

# Family impact of microdeletion 22q11 and unveiling of the diagnosis

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# Introduction

- The presence of a different child profoundly affects the functioning of a family
- An abundant scientific literature highlights the increase in stress among parents of a disabled child, it leads to lower family income, greater difficulty for mothers to pursue their training and professional careers
- For parents, more risk of separation, more physical and psychological health problems, more difficulty with memory in the second part of life due to chronic stress, more anxiety and depression risk for the parents
- However, in the current presentation, I have chosen to focus mainly on siblings and the need to take into account the needs of other children



- Chapter 7: I take into account the needs of my other children. Siblings and family dynamics

# A principle of equity overturned

- Children generally expect a parent to devote the same amount of time to each of their children
  - It is accepted that a mother should devote more time to her young children. Because each child is convinced that when he or she was younger, he or she, in turn, received more attention and care
  - The different child disrupts the principle of equity
  - Regardless of his age or order in the siblings, he will encourage more investment and vigilance on the part of parents than for his brothers and sisters.
- **The different child challenges the principle of educational equity**

# Recognize this difference in treatment

- Parents often feel some form of guilt because of the lack of respect for this fairness, but they have no choice
- Guilt is a source of misunderstanding
- Indeed, parents may minimize the difference and trivialize the time and attention devoted to the sick child:

"We all love you the same way."

# Recognize the difference

Acknowledging the unfairness of the situation highlights the fact that even if it is a parental choice (imbalance of attention, care, time for the different child), it is a constrained choice and does not result from the preference for one child over another

**«We love you the same but we don't treat you the same because a child is different»**

# The search for artificial serenity

- Some parents wish not to expose siblings to knowledge of the disease and the possible risks associated with it. Parents say little or nothing to siblings
- The idea is to keep the brothers and sisters in a calm situation, with the slightest possible concern: "he is like you, he is the same".
- This attitude often leads to misunderstandings, as it becomes very difficult for siblings to assess the true severity of the difference and to understand the hyper-investment of parents, as well as the differences in treatment and attention to the different child
- Risk, especially in early adolescence, of some form of sibling coalition against the different child receiving "preferential" treatment

# Have the disease explained by a third party

- Sometimes parents prefer that it is a third party, such as the therapist, who informs other children about the illness or disability of the different child:  
"Our child's siblings have many questions. They don't realize the seriousness of the problem and are sometimes a little hard on him."
- The work then consists, with the siblings gathered, in relating the physical and psychological problems encountered by the brother or sister to the objective evaluation of the differences he or she presents.
- These differences should be related to the observations made by the siblings themselves
- Also explain what is generally known about the disorder affecting the child



# Situational awareness by siblings

- Although there are no other options for the whole family to understand the situation, sometimes sudden understanding can have an impact on siblings.
  - They become more objectively aware of the situation and sometimes feel extremely guilty about the hardness they have shown and the injustices they have caused because of jealousy or envy towards their brother or sister
  - Risk of falling into an attitude of hyper solicitude (hiper solitud), or even that they want to take over from parents for life
  - Need to present the position of hyper solicitude honestly as a risk
  - Only a balanced and harmonious commitment is possible over time
- **Balance the satisfaction of all siblings, including the different child**

# The temptation to idealize the difference

- The temptation to idealize difference may arise when parents or siblings are unable to identify or accept some of the frustration, sometimes even aggressiveness, caused by the disability of the different child:

*"We are lucky to have this child. Through his presence, he showed us all and taught us all things. It has allowed us to open our minds rather than be in an individualistic world where everyone cares only for themselves."*

- A profoundly correct statement, but one that acquires all its authenticity only because precisely the totality of reality is taken into account. This reality also includes the very constraining, difficult and painful nature of the difference, both for the affected child and for the rest of the family

- For any of the siblings, because of the unspoken accompanying suffering, there is rarely a frontal conflict. More often, in late adolescence or early adulthood, a sibling may feel that they no longer belong in the family project. He withdraws and gradually cuts himself off from his family

➤ **Hence the risk of a feeling of deep loneliness, of breaking up with one's family**

# The role of position of siblings in order of birth

- Different impact depending on the position of siblings in the order of birth
- If the different child is the eldest:
  - The unavoidable nature of the needs will lead parents to involve cadets in the therapeutic and pedagogical project
- If the different child is the younger one:
  - parents can justify part of the special attention it requires other than by the difference it makes
  - Seniors can then take the side, by necessity, of creating a dynamic where they are self-sufficient. They allow parents to devote themselves fully to taking into account the needs of their younger brother or sister
- When the different child is neither the first nor the last:
  - It is not uncommon for one of the younger children to embrace the family pedago-therapeutic project in order to keep a privileged place with the parents
  - He can become the one who implicitly will be the guarantor of the different child's project, even the day when the parents are no longer there

# Acknowledge and accept the feelings of siblings

- Parents' over-investment can lead to a feeling of being left to their own devices, a feeling of aggression towards the different sibling, or a feeling of injustice in non affected children.
- Siblings may feel guilty about their own feelings, about aggression towards the different sibling, but also about parents
- Finally, the dominant feeling can be hyper solicitation, sometimes excessive

- In all these situations, it is central to be able to identify and name feelings. They can be successive, contradictory, but they are always real, because they represent an emotion that we experience
- Each family member should be able to recognize their emotions (even if sometimes contradictory) in themselves and in others
- The emotions can be received without any other form of judgment, simply because it is a difficult situation and nothing can prepare a family to live it

# Consult a psychiatrist for a better exchange

- Providing a space for exchange where the emotions of each other are identified is one of the most important things a therapist can bring
- For this to happen, the psychiatrist or psychologist must have knowledge of the difficulties and specific difference (22q11 DS) affecting the different child (he/she doesn't need to be a specialist)
- This makes it more credible to the family. He is listened to because of his understanding of the severity and impact of difficulties on family dynamics
- No specific recipe for meeting spaces. The wishes that are expressed are necessarily correct

- Each family member can be received individually, in a group, with or without the different child, the group of single siblings, the parents together, a parent and a specific sibling, a single brother or sister
- Within the siblings everyone can understand that their needs are not the same as those of others

When travelling, you need a companion and in life, compassion

*Haruki Murakami*