

# SOCIAL INEQUALITIES AND MENTAL DISTRESS OF MOTHERS RAISING CHILDREN WITH AUTISM: A QUALITATIVE APPROACH

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# The concepts

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- Raising a child with ASD is a major life changing event / experience
  - ⇒ Intense emotional reactions
  - ⇒ New and life-long demands
  - ⇒ Restructuring of parental role
  - ⇒ Re-disposition of personal and social relationships

Jones, 1997; Sharpley και Bitsika, 1997; Zissi & Mavropoulou

# Research review- 1

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Autism is related with:

- High maternal stress

(Bristol, 1987; Frey et al, 1989, Marcus, 1984, Yamada, Suzuki, Kato, Suzuki, Tanaka, Shindo et al., 2007. Lee et al., 2009)

- High depression

(Carter, Martinez-Pedraza & Gray, 2009. Hastings, 2003, Ingersoll & Hambrick, 2011)

- Poor quality of life (QoL)

# Research Review- 2

QoL in ASD is affected by:

Socio-economic factors/ parameters:

- Social status
- Level of education
- Income
- Type of residence
- Access to resources

(Emerson, 2003; Hastings & Brown, 2002; Lee, Harrington, Louie & Newschaffer, 2008; Nachshen & Minnes, 2005; Newland, Crnic, Cox, & Mills-Koonce, 2013)

# Research Review- 3

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Quality of life in ASD is affected by:

**Intrapersonal factors:** cognitive processes

- Beliefs
- Interpretations
- Expectations
- Personal values
- Personal efficacy
- Coping skills
- Positive outlook to life

# Research Review- 4

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## Social support as a protective mechanism

- Resources (material, practical, socio-emotional)
- Self-perceptions about availability and quality of resources

Dunn et al., 2001; Boyd, 2002; Bromley et al., 2004; Freedman & Boyer, 2000; Gill & Harris, 1991; Gray & Holden, 1992; Siman-Tov & Kaniel, 2010; Smith, Greenberg, Seltzer, 2012

- Social networks

Ekas, Lickenborck & Whitman, 2010; Weiss, 2002

# Research Review- 5

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## Quality of marital relationships

- Couple rapport
- Single parent families

Abbott & Meredith, 1986; Bromley, Hare, Davison & Emerson, 2004

# Research Review- 6

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## Social networks

- Size
- Density
- Distance
- Neighborhoods
- Parent self-help/support groups

Benson, 2012; Haines, Beggs & Hurlburt, 2002; Smith, Greenberg & Seltzer, 2012; Zissi & Mavropoulou



# Research Review- 7

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Personal self-related elements :

- Resilience
- Problem solving skills
- Perception of control
- Reflective life approach

Bristol & Schopler, 1983; Cappe, Wolff, Bobet & Adrien, 2011; King, Baxter, Rosenbaum, Zwaigenbaum & Bates, 2009; Woodgate, Ateah & Secco, 2008

