

**Feeling of grief and loss in parental caregivers of adults diagnosed with intellectual disability**

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**Keywords:** grief, loss, intellectual disability, qualitative, parents, chronic sorrow.

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**Title:** Feeling of grief and loss in parental caregivers of adults diagnosed with intellectual disability

### **Abstract**

*Background:* The diagnosis of intellectual disability in children can produce complex grief-related feelings in their parents. Previous studies have focused on the moment of the diagnosis or the early life of the children, and little research has been conducted on their feelings of grief in adulthood. The objective was to analyze the process of grief/loss in parents of adult offspring with intellectual disability.

*Method:* The intentional sampling included sixteen parents who responded to semi-structured interviews. A qualitative study was conducted based on grounded theory.

*Results:* Five categories were identified: “Reception of the diagnosis”, “Emotional bonds with the child”, “Experience of loss and feelings in response to intellectual disability diagnosis”, “Recurrent grief”, and “Coping strategies”.

*Conclusions:* Recurring feelings of loss experienced by parents in relation to their child's diagnosis persist over time. Specialized emotional interventions are needed to help parents to reduce the intensity of their feelings of grief.

*Keywords:* grief, loss, intellectual disability, qualitative, parents, chronic sorrow.

### **1. Introduction**

Intellectual disability is characterized by a significant limitation in intellectual functioning and adaptive behavior before the age of 18 years (American Association on Intellectual and Developmental Disabilities, 2010). The diagnosis considers disorders in conceptual, social, and practical domains, according to the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013). More than 1,000 million people worldwide are considered to suffer some type of disability, and it has been estimated that there are 273,418 people with intellectual disability in Spain (Institute for the Elderly and Social Services, 2017; World Health Organization, 2011).

An intellectual disability diagnosis can have a major impact on families, especially when unexpected (Bourke-Taylor, Howie, & Law, 2010; Van der Steen et al., 2016). It has been reported that parents first experience strong emotional shock, confusion, surprise, sadness, frustration, guilt, and/or resentment, even denying the reality of the diagnosis (Badu, 2016; Fernández-Alcántara et al., 2017; Kimura & Yamazaki, 2013; Oti-Boadi, 2017). This is followed by physical and psychological alterations that can produce such symptoms as muscle pain, joint stiffness, sleep disorders, and impaired psychological adjustment (Ha, Hong, Seltzer, & Greenberg, 2008) alongside high levels of stress, anxiety, and depression (Giallo et al., 2013; Huang, Chang, Chi, & Lai, 2014; Meirsschaut, Roeyers, & Warreyn, 2010). However, parents can simultaneously have positive feelings about their children that help them to redefine their life priorities (Fernández-Alcántara et al., 2015; Lee, Park, & Recchia, 2015).

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Besides these physical and emotional reactions, an intellectual disability diagnosis has been associated with feelings of grief and loss, with the ending of parents' hopes for their children and of the future they expected to share with them (Fernández-Alcántara et al., 2015; Ponte et al., 2012). The term chronic sorrow was coined to describe the experience of loss by parents whose children suffer from chronic disease (Brown, 2013; Coughlin & Sethares, 2017) and has been characterized as cyclical, progressive, recurrent, and persistent, with an intensification of these feelings at milestones in the development of their children (Bravo-Benítez, Pérez-Marfil, Román-Alegre, & Cruz-Quintana, 2019; Broberg, 2011; Krishnan, Russell, & Russell, 2017). The persistence of feelings of grief and loss can have important negative consequences for the parents of children diagnosed with intellectual disability, including typical grief responses such as denial, anger, bargaining, or depression (Corr, 2019; Kübler-Ross, 1969) and symptoms of shock, stress, concern, frustration, and impotence, even some years after the diagnosis (Gillan & Coughlan, 2010; Oliva-Zárate, Fernández-Rosario, & González-Flores, 2014). As indicated in the Dual Process Model (DPM: Stroebe, Schut, & Boerner, 2017), the ability to cope with feelings of grief depends upon the capacity of parents for oscillation between processing the meaning of loss and moving forward, especially in cases in which a high care load and stress is caused by the disability (Stroebe & Schut, 2016) and by changes in the family structure (Stroebe & Schut, 2015). In relation to the adjustment of parents to the disability, its chronic nature and the difficulty to accept the diagnosis mean that they may experience multiple crises as their children reach the different developmental milestones (Whittingham, Wee, Sanders, & Boyd, 2013).

