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THALASSEMIA LITERACY: INCREASING KNOWLEDGE OF ORPHAN ADOLESCENTS ON THALASSEMIA THROUGH SYNCHRONOUS AND ASYNCHRONOUS LEARNING

LITERASI TALASEMIA: MENINGKATKAN PENGETAHUAN REMAJA YATIM TENTANG TALASEMIA MELALUI PEMBELAJARAN SINKRONUS DAN ASINKRONUS

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Abstract

Thalassemia is the most common monogenic disease in Asia, including Indonesia that causes burdens for the government, patients, and families. As the sixth most non-communicable disease, thalassemia utilized IDR 600 billion in 2022 for more than 300 thousand cases. With, 3.8% of Indonesians carrying a mutation of thalassemia on their globin gene, this economic burden is projected will increase if no preventions are taken. On the other hand, child marriage is reported to increase every year, including among orphans. BPS reported that marriages between teenagers aged 16-18 years would be 19.62% in 2022. Without proper knowledge and genetic testing on thalassemia, child marriage might contribute to the increasing of thalassemia patients. Thus, increasing knowledge on thalassemia among orphan adolescents is important to encourage awareness of early screening before marriage, and might reduce thalassemia major cases. This community development uses several methods, including synchronous method: seminar and discussion; and asynchronous method: book and poster, targeting the orphan adolescents (n= 40) in Mojokerta, East Java. A questionnaire on thalassemia was used to measure the knowledge, before and after the activity. The results show that the respondents have a moderate knowledge about thalassemia (median= 4 (0-9)), and increase to median=9 (3-10)) after the activities (p< 0.001). Even though overall knowledge is increased, several information including thalassemia is a genetic disease, not similar to blood cancer, not the only type of anemia (Q6), and how to diagnose thalassemia (Q9) still need to be emphasized. Taken together, direct and indirect approaches, such as seminar, discussion, book, and poster are effective in increasing thalassemia knowledge among orphan adolescents. These activities are more effective in targeting late adolescents, compared to early and middle adolescents. However, more effective methods are necessary to target Generation Z who are more familiar with the internet.

Keywords: *Genetic Testing; Health Equity; Hemoglobinopathy; Knowledge.*

Abstrak

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Thalassemia merupakan penyakit monogenik terbanyak di Asia, termasuk Indonesia yang menimbulkan beban bagi pemerintah, pasien, dan keluarga. Sebagai penyakit tidak menular terbanyak keenam, Thalassemia menghabiskan dana sebesar Rp600 miliar pada tahun 2022 untuk lebih dari 300 ribu kasus. Dengan 3,8% penduduk Indonesia yang membawa mutasi thalassemia pada gen globinnya, beban ekonomi ini diperkirakan akan bertambah jika tidak ada tindakan pencegahan yang diambil. Di sisi lain, perkawinan anak dilaporkan meningkat setiap tahunnya, termasuk di kalangan anak yatim. Dilaporkan BPS bahwa pernikahan remaja berusia 16-18 tahun sebanyak 19.62% di tahun 2022. Tanpa pengetahuan yang memadai dan pengujian genetik terhadap thalassemia, pernikahan anak dapat berkontribusi pada peningkatan jumlah penderita thalassemia. Oleh karena itu, peningkatan pengetahuan tentang thalassemia pada remaja yatim menjadi penting untuk mendorong kesadaran melakukan skrining dini sebelum pernikahan, sehingga kasus thalassemia mayor dapat menurun. Pengembangan masyarakat ini menggunakan beberapa cara termasuk metode sinkronus: seminar dan diskusi; serta asinkronus: buku, dan poster dengan sasaran remaja yatim (n= 40) di Mojokerta, Jawa Timur. Kuesioner talasemia digunakan untuk mengukur pengetahuan sebelum dan sesudah kegiatan. Hasilnya menunjukkan bahwa responden memiliki pengetahuan sedang tentang thalassemia (median= 4 (0-9)), dan meningkat menjadi median=9 (3-10)) setelah kegiatan (p< 0.001). Meskipun pengetahuan secara keseluruhan semakin meningkat, beberapa informasi antara lain thalassemia adalah penyakit genetik, bukan kanker darah, bukan satu-satunya jenis anemia (Q6), dan cara mendiagnosis thalassemia (Q9) belum dipahami secara menyeluruh. Dapat disimpulkan, pendekatan langsung dan tidak langsung, seperti seminar, diskusi, buku, dan poster efektif dalam meningkatkan pengetahuan thalassemia di kalangan remaja yatim. Kegiatan-kegiatan tersebut lebih efektif menyasar remaja akhir, dibandingkan remaja awal dan pertengahan. Namun, diperlukan metode yang lebih efektif untuk menyasar Generasi Z yang lebih akrab dengan internet.

