

Psychosocial Characteristics and Experience of Discrimination and Stigmatization among Spouses of HIV/AIDS Infected Husbands: A Study from India

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Abstract: *The strains of those caring for people with HIV/AIDS are enormous. The purpose of this study was to ascertain the socio-demographic characteristics of spouses of HIV/AIDS infected husbands, frequency of depression/depressive symptoms and the various correlates associated and the experience of discrimination and stigmatization. Thirty caregivers were recruited from a rehabilitation agency where their husbands were admitted. Spouses were interviewed using structured instruments. Majority were within 40 years of age; with primary education, married for last 5 years with good- satisfactory marital life. 24(80%) tested as positive and aware of the implications of their illness; 27 (90 %) fulfilled a criteria for a depressive disorder. It was found that in almost all settings of life stigma and discrimination was seen. However the community reactions were comparatively lesser than in other settings. The implications of the findings discussed in the light of interventions proposed for the spouses.*

Introduction

Current research has tended to exclude the wellbeing of caregivers in favor of focusing on HIV patients. The impact of caring for a chronically ill person or a person with a disability on the physical and mental health of the caregivers has, however, been long recognized and studied (Baumgarten(1989); Pinguart & Sörensen 2003; Pinguart & Sörensen 2007; Prachakul & Grant 2003; Pruchno 1990; Saunders 2003 ; Savage & Bailey 2004; Vitaliano et al 2003).On the whole caregivers were significantly depressed, experienced more stress, and had lower self-efficacy than non-caregivers (Pinguart & Sörensen 2003).

Results from review studies have suggested that sociodemographics, such as gender, lower socioeconomic levels, relationship between caregivers and patients, lack of social support, poorer physical health status and risky health behaviours are associated with mental ill-health of caregivers(Connell et al 2001 ; Cooper et 2007 ; Haley 2003 ; Klassen et al 2007; Savage & Bailey 2004; Van der Vooprt, et al 2007).

The caregivers in many situations are predominately female and the people they care for are usually their partners or older adults. The spouses are one of the main care givers in the family. The strains on those caring for people with HIV/AIDS are enormous. The caregivers are a

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precious resource. The quality of care they provide and their ability to do so over a sustained period depend on the protection of their own well-being and morale.

The acute and chronic aspects of HIV disease place profound demands on the spouses for practical support. The unpredictability of the disease, the uncontrollability of symptoms and the debilitating effects of disease contribute to stress and depression of spouses (Cohen, & Lazarus 1979). Unlike professional caregivers, partners do not have the protection of a limited work day of professional distance. In addition many spouses have not taken care of a seriously ill person, nor have they seen someone die.

Care giving to people with chronic illnesses has been found consistently to have negative effects on the informal care giver's health and well-being. It has been documented that care givers experience various physical health problems; depression; disruption in interpersonal relationships, social life; work life and financial strain associated with care giving (Given & Given 1998).

Depressive mood is the distressing emotion most frequently reported in care givers of people with AIDS (Given & Given 1998; Bergman-Evans 1994; Knop et al 1998; Turner & Catania 1997; Flaskerud, & Tabora 1998; Wight 2000; Land et al 2003). In a study where depressive mood was considered an outcome measure also found it to be a strong predictor of poorer physical, social and role functioning, as well as perceived physical health (Flaskerud, & Tabora 1998). Although this is well recognized in principle, care for the carers is rarely given the priority it deserves.

Stigmatization and discrimination

Social reactions to people with AIDS have been overwhelmingly negative. Stigma is triggered by many forces, including lack of understanding of the disease, myths about how HIV is transmitted, prejudice, lack of treatment and irresponsible media reporting on the epidemic. HIV/AIDS related stigma and discrimination also interact with pre-existing fears about contagion and disease. The existence of HIV/AIDS-related stigma has been widely documented all over the world (Herek & Capitanio 1999; Klein et al 2002; Snyder et al 1999; Herek 1999; McGrath et al 1993; Ambati et al 1997; Bharat & Aggleton 1997; Bharat et al 2001). HIV infection fits the profile of a condition that carries a high level of stigmatization (Herek 1999; Goffman 1963; Jones et al 1988). According to UNAIDS, HIV/AIDS related stigma and discrimination are linked to the actions and attitudes of families, communities, and societies (UNAIDS, 2002).

The impact of HIV/AIDS on women is particularly acute. The existing social inequalities- especially those of gender, sexuality, and race are at the root of HIV-related stigma. In many developing countries, women are often economically, culturally and socially disadvantaged and lack equal access to treatment, financial support and education.

