## MEANINGS OF CARE IN THE PHYSICAL DISABILITY<sup>1</sup>

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#### **ABSTRACT**

This is a qualitative and exploratory study, developed with the purpose of understanding care in the context of physical disability from the perspective of people who experience this condition, their main family caregivers and nursing professionals. This context occurs with people linked to a public health institution that serves people with disabilities exclusively, a young woman with disabilities, her mother, who is the family caregiver, and three nursing professionals. The data collected through interviews and subjected to thematic analysis allowed perceiving that care, from the perspective of the person with disability, is understood as a "self-care" that emphasizes the person's identity. For the mother, care involves the search for the independence of her daughter and, for nursing professionals, care integrates values about the person's family and life. The meanings present in each perspective reveal that they tend to integrate moments, movements and temporalities: they associate life projects; allow the visualization of responsibilities produced in interaction and at the same time that they optimize it they enrich the subjects and their horizons.

Keywords: People with Disabilities. Care. Caregivers. Family. Nursing.

#### INTRODUCTION

People with physical disabilities have been increasingly visible in our reality, and these disabilities result from chronic diseases, urban population violence. aging, therapeutic treatments and people's access to services, but also of political movements that seek to include them in society. It is estimated that 15% of the world population has some form of disability<sup>(1)</sup>.

The rapprochement between people with disabilities, family caregivers and health professionals has been a challenge to professional practices in health services, since each individual understands life, health-care and diseases in a particular way, though they share socially constructed values and beliefs. People with disabilities experience prejudice, despite the political and social movements that aim to integrate them more and more into society. It is recognized that the confrontation of prejudice in its various forms, in relation to physical disability, is a movement exerted by each one from their point of view, but on the basis of shared values and beliefs in social groups where each individual is inserted.

It is considered that in the health-disease process, experiences of people who attach meanings based on practical rationalities, built in life stories, externalizing behaviors expressed in both languages as by means of their movements, are confronted and need to be understood with a view to humanized health practices. It is noteworthy that the practical rationality of health professionals has as an instrument domain references on the disease, giving those who share it ethical, moral and political validity<sup>(2)</sup>. Thus, when revealing the challenges that the services under the Unified Health System (UHS) face to humanize health practices for persons with physical disabilities, we began to question: How does one live with the condition of physical disability? How do people experience physical disability? How does an individual take care of disability from his experiences? Given this, we set the objective of this study to understand the meaning of care in the context of disability from the perspective of a person who experiences this condition, her family caregiver and nursing professionals.

We believe that care is not limited to the action of providing treatment, of taking care, of worrying about others, of paying attention, of

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doing something, but something beyond these factors. Care means focusing on the presence of the other, as an optimization of the interaction and as broadening horizons that integrate the experience of each one to the present, past and future; it is as a movement motivated by interest and by the construction of identities; a space of interaction in which we shape stories and recognize the human plasticity; it is a care that enables designing and building projects and, for seeking to instigate the other, it is also reflective<sup>(3)</sup>. It is a care that considers that it is in the rise of existence that it makes sense and allows the individual to take responsibility for himself; a practical attitude; a therapeutic action that reflects an interaction between two or more subjects, aimed at relieving the suffering or reaching a welfare, always mediated by specifically targeted knowledge for purpose<sup>(3)</sup>. We recognize nursing as a profession that sees care as its core and as an intentional phenomenon that is essential to life, which occurs in the encounter with human beings that interact by means of actions involving attention, care, solicitude<sup>(4)</sup>.

In this context, this study makes it possible to give visibility to the rationalities of different people on disability, review the concepts on health, illness and care, in addition to recognizing the narrative as a powerful instrument for nursing care, since, in the meanings of the experiences, the social and cultural issues that need to be understood when seeking humanization in health are integrated. We believe that understanding the meanings of the different perspectives that we propose here constitutes an important aspect for nursing and may provide support to the understanding of care.

#### **METHODOLOGY**

This is a qualitative, exploratory study, a case study, derived from a master dissertation in nursing<sup>(5)</sup>. It was approved by the Research Ethics Committee of the Julio Muller University Hospital, under the opinion number 018/CEP-HUJM/2011, following the resolution of the National Health Council No. 196/96. The study was conducted in a public health institution, fictitiously named by Special Center. The

participants were people linked to this institution: one (01) person with a physical disability, young, 20 years old, suffering from cerebral palsy, her fictitious name is Angelina and she was chosen for her dependence on daily care; a (01) mother, caregiver of the family, simply named Mother and three (03) nursing professionals, in which case one (01) is a nurse and two (02) are nursing technicians. They have been named Rita, Auxiliadora and Rosária, respectively and worked at the institution for over a year.

