

Adult ADHD: a study on evaluation and treatment pathways in Italian Mental Health Services.

A black hole in the National System and the European Health System

Adult ADHD: uno studio sui percorsi di valutazione e cura nei Servizi di Salute Mentale italiani.

Un buco nero nel Sistema Nazionale e nel Sistema Sanitario Europeo

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SUMMARY. Attention Deficit and Hyperactivity Disorder (ADHD) is a neurodevelopmental disorder that often persists into adulthood. The Italian situation regarding the clinical management of childhood ADHD shows some criticalities, despite the high prevalence rate: diagnostic assessments are often inaccurate, protocols for transition from childcare services are almost non-existent and the Italian National Registry for ADHD in childhood was drawn up only in 2007, hence the first specialized services were created later than the rest of Europe. On the basis of these issues, we investigated the Italian situation with regard to disorders in adulthood, comparing the different European operational models, assuming that these critical issues are reflected in the clinical management of the disorder in adulthood. In fact, unlike other European countries, there are no official guidelines governing the clinical management of the disorder in adulthood and evidence-based pharmacotherapies, available in most European countries, are off-label or not allowed in Italy. The aim of the study is to evaluate the current state of knowledge and working method in relation to adult ADHD in the Italian background and to identify the main evaluation and treatment pathways in Italian Mental Health Services. The study is also an attempt to clarify which services are operational on the Italian territory, with the aim of improving the quality of interventions for the clinical population. Three hundred thirty-eight services have been identified in all Italian Regions and Autonomous Provinces, including Mental Health Centres (CSM), Pathological Addition Services (SERD), Psychiatric Diagnosis and Treatment Services (SPDC). An ad-hoc survey with closed-ended questions was administered by telephone to each selected centre and the results were compared with the European literature.

KEY WORDS: adult ADHD, diagnosis, treatment, mental health services.

RIASSUNTO. Il disturbo da deficit di attenzione, iperattività/impulsività (Attention Deficit and Hyperactivity Disorder - ADHD) è un disturbo del neurosviluppo che spesso persiste anche in età adulta. La situazione italiana riguardo la gestione clinica del disturbo ADHD nell'infanzia mostra delle criticità, nonostante gli alti tassi di prevalenza: la creazione del Registro Nazionale Italiano per l'ADHD nell'infanzia è stato redatto solo nel 2007, come tentativo di colmare un gap culturale lungo 40 anni. Abbiamo dunque ipotizzato che questa situazione possa riflettersi sui modelli operativi dei servizi che trattano il disturbo in età adulta che, a differenza di quanto avviene nel resto d'Europa, non hanno a disposizione linee guida utili a supportare la gestione clinica del disturbo. Inoltre, i possibili farmaci, efficaci sulla base della letteratura scientifica, sono off-label o non consentiti per la popolazione adulta. Questa situazione riflette la necessità di una maggiore chiarezza dei modelli operativi italiani. Lo scopo dello studio è valutare lo stato attuale delle conoscenze e i metodi di lavoro in materia ADHD nell'adulto e di identificare quelli che sono i percorsi di valutazione e trattamento nei servizi psichiatrici italiani. Sono stati individuati e contattati 338 servizi italiani tra centri di salute mentale (CSM), servizi per le dipendenze patologiche (SERD) e servizi psichiatrici di diagnosi e cura (SPDC). A ogni responsabile dei servizi è stata somministrata un'intervista telefonica appositamente costruita ai fini dello studio e i risultati sono stati confrontati con la letteratura scientifica europea.

PAROLE CHIAVE: ADHD nell'adulto, diagnosi, trattamento, centri di salute mentale.

INTRODUCTION

Attention Deficit and Hyperactivity Disorder (ADHD) is a neurodevelopment disorder with child-onset. Symptoms are variable at the interindividual level, and over time also at the intraindividual level, giving rise to 3 different configurations of the disease: predominantly inattentive, predominantly hyperactive-impulsive or with a mixed clinical presentation of the two domains¹. ADHD is among the most common psychiatric disorders of childhood that often persist into adulthood: according to available evidence from longitudinal studies, approximately two-thirds of youths with ADHD maintain impairing symptoms of the disorder into adulthood, with consequent impairment in social, school and work functioning^{2,3}. Adult ADHD is associated with poor quality of life, unhealthy life habits (e.g., smoking, alcohol and drug use, and risky sexual behaviour), and altered sleep patterns⁴. It is also frequently comorbid with psychiatric illnesses, such as depressive and bipolar disorders, anxiety disorder, substance abuse and personality disorders⁵ and shows a higher suicide risk even without any psychiatric disorders⁶.

The prevalence of ADHD in the general adult population is about 2.8%, ranging from 1.4% to 3.6%⁷, particularly in Italy there is a prevalence in the general population of 2.8%⁷. These figures could underestimate the true rates of adult ADHD because the disorder in the adults is often underdiagnosed or misdiagnosed⁸.

