



Simple Coaching Clinic to Improve Nurse's Knowledge of Genetic Counseling among Thalassemia Patients

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ABSTRACT

Introduction: The coaching clinic is one of the strategies designed to increase nurses' knowledge in conducting genetic counseling for patients and families of thalassemia patients. Nurses will not only be given information, but they will also be taught how to communicate and how to use genetic counseling to make sure the coaching clinic's goals are met.

Objective: This study aims to describes the effect of a simple coaching clinic on nurses' knowledge of genetic counseling implementation in thalassemia care.

Methods: This research used a quantitative approach and was conducted on August 20th–21st, 2022. The design of this study was quasi-experimental without a control group. This study obtained a total sample of 29 nurses using a proportional sampling technique and inclusion criteria. The inclusion criteria in this study were nurses with a diploma degree, an undergraduate education background, and registered nurses. The data collection instrument was a 30-questions genetic counseling questionnaire. IBM SPSS version 25.0 was used to analyze the data using the Wilcoxon test.

Results: Simple coaching clinic proved to have a significant effect in improving the knowledge level of nurses in general with p-value = 0.004. Knowledge level improvement can be seen from Mean (+SD) 53.67 (+13.64) to 69.67 (+8.26). Likewise with nurses' knowledge about thalassemia, genetic counseling and bio-informatics, the majority of respondents experienced positive changes. In contrast to the genetic topic, the majority of respondents did not experience a change in their level of knowledge so that a p-value >0.05 was obtained.

Conclusions: Changes in level of knowledge indicated that the coaching clinic's effects on level of knowledge are significant and have an impact on health services across a variety of health institutions, including clinics and hospitals. As a result, it is critical to have a health strategy that promotes the accessibility of genetic counseling services for patients with thalassemia and other genetic illnesses.

Keywords: coaching clinic, genetic counseling, knowledge, nurses, thalassemia

Introduction

Thalassemia is a group of genetic disorders that are inherited due to a lack of red blood cells in the human body so that hemoglobin production is reduced. Through its official website, the World Health Organization (WHO) states that 7% of the total world population are carriers of thalassemia traits. In addition, there are 300-400 thousand new births of thalassemia per year (Setiawan, et al., 2021). The condition is becoming a global public health concern as it spreads to regions of the world that were previously not presumed to be thalassemia endemic simply due to considerable population movement (Kasper et al., 2015). This is accompanied by previous findings that Southeast Asia is a well-known thalassemia hotspot (Colah et al., 2010). Thalassemia cases in Indonesia continue to increase based on UKK Hematology data from the Indonesian Pediatrician Association, in 2016 in Indonesia the prevalence of thalassemia major patients was 9,121 people (Agustin & Zuraida, 2020). The Indonesian government, through its official website, explains that thalassemia is the highest cause of death, if it is not treated seriously. Based on data from the Indonesian Thalassemia Foundation/Association of Parents of Sufferers is known that people with thalassemia in Indonesia have increased from 4,896 thalassemia sufferers in 2012 to 9,028 people with thalassemia in 2018 (Syobri, et al., 2020).

Thalassemia can occur as a result of alterations in the synthesis of alpha or beta globin. Beta-thalassemia is caused by a lack of beta globin chains. Inadequate globulin supply leads to reduced hemoglobin tetramer generation, which causes hypochromia and microcytosis (Huda & Indrayati, 2019). The globin gene is part of a group of genes located on chromosome 11. Decreased production of the globin gene product, either -1 globin or -2 globin (the -globin gene is present in duplicate located on chromosome 16 to be exact at 16p13.3 either Both HBA1 and HBA2), produce a relative beta chain excess, which results in a less stable chain, causing a clinical disease known as alpha thalassemia. Similarly, decreased production of the -globin gene product manifests with a more severe disease known as beta thalassemia (Aghbabak Maheri *et al*, 2018).

Thalassemia is a chronic condition for which non-allopathic treatment is currently available. At the time of disease onset or beginning, obtaining care from a nonallopathic provider is simply unnecessary, as it not only delays required management of the child, but also provides an unneeded financial burden to their caregiver. Following a thalassemic diagnosis, seeking treatment from a nonallopathic provider in addition to allopathic care exposes the kid to unnecessary risks (i.e. infection) and excessive psychological and financial burden (due to prolonged unnecessary treatment) (Biswas et al., 2017). Therefore, patients and families need to understand comprehensively about the disease prognosis and treatment management. Nurses play an important role in supporting health care for thalassemia patients and their families (Skirton, et al. 2015).

