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Improving The Quality Of Life Of People Living With HIV Through Training Of Their Spouses In Nursing (Care) Skills

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Abstract

Background: During the last few decades, because of the use of antiretroviral medication, Human Immunodeficiency Virus (HIV) has converted to a chronic illness rather than a disease that quickly directs to severe sickness and death. Due to antiretroviral therapy (ART), HIV-infected patients' life expectancy has been increased; spouse training can play a vital role.

Objective: To assess the quality of life (QOL) and antiretroviral therapy (ART) adherence among PLWHIV after spouses training in nursing skills.

Methods: A randomized control trial was conducted. Blood test for HIV was done for 250 families, out of which 60 females were selected whose spouse's test was positive for HIV on Elisa's kit while they were HIV negative. The experimental group was trained in nursing skills, which consists of care for wounds and their prevention, hand washing and nail care, care of mouth, care of body wash, hair wash and towels, comb, and toothbrushes.

Result: There were 30 patients in the control group and 23 in the intervention group. The proportion of education type in the intervention group was not entirely different; however, in the control group, most of the patients were illiterate or primarily educated. There were 86.7% symptomatic in the control group and 43.5% and 56.5% asymptomatic, respectively, and AID converted in the intervention group.

Conclusion: The nursing training for spouses of HIV patients improves the quality of life of HIV-affected patients and also adheres to ART. Regular assessments of health-related quality of life may deliver significant indicators for monitoring and assessing HIV/AIDS services.

Keywords: Caregiver, HIV, ART, Quality of Life, Randomized Trials

Introduction

HIV is the state in which the individual has a long-life disease and needs care throughout his life span. In Pakistan, the prevalence is low compared to other countries, but it is increasing daily. If their spouses can provide health care at home, it will benefit their family. During the last few decades, because of the use of antiretroviral medication, Human Immunodeficiency Virus (HIV) is now a chronic illness where those affected have a longer lifespan. However, it is a very deliberating illness that leads to disability, health-related problems, poor quality of life and even death. In addition, HIV causes the challenges of poor cognitive, physical and social changes in adolescents, which have increased chances of health outcomes. Presently, HIV-linked quality of life mortality and morbidity have significantly improved with the accessibility of life-saving ART (antiretroviral therapy) because of virologic suppression (1).

Historically, HIV infection has been thought to be a disease only in young adults (7). However, evidence from epidemiological studies confirms that adults aged 50 or more years are now an ever-rising proportion of HIV/AIDS cases globally (8, 9). Furthermore, mental problems like anxiety and depression are not rare among PLWH (17-19). Among PLWH, the percentage of clinically depressive indicators or mood disorders is about 33% (20), and anxiety disorders prevalence is around 20% (21). Various psychosocial aspects, for example, stigma, isolation, lack of support, drug abuse and discrimination, may lead to feelings of anxiety and depression (20-22). Hence, mental health-related issues can have a substantial negative impact on PLWH. It has been presented that there is a greater chance of poor adherence to antiretroviral therapy (ART) for the PLWH having depressive symptoms; such people are also at high risk of mortality and morbidity related to HIV (23). ART is based on the usage of three or more antiretroviral (ARV) medicines to suppress HIV and cease the development of HIV disease (2). The World Health Organization circulates a uniform instrument for the assessment of quality of life explicitly adapted for people with HIV (WHOQOL-HIV). This has been used widely and is a valued instrument for assessing patients' perceptions of their quality of life (24). The WHOQOL-HIV is a multidimensional measure made by an exceptional international collaboration. Researchers from various cultures met to pool and approve 'universal' concepts of quality of life significant in HIV patients (25).

HIV patients regularly face deterioration in quality of life because of factors other than physical condition and disease stage, like depression, anxiety, addiction, violence, and poverty. It is hoped that a trained, caring person, up to some extent, lowers the factors mentioned above. Therefore, we aimed that this study would play a vital role in improving the quality of life of HIV-infected persons by training their spouses in nursing skills, ensuring their spouse complies with ART, maintaining adequate health charts/vital signs and ensuring they attend health care services at an early stage of any health-related problems. Furthermore, these HIV/AIDS patients are a burden on the family as they cannot work correctly and do not have enough money for themselves and their families to survive. Furthermore, no study has ever been conducted in Pakistan about improving the quality of life of people living with HIV through the training of their spouses. Spouse training can play a vital role because they can take care of their partner better, ultimately decreasing healthcare costs.

