

# Care of children with disabilities, attitudes of caregivers and surrogate mothers

El cuidado de niños con discapacidad, actitudes de cuidadores y madres sustitutas

O cuidado de crianças com deficiência, atitudes de cuidadores e mães substitutas

Nidia Johana Arias-Becerra<sup>1</sup>

Alejandra Lopera-Escobar<sup>2</sup>

Jessica María Ayala-Hernández<sup>3</sup>

## Abstract


**Introduction:** caring for children with disabilities in early childhood is mediated by many elements, not only by the practices and knowledge of their caregivers but also by their attitudes. Understanding the term attitude is complex; for its analysis, the self-determination theory is considered, since motivation is fundamental in the work performed by a caregiver and determines the attitude with which circumstances are faced. **Objective:** understand the attitudes towards caregiving constructed by the caregivers of children with physical disabilities. **Materials and methods:** a qualitative study, based on grounded theory. Twelve surrogate mothers in charge of children under 6 years of age with motor disabilities were invited to participate through a convenience sampling, which ended with the theoretical saturation of the categories. The collection of information was carried out through semi-structured interviews, which were audio-recorded and later transcribed for analysis. The scope of the theoretical construction reached the theorization of attitudes towards caregiving. **Results:** Historically, it is women who assume the caregiving roles. The attitudes of caregivers can be classified into affective, cognitive and behavioral dimensions, which allows us to understand the nature of these attitudes. On the other hand, motivation and self-determination are those who define the reason for choosing a task such as caregiving. **Conclusions:** Caregiving, analyzed in the context of surrogate mothers transcends the figure of a paid job, towards the construction of a role that brings enjoyment and meaning to life.


**Key words:** Attitude; disabled children; caregivers; child care.

## Resumen

**Introducción:** La labor del cuidado de niños con discapacidad en primera infancia, esta mediada por las prácticas y los conocimientos de sus cuidadores y de sus actitudes. Entender el término actitud es complejo; para su análisis, se retoma la teoría de la autodeterminación, ya que la motivación es fundamental en la labor realizada por un cuidador y determina, en gran medida, la actitud con la que se afrontan las circunstancias. **Objetivo:** Comprender las actitudes que tienen los cuidadores de niños con discapacidad física. **Materiales y métodos:** Estudio cualitativo, basado en la teoría fundamentada. Participaron 12 madres sustitutas a cargo de niños menores de 6 años con discapacidad motora. Se utilizó un muestreo por conveniencia, que finalizó con la saturación teórica de las categorías. La recolección de la información se llevó a cabo por medio entrevistas semiestructuradas, las cuales fueron audio

## Autor de correspondencia\*

<sup>1</sup> Doctorante en Ciencias biomédicas. Ms. En Neurorehabilitación. Fisioterapeuta. Docente Universidad CES. Correo: [narias@ces.edu.co](mailto:narias@ces.edu.co). Medellín, Colombia.  [000-0002-4261-3310](https://orcid.org/000-0002-4261-3310)

<sup>2</sup> Ms. En Salud Pública. Fisioterapeuta. Docente Universidad CES. Medellín, Colombia. Correo: [aloperae@ces.edu.co](mailto:aloperae@ces.edu.co).  [0000-0001-7557-6053](https://orcid.org/0000-0001-7557-6053)

<sup>3</sup> Ms. En Salud Pública. Fisioterapeuta. Docente Universidad CES. Medellín, Colombia. Correo: [jayala@ces.edu.co](mailto:jayala@ces.edu.co). [0000-0002-3385-3355](https://orcid.org/0000-0002-3385-3355) 

**Recibido:** 12 julio 2021

**Aprobado:** 24 octubre 2021

## Para citar este artículo

Arias-Becerra NJ, Lopera-Escobar A, Ayala-Hernandez JM. El cuidado de niños con discapacidad, actitudes de cuidadores y madres sustitutas. 2022; 19(1):9-18. <https://doi.org/10.22463/17949831.3085>

© Universidad Francisco de Paula Santander. Este es un artículo bajo la licencia CC-BY-NC-ND



grabadas y posteriormente transcritas para su análisis. Teóricamente se estudiaron las actitudes de cuidadoras de niños con discapacidad motora. **Resultados:** Las actitudes de las cuidadoras pueden clasificarse en tres dimensiones: afectivas, cognitivas y comportamentales, lo que permite entender su naturaleza. Por otro lado, la motivación y la autodeterminación son elementos que determinan el por qué elegir una labor como el cuidado de otra persona. **Conclusiones:** El cuidado, analizado en el contexto de madres sustitutas trasciende la figura de un trabajo remunerado, hacia una construcción de un rol que aporta disfrute y le da sentido a la vida.

