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Development and evaluation of a website with Alzheimer´s disease information and its consequences for communication

Desenvolvimento e avaliação de um *website* sobre a Doença de Alzheimer e suas consequências para a comunicação

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ABSTRACT

Purpose: To present the development of a website with information about Alzheimer's disease (AD) and its consequences to communication, and verify the technical and information quality provided to the elderly, elderly caregiver and Speech Language pathology therapist public. **Methods:** A website containing information about AD was developed, attempting to use simple and clear language with concise content, analyzed by the Flesch index, which showed most of content (75% of the submenus) with readability related to the percentile "easy". The website development followed the steps of analysis and planning, modelling, implementation and evaluation. The evaluation was performed by 16 elderly, 12 caregivers of the elderly and 28 SLP therapists. Statistical analysis was performed using the Kruskal-Wallis and Spearman's Correlation Coefficient test. **Results:** The survey had the participation of people with different educational levels, who frequently accessed the internet, with prevalence of the female gender. Content analysis showed statistically significant difference in the overall score between elderly versus caregivers and SLP therapists, as well as submenus related to the brain and AD, the phases and the impact on the communication. The website content was rated as "excellent". The website technical quality evaluation presented as "adequate". **Conclusion:** The website was developed within the proposed stages and its technical quality and contents on AD are a reliable reference source or complementing information. Content adjustments of some submenus can be performed to attend to the elderly public; however, the technical support is present in regard to Speech Language pathology therapist evaluation.

Keywords: Alzheimer disease; Speech, Language and Hearing Sciences; Aged; Caregivers; Health Promotion, Internet

RESUMO

Objetivo: Apresentar o desenvolvimento de um *website* com informações sobre a doença de Alzheimer (DA) e suas consequências para a comunicação e verificar a qualidade técnica e das informações fornecidas ao público idoso, cuidadores de idosos e fonoaudiólogos. **Métodos:** Foi elaborado um *website*, contendo informações sobre a doença de Alzheimer, buscando-se uma linguagem simples e clara, com conteúdo sucinto, analisadas pelo índice de Flesch, que demonstrou a maior parte do conteúdo (75% dos submenus) com grau de legibilidade relacionado ao percentil correspondente a "fácil". A elaboração do *website* seguiu as etapas de análise e planejamento, modelagem, implementação e avaliação. A avaliação foi realizada por 16 idosos, 12 cuidadores de idosos e 28 fonoaudiólogos. A análise estatística foi realizada por meio do teste Kruskal-Wallis e coeficiente de correlação de Spearman. **Resultados:** A pesquisa contou com a participação de pessoas com diferentes níveis educacionais, que acessavam a Internet com frequência, observando-se prevalência do gênero feminino. A análise do conteúdo apontou diferença estatisticamente significativa no escore geral entre idosos *versus* cuidadores e fonoaudiólogos, além dos submenus relacionados ao cérebro e à DA, as fases e os impactos na comunicação. O conteúdo do *website* foi avaliado como "excelente" e qualidade técnica do *website* apresentou-se como "adequada". **Conclusão:** O *website* foi desenvolvido dentro das etapas propostas, sendo sua qualidade técnica e conteúdo uma fonte de consulta ou de complementação de informações fidedignas. Ajustes dos conteúdos de alguns submenus podem ser realizados para atender ao público idoso, porém, o respaldo técnico mostra-se presente frente à avaliação dos fonoaudiólogos.

Palavras-chave: Doença de Alzheimer; Fonoaudiologia; Idoso; Cuidadores; Promoção da Saúde; Internet

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INTRODUCTION

Demographic and epidemiological transition has traced a population profile that reflects in the sharp transformation of the age pyramid. Investment in health and education can be considered essential for the population to be able to experience this moment, in which elaboration and development of public policies are necessary, enabling the integration of economic and social aspects to the well-being of society, the environment, and last but not least, health[1]. Health promotion has been one of the tools used in the development of health policies, and can provide population empowerment through health education. This is not only limited to transmitting knowledge, but it also establishes links between the different social actors, those assisted and professionals, involving the community, social inclusion and constant conceptual remodeling of these individuals, as well as habits that compromise health and quality of life of the population, such as the one that ages[2].

