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Effectiveness of Comprehensive Hemophilia Education Program (CHEP) on health related Quality of Life and Clinical outcomes of children and young people with hemophilia in selected hemophila clinics of Karnataka.

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ABSTRACT

Hemophilia is a genetic disease that impairs quality of life due to its chronicity of nature where the individual will experience spontaneous bleeding or bleeding after an injury which requires frequent visits to the hospital for treatment. Nurses have a major role in creating awareness which influence quality of life and clinical outcomes.

A research study entitled "Effectiveness of Comprehensive Hemophilia Education Program (CHEP) on health related quality of life and clinical outcomes of children and young people with hemophilia in selected hemophilia clinics of Karnataka" was carried out at MAHE, Manipal by Ms.Anjalin Dsouza for the award of PHD Nursing degree.

The objectives of the study was to explore the perceived barriers to hemophilia treatment and to find the effectiveness of the comprehensive hemophilia education program in terms of improvement in knowledge among mothers' of children and young people. The study also aimed to find out the effectiveness of CHEP on health related quality of life and clinical outcomes.

The conceptual framework for the study was based on Nola J Pender's Health Promotion Model (HPM). A Quasi-experimental design with nonequivalent groups was adopted for the study. The purposive sampling technique was used. The experimental group received CHEP and the control group received routine care. Perceived barriers to hemophilia was measured at baseline and clinical outcomes were measured at baseline and at 18 months. Knowledge on hemophilia and HRQoL was measured at baseline, six months, 12 months and 18 months.

The data collection tools used were: Proforma on baseline data and disease variables, socioeconomic status scale, structured knowledge questionnaire on hemophilia, Hemo QoL, A36 Hemofilia-QoL, perceived barriers to hemophilia treatment and hemophilia joint health Score.

Content validity was established by giving the tools to experts for review a feedback, pretesting and reliability was done. All the required permissions were sought, including the approval from Institutional Ethical Clearance Committee before the commencement of the study. Informed consent was obtained from participants and parents.

People with hemophilia visiting the hemophilia treatment centre and Hemophilia Society Manipal chapter was selected as the intervention group and the Hemophilia Society Bangalore chapter was the control group. The pilot study was conducted and the study found to be feasible. Data was collected from 82 participants from experimental group and 83 from control group.

The gathered data was coded and summarized in a master data sheet and was analyzed using Statistical Package for Social Sciences (SPSS) 16.0 version. Both the descriptive and inferential statistics were used identifying the results.

The results of the study showed that mean age of pwh in experimental group was 13.93±6.05 years and 13.51±5.06 years in the control group. Majority of participants in experimental and control group (86.6% and 84.2%) were having hemophilia A. Similarly majority of participants (53.7% in experimental group and 56.6% in control group) were having moderate hemophilia.

Study revealed that perceived barriers were similar in both the groups. Mean scores were higher (>3.0) in the area of financial difficulty, difficulty in accessing to hospital, no effect of treatment on symptoms, social and family issues and difficulty in accessing information materials. Mothers' of children [$F(1, 67) = 23.209$ and, $p < 0.01$] and young people [$F(1, 93) = 13.12$ and , $p < 0.01$] in the experimental group showed significant improvement in the knowledge.

There was a significant improvement in HRQoL among 8-12years of experimental group [$F(1,43) = 5.61$, $p = 0.01$] when compared to the control group. The educational program was

effective in improving HRQoL in the domains of family, perceived support and future among pwh of 13-16 years. The study also found that there was no significant improvement in HRQoL among 6-7 years and 17-24 years. The findings of the present study showed that, in comparison to the control group statistically significant reduction in number of bleeds was obtained among participants of experimental group from first 6 months to 7-12months ($t = 3.24$, $p<0.01$).

Study concluded that, educational program was found to be informative, comprehensive and easy to understand. Nurses play an important role in improving knowledge and HRQoL among pwh through educational program.

Key words: Hemophilia, Children and young people, Knowledge, Clinical Outcomes, Health Related Quality of Life, Hemo-Qol, Comprehensive Hemophilia Education Program.