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RESEARCH ARTICLE

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Pathways to specialist care for eating disorders: An Italian multicentre study

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Abstract

Two hundred forty six patients with eating disorders (EDs) recruited from eight Italian specialized treatment centres were administered with the World Health Organization "Encounter Form," a standardized schedule that makes it possible to characterize the clinical pathways that patients follow to reach specialized care.

The median time from symptoms onset to specialized care was 114 weeks. Primary "points of access to care" were general practitioners (25%), psychiatrists (18%), and clinical nutritionists (17%), followed by various other carers. All patients received specific psychotherapy, whereas only 11% of them were given psychotropic drugs. EDs are characterized by complex care pathways, with low rates of direct access to specialized care. Although the role of general practitioners remains crucial, they tend to follow different clinical routes to refer ED patients. Educational programmes on EDs should be addressed to general practitioners and clinical nutritionists, in order to ease the transition of ED patients to a mental health care setting.

KEYWORDS
anorexia nervosa, binge eating disorder, bulimia nervosa, duration of untreated illness, eating disorders, health care policy, pathways to care

1 | INTRODUCTION

Eating disorders (EDs) still represent the most common enduring mental illness in adolescence and have gained increasing attention from clinicians and researchers in recent years. Although, numerous studies have focused on the clinical course of EDs and their treatment, this group of illnesses continues to constitute a clinical challenge for psychiatrists in terms of clinical care and management (Treasure, Claudino, & Zucker, 2010).

Although the available research has produced clear indications on how to diagnose and treat EDs, it is no simple task to introduce a multidisciplinary treatment team and implement a comprehensive specialized service for ED care (Halmi, 2009) in routine conditions and these are often not widely available. This may explain why such patients are still suboptimally treated under routine conditions in psychiatric settings and tend to make considerable use of mental health services (Patton, Coffey, Carlin, Sanci, & Sawyer, 2008), generally with poor prognosis (Kaplan et al., 2009). The introduction of several innovative therapeutic approaches for EDs (Fittig, Jacobi, Backmund, Gerlinghoff, & Wittchen, 2008; Hailey, Roine, & Ohinmaa, 2008; Mitchell et al., 2008; Robinson & Serfaty, 2008; Ter Huurne et al., 2015; Gutiérrez-Maldonado, Wiederhold, & Riva, 2016) have not yet had a significant impact on the therapeutic approach adopted in the "real world" of mental health services. It should also be considered that the available evidence is not always sufficient to support the use of some of these approaches in routine conditions (Perkins, Murphy, Schmidt, & Williams, 2006; Sysko & Walsh, 2008; Vocks et al., 2010).

A recent retrospective study conducted in British specialist and non-specialist care centres for EDs have revealed that specialized outpatient units (in which evidence-based approaches are routinely used with a multidisciplinary approach) are to be considered the preferable treatment setting for EDs, in terms of clinical outcomes, consistency of care, and cost reduction (House et al., 2012). However, some authors have suggested that improvements in the everyday care of EDs are foreseeable if the development of such specialist outpatient services within the National Health System and the direct access from primary care to such services is ensured in the future.

Unfortunately, EDs typically tend to evade detection and are associated to prolonged premorbid phase and/or delayed treatment: A recent study (Neubauer et al., 2014) on paths to first treatment has reported a mean of 25.14 months of untreated anorexia nervosa (AN). The delay to treatment in psychiatry has been correlated with a usually long duration of illness and negative influences over the further outcome for several psychiatric disorders, whereas a recent meta-analysis on schizophrenic psychoses has supported the association of early diagnosis and more favourable clinical outcomes (Penttilä, Jääskeläinen, Hirvonen, Isohanni, & Miettunen, 2014). In the case of EDs, it is well known that illness duration is a relevant predictor of outcome (Steinhausen, 2002), and several clinical ED treatment models support the implementation of early interventions (Fairburn, Welch, Doll, Davies, & O'Connor, 1997; Lewinsohn, Striegel-Moore, & Seeley, 2000; Currin & Schmidt, 2005; McClelland et al., 2018).

