



Prevalence and correlates of common mental disorders among HIV uninfected women caregivers in HIV sero-discordant setting in Pune, Maharashtra



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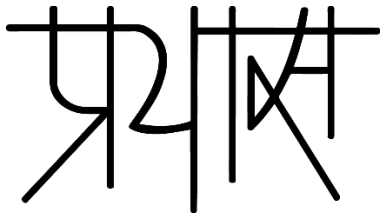
Prevalence and correlates of common mental disorders among HIV uninfected women caregivers in HIV sero-discordant setting in Pune, Maharashtra

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Prayas (Initiatives in Health, Energy, Learning and Parenthood) is a non-governmental, non-profit organization based in Pune, India. Prayas Health Group (PHG) is committed to generate evidence-based discourse on emerging issues on sexual and reproductive health and rights (SRHR). PHG is actively involved in socio-behavioral and epidemiological research, awareness building, programmatic interventions and provision of clinical and counseling services especially to persons living with HIV and youth.

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Introduction

Common mental disorders (CMDs), a term coined by Goldberg and Huxley in 1992 (Goldberg D 1992), denotes a shift of psychiatry from tertiary mental health centers to the community (Chadda 2015) and includes non-psychotic psychiatric disorders that are classified in ICD-10 (1992) as: “neurotic, stress-related and somatoform disorders” and “mood disorders”. (Patel and Kleinman 2003) CMDs, often assuming chronic nature, frequently result in significant occupational role dysfunction, interpersonal difficulties and physical disability which is unexplained by physical health status thus causing major social and financial burdens for persons affected as well as families, friends and employers. (Lazarus and Freeman 2009) ‘Depression’ is the theme for 2017 World Health Day, which highlights the need to address high burden of mental illness resulting from the epidemiological and socio-demographic transitions globally.

Burgeoning literature on CMDs suggests that its prevalence in general population is significantly high in the world as well as in India. The summary report of the recent National mental health survey carried out by the Ministry of Health and Family Welfare, Government of India and NIMHANS to develop data on prevalence, pattern and outcomes for mental disorders in the country showed that nearly 10% of Indian population is suffering from some form of CMD such as depression, anxiety disorders and substance use disorders. (Gururaj G, Shibukumar TM et al. 2016)

The devastating impacts of infection with Human Immunodeficiency Virus (HIV) on families have been documented earlier. Also the psychological impact of HIV infection has been explored globally as well as in India among people living with HIV (PLHIV). (Chandra, Desai et al. 2005; Jayarajan and Chandra 2010; Kamath, Robin et al. 2014; Ghate, Marcotte et al. 2015). However, the psychological impact of HIV diagnosis and living with HIV does not remain confined to those who are infected but is also evident in those who are affected; especially the caregivers.

Caregivers can face unique stressors. In the context of HIV, especially in HIV serodiscordant setting, if men are HIV infected, the role of caregiving inevitably comes to their uninfected wives. Apart from stressors of caregiving which itself can lead to various mental disorders (Sherwood, Given et al. 2005; Vanderwerker, Laff et al. 2005; Steele, Maruyama et al. 2010; Yusuf and Nuhu 2011), couples in such setting struggle to maintain marital relationship with constant fear of transmission of infection. Dilemma about altered reproductive possibilities, shifts in patterns of sexual and emotional intimacy, stigma and discrimination, coping with thoughts of impending illness, lack of social support, addiction, financial stress etc. can act as additional stressors. (Beckerman 2002; Pirraglia, Bishop et al. 2005; Nega Jibat, Berihanu Nigussie et al. 2014; Pei lin

Lua 2014) More importantly, there can be strong sense of betrayal associated with disclosure of HIV positive status of spouse, especially in settings like India, where monogamous marital relationship is a norm and is considered a moral obligation, which will add to the stress. This can result into negative connotations towards care recipient such as anger, guilt, resentment (Gonyea, Paris et al. 2008; Macneil, Kosberg et al. 2010) and various common mental disorders, especially depression and anxiety (Pirraglia, Bishop et al. 2005) (Ghate, Marcotte et al. 2015).

Being a woman and a spouse caregiver increases the vulnerability of this population. Women caregivers perceive higher caregivers' burden compared to men caregivers. (Chandra and Satyanarayana 2010; Kohli, Purohit et al. 2012) It can be due to gender disadvantages among women such as poverty, discrimination, powerlessness and limited access to resources and restricted choices. Literature also suggests that spouse, men or women, caregivers perceive more burdens of care, lower psychological and physical wellbeing, greater financial hardship and number of depressive symptoms than other family caregivers. This can be because of closer attachment, more amount of time spent with care recipient and thoughts of impending loss of spouse. (Pinquart and Sorensen 2011)

Despite of being a highly vulnerable group, mental health of HIV uninfected women spouses of HIV infected men have received limited attention. Globally, the studies carried out in serodiscordant setting have focused more on the prevention of transmission of HIV to uninfected partners and hardly on the issues of emotional and psychological effects of living in such settings. Though some studies have explored psychological and physical effects of informal care-giving to PLHIV/AIDS, on family members and friends (Orner 2006; Santiesteban, Castro et al. 2012; Burgess and Campbell 2014; Ghate, Marcotte et al. 2015) there is little known about the prevalence of CMDs in this population and the burden of care as perceived by them.

In India currently 2.117 million people are living with HIV infection. (National AIDS Control Organisation & National Institute of Medical Statistics 2015) of which 12.9 Lakhs (59.5%) are men. It is estimated that around 44% of HIV infected individuals in India have uninfected partners. (Chemaitelly and Abu-Raddad 2016). This means an approximately 0.56 million women are living in a serodiscordant relationship in India.

One of the important barriers in effectively treating mental illnesses is lack of screening tools that can be used by people with no or little training. Though there are many short screening tools used globally for screening CMDs, the performance of these tools depends on the cultural factors and the disease prevalence. Therefore validation of screening tool for specific populations is important before their application in practice.

This study aims to understand the prevalence and pattern of CMDs among the study population and to validate a locally developed short screening tool among the same.

Methodology

Study design and setting

This was a cross sectional study conducted at Prayas Amrita Clinic in Pune, Maharashtra.

Prayas is a NGO working primarily in the area of HIV/AIDS since 1994. Amrita clinic, managed by Prayas, is a specialized center catering to the clinical and psychological needs of HIV infected and affected persons in Pune and outside. Approximately 2440 HIV infected individuals are seeking active care in Amrita clinic and approximately 400 men in this cohort are living with their HIV negative wives (serodiscordant).

Study population

Study participants were HIV uninfected women, whose HIV infected partners were accessing care at Prayas Amrita clinic. HIV infected men living in serodiscordant setting were identified through their clinical records. These men were informed about the study during their clinical visit in the study period and their written assent to contact their wives was sought. Women were then contacted and informed about the study. If women agreed to participate they were invited to Amrita clinic for interview. HIV testing was carried out for women consenting to participate in the study prior to any data collection.

Eligibility criteria

Women who were screened negative for HIV, who were aware of the husband's HIV positive status for more than 6 months and who were willing to provide written consent were eligible to participate. Women having prior history of known psychiatric illness, women who were recently disclosed their husband's HIV positive status (less than 6 months back) and women who were not living with husband for six months or more were considered not eligible to participate in the study.

Data collection

The data were collected from April 2015 to September 2016. All the eligible women were interviewed by the research assistant and clinical psychologist separately on the same day in face to-face interview. The trained clinical psychologists who was blind to the findings of CBMSQ administered structured diagnostic interview, MINI 5.0 (Lecrubier, Sheehan et al. 1998). The data collection flow is shown in the schematic diagram given below.

Routine physical examination was performed by a clinician and vital parameters were noted. Haemogram, random blood sugar levels and test for thyroid function (TSH) were performed for every woman to exclude the common biological causes of psychosomatic symptoms.

Data was entered by trained data entry operators into Epi-Info.

Ethical approval

The study was approved by the Independent Ethics Committees for Research (IECR) of PRAYAS (registration number: ECR/146/Indt/MH/2014). Written informed consent was sought from

eligible women before enrollment in the study. Women diagnosed with CMD were informed about appropriate care services and were assisted in accessing these services. Consent for appropriate mode of contacting the women to inform her blood test report was sought and blood reports were informed accordingly. Women were given travel reimbursement according to the distance from the study center.

