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The Duty of Love: Kinship and Identity in the Face of Disability in Madrid

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ABSTRACT

Life with a disability in Spain implies a constant struggle not just for the person with disabilities but also for their family, who must mobilise enough care resources to compensate for the lack of social support they receive. This paper focuses on the ways in which having a family member with a cognitive disability shapes kinship relations, and how the impact related to having a family member with a disability shapes the construction of the family unit as well as the identity of the able-bodied family members. I argue that the narrative of "unconditional love" within the family unit is what enables many families to naturalise the extra work involved in caring for a person with disabilities as part of what it means to be a family – and not as a chore. Care becomes the idiom of their love as it acts as a relational activity through which personhood is created. By humanising the child with disabilities in this way, care is accepted as a "natural" part of their kinship relations.

Keywords: kinship; disability; care; moral values

Life with a disability in Spain, despite its recognition as one of the most inclusive European countries by the International Disability Rights Monitor (IDRM 2017, i), still carries troublesome implications not just for the person with disabilities themselves but also for their family. While Spain has ratified practically all international protections available to safeguard people with disabilities (IDRM 2007, 444), the dissimilarities between regional governments, the aggressive and long-lasting effects of the economic crisis that overwhelmed Spain during the last decade (CERMI 2017, 9), and the difficulties involved in accessing bureaucratised social aid in Western states (Rapp and Ginsburg 2001) have created a situation where, beyond mere legislation, the responsibility of assuring the welfare of people with disabilities falls onto the family unit. This mostly encompasses the mothers, fathers, and siblings of children with disabilities. The Spanish family, despite its changing nature during the past few decades towards smaller and more diverse models (Fundación Adecco 2019, 8), has maintained its role as the main place where social and moral values are shaped and shared. Familial relations, when faced with disability, face particularly difficult demands since the great majority of them do not receive enough state support to normalise their life.

Having to rely on their own efforts to ensure the care of their relatives with disabilities, families often experience emotional, social, professional and economic challenges (Fundación Adecco 2019, 8-9). Having a family member with a disability not only reduces the family's standard of living but contributes to feelings of despair and failure. In this sense, the families of children with disabilities constitute a unique social group with their own distinctive problems, needs, and experiences. These come from having to carry what I, following my informants, term the "extra weight" of disability. The situation of these families has been overlooked in favour of an isolating focus on the person with disabilities themselves, not just in academic literature but also in the legislation itself, where there is a notorious lack of consideration for the families of children with disabilities (Alvarez Ramirez 2015, 11).

This paper focuses on how cognitive disability (McKearney and Zoanni 2018, 6) can affect family relations, and how the impact related to having a family member who has disabilities shapes the construction of the family unit as well as the identities of the individual able-bodied family members. Commonly referred to as "special families" (*familias especiales*) in Spain, it is common to hear the families of people with disabilities and their friends say that disability deeply transforms the lives of all touched by it, making them "better" people (*mejores personas*). I began my fieldwork curious to see how disability transforms kinship relations in practice.

My fieldwork took place during July and August of 2020 in a predominantly middle-class area in Western Madrid, Spain, amid the Covid-19 pandemic. Having grown up in Madrid, I was able to get in touch with six different families by asking friends and teachers if they knew anyone who had a relative with a disability. The four families I selected had the "typical" family structure in the area: heterosexual parents with at least two children and white-collar jobs. However, the fact that they also have a child with a disability differentiates them. An exploration of these families offers a comparative perspective among people from the same social stratus. I demonstrate that, despite not having identical lives, they ended up having very similar experiences due to one of their children having a disability. I introduce the families during the text according to the topics covered in interviews to compare the ways they encountered a shared set of challenges.

To respect their wishes for anonymity, I changed my informants' names and limited the number of details provided about their lives outside of their kinship relationships. I did not conduct interviews with people with disabilities or minors due to their inability to obtain informed consent. While I was only able to interview the family members online at first, the alleviation of the Covid-19 measures by the middle of the summer meant that I was able to meet two of the families in person and carry out participant observation within the family home on those occasions.

The Álvarez family (Figure 1) is comprised of Diana and Daniel, the parents, and five children. I mainly talk about Dada, who has a cognitive disability, and Lorena, the eldest sister. The Benito family (Figure 2) consists of the mother and widow Laura and her children: Lucía and her twin Adri, who has disabilities. The Cortés family (Figure 3) is made up of Alicia and her husband, and their three daughters: Greta, who has disabilities, a middle sister, and Alejandra. The Diaz's (Figure 4) parents are divorced. I was able to meet the father, Alonso, whose eldest daughter, Sol, has disabilities. Their youngest daughter is a minor.

I had not anticipated the deep transformation that disability provoked in the families, going beyond just their kinship relations to encompass the whole of their identity, both as a family and as individuals. The term "unconditional love" has been used by Landsman (1999) to describe how families relate to their children with disabilities. I was surprised to find my informants using the equivalent phrase in Spanish (*amor incondicional*) to refer to the devotion they experience for their relative with disabilities. I make understanding this idea of "unconditional love" for one's family central to the paper. I argue that its importance within the family unit is that it enables the families to naturalise the extra weight of disability care as part of what it means to be a family—and not as a chore.

