

**Caregiving Practices for Children with Disabilities Constructed by Caregivers
at the Instituto de Capacitación Los Álamos**

**Prácticas sobre cuidado de niños con discapacidad construidas por cuidadores
del Instituto de Capacitación Los Álamos**

**Práticas sobre o cuidado de crianças com deficiência construídas pelos cuidadores
do Instituto de Capacitación Los Álamos**

*Nidia Johana Arias Becerra*¹, ORCID 0000-0002-4261-3310
*Jessica María Ayala Hernández*², ORCID 0000-0002-3385-3355
*Andrea Taborda Mazo*³, ORCID 0000-0003-0364-7734
*Andres Choperena Posada*⁴, ORCID 0000-0003-1423-4353
*Alejandra González Mejía*⁵, ORCID 0000-0002-3585-9857
*Juan Felipe Naranjo Lopez*⁶, ORCID 000-0002-5093-5424
*María Clara Tuberquia Velásquez*⁷, ORCID 0000-0002-5453-9875

^{1 2 3 4 5 6 7} Universidad CES, Colombia

Abstract: Introduction: Many elements, including practices, mediate the work of caring for children with disabilities in early childhood. As a result of the disability and age of the children, their caregivers commonly become responsible for their well-being. Understanding the practices of caregivers allows optimizing and implementing functional routines that promote the well-being and quality of life of children and their caregivers. Objective: To understand the practices of caregivers of children aged 1-6 years with disabilities at the Instituto de Capacitación Los Álamos (Itagüí, Colombia). Method: Qualitative study focused on grounded theory. The participants were twelve surrogate mothers from the institute; a convenience sampling was carried out until theoretical saturation. Results: The practices consisted of care routines, including activities specifically for children with disabilities such as massages, therapies, adaptations of the space for postural control and participation. Moreover, activities such as feeding, and massages are equally important when caring for a child with a disability. Conclusion: Caring for children with disabilities involves multiple activities and practices specific to the child's condition. Despite their difficulty, they become immersed in a compilation of routines incorporated into the family's daily life.

Keywords: children with disabilities; caregivers; childcare; everyday activities.

Resumen: Introducción: La labor de cuidado de niños con discapacidad en primera infancia está mediada por muchos elementos, entre ellos, las prácticas. Dada la discapacidad y la edad de los niños, es habitual que sean sus cuidadores los responsables de su bienestar. Comprender las prácticas de los cuidadores permite optimizar e implementar rutinas funcionales, que propendan al bienestar y la calidad de vida de los niños y sus cuidadores. Objetivo: Comprender las prácticas de personas encargadas del cuidado a niños con discapacidad, de 1 a 6 años de edad, en el Instituto de Capacitación Los Álamos (Itagüí, Colombia). Método: Estudio cualitativo enfocado en la teoría fundamentada. Se invitó a participar 12 madres sustitutas del instituto, se realizó un muestreo a conveniencia hasta la saturación teórica. Resultados: Las prácticas se constituyen en rutinas de cuidado que incluyen actividades que son específicas para los niños con discapacidad, tales como masajes, terapias, adaptaciones del espacio para el posicionamiento y la participación, entre otros. Actividades como la alimentación y el masaje son igual de importantes a la hora del cuidado de un niño con discapacidad. Conclusión: El cuidado de niños con discapacidad supone la realización de múltiples actividades y diferentes prácticas específicas para la condición del niño. A pesar de lo difíciles que son, terminan estando inmersas en un compilado de rutinas que se incorporan al día a día de la familia.

Palabras claves: niños con discapacidad; cuidadores; cuidado del niño; actividades cotidianas.

