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Quality of websites for gamete donation

Websites de qualidade na doação de gametas

Sitios web de calidad en la donación de gametos

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Abstract

This study aims to assess the quality of online health information about gamete donation based on a quantitative analysis of websites from fertility-clinics in Portugal. All websites providing information about gamete donation were comprehensively screened in June 2017. The reliability and usability of 43 webpages were assessed through the Website Information Evaluation Instrument from the Office of Disease Prevention and Health Promotion (ODPHP). None of the webpages met the purpose, content development, and updating criteria set by the ODPHP. Several shortcomings were observed: limited accessibility for users with disabilities, lack of simplified user experiences and easy search functionality, and lack of users' interaction with content. The quality of online information on gamete donation in fertility-clinics' websites requires improvement to become user-friendly. The development of specific guidelines and periodic evaluations of these websites using sensitive instruments, merging quantitative and qualitative assessments, is required to guarantee the quality of information that aims to improve reproductive health literacy through people-centered communication.

Keywords: Donor conception; Quality assurance, Health care; Patient education; Internet; Consumer health information.

Resumo

Este estudo pretende avaliar a qualidade da informação *online* sobre doação de gametas em sites de clínicas de fertilidade em Portugal. Todos os sites com informação sobre doação de gametas foram escrutinados em junho de 2017. A confiabilidade e usabilidade de 43 páginas web foram avaliadas usando o instrumento Website Information Evaluation do Office of Disease Prevention and Health Promotion. Nenhuma página cumpriu os critérios de propósito, desenvolvimento e atualização de conteúdo. Encontraram-se várias lacunas na usabilidade: acessibilidade limitada para usuários com incapacidade, falta de clareza e de simplicidade de utilização, e impossibilidade de interagir com os conteúdos. Importa melhorar a qualidade da informação online sobre doação de gametas em clínicas de fertilidade, tornando-a mais amigável para o usuário. É necessário desenvolver guias específicos e avaliar periodicamente estes sites, usando instrumentos sensíveis que contemplem análises quantitativas e qualitativas, garantindo a sua qualidade para promover literacia em saúde reprodutiva através da comunicação centrada nas pessoas.

Palavras-chave: Concepção de doadores; Garantia da qualidade dos cuidados de saúde; Educação de pacientes; Internet; Informação de saúde ao consumidor.

Resumen

Este estudio evaluó la calidad de la información sobre la donación de gametos en sitios web de clínicas-de-fertilidad. Todos los sitios web de clínicas en Portugal fueron examinados (junio 2017). La confiabilidad y usabilidad de 43 páginas web fueron evaluadas con el Website Information Evaluation do Office of Disease Prevention and Health Promotion. Ninguna de las páginas cumplió con los criterios de propósito, desarrollo de contenido y actualización. Se observaron deficiencias: accesibilidad limitada para los usuarios con discapacidades, falta de una experiencia del usuario simplificada y baja funcionalidad de búsqueda fácil, y falta de interacción de los usuarios con el contenido. Importa mejorar la calidad de la información online sobre la donación de gametos en clínicas de fertilidad, para convertirse en fácil de usar. Es necesario el desarrollo de guías específicas y evaluaciones periódicas de los sitios web, utilizando instrumentos sensibles que combinen evaluaciones cuantitativas y cualitativas, promoviendo la alfabetización en salud reproductiva.

Palabras-clave: Concepción de donantes; Garantía de la calidad de atención de salud; Educación del paciente; Internet; Información de salud al consumidor.

INFORMAÇÕES DO ARTIGO

Contribuição dos autores: The study was designed by Silva S. Baía I wrote the first draft of the manuscript. Baía I, Samorinha C, and Silva S designed the analysis strategy. Samorinha C and Baía I collected and analyzed the data. All authors gave substantial contribution to the interpretation of data, critical discussion, revision of the manuscript, and approved its final version. All authors agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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Introduction

Websites of *in vitro* fertilization (IVF) clinics are privileged vehicles for search and provision of fertility-related consumer health information to patients[1,2,] gamete donors[3], and the general public[4]. These sites are also important sources of psychosocial support for patients, namely through internet forums[2]. They are also used as marketing tools, assisting clinics in advertising, recruiting, and matching donors to recipients in need of such services[3,5]. They may contribute to foster awareness and education about the causes of infertility and their treatments, benefits, and risks of gamete donation, and regulatory frameworks[6,7]. Thus, websites of IVF-clinics constitute major opportunity to foster reproductive health literacy and promote people-centered communication[8] by providing clear, accurate, understandable, and up-to-date information[7,9].

