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Characterizing Online Patient Education Materials on Phakomatoses with Analysis of Artificial Intelligence Chatbot Responses

Introduction: Phakomatoses are a group of congenital neurocutaneous syndromes characterized by tumor formation across organ systems with additional cutaneous and neurologic features. Due to systemic complications, these conditions are managed through multidisciplinary care. These conditions are rare, and effective counseling at diagnosis is improved by providing access to patient educational material. We therefore sought to characterize the presence and readability of currently available online medical information in a question-and-answer (Q&A) format on phakomatoses.

Methods: We searched UpToDate and patient-centered support organizations for information in a Q&A format on six of the most common phakomatoses: neurofibromatosis type 1, NF2-related schwannomatosis, tuberous sclerosis complex, von Hippel Lindau disease, ataxia telangiectasia, and Sturge-Weber syndrome. We then queried an artificial intelligence (AI) chatbot, ChatGPT 4.0, to ask a set of 10 questions for each syndrome. 60 ChatGPT responses were examined using sentence-level analytics (words and sentences per response) and readability analytics (Flesch Reading Ease and Flesch Kincaid Grade Level).

Results: UpToDate had patient information available for one syndrome, neurofibromatosis type 1. All six phakomatoses had comprehensive patient education from patient-centered support organizations, defined as ≥ 10 Q&A responses, though sometimes across many weblinks. Analysis of ChatGPT 4.0 transcripts revealed an average of 348.6 words per response and 23.05 sentences per response. On average, Flesch Reading Ease across responses was 28.43 and Flesch Kincaid Grade Level was 12.34.

Discussion: Online patient education materials on phakomatoses are limited and AI-generated responses are above the recommended reading level for patient education materials. Our results reveal challenges with obtaining accessible medical information online and highlight a need for additional education materials on phakomatoses.