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Original Article

Gender dysphoria: Quality of online information for gender reassignment surgery

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ABSTRACT

An ever-increasing number of patients are using the Internet to learn about medical conditions. This study aimed to evaluate the quality of Internet-based patient information on gender reassignment surgery for people who suffer from gender dysphoria.

Twenty websites identified using Google and Yahoo search engines were selected and evaluated based on the modified Ensuring Quality Information for Patients (EQIP) instrument (36 items).

The EQIP tool comprises 36 questions to which the answer can be "yes" or "no". The final score for each website can be between 0 and 36. An overall score of 26 or above was considered high, because it co-related to the 72nd percentile. The average of the scores turned out to be 22.5 points, lower than our target; 7 (35%) sites were rated higher than the average and 13 (65%) were rated lower.

The assessment of the websites included in the study showed a lack of information about the sequence of the medical procedures, perioperative criticalities and qualitative risks and side-effects descriptions. The overall quality of published information on gender reassignment surgery is very low. We believe that the Internet

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should not be used as the main source of medical information, and physicians should maintain the leadership in guiding patients affected by gender dysphoria.

Level of Evidence: Level IV, case study.

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Introduction

Patients who suffer from gender dysphoria experience a discrepancy between their birth gender and the basic sense of self as a man or a woman (a person's gender identity), which causes them an internal conflict.¹ They feel constant disquiet with their anatomical sex, they believe they were born of the wrong sex² and use the opposite gender role.³

To date, the prevalence of gender dysphoria is estimated to be up to 1.3 percent of the world population⁴⁻⁶ and the incidence is one in every 60,000 people, with a four times higher frequency of male-to-female transsexuals than female-to-male transsexuals.⁷⁻⁹

The term "Transsexualism" appeared for the first time in the Diagnostic Psychiatric Manual and Statistical Manual of Mental Disorders, Third Edition, in 1980; in the Fourth Edition, the term was dropped because it was starting to be considered a purely sexual disorder instead of a gender identity disorder.²

The etiopathogenesis of gender dysphoria is still unknown and further studies are needed. Still, currently, some theories define social and external psychological factors as the cause of gender identity disorder, whereas other studies emphasise the role of biological factors. These studies can be categorised into three groups. The first group claims that hormonal abnormalities such as androgen resistance or adrenal hyperplasia have a role in gender identity disorders. The second category of studies associates gender identity disorders with anomalies in the secretion of gonadotropins. The third, conducted since the mid-1990s, supports the role of sexual morphological differentiation of the brain. The main argumentation used to support this theory is based on the analysis of the volume of the central subdivision in the bed nucleus of the stria terminalis (BNST) - a part of the brain involved in sexual behaviour—which is usually larger in men, than in women. The theory was based on the fact that female-sized BNST was found in male-to-female transsexual individuals.¹⁰⁻¹⁴

It is widely demonstrated in the literature that the best way to assist individuals with severe forms of gender dysphoria is to perform gender reassignment surgery, which is defined as the whole genital, facial and body surgical procedures required to create an opposite gender appearance.^{15,16}

The study aims to evaluate the quality of information accessible on the Web about gender reassignment surgery through a validated method for the critical analysis of the quality of health information, the modified Ensuring Quality Information for Patients (EQIP) instrument.^{17,18} The EQIP scale has also been employed in other studies, demonstrating its effectiveness in evaluating the information available online about other fields of plastic surgery.¹⁹⁻²¹

Materials and methods

Google and Yahoo are the most commonly used search engines worldwide. The following keywords were used in those search engines to perform our study: "Gender" AND "reassignment" AND "surgery". The first 50 webpages shown with the online search results were included. The following exclusion criteria were used: unsuitable content such as duplicates, blogs, and peer review papers. The webpages that accomplished the inclusion criteria were grouped into five units (practitioners, hospitals, healthcare portals, professional societies, and encyclopaedias) and were assessed using the expanded EQIP scale. The EQIP scale is a questionnaire consisting of 36 questions divided into

three sections: content (items 1–18), identification data (items 19–24) and structure (items 25–36) and canonically be answered with “YES” or “NO” for each item. Contents of the data section feature, for example, questions about the definition of which subjects will be covered, the description of alternative treatments (including no treatment at all), the description of the safety measures that the patients must undertake, qualitative and quantitative benefits and risks, and the sequence of the surgery. In this scale, “Qualitative benefits/risks” refers to risk–benefit ratio related to the procedures, such as feeling comfortable with the new body image or common complications. “Quantitative benefits/risks” refers to if we find statistical analysis and values about benefits or risks. Another section is called “identification data”, with questions regarding who financed or produced the webpage and if there is a logo, date of production, or a references to support the reported data. The last section attempts to determine whether the written information is understandable by each user and whether the layout and digital content are pertinent and suitable. Each positive answer to each question is worth 1 point, whereas a negative answer warrants no points. A score is attributed to each website, ranging from a minimum of 0 to a maximum of 36. With 26 or more points, equivalent to the 72 nd percentile, the website was considered a high score. Fewer than 26 points defined a low score.