The analysis was procedural and organized into thematic categories that emerged from the core meanings. And after several comings and goings accompanied by reading and interpreting the data collected, we realized that the groupings from all over the analysis corpus revealed three categories: The "taking care" of people with a physical disabilities; Care of mother to his disabled daughter; professional care for people with disabilities.

#### **RESULTS**

The meanings of care to and for people with physical disabilities point to different ways of living, of understanding and being, which vary according to the socio-cultural concepts that are impregnated therein and to the position that such a person occupies in the experience in relation to this condition.

# The "taking care" of people with physical disabilities

Angelina is collaborative, communicative and has a remarkable positivity considering her condition. Among her limitations we may highlight involuntary motricity and her inability to walk, eat or drink alone. In her daily life and health, we observed the care that she has with herself, which can be seen from the way he refers to herself when identifying herself in the report:

I am a carrier of cerebral palsy so I have some physical problems, I'm pretty slow. [...] Because I have very jerky movements, I get tired very easily, and this is the major problem of a CP [cerebral palsy]. At night, wow, I realize I did almost nothing! Wow! I get exhausted! It is a very annoying thing and it doesn't let me do much because I get tired very fast. (Angelina)

The way she identifies herself relates the terms carrier, cerebral palsy and physical problems, referring to the jerky movements, as a defect of the disease, as well as her limitations, characteristics of her body. The symbol of the disability relates the theoretical models, especially the religious and medical: the first founded on the belief that evil spirits and the second in the disease<sup>(2)</sup>. The impact of disability and illness are expressed based on physical changes, however currently it tends to the displacement of the disability on the social and cultural structures, since they do not welcome them in a dignified manner. When we use the term carrier, we give visibility to the deficiency of her body. Visibility can be exacerbated when the signals are embodied in the appearance, shape, functionality<sup>(6)</sup>. This form of identification provides a relevant expression to the deficiency of the body and less to the individual as a person, which may make the person susceptible to prejudice, given that the centrality of the disability on the body was a designation throughout history, allowing further recognition, before others, of this social value. The verbalized recognition about his body's disabilities constitutes a temporal and interactional process that defies his own significance as a disabled person and a reconstruction of his normative horizons. The human corporeality is a social and cultural phenomenon, has symbolic motivation and is the subject of representations and imaginary, with the semantic vector by which the evidence of the relationship with the world is constructed<sup>(7)</sup>. Therefore, the identity of each person is permanently under construction in social relations and practices. Identity cannot be seen as inherent to people, but it results from discursive and social practices<sup>(8)</sup>.

The "taking care" means not only reporting your physical limits, but also the way it is:

This is the person Angelina. Let me see. This is a person who wants the best for herself. There are times when she cries a lot willing something, but not getting it because of her limitations. Wishing to live better. A clumsy young girl who is cheerful, but gets sad some days. This is me. I like my friends, I like laughing and I like to live. That's it. That's me! (Angelina)

Although she does not see herself within the standards, she reveals desires and seeks to achieve them and, by being so, she establishes her own standards. It is normal to be normative, being able to introduce new standards, even the organic ones<sup>(9)</sup>. Angelina's wishes to have friends, to laugh and live are related to the socially constructed and legitimated values given the diversity of meanings shared in her social life and in her group. The assumed identity goes beyond the physical dimension and relies on cultural benchmarks, put into interaction in everyday life<sup>(7)</sup>. The way one takes care of himself results from his social interaction and his recognition before his limits and needs of help:

It influences a lot. But I have to deal with it all, right? This thing of not getting nervous is just like me, like, oh you didn't do it? Do it again! If you can't, ask for help! It's complicated, but you must have an open mind, otherwise... The thing is, it's in me, it won't go away and I have to deal with it. And that's how it is. (Angelina)

The terms "do not get nervous", "ask for help", "you must have an open mind", "you have to live with it" show that it is necessary to cope emotionally with the permanent condition of dependence and physical limitations, and at the same time with its potentialities:

That's right, my head thinks one way and my body is something else. So I have to tame both of them and try to put them in the same condition. I confess to you that it is not easy to do that: to have such a... how can I put this? Good mind! (Angelina)