***Kata kunci**: Tes Genetik; Pemerataan Kesehatan; Hemoglobinopati; Pengetahuan.*

INTRODUCTION

Thalassemia is the most prevalent monogenic disease in Asia, China, and the Mediterranean, including Indonesia (Bajwa and Basit 2023). Mutations or deletions in the α- and β-globin genes responsible for the unfunctional α- and β-globin proteins, and further caused the reduction of the patient's hemoglobin. The main symptom of thalassemia is anemia, ranging from mild to severe anemia. Based on the anemia level, thalassemia patients are divided into thalassemia minor, intermedia, and major. The first group do not exhibit symptom and do not require any treatment. While the second group might have moderate anemia and require irregular blood transfusion. The burden increases in the third group, thalassemia major, which has severe anemia and needs regular blood transfusions and iron chelation consumption to reduce iron deposition in the organs. Untreated thalassemia major can lead to systemic symptoms, such as hepatosplenomegaly, extracellular erythropoiesis, endocrine problems, cardiovascular problems, etc. (d'Arqom 2020, d'Arqom, et al. 2021a, Thein 2017).

With those characteristics, thalassemia caused physical, psychological, and financial burdens for the patients, families, and the government. In Indonesia itself, this disease utilized IDR 600 billion in 2022, which increased from IDR 500 billion in 2021. This cost was used to cover the treatment of approximately 305,369 cases (Asa, et al. 2021, Azizah 2023). It is reported that 3.8% of the Indonesian population carries genetic mutations or deletions of the globin gene (Kemenkes 2019). With this number, it is projected that the number of thalassemia major patients will increase every year if no action is taken. Early

detection and genetic screening are crucial to stop the escalation of thalassemia, as reported in Cyprus and Italy. This action is more effective to be performed before marriage or pregnancy (Cao and Kan 2013).

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As the amendment of minimum of marriage age law no 16 of 2019, both groom and bride should reach age minimum 19 years old (Kemenkumham 2019). Unfortunately, child marriage was reported to be increasing in Indonesia. Based on National Bureau of Statistics data in 2022, there were 19.24% of adolescents married for the first time when they were 16-18 years old, and 2.26% of them married before 15 years old (Finaka, et al. 2023). In another study involving 6,578 20-24 years old Indonesian females, 23% of them reported experiencing child marriage (Rumble, et al. 2018). With this number, Indonesia is the second most ASEAN country with child marriage or the eighth in the world (Nasution 2023). Moreover, a study involving 105 Ethiopian females and 100 Indian females (aged 13-23 years old) reported that girls from deceased or unstable families, particularly fathers, are more susceptible to early marriage due to perceived burden or risk in their natal families (McDougal, et al. 2018). This finding also supported by a study in several African countries which concluded that orphanhood is related to early marriage and or early sexual life (Chae 2013). Following the recent pandemic, number of orphans are reported to be increased (Chu, et al. 2022).

Even though there is no study shows direct evidence between child marriage with genetic diseases, including thalassemia, child marriage related with negative consequences on health, such as mental health disorder, cancer, sexual transmitted diseases, etc (Aggarwal, et al. 2023, Irani and Latifnejad Roudsari 2019). However, child marriage of adolescent couples with little or no knowledge about thalassemia might contribute to the escalation

of thalassemia major cases, because the unknown thalassemia status of the bride and groom. Thus, education on thalassemia-targeted adolescents is crucial to promote the early screening, especially before marriage, which might lead to reducing the number of thalassemia major cases.

To solve this problem, this community development utilizes direct and indirect approaches to disseminate information about thalassemia, such as seminars, discussion, books, and posters. As a pilot study, this study was conducted in one of the most accessible orphanages in Mojokerto. The effectiveness of the activity was further measured and the correct answer to each question was evaluated.