In summary, over the past decade, researchers have described the emergence of symptoms of grief and loss in parents of children with some type of intellectual

disability or chronic disease, especially immediately after the diagnosis or during childhood and adolescence (Badu, 2016; Boström, Broberg, & Hwang, 2009; Fernández-Alcántara et al., 2015; 2017; Kimura & Yamazaki, 2013; Oti-Boadi, 2017; Ponte et al., 2012; Sheehan & Guerin, 2018). However, few studies have analyzed in depth the development of this process of grief at later stages or the experience of parents when the children are adults. For example, using a qualitative approach, Brown (2013), indicated that mothers of children diagnosed with intellectual disability remain in a process of unresolved grief when these enter early adulthood, with particular concerns about their future prospects. Budak, Küçük & Yaprak (2018) confirmed the concerns of these mothers about the future of their children but found that not all of them perceived the diagnosis in a negative manner. Both studies acknowledged their small sample sizes and the low participation of men as limitations. Therefore, the main objective of this study was to analyze in depth the process of grief and loss (including obstacles, facilitators, and coping strategies) in parental caregivers (mothers and fathers) of adult children diagnosed with intellectual disability.

## **2. Method**

### *2.1 Design*

We conducted a qualitative study based on the grounded theory of Strauss and Corbin (2002), which aims to develop a theory based on the experience systematically reported by participants.

### *2.2 Participants*

An intentional sampling (Flick, 2007) procedure was used to enroll the parents of children diagnosed with intellectual disability receiving care in an association for people with an intellectual disability diagnosis in Granada province, Spain. Study

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inclusion criteria were: having son/daughter aged  $\geq 18$  years diagnosed with intellectual disability according to DSM-5 criteria (American Psychiatric Association, 2013), being his/her main caregiver, and spending at least 3 days/week with him/her.

As exhibited in Table 1, the final sample included 16 participants: 5 fathers (31.25%) and 11 mothers (68.75%) aged between 53 and 83 years (Mean=64.43; SD=7.65). The 16 children were aged between 18 and 40 years (Mean= 32.3; SD= 6.96), 5 were diagnosed with intellectual disability from birth (until the age of 1 year) and 11 were diagnosed later (between ages of 1 and 13 years). The mean age at diagnosis was 4.37 years (SD= 4.16). All of them lived with their parents except for 4 children who lived in a residence part-time (spending 3-4 days/week at home). According to the International Classification of Functioning, Disability and Health of the World Health Organization (2001), the degree of severity of the disability of the children ranged between 33 % and 99 % (Mean=61.5, SD=23.10). The diagnosis was always performed by physicians.

Participants were cyclically recruited; therefore, the 16 interviews were being performed at the same time as data were being analyzed. A constant comparison strategy was used, and the data gathering ended when theoretical saturation was reached in the main codes and categories (Flick, 2007).

-----Insert Table 1 here-----

### *2.3 Procedure*

We first held a meeting with the association from which the participants were recruited to describe our proposed study and explain its objectives. Next, parents known by the association to meet the inclusion criteria were invited to meet with the research team for a presentation of the characteristics and objectives of the study, and their

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collaboration was sought. Those who voluntarily accepted participation received a document with information on the study and signed their written informed consent. Participants received no remuneration for participation. Each participant was assigned an alphanumeric code to preserve their anonymity, and the names of people and places were not transcribed to guarantee data confidentiality. All information was treated anonymously. The study was approved by the Human Research Ethics Committee of the local University (Ref: 445/CEIH/ 2017).

Data were gathered in individual semi-structured interviews with a researcher previously trained in qualitative techniques and analyses, who had no previous relationship with the association or contact with the participants. As shown in Table 2, open questions were used to gather information on: the progress of the children; the relationship/bond established with them; the different emotions experienced, both at the time of the diagnosis and currently; the strategies adopted in response to the diagnosis; and the problems or obstacles faced. Interviews were conducted in the association center between July 2017 and January 2018. Their duration ranged from 45 to 90 minutes. All interviews were recorded for subsequent transcription. f4software (Audiotranskription, 2019) was used to digitally record and textually transcribe these recordings.

