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CACTO DEVELOPMENT: CARE PROGRAM FOR MOTHERS OF CHILDREN WITH CONGENITAL ZIKA SYNDROME

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ABSTRACT

Objective: to develop a unitary caring program for mothers of children with Congenital Zika Syndrome.
Method: this is a methodological study, based on Unitary Caring Science, developed in two phases: creation, consisting of six moments, and content validity, through the participation of 36 experts on the subject, professional caregivers and mothers. The Content Validity Index and the Content Validity Ratio were used for data analysis.
Results: the program was named *CACTO*, composed of seven care modalities: Taking care of my mind; Upright and correct position; Taking care of my sleep; Family that is together; Mirror mirror on the wall; Mother who takes care of mother; Facing prejudices. *CACTO* was validated with a Content Validity Index ≥0.88 and critical Content Validity Ratio values greater than or equal to the cutoff point defined for each group of experts.
Conclusion: the translation of Unitary Caring Science into a care program encourages professionals to promote innovative care, valuing acceptance, autonomy, citizenship and critical awareness, advocating in favor of emancipatory interactional care. *CACTO* is a technological innovation that can transform professional care, promote the resolution of mothers' health needs and enhance the quality of life of children with Congenital Zika Syndrome, family and caregivers themselves.

DESCRIPTORS: Disabled Children. Caregivers. Zika Virus Infection. Mother-Child Relations. Caregiver Burden. Maternal-Child Health Services. Culturally Appropriate Technology. Nursing Methodology Research.

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DESENVOLVIMENTO DO CACTO: PROGRAMA DE CUIDADO ÀS MÃES DE CRIANÇAS COM SÍNDROME CONGÊNITA DO ZIKA

RESUMO

Objetivo: desenvolver um programa de cuidado unitário às mães de crianças com Síndrome Congênita do vírus Zika.
Método: estudo metodológico, fundamentado na Ciência do Cuidado Unitário, desenvolvido em duas fases: criação, constituída por seis momentos, e validação de conteúdo mediante participação de 36 *experts* na temática, cuidadoras profissionais e mães. O Índice de Validação de Conteúdo e o *Content Validity Ratio* foram utilizados para análise dos dados.
Resultados: o programa foi nomeado de CACTO, composto por sete modalidades de cuidado: Cuidando da minha mente; Posição ereta e correta; Cuidando do meu sono; Família que chega junto; Espelho espelho meu; Mãe que cuida de mãe; Enfrentando preconceitos. O CACTO foi validado com Índice de Validação de Conteúdo ≥0,88 e valores do *Content Validity Ratio* crítico maior ou igual ao ponto de corte definido para cada grupo de *experts*.
Conclusão: a translação da Ciência do Cuidado Unitário em programa de cuidado estimula as profissionais a promoverem cuidados inovadores, valorizando o acolhimento, autonomia, cidadania e consciência crítica, advogando em favor do cuidado interacional emancipatório. O CACTO é uma inovação tecnológica que pode transformar os cuidados profissionais, promover resolutividade das necessidades de saúde das mães e potencializar qualidade de vida da criança com Síndrome Congênita do vírus Zika, família e das próprias cuidadoras.

DESCRITORES: Crianças com deficiência. Cuidadores. Infecção por Zika virus. Relações mãe-filho. Fardo do cuidador. Serviços de saúde materno-infantil. Tecnologia culturalmente apropriada. Pesquisa metodológica em Enfermagem.

DESARROLLO DE CACTO: PROGRAMA DE ATENCIÓN A MADRES DE NIÑOS CON SÍNDROME DE ZIKA CONGÉNITO

RESUMEN

Objetivo: desarrollar un programa de atención unitaria para madres de niños con síndrome congénito causado por el virus Zika.
Método: estudio metodológico, basado en la Ciencia del Cuidado Unitario, desarrollado en dos fases: creación, compuesta por seis momentos, y validación de contenido a través de la participación de 36 expertos en el tema, cuidadores profesionales y madres. Para el análisis de los datos se utilizaron el Índice de Validez de Contenido y la Razón de Validez de Contenido.
Resultados: el programa se denominó CACTO, compuesto por siete modalidades de atención: Cuidando mi mente; Posición erguida y correcta; Cuidando mi sueño; Familia que llega junta; Espejo, espejo mío; Madre que cuida a la madre; Enfrentando los prejuicios. CACTO fue validado con un Índice de Validez de Contenido ≥0.88 y valores críticos de Relación de Validez de Contenido mayores o iguales al punto de corte definido para cada grupo de expertos.
Conclusión: la traducción de la Ciencia del Cuidado Unitario en un programa de cuidado alienta a los profesionales a promover un cuidado innovador, valorando la aceptación, la autonomía, la ciudadanía y la conciencia crítica, abogando por el cuidado interaccional emancipador. El CACTO es una innovación tecnológica que puede transformar la atención profesional, promover la resolución de las necesidades de salud de las madres y mejorar la calidad de vida de los niños con síndrome congénito causado por el virus Zika, la familia y los propios cuidadores.

