THE POWER OF LOVE: AFFECTIVE BONDING AND EMOTIONAL HEALTH OF CAREGIVERS OF CHILDREN AND ADOLESCENTS WITH INTELLECTUAL DEVELOPMENT DISORDER

A FORÇA DO AMOR: VÍNCULO AFETIVO E SAÚDE EMOCIONAL DOS CUIDADORES DE CRIANÇAS E ADOLESCENTES COM TRANSTORNO DO DESENVOLVIMENTO INTELECTUAL

EL PODER DEL AMOR: VÍNCULO AFECTIVO Y SALUD EMOCIONAL DE LOS CUIDADORES DE NIÑOS Y ADOLESCENTES CON TRASTORNO DEL DESARROLLO INTELECTUAL

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ABSTRACT: This qualitative study aimed to understand the emotional aspects and the relationship between care and possible illness of the caregiver with an affective bond of children and adolescents with Intellectual Development Disorder (IDD). The research was carried out through semi-structured interviews and the application of the DASS-21 scale. The results indicated that most participants were women, mainly mothers of children and adolescents. These evidenced that the news of the condition, the visualization of the future, the challenges related to Intellectual Development (ID), and the follow-up were factors that led to negative feelings. However, there is great resilience, and many caregivers do not recognize the burden arising from daily care. In conclusion, this study provided a deeper understanding of the emotional experience of caregivers with an affective bond of children and adolescents with ID, highlighting the importance of support and support for caregivers.

KEYWORDS: Intellectual Developmental Disorder. Informal caregivers. Affective attachment caregivers. Family caregivers.

RESUMO: *Este estudo qualitativo teve como objetivo compreender os aspectos emocionais e a relação entre cuidado e possível adoecimento do cuidador com vínculo afetivo das crianças e adolescentes com Transtorno de Desenvolvimento Intelectual (TDI). A pesquisa foi realizada por meio de entrevistas semiestruturadas e aplicação da escala DASS-21. Os resultados indicaram que a maioria dos participantes eram mulheres, principalmente mães das crianças e adolescentes. Estas evidenciaram que, a notícia da condição, a visualização do futuro, os desafios relacionados ao Desenvolvimento Intelectual (DI) e o acompanhamento foram fatores que levaram a sentimentos negativos. No entanto, há grande resiliência e muitos cuidadores não reconhecem a sobrecarga advinda do cuidado diário. Em conclusão, este estudo forneceu uma compreensão mais profunda da experiência emocional dos cuidadores com vínculo afetivo de crianças e adolescentes com DI, destacando a importância do apoio e suporte aos cuidadores.*

PALAVRAS-CHAVE: *Transtorno do Desenvolvimento Intelectual. Cuidadores informais. Cuidadores com vínculo afetivo. Cuidadores familiares.*

RESUMEN: *Este estudio cualitativo tuvo como objetivo comprender los aspectos emocionales y la relación entre el cuidado y la posible enfermedad del cuidador con vínculo afectivo de niños y adolescentes con Trastorno del Desarrollo Intelectual (TID). La investigación se realizó a través de entrevistas semiestructuradas y aplicación de la escala DASS-21. Los resultados indicaron que la mayoría de los participantes eran mujeres, principalmente madres de niños y adolescentes. Éstos evidenciaron que la noticia de la condición, la visualización del futuro, los desafíos relacionados con el Desarrollo Intelectual (DI) y el seguimiento fueron factores que llevaron a sentimientos negativos. Sin embargo, existe una gran resiliencia y muchos cuidadores no reconocen la carga derivada del cuidado diario. En conclusión, este estudio proporcionó una comprensión más profunda de la experiencia emocional de los cuidadores con un vínculo afectivo de niños y adolescentes con DI, destacando la importancia del apoyo y apoyo para los cuidadores.*

PALABRAS CLAVE: *Trastorno del Desarrollo Intelectual. Cuidadores informales. Cuidadores con vínculo afectivo. Familiares cuidadores.*

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Introduction

The informal caregiver is generally someone with an emotional bond with the person being cared for, such as family members and close friends (LEOCADIE *et al.*, 2018). However, the act of caring is complex, especially when there is a bond with the person being cared for, and the informal caregiver is often not prepared or qualified to perform this role. Caring for a person with a disability is a job that involves physical, mental and social aspects and requires full-time dedication, which can cause significant changes in the caregiver's habits (SIT *et al.* 2020).

Disability is a global reality, according to the World Health Organization (WHO, 2011), 15% of the world's population lives with some type of disability. In Brazil, the situation is no different, research by the Brazilian Institute of Geography and Statistics (IBGE, 2010) found that approximately 45 million Brazilians have some type of disability, which represents 24% of the Brazilian population. Of these, 3,905,235 people are in the age group 0 to 14 years old and 391,266 have Intellectual Development Disorder.

Previously known as mental retardation, ID is a condition in which there are significant limitations in intellectual capacity and adaptive functioning. People with intellectual disabilities have difficulties in areas such as reasoning, learning, problem-solving, and social skills. These limitations hinder a person's overall development and daily activities. In Brazil, intellectual disability affects a significant portion of the population (GUSMÃO *et al.*, 2019).

According to the 2010 Census from the Brazilian Institute of Geography and Statistics (IBGE, 2010), around 2.8% of Brazilians have some type of intellectual disability. This equates to around 5.8 million people. It is important to emphasize that these numbers are estimates and the real prevalence may be higher due to underreported and underdiagnosed problems.

The Brazilian Disabled Persons Inclusion Law of 2015 (Law of Persons with Disabilities) aims to guarantee the rights and social inclusion of people with disabilities, including those with intellectual disabilities. The law establishes guidelines to promote equal opportunities, access, and full participation in society, ensuring protection and respect for people with disabilities. Within the scope of this law, studies have been developed to understand the impact and advances related to the inclusion and quality of life of people with intellectual disabilities in the country (BRASIL, 2015).

It is believed that these numbers are even higher today, considering the important historical milestones in relation to public health, such as the Brazilian zika virus epidemic that occurred in 2015 and 2016 and caused malformations in babies whose mothers were infected

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by the transmitting mosquito (OPAS, 2016). Among the malformations are microcephaly. According to the Brazilian Ministry of Health, between October 2015 and January 2019, more than 3,000 cases of microcephaly in newborns were reported. Of these, 42% of children had intellectual disabilities (FRANÇA *et al*., 2018).

