

Full Length Research Paper

Support groups for HIV positive mentally ill patients

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The aim of this study was to describe the demographics, clinical characteristics and expectations of the members of a newly established support group for HIV positive mentally ill patients. The factors associated with disclosure of status and expectations of the group, were also to be determined. All mental health care users, aged 18 years and older, with HIV and admitted to Chris Hani Baragwanath Hospital (CHBH) between March and June 2008 were invited to participate in the support group at Luthando Psychiatric HIV clinic. All the members of the support group were asked to complete a questionnaire at the first group session they attended. The questions related to demographic data (age, gender, home language, employment status, marital status, level of education, number of children); clinical data [past psychiatric illness; current diagnosis, on Antiretroviral treatment (ART)]; if they had disclosed their HIV status and the expectations of the members of the group were collected. All fifty members of the support group volunteered to complete the questionnaire resulting in a 100% response rate. The majority of the subjects were in the age range 26 - 35 years (44%); female (78%); single (88%); had 2 or more children (71%); had less than a grade 10 level of education (44%) and were unemployed (68%). The common spoken first languages of the subjects were Zulu (34%) and Tswana (20%). Only 6% of the subjects reported English as their first language. Approximately two thirds (60%) of the subjects had been diagnosed with a psychiatric illness. The current diagnoses of the members of the group included mood or psychotic symptoms secondary to HIV (25%); bipolar disorder (33%); anxiety disorders (3%) and schizophrenia (3%). Only one third of the group had been commenced on antiretroviral treatment (ARV) treatment. Two out of every three members (68%) in the group were aware of their HIV status for longer than six months. The majority (70%) of the members of the group had disclosed their status either to a family member or friend. The common expectations of the group included education (36%) and support (32%), whilst 32% had other expectations or were unsure of their expectations. This study found that mostly young females, who had dealt with the issues of disclosure of their diagnosis to a family member or friend, joined the support group with the expectation of receiving emotional support and education. The inability of individuals to cope with the burden of HIV and AIDS and a co-morbid mental illness may be associated with feelings of hopelessness and a depressed mood which may lead to decreased adherence to medication regimes, suppression of immunity and accelerated disease progression. This may also be closely associated with HIV transmission risk behaviours and increased risk of suicide attempts. It is imperative that all mentally ill patients with HIV and AIDS receiving ART be a member of a support group as it will help improve adherence and functioning.

Key words: support group, HIV/AIDS, mental illness, antiretroviral treatment (ART).

INTRODUCTION

In mid 2006 approximately 5.5 million South Africans were diagnosed with HIV in a total population of around

48 million, which converts to a prevalence rate of about 11% (UNAIDS, 24 April 2008). Approximately 10% of these HIV positive people were also diagnosed with acquired immunodeficiency syndrome (AIDS). The introduction of antiretroviral therapy (ART) for the treatment of AIDS has reduced AIDS related deaths by around 100,000

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per year. Consequently, it is estimated that the number of people living with HIV and AIDS and on ART by the year 2015 will be close to 2 million people, if rollout of ART increases as proposed (UNAIDS, 24 April 2008).

The availability of ART means that those diagnosed with HIV and AIDS will probably live longer. In turn these people will more likely have to deal with the challenges related to living with this illness. These include somatic preoccupations; fear of death; feelings of "unlovability", social ostracism; anger; frustration; anxiety and depression (Beckett and Rutan, 1990). Furthermore, people living with HIV and AIDS have an increased risk of developing serious mental illnesses and the burden of a second chronic illness (Joska et al., 2008). In the United States, the prevalence of HIV and mental illness is estimated to be 4-23% (Senn and Carey, 2009). Coping with mental illness and HIV and AIDS involves many complex issues such as cognitive deficits that impact on their ability to perform daily tasks independently; substance abuse and dependence; complicated treatment regimes; role disruption; financial burden and stigma (Spiegel et al., 1981). It is therefore necessary to focus on both of these chronic and debilitating diseases when treating these patients.