HIV-related stigma manifests itself in various ways. HIV-positive individuals, their loved ones, and even their caregivers are often subjected to rejection by their social circles and communities when they need support the most. Stigmatized individuals may suffer discrimination that can lead to loss of employment and housing, estrangement from family and society, and even increased risk of violence (Herek 1999; Gielen et al 1997; Zierler 1997). The forms of discrimination against women included being refused shelter; denied a share of family property; denied access to treatment and care; being blamed for husband's HIV diagnosis when the diagnosis is made soon after marriage (Bharat 1996). HIV/AIDS-related stigma compromises the well-being of people living with the disease.

Family responses to the infected relative was influenced by community perception of the disease and such responses included fear of isolation and ostracism (McGrath et al. 1993; Bharat & Aggleton 1999 Warwick et 1998) leading to concealment of diagnosis leading to stress and depression within the family Bharat & Aggleton 1999.

The present study aims to assess the frequency of occurrence of depressive symptoms/clinical syndrome and frequency of occurrence of stigma and discrimination and its nature in spouses of HIV/AIDS infected persons and the various correlates of the same.

Materials and Methods

The sample was taken from the Rehabilitation Centre for HIV/AIDS, Mangalore which comprised of 30 spouses of HIV/AIDS infected husbands who were admitted in the facility for management of infections and other symptoms. Permission was sought from the authorities of the centre and as the study did not involve any interventions no ethical clearance was required at that period when the study was conducted. The purpose and format of the study were explained and consent was taken. Of the forty five who were approached to participate in the study fifteen declined. Interviews were conducted in privacy. A clinical interview was conducted to generate ICD-X diagnosis. The interview seemed to provide an outlet for the expressions of emotions for the participants, as many were overwhelmed with the experience of care giving and worried for their own health and future. Consequently each interview lasted from 1^{1/2} -2 hours. Extensive notes were taken to record the qualitative comments of the spouses, in addition to their responses to the structured questionnaires. Those satisfying the inclusion criteria were taken. Standardized

tools were used for sociodemographic data which included details such as age of the spouse, education, and religion and employment status, the head of the family, family type, sero status of the spouse and child/children, reactions of the family, marital details like duration of marriage and quality of marriage. In addition social support and coping strategies were also enquired. To quantify depression Hamilton Rating Scale for Depression (Hamilton 1960) and Beck's Depression Inventory (Beck et al 1974) were used. The schedules to evaluate the experience of stigma and discrimination among wives of patients with seropositivity in various settings were assessed.

Instruments

Hamilton Rating Scale for Depression -HDRS (1960)

The Hamilton Depression Rating Scale (Hamilton 1960) has been the gold standard observer rated scale for the assessment of depression for more than 40 years. The Hamilton Depression Rating Scale (HAM-D) has become the most widely used depression severity rating scale in the world. It was originally published by Max Hamilton in 1960 (Hamilton 1960) to measure severity of depression in previously diagnosed depressed inpatients. Since that time, multiple versions of the scale have been created. In addition, structured interview guides, self-report forms, and computerized versions have been developed in an effort to standardize administration of the scale and improve the psychometric characteristics of the individual items. Many of the psychometric properties of the Hamilton depression scale are adequate and consistently meet established criteria. Internal reliability estimates ranged from 0.46 to 0.97. Retest reliability for the Hamilton depression scale ranged from 0.81 to 0.98. The 24-item version was used. Items on the HAM-D are scored 0 to 4. The rater enters a number for each symptom construct that ranges from 0 (not present) to 4 (extreme symptoms). The cut off is as follows: 0 - 4 normal, depending on age, education, complaints, 5 - 8 mild; 8 - 11 moderate; 12 - 15 severe. Ratings are completed by the examiner on the basis of patient interview and observations.

Beck Depression Inventory (Beck et al 1967)

Beck Depression Inventory (BDI) (Beck et al 1974) is a 21 item, self rated inventory with each item rated with a set of four possible answer choices of increasing intensity. When the test is scored, a value of 0 to 3 is assigned for each answer and then the total score is compared to a key to determine the depression's severity. The total score ranges from 0 to 84. Scores of 0 to 9 are considered minimal; 10 to 16, mild; 17 to 29, moderate; and 30 to 63, severe. Internal consistency has been high in numerous studies. The reliability figures here were above .90. Internal consistency studies demonstrated a correlation coefficient of .86 for the test items, and

the Spearman-Brown correlation for the reliability of the BDI yielded a coefficient of .93. Validity is supported by correlation with other depression measures. Because it is a self-report instrument, it is sometimes used to screen for major depression, for instance in medical outpatients.

