# Marital adjustment and quality of life among HIV discordant couples

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#### **Abstract**

**Introduction:** Human immunodeficiency virus (HIV) is spreading at a very fast pace. HIV is still a global epidemic with number of treatment module, yet there is no vaccine to prevent. Number of efforts made by the World Health Organization, National Governments and humanitarian organizations to spread awareness and provide support. In India National AIDS Control Society (NACO) is the nodal agency under Ministry of Health and Family Welfare to work on this public health issue. Within the people living with HIV/AIDS (PLWHA), one of the typical groups is the Discordant Couples (DCs). HIV discordant couple (DC), live as family unit, in sexual relationship having mismatch HIV status.

**Material and methods:** The present study was conducted with 200 discordant couples of India. For this quantitative study, sociodemographic schedule and two scales were administered. Marital adjustment was measured through marital adjustment scale and WHOQOL-BREF scale used to measure quality of life (QOL). Data was analyzed through SPSS v16.

**Results:** Result revealed marital adjustment was good among most of the couples and QOL was moderate. It was found that couples faced number of discriminations, stigma, and always had apprehension about disclosure of the HIV positive status to the neighbors, employers, extended family members that impacted quality of life.

**Conclusions:** With strong marital bond and adjustment, the couples supported each other to deal with the situation. Though these couples were receiving medical support from the government run counselling centers, yet the lack of specific service protocol for the DCs is a major gap in the service provisions.

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Key words: quality of life, marital adjustment, infected, discordant couples, uninfected.

## Introduction

Human immunodeficiency virus (HIV) is a virus that weakens the immune system (defense mechanism to fight different infections) of the human body. Acquired immune deficiency syndrome (AIDS) is a group of symptoms or diseases caused by the infection of HIV. The transmission of HIV occurs via body fluids (blood, serum and breast milk).

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HIV infected person transmits the virus to an uninfected person by any of these routes. The AIDS comes after eight to ten years of onset of infection without taking any treatment. People living with HIV/AIDS (PLWHA) was first identified in 1981 in the United States [1]. In India the first case of HIV was detected in Chennai, in 1986 and the virus was detected in the blood of a female sex worker [2]. HIV is spread-

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ing rapidly. According to UNAIDS, 75.7 million people got infected by the end of 2019. Even after a lot of awareness campaign, about 1.7 million people got infected in 2019 and PLWHA are 38 million globally [3].

In India, the conservative mindset and stigma associated with the disease often is the major hindrance for the PLWHA to disclose their HIV status to anyone - family, relatives, and friends and or even to their spouse. According to a qualitative study done in the US revealed, HIV discordant couple faces difficulty disclosing serostatus and fear of infection affects sexual life and it may also lead to denial or unprotected sex [4]. In case of married people either they start living in their own cocoon and develop psychological problems or continue unprotected sex with their regular partners. They don't want to change their behaviour because the changed pattern of behaviour can be doubtful for a partner and may lead to any adjustment issue. So, the infected person can't ask for an HIV test of a partner. The partner may not be or may be HIV infected. Often there is tendency of not practicing safe-sex behavior, like using condom, or avoiding any unprotected intercourse. According to WHO, half of PLWHA are living in a discordant relationship without knowing their HIV status [5]. As per study led by Tumwesigye of Uganda in 2006, 96% had not used a condom in their last encounter among sexually active discordant couples. In Uganda, the study found that new infection is increasing among married people of ages 30-40. According to WHO (2005), up to 50% of people infected with HIV are in a discordant relationship, while this ratio in African countries is more than 66% [5]. The frequency of discordant couples is 30-50% among South Africans. Around 2/3rd of heterosexual couples are in a discordant relationship. The infection rate among HIV uninfected partner is 1.2% per year as per a study conducted in India while it ranges 10-20% in South Africa, and in Sub-Saharan Africa, it is 10-100 fold [6]. It is reported in various studies that the quality of life among the PLWHA is quite low because of poverty, lack of employment opportunities, low accessibility of various services, social discrimination, and poor health status [7, 8].

#### Material and methods

# **Review of literatures**

HIV is spreading at a fast pace. A person of any age, sex, community, cultural group, economic or social environment can be infected. There is 95% chances of infection through blood transfusion. According to WHO, 24% of blood donation in low income countries, not screened [9]. In India, 571 cases found infected in Andhra Pradesh through blood transfusion, which is quite high in last 4 years [10] and/or with used unsterilized HIV infected syringe (knowingly or unknowingly). No data found about mode of infection among the people who got HIV infection after marriage, but this study depicted most of the couple became discordant after marriage.

