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'I Bambini e le Droghe': The Right to Ritalin vs the Right to Childhood in Italy

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Abstract

Despite the widespread consumption of stimulant drugs such as Ritalin (methylphenidate) for the treatment of children with attention deficit/hyperactivity disorder (ADHD), understanding of the differing national realities of the ADHD/methylphenidate phenomenon is especially impoverished. In this article, we give an introductory description of the scientific-historical, cultural and ideological factors that have shaped the diagnosis of ADHD and its treatment in Italy. Qualitative empirical analysis of the national debate on the use of methylphenidate and of parents' experiences with the drug reveals that, in the Italian context, the evolution of the ADHD/Ritalin phenomenon has been largely shaped by dynamics within the country's psychiatric practices and health system, as well as by attitudes towards mental illness. We suggest that in Italy, the current dynamics in the regulation of methylphenidate inscribe ADHD diagnosis and stimulant drug treatment as moral choices. On both the political and the familial level, these choices are grounded in sometimes opposing conceptions of vital civil rights and national ideals: the 'right to medication', the 'right to mental health care' and the 'right to childhood'. Our study illustrates that close analysis of specific cultural contexts can be useful in understanding how attitudes towards mental disorders and the use of psychotropic drugs can be shaped by the social practices and medical habits of a country.

Keywords attention deficit/hyperactivity disorder (ADHD), childhood, Italy, neuroethics, Ritalin, stigma

Background

The unprecedented escalation in the use of psychopharmaceuticals has ignited opposing opinions over the justifiability and legitimacy of their increasing use. Psychotropic drugs have made a positive difference in psychiatry: they have significantly altered and eased patients'

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experiences of a range of psychiatric disorders. However, some drugs have been criticized for unrealistic claims about their targeted efficacy. Moreover, there have also been ethical concerns about whether they are being used for treatment of a legitimate disorder or as enhancement of normal functioning (Parens, 1998). Although the distinction is often hard to maintain, a drug for treatment is generally intended to grant and restore ‘normal’ functioning, whereas enhancement drugs are viewed as an intervention which improves human performance and behaviour beyond normality. While some argue that drugs for purposes of enhancement are legitimate, others consider them unnecessary, excessive or artificial (Sabin and Daniels, 1994). Confusion and controversy over the treatment–enhancement distinction surfaces particularly when a psychotropic drug is used to treat a disorder with ambiguous diagnostic criteria and/or individuals who have been given inappropriate diagnoses or individuals with mild symptoms. One such case is the treatment of attention deficit/hyperactivity disorder (ADHD) with the psychostimulant methylphenidate. ADHD is a childhood behavioural disorder which primarily affects boys and whose core features, according to diagnostic manuals, are inattention, impulsivity and hyperactivity.

The significant rise in ADHD diagnoses has spawned a long, often heated, debate on the validity of this condition, making it an emblematic example of the labelling and medicalization of childhood behaviours and of deviance (Conrad, 1975; Conrad and Potter, 2000; Conrad and Schneider, 1982). At stake has been ADHD’s identity as a *bona fide* mental disorder as opposed to a cultural and social construction, emerging from, in particular, a permissive Western culture (Moffitt and Melchior, 2007). It is estimated that 6.7% of American school-age children are affected by ADHD, although estimates range between 1.7% and 16% (Barbaresi *et al.,* 2004; Woodruff *et al.*, 2004). In Europe estimates of the prevalence of the broad category of ADHD vary from 2% to 5%; however, prevalence can vary amongst different European countries (Buitelaar, 2006; Ralston and Lorenzo, 2004).

Methylphenidate (marketed as Ritalin, Concerta, or Ritalin LA) is used as a first-line psychotropic drug for the treatment of ADHD[1] and it has been shown to be the most effective treatment for symptoms of this disorder. Most patients now take the long-acting form of the drug, Concerta or Ritalin LA. Like the short-acting Ritalin, long-acting forms of methylphenidate are effective within 30 minutes to one hour after ingestion, but they use a drug delivery system that dispenses doses of the drug gradually over 8–12 hours. Studies by the MTA Cooperative Group suggest that a therapy based on drug medication or combined therapy (medication and behavioural modification) was more effective than behavioural modification alone in the treatment of ADHD (MTA Group, 1999). There are significant, though usually mild, side effects of methylphenidate: insomnia, lack of appetite and reduced growth. However, few studies have examined the long-term safety and efficacy of the drug treatment (Charach *et al.,* 2004; Hechmann and Greenfield, 2003).

Despite the prolific ethical discourses surrounding the legitimacy of behaviour-modifying drugs in general, and of Ritalin in particular, there has been little engagement with the lived realities of ADHD symptoms and drug treatment (Singh, 2005). This deficit in field data has left the debates largely abstract, and there is a timely need to enrich neuroethical concerns about drugs such as methylphenidate with context-specific data. The parameters of ‘context’ can vary from a narrow, in-depth focus on an individual school or family,

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[1] In 2005 American use of methylphenidate made up 80% of the world’s consumption of the drug (United Nations International Narcotics Control Board, 2005).

to a broader characterization of the history and experiences of ADHD diagnosis and methylphenidate in a given country. Partly because methylphenidate consumption has long been seen as an American problem, we have an especially impoverished understanding of the differing national characteristics of the ADHD/methylphenidate phenomenon. Understanding the national variations in these debates can contribute to a more comprehensive picture of the interplay of scientific and cultural factors in the establishment and experiences of mental disorder and treatment. Moreover, national analyses help us see more clearly how attitudes towards mental disorders and the use of psychotropic drugs are shaped by the social practices and medical habits of a country.

The main aim in this article is to describe the emergence of ADHD as a clinically defined disorder within Italy. Our analysis focuses on two interlinked phenomena: the debate around the acceptance of ADHD as a legitimate diagnosis; and the public debates, policy and clinical debates around the employment of methylphenidate as a therapeutic option. We will attempt to contextualize ADHD and methylphenidate use within the Italian social setting by outlining the scientific-historical, cultural and ideological factors that have shaped its diagnosis and treatment. We will suggest that the specific dynamics in the evolution of the ADHD and methylphenidate phenomenon in Italy are strongly rooted within the country's psychiatric tradition and health system, as well as in national attitudes towards mental illness.

