

DEVELOPMENT OF AN INFORMATION BOOKLET FOR FAMILY MEMBERS AND CAREGIVERS OF CHILDREN WITH AUTISM

ELABORAÇÃO DE UMA CARTILHA INFORMATIVA PARA FAMILIARES E CUIDADORES DE CRIANÇAS COM AUTISMO

ELABORACIÓN DE UN FOLLETO INFORMATIVO PARA FAMILIARES Y CUIDADORES DE NIÑOS CON AUTISMO

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Objective: to describe the development of an informative booklet for families and caregivers of children living Autism Spectrum Disorder. **Method:** methodological research, conducted between September 2019 and July 2022, in southern Brazil. **Results:** the creation involved the theoretical stage, content validation and construction of the booklet called "Autistic Children": Booklet for Families and Caregivers. Composed of six chapters: characteristics of the disorder, behavior of the child, rights, future of children with autism and sharing experiences and views. The content was validated, and, for the construction of the booklet, the preferences of technological devices and layout of informative resources by the relatives were investigated; after, the prototype of the booklet went through usability and navigation test, hosted on Articulate Storyline Software and is available to the target audience. **Final considerations:** the process of developing educational resources for families can help other researchers with interest in the area.

Descriptors: Access to Information. Child. Family. Autism Spectrum Disorder. Nursing Research.

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** Children with autism.

Objetivo: descrever a elaboração de uma cartilha informativa para familiares e cuidadores de crianças que vivem Transtorno do Espectro Autista. Método: pesquisa metodológica, realizada entre setembro de 2019 a julho de 2022 no sul do Brasil. Resultados: a elaboração envolveu a etapa teórica, validação de conteúdo e construção da cartilha denominada “Crianças autistas”: cartilha para familiares e cuidadores”. Composta com seis capítulos: características do transtorno, comportamento da criança, direitos, futuro da criança com autismo e compartilhando experiências e visões. O conteúdo foi validado e para a construção da cartilha foram investigadas as preferências de dispositivos tecnológicos e layout de recursos informativos pelos familiares; após, o protótipo da cartilha passou por teste de usabilidade e navegação, hospedada no Articulate Storyline Software e está disponível para o público-alvo. Considerações finais: o processo de elaboração de recursos educativos para familiares pode auxiliar outros pesquisadores com interesse na área.

Descritores: Acesso à informação. Criança. Família. Transtorno do Espectro Autista. Pesquisa em Enfermagem.

Objetivo: describir la elaboración de un folleto informativo para familiares y cuidadores de niños con Trastorno del Espectro Autista. Material y método: investigación metodológica realizada entre septiembre de 2019 y julio de 2022 en el sur de Brasil. Resultados: la investigación incluyó una etapa teórica, la validación del contenido y la construcción de un folleto llamado “Niños autistas”: folleto para familiares y cuidadores”. Consta de seis capítulos: características del trastorno, comportamiento del niño, derechos, futuro de los niños con autismo y compartir experiencias y visiones. Se validó el contenido y, para elaborar el folleto, se investigaron las preferencias de los familiares en cuanto a dispositivos tecnológicos y disposición de los recursos informativos; a continuación, el prototipo de folleto se sometió a pruebas de usabilidad y navegación, se alojó en Articulate Storyline Software y ya está a disposición del público destinatario. Consideraciones finales: el proceso de desarrollo de recursos educativos para familiares puede ayudar a otros investigadores interesados en el área.

Descriptorios: Acceso a la información. Niños. Familia. Trastorno del Espectro Autista. Investigación en Enfermería.

Introduction

In healthcare, families and patients need information and this is an integral part of professional practice in various areas, including nursing. Nurses have the task of empowering families with the knowledge to make decisions about the health of their members⁽¹⁾; making it relevant to develop information content to guide families in the face of altered health situations or those undergoing recovery or rehabilitation.