In Europe, guidelines for the diagnosis and treatment of adult ADHD have been recently published^{9,10}, nevertheless, the disorder continue to be undertreated and when recognized not treated at all⁸. Lack of resources for the diagnostic process, lack of specific therapeutic treatment protocols for the treatment¹¹, and scarce academic training on adult ADHD^{12,13} limit the effectiveness of mental health services directed to adult ADHD patients^{14,15}.

The existing European guidelines agree on the importance of the diagnosis being carried out by experienced staff and a multidisciplinary team and point out the importance of using a valid and reliable test battery to support clinical judgment and the diagnosis process⁹. Indeed, the diagnosis of adult ADHD requires a multimodal approach, including clinical interviews, the use of neuropsychological and personality tests, and reports from family members. Moreover, treatments should include pharmacotherapy and psychological interventions, such as psychoeducation and cognitive behavioural therapy⁸. Psychostimulants (e.g., methylphenidate and amphetamines in different slow or fast release formulations) are considered first-line treatments, while Atomoxetine is only considered a second-line therapy^{8,16}. European guidelines also suggest planning carefully the transition from childcare to adult services, and a re-evaluation of the clinical characteristics of the patient to assess eventual changes in therapeutic needs of the ADHD patient^{8,9}.

The peculiarity of the Italian situation starts from the clinical management of the disorder in childhood. In 2002 the Italian Society for Childhood and Adolescence (SINPIA) published the national guidelines for the treatment and diagnosis of childhood ADHD, lastly updated in 2007¹⁶; this publication occurred with an average delay of 5 years, compared to other European countries. Finally, some resistance from protest movements of Italian opposing parents with the prescription of psychostimulants to children, contributed to make matters

worse: Methylphenidate, the first choice drug for the treatment of the disorder⁸, became a label drug only in 2007 by implementation of an Italian register, which assumes a significantly lower prevalence (1%), compared to countries such as the UK (5%) or the USA (8%). Therefore, in Italy, the first specialized services for ADHD have been developed later and the data underestimate the real prevalence: the specialization of working methods has developed slowly, reflecting the current inadequacy of operational models. In addition, the National Registry also has a section containing all the 110 specialized services for childish ADHD on Italian national territory, but only 30% would effectively be operational¹⁷.

The establishment of the Italian register for ADHD mainly collecting data on side effects is an attempt to create a cultural revolution and aims to overcome a 40-year gap, but the inherent critical issues in diagnostic and treatment approaches for ADHD in childhood are inevitably reflected in the context of ADHD in adulthood.

To date, no national guidelines for adult ADHD have been published in Italy. This situation precluded the institution of specialized services for adult ADHD and specific training for physicians, determining no offer at all or offer of suboptimal diagnostic and therapeutic protocols¹⁸. Only recently, forty-eight Psychiatric Departments of the National Health Service (Servizio Sanitario Nazionale) located in six regions of Italy (Emilia-Romagna, Lazio, Veneto, Lombardia, Piemonte, Sardegna) and in the Autonomous Province of Bolzano were indicated as regional reference centres for the diagnosis and treatment of adult ADHD by the Italian Health Ministry¹⁷. However, these centres are not generally fully operational in the treatment of adult ADHD¹³. Furthermore, only Atomoxetine is authorized and refunded for the treatment of ADHD diagnosed in the adulthood, Methylphenidate is exclusively a label drug for ADHD patients diagnosed in the childhood or at least before 18 years of age and used as maintenance therapy till the maximum of the 25 years of age, and amphetamines are not available on the Italian territory at all.

Considering the paucity of information on the actual knowledge and working methods in relation to adult ADHD on the Italian background it is important and significant for the public health, for the single patient, for professionalizing and for ethical reasons to grasp the actual is-state, gathering information on which services deal with ADHD and how many patients had in the last year, the transition and diagnosis pathways, what tools are used and what pharmacological and psychological treatments are offered.

Consequently, we conducted an ad-hoc survey based on the European guidelines for diagnosis and treatment of ADHD. The survey was administered by telephone to medical doctors of the different mental health services for adults in Italy, inquiring the methods of taking charge, assessment, diagnostic evaluation, and options for treatment.

METHODS

Procedures

Italian Mental Health Public Services eligible for the present research were retrieved from lists of health services published by the Italian Association of ADHD Families (AIFA Onlus) and the Italian National Institute of Health (ISS), and from registers maintained

by Regions and Autonomous Provinces. Services could be included if they offered assessment and treatment protocols to psychiatric adult in- and out-patients and adult patients treated for behavioural and substance dependence and addiction. Health Services not primarily dedicated to the assessment and treatment of mental health disorders, or to the assessment and treatment of adult psychiatric patients were not eligible for the research. Mental Health Centres (Centri di Salute Mentale - CSM), Pathological Addiction Services (Servizi per le Dipendenze Patologiche - SerD), and Psychiatric Diagnosis and Treatment Services (Servizi Psichiatrici di Diagnosi e Cura - SPDC) satisfied the above inclusion and exclusion criteria.

