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AN ASSESSMENT STUDY OF FELT NEEDS OF PLWHA ATTENDING AN URBAN HEALTH CENTRE

Suryawanshi D. M¹, Panchal S², Shinde R. R³

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ABSTRACT: BACKGROUND: The global HIV pandemic has shown signs of slowing. Advent of Anti-retroviral drugs have increased the longevity of People living with HIV/AIDS (PLWHA). Increase in Longevity brings forth multiple issues like stigma, discrimination, lack of accessibility to basics facilities and health care. The needs of PLWHA differ from the general population, so the study was conducted to assess the felt needs of PLWHA. **OBJECTIVES:** 1) Study the socio-demographic profile of PLWHA. 2) Identify the epidemiological factors that influence their HIV status. 3) Assess and prioritize the felt needs of the PLWHA. **MATERIAL AND METHODS:** The study was a descriptive cross sectional Study conducted on PLWHA in ICTC of an urban health centre of a tertiary care institute during June 2009 to May 2010. 200 PLWHA were interviewed using a semi structured open ended questionnaire. Data was sought on socio demographic profile, discrimination, priority needs and access to care and support services. Chi-square was applied as the Test of significance at appropriate places. **RESULTS:** 96% of Study subjects had disclosed their HIV status to their spouse and near relatives. 38 % gave history of discrimination by family, 22% were told to leave the house and 20% respondents were forced to eat of other utensils. Comparison between male, female showed no discrimination based on gender ($p > 0.05$). 47% of respondents felt financial as a priority need, 34% as psychosocial, and 17% had multiple needs. 12% of study respondents had access to free treatment services.

KEYWORDS: PLWHA: People living with HIV AIDS, UHC: Urban Health centre.

INTRODUCTION: Globally, an estimated 35.3 (32.2–38.8) million people were living with HIV in 2012. There were 2.3 (1.9–2.7) million new HIV infections globally, showing a 33% decline in the number of new infections from 3.4 (3.1–3.7) million in 2001..The annual number of new HIV infections continues to decline, with especially sharp reductions in the number of children newly infected with HIV. Increase longevity has given rise to new issues like amelioration of stigma and discrimination associated with PLWHA and their felt needs.⁽¹⁾

Stigma and discrimination remain common in many parts of the world; numerous studies have linked HIV-related stigma with non-disclosure to partners and poor engagement with HIV services. People who experience stigma and discrimination report loss of income, isolation from communities and inability to participate as a productive member of society as a result of their HIV status.⁽¹⁾

When the human rights of People living with HIV/AIDS (PLWHA) people are not protected, they suffer stigma and discrimination, unable to support themselves and their families, and if not provided treatment, they die ⁽²⁾. In such a situation, care and support needs of PLWHA include access to health care, financial assistance for daily necessities, and some security for survivors. The new concept of 'comprehensive care involves the major components of clinical care, psychological support

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(Counselling), socioeconomic support, and support for human and legal rights of People affected by HIV/AIDS.⁽³⁾

People living with HIV have a wide range of care and support needs. These include psychosocial support as well as treatment for 'opportunistic infections' (Financial assistance). AIDS-related care and support are key elements in the response to the epidemic, not only do they directly benefit people living with HIV, but they help also to reduce the social and economic impact of the epidemic and to boost HIV prevention.⁽⁴⁾ Therefore, primarily, this study was conducted to assess HIV/AIDS needs, care and support services.

MATERIAL AND METHODS: The study was a Descriptive cross sectional study carried out during June 2009 to May 2010, in the integrated counseling and Testing Centre (ICTC) of an urban health centre (UHC). The UHC is situated in an urban slum of Mumbai city and comes under the field practice area of a Tertiary care institute. The study was conducted on enrolled and eligible follow-up PLWHA by universal sampling technique. It means that all the eligible PLWHA were included in the study. Before commencement of study, appropriate consent from the participants was taken. During the study period 263 PLWHA followed up in the ICTC of the urban health centre, 29 refused to give consent for the study, 24 were diagnosed as positive with less than 6 months of illness. 10 were suffering from terminal AIDS complex. So the total sample size was 200. With the help of the counsellor, rapport was build, the objectives of the study were explained and the informed consent was taken in their local language of those who were willing to participate in the study.