Support groups are one of the most widely used approaches to deal with the ability to cope with both illnesses (Spiegel et al., 1981). Support groups are regarded by patients as less stigmatizing and by health care providers as more cost effective and more beneficial than individual therapy. Support groups are less structured and encourage ventilation of feelings and sharing of experiences (Kelly et al., 1993). They provide peer support and emotional encouragement from others undergoing similar difficulties and offer the opportunity for people with a common challenge to give and receive practical and emotional support (Sherman et al., 2004). In a publication by the Department of Psychiatry at the University of Illinois, mental health consumers with HIV reported that they joined a support group to gain useful information on coping, accelerate or sustain health promotion activities, to reduce isolation associated with stigmatized conditions and to develop relationships that provided emotional support and comfort in times of crisis (Hamilton et al., 2002). They reported that it was more beneficial to discuss problems relating to HIV and mental illness with others who had shared the same experiences.

Patients presenting with mental illness and HIV and AIDS in South Africa are common (Ciesla and Roberts, 2001) and it would appear that support groups would be beneficial to such patients. Also, support groups may be the most cost effective and efficient way to provide an integrated approach to help patients cope, accept their diagnosis and adhere to their treatment. Such support groups for HIV positive mental health care users in South Africa are not readily available and thus the initiative to start the service at Chris Hani Baragwanath Hospital (CHBH).

The aim of this study was to describe the demographics,

clinical characteristics and expectations of the members of a newly established support group for HIV positive mentally ill patients and to determine, if any, the factors associated with disclosure of status and expectations of the group.

METHOD

All mental health care users aged 18 years and older with HIV and admitted to CHBH between March and June 2008 were invited to participate in the support group run at Luthando Psychiatric HIV clinic. The support group was facilitated by a Clinical Psychologist and all processes were conducted in English. All the members of the support group were asked, following a full explanation and written informed consent, to complete a questionnaire at the first group session they attended. The questionnaires were written in English and not formally translated into any of the various first languages of the participants. However, assistance was provided by the facilitator in translation of specific questions into participants' first language when it was requested. The questions related to demographic data (age, gender, home language, employment status, marital status, level of education, number of children); clinical data (past psychiatric illness; current diagnosis, on ART); status of disclosure of HIV and the expectations of the group.

All information was kept anonymous. Descriptive statistics were computed as mean and frequencies (count and percentages). The study population was divided into groups based on disclosure of their HIV status and their expectations. Comparisons between the groups were examined with the use of contingency tables (chi-squared test with Yates correction, Fischer's exact test and Odds Ratios). All analyses were done using the Statistical Package for Social Sciences 10.0 for windows (SPSS inc., Chicago, IL., USA). The study was approved by the Human Research Ethics Committee (HREC) of the University of the Witwatersrand.

RESULTS

Characteristics of the study population

All fifty members of the support group completed the questionnaire resulting in a 100% response rate. The majority of the subjects were in the age range of 26 - 35 years (44%); female (78%); single (88%); had 2 or more children (71%); had less than a grade 10 level of education (44%) and were unemployed (68%). The most common spoken first languages of the subjects were Zulu (34%) and Tswana (20%). Only 6% of the subjects reported English as their first language.

Female subjects were more likely to be younger (26 - 35 years) ($p = 0.048$) and more likely to have two or more children as compared to males ($p = 0.044$) (Table 1).

Approximately two thirds (60%) of the subjects had been diagnosed with a psychiatric illness which included amongst others bipolar disorder and schizophrenia. For the rest of the subjects (40%), this was their first presentation with a mental illness. The current diagnoses of the members of the group included mood or psychotic symptoms secondary to HIV (25%); bipolar disorder (33%); anxiety disorders (3%) and schizophrenia (3%). None of the subjects had a diagnosis of substance induced psychosis while 12% of the subjects were unaware

Table 1. Comparisons between male and female members with respect to age and number of children.