**Palabras clave:** Actitud; niños con discapacidad; cuidador; cuidado del niño.

## Resumo

**Introdução:** O cuidado de crianças com deficiência na primeira infância, está influenciado pelas práticas e conhecimentos dos cuidadores e as suas atitudes. Compreender o conceito atitude é complexo; para a sua análise considera-se a teoria da autodeterminação, principalmente porque a motivação é fundamental no trabalho do cuidador e determina em grande medida, a atitude com a qual afrontam as situações. **Objetivo:** Compreender as atitudes que tem os cuidadores de crianças com deficiência física. **Materiais e métodos:** Estudo qualitativo, baseado na teoria fundamentada. Participaram 12 mães substitutas a cargo de crianças menores de 6 anos com deficiência motora. Utilizou-se a amostragem por conveniência, que finalizou com a saturação teórica das categorias. A recolha da informação realizou-se através de entrevistas semiestruturadas que foram áudio-gravadas e posteriormente transcritas para a análise. **Resultados:** As atitudes dos cuidadores classificaram-se em três dimensões: afetivas, cognitivas e comportamentais, permitindo estabelecer a sua natureza. Por outro lado, a motivação e a autodeterminação foram elementos que determinaram o porquê escolher o trabalho de cuidar de outra pessoa. **Conclusão:** O cuidado, analisado no contexto de mães substitutas transcende a figura do trabalho remunerado à construção de um papel que fornece prazer e sentido à vida.

**Palavras-chave:** Atitude; crianças com deficiência; cuidador; cuidado da criança.

## Introduction

Children with disabilities in early childhood and highly dependent in their functioning require the unconditional accompaniment of a person who can assist them in their care (1). The work of caring for children with disabilities is mediated by many elements, not only by the practices and knowledge of their caregivers, but also by their attitudes (2,3). Attitudes towards caregiving can make a difference in how well it is performed, especially considering that these attitudes will also impact the health and well-being of the child being cared for. Understanding the term attitude is complex, since it is in constant evolution, according to different theories

and perspectives (4,5). For the analysis of this concept, the theory of self-determination is taken up again, since motivation is fundamental in the work carried out by a caregiver, as it determines to a great extent the attitude with which he/she faces the circumstances (6). Findler conceptualizes the term attitude through three dimensions: affective, cognitive and behavioral (7). Regarding the caregiver, Fernández differentiates between the formal and informal caregiver, indicating that the former receives economic retribution without there necessarily being a family link (8).

It should be noted that formal caregivers from the Los Alamos Training Institute (INCLA) participated in this

project as foster mothers. Under Colombian legislation, a foster home is a temporary protection measure taken by the competent authority. It consists of placing the child with a family that undertakes to provide the necessary care and attention in place of the family of origin. The foster homes receive financial recognition for the maintenance expenses of the children; in addition, the foster mother receives financial remuneration for her work (9). It should be pointed out that caring for another person implies an additional effort and a complete change in routine, which may be bearable depending on the personal, family, social, economic and even spiritual condition of the caregiver.

It should also be mentioned that many of the obstacles encountered by people with disabilities are due to societal attitudes. When social attitudes are positive, they can facilitate inclusion, which facilitates the acceptance of the disability by family, friends, etc. When attitudes are negative, they can seriously hinder inclusion by seriously affecting relationships, altering coexistence at the family, personal, social or vocational level.

To manage this, it is important to understand the structure and nature of attitudes towards people with disabilities. Attitudinal barriers encountered by people with disabilities have been invisible for a long time (10, 11), even more so if they are found within the family. Hence, the identification of these factors allows professionals to generate relevant intervention strategies that impact the lives of people and their families; likewise, they provide an additional perspective and are close to the reality that is lived in the day to day of the caregiver (12).

It should be emphasized that the recognition of attitudes promotes understanding about the nature and motivation of the caregiving role and at the same time facilitates the identification of the reasons for them (7). Based on the above, the objective of this project is to understand the attitudes towards caregiving constructed by caregivers of children with physical disabilities at INCLA.