Dealing with grief

Greta's mother, Alicia Diaz, told me that before her daughter was born, she wrote a poem for her. The first verse said "*Te tenemos preparada una cuna de paja y un mundo major*" (we have a straw cot and a better world ready for you). Greta's complicated birth was initially thought to have caused her disability, but it was later discovered to be genetic. Her mother remembers giving birth as the moment where both her and her daughter were irreparably "broken," and so the better world that she had wanted for her daughter did not have a place for "someone like her." Instead, only the warm cot that was her loving family was waiting for her. Her cognitive disability not only destroyed all the dreams and hopes that Greta's family had for her, but it also tied Greta to them in an unusual way, as she became an obligation that no one had expected. Greta's mother recalls how accepting her family's new situation was a long process.

In this section I will explore how parents narrated to me their initial reaction when they found out their child had a cognitive disability, which I understand to be marked by grief. This grief, I will argue, originates from a sense of failure to comply to normative models of the family and from the fear linked to the lifelong difficulty of caring for a child with special needs. Parents often exchange their normative ideals of parenthood for their own unique model of what successful parenting means when you have a child with disabilities. For my informants, this means maintaining the happiness and wellbeing of their child despite their disability.

Rapp and Ginsburg's (2001, 537) account of parents whose children have a cognitive disability in the United States highlights the lack

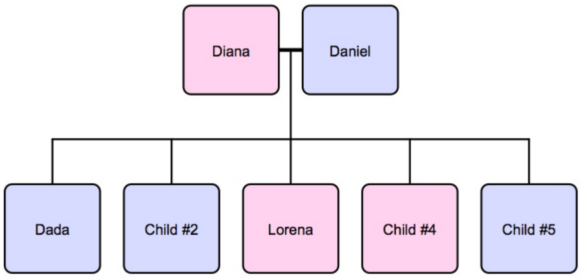
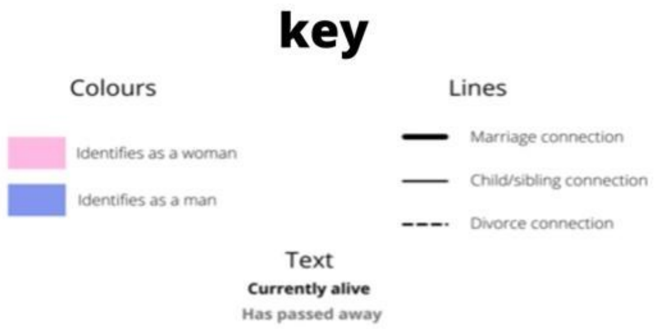


