

Assessment of Genomic Literacy, comfort level Among Baccalaureate Nursing Students

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Abstract: As we move into the 21st century, genetics/genomics has emerged as a central science for all health professionals, including nurses increasingly will underlie all of health care and therefore is fundamental to all nursing practice. Aim of the current study is to assess the genomic-genetic literacy and comfort level regarding integration of genetics in clinical practices among nursing students in an undergraduate program at a selected faculty of nursing affiliated to one university in Cairo-Egypt. Study Design: A descriptive exploratory design was utilized for conducting the current study. Results:, the current study finding revealed that the majority of the study participants had no knowledge regarding genetic terms, genetic disorders except about breast cancer, thalassemia and sickle cell disease & no knowledge to genetic related procedures .Also the current study showed low comfort level of genetic knowledge regarding patient and family history, making referral for a patient with genetic questions, sharing in a support group to a patient with genetic disease. Conclusion: Based on the results the study findings revealed that the majority of the study participants had no knowledge regarding genetic, and genetic related procedures. In relation to genetic disorders all the study participants had no knowledge except about breast cancer, thalassemia and sickle cell disease. The study participants were not comfort regarding integration of genetics in clinical practices. Recommendations: Nursing genetic should be included as an essential part of faculty nursing curricula either for theoretical and practical aspects.

Keywords: Genomic Literacy, comfort level, Baccalaureate Nursing Students.

I. INTRODUCTION

As we move into the 21st century, genetics/genomics has emerged as a central science for all health professionals, including nurses increasingly will underlie all of health care and therefore is fundamental to all nursing practice [1]. Undoubtedly Genetic and genomic science is redefining the understanding of the continuum of human health and illness [2]. Genetics scrutinize the functioning and composition of the single gene where genomics addresses all genes and their inter relationships coupled with the influences of the environment, personal lifestyle, as well as psychosocial and cultural factors in order to identify their combined influence on the growth and development of the organism [3].

The top 15 causes of death in the United States have a genetic and/or genomic component, with heart disease, cancer, were the first and second leading causes of death. In 2015, these two causes accounted for 45% of all deaths. While cerebrovascular stroke and diabetes represent fifth & seventh respectively [4]. Although nurses mostly have been required to care for patients with rare inherited diseases, evidence of the genetic contribution to common conditions such as diabetes, coronary heart disease, and cancer has increased the focus on genomics in nursing. The potential influence of nurses in this area was emphasized in a study indicating that patients regarded advice about genetic testing as equally valuable whether it was given by an expert nurse or an expert physician [5].

Health care has increasingly integrated genomic information and technology along the pathways of prevention, screening, diagnosis, prognosis, treatment selection, and monitoring of therapy effectiveness. It's crucial for nurses to have proper knowledge and skills to provide safe and effective nursing interventions in recognition of evolving science [6]. Thereafter

knowledge of genomics is required to ensure appropriate referral and education of patients who would benefit from genetic services what's more, nurses tailor interventions to individual patients based on various factors, including the patient and family perception of needs, patient preferences, physical and psychosocial assessment and current evidence. However these factors remain vital, genetic/genomic variability could further inform nursing interventions and lead to improved outcomes for patients. Applying knowledge about genetic/genomic variability will be valuable in several arenas, as but not limited to health promotion, disease prevention and symptom management [7].

Implementing genomics across nursing practice needs to be an evolution, not a revolution. Subsequently; incorporating genetics into nursing has arguably become one of the most pressing issues in nursing education. Experts in the field of nursing recognize that genetics expertise is integral to nursing practice, research, and education. [8]. In Egypt the importance of medical genetics started in the Twentieth century in the early 1960s it was well appreciated at Cairo and Ain Shams Universities. In 1966, the specialty of Human genetics at the National Research Centre was established. In 1967, the medical genetics unit at the Medical Research Institute in Alexandria was started. This was followed by the initiation of medical genetics units in other universities such as El-Mansoura and Alexandria Universities. Mubarak City of Scientific Research encompasses centers for frontier sciences including genetic engineering and biotechnology [9].