Resumo: Introdução: O trabalho de cuidar de crianças com deficiência na primeira infância é mediado por muitos elementos, incluindo práticas. Dada a deficiência e a idade das crianças, é comum que seus cuidadores sejam responsáveis por seu bem-estar. A compreensão das práticas dos cuidadores permite otimizar e implementar rotinas funcionais que promovam o bem-estar e a qualidade de vida da criança e de seus cuidadores. Objetivo: Compreender as práticas sobre o cuidado de crianças com deficiência física na primeira infância, construídas por cuidadores pertencentes ao Instituto de Capacitación Los Álamos. Método: Estudo qualitativo com foco na teoria fundamentada. Doze mães de aluguel foram convidadas a participar, sendo realizada uma amostragem por conveniência até a saturação teórica. Resultados: As práticas se constituem em rotinas de cuidado, que incluem atividades específicas para crianças com deficiência, como massagens, terapias, adaptações do espaço para posicionamento e participação, entre outras. Atividades como alimentação e massagem são tão importantes quanto ao cuidar de uma criança com deficiência. Conclusão: Cuidar de crianças com deficiência envolve a realização de múltiplas atividades e diferentes práticas específicas à condição da criança. Por mais difíceis que sejam, acabam imersos em uma compilação de rotinas que se incorporam ao dia a dia da família.

Palavras-chave: crianças com deficiência; cuidadores; cuidado da criança; atividades cotidianas.

Received: 03/05/2021

Accepted: 10/29/2021

How to cite:

Arias Becerra NJ, Ayala Hernández JM, Taborda Mazo A, Choperena Posada A, González Mejía A, Naranjo Lopez JF, Tuberquia Velásquez MC. Caregiving Practices for Children with Disabilities Constructed by Caregivers at the Instituto de Capacitación Los Álamos. *Enfermería: Cuidados Humanizados*. 2021;10(2):191-203. DOI: 10.22235/ech.v10i2.2485

Correspondence: Nidia Johana Arias Becerra, e-mail: narias@ces.edu.co

Introduction

According to the 2011 World report on disability, disabilities are part of the human condition. Almost everyone will experience some form of temporary or permanent disability at some point in their life. More than one billion people live with some form of disability; that is, about 15% of the world's population, according to 2010 world population estimates. ⁽¹⁾

According to the World Health Survey, the global burden of disease alone measures childhood disabilities in children aged 0-14 years, estimating that from 95 million children (5.1%), 13 million (0.7%) have "severe disability," i.e., very significant difficulties in functioning. ⁽²⁾

Children who experience disability from the earliest years of life are exposed to risk factors such as poverty, stigma, discrimination, poor interaction with caregivers, violence, abuse, neglect, and limited access to programs and services, which can significantly affect their survival and development, causing them to take a back seat. ⁽³⁾

The protection of these children's rights is governed by the Convention on the Rights of the Child (CRC) and the Convention on the Rights of Persons with Disabilities (CRPD). However, multiple violations still occur. Children in early childhood are highly dependent on their caregivers; hence the practices of caregivers take on a particular value. ⁽³⁾

Caregiving practices mark the course of the child's condition, which can improve or worsen it and thus have a positive or negative impact on the situation of the family nucleus. Practices related to care, including posturing control activities, become evident only when they are not performed correctly, because time makes it difficult to reverse their consequences. Therefore, excellent and continuous training for caregivers and empowerment of their role makes caregiving a critical factor in including children with disabilities. ⁽⁴⁾ Furthermore, understanding how care is performed allows caregivers to validate their practices with an interdisciplinary team and generate essential changes in theirs and other professionals working in the institution.

The objective of this paper is to characterize the caregiving practices for children with disabilities constructed by Los Álamos institute caregivers. As a specific objective, it was proposed to identify the types of practices constructed around the care of children with disabilities.

Method

We performed a qualitative study to understand the world of lived experience based on the practices of caregivers of children with disabilities. The inquiry process was inductive, and the researchers interacted with the participants in search of answers that focused on the

experience as a caregiver. The study was based on grounded theory, the theoretical categories derived from the data using a comparative method, which allowed the scope of the substantive theoretical construction, the theorization of caregiving, and its activities.

Twelve women, surrogate mothers in charge of children aged between 1 and 6 years with motor disabilities, participated in the study. The participants belonged to socioeconomic stratum 2 and 3. Eight lived in the urban area of the Medellín metropolitan area. They were contacted from the database provided by the Training Institute and subsequently invited to participate in the study.