## Materials and methods

This is a qualitative study, based on grounded theory (13). The scope of the theoretical construction included the theorization (14) on the attitudes towards care in this community of surrogate mothers. This study in-

cluded a group of 12 surrogate mothers belonging to INCLA, a program operator of the Colombian Institute of Family Welfare (ICBF). The mothers were in charge of children between 0 and 6 years old with motor disabilities. The study was conducted between 2018 and 2019.

Sample selection: mothers in charge of children under 6 years of age with motor disabilities, residing in different areas of the metropolitan area, were invited to participate through a convenience sampling (15), which ended with the theoretical saturation of the categories. No member of the research team had a previous relationship with the study participants.

With respect to the collection of information, semi-structured interviews were conducted with prior signature on informed consent approved by the ethics committee of the CES University and INCLA. The research team was trained in the collection technique. In addition, an interview guide was constructed and validated through a pilot test. The interview guide contained questions related to the meaning of caring for a child with a disability, attitudes and practices towards caring for these children and how these have been learned and implemented. The interviews were audio-recorded only and were conducted in the participants' homes to maintain the context of the information. All audios were then transcribed verbatim for later analysis.

Once the information was obtained, open coding was applied in the software ATLAS.ti version 7, followed by axial coding, where categories and subcategories were identified to finally perform selective coding and thus establish relationships between them (16). The analysis explored the links of association, contradiction or inclusion between the codes, and their density as units of meaning. Also, the triangulation of the analysis of the information between principal investigators and co-researchers was carried out, followed by their respective triangulation with the literature (17).

It should be noted that throughout the research process, the criteria of methodological rigor related to credibility, auditability and transferability were applied (18).

It should be indicated that this study was carried out according to the ethical principles established in the Declaration of Helsinki (19) of the World Medical Association; in addition, it obtained the ethical endorsement

by the Institutional Committee of Ethics in Humans of the CES University, with the purpose of guaranteeing the well-being of the participants as a priority over any interest of the research team. Therefore, this research was characterized by honesty and respect for the participants, from the formulation of the proposal, the collection of information, analysis, interpretation and publication of the results.

In accordance with Resolution 8430 of the Government of Colombia (20), this research was of minimal risk. In this regard, care was taken not to create any physical, psychological or social risk for the informants. Collaboration was voluntary and all persons who chose to participate were treated with respect and without discrimination; likewise, participation in the study did not generate any consequences for the name, reputation, economic or work status and was not related to matters of private life of those who participated in this study. As has been said, the information provided by the in-

formants in the development of this research is anonymous; their identity was protected by assigning them a respective code. Before each interview, the informed consent, risks, benefits, objectives and procedures of the project were explained in detail. Once understood by the participants, they signed their consent

## Resultados

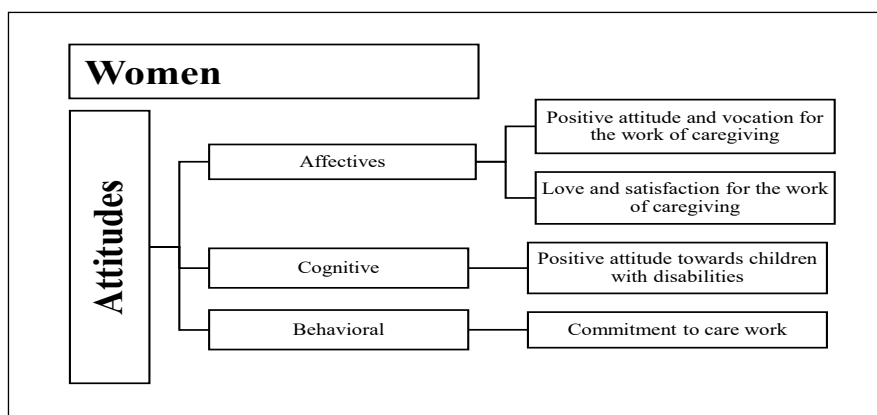
All the participants were women. They belonged to the socioeconomic strata 2 and 3, most of them had high school education. The experience they have had as caregivers has been extensive, ranging from 6 to 10 years. 83% of them have received some type of training for their activities as caregivers; nevertheless, they emphasize that a great part of their knowledge was acquired by their own experience.

