Epidemiology and social costs of haemophilia in India

India lacks a national policy on the prevention and control of genetic disorders. Although the hemoglobinopathies have received some attention, there is very little data on the epidemiology of other genetic disorders in India. Haemophilia, an inherited single gene disorder with an incidence of 1 per 10,000 births, manifests as spontaneous or trauma-induced hemorrhagic episodes in patients, progressing to chronic disability and premature mortality in untreated patients or patients with sub-optimal treatment. Although the genetic basis of this disorder has been well studied in India, data on the number of patients, trends of the disorder in India, social costs of the condition and opportunities and competencies for offering genetic counseling through a public health programme have not been reported. Our research using haemophilia demonstrates the need for prevention and for the provision of care for patients. We have reported that India harbors the second highest number of global patients with bleeding disorders. The number of patients reported annually from India during the last five years, is more than those being reported from developed nations.

Completed /ongoing studies:

**Trends of haemophilia in Maharashtra, India:** India has the third highest global number of patients. We are analyzing twenty year data on trends of haemophilia in the state of Maharashtra, India. Using sixteen key variables, our analysis shows increasing annual case registrations, increase in the number of moderate and mild haemophilia cases, cases of other bleeding disorders, increasing registration of female patients, increasing numbers of patients from rural areas, earlier age at diagnosis—all indicative of improving diagnosis and increasing prevalence of the disorder. Our estimates suggest that there may be about 77,000 patients with haemophilia A and B in the country, even as there is no provision for prevention or treatment for these conditions.[Ref 1,5,8,10]

**Treatment and out of pocket expenditure:** Using a follow up study, we analyzed bleeding patterns, treatment and out of pocket expenditure on haemophilia treatment. The results showed that due to financial reasons, only one in four bleeding episodes were treated by families. Annualized bleeding rate was 10.8 for patients with severe hemophilia. If all bleeding episodes were to be treated, the monthly expenditure would range from 25 to 255 times the monthly income of families.[Ref 4,3]

**Disability in patients with haemophilia:** Lack of treatment of haemophilia results in progressive disability. The consequence of lack of treatment was measured in a study that estimated the prevalence and risk factors of disability amongst patients attending three clinics in Western India and two clinics from Eastern India. Only nine of 148 patients were free of disability. The proportion of disability free patients in the 5–12, 13–24 and 25+ age groups were 14.3%, 4.4% and 0% respectively.[Ref 6]
Hemophilia genetics: A retrospective analysis from pedigree data indicated that in case of familial haemophilia, there was no significant reduction in the number of families with more than one haemophilic son over a generation. In families, without a history of haemophilia, a reduction in the number of families with more than one affected son was observed. This indicated that genetic counselling was not effective in families with history of haemophilia. A more recent study demonstrated the possible impact of genetic counseling, as there was a significant reduction in the number of families with more than one affected son. (More than one son with haemophilia would indicate the lack of outreach of genetic counseling services) [Ref 2,7,9]

Psychosocial intervention for improving the Quality of Life of parents of patients with haemophilia: This study measures the QoL of parents of children with haemophilia. The study has developed and is testing the impact of a contextualized psycho-social intervention tool in impacting the QoL of parents of children with haemophilia.

Publications :
1. Kar A, Phadnis S, Dharmarajan S, Nakade J. Epidemiology and social costs of haemophilia in India. ( Ind.J.Medical Res. ms.in press,)
2. Nakade J, Potnis Lele M and Kar A Reduction in families with more than one son with haemophilia in the Indian state of Maharashtra (Haemophilia, ms in press).