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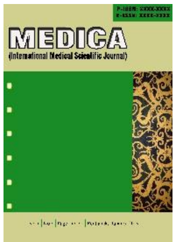

The Effectiveness of Application (Adolescent Thalassemia Self) on the Quality of Life of Children with Thalassemia

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Abstract

Thalassemia is a chronic hereditary blood disorder that requires lifelong blood transfusions and iron chelation therapy, significantly affecting the physical, emotional, social, and academic functioning of adolescents. These challenges highlight the need for innovative, technology-based interventions to support sustainable self-care. This study aimed to determine the effectiveness of the SETARA (Self-Care Thalassemia Adolescents) application in improving the quality of life among adolescents with thalassemia compared to standard education. A quasi-experimental pre–post design with a control group was conducted involving 34 adolescents aged 12–18 years with transfusion-dependent thalassemia. Participants were equally divided into intervention and control groups ($n = 17$ each). The intervention group used the SETARA application for 4–8 weeks, while the control group received standard education. Quality of life was measured using the PedsQL Thalassemia Module and analyzed using a paired samples t-test. The results showed a statistically significant improvement in the quality of life in the intervention group ($p < 0.001$), indicating the effectiveness of the SETARA application. In contrast, the control group did not show a significant change ($p = 0.205$). In conclusion, the SETARA application is effective in improving the quality of life of adolescents with thalassemia and has the potential to complement standard education and clinical care. It is recommended that adolescents use the application regularly, and healthcare professionals integrate it into patient education and family support programs.

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1. INTRODUCTION

Thalassemia is a genetic disorder characterized by abnormal hemoglobin production, often requiring lifelong blood transfusions and iron chelation therapy (Andriani et al., 2022). This hereditary blood disorder is caused by mutations in globin genes, leading to reduced or ineffective hemoglobin synthesis and resulting in chronic hemolytic anemia, with clinical manifestations ranging from asymptomatic conditions to severe thalassemia major that necessitates lifelong transfusions (Tuo et al., 2024). Thalassemia is broadly classified into α-thalassemia, β-thalassemia, and other rarer forms, with α and β types being the most prevalent and representing a major focus of global health services (Tuo et al., 2024). Globally, the prevalence of thalassemia was estimated at 1,310,407 cases in 2021, with an age-standardized prevalence rate of 18.28 per 100,000 population and an incidence rate of 1.93 per 100,000 per year (Tuo et al., 2024). Hemoglobinopathies, including thalassemia, contribute substantially to the global disease burden, with approximately 300,000–400,000 children born annually with severe forms and around 4.4 per 10,000 live births affected, particularly in regions such as the Mediterranean, Africa, the Middle East, Southeast Asia, and southern China (BGI Genomics, 2023). Asia, especially East and Southeast Asia, is recognized as the “thalassemia belt,” with high prevalence rates reaching 54.26 per 100,000 and 43.38 per 100,000, respectively, in 2021 (Tuo et al., 2024).

Indonesia is part of this high-burden region, with a significant number of β-thalassemia major cases requiring long-term transfusion and iron chelation therapy (Weatherall, 2023). National data indicate a continuous increase in the number of thalassemia cases, rising from 10,973 in 2021 to 12,155 in 2022, reflecting a growing demand for healthcare services (Ministry of Health of the Republic of Indonesia quoted in CNN Indonesia, 2025). West Java Province accounts for the highest proportion of cases, with approximately 4,717 patients, representing more than one-third of the national burden (CNN Indonesia, 2025). Earlier reports also showed that West Java contributed around 35% of total cases in Indonesia, with an estimated 500–600 infants born annually with severe thalassemia if the carrier frequency reaches 5–10% (Yayasan Talasemia Indonesia – POPTI, 2011). These data highlight that thalassemia remains a significant public health concern in Indonesia.

At the regional level, Sukabumi City and Regency have experienced an increasing number of thalassemia cases, with approximately 180 patients registered in POPTI Sukabumi and an addition of 3–4 new cases per month (Yayasan Talasemia Indonesia – POPTI, 2011). This trend underscores the importance of preventive strategies such as carrier screening, genetic counseling, and premarital education to reduce the incidence of thalassemia major (Yayasan Talasemia Indonesia – POPTI, 2011). Thalassemia is inherited in an autosomal recessive pattern, where children are at risk of developing severe disease if both parents are carriers, while carriers themselves are often asymptomatic or present with mild anemia (Unissa, 2018). The underlying pathophysiology involves mutations or deletions in globin genes (α, β, or δ), leading to ineffective erythropoiesis and hemolysis (Yuanyuan Tuo et al., 2024).

