International Journal of Public Health and Epidemiology (ISSN: 2169-303X) Vol. 2 (3), pp. 067-071, March, 2013. Available online at thttp://internationalscholarsjournals.org © International Scholars Journals

Full Length Research Paper

Perceived social support among the spouses of men living with HIV infection

Mohanarani Suhadev [1], Udaya Mahadevan[2], Beena E Thomas[1] & Soumya Swaminathan[1]

[1]National Institute for Research in Tuberculosis (Indian Council of Medical Research), Chennai, India.
[2]Loyola College, Chennai, India.

Accepted 13 February, 2013

Social support is an important buffer for the spouses of HIV infected men. This paper aims to find out the support systems from three different sources namely relational, friends and professional for the women who are the family caregivers. The study included 201 women who accompanied their spouses and children to 3 hospitals at Chennai and Vellore, Tamilnadu, India, during January to June 2007. Social Support was measured by a 9 item scale used in the RAND Medical Outcome Study (Sherbourne & Stewart, 1991). Majority of the respondents were sero-positive (69%) and marriage was the only risk factor for them. Of 201 women, 122 (61%) reported that they disclosed their diagnosis of HIV to others and the scale measured different kinds of support namely companionship, intimacy and understanding and physical assistance. One fifth of the respondents did not get any support from others. About 59% of the respondents had someone to show love and affection and 46% had some persons to listen to them most or all of the time. But, they lacked persons to give them good advice and guide properly (41%). Most women caregivers of HIV infected men received social support mostly from their natal families and urban women enjoyed better social support.

Key words: Social Support, Spouses of HIV infected men, RAND Medical Outcome Study, Tamilnadu.

INTRODUCTION

In India, married women are not considered as high-risk group for contracting or transmitting HIV as sexual relationships are considered to be monogamous in marriage. However, many studies suggest that married women are at risk of acquiring HIV (Gangakhedhar et al., 1997; Kumar et al., 2006; Mehta et al., 2006). Social support is an important buffer for the spouses of HIV infected men who are the primary family caregivers ((D'Cruz, 2002). Social support has been shown to be positively related to good health. It is associated with better health outcomes, better coping and less negative effects of stress (Cohen & Syme, 1985). The way through which social support exercise its useful effects are not clear, but its role in getting compliance, improved access to health care, better psychosocial and nutritional status and immune function, and reduction in the levels of stress are very useful (Uchino et al.,1996; Uchino, 2004). Previous studies have found a significant association of social support with psychological and physical concerns for HIV-infected individuals (Leserman et al., 1999; Namir et al., 1989; Ostrow et al., 1989). The function of social support is commonly viewed to diminish feelings of helplessness and to boost self-esteem, which in turn reduce stress-related depression (Becker and Schmaling, 1991). According to Unnikrishnan (Unnikrishnan et al., 2012), in India women get very good social support because of closely knit family system and spouse. But, there is a dearth of information regarding the type and extent of the social support provided by different people which play an important role in the severely stressed life of the spouses of HIV infected men. Hence, this paper aims to look at the support systems under three different sources namely relational, friends and professional which include the support from health care providers and NGOs and the type of support extended to the wives of HIV infected persons.

METHODOLOGY

This is a multicentre cross sectional study and a total of 201 married women were recruited from 3 different centres. They are National Institute for Research in

*Corresponding author.Email:mohanasuhadev@yahoo.com. Tel: 91 044 28369513

Tuberculosis (NIRT) previously Tuberculosis Research Centre (TRC), Chennai, Government Hospital for Thoracic Medicine (GHTM), Tambaram, Chennai, and Vellore Government Medical College Hospital (VGMCH), Vellore. The study included those women who accompanied their spouses and children for HIV treatment during January 2007 to June 2007 after screening them as per the inclusion criteria. The inclusion criteria were that women respondents should be aware of their husbands' HIV status and they should be living with them. A pretested, semi structured interview schedule consisting of both open as well as closed questions along with a standardized scale were used to collect data. The study participants were interviewed by the researcher in a private room and the participants were given the informed consent agreement to read or to be read, which provides information on the study and the risks and benefits of their participation. Participant confidentiality was assured in the informed consent agreement.

MOS Social Support Survey (Sherbourne & Stewart, 1991).

Social Support is measured by a 9 item scale used in the RAND Medical Outcome Study. Each item had a five response category - none of the item, little of the time, some of the item, most of the time and all of the time. The items elicited information about how often respondents have spouse, family members and friends available to help them whenever they are in need of visiting the health hospitals or giving them moral support and strength to ventilate their fear and anxiety due to their as well as husbands illness. The scores are given in the following ascending manner: None of the time=1, A little of the time=2, Some of the time=3, Most of the time=4 and All of the time=5. The calculated coefficients (0, 905) indicate that the scales of the measuring instruments provide high internal consistency measures.
For the purpose of analysis, the responses under little of the time and some of the time were grouped together and again most of the time and all of the time were grouped together since there was not much difference between these time points. The total items in the measurement scale were 9 and they were under different kinds of support namely companionship, intimacy and understanding and physical assistance.

