

Study Protocol

To Assess Effectiveness of Informational Booklet on Knowledge Regarding Bardet- Biedl syndrome among Nursing Students.

ABSTRACT

BACKGROUND :- Bardet–Biedl syndrome is an inherited hereditary multiple organ systems illness caused by mutations in proteins that are found in the main cilium and basal .body complex. To date, 21 genetic disorder genes have. being discovered. It's one of the most researched ciliopathies (a group of illnesses caused by faulty cilia). In this study article review , researcher have been provided an diagnostic improvement and it's , clinical features, and therapeutic improvement for Bardet–Biedl syndrome.

OBJECTIVES

- To assess the existing knowledge regarding Bardet- Biedl syndrome among nursing students.
- To assess the effectiveness of informational booklet on Bardet- Biedl syndrome among nursing students.
- To associate post test and pre test knowledge score among nursing students with selected demographic variables.

Material and Method:- A one-group .pre-test-post-test research design was used to evaluate the effects of an information booklet on nursing students' understanding of Bardet-Biedl syndrome. Non probability purposive sampling technique is used. In this study a total number of 300 students who fulfil the inclusion criteria were selected the setting of the study is selected Nursing College Wardha.

Expected result :- This study is planned to assess the Effectiveness of Information Booklet on knowledge regarding Bardet- Biedl syndrome among Nursing students, As a result, it is expected to determine the nursing student's degree of knowledge of the Bardet-Biedl Syndrome and to improve that knowledge.

Keywords:- Rare disease, Bardet Biedl Syndrome , Genetic therapies, Nursing Student

INTRODUCTION

Biedl syndrome is a one of the rare autosomal recessive illness ciliopathy characterized by learning impairments, retinal degeneration, renal failure, obesity, post-axial polydactyly and hypogonadism. Many small traits that are connected with BBS might benefit in diagnosis and are essential in therapeutic care.[1]According to population trends, there are approximately 3000 persons living with BBS in the United States and Canada, with less than 15 cases documented from India. BBS prevalence varies greatly between communities, ranging from 1:160 000 in northern European villages 5 to 1:13 500 and 1:17 5000 in segregated communities in the Kuwait and Newfoundland, respectively, where consanguineous marriage is more widespread.[2]

Nurses are expected to be knowledgeable of genetic disorders such as Bardet Biedl syndrome that can be applied in medical practice. However, researchers are discovering that, despite the fact that student nurses will soon be working in hospitals, they are not knowledgeable or comfortable with clinical applications of genetics and genomics. The goal of this study was to assess nurse undergraduate students' knowledge of the Bardet-Biedl syndrome and to learn about their attitudes toward applying that knowledge in practice. Nurses were responsible for advising patients and family members about genetic counselling and allowing them to make an informed decision.[3]

BACKGROUND

Bardet–Biedl syndrome is an inherited hereditary multiple organ systems illness caused by mutations in proteins that are found in the main cilium and basal .body complex. To date, 21 genetic disorder genes have. being discovered. It's one of the most researched ciliopathies (a group of illnesses caused by faulty cilia). In this study article review , researcher have been provided an diagnostic improvement and it's , clinical features, and therapeutic improvement for Bardet–Biedl syndrome. As advances occur in the diagnostic technology, including as exome and whole genomic studies, are broadening the range of people and diagnosed with the Bardet– Biedl syndrome and raising the amount of such cases with diagnostic ambiguity. As per result came of diagnostic improvements, a limited percentage of patients been seen with only 1 or 2 clinical symptoms of Bardet–Biedl syndrome are now being discovered.[5]

Need of the Study

Bardet Biedl syndrome Knowledge is needed by student nurse for the health care of their clients and their families. The goal of this study was to evaluate nursing students' current genetic understanding of hereditary illnesses such Bardet Biedl syndrome. This research enlightens knowledge of student nurses about Bardet Biedl syndrome . Nurse scientists around the world are increasingly integrating genomics into their programmers of research . Nurses require knowledge of Bardet Biedl syndrome for identification, support and guidance of clients either at the risk of genetic disorder as Bardet Biedl syndrome or inherited a genetic

mutation . Through their focus on health and it's promotion, screening, , prevention ,caring of the patient and family, community ties nurses have the chance to provide a unique viewpoint to genetic and also genomic healthcare.[6]

Methodology

The research was conducted using an evaluative research approach with a one-group pretest post-test research design. A non-probability and purposive sampling technique was utilised, with 300 samples taken from selected Nursing College Wardha second , third , and fourth year B.BSC student nurses.

CRETERIA OF STUDY

Inclusion Criteria:-

Student Nurses those who are:-

- Want to be participate.
- Present on the day of data collection

Exclusion Criteria:- .

Nursing students those who are:-

- Participated in similar type of study

Randomization

All participants are selected by sequentially numbered list at random.

Intervention

To evaluate the Effectiveness of Information Booklet on knowledge regarding Bardet- Biedl syndrome among Nursing students.

