

Effectiveness Of Educating HIV Patients And Improvement In Quality Of Life

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Abstract: *To investigate the effectiveness of Psycho-education on Quality of life (QOL) among People living with HIV/AIDS (PLWHA). A convenience sample of 120 people living with HIV/AIDS between the age of 20-40 years who have low QOL score in HAT-QOL scale were selected and divided into experimental and control group after initial scrutiny. Experimental group was given psycho-education and control group was kept under observation. Data analysis involved General linear model repeated measures of ANOVA to measure the effect of Psycho-education on QOL. Findings indicated that Psycho- education improve the level of QOL among the target population and there was a positive effect on QOL and its factors namely overall function, life satisfaction, health worries, financial worries, medication worries, HIV mastery, disclosure worries, provide trust, sexual function.*

Keywords: Quality of life, Psycho-education, PLWHA

1. Introduction

Human immunodeficiency virus (HIV) is a retrovirus that infects cells of the immune system, destroying or impairing their function. As the infection progresses, the immune system becomes weaker, and the person becomes more susceptible to infections. The most advanced stage of HIV infection is acquired immunodeficiency syndrome (AIDS). It may take 10-15 years for an HIV-infected person to develop AIDS (WHO).

According to UNAIDS global report (2009), it is estimated that there are 33.3 million people worldwide and 4.9 Million people in Asian continental infected with HIV/AIDS. According to National Aids Control Organization (NACO) report 2010, India has 2.27 million HIV-infected persons, the third highest in the world after South Africa and Nigeria. According to Karnataka State Aids Prevention Society (KSAPS) Consolidated ART report July 2012, the scenario of Karnataka state is 0.223 million adult. HIV/AIDS researchers are projecting an estimated 65 million deaths from AIDS by the year 2020; more than triple the number who died in the first 20 years of the epidemic unless major efforts are put toward primary prevention or major developments in treatment take place (Altman, 2002).

People living with HIV/AIDS [PLWHA] struggle with numerous social problems such as stigma, poverty, depression, substance abuse, and cultural beliefs. This can affect their QOL not only from the physical health aspect, but also from mental and social health point of view and cause numerous problems in useful activities and interests of the patients (Aranda-Naranjo, 2004).

1.1 Quality of life

Quality of life (QOL) is a term that is popularly used to convey an overall sense of well-being and includes aspects such as happiness and satisfaction with life as a whole.

World Health Organization (WHO 1998) has defined QOL as "Individuals perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, standards, expectations and concerns." The Constitution of the World Health Organization (WHO) defines health as "A state of complete physical, mental, and social well-being not merely the absence of disease.

"Quality of life relates both to adequacy of material circumstances and to personal feelings about these circumstances. It includes "overall subjective feelings of well being that are closely related to morale, happiness and satisfaction". Further as health is generally cited as one of the most important determinants of overall quality of life, it has been suggested that quality of life may be uniquely affected by specific disease process such as AIDS (Watchel & Piette 1992)

Previous studies have examined the relationships between health-related quality of life (HRQOL) and depression, social supports, HIV infection stage, functioning in daily living, employment, perceived health status, severity of HIV infection symptoms, stress and adverse effect of treatments for HIV infection among subjects living with HIV infection (Murri, Fantoni, Borgo (2003). Living with HIV can impact upon many of the factors that affect our quality of life; not only our physical health, but also our mental and social well-being. After all, HIV is not simply a virus that causes disease, but also a social and historical event that impacts how others react towards us. Issues including personal safety and human rights as well as other aspects of the political and social infrastructure can radically affect our quality of life.

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rights as well as other aspects of the political and social infrastructure can radically affect our quality of life.

There have been many papers published from studies on factors influencing the QOL in patients with HIV, but the results from our study are interesting because of intervention that we are using to change/improve QOL in PLWHA.

Abasiubong, Festus, Ekott, John (2010) have compared QOL in males and females of PLWHA. Females showed lower quality of life in comparable domains than males. The differences in life satisfaction and health worries were statistically significant. Lechner, Antoni, Tobin, Weiss. (2003) in their study tested the effects of a 10-week group-based cognitive-behavioral stress management/expressive-supportive therapy intervention (CBSM+) and a time-matched individual psycho-educational. While women in the CBSM+ group condition showed a significant improvement in mental health QOL from pre- to post-intervention, women in the individual condition did not change. Hasanah, Zaliha, Mahiran (2010) the y suggests that the patients with HIV infection should receive better psycho-education and psychological intervention.

