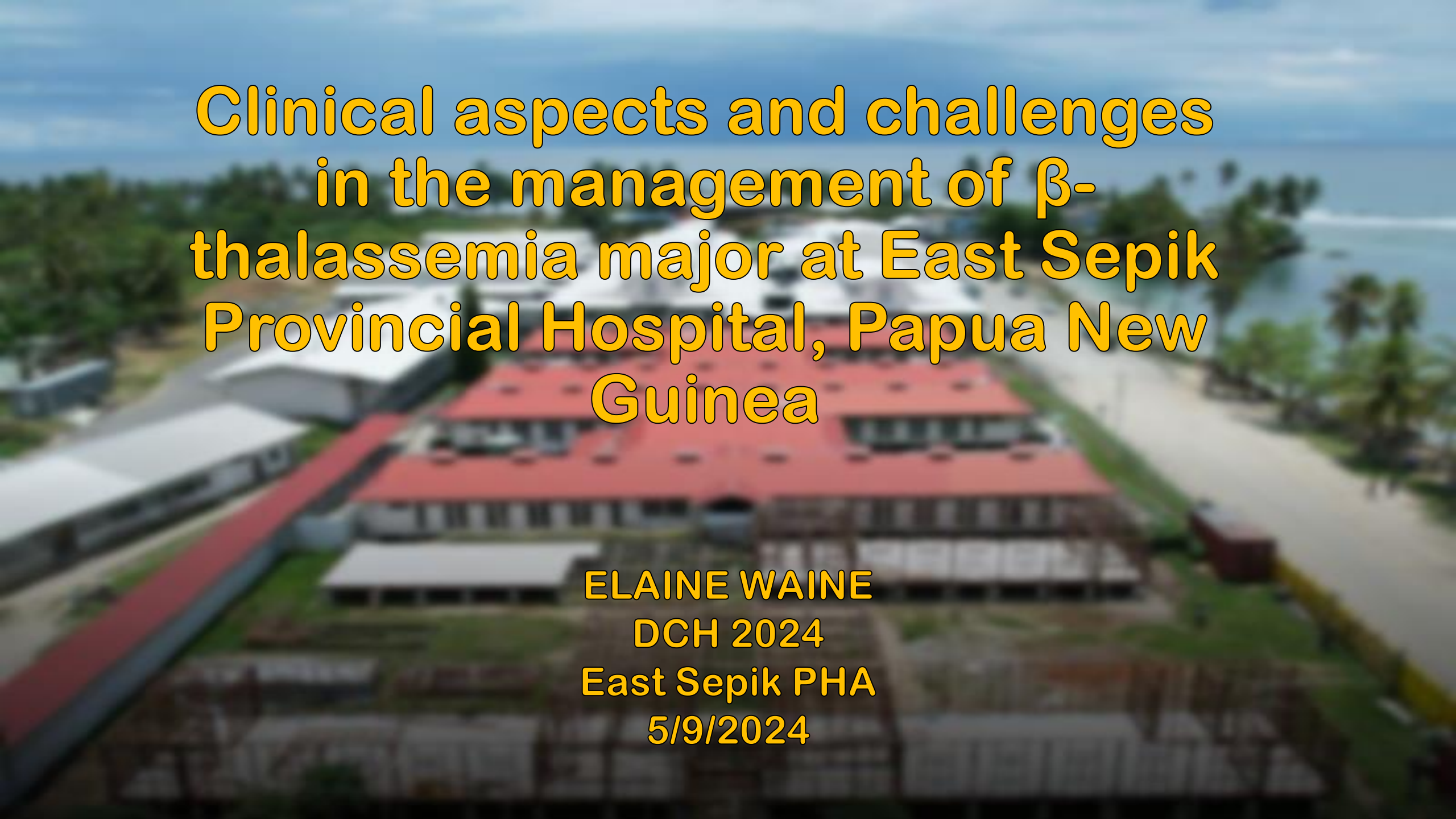

Clinical aspects and challenges in the management of β-thalassemia major at East Sepik Provincial Hospital, Papua New Guinea