Two researchers independently inspected list of Mental Health Services and Registers and created two lists of potential Mental Health Services satisfying inclusion and exclusion criteria. With the aim of determining which centres are actually operating, we have reviewed the two lists to integrate them and to identify the services actually present on the Italian territory. Finally, a definitive list of Mental Health Services to be contacted was created.

An email was sent from the regional centre of Bolzano to all the Services included in the list requesting to participate in the Survey. The email explained the objectives and methods of the present survey, asking to reply to the email with explicit consent to contact a doctor in charge of the Service for a future telephone interview.

Information about the identity and role of the contact person at the Services were not recorded. During the interview the contact person gave orally his/her informed consent to participate in the study.

The Survey

An ad-hoc survey with closed-ended questions was devised by the authors of the present research. GG and AC created a first draft of potential topics to be covered by the survey. A focus group discussion was scheduled to propose specific questions to cover the topics indicated in the previous step. The group created a first draft of the questionnaire to be administered and proposed a close-ended and open-ended format of response. The questionnaire was sent to MI for a final judgement on its suitability and possible amendments. No changes were requested at this stage.

The final questionnaire included fifty questions with a dichotomous format (YES/NO) (Table 1). Only the first five questions were planned to be administered to all the respondents. These questions investigated the present knowledge about ADHD, the presence of any assessment and treatment protocols within the Service, the presence of continuity of care and transition protocols for ADHD patients diagnosed in the childhood and who became adults (18 years old for the Italian Law). If respondents answered NO to one or more of the first five questions, the interview ends.

In the case the respondent gave a positive answer to all the first five questions, the remaining part of the questionnaire was administered. Other questions investigated the protocols for patient guidance, assessment and diagnosis, and treatment of adult ADHD patients.

RESULTS

Three hundred thirty-eight Mental Health Services have been identified in all Italian regions and Autonomous provinces, including 152 Mental Health Centres (CSM), 70 Addiction Services (the Italian SerD), 116 Psychiatric Diagnosis and Treatment Services (SPDC),

Of the 338 Mental Health Services that have been contacted, 109/338 (32.5%) did not respond to the interview. Thus, the participating Services were 229/338 (67.5%)

Regarding the services that have agreed to participate in the interview, only 29/229 (12.7%) completed it, whereas 199/229 (87.3%) stopped at question 4-bis highlighting – as Table 2 summarises – that only a small percentage of Italian mental health services deals with ADHD in adulthood. Of all the centres that have been contacted 77/229 (33.4%) indicated that they did not know the main features of the disorder instead 29/338 (12.7%) specifically deals with it.

As regards the measures adopted to manage the transition from child and adolescent psychiatry to the adult service, 54/229 (29.9%) of mental health services affirms the existence of a continuity of taking charge between child and adolescent and adult services, but only 25/229 (11.3%) of mental health services has a specific protocol to regulate the transition specifically for ADHD.

The first part of the interview ends with question 4-bis, as a result of which the interview ends if the answers so far recorded indicate that the centre does not deal with the ADHD disorder.

150/229 (65.5%) of participants answer to this question identifying the need for an in-depth analysis of ADHD in adults, while a small percentage, equal to 4/229 (1.8%), denies the need. These results are briefly listed in Table 3.

As regards the number of patients taken in charge, it appears that only 4/229 (1.8%) of the centres had more than 50 patients in the last year, while 17/229 (7.4%) had less than 10 and 6/229 (2.7%) a number between 10 and 50. There was several ways of sending patients to the services: 14/229 (6.5%) cases it was recommended by the general practitioner, 18/229 (8%) by a psychiatrist, 20/229 (8.9%) by another mental health service and 20/229 (8.6%) patients came to the service independently.

It also appears that in 17/229 (7.4%) of cases patients have access to the services even if they do not reside in the territory in which the services are located, and in 5/229 (2.4%) of cases waiting times are less than 7 days, in 16/229 (7.1%) between 7 and 30 days and in 7/229 (3.2%) higher than 30 days.

Concerning the diagnostic process, it appears that: 21/229 (9.2%) of all the interviewed services which have completed the questionnaire carries out the diagnostic process, in 9/229 (4.1%) of the services the diagnostic process related to ADHD is carried out by all the doctors of the mental health service, while in 16/229 (7.2%) by psychiatrists or specialized psychologists with training and specific skills in the diagnosis of ADHD. 17/229 (7.4%) of services collects preliminary information to support diagnosis through report cards or reports of parents or teachers, instead the screening questionnaires are used in 13/229 (5.9%) of cases of the total sample, in particular: CAARS 6/229 (2.7%); BADDS 10/229 (4.7%); ADHD-RS 5/229 (2.4%); ASRS 10/229 (3.8%); SCL-90 4/229 (1.8%); WURS 7/229 (3%); in 4/229 (1.8%) of cases the services respond that they use other screening questionnaires. As regards the use of diagnostic support questionnaires, 14/229 (6.2%) of services use diagnostic support questionnaires, in particular the DIVA 2.0 diagnostic interview in 15/229 (6.5%), and the CAADID in 2/229 (0.9%), while in 5/229 (2.4%) of cases other diagnostic questionnaires are employed. In addition, 14/229 (6.2%) of the interviewed services

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Table 1. The questionnaire.

