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Evidence Summary

German-Language Websites Containing Information About Rare Diseases Lack Quality Indicators

A Review of:

Pauer, F., Litzkendorf, S., Göbel, J., Storf, H., Zeidler, J., & Graf von der Schulenburg, J.-M. (2017). Rare diseases on the Internet: An assessment of the quality of online information. *Journal of Medical Internet Research*, 19(1), e23. <https://doi.org/10.2196/jmir.7056>

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Abstract

Objective – To evaluate the quality of the information contained in websites about rare diseases and to determine if quality varies based on the supplier category of the website.

Design – Questionnaire and content analysis.

Setting – Germany

Subjects – 693 German-language websites

Methods – Websites were identified through a Google search: All 8,000 rare diseases (as listed

on Orphanet) and their synonyms were entered into Google; the first 20 results for each disease were scanned for sites written in German. A questionnaire designed to measure the quality of information found on the websites was mailed to each identified website provider. For those who did not respond, the survey was completed by the authors using information from the site. A *t* test was used to examine differences in the quality of information among the types of information providers.

Main Results – A total of 693 information suppliers were identified. The suppliers

completed 17.7% of the surveys; the other 82.3% were completed by the authors. The majority of information providers were patient organizations/support groups (38.8%) followed by medical institutions (26.8%). Information provided by individuals had the lowest quality rating. There were no statistically significant differences between the quality of information supplied by patient support groups and medical institutions. The highest quality rating was provided by associations/sponsoring bodies.

Conclusion – There is not much information available on the Internet regarding rare diseases. Patient support groups and organizations are the largest provider of information. The overall quality rating of information on rare disease websites was found to be low, particularly in areas of accessibility. Website providers should be made aware of how to produce websites of higher quality with greater accessibility.

Commentary

Based on a brief literature review on the subject of rare disease websites, there has not been a great deal of research conducted in this area. This study helps to fill that gap. It is important to note that the website quality evaluation tool used in this article had been developed previously by several of the authors of this article (Pauer et al., 2016). The questionnaire consists of a series of questions across several quality domains.

The quality of this study was appraised using “The CAT: A Generic Critical Appraisal Tool” created by Perryman and Rathbun-Grubb (n.d.). Overall, the article was found to be of relatively high quality based on this assessment. The authors have academic credentials related to the subject area and have published on this topic previously. The research questions and methods were explained. The previous relevant literature was included throughout the article.

There were several limitations to this research, as stated by the authors. The websites that

were examined were specific to Germany, Austria, and Switzerland (German-speaking countries) and might not be applicable to other geographic regions. In addition, the accuracy of the medical information contained in the websites was not evaluated; however, this was most likely beyond the scope of the project.

There were other limitations to the methodology of this study. The fact that website providers were asked to rate their own sites potentially introduces significant bias. In addition, the information obtained from the respondents may have differed from that obtained by the authors, and the reliability between these sources was not addressed. There was also no breakdown of the types of providers who responded to the survey and those who did not. Also, a thorough examination of the websites of those providers who did not respond could not be completed as certain data could not be extracted by the authors; therefore, this information was not included in the study.

There are several statistical concerns as well. There is no description of how questionnaire responses were scored, or how means were obtained from the results. There are also not enough data provided on the *t*-test results. Due to these factors, the reader is unable to determine the strength of evidence.

Overall, this article provides information on the quality of rare disease websites, which has not been studied extensively. As stated by the authors, patients with rare diseases often turn to the Internet for more information about a disease and to connect with others who have the same condition. The conclusions of this research indicate that rare disease website providers should be more vigilant in providing higher quality websites and information. Librarians should exercise caution when referring patrons to websites about rare diseases and evaluate them carefully to ensure that they are of sufficient quality. Librarians might also consider providing curated research guides (or incorporating into existing guides) reliable information sources on rare diseases.

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