Schedule to evaluate discrimination and stigma

A schedule to tap the discrimination and stigma in various settings such as hospital, family, community, schools and work place was prepared by the authors after going through the previous literature related to the topic and in consultation with the experts who validated the same.

Data Analysis

Statistical analysis was carried out with the Statistical Package of Social Sciences (SPSS). Descriptive statistics were used to determine the background characteristics of the sample such as age, education, religion, employment status and family type. Mean scores were computed for depression. Due to small sample size appropriate statistics could not be applied.

Results

The mean age of the spouse was 33.6(S.D.7.94) with a range of 19-56 years and the infected husband was 36.00(S.D.7.78) with a range of 25-60 years. Majority of the spouses i.e., 50% were in the age group of 31-40 and 21-30 years was 23%. As regards education 40% had primary education; 27% high school and about 20% had attended college. The distribution of religion of the spouses was 37% Hindus; 30% Christians and 23% Muslims and 10% from other religions. Employment status of the spouses varied, working in semiskilled or unskilled jobs 40%; professionals 10% and rest were housewives; majority from rural or semi urban background; 50% hailing from nuclear and the rest from non-nuclear families. In 43%, the husbands and 33% of spouses were the main bread winners and 60% of husbands were the head of the family. The socioeconomic status ranged from lower to lower middle class.

The duration of marriage: 36% married for 1-3 years and 47% married between 3-10 years. Regarding the quality of marital life 57% rated their marriage to be good-satisfactory. Of the 26 spouses, who tested their blood for HIV, 24(80%) tested as positive and except 17% the rest were aware of the implications of their illness. There was not much difference in the duration of contact of HIV in husbands and their spouses. Among the spouses in 23.3% the duration of infection was less than 1 year; 20% >1-3 years; 20% >3-5 years and in 20.6% 5-10 years. Among the spouses who tested their children (mean number of children 1.2) -24(80%) tested as positive.

The most commonly reported physical manifestations among the spouses were: STD 17 %; skin lesions 13%; fever and cough 10 %; and lymphadenopathy 10%; tuberculosis 7%.

The spouses described their emotional reactions towards their husbands after diagnosis was confirmed: 64% denied any emotions; 43% were angry; 30% sympathetic and 17% continued to care for their husbands as earlier. Many of them reported more than one reaction. In the sample 27(90 %) fulfilled a criteria for a depressive disorder and 3(10 %) a mixed state of depression and anxiety.

Table 1 Distribution of Sociodemographic characteristics of the sample

Variable	%
Age	
Mean Age of the Spouse(wives)	33.6
S.D.	7.94
Range	19-56
Mean Age of Husbands	36.00
S.D.	7.78
Range	25-60
Education	
Primary	40.00
High school	27.00
College	20.00
Religion	
Hindus	37.00
Christians	30.00
Muslims	23.00
Other	10.00
Employment status	
Semiskilled	40.00
Professional	10.00
Housewives	50.00
Type of Family	
Nuclear	50
Non- nuclear	50
Main bread winner	
Husband	43.00
Self (wives)	33.00
Others	24.00
Head of family	
Husband	60.00
Others	40.00
Duration of marriage	
< 1year	13.00
1-3 years	23.00
3-5	20.00
5-10	27.00
> 10	17.00

