

# Employment and workplace issues in haemophilia in Northern India- A review of 95 case studies

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## OBJECTIVES

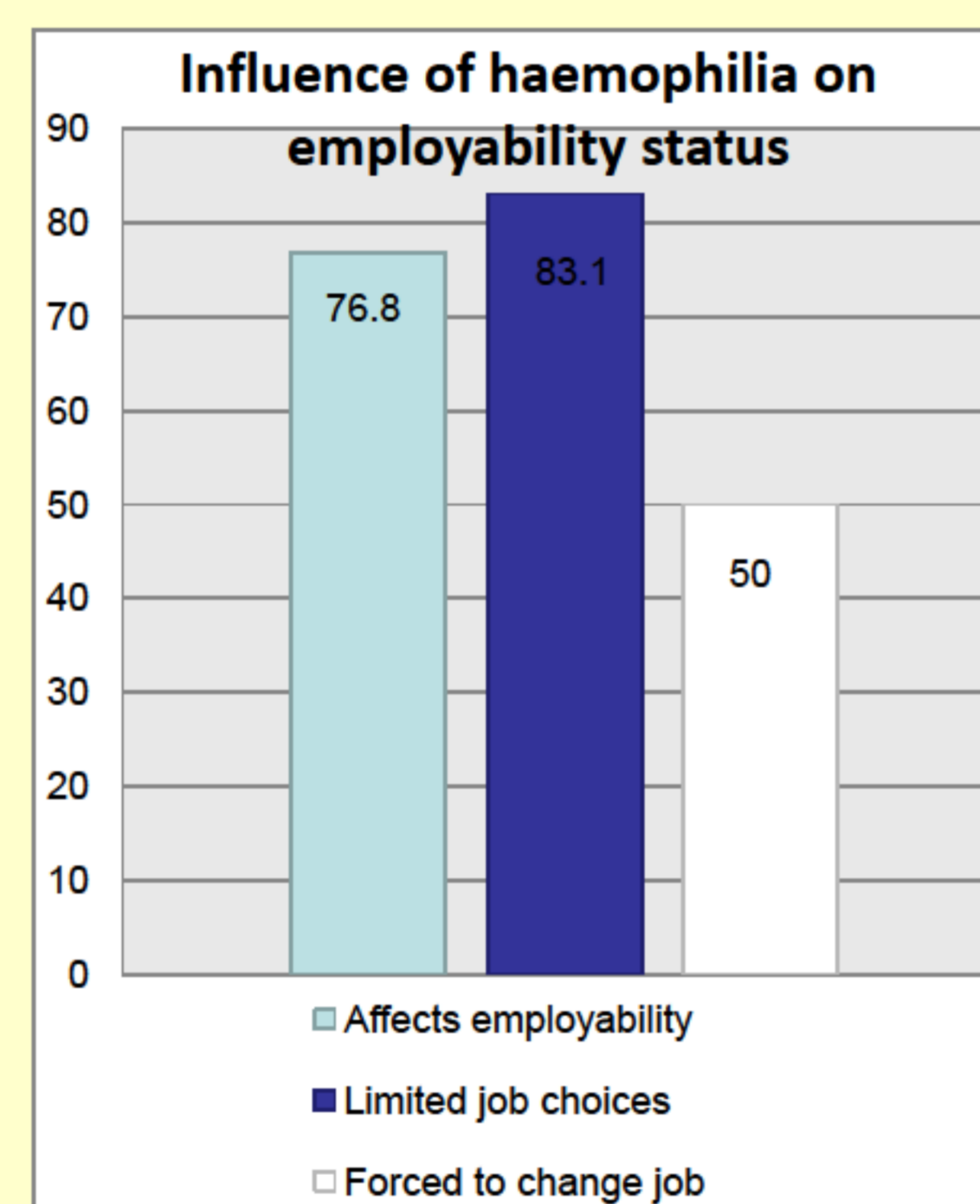
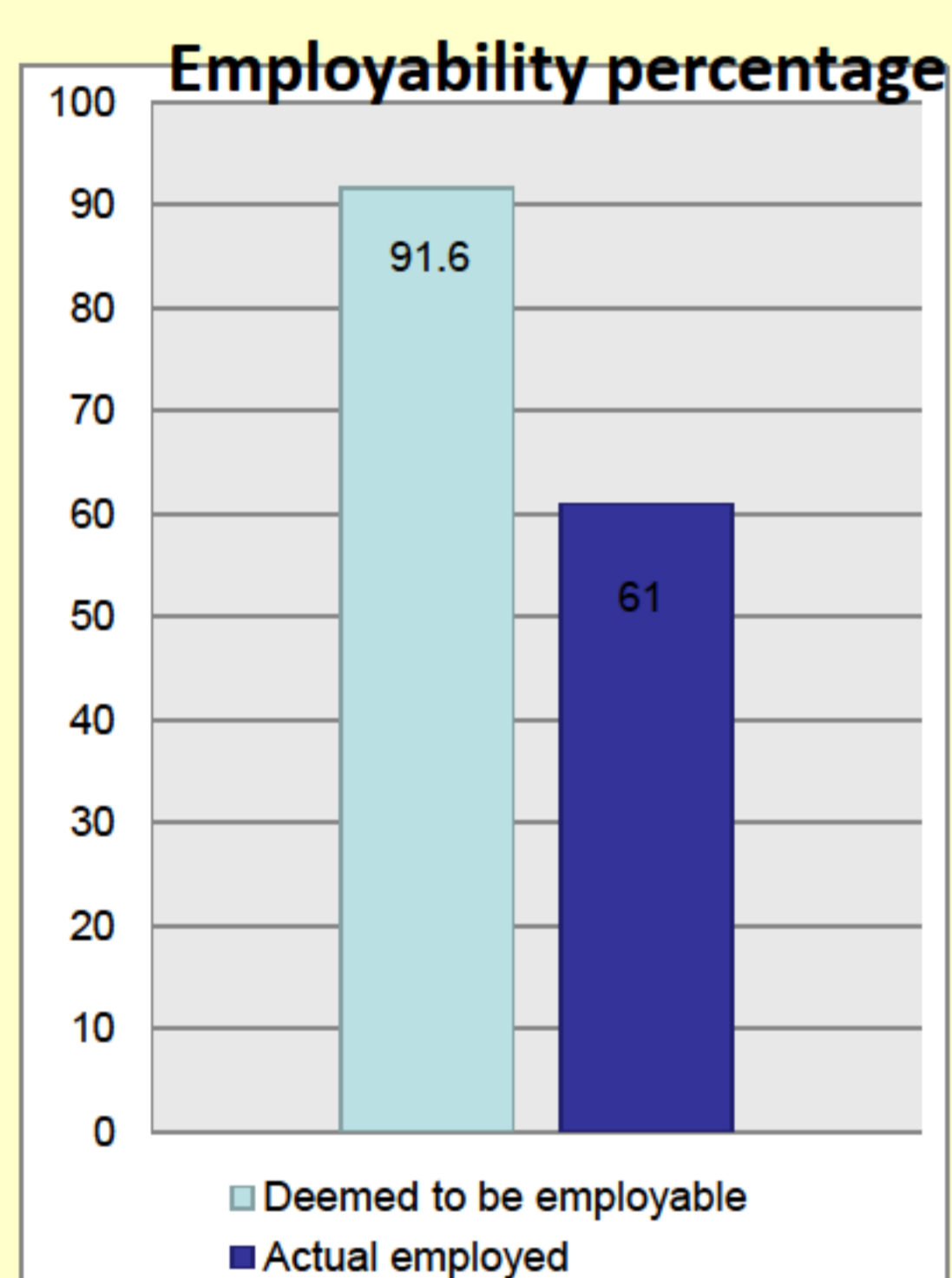
Haemophilia with musculoskeletal disabilities from inadequate treatment, may affect employment and workplace issues in developing countries. This paper deals with the perceptions amongst haemophilia community on the impact of haemophilia on their employability and occupational environment.

