JOURNAL OF NURSING UPDATES
(A peer reviewed journal)

Journal Office
Govt. College of Nursing, Medical College P.O., Thiruvananthapuram -11, Ph : 0471 - 2444290

May 2020 | Volume IV | Issue II

FOR INTERNAL CIRCULATION ONLY

Printed and Published by Dr. Bincy R on behalf of Govt. College of Nursing printed at Orange printers Pvt. Ltd., T.C-25/1993, Gandhari Amman Covil Jn. in Thiruvananthapuram-695001 published at Govt. College of Nursing, Thiruvananthapuram-695011. Editor: Dr. Premaletha T. Telephone No: 0471-2444290 E-mail: editor.jnucnt@gmail.com

JOURNAL OF NURSING UPDATES

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From Chief Editors Desk

Learning gives creativity, creativity leads to thinking.
Thinking provides knowledge, knowledge makes you great

- A P J Abdul Kalam

Nursing research is an essential segment of nursing profession and is a requisite for continuing advancements that promote optimal nursing care. Publishing your research findings may be one step to make your research known to the nursing community.

Well conducted research is vital to the success of Global health endeavours. A major challenge that often faced in progress in global health is the slow translation of research in to practice.

The aim of this journal is to contribute to the growth of nursing practice and provide a platform for nursing researchers to show case the findings.

I sincerely congratulate the editorial board members for their hard work and dedication. I wish all the success for publishing this journal.

World Health Day theme 2021 is "Building a fairer, healthier world". On 7th April 2021, we will be kick starting a new campaign to build fairer, healthier world.

We are releasing the first issue of 2020 and plan to release the issues regularly.

Dr. Bincy R

Effectiveness of Nursing Interventions on Functional Ability of Patients Undergoing Above Knee Amputation in A Tertiary Care Hospital at Thiruvananthapuram

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Abstract

Lower limb amputation is accompanied by significant mortality and morbidity and a high risk of secondary amputations. Moreover, amputation is one of the most feared and costly complication related to diabetes mellitus (DM). Nurses are integral to optimal recognition, assessment and prevention of complications by virtue of their 24-hour presence at the bed side and professional responsibilities. The present study was carried to evaluate the effectiveness of nursing interventions on functional ability of patients undergoing above knee amputation. The theoretical framework of this study is based on Orem's self- care deficit theory. Objective of this study is to evaluate the effectiveness of nursing interventions to improve the functional ability among patients underwent above knee amputation. The research approach adopted for the study was quantitative approach and research design selected was quasi-experimental; post - test only control group design. Samples were 40 patients consecutively selected from surgical wards and surgery outpatient department of Medical College Hospital, Thiruvananthapuram. Data were collected using structured questionnaire and review of clinical records. The data collected were analyzed using SPSS. Demographic Proforma was analyzed using descriptive statistics such as frequency and percentage. Effectiveness of nursing intervention package was analyzed using Mann Whitney U test. Study results showed that there was a significant improvement in functional ability in patients who received the nursing intervention package.

Key words: *above knee amputation, functional ability, nursing interventions.*

INTRODUCTION

Amputation is sometimes the only option if a limb has been damaged through vascular disease, diabetes, trauma, tumours, infection or congenital deformities resulting in viability loss of the limb. The amputation of a limb is likely to be accompanied by a profound sense of loss and psychological stress since it lead to an altered body image, loss of mobility, restrictions in terms of leisure and employment as well as unforeseen expenses and possibly loss of income. From a socio-cultural perspective people who have had an amputation may experience discrimination and stereotyping. Therefore comprehensive rehabilitation is very important to retain physical and functional abilities, to assist with psychological and emotional adjustment and to ensure social and community integration.[1]

Rehabilitation programmes are designed to restore mobility and regain an acceptable level of functioning.[2] The rehabilitation of the leg amputee requires a multidisciplinary team that treats the medical, psychological, social and vocational aspects of amputation. Friedmann- states that the primary determinants of success in the treatment of the limbless are the generality of care an amputee receives and the amputee's innate characteristics. Care begins at the preoperative stage and continues till the amputee is helped to readjust to the social and vocational roles in the community.[3]

Therapy programs for range of motion, conditioning exercises, correct positioning of the residual limb, ambulation with gait aids, relaxation techniques, and activities of daily living should be started as soon as medically appropriate. Contractures are preventable through post-operative therapy program that emphasizes range of motion exercises and early mobilization. Strengthening of muscle groups that biomechanically substitute for the lost function of the limb is needed. Exercise programmes are required to accomplish this task.[4]

Objective of the study

To evaluate the effectiveness of Nursing interventions on functional ability of patients undergoing above knee amputation in a tertiary care hospital, Thiruvananthapuram.

Materials and methods

The research approach adopted for this study is quantitative approach. Selection of the particular approach is based on the purpose of the study and the type of the variables. The present study is a quantitative study which involves evaluation of the effectiveness of the Nursing interventions. The research design selected for the present study was a Quasi experimental –post-test only control group design. The present study was conducted in surgical wards and surgery out patient department, in Medical College Hospital, Thiruvananthapuram. The population for the present study consists of patients who underwent above knee amputation in Medical College Hospital during the study period. In the present study, Participants in the experimental group were selected from the surgical wards of Medical College Hospital and those in the control group were selected from surgical out-patient department, Medical College Hospital Thiruvananthapuram. The participants in the present study were selected consecutively because it includes all the subjects that are available which makes the sample better representation of the entire population.

After obtaining clearance from the Research committee and Institutional Ethics Committee of Govt. College of Nursing, the patients who satisfied the inclusion criteria were selected for the study. After obtaining informed consent from the participants, data were collected by structured questionnaire. The data collection period was

from 7th January 2019 to 16th February 2019. Data were collected from 40 patients who underwent above knee amputation in Medical College hospital, Thiruvananthapuram. 20 participants in the experimental group were given with interventions from first post-operative day onwards to decrease pain and to improve mobility. The interventions were given 3 times a day for 6 days, and both groups were given the post- test two weeks after the discharge. Duration of the data collection was approximately 30 minutes for each patient. The data collection period of the study was six weeks. The data obtained from structured questionnaire were analyzed on the basis of the objectives by both descriptive and inferential statistics. Statistical analysis was done using Mann Whitney U test.

Results

On statistical analysis it was understood that both groups are comparable on the basis of baseline socio demographic and clinical data.

Effectiveness of Nursing Interventions on functional ability by amputee mobility predictor.

Functional ability of patients	*Control*		*Experimental*		*Z#*	*p*
	Frequency(f)	*Percentage(%)*	*Frequency(f)*	*Percentage(%)*		
K0	*6*	*30.0*	*0*	*0.0*	*3.53*	*p<0.01*
K1	*9*	*45.0*	*5*	*25.0*		
K2	*3*	*15.0*	*5*	*25.0*		
K3	*2*	*10.0*	*10*	*50.0*		

30.0% of the participants in the control group did not have the ability or potential to ambulate or transfer safely with or without assistance (K0),45.0% of the control group and 25.0% of the experimental group had the ability or potential to use a prosthesis for transfers or ambulation in level surfaces(K1), 15.0% of the control group and 25.0% of the experimental group had the ability or potential for ambulation with the ability to transverse low-level environmental barriers (K2) and 10.0% of the control group and 50.0% of the experimental group had the ability or potential for ambulation with variable cadence, has the ability to transverse most environmental barriers (K3). Since the p value is less than 0.01 the test is statistically significant. So it is evident that exercise programme after above knee amputation helps to improve functional ability.

Discussion

Lower extremity amputation is performed to remove ischemic, infected, necrotic tissue or locally unresectabletumour, and at times, is a life-savingprocedure. [4] Diabetes mellitus continues to be the major risk factor associated with amputation.