In India, HIV/AIDS remains a taboo and people with known HIV positive status face number of subjugation and discrimination from the relatives and neighbors. The social acceptance is an issue and invariably they become cocooned in their own little circle. According to National AIDS Control Organization (NACO) at Integrated Counseling and Testing Center (ICTC) HIV infected patients are encouraged to disclose their HIV status to their close relations to facilitate better acceptance and support [11], though one can maintain confidentiality about his/her HIV status. No one can compel to disclose HIV status as per law [12], as well as High court, issued a circular for doctors and their staff, not to disclose anyone's medical status [13]. Therefore, the family can't know the HIV status of any family member until the concerned person disclose the same. Here the role of counsellor is very important. The discordant couple is a very high-risk group [14]. In India, no data is available about HIV discordant couple because officials are treating the discordant couple as individuals, not as a couple or a high-risk couple whereas WHO says 50% of PLWHA are living in a discordant relationship [5].

In marital relation living with a partner having chronic diseases like HIV AIDS is a life changing experience, for both the patient and for the partner in romantic relationship [15]. Discordant couples face many challenges in their life as a disruption in an interpersonal relationship, fear of isolation, the problem in intimacy, ceased sexual relationship, reproductive desire, loneliness etc. Couple's relations are bad in most cases and may cause physical abuse [16]. They continuously encounter multiple challenges like, illness progression, fear of transmission, fear of disclosure of HIV status to friends and family, difficulties in family planning, worries of social rejection, stigma, alterations in physical abilities and functioning, and receiving and proving support to manage day to day activities [17, 18]. Poor relationship between the partners in serodiscordant relationship caused stress [19], further chronic progressive illness is associated with decreased closeness among couples [20]. Seven percent of discordant couples reported violence at the time of status disclosure while 50% to 65% men are violent among discordant couples, and violence in marital relationship depends on the level of marital stress [21]. According to a study conducted in Tanzania, couple's discordancy, inequitable attitude and actual imbalance in relationship power increase the risk of intimate partner violence [22]. In U.S. around half of the HIV infected women face intimate partner violence, physical and emotional abuse [23]. Psychosocial stress affect fertility desire and their outcome among PLWHA and antiretroviral therapy (ART) may be toxic for gametes and embryos [24]. Strained relationship is also reported by discordant couples [25]. The negative effect of the regimen, caring for infected partner and fear of uninfected partner of being infected etc. interfere with sexual relations. Life-threatening diseases have a unique impact on the marital relationship and family functioning whereas marital and family relationship affects health [26]. A study about the dyadic coping among the discordant couple revelated that positive relationship, and support help to develop better adjustment among couples. Dyadic coping is process of interdependency in relationship, while one partner's stress signal evokes other person's coping response. Stress signals are perceived, and decoded with dyadic coping response. This process evolves dyadic adjustment. Higher level of dyadic coping led to high dyadic adjustment in the marital relationship among the discordant couples [15].

HIV infection affects the life of a discordant couple physically, mentally as well as economically. A study in Uganda reported that the spread of the disease was associated with lack of information and misunderstanding about serodiscordant status among the discordant couples and counselors too. At times there was denial of the risk of spread of HIV to the un-infected partner and increased the risk of infection. Even there was belief that God will protect. The poor socio-medical condition was evident among the HIV discordant couple [27]. Their economic condition becomes poor due to loss of earning sources. They are often unable to work because of physical weakness or fired from job after status disclosure and discrimination by employers or colleagues. Increased medical expenditure, increased chance of opportunistic infections, physical weakness, need of healthy diet and rest caused higher unemployment and economic burden. Most of the discordant couples living in low socioeconomic condition and women living with the infection have to maintain household courses even after own illness [28]. In Africa, employment is a prime concern than HIV infection among PLWHA [29]. A study Sallay et al. [30] with chronically ill patients in household setting was conducted to study the couples' relationships and adjustment. If partners in marital union can use the available resources together and can jointly take responsibilities of coping with disease and if they perceive the disease as an intricately shared responsibility (we-disease), they can achieve better quality of life. In such case, the couple can develop synchronize efforts and emotional sharing which lead to increased well-being and adjustment of both partners. In serodiscordant couple relationship, while both the partners appraise a stressor (e.g. HIV transmission or disease progression, maintaining protective behavior) as "our" issue rather than "yours" or "mine" and adapt strategies to work on "we"-based actions, has higher chance to achieve better health outcomes [31]. Further, health care facilities, adequate social support, mental health care, regular contact with the counseling center play important role in improving the quality of life of the serodiscordant couples [18]. Marital satisfaction is a very important component of life, that facilities higher quality of life. Faraji et al. reported that marital contentment and the quality of life were low among the serodiscordant couples than the non-HIV couples in all four domains, i.e. physical, psychological, social and environmental. Fatigue, sleep disturbances are the major physical health issues among the HIV infected persons. Anxiety, depression created vicious cycle of psychological issues, and lack of mental health services in community increased the intensity of the problem in psychological domain. Poor socioeconomic condition added to poor quality of life. This study reported twice number of infected males that of the infected females among the HIV-discordant couples. Further, males had higher marital contentment than female among HIV discordant couples [32].