Data analysis

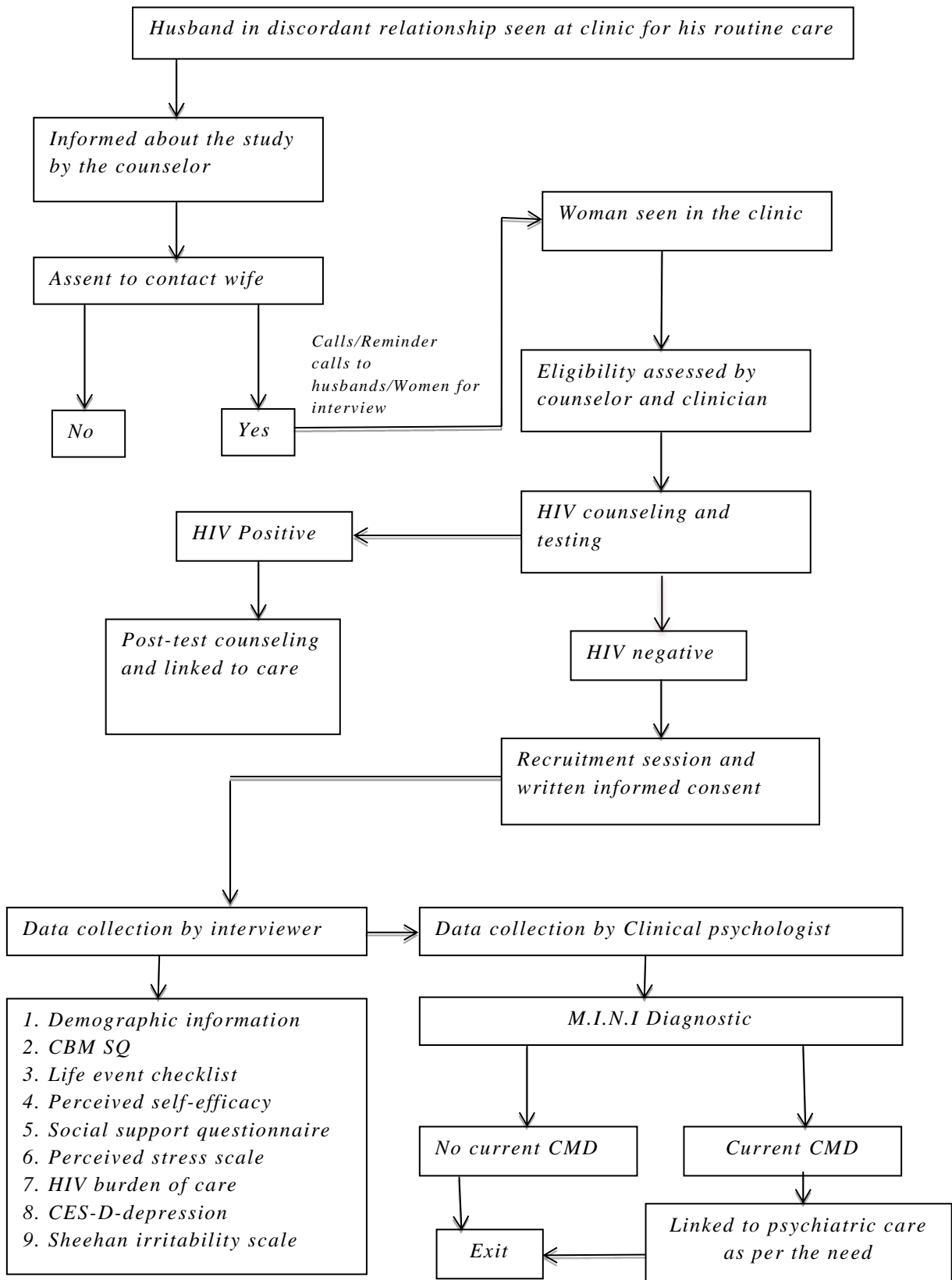
Statistical analysis was done using SPSS 16 statistical software, Microsoft Excel 2010 and R 3.2.4 revised (RCoreTeam Vienna 2016)

To estimate the prevalence of CMDs in study population, the sample was categorized as cases and non-cases based on ICD-10 diagnosis as per the MINI International Neuropsychiatry Interview (5.0.0). Relationship was assessed between different socio-demographic, general health condition parameters, HIV related factors and CMD by univariate and regression analysis. Univariate analysis was done using chi-square where the independent variables were categorical or Point Biserial correlation coefficient when they were continuous.

To validate screening tool, we calculated sensitivity, specificity, positive and negative predictive values and positive and negative likelihood ratios of the CBMSQ against the MINI diagnoses of any CMD. We plotted receiver operating characteristic (ROC) curve and area under the curve (AUC) value to estimate predictive value of the tool for at least one CMD and separately for different disorders. Detailed description is given under the section of CBMSQ.

Details of data analysis for all the tools used in the study are given under the results section for each tool separately.

Figure 1 Schema of data collection



Description of tools used in the study

Diagnostic tool for CMD

- Mini- International Neuropsychiatry Interview (M.I.N.I.)(5.0.0)

The reference standard diagnostic interview was MINI International Neuropsychiatry Interview (5.0.0). MINI was designed as a brief structured interview for the major Axis I psychiatric disorders in DSM-IV and ICD-10. The results of validation and reliability studies show that the MINI has acceptably high validation and reliability scores. (Lecrubier, Sheehan et al. 1998) MINI is useful to diagnose current as well as past presence of all the common mental disorders.

Additional module for PTSD in past was developed and administered by trained psychologist considering the unique need of the study population. (Appendix)

Screening Questionnaire

- **The Centre of Behavioral Medicine Screening Questionnaire (CBMSQ)**

This tool is for screening CMD and was developed as a part of previous ICMR supported study to understand the mental health consequences of earthquake in Marathwada. One of the investigators, Dr. Phadke played instrumental role in developing this tool. The tool is developed in Marathi, the local language of the state.

It is a 9 item questionnaire. The first 7 questions are intended to screen CMD while 8th and 9th questions are for screening psychosis and substance use disorders respectively. The scale is dichotomous with possible answers as yes and no and score of 1 and 0 thus having possible range of score from 0 to 9. The positive answer to 8th and 9th question can independently indicate positive screening result. The time frame for symptoms asked in the tool is for 15 days.

Other tools

- **Burden of HIV care**

The tool was adopted to assess the burden of caregiving for HIV infected partner and its impact on different domains of life such as work, other relations, feelings towards partner, finances etc. The tool was modified to capture added impact of stigma, fear of transmission and sense of betrayal revolving around HIV on physical and emotional health of the women. All the items in the tool were followed by assessment of the relatedness with HIV. Thus burden of caregiving in general and burden attributable to the HIV as an illness could be assessed.

- **Life Events Checklist (LEC or LEL)** assessed exposure to 22 life events in recent past, both positive and negative and experienced by both the respondents and the significant others with the rating of respondents about the feelings towards the events. (Irwin G. Sarason 1978)
- **General Self-Efficacy Scale (GSES)** was used to assess optimistic self-beliefs to cope with a variety of difficult demands in life (Schwarzer 2014).
- **The Social Support Questionnaire (SSQ)** the short version (Irwin G. Sarason 1983) was used to quantify the availability and satisfaction with social support that the women have before and after the disclosure of husband's HIV status.

Tools employed for the purpose of triangulation of data

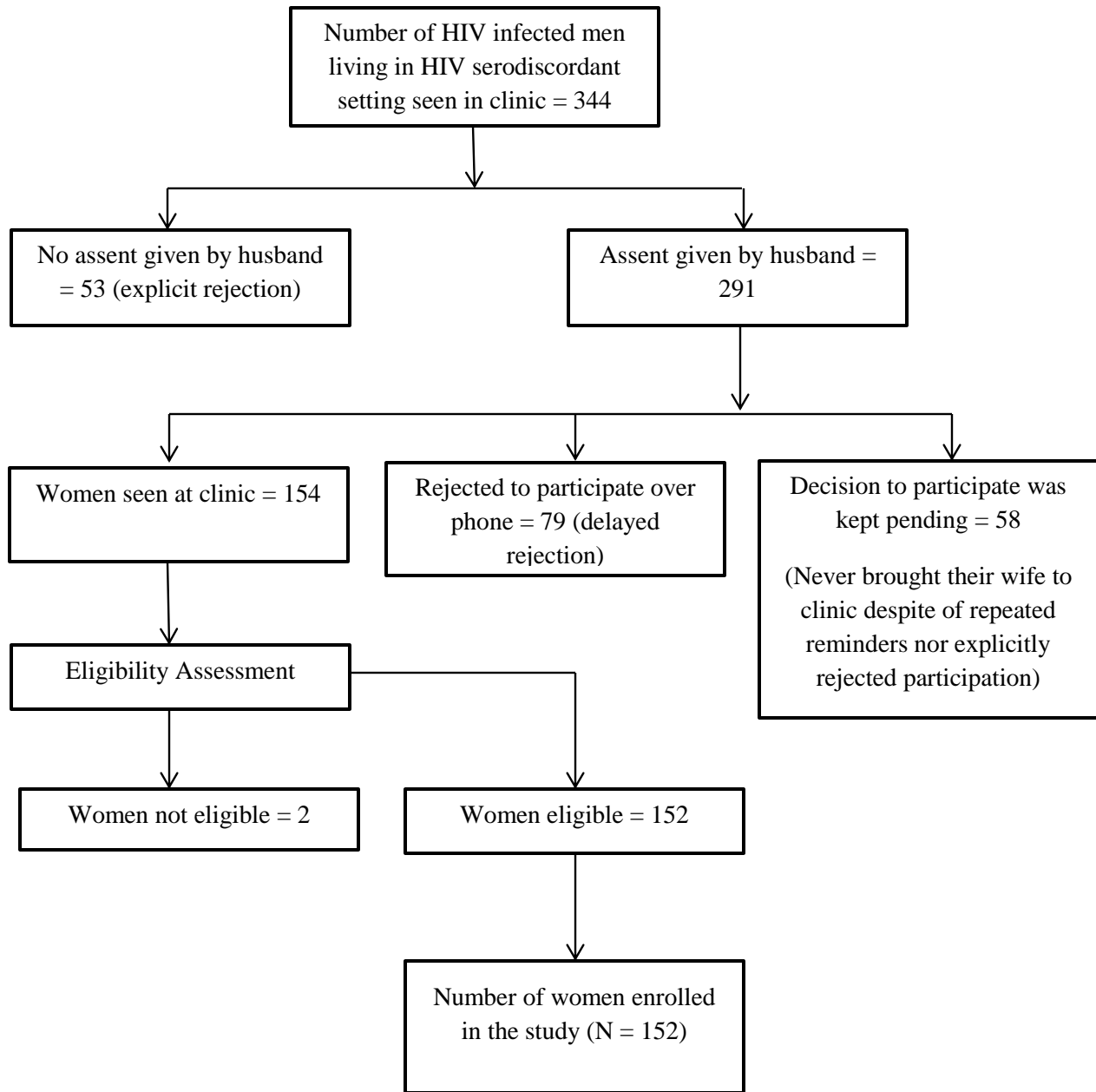
- **Center for Epidemiologic Studies - Depression (CES-D)** is a frequently used instrument for the study of depression in the general population and is designed to measure current levels of depressive symptomatology. (Santor 1997)
- **Sheehan Irritability Scale (SIS)** is a short patient reported scale which has been used extensively in depression studies. (Khan, Revicki et al. 2016)
- **Perceived Stress Scale** the PSS evaluates participants' feelings about how they were able to handle day-to-day problems and hassles, how often they felt nervous and stressed and how often they felt things were going well. Responses are made on a 5-point scale. (Cohen 1994)

