

Research Article

A Coping Strategies Intervention makes a Difference on Coping, Social Support and Quality of Life of People Living with HIV/AIDS (PLWH)

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Abstract

Background: Most patients with HIV confront a range of psychological challenges, including the prospect of loss of social support, worsening quality of life, and coping with uncertainty.

Objective: This study aimed to assess the coping, social support and quality of life of PLWH and to determine effect of coping strategies intervention on coping, social support and quality of life of PLWH.

Methods: A pre-experimental-one group pre-test post-test time series design was used on 200 PLWH who were sero-positive for last six months and were recruited for the study from ART clinic of a tertiary care hospital in Northern India. BREF COPE, MOS Social support and WHOQOL-BREF HIV questionnaires were administered to assess the coping, social support and quality of life of PLWH respectively at baseline, posttest-1 (after one month) and posttest 2(after three months).

Results: The most commonly used coping styles were acceptance and religion. The social supports mostly used by PLWH were tangible support and affectionate support, and least used support was positive social interaction. The lowest quality of life was seen in social relations, followed by physical quality of life. There was statistically significant increase in coping, social support and quality of life after the administration of coping strategies intervention. The structured coping intervention was found effective in improving coping, social support and quality of life.

Conclusion: The findings of this study suggest that coping strategies intervention improved coping, QOL and social support in People living with HIV.

Introduction

HIV as an illness affects the person at the biological level in the form of an aggressive virus that compromises immunity. Every illness experience represents a unique and dramatic negative experience for the patient; it is associated with a profound and authentic psychological engagement of patients themselves and the significant people in their lives.

HIV infection adds stress to the already compromised coping skills of the person. Having HIV can affect other social relationships because infected adults need to make decisions regarding levels of HIV diagnosis disclosure. For a certain period, the illness

can take away the person's ability to work and keep a job, thereby affecting the sense of productivity, self-control, and security of daily life. Redefining identity through the condition of HIV can be a big challenge because it can come in deep contradiction with life goals and plans. Most people find that they need a period of adjustment following their diagnosis. But once they learn more about their condition and acquire the necessary skills to enable them to live with a chronic illness, life with HIV can be remarkably normal. The provision of psychosocial support is an important part of care at both institutional and community level. After the administration of Cognitive behavioral stress management in HIV-symptomatic gay men, which used group interventions to target enhance social

support and facilitate more active coping strategies. It was found that cognitive behavioral interventions using either guided imagery or progressive muscle relaxation in HIV-positive individuals at different stages have significantly improved perceived health status, but not QOL. Coping effectiveness training have shown to help patients develop coping strategies corresponding to specific stressful situations and improve QOL.

Aim

To explore coping, social support and quality of life of PLWH and develop a Structured Coping Strategies Intervention model and assess its effectiveness on improving coping, social support and quality of life.

The Research Questions

- What are the coping strategies of PLWH ?
- What are the social supports for PLWH ?
- What is the QOL of PLWH ?
- Is the coping strategies intervention effective in improving coping, social support and quality of life of PLWH ?

Methods

The study design was Pre-experimental-one group pretest post-test time's series design. The data was collected at three points of time at baseline, after one month of the intervention (posttest 1) and three months after intervention (posttest2) from a sample of 200 PLWH. The variables assessed were coping, social support and QOL.

Sample and Sampling Technique

The study sample comprised of PLWH using convenience sampling technique as HIV has innumerable psychosocial sensitive issues only consenting to be a part of the study who met the inclusion criteria were enrolled into the study.(Patients who were HIV positive for more than six months were taken ,as initially after diagnosis of HIV ,the person within the first few months is in turmoil and disclosure issues so may be not respective and after 6 months comes in term with the sero-positive status) , who were above 18 years of age, can speak and understand Hindi/English, attending A.R.T clinics of All India Institute of Medical Sciences, New Delhi,). Patients who had psychiatric illness were excluded study as it could affect study results.

Study Site

All-India Institute of Medical Sciences, New Delhi, a tertiary care, super specialty 2400 bedded hospital. The hospital has twenty-five clinical departments including four super specialty centers manage practically all types of disease conditions with support from pre- and Para-clinical departments. The data was collected at the Medicine OPD of All India Institute of Medical

Sciences, New Delhi which runs an ART clinic. It is located at the ground floor of the OPD block. The daily census of the Medicine OPD is 350-400. It runs special clinics in the afternoons and runs Integrated Counseling testing Centre (ICTC) and Anti Retro Viral Treatment (ART) clinic. The ART clinic runs daily from Monday to Saturday from 8:30 AM to 5 PM.