Thus, one of the main challenges for the treatment and care of EDs remains the development of reliable clinical pathways that may lead ED patients through the complex and highly integrated ED care network in order to reduce the delay in diagnosis and ensure rapid access to specialist care.

"Pathways to care" studies have long been shown to represent an effective and inexpensive method to characterize the help-seeking behaviour of those suffering from severe illnesses with longitudinal course in various fields of medicine (Campbell, Hotchkiss, Bradshaw, & Porteous, 1998; Rogler & Cortes, 1993). The evaluation of pathways to care in mental health is particularly necessary, also in consideration of the high level of stigma attached to mental illnesses and the difficulties that psychiatric patients experience when accessing psychiatric care (Thornicroft et al., 2009; Schnyder, Panczak, Groth, & Schultze-Lutter, 2017).

One of the earliest studies on the pathways to mental healthcare was performed in collaboration with the World Health Organization (WHO). Besides confirming the difficulties and disparities in accessing mental healthcare in different countries and settings, the study also furnished a specific and standardized tool (the "encounter form") to quickly and reliably assess the routes followed by psychiatric patients in order to reach specialized care for their mental health issues (Sartorius et al., 1986). Over the past few decades, the availability of such tool has allowed

Highlights

- Pathways to specialist care for eating disorders are varied and may hamper early diagnosis.
- The systematic study of pathways to care may help in implementing clinical care programmes for eating disorders.
- General practitioners and nutritionists should be a specific target of educational programmes for eating disorders.

valuable comparisons to be made between different health care systems in different countries of the world and has shown the utility of such an approach for monitoring the current needs and gaps in mental healthcare (Volpe, Mihai, Jordanova, & Sartorius, 2015).

The use of such a standardized approach to investigate the pathways to mental healthcare in all regions of Italy, Volpe et al. (2014) has recently shown that, compared with previous non-standardized evidence (Amaddeo, Zambello, Tansella, & Thornicroft, 2001; Balestrieri, Bon, Rodriguez-Sacristan, & Tansella, 1994), the prevalence of EDs has greatly increased. However, given that the study focused on the pathways followed by patients with any mental disorder to general psychiatric services, no data were available concerning the pathways specifically followed by patients with EDs to reach specialist care in Italy. A previous study in Germany attempted to characterize the routes followed by ED patients to reach dedicated care: Neubauer et al. (2014) reported that AN patients had their the first contact with health care facilities mostly through general practitioners and paediatricians, with a long duration of untreated illness (2 years, on average). However, the authors used a non-standardized questionnaire to retrieve information about clinical pathways and limited the investigation only to patients with AN reaching the first step of care. A subsequent study by the same group (Gumz, Weigel, Wegscheider, Romer, & Löwe, 2017) aimed to evaluate the impact of a systemic public health intervention on pathways to ED care. The authors had to recognize that the implementation of the “psychenet Healthcare Network Campaign” in Germany did not positively affect the time of “untreated AN”, and made a strong plea for the redesigning of health care policies, the improvement of early detection and the implementation of steps to ensure timely treatment for patients with EDs in order to prevent chronic evolution of the disease and more severe complications in the long term.

The aim of the present multicentre study was to use a standardized and validated tool in order to investigate the pathways followed by patients with EDs to reach specialist care. In this way it would be possible to determine how patients with EDs reach specialist carers, to identify delays/barriers to specialist treatment and to describe treatment choices in standard clinical care.