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DCH 2024
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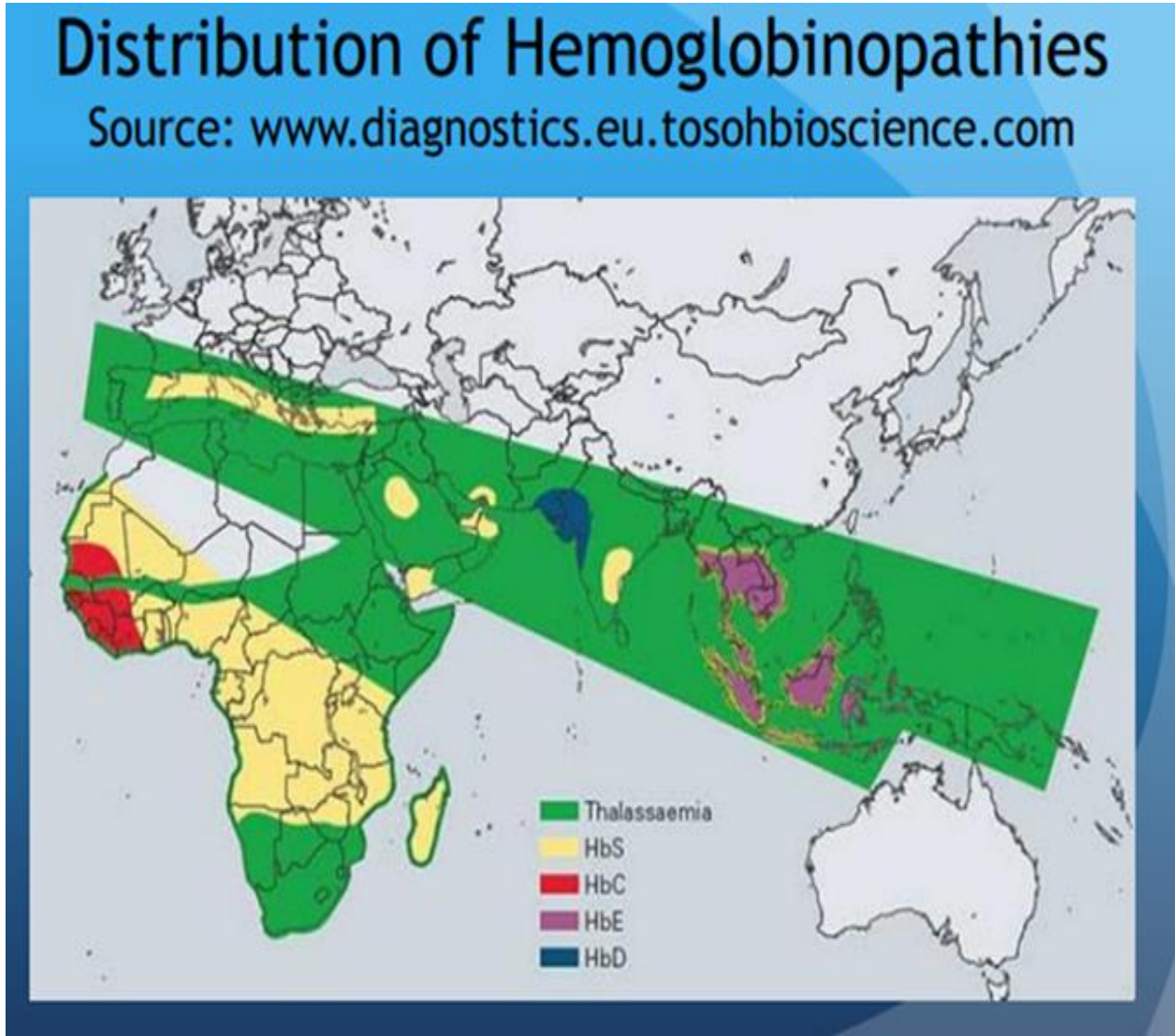
INTRODUCTION

β-thalassemia

- 1925 → first described by Dr. Cooley (Cooley's anaemia) → thalassemia belt.
- 1961 → First reported in PNG.
  - **Sepik region had the 3rd highest carrier rate in 1980s**.
- East Sepik Province (31 patients)
  - **All transfusion-dependent.**



- This study was designed to:

  - **Identify problems and difficulties faced by families** of children affected with this disorder & look at ways to rectify them.