Figure 1: Alvarez Family Tree



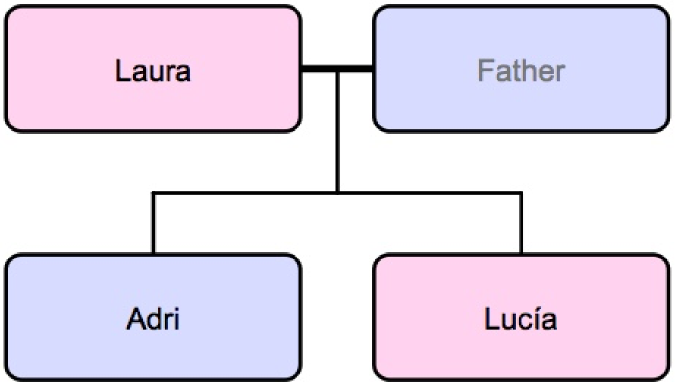


Figure 2: Benito Family Tree

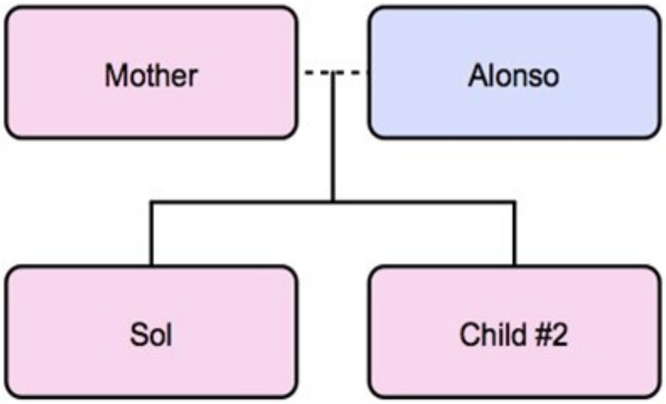


Figure 3: Cortes Family Tree

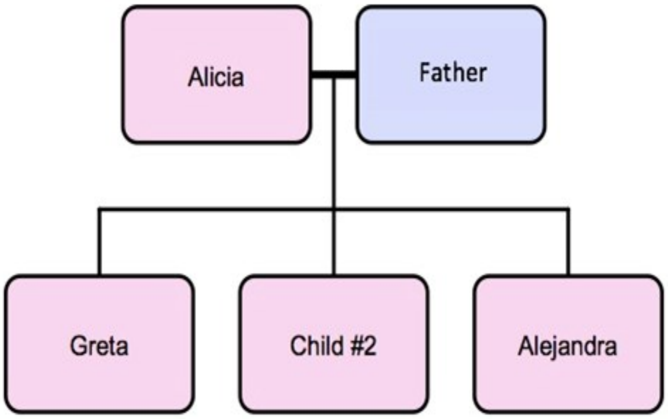


Figure 4: Diaz Family Tree

of attention that people with disabilities receive from the state. The care of people with disabilities, they argue, falls onto their families in a disproportioned manner when compared to able-bodied children. The difficulties involved in mobilising not just medical (Mattingly 2010, 55), therapeutic and social support, but also constant supervision and care for a child with disabilities is feared by most families, since it is identified as an added obligation that overwhelms many families financially and psychologically. A cognitive disability diagnosis, I argue, carries with it the destruction of all the expectations that the family had for their new child and marks them as an unwanted responsibility. Furthermore, the stigmatisation of dependent persons in liberal societies who place a high value on independent and self-reliant individuals (Kittay 2019, 147; McKearney 2020, 2), means that families must come to terms with the lifelong lack of social recognition endured by their relatives with disabilities (Taylor 2010, 42).

Alicia: Replacing grief with the success of a strong support network

Alicia explained in our first meeting that Greta's diagnosis "broke" her. In Spanish, it is usual to define traumatic experiences as capable of "breaking" (*romper*) a person, in the sense that their emotional wellbeing is severely damaged, like a "broken heart" that encompasses the whole of one's life. For many years, she blamed her own inexperience as a mother and her choice to give birth abroad for her daughter's disability. Alicia's narrative of Greta's first few years was marked by her deep sense of failure to produce a child "like everyone else's." She linked that grief to her difficulty to find pride and satisfaction in a child that developed atypically. Despite loving her fiercely, she admits that her daughter's disability created a feeling of rejection for her daughter that manifested as a parental breakdown. However, she slowly started to learn to "live with it" by finding pride in Greta's slow development, seeing her daughter's undying happiness as proof of her hard work as a mother. Alicia told me that knowing she had been able to secure a dignified life for her daughter, through what she sees as long-lasting safety, protection, and happiness, gives her an immense sense of victory.

Alicia's initial feeling of defeat is linked to a social failure to fully include people with disabilities into a community (Rapp and Ginsburg 2001, 541), which is evidenced in the difficulties families go through to assure their children have access to the resources needed to guarantee their ability to live an autonomous life beyond the care of their parents. Alicia expressed feeling guilty for bringing a child into a world "not made for her."

I met Alicia's youngest daughter, Alejandra, who told me she used to compare herself to a "test-tube baby" that is born to save her sibling from a genetic illness. However, on this occasion, she was meant to save Greta from the social abandonment that surrounds people with disabilities whose families are not able to care for them. Both Biehl (2005) and Taylor (2010, 36) have described how institutionalisation can not only entail social isolation, but also "social death." Alicia and Alejandra feared this fate for Greta. They both regularly volunteer at a shelter for disabled elderly women, and they fear that Greta could end up alone and defenceless in a shelter due to her inability to express and defend herself. Alejandra refuses to "abandon" Greta in a place she doesn't know, so she has planned her future around her eldest sister.

Once Alicia felt confident in Alejandra's guarantees to care and support Greta after her parents die, she was able to come to terms with the fact that her daughter's life is not "tragic, just a bit harder." Being able to keep Greta in an environment where she is comfortable and loved has been Alicia's main goal since her daughter was born. Succeeding despite the added difficulty makes her feel accomplished in her role as a mother.

Diana and Alonso: Overcoming physical illness and turning grief into hope

The sense of success at seeing one's child develop happily in a safe environment is shared by the parents of two of my informant families: Diana and her husband Daniel, and Alonso. They each have a child with disabilities. I met both through my former schoolteacher and was surprised by the similarities of their experiences despite the difference in age of their children with disabilities. Therefore, their situations are better understood when presented together. Diana's son Dada and Alonso's daughter Sol were both born with considerable health complications. Despite not knowing each other, they both told me how at first their life as parents was marked by going to doctors and worrying about a child whose future was not certain. They both emphasised how the physical side of their children's difficulties was the most terrifying part.

Twenty years ago, Sol was born with birth defects that complicated her chances at survival, making her first two years of life full of hospital visits and medical scares. Alonso narrated to me his previous experience as a parent of an ill child as more disturbing and frightening than the time he had a physically healthy yet disabled daughter. Once Sol's health stabilised, Alonso and his ex-wife discovered she had a cognitive disability as well. But Alonso recalls that they were able to accept this reality quite quickly because this was not a life-threatening condition for their daughter. "This was secondary, if she's already overcome the other [health complications], well… maybe she can keep improving." Sol's disability was therefore met as any other complication that may make a child's life slightly more difficult, but not as something disastrous. His testimony is similar to Landsman's (2009, 157) concept of hope for mothers of children with disabilities, as the sentiment that makes them see beyond their children's diagnosis to consider that development and progress are a viable option. The fact that Sol had the opportunity to live and "keep improving" and developing was appreciated by her parents, who gladly took the added responsibility of having a child with disabilities whose body had already showed the potential of being "fixable" (Mattingly 2010, 60) to some extent. The grief provoked by her previous health problems was replaced by a sense of hope that was too strong to be weakened by her new diagnosis. Sol's chance at life and her potential for improvement was enough to maintain this hope, regardless of how different that life would be compared to the "perfect babies" (Landsman 1999, 139) most people have.