# The theoretical model

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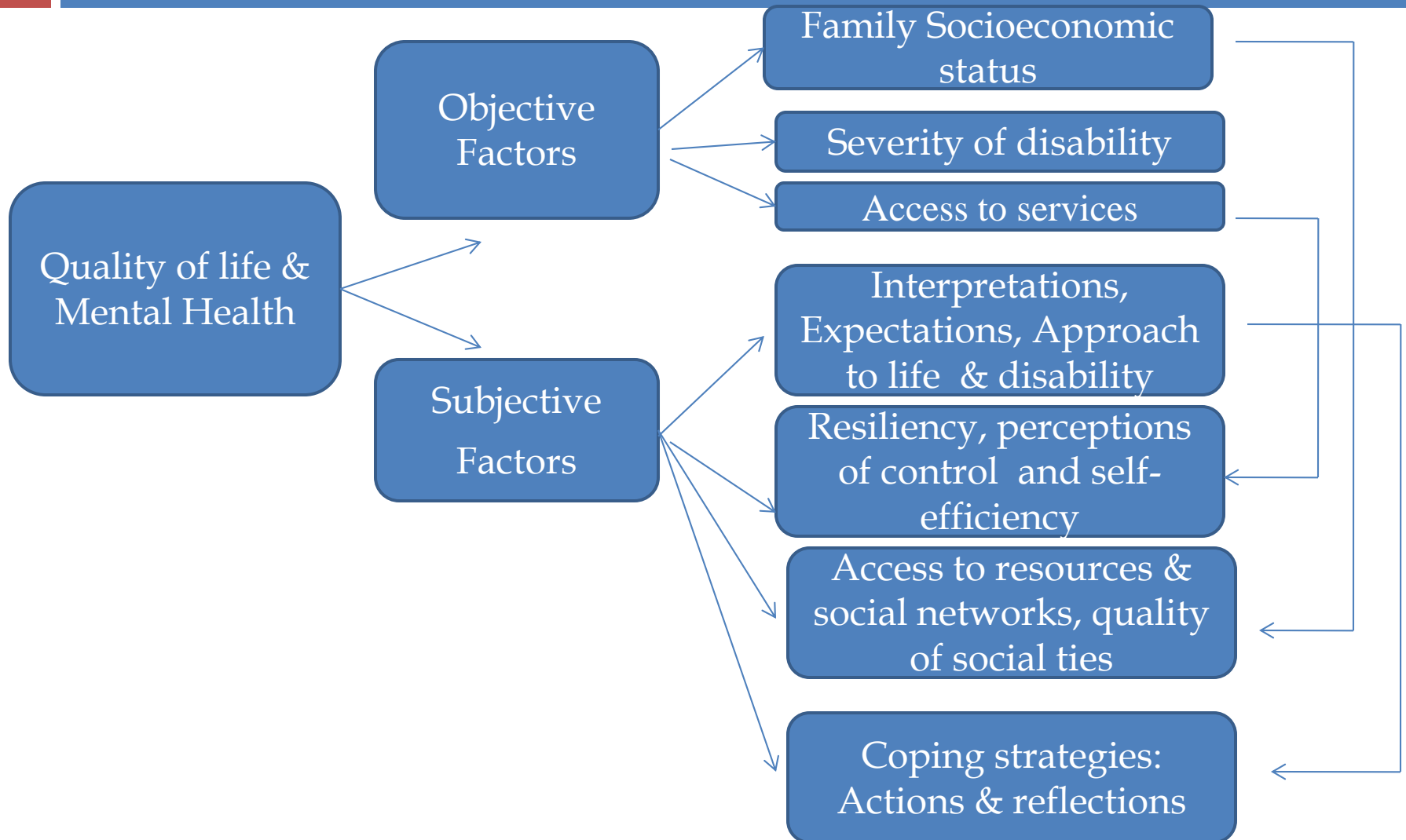
Quality of life can be understood and interpreted as the result of inter-relationships between a variety of factors related with the individual:

- ⇒ Objective living conditions
- ⇒ Socio-psychological processes

# The mediational model

(based on Zissi & Barry, 2006)

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# The main premise of the study

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- Motherhood and mental distress of mothers are differentiated depending on household's position in the social stratification, reflecting inequities in various forms of capital (symbolic, social, cultural, material) and subsequent access to resources.

# The approach and the method

- A qualitative approach to explore the underlying mechanisms for the interrelationships between social factors such as social class, socio-economic status, profession, social capital and mental distress of mothers raising children with autism.
- An in-depth semi-structured interview guide was developed drawing from the biographical method.

# The central aims of the study

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1. To offer an alternative research paradigm for the study of mental health in the area of autism.
2. To extend the prevailing quantitative research on the mental health of mothers of children with autism.

