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Developmental Regression in Down Syndrome: Family Survey

Elise M. Sannar MD^{ab}, Lina R. Patel PsyD^b, and Eileen A. Quinn, MD^c

Anna and John J. Sie Center for Down Syndrome^a, Children's Hospital Colorado
Department of Psychiatry, University of Colorado, Anschutz Medical Campus, CO^b
and University of Toledo College of Medicine and Life Sciences^c



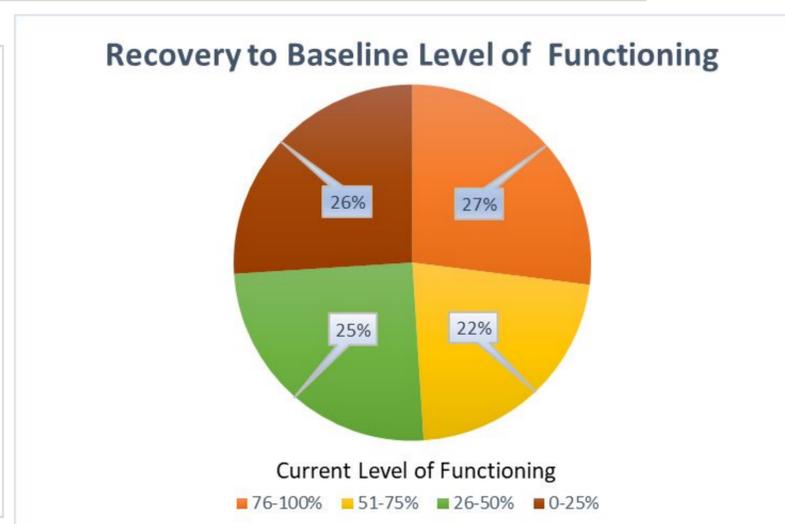
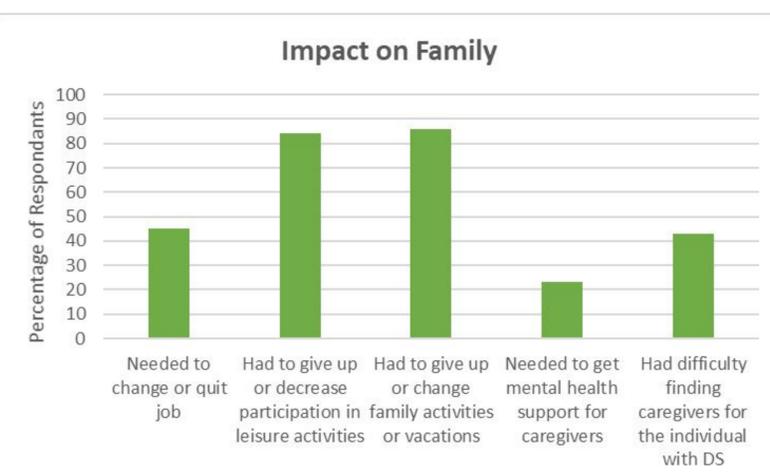
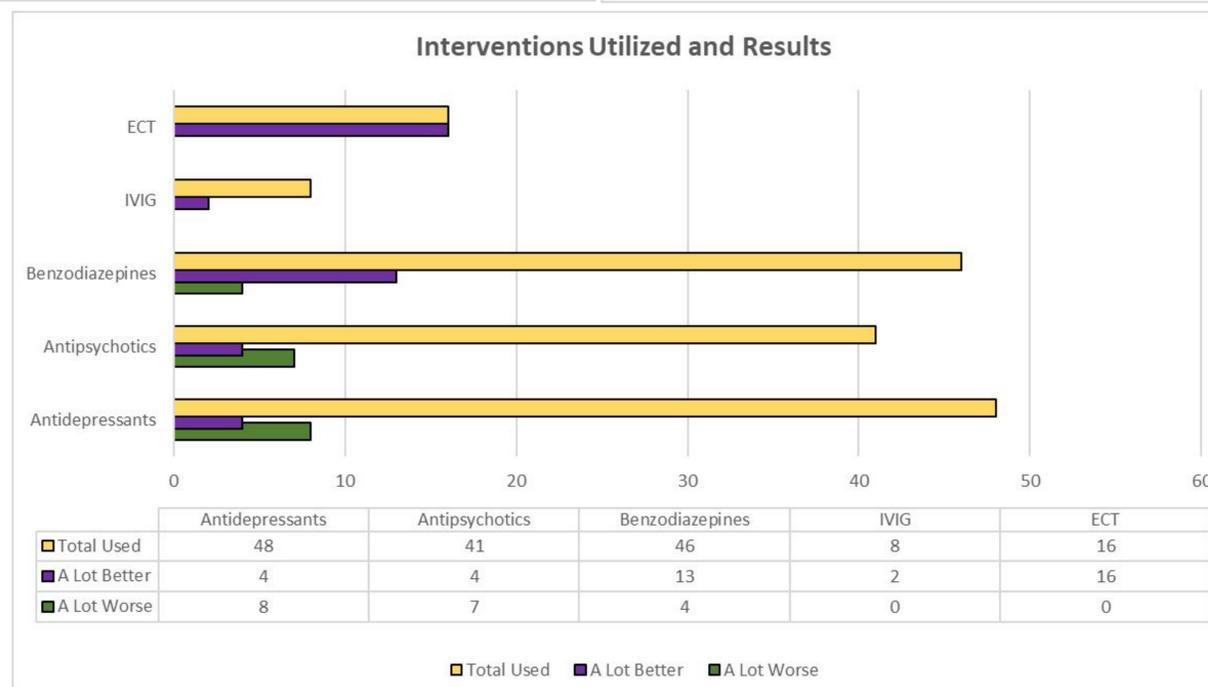
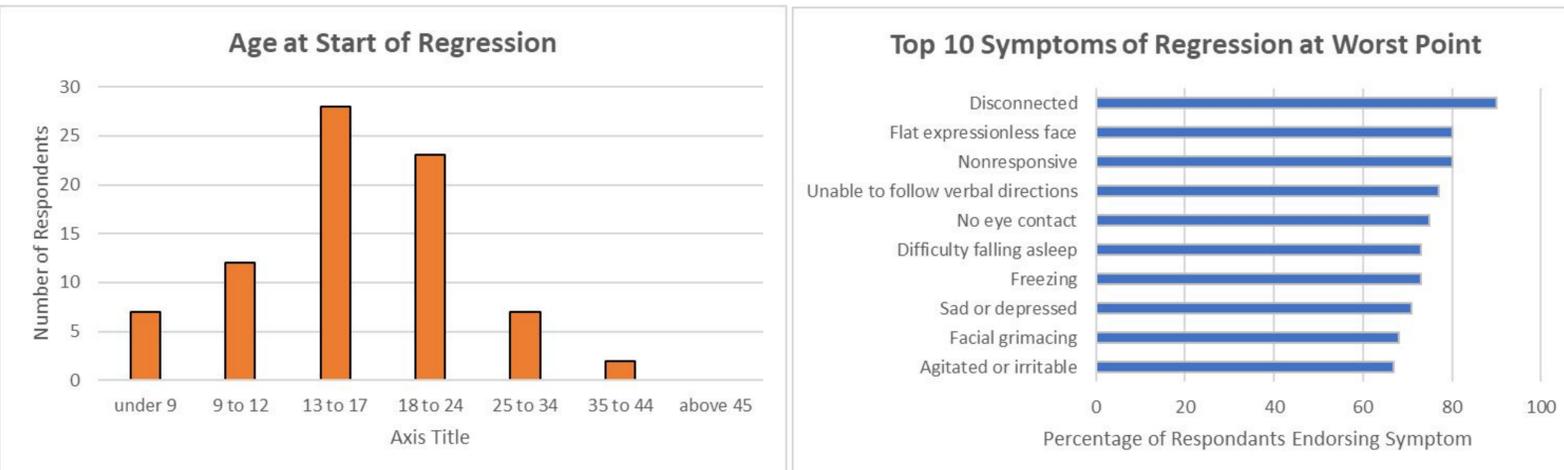
Background/Objective

