EDUCATIONAL SUPPORT GUIDE FOR FAMILY MEMBERS AND CAREGIVERS OF THE ELDERLY WITH ALZHEIMER'S: CONTENT VALIDATION

GUIA EDUCATIVO DE APOIO A FAMILIARES E CUIDADORES DE IDOSOS COM ALZHEIMER: VALIDAÇÃO DE CONTEÚDO

GUÍA EDUCATIVA PARA APOYAR A FAMILIARES Y CUIDADORES DE ANCIANOS CON ALZHEIMER: VALIDACIÓN DE CONTENIDO

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Objective: to create and validate an educational guide as a technological resource to support caregivers and family members of the elderly with Alzheimer's. Method: methodological research guided by Pasquali's model for content validation, developed in four stages: literature review, in the search for knowledge synthesis; construction of the first version and production of the educational guide; content validation by expert judges; construction of the second version. The data obtained were statistically analyzed based on the minimum agreement index of 80%. Review of the guide for drafting the final version in the fourth stage. A study conducted nationwide, through digital means, reaching the North, Northeast and Midwest regions of Brazil. Results: 15 expert judges participated in the validation. The content of the educational guide obtained a global content validity index of 0.90 in a single round. Conclusion: the educational guide proved to be adequate and valid as a technological resource in supporting family members and caregivers of elderly people with Alzheimer's.

Descriptors: Alzheimer Disease. Old Age Assistance. Quality of Life. Validation Study. Health Education. Educational Technology.

Objetivo: criar e validar um guia educativo como recurso tecnológico no apoio a cuidadores e familiares de idosos com Alzheimer. Método: pesquisa metodológica guiada pelo modelo de Pasquali para validação de conteúdo, desenvolvida em quatro etapas: revisão da literatura, na busca da síntese do conhecimento; construção da primeira

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versão e produção do guia educativo; validação de conteúdo por juízes-especialistas; construção da segunda versão. Os dados obtidos foram analisados estatisticamente com base no índice de concordância mínima de 80%. Revisão do guia para elaboração da versão final na quarta etapa. Estudo realizado em âmbito nacional, por meio digital, atingindo regiões Norte, Nordeste e Centro-Oeste do Brasil. Resultados: participaram da validação 15 juízes-especialistas. O conteúdo do guia educativo obteve índice de validade de conteúdo global de 0,90 em uma única rodada. Conclusão: o guia educativo revelou-se adequado e válido como recurso tecnológico no apoio a familiares e cuidadores de idosos com Alzheimer.

Descritores: Doença de Alzheimer. Assistência a Idosos. Qualidade de Vida. Estudo de Validação. Educação em Saúde. Tecnologia Educacional.

Objetivo: crear y validar una guía educativa como recurso tecnológico de apoyo a cuidadores y familiares de ancianos con Alzheimer. Método: investigación metodológica guiada por el modelo de validación de contenido de Pasquali, desarrollado en cuatro etapas: revisión de la literatura, en la búsqueda de síntesis de conocimiento; construcción de la primera versión y producción de la guía educativa; validación de contenido por jueces expertos; construcción de la segunda versión. Los datos obtenidos fueron analizados estadísticamente en base al índice mínimo de concordancia del 80%. Revisión de la guía para la redacción de la versión final en la cuarta etapa. Un estudio realizado a nivel nacional, a través de medios digitales, llegando a las regiones Norte, Nordeste y Medio Oeste de Brasil. Resultados: 15 jueces expertos participaron en la validación. El contenido de la guía educativa obtuvo un índice global de validez de contenido de 0,90 en una sola ronda. Conclusión: la guía educativa demostró ser adecuada y válida como recurso tecnológico en el apoyo a familiares y cuidadores de ancianos con Alzheimer.

Descriptores: Enfermedad de Alzheimer. Asistencia a los Ancianos. Calidad de Vida. Estudio de Validación. Educación en Salud. Tecnología Educacional.

Introduction

Chronic noncommunicable diseases (CNCDs) represent an important public health problem in the world, affect about 60% of deaths and have gradual growth in countries considered low-middle and low income[1].