2 | METHOD

2.1 | Subjects

All patients with any ED (outpatients, emergency assessments, or newly referred patients for admission), who had access to one of the participating specialist ED centres (Catanzaro, Florence, Lecce, Milan, Naples, Padua, Turin, and Udine) between October 1st and November 1st 2016, were included in the study. The Italian National Health System is founded on the principles of universal coverage (through general taxation) and free access to the health care services; primary care is widely distributed in the community and general practitioners/paediatricians are expected to act as “gatekeepers” for subsequent healthcare steps. However, over recent years, a growing number of patients have been turning directly to public mental health centres (Volpe et al., 2014). Free access to hospital care and freedom to choose private professional health carers are also available options in Italy. Guidelines for the treatment of EDs have recently been licenced by the Ministry of Health and follow the most common international evidence-based treatment options (Ministero della Salute, 2013).

As usual in pathways studies (Gater et al., 1991, 2005), 1 month was considered a valid timeframe to provide a quick yet reliable representation of the typical recruitment month. In conformity with previous pathways methods (Gater et al., 2005), no exclusion criteria were applied, and the only conditions that had to be satisfied were that the patient had to be newly referred to the ED facility (i.e., that he or she had not sought care from any specialist ED service within the previous12 months) and had given informed consent to participate in the study. All included centres interviewed patients with such characteristics until the target of at least 25 participants was achieved.

The study was approved by the Ethical Committee of the Coordinating Centre (i.e., University “L. Vanvitelli,” Naples, Italy), and all included subjects gave their written informed consent to participate in the study after they had been provided with a complete description of the study aims and methods.

2.2 | Materials

We examined pathways to care of people with EDs in eight Italian specialist mental health services, using a semi-structured interview (Encounter Form) to record information about pathways to care (Gater et al., 1991). The validated Italian version of the Encounter Form (Volpe et al., 2014), was slightly modified only by adding a group of specific carers for EDs (namely: endocrinologists, paediatricians, gynaecologists, gastroenterologists, and nutritionists), not included in the original version.

The psychiatrist-in-charge conducted the questionnaire, which took 5-10 minutes. An instruction and coding manual was supplied to each psychiatrist who took part in the field work. The Encounter Form made it possible to record, for each enrolled patient, the basic socio-demographic characteristics, the main psychiatric problem(s) presented (including eating and behavioural symptoms), the source/type of care received before seeing a mental health professional, and the interval from the onset of mental health problems to contact with mental health professionals, at each step of care. If patients were not entirely able to provide reliable information about previous care routes or about the timing of each care step, investigators were allowed to retrieve complementary information from family members or previous therapists. For each patient, diagnoses, according to the *International Classification of Diseases–10th revision* (ICD-10; World Health Organization, 1992) and to the DSM-5 (American Psychiatric Association, 2013), as well as the list of received treatments were obtained.

2.3 | Analyses

The routes taken by participants seeking mental healthcare were combined in a Pathway Diagram, which describes the steps needed to reach psychiatric care, from the onset of psychiatric disease onward (Gater et al., 1991, 2005). The proportion of patients taking each step on the pathway diagram is mapped onto the diagram, along with the mean time intervals occurring at each step. Time to reach specialist and non-specialist care was described for major pathways, different diagnostic groups and clinical presentations. We obtained mean (±standard deviation, *SD*) values for major variables, but when comparing time, we provided median values as the distribution of time intervals was significantly skewed. Categorical data were analysed using the Chi-square test, whereas continuous variables were analysed through the analysis of variance (ANOVA). All statistical analyses were performed with the SPSS software (version 19.0; SPSS Inc., Chicago, USA) and the level of significance was set at $p < 0.05$ for all analyses.

