



Original Research Article

Effect of Occupational Therapy Intervention on the Quality of Life of HIV Positive Clients and Study of Knowledge about HIV on Clients and Occupational Therapists

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ABSTRACT

HIV infection is a serious health issue, not only in India, but across the world. Not only does it have physical implications, it also is associated with a lot of psychological issues, which together lead to poor quality of life of such individuals. A lot of myths and misconceptions are associated with this disease, not only amongst the individuals with HIV but also amongst the health care professionals. Keeping these in mind, this study was conducted to find out how occupational therapy brings about a change in the quality of life of HIV positive clients, the awareness they have about this disease, and also to explore the knowledge about HIV amongst the occupational therapists. 30 HIV positive clients were conveniently selected for this study and their quality of life was found through the WHOQOL - BREF. The knowledge was found by the HIV-Knowledge Questionnaire. The results showed that there was an improvement in the QOL of the clients, especially in the 'physical' and 'psychological' domains. The knowledge was quite poor amongst the HIV clients and was not very satisfactory amongst the occupational therapists.

Keywords: HIV Knowledge, Quality of life, Occupational Therapy

INTRODUCTION

Since the start of the HIV epidemic, around 78 million people have become infected with HIV and 39 million have died of AIDS-related illnesses. In 2013, there were 35 million people living with HIV. [1] India has the third highest number of HIV positive individuals in the world and only 36 percent have treatment coverage. [2] HIV infection has been reported in all states and union territories. The pandemic of HIV infection and AIDS is a serious health problem of extraordinary scale and extreme

urgency in India. It is prevalent in both urban and rural areas of our nation. [3]

According to National AIDS Control Organization (NACO), the annual number of AIDS related deaths was reported to be 172000 in 2009. [4] It is worth mentioning that many AIDS-related deaths go unreported in India, due to unprecedented levels of stigma and discrimination. In many situations a patient may die without HIV having been diagnosed, and with the death being attributed to an opportunistic infection, such as tuberculosis.

HIV infection affects people regardless of gender, age, race or sexual orientation. The implications of being HIV positive are manifold. Not only does he have to cope with the realization that he/she faces a progressive, unpleasant death, but also an immense psychological burden, due to the multifaceted social and moral pressures. Stable support within a caring relationship may get shaken. There may be financial implications surrounding the knowledge that one is HIV positive. All these issues may have a profoundly deleterious effect on the quality of life (QOL). According to WHO, QOL is a broad concept incorporating, in a complex way, an individual's physical health, psychological state, level of independence, social relationships, personal beliefs and his/ her relationship to the salient features of the environment. [5] Physical manifestations, antiretroviral therapy, psychological well-being, social support systems, coping strategies, spiritual well-being, and psychiatric co-morbidities are important predictors of QOL in this population. Consequently, the impact of HIV infection on the dimensions of QOL, including physical and emotional well-being, social support systems, and life roles, has emerged as a key issue for persons infected with HIV. [6] Christine et al conducted a survey to examine the experiences of women living with HIV/AIDS and found that four themes-fearing disclosure, experiencing challenges (physical and psychological), having supportive networks and coping positively with being HIV positive (spirituality and opportunity for living and learning) were of prime importance to the clients. [7] Women with HIV are about four times more likely to be depressed than those who are not infected. [8]

Since there is neither a cure nor a vaccine against HIV, improving their quality of life seems as significant an objective as is

controlling the symptoms. While the HIV positive person is asymptomatic, psychosocial intervention takes priority. Role and habit changes and transitions are emphasized and occupational therapy strategies to provide opportunities for more control and choice in the patients' life are recommended. The occupational therapist, through occupation and adaptation, can provide opportunities for the patient to "live with HIV" rather than "die from HIV". Wellness programs that focus on productivity should be a part of the intervention. This quality of life depends a lot upon the knowledge about HIV. There are hundreds of myths and false beliefs about HIV/ AIDS. Such issues are seldom focused or discussed by appropriate and informed agencies. Many young people have serious misperceptions about sexually transmitted diseases (STDs) and HIV/AIDS. [9] The various sources that are available or accessible are not scientific or reliant. Due to the lack of scientific knowledge, people easily derive unscientific cause and effect equations. [10] Under these circumstances, there is a great need to make a person aware of the myths associated with this disease. The misconceptions about HIV in the Indian population seem to outweigh the actual knowledge of HIV. Educating such individuals about the various routes of transmission and the preventive aspects can bring about a change in their ways of life. Fears about transmitting HIV to others, worries about the future, self-esteem problems, difficulty sleeping and treatment issues are now important quality of life concerns for people living with HIV that are not measured by existing resources. [11]

