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Post-Traumatic Stress and Coping Mechanisms Among Mothers of Children with Down Syndrome

التريزوميا كحدث صدمي وأساليب المواجهة لدى بعض الأمهات

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Abstract:

Down syndrome, also known as Trisomy 21, is frequently associated with intellectual disability and a range of developmental and health-related complications. Among the most significant challenges are weight gain, often resulting from excessive eating and limited physical activity, which is further exacerbated by muscle hypotonia and delayed motor development. Additionally, many children with Down syndrome present with congenital heart defects, including atrial and ventricular septal defects and valvular abnormalities. Other common medical concerns include partial or complete hearing loss, visual impairments, and thyroid gland disorders, alongside a spectrum of related health conditions.

This paper investigates the psychological trauma experienced by mothers of children with Down syndrome. At the heart of this trauma lies the collapse of the narcissistic ideal—the imagined perfect child—replaced by a reality marked by medical uncertainty and emotional upheaval. The study further examines the coping strategies these mothers employ to navigate their new reality, adapt to their circumstances, and gradually reconcile with the profound shock of the diagnosis.

Keywords: Down Syndrome, Post-Traumatic Stress Disorder, Coping Mechanisms, Maternal Psychology

الملخص

يرتبط عرض داون (متلازمة داون) بالإضافة إلى التخلف العقلي بجملة من المشاكل الصحية، والاضطرابات النمائية ومن أهمها:

- زيادة الوزن بسبب كثرة الأكل وقلة الحركة، والإصابة بالارتخاء العضلي، إضافة إلى تأخر المشي والحركة.
- أمراض القلب، ومن أهمها: العلل القلبية، انتشار الثقوب في الجدران وسط القلب، وثقوب وعجز في البطين والأذنين، وتشوهات صمامات القلب.

- فقدان حاسة السمع في أذن واحدة أو كليهما.

- اضطراب النظر ومشاكل في الغدة الدرقية، وغيرها من الأمراض.

من خلال هذه الورقة، أحاول التطرق للحدث الصدمي الذي تمر به أمهات أطفال عرض داون، وذلك كخبرة أمل للحلم النرجسي للطفل المنتظر وأساليب المواجهة التي تتبناها الأمهات للتمكن من المعيشة وتجاوز الصدمة. الكلمات المفتاحية: متلازمة داون، اضطراب ما بعد الصدمة، آليات التكيف، علم نفس الأمهات.

1. INTRODUCTION

The birth of a child with chromosomal abnormalities, such as Down syndrome (Trisomy 21), introduces an overwhelming tide of sorrow and confusion into the family. The mother may initially interpret the baby's slanted eyes as a familial trait—perhaps resembling her own or the father's—but the eventual clinical confirmation shatters this illusion, announcing the presence of Trisomy 21.

Awaiting the final medical report, the mother is flooded with anxious questions: Why did this happen to me? Should I quit my job? What will happen to my child? Will they be bullied? Who will care for them after I'm gone? This emotional turmoil often triggers denial. Fathers may express their grief through tears or rejection.

Down syndrome is a chromosomal anomaly caused by abnormal cell division, resulting in a full or partial extra copy of chromosome 21. This leads to developmental changes and distinct physical features. The emotional shock a mother experiences in such cases produces intense psychological stress, often escalating into post-traumatic stress disorder (PTSD). This condition is marked by persistent anxiety, intrusive memories, and uncontrollable thoughts—compelling the mother to adopt various coping mechanisms in response to both her grief and society's judgment.

1. Research Problem

Serge Lebovici, a psychiatrist and psychoanalyst, argued that every real child is preceded by an imagined child—a narcissistic fantasy projected by the expecting mother. This "phantasmic child" only gains form at birth. The arrival of a child is thus an unpredictable experience, a dream of happiness intertwined with the hope of parenthood.

Freud conceptualized the desire for a child as a narcissistic wish—an aspiration for immortality and continuity through procreation. Winnicott, a pediatrician and psychoanalyst, described the mother's psychological state during pregnancy and early motherhood as a form of narcissistic

withdrawal focused entirely on the newborn. This phase is essential for bonding and the child's emotional development (Clotilde Perrault, 2015, p. 6).

After birth, mothers often experience ambivalent emotions, a paradoxical coexistence of love and resentment. The longing for the child's life may be shadowed by a contradictory desire for its end—stemming from profound disappointment in the real child not living up to the imagined ideal. Childbirth marks a psychological turning point for both parents, especially the mother. The role of parenthood offers narcissistic gratification, as it reflects parental ideals and aspirations—thus the birth of a child with Down syndrome deeply disrupts this dynamic (Clotilde Perrault, 2015, p. 6).