DESCRIPTORES: Niño con Discapacidad. Cuidadores. Infección por el Virus Zika. Relaciones Madre-Hijo. Carga del Cuidador. Servicios de Salud Materno-Infantil. Tecnología Culturalmente Apropiada. Investigación Metodológica en Enfermería.

INTRODUCTION

Congenital Zika Syndrome (CZS) is manifested by a set of neurological repercussions caused by the Zika virus and transmitted through the maternal-fetal route, resulting in craniofacial disproportion, spasticity, seizures, irritability and other brain anomalies[1]. Despite the end of the epidemic period of CZS, children with CZS continue to be born and new women may suffer psychosocial repercussions typical of the condition of being a mother of a child with CZS[2].

Mothers of children with CZS live with the social judgment that attributes the cause of illness to their behavior, face discriminatory comments and assume the role of child care. Mothers are responsible for comprehensive and exclusive care of their child, a socially imposed condition that can undermine personal and professional life projects, restricting their autonomy over the decision-making processes of their own way of mothering[3].

Mothers lose formal employment, go through exhausting therapeutic itineraries with the child, live with increased monthly financial costs, low levels of mental health and satisfaction with life, in addition to poor sleep quality, domestic violence, low self-esteem, deep sadness, pain and joint damage, aspects that result in the abandonment of their personal projects[4]. Such a way of life, aggravated during the COVID-19 pandemic, represents a biographical rupture for these mothers and families[5].

Most mothers of children with CZS belong to undervalued classes in which "marks"[6] of oppression intersect for being a woman, black/brown, northern/northeastern, single mother, low income and education and still generating an "imperfect" child[7]. Immersed in different vulnerabilities, mothers find little significant care in health services, where professionals emphasize child care, while scarce care initiatives are directed at mothers[7].

Such conditions reinforce the prejudice against women solely as reproducers[7] and reaffirm the notion of disability as incapacity[8], which results in unique care needs. Therefore, the development – creation and validity – of a specific care program for mothers of children with CZS is urgently relevant.

The Unitary Caring Program (UCP) is characterized as a set of specific care that seeks to promote well-being, reduce vulnerabilities, enhance human existence and restore people (healing) belonging to a certain population group based on their needs[9–10]. The UCP is based on the Unitary Caring Science (UCS) developed by theorist Jean Watson in 2018[10], establishing the Unitary Transformative paradigm, which considers that all beings are interconnected by universal cosmic energy, a source of life that is love, the starting point of the ontology of unitary being[10].

Therefore, "unitary caring" is adopted as a way of expressing the intention to do good; appreciating the existence of the person being cared for without judgment; tuning into the existing energy field and universal energy, love; constituting a biogenic relationship of giving and receiving[10]; opening up to infinite possibilities of expression by mothers of children with CZS as existential beings.

Given the above, this article aims to develop a UCP for mothers of children with CZS.

METHOD

Study design

This is a methodological study, based on the frameworks of Jean Watson's UCS[10] and methodological principles of the logical model for the development of complex interventions to improve health (dynamicity, interactivity, creativity, openness to changes and thinking about assessment)[11]. The Revised Standards for Quality Improvement Reporting Excellence (SQUIRE 2.0) guidelines were adopted, which guide the description of new modes of care in favor of quality, safety and improvement of health care.

Program construction phase

The program was constructed between September 2018 and March 2022 during six moments: theoretical, comprehensive, creative, care modalities, Caritas-Veritas attribution and layout (Chart 1). The moments were fulfilled in a successive but unlimited way, now moving away, now integrating.

Chart 1 – Moments of Unitary Caring Program development for mothers of children with Congenital Zika Syndrome and their respective characteristics, Feira de Santana, Bahia, Brazil, 2022.

