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**Article:**

Accurso, E.C. and Waller, G. [orcid.org/0000-0001-7794-9546](https://orcid.org/0000-0001-7794-9546) (2021) Concordance between youth and caregiver report of eating disorder psychopathology : development and psychometric properties of the Eating Disorder-15 for Parents/Caregivers (ED-15-P). *International Journal of Eating Disorders*, 54 (7). pp. 1302-1306. ISSN 0276-3478

<https://doi.org/10.1002/eat.23557>

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This is the peer reviewed version of the following article: Accurso, E. C., & Waller, G. (2021). Concordance between youth and caregiver report of eating disorder psychopathology: Development and psychometric properties of the Eating Disorder-15 for Parents/Caregivers (ED-15-P). *International Journal of Eating Disorders*, 54( 7), 1302–1306., which has been published in final form at <https://doi.org/10.1002/eat.23557>. This article may be used for non-commercial purposes in accordance with Wiley Terms and Conditions for Use of Self-Archived Versions.

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1 Running head: CAREGIVER REPORT OF EATING DISORDER PSYCHOPATHOLOGY

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6 Concordance between youth and caregiver report of eating disorder psychopathology:

7 Development and psychometric properties of the Eating Disorder-15 for Parents/Caregivers (ED-

8 15-P)

9

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17

18 **Keywords:** assessment; eating disorder psychopathology; psychometrics; routine outcome  
19 monitoring; caregiver-report; parents and caregivers; children and adolescents

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21 Abstract word count: 199

22 Manuscript word count: 1999

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**Data Sharing**

The data that support the findings of this study are available from the corresponding author upon reasonable request. The data are not publicly available due to privacy and ethical restrictions.

**Acknowledgments**

The first author is supported by the National Institutes of Mental Health (K23 MH120347) and the National Center for Advancing Translational Sciences, National Institutes of Health, through UCSF-CTSI Grant Number KL2 TR001870. We are grateful to the youth and their families who participated in this study.

**Conflict of Interest Statement**

The authors have no conflict to declare.

**Abstract**

1  
2 **Objective:** Outcome measurement in youth with eating disorders relies heavily on self-report,  
3 which is problematic in a population that may deny or minimize symptoms. Caregiver-report  
4 measures are lacking. This study examined the psychometric and clinical properties of a newly-  
5 developed measure designed to assess short-term change in eating disorder symptomatology as  
6 observed by caregivers—the Eating Disorder-15 for Parents/Caregivers (ED-15-P). **Method:** At  
7 initial presentation to an outpatient eating disorders assessment, 206 families (primary caregiver  
8 and their child up to 18 years old) completed psychological measures. **Results:** The ED-15-P  
9 demonstrated excellent reliability, preliminary evidence of discriminant and concurrent validity,  
10 and good sensitivity to change early in treatment (first eight weeks). Agreement between primary  
11 caregivers and children on eating disorder psychopathology was moderate, while agreement  
12 between pairs of caregivers was relatively strong. Level of agreement varied across behaviors  
13 and informants, with poorer caregiver-child agreement on dieting and driven exercise.

14 **Conclusions:** Agreement was stronger within caregiver pairs than caregiver-child pairs,  
15 indicating that caregivers and their children have related but unique perspectives on eating  
16 disorder symptoms, highlighting the importance of multi-informant assessment. The ED-15-P  
17 complements a parallel youth report measure to more comprehensively assess eating disorder  
18 psychopathology, with high utility for measuring change over time.

19  
20 *Keywords:* routine outcome monitoring; assessment; eating disorder psychopathology;  
21 psychometrics; parents and caregivers; children and adolescents

22  
23 *Public Significance Statement:* Caregivers have been neglected in the assessment of youth with

1 eating disorders. This study describes the development of a brief caregiver report measure of  
2 eating disorder psychopathology that demonstrated excellent reliability, validity, and sensitivity  
3 to change over time. Caregivers have a unique perspective on eating disorder psychopathology,  
4 and the inclusion of caregiver-reported outcomes is critical to advancing our understanding of  
5 eating disorder recovery. (63/70 words)

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## 1 Introduction

2 While routine outcome monitoring throughout treatment enhances clinical benefits  
3 (Bickman et al., 2011), it is not widely used in treatment of youth with eating disorders (EDs),  
4 where outcomes are modest (Lock, 2015). Development of measures for weekly assessment of  
5 eating pathology among youth has been limited by relatively complex language. For example,  
6 the brief Eating Disorders Examination–Questionnaire (EDE-QS; Gideon, Hawkes, Mond,  
7 Saunders, Tchanturia, & Serpell, 2016) addresses symptoms weekly, but requires advanced  
8 reading skills (10<sup>th</sup> grade level with Flesch-Kincaid score of 9.9). Another adapted version of the  
9 EDE-Q uses more appropriate language but has a two-week timeframe (Carter, Stewart, &  
10 Fairburn, 2001).