Alzheimer's disease (AD) is one of the diseases whose main risk factor is age[3], being a topic of paramount importance to be discussed in an aging country, since epidemiological data point to it as corresponding to 60-70% of all dementias[4]. The disease delineates a complex picture of slow development and is of insidious, degenerative and progressive origin, whose major loss is memory deficit. Changes in memory become evident over the years and it is associated with temporo-spatial, visuomotor, visual-spatial, attention, behavioral and language disorders[5].

The process of communication can be altered by numerous pathologies, including those involving the dementia process[6]. Confronting the clinical profile is that there is no possibility of cure. Treatment involves multidisciplinary work, and the speech-language pathology (SLP) therapist is one of the people responsible for maintaining the quality of life of individuals and their family and/or caregivers.

Considering that AD has become a public health problem worldwide[4], it is necessary to prepare informative materials accessible to the population, seeking to use simple, clear and objective language. The Internet becomes a tool for disseminating knowledge, which can help in the flow of information related to AD. The new information and communication technologies (ICT) associated with the Internet allow the flow of information to be spread in an equitable way, enabling society to access information without limitation of time and space[7].

The use of health-related technologies is called TeleHealth, a branch of medicine which involves the provision of health services, seeking to simplify and streamline procedures, qualify and improve clinical care, and promote the tele-education process[8]. Related materials were developed with a focus on different life cycles, such as children's health and aspects relating to SLP[9] and the elderly[10].

When it comes to the search for information online, caution is needed, since in addition to the need for access to the Internet, control is limited to the information disclosed, as well as the possibility of containing other interests, such as economic ones through which information is provided, hence the importance of quality and evaluation of websites[11].

In order to generate education, promotion and prevention in health to the population, especially to the elderly and caregivers of the elderly, it is important to develop a democratic access tool, with regard to the aspects that permeate AD and its interrelation with SLP therapy.

The present study aimed to present the development of a website, with information about Alzheimer's disease and its consequences for communication, and to verify the technical quality and information provided to the public composed of elderly people, caregivers of elderly people and SLP therapists.

METHODS

It is a cross-sectional study, starting with the elaboration of an online educational material and its subsequent evaluation by different publics, such as the elderly, caregivers of the elderly and SLP therapists.

The production of the material followed the phases of development of instructional design, proposed by Filatro and Piconez[12]: analysis and planning, modeling, implementation and evaluation. All stages of project development were carried out with the accompaniment of a researcher.

For the first stage, called analysis and planning, the collection of information in books and scientific articles indexed in the databases Lilacs, Medline, PubMed and SciELO on Alzheimer's disease and the consequences in the communication of the elderly were carried out. The data search was directed to feed the following submenus (S): What is Alzheimer's disease; The brain and Alzheimer's disease; Signs and characteristics of Alzheimer's disease; Phases of Alzheimer's disease; Speech-language pathology on Alzheimer's disease; Treatment of Alzheimer's disease; Impacts in communication generated by Alzheimer's disease and The role of the caregiver/family. The search was performed through the use of keywords such as Alzheimer's disease, caregiver, speech-language and hearing sciences and public health. Other sources of information were consulted, such as books and official websites related to the subject.

The contents of the submenus were defined and elaborated based on clinical and research experiences of the Study and Research Group on Aging (Grepen), registered in the National Council of Scientific and Technological Development (CNPq), for the care of the adult and elderly population carried out in the Speech-Language Pathology Department, Bauru School of Dentistry - *Universidade de São Paulo* (FOB-USP), as well as the discussions that emerged during an extension course (process nº 12.1.06450.25.7) offered by FOB-USP focusing on the skills of caregivers of the elderly.

The second step, modeling phase, included the use of three models: 1. conceptual, which established how the content would be presented to the target audience; 2. navigation, in which the mode of access to the contents was defined; 3. interface, in which the layout of the screens was established according to the content and the target audience, creating the visual identity of the material. For the transmission of information related to AD, the present study used a virtual, web-based environment, i.e., a website. The design provided and the images were prepared in conjunction with a company specialized to perform visual programming activities.

In this phase, the material that is available on the website was also prepared by adjusting the level of intelligibility of the text and illustrating the contents with static images. Textual analysis was performed using the Microsoft Word® tool. In Brazil, one of the most popular formulas used is the Flesch Reading Ease, an index based on the number of words of the sentences and the number of syllables per word, and is used to evaluate the degree of difficulty/ease of the text, by providing a percentile

that varies from very easy to very difficult[13], being a metric of intelligibility adapted to Portuguese. All submenu content was reviewed by Microsoft Office Word®, using the Flesch index and selecting the essay style in the colloquial option.