Moment	Characteristics
Theoretical	With a cross-sectional character, the authors deepened the reading of Watson's main works[10,12–13], carried out an exploratory search, identified and read scientific articles and participated in scientific events.
Comprehensive	Sought to understand the health needs of mothers of children with CZS through observational and review studies.[5,7, 14]
Creative	Mothers' health needs were grouped according to case-by-case similarity, then the authors created care for each group of needs.
Care modalities	The creation of the modalities respected the logical sequence: description of the type of modality, its characteristics and objectives; presentation of information on the basic knowledge of the subject; guidelines for modality operation and interaction and bonding between people; the essence of the care modality; free time from the experience of caring/being cared for; encouragement of necessary adaptations and transformations in mothers' routine.
Caritas-Veritas	Indication of the respective Caritas-Veritas for each type of care. Caritas-Veritas stands for vibrant words that carry the moral values that professional caregivers must apply.
Layout	Performed by a design professional using the CorelDraw Graphics Suite software version 2018, following the researchers's guidelines.

Program validity phase

The moment of validity occurred between October 2021 and March 2022 based on the judgment of three groups of experts. This study met the national ethical standards for research with human beings and was approved by the Research Ethics Committee.

Experts participating in the study

As experts at the UCS (group 1), members of the Brazilian Network of Unitary Caring Science (RBCCU – *Rede Brasileira da Ciência do Cuidado Unitário*) were selected based on the following inclusion criteria: having professional experience in care or research or teaching with the theme of unitary caring. RBCCU, founded in October 2020, brings together researchers from Brazil who study and investigate UCS and seek to spread science in research, teaching and assistance spaces.

The second group of experts included professional caregivers of families of children with CZS (group 2) linked to the *Instituto Pais de Anjos da Bahia* (IPAB) or *Associação aBRAÇO a Microcefalia* (Abraço). Meanwhile, the third group of experts (group 3) included mothers of children with CZS and being associated with IPAB or Abraço. Due to the difficulties in ensuring the participation of experts in validity studies and the lack of aspects that could result in heterogeneity of included groups, there were no exclusion criteria, avoiding increasing selectivity and reducing participants.

IPAB was founded in 2017, has approximately 100 registered families, while Abraço, founded in 2016, has around 200 associated families. Both institutions are headquartered in Salvador, Bahia, Brazil. The research team's initial contact with the institutions' boards took place through the exchange of messages via WhatsApp.

The sample of each group of experts was of the intentional non-probabilistic type. The option to invite the maximum possible number of participants is in line with UCS teachings, considering that all knowledge and cultural value is relevant[10], in addition to believing that the participation of the person to be cared for in the moments of development of a care program favors its representativeness, compliance with the program and effectiveness[15].

In order to issue the invitations to participate, the RBCCU board made the email contacts of all 22 members available, then the researchers sent the individual invitations with the link to access the data collection questionnaire. The validity stage took place during a period of health restrictions to control the COVID-19 pandemic. Therefore, for access to the participants in groups 2 and 3, the researchers sent the invitation and the link to access the data collection questionnaire to the board of IPAB and Abraço, which they forwarded to participants via WhatsApp group. All mothers and 18 professional caregivers, linked to the institutions, participated in the WhatsApp group of each institutions.

For the composition of groups 2 and 3, the snowball technique was used to identify and reach new experts. This technique consists of indicating other participants by the first ones (seeds) who had access to the research invitation[16]. By using the snowball technique, the exact number of people who received the invitation to participate in the research is unknown as well as the justification of those who did not respond to the invitation sent on three occasions.

Data collection instruments

Through Google Forms application, the research questionnaire was prepared, containing in part I the Informed Consent Form and information on expert sociodemographic, economic and professional characterization. Part II consisted of the access link to the full care program, with all care modalities, and the validity instrument. It is noteworthy that each group of experts accessed a specific validity instrument.

The instruments had eight assessment domains (content, language, illustration, layout, motivation, culture, applicability, overall impressions) and 29 criteria with five response options for each: strongly agree, agree, disagree, strongly disagree, don't know and one open space for free contribution. To encourage mothers' participation, the validity instrument used by group 3 was simplified, resulting in 20 criteria, which reduced mothers' response time.

Conducting the validity complied with the Delphi technique recommendations, in which assessment rounds are performed until reaching the percentage of agreement desired by the researchers, in addition to ensuring independent and blind responses from experts[16].

Data analysis

The responses were stored and coded in a Microsoft Office Excel® version 14 spreadsheet and then transferred and processed by the Statistical Package for Social Sciences (SPSS), version 20.0, through descriptive statistics. The Content Validity Index (CVI) for each group of experts was calculated by adding the number of experts who chose the "strongly agree" and "agree" options, divided by the total number of experts who participated in each round[16]. The CVI considered acceptable was at least 0.75 and preferably greater than 0.80[16].

The Content Validity Ratio (CVR) was used to assess the degree of agreement of the responses given by experts. The CVR value varies between -1 (perfect disagreement) and +1 (perfect agreement). The critical value of CVR, which considers whether the content will be validated, depends on the number of experts, that is why Lawshe Schipper in 1975 elaborated the table of standard values that determines the cut-off point to consider each item assessed as essential or non-essential[17].