STATISTICAL ANALYSIS

Statistical analysis done by descriptive and inferential statics SP²⁷

Ethics and dissemination

Datta Meghe Institute of Medical Sciences (Deemed to be University), DMIMS(DU/IEC/2021/303).

Expected outcome / result

This study to evaluate the effectiveness of information booklet on knowledge regarding Bardet- Biedl syndrome among Nursing students Hence, It is expected to identify the level. of

knowledge and give information to Student Nurses regarding Bardet Biedl syndrome with the help of information booklet .

DISCUSSION

It is clear that the nurses must expand their understanding of hereditary diseases, such as Bardet-Biedl syndrome, as well as health and nursing. Kim found a link between nurses' and their level of the knowledge and their interest in hereditary disorders in a study of 969 nurses.[7]. Human genetics principles and material are currently being incorporated into nursing education programmes. For example, Hertzberg et al. examined Eight Hundred Seventy Nine basic nursing programme. 66 percent of BSN programmed in the research said their courses contained medical genetics expertise. In 1996, BSN and Associate Degree in Nursing (ADN) RN programmes spent 6.0 and 6.3 hours on human genetics, respectively. According to Monsen et al., only a minority groups reported that genetics, inherited illnesses, and/or the human genetic basis for disease were covered in RN education programme standards. Furthermore, a recent review of 49 nursing schools in the one of the north eastern US found that none of student nurses taught genetics as part of their medical syllabus .

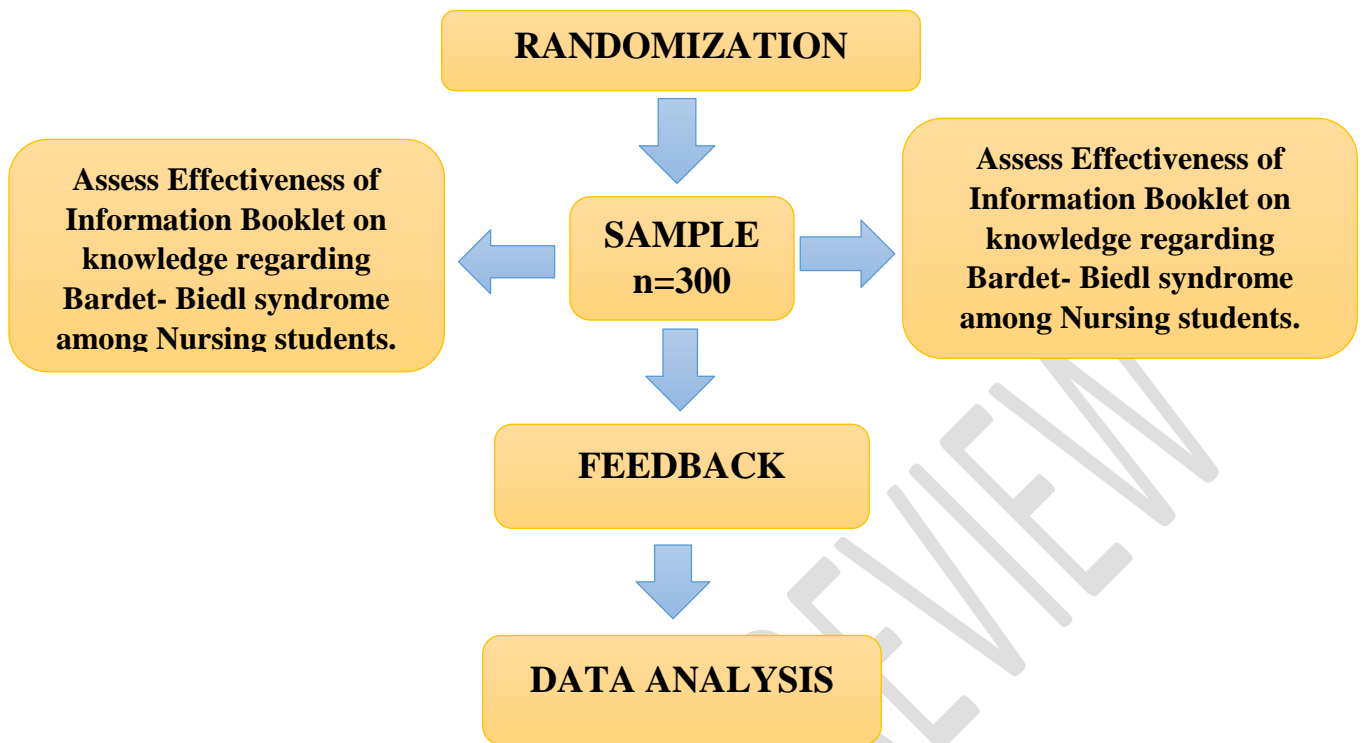
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Fig 1- Schematic diagram of study methodology

ALLOCATION OF SAMPLE





UNDER PEER REVIEW