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Stigma, Stress and Social Support among Primary Care Givers of People Living with HIV/AIDS

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Abstract:
Stigma, stress and inadequate social support among primary care givers of People Living with HIV/AIDS (PLHA) can affect the mental health of both PLHA and their care givers.
Method: A cross sectional study was conducted at a government hospital, Bangalore district of Karnataka state, India. Thirty samples were collected purposively for the study.
Results: Perceived stigma and perceived stress are high among the primary care givers while perceived social support is adequate. The predictor variables for perceived stress are perceived social support. The predictor variable for perceived social stigma is perceived social support.
Conclusion: This study aims to understand the gravity of stigma and stress of the primary care givers of PLHA through developing the systematic knowledge base and it is critical to health and mental health professionals to be equipped in dealing with the problems of the primary care givers.

Keywords*: Stigma, stress, social support, People Living with HIV/AIDS, primary care givers*

1. Introduction

Providing care to an ill member can be a stressful experience for the entire family. Caregiving placed considerable demands on caregivers, which is exacerbated by insufficient support, poverty and the added responsibilities of caring for other household members. Stigma and prejudice towards caregivers is common and exacerbates stress levels (Orner, 2006). Within the family, caregivers, who have a greater degree of involvement in the care giving process, are subject to more adverse outcomes. These include experiences of objective and subjective burden, and detrimental effects on physical and mental health (Berg-Weger, Rubio, & Tebb, 2000).

Explorations of caregiver experiences are particularly relevant in the context of HIV/AIDS. The progressive, long-drawn and terminal nature of the infection compound the stress engendered by the caregiving role but the stigmatizing nature of the virus circumscribes caregivers from seeking and receiving much needed support. Because of the stigma and care burden, the caregivers lose their full potential to live their life happily. Their poor social support, increased stress of caring, poor coping and the impact of social stigma affect their life and it directly and indirectly affect the life of people living with HIV/AIDS (PLHA) and whole family itself. This affect the caring of PLHA and it decrease the quality of life of both the PLHA and family. This may lead to the family dysfunction and can affect the whole community. The current study focuses on the intensity of stigma the primary caregiver faces, their stress, and perceived social support.

2. Methodology

The aim of the study is to understand the socio demographic characteristics, stigma, stress and social support of the primary caregivers (spouse/siblings/children/parents and other close relatives who presented the family, those who have best interest, taking the responsibility and does day to day care for PLHA). Descriptive research design is adopted in the current study. The sample consisted of thirty primary caregivers of PLHA. Sample was collected from a government hospital, Bangalore, Karnataka state, India. Purposive sampling method was used in the study with inclusion criteria that caregivers in the age group of 15 to 60 years with only one family member affected with HIV/AIDS would be included. Caregivers of those who were diagnosed with psychiatric illness/mental retardation/any serious physical problems, disability and diagnosed with HIV/AIDS were excluded. Instruments used for the study were; sociodemographic profile, which is developed by the researchers, Perceived Stigma Scale by Berger, Ferrans and Lashley (2001) (Berger, Ferrans, & Lashley, 2001), Perceived Stress Scale by Cohen (1983) (Sheldon Cohen, Kamarck, & Mermelstein, 1983) and Perceived Social Support Scale by Alan Vaux, Phillips Holly, Thomson, Williams and Stewart (1986) (Vaux et al., 1986). Informed consent was obtained from the subjects and ethical clearance was obtained from the hospital.

- **Statistical Analysis:** Basic descriptive statistics, t-test, correlation, multiple linear regression analysis and Man Whitney test was also considered wherever the numbers were very less.

3. Results

Sociodemographic details of respondents show that the minimum age of the respondents is 19 and the maximum age is 56 the mean age is 35. The monthly income varied from Rs.1000 to Rs.20000. The male-female ratio of the participants was 30:70. Regarding the education, 23.3% of the respondents were illiterate and 40% of them were educated from 1st to 5th standard, 16.7 % of them studied up to 5th to 10th standard. Only 20 per cent of them had either Pre University Course (PUC) or above. The occupation details show that 10% of the respondents were unskilled laborers, 26.7% of them are engaged in semiskilled work and only 16.6% were having either skilled or professional jobs and majority of the respondents didn't have any particular jobs. The marital status of the respondents shows that 60% of them are currently married, 13.3% of them are widow/widower and 26.7% of them are not married. Religion wise, majority (56.7%) of the respondents belong to the Hinduism, 13.3% belong to Christianity and 30% of the respondents belong to Islam. The domicile data show that majority (60%) of the respondents were from urban areas and 40% of them from rural areas. The family profile of the respondents shows that 60% of them belong to the nuclear family and 40% of them belong to joint/extended family. Family support wise, 56.7% of the respondents were supported by their family but 43.3% of them were not supported.

