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The Role of Nurses to Control Beta Thalassemia Disease in Indonesia: A Perspective

--Manuscript Draft--

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Abstract:	<p>Thalassemia is the most common genetic disease in Indonesia and is passed on to the next generation following an autosomal recessive Mendelian inheritance pattern. The number of thalassemia sufferers in Indonesia increased from 4,896 in 2012 to 8,761 in 2018. The latest data in 2019 shows a significant increase to 10,500 patients. Community nurses who work at the Public Health Center, have full roles and responsibilities in carrying out promotive and preventive efforts against thalassemia cases. Promotive efforts that can be carried out are guided by government policies (Ministry of Health, Republic of Indonesia) which stipulate primary efforts in the form of education about thalassemia disease, prevention efforts, and diagnostic tests that can be taken. To optimize the promotive and preventive efforts, community nurses need to collaborate with midwives and cadres at integrated service posts. Interprofessional collaboration between stakeholders can strengthen the government's consideration in making policies for dealing with thalassemia cases in Indonesia.</p>
Suggested Reviewers:	<p>Niken Safitri Dyan Kusumaningrum, PhD Department of Nursing, Diponegoro University niken.safitridk@fk.undip.ac.id She was join as a member of Indonesian Association of Genomic Nursing and consent in Genetic problem.</p> <p>Ai Mardhiyah, PhD Faculty of Nursing, Lincoln University College aimardiyah@gmail.com She is an expert researcher in Thalassemia.</p>
Response to Reviewers:	<p>1.The context of this article is in Indonesia, doesn't it? So, you need the national data instead of only Ciamis data. Our Response: We added the data in abstract and main text (paragraph 1)</p> <p>2.In my opinion, most people are unaware that thalassemia is a kind of genetic disease. So, they do not consider that they need to do a screening or genetic testing. Therefore, you need to give a brief overview about Thalassemia as genetic disease and its impact in daily life before continue to specific role of nurse. Our Response: We mentioned it on paragraph 1.</p> <p>3.You have to explain what are the exact roles of nurse in this context. Our Response: Nurses: Promotion and prevention efforts that was mentioned, I wrote about screening, tracing and genetic counseling (paragraph 3-4) Midwives: has role in obstetrical health checks, which are the main requirements before marriage (paragraph 6) Cadres: has role in providing assistance to families and communities diagnosed with carriers..... (paragraph 6)</p>

Government: has role in making policies for dealing with thalassemia cases in Indonesia. (paragraph 6)

Letter of Response

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Title Page

The Role of Nurses to Control Beta Thalassemia Disease in Indonesia: A Perspective

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The Role of Nurses to Control Beta Thalassemia Disease in Indonesia: A Perspective

Abstract

Thalassemia is the most common genetic disease in Indonesia and is passed on to the next generation following an autosomal recessive Mendelian inheritance pattern. The number of thalassemia sufferers in Indonesia increased from 4,896 in 2012 to 8,761 in 2018. The latest data in 2019 shows a significant increase to 10,500 patients. Community nurses who work at the Public Health Center, have full roles and responsibilities in carrying out promotive and preventive efforts against thalassemia cases. Promotive efforts that can be carried out are guided by government policies (Ministry of Health, Republic of Indonesia) which stipulate primary efforts in the form of education about thalassemia disease, prevention efforts, and diagnostic tests that can be taken. To optimize the promotive and preventive efforts, community nurses need to collaborate with midwives and cadres at integrated service posts. Interprofessional collaboration between stakeholders can strengthen the government's consideration in making policies for dealing with thalassemia cases in Indonesia.

Keywords: beta thalassemia; community nurses; preventive; promotive

Dear Editor,

Thalassemia is the most common of inherited genetic disease in Indonesia and is passed on to the next generation following an autosomal recessive Mendelian inheritance pattern. The number of thalassemia sufferers in Indonesia increased from 4,896 in 2012 to 8,761 in 2018. The latest