The third stage was related to implementation, another moment in which the contact with the specialized company was important combined with the researchers, for the organization of the material to the public.

Finally, the stage of evaluation, counted on the participation of three publics, composing of different categories: Elderly (E), Elderly Caregiver (EC) and SLP Therapist (T), with no restrictions of age and gender for all of them and without restriction of schooling for E and EC. All were invited by invitation letter and accessed the website to participate in the research, constituting a convenience sample.

Assessment tools

Three instruments were used, one for the characterization of the study population and the use of the Internet, a second instrument based on a questionnaire to evaluate a blog of SLP Therapy and Pediatrics (Chart 1)[14], in order to evaluate the content on AD, and finally, an instrument for evaluating the technical quality of the website, which was elaborated through the adapted Health-Related Web Site Evaluation Form (Emory) questionnaire[14,15], which addresses topics related to content, accuracy, authors, updates, public, navigation, links and structure.

Data were treated using descriptive and inferential statistics. Statistical analysis was performed using the Statistica 9.0 software, adopting a significance level of 5% (p <0.05). The Kruskal-Wallis test was used when comparing the categories with the general score of the questionnaires that evaluated the content and the technical quality of the website, as well as the score of each topic and the subscales. The same test was used to compare schooling with the overall score of the referred questionnaires and with the frequency of Internet use. For the correlation between the frequency of Internet use and age and schooling of participants, the Spearman correlation coefficient was used.

The study protocol was approved by the Human Research Ethics Committee of FOB-USP under CAAE: 20836813.0.0000.5417. Initially, to carry out the evaluation of the contents of the website, participants should agree to the Free and Informed Consent Form, available on the website, and if accepted, by means of a signature, directed to the completion of the questionnaires, aspect pointed out by said Ethics Committee. All agreed to voluntarily participate in the research, following the recommendations of the National Health Council.

RESULTS

The content of the material included in the category Alzheimer's Disease, according to the analysis and planning stage (Figure 1) presented the level of textual intelligibility (Chart 2) ranging from easy to difficult, following the modeling step.

Chart 1. Content Assessment Protocol on Alzheimer's Disease

How would you judge the quality of the content presented for Alzheimer's disease?						
Submenus (S)	**Very poor**	**Poor**	**Regular**	**Good**	**Very good**	**Not accessed**
S1. What is Alzheimer's disease?						
S2. The brain and Alzheimer's disease?						
S3. Signs and characteristics of Alzheimer's disease						
S4. Phases of Alzheimer's disease						
S5. S5. SLP guidance on Alzheimer's disease						
S6. Treatment of Alzheimer's disease						
S7. Impact of information generated for Alzheimer's disease						
S8. Role of caregiver/family						

