A study to evaluate the effectiveness of a structured counselling programme on the knowledge of self care behaviour, coping strategies and quality of life among HIV infected postnatal mothers and a qualitative analysis of their lived experiences in selected hospitals of Belgaum, Karnataka.

By
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ABSTRACT
The study entitled “A study to evaluate the effectiveness of a structured counseling programme on the knowledge of self care behavior, coping strategies and quality of life among HIV infected postnatal mothers and a qualitative analysis of their lived experiences, in selected hospitals of Belgaum Division, Karnataka,” was conducted by Prof. (Mrs) Sudha A. Raddi in partial fulfillment of the requirements for the award of the degree of Doctor of Philosophy under the Rajiv Gandhi University Health Sciences, Bangalore, Karnataka.

BACKGROUND OF THE STUDY
More than 25 million people have died of AIDS since 1981. By the end of 2005, women accounted for 48% of all adults living with Human Immuno Deficiency Virus (HIV) worldwide. As per the update information on 1st July 2006, world over 30-40 million people are HIV infected with means 1 in 250 persons is HIV infected. Ninety percent of HIV cases are in the developing countries. Twelve thousand of the new infections occurring everyday are among people aged between 15-49, the reproductive and economically productive age group. Fifty percent of the new
infections in this age group occur among women and 50% are in the age group of 15-24, the youth of the countries.

"I would rather be HIV positive than barren woman", said Aruna, one HIV infected woman whose husband was HIV positive. Such is the personal and social scenario of women in India who cannot escape this death trap of HIV/AIDS. Each mother's death is an individual tragedy, made inevitable by the inequalities that condition women's lives. Peter Piot, the executive Director of UNAIDS, remarked that there has been 'Ferminization of the epidemic of HIV/AIDS'. He said "Every year we seen an increase in the number of women infected with HIV. And since women are the main caregivers and source of household labour, their illness means the collapse of the family community care systems and household protection. Every 20 seconds a new infection occurs in a woman somewhere in the world.

India has the second highest number of people living with HIV/AIDS in the world. After south Africa, India accounts almost 10% of the 40 million people living with HIV/AIDS globally and over 60% of the 7.4 million people living with HIV/AIDS in the Asia and pacific region.

The study is a blend of both quantitative and qualitative perspective and highlights on how self care behaviour, coping strategies, quality of life and lived experiences are inter linked and are basic measures to plan health promoting behaviours in postnatal mothers infected with HIV. It is significant to nursing because exploring the self care behaviour, coping strategies, quality of life and measuring the effectiveness of structured counseling programme on these variables will lead nurses in planning holistic care and developing new interventions aimed at reducing apprehension, anxiety and knowledge deficit regarding HIV status, and identify coping strategies, quality of life and lived experiences of postnatal mothers infected with HIV.

Objectives of the study are to
1. assess the knowledge of HIV infected postnatal mothers regarding self care behaviour using a structured knowledge questionnaire.

2. identify coping strategies used among HIV infected postnatal mothers using Jaloweic's coping scale.

3. determine the quality of life (QOL) of HIV infected postnatal mothers as measured by HAT QOL scoring guide.

4. Evaluate the effectiveness of structured counseling programme in terms of
   a. gain in knowledge on HIV and self care behavior scores
   b. increase in use and effectiveness of coping strategies scores
   c. increase in QOL scores

5. find the association between pretest level of knowledge, coping strategies & QOL with selected variables.

6. analyze the lived experiences of HIV infected postnatal mother using a phenomenological approach.

**RESEARCH METHODS**

The conceptual frame work used for the present study was based on Imogene M. King’s Theory of Goal Attainment. It identifies factors of perception, judgment, interaction and transaction between the research investigator and postnatal mothers regarding HIV. The model contributes a solution for understanding how clients can gain knowledge of self-care behavior, improve coping strategies and quality of life through structured counseling programme.

