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PERCEIVED SOCIAL SUPPORT AND HIV SELF-MANAGEMENT AMONG THE PEOPLE LIVING WITH HIV/AIDS (PLHAS) IN TAMIL NADU WITH SPECIAL REFERENCE TO DISTRICT LEVEL NETWORKS (DLNS)

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Abstract
Worldwide 35 million People are living with HIV (PLHIV). Currently around 24 lakhs of PLHIV are living in India in which about 2 lakhs are from Tamil Nadu. India has the third highest number of estimated people living with HIV in the world and the second largest number of people on treatment in any single country. A high level of social support improves mental health, provides more days of vitality and, most importantly, better social support has been found to be associated with improved Quality of Life (QOL). Social support seem to exert positive influence on health-related variables that might influence the health outcomes (Jin Na Wang &Rui Ming Li,2011).However there are limited findings to explore the level of social support among the PLHAs in Tamil Nadu. This paper is one such attempt in the direction.

Aim and Objective*; (1)To study the demographic characteristics, health status , social support among people living with HIV/AIDS (2) To find out the correlations of demographic characteristic ,health status and social support among the PLHAs.*

Methodology*: The study was descriptive in nature. Data collected from 6 districts level networks of PLHAs who have been providing care and support services to their members. Interview schedule was used and the data were collected from March –August 2014. PLHAs who visited for the District services centers were selected through simple random method.*

Conclusion :*It has been found out that one of the dependent variable of social support and daily self-management, chronic nature of HIV self-management are positively and significantly associated with social support ($r = 1$ $P < 0.01$) which mean higher the daily self-management, chronic nature of HIV self-management & Self efficacy higher will be the social support. The study found that the PLHAs who attend regular monthly support group meetings and capacity building training of the network have got high level of self-efficacy.*

Key words: PLHAs, Daily Self –Management, Social Support, District Level Networks.

INTRODUCTION

Worldwide 35 million (WHO, 2013) People are Living with HIV/AIDS (PLHA). Currently around 24 lakhs of PLHIV are living in India in which about 2 lakhs are from Tamil Nadu (NACO, 2014). In India most of the affected population is from lower socioeconomic class and reproductive age group i.e. 15-49 years which increases the economic burden and affects the overall development of the family, community and the country (NACO, 2009).

According to UN GAP Report 2014 India has the third highest number of estimated people living with HIV in the world and the second largest number of people on treatment in any single country. Life expectancy in people living with HIV and AIDS (PLWHA) has increased tremendously with the successes of anti-HIV medications which have transformed HIV to a chronic disease (Yadav.S, 2010,). Chronic conditions refer to ailments with which patients live with for many months or years, with resultant increase demand for care and support. In order to fulfill the demand for care and treatment, family, friends, and the community can be major sources of support (Greenberger. E, et. al, 2000). A higher level of social support improves mental health, provides more days of vitality and, most importantly, better social support has been found to be associated with improved QOL.(Jia H, el,2005).

HIV/AIDS has weakened the **t**raditional social support mechanisms that have long provided safety nets for individuals and communities, especially in terms of moral, psychosocial and material support. The extended family network in particular has been weakened. (Faustine Nakazibwe, 2009). Stigma and discrimination, human rights and personal safety are rapidly affecting the PLHIVs' quality of life. Access to Care, Support and Treatment is always a struggle for PLHIVs due to financial, social, physical and organizational barriers (PFI, 2006)

However India had responded promptly to the HIV/AIDS challenge from the initial stage. The Antiretroviral Treatment (ART) Opportunistic infection management (OI) and Care and Support programs have made HIV/AIDS as a manageable

chronic disease (NACO,2013). Care and support services are critical to improve the quality of life of PLHIVs, their families and communities by enhancing the health and well-being, improving treatment adherence, increasing acceptance by reducing stigma and discrimination and reducing costs of service delivery. People living with HIV/AIDS can live healthy and productive lives when they have access to Information, Treatment, Care and Support.

District level Networks (DLNs) of People Living with HIV/AIDS have emerged as community based Care and Support organizations in Tamil Nadu in the early 2000 and play the pivotal role on several fronts: HIV prevention activities, community based care and support services, treatment adherence follow up through outreach, and representing and protecting the interests of PLHAs in the civil society. Provide psycho-social support, address the issues of stigma and discrimination, enhance linkage between testing and ART service provision, enable and increase access to treatment, conduct follow-up of PLHA initiated on ART, increase compliance to treatment adherence, advocate with key stakeholders at the district and state level to enable access of social security schemes and link with income generation activities are the main activities of DLNs. Therefore community driven initiatives to improve the quality of life of PLHAs is one of the evidence based practices in Tamilnadu.

