

Editorial Perspective: The importance of considering parent's preferences when planning treatment for their children – the case of childhood obsessive-compulsive disorder

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The critical nature of assessing patient preferences, values, and beliefs regarding treatment cannot be overstated. Treatment preference and acceptability are associated with improved outcomes, adherence, alliance, and reduced dropouts (Swift & Callahan, 2009). Given that parents ultimately consent and decide upon treatment for their children, assessment of parental treatment and subsequent matching of prescribed treatment is of particular importance for pediatric obsessive-compulsive disorder (OCD) given the availability of (and potential choice from) multiple evidence-based treatments: exposure and response prevention therapy (ERP), serotonin reuptake inhibitors (SRI) and their combination (COMB). Notably, favorable parental treatment expectations are linked to improved outcomes and adherence in youth with depression (Stevens et al., 2009) and OCD (Lewin, Peris, Bergman, McCracken, & Piacentini, 2011). The only empirical study of patient preferences for the treatment of OCD was in 89 treatment-seeking adults (Patel & Simpson, 2010) reporting preference for COMB (43%) or ERP (42%) over SRI (16%).

We examined parental treatment preference for childhood OCD, approximating and expanding the methodology employed by Patel and Simpson (2010). Participants were parents of youth who called the University of South Florida's Child OCD Clinic (a multispecialty clinic with multiple child psychiatrists and psychologists) for an initial intake evaluation during an 18-month period. Detailed phone screens were conducted with 137 parents seeking OCD treatment for their child, resulting in 101 youth meeting diagnostic criteria for OCD who are the basis for all subsequent discussion. Screenings were conducted prior to the initial clinician appointment to reduce potential bias of expert clinician recommendation on parental preference. Diagnosis of OCD was later verified via clinician assessment and structured diagnostic interview. Participant characteristics were as follows: 55% male, mean age = 11.4 years ($SD = 3.2$; range 5–17), 66% OCD treatment naïve, 89% Caucasian, and 47% on psychiatric medication (32% on SSRI). Comorbidity included the following: anxiety (34%), disruptive behavior disorder (25%), mood disorder (13%), and chronic tic disorder (21%).

Parent treatment preference: To assess relative preference, parents were provided a brief description of treatment options, and were then asked to select their preferred treatment (psychotherapy, pharmacotherapy, or combination). The preponderance of parents (>99%) preferred treatments containing ERP. Forced choice parental treatment preference was as follows: ERP alone (68%), COMB (32%) and SRI (1%). Severity of youth OCD symptoms did not differ as a function of treatment preference. Parents of youth currently prescribed that psychiatric medication did not exhibit differential preference between ERP and COMB treatment, whereas parents of medication naïve youth overwhelmingly preferred ERP over COMB. Parents of younger children (ages 5–11; $n = 48$) exhibited a higher preference for ERP (75%) compared to COMB treatment (25%), whereas parents of adolescents (ages 12–17; $n = 51$) exhibited less divergence in preference between ERP (61%) and COMB treatment (39%). Notably, 89% parents of youth under age 9 years indicated preference for ERP only. Qualitatively, concern about side effects and safety appear to contribute to parent preference to a greater extent than positive factors regarding behavioral therapies. Parents were queried for rational behind their preference. Opposition to medication – rather than favorability of ERP – appeared to drive ratings. A majority of parents (70%) reported concerns regarding medication (concerns about side effects, significant safety concerns, concerns about developmental effects, and fundamental opposition to pharmacotherapy), whereas 24% identified favorable factors regarding ERP guiding their preference.

Treatment acceptability: Parents rated acceptability of each treatment option on a five-point scale ranging from 'completely unacceptable' to 'completely acceptable.' Parents' treatment acceptability ratings for ERP, SSRI, and COMB treatment told a similar story. Large effects favored ERP relative to SSRI (Cohen's $d = 1.79$) and ERP relative to COMB treatment (Cohen's $d = 1.12$), while a medium effect was present favoring COMB relative to SSRI ($d = 0.55$). Child medication status did not affect parental treatment acceptability of ERP. However, parents of youth prescribed psychiatric medication reported higher acceptability for both SSRI and

COMB treatment in contrast to parents of youth not prescribed pharmacotherapy. Comorbidity did not affect parent acceptability for ERP. However, the presence of multiple comorbidities increased parental acceptability for medication and combination therapies. Parents of youth with both comorbid internalizing and externalizing disorders provided relatively higher acceptability of both COMB and SSRI treatments (when compared to parents of youth with OCD and no comorbidity). Regardless of comorbidity or child medication status, the overall order of parent acceptability remained unchanged: parents identified ERP to be most acceptable, followed by COMB, and finally SSRI. Notably, parental acceptability did not differ with respect to child demographic factors, parental treatment history, or child OCD treatment history.

Factors influencing parent decision for treatment: Most parents (58%) identified exploring treatment options via the Internet. Other common resources included medical providers (35%), mental health providers (42%), friends (23%), family members (25%), and books/academic articles (30%).