PLWHA were asked to follow up on the same day or on a particular day, and they were interviewed by the investigator. PLWHA who gave consent, PLWHA who belonged to study area who were regularly following up in the ICTC for past one year and PLWHA who were positive for more than 12 months were taken as study subjects. More than 12 months period was taken as a cut off point for the enrolment of the study subjects because the participants were asked questions based on their past 12 months experiences. This period was presumed to be minimally adequate to crystallize the needs of the PLWHAs. Data was collected by a semi structured questionnaire which was initially pilot tested and administered in appropriate language which the study respondents could understand. Data on Base line demographic information, epidemiological factors responsible for susceptibility to HIV infection and data on felt needs of PLWHA was collected. Questions on felt needs were kept open ended so that Study subjects were able to voice their needs freely.

RESULTS: In the Present study, Out of the 200 study respondents attending the ICTC, 136(68%) were male and 64 (32%) females. The mean age of respondents in the study was 37 years with a standard deviation (SD) of 8.3 years, minimum age of 15 years and maximum of 60 years. Maximum respondents 81 (41%) were from the age group of 36 to 45 years. Majority of respondents 160 (80%) belonged to Hindu religion.

Maximum respondents 151(76%) were married, 30 (15%) Single, 17(9%) widowed and 2 (1%) divorced. Majority of the respondents, 74(37%) were educated till primary level, majority 117(59%) of them were semiskilled labourers with 176(88%) having a Per capita Income of 500 to 1000 rs /month. In the study, 149(75%) respondents lived in a nuclear family. (Table no 1)

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Epidemiological Factors which Lead to the susceptibility for HIV Infection (Table No.2): In the present study 187 (94%) respondents practiced heterosexuality, 4(2%) homosexuality, while 9 (5%) practiced both heterosexual and homosexual behaviour. 75 (38%) respondents gave a history of high risk behaviour while 35 (17.5%) responded that their partners have indulged in high risk behaviour. 72 (96 %) of the 75 respondents (N 75) gave a history of multiple sex partners. Of the 75, 69 were male, 6 female.

28(14%) Respondents gave a history of sexually transmitted infection in past 6 months. The main STI complaints in decreasing order of frequency were urethral discharge, white discharge per vaginum, followed by swelling on vulva.

Discrimination (Table No 3): In the present study almost all of the study respondents have confided their HIV positive status. Out of the 200 respondents, 99(50%) had first confided their HIV positive status report to their spouses, 53(28%) to a trusted relative, 35(18%) to one of the parent, 3(2%) to a close friend.

43 (21.5%) PLWHA replied that they are facing discrimination at home. Out of those 43, 21 (16.2%) replied that sarcastic remarks are passed against them. 17 (41.8%) replied that they are told to leave house, while 15(34.8%) replied that they are forced to eat of separate utensils. Comparison between male, female showed that there was no discrimination based on gender ($p > 0.05$).

Needs of PLWHA (Table No. 4): Of the 200 study respondents, 142 respondents put forward their priority needs. Out of those 142 respondents, 67(47%) felt Financial need a priority, 48 (34%) replied psychological, 25(17%) replied that their needs were multiple while 2 (1%) people replied that provision of medicines was their priority need.

Financial Need: Out of 67 study respondents who had financial needs as a priority, 34(51%) replied that spending on health care was a priority, 26(39%) replied monthly ration while 7 (10%) replied others needs like spending on travelling and school children expenses.

Majority of study respondents, 176 (88%) were spending from out of pocket for treatment of minor illness. 107(53.5%) respondents were spending between 0-200 Rs per month, 34(17%) were spending around 200-400 Rs/-. 26(13%) on 400-600 Rs/-. and 9 (4.5%) were spending >600 Rs/month. Only 24 (12%) were having access to free treatment services.

Psychosocial Need: Out of the 48 people, who replied psycho-social as priority need, Family, friends support and acceptance by the society were considered as important psychosocial needs.

Sexual Need: Out of the 200 respondents, who were asked whether they continue to have sexual relationship with their partner, 161(80.5%) replied in affirmative?