Results

Our study conducted a search on Google and Yahoo as search engines. After implementing the inclusion mentioned above and exclusion criteria, 20 qualified webpages were selected as appropriate for this research. We found three practitioners’ websites (15%), two hospital websites (10%), seven healthcare portals (35%), seven professional societies websites (35%) and one Encyclopaedia (5%). The expanded EQIP tool was chosen to assess those websites using qualitative and quantitative methods.

We considered an overall score of 26 or above a high score and found that the mean score was 22.5 points, dramatically lower than our target score. Overall, seven websites (35%) with a high score and 13 (65%) with a low score (Table 1). Practitioners’ websites had a mean score of 23 points, hospitals of 19,5 points, healthcare portals of 19,1, Professional societies of 20 points and Encyclopaedia of 22 points. When considering the weighted average, a similar trend was obtained.

Healthcare portals and Hospital webpages obtained the worst scores. Both groups represented most of the results in the first 50 hits on the search engines. Conversely, practitioners’ websites achieved the highest mean score, though they were only three (15%) among total hits, approximately half of all high-scored Web pages. In the results of content data, the sequence of the procedures, quantitative benefits, side effects and risk had the worst descriptions, which led to the lowest scores.

There was a deficiency regarding how potential complications would be dealt with and the alert signs that a patient might detect. Only two websites included all the appropriate themes of the topic. In detail, analysing identification data, we noticed all the websites reported a logo and most specified the revision date (85%). Only three websites (15%) reported references to evidence-based data used. Regarding the Structure data analysis, we observed that the language used was clear, understandable, with a respectful tone and use of everyday language. There was no balance among benefits and risk (only for 35%) and no websites included a consent form, but almost all the websites presented a good layout (75%) and appropriate digital content.

Discussion

Gender dysphoria is nowadays considered a well-defined and discussed health impairment.^{4–6} The problem of the discrepancy between gender identity and gender assigned at birth requires complex management. To take care of transgender individuals, a multidisciplinary approach is needed through medical, surgical, psychological and social support. The burden of psychological involvement is very high for transgender patients and clinicians have to consider this aspect. Current evidence has demonstrated that Gender identity conversion efforts are harmful, increasing the risk of adverse mental health outcomes in adulthood and suicide attempts among youth.^{22,23}

Conversely, gender-affirming surgery has been associated with improved mental health outcomes, highlighting the strong correlation between providing gender-affirming surgery and psychological benefits for transgender people.^{24,25} Sex reassignment surgery plays a central role in establishing the har-

Table 1
EQIP tool results applied to the 20 eligible websites about “Gender reassignment surgery” research on Google® and Yahoo®.

Question	Yes (%)	No (%)
Content data		
1. Initial definition of which subjects will be covered	20 (100%)	0 (0%)
2. Coverage of the above-defined subjects	20 (100%)	0 (0%)
3. Description of the medical problem	20 (100%)	0 (0%)
4. Definition of the purpose of the medical intervention	20 (100%)	0 (0%)
5. Description of treatment alternatives (including no treatment)	15 (75%)	5 (25%)
6. Description of the sequence of the medical procedure	10 (50%)	10 (50%)
7. Description of qualitative benefits	19 (95%)	1 (5%)
8. Description of quantitative benefits	1 (5%)	19 (95%)
9. Description of qualitative risks and side-effects	13 (65%)	7 (35%)
10. Description of quantitative risks and side-effects	1 (5%)	19 (95%)
11. Addressing quality of life issues	20 (100%)	0 (0%)
12. Description of how potential complications will be dealt with	6 (30%)	14 (70%)
13. Description of precautions that the patient may take	10 (50%)	10 (50%)
14. Mention of alert signs that the patient may detect	3 (15%)	17 (85%)
15. Addressing medical intervention cost and insurance issues	10 (50%)	10 (50%)
16. Specific contact details for hospital services	18 (90%)	2 (10%)
17. Specific details of other sources of reliable information/support	16 (80%)	4 (20%)
18. The document covers all relevant issues on the topic	2 (10%)	18 (90%)
Identification data		
19. Date of issue or revision	17 (85%)	3 (15%)
20. Logo of the issuing body	20 (100%)	0 (0%)
21. Name of persons or entities that produced the document	8 (20%)	12 (60%)
22. Name of persons or entities that financed the document	1 (5%)	19 (95%)
23. Short bibliography of evidence-based data used in the document	3 (15%)	17 (85%)
24. The document states if and how patients were involved/consulted in its production	0 (0%)	17 (85%)
Structure data		
25. Use of everyday language, explains complex words or jargon	19 (95%)	1 (5%)
26. Use of generic names for all medications or products	20 (100%)	0 (0%)
27. Use of short sentences	20 (100%)	0 (0%)
28. The document personally addresses the reader	20 (100%)	0 (0%)
29. The tone is respectful	20 (100%)	0 (0%)
30. Information is clear	20 (100%)	0 (0%)
31. Information is balanced between risks and benefits	7 (35%)	13 (65%)
32. Information is presented in a logical order	20 (100%)	0 (0%)
33. The design and layout are satisfactory	15 (75%)	5 (25%)
34. Figures or graphs are clear and relevant	10 (50%)	10 (50%)
35. The document has a named space for the reader's notes	2 (10%)	18 (90%)
36. The document includes a consent form, contrary to recommendations	0 (0%)	20 (100%)

