Perspectives and recommendations: Disclosure of pediatric obsessive-compulsive disorder in the school setting

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Introduction

Pediatric obsessive-compulsive disorder (OCD) commonly impairs school functioning in terms of concentration, homework completion, certain subject material, executive function, and overall graduation rates.^{1,2} Direct disclosure of an OCD diagnosis to school personnel by an affected youth may improve school functioning by increasing awareness and accelerating the initiation of necessary support.

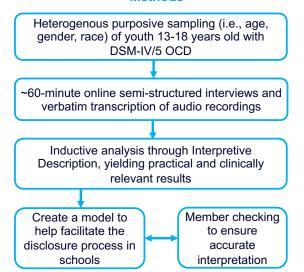
A previous quantitative study has shown that while nearly all who disclosed to schools said they would do it again, there was a significant number who feared that disclosure would make things worse for their child.3 Identified disclosure barriers included bullying by peers and fear of a permanent mental illness record.3 Little is known about the high school disclosure process from the perspective of youth living with OCD.

Study Aims

Our study aims to qualitatively explore the perspectives of youth with OCD surrounding:

- 1. Disclosing or concealing their diagnosis in the high school setting
- 2. Current school-based disclosure supports
- 3. Improving the school disclosure process

Methods



Youth with OCD need improved awareness, safe space, connection, and confidential personalized supports to facilitate their journey from concealment to disclosure of their diagnosis in the school.

Journey from concealment to disclosure of OCD theoretical model

Key characteristic of the disclosure phase

Recommendation by youth with OCD

PHASE 1: STIGMA SURROUNDING DIAGNOSIS

Negative internalized beliefs

Meaningful education for school staff and classmates

PHASE 2: INTERNAL BARGAINING

Individualized disclosure boundaries

Creating a safe space

PHASE 3: TRUST BUILDING

Affinity of pre-existing relationships

Deep and reciprocal connections

PHASE 4: EMPOWERMENT

Viewed and treated as a person first

Confidential and personalized supports







Results

12 participants (6 male, 5 female, 1 non-binary)



15 years old on average (range: 13-17)



10 out of 12 identified as White



65-minute interviews on average

- 1. Shame and stigma are initial barriers to disclosure. Meaningful education surrounding OCD and mental illness is warranted to alter the internalized beliefs held by school staff and classmates.
- 2. Youth only disclose information that fits within their individualized boundaries. A safe space created by school members allows them to independently choose how much they want to disclose and to whom.
- Building trust with target(s) of disclosure is paramount for success. Superficial and unrelatable connections were barriers to developing trust, as opposed to deep and reciprocal (i.e., sharing struggles, interests) connections.
- 4. Youth feel empowered when they are treated as a person rather than a diagnosis. Confidential and personalized supports can assist to empower them.

Conclusion

The "Journey from concealment to disclosure of OCD" theoretical model can inform school disclosure strategies and optimize support for vouth. Future research can explore its' utility and the perspectives of school personnel and parents on its' applicability.

Acknowledgements and References

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- 1. Piacentini J, Bergman R, Keller M, McCracken J. Functional impairment in children and adolescents with obsessive-compulsive disorder. Journal of Child and Adolescent Psychopharmacology. 2003;13(1):61-69.
- 2. Negreiros J, Belschner L, Selles R, Lin S, Stewart E. Academic skills in pediatric obsessive-compulsive disorder: A preliminary study. Annals of Clinical Psychiatry. 2018;30(3):185-195.
- 3. Negreiros J, Best J, Vallani T, Belschner L, Szymanski J, Stewart S. Obsessive-compulsive disorder (OCD) in the school: Parental experiences regarding impacts and disclosure,. Journal of Child and Family Studies. 2022;47.