# The recruitment process

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How:

- Formal letter
- Personal communication

Sources:

- Special schools
- Parents' Associations in schools
- Day centres
- Professionals (in private practice)

# The participants: mothers

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**Low SES**

**N=20, M<sub>age</sub>= 41.1yrs**

**Middle SES**

**N=21, M<sub>age</sub>= 46yrs**

**82 mothers**

**Low-Middle SES**

**N=22, M<sub>age</sub>= 42.64yrs**

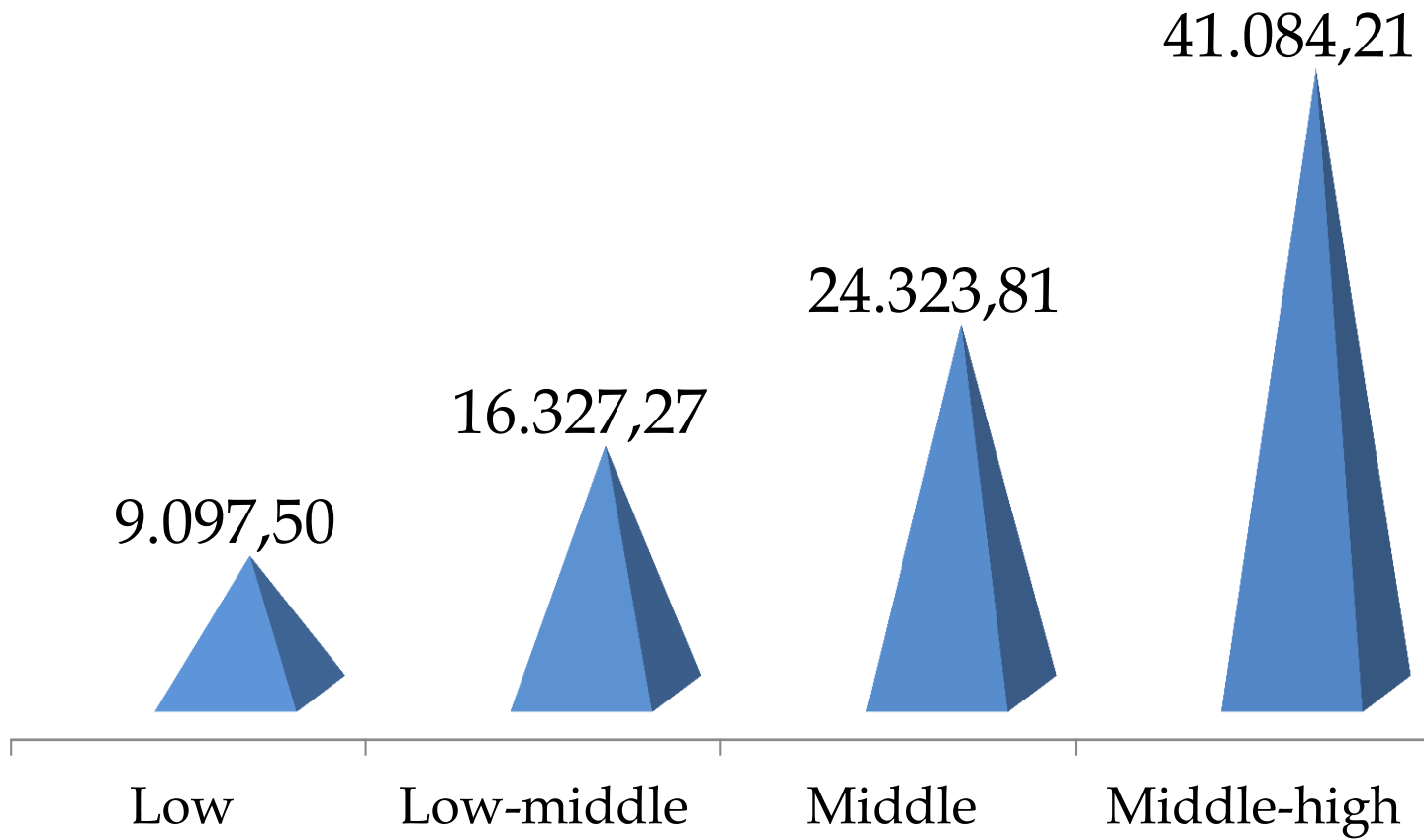
**Upper-Middle SES**

**N=19, M<sub>age</sub>= 45.31yrs**



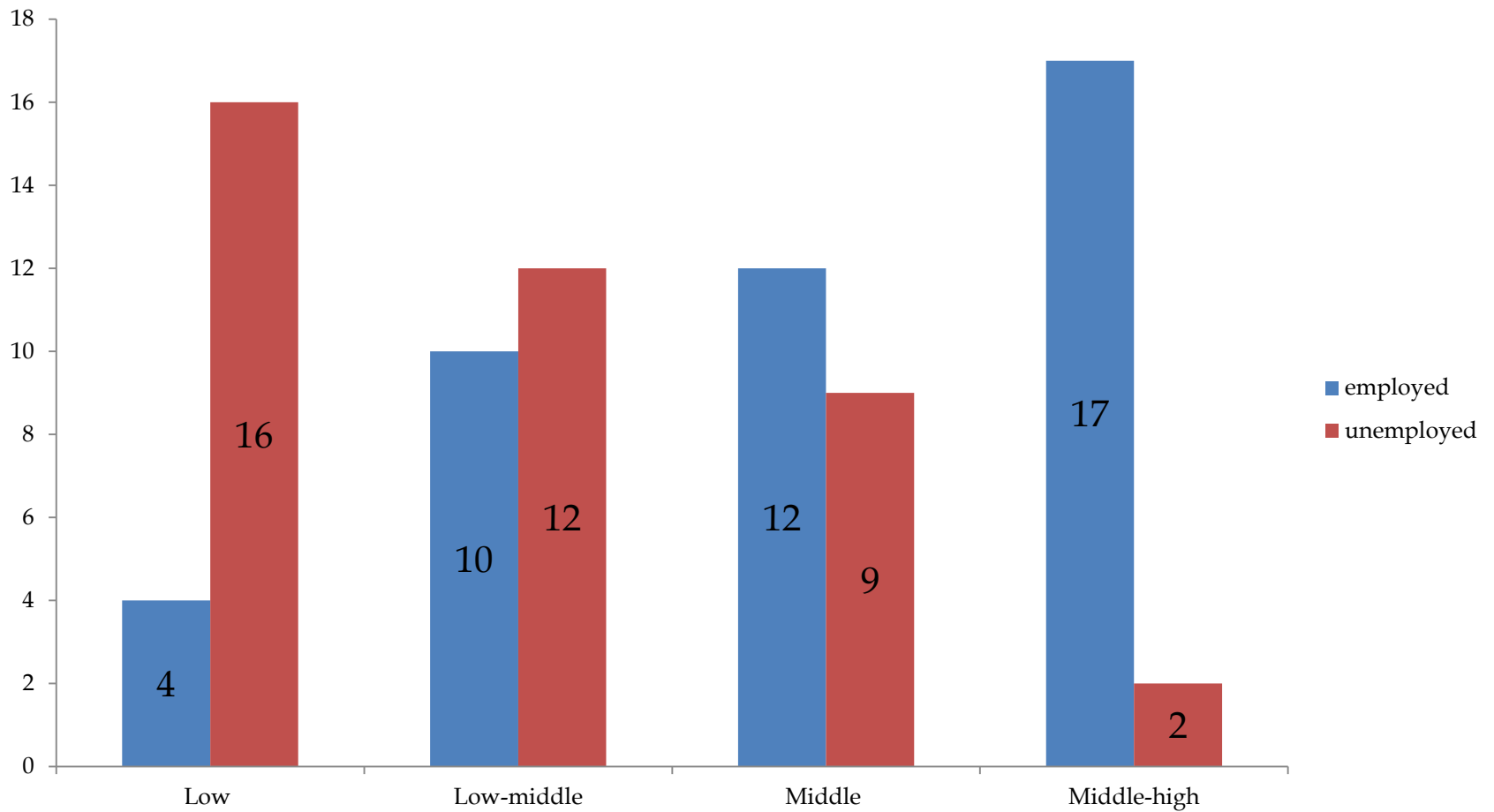
