Health Literacy of People with Haemophilia in China – Results of a Cross-sectional, Community-Based Survey

Abstract ID 1734852

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INTRODUCTION / AIMS

- The CDC defines health literacy as the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.
- Studies have shown that people with adequate health literacy are more likely to sustain healthy behavior, have less hospitalization and exhibit better health outcomes.
- Assessing health literacy will contribute to optimizing patient education and health preservation; however, few research examines health literacy of people with haemophilia (PwH).
- **Aim: To evaluate the current level of health literacy and information preferences among adult PwH in China**

METHOD

- Cross-sectional survey of hemophilia A or B patients 18 years or older residing in provinces/centrally-administered municipalities across Eastern, Central and Western China, using ethics review board-approved questionnaire
- Established Hemophilia Treatment Centers were tapped to collaborate in the survey, acting as recruitment hubs through which eligible patients were invited to participate in the survey
- Questionnaire was self-administered electronically by prospective respondents
- The questionnaire, custom developed by the study team, consists of the following sections:

Section	Sub-section
Demographics & Basic Personal Health Information	• Administrative • Demographics • Healthcare coverage • Physical and medical information
Medical History and Self-directed Management	• Hemophilia-related medical history • Disease self-management measures
Healthcare Seeking and Consumption	• Healthcare resource utilization • Disease burden
Patient-reported Outcomes and Coping Mechanism	• Mental health • Health-related QoL • Support system • Self-efficacy
Hemophilia-focused Health Literacy	• **Foundational knowledge of hemophilia** • **Reading comprehension of health education materials** • **Dose calculation based on Package Insert (health numeracy)**
Information Preferences	• **Channel** • **Content**

RESULTS

- **1765 adult PwH (1010 aged 18-34, 755 aged 35 and above) were recruited from Hemophilia Treatment Centers throughout the country to take part in the web-based survey of disease-focused health literacy and information preferences from September to October 2023.**
- **The average age of adult PwH was 33.8±10.1 years, of whom 86.8% were diagnosed with haemophilia A, 64.0% had severe disease (<1% IU/dL), 37.7% were diagnosed before age of two, 12.6% developed inhibitors and 50.2% have relevant family history.**
- **In terms of hemophilia-related medical history, 48.6% had ≥3 target joints, 62.8% suffered from haemophilic arthropathy, 31.1% had joint surgery and 80.5% experienced physical disability due to hemophilia.**

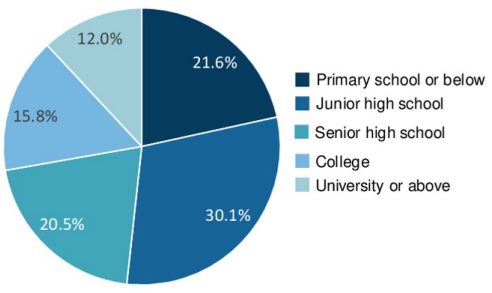

Figure 1 The highest education attained by adult hemophilia respondents

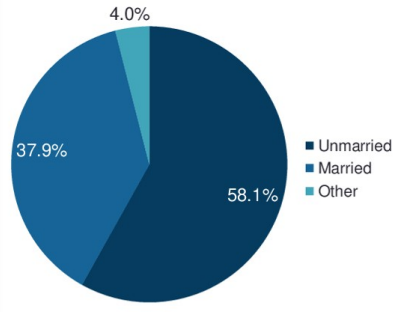

Figure 2 Marital status of adult hemophilia respondents

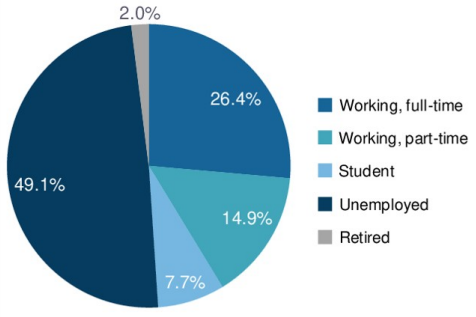

Figure 3 Employment status of adult hemophilia respondents

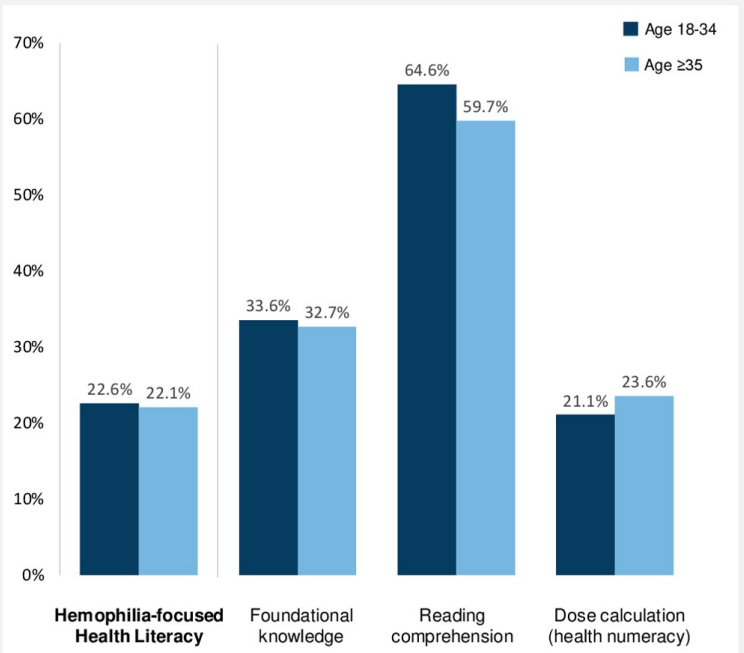

Figure 4 Proportion of adult hemophilia respondents deemed to demonstrate health literacy, by age groups