Results

From April 2015 to September 2016, 344 men living in HIV serodiscordant setting were informed about the study, out of which wives of 154 men were seen at the clinic and assessed for eligibility. Of which 2 were not eligible to participate and 152 completed the interview. Response rate was 44.1%. Among those 190 who rejected to participate in the study, 53 (15.4%) men refused assent at the first visit to clinic while 79 (22.9%) men first provided assent but later on refused over phone. Thus the explicit rejection rate was 38.3%. We could not contact wives of many men who refused to participate later on as the contact details (Mobile number) provided by men did not belong to their wives; thus cannot comment on whether reason of non-participation was on the part of men or their wives. Decision to participate in the study was kept pending by 58 (16.8%) men/wives who never explicitly rejected to participate in the study. Adding this 'delayed rejection' refusal rate was 55.9%.

The detailed schema of accrual of study participants is given in figure 2.

Figure 2 Schema of accrual of study participants



Socio-demographic profile

Among the 152 women enrolled in the study the mean age was 40.1 years (SD \pm 8.06). The women had mainly come from Pune district (65.1%). Majority of the women (58.5%) were from upper middle socio-economic strata. Half of the women were doing some or the other remunerated work and half of those who were working were self-employed, the most common occupations being farming and tailoring. Husbands of all the women except one were taking Anti-retroviral drug therapy. Most (70%) of the women knew about husband's HIV status for more than 5 years at the time of interview. Table 1 gives the socio-demographic profile and HIV related characteristics of the women.

Table 1 Socio demographic and HIV related -characteristics of study population with association with CMD

Socio-demographic factors		Total (N=152)	Current CMD (N=54)	p-value
Age (in years)	25-35	45 (29.6)	18 (33.3)	0.407
	36-45	79 (52.0)	29 (53.7)	
	46 and above	28 (18.4)	7 (13.0)	
Place of residence	Urban	107 (70.4)	36 (66.7)	0.455
	Rural	45 (29.6)	18 (33.3)	
Education (years)	0 to 7	38 (25.0)	14 (25.9)	0.512
	8 to 12	68 (44.7)	21 (38.9)	
	13 and above	46 (30.3)	19 (35.2)	
Work for remuneration	Yes	81 (53.3)	26 (48.1)	0.346
	No	71 (46.7)	28 (51.9)	
Number of family members	1 to 4	82 (53.9)	27 (50.0)	0.756
	5 to 7	51 (33.6)	20 (37.0)	
	8 and above	19 (12.5)	7 (13.0)	
Socio Economic Status	Lower	35 (23)	14 (25.9)	0.763
	Middle	24 (15.8)	9 (16.7)	
	Upper	93 (61.2)	31 (57.4)	
Marital information				
Age at marriage	< 18 years	72 (47.4)	30 (55.6)	0.133
	≥ 18 years	80 (52.6)	24 (44.4)	
Duration of marriage	< 10 years	11 (7.2)	5 (9.3)	0.740
	10-20 years	81 (53.3)	29 (53.7)	
	≥ 21 years	60 (39.5)	20 (37.0)	
Marriage to disclosure (Years)	0-5	43 (28.3)	16 (29.6)	0.469
	6-10	35 (23.0)	15(27.8)	
	More than 10	74 (48.7)	23(42.6)	
Reproductive history				
No of live children	0	8 (5.3)	3 (5.6)	0.763
	1	39 (25.7)	12 (22.2)	
	2	67 (44.1)	23 (42.6)	
	>2	38 (25.0)	16 (29.6)	
Death of a child	Yes	14 (9.2)	3 (5.6)	0.381
	No	138 (90.8)	51 (94.4)	
Substance use				
Substance use among husband	No	80 (52.6)	26 (48.1)	0.257
	Yes (any)	72 (47.3)	28 (51.9)	
Type of substance (husband)	Tobacco chewing	55 (36.2)	20 (37.0)	0.972

	Tobacco smoking	13 (8.6)	8 (14.8)	0.068
	Alcohol	38 (25.0)	18 (33.3)	0.078
Substance use among women	No habit	128 (84.2)	43 (79.6)	0.250
	At least one habit	24 (15.8)	11 (20.4)	
HIV related characteristics				
Knows about husband's HIV since (years)	0-2	15 (9.9)	5 (9.3)	0.801
	2-5	30 (19.7)	9 (16.7)	
	6-10	60 (39.5)	24 (44.4)	
	More than 10	47 (30.9)	16 (29.6)	
Duration of ART husband (n=119)	< 5 years	35(29.4)	12 (22.2)	0.364
	6-10 years	56 (47)	23 (42.6)	
	11-15 years	23 (19.3)	9 (16.7)	
	16 years and more	5 (4.2)	0 (0)	
Disclosure of Husband's HIV status	No one outside family	23 (15.1)	7 (13.0)	0.366
	Close relatives in family	51 (33.6)	15 (27.8)	
	Others outside family	78 (51.3)	32 (59.3)	
Unprotected sex in last 3 months	Yes	6 (3.9)	3 (5.6)	0.667
	No	146 (96.1)	51 (94.4)	
Any other care recipient in family	Yes	11 (7.2)	3 (5.6)	0.747
	No	141 (92.8)	51 (94.4)	
General health condition				
Presence of any chronic illness	No illness	123(80.9)	45(83.3)	0.574
	At least one illness	29 (19.1)	9 (16.7)	
Types of illness present	Hypertension	17(11.2)	5(9.3)	0.603
	Diabetes	7(4.6)	1(1.9)	0.422
	Asthama	2(1.3)	0 (0)	0.535
	Thyroid disorders	7(4.6)	3(5.6)	0.704
Blood investigation findings	TSH in normal range	137(90.1)	50(92.6)	0.575
	TSH < or > normal range	15(9.9)	4(7.4)	
	Anemia (HB <12 gm%)	57(37.5)	21(38.9)	0.793
	Random blood sugar > 140 mg/dl	19(12.5)	5(9.3)	0.370

Prevalence and pattern of CMD

Of the 152 women in the study, 54 women had at least one current CMD as the MINI diagnostic interview, amounting to the prevalence of current CMD as 35.5% (95% CI – 28 to 44 (Clopper-Pierson Exact method)). In other words, approximately 4 of 10 women were having at least one CMD in the current situation. The commonest diagnoses were mixed anxiety depressive disorder followed by major depressive episode (MDE). Post-traumatic stress disorder (PTSD) was seen in 5 women. The distribution of CMDs diagnosed (current, past and lifetime) is given in table 2. Out of those women who had current CMD, 8 women were found to be in significant distress as assessed by clinical psychologist and were prescribed medication by psychiatrist.

Past history of symptoms of CMDs investigated through MINI, revealed that 49.3% (95% CI 41-58) of the women had suffered from symptoms of at least one of the CMDs in the past. The commonest disorders were major depressive disorder, PTSD and panic disorder. PTSD was seen in 23 women and all of them suffered it after disclosure of husband's HIV positive status. Among the women who reported CMD in the past, most of them (88%) had the onset at the time of disclosure of husband's HIV positive status.

The prevalence of CMD at least once after disclosure of husband's HIV status was 56.5% (95% CI 48 - 65) excluding 9 women who had suffered from symptoms of CMD in past, but before the disclosure.

Table 2 Prevalence of CMD among HIV uninfected women caregivers in sero-discordant setting

ICD 10 Diagnosis of CMD	N(%)	95% Confidence Interval
At least one CMD at present	54 (35.5)	28-44
At least one CMD in past	75 (49.3)	41-58
At least one CMD after disclosure	86 (56.5)	48-65
At least one CMD in lifetime	95 (62.5)	54-70

Table 3 Pattern of ICD 10 diagnoses of CMD among HIV uninfected women caregivers in sero-discordant setting

ICD 10 Diagnosis of CMD	Current N(%)	Past N(%)
F 41.2 Mixed Anxiety Depressive Disorder	18 (11.8)	0
F 32 Major depressive Episode (MDE)	10 (6.6)	64 (42.1)
F 43.1 Post-traumatic stress disorder (PTSD)	5 (3.3)	23 (15.1)
F 43.2 Adjustment Disorder	6 (3.9)	0
F40.01-40.1 Panic Disorder	4 (2.6)	2 (1.3)
F42.8 Obsessive compulsive disorder (OCD)	2 (1.3)	0
F41.1 Generalized anxiety disorder (GAD)	1 (0.7)	0
F60.2 Somatization Disorder	1 (0.7)	0

F50.2 Bulimia Nervosa	1 (0.7)	0
F38.8 Other specified mood [affective] disorders (premenstrual dysphoric disorder)	7 (4.6)	0
F34.1 Dysthymia	4 (2.6)	0

Validation of the Centre of Behavioral Medicine - Screening Questionnaire (CBMSQ)

A locally developed screening tool, CBMSQ was validated.