The mothers were part of the Instituto de Capacitación Los Álamos, operator of the Instituto Colombiano de Bienestar Familiar (ICBF) programs. The term surrogate mother is supported by what De la Cuesta & Benjumea call a formal caregiver since they receive economic remuneration for their work.⁽⁵⁾ A convenience sampling was carried out, ending with the categories' theoretical saturation.⁽⁶⁾ No member of the research team had a previous relationship with the study participants. The study was conducted between 2018 and 2019. The researcher's group consisted of 5 women and two men with experience approaching, constructing, and conducting fieldwork in qualitative approaches. Likewise, different meetings were held to co-create the tools to work with the participants. The interviews took place at the caregiver's homes, previously agreeing on the space, time, and place; the caregivers signed the informed consent form. The researchers conducted audio-recorded interviews to ensure reliability and trust in the Training Institute and the caregivers, and the interview guideline was validated among the researchers. Additionally, the study was approved by the Ethics Committee of Universidad CES and Los Álamos.

Data processing started with open coding using the ATLAS.Ti version 7 software. Through axial coding, categories and subcategories were identified by contrasting the emerging information with that previously analyzed. Finally, selective coding was performed to establish the definitive categories and define caregivers.^(7, 8)

For theorization, we explored the links of association, contradiction, or inclusion between the codes and their density as units of meaning. Triangulation of the analysis of the information was performed between principal investigators and co-investigators.⁽⁹⁾

The methodological rigor criteria of credibility, auditability, and transferability were applied.⁽¹⁰⁾

Results

The Colombian population is classified in socioeconomic levels or stratum; 1 is the lowest and six the highest. Our participants belonged to strata 2 and 3, and most of them had a high school diploma. Their experience as caregivers had been extensive; most of them had 6 - 10 years of experience. Ten participants received some type of training as caregivers, but most of their knowledge had been acquired through experience.

Table 1. Sociodemographic Characterization

Variables		Frec.
Gender	Female	12
Age	25 - 35 years old	4
	35 - 45 years old	6
	45 - 55 years old	2
Stratum	1	0
	2	6
	3	6
Educational level	Elementary	0
	High school	11
	Technical	1
Experience as a caregiver (years)	From 0 to 5 years	2
	From 6 to 10 years	4
	From 11 to 15 years	3
	From 16 to 20 years	1
	From 21 to 25 years	2
Courses or training programs as a caregiver	Yes	10
	No	2
Where did they get most of their training as caregivers	Self-Acquired knowledge	6
	Education with other caregivers	1
	Training	5

Source: Own elaboration (2020)

The surrogate mother profile is a figure full of nuances. Although they voluntarily decide to take care of a child, they receive economic remuneration. ⁽¹¹⁾ The interviews often indicated that it is a labor of love because their income is often insufficient to care for a child with a disability. Conversely, most of them do not have professional training; they provide care based on experience, showing that women generally take on this type of responsibility. ⁽¹²⁾

Historically, women's upbringing in different cultures has revolved around caregiving, especially for the most vulnerable. ⁽¹³⁾ In addition, the care at home is generally associated with care work, without any economic remuneration, although in this case, they had it. ⁽⁵⁾

After the open coding process began, one element was remarkable: daily routines as the main category. As the axial coding continued, the other emerging codes entered into a relationship of subordination and belonging with the routines. Finally, the establishment of routines as the main category and the other subcategories from the selective coding was defined (Figure 1).