  - Determine the **burden placed on the hospital system** due to frequent readmissions, prolonged hospital stays and repeated blood transfusion.

METHODS

- **4 month cross-sectional** study at ESPH of children with β-thalassemia.
- Structured questionnaires used to interview parents.
- Costs of services provided at the hospital was obtained from:
  - Ration store team
  - Blood transfusion services
  - Pharmacy team
  - Hospital's administration team.
- Data →entered onto Microsoft Xcel spreadsheet analyzed.
- **Ethical clearance** was given by CEO – ESPHA
- **Informed consent** was obtained from the parents.

RESULTS

Table 1. DEMOGRAPHY OF THE PATIENTS (n = 21)		
Gender	n	%
Female	10	48
Male	11	**52**
Age in years		
0-5	7	**33**
6-10	9	**43**
≥ 11	5	24
Age at diagnosis		
<2	13	**62**
> 2	8	38
District of origin		
Yangoru - Sausia	12	**55**
Other 5 districts	9	45

64% live in remote villages → spend between K30 to K100 to/from hospital.

	n=21	%
ABO Blood Group		
A	6	29
B	8	**38**
AB	2	10
O	5	24
Co-infections		
ALRTI	7	**33**
Malaria	5	**24**
Sores	3	14
Diarrhea	1	5
None	2	10
Heart Failure	20	**95**

Table 2. BACKGROUND OF PARENTS/CAREGIVERS (n = 22)			
Knowledge on thalassemia		n	%
Yes		8	36
No		14	**64**
Education level			
None		6	14
Primary Level		15	**34**
Secondary		19	**43**
Tertiary		4	9
Marital status			
Married		20	**91**
Widow/Widower		1	5
Separated		1	5
Employment Status			
Employed with fortnightly salary		8	36
Unemployed/informal sector marketing and income		14	**64**

Table 3. PROBLEMS & DIFFICULTIES EXPERIENCED BY PARENTS (n = 22)		
1. Family support	n	%
Yes	5	23
No	17	**77**
2. Financial Difficulties		
Yes	20	**91**
No	2	9
3. Blood Donation		
Volunteer donors	1	5
Pay donors	21	**95**
Pay K20-40		24
Pay K50		14
Pay > K100		**62**
4. **Experienced stigma**	16	**73**
5**. Limitation to family activities due to treatment plan**	11	**50**

Impact on the quality of life (n = 22 careivers)

- All caregivers experienced physical and emotional stress.
- Over 80% experienced sadness, anger, anxiety, helplessness and worry.
  - Between 80-95% of parents worried about the following:
    - Early death,
    - delayed blood transfusion
      - (86% have had arguments when blood was not transfused soon after admission).
    - repeated painful procedures, and
    - blood transfusion infection.

Burden on hospital system:

- Length of hospital stay (LOHS)
  - **Total days** (n = 21): **267 days**
  - Average: 12 days
  - Minimum: 2 days , Maximum: 47 days.
- Hospital costs (daily):
  - per guardian: **K37.90**
  - per patient : **K 130.90**
- Hospital costs over study period:
  - Estimated at **K956, 580.90**

Figure 1. Cost of ESPH services for β-thalassemia patients & guardians (n=21).