Data Analysis

Statistical analysis was done using SPSS 16 statistical software, Microsoft Excel 2010 and R 3.2.4 revised (Irwin G. Sarason 1978). The sample was categorized as cases and non-cases based on the MINI diagnosis, thus women fulfilling the criteria of ICD -10 diagnoses on MINI were considered as cases. Sensitivity, specificity, positive and negative predictive values and positive and negative likelihood ratios [i.e. sensitivity / (1 – specificity) and (1-sensitivity)/specificity; Zweig & Campbell, 1993] were calculated respectively for each cut-off score of the CBMSQ against the MINI diagnoses of any CMD. Receiver operating characteristic (ROC) curve was plotted and area under the curve (AUC) value was drawn to estimate predictive value of the tool for at least one CMD and separately for different disorders. Internal consistency of the tool was calculated by using Kuder Richrdson 20 (KR 20) index (Ferguson 1951). The overall rate of agreement was calculated by dividing total true positive and true negative cases by total number of sample.

The best possible cut off to determine caseness on CBMSQ score was identified by using 3 methods suggested in the literature. In first method, we calculated the value of $(1 - \text{sensitivity})^2 + (1 - \text{specificity})^2$ for each possible score (Akobeng 2007). The score with the lowest value was defined as the cut off. In second method, we calculated Youden index (J) (maximum of sensitivity + specificity – 1). The score corresponding to J was determined as cut off (Akobeng 2007). According to the third method we defined choice of cut-off scores with an optimal balance between sensitivity and PPV (minimum of 50% for both the values).(Patel, Araya et al. 2008)

Results of CBMSQ

The mean score of CBMSQ was 3.2 (SD 2.28) for whole sample whereas it was 4.7 (1.9) for women having at least one CMD on MINI. Table 4 provides original set of items (Marathi) in CBMSQ, their translation in English with the frequency of positive answers for each item.

Analysis of data using recommended approach yielded a cutoff of 3. With this cutoff, the tool was 85% sensitive and 64% specific (Table 5). The corresponding positive predictive value or the percentage of sample classified by the CBMSQ as having CMD, who had CMD on the MINI, was

57 and negative predictive value or the percentage of women classified as not having CMD by the CBMSQ who were also not having CMD on the MINI, was 89.

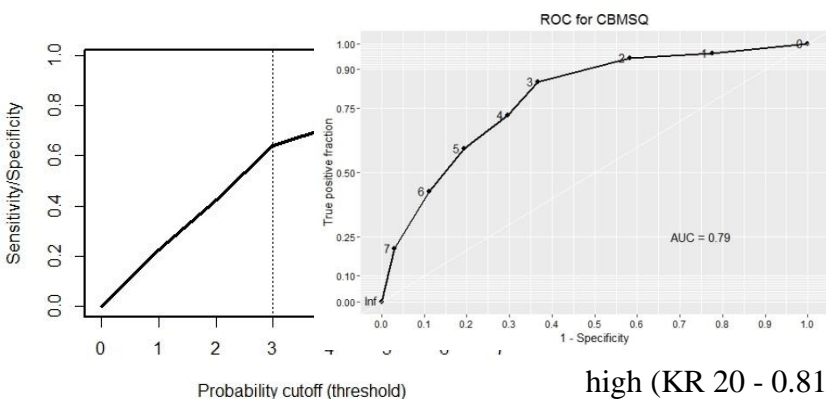
Table 4 Frequency distribution of positive answers for each item in the tool

Item No	Item (Marathi)	Item (English)	No of women with positive response	% of women with positive response
1	उदासपणा जाणवत असतो आणि कशात मन लागत नाही असे होते का ?	Do you often feel sad/depressed and find unable to enjoy/focus on anything?	74	48.7
2	बरेचवेळा धास्ती किंवा भितीवाटते का, किंवा घाबरल्यासारखे होते का ?	Do you often feel frightened?	50	32.9
3	झोपेचा त्रास आहे का ?	Do you have any sleep problem?	41	27
4	सारखी चिंता - काळजी असते का ?	Do you constantly find yourself anxious/worrying about something?	98	64.5
5	चिडचिड - राग वाढला आहे का ?	Do you feel more angry or irritated these days?	79	52
6	एखादी गोष्ट मनातून जात नाही व त्याचा त्रास होतो असे आहे का ?	Do you constantly find yourself pondering/brooding upon something which is causing distress to you?	59	38.8
7	वरचेवर किरकोळ आजारपण सुरू असते का (उदा. अगदुखी, डोकेदुखी, मुकेवर परिणाम, वजन कमीजास्त, बायकाना पाळीचा त्रास, इ.) ?	Do you frequently have minor physical ailments? (e.g. body ache, headache, change in appetite, change in body weight, menstrual problems in women etc.)	84	55.3
8	मद्य (दारू) किंवा इतर काही नश्याचे पदार्थ (उदा. गाजा-भाग, छस, इ.) घेता का ?	Do you habitually consume alcohol/ narcotic drugs?	0	0
9	भास होणे, सशय घेणे किंवा विमनस्क मनःस्थिती असा काही प्रकार आहे का ?	Do you often feel suspicious/distracted or have illusions?	22	14.5

In other words, if a screening test result is positive, i.e the score on CBMSQ is 3 or above, there is 57% chance of that person actually having at least one CMD. Whereas if a person scores less than 3 on CBMSQ i.e. if the test result is negative there is 89 percent chance of person actually not having any CMD. The overall correct classification rate was 0.71 i.e. the tool was 71% in agreement with MINI diagnosis.

Figure 4 Cut off for CBMSQ

Figure 3 ROC Curve for CBMSQ for any CMD



Internal consistency, as assessed by drawing Kuder Richardson 20 (KR 20) (for dichotomous outcomes) index was seen to be high (KR 20 - 0.81) suggesting high internal consistency. Receiver operating characteristic (ROC) was plotted (fig 4.) to assess case detection properties of CBMSQ against ICD 10 diagnoses by MINI. Area under the curve (AUC) was found to be 0.791 [CI 0.718, 0.865] suggesting fair to good diagnostic accuracy.

Table 5 Sensitivity, Specificity, Positive Predictive Value, Negative Predictive Value, Area Under the Curve, Positive and Negative likelihood ratio for each possible cut off on CBMSQ.

Score	Sensitivity	Specificity	PPV	NPV	AUC	PLR	NLR
1	0.96	0.23	0.41	0.92	0.594	1.25	0.16
2	0.94	0.42	0.48	0.93	0.681	1.64	0.13
3	0.85	0.64	0.57	0.89	0.742	2.36	0.23
4	0.72	0.71	0.58	0.82	0.713	2.50	0.39
5	0.59	0.81	0.64	0.78	0.699	3.19	0.50
6	0.43	0.90	0.70	0.74	0.657	4.13	0.64
7	0.20	0.98	0.85	0.69	0.587	9.88	0.81

Burden of HIV caregiving

Burden of providing care to HIV infected husband was assessed using structured questionnaire that was adopted for this project.

About the tool

The tool was developed with the view that in a serodiscordant setting, unlike other illnesses, an informal caregiving assumes a broader meaning and measures burden and its impact on women. Accordingly, the burden of caregiving was measured in 8 major domains of life. viz.,

1. Burden of change in family and social relations
2. Burden of women's negative feelings towards husband
3. Burden of perceived low efficacy
4. Burden of care recipient's dependence for daily activities

5. Impact on physical health
6. Impact on emotional health
7. Burden of fear of transmission
8. Financial burden

The timeframe of items was last one month. Different modules of questions were developed to measure each domain. The questionnaire contains total 34 items with responses as Never (1), Seldom (2), Sometimes (3), Most of the time (4) and Always (5). Additionally for every question women were asked to report if the burden is perceived to be related to HIV of the husband.

Scores for all the questions in each module were added and the final score was dichotomized according to the median of observed scores as high burden = score above median and low burden = score below median. Chi square test was used to see the relationship between caregiving burden and presence of any CMD.

Burden attributable to HIV

When the participant experiences the burden and when she perceives it to be related to HIV then it is considered as burden attributable to HIV. All the items were followed by question of relatedness of the response with husband’s HIV status. The responses were dichotomized as 1) related to HIV and 2) not related to HIV. Additionally, a single question was asked at the end of the questionnaire where women were asked to rate their perceived level of caregiving burden in a five point scale.

Results

Most of the women (63.1%) perceived burden of caregiving. Of the total, 36.9% of women rated perceived burden of caregiving to be of moderate or severe level. Table 6.