On the other hand, Diana and Daniel's son's health problems were related to his disability from the very beginning. Diana and Daniel were inexperienced parents and felt overwhelmed by the difficulties of their son's health. Once Dada started at his "special education" school and combined his frequent doctor's appointments with motor and social stimulation, his parents were able to see him improve not just medically but also psychologically and physically. Being able to provide enough care for Dada, coming both from themselves and from health professionals, therapists, and teachers, contributed to a sense of achievement felt by Dada's parents, who experienced his improvement as a familial accomplishment. Even though Dada's disability is still completely life-changing for the family in terms of the care it requires, the fact that they can now do many family activities that they could not do before, such as going to a restaurant, consolidates the family's efforts to make Dada's life as normal and happy as possible.

The three families I introduced in this section narrate their experience of parenthood as a journey that took them from an initial reaction of grief and a sense of failure as a family (linked not just to the inability to produce a "normal" child, but also to the struggle involved in mobilising the resources that are crucial to guarantee a dignified life for a person with disabilities and are rarely provided by the state) to a process of acceptance of the disability and mending of the parents' sense of self. This involves not only a shift in their sense of what chances their child has of a meaningful life, but also a redefinition of what a "meaningful life" (*vida digna*) is in the first place. This leads to a change in what "success" in their parenting endeavours mean. Furthermore, the shift they describe has not simply affected their child's life but also their understanding of the meaning of parenthood.

The extra weight

By using the term "extra weight," families refer to the time, resources and emotional burden that goes into raising and ensuring the happiness of a child with disabilities. These responsibilities are usually not present when raising able-bodied children. Families try to manage the extra weight by framing their care as "unconditional love" to justify happily taking on this extra weight while "humanising" (Aulino 2016, 92) their child.

Madrilenian ideas about what humanises the subject of care focus on what my informant Alicia called "vida digna," which can be most accurately translated as a life that, by being meaningful and dignified, is worth living. While my informants expressed how unconditional love, for the child and for the whole family, manifest as an obligation to care for everyone, it is important to emphasise that this care is intended as the tool to create the dignity that they believe everyone should experience despite their cognitive abilities.

After she started to notice that something was "wrong" with Greta, Alicia and her husband took the baby to numerous doctors who, unable to fully diagnose her, told her parents there was no chance of improvement, leaving them with the whole burden of Greta's care. The family narrates the struggle of raising Greta as a weight that exclusively fell on their own efforts. Still, these narrations should not be seen exclusively as a representation of the facts, but as a "scene" (Mattingly 2010, 44) that is morally weighted, and in a sense, agentive. Alicia's "storytelling narrative" (Mattingly 2010, 49) strongly influences both how the present is lived and how future action is anticipated. Her focus on her family's social hardship and their exceptional willingness to fight for Greta represent not just her present experience but also the reality that will perpetually shape her life: "It's like I have to do everything twice. I always carry around an extra weight, but I do it gladly because it is not her fault, and someone has to do it." Her identification of her care responsibilities with the physical experience of carrying weight can be compared with Aulino's account of long-term care as an embodied practice that is habituated through a ritualistic performance of acts of care (Aulino 2016, 81).

Laura, the mother of Adri, and member of the fourth and final family that I present, agreed with Alicia. She indicated that every decision she makes must take her son Adri into consideration, especially since her husband passed away. "Even when I want to meet with my friends," she complained, "I have to think about who is going to stay with Adri." Keeping their children with disabilities entertained, busy, and safe is always in the background of Alicia’s and Laura’s thoughts. Therefore, balancing family life becomes harder, due to the necessity of giving up certain aspects of it to ensure the proper care of the child with disabilities.

Adri’s twin sister Lucía expressed that she has always had a hard time accepting his condition. This is because the extra attention her parents paid to Adri took away from the attention they paid to her. Her mother recalls seeing a video of their seventh birthday where everyone was singing happy birthday to Adri and Lucía was just standing alone at the side. Although Laura feels guilty about Lucía’s occasional feelings of abandonment and is actively trying to balance her attention to the twins now that she doesn’t have the help of her husband, she believes focusing on Adri and not Lucía was inevitable due to the level of exhaustion that comes with having twins. The twins are now twenty years old, and the conflict still arises occasionally. When I talked to Laura the first time, she still felt guilty about the last conflict between Adri and Lucía, where she noticed Lucía ended up crying due to her brother ruining her end-of-exams dinner, because he insisted on picking up their mother from her painting class and got lost on the way. Had Laura told Adri not to come, Laura confessed, they would have been able to enjoy dinner together.

However, Laura argued that convincing Adri would have been exhausting and she chose to let him walk to her class, despite knowing it would make them a bit late. However, she said that she did not expect Adri to get lost and ‘ruin the dinner’ altogether. While her children were not present in this interview, I noticed that she still felt like she needed to defend her role as a good mother, not just to me but also to herself. The difficulties that she experiences to hold the “extra weight,” therefore, often become too much to handle when they are combined with the rest of her familial obligations. Situations such as this one test Laura’s ability to act as her idea of a “good mother,” producing the guilt that marks her narrations.