Given the increasing incidence and prevalence of HIV/AIDS and its enormous impact on health system, it is important to know the level of knowledge about HIV/AIDS among the occupational therapists as well. Occupational therapists

are one of the team members amongst the various health care professionals dealing with an HIV positive individual. They are responsible for the care of patients and hence come in close contact. It hence becomes necessary that their knowledge about HIV be assessed. Biases, misconceptions and negative feelings held in the minds of the therapists during the period of their clinical rotation or training can result in unwillingness, or even refusal to treat certain patients. Fear of contagion and issues related to working with terminally ill patients may cause the therapist anxiety about working with the HIV positive clients. The therapist hence needs to keep himself updated and apprised with the latest knowledge about HIV infection. Not only this, it is also one of the responsibilities of the occupational therapist to disseminate correct information about the various aspects of the disease, to clear out all myths and misconceptions from the minds of the HIV positive individual himself as well as the caretakers and the community at large, and to provide appropriate counseling. From the client's perspective, people living with HIV in India often experience discrimination while receiving health care due to inadequate knowledge and fear among health care professionals. [12] Health education about HIV/AIDS amongst the health care professionals hence has an important role in the proper care of the people living with HIV/AIDS.

With this back drop, this study was done to understand the quality of life in HIV positive clients, and also to identify and differentiate the myths and facts and the areas of confusion that might serve as an important aspect of educational intervention. Also the study explored the level of knowledge the occupational therapists had about this disease.

MATERIALS AND METHODS

This quasi-experimental single group pre-post study was carried out on 30 clients with HIV positive status. After having explained about the study objectives, the clients were screened for inclusion and exclusion criteria. The clients, both males and females, between 21-50 years were included if they were diagnosed as HIV positive on Elisa test, in stage I-III. The clients were excluded if they had any diagnosed cognitive issue.

Written informed consent was taken from the clients who were enrolled for the study. The demographic details were taken. The selected clients were then evaluated for their quality of life and their level of knowledge about HIV on the WHOQOL BRIEF & the HIV Knowledge Questionnaire, respectively.

WHOQOL-BREF is a self-administered, interviewer-assisted or interview administered questionnaire. It has a total of 26 questions. To provide a broad and comprehensive assessment, one item from each of the 24 facets, belonging to four domains of life, i.e. 'Physical', 'Psychological', 'Social' and 'Environmental', has been included. In addition, two items from the Overall Quality of Life and General Health Facets have been included. [13]

HIV - Knowledge Questionnaire is a self-administered 45-item questionnaire of knowledge about human immunodeficiency virus (HIV) infection. It consists of questions regarding the modes of transmission, risk behaviors and common misconception about the disease. The subject is required to answer the questionnaire in either "yes" or "no". [14]

The participants were given the option to withdraw their participation any time during the course of the study without any fear or obligation. However, there were no such withdrawals. They were requested

to scrutinize the questionnaire for completeness before returning.

The selected 30 clients were given occupational therapy intervention. Clients were followed-up twice a week for four weeks. The intervention included-counseling the clients and helping them to gradually come to terms with the fact. The clients were educated about HIV, its modes of transmission and its modes of action in the body. Also various handouts and pamphlets regarding this, in simple language, were given. All queries about HIV were cleared up. The various risk behaviors regarding the transmission of HIV were made understood to the clients. Each client's therapy program was tailor-made. Stress management and relaxation techniques in the form of deep breathing exercises, mental imagery, and writing down the stress factors etc. were emphasized upon. Also they were taught to cognitively restructure various threatening experiences, such as rejection and conflict with close relations; to reduce stress and maintain emotional equilibrium. Dietary modifications, adoption of healthy lifestyle and the importance of the elimination of alcohol and nicotine were explained to the clients. They were explained how such behavioral changes slow down the disease progression and reinforce perceptions of oneself as healthy. Apart from this, symptomatic occupational therapy was given. Most of the clients had complaints of easy fatigability and generalized weakness. They were given conventional occupational therapy conditioning and strengthening exercises. Also a home program was chalked out for them.

Four female clients discontinued therapy after two to three weeks. Further as the therapy progressed, 16 more clients gradually discontinued therapy. So, finally the total number of clients was 10.

Post-therapy reading was taken on the same outcome measures at the end of four weeks.

Knowledge about HIV in Occupational Therapists: This cross-sectional descriptive survey was undertaken to find out the level of knowledge amongst the qualified occupational therapists.

50 qualified occupational therapists, both males and females were conveniently selected. After explaining the study objectives, seeking informed written consent and ensuring confidentiality, the demographic details were taken. The "HIV - Knowledge Questionnaire" was then administered.