-----Insert Table 2 here-----

### *2.4 Data analysis*

Analyses were based on constant comparison using three main strategies, as proposed by Strauss and Corbin (2002). First, fragments of the parents' discourse were encoded using an inductive approach (open coding), and the codes that emerged were delimited and defined by consensus among three experts (MIFA, MFA and MNPM) in

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a qualitative analysis. Second, categories were established by grouping codes according to their characteristics, identifying five main categories and organizing the most complex codes into subcategories (axial coding) as shown in Table 3. Integration of these categories produced a central category and the most important subcategories for developing a theoretical framework to explain the phenomenon (selective coding), as depicted in Figure 1. The interviews were analyzed in Spanish and subsequently selected for translation into English, which was revised by the main researchers. Triangulation between researchers was used to maintain the rigor and trustworthiness of the findings. Atlas.ti version 7.5.4 (Scientific Software Development, 2019) was used for data analyses.

-----Insert Table 3 here-----

### **3. Results**

#### *3.1 Reception of the Diagnosis*

Most parents identified childhood as the most challenging period, given the initial medical complications. They detected delays in the development of their children's gait (e.g., poor balance) and of their speech, also reporting their blank stare. The process involved in obtaining the diagnosis of their children (diagnostic journey) was also difficult and distressing, involving multiple medical tests, mis-diagnoses, and numerous interventions until the diagnosis of intellectual disability was confirmed.

*“At the medical check-up they told us that she was very still, that we should stimulate her. The girl didn't crawl, she didn't look at us when we talked to her, sometimes she did, other times she didn't, she didn't laugh, and therefore we started to do tests. We did everything we were told... They did a CT and they told us she had a little lesion...that she was a borderline child they told us...”(I02 Mother)*

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Half of the parents described adolescence as a period of greater aggressiveness and irritability, not uncommon among adolescents in general, with the onset of depressive symptoms. The current adult stage of their offspring was characterized by impaired physical and psychological health.

*“From adolescence he tries to kick me if he’s lying on the sofa, and he insults me, and calls me everything, everything, it’s just that it’s like you get used to it” (I16 Mother)*

### *3.2 Emotional bonds with the child*

Their current relationship with their children was based on fondness and affection, and virtually all of their time was devoted to their care. Some parents described “speaking for them”, deducing what they wanted in certain situations and when they might be in some discomfort or pain. Almost all of the parents treated them as if they were children, overprotecting them to avoid any harm or suffering. They considered themselves to be the only ones responsible for their offspring, rejecting help offered by professionals or even by their own family members. Some parents described their increased sorrow during times when their offspring showed awareness of their disability, when they felt the need to protect them even more.

*“We have nothing else apart from her, we have to love her, there’s no choice [...]. It’s just like we always say at home, that we don’t know if it’s a tragedy or a blessing, because what we’re enjoying with my daughter, nobody knows” (I01 Mother)*

*“Our close friends have mentioned our overprotection of our child more than our own family, because we’ve never wanted to leave him with anyone, we’ve wanted to be too much with him as parents...but they were all ready to help” (I11 Father)*

### *3.3 Experience and feelings of loss in response to the intellectual disability diagnosis*

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For the majority of parents, knowledge of the intellectual disability diagnosis produced shock, sorrow, and a feeling of the loss of their ideal child and life project, among other emotional reactions.

*“Loss of everything, loss of the child, loss of the relationship, everything... So many things came to mind... It was a huge blow to us...” (I03 Father)*

*“When she suffered encephalitis, we lost everything. It was as if she had died... My world had ended. I am in the world because I have to be...” (I01 Mother)*

*“It was like a big storm cloud... I wanted to die with him, I really did. I was very frightened, I didn't know what was going to happen, I didn't know anything” (I12 Mother)*

Another emotional reaction described by more than half of the parents was denial, a belief that the diagnosis was wrong or not so serious and that their child was going to be fine. Denial was also demonstrated by hiding the diagnosis from their family and social circles.

*“It was like I didn't expect it... I thought at the time that the physician was wrong. How was he going to know so soon that my son was not well” (I04 Mother)*

*“How can you explain to another person that my son has a disability? I think that was and is the biggest problem. For me it's a problem to tell someone that my son has a disability, because in appearance you don't notice that he has a disability...maybe I would still feel unable to talk about it. It's like that's it, you don't have to publish it [...]” (I09 Father).*

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All parents also emphasized a continuous search for meaning in attempts to find out why it happened and in the search for solutions. Loss-related emotions varied in intensity according to the stage of life of their offspring.

*“It’s that you can’t get over it... because we see my nieces and nephews, we see anyone and we think, why did it happen to us?” (I10 Mother)*

Emotions at the time of diagnosis included sadness (associated with the perceived suffering of their child), fear (related to uncertainty about what would happen to their child in the future), and anger (mainly aimed at healthcare professionals for their perceived failure to take appropriate action).

