International Journal of Science and Research (IJSR)
ISSN: 2319-7064
SJIF (2022): 7.942

Social Support Issues of Persons Living with HIV AIDS in Delhi, India - An Exploration

Sangeeta Sharma Dhaor

Associate Professor, Department of social work, Dr B. R. Ambedkar College, University of Delhi, India
ORCID: 0000 0003 4621 9721
Corresponding Author Email: *sdhaor[at]gmail.com*

Abstract: ***Introduction: Enabling the environment has been one of the significant components of HIV prevention programs nationwide. Unfortunately, many studies of the social support for HIV positive persons found low social support for PLHA. Therefore, there is a need to assess the availability of social support to HIV positive persons in light of the new drug regime and support networks developed by the National AIDS control policy. Social support is the perceived support during times of crisis. It may include tangible as well as intangible support. Method: The researcher interviewed 105 HIV positive persons using a semi-structured interview schedule, to get their profile. A total of 60 (57.1%) were males, 40 (38.1%) were females, and 05 (4.8%) were transgender. A total of 34 (32.5%) were illiterate, 47 (44.8%) studied up to middle school level, and 24 (22%) studied above middle school. A total of 47 (44.8%) earned Rs 500-4000/ per month, 28 (26.7%) earned more than Rs 4000 per month, whereas 30 (28.6%) had no income. A total 77 (73.3%) were beneficiaries of Targeted Intervention projects, while 28 (26.7%) were not. Duke's 11 point Social Support scale that had social interaction and social satisfaction com ponents was used to assess social support. Results: The social support was low. None of the respondents had good social support. The duration of HIV infection too affected the social support significantly at p^2 0.05. Moreover, FGD revealed that as time passes, they develop a new support group of positive persons. Knowledge of Anti-Retroviral Therapy was affected by social support though negatively but significantly. Knowledge of ART services affected the social support significantly at p2 0.05. The researcher found that more persons with low Social Support knew about ART Services. Conclusion: The social support is low for persons living with HIV AIDS .PLHA infected develop social support once they are ousted from one social group. Reduced social support is true for all the marginalized sections of society due to deviation from normative behaviour. We must not lose sight of the importance of enabling the environment while addressing the need to restore the individual to the previous group or create a new support group to lessen his feeling of maladjustment.***

Keywords: Social support, HIV stigma and discrimination, Internalization of stigma.

1. Introduction

Man is a social animal. Social groups are vital in instilling a sense of belongingness and are instrumental in bringing a desired change in the participants. Unfortunately, society has certain notions of including and excluding persons from its social fabric. Any abrasion from normative is intolerable, and there is a stigma of being "others" as against "us". Persons living with HIV AIDS, owing to the mode of infection perceived to be immoral, including but not limited to intravenous drug use, homosexual behaviour, and commercial sex work, are excluded from society. This exclusion is communicated in more than one way, resulting in cocooning, withdrawing, and segregating them. Although we are basking in the glory of a controlled pandemic with reduced prevalence and numbers, there is a need to check the social support available to PLHA. They are a subject of ridicule and discrimination. Social Support is the anticipated support from the family and friends during a crisis and its role particularly in improving unhealthy peoples' life has been proven (Lesserman (1999).

The stigma of HIV emerges from the fact that it is sexually transmitted and occurs in certain population groups whose sexual behavior is not socially acceptable (Sontag 1989). The stigma has many layers; there is a layer of immoral behaviour, as stigma emanates not only from the infection but also from the way and mode of the infection. The negative social construction of HIV exists as people associate a deviant, low morale person with HIV. Since behaviours are learned and controllable, the onus of contracting HIV is also on the infected, and it is considered an invited disease (Goffman 1963). Hence the usual sympathy which accompanies any fatal illness is missing for HIV positive persons (Davies et al.2006; Vyavaharkar 2007). They have been a victim of social stigma and discrimination, and hence their social support needs to be assessed.

Li et al., (2017) assessed the impact of social support. They found significant differences in physiological function, general health, vitality, social function, mental health, health transition and total score of quality of life. Existing studies have suggested that a higher level of social support (either general or HIV-specific) might be generally related to fewer HIV-related risk behaviours among FSWs PLWHIV and heterosexual adults. However, results about relationships between social support and HIV-related risk behaviours varied across populations, and they were inconsistent among drug users, MSM, and adolescents (Qiao, 2014).