To carry out their roles and functions, nurses need to know and understand comprehensively the scope of genomics because professional nursing practice is closely related to nurse knowledge. The competencies and scope of genomics that nurses need to understand, have been compiled in a consensus panel convened by the American Nurses Association (ANA) on September 21-22, 2005 in Maryland and published in 2011 for the third edition (Tomatir et al., 2006). This is closely related to the genetic counseling process that must be carried out by nurses to patients who experience diseases or genetic disorders in the standard of Nursing Care which includes assessment, nursing diagnoses, interventions, implementation and evaluation (Andrews et al., 2014).

The coaching clinic is one of the strategies designed to increase nurses' knowledge in conducting genetic counseling for patients and families of thalassemia patients. Nurses will not only be given information, but they will also be taught how to communicate and how to use genetic counseling to make sure the coaching clinic's goals are met (Dyess, et al., 2017). A previous pilot study on multiple sclerosis nurses and physicians demonstrated promising findings in terms of the decision coaching program's acceptability and feasibility (Rahn et al., 2018). However, only a few studies have explored the effect of coaching on nurses caring for thalassemia patients. Despite these findings and previous studies about coaching for nurses on thalassemia cases, they have not been systematically implemented in Indonesia.

Objective

This study aims to describes the effect of a simple coaching clinic on nurses' knowledge of genetic counseling implementation in thalassemia care.

Method

Research design

This research was a quantitative analytical research with a quasi-experimental approach without control group.

Population and sample

The research was conducted at the Nursing Diploma Research Center of STIKes Muhammadiyah Ciamis on August 20th-21st, 2022. The population in this study were nurses who worked in inpatient rooms of hospital and public health center. The number of samples was calculated using the proportional sampling method with a simple random sampling approach from whole hospitals and public health centers in Ciamis district so that 29 respondents were obtained. The inclusion criteria of this study were nurses with a diploma, bachelor and registered nurse educational background. Community nurses, psychiatric nurses, and nurse educators were excluded from this study. All nurses involved received an informed consent form and stated that they were willing to be included as respondents in this study.

Intervention

The intervention given to respondents was a simple coaching clinic with lecturing, demonstration, and hands on to the patient caregivers. The lecturing method was carried out by online using the Zoom Meeting video conference application. The demonstration was carried out by providing examples of the implementation of genetic counseling to thalassemia patient caregivers, played by research assistants, and the use of bio-informatics in preparing genetic counseling interventions. The two methods were carried out at the Nursing Diploma

Research Center of STIKes Muhammadiyah Ciamis. The hands on to the patient caregiver was carried out at the General Hospital of District Ciamis so that respondents had direct experience in providing genetic counseling interventions. Table 1 describes the intervention process covering topics, methods, place and duration.

Tabel 1. Process of simple coaching clinic

Topics	Delivery methods	Duration	Site
Genetic <ul style="list-style-type: none"> • Basic concept of genetics • Chromosomal aberration • Genetic contribution on disease 	<ul style="list-style-type: none"> • Lecturing using PowerPoint provided by HS^a 	45'	<ul style="list-style-type: none"> • Virtual Meeting from Center of Diploma Nursing Research, STIKes Muhammadiyah Ciamis
Thalassemia <ul style="list-style-type: none"> • Definition • Etiology • Patophysiology • Clinical manifestations • Treatment management • Complication • Nursing diagnosis 	<ul style="list-style-type: none"> • Lecturing using PowerPoint provided by HS^a 	45'	<ul style="list-style-type: none"> • Virtual Meeting from Center of Diploma Nursing Research, STIKes Muhammadiyah Ciamis
Genetic counseling <ul style="list-style-type: none"> • Definition • Objectives • Procedures • Environmental preparation • Family pedigree construction • Risk calculation • Screening and diagnostic test • Marital planing 	<ul style="list-style-type: none"> • Lecturing using PowerPoint provided by HS^a • Demonstration provided by HS^a and AF^a • Hands on provided by HS^a and pediatric nurses^b 	45' 60' 60'	<ul style="list-style-type: none"> • Virtual Meeting from Center of Diploma Nursing Research, STIKes Muhammadiyah Ciamis • Thalassemia room, General Hospital of Distric Ciamis
Bio-informatics <ul style="list-style-type: none"> • Online Mendelian Inheritance in Man (OMIM) • Progeny for pedigree online tools 	<ul style="list-style-type: none"> • Lecturing using PowerPoint provided by HS^a • Demonstration provided by HS^a and AF^a 	45' 45'	<ul style="list-style-type: none"> • Virtual Meeting from Center of Diploma Nursing Research, STIKes Muhammadiyah Ciamis

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Research instrument

The instrument used in this study was an instrument of knowledge about the implementation of genetic counseling in thalassemia patients. Referring to the procedure for implementing genetic counseling, the questionnaire made up of 30 questions consisting of 4 subvariables, namely questions about genetics (6 questions), thalassemia (11 questions),

genetic counseling (9 questions), and bio-informatics (4 questions). The questionnaire was a self-assessment using a Likert scale. The questionnaire was declared valid with a Pearson correlation value of 0.773 and reliable with a Cronbach value of 0.560.