Methodology

Background information on the emergence, development and current management of ADHD diagnosis in the Italian context was gathered through analysis of the existing national psychiatry literature as well as through semi-structured interviews with Italian child psychiatrists and paediatricians involved in clinical ADHD work. Research on the current public debate on ADHD and methylphenidate was conducted following the grounded theory approach (Corbin and Strauss, 1990). Data collected were analysed immediately and used to direct and guide further observation and data collection. Repeatedly observed incidents were recognized through the method of constant comparison as potential phenomena and were later given specific labels and inscribed into higher-order conceptual categories. Data were drawn from various sources. Initially, public attitudes towards ADHD and methylphenidate, as well as parents' experiences with the diagnosis and the pharmacological treatment, were gathered from national ADHD-related websites and from parents' blogs, mainly www.aifa.it and www.provinciabile.it/blogabile. Because of the accessibility of the debate on the internet, entries were made from people living in many regions of Italy.[2]

In parallel, parents' experiences were also collected for this study in two stages from members of the Italian Association of ADHD Parents (Associazione Italiana Famiglie ADHD, AIFA). First, mothers and fathers were given a form and asked individually to provide a short account in writing of how they generally felt about the current national regulations on the use of stimulants for children, and also how they felt about their child being diagnosed with ADHD and being prescribed psychostimulants. The question was formulated in an open-ended fashion so as to give interviewees the opportunity to express their own

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[2] Consent was obtained for this web-observation.

experiences without being biased or guided in any direction. In a second phase, parents who had completed the form were asked to participate in a follow-up interview to talk about what they had written. During the course of the interview, parents had a chance to be more detailed and to expand on their original accounts.

Seventeen mothers and 14 fathers provided written reports and were interviewed. All narratives collected were in Italian and have been translated by the first author. All names given to the parents in the text are entirely fictitious and do not correspond to the real names of parents or children involved.[3]

Paediatric mental health in Italy and emergence and prevalence of ADHD

Child psychiatry in Italy has developed at a slower pace than adult psychiatry. The field has also been slower to develop in Italy in comparison to development in other countries. For the greater part of the twentieth century, Italian child psychiatry was associated with a neurological tradition (Migone, 1996, 1999). What lends singularity to child psychiatry, and to psychiatry in general in Italy today, is the legacy of the mental health system transition in the late 1970s. During this period the anti-psychiatry movement was in ascendance in Italy (Basaglia, 1982), eliciting animated political and public debate (Berlim *et al.*, 2003).

Few large-scale epidemiological studies have been conducted on paediatric mental health within the Italian population and any existing results have been conflicting. A recent summary report published in 2005 by the Burlo Garofolo Paediatric Institute in collaboration with the Cultural Association for Paediatricians (Associazione Culturale Pediatri) and the Centre for Paediatric Health (Centro per la Salute del Bambino; Ronfani *et al.,* 2005) indicated depression to be the most prevalent disorder (8%), followed by learning disorders (5–6%) and severe behavioural disorders (1.6%). The Italian Preadolescent Mental Health Project (PrISMA, Progetto Italiano Salute Mentale Adolescenti) was a mental health screening programme introduced within schools in seven major Italian towns. It was designed to estimate the prevalence of mental disorders among the preadolescent population in the country (children aged 10–14 years old) and to analyse the demographic and biological correlates of emotional and behavioural problems (Frigerio *et al.*, 2006). Based on a screening phase and a clinical assessment phase that involved preadolescents and their parents, the project revealed that 9.1% of the population screened met criteria for a psychiatric disorder while less than 2% fell within the category of behavioural disorders (Frigerio *et al.*, 2006).

However, with respect to behavioural disorders in particular, Tancredi *et al.* (2002) found prevalence rates consistent with international studies, although it has also been observed that many of the children who fall into this category are not referred to mental health services. An epidemiological survey by Levi and Penge (1999) found that 20% of children with behavioural disorders were not referred to mental health services. In general, paediatric mental health services in Italy still favour the provision of psychotherapeutic over pharmacological interventions. A survey of paediatric mental health and rehabilitation services within the Lazio region of Italy found that there were five times as many children

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[3] Consent was obtained from all participants. Permission to interview AIFA members was obtained from the AIFA President.

receiving psychotherapeutic interventions as pharmacological interventions (Agency for Public Health, 2002).[4] The Italian medical literature specific to ADHD remained sparse until the 1990s. The first case report, involving 19 children with behavioural problems, was published in 1971, providing the first nosographic validity of what was then called 'hyperkinetic syndrome' (Guareschi-Cazzullo and Mazzini-Tomazzolli, 1971). As was the case in all European countries, early attitudes towards ADHD in Italy differed from American attitudes with regard to prevalence, diagnosis, referral and treatment (Sergeant and Steinhausen, 1992). A revealing transnational report published in 1984 presented a specific discrepancy between Italy and the United States in both the quantitative measurement and qualitative perceptions of ADHD. In the assessment, the same clinical case information that included symptoms and behaviours typical of a child with ADHD was independently presented for interpretation and clinical assessment to an American and an Italian team, composed of both paediatricians and psychologists (O'Leary *et al.*, 1984, 1985). While American professionals interpreted the clinical issues within an organic and biological framework, the Italian professionals interpreted the same case information within a psychodynamic and socio-environmental framework. Americans more often indicated 'hyperactivity' or 'behavioural disorder' as their diagnosis and opted for more active psychological interventions such as environmental modification and behavioural therapy. Italians chose 'personality disorder' and 'learning disability' as their preferred diagnosis and supported psychodynamic therapy and tutoring more frequently. American physicians and psychologists had a more conservative attitude toward mental health than either professional group in Italy, and having a conservative attitude was found to be positively correlated with diagnosis and use of medication.

