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Review article

Meta-analysis of age at help-seeking and duration of untreated illness (DUI) in obsessive-compulsive disorder (OCD): The need for early interventions

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ABSTRACT

Introduction: Obsessive-compulsive disorder (OCD) is a chronic neuropsychiatric disorder that often begins early in childhood. Patients with OCD are known to seek help late after disorder onset, and therefore have a long duration of untreated illness (DUI), which is found to correlate with negative clinical outcomes. No meta-analysis has previously investigated this issue.

Methods: Our protocol was pre-registered with PROSPERO (CRD42020165226). We followed PRISMA-guidelines and searched for relevant articles in four electronic databases. Meta-analyses of means based on random-effects (Der-Simonian-and-Laird-method) were used to derive the pooled estimates. Subgroup-analyses and meta-regressions were conducted to explore possible factors affecting help-seeking and DUI.

Results: We included $N = 31$ studies in the quantitative synthesis, with 16 studies proving data for age at help-seeking and 16 studies providing data for duration of untreated illness. The pooled mean age at help-seeking was 28.66 years (95 % CI: 27.34–29.98), while the pooled mean interval between age at disorder onset and help-seeking was 6.97 (95 % CI: 5.69–8.24), and the pooled mean duration of untreated illness was 80.23 months (68.72–91.75), around 6.69 years, all with $p < 0.001$. Specific OCD-related factors affected help-seeking and duration of untreated illness.

Conclusions: Patients with OCD seek for help late in the course of the disorder and have a long duration of untreated illness, which is associated with more negative prognosis. This meta-analysis confirms the long duration of untreated illness in OCD and proposes possible factors associated with the length of the help-seeking process and DUI.

1. Introduction

Obsessive-compulsive disorder (OCD) is a debilitating and chronic condition characterized by a combination of recurrent and repetitive obsessional thoughts and compulsive behaviours (Fineberg et al., 2020). OCD is not rarely a treatment-resistant condition; furthermore, it has been linked to substantial impairments in both functioning and quality of life and has a major global disability burden (Hollander et al., 2010; Kochar et al., 2023; Pellegrini et al., 2022). The lifetime prevalence of OCD in the general population has been estimated to be around 3.5 %; the disorder onset is in childhood/adolescence with a peak age of fourteen years. Onset in adulthood is possible ranging between the ages of eighteen and twenty-five years; this peak may possibly include the newly diagnosed cases, which may have stared earlier in their course but not been identified (Albert et al., 2015; Fineberg et al., 2013; Solmi et al., 2022). The onset of subclinical symptoms precedes the onset of the disorder, with the majority of cases having obsessive-compulsive symptoms before the age of fourteen years (Albert et al., 2015).

Research indicates that the 12-month prevalence estimates for adults are 0.75–0.30 % and for children are 0.75–3.0 % (Kessler et al., 2007;

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Ruscio et al., 2010). A substantial proportion of the population - estimated at 21 % and 28 % in the studies by Ruscio et al. (2010) and Fineberg et al. (2013) - report subthreshold obsessive compulsive symptoms.

Typical treatments for OCD include pharmacotherapy with selective serotonin reuptake inhibitors (SSRIs), the serotonergic tricyclic clomipramine, and/or cognitive behavioural therapy with exposure and response prevention (ERP) (Fineberg et al., 2020). Although both pharmacotherapy and psychotherapy are recommended treatment options, there is scarce evidence to determine which one is more effective, under what circumstances one should be recommended over the other, or whether combination treatment (i.e., SSRI plus CBT) is more effective (Fineberg et al., 2018; Fineberg et al., 2020). CBT is particularly indicated for the mild cases, where the gains achieved through CBT are maintained over time (Nezgovorova et al., 2022; Öst et al., 2022). Some evidence exists showing that combination treatment (pharmacotherapy and psychotherapy) might be more effective than both treatments alone (Reid et al., 2021).

Despite the availability of efficacious therapeutic options, the treatment gap for obsessive-compulsive disorder (individuals with OCD not seeking treatment) was estimated to be 25 % in Europe in 2004 (approximately 50 % worldwide) (Hirschtritt et al., 2017; Kohn et al., 2004; Skapinakis et al., 2016). In more recent epidemiological research, the proportion of patients not receiving therapy is quite variable, estimated to range from 22 to 92 %, with a broad range of 38 to 90 % of people not even seeking treatment or guidance for their OCD (García-Soriano et al., 2014).

Another issue is the misidentification and misdiagnosis of OCD, an example of this being the study by Glazier et al. (2013), who found that obsessions about homosexuality are misdiagnosed 77 % of the times. An important aid in the diagnostic process may come from the new ICD-11 nosological system, which has improved the classification of the family of obsessive and compulsive related disorders by including also hypochondriasis and olfactory reference syndrome to the group. To corroborate this hypothesis, Kogan et al. (2020) conducted a field study in which they found that the use of the ICD-11 criteria was more effective and accurate in identifying the correct diagnosis compared to the ICD-10 criteria.

Delays in help-seeking, diagnosing and in administering the proper treatment could contribute to a longer duration of untreated illness (DUI), a concept adapted from the duration of untreated psychosis (Howes et al., 2021) and applied to OCD. DUI is defined as the time interval between the age at disorder onset and the age at the first adequate treatment (appropriate medication, at minimally effective dosages, administrated for an adequate period of time depending on the specific psychiatric disorder in accordance with the World Federation of the Societies for Biological Psychiatry guidelines) (Albert et al., 2019a, 2019b; Dell'Osso et al., 2010; Bandelow et al., 2012). In clinical studies, the mean DUI was found to be between 87.5 and 94.5 months (García-Soriano et al., 2014; Perris et al., 2023). The adequate treatment for OCD is disorder-specific, and to produce a therapeutic response, moderate-to-high doses of SSRIs must be administered for at least 12 weeks, and maintenance therapy should continue for at least 1 year following the response (Fineberg et al., 2020). When it comes to choosing the appropriate medication (SSRIs or clomipramine), it is not uncommon for subjects with OCD to receive inadequate treatment, both in terms of dosage (sub-therapeutic doses), and/or duration (clinicians may switch to other treatments after only 4 to 6 weeks, as in the case of depression, overlooking the fact that it takes 12 weeks for an anti-obsessional treatment to work); therefore, the duration of untreated illness (DUI) is prolonged.

It is now clear, from several individual studies, that a long duration of untreated illness is a negative prognostic factor and is responsible for treatment resistance (Albert et al., 2019a, 2019b; Dell'Osso et al., 2010). The reasons for this phenomenon could be several, one of them being that, as the disorder remains untreated, the compulsive behaviours could become habitual in nature and could develop as habits or automatic rituals, apparently no longer linked with obsessions; this could make the OCD more difficult to treat (Gillan et al., 2016). The fact that repetition of compulsions leads to habit learning, involving different brain mechanisms that may not respond to standard OCD treatments (Gillan et al., 2015, 2017), makes this disorder perfectly suitable for early interventions. Additionally, a potential neurotoxic effect of DUI has been suggested (Anderson et al., 2014). For all these reasons, the DUI is a very important parameter to be considered by clinicians, given its modifiable nature: by improving diagnosis and ensuring adequate treatment for OCD, as well as implementing preventive strategies such as educational campaigns, DUI can potentially be reduced, leading to better outcomes for patients. In a study by Brakoulias et al. (2021), the first early intervention program for people with OCD was investigated; however, the authors concluded that this type of service was not effective in helping patients during the early stages of their condition and that it could be more useful to concentrate efforts on screening of children in non-clinical settings and on education.

