



## Development of Educational Leaflet for Genetic Counseling and Premarital Screening of Thalassemia for Prospective Couples

Henri Setiawan<sup>1\*</sup>, Irpan Ali Rahman<sup>1</sup>, Nur Hidayat<sup>1</sup>, Heni Marliany<sup>1</sup>, Yuyun Rahayu<sup>1</sup>  
<sup>1</sup>Department of Nursing, STIKes Muhammadiyah Ciamis, West Java, Indonesia

Correspondence author: Henri Setiawan

Email: [henrisetiawan1989@gmail.com](mailto:henrisetiawan1989@gmail.com)

Address: Jln. KH. Ahmad Dahlan No. 20 Ciamis, West Java, Indonesia Telp. 085295203494

DOI: <https://doi.org/10.56359/gj.v5i2.316>



This work is licensed under a [Creative Commons Attribution 4.0 International License](https://creativecommons.org/licenses/by/4.0/)

### ABSTRACT

**Introduction:** Thalassemia is a common hereditary blood disorder with a significant impact on public health, particularly in high-prevalence areas. Genetic counseling and premarital screening are critical for educating couples at risk, helping to reduce the incidence of thalassemia. However, there is often a lack of accessible and comprehensible information on this topic for prospective couples, especially at the community health level.

**Objective:** This study aimed to develop an educational leaflet tailored for prospective couples, focusing on genetic counseling and premarital screening for thalassemia. The leaflet is designed to enhance awareness, provide clear information, and encourage informed decision-making among couples.

**Method:** A descriptive research design was employed to create and validate the educational leaflet. The development process included a needs assessment through surveys and focus group discussions with nurse educators and couples in the target population. Content was adapted based on expert feedback from genetic counselors and nurses educators to ensure accuracy, readability, and cultural relevance.

**Result:** The finalized leaflet contains essential information on thalassemia, genetic counseling, and the importance of premarital screening. It is structured in a user-friendly format, including illustrations and a simplified language level to facilitate understanding.

**Conclusion:** The educational leaflet effectively provides prospective couples with critical information on thalassemia, genetic counseling, and premarital screening. This tool can serve as a valuable resource in public health centers to promote awareness and preventive measures for hereditary diseases. Further research is recommended to evaluate its long-term impact on reducing thalassemia incidence.

**Keywords:** educational leaflet, genetic counseling, premarital screening, thalassemia

## **Introduction**

Thalassemia is an inherited blood disorder characterized by abnormalities in hemoglobin production, a protein responsible for transporting oxygen in the blood (Setiawan et al., 2022, 2023). It is one of the most common genetic disorders worldwide, particularly prevalent in Southeast Asia, including Indonesia. According to the World Health Organization (WHO), approximately 5-7% of the global population are carriers of thalassemia, with the highest prevalence in the Mediterranean, Middle East, South Asia, and Southeast Asia (Ebrahim et al., 2019). In Indonesia, the high number of thalassemia cases indicates a pressing need for focused prevention and control efforts (Setiawan, et al., 2021).

Thalassemia is classified into several types, including major, minor, and intermediate forms, with thalassemia major being the most severe. Patients with thalassemia major require lifelong blood transfusions to maintain adequate hemoglobin levels, which has a significant impact on their quality of life and imposes substantial healthcare costs (Mettananda et al., 2019; Rahmah & Makiyah, 2022). Additionally, limited public awareness about thalassemia, particularly regarding its genetic transmission, often leads to the condition being overlooked in premarital planning (Setiawan et al., 2023).

From a public health perspective, preventive approaches through genetic counseling and premarital screening play a crucial role in reducing the prevalence of thalassemia. Genetic counseling aims to provide prospective couples with an understanding of the hereditary risks they may face if both partners are thalassemia carriers (Dhamcharee et al., 2001). Through this counseling, couples can make more informed decisions regarding marriage and potential pregnancies. Premarital screening, on the other hand, helps identify carriers, allowing preventive measures to be taken to avoid the birth of children with thalassemia major (Setiawan et al., 2023).

However, many prospective couples remain unaware of the importance of genetic counseling and premarital screening for thalassemia. Limited access to clear and accessible information presents a significant barrier. In many healthcare facilities, particularly at public health centers, educational materials specifically addressing thalassemia are still scarce. This lack of accessible information contributes to limited public awareness of the importance of screening and genetic counseling before marriage (Malik-Soni et al., 2022; Setiawan et al., 2022).