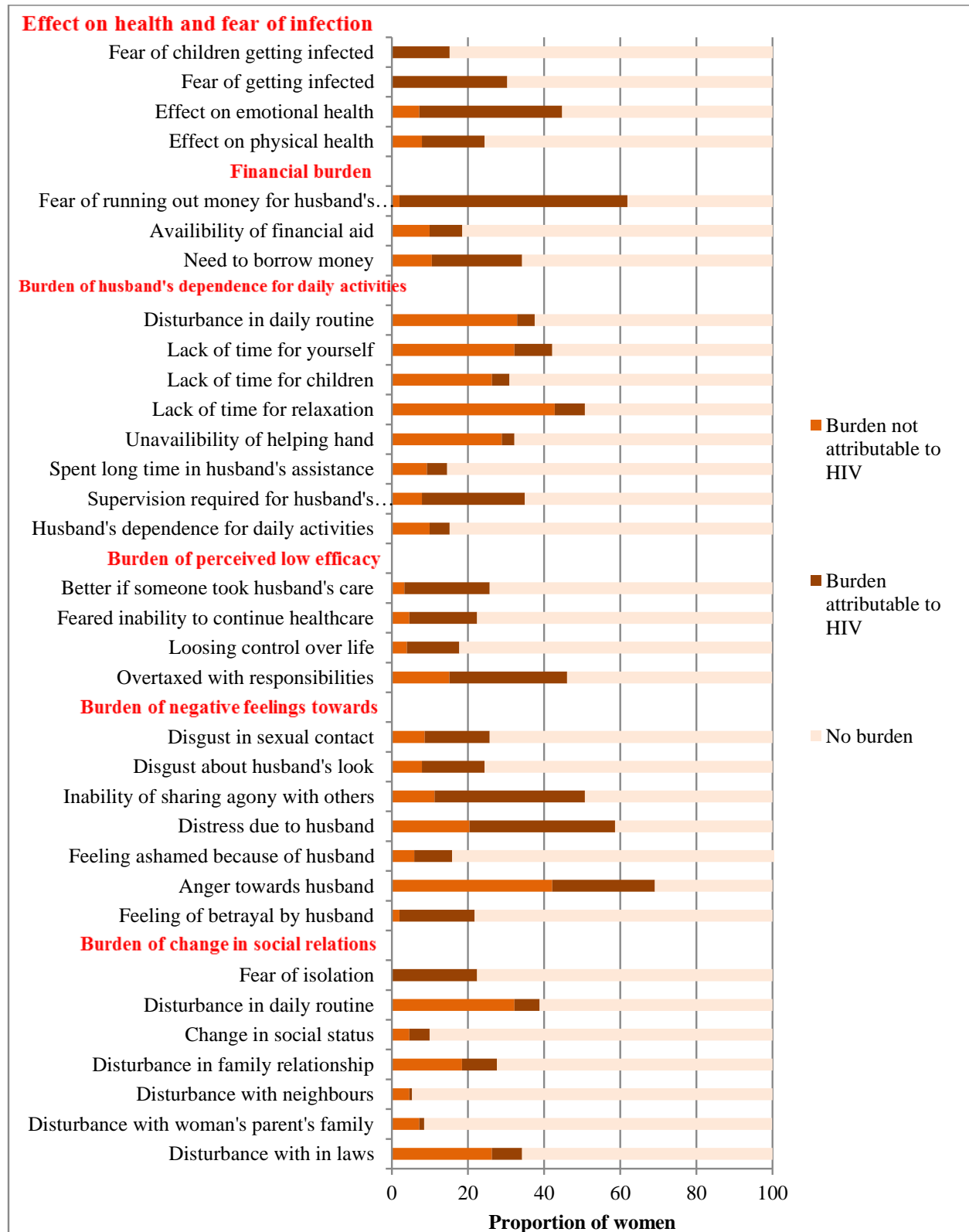
Table 6 Perceived level of burden as rated by women

Perceived level of burden	N (%)	CMD N (%)	p value
Not at all	32 (21.1)	1(0.65)	0.000
Cannot tell	24 (15.8)	9 (5.9)	
Mild	40 (26.2)	13 (8.5)	
Moderate	29 (19.1)	13 (8.5)	
Severe	27 (17.8)	18 (11.8)	

The item wise distribution of burden of caregiving and burden attributable to HIV is presented in figure 6.

Fear of running out of money, feeling of anger/resentment towards husband, feeling overtaxed with responsibilities, inability of sharing agony with other were some of the important contributors for perceived burden related to HIV status of the husband.

Figure 5 Burden of HIV caregiving



Majority of women reported burden of negative feelings towards husband. This underlines the complex nature of relationship between care recipient and caregiver in case of sero-discordant couples. Burden reported in all the domains were significantly related to presence of CMD except financial burden and burden of care recipient's dependence for daily activities. (Table 7)

Table 7 Burden of caregiving and its relation with CMD

Domain	High burden N(%)	CMD present N(%)	p value
1. Burden of change in family and social relations	74 (48.6)	38 (70.4)	0.000
2. Burden of women's negative feelings towards husband	76 (50)	42 (77.8)	0.000
3. Burden of perceived low efficacy	63 (41.4)	38 (70.4)	0.000
4. Burden of care recipient's dependence for daily activities	69 (45.3)	27 (50.0)	0.397
5. Impact on physical health	27 (17.7)	17 (31.5)	0.001
6. Impact on emotional Health	55 (36.1)	33 (61.1)	0.000
7. Burden of fear of transmission	53 (34.8)	30 (55.6)	0.000
8. Financial burden	67 (44.0)	27 (50.0)	0.275

Caregiver's perception of illness

Illness cognition has been given due importance in literature hitherto. It is believed that the way individuals perceive their illness provides a framework based on which they comprehend their symptoms, evaluate their health risks and accordingly take actions to cope up. In case of caregivers, the perception of illness can have an impact upon level of distress felt by them in many ways. (Barrowclough, Lobban et al. 2001) For example beliefs such as; illness is going to last for long time; illness is not controllable by treatment; the patient can have greater personal control over the illness; patient as well as caregiver have to suffer negative consequences due to illness and the illness provokes painful emotions such as anxiety and fear; may result in significant amount of distress among caregivers. (Rexhaj, Python et al. 2013)

The different techniques used in research to assess the illness perception have identified five major cognitive themes around which most of the patients build their ideas about illness. These are –

1. Identity - which is comprised of the label of the illness and the symptoms the patient views as being part of the disease

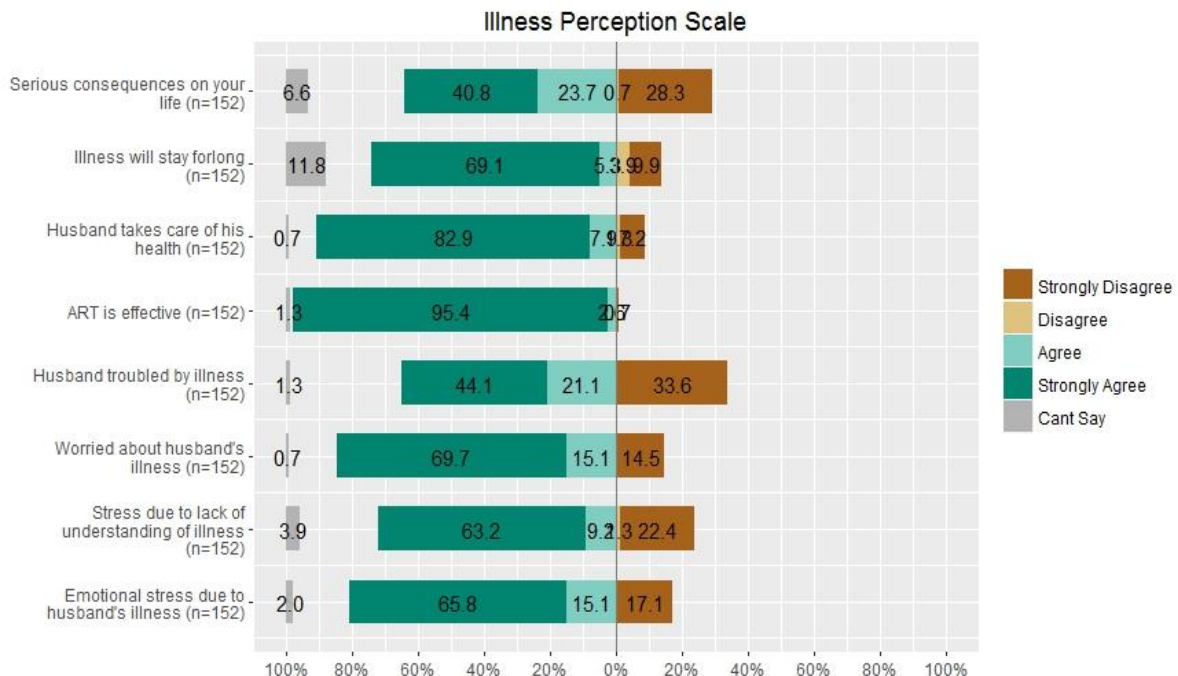
2. Cause - personal ideas about etiology which may include simple single causes or more complex multiple causal models
3. Time-line - how long the patient believes the illness will last. These can be categorized into acute, chronic or episodic
4. Consequences - expected effects and outcome of the illness
5. Cure/control - how one recovers from, or controls, the illness.

The brief illness perception questionnaire (Broadbent, Petrie et al. 2006) was modified with respect to HIV caregiving to understand the meaning women ascribe to the condition and how they perceive its impact on their lives. The scale measures 7 domains of illness perception viz. Consequences, timeline, personal control, treatment control, concern, understanding, and emotional response.

Interpretation: The responses are in five point Likert scale. When combined together, the total score indicates severity of illness perceived by respondent, meaning higher the score, more is the perceived severity of illness. The total score was calculated to see the difference of mean score of those having and those not having CMD.

Figure 7 illustrates the illness perception of women in different domains. The emotional stress due to husband’s illness and lack of understanding about it was reported by 65.8 and 63.2 percent women respectively. Majority (95.4%) of women believed that ART is an effective treatment to curb their husband’s illness. Though majority of the women seem to perceive that HIV will last

Figure 6 Likert scale distribution of all the items in IPS



for a long time there were approximately 12% of women who did not believe so which could be out of hope that soon there might be cure for HIV.