Given the paramount importance of the topic, the high heterogeneity and variability in terms of the dimension of the phenomenon and the different lengths of the help-seeking process and the untreated OCD from individual studies, we decided to perform this pooled mean meta-analysis in order to derive the pooled mean age at help-seeking and the pooled mean DUI in OCD. Secondarily, we aimed to investigate factors that potentially could affect help-seeking and duration of untreated illness.

2. Materials and methods

2.1. Search strategy

The systematic review of the literature was conducted following the guidelines reported in the PRISMA (Preferred Reporting Items for Systematic reviews and Meta-analysis) Statement (Moher et al., 2009). Our protocol was pre-registered with PROSPERO (CRD42020165226). The search strategy and keywords used included terms related to OCD, duration of untreated illness and help-seeking. The literature search, updated to June 30th, 2024, was conducted across four electronic databases: Medline, PsycINFO, Web of Science and CINAHL, and by manually examining the bibliographies of the included articles. No restrictions on the year of publication of the articles were applied during the search to ensure the completeness of our search. Additionally, the list of references used in the identified relevant articles was manually reviewed to identify more relevant studies.

2.2. Article selection and review strategy

Articles were identified and assessed for eligibility by two reviewers (LP and SG), who independently decided which articles to include according to eligibility criteria (see below). In case of disagreement, a third author (UA) was consulted to reach consensual decisions. Duplicate studies were excluded, and cross-references within the identified articles were also examined.

2.3. Eligibility criteria

We included any quantitative studies study (longitudinal or cross-sectional) providing data on help-seeking and duration of untreated illness in OCD (no conference papers, book chapters or dissertations included). Case studies, qualitative studies, non-empirical studies and reviews were excluded from this systematic review. Included studies sampled both clinical and non-clinical populations and reported data on help-seeking behavior and/or the duration of untreated illness in OCD. Additionally, the OCD diagnosis needed to be made using a reliable, structured and validated assessment.

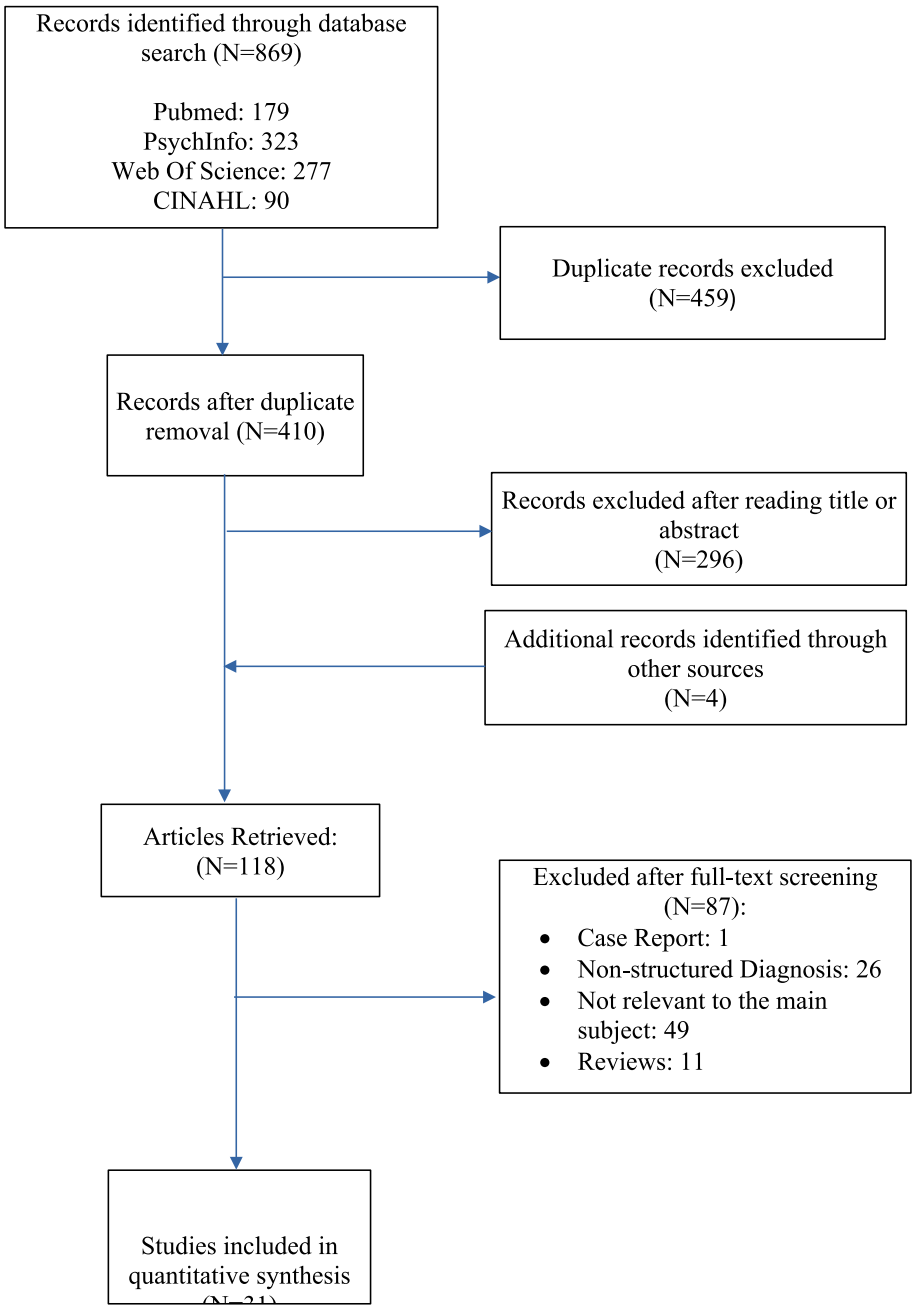

Fig. 1. PRISMA flow-chart.

2.4. Data extraction and imputation

Data on DUI and/or help-seeking, as well as the possible socio-demographic/clinical factors affecting these metrics, were extracted from the articles retrieved. Two authors (LP and SG) independently extracted the following information (preregistered on Prospero): study-related variables (e.g., study design, type of study - clinical or general populations) and participants-related variables including sociodemographic details (e.g., age, gender, geographical region, occupation, education) and clinical characteristics (e.g., OCD severity (Y-BOCS), OCD dimension, depressive symptoms, comorbidities with other disorders).