Intellectual Development Disorder is especially delicate, as it requires specific and continuous care. In this context, informal caregivers play a fundamental role, offering physical, emotional, and social support to people with intellectual development disorders and helping them carry out their daily activities (PARK *et al*., 2021).

The International Classification of Diseases version 11 (ICD-11) describes intellectual developmental disorders (IDDs) characterized by limitations in intellectual functioning and adaptive behavior. These are related to the conceptual, social, and practical skills of individuals. These limitations may also exist in conjunction with other comorbidities and neuropsychiatric disorders, such as, for example, autism, cerebral palsy, attention deficit hyperactivity disorder and Down syndrome (ICD, 2018).

Among some examples, it is possible to mention the presence of psychiatric morbidity in informal caregivers and its relationship with the care provided to children with Intellectual Development Disorder and work overload, stress and vulnerability to problems related to mental health (KHALID *et al*., 2021), emotional overload and lack of community support (SIT *et al*., 2020).

In this reality, the person with a disability is the only one who receives care, and there is a strong cultural association with the social demands imposed on caregivers. Furthermore, in South Korea, the quality of life of caregivers was associated with the severity of the patient's symptoms and the type of emotional bond (SONG *et al*., 2020). Likewise, in Brazil, the burden of care is greater for caregivers with an emotional bond. This is also associated with the severity of symptoms and the number of hours dedicated to care (SILVA; PASSOS; BARRETO, 2012).

The International Classification of Diseases version 11 (ICD-11) describes Intellectual Development Disorders (IDDs), due to limitations in intellectual functioning and adaptive behavior, affecting individuals' conceptual, social, and practical skills (ICD, 2018). These limitations often coexist with other comorbidities and neuropsychiatric disorders, such as autism, cerebral palsy, attention deficit hyperactivity disorder, and Down syndrome.

These individuals need help and care. Thus, caregivers emerge. These can be formal (psychologists, nurses, hiring specialized people) and informal (family, friends and people close to you). Informal caregivers of people with ID usually dedicate their lives to care and, therefore,

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it is common for them to develop psychological illness. These, in turn, can affect the care provided and cause work overload, stress and vulnerability related to mental health (KHALID *et al.*, 2021). Likewise, emotional overload and lack of community support can also contribute to caregivers' difficulty in providing adequate care (SIT *et al.*, 2020).

In several countries, including South Korea and Brazil, the quality of life of caregivers is influenced by the severity of the patient's symptoms and the type of emotional bond between the caregiver and the patient (SONG *et al.*, 2020; SANTOS *et al.*, 2020). Furthermore, the burden of care is greater for caregivers with an emotional bond and is associated with the number of hours dedicated to care and the severity of the patient's symptoms.

Caregivers face a series of challenges that can have significant impacts on their health and well-being. One of the main challenges is the lack of specific programs and guidelines for caregivers' health care. Often, these people put their own health needs second, prioritizing the care of others. The absence of adequate support can lead to physical and mental problems, such as stress, fatigue, depression, and even chronic illnesses (MARQUES *et al.*, 2011).

Another challenge faced by caregivers is the difficulty in accessing public health services, such as the Unified Health System (SUS). Bureaucracy, lack of resources and high demand can result in long waits and difficulties in obtaining adequate care. Furthermore, many caregivers also face double working hours, having to balance care with other family and professional responsibilities, which can lead to exhaustion and emotional overload (SILVA; PASSOS; BARRETO, 2012).

However, there are strategies and approaches in Health Care and Promotion that aim to support caregivers. It is essential to promote awareness about the importance of self-care and provide information and resources so that caregivers can take care of themselves. Qualification programs, psychosocial support and support groups can play an important role in promoting the health of caregivers (FARIA *et al.* 2022).

The impacts of health, social and economic vulnerability are also relevant. Caregivers often face financial difficulties, lack of social support and isolation. These factors can worsen the vulnerability of caregivers and have negative consequences for their physical and mental health. In this sense, according to Ballarin *et al.* (2016), it is common for informal caregivers to neglect their own self-care, putting their life in the background. This behavior is observed mainly among mothers who care for their children, and this factor is considered important for the caregiver's illness, since their actions become directed towards the family member who requires care.

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Given this context, the present study seeks to understand the relationship between the act of caring daily and the possible illness suffered by the caregiver, observing the aspects involved, the motivations and the consequences of care, with the following research problem "What are the emotional aspects of caregivers with emotional ties to children and adolescents with Intellectual Development Disorder?"

This article is organized into an introduction, theoretical framework, methodological outline, results and discussions and final considerations.

Theoretical Framework

Affective bonds are essential for the personality development of children and adolescents, as they provide security and emotional stability (BAIRROS *et al.*, 2011). Care is a complex activity, which involves a series of functions, from individualized attention to medication administration and finance management (MARONESI *et al.*, 2014; SANTOS; SILVA; SILVA, 2020). In general, women assume the role of caregivers, often giving up other opportunities and projects in their lives (GUEDES; DAROS, 2009).

In addition to being emotionally challenging and significantly impacting the health of the caregiver, in the specific case of Brazil, where there is a significant gap in the provision of services and support for people with IDD, data shows that many caregivers of people with disabilities face difficulties in accessing health services, mainly in the Unified Health System (SUS). Therefore, the shortage of specialized professionals, the lack of support programs, and the overload of the public health system can make access to adequate treatments and support difficult (GOMES, 2017).

Another point to be discussed is the lack of specific programs and guidelines for the health care of caregivers, which is also present in Brazilian reality. There are few initiatives aimed at providing emotional support, qualification, and guidance for caregivers, which can increase the risk of physical and mental illness for these people (GIORDANI, 2015).

The impact of the lack of support for caregivers is reflected in their health conditions. Studies have shown high rates of stress, anxiety, depression, and exhaustion among caregivers of people with DID. Emotional overload and constant demand for care can lead to chronic health problems, decreased quality of life and even affect the caregiver's ability to maintain the emotional bond with the person being cared for (CAMACHO, 2021).