Elisabeth Zinschitz (2007) viewed the diagnosis of a child's disability as the starting point of a new story—a radical rewriting of the anticipated parent-child narrative. Similarly, Patrick Ben Soussan (2007) argued that the birth of a child with congenital anomalies thrusts parents into a state of shock and emotional rupture, where their hopes are replaced with fears, and dreams turn into a struggle between hardship and latent resentment.

With time, parents begin to search for meaning: Why did this happen? Their answers oscillate between innocence and guilt. This emotional turbulence poses a central question: how does the mother's attachment to her dream of motherhood—a dream imbued with joy, anticipation, and narcissistic imagery—cope with the reality of raising a child with Down syndrome?

Cohen (1999, p. 53) found that many parents—especially mothers—struggled for years, often decades, to articulate their pain. The day they learned their child had Down syndrome remained emotionally vivid and traumatic.

Research by Korff Sausse (1990, 1995, 1996) showed that such events profoundly affect maternal identity and family dynamics. When a child has an obvious congenital anomaly like Down

syndrome, the mother must employ significant psychological strategies—often marked by contradiction and ambivalence—to cope.

These shifting emotional states give rise to various coping methods: denial of the diagnosis, self-blame as a form of guilt expiation, or a turn toward acceptance, spiritual surrender, and religious faith.

2. Research Focus and Questions

This study investigates post-traumatic stress and coping mechanisms among mothers of children with Down syndrome. The research aims to answer the following questions:

1. Does giving birth to a child with Down syndrome lead to symptoms of post-traumatic stress in the mother?
2. What are the most commonly reported symptoms of PTSD among these mothers?
3. What coping strategies are most frequently employed by mothers of children with Down syndrome?

3. Hypotheses

1. The birth of a child with Down syndrome leads to the development of post-traumatic stress symptoms in the mother.
2. Traumatic experiences are the most prevalent PTSD symptoms among mothers of children with Down syndrome.
3. Problem-focused coping strategies are the most commonly used by these mothers.

4. Conceptual Definitions

➤ Post-Traumatic Stress Disorder (PTSD):

A form of anxiety disorder, classified under DSM-IV-R, characterized by reliving the traumatic event, avoidance of related stimuli, poor concentration, irritability, hypervigilance, and disturbing dreams (DSM-IV, 1999, p. 136).

Operational definition: The score obtained by the participant on the Davidson PTSD scale, translated into Arabic by Abdelaziz Tabit. It measures PTSD symptoms across three dimensions:

- a) Re-experiencing the trauma
- b) Avoidance
- c) Hyperarousal (Annie Perreaut, 2000, p. 50)

➤ Coping Strategies:

According to Khalifa et al., coping strategies encompass all cognitive, emotional, and behavioral efforts made by an individual to deal with stressors and maintain emotional equilibrium and psychological well-being (Mohammed Jamil Al-Saadi Al-Harbi, 2021, p. 905).

Operational definition: The score obtained by the mother on a standardized coping strategy scale indicating the methods she uses to manage the traumatic event.

➤ Down Syndrome:

Psychological Dictionary: A chromosomal disorder arising from abnormal cell division during gametogenesis or early embryogenesis, resulting in an extra chromosome (N. Sillamy, 1997, p. 177).

Speech Therapy Dictionary: A disorder explained by an extra chromosome in the cell, leading to both psychomotor delays and distinctive physical features (F. Brin, 1977, p. 228).

Clinical Features: Accompanied by intellectual disability, muscle hypotonia, and morphological traits such as flat face, small head, short neck, protruding tongue, upward-slanting eyes, epicanthic folds, abnormally shaped ears, and single palmar crease. Diagnosis is confirmed through a karyotype test, which distinguishes between different types of Trisomy 21, including mosaic and translocation variants (Sabrina Khaldoun, 2020, p. 8).

5. Methodology and Tools

Research Method:

The study employs the clinical case study approach, ideal for investigating PTSD in mothers of children with Down syndrome and their coping mechanisms. This method involves gathering data through observation, interviews, case histories, and psychological assessments.