Clinically, thalassemia major leads to severe anemia, requiring regular transfusions and resulting in iron overload that can damage multiple organs, including the heart, liver, endocrine system, and kidneys (Tuo et al., 2024). Patients often experience growth retardation, delayed puberty, bone deformities, and chronic fatigue, all of which significantly impair quality of life. Moreover, the disease has profound psychosocial impacts, affecting school performance, social relationships, and mental health, with increased risks of anxiety and depression when disease management and psychosocial support are inadequate (Soteriades et al., 2025). Although primary prevention efforts such as mass screening and public awareness campaigns have been implemented, including those by POPTI Sukabumi, management strategies still predominantly focus on clinical treatment rather than holistic patient-centered care (Yayasan Talasemia Indonesia – POPTI, 2011).

Standard management includes maintaining hemoglobin levels through regular transfusions and preventing iron overload chelation therapy. While curative approaches such as hematopoietic stem cell transplantation and gene therapy are emerging, their implementation is limited due to high costs, donor availability, and associated risks (Tuo et al., 2024; Soteriades et al., 2025). In this context, digital health interventions, such as mobile and web-based applications, have been developed to enhance self-care, treatment adherence, and health literacy among adolescents with thalassemia. However, existing applications largely focus on monitoring and reminders, with limited emphasis on interactive education, psychosocial support, and quality of life outcomes (Janatri, Kuan, & Harun, 2024). Although mobile-based genetic counseling has shown promising results in improving knowledge, satisfaction, and psychological well-being, evidence regarding the effectiveness of comprehensive self-care applications for adolescents remains scarce. Therefore, this study aims to determine the effectiveness of the SETARA (Self-Care Thalassemia Adolescents) application in improving the quality of life among adolescents with thalassemia.

2. METHOD

This study employed a quasi-experimental design with a pre-test and post-test control group to evaluate the effectiveness of the SETARA (Self-Care Thalassemia Adolescents) application on the quality of life of adolescents with thalassemia. The study involved 34 adolescents aged 12–18 years diagnosed with transfusion-dependent thalassemia major. Participants were selected using a purposive sampling technique based on predefined inclusion and exclusion criteria. The inclusion criteria were adolescents diagnosed with thalassemia major who underwent regular blood transfusions, were able to operate a smartphone, and were willing to participate in the study. Exclusion criteria included adolescents with cognitive impairments or severe comorbid conditions that could hinder participation.

Participants were allocated into intervention and control groups using a non-randomized approach while ensuring comparability of baseline characteristics between groups, with 17 participants in each group. The intervention group received access to and used the SETARA application for a duration of 4–8 weeks, whereas the control group received standard care without the application.

Quality of life was assessed using the Pediatric Quality of Life Inventory (PedsQL) Thalassemia Module, which was administered before and after the intervention period. Data analysis was performed using the paired samples t-test to evaluate within-group changes in quality-of-life scores before and after the intervention.

The sample size was determined using a formula for quasi-experimental studies with two groups, considering a 95% confidence level and 80% statistical power. Ethical approval for this study was obtained from the Ethics Committee of the Faculty of Medicine under ethical clearance number 164/KET/KE-FKES/I/2026. Written informed consent was obtained from all participants and their parents or legal guardians after a thorough explanation of the study objectives, procedures, and potential benefits.

3. RESULTS AND DISCUSSION

Table 1. Distribution of Respondents by Age.

Variable	Average	Std. Deviation	Minimum	Maximum
Age of Intervention Group	14.06	2.461	10	18
Age of Control Group	14.24	2.463	10	18

Table 1 shows that the sample in this study who became respondents in the intervention group, the average age of the respondents was 14.06 years old with a minimum age of 10 years and a maximum age of 18 years. And in the control group, the average age of respondents was 14.24 years old with a minimum age of 10 years and a maximum age of 18 years.

Table 2. Distribution of respondents by Late Education.

Variable		Quantity	(%)
Latest Education Intervention Group	Not in school	1	5.9
	Elementary School	5	29.4
	Junior High School	7	41.2
	High School	4	23.5
Latest Education Control Group	Not in school	1	5.9
	Elementary School	4	23.5
	Junior High School	8	47.1
	High School	4	23.5
Total		17	100

Table 2 shows that almost half of the final education of the intervention group that became respondents were junior high school graduates, as many as 7 people (41.2%). And almost half of the final education of the control group that became respondents were 8 people (47.1%) with a junior high school education.

