



# EFFICACY OF PSYCHOLOGICAL SUPPORT ON THE INTERNET FOR HIV POSITIVE WOMEN: A PRELIMINARY INVESTIGATION

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## Abstract

*The human immunodeficiency virus (HIV) poses one of the greatest health threats in modern times. More than 25 million people have died of AIDS since 1981. At the end of 2006, women accounted for 48% of all adults living with HIV worldwide with an estimated 17.7 million women living with HIV/AIDS. In this alarming scenario, the authors of this paper conducted a preliminary investigation of the online support services through 'e-groups' for HIV positive women with a view to assessing the quantum of information about HIV and AIDS being made available to the group to understand its likely implications. Peer support is consistently and unambiguously recognized as benefiting promotion of self-care. However, face-to-face peer support interventions, such as self-help groups, are underutilized due to travel*

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*needed to get to such groups, time investment, fatigue, stigma, and other factors that may limit participation. The internet is becoming an attractive medium for health promotion and delivery of behaviour-change intervention. It is an exciting and potentially valuable tool in delivering psychosocial and educational interventions to persons with illnesses, including being used as a conduit for peer support. Internet peer support is accessible 24 hours a day, seven days a week - features that plausibly increase the accessibility and utilization of peer support for those who do not attend face-to-face support. Despite the promise of online resources to help individuals manage and cope with their illness, few studies have investigated their use.*

**Key words:** HIV & AIDS, Internet support group, HIV Positive Women.

This study attempted to explore the nature of support provided over the internet specifically for HIV positive women. The study employed primarily a quantitative design that also used analysis of messages in HIV positive women's online e-groups. A sample of 125 messages from a popular e-group with 99 registered members were analysed and categorised. The messages analysed were posted on the e-group between August 2004 and December 2006. Two research questions guided this study: (1) what are the various forms of support that the e-group messages provide? (2) To what extent is psychosocial support being provided over these e-groups? The findings and scope of this preliminary investigation are discussed in this paper. The findings reveal that this e-group primarily provides HIV related information, news and research. There are also a few instances where the e-group is used to share personal comments, real life stories and event notices. It was found that this e-group provided no form of explicit psychological support to its large group of HIV positive women. The authors suggest a vital need to use such media for provision of psychological support and mental health services with professional and peer counselling/ support. Furthermore, comprehensive research needs to be undertaken on the use of the various internet and multimedia services for peer psychological support and its longitudinal efficacy on various groups of people.

## Introduction

### HIV Scenario

The Acquired Immuno Deficiency Syndrome (AIDS) is a profound human tragedy and has been referred to as the "world's most deadly undeclared war". Detected decades back, HIV/AIDS is not only a medical issue but also a psychosocial one. The Human Immunodeficiency Virus (HIV) and AIDS continue their devastating

spread, affecting the lives of over 16,000 people each day with women, babies and young people being increasingly targeted. HIV poses one of the greatest health threats of modern times to mankind. More than 25 million people have died of AIDS since 1981. At the end of 2006, women accounted for 48% of all adults living with HIV worldwide with an estimated 17.7 million women living with HIV/AIDS. The epidemic is shifting toward women and young people, with about 25 percent of all HIV infections occurring in women.

## National Impact of HIV/AIDS

The global trend, to which India is no exception, is that 89 per cent of the reported cases are from the sexually active and economically productive age group of 15-49 years (HIV/AIDS Surveillance in India, as reported to NACO, December 2005). At a macro level, this has serious social and economic repercussions since the country stands to lose its precious productive human resources. The alarming rate of HIV infected people therefore urgently needs to be curbed. Initially in India, HIV was seen as being confined to so-called 'high-risk groups' and to certain geographical areas, but the changing epidemiological data now show that HIV is increasingly being reported amongst the general population across the country.

The absence of a cure for HIV/AIDS makes it all the more essential that the growing rates of HIV/AIDS patients be curbed through prevention and care. HIV/AIDS is a behavioural disease, in that risk behaviours and negative attitudes play an important role in increasing the likelihood of its transmission. At the prevention level, it is necessary to build in awareness among the general population about risk behaviours and the nature of problems associated with the same. Moreover, because of the stigma and fatality attached to a HIV diagnosis, the psychosocial needs of the patients and the people living with them have to be addressed. The care aspect of HIV/AIDS continues to be a great problem due to the social stigma and misinformation attached, which makes difficult, the delivery of services to those infected or affected.

