they will support a person who is HIV positive but wouldn't themselves disclose their status to their friends or bosses as they don't know how they would react on that information, and 28% said they don't know whether they will know how to support a person who is HIV positive. About 96% of respondents believed that mothers who are HIV positive must be given a freedom to have babies if they want to as long as the person contacted her doctor first before falling pregnant, knows the risks of having a baby when you are HIV positive or had AIDS and take the necessary precautions. And 4 % believed that mothers who are HIV positive or had AIDS must not be allowed to have children because those kids will grow up without parents.

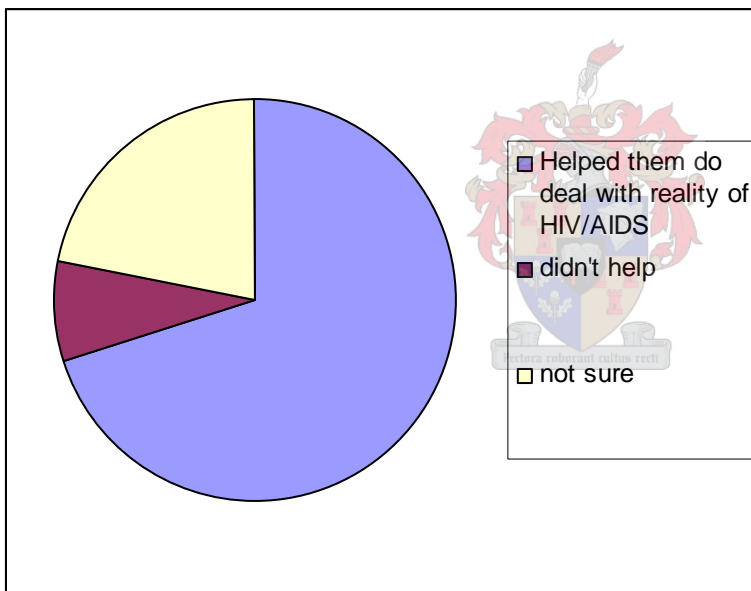
Most of them have different partners, and some of them have 2 or 3 different partners in the same organization and a wife or husband at home. About 38 % of the respondents who are married said they don't use condoms with their husbands or wives but use them with other partners. Twenty six percent said they sometimes use condoms, especially when the relationship is new or when they discovered that the other partner is cheating; 24% said they use condoms all the time in the relationship that they are in at the moment as they believe in being responsible for their own lives; and 12 % of respondents said they don't use condoms at all as they are married and that their partners will think they are cheating if they suggested using condoms.

Regarding testing, 32% of the participants never had an HIV test before the one the prevalence survey, as they never saw the need of doing it as they believed they were not at risk. About 26% did the test less than a year ago with the partner as they felt they needed to plan for the future; about 22% did the test 2 years ago as they were taking out insurance but don't know the results of the test; and about 20% did the test 3 years ago because they were sick, and in once case, because she was pregnant.

Question 4 participants were assigned to 3 groups:

1. Those who believed that emotional and psychosocial support will help them deal better with HIV/AIDS
2. Those who believed that emotional and psychosocial support is not helping them.
3. Those who were not sure whether it helps them or not.

However, as we can see from the figure below, the emotional and psychosocial support programme was a success. More than 70% of the respondents believe that emotional and psychosocial support helped them deal with the reality of being HIV positive. Almost 8% believe the programme didn't help them to deal with their own issues. About 22% of the participants were not sure whether the programme helped them or not.



The success rate of emotional and psychosocial support for employees infected and affected by HIV/AIDS.

Helped 70%
to deal with
their problems

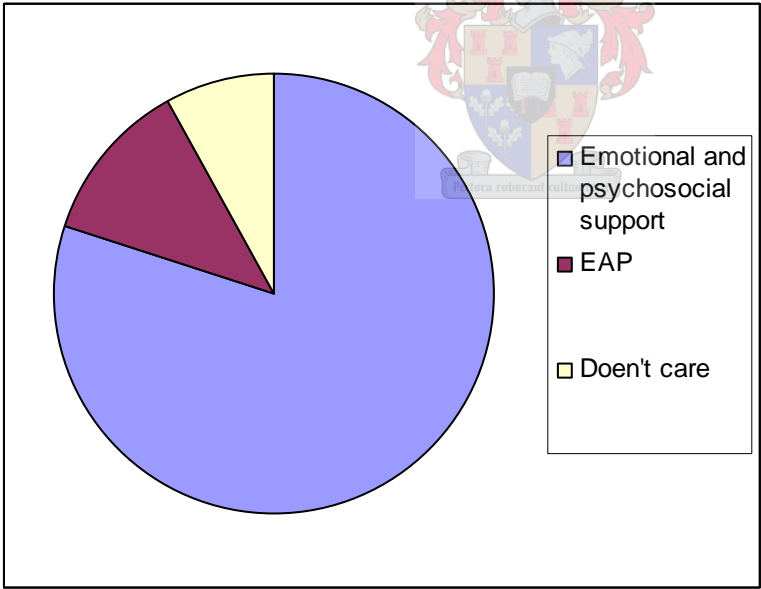
Didn't help 8%

22% were not sure

Question 5 was about making choices, if they have to choose to go to the EAP specialist or go to the councilor who is specializing in HIV/AIDS for emotional and psychological support. They had to choose between 3 answers:

1. Those who prefer to go to the EAP specialist
2. Those who prefer to go to the councilor specializing on HIV/AIDS emotional support
3. Those who don't care whether s/he goes to the EAP specialist or HIV/AIDS councilor

As can be seen in the figure below, more than 80% of the respondents said they will go to an HIV/AIDS emotional and psychological councilor because there they are focusing on HIV/AIDS and there is also a support group that helps to deal with issues. Less than 12 % said they will choose to go to the EAP specialist. Almost 8 % said it does not matter to them they can go to either group.



Employees' views: which programme they will choose in future if they have a choice.

12% 80% 8%
EAP Councilor Don't care where they go

Discussion of the Likert Scale Survey for questions 2, 4 & 5.

The answers to question 2, 4 and 5 in the survey are examined and analyzed by:

- Comparing the mean responses of 2 groups for question 2, and 3 groups for question 4 and 5
- Using analysis of variance ANOVA to determine significant differences in the mean responses of the 3 groups at a 5% significance ($p < 0.05$)
- Discussing the relevance of these differences or lack of differences.

Firstly, what is the mean? Christensen defines it as “arithmetic average of a group of numbers, it is computed by dividing the sum of all scores by the number of scores in the group” (Christensen, 2001:328).

However, as we are studying the lack of emotional and psychosocial support for people infected and affected by HIV/AIDS I decided to check their level of HIV/AIDS information. So in question 2 participants were asked about HIV/AIDS information, whether they participate in HIV/AIDS activities in their organizations or their communities, if they talk openly about HIV/AIDS in their organization or communities, and what they know about HIV/AIDS as they have peer educators who train them on HIV/AIDS.

The participants were assigned to 2 groups; there was an experimental group of participants who were trained on HIV/AIDS by our councilors who gave them results during prevalence survey did follow up sessions and support groups with them. There was also a group of people who were given general information on anything that they wanted to talk about. At the end of the 10 session in both groups all participants who attended session were given scores. The scores of the tests start from 0 up to 100.

	Group A (trained)	Group B (non- trained)
	98	84
	93	78
	90	72
	89	67
	87	65
	87	64
	84	62
	81	62
	78	57
	71	51
	66	46
Mean	84	64.36

Data and descriptive statistics for the test results for counseled individuals on emotional and psychosocial support (trained) and non- counseled (trained) subjects during support group.

Looking at the table of the hypothetical data for the results of the two groups of participants, firstly we see that there is a difference in mean (average) scores between the groups, as we can see the mean difference for each group shown above, which is 84 for the trained and 64.36 for the non-trained. There are also differences among the scores within each group. That is, the scores in group A range from 66 to 98 and those in group B range from 46 to 84. That means there is the difference between the two groups and the difference is not due to chance really when people infected and affected by HIV/AIDS get emotional and psychosocial support they can deal better with their problems, (see: Christensen, 2001).

We also find that there is an individual difference in terms of being open about their status and in terms of participating in organizations or community activities. Those who were trained had more knowledge about HIV/AIDS and were talking openly to other participants about their status. So as they disclose their status to members in their organization as well as to the community they get more emotional and psychosocial support. That means as

participants get more information or good counseling about HIV/AIDS the more they come to terms with the fact that they are HIV positive. This clearly means that the group of individuals who received information about HIV/AIDS during follow-up sessions as well as during support groups did much better than those who didn't receive any HIV/AIDS information during these sessions. That means this data indicates that emotional and psychosocial support makes a difference in the lives of people infected and affected by HIV/AIDS in that case null hypothesis should be rejected. Christensen states that, "...to determine whether the difference between the group mean scores is due to chance or to the independent variable, we need some indication of the variability of the participants scores in each group" (Christensen, 2001:330). Hence, we can see the difference in the scores of the people who were trained on HIV/AIDS information and those who were not trained.

Question no 4 and 5 respondents were assigned to 3 groups. Question no 2 was about feelings, was asking respondents how would they feel about having an emotional and psychosocial support in their organization and why. They had to choose between 3 choices:

- Those who believe that emotional and psychosocial support will help them to face the reality of HIV/AIDS.
- Those who feel that emotional and psychosocial support is not going to help them.
- Those who are not sure whether it is going to help them or not.

These were compared with the results of question 5 (question 5 was about making choices and why would they decide to take those choices.