Data collection

The instruments distributed by enumerators to respondents used the WhatsApp application via a link that was directly connected to the Google form, so that the respondents' answers are directly stored in the Data Cloud online by Google. The collected data was transferred to Microsoft Excel for coding and cleaning processes. The questionnaire was filled out 2 times, namely before and after the simple coaching clinic was conducted (see on Figure 1).

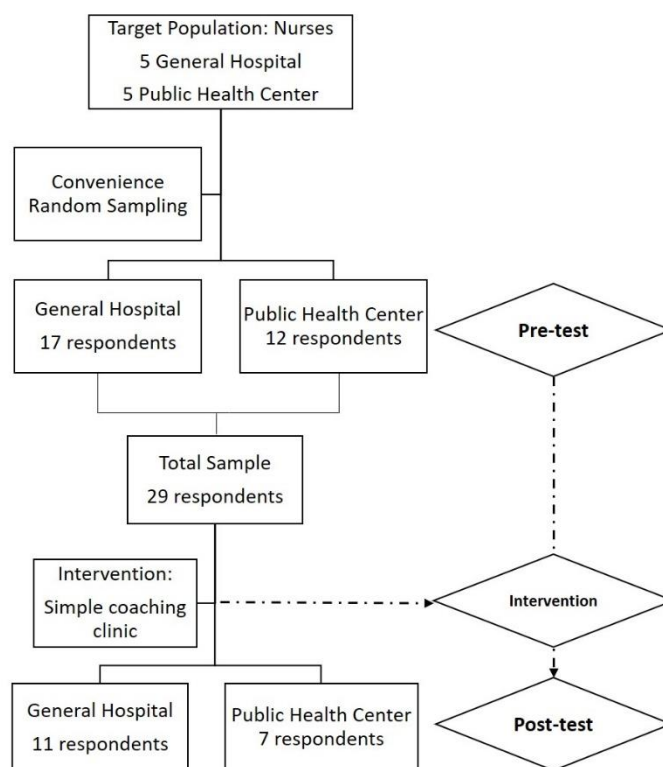


Figure 1. Protocol

Data analysis

Data were analyzed using the IBM SPSS Version 25.0 application. Data analysis was carried out to display the characteristics of respondents, assess differences in pre-post knowledge scores, and measure the effect of interventions on outcomes. Characteristics of respondents are displayed with frequency and percentage. The difference in the pre-post knowledge score was measured using the mean difference test. Meanwhile, the effect of simple coaching clinic on nurses knowledge was analyzed using the Wilcoxon test.

Result

Respondents Characteristic

Data collected from respondents, it can be seen that the majority of respondents are women (79.31%), with the lowest age being 21 years and the highest being 55 years. There

are more diploma graduates (55.17) than registered nurses (41.38%) with the majority of work experience <5 years and income <USD 127. For more details, an explanation of the characteristics of respondents can be seen in table 2.

Tabel 2. Respondents characteristic

Variables	f	%
Sex		
<i>Male</i>	6	20.69
<i>Female</i>	23	79.31
Age		
\leq Mean	21	72.41
$>$ Mean	8	27.59
<i>Mean \pm SD</i>	28.14 ± 8.13	
<i>Min \pm Max</i>	21 ± 55	
Education		
<i>Diploma</i>	16	55.17
<i>Bachelor</i>	1	3.45
<i>Registered Nurse</i>	12	41.38
Job Experience		
\leq 5 years	21	72.41
$>$ 5 years	8	27.59
Salary		
\leq USD 127	17	58.62
$>$ USD 127	12	41.38

Knowledge level comparison (pre-post)

The results of the normality and homogeneity test of the data showed p -value = 0.195 and = 0.460, which means that the data is normally distributed and homogeneous. In general, respondents' knowledge level has increased with the score disparity decreasing from mean+SD=53.67+13.64 to 69.67+8.26. The details of the difference in scores analyzed using the mean difference test can be seen in table 3.

Tabel 3. Knowledge level comparison (pre-post)

Variables	Pre-test		Post-test	
	f	%	f	%
Knowledge Level				
<i>High</i>	0	0.00	3	16.67
<i>Moderate</i>	12	41.38	14	77.78
<i>Low</i>	17	58.62	1	5.56
<i>Mean \pm SD</i>	53.67 ± 13.64		69.67 ± 8.26	
<i>Min \pm Max</i>	25.00 ± 75.00		50.83 ± 77.50	
Subvariables				
Genetic				
<i>High</i>	0	0.00	0	0.00
<i>Moderate</i>	17	58.62	4	22.22
<i>Low</i>	12	41.38	14	77.78
<i>Mean \pm SD</i>	56.64 ± 15.55		69.44 ± 9.80	
<i>Min \pm Max</i>	25.00 ± 75.00		50.00 ± 75.00	