# SES & Annual family income

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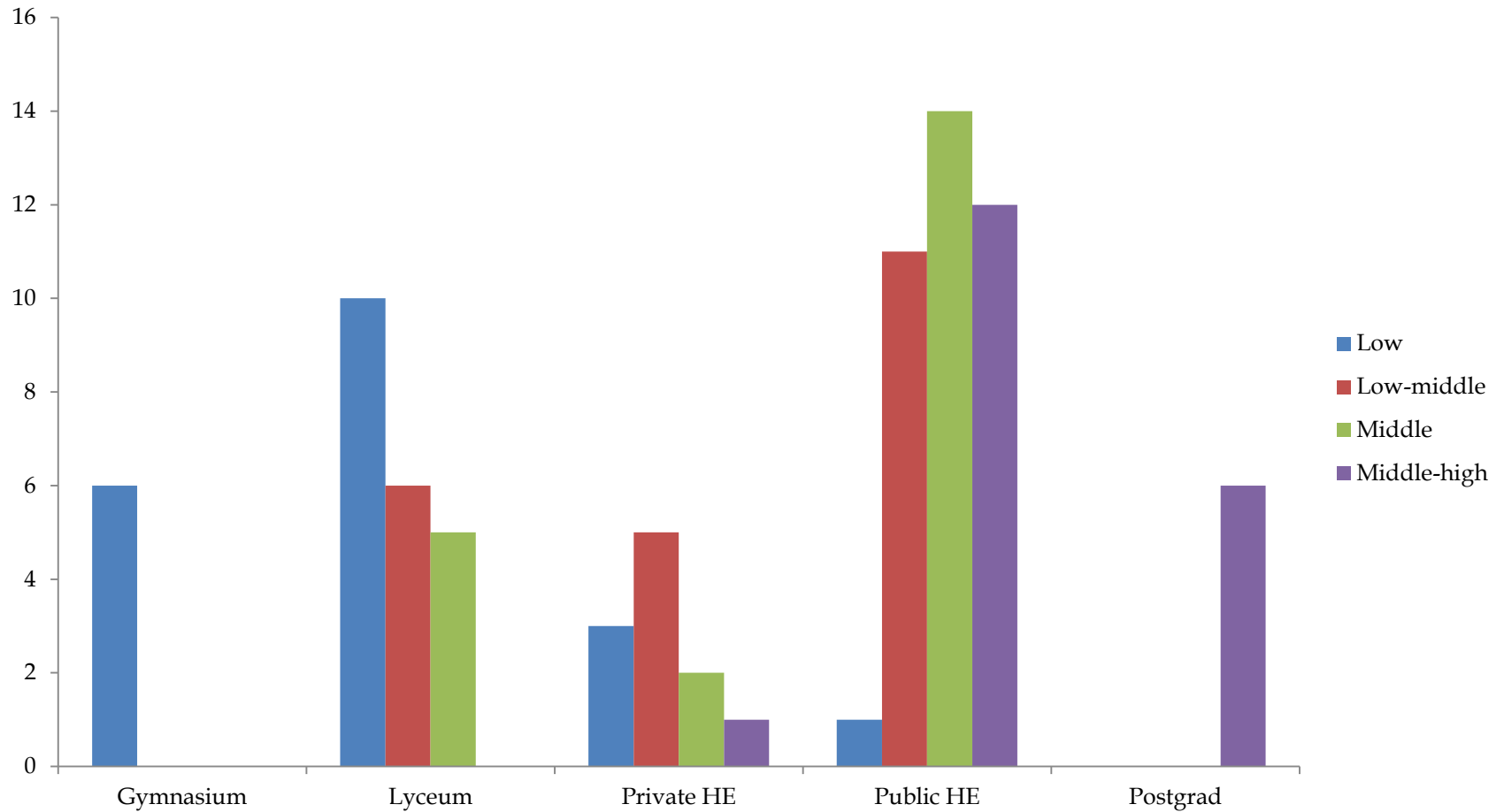
# SES & employment

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# SES & highest educational degree

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# The participants: children