11 Developed more recently, the ED-15-Y (Accurso & Waller, 2021), based on the ED-15  
12 (Tatham et al., 2015), allows weekly outcome monitoring while using appropriate language for  
13 children and adolescents (3<sup>rd</sup> grade level). ED psychopathology assessment is limited by the  
14 paucity of developmentally appropriate measures for youth, especially brief measures, as well as  
15 the lack of parallel measures for caregiver informants. However, assessment is also limited by  
16 historical reliance on self-report (Lock, 2015) even though youth may minimize or deny  
17 symptoms due to shame and/or the ego-syntonic nature of their disorder. Poor concordance  
18 between youth and caregivers (Couturier, Lock, Forsberg, Vanderheyden, & Lee, 2007) indicates  
19 the need for multiple informants. Therefore, a caregiver-report measure of weekly ED  
20 psychopathology is needed.

21 This study examines the psychometric and clinical properties of a new caregiver version  
22 of the ED-15-Y—the ED-15 for Parents/Caregivers (ED-15-P). It addresses the convergence of  
23 youth and caregiver perspectives of ED symptoms, comparing the utility of the ED-15-Y and

1 ED-15-P with the Eating Disorders Examination–Questionnaire (EDE-Q; Fairburn & Beglin,  
2 2008) and Parent EDE-Q (P-EDE-Q; Parter, Loeb, Hail, McGrath, & Fairburn, 2015).

### 3 **Methods**

4 All procedures were approved by the Institutional Review Board at the University of  
5 California, San Francisco.

#### 6 **Participants and Procedures**

7 Participants were youth ( $\leq 18$  years) and their caregivers evaluated at a specialty ED  
8 program (11/2015-04/2020). When two caregivers consented, the one who scheduled the  
9 appointment was designated as primary caregiver. Demographic and clinical information was  
10 collected during the intake interview. ED diagnosis was made by a clinical psychologist or  
11 supervised psychology intern using the Eating Disorder Assessment for DSM-5 (EDA-5; Sysko  
12 et al., 2015).

#### 13 **Measures**

14 **Eating Disorder-15 for Youth (ED-15-Y; Accurso & Waller, 2021).** The ED-15-Y is a  
15 brief measure of ED psychopathology over the past week for youth  $\geq 8$  years. The measure was  
16 adapted from the adult ED-15 (Tatham et al., 2015) by simplifying language for each item,  
17 including 10 attitudinal items (measured on a 1-5 scale) and five behavioral items (frequency of  
18 dieting, binge eating, vomiting, laxative use, driven exercise). The attitudinal items were also  
19 rated on modified five-point scale (1-5) rather than the original seven-point scale (0-6). It has  
20 demonstrated excellent reliability, validity, and sensitivity to change over time in youth with EDs  
21 (Accurso & Waller, 2021). At assessment, youth  $\geq 8$  years completed the ED-15-Y.

22 **Parent/Caregiver ED-15 (ED-15-P).** A parallel caregiver-report version (ED-15-P, see  
23 Supplementary Materials) was developed by changing first- (e.g., *I*) to third-person referents

1 (e.g., *my child*). Caregivers completed the ED-15-P at assessment and at each session through  
2 session eight if their child engaged in treatment (10/2015-10/2018) for an ED involving weight  
3 and shape concerns. The version for this study used binary gender pronouns (e.g., he/she), which  
4 have been updated to be more gender-inclusive.