Demographic data of the participants revealed that 50% of the experimental group were in the age group of 51-60 years. This study finding was in line with a study conducted by Jerome P Frederiks, Suronavisagie which revealed that 70% of the study participants were between 51-60 years old . [3] In a Study, conducted by Jason T Kahle , M. Jason highsmith, the subjects described had a mean age of 57.3 years. So the study is in concordance with the findings.

In the present study 60% of the experimental group were males. This result is agreed with Mohammed A. Alsofyani who stated that more than half (69.4 %) of the study participants were males.[2]In the current study, it was found that 55% of experimental group were lived in urban areas. This finding is not in line with the study conducted by Neema M. Mostafa etal which revealed that majority of the participants (86.7%) belong to rural areas.

In the current study, it was revealed that 80.0% of the experimental group were illiterate or only had primary education. This study finding was agreed with a study conducted by Neema M. Mostafa etal, found that 76.7% of the experimental group were not educated.In the present study, the indication for amputation in 40.0% of both the control group and experimental group was diabetes mellitus. A study conducted byMohammed A. Al sofyani showed that 63.6% participants underwent above knee amputation because of diabetes mellitus. Similar study conducted by Krasner etal., revealed that lower limb amputation is often performed in patients with reduced wound healing ability associated with increased age, diabetes mellitus, smoking, on-going bacterial colonization and underlying vascular disease leading to poor tissue perfusion.[5]

In the present study, 60% of the experimental group underwent right limb amputation. This finding is congruent with the study conducted byMohammed A. Al sofyani who showed that 52.1% of participants underwent right limb amputation.

In the present study, it is revealed that 50.0% of the experimental group had the ability or potential for ambulation with variable cadence, has the ability to transverse most environmental barriers (K3). Among patients who received interventional program there is improvement in functional ability as evidenced by increase in the K level.($p<0.01$). This finding is in concordance with a retrospective study conducted by Kaluf, Brian BSE, the number of patients in each K-level group, the K3 patients (Had the ability or potential for ambulation with variable cadence, had the ability to transverse most environmental barriers) were the most prevalent and made up 75% of all patients. There were no K1 patients (had the ability or potential to use a prosthesis for transfers or ambulation in level surfaces) during the period reviewed.[6]

Stefan reported that successful rehabilitation depends on systematic treatment by an interdisciplinary team of experienced specialists, can provide patients with the best functional results. In the area of functional restoration, there has been major progress in our understanding of the physiology of learning, relearning, and training. Further experimental and clinical studies will be needed to expand our knowledge and to improve the efficacy of rehabilitation.[7]

Conclusion

Amputation is the last resort when limb salvage is impossible or when the limb is dead or dying, viable but non-functional or when it is threatening the patient's life. Promoting functional mobility is an essential part of health care and can greatly impact one's quality of life. Exercise programme for patients after above knee amputation helps to improve functional ability. So it is mandatory to include exercise programmes in nuring care services of patients undergoing above knee amputation. Nursing intervention improves both physical & psychological well being in clients undergoing amputation.

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PSYCHOSOCIAL IMPAIRMENT OF CHILDREN WITH REACTIVE AIRWAY DISEASE

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Abstract

Reactive Airway Disease (RAD) is a major cause of hospitalization in children which interferes with their normal activity. It impairs not only respiratory functions, but also physical, social, and emotional components of life. The study was aimed to assess the psychosocial impairment of children with Reactive Airway Disease attending a tertiary care hospital at Thiruvananthapuram. The study used a quantitative approach with descriptive cross sectional survey design. Permission was obtained from Institutional Research Committee and Institutional Ethics Committee. Data regarding socio demographic variables, clinical variables and psycho social impairment were collected from 250 children who were consecutively selected from out-patient department and medical wards of a tertiary care hospital. A 'Paediatric Symptom Checklist' was used to collect data regarding psycho social impairment. Data were analysed using descriptive and inferential statistics. Findings revealed that 11.2% of children under study had psychosocial impairment. There was significant association between psychosocial impairment and nature of parenting, control of asthma, severity of asthma and history of hospitalization due to asthma. The findings of the study suggest the need for early identification of the psychosocial impairment in children with RAD.

Keywords: *Reactive airway disease, Psychosocial Impairment, Children*

Introduction

Reactive airway disease is the most common chronic lower respiratory disease of childhood throughout the world. It most often starts early in life and has variable courses which may progress or remit over time. The impact of asthma on the quality of life of children is quite significant. According to World Health Organisation (2004), 300 million people suffer from Asthma around the globe. India has an

estimated 15-20 million asthmatics with prevalence between 10 to 15% among children in the age group of 5 – 11years [1].

It has long been thought that psychological factors may play an important role in bronchial asthma[2]. Research published during the last few decades illustrates that psychological disorders are more common in individuals having bronchial asthma, especially if it is poorly controlled[3]. For instance, children with asthma are more likely than children without asthma to have anxiety and depression [4].

Statement of the problem

Assessment of psychosocial impairment of children with Reactive Airway Disease attending a tertiary care hospital, Thiruvananthapuram.

Objectives of the study

1. *Assess the psychosocial impairment of children with Reactive airway disease attending a tertiary care hospital, Thiruvananthapuram.*
2. *Find out the association between psychosocial impairment and selected socio demographic and clinical variables of children.*

Hypothesis

H1: There will be an association between psychosocial impairment and selected socio demographic variables of children with Reactive Airway Disease.

H2: There will be an association between psychosocial impairment and clinical data of children with Reactive Airway Disease.

Materials and methods

The research approach adopted for the study was quantitative approach and the research design was descriptive cross sectional survey design. The present study was conducted among children in the age group of 4 to 12 years with reactive airway disease attending Sree Avittom Thirunal hospital, Thiruvananthapuram. Administrative permissoion, IRC and IEC clearance were obtained before data collection. A total of 250 children were recruited consecutively from outpatient department and medical wards of Sree Avittom Thirunal hospital, Thiruvananthapuram. Structured interview schedule was used to assess the socio-demographic and clinical data of the children. Psychosocial impairment was assessed using Paediatric Symptom Checklist (PSC). It is a standardized tool which consists of 35 items arranged under the five major domains such as mood, play, school, friends, and family relations. Test /retest reliability of the PSC ranges from r = 0.84 - 0.91 and inter item analysis shows strong internal consistency (Cronbach alpha = .91). Socio demographic and clinical data were described in terms of frequency and percentage. Psychosocial impairment of children was described using proportion and association between psychosocial impairment and selected socio demographic and clinical variables were analysed using chi- square test.

Results

Findings revealed that majority (73.2%) of the children belong to the category of 6-12 years and rest 26.8% were in the age group of 4-5 years. Gender distribution shows that 56.8% of children were boys. Majority (83.2%) of children were taken care of by both parents, 15.2% by a single parent and 1.6% by other relatives. About 11.2% of children under study had psychosocial impairment. There was significant association between psychosocial impairment and nature of parenting(χ^2= 8.66, p=0.013), control of asthma (χ^2= 9.86, p=.007), severity of asthma (χ^2= 9.14, p=.010) and history of hospitalization due to asthma(χ^2= 8.66 , p=.013.). The findings of study suggest the need for early identification of the psychosocial impairment in children with RAD.

Table I : Chi square test to find out association between psychosocial impairment and selected Socio demographic and clinical variables n=250

Demographic variables and Clinical Variables		*Psychosocial impairment*				χ^2	*p*
		No		*Yes*			
		Frequency	*Percentage*	*Frequency*	*Percentage*		
Nature of Parenting	By both parents	187	89.9	21	10.1		
	Single parent	33	86.8	5	13.2	6.46*	0.040
	By other relatives	2	50.0	2	50.0		
Control of asthma	Well controlled	55	98.2	1	1.8		
	Partly controlled	140	88.1	19	11.9	9.86**	0.007
	Poorly controlled	27	77.1	8	22.9		
Severity of asthma	Mild	175	90.7	18	9.3		
	Moderate	6	60.0	4	40.0	9.14*	0.010
	Severe	41	87.2	6	12.8		
History of hospitalization	No	143	92.3	12	7.7		
	1-3	71	85.5	12	14.5	8.66*	0.013
	4-6	8	66.7	4	33.3		

Routine psychosocial assessment and care for children with asthma can be introduced to protect children from avoidable suffering.