6. Study Parameters

Fieldwork Location:

The field study was conducted at the Psychological and Educational Center in Draa El-Samar, which offers daytime care for intellectually disabled children in Médéa Province. The center operates from 9 a.m. to 3 p.m. and caters to children aged 5 to 19 with

varying degrees of disability—mild, moderate, severe, and complex cases with associated conditions such as psychosis or hyperactivity.

7. Research Sample

The sample was selected based on a preliminary survey. Out of 9 assessed cases, 5 were selected based on their PTSD scale results, confirming their experience of post-traumatic stress following the diagnosis of their child with Down syndrome.

Case N°	Current Age	Marital Status	Socioeconomic Level	Mother's Age at Childbirth	Child's Current Age
01	36	Married	Middle	20	15
02	47	Married	Middle	39	8
03	43	Married	Middle	30	13
04	36	Married	Middle	25	9
05	53	Married	Middle	40	13

7. Instruments Used:

A. Clinical Interview:

The purpose of the guided clinical interview was to gather multifaceted information concerning each case, particularly focusing on the family atmosphere, and to validate data relevant to the subject of the study.

The researcher employed a semi-structured clinical interview guide containing preformulated questions directed at the mother, timed appropriately during the session. The preparation of the interview form followed these steps:

In-depth familiarization of the researcher with the subject matter.

Identification of the interviewees, location, and timing of the interview.

Introduction of the mothers to the study with the assistance of the center's specialist.

Scheduling the interview sessions according to the mothers' availability, in a respectful and comfortable setting.

Interview Topics:

First Axis:

Mother's perceptions of her child during pregnancy and the associated symbolic representations.

Instruction: What were your dreams and imagined qualities of your child during pregnancy?

Second Axis:

The mother's reaction upon learning the shocking news that the newborn has Down syndrome, as well as the reactions of her husband and extended family, and the emotional impact of others' perceptions.

Instruction: How did you find out your child had Down syndrome, and how did you, your husband, and your family react? How did the community's view affect you?

Third Axis:

The psychological pressures experienced by the mother and the challenges she faced in raising the child.

Instruction: How has raising your child been? What were the major difficulties you encountered?

Fourth Axis:

Coping strategies used by the mother to deal with the shock and stressful situations she experiences.

Instruction: How do you currently deal with your child and what do you see in his future?

When you feel overwhelmed or helpless, how do you deal with it?

2. The Post-Traumatic Stress Scale (Davidson Scale):

The Davidson Trauma Scale (translated by Abdel Aziz Thabet) consists of 17 items corresponding to the diagnostic criteria of the DSM-IV. The scale is subdivided into three subscales:

1. Re-experiencing the Trauma: Items 1–2–3–4–17

2. Avoidance of the Trauma: Items 5–6–7–8–9–10–11

3. Hyperarousal Symptoms: Items 12–13–14–15–16

Each item is rated on a five-point scale from 0 to 4. The subject is asked to assess symptoms experienced during the past week. The maximum total score is 153.

Results:

Full Report on Case 01:

Name: N

Age: 36 years

Pregnancy: Intended

Education: Completed middle school (Grade 9)

Number of Children: 4

The subject is a 36-year-old woman who left school after obtaining her middle school certificate, as per her father's decision. She entered a traditional marriage. She did not disclose her husband's occupation, stating only that their living standard is moderate. N is the mother of four children, her firstborn being delivered at age 20. This child, now 15, has been diagnosed with a 100% disability.

The subject consented to the interview and initially appeared calm and cooperative, responding to both verbal and written questions naturally. However, when discussing the traumatic event, visible signs of sorrow emerged.

She appeared neat, with well-coordinated clothing, and in overall good physical health, although signs of fatigue and facial pallor were observed.

Analysis of the First Semi-Structured Interview:

Upon agreement to answer the prepared questions based on the outlined axes:

N described the typical hopes of an expecting mother for her firstborn, stating: "I dreamt of a healthy child." She was initially informed by the doctor that the baby would be a girl, which turned out to be incorrect: "They told me it was a girl."

The greater shock, however, came when she discovered her son had a disability: "When the doctor told me my son was sick, I said 'Oh God!' I will never forget that day. It was a shock, a day I will always remember."

1. Results of the Post-Traumatic Stress Scale – Case 01:

Category	Items	Score
Traumatic Re-experience	1-2-3-4-17	3
Avoidance Symptoms	5-6-7-8-9-10-11	5
Hyperarousal Symptoms	12-13-14-15-16	4

As shown in Table 01, the subject exhibited three re-experiencing symptoms (vs. only one expected), five avoidance symptoms (vs. three expected), and four hyperarousal symptoms (vs. one expected). These results clearly indicate that N is experiencing symptoms of post-traumatic stress, as confirmed by the scale.