The patient of visiting the ART clinic ranges from 50 to 90 per day. The number of patients enrolled in the clinic are 2300 and 1600 are on regular follow up. The NGO attached to ART Centre is Delhi Mahila Samiti.

Instruments

The Brief COPE scale (Carver, 1997), a 28-item self-report measure of both adaptive and maladaptive coping skills. The Brief Cope had 14 domains with two items each for every coping style. It comprised of self-distraction, active coping, denial, substance use, use of instrumental support, use of emotional support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, use of religion and self-blame. The reliability coefficient was 0.969 [1].

Medical Out come Study Social Support Survey (MOSS-SS)

The MOSSSS is a multidimensional, self-administered tool encompassing questions addressing four functional support scales (emotional/informational, tangible, affectionate, and positive social interactions) and an additional item (someone to do things with to help you get your mind off things) by Sherbourne CD, Stewart AL (1991). The reliability of the tool is >0.91 [2].

WHO QOL-HIV BREF

The WHOQOL-HIV BREF consists of six domain scores. It has only one item to present each facet. Included in these, there are two items that examine General quality of life. Hence there are 31 items, representing the 30 facets. Five of these facets are specific to HIV/AIDS. The individual items are rated on a 5 point Likert scale where 1 indicates low, negative perceptions and 5 indicates high, positive perceptions. WHO QOL Cronbach's Alpha is -0.992 [3].

- **Domain I:** Physical -comprising of pain, discomfort, energy, fatigue, sleep and rest.
- **Domain II :** Psychological-constitues positive feelings, thinking, Learning, Memory, self-esteem, body image, negative feelings and apparence.
- **Domain III:** Levels of Independence-includes mobility, activities of Daily living, work capacity.
- **Domain IV:** Social relations- encompass personal relationship, social support, and sexual activity.
- **Domain V:** Environment-which includes physical safety and

security, home environment, financial resources, health and social care, participation in recreation/leisure activities.

- **Domain VI :** Spiritual-includes for givenness and blame, concerns about future, death and dying. Each domain and facet scores are scaled in a positive direction where higher scores denote higher quality of life. Some facets (Pain and Discomfort, Negative Feelings, Dependence on Medication, Death and Dying) are not scaled in a positive direction, meaning that for these facets higher scores do not denote higher quality of life. These need to be recoded so that high scores reflect better QOL. Items are organized by response scale (capacity, frequency, intensity or satisfaction)

Ethical Clearance

The permission for collecting data was obtained from the Ethics Committee, AIIMS. Written informed consent was taken from PLWH and confidentiality was assured.

Development of Intervention

Intervention framed included coping styles, seeking social support and living positively with HIV. A focus group discussion was carried out with 8 PLWH regarding their coping, social support and quality of life before the intervention and based on the findings the intervention was framed. All the PLWHA (8) reported they were under immense stress and anxiety. They had doubts regarding their future and their quality of life. They were worried about the status of their family. They had a feeling that their days are numbered. Six out of eight PLWHA had told their spouses about their HIV status. Most of them had disclosure concerns. Most of them had no information regarding how to cope with the illness; they did not receive any information regarding this aspect from any Health Care Professional. The intervention focused on informational support, coping styles, relaxation therapy, seeking social support.

Topics of the intervention includes: Informational support about HIV and what to do when diagnosed with HIV Session II Coping with HIV and how to improve mental health Session III Seek family support and network building Session IV Know your rights Session V Living positively with HIV Session VI Positive Thinking Session VII How to relax. It was interactive two hours' session done in a room of the OPD.

Duration of Data Collection

The data was collected from July' 12 to March' 13 at the ART Clinic for the study.

Data Analysis

SPSS 17 was used for data analysis. Descriptive and inferential statistics was used to analyze the data. The baseline variables were assessed using descriptive statistics of mean and frequency

percentages. The correlation between the variables of coping, social support and quality of life was done by using Pearson's correlation.