After that, the Human Genetics and Genome Research Division at the National Research Centre were established, until it became the main unit dealing with genetic diseases in Egypt. Today people from all Egyptian governorates and neighboring Middle East countries seek diagnosis, treatment, and medical advice at the Center. Nowadays, human genetic courses are included in the curriculum of medical students in most Egyptian universities. In addition, specialized postgraduate degrees in the field of Medical Human Genetics are offered to graduates from Medical schools in Egypt at Ain Shams and Alexandria Universities [10].

In the light of concerns about the genetics/genomics education of nurses and their subsequent fitness to practice, a question arises as to whether nurses have adequate knowledge of genetics or genomics. Current academic nursing education does not adequately prepare nurses for their evolving role in today's genomic era. Previous research has revealed that many nurses have minimal training in genetics and genomics. The American Association of Colleges of Nursing (AACN) now integrates genetic/genomic concepts as foundational for all baccalaureate nursing curriculum. Increasingly, some professional nursing organizations include genetics/genomics in annual education programs; moreover 49 professional organizations endorsed the U.S. genetic/genomic nursing competencies [11].

Thus, the aim of this study is to investigate the perceived knowledge and comfort level with genetics among nursing students at a selected faculty of nursing in Egypt. It can be an initial step to assess current knowledge and comfort with genetic nursing which needed to identify the changes looked-for in nursing curricula and practices.

Significance of the study:

The mission of the National Coalition for Health Care Professionals Education in Genetics (NCHPEG) is to integrate information in human genetics and genomics into health professional education and to apply these scientific advances to promote health care. It is vital for health professionals and students of the health professions throughout the world to possess a fundamental understanding of genetic and genomic information [12]. A small collection of studies have evaluated nurses' knowledge of genetics. To date, much of the existing research on knowledge of genetics/genomics among nurses and physicians has been conducted with healthcare professionals from either North America or Europe [13]. Therefore, there is scarce research of genetic education, knowledge and experiences between nurses student in Egypt. So as a first step, current knowledge and comfort with genetic nursing need to be assessed to identify the changes required in nursing curricula to pace with international genetic/genomic nursing education.

II. MATERIAL & METHODS

The Aim:

The of the current study is to assess the genomic-genetic literacy and comfort level regarding integration of genetics in clinical practices among nursing students in an undergraduate program at a selected faculty of nursing affiliated to one university in Cairo-Egypt.

Research Question?

- 1- What is the genomic-genetic literacy among Baccalaureate nursing students in one faculty of nursing-Egypt?
- 2- What is the comfort Level of Baccalaureate nursing students regarding integration of genetics in clinical practices in one faculty of nursing-Egypt?
- 3- What are the educational activities/strategies that improve genomic-genetic Knowledge as reported by the study participants?

Research Design: A descriptive exploratory design was utilized for conducting the current study.

Setting: The study was conducted at a selected faculty of nursing affiliated to one university in Cairo-Egypt.

Subjects:

194 undergraduate nursing students enrolled in a nursing program at a university in Egypt during April semester of 2017 were invited to participate in the study. Of these, 300 students (response rate = 64.6%) completed the self-report questionnaire. Inclusion criteria were that the nursing student (a) had taken a basic bioscience course and (b) could speak or understand English. Verbal and written instructions were explained to nursing students by the researchers to fulfill the self-reported questionnaire.

Tools:

In order to achieve the purpose of the study The “Genetics Needs Assessment Survey” was developed by [14] was used. The survey developers established content validity by the use of a panel of expertise in medical genetics and healthcare evaluation. The paper-and-pencil survey consisted of 70 multiple-choice and dichotomous items. Three items assessed demographics, 52 items evaluated the student's perceived knowledge of various genetic concepts, 9 items examined the student's comfort with genetics in the clinical setting, and 6 items assessed the way students would like educational activities to be conducted in regard to genetics.