This study was important in revealing the specific attitude towards the aetiology and ideology of ADHD in the Italian context. Although the behaviours characteristic of ADHD were recognized as deviant and unusual, they were not conceptualized as a biological syndrome or as a distinct diagnostic and nosological entity, worthy of clinical attention and intervention. It has also proved difficult to arrive at the incidence or the prevalence of this disorder based on national health statistics or case records. Three epidemiological studies conducted in two different regions in Italy on relatively small populations of children revealed that when screening for ADHD, the frequency of the disorder was about 4%, a figure within the range of those of North American and Northern European countries. These studies were conducted using questionnaires for teachers, who were asked to observe and score the behaviour of their pupils for a minimum of three months (Camerini *et al.*, 1996; Gallucci *et al.*, 1993; Marzocchi and Cornoldi, 2000; Swanson *et al.*, 1998). Despite the evidence that symptoms of ADHD occurred in Italy probably in the same proportions as elsewhere, a qualitative assessment of views about ADHD and its treatment among Italian clinicians revealed that the majority of them did not know much about ADHD as described in the updated editions of diagnostic manuals (Bonati, 2005; Gallucci *et al.*,1993). In addition, the majority of clinicians subscribed to a more psychodynamic-psychoanalytic approach and limited their diagnosis to a generic and noncommittal label of 'developmental difficulties' or that of a 'problem child' (Bonati, 2005; Gallucci *et al.*,1993).

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[4] 'Interventions' were also considered to include school counselling, neuro/psycho-motor rehabilitation, rehabilitative learning therapies, psychotherapy for parents and other therapies.

Ritalin comes in and out of the Italian pharmacopoeia

Ritalin first came on the Italian market in the late 1950s, more or less at the same time as in most other European countries. However, its use for the treatment of attention deficits in children was scant. Repeated and increasing incidences of illicit use as a stimulant by university students in the 1960s and 1970s pushed the Ministry of Health to suspend the availability of methylphenidate in 1989. This coincided with Ciba-Geigy's decision to withdraw the stimulant from the Italian market, probably because of low profits. The Italian Drug Agency (Agenzia Italiana del Farmaco) ranked methylphenidate alongside cocaine and other illicit drugs in the Table I list of the Italian pharmacopoeia forbidding its prescription. After the withdrawal of Ritalin from the market in Italy in October 1989, the few recognized ADHD cases were treated with tricyclic antidepressants, benzodiazepines and other drugs. For more than a decade, the lack of Ritalin for therapeutic use was not a concern for the Ministry of Health. There seemed to be no urgency for the re-introduction of methylphenidate as a prescription drug to treat ADHD. Among Italian paediatricians, knowledge about the symptoms of the debated disorder also remained poor during these years. In 2001, a survey of primary care paediatricians in Northern Italy revealed that 30% of them had never heard of ADHD; approximately 60% were aware of the existence of the disorder, but did not know how to diagnose it; and only 10% were following up cases directly (Bonati *et al.*, 2001; Marchini *et al.*, 2000).

A significant development in the sensitization of the clinical world to ADHD was made possible by the engagement of a group of parents, who in 2000 created a project called 'Parents for Parents'. The project started as a vehicle for the dissemination of information among ADHD families, but it soon became a driving force for the Italian Association of Paediatricians and local and national authorities to raise awareness of the existence and prevalence of ADHD, and the existence of Ritalin as a treatment (Bonati, 2005). The 'Parents for Parents' project expanded into the creation of the Italian Association of ADHD Parents (Associazione Italiana Famiglie ADHD, AIFA), who set up a public portal, www.aifa.it. Today the website is a key support and reference resource for most Italian families whose children are diagnosed with ADHD. In 2002, the Italian Society for Child and Adolescent Neuropsychiatry (Societa' Italiana di Neuropsichiatria dell' Infanzia e dell' Adolescenza, SINPIA) unanimously approved and subsequently published national 'Guidelines on the Diagnosis and Therapy of ADHD' (see www.aifa.it/documenti/LGAdhdSINPIA02-doc.zip). The Italian guidelines were aligned with international guidelines released in 2000 and 2001 by the American Academy of Paediatricians (see www.aap.org/policy/adhd) and were intended to provide tools for a unified and rigorous diagnosis in Italy. Publication of these guidelines prompted a National Consensus Conference, which resulted in the production of a consensus document, acknowledging ADHD as a psychiatric pathology, describing the diagnostic pathway and justifying pharmacological therapy as a legitimate therapeutic intervention (Zuddas and Bonati, 2003). In the same year, following the publication of the National Consensus Statement, the Ministry of Health, in conjunction with the Ministry of Justice, re-admitted methylphenidate into the rank of legal drugs. In the text of the legal decree, the ministry recognizes methylphenidate as a pharmacologically effective drug in the treatment of ADHD and grants its approval for administration only in cases where a detailed and careful diagnostic path has been followed (*Gazzetta Ufficiale*, 2003).

This approval, however, did not result in Ritalin becoming available in Italian pharmacies. On the contrary, Ritalin prescription and administration are tightly controlled and regulated, and the medication is only available through authorized centres with experience in the management of ADHD. In practical terms, this means that Italian children who receive a diagnosis of ADHD can be prescribed Ritalin, but the stimulant cannot be purchased in Italian pharmacies. It can only be dispensed to families by the specialist centre where the diagnosis is made.

Methylphenidate is now not the only effective drug for the treatment of hyperactive children. An Eli Lilly drug called atomoxetine has been marketed in the US in 2002 and in the UK in 2004. Atomoxetine is the first non-stimulant medication to be specifically developed for the treatment of ADHD. There is evidence that atomoxetine-related clinical changes in ADHD symptoms are effective and lead to meaningful functional improvements, valued by patients and families. However, potential side effects have not been exhaustively researched (Faraone *et al.*, 2005; Michelson *et al.*, 2001, 2002; Spencer *et al.*, 2005). Clinicians involved in the practice of pharmacological treatment in Italy have also recently scrutinized this drug for the treatment of ADHD. We need to stress here that during the past couple of years there has been unlicensed utilization of these drugs in experimental trials. Both methylphenidate and atomoxetine have been administered to a few hundred Italian children referred to specialized centres, and efficacy and compliance with the drug has been monitored within pilot trials that have also contributed to a number of epidemiological studies involving international collaborations (Buitelaar *et al.*, 2004, 2006, 2007; Di Martino *et al.*, 2004; Hazell *et al.*, 2006; Michelson *et al.*, 2004).