2.5. Appraisal of methodological quality

The methodological quality of the studies was assessed by two independent raters (LP and SG) using a modified version of the Quality Assessment Tool (QAT) for Observational Cohort and Cross-Sectional Studies (https://www.nhlbi.nih.gov/health-topics/studyquality-). This tool includes 14 items that address specific methodological issues. We excluded five items that did not fit with the nature of most studies here considered: item 5 (sample selection procedures), item 6 (exposure assessed prior to outcome measurement), item 10 (repeated measurement of the exposure), item 12 (blinded outcome measurement) and item 13 (follow-up loss rates). For each items satisfied, a point was assigned (yes = 1; item not satisfied or for which no sufficient information was available = 0). A sum score ranging from 0 to 9 was then calculated.

2.6. Data analysis

A systematic analytical approach was used to perform meta-analyses of proportions and to compute the pooled means for both age at help-

Table 1
Age at help-seeking in obsessive-compulsive disorder (OCD) - descriptive characteristics of studies included in the meta-analysis ($N = 16$).

Study	Country	Study design	Type of study	Screening tool for OCD	Help-seeking definition	Help-seeking evaluation	Target population	OCD sample size N	Including adolescents or children	Men (%) OCD sample	Age (years)	Age at OCD onset (years)	Mean age (years) at help-seeking
Albert et al. (2019a, 2019b)	Italy	Longitudinal retrospective	Clinical	DSM-IV criteria, Structured Clinical Interview for DSM-IV Axis I Disorders (SCID-I)	Age at which people with OCD sought first professional help	Clinical evaluation	Patients with OCD	251	Not included	53.8	M = 37.36 (SD = 13.62)	M = 22.21 (SD = 9.19)	M = 29.03 (SD = 12.05)
Belloch et al. (2009)	Spain	Cross-sectional	Clinical	DSM-IV criteria, Anxiety Disorders Interview Schedule for DSM-IV – lifetime version (ADIS-IV-L)	Age at the first voluntary contact with a formal health provider (GP or other physician, psychiatrist, clinical psychologist, or social worker)	Interview on Help Seeking (IH-S)	Outpatients with OCD	26	Not included	38.5	M = 32.85 (SD = 9.39) Range 21–60	n/r	M = 27.58 (SD = 9.94)
Benedetti et al. (2014)	Italy	Cross-sectional	Clinical	DSM-IV criteria, Structured Clinical Interview for DSM-IV Axis I Disorders (SCID-I)	Age at the first contact with mental health professionals	Clinical evaluation	Sample 1: Drug-naïve patients with OCD Sample 2: Drug-treated patients with OCD	Sample 1: 20 Sample 2: 46	n/r	n/r	Sample 1: M = 33.77 (SD = 12.13) Sample 2: M = 36.12 (SD =11.45)	Sample 1: M = 18.28 (SD = 9.35) Sample 2: M = 19.92 (SD =11.09)	Sample 1: M = 31.75 (SD = 8.89) Sample 2: M = 27.19 (SD = 7.44)
Del Valle et al. (2017)	Spain	Cross-sectional	Clinical	DSM-IV-TR criteria	Age at the first consulting about their mental-health symptoms	Interview on Help-Seeking for Mental Health (IHS-MH)	Individuals with OCD, AGO, MDD, AN and COC	71	Not included	39.4	M = 34.17 (SD = 11.38)	n/r	M = 28.99 (SD = 8.45)
Demet et al. (2010)	Turkey	Cross-sectional	Clinical	Structured Clinical Interview for DSM-IV Turkish Version	Age at pursuing help in psychiatry	Clinical evaluation	Outpatients with OCD and dermatology patients with OCD	132	Included adolescents (older than 15 years old) - N n/r	31.1	M = 31.9 (SD = 12.7) Range: 15–69	M = 22.4 (SD = 10.97)	M = 30.2 (SD = 10.04)
Juang and Liu (2001)	Taiwan	Cross-sectional	Clinical	DSM-IV criteria	Age of the patients at their initial visits in the psychiatric clinic	Clinical evaluation	Outpatients with OCD	200	Included children and adolescents (older than 7 years old) – N n/r	53.0	M = 28.9 (SD = 12.8) Range: 7–74	M = 23.4 (SD = 10.9)	M = 28.9 (SD = 6.65)
Karadağ et al. (2006)	Turkey	Cross-sectional	Clinical	DSM-IV criteria, Structured Clinical Interview for DSM-IV Turkish Version	Age when patients first sought treatment	Clinical evaluation	Outpatients with OCD	141	Included adolescents – N n/r	29.8	M = 30.53 (SD = 13.06)	M = 23.36 (SD = 10.69)	M = 27.81 (SD = 12.69)

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Table 1 (*continued*)

Study	Country	Study design	Type of study	Screening tool for OCD	Help-seeking definition	Help-seeking evaluation	Target population	OCD sample size N	Including adolescents or children	Men (%) OCD sample	Age (years)	Age at OCD onset (years)	Mean age (years) at help-seeking
											Range: 16–73		
Mahintorabi et al. (2015)	Iran	Cross-sectional	Clinical	n/r	Age when first sought help for OCD	Clinical evaluation	Sample 1: High Religious Muslim women with OCD Sample 2: Low Religious Muslim women with OCD	Sample 1: 33 Sample 2: 31	Not included	Sample 1: 0 Sample 2: 0	Sample 1: M = 40.06 (SD = 12.3) Sample 2: M = 35.19 (SD = 10.8)	Sample 1: M = 21.18 (SD = 8.14) Sample 2: M = 17.19 (SD = 3.61)	Sample 1: M = 37.48 (SD = 13.56) Sample 2: M = 25.19 (SD = 9.25)
Mahintorabi et al. (2017)	Iran	Cross-sectional	Clinical	DSM-IV-TR criteria	Age first discussed OCD symptoms with Imam	Clinical evaluation with Semi-Structured Interview	Muslim women who had immigrated to Australia and were diagnosed with OCD washing subtype	5	Not included	0	M = 39 (SD = 4.9) Range: 33–45	n/r	M = 21.4 (SD = 3.9)
Marques et al. (2010)	USA	Cross-sectional	Epidemiological	n/r	Age first sought treatment	Internet survey	Individuals with OCD	175	Not included	20.6	M = 30.92 (SD = 11.27) Range: 18–58	M = 13.48 (SD = 7.88)	M = 23.07 (SD = 9.43)
Mavrogiorgou et al. (2015)	Germany	Cross-sectional	Clinical	DSM-IV criteria	Age at first seeking professional contact	Clinical evaluation	Outpatients with OCD	40	Not included	42.5	M = 39.4 (SD = 10.1) Range: 22–55	M = 21.9 (SD = 10.3)	M = 28.4 (SD = 8.95)
Stengler et al. (2013)	Germany	Cross-sectional	Clinical	ICD 10 criteria, Composite International Diagnostic Interview (CIDI)	Age at utilization of professional help	Questionnaire for the utilization of professional help in OCD (FIPZ)	Outpatients with OCD	84	Not included	43.2	M = 38.7 (SD = 13.4) Range: 18–77	M = 23.0 (SD = 11.5)	M = 31.10 (SD = 10.4)
Stobie et al. (2007)	UK	Cross-sectional	Clinical	n/r	Age first sought treatment	Clinical evaluation	Individuals with OCD	57	Not included	43.9	M = 38.35 (SD = 11.4) Range: 19–66	M = 20.23 (SD = 9.9)	M = 26.05 (SD = 10.2)
Torresan et al. (2013)	Brazil	Cross-sectional	Clinical	DSM-IV criteria, Structured Clinical Interview for DSM-IV Axis I	Age at treatment seeking	Clinical evaluation	Individuals with OCD	858	Not included	41.3	M = 35.4 (SD = 12.1)	M = 22.1 (SD = 10.5)	M = 29.9 (SD = 12.2)