The questionnaire used in this study was a modified version of The “Genetics Needs Assessment Survey” was developed by [14], to assess perceived genetics knowledge of students in various health disciplines. Initial revisions to the survey were based on an extensive review of latest work to integrate genetic content into nursing curricula. Then, two experts in genetics and three nursing education were asked to review each item of The “Genetics Needs Assessment Survey” to ensemble and modify the content validity of the items for Egyptian nursing students. In addition to exclusion of uncommon genetic conditions which are very rare or seldom occurs in Egyptian population as myotonic dystrophy, neurofibromatosis and hardy Weinberg equilibrium was done. The modified version included 46 items: (a) five demographic items; (b) 31 items to assess perceived knowledge of human genetic principles and disorders (c) 4 items evaluate clinical comfort with genetics (d) 6 items regarding educational methods of teaching genetics with a response of 1 if the answer is yes and zero if the answer is no. The average content validity index for the modified version was measured indicating adequate content validity. The modified version was then piloted with 10 nursing students, and minor revisions were incorporated. The study participants indicated that the questionnaire took approximately 15 to 20 min to complete, and no difficulties were reported in understanding either the questions or the response.

Ethical consideration:

An official permission was obtained from corresponding authority. A cover letter reflecting the elements of informed consent as well as nature, purpose and benefit of the study was given to subjects before they received the survey. Potential study participants were informed that their participation was voluntary, their information would be kept confidential & anonymity will be assured too through coding the data. They would not be penalized for answering the questions incorrectly, and their standing in the nursing class would not be affected whether or not they participated. Subjects were instructed not to put their names on the survey.

Procedures:

After official permission, the researchers arranged time with coordinators of each nursing specialty to meet students and give full description for research aim and procedure and written informed consents were collected from students who agreed to participate in the study. Self-reported questionnaire were given to potential study participants. A return envelope was provided in the classroom for students who chose to complete the survey on site, and the students who chose to complete the survey later were instructed to return the completed questionnaire to the researcher within one week.

III. RESULTS

Results of the study are presented in four major parts; the first part is descriptive statistics that included the personal characteristics of the study participants. Second part is related to students' perceived knowledge of genetics. Third part is related to comfort level regarding integration of genetics into clinical practices. The last part is related to educational activities that improve genetic knowledge as reported by the study participants.

Table (1): Demographic data of the study participants (n=194).

Variables	Category	Study participants	
		No.	%
Gender	Male	64	43.3
	Female	130	56.7
Age	18-	15	7.73
	19-	30	15.4
	20-	38	19.5
	21-	77	39.6
	22-	16	8.24
	23-24	18	9.27
Study Year	One	45	23.19
	Two	78	40.2
	Three	35	18.3
	Four	36	18.55

Table (1) shows that 56.7 % of the study participants were female while 43.3 were male. Regarding age, 39.3% of the study participants had age range from 21 to less than 22 years old while 15 % had age range from 18 to less than 19 years old. As regards study year, 40.2 % of the study participants were in second year, 23.19 % were in first year in addition to 18.3 % & 18.55 % of the study participants were in third and fourth year of study respectively.

Table (2): Number & Percentage of nursing students' Knowledge selected Genetic Topics among the study participants (n=194).

Genetic Topics	No Knowledge N (%)	Some Knowledge N (%)	High level of Knowledge N (%)
Genetic Terms			
Mitosis	124 (63.91)	60 (30.92)	10 (5.15)
Meiosis	134 (69.07)	50 (25.77)	10 (5.15)
transcription	174 (89.6)	20 (10.3)	0 (0)
translation	184 (94.8)	10 (5.15)	0 (0)
Mutations	134 (84.5)	30 (15.4)	30 (15.4)
DNA replication	159 (81.95)	15 (7.73)	20 (10.3)
DNA structure/function	83 (47.9)	101 (52)	10 (5.15)
RNA structure/function	176 (90.72)	3 (1.54)	15(7.73)
Autosomal dominant inheritance	184 (94.8)	10 (5.15)	0 (0)
Autosomal recessive inheritance	194 (100)	0 (0)	0 (0)
X- linked inheritance	194 (100)	0 (0)	0 (0)
Mitochondrial inheritance pattern	194 (100)	0 (0)	0 (0)
Protein synthesis	184 (94.8)	10 (5.15)	0 (0)
Genetic Conditions			
Gausher disease	194 (100)	0 (0)	0 (0)
Familial hypercholesterolemia	194 (100)	0 (0)	0 (0)
Duchenne's muscular dystrophy	194 (100)	0 (0)	0 (0)
Trisomy 21 (Down syndrome)	170 (87.6)	20 (10.3)	0 (0)