Out of the 39 respondents who denied having sexual relationship presently, 16 (41%) replied that do not have sexual relationship due to the fear of transmitting HIV infection to the partner, other 16 (41%) replied that they were not in relationship because their spouse had died, other 4 (10.2%) replied of Sexual frigidity and 3(7.6%) replied spouse wanted abstinence. On asked whether they were willing to marry a HIV positive person, 18 (36.7%) PLWHA replied affirmatively.

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Care and Support Groups (Table no 5): In the study, 110 study respondents replied that they have access to various supports groups. Majority of the respondents 86(78%) replied that they have access to informal support groups, 12(%) replied they have access to formal support groups while 12 (%) had access to both.

Type of Support provided (Table no 5): Of the 86 respondents who had access to informal support groups, 38(44%) replied that they provided psychosocial support, 36(42%) responded that they provide both psychosocial and financial support while 12(14%) replied that they provide only financial support.

Of the 12 respondents who had access to formal support groups, 6(50%) replied that they helped both psychologically and financially, 3(25%) replied that it made life better for them, while remaining 3(25%) replied that it provided them psychosocial support.

Integration of Services: Majority of the study respondents 109(54.5%) were against integration of HIV related services with health services of chronic diseases. While 84 (42%) replied that they favour integration of services.

DISCUSSION: The study made an attempt to assess and prioritizes the needs of PLWHA. In the present study it was observed, that the mean age of Study Participants was 37 yrs which is comparable to study done by Adediga MA where the median age respondents was 34 yrs.⁽⁵⁾ In the present study, majority of study respondents were male in contrary to similar studies conducted by Adediga MA⁽⁵⁾ and Folami S Harris⁽⁶⁾ where 63.9% and 69% respondents were females respectively. This may be due to inability of female to disclose their HIV status and seek early care in the study area.

In the present study majority of the study respondents (37%) were educated till primary level. In similar study conducted by Dixit S et al 34.7% were illiterates.⁽⁷⁾ In the Present study 85 % of respondents were earning < Rs 2500. In study conducted by Dixit S et al (88%) had a monthly family income of less than Rs 5000.⁽⁷⁾

In the present study 94% respondents practiced heterosexual behavior. 38% respondents gave a personal history of high risk behavior while 17.5% responded that their partners have indulged in high risk behaviour. 96 % of the 75 respondents (N 75) gave a history of multiple sex partners. 14% of study respondents gave a history of sexually transmitted infection.

Almost all (96%), PLWHA had disclosed their HIV status to their spouse, close family members, parents, sibling, and close friend. In the present study 38% respondents gave a history of discrimination by family members. In the study out of 76(38%) respondents who were discriminated by family members 28% replied that Sarcastic remarks are passed against them, 22% were told to leave the house, while 20% respondents were forced to eat of other utensils.

Comparison between male, female showed that there was no discrimination based on gender ($p > 0.05$). In the present study, 6% of the females who faced discrimination were told to leave house as compared to 15% men. There was no significant difference noted between Male and Female who were told to leave house in the study ($p > 0.05$). This is contrary to the study In the joint study of NACO and UNDP conducted by NCAER where nearly 5.5% of female PLWHA have been asked to leave home in comparison to only 1.9% of male PLWHA.⁽⁸⁾

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None of the PLWHA had faced work place discrimination or they were removed from job because of their HIV positive status. This may be, because the PLWHA had not revealed their status to the Employer or their colleagues at their work place. In the joint study of NACO and UNDP conducted by NCAER 74% of respondents did not disclose HIV status at work place.⁽⁸⁾

In the present study out of 142, 47% of respondents felt Financial as a priority need, 34% had psychosocial, and 17% replied that they were multiple while 1% replied that provision of medicines was their priority need. The present finding is similar to study conducted by UNDP Gambia, where financial support was most common perceived need of the PLWHA.⁽⁶⁾ In the present study, 80.5% of study respondents replied that they still continue to have sexual relationship with their partners while 9% were willing to get married. The present finding is comparable to the study done in Sao Paulo, Brazil, where out of the 250 men living with HIV, 80% of men wanted sexual relationships and 43% wanted more children.⁽⁹⁾ In the present study psychosocial needs was felt needs of 34% respondents. In a similar study Uwimana J in Rwanda (2007), 77% felt psychological needs, needs for financial assistance and medical needs as important needs.⁽¹⁰⁾

In the Present study spending on health care was the priority financial need followed by monthly ration and others like spending on travelling and children's school expenses. Only 12% of study respondents had access to free treatment services. In the present study family, friends support and acceptance by the society were considered as important psychosocial need by the study respondents.