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Recent studies highlight the prevalence of women as informal caregivers in different countries (SIT *et al.*, 2020; SILVA; FEDOSSE, 2018). The reasons for becoming an informal caregiver vary, but include love, gratitude, morality, solidarity, and self-will (RICARTE, 2009). However, care can also lead to physical, emotional, psychological, social, and financial burdens, leaving little time for caregivers to take care of themselves (AMARAL *et al*., 2011). Despite the challenges, caregivers also report emotionally rewarding feelings, such as love and connection (RICARTE, 2009).

Additionally, caring for people with chronic or progressive illnesses can be particularly challenging for caregivers. This occurs because mothers of children with disabilities have a higher risk of developing clinical depression compared to mothers of children with typical development (KHALID *et al.*, 2020). Likewise, mothers of children with autism spectrum disorders experience high levels of stress and anxiety (MINIARIKOVA *et al.* 2022).

Therefore, it is important that informal caregivers receive adequate support and resources to help them deal with the challenges of caregiving and care for themselves. As stated by Bai *et al.* (2021), "social support, including financial resources, helpful information, and emotional support, can help reduce the burden on caregivers and improve their quality of life".

Methodological outline

This research was developed through a qualitative approach, using a case study procedure and a semi-structured open interview technique containing twenty-two questions. Of these, fifteen are closed to characterize the participants, and seven are open, aimed at understanding the emotional aspects of caregivers with an emotional bond with children and adolescents with Intellectual Development Disorder. The DASS-21 Depression, Anxiety, and Stress Scale was also applied.

The Depression, Anxiety, and Stress Scale (DASS-21) was developed in 1995 to measure and differentiate symptoms related to stress, anxiety, and depression according to psychometric order. Based on a tripartite model, the scale proposes that three basic structures are grouped with symptoms. The first is related to the presence of negative emotions and symptoms related to depression and anxiety, the second goes to specific symptoms of depression and the last to particular symptoms of anxiety (PATIAS *et al.*, 2016).

DASS-21 is a self-report scale that contains a set of three four-point Likert-type subscales (0, 1, 2, and 3) about the statements present in it, with 0 being “not applicable at all”

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and 3 “applied most of the time.” Each subscale consists of 7 assessment items regarding the topics of depression, anxiety, and stress (VIGNOLA, 2013). This offers parameters to investigate affects, providing clues to help with possible prevention strategies or even intervention, if necessary (MARTINS *et al.*, 2019).

For this research, a multiple case study was used, which, according to Godoy (1995), is characterized as research whose purpose is to analyze a combination of data from one or more people.

Participants were selected through convenience sampling in three institutions and made up of a total of 16 female and male caregivers with an emotional bond. The study had the following inclusion criteria: 1) Being a caregiver with an emotional bond of a child or adolescent with Intellectual Development Disorder; 2) Being a resident of *Jaraguá do Sul/Santa Catarina* and the region; 3) Being related to the following institutions: A, B, and C.

The institutions in question provide care to people with ID, with institution A being a non-profit institution formed by parents who work towards improvements in the inclusion of people with disabilities. Institution B provides services in the areas of social assistance, education and health, through therapeutic and assessment services for people with disabilities. Institution C is a School Service where one of the activities carried out by academics corresponds to the Psychology course, which provides psychological assessment and psychotherapy services for all types of people with or without disabilities.

The average interview time was 30 minutes to 1 hour. These were analyzed through content analysis, since the main objective of this is to carry out an analysis of communications using a set of investigation techniques.

According to Bardin (1977), one must go through three necessary processes to carry out a content analysis: 1) pre-analysis, 2) exploration of the material and 3) treatment of results, inference and interpretation.

The possible domains for applying content analysis are: Linguistic (written and oral), Iconic (signs, images, photographs) and other semiotic codes (everything that has meaning, for example, music and behaviors) (BARDIN, 1977).

Thus, in this study, a classificatory content analysis of linguistic mastery was carried out, conducted by dual communication, using an open semi-structured interview as a guide. To organize the text, the caregivers are identified as: P1, P2, P3 and so on. This study was approved by the CAAE Ethics Committee number: 61400722.6.0000.5098.

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Results and analysis

The results showed that the sociodemographic profile of the participants is mostly characterized by people from the state of Santa Catarina, Paraná, among other regions of the country.

The study makes it possible to state that most participants were women (13), married and mothers of children and adolescents with Intellectual Development Disorder (ID) who are currently aged between 30 and 59 years. Of these, 9 people have completed higher education. The majority have their own house-type residence.

It was also noticed that the dependent family member in 15 cases was the child, with the conception originating in a planned manner in 13 of the participants. The participants' family nucleus corresponds to the father, mother and two children. With regard to physical or psychological illnesses, 11 participants reported not having them. However, a family history of depression exists in 9 participants.

The application of the Dass-21 Scale, which measures the levels of Depression, Anxiety and Stress, characterized that in relation to depressive symptoms, the levels were normal for 13 participants, with the remainder, 1 mild case and 2 at a moderate level.

Anxiety levels corresponded to normal in 9 participants. There are also 2 mild cases, 1 moderate level, 2 severe cases and 2 extremely severe cases. Likewise, regarding stress levels, the scale showed that 7 of the participants were normal. There are also 3 mild cases, 5 moderate cases and 1 severe case.

The data obtained in the interview resulted in 7 categories and 14 subcategories, related to emotional aspects, respectively: Reaction to the news of ID, Perception of the future in relation to ID, Challenges related to ID, Monitoring, Current perception of ID, Feelings about in relation to DI and Learning provided, described as shown in Figure 1.