Discussion

The present study emphasised to assess the psychosocial impairment of children with Reactive airway disease. In the present study majority (73.2%) of the children belonged to the category 6-12 years and 56.8% of the children were boys and rest 43.2% were girls. It has been emphasized in the literature that boys are more affected than girls[5]. A study conducted in Sree Avittom Thirunal hospital, Thiruvananthapuram regarding stress and coping strategies of parents of children with bronchial asthma, supports the same trend of the present study that the prevalence of bronchial asthma is more in boys than girls[6].

Department of economics published the gender statistics 2016-2017 based on the 2011 census shows that the majority of people in Thiruvananthapuram district belong to Hindu (66.9%) religion. This similar demographic profile was seen in the present study were 65.6% of children under the study belong to the Hindu religion.[7]

The interpretation of the results of the present study reveals that chronic health problems in childhood may affect the behavior of the child. Physical, as well as the emotional stress, may often cause acute exacerbations among asthmatics. Hence it may contribute to the vicious cycle of repeated acute episodes, hospitalization and psychosocial problems. This finally leads to difficulty in following the treatment, which also increases functional impairment and the severity of disease. Hence, efforts need to be made to keep the child's asthma under control.

Conclusion

Reactive airway disease is a widespread public health problem and the most common chronic illness in childhood and adolescence. This study aimed to identify the psychosocial impairment of children with RAD. The study revealed that 11.2% of children with reactive airway disease were having psychosocial impairment and there is a significant association between psychosocial impairment and the nature of parenting, control of asthma, severity of asthma and history of hospitalization due to asthma. Findings of the present study have implications in Nursing Service, Education and Research. Nurses can impart health education to parents of children with RAD about possible psycho social impairment and parenting skills. Nurses working in Pediatric health departments can do the screening of psychosocial problems among children with RAD.

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Knowledge And Attitude Regarding Preconception Care Among Graduate Students in Thiruvananthapuram Corporation

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Abstract

Preconception care is promoting the health of the women of child bearing age before conception to improve pregnancy related outcome. The present study was carried out to identify the knowledge and attitude regarding preconception care by graduate students in Thiruvananthapuram Corporation. The study was cross sectional, conducted over a period of 6 weeks among 400 graduate students. The study result shows that majority (37.2%) of the participants have average knowledge and 36.5% of participants have poor attitude Significant association was found between with the level of knowledge regarding preconception care and maternal education status.

Key words: *Knowledge, Attitude, Preconception care, Graduate students*

Introduction

Pregnancy is common among women in reproductive age. The first trimester is a crucial period for the development of important organs. Many poor outcomes may have already been determined prior to women's first antenatal visit. Therefore J.W. Ballantyne - originated concept of preconception care. Preconception care is promoting the health of the women of child bearing age before conception to improve pregnancy related outcome. The benefits of preconception care are to reduce the risks of adverse health effects for women, fetus or neonate by optimizing the health and knowledge before planning and conceiving a pregnancy[1].

Recent studies found that not much is known about the knowledge, attitude and practices of preconception care, although these factors are known to contribute to good pregnancy outcomes. Thus, the objective of this study was to determine the knowledge and attitude of graduate students regarding preconception care.

Objectives

a. Primary objectives

1. Assess the level of knowledge regarding

preconception care among graduate students in Thiruvananthapuram Corporation.

2. *Assess the attitude towards preconception care among graduate students in Thiruvananthapuram Corporation.*

b. *Secondary objective*

3. *To find out the association between level knowledge score regarding preconception care with selected demographic variables.*

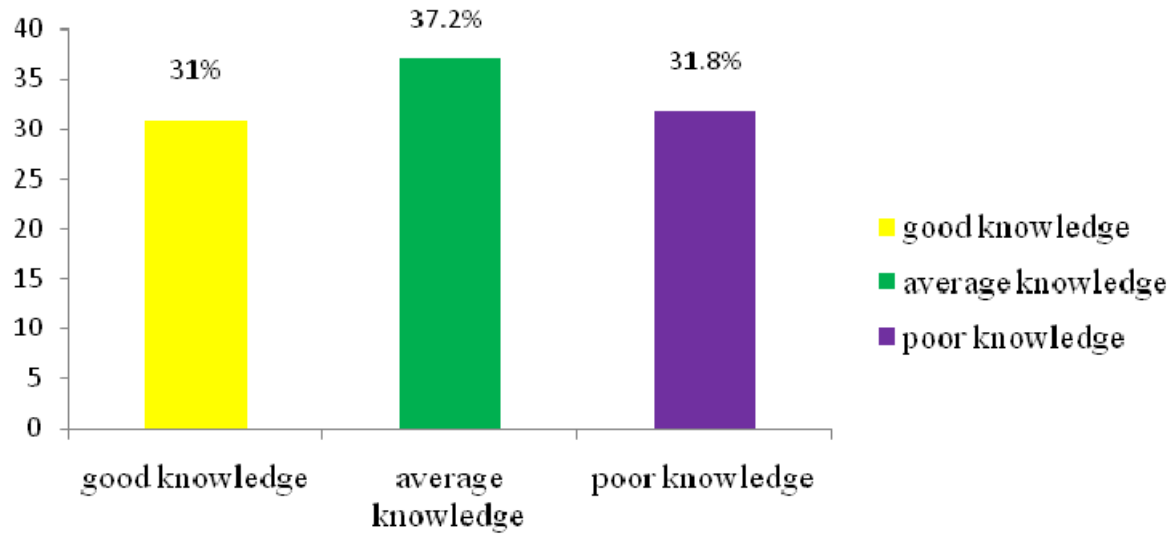
Materials and methods

The present study was conducted to assess the knowledge and attitude regarding preconception care among 400 graduate students in Thiruvananthapuram corporation. Quantitative approach and cross sectional research design was adopted for the study. In this study researcher used a structured questionnaire to assess knowledge of graduate students about preconception care. It includes two parts: 10 questions regarding socio demographic data and 30 questions about knowledge regarding preconception care. It include the following components; General awareness & physical assessment, risk screening & routine checkup, vaccination, behavior modification and genetic counseling. The attitude regarding preconception care was scored in a five point Likert scale. In the present study the researcher used standardized tool from Institute of General Practice and Primary care. The scale consists of both positive and negative statements. The data collected were assessed by using Statistical Package for Social Sciences (SPSS 16) software. Data analysis was done using descriptive and inferential statistics based on the objectives.

Results of the study

Section 1:Knowledge of graduate students regarding preconception care.

Figure 1 : Knowledge of graduate students regarding preconception care (n=400)

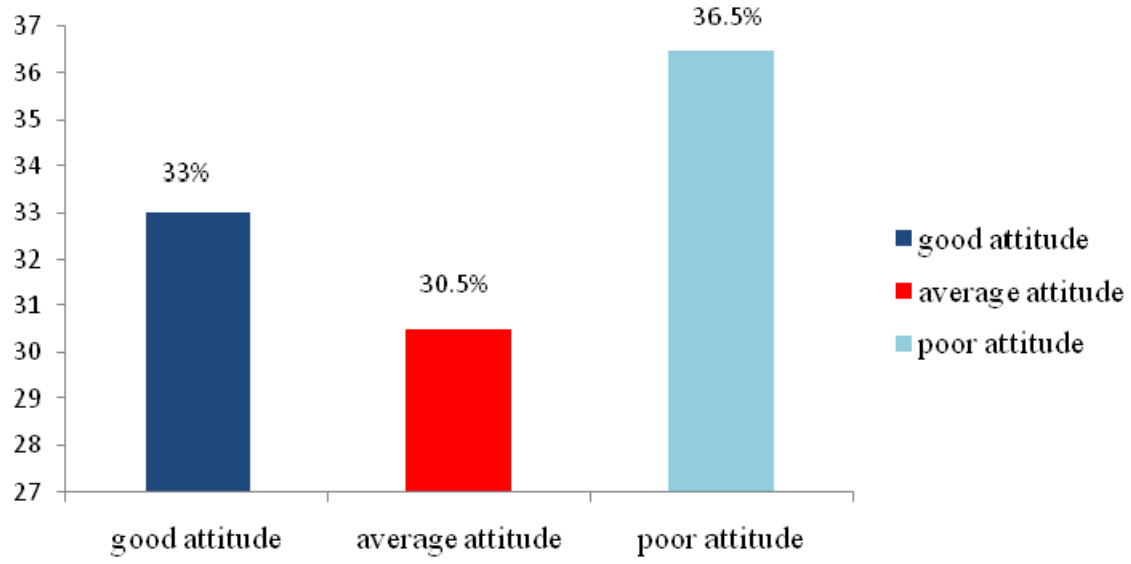


The present study shows that 37.25 of graduate students in Thiruvananthapuram Corporation had average knowledge regarding preconception care.