Among the different health conditions is Autism Spectrum Disorder (ASD), a life condition that requires family members and caregivers to face different challenges and great dedication to the child, requiring informational support based on their needs, to help them make decisions to provide care for the child⁽²⁾. However, families often report difficulties in accessing information and resources for childcare⁽³⁾.

With this in mind, health researchers have developed educational/informational materials, such as booklets, videos, apps and more^(4,5). These constitute informational support, which is defined as providing information to a person/

family in order to help them deal with personal issues and day-to-day problems. Consequently, this type of support can help them make decisions⁽⁶⁾ about health issues in which they are involved, as in the case of family members and caregivers of children who have Autism Spectrum Disorder.

Method

This is a methodological study on the development of an interactive information booklet for families and caregivers of children with ASD, developed between March 2019 and July 2022 at a public university in southern Brazil. This research is part of a *Stricto Sensu* postgraduate doctorate in nursing. The booklet was developed in the following stages: 1) theoretical content survey; 2) content validation; and 3) prototype/booklet construction.

The first stage involved an integrative literature review and semi-structured interviews with 60 family members of children with ASD.

The inclusion criteria were family members of children aged between four and ten who lived in the same house with the child. The exclusion criterion was under 18 years of age. Data collection took place in public and non-governmental health and education services that care for children with autism, in different municipalities in the states of Paraná, Ceará and Amapá (multicenter project), Brazil. A semi-structured instrument was used with questions aimed at surveying the target audience's need for information support. The interviews were audio-recorded and later transcribed.

The data from the integrative review and the interviews were subjected to thematic categorical analysis⁽⁷⁾ and were named, respectively, "Information needed by families of children with autism spectrum disorder: an integrative review" and "Information needed by families of children with autism spectrum disorder: an integrative review".

The second stage of the research (content validation) was carried out using the Delphi technique. The participants worked in nursing, medicine, psychology, speech therapy, occupational therapy, physiotherapy, music therapy, physical education, social work, law and pedagogy. They were selected through the Lattes Platform (Curriculum Lattes) of the National Council for Scientific and Technological Development and an invitation was sent to those who obtained at least 10 points, according to their professional performance in the field of ASD in the last five years⁽²⁰¹⁵⁻²⁰²⁰⁾, according to the following criteria:

In terms of qualifications and intellectual production: doctor: 10 points; master: 7.5 points; specialist: 5 points; publication of scientific articles: 2.5 points; research project coordinator: 5 points; book chapter: 2.5 points; abstracts in event proceedings: 1 point; publication of expanded abstracts: 2 points; further training (courses): 2.5 points; participation in events/congresses: 1 point. With regard to teaching experience, a minimum of five years: 5 points; experience of ten years or more: 10 points; undergraduate academic supervision: 1 point;

master's supervision: 2.5 points; doctoral supervision: 4 points. Healthcare experience of at least five years: 5 points; and healthcare experience of ten years or more: 10 points.

The sample of experts was six respondents per content, as the recommendation is five to ten respondents per content⁽⁸⁾. A data collection tool was adapted from another study with content validation⁽⁹⁾, using the following questions: Does the content address important information for family members of children with ASD? Are the messages presented clearly and objectively? Is the information up-to-date and in line with scientific literature? The answer options were "Agree" or "Disagree".

Once the experts had been identified on the Lattes Platform, they were contacted by e-mail and sent a link which, when clicked, directed them to the Typeform software (online tool) where the research questionnaire was to be found. The participants were informed of the return of the evaluations within 15 days, after which the completed questionnaires were stored, tabulated in Microsoft Excel and the content validity index (CVI) for each item and the overall CVI for each questionnaire were calculated.

To calculate the CVI, the number of "Agree" responses was added up and divided by the total number of responses. The overall CVI was determined by adding up all the CVIs calculated separately, divided by the number of items in each questionnaire. Content with a minimum CVI of 75% was considered valid, both for each item and for the overall assessment.