RESULTS

The UCP was named "*CACTO*" in allusion to the characteristics of a species of vegetation found in arid and hot environments such as the Brazilian Northeast. It keeps its juicy interior and symbolizes resistance and strength, its sharp thorns guarantee its survival, it is its own guardian. Is ready for adverse situations, but needs care, just like mothers of children with CZS.

The *CACTO* program aims to encourage interdisciplinary care for mothers of children with CZS, in order to healing their health-disease process; offer care modalities for nursing practice, professional caregivers and mothers of children with CZS. According to the principles of UCS, *CACTO* is not an inflexible and protocol care program, with successively obligatory steps, on the contrary, it encourages mothers' protagonism and the autonomy of nursing and professional caregivers to make due adjustments in the care modalities and innovate from these.

CACTO is presented with pre-textual elements, introduction, objectives, development, expected results and final notes. Chart 2 presents a summary of the sections that make up *CACTO*.

Chart 2 – Summary of the sections that make up *CACTO*, Feira de Santana, Bahia, Brazil, 2022.

Part I		
Considerations about the health needs of mothers of children with CZS and UCS		
Part II		
CACTO: UCP to mothers of children with CZS		
Moment of care Description of six steps that intend to help the development of the moment of care and reach of transpersonal care from Caritas-Veritas (C-V).		
Care modalities		
Type/Title of care modality	**Objective (s)**	**Self-care practice**
Booklet: Taking care of my mind	Instruct mothers, nurses and professional caregivers to practice contemplation (silence, reflection, admiration and self-knowledge).	Carry out contemplative practices for 21 days, being able to use the audio guides available in the care modality.
Card: Upright and correct position	Guiding mothers about the proper posture for carrying out daily activities, in order to avoid pain, injuries and fatigue.	Pin a card to one's favorite place, or send a card to a person who can remind them to practice.
Family care: Family that is together	Strengthen harmonious and solidary family relationships, mediate conflicts, encourage the sharing of household chores and alleviate mothers' burden of care.	Consisting of nine self-care meetings, such as involvement of family members in daily activities at home, for instance.
Step by step: Taking care of my sleep	Help mothers to adopt care that can improve quality of sleep.	After practicing the step by step, post the phrase "sleep ok" in the group on social networks.

Chart 2 – Cont.

Meeting: Mirror mirror on the wall	Share experiences about satisfaction and care for the body, discuss body acceptability as it is and motivate them to self-care.	Take a selfie, send it to a WhatsApp contact and when one receives it, reply to themselves with words of self-esteem.
Meeting: Mother who takes care of mother	Encourage the sharing of emotions, challenges, overcoming and positive experiences about being a mother of a child with CZS, sharing experiences.	The self-care practice will be carried out collectively on the questions: If you could take care of another mother, how would you take care of her? What would you say?
Meeting: Facing prejudices	Share experiences about prejudice and discrimination, discuss coping with prejudice and discrimination, and motivate them to take care of themselves.	Disseminate on social networks the images and phrases created to answer the question: What attitude to take in a situation of prejudice?

The sample corresponded to 11 participants from group 1, 12 from group 2 and 13 from group 3. Table 1 shows the variables common to the three groups of experts.

Table 1 – Characterization of participating experts (n=36) of *CACTO* validity, Feira de Santana, Bahia, Brazil, 2022.

Variables	Researchers		Caregivers		Mothers	
	n=11	%	n=12	%	n=13	%
Age						
18 to 30	1	9.0	3	25.0	3	25.0
31 to 40	4	36.4	5	41.7	7	53.8
41 to 50	2	18.2	3	25.0	3	23.1
51 to 70	4	36.4	1	8.3	-	-
Federation state						
Amazonas	-	-	-	-	1	7.7
Bahia	2	18.2	12	100.0	10	76.9
Goiás	-	-	-	-	2	15.4
Paraná	5	45.5	-	-	-	-
Piauí	1	9.0	-	-	-	-
Rio Grande do Sul	3	27.3	-	-	-	-
Education						
Incomplete elementary school	-	-	-	-	1	7.7
Incomplete high school	-	-	-	-	4	30.8
Complete high school	-	-	-	-	7	53.8
Complete higher education	-	-	2	16.6	1	7.7
Incomplete graduate degree	-	-	2	16.6	-	-
Complete graduate degree	11	100	8	66.8	-	-
Religion						
Catholic	7	63.6	8	66.8	2	15.4
Evangelical	2	18.2	1	8.2	7	53.8
Spiritist	1	9.1	-	-	-	-
Does not attend religion	1	9.1	3	25.0	4	30.8

Table 1 – Cont.