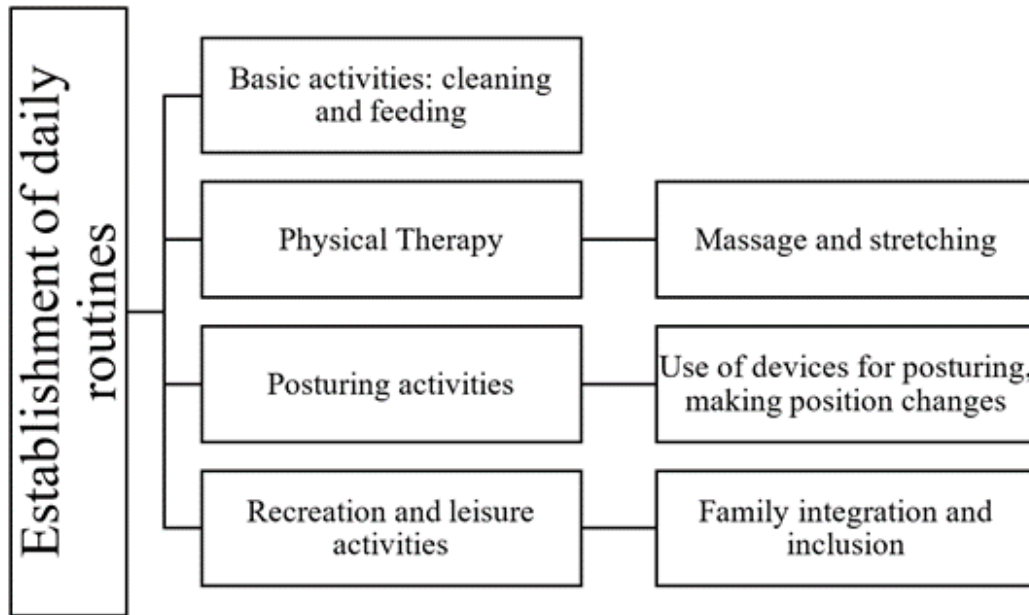


Figure 1. Categories and subcategories. Source: Own elaboration (2020)

Daily routines: Grooming and feeding

Routines are essential to perform all the additional care activities required by a child with a disability. They modify the family dynamics, but they accept and live them naturally; routines become part of daily life, forgetting at times about the complexity of the task.

A normal day is: bathing, personal hygiene, brushing, nail clipping, cleaning the "gastro" [gastrostomy tube]. (C3)

Everyday things, bathing them, cleaning them, brushing their teeth, feeding them on time... with the girl with a disability, it is more complicated because of the wheelchair. (C9)

Cleaning and feeding are activities that children do autonomously, but they become evident in children with disabilities since they require assistance, and their poor performance leads to multiple complications. In addition, these activities require time and, in some cases, specific knowledge to perform. One of the caregivers shared the feeding routine of some of the children:

One boy eats standing up, and with his head between my legs I give him the food because in another position it is impossible... and the other one I put him here on my leg and place the gastro [gastrostomy tube] and keep him seated because after he eats, he must remain seated for at least 40 minutes so that he does not bronchoaspire. (C6)

Physical therapy

For most caregivers, physical therapy and massage become relevant considering the alterations in the children's functioning. These activities become crucial elements of the routine that usually help maintain their good health, are part of their daily routine, and are

not believed an additional caregiving activity. The following testimonies show that therapy is part of the routine:

The first thing I do when I pick them up is to stretch them, that is, I lift their little hands, I pull them backward, I position their spine because they were lying down, then I sit them down and make certain movements. I prepare them, bathe them, and after the bath, I do half an hour of therapy with them. (C6)

In the afternoon, I do the exercises again because I see that her little fingers are sticking a lot, so the exercises I do are mostly for her hands because they feel very stiff. (C5)

Physical therapy and all its elements become a daily activity, something that may not happen when caring for children without disabilities, as evidenced in the following testimonies:

I get up at 6 o'clock, and the first thing I do is bathe them; we bathe them and then after the bath follows breakfast and what I do then in the bath I told you about, is the exercises and all of that. (C2)

Well, the girl gets up every day at 4 a.m., she is given her milk, the "pediasure," at 6 a.m. the girl is already taking a bath, I give her little massages, therapies after the bath, I put cream all over her body, I especially focus on doing the hand therapies, I organize her, and put her to bed for a while. (C5)

Postural control and recreational activities

Starting the project, we wanted to determine whether caregivers identified postural control activities as a caregiving strategy; and it emerged clearly and naturally how these activities were of extreme importance when they involve participation activities such as playing or feeding:

With a good posture they gain strength, they gain security, for example, one of the children, when he was handed over to me, always had his head down, but he has been able to acquire much strength and, besides that, with a good posture, digestion works better. (C6)