Variables	Pre-test		Post-test	
	f	%	f	%
Thalassemia				
High	1	3.45	2	11.11
Moderate	17	58.62	14	77.78
Low	11	37.93	2	11.11
Mean + SD	58.17 ± 17.19		71.59 ± 6.20	
Min + Max	25.00 ± 75.00		56.82 ± 77.27	
Genetic Counseling				
High	0	0.00	4	22.22
Moderate	8	27.59	12	66.67
Low	21	72.41	2	11.11
Mean ± SD	51.82 ± 12.93		68.98 ± 10.96	
Min ± Max	25.00 ± 75.00		47.22 ± 83.33	
Bio-Informatics				
High	0	0.00	0	0.00
Moderate	1	3.45	7	38.89
Low	28	96.55	11	61.11
Mean ± SD	41.02 ± 13.46		61.81 ± 14.84	
Min ± Max	25.00 ± 75.00		25.00 ± 75.00	

The effect of simple coaching clinic on knowledge level

Simple coaching clinic proved to have a significant effect in improving the knowledge level of nurses in general with p -value = 0.004. In detail, the changes and the significance of the intervention effect on the outcome can be seen in table 4.

Table 4. Changes and significance of intervention effects on outcomes

Variables	Positive Rank		Negative Rank		Ties		p -Value
	f	%	f	%	f	%	
Knowledge	10	55.56	1	5.56	7	38.88	0.004
Subvariables							
Genetic	7	38.89	2	11.11	9	50.00	0.096
Thalassemia	9	50.00	1	5.56	8	44.44	0.007
Genetic Counseling	14	77.78	2	11.11	2	11.11	0.001
Bio-Informatics	11	61.11	0	0.00	7	38.89	0.000

Discussion

The respondents characteristics involved several variables, namely sex, age, education background, job experience, and salary. Education background and job experience are two important variables related to knowledge. The higher the education background, it can be ascertained to have higher knowledge. Similarly, the longer the job experience of a nurse, the higher the knowledge about the work that is her duties and responsibilities as a nurse. Person's level of education is directly proportional to his/her knowledge (Setiawan, et al., 2021). Therefore, people with higher educational backgrounds will have higher knowledge than people with lower educational backgrounds.

Job experience is an important thing in the process of developing skills, but it really depends on the educational background and training that he/she participates in. This experience and training will be gained through a period of work. Through the job experience,

a person consciously or unconsciously will learn, capture information and analyze situations so that it has an impact on technical skills. However, although respondent data was obtained which showed that the majority of respondents were diploma nursing graduates (55.17%) with job experience < 5 years (72.41%), researchers did not conclude that there were differences in knowledge about the implementation of integrated genetic counseling in nursing care for patients and families with thalassemia patients.

At least, there are several reasons why researchers do not link education background and job experience with the level of nurse's knowledge. First, genetic counseling is a new intervention that is still being developed in the research and education stage in Indonesia. Second, genomic nursing content that is closely related to genetic counseling interventions has not been integrated with the educational curriculum issued by the Association of Indonesian Nursing Vocational Education Institutions for Diploma Nursing, nor the curriculum issued by the Association of Indonesian Nurses Education Institutions for Bachelor of Nursing (Setiawan, et al., 2021). Third, there is no support by government for genetic counseling intervention, and there is no recognition of the genetic counselor profession (Ariyanto, et al., 2021). Fourth, the genomic nursing collegium under the coordination of the Indonesian National Nurses Association has not yet been formed. Fifth, the credentials of genomic/genetic nurses in Indonesia have not been recognized. These five reasons show that genetic counseling intervention in Indonesia is a new thing that is still in the initiation stage, so that information about genetic counseling has not been spread strongly among nurses. (Rujito, 2018).

The effect of simple coaching clinic on knowledge level

Simple coaching clinic proved to have a significant effect in improving the knowledge level of nurses in general with p -value = 0.004. Coaching has been shown to be effective in supporting people in achieving significant goals in psychology, athletics, business, and, more recently, nursing. Coaching may be extremely helpful at encouraging, inspiring, and empowering patients to maximize their health potential, especially when lifestyle changes are required (Hayes & Kalmakis, 2007). Apart from nurses and genetic counsellors contribution to the expert genetics team, they are increasingly considered integral to the provision of patient care in non-genetics settings. These practitioners provide genetic counseling and testing to patients in a variety of specialties, including cardiology, cancer, and endocrinology (Cordier et al., 2012; Oliver et al., 2011). They are usually well-trained and experienced in their field of work, but they need more knowledge to learn how to work in a genetic setting (Cordier et al., 2012). Despite the fact that counsellors spent more time enabling clients to express emotional responses than they did supporting cognitive processing of the information provided. The previous study discovered that both responsiveness to client emotions and enabling cognitive processing are necessary for clients to process the information provided and use it effectively in decision making (Skirton et al., 2015).