We see the people internalizing the stigma, cocooning themselves, and avoiding loved ones. Hence, we see that the avoidance is two-way, the infected person starts avoiding the loved ones for fear of discrimination, and the loved ones and friends also start avoiding the infected. It results in a deterioration in the quality of life of the infected persons. Social support is crucial for having a positive view of self and medication adherence. Many researchers have tried to assess the social support of HIV positive persons and found it low. New interventions and enabling environment being one of the vital components of NACP III, we expect that

social support would have improved. Fisher suggested that social norms prevalent in the support groups, consistent with HIV prevention efforts, promote protective behaviours. In contrast, those inconsistent with HIV prevention will be barriers to positive behaviour change (Fisher 1988).

Social Support is known to affect the health of people. However it is found that social support is not associated with adherence (Ncama et al., 2008) . Though, Lesserman (1999) found that social support reduces stress which in turn affects health. This field of study is called psycho-neuro-immunology. For each 1-point decrease in cumulative average social support, the risk of AIDS increased almost three-fold. Only stress and social support remained significant in the model (Lesserman, 1999).

Relationships with family and friends affected social support and disclosure. Disclosure was made to family and friends where relationships with them were open (DiMarco 2003; Mukesh D (2016) also found that the support of family was positive when disclosure was made. But many PLHA refrains from disclosing, fearing losing social support.

In most of the studies conducted on HIV positive persons, the social support of infected persons was low. There is a need to understand social support of PLHA and its relationship with other variables. The present study used Duke's abbreviated eleven-point scale to measure the social support of the respondents.

2. Methods

The purpose of the current research is to assess the social support of HIV infected adults. The data was collected from April 2010 to February 2011. The researcher training the key populations and project managers and outreach workers of HIV prevention projects, as master trainer. This helped the researcher develop familiarity and with the infected population. They were comfortable sharing their deep-rooted issues and problems with the researcher. The researcher used Duke's social support tool was used to assess social support.

Participants

The researcher recruited 105 HIV positive consenting adults. They are hidden population, hence, the researcher approached them through snowball sampling. The researcher selected the primary person from the NGO and started the snowballing till a reasonable number was contacted. The sample had 60 males, 40 females and five transgender women. Out of 105 total of 63 were married, while 23 were married earlier but now were either divorced or widowed, and 19 were unmarried. An overwhelming majority of 84 respondents reported being heterosexual, 13 homosexual and 07 bisexual. The people who had attained the age of 18 years, conversant in Hindi or English and consented to participate were included in the research. Respondents who did not consent were not included.

Tools

In the present research, the researcher used Dukes' social Support tool to assess social support after adapting it to the Indian setting. The scale included social interaction scale as well as social satisfaction scale. The researcher manually administered it, and the response rate was 100%. It has a maximum score of 33 and a minimum score of 11 points. For this set, 22 points were considered as the average score. The reliability as measured by Cronbach alpha was 0.89. The researcher transalated the tool into the native language, Hindi, as respondents spoke Hindi. The researcher used the abbreviated 11point Duke's Social Support tool. Later the coding was done as per the manual. It was a reliable tool.

The setting:

This study was conducted as partial fulfilment for the doctoral degree. The study was conducted in the national capital territory of Delhi. According to the Delhi State AIDS Control Society (DSACS). The prevalence of HIV in the capital city of India is 0.20 to 0.27 in the year 2012 (World Bank 2012). Targeted interventions (TI) are the projects of the national AIDS control program (NACP) of the government of India, working with high-risk groups, bridge populations and vulnerable groups. They are motivated for HIV tests; Positive persons requiring intensive care go to 'care homes'. In addition, the HIV prevention projects conduct support group meetings on fixed days with HIV positive persons and their partners and family members.

Respondents and Sampling

The respondents comprised a hidden, hard-to-reach population. As HIV status is kept confidential, the list of HIV positive persons is not shared. Hence, the researcher recruited the respondents from targeted intervention (TI) projects of NGOs and care homes catering to HIV positive persons using the snowball method. The project managers were informed about the research objective and asked to introduce the researcher to potential respondents. The project managers provided a separate room (counselling room) for confidential interview sessions. Eligibility criteria included HIV positive persons above 18 years of age and willing to participate in the research. The first participant in each setting introduced other respondents to the researcher. Then, the questions related to social support were asked in one to one sessions.

3. Analysis of Data

The researcher analysed the quantitative data using the Statistical Package for Social Sciences and conducted a chi-square test for association between different variables. The researcher used Duke's social support scale. The researcher did the coding as suggested in the manual. The highest obtainable score was 33, while the lowest was 11. Score categories were as follows

Above 25 was assumed to be good Social Support
between 18-24 moderate Social Support
between 11-17 Low social Support

The social support as the dependent variable was tested with education, income, gender, association with NGO and duration since HIV diagnosis.

