



Education in People with Hemophilia – Insights from the PROBE Study




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Alexandra Kucher 1; Chatree Chai-Adisaksopha 2,3; Randall Curtis 4; Neil Frick 5; Alfonso Iorio 6,7; Michael Nichol 8; Declan Noone 9,10; Brian O'Mahony 11,12; David Page 13; Mark W. Skinner 6,14; Jeff Stonebraker 15



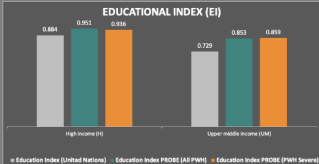
INTRODUCTION

Education is one of the key components relating to quality of life. The aim of this analysis was to examine the reported educational level of men with hemophilia in the Patient Reported Outcomes Burdens and Experiences (PROBE) study and compare it to the national average reported by the United Nations Development Programme (UNDP).




RESULTS

- Mean (SD) number of years of education was 15.5 (4.5) years with a range of 2-33 years
- GNI: High Income - 15.6 (4.3); Upper Middle-Income - 15.5 (4.7)
- There is not significant difference in years of education reported between severe PWH and mild/moderate PWH by country or GNI region.
- United Nations Development Programme Educational Index (EI):
 - High Income (0.884)
 - Upper Middle-Income (0.729)
- PROBE Educational Index (EI) for all PWH:
 - High Income (0.951)
 - Upper Middle-Income (0.853)
- PROBE Educational Index (EI) for PWH with Severe factor:
 - High Income (0.936)
 - Upper Middle-Income (0.859)



CONCLUSIONS

EI calculated on PROBE data indicates that PWH aim to receive a higher education than those in the general population. This finding may be due to selection bias for the PROBE population or to PWH pursuing higher education in the face of career limitations imposed by hemophilia to increase their quality of life. Further investigation is required to understand the finding.



METHODS

UNDP Educational Index (EI), reports the highest degree of education an individual has completed. PROBE collects self-reported data on years of education.

Data set information:

- Data from Phase 1, 2 and 3
- People with hemophilia (PWH) > 25 years of age
- 746 people with hemophilia (PWH) from 17 countries
- Mean (SD) age of 45.4 (14.7)
- 80% - Hemophilia A
- 65% - Severe hemophilia
- Data grouped by country and Gross National Income category

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INSTITUTIONS and ACKNOWLEDGMENT

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PRESENTED AT:



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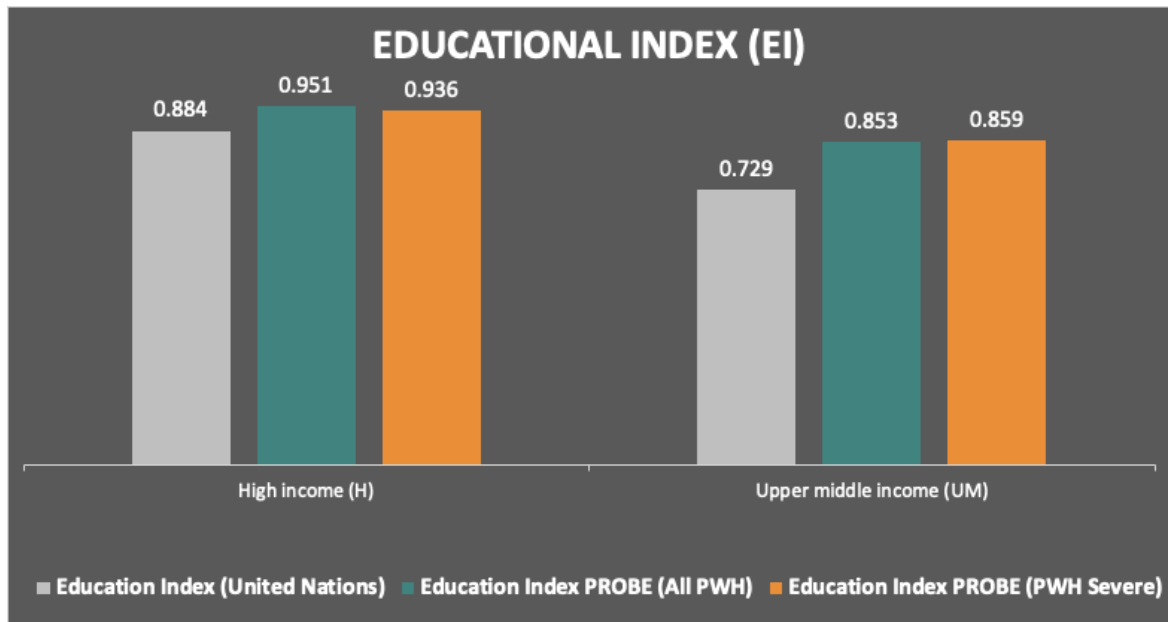
Education Index (EI) assessment is composite of two indices:

- Mean Years of Schooling Index (MYSI)
- Expected Years of Schooling Index (EYSI)

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For more information visit:

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AUTHOR INFORMATION

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Education & Training

2018-Present	NJIT, New Jersey	MS in Biostatistics
2018-Present	HIPPA Training	HIPPS Certification
2018-2020	CITI College	Ethics for Clinical Trials Cert.
2012-2014	Pace University	BS in Economics

Publications

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ABSTRACT

Introduction: Education is one of the key components relating to quality of life. The aim of this analysis was to examine the reported educational level of men with hemophilia in the PROBE study and compare it to the national average reported by the United Nations Development Programme (UNDP). **Methods:** Annually, the UNDP Educational Index (EI), reports the highest degree of education an individual has completed. PROBE collects self-reported data on years of education. Data from all phases of PROBE were compiled on male PWH >25 years of age. To minimize the impact of patient duplication bias in the data set, for each pair of individuals from the same country, with the same hemophilia type and severity, born in the same year, and who reported the same number of years of education, one was excluded from the analysis. In total, 746 PWH from 17 countries, with a mean [SD] age of 45.4 [14.7] were analyzed. 80% had hemophilia A and 65% had severe hemophilia. Data was grouped by country and GNI category. **Results:** The mean number of years of education reported was 15.5 [4.5] years with a range of 2-33 years with similar dispersion in both high (15.6 [4.3]) and upper middle-income countries (15.5 [4.7]). There was no significant difference in years of education reported between severe patients and mild/moderate patients by country or GNI category. In relation to EI, the mean UNDP data for high and upper middle-income countries whom participated in PROBE were 0.884 and 0.729 respectively; the mean EI data for the same countries were 0.951 and 0.853 for all PWH respectively and 0.936 and 0.859 for those with severe hemophilia ($p<0.01$). **Conclusions:** EI calculated on PROBE data indicates that PWH aim to receive a higher education than those in the general population. This finding may be due to selection bias for the PROBE population or to PWH pursuing higher education in the face of career limitations imposed by hemophilia to increase their quality of life. Further investigation is required to understand the finding.