Lucía’s narration of the event follows similar lines: while she says she recognises her mother often gets exhausted when dealing with Adri, she resents that her brother made it so difficult for her mother to manage that situation. Despite her conflictive relationship with her brother, Lucía said she knows that he cannot help needing extra care. Therefore, she tries to be patient with him and find other spaces outside of her family where the focus is on her. The twins went to the same school, where Lucía says she became “Adri’s sister” for everyone, instead of being regarded individually. This shaped her identity at school, where Lucía believes she was her brother’s “shadow.” Nevertheless, she eventually found a group of friends outside of school that noticed her individuality. Laura and Lucía both believe this friendship is what shaped her daughter and allowed her to fully express herself outside of an environment where she was just another caretaker for her brother.

Similarly, Dada’s sister, Lorena, describes her bond with him as a “love-hate” relationship. Her childhood and teenage years were full of things she could not do because either her or her parents had to take care of her brother and couldn’t afford the distraction. Her mother, Diana, told me that waiting to get attention until Dada was settled and satisfied was a very frequent event for their able-bodied children. “If they had a headache or were hungry, they had to wait until we were done taking care of Dada to let us know.”

However, as Lorena grew up, she realised her relationship with Dada had made her patient and loving, qualities that shape how she acts beyond her family. She told me she has come to appreciate Dada’s affectionate nature and instead of blaming him for his occasional violent outbursts, she learned that they are part of who he is: someone worthy of her love despite needing a different kind of it. Diana believes the experience of living with a sibling who has disabilities made her younger children more independent, avoiding a heavy reliance on her and her husband and forcing them to do things by themselves, which has developed their ability to be self-sufficient and creative when dealing with difficulties. Diana said that despite them getting slightly less individualised attention than what she believes other children get, her children have always had their needs and wants covered. She told me how her husband and her always made sure to take them to extracurricular activities and sports.

Diana’s perspective, however, needs to be understood as an effort to rationalise the impossibility of being the perfect mother for her able-bodied children even when she did her best. Her daughter Lorena lived the situation quite differently. She remembers feeling very frustrated when she was a kid since there were many things they could not do as a family, such as going out for a meal or visiting her friends’ families. She resented both her brother and her parents, but she told me that as she grew up, she began to agree that her parents did their best in a hard situation.

As well as changing the dynamics of the relationship between parents and their able-bodied children, a disability also creates a distinctive relationship between the person with disabilities and their family members. Alicia told me that an able-bodied child offers parents care, company, support, and social status linked to their success in life. This, in turn, is understood as a result of their parents’ efforts in raising them. Their relationship is thus shaped by a reciprocity that is understood as originating from “familial love,” which includes the children’s obligations to give back to their parents in both companionship and social and financial backing. While this is an unspoken expectation, most Spanish children would agree that if one *loves* their parents, they must return the care they received in childhood as their parents get older. It is very normal to hear parents joking and asking their children not to be “sent to a care home” once they are old since they were “good to them” when they were little. Spanish people tend to pity care home residents. They are perceived to have been “abandoned” by their children, who “didn’t love them enough” (*no les quieren lo suficiente*) to care for them. While it is commonly known that there are many other reasons for an elder to end up in a care home, even my own Spanish parents have jokingly made me promise to never send them to a care home regardless of the situation. My “job” as their daughter is to reciprocate the care I have received, even if this is not stated explicitly.

However, the relationship a parent has with a child with disabilities is completely different: “a[n able bodied child] steals a few years of your life, and then develops, becomes free and flies away,” Alicia described, “but this is a child that doesn’t fly, you’re always dealing with the level of dependence of a baby.” Therefore, a child with a disability does not offer the opportunity to rely on them as one gets older, which is something Alicia misses from her eldest daughter. Specifically, Alicia believes Greta would have become an emotional support for her mother. Alejandra, the family’s youngest daughter, also misses that from Greta. The relationship she has with Greta resembles the asymmetrical one Greta has with her mother, instead of what she understands to be a usual relationship between sisters: a reciprocal “friendship” based on mutual understanding. Therefore, while Alicia and Alejandra are “sacrificing” their time and energy caring for Greta, Greta cannot give this back.

Therefore, caring for a child with disabilities, as my informants frame it, acts as a true sacrifice that is not desired, yet performed anyway (Mattingly 2010, 63) out of what my informants call “love” for their child. In this relationship of care receiving care back stops mattering. Thus, my informants frame the extra weight as a sacrifice, narrating the resource of “unconditional love” as something absolute: even when parents don’t expect to get anything in return for their enormous efforts, they do not feel any hesitation to perform it. In other words, their narration of love portrays it as an unconditional reality because it is maintained even through a lack of reciprocity.