	Items
	1. Do you know the Attention Deficit and Hyperactivity Disorder (ADHD)?
General	2. Does the Service deal with ADHD?
	3. Is there continuity of care/transition between child services and yours?
	4. Are there any transition protocols?
	4 bis. In your opinion, is there a need for further knowledge about ADHD?
	5. Number of ADHD patients in the last year
	6. Are patients usually referred to their psychiatrist?
	7. Are patients usually referred to the general practitioner?
	8. Are patients usually referred to the other psychiatric services?
	9. Do patients usually arrive on their own?
	10. Can patients access your service even without residence?
Diagnosis and assessment	12. Is the diagnostic assessment carried out in your service?
	13. Is the diagnostic assessment carried out by all physicians?
	14. Is the diagnostic assessment carried out by physicians specialized in adult ADHD?
	15. Do you gather any information to support the diagnosis? (school reports and accounts from parents or teachers)
	16. Do you use screening questionnaires?
	17. Conners' Adult ADHD Rating Scale (CAARS)
	18. Brown Attention-Deficit Disorders Scales (BADDs)
	19. ADHD Rating Scale IV (ADHD-RS)
	20. Six Item World Health Organisation Adult ADHD Self-Report Scale (ASRS)
	21. Symptoms Checklist- 90 (SCL-90)
	22. Wender Utah Rating Scale (WURS)
	23. Do you use other screening questionnaires?
	24. Do you use diagnostic interviews?
	25. Diagnostic Interview for ADHD in Adults (DIVA)
	26. Conners Adult ADHD Diagnostic Interview for DSM-IV (CAADID)
	27. Do you use other clinical interviews?
	28. Do you use questionnaires for comorbidity and differential diagnosis?
	29. Beck Depression Inventory II (BDI-II)
	30. Hypomania Check List (HCL-32 R1 Questionnaire)
	31. Temperament Scale from Memphis, Pisa, Paris, and San Diego-Autoquestionnaire (TEMPS-A)
	32. Structured Clinical Interview for DSM-IV Axis II Disorders (SCID-II)
	33. Wechsler Adult Intelligence Scale (WAIS)
Treatment protocols	34. Do you prescribe therapy?
	35. Do you prescribe multimodal treatment?
	36. Do you prescribe medications?
	37. Atomoxetine
	38. Methylphenidate
	39. Other medications
	40. Are the effects of the prescribed drug monitored through the detection of vital parameters? (ECG, blood analysis, blood pressure)

(Continued)

(Continued) Table 1. The questionnaire.

	Items
	41. Are the effects of the medications monitored through structured methods? (performance tests, questionnaires)
	42. Are the effects of the medications monitored through regular check-ups?
	43. Are psychological treatments offered for ADHD?
	44. Psychoeducation
	45. Cognitive and behavioural therapy
	46. Family therapy groups
	47. Self-help groups
	48. Other psychological/psychosocial interventions
	49. Are family members involved in the treatment?

Table 2. Services that have agreed to participate in the interview.

Services that have been contacted	N. 338
Services that have responded	229/338 (67.5%)
Services that have completed the interview	29/229 (12.7%)
Services that didn't know the disorder	77/229 (33.4%)
Services that deal with the disorder	29/229 (12.7%)

Table 3. Results of the total sample of answers given by the services up to and including question 4bis.

	Total sample
2. Centers that deal with ADHD	29/229 (12.7%)
3. Continuity of taking charge of pediatric and adulthood services	54/229 (29.9%)
4. Specific transition protocols for ADHD	25/229 (11.3%)
4bis. Need for a deeper understanding	150/229 (65.5%)

use a test battery to assess the possible symptoms in comorbidity with ADHD disorder or to support the differential diagnosis process, in particular: BDI-II 5/229 (2.4%), HCL-32 R1 5/229 (2.4%), TEMPS-A 5/229 (2.4%), SCID II 10/229 (4.4%), WAIS 12/229 (5.3%). Therefore, it seems that among the services which respond to diagnoses, 81/229 (35.5%) uses screening and diagnostic questionnaires and 133/229 (58.1%) questionnaires for comorbidity differential diagnostics.

Regarding the treatment, it was found that in 26/229 (11.2%) of services a multimodal therapy for ADHD disorder is prescribed in 18/229 (7.7%) of the total sample cases and in 151/229 (65.8%) of services that claim to prescribe treatments. Drug therapy is prescribed in 24/229 (10.7%) of centres of the total sample and it appears to be: Strattera (atomoxetine) in 18/229 (8%) of cases, Ritalin (methylphenidate) in 18/229 (7.7%) of cases, while in 12/229 (5.3%) of cases centres claim to prescribe for the treatment of ADHD other psychotropic drugs including serotonergic and, in a few cases, atypical antipsychotics.