**Table 1:** Sociodemographic Characterization

	Features	n	%
<b>Genre</b>	Female	12	100
<b>Age</b>	25 - 35 years old	4	
	35 - 45 years old	6	
	45 - 55 years old	2	
<b>Stratum</b>	2	6	50,0
	3	6	50,0
<b>Educational level</b>	Bachelor	11	91,7
	Technician	1	8,3
<b>Experience as a caregiver (years)</b>	From 0 to 5 years old	2	16,7
	From 6 to 10 years old	4	33,3
	From 11 to 15 years old	3	25,0
	From 16 to 20 years old	1	8,3
		2	16,7
<b>Courses or training as a caregiver</b>	Yes	10	83,3
	No	2	16,7
<b>Choose from where you have had the most training as a caregiver</b>	Own knowledge,	6	50,0
	Education with other caregivers,	1	8,3
		5	41,7

Source: Own elaboration

From the analytical process, 120 codes emerged, which formed a scheme of 5 categories related to the role of caregiver, which are developed below.



**Figure 1:** Categories and subcategories of analysis

**Source:** Own elaboration

## Women in care work

Those women belonging to ethnic minorities and of low economic resources are the candidates to assume the role of caregiver (21), given that, in these conditions, there is a differentiation of the activities typically carried out by men and women. While women, regardless of their activity, can always exercise the role of caregiver, men will only do so if they have the time to do so (22). Caring for another person, in a vulnerable situation, is generally an instinctive activity for women, not for men. In short, these conceptions have cultural and traditional overtones (23).

It is known that historically, women's upbringing in different cultures has revolved around being the figure with the capacity to care, especially with those who are most vulnerable (24). Similarly, this care that takes place in the home environment is generally associated with care work, without any economic remuneration, which in the case of surrogate mothers there is (25).

However, the profile of the surrogate mother is a figure that presents many nuances; although they are generally mothers who voluntarily decide to take care of a child (26) and who receive economic remuneration for it. However, during the interviews, they often mention

that it is a labor of love, given that the money they receive is not comparable to what it implies to take care of a disabled child. On the other hand, many of these substitute mothers do not have a professional formation, and they work from experience, demonstrating that generally, they are the women who adopt this type of responsibility (8).

*"This work that we do as surrogate mothers is very poorly paid. For what it includes to do all this, it is very poorly paid" (C11).*

## Affective, cognitive and behavioral attitudes

Based on Findler's approach to surrogate mothers' attitudes, due to their complexity, they have been grouped according to their dimensions, allowing their density and foundation to be revealed through the emerging categories. One of them is associated to affective attitudes, related to positive or negative emotions towards a subject or activity (27). It can be suggested that these attitudes can directly mediate in the choice and continuity of the work as a caregiver and are related to: positive attitude and vocation for being a caregiver, love and satisfaction for the work of being a caregiver, loving and familiar disposition towards caregiving.

"(...) give him a lot of love, a lot of affection, a lot of stability and worry about him (the child)" (C2).

"(...) to be able to fight side by side with them (the children), so that they know they have support" (C3).

Cognitive attitudes are known to refer to thoughts, ideas, perceptions, beliefs and opinions. A positive attitude towards children with disabilities is reflected in the belief that children with disabilities can participate as active members of the community and are self-determining (28). Ultimately, behavioral attitudes are defined as the tendency to act in a certain way in the presence of a subject or when performing a certain activity. Many surrogate mothers have learned this trade from their mothers or have grown up in homes where they have been delegated the care of their younger siblings. From there, the commitment to the work of the caregiver arises. That is to say, they always have this vigilant and committed attitude in the presence of a vulnerable person, which in this case are children with disabilities.

### **Positive Attitudes and Vocation = Motivation and Self-Determination**

The role of a caregiver under the figure of home or surrogate mother can be analyzed through the self-determination theory, since it provides an explanatory model of human motivations, especially in everything related to the behaviors that are self-determined or autonomous; that is, that has to do with the degree in which people carry out their actions with a voluntary experience or their own choice (29). The participants in their stories repeatedly stated that they played this role with an authentic motivation, completely changing the course of their lives and those of their families; they assumed the role regardless of the difficulties they had to face.

It should be noted that the reasons or motivations for acting in a certain way can range from a controlled to an autonomous range. The controlled range refers to an external motive, where the behavior is adopted as a function of an external force, related to a reward or punishment. Caring as a response to this motivation is to act in order to feel a worthy person or to avoid guilt or shame (30). In terms of the autonomous, there is an identified motive. In this case, a member of a group or society fully accepts and voluntarily participates in behaviors related to a certain collective that values them.