- Those who prefer to go to the EAP specialist.
- Those who prefer to go the councilor who gave them their results.
- Those who don't care whoever they go to.

Table giving an overview of descriptive statistics for 3 groups regarding survey questions no 5.

Question 4	Question 5 Mean	Question 5 St. Err	N
Group 1	3.22	0.18	12
Group2	2.44	0.08	68
Group3	2.86	0.06	48

According to the above table all 3 groups either agreed or strongly agreed that emotional and psychosocial support could motivate individuals infected and affected by HIV/AIDS to cope better with their problems. In all groups we found out that emotional and psychosocial support could be instrumental in influencing employees infected and affected by HIV/AIDS to cope better with their problems. Group 4 had a higher average than the other 2 groups.

- Emotional and psychosocial support can help to eliminate stigma around HIV/AIDS in our organizations.
- More people the organization will have more knowledge or facts about HIV/AIDS
- More people will disclose their status as they will understand that being HIV positive is not the end of their lives – it’s just a virus affecting our bodies – and at that level, it’s manageable.

For question 6, 7 and 8 we are going to use the Pearson product moment correlation to measure the relationship between the variables. Graziano & Raulin (Graziano & Raulin, 1993) state that, the product moment correlation can range from -1.00 to + 1.00. When +1.00 it means that there is a relationship between the 2 variables. For instance, Question 8 is asks the respondent: What services do you think people infected and affected by HIV/AIDS need in your organization to solve their problems?

More than 0.92 indicated that they need an emotional and psychosocial support program as they don’t have any available at the moment. They said in this company people are dying alone and silently and they don’t tell anyone what’s wrong with them. So they believe that

if there can be a support system in place for people infected and affected by HIV/AIDS at least people will get help where counseling is concerned and see that they are not alone there are hundreds or thousands of people infected and affected by the same virus in the same organization. Less than 0.08 said they don't know which service is needed but they believe people infected and affected by HIV/AIDS in order to survive, whether the EAP programme or emotional and psychosocial support. That means there is a stronger relationship between being infected and affected by HIV/AIDS as well as need for emotional and psychosocial support.

Question 6 asked: Where can individuals infected and affected by HIV/AIDS go if they want emotional and psychosocial support in your organization?

More than 0.88 said most of the people go to the public health clinics. They also mentioned that, if they are going to the health centre for emotional and psychosocial support, they had to be absent at work or leave early from work if they are going for the support group. Less than 0.04 said they did go once to the EAP councilor; and that it didn't help them much after that – they didn't know where they can go as the public health centers are only open when they are at work and closed during the weekend. Less than 0.08 said they never thought about it as they discovered that they are HIV positive few days ago, but as they were involved in survey of emotional and psychosocial support it helped them a lot to come in terms with their status and they believe can help other people too.

Question 7 was about whether individuals have ever used services mentioned above such as emotional and psychosocial support in a public health clinic, EAP; and what they liked and disliked about them. Those who went to the public health clinic said they liked the fact that there was ongoing counseling as well as support groups, and that the support group was not formal so that anyone who is HIV positive or has AIDS can come anytime, so you can end up running to someone you don't want to see in the support group. They didn't like the fact that they had to be absent at work to get emotional and psychological support and the fact that they have to travel.

Those who went to the EAP in their workplace said they didn't find much information on HIV/AIDS so they decided to quit. They liked the fact that EAP was in their workplace so they could go to it anytime they felt like going, and also that they don't have to spend money to go to it.



5. CONCLUSION AND RECOMMENDATIONS

5.1 Conclusion

The HIV/AIDS epidemic in South Africa has begun to have an impact on all areas of life and society. The emotional, social, and economic impact of HIV/AIDS is felt by society at all levels, from individual, to family, organizations as well as the community.

However, within the workplace, those infected and affected by HIV tend to need emotional and psychosocial support to cope with their problems because HIV brings other problems in their lives, such as how to tell the partner or parents about the results. At present in most of the organization there is no support system in place to help these individuals to deal with these problems. As a result, most of the individuals in this organization die alone because there is no one to whom they can disclose, as their families are far away so they keep the burden of living with HIV/AIDS to themselves and end up being depressed, and some die alone. After they are told that they are positive after the prevalence study and then referred to their doctors, disease management companies or a public clinic, there is no one who checks if they go where they are referred. As a result most of them end up denying the fact that are HIV positive and sleep around, and those who are affected also come with their problems to the organization, which at the end of the day has an impact on productivity as well as on the profits of the organization. That is why there is the need for the programme like this to help both employees infected and affected by HIV/AIDS. It can be of benefit to the organization too as now they won't have to go to the public health centre to get emotional and psychosocial support.