In India, a study with few discordant couples showed that the children of discordant couples could not get proper food and become the victim of malnutrition, in addition to various problem in education and other opportunities [25]. The economic problem causes conflicts between married and concordant couples [33]. Couples in India have blind faith on their spouse, due to various belief systems, and cultural practices, as a result adopted defense mechanism of denying the problems [34]. A study with discordant couple in Puducherry, India reported that both the partners experience moderate level of depression, stress and high level of anxiety. Men had higher level of depression then women and poor socio-economic condition caused higher level of distress and poor quality of life [35]. Ability to plan the life and faith in God, practicing religious rituals helped in reducing the level of stress [36]. Shukla et al. [8] reported that quality of life was better for the HIV positive patient who attended counselling session and adhered to the treatment in last three months. The poor economic condition, job loss impacted the quality of life.

There are number of studies have been conducted with PLWHA in India and in other countries but the scantiness of the study with HIV discordant couples, is quite prominent. Few studies have dealt with the physical problems and the stigma, but there is no specific research work to understand the marital adjustment or issues and also the quality of life (QOL) of the discordant couples. The couples as a family unit have multiple responsibilities towards the children and also have their own demands of marital and sexual life. The experiences of marital conflict, abuse and violence are quite stressful and in addition the HIV positive status of one of the partners and added medical cost are important issues to explore through marital adjustment and quality of life among the discordant couples. Thus, the aim of present study is to explore quality of life and marital adjustment among HIV discordant couples, in three states of North India. A study with HIV discordant couple in Karnataka, India reported intervention targeting the uninfected partner is important, in addition to promoting treatment adherence, voluntary counselling to facilitate well-being.

# Theoretical perspective

The theory 'hierarchy of needs' propagated by Abraham Maslow (1962), established the foundation of understanding quality of life. It highlighted the personal growth through need satisfaction that is marked as existentialist psychological paradigm. The higher the need satisfaction the greater the quality of life. Thus, maintaining quality of life becomes very important to be healthy. Many chronic diseases do not just disappear with best of pharmacological treatment, but the patient improves while having a sense of happiness, power, and abilities to deal with challenges. HIV AIDS is a chronic diseased condition that imposes a lot of limita-

tions to maintain adequate quality of life. Thus, helping discordant couples to improve their quality of life is needed to facilitate healthy living with adequate medical and social support. Facilitating accomplishment of needs is crucial of discordant couples. The important hidden potential for improving the quality of life lies in helping the patients to understand and acknowledge that he/she can still contribute towards self-help, to family, and can enjoy life [37]. Structure of relationship changes with the progression of illness and renegotiation takes place between the couples. Interpersonal relationships conversely affect health. Thus, positive relationship between couples brings better health outcome [38]. Strong and most essential support comes from family, and particularly from spouse in a marital relationship. Usually, couples' relationship and marital satisfaction decline with onset of illness [39]. The equity theory of marital adjustment proposes equal satisfaction and responsibility from marriage while both the partners have relative gain [40]. But this is also seen that the women 'gives more' in the marriage and derive subjective satisfaction due to various cultural, and social construct. This also raises men's marital satisfaction at any marital duration [41]. In case of discordant couples, the relationship and marital satisfaction largely depend on their mutual support and adjustment. Therefore, developing equitable relationships among the partners in discordant relation is equally essential for improving marital adjustments.

# Methodology

Three states of India (Delhi, Haryana and Punjab) were selected for the study. Hundred discordant couples (200 individuals) were selected through purposive sampling technique. The distribution of the sample is shown in the following Table 1.

To collect data, demographic information was collected through socio-demographic information schedule with each one of the partners separately. This tool comprised of three sections, namely, personal, family and information related to illness. During interview two standardized scales were used to assess marital adjustment and QOL. Marital adjustment scale is constructed and standardized by Parmod Kumar and Kanchan Rohatgi in 1976 [42], based on the relationship of husband and wife in a marital union of opposite sex. In its standardized Hindi version, there are 25 items and the tool is designed to get a single composite marital adjustment score. WHOQOL-Bref Scale developed by World Health Organization (WHO) in 2004 [43]. It was translat-

**Table 1.** Distribution of the respondents according to gender and HIV infection status

HIV infection status	Male	Female	Total
Infected	78	22	100
Uninfected	22	78	100
100 couples	100	100	200

ed in Hindi following the translation and back translation methods to ensure its content validity. This WHOQOL-Bref contains a total of 26 items. The tool QOL measures viz. (1) Physical health domain includes activities of daily living, dependence on medicinal substances and medical aids, energy, and fatigue, sleep and rest work capacity etc. (2) The psychological domain includes positive and negative feelings, self-esteem, thinking, learning, memory, and concentration. (3) Social relationship domain includes personal relationship, social support, sexual activity etc. (4) Environment domain includes financial resources, freedom, physical safety and security, home environment etc. Both these scales were culturally appropriate for use in Indian population.