4. Results

The social support was low for 88 (82.1%) respondents and moderate for 17 (17.9%) respondents. No respondent had good social support.

The researcher explored the association of social support with gender. The not significant chi-square fails to reject the null hypothesis that gender does not affect social support.

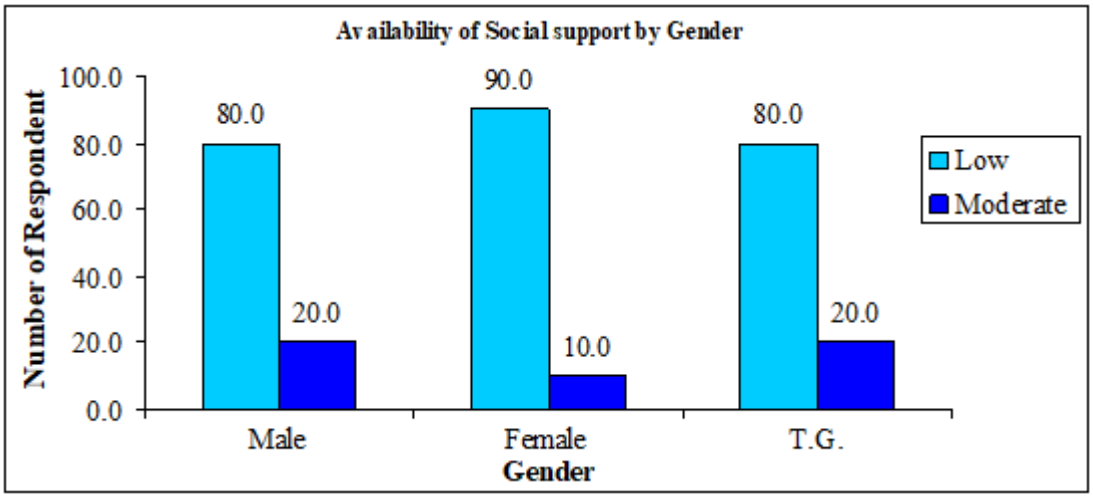

Figure 1: Availability of Social Support by Gender

Although data suggested that more males, 20%, had moderate social support, only 10% of females had moderate social support score. Total 80% of males had low social support compared to 90% of females. Social support for transgender was as good or bad as for males. Social support does not get affected by the education level of the respondent. No significant relationship exists. The data showed that the income of the respondents impacted the social support. As the income of the respondent increased, social support also improved.

Table 1: Social support by the income of respondent

Social support	Below Rs 500 N=30	Rs 500=3000 N=47	Rs 3000 above N=28	Total
Low	29 (96.7)	40 (85.1)	19 (67.9)	88 (83.8)
Moderate	01 (3.3)	07 (14.9)	09 (32.1)	17 (16.2)
Total	30	47	28	105

Note: Chi-Square cannot be computed as in some cells, the expected frequency is less than 5.
Note: Figures in parenthesis are percentages

Social support increased with an increase in income. Moderate social support increased with an increase in income of the respondent, as the table reflects a total of 29 (96.7%) respondents earning less than Rs 500, including those who do not have any source of income and have low social support. Total 40/47 (85.1%) respondents earning Rs 500-3000 have low social support. A total of 19/28 (67.9%) persons with the highest income of Rs 3000/-and above have low social support, and 09/28 (32.1) have good social support. Chi sq test could not be conducted, but data shows some association.

Table 2: Social Support by marital status of the respondent

Social support	Married	Unmarried	Ever married	Total
Low	54 (85.7)	14 (73.7)	20 (87.0)	88 (83.8)
Moderate	09 (14.3)	05 (26.3)	03 (13.0)	17 (16.2)
Total	63 (100)	19 (100)	23 (100)	105 (100)

Note: Chi-Square can not be computed as some cells have an expected frequency of less than 5.
Note: Figures in parenthesis are percentages

An interesting fact has been reflected amongst married and unmarried groups. Both the married and ever married groups have a higher percentage of respondents with low social support than the unmarried group.

Out of all married 63 respondents, 54 (85.7%) married respondents had low social support, comparable to the ever married group at 20 (87%). A lesser per cent 14 (73.7%) unmarried respondents had low social support.

Moderate (better) social support was highest for the unmarried group at 05 (26.3%). Unmarried persons in the sample enjoy better social support than married/ ever married persons. On a closer look, most unmarried have not disclosed their status.