Genetic nurses should be well-versed in order to effectively convey information and assist patients in making decisions. Coaching to provide adequate information is an alternative to increasing nurse knowledge. Prior studies on coaching healthcare workers showed immediate improvements in knowledge and skills, but then deteriorated over time (Tosif et al., 2020). However, healthcare workers who applied the skills on a consistent basis received higher scores.

Previous research showed that despite a large number of perceived hurdles, healthcare practitioners, in general, have adequate knowledge that leads to adequate counseling practice (Al-Ashwal et al., 2020). However, genetic counseling is a special intervention that is different from the usual daily counseling for patients. Genetic counseling is not only encourages patients and caregivers to understand genetic diseases and contribution of genes to the disease, but also encourages them to adapt with their genetic problems so that they are able to make right decisions related to screening, testing, marital planning, and pregnancy planning (Resta et al., 2006). Therefore, nurses have not been exposed to much information related to genetic counseling.

Basic knowledge of genetic

The simple coaching clinic conducted among respondents did not have a significant impact on the sub-variable genetic with p-value = 0.096. This is reinforced by data showing that the majority of respondents did not change in knowledge level (50.00%) after the intervention was given. The results of this study strengthen the research conducted by Tomatir et al., (2006) which states that the majority of nurses do not understand genetics due to lack of literacy and information. Nurse literacy on the topics of gene, mutation, Mendelian inheritance pattern, chromosomal aberration, human genetic diseases, and recurrent risk still needs to be studied more deeply. The integration of genetic/genomic nursing in the nursing education curriculum is a solution to overcome this problem (Dumo et al., 2020; Sharoff, 2015).

Basic knowledge of thalassemia

The majority of nurses' knowledge about thalassemia was at a moderate level both before the intervention (58.62%), and after the intervention (77.78%). However, the change in knowledge scores that increased only occurred in 50.00% respondents with p-value = 0.007. This shows that nurses' literacy about thalassemia is inadequate or in other words is still very weak. This is reinforced by Chouhan & Pujari (2021) in the results of their study which states that the majority of nurses knowledge about thalassemia is on the poor level (59.2%).

The lack respondents' knowledge about thalassemia is closely related to the work experience of nurses in hospitals and public health centers (Kafl & El-Shahat, 2020). Respondents who participated in this study were not tasked with caring for thalassemia patients. Moreover, in public health centers, there are no thalassemia patients treated, so the results of this study cannot generalize the level of knowledge of nurses. In contrast to research conducted by Alnaami & Wazqar (2019), 100 respondents who filled out a knowledge questionnaire consisted of 20 questions, the majority were able to answer questions correctly >75.00%. Only on questions about transfusion and inheritance pattern, the majority answered wrong.

Basic knowledge of genetic counseling

This study shows that the most positive changes in respondents after attending a simple coaching clinic is the status of knowledge about genetic counseling with a total number 77.78% and a p-value of 0.001. This positive change is because genetic counseling content is not only delivered by lecturing, but also demonstrations and hands on to patients directly. Clinical practice through demonstrations and hands on with patients directly, is known to have a stronger effect in improving knowledge than only by lecturing (Chuang et al., 2018; Delnavaz et al., 2018).

Nurses in charge of providing nursing care for thalassemia patients and caregivers need to understand the concept of genetic counseling intervention. There is the most important problem to convey to thalassemia patients and caregivers besides information about the basic concepts of the disease, because there are fundamental differences between health education which is usually done with genetic counseling practice. Patients need to get important information such as recurrent risk calculation, premarital screening, and pregnancy planning (Blencowe et al., 2018), so that patients and caregivers can make informed decisions about appropriate treatment options. Therefore, nurses' knowledge about definitions, objectives, benefits, procedures, and the role of nurses in providing genetic counseling services needs to be strengthened so that optimal outcomes are achieved (El-Hosany & Khaton, 2021).

Basic knowledge of bio-informatics

Changes and the significance effect of the simple coaching clinic on basic knowledge about bio-informatics has a p-value = 0.000. The result shows that nurses can understand the use of bio-informatics in preparing genetic counseling interventions after a simple coaching clinic is carried out. Researchers found two things that could be used from bio-informatics, namely the process of constructing family pedigrees and basic information on genetic contributions to disease. Pedigree family construction can be done by using the free online pedigree tools progeny® at the website address <https://pedigree.progenygenetics.com/>. These tools make it easier for nurses to analyze family medical history, especially in patients who have genetic problems and are passed on to the next generation such as thalassemia (Drohan et al., 2012; Olinger et al., 2021). While the basic information about disease and genetic contribution to disease, nurses can use the Online Mendelian Inheritance in Man (OMIM®) at the website address <https://www.omim.org/>. Through this website, nurses can explore a variety of information related to genetic diseases such as thalassemia (J. Amberger et al., 2011; J. S. Amberger & Hamosh, 2017).