The mean score of illness perception scale is significantly related to having CMD among women (Table 9)

Table 8 Illness Perception Scale score and its relation with CMD

Tool	Range	Mean (SD)	CMD - Mean (SD)	No CMD - Mean (SD)	p value
IPS	0 to 32	17.8 (7.4)	21.8 (4.2)	15.7 (7.9)	0.000

Life events

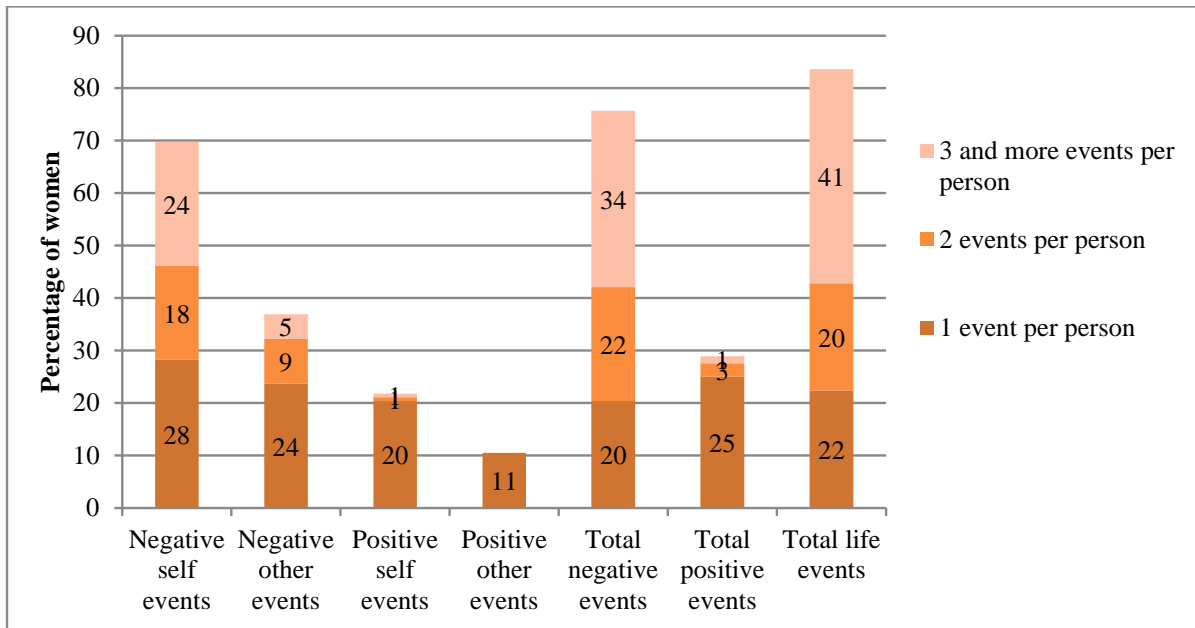
Life events checklist (LEC or LEL) (Irwin G. Sarason 1978) was used to understand the correlation between life events experienced in last one year (other than HIV disclosure) and CMDs.

LEC is a short self-administered questionnaire which assesses exposure to 22 life events out of which both negative and positive events happened with self and closed ones are counted along with the rating of distress associated with the events.

Results –

Figure 8 presents number of women who experienced different types of life events in last one year. The number of negative events was higher than positive ones in both self-experienced events and those experienced by the significant others as well as in total. Also the events experienced by self were more in number than those experienced by others.

Figure 7 Proportion of women reporting number and types of life events experienced in last one year



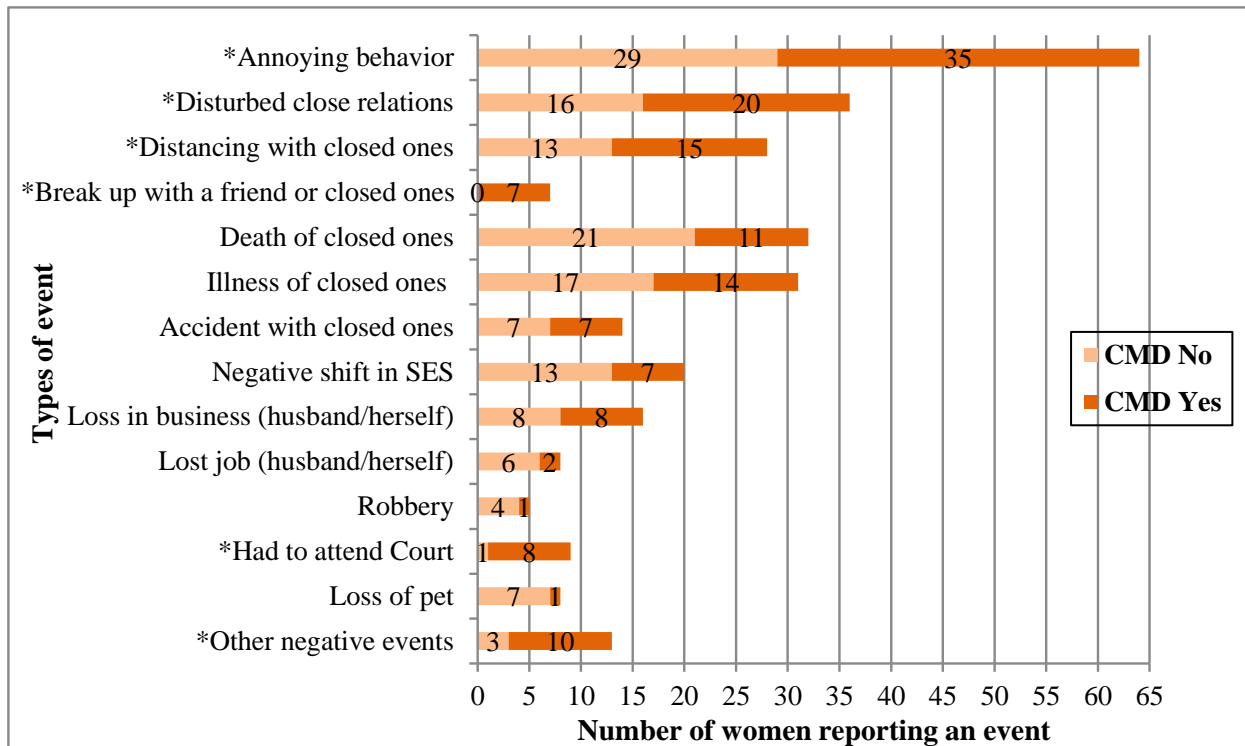
Highest prevalence of CMD was seen among those who had faced at least 3 negative life events in last one year. Significant relation was seen between a history of negative life event and presence of any CMD. See table 9.

Table 9 Negative life events in last one year and its relation with CMD

Negative life events	N (%)	CMD N (%)	p value
No negative life event	38 (25.0)	8 (14.8)	0.000
One	31 (20.4)	5 (9.3)	
Two	35 (23.0)	12 (22.2)	
Three and more	48 (31.6)	29 (53.7)	

Figure 9 illustrates the events that commonly happened in last year. It can be seen that most of the events revolved around disturbances in the personal and social relationships and were significantly associated with CMD along with the event of attending court and other events deemed significant by women.

Figure 8 Types of negative life events with association with CMD



*= $p < 0.05$

Change in satisfaction about social support

The **Social Support Questionnaire (SSQ)** the short version (Irwin G. Sarason 1983) was used to quantify the availability and satisfaction with social support that an individual has. The tool presents certain life situations in which respondents were asked to enumerate number of people on whom they can really count upon to provide support and to rate their satisfaction about available support. The composite score for availability of the support (SSQN) was drawn by adding number of people available in all the situations and dividing it by number of items. The satisfaction about available support score (SSQS) was calculated by adding all the rating of satisfaction and dividing it by number of items.

Additionally, women were asked to enumerate number of people available to provide support and rate their satisfaction for the similar situations before and after knowing about husband's HIV status. The aim was to assess change in availability and satisfaction of social support before and after disclosure of husband's HIV status to women.

Results –

The mean SSQN depicting availability of social support was increased slightly after disclosure from 1.58 to 1.68; the difference being non-significant Table (10). However the satisfaction of available social support as shown by mean SSQS had been significantly reduced after the

disclosure of husband’s HIV status to women. Figure 10 shows the proportion of women reporting change in social support after the disclosure. As can also be seen in the figure, the significant proportion of women reported reduction in satisfaction about the social support after disclosure of HIV to them.

Figure 9 Proportion of women reporting change in availability and satisfaction of social support after disclosure of husband’s HIV status

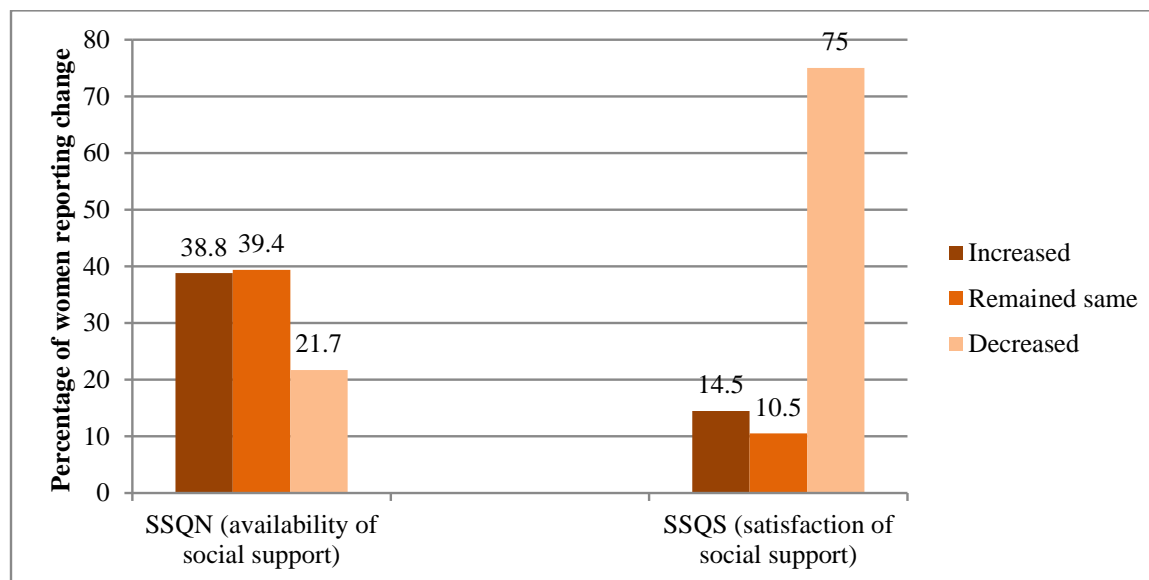


Table 10 Comparison of SSQN and SSQS before and after disclosure of husband's HIV status

Score	Before disclosure (Mean)	After disclosure (Mean)	p value
SSQN (availability of social support)	1.58	1.62	0.244
SSQS (satisfaction of social support)	1.65	1.48	0.000

The information about disclosure of husband’s HIV status among the people who are providing social support was not available hence the change in social support after HIV status of the husband could not be fully explained. However, lower satisfaction with the available social support indicates lack of spaces where women can speak about actual stressors and get support.