3 | RESULTS

3.1 | Subjects

Although 25 patients per centre were sought for recruitment, centres were also allowed to recruit referred patients during the month-long study period. As there were no refusals and no patient was excluded in any of the centres, an average (±SD) of 31.5(±4.6) patients were recruited in each centre. Thus, we recruited a final number of 246 patients, who were mostly female (88.8%; n = 218) and of Caucasian ethnicity (100%). Their mean (±SD) age was 28.8 (±4.9) years. A simplified measure of socio-economic status (a scale ranging from 1 = "low" to 3 = "high," based on the Hollingshead's Index of Social Status; Hollingshead, 1975) revealed that most of the patients were middle class (60%; n = 148), whereas 23% (n = 57) of them were in the lower and 39% (n = 39) in the higher socio-economic class. The majority of them were neither married nor engaged in a significant relationship (75%; n = 172). No significant differences in terms of age, gender, socio-economic, and marital status emerged among the subjects recruited in different centres. None of them had a history of traumatic brain injury or any other neurological illness, nor were they suffering from current drug/alcohol abuse or dependence, or any major medical illness or physical condition (e.g., pregnancy) known to influence eating and body weight/size.

3.2 | Problem presentation and diagnosis

The most frequent diagnosis for referral was bulimia nervosa (BN; 23.6%; n = 58), followed by other EDs (21.5%; n = 53); however, the total of typical (17.4%; n = 43) and atypical (16.1%; n = 40) forms of AN accounted for 33.5% (n = 83) of the sample, while atypical BN was present only in 1.7% (n = 4) of the cases. Overeating associated with other psychological problems accounted for 5.4% (n = 13) of the sample, whereas unspecified EDs accounted for 11.6% (n = 29). No ED was found in 2.7% (n = 6) of the cases (due to misdiagnosed anxiety disorders, somatoform disorders and psychosis; such cases were excluded from further analyses).

The suggestion to first seek care for disturbed eating behaviours came from patients themselves, only in less than half of the cases (43.9%; n = 108); whereas most often (56.1%; n = 138), patients were asked to seek mental health care by a relative (32.5%; n = 80), a health professional (21.1%; n = 52), or a friend (2.5%; n = 6).

Only a minority of patients (17%; n = 39) sought specialist ED care directly, while the relative majority of reached specialized services by first accessing either primary care (23%; n = 62) or mental health care (18%; n = 44). Although psychologists were first approached only in 8% (n = 20) of the cases, nutritionists were the first point of contact for 17% (n = 42) of the patients. Other professionals involved as the first node of the mental health care network for EDs were hospital doctors (7%; n = 17), other doctors (including endocrinologists, gynaecologists, gastroenterologists; 4%; n = 10), private care doctors (4%; n = 10), and social workers (1%; n = 2). As general practitioners constituted the main point of access to specialist care for EDs, it has to be noted that only a minority of the cases (26% of the patients seen by them) were then directly sent to a specialist care setting. However, after reaching one health care professional, the rate of patients who reached specialist care settings was 45% and this number doubled after meeting two carers. A third and a fourth carer were needed only in 14% and 4% of the cases, respectively.

A more detailed representation of the pathways, followed by ED patients in order to reach specialist care is provided in the Pathways Diagram (Figure 1).

3.3 | Treatment

Psychological treatment was offered to every patient enrolled in the study, within a cognitive-behavioural framework. Pharmacological treatment was necessary in 11.4% of the cases only and the most frequently prescribed drugs were selective serotonin reuptake inhibitors (paroxetine: 17.9%; fluoxetine: 7.1%; escitalopram: 3.6% of prescribed drugs), although trazodone, lamotrigine, and levosulpride were also used, each in less than 5% of the cases.

3.4 | Delays and barriers to specialist care

In more than half of all cases (54%), patients reached the specialist ED care centres from outside their catchment area. In all centres combined, the median total duration of time from the onset of main problem to arrival at the ED specialist service was 114 (*SD*, 60) weeks, whereas the median time between first seeking care and arrival at the ED specialist services was 28 (*SD*, 36) weeks or less. A graphical account of the mean total duration of problems for individual diagnostic subgroups is provided in Figure 2.

