

ORIGINAL ARTICLE

VALIDATION OF DIVERSE INFORMATION TO PREPARE AN INTERACTIVE BOOKLET FOR FAMILIES OF AUTISTIC CHILDREN

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ABSTRACT

Objective: to validate content and face of diverse information to prepare an interactive booklet for families of children with Autism Spectrum Disorder. Method: a methodological research study conducted in Curitiba-PR, Brazil, with 86 experts between June and November 2020 and using the Delphi technique. An instrument with variables about relevance of the content, clarity and objectivity and scientific topicality was used for data collection. In data analysis, the Content Validity Index was set at $\geq 75\%$. Results: the content about the characteristics of autistic children, their diagnosis, behavior and rights was considered valid by the experts in the first round. The diverse information about the signs in autistic children and their future were validated in the second round, after the reformulations suggested by the experts. Conclusion: this educational resource has the potential to contribute in health education for the families of autistic children.

DESCRIPTORS: Autism Spectrum Disorder; Family; Child; Access to Information; Validation Study.

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INTRODUCTION

Changes in children's health status can generate stress, concern and worries in the families. Currently, there is an increasing number of children with Autism Spectrum Disorder (ASD): the estimates show that one out of 59 children presents the disorder¹. It is a condition that involves changes in communication, social interaction, behavior and sensory system². In addition to the aspects that affect children, there are several care demands to be addressed by the family members, as they need to learn how to take care of a child with ASD, to understand all their peculiarities, and to search for specialized care³.

Faced with ASD diagnosis, families start to request information³ and to search for it with professionals of different areas and also from other sources, such as those freely and openly available⁴. However, the families themselves report that much of the free information is not reliable⁵⁻⁶.

Access to low-quality information can lead some families to make wrong decisions⁷, raising concerns in the professionals who care for children with different profiles of chronic diseases and their families; therefore, these professionals have developed contents using different free-access dissemination media such as You Tube, podcasts and/or vodcasts, among other online resources, providing families with useful and reliable information⁸⁻⁹. These strategies can also be used for families of children with ASD; however, the information needs to be systematized by professionals with experience with this population. Given this scenario, it is indispensable that the health team promotes ways to provide informational support, turning professionals into facilitators of the process to engage the family in the care of children with ASD.

Digital interventions in the health area are flourishing every day. Patients, family members and professionals alike are surrounded by digital tools; therefore, it seems natural that society starts using them more frequently. The benefits from using these resources include low cost and good accessibility for the families. Therefore, a number of studies indicate a gap in the reliability and quality of the diverse information made available⁴⁻⁷.

Given the limited materials aimed at families of children with ASD⁴⁻⁷, it becomes necessary to elaborate resources for such families. Thus, elaboration of an interactive booklet for the target population was designed. However, in addition to that, it is necessary to identify what information the professionals specialized in ASD consider important to include in the interactive booklet under development, as a way to provide qualified and safe information by means of education in health. Thus, this study aimed at validating content and face of diverse information to prepare an interactive booklet for families of children with ASD.

METHOD

This is a methodological research study for content and face validation, conducted in Curitiba-PR, Brazil. In order to select the contents for the interactive booklet, interviews with the families and an integrative review were conducted to identify their information needs. The interviews took place between September 2018 and September 2019 and were entitled "Demand for information by the families of children with Autism Spectrum Disorder"⁶. The integrative review was conducted between September 2019 and February 2020 and was called "Information requirements by the families of children with Autism Spectrum Disorder: An integrative review"⁴.

These data allowed understanding the experience of families of children with

ASD, extracting important contents to inform them and, thus, plan preparation of the information to development the booklet. Subsequently, the following informative contents were selected in the scientific literature: characteristics; diagnosis; behavior; signs; right to health; and future of children with ASD, and they were presented in the thesis entitled "Informational support for the families of autistic children: Content validation"¹¹. Such being the case, this study will present the content and face validation procedure from the perspective of the experts in ASD.