Inclusion criteria for the sample were discordant couples receiving services from the antiretroviral therapy (ART) centre, availed the service for at least once in the last six months, and both partners live together for all practical household purposes as a family. While exclusion criteria were one of the partners is too weak to talk, and homosexual couples. There is recent development about the HIV undetectable = untransferable (U = U) concept that showed with adequate ART treatment transmission of HIV can be prevented [44]. In the present sample of the discordant couples there was no information about U = U status of the infected partner. Following all ethical standards, confidentiality was very crucial for working with discordant couples. The research proposal was approved by the university ethical committee for doctoral research. Data was collected through proper ethical permission from NACO because this population is highly sensitive and hidden. Every participant was explained about the purpose of the research and consent form to participate in the research as a volunteer was filled up. The Data was collected while the couple visited the Integrated Counselling and Testing Centres (ICTCs) or Anti-Retroviral Therapy Center (ARTC) supported NACO. For the purpose of data collection, the researcher established rapport with the person and discussed various issues in their day-to-day life to obtain a fair understanding. It was essential to gain trust and proceed slowly with the data collection. Each of the clients was met at least twice to gain all the information required for the study. The quantitative result is described with available relevant literature and information gained through the interviews. The data collection was done from the mid of 2017 to end of 2018. The study was a quantitative exploratory study in which data were analyzed with the help of SPSS v16.

### **Results and discussion**

In this study, out of 200 respondents (100 discordant couples), 50% were infected and 50% were uninfected and out of 100 infected respondents 78 respondents were male while 22 respondents were female. The demographic details is presented in Table 2.

The gender distribution showed that a greater number of male (78) have HIV positive status, than female (22). Similar trend of gender distribution among the infected partner was

**Table 2.** Demographic details of the respondents

/ariable/Value level	Infected	(n = 100)	Uninfected	$\chi^2$	
	Male (n = 78)	Female ( <i>n</i> = 22)	Female (n = 78)	Male (n = 22)	
Age in year					
21-30	8	9	29	6	0.019*
31-40	36	8	29	10	
41-50	23	3	15	5	
51 and above	11	2	5	1	
Education					
Illiterate	10	6	13	3	0.017*
Primary	6	1	16	3	
High school	57	15	38	16	
College and above	5	0	11	0	
Occupation	-				
Working	72	5	29	18	0.000*
Non-working	6	17	49	4	
Monthly family income in rupee	!S	•		<u> </u>	
0-10000	50	13	50	13	0.970 NS
10001-20000	13	6	13	6	
20001-30000	6	1	6	1	
30001 and above	9	2	9	2	
Living with infection in months		1			
12-24	21	7	21	7	1.000 NS
25-36	11	4	11	4	
37-48	7	2	7	2	
49-60	9	2	9	2	
61 and above	30	7	30	7	
No. of children		1			
1	10	5	10	5	0.473 NS
2	33	5	33	5	
3	15	7	15	7	
4	10	2	10	2	
First reaction of spouse after d	etection	•			
Cried	33	8	44	6	0.050*
Angry	8	1	2	1	
Silent	28	10	16	10	
Any other	9	3	16	5	
Reaction of spouse now	ı	1		J	
Cried	2	1	4	0	0.827 NS
Angry	5	0	3	0	
Silent	68	21	67	22	
Scold	2	0	2	0	
Any other	1	0	2	0	

NS – not statistically significant.

reported in the study by Faraji et al. [32]. Among the male highly infected group age group was 31-40 years. The significant difference of infection status across the gender and age group denoted that young and middle-aged person had more infection. The distribution of respondents according to their educational attainment denoted the respondent completed high-schools are having higher infection, that can be attributed to the high mobility of this group for the purpose of livelihood opportunities. In consonance with the same, the working group has more infection than the non-working groups. Crying and being quite was found to be most common emotional reaction of partner as came to know about the HIV positive status of partner. Gradually, partners have accepted each other's situation and often choose to be silent about the matter and continued the required treatment and other household engagements of leading family life. In various studies it has been found that there is increased stress as the disease progress [20, 32] and at the time of disclosure of the HIV positive status to the partner [17, 21].