Clinical implication

Simple coaching clinic can be recommended as a strategy to increase nurses' knowledge about genetic counseling. The Indonesian National Nurses Association, the Association of Indonesian Nursing Vocational Education Institutions and the Association of Indonesian Nurses Education Institutions, need to collaborate in improving the knowledge and competence of nurses in performing nursing care that integrates genetic counseling interventions, especially for patients with genetic problems. This effort can be done by including genomic/genetic nursing content in the nursing education curriculum, for both diploma and bachelor's degrees. Meanwhile for nurses who work in hospitals and public health centers, simple coaching clinic was an effective and efficient alternative program.

Limitation of study

The simple coaching clinic is carried out in a hybrid way through the Zoom meeting application and hands on to the thalassemia caregiver patients. During the lecturing, many participants closed their cameras due to inadequate internet signal. When respondents closed the camera, the researcher could not control their position and attitude during the coaching clinic session. As a result, the researcher could not be sure whether the respondents really listened and paid attention to the topic presented by the speaker in full or not.

Conclusion

Changes in level of knowledge indicated that the coaching clinic's effects on level of knowledge are significant and have an impact on health services across a variety of health institutions, including clinics and hospitals. As a result, it is critical to have a health strategy that promotes the accessibility of genetic counseling services for patients with thalassemia and other genetic illnesses. This conclusion recommends a simple coaching clinic to be considered by the government and nursing professional associations as a strategy to increase nurses' knowledge about genetic counseling.

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Authors' contribution

Concept and design (HS, AF), data collection (SDR), data analysis and interpretation (HTY, TARKP), drafting of the manuscript (HS, NH), critical revision of the manuscript (HS, HA), final approval and accountability (HS, AF), supervision (HA).

Conflict of interest

The researchers stated that there is no conflict of interest related to the implementation and publication of the results of this research. The entire research process, from planning, data collection, analysis, to report preparation, was carried out independently without any influence or pressure from any third party. A commitment to research ethics is upheld throughout the research process, ensuring transparency, accuracy and honesty in reporting results. Respondents' participation was voluntary with informed consent, and their confidentiality and privacy were maintained in accordance with applicable research ethics standards. With this statement, researchers hope that the research results can be trusted and used as a valid reference for the development of science and health practices related to ethnomedicine and reproductive health.

Ethical consideration

This research was passed in ethical review and approved by Health Research Ethics Committee of Universitas Muhammadiyah Gombong with number No.136.6/II.3.AU/F/KEPK/III/2021. In accordance with the Declaration of Helsinki, participants were informed about the aim of the study, and the study consisted exclusively of participants who had provided their written, informed consent and who were informed that they could leave the study at any time. The authors declare that they have no conflict of interests.

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References

1. Aghbabak Maheri, et al. (2018). Depression, Anxiety, and Perceived Social Support among Adults with Beta-Thalassemia Major: Cross-Sectional Study. *PubMade*, 1, 101–107. <https://doi.org/10.4082/kjfm.2018.39.2.101>
2. Agustin, R., & Zuraida, R. (2020). Penatalaksanaan Holistik pada Pasien Anak Usia 8 Tahun dengan Diagnosis Talasemia Melalui Pendekatan Kedokteran Keluarga. *MAJORITY*, 9(1), 157–166.
3. Al-Ashwal, F. Y., Kubas, M., Zawiah, M., Bitar, A. N., Saeed, R. M., Sulaiman, S. A. S., ... Ghadzi, S. M. S. (2020). Healthcare workers' knowledge, preparedness, counselling practices, and perceived barriers to confront COVID-19: A cross-sectional study from a war-torn country, Yemen. *PLoS ONE*, 15(12 December), 1–16. <https://doi.org/10.1371/journal.pone.0243962>
4. Alnaami, A., & Wazqar, D. (2019). Disease knowledge and treatment adherence among adult patients with thalassemia: a cross-sectional correlational study. *Pielegniarstwo XXI Wieku/Nursing in the 21st Century*, 18(2), 95–101.
5. Amberger, J., Bocchini, C., & Hamosh, A. (2011). A new face and new challenges for Online Mendelian Inheritance in Man (OMIM®). *Human Mutation*, 32(5), 564–567.
6. Amberger, J. S., & Hamosh, A. (2017). Searching online mendelian inheritance in man (OMIM): a knowledgebase of human genes and genetic phenotypes. *Current Protocols in Bioinformatics*, 58(1), 1–2.
7. Andrews, V., Tonkin, E., Lancaster, D., & Kirk, M. (2014). Using the Diffusion of Innovations theory to understand the uptake of genetics in nursing practice: identifying the characteristics of genetic nurse adopters. *Journal of Advanced Nursing*, 70(4), 878–893.
8. Biswas, B., Naskar, N. N., Basu, K., Dasgupta, A., Basu, R., & Paul, B. (2017). Health seeking behavior of β -thalassemia major children and its attributes: An epidemiological study in Eastern India. *Journal of Family Medicine and Primary Care*, 6(2), 169–170. <https://doi.org/10.4103/jfmpc.jfmpc>
9. Blencowe, H., Moorthie, S., Darlison, M. W., Gibbons, S., & Modell, B. (2018). Methods to estimate access to care and the effect of interventions on the outcomes of congenital disorders. *Journal of Community Genetics*, 9(4), 363–376.
10. Chouhan, M. S., & Pujari, J. (2021). Nurses' Knowledge and Role on Care of Children with Thalassemia. *International Journal of Health Sciences and Research*, 11(3), 156–161. Retrieved from https://www.ijhsr.org/IJHSR_Vol.11_Issue.3_March2021/IJHSR-Abstract.025.html
11. Chuang, Y.-H., Lai, F.-C., Chang, C.-C., & Wan, H.-T. (2018). Effects of a skill demonstration video delivered by smartphone on facilitating nursing students' skill competencies and self-confidence: A randomized controlled trial study. *Nurse Education Today*, 66, 63–68.
12. Colah, R., Gorakshakar, A., & Nadkarni, A. (2010). Global burden, distribution and prevention of β -thalassemias and hemoglobin e disorders. *Expert Review of Hematology*, 3(1), 103–117. <https://doi.org/10.1586/ehm.09.74>