Results

Demographic Profile

The mean age of PLWH was 39.8±8.1, ranging from 21 to 61 years. The majority of PLWH were males (76%). 39% were educated till class 10th, 75% were married. Majority (76%) had income between 5000-10,000/-INR per month. The health status of majority (51%) of PLWH was good, as reported by them, (61%) of PLWH did not feel sick. In reference to the HIV illness status more than half (69.5%) reported as asymptomatic. Most of them (48.5%) had CD4 in the range of 200-400. The mode of transmission of HIV (61.5%) was through heterosexual contact and (42.2%) had acquired infection between 2006-2012. However, majority of PLWH (67.0%) had got tested for HIV infection during 2006-2012.

The most commonly used coping styles were acceptance and religion. The moderately used coping strategies included self-distraction, active coping, emotional support instrumental support and positive framing. The least used coping methods were self-blame, venting, humor, denial and substance use indicating that mostly adaptive coping strategies were used by PLWH to face psychosocial and illness related issues of HIV (Table 1).

Domains	Baseline Mean±SD	First Month Mean±SD	Third Month Mean±SD
Self-distraction	2.6±0.8	2.5±0.9	2.4±0.8
Diff(95% CI)		-0.01(-0.14,0.11)	-0.16(-0.29,-0.03)
p value		0.79	0.01*
Active coping	2.7±0.8	3.6±0.5	2.6±0.6
Diff(95% CI)		0.82 (0.68,0.95)	-0.14(-0.28,-0.01)
p value		0.001**	0.03*
Denial	1.8±0.9	1.7±0.9	2.8±0.9
Diff(95% CI)		-0.03(-0.18,0.11)	1.09(0.94,1.2)
p value		0.63	0.001**
Substance use	1.2±0.5	1.2±0.6	1.6±0.7
Diff(95% CI)		-0.02(-0.12,0.08)	0.36(0.25,0.46)
p value		0.71	0.001**
Emotional support	2.5±1.0	3.6±0.5	2.8±0.6
Diff(95% CI)		1.1(0.96,1.2)	0.31(0.16,0.46)
p value		0.001**	0.001**
Instrumental support	2.4±0.9	3.4±0.6	2.7±0.7

Diff(95% CI)		1.02(0.87,1.1)	0.33(0.18,0.48)
p value		0.001**	0.001**
Behavioral disengagement	1.7±0.8	1.6±0.8	2.0±0.7
Diff(95% CI)		-0.04(-0.16,0.08)	0.36(0.23,0.48)
p value		0.50	0.001**
Venting	2.0±0.7	2.0±0.7	1.6±0.6
Diff(95% CI)		-0.03(-0.14,0.07)	-0.41(-0.52,-0.30)
p value		0.57	0.001**
Positive framing	2.9±0.8	2.8±0.9	2.8±0.9
Diff(95% CI)		-0.04(-0.18,0.10)	-0.05(-0.19,0.09)
p value		0.60	0.51
Planning	2.5±0.8	2.5±0.9	2.5±0.7
Diff(95% CI)		-0.03(-0.17,0.21)	-0.07(-0.21,0.08)
p value		0.73	0.36
Humor	1.1±0.3	1.1±0.3	1.1±0.3
p value		0.40	0.44
Acceptance	3.1±0.6	3.4±0.6	3.2±0.7
Diff(95% CI)		0.30(0.17,0.42)	0.10(-0.02,0.22)
p value		0.001**	0.10
Religion	3.0±0.8	3.6±0.5	3.1±0.8
Diff(95% CI)		0.55(.40,0.70)	0.05(-0.09,0.19)
p value		0.001**	0.50
Self- blame	2.0±1.0	2.0±1.0	2.0±0.8
Diff(95% CI)		-0.03(-0.18,0.11)	-0.02(10.17,0.12)
p value		0.67	0.77
Generalized Estimating Equation $p \leq .01^{**}$; $p \leq .05^{*}$.			

Table 1: Comparison of Coping styles of PLWH as assessed by BREF COPE n=200.