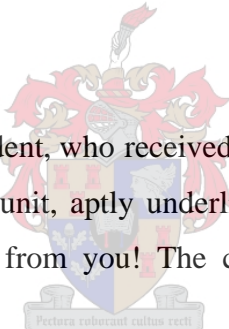
5.2 Recommendations

In one of the popular magazines (*True Love Magazine, January 2006, 14*), Judge Cameron stated that, close to 30 million Africans (including at least 4 to 5 million South Africans) are HIV positive, the majority of whom will die of their condition within 20 to 30 years, unless immediate intervention is done. Most of them are between the ages of 19 and 30; the young, who are the ones who are supposed to contribute to the development and economic growth of our country. That is why organizations need to implement emotional and

psychosocial support for infected and affected individuals to empower them to cope better with their problems. The results this study shows the need for it. Therefore these recommendations were suggested by the respondents and by myself.

Firstly, the organizations, in general especially those that have high prevalence rates, need to do strategy planning of our programme by advertising it to the top management, the board of directors and union leaders. The board of directors needs to be involved as they will set the tone for the rest of the organization to incorporate the programme seriously. It is recommended that Unilever needs a comprehensive intervention programme to deal with the impact of HIV/AIDS in their organization, one that not only focuses on the physical well-being of their employees, as the emotional well-being of an employee is as important as their physical well-being. They need to incorporate emotional and psychosocial support with the disease management programme that is already being implemented in the organization.

The following words of one respondent, who received emotional and psychosocial support after diagnosis in a research clinic unit, aptly underline the need for such a programme. “HIV takes so many things away from you! The clinic gave me so much more than medication....they gave me hope.”



After diagnosis most of the employees who are infected by HIV need emotional and psychosocial support in order to be able to cope with changes that might happen in their lives. At this time most of them lose hope; some leave their jobs or are frequently absent from work. They need someone to guide them, to assure them that their perception of the situation will improve over time, and that their feelings are normal. They have many decisions they have to make, such as when to take treatment, and advantages and disadvantages of Antiretroviral drugs, particularly the side effects, before they take the decision of being on treatment, because if they do not get proper counseling they end up not complying with the treatment, or relapsing and becoming resistant to the treatment.

It is essential that organizations work towards de-stigmatizing HIV and AIDS within their environments, so that individuals infected and affected by HIV/AIDS are more willing to participate in the programme.

Most respondents said their organization has been responding positively with HIV/AIDS policy and other programmes such as prevalence surveys and VCT, but they believe there is a need for a programme that emotionally supports people infected and affected by HIV/AIDS.

The follow up, ongoing counseling, as well as support groups must be provided on site, because it is convenient for the respondents. Other researchers have argued that, given the proven efficacy in settings where HIV prevalence is high, the ability to provide such counseling onsite is a priority (CDC, 2005). In some organizations space constraints can be a barrier to provide HIV and AIDS emotional support. In the interim, alternative resources should be identified, and clearly defined referrals should be made to settings that can provide high quality emotional and psychosocial support and systems to ensure that referrals are completed should be established. Clients must be referred to known and trusted services. And after referral the councilor must follow that up to see if the client is getting emotional and psychosocial support (CDC, 2005).

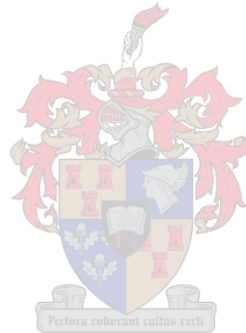
When this programme is implemented, a full time coordinator must be employed to ensure the quality of the programme. It must be ensured that councilors deliver counseling that is going to be effective to the participants. According to experienced councilors clients who agree to follow-up counseling but decline support groups, often report the lack of time or already are aware of HV transmission mode. They might refuse because they think or believe is not beneficial to them. They need councilor who will be able to convince them about the importance of the programme.

The coordinator must conduct routine assessments for quality assurance to ensure that the counseling being provided meets its goal-setting. Counseling sessions must be provided that are appropriate to the client's culture, language, sexual orientation, age and

development. Since employees might be poor, and fear discrimination and loss of employment, they will need the appropriate education about emotional and psychosocial support in a way that is sensitive to their culture.

When this programme has been implemented, it is very important to ensure that the client returns to the same councilor because consistency of the client and the councilor relationship helps the client to feel secure, reduces misunderstanding, and promotes the likelihood of effective risk reduction. When follow-up sessions and support group sessions are going to be provided by a different councilor, careful record keeping is recommended to ensure high quality counseling (CDC, 2002).

This programme can also be used as a prevention programme for HIV negative people are affected by HIV/AIDS by getting information through counseling.



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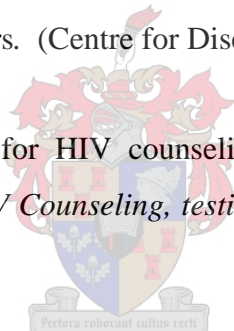
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