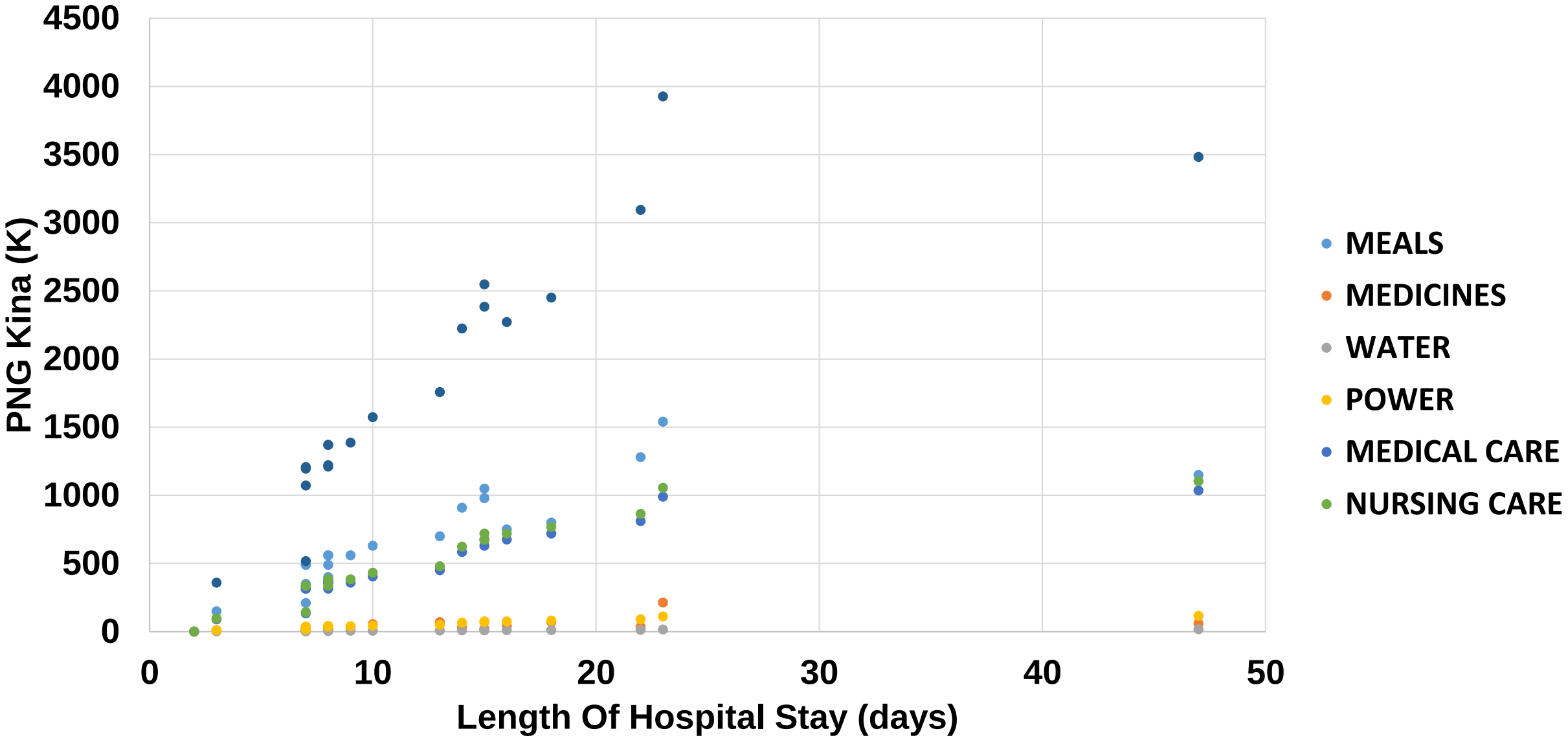
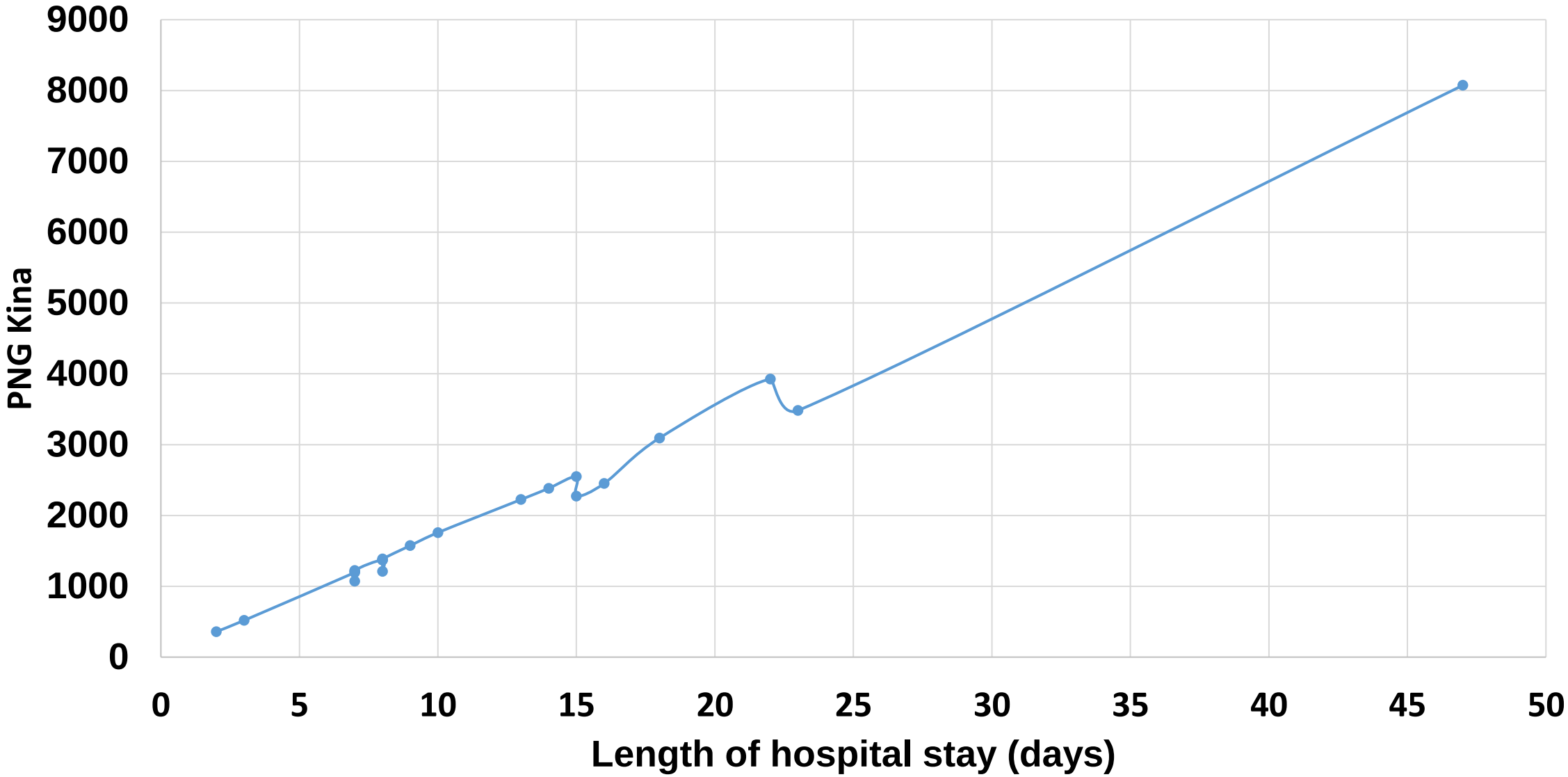