In the elderly population, CNCDs can affect individuals throughout their aging process, resulting in several difficulties, such as loss of independence and ability to perform basic daily activities[2]. As an example, dementias stand out, which affect not only the sick person, but also the entire family and society, causing a great psychosocial and economic impact[3].

Among the dementias described in the literature, Alzheimer's Disease (AD) is the one that most affects the population aged 60 years or more[4], affecting about 35.6 million people globally. Its progression to 2050 is approximately 65.7 million cases[1]. AD is a primary degenerative brain disease of unknown etiology, with neuropathological and neurochemical aspects, which affects multiple cortical functions and involves understanding, language, behavior and memory (ICD-102)[3].

The AD is silent and affects even the most prepared, weakening the family group completely, triggering countless feelings in the caregiver, such as concern, sadness, remorse, among others. The family becomes the main source of care for people living with AD[5]. This is due to family concern or legal responsibility, despite the lack of knowledge about the care to be provided to these people[5]. In this sense, the interest emerged to produce an educational technology (ET) that could contribute to the provision of care to the elderly with Alzheimer's disease, based on the need for a validated production that would provide not only the improvement of the care offered, but also the quality of life of the individual and his/her caregivers.

In the context of health and nursing practice, educational technologies have been produced, but the vast majority are neither validated nor evaluated. Printed educational materials, of the type of posters, booklets, handbooks, guidance books or handouts, are usually made available to the population before being tested and are

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not always (or almost never) submitted to a validation process. This is mainly due to the fact that many health and nursing professionals do not know this process[6].

Based on the above, the following questions arose: A guide on AD produced based on the synthesis and translation of knowledge available in the literature, after content validation, proves to be appropriate for people who live and care for elderly people with Alzheimer's? What are the suggestions of expert judges about the guide?

This study aims to create and validate an educational guide as a technological resource to support caregivers and family members of elderly people with Alzheimer's.

Method

This is a methodological research[7], with a quantitative approach, developed in four stages (Figure 1).

Figure 1 – Flowchart of the steps of the methodological research validation of the educational guide
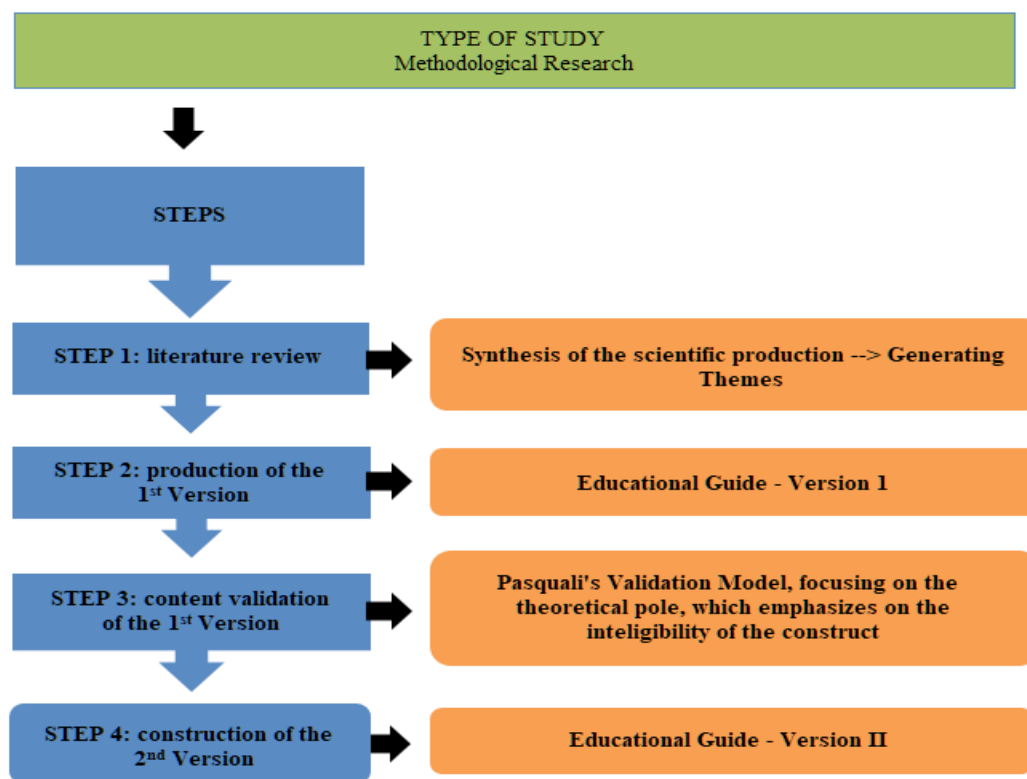
Source: Created by the authors.