COMMUNITY SERVICE METHOD

This community development was approved by the Ethical Committee of the Faculty of Medicine, Universitas Airlangga (No. 127/EC/KEPK/FKUA/2023). The location of this study is in Mojokerto, East Java, Indonesia, with orphan adolescent respondents (10-19 years old). The informed consent was given by the guardian for respondents below 18 years old, and the respondent himself for those older than 18 years old. For respondents under 18, the research team explained the activity in detail to the heads of the orphanages and two guardians before acquiring their consent. For respondents over 18, the students were gathered to receive the explanation and provide their own consent.To disseminate the knowledge on thalassemia, several activities were conducted in this community development. The first activity was seminar and discussion led by a medical doctor which provided learning using synchronous learning method. After the seminar, book and poster about thalassemia were distributed, to facilitate asynchronous learning method. The book was written by several medical doctors and thalassemia patients/families, while the poster was drawn by the cadres of Sahabat Thaler. This education and the media were disseminated during April-June 2023 to the respondents who were willing to participate. The respondents' knowledge on thalassemia was measured using the previously established questionnaire before the seminar and after the asynchronous learning activities.

The questionnaire consisted of 11 closed-ended questions with yes/no/does not know options. The correct answer was measured as 1, while the wrong and I do not know answer were measured as 0. The total score of the correct answer was summed and categorized as poor (0-3), moderate (4-7), and good (8-11). The Cronbach's alpha for the knowledge was 0.843. The association between the knowledge and basic demographic data was measured using the Fisher exact test. The descriptive and inferential analysis were performed using SPSS 25.00 (IBM, Chicago, IL) and Graph PRISM version 5.00 (La Jolla, California USA).

RESULTS AND DISCUSSIONS

To increase thalassemia knowledge, seminar, book, and posters were prepared with the topic the cause, type, treatment, and prevention of thalassemia. The seminar was delivered by the medical doctor, followed by discussion and circulation of the book and poster (Figure 1).

Figure 1. *The community development activities (seminar, poster, and book).*

This activity was held during April-June 2023 in one of the orphanages in Mojokerto, East Java. Forty adolescents' respondents participated in this activity and completed the pre-test and post-test. The activity was followed by forty students, more than a half was female. Almost two third of them were early and middle adolescents, and study on elementary and junior high school. Characteristics of the respondents were summarized in table 1.

Table 1. *Characteristic of Respondents*.

Characteristic	N (%)
Age	
Early and Middle Adolescents	23 (57.5%)
Late Adolescents	17 (42.5%)
Sex	
Male	18 (45%)
Female	22 (55%)
Current Education	
Elementary School	13 (32.5%)
Junior High School	10 (25%)
Senior High School	17 (42.5%)

To measure the effectiveness of the education, 11-item questionnaires were given before and after the activities. The results showed the respondents' knowledge about thalassemia was moderate (median= 4 (0-9)). The score was increased after the activity into median= 9 (3-10) ($p<0.001$ Figure 2). The increasing score was observed both in early and middle adolescents and late adolescents, even though the score was higher in the older respondents ($p<0.001$, Figure 2A). Moreover, even though there was increasing knowledge in male and female adolescents ($p<0.001$), however, there was no significant difference between the two groups (Figure 2B). The differences also observed when grouping the respondents based on their education. In line with the age, higher education scored higher scores compared to elementary school and junior high school students ($p<0.001$, Figure 2C).

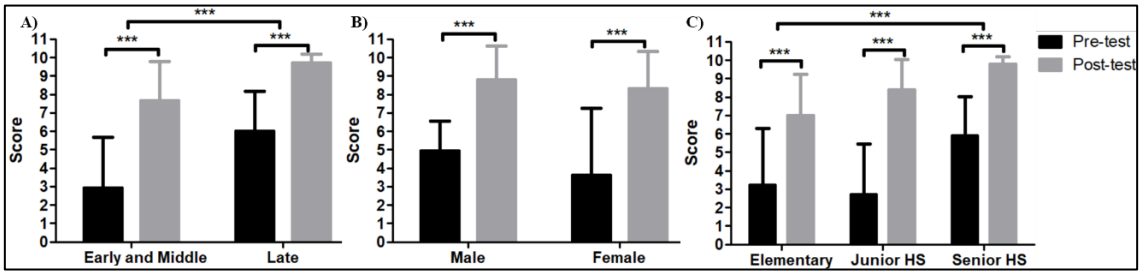

Figure 2. *Increasing of thalassemia knowledge. A) based on age, B) based on sex, and C) based on current education*.