The third stage of the research was carried out in partnership with a professor/researcher and students from the Graduate and Undergraduate Design Program at a public university in Paraná, Brazil. Based on the validation of the information, a prototype of the information content was developed in the format of an interactive booklet. To create the booklet, similar materials on the internet were analyzed to understand the layout choices of information materials on autism.

The profile of the target audience was also researched. This data was obtained by applying a Google Forms form to 33 family members

of children with autism. The family members were selected through groups of parents using the Whatsapp application and social networks: eight pages and eight Facebook groups aimed at people who have contact with autistic people.

The questionnaire consisted of the sociodemographic profile of the target audience; data on the most suitable device (cell phone, tablet, computer) to be used; questions about layout preferences, such as colors, use of text and images; and the following research question: "What do you think should not be missing from digital material to inform parents and relatives of autistic children?"

Subsequently, the booklet prototype was produced in Power Point and each screen was saved in Portable Network Graphics format and imported into FIGMA (a user interface creation and prototyping tool) in order to simulate interaction with the user. The first chapter of the prototype was used to test usability, as well as reviewing preferences for the graphic presentation of information. Ten people took part, as the aim was to evaluate navigation. People exclusively involved with children with autism did not take part.

An individual interview was held with each participant via video call, and the user was given the link to access the prototype to be evaluated. The participant shared the screen of the device they were using so that the interviewers could follow their interaction with the booklet. A list of tasks was dictated to the users while they interacted with the material.

The interactions were then entered into the Articulate Storyline. The use of this resource

was made possible through a partnership with a team that works with information technology at a School of Public Health in the state of Paraná, Brazil.

This research followed the norms of Resolution 466/2012 of the Brazilian National Health Council, which complies with the ethical precepts of research with human beings. The project was approved by the Ethics Committee with CAAE registration number 73197617.0.1001.0102 and Opinion number 2.327.633 in October 2017, and Opinion 3.312.897 in May 2019. Likewise, this study followed the research guidelines at all stages.

Results

Stage 1 – Survey of the theoretical content

The integrative review and interviews allowed a theoretical synthesis of the information needs of family members and caregivers, as shown in Chart 1 and 2.

The characteristics of the interviewed family members showed that the average age of the participants was 37 years, 97% (n=58) were female, 47% (n=28) married. Regarding schooling, 45% (n=27) had 9 to 11 years of schooling. Regarding employment, 58% (n=35) were unemployed. As for the bond with the child, the vast majority, 88% (n=53), were mothers of children who had ASD. Regarding family income (minimum wage (MW) of the year 2020 was 1,039.00 BRL), 35% (n=21) reported having an income below one minimum wage.

Chart 1– Synthesis of information required by family members and caregivers about the characteristics of Autism Spectrum Disorder and the child's behavior. Amapá, Ceará, Paraná, Brazil – 2020 (continued)

Theoretical data from the Integrative Review	Empirical data (interviews with family members)
Characteristics of Autism Spectrum Disorder	
Definition of the disorder	[...] because I didn't know what autism is and to this day I need to inform myself, seek and study so that I can understand and accept. (AP-CEC-19).

Chart 1– Synthesis of information required by family members and caregivers about the characteristics of Autism Spectrum Disorder and the child's behavior. Amapá, Ceará, Paraná, Brazil – 2020 (conclusion)

Theoretical data from the Integrative Review	Empirical data (interviews with family members)
Cause	<i>We never know what causes it, why children are born with it. (CE-RC-1).</i>
Signs	<i>It was hard, because we couldn't what the child had, what was age-related or disease-related, syndrome-related. (PR-CNI-1).</i>
Cure	<i>[...] actually we don't know if there's a cure or not. (AP-CEC-9).</i>
Risk of having another child with Autism Spectrum Disorder	<i>[...] [the second child with autism] was born, I thought he wouldn't have this problem [autism], but it has nothing to do. (AP-CEC-3).</i>
Diagnosis	Not identified.
Tests	Not identified.