# Marital adjustment among the discordant couples

The scores from the scale of marital adjustment revealed the level of adjustment among the couples (Table 3). The item analysis of the marital adjustment scale denoted good adjustment between the partners that depicted mutual support and acceptance to deal with the issues of family life on day-to-day basis. There was no significant difference in all items of the marital adjustment scale between the groups of infected and uninfected partners. The following table showed the item wise score of the marital adjustment scale of all 25 items. There was no significate difference found among the male and female between the infected and uninfected partners, denoted that on different aspect of daily living the husband and wife in a marital union were supporting each other.

In all the items the higher positive response depicted that both the husband and wife within their couple relationships are supportive for each other. The majority of the responded said that they prefer to go out together (item 1), thus feel for each other (item 8), find time for each other (item 11), feel proud for each other (item 13), accepted each other more as partner not mere husband or wife (item 15), takes care of each other's interest (item 17) and such things that are crucial for living in harmony and to maintain the daily course of household. Some of the items reflected joint decision making (items 14 and 18), taking care of family matters, up bring of children (item 5), family planning (item 6) and the sexual relationships (items 9, 20, 23 and 25). There were situations where couples expressed their mutual faith, appreciation for each other (items 2 and 16), and expressed their reciprocal respectful relationship (item 12). Good marital adjustment is a matter of being accommodative to each other and providing support as per the situation. Better marital adjustment can give strength to deal with difficulties. In discordant relationship the couples had equity in relationship and they were well about their overall situation, and mutual support that they need to give each other to maintain family life. All the items revealed good marital adjustment. Family tensions reported in dealing with family expenditure (items 4 and 19), and at times each of them had some personal secret that they did not share with the partner (item 10). Except one respondent, all have said that they have faith on God (item 3). In India religiosity is high and often praying and faith in God helped to deal with the difficulties. The Table 4, further reconfirmed that the difference between the mean score of males (21.78) and females (21.38) on marital adjustment scale is not significant. This denoted the male and female are equally adjusted, though according to mean score the male partners were more adjusted than the female partners. Faraji et al. [32] also reported male had more marital contentment than female in discordant relationship. In marital relationship both the partner feels satisfied while both have relative gain [40]. Discordant couples were dependent on each other for all their practical purposes of maintain the family life and responsibilities. Subsequently, the Table 5, represented no significant difference between the infected and uninfected partners within the marital union. The highest score, denoted that the infected respondents (21.63) were more adjusted than uninfected respondents (21.53). This may be attributed to the reason that the infected couple were more dependent on their partners and made additional effort to be in good relations. Both the partners made efforts to deal with the challenges due to HIV infection and disease progression. While the partners in couple relationship accepted the realities and challenges to live with serodiscordant HIV status and considered the medical problem as "we-disease", they developed better adjustment [31]. In various chronic diseased condition similar trend of accepting the diseases and related challenges together by both the partner in marital relationship, facilitated better well-being, satisfaction and adjustment [30].

The analysis of marital adjustment score denoted that most of the partners among the discordant couples are well adjusted and supporting each other. The male partners are better adjusted, and the infected partners too better adjusted. The marital adjustment between the partners can be understood here from the cultural perspective. India traditional culture of patriarchy is quite dominating for women, and women are expected to scarifies their personal choices and happiness for taking care of their family. Often, they are expected to behave according to the demands of their husband. Females living in a discordant relationship are hesitant to talk about their personal issues with others and prefers to be quite as HIV infection is commonly interpreted with matters of promiscuous sexual relationship. During the interview a female respondent told, when her husband was detected as HIV positive, her parent in-law advised her to leave her husband and to go back to her parents. But she denied as she will also not be accepted by her parental family, further she will become more vulnerable. Hence, she decided to be with her husband and continue their marital unit as family, though she expressed various financial constrain due to the onset of the disease. Living with chronically ill partner often become life changing