The creation of a national registry

These studies provided a valuable initial clinical assessment of the pharmacological therapy and its protocols, safety, efficacy and side effects. However, they were based on a limited population of children and could provide neither a systematic estimate of the prevalence of paediatric ADHD in Italy, nor of the national consumption of the medication. This motivated a group of psychiatrists, paediatricians and epidemiologists to set up a National ADHD Registry (Panei *et al.*, 2004). The registry has two primary aims. First, it helps keep records of all children and adolescents diagnosed with ADHD across the national territory, ensuring a standardized diagnostic and therapeutic pathway. Second, it aims to systematically monitor the safety and efficacy of the pharmacological treatment (alone or in association with other non-pharmacological treatments) as well as treatment compliance. Children from all regions in the country diagnosed with ADHD are included in an open cohort and listed in the registry, coordinated by the Italian National Institute of Health (Istituto Superiore di Sanita', ISS) and the Italian Drug Agency. However, despite the investment since 2004 of sufficient human, techno-scientific and economic resources, and despite the implementation of standardized operational procedures by a list of authorized centres (including appropriate IT platforms), the registry has not been in use. The delay was due to the fact that the executive council of the Italian Drug Agency did not authorize the controlled prescription and administration of methylphenidate and atomoxetine within the registry proceedings. After a very long evaluation, in early March 2007 the Italian Drug Agency authorized the registry protocols and granted approval for the utilization of both drugs under strictly monitored conditions. This recent step is the culmination of a very long and troubled pathway and is, potentially, a turning point in the management of ADHD diagnosis in Italy. The Italian ADHD registry is an unprecedented instrument for epidemiological assessment and for providing an overview of medication consumption at an international level. In time it could prove to be very valuable.

According to its dedicated website, the registry became operative on 18 June 2007 (www.iss.it/adhd). The extended resistance to its implementation is remarkable considering the current estimates of use and modalities of prescription of other paediatric psychotropic drugs. Despite the fact that the prevalence of psychotropic drug prescriptions in Italy is still considerably lower than that of the United States (10–20%), and is half that of other European countries (3.7–6.0%) (Clavenna *et al.*, 2007), there is nevertheless concern about the increased prescription rate of antidepressants to children, in particular SSRIs (selective serotonin re-uptake inhibitors;) (Bonati and Clavenna, 2005; Clavenna *et al.*, 2007). Based on the findings of a recent drug utilization study, it was observed that there had been a 4.5-fold increase in the prescription of SSRIs between the years 2000 and 2002 (Clavenna *et al.*, 2007). The study also found that the number of Italian children and adolescents currently receiving psychotropic medication could be estimated to be between 28,000 and 30,000.[5] The authors of the study are concerned not only by the increased prescription rates but also by what they argue is a prescribing pattern that is not based on the available evidence base. Fluoxetine, which is the only SSRI licensed for the treatment of depression in children aged 8 and older in the US (FDA, 2003), is prescribed to a lesser extent in Italy as compared with sertraline, paroxetine and citalopram, which are unlicensed. These drugs are therefore often used ‘off-label’.

A national Ritalin debate

Although in Italy the ADHD and Ritalin phenomenon is of a smaller scale compared to the United States or other European countries, it has ignited expressions of both public approval and condemnation that have not been inconsequential for health policy decisions. Very often, much of the polemic on ADHD is centred around the role played by clinicians in diagnosing or discounting the disorder and in prescribing the medication. However, when conditions previously viewed as non-medical are redefined as sickness, a variety of non-medical groups are also involved in disseminating, reinforcing or discrediting understanding of the new sickness (Conrad, 1992). An ADHD debate can involve the intricate participation of clinicians and teachers as well as awareness campaigns by parents’ associations. It can also involve the influence of pharmaceutical industries with marketing interests.

There are currently four main groups actively expressing their voices in the public debate on ADHD in Italy. One is the above-mentioned association of families with ADHD children, AIFA, which, allying with medical experts, played a pivotal role early on in sensitizing clinicians and government to the existence of ADHD and to the possibility of a pharmaceutical option. As we will later outline, this group argues that ADHD has not been properly

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[5] Of these, 23,600 receive antidepressant medication and nearly 6,800 receive anti-psychotics. School-age boys receive antidepressants more frequently in comparison to school-age girls.

recognized and treated. Another advocacy group is AIDAI (Associazione Italiana Disturbi Attenzioni e Iperattività, Italian Association for Attention and Hyperactivity Disorders), a non-profit organization founded in 1996. In a similar fashion to AIFA, AIDAI provides support and resources related to ADHD. However, AIDAI is primarily made up of clinicians, psychologists and educators, with the aim of promoting courses, scientific meetings and awareness on ADHD within scientific and pedagogical communities. This group favours a psychological therapy (behavioural, cognitive and dynamic), over psychopharmacological treatment.