Trisomy 18	194 (100)	0 (0)	0 (0)
Trisomy 13	194 (100)	0 (0)	0 (0)
Turner syndrome	194 (100)	0 (0)	0 (0)
Klinefelter syndrome	194 (100)	0 (0)	0 (0)
Cystic fibrosis	180 (92.7)	10 (5.15)	4 (2.06)
Breast cancer	40 (20.6)	24 (12.3)	130 (67.01)
Ovarian cancer	125 (64.4)	39 (20.1)	30 (15.4)
Thalassemia	24 (12.3)	40 (47.9)	130 (67.01)
Sickle cell disease	81(41.7)	113 (58.2)	0 (0)
Fragile X	194 (100)	0 (0)	0 (0)
Genetic related procedures			
Polymerase chain reaction (PCR)	194 (100)	0 (0)	0 (0)
Gene therapy	147 (75.7)	47 (24.2)	0 (0)
Genogram	164 (84.5)	30 (15.4)	0 (0)
Pharmacogenesis	180 (92.78)	14 (7.21)	0(0)

Table (2) revealed that the majority of the study participants had no knowledge regarding genetic terms as Autosomal dominant inheritance , translation , RNA structure/function, transcription , mutations and DNA replication (100% , 94.8 % , 90.72% , 89.6% , 84.5% & 81.95%) respectively. The same table showed all the study participants had no knowledge as regards genetic conditions as Gausher, Familial hypercholesterolemia, Duchenne's muscular dystrophy, Trisomy 18, Trisomy 13, Turner syndrome, Klinefelter syndrome& Fragile X diseases while 67.01 % of the study participants had a high level of knowledge as regards breast cancer and thalassemia, in addition to 58.2 % and 47.9 % of them had some knowledge regarding Sickle cell disease and Thalassemia respectively. It was found that (100% , 92.78% , 84.5 & 75.7%) of the study participants had no knowledge of genetic related procedures as Polymerase chain reaction , Pharmacogenesis , Genogram and Gene therapy respectively, only 24.4 of the study participants has some knowledge regarding gene therapy

.Figure (1): Comparison of Nursing Students' Knowledge of Genetic Terms among the study participants as regards to their study year (n= 194).

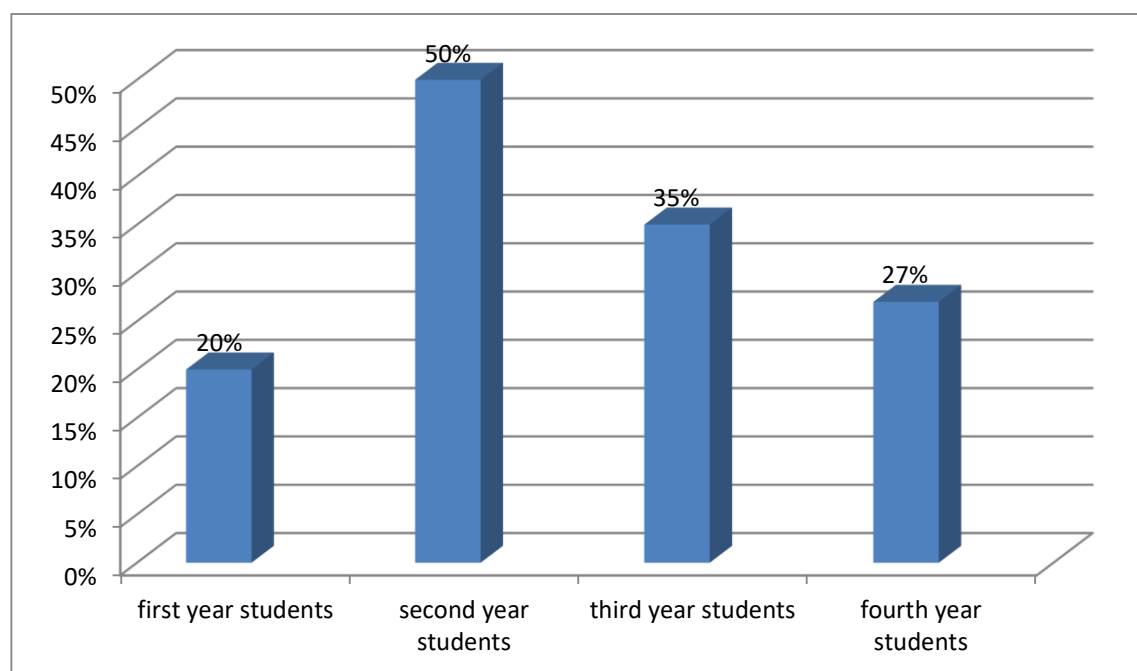


Figure (1): illustrated that 50 % of knowledge related to genetic terms was reported by second year students.