The effects of the prescribed drug are monitored through the detection of parameters (EEG., EKG, blood tests) in 22/229 (9.8%) of services and in a structured way through performance tests or questionnaires in 9/229 (4.1%) of cases. Psychological/psychosocial treatments focused at ADHD are offered in 13/229 (5.9%) of interviewed services, in particular: psychoeducation in 13/229 (5.9%) of cases; cognitive behavioural therapy in 9/229 (4.1%), family therapy groups in 3/229 (1.5%), self-help groups in 4/229 (1.8%), other psychological treatments in 3/229 (1.2%).

It appears that 80% of services, which deal with the treatment of the disorder, prescribe a drug therapy, in particular: Atomoxetine in 18/229 (8%) and Methylphenidate in 17/229 (7.7%). Furthermore, among the services that have claimed to offer treatment, 13/229 (5.9%) offers psychological treatments, such as: psychoeducation 13/229 (5.9%), cognitive behavioural therapy 9/229 (4.1%), family therapy groups 2/229 (1.3%), self-help groups 2/229 (1.3%). The results relating to the methods of intervention of the services – with respect to the total sample and to the services that have completed the interview – are summarized in Table 4.

Table 4. Clinical management of ADHD in Italian services.

	Total sample	Services that complete the questionnaire
Services using valid and reliable questionnaires as a support to diagnosis	13/229 (5.9%)	13/29 (44.8%)
Services having multimodal therapies	18/229 (7.7%)	18/29 (62%)
Services prescribing drug treatment	24/229 (10.7%)	24/29 (82.7%)
Services prescribing Atomoxetine	18/229 (8%)	18/29 (62%)
Services prescribing Methylphenidate	17/229 (7.7%)	17/29 (58.6%)
Services offering psychological and psychosocial therapies	13/229 (5.9%)	13/29 (44.8%)

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Finally, it appears that in the therapeutic process patients' family members are involved in 15/229 (6,5%) of cases of the total sample, so only in 54.1% of the services that report prescribing treatments.

DISCUSSION

Our research shows that the state of knowledge on Adult ADHD in Italian psychiatric services is still inadequate to support what, according to epidemiological data, represents a significant public health problem¹⁸. Starting from the critical issues concerning the working models and operating methods of childcare services, due to the cultural delay regarding ADHD in the Italian context, the study investigated how the data is reflected in adult health services, although the organization and the number of centres dealing with the disorder in childhood is currently relatively more efficient than it is for adults. In fact there is ample evidence in the scientific literature of the persistence of the disorder in adulthood and that approximately two thirds of young people with ADHD maintain disabling symptoms in later life, but ongoing an Italian cultural bias regarding the disorder as present only in childhood. In Italy, since 2007, the Istituto Superiore di Sanità (ISS) has drawn up a National ADHD Register to monitor the use of pharmacological treatments. Only in 2016 the register was extended to the adult population; in the same year 12 adult patients were registered and 48 accredited centres were reported. These centres are those indicated by the Regions and Autonomous Provinces as suitable for the diagnosis and preparation of the therapeutic plan for adults, and they should be accessible to all patients regardless of the age of onset or diagnosis of ADHD. In addition, the link between the ADHD accredited centre and the mental health local services would depend on the organizational aspects of the individual Regions, and this is still a deficit in terms of collaboration between Psychiatric Services, Mental Health Centres and Addiction Services. Except for the first list published by the ISS in 2016, there are no official updated lists (AIFA, 2016). On the contrary, the Child and Adolescent Neuropsychiatry Services specialized in ADHD are present on the Italian territory in greater numbers (110 centres accredited according to data from the ISS updated to 2016) and their organization is characterized by better compliance with European guidelines: as a matter of fact, the centres are frequently multidisciplinary, with greater collaboration with educational and social services and training programs for parents and teachers¹⁹.

Moreover, since May 2019, the identification of specialized ADHD centres has been assigned to the Italian Association of ADHD Families (AIFA Onlus), taking responsibility away from the ISS. At present the internal organization of AIFA is working to update this list, but no exhaustive and updated list has been compiled yet. The result is a substantial difficulty for patients with ADHD to identify which services can provide specific support for the disorder in question¹⁷. The results of our study show that slightly more than 10%, 12/229 (12.7%), of the Italian services deal with ADHD disorder in adulthood: few centres are equipped to start a diagnostic process and equally few are able to provide multimodal treatment, as indicated by the European guidelines.