From the latter perspective, the participants not only enjoyed the role they were playing but perceived that they were performing an activity that was highly valued by society; therefore, they are seen as models of generosity and authentic altruism.

From another point of view, in the most autonomous form of motivation, the person blends this social value with other aspects of the self, such as loving and respecting the recipient of care, as well as recognizing that care provides meaning in life.

*"(...) Why do I do it? (being a caregiver), on a personal level, I think that we people can make the world a little better than it is if we do our bit to collaborate" (C2).*

*"On a personal level I have always wanted to be there doing this work, it comes from my heart and I do it with all the love in the world because it is what I am born to do" (C2).*

This is where it is explained why the vocation, satisfaction and commitment to the work of being a caregiver became a category. Being caregivers, in this context, gives them a clear purpose to their lives.

*"(...) I feel satisfied, because of the achievements that I have seen and that sometimes others do not see or do not know, but the things that I know about my children, I know them and it gives me satisfaction for every little thing that I achieve for them" (C7).*

*"But one feels very satisfied with them, to know that they are so rejected and everything, and to be able to fight side by side with them, that they know that they have support, that my mother is here, that my family is here and everything" (C5).*

When care is mentioned in order to maintain the well-being and health of another person, there is an identified motivation, it is also integrated with what is considered valuable for society. In this context, the controlled and autonomous is indistinguishable; it is the maximum point of motivation; hence, there is a direct implication on attitudes, therefore, the familiar is identified with this category: to have a positive and loving attitude towards the work of care.

*"I feel very good, I like what I do and I do it with love"*

(C6).

On the other hand, when the caregivers are the ones who choose their role, they have more positive experiences; in addition, they experience their behavior as something that they freely chose and thus they value it (31). This motivation is determinant for the construction of their own attitudes, which in the population of this study were mostly positive. The positive attitudes present in the participants are given by autonomous and legitimate motivations, this explains why a work that for many can be difficult and not pleasant, for them is a purpose, a life mission.

*"(...) I like it (being a caregiver), since I like it, I don't find it very complicated, but it is a lot of responsibility! but I don't mind this role I am doing, I like it!" (C1).*

## Discussion

The attitudes towards caregiving constructed by the caregivers of children with physical disabilities who participated in this research are expressed from an affective point of view through positive attitudes related to vocation, love, familiarity and satisfaction with the work of being caregivers. Similarly, the cognitive aspect refers to the belief that these children can participate as active members of the community and at the same time allow them to be self-determined in their role as carers. Behaviorally, caregiving is an activity learned by observing their mothers and grandmothers in this role. It is important to mention that positive attitudes arise from intrinsic self-motivation, which is explained through self-determination. In other words, caring for a child with a disability is a fulfilling activity and is seen as a legitimate motivation.

In this regard, Zheng et al. (32) explored the attitudes of caregivers of people with disabilities and ordinary people towards people with disabilities. They found that there is greater negativity in the attitudes towards disability of those who have been caregivers for the longest time, 90% of whom are members of the same family. These conclusions show that, if this work is not remunerated, it has a direct impact on the attitude of the caregivers.

In contrast to the findings of this study, it is observed

that most of the attitudes of the caregiving mothers were very positive; however, all the participants were surrogate mothers, which is why there are no family ties. On the other hand, in their condition of surrogate mothers, they receive economic remuneration, constituting another factor that Zheng et al. mentioned as a differentiating element in the attitudes towards people with disabilities (32). Taking into account the above, it can be inferred that when there is no direct family link, but economic remuneration is received for the work performed, it favors the positive attitudes of the caregivers since they receive remuneration for the work performed in all aspects.

It is important to note that the attitudes of caregivers can have direct implications on the quality of life and the care provided. Mattevi et al. (33) explored this relationship, finding that the more qualified the caregiver is, the better the quality of life of the people receiving care. Comparing the previous results with this study, it should be noted that many of the surrogate mothers, because of their status as caregivers, are always training, either formally or informally; in this regard, they mention that most of their knowledge comes from experience, which shows that a more experienced caregiver will be able to provide better care. At the same time, training is also seen as the possibility of improving performance in their work, in this case "caring better". From a caregiver's point of view, training in their work allows them to better attend to the person they are caring for; it is also important to point out that the fact that they have been surrogate mothers of different children throughout their profession gives them many more tools to provide better care, but also enriches them in the exercise of their work.