*“Sad, very sad because, why deny it? I still cry to myself many times, I bear the sadness and I always will” (I05 Mother)*

*“I must say that I looked at the cot and I don’t know what I wanted to find... I was afraid to face what I had in front of me, I didn’t know if I was going to love him, I didn’t know how I was going to react...” (I12 Mother)*

*“What did I think? I’ve been very angry, very, very angry. Well yes... against the system and against I don’t know... I don’t know what to say... It’s that we’re very tired, you talk about it everywhere and it’s no use, maybe, you know what it’s useful for? For people to be sorry for you. You see a lot of discrimination, people discriminated everywhere, many people have talked to me with a tremendous lack of respect, I mean treating me very badly” (I15 Mother)*

### 3.4 Recurrent grief

As shown in Table 4, grief-related feelings and emotions appear to reactivate at different times with a similar intensity to that experienced at the beginning. Almost all

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of the participants found that reaching a degree of acceptance of the diagnosis involved a long arduous journey that was not free of difficulties.

Obstacles to accepting the diagnosis include making comparisons of their children with children without intellectual disability or with a lesser disability and comparisons of themselves with other parents. Half of the mothers reported feeling stuck in the past, with recurrent thoughts and emotions that took them back to the diagnosis. There were also references to guilt, a feeling that they could have done something to avoid their child's intellectual disability. In addition, all parents describe a reactivation of grief associated with development milestones, triggering sadness and frustration.

The concerns of parents centered on their children's future. They first emphasized that they wanted their children to be as happy as possible now and in the future. They were also uncertain and concerned about what would happen to their offspring when they died and who would then be responsible for their care; 60% of parents reported that they would ideally prefer not to die before their offspring with intellectual disability because it would leave them unprotected and would cause them suffering.

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### *3.5 Coping strategies to face loss and grief*

The parents described various coping strategies, many facilitating the integration of feelings of loss but others hampering this process.

With respect to facilitating strategies, we highlight the request for assistance and support from healthcare and education professionals to cover the special needs of their

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child, and the constant struggle and determination of the parents to improve the health of their children.

*[...] I took her and they started to do tests and they told me everything was fine... and like that until once, one year after the check-up they told me that the maturity process had stagnated and that she had a problem... Then, from when she was little we went to the psychologist, to the center for the disabled that they sent me to, to see about therapies and things... Later, we began to go to the physiotherapist and to the speech therapist". (I06 Mother)*

*"We go every year so the heart specialist sees him and also to another respiratory doctor. We have always gone to his check-ups since he was born" (I04 Mother)*

Parents also indicated that pleasurable activities with the children helped them disconnect and carry on, although some parents commented that their children always participated in their leisure time and that they did nothing without them.

*"Since not going to work, and as she goes to the association, I go in the morning to the civic center, I do Pilates, and another day I go to the memory workshop, because I talk to other people and in order to change my routine a bit." (I05 Mother)*

Family and/or social support was described by half of the parents as essential for facing the difficulties that followed by the diagnosis. However, the other half was not satisfied with the help and emotional support received from their social environment and even experienced some estrangement with people who did not empathize enough with them and whom they thought did not understand their situation.

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*“In my family we’ve been lucky, very lucky, because despite the time when he was born and the difficulty he had, I had a very big support in my life, which was my mother.”* (I12 Mother)

Despite these multiple obstacles, almost all parents reported that their children offered positive elements in their lives, making them more active and loving.

*“Now I think that having a child with problems is the best thing God has given me. The best thing God has given me. But really, very unlike forty thousand children I might have had”* (I14 Mother)

Finally, a minority of parents talked about a change in their perspective, seeing that the intellectual disability was something that had happened to them and was part of life, arguing that parents with children without intellectual disability can face other types of problem, and it does not mean their lives are better.

*“I have that problem, and those who have children with no disability will have other problems: that they come back drunk, that they start smoking, that they go out on a motorbike ...”* (I09 Father)

The grieving process can be hampered by self-criticism and problem avoidance. Several parents reported feeling guilty and constantly criticizing themselves for not having acted at some key moment in the past, thinking that this would have changed the reality of their child.