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Table 1 (*continued*)

Study	Country	Study design	Type of study	Screening tool for OCD	Help-seeking definition	Help-seeking evaluation	Target population	OCD sample size N	Including adolescents or children	Men (%) OCD sample	Age (years)	Age at OCD onset (years)	Mean age (years) at help-seeking
				Disorders (SCID-I)									
Tripathi et al. (2018)	India	Cross-sectional	Clinical	DSM-5 criteria, Structured Clinical Interview for DSM-5-Research Version (SCID-5-RV)	Age at first consultation	Clinical evaluation	Individuals with OCD	945	Not included	59.7	Range: 18–77 M = 32.62 (SD = 10.34) Range: 18–72	M = 25.61 (SD = 8.85)	M = 28.26 (SD = 9.24)
Veldhuis et al. (2012)	Netherlands	Longitudinal retrospective	Clinical	International Classification for Primary Care (ICPC)	Age at OCD treatment-seeking (i.e. first GP visit for OCD)	Database consultation	Individuals with OCD	346	Not age limitation – N n/r	36.0	n/r	n/r	M = 34.9 (SD = 16.0)

Note: M = mean; SD = standard deviation; n/r = not reported.

seeking and duration of untreated illness, to obtain exact binomial confidence intervals and to produce forest plots. The pooled estimates were calculated after Freeman-Tukey Double Arcsine Transformation (Freeman and Tukey, 1950) to stabilize the variances.

A random-effects model was selected, using proportions and 95 % confidence intervals (CIs). Heterogeneity among studies was assessed using Cochran's Q test and the I2 statistic. I2 > 50 % was considered to denote substantial heterogeneity and in such cases the sources of heterogeneity were explored. Subgroup analyses by type of population (general, clinical), age group (adults, adolescents, mixed) and geographical area were performed to investigate heterogeneity. In addition, the effect of continuous covariates was tested by univariate random meta-regression based on the DerSimonian and Laird (1986) method.

We used the method of moments to estimate the additive (between-study) component of variance $\tau 2$. Meta-regressions were performed when a covariate was available for at least four studies. The significance level was set at $p < 0.05$. All statistical analyses were performed using JASP Statistical Software (Version 0.18. 3) and Comprehensive Meta-analysis Version 4.

3. Results

We included 31 studies in the quantitative synthesis; 16 studies (total patients sample: $N = 3461$) provided data for age at help-seeking (k = 18 independent samples) and 16 studies (total patients sample: $N = 2750$) provided data for duration of untreated illness (k = 17 independent samples) (Fig. 1).

Characteristics of the studies are reported in Tables 1 (for age at help-seeking) and 2 (for DUI).

The pooled mean age at help-seeking was 28.66 years (95 % CI: 27.34–29.98), $p < 0.001$, with a heterogeneity score of I^2 (%): 90.29 (Fig. 2).

The pooled mean interval between age at disorder onset and help-seeking was 6.97 years (95 % CI: 5.69–8.24), $p < 0.001$, I^2 (%): 67.80 (Fig. 3).

The pooled mean of duration of untreated illness was 80.23 months (95 % CI: 68.72–91.75), $p < 0.001$, I^2 (%): 95.08; around 6.69 years. The pooled metric for DUI was calculated in months because most of the studies provided data for this parameter in months; converting it to years, we would get approximately 6.69 years (Fig. 4).

Finally, the pooled mean age at disorder onset, for the studies included in our analysis that provided this metric, was 22.07 (95 % CI: 21.05–23.09), $p < 0.001$, I^2 (%): 94.91 (Fig. 5).

Specific factors associated with a shorter or a longer help-seeking process and/or duration of untreated illness were identified through meta-regression analyses The presence of checking compulsions was related a lower pooled mean age at help-seeking ($Z = -2.90$, $p < 0.001$, I^2 (%): 77.95) (Fig. 6).

On the other end, the presence of aggressive and sexual obsessions were associated with a longer pooled mean interval between age at disorder onset and age at help-seeking behavior: $Z = 2.72$, $p < 0.001$, I^2 (%): 17.76 and $Z = 2.38$, $p = 0.02$, I^2 (%): 32.44, respectively (Fig. 7).

Intriguingly, contamination and somatic obsessions were also related to a longer interval between age at disorder onset and help-seeking behavior ($Z = 2.86$, $p < 0.001$, I^2 (%): 11.96 and $Z = 3.16$, $p < 0.001$, I^2 (%): 0.00, respectively) (Figs. 8 and 9).

Finally, a greater severity on the compulsions sub-scale of the Y-BOCS was related to a longer duration of untreated illness ($z = 2.65$, $p < 0.001$, I^2 (%): 86.44) (Fig. 10).

We also assessed the quality of the studies by using our modified version of the Quality Assessment Tool (QAT) for Observational Cohort and Cross-Sectional Studies (see Tables 3 and 4 in the supplementary material). The quality of the studies included in this meta-analysis was generally low to moderate (scores from 4 to 7), apart from some studies that were characterized by a greater methodological rigor (scores 8 or

Table 2
Duration of Untreated Illness (DUI) in Obsessive-Compulsive Disorder (OCD) - Descriptive characteristics of studies included in the meta-analysis (N = 16).