Variables	Researchers		Caregivers		Mothers	
	n=11	%	n=12	%	n=13	%
Race/skin color						
White	8	72.8	5	41.7	1	7.7
Brown	1	9.0	5	41.7	9	69.2
Black	2	18.2	2	16.6	3	23.1
Profession/occupation						
Social worker	-	-	1	8.2	-	-
Housewife	-	-	-	-	12	92.3
Nurse	11	100.0	-	-	-	-
Physiotherapist	-	-	4	33.4	-	-
Speech therapist	-	-	3	25.0	-	-
Advertising and marketing	-	-	-	-	1	7.7
Occupational therapist	-	-	4	33.4	-	-
Family income						
None	-	-	-	-	1	7.7
Between R$ 500.01 and R$ 1.500.99	-	-	-	-	11	84.6
Between R$ 1,501.00 and R$ 2,000.99	-	-	1	8.2	-	-
Between R$ 2,001.00 and R$ 2,500.00	-	-	2	16.7	1	7.7
More than R$ 4,000.00	10	91.0	7	58.4	-	-
I prefer not to reveal	1	9.0	2	16.7	-	-

T.N.: R$ is Brazil's currency (R$1.00 = US$5.5).

As for the gender expression variable, 91% of researchers declared themselves to be women, while the percentage was 100% among caregivers and mothers. Among participants in group 1 researchers, 54.5% had 20 years or more of nursing training.

Among the members of group 2 (caregivers), 75% and 8.4% have a lato sensu and stricto sensu specialization course as the highest degree, respectively. Among the courses cited were neonatology, neurology, pediatrics and public health. In group 3, 53.8% live with the child and parent in the same household.

As indicated in Table 2, the "Illustrations have graphic quality", "Illustrations are in line with UCS principles", "Visual composition is attractive and well organized" and "The program size and the number of pages are adequate" criteria reached CVI-C of 0.73 and CVR 0.454 in the first Delphi round of group 01, therefore lower than the adopted reference. The suggestions issued by experts to improve the mentioned criteria were: *I suggest decreasing the textual part. Content too extensive for the format presented. As a suggestion, create callouts and cards with conceptual information* (G1-P4). *Maybe it would be interesting to put more attractive images with better quality and resolution* (G1-P6).

After making adjustments to reduce the number of characters in *CACTO*, modifying the layout, replacing and adding new illustrations, the new version was submitted to the second Delphi round. CVI-C and CVR indexes were higher, although two experts did not participate in the second round.

Table 2 – Distribution of responses by experts in Unitary Caring Science (n=11/n=9) and the respective Content Validity Index – Criterion, Overall Content Validity Index and Coeficient Validity Ratio per round, Feira de Santana, Bahia, Brazil, 2022.

Criteria	CVI-C[a]		CVR[c]	
	Rod.[b] 1 (n=11)	Rod. 2 (n=9)	Rod. 1	Rod.2
Content				
Content is scientifically correct	1.00	1.00	1	1
Content is suitable for use by nurses and health professionals	1.00	0.88	1	0.778
Content is logically organized	1.00	1.00	1	1
Language				
Writing style reflects UCS constructs	1.00	1.00	1	1
The writing used is attractive	0.82	1.00	0.636	1
Text language is clear and objective	0.82	0.88	0.636	0.778
Text language is easily understood by nurses and health professionals	0.91	0.88	0.818	0.778
Illustrations				
Illustrations are relevant to material content and elucidate the content	0.82	0.88	0.636	0.778
Illustrations are clear and convey ease of understanding	0.82	0.88	0.636	0.778
Illustrations have graphic quality	0.73	0.88	0.454	0.778
Illustrations conform to UCS principles	0.73	1.00	0.454	1
The presence of each of the illustrations is relevant	0.82	0.77	0.636	0.778
Layout				
The typeface used makes it easy to read	0.82	1.00	0.636	1
The colors applied to the text are relevant and easy to read	0.91	1.00	0.818	1
Visual composition is attractive and well organized	0.73	0.88	0.454	0.778
The program size and the number of pages are adequate	0.73	0.88	0.454	0.778
The division of parts and sections of the program is adequate	0.82	0.88	0.636	0.778
The font size of titles, subtitles and text is adequate	0.82	1.00	0.636	1
Motivation				
The *CACTO* program is motivating and encourages nurses and health professionals to continue reading	0.91	0.88	0.818	0.778
The *CACTO* program awakens the interest of nurses and health professionals	1.00	1.00	1	1
The *CACTO* program can answer questions, clarify and assist nurses and health professionals in caring for mothers of children with CZS	1.00	1.00	1	1
Culture				
The program can be used by any nurses and health professionals	0.91	1.00	0.818	1
The program can be applied to any mother of a child with CZS, respecting the culture of each mother	0.91	1.00	0.818	1

Table 2 – Cont.