Section II: Attitude of graduate students regarding preconception care

Figure 2 : Attitude of graduate students regarding preconception care

n=400



The present study shows that 36.5% of graduate students in Thiruvananthapuram Corporation had poor attitude regarding preconception care.

Section III – Association of level of knowledge score with demographic data

In this section the association of level of knowledge with demographic variables of respondents was done. Chi- square test was used for finding out association between knowledge score and selected socio demographic variables.

Table 1

Association of level of knowledge with maternal education status

n=400

Mother's education	Good knowledge		Average knowledge		Poor knowledge		x^2	df	p
	N	%	N	%	N	%			
Illiterate	10	52.6	8	42.1	1	5.3	32.47	16	0.009
Primary	15	30.6	16	32.7	18	36.7			
Secondary	18	22.5	41	51.2	21	26.2			
Higher secondary	36	38.7	33	35.5	24	25.8			
Technical education	13	36.1	14	38.9	9	25			
UG degree	17	26.6	18	28.1	29	45.3			
PG degree	6	20	13	43.3	11	36.7			
Professional	7	41.2	3	17.6	7	41.2			
Others	2	16.7	3	25	7	58.3			

The calculated P value was less than 0.05. So there is significant association between level of knowledge with maternal education status of the participants.

Discussion

The assumption of the present study was students have some knowledge regarding preconception care. The present study shows that majority of the students (37.2%) have average knowledge, and 31%have good knowledge regarding preconception care. A community based cross sectional study conducted by Ayalaw and Mulet et.al. to assess knowledge of preconception care among 422 systematically selected women of reproductive age group. The data was collected using structured questionnaire and face- to- face interviews. The study revealed that 35.5% have good knowledge 37% have average knowledge and 27.5% have poor knowledge regarding preconception care[2].

The assumption of the present study was students have positive attitude regarding preconception care. The present study shows that majority (36.5%) of participants have poor attitude, 33% had good attitude and 30.5% have average attitude regarding preconception care.Survey study conducted by Rosnani Kasim & Nani Draman to assess knowledge, attitude and practice of preconception care among women attending maternal health clinic in Kelantan shows that majority of women possessed a poor attitude (68.5%) towards preconception care, with 31.5% having a good attitude. A total of 89.6% of the respondents agreed and strongly agreed that preconception care is an important health issue during the reproductive age[3].

The present study shows that there is significant association between mother's education with the level of knowledge regarding preconception care. This result was supported by a descriptive study which was conducted in selected villages of Vallioor, Kanyakumari District among 100 adolescent girls. This study revealed that 53% of the sample had inadequate knowledge, 46% had average knowledge and only 1% had adequate knowledge. This study also shows that there is significant association between knowledge and parent's educational status, family monthly income and source of information[4].

Conclusion

Preconception care is an essential component of reproductive health which focuses on the condition and risks that could affect a woman if she becomes pregnant. Knowledge of reproductive health should be given to the adolescent period itself as they were the future parents. The present study showed that most of the samples had inadequate knowledge and unfavorable attitude regarding preconception care. It highlights the need of health education programmes to the public to improve knowledge attitude regarding preconception care.

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Burnout Syndrome Among Nurses Working in The Pediatric Care Setting of A Tertiary Care Hospital, Thiruvananthapuram

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Abstract

Nursing profession involves spending a great deal of mental, emotional and physical energy on caring for others. They are often caught between a complex hierarchy of authority of doctors, nurse administrators, families or care takers.This makes them more exposed to develop burnout. The present study was intended to assess the burnout syndrome among nurses working in the pediatric care setting of a Tertiary Care Hospital, Thiruvananthapuram. The objectives of the study were to evaluate the occurrence of burnout syndrome and to identify the factors associated with it. The research approach of the study was a quantitative approach and research design was descriptive.The sample size was 110 staff nurses who were consecutively selected. Maslach burnout inventory (MBI) was used to assess burnout syndrome. The collected data were analyzed using SPSS (version 20). Chi-square test was used to assess the factors associated with burnout syndrome. The present study shows that 19.1% of participants were working in medical wards, 17.3% in the inborn nursery, 11.8% in out-born nursery, 15.5% in PICU, 13.6% in specialty wards, 8.2% in surgical wards, 4.5% in casualty and 9.1% in isolation ward. According to the level of burnout in emotional exhaustion, 70% have low burnout. In depersonalization, 57.3 % have low level burnout. In personal achievement 29.1% have high level burnout. The factors associated with burnout syndrome in this study are night duty within a short interval, staying away from their spouse, type of nursing care delivered, years of professional experience and area of work. The study findings revealed thatnurses working in surgical wards have high burnout in emotional exhaustion. Nurses working in medical wards and NICU have high burnout in depersonalization. The reduction in personal achievement was identified among nurses working in NICU.

***Keywords**: burnout, emotional exhaustion, depersonalization, personal achievement*

Introduction

Health care has emerged as one of the most progressive and largest service sectors in India. Health care workers are involved in promoting health, preventing diseases and helping patients cope with illness. As the health care industry is growing more importance is given to the health care professionals like nurses.[1]

The nursing profession is considered a caring profession. To begin with, it was an art and a vocation. Now, it is considered as scientific profession, nursing care is defined as the care of the patient with regard to nursing needs, with the ever-increasing dimension of medical sciences quantitatively and qualitatively. So, nursing care is becoming more and more complex with its management services[2]*. Nursing is generally perceived as a demanding profession. Nurses are considered as the best friend of patients.*[3] *Along with the increased demand and progress in the nursing profession, stress among nurses has also increased.* [4]

Pediatric hospitals are known to be a highly stressful workplace as the emotional impact of seeing sick or dying children. Nurses may experience, overwhelming emotional stress, helplessness pain, and sadness while working with sick or dying children and their families. So, they need to develop specialized skills, qualities arising from compassion and professional commitment and abilities to handle the stressful situations. So, nurses experience a greater level of burnout in children's hospital setting.[5]

Objectives

- *To evaluate the occurrence of burnout syndrome among nursesworking in the pediatric care setting of Sree Avittom Thirunal Hospital, Thiruvananthapuram.*
- *To identify the factors associated with burn out syndrome of staff nurses working in the pediatric care setting of Sree Avittom Thirunal Hospital, Thiruvananthapuram.*

Methods and materials

The research approach of the study was a quantitative approach and research design was descriptive. 110 staff nurses were consecutively selected for the study. Maslach burnout inventory (MBI) was used to assess burnout syndrome. The collected data was analyzed using SPSS. Chi-square test was used to assess the factors associated with burnout syndrome. Duration of the study was 6 months including 6 weeks period for data collection. The data collection period was 07/01/2019 to 16/02/2019. Maslach burnout inventory is designed to assess the three components of burnout syndrome. It includes Emotional Exhaustion (EE), Depersonalization (DP) and Personal Achievement (PA)[6]*. There are 22 items, which are divided into three subscales. The items are written in the form of statements about personal feelings or attitudes.Collected data were analyzed using SPSS software. Both descriptive and inferential statistics were used.The demographic variables and job status of study participants were analyzed usingdescriptive statistics (mean, standard deviation, frequency and percentages). Chi square test was used to assess the factors associated with burnout syndrome among staff nurses.*

Results

On statistical analysis it was interpreted that nurses working in surgical wards have high burnout in emotional exhaustion. Nurses working in medical wards and NICU have high burnout in depersonalization. The reduction in personal achievement was identified in NICU.The result

revealed that in emotional exhaustion, 70% have low burnout, 28.2% have moderate level burnout and 1.8% have high level burnout. In depersonalization, 57.3 % have low level burnout, 32.7% moderate burnout and only 10% high level burnout. In personal achievement 55.5% have low level burnout, 15.5% have moderate level burnout and 29.1% have high level burnout.

