

Parents' resolution with their child's diagnosis, parent-child communication about the diagnosis, and the well-being of adolescents and young adults with vision loss.



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Purpose

- Rates of mental health problems among individuals with vision loss are high¹ but are only partially explained by the severity of the diagnosis.
- We examined the role of the parent-child relationship in the mental health and daily functioning of adolescents and young adults with visual loss.
- We focused on parents' resolution with their child's diagnosis and open and positive parent-child communication about the diagnosis.

Hypotheses

- Parents who are more resolved with their child's diagnosis would report more frequent and positive communication with their child about the diagnosis.
- Adolescents and young adults with vision loss who experience more frequent and positive communication with their parents about the diagnosis will show higher acceptance of their diagnosis, better daily functioning, and increased mental health (i.e., higher sense of belonging to the visual loss community, more positive global self-esteem, and fewer symptoms of depression and anxiety).

Participants

- 15 parents of children (94% mothers, 6% fathers, child age 5-33 years)
- 25 adolescents and young adults (56% male, 44% female, age 18-40) with vision loss.

Procedure and Measures

<u>Parents</u> completed the Reaction to Diagnosis Questionnaire² - 42 items assessing feelings and thoughts regarding the child's diagnosis (e.g., "When I think about being a parent of a child with special needs, I feel guilty.")

Parents & youth completed the Child and Parent Perspectives on Communicating about Epilepsy Questionnaire³, adapted to the context of vision loss - 42 items tapping the frequency and positivity of communication (e.g., "talking to my child/parents about epilepsy makes me feel optimistic.")

The youth completed the following self-reports:

- 1. Diagnosis Acceptance Questionnaire for Adolescents/Adults
- 10 items (e.g., "Every time I think about having visual loss, I feel sad and angry.")
- 2. The NEI Visual Function Questionnaire (VFQ-25) evaluates their daily functioning (e.g., "How much difficulty do you have reading ordinary print in newspapers?").
- 3. The Disability Identification Scale⁴ 5 items (e.g., "Being a member of the disabled community is central to my identity."
- 4. **The Self-Esteem Scale**⁵ 10 items (e.g., "At times I think I am no good at all.")
- 5. The Depression Anxiety and Stress Scale⁶ 14 items, (e.g., "I felt down-hearted and blue".)

Results

- Parents' higher resolution with their child's diagnosis was associated with greater openness and positivity in communication with their child.
- Youth reports of more frequent and positive communication with parents were associated with greater acceptance of the diagnosis and a higher sense of belonging to the visual loss community, but not with their daily functioning or their selfesteem and depression and anxiety symptoms.

Table 1: Correlations between study variables

	Frequent & Positive Communicating
Parents' resolution with their child's diagnosis	.50*
Youth diagnosis acceptance	.45*
Youth daily functioning	16
Youth disability group identification	.61**
Youth self-esteem	07
Youth depression symptoms	35
Youth anxiety symptoms	19

^{**} *p* < .01. * *p* < .05.

Conclusions

- The study highlights the importance of considering parents' resolution with their child's visual loss & parent-child communication about the diagnosis, in efforts to support the well-being of individuals with vision loss.
- Further research with a larger cohort is needed to validate & expand these findings.

References

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- specific emotional well-being in a Chinese population. BJO 101 (5), 686–690.
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