Due to the development of ART, a shift of awareness of HIV/AIDS from a deadly to a chronic and possibly controllable disease has been observed. The ART can improve survival, reduce the incidence of HIV-linked opportunistic infections, and improve the quality of life of the patients (32). However, the overall evaluation of QOL among individuals surviving HIV/AIDS is now getting more interest as more straightforward and more effective treatments are now accessible. Clinically and scientifically, ART is very productive and capable of effect significant advantages, which, regardless of a few non-positive impacts, have a positive universal effect on the quality of life and individuals' general health surviving with HIV (33). A study accomplished by Mannheimer et al. (34) among HIV people found substantial perfections in mean quality of life when enrolled in 2 clinical trials, which were multicenter antiretroviral, after one and four months on new ART treatments, and the enhancements continued one year.

Materials And Methods

This study was a randomized control trial design. Study participants were selected using non-probability and purposive sampling techniques. Discordant couples (when the husband or wife of any one of the couples is infected and the other is not) are people living with HIV, and their spouses are registered with the CHBC program. Sixty HIV-negative spouses of HIV-positive individuals were randomly selected. Of them, 30 were randomly assigned to group A in the intervention arm and 30 in the control group B. A self-developed follow-up questionnaire was used in this study (Index-I). This questionnaire also contains WHOQOL-HIV brief quality of life information of spouses living with HIV positive, and also a follow-up questionnaire related to the use of personal protective equipment (PPE), such as gloves and masks, disposal of contaminated materials and sharps, antiseptic dressing, wound care, back care, nebulization. Personal hygiene included using separate combs, towels and toothbrushes, nail care, specimen collections and transportation, and administering injections.

Results

The demographic characteristics of HIV spouses are considered in this research study. There were 30 spouses in the control group and 23 in the intervention group. The majority of the spouses in both groups were married. For the control group spouses, two-thirds of spouses' health, in general, was poor, whereas, in the intervention group, 87% of spouses' health, in general, was neither poor nor good. In the control group, almost all spouses considered themselves ill, whereas in the intervention group, 70% of spouses did not consider themselves ill.

Table 2. HIV characteristics of positive spouses

Groups	**Control (n = 30)**		**Intervention (n = 23)**		**Chi-square test**	
characteristics	**Frequency**	**Percentage**	**Frequency**	**Percentage**	**statistic**	**p-value**
HIV serostatus					41.36	<0.001
Asymptomatic	4	13.3%	10	43.5%		
Symptomatic	26	86.7%	0	.0%		
AIDS converted	0	.0%	13	56.5%		
Cause of infection with HIV					2.711	0.064
Sex with a man	0	.0%	2	8.7%		
Injecting drugs	30	100.0%	21	91.3%		
year of infected with HIV						

The HIV characteristics of the study patients. HIV serostatus showed significant association with group variable p-value <0.05; there were 86.7% symptomatic in the control group and 43.5% and 56.5% asymptomatic and AID converted in the intervention group, respectively. Furthermore, for the majority of patients in both groups, the cause of infection with HIV was injecting drugs. They exhibit the physical characteristics of the HIV patients. When it was asked whether physical pain prevents you from doing what you need to do, 40% of the patients in the control group mentioned it very much, and 35% in the intervention group reported a moderate amount. A similar trend was also observed when they were asked about physical problems related to HIV infection. When it was asked about bothering from any physical problem associated with HIV infection, 63.3% of patients in the control group reported a little, whereas, in the intervention group, 47.8% and 21.7% of patients reported a moderate amount and very much, respectively. In response to the question related to sleep satisfaction, 60% of patients in the control group were dissatisfied, and nearly half a cent of patients in the intervention group were neither satisfied nor dissatisfied—the psychological characteristics of the patients. Sixty per cent of patients from the control group enjoyed their lives a little, whereas only 17.4% of patients from the intervention group enjoyed their lives very much. Only 6.7% of patients in the control group could concentrate, whereas 21.7% of patients in the intervention group could focus. 43.3% and 47.8% of patients from the control group were neither satisfied nor dissatisfied with themselves. 50% of patients in the control group had negative feelings; however, 48% of patients in the intervention group often had negative feelings.