This paper aims to describe the Daily Self –Management Health Practices and Social Support of People Living with HIV/AIDS who had received Care and Support Services in District Level Networks of Tamil Nadu for future planning and managing of HIV/AIDS and Care and Support initiatives.

METHODS AND METHODOLOGY

Aim and Objective; (1)To study the demographic characteristics, health status and social support among people living with HIV/AIDS (2) To find out the correlations of demographic characteristic ,health status and social support among the PLHAs.There were 30 District Level Networks (DLN) established under GFATM Round –IV project since April 2005 and 28DLNs were functional till 2013. Madurai, Trichy, Tuticorin and Thiruvannamalai of category A and Ariyalur and Nagapattinam of category B&C categories district of NACO were selected for the study by using simple random method. The study was descriptive and mixed methods (quantitative and qualitative method). PLHAs aged 20 years and above, who has enrolled in the DLN on or before Jan 2013(One year before the interview) were selected for the study. 360 respondents were interviewed by using interview schedule. Schedule consists of questions on socio demographic and economic condition, status of health and adherence and social support. The multidimensional scale of perceived social support (MSPSS) provides assessment of three sources of support: family, friends and significant others. (Zimet et al.1988, Chou 2000, Wang et al.2001, Clara et al. 2003). The HIV Self- Management Scale consists of three domains measuring daily health practices, social support and the chronic nature of HIV. There is a total of 20items with 12 items in the first domain, 3 items in the second domain and 5items in the third domain. The tools ware translated into Tamil. The data's were collected from March 2014 to August 2014. Prior to the interview, the purpose of the study was explained to the participants. Written Consent was collected from the respondents.

REVIEW OF LITERATURE

Social Cognitive Theory proposes that individuals do not simply respond to environmental influences, but rather they actively seek and interpret information (Nevid, 2009).According to Bandura (2005), social cognitive theory takes on an agent-like perspective to change, development and adaptation. Bandura describes an agent as someone who intentionally influences one's functioning and life circumstances; "In this view, people are self-organizing, proactive, self-regulating, and self-reflecting. They are contributors to their life circumstances not just products of them" (Bandura, 2005, p. 1)

Social support is a concept recognizing that people exist to varying degrees in networks through which they can receive and give aid, and in which they engage in interactions (Patel et al., 2005). Although definitions of social support vary in the literature, most include both tangible components, such as, financial assistance and physical aid, and intangible components, such as, encouragement and guidance (Heitzmann & Kaplan, 1988).

Different types of social support have been discussed in the literature, for example, informational, instrumental, and emotional (Friedland, et.al, 1996; Sherbourne & Stewart, 1991; Simoni et.al, 2005). Social support can be obtained from family, friends, coworkers, spiritual advisors, health care personnel, or members of one's community or neighborhood. Several studies have demonstrated that social support is associated with improved outcomes and

improved survival in several chronic illnesses, including cancer and end-stage renal disease (Bisschop, Kriegsman, Beekman, Deeg, 2004).

Perceived social support (PSS) refers to the beliefs or evaluations that one has about the relationships in one's life, Galvan, et, al .(2008).Social support is said to be the feeling of being cared for, loved, valued and esteemed or being able to count on other people if a need arises. It also refers to the perceived comfort, care, esteem, or help a person receives from other people or groups.(Ahmed, S.M. et,al,2007). Research on PLWHA indicates that a supportive social environment, particularly friends and family acceptance, was significantly associated with quality of life (Friedland, J. et, al, 1996: Ichikawa, M.et, al 2006).

RESULTS AND DISCUSSION

34.1 percent of the male and 65.3percent of the female and 0.6 percent of the transgender respondents were interviewed. 68.3 percent of them were from rural area and remaining 31.7 percent were from urban area. The half of respondents 52.5 percent were in the age group between 31-40 yrs while 21.1 percent of them were between 41-50 yrs and 20.6 percent of them were between 21-30 yrs and 4.2percent of them were above 50yrs and the remaining 1.7 percent of them were below 20 yrs. The majority (88.8%) of the respondents belonged to Hindu religion while 8.9 percent of them belonged to Christianity and 3.1 percent of them were Muslims. 40.8 percent of the respondents had studied upto primary school while 23.6 percent of the respondents had studied upto middle school and 14.7 percent of the respondents had studied upto high school. 6.6 percent of them were studied still higher secondary.14.2 percent of them were illiterate. More than half respondents 59.7 percent were married while 34.5 percent of them were widow/widower and very less number (1.9%) of them were un- married and separated.