"A limited body" and "good mind" require a search for a balance between opposites: body and mind. When the physical limitations are observed in people, but without the neurological and cognitive impairment, it is a challenge to face the limits of the body:

My mind is very good, but having a strong limitation like this is complicated! (Angelina)

In the report, she reveals the limits of her body and its possibilities:

Well, I can do my hygiene myself, my bath, everything. [...] I can type on the computer. And that's it. (Angelina)

The independence to do her hygiene, use the computer, revealed by sentences such as "I can"

and "take care", indicates active movements, commitment and effort prints out by her motivation. Locomotion by means of a wheelchair and other activities such as getting dressed, eating and writing are developed by she herself, according to her time:

I go places with my chair... but I am very slow. [...] But to be faster, when I change clothes, my mother helps me. To eat I don't have any coordination either; neither to write. But that's it, huh? (Angelina)

Taking care of yourself also means facing prejudices:

Poor thing! These days I was waiting for the Restricted Special Transportation at school when a man came to me and he was like [said]: Poor thing, so young! Then I looked at him and said: And is it necessary to have a specific age to have a wheelchair? If so, I don't know! I wondered. Just imagine the idea of this man: "Poor thing, so young in a wheelchair." Just because you're in a wheelchair you are poor thing, you are pitiful, a cripple! But it's not like this, you should see who's sitting on it; not jump to any conclusion by the first look, but you should get to know the person and try to learn what happened. If you come and look, look at me, I will not like it. But if you come and ask me, I'll be glad to answer. Now staring from foot to head is horrible, very ugly! (Angelina)

Overcoming prejudice includes being active in this process:

I think the limitations are in people's minds. Thank God my mother raised me well to get over it. And that's it. (Angelina)

Hearing and seeing the prejudice of others about themselves has led individuals to coping reactions revealed in the gaze, in the words, thoughts, speeches and the non-acceptance of adjectives such as "pitiful" and "crippled", which refer to values related to imperfection, disability and, particularly, the disadvantage of the body. The social image of the disabled person, who is referred to as "poor thing" by making use of a wheelchair, is associated with the view of disability as a condition that makes the person's life impossible, making it sad, limited, slow, unproductive, unable to care for itself being, therefore, pitiful, as the person needs help and the piety of others<sup>(2)</sup>. In assuming his condition, his autonomy is

revealed, his ability to speak for himself and take decisions, opposing to the standards of being subject to prejudices. The idea of being insufficient, heavily influenced by the ways in which the body was constituted throughout history, sustained by a religious model associated with charity generating pious and aversive attitudes toward the individual and the body with impairments, the full and effective by restricting participation of the person, supported by the biomedical model, are standards that demonstrate socially and publicly the inability of the person<sup>(9)</sup>. Social resources and adequate infrastructure can provide support to the positive reframing of the life of these individuals, as the social contexts are still insensitive to people marked by the limitations of any kind.

In the daily life of a person who experiences physical disability, "taking care" is related to his rules and his desire, considering his physical limitations:

"And taking care (of the body) to avoid atrophying, to avoid hardening. And so it is." (Angelina)

When designing in her care the idea of not being atrophied and not getting hardened, which are negative expressions involving her seeks avoid movements, she to consequences, minimizing her body deterrent. This reveals the production of "self-care", with developed knowledge in a very personal way and within the possible conditions that individuals have in their lives, making them capable of strengthening their own health. The care that the person has with himself and that changes it is produced by the person himself and is inserted into the paradigm of concurrency; he goes beyond the need to adapt himself to the environment, which is understood as self-care and is centered in the paradigm of totality<sup>(10)</sup>.

The expression "taking care" of people with physical disabilities concerns the self-care that the individual has with himself and that includes identifying himself, recognizing his limits, but also seeing potentialities in his lifestyle and health.

# The care of the mother toward her disabled daughter

The care provided by families has influenced the quality of life of people affected by chronic conditions; on the other hand it has generated implications in the various dimensions of the caregiver's life<sup>(11)</sup>.

Historically, the natural responsibility for the care of the family is assigned to the mother. Such a natural responsibility promotes a moral value that is attributed by the society. Socially, it is expected for women to take the role of a caretaker<sup>(12)</sup>.