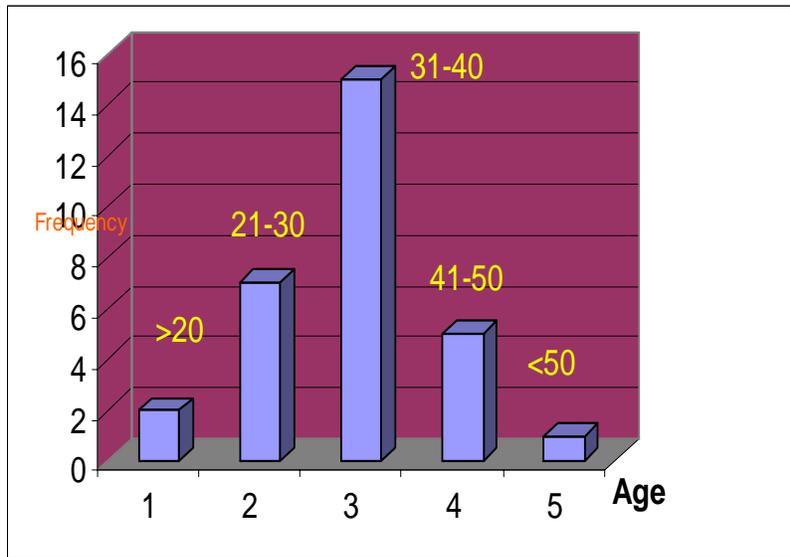


Figure 1: Distribution of the Age groups in the sample

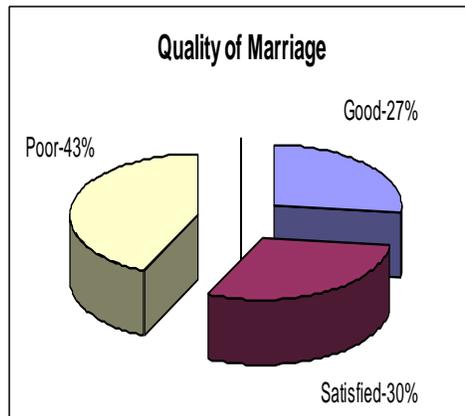


Figure 2: Quality of Marital Life

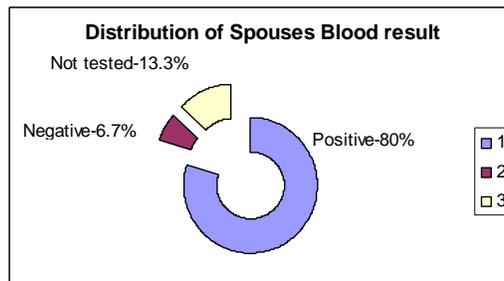


Figure 3: Distribution of Spouse's Blood Result

The mean BDI scores were 28.8 (S.D.8.7) with an observed range of 14-53.and on the HDRS the mean were 45.4(S.D.10.7) with an observed range of 30-69. On BDI 18(60%) fell in the moderate degree of depression and 36.7% severe degree on the other hand on HDRS all of them were in the severe category of depression.

Table 2: Distribution of Mean & S.D. of Depression Severity of BDI & HDRS

Variable	BDI*	HDRS [§]
Mean	28.8	45.4
S.D.	8.7	10.7
Observed Range	14-53	30-69
Severity		
Normal	--	--
Mild	1	-
Moderate	18	-
Severe	11	30
Total	30	30

*BDI- Beck Depression Inventory [§]Hamilton Depression Rating Scale

The most frequently reported symptoms given in a rank order, were sadness-1 (95%); hopelessness-2(85%); sleep problems-3(83%); guilt-4(67%); blame oneself-5(65%); being punished-6(63%).

Table 3: Most Frequently Reported Symptoms

Symptoms	%	Rank
Sadness	95.00	1
Hopelessness	85.00	2
Sleep problems	83.00	3
Guilt	67.00	4
Self blame	65.00	5
Being punished	63.00	6
Anxious	40.00	7

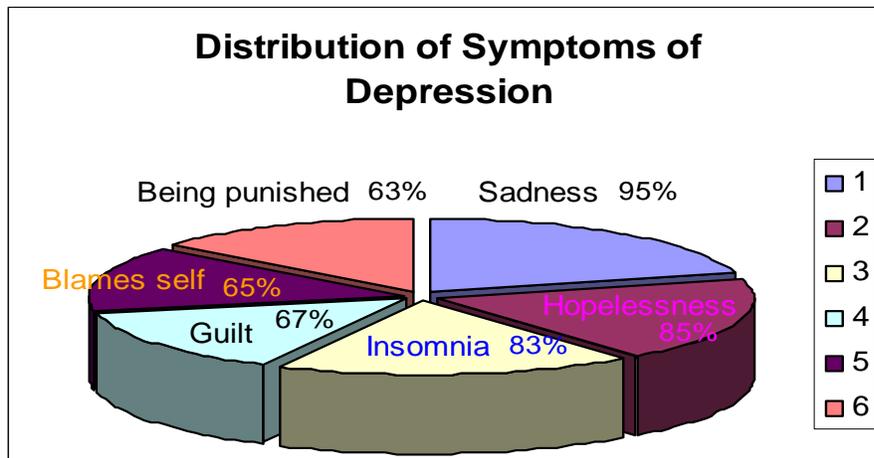


Figure 4: Distribution of the Common Depressive Symptoms Reported by Spouses

The coping strategies commonly utilized by spouses were consulting relatives/friends/ professionals 87%; pray to God-80%; try to think of alternatives 20%; and excess caffeine intake-13%. The social support network were poor 37% reported just one or two members in their network from whom they could derive assistance, whereas about 43% had up to 5 members to contact in times of need.