Table No- 1

S.No	Social Support	Mini	Max	M	SD
1.	I feel better while talk with DLN officers and to participate the support group meeting	1	4	3.01	.592
2.	I consider myself to participate on support group meet is a way of strategy	2	4	3.13	.674
3.	As I participate on this meet that will increase hear of caring those who sharing their experience and words.	1	4	3.24	.725
Social Support (Family, Friends, And Significant Other)					
1	Family	1	7	4.92	1.19
2	Friends	2	7	4.62	1.11
3.	Significant others	1	7	4.73	1.14

Source – Primary Data. Mini-Minimum, Max-Maximum, M-Mean, SD-Standard Deviation

The MPSS contained 12 items, each scored from 1-7 and the total score ranged from 12 – 84 it had three dimensions, support from, friends, and significant others, each included four items.

The support group meetings were organized by the DLNs on a monthly basis and provided psycho-social support to their peers at the community and household level and linked them to care and support services. The vast majority percent of the respondents felt better while talk with DLN staff and members and participated the support group meeting. Similarly they were also felt that participating support group meeting is a way of strategy to improve their quality of life.

DLN had played a vital role in developing and strengthening social relationship among the PLHAs which resulted that PLHAs have good relationship in the family and communities and also have a significant others –mostly within the PLHA groups as a trusted person to whom they can share their feelings.

Table No: 2 relationships between demographic variables and social support

S.No	Factors	Age of the respondents	No. of family members	No. family members	Income of family
1.	Social support	.222	.069	-.147	.001

Source – Primary Data , ** Correlation is significant at the 0.01 level (2-tailed).

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It has been found out that the demographic characteristics such as age of the respondents, number of family members and income of the family of the respondents are positively and significantly associated with social support (r = 1 P <0.01).

Spearmen's Rank Correlation

Self-Support of daily activities

S.No	Factors	W total	Age of the respondents	gender	No. of family members	Education
1.	W total	1				
2.	Age of the respondents	.056	1			
3.	Gender	-.007	-.293*	1		
4.	No. of family members	-.022	.095	-.172**	1	
5.	Education	.015	-.073	.004	.009	1

Source: Primary Data

** Correlation is significant at the 0.01 level (2-tailed).

Table 2 explains the type of association, degree as well as the direction of association between the variables under the study. It has been found out that, one of the independent variable of socio demographic namely age of the respondents is positively and significantly associated with total daily self-management of healthy activities score (r = 1 P <0.01) which means higher the age higher will be the daily self-management of healthy practices. It has been found out that, one of the independent variable of socio demographic namely education is positively and significantly associated with total daily self-management of healthy activities score (r = 1 P <0.01) which means higher the education higher will be the daily self-management of healthy activities. Finally, it has been found out that socio demographic variables are positively and significantly associated with total daily self-management of healthy activities score (r = + 1 P<0.01) which clearly indicates that there is a relationship between socio demographic factors and total daily self-management of healthy activities score .

Spearmen correlation
Social Support (Family, Friends and Special Persons)

S.No	Factors	Social Support	Age of the respondents	Gender	No. of family members	Education
1.	Social support	1				
2.	Age of the respondents	.056	1			
3.	gender	-.007	-.293*	1		
4.	No. of family members	-.022	.095	-.172**	1	
5.	Education	.015	-.073	.004	.009	1

Source: Primary Data

** Correlation is significant at the 0.01 level (2-tailed)
The table explains the type of association, degree as well as the direction of association between the variables under the study. It has been found out that, one of the independent variable of socio demographic namely age of the respondents is positively and significantly associated with total social support score (r = 1 P <0.01). Which means higher the age higher will be the social support? It has been found out that, one of the independent variable of socio demographic namely number of family members and education is positively and significantly associated with total social support score (r = 1 P <0.01) which means higher the number of family members and education higher will be the social support. Finally, it has been found out that socio demographic variables are positively and significantly associated with total social support score (r = + 1 P<0.01) which clearly indicates that there is a relationship between socio demographic factors and total social support.

SUGGESTIONS AND CONCLUSION

It has been found out that, one of the dependent variable of Social Support and daily self-management, chronic nature of HIV self-management, are positively and significantly associated with Social Support which mean higher the daily self-Management, chronic nature of HIV self-management higher will be the Social Support .The study also found that the respondents who were regular to the DLNs support group meeting and capacity building training have high level of Social Support. Hence the services of District Level Networks have played a vital role in the improvement of Social support which improved the quality of life of PLHAs. Therefore community driven initiatives need to be promoted.

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