The participants were experts selected through their Lattes Curriculum (LC), being considered people whose knowledge allowed them to master a specific knowledge area¹⁰. Searches for the LC were conducted by the subject matter of "autism", Brazilian nationality, PhD academic training, and the following professional activities with the respective number (n) of invitations by professional category: social worker (14), law professional (7), physical educator (20), nurse (13), physiotherapist (21), speech-language pathologist (47), physician (23), music therapist (17), nutritionist (19), pedagogist (26), psychologist (54), and occupational therapist (39). The invitations were sent to the previously described experts who presented qualifications in the area of research, teaching and/or care, with a minimum sum of 10 points in the activities developed in the last five years (from 2015 to 2020), according to the order in which they were mentioned in the LC. The criteria were as follows:

PhD with a thesis in the area of interest: 10 points; MSc with a dissertation in the area of interest: 7.5 points; Specialist in the area of interest: 5 points; Production of scientific articles on ASD: 2.5 points; Coordinator of a research project on the area of interest: 5 points; Publication of a book chapter on the area of interest: 2.5 points; Abstracts published in the annals of events on the area of interest: 1 point; Publication of expanded abstracts on the area of interest: 2 points; Complementary training – update courses on the area of interest: 2.5 points; and Participation in scientific events/congresses: 1 point.

At least five years of teaching experience in the area of interest: 5 points; Ten or more years of teaching experience in the area of interest: 10 points; Undergraduation academic supervision in the area of interest: 1 point; Master's degree academic supervision in the area of interest: 2.5 points; PhD academic supervision in the area of interest: 4 points.

At least five years of assistance-related experience in relation to the ASD area: 5 points; and At least ten years of assistance-related experience in the area of interest: 10 points.

Invitations were sent until achieving the minimum sample of six respondents for each content, according to the guidelines set forth in the Guide by the American Association of Orthopaedic Surgeons/Institute of Work and Health¹².

Data collection took place between June and November 2020. The research invitations were emailed along with a link to access the questionnaire. If no response was obtained, a new invitation was sent one week after the first one, and a third invitation was sent one more week later if lack of response persisted. A total of 247 invitations were sent in the first research round, receiving answers from 63 respondents (25%). 53 invitations were made in the second round with answers from 23 respondents (43%), totaling 86 research participants.

The data collection instrument included the following experts' sociodemographic data: age (years old), gender, geographic region of residence, training, function/position in the area of professional performance, and time of professional performance (years). In addition to these data, the instrument was based on criteria for the validation of materials¹³ and adapted from another study¹⁴ which validated content and face of the booklet. Thus, the following aspects were adopted: content validation (scientific relevance and topicality) and face validation (clarity and objectivity).

Eight questionnaires were created in the Typeform software (digital tool), according to the thematic categories of the diverse information prepared, in order to make them

less extensive/exhaustive and facilitate the experts' adherence to the research. The questionnaires were the following: 1- Characteristics of children with ASD; 2- Diagnosis of children with ASD; 3- Behavior of children with ASD; 4- Signs in children with ASD; 5- Right to health; 6- Right to education and work, protection against discrimination; 7- Social right; and 8- Future of children with ASD.

To validate content and face, it was decided to use two levels of answer choices ("I agree" or "I disagree"), as the pre-test verified that, when increasing the number of answer choices by including "I partially disagree" and "I partially agree", no suggestions for content improvements by the experts were obtained. The "I agree" or "I disagree" options were selected so that, when the experts selected "I disagree", a questionnaire field was opened automatically to describe the reason, thus enabling the researchers to reformulate the contents. The Delphi technique was used, whose objective is to assess agreement among the experts in relation to the content evaluated.

For data analysis, the experts' sociodemographic information was organized in a spreadsheet and absolute, percentage and mean frequencies were calculated. The Content Validity Index (CVI)¹⁵ was used to determine agreement among the experts for content validation. This method allows assessing the percentage of experts that agreed or not with the content. The CVI was calculated by adding up the number of "I agree" answers and dividing it by the total number of items included in the questionnaire. All the content with CVI values equal to or greater than 75% were considered as validated, and those with CVI values <75% were reformulated and forwarded to a second validation round.

