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World Federation of Hemophilia Annual Global Survey analysis of age distribution of patients with hemophilia

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Quality of Life/Outcomes Research

Abstract

Objectives: The quality of life in people with hemophilia (PWH) varies greatly according to socioeconomic status as well as demographic characteristics such as age. Over the past 50 years, there have been substantial improvements in hemophilia care resulting in increased quality of life and a higher life expectancy for those affected by this inherited condition. In this report, we will describe the age distribution of PWH regionally, and by gross national income (GNI), as reported in the Report on the Annual Global Survey (AGS) 2017. The AGS data including the age information can be a useful tool for advocacy in the care of PWH. Methods Data on age distribution of hemophilia patients from the AGS published by the World Federation of Hemophilia was analyzed. This is an annual cross-sectional survey. The AGS 2017 report included responses on age breakdown of PWH from 93 countries. This report uses five age categories: 0-4, 5-13, 14-18, 19-44, 45+. These age categories included 122,336 people with hemophilia A (PWHA) and 24,895 people with hemophilia B (PWHB) worldwide. Gross national income (GNI) per capita categories from the World Bank Group were used. Summary The 2017 AGS report revealed that 31% of PWHA in European countries fall into the 45+ age category, compared to only 14% in Africa, 7% in South East Asia and 8% in the Eastern Mediterranean (Figure 1). For PWHB, the trends were similar, with 32% of patients above 45 years of age in European countries. This ratio was 11% in Africa, 10% in South East Asia and 7% in the Eastern Mediterranean region (Figure 1). When comparing pediatrics to adults by GNI, the ratio of adults increased as GNI increased (Figure 2). In the lower income level countries, there were 56% of PWH under 19 and 40% over the age of 19 whereas in high income countries, the proportions were 31% and 68% respectively. The percentage of PWH over the age of 45 is higher in countries with higher income (29%), than those with lower income (4%) (Figure 3). Conclusions: The analysis of age in PWH can have great indications about the quality and access to care within a country. Increased access to treatment and comprehensive health care services, can lead to better patient outcomes, and PWH can come close to achieving normal life expectancy. As quality and access to care improve, the percentage of PWH in older age categories is expected to increase. Analysis of the AGS data indicates that, despite the continuous improvement in quality of care, the developing regions continue to have additional need for adequate resources when compared to the developed regions.