The hypothesis formulated for the present study were:

**H1**: The mean post test knowledge scores of the HIV infected postnatal mothers on knowledge of self care behaviour will be significantly higher than their mean pre-test knowledge scores as measured by the structured knowledge questionnaire at 0.05 level of significance.
**H2**: The mean post test scores of coping strategies among HIV infected postnatal mothers will be significantly higher than their mean pre-test coping scores as measured by the Jalowiec coping scale at 0.05 level of significance.

**H3**: The mean post test scores of QOL among HIV infected postnatal mothers will be significantly higher than their mean pre-test QOL scores as measured by the HAT QOL scale at 0.05 level of significance.

**H4**: There will be a significant association between the pretest level of knowledge, coping strategies & QOL with selected variables at 0.05 level of significance.

Multimethod Research methodology with a blend of both quantitative and qualitative perspective was used for the study. True experimental - Solomon Four group design and Phenomenological Design, with Evaluative and Qualitative approaches respectively were used for the study. The Independent variable of study was structured counseling programme on self care behaviour for HIV infected postnatal mothers and Dependent variable were Knowledge regarding self care behavior, quality of life and coping strategies.

The study was conducted on 90 HIV infected postnatal mothers attending ART centres of selected hospitals and selected NGO’s of Belgaum. The sample for the present study were in Phase I, 80 HIV infected postnatal mothers who were selected by Random sampling; In Phase II, 10 HIV infected postnatal mothers who were selected by using Criterion sampling technique. Data was collected through structured knowledge questionnaire, Jaloweic's coping scale, William C. Holmes HIV/AIDS-Targeted QOL Scale (HAT-QOL Scale) and Semistructured interview schedule. The data obtained was tabulated and analyzed

Phase I: Descriptive and inferential statistics

Descriptive statistics: Frequency, percentage, mean, median, standard, deviation

Inferential statistics: Paired ‘t’ test
Phase II: Followed steps of coloizzi's method of phenomenology in transcribing the data and deriving formulated meaning from significant statements and form main emergent themes.

MAJOR FINDINGS OF THE STUDY:

Phase I:
Findings related to Background information on HIV infected postnatal mothers.

According to the age group majority 45 (56.25%) were in the age group of 25-29 years, and 03 (3.75%) were below 19 years.

With respect to the marital status 42 (52.5%) were married, 3 (3.75%) were unmarried, 17 (21.25%) were divorcee and 18 (22.5%) were widow.

Majority 38 (47.5%) belonged to nuclear family, 11 (13.75%) belonged to extended family.

Majority of women, 57 (71.25%) expressed unsatisfactory relationship with their spouse, only 23 (28.75%) expressed satisfactory relationship with their spouse.

24 (30%) of HIV infected postnatal mothers had higher secondary education, while 24 (30%) had primary, 18 (22.5%) had secondary and 13 (16.25%) had graduation completed.

Similarly among husbands of the HIV infected postnatal mothers majority 35 (43.75%) had primary education while 22 (27.5%) had secondary, 13 (16.25%) had higher secondary and 10 (12.5%) had completed graduation.

About the occupation among HIV infected postnatal mothers majority 32 (40%) were skilled workers, 24 (30%) were unskilled workers, 21 (26.25%) were unemployed and minimum 3 (3.75%) were professional.
Regarding their husbands, maximum 45 (56.25%) were skilled workers, 33 (41.25%) were unskilled, 12 (15%) were professional and minimum 10 (12.5%) were unemployed.

Maximum 42 (52.5%) had monthly income of Rs.4001 – 5000, 22 (27.5%) had income of Rs. 5001 & above, 12 (15%) had Rs.3001 – 4000 and minimum 4 (5%) had below Rs.2000 monthly income.

Maximum support for the HIV infected postnatal mother was through their parents 35 (43.75%), spouse support among 22 (27.5%), inlaws 13 (16.25%) support and 20 (25%) from significant others.

Majority of the husbands 56 (70%) were HIV infected, 18 (22.5%) were not infected and 6 (7.5%) were not knowing whether their husbands were HIV infected or no.