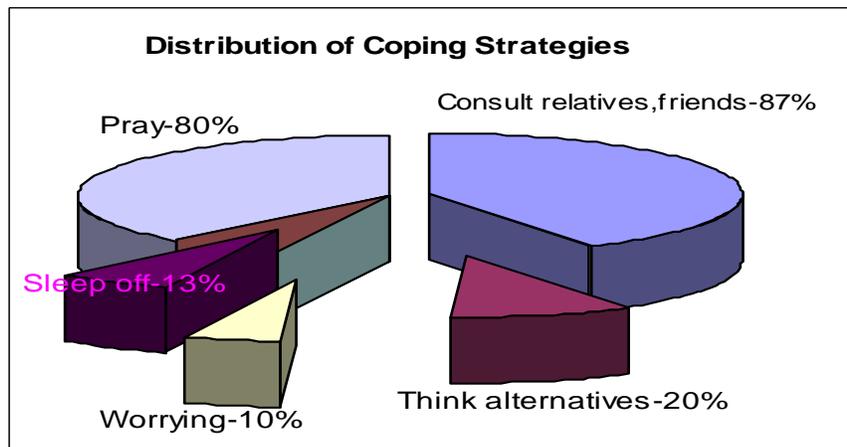


Figure 5: Distribution of Coping Strategies

Stigmatization and discrimination

The discrimination and stigma towards the spouses in the various settings and contexts are described separately. In all the contexts, the reactions towards the spouses were more than one.

Family context

The most common reactions of the family members toward the spouse is given in a rank order (a) 21 (70%) stigmatized the infected spouses as of loose character ; (b) 15(50%) physical isolation at home-2; (c) 11(37%) denial of share of property; (d) 9(30%) blamed as passing virus to others-4; and (e) 6 (20%) had severed relationship /deserted.

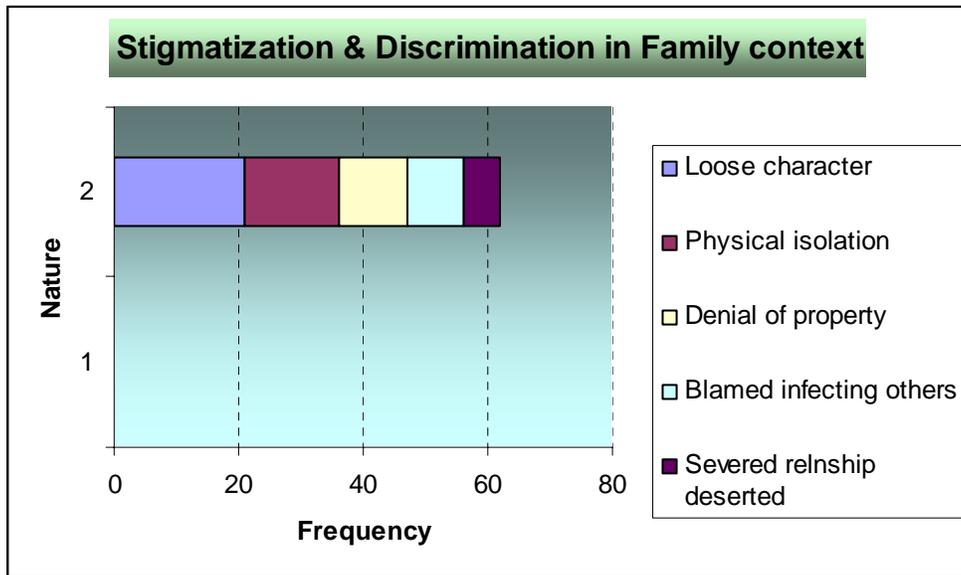


Figure 6: Stigmatization and Discrimination in Family Context

Social and educational settings.

The nature of discrimination against children is given in rank order (a) 20 (67%) experienced discrimination and separation from others; (b) 16 (53%) prohibited to mingle with friends and others; (c) 8 (27%) experienced denial of admission to institutions; (d) 10 (9%) were dismissed from school.