Study	Country	Study design	Type of study	Screening tool for OCD	DUI definition	Target population	OCD sample size N	Including adolescents or children	Men (%) OCD SAMPLE	Age (years)	Age at OCD onset (years)	DUI (months)	DUI (years)
Abdelgadir and Ibnauf (2022)	Sudan	Cross-sectional	Clinical	DSM-5 criteria	The period between OCD onset and the first appropriate pharmacological treatment.	Patients with OCD	89	n/r	61.8	M = 27.12 (SD = 8.72)	M = 21.72 (SD = 7.51)		M = 5.41 (SD = 5.53)
Aguglia et al. (2018)	Italy	Cross-sectional	Clinical	DSM-IV-TR criteria, Structured Clinical Interview for DSM-IV Axis I Disorders (SCID-I)	The interval between OCD onset and the first correct treatment received.	Patients with OCD	162	Not included	59.3	M = 35.6 (SD = 14.4)	M = 19.3 (SD = 7.3)	M = 115.9 (SD = 113.6)	
Albert et al. (2019a, 2019b)	Italy	Longitudinal retrospective	Clinical	DSM-IV criteria, Structured Clinical Interview for DSM-IV Axis I Disorders (SCID-I)	The interval between OCD onset and the first adequate treatment according to WFSBP Guidelines (clomipramine and/or SSRIs, for at least 12 weeks, at adequate dose).	Patients with OCD	251	Not included	53.8	M = 37.36 (SD = 13.62)	M = 22.21 (SD = 9.19)	M = 106.19 (SD = 118.14)	
Altamura et al. (2010)	Italy	Cross-sectional	Clinical	DSM-IV criteria, Structured Clinical Interview for DSM-IV Axis I Disorders (SCID-I)	The interval between the onset of the disorder and the administration of the first pharmacological treatment at adequate dosage and for a proper period, according to currently available guidelines (for OCD: WFSBP Guidelines[a]).	Outpatients with MDD, BD, GAD, PD and OCD	51	n/r	41.2	M = 41.9 (SD = 12.83)	M = 25.78 (SD = 12.17)	M = 90.57 (SD = 106.11)	
Benatti et al. (2016)	Italy	Cross-sectional	Clinical	DSM-IV-TR criteria, Structured Clinical Interview for DSM-IV-TR Axis I Disorders (SCID-I)	The interval elapsing between the onset of the disorder and the administration of the first adequate pharmacological treatment, at an appropriate dosage and for an adequate period, in compliant patients, in agreement with international treatment guidelines (for OCD: WFSBP Guidelines[a]).	Inpatients and outpatients with OCD, PD and GAD	40	n/r	57.5	M = 40.05 (SD =13.02)	M = 28.07 (SD = 11.07)	M = 90.6 (SD = 112.1)	
Costa et al. (2022)	Brazil	Cross-sectional	Clinical	DSM-IV criteria, Structured Clinical Interview for DSM-IV Axis I Disorders (SCID-I)	The interval between OCD onset and the OCD treatment initiation. All treatment modalities were considered, even if they were not fully evidence-based and did not necessarily follow international guidelines (e.g., any pharmacological or psychological interventions sought specifically to treat OCD).	Outpatients with OCD	863	Included children/ adolescents - *N* = 33	42.3	M = 35.0 (SD = 12.9)	n/r		M = 7.96 (SD = 9.54)
Dell'Osso et al. (2010)	Italy	Longitudinal prospective	Clinical	DSM-IV-TR criteria, Structured Clinical Interview for DSM-IV Axis I Disorders (SCID-I)	The time elapsing between the onset of a psychiatric disorder and the administration of the first pharmacological treatment – provided at adequate dosages and for a proper period.	Outpatients with OCD	66	Not included	37.9	M = 40.2 (SD = 13.8)	M = 24.39 (SD = 11.84)	M = 93.09 (SD = 110.99)	
Dell'Osso et al. (2013)	Italy	Cross-sectional	Clinical	DSM-IV-TR criteria, Structured Clinical Interview	The interval between the onset of a specific psychiatric disorder and the subsequent administration of the first pharmacological treatment at standard dosages and for an adequate	Outpatients with OCD, PD and GAD	85	Included adolescents (older than 16 years old) – N n/r	40.0	M = 40.07 (SD = 13.93)	M = 24.27 (SD = 12.95)	M = 94.51 (SD = 107.33)	

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Table 2 (*continued*)

Study	Country	Study design	Type of study	Screening tool for OCD	DUI definition	Target population	OCD sample size N	Including adolescents or children	Men (%) OCD SAMPLE	Age (years)	Age at OCD onset (years)	DUI (months)	DUI (years)
				for DSM-IV Axis I Disorders (SCID-I)	period in compliant subjects based on current international treatment guidelines (for OCD: Practice Guidelines of American Psychiatric Association[b]).					Range: 16–82			
Dell'Osso et al. (2015)	Italy	Cross-sectional	Clinical	DSM-IV-TR criteria, Structured Clinical Interview for DSM-IV Axis I Disorders (SCID-I)	The latency between disease onset and first adequate pharmacological treatment.	Outpatients with OCD	114	n/r	46.5	M = 40.11 (SD =14.63)	M = 23.02 (SD = 2.01)	M = 87.35 (SD = 11.75)	
Dell'Osso et al. (2017)	Italy	Cross-sectional	Clinical	DSM-5 criteria, Structured Clinical Interview for DSM-IV Axis I Disorders (SCID-I)	n/r	Outpatients with OCD	124	Included adolescents – N n/r	50.0	M = 40.2 (SD = 14.6)	M = 23.3 (SD = 11.9)	M = 87.5 (SD = 108.8)	
Girone et al. (2024)	Italy	Cross-sectional	Clinical	DSM-5 criteria, Structured Clinical Interview for DSM-5 Disorders (SCID-5-CV)	n/r	Outpatients with OCD	284	Not included	51,8	M = 39.38 (SD = 14.23) Range: 18–70	M = 22.29 (SD = 11.16)		M = 6.57 (SD = 8.61)
Matsumoto et al. (2021)	Japan	Cross-sectional	Clinical	DSM-5 criteria	The period between the onset of OCD and the start of taking an adequate dosage of appropriate medication for an appropriate period or undergoing adequate CBT based on Practice Guidelines of American Psychiatric Association[b].	Outpatients with OCD	71	Included adolescents (older than 13 years old) – N n/r	38.0	M = 32.1 (SD = 12.7) Range: 13–67	M = 56.4 (SD = 87.6)		M = 4.7 (SD = 7.3)
Perris et al. (2021)	Italy	Longitudinal prospective	Clinical	Structured Clinical Interview for DSM-IV Axis I Disorders (SCID-I)	The interval between the onset of OC symptoms satisfying the diagnostic threshold for OCD and the first adequate treatment, defined as a treatment in compliance with the international guidelines for OCD therapy (OCD Clinical Practice Review Task Force, 2015[c]).	Outpatients with OCD	83	Not included	51.8	M = 31.5 (SD = 10.2) Range: 18–65	M = 22.9 (SD = 9.1)		M = 7.3 (SD = 5.8)
Poyraz et al. (2015)	Turkey	Cross-sectional	Clinical	DSM-IV-TR criteria, Structured Clinical Interview for DSM-IV Axis I Disorders (SCID-I)	The interval between the onset of a specific psychiatric disorder and the administration of the first pharmacological treatment.	Outpatients with OCD	96	Not included	42.8	M = 32.5 (SD = 10.1) Range: 18–52	M = 19.71 (SD = 9.15)		M = 7.02 (SD = 8.52)
Viswanath et al. (2011)	India	Longitudinal retrospective	Clinical	DSM-IV criteria, OCD clinic work-up proforma.	n/r	Sample 1: Individuals with familial OCD Sample 2: Individuals with sporadic OCD	Sample 1: 84 Sample 2: 80	n/r	Sample 1: 65.5 Sample 2: 63.8	Sample 1: M = 28.32 (SD = 11.52) Sample 2:	Sample 1: M = 20.33 (SD = 10.05) Sample 2:	Sample 1: M = 61.36 (SD = 78.09) Sample 2:	

(*continued on next page*)

Table 2 (*continued*)

Study	Country	Study design	Type of study	Screening tool for OCD	DUI definition	Target population	OCD sample size N	Including adolescents or children	Men (%) OCD SAMPLE	Age (years)	Age at OCD onset (years)	DUI (months)	DUI (years)
										M = 30.04 (SD = 10.67)	M = 24.15 (SD = 10.22)	M = 34.03 (SD = 39.78)	
Zheng et al. (2021)	Cina	Longitudinal prospective	Clinical	DSM-5 criteria, Structured Clinical Interview for DSM-IV Axis I Disorders (SCID-I)	The latency between disease onset and first adequate treatment.	Outpatients with OCD	207	n/r	50.7	M = 25.89 (SD = 10.06)	M = 19.62 (SD = 8.32)		M = 4.07 (SD = 3.49)

Note: M = mean; SD = standard deviation; n/r = not reported.