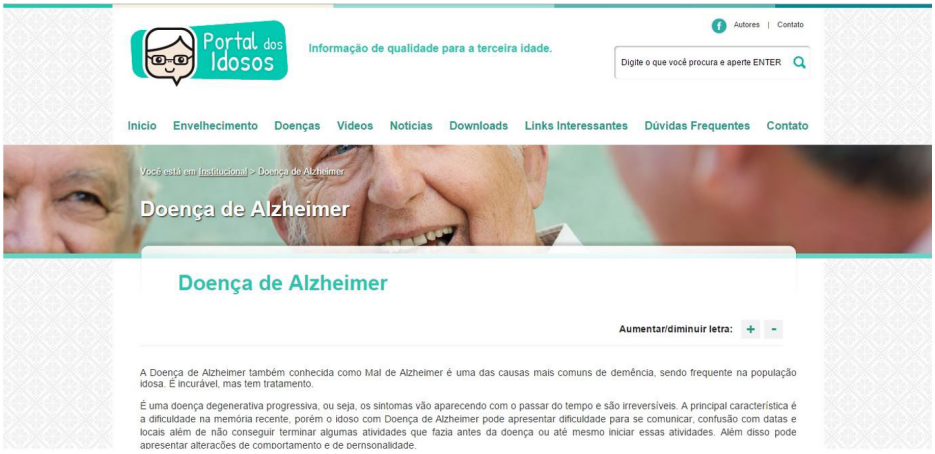

Figure 1. Screen of the specific page on Alzheimer's disease

Chart 2. Text intelligibility values of the topics according to the Flesch index

Submenus (S)		Flesch index %	Classification
S1.	What is Alzheimer's disease?	65	Easy
S2.	The brain and Alzheimer's disease?	50	Easy
S3.	Signs and characteristics of Alzheimer's disease	52	Easy
S4.	Phases of Alzheimer's disease	55	Easy
S5.	S5. SLP guidance on Alzheimer's disease	44	Difficult
S6.	Treatment of Alzheimer's disease	49	Difficult
S7.	Impact of information generated for Alzheimer's disease	55	Easy
S8.	Role of caregiver/family	58	Easy

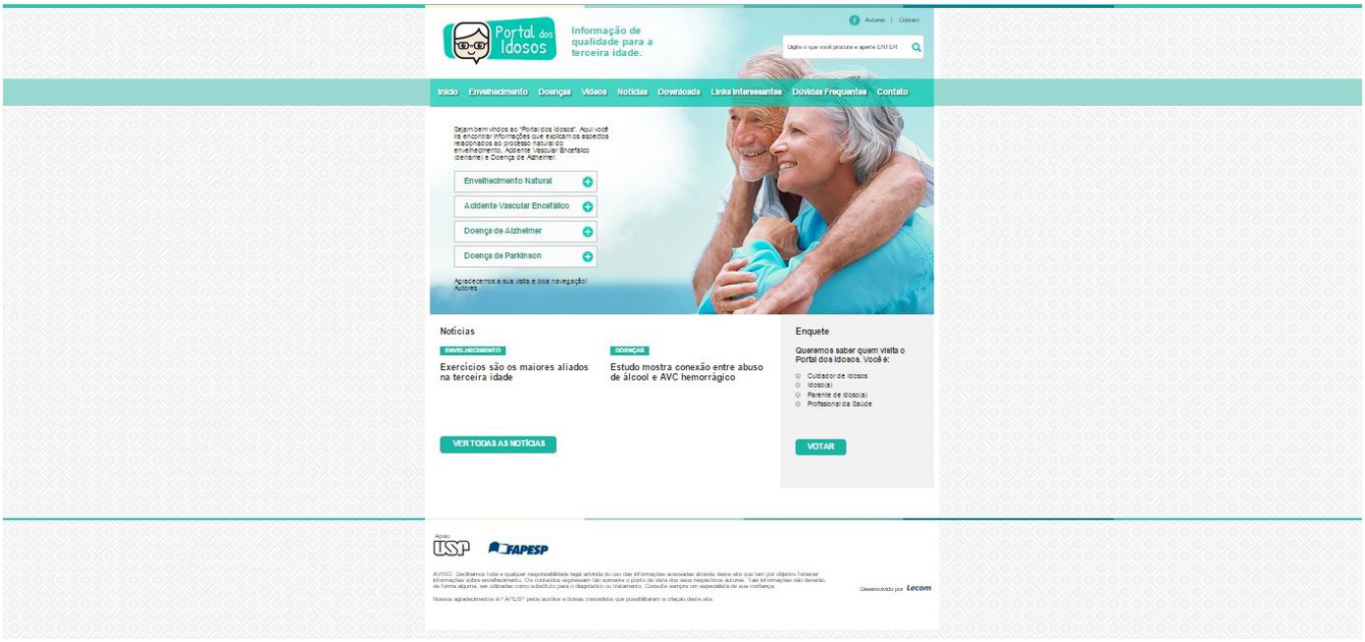

Figure 2. Homepage screen of Portal of the Elderly

The Portal for the Elderly, following the modeling stage, as well as the Alzheimer's Disease menu, were designed with a responsive layout, which allows access through different technologies, such as tablets, cell phones with access to the Internet (smartphones), or desktop or notebook computers, regardless of operating system, through the main browsers available in the market - Internet Explorer, Mozilla Firefox, Google Chrome and Apple Safari - without losing functionality and without using flash player technology. The use of technologies in TeleHealth can be defined as *e*Health (includes a spectrum of technologies such as computers, telephony and wireless communications) and *m*Health (refers to the provision of these services through cell phones). Both aim to provide information for health care, improve quality of care and reduce present disparities in health[16].