Behavior of children with Autism Spectrum Disorder

Communication	<i>[...] I'd like information about how to deal with crises. (PR-PSCC-1).</i>
Daily routines	<i>[...] sometimes he feels pain, sometimes more intensely, sometimes he feels no pain. I have too much to learn about it. (CE-APFE-2).</i>
Children's sleep rest	<i>[...] she didn't like hearing the noise of a blender, a hairdryer, all that. (AP-CEC-13).</i>
Children's self-care	<i>I'd like to know how he [child] sleeps, what I do to make him sleep. (CE-RC-1).</i>
Leisure activities	<i>[...] I'd like to know how to draw the line, what he can do and what he can't. (PR-CNC-16).</i>
Sensory abilities	
Aggressive behaviors, tantrums and stims	
How to deal with sexuality	

Source: created by the authors.

Notes: AP- Amapá; CEC- Child Education Center; CE- Ceará; RC- Rehabilitation Center; PR- Paraná; CNC- Child Neurology Center; PSCC- Psychosocial Care Center; APFE- Association of Parents and Friends of the Exceptional.

Chart 2 shows the category of rights, classified in the following subcategories: legislation, protection against discrimination, right to health, right to education and right to social care; and

the category future of children with ASD, in which two subcategories emerged: prognosis and future prospects.

Chart 2 – Synthesis of information required by family members and caregivers about the rights and future of children with ASD. Amapá, Ceará, Paraná, Brazil – 2020 (continued)

Integrative Review Data	Empirical data (interviews with family members)
Rights	
Legislation: rights, Policies, Legislation	<i>I don't know the rights. (CE-RC-8).</i>
Protection against discrimination: Strategies for explaining Autism Spectrum Disorder to other people	<i>I had to be on the priority queue, they wanted to take me by force [...] I had to show the medical report [of the child with ASD]. (AP-CEC-11)</i>
Right to health: diagnostic services, therapies, rehabilitation services, specialized professionals	<i>Telling the truth, I don't know any right, I managed to get his therapies... But, I mean, I don't know his rights. (PR-CNC-7).</i>
Right to education: education services for children with Autism Spectrum Disorder	<i>I really wanted to enroll her [child] in APFE, but I don't know how to get it, because it's always full. (CE-RC-13).</i>
Right to social care: government subsidies for people with disabilities	<i>Actually, we have many doubts about the subsidies. (PR-CNC-9).</i>

Chart 2 – Synthesis of information required by family members and caregivers about the rights and future of children with ASD. Amapá, Ceará, Paraná, Brazil – 2020 (conclusion)

Integrative Review Data	Empirical data (interviews with family members)
Future of children with Autism Spectrum Disorder	
Prognosis Speech development Possibilities for the child to communicate Physical growth and development, developmental milestones and transitions	<i>I longed for it, I've always hoped he would speak again.</i> (PR-CNC-8). <i>We're doing our best for him [child] to develop.</i> (AP-CEC-05).
Future perspectives: Socialization Work/employment Be independent Be happy Puberty and sexual development until adulthood	<i>I hope that, in the future, they can even work, be independent.</i> (PR-CNC-13). <i>[...] I've seen on TV that autistic people can be doctors, they can have everything a normal person has?</i> (CE-APFE-3).

Source: Created by the authors

Notes: AP- Amapá; CEC- Child Education Center; CE- Ceará; RC- Rehabilitation Center; PR- Paraná; CNC- Child Neurology Center; PSCC- Psychosocial Care Center; APFE- Association of Parents and Friends of the Exceptional.

After knowing the demands of the target audience, the information required was searched in books of experts in the field of autism and in three comprehensive and multidisciplinary databases: DynaMed Plus, Pubmed and Google Scholar grouped into features of the disorder, child behavior, health rights, rights of child with autism, future and sharing experiences and views of child with autism.

