

Understanding Health Literacy Among Adults with Brachial Plexus Birth Injury: Opportunities to Improve the Healthcare Experience

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INTRODUCTION: Brachial Plexus Birth Injury (BPBI) can cause permanent neuromusculoskeletal sequelae and functional impairments that persist into adulthood. BPBI-affected adults report varied health-related quality of life experiences and diverse health concerns which they attribute to BPBI. While resources and research to guide the care of children with BPBI are abundant, little information exists to guide healthcare providers in delivering care for affected individuals in adulthood. In this analysis we sought to understand the healthcare experience of BPBI-affected adults drawing upon the World Health Organization’s (WHO) broad definition of health literacy: a person’s ability to access health information and act to improve their health. The current analysis utilizes a sequential mixed methods approach to examine health literacy among adults with BPBI.

METHODS: This analysis is part of a larger sequential mixed methods study focused on understanding health-related quality of life and the health literacy of BPBI-affected adults. We received approval from our institutional IRB and obtained participant consent in accordance with IRB guidelines. First, BPBI-affected adults were recruited from two online support groups to participate in a survey designed to obtain the breadth of health-related quality of life and healthcare experiences of BPBI-affected adults. Next, a purposively diverse sample of twelve consented respondents participated in individual semi-structured interviews to explore the health-related quality of life and health-care experiences in depth. Then the qualitative responses from the surveys and interviews were systematically pooled and linked to numeric codes in the International Classification of Functioning, Disability and Health (ICF) taxonomy to identify a subset of patient reported outcome measures (PROMs) that aligned with measuring the respondents reported health-related quality of life and health literacy experiences. Qualitative data pertaining to participants’ experiences with healthcare linked to 5/9 scales of the Health Literacy Questionnaire (HLQ). We returned to both online support groups to administer a survey of all PROMs, including the five HLQ scales: Feeling understood and supported by healthcare providers (HLQ1); Having sufficient information to manage my health (HOQ2); Actively managing my health (HLQ3); Ability to actively engage with healthcare providers (HLQ6); Navigating the healthcare system (HLQ7). Each HLQ scale consists of 4-6 questions with a 4-5 level Likert response scale with higher numbers representing more positive ratings. Responses for each subscale were described using means/medians with 95% confidence intervals which were then compared to HLQ published scores for five other adult chronic health conditions: heart disease, kidney disease, kidney transplant, prostate cancer, psoriasis. Additionally, two investigators individually performed content analysis of the pooled qualitative data and then met with a third researcher to resolve inconsistencies and reach consensus regarding themes of the health-literacy experience.

RESULTS SECTION: Results of the first survey were obtained from 183 respondents, 21 to 87 years of age, including 152 females. In the interview portion of the study, there were 12 interview participants, 26 to 81 years of age, 7 of which were female, 4 of whom had a history of childhood surgery. In our second survey, we received complete HLQ forms from 147 participants, 22 to 88 years of age, including 119 females. Means (±SDs) for each HLQ scale were as follows: HLQ1: 2.67±0.88 (4-level Likert scale); HLQ2: 2.83±0.73 (4-level scale); HLQ3: 2.75±0.64 (4-level scale); HLQ6: 3.47±0.88 (5-level scale); HLQ7: 3.25±1.07 (5-level scale). When these five HLQ scale mean scores were compared to the corresponding published HLQ scale scores from the five other chronic conditions (Figure 1), BPBI-affected adults reported lower scores in 17 of these 25 comparisons (i.e., five scales across all five comparison conditions), higher in 6/25, and no difference in 2/25. BPBI-affected adults scored lower than those with all other conditions, except for psoriasis, on HLQ3, HLQ6 and HLQ7. Findings from the qualitative portion of the analysis revealed a range of health literacy experiences for BPBI-affected adults, including: 1) A spectrum of experiences, skewed towards feelings of being dismissed and distrust; when affected adults felt their healthcare providers (HCPs) sought to understand them, the quality of care was perceived more positively. 2) Varied knowledge of BPBI among affected adults and an expressed desire to know more about the progression of BPBI and associated sequelae, as well as long-term health-related life outcomes. 3) A range in the amount and types of healthcare services utilized throughout the lifespan among affected adults. 4) Diverse communication experiences, from BPBI-affected persons receiving conflicting or inadequate information to experiencing communication that facilitated positive healthcare experiences and access to care. 5) Varied levels of difficulty with accessing healthcare providers with knowledge of BPBI in adults and resources pertaining to BPBI affected adults.

DISCUSSION: Overall, the current analysis suggests that the health-literacy experience of BPBI-affected adults falls below that measured in populations of adults with other chronic medical conditions. Opportunities exist for improving the health literacy experience including 1) Affected individuals’ ability to access care for their BPBI affected extremity and associated sequelae, 2) Communication and supportive relationships with HCPs to foster improved experiences with seeking care for BPBI in adulthood, 3) Accessible information about BPBI prognosis, treatment, and long-term health related quality of life outcomes, and 4) Availability of HCP knowledgeable of BPBI care for affected adults. Our analysis does not include personal factors, such as income, education level, and participant zip code, limiting our ability to analyze the social determinants of health among our population with respect to health literacy scores. Despite these limitations, this analysis provides the first picture of the health literacy experience of BPBI-affected adults.

SIGNIFICANCE/CLINICAL RELEVANCE: This analysis elucidates the scope of the health literacy experience of BPBI-affected adults and identifies opportunities to improve the delivery of care for adults with this childhood onset condition.

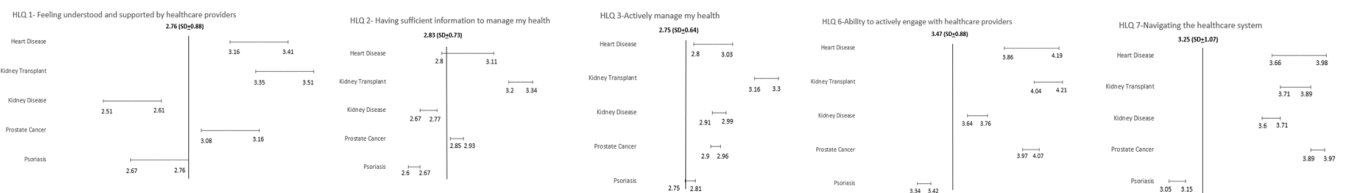


Figure 1: Mean HLQ scores for each HLQ scale compared to confidence intervals of HLQ scores of comparison studies.