

Reproductive Decision-Making in People with Transfusion-Dependent-Thalassemia

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ABSTRACT

The benefits of genomic science might seem elusive for individuals living with genetic conditions such as transfusion-dependent-thalassemia (TDT) in low-middle-income countries (LMICs) such as Indonesia. While there is ample excitement for gene therapies for TDT (CASGEVY, which received conditional marketing authorization from the UK Medicines and Healthcare Products Regulatory Agency in November 2023), anticipated costs of ~\$2 million per patient subdue that excitement.

Reproductive decisions are particularly challenging for individuals with TDT and are likely to remain so notwithstanding the emerging gene therapies that ultimately could prove transformative. An improved understanding of the reproductive decision-making process of pregnant persons with TDT in LMICs is needed to improve culturally relevant competencies for both nurses and genetic counselors.

To gain a better understanding of reproductive decision-making by pregnant persons with TDT, we performed semi-structured interviews with 11 participants recruited from three hospitals in West Java, Indonesia in Summer 2023. Inductive content analysis revealed five themes: 1) imbalanced reproductive decision-making; 2) family's concerns regarding high risk of thalassemia pregnancy; 3) instincts to procreate; 4) pregnancy is a blessing; 5) awareness of socio-individual determinants of health. Our research highlights challenges faced by individuals with TDT regarding exercise of their reproductive rights, finding such decisions often being influenced by religious beliefs and culture and also finding tensions involving autonomy and social responsibility shaping the reproductive decision-making process.

Finally, we outline how these findings can inform future efforts needed to promote equity in genomic nursing and gene therapies for individuals with TDT globally.

Keywords: Equity and justice in genetics, global health, and reproductive genetics

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Introduction

- Transfusion-Dependent-Thalassemia (TDT) is an inherited disorder resulting in severe anemia & multiple chronic conditions.
- TDT patients require blood transfusions throughout life.
- Reproductive decisions aim to prevent high-risk pregnancy & suppress thalassemia births.

Purpose

- To gain an understanding of TDT mothers' decision-making process when considering a high-risk pregnancy with thalassemia.

Methods

- **Location:** three thalassemia units in distinct districts in West Java Indonesia.
- **Methods:** qualitative descriptive design; purposive sampling of 11 women with TDT; data collection from July to August 2023; & Penn State IRB approval: #STUDY00022390.
- **Data collection:** individual online semi-structured interviews.
- **Analysis:** inductive content analysis.

Demographics

Characteristics	Respondents (N = 11)	
	n	%
Age		
20-30	6	54.54
31-40	4	36.36
≥41	1	9.09
Education		
≤High School	8	72.72
College Graduate	3	27.27
Number of child(s)		
0	1	9.09
1-2	8	72.72
3-4	2	18.18
Last Hemoglobin level (g/dl)		
5-5.9	1	9.09
6-6.9	3	27.27
7-7.9	5	45.45
8-8.9	2	18.18
Frequency of blood donors monthly		
1	7	63.63
2	4	36.36
Duration of iron chelation therapy		
1-4 years	1	9.09
5-10 years	4	36.36
≥ 11 years	6	54.54
Total child(s) with thalassemia		
One child	2	18.18
None/not tested	9	81.81
Parents or siblings have thalassemia		
Yes	7	63.63
None/not tested	4	36.36

Results

THEME 1: Imbalanced Reproduction Decision-Making

Sub-theme 1; Partner's desires: *Yeah, maybe my husband is the one who wants to a child as soon as possible...there were discussions, like a debate, afraid that it will passing down to the child, worried, but well that is how guys are, selfish (R9).*

Sub-theme 2; Family's desires: *...My parents also support me for having a child...even though we know about thalassemia. Maybe because my father is afraid that his descendants would be limited, because he only has 3 children (R11).*

THEME 2: Family's Concern Related to High-Risk of Thalassemia Pregnancy

Sub-theme 1; Providing explanation: *My mother did not give an approval of me having a child...my parents would be angry if they knew I was pregnant...I gave them explanation that it had already happened...this is my fortune...(R2).*

Sub-theme 2; Family's coercive advice: *My own parents have not agree yet due to their fears...They said we should not rush because they are afraid the child might face challenges, it is like they have a bit trauma (R4).*

THEME 3: Instinct to Procreate

Sub-theme 1; One child is enough: *It feels like wanting to have another one, but at different point, I am a bit hesitant, Sir, afraid it happen again...because I am also thalassemician (R8).*

Sub-theme 2; Desire to be a mother: *If you do not have descendants, people will say that is imperfect, so it is a bit of a dilemma...I want to have descendants, want to prove that even though I am a thalassemician, can have a healthy child (R4).*

THEME 4: Pregnancy is a Blessing

Sub-theme 1; Maintain risky pregnancy: *...For instance, I am tested and found having thalassemia, I would choose to stay pregnant...not consider abortion (R1).*

Sub-theme 2; Child is a divine fate: *...Everything is already determined by Allah, fate cannot be changed, maybe it is my destiny to have a child who suffered like me (R4).*