Next, we have the implementation phase, in an accepted domain, available at the electronic address[17], so that, after the evaluations, it is implemented in a domain registered by the researchers, electronic address.

There are 9 items in the Portal for the Elderly that make up its main menu, one of them being "Alzheimer's Disease", with 8 submenus and its bibliographic reference. Other menu items also have aspects related to DA, such as "News", "Videos", "Interesting Links" and "Downloads". In addition, in order to establish a link with the community that visits the website, an e-mail was created in the "Contacts" menu and it is also possible to locate the institutional link and promotion body (Figure 2).

The material contains a scroll bar on the sides of navigation pages, which helps the user to explore the content according to their needs, and also has flags that highlight the selected tab. The website structure has a reading assistant that enables the user to increase the font size of the text.

Characterization of the sample

The evaluation of the material was performed by a total of 56 individuals, 16 elderly, 12 elderly caregivers and 28 SLP therapists. The identification variables of the sample are shown in Table 1.

It was possible to observe the prevalence of the female gender in all categories and the diversity in the instructional level of the Elderly category (Table 2).

Frequent access to the Internet was observed in 31.3% of the elderly, 81.8% of caregivers and 92.9% of SLP therapists, with prevalence of home access in all categories.

When performing the inferential analysis of data related to access, the Kruskal-Wallis test presented a statistically

Table 1. Data of identification of the total sample, category and schooling

Mean age / standard deviation	45.04 / 21.13
Gender *n* (%)	
Female	45 (80.36)
Male	11 (19.64)
Category n (%)	
Elderly	16 (28.57)
Caregiver of elderly	12 (21.43)
Speech-language pathologist	28 (50.00)
Schooling n (%)	
Incomplete elementary or 1 to 3 years of study	6 (10.71)
Complete elementary / Incomplete junior high or 4 to 7 years of study	2 (3.57)
Completed junior high school / Incomplete high school or 8 to 10 years of study	5 (8.93)
Completed high school / Incomplete secondary or 8 to 14 years of study	6 (10.71)
Completed secondary or 15 or more years of study	37 (66.07)
Internet user profile *n* (%)	
Rarely	17.86%
Sometimes	8.93%
Often	73.21%

Table 2. Distribution of the mean age, gender and schooling, according to categories

	Age	Female	Male	A	B	C	D	E
	x	*n*	*n*	*n*	*n*	*n*	*n*	*n*
	(±SD)	(%)	(%)	(%)	(%)	(%)	(%)	(%)
E	74.13 (8.83)	10 (62.50)	6 (37.50)	6 (37.50)	2 (12.50)	2 (12.50)	4 (25.00)	2 (12.50)
EC	41.50 (16.05)	10 (76.92)	3 (23.08)	0	0	3 (23.07)	1 (7.69)	9 (69.23)
T	29.93 (6.12)	25 (89.28)	3 (10.71)	0	0	0	0	27 (100.00)

Subtitle: x = average age; ±SD = Standard deviation; **A =** Incomplete elementary or 1 to 3 years of study; **B =** Complete elementary/ incomplete junior high or 4 to 7 years of study; **C =** Completed junior high/ incomplete high school or 8 to 10 years of study; **D =** Complete high school / incomplete secondary or 11 to 14 years of study; **E =** Secondary complete or 15 or more years of study. E: Elderly, EC: Elderly Caregiver, T: SLP therapist

significant difference, when the frequency of Internet use by the participants was analyzed according to schooling. This difference was found between the individuals who studied until the 3rd grade of elementary school and those who had completed higher education (p <0.001). When correlating the frequency of Internet access with age and schooling, a difference was obtained, with p <0.05 (r = - 0.58, r = 0.72, respectively).

Content evaluation

In the general analysis of the content related to AD, the excellence of the material was predominant in all submenus. When checking the classification of AD data according to each category, it was considered "adequate" by 75% of the elderly, "excellent" by 84% of caregivers and 82% of SLP therapists (Figure 3).

When comparing the general score of the content evaluation questionnaire, among the categories, we found a difference between the elderly versus the caregivers and SLP therapists, with p = 0.015 and p = 0.003, respectively, according to the Kruskal-Wallis test.

When analyzing each submenu, according to the categories, a statistically significant difference was observed in the submenus on the brain and AD, the phases, communication impacts and the general score between categories (Table 3). The comparison of the general score with schooling did not show a statistically significant difference.