5 **Eating Disorder Examination Questionnaire (EDE-Q; Fairburn & Beglin, 2008) and**  
6 **Parent Version of the Eating Disorder Examination Questionnaire (P-EDE-Q; Parter et al.,**  
7 **2015).** The EDE-Q global scale has demonstrated good reliability in adolescents with  
8 adolescents with EDs (Jennings & Phillips, 2017). The P-EDE-Q measures ED psychopathology  
9 from the perspective of parents/caregivers, exhibiting excellent reliability and validity in parents  
10 of adolescents seeking EDs treatment (Parter et al., 2015).

11 **Symptoms and Functioning Severity Scale (SFSS; Bickman et al., 2010).** Caregivers  
12 completed a measure of global child psychopathology that has demonstrated excellent reliability  
13 and validity in caregivers of youth receiving mental health services (Athay, Riemer, & Bickman,  
14 2012).

## 15 **Data analyses**

16 Given interdependence of data, analyses utilized data from the primary caregiver only  
17 unless otherwise noted. IBM SPSS Statistics v.27 was used. Significance level was set at  $< 0.01$   
18 given the number of planned analyses. Internal consistency of the ED-15-P and split-half  
19 reliability (first five versus last five items) were examined using omega (McDonald, 1999),  
20 Cronbach's alpha, and Spearman-Brown coefficients. The factor structure for the ten attitudinal  
21 items was examined with principal axis factoring (unrotated, no predetermined number of  
22 factors) to establish whether the items load on one latent factor. Convergent validity between the  
23 ED-15-P and the ED-15-Y and between the P-EDE-Q and EDE-Q, and discriminant validity

1 between the ED-15-P and SFSS were measured using Spearman's rho. Inter-rater agreement  
2 between caregivers (ED-15-P) and youth (ED-15-Y) on behavioral items was tested using  
3 percentage of exact agreement (PEA) (i.e., percentage of caregiver-youth pairs who agreed on  
4 the presence or absence of a behavior), prevalence and bias adjusted kappa (PABAK), and  
5 kappa. Kappa coefficients  $>.40$  were considered moderate,  $>.60$  substantial, and  $>.80$  almost  
6 perfect. Convergence between "primary" and "secondary" caregivers was also examined (PEA,  
7 PABAK,  $k$ ; paired t-test). Convergent validity was established through Spearman's rho  
8 correlation between the ED-15-P and P-EDE-Q. Chi-squared tests examined the association of  
9 ED-15-P behavioral items and parallel P-EDE-Q items. Concurrent validity was examined by  
10 comparing ED-15-P scores by ED diagnoses. To assess sensitivity to change over time,  
11 multilevel mixed-effects models were used to examine weekly change in ED-15-P total scores  
12 from treatment sessions 1 to 8, adjusting for baseline ED-15-P score and session. A Reliable  
13 Change Index was calculated (Jacobson & Truax, 1991) from ED-15-P scores ( $SD$  and  $\alpha$ ) to  
14 determine what proportion of patients made reliable changes (95% criterion) in caregiver-  
15 reported symptoms.

## 16 Results

17 Of 301 patients approached, 86.7% ( $n=261$ ) agreed to participate. ED-15-P data were  
18 missing for 55 (21.1%) primary caregivers, resulting in a final sample of 206 families (i.e.,  
19 primary caregiver and youth) (see Supplementary Figure 1 for participant flowchart). Primary  
20 caregivers were on average 48.90 years old ( $SD=7.66$ ) and included 175 mothers, 30 fathers, and  
21 one grandmother. Secondary caregivers ( $n=108$ ) included 86 fathers, 20 mothers, one adoptive  
22 father, and one stepmother. Youth ( $n=206$ ) were on average 14.81 years old ( $SD=2.32$ , range:  
23 [6,18]) with a mean duration of illness of 2.07 years ( $SD=2.96$ ); fifty-one spent time in multiple

1 households (see Supplementary Table 1 for participant characteristics).

## 2 **Reliability and Factor Structure**

3 The ED-15-P demonstrated excellent internal consistency ( $\omega=.917$ ,  $\alpha=.913$ ) and  
 4 split-half reliability (Spearman-Brown=.876). Omega and alpha for other measures were also  
 5 high (ED-15-Y: .949, .946; EDE-Q: .976, .973; P-EDE-Q: .960, .956; SFSS: .921, .918,  
 6 respectively). Factor analysis of the ED-15-P revealed one factor (eigenvalue=5.725) consisting  
 7 of all ten items (loadings 0.504-0.902), indicating a single latent factor.