Regarding what is directly related to the attitudes Mattevi et al. (33), mentioned some attitudes present in the caregivers such as: solidarity, empathy and support. When comparing them with the results of this research it is evident that there is a similarity, in the function of the fact that the work of the caregiver requires a profile and qualities that must be present to adequately perform this role; in the same way, they must enjoy it and live it as mentioned by the participants. In addition, Mattevi found in her study that acceptance is one of the most important attitudes since it allows the aforementioned attitudes to emerge.

At the national level and with a more contextualized look at the role of surrogate mothers in Colombia in 2016, Bedoya (34) investigated the vocation of community mothers in the department of Antioquia. In this study, a reflection is made about the fact of being or becoming a community mother in this case, surrogate. It is necessary to specify that to be a community mother implies not only accepting it, it also requires to be constructing an identity that allows them to feel themselves community mothers and from the experience, to provide better care. In relation to this research, it can be inferred that becoming a substitute mother implies betting on self-determination and taking into account those elements where taking care of another implies giving meaning to life itself. In this regard, Bedoya (34) mentions that the internal and external motivations have a direct influence on a community mother to stay in this work, which could be detected in the present study

## Conclusion

An approach to attitudes related to the care of children with physical disabilities on the part of surrogate mothers in an institution in Antioquia suggests that the work of caregiving goes beyond performing a job with a certain remuneration, because this experience links affective aspects and self-determination of the subject, giving enjoyment, as well as giving meaning to one's own life. It is precisely the attitudes and motivations of caregivers and surrogate mothers that allow the historical role assumed by women to continue to prevail in our current context

## Conflictos de interés

The authors declare that they have no conflicts of interest

## Bibliographic references

1. UNICEF, others. El desarrollo del niño en la primera infancia y la discapacidad: un documento de debate. 2013 [citado 21 de julio de 2015]; Disponible en: <http://apps.who.int/iris/handle/10665/78590>
2. Montalvo-Prieto A, Flórez-Torres IE, Vega DS de. Cuidando a cuidadores familiares de niños en situación de discapacidad. Aquichan [Internet]. 2008 [citado 6 de agosto de 2021];8(2):197-211. Disponible en: <https://www.redalyc.org/articulo.oa?id=74180207>
3. Dada S, Andersson AK, May A, Andersson EE, Granlund M, Huus K. Agreement between participation ratings of children with intellectual disabilities and their primary caregivers. Res Dev Disabil [Internet]. septiembre de 2020 [citado 8 de octubre de 2021]; 104:103715. Disponible en: <https://linkinghub.elsevier.com/retrieve/pii/S0891422220301451>
4. Seccombe JA. Attitudes towards disability in an undergraduate nursing curriculum: A literature review. Nurse Educ Today [Internet]. julio de 2007 [citado 12 de mayo de 2020]; 27(5):459-65. Disponible en: <https://linkinghub.elsevier.com/retrieve/pii/S026069170600133X>
5. Srinivasan S, Bhat A. Differences in caregiver behaviors of infants at-risk for autism and typically developing infants from 9 to 15 months of age. Infant Behav Dev [Internet]. mayo de 2020 [citado 8 de octubre de 2021]; 59:101445. Disponible en: <https://linkinghub.elsevier.com/retrieve/pii/S0163638319301341>
6. Olson JM, Zanna MP. Attitudes and Attitude Change. Annu Rev Psychol [Internet]. enero de 1993 [citado 9 de septiembre de 2020];44(1):117-54. Disponible en: <http://www.annualreviews.org/doi/10.1146/annurev.ps.44.020193.001001>
7. Findler L, Vilchinsky N, Werner S. The Multidimensional Attitudes Scale Toward Persons With Disabilities (MAS): Construction and Validation. Rehabil Couns Bull [Internet]. abril de 2007 [citado 22 de abril de 2020];50(3):166-76. Disponible en: <http://journals.sagepub.com/doi/10.1177/00343552070500030401>
8. Coira-Fernandez G, Bailon-Muñoz E. La invisibilidad de los cuidados que realizan las mujeres. Aten Primaria