Important elements in psycho-education are:

- Information transfer (symptomatology of the disturbance, causes, treatment concepts, etc.)
- Emotional discharge (understanding to promote, exchange of experiences with others concerning, contacts, etc.)
- Support of a medication or psychotherapeutic treatment, as cooperation is promoted between the mental health professional and patient (compliance, adherence).
- Assistance to self-help (e.g. training, as crisis situations are promptly recognized and what steps should be taken to be able to help the patient).

Psycho-education is not necessarily psychotherapy as it does not exclusively deal with psychological or mental illness' but rather any condition you or a relative or a friend is experiencing. For example breast cancer is not a mental illness however a person with breast cancer may feel anxious, disheartened and scared about their condition and therefore it is said that the cancer is bringing about psychological stressors. Research has shown that the more a person is aware of their illness and how it affects their own lives and that of others, the more control that person has over their illness. This means that, with appropriate knowledge and techniques, episodes of mental illness occur less often and are usually less severe in intensity and duration

Psycho-education can be implemented in a number of different formats and settings. The format depends entirely on the disorder, the developmental age of the individual and their individual needs. Psycho-education can be

1. Individual based
2. Family based
3. Group based

Psycho-education most commonly involves the individual with the disorder, the patient or client, but in some situations psycho-education is implemented only to the people who deal with the patient on a day to day basis such as family, friends, teachers or caretakers.

1.2 Carol m Anderson's Psycho-education

The popularization and development of the term psycho-education into its current form is widely attributed to the American researcher Anderson in 1980 in the context of the treatment of schizophrenia. His research concentrated on educating relatives concerning the symptoms and the process of the schizophrenia. Also, his research focused on the stabilization of social authority and on the improvement in handling of the family members among themselves. Finally, Anderson's research included more effective stress management techniques. So, the present study carried out with an aim of introducing Psycho-education to improve QOL among PLWHA.

2. Rationale for the study

A number of studies (Murri, Fantoni, Borgo and others (2003), Abasiubong, Festus ,Ekott, John and others (2010) have reported on QOL in PLWHA but very few studies (Lechner ,Antoni, Tobin, Weiss and others (2003) have used intervention to improve the factors of QOL.

The reason for using Psycho-education group intervention is because of the short duration which has a long-term effect on coping methods. The group model is applicable because of its cost-effectiveness and also because the interaction of patients within the group provides a significant source of emotional support.

3. Objective

To study the effect of Psycho-education on QOL among people living with HIV/AIDS.

4. Hypotheses

- H1: Psycho-education will improve QOL among PLWHA
- H2: There is a significant difference in rate of improvement on QOL in men and women

5. Method

5.1 Participants

The study sample consists of 120 PLWHA between the ages of 20-40 years who has registered in ART centre, KR Hospital Mysore. HAT-QOL scale was administered to a large group and selected only 120 PLWHA, who have low score on QOL scale. Participants who have any other disease like TB, STD and the like rather than HIV were excluded.

5.2 Instruments

1. Personal information schedule (PIS): This was been developed by investigator and it includes identification data, socio economic status, etc
2. HAT-QOL instrument: HIV/AIDS Targeted Quality of Life instrument (HAT-QOL) (William.C.Holmes 1999). This

quality of life measure is a validated 34-item instrument that is HIV disease specific and measures nine dimensions: overall function, life satisfaction, health worries, financial worries, medication worries, HIV mastery, disclosure worries, provider trust, and sexual function. Holmes (1998, 1999) reported on the development and validation of the scale. The subscale consists of four Likert scaled items. The subscale is scored so that the final score is transformed into a linear 0–100 scale, where 0 is the worst score possible and 100 is the best score possible. The Cronbach alpha reliability coefficient of this 4-item revised scale was 0.86 in this sample; Construct validity was determined through various self-reported HIV disease markers and self-reported socio-demographic variables, internal

5.3 Procedure

Ethical consideration: Permission was obtained by the University of Mysore and Institutional Human Ethical Committee (IHEC), University of Mysore, to conduct the research study on human beings and to use psycho-education intervention.