Therefore, the development of an educational leaflet on genetic counseling and premarital screening for thalassemia is expected to provide a practical solution to this challenge. Leaflets serve as a simple yet effective educational medium, providing concise and easily understood information (Mbanda et al., 2021). With this educational leaflet, prospective couples can obtain adequate information about thalassemia risks and the preventive steps they can take. Additionally, the leaflet will support healthcare providers at public health centers in delivering more systematic and consistent education (Minutolo et al., 2022).

## **Objective**

This study aimed to develop an educational leaflet tailored for prospective couples, focusing on genetic counseling and premarital screening for thalassemia. The leaflet is designed to enhance awareness, provide clear information, and encourage informed decision-making among couples.

## **Method**

To plan and design the educational leaflet on genetic counseling and premarital screening for thalassemia, a multidisciplinary meeting was held involving genetic counselors, healthcare providers, and public health experts. This meeting aimed to discuss the key information on thalassemia, genetic counseling, and premarital screening that should be included to effectively address the needs of prospective couples. The meeting also considered the cultural relevance and readability of the material, ensuring that the leaflet would be understandable and accessible for the target audience.

Guidelines from relevant health authorities, including WHO guidelines on genetic counseling and thalassemia prevention, as well as existing educational materials from similar public health initiatives, were reviewed and adapted. These resources provided foundational content and evidence-based recommendations, which were tailored to suit the local cultural context and literacy levels of the target population. Feedback from this multidisciplinary team was then integrated to develop a preliminary version of the leaflet, which was subsequently validated and refined based on pilot testing and additional expert input.

## **Result**

The leaflet was initially designed using Microsoft PowerPoint, with visuals and diagrams developed to illustrate key points on genetic counseling and premarital screening for thalassemia. The images were then digitally enhanced in Adobe Photoshop to optimize contrast and brightness, making them easier to reproduce and visually accessible for all literacy levels. The finalized layout and content were translated into the Indonesian language by a certified health translator, ensuring accuracy and readability for the target audience.

Existing educational leaflets from general hospital and global health guidelines served as references. These resources, which often contained detailed text-based explanations and contact information, were adapted to fit the local healthcare context. Unlike healthcare systems in higher-income settings that rely on phone and online resources for follow-up. Therefore, the images and simple language in the leaflet were crucial to ensuring that couples could easily understand the information and feel encouraged to seek further support at the health center if needed.

Healthcare providers, including genetic counselors and community nurses, noted that the leaflet was an effective educational tool. The simplified illustrations and clear explanations helped guide discussions on genetic risks and encouraged proactive health decisions among couples. The leaflet was found to be a cost-effective and accessible method for delivering essential information on genetic health in community settings, where resources for continuous patient support may be limited. Leaflet design can be seen on Figure 1.

## **Discussion**

The high prevalence of thalassemia presents both medical and social challenges, impacting affected individuals and their families emotionally, psychologically, and financially (Setiawan et al., 2018). Inherited blood disorders like thalassemia can lead to chronic health complications and lifelong dependence on medical care, which can burden both families and the healthcare system. Genetic counseling and premarital screening are vital in mitigating the spread of thalassemia through informed health decisions (Saffi & Howard, 2015). Studies have shown that education on genetic risks significantly reduces anxiety and fosters greater health

awareness in communities, making the development of educational materials a priority in thalassemia prevention efforts (Setiawan, et al., 2021).



STIKes Muhammadiyah Ciamis  
Department of Nursing

# Mari Kita Cegah THALASSEMIA

**!** **Thalassemia** dapat menurunkan kualitas hidup, merusak kesehatan mental, serta ketergantungan terhadap **transfusi darah**.

## Apa sih **Thalassemia** itu?

- ❖ Thalassemia adalah kelainan darah genetik yang mempengaruhi produksi hemoglobin, sehingga menyebabkan anemia (kekurangan sel darah merah). Penyakit ini diwariskan dari orang tua yang membawa gen thalassemia (carrier).

## Apa sih gejala **Thalassemia** yang muncul?

- ❖ Anemia berat
- ❖ Kelelahan
- ❖ Kulit pucat
- ❖ Hambatan pertumbuhan
- ❖ Pembesaran limpa atau hati

Parents



Child (healthy)    Child (carrier)    Child (carrier)    Child (with disorder)

## Thalassemia dapat dicegah dengan:

- ❖ **Skrining pra-nikah**  
Pemeriksaan laboratorium bagi pasangan calon pengantin untuk memastikan bebas dari gen pembawa thalassemia (carrier).
- ❖ **Konseling genetik**  
Konsultasi terkait hasil pemeriksaan dan perencanaan kesehatan keluarga dengan konselor genetik, dokter dan perawat.