mony between body and self-identity. To achieve this goal, plastic surgeons perform a wide range of procedures. The transition is developed both through gender confirmation surgery (vaginoplasty or phalloplasty) and body contouring interventions, such as mastectomy or mammoplasty and other minor procedures. All these efforts are made to reach the target of restoring healthy psychological and physical harmony.

In modern society, the main source of information is the Internet. It is estimated that health-related websites are around 20,000 to 100,000 and patients are used to search the Internet for information regarding their conditions.^{26,27} Hence, patients affected by gender dysphoria can also find many inputs related to their clinical condition and surgical solutions on the Web. We believe this phenomenon can be dangerous if the sources used are unreliable. An interesting phenomenon is the variation of trends searched on Google or Yahoo after public announcements made by celebrities about their medical conditions.²⁸ Our study was stimulated by the need to prove and examine the quality of information related to this theme and its related therapeutic surgery. We used the EQIP scale to analyse various aspects of 20 medical Web pages by rating the accuracy of the data provided. The broad use of the Web as a source of medical knowledge leads the patients to be wrongly well- and

self-informed before the consultation with clinicians. However, the quality of this knowledge has to be thoroughly evaluated.

We found that an enormous number of sources is rarely related to a good level of the offered information, especially for pages from hospitals and healthcare portals. Practitioners' websites, instead, scored the highest for the reliability of the data provided, but there were only a few among all sites examined. Indeed, our work highlighted a critical lack of qualitative data supplied, despite the huge quantity of content. We discovered a dramatic absence of the procedure's description, risks and side effects, with a shortage of precautions that patients should take (it was reported in only 10% of sites). Furthermore, the constant lack of evidence-based references and the date of revision (absent in 15%) weakens the strength of the data provided.

It can be useful for clinicians involved in managing this complex pathology to be aware of the data available on the Web. Their knowledge is useful to understand the quality of information that patients can find on the Internet, to prevent any misapprehension.

Gender reassignment surgery may improve the quality of life, but it has its intrinsic risks. All surgical interventions are related to a variable number of complications, the most feared and demanding ones are related to the neo-urethra creation, ranging from 4 to 50%, especially in male-to-female surgery.^{26,27} Postoperative functional or aesthetic complications are common side effects, including vaginal stenosis, infections, and perineal muscle hyperspasticity, sometimes requiring secondary revision surgery.²⁹ Moreover, all the well-known complications related to breast implants (infections, contracture, poor aesthetic outcome, exposure of prosthesis) and body contouring surgery in general should be considered. Finally, haemorrhagic complications, even requiring transfusion in up to 45% of cases, are dangerous and should be well understood by patients.^{28,29} This large amount of side effects leads to a high rate of re-interventions.

Conclusion

The quality of information provided by the Web regarding gender reassignment surgery was not satisfactory. Healthcare portals and hospitals reported a lower score than practitioners' websites, conversely achieving the best scores. This difference may be because this surgery is performed only in highly specialised centres and such procedures are not commonly performed.

As a result of our observations, we believe that the Internet should not be used as the main source of medical information, and physicians should maintain the role model, walking these patients through the intricacies of gender reassignment surgery. Therefore, the information on the Web has to be well-planned and reviewed by specialists. Reliable data, expressed through clear language, must be reported on online pages. Complications should be cited to provide complete knowledge. Only this way can it be possible to supply good quality information on the Web to support patients' decisions and the correct Internet use.

Conflict of Interest

The authors declare no potential conflicts of interest regarding this article's research, authorship, and/or publication. The authors who have taken part in this study declare that they do not have any commercial associations that might pose or create a conflict of interest with the information presented in this article.

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Ethical Approval

Not required.

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