Repeatedly in their speeches, the caregivers mention the importance of adapting the spaces where the child will be so that he/she can participate in activities such as play and recreation, not only for essential activities such as feeding:

Around 7:30 or 8 o'clock, I give her breakfast, I put her in the chair, I put her to play with toys because she already likes to sit in the chair. (C5)

Moreover, it became evident how these practices can be carried out intuitively with elements present at home or even be acquired if it is clear to the caregiver the benefit it generates in the child's health and functioning; this can be evidenced in the following statement:

Yes, I put them [cushions], well, I make a little cave for her to sit on because she cannot hold her head. (C7)

No, I also put all this [showing cushions and blankets] in case he suddenly loses his balance and falls, so he does not hit himself. (C2)

Discussion

Caring for children with disabilities involves multiple activities and different practices specific to the child's condition. Despite their complexity, they become immersed in a compilation of routines that the family incorporates into their daily life. Understanding how physical therapy and feeding can be equally important in caring for a child with a disability allows us to address caregivers' work and better understand the complexity of their work.

Daily routines

Routines can be behaviors linked to regular daily activities related to the maintenance of health. Establishing these routines in the care of a child with a disability provides a glimpse of the family's commitment to maintaining good health. Adequate or inadequate routines may have a direct bearing on the presence or absence of disease. In addition to care and health, routines are essential for three reasons: first, they represent the main focus of the family; second, they are immersed in the context and culture in which families live; and third, they are the interaction between the person and the dynamics of the family. ⁽¹⁴⁾

Although caregivers establish daily care routines, caring for a child with a disability usually implies changes, sometimes including more complex routines. The care activities immersed in the routines are learned through daily practice and by implementing the advice and recommendations of some health professionals. However, their daily implementation is a direct responsibility of the caregiver. ⁽¹⁵⁾ One of the activities requiring a more remarkable dedication of time and skill is feeding; since it can become a specialized activity, it is perfected with experience. ⁽¹⁶⁾ Feeding brings significant challenges to a child with a disability and his or her caregiver. However, it becomes an essential daily activity that impacts the family's feeding routine and rituals. ⁽¹⁷⁾ Thus, care routines take on other meanings; they become rituals of care that maintain the person's health and integrity and involve the whole family.

Physical therapy

Physical therapy is an activity that has been incorporated into caregiving routines and occupies a large part of them. Activities have focused primarily on massage and stretching, activities that caregivers have perfected through daily practice. The caregivers' knowledge of "therapeutic" activities is immersed in their daily work. It is not seen as an additional activity but as part of the child's daily care routine. ⁽¹⁸⁾ Systematic performance of the activities by caregivers has positive effects on the children's health. However, Gorgon reveals how health professionals usually minimize this task, as caregivers are not treated as active actors in the process. ⁽¹⁹⁾

Regarding the activities carried out by caregivers at home, it is remarkable that as traditional activities such as massage are helpful, they require much time to perform and are classified as therapeutic. ⁽²⁰⁾ For Nobakht, caregivers must invest much time in the care of children, which can affect their physical and psychosocial health in the long term. However, one way to optimize caregiving and caregiving training is to receive virtual counseling in real-time. ⁽²¹⁾ In addition, Pereira mentions that physical therapy provided by home

caregivers should be focused on seeking independence for children and their families. This way, the burden of care can be lessened, and more efficient activities for the whole family can be accomplished. ⁽²²⁾

Postural control activities

Good postural control activities of children with disabilities and motor impairments are part of daily care; they generate well-being and prevent skin lesions and musculoskeletal distortions. ^(23, 24) Postural control is about using support devices and their shape and time of use and the skills and knowledge of the caregivers. The more regular these practices are, the greater the benefit for the child. ⁽²⁵⁾

Regarding assistive devices, evidence shows that technical and homemade devices report benefits in children's functioning and participation. ⁽²⁶⁾ Participation as a physical presence, including elements of affection, motivation, and social connection, includes behavioral elements, which are not often evidenced when addressing the participation of children with disabilities in various activities. In this context, suitable postural control activities favor authentic participation. ^(27, 28)