## METHODS

From the 1,620 haemophilia patients in our Haemophilia Centre, 95 consecutive potentially employable cases were assessed on a pre-designed, structured 15-point questionnaire assessing their perceptions on employability, workplace environment and haemophilia.

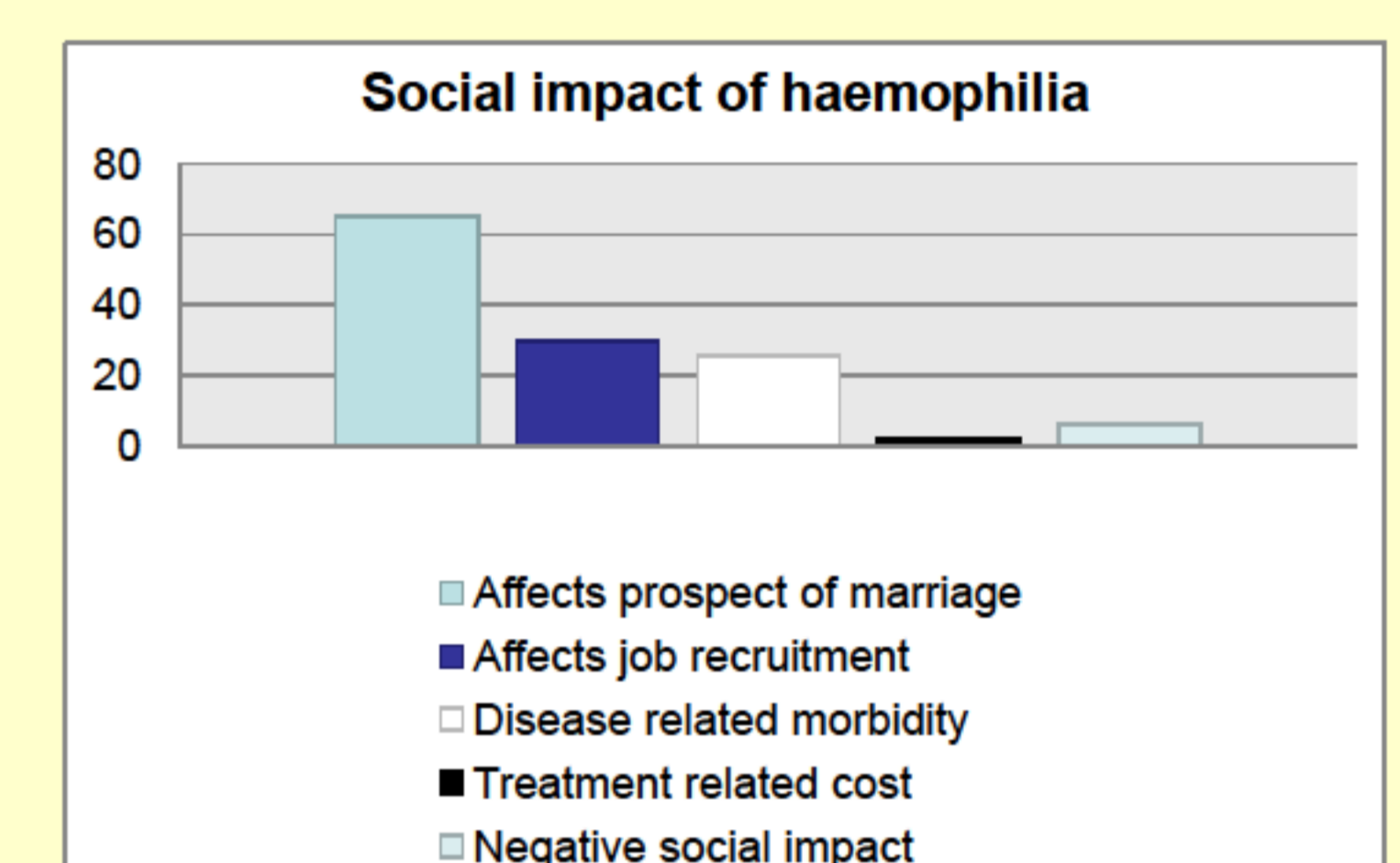
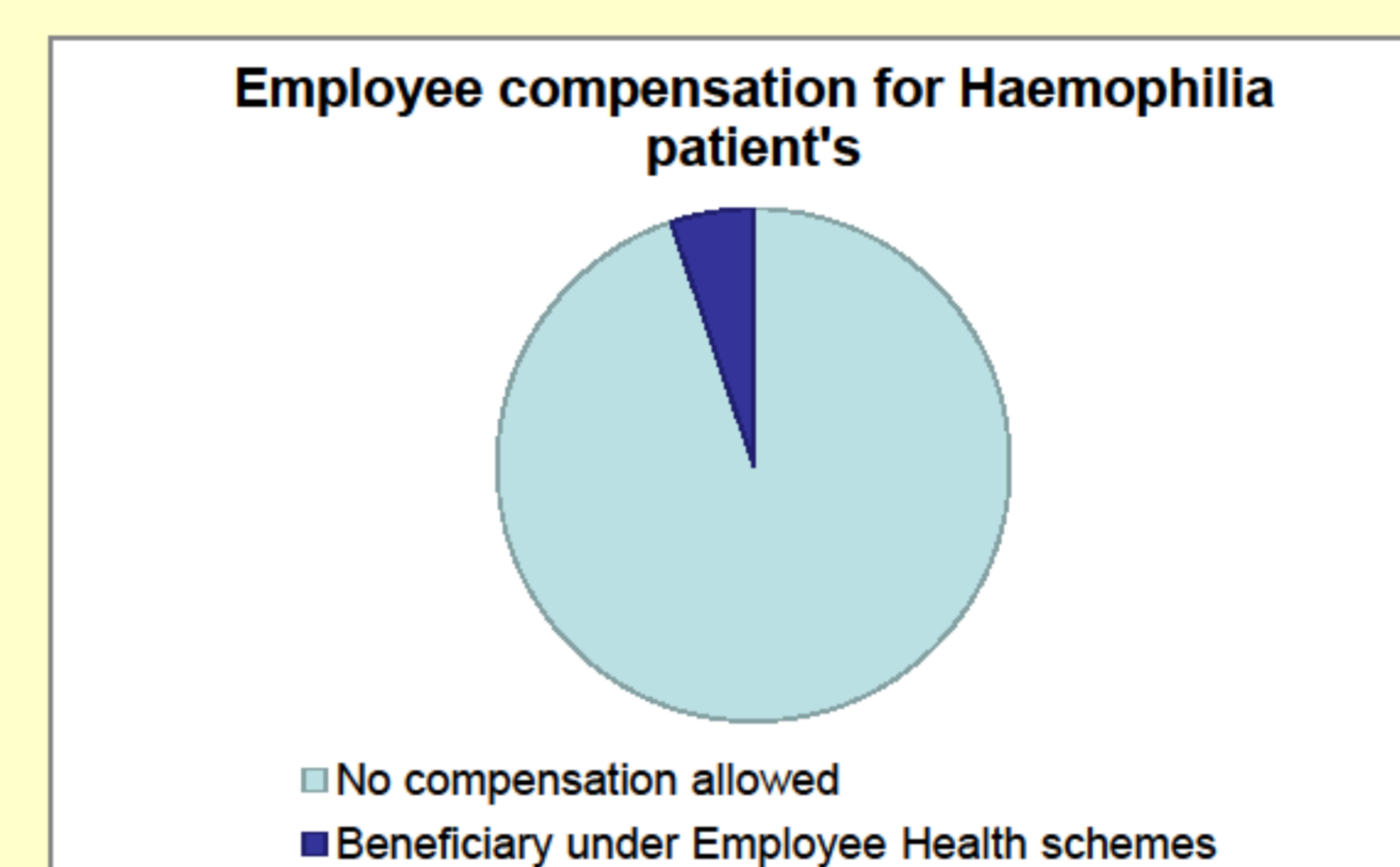
## OBSERVATION AND RESULTS