In the present study, 55% study respondents had access to various supports groups. Majority of these respondents (78%) had access to informal support groups. These supports groups provided both Psychosocial and financial support to the study respondents. In study conducted by UNDP Gambia almost half (46%) of PLWHA said that family was their current support system.⁽⁶⁾ All of the PLWHA had registered in the Integrated counselling and testing centre of the Urban health centre. Only 3.5% were aware of the formal support groups (MSW, ICTC, NGOs, Psychologists and PLWHA). The people who were aware of the services were availing services from various formal sources like Medical social workers, ICTC counsellors and NGOs.

They were availing services from the NGO which provided microfinance and ration (food) to eligible PLWHA. PLWHA explained that these support groups provided financial and psychological support and made life better for them. This is comparable to study done by Dixit S et al where 48% of study subjects at Ujjain were getting free ration every month from support groups.⁽⁷⁾

CONCLUSION: PLWHA faced discrimination at home because of their HIV status and face social ostracism which shows knowledge and attitude regarding spread of HIV infection and care of HIV PLWHA is still at a nascent stage in the general population. Financial followed by psychosocial needs were the priority needs of the Study respondents. PLWHA are less aware of formal support groups and prefer access to Informal support services. Presently Integration of HIV linked health services with other chronic diseases is not favoured. Sexual and reproductive needs of PLWHA remain unaddressed.

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		Female (n =64)		Male (n =136)		Total	
		n	%	n	%	n	%
Age	< 15	0	0	1	1	1	1
	16 - 25	7	11	5	4	12	6
	26 - 35	31	48	48	35	79	40
	36 - 45	22	34	59	43	81	41
	46 - 55	4	6	18	13	22	11
	56 - 65	0	0	5	4	5	3
	Total	64	100	136	100	200	100
Religion	Hindu	51	80	109	80	160	80
	Buddhist	6	9	15	11	21	11
	Muslim	5	8	4	3	9	5
	Christian	2	3	7	5	9	5
	Sikh	0	0	1	1	1	1
	total	64	100	136	100	200	100
Caste (N 154)	Others	10	20	32	31	42	27
	OBCs	35	69	56	54	91	59
	SCs	6	12	15	15	21	14
	Total	51	100	103	100	154	100

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Marital status	Married	46	72	105	77	151	76
	Single	4	6	26	19	30	15
	Divorced	1	2	2	1	2	1
	Widowed	13	20	3	2	16	8
	Total	64	100	136	100	199	100
Education	Illiterate	20	31	23	17	43	22
	Primary	21	33	53	39	74	37
	Secondary	18	28	47	35	65	33
	Higher Secondary	3	5	5	4	8	4
	Graduate	2	3	7	5	9	5
	PG	0	0	1	1	1	1
	Total	64	100	136	100	200	100
Occupation	Unemployed	0	0	16	12	16	8
	Housewife	40	63	0	0	40	20
	Unskilled	14	22	12	9	26	13
	semiskilled	10	16	107	79	117	59
	Skilled	0	0	1	1	1	1
		64	100	136	100	200	100
Income/month	1 - 500	6	11	14	10	20	10
	501 - 1000	24	42	53	39	77	40
	1001 - 1500	12	21	26	19	38	20
	1501 - 2000	6	11	15	11	21	11
	2001 - 2500	1	2	6	4	7	4
	2501+	8	14	21	16	29	15
		57	100	135	100	192	100
Job Migration	Yes	7	11	24	18	31	16
	No	57	89	112	82	169	85
		64	100	136	100	200	100
Sexuality	Heterosexual	64	100	123	90	187	94
	Homosexual	0	0	4	3	4	2
	Both	0	0	9	7	9	5
	Total	64	100	136	100	200	100