Most of the HIV infected postnatal mothers 53 (66.25%) did not have any information about HIV prior to diagnosis and minimum 27 (33.75%) had some information about HIV prior to diagnosis.

Maximum 34 (42.5%) HIV infected postnatal mothers were infected since 3-5 years, 20 (25%) since 1-3 years, 14 (17.5%) since more than 5 years and 12 (15%) since less than 1 year.

Most of the HIV infected postnatal mothers child 34 (42.5%) were not infected with HIV, 24 (25%) were infected with HIV and 22 (27.5%) were infected.

46 (38.33%) HIV infected postnatal mothers did not know how they have contracted HIV infection, 18 (15%) said they contracted from sexual partners, 13 (10.83%) from mothers and 3 (2.5%) from hospital.

**Findings related to knowledge of self care behavior among HIV infected postnatal mothers.**

Prior to the administration of the structured teaching programme the HIV infected women had maximum knowledge (53.6%) in the area of HIV/AIDS while
minimum knowledge (48.2%) about health promoting behaviour. However, on administration of the structured teaching programme, the scores showed considerably greater gain (41%) in the area of health promoting behaviour. The difference between the mean pre-test and the post-test percentage scores indicates the actual gain. The difference between the mean pre-test percentage score and the possible score is a measure of possible gain. (e.g. mean pretest percentage in the knowledge area of HIV / AIDS is 53.6%. The possible percentage score expected is 100%. Therefore 100% - 53.6% = 46.4 is the possible gain).

**Effectiveness of structured counseling programme in terms of**

**A. Gain in knowledge scores:** The mean post test knowledge scores of the HIV infected postnatal mothers on knowledge of self care behavior will be significantly higher than their mean pre test knowledge scores as measured by the structured knowledge questionnaire at 0.05 level of significance.

**B. QoL Scores:** The mean post test scores of QoL among HIV infected postnatal mothers will be significantly higher than their mean pre test QoL scores as measured by the HAT QoL BREF scale at 0.05 level of significance.

**C. Coping Scores:** The mean post test scores of coping strategies of use among HIV infected postnatal mothers will be significantly higher than their mean pre test coping scores as measured by jaloweic coping scale.

**Findings related to the association between pretest level of knowledge, coping strategies & QOL with selected variables.**

**A. Association between pretest level of knowledge & selected demographic variables.**

The chi-square value computed between knowledge & selected demographic variables did not show a statistically significant association. The variables like
age ($\chi^2=2.808$ at df 6), marital status ($\chi^2=0.557$ at df 6), type of family ($\chi^2=0.888$ at df 4), educational status (self) ($\chi^2=0.837$ at df 6), educational status (husband) ($\chi^2=0.994$ at df 6), occupational status (self) ($\chi^2=0.822$ at df 6), occupational status (husband) ($\chi^2=0.289$ at df 6), monthly income of family ($\chi^2=0.976$ at df 6), support in time of need ($\chi^2=0.570$ at df 6), husband’s HIV infection status ($\chi^2=0.7909$ at df 4), information about HIV prior to diagnosis ($\chi^2=0.0383$ at df 2), knowing since when you are HIV infected ($\chi^2=0.9737$ at df 6), status of child infected with HIV ($\chi^2=0.7890$ at df 4), how do you think you have contracted HIV infection ($\chi^2=0.9841$ at df 6) among HIV infected postnatal mothers at 0.05 level of significance. Hence null hypothesis $H_0$ is accepted. Thus it was inferred that the pretest level of knowledge was independent of selected variables.