13. Cordier, C., Lambert, D., Voelckel, M. A., Hosterey-Ugander, U., & Skirton, H. (2012). A profile of the genetic counsellor and genetic nurse profession in European countries. *Journal of Community Genetics*, 3(1), 19–24. <https://doi.org/10.1007/s12687-011-0073-x>
14. Danjou, F., Anni, F., & Galanello, R. (2011). Beta-thalassemia : from genotype to phenotype. *Hematologica*, 96(11), 1573–1575. <https://doi.org/10.3324/haematol.2011.055962>
15. Delnavaz, S., Hassankhani, H., Roshangar, F., Dadashzadeh, A., Sarbakhsh, P., Ghafourifard, M., & Fathiazar, E. (2018). Comparison of scenario based triage education by lecture and role playing on knowledge and practice of nursing students. *Nurse Education Today*, 70, 54–59.
16. Drohan, B., Roche, C. A., Cusack, J. C., & Hughes, K. S. (2012). Hereditary breast and ovarian cancer and other hereditary syndromes: using technology to identify carriers. *Annals of Surgical Oncology*, 19(6), 1732–1737.
17. Dumo, A. M., Laing, B., Lim, A. G., Palaganas, E., Abad, P. J., Valdehueza, O., ... Mandysova, P. (2020). Randomized controlled trial on the effectiveness of web-based Genomics Nursing Education Intervention for undergraduate nursing students: a study protocol. *Journal of Advanced Nursing*, 76(11), 3136–3146.
18. Dyess, S. M., Sherman, R., Opalinski, A., & Eggenberger, T. (2017). Structured coaching programs to develop staff. *Journal of Continuing Education in Nursing*, 48(8), 373–378. <https://doi.org/10.3928/00220124-20170712-10>
19. El-Hosany, E. A.-E., & Khaton, S. E. (2021). Knowledge and Attitudes among Tanta University Students Regarding to Genetic Disorders and Genetic Counseling. *Tanta Scientific Nursing Journal*, 21(2), 74–99.
20. Hayes, E., & Kalmakis, K. A. (2007). From the sidelines: Coaching as a nurse practitioner strategy for improving health outcomes. *Journal of the American Academy of Nurse Practitioners*, 19(11), 555–562. <https://doi.org/10.1111/j.1745-7599.2007.00264.x>
21. Heri Ariyanto, Nurapandi, A., Purwati, A. E., Kusumawaty, J., & Setiawan, H. (2021). Genetic counseling program for patient with hyperglycemic syndrome. *Journal of Holistic Nursing Science*, 8(2), 2–9.
22. Huda, C., & Indrayati, A. (2019). Molecular Detection of Exon 3 of Beta Globin Gene from Thalassemia Beta Major Patients in RSUD DR . Soeroto Ngawi using Polymerase Chain Reaction – Single Strand Conformation Polimorfism Method. *Farmasi Indonesia*, 16(1), 24–33.
23. KafI, R. H., & El-Shahat, H. T. M. (2020). Effect of an Educational program on Nursing Care Practices regarding Pediatric Transfusion-Dependent β -Thalassemia Major. *International Journal of Novel Research in Healthcare and Nursing*, 7(1), 460–470.
24. Kasper, D., Fauci, A., Hauser, S., Longo, D., Jameson, J., & Loscalzo, J. (2015). *Harrison's Principles of Internal Medicine* (19th ed.). New York: McGraw-Hill Medical Pub. Division.
25. Olinger, E., Alawi, I. Al, Al Riyami, M. S., Salmi, I. Al, Molinari, E., Faqeih, E. A., ... Al-Hussaini, A. A. (2021). A discarded synonymous variant in NPHP3 explains nephronophthisis and congenital hepatic fibrosis in several families. *Human Mutation*, 42(10), 1221–1228.
26. Oliver, J., Goodfellow, J., Smyth, L., Bourne, R., Brennan, P., & Farrer, M. (2011). Using patient experiences to develop a pre genetic service around family needs. *British Journal of Cardiac Nursing*, 6(6), 291–294. <https://doi.org/10.12968/bjca.2011.6.6.291>
27. Rachmilewitz, E. A. (2017). Pathophysiology and treatment of patients with beta-thalassemia – an update [version 1 ; referees : 2 approved] Eitan Fibach Referee Status :