Criteria	CVI-C[a]		CVR[c]	
	Rod.[b] 1 (n=11)	Rod. 2 (n=9)	Rod. 1	Rod.2
Applicability				
The *CACTO* program has practical applicability	1.00	1.00	1	1
Nurses or health professionals can conduct the *CACTO* program with mothers	0.91	1.00	0.818	1
The *CACTO* program applicability can lead to positive results in the health-disease process of mothers of children with CZS	1.00	1.00	1	1
Overall impressions				
The name of the program is suitable	1.00	1.00	1	1
The program logo is suitable	0.91	1.00	0.818	1
The *CACTO* program is theoretically based on UCS	0.91	1.00	0.818	1
Overall CVI	0.88	0.95		

*CVI-C: Content Validity Index – Criterion; †Rod.: Round; ‡CVR: Content Validity Ratio. The critical CVR value for 11 experts is 0.636, while for 09 experts the value is 0.778.

The CVI-C for the responses of groups 2 and 3 were greater than 0.83 after the first round of judgment. Table 3 informs the values of CVI-C, overall CVI and CVR.

Table 3 – Distribution of answers from professional caregivers and mothers (n=12/n=13) and the respective Content Validity Index – Criterion, Content Validity Index – Overall and Coeficient Validity Ratio per round, Feira de Santana, Bahia, Brazil, 2022.

Criteria	Caregivers (n=12)		Mothers (n=13)	
	CVI-C[a]	CVR[b]	CVI-C[a]	CVR[b]
Content				
Content is scientifically correct[c]	0.83	0.667	-	-
Content of the *CACTO* program reflects the lives of mothers of children with CZS[d]	-	-	0.84	0.692
Content is suitable for use by nurses and health professionals[c]	0.91	0.833	-	-
Content of the *CACTO* program is good for mothers of children with CZS[d]	-	-	0.92	0.846
Content presents logical organization[c]	1.00	1	-	-
Language				
Writing style reflects UCS constructs[c]	1.00	1	-	-
The program writing attracted me to read[d]	-	-	0.92	0.846
The writing used is attractive	0.91	0.833	-	-
Text language is clear and objective	1.00	1	0.84	0.692
Text language is easily understood by nurses and health professionals[c]	1.00	1	-	-
Text language is easily understood by mothers of children with CZS[d]	-	-	0.84	0.692
Illustrations				
Illustrations are relevant to material content and elucidate the content[c]	1.00	1	-	-

Table 3 – Cont.

Criteria	Caregivers (n=12)		Mothers (n=13)	
	CVI-C[a]	CVR[b]	CVI-C[a]	CVR[b]
Illustrations are clear and easily understood	0.91	0.833	0.84	0.692
Illustrations have graphic quality	0.91	0.833	0.84	0.692
Illustrations conform to UCS principles[c]	0.83	0.667	-	-
Figures are important and appropriate to the context of mothers of children with CZS[d]	-	-	0.84	0.692
The presence of each of the illustrations is relevant[c]	1.00	1	-	-
Layout				
Typeface used makes it easy to read	0.91	0.833	0.92	0.846
The colors applied to the text are relevant and easy to read	0.91	0.833	0.92	0.846
Visual composition is attractive and well organized	0.91	0.833	0.92	0.846
The program size and the number of pages are adequate	1.00	1	0.84	0.692
The division of parts and sections of the program is adequate	1.00	1	0.84	0.692
Font size is adequate	0.91	0.833	0.84	0.692
Motivation				
The *CACTO* program is motivating and encourages nurses and health professionals to continue reading[c]	0.91	0.833	-	-
I am motivated to be cared for through the *CACTO* program[d]	-	-	0.92	0.846
The *CACTO* program awakens the interest of nurses and health professionals[c]	0.91	0.833	-	-
The *CACTO* program can answer questions, clarify and assist nurses and health professionals in caring for mothers of children with CZS[c]	0.91	0.833	-	-
Culture				
The program can be used by any nurse and health professional, respecting the culture of each one[c]	1.00	1	-	-
The program can be applied to any mother of a child with CZS, respecting the culture of each mother	1.00	1	0.84	0.692
Applicability				
The *CACTO* program has practical applicability[c]	1.00	1	-	-
I wish to participate in the *CACTO* program[d]	-	-	1.00	1
Nurses or health professionals can conduct the *CACTO* program with mothers[c]	1.00	1	-	-
The *CACTO* program can have positive health outcomes for mothers of children with CZS	0.91	0.833	0.84	0.692
Overall impressions				
The name of the program is suitable[c]	0.91	0.833	-	-
I liked the name of the program (*CACTO*)[d]	-	-	0.92	0.846
The program logo is suitable	1.00	1	0.92	0.846
Overall CVI	0.94	0.88		