Table 3. Responses to marital adjustment

	Variables	Infected		Uninfected			χ²			
		Male		Fen	nale	Fen	nale	Male		
		Υ	N	Υ	N	Υ	N	Υ	N	
1	Go out together	58	20	21	1	65	13	17	5	0.135 NS
2	Faith on each other	75	3	22	0	73	5	22	0	0.389 NS
3	Believe in God	77	1	21	1	78	0	22	0	0.276 NS
4	Tension for home expenditure	41	37	12	10	46	32	10	12	0.688 NS
5	Partners' responsibility to bring up children	74	4	21	1	75	3	20	2	0.800 NS
6	Believe in family planning	73	5	21	1	74	4	21	1	0.974 NS
7	Married at proper age	72	6	19	3	67	11	20	2	0.598 NS
8	Incomplete without each other	65	13	19	3	64	14	20	2	0.772 NS
9	Enjoy sexual life	61	17	17	5	59	19	15	7	0.808 NS
10	Keep some personal things secret	27	51	9	13	27	51	8	14	0.952 NS
11	Find more time for each other	76	2	20	2	71	7	22	0	0.177 NS
12	Respect to each other's family	73	5	20	2	78	0	21	1	0.115 NS
13	Feel proud on each other	77	1	21	1	75	3	22	0	0.573 NS
14	Find solution of family problems	77	1	22	0	76	2	22	0	0.731 NS
15	Realize as a partner than husband/wife	76	2	22	0	76	2	22	0	0.765 NS
16	Appreciate each other	75	3	22	0	76	2	22	0	0.635 NS
17	Take care of each other	76	2	21	1	77	1	22	0	0.680 NS
18	Agree about the number of children	68	10	15	7	69	9	20	2	0.081 NS
19	Argue on domestic things	34	44	9	13	39	39	10	12	0.821 NS
20	Care each other in sexual relationship	72	6	19	3	69	9	20	2	0.799 NS
21	Was good to marry each other	76	2	20	2	74	4	20	2	0.470 NS
22	Absence of any one cause displeases	68	10	19	3	65	13	17	5	0.695 NS
23	Married life gave complete sexual enjoyment	71	7	19	3	74	4	22	0	0.258 NS
24	Same interests and expression	67	11	20	2	69	9	22	0	0.309 NS
25	Maintain newness in sexual relationship	57	21	10	12	45	33	13	9	0.062 NS

 $NS-not\ statistically\ significant.$ 

**Table 4.** Comparison of marital adjustment between female and male respondents

Gender	n	Mean	SD	χ²
Female	100	21.38	2.268	1.273 NS
Male	100	21.78	2.172	

 ${\it NS-not\ statistically\ significant}.$ 

experience, particularly in case of HIV-AIDS infection [15]. Most of the respondents did not disclose their mode of HIV transmission. Women express a lot of faith on their husband that is often a reflection of their dependency and in poor family women have low control over the family owed resources. A female respondent told "my husband can't have extramarital relationship", while her husband accepted having extramarital sexual relationship. Due to stigma most of the respondents did not disclose their HIV status to their extended family members, relatives, friends and neighbors

**Table 5.** Comparison of marital adjustment between infected and uninfected respondents

Gender	n	Mean	SD	χ²
Infected	100	21.63	2.27	0.317 NS
Uninfected	100	21.53	2.18	

NS – not statistically significant.

as they expressed their apprehensions like, "we didn't disclose it to anyone, as they might stop talking to us, and we too would feel ashamed to visit them". Commonly, without disclosing about their HIV positive status the respondents were able to maintain cordial relationship with others. One of them said, "we do not want to spoil our relationships with others, so we don't want to disclose our HIV status". Fear of social rejection, stigma is common problem among the discordant couples. Various studies reported that they often prefer the keep the information secret from close

friends, colleagues and neighbors [17, 21, 34]. Most of the respondents were worried about financial problems and said, "due to infection I have to go to ARTC and have to take good food. But I can't do enough work because, I feel fatigued and can't ask for money regularly to any one". A male respondent with HIV positive status said "sometimes we (couple) quarrel for money because I can't spend money like before, I have to save money for future. I am worried, if I die what will happen to family and children because my wife is not earning". Increased stress in marital relationship among the discordant couple has been reported in few studies [20, 22], though supporting each other and dyadic coping, emotional bonding and concerns for each other helped them to deal with the problems [15, 31]. In the response of adherence to treatment protocol of ART, a man told, "my wife takes care about my medicine, and if I am out of home, she calls me to take medicine on time". When asked about outing with family, most of them responded, "no, we stopped going out after infection, because of financial crunch and even don't feel like going out". When asked about sexual relationship most of the female respondents said about "ceased sexual relation after infection", but male respondents responded this question "yes". Those who lost job due to weakness or discrimination, their partners started working to deal with the financial issues. Both the partner made efforts to support the family requirement and expressed concerns for each other. These facts and findings could be attributed as the reasons for the strong bonding between the discordant couples living within marital relationship. Positive relationship between the couple always helps in deriving better health outcome and adjustment [38]. Thus, the findings of marital adjustment score showed that the couples had good adjustment. This finding is contradictory to some

of the previous researches, that mentioned the disturbed relationship among the HIV positive and discordant couples. Lack of concerns, and emotional bonding between the partner increase the chance of abusive relationship and domestic violence among the HIV discordant couples.

# Quality of life among the discordant couples

Quality of life among the discordant couple is assessed to explore the four dimensions of health. Though it is well researched and found that the QOL is quite poor among the PLWHA, yet there is paucity of study to understand the issues of QOL among the partners living in HIV discordant relationship.