Consent form: standard consent form was used to take consent from PLWHA

The study was carried out in three phases:

Phase1: Equating the two groups and Pretest

Phase2: Intervention

Phase3: Post test and follow up

Phase 1: Equating the two groups and Pretest administration

The scale was administered to a large group approximately 300 PLWHA, only 120 PLWHA were selected who have low score on HAT-QOL scale. The participants were divided into two group's i.e. experimental group and control group. Selected participants were asked for written informed consent to participate in the study. Experimental group further randomly divided into four groups; each group consists of 15 subjects. Each sub group was given six sessions for 60-min about duration of a week. Control group was kept under observation

Table 1: Details of session

No. Of Groups	4
Group Size	15
No. of sessions	6
Session duration	60 min
Session interval	1 week
Total duration	6 hours

Phase 2: Intervention

Psycho-education refers to the education offered to people who live with a psychological disturbance. Psycho-education is not a treatment. It is designed to be part of an overall treatment plan. Psycho-education has been around for a long time. It has remained consistently popular as a tool for families and caregivers to be able to make sense of what is

happening to a person who is experiencing a mental disturbance. The concept consists of four elements:

1. Briefing the patients about their illness
2. Problem solving training
3. Communication training
4. Self-assertiveness training

The Psycho-education was done in six sessions for experimental group. The intervention session's abstract is as follows.

Session 1: Rapport building was done by introducing myself and making participants to introduce each other and had a casual talk. Presented the game "out of the box thinking" as an icebreaker and to showcase different perceptions.

Before briefing the group about HIV causes, symptom and treatment, experimenter tried to collect information what they know about HIV. Participants were asked some questions like;

What is HIV? How it is transmitted? What are the symptoms? Dos and Don'ts?

It was an exchange of thoughts on what they know and experienced being HIV. After the discussions on HIV researcher tried to remove the misconceptions by educating them on HIV through lecture and ppt slides. Gave them complete confidence of keeping things confidential and anonymous.

Session 2: Negative emotions were reduced by giving motivational quotes and telling inspiring stories of great personalities who undergone incurable diseases to the subjects. To fill hope and inspiration to live with all distress and disharmony they were given talk on motivational quotes by Vivekananda, Ramakrishna paramahamsa (spiritual leaders). They were told story about veenadhari, Ramakrishna Paramahamsa.

Session 3: Highlighted about the harm and danger of stigma and discrimination through role play on fear about disclosing HIV, ignoring stigmatizes, avoiding situations and the like. Two skits were played by a group of girls before PLWHA. One skit was on stigma and its danger another role play was on discrimination. At the end PLWHA were made to discuss on role play, it was an open discussion.

Session 4: Provided education on relevant rights and laws on HIV stigma and discrimination. NACO/KSAPS role in legal literacy and make the participants to become familiar with legal information and facilities available. First they were asked whether they are aware of any legal information on HIV stigma and discrimination. Later they were provided information on sources of law and law related to discrimination like article 14, 15, 16 which is a fundamental law. Information on consent and confidentiality were also given talk on .Toll free number of HIV legal service centre was provided to ask any queries. KSAPS plan of legal service centers on all ART centers i.e., 41 centers in 30 districts information was also given.

Session 5: Self assertiveness training was provided. First they were told the difference between an assertive person and non assertive person. Given some tips to help build, boost, and develop self-confidence and assertiveness. Assertive techniques 1. Broken Record - Be persistent and keep saying what you want over and over again without getting angry, irritated, or loud. Stick to your point. 2. Free Information - Learn to listen to the other person and follow-up on free information people offer about themselves. This free information gives you something to talk about. 3. Self-Disclosure - Assertively disclose information about yourself - how you think, feel, and react to the other person's information. This gives the other person information about you. 4. Fogging - An assertive coping skill is dealing with criticism. Do not deny any criticism and do not counter-attack with criticism of your own. Make the group open minded, self confident.

Session 6: Suggestions were given to improve quality of life by giving talk on practicing healthy habits like exercise, meditation, walking, and positive thinking. Role of diet and nutrition in the management of PLWHA were provided like meal plan, what to eat and what to avoid. Uses of pranayama and meditation and yoga were also told. Some of the exercise postures were shown through slides to practice all this was done to boost participants to manage with their symptoms and live with hope. Finally gave summary on overall sessions based on observations and also took feedback.

Phase 3: Post test and follow up

After one week of last session of intervention, HAT- QOL scale was administered once again for both the groups. The same intervention was given to the control group also from ethical point of view.

5.4 Data analysis

In order to test the hypotheses, a computer based SPSS package was used to analyze the data. The ‘t’ test was used to equate the groups and General Linear Model- repeated measures of ANOVA were utilized to find out the significance of variance within-subjects group effects and between-subjects group effects.

6. Results and Discussion

Table 2: Mean and S.D. of pre-test and post-test scores on QOL of male and female of both experimental and control groups.