Stage 2 – content validation

Following the creation of the content, there was its validation. In the first round, 63 experts participated, and, in the second 22, totaling 86 experts. The mean age was 42 years; 91% (n=78) were female; 54% (n=46) from the Southeast Region of Brazil, 22% (n=19) from the south, 15% (n=13) from the northeast and the others from the north and midwest. Participation was higher among physiotherapists (14%, n=12), speech therapists (15%, n=13), psychologists (18%, n=15), occupational therapists (16%, n=14) and lower in other professional categories (37%: 4 social workers, 6 physical educators, 6 nurses,

2 doctors, 1 music therapist, 3 nutritionists, 9 pedagogues, 1 professional graduated in Law). Concerning the work area, education 52% (n=45), 28% (n=24) assistance, 15% (n=17) research and 2% (n=2) management. The average professional time was 18 years.

The experts were distributed among eight questionnaires with a total of 52 items: 1 - Characteristics of the child who has ASD; 2 - Diagnosis of the child with ASD; 3 - Behavior of the child who has ASD; 4 - Signs of the child who has ASD; 5 - Right to health; 6 - Right to education and work, protection against discrimination; 7 - Social right; 8 - Future of children with ASD.

In some questionnaires – signs of the child who has ASD, behavior and future – the global CVI obtained was >75%, but there were items with CVI <75%, thus the content was reformulated and submitted to a new validation round. The questionnaires that went through two rounds of validation were: signs of the child with ASD, behavior and future of children with ASD (Table 1). The other contents were validated in the first validation round.

Table 1 – Global Content Validity Index of relevance, clarity, objectivity and scientific update of informative content. Curitiba, Paraná, Brazil – 2021

Questionnaires	Relevance		Clarity and objectivity		Scientific update	
	1 st Round %	2 nd Round %	1 st Round %	2 nd Round %	1 st Round %	2 nd Round %
1-Characteristics of children with ASD (n=7)	91	-	94	-	94	-
2-Signs of children with ASD (1 st round n=7/2 nd round n=8)	83	97	67	84	88	94
3-Diagnosis of ASD (n=9)	83	-	85	-	87	-
4-Behavior of children with ASD (1 st round n=15/2 nd round n=8)	76	88	57	88	63	80
5-Future (n=7)	79	89	86	96	96	96
6-Right to health (n=6)	96	-	88	-	96	-
7-Right to education (n=6)	89	-	94	-	97	-
8-Social right (n=6)	100	-	92	-	100	-

Source: created by the authors.

Note: Conventional signal used:

- Numerical data equal to zero not resulting from rounding.

ASD: Autism spectrum disorder.

Stage 3 – Construction of the prototype/ booklet

Of the target audience interviewed, 97% (n=32) were female, most (52%, n=17) were between 30 and 39 years old. Regarding schooling, 58% (n=19) had completed higher education. Regarding monthly income, 30% (n=10) received up to 2 MW, the others being distributed in other higher income ranges, but in lower percentages. Regarding the region of housing, 42% (n=14) lived in the Northeast.

The research showed preference of family members as to the use of smartphone both to access the internet and to read information and mainly like videos. They opt for moderate amount of text in an informative material, use of cheerful colors and realistic illustration style. In addition

to the research with the target audience, similar materials were investigated on the internet to know the trend in the use of colors, successes and mistakes in information architecture, interaction design and graphic information.

The prototype of the booklet had the following composition: cover; presentation of the booklet; *about the booklet* icon, contemplated by the information of the authors, partners and collaborators; six chapters; and the bibliographical references. The chapters were as follows: 1 - Characteristics of children with ASD; 2 - Behavior of children with ASD; 3 – Rights to health; 4 - Rights of children with ASD; 5 - Future of children with ASD; 6 - Sharing experiences and views.

Chapter 6 was added as suggested by experts, justifying the need to share experiences with

other family members as a form of mutual support. Furthermore, in the survey with family members, it was also mentioned that they liked information through videos. The experience of three professionals in the area was included: a mother of a child with ASD, a nurse, professor and mother of two children with ASD, and a doctor specialized in pediatric neurology.