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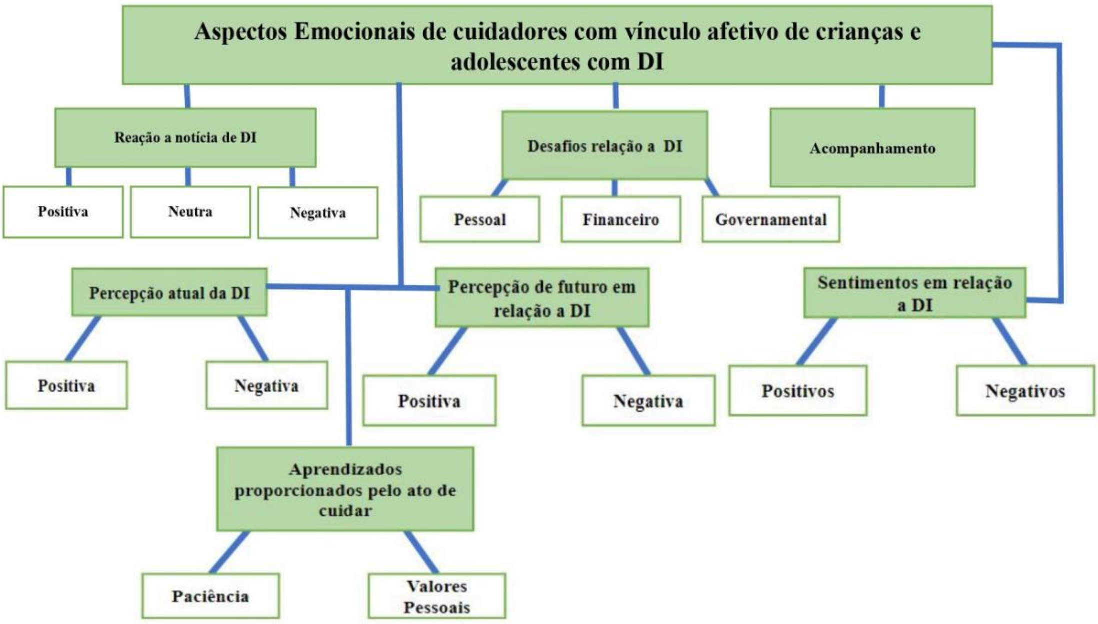
Figure 1 – General data[4]



Source: Data from research prepared by the author (2022)

The first category concerns “reaction to the DI news”. This category is related to the reaction that participants had upon learning that the person being cared for had Intellectual Development Disorder. It is divided into three subcategories: “negative” (10 mentions), “positive” (4 mentions), and “neutral” (2 mentions).

The data in this category showed that of the 16 participants, 10 had immediate reactions linked to negative feelings, as can be seen in the statements:

> *“[...] I was outraged! And it’s a moment when we say it’s a moment of mourning, right?” (P5)*
> *“[...] It was very difficult. Very difficult! As if I had been thrown into a black hole. That’s the feeling!” (P6)*
> *“[...] It was a fright at the time, you know? Because (X) has Down Syndrome and so, we did all the prenatal care and never presented anything like that that could have caused him to have a disability.” (P11)*

It was also shown that 4 people had immediate reactions linked to positive feelings, as demonstrated in the statements:

> *“[...] This process was very smooth for us, because we were the ones who noticed, right?” (P13)*

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[4] See Annex A

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> *"[...] It was very calm, in fact before (B) we had (G) and she had, at 3 months, a very complicated surgery [...] And I never saw Down Syndrome as something… Like a problem like that, I never saw it as a problem." (P15)*

Regarding the neutral response, 2 participants reported: *"[...] And for me, it didn't change anything. Nothing, nothing, nothing" (P7) and "[...] At the time I didn't even know what it was, so I wasn't very surprised or anything like that" (P10).*

The category "perception of the future in relation to ID" is linked to the way in which caregivers visualize their future and that of the person being cared for, in relation to their development, being divided into two subcategories, "positive" (11 mentions) and "negative" (5 mentions). These are evidenced in the statements:

> *"[...] In relation to him. I believe he will be literate and will have a future. We are working towards this." (P2)*
> *"[...] So, if everything goes well! If everything goes well! I think (X) will be an independent person." (P5)*
> *"[...] I have a lot of hope for his development, he is a very active and happy person". (P7)*
> *"[...] I look at this aspect of the delay in the phases, right? I think he'll stay with us always, right? As long as we're here." (P6)*
> *"[...] I think a mother's every fear is, what will it be like when my child doesn't have me anymore?" (P8)*

In the category "challenges in relation to DI", the interviewees highlighted the challenges they experienced in the personal, financial and governmental spheres that they need to face in their daily lives. Thus, the "personal" subcategory refers to the challenges experienced on a daily basis at home, in relation to hygiene, household chores, and health care at home. In this subcategory, 15 of the 16 participants reported the challenges: *"[...] When I don't sleep well, I have to manage everything I need during the day" (P9) and "[...] It seems like I don't manage it and I won't manage it" (P10).*

In the "financial" subcategory, there are day-to-day challenges in relation to the financial costs that arise in relation to care, being exposed by 5 of the 16 participants, as per the reports below:

> *"[...] And how are you going to pay for the therapies if you don't work?" (P3)*
> *"[...] It has a very high financial expense! Today, just on ecotherapy and speech therapy, I spend R$1,000.00 per month. Apart from special food. Because he eats gluten-free, sugar-free, and dairy-free… He takes several supplements. So, it's a lot of expense." (P6)*
> *"[...] I had a huge spike in stress, before that my husband left work so he could be with her, and then he came back because the bills are coming, right". (P9)*

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> *“[...] Sometimes we have to stop eating the best food to cover the medical costs of (X)”. (P12)*

The last subcategory, “governmental,” pertains to challenges such as therapy assistance, specialized medical care within the Unified Health System (SUS), and policies for inclusive public education. In this subcategory, 9 out of 16 participants reported facing challenges in their daily lives, as outlined in the provided accounts:

> *“[...] If we were to depend on government resources, it would be very precarious. I tried to look for a speech therapist through the SUS and it's one speech therapist per month! There's no condition, right? One speech therapist per month, so it's practically non-existent. So, I think it’s pretty flawed.” (P6)*
> *“[...] I think that the issue of disability today is not a problem”. (P8)*
> *“[...] there is a lack of structure for us to be able to provide a better quality of life for them! [...] (X) does not receive any benefit. Never received! We spend a lot, a lot on doctors.” (P12)*
> *“[...] You can’t get follow-up with a doctor. For example, a quality ophthalmologist. Also, a quality otolaryngologist! You can’t get quality medical care for them!” (P3).*

The “monitoring” category showed that the majority need to undergo specialized therapeutic monitoring, mainly in Speech Therapy (17 mentions), Occupational Therapy (12 mentions), Physiotherapy (7 mentions), Psychopedagogy (7 mentions) and Psychotherapy (5 mentions) and Therapies Alternatives (7 mentions).