In opposition to these support organizations, there is one main anti-ADHD/Ritalin organization, a lobby group eloquently called 'Giù le mani dai bambini' ('Hands Off Children'). This group has launched an awareness campaign primarily focused on the potential abuse of psychotropic drugs for children. In 2005, 'Giù le mani dai bambini' released a consensus statement, following a statement released by AIFA. In the document, the use of the terms 'illness' or 'disease' to describe ADHD is discredited and considered 'scientifically illegitimate'. ADHD, according to this lobby group, is simply a 'list of dysfunctional behaviours' and is therefore impossible to categorize as a psychopathology. Most importantly, the administration of psychotropic drugs to children is treated with scepticism and condemnation. Members of almost 100 voluntary organizations have subscribed to the mission of 'Giù le mani dai bambini'. The website claims a membership of almost 8 million people from all over Italy. The organization is also supported by a number of politicians of diverse political stances. The group has drawn on the media to disseminate its campaign at a wider level and has sought endorsement of their mission from national and international celebrities. Recently, another non-profit organization named 'Perché non accada' ('So that it won't happen') has made its entry into the quarrel with an anti-Ritalin position. This group, although considerably smaller than 'Giù le mani dai bambini', is also concerned with the uncontrolled use of psychotropic drugs for children. Fearing that the current education on ADHD is distorted and superficial, their primary goal is to promote an information campaign on ADHD. Towards this aim the group has disseminated information leaflets to teachers and schools all over the country, as well as to MPs and local town halls, and to all the national media. 'Perché non accada' has also asked for control over the introduction and implementation in Italian schools of mass surveys and diagnostic tests for screening ADHD or other mental disorders, such as the PrISMA project mentioned above.

Clinicians have also been divided in their beliefs about ADHD. Both advocacy and opposition campaign groups have received support from medical experts. The child psychiatrists and paediatricians, who supported AIFA and who have worked toward the implementation of the national registry, argue that the anti-ADHD scepticism among certain clinicians may be traced to an old national anti-psychiatry tradition, and also to the psychodynamic-psychoanalytical education of professionals. Those clinicians supporting ADHD have worked toward the empirical verification in Italy of the neuropsychological constructs underlying the diagnostic criteria of behavioural disorders. These constructs had been generated in a predominantly Northern American context (Zuddas *et al.*, 2006). By contrast, a large fraction of the medical experts sitting on the scientific committee of 'Giù le mani dai bambini' are, indeed, committed to a more neurological and psychoanalytic approach. Some of them were, in fact, students or followers of the ideas of Franco Basaglia, who regarded any purely technical treatment, such as psychopharmacology, as worse than mental disorders themselves, because of the tendency to 'objectivize' the patient (Basaglia, 1982).

Since the symptoms of ADHD tend to manifest themselves in educational settings, schools and teachers have a role in advocating the illness or in choosing, along with parents, to administer the medication (Phillips, 2006). Diagnostic criteria accord teachers a formal role in the diagnosis through specialized assessment instruments and it is sometimes teachers who first identify the symptoms (there is no legal obligation on the part of teachers, however, to administer the drug in any country). In Italy, the very first ADHD epidemiological surveys in schools were primarily based on teachers' observations (Camerini *et al.*, 1996; Gallucci *et al.*, 1993) and the current diagnostic guidelines include a teachers' assessment component. However, just as teachers may play a significant role in recognizing the disease and in advising on the different forms of treatment (Phillips, 2006), they can also contest the diagnosis and reject treatments. In Italy, AIDAI is the only ADHD advocacy group that involves teachers directly. However, as has been found in other contexts (Malacrida, 2004), parental concerns that children are afflicted by ADHD may also be discounted by teachers in Italy.

Because of the low profit market prospects in the country, pharmaceutical industries have not made efforts towards the re-commercialization of methylphenidate, nor have they been overtly involved in setting up or in funding any of the support groups.[6] However, it is remarkable that Eli Lilly, the manufacturers of atomoxetine, have paid the Italian clinicians who participated in international collaborative studies on the safety and efficacy of the drug to act as consultants and investigators.

Although the organized infiltration of pharmaceutical companies in schools through dissemination of online branded educational material is an emerging phenomenon (in the US or UK context, for example; Phillips, 2006), it has not been an issue in Italy.

The right to health, the right to medication

The predominant narrative emerging from the analysis of the public debate and of parents' experiences with the diagnosis is imbued with issues of health policy and of rights to mental health. These narratives are framed within the current Italian predicament over ADHD, the public unavailability of methylphenidate and the relevant regulations for its dispensation.[7]

Within this scenario, both proponents and opponents of the use of methylphenidate have claimed the health of children as a universal right. For parents who have decided on Ritalin treatment for their children, the right to health becomes the right to 'cure' and the right to 'medication'. The majority of parents feel that being denied access to the drug deprives them of their right to medication and to grant their children a cure they deserve. This sentiment was expressed in an official letter that the representatives of the AIFA parents, together with the members of the Scientific Committee of the National Registry, signed and sent to

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[6] In response to a question by the first author, current AIFA President Patrizia Stacconi denied that the parents' association had received any form of industry funding from the time of its foundation.

[7] Hereafter, we will refer to the debate on the pharmacological treatment as the debate on methylphenidate or Ritalin. Much of the public debate was centred around methylphenidate in particular, and all the children of the parents interviewed were administered this drug. Because of the emergence of atomoxetine as a second-line treatment for ADHD and its inclusion in the Italian national registry, a future study comparing the lived realities specific to the two different drugs could be revealing.

the present Minister of Health in June 2006. In the letter, approval and intervention from the ministry, and therefore the effective launch of the National Registry, are considered an essential action to guarantee children a 'universal right to adequate public health' (Bonati *et al.*, 2006).

Pro-Ritalin parents express their 'anger' and 'dismay' at the absence of a medication that is more easily available in other countries and for a condition that they think is ignored or only superficially considered by the health authorities in their country. They consider the current unavailability of the medication as 'absurd', 'unjust' and 'totally incomprehensible':

> It is unconceivable that this drug [Ritalin] is not available in Italy as it is in many other countries.... What kind of country is it that does not give importance to a drug with the capacity to cure suffering children and [help] suffering families?

One of the fundamental changes to the Italian National Health Service introduced in 1978 was the provision of comprehensive health care free of cost or at a nominal charge through a network of local health units which each cover an average of 300,000 people. Parents dealing with their children's ADHD diagnosis complained about the absence of competent ADHD trained child psychiatrists in local mental health units (as well as informed teachers and educators in schools). Currently, parents of ADHD children are obliged to refer to the very few specialized centres in the country, and when their requirements for the drug exceeds the amounts dispensed to families through the centres, they have to travel abroad and buy the medication at their own expense. They would like Ritalin to be prescribed, made available and administered at local mental health units, or alternatively made available in pharmacies:

> We really hope that we won't be obliged to leave this country, which seems to forget its own children, forcing families into isolation and ignorance [on ADHD and the relevant cures] and which, above all, forgets to implement adequate policies to grant equal rights to all families.