- PubMed*, 6(0), 1–12. <https://doi.org/10.12688/f1000research.12688.1>
28. Rahn, A. C., Köpke, S., Backhus, I., Kasper, J., Anger, K., Untiedt, B., ... Heesen, C. (2018). Nurse-led immunotreatment DEcision Coaching In people with Multiple Sclerosis (DECIMS) – Feasibility testing, pilot randomised controlled trial and mixed methods process evaluation. *International Journal of Nursing Studies*, 78, 26–36. <https://doi.org/10.1016/j.ijnurstu.2017.08.011>
 29. Resta, R., Biesecker, B. B., Bennett, R. L., Blum, S., Hahn, S. E., Strecker, M. N., & Williams, J. L. (2006). A new definition of genetic counseling: National Society of Genetic Counselors' Task Force report. *Journal of Genetic Counseling*, 15(2), 77–83. <https://doi.org/10.1007/s10897-005-9014-3>
 30. Rujito, L. (2018). Genetic counseling in Indonesia as a mandatory service. *Jurnal Kedokteran Dan Kesehatan Indonesia*, 9(1), 1–2. <https://doi.org/10.20885/JKKI.Vol9.Iss1.art1>
 31. Setiawan, H., Lutfi Sandi, D. Y., Andarini, E., Kurniawan, R., Richard, D. S., & Ariyanto, H. (2021). Vliv genetickeho poradenstvi na depresi, uzkost a uroven znalosti u pacientu s onemocnenim diabetes mellitus. *Kontakt*. Retrieved from <https://kont.zsf.jcu.cz/artkey/knt-000000-0774.php>
 32. Setiawan, H., Setiawan, D., & Mustopa, A. H. (2021). Development of Android-based Mobile Application “Cyber Gen” for Genetic Counselling Implementation among Thalassemia Patients. In *Journal of Physics: Conference Series* (Vol. 2111, p. 12037). IOP Publishing.
 33. Setiawan, H., Suhandi, S., & Setiawan, D. (2021). Coaching Clinic as a Strategy to Improve Knowledge and Competence of Nurses in Providing Genetic Counseling Interventions among Thalassemia Patients. *International Journal of Community Based Nursing & Midwifery*, 10(1), 84–85. <https://doi.org/10.30476/ijcbnm.2021.92764.1883>
 34. Sharoff, L. (2015). Genetics and genomics integration into undergraduate nursing education. *J Nurs Educ Pract*, 5(4), 13–18.
 35. Skirton, H., Cordier, C., Ingvoldstad, C., Taris, N., & Benjamin, C. (2015). The role of the genetic counsellor: A systematic review of research evidence. *European Journal of Human Genetics*, 23(4), 452–458. <https://doi.org/10.1038/ejhg.2014.116>
 36. Syobri, M., Mustofa, F. L., & Triswanti, N. (2020). Hubungan Kepatuhan Konsumsi Kelas Besi Terhadap Pertumbuhan Anak Dengan Thalassemia. *Jurnal Ilmiah Kesehatan Sandi Husada*, 9(1), 387–391.
 37. Tomatir, A. G., Sorkun, H. C., Demirhan, H., & Akdag, B. (2006). Nurses' professed knowledge of genetics and genetic counseling. *The Tohoku Journal of Experimental Medicine*, 210(4), 321–332. <https://doi.org/10.1620/tjem.210.321>
 38. Tosif, S., Jatobatu, A., Maepioh, A., Gray, A., Sobel, H., Mannava, P., & Duke, T. (2020). Healthcare worker knowledge and skills following coaching in WHO early essential newborn care program in the Solomon Islands: A prospective multi-site cohort study. *BMC Pregnancy and Childbirth*, 20(1), 1–9. <https://doi.org/10.1186/s12884-020-2739-z>