2. Results of the Coping Strategies Scale – Case 01:

Coping Style	Items	Score
Problem-focused coping	1-4-7-13-16-19-22-25-27	26
Emotion-focused coping	2-5-8-11-14-17-20-23-26	23
Social support-seeking	3-6-9-12-15-18-21-24	19

According to Table 02, the mother primarily employed problem-focused coping (score: 26), reflecting her attempt to manage or reduce the emotional distress she experiences. This was followed by emotion-focused coping (score: 23), indicating strong emotional reactions such as anger, stress, and difficulty accepting her son's condition. The least utilized strategy was seeking social support (score: 19), suggesting she received insufficient emotional or social backing.

General Analysis of Case 01:

The content analysis of the semi-structured interview and scale results suggests that the mother (N) remains in a state of psychological shock and denial. Her repeated description of the experience as a "shock" — "a day I will never forget, a moment of disbelief" — reflects her difficulty in accepting the unexpected event. She reported significant challenges in managing her son's behavior and her relationship with his father, stating: "As he grew up, he became difficult. I have issues with his father who treats him as if he's sick. He now dominates both of us. He even calls me mean because I discipline him when he misbehaves."

These reports are consistent with the high scores obtained in the PTSD scale: 3 symptoms of traumatic recall, 5 avoidance

symptoms, and 4 hyperarousal symptoms, all exceeding the expected thresholds.

Although deeply affected by trauma, N exhibits a commendable effort to cope, especially through problem-focused strategies (score: 26), as seen in responses like: "I knew what needed to be done, so I doubled my efforts. I found one or two solutions to the problem."

Her elevated emotion-focused score (23) also indicates she frequently experiences emotional distress, as confirmed by her statement: "Yes, I feel anxious and tense. I don't know... it really affected me. It got harder as he grew."

Summary of Case 02:

Name: G

Age: 47 years

Pregnancy: Unintended

Socioeconomic Level: Middle

Number of Children: 4

G is a 47-year-old mother of four (three sons and one daughter), with a modest socioeconomic background. She never attended school and is married to her cousin. She gave birth to her child with Down syndrome at the age of 39 following an unwanted pregnancy that was also marked by complications. The delivery was natural, and the child — now 8 years old and her youngest — was diagnosed by a physician as having Down syndrome.

The interview was conducted in the presence of her daughter and the affected child. Initially, G displayed ambiguous, subdued behavior, as seen in her tone and facial expressions. She appeared physically well but had noticeable facial pallor. Her answers were reserved, likely due to her daughter's presence, who at times answered on her behalf. Therefore, a second, private session was conducted.

G responded to the pregnancy-related questions with "normal." Her husband's reaction was similarly described as "normal," stating: "God gave him to me." However, her in-laws did not accept the child, and she was clearly affected by society's gaze: "I was hurt by how people and society looked at me."

G expressed her emotional shock clearly: "I was shocked... it's trisomy." She also struggles with her son's care, particularly his lack of independence, stating that he "still wears diapers" and that she has "failed to teach him basic self-care." She once held hope that he would improve like a neighbor's child with a disability but now lives with fear for the future.

3. Results of the Post-Traumatic Stress Scale Application

Category	Items	Score
Traumatic Experience Symptoms	1-2-3-4-17	5
Avoidance Symptoms	5-6-7-8-9-10-11	6
Arousal Symptoms	12-13-14-15-16	4

The table shows that the case subject presented with five symptoms related to traumatic experiences—a significantly high score—indicating that the individual has been exposed to considerable psychological stress. Additionally, six avoidance symptoms were identified, which is also above average. This suggests that avoidance symptoms and traumatic experience symptoms are the most prominent in this case.

4. Results of the Coping Strategies Scale

Category	Items	Score
Problem-Focused Coping	1-4-7-10-13-16-19-22-25-27	28
Emotion-Focused Coping	2-5-8-11-14-17-20-23-26	28
Social Support-Focused Coping	3-6-9-12-15-18-21-24	20

The data reveal that the subject (G) scored 28 points on both problem-focused and emotion-focused coping strategies, and 20 points on coping strategies related to seeking social support.