Next, we have the category “Current perception of ID”, which refers to the perception of caregivers today and how they understand the disability. This category was characterized into two subcategories, namely “positive” and “negative”. The results revealed that of the 16 interviewees, 11 reported positive perceptions and were currently considering the reaction when they received the news about DI, and 5 had negative perceptions. According to reports:

> *“[...] The way of dealing with things has improved from what it was before. We learn, we see that we have to adapt to them, right?” (P1)*
> *“[...] I consider it normal; I see that the path is already well developed.” (P2)*
> *"[...] One day at a time! We must think like this, one day at a time.” (P6)*
> *“[...] If I told you like this, that I accepted it 100%... No! Because then we look at another child and end up comparing it to your child, right? With my son on the case!” (P5)*
> *“[...] It's difficult... I don't know how to deal with it yet, there are times when I bite myself. I don’t know, it’s stressful.” (P10)*
> *“[...] I'm still learning to... It's very difficult for me on a daily basis with him, because new situations always arise”. (P15)*

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Regarding the category “Feelings regarding ID”, it refers to the feelings of caregivers with an emotional bond with children and adolescents with ID in relation to the act of caring, involving all the other categories presented previously. In this regard, the category was divided into two subcategories, the first being related to “positive” feelings and the second to “negative” feelings.

In the subcategory of positive feelings, 6 presented feelings such as love and happiness, as can be seen in the following reports:

> *“[...] Love is also one. I don't know what it's like. Because we don't know what it's like to have children who don't have disabilities. But the love we feel for them, I can’t tell you.” (P1)*
> *“[...] A feeling of a lot of happiness, a lot of love.” (P3)*
> *“[...] Love mainly”. (P7)*
> *“[...] That love breaks down barriers!” (P9)*
> *“[...] Love always wins, in any fight or battle, if there is love involved, dedication is enough to succeed.” (P13)*
> *“[...] It’s a very big love… Very big, like I said, if I had to do it, I would do it all over again.” (P16)*

In the second subcategory related to negative feelings, it can be observed that 12 of the 16 participants reported having feelings such as fear, anguish, impotence, frustration, sadness, guilt and incapacity, all feelings arising from aspects that are part of the act of caring, as demonstrated in the stories below:

> *“[...] The fear that one day they will have to stay like this, in the hands of other people. I think it’s a common fear among parents of children with disabilities.” (P1)*
> *“[...] Everything takes longer, more difficult. So, it makes me anguished. I think that’s the word.” (P4)*
> *“[...] Sometimes I feel helpless, you know? Of not being able to do more.” (P5)*
> *“[...] We feel very frustrated, right?” (P6)*
> *“[...] I feel uncomfortable, right? Because then, you must demand from people what they should be doing for themselves.” (P8)*
> *“[...] Sadness, anguish because we try to live one day at a time, so we don’t get depressed, we don’t get anxious about all this.” (P14)*
> *“[...] We sometimes, right? You must go a little harder on him. But he is very affectionate, so sometimes he sees that he did something wrong, and we feel guilty, right? The feeling of guilt”. (P15)*

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The last category presented was “proportional learning”. These relate to care linked to “patience” (7 mentions) and “personal values” (15 mentions). Of the 16 participants, 7 reported progress in terms of patience compared to the period prior to the birth of their child:

> *“[...] I see that this makes us have greater patience because you have to exercise this when you are the father of a child with a disability. You have to be calm and talk, and if it doesn’t work one way, we try another. I think this had a positive impact, you know?” (P1)*
> *“[...] Learning to be patient, a lot of patience with this girl… Patience. So, a lot of patience.” (P3)*
> *“[...], but it brings a lot of learning. You can see life in a different way.” (P2)*
> *“[...] Sometimes it’s about appreciating the little things, because every small victory is also a reason to be grateful and celebrate.” (P9)*
> *“[...] She teaches me every day! And sometimes I think she came to my husband and me to change us. Modify!". (P12)*
> *“[...] she brought me several lessons. First, it would be to be more human, about valuing what we have, being more grateful, there are things that are normal for us, but for him it is a huge challenge”. (P14)*

Analysis and discussion of results

Physical and mental fatigue are considerable factors and the feeling of guilt, accompanied by frustration, adds to the feeling of the need to manage all daily activities. The research demonstrated that stimuli such as patience and love are brought out in caregivers during the act of caring, as explained by Ricarte (2009), even if there are high levels of overload, it may coexist with the presence of emotional, rewarding feelings, acting in a particular perspective according to each person.

Most caregivers with an emotional bond participating in this research are female, mothers of children and adolescents with ID, which reinforces other studies already carried out, such as that by Sit *et al.* (2020). In this case, attention is drawn to the fact that women are most informal caregivers (78.21%), also revealing the fact that being female is directly associated with a greater burden of care. The results of this research are also compatible with another study carried out in Brazil, in a small town in the state of Rio Grande do Sul, with 75 participants, showing that 82.66% of caregivers are women, and of these, 61.33% were mothers, of the person with intellectual disability (SILVA; FEDOSSE, 2018).

Caring, related to a positive perspective, has an existential meaning. Aspects linked to personal development include pride, the progressive increase in the feeling of accomplishment, the ability to face new challenges and development in an interpersonal way, increasing the meaning of life, well-being, pleasure and satisfaction with oneself (APERTA, 2015).

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It is also possible to mention the following categories to explain illness and stress among caregivers: Reaction to the news of ID, Visualization of the future, Challenges in relation to ID and Follow-ups that demonstrate negative feelings as presented in the results of the Feelings towards ID category. DI. This corroborates the study by Amaral *et al.* (2008), which exposes the overload in different aspects of life: physical, emotional, psychological, social, and financial, as the act of caring includes serving and helping whenever necessary, ensuring the well-being of those who have limitations.

It is a full-time donation of yourself. This fact creates a lack of time for oneself and difficulty in recognizing the overload arising from care. Given this, there are still other studies that demonstrate the existence of symptoms such as anxiety and depression in 70% of caregivers (KHALID, *et al.*, 2020). Such factors could justify the possible incompatibility of results in the levels of the Dass-21 scale with the answers obtained in the interviews.