Reveals the independence characteristics of the patients. When patients were asked about the need for any medical treatment to function in their daily lives, 80% of patients from the control group replied a moderate amount or very much. In contrast, more than 61% of patients in the intervention group reported a little or moderate amount. It was found that 70% of patients in the control group could get around. However, 52% of patients from the intervention group were neither poor nor good to get around. Only 3.3% of patients from the control group were satisfied with their ability to perform daily living activities, whereas 17.4% of patients from the intervention group were satisfied to do so. The social characteristics of study patients. None of the patients from the intervention felt accepted by the people they knew. However, 30% of patients from the control group felt accepted by the people they knew. 46.7% and 34.8% of people in the control and intervention groups were neither satisfied nor dissatisfied with their relationship. The percentage of patients in the control group was almost three times higher than the intervention group, who were satisfied with their sex life and represented the environmental characteristics of the patients. Three-fourths of the patients from the control group were not all healthy in their physical environment, whereas 43.5% of patients in the intervention group were moderately amount of healthy in their physical environment. Nearly 50% of the patients in the intervention group had moderately enough money to meet their needs. For 61% of patients in the intervention group, moderate information was available in day-to-day life, whereas 47% of patients in the control group had similar types of information. The majority of the intervention group patients (74%) were neither satisfied nor dissatisfied with the condition of their living place; however, most of the (46.7%) control group patients were dissatisfied. Half of the control group patients were neither satisfied nor dissatisfied with access to health services, whereas only one-fourth of the intervention group patients were satisfied with access to health services. Spiritual characteristics of the study patients. Most patients (40%) in the control group reported feeling life to be meaningful to a very extent, whereas a similar proportion of the patients felt it to a moderate extent. Two-thirds of the patients in the control group reported that they were bothered a little by people blaming them for their HIV status. More than 50% of the patients in the intervention group reported that they worried a moderate amount about their death; however, only 13.3% of patients in the control group showed a moderate amount of worry about their death. Table 9 shows the hand-washing characteristics of spouses of HIV patients. All spouses of control group patients washed their hands before and after serving meals to them; however, 82% of spouses of intervention group patients did the same practice. Two-thirds and 50% of the spouses of the control and intervention groups wash their hands before and after dressing. The chi-square test was also used to identify any association of characteristic variables with grouping variables. It was found that variables always washed their hands before and after serving the meal, and wash your hands showed significant association with grouping variables p-values of < 0.005. The vital sign characteristics of HIV patients. For almost all patients in the control group, their temperature was recorded by their spouse, whereas this percentage for intervention group patients was 73.9%. None of the patients in the control group recorded their respiration and pulse, whereas 73.9% and 82.6% of patients in the intervention group recorded their pulse and respiration respectively. All three variables, temperature, pulse and respiration, showed significant association with grouping variable p-values < 0.05. It was felt that the spouse should be taken to the doctor in an emergency. None of the spouses felt for HIV patients from the control group that if their temperature is more than 102F, their spouse should be taken to the doctor. However, 50% of spouses felt patients in the intervention group that their spouse should be taken to the doctor. When asked about the difficulty in breathing, 50% and 60% of spouses replied yes for control and intervention group patients, respectively. When asked about severe uncontrolled diarrhoea and vomiting, 73.3% and 60.9% of spouses replied yes for control and intervention group patients, respectively. Variables of temperature over 102F, bed smell from wound, bleeding, unconscious fever, loss of appetite, and mild to moderate pain showed significant associations with grouping variable p-values < 0.05. Check the weight record of their spouse. For most patients (93.3) in the control group, their spouse did not record their weight, whereas 78.3% of patients in the intervention group recorded their weight. Here, both variables, record weight off your spouse and back care to prevent bad sore, showed significant associations with grouping variables p-values < 0.05. Steps the spouse followed while dressing the wound. None of the spouses of the control group patients always wore gloves; however, most spouses of intervention group patients always wore gloves. Most spouses for both groups of patients used clean clothes for bandaging. Always wearing gloves, washing the wound with an antiseptic solution and covering the wound with sterilized bandages showed significant association with grouping variable p-values < 0.005. Table 14 exhibits spouse mouth observation. Most of the spouses of the control group patients did not observe the mouth of their spouse for ulcers, bleeding, swelling, bed smell, or pain in the gums. However, many spouses in the intervention group observed their spouses' mouths for the above-said problems. Furthermore, all said variables showed significant association with grouping variable p-values < 0.005. Most of the spouses of the intervention group patient gave intramuscular injections last month, maintained the medication record, and gave medication at proper timing. None of the spouses of the control group patients performed the practices above. Two variables were given intramuscular injections last month, and maintained medication records showed significant associations. Personal hygiene of spouses: For most of the spouses of the intervention group, patients performed nail cutting, used towels and tooth brushing, used new blades for shaving, and assisted in hair washing. However, none of the spouses of the control group patient did the above-mentioned practices.

