

# Gender dysphoria in adolescents: the need for a shared assessment protocol and proposal of the AGIR protocol

*La disforia di genere negli adolescenti: la necessità di un protocollo di assessment condiviso e la proposta del protocollo AGIR*

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## Summary

In the Center of Expertise on Gender Dysphoria at the VU University Medical Center in Amsterdam, a structured assessment and treatment protocol for adolescents with atypical gender identities is used. This multidimensional approach includes specific phases: psychological assessment, medical evaluation, possible psychotherapy, gonadotropin-releasing hormone (GnRH) analogues and cross-sex hormone therapy, which are differentiated according to age and specific requirements of each individual case. Recently, a collaborative study called AGIR (Adolescent Gender Identity Research) has been proposed by the Dutch clinic to allow international and cross-clinic comparisons with regards to referral background and psychological functioning, and to evaluate the treatment of gender dysphoric adolescents. An extensive assessment and timely treatment of adolescents

with gender dysphoria seems essential to support the process of awareness and structuring of the dimensions of sexual identity, to prevent frequent associated psychopathologies and to improve quality of life by promoting more adequate psychosocial adaptation. Currently, transgender health care in Italy is characterized by isolated practitioners. Thus, it is particularly important to create specialised services that use a common protocol and that are coordinated at both the national and international levels in order to respond to the increasing number of requests in this age group.

## Key words

Gender identity • Gender Dysphoria • Assessment • Intervention • Protocol • Adolescents

## Introduction

There is perhaps no area of transgender health care that elicits as much controversy as the issues raised regarding the psychotherapeutic and medical needs of gender variant and gender dysphoric youth<sup>1</sup>. These issues are increasingly a matter of interest in the media and scientific literature. In particular, gender identity consists in the continuous and persistent sense of the Self as a male, a female<sup>2</sup>, or as another gender, different from the binary of two genders. Gender Dysphoria (GD) is expressed by significant discomfort that is usually associated with the incongruence between gender at birth and gender identity<sup>3</sup>, and represents a dimensional phenomenon that can occur with different degrees of intensity, of which the most extreme form is accompanied by a desire for gender reassignment (GR).

Aetiopathogenic theories are still uncertain, and debates on which treatment approaches to refer to are on-going,

particularly when it comes to early GR in adolescents<sup>4-5</sup>. No unequivocal aetiological factor or set of factors determining atypical gender development has been found to date. With the current state of knowledge, it remains plausible that a complex interaction between a biological predisposition in combination with intra- and interpersonal factors contribute to a development of gender dysphoria, which may come in different forms and intensities<sup>6</sup>.

Gender dysphoria can have an early onset, since preschool age, with extremely variable and hard to predict clinical outcomes. Children with atypical gender identity, in fact, represent a heterogeneous group, whose psychosexual and sexual identity development are still in progress<sup>5</sup>. The diagnostic criteria of GD in children and adolescents, as described in DSM 5, may therefore be indicators of a slight form of gender variance, or an early expression of a homosexual, bisexual, transgender, or gender queer development, which may or may not be accompanied by gender dysphoria<sup>6</sup>.

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From current studies, it seems that only a percentage of 12-27% of children diagnosed with GD in childhood will also manifest gender dysphoria in adolescence and adulthood<sup>8</sup>, and will ask for a complete GR<sup>4-5</sup>. To date, it is not known when or how gender dysphoria persists or desists. Clinical experience has shown that this often happens just before or just after the onset of puberty<sup>6-8</sup>. While childhood GD includes a wide range of outcomes, when it persists in the beginning of puberty, it will rarely desist into later adolescence and adulthood<sup>6</sup>. The WPATH (*World Professional Association for Transgender Care*) in its current 7<sup>th</sup> edition of the SOC<sup>9</sup> emphasises the differences between GD in childhood from that in adolescence and in adulthood, as it is characterised by greater fluidity and variability in outcomes, especially in prepubertal children.

At present, the majority of demographic information about transgender youth comes from research performed in the main clinics specialised in gender dysphoria: Canada, the United Kingdom, and the Netherlands<sup>10-11</sup>. There is virtually no record of the characteristics of children or teenagers who are gender variant, but do not have GD or who seek other help than in specialised clinics. Regarding the situation in Italy, a study was conducted by Dèttore, Ristori and Casale (2011)<sup>12</sup> on 350 children aged between 3 and 5 years with the specific aim of defining the main descriptive characteristics of gender identity in preschool age and to estimate the prevalence of atypical gender behaviour through the administration of the Gender Identity Interview for Children<sup>13</sup>. In this study, the prevalence of gender variant responses was found to be 5.23% in males and 3.93% in females, and 4.57% in the total sample<sup>12</sup>.