Self-efficacy

Perceived Self-Efficacy Scale is designed to assess optimistic self-beliefs to cope with a variety of difficult demands in life (Schwarzer 1995)

The tool has total 10 items. Responses are coded as 1 = not at all, 2=sometimes, 3=most of the times, 4=always. There is no specific recall period.

Figure 11 shows item wise distribution of general self-efficacy scale.

The mean score for study population (30.9) is comparable with many samples in literature (29). (Schwarzer 2014)

The median score was 30.5. When women were classified of having high and low self-efficacy according to the score below and above the median, significantly higher number of women having low self-efficacy had CMD in current situation. (Table 12)

Figure 10 Item wise distribution of general self-efficacy scale

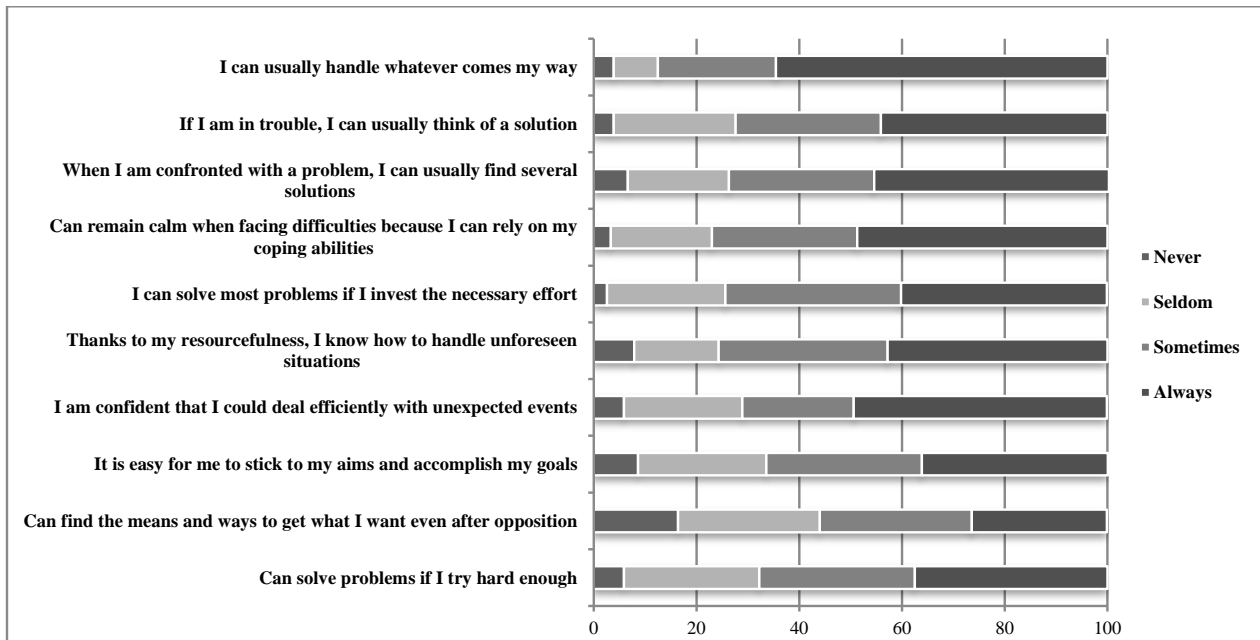


Table 11 Level of self-efficacy with its association with CMD

Self-efficacy	CMD N(%)	p value
High (score above median) n=76	20 (37.0)	0.027
Low (score below median) n=76	34 (63.0)	

Cross-checking of CMD diagnosis

MINI is a diagnostic tool and hence is subject to interpretation on the person administering the tool. In order to cross-check the data coming from MINI regarding the prevalence of CMD, we administered standardized tools and co-related them with MINI diagnosis.

1. Centre of Epidemiological Studies Depression (CESD) Scale -

Centre for epidemiological studies scale is a standard tool for screening depression. (Santor 1997) This tool was used for cross checking the diagnosis on MINI. The tool has total 20 items in it

having responses in Likert scale. The possible range of score is zero 60 and the standard cut off is score of 16.

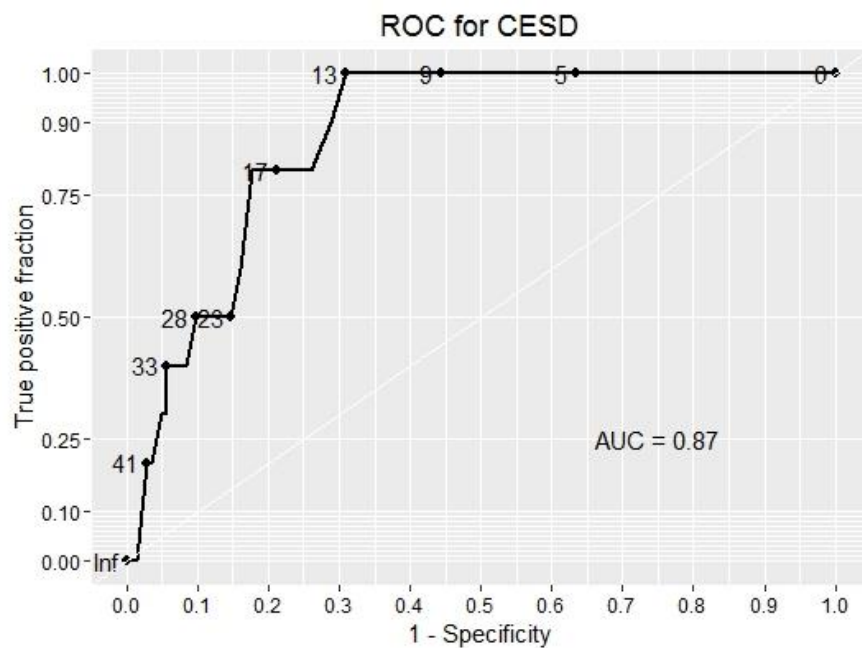
According to this scale 51 (33.6%) women were screened positive for Major depressive episode (MDE) out of which 10 women were diagnosed of having MDE according to diagnostic tool MINI. This yielded the sensitivity of tool to be 83%. The tool identified 101 women as not having MDE out of which only 2 women were diagnosed as having MDE on MINI. This gave specificity of 80%. Receiver operating characteristics curve (ROC) was drawn for the tool with respect to standard tool MINI for only MDE. The area under the curve was 0.902. These results are comparable with other studies.

The results were coherent with diagnosis by clinical psychologists using MINI. The results also suggest that CESD can be effectively used to screen depression among the study population in clinical setting.

Table 12 Centre for Epidemiological Study Depression (CESD) score and its association with CMD

CESD screening result	N (%)	MDE diagnosed on MINI N(%)	p value
Screened positive for MDE	38 (25.0)	8 (14.8)	0.000
Screened negative for MDE	114 (75.0)	2 (3.7)	

Figure 11 Centre for Epidemiological Study Depression (CESD) score and its association with CMD



2. Perceived stress scale –

The Perceived Stress Scale (PSS) is the most widely used psychological instrument for measuring the perception of stress. (Cohen, Kamarck et al. 1983) It is a measure of the degree to which situations in one's life are appraised as stressful. The scale seeks to measure current level of stress experienced by respondents and how unpredictable, uncontrollable and overloaded they perceive their life. The questions in the PSS ask about feelings and thoughts during the last month. In each case, respondents were asked how often they felt a certain way.

There are 10 items in the tool with Likert scale responses, total scores are obtained by reversing responses (e.g., 0 = 4, 1 = 3, 2 = 2, 3 = 1 & 4 = 0) to the four positively stated items (items 4, 5, 7, & 8) and then summing across all scale items. Higher scores indicate higher perceived stress.

Results –

While the mean score on PSS was comparable with other studies carried in general population (13.7)(Cohen 1994), PSS mean score was seen to be significantly higher among those having CMD than those not having CMD, thus supporting the diagnosis of CMD.

Table 13 Perceived stress scale score and its association with CMD

Range	Mean (SD)	CMD Mean (SD)	No CMD Mean (SD)	p value
0 to 40	13.8 (7.4)	18.1 (7.4)	11.4(6.4)	0.000

3. Sheehan Irritability Scale

Common mental disorders especially depressive disorders are commonly manifested with heightened irritability. (Khan, Revicki et al. 2016). There is established relationship between irritability, anger and frustration with underlying common mental disorders. Hence the construct can be taken as an indicator of presence of CMD especially depression.