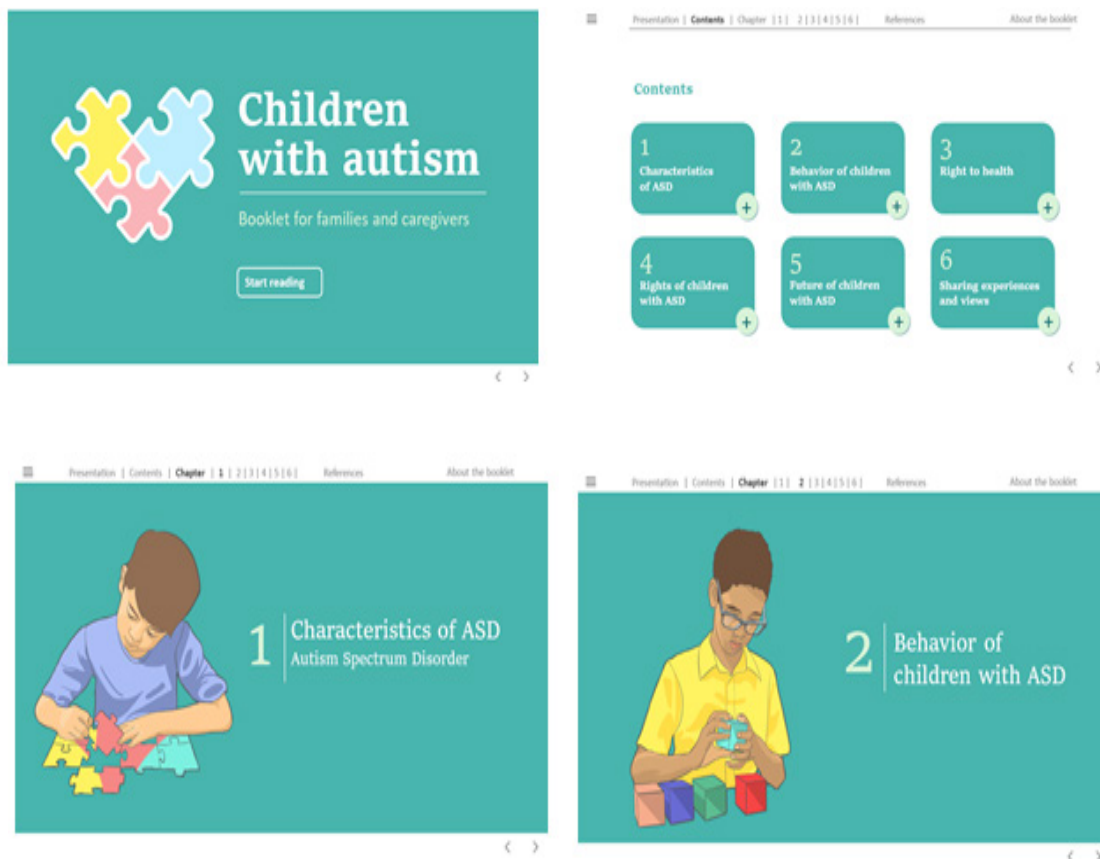
This chapter consisted of audios and videos sharing the maternal experience on the process of perception of the signs of children with ASD; the challenges faced in the search for professionals, diagnostic support services, treatment/therapies and education; the positive transformations in personal life, experienced as mother and family of a child with ASD.

Videos were created about the importance of early diagnosis, warning signs for ASD, treatment, importance of monitoring the child with a multidisciplinary team, education professionals and the importance of family in child care.

The interactivity of the booklet allows navigating through the material and search for the content of interest in the table of contents, using navigation bars, opening and closing content boxes, as well as clicking buttons to access the information in the booklet.