RESULTS

The demographic profile of the 30 clients included in the study has been shown in Table

Table 1: Demographic profile of the clients (n=30)

VARIABLES	No. of clients	
Stage of illness	II	11
	III	19
Mode of contact	Sexual exposure (other than with spouse)	19
	Spouse	6
	Others	5
Duration from diagnosis of HIV (months)	<6	14
	>6	16
Age group (years)	21-35	16
	36-50	14
Gender	M	26
	F	4

The pre and post data for the overall quality of life as well as for the four sub-domains (Physical Psychological, Social and Environmental) of WHOQOL-BREF was analysed using paired t test (Table 2)

For the purpose of further analysis, the 30 clients were divided into two age groups: Group 1 (21-35) years and Group 2 (36-50) years.

Table no. 3 shows, that there was no statistically significant difference in the QOL in the two age groups; but there is a difference in the mean values, which show

that the overall QOL is better in Group 1 i.e. clients falling in the age group 21-35 years.

TABLE 2: Comparison of QOL pre and post intervention

Variable	Mean	SD	T	2- tail probability
QOL-A	49.725	2.227	2.43	0.22
QOL-B	53.575	3.575		
PHY-A	47.8	19.338	1.31	0.222
PHY-B	57.7	19.883		
PSY-A	48.7	12.102	1.14	0.285
PSY-B	53.1	15.545		
SOC-A	47.9	25.41	0.15	0.885
SOC-B	48.9	24.104		
ENV-A	54.5	15.16	0.03	0.979
ENV-B	54.6	15.735		

Where, QOL-A = overall QOL, pre-therapy
 QOL-B = overall QOL, post-therapy
 PHY-A = Physical domain, pre-therapy
 PHY-B = Physical domain, post-therapy
 PSY-A = Psychological domain, pre-therapy
 PSY-B = Psychological domain, post-therapy
 SOC-A = Social domain, pre-therapy
 SOC-B = Social domain, post-therapy
 ENV-A = Environmental domain, pre-therapy
 ENV-B = Environmental domain, post-therapy

TABLE 3 Comparison of QOL in two age groups

Group	Variable	Mean	SD	T	2- tail probability
1	QOL	54.72	3.16	1.20	0.242
2	QOL	48.25	7.59		

Similarly, the 30 clients were divided into two groups according to the 'duration from the diagnosis of HIV. -Group 1: Less than 6 months and Group 2: More than 6 months.

Table no. 4 shows, that there was no statistically significant difference in the QOL in the two groups; but there is a difference in the mean values, which show that the overall QOL is better in the clients who had been knowing that they are HIV positive for less than 6 months, than those who had been knowing for more than 6 months.

TABLE 4 Comparison of QOL in two groups according to duration from diagnosis

Group	Variable	Mean	SD	T	2- tail probability
1	QOL-A	54.50	3.10	1.16	0.326
2	QOL-B	49.08	4.57		

Knowledge about HIV in HIV Positive Clients: Amongst the HIV positive clients, when the questionnaire was administered, the results showed that many of them were not aware of the fact that HIV is not curable. They had little knowledge about the various means of transmission of this disease, and the methods of protection one can adopt to prevent transmission. It was found that a few myths and misconceptions were prevalent in most of the clients such as shaking hands with an HIV positive client can transmit HIV, use of condoms is a foolproof method of preventing transmission of this disease, or a person can get HIV by donating blood. They were not aware that sharing needles used for tattoos or drugs can transmit HIV.

Table 5 shows that there was a statistically significant difference in the knowledge about HIV before and after occupational therapy intervention, after 4 weeks. The percentage difference i.e. the improvement in the knowledge was calculated, using the formula $Pi = a_2 - a_1 \times 100$, where a_1 = maximum value a_2 = minimum value, and was found to be 21.1%.

TABLE 5: Improvement In The Knowledge About HIV

Variable	Mean	SD	T	2- tail probability
KN-A	22.9	3.665	10.65	0.00*
KN-B	31.8	2.781		

Where, KN-A = Knowledge before therapy
 KN-B = Knowledge after therapy
 * = Significant

Knowledge about HIV in Occupational Therapists: In the study done on the occupational therapists, the mean percentage of correct responses, in the 45- item questionnaire was calculated and found to be 78.80%.

Overall it was observed that the main areas of confusion were in areas related to modes of transmission and what measures could be taken to prevent transmission of the HIV. Many therapists were not aware of the various body fluids that may have the virus

present in them, like, semen, saliva, blood etc. It was also found that a few therapists were not aware of the difference between HIV positive status and AIDS.

DISCUSSION

Quality of life provides a measurement of functioning and well being rather than of disease and disorders. It guides appropriate management strategies and also acts as one of the outcome measures for comparing them. QOL of HIV positive individuals depends a great deal on psychological and social factors. It has been seen that the knowledge that a common man has about HIV is not enough to eliminate the fear and stigma surrounding this disease.

