

Understanding the Relationship between Psychosocial Factors and Unexplained Regression in Individuals with Down Syndrome



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BACKGROUND

There is an increasingly recognized phenomenon of regression in individuals with Down syndrome (DS), in which previously acquired skills are lost. Symptoms may present in an acute rapid decline¹ or in a gradual manner². Individuals with this presentation may have varying underlying etiologies, such as underlying mental health conditions, trauma, environmental factors, and neurological disorders³. However, there is limited research focusing on the effect of psychosocial stressors on the development of regression.

OBJECTIVES/AIMS

We explored different types of psychosocial stressors and their incidence in the year preceding the onset of developmental regression in individuals with DS.

DESIGN/METHODS

A **retrospective chart review** (N =13) was conducted on individuals with a diagnosis of **DS** and **regression** looking at specific psychosocial information collected through clinical care.

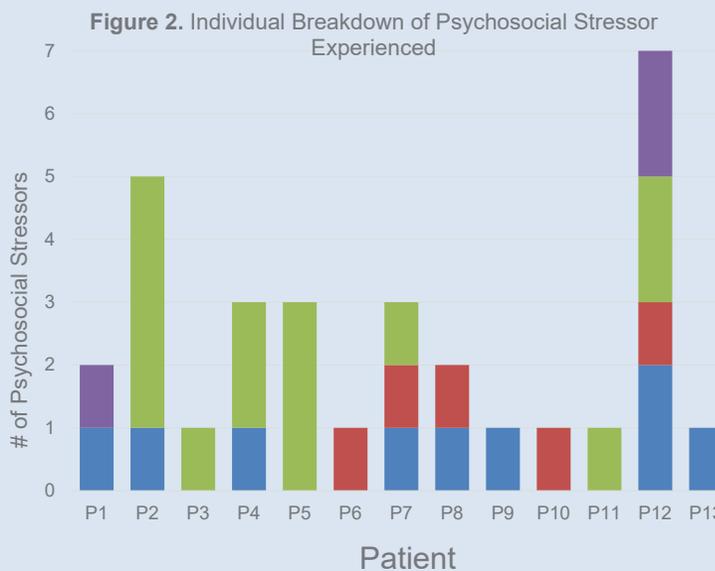
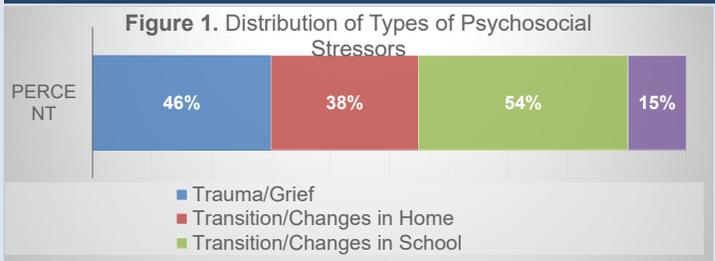
The psychosocial stressors were divided into four categories:

- *Trauma and/or Grief*
- *Changes in Home Structure*
- *Transition/Changes in School*
- *Changes in Social/Peer Relationships*

For the current study, only psychosocial history that occurred *within the time frame of one year prior to regression* of skills was examined.

Basic frequencies were calculated to determine prevalence of each psychosocial stressor for each patient.

RESULTS



Summary

- All individuals with unexplained regression had some sort of psychosocial stressor (e.g. has experienced at least 1 psychosocial stressor)
- Over 1/2 (54%) experienced a **transition/change in school**
- 46% of individuals experienced 2 or more psychosocial stressor one year prior to regression in skills

Table 1. Breakdown of Psychosocial Stressors

Stressor	N	%	
Trauma or Grief	Hospitalization causing trauma	3	20
	Other (puberty causing distress/fight with mom)	2	13
	Abuse	1	7
	Awareness of disability	1	7
	Illness of friend or family member	1	7
Changes at Home	Loss of family/peer/pet	1	7
	Family member moved away	3	20
	Moved to new home	1	7
Transition/Changes at School	Changes in parent relationship (i.e. divorce, separation, new marriage)	1	7
	New school	5	33
Changes in Social/Peer Relationships	Changes in teacher	4	27
	Classroom changes	3	20
	Changes in services/supports	2	13
Changes in Social/Peer Relationships	Loss of a relationship	1	7
	Changes in peer relationships	1	7
	Changes in extracurricular activities	1	7

***All 0% responses not included in the table: teasing, domestic disputes, near death experience, loss of pet/friend, family/friend moved into home, transition to adult life and loss of social support*

CONCLUSIONS

The data suggest that a wide variety of life changes and psychosocial stressors appear to play an important role in unexplained regression in DS.

Limitations:

- Psychosocial history not captured systematically in clinical note

Future Directions Should:

- Determine whether having more psychosocial stressors leads to poorer outcomes.
- Capture psychosocial history **prospectively & specifically** for all clinic patients via clinical improvement.
- Include assessment of psychosocial risk factors collected across institutions in the Down Syndrome Consortium.

REFERENCES

¹Devenny, D., & Matthews, A. (2011). Regression: atypical loss of attained functioning in children and adolescents with down syndrome. *International Review of Research in Developmental Disabilities*, 41, 233-264

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³Jacobs, J, et al. (2016). Rapid Clinical Deterioration in an Individual with Down Syndrome. *American Journal of Medical Genetics, Part A* 170A, 1899-1902