DIAGNOSTIC AND MANAGEMENT STRATEGIES OF THALASSEMIA IN INDONESIA

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DIAGNOSIS & MANAGEMENT STRATEGIES OF THALASSEMIA

Demography

Health insurance

Referral system

Thalassemia Community/organization

PROGRAM

?
DEMOGRAPHY OF INDONESIA

Area:
- 1,811,569 km² (land), > 17,000 islands
- 93,000 km² (inland seas: straits, bays, and other bodies of water)

Population:
- 266,610,180
- 56.7% lives on Java

Ethnic & linguistic groups: (300)
- Javanese 40.22%
- Sundanese 15.5%
- others 44.28%
National Referral Hospital = 14
Regional Referral Hospital = 110
• Type A = 3, Type B = 48, Type C = 52, Type D = 7
THALASSEMIA MANAGEMENT PROGRAM IN INDONESIA

• Diagnosis

• Therapy
  – “Safe” blood transfusion
  – Appropriate iron chelation

• Prevention
  – Screening
  – Prenatal Diagnosis
KEPUTUSAN MENTERI KESEHATAN REPUBLIK INDONESIA
NOMOR HK.01.07/MENKES/1/2018
TENTANG
PEDOMAN NASIONAL PELAYANAN KEDOKTERAN TATA LAKSANA THALASEMIA
BUDGET COVERAGE FOR THALASSEMIA

- 2010: Jampelthas → 50.6%
- 2014: National Health Insurance → 99.6%
  - Divided 5 regions → different cost
SERVICES FOR CATASTROPHICS DISEASE

DISEASE
- Renal disease
- Heart disease (invasive & non invasive)
- Cancer
- Blood disease (Thalassemia & hemophilia)
- Use of advanced medical devices

BENEFITS
- Accommodation, diagnostic, laboratory, other medical action for catastrophic as a major disease or It’s complicated condition
- MRI
- MSCT
- Radioisotope
- Radiotherapy

NO PAY FEES
BUDGETING

2015: 299,884,058,459
2014: 215,122,989,388

:BPJS Kesehatan, 2015
CODING OF THALASSEMIA (INSURANCE)

Severity Level 1

- Thalassemia
  - Cost: Rp. 1,816,056
  - $140

- Thalassemia + Cardiomyopathy
  - Cost: Rp. 2,564,936
  - $197

- Thalassemia + Cardiomyopathy (comorbid) + Malnutrition (complication)
  - Cost: Rp. 4,340,718
  - $334
• New policies (2017) → 40%
• Only transfusion and chelation: US $ 1,000 – 1,800 per month
HOW TO DIAGNOSIS THALASSEMAIA –BASED OF REFFERAL SYSTEM?

Ax & Physical examination → Routine blood examination

Level I

Hb Analysis

Level II

Thalassemia (+)

DNA analysis

Thalassemia (-), but still confuse

Level III

Management Thalassemia

Atmahkusuma et al, 2010
BLOOD TRANSFUSION

• “SAFE”
• NAT screening
  – only available in 4 big cities
  – Jakarta start 2015 for free
• Leukodepleted blood
• Blood filter
IRON CHELATORS

• 3 iron chelators
• Single or combination
• Cost? (US $ 1,000 – 1,800 per month)

Monitoring with ferritin level
THALASSAEMIA COMMUNITY

- VOLUNTEER
  - YTI-NGO
    - THALASSAEMIA FOUNDATION
      - ESTABLISHED 1987
      - 9 BRANCHES
      - UNDER STATE REG. BY MIN. OF LAW & HUMAN RIGHTS

- PARENT
  - POPTI
    - PARENTS ASSOCIATION
      - ESTABLISHED 1984
      - 47 BRANCHES

- PATIENT
  - PPTI
    - PATIENTS ASSOCIATION
      - ESTABLISHED 1993

OBJECTIVE

EXTERNAL RELATION

INTERNAL RELATION
THALASSAEMIA FOUNDATION ACTION PROGRAM

- Creating Patient’s Database across Indonesia.
- Thalassemia Campaign For the Community And All Stakeholders.
- Conduct meetings on regular basis with all branches across Indonesia to promote The Thalassemia Treatment And Service Insurance Program.
FREQUENCY OF BETA & HbE THALASSEMIAS CARRIER

Gambar 1. Peta frekuensi gen pembawa sifat thalassemia beta dan HbE di Indonesia

Jika dihitung menggunakan prinsip Hardy-Weinberg tentang frekuensi alel dari generasi ke generasi maka setiap tahunnya akan lahir 2500 bayi dengan thalassemia mayor. Andaikan saja ada 1500 bayi yang terdaftar setiap tahunnya, dapat dibayangkan berapa banyak anak thalassemia mayor, untuk 10 tahun ke depan yang harus dibiayai negara.