Pro-medication parents regard the legitimate re-introduction of methylphenidate as the recovery of a therapeutic tool. Advocating her right to Ritalin, Maria wonders:

> Shouldn't our hyperactive children ... be cured? Must a short-sighted person not wear glasses? Or a diabetic not take insulin? Or an epileptic child not be treated with anticonvulsants? Why should an ADHD child not be treated with Ritalin?

Similarly, Pietro adds:

> Chemotherapeutic drugs can cause damage in children affected with cancer, but at the same time they can save their life; the same holds for Ritalin: it may have negative effects, but at the same time it is the only possibility to cure a disorder, which is otherwise destined to have dramatic consequences.

However, several parents who adopted the pharmacological treatment also stressed that, when presented with the option by the psychiatrist, a sort of 'protective instinct' had led them to initially refuse it. The prospect of a pharmacological treatment was given lengthy consideration. Potential adverse side effects, and especially the risk of addiction to the drug, were concerns for most parents. The decision to administer the drug came only later, when parents thought that to avoid the pharmacological treatment would be to deny their children a fundamental resource for the attainment of their health.

As has been extensively explored, the expression ‘right to health’ is often used as a shorthand for expressions such as ‘right to health care’ or ‘right to healthy conditions’ (Gostin, 2001; Leary, 1994). This reflects the predicament that ‘health’ per se poses as a vague and subjective notion that cannot be guaranteed to assume meaning as an enforceable right. On the other hand, specific provisions and treatments for specific conditions do bear a more concrete meaning. What is demanded here, in fact, is the implementation of an efficient mental health care system and the recognition of a medication as a therapeutic tool.

Conversely, opponents of the pharmacological treatment condemn the use of Ritalin to cure hyperactive children and worry about its authorized reintroduction into the market fearing an outbreak of an uncontrolled and unjustified ADHD epidemic, often compared to the US scenario. Ritalin, it is claimed, is a threat to the health of the child and is perceived as a medication with enormous and irrevocably deleterious effects.

Not surprisingly, the two factions employ different conceptions of a healthy child and support opposing strategies in their common concern for the ‘health’ of the child. For Ritalin supporters, the pharmacological treatment is an important step towards achieving health, and ought to be a right for everyone. For the anti-Ritalin faction, it is exactly the right to medication that compromises the right to health. On the opening page of the ‘Hands Off Children’ portal, their mission is bluntly presented as the ‘most visible campaign for the defence of children’s right to health in Italy’ and it is currently the largest and most rapidly growing campaign of its kind in comparison to similar initiatives in Europe.

Parents’ experiences with ADHD symptomatic behaviours: the impact of diagnosis and the pharmaceutical option

The range of ADHD symptomatic behaviours highlighted by parents includes disciplinary problems such as aggressiveness; inability to follow rules; inability to be responsible and to organize activities (and especially to organize time); emotional and social problems with parents and peers; difficulty engaging in social activities and sports. Of equal concern are more specific school performance problems, including children’s inability to learn and keep up with the curricula, and their continued under-achievement.

Like the US mothers described in Singh (2004), the emergence of these behaviours in children is a cause of feelings of guilt and inadequacy in Italian mothers. Italian mothers also become targets of fierce and spirited accusations for being the origin of their children’s problematic behaviours. Mothers by and large express a sense of powerlessness in dealing with their children’s behaviour and also feel angry at themselves for failing as a parent. In this sample, mothers, but also fathers, expressed sentiments of inadequacy, powerlessness and anger. In addition, a strongly emphasized consequence of the children’s behaviours is the effect they have on parents’ ideal of family union. Luisa describes this as follows:

> We needed to live more peacefully, like everyone else, to have more calm at home, even among us.... Before discovering what Federico’s problem was, my husband and I couldn’t stop arguing ... we accused each other of being too hard or too tolerant

> with him, guilty and incapable … we realized that our family and our relationship had to be saved.

The unsettling sense of powerlessness is not experienced solely as an individual problem, but is shared with the partner and is an extended concern for the well-being of the entire family.[8]

Parents of children with ADHD reported that acknowledging a biological origin for their child's behaviour allowed them to 'name' the disorder and in this way helped to relieve the impact that ADHD has had on the family. The existence of a drug that 'fixes' the disorder presents a further opportunity to repair a troubled family. The sense of powerlessness and failure recedes when the diagnosis is made and revealed. Giulia thus expresses her relief:

> As mother of an ADHD child, I experienced the time of the diagnosis as a 'victory'. Being aware that my child had a precise pathology has given me relief.

Francesco recalls, as a father, the change after the medication:

> The diagnosis ADHD made me no longer think that I was an idiot, incapable of educating my child.… Paolo [son] was a blank wall on which you couldn't write anything. Whatever you wrote, got cancelled. You couldn't involve him in anything at all. [After Ritalin] we were able to write something on it. Ritalin was the door that allowed us to get in.… Ritalin has allowed us to enter Paolo's brain

The sense of his son's inaccessibility is confirmed in Francesco's next statement, which evokes his feeling of powerlessness in establishing an emotional bond with his own child:

> I could never hug him. It was impossible. He would go away from me. On the contrary, now, [after Ritalin] you can talk to him.… Now there is a relationship, you know, a relationship as for all other parents.

Francesco credits Ritalin for re-establishing contact with his son and for allowing a rewarding relationship between them to re-emerge. The most important and beneficial effect of the drug is that now Francesco can even hug Paolo.