4 | DISCUSSION

Our study shows, with a methodology specifically standardized to delineate pathways to psychiatric care, that ED patients follow complex, varied, and different clinical pathways to reach specialist care in Italy. Furthermore, ED subjects from our sample also displayed a large individual variability in the timing of access to care: Our data tend to point to a tendency for ED patients to postpone access to specialized care, with an average 2-year gap between symptoms onset and access to care. This might be partially due to factors related to the patients themselves: Previous studies have shown that ED patients often show initial denial of their illness, low motivation to change, low illness insight, and that the so called "maintaining factors" for EDs may exert a significant influence over access to care and treatment outcome (Abbate-Daga, Amianto, Delsedime, De-Bacco, & Fassino, 2013). However, the evidence from our study is

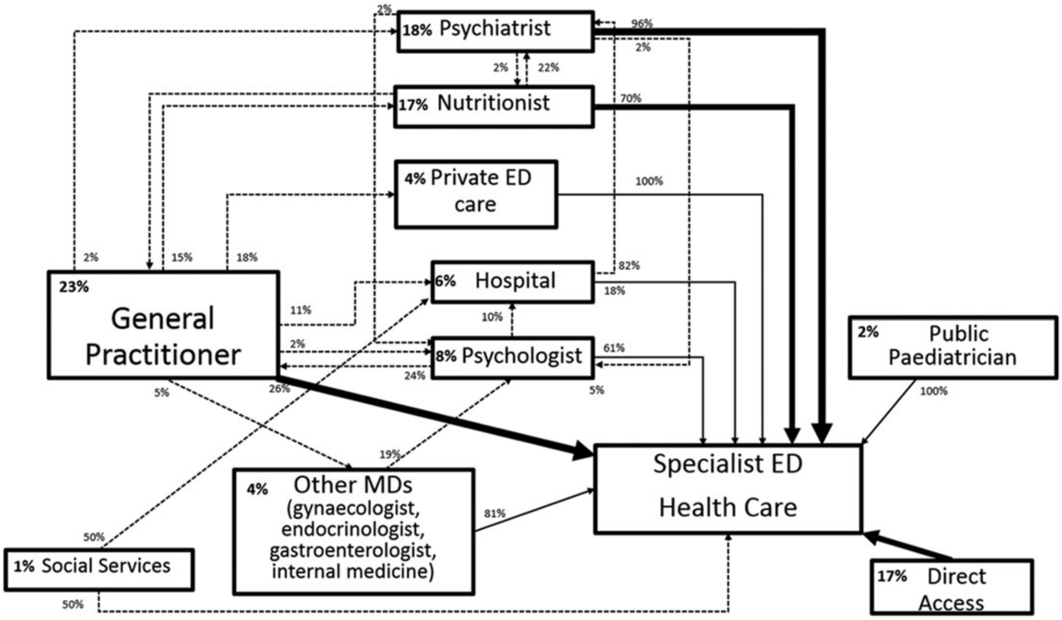

FIGURE 1 The "Pathways Diagram." The "first contact" ratios are presented within each block; each ratio over an arrow represents the percentage of patients that have gone from one carer to another, for each subsequent step of the pathways to specialist eating disorder (ED) care (represented as arrows). The thickness of the arrows provides a graphical representation of the proportion of patients taking each route. Solid lines represent the pathway to the final referral to a specialist care centre, whereas dotted lines represent all previous care steps. ED: eating disorder; MD: medical doctor