- [Internet]. junio de 2014 [citado 31 de marzo de 2020];46(6):271-2. Disponible en: <https://linkinghub.elsevier.com/retrieve/pii/S0212656714001772>
9. 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. Disponible en: [https://www.icbf.gov.co/cargues/avance/docs/resolucion\\_icbf\\_5930\\_2010.htm#inicio](https://www.icbf.gov.co/cargues/avance/docs/resolucion_icbf_5930_2010.htm#inicio)
  10. Vélez-Álvarez C, Claros JAV, Hormaza M, Chía SL. Determinantes sociales de la salud y discapacidad, Tunja 2012. Arch Med Col [Internet]. 2014 [citado 6 de agosto de 2021];14(1):51-63. Disponible en: <https://www.redalyc.org/articulo.oa?id=273832164006>
  11. Casteblanco-Niño ML, Cerquera-Guerrero L, Vélez-Álvarez C, Vidarte-Claros JA. Caracterización de los determinantes sociales de la salud y los componentes de la discapacidad en la ciudad de Manizales, Colombia. Divers Perspect En Psicol [Internet]. 2014 [citado 6 de agosto de 2021]; 10(1):87-102. Disponible en: <https://www.redalyc.org/articulo.oa?id=67935714006>
  12. Pérez-Castro J. Entre barreras y facilitadores: las experiencias de los estudiantes universitarios con discapacidad. Sinéctica [Internet]. 2019 [citado 6 de agosto de 2021];(53):01-22. Disponible en: <https://www.redalyc.org/journal/998/99862930003/>
  13. Restrepo-Ochoa DA. La Teoría Fundamentada como metodología para la integración del análisis procesual y estructural en la investigación de las Representaciones Sociales. 2013;13.
  14. Strauss AL, Corbin J. Bases de la investigación cualitativa: técnicas y procedimientos para desarrollar la teoría fundamentada. Medellín: Universidad de Antioquía; 2012.
  15. Hernández-Sampieri R, Fernández-Collado C, Baptista-Lucio MP. Metodología de la investigación. México: McGraw-Hill; 2014.
  16. Coffey A, Atkinson P. Encontrar el sentido a los datos cualitativos: estrategias complementarias de investigación. Universidad de Alicante, Servicio de Publicaciones [Internet]. 2005 [citado 22 de abril de 2021]. Disponible en: <https://dialnet.unirioja.es/servlet/libro?codigo=256853>
  17. Morse JM. Asuntos críticos en los métodos de investigación cualitativa [Internet]. Universidad de Antioquia; 2003 [citado 22 de abril de 2021]. Disponible en: <https://dialnet.unirioja.es/servlet/libro?codigo=663465>
  18. 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]. junio de 2002 [citado 4 de marzo de 2021]; 1(2):13-22. Disponible en: <http://journals.sagepub.com/doi/10.1177/160940690200100202>
  19. Manzini JL. Declaración de helsinki: principios éticos para la investigación médica sobre sujetos humanos. Acta Bioethica [Internet]. diciembre de 2000 [citado 6 de agosto de 2021];6(2). Disponible en: [http://www.scielo.cl/scielo.php?script=sci\\_arttext&pid=S1726-569X2000000200010&lng=en&nrm=iso&tlng=en](http://www.scielo.cl/scielo.php?script=sci_arttext&pid=S1726-569X2000000200010&lng=en&nrm=iso&tlng=en)
  20. República de Colombia. Ministerio de Salud. Resolución No 008430 de 1993, octubre 4, por la cual se establecen las normas científicas, técnicas y administrativas para la investigación en salud [Internet]. Santa Fe de Bogotá: El Ministerio; 1993 [citado 6 de agosto de 2021]. Disponible en: [https://www.hospitalsanpedro.org/images/Comite\\_Investigacion/Resolucion\\_8430\\_de\\_1993.pdf](https://www.hospitalsanpedro.org/images/Comite_Investigacion/Resolucion_8430_de_1993.pdf)
  21. Arksey H, Glendinning C. Choice in the context of informal care-giving. Health Soc Care Community [Internet]. 2006 [citado 9 de junio de 2020]; 15(2):165-175. Disponible en: <http://doi.wiley.com/10.1111/j.1365-2524.2006.00671.x>
  22. Zueras P, Spijker J, Blanes A. Evolución del perfil de los cuidadores de personas de 65 y más años con discapacidad en la persistencia de un modelo de cuidado familiar. Rev Esp Geriatria Gerontol [Internet]. marzo de 2018 [citado 8 de octubre de 2021]; 53(2):66-72. Disponible en: <https://linkinghub.elsevier.com/retrieve/>