Illness related information of PHLA shows that majority (53.3%) of the PLHA's duration of illness was less than five years and 33.33% of them had the duration of illness from 5-10 years and the rest of them with more than 10 years. In case of awareness about the diagnosis among the PLHA (as reported by respondents) 83.3% know about their diagnosis. All respondents reported that they have minimal knowledge about HIV/AIDS. Regarding opportunistic infections (OIs), 96.7% of the PLHA has OIs and therefore 80 percent of them were on Anti Retroviral Therapy.

Perceived stigma was found to be high among the caregivers. Other areas of perceived stigma such as personalized stigma, negative self image, public attitude and disclosure were also high. There was no significant difference between married (M=135.64, SD=16.32) and unmarried. Also there was no significant difference between spouses (M=130.80, SD=13.64) and non spouses (M=141.73, SD=15.70) of PLHA.

The total perceived stress score shows high stress among the caregivers. Perceived stress was found to be high among illiterates (M=39.14, SD=3.63) compared to literates (M=32.35, SD=7.14). Perceived stress was high among unmarried group (M=38.63, SD=3.6) compared to married (M=32.23, SD=7.3value). Perceived stress was found to be high in non-spouse relationship (parents, siblings or other relatives) (M=37.53, SD=6.5) compared to spouse relationship (M=30.33, SD=5.78). The independent t-test computed for this showed significant differences ($t= -3.206$, $p<0.005$).

Scores on different domains of perceived social support (support from family, friends and others) and total scores of perceived social support show adequate social support among the caregivers. Perceived social support among married (M=46.4, SD=9.9) and unmarried (M=50.50, SD=6.50) did not have any significant difference. Perceived social support had significant negative correlation with income ($r=-0.393$, $p<0.05$).

Perceived stigma and perceived stress were found to be significantly correlated ($r=0.623$, $p<0.01$). Similarly, perceived stigma and social support had significant ($r=0.492$, $p<0.01$) correlation. With regard to perceived stress and social support, the correlation is significant ($r=0.671$, $p<0.01$).

Self disclosure with perceived family support and perceived stress are significantly (<p 0.01) correlated. Negative self image and family support was significantly (<p 0.01) correlated. The fourth domain of perceived stigma (public attitude) and perceived stress and support from family was significantly (<p 0.01) correlated. Perceived social support from family is significantly (<p 0.01) correlated with perceived stress. Perceived social support from others are significantly (<p 0.01) correlated with perceived stress.

Multiple linear regression analysis was carried out to know the predictors of perceived stress. Result shows that perceived social support account for 64% variance on perceived stress. In case of predictors of perceived stigma the analysis showed that the perceived social support is the major predictor accounting for 24% of variance on perceived stigma.

4. Discussion

The study made an attempt to understand the stigma, stress, coping and social support of primary caregivers of PLHA. It shows that the stigma and stress are high among primary caregivers while the perceived social support is adequate.

When analyzing the socio-demographic profile, the age of the respondents spread from teenage to middle age. The minimum age is 19 and the maximum age is 56. The mean age is 35. This indicates that the care givers belong to the productive age group and it may affect the growth of the country since both the PLWHA and the care givers are in the productive age group. With regard to the economic status, caregivers belong to range of lower income to higher income group. This can be interpreted that HIV/AIDS has reached in all strata of society. Majority (70%) of the respondents is female gender. But this findings is contrary to the findings in the study conducted by Pundit, Lakhsmi and Vishnuvardhan (Pandit & Vishnuvardhan, 2013). Regarding the domicile, majority of the respondents belong to the urban area compared to rural population. This may be because sample was collected from an urban based hospital.

Majority comes under education level of 5^{th} standard or below. The family type of respondents show that majority of them belong to nuclear family. Half of the respondents are getting support from other family members in taking care of PLHA. Around half of the respondents are non-spouse relationship with PLHA. And the study shows longer duration of care giving experience in the care givers. Majority of the PLHA are with OIs and on ART. The lack of family support indicates the lack of understanding about HIV/AIDS among the other family members also. And all the respondents are having only minimal knowledge about HIV/AIDS. All these factors such as lower education level, lack of family support, nuclear family system, long duration of caregiving

experience and OIs in PLHA, minimal knowledge about HIV/AIDS etc. will increase the stress among primary care givers. This will affect both the care giver and PLHA in all the ways.