## Impact of HIV on Family

The psychological and social sequela of HIV and AIDS infection is devastating to children, adolescents, women, and their families. HIV and AIDS is a chronic/terminal illness that forces individuals and their families to cope with an uncertain progression of disease, complicated medication regimes, and the grief related to the loss of health and possibly the loss of family members. Unlike other chronic/terminal illnesses HIV and AIDS infection is further complicated by the stigma related

to the transmission of HIV infection (i.e., sexual activity and intravenous drug use). Due to disclosure fears and stigma associated with HIV and AIDS, many families isolate themselves from their extended family and communities to protect themselves and their children from maltreatment. Thus, they are cut off from valuable supports. In conjunction with coping with the psychological and emotional ramifications of being infected with or affected by HIV and AIDS, these individuals are forced to deal with a multitude of stressors with little support. These factors place these individuals and their family members at risk for mental health disorders (e.g., depression, post-traumatic stress disorder, and anxiety), developmental deficits, and behavioural problems (e.g., drug or alcohol use, school failure, inability to maintain a job, and criminal behaviour). These issues complicate the HIV and AIDS infected children, adolescents, and women's ability to access medical care and comply with complicated medication regimens. The goal of this article is to provide an overview of the psychological and social issues, which impact families that are affected by HIV and AIDS.

## Impact of HIV on Women

The impact of HIV/AIDS on women has been referred to as 'triple jeopardy' (Bennett 1990). This addresses the key gender roles that women are generally expected to fill: productive, reproductive, and community. HIV/AIDS affects women as individuals, mothers and caregivers in these socially defined roles. The socially defined roles of men and boys will also condition the impact of the epidemics on them. Women as individuals are affected by HIV/AIDS but in programmes focusing on HIV/AIDS they are often represented as mothers and carers only.

A study in Durban, South Africa, focusing on the experiences of women living with HIV who were pregnant highlighted the extent to which women's empowerment has been neglected. Women interviewed had limited understanding of and information about AIDS and other STIs. Many of the women acknowledged that their partners were not monogamous, but had not had the opportunity and space to think through, analyse and personalise what this could mean for them. Women stayed in these relationships mainly through fear of violence, and because of financial dependence on men. This was exacerbated by the fact that many of the women were unemployed, and few had skills that would make them employable.

Sexist customs and practises such as the payment of lobola (bride wealth) and inhlawulo (payment of 'damages' to the women's family for pregnancy) were dominant themes in the study (Tallis 1997). Women as mothers with HIV/AIDS are affected in three ways:

- Firstly, many mothers of young adults are fearful of their children becoming infected with HIV but often lack the skills to discuss sexuality openly with them
- Secondly, more and more mothers have to care for their young and adult children as well as the partners of their children when they become sick
- Finally, for a mother who is HIV-positive there is the risk of transmitting HIV to her child, during pregnancy, during birth or after birth through breast-feeding. The latter may occur if a mother is unaware of the risk or is not in an economic position to afford formula feed (Tallis 1998)

Women are bearing the burden of AIDS care. This is true both in the formal or informal sectors. The majority of nurses and social workers (the formal care sector) are women. In a developing country, the bulk of AIDS care happens in the community, informally, with women caring for their partners and children. Grandmothers often have to take care of their grandchildren whose parents are unable to care for them or have died (Tallis 1998). May (2000) refers to the 'time poverty' experienced by women which is the result of the long hours women spend on their reproductive roles – collecting fire-wood, water, childcare, cooking and cleaning – to the detriment of their own well being. Many women living with HIV also have the added pressure of being ill themselves and having to provide care for their partner and / or sick child. For a woman living with HIV, such an increase in workload often means that she does not have time to adequately care for herself and attend to her own needs (Bennett 1990). As noted by Mary Crewe (2002), home-based care is a middle-class concept as it assumes that the resources (including human) are available in the home but it is usually not the case.

The contribution of women in prevention and care is seldom recognised and quantified. Research has also shown that health-seeking behaviour differs between men and women. Women's health-seeking behaviour is more often than not determined by reproductive roles, either as a pregnant woman or as a mother with a sick child. Factors which impact on health seeking behaviour include money, time, attitude of healthcare workers and mobility. Research also shows that men often receive better care than women. Men are more likely to have access to better healthcare through the private sector, for example access to workplace clinics or access to medical benefits which increase the quality of care available (Tallis 2001).