Adolescents with GD, often have emotional and behavioural problems, self-harm, use and abuse of drugs, isolation from homophobic and transphobic families, higher suicide risk and are victims of violence with higher psychiatric comorbidities<sup>14-16</sup>. In particular, adolescents seen in gender identity clinics report higher rates of internalising psychopathologies compared with peers in the general population<sup>15-17</sup>. However, adolescents seen at the Dutch clinic report less psychiatric comorbidity than a clinically referred psychiatric population<sup>15</sup>. Adolescents who experience GD often suffer marginalisation and social stigma, issues that also affect gender dysphoric adults<sup>18-19</sup>. However, in the case of teenagers marginalisation and social stigma have a specific meaning (in terms of content and consequences) and must therefore be carefully addressed, taking into account the complex changing mechanisms on both the physical and psychological levels<sup>20</sup>.

Early assessment of gender variant youth seems important to support awareness and structuring of sexual identity dimensions, to prevent associated psychopathology (if

present), and consequently to improve the quality of life and psychosocial wellbeing<sup>6</sup>.

Treatment of gender dysphoric adolescents is controversial and there is currently no consensus on psychological and medical intervention. This is likely related to the fact that there are no properly designed outcome studies evaluating psychological interventions, and only a few studies evaluating medical interventions. From the available studies, it appears that administration of gonadotropin releasing hormone (GnRH) analogues (at tanner stage 2-3) to suppress puberty and early cross-sex hormone treatment (between 16 and 18 years), followed by GR surgery at 18 years, can be effective and positive for both general and psychological functioning of selected adolescents with GD<sup>6-21</sup>.

The Dutch Approach, including the AGIR protocol ("Adolescent Gender Identity Research" Group), proposed by the *Center of Expertise on Gender Dysphoria* of the *VU University Medical Center* in Amsterdam, is becoming a worldwide benchmark for evaluation and treatment of children and adolescents with GD<sup>6</sup>.

## Diagnosis

At present, the patho-biological basis of GD is unknown. Diagnosis is based primarily on psychological methods<sup>20</sup>. In May 2013, the DSM-5 was published with changes in name (*Gender Dysphoria*) and criteria, as follows:

- A) A marked incongruence between one's experienced/expressed gender and assigned gender, of at least 6 months duration, as manifested by 2 or more of the following indicators:
- a marked incongruence between one's experienced/expressed gender and primary and/or secondary sex characteristics (or, in young adolescents, the anticipated secondary sex characteristics);
  - a strong desire to be rid of one's primary and/or secondary sex characteristics because of a marked incongruence with one's experienced/expressed gender (or, in young adolescents, a desire to prevent the development of the anticipated secondary sex characteristics);
  - a strong desire for the primary and/or secondary sex characteristics of the other gender;
  - a strong desire to be of the other gender (or some alternative gender different from one's assigned gender);
  - a strong desire to be treated as the other gender (or some alternative gender different from one's assigned gender);
  - a strong conviction that one has the typical feelings and reactions of the other gender (or some alternative gender different from one's assigned gender);

B) The condition is associated with clinically significant distress or impairment in social, occupational, or other important areas of functioning, or with a significantly increased risk of suffering, such as distress or disability.

The diagnosis specifies two subtypes, with or without Disorders of Sexual Development (DSD). In the DSM-5 diagnosis, DSM-4-TR criterion C (the disturbance is not concurrent with a physical intersex condition) has been abandoned.

### *Differential diagnosis in adolescence*

In adolescence, the main differential diagnoses in GD are ego-dystonic homosexual orientation, transvestic fetishism, disorders in the psychotic spectrum<sup>5</sup> and body dysmorphic disorder<sup>22</sup>. Not all adolescents with GD manifest a clear and explicit desire for medical/surgical GR, and they can be concerned about only some aspects of their gender identity or other dimensions of sexual identity in general. For example, adolescents with a homosexual orientation often have a history of cross-gender behaviours and interests in childhood. They may therefore have trouble distinguishing the dimension of sexual orientation from gender identity, or may find it difficult to accept their homosexuality due to more or less severe forms of internalised homonegativity<sup>23</sup>. In other cases, cross-dressing behaviours may be transient, occasional, compulsive, or associated with a state of sexual arousal (as in transvestic fetishism), and may be mistaken for a desire for hormonal/surgical GR. This can occur in individuals with or without psychiatric disorders. For example, in case of psychotic spectrum conditions, delusions of belonging to the other gender may be present. In cases of major psychopathologies, the opportunity for medical transition must be carefully evaluated and postponed in order to allow treatment of the psychiatric disorder and assess the levels of the psychosocial functioning over time<sup>19</sup>.