The coping strategies intervention was found effective in improving active coping at posttest 1 and posttest 2 with significant $p=0.001$, $p=0.03$ respectively. The coping style of venting was decreased after three months. The decrease in the use of venting from baseline to three months was statistically significant ($p=0.001$). The coping strategies intervention was found statistically effective in improving the use of religion (relationship with God) as a way of coping after one month; ($p=0.001$) after the first month post intervention. The increase in the use of religion domain in first month reflects that the effect of the intervention lasted for a month. In emotional support the p value was significant (0.001)

at first and third month. The instrumental support showed a significant ($p=0.001$) difference in coping at the first and third month after administration of the intervention

Social Support	Baseline Mean±SD	First Month Mean±SD	Third Month Mean±SD
Emotional support	3.1±1.0	3.1±1.1	3.1±1.1
Diff(95% CI)		0.01(-0.05,0.08)	-0.03(-0.10,0.03)
p value		0.74	0.35
Tangible support	3.2±1.1	2.8±1.3	3.1±1.2
Diff(95% CI)		-0.39(-0.47,-0.31)	-0.03(-0.11,0.04)
p value		0.001**	0.356
Affectionate support	3.2±1.2	3.4±1.2	3.2±1.3
Diff(95% CI)		0.17(0.08,0.27)	-0.01(-0.11,0.75)
p value		0.001**	0.703
Positive social interaction	2.8±0.9	3.7±0.7	3.7±0.8
Diff(95% CI)		0.93(0.80,1.06)	0.85(0.72,0.98)
p value		0.001**	0.001**
Generalized Estimating Equation $p \leq .01^{**}$; $p \leq .05^{*}$.			

Table 2: Comparison of Different Domains in Social Support Domains of PLWH n =200.

The social support used by PLWH are most of them used tangible support and affectionate support, followed by emotional support and least used support was positive social interaction. This reflects that though social support was available to PLWH but there was social distancing because of HIV infection. PLWH refrain from interacting with others mainly due to fear of discrimination. When they feel sick their needs were catered and disease related support was available to them i.e., taking them to the doctor in case they were unable to do themselves. The affectionate support was available hence PLWH had support available to them in terms of rendering them affection and love.

There was a significant ($p=0.001$) reduction intangible support from baseline to first month, however the reduction from baseline to the third month was not statistically (0.356) significant. This indicates that after the intervention the PLWH asked less help from others to meet their daily needs. Affectionate support increased significantly ($p \leq 0.01$) after first month but there was no improvement at third month indicating that the effect of the intervention lasted for one month. This suggests that the regular coping and support capsule or counseling is required. The positive social interaction at baseline, after one month and after three

months was 2.8±0.9, 3.7±0.7 and 3.7±0.8 respectively. The p value was significant at first and third month (p=0.001). This implies that there was a significant improvement after the administration of the intervention. The intervention was able to make a difference in the most affected area of PLWH. After the intervention, the PLWH were able to improve themselves in socialization.

The lowest score of QOL was seen in domain of social relations followed by physical domain reflecting the social implication of the disease. QOL in physical domain was largely dependent on discomfort reported arising from HIV-associated symptoms and treatment. This suggested that PLWH experienced discomfort from symptoms associated with HIV. The score in the psychological domain of QOL was higher than the independence and spirituality domain. QOL in psychological domain was largely explained by perceived stress, positive thinking, self-esteem, body image and appearance. This implied that PLWH experienced less stress than the issues encountered by them in the independence domain. 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 PLWH.

As evident from (Table 3), QOL in psychological domain had significant p value (0.001). There was increase in the mean scores after one month (74.3) and three months (80.4) from the baseline (58.7). This reflects that intervention was able to make a difference in the psychological domain of PLWH. In the domain of social relations there was a significant (p=0.001) increase in the mean scores at one month and at third. The PLWH went into social exclusion due to fear of stigma and discrimination. This implies that after the administration of the intervention the personal relations, social support and sexual activity of PLWH improved.

Domains	Baseline	First Month	Third month
Domain I (Physical)	53.4±9.4	52.2±11.3	52.2±12.2
Diff (95% CI)		-0.78(-2.6,1.1)	-1.2(-3.0,.69)
P value		0.41	0.21
Domain II (Psychological)	58.7±9.0	74.3±12.6	80.4±13.8
Diff (95% CI)		15.5(13.3,17.8)	21.7(19.4,23.9)
P value		0.001**	0.001**
Domain III (Independence)	56.8±13.0	56.0±14.5	55.3±13.4
Diff (95% CI)		-0.76(-3.13,1.6)	-1.52(-3.8,0.85)
P value		0.53	0.21
Domain IV (Social relation)	53.2±13.5	62.4±11.2	60.6±12.9
Diff (95% CI)		9.2(6.8,11.5)	7.38(5.0,9.6)
P value		0.001**	0.001**

Domain V (Environment)	114.6±23.8	113.0±27.4	112.9±29.0
Diff (95% CI)		-1.58(-6.0,2.8)	-1.66(-6.1,2.8)
P value		0.48	0.46
Domain VI (Spirituality/Religion/ Believes)	56.9±10.9	56.0±12.9	55.9±13.9
Diff (95% CI)		-.92(-3.0,1.2)	-1.0(-3.2,1.1)
P value		0.40	0.34
Generalized Estimating Equation p≤.01**; p≤.05*.			