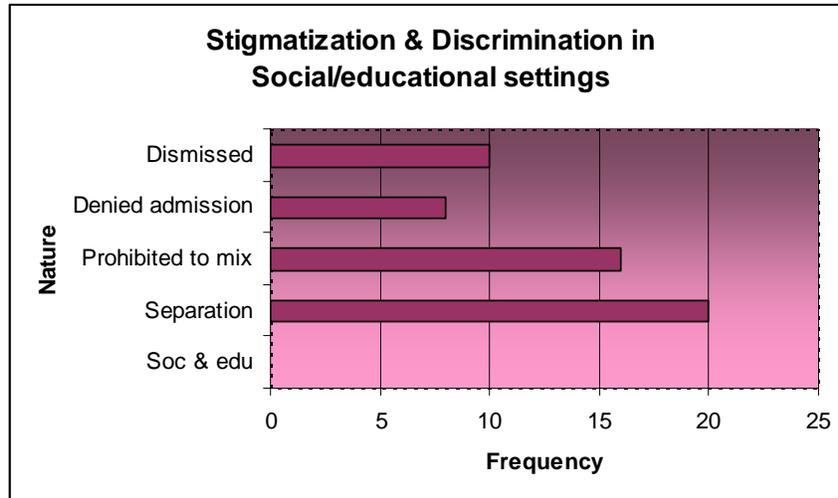


Figure 7: Stigmatization and Discrimination in Social/Educational Settings

Attitudes of the community towards the couple

The usual types of attitudes of discrimination towards the couple is put in a rank order (a) 18(60%) stigmatization as loose character; (b) 15(50%) labeling and name calling; (c) 13 (43%) the blocked entry to common areas; (d) 13(43%)-restricted from attending religious ceremony and (d) 3(10%) denial of death ritual to husbands.

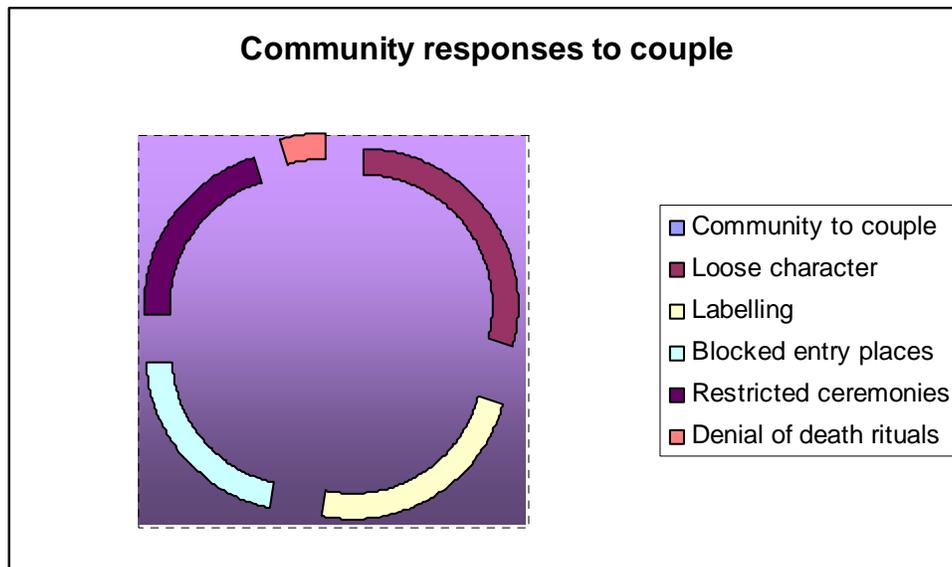


Figure 8 Community Responses to Couple

Public/community reactions

Of the thirty spouses 22(73%) experienced the reactions such as being insulted or teased by others 11(37%) and 11(37%) respectively and 8(27%) reported being belittled by the public.

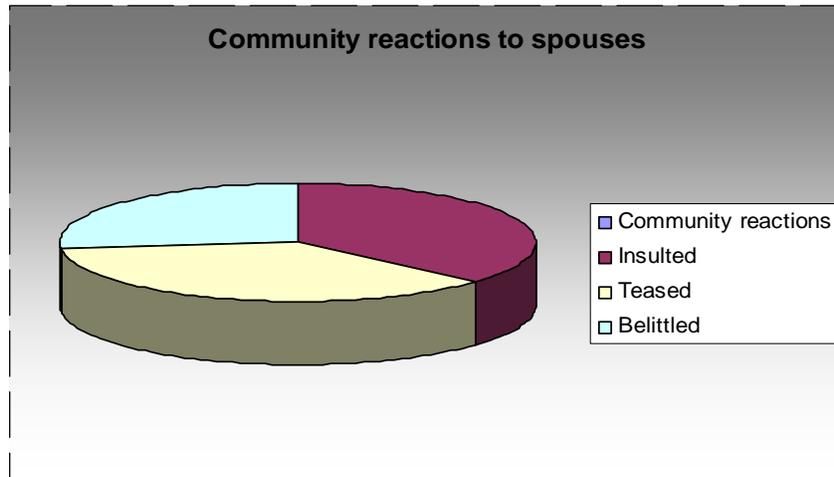


Figure 9: Community Responses to Spouses

Hospital and health care settings

The total sample of thirty spouses 16(37%) reported that they and their husbands were refused treatment; followed by physical isolation in the wards 15 (50%); refused admission in hospitals 13(43%); easily discharged from the hospitals 13(43%) and 10(33%) experienced the unnecessary use of protective gears by hospital staff.