The goal of this study is to gather information from family members of individuals with Down syndrome (DS) who have experienced developmental regression. Developmental regression in Down syndrome is defined as a rapid and atypical loss of skills in cognition, socialization, and daily life activities. The experience for family members can be devastating and frustrating. The phenomenon is underrecognized outside of DS specialists and treatment options can be difficult to access.

Methods

After obtaining approval from the Colorado Institutional Review Board, a survey was posted to a private Facebook website for family members whose loved ones have experienced regression. Access to the Facebook page was granted by a medical doctor with expertise in Down syndrome and regression. The page is also open to professionals. The survey was designed to elicit information about family experiences. SurveyMonkey software was utilized to create the survey and analyze responses. Seventy-nine responses were collected, all from parents. Questions included description of symptoms before the regression, at its worst point, and at the time of the survey. Additional questions included treatment interventions and response and family impact.

Results



Limitations

Limitations include:

- Self selection of respondents. Families in the Facebook group are not a representative sample of all individuals impacted by regression as participants join based on word of mouth.
- Survey results are based on parent report and did not include any objective measures of regression or professional perspectives.
- No statistical analysis was performed.

Conclusions

- Families whose loved ones experience regression have diverse experiences.
- Age of onset of regression is most common in adolescence and early adulthood.
- The most common symptoms reported include disconnection and lack of responsiveness.
- Electroconvulsive therapy is the treatment intervention associated with the most positive response.
- Other treatment interventions have mixed results, including making some individuals worse.
- Family impact is significant.
- Less than 50% of respondents report that their loved one has achieved at least 50% of their baseline functioning since the onset of the regression.
- When asked what advice they would give to families in a similar situation, the overwhelming response was to connect with a Down syndrome expert or center and join a support group.