



Pakistan

The situation from the TIF view





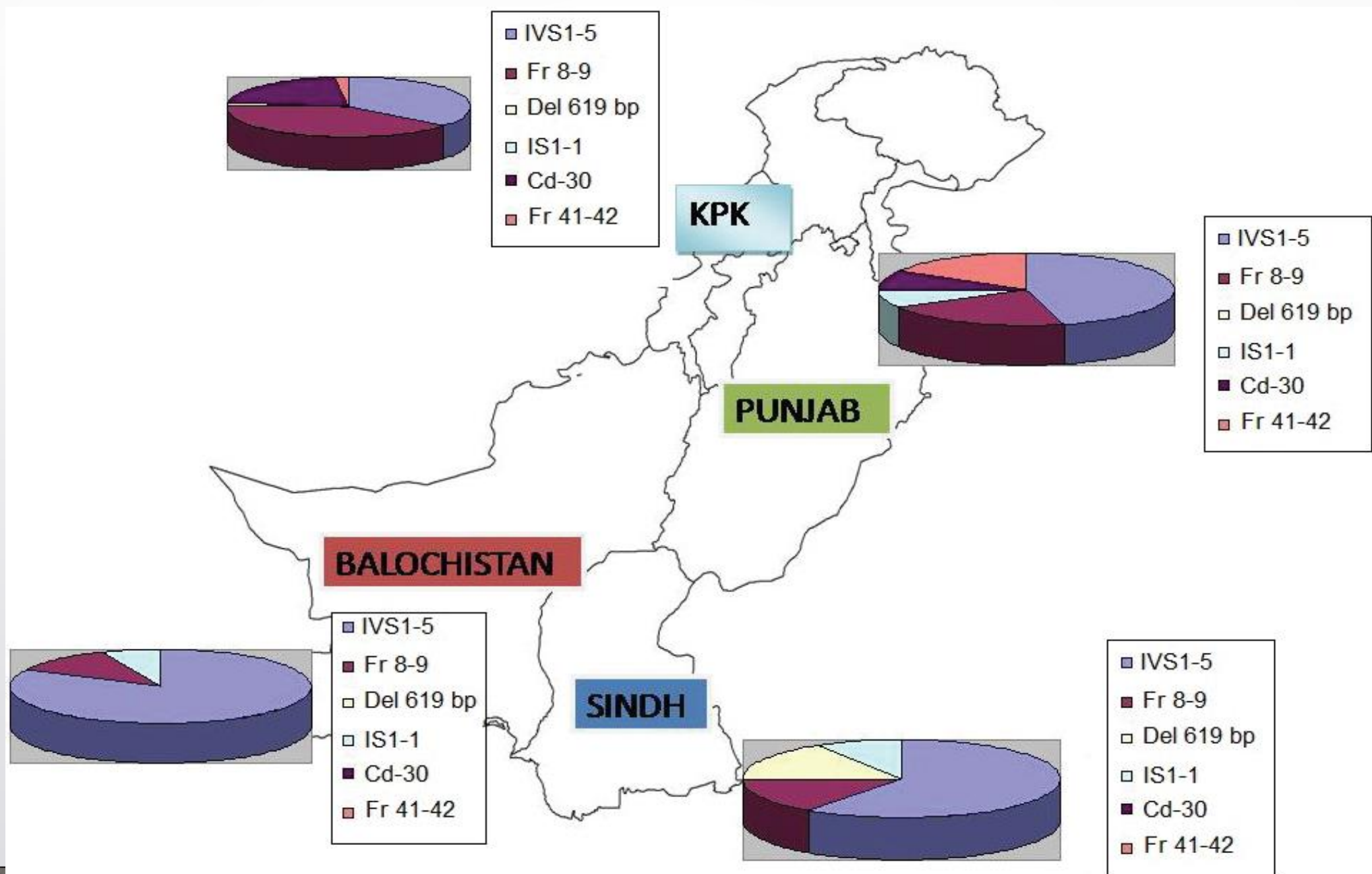
Overall burden of disease in Pakistan

- Alpha thalassaemia carriers 8.3%
 - Beta thalassaemia carriers 5-6 %
 - HbE carriers 0.3%
 - HbS carriers 0.25%
- Out of 4.5 million births/year
- 4443 will have a beta thalassaemia syndrome
 - 344 will have a sickle cell syndrome

Micromapping of Pakistan



Tribal carriers of beta thalassaemia:	
Punjabis	4.6%
Pathan	5.2%
Sindhi	4.3%
Beluchi	8.0%
Urdu speaking	5.3%





Number of patients

- No national registry – so exact numbers are not known
- Estimates of 100000 are quoted
- From centre reports about 22000 are registered
- The annual collection of blood in Pakistan is estimated to be 3 million. It is estimated that about 40% of these donations are transfused to thalassaemia patients.