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**Low SES**

**N=20, M<sub>age</sub>= 9.6yrs**

**Middle SES**

**N=23, M<sub>age</sub>= 12.93yrs**

**89 children**

**F=1,90, n.s.**

**Low-Middle SES**

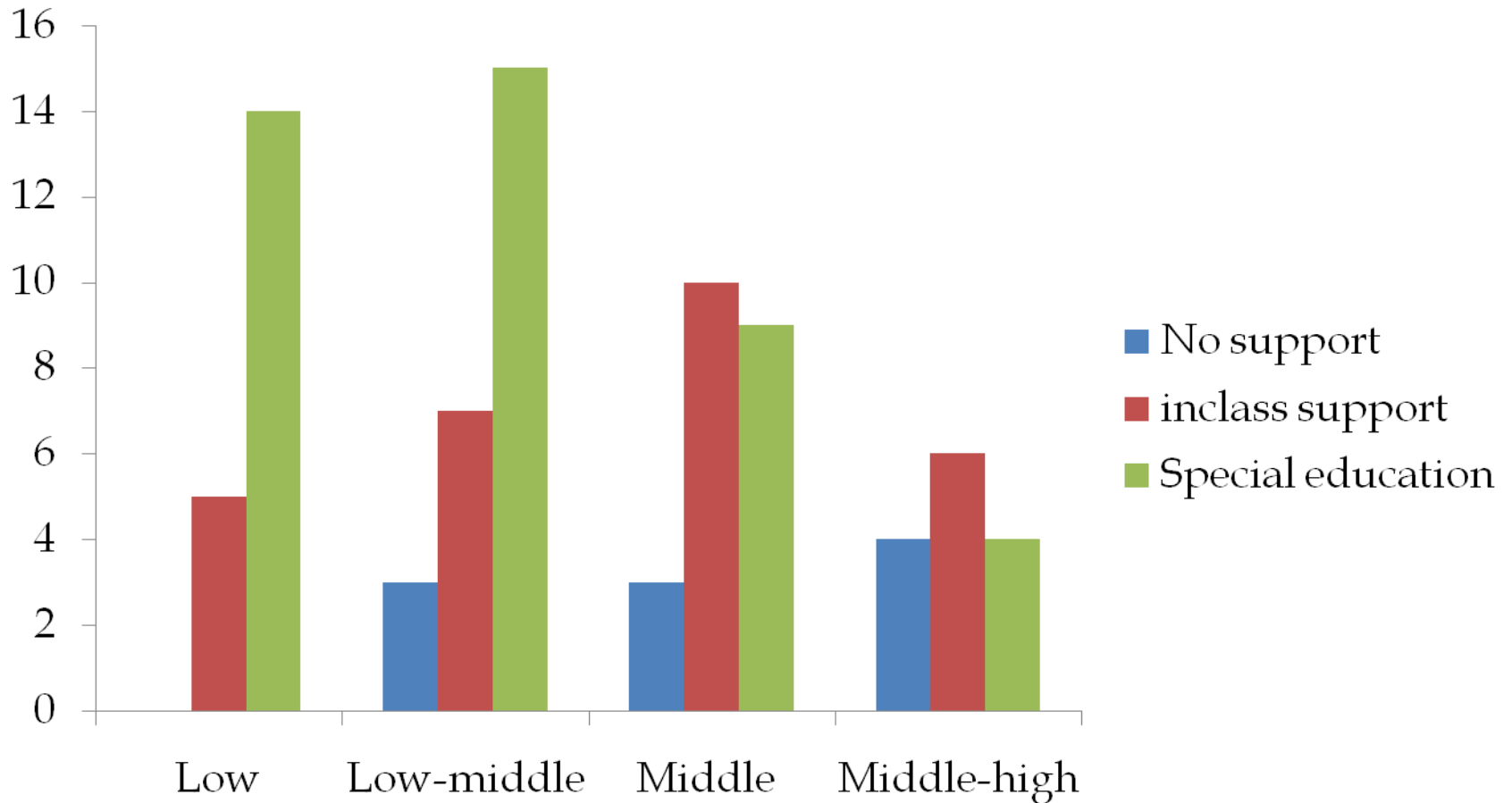
**N=26, M<sub>age</sub>= 10.13yrs**

**Upper-Middle SES**