The situation of the siblings is very similar. While it is true that their moral and legal obligations towards the child with disabilities are not as strong as their parents’ for most of their lives, it is worth noting that they also feel the extra weight falling on them, both as current secondary carers and as future primary carers when their parents get old. While they complained about missing out on the experience of having a sibling who relates to their own experience and can offer advice and friendship, the siblings I interviewed take on the duty to support not just their sibling, but also to help their parents. In other words, the reciprocity they offer their parents also includes taking the weight of the responsibility for the child with disabilities off their shoulders. The siblings' narrations explicitly mention that this is mostly done out of love for their sibling, towards whom they feel an enormous sense of obligation and protection. However, in my few visits I observed how my informants' interactions with their parents suggest that siblings take care of their parents, in part, by relieving them of responsibility. Often, the children openly offered to help when their parents seemed overwhelmed. The fact that they add this consideration to the usual reciprocal relationship Spanish people have with their parents is felt as an imbalance in the relationship since they also receive less attention. The feelings of frustration, resentment and anger that some of my informants experience towards their parents also are best understood in relation to this. Children are aware that by replacing their parent in a situation of care, they lower their extra weight. And while they see this as the "right" thing to do, it also creates an imbalance that can either be justified through the narrative of unconditional love or lead to anger. It is worth noticing how the unconditional love narrative therefore affects the whole of their familial relationships, not just those that include the child with disabilities.

The relationship among the family members of a child with disabilities is therefore narrated in terms of what I term the 'extra weight' of their care. The distribution of this weight, and how it is lifted from some members, shapes their relations of reciprocity. While the parents sacrifice considerable time and energy caring for the child with disabilities singlehandedly, trying to offer their other children a chance at a 'normal' life, their able-bodied children use the lifting of the weight off their parents' shoulders to give back for these efforts. The fact that their childhoods were often lived as constrained despite their parents' best efforts can be a source of frustration. Furthermore, the true sacrifice that families offer to their child with disabilities is often justified in terms of the love they feel for them. Thus, this use of unconditional love as a resource to manage their situation means that that they are willing to redirect their lives and change their own model of the family to assure a full integration of the child with disabilities into family relations and to cope with their unwanted situation by naturalising it. I will explore both issues in the next two sections.

A holistic family unit

Dada's father, Daniel, emphasised their family's distinction from the members of a usual Madrilenian family who independently forge their own futures. Normally, he argued, Madrilenian middle-class parents like him raise their children to be able to live independently from their care once they grow up. A big part of his experience as a parent has been shaped by being able to adapt to this difference. Alicia's testimony conforms to this concept. She defined raising able-bodied children as a process of sacrificing a few years of your life so that your children can ultimately "separate from you and fly away." Both Alicia and Daniel imagine their family's situation as different from the regular Madrilenian family because their children with disabilities "never fly away."

Robbins' (2013) study of social ideologies as shaped by a "paramount value" (Dumont 1977) that encompasses other less central values, helps articulate how the families I interviewed are so cohesive and inter-reliant. I argue that typical, able-bodied Madrilenian families follow a moral code based on self-sufficiency and independence where they each work for their own personal good. Parents achieve their goals when their child is independent because that makes them personally a good parent. Children, equally, succeed in their role as sons and daughters once they are able to leave the parental home and form a new family unit sustained by their own career, since it shows that they have grown up to take a "proper" place in society instead of becoming a 'failure' (*un fracasado*). While it is true that the "soft" individualism present in Madrid does not create totally independent people, familial relationships are based on individualistic yet reciprocal roles where parents try to teach their children to do well in life without their guidance or help.

Families with a member who has disabilities, however, work in a distinctive way. My informants raise their able-bodied children to be somewhat independent by getting a job and moving out, but they do not expect nor want them to "fly away." Instead, they try to raise children who will fly alongside them and their sibling who has disabilities, contributing to their care and wellbeing until they finally become their primary carers. Independence is only useful for their families to the point where it contributes to the overall maintenance of the family. For example, getting a job would be beneficial for the family as it would help with the financial aspects of care. Moving out, similarly, would allow parents to reduce their housework through the reduction in the size of their household. In Madrid, it is typical to move to a different town or neighbourhood within the province to start a separate life from one's family. However, all of my informants want to keep living very close to each other so that the person with disabilities can travel between households, to ensure the responsibility of their care keeps is distributed among the family members. Thus, while it is true that my informants strive towards their individual success, this value can conflict with the more cohesive and holistic set of values that the family unit is working towards. They never fully dissolve the family unit, and they always keep contributing towards the care of the child with disabilities. Once the parents grow old and are unable to keep up with their care responsibilities, their able-bodied children become the guardians and primary carers of the sibling who has disabilities. In my interactions with the families, I noted that their level of commitment to the child with disabilities creates a cohesive family unit that collaborates to ensure the wellbeing of that sibling. I observed the families to be completely in sync in their care, working together through their kinship roles for what I clearly noted was the family's main duty: the care of the child with disabilities. They organize their family schedule, outings, individual social events, and even the layout of their house, in a way that ensures that the child with disabilities can live the best life possible. They exhibit some features of Dumont's (1977) holism, since they are using their roles collaboratively to work towards the family's overall benefit. In Lorena's words, their "whole life revolves around Dada." Looking at my experiences with the other families, I am certain that this is shared by all.

Thus, my informants' family unit has distanced itself from the typical Madrilenian individualistic stance towards a more holistic position in life due to their care responsibilities, which forces them to work collaboratively and cohesively to prevent their family unit from collapsing. Thus, their family life becomes an integrated whole. The life of my informants is not just oriented but ultimately devoted to the care of the family member who has disabilities in a way that maximises the wellbeing of the entire family. The families of children with disabilities become holistic to the point where they live as a unit that plan every aspect of their lives around the capacities of the member who has disabilities, oftentimes forgetting their own wants and needs for the benefit of the member who has disabilities and the family as a whole.