From a report by Prof Hassan Abbas Zaheer



The health care system

- 25% is provided by state run services 75% by private initiative
- For thalassaemia since governmental coverage was not universal, the NGOs developed their own services
- NGO services include blood banks, donation campaigns, free or reduced cost iron chelation
- The initiative for creating a Non Profit Organisation was by the late Mr. Nazim Jiwa in 1978 in Karachi, who founded the Fatimid Foundation and was a founder member of TIF.



NGO SERVICES

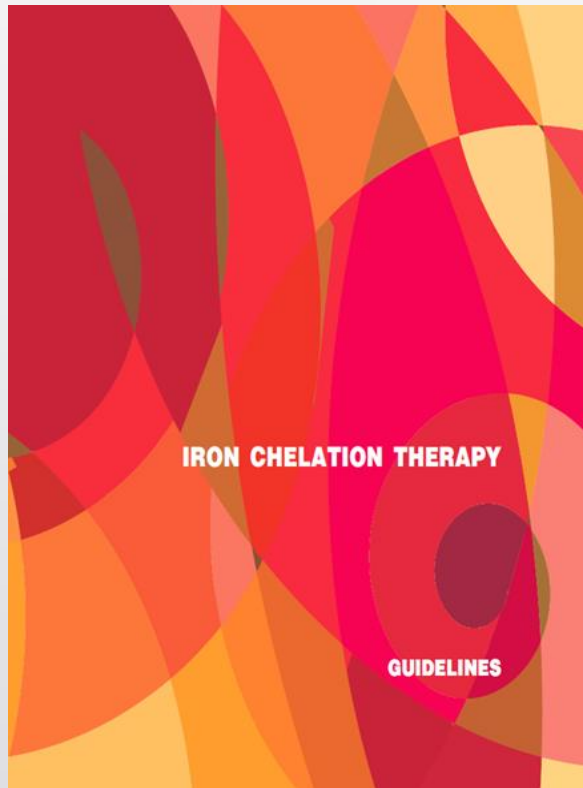
- Who is responsible for quality control? (especially of blood services)
- What iron chelating agents do they use (generics vs brand)?
- What is the quality of clinical care?
- Is there multidisciplinary support? (evidence in some centres)
- Who monitors outcomes?
- 96% of patients have difficulty finding donors & 44% of patients not using iron chelation since they cannot afford – *Glilani I et al. PJPB Dec 2011*
- In the meeting organised in 2016 public private partnership was agreed – with the governmental agencies to monitor and audit. Is this in effect?



Standards of care

- Pre-transfusion Hb >9g/dl only selected patients
- Ferritin measured every 6 months (standard is every 3 months)
- MRI only selected patients occasionally
- Rarely seen by a specialist
- HBV infections in thalassaemia patients 3%
- HCV infection in thalassaemia patients 55.73% (100% of patients over 20 years) – *Saeed U et al. Virol Res & Treatment 2015:6*

Standards of care



- Are the Pakistan standards of care widely available?
- Are they kept by the NGOs?

Standards of care

- Quality Audit Meeting for the Auditors of Thalassaemia Centre Blood Banks
January 29, 2018, Marriott Hotel, Karachi



Conclusion

The blood transfusion regulation sector has demonstrated remarkable achievements in the last 2-3 years through commitment and devotion and no resources

Institutionalization of the blood transfusion regulation system backed with political commitment and the consumer (patient & physician) demand for improved standards can yield tremendous results in terms of blood safety



Standards of prevention

- Screening by provincial government of Punjab covers 56% of the population (PTPP)
- Screening has started in Sindh and Baluchistan?
- Genetic counselling – by whom?
- Prenatal diagnosis available to a limited number of at-risk pregnancies



The Thalassaemia Pakistan Federation

- The Federation was established in 2004 and has 46 member societies working throughout the country.
- A trade union of NGO s
- Inadequate patient representation
- Active in prevention?

Asking questions will lead us to the true situation
Thank you for being with us



Lahore Fort