The social impacts do not just affect adults but children as well. A growing trend is to take children, especially girls, out of school to care for the sick and help with other household duties. For example in Swaziland school enrolment has fallen by 36 per cent due to HIV/AIDS with girls most affected. This impacts on their education and future prospects (Desmond et al. 2000). Although withdrawal from school is

often associated with girls, studies show that in certain cases boys are also withdrawn from schools when relatives become ill or die. However, it is more likely that they will be expected to supplement family labour on farms or in income generating activities (Bennell, Hyde, and Swainson 2002).

## Psychosocial Support for PLWHA

Psychosocial support has been defined as an ongoing process of meeting emotional, social, mental and spiritual needs, all of which are considered essential elements of meaningful and positive human development. Psychosocial support addresses the ongoing psychological and social problems of HIV infected individuals, their partners, families and caregivers.

It is important because: HIV infection affects all dimensions of a person's life: physical, psychological, social and spiritual. Counselling and social support can help people and their carers cope more effectively with each stage of the infection and enhance quality of life. With adequate support, PLWHA are more likely to be able to respond adequately to the stress of being infected and are less likely to develop serious mental health problems. Assessment and interventions may be aimed at the acutely stressful phase following notification of HIV infection, the ensuing adjustment period, and the process of dealing with chronic symptomatic HIV infection and disease progression through to death.

HIV infection often can result in stigma and fear for those living with the infection, as well as for those caring for them, and may affect the entire family. Infection often results in loss of socio-economic status, employment, income, housing, health care and mobility. For both individuals and their partners and families, psychosocial support can assist people in making informed decisions, coping better with illness and dealing more effectively with discrimination. It improves the quality of their lives, and prevents further transmission of HIV infection.

For people with HIV/AIDS who must adhere to TB treatment, long-term prophylaxis or antiretroviral therapy, on-going counselling can be critical in enhancing adherence to treatment regimens. Studies in the area of ART, adherence, side-effects and quality of life in Bangalore stress the importance of adherence for enhanced physical quality of life (Liju, 2005).

## Internet Usage

The number of Internet users has more than doubled since the year 2000, and now, in 2006, it is available to over one billion people worldwide. Future growth is expected from countries with large populations.

According to a release dated September 19, 2006, the Internet and Mobile Association of India (IAMAI) and IMRB International, Internet users in India have reached 37 million in the month of September 2006, up from 33 million in March 2006. During the same period the number of "active users" has risen from 21.1 million in March 2006 to 25 million in September 2006. "Active User" is an internationally accepted and widely used category to define users who have used the internet at least one in the last 30 days. IWS considers that the number of Internet users in India is now 40,000,000.

## Psychosocial support over the Internet

The Internet is becoming an attractive medium for health promotion and delivery of behaviour change intervention (Glasgow et al., 1999; Sharp, 1999; Winker et al., 2000). The future for such intervention appears bright, with advantages such as cost-effectiveness, convenience and 'mass media' ability to reach many persons with relevant, tailored information (Gustafson et al., 1999). There are, however, some important considerations for Internet intervention, including barriers we face in implementation.

The Internet provides unparalleled access to resources that can assist individuals coping with HIV infection. Despite the promise of online resources to help individuals manage and cope with their illness, few studies have investigated their use. Of those studies, most have looked at the experience from a group perspective. These studies were usually "bounded" as well, focusing on electronic support groups or highly structured computer-based support systems that offer users prescribed resource options. Little is known about how individuals who are "on their own" use the vast, unstructured array of resources available through the Internet.

This study is a preliminary exploration into the nature of support provided over the internet specifically for HIV positive women.

# Methodology

## **Aim:**

To explore the nature of support provided over the internet for HIV positive women.

## **Objectives:**

1. To examine the nature of support provided over an e-group for HIV positive women.

## **Abbreviations and Operational Definitions:**

1. **ART:** Antiretroviral Therapy
2. **E-group:** An online community of people generally based on a common theme like interests, location, activities etc. Generally e-groups have a messaging forum through which the members communicate with each other.
3. **HIV real-life stories:** This term refers to e-group messages that contain life stories or experiences of HIV affected or infected persons.
4. **HIV related general information:** This term refers to e-group messages that contain any information that is directly or indirectly related to HIV/AIDS.
5. **HIV related news items:** This term refers to e-group messages that contain published news items or press releases that are directly or indirectly related to HIV/AIDS.
6. **HIV research studies:** This term refers to e-group messages that contain published research papers, abstracts, references or findings that are directly or indirectly related to HIV/AIDS.
7. **Online support groups:** The term online support groups refers to an online community where members provide each other with various types of nonprofessional, nonmaterial help for a particular shared burdensome characteristic. The help may take the form of providing relevant information, relating personal experiences, listening to others' experiences, providing sympathetic understanding and establishing social networks.
8. **PLWHA:** People Living With HIV/AIDS.



