THE JOURNEY OF THALASSAEMIA PATIENT IN SEEKING TREATMENT IN MALAYSIAN HEALTHCARE

Noor Syahireen MOHAMMED[1], Asrul Akmal SHAFIE[1], Jacqueline Hui Yi WONG[1], Hishamshah Mohd IBRAHIM[2]

[1]School of Pharmaceutical Sciences, Universiti Sains Malaysia, [2]Paediatric Institute, Hospital Kuala Lumpur

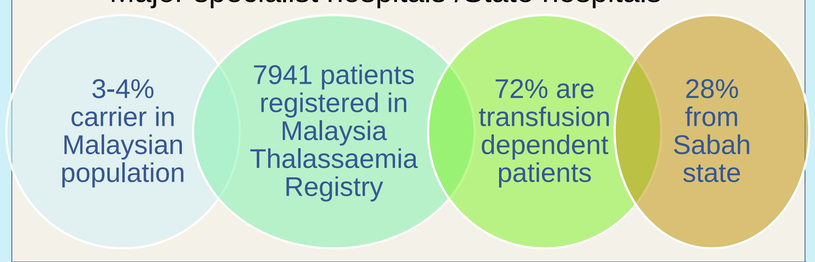
Introduction

Thalassaemia

- Thalassaemia is a complex inherited blood disorder and has high prevalence in Malaysia.
- Thalassaemia can be classified into two types, which are alpha thalassaemia and beta thalassaemia.
- Clinically divided into transfusion-dependent thalassaemia (TDT) and non-transfusion dependent thalassaemia (NTDT).
- There are 7848 TDT patients in Malaysia requiring regular blood transfusions.

Healthcare in Malaysia

- Malaysia provides universal healthcare access to its citizen
- Public healthcare is tax-funded and centrally administered
- Public hospitals divided into several categories:
  - District hospitals
  - Minor specialist hospitals
  - Major specialist hospitals /State hospitals



Significance of study

1) Provide insight for policymaker to improve service delivery and achieve treatment goal
2) No other study focusing on thalassaemia patients' perspective while getting treatment in Malaysian public hospitals

Objectives

1) Explore the journey of transfusion-dependent thalassaemia patients in seeking treatment in Malaysian public hospitals.
2) Identify the loopholes in current treatment pathways to increase quality of service delivery
3) Identify the challenges patients encountered in seeking treatment

Methodology

Study design	• Qualitative study • Patient Journey Mapping
Population	• Adult thalassaemia patients • Caregiver to paediatric patients
Sampling technique	• Purposive
Inclusion criteria	• Diagnosed with thalassaemia for >1 year • Undergo regular transfusion at hospital
Ethical consideration	• Approved by Malaysia Medical Research Ethics Committee • Participant's identity kept anonymous
Study sites	• 7 public hospitals across 5 states



Figure 1 Map of study sites

Patient Journey Mapping

- Patient journey mapping provides healthcare provider to see and understand the experience of patient or journey during an episode of care.
- Patient experience formed during the moments when the operation (health service) and patient meet.
- This is based on mapping a consecutive series of 'touch points' between the patient and the service where patient experience is actively shaped.
- The resulting integrates both physical which is the functional aspect and also emotional journey of the patient in order to capture patient behaviour, feelings, and motivations across the whole episode of care.
- The advantage of this method is that it will represent a comprehensive patient's experience from the patient's perspective itself.

Analysis

- Audio recording were transcribed verbatim
- The recordings were transcribed by different investigators and transcriptions were compared to ensure validity

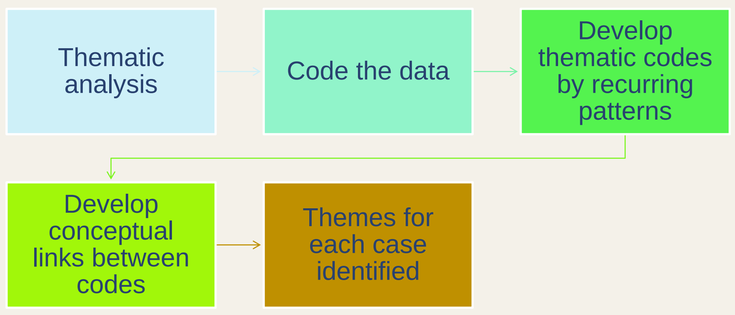


Figure 2 Flow of thematic analysis

Results & Discussion

1) 23 participants from various hospitals in 5 states were interviewed.
2) Findings showed similar patient flow in most public hospital
3) Referring to Figure 3, major difference (red box) some centre, pre-transfusion blood tests and transfusions will all be done on the same day whilst some may need to come again on a different day (due to staff insufficiency and department management or depends on availability of blood supply)
4) 82.9% participants reported to having multiple visits to hospitals causing loss of productivity and financial strain.
5) Participants from rural areas reported difficulty having to take several modes of public transportation to reach the hospitals.