Data Analysis

The analysis of the data was done using the Statistical Package for Social Sciences (SPSS), version 15.0. The data were validated and analyzed. General descriptive statistics such as frequencies were calculated. Cross-tabulations were done to probe further into the impact of HIV infection on families, and charts were used for the description of the data.

RESULTS

Out of 201 respondents, 96% women belonged to the age group of 20-40 years and only 4% of women were more than 40 years. Of the 201 women, 45% lived in rural areas, 55% lived in urban and semi-urban areas. Majority of the respondents (67 %) were educated up to high school, 51 women (25%) did not have any formal education and only 16 (8%) women had higher education. Of the total 201 women respondents, 138 (69%) were sero-positive, 55 (27%) were sero-negative and 8 (4%) did not know their HIV status.
All the spouses of 201 women most of whom were the breadwinners of the families were HIV positive persons and another 69 % of these women respondents were not only caregivers, but HIV care recipients also. The women caregivers had to perform twin functions, namely, to contribute to the income of the household and to look after their HIV infected husbands.

Different sources of support

The sources of support were divided into 3 categories- Relatives, friends and professionals, which include medical care, counseling and other support by NGOs. Natal family, in-laws and other relatives who were related either by blood or social ties were the major sources of support for women caregivers of HIV infected persons. Among 137 women who had disclosed to their parents, 94(47%) had received the parental support whereas among 108 women who had disclosed to their in-laws, 23% only got the support.

(i) Parental Support

Many respondents or their husbands who were hospitalized for their illness had to take financial support from their family at least for some period. Mostly, parents, brothers and in-laws and in few cases both parents and in-laws together helped them financially during the time of crisis and in taking care of their small children. But, that did not mean that they were aware of the HIV status of the respondents or their husbands in all cases.

(ii) Support from in-laws

The respondents reported less support from their in-laws when compared to the quality and quantity of help forthcoming from their parents. In some cases, in-laws were not informed about their HIV status also. They were told about their TB infection only. Men perceived their brothers as most supportive whereas for women, their parent's support was the most important. In very few cases, the in-laws did not understand the gravity or serio-usness of the disease. Some in-laws were very old and

Table 1. Percentage of social support available for the respondents (No=201).

Item No	Items	No support	Sometimes	Most/All times
	Companionship			
1	Someone you can count on to listen to you when you need to talk	22	32	46
2	Someone to give you good advice about a crisis	21	38	41
4	Someone who shows you love and affection	21	20	59
	Intimacy & Understanding			
5	Someone to confide in or talk to about yourself or your problems	25	53	22
7	Someone to share your most private worries and fears with	26	54	20
8	Someone who understands your problems	21	55	24
9	Someone to love and make you feel wanted	20	55	25
	Assistance			
3	Someone to take you to the doctor if you needed	21	20	59
6	Someone to help you if you were sick	20	26	54

dependants.

(iii) Professional Support

Apart from the familial support, the respondents mentioned about the professional support by the doctors, counselors and nurses in care and management of HIV/AIDS in the study hospitals. In all three study sites namely NIRT, GHTM, both at Chennai and GVMCH, Vellore, trained counselors were available and all the respondents were making use of the counseling services available in these places. One respondent informed that she gave up her suicidal attempt after undergoing counseling on HIV/AIDS. Some of the respondents reported that the counseling received from the counselors helped them to come to terms with the situation. Counseling the spouse was also an important aspect of formal support. It helped the spouse to find out their HIV status and to accept the person without any undue fear of contracting the infection through casual contacts. The respondents did mention about the NGOs and other private hospitals working in the field of HIV/AIDS and their major role in rehabilitation services.

MOS Social Support Scale (Table1)

For the purpose of analysis, the total 9 items were grouped into 3 different kinds of support namely companionship, intimacy and understanding and physical assistance.

(i) Companionship

The table shows that one fifth of the respondents did not get the support or assistance covered by the measurement scale. About 59% of the respondents had someone to show love and affection and 46% had some persons to listen to them most or all of the time. But, they lacked persons to give them good advice and guide properly (41%).

(ii) Intimacy and Understanding

Another 4 items came under more intimacy and understanding of the respondents, their mental trauma and helplessness due to HIV/AIDS. The respondents had close persons or friends some of the time only to confide

Table 2. Cross tabulation of Social Support and place of residence (No=108).