Table 3. Distribution of respondents by gender.

Variable		Quantity	(%)
Gender of the intervention	Male	8	47.1
	Women	9	52.9
Gender of the intervention	Male	6	35.3
	Women	11	64.7
Total		17	100

Table 3 shows that most of the gender respondents in the intervention group were women, as many as 9 people (52.9%), and most of the gender respondents in the control group were women, as many as 11 people (64.7%).

Table 4. Frequency of Quality of Life of Children with Thalassemia before and after the SETARA (*Adolescent Self Care* Thalassemia) intervention.

Quality of Life	Average	Std. Deviation	Minimum	Maximum
Intervention Groups				
Pre-test	20.53	3.356	13	26
Post test	52.24	8.066	40	67
Control Group				
Pre-test	19.06	4.697	12	27
Post test	19.76	4.024	12	27

Table 4 shows that the results of the study on the frequency of quality of life of children with thalassaemia before the intervention of SETARA (*Adolescent Self Care* Thalassemia) application in the intervention group averaged 20.53, the Std. Deviation value was 3.356, the lowest score was 13 and the highest was 26. And the average score after the intervention was 52.24, the Std. Deviation score was 8.066, the lowest score was 40 and the highest was 67. The frequency of quality of life of children with thalassemia before the intervention of SETARA (*Adolescent Self Care* Thalassemia) application in the control group averaged 19.06, Std. Deviation value 4.697, lowest score 12 and highest 27. And the average score after intervention was 19.76, the Std. Deviation score was 4.024, the lowest score was 12 and the highest score was 27.

Table 5. Analysis of the effectiveness of SETARA (*Adolescent* Thalassemia Self) application on the quality of life of children with thalassaemia.

Variable	**Paired Differences**					**t**	**p-value**
	Network	**Std. Deviation**	**Std. Error Mean**	**95% Confidence Interval of the Difference**			
				Lower	**Upper**		
Intervention Quality of Life Pretest – Intervention Quality of Life Posttest	-31.706	9.211	2.234	-36.442	-26.970	-14.192	<0.001
Quality of Life Pretest Control – Quality of Life Posttest Control	-0.706	2.201	.534	-1.838	.426	-1.322	0.205

Based on table 5, the results of the statistical test with *the Paired Samples Test* in the intervention group obtained a P value of <0.001 (p-value < 0.05), where it can be concluded that there is an effectiveness of the application of SETARA (*Self Care* Adolescent Thalassemia) on the quality of life of children with thalassemia in the intervention group. Meanwhile, in the control group, a p-value of 0.205 (p-value >0.05) was obtained, where it can be concluded that there was no difference in the quality of life of children with thalassaemia in the control group without being given the SETARA (*Adolescent* Thalassemia Self) application.

The findings of this study demonstrated a substantial improvement in the quality of life (QoL) of adolescents with thalassemia in the intervention group following the use of the SETARA (Self-Care Thalassemia Adolescents) application. The mean QoL score increased markedly from 20.53 (SD = 3.356) to 52.24 (SD = 8.066), indicating a statistically and clinically significant improvement. The magnitude of change reflects a very large effect size (Cohen's d ≈ 4.7), far exceeding the conventional threshold for a large effect (>0.8), and surpassing findings from similar studies such as the moderate increase in self-efficacy reported by Kharaman-nia et al. (2023). These results are consistent with the findings of Andriani (2025), who reported that the SETARA model significantly improved knowledge, transfusion adherence, and self-care behaviors among adolescents with thalassemia in Indonesia. However, the interpretation of a "very strong effect" should be approached cautiously due to the limited availability of direct comparisons with nondigital control groups, as highlighted by Ayu and Mulyono (2023), who found positive but still limited and evolving evidence regarding mobile applications and QoL outcomes.

The observed improvement in QoL can be explained by the mechanisms embedded within the SETARA application, including interactive reminders, multimedia-based education, and family involvement, which collectively enhance self-efficacy. This aligns with the Self-Determination Theory (SDT), which emphasizes autonomy, competence, and relatedness as key drivers of intrinsic motivation in managing chronic diseases (Fauziyah, 2025). Similar findings were reported in studies referenced by Kharaman-nia et al. (2023), where smartphone-based interventions improved self-efficacy more effectively than conventional educational approaches due to greater accessibility and user engagement. Furthermore, the integration of family-centered approaches, as demonstrated by Kharaman-Nia et al. (2023), reinforces the importance of parental involvement in improving QoL outcomes, supporting the conceptual framework underlying the SETARA intervention.