The Table 6 showed that in psychological domain there is a significant difference between male and female respondents. The higher mean score of male (3.79) denoted that the male were maintaining better psychological health then the female respondents (3.57). In India the mental health vulnerabilities are higher among the women, as often assume more responsibility in maintaining the daily needs and considered as the home manager to manage the daily needs and provide care to the children, elderly of sick family members. Such caring burden often makes the women psychologically more impacted than men [45, 46]. In case of discordant couples too, the psychological sufferings among the women were more. A study in India reported that both the partners in discordant relationship experience moderate level of depression and stress, while men had more anxiety [35]. In social relationship and environmental domain, the female has lower score than male respondents, though the difference is not significant. Whereas the physical health is almost same,

Table 6. Comparison of quality of life between female and male respondents

Dimensions	Female (n = 100)		Male (n	χ²	
	Mean	SD	Mean	SD	
Physical health	3.71	0.767	3.70	0.803	0.039 NS
Psychological health	3.57	0.762	3.79	0.784	2.041*
Social relationship	3.40	0.945	3.42	1.042	0.118 NS
Environmental	3.44	0.632	3.48	0.718	0.326 NS

<sup>\*</sup>Statistically significant at 0.05 level. NS – not statistically significant.

Table 7. Comparison of quality of life between infected and uninfected respondents

Dimensions	Infected	Infected (n = 100)		Uninfected (n = 100)		
	Mean	SD	Mean	SD		
Physical health	3.53	0.739	3.88	0.792	3.204**	
Psychological health	3.65	0.777	3.71	0.785	0.483 NS	
Social relationship	3.40	1.02	3.42	0.961	0.118 NS	
Environmental	3.45	0.708	3.47	0.644	0.196 NS	

<sup>\*\*</sup>Statistically significant at 0.01 level. NS – not statistically significant.

with a mild higher score of the female respondent (3.71). The scores in all domains showed that both male and female respondents were maintaining moderate quality of life.

The Table 7 depicted the comparison between infected and uninfected respondents, in respect to the all four domains of quality of life. There was a significant difference in the physical health, and the infected respondent has significantly low physical health status. HIV positive people often reports high level of tiredness, lack of every, easily tired and inability to perform any hard work. The physical fatigue causes a subjective feeling of unpleasantness and disabling symptoms. Though there is no significant difference in other domain of QOL, but in all other three domains namely, in psychological health, social relationships and environmental domain, the score of the infected respondent was lower than the uninfected respondents. This finding shows that the infection caused a major problem and that is obviously impacting the life of the discordant couple. As like previous Table 6, the result of Table 7, reflected that score in all domains for both infected and uninfected respondents. All the discordant couples are maintaining moderate quality of life.

The interaction with the respondent about quality of life has revealed that the infected male respondents (78 respondents) faced multiple difficulties in performing their family responsibilities and also had higher medical dependency, need of regular medical aid and required sleep, rest, adequate nutrition. Such, physical health condition corresponded to the difficulties in social relationships. Often, they avoid going out, be aloof and restrict to interact with relatives, friend and neighbor to hide the information about HIV positive status. Such situation also impacted their financial security, caused lack of resources and they are pushed into poverty. On other hand the uninfected female respondents (78, the wives of the infected male) had to take the major burden of the house, caused more psychological distress, as they became the major care givers in the family and tried to maintain all the social and familial responsibilities keeping their family privacy secured. The female respondent made their best efforts to keep a good relationship with family and neighbors. They also had to work extra hours to meet the family needs. The correlations between the scales were conducted to reflect the situation of the HIV discordant Couples, presented in Table 8. Marital adjustment is positively corelated with all the domains of QOL, expect the environmental domain. Marital adjustment is corelated at 0.01 level with psychological and social relationship domain. This denoted that the higher marital adjustment positively contributed towards developing better psychological state and social relationships among the discordant couple [32]. It has been found that the couples in discordant relationship are more supportive towards each other and maintaining the family relationships in greater harmony. Accepting the disease and emotional support between the couple in discordant relationship facilitate positive health outcome and reduction of stress [15, 31]. The couple came as support for each other and made efforts to work together the daily life difficulties. It is pertinent to mention here that all the discordant couples were getting limited counselling support and they were regularly attending the treatment centers, that provided medical support and occasionally facilitated connecting with civil society organizations for other support services. Marital adjustment was positively correlated at 0.05 level with physical domain reaffirm the similar findings that better physical health status was an outcome of good marital adjustment or vice-versa among the discordant couple [38]. It was seen that the couple were careful about each other medical needs and also other requirements for maintaining better physical health. As a whole the findings of this study contradict with many other studies [5, 22, 23] that found the partner violence, abuse, marital discord is higher among the HIV/AIDS infected person and often their family life is disturbed. In India continuing marriage as social and religious obligation is a cultural practice, further leaving partner, divorce is attached with social stigma [47]. Thus, couples try to stay together and manage their issues. In the case of discordant couples, too, a similar trend of continuing the marriage was observed. Women often have to compromise more to continue the marital union [32, 36].