Figure 1 Distribution of participants according to level of burnout

(n=110)

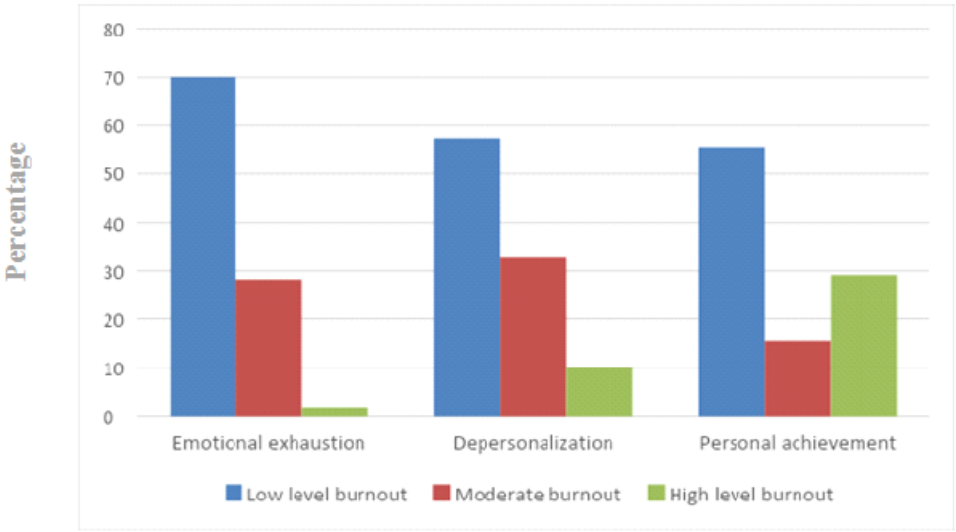

Figure 1 illustrates that in emotional exhaustion majority 70% of staff nurses have low burnout,28.2% have moderate level burnout and 1.8% of staff nurses have high level burnout.In depersonalization 57.3 % of staff nurses have low level burnout, 32.7% moderate level burnout and only 10% high level burnout. In personal achievement 55.5% have low level burnout, 15.5% have moderate level burnout and 29.1% have high level burnout.

Factors associated with emotional exhaustion of staff nurses

Table 1 Association of job status and nature of work with emotional exhaustion of staff nurses (n=110)

Job status and nature of work		*Low level burnout*		*Moderate/High burnout*		χ^2	*P*
		f	*%*	*f*	*%*		
Frequency of night duty	Less than 10 days	14	43.8	18	56.3	14.81**	p<0.01
	between 10 -15 days	63	80.8	15	19.2		
Nursing care delivery system	Patient assignment	50	72.7	10	14.3	8.31**	0.004
	functional nursing	27	54	23	46		

** - significant at 0.01 level, *: - significant at 0.05 level

Table 1 shows that there is a significant association between emotional exhaustion and frequency of night duty (x^2= 14.8 and p=< .001) and delivery of nursing care system (x^2= 8.31 p =0.004)

Factors associated with depersonalization of staff nurses

Table 2 Association of personal history with depersonalization of staff nurses

(n=110)

Personal History		*Low level burnout*	*Moderate burnout*	*High level burnout*	χ^2	*P*
Living away from spouse	Yes	20 (62.5)	6 (18.8)	6 (18.8)	7.37*	0.025
	No	36 (56.3)	25 (39.1)	3 (4.7)		
Interval of meeting the spouse	Weekly/Monthly once	4 (36.4)	6 (54.5)	1 (9.1)	10.97**	0.004
	Yearly once / Without specific interval	17 (77.3)	1 (4.5)	4 (18.2)		

** - significant at 0.01 level, *: - significant at 0.05 level

Table 2 indicates that there is significant association between depersonalization and living away with the partner (x^2= 7.37 p= .0.025) and interval of meeting the partner(x^2=10.97 p = 0.004)

Table 3 Association of job status and nature of depersonalization of staff nurses

(n=110)

Job status and nature of work		***Low level burnout***	***Moderate burnout***	***High level burnout***	χ^2	***P***
Frequency of night duty	Within 10 days	11 (34.4)	17 (53.1)	4 (12.5)	10.15**	0.006
	Between 10 to 15 days	52 (66.7)	19 (24.4)	7 (9)		
Nursing care delivery system	Patient assignment	42(70)	14 (23.3)	4 (5.8)	9.56**	0.008
	Functional nursing	20 (40)	22 (44)	8(16)		

** significant at 0.01 level * significant at0.05 level

Table 3 reveals that there is a significant association between depersonalization and years of experience staff nurse (x^2= 10.15 p= 0.006) and delivery of nursing system (x^2= 9.56 p= 0.008)

Factors associated with personal achievement of staff nurses

Table 4 Association between area of work and years of experience as staff nurse with personal achievement of staff nurses

(n= 110)

		High level burnout	***Moderate burnout***	***Low level burnout***	χ^2	***P***
Area of work	Out born/inborn nursery	2 (6.1)	4 (12.1)	27 (81.8)		
	PICU	9 (52.9)	3 (17.6)	5 (29.4)		
	Medical/Surgical wards	15 (50)	4 (13.3)	11 (36.7)	23.72 **	p<0.01**
	Specialty/casualty / isolation ward	6 (20)	6 (20)	18 (60)		
Experience as staff nurse in years	<5	7 (19.4)	7 (19.4)	22 (61.1)		
	5 – 9	22 (42.3)	8 (15.4)	22 (42.3)	10.74*	0.030
	>=10	3 (13.6)	2 (9.1)	17 (77.3)		

** significant at 0.01 level * significant at 0.05 level

Table 4 represents that there is a significant association between personal achievement and area of work ($x^2$23.72 p= <0.001) and years of experience as the staff nurse(x^2 =10.74 p = 0.03)

The present study reveals that the factors associated with burnout in emotional exhaustion were night duty within a short interval and in functional nursing care areas. The high level of burnout in emotional exhaustion was observed in nurses working in surgical wards.

The factors associated with burnout in depersonalization are staying away with their spouse, night duty within short interval and functional nursing care areas. Nurses working in medical wards and NICU have high burnout in depersonalization.

The factors associated with reduced personal achievement are area of work (NICU) and burnout decreases with increased working experience. Nurses working in neonatal ICU have high burnout in personal achievement.

Discussion

Nurses are one of the important pillars of health care organizations, and any shortcomings in this group will have irreparable consequences due to their important role in patient treatment.

Nurses are exposed to the highest levels of occupational harms, including burnout, due to exposure to physical, psychological, and emotional stressors. This problem is one of the main factors in reducing efficiency, loss of human resources, and physical and mental health problems[7]

The present study showed that nurses working in medical wards and NICU have high burnout in depersonalization. The reduction in personal accomplishment was identified in NICU.The factors associated with burnout in this study were night duty within a short interval, staying away from their spouse, type of nursing care delivered, years of professional experience and area of work.