Responding to individuals' preferences, needs, and values is a central goal of integrated people-centered healthcare services[10,11]. To achieve this goal, it is necessary to promote individuals' health literacy[12] and improve people-centered communication[13,14]. This may require the provision of and access to inclusive and equitative quality health education for all individuals[15]. One way to expand access to health education is investing in the delivery of online health information. Increasing access to online health information for patients and the general public has the potential to not only help improve health literacy but also empower them to undertake a more active role in decisions regarding their own health[16-18]. Guaranteeing the quality and credibility of health information websites is, thus, crucial to assure that the decisions made produce the best possible outcome for all parties involved[17,18].

The importance of ensuring transparency, trustworthiness, privacy, accountability, reliability and accuracy of health information made available online to the public was recently reinforced by the World Health Organization[19], the European Group on Ethics in Science and New Technologies[7], and the American Society for Reproductive Medicine[20], calling for the evaluation of health information made available online to citizens. Quality websites contribute to patient participation by increasing their confidence, autonomy, and self-determination[21], enhancing patient and clinician communication[22], and helping gamete donors and recipients to make informed decisions[23]. Quality websites are also particularly relevant in the search for cross-border reproductive care[24] and transnational flow of gametes[25]. Conversely, poor-quality websites, which are difficult to use and are not reliable, can preclude adequate accessibility and understanding of information from users[26].

Despite the consensual recognition of the need for quality websites, no empirical studies assessed the quality of information about gamete donation delivered by IVF-clinics websites. This study aimed to assess the quality of online health information about gamete donation based on a quantitative assessment of websites from IVF-clinics in Portugal.

Methods

On June 2017, the webpage of the Portuguese National Council for Assisted Reproductive Technologies was searched to identify all IVF-clinics providing treatments with gamete donation in Portugal[27]. From the 18 identified IVF-clinics, 13 out of the 15 private clinics provided online information about gamete donation, and the National Health Service provided information about the 3 public clinics. A total of 14 websites were comprehensively screened to select all webpages related to gamete donation. The final sample included 43 webpages (Chart 1).

Chart 1 – Webpages included in the analysis

Website	Webpages
www.avaclinic.pt	www.avaclinic.pt/doacao
	www.avaclinic.pt/doacao-feminina
	www.avaclinic.pt/doacao-masculina
	www.avaclinic.pt/doacao/a-dadora-de-ovulos
	www.avaclinic.pt/doacao/a-receptora
	www.avaclinic.pt/doacao/a-dadora-na-ava-clinic
	www.avaclinic.pt/tratamentos/casais-mulheres-sem-parceiro
	www.avaclinic.pt/tratamentos/fertilizacao-reciproca-metodo-ropa
www.british-hospital.pt	www.british-hospital.pt/pt/especialidades/detalhe/pagina/especialidades-centro-de-medicina-da-reproducao
www.ceie.pt	www.ceie.pt/ceie/doacao
www.cemeare.pt	www.cemeare.pt/tratamentos-infertilidade-clinica-lisboa.php
	www.cemeare.pt/infertilidade-conjugal-doar-ovulos-ovocitos-clinica-lisboa.php
www.ceti-porto.com	www.ceti-porto.com/quero-doar-c13qx
	www.ceti-porto.com/doacao-de-ovocitos
	www.ceti-porto.com/doacao-de-espermatozoides
	www.ceti-porto.com/quero-doar-cw0u
	www.ceti-porto.com/perguntas-frequentes
www.cgrabarros.pt	www.cgrabarros.pt/doacao.htm
	www.criarfamilias.com.pt
www.clinicafertimed.org	www.clinicafertimed.org/inseminacao-artificial-tratamento-da-esterilidade-e-da-infertilidade
	www.clinicafertimed.org/fertilizacao-vitro-tratamento-da-esterilidade-e-da-infertilidade
www.clinimer.com	www.clinimer.com/tratamentos
www.ferticare.pt	www.ferticare.pt/servicos
www.ferticentro.pt	www.ferticentro.pt/doarovulos
	www.ferticentro.pt/doaresperma
	www.ferticentro.pt/pt/tratamentos/doacao_ovulos
	www.ferticentro.pt/pt/tratamentos/doacao_esperma
	www.ferticentro.pt/pt/tratamentos/doacao_esperma1
www.ivi.pt	www.ivi.pt/tratamentos-reproducao-assistida/doacao-de-semen
	www.ivi.pt/tratamentos-reproducao-assistida/doacao-de-ovocitos
	www.ividoa.pt
	www.ividoa.pt/porque-ser-dadora-ovulos
	www.ividoa.pt/doar-e-recompensado
	www.ividoa.pt/o-processo-doacao-de-ovulos
	www.ividoa.pt/nosotras
	www.ividoa.pt/blog
	www.ividoa.pt/faqs
www.maloclinic-ginemed.com	www.maloclinic-ginemed.com/reproducao-assistida/dadores
	www.maloclinic-ginemed.com/reproducao-assistida/doacao-de-ovulos
	www.maloclinic-ginemed.com/reproducao-assistida/dupla-doacao
	www.maloclinic-ginemed.com/reproducao-assistida/resultados/doacao-ovulos
www.meka.pt	www.meka.pt/doacao_ovulos
www.sns.gov.pt	www.sns.gov.pt/cidadao/banco-publico-de-gametas-2

Source: Search data (2017).