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Figure (2): Comparison of Nursing Students' Knowledge of Genetic Conditions among the study participants as regards to their study year (n= 194).

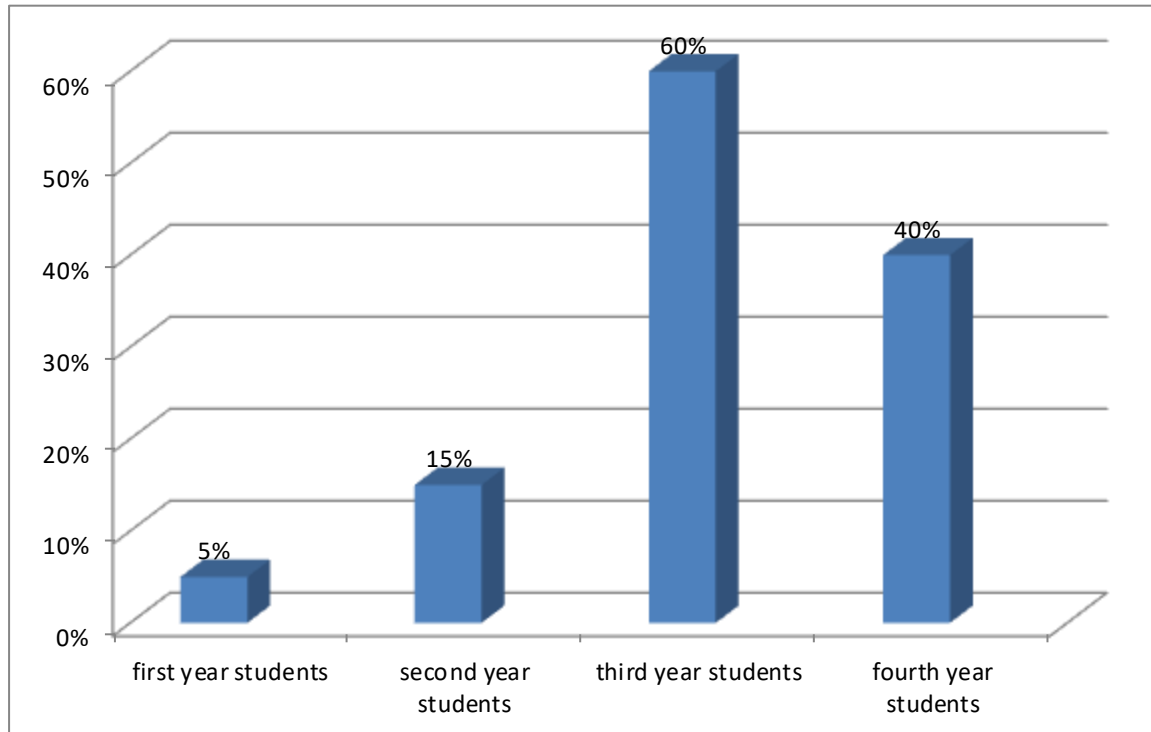


Figure (2): showed that 60 % of knowledge related to genetic conditions was reported by third year students.

Figure (3): Comparison of Nursing Students' Knowledge of Genetic related procedures among the study participants as regards to their study year (n= 194).