Nevertheless, as a quasi-experimental study without full randomization, the results are potentially influenced by selection bias, where participants in the intervention group may have had higher baseline motivation or better access to digital resources. This limitation is consistent with concerns raised in thalassemia research regarding non-randomized designs and the potential influence of confounding variables such as disease severity (Ahmed Mohamedain et al., 2025; El-Khalifa, et al., 2025; Mohamedain, 2025; Indriani, Triyono, & Mulyono, 2025; Rahman et al., 2025). Additionally, the improvement in QoL may partly reflect the Hawthorne effect, where participants modify their behavior due to awareness of being observed. External factors such as existing social and family support systems in Indonesia, where thalassemia prevalence is relatively high and baseline QoL is often low, may also contribute to the observed improvements (Fauziyah et al., 2025). Comparatively, evidence from randomized controlled trials, such as genetic counseling applications, suggests that while digital interventions can produce significant short-term benefits, their long-term effects may diminish over time.

In contrast, the control group did not demonstrate a meaningful improvement in QoL, with mean scores remaining relatively stable (19.06 to 19.76) and a non-significant statistical result ($p = 0.205$). This finding is consistent with previous studies indicating that QoL improvements are more likely to occur in groups receiving structured interventions. For example, Borhani, et al. (2011) reported significant improvements in intervention groups exposed to family-centered empowerment programs or smartphone-based education, while control groups showed minimal or no change. Similarly, Janatri, Kuan, & Harun (2024) emphasized that the effectiveness of mobile and web-based interventions is predominantly observed in intervention groups, with comparison groups typically demonstrating negligible changes. These findings support the interpretation that without structured educational or psychosocial interventions, QoL among adolescents with thalassemia tends to remain stable in the short term.

The effectiveness of the SETARA application is further supported by the statistically significant results in the intervention group ($p < 0.001$), indicating that digital self-care interventions can play a crucial role in improving QoL. Smartphone-based self-care education significantly enhances self-efficacy compared to traditional methods. Additional support is provided by Ayu & Mulyono (2023), who reported that mobile applications for thalassemia are well-received and have the potential to improve psychosocial functioning. Moreover, structured interventions combining education, psychosocial support, and self-care strategies are effective in improving QoL in thalassemia patients. These findings reinforce the notion that the SETARA application, as a structured and interactive digital intervention, contributes not only to knowledge improvement but also to behavioral changes and enhanced self-management capacity.

From a theoretical perspective, these findings are consistent with self-care theory and behavior change models, which emphasize the importance of knowledge, skills, motivation, and social support in achieving better health outcomes (Borhani, et al., 2011). The absence of significant improvement in the control group further supports Orem's Self-Care Deficit Nursing Theory, which posits that improvements in QoL require structured support systems rather than routine care alone (Khademian, Kazemi Ara, & Gholamzadeh, 2020; Khazaei, Razaghi, & Vashani, 2021; Urtekin, & Eroglu, 2024; Xie et al., 2025). Evidence from other studies, such as Kharaman-Nia et al. (2023), also highlights that meaningful improvements in QoL are typically achieved through sustained and comprehensive interventions rather than short-term or unstructured approaches. In the Indonesian context, where socioeconomic challenges, stigma, and limited access to healthcare services persist, digital interventions such as SETARA offer a practical and scalable solution to enhance patient engagement and self-care behaviors (Janatri, Kuan, & Harun, 2024; Mardhiyah et al., 2024).

Despite these promising findings, several limitations must be acknowledged. First, the quasi-experimental design without randomization introduces potential selection bias and limits causal inference. Second, the relatively small sample size and single-center setting reduce the generalizability of the findings. Third, the short duration of the intervention limits the ability to assess long-term sustainability and clinical outcomes, such as serum ferritin levels. Fourth, the use of self-reported QoL instruments may introduce reporting bias, particularly in the absence of blinding. Additionally, variability in external factors such as family support, internet access, and socioeconomic status may have influenced the outcomes. Finally, the lack of comparison with other structured educational interventions makes it difficult to determine the relative superiority of the SETARA application. Future studies are recommended to employ randomized controlled trial designs, larger multi-center samples, longer follow-up periods, and additional objective clinical indicators to strengthen the evidence base.