Table 3: Social Support by 'Association with HIV Project NGO'

Social support	Associated with NGO N=77	Not associated with NGO N=28	Total N=105
Low	67 (87)	21 (75)	88 (83.8)
Moderate	10 (13)	07 (25)	17 (16.2)
Total	77 (73.3)	28 (26.7)	105 (100)

Note: Chi-Square 2.183, not significant
Note: Figures in parenthesis are percentages

Association with NGO does not have any effect on the social support of the respondents as 10/77 (13%) of respondents associated with NGO have moderate social support as compared to respondents who are not associated with 7/28 (25%). More than 67/77 (87%) persons who are associated with NGOs have low social support as compared to 21/28 (75%) of the non-associated ones.

It was expected that Association with NGO would improve the Social Support of the individuals associated. No association between social support and an individual's association with NGO was found.

Table 4: Social Support by 'Duration since HIV Diagnosis' of the respondents

Social Support	Less than 1 yr of diagnosis	One Yr to 3 Yrs of HIV	3-8 Yrs of HIV	Total
Low	22 (68.8)	31 (91.2)	35 (89.7)	88 (83.8)
Moderate	10 (31.3)	03 (8.8)	04 (10.3)	17 (16.2)
Total	32 (100)	34 (100)	39 (100)	105 (100)

Note: Chi-Square 7.72 significant at.05 level.
Note: Figures in parenthesis are percentages

The duration of HIV infection seems to affect the social support available to the respondents. A lesser per cent 22 (68.8%) of newly diagnosed have low social support, and 31.3 per cent have moderate social support available to them. However, with progression in the duration of infection, the per cent of respondents having low social support is increasing 31 (91.2%) and 35 (89.7%). At the same time, the moderate or better social support of the respondents is reduced with an increase in the duration of HIV infection. Hence the duration of HIV infection affects social support, which shows a reducing trend with HIV progression.

Table 5: Knowledge of Ante Retroviral Services (ART) Service by Social Support

Social Support	Knows about ART N=73	Doesn't know about ART N=32	Total N=105
Low	65 (89.0)	23 (71.9)	88 (83.8)
Moderate	08 (11.0)	09 (28.1)	17 (16.2)
Total	73 (100)	32 (100)	105 (100)

Note: Chi-square is 4.83, significant at.05
Note: Figures in parenthesis are percentages

Out of 73 respondents who knew about ART services, 65 (89%) respondents had low social support, and 8 (11%) respondents had moderate social support.

Out of a total of 32 respondents who did not know about institutes giving ART services, 23 (71.9%) had low social support compared to 09 (28.1%) who had good social support.

5. Discussion

The social support of the HIV positive persons is low in the present study. The persons living with HIV often cut them off from others and, more important, from themselves (Davies et al, 2006; Vyavaharkar et al, 2007). Social support is an anticipation, a belief and a feeling that someone will help. Social support in the sample was poor or moderate. This was not affected by gender or marital relations. Although in a study Garfin (2019) found that Social Support affects the quality of life of women living with HIV AIDS in India.

It was assumed that NGO association would improve the social support to the persons associated, but it seems to have no such effect. Social Support was not affected by the NGO contact of the respondent; there was no research study found that could have established the relationship between NGO association of the respondent with social support. However, we also could not establish any association.

The social support was affected by 'duration since diagnosis', meaning that as the person grows with HIV, their social support keeps decreasing. The data shows that the social support initially takes a dip and later increases which could have been due to the emergence of new social support of HIV positive persons. This finding supports the study in Dublin with older persons living with HIV AIDS, where people infected for a longer duration had good social support (Okonkwo et al., 2016)

We found that Social support was affected by knowledge of ART services though negatively, as people with low social support had better knowledge of the ART services, which could be because they were taking their illness seriously and retaining the information. This was not found in any other study. Here knowledge of services is affected by social support.

6. Recommendations

Health workers have to be mindful of the paradox that people living with HIV endure. Helping professionals facilitate wellness for people living with HIV in three areas, personal, relational and collective. At the centre of wellness are power, capacity and opportunity." (Poindextor 2010, p. p.33-34). It is important to connect the person living with HIV AIDS with an alternative support system, as the previous one (family, friends) falls apart post-HIV diagnosis. This support helps the person overcome alienation and fills him with a feeling of belonging to a new group where the members share the infection and life experiences. This support reduces the anxieties related to getting infected. It gives strength to the members and gives them a voice. Support group leads to a sense of contentment, helps the individual reach a certain level of satisfaction. Achievement of certain tasks and contentment deriving from them results in reduced stress. The group can act as a new support system for positive persons.