The centres dealing with the disorder apply heterogeneous evaluation pathways: not all have a protocol for the transition from child neuropsychiatry to adult services, and the diagnostic methods, tests and timetables vary from centre to centre. To aggravate the picture of a huge shortage of specialised services there is the absence in Italy, unlike England and Germany, of official guidelines for ADHD in adults¹³. Despite the evident problems of the Italian context, there is a growing interest in improving knowledge of the adult ADHD features as attested in our research and proven by the rapid evolution of scientific literature. In the European context, according to the latest update of the European Statement of Adult ADHD dating back to 2018, it appears that the disorder is still under-diagnosed and, therefore, under-treated in several countries, due to the lack of specialised centres and a scarcity of evidence-based intervention models, which increase the burden of individual patients who, in a still large percentage, do not receive adequate support¹¹. In Germany, with the increase in knowledge about ADHD in adulthood and the development of official guidelines for the diagnosis and treatment of adult ADHD, also the number of specialised outpatient clinics has gradually increased, but despite this encouraging data, the management of the disorder remains unsatisfactory from an expert perspective²⁰. In the UK, ADHD services in adults are unevenly distributed. This makes it difficult for doctors to send patients to specialists²¹; it also appears that a significant portion of British patients would have been treated for another psychiatric condition prior to the diagnosis of ADHD in adulthood, highlighting the difficulty for clinicians to recognise and diagnose the disorder in a timely manner²². As regards the transition protocols in Germany, there is a decrease in the treatment rate from 51.8% to 6.6% for the 18-20 age group, comparable to the situation in England, reflecting a plausible inadequacy of the transition protocols for adult services^{20,23,24}. The Spanish situation similarly shows poor transition protocols, with significant drop-out rates between 16 and 17 years of age^{25,26}. In Sweden, 57% of adult ADHD patients receive non-specific treatment for the disorder for many years before receiving a correct diagnosis, due to a shortage of medical staff specialising in the diagnosis of ADHD in adulthood²⁷. Several studies have shown that the failure to recognize the disorder is associated with an increasing of the development of comorbid psychiatric disorders, such as depression, anxiety and substance abuse, which greatly complicate the clinical presentation of the disorder, also affecting the severity of ADHD symptoms⁵. In the Netherlands, as an attempt to address the problem, treatment programmes for ADHD in adults have been established at 28 locations via PsyQ, starting a widespread practice in this country. A protocol has been drawn up by a multi-professional team to provide standardized steps, such as: accurate diagnostic assessment with tests including differential diagnostics carried out on incoming patients, counselling and multimodal treatment consisting of pharmacotherapy, psychoeducation, individual coaching and ADHD skill training¹¹.

In Italy, a further problem concerns the pharmacological offer: unlike other European countries, the class of psychostimulants is not available and refunded by the national health system for those patients who receive a diagnosis after 18 years old, despite the guidelines recommend amphetamines and methylphenidate as first choice drugs⁸ and

methylphenidate is available only since 2007 for children and adolescents with ADHD.

According to our research data, Atomoxetine would be the most widely prescribed drug among the services reporting to offer targeted treatment for ADHD in adulthood, accounting for 18/29 (62%) of cases, followed by Methylphenidate, prescribed in a slightly lower percentage of 17/29 (58.6%), despite proven difficulties in prescribing an off-label medication. It is also significant that only 11% of the total sample of services contacted prescribes evidence-based medication treatment, therefore only a small percentage provides an evidence-based treatment plan. In Europe, Methylphenidate is the most widely prescribed drug in the treatment of the disorder in adulthood. According to data updated to 2019, 15 countries in Europe have approved at least one form of Methylphenidate, becoming a prescription medicine to patients with a post-18 years old ADHD diagnosis: Spain, Portugal, United Kingdom, Ireland, Iceland, Norway, Sweden, Finland, Germany, the Netherlands, Belgium, Austria, Poland, Hungary and Denmark; for the remaining EU countries Methylphenidate is off-label for patients who receive a late diagnosis of ADHD²⁸. Regarding the prescription of Amphetamines, which according to the latest data in the scientific literature are the first choice drugs for the treatment of the disorder in adulthood²⁹, a minority of countries in Europe has authorized their use for ADHD³⁰. The prescription of Lisdexamphetamines would be allowed in UK, Denmark, Germany, Ireland, Norway, Sweden, Switzerland and Spain, but in the latter case only if the treatment started before the patient's 18th birthday^{31,25}. In the Italian context there is a substantial issue related to the prescription of drugs: according to regional provisions, it is possible to have access to treatment with a medicine regularly on the market but for an indication other than that for which it has been authorised, even in the presence of duly authorised therapeutic alternatives, but, as highlighted in our study, the Methylphenidate's prescription centres are 7.7% of the 338 contacted and interviewed: this means that there is not a sufficient number of facilities that can meet the needs of the clinical population. The result is a clear difficulty for Italian patients to receive the prescription of a potentially useful medication because few doctors are willing to prescribe an off-label drug, causing serious difficulties even in the continuation of therapy in the long term. This aspect leads to an inevitable increase in the burden of ADHD patients. The small choice of medication for this clinical population affecting many European countries, and produces a specific problem related to the effectiveness of treatment: in several countries only Atomoxetine is the label drug for the treatment of ADHD in adulthood, and many patients have difficulty in receiving the prescription of Methylphenidate in territories where it is off-label. In the specific case where the Atomoxetine is not effective or not well tolerated, the therapeutic treatment may be insufficient. A longitudinal study conducted on a large Dutch sample showed that with the introduction of Methylphenidate in both slow and immediate release formulations as a label drug for ADHD, there was a decrease in the drop-outs of patients undergoing drug treatment, with the possibility to change drug therapy more easily if the first drug prescription did not produce the desired results³².