The review stage took place from August to December 2019; the first version of educational technology was produced from January to May 2020; the content validation of the educational technology by expert judges[8] took place from June to August 2020; and the construction of the second version of educational technology took place between August and September 2020.

For the literature review, the following question was used: What information is needed to support caregivers and relatives of elderly

people with Alzheimer's to ensure quality of life in the home context? Next, the following were defined as descriptors: Alzheimer Disease; Old Age Assistance; Quality of Life; Validation Study; Health Education; Educational Technology. For the combination of health descriptors, Boolean operators AND and OR were used. Inclusion criteria were: complete scientific articles, freely available, published in the past ten years (2009-2020), in the Portuguese, English and Spanish languages. Exclusion criteria

were: theses, dissertations, editorials, duplicate publications and those that did not answer the research question formulated. After the selection, the complete texts were read and the synthesis of the scientific production was made, with a view to identifying the generating themes.

For the production of the first version of the educational guide, the identified generating themes were taken as reference. After selecting the contents and illustrations, the editing and diagramming were made according to criteria related to the content (care of the elderly with Alzheimer's) and the structure-organization (printed format), with special attention to the aspects of language, layout, design and cultural sensitivity.

For content validation, the expert judges were selected through inclusion criteria – expertise within the scope of ET (Educational Technology), by consultation at the Lattes platform – and exclusion - not responding to electronic contact for 20 days during the period of data collection. Regarding the definition of the number of expert judges, the sample considered was between 17 and 24 judges[9]. Thus, 24 specialists were identified. After the invitation, 21 agreed to participate in the study. After sending the instrument, 15 returned within 20 days.

Data collection was performed by e-mail, with the forwarding of an inviting e-mail. After reply, a new e-mail was sent with a copy of the ET in PDF, a copy of the instrument and a copy of the Informed Consent Form (ICF), through a form on the Google Forms platform.

The questionnaire was validated and organized according to the Likert[10] scale, with questions related to the evaluation of the content of the ET, with three parts: identification, completion orientation and Likert scale. Each judge-specialist expressed his/her assessment in grades 1 through 4, being 1 (Totally adequate), 2 (Adequate), 3 (Partially adequate) and 4 (Inadequate), in order to obtain the Content Validity Index (CVI). This was calculated by the sum of agreement of the items marked "1" and "2", divided by the total responses.

After collection, the data were inserted into a spreadsheet in Microsoft Excel®, version 2013, and later statistically processed. The quantitative analysis was based on a CVI equal to or greater than 80%. For the production of the second version of the educational guide, the suggestions forwarded by the judges were considered.

According to the ethical recommendations of the Ministry of Health[11], in Resolution n. 466/12, item II, point 5, each judge signed the ICF. This research is a subproject of an integrated project, approved by the Research Ethics Committee of the Lutheran University Center of Manaus, according to certificate of presentation of ethical appreciation (CAAE) n. 88932418.3.0000.5014.

Results

In the literature review (Stage 1), 16 articles were obtained, which were coded by Arabic numerals (1, 2, 3 ... 16). After thorough reading of the articles, 13 significant themes were listed to make up the educational guide (Chart 1).

Chart 1 – Generating Themes according to identification of the articles in which they were cited

(continued)

Generating Themes	Identification of the articles in which they were cited
1 – Definition of Alzheimer's Disease	1, 2, 3, 5, 6, 7, 8, 9, 10, 12, 15,16
2 – Classifications and internships	1, 2, 3, 5, 6, 16
3 – Signs and symptoms	1, 2, 3, 5, 6, 7, 9, 10, 12, 14
4 – Autonomy	1, 3, 6, 10
5 – Communication	1, 2, 9, 12
6 – Security and protection	1, 3, 5
7 – Physical activity and leisure	1, 4, 13
8 – Support group	1, 2, 3, 8

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Chart 1 – Generating Themes according to identification of the articles in which they were cited

(conclusion)

Generating Themes	Identification of the articles in which they were cited
9 – Home infrastructure	1, 10
10 – Hygiene	1, 2, 3, 4, 5, 7
11 – Nutrition and hydration	1, 4
12 – Medications	1, 2, 3, 4, 11
13 – Skin Integrity/Decubitus Change	1, 4

Source: Created by the authors.