Mean age of the subjects was 29 years, range 18-58. Although 87 (91.6%) deemed themselves employable, **only** 53 (61%) were employed. Haemophilia was perceived to affect employability by 73 (76.8%) subjects whereas 79 (83.1%) felt their job choices were limited by it esp. when disease was severe (53.1%). Sixty three (66.3%) suffered unemployable condition for a mean period of 24.9 months, whereas 47 (50%) were forced to change their jobs repeatedly.



Social discrimination at workplace attributable to haemophilia was faced by 54 (56.8%), even when 74 (77.9%) found their fellow co-workers to be understanding and helpful. Fifty three (55.8%) believed workplace also impacts the haemophilia

disease state, medically alone in 36 (73.4%) and more widely (medically, socially and financially) in 6 (6.3%).



The employer did not provide for haemophilia care in 90 (94.8%) instances and only 5 patients (5.2%) were beneficiaries under employees' health scheme of State.

Haemophilia was believed to affect prospects of marriage (65.2%). Amongst 18-48 year olds, 44 (51.8%) were unmarried.

Haemophilia affected job recruitment adversely for 29.8% subjects, disease related morbidity (25.5%) and treatment-related cost issues (2%). Negative social impact of haemophilia was felt by 6.1%.

## CONCLUSIONS

Presence of haemophilia has varied impacts on employability, its sustainability, and workplace environment and is generally adverse when haemophilia care is excluded from the medical benefits provided by employer. Considering that an adult may spend a third of his life in a job, the issues of employability, workplace and haemophilia are central but often neglected in developing country.

## REFERENCES:

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2. H. K. Hartl, S. Reitter, U. Eidher, H. Ramschak, C. Ay, I. Pabinger. The impact of severe haemophilia on the social status and quality of life among Austrian haemophiliacs, *Haemophilia*, 2008, 14, 4.