In the context of families, the exclusivity of care falls on the shoulders of the mothers, changing their routine and income. The mother, as the main caregiver in the family, states her accountability for care:

I think that Angelina represents 70% of my life. (Mother)

This commitment and this emotional bonding on the part of women, mothers, explains a greater burden<sup>(12)</sup>. In this case, the care focused on the daughter also reduces the mother's time and care toward others, strengthening the bond between mother and daughter:

My mother is my foundation. My everything [...] Of course, she has her small moments, for goodness sake! [Referring to the moodiness and anger of the mother] But without her I know I would be nothing [...] My mother is everything to me! What I am, the way I am, it's 100% because of her. (Angelina)

[...] I always say this to her: Look, you have to make the most of it, make things so you can learn, so you can improve your condition. Why? Because I'm still young. There is no sacrifice for me to help you, to take what you need to the course, take you to school. I can still keep up with you [...] I'm getting old, you know? Enjoy it! (Mother)

The strengthening of the mother-daughter bond is procedural. It involves a relationship between both of them, since they interact among themselves and take responsibility for each other. The positivity concerns the way she seeks to develop the autonomy and independence of her daughter:

[...] Often, she can bathe alone, but I have to help her get dressed because she takes a long time to

do it [...] I say: You have to ask when you can't do something! Until recently, she wouldn't go to her grandmother's house because of it. She said: I have to ask my cousins and my aunt to help me. I say: there is no problem! Her aunt said: Look, we help, there is no problem. We are women just like you. There's nothing there that we don't know. Oh, she did it, now she goes to her grandmother's home, which is a country house [...] she stays there for a week, five days, then she comes back, no problem. But before, she wouldn't go there at all. (Mother)

The care of the Mother emphasizes the promotion of independence of the daughter in relation to the Mother herself, as follows:

I've tried to work and leave a person watching her, but it didn't work [...] she would go to school without eating, you know? I would come home and she wouldn't have taken a shower! She had no responsibility. Thus. occupational therapist said: Look, it'll be nice for you found a job and a person her age to stay with her for company. She'd have someone to talk to and to share her thoughts and ideas. Then I tried to work for a while, and left a girl with her. I would leave everything ready, but the girl wouldn't give it to her! [...] I paid the person, but she didn't do her job. Her only responsibility was to help her dress the clothes, give food, send her to school, but, even so, she wouldn't do the service right [...] (Mother)

The references for the care of the daughter were related to nutrition. hygiene, accountability, companion, becoming independent of the mother, talking, having an age close to the daughter and care. Although they have not been realized, they revealed values based in addressing the stigmas and prejudices about disability. As we seek to challenge prejudice among themselves and within the family, care in the family has also been featured since the Grandmother's care was reported in the context of Mother:

Because my grandmother is 80 years old, you know? And my grandmother cooks, washes her bowl, but she does not do service that requires physical exertion. She is diabetic. Then I think that, whatever I can do to help when I am 70, 80 years of age I will help, you know? (Mother)

The continuity of family care to people with physical disabilities who require permanent care

was highlighted as a concern of the mother, encouraging their independence:

Taking care of her? No, it doesn't make me tired. I often tell her: Look, you have to make the most of it, make things so you can learn, so you can improve your condition [...] I'm getting old, [...] (Mother)

In the interaction with the daughter, the mother encourages her to take care of herself. This incentive is associated with the understanding that the disabled person is not more like a disabled and unproductive being, but as someone efficient and potential.

The exclusive care to the physically disabled daughter, by the mother, was highlighted:

I am the only person who cares, that's right. I was the only person who brought Angelina up, I was the only person that was around in any situation, you know? My mother doesn't know how to handle the wheelchair, if she needs help in the shower, food, she knows, but handling the wheelchair, she doesn't know. The paternal grandmother had no interaction, you know? So I always have to be tough with her and speak firmly, look at her, be harsh and then we see that it is not easy. (Mother)

At the same time that this exclusivity reveals the affection and the strengthening of ties, this can also result in overcharging the family member because this care is not limited to family level, but also to meeting the needs of socialization of their daughter, from leisure, school, to life for the work and the demands on health. This implies burden on the mother, who not only needs to be recognized by the family, but also by public and social institutions. The mother's care needs to be highlighted, since it shows its importance, however little has been done yet in the search for support, and care to this mother, or to any other family member who cares, since social, cultural and family issues integrate the demands of these caregivers' families, whose needs have been increasingly present in our reality.