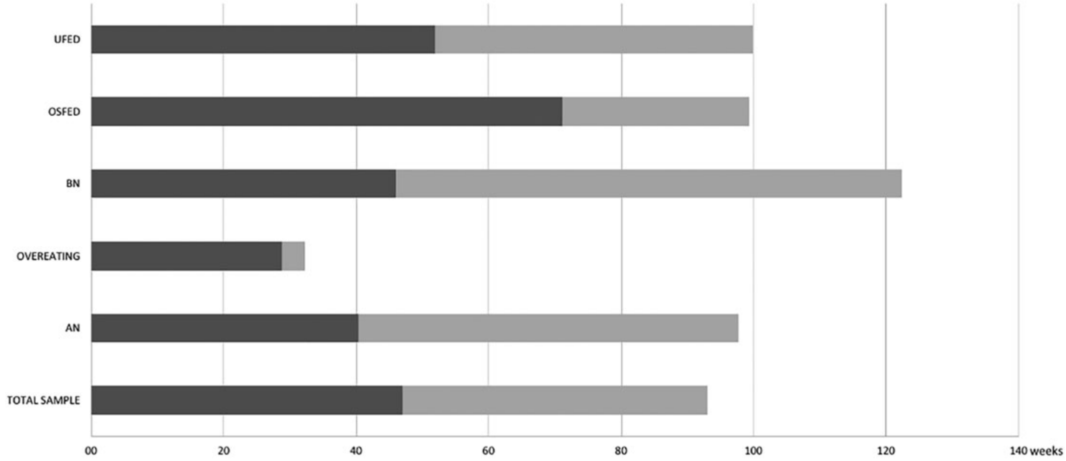

FIGURE 2 Delays in reaching specialist eating disorder (ED) care. Mean values of delay from ED onset to first seeking of care (in black) and from first carer to last carer (i.e., the specialist ED care centre; in grey) are shown for the total sample (bottom) and for each diagnostic subgroup (up). UED: unspecific eating disorders; OED: other specific eating disorders; BN: bulimia nervosa; AN: anorexia nervosa

also particularly relevant in the light of the available evidence concerning the optimal setting and timing of ED care. Indeed, experts in the field tend to highlight that ED patients are best treated in specialized care centres, in consideration of the great difficulties and specific challenges that ED patients pose in terms of care and treatment (Halmi, 2009). Given the high rates of psychiatric and medical comorbidity, specialist ED care should be delivered through multidisciplinary teams, in which various health care professionals (above all psychiatrists but also other medical specialists, psychotherapists, and nutritionists) should be included and should be able to provide evidence-based specific treatment under the coordination of a team leader; finally, such different health care professionals and clinical approaches should be available throughout different levels of care (i.e., outpatient, inpatient, and day care; Halmi, 2009). Although ED patients usually exhibit a high level of health care use, the above requisites are rarely fulfilled by standard psychiatric services (Treasure et al., 2010). Our data shows that a long time is needed to reach specialized care (almost 2 years as a median value with a standard deviation of 60 weeks) and that there is still a significant lack of coordination within the health care system for EDs. Our study thus tends to confirm that a greater effort on ED care coordination is still absolutely necessary and that collaboration between the different nodes of the ED healthcare network needs to be much more close-knit.

The most up-to-date clinical guidelines on EDs tend to converge towards an integrated model of care for EDs, but they also highlight that it is essential that the treatment of EDs should be delivered at the earliest opportunity. For example, the recently released NICE guidelines on EDs (National Institute for Health and Care Excellence, 2017) clearly state that a tailored set of interventions should receive high priority, in order to avoid the negative additional effects of chronicity, of psychiatric comorbidity, and of physical complications due to malnutrition. NICE also further clarifies that "if an eating disorder is suspected" the clinicians should "immediately refer to a community-based, age-appropriate eating disorder service". Our data tend to show that although the above may be considered a more than desirable objective for ED specialist care, a rapid and efficient referral to specialist ED care is probably a result we still have to achieve, at least under routine clinical practice conditions in Italy. However, our data are in line with the recent international observations concerning the lack of dissemination, the unsatisfactory implementation, and the low adherence to the recommendations provided by major international guidelines for EDs in clinical practice (Hilbert, Hoek, & Schmidt, 2017; AlañónPardo, Ferrit Martín, Calleja Hernández, & MorillasMárquez, 2017).

