

Rare Disease, Rare Information: Investigating Healthcare Information Use in Online Global Disability Support Groups

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ABSTRACT

This study aimed to uncover the types of daily healthcare information provided by hospitals to family caregivers of individuals with rare diseases and determine whether the information provided met the family caregivers' information needs to improve digital information access and use by family caregivers. This study used a quantitative cross-sectional survey with multi-question to identify types of healthcare information delivered by hospitals, types of healthcare information needed by family caregivers, preferred healthcare information formats and channels by family caregivers, and relationships between demographics and information satisfaction. Findings show that most hospitals did not provide family caregivers with needed healthcare information, resulting in family caregivers experiencing low satisfaction with their access to information regardless of various demographic factors. It is particularly noteworthy from the findings in this study that the clinical diagnosis of a rare disease is a watershed moment for family caregivers' because it enables them to identify specialists better, improve their access to healthcare information, and focus on the symptoms observed in their family member with a rare disease. However, a general lack of information about rare diseases resulted in a lack of knowledge among medical and healthcare providers, resulting in delayed or no clinical diagnosis. By cooperating with medical librarians and parent support groups, hospitals can establish digital platforms that provide systematic healthcare information on rare diseases, meet the information needs expressed by medical professionals and family caregivers, and improve diagnosis opportunities.

ALISE RESEARCH TAXONOMY TOPICS

Information needs; Information use; Specific populations; Critical librarianship

AUTHOR KEYWORDS

Healthcare information; Family caregivers; Rare diseases; Digital information platforms.