The shaping of the self

Despite the added responsibilities and worries that come with caring for a child with disabilities, I was surprised to see how all the families I interviewed did not narrate the extra weight of care as a burden but as a moral duty. They discussed how care has become something natural for their relationship as kin, and how that relationship has changed who they are as a person. The duty of care that my informants feel towards their child with disabilities not only changes the obligations that are naturalised in a certain kinship relations, but also redefines and shapes the selfhood of those involved. This is caused by a change in the concept of love that shapes kinship relations, going from what both my informants and I considered to be the usual reciprocal love of regular Spanish kinship relations during our conversations, to the unconditional love they described. Through unconditional love, my informants make care a relational activity by establishing it as a part of the duty of love that is included in kinship relations, and thus humanise their children with disabilities as relational people.

Other anthropologists have explored how the use of the resource of "unconditional love" to manage relationships between mothers and their children with disabilities can influence familial relationships. Landsman's (1999) work in the United States covers the transformation that American mothers undergo due to having to care for a child with disabilities, becoming what she describes as "special." Rejecting the idea that children with disabilities are born into "special" families that are destined to care for them, Landsman (1999) explores how the "specialness" held by her informants is not something that happens a priori, but rather it develops gradually as the family learns to care for the child. Mothers say that children with disabilities offer them the gift of the knowledge of unconditional love in exchange for their care, and generally make them better people who can love without expectations and who have put things in perspective, reassessing their own moral values (Landsman 1999, 146). Similarly, Mattingly (2010, 63) describes this process as a transformative journey that the families of children with disabilities undergo as they get older. Following the logic of a "quest" (Frank in Mattingly 2010, 63), the transformative journey entails a transformation of the person, the family, and sometimes the larger community.

This transformative journey allows families to recognise their children with disabilities as people who relate in a *different* way, rather than people who primarily *do not* relate in a reciprocal way. My informants live in a social world where the obligation to care for their child is exclusively theirs—like it is for all families. But their child with disabilities requires more care. Thus, they imagine this added struggle as an "extra weight," to recognise the difficulty and the difference, instead of pretending to be the same as other able-bodied families. However, to imagine the weight as a tragedy and a burden risks dehumanising their child with disabilities—thus, making them feel worse about the obligation they have, and their difference from other families. Through their transformative moral journey, they create ideas about the "specialness" of the person with disabilities, changing them from a burden into a blessing, and from someone who is outside of the community to someone who relates. The families see their child with disabilities' agency as originating from the emotional and sensitive, rather than the rational, which makes their relationship feel actively genuine and truthful. Caring for their children with disabilities has changed the way they conceptualise family relations, as well as the way they understand love and ethics to work. Their own identity both as a family member and as an individual has been affected by having a disability present in their family.

Greta's sister Alejandra told me that loving someone means accepting who they are, which includes "their strengths and weaknesses." The fact that Greta is a "special person," she argued, means that she needs special care that they have had to adapt to daily life. However, she does not see this as an obligation, but as the expression of her love for Greta. Greta is often described as being "full of pure love" for everyone around her, which she proves through the few words she knows and through her emotional behaviour. Greta has "taught them to love her unconditionally," and to express this through the care they provide to her. "Caring for her is also loving her." Alejandra compares the situation to her parents adapting their lifestyles to adapt to their other sister and Alejandra when they were born. Because every child introduces a change into the family's life and each needs a certain type of care, she told me, part of their role as kin is to care for each other in the way they need. The fact that Greta's care "weighs" more on their shoulders expands their kinship relations to include her care as a relational activity inherent to them. Greta's mother Alicia has seen the unconditional love that her daughter has taught her permeate most areas of her social life, to the point where being a carer has become part of her identity. Not only does she care for Greta full time, but she also volunteers at a local residence for disabled women, assists her elderly mother, and helps many other people financially. When talking to her, I noticed that her attitude was very affectionate, involved and maternal with everyone present, including me. This led me to think that Alicia places such great value in giving unconditional love to her daughter Greta that she has internalised it to the point where it permeates her whole identity.

Anthropological approaches to moral self-fashioning, understood as the way people create and recreate their selves during their life, can help us understand my informants' narration of identity modification throughout their experience. In Foucault's genealogy of ethics, he argues that rather than being dominated by strict moral rules that disallow any individuality, people self-fashion themselves as moral beings. This process, also known as subjectivation, is done with freedom within the resources of the particular contexts in which one finds oneself (Foucault, 2000). While Butler's (1999) well-known notion of performativity is useful to understand subjectivation as something that happens through repeated performance, Mahmood (2005) adds that performativity must be understood as having a cumulative character, slowly building until the virtue is naturalised. While the care rituals described by Aulino (2016, 81) limit the habituation of care to bodily practices, I have observed how care is naturalised into the morality of my informants as well as into their practices, permeating all aspects of their selves.