Finally, what emerges from our study is that only half of the services dealing with treatment for ADHD in adults offers psychological therapy, although European guidelines

have stressed the importance of a multimodal and multidisciplinary approach. Although some studies, mainly conducted in Germany, have shown the effectiveness of medication alone for the treatment of ADHD, the greatest efficacy of a multimodal intervention, such as medication and CBT, is widely proven in scientific literature³³. Several studies also show that, when a multimodal therapeutic approach is used, there is a significant rate of improvement in the symptoms of patients diagnosed with ADHD³⁴.

LIMITS OF THE STUDY

The study has limitations related to the low number of the sample, the low number of services that responded to the interview, equal to 30%, and the still lower number of those who completed it, equal to 12%. A further limitation is the scarcity of studies in the scientific literature that have addressed the topic, thus reducing the possibility of comparing the data of the study with others that reflect the European situation.

CONCLUSIONS

In Italy, although interest are rapidly expanding, a lack of knowledge is evident: there is a shortage of services that can diagnose and treat ADHD in the adult population, unlike in childhood and adolescence. This situation reflects at least in part the European situation, where similarly the organisation of services is often judged problematic, transition protocols do not always appear adequate and recognition of the disorder in adulthood may not be prompt. However, Italy highlights significant problems that make the picture even more serious: unlike other European countries, there are no official guidelines governing the clinical management of the disorder and evidence-based pharmacotherapies, available in most European countries, are off-label or not allowed in Italy. Finally, there is a significant discrepancy between the national programs of the Italian Association of ADHD Families (AIFA Onlus) and the ISS, which underline the need of at least one specialist service for ADHD for adults in each region, and the actual programs: unlike what happens for children's services, there are too few centres for adults that deal with a public health problem such as ADHD in adulthood. This situation could depend on the cultural deficit that leads to consider the disorder as a childhood condition; likewise, there are drugs whose effectiveness is widely proven by the scientific literature that are still off-label. This overview reflects the need to clarify which services are operational on the Italian territory, with the aim of improving the quality of interventions for this clinical population.

Data availability: the data that support the findings of this study will be shared upon request from the corresponding author of this study.

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Adult ADHD: a study on evaluation and treatment pathways in Italian Mental Health Services