	Male (n = 11)	Female (n = 39)	
Age groups (years)			
18 - 25	0	4	p = 0.048
26 - 35	3	19	
36 - 50	8	11	
51 - 60	0	5	
Number of children			
0	5	5	p = 0.044
1	1	8	
2	1	16	
> 2	4	10	

are of their psychiatric diagnosis. Only one third of the group had been commenced on ARV treatment.

Two thirds of the members (68%) of the group were aware of their HIV status for longer than six months. The majority (70%) of the members of the group had disclosed their status either to a family member or friend. The most common expectations of the group included education (36%) and support (32%), whilst 32% had other expectations or were unsure of their expectations.

Factors associated with expectations and disclosure of status

Education and support were most desired by those who had disclosed their status as compared to those who had not disclosed ($p = 0.0002$) (Table 2). Similarly, subjects that had known their diagnosis for longer than six months, desired support and education from the group sessions whilst those who had only recently discovered their HIV status (< 1 month) had expectations other than education and support ($p = 0.0318$). The few members that were on ART joined the groups with a desire to receive education whilst those not on ART desired more support. ($p = 0.0065$).

The majority of the subjects who had disclosed their status were between the ages of 26-35 years, as compared to those who had not disclosed which were between the ages of 36 - 50 years ($p = 0.0404$) (Table 3). There was a strong association between disclosure of status and time since HIV diagnosis ($p = 0.001$). 83% of those who had known their status for longer than 6 months had disclosed their status. Only one of the members on ART had not disclosed, while 60% of those not on ART had not disclosed ($p = 0.018$).

DISCUSSION

Over the past three decades, the influence and importance of social support has been well documented and

the findings have suggested a beneficial effect on stress-related situations, mental and physical health and social functioning. However, participation in such support groups vary. Qualitative data indicated that although monetary incentives play some role in the decision to participate, other factors include support group size, salience of the group content, consistency of group leadership and use of peer leaders along with professional facilitators (Van Devanter et al., 1999). In our study all 50 members of the support group completed the questionnaire. Our participants were not offered any monetary incentive to complete the questionnaire, however, our group was small and there was consistency in group leadership. It is most likely that the high response rate for completion of the questionnaire was due to adequate explanation as to why this type of research was necessary and encouragement from a very supportive group facilitator. This was further enhanced by incorporating the completion of the questionnaire as a part of the group process.

Only a third of the respondents commenced antiretroviral treatment. The guidelines as issued by the National Department of Health in South Africa state that one is only eligible for antiretroviral therapy if one has a CD4 count of ≤ 200 cells/mm³ or WHO stage IV illness (National Antiretroviral Treatment Guidelines. National Department of Health, 17/03/2009). Further, the unique characteristics of HIV require near perfect adherence to maintain therapeutic levels and to achieve complete viral suppression (Garcia et al., 2003). It is generally accepted that missing more than 5 - 10% of ones prescribed drugs is linked to incomplete suppression of viral replication, declining CD4 cell counts, clinical progression to AIDS and the development of antiretroviral drug resistance (Gill et al., 2005). However, reported estimates of average rates of adherence range from 50% to 70% in many different social and cultural settings (Liu et al., 2001). Similar adherence rates of 54% to 98% have been reported in Africa in general (Hardon et al., 2007). Studies have reported that patients with psychiatric disorders

Table 2. Significant associations between expectations and patient characteristics.

	Education (n = 18)	Support (n = 16)	Other (n = 16)	
Status disclosed				
Yes	16	14	5	p = 0.0002
No	2	2	11	
Time since diagnosis				
< 1 month	1	0	6	p = 0.0318
1 - 6 months	2	2	2	
> 6 months	15	12	7	
unknown	0	2	1	
On antiretroviral therapy				
Yes	10	4	1	p = 0.0065
No	8	12	15	

Table 3. Significant associations between disclosure of status and patient characteristics.