Resolution No. 466/2012 of the National Health Council was followed, which approves the guidelines and regulating norms for research involving human beings. The research was submitted to a Research Ethics Committee and was approved under Opinion No. 3,312,897.

RESULTS

The study participants were 86 experts aged from 27 to 62 years old, with a mean of 42. Seventy-eight (91%) were female and the mean, minimum and maximum time of professional performance corresponded to 18, 1 and 42 years, respectively.

Table 1 - Characterization of the experts. Curitiba, PR, Brazil, 2020

Brazilian region	n (86)	%
South	19	22
Southeast	47	55
North	1	1
Midwest	6	7
Northeast	13	15
Professional Training	n (86)	%
Social Worker	4	5
Physical Educator	6	7
Nurse	6	7
Physiotherapist	12	14

Psychologist	15	17
Physician	2	2
Music Therapist	1	1
Speech-Language Pathologist	13	15
Nutritionist	3	3
Pedagogue	9	10
Law Professional	1	1
Occupational Therapist	14	16
Function/Position in the area of professional performance	n (86)	%
Teaching	45	52
Care	24	28
Management	2	2
Research	15	17

Source: The authors (2020).

Based on the following topics: characteristics, diagnosis, behavior, signs, right to health, and future of children with ASD, 52 items were created and validated, referring to the diverse information directed to the families of children with ASD that should be included in the booklet. Table 2 presents the content and face validation data about the characteristics, diagnosis and behavior of children with ASD. All these contents were validated in the first round, as can be seen in the CVI.

Table 2 - Content and face validation regarding the characteristics, diagnosis and behavior of children with ASD (1st round). Curitiba, PR, Brazil, 2020

Content	R			CO			ST		
	A	D	CVI (%)	A	D	CVI (%)	A	D	CVI (%)
Characteristic of children with ASD (n=7)									
1.0 What is ASD?	6	1	85	6	1	85	6	1	85
1.1 Are there many ASD cases?	7	0	100	7	0	100	7	0	100
1.2 What causes ASD?	6	1	85	7	0	100	6	1	85
1.3 Risk for another child to be born with ASD	7	0	100	7	0	100	7	0	100
1.4 Is there a cure for ASD?	6	1	85	6	1	85	7	0	100
Diagnosis of children with ASD (n=9)									
2.0 How is the ASD diagnosis made?	7	2	77	8	1	88	8	1	88
2.1 Tests	8	1	88	7	2	77	7	2	77
2.2 Importance of early diagnosis	7	2	77	8	1	88	8	1	88
Behavior of children with ASD (n=8)									

3.0 Behavior of children with ASD	7	1	87	8	0	100	7	1	87
3.1 Why do children with ASD present undesirable behaviors?	7	1	87	6	2	75	6	2	75
3.2 What is a behavior?	7	1	87	7	1	87	7	1	87
3.3 How to reduce inappropriate behaviors?	8	0	100	8	0	100	7	1	87
3.4 Choose a reward for your child's behavior	7	1	87	6	2	75	6	2	75
3.5 Use of reinforcers	7	1	87	7	1	87	6	2	75
3.6 Behaviors when children want to avoid something they don't like	7	1	87	7	1	87	6	2	75
3.7 Cessation of behaviors	7	1	87	7	1	87	6	2	75
3.8 Identify what happened before your child's behavior	7	1	87	7	1	87	6	2	75
3.9 Use the antecedent, behavior and consequence to teach new skills and behaviors	6	2	75	7	1	87	7	1	87

Source: The authors (2020).

Key: R: Relevance of the content; CO: Clarity and Objectivity; ST: Scientific Topicality; A: Agree; D: Disagree; CVI: Content Validity Index; ASD: Autism Spectrum Disorder.

Table 3 presents the content and face validation data regarding the signs in children with ASD. Two rounds were necessary to reach the minimum CVI of 75%, mainly in the Clarity and Objectivity aspect. Item 4.6 was validated in the first round and the experts suggested adding the contents of items 4.2 to 4.4 and of item 4.14.