Conversely, sceptics of ADHD and opponents of the pharmacological treatment employed the same narrative of good parenthood as a slogan to sustain their campaign and discredit the existence and importance of the disorder. To this group, ADHD is a 'nomenclature', an 'invented disease' and methylphenidate is the 'easiest road to solve the problem', a scapegoat for busy and reckless parents to 'wash their hands of the matter'. In one of the entries in a parents' blog, Giulia, a mother, says:

> Behind any child discomfort… there is often the absence of parents or the inability of parents to manage certain types of difficulties. Medications like Ritalin legitimize this

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[8] Mothers and fathers contributed almost equally to the narratives we collected, and it did not appear that mothers were any more involved in the management of their child's behaviour, the diagnosis of the disorder and the approach to the drug. Except for a few cases, where the father was no longer present in the family setting for circumstantial reasons, personal stories were described by either parent and very often told using the pronoun 'we' and not 'I', indicating a collaborative action. Although we assume that an extensive gender-specific study would surely be revealing, this current analysis speaks to a balanced familial participation in the resolution of mental health matters and to an ideal of family union. The affiliation with AIFA and their spirit of cooperation, may be a reason for inter-parental collaboration and union in facing the family problem.

> absence and de-responsiblize parents.… It is easier to administer a drug than it is to listen [to children].

Anti-Ritalin campaigners expect ‘affection’, ‘communication’ and ‘understanding’ on the part of parents and regard these forms of parent–child relationships as a more effective treatment than the drug. On the other hand, these are exactly the same forms of relationships which ADHD families long for (as described by Francesco) and which they claim Ritalin has the power to restore.

Public judgement and stigma

In general, parents’ preoccupations about their inadequacy are only exacerbated by external judgement, from colleagues, relatives, friends, teachers and parents of other children (Singh, 2004). Everyday visits to shops, churches, restaurants and cinema theatres are disrupted and rendered an ordeal by the impossible conduct of the child or are suspended or avoided to minimize public judgement. This is clearly exemplified by Guido, who says:

> We are terrified when we enter shops or restaurants. My wife and I have been threatened by passers-by, who wanted to call social workers.… [When our child has] nervous breakdowns in public, the crowd looks at me, as if I am torturing my child with some medieval system … in town everyone points at us.… My child has been nicknamed Attila the Hun …

Raffaella’s experience, more closely points to the perceptions of her role as a mother in school and by other parents:

> When I arrive in front of the school to pick up my child everyone gives me this look, as if it was my fault that my child is like this. The mother of one of his classmates told me that my husband and I are not capable of being parents and that it is an impossible situation that our child bothers their children almost on a daily basis.… I would like to flee to a desert and cry …

The behaviour of the child also became a reason for the social isolation of the entire family, who were no longer invited to participate in social occasions or community gatherings, to avoid the child’s disruptive outbursts of hyperactivity. This is perceived as discrimination by the parents. Alongside this sense of guilt coupled with social judgement, another substantial concern emerging from the analysis of parents’ narratives is the stigmatization of their children and their condition. Parents expressed their worry for the future of their child in a context where being affected by psychopathology is not easily accepted and where it negatively impacts on the establishment of social relationships and insertion into the working world. This is conveyed in Rodolfo’s statement:

> His ADHD condition makes him behave in a bizarre fashion that segregates him from his peers.… I start to wonder whether this might compromise my son’s relationship with his friends, cause problems or trigger discrimination against him.… In the society in which we live he, I, our family cannot afford isolation … we need to face society.

Not enough attention has been paid to the relationship in Italy between the new psychiatric assistance system and people's general attitudes towards psychiatric disorders, their causes and their treatments (Vezzoli *et al.*, 2001). On the one hand, the psychiatric reform and de-institutionalization of psychiatric clinics which took place in 1978 consolidated a vision of the psychiatric patient as a victim of social alienation. However, after those important changes were made and the new psychiatric facilities created, an even less enthusiastic and less tolerant attitude than before seemed to emerge (Volpe *et al.*, 1987). This was probably due to the fact that people were ill-prepared for the confrontation with psychiatric illness and patients. Both the limited knowledge on ADHD, along with the lack of a widespread competence and expertise in the treatment of ADHD across the health system, are perceived by parents facing ADHD in their families as an obstacle for its public acceptance and as a contributing factor to the discrimination of their children and the resolution of their future. Roberta explains:

> I have always been told that Italy is a country where children are highly respected.. . . I cannot agree, since they are instead abandoned in such conditions. There is still so much widespread ignorance on ADHD! My son risks dragging this problem with him into adulthood: what a burden, what a life-time mortgage for his future!

Italian parents' experiences with the symptomatic behaviours of ADHD as described above, along with reactions to the diagnosis and concerns over the disruption to family life, align with data observed in other contexts (Klasen, 2000; Singh, 2004). Sentiments of inadequacy, guilt and anger may therefore be regarded as consistent across different national realities. However, when contextualized within the current regulatory framework on methylphenidate, the sense of powerlessness and inadequacy lose their strictly personal dimension in light of the political and civic dimensions. Parents are often not in the position to help their children as adequate mental health care and medication are not available. Their self-blame is imbued with dissatisfaction with the Italian political circumstances around ADHD. Similarly, parents' concerns over public judgement on their role as educators is accompanied by fear of the stigmatization of their children, which they think is located in the ill-preparedness of the social context for the acceptance of mental disorders.

Vivacity and the right to childhood

Interestingly, both pro- and anti-Ritalin groups often employed the same type of narrative to justify their compliance with or dissociation from the pharmacological treatment. The narrative that emerges is the 'right to boyhood' and to 'vitality'. In this vision, a healthy child is a child who is given the opportunity to be a 'normal boy' and to be 'lively'.

Behind the slogan 'Yes to Childhood, No to Ritalin', supporters of the anti-Ritalin campaign are concerned that drugs may compromise young children's childhood by not allowing them to live 'freely' and with 'lucidity', and instead restricting them to a state of 'sedation'. This is starkly evident in one of the entries:

> Ritalin is a sedative drug against the development . . . of thoughts and against free and revolutionary minds, [Ritalin] is for a lobotomized and atrophized childhood and [is leading] towards a standardization of brains . . .

