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The accessibility, readability, and quality of online resources for gender affirming surgery

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ABSTRACT

Background: The transgender population is disproportionally affected by health disparities related to access to care. In many communities, transgender specialists are geographically distant and locally available medical professionals may be unfamiliar with unique needs of transgender patients. As a result, use of Internet resources for information about gender affirming surgery is particularly important. This study simulates a patient search for online educational material about gender affirming surgery and evaluates the accessibility, readability, and quality of the information.

Methods: An Internet search for the term "transgender surgery" was performed, and the first 10 relevant hits were identified. Readability was assessed using 10 established tests: Coleman—Liau, Flesch—Kincaid, FORCAST, Fry, Gunning Fog, New Dale-Chall, New Fog Count, Raygor Estimate, Simple Measure of Gobbledygook, and Flesch Reading Ease. Quality was assessed using Journal of the American Medical Association criteria and the DISCERN instrument.

Results: Review of 69 results was required to identify 10 sites with relevant patient information. There were 97 articles collected; overall mean reading level was 14.7. Individual Web site reading levels ranged from 12.0 to 17.5. All articles and Web sites exceeded the recommended sixth grade level. Quality ranged from 0 to 4 (Journal of the American Medical Association) and 35 to 79 (DISCERN) across Web sites.

Conclusions: Web sites with relevant patient information about gender affirming surgery were difficult to identify from search results. The content of these sites universally exceeded the recommended reading level. A wide range of Web site quality was noted, and this may further complicate successful navigation. Barriers in access to appropriately

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written patient information on the Internet may contribute to disparities in referral, involvement, satisfaction, and outcomes.

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Introduction

Multidimensional barriers in access to healthcare have been described with respect to minority populations, ranging from geographic availability of trained specialists, to financial considerations, to unique information needs. Health literacy is defined by the Department of Health and Human Services as "the degree to which individuals have the capacity to obtain, process, and understand basic health information... needed to make appropriate health decisions" and has a pervasive effect on the ability of individuals to successfully navigate the healthcare system and to overcome barriers to care. The transgender population is disproportionally affected by significant health disparities related to access to care, not only limited to discrimination but also economic disadvantage and fewer average years of formal education relative to cis-gender populations. ²

In many communities, transgender specialists may be geographically distant or difficult to identify, and locally available medical professionals may be unfamiliar with the unique needs of this population.³⁻⁵ As such, use of the Internet for information about important topics, including gender affirming surgery, is particularly relevant. Previously published studies of available online resources for other common medical concerns have found that college-level literacy skills would be required for content interpretation.⁶⁻⁸ Although United States-specific data are lacking in the literature, study of transgender populations in Spain has revealed that 24% of transgender patients had only elementary level education; another 60% had attained only secondary education.9 If available resources for transgender individuals are similarly difficult to read, the mismatch between literacy skills and available resources could represent a significant barrier in access to care with a compound effect on this group.

Inadequate functional health literacy has been found to contribute to poorer health status, 10 increased mortality, 11 less awareness of preventative health measures, 10 decreased understanding of personal medical conditions, 10 greater likelihood of hospitalization, 12 higher health care costs, 13 lack of self-empowerment, 10 less participation in decision-making in the course of care, 14 and overall worse health outcomes. 15 Minority populations are known to be particularly at risk for these health disparities. 14,16,17 As such, increasing the number of quality health-related Web sites, increasing the proportion of online health information seekers who report easily accessing health information, and increasing health literacy are specifically included as objectives in the national Healthy People 2020 action plan. 18 To provide resources for the 36% of American adults with "basic" or "below basic" health literacy skills, the American Medical Association (AMA) and National Institutes of Health (NIH) have published recommendations for the provision of health-related patient information at or below the sixth grade reading level. 10,19

This study aims to simulate a patient or caregiver's Internet search for information about gender affirming surgery to assess the availability of online material and to evaluate the readability and quality of the resulting resources in the context of AMA and NIH recommendations. As such, we hope to provide a practical assessment of this important issue to guide further interventions in addressing health literacy, improving resource availability, increasing quality, and facilitating access to surgical care for the transgender population.

Methods

Resource identification and data collection

An online Google (Google Inc, Mountain View, CA) search was performed on June 9, 2016, for the term "transgender surgery" and the first 10 relevant Web sites were identified. 20-29 The same search was performed using Bing (Microsoft Corp, Redmond, WA) productive of the same first 10 relevant Web sites, but with several transpositions in their order which did not alter our results. To avoid inadvertent search result bias, user, account, and location filters were disabled. Links to online news media articles, social media hits, funding Web sites, and insurance policy statements were excluded. Private surgeon or practice Web sites were included if relevant, educational material was provided, but excluded if only contact, service, fee, or appointment scheduling information was available. Each Web site was accessed directly from the search result link, and relevant, patient-directed information immediately available from the primary page was included in the study. Articles were identified within each site based on subtopics (e.g., procedure details, preparation, eligibility, cost, risks, benefits, outcomes, and postoperative care), each with a minimum of 100 words. These articles were downloaded into individual Microsoft Word 2007 (Microsoft Corp, Redmond, WA) documents and formatted as plain text. Third party advertisements, outside links, pictures, and user comments were removed before analysis.

Readability analysis

Ten established tests of readability were performed using Readability Studio Professional Edition v2012.1 software (Oleander Software, Ltd, Vandalia, Ohio), each evaluating characteristics of text difficulty: Coleman—Liau Index, Flesch—Kincaid Grade Level, FORCAST Formula, Fry Graph, Gunning Fog Index, New Dale-Chall, New Fog Count, Raygor Readability Formula, Simple Measure of Gobbledygook (SMOG) Readability Formula, and Flesch Reading Ease (FRE; Table 1). Initially, all articles were analyzed as a group to calculate overall content reading level. Secondary analysis of readability was performed with articles grouped by Web site for

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