*“I should have hired someone to help her, no? I should have paid a girl to keep her company, because if we go to the beach, with us two she gets bored, I understand, she would like to have friends. I blame myself”.* (I07 Mother)

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*“The future... sometimes I don’t even like to think...because I don’t know... he doesn’t like to make many efforts, you know? not psychological or anything, then you ask him, what would you like to work as? He answers “me, with cellphones”, he always says the same thing, “me, in a cellphone store” And that’s my concern, that when we’re not here, what will happen to him...?” (I08 Mother)*

### *3.6 Differences as a function of the time of diagnosis and the intellectual disability severity*

Although all parents reported a feeling of shock after diagnosis, it appeared to be more intense in those who knew immediately after the birth in comparison to those who received the news at a later stage and may have anticipated that something was wrong with their child.

*“At the time I couldn’t understand. I remember that in the morning the day after labor the doctor and the pediatrician came to see us and it was very cold in the room, I don’t know what the cold of death is like, but I felt cold, and one thing, I don’t know if it was because I was waking up from the anesthesia but I felt cold in my soul because of the diagnosis.”(I12 Mother-Diagnosis at Birth)*

*At the time of diagnosis, I was sad to say my God... he could be a normal boy, no?, but we didn’t suffer it too much because we had seen him, we noticed, we didn’t need any doctor to tell us anything...” (I08 Mother-Post-Birth Diagnosis).*

Most parents indicated that they had partially accepted the diagnosis and the feeling of loss. This process was easier when the child had milder intellectual disability, who they thought had a greater chance of independence and progress in the future.

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*“Now she has a part-time job in the laundry. She comes back very content, and she’s happy. Before leaving, she prepares her breakfast, makes her bed, tidies her room, everything. I think she can continue living and be happy [...]. Now I’m less worried about her future...”* (I-14 Mother of a Daughter with Mild Intellectual Disability).

*“We’ve seen that his development within the disabilities produced by his two syndromes, well it’s limiting... I’m worried about his future, about what the world is like, and he’s still vulnerable. [...] He doesn’t have the same defenses as others, he can’t defend himself or act for himself...”* (I-12 Mother of Son with Severe Intellectual Disability).

### 3.7 Generated theory

Knowledge of the diagnosis at the time of birth or after warning signs was directly associated with an experience of loss of the ideal child, triggering a series of emotions and cognitions, including sadness, sorrow, fear, anger, guilt, shock or trauma, denial, and a search for meaning. The resolution of this grieving process is constantly affected and influenced by the emotional obstacles that the parents face, by their relationship with their child, and also by their utilization of coping strategies, as depicted in Figure 1.

-----Insert Figure 1 here-----

## 4. Discussion

The objective of this study was to analyze in depth the processes of grief and loss in parental caregivers of adult children diagnosed with intellectual disability, including obstacles, facilitators, and coping strategies. The results identified the central

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category of recurrent loss and its characteristics: emotions, coping approaches, barriers, and facilitators, alongside the influence of the relationship established with their child.

Previous investigations confirmed the experience of symbolic loss of the ideal child suffered by parents of children with intellectual disability in response to the unexpected crisis produced by the diagnosis (Brown, 2013; Fernández-Alcántara et al., 2015). According to the present results, the participants described shock as their main reaction at the time of diagnosis, in agreement with previous studies (Brostöm & Broberg, 2014; Fernández-Alcántara et al., 2016). This shock results from their inability to assimilate such painful news, with feelings that their life has been devastated and sometimes even wishing to die. In the present study, shock was more intense in parents who received the diagnosis of their children soon after their birth. The surprising and unpredicted nature of the news triggered emotions that were difficult to manage, due to the loss of the ideal child they had imagined (Fernández-Alcántara et al., 2015). The surprise was lesser for parents who were informed of the diagnosis years later, because they had already suspected that all was not well with their child, diminishing the emotional impact of the news (Fernández-Alcántara et al., 2016). For its part, denial takes the form of believing the diagnosis to be wrong or less severe than stated (O'Halloran, Sweeney, & Doody, 2013) or trusting in an impossible cure (Aldersey, 2012), and it can be understood as a protective response. Finally, these parents also ask existential questions and search for meaning, a reason for what has happened, and solutions to help relieve their sorrow (Budak et al., 2018). Professionals should be aware of the need to communicate the diagnosis in an appropriate manner and to provide emotional support to parents in order to reduce the intensity of their psychological anxiety (Alsem et al., 2017; Bray, Carter, Sanders, Blake, & Keegan, 2017; Ponte et al., 2012).