REFERENCES

1. Reale L, Bartoli B, Cartabia M, et al. Comorbidity prevalence and treatment outcome in children and adolescents with ADHD. *Eur Child Adolesc Psychiatry* 2017; 26: 1443-57.
2. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders*, 5th ed. Washington, DC: Raffaello Cortina Editore, 2013.
3. Faraone SV, Asherson P, Banaschewski T, et al. Attention-deficit/hyperactivity disorder. *Nat Rev Dis Primers* 2015; 1: 15020.
4. Helfer B, Cooper RE, Bozhilova N, et al. The effects of emotional lability, mind wandering and sleep quality on ADHD symptom severity in adults with ADHD. *Eur Psychiatry* 2019; 55: 45-51.
5. Katzman MA, Bilkey TS, Chokka PR, et al. Adult ADHD and comorbid disorders: clinical implications of a dimensional approach. *BMC Psychiatry* 2017; 17: 302.
6. Giupponi G, Giordano G, Maniscalco I, et al. Suicide risk in attention-deficit/hyperactivity disorder. *Psychiatr Danub* 2018; 30: 2-10.
7. Fayaad J, Sampson NA, Hwang I, et al. The descriptive epidemiology of DSM-IV Adult ADHD in the World Health Organization World Mental Health Surveys. *Atten Defic Hyperact Disord* 2017; 9: 47-65.
8. Targum SD, Adler LA. Our current understanding of adult ADHD. *Innov Clin Neurosci* 2014; 11: 30-5.
9. Attention deficit hyperactivity disorder: diagnosis and management. NICE guideline [NG87]; 2018.
10. Kooij JJS, Bijlenga D, Salerno L, et al. Updated European Consensus Statement on diagnosis and treatment of adult ADHD. *Eur Psychiatry* 2019; 56: 14-34.
11. Ramos-Quiroga JA, Montoya A, Kutzelnigg A, Deberdt W, Sobanski E. Attention deficit hyperactivity disorder in the European adult population: prevalence, disease awareness, and treatment guidelines. *Curr Med Res Opin* 2013; 29: 1093-104.
12. Kooij SJJ, Bejerot S, Balckwell A, et al. European consensus statement on diagnosis and treatment of adult ADHD: The European Network Adult ADHD. *BMC Psychiatry* 2010; 10: 67.
13. Zadra E, Giupponi G, Migliarese G, et al. Survey on centres and procedures for the diagnosis and treatment of adult ADHD in public services in Italy. *Riv Psichiatr* 2020; 55: 355-65.
14. French B, Sayal K, Daley D. Barriers and facilitators to understanding of ADHD in primary care: a mixed-method systematic review. *Eur Child Adolesc Psychiatry* 2019; 28: 1037-64.
15. Ebert D, Krause J, Roth-Sackenheim C. ADHD in adulthood-guidelines based on expert consensus with DGPPN support. *Der Nervenarzt* 2003; 74: 939-46.
16. Linee-guida per la diagnosi e la terapia farmacologica del Disturbo da Deficit Attentivo con Iperattività (ADHD) in età evolutiva. [Guidelines for the diagnosis and treatment of attention deficit hyperactivity disorder (ADHD) in children and adolescents]. SINPIA - Italian Society of Neuropsychiatry of Childhood and Adolescence, 2002.
17. Germinario EAP, Arcieri R, Marzi M, et al. Registro nazionale dell'ADHD (Attention-Deficit/Hyperactivity Disorder): dati dal 2007 al 2016. *Rapporti ISTISAN* 2016; 37 (supp. 7): 1-34.
18. Valsecchi P, Nibbio G, Rosa J, et al. Adult ADHD: prevalence and clinical correlates in a sample of Italian psychiatric outpatients. *J Atten Disord* 2018; 1: 10.
19. Bonati M, Reale R, Zanetti M, et al. A Regional ADHD Center-Based Network Project for the diagnosis and treatment of children and adolescents with ADHD. *J Atten Disord* 2018; 22: 1173-84.
20. Bachmann CJ, Philipsen A, Hoffmann F. ADHD in Germany: trends in diagnosis and pharmacotherapy. A country-wide analysis of health insurance data on attention-deficit/hyperactivity disorder (ADHD) in children, adolescents and adults from 2009-2014. *Dtsch Arztebl Int* 2017; 114: 141-8.
21. Price A, Janssens A, Dunn-Morua S, et al. Seven steps to mapping health service provision: lessons learned from mapping services for adults with Attention-Deficit/Hyperactivity Disorder (ADHD) in the UK. *BMC Health Serv Res* 2019; 19: 468.
22. McCarthy S, Wilton L, Murray M, et al. Management of adult attention deficit hyperactivity disorder in UK primary care: a survey of general practitioners. *Health Qual Life Outcomes* 2013; 11: 22.
23. Eklund H, Cadman T, Findon J, Hayward H. Clinical service use as people with Attention Deficit Hyperactivity Disorder transition into adolescence and adulthood: a prospective longitudinal study. *BMC Health Serv Res* 2016; 16: 248.
24. Price A, Ford T, Janssens A, et al. Regional analysis of UK primary care prescribing and adult service referrals for young people with attention-deficit hyperactivity disorder. *B J Psych Open* 2020; 6: 7.
25. Irastorza LJ. Questions about adult ADHD patients: dimensional diagnosis, emotion dysregulation, competences and empathy. *Acta Psychopathol* 2016; 2: 5.
26. Irastorza LJ, Bellon JM, Mora M. Comorbilidad de trastornos de personalidad y trastorno por déficit de atención e hiperactividad en adultos. *Rev Psiquiatr Salud Ment* 2018; 11: 151-5.
27. Ahnemark E, Di Schiena M, Fredman AC, Medin E, Söderling JK, Ginsberg Y. Health-related quality of life and burden of illness in adults with newly diagnosed attention-deficit/hyperactivity disorder in Sweden. *BMC Psychiatry* 2018; 18: 223.
28. Chappuy M, Boulanger A, Nourredine, et al. Disparate regulatory status of methylphenidate for adults with ADHD across European Union countries. *Lancet Psychiatry* 2020; 7: 1-2.
29. Cortese S, Adamo N, Del Giovane C, et al. Comparative efficacy and tolerability of medications for attention-deficit hyperactivity disorder in children, adolescents, and adults: a systematic review and network meta-analysis. *Lancet Psychiatry* 2018; 5: 727-38.
30. Raman SR, Man KKC, Bahmanyar S, et al. Trends in attention-deficit hyperactivity disorder medication use: a retrospective observational study using population-based databases. *Lancet Psychiatry* 2018; 5: 824-35.
31. Zimovetz EA, Joseph A, Ayyagari R, Mauskopf JA. A cost-effectiveness analysis of lisdexamfetamine dimesylate in the treatment of adults with attention-deficit/hyperactivity disorder in the UK. *Eur J Health Econ* 2018; 19: 21-35.
32. Van den Ban E, Souverein PC, Swaab H. Less discontinuation of ADHD drug use since the availability of long-acting ADHD medication in children, adolescents and adults under the age of 45 years in the Netherlands. *Atten Defic Hyperact Disord* 2010; 2: 213-20.
33. Lopez PL, Torrente FM, Ciapponi A, et al. Cognitive-behavioural interventions for attention deficit hyperactivity disorder (ADHD) in adults. *Cochrane Database Syst Rev* 2018; 3: CD010840.
34. Magnin E, Maurs C. Attention-deficit/hyperactivity disorder during adulthood. *Rev Neurol* 2017; 173: 506-15.