Mean WHOQOL-HIV-Brief score in HIV-infected patients

Groups	**Control (n = 30)**		**Intervention (n = 23)**		**Independent samples t-test**	
Mean score	**Mean**	**SD**	**Mean**	**SD**	**statistic**	**p-value**
Physical	8.9667	2.07586	12.6522	1.36877	-7.768	<0.001
Psychological	13.9333	2.08332	14.1739	2.14587	-.410	0.684
Level of Independence	9.3333	1.86313	12.0435	1.91829	-5.161	<0.001
Social Relationships	11.2333	1.69550	11.3478	1.99109	-.221	0.826
Environment	19.0667	2.75347	22.2609	3.26437	-3.775	<0.001
Spirituality	9.7667	2.41666	11.4783	1.75472	-2.986	0.004
Total score	76.9000	7.17923	89.5652	7.27278	-6.319	<0.001
SD; Std. Deviation						

The mean WHOQOL-HIV brief score in HIV-infected patients. Mean scores of physical and psychological levels of independence, social relationships, environment, and spirituality for intervention group patients were higher than those of control group patients. Two independent t-tests showed significant differences in physical, level of independence, environment and total score between patients of control and intervention groups p-values < 0.05.

DISCUSSION

This study aimed to assess the effectiveness of intervention (training of spouses) through the quality of life of HIV-infected patients. This study included 53 patients, 30 in the control and 23 in the intervention group. The level of education of patients in both groups was not entirely dissimilar. Variables, such as general health and considering yourself ill, showed significant associations with grouping variables (control and intervention). Concerning HIV serostatus, the majority, 86.7% in the control group, was symptomatic, and in the intervention group, 43.5% and 56.5% were asymptomatic and AID converted, respectively. It was mentioned that physical pain prevented 40% of the control group patients very much from doing what they needed to do, and 35% in the intervention group were prevented a moderate amount by physical pain from doing what they needed to do. 60% of control group patients enjoyed their lives a little; however, only 17% of patients from the intervention group enjoyed their lives very much.

Moreover, 50% of patients in the control group have always had negative feelings; however, 48% of patients from the intervention group have these negative feelings quite often. This study found that 80% of patients in the control group needed a very small or moderate amount of any medical treatment to function in their daily lives. In contrast, more than 61% of patients in the intervention group needed a little or moderate amount.

All spouses of control group patients and 82% of spouses of intervention group patients washed their hands before and after serving meals to them. Variables: always wash your hands before and after serving meals, and wash your hands were found to be significantly associated with grouping variables. In almost all patients in the control group and 74% in the interventional group, their spouse recorded their temperature. It was found that variables such as temperature, pulse, and respiration were significantly associated with grouping variables. 50% and 60% of spouses mentioned difficulty in breathing for control and intervention group patients, respectively. Variables of temperature over 102F, bed smell from wounds, bleeding, unconscious fever, loss of appetite, and mild to moderate pain exhibited significant associations with grouping variables. Most patients in the control group and their spouse did not record their weight. However, the spouse of 78.3% of patients in the intervention group recorded their weight.