Irritability was measured by Sheehan Irritability Scale (SIS). SIS is a short patient reported scale which has been used extensively in depression studies. There are total 8 items. First 7 items have responses in numbers from 0 to 10 (representing percentages e.g. 1 =10% and 10 = 100%). They measure following constructs –

- Irritability
- Frustration
- Edginess/Impatience/Overreaction
- Moodiness
- Anger with self
- Anger with others
- Temper

Recall period is last one week. 8th item measures average number of days suffered in last one week.

Results –

The results suggest that the women having CMD had significantly higher irritability score than those who did not have CMD.

Table 14 Sheehan’s Irritability Scale score and its association with CMD

Tool items	Range	Mean (SD)	CMD Mean (SD)	No CMD Mean (SD)	p value
SIS – First 7 questions	0 to 70	14.5 (13.7)	19.3 (14.9)	11.9 (12.4)	0.001
SIS Question no. 8 (Days affected due to irritability)	0 to 7	1.9 (1.7)	2.5 (1.9)	1.6 (1.5)	0.001

Conclusions

The current prevalence of CMD among HIV uninfected women caregivers living in HIV serodiscordant setting in Maharashtra was as high as 35.5%. While 49.3% of women have had CMD in past, more than half of the women had suffered from CMD at least once after the disclosure of HIV status of the husband to them. The locally developed screening tool for CMD, CBMSQ, appears to be a useful tool with high sensitivity (0.85) and fair to good diagnostic accuracy (AUC=0.791). Burden of HIV caregiving, perceived severity of the illness, negative life events in recent past, perceived reduction in satisfaction of social support after the disclosure of husband’s HIV status, low perceived self-efficacy, perceived level of stress and irritability seem to have significant association with current CMDs among the women.

The observed prevalence appears to be significantly higher than that found among the general population (10%) in India (Gururaj G, Shibukumar TM et al. 2016) which highlights the vulnerabilities of this group and the need for immediate attention and care. The observed pattern of CMDs also differs from that seen in community based Indian population with substantially high prevalence of posttraumatic stress disorder, suicidality and other anxiety disorders. The considerably high prevalence of posttraumatic stress disorder around the time of disclosure of husband’s HIV status suggests the severity of psychological trauma of disclosure.

Apparently the socio-demographic characteristics of the women do not seem to have any correlation with CMDs suggesting that the vulnerabilities of these women and the possible coping strategies are beyond the socio-demographic differences. This also underscores the need to investigate further why certain women were able to cope with the stress of knowing husband’s HIV status (as resulted in no CMDs) compared to women who had repeated CMDs.

Currently there is no focus on diagnosis and treatment of mental illnesses of HIV infected and affected people. One of the barriers is lack of short, effective and validated screening tool to identify people who are in need to care. This is the first study from India to validate a screening tool among this population. The screening tool CBMSQ is comparable to the other screening tools validated in India e.g. PHQ-9, GHQ-5, GHQ-12, SRQ-20, K-6, K-10 (Ali, Ryan et al. 2016) in many aspects such as diagnostic accuracy, internal consistency and shortness. The tool is culturally appropriate, less time consuming, easily administered and requires negligible amount of training for administration. The dichotomous nature of responses facilitates avoidance of social desirability bias.

The statistically significant association of CMDs with perceived burden of caregiving in different domains of life highlights the stress of living in a serodiscordant setting in general and caregiving to the HIV infected husbands in particular. The severity of HIV infection as perceived by the women caregivers and perceived self-efficacy might have effect on their coping with the illness. Previous studies have shown the effect of stress caused by life changes, especially undesirable ones, on emotional health of individuals. (Irwin G. Sarason 1978). The similar findings of the study suggest that higher prevalence of CMDs among the study population can be explained by presence of additional stressors revolving around HIV apart from the daily life hassles and stressful life changes faced by general population.

The protective role of social support among HIV infected people in coping with challenges imposed by HIV has been shown in various studies. However, the literature on HIV/AIDS has more focused on the HIV positive individuals with more emphasis upon its effect on adherence and risk behavior rather than the HIV negative ones in the couple, for whom it may also be difficult to find or receive support. (Pacheco 2013) The significant reduction in satisfaction women felt about the social support after the disclosure of husband's HIV status could also affect coping with the stressors.

The prevalence is based upon the diagnosis of CMDs by psychiatrist and clinical psychologists and the diagnosis can be said to have high accuracy which is evident through the results of the three other tools used to validate the data viz. CESD, PSS and SIS. The 95% confidence interval of observed prevalence is 28% to 44%. Although the interval is wide, the lowest value of 28% is way higher than that observed in the general population thus underlining the mental health needs of the study population.

One of the limitations of the study could be representativeness bias inherent in the clinic based studies; However community based studies among HIV infected and affected population are difficult. The characteristics of those women who participated and who or their husbands refused to participate could not be compared, thus making it difficult to comment on the prevalence of CMD among those who refused to participate. Nevertheless we estimate it to be similar or even higher owing to the fact that the major reason for refusal was the hesitation on the part of men to discuss about their HIV status and fear of resurfacing the troubling issues.

Such a high prevalence of CMD among the study population calls for immediate attention on the policy and programme level to address the mental health needs of this population. There is a need of shifting the focus from just prevention of transmission of infection among serodiscordant couples to comprehensive care to the affected persons.

Prevalence of psychiatric morbidities is very high even among HIV infected people. No screening tool for CMD has been validated among HIV infected people in India. The existing structure to address mental health issues of HIV positive people is inadequate to address the tremendous burden of mental health needs of both HIV infected and affected people. The need is to bring mental health at the forefront of HIV care policy agenda involving equally both infected and affected.

Recommendations -

1. Various stakeholders involved in the care of HIV infected and affected individuals at multiple levels should be brought together for a steering discussion to explore possible interventions to prevent, diagnose and manage CMDs among HIV infected as well as affected individuals.
2. One of the possible ways could be to adopt a screening tool validated in the study after training counselors at ART centers and to administer the screening tools periodically to both HIV infected and affected.
3. The ART physicians should be trained to diagnose CMD, provide primary mental health care and identify need for further referral. One of the possible ways to achieve this could be to develop and validate the algorithms of treating CMDs at primary level. Further referral linkage could be integrated with existing mental health programme.
4. The screening tool for CMD should be validated among HIV infected people. Further research should focus more on understanding the dynamics of living in serodiscordant setting and designing intervention strategies.

Summary

Objectives: 1. To understand prevalence and pattern of common mental disorders (CMD) among HIV uninfected women caregivers living in HIV serodiscordant setting in Pune, Maharashtra. 2. To validate CBMSQ - a brief screening tool for CMD among the same population.

Methods: Between April 2015 to September 2016, 152 HIV uninfected women caregivers who are wives of HIV infected men attending Prayas Amrita Clinic were interviewed by trained clinical psychologist and psychiatrist. The ICD 10 diagnosis of any of the CMDs was done using standard structured diagnostic interview MINI 5.0.0. Various standardized tools were adopted to study the correlates of CMD. Current, past, lifetime and after HIV disclosure prevalence was drawn for CMD. The screening tool was validated and cut off was calculated.

Results: The study found 35.5% current, 49.3% past, 62.5% lifetime prevalence of at least one CMD among the study population with commonest diagnoses as mixed anxiety depressive disorder, major depressive disorder and posttraumatic disorder. High to moderate suicidality was seen among 12 women. The screening tool showed good diagnostic accuracy with AUC 0.791. At the best suited cut off of 3, the tool yielded 85% sensitivity and 64% specificity. Internal consistency as measured KR20 was 0.81. Burden of HIV caregiving, perceived severity of the illness, negative life events in recent past, perceived reduction in satisfaction of social support after the disclosure of husband's HIV status, low perceived self-efficacy, perceived level of stress and irritability were found to have significant association with current presence of CMDs among the women.

Conclusion: Significantly higher prevalence and different pattern of CMD among the women caregivers living in HIV serodiscordant setting in India highlights their vulnerabilities and calls for immediate attention and need for strategic shift of focus from mere prevention of HIV transmission among serodiscordant couples to comprehensive mental health care for both infected and affected.

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Appendix

Past History Module for PTSD

J1. Have you ever experienced or witnessed or had to deal with an extremely traumatic event that included actual or threatened death or serious injury to you or someone else?

J2. Did you respond with intense fear, helplessness or horror?

J3. Had you experienced this traumatic event (you mentioned above) in a way (such as dreams, intense recollections, flashbacks or physical reactions)? How many days/months after the event?

J4. At that time when you had this traumatic experience:

- a. Had you avoided thinking or talking about the event (that particular event) during that period?
- b. Had you avoided activities, places or people that were reminding you of that event during that period?
- c. Had you had trouble recalling some important part of what happened (about that particular event) during that period?
- d. Had you become much less interested in hobbies or social activities during that phase?
- e. Had you felt detached or estranged from others in that period?
- f. Had you noticed during that phase that your feelings are numbed?
- g. Had you felt that your life will be shortened or that you will die sooner than other people during the same phase?

J4 (summery): Are 3 or more J4 answers coded YES?

J5. At that time when you had this particular traumatic experience:

- a. Had you had difficulty sleeping in that period?
- b. Were you especially irritable or did you had outbursts of anger during that period?
- c. Had you difficulty concentrating in that phase?
- d. Were you were nervous or constantly on guard in that phase?
- e. Were you easily startled during that phase?

J5 (summery): Are 2 or more J5 answers coded YES?

J6. During that particular period/phase had these problems significantly interfered with your work or social activities, or caused significant distress?

If J6 is coded YES-

How many days/months all these trouble/symptoms were going on after the event?