4. CONCLUSION

Based on the results of the analysis, the implementation of the SETARA (Self-Care Thalassemia Adolescents) application was found to significantly improve the quality of life of adolescents with thalassemia in the intervention group, while no significant change was observed in the control group. These findings indicate that the use of the SETARA application is effective in supporting adolescents in enhancing self-care skills, promoting independence in disease management, and fostering a more positive perception of their health condition. Conceptually, this study confirms that digital-based interventions focusing on strengthening knowledge and self-care capacities can contribute to improvements across physical, psychological, social, and environmental domains of quality of life in adolescents with thalassemia.

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REFERENCES

Ahmed Mohamedain, O. M., Malik, M. M., Elnaseeh, W. M., Hasan, A., Taha, S. O., Taha, H. O., ... & Qureshi, H. A. (2025). Co-inherited α-Thalassemia and β-Globin Haplotypes as Determinants of Vaso-Occlusive Crisis, Stroke, and Mortality in Sickle Cell Disease: A Systematic Review. *Vascular and Endovascular Review*, 8(13s), 33-42. Retrieved from https://verjournal.com/index.php/ver/article/view/983

Andriani, R. (2025). *Model "SETARA" Tingkatkan Manajemen Diri Remaja Penyintas Talasemia: Riset Doktor FIK UI Bawa Harapan Baru bagi Generasi Muda [Internet].* Fakultas Ilmu Keperawatan, Universitas Indonesia. Retrieved from https://nursing.ui.ac.id/model-setara-tingkatkan-manajemen-diri-remaja-penyintas-talasemia-riset-doktor-fik-ui-bawa-harapan-baru

Andriani, R., Nurhaeni, N., A., & Safariyah, E. (2022). Andriani, R., Nurhaeni, N., & Safariyah, E. (2022). Mother's fortitude in taking care of children with thalassemia in Indonesia. *KnE Life Sciences*, 7(2), 574-584. https://doi.org/10.18502/kls.v7i2.10358

Ayu, A., & Mulyono, S. (2023). A Mobile App Deployment for Quality-of-Life Patient with Thalassemia: A narrative review. *Jurnal Berita Ilmu Keperawatan*, 16(1), 116-124. https://doi.org/10.23917/bik.v16i1.1371

BGI Genomics. (2023). *State of thalassemia awareness 2023 report [Internet].* News-Medical. Retrieved from https://www.news-medical.net/whitepaper/20231206/State-of-Thalassemia-Awareness-2023-Report.aspx

Borhani, F., Najafi, M. K., Rabori, E. D., & Sabzevari, S. (2011). The effect of family-centered empowerment model on quality of life of school-aged children with thalassemia major. *Iranian journal of nursing and midwifery research*, 16(4), 292–298. Retrieved from https://pmc.ncbi.nlm.nih.gov/articles/PMC3583099/

CNN Indonesia. (2025). *Kasus Talasemia Terus Meningkat di RI, Jawa Barat Tertinggi [Internet].* CNN Indonesia. Retrieved from. https://www.cnnindonesia.com/gaya-hidup/20250521131109-255-1231547/kasus-talasemia-terus-meningkat-di-ri-jawa-barat-tertinggi

El-Khalifa, B. M., Soliman, W. A., Mazy, H. M., Ahmed, M. G., Al-Trad, H., Elmeneizee, T. H., ... & Morsi, M. H. (2025). Crispr/Cas9 gene editing in transfusion-dependent β-thalassemia and sickle cell disease: a systematic review of non-randomized clinical trials. *Egyptian Journal of Medical Human Genetics,* 26(1), 177. https://doi.org/10.1186/s43042-025-00806-4

Fauziyah, A. S. (2025). Self-Care Pada Anak Dengan Thalassemia Mayor Usia Adolescent. *S1 thesis.* Universitas Pendidikan Indonesia. Retrieved from http://repository.upi.edu/141066/

Indriani, V., Triyono, T., & Mulyono, B. (2025). Using Blood Group Genotyping to Predict Hemolysis in Patients With β-Thalassemia Major With Frequent Transfusions: Protocol for a Cross-Sectional Study. *JMIR Research Protocols*, 14(1), e64379. Retrieved from https://www.researchprotocols.org/2025/1/e64379

