

3rd Meeting "Lived experience"

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LECTURE 2

Parents

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OUTLINE:

- *Mothers roles*
- *Mothers feelings*
- *Fathers role*
- *Fathers feelings*



Parents



LEARNING OUTCOMES

- Understand the roles partners have in a family with a child diagnosed with ASD
- Develop understanding of the feelings and lived experience of parents
- Get to know how these feelings build up and what can cause them
- Ways to overcome negative feelings and build competencies

RAISING A CHILD

“IT TAKES A VILLAGE TO RAISE A CHILD”

- Proverb of African Origin
- What do you think it means?
- Basically it states that an entire community of people must provide for and interact positively with children for those children to experience and grow in a safe and healthy environment.
- Do you think that this is the case?



RAISING A CHILD (with ASD)

What about a child with ASD?

How many villages, do you think, need to raise a child with ASD?

- Maybe a lot more many
- That is because parents must provide a certain level of care to meet a typically developing child's physical, emotional, and cognitive needs. As the child grows, this level will reduce.
- In contrast for parents of children with ASD, this level of care may need to be maintained throughout the child's life
- Parents with children with ASD are in for the long mile and that alone can be extremely cumbersome for the whole family



PARENTAL PSYCHOLOGICAL STATE IN FAMILIES WITH A CHILD DIAGNOSED WITH ASD

Raising a child with ASD :



- It has been shown that parents with a child with ASD exhibit higher stress levels than parents with typically developing children
- It is also true that parents with a child with ASD seem to be more stressed even in comparison to parents with a child diagnosed with a developmental disorder other than ASD



PARENTAL PSYCHOLOGICAL STATE IN FAMILIES WITH A CHILD DIAGNOSED WITH ASD

Why is that families with a child with ASD are prone to elevated stress levels?

Studies show that this phenomenon can be explained by taking in mind 3 factors often intertwined with each other:

- The manifestations of the disorder itself (behavior, sensory issues, communication/socialization...)
- The support systems that can accompany a family in time (services, education, community...)
- The life stage of each family (child's age)



PARENTAL PSYCHOLOGICAL STATE IN FAMILIES WITH A CHILD DIAGNOSED WITH ASD

Most studies on parental distress, carried out mainly on parents with children of small ages, show convincingly that:

- Child's challenging behaviors and meltdowns have a toll on the parents well-being and health (both psychological and physical)
- The lack of supporting systems of family in terms of quality and quantity can also lead in higher stress level of both parents

PARENTAL PSYCHOLOGICAL STATE IN FAMILIES WITH A CHILD DIAGNOSED WITH ASD

Yet another factor that can be correlated with overall distress, is the life stage of the family (child's age):

1. Parents with children aged 2 to 3 that begin the “Diagnostic Odyssey”, also seem to exhibit high levels of stress that can be attributed to thoughts about the future of the child but also to the time and the efficacy of the whole procedure (time, guidance, support)
2. Parents of older age with adult children diagnosed with ASD, have to deal with the future of their child (what will happen, who will take care of him/her, will be able to find a job or get married)

Impact on family



Common mental states and situations parents go through:

- Feelings of shock, denial, mourning, anxiety, regret, depression, guilt, anger, sadness, exhaustion can be seen in families with a child with ASD
- Not rarely the couple may face also physical exhaustion, economic hardships, social exclusion and very often, little time to share together.
- Elevated stress levels can take a toll on the family, affecting both quality of life and relationships between all stakeholders.

***Take in mind:**

Although there has been a study concerning higher divorce rates in couple with a child with ASD, this data haven't been replicated in other studies

How partners feel

A mother's role

Usually mothers seem to embrace the following integral roles in the lives of their children:

- Mothers (meeting every child's needs)
- Caregiver (care, supervision)
- Educator (reinforcing skills acquired during therapy sessions)
- Household (keeping home in order)
- Social worker (finding and contacting the appropriate services)
- Sacrificing career (many mothers choose to drop their careers)
- Following a career
- Advocating for their child

* though not so common, in western societies many fathers also seem to take up these roles



HOW PARTNERS FEEL

Mother's feelings:

Most studies show that mothers' high levels (often higher than their male partners) of anxiety

But also feelings of:

- Depression (studies show that mothers are more prone to depression)
- Disappointment and exhaustion
- Social isolation
- Rejection by the child
- Guilt and inadequacy
- Alone without support
- Having made too many sacrifices



HOW PARTNERS FEEL

Father's role:

Fathers in families with ASD mostly:

- Are burdened with the income provision for family needs
- Share secondary care-giving duties with their partner (usually)
- Are involved in their children's most energetic activities (walks, physical play)
- Advocating for their child
- Support partner



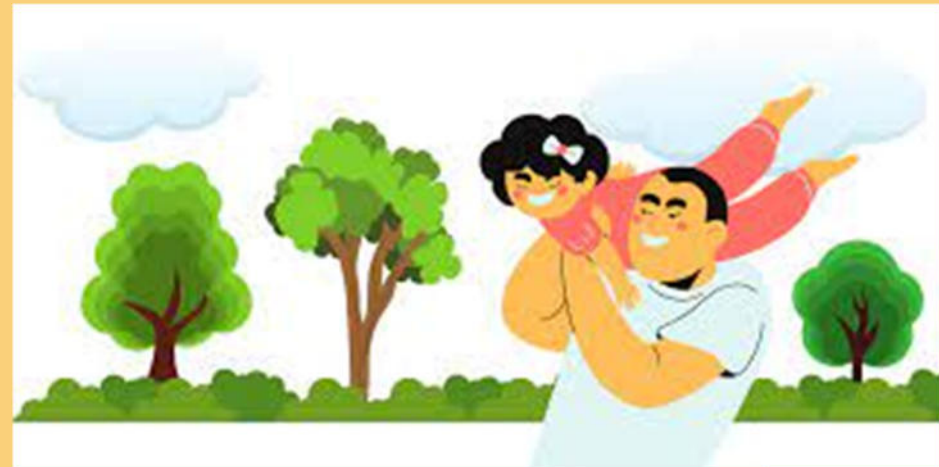
HOW PARTNERS FEEL

Father's feelings (not so many studies with no final conclusions):

Most studies show that fathers also exhibit lower levels of anxiety in comparison to their partners, but higher levels when compared with other fathers

Moreover fathers also usually feel:

- Depressed
- Anger
- Guilt
- Inadequate
- Pressure by the ongoing costs

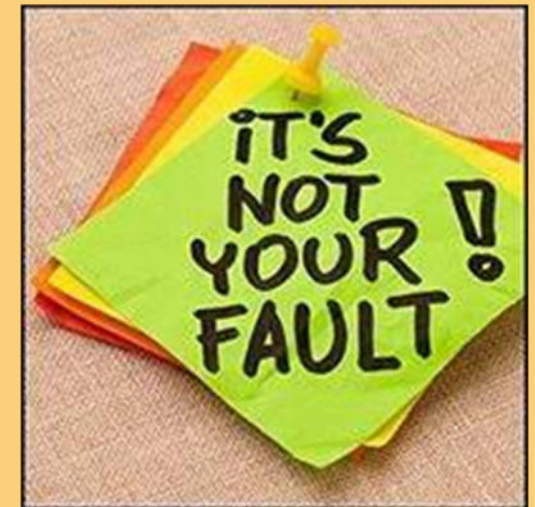


HOW PARTNERS FEEL

Keep on mind

High anxiety levels and other negative feelings parents exhibit cannot be considered as an exclusive characteristic of all families with a child with ASD, but rather can be traced :

- On certain family “hostile” services (I.e. diagnosis time consuming and with no support)
- On the lack of supporting systems (state services, extended family)
- On the lack of social awareness (stigma, social rejection)
- On specific manifestations of the disorder on some occasions (sensory issues, challenging behaviors etc)
- On the lack of educational modules for parents



CRUCIAL INFORMATION TO KEEP IN MIND

Also gender differences in lived experience may:

- The under-representation of male parents in the studies on families
- The specific role of a parent in the family (mostly women were the primary caregiver of the family)
- Most studies have been conducted on families with small aged children

*In the recent years in western societies more men have chosen to be the primary caregiver, that turn could replicate the same results in studies, thus showing the impact on how a person feels when burden with caregiving responsibilities

WAYS TO DECREASE ANXIETY LEVELS AND NEGATIVE FEELINGS

Studies show that families start to cope with everyday life when:

- Have access to quality and mindful services
- Learn coping-strategies focused on problem solving
- Increase their knowledge about ASD combined with better understanding of their child (psychoeducation, educational modules, hands-on seminars)
- Share their feelings and experiences with other parents
- Strengthen relationships with partner
- Seek help from professionals
- Enable the involvement of other family members or even friends



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THANK YOU!

*ADD HERE THE SPEAKER AND
ORGANIZATION'S CONTACT
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