The classification of the quality of the website according to the categories was evaluated as "excellent" by 88% of the elderly, 75% of the caregivers of the elderly and 71% of SLP therapists (Figure 4). Statistical analysis of the subscales of the Health-Related Web Site Evaluation Form (Emory) questionnaire and the categories did not present a statistically significant difference.

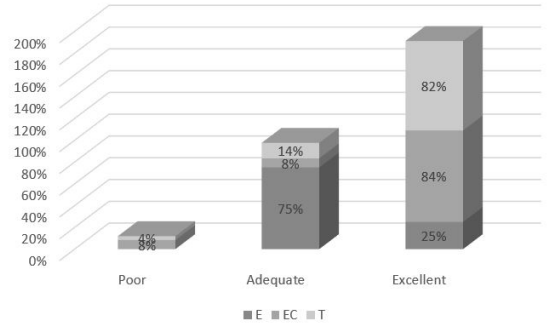

Figure 3. Evaluation of content by different categories
Subtitle: E: Elderly, EC: Elderly Caregiver, T: SLP therapist

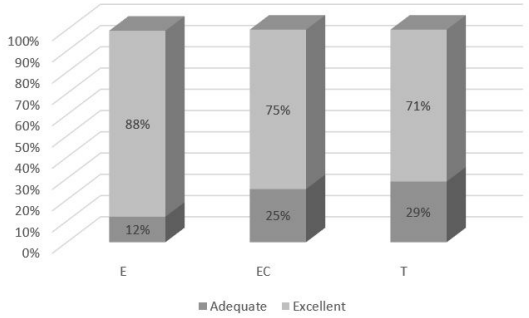

Figure 4. Evaluation of the website according to the different categories
Subtitle: E: Elderly, EC: Elderly Caregiver, T: SLP therapist

Table 3. Association measures performed between submenus and categories that evaluated website content

Submenus (S)	ExEC	ExT	ECxT
What is Alzheimer's disease?	0.417	0.384	1.000
S1. The brain and Alzheimer's disease?	0.206	0.002*	0,844
S2. Signs and characteristics of Alzheimer's disease	0,417	0,380	1.000
S3. Phases of Alzheimer's disease	0.033*	0.007*	1.000
S5. SLP guidance on Alzheimer's disease	0.676	0.207	1.000
S6. Treatment of Alzheimer's disease	0.156	0.050	1.000
S7. Impact of information generated for Alzheimer's disease	0.060	0.006*	1.000
S8. Role of caregiver/family	0.075	0.106	1.000
General	0.016*	0.003*	1.000

*statistically significant difference: Kruskal-Wallis test
Subtitle: E: Elderly, EC: Elderly Caregiver, T: SLP therapist

DISCUSSION

The website was developed with the involvement of a multidisciplinary team, mainly formed by SLP therapists and professionals involved with ICT. The Portal of the Elderly can contribute to the enrichment of health websites, with emphasis on the elderly, available in the Portuguese language.

In order to facilitate the readability and accessibility of the material, the Flesch Index was used, with only two texts (from two submenus) characterized as difficult, being "SLP Therapy Guidelines on Alzheimer's Disease" and "Treatment of Alzheimer's Disease". The index had difficulty in legibility, since the information was made available in topic format, which influenced the calculation based on sentences and words. The second was given as "difficult", but its percentile approached the "easy".

Other aspects to improve the accessibility of the website were scored, agreeing with the web accessibility assessment checklist for elderly users[18]. The website has characteristics that match this checklist, such as the presence of textual descriptions of images and videos, the absence of intermittent images and auxiliary windows, and the presentation of search functions and texts in plain and clear language, the content of which is concise.

The language used should facilitate the understanding of the individual, providing greater retention of information[19]. Thus, the written material was prepared in non-serif fonts, double-spaced, left-aligned, with a reading assistant to increase the font size, absence of abbreviations and attention to the colors in the letters and background colors used in the website.

The colors influence the receptivity of the public, to trigger feelings and sensations, focusing on the productivity and quality of the activities developed, because they attract attention, according to their visibility, contrast and purity. It is, therefore, an important aspect in the visual identity of a product, possessing symbolism, such as purity, represented by blue color and hope, by the color green[20]. The colors used in the elaboration of the website correspond to the combination of "legibility of colors" between the color of the letter and the background, pointed out by the authors previously, being these combinations between green and white, black and white, white and green, corresponding to letter and background, respectively.