9. **Psychological support:** This term refers to providing support of psychological nature involving active listening to sharing of personal experiences and providing empathetic understanding.
10. **Psychosocial support:** This term refers to the ongoing process of meeting emotional, social, mental and spiritual needs, all of which are considered essential elements of meaningful and positive human development.

**Data Source:**

The preliminary investigation for this exploratory research was conducted on HIVPositiveWomen@groups.msn.com, an e-group with a membership of 101 members primarily designed for HIV positive women. The personal and socio-demographic details of the members were unavailable. The e-group was shortlisted based on the following criteria:

- Internet based community/group
- Common email/messaging service
- Membership designed for HIV+ women
- Active Group
- Activity for minimum one year or more

Given below is the profile of the data-source

**Group Name:** HIVPositive Women

**Internet Address:** <http://groups.msn.com/HIVPositiveWomen>

**Description:** A moderated support group for HIV positive women. Topics include paediatric AIDS, breastfeeding and risk assessment. A friendly place for women of all ages to meet and discuss the topic. COME JOIN OUR HAPPY FAMILY TODAY. While almost no women actually contract so called 'AIDS' (29 old non viral epidemic diseases now lumped together and renamed 'AIDS") many live in fear of this mythical 'syndrome', and let that fear have an adverse effect on their quality of life.

**Membership Settings:** Public

**Rating Level:** Appropriate for all ages

**Category:** AIDS & HIV

**Keywords:** women with AIDS, female AIDS, AIDS and children, AIDS kids

**Language:** English

**Group Current Status:** Active

**Data:** A sample of 125 messages were analysed and categorised. The messages were posted on the e-group between August 2004 and December 2006.

## Results and Discussion

The findings of the preliminary exploration are given in the table below. These findings were arrived at by categorizing the messages posted on the e-group forum.

**Table 1:** showing the number of items under each category

Sl No	Categories	Messages	Percentage %
1	HIV Related General Information	58	46.4
2	HIV Research Studies	24	19.2
3	HIV Related News Items	22	17.6
4	HIV Real-life stories	10	8
5	Event / Meeting Notices	5	4
6	Personal Comments / Responses	5	4
7	Unrelated Information	1	0.8
8	Explicit Psychological Support	0	0

The above table shows the quantitative findings of the qualitative analysis. One hundred and twenty five e-group messages were analysed based on the nature of the content (Ref Table 1). The findings show that most messages deal with HIV related general information, HIV research studies, HIV related news items and HIV real-life stories with 58, 24, 22 and 10 messages under these areas respectively. Fewer messages deal with Event/meeting notices, Personal Comments/Responses, and Unrelated information with 5, 5 and 1 messages respectively. There are no messages which provide any form of explicit psychological support to the HIV positive members of the group.