Final considerations

The way each caregiver reacts when they learn about ID reflects the diversity of feelings that family caregivers experience. Such feelings can influence how caregivers deal with disability over time. Negative statements point to the need for emotional and psychological support for these caregivers, while positive statements can be useful in understanding the sources of resilience in these caregivers.

Regarding future expectations, it is important because it can influence the care strategies that are adopted. The “positive” and “negative” subcategories show that caregivers have different views about the future of the person being cared for, which can be useful for planning and developing intervention strategies.

Furthermore, it is relevant to understanding the difficulties faced by family caregivers in daily care and can be useful for the development of public policies and support programs for these caregivers. The “personal” subcategory reveals the work overload that caregivers face and the need for support to take care of themselves. The “financial” subcategory highlights the economic difficulties that caregivers face, as well as the need for public policies that guarantee access to health services and therapies.

In practical terms, the research results can be useful for developing support programs for family caregivers of people with ID, including emotional and psychological support, training programs in health care and therapies, respite services, financial subsidies and public

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policies for guaranteed access to health and education services. Furthermore, the results can be used to promote awareness about intellectual disability and reduce the stigma and discrimination associated with it.

Although the present study has made some important theoretical and practical contributions, there are still research gaps to be filled and suggestions for future research, such as: Exploring the experiences of family caregivers of people with ID in different cultures and socioeconomic contexts. The current research was conducted in a specific context, so it is important to examine whether the findings apply to other populations.

It is also possible to investigate the challenges faced by family caregivers of people with ID at different stages of the person being cared for, such as children, adolescents, young adults and the elderly. This would allow for a more comprehensive understanding of caregivers' needs and how they change over time. It is also possible to investigate the influence of the quality of the relationship between the caregiver and the person being cared for on the emotional well-being of caregivers. This could help identify protective and risk factors for caregivers' emotional well-being and inform the development of effective interventions.

There is also the possibility of exploring the role of support networks for family caregivers of people with ID and how they can influence the emotional well-being of caregivers, investigating the barriers and facilitators for family caregivers of people with ID to access health services. Support, including health services, therapies, and public policies. This could help identify gaps in service delivery and inform the development of public policies that meet the needs of caregivers. And even examine the impact of intellectual disability on family dynamics, including the relationship between siblings and the relationship between the person with ID and other family members. This can inform family intervention and help develop healthy relationships and mutual support strategies.

These suggestions for future research can help fill research gaps and provide valuable information to inform clinical practice and public policy development.

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REFERENCES

AMARAL, E. *et al.* Qualidade de vida e sobrecarga em cuidadores de crianças com síndrome de down. **Movimenta,** *[S. l.]*, v. 4, n. 2, p. 99- 108, 2011. ISSN: 1984-4298. Available at: https://www.revista.ueg.br/index.php/movimenta/article/view/7142/5243. Accessed in: 15 July 2023.

APERTA, J. **Aspectos positivos do cuidar e o apoio social percebido nos cuidadores informais de pessoas com demência**. Instituto politécnico de Bragança. Dissertação **(**Mestrado em Cuidados Continuados) – Instituto politécnico de Bragança, Escola Superior de Saúde de Bragança, Bragança, Portugal, 2015.

BAI, X. *et al.* Understanding the impacts of social support on the well-being of caregivers of individuals with disabilities in China. **International Journal of Environmental Research and Public Health**, *[S. l.]*, v. 18, n. 4, p. 1934, 2021. DOI: 10.3390/ijerph18041934. Available at: https://doi.org/10.3390/ijerph18041934. Accessed in: 15 July 2023.

BAIRROS, J. *et al.* Infância e adolescência: A importância da relação afetiva na formação e desenvolvimento emocional. *In*: SEMINÁRIO INTERINSTITUCIONAL DE ENSINO, PESQUISA E EXTENSÃO, 16., 2011, Cruz Alta. **Anais** [...]. Cruz Alta, RS: Universidade de Cruz Alta, 2011.

BALLARIN, M. L. G. S. *et al.* Perfil sociodemográfico e sobrecarga de cuidadores informais de pacientes assistidos em ambulatório de terapia ocupacional. **Cadernos Brasileiros de Terapia Ocupacional**, São Carlos, v. 24, n. 2, p. 315-321, 2016. DOI: 10.4322/0104-4931.ctoAO0607. Available at: https://doi.editoracubo.com.br/10.4322/0104-4931.ctoAO0607. Accessed in: 15 July 2023.

BARDIN, L. **Análise de Conteúdo**. França: Pressees Universitaires France, 1977.

BRASIL. Lei n.º 13.146, de 6 de julho de 2015. Institui a Lei Brasileira de Inclusão da Pessoa com Deficiência (Estatuto da Pessoa com Deficiência). **Diário Oficial da União**: seção 1, Brasília, DF, p. 2, 2015. Available at: https://www2.camara.leg.br/legin/fed/lei/2015/lei-13146-6-julho-2015-781174-publicacaooriginal-147468-pl.html. Accessed in: 15 July 2023.

CAMACHO, S. **Prevenção da sobrecarga do cuidador informal na prestação de cuidados ao idoso dependente**. Dissertação (Mestrado em Enfermagem Comunitária e de Saúde Pública) **-** Universidade de Évora, Instituto Politécnico de Portalegre, Instituto Politécnico de Setúbal, Instituto Politécnico de Castelo Branco, 2021.

Classificação Internacional de Doenças 11 (CID-11). **Transtornos do desenvolvimento intelectual**. Organização Mundial da Saúde, 2018.

FARIA, R. A. P. *et al*. Promoção da saúde mental positiva nos enfermeiros de um serviço de psiquiatria português: dados preliminares. **Sağlık Akademisi Kastamonu**, *[S. l.]*, p. 191-192, 2022. DOI: 10.25279/sak.1138812. Available at: https://dergipark.org.tr/tr/pub/sak/article/1138812.Accessed in: 15 July 2023.

BY-NC-SA

FRANÇA, G. V. A. *et al.* Síndrome congênita associada à infecção pelo vírus Zika em nascidos vivos no Brasil: descrição da distribuição dos casos notificados e confirmados em 2015-2016. **Epidemiologia e Serviços de Saúde**, *[S. l.]*, v. 27, n. 2, p. e2017473, 2018. DOI: 10.5123/S1679-49742018000200014. Available at: https://www.scielo.br/j/ress/a/nvpwC7jVqpBg6Y5Z4zRJwzd/. Accessed in: 15 July 2023.