Finally, our data reveals that the time taken for patients to access ED specialist care is longer than desirable, with a median value of about 2 years from symptom onset to first clinical contact. It is well known that specialized care for the treatment of EDs is often not accessible to ED patients (Treasure et al., 2010). This may be partially due to the presence of different barriers that ED patients may face before reaching specialized clinical care, often represented by external stigma and desire for social distance, which often significantly contribute to preventing patients from seeking help (Doley et al., 2017). Such a long time to reach care is likely to represent a specific risk in this clinical population. Recently, several lines of evidence have shown that the age at onset for ED is decreasing compared with a few decades ago (Favaro, Caregaro, Tenconi, Bosello, & Santonastaso, 2009; Matsumoto et al., 2001; Volpe et al., 2016). Such precession of age at onset does not seem to be a random phenomenon, as it is related to specific clinical and psychological features and to a less favourable course (Abbate-Daga et al., 2007). Clearly, in those cases, a longer time needed to reach specialist ED care may imply the risk of higher degrees of chronicity and a worse outcome (Broomfield, Stedal, Touyz, & Rhodes, 2017). Although experts in the field have recently pleaded for the introduction of an "early intervention" approach for EDs and the reduction in the time of untreated symptoms in EDs, they have also recognized that in order to achieve such goals, services will need to be reconfigured to match different clinical phases and settings in the future (Treasure & Russell, 2011). Our data tend to show that, besides some virtuous exceptions, the evolution of primary and secondary care has still to be achieved in routine conditions to truly meet ED patients' needs. This evidence, together with the above reported tendency of a decreasing age at onset for EDs, also calls for greater collaboration with other professionals (such as school counsellors, psychologists, and teachers, as well as sport counsellors) in order to ensure proper prevention and timely recovery from ED during adolescence (Knightsmith, Treasure, & Schmidt, 2013).

Of course, the results of our study have to be considered in the light of several methodological limitations. First, biases concerning the setting and sampling may affect our final results, for example, specialist centres are probably reached by a more severe clinical population, which may explain the relatively higher number of AN and lower number of BED patients, with respect to the data available in the general population; furthermore, atypical ED patients and those who tend to overlook specialized treatment may have been underrepresented in our sample. Second, the generalizability of our study is also relatively hampered by the fact that the study was conducted in several centres, all located in Italy. This inhibits a wider sociocultural perspective for our data as the Italian psychiatric context may represent a "special one" since the1978 psychiatric reform law may have exerted significant effects on psychiatric care in general and in particular for ED care (Volpe et al, 2013). Another possible limitation of our study is its retrospective nature. We used a standardized questionnaire to ensure a careful reconstruction of clinical history and of the care routes followed by each patient, but we did not always have access to original clinical notes; as we could not control for variability in the quality of documentation and previous raters' judgments, some recall bias cannot be completely ruled out.

Finally, also the relatively low number of patients enrolled in the study calls for further research in the field, with a higher number of subjects, more countries included, and a parallel investigation in psychiatric (non-specialist) care settings and in the general population.

Bearing these limitations in mind, our study indicates that the complex needs of people with EDs are still far from being satisfactorily met under routine care conditions, that many non-psychiatric healthcare professionals are involved in the first steps of ED care (most notably, general practitioners, paediatricians, and nutritionists), and that the general population might still face many barriers to access to ED specialist care. Thus, in the future, new strategies aiming to increase awareness about EDs in the general population, within schools and sport facilities, and among different health care professional figures will have to be implemented in order to ensure that ED patients will promptly receive specialized care and appropriate evidence-based treatment.

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CONFLICT OF INTERESTS

The authors certify that they have no affiliations with or involvement in any organization or entity with any financial interest (such as honoraria; educational grants; participation in speakers' bureaus; membership, employment, consultancies, stock ownership, or other equity interest; and expert testimony or patent-licencing arrangements) or non-financial interest (such as personal or professional relationships, affiliations, knowledge, or beliefs) in the subject matter or materials discussed in this manuscript.

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