The first version of the guide (Step 2) was based on the themes identified in the literature review. Texts were produced in the format of dialogue between the main character, entitled "Dona Lu", which addresses the themes of care for the elderly with Alzheimer's disease, and the character "Dona Maria". After the creation of the content, both textual and imagery, the first version, entitled "Guide for Family members and caregivers: Alzheimer's disease", contained 88 pages. It was developed in the CANVA program. The first version was made available to the expert judges in the digital format for evaluation.

For the content validation process (Step 3), 15 expert judges, aged 31 to 57 years (mean 44.66 years), from the areas of Medicine, Nursing and Psychology (Table 1) were selected.

Table 1 – Sociodemographic profile of expert judges. Manaus, Amazonas, Brazil – 2020. (N=15)

(continued)

Variables	n	%
Gender		
Male	1	6.67
Female	14	93.33
Age – Mean	44.66 years	
Age Group		
30-35	3	20
36-40	3	20
41-45	2	13.33
46-50	2	13.33
51 or +	5	33.33
Residence region		
North	12	80
Northeast	1	6.67
Southeast	-	-
South	-	-
Midwest	2	13.33
Training area		
Nursing	13	86.67
Psychology	1	6.67
Medicine	1	6.67
Occupation		
University professor	8	53.33
Care nurse	4	26.67
Care doctor	1	6.67
Municipal Secretary of Elder Health	2	13.33

Table 1 – Sociodemographic profile of expert judges. Manaus, Amazonas, Brazil – 2020. (N=15)

(conclusion)

Variables	n	%
Time of professional training		
5-10 years	4	26.67
11-15 years	3	20
16-20 years	1	6.67
21-25 years	2	13.33
26-30 years	5	33.33
Degree		
Specialist	4	26.67
MCs	6	40
PhD	5	33.33
Total	**15**	**100**

Source: Created by the authors.

Note: Conventional signal used:
- Numeric data equal to zero not resulting from rounding.

The objective aspects, structure and presentation and also relevance, which is expected to be achieved with the use of the guide, are exposed in three blocks.

In the "Block 1 - Objectives", which refers to the objectives it proposes to achieve with the use of the guide and goals, the validated and organized questionnaire was applied according to the Likert[10] scale, with questions related to the evaluation of the content of the ET, with three parts: identification, completion orientation and Likert scale. Each judge-specialist expressed his/her assessment in grades 1 through 4, being 1 Totally Adequate (TA), 2 Adequate (A), 3 Partially Adequate (PA), 4 Inadequate (I).

There were 49 (65.33%) assessments for TA, 23 (30.67%) for (A), 3 (4%) (PA) and none Inadequate. According to the answer options given by the judges, the TA and A scores totaled 72, which corresponded to a Content Validity Index (CVI) of 0.96.

Regarding "Block 2 - Structure and presentation", which refers to the presentation of the guidelines of the guide, structure, appearance, coherence and formatting, 95 (52.78%) for TA, 58 (32.22%) for A, 22 (12.22%) for PA, and 5 (2.78%) I according to the judges' assessment, 153% of the judges, according to the judges' evaluation, represented 85% of the valid answers. The CVI was 0.85.

Regarding the "Block 3 – Relevance", which refers to the meaning of the educational technology produced, 50 (66.67%) TA markings, 21 (28.00%) markings for A, 4 (5.33%) PA according to the response options given by the judges, none for I, the TA and A scores totaled 71, which is equivalent to 94.67% of the valid answers. This block reached CVI of 0.95.

The ET obtained 194 (58.78%) TA markings and 102 (30.90%) A markings, totaling 296 markings. There were 29 (8.78%) PA and 5 (1.5%) I. A general CVI of 0.90 was reached. Regarding CVI, among the 22 items, 21 items above 0.70 and 1 below 0.70 were obtained.