GIORDANI, A. T. **Humanização da saúde e do cuidado.** Difusão Editora, 2015.

GODOY, A. S. Introdução à pesquisa qualitativa e suas possibilidades. **RAE - Revista de Administração de Empresas**, São Paulo, v. 35, n. 2, p. 57-63, 1995. Available at: https://www.scielo.br/j/rae/a/wf9CgwXVjpLFVgpwNkCgnnC/?format=pdf&lang=pt. Accessed in: 15 July 2023.

GOMES, G. B. **Manejo familiar da criança com transtorno do espectro do autismo**. 2017. 119 f. Dissertação (Mestrado em Saúde da Família) – Universidade Federal do Ceará, Sobral, 2017.

GUEDES, O. S.; DAROS, M. A. O cuidado como atribuição feminina: contribuições para um debate ético. **Serv. Soc. Rev.**, *[S. l.]*, v. 12, n. 1, p. 122-134, 2009. Available at: https://www.uel.br/revistas/uel/index.php/ssrevista/article/viewFile/10053/8779. Accessed in: 15 July 2023.

GUSMÃO, E. C. R. *et al.* Habilidades adaptativas sociais e conceituais de indivíduos com deficiência intelectual. **Revista da Escola de Enfermagem da USP**, *[S. l.]*, v. 53, p. e03481, 2019. DOI: 10.1590/S1980-220X2018014903481. Available at: https://www.scielo.br/j/reeusp/a/nbpJj4XmhNMFJtYs8gjdPCx/. Accessed in: 15 July 2023.

IBGE. **Censo demográfico 2010.** Características Gerais da População, Religião e Pessoas com Deficiência. Rio de Janeiro: IBGE, 2010. Available at: https://biblioteca.ibge.gov.br/visualizacao/periodicos/94/cd_2010_religiao_deficiencia.pdf. Accessed in: 15 July 2023.

KHALID, H. *et al.* Psychiatric morbidity among informal caregivers of children suffering from intellectual developmental disorders. **Journal Of The Pakistan Medical Association,** *[S. l.]*, v. 71, n. 8, p. 2005-2008, 2021. DOI: 10.47391/JPMA.20-584. Available at: https://ojs.jpma.org.pk/index.php/public_html/article/view/58. Accessed in: 15 July 2023.

LEOCADIE *et al.* Barriers and enablers in the use of respite interventions by caregivers of people with dementia: an integrative review. **Archives of Public Health**, *[S. l.]*, v. 76, n. 72, 2018. DOI: 10.1186/s13690-018-0316-y. Available at: https://archpublichealth.biomedcentral.com/articles/10.1186/s13690-018-0316-y. Accessed in: 15 July 2023.

MARQUES, A. K. M. C. *et al.* Apoio social na experiência do familiar cuidador. **Ciência & Saúde Coletiva,** *[S. l.]*, v. 16, p. 945-955, 2011. Available at: https://www.scielosp.org/article/ssm/content/raw/?resource_ssm_path=/media/assets/csc/v16s1/a26v16s1.pdf. Accessed in: 15 July 2023.

BY-NC-SA

MARTINS *et al.* Escala de Depressão, Ansiedade e Estresse: propriedades psicométricas e prevalência das afetividades. **Jornal Brasileiro de Psiquiatria**, *[S. l.]*, v. 68, n. 1, p. 32-41, 2019. DOI: 10.1590/0047-2085000000222. Available at: https://www.scielo.br/j/jbpsiq/a/SZ4xmWDdkxwzPbSYJfdyV5c/?lang=pt. Accessed in: 15 July 2023.

MINIARIKOVA, E. *et al*. Anxiety and depression in parents of children with autism spectrum disorder during the first COVID-19 lockdown: Report from the ELENA cohort. **Journal of psychiatric research**, *[S. l.]*, v. 149, p. 344–351, 2022. DOI: 10.1016/j.jpsychires.2021.11.022. Available at: https://pubmed.ncbi.nlm.nih.gov/34776249/. Accessed in: 15 July 2023.

MORONESI, L. C. *et al.* Indicadores de estresse e sobrecarga em cuidadores formais e informais de pacientes oncológicos. **Estud. pesqui. Psicol.**, *[S. l.]*, v. 14, n. 3, p. 877-892, 2014. Available at: http://pepsic.bvsalud.org/pdf/epp/v14n3/v14n3a10.pdf. Accessed in: 15 July 2023.

ORGANIZAÇÃO MUNDIAL DA SAÚDE (OMS). **Relatório Mundial Sobre a Deficiência**. São Paulo: OMS, 2011. Available at: http://apps.who.int/iris/bitstream/handle/10665/70670/WHO_NMH_VIP_11.01_por.pdf;jsessionid=5D3932363226EDBC2778C234AA16DC49?sequence=9. Accessed in: 15 July 2023.

ORGANIZAÇÃO PAN-AMERICANA DE SAÚDE (OPAS). **Zika**: Atualização Epidemiológica. Washington: OPAS, 2016. Available at: https://www3.paho.org/bra/images/stories/SalaZika/boletim%20016.pdf. Accessed in: 15 July 2023.

PATIAS *et al.* Depression Anxiety and Stress Scale (DASS-21) - Short Form: adaptação e validação para adolescentes brasileiros. **Psico-Usf**, *[S. l.]*, v. 21, n. 3, p. 459-469, 2016. DOI: 10.1590/1413-82712016210302. Available at: https://www.scielo.br/j/pusf/a/CtJv6LTmfYxKfXzmP4j6q5g/?format=pdf&lang=pt. Accessed in: 15 July 2023.

RICARTE, L. F. C. S. **Sobrecarga do cuidador informal de idosos dependentes no Concelho da Ribeira Grande**. 134 f. Dissertação (Mestrado em Ciências de Enfermagem) - Curso de Ciências de Enfermagem, Universidade do Porto, Porto, 2009.