There are also cases of individuals with GD who do not require a full transition, but rather try to integrate their own masculine and feminine aspects by adopting an androgynous or bi-gendered form of gender expression. In these cases, requests are more frequently oriented towards hormone therapy or surgery that only minimises the male or female phenotypic characteristics, but not forward a complete GR. However, these cases tend to appear more rarely in adolescence, probably because individuals with an early GD onset tend to have more extreme forms of GD. Considering the developmental processes of adolescence, which often include testing of different identities and expressions of the Self, special attention is required in the case of adolescents who arrive with a specific request for partial changes<sup>20</sup>. In these cases,

forms of psychotherapy are probably more appropriate to clarify their situation and observe the evolution to ensure that any decision will be taken in a conscious manner. Even in cases of adolescents who have a clear diagnosis of GD, but who do not show any psychological skills of resilience and who do not have adequate social support, it is sometimes advisable to postpone cross-sex hormone treatment and/or surgery and try to create the basis for a positive outcome in the event of a possible GR<sup>20</sup>. Finally, the importance and clinical utility of a dimensional measure of gender identity/gender dysphoria in adolescents is clear. Even though GD has a low prevalence<sup>7</sup>, the number of individuals who identify themselves as transgender individuals and who do not apply for GR seems to be far more prevalent than individuals who seek GR<sup>24</sup>. This makes a more sophisticated clinical approach of transgender applicants necessary instead of only assessing whether someone fulfils criteria for a complete GR.

### **Assessment**

The assessment of GD is a complex process. However, the importance of an early and individualized assessment seems crucial in order to carefully evaluate the transgender identification, comorbidities and planning of an appropriate intervention<sup>4-20</sup>.

### *The Dutch Protocol*

In line with current guidelines (Hembree, 2009), health care professionals who work with GD in adolescents tend to refer increasingly to the Dutch Protocol, developed by the team at the Center of Expertise on Gender Dysphoria at the VU University Medical Center (VUMC) in Amsterdam. In particular, their model is described in the document *Caring for Transgender Adolescents in BC: Suggested Guidelines Clinical Management of Gender Dysphoria in Adolescents*<sup>19</sup> and in the more recent article *Clinical Management of Gender Dysphoria in Children and Adolescents: the Dutch Approach*<sup>6-25</sup>. The Dutch approach was revolutionary in this field as it was the first to offer early medical interventions to adolescents. Treatment was very closely monitored and based on on-going evaluation, as shown by the publications on the subject<sup>6-25</sup>. In particular, it is characterised by a multidimensional approach that includes different phases (*medical and psychological assessment, puberty suppression, and hormonal and surgical reassignment*). Ideally, it requires a multidisciplinary team consisting of child psychologists, child psychiatrists, psychometrists, paediatric endocrinologists, and – in the later surgical stages – plastic surgeons, gynaecologists and urologists. This approach emphasises that the assessment process has to be extensive, thorough and include different stages.

According to the Dutch Protocol, assessment of a gender variant adolescent requires psycho-diagnostic evaluation that includes general development, functioning in the different life areas and assessment of associated psychopathologies. Moreover, it is important to explore how the parents have raised the child, family history, family functioning and cultural and religious values. Specific assessment of GD should clarify whether the adolescent fulfils DSM diagnostic criteria for GD, excluding reactive forms or other differential diagnoses, excluding associated psychopathologies, and identify potentially predisposing and maintaining factors. It is also useful to reconstruct the onset of atypical gender behaviour, along with its characteristics and pervasiveness of expression in different life contexts. The methodology includes interviews with the adolescent and parents together with psychometric tests. During interviews with parents, one should assess the concordance of parental expectations and treatment objectives, as well as the opinions of both parents about their child's eventual psychosexual outcome, e.g. a future homo- or bi-sexual orientation. In the diagnostic phase, furthermore, the adolescent has to be accurately informed about the short and long-term consequences, and also regarding the limits of hormonal and surgical treatment to circumvent unrealistic expectations. The assessment also evaluates psychological and/or social risk factors that could possibly interfere (e.g. social phobia) with a good outcome of the intervention and that, if present, should be treated, sometimes even before the GD<sup>1</sup>. A particularly important aspect of investigation in the case of adolescents with GD is body image. It can happen that adolescents, who have received a treatment that has delayed pubertal development, are frustrated because they perceive the waiting period for the cross-sex hormone therapy as too long, as their bodies will not feminise or masculinise at the same pace as in their peers<sup>20</sup>. Moreover, greater internal conflicts and stronger negative emotions may be present if secondary sex characteristics are already developed before treatment. In fact, this frequently leads to breast binding or to other attempts of concealing breasts, penis and/or testicles. In these cases, emotions and feelings of shame, frustration and regret can be present because the treatment was not started earlier. Some adolescents may feel extremely confused to maintain their genitals of the natal sex, when the rest of their body is already changing, as a result of treatment with cross-sex hormones<sup>20</sup>. Regarding the therapeutic relationship, it is fundamental that the clinician holds a neutral attitude regarding any possible outcome in order to help the adolescent to explore openly his/her gender dysphoria and the desire for treatment<sup>6</sup>.