My informants' kinship experiences correlate with Mahmood's notion of cumulative self-fashioning. Since the moral self is "learned and negotiated" (Mattingly 2014, 64) in life's most important domains, it is understandable that kinship relations in Spain, where the family unit is the foundation of social life, can influence my informants' self to such an extent. Thus, Lorena's account of her love-hate relationship with Dada shows how it slowly turned into a completely loving relationship as she grew older and realised how important everything he taught her was for her identity. Despite the difficulties her family had to secure Dada's care while caring for their four other children, Lorena said she would not change her upbringing. Through the example set by her parents and her older brother, Lorena has cumulatively internalised a sense of doing things because "it is what is right" or "it is what you have to/are supposed to do." "I must have heard those two sentences a thousand times," she told me, "and truthfully, they're right." Her parents uttered those same sentences when referring to her moral responsibilities as a sister when she was growing up, which included helping her siblings, both Dada and her younger siblings. Therefore, she sees caring for Dada as equivalent to caring for any of her siblings, because he is "a member of our family like any other."

Nevertheless, Lorena acknowledged that this was not always the case, the extra weight involved in raising Dada used to be something that bothered her as she felt like she was being robbed of some experiences that her classmates enjoyed. However, she thinks that "whether we wanted it or not," the desire to care for Dada has slowly but surely grown inside of her and her other able-bodied siblings. In other words, their continued relationship with Dada has stopped feeling like a chore or duty and started feeling natural as they become habituated to values that have not only changed the way they understand their role as a sibling but also their identity as a whole, as their values permeate all aspects of their social life. The naturalisation of unconditional love to their kinship roles enables the families to incorporate care into the relational activities that are inherent to being a sibling or a parent, which humanises Dada by making him a relational member of the family like any other. Lorena argued that her family is tied together by a bond that justifies their responsibilities. Without that bond, none of the value learning and internalisation would have been required. When asked about the bond's exact meaning, my informants emphasised that what makes this bond remarkable is the fact that they are *family*. Kinship for them, therefore, comes with certain expectations tied to that bond. Lorena's family did not just teach her the usual Madrilenian values, she believes, but they also included the teaching of values needed to both care for her brother and appreciate his agency as valuable. Both things shaped her subjectivation. Thus, the unconditional love Dada's disability created did not just influence the behaviour of his family members, but it ultimately became so habituated into their moral selves by the cumulative repetition of his care that it became as naturalised as any other kinship duty underlying their roles as parents and siblings. Thus, caring for Dada is experienced as a natural part of the family's kinship relationships, instead of feeling like a chore.

In both Lorena's and Lucía's case, I noticed that they understand caring for their disabled brothers as something taken for granted that they "have to do" because they love their siblings, and it is this bond of love and kinship that justifies their sacrifice and dedication as a family member and makes their duty towards their sibling unnegotiable and unbreakable. In the same way that the naturalisation of unconditional love helps Dada be humanised, it also shapes the extra weight as normal, pushing away the painful notion that the family has had to compromise or lose certain things. Their moral understanding of love as whatever the other person needs is what erases the feeling of burden from the act of care, humanising the sibling who has disabilities rather than seeing him as a burden. The latter would ultimately worsen both of their lives. They are giving love unconditionally and as something that they owe their sibling due to both their relationship duties and all they have learned from them.

Thus, the subjectivation of the family members of children with disabilities is shaped by their experience with disability and care. Learning unconditional love from the child with disabilities provides them with the necessary tools to identify care as the type of love their sibling or child needs. Because loving your family is included in the typical Madrilenian model of kinship, it makes sense that families of children with disabilities not only learn to naturalise the extra weight as something natural to their relationship, but also that the change to their identity is linked to concepts of love. Family members internalise this love, and this process not only shapes their relationship with their family, marked by infinite dedication and patience, but it also shapes how they perceive social relations as a whole, and how they position their self in social spheres. I therefore argue that the subjectivation of their selves based on unconditional love and its values undoubtedly makes families of children with disabilities different beyond the care of their child, since they reorient their whole way of operating towards these values.

Conclusion

The motivation behind the moral transformation originated in my informants' narratives about the enormous sense of moral duty that they feel towards their family. Going back to the quote that introduces the paper, the promise Alicia made to her yet unborn daughter, "we have a straw cot and a better world ready for you," I argue that the families I worked with have felt bound to ensure that they could provide a better world for their children by creating a "cot" (understood as family) so strong that it could compensate for all of the deficiencies of an outside world that they can't change. Seeing their children confined to their family life and rejected by Spanish society, they decided to create that 'better world' in themselves. Lastly, the answer to why these families decided to completely alter their moral world to fit their child with disabilities in it goes beyond their legal obligations as guardians of the child with disabilities and back to the necessity of adopting unconditional love as a mechanism to deal with the extra weight of disability without dehumanising their child. Landsman's (2009) piece quotes the mother of a child with disabilities who, when he was born, wished she "didn't love him" so she would not feel so compelled to make the efforts that raising a child with disabilities involves. Love, for my informants, means accepting the other person for who they are. Thus, when a child with disabilities was born in my informants' families, they had to learn a new way of including someone who exists in a completely different way in their family life. Through this transformative journey, the families overcame the grief that originates from feelings of being different from other families. Care became the idiom of their love as it acts as a relational activity through which personhood is created. By humanising the child with disabilities, care was accepted as a way of loving someone like any other.

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