The expert judges offered the following suggestions: reduce the number of pages of the guide by compiling subjects; include images where there is too much text; attention to care that is specific to nursing; review spelling and formatting; apply Portuguese language standards; replace technical terms with colloquial terms or enter the setting. They concluded that all professionals can use it, but it is directed mainly to the family caregiver; highlighted the great importance for the intended audience and for the wide range of content.

The second version of the educational guide (Step 4) was organized as follows: thanks, summary, presentation, Part 1 *Alzheimer's disease, with sections* 1.1 Forgetfulness and

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1.2 Stages of the disease; Part 2 *What is important to know about Alzheimer's Disease*, with sections 2.1 Memory, 2.2 Music, 2.3 Communication, 2.4 Care and Personal Hygiene, 2.5 Clothing, 2.6 Eliminations, 2.7 Change of decubitus, 2.8 Medication, 2.9 Hydration, 2.10 Food, 2.11 Physical Structure of Residence, 2.12 Protection and Safety, 2.13 Socialization, 2.14 Support Network, 2.15 Physical Activity and Leisure, 2.16 Sleep and Rest, Final Words and References. This version was 51 pages long.

Figure 2 shows the cover of the final version.

Figure 2 – Educational Technology Cover of the Guia para Familiares e Cuidadores sobre a Doença de Alzheimer
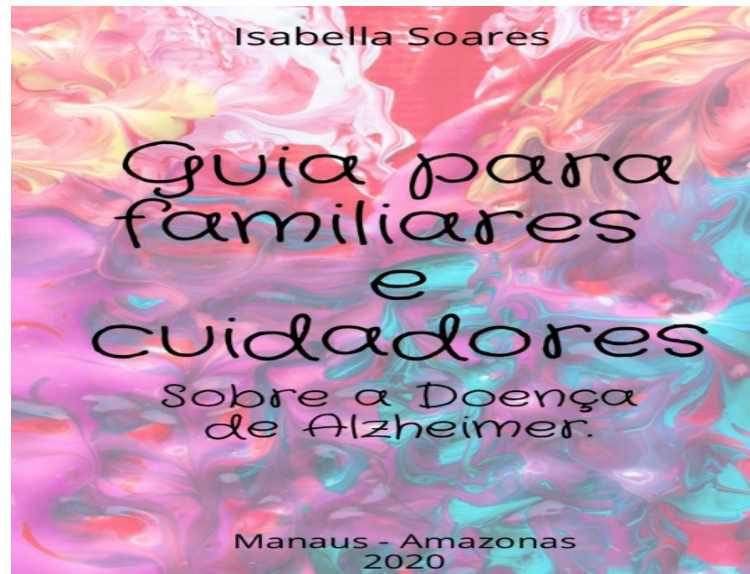
Source: Created by the authors.

Discussion

The literature review allowed extracting information on the main themes related to AD and the demands of care for the elderly, in addition to the construction of a support guide for their family members and caregivers. The 12 themes selected for the illustrated guide included the concept of AD, the main manifestations, its phases and primary care related to existing cognitive alterations, according to the evolution of the disease.

A study points out that the development of ETs guided by reviews of scientific literature provide the use of concepts and principles that strengthen the achievement of the objectives of the expected educational process. In addition, the study identified that only one third of the ET research in the elderly used scientific foundation in the construction process[12].

A research[5] recognizes that the family is the main source of care, due to family concern or legal responsibility, even though there is a lack of knowledge about the care to be provided to people with AD. Studies conducted with caregivers of elderly people with care needs reveal that the family is the most important social source of care for these individuals. They also highlight that the family develops emotionally, mentally and spiritually in interrelational spaces of conflicts, and that, in situations of illness, family members usually rely on each other to face and overcome the difficulties experienced[13-14].

In this direction, there is the importance of care relationships between the family and the elderly, the family of the elderly and the caregiver and the caregiver with the elderly and the family context. Thus, it is emphasized that the provision of care, both by the family member and by the caregiver, must be supported by ethics, respect

and affection, in order to establish forms of mutual relationship, meeting the needs imposed by the real situations of illness and well-being of the elderly with AD[15].