Similarly:

> . . . it is not admissible to transform vivacious children . . . into a group of chemically sedated zombies . . .

Other parents used words such as ‘silenced’ or ‘switched off’ to describe the condition of children taking Ritalin. Others even compared the effect of Ritalin to the effects of excessive exposure to trash TV. What seems to be threatened is the ‘liveliness’ and the ‘freedom’ of the child:

> It is unthinkable that a vivacious child should be tamed with a psychotropic drug. [This way] it is like renouncing life . . .

And again, Sandra reiterates the need to protect children’s livelihood:

> . . . if parents learned more about these wonderful human beings [children], they would understand that activity and creativity are the panacea for our future . . .

In other words, hyperactivity and the excesses in vivacity, which are potentially symptoms in need of control and management, become advocated features of a healthy and normal child.

In sharp contrast to this deployment of children’s rights, pro-Ritalin parents report that Ritalin is what brings their children ‘back to life’, what allows them to be ‘reborn’:

> With the [pharmacological] therapy, the child becomes ‘normal’, and is not ‘sedated’ or does not ‘hallucinate’. He is serene.

Furthermore:

> [After Ritalin], it’s as if Giovanni woke up from a long sleep.. . . He organizes his time, makes plans . . . and most strikingly, he thinks about his future.

or:

> . . . after Ritalin, Sergio has bloomed.

It is evident that in relation to the debate over the use of stimulant drugs, the ‘right to health’ and the ‘right to childhood’ are dualistic concepts, informing both a pro- and an anti-drug position. Parents’ uses of the same ‘rights discourse’ to defend their perspectives on methylphenidate reflect the more general problematics inherent in the ADHD diagnosis. Notions of what constitutes a normal or a deviant childhood have become very difficult to define in our contemporary society. These notions have certainly been subject to changing political and social circumstances in different contexts. The right to childhood and vitality expressed by the parents aligns with a general principle in contemporary thinking on children’s rights and welfare, according to which childhood must be a safe, secure, carefree and happy phase of human existence (Sommerville, 1982). In some of the narratives above, the alarm over the potential of Ritalin to create a population of ‘sedated zombies’ with a severely compromised future echoes Brock’s ideas about the respect for the ‘originality’ and ‘personal autonomy’ of children, which he feels stimulants have the potential to compromise (Brock, 1998). Depending on the perspective therefore, psychiatry, medicalization and psychopharmacology may be seen to have the power to either threaten or to protect children and their childhood.

Conclusions

We have provided a short description of the recent emergence of ADHD in Italian child psychiatry and its controversial acceptance as a legitimate psychiatric diagnosis. We have also reported on the development of restrictions over the use of methylphenidate as a therapeutic treatment for children with ADHD and on parents' experiences with ADHD symptomatic behaviours and the use of psychostimulants.

In general, the Italian context reflects widespread concerns about the biologization of hyperactivity, the reification of deviance from social behavioural norms as mental illness, and the medicalization of children. The attempt to biologize children's behaviour and describe it in organic and molecular or genetic terms has been defied. This is apparent not only in clinical practice, but also in the national public debate that surrounds the diagnosis in Italy. The reactions and attitudes from the social body, as exemplified by parents' narratives, challenge scientific explanations of ADHD and the efficacy of the pharmacological treatment.

In part, the discourses and debates in Italy overlap with debates taking place in the US and elsewhere (Conrad, 1975; Conrad and Potter, 2000; Conrad and Schneider, 1982; Diller, 1998). However, what makes the Italian debate of particular interest is that positions for and against ADHD and the pharmacological treatment are embedded in valued civil and cultural ideals as well as socio-political and governmental practices. The current political dynamics in the regulation of methylphenidate inscribe ADHD diagnosis and stimulant drug treatment as moral choices. On both the political and the familial level, these choices are grounded in sometimes opposing conceptions of vital civil rights and national ideals: the 'right to medication', the 'right to mental health care' and the 'right to childhood'. The impact of medication may be either endorsed or condemned for the sake of children's health, and in order to guide mental health policy and governmental action. As has been emphasized elsewhere, the concept of health is 'indeterminate'; 'health' is a product of the tensions between 'normativity' and 'normality', between organic and vital norms of health and social and moral judgements of health status. Moreover, these dynamic tensions are intimately informed by new available technologies (Greco, 2004). The provision of methylphenidate extends the limits of what is technically feasible in achieving 'healthy' behaviour. However, the notion of 'healthy' behaviour remains disputed by a plurality of vital norms on the one hand, and moral and social notions of normality on the other, all of which become incorporated into policy concerns (Greco, 2004; Rose, 2001).

Our data also illustrate that the context-specific dynamics of ADHD management and methylphenidate treatment pervade parents' experiences with the disorder and with the administration of the drug. Parents' individual self-blame and sense of powerlessness in dealing with ADHD in their family are compounded by the inadequacy of the national mental health care system in dealing with this new disorder. Similarly, parents' anxiety about public judgement and social stigma is also ascribed to the scarcely disseminated knowledge of ADHD and to the poor acceptance of mental disorders in general in the country. Unlike other contexts, such as the American one, in which sentiments of inadequacy are perceived within a strictly personal sphere (Singh, 2004), in Italy the same problematic experiences assume a collective and civil dimension.

Our study is an initial account of the Italian experience with ADHD and is limited to a critical description of the national circumstances and primarily to the views of a small group of parents. Further in-depth analysis of other interest groups, as well as of the lived realities specific to other medications such as atomoxetine, would be informative.

The case of Ritalin in Italy poses a clear example of how attitudes towards the use of psychotropic drugs are strongly shaped by social and cultural values and by the psychiatric tradition of a country. Significant changes in the current management of ADHD and in the regulation of paediatric psychotropic drugs (e.g. the activation of the National Registry), potentially represent a shift in child psychiatry in Italy towards its realignment with psychiatry practices in other European and North American countries. Future analysis of the developments of the current situation will prove to be revealing.

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