[a] Bandelow B, Zohar J, Hollander E, Kasper S, Moller HJ. World Federation of Societies of Biological Psychiatry (WFSBP) Guidelines for the Pharmacological Treatment of Anxiety, Obsessive-Compulsive and Post-Traumatic Stress Disorders-First Revision. World J Biol Psychiatr. 2008; 9: 248–312.

[b] Koran LM, Hanna GL, Hollander E, Nestadt G, Simpson HB; American Psychiatric Association. Practice guideline for the treatment of patients with obsessive-compulsive disorder. Am J Psychiatry. 2007 Jul; 164 (7 Suppl): 5–53.

[c] Rodriguez C, Bloch M, Sachs R, Williams M; OCD Clinical Practice Review Task Force. Clinical Practice Review for OCD. https://adaa.org/resources-professionals/practice-guidelines-ocd, 2015.

9). No significant difference in terms of pooled mean age at help-seeking and pooled mean DUI was detected comparing studies with higher quality against studies with a lower one.

4. Discussion

OCD is a chronic mental disorder, the severity of which tends to increase over time, leading to a considerable impairment of the subject's functioning and quality of life (Albert et al., 2010). Early treatment is key for improving outcomes, as timely intervention is associated with better treatment responses. DUI in OCD represents a significant public health concern that has important clinical implications, as longer DUIs are associated with worse treatment outcomes and greater functional impairment, highlighting the need for early identification and intervention (Albert et al., 2019a).

Improving access to mental health services, enhancing the ability of primary care physicians and mental health professionals to recognize OCD, and disseminating best-practice prescription guidelines are crucial to shortening the DUI in OCD. Additionally, creating brand-new heuristics for investigating the neural systems that control the 'toxic' effects of prolonged untreated OCD is of foremost importance. Obsessive-Compulsive Disorder (OCD) is markedly undertreated, with about 40 % of patients obtaining any kind of therapy, and a mere 5 % getting Cognitive Behavioural Therapy (CBT) (Lattie and Stamatis, 2022). Considering these statistics and the restricted availability of adequately educated mental health practitioners to provide proper treatment for OCD, there is an immediate need to enhance the accessibility of suitable therapy for this disorder (both pharmacological and psychological). The implementation of accessible therapies for OCD is crucial for addressing the mental health requirements of the global population (Lattie and Stamatis, 2022).

Recent research indicates that insufficient understanding among clinicians and patients on OCD, together with misdiagnosis, leads to its under-recognition. The inadequate prescription of selective serotonin reuptake inhibitors and the restricted use of exposure and response prevention as a primary psychotherapy contribute to the undertreatment of OCD. In this perspective, digital health technologies might have potential in enhancing OCD identification, facilitating access to evidence-based treatment, and maintaining continuity of care. Technological advances create new ways to deliver more accessible interventions to individuals with limited options. Addressing deficiencies in OCD treatment can mitigate the substantial rates of impairment, morbidity, and death linked to this disorder, hence alleviating the mental health burden (Senter et al., 2021).

An enhancement in public awareness of OCD and a decrease in stigma may correlate with earlier identification of OCD, an increased propensity to seek care and an easier access to mental health services, perhaps leading to improved wellbeing. Furthermore, normalising intrusions and understanding the cognitive paradigm of OCD may function as a protective factor for susceptible people (Chaves et al., 2022). It is pivotal that individuals with OCD and related disorders have improved access to effective treatment and adequate support in their communities, and that treating clinicians in every profession have improved capacity to provide effective therapeutic options.

One barrier to appropriate access to mental health services, from the patients' perspective, is the possible fear and anxiety related to change and the beginning of new form of treatments. Compulsive behaviours have a specific purpose in regulating emotions and reducing anxiety in everyday life, so patients might be afraid of therapy due to the fact that they would have to change their behavior and possibly experience more anxiety. With regards to this latter point, there may be similarities with addictive disorders, in which individuals might be afraid of experiencing withdrawal.

In this meta-analysis, including 31 studies and a total sample size of $N = 5960$ patients, we confirmed that individuals with OCD seek help late in their life and the DUI of this disorder is particularly long. We

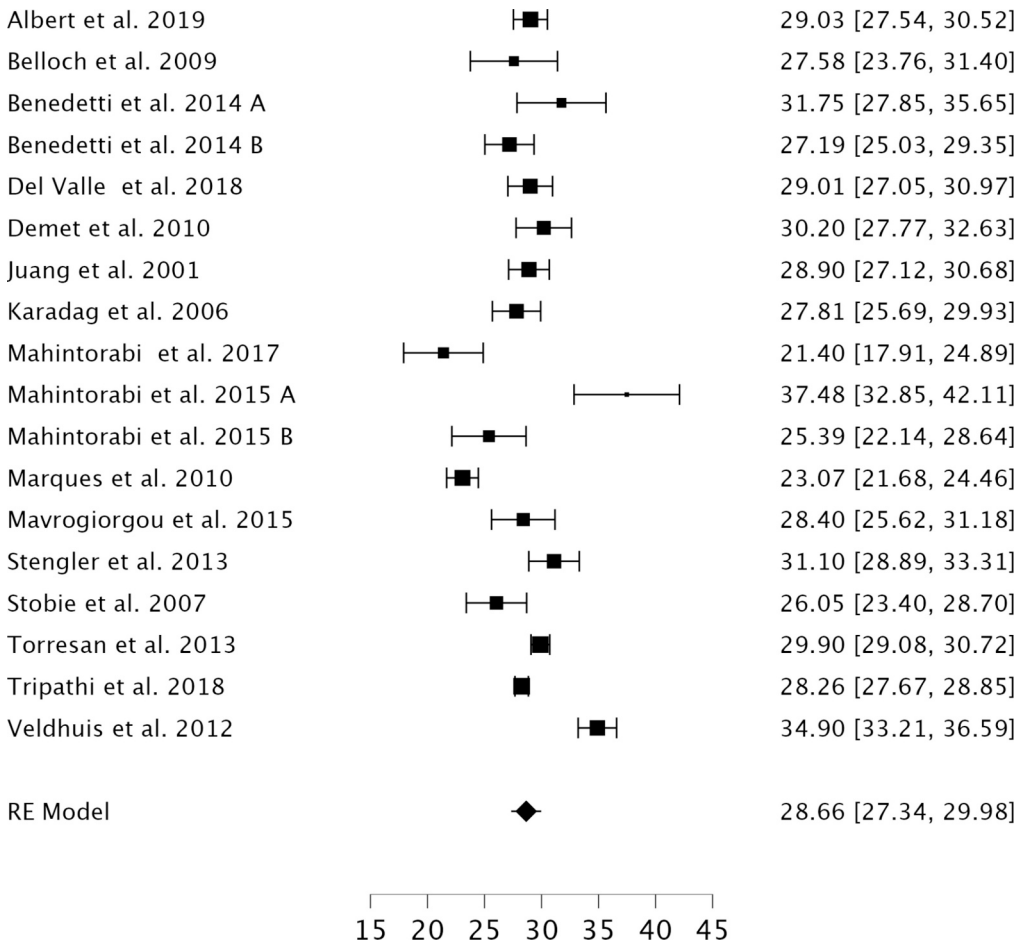

Fig. 2. Forest plot of the pooled mean age at help-seeking (years).