B. Association between pretest level of coping strategies & selected demographic variables.

The chi-square value computed between selected variables and coping strategies did not show a statistically significant association. The use and effectiveness of coping strategies were independent of variables like age ($\chi^2=0.988$ (use), $\chi^2=0.999$ (effect) at df 3), marital status ($\chi^2=0.515$ (use), $\chi^2=0.616$ (effect) at df 3), type of family ($\chi^2=0.995$ (use), $\chi^2=0.998$ (effect) at df 2), educational status (self) ($\chi^2=0.884$ (use), $\chi^2=0.622$ (effect) at df 3), educational status (husband) ($\chi^2=0.219$ (use), $\chi^2=0.026$ (effect) at df 3), occupational status (self) ($\chi^2=0.977$ (use), $\chi^2=0.603$ (effect) at df 3), occupational status (husband) ($\chi^2=0.999$ (use), $\chi^2=0.676$ (effect) at df 3), monthly income of family ($\chi^2=0.793$ (use), $\chi^2=0.845$ (effect) at df 3), support in time of need ($\chi^2=0.181$ (use), $\chi^2=0.991$ (effect) at df 3), husband’s HIV infection status ($\chi^2=0.999$ (use), $\chi^2=0.571$ (effect) at df 1), information about HIV prior to diagnosis ($\chi^2=0.733$ (use), $\chi^2=0.644$ (effect) at df 1), knowing since
when you are HIV infected ($\chi^2=0.886$ (use), $\chi^2=0.876$ (effect) at df 3), status of child infected with HIV ($\chi^2=0.359$ (use), $\chi^2=0.426$ (effect) at df 2), how do you think you have contracted HIV infection ($\chi^2=0.999$ (use), $\chi^2=0.558$ (effect) at df 3) among HIV infected postnatal mothers at 0.05 level of significance. Hence null hypothesis $H_{02}$ is accepted. Thus it was inferred that the use and effectiveness of coping strategies were independent of selected variables.

C. Association between pretest level of QOL & selected demographic variables.

No statistically significant association was found between quality of life and selected variables like age ($\chi^2=0.951$ at df 3), marital status ($\chi^2=0.992$ at df 3), type of family ($\chi^2=0.994$ at df 2), educational status (self) ($\chi^2=0.884$ at df 3), educational status (husband) ($\chi^2=0.972$ at df 3), occupational status (self) ($\chi^2=0.978$ at df 3), occupational status (husband) ($\chi^2=0.999$ at df 3), monthly income of family ($\chi^2=0.793$ at df 3), support in time of need ($\chi^2=0.181$ at df 3), husband’s HIV infection status ($\chi^2=0.9991$ at df 2), information about HIV prior to diagnosis ($\chi^2=0.7331$ at df 1), knowing since when you are HIV infected ($\chi^2=0.8861$ at df 3), status of child infected with HIV ($\chi^2=0.3592$ at df 2), how do you think you have contracted HIV infection ($\chi^2=0.9999$ at df 3) among HIV infected postnatal mothers at 0.05 level of significance. Thus in relation to above finding the null hypothesis, $H_{03}$ is accepted. This indicates that the quality of life is independent of selected variables.

Phase II: Lived experiences of HIV positive postnatal mothers major themes were identified.

From HIV infected mothers perspective four essential themes were developed and were as follows:

1. “Living with HIV status”
2. “Accepting motherhood with uncertainty”
3. “The life world of an HIV positive postnatal mother”
4. The hope of having a normal life or self and child”

Recommendations:

- Randomized control trial can be carried out to evaluate effectiveness of a structured teaching programme on the knowledge and practice of self care behaviour among HIV infected postnatal mothers.
- A cross sectional study can be conducted to assess the knowledge of self care behaviour among HIV infected postnatal mothers in different stages of the disease.
- A descriptive study can be conducted to identify the psychosocial and psychological correlates of self care among HIV infected postnatal mothers in view of developing a training module for comprehensive HIV / AIDS nursing care.
- The findings of the study can be used as evidence based result in implementing policies & health care measures for the HIV mothers by Government agencies & NGO’s.
- The evidence based results can be used as a benchmark to assess the knowledge of self care behaviour, coping strategies, QOL & other parameters like stigma, hope among HIV patients before & after implementation of modules related to Health Education & Self Care Measures.