Table No 1: Socio Demographic Characteristics of Study Participants

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		Female	Male	Total	%	P value
Chronic illness (n= 26)	Tuberculosis	8	13	21	80.7	P > 0.05
	Hypertension	0	4	4	15.3	
	Diabetes	1	0	1	3.8	
	Total	9	17	26	100	
H/o High Risk behavior(n = 200)	Yes	6	69	75	37.5	p< 0.05
	Denied	58	67	125	62.5	
	Total	64	136	200	100	
a) Multiple sex partners (n = 75)	Agreed	3	69	72	96	p > 0.05
	Denied	3	0	3	4	
	Total	6	69	75	100	
b) Presence of STI (n = 200)	Agreed	9	19	28	14	p > 0.05
	Denied	55	117	172	86	
	Total	64	136	200	100	

Table 2: Epidemiological factors affecting susceptibility

		Female	Male	Total	%	P value
First report confided (n =198)	Spouse	28	71	99	50	P > 0.05
	Parents	16	19	35	17.6	
	Trusted friend	1	2	3	1.5	
	Trusted Relative	19	34	53	26.7	
	None	0	8	8	4	
	Total	64	134	198	100	
Experiencing Discrimination (n= 200)	Yes	23	53	76	38	p > 0.05
	No	41	83	124	62	
	Total	64	136	200	100	
Type of discrimination (n = 76)	Neglect	5	15	20	26.3	P > 0.05
	Pass sarcastic remarks	6	15	21	27.6	
	Change in attitude	3	0	3	3.9	
	Forced to eat in separate utensils	4	11	15	19.7	
	Told to Leave house	5	12	17	22.3	
	Total	23	53	76	100	

Table 3: Discrimination by family

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		Female	Male	Total	%	P value
Priority Felt needs (n =142)	Financial	22	45	67	47.1	p > 0.05
	Psychosocial	16	32	48	33.8	
	Medicinal	2	0	2	1.4	
	Multiple needs	8	17	25	17.6	
		48	94	142	100	
Financial Services (n =67)	Health services	14	20	34	50.7	p > 0.05
	Monthly ration	8	18	26	38.8	
	Multiple	0	7	7	10.4	
		22	45	67	100	
Psychological Needs (n = 200)	Family & Friends Support	35	66	101	50.5	p > 0.05
	Social acceptance to PLWHA	19	44	63	31.5	
	Both	10	26	36	18	
		64	136	200	100	

Table 4: Felt Needs

		Female	Male	Total	%	P value
Access to various support groups (n =110)	Informal	36	50	86	78.1	p > 0.05
	Formal	3	9	12	10.9	
	Both	3	9	12	10.9	
	Total	42	68	110	100	
Type of Support provided by informal groups (n=86)	Financial	4	8	12	13.9	p > 0.05
	Psychological	16	22	38	44.1	
	Both	16	20	36	41.8	
	Total	36	50	86	100	
Type of Support provided by formal groups (n= 12)	Financial	3	5	8	66.6	p > 0.05
	Psychological	0	3	3	25	
	Both	0	1	1	8.3	
	Total	3	9	12	100	
Accessing Various formal services (n= 12)	Medical social workers	3	8	11	NA	NA
	Psychologist	3	9	12	NA	
	NGOs	3	8	11	NA	
	PLWHA networks	3	8	11	NA	
Integration with other Chronic illness services (n =193)	Yes	32	52	84	43.5	p > 0.05
	no	30	79	109	56.4	
	Total	62	131	193	100	

Table 5: Support Needs

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AUTHORS:

1. M. Suryawanshi
2. Panchal S.
3. Shinde R. R.

PARTICULARS OF CONTRIBUTORS:

1. Assistant Professor, Department of Community Medicine, Dhanlakshmi Srinivasan Medical College and Hospital, Perambalur, Tamilnadu.
2. Associate Professor, Department of Community Medicine, Seth GSMC & KEM Hospital, Parel, Mumbai.
3. Professor and HOD, Department of Community Medicine, Seth GSMC & KEM Hospital, Parel, Mumbai.

NAME ADDRESS EMAIL ID OF THE CORRESPONDING AUTHOR:

Dr. M. Suryawanshi,
Academic Block,
Department of Community Medicine,
Dhanlakshmi Srinivasan Medical College
& Hospital, Perambalur-621212,
Tamilnadu.
E-mail: drdeodattms1983@gmail.com

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