*CVI-C: Content Validity Index – Criterion; †CVR: Content Validity Ratio. The critical CVR value for 12 experts is 0.667, while for 13 experts the value is 0.538. ‡Item answered exclusively by expert caregivers; [d]Item answered exclusively by mother experts.

Group 2 participants comment on the relevance of *CACTO* and its applicability: *the power of CACTO lies in the importance of teamwork, matrix support, sharing care, knowledge and actions between different categories. The professional who will provide health care is motivated by this proposal. I already want to use it as a reference in mothers' groups* (G2-E4).

While mothers showed motivation and anxiety to be cared for: *Anxious to know a real project for the care of mothers, we are forgotten and are suffering a lot, with depression, anxiety, phobia, being alone, etc. Something aimed especially at mothers will be very good. We are mothers full of thorns and succulent love, so I think (CACTO) represents us well* (G3-E2). *Thank you for looking out for us mothers. That most of the time we are invisible to society* (G3-E7).

DISCUSSION

Developing a specific care program for mothers fills a lack of health care for these women[7]. *CACTO* brings together a set of scientific, original and creative knowledge that gives it an innovative character and enables transformations in the ways of caring, with consequent improvement in the health-disease process of mothers and children, characteristics that allow classifying it as a technological innovation in health[18]. The translation of UCS into a care program encourages health professionals to innovate in their care, welcoming, autonomy, citizenship and critical awareness, advocating in favor of emancipatory interactional care[19].

In this regard, *CACTO* brings together different care modalities, with actions ranging from introspection and self-knowledge, such as the booklet, to empowerment and collective confrontation of prejudices, in addition to intra-family interactional care, such as family care. The booklet "Taking care of my mind", for instance, proposes a conscious break in the exhausting routine of nurses, professional caregivers and mothers. It is a set of actions for self-knowledge, inflection and contemplation of oneself and everything that surrounds them. This orientation of thought to contemplate favors energetic vibration[10], decreases stress, anxiety, depression, improves the feeling of pain[20], sleep disorder aspects and fatigue[21].

For UCS, every way of knowing and doing is equally important, the diverse knowledge, cultural expressions and ways of caring enable the action of transdisciplinary care[10]. In line with these ideas, professional caregiver experts highlighted the importance of matrix support and integration between different professional categories as a power for the practical application of *CACTO*.

Criteria related to the "illustrations" and "layout" domains reached lower CVI and CVR values in the first Delphi round by RBCCU researchers. In these questions, experts pointed out the need to readjust content size and illustration quality in order to enhance the program. Success in adopting these considerations in the material was evidenced by a satisfactory CVI and CVR in the second Delphi round. It is justified that the entire development process of *CACTO* took into account mothers' socioeconomic and cultural profile and health needs. Therefore, as a result of the sovereign social structure that oppresses groups of people because of their ancestors, ideology and cultural expression[22], there are few illustrations of black or brown mothers with children with congenital anomalies in public domain repositories.

Even in the case of illustrations in the public domain, the developers respected the copyright of the images and did not use resources to improve quality or resolution. With a view to better illustration representation and improvement, it is intended, during the *CACTO* implementation, to carry out photo sessions with the mother-child dyad, with documented authorization.

As for the layout and number of pages, it is explained that *CACTO* is not a program with a beginning, middle and end that can be used linearly, since it is mothers' emerging needs that will guide the applicability of each type of care. Thus, *CACTO* implementation will follow the sequence agreed

upon between mother, nurse and/or professional caregiver according to their priorities, respecting mothers' role and professional autonomy.

Moreover, the *CACTO* implementation project aims to make it available on websites and social networks, in addition to the development of prototype applications for mobile devices in order to help those who wish to apply it. Such strategies can overcome researchers' disagreement regarding the size and number of pages of the program as well as enhance its applicability in different territories of Brazil. However, professional caregivers did not mention the number of pages as a limitation for *CACTO* application, they highlighted matrix support, teamwork, sharing care and knowledge as potentialities of the program.