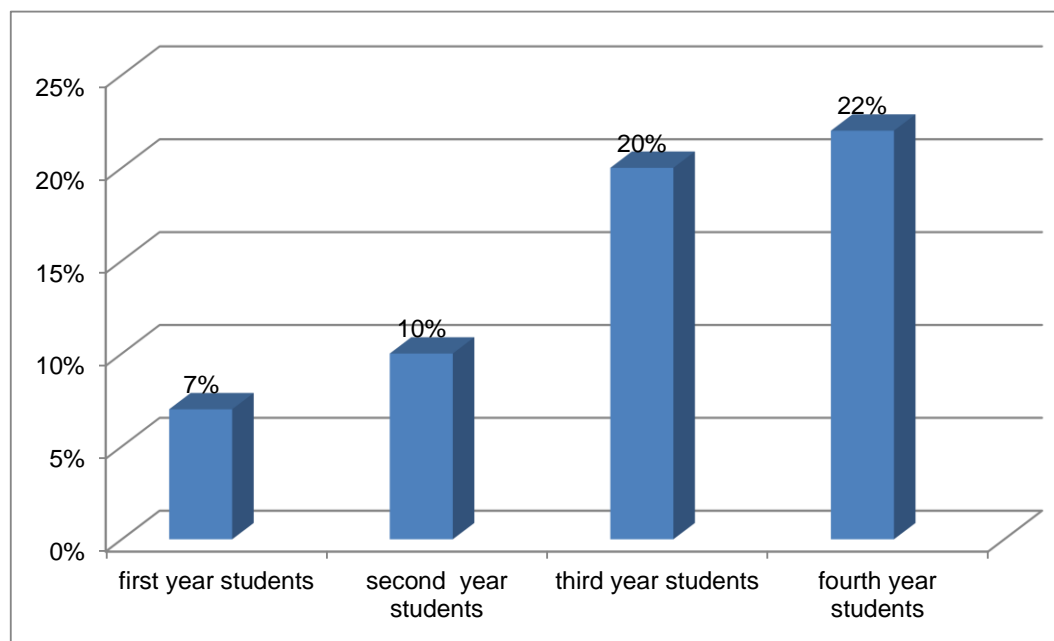


Figure (3): revealed that 22 % of knowledge related to genetic procedures was reported by fourth year students.

Figure (4): Comfort Level of nursing students regarding integration of genetics in clinical practices among the study participants (n= 194).

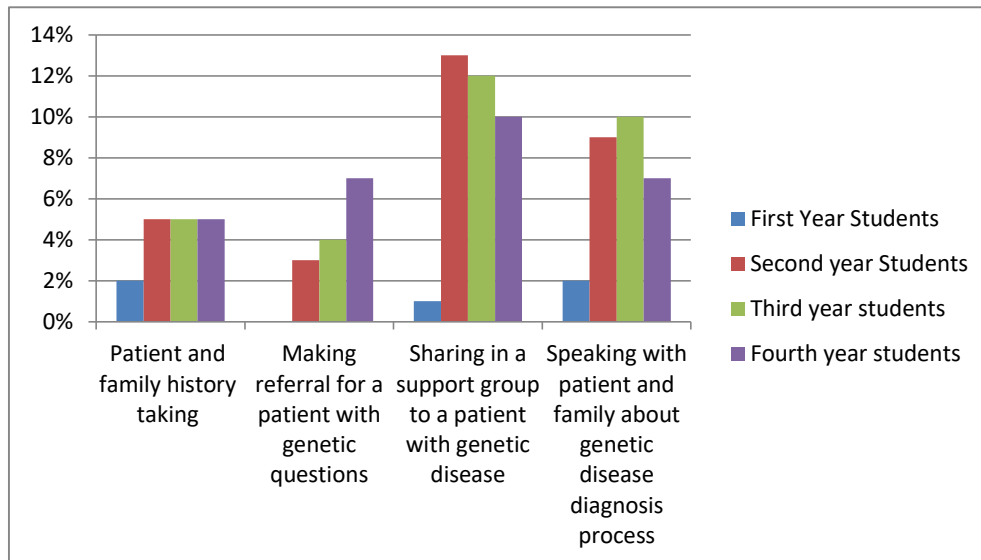


Figure (4): revealed that second, third and fourth year students had 5 % comfort level of their genetic knowledge regarding patient and family history. Also it noted that the fourth , third and second year students had (7 %, 4% and 3%)comfort level respectively as regards making referral for a patient with genetic questions while the first year students had zero comfort level in this issue. The same table showed that , only 13 %, 12% and 10% of the fourth , third and second year students respectively reported that they were comfort in relation to genetic knowledge of sharing in a support group to a patient with genetic disease. Also it was found that 10 % of the third year students and 9% of the second year students were comfort with their genetic knowledge as regards making speaking with patient and family about genetic disease process.