The results of this study showed that there was only marginal improvement in the 'social relationship' domain of the QOL, as compared to 'physical' and 'psychological' domains. This may be because our intervention did not include educating and counseling the family members, close relatives and friends of the client. Only the client himself received therapy in the form of psychological counseling and education. This may have made a difference to them psychologically, as knowledge eliminates the fear of the unknown. Also the client's perception and understanding of the illness critically affect his adaptation and adjustment. This is supported by a study done by Shirley J. Semple in 1997, [15] who said that clients who perceived themselves as permanently ill were less likely to be active in their attempts to control the disease. The need to educate and counsel the family has also been supported by Li et al. He found that the support provided by the family makes multiple levels of positive impact on people living with HIV/AIDS, suggesting the importance of including families in HIV/AIDS interventions. [16] Sushil Yadav reiterated that community-based support is vital for issues of quality of

life, and had strongly encouraged strategies to improve social support and hope intervention programs. [17] Similarly, Khumsaen et al, in his study, confirmed that social support was a statistically significant predictor of QOL. When examining the relationship between personal characteristics, coping style, and social support on QOL among Thai people living with HIV/ AIDS. They also found QOL to be related to social support, living with family members, spiritual wellbeing, and monthly income and coping style. [18]

However, this study could not bring a statistically significant difference in the QOL of these clients, probably because, firstly, the sample size was less; and secondly, the clients received therapy only for a period of four weeks, which probably is not enough to bring a significant difference in their QOL. However, it becomes imperative here to highlight the fact that considering the stigmatic perception of this disease by the client himself and by the society, even a minimal improvement in their QOL is worth an appreciation. Moreover, the client population who came for full four weeks of therapy was 10; the rest gradually stopped coming after two to three weeks of follow-up. The main reason for this could be that the clients had not disclosed about them being HIV positive to their family members and colleagues, and so were fearful that coming for regular follow-ups may raise a doubt in others' minds and may lead to the disclosure of their HIV status. This further highlights the need to bring about a social change in the minds of the HIV positive individual himself as well as the caregivers and the society at large.

It is evident from the results that QOL is better in the younger age group. This can be justified by the fact that health becomes poorer as this disease progresses and so are the related social and

psychological aspects of well being. Psychological and social well being is further affected, as during the later stages of the disease, more and more people, on society and work place, come to know of the patients HIV positive status, subjecting him to more of rejection, condemnation and isolation and hence making his life miserable. His relationship with his family members and friends is also better at younger age as they usually come to know at a later stage when the debilitating physical signs of this disease begin to show. These may also be the reasons behind another finding of this study, that the QOL is better in those clients who have recently come to know (i.e. six months or less) that they are HIV positive than those who have known it for quite some time.

The demographic data collected also show that in 63% of the studied population, the mode of contact of HIV was sexual exposure (other than with spouse). All other modes of contact such as infected needles (including surgical procedures, drug abuse, tattoo etc.), HIV positive spouses and contaminated blood together constituted 47%. This is an alarming data, in the Indian population, and calls for an urgent need to educate the general population regarding protected sex and the importance of practicing monogamy.

The data also show that out of a total of 30 HIV positive clients, only four were females. This implies that female HIV clients are still scared to come out and seek help. The familial and societal pressures and the fear of condemnation have a strong hold on the psyche of these clients. Moreover, during the course for the therapy, it was observed that all these four clients discontinued therapy after following up for the period one to three weeks. QOL of HIV positive clients depends a great deal on psychological and social factors. It has been seen that the knowledge that a common man

has about HIV is not enough to eliminate the fear and stigma surrounding this disease.

Regarding the knowledge about HIV amongst the HIV positive clients, most of the clients were not even aware of the fact that there is a difference in HIV and AIDS, leave aside what is the difference. They were not aware of the severity of the disease and its long term implications. They had quite a few misconceptions regarding how to get rid of HIV after having been infected.

Most of the clients were not aware about the various modes of transmission of the virus and the means of protection. Various myths seemed to prevail regarding this disease.

Regarding the knowledge about HIV in occupational therapists, though the percentage knowledge was not very bad, but efforts still need to be done to improve their knowledge levels because the onus is on them to disseminate correct information to their HIV positive clients, and hence be able to give them proper guidance and counseling.

CONCLUSION

Occupational therapy intervention is helpful in bringing a change in the quality of life of HIV positive individuals. Various myths prevail regarding the knowledge about HIV/ AIDS amongst clients and to some extent amongst the occupational therapists. Further studies need to be done to find out how much change occupational therapy intervention can bring in a client's life when his family members, friends and colleagues and other members of the society are also involved in counseling and education.

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