## 8 **Do caregivers agree with their child on ED symptoms?**

9 ED-15-Y data were available for 89.3% ( $n=184$ ) of youth. Table 1 provides descriptive  
 10 statistics and correlation table for the ED-15-P and other measures. For the 184 youth-caregiver  
 11 pairs, ED-15-Y and ED-15-P scores demonstrated moderate convergence ( $r=.55$ ), as found  
 12 between the EDE-Q and P-EDE-Q ( $r=.64$ ) and the ED-15-P and the EDE-Q ( $r=.58$ ).

13 INSERT TABLES 1 AND 2 ABOUT HERE

14 Table 2 shows strong convergence across all five behaviors (dieting:  $\chi^2=36.268$ , binge  
 15 eating:  $\chi^2=40.735$ , vomiting:  $\chi^2=88.784$ , laxative misuse:  $\chi^2=59.319$ , driven exercise:  $\chi^2=28.920$ ,  
 16  $ps < .001$ ). Interrater agreement between youth and their primary caregiver on the ED-15-Y/ED-  
 17 15-P reached >80% exact agreement with moderate to substantial agreement for binge eating  
 18 (PEA=80.6%, PABAK=.611,  $k=.471$ ), vomiting (PEA=93.9%, PABAK=.877,  $k=.698$ ), and  
 19 laxative misuse (PEA=97.8%, PABAK=.956,  $k=.492$ ). However, there was more moderate  
 20 agreement for dieting (PEA=71.5%, PABAK=.430,  $k=.438$ ) and driven exercise (PEA=73.3%,  
 21 PABAK=.467,  $k=.400$ ). Caregivers reported greater levels of dieting than their child, whereas  
 22 youth endorsed the presence of other behaviors more often than caregivers. When behaviors  
 23 were endorsed, correlations of the frequency of behaviors were moderate-strong for dieting

1 ( $r=.45$ ), binge eating ( $r=.45$ ), vomiting ( $r=.73$ ), laxative misuse ( $r=.58$ ), and compensatory  
 2 exercise ( $r=.45$ ) ( $ps\leq.001$ ).

### 3 **Do caregivers agree with each other?**

4 ED-15-P ( $r=.73, p<.001; n=108$ ) and P-EDE-Q scores ( $r=.75, p<.001$ ) converged  
 5 strongly within caregiver pairs. There was no significant ED-15-P score difference between  
 6 caregivers ( $M$  difference=0.016,  $SE=0.073, t=2.205, p=.030$ ). Reported frequency of behaviors  
 7 by caregivers on the ED-15-P converged well (dieting:  $\chi^2=29.913$ , binge eating:  $\chi^2=21.266$ ,  
 8 vomiting:  $\chi^2=12.527$ , laxative misuse:  $\chi^2=27.329$ , driven exercise:  $\chi^2=35.999, ps<.001$ ) (see  
 9 Supplementary Table 2). Agreement on behaviors as indicated by the PABAK was almost  
 10 perfect for laxative misuse (PEA=98.3, PABAK=.965,  $k=.391$ ); moderate for binge eating  
 11 (PEA=82.4%, PABAK=.647,  $k=.330$ ), vomiting (PEA=89.4%, PABAK=.788,  $k=.256$ ), and  
 12 driven exercise (PEA=78.0%, PABAK=.560,  $k=.444$ ); and fair for dieting (PEA=67.3%,  
 13 PABAK=.345,  $k=.366$ ). Primary caregivers were more likely than secondary caregivers to state  
 14 that their child engaged in dieting and driven exercise. When caregivers agreed on the presence  
 15 of dieting or driven exercise, their reports of behavioral frequency were moderately correlated  
 16 (dieting:  $r=.49, p<.001$ ; driven exercise:  $r=.64, p<.001$ ). Other behaviors were too rarely  
 17 identified for meaningful comparisons between caregivers.