**!** Pasangan pembawa gen **thalassemia** (Carrier) berpotensi melahirkan anak thalassemia sebesar 25 %.

### Layanan konseling genetik:

Ns. Henri Setiawan, M.Si.Med., Ph.D.  
STIKes Muhammadiyah Ciamis  
Jln. KH. Ahmad Dahlan No. 20 Ciamis, Jawa Barat  
WhatsApp 085295203494

**Referensi**

- <https://www.andersondiagnostics.com/genetics/genetic-counseling/>
- <https://www.ausmed.com/learn/articles/haemoglobin-disorders>



**GRATIS**  
Tidak dipungut biaya

Figure 1. Leaflet design

Despite the availability of resources in high-income countries, similar approaches are often challenging to implement in Indonesia's rural areas due to limited resources, varying literacy levels, and cultural differences (Wenang et al., 2021). Public health centers often lack access to ongoing support systems, such as helplines or digital resources, making face-to-face educational materials essential. Addressing these challenges, the educational leaflet was carefully designed with minimal text and culturally appropriate visuals to maximize accessibility for the target population, which often includes individuals with limited literacy (Colledge et al., 2008; Maat & Lentz, 2010).

Literacy rates in Indonesia vary widely, with certain rural regions experiencing much lower literacy levels compared to urban areas (. & Mubarokah, 2019; Natasya Nazla Prasetyo et al., 2023). Consequently, the emphasis on clear, culturally relevant illustrations in the leaflet was crucial. Previous studies indicate that illustrated educational materials are more effective for populations with limited literacy, as they aid in better comprehension and retention of information (Mbanda et al., 2021; Park & Zuniga, 2016).

High-quality, accessible educational materials must be regularly updated to maintain accuracy and relevance in addressing public health issues (Berland et al., 2001; Sørensen et al., 2012). This leaflet represents one of the first culturally tailored educational tools for genetic counseling and premarital screening in Indonesia. It has demonstrated the potential to not only improve knowledge about thalassemia but also reduce the stigma associated with genetic conditions by empowering couples to make informed decisions about their reproductive health. Future improvements and evaluations of the leaflet can further enhance its impact, making it a valuable resource in Indonesia's public health toolkit for genetic health awareness.

## **Conclusion**

Genetic counseling leaflets play a crucial role in providing clear and accessible information to patients, particularly in managing health risks based on genetic information. The primary challenges identified during the creation of the leaflet include low education levels, varying literacy rates, and limited understanding of genetic disease processes. Therefore, it is essential to design leaflets using simple language, accompanied by visual aids, to facilitate comprehension. It is hoped that these efforts will reduce patient anxiety and assist in making informed health decisions.

## **Acknowledgement**

Not applicable.

## **Authors' contribution**

Each author contributed equally in all the parts of the research. All authors have critically reviewed and approved the final draft and are responsible for the content and similarity index of the manuscript.

## **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**

Not applicable.

#### **Funding**

This research is not funded by any party and is not intended for any financial gain.

#### **References**

1. Berland, G. K., Elliott, M. N., Morales, L. S., Algazy, J. I., Kravitz, R. L., Broder, M. S., Kanouse, D. E., Muñoz, J. A., Puyol, J. A., Lara, M., Watkins, K. E., Yang, H., & McGlynn, E. A. (2001). Health information on the internet: Accessibility, quality, and readability in English and Spanish. *JAMA*, *285*(20). <https://doi.org/10.1001/jama.285.20.2612>
2. Colledge, A., Car, J., Donnelly, A., & Majeed, A. (2008). Health information for patients: Time to look beyond patient information leaflets. In *Journal of the Royal Society of Medicine* (Vol. 101, Issue 9). <https://doi.org/10.1258/jrsm.2008.080149>
3. Dhamcharee, V., Romyanan, O., & Ninlagarn, T. (2001). Genetic counseling for thalassemia in Thailand : Problems and solution. *Southeast Asian Journal of Tropical Medicine and Public Health*, *32*(2).
4. Ebrahim, S., Raza, A. Z., Hussain, M., Khan, A., Kumari, L., Rasheed, R., Mahmood, S., Khatri, M. A., Bijoora, M., Zaheer, R., Sattar, N., Sohail, W., Zakir, H., Jafry, F. H., Memon, A., Anwer, S., & Fatima, K. (2019). Knowledge and Beliefs Regarding Thalassemia in an Urban Population. *Cureus*. <https://doi.org/10.7759/cureus.5268>
5. Malik-Soni, N., Shaker, A., Luck, H., Mullin, A. E., Wiley, R. E., Lewis, M. E. S., Fuentes, J., & Frazier, T. W. (2022). Tackling healthcare access barriers for individuals with autism from diagnosis to adulthood. In *Pediatric Research* (Vol. 91, Issue 5). <https://doi.org/10.1038/s41390-021-01465-y>
6. Mbanda, N., Dada, S., Bastable, K., Ingalill, G. B., & Ralf W., S. (2021). A scoping review of the use of visual aids in health education materials for persons with low-literacy levels. In *Patient Education and Counseling* (Vol. 104, Issue 5). <https://doi.org/10.1016/j.pec.2020.11.034>
7. Mettananda, S., Pathiraja, H., Peiris, R., Bandara, D., De Silva, U., Mettananda, C., & Premawardhena, A. (2019). Health related quality of life among children with transfusion dependent  $\beta$ -thalassaemia major and haemoglobin e  $\beta$ -thalassaemia in Sri Lanka: A case control study. *Health and Quality of Life Outcomes*, *17*(1). <https://doi.org/10.1186/s12955-019-1207-9>
8. Minutolo, A., Damiano, E., De Pietro, G., Fujita, H., & Esposito, M. (2022). A conversational agent for querying Italian Patient Information Leaflets and improving health literacy. *Computers in Biology and Medicine*, *141*. <https://doi.org/10.1016/j.compbiomed.2021.105004>