Several studies (51-56) reported relationships between membership and appearance at support groups and various quality-of-life measures. Measures differed by study and comprised development in improved self-esteem and confidence, better coping abilities, and a perceived decrease in stigma. Researchers mentioned that the contribution of support groups allowed patients to seek care and start ARVs (50). Other advantages reported by Kim et al. were spill-over effects to the public, where HIV-ill individuals who were not in support groups were fortified to seek care (54). Though the benefits were generally positive, Mfecane et al. found that the male cohort who joined support groups found that participation forced them to conform in a way that negatively affected their perception of maleness (56). Several other research studies (53, 54, 57-61) reported on outcomes that may indirectly or directly influence HIV transmission, e.g., hazardous sexual behavior and exposure to HIV-positive sex partners. Gaede et al. (59). found a positive relationship between presence at support groups, health behaviors, and the use of condoms. Few researchers (57, 58, 60, 61) showed mixed findings related to the association between disclosure of HIV status and support group involvement: Skogmar (60) reported no statistical difference in disclosure rates between those who obtained either professional counseling or contributed to support groups and those who received pre and post-test counseling (standard of care). Wolters (61) reported that the help of community health workers and support group contribution led to the disclosure of the status of HIV to non-family members only in the 2nd year of program application; however, the separate effect of support groups was not shown. Another study by Hardon et al., in a mixed method involving participants from 4 African countries, Kenya, Malawi, (Uganda, and Burkina Faso), reported that involvement in a support group was linked with not revealing to partners for fear of stigma (57). Furthermore, though a randomized control trial accomplished in Tanzania found a twenty percent increase in disclosing for support group members compared to controls, the difference was not significant (Relative Risk=1.99, 95% CI: 0.909–1.59, P-value=0.189), and twelve percent of those who provided feedback regarding the disclosure reported adverse reactions like blame, anger and being asked to leave the household (58). Two research studies (53, 54) showed a relationship between support group presence and higher disclosure to other family members and spouses.

Few researches showed that support groups were linked with a decreased frequency of HIV-related symptoms- anxiety, somatic symptoms, insomnia (51), and depression (58, 62, 63). Other advantages comprised better access to ART, ART adherence, and treatment success (61, 64-66), measured as decreased risk of detectable viremia and duration of treatment failure. Achieng et al. mentioned that treatment failure time was more significant in support group patients (64). Findings from a study of a South African cohort of two hundred and sixty-eight PLHIV registered in the HIV treatment program (public sector) mentioned involvement in a support group as a forecaster of treatment success during the first six, twelve, and twenty-four months of ART (61). Muchedzi study (66) showed that women who have been tested for HIV to prevent mother-to-child transmission (PMTCT) program and registered in a support group were two times as likely to receive treatment and access care (Odds ratio = 2.33, 95% CI: 1.129–4.879) however their treatment outcomes has not been shown. Few studies reported low losses to follow-up for patients receiving ART involved in support groups. Decroo et al. found more excellent retention, with nearly 97% of patients remaining in treatment for follow-up duration with a median of 12.88 range of 8.49–13.9 months (67) and 91.79% at four years (68). Generally, the authors found that attrition in the cohort was lesser compared with the countrywide twelve-month average for Mozambique (15%) and lesser still than proportions found for sub-Saharan Africa (1.19–25.9%) (69).

Conclusion

It was concluded from this study that nursing training for spouses of HIV patients improves the quality of life of HIV-affected patients and also adherence to ART. Regular assessments of health-related quality of life may deliver significant indicators for monitoring and assessing HIV/AIDS services.

Recommendation

No previous research study has ever been conducted in Pakistan regarding the assessment of spouse training for improving health-related quality of life of HIV patients. It is recommended to expand the extent of such study to the larger scale through different community home-based programs so that improving results can be generalized to the larger population, ultimately beneficial for patients who already lost their hopes of life.

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