[pii/S0211139X17301701](http://hdl.handle.net/10481/66364)

23. Hernández-Prados MÁ, Belmonte ML, Lara-Guillen B. El reflejo de una tradición: feminización de la vida familiar. REIDOCREA [Internet]. 30 de noviembre de 2020 [citado 8 de octubre de 2021]; 9(17): 232-243. Disponible en: <http://hdl.handle.net/10481/66364>
24. Linnan L, Arandia G, Bateman L, Vaughn A, Smith N, Ward D. The Health and Working Conditions of Women Employed in Child Care. Int J Environ Res Public Health [Internet]. 9 de marzo de 2017 [citado 4 de marzo de 2021]; 14(3):283. Disponible en: <http://www.mdpi.com/1660-4601/14/3/283>
25. Massé-García MC. La mujer y el cuidado de la vida. Comprensión histórica y perspectivas del futuro. Cuadernos de Bioética. [Internet] 2017; XXVIII. Disponible en: <http://aebioetica.org/revistas/2017/28/94/291.pdf>
26. Martínez-Marcos M, DelaCuesta-Benjumea C. La experiencia del cuidado de las mujeres cuidadoras con procesos crónicos de salud de familiares dependientes. Aten Primaria [Internet]. febrero de 2016 [citado 31 de marzo de 2020]; 48(2):77-84. Disponible en: <https://linkinghub.elsevier.com/retrieve/pii/S0212656715001249>
27. Antonak RF, Livneh H. Measurement of attitudes towards persons with disabilities. Disabil Rehabil [Internet]. enero de 2000 [citado 9 de septiembre de 2020]; 22(5):211-24. Disponible en: <http://www.tandfonline.com/doi/full/10.1080/096382800296782>
28. Morin D, Rivard M, Crocker AG, Boursier CP, Caron J. Public attitudes towards intellectual disability: a multidimensional perspective: Attitudes on intellectual disabilities. J Intellect Disabil Res [Internet]. marzo de 2013 [citado 22 de abril de 2020]; 57(3):279-92. Disponible en: <http://doi.wiley.com/10.1111/jir.12008>
29. Ryan RM, Deci EL. Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. Am Psychol [Internet]. 2000 [citado 5 de junio de 2020]; 55(1):68-78. Disponible en: <http://doi.apa.org/getdoi.cfm?doi=10.1037/0003-066X.55.1.68>
30. Kim Y, Carver CS, Cannady RS. Caregiving Motivation Predicts Long-Term Spirituality and Quality of Life of the Caregivers. Ann Behav Med [Internet]. agosto de 2015 [citado 21 de mayo de 2020]; 49(4):500-9. Disponible en: <https://academic.oup.com/abm/article/49/4/500-509/4562686>
31. Kietzman KG, Benjamin AE, Matthias RE. Whose choice? Self-Determination and the Motivations of Paid Family and Friend Caregivers. J Comp Fam Stud [Internet]. julio de 2013 [citado 5 de junio de 2020]; 44(4):519-40. Disponible en: <https://utpjournals.press/doi/10.3138/jcfs.44.4.519>
32. Zheng Q, Tian Q, Hao C, Gu J, Tao J, Liang Z, et al. Comparison of attitudes toward disability and people with disability among caregivers, the public, and people with disability: findings from a cross-sectional survey. BMC Public Health [Internet]. diciembre de 2016 [citado 27 de julio de 2020]; 16(1):1024. Disponible en: <http://bmcpublihealth.biomedcentral.com/articles/10.1186/s12889-016-3670-0>
33. Mattevi BS, Bredemeier J, Fam C, Fleck MP. Quality of care, quality of life, and attitudes toward disabilities: perspectives from a qualitative focus group study in Porto Alegre, Brazil. Rev Panam Salud Pública [Internet]. marzo de 2012 [citado 27 de julio de 2020]; 31(3):188-96. Disponible en: <https://scielosp.org/pdf/rpsp/2012.v31n3/188-196/en>
34. Bedoya-Hernandez MH. Madres comunitarias antioqueñas y su vocación por el cuidado. Rev Virtual Univ Católica Norte [Internet]. mayo de 2016; 47:113-27. Disponible en: <http://revistavirtual.ucn.edu.co/index.php/RevistaUCN/article/view/745/1271>