Postural control depends on the caregiver's knowledge of the child's needs and communication. ⁽²⁹⁾ Lyons explores how elements of postural control could be successfully adapted as long as there is accurate communication reading the child's emotions. This task is easier for a caregiver who is convivial and interested in the children's well-being. The postural control activities and communicative interactions show a genuine commitment to caregiving. Also, the caregiver may not have technical and scientific knowledge about postural control, but his or her actions are framed by empathic behaviors in reaction to children's expressions or feelings, comfort or discomfort. Thus, empathy depends on the characteristics of the perceived stimuli, the observer's knowledge, and his willingness to help. ⁽³⁰⁾

Finally, Geere states that having access to support devices is beneficial for the child and the caregiver. ⁽³¹⁾ This was evidenced by the participants when they reported that they could feel calmer once they helped the child to have appropriate postural control.

Conclusion

The care practices carried out by the institute's caregivers reveal how the caregiving of children with motor disabilities from 1 to 6 years old is performed. Despite their execution complexity and knowledge required, these activities become indispensable routines framed in care rituals for each family. Knowledge of practices and all the elements involved allows us to understand the logic behind the caregiver's action to better approach this population according to their needs. A routine in a familiar context is an activity that may go unnoticed, but it is evident that it is the critical element of caregiving in this population.

Awareness of how routines constitute the care of a child with a disability validates and legitimizes the work of caregivers and provides indispensable elements for professional caregivers and institutions to make adjustments in their practices. The results of this project provide a different view of how this issue should be approached. Although caregivers have extensive practical knowledge, efforts should no longer be based on training the caregiver but on generating collective knowledge between caregivers and professionals, thus acknowledging and legitimizing the practices built through experience.

Financing: Project funded by the Faculty of Physiotherapy and the Direction of Research and Innovation of Universidad CES, Medellín, Colombia.

Bibliographical references

1. United Nations. Convención sobre los Derechos de las Personas con Discapacidad Guía de Formación [Internet]. UN; 2014 [cited 25 Feb 2021]. Available from: <https://www.un-ilibrary.org/content/books/9789210564977>
2. Discapacidad Informe Mundial 2011 OMS [Internet]. [cited 25 Feb 2021]. Available from: <http://www.codajic.org/sites/www.codajic.org/files/Discapacidad%20Informe%20%20Mundial%202011%20OMS.pdf>
3. Organización Mundial de la Salud & United Nations Children's Fund. El desarrollo del niño en la primera infancia y la discapacidad: un documento de debate. 2013 [cited 21 Jul 2015]. Available from: <http://apps.who.int/iris/handle/10665/78590>
4. Pérez-de la Cruz S. Parálisis cerebral infantil y el uso de sistemas de posicionamiento para el control postural: estado actual del arte. *Neurología*. 2017[cited 20 Feb 2018];32(9):610-615. Available from: <http://linkinghub.elsevier.com/retrieve/pii/S0213485315001516>
5. Martínez Marcos M, De la Cuesta Benjumea C. La experiencia del cuidado de las mujeres cuidadoras con procesos crónicos de salud de familiares dependientes. *Aten Primaria* [Internet]. 2016[cited 31 Mar 2020];48(2):77-84. Available from: <https://linkinghub.elsevier.com/retrieve/pii/S0212656715001249>
6. Hernández Sampieri R, Fernández Collado C, Pilar Baptista Lucio M. *Metodología de la investigación*. México: McGraw-Hill; 2014.
7. Coffey A. Encontrar el sentido a los datos cualitativos [Internet]. [cited 22 Apr 2021]. Available from: <https://www.fceia.unr.edu.ar/geii/maestria/2014/DraSanjurjo/8mas/Amanda%20Coffey,%20Encontrar%20el%20sentido%20a%20los%20datos%20cualitativos.pdf>
8. Vivar CG, Arantzamendi M, López-Dicastillo O, Gordo Luis C. La Teoría Fundamentada como Metodología de Investigación Cualitativa en Enfermería. *Index Enferm* [Internet]. 2010[cited 29 Apr 2021];19(4):283-288. Available from: https://scielo.isciii.es/scielo.php?script=sci_abstract&pid=S1132-12962010000300011&lng=es&nrm=iso&tlng=es
9. Morse JM. Asuntos críticos en los métodos de investigación cualitativa [Internet]. Universidad de Antioquia; 2003 [cited 22 Apr 2021]. Available from: <https://dialnet.unirioja.es/servlet/libro?codigo=663465>