	HIV status disclosed (n = 35)	HIV status not disclosed (n = 15)	
Age			
18-25 years	3	1	p = 0.0404
26-35 years	18	4	
36-50 years	9	10	
51-60 years	5	0	
Time since diagnosis			
<1 month	1	6	p = 0.001
1-6 months	4	2	
>6 months	29	5	
unknown	1	2	
On ARVs			
Yes	14	1	p = 0.018
No	21	14	

show a greater degree of non-adherence to treatment than those with physical disorders and that about 30% of all patients with psychiatric disorders discontinue their medication in the first month while 44% discontinue it within the first 3 months of initiation of treatment (Cramer and Rosenbeck, 1998; Venturini, 1999; Lin, 1995). These reports together with the general perception that mentally ill patients are 'naturally non adherent' to their medication and partake in risky sexual behaviour result in them being discriminated against and not accessing free antiretroviral therapy from the state. The above reasons may explain why our study had a relatively small number of patients on antiretroviral therapy.

Living with HIV/AIDS and a co-morbid mental illness

can be extremely stressful and can cause immense human suffering. The most obvious effects are a decline in health and death, but the impact extends to households, schools, workplaces and economies. The poorest sectors of society are most vulnerable and the loss of income, additional care-related expenses and medical fees push affected households deeper into poverty. This may in part explain the high unemployment rate that was found amongst members of this study group. It must be emphasized that the high unemployment rate may not be unique to this support group, but possibly a reflection of the high unemployment rate of the general population from where this sample was obtained (PO210 - Labour Force Survey (LFS), 16/08/2008). As a result of the finan-

cial burden people living with HIV and AIDS are faced with, it could be practically useful to include food garden/nutrition security programmes or creativities projects. Participation in a gardening project with the objective to grow and sell vegetables is initially aimed at providing the patients with a source of nutritious foods. The effects of poor diet on immuno-compromised individuals are devastating to their already poor health. At a later stage the produce can be sold to serve as a source of income. As in the gardening project, groups may benefit from participation in creative activities. Aside from benefiting financially from the products sold, transfer of essential skills occurs. Members may eventually be "discharged" from the group and sustain these activities at home. This will help to foster independence and autonomy and does not merely relieve members from their situation but empowers them.

Almost invariably, the burden of coping rests with women and they are faced with stepping up to a role as income-earners, mothers and housekeepers. It is therefore not surprising that in this study more females admitted to CHBH, accepted the invitation to participate in the support group. This is further supported by a study done in Australia which reported that HIV positive patients at initial presentation to psychiatric services were generally younger females (Mijch et al., 2006). As a result of the change in the demographic nature of the disease over time, the emerging population at risk of HIV are women (Himmelhoch, 2007). Effective interventions targeting women with mental illness are essential, as depressed women with HIV have been shown to have increased mortality (Ickovics et al., 2001).

The coping abilities and styles HIV positive individuals utilize to deal with the stresses of the disease have an influence on the psychological impact this illness has. Hopelessness and despair are commonplace in the lives of individuals with HIV and AIDS. It has been reported that in coping with HIV and AIDS, females tend to adopt more of an "adaptive coping mechanism" (such as planning and religious activities) than an avoidant coping mechanism (Olley et al., 2003). Whilst women actively seek out the support to cope with the illness, efforts should be made to encourage men to accept their illness and take a less avoidant approach.

Disclosure of HIV status is an important issue that often needs to be dealt with either in group and/or individual therapy (Wouters et al., 2009). Disclosure of HIV status can be extremely stressful. While one may receive love and support from some, others may not be as accepting. Disclosure of one's HIV status may also have an effect on the person or people that are told. Friends and family may immediately accept the diagnosis, whilst others may react negatively or need time to overcome fears or preconceived ideas they have about HIV (Greef et al., 2008). Derlega et al. (2002) in a study involving 145 men and women, indicated that reasons against disclosing one's status included concerns about self-blame, fear of

rejection, communication difficulties and a desire to protect the other person. In addition, the authors report this HIV-related stigma limited disclosure to a parent but not to a friend or intimate partner. Similarly, Akani et al. (2006) reported that, in Nigeria, the barriers for disclosure included fear of stigmatization, victimization, fear of the spread of the news of their sero-status and fear of accusation of infidelity and abandonment. Simbayi et al. (2007) in a study in Cape Town established that disclosure of their HIV status to partners was associated with having lost a job or a place to stay. Other factors associated with higher rates of disclosure are being female, married, having higher education and expectations of economic, spiritual, emotional and social support (Simbayi et al., 2007). It is clear that disclosure of HIV sero-status is a difficult emotional task that creates an opportunity for both support and rejection.