The Office of Disease Prevention and Health Promotion Website Information Evaluation Instrument was used to assess quality in the selected webpages. This instrument was developed by experts in health communication and technology in the framework of Healthy People 2020[28], aiming to improve the quality and accessibility of online health information. It provides a standardized and validated tool to assess the following two formal components of quality in websites and is the most complete tool compared to others[29,30]: a) reliability, which evaluates accuracy and credibility of the website content as well as transparency in its purpose and ownership; and b) usability, referring to site assessment, content design, and information architecture, which affect users' ability to access, understand, and obtain online information. Reliability includes six criteria that measure 15 items: identity (name and address of the entity responsible for the website and funding sources); purpose (website mission, uses and limitations, and association with commercial products); content development (advertising, editorial policies, and content authorship); privacy (privacy policies description); user feedback (feedback forms); and content updating (date of content creation and revision). Each of these items is classified as present or absent ("Yes/No" answers), and each criterion is fulfilled only if all its items are present. Usability comprises 19 principles across 59 task-based measures ranked in a 4-point scale from 1 [task failure] to 4 [minimal problems] and based on the level of difficulty performing the task when assessing the webpage to search for information. An average rating score is calculated for each usability principle. A score of ≥3.5 is required to comply with each principle[28]. In the case of reliability, two researchers assessed all the webpages independently, and a third researcher sorted out ambiguities by assessing the webpage based on the same criteria. The total consensus was reached for the reliability criteria. The rating score for each usability principle was calculated based on the arithmetic mean of the scores given by two researchers. The fact that usability is scored on a 4-point scale increases the difficulty in reaching interrater reliability (IRR) in this component[28]. To ensure IRR, both reviewers assessed the same websites during an initial training process, calculated the IRR for each assessment, identified discrepancies, and resolved them between the two reviewers until IRR scores met benchmark kappa scores. A good intraclass coefficient (ICC=0.62) was reached for the usability evaluation, which met the proposed benchmark score[28].

A descriptive analysis was performed to present the proportion of webpages depicting reliability criteria and usability principles. The corresponding 95% confidence intervals (95% CI) are presented. The statistical analysis was conducted using IBM SPSS Statistics, version 23.0.

Results

The reliability of the assessed webpages was poor. None of them met the criteria of purpose, content development and content updating, and only one met the identity requirement. There was a lack of identification of uses and limitations of these webpages and failure to describe editorial policies, authorship, dates, and responsibility of content creation and updating [Chart 2]. All the webpages provided the possibility of user feedback (e.g., feedback form, email address). However, only 30.2% (95% CI, 17.2-46.1) met the privacy criteria (i.e., describing confidentiality policies and explaining how users' personal data is protected).

Chart 2 – Count and proportion of webpages (N=43) presenting fulfilled reliability criteria

Reliability criteria	Count	% (95% CI)
Identity	1	2.3 (0.0-12.3)
Name	43	100.0 (n.a)
Street address	42	97.6 (87.7-99.9)
Funding sources	1	2.3 (0.0-12.3)
Purpose	0	0.0 (n.a)
Purpose or mission	39	90.7 (77.9-97.4)
Uses and limitations	23	53.5 (37.7-68.8)
Association with commercial products	0	0.0 (n.a)
Content Development	0	0.0 (n.a)
Identification of advertising content	0	0.0 (n.a)
Description of editorial policy	2	4.7 (0.6-15.8)
Authorship	17	39.5 (25.0-55.6)
Privacy	13	30.2 (17.2-46.1)
Privacy policy	13	30.2 (17.2-46.1)
Description of protection of personal information	13	30.2 (17.2-46.1)
User Feedback	43	100.0 (n.a)
Feedback mechanism	43	100.0 (n.a)
Content Updating	0	0.0 (n.a)
Display date created	0	0.0 (n.a)
Display date reviewed or updated	0	0.0 (n.a)

Source: Search data (2017).
* n.a – not applicable.

Concerning usability, 41.9% of the webpages complied with less than 10 out of 19 principles (data not shown). Major shortcomings were observed regarding accessibility for users with disabilities by providing a simplified user experience (print options, feedback mechanisms for users, and accessibility of the homepage) in the absence of an easy search functionality and options for users' interaction with content. These issues prevented users the ability to input information and choose preferences or share content with others; none of the evaluated webpages complied with these principles. Only one webpage presented a clear visual hierarchy (2.3% [95% CI, 0.1-12.3]). The highest compliance was reached for the following principles [Chart 3]: the back button behaves predictably (97.7% [95% CI, 87.7-99.9]); easiness to read elements on the page (93.0% [95% CI, 80.9-98.5]); clearly labelled content categories (90.7% [95% CI, 77.9-97.4); and usage of user-friendly language minimizing jargon and technical terms (90.7% [95% CI, 77.9-97.4]).