CACTO was designed to face the precepts of heteronormative society that abstain children's parents, attributing the cause of disability to mothers and reaping their personal and professional projects, attributing to them the comprehensive care of children[7]. To the same extent, corporative society understands mothers' body as an extension of children's body; therefore, they experience prejudiced judgments of economically incapable, generating costs for the State and resulting from divine justice to moral "deviations"[7]. Based on such evidence, the social disability concept, as a product of social interactions[8], supported the development of care modalities. Therefore, it strives to offer, through self-care practices, possibilities to challenge established social rules and the tyranny of individuality[23], such as exposure in public spaces and social networks of photos and phrases constructed by mothers during meetings.

Despite the recommendation for *CACTO* applicability by professional caregivers, it is understood that nursing leadership can favor the achievement of positive results from the program, corroborating what was found in the Survival Care Program (SCP)[24]. The efficiency of SCP is justified by nurses' skills in listening carefully, accepting health needs without judgment, offering emotional support and motivating social relationships, objectives that are aligned with the objectives of *CACTO*[24].

Like the My Back My Plan (MBMP) program[25], *CACTO* seeks to emancipate families from the structuring logic of oppression[6], giving them back power over their bodies[26], as opposed to hegemonic interventionist care. The MBMP was developed by people in care and primary care health professionals in Sydney, Australia, to treat acute low back pain. Such a program is at an advanced stage of implementation, standing out for the uniqueness of care, target audience's role, appreciation of self-care and positive impacts on the health-disease process[25]. *CACTO* reserves the potential to awaken in mothers the ownership of their existence and their work in the world, aspects restricted by the dominant discourses of subjection to corpo-normative "marks"[26] of being a woman who occupy a subordinate position with low income and education[7].

CACTO was designed to be applied in any health facility, by an interested professional caregiver; however, the principles of capillarity, bonding, health responsibility, social participation, in addition to routine care for populations in vulnerable situations[27], may favor better results when applied in Primary Health Care.

Meetings between professional caregivers in medium-density technological establishments will favor interprofessional action, matrix support practices, health education and improvement of coexistence environments. These results are found during the implementation of Adaptive Care: a mental health care program for autistic children[28]. However, this option can strengthen the social isolation experienced by mother and child[29], making it difficult to face the stigma and restricting the child's inclusion in other spaces that he/she wants or needs to attend.

The efficiency of *CACTO* can be verified from the application of measurement scales for anxiety, depression, fatigue, sleep quality, quality of life and resilience, before, during and after implementation, in addition to assessing the program's cost-effectiveness. New studies are recommended to reinforce

CACTO validity/capacity by means of objective measures, which allow assessing the impact/effect on mothers' quality of life.

CACTO has the potential to become a social technology, considering the elements of associativism, collective ownership, control and cooperation, indicating a social agreement between mothers, and self-management of technology in a voluntary and participatory way by them[30]. Successful care attitudes by the nursing team and the mastery of nursing theories can support the unprecedented development of specific care programs for populations in vulnerable situations. Therefore, it is opportune for nursing to value the theoretical constructs of the profession, cultivate creative sensitive thinking and boost its work as a professional category that recognizes the moral value of care.

A limitation of this study resides in the application of validity instruments and availability of *CACTO* via electronic questionnaire, which limited the participation of other experts who have difficulties in accessing electronic resources and the internet. Furthermore, due to the physical distance caused by the COVID-19 pandemic, the participation of professional caregivers and mothers did not occur in the initial stage of development of *CACTO*.

CONCLUSION

CACTO was assessed by RBCCU researchers, professional caregivers of family members of children with CZS and mothers, with an overall CVI range ≥ 0.88 and a critical CVR above the recommended level; therefore, it is understood that *CACTO* has evidence of validity that allows recommending it for clinical practice centered on the care of mothers and families. It is communicated that the *CACTO* development team has started the copyright registration process with the Brazilian National Library (nº 2022RJ11751) and, upon completion, the program will be made available in full.

The life experience of CZS mothers is similar to the experience of other mothers of children with congenital anomaly and chronic conditions; thus, except for the necessary specificities and adaptations, the number of people to be cared for through *CACTO* can be expanded, such as for mothers of children with chronic illness.

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NOTES

ORIGIN OF THE ARTICLE

Extracted from the thesis – *Desenvolvimento do programa de cuidado unitário às mães de crianças com síndrome congênita do vírus Zika*", presented to the Graduate Program in Collective Health, at the Universidade Estadual de Feira de Santana, in 2022.

CONTRIBUTION OF AUTHORITY

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Discussion of results: Vale PRLF, Costa JSP, Freitas KS, Lacerda MR, Carvalho RC, Carvalho ESS.
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There is no conflict of interest.

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