The constructed guide was intended to assist mainly family members and informal caregivers, by bringing a colloquial language and an interactive dialogue with the reader, in order to make the reading easier and more comprehensive, and to use, for the most part, self-explanatory illustrations.

Concerning the validation of the first version of this guide, the expert judges stressed the importance of directing the caregiver/family member, as they described: "[...] of great importance to the intended audience, with a wide reach. Wonderful content" and "All professionals can use it, but it is very targeted at the family caregiver". The guide obtained a global CVI from the expert judges of 0.90, presenting the validation of its content comparing it with other studies in this context of the construction and validation of a product[16-18].

The construction of the guide observed the study orientation[10] on attitude measurement scales, in which the production of printed ETs requires the fulfillment of stages and paths, such as: survey of scientific evidence; definition of the objective and purposes of the ET; selection of ET's target audience; choice of ET format (guide, folder, brochure, handbook, etc.); definition of content and illustrations; planning of actions; and, finally, the elaboration of the "pilot" of the ET.

After validation, the suggestions of the expert judges were listed and analyzed resulting in the following changes in the second version of the guide: reduction of the number of pages, orthographic review, synthesis of the contents addressed, exchange of technical terms for similar ones or addition of its concept. This last change resulted from the understanding that, because it is an educational technology, it would be necessary to analyze the target audience and the current context in which it was inserted. It was necessary to create opportunities for caregivers and family members to know the disease, to understand the patient and, consequently, the

possibilities of action (safe and effective) in this patient[4].

In the guide, the option for the use of dialogue as a textual genre was purposeful, thinking about the very concept of health education. The direct relationship of the educator with the student was aimed at the same level, considering that the student participates in his/her autonomy, in the development of his/her own knowledge. Thus, there is not only the transfer of information on a given subject, but the progress of this individual[19].

It is important to inform that the study results[20] showed that, in most cases, the knowledge and information of caregivers about Alzheimer's disease were acquired through information provided by the media, which ended up generating a type of erroneous care. In addition, in the case of this study, 65% of the caregivers reported not having received any type of guidance from the health team about the necessary care and/or the disease and only 50% of patients with Alzheimer's disease received the assistance of some type of health team professional in the home environment. Thus, there is the need to provide this public with a validated technology about the theme, to support not only the care provided by the caregiver, but also to help health professionals to provide health education for this population.

Nurses, as part of the multidisciplinary health team, can offer caregivers subsidies for the instrumentalization of care and guide their adaptation in the home context, referring to the progressive dependence of the elderly resulting in Alzheimer's disease, both in the most complex activities and in basic needs[21]. Thus, the inclusion of ET comes to assist in the promotion of health education, not only for the individual, but also for society.

A difficulty, in this study, was the task of selecting specialists and the return of online responses in the validation process of ET. As limiting factors, there stands out the scarcity of recent studies in the scope of ET for the elderly with AD and the non-participation of the

guide's target audience in the content validation stage, with perspectives for further research.

Although this study has achieved potentially positive results for the applicability of the guide, future studies are needed that can carefully evaluate the use of this ET with the target audience.

Conclusion

The educational guide created as a technological resource to support caregivers and relatives of elderly people with Alzheimer's was considered statistically valid by the expert judges who participated in the validation stage. The illustrated guide will be registered and made available in printed media. Thus, in the context of health education, ET is adequate and may contribute to the knowledge and practice of care with family members and caregivers of elderly people affected with Alzheimer's disease, as well as will support nurses and other health professionals in the mediation of care.

Moreover, the ET structured based on scientific knowledge and validated are dynamic, creative and valuable tools for the transformation of the health and disease process of individuals. In this sense, they enable the promotion of care and quality of life for the elderly and their caregivers.

Collaborations:

1 – conception, design, analysis and interpretation of data: Isabella Pinheiro Pinto Soares and Elizabeth Teixeira;

2 – writing of the article and relevant critical review of the intellectual content: Isabella Pinheiro Pinto Soares and Elizabeth Teixeira;

3 – final approval of the version to be published: Isabella Pinheiro Pinto Soares, Elizabeth Teixeira, Aldalice Aguiar de Souza, Anete de Oliveira Leda, Aline de Souza Lima and Karolina Dessimoni Victoria.

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