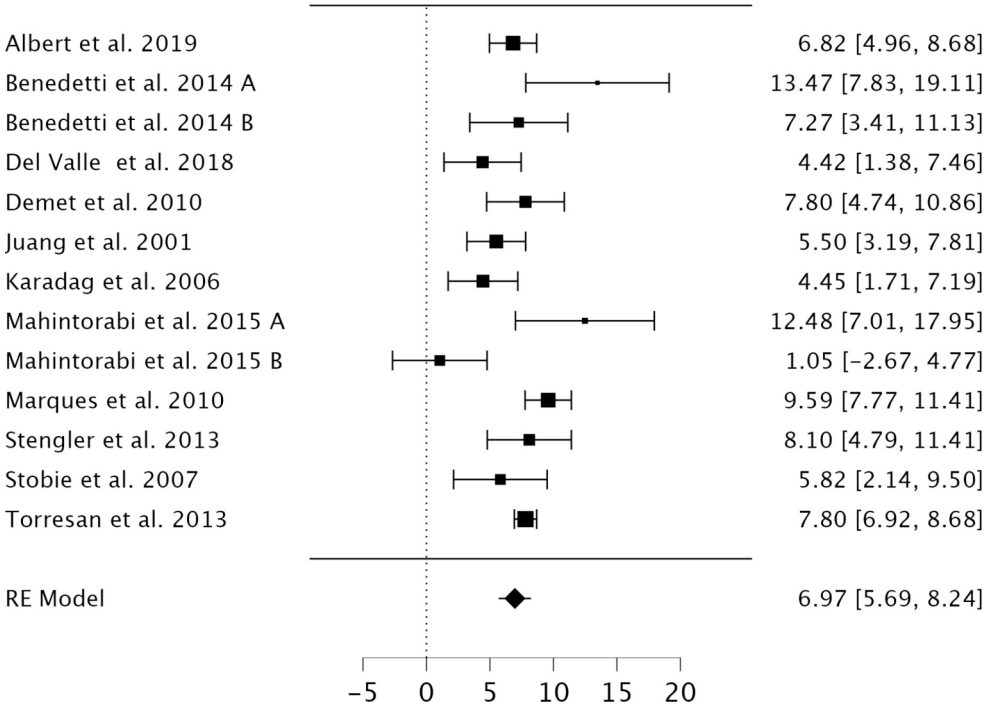

Fig. 3. Forest plot of the pooled mean interval between age at disorder onset and help-seeking (years).

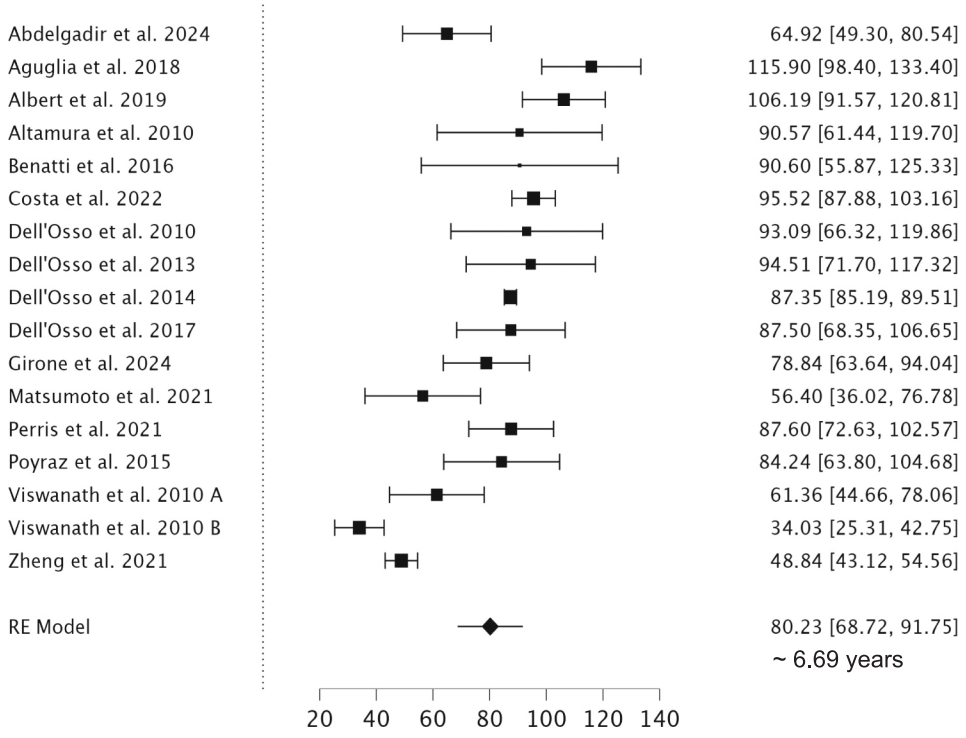

Fig. 4. Forest plot of the pooled mean of duration of untreated illness (months).