Table 4 presents the data referring to content validation about the rights (validated in the first round) and future of children with ASD (validated in the second round). The content about the children's future, item 6.1, was not validated in the first round.

Table 3 - Content and face validation regarding the ASD signs (1st round: n=7/2nd round: n=8). Curitiba, PR, Brazil, 2020

Content	R			CO			ST		
	A	D	CVI (%)	A	D	CVI (%)	A	D	CVI (%)
	1 st /2 nd r	1 st /2 nd r	1 st /2 nd r	1 st /2 nd r	1 st /2 nd r	1 st /2 nd r	1 st /2 nd r	1 st /2 nd r	1 st /2 nd r
4.0 Which are the ASD signs?	6/8	1/0	85/100	4/6	3/2	57/75	7/8	0/0	100/100
4.1 What does Spectrum mean when talking about ASD?	4/8	3/0	57/100	6/7	1/1	85/87	7/7	0/1	100/87
4.2 Level 1 of ASD severity	7	1	87	6	2	75	7	1	87
4.3 Level 2 of ASD severity	7	1	87	6	2	75	7	1	87
4.4 Level 3 of ASD severity	7	1	87	6	2	75	7	1	87
4.5 Which are the changes in terms of communication?	6/8	1/0	85/100	5/7	2/1	71/87	7/7	0/1	100/87

4.6 Which are the main changes in the relationship/ interaction?	6	1	85	6	1	85	6	1	85
4.7 Which are the main changes regarding interests, activities and behaviors?	6/8	1/0	85/100	4/7	3/1	57/87	7/8	0/0	100/100
4.8 Which are the main sensory-related changes?	6/8	1/0	85/100	4/7	3/1	57/87	5/8	2/0	71/100
4.9 How do you know if your child is developing as it should?	3/8	4/0	42/100	6/7	1/1	85/87	5/8	2/0	71/100
4.10 Warning signs for ASD from 0 to 6 months old	6/8	1/0	85/100	5/7	2/1	71/87	6/8	1/0	85/100
4.11 Warning signs for ASD from 6 to 12 months old	7/8	0/0	100/100	4/7	3/1	57/87	6/8	1/0	85/100
4.12 Warning signs for ASD from 12 to 18 months old	7/8	0/0	100/100	5/7	2/1	71/87	6	1	85/87
4.13 Warning signs for ASD from 18 to 24 months old	7/8	0/0	100/100	4/7	3/1	57/87	6/8	1/0	85/100
4.14 Warning signs for ASD from 24 to 36 months old	8	0	100	7	1	87	7	1	87
4.15 Warning signs for ASD from 3 to 5 years old	6/8	1/0	85/100	4/7	3/1	57/87	6/8	1/0	85/100

Source: The authors (2020).

Key: R: Relevance of the content; CO: Clarity and Objectivity; ST: Scientific Topicality; A: Agree; D: Disagree; CVI: Content Validity Index; ASD: Autism Spectrum Disorder; 1st/2ndr: First and second rounds.

Table 4 - Content and face validation regarding the rights and future of children with ASD. Curitiba, PR, Brazil, 2020

Content	R			CO			ST		
	A	D	CVI	A	D	CVI	A	D	CVI
	1 st /2 nd r	1 st /2 nd r	1 st /2 nd r	1 st /2 nd r	1 st /2 nd r	1 st /2 nd r	1 st /2 nd r	1 st /2 nd r	1 st /2 nd r
The right to health (n=6)									
5.0 Which are the health-related rights of people with ASD?	6	0	100	5	1	83	5	1	83
5.1 Child's care by health insurance	6	0	100	6	0	100	6	0	100
5.2 Care priority.	5	1	83	5	1	83	6	0	100
5.3 Medication use in ASD	6	0	100	5	1	83	6	0	100
The right to education and work, protection against discrimination (n=6)									
6.0 Who are considered people with ASD?	5	1	83	6	0	100	6	0	100
6.1 Comparison of ASD with disability	5	1	83	5	1	83	6	0	100
6.2 Protection against discrimination	5	1	83	6	0	100	6	0	100
6.3 The right to education	5	1	83	5	1	83	5	1	83
6.4 Quota Law – vocational training	6	0	100	6	0	100	6	0	100
6.5 Labor market and Social Security	6	0	100	6	0	100	6	0	100