Gambar 2. Perkiraan jumlah anak dengan thalassemia mayor dengan perhitungan menggunakan prinsip Hardy-Weidberg


Lani, 2008
GENETIC SERVICES IN INDONESIA

• Molecular cytogenetic analysis has been done on research based
  – Eijkman Institute (research & services)
  – CEBIOR (Center for Biomedical Research) at faculty of Medicine, Diponegoro University, is also one of the leading centers providing genetic laboratory service in Indonesia since 1999.
  – Other centers, especially in Academic health center and Faculty of Medicine (Jendral Soedirman, UGM )

Arieani et al, Molecular genetic & Genom, 2010
FREQUENCY OF BETA & HbE THALASSEMIA CARRIER

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Data yang didapat dari seluruh rumah sakit pendidikan ternyata hanya terdaftar sekitar 7670 pasien thalassemia mayor di seluruh Indonesia. Distribusi thalassemia mayor di Indonesia dapat dilihat pada Gambar 2.

Lani, 2008
TARGET SCREENING/ PREVENTION PROGRAM

- Family with thalassemia major
  - Pregnancies woman
    - Preconception
    - Premarital
  - Massal screening

[National guidelines for Thalassemia, 2018]

- Eijkman Institute
- Indonesia Thalassemia Foundation with NGO (Rotary)
- Research by Trainee, PhD student
PRENATAL DIAGNOSIS

• Started in 1998
• Cases (2014) : 114

- High risk couple
- At 10-12 weeks
- Few places
- Collaboration: pediatric & adult hematologist, obstetrical gynecologist, laboratory
Increase thalassemia awareness:

- Curriculum
- Public:
  - Seminar and workshop
  - Thalassemia Icon
  - Media (TV, radio, newspaper, magazines)
  - Thalassemia bulletin (thalassemia foundation)
  - Social event: fun bike, fun rising
THALASSAEMIA PATIENT IN PERCENTAGE IN SOME OF INDONESIAN PROVINCES UP TO JULI 2017

WEST JAVA 40.2 %

CENTRAL JAVA 14.43%

EAST JAVA 9.13 %

ACEH 3.1 %

BANTEN 7.37 %

JAKARTA 7.83 %

KALTIM 1.48 %

UP TO JULI 2017

YTI-POPTI/INDS/2017
OBSTACLES

• The national program can not be optimal yet, due to demographic, culture, ethnic, diversity factors

• Increase in the number of new patients each year

• Diagnostic:
  – Limited number of laboratories (8 national referral hospitals/province)

• Treatment:
  – High cost
  – Inadequate quality and quantity of blood product
  – Monitoring iron overload
  – Under dose iron chelation
  – Limited of number hematologist
<table>
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<tr>
<th>OBSTACLES: GENETICS AND GENOMIC MEDICINE IN INDONESIA</th>
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<tr>
<td>• Lack of awareness of health professionals and government</td>
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<td>• Lack of interest of researcher on genetic diseases,</td>
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<td>• limited research funding,</td>
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<td>• limited access to high technology,</td>
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<td>• low national health budget and low income family.</td>
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<td>• But, several research centers still managed to do some studies and few numbers of genetic testing.</td>
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<td>• Several collaborations with countries abroad have been done to overcome some obstacles.</td>
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<td>• Mentoring and collaborations are needed to enable Indonesia in doing so.</td>
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Ariani et al., Molecular Genetic & Genomic Medicine, 2017
1. The number of thalassemia cases are increasing
2. Thalassemia has become a priority program in Indonesia
3. Thalassemia community/organization very important role especially related to the population-based programs, negotiations, lobbying with the government
4. Indonesia has improved on thalassemia management program but it still need a lot of budget to support
5. Prevention is a MUST. Carrier screening protocol and prenatal testing have to be designed on a regional basis
Acknowledgments

1. Pediatric hematology-oncology group work unit, Indonesian Pediatric Association
2. Indonesian Thalassemia Foundation and Parent association of thalassemia
3. Indonesian hematology-blood transfusion association