Figure 2. Total cumulative hospital cost of inpatient care.



DISCUSSION

- Parents have limited knowledge on illness.
- Parents experience financial, physical, emotional and social stress as well as stigma.
- Other similar studies also identify these problems and challenges faced by caregivers Nagiria *etal* (10) in 2021 and Yousuf *etal* (14) in 2022.
- Cost of care is a burden to the hospital system;
  - Almost a million kina to look after affected children. **(could be more)**
  - It would cost more if all 31 patients were admitted and length of stay prolonged due to delay in receiving blood transfusion.
- Most children with β-thalassemia major presented with heart failure.
  - Blood bank services stressed to meet high demand.
  - Pediatric Dept. is overwhelmed.
- Despite prolonged length of stay patients receive 2 to 3 units intra-venous packed cells (IVPC).

Relieving burden;

- Knowledge → prevention, understanding the illness thus influence their quality of life. Advocate for family planning for families >1 affected child.
- Relieve hospital burden:
  - Conduct monthly review of β-thalassemia patients as outpatient.
  - Hospital need for a thalassemia bay.
- Awareness/Funding:
  - Recruit more volunteer donors.
  - Establishment of Blood Bank/Transfusion services (BTS) at district hospitals.
    - Patient transfuse sooner than wait.
    - Closer to the villages → save costs of travel/inpatient costs.
    - More closer to family → save costs for paying donors, more family support when closer.

CONCLUSION

- There is overwhelming stress on the parents, caregivers and hospital system.
- Empowering caregivers with knowledge of thalassemia; conducting more awareness; opening more BTS at district level and involving charity organizations to assist will relieve the huge financial strain on families/hospital.
- Availability of blood at the Hospital would alo lead to shorten hospital stay and relieve some financial burden.

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