For the individual, some of the advantages are:

1) Meeting other people with problems can lend a broader perspective to one's problems.
2) listening to others provides options about how to view and cope with issues.
3) There is an opportunity for mutual encouragement and emotional support, a general feeling or the human conditions.

Although groups vary but the therapeutic effects of being a part of a group remain for all support groups by instilling hope and imitating the behaviour of other members and the facilitator. Altruism, development of socializing techniques, and Universality (a feeling that one is not alone) are essential to self-esteem and self worth.

Helping principals also invite us to enter into a spirit of hope and witness as helpers. We are called to hold hope in the face of despair and doubt. People living with HIV are threatened with a loss of hope. Society exacerbates their sense of alienation. We need to challenge the dominant stories that often oppress and marginalize other stories.

References

[1] Davies, G., Koenig, L. J., Stratford, D., Palmore, M., Bush, T., Golde, M.,. . . Ellerbrock, T. V. (2006). Overview and implementation of an intervention to prevent adherence failure among HIV-infected adults initiating antiretroviral therapy: Lessons learned from Project HEART. AIDS Care, 18, 895903. doi: 10.1080/ 09540120500329556)

[2] DiMarco, M. (2003). Stress, Social Support, and HIV-Status Disclosure to Family and Friends Among HIV-Positive Men and Women. Journal of Behavioral Medicine *Vol.26, No.4, August 2003*

[3] Fisher JD. (1988) Possible effects of reference group-based social influence on AIDS-risk behaviour and AIDS prevention. Am Psychol.1988; 43 (11): 914–20.

[4] Garfin, D. R., Shin, S. S., Ekstrand, M. L., Yadav, K., Carpenter, C. L., Sinha, S., &Nyamathi, A. M. (2019). Depression, social support, and stigma as predictors of quality of life over time: results from an Asha-based HIV/AIDS intervention in India. *AIDS care*, *31* (5), 563-571.

[5] Indian Council of Medical Research (2006). Ethical Guidelines for biomedical research in human participants. Retrieved from http: //icmr. nic. in/ethical_guidelines. pdf p. p.21

[6] Koening H.G.,Westlund R.E., George L.K., Huges D.C., (1993) Abbreviating the Duke Social Support Index for Use in Chronically Ill Elderly Individuals. *Psychosomatics*, Vol 34, Issue 1 January-Februrary 1993, Pages 61-69

[7] Lesserman, J., Jackson, E. D., Petitto, J. M., Golden, R. N., Silva, S. G., Perkins, D. O.,. . . & Evans, D. L. (1999). Progression to AIDS: the effects of stress, depressive symptoms, and social support. *Psychosomatic medicine*, *61* (3), 397-406.

[8] Li, X., Yuan, X., Wang, J., Zhang, W., Zhou, Y., & Liu, G. (2017). Evaluation of impact of social support and care on HIV-positive and AIDS individuals' quality of life: a nonrandomised community trial. *Journal of Clinical Nursing*, *26* (3–4), 369–378. https: //doi. org/10.1111/jocn.13377

[9] Mukesh D 2016). Disclosure of HIV Status and Social Support Among People Living With HIV. Medical Science, 5 (6).

[10] Ncama, B. P., McInerney, P. A., Bhengu, B. R., Corless, I. B., Wantland, D. J., Nicholas, P. K., McGibbon, C. A., & Davis, S. M. (2008). Social support and medication adherence in HIV disease in KwaZulu-Natal, South Africa. *International Journal of Nursing Studies*, *45* (12), 1757–1763. https: //doi. org/10.1016/j. ijnurstu.2008.06.006

[11] Okonkwo, N. O., Larkan, F., & Galligan, M. (2016). An assessment of the levels of perceived social support among older adults living with HIV and AIDS in Dublin. *SpringerPlus*, *5* (1), 726. https: //doi. org/10.1186/s40064-016-2302-6

[12] Pointdexter C. C. (2010) Handbook of HIV and Social Work: Principles, Practice, and Populations. Wiley and Sons. ISBN-10: 0470260939

[13] Vyavaharkar, M., Moneyham, L., Tavakoli, A., Phillips, K. D., Murdaugh, C., Jackson, K., &Medings, G. (2007). Social support, coping, and medication adherence among HIV-positive women with depression living in rural areas of the Southeastern United States. AIDS Patient Care and STDs, 21, 667680. doi: 10.1089/ apc.2006.0131

[14] The world bank (2012) HIV AIDS in India, July 12, 2012 accessed at https: //www.worldbank. org/en/news/feature/2012/07/10/hiv-aids-india