SILVA, C. F.; PASSOS, V. M. A.; BARRETO, S. M. Frequência e repercussão da sobrecarga de cuidadoras familiares de idosos com demência. **Revista Brasileira De Geriatria E Gerontologia**, *[S. l.]*, v. 15, n. 4, p. 707–731, 2012. DOI: 10.1590/S1809-98232012000400011. Available at: https://www.scielo.br/j/rbgg/a/7Ydj3ySk8N4Fgcng74DBpzC/?lang=pt#. Accessed in: 15 July 2023.

SANTOS, S. E.; SILVA, N. R.; SILVA, M. L. Sobrecarga em cuidadores informais de crianças em sofrimento psíquico. **Laborativa***, [S. l.]*, v. 9, n. 2, p. 47-63, 2020. Available at: http://ojs.unesp.br/indexphp/rlaborativa. Accessed in: 15 July 2023.

BY-NC-SA

SILVA, R. S.; FEDOSSE, E. Perfil sociodemográfico e qualidade de vida de cuidadores de pessoas com deficiência intelectual. **Cadernos Brasileiros de Terapia Ocupacional,** *[S. l.]*, v.26, n. 2, p. 357-366, 2018. DOI: 10.4322/2526-8910.ctoAO1220. Available at: https://www.scielo.br/j/cadbto/a/BNTfTGcSzDMV63f9njY3M3b/abstract/?lang=pt. Accessed in: 15 July 2023.

SIT, H. F. *et al.* Caregiving burden among informal caregivers of people with disability. **British Journal Of Health Psychology,** *[S. l.]*, v. 25, n. 3, p. 790-813, 2020. DOI: 10.1111/bjhp.12434. Available at: https://bpspsychub.onlinelibrary.wiley.com/doi/abs/10.1111/bjhp.12434. Accessed in: 15 July 2023.

SONG, Y., *et al.* Comparison of caregiver burden and quality of life among primary caregivers with different relationships to care recipients. **International Journal of Environmental Research and Public Health**, *[S. l.]*, v. 17, n. 22, p. 8499, 2020. DOI: 10.3390/ijerph17228499. Available at: https://www.mdpi.com/1660-4601/17/22/8499. Accessed in: 15 July 2023.

SOUZA, C. C. B X. **Desigualdades de acesso aos serviços de saúde no SUS**: os direitos das pessoas com deficiência na periferia do capitalismo. 2022. Tese (Doutorado em Humanidades, Direitos e Outras Legitimidades) – Faculdade de Filosofia, Letras e Ciências Humanas, Universidade de São Paulo, São Paulo, 2022.

VIGNOLA, R. C. B. **Escala de depressão, ansiedade e estresse (DASS)**: adaptação e validação para o português do Brasil. 56 f. Dissertação (Mestrado em Ciências da Saúde) – Curso de Ciências da Saúde, Universidade Federal de São Paulo, São Paulo, 2013.

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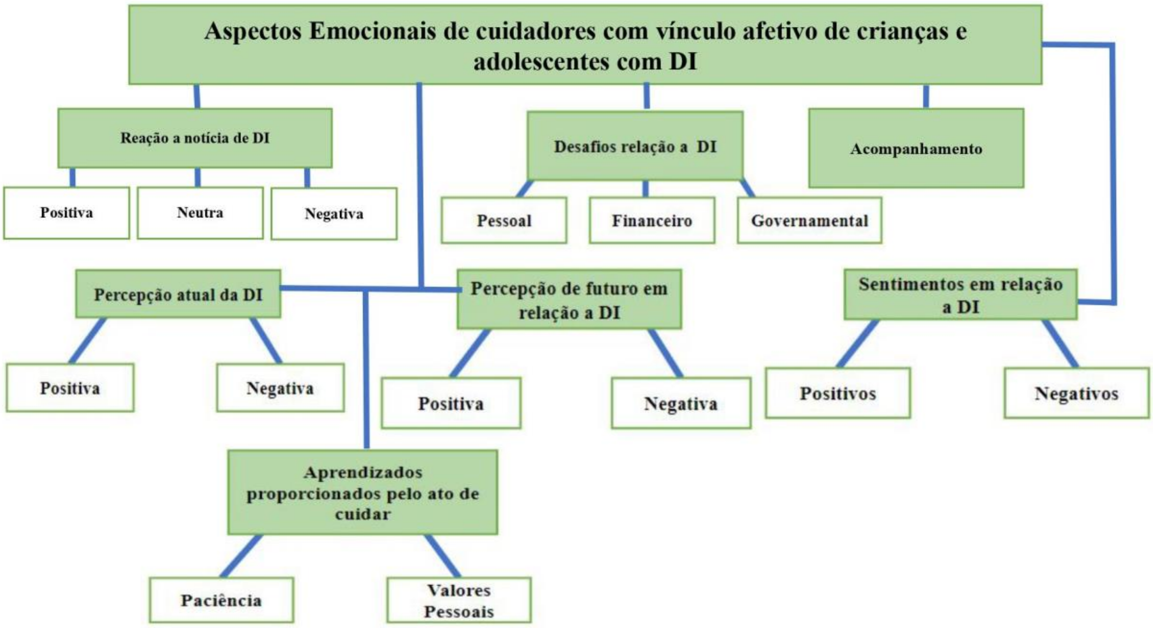
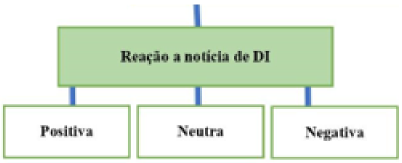
Annex A

Figure 1 – General data



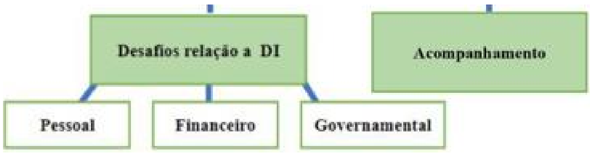
In english:

Emotional aspects of caregivers with emotional ties to children and adolescents with ID



Reaction to DI News

Positive / Neutral / Negative



Challenges in relation to DI **Monitoring**

Personal / Financial / Governmental

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Current perception of DI

Positive / Negative

Perception of the future in relation to DI

Positive / Negative

Feelings in relation to DI

Positive / Negative

Learning provided by the act of caring.

Patience / Personal Values

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