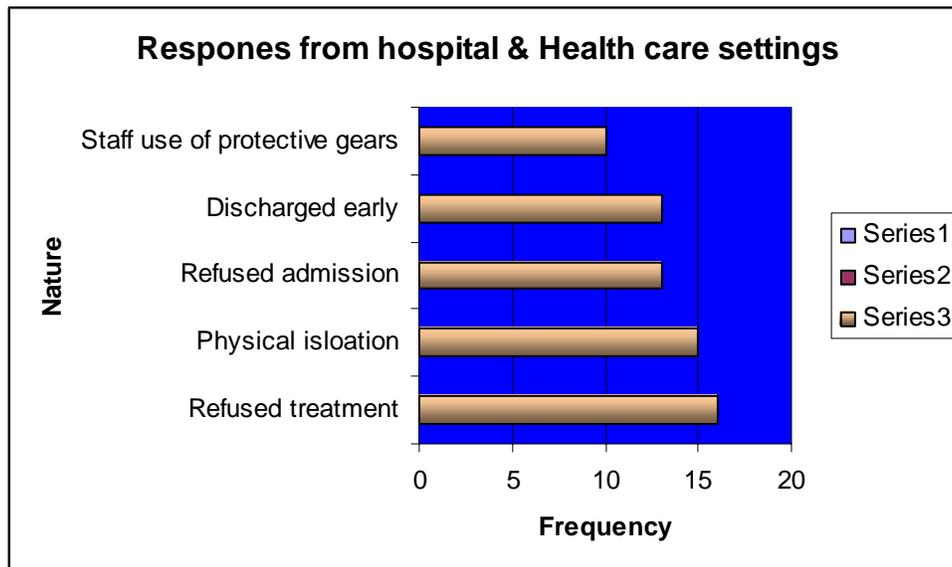


Figure 10: Responses from Hospital and Health Care Setting

Work settings

Of the thirty spouses 20(67%) of them faced social distance in the society; followed by the 15(50%) labeling and name calling; 8(27%) removed from the job; 5(17%) forced resignation and 5(17%) withdrawal of health insurance benefit.

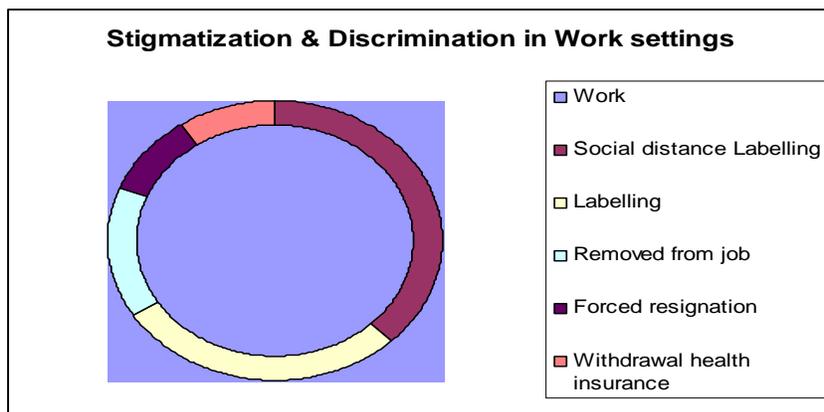


Figure 11: Stigmatization and Discrimination in Work Setting

Discussion

In the present study both the infected husbands and their wives were in their third or fourth decade of life and in the IV stage of family life cycle i.e., couple with preschool children (Olson, 1989). In this stage of life and family life cycle the source of stress are multiple. Most of them were married for the last 5 years and usually in the early phase of marriage; partners are still in the process of building up close relationship with spouses. In addition to developing careers, they were caring for their dependent children and other members, if they are in an extended family. In this study fifty percent were from joint or extended families. Thus spouses of people with AIDS are premature in their care giving role due to their age compared with traditional caregivers. This premature characteristic of care giving can create additional stress over and above the stress associated with care giving.