THEME 5: The Awareness of Socio-individual Determinants of Health

Sub-theme 1; Burdens concern: *...burden for the country because we are covered by country's health insurance, so there is thought in that way (R1).*

Sub-theme 2; Genetics disease risk concern: *The confusion is between being ready and not ready...the unreadiness is the fear of my child having thalassemia. So maybe the husband needs to undergo screening...(R3).*

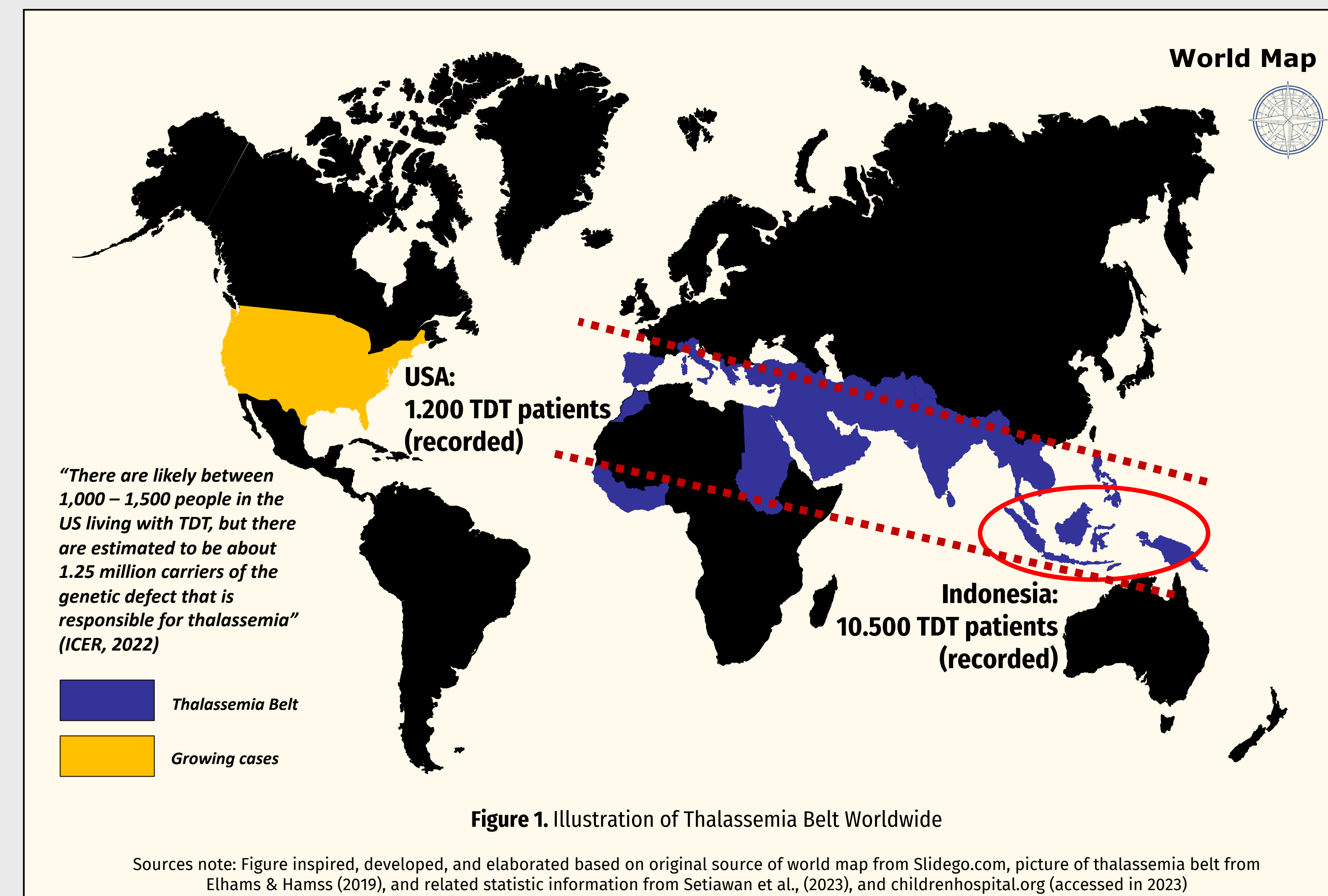


Figure 1. Illustration of Thalassemia Belt Worldwide

Sources note: Figure inspired, developed, and elaborated based on original source of world map from Slidigo.com, picture of thalassemia belt from Elhams & Hamss (2019), and related statistic information from Setiawan et al., (2023), and childrenhospital.org (accessed in 2023)

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Conclusions

- An ethical dilemma arises concerning how mothers with TDT exercise reproductive rights when deciding whether or not to continue a pregnancy when there is a high risk of passing along thalassemia.
- Religious beliefs & culture influences decisions.
- Individual autonomy & social responsibility, shape the decision-making process.

Implication & Future Directions

- This knowledge will facilitate the provision of improved & culturally sensitive counseling.
- Nurses need to develop competence & enhance genetic counseling roles within their local setting including promote new excitement of gene therapies, while staying mindful of the religious beliefs & culture of their patients.

References

- References could be accessed through scan QR code.