The right to social assistance (n=6)										
7.0	The right to social assistance	6	0	100	6	0	100	6	0	100
7.1	Social programs and benefits	6	0	100	5	1	83	6	0	100
7.2	The right to housing and transportation	6	0	100	5	1	83	6	0	100
7.3	Laws about the rights	6	0	100	6	0	100	6	0	100
The future of children with ASD (n=7)										
8.0	Prognosis	6	1	85	7	0	100	6	1	85
8.1	Development indicators	4/7	3/0	57/100	4/7	3/0	57/100	7/7	0/0	100/100
8.2	Future perspectives	6	1	85	6	1	85	7	0	100
8.3	What can the family do for the sake of the child's future?	6	1	85	7	0	100	7	0	100

Source: The authors (2020).

Key: R: Relevance of the content; CO: Clarity and Objectivity; ST: Scientific Topicality; A: Agree; ID: Disagree; CVI: Content Validity Index; ASD: Autism Spectrum Disorder; 1st/2nd: First and second rounds.

The interactive booklet is under development by the same research group, and, subsequently, it is intended to submit it to a navigation and usability test with families of children with ASD.

The figure below presents the cover page corresponding to the first topic of the booklet.

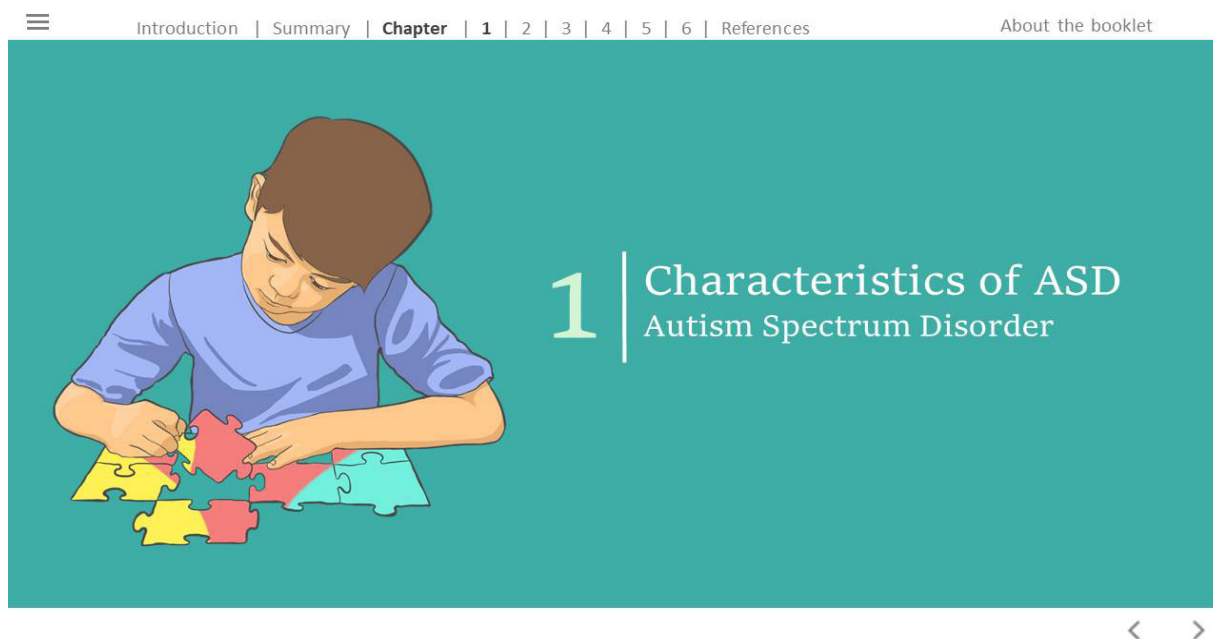


Figure 1 - Cover page (prototype) of Chapter 1 from the interactive booklet for families of children with ASD. Curitiba, PR, Brazil, 2020

Source: The authors (2020).