GROUP	GENDER	PRETEST		POSTTEST		CHANGE
		MEAN	SD	MEAN	SD	
EXPERIMENTAL	MALE	87.03	10.662	120.13	10.576	33.1
	FEMALE	87.57	11.313	118.03	9.768	30.46
	TOTAL	87.30	10.902	119.08	10.149	31.78
CONTROL	MALE	86.50	14.056	89.53	12.846	3.03
	FEMALE	82.67	13.932	85.53	13.059	2.86
	TOTAL	84.58	14.009	87.53	13.000	2.95
TOTAL	MALE	86.77	12.372	104.83	19.343	17.76
	FEMALE	85.12	12.822	101.78	19.981	16.06
	TOTAL	85.94	12.573	103.31	19.642	17.37

Table 3: A summary result of GLM repeated measures ANOVA within and between subjects of qol (total) of male and female both experimental and control groups in pretest and post test situation

SOURCE OF VARIANCE	WITHIN SUBJECT EFFECTS		F	P
	SUM OF SQUARES	MEAN SQUARES		
Change pre & post test	18096.067	18096.067	1122.357	.000
Change experimental & control group	12470.417	12470.417	773.442	.000
Change Gender	29.400	29.400	1.823	.180
Interaction exp-cont groups & gender	22.817	22.817	1.415	.237
Error (change)	1870.300	16.123		
	BETWEEN SUBJECT EFFECTS			
	SUM OF SQUARES	MEAN SQUARES		
Exp-cont groups	17613.067	17613.067	63.377	.000
Gender	331.350	331.350	1.192	.277
Exp-cont groups & gender	147.267	147.267	.530	.468

In QOL scores, Repeated Measures of ANOVA revealed a significant increase from pre to post test situation irrespective of the groups. ‘F’ value is 1122.357 was found to be highly significant (p = .000). Irrespective of the groups in pre-test, the mean QOL score was 85.94 is increased to 103.31 with the increase of 17.37 scores which found to be significant. When increase in the QOL scores with reference to groups are concerned again a significant ‘F’ value was observed (F=773.442; p = .000) indicating a differential increase for experimental and control groups. From mean values it is evident that experimental group had an increase of 31.78 scores (from 87.30 to 119.08), whereas control group had increase of only 2.95 scores (from 84.58 to 87.53). So the increase in the QOL has basically in the experimental group which can be attributed to the effectiveness of Psycho-education. However the interactions between gender with respect to change in the scores and gender with respect to groups and change in scores were found to be non-significant.

In between-subjects effects between groups (irrespective of conditions) together significant difference were observed (F = 63.77; p = .000). However gender wise and interaction between groups and gender was found to be non-significant. The overall result indicates that Psycho-education intervention is highly effective in improving QOL and domains of QOL like overall function, life satisfaction, health worries, financial worries, medication worries, HIV mastery, disclosure worries, provide trust and sexual function of PLWHA.

Lechner ,Antoni,Tobin,Weiss .(2003) in their study tested the effects of a 10-week group-based cognitive-behavioral stress management/expressive-supportive therapy intervention (CBSM+) and a time-matched individual psycho-educational condition QOL scores increased over the course of both interventions for the total QOL score and the QOL domains, While women in the CBSM+ group condition showed a significant improvement in mental health QOL

from pre- to post-intervention, women in the individual condition did not change. Findings of the present study also report the same of intervention being effect in improving QOL.

Chandra, Satyanarayana , Satishchandra and others (2009) Findings says men reported significantly higher QOL in the following facets-positive feeling, sexual activity, financial resources and transport, while women reported significantly higher QOL on the forgiveness and blame facet. Men reported better QOL in the environmental domain while women had higher scores on the spirituality/religion and personal beliefs domain. Understanding these gender differences may provide potentially useful information for tailoring interventions to enhance QOL among PLWHA. Fatiregun, Mofolorunsho and others (2009) Result indicates opposite finding of Chandra(2009) i.e., women had a higher QOL score compared to men in virtually all domains and a significantly higher level on the independence domain.

Findings of the present study support the above studies of intervention being effect in improving QOL and do not support the differences in gender because there is no differences between the genders in QOL were found. From this study it is evident that the effect of Psycho-education is same irrespective of gender. The reason for the observed QOL scores in women equal to men could be due to show of concern and equal opportunity in sessions among the females in our study environment. The experimental group is found to have improved its QOL compared to the control group after the Psycho-education intervention.

7. Conclusions

1. The Psycho-education has made a positive effect on improving QOL and its factors namely, overall function, life satisfaction, health worries, financial worries, medication worries, HIV mastery, disclosure worries, provide trust and sexual function of PLWHA.
2. There is no difference between men and women in rate of improvement on QOL.

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