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The most frequent emotions in reaction to the diagnosis are guilt, sadness, fear, and anger. Guilt derives from the thoughts of some parents that they were in some way responsible for their child's disorder (Findler, Jacoby, & Gabis, 2016; Malhotra, Khan, & Bhatia, 2012). Sadness and fear are related to sorrow about the diagnosis and uncertainties about the future and how the children will see themselves. They are sad not only about their own situation but about how their children will suffer if they become aware of their disability (Fernández-Alcántara et al., 2015; Hallberg, Óskarsdóttir, & Klingberg, 2010; Kilic, Gencdogan, Bag, & Arican, 2013). It has previously been reported that anger can be directed at professionals when the parents do not feel adequately supported, including emotional care (Huang, Kellett, & St-John, 2012; Thwala, Ntinda, & Hlanze, 2015). In this context, interventions based on mindfulness and self-acceptance can contribute to improving the emotional wellbeing of these parents (Blackledge & Hayes, 2006; Masulani-Mwalea, Mathanga, Kauye, & Gladstone, 2018).

The present findings identify major difficulties and obstacles that hamper the grieving process and adaptation to the new situation from the moment of the diagnosis (Mitchell & Holdt, 2014). The sorrow of the parents becomes chronic and persists during the adulthood of the children, characterized by a wide range of reactions that have been described in classic models of grief (Kübler-Ross, 1969). The persistence of grief-related reactions are in line with the Chronic Sorrow Model (Coughlin & Sethares, 2017) and the Dual Process Model (Stroebe et al., 2017), with the observation of chronic feelings of sorrow after the diagnosis of other types of disability, such as autism (Fernández-Alcántara et al., 2016), cerebral palsy (Fernández-Alcántara et al., 2015), and sickle cell disease (Olwit, Mugaba, Osingada, & Nabirye, 2018). Various explanations have been proposed for this chronic grief.

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Parents constantly compare their children with intellectually “normal” children, idealizing what their life might be without the child’s intellectual disability, and they blame others and themselves for the situation, hindering their adaptation to an acceptance of the reality of their children. In particular, feelings of grief are reactivated when the children do not reach the expected objectives at different developmental stages, generating a cyclic process from which it is difficult to escape (Lee et al., 2015). These findings suggest that parents progressively come to terms with the diagnosis of intellectual disability and loss-related emotions in a progressive manner and at different time points.

The grieving process can be impaired by the stress and overload involved in caring for the children (Bravo-Benítez et al., 2019; Stroebe & Schut, 2016). The parents feel responsible for the state of mind of their children, and desire for their happiness leads them to make great efforts, trying everything they can. A generally overprotective approach to their children means that they spent virtually all of their time with them at the expense of other life activities; hence, the parent becomes exclusively a caregiver (Meirsschaut et al., 2010; Piquart, 2013), which may affect their physical, psychological, and social wellbeing (Ha et al., 2008; Hernández, Calixto, & Aguilar, 2012). These challenges are more intense when the child’s disability is more severe, as observed in other populations (Fernández-Alcántara et al., 2016). Trepidation and fears about the future of their children can be so extreme that parents avoid thinking about it and do not address the problem or search for solutions. This type of non-active coping has been related to the non-adaptation of parents (Carona, Silva, Crespo, & Canavarro, 2014).

However, the discourse of parents revealed evidence of adaptive coping strategies involving the search for solutions and support from relevant professionals and

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constantly striving on behalf of their child (Oñate & Calvete, 2017; Santos & Pereira-Martins, 2016). These types of strategy, alongside physical and emotional self-care, contribute to the well-being of the caregivers and can diminish their overload (Kim, Greenberg, Seltzer, & Krauss, 2003; Oñate & Calvete, 2017; Piazza, Floyd, Mailick, & Greenberg, 2014). This is essential for these parents, who emphasized their need for more time for leisure activities and personal enjoyment, i.e., self-care, which had not been possible since the diagnosis due to the care demands of their children, as previously reported (Kuhaneck, Burroughs, Wright, Lemanczyk, & Rowntree, 2010).

Participants also stressed the importance of support from professionals and from their close family and social environment. The receipt of formal and/or informal support, offering the feeling of being listened to and understood, has been found to reduce stress levels and increase the wellbeing and satisfaction of the parents of children diagnosed with intellectual disability (Chadwick et al., 2013; Ekas, Lickenbrock, & Whitman, 2010; Perera & Standen, 2014). However, although needing the assistance of their environment, some reported dissatisfaction with the support received by their loved ones, even a feeling of being abandoned (Dyson, 2010; Meirsschaut et al., 2010). A failure to present the intellectual disability diagnosis directly in a process of grieving and loss can also hamper their receipt of adequate support to face their complex emotions.