9. N. Mubarokah, K. (2019). Health Literacy and Health Behavior in the Rural Areas. *KnE Life Sciences*, 4(10). <https://doi.org/10.18502/cls.v4i10.3702>
10. Natasya Nazla Prasetyo, Keren Stelin Maliangkay, Putri Andini Novianti, Risma Pertiwi, & Sarah Rania Annisa. (2023). Health Accessibility In Rural Areas For The Elderly In Indonesia. *Jurnal Rumpun Ilmu Kesehatan*, 3(2). <https://doi.org/10.55606/jrik.v3i2.1716>
11. Pander Maat, H., & Lentz, L. (2010). Improving the usability of patient information leaflets. *Patient Education and Counseling*, 80(1). <https://doi.org/10.1016/j.pec.2009.09.030>
12. Park, J., & Zuniga, J. (2016). Effectiveness of using picture-based health education for people with low health literacy: An integrative review. *Cogent Medicine*, 3(1). <https://doi.org/10.1080/2331205x.2016.1264679>
13. Rahmah, R., & Makiyah, S. N. N. (2022). Quality Of Life of Children with Thalassemia in Indonesia: Review. *IJNP (Indonesian Journal of Nursing Practices)*, 6(1). <https://doi.org/10.18196/ijnp.v6i1.10477>
14. Saffi, M., & Howard, N. (2015). Exploring the Effectiveness of Mandatory Premarital Screening and Genetic Counselling Programmes for  $\beta$ -Thalassaemia in the Middle East: A Scoping Review. In *Public Health Genomics* (Vol. 18, Issue 4). <https://doi.org/10.1159/000430837>
15. Setiawan, H., Ediati, A., & Winarni, T. I. (2018). *Genetic Counseling to Reduce the Level of Depression in Parents of Children with Thalassemia Major*. <https://doi.org/10.5220/0007055801020106>
16. Setiawan, H., Firmansyah, A., & Richard, S. D. (2023). The role of nurses to control beta thalassemia disease in Indonesia: A perspective. *Journal of Taibah University Medical Sciences*, 18(5). <https://doi.org/10.1016/j.jtumed.2023.02.007>
17. Setiawan, H., Sandi, Y. D. L., Andarini, E., Kurniawan, R., Richard, S. D., & Ariyanto, H. (2021). The effect of genetic counseling on depression, anxiety, and knowledge level among diabetes mellitus patients. *Kontak*, 23(4). <https://doi.org/10.32725/kont.2021.035>
18. Setiawan, H., Setiawan, D., Suhanda, S., & 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, Issue 1). <https://doi.org/10.1088/1742-6596/2111/1/012037>
19. Setiawan, H., Suhanda, S., & Setiawan, D. (2022). 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 and Midwifery*, 10(1), 84–85. <https://doi.org/10.30476/IJCBNM.2021.92764.1883>
20. Sørensen, K., Van Den Broucke, S., Fullam, J., Doyle, G., Pelikan, J., Slonska, Z., & Brand, H. (2012). Health literacy and public health: A systematic review and integration of definitions and models. In *BMC Public Health* (Vol. 12, Issue 1). <https://doi.org/10.1186/1471-2458-12-80>
21. Wenang, S., Schaefers, J., Afdal, A., Gufron, A., Geyer, S., Dewanto, I., & Haier, J. (2021). Availability and Accessibility of Primary Care for the Remote, Rural, and Poor Population of Indonesia. *Frontiers in Public Health*, 9. <https://doi.org/10.3389/fpubh.2021.721886>