The percentage of the correct answer of pre-test (38.41%) was increased to 77.50% in the post-test. The respondents understood that thalassemia was a blood disease (Q3) and inherited from the parents (Q1) with the symptom easy to feel fatigued, icteric sclera, pale skin, etc (Q5). They also recognized the burden of this disease including receiving regular blood transfusion (Q7), physical, emotional, and financial burden for the patients and the families (Q11). The respondents also understood one way to prevent thalassemia eas by not getting married between thalassemia carriers or patients (Q8). The necessity of blood donation in helping thalassemia patients was also well received by the respondents (Q10). Unfortunately, there were four questions which still need to be emphasized since the score is still lower than 70% (Table 2). The respondents were still confused if thalassemia is genetic diseases (Q2), not similar to blood cancer (Q4), not the only type of anemia (Q6), and how to diagnose thalassemia (Q9). The low score of these questions indicated the methods used in this community development were party effective in increasing the respondents' knowledge on thalassemia.

Adolescence period is a crucial development stage as a human being, thus health literacy, as defined as "*the ability to obtain, process, and understand health information*" (Ratzan, et al. 2000) is important to have and to get a good health status. Health decision-making in adolescents is correlated with perceived health status, mental health, and regular exercise (Chu-Ko, et al. 2021). A study of 857 Japanese adults reported that health literacy in genomic is correlated with genetic testing decision. In Indonesia itself, a study involving 906 youth respondents concluded that almost two third of the respondents have a poor knowledge about thalassemia, including their hesitation to conduct the genetic testing (Wahidiyat, et al. 2021). Interestingly, the knowledge of 75 public respondents on thalassemia was good (9.74$\pm$2.4) which higher compared to the knowledge of the orphans

in this study (4.2±2.9). Thus, finding a more effective approach to reach adolescents in this generation which is more dependent on the internet is crucial (Issa and Isaias 2016). This gap might be reduced by empowering thalassemia patients to involve in thalassemia health education (Asa, et al. 2021). Internet based media and peer-group cadre might increase the effectiveness of increasing adolescents' knowledge on thalassemia (d'Arqom, et al. 2021, d'Arqom, et al. 2021b). A holistic approach on the education must be performed during adolescence, since the prevention and the screening test must be carried out before marriage or before pregnant (Wong, et al. 2011).

Table 2. *List of Questions on the Pre-test and Post-test*.

Item	Pre-test (%)	Post-test (%)
Q1: Do thalassemia can be inherited from one or both parents?	57.5	95
Q2: Is thalassemia an infectious disease?	30	62.5
Q3: Is thalassemia a disease with a defect in red blood cells?	57.5	85
Q4: Is thalassemia similar to blood cancer?	25	55
Q5: Do anemia, fatigue, pale skin, yellow sclera are the symptoms of thalassemia?	50	97.5
Q6: Do all anemia is thalassemia?	37.5	52.5
Q7: Does thalassemia major need blood transfusion whole life?	22.5	95
Q8: Does thalassemia can be prevented by not marrying between thalassemia carriers or patients?	35	87.5
Q9: Does knowing the history of thalassemia in the family, repeated blood transfusion, anemia, and blood checking can help to diagnose thalassemia?	25	50
Q10: Does blood donation can help thalassemia patients	45	90
Q11: Does negative stigma, economic problems, physical changes cause mental illness in thalassemia patients?	37.5	82.5
Mean	38.41	77.50

CLOSING

Conclusion. This community development highlighted the importance of thalassemia literacy among adolescents. As hypothesized, orphan adolescents in Mojokerto were unfamiliar with thalassemia, and their knowledge was increase after the activity. Despite, having complicated and new medical terms, this study succeeded to increase the knowledge on thalassemia among orphans. However, mature adolescents might find it easier to receive the medical terms, the connection between several activities, etc.

Suggestion. Hence, future activities might bring more benefits if targeting middle and late adolescents, instead the early adolescents. Moreover, several points need to be emphasized, and more effective and interesting methods are needed to reach the adolescents in this generation which are more rely to the internet.

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