10. Morse JM, Barrett M, Mayan M, Olson K, Spiers J. Verification Strategies for Establishing Reliability and Validity in Qualitative Research. *Int J Qual Methods* [Internet]. 2002[cited 4 Mar 2021];1(2):13-22. Available from: <http://journals.sagepub.com/doi/10.1177/160940690200100202>
11. Instituto Colombiano de Bienestar Familiar (ICBF). Lineamiento Técnico para las Modalidades de Vulneración o Adoptabilidad para el Restablecimiento de Derechos de Niños, Niñas y Adolescentes y Mayores de 18 años con Discapacidad, con sus Derechos Amenazados, Inobservados o Vulnerados. [Internet]. Resolución 5930 de 2010. Available from: https://www.icbf.gov.co/cargues/avance/docs/resolucion_icbf_5930_2010.htm#inicio
12. Coira Fernandez G, Bailon Muñoz E. La invisibilidad de los cuidados que realizan las mujeres. *Aten Primaria* [Internet]. 2014[cited 31 Mar 2020];46(6):271-2. Available from: <https://linkinghub.elsevier.com/retrieve/pii/S0212656714001772>
13. Massé Garcia MC. La mujer y el cuidado de la vida. *Comprensión histórica y perspectivas del futuro. Cuadernos de Bioética XXVIII*; 2017.
14. Fiese BH. Dimensions of Family Rituals Across Two Generations: Relation to Adolescent Identity. *Fam Process* [Internet]. 1992[cited 26 Feb 2021];31(2):151-62. DOI: 10.1111/j.1545-5300.1992.00151.x
15. Denham SA. Relationships between Family Rituals, Family Routines, and Health. *J Fam Nurs* [Internet]. 2003[cited 25 Feb 2021];9(3):305-30. Available from: <http://journals.sagepub.com/doi/10.1177/1074840703255447>
16. Adams MS, Khan NZ, Begum SA, Wirz SL, Hesketh T, Pring TR. Feeding difficulties in children with cerebral palsy: low-cost caregiver training in Dhaka, Bangladesh. *Child Care Health Dev* [Internet]. 2012[cited 28 de Apr de 2021];38(6):878-88. Available from: <https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1365-2214.2011.01327.x>
17. Russell M, Jewell V, Poskey GA, Russell A. Enteral feeding and its impact on family mealtime routines for caregivers of children with cerebral palsy: A mixed method study. *Aust Occup Ther J*. 2018;65(1):25-34.
18. Kruijsen-Terpstra AJA, Ketelaar M, Boeije H, Jongmans MJ, Gorter JW, Verheijden J, et al. Parents' experiences with physical and occupational therapy for their young child with cerebral palsy: a mixed studies review: Parents' experiences with their child's therapy. *Child Care Health Dev* [Internet]. 2014[cited 25 Feb 2021];40(6):787-96. DOI: 10.1111/cch.12097
19. Gorgon EJ. Caregiver-Provided Physical Therapy Home Programs for Children with Motor Delay: A Scoping Review. *Phys Ther* [Internet]. 2018[cited 29 Apr 2021];98(6):480-93. Available from: <https://academic.oup.com/ptj/article/98/6/480/4813621>