A high proportion of the sample of spouses suffered from moderate to severe depression, with depressive cognitions and sleep disturbance, as the formal assessment indicated. Periods of extreme distress, grief, despair hopelessness and helplessness may be common among care givers. In addition many of them had various physical symptoms and infections related to AIDS. The disease progression in their partner portends not just the loss of the partner but their own psychological vulnerability to the extent that they see their partner's disease progression as a forecast of their own future and they are physically vulnerable as their own disease progresses. HIV+ care givers whose own health deteriorates are likely to be concerned about being able to provide care while also needing to receive care. Depressive mood is the distressing emotion most

frequently reported in care givers of people with AIDS (Given, & Given 1998; Bergman-Evans 1994; Knop et al. 1998; Turner & Catania 1997; Flaskerud, & Tabora 1998)

Sleep problems in caregivers of people with AIDS, occur frequently and seem to be associated intimately with the care giving experience (Knop et al 1998; Flaskerud, & Tabora 1998). Sleep problems are also highly correlated with depressive mood and anxiety (Mcenany et al 1996). The existing literature suggests that caring for a loved one with human immunodeficiency virus (HIV) presents unique demands for the caregiver. Because many HIV caregivers are sexual partners of the care recipients, they may struggle with concerns about their own health risks in addition to that of their partner (Turner, & Catania 1996).

The physical and psychiatric morbidity of care giving as have been recognized usually are transient and circumscribed to the period of care giving. But in the case of informal caregivers especially in spouses it is not transient and circumscribed. These findings explain the presence of depressive symptoms associated with care giving in those without a prior psychiatric history (Schulz, et al 1990). Spouses who experience a conflict between their work and care giving roles are faced with a dilemma. On the other hand, spouses have major commitment to their partner's well-being.

In this study many spouses tried to cope with stress either by consulting relatives, friends or professionals or praying to God. Seeking social support and religious coping are strategies that involve elements of both problem-focused and emotion-focused coping. Support seeking may include asking for advice, concrete aid, emotional support, or justification for one's perceptions and/or actions (Thoits, 1986). Similarly, religious coping, which includes prayer, is generally considered a form of emotion-focused coping, but may involve asking for advice or even concrete aid. The study of religious coping strategies is as yet in its infancy (Pargament 1997). In general, religious coping may be most helpful with uncontrollable stressors (Aldwin 1994) or people facing chronic stressors such as caregiving, especially those in lower socioeconomic status groups (Cupertino et al 2000).

It is evident from this study that the spouses were discriminated against in all the settings- intimate as well other more impersonal or public settings. In most societies, AIDS is associated with groups whose social and sexual behaviour does not meet with public approval (Ambati et al. 1997). Negative responses and attitudes towards people suffering from AIDS are strongly linked to general levels of knowledge about AIDS and HIV and, in particular, to the causes of AIDS and routes of HIV transmission (Ambati et al 1997), Studies have reported that younger and more

highly educated people typically manifest lower levels of HIV-related stigma than older people and those who are less educated (Herek 1999).

With these findings in mind, it is perhaps not surprising that virtually every Indian setting in which HIV-positive people interacts with other people provides a back-drop for discrimination, stigmatization, and denial. Studies have documented HIV/AIDS-related DSD in contexts such as the family, the community (Bharat & Aggleton 1999; Bharat et al 2001; Bharat 1996; Warwick et al 1998) ; the health care system,(Tirelli et al 1991; Shisam 1993; Daniel & Parker 1990; Ogola 1990; Bharat 1996) and the workplace (Chinai 1995).

Due to stigma and HIV/AIDS-related discrimination, the rights of people living with HIV/AIDS and their families are frequently violated simply because they are known, or presumed, to have HIV/AIDS. This violation of rights hinders the response and increases the negative impact of the epidemic. Freedom from discrimination is a fundamental human right founded on principles of natural justice that are universal and perpetual. The basic characteristics of human rights are that they are inherent in individuals because they are human and that they apply to people everywhere (Fact Sheet: UNAIDS HIV/AIDS 2001). Stigmatization, therefore, can cause denial of treatment to patients.

This study is limited by small convenience sampling, the number of participants involved and the settings of the study. This may limit the generalizability of the results. Nevertheless, the study throws some light on the psychological status of the spouses of HIV+/AIDS infected husbands and the various correlates.

Implications

This study has important therapeutic implications. Detail assessment of caregivers should be a routine which helps in a comprehensive intervention programme. Therapies should be tailored to the spouses or other caregivers' psychosocial, cultural and economic situation. Mental health professional be actively involved in treating depressive mood, anger, anxiety and sleep problems in care givers.

To conclude the level of care giving needed by persons with AIDS can be all-consuming and utterly exhausting emotionally as well as physically. Health professionals can play an important role validating caregiver's experience, helping them anticipate what is ahead, and guiding them to obtain additional practical and emotional support. Legal protections are essential components of the societal response to stigma and discrimination. The recognition of the negative consequences of HIV/AIDS stigma, for individuals as well as for the public health, have led to the enactment of

statutory provisions for people living with HIV disease in many Western countries and we have a long way to go before we achieve a society where HIV related discrimination cease to exist.

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