Table 3: Comparison of QOL of PLWH as assessed by WHOQOL-HIV BREF n=200.

Discussion

The most commonly used coping styles were acceptance and religion. The most commonly used coping styles were acceptance and religion and were congruent in a study by Trevino KM [4]. The social support used by PLWHA was tangible support and affectionate support. The lowest QOL was seen in social relations, followed by physical QOL. The lowest QOL was seen in social relations, this was congruent with the study done by Miles [5].

The coping strategies intervention was found effective in improving active coping, instrumental support, emotional support and positive social interaction at post-test 1(after one month) and post-test 2(after three months) with significant p value for both the post test. This was congruent with Heckman [6]. The religion as a way of coping was significant at first month. The increase in the religion domain in first month reflects that the effect of the intervention lasted for a month. This was congruent with the findings of Kremer [7]. The social support used by are most of PLWH is used tangible support and affectionate support, followed by emotional support and least used support was positive social interaction. This finding was congruent with the study of Desantis [8]. There was significant increase in positive social interaction after one month and after three months with the p value was significant at first and third month.

There was significant improvement in psychological QOL after administration of coping strategies intervention from the baseline at the first month, and after three months with the significant p value at first and third month respectively. In the social relations domain, there was a significant improvement from the baseline mean score and, after one month, then after three months after receiving the coping intervention which is statistically significant. This was concordant with the study of Weiss [9]. This reflects that intervention was able to make a difference in the psychological domain in the QOL of PLWH. This was congruent with Scott-sheldon [10] where investigators have developed and evaluated interventions to reduce stress as a means to improve health among persons living with HIV.

There is a dearth of literature available from the south East Asian Subcontinent and socio-culturally as well as demographically people living with HIV are diverse in relation to their western counter parts, hence the apparent need to conduct the study in the psycho social domain was perceived by the researcher.

Conclusion & Implications

The structured coping intervention was found effective in improving coping, social support and quality of life. Nurses working need to be prepared to manage the psychosocial implications of the disease as they play a key role in empowering PLWH. The informational support requires to be enhanced for them. Nurses can create awareness regarding the issues faced by PLWH to the public and can sensitize the public regarding the vulnerabilities of PLWH. Nurses can educate the caregivers on importance of social support. The need to organize holistic health services for PLWH in the community. It further emphasizes the need to be identified for presence of any deviant behavior related to the stress posed by HIV. So, timely help can be given and it improves the patient outcome. Special strategies should be tailored to help illiterate PLWH cope with the disease. More Psychosocial Support to be given to newly diagnosed PLWH as the resilience is poor as evident from the study. These findings suggest a need for exploring the promotion of social support as a useful tool in management of PLWH. Providing psycho-social support would help people living with HIV/AIDS to utilize effective ways of coping with the negative sequelae of the infection. Mental health nurses need to focus on building up effective coping strategies and enhancing strategies to improve social support by generating awareness in the community.

Strengths

Focus group discussion was done to identify the needs of the PLWH and made intervention need based. Intervention was provided on one to one basis. Ethical clearance was obtained. Instruments used were standardized. The permission was obtained by the authors of three instruments.

Limitations

The study was limited to assess the effect of the structured coping strategies intervention on coping, social support and quality of life after one month and three months only. Hence, long term effects of the intervention were not studied. The study was limited to single setting so to avoid contamination no control group was

taken. The exposure to any other information during the post intervention phase was not prevented by the researcher.

Recommendations

A similar study could be conducted with a true experimental design like pre-test post-test control group design. A Cognitive Behavior Therapy intervention for longer duration can be administered to PLWH and follow up study can be done to study its effect on other variables. The long-term effect of the coping strategies intervention can be evaluated. Other outcomes like level of disease burden, anxiety, depression, subjective wellness, stress related to disease condition can be assessed.

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