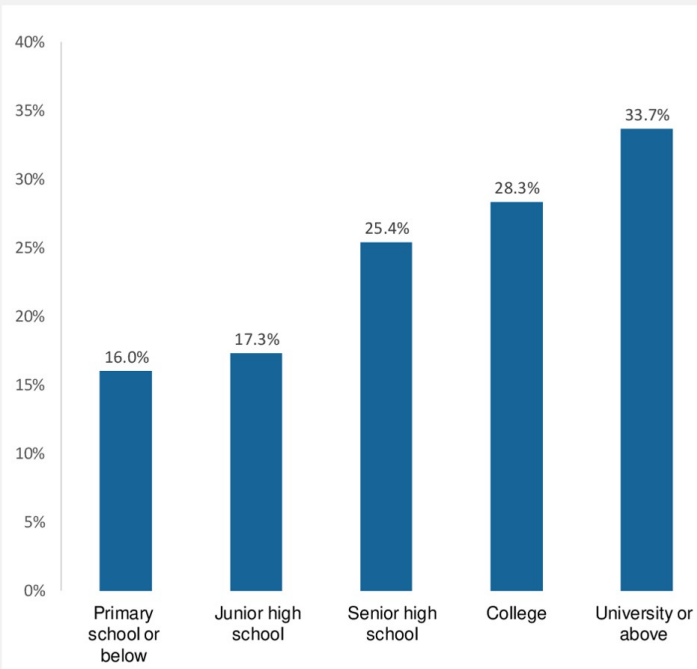

Figure 5 Proportion of adult hemophilia respondents deemed to demonstrate health literacy, by educational background

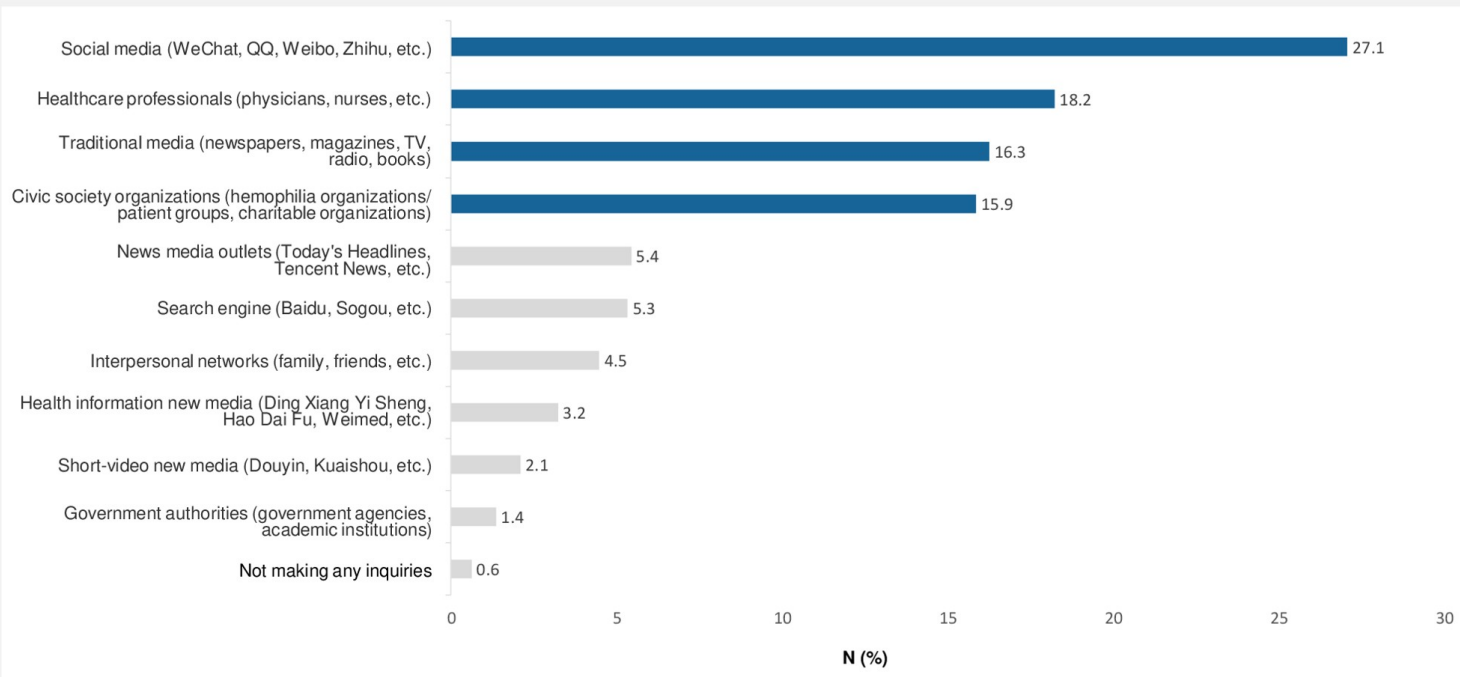

Figure 6 Information channel preferences of adult hemophilia respondents

CONCLUSION

Slightly over 1/5 of adult hemophilia patients demonstrated possession of disease-focused health literacy, which showed an upward trend with more advanced levels of educational background. Social media remained the most preferred information acquisition channel. This was the first study of health literacy among adult haemophilia patients in China.

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