Theory generated in the present study identified aspects that helped parents to overcome their grief feelings as well as aspects that hindered their process of loss. Theoretical models such as the Dual Process Model describe the process of grief as oscillating between loss and restoration-oriented coping. In a previous application of this model to parents of children diagnosed with intellectual disability, Sheehan and Guerin (2018) identified more loss-related coping in parents during the first years after

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the diagnosis, including feelings of deep sadness and wishful thinking. In addition, there was a shift toward restoration-oriented coping when parents begin to envision a future with their child and reflect about what they have learnt.

Finally, despite these obstacles, virtually all participants reported that their children provided positive elements in their lives. In line with previous studies, many of them affirmed that no-one can bring them the love they receive every day from their children, that the pleasure of being with them cannot be compared to anything else, that their priorities have changed, and that they have even been helped to become more active and stronger (Beighton & Wills, 2017; 2019), which may have acted as a protective factor (Oñate & Calvete, 2017).

This study has strengths and limitations. One of the main strengths is that it is one of the first studies to analyze in depth processes of grieving and loss in the parents of adult offspring with intellectual disability. We developed a theoretical model based on their subjective experiences, indicating behaviors that hinder or facilitate resolution of the grief process from the intellectual disability diagnosis to the present time and identifying obstacles. Data were gathered in semi-structured interviews, and triangulation was conducted among experts to establish categories and subcategories and to select verbatim quotations, to improve the rigour of the study. Finally, further research is warranted to develop and implement intervention programs to support these parents in their grief process and to prepare them for the future. Study weaknesses include its single-center design, limiting the extrapolation of results. The study was also limited to the experience of the parents, and the experience of siblings of the children would also have been of interest. It is also necessary to compare the overload and feelings of grief/loss observed here with those of caregivers who are not dedicated full-time to the care of their children. There is also a need for quantitative studies in order to

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explore the association of grief manifestations and symptoms with different psychopathologies.

### **5. Conclusions**

In conclusion, the parental caregivers in this study experienced recurrent feelings of loss in relation to the intellectual disability diagnosis of their child. Emotions of sadness, sorrow, guilt, and fear persisted over time, and their intensity varied at different stages of the child's life. The grief process of parents begins with the crisis created by the diagnosis and is not completely resolved because of difficulties in managing the obstacles that appear. Many parents referred to adaptive and facilitating responses that can help to complete this process. The intervention of healthcare professionals, as well as informal support, is needed to provide these parents with emotional support and guidance.

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**Table 1.** Sociodemographic characteristics of the sample

Parents	Sex	Age	Kinship	Educational level	Occupation	Marital status	Offspring Sex-Age	Timing of diagnosis	Degree of ID	Comorbidity	Residence
I 01	F	71	Mother	Primary	Homemaker	Married	F-39	Post-Birth (2 years)	86%	Monoplegia	Family
I 02	F	59	Mother	Primary	Homemaker	Married	F-27	Post-Birth (2 years)	84%	Autism	Residence
I 03	M	69	Father	Primary	Retired	Married	M-37	Birth (3 months)	99%	Blindness	Family
I 04	F	83	Mother	Primary	Homemaker	Married	M-40	At the Birth	79%	None	Residence
I 05	F	71	Mother	Primary	Homemaker	Widow	F-31	Post-Birth (3 years)	65%	None	Family
I 06	F	63	Mother	Primary	Homemaker	Married	F-36	Post-Birth (10 years)	70%	None	Family
I 07	F	66	Mother	Primary	Retired	Married	F-32	Post-Birth (10 years)	75%	None	Family
I 08	F	54	Mother	University	Homemaker	Married	M-18	Post-Birth (4 years)	48%	None	Family
I 09	M	53	Father	Secondary	Unemployed	Married	M-18	Post-Birth (5 years)	48%	None	Family
I 10	F	56	Mother	Primary	Employed	Married	M-31	Post-Birth (1 month)	75%	Monoplegia	Family
I 11	M	67	Father	Secondary	Retired	Married	M-39	At the Birth	98%	Tetraplegia	Residence
I 12	F	62	Mother	University	Homemaker	Married	M-39	At the Birth	98%	Paraplegia	Residence
I 13	M	72	Father	Secondary	Retired	Married	F-39	Post-Birth (3 years)	86%	Hyperactivity	Family
I 14	F	65	Mother	Secondary	Freelance	Married	F-36	Post-Birth (2 years)	33%	None	Family
I 15	M	64	Father	University	Retired	Married	M-27	Post-Birth (13 years)	75%	None	Family
I 16	F	56	Mother	University	Unemployed	Married	M-28	Post-Birth (11 years)	36%	None	Family

