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 Becerra1, ORCID 0000-0002-4261-3310
Jessica María Ayala Hernández2, ORCID 0000-0002-3385-3355
Andrea Taborda Mazo3, ORCID 0000-0003-0364-7734
Andres Choperena Posada4, ORCID 0000-0003-1423-4353
Alejandra González Mejía5, ORCID 0000-0002-3585-9857
Juan Felipe Naranjo Lopez6, ORCID 0000-0002-5093-5424
María Clara Tuberquia Velásquez7, 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.

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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. A convenience sampling was carried out, ending with the categories' theoretical saturation. 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. 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.

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

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

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

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).
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.
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**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.

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