A study conducted regarding nurse burnout and stress in the NICU it shows that NICU nurses can experience high levels of psychological and physical stress. Burnout is a response to workplace stress that results in emotional and mental exhaustion, depersonalization, and decreased sense of the personal accomplishment. This result is supported by a study conducted in NICU shows high levels of absenteeism, low morale, mental fatigue, and exhaustion can have detrimental effects on neonatal care. Burnout is a response of workplace stress that results in emotional and mental exhaustion, depersonalization, and decreased the sense of personal accomplishment.[6]*A similar study shows that NICU nurses have a moderate level of emotional exhaustion and personal accomplishment and low level of depersonalization.*[5]

In contrast, a study conducted in Jordan shows that there is no significant association between burnout and type of nursing care delivered.[8]*A study conducted among health professionals in Kerala shows that 60.4% had job related stress due to night shifts.*[9]

Conclusion

The present study assessed the occurrence of burnout syndrome among nurses working in pediatric care setting of SreeAvittomThirunal Hospital, Thiruvananthapuram. The finding suggests that nurses working in surgical wards have high burnout in emotional exhaustion The nurses working in medical wards and NICU have high burnout in depersonalization. The reduction in personal accomplishment was identified in NICU. The factors associated with burnout in this study are night duty within a short interval, staying away from their spouse, type of nursing care delivered, years of professional experience and area of work.

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Effect of Structured Teaching Programme on Knowledge and Attitude Regarding Preconception Care Among Postgraduate Students in Selected Arts and Science Colleges in Alappuzha

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Abstract

Background Preconception care is preventive medicine for obstetrics. It helps in identifying risk factors that could potentially affect perinatal outcome.

Aim The present study aims to assess the effect of structured teaching programme on knowledge and attitude regarding preconception care among postgraduate students. **Objectives** to assess the knowledge, and attitude of postgraduate students regarding preconception care , to evaluate the effectiveness of structured teaching programme on knowledge and attitude regarding preconception care among postgraduate students and to find out the correlation between knowledge and attitude .

Methods Quasi- experimental approach was adopted for the study and the research design used was one group pre test post test design.160 postgraduate students from five selected Arts and Science Colleges of Alappuzha District were identified by using multistage cluster sampling technique. Structured questionnaire was used to assess the knowledge and attitude scale for attitude of postgraduate students and a structured teaching programme for one hour was given. A post test was conducted with the questionnaire after two weeks to assess the effect of structured teaching programme. The data were tabulated using descriptive and inferential statistics.

Results of the study revealed that all the postgraduate students had acquired good knowledge regarding preconception care through the structured teaching programme. The findings indicate that the structured teaching programme had significant effect in improving the knowledge and attitude regarding preconceptioncare

Key words: Structured teaching programme; postgraduate students; preconception care

Introduction

Pregnancy is a unique, exciting and often joyous time in a women's life. It highlights a woman's amazing creative and nurturing powers while providing a bridge to the future.[1]In particular, maternal wellbeing before during and between pregnancies matters for child's health. An individual's health at birth, in infancy and in early childhood influences their later life, health, educational attainment and overall wellbeing.[2] Therefore there is a need for improving the health of women of childbearing age so as to reduce the risk of adverse birth outcomes.[3] Although most of the pregnancy have good outcome, some pregnancy can lead to adverse health effects for the women, foetus or neonate due to poor preconception knowledge[4,5].

Preconception care is the provision of biomedical, behavioural and social health interventions to women and couples before conception occurs. It aims at improving their health status, and reducing behaviours and individual and environmental factors that contribute to poor maternal and child health outcomes. The components of preconception care include identification of risks related to pregnancy, education, and initiation of interventions to ensure optimal pregnancy outcome[6].

A randomized controlled trial of folic acid supplementation for women with a previous pregnancy with Neural Tube Defect (NTD) indicates a 70% reduction in recurrence. For Neural Tube Defect, primary prevention through folic acid supplementation, suggested a reduction of 62%[6].An observational study conducted in samples for examining folic acid food fortification gave an estimated reduction in neuraltube defect incidence of 46%.In low-income countries an estimated 29% of neonatal deaths related to visible congenital abnormalities are attributed to neural tube defect. The evidence supports both folic acid supplementation and fortification was effective in reducing neonatal mortality from neural tube defect.[7] A study was conducted on preconception care among women with diabetes mellitus reported a reduction in the risk of spontaneous abortion and congenital malformations.[8]

The most critical period for organ development occurs before many women even know they are pregnant, the first contact with antenatal care is often too late for advice about health-promoting changes in lifestyle. Globally, at least four out of ten women report that their pregnancies were unplanned, highlighting the need for population-wide approaches for evidence-based preconception care. So disseminating knowledge regarding preconception care is important so that women in child bearing age group can adopt healthy lifestyle .Post graduate students are the future mothers and this education will help them to adopt healthy lifestyle and plan their pregnancy.

STATEMENT OF THE PROBLEM

Effect of structured teaching programme on knowledge and attitude regarding preconception care among postgraduate students in selected Arts and Science colleges in Alappuzha.

OBJECTIVE

1. *To assess the knowledge regarding preconception care among postgraduate students*
2. *To assess the attitude regarding preconception care among postgraduate students.*
3. *To evaluate the effectiveness of structured teaching program on knowledge regarding preconception care among postgraduate students.*
4. *To evaluate the effectiveness of structured teaching program on attitude regarding preconception care among postgraduate students*

5. *To find out the correlation between knowledge and attitude regarding preconception care among postgraduate students.*

RESEARCH METHODOLOGY

Research approach

Quantitative approach

Research design

Quasi experimental one group pre-test post-test design

Variables

Independent variable - Structured teaching programme regarding preconception care Dependent variables – Change in knowledge and attitude .

Setting

Selected Arts and Science colleges of Alappuzha district

Population

The population of the study comprised of postgraduate students

Sampling technique & Sample size

Sampling technique was Multistage cluster sampling .Using simple random sampling five arts and science colleges from Alappuzha district was selected, cluster sampling was used to select 160 postgraduate students of age 21 -29 years. Informed consent was taken from all study participants.

Tool

The tools used for the study include Socio personal data sheet, structured questionnaire to assess knowledge regarding preconception care, and Preconception care attitude scale was used to assess the attitude regarding preconception care. Structured knowledge questionnaire consist of seven items, the total score was 31 and those who scored more than 22 was considered as having good knowledge, less than 10 poor and 11 to 21 average. Preconception care attitude scale is a five point Likert scale, consisting of nineteen statements. Content validity was done by subject experts. Reliability of the tool was checked using Karl Pearson correlation coefficient and found to be 0.78 for knowledge questionnaire and 0.85 for attitude scale.

The structured teaching programme included six aspects of preconception care female reproductive system,medical conditions, risk identification, envirornmental factors, health promotion and lab investigations.

Data analysis

- *Frequency and percentage distribution was used to analyse socio personalvariables.*
- *Paired 't' test were used to assess the effect of structured teaching programme on knowledge and attitude*
- *The correlation between level of knowledge and attitude of postgraduate students regarding preconception care as analysed using Karl Pearson correlation coefficient.*

RESULTS

Table 1 Frequency distribution and percentage of postgraduate students based on demographic data (n =160)

Place of residence	***f***	***%***
Panchayat	*135*	*84.4*
Municipality	*25*	*15.6*
Monthly family income	***f***	***%***
<5000	*22*	*13.8*
5001–15000	*86*	*53.7*
>15001	*52*	*32.*

In the present study all the post graduate students were at the age of 21. 84.4 % were residing at panchayat and 53.7% had monthly income 5001 to 15000.