After the development of the prototype, a navigation and usability test was carried out with 10 people, aged between 21 and 58 years (mean 30-40 years) and with complete high school, which allowed adjustments in the material. The prototype navigation evaluation indicated that some tools, such as interactive buttons and navigation bars, were not always intuitive and were therefore modified. In addition, the families indicated the need to review some of the illustrations, as they reported that they did not match the reality of children with autism. Next, Figure 1 shows a graphic representation of the cover of the booklet, chapters and content information menu.

Figure 1 – Graphic representation of the interactive booklet named *Autistic children: booklet for families and caregivers*. Curitiba, Paraná, Brazil – 2022





Source: created by the authors.

The booklet was inserted in the Articulate Storyline Software that enables the creation of interactive materials and is available for access to the community. The material can be accessed for free, through the creation of a user with login and password in the Virtual Learning Environment of the Unified Health System (AVASUS)⁽¹⁰⁾.

Discussion

Families of autistic children seek information in the digital environment, including informal sources such as blogs, WhatsApp and websites. The freely available reports generate concern about their reliability and how critically families exercise when accessing these materials. This context generates a new demand from society, since the impact that the contents of informal sources can generate on people's health is not known⁽¹¹⁾.

The new demand for professionals and society refers to the premise of integrating the informational support to the digital technologies available, because this context must be socially recognized as allies in the health promotion of autistic people and their families. However, they need to be systematized and made available safely⁽¹¹⁾.

The process of construction of the booklet *Autistic Children: booklet for family members and caregivers* followed methodological rigor and is validated by experts for the use of the target audience. In the theoretical stage related to the informational needs of the families, it was noticed the similarity between the families in their requests, which allowed the verification that the demands were not restricted to a small population group. Listening to the target audience brings the cultural perspective and the real informational needs. The inclusion of family members from different regions of the

country and the use of different methodological strategies allowed empirical data and scientific literature to support the demands of families.

Families reported that they would like to have more knowledge about the disorder, to be able to talk about this condition to people in the community. Thus, they can make other people have more information about the disorder and thus reduce prejudice and increase the social inclusion of people who have ASD⁽¹²⁾.

For the creation of informational materials on health issues, it is necessary to establish methodological strategies that assist in the process of selection, organization and structuring of contents. In addition, theoretical aspects and literature data on the subject should be collected and explore directly with the target population their needs. This allows the selection of relevant and reliable information, based on scientific evidence, that represent the reality of the population and subsidize their information requirements, thus defining the content of the information material to be produced. This should be validated both with experts on the subject and with the target audience⁽¹³⁻¹⁴⁾.

Regarding the validation process of this technological resource, experts from different geographic regions of Brazil were selected, through the Lattes Curriculum, and from different backgrounds, to allow national representation of experts in the area. Content validation by health experts is a frequently used method⁽¹⁵⁾ and refers to a fundamental step to make the interactive booklet a complete and effective technological resource, attested by experts in the field.

The relevance of the content obtained agreement from the experts, but the CVI score was low in some items on the signs of ASD, behavior and future of children with ASD. The experts made suggestions, the material was submitted to a second round of validation to promote its greater qualification. Regarding clarity and objectivity, a lower CVI score was obtained than stipulated in the method, thus, some items were reviewed and submitted to a new validation cycle. These requirements are very important because, in the scientific

literature, families mention some difficulties in understanding technical terms used in the health area and report that, when accessing different sources of information, there is an exorbitant amount of information and they would like the contents to be more succinct⁽¹¹⁾.

Therefore, it is important to reduce them, so that the information is sufficiently available, objective and clear. It is emphasized once again the need to develop content for the community, being a challenge for professionals to make them available with language and format appropriate to the target audience. Thus the importance of validation to assist in this regard. The importance of social class, region and culture in which families and caregivers are inserted is emphasized, because they match the knowledge they already have about autism and for the understanding of instructional materials.