Figure (5): Educational activities that improve Genetic Knowledge as reported by the study participants (n= 194).

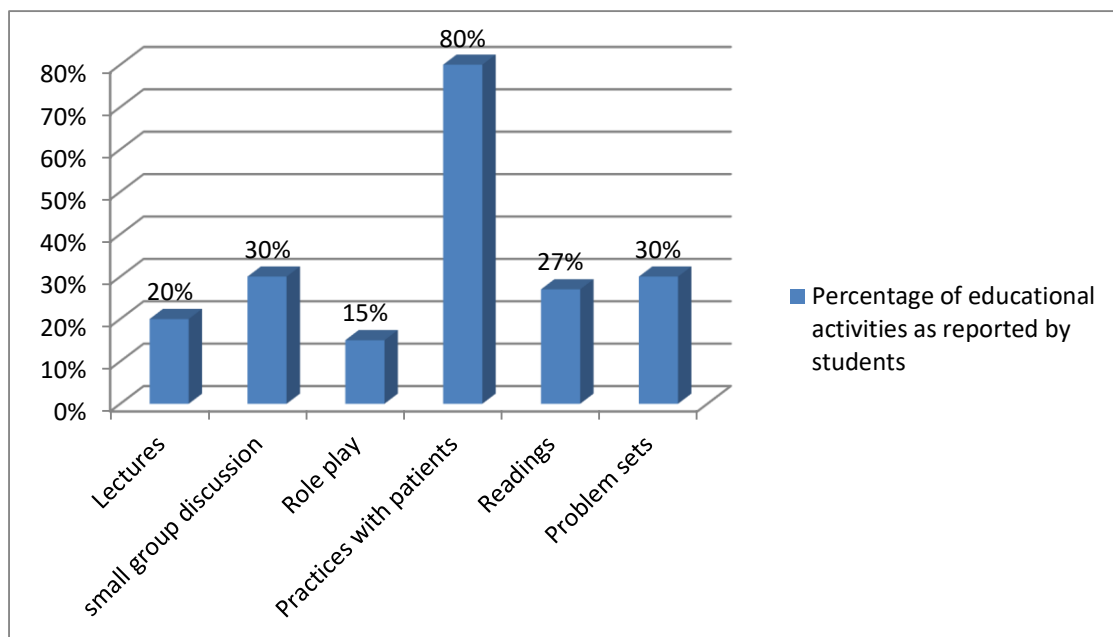


Figure (5): illustrated that 80 % of the study participants preferred practices with patients and 30 % of them preferred both small group discussion and problem sets as an educational activities to improve their genetic knowledge.

IV. DISCUSSION

This study is one of the first in Egypt to examine genomic literacy, clinical comfort level of genetics/genomics, and genetic education in the nursing curriculum. Findings will add to the emerging body of evidence on the significant gap in undergraduate nursing students' knowledge regarding genetic/genomic concepts, principles, conditions, and diagnostic measures. Nursing Students participated in this study were dominantly female (56.7%), this could be attributed to the fact that males were recently introduced to the nursing faculties in Egypt. The students' age ranged from 18 to 24 years old & this is matched with the formal education system in Egypt. Amusingly, in a study done by [15] showed that the vast majority of nursing students participated were female (90%) with ages ranged from 18 to 58 years (mean [SD], 23.9 [5.6] years).

With reference to the **first research question**, the current study revealed that the majority of the study participants had no knowledge regarding genetic terms as translation, RNA structure/function, transcription, mutations and DNA replication. Up till now there is a considerable gap in nurses' genetic knowledge and ability to integrate that knowledge into practice.[10] Several Studies exploring perceived genetic-genomic knowledge and teaching strategies relevant to the inclusion of genetic content into nursing curricula has been conducted in the United Kingdom; New Zealand; Japan; Turkey; Taiwan; and the United States, these studies revealed that perceived genetic knowledge and clinical comfort remain inadequate among pre-licensure nursing students or advanced practice nursing students[2]. Speaking the same language, [15] Linda D. Ward, Janet Purath, & Celestina Barbosa-Leiker, (2016) emphasized that, understanding of concepts that collectively comprise genomic literacy for nurses is low, particularly regarding foundational concepts about genome structure and function. The reported findings of higher student scores on items that test understanding of Mendelian inheritance may reflect a longstanding focus on Mendelian genetics beginning with primary and secondary science education.