Chart 3 – Count and proportion of webpages presenting fulfilled usability principles

Usability principles	Count	% (95% CI)
Site Design		
1. Uses conventional interaction elements	12	36.4 (20.4-54.9)
2. Makes it obvious what is clickable and what is not	34	79.1 (64.0-90.0)
3. Minimizes vertical scrolling	30	69.8 (53.9-82.8)
4. Ensures that the back button behaves predictably	42	97.7 (87.7-99.9)
5. Provides clear feedback signals for actions	27	62.8 (46.7-77.0)
6. Ensures site is accessible for users with disabilities and uses elements of 508 compliance	0	0.0 (n.a)
7. Provides a simplified user experience	0	0.0 (n.a)
8. Incorporates multimedia	7	16.3 (6.8-30.7)
9. Offers a functional home page	36	83.7 (69.3-93.2)
Information architecture		
10. Presents a clear visual hierarchy	1	2.3 (0.1-12.3)
11. Provides easy search functionality	0	0.0 (n.a)
12. Clearly labels content categories	39	90.7 (77.9-97.4)
13. Makes pages easy to skim or scan	23	53.5 (37.7-68.8)
14. Makes elements on the page easy to read	40	93.0 (80.9-98.5)
15. Visually groups related topics	35	81.4 (66.6-91.6)
16. Makes sure text and background colours contrast	31	72.1 (56.3-84.7)
Content design		
17. Focuses the writing on audience and purpose	11	25.6 (13.5-41.5)
18. Uses the users' language; minimizes jargon and technical terms	39	90.7 (77.9-97.4)
19. Allows for interaction with the content	0	0.0 (n.a)

Source: Search data (2017).

*n.a – not applicable.

Discussion

The assessment of the quality of online health information on gamete donation provided by the websites of IVF-clinics located in Portugal reveals gaps regarding both reliability and usability. The promotion of transparency, trustworthiness, accountability, and accuracy requires the development and update of content, improved privacy practices and policies, identification of funding sources, and clarification of associations with commercial products[5,7]. Previous studies highlight patients' difficulties in evaluating the quality of online information about infertility mainly due to lack of identification of sources of information in websites[31] and absence of a peer review process and editorial oversight of contents and updates[32].

This type of surveillance on sources of online health information is particularly relevant to ensure that the information provided is still accurate, understandable, and targeted for the users' needs and preferences[33].

A lack of focus on the user is evidenced by the following aspects: lack of website's accessibility for users with disabilities and lack of a simplified user experience; scarce incorporation of multimedia without clear visual hierarchy; absence of easy search functionalities; and difficulties in users' interaction with content. The incorporation of multimedia patient education and consent tools can increase the accessibility and user-friendliness in websites[31]; this will make websites important mediums for fostering awareness and education in fertility[6,7] while potentially decreasing the feeling that consent is a bureaucratic routine[34] by grounding it in informed shared decision-making.

Furthermore, the results of this study draw attention to the need to disseminate guidelines aimed at promoting user-friendly websites. The traditional focus on service providers as the main agents responsible for the evaluation of the quality of online health information needs to be challenged by highlighting the co-responsibility of health institutions and policy-makers in the development of specific guidelines and periodic evaluations of websites that take into account the socioethical implications of gamete donation[35]. Quality gold-standard guidelines should be developed by a multidisciplinary team to guide those responsible for website development on the type of information and the way they should be provided[31,32]. The development of websites that are evaluated and certified by independent health authorities is, therefore highlighted[7].

Final considerations

This study constitutes an exploratory first step in the assessment of the quality of online information on gamete donation. Based on websites of fertility clinics in Portugal, the study revealed that the quality of online information on gamete donation requires improvement to become user-friendly and assurance of the websites' usability and reliability. Based on quantitative indicators, these findings provide relevant information that can be used by fertility clinics in making improvements to their websites available to the public.

Considering the absence of standardized criteria for evaluating web-based health information on gamete donation, it is of utmost importance to develop these criteria to assess the quality and adequacy of content in these websites; similarly, these criteria are relevant to those already existing websites related to other health topics[36]. The development of tools that integrate quantitative and qualitative indicators, sensitive to gamete donation and including content analysis of websites, should be performed to improve reproductive health literacy through people-centered communication. Finally, evidence on the perspectives and needs of users regarding their experiences with websites is needed to promote people-centered models for the development of webpages related with gamete donation.

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