Table 2

Frequency distribution and percentage of postgraduate students based on pre-test post test knowledge score regarding preconception care (n=160)

Knowledge	Pretest		Posttest	
	f	%	f	%
Poor (0-10)	63	39.4	0	0
Average (11-21)	97	60.6	0	0
Good (22-31)	0	0	160	100

In the study 39.4% postgraduate students had poor knowledge regarding preconception care and none of the postgraduate student had good knowledge before the structured teaching programme and all the postgraduate students had good knowledge after the teaching programme. (Table2)

Table 3

Mean standard deviation and t value showing the effect of structured teaching programme on knowledge scores of regarding preconception care among postgraduate student (n=160)

Knowledge	Mean	S.D	t value
Pretest	12.22	4.04	
			35.50^{***}
Posttest	25.67	2.7	

*** *Significant at 0.001 level*

The findings of the study showed that the mean and standard deviation of pretest and posttest knowledge scores were 12.22±4.04 and 25.67±2.7respectively. Thus it can be concluded that structured teaching programme was effective in improving knowledge of postgraduate students regarding preconception care (Table 3).

Table 4

Effect of structured teaching programme on attitude regarding preconception care among postgraduate students (n=160)

Attitude	Mean	S.D	t value
Pretest	27.69	7.49	
			30.43^{***}
Posttest	59.59	10.62	

*** *Significant at 0.001 level*

The results of the study showed that the mean and standard deviation of pretest and posttest attitude score were 27.69±7.49 and 59.59 ±10.62 respectively, it can be concluded that structured teaching programme was effective in improving attitude of postgraduate Students regarding preconception care. (Table4).

Table 5

The r value showing correlation between knowledge and attitude regarding preconception care among postgraduate students.

Variables	Mean	SD	R
Knowledge	12.22	4.04	
			0.09
Attitude	27.69	7.49	

Theresults showed that the r value 0.1which indicates no correlation between knowledge and attitude among postgraduate students regarding preconception care. Thus it can be concluded that there is no correlation between knowledge and attitude (Table5).

DISCUSSION

In the present study, the knowledge regarding preconception care among postgraduate students were average among 60.6% of the study participants and poor among 39.4% before the administration of structured teaching programme.

This finding is congruent with two other studies conducted in Bangaluru and Birgunj.

A study conducted at Bengaluru among women in the reproductive age group found that 65% had average knowledge and 43% had poor knowledge regarding preconception care before administration of structured teaching programme.[9]

A similar study conducted in Birgunj, majority had moderate knowledge level (69.09%) regarding preconception care before administration of structured teaching programme.[10]

In the light of study conducted at Nepal, Lalitpur District, pre-test knowledge of various domains regarding preconception care included the concept of preconception care (65.5%), in reproductive risk factors (68.19%), and poor knowledge health promotion (48%) before administering structured teaching programme.[11]

The present study highlights that the structured teaching programme was effective in increasing the mean pretest knowledge score (12.22±4.04) to post-test mean knowledge score (25.67±2.7).

The study is concordant to a study conducted at Bengaluru, about 60 eligible couples, who were residing in Shanthigrama, after the structured teaching programme it was concluded that there was significant increase in mean pretest knowledge score(10.24±3.05) to post-test mean knowledge score(23.34±3.3).[12]

It is evident that a study conducted at selected colleges of Bengaluru, about 40 postgraduate students were selected and by structured interview technique data collection done.

There was increase in pretest mean attitude score (23.69±4.5) to post-test mean attitude score (54.45±9.7) regarding preconception care after giving structured teaching programme.[6] *The study is consistent to the present study findings.*

Another study conducted among women with age between 15-35 years at Hosakote, Bengaluru showed that there was an increase in mean knowledge (28.29±2.7) and attitude score (55.23±10.45) after structured teaching programme.[13] *The study is consistent to the present study*

The present study findings was consistent with the study conducted in AKM Higher secondary school, Poochety, Trissur among 30 adolescent girls. It was found that the post-test mean knowledge score28.93± 48.70 and post-test attitude was found to be 32.29±38.22 ($p<0.001$).[14]

In the present study the correlation between knowledge and attitude (0.09) is not significant ($p>0.005$).It shows that there is no correlation between knowledge and attitude.

The findings are also concordant with a study done at AKM Higher secondary school, Poochety, Trissur. As the findings showed that there is no correlation between knowledgeand attitude(0.234).The structured teaching programme was effective in improving knowledge and attitude regarding preconception care and as potential mothers they can utilize this.

Limitation of the study

The study was conducted among the 1st year post graduate students only as the seniors were having University examinations

Recommendations

- *An extensive teaching strategy using structured teaching programme regarding all aspects of preconception care should be provided for all young women. For preconception healthcare to be successful, preconception, education and counseling must be addressed by nurses every time a young woman receives care.*
- *A similar study can be conducted among school and college teachers regarding preconception care.*

Conclusion

The structured teaching programme had a significant effect in improving the knowledge and attitude regarding preconception care among postgraduate students. This throws light to the fact that structured teaching programme was an effective intervention in improving knowledge and attitude regarding preconception care among postgraduate students without any financial burden .

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WERDNIG-HOFFMANN DISEASE : A CASE REPORT

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Abstract

Werdnig-Hoffmann disease is a type of spinal muscular atrophy (SMA), a rare form of motor neuron disease. It is the most common type of SMA and accounts for about 80% of individuals with this condition. There are 4 types of SMA, Werdnig-Hoffmann disease, also known as SMA1 is the most severe form, and infants with this condition experience severe muscle weakness with onset before 6 months of age and presenting symptoms include severe motor weakness, poor muscle tone and lack of motor development. Werdnig-Hoffmann disease is a motor neuron disease in which there is anterior horn cell degeneration of the spinal cord. In utero, there is an excess of motor neuroblasts with only half surviving until birth. After birth, the disease is progressive with continued loss of motor neurons in the spinal cord and brainstem. We report a case of a newborn baby inpatient in Newborn Intensive Care Unit (NICU) in a tertiary care setting Thiruvananthapuram. Physical examination reveals that features of Werdnig-Hoffmann disease. The baby was on ventilated and supportive care given. Baby discharged from the hospital with follow up advice.

Keywords: *Werdnig-Hoffmann disease, spinal muscular atrophy, NICU, motor neuroblasts*

Introduction

Werdnig-Hoffmann disease, which is also known as spinal muscular atrophy type 1 (SMA1) or acute spinal muscular atrophy, it occurs individuals who have symptom onset prior to 6 months of age. All the SMAs are inherited as an autosomal recessive trait. Molecular genetic testing has revealed that all types of autosomal recessive SMA are caused by disruptions or errors (mutations) in the SMN1 (survival motor neuron 1) gene on chromosome 5. The symptoms and progression of SMA1 or Werdnig-Hoffmann disease varies among affected individuals.

Werdnig-Hoffmann disease is a rare disorder

that affects males and females in equal numbers. The prevalence of all types of spinal muscular atrophy has been estimated to be 4-7.8 per 100,000 live births (Kolb SJ, Kissel JT, 2015). Approximately 80% of SMA patients have the Werdnig-Hoffmann form.

Werdnig-Hoffmann is a disease of the anterior horn cells. These neurons, located in the spinal cord, are the main motor nerves that transmit nerve impulses from the spinal cord or brain to muscular or glandular tissue. Molecular genetic testing has shown that all types of autosomal recessive SMA are caused by mutations in the survival motor neuron (SMN) gene on chromosome 5. Deletion of the neuronal apoptosis inhibitory protein (NAIP) gene close to the SMN gene also is associated with SMA. More patients with Werdnig-Hoffmann disease than other type of SMA have NAIP deletions (Neil EE, Bisaccia EK. Nusinersen, 2019). Spinal muscular atrophy destroys nerves controlling voluntary muscle movement, affecting crawling, walking, head, neck control, and swallowing.

Case report

On the first day of life a baby admitted in NICU with complaints of poor muscle tone, excessive drooling of saliva, abnormal tongue movement and poor respiratory effort.