found that specific OCD dimensions were associated with the length of the help-seeking process or the DUI. In particular, checking compulsions were associated with a lower age at help-seeking, hinting at the possibility that this subgroup of patients looks for help earlier in their course of illness. This may be explained by the fact that checking compulsions (e.g., checking doors locks, gas knobs, etc.) are overt in nature and among the most known and stereotypical presentations of OCD in public culture. On the other hand, some of the so called *taboo obsessions* (aggressive and sexual obsessions) were related to a longer interval between age at the disorder onset and help-seeking. "Sexual OCD" and "Harm OCD", involving intrusive and unwanted sexual and violent thoughts, images, and urges, are terrifying experiences for the person, that may be worried about explaining these symptoms and burdened by the guilt the thoughts might cause. Contamination obsessions were also linked to a greater gap between disorder onset and help-seeking: this finding might underpin the strong fear of getting contaminated and, therefore, the aversion to seeing a doctor or entering a medical setting, where the risk of contamination with viruses, bacteria or other agents could be perceived as greater. Finally, somatic obsessions were associated with a longer interval between age at disorder onset and help-seeking: this particular type of obsessions could delay help-seeking because patients might be afraid of being ill and could therefore avoid medical advice. In accordance with our findings, individuals with OCD often hide their intrusive thoughts and defer help-seeking for fear of being stigmatized. A recent study showed that obsessions related to contamination, harming, and sexual obsessions were more likely to be socially rejected or cause concern in clinicians than scrupulous obsessions, and that patients would be less likely to reveal sexual obsessions compared to other types of obsessions (Steinberg and Wetterneck, 2017). Another study investigating the public's stigmatizing attitudes towards checking, contamination, sexuality, aggression, and religion-related OCD symptoms, when compared to schizophrenia, indicated that social distance towards violence and sexuality-related OCD symptoms and schizophrenia did not differ. However, social distance towards violence and sexuality-related OCD was higher than religion, contamination, and checking OCD dimensions. Consequently, this implies that there is a difference in public stigma among various forms of OCD and symptoms related to sexuality and violence, are associated with more social rejection. Hence, the general public needs access to educational methods of intervention to eliminate stigma and improve the quality of life for people with this mental disorder (Durna et al., 2019). Intriguingly, in our analysis, only severity of compulsions, and not obsessions, was correlated with a longer DUI: the longer the duration of untreated illness, the more the compulsions could become habitual in nature and intensify in severity. The compulsions becoming habits could then constitute the main factor in determining treatment resistance of patients with a longer DUI. The long duration of untreated illness, therefore, might increase OCD severity by making compulsions worse (possibly increasing the habitual component of compulsive behaviours) (Gillan et al., 2017, 2016, 2015). Nevertheless, individuals with obsessive-compulsive disorder (OCD) are at risk of suicide and this risk could increase as the disorder remains untreated for a long time (Albert et al., 2019b; Benatti et al., 2021; Pellegrini et al., 2021).

When analyzing the nature of help-seeking behaviours, we should take into account that between the ages of twenty-five and thirty years old, the social aspect might play an important role: during this time of life, the demands from the community and the pressure from the external environment to properly function and lead an independent life may increase the level of suffering, therefore contributing to increase the help-seeking behaviours in this age group.

Early interventions for OCD illnesses are desperately needed in order to lessen the needless suffering and expensive burden caused by undertreatment. Clinicians and healthcare providers should be aware of the negative impact of longer DUI on treatment outcomes and should actively seek to reduce DUI in individuals with OCD. Future research should focus on identifying effective interventions to reduce DUI in OCD and on improving our understanding of the mechanisms underlying the negative impact of longer DUI on treatment outcomes.

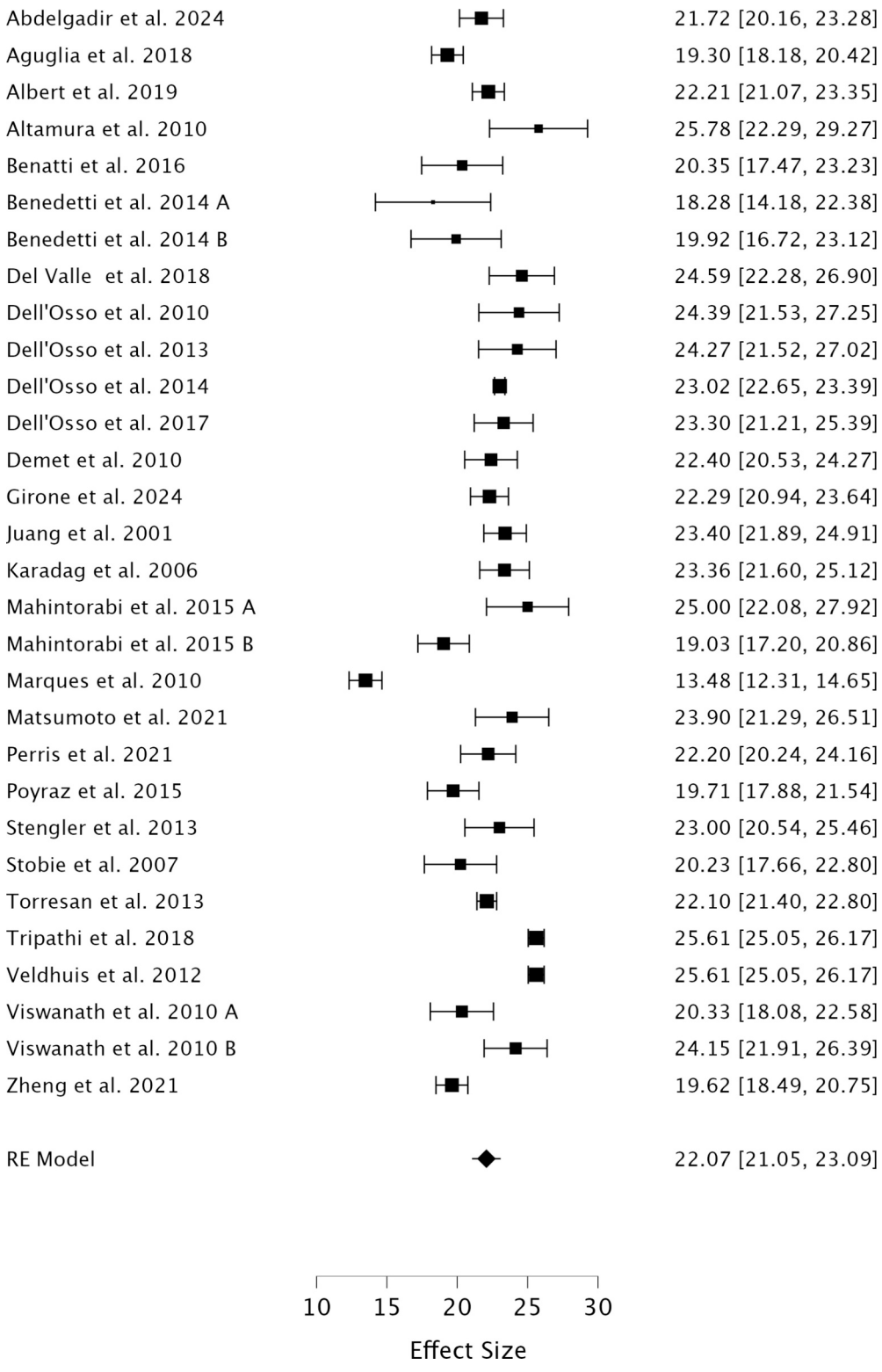

Fig. 5. Forest plot of the pooled mean age at disorder onset (years).

CRediT authorship contribution statement

Luca Pellegrini: Writing – review & editing, Writing – original draft, Methodology, Formal analysis, Data curation, Conceptualization. **Sofia Giobelli:** Writing – review & editing, Methodology, Formal analysis, Data curation. **Sofia Burato:** Methodology, Formal analysis, Data curation, Conceptualization. **Gabriele di Salvo:** Writing – review & editing. **Giuseppe Maina:** Writing – review & editing, Visualization, Conceptualization. **Umberto Albert:** Writing – review & editing, Writing – original draft, Supervision, Methodology, Investigation,

Formal analysis, Data curation, Conceptualization.

Declaration of competing interest

The authors have no interest to declare.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.jad.2025.03.090.

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