The perceived stigma among the primary care givers is very high. This result goes along with the study conducted by Herek et al, 1998 (Herek GM, 1998). The perceived stigma (personalized stigma and public attitude domains) is closely associated with the no-spouse relationship (parent or sibling relationship or children) of primary care givers with the PLHA. This may be because of that, if the spouse is infected with HIV/AIDS, it is easy to hide the HIV status as within them much as the couples could.

The current study reveals the perceived stress among the primary care givers is very high. The current study correlates with the study conducted at Taiwan by Feng et.al (Feng MC, 2009) reveals that the family caregivers felt most stressful on disclosure and stigma issues, and most worried about patients' interpersonal relationships. The study shows that the perceived stress is more among the illiterates. It may be because of the inability to understand about the illness and to adjust with the same. The illiteracy prevents them to seek knowledge and information about HIV/AIDS and services available in the society. The lack of education may preserve the misconception about the HIV/AIDS in their mind. It prevents them to give care and support to the PLWHA also may lead to the spread of HIV/AIDS. Those who never married are high stressed compared to ever married respondents; they may think that the possibility of getting married in their life is questionable because of the stigma persisting in the society. The high stress among the primary care givers may lead to the development of mental health issues like; anxiety, depression etc. It has proved in many studies that stress may cause for mental health problems (Dohrenwend, 1998; Johnson & Sarason, 1978).

The study shows that the care givers' perceived social support is adequate. These observation is consistent with the study conducted in India, by D'Cruz (D'Cruz, 2002, September) in 2002, that the primary care givers getting spontaneous support and solicit support (getting emotional, financial and material support). While caregiving research has disproportionately focused on negative caregiver outcomes, it has devoted limited attention to the role of social support in buffering them (Jankowski, Videka-Sherman, & Laquidara-Dickinson, 1996). Studying this aspect is of significance because 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 (S. Cohen & Wills, 1985).

The interesting findings in the study are that the major predictor for perceived stigma is perceived social support and the major predictor for perceived stress is perceived social support and perceived stress and perceived stigma are significantly correlated. Social support is considered to be reducing stress and this has been shown in many studies (Hansell et al., 1998; Su et al., 2013), across the world in the field of HIV/AIDS. Contrastingly in this study, social support is the reason for stigma and stress. This can be because, though primary care givers perceive presence of adequate social support at the same time, they are afraid of the discrimination and rejection that can arise from the significant others which forms the same social support. Hence it leads to higher stress among them. And it may result in not seeking or accepting the support whenever needed and it may increase the care giver burden and quality of care for PLHA and may result in family dysfunction also.

The above findings indicate that the immediate attention is needed to address the stigma, stress, difficulty to seek and accept social support and the burden of caregiving process. Otherwise it may affect the mental and physical health of primary care givers. Because, the high level of stigma and stress may contribute in developing mental illness like depression and anxiety and if they don't seek or acceptance social support, it may worsen the situation further. This finding goes with the findings in the studies of Santiesteban, Castro, Calvo (Santiesteban, Castro, & Calvo, 2012), Kagotho, Ssewamala(Kagotho & Ssewamala, 2012) , Abasiubong, Bassey, Ogunsemi, Udobang (Abasiubong, Bassey, Ogunsemi, & Udobang, 2011), Mitchell, Knowlton,Kipp (Kangethe, 2009), Matukala, Nkosi, Laing, Jhangri (Kipp, Matukala Nkosi, Laing, & Jhangri, 2006).

The study indicates special attention for HIV/AIDS stigma reduction programme globally. To manage the stigma and stress among care givers; care giver support group; training for counsellors working in HIV/AIDS field with special attention to address the psychosocial needs of primary care givers; HIV/AIDS education and care giver training programme for primary care givers; availability of palliative care in community; establishment of respite care centres; adequate community care centres etc. can be considered. Policy makers should address the primary care givers also when they formulate policies and HIV/AIDS control programmes in the country. And primary care givers deserve special attention from health and mental health professionals. Also, the study reminds further deeper investigations to explore the family function of primary care givers after diagnosis of HIV and development of AIDS.

5. Conclusion

The study shows the perceived stigma and stress is high among the primary care givers of PLHA and it can affect quality of life of both the care givers and PLHA. This indicates the need to developing psychosocial interventions, programmes and facilities to address the above problems of primary care givers. Primary care givers also need attention; almost the same attention given to PLHA from health and mental health professionals.

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