General Analysis of Case Two

The subject's initial reactions were marked by shock following the birth of her child diagnosed with Trisomy 21. Referring back to the results of the PTSD scale, she exhibited five trauma-related symptoms (out of one listed), six avoidance symptoms (out of

three), and four arousal symptoms (out of one). These findings are supported by the observable avoidant and reserved behavior during the clinical interview. The subject also expressed ongoing stress stemming from family and spousal dynamics, saying:

“I’m not living normally, it’s because of them... even my husband wasn’t accepting it—only recently has he become okay.”

The subject employs two primary coping styles: problem-focused coping (28 points), which is generally positive and effective in mitigating the psychological impact and stress intensity, and emotion-focused coping (also 28 points). These are followed by a moderate reliance on social support (20 points).

Discussion of Hypotheses

This study aims to explore the psychological impact of giving birth to a child with Down Syndrome, a condition that is not only associated with intellectual disability but also characterized by distinct physical traits. The findings derived from the tested hypotheses are summarized below:

1. Hypothesis One: Giving birth to a child with Down Syndrome results in PTSD symptoms among mothers.

This is supported by all five cases examined, where mothers exhibited varying degrees of PTSD symptoms. This is consistent with literature that considers such symptoms to be a natural response to deeply distressing or traumatic life events. (Zahid Bouaicha, 2012, p.15)

2. Supporting Literature: A study by Widad Mabrouki (2014) confirmed that mothers of children with Down Syndrome suffer from both physical and psychological strain, leading to stress that is difficult to overcome. This justified her implementation of a cognitive-behavioral group therapy program to reduce PTSD symptoms.

3. Hypothesis Two: Avoidance symptoms are the most prevalent PTSD symptoms among mothers of children with Down Syndrome.

This was observed across the board, with mothers showing reluctance to discuss their perceptions, especially concerning motherhood, femininity, and spousal

relationships. Their communication was often characterized by silence, brevity, and visible discomfort when discussing emotionally charged topics.

Case	Trauma Symptoms	Avoidance Symptoms	Arousal Symptoms
Case One	3	5	4
Case Two	5	6	4
Case Three	3	5	4
Case Four	4	5	5
Case Five	3	3	5

These results confirm that avoidance is the dominant reaction, with mothers providing superficial responses and avoiding detailed accounts of their emotional experiences.

4. Hypothesis Three: The most commonly used coping strategy among mothers of children with Down Syndrome is problem-focused coping.

This hypothesis is supported by the data, which indicate that all participants predominantly employed problem-solving strategies, followed by emotion-focused approaches and, lastly, social support.

Case	Problem-Focused	Emotion-Focused	Social Support
Case One	26	23	19
Case Two	28	28	25
Case Three	24	25	25
Case Four	30	30	23
Case Five	30	30	24

This pattern suggests that most women rely on problem-focused coping to reduce stress. Emotion-focused coping is also commonly used due to the comprehensive physical and emotional toll of the child’s condition. According to Lazarus and Folkman, coping involves persistent cognitive and behavioral efforts to manage internal and external demands that exceed personal resources. (Samer Jamil Radwan, 2012, p.204)

Folkman (1984) also notes that individuals confronted with traumatic situations tend to adopt emotion-focused coping when the problem is perceived as uncontrollable, whereas they use problem-focused coping when they believe they can exert influence over the situation. (Ahmad Eid Mutie Al-Shakhanbeh, 2010, p.38)

All five mothers in the study relied primarily on problem-focused coping. According to Lazarus, this approach aims to modify the relationship between the individual and their environment by altering behavior and seeking relevant information to manage stressors. It is a constructive strategy for alleviating pressure and finding adaptive ways to raise their children. Mothers also resorted to defensive mechanisms such as denial, distraction, optimism, and emotional support, along with avoidance of stress triggers. (Fatima Hassani, 2015, pp. 38–39)

GENERAL CONCLUSION

There is no universally correct way to deliver bad news, but some methods are significantly less harmful than others. Bad news fundamentally alters the patient's perception of their future—often in irreversible and negative ways. The issue is not merely diagnostic; it encompasses long-term emotional, social, and existential consequences.

Delivering such news is not only challenging for the patient but also for the physician, whose emotional burden must not be overlooked. The way the news is communicated, the terminology employed, and the professional's demeanor all play critical roles and carry potential risks. Mishandling this moment can undermine the child's developmental prospects and obstruct timely, empathetic intervention.

Ultimately, what matters is not what is said, but what is understood. The goal is to tailor information to the patient's immediate psychological needs. Always remember: what is said is not necessarily what is heard, and it is the patient who must walk the path toward acceptance and healing.

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