Parent-reported barriers to treatment: Over half of parents (51%) reported that distance was an obstacle, with other common barriers including limited ERP clinician availability (32%), treatment cost (25%) and school/work impediments (21%). These barriers are important to consider in conjunction with the overwhelming preference for treatments involving ERP. Experts in ERP for childhood OCD are few and are unfortunately inaccessible to many families given the barriers endorsed above. Improving the dissemination and availability of ERP trained therapists for child OCD is compelling given strong efficacy data, practice recommendations, and overwhelming parental preference in spite of significant barriers. Innovative methods such as video/telemedicine-based treatments, shortened or condensed protocols, and stepped-care approaches may facilitate overcoming traditional barriers to care.

Overall, this study reified robust parental preference for OCD treatments that contain ERP. Findings are consistent with a study of parent preference for child non-OCD anxiety treatment (Brown, Deacon, Abramowitz, Dammann, & Whiteside, 2007) in which 92.7% of parents reported preference for either psychotherapy or COMB. Results also parallel findings in adults (Patel & Simpson, 2010) in which 85% preferred treatments containing ERP compared to 16% preferring pharmacotherapy. However, whereas among adult respondents, Patel and Simpson (2010) found a slight majority preference (51%) for COMB, only 22% of parents in our study preferred COMB.

Despite the present findings suggesting higher parent preferences for behavior therapy over medication, prescription rates of psychotropic medication for youth are rising. Off-label prescribing in youth

(e.g. antipsychotics among patients without psychotic symptoms, polypharmacy, and medicating very young children) has all risen in recent years. These pharmacoepidemiological trends are not only concerning from an efficacy and safety standpoint, but are at odds with family preferences.

In childhood OCD (Lewin et al., 2011) and other psychiatric illnesses, parent/patient expectations and attitudes towards treatment impact outcomes and adherence. It is critical that providers assess patient attitudes towards treatment and preferences when there are choices available. Notably, providers are poor predictors of patient preference without a direct inquiry (Benbassat, Pilpel, & Tidhar, 1998) and their accuracy generally does not improve with professional experience or with longer-term patient-clinician relationships (Druley et al., 1993). A key role of the clinician is to ensure that the patient understands the available treatment options, associated empirical support, and risks and benefits of potential treatment options (Haynes, McDonald, & Garg, 2002). Family accommodation, insight and motivation are other important factors to assess in the context of family attitudes and preferences (see, for example, Lewin et al., 2010). Understanding parental attitudes towards pharmacotherapy may be particularly relevant – parents of youth with depression reported lower acceptability of antidepressants despite perceiving them to be more effective than psychotherapy (Stevens et al., 2009). The present data suggest efforts are needed to educate parents on benefits of pharmacotherapy for OCD in the face of low acceptability of this evidence-based approach.

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References

- Benbassat, J., Pilpel, D., & Tidhar, M. (1998). Patients' preferences for participation in clinical decision making: a review of published surveys. *Behavioral Medicine*, 24, 81–88.
- Brown, A.M., Deacon, B.J., Abramowitz, J.S., Dammann, J., & Whiteside, S.P. (2007). Parents' perceptions of pharmacological and cognitive-behavioral treatments for childhood anxiety disorders. *Behaviour Research and Therapy*, 45, 819–828.
- Druley, J.A., Ditto, P.H., Moore, K.A., Danks, J.H., Townsend, A., & Smucker, W.D. (1993). Physicians' predictions of elderly outpatients' preferences for life-sustaining treatment. *The Journal of Family Practice*, 37, 469–475.
- Haynes, R.B., McDonald, H.P., & Garg, A.X. (2002). Helping patients follow prescribed treatment: clinical applications. *JAMA*, 288, 2880–2883.
- Lewin, A.B., Bergman, R.L., Peris, T.S., Chang, S., McCracken, J.T., & Piacentini, J. (2010). Correlates of insight among youth with obsessive-compulsive disorder. *Journal of Child Psychology and Psychiatry*, 51, 603–611.
- Lewin, A.B., Peris, T., Bergman, R.L., McCracken, J., & Piacentini, J. (2011). The role of treatment expectancy in youth receiving exposure-based CBT for obsessive compulsive disorder. *Behaviour Research and Therapy*, 49, 536–543.
- Patel, S.R., & Simpson, H.B. (2010). Patient preferences for obsessive-compulsive disorder treatment. *Journal of Clinical Psychiatry*, 71, 1434–1439.
- Stevens, J., Wang, W., Fan, L., Edwards, M.C., Campo, J.V., & Gardner, W. (2009). Parental attitudes toward children's use of antidepressants and psychotherapy. *Journal of Child and Adolescent Psychopharmacology*, 19, 289–296.
- Swift, J.K., & Callahan, J.L. (2009). The impact of client treatment preferences on outcome: a meta-analysis. *Journal of Clinical Psychology*, 65, 368–381.

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