Note. M=Male, F= Female

**Table 2.** Semi-structured interview schedule

Themes	Questions
Development of child	Can you describe to me the development of your son/daughter during the different stages of his/her life (childhood, adolescence, maturity)? What types of treatment has he/she received?
Relationship with child	What relationship did you have with him/her during his/her childhood and adolescence? What relationship do you currently have with him/her? Has anything changed?
Timing of the diagnosis	When did you or another family member notice that something was not going well with the development of your child? In what way? What did you observe? At what age of your child? How did you feel at that time? What did you do? Who did you ask for help? Who communicated your child's diagnosis to you? How old was he/she at the diagnosis? How did you feel on hearing the diagnosis? What thoughts did you have to try and understand the diagnosis? What did you do about it?
Emotional aspects	As time passed after the diagnosis and you were assimilating this situation, what types of feelings and emotions did you have? How do you feel emotionally now?
Difficulties in upbringing	In what part of the upbringing of your child did you meet the greatest difficulties/problems/obstacles? In what way? What types of strategy have you used to resolve your problems?

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**Table 3** Main categories and subcategories after analysis

Reception of diagnosis	Emotional bonds with the child	Experience and feelings of loss in response to intellectual disability diagnosis	Recurrent grief	Coping strategies to face loss and grief
Obtaining of diagnosis	Current affection-based relationship	Loss of the ideal child	Process of diagnosis acceptance	Search for solutions
Warning signs	Devoted in body and soul	Shock	Comparison to others	Struggle and determination
Diagnostic journey	Speaking for him/her	Denial	Guilt	Performing pleasurable activities
Development during adolescence	Overprotection	Search for meaning	Re-experiencing the past	Family and social support
Health problems		Sadness	Developmental Milestones	Perspective-taking
		Anger	Concerns for the future of their offspring	Self-criticism
		Fear		Problem avoidance
				Positive aspects

**Table 4.** Quotations associated with the category “Recurrent grief”

Codes	Quotations
Process of diagnosis acceptance	<i>“You never completely accept it. It’s there, you have your sadness...The sadness that he could have been normal. What can I do? It’s not the way it is. Well, resignation, resignation.....and it’s painful. I feel pain and sadness... I didn’t expect him to be much, I mean, I expected something normal, but he’s like this, well you see, it’s distressing.” (I09 Father)</i>
Comparison with others	<i>“A good period, of happiness, we’ve had none... We really haven’t. I have 6 or 7 colleagues who have a different life from ours. We made comparisons, and they went in and out of their houses, something that we couldn’t do, and that was affecting us, hurting us ... Comparing with others gradually consumes you, you get consumed little by little” (I03 Father)</i>
Guilt	<i>“I got no care (from doctors) at all. I feel like guilty for not having done more and maybe things would have gone better. I trusted the doctors that saw me... I miss that. Because I feel that if I’d gone ahead of the doctors I would have helped my daughter more ...” (I06 Mother)</i>
Reactivation of grief (Developmental Milestones)	<i>“If I saw the girl... that she hadn’t studied because she didn’t want to, well she would’ve been a worker or would’ve been ... I don’t know... because if I saw her as I see you, like thousands of girls ... well what a satisfaction, no? well I would have that satisfaction, no? I have the other one, I have a great big sadness...” (I05 Mother)</i> <i>“I think that parents who have a child like this, it’s also an end to expectations, because I’d like him to be a normal boy, to do ... I don’t know, not a degree, but that he studied or something ... We all think that way ...just yesterday we were talking about that: “when you’re 18 you’ll work in a fruit plantation of the neighbor, you’ll go to work”... but I don’t know ... we can’t do anything ...” (I08 Mother).</i>
Concerns for the future of their parent	<i>“Yes, I think about it (child dying first) so I could die more peacefully. When I had panic attacks, my heart raced and I thought that I was going to die and leave him alive, It was one of my worst moments, and I thought about us taking poison and both dying. (I16 Mother)</i> <i>“What will happen to her? She has her brothers and they love her. But of course, they each have their lives, their homes, their children ... And I tell you, I think about a residence... I save the little money I have for the girl. That’s why, in the future, in case she needs it for a residence” (I13 Father)</i>

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Figure 1. Generated theory