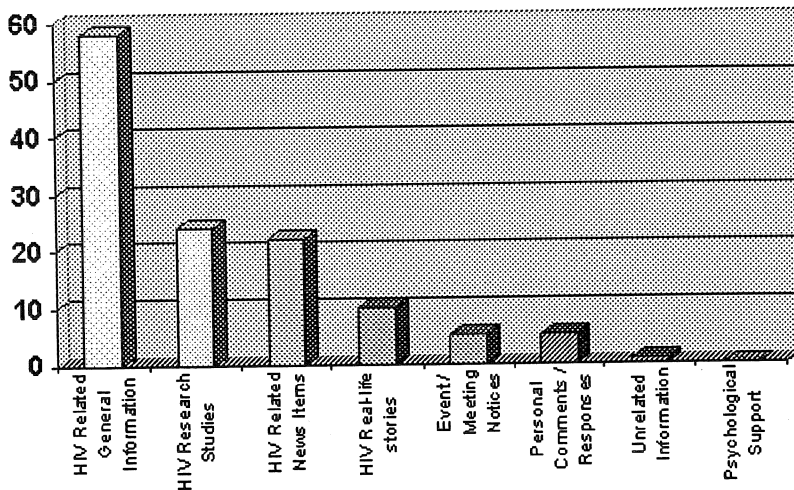


Figure 1: showing a bar graph representation of the findings

'HIV Research Studies' included primarily researches against Antiretroviral Therapy (ART). A large number of these scientific studies focus on the lack of efficacy of ART. Many studies also deal with other issues in the field of HIV/AIDS. These studies include researches that do not support the widely held view that HIV virus leads to AIDS. Some studies also suggest other effective therapies as a better alternative for ART. 'HIV General Information' primarily included issues in the field of HIV/AIDS. Many of these articles question widely held beliefs regarding HIV/AIDS. These articles question the established cause of AIDS, the ART issues, treatment rationale, the monopoly of pharmaceutical companies, wonder cures, and the politics in this field. There were also a few articles on statistics and HIV scenarios around the world. 'HIV Real-life Stories' included stories of various persons who were affected by HIV. The stories include various personal, social, legal and political issues that were faced by some HIV affected persons. 'Event/Meeting Notices' were messages posted for invitations to group meetings and other events with details of date, time, place, venue and other relevant information. 'Personal Comments/Responses' included responses to some of the messages posted and New Year greetings.

It is relevant that such information be made available to HIV positive persons over the internet as this protects the privacy of the individual to a certain extent. This information if received by the individual in the form of newsletters, mail, brochure, pamphlets or flyers may be a source through which privacy may be compromised.

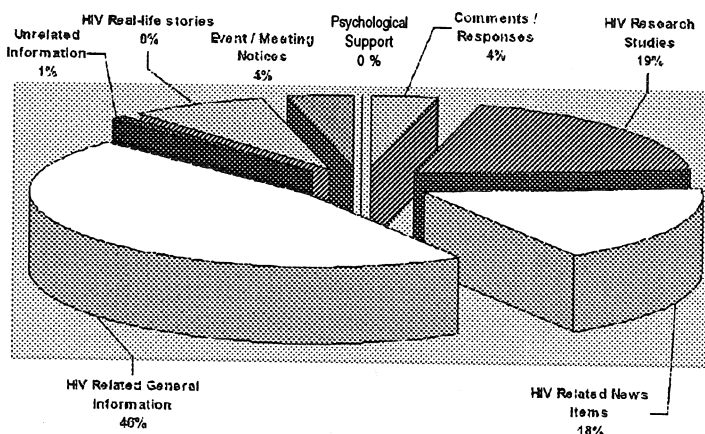


Figure 2: showing a pie chart representation of the findings

The greatest advantage of using internet to reach HIV positive people is that a lot of information was made available to the group without intruding on their privacy. This very same information usually made available through newsletters, brochures, other literature usually exposes the reader to unwanted attention and therefore many may not actually request such literature for the fear of being stigmatized.

The findings reveal that 46.4% of the messages were devoted to giving HIV related general information, 19.2% of the messages focused on HIV research studies and 17.6% of the messages contained HIV related news items. From this, it is evident that though these messages are normally very brief, they have conveyed quite effectively all the very essential information regarding HIV to the target group. This way the researchers would like to claim that online support groups may be as effective as face to face information giving sessions. Therefore hereafter online groups can be used in a big way to reach more sections of the target group. In fact such forum messages may work better because of the privacy associated with the internet.

However from the analysis of the messages it is also found that almost 83% of them have been utilized for information sharing while off the remaining 17%, 8% has been used for real-life stories and 4% each for personal comment/responses and meeting notices and events. Considering this, the researchers feel that through properly planned utilization of this media, all essential information regarding, HIV/AIDS and its treatment and support can be given effectively through the internet. Some percentage of messages can also be devoted for peer counselling and psychological support. This way, the efficacy of the online support group can be enhanced.

Finally, it was found that there is no explicit psychological support provided for the target group through these messages. However, the messages contain HIV related information and stories. This can be taken as an attempt to make the target group aware that there are many more people suffering like them, which itself serves as a form of psychological consolation. However, by planning the composition of the messages, with peer and professional support, the internet support group can be as effective as a face to face helping session. But we stress that this will not serve as an alternative for personal counselling but may be used as a supplementary support strategy.

In conclusion, one may also say that the internet support group lacks the warmth of personal human support. This can be considered as a limitation to this approach. However considering the increasing number of victims of HIV/AIDS, we cannot ignore the internet as a plausible supplementary alternative for support. The researchers would like to conclude that considering the potential benefits of the internet in the field of HIV/AIDS, there is an urgent need to further study, research and document ways and means of utilizing the maximum potential of the internet and information technology as a medium to prevent HIV and support affected individuals around the world.

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