**N=20, M<sub>age</sub>= 13.56yrs**

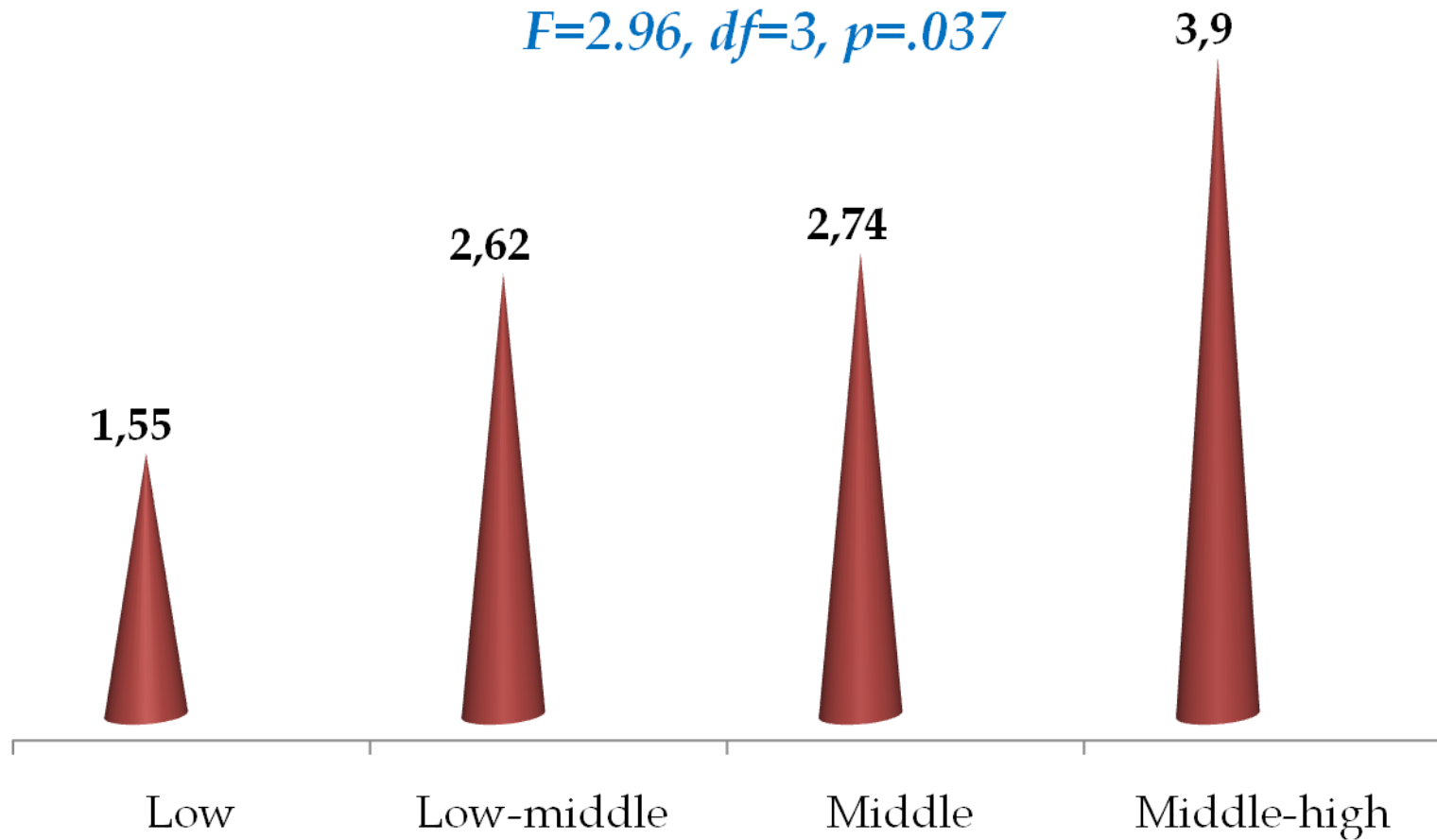
# The participants: children (ASD severity & SES)

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# The participants: children SES & programs

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# The thematic structure of the interview guide