DISCUSSION

This study evaluated content and face validity of the diverse information directed to families of children with ASD together with specialists in the disorder in order to make it available as an interactive booklet. The referred content can be considered a technological innovation because, despite the availability of online informative contents, the families report poor quality, a massive amount of information, and use of technical terms that hamper its understanding^{7,16}.

One of the requirements that were considered to select the contents was their relevance for the target audience. Information in the scientific literature considered important for the families was selected, such as characteristics of the disorder, ASD diagnosis, clinical signs in children, how to deal with their behavior, and their rights and future^{4,6}.

Validation of some items about the disorder signs and the future of children with ASD in the relevance, objectivity and clarity aspects was achieved in the second round. Likewise, validation of some items about the signs in children with ASD in the scientific topicality aspect was achieved after a number of reformulations in the second round.

Relevant, timely and safe information represent a starting point for knowledge acquisition and for development of skills and competencies. This information allowed parents of children with ASD to take rapid and successful actions with regard to rehabilitation of their children and to exercise the rights of children and their parents³. Considering the above, it became essential to involve the professionals that monitor these families every day in the validation process corresponding to the informational content.

These professionals have expertise in the field and are capable of preventing development of materials with inaccurate or tendentious results that may lead to wrong conclusions, resulting in more qualified materials that can be better used by the target population¹⁷.

The experts participating in this study had experience in the teaching, research and care areas. These data are important because they show that the participants were skillful in theoretical judgment of the content and had care experience with the families, evidencing the potential of the material they validated regarding applicability and reliability of the diverse information for the target population.

Another important requirement for the validation of materials for families were clarity and objectivity, as controversial information may represent, to parents, a source of inaccuracy and ambiguity in understanding the disorder¹⁸⁻¹⁹. A number of studies indicate that parents report difficulties understanding the written texts provided by professionals, as they normally include technical terms and lack clear information without jargons^{7,20}. In addition to that, the parents reported finding a massive amount of online information, although they mentioned delay and difficulty finding information applicable to the situations they are searching for²¹.

Another obstacle faced by the parents is the abundance of non-validated information available in online media. This information is often accessed by the family members, and not all of it is made available by people with expertise in the field, which makes it possible to question reliability and safety of using this information²²⁻²³. In view of the above, the importance of surveying updated information in the scientific literature was accentuated, obtained from scientific databases, safe sources and submitted to validation with experts in ASD, as collective judgment in the validation process adds reliability to the materials²³.

Considering the complex nature of ASD, information provision must be based on the assessment of different areas of professional performance. Therefore, the multidisciplinary composition of the group of experts who participated in this research allowed for a comprehensive and thorough evaluation, with pertinent and complementary remarks,

which enabled to adjust contents and to qualify the material.

With regard to the study limitations, as it involves informative content, periodical reviews should be conducted for the content to remain updated and be continuously used with the families, remaining focused on scientifically proven reports for the care of children with ASD.

FINAL CONSIDERATIONS

This study allowed the specialists to analyze the diverse information proposed in several aspects, in order to ease its understanding and making it practical and of high-quality to the families. The current study also contributed in turning a scientific, academic and dense content into objective, clear information easily understandable information by the families and updated according to the scientific literature.

Information is essential for the families, and it is up to the professionals and managers working in the health area and in other fields to organization care so that these needs are met. The information must be readily available and shared via medical, educational and other institutions. Therefore, the current research contributed as an innovation in care for nurses and other health professionals, as they will be able to use the content and the booklet in their clinical practice with patients and families.

The same research group is incorporating the validated content in the format of an interactive booklet, which will be subsequently subjected to a navigation and usability test with the family members. The potential of the validated content for serving its target population is noted.

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Substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work - Weissheimer-Kaufmann G, Mazza V de A; Drafting the work or revising it critically for important intellectual content - Weissheimer-Kaufmann G, Mazza V de A, Ruthes VBTNM, Oliveira LF de; Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved - Weissheimer-Kaufmann G, Mazza V de A. All authors approved the final version of the text.

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