The  $\chi^2$  test was done with the background variables and all four domains of the QOL, revealed that there is no significant difference between the groups, expect family income with the social relations domain. This determined, the increased family income led to better social relationship. This is commonly understood that better income is essential for maintaining social relationship between the couples, and also with the neighbors and others. The nil-significant relationship with background variable proved that the gender, education, occupation did not have much impact on the QOL.

Table 8. Correlation between marital adjust and four domains of OOL

Domains	Marital adjustment	Physical domain	Psychological domain	Social relationship domain	Environmental domain
Marital adjustment	1				
Physical domain	0.154*	1			
Psychological domain	0.257**	0.627**	1		
Social relationship domain	0.272**	0.363**	0.468**	1	
Environmental domain	0.129	0.521**	0.672**	0.473**	1

<sup>\*</sup>Correlation statistically significant at 0.05 level. \*\*Correlation statistically significant at 0.01 level.

Similarly, it is important to note that all the sample has similar background and largely they were from poor socio-economic background with number of daily life challenges. Poor socio-economic and socio-medical condition often caused lower quality of life discordant couples [27, 34, 35]. The respondents were quite concerned to keep their HIV/ AIDS status confidential to any of their relatives, neighbors and friends with the fear of having social stigma leading to further subjugation and isolation. Some of them mentioned they were fired from their job, as their employer got to know about his HIV positive status. The respondents belong to poor socio-economic standards engaged in unskilled job in unorganized sector were devoid of social security benefits. Similar problem was reported in other studies with HIV positive patient in India [7, 8]. Some of them also changed their residence as they got to know their HIV positive status and they preferred to conceal their visit to the ART centers. There was no doubt that the life of discordant couples were quite difficult in the circumstances where they lived yet, their marital adjustment and subjective sense of well-being helped to maintain better QOL. Their visit to ICTC or ARTC had contributed towards maintaining moderate level of QOL. Availability of HIV AIDS counseling center, and regular support from the counselors help in reducing the problems and maintain well-being [18, 32].

#### **Conclusions and recommendations**

Marital adjustment was good in most of the cases but fear of stigma and discrimination always caused major strain. The couple living in discordant relationships helped each other and that contributed to maintaining a better quality of life. The people living with HIV positive status faced multiple issues in daily living, due to illness, low physical capacity, and mutual dependency on each other. Financial crisis, concern for future often became a source of stress. In India NACO has no specific guidelines for discordant couples to focus on the special needs of the couples living in discordant marital relationship. Often the infected (due to illness) partner was weak to work, and they require various social security measures for their personal care and for maintaining the family responsibilities, including caring for the spouse and children. Though there was counsellor in the ARTC or ICTC, but often they could not spend enough time with the couples to help them to improve their sexual life and relationship. The counsellors did not have special training to understand the specific issues of the discordant couples, thus could not provide any focused intervention. The quality of life is affected due to HIV positive status of one of the partners in the family. But the couples have supported each other to deal with many challenges in the daily life and health related issues that contributed in maintaining moderate quality of life.

Based on these key findings few suggestive measures for improving the support system for HIV discordant couple are formulated here. First, A focused intervention is needed to improve the QOL and marital adjustment of the discordant couples. The intervention must facilitate family empowerment

that can help the couples to deal with their daily life challenges. The intervention should focus on power imbalance, improving commitments in relationships, satisfaction and intimacy among the sero-discordant couples [18]. Second, a communitybased care model is needed for facilitating better relationships with the neighbors and other social agencies to improve the QOL of the persons living with positive HIV status and the discordant couples specifically. Third, an integrated rehabilitation and care model should be promoted that can facilitate livelihood support, financial security, and caring for their children to maintain a better quality of life. Fourth, the counselors working with discordant couples must be trained to understand the relationship issues among the couple in their family and sexual life, thus, helping them to adopt adequate coping strategies. Fifth, there must be policies formulated by NACO to provide specific health care benefits and financial assistance to discordant couples. Civil society organizations can be used to facilitate various services at the doorstep without compromising the confidentiality of the discordant couples. A multisectoral team engagement comprised of health care professionals like, doctor nurse, mental health expert, livelihood expert, family counselor, will be essential to develop and deliver a complete care to the discordant couples in the community and clinics. Sixth, the treatment adherence of the discordant couples must be monitored and they should be given adequate knowledge of U=U status, to facilitate better quality of life and satisfaction. Such efforts will help to neutralize the stigma and will help to improve the life of the discordant couples.

#### **Disclosures**

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- 3. Financial support and sponsorship: None.
- 4. Conflicts of interest: None.

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