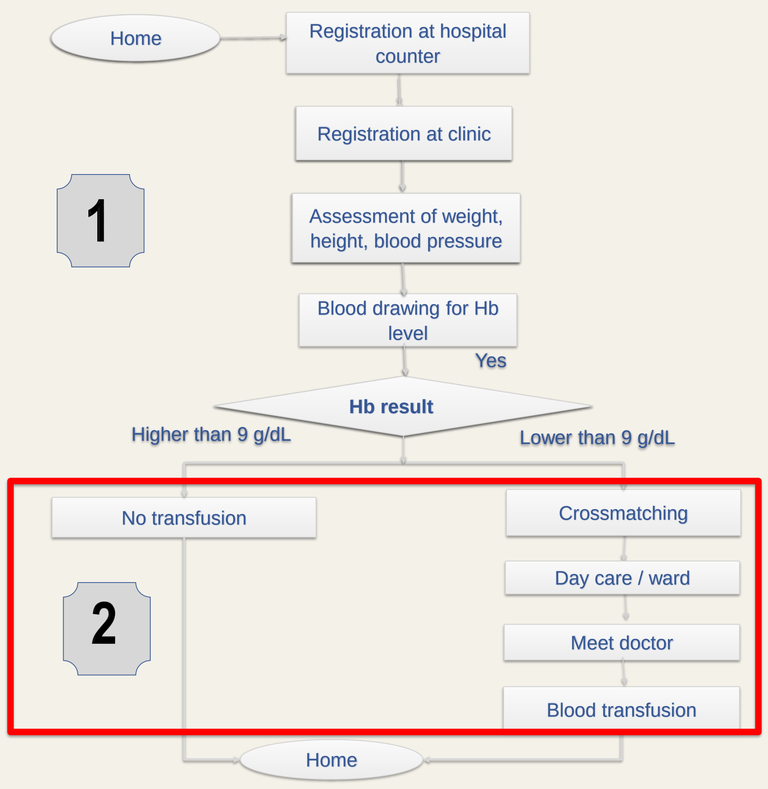


Figure 3 Thalassaemia patient journey flow in Malaysian public hospital

Results & Discussion

6) Five themes were identified from all interviews. There are
   i. Access to diagnosis and treatment
   ii. Awareness and knowledge on thalassaemia
   iii. Challenges during their journey in seeking treatment
   iv. Emotional journey
7) All participants reported satisfactory access to initial diagnosis and treatment in public healthcare.
8) Overcrowding in public hospitals put further strain in patients' adversity.

Table 1 Themes identified

Theme	Quote
Good access to treatment and screening	*"After not gaining any weight, I brought her to the health clinic where they took some blood and they said she got thalassaemia."* ***Caregiver, 36 years old*** *"We got the entire family screened after my brother was diagnosed with thalassaemia."* ***Caregiver, 48 years old***
Poor awareness and lack of knowledge on disease	*"A lot people in my area don't know what is thalassaemia"* ***Adult patient, 42 years old*** *"I wonder, is thalassaemia an inherited disease? Or else how can I get this disease? My parents had never done a screening on this disease before, so I do not know if I inherit it from them."* ***Adult patient, 28 years old***
Challenges in lack of blood supply and hospital facilities	*"After blood check like today, sometimes we had to wait till up to two weeks for blood supply"* ***Caregiver, 29 years old*** *"If we were late, there'll be no more seats."* ***Caregiver, 59 years old***
Emotional journey	*"Having to come here several times for check-up costs me quite a lot of money but still I have to follow procedure"* ***Adult patient, 20*** *"It is hard sometimes leaving work too many times to come to hospitals for blood tests and again for transfusion"* ***Adult patient, 22***

Conclusion

This study reveals vital insight of patient's challenges in getting treatment in public hospitals. The findings suggest some correctional measures must be taken by service provider to ensure optimal healthcare delivery to thalassaemia patients in Malaysia.

References

1.Ministry of Health Malaysia. Clinical Practice Guideline: Management of Transfusion Dependant Thalassaemia. 2009.
2. Jaafar S, Noh KM, Muttalib KA, Othman NH, J. H, Maskon K, et al. Malaysia health system review. 2013.

Contact Information

Noor Syahireen Mohammed
syahireenmohammed@gmail.com
School of Pharmaceutical Sciences,
Universiti Sains Malaysia