The context that the participants of this study were inserted were public intuitions and non-governmental organizations. Most family members had elementary school and income of up to two minimum wages. This demonstrates reading ability and low purchasing power. Thus, the importance of developing clear and objective materials is reiterated, in addition to exploring the profile of the public during the development of instructional materials, as carried out in this study. Moreover, free resources should be created and intended for this population, because they are the people who need it most due to low purchasing power.

To verify the social data in Brazil, the general proportion of people aged 25 years or more who finished high school remains in a growth trajectory and reached 53.2% in 2022. The percentage of people with completed higher education rose from 17.5% in 2019 to 19.2% in 2022. Despite this growth, in 2022, there were 9.6 million people aged 15 years or older illiterate, equivalent to an illiteracy rate of 5.6%. This rate is lower among people aged between 25 and 40 years⁽¹⁶⁾.

In 2021, the average household income per capita was R\$1,353.00 for the Brazilian population. Compared to 2020, the average household income per capita decreased by 6.9%⁽¹⁷⁾. These

data are consistent with the income of the public included in this study⁽¹⁷⁾.

Concerning the scientific update of the material, some items were reformulated and submitted to a new validation round, according to the calculation of the CVI and the suggestions of the evaluators. The importance of the participation of experts in the process of construction and validation of information materials is highlighted, since these have mastery in specific themes. Materials with qualified information enhance the development of family knowledge and care about the disorder.

The scientific literature⁽¹⁸⁻¹⁹⁾ revealed studies that developed informative materials for the same population profile, however in folder format. Although following specific methodologies for its creation, not all went through a validation process with experts, but described about this need.

The development of information material is a broad process, requires many stages of research for the theoretical basis, selection of scientific evidence, preparation and validation of content, research with the target audience on the use of digital tools, consumption of information, prototype development, navigability of the prototype with public and, finally, programming of the material and availability to society. Thus, the complexity for the development of this type of resource is perceived, especially when the research is not funded, and there is the challenge of including different areas of knowledge for the development and availability of a quality material and according to the profile of the target audience.

A limitation of this research concerns the large amount of content in different questionnaires, which hindered experts to have a global view of the material, but submitting an extensive amount of content for each expert was considered impossible, because adherence to research could be low. Nevertheless, the method used met the proposed objective, as it enabled the deepening in each theme, and the content is validated and qualified for families of children who have ASD.

This study contributes to society, because the booklet aims to provide information to the target audience and can also be used as a resource for health professionals in outpatient clinics, offices, schools, among others, which may indicate its use for families.

Final Considerations

It is considered that the objective of this study was achieved, because the booklet was built and validated for families and caregivers of children who have ASD. The importance of the University and its Postgraduate Programs in the commitment to the community is evident, regarding the preparation of materials intended for the population, accessible and understandable, and that indeed support society. For this to be possible, articulation between the different areas of knowledge is necessary, as carried out in the present study. There is need to transform a scientific, academic and dense content into a format with a friendly interface, with secure information, with clear terms and accessible to families.

This work emphasizes the translation of knowledge that brings to the population a qualified content, able to contribute to the quality of family care with children living with ASD. Families can have direct access to the booklet, as well as this technological resource can be used by health professionals to guide families and caregivers of children who have ASD, which is one of the essential functions in care.

Collaborations:

1 – conception and planning of the project: Gisele Weissheimer and Verônica de Azevedo Mazza;

2 – analysis and interpretation of data: Gisele Weissheimer and Verônica de Azevedo Mazza;

3 – writing and/or critical review: Gisele Weissheimer, Verônica de Azevedo Mazza, Carla Galvão Spinillo, Fernanda Cassanho Teodoro, Vanessa Ferreira de Lima and Julia Elice Jurczynszyn;

4 – approval of the final version: Gisele Weissheimer, Verônica de Azevedo Mazza, Carla Galvão Spinillo, Fernanda Cassanho Teodoro, Vanessa Ferreira de Lima and Julia Elice Jurczynsyn.

Competing interests

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