### 18 **Are caregivers consistent in their reports across measures?**

19 ED-15-P scores converged well with P-EDE-Q scores ( $r=.85, p<.001$ ) and ED behaviors  
 20 (dieting:  $\chi^2=70.926$ , binge eating:  $\chi^2=70.144$ , vomiting:  $\chi^2=89.773$ , laxative misuse:  $\chi^2=35.256$ ,  
 21 driven exercise:  $\chi^2=82.930, ps<.001$ ) (see Supplementary Table 3). Caregiver report suggests that  
 22 between  $\approx 5$ -20% of ED behaviors occurred in the past month but not the past week, but (as  
 23 expected) this pattern was not reflected the other way round. Correlations of ED-15-P and P-

1 EDE-Q behavior frequencies were relatively strong: restraint ( $r=.60$ ), objective binge eating  
 2 ( $r=.46$ ); vomiting ( $r=.59$ ); and driven exercise ( $r=.68$ ) ( $ps<.001$ ). No correlation was calculated  
 3 for laxative misuse ( $n=2$ ).

#### 4 **Differentiation of diagnostic groups**

5 ED diagnosis was significantly associated with ED-15-P scores ( $F=25.443$ ,  $p<.001$ ; no  
 6 ED:  $n=15$ ,  $M=2.01$ ,  $SD=0.90$ ; ARFID:  $n=27$ ,  $M=1.84$ ,  $SD=0.69$ ; AN:  $n=61$ ,  $M=3.36$ ,  $SD=0.83$ ;  
 7 Atypical AN:  $n=50$ ,  $M=3.44$ ,  $SD=0.83$ ; BN/atypical BN:  $n=16$ ,  $M=3.31$ ,  $SD=0.92$ ]. Post-hoc  
 8 comparisons indicated that scores for the first two groups were significantly lower than scores in  
 9 the other three groups (EDs involving weight and shape concerns), with no difference between  
 10 individuals with ARFID and those with no eating disorder.

#### 11 **Do caregivers report reductions in eating pathology early in treatment?**

12 For the subset of youth with EDs involving weight and shape concerns ( $n=60$ ), there was  
 13 a significant effect of session on ED-15-P scores, after adjusting for baseline ED-15-P score  
 14 ( $B=0.593$ ,  $SE=0.121$ ,  $F=24.118$ ,  $t=4.911$ ,  $p<.001$ ). There was as an overall decrease of 0.744  
 15 points ( $SE=0.017$ ,  $F=39.062$ ,  $t=-6.250$ ,  $p<.001$ ) in the early phase of treatment. The Reliable  
 16 Change Index for the ED-15-P ( $SD=1.04$ ;  $\alpha=.913$ ) was 0.85. Of the 29 patients with at least  
 17 one ED-15-P score between sessions 6-8, 51.7% ( $n=15$ ) achieved reliable improvement and none  
 18 showed reliable deterioration.

#### 19 **Discussion**

20 Caregiver perspectives on ED recovery have been neglected despite their clinical  
 21 significance (Accurso, Sim, Mulheim, & Lebow, 2020). The ED-15-P is the first caregiver report  
 22 measure of ED psychopathology that enables tracking of session-to-session change. It  
 23 demonstrated strong convergent validity, moderate discriminant validity, excellent concurrent

1 validity with ED diagnosis, and reliable sensitivity to change early in therapy. Caregivers agreed  
2 with each other in their assessment of eating problems, but less so with youth, particularly  
3 around less obvious behaviors (restriction and driven exercise), as shown elsewhere (e.g.,  
4 Mariano, Watson, Leach, McCormack, & Forbes, 2013), supporting the importance of obtaining  
5 multiple perspectives on eating pathology in youth. Measures of early improvement have mostly  
6 focused on weight and binge/purge behavior. While such changes are critical determinants of  
7 outcome at the end of treatment and/or follow-up (Matheson et al., 2020), they ignore key  
8 changes in psychological symptoms.

9       Limitations include a relatively small sample size, missing data for secondary caregivers,  
10 and the absence of data on community or non-treatment-sample samples. Further research is  
11 needed to examine the clinical applications of this measure in different therapies and cultures,  
12 and to determine whether measurement feedback systems using the ED-15-P can improve patient  
13 outcomes. Evidence-based assessment that integrates multiple perspectives might help to  
14 augment current modest outcomes of evidence-based treatment for youth with EDs. Given its  
15 brevity and the availability of a parallel youth-report measure, the ED-15-P has potential to track  
16 progress for children or adolescents across treatment. Future directions include integrating ED-  
17 15-Y and ED-15-P scores and evaluating the clinical utility of routine outcome monitoring in  
18 youth with EDs.

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