Other aspects were inserted and are in accordance with the proposed checklist, such as the identification of titles and headings, figure legend and definition of a standard layout. The bibliographic references, the absence of advertisements (advertising and marketing), the presence of authorship, as well as the possibility of making contact with the authors, on all pages, sought to convey reliability in the tool available.

Regarding Internet access, it was observed that the category referring to the elderly was the one that presented the lowest access index. The elderly are those with less representativeness between the age groups, regarding the use of the Internet in Brazil[21]. Age, schooling and lack of digital inclusion projects are some of the barriers to Internet use, along with the emergence

of new technologies, which are constantly improving, requiring learning associated with usability, accessibility and intelligibility[22].

Home access to the Internet, in the present study, was prevalent in all categories. The ICT Health Study 2013 conducted a survey among medical professionals and nurses, showing that access is practically universalized, with 99% of physician and nurse Internet users[23]. This result expresses the relationship with the SLP professionals who participated in the present study, since 92.9% use the Internet frequently and 60.7% in their homes.

The prevalence of the female gender in all the categories studied was observed in this study, which may be justified by the fact that women are more likely than men to seek health information on the Internet[24]. The presence of elderly caregivers of the elderly is an aspect to be considered in planning health care services, as well as the information provided to this population[25].

The website content was rated following the Emory questionnaire classification. A statistically significant difference was observed between the elderly category and the other categories, indicating the need for content adjustments and subsequent re-evaluation. In the evaluation of the categories, the website was found to provide relevant information and could be navigated without many problems. It should be noted that the evaluation referred to as "excellent", by the aforementioned categories, is extremely important to justify the quality of the work, and the evaluation of the SLP therapists is an indication to obtain the technical support of the material.

Access to online health information allows the empowerment of the individual, transforming the relationship between the health professional and the patient, in opposition to the paternalistic model, in which the patient was passive in relation to his own health. In this context, there is a new social actor, the expert patient, who seeks information on diagnoses, diseases, symptoms, medications and costs of hospitalization and treatment, composing virtual communities, most of which are individuals affected by chronic diseases, rare or stigmatizing[26].

A study carried out with patients and caregivers/care providers pointed to the preference for data sources related to information technologies, such as those referring to the use of computers, websites and videos, followed by orientations made by people, and finally, printed materials[27]. Therefore, a way of communicating, guiding and retaining information can be promoted, favoring better results in caring for patients, relatives and caregivers.

The search for health information (of a disease or treatment) on the Internet may be important for the patient to obtain specific information related to his/her health condition; however, it is suggested that the medical staff be involved in order to help the individual organize their thoughts before and after the search for a second opinion, either with another physician or on a website[28].

The actions in health promotion in AD are present in the literature, through extensive studies focusing on caregivers, especially informal ones. The informational support is fundamental so that the caregivers can offer better conditions of care to the elderly, either on the treatment of the illnesses or for a harmonious coexistence before the difficulties of behavior of the individual[29].

Online information consultation may not be the most appropriate way to reduce caregiver stress, but it may be one of the tools to help overcome some of the barriers imposed by AD.

The Emory questionnaire was selected and used in the present study because it presented a website evaluation tool with reliable results and a greater ease of understanding between the questions[11].

The analysis of the quality of the website as a whole was presented as "excellent". There was no statistically significant difference between the subscales or the overall score.

The web provides spaces for the dissemination of knowledge related to health, and it is possible to observe the focus on risk prevention in the context of dementia, referring to self-care and self-responsibility in the health and disease process. The sites can aid in brain injury risk and dementia risk reflection, as well as provide information on risk factors associated with AD[30].

Health education is seen as a promotional tool and a stimulus to self-care, generating opportunities for the elderly and those around them to become aware of and empower themselves, aiming at their quality of life (3).

Because the data collection process was linked to the access of participants to the online system, it may be difficult to increase the size of the study population in the different categories analyzed. Further research is needed to establish a detailed description of access to themes and related areas in order to direct actions involving health professionals to new information and communication technologies.

CONCLUSION

The website was prepared following the proposed steps of analysis and planning, modeling and implementation. The content of the website was evaluated as "excellent" and its technical quality as "adequate", and is therefore considered a material with information about AD, which is a reliable source of information or information supplementation.

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