Unexpectedly, most of the members of our support group had already dealt with the issues of disclosure of their HIV status either to a family member or a friend prior to joining the group. Akani et al. (2006) reported similarly high disclosure rates (77%) amongst their patients. These rates of disclosure are much higher than that found amongst HIV positive mentally ill patients in developed countries, despite the fact that, in South Africa, stigma associated with HIV and AIDS is so prevalent (South African national HIV prevalence, HIV incidence, behaviour and communication survey, 2005). There are several possible reasons that may explain the higher rates of disclosure. Most of the members of this support group were mentally ill patients who are dependent on families and caregivers to help them cope with the burden of their mental illness. It is highly likely that the families and caregivers were involved in the process of consenting for the HIV test or involved in the post test counseling as current department of health guidelines stipulate getting family to give proxy consent for HIV testing (National Antiretroviral Treatment Guidelines. National Department of Health, 17/03/2009). Furthermore, due to a lack of resources for mentally ill patients in South Africa, it may have taken more than six months before these patients had been exposed to any HIV related intervention. It may also be assumed that knowledge of HIV status for more than six months would have afforded the members sufficient time within which to deal with issues of disclosing to some of their family members. Finally, the majority of our support group members were females, who have been reported to be less avoidant and more likely to disclose. Utilization of support groups for mentally ill patients after diagnosis of HIV could encourage earlier disclosure of status and consequently earlier HIV related intervention strategies.

Most of the members of this group had joined the group with the expectation of receiving emotional support and education, particularly for those that had been commenced on ART. This is contrary to the findings of a study done at the general ART roll out clinic at CHBH,

where most of the subjects had good knowledge of both HIV/AIDS and ART (Nachega et al., 2004). HIV positive patients with mental illness appear to require more education despite having received pre and post test counseling and being aware of their status for longer than six months. Both HIV and AIDS and mental illness affect cognitive functioning and it is possible that this combination affects the ability of the individual to learn and internalize new information (Odiase et al., 2007).

Certain limitations of the study warrant consideration. The questionnaire was not translated into different languages, which in this study would have meant at least five different local languages. Although it was not their home language, the participants indicated that they understood the contents and were able to complete the questions. Assistance was provided in interpreting some questions when it was requested and this may have influenced participants' response to questions, particularly those regarding their expectations of the group. In addition, the sample consisted of a select group of patients that attended Luthando Psychiatric HIV clinic at a tertiary academic hospital and may not be representative of the population in general. Further, the relatively small sample size may have hampered statistical comparisons between the groups. Notwithstanding these limitations, the findings support the establishment of support groups and warrant further research.

Conclusion

The difficulty individuals have in coping with the burden of HIV/AIDS and a co-morbid mental illness may be associated with feelings of hopelessness and a depressed mood. This may lead to decreased adherence to ART, further suppression of immunity and accelerated disease progression. It is also closely associated with HIV transmission risk behaviours and increased risk of suicide attempts.

This study found that young women, who had dealt with the issues of disclosure to a family member or friend, opted to join our support group with the expectation of receiving emotional support and further education. Although not conclusive, this research clearly outlines the need for support groups in mentally ill patients with HIV and AIDS. It behooves the mental health professionals to conduct further research, using larger numbers and the first languages of the participants into the factors that support or prevent long term participation in such support groups. Objective outcomes should be improved adherence to ART, improved social and occupational functioning and reduction in risky sexual behaviours. In the interim, it is recommended that an intensification of support group interventions combining providers, patients and the community occurs. These groups should focus particularly on the aspects of education, emotional support, stigma and skill building. It is essential that all mentally ill patients (including males) with HIV and AIDS

receiving ART be a member of such support groups.

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