20. Weekly T, Riley B, Wichman C, Tibbits M, Weaver M. Impact of a Massage Therapy Intervention for Pediatric Palliative Care Patients and Their Family Caregivers. *J Palliat Care* [Internet]. 2019[cited 26 Feb 2021];34(3):164-7. Available from: <http://journals.sagepub.com/doi/10.1177/0825859718810727>
21. Nobakht Z, Rassafiani M, Hosseini SA, Hosseinzadeh S. A web-based daily care training to improve the quality of life of mothers of children with cerebral palsy: A randomized controlled trial. *Res Dev Disabil*. 2020;105:103731. DOI: 10.1016/j.ridd.2020.103731
22. Pereira A, Moreira T, Lopes S, Nunes AR, Magalhães P, Fuentes S, et al. «My Child has Cerebral Palsy»: Parental Involvement and Children's School Engagement. *Front Psychol*. 2016;7:1765. DOI: 10.3389/fpsyg.2016.01765
23. Angsupaisal M, Maathuis CGB, Hadders-Algra M. Adaptive seating systems in children with severe cerebral palsy across International Classification of Functioning, Disability and Health for Children and Youth version domains: a systematic review. *Dev Med Child Neurol* [Internet]. 2015[cited 20 Feb 2018];57(10):919-30. DOI: 10.1111/dmcn.12762
24. Ágústsson A, Sveinsson Þ, Rodby-Bousquet E. The effect of asymmetrical limited hip flexion on seating posture, scoliosis and windswept hip distortion. *Res Dev Disabil*. 2017;71:18-23.
25. Sato H, Iwasaki T, Yokoyama M, Inoue T. Monitoring of body position and motion in children with severe cerebral palsy for 24 hours. *Disabil Rehabil* [Internet]. 2014 [cited 4 Apr 2018];36(14):1156-60. Available from: <http://www.tandfonline.com/doi/full/10.3109/09638288.2013.833308>
26. Henderson S, Skelton H, Rosenbaum P. Assistive devices for children with functional impairments: impact on child and caregiver function. *Dev Med Child Neurol* [Internet]. 2008 [cited 25 Feb 2021];50(2):89-98. DOI: 10.1111/j.1469-8749.2007.02021.x
27. Alghamdi MS, Chiarello LA, Palisano RJ, McCoy SW. Understanding participation of children with cerebral palsy in family and recreational activities. *Res Dev Disabil* [Internet]. 2017 [cited 2 Mar 2021];69:96-104. Available from: <https://linkinghub.elsevier.com/retrieve/pii/S0891422217301798>
28. Imms C, Adair B, Keen D, Ullenhag A, Rosenbaum P, Granlund M. 'Participation': a systematic review of language, definitions, and constructs used in intervention research with children with disabilities. *Dev Med Child Neurol* [Internet]. 2016 [cited 3 Mar 2021];58(1):29-38. Available from: <https://onlinelibrary.wiley.com/doi/abs/10.1111/dmcn.12932>
29. Hotham S, Hamilton-West KE, Hutton E, King A, Abbott N. A study into the effectiveness of a postural care training programme aimed at improving knowledge, understanding and confidence in parents and school staff: Effectiveness of a postural

- care training programme. *Child Care Health Dev* [Internet]. 2017 [cited 20 Feb 2018];43(5):743-51. DOI: 10.1111/cch.12444
30. Lyons EA, Jones DE, Swallow VM, Chandler C. An Exploration of Comfort and Discomfort Amongst Children and Young People with Intellectual Disabilities Who Depend on Postural Management Equipment. *J Appl Res Intellect Disabil* [Internet]. 2017 [cited 20 Feb 2018];30(4):727-42. DOI: 10.1111/jar.12267
31. Geere JL, Gona J, Omondi FO, Kifalu MK, Newton CR, Hartley S. Caring for children with physical disability in Kenya: potential links between caregiving and carers' physical health. *Child Care Health Dev* [Internet]. 2013 [cited 28 Apr 2021];39(3):381-92. Available from: <https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1365-2214.2012.01398.x>

Contribution of the authors: a) Study conception and design, b) Data acquisition, c) Data analysis and interpretation, d) Writing of the manuscript, e) Critical review of the manuscript.

N. J. A. B. has contributed in a, b, c, d, e; J. M. A. H. in b, c, d, e; A. T. M. in b, c, d; A. C. P. in b, c, d; A. G. M. in b, c, d; J. F. N. L. in b, c, d; M. C. T. V. in b, c, d.

Managing scientific editor: Dr. Natalie Figueredo