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4 data in 2019 shows a significant increase to 10,500 patients. This data is predicted to continue to
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6 grow with as many as 1,500 new cases diagnosed each year.¹ An identified genetic disorder
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8 caused by mutations on chromosome 11 and chromosome 16.² This mutation is the cause of the
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10 loss of the β -globin gene (the cause of β -thalassemia) and the α -globin gene (the cause of α -
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12 thalassemia). Genetically, this mutation causes a decrease or loss of β -globin chain synthesis,
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14 which is the largest component of adult hemoglobin. This situation directly affects the physical
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16 health of the patient and indirectly impacts the psychosocial status of the patient, parents
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18 (caregiver) and family.¹ Anemia is a characteristic of thalassemia sufferers impact to depend on
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20 routine blood transfusions for their whole life. Other clinical manifestations that appear are
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22 splenomegaly, short stature, pale, and fatigue which have an impact on limiting the patient's
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24 activities. Depression, anxiety, worry and quality of life are psychosocial problems that are often
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26 reported in sufferers and families with thalassemia.³
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33 Apart from consanguinity or marriage in the same family, awareness of carrying out carrier
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35 screening in hospitals and laboratories is still very low. Even families who have children with
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37 thalassemia do not do genetic testing. The most compelling reason given by the family was that
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39 the examination fee was expensive and not covered by health insurance.⁴ As a result, carrier
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41 tracking cannot be carried out, so it is possible for inter-carrier marriages to occur which have
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43 the potential to pass on 25% of offspring with thalassemia disease and 50% of new carriers. This
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45 bad potential must be prevented by strengthening the role and function of health workers,
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47 especially community nurses.
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53 Community nurses who work at the Public Health Center, have full roles and responsibilities
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55 in carrying out promotive and preventive efforts against thalassemia cases. Promotive efforts that
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4 can be carried out are guided by government policies (Ministry of Health, Republic of Indonesia)
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6 which stipulate primary efforts in the form of education about thalassemia disease, prevention
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8 efforts, and diagnostic tests that can be taken. The hope is that the public will have early
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10 awareness of thalassemia disease.⁵
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14 The preventive efforts that can be made are screening, tracing, and genetic counseling.
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16 Thalassemia screening can be done in all public hospitals by examining MCV (mean corpuscular
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18 volume), MCH (mean corpuscular hemoglobin), and MCHC (mean corpuscular hemoglobin
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20 concentration). To be more sure, further examination can be done with electrophoresis in
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22 hospitals and more complete laboratories.⁶ This screening is very important, especially for
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24 couples who are about to get married (premarital screening), so nurses need to collaborate with
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26 the Office of Religious Affairs, which has authority over the marriage process. Genetic
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28 counseling is given before and after carrier screening is taken, so that individual couples can
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30 make choices after getting strong information regarding the results of the examination. Although
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32 the nurse as a counselor does not have the authority to make choices, a detailed explanation
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34 regarding the risks arising from inter-carrier thalassemia marriage can be a strong consideration
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36 for couples.⁷
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43 Tracing begins with drawing a family pedigree on families who have children with
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45 thalassemia or microcytic anemia. The description of family pedigree involves at least three
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47 generations in one family, so identification is taken comprehensively, including planning genetic
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49 counseling to be carried out. Parents who have children with Thalassemia should be suspected of
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51 being a carrier partner.² Likewise, with family members in one pedigree, there may be carrier
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53 thalassemia. However, this allegation still needs to be proven by further investigations such as
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4 electrophoresis, because there are other possible causes of mutations (besides being inherited
5 from a carrier partner), such as radiation, infection, toxicity, pollution, and even de novo. The
6 results of this examination will be taken into consideration by parents in planning their next
7 pregnancy. For other family members who are diagnosed as carriers based on the results of the
8 examination, it is necessary to plan premarital screening for couples who are getting married.²

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16 To optimize the promotive and preventive efforts, community nurses need to collaborate with
17 midwives and cadres at integrated service posts. In addition to playing a role in obstetrical health
18 checks, which are the main requirements before marriage, midwives can improve information
19 about thalassemia, the importance of carrier screening, and emotional support.⁸ The cadres play
20 an important role in providing assistance to families and communities diagnosed with carriers, so
21 that awareness grows to participate in screening, tracing, and genetic counseling programs in
22 public health centers and hospitals. Interprofessional collaboration between stakeholders can
23 strengthen the government's consideration in making policies for dealing with thalassemia cases
24 in Indonesia.

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40
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43 44 45 46 47 **Conflict of interest**

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49
50 There is no conflict of interest.

51 52 53 **Ethical approval**

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4 This research was approved by Health Research Ethics Committee, University of
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6 Muhammadiyah Gombong in August 19, 2021 with the number
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12 **Authors' contribution**

14
15 Each author contributed equally in all the parts of the research. All authors have critically
16
17 reviewed and approved the final draft and are responsible for the content and similarity index of
18
19 the manuscript.
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21

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