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- Review history: first experience, emotions, significant facts (*4 questions*)
- Mental models, representations, theories and transformations (*8 questions*)
- Present state, quality of life, relationships, social support (*10 questions*)
- Overall reflection on personal journey (*4 questions*)
- Overall/general evaluation of the school, educational and therapeutic course and projection to the future/ future expectations (*5 questions*)

# The method of analysis

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- Constant comparative method
- Thematic analysis
- Thematic nodes
- Thematic codes



# Thematic Nodes (1-3)

1. First experience with Autism/ The “disclosure” of the disorder (A1, A2, A3, A4)
2. Mothers’ representations for their child’s communication with others and his self-awareness (B2, B5, B6) & Marital quality relationship and future expectations (B1, Γ1, Γ2, Γ3, Γ4, E4, E5).
3. Motherhood experience of raising a child with autism (B3, B4, Δ2) & Mothers’ representations and processes for restructuring their role (Δ1.1, Δ2.1).

# Thematic nodes (4-6)

4. Lay models for the interpretation of autism (B7, B8, B8.1) & Therapeutic pathways (E1, E2, E3, E3.1, E3.2)
5. Marital quality, social support and networks ( $\Gamma$ 5,  $\Gamma$ 6,  $\Gamma$ 8,  $\Gamma$ 10)
6. Personal development and coping strategies ( $\Delta$ 1,  $\Gamma$ 7,  $\Gamma$ 9)

# Preliminary findings

- Interesting patterns emerged among mothers' according to their child-rearing practices, their everyday models for the explanation of autism, their notions and experiences of motherhood, their perceptions of the quality of their marital relationship, their coping strategies, the therapeutic paths and their future expectations.

# Thematic node 1: First experiences

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## Thematic Units:

- First signs of autism
- Diagnostic experience
- Emotional reactions

- Thematic Unit: First signs of autism

Thematic Categories:

- Quality of mother reporting
- Description of first signs

- Thematic Unit: Diagnostic experience
- Thematic categories:
  - Positive diagnostic experience
  - Negative diagnostic experience
- Thematic code:
  - Open/supportive vs Restrictive communication

## *Hypotheses*

1. Mothers from middle/upper-middle SES are expected to be more observant and accurate in their reports, while mothers from low SES may lack the ability to process of first signs and their reports may reflect confusion.
2. Mothers from middle/upper-middle SES are expected to obtain a timely professional diagnosis and guidance.
3. Social class variability is not expected about the emotional reactions to the diagnosis.

# Thematic node 5

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Thematic Unit: Coping strategies (range and types)

Thematic Categories:

- Problem-focused strategies
- Emotion-focused strategies
- Resilience
- Avoidance and rejection



- Thematic Category: Problem-focused strategies

Thematic codes:

- Type and range of therapeutic interventions
- Negotiation skills
- Changes in the environment
- Advocacy

□ Thematic category: emotion-focused strategies

Thematic codes:

- Spirituality
- Unrealistically optimistic perspective
- Unrealistic expectations for the future of the child
- Open communication of feelings
- Hope for a miracle cure

## □ Thematic category: Resilience

### Thematic codes:

- External vs internal locus of control
- Commitment to a life course
- Cognitive restructuring
- Reflective-Philosophical outlook to life
- Acceptance of autism and overall approach to disability

□ Thematic category: Avoidance and rejection

Thematic codes:

- Avoidance
- Non-acceptance
- Social withdrawal
- Substance use
- Persistent distancing from the stressor

□ Thematic category: Social support

Thematic categories:

- Range-size of social networks
- Type of social support

Thematic codes:

- ❖ Restricted social support vs expansive social support
- ❖ Satisfactory vs non-satisfactory social support

- Thematic unit: marital quality
- Thematic category: appraisal
- Thematic codes:
  - Positive
  - Negative

- Thematic unit: Responses from social environment
- Thematic category: appraisal
- Thematic codes:
  - Negative
  - Positive
  - Neutral
  - Combined

Hypotheses: social class may reflect differences.

- Mothers from low SES may report avoidance strategies and appraise resilience.
- Mothers from middle high SES may report greater ability to solve practicalities.



*Thank you for your attention!*

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