Place of residence	Parents support*						In-laws support					
	Yes		No		Total		Yes		No		Total	
	No	%	No	%	No	%	No	%	No	%	No	%
Urban/Semi-urban	52	55	23	53	75	55	22	47	33	54	55	51
Rural	42	45	20	47	62	45	25	53	28	46	53	49
Total	94	100	43	100	137	100	47	100	61	100	108	100

*Pearson Chi Square 0.040

in (53%) or to share their most private worries and fears (54%) or to understand their problems (55%), or to love and make them feel wanted (55%).

(iii) Physical Assistance

More than half of the respondents had informed that they had somebody most of the time to take them to the doctor (59%) and help them during their sickness (54%). The descriptions of the kind of support received by the respondents from different sources pointed out to financial support, emotional support, material support, informational support, medical support, physical support in the execution of care giving tasks etc;

Social Support available for urban and rural women (Table 2)

Cross tabulations were done to find out the availability of support from the natal family and in-laws for the respondents coming from urban and rural areas. Table 2 shows that the difference in parental support available to the urban and rural respondents is statistically significant (Chi square = 0.040). The urban respondents got more support from their parents or brothers in comparison to their rural counterparts. But, there is no significant difference between the in-laws support availed by the urban and rural respondents as far as HIV/AIDS is concerned.

DISCUSSION

Of 201 women, 122 (61%) reported that they disclosed their diagnosis of HIV to others. According to Tolliver (2001), the stigma associated with HIV/AIDS can damage support systems and prevent the caregiver from seeking help. Among 122 married women who had disclosed to others, majority had disclosed their/spouse's HIV status to their natal families, which led to financial and social support later (Suhadev M. 2010). Among those who had disclosed to their parents, 47% had received the parental support whereas only 23% received in-laws support. Half of the respondents received support mostly from their parents not only financial help, but in the other areas also such as taking care of children, giving psychological support etc; In a study on "Coping & social support among wives of HIV zero-positive men in Bangalore", (Kamath, 1996) most women reported family support as being the most important form of social support MOS Social support scale reveals that one fifth of the respondents did not get the support or assistance covered by the measurement scale. In Indian setting, women get very good social support because of closely knit family system and spouse support, this may be the reason for not finding association between social support and depression as seen in a study from coastal South India, (Unnikrishnan, 2012). On the contrary, many studies show that social support has protective influence on depression (Chandra et al., 1998, Klein et al., 2008, Simoni et al., 2006) It is seen that social support is inversely related to depression (McDowell and Serovich, 2007).

MOS Social support scale covers different types of social support namely companionship, intimacy and understanding and physical assistance for the women respondents. But, we have not found out the importance of these different types of social support as perceived by the respondents. In Nigeria, a study investigated social support systems of 81 HIV/AIDS rural women to find out the most important/needed social support systems required by them. The study showed that the most important social support needs required by these respondents were healthcare/promotion (90.1%), emotional support (83.9%), nutritional support (76.5%), financial support (54.3%) were the most important as indicated by the respondents. On the other hand,

physical support (29.6%) and others (25.9%) were perceived to be less important to them (Dimkpa and Daisy, 2011)

The urban and rural divide in the area of social support seems to be significant in terms of help to go to doctor (=0.0164), love and affection (p=0.017), help during sickness (p=0.048), loving and feel the HIV infected persons wanted (0.009). Rural women were found to be more depressed than urban women. This is because rural women are isolated from social services and health care services because of lack of transportation and conservative society in rural areas which forces them not to disclose their HIV status thus depriving them of the social support and ultimately leading to depression (Vyavaharkar, 2012).

To conclude, most women caregivers of HIV infected men received social support mostly from their natal families and urban women enjoyed better social support than their rural counterparts due to stigma.

Limitations of the study

The research is clinic-based and the selection of respondents from the health facilities poses special problems regarding generalization. Hence, replicating the present study in the larger communities where there are true distinctions between urban, suburban and rural areas may yield change in the results. A case-control study with the of wives of HIV negative persons as controls and comparison of results obtained from the wives of HIV positive persons will be more reliable and rewarding.

Future Implications

The findings might help in formulation of future prevention strategies from the service providers more effectively and efficiently to control the spread of HIV/AIDS. As a part of this, elucidating to families the relevance of support in stalling the progress of the infection would be useful. Families also need help to develop into systems, which support caregivers in positive and appropriate ways. Special programs of support including self-help groups, support groups, material and financial assistance and respite care need to be created for zero positive care giving wives who face extraordinary problems that compound the strain of care giving roles.

ACKNOWLEDGEMENT

The authors are grateful to the Superintentdents of Government Hospital for Thoracic Medicine, Tambaram and Vellore Government Medical College Hospital (VGMCH), Vellore in Tamilnadu for granting permission to interview the patients and their attendants. Dr. P.R. Narayanan, Director, Tuberculosis Research Centre, provided guidance and constant encouragement throughout the study. We are also indebted to the study participants who contributed their personal information without which we could not have conducted the study.