***On physical examination**, it was found that the baby was conscious and alert and abnormal flexibility (hypermobility) of the joints, twitching (fasciculation) of the tongue, absent deep tendon reflexand frog-like position with the hips moved apart (abducted) and knees bent or flexed. Vital signs are stable.*

***Birth history**: Full term normal vaginal delivery. The birth weight of the baby was 1.2 kg. Baby did not cried soon after birth. APGAR score was 2 at 1 minute. So baby was intubated and ventilated in the labour room itself and shifted to NICU.*

***Family history:** Baby was a third child of non consanguineous marriage. First sibling died on 45thpostnatal day due to congenital myopathy. Second sibling is normal. No other history of any childhood illness in the family.*

Investigation

All routine investigations done, there is no abnormal findings. Vidrolaryngoscopy was done it shows bilateral vocal cord palsy.

Medical management

Treatment is aimed at the specific symptoms that are present in each individual. For this, baby did not cried soon after birth. APGAR score was 2 at 1 minute. So baby was intubated and ventilated in the labour room itself and shifted to NICU. Feeding difficulties cause nutritional concerns so oropharyngeal tube placed and IVF (Dextrose 10% 70 ml/kg/day) given.

Baby was on,

- *Inj Vitamin K 0.5 mg (anticoagulant) I/V single dose*
- *Inj Pipzo 83mg (antibiotics) I/V 12th hourly for 6 days*
- *Inj Caffeine 16 mg (bronchial smooth muscle relaxant) I/V once dailyfor 3 days*
- *Inj Aminoven 4mg (amino acid supplement) I/V 6th hourly for 6 days*
- *IVF Dextrose 10% 70 ml/kg/day (3ml/kg/ hour) for 6 days*

Nursing care

The baby with progressive muscle weakness requires nursing care similar to that of the immobilized child. However, the underlying goal of treatment should be to assist the baby and family in dealing with the illness while progressing toward a life of normalization within the baby's capabilities.

Nursing management

Assessment

- *Vital signs*

  Temperature : 98.6^0 C

  Pulse : 132/mt

  Respiration : 34/mt

  Blood pressure : 77/57 mm/Hg

  Oxygen saturation: 89%

- *Absent deep tendon reflex and frog-like position with the hips moved apart (abducted) and knees bent or flexed*
- *Redness over the cannulated site.*
- *Less response to sensory stimulation.*
- *Parents asking more doubts about new-born care.*

Nursing diagnosis

1. *Ineffective breathing pattern related to pulmonary neuromuscular deficit as evidenced by poor respiratory effort.*
2. *Impaired physical mobility related to neuromuscular deficit as evidenced by abnormal flexibility.*
3. *Risk for impaired skin integrity related to neurologic motor deficit.*
4. *Risk for infection related to the invasive line and procedures and poor nutritional status.*
5. *Sensory deprivation related to neurological deficit as evidenced by not responding to sensory stimulation.*
6. *Deficient knowledge of parents related to care of the baby, progression of the disease.*
7. *Anxiety of parents related to physical defect and outcome of the treatment.*

Goal

- *Baby maintain adequate gas exchange.*
- *Baby maximize the mobility.*
- *Baby remains free from infection.*
- *Baby maintain intact skin.*
- *Baby receive sensory stimulation.*
- *The parents demonstrate adequate knowledge for care of the child.*
- *The parents remains free from anxiety.*

Nursing intervention

Facilitation of respiration

- *Assessed respiratory rate, breathing pattern frequently.*
- *Monitored oxygen saturation continuously.*
- *Cleared airway by suctioning.*
- *Provided comfortable position and changed position 2nd hourly.*
- *Administered humidified oxygen.*

Promoting mobility

- *Assessed the degree of mobility impairment.*
- *Used Bradford frame to maintain correct position.*
- *Performed passive range of motion exercises gently to prevent contracture.*

Maintaining skin integrity

- *Changed position frequently*
- *Kept the skin clean and dry.*
- *Massaged with lotion to stimulate circulation over pressure points.*
- *Offered adequate fluids.*

Preventing infections

- *Practiced good hand washing and aseptic care.*
- *Inspected invasive lines and daily noted the characteristics.*
- *Administered antibiotics as prescribed.*

Parental education and reassurance

- *Provided all necessary information to parents regarding care of baby.*
- *Involved parents in baby care.*
- *Discussedtheir concerns regarding the baby.*

Evaluation

- *Vital signs*

  Temperature : 98.6^0 C

  Pulse : 125/mt

  Respiration : 30/mt

  Blood pressure : 77/57 mm/Hg

  Oxygen saturation: 96%

- *No evidence of infection.*
- *Parents got enough knowledge about new-born care.*
- *Anxiety of parents reduced*

Prognosis

Baby was discharged on 6th day, on discharge baby was symptomatically better, vital signs were stable.

Discussion

Werdnig-Hoffmann disease is the most severe type of spinal muscular atrophy (SMA). Known as "infantile SMA," Werdnig-Hoffmann is a rare, inherited, autosomal recessive neuro-muscular disease. Both parents unknowingly carry the gene for the disorder, and when the child inherits the defective gene from both parents, the disease develops. Approximately 1 in 50 people or 1 in 2,500 couples in the United States are carriers. When both parents carry the gene, the likelihood of the child inheriting the disease is one in four or a 25% chance with each pregnancy (Neil EE, Bisaccia EK. Nusinersen 2019). Since the 1990s, prenatal and carrier testing have been made available to families.

In this present case report, the cause of Werdnig-Hoffmann disease is unknown. The symptoms and progression of SMA1 or Werdnig-Hoffmann disease varies among affected individuals. Affected infants are weak before 6 months of age. The early signs include a generalized muscle weakness, diminished muscle tone (hypotonia) resulting in "floppiness," abnormal flexibility (hypermobility) of the joints, absent tendon reflexes, twitching (fasciculation) of the tongue, a frog-like position with the hips moved apart (abducted) and knees bent or flexed, and an alert appearance. Muscles of the face are not affected initially. Mental development is usually normal. Typically, the child does not gain head control, cannot turn over and is unable to sit or stand. In addition, children with SMA may develop difficulties sucking, swallowing, and breathing; have an increased susceptibility to respiratory infections, or develop other complications that may lead to potentially life-threatening abnormalities within the first months or years of life.

The rate of progression of Werdnig-Hoffmann disease varies. Within a few months, breathing (respiratory) and bowel (constipation) difficulties may develop. The infant may be unable to swallow. Respiratory failure may occur or food inhaled into the lungs (aspiration) may cause choking. Most affected children die before 2 years of age but survival may be dependent on the degree of respiratory function.

All forms of spinal muscular atrophy are caused by mutations in the SMN1 (survival motor neuron 1) gene at chromosomal locus 5q11-q13 (Kolb SJ, Kissel JT 2015). A second gene, known as the SMN2 (survival motor neuron 2) gene, plays a role in the development of SMA.

A diagnosis of SMA may be suspected based upon a detailed patient history, a thorough clinical examination and identification of characteristic findings. A diagnosis may be confirmed through molecular genetic testing, which can determine whether a mutation is present in the SMN gene.

SMA is caused by a partial or complete loss of the SMN gene and about 95 percent of those affected will show a deletion of both copies of a specific portion (exon 7 or exon 8) of the gene. About 5 percent of those affected will show a deletion of exon 7 in one copy of the SMN gene and a different mutation in the other copy of the SMN gene (Farrar MA,Kiernan MC 2015).

In 2017, Spinraza (nusinersen) was FDA (Food and Drug Administration) approved as the first drug to treat children and adults with SMA. Spinraza is manufactured by Biogen.

Conclusion

On the first day of life baby admitted in NICU, baby did not cried soon after birth and complaints of poor muscle tone, poor respiratory efforts, abnormal tongue movements. APGAR score was 2 at 1 minute. So baby was intubated and ventilated in labour room itself and shifted to NICU. On physical examination and investigations reveals that features of Werdnig-Hoffmann disease. Treatment given based on specific symptoms and supportive care provided. Baby was discharged on 6th day, on discharge baby was symptomatically better, vital signs were stable.Advise given to parents, to prevent muscle and joint contractures, promote independence in performance of ADLs as they grows.

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