Janatri, S., Kuan, C. S., & Harun, Z. (2024). Mobile and Web-Based Apps to Support Self-Care in Adolescents with Thalassemia: A Systematic Review. *International Journal of Biotechnology and Biomedicine (IJBB),* 1(2), 10-23. https://doi.org/10.31674/ijbb.2024.v01i02.002

Khademian, Z., Kazemi Ara, F., & Gholamzadeh, S. (2020). The Effect of Self Care Education Based on Orem's Nursing Theory on Quality of Life and Self-Efficacy in Patients with

Hypertension: A Quasi-Experimental Study. *International journal of community based nursing and midwifery,* 8(2), 140–149. https://doi.org/10.30476/IJCBNM.2020.81690.0

Kharaman-Nia, F., Rezaei, H., Roustaei, N., Etemadfar, P., & Hosseini, N. (2023). Comparing the effects of self- care education by lecture and smartphone application on self-efficacy of patients with thalassemia. *BMC medical informatics and decision making,* 23(1), 21. https://doi.org/10.1186/s12911-023-02097-4

Khazaei, F., Razaghi, N., & Vashani, H. B. (2021). Effectiveness of a Support-Training Program based on the Orem's Self-Care Deficit Theory on the Quality of Life of Children Undergoing Hemodialysis. *Journal of Evidence-based Care*, 11(1), 7.

Mardhiyah, A., Panduragan, S. L., Mediani, H. S., & Yosep, I. (2024). Factors Associated With Quality of Life Among Adolescent With Beta Thalassemia in Indonesia: A Cross-Sectional Study. *SAGE open nursing*, 10, 23779608241255638. https://doi.org/10.1177/23779608241255638

Mohamedain, A. (2025). Pregnancy and Perinatal Outcomes among Women with Sickle Cell Disease in Saudi Arabia: A Systematic Review. *Vascular and Endovascular Review*, 8(8s), 1-8. https://verjournal.com/index.php/ver/article/view/634

Rahman, I. U., Khan, M. T. M., Ali, Z., Ahmad, S., Shahid, M., Zafar, S., ... & Siraj, S. (2025). Thalidomide confers therapeutic benefit in beta thalassemia patients by enhancing hemoglobin and hematopoietic gene expression: A non-randomized clinical trial. *Blood Cells, Molecules, and Diseases,* 113, 102936. https://doi.org/10.1016/j.bcmd.2025.102936

Soteriades, E. S., Angastiniotis, M., Economidou, E. C., Farmakis, D., Avraam, D., & Eleftheriou, A. (2025). The disease burden of β-thalassaemia revisited. *Hematology,* 30(1), 2551450. https://doi.org/10.1080/16078454.2025.2551450

Tuo, Y., Li, Y., Li, Y., Ma, J., Yang, X., Wu, S., Jin, J., & He, Z. (2024). Global, regional, and national burden of thalassemia, 1990-2021: a systematic analysis for the global burden of disease study 2021. *EClinicalMedicine,* 72, 102619. https://doi.org/10.1016/j.eclinm.2024.102619

Unissa, R., Monica, B., Konakanchi, S., Darak, R., Keerthana, S. L., & Kumar, S. A. (2018). Thalassemia: a review. *Asian Journal of Pharmaceutical Research*, 8(3), 195-202. Retrieved from https://indianjournals.com/article/ajpr-8-3-014

Urtekin, D., & Eroglu, S. A. (2024). Effect of training based on Orem's self-care deficit theory on breast cancer patients' management of chemotherapy-related side effects and self-care behaviors: A randomized controlled trial. *European Journal of Oncology Nursing*, 73, 102698. https://doi.org/10.1016/j.ejon.2024.102698

Xie, Y., Wang, D., Zhou, J., Zhou, T., Huang, Y., Zhang, K., & Li, H. (2025). Impact of nursing based on Orem's self-care theory on self-care behaviours in older patients with heart failure: A randomised controlled trial. *Australasian Journal on Ageing*, 44(3), e70059. https://doi.org/10.1111/ajag.70059

Yayasan Talasemia Indonesia – POPTI. (2011). *Jawa Barat menempati peringkat pertama dalam jumlah pasien talasemia. Rumah Sakit Dr. Hasan Sadikin Bandung [Internet]*. Yayasan Talasemia Indonesia – POPTI. Retrieved from https://web.rshs.go.id/jawa-barat-ranking-1-penderita-thalassemia