REFERENCE

Becker J, Schmaling K (1991). Interpersonal aspects of depression from psychodynamic and attachment perspectives. In J. Becker & A. Kleinman (Eds.). Psychosocial aspects of depression. Hillsdale, NJ: Lawrence Erlbaum.

Cohen S, Syme SK (1985). Social support and health,Orlando: Academic Press.

D'Cruz, P (2002). Caregivers' experiences of Informal support in the context of HIV/AIDS: The Qualitative Report, 7.

Dimkpa, Daisy I. (2011). Social Support Systems of HIV/AIDS Rural Women British Journal of Arts and Social Sciences. 1:1.

Gangakhedkar RR, Bentley ME, Divekar AD, Gadkari D, Mehendale SM, Shepherd ME, Robert C, Bollinger, Thomas C, Quinn. (1997). Spread of HIV infection in married monogamous women in India, Journal of the American Medical Association. 278 (23): 2090–2092. Klein H, Elifson KW, Sterk CE (2008). Depression and HIV risk behavior practices among "At Risk" women, Women and Health, 48: 2: 167–188.

Simoni JM, Huang B, Goodry EJ, H. D. Montoya,(2006) Social support and depressive symptomatology among HIV-positive women:the mediating role of self-esteem and mastery, Women and Health, 42:4:1–15.

Kamath KD (1996). Coping & social support among wives of HIV sero-positive men in Bangalore. Unpublished M.Phil Psychiatric Social Work dissertation. Bangalore NIMHANS.

Kumar R, Jha P, Arora P, Mony P, Bhatia P, Millson, Dhingra N, Bhattacharya M, Robert S, Remis B, Nagelkerke N. (2006). Trends in HIV-1 in young adults in south India from 2000 to 2004: a prevalence study. The Lancet. 367(9517): 1164–1172.

Leserman J, Jackson ED, Petitto JM, Golden, Silva RN, Perkins DO, Evans DL. (1999) Progression to AIDS: the effects of stress, depressive symptoms, and social support. Psychosomatic Medicine, 61, 397- 406.

Mehta SH, Gupta A, Sahay S, Godbole, SV, Joshi, SN, Reynolds, SJ, Celentano, DD, Risbud,A, Mehendale, SM, Bollinger, RC. (2006). High HIV prevalence among a high-risk subgroup of women attending sexually transmitted infection clinics in Pune, India. Journal of Acquired Immune Deficiency Syndromes. 41(1): 75–80.

Suhadev M, Mahadevan U, Dilip M, Suryanarayanan D, Sikhamani R, Thomas BE..(2011).Percentages, Process and Patterns of HIV Disclosure among the spouses of

HIV infected men in South India. J. Int. Assoc. Physicians in AIDS Care. 10(1): 26-29. Namir S, Alumbaugh MJ, Fawzy FI, Wolcott DL (1989). The relationship of social support to physical and psychological aspects of AIDS, Psychology and Health 3, 7–86.

Ostrow D, Joseph J, Kessler R, Soucy J, Tal, M., Eller,M., Chmi J. Phair, J. (1989). Disclosure of HIV antibody status: behavioral and mental health correlates, AIDS Education and Prevention 1, 1–11.

Chandra PS, Ravi V, Desai A D, K. Subbakrishna. (1998.). Anxiety and depression among HIV- infected heterosexuals - a report from India, J. Psychosom. Res. 45:5. 401–409.

Sherbourne CD, Stewart AL (1991). The MOS social support survey. Social Science & Medicine, 32(6): 705-714.

McDowell TL, Serovich JM (2007).The effect of perceived and actual social support on the mental health of HIV-positive persons, AIDS Care, 9: 10 :1223–1229.

Tolliver DE (2001). African-American female caregivers of family members living with HIV/AIDS. Families in Society: J. Contemp. Human Services.82(2):145-156.

Uchino BN (2004). Social support & physical health: Understanding the Health on sequences of relationships. New Haven, CT: Yale University.

Uchino BN, Cacioppo JT, Kiecolt-Glaser JK. (1996). The relationship between social support and physiological processes: a review with emphasis on underlying mechanisms and implications for health. Psychology Bulletin, 119, 488-531.

Unnikrishnan B, Vinitha Jagannath, John T Ramapuram, B, Achappa, Madi D. (2012). Study of Depression and Its Associated Factors among Women Living with HIV/AIDS in Coastal South India. ISRN AIDS 2012, Article ID 684972.

Vyavaharkar L, Moneyham C, Murdaugh Tavakoli A. (2012). Factors associated with quality of life among rural women with HIV disease. AIDS and Behavior. 16(2):295–303.