Family caregivers still "naturalized and invisible" demand being highlighted and recognized by health professionals as they need support and care to take care of their family members suffering from chronic conditions. The family caregiver is a fundamental piece in care, therefore, the attention given to it by the health

team must be seen with commitment, promoting orientations and decreasing the difficulties that he experiences in his daily life, in which case this attention to caregiver may reflect positively on the health of the person requiring care<sup>(12)</sup>.

### The professional care to disabled people

The nursing professionals evidenced that caring for people with physical disabilities is special because it requires patience, affection and closeness, highlighting how essential communication, physical contact and the sharing of "experiences" on coexistence among nursing professionals, people with disabilities and their families:

I have no prejudice, I like to pick them up, touch, I like talking with the family, with mothers. (Rosária)

Sensitivity was related to the ability of perception of the behavior to observe the needs and demands as they are seized by the look:

You have to be more sensitive, because to work with special patients you have to grasp things, feel, see, look. The look has to be different. (laughs). This is hard, isn't it? Taking into account our busy lives! (Auxiliadora)

Working life is an act of helping. So I think I need to improve my emotional, like I told it, because here we have to take care of these people. So you have to focus, because they are people who really need you. It depends on how you help them better, you have to do your best, like I told you, until you notice, because they do not speak or listen, you know? You need to have this characteristic, because if you, for example, get thirsty, you say: I'm thirsty! You have to note, look at the color, see if he is cold (laughs), you know? You need to have this notion. (Auxiliadora)

This care for people with physical disabilities is not limited to a technical care, but the recognition of the ways they express themselves and, in these situations, the observation becomes an important feature. The professional in this context captures a particular mode of interaction and care. For professionals, the new meaning of their work and life and the professional and personal growth are evident, as well as the pleasure in working, as an exchange of experience made possible by the interaction of the nursing professionals with work and with other professionals and by the appreciation and

recognition of the work as a significant and important task:

So I think we learn a lot right here; professionals who come; the ones that are still there, enjoy it. They learn to work. (Rita)

So for me it's really rewarding to work with them and the fact that I worked here before working at the Center helped me a lot too, so, it helped me in every way; I have no complaints. (Rosária)

You even grow as a person, when you work with these people, I like it. (Auxiliadora)

In the work of a professional, aspects of life and particular experiences of each are integrated, and women and their mothers resignify their ways of caring:

I love it, I like it very much. It makes me feel very professional. (Rosária)

I particularly enjoy working with them. I dedicate myself a lot, despite always having worked in an ICU [Intensive Care Unit]. (Rita)

I like it. I like it because you see that life is worth it. They show that it is really worth it! (Auxiliadora)

The care of people with disabilities brings consequences for the personal life by implying and reframing their beliefs and values on the physical body, family and children:

Guys, sometimes we complain [...] then you see these patients. You think your problem is the biggest in the world, but then you see that your problem is the smallest one, compared to some people, you know? (Rita)

[In relation to life] It changed indeed, because we can see that it changed [...] As for giving greater value, I have already given, you know? Health, the health of my children, then I say: I'll take care of my children! So you see that the family is the most important thing, you know? It has changed the way I thought. (Auxiliadora)

You feel a peace, you give greater value to life, you value everything you can acquire in your achievements. You give greater value to life! (Rosária)

The professional care to these people is also marked by the unpreparedness, because over time, the society used to segregate these individuals by considering them disabled<sup>(13)</sup>. Importantly, care for the communication, including the Brazilian Sign Language and other

forms of care for the caregiver, among others, are important given the diversity of people requiring care. In this regard, we emphasize the importance of including in the nursing training care demands in order to include people who require care in diversity<sup>(14)</sup>.

Among the demands of people with disabilities, the professionals highlighted the interaction, communication, dependence for everyday activities, vulnerability, care of the body, mother's care, family care, the care of importance of social friends, the professional network care, mobility, the importance of the place where they stay, the ambient temperature and comfort:

[...] The name itself says it all: special. They need more care than we do. [...] The transportation care; a place to stay. And one thing, if you stay there at the reception, and if it's hot, I say, hey mom, it's hot, isn't it? Even the person who is there has to know if the person is feeling hot, cold, if they need a more airy place for them to stay. (Auxiliadora)

Vulnerability associates physically disabled people with the idea of fragility, of a very sensitive person, little protected, dependent and susceptible to diseases, injuries or incidents. This idea is also mentioned by the professional:

I see her as a fragile person who needs help, since she doesn't have it, even if the relatives are there to safeguard her; she needs us, the nursing professionals; she needs all health professionals to take care of her, so, in a sense, I see a frail and totally dependent person [...] (Rosária)

Present in professionals, this idea is associated with the idea of body presenting flaws, with injuries and limits and it may produce feelings of incapacity that are cared for. This vision needs to be re-signified to a vision of caring as an interaction and as a constant construction of normative horizons, taking life projects into account. Health professionals and, in particular, nursing professionals are essential so that caregivers feel assisted, informed and supported in the performance of care<sup>(13)</sup>. Care that takes into account the integration of moments, movements, temporality, life plans of whom is cared for and the caregiver, whose responsibility is to interact and, at the same time, optimize and enriche the subjects and their horizons<sup>(2)</sup>. Nursing as a care profession, must engage in the struggle for inclusion measures of caregivers and people with disabilities into society, as a condition inherent in the right to health for all<sup>(15)</sup>.

#### FINAL CONSIDERATIONS

Although people share values socially constructed on disability, each one establishes individual meanings and senses, thus this study does not exhaust the subject, but seeks composing knowledge in disability issues, revealing how is care under each perspective and to what extent their horizons were being enriched, by having references values of body, health, illness, disability, family and care.

With regard to care in physical disabilities, there are individual and subjective dimensions that must be considered by the society and health professionals. And knowing how people give meanings to the study of the experience of disability in their views leads us to understand the meanings of care for each individual and grasp how they integrate their lives, their desires, their projects, their movements and re-signify their lives, health and care. We believe that giving visibility to questions guides the search for humanized nursing practices, inserting social and cultural issues as important as they give focus to the subjectivity of the people who experience them.

### SIGNIFICADOS DO CUIDADO NA DEFICIÊNCIA FÍSICA

#### **RESUMO**

Estudo qualitativo-exploratório desenvolvido com o objetivo de compreender o cuidado no contexto da deficiência física, na perspectiva da pessoa que vivencia esta condição, de sua principal cuidadora familiar e de profissionais de enfermagem. O contexto se dá com pessoas vinculadas a uma instituição pública de saúde que atende exclusivamente pessoas com deficiência, uma jovem com deficiência física, a mãe, que é a cuidadora familiar, e três profissionais de enfermagem. Os dados coletados por meio de entrevista e submetidos à análise temática possibilitaram visualizar que o cuidado na perspectiva da pessoa com deficiência é um "se cuidar" que dá relevância à sua identidade. Para a mãe, o cuidado envolve a busca pela independência da filha, e para os profissionais de enfermagem, o cuidado integra valores sobre sua família e sua vida. Os significados presentes em cada perspectiva revelam que se tende à integração de momentos, a movimentos e temporalidades, associam projetos de vida, visualizam-se responsabilidades produzidas em interação e que, ao mesmo tempo, que a otimizam, enriquecem os sujeitos e seus horizontes.

Palavras-chave: Pessoas com Deficiência. Cuidado. Cuidadores. Família. Enfermagem.

## SIGNIFICADOS DEL CUIDADO EN EL CONTEXTO DE LA DISCAPACIDAD FÍSICA

Estudio cualitativo-exploratorio desarrollado con el objetivo de comprender el cuidado en el contexto de la discapacidad física, en la perspectiva de la persona que vive esta condición; de su principal cuidadora familiar y de profesionales de enfermería. El contexto ocurre con personas vinculadas a una institución pública de salud que atiende exclusivamente personas con discapacidad: una joven con discapacidad física, la madre, que es la cuidadora familiar, y tres profesionales de enfermería. Los datos recolectados por medio de entrevista y sometidos al análisis temático posibilitaron visualizar que el cuidado en la perspectiva de la persona con discapacidad es un "cuidarse" que da relevancia a su identidad. Para la madre, el cuidado involucra la busca por la independencia de la hija; y para los profesionales de enfermería, el cuidado integra valores sobre su familia y su vida. Los significados presentes en cada perspectiva revelan que se tiende a la integración de momentos, a movimientos y temporalidades, asocian proyectos de vida, se visualizan responsabilidades producidas en interacción y que, al mismo tiempo que la optimizan, enriquecen a los sujetos y sus horizontes.

Palabras clave: Personas con Discapacidad. Cuidado. Cuidadores. Familia. Enfermería.

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