The current study shed light on, almost all the study participants had no knowledge as regards genetic conditions as Gausher, Familial hypercholesterolemia, Duchenne's muscular dystrophy, Trisomy 18, Trisomy 13, Turner syndrome, Klinefelter syndrome & Fragile X diseases. It was found that the majority of the study participants had no knowledge of genetic related procedures as Polymerase chain reaction, Pharmacogenesis, Genogram and Gene therapy. A plausible explanation for this, the students didn't receive a stand-alone genetic disease courses. However, around two thirds of the participated students had a high level of knowledge regarding breast cancer and thalassemia, in addition to around half of them had some knowledge regarding Sickle cell disease and Thalassemia. These results might be attributed to such disorders were threaded into some the nursing courses. Also this could be supported by the results of the current study which revealed that around two thirds of knowledge related to genetic conditions were reported by third level (junior) students who could studied conditions as breast cancer, Thalassemia and Sickle cell disease in medical surgical nursing and pediatric nursing courses.

With respect to Comfort Level of nursing students regarding integration of genetics in clinical practices among the study participants which is the **second research question**, the current study showed low comfort level of genetic knowledge regarding patient and family history, making referral for a patient with genetic questions, sharing in a support group to a patient with genetic disease and speaking with patient and family about genetic disease diagnosis proces. [16] Bankhead et al. (2001) found that practicing nurses in England routinely took family histories, but needed further education on family history and genetic information. A supported study on genetics knowledge and clinical comfort among Taiwanese nurses ($n = 190$) found that although most reported 'some' to 'high' knowledge of genetic terms, the majority indicated 'none' or 'minimal' knowledge about genetic conditions and limited comfort in relation to clinical tasks. [17] (Hsiao *et al.* 2012). Interestingly, [2] compared the perceived genetic-genomic knowledge of nurse educators and graduate degree nursing students however, majority (> 75%) were not comfortable with teaching or explaining this material. The later result could explain why students have low comfort level regarding integration of genetics in clinical practices inherited on one hand from the nurse educator who are not well prepared and on the other hand from lack of genomic-genetic knowledge in nursing curricula.

Referring to the last research question our study illustrated that 80 % of the study participants preferred practices with patients and 30 % of them preferred both small group discussion and problem sets as an educational activities to learn and improve their genetic knowledge. In the sideline of our results [18] reported that, simulation can be used in conjunction with teaching strategies such as lecture and discussion to allow students to practice skills such as speaking to patients about genetics-related topics.

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To sum up, nurses need to have more education related to genomics-genetics in accordance with advances in human genomics to optimize health care.

Conclusion of the study:

The study findings revealed that the majority of the study participants had no knowledge regarding genetic terms and genetic related procedures. In relation to genetic disorders all the study participants had no knowledge except about breast cancer, thalassemia and sickle cell disease. Also the current study concluded that the study participants were not comfort regarding integration of genetics in clinical practices.

Recommendations of the Study:

Based on the study results, the following recommendations were concluded:

1. Nursing genetic should be included as an essential part of faculty nursing curricula either for theoretical and practical aspects.
2. Nursing genetics as a part of nursing curricula should be a prerequisite for national accreditation of nursing faculties.
3. Genomics should be an established core competency for all registered nurses regardless of academic preparation, clinical role, or specialty.
4. Replicate the study on a larger study sample in different settings to generalize the results.

Nursing implication of the study:

Students' nurses must be knowledgeable on genetic principles, and the ethical, legal, and social implications related to genetics to increase the ability to provide effective and comprehensive care for individuals and families. Students' nurses should be familiar with the clinical course of each type of genetic disorders in order to provide explanations and initiate patient education and counseling for patients and their families. Therefore, they can provide information and counseling to help patients to develop a realistic picture of the disorder, the benefits of treatment, and expectations related to its management. In addition to providing health promotion strategies and preventive health care and screening, early detection including the importance of regular follow-up with healthcare team

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