According to the Dutch Protocol, there are three types of interventions in adolescents: fully reversible, partially reversible and irreversible<sup>6-20</sup>. Fully reversible interventions

include therapeutic procedures whose effects are temporary, and allow to completely reinstall the initial situation in the case of suspension of the therapy. In particular, the administration of specific compounds, namely GnRH analogues, is considered. These are used in order to block puberty, or the processes of masculinisation/feminisation that characterises pubertal development. In the Netherlands, this possibility is given to carefully selected adolescents from 12 years on, who are at least in Tanner stage 2 or 3, live in a supportive environment, and have no serious psychosocial problems that interfere with diagnostic assessment or treatment<sup>20</sup>. Adolescents can thus explore their GD more extensively, and any desire to social or medical transition, without experiencing the distress of pubertal development. It is assumed that emotional problems that many young people with GD experience at the onset of puberty can thus be prevented<sup>6-26</sup>. Furthermore, blocking the development of secondary sex characteristics facilitates the transition to the desired gender role and later functioning in that role. For these reasons, this phase is considered as a part of the diagnostic process, and in the assessment phase it is explicitly discussed that such treatment can be interrupted at any time, thus leaving open all possible outcomes<sup>6</sup>.

A recent study has shown that the overall psychological functioning of adolescents diagnosed with GD improved after an average time of two years from the beginning of treatment with GnRH analogues. In particular, a lower percentage of emotional and behavioural problems and depressive symptoms was found. However, this treatment had no effect on the levels of GD, thus supporting the hypothesis that adolescents who are accurately diagnosed maintain unaltered levels of GD in the remainder of adolescence and into adulthood, unless treated<sup>19</sup>. Previous studies have also shown that only cross-sex hormone therapy or GR surgery was likely to have an impact on the levels of GD<sup>27</sup>. These results were confirmed by a recent study in adolescents, which seems to show that GR surgery preceded by GnRH analogue treatment is effective in overcoming GD (de Vries, 2012). The concerns that early physical intervention will have unfavourable physical effects have not been confirmed<sup>26-28</sup>.

Partially irreversible interventions refer to cross-sex hormone therapy, which represents the first step of an actual GR. According to the Dutch Protocol, adolescents are eligible for such treatment if they meet the aforementioned criteria and if they have at least reached the age 16<sup>6</sup>, unless there are medical reasons (e.g. expected tall height in male-to-females) to start somewhat earlier. Finally, completely irreversible interventions refer to sex reassignment surgery, the last step of the GR trajectory, which are possible after the person has reached the age of 18.

## The AGIR (Adolescents Gender Identity Research Group)

Given the current difficulties in the assessment of gender identity in developmental age and considering the need for a shared protocol, the Dutch team has agreed with a number of centers to use a battery of tests that are clinically useful and enable cross-clinic research, e.g. permit evaluative comparisons or descriptions of populations<sup>\*</sup>. As a part of the AGIR project, structured assessment of the adolescent's overall functioning and GD is performed. Specifically, the first part involves the administration of the following instruments:

- *Child Behavior Checklist* (CBCL)<sup>29</sup>;
- *Youth Self Report* (YSR)<sup>29</sup>;
- *Teacher's Report Form* (TRF)<sup>29</sup>;
- *The Children Global Assessment Scale* (CGAS)<sup>30</sup>.

The CBCL, YSR and TRF tests are part of the *System of evaluation on empirical basis* by Achenbach et al. (2008) and allow description of the child's behavioural and emotional repertory through the reports given by parents, teachers and the children themselves with the aim of evaluating the presence of potentially problematic behaviours listed within behavioural scales<sup>29</sup>. The answers can be rated on a 3 point scale (0 = not true; 1 = sometimes true; 2 = very true). The scales consist of about 100 items, grouped in 8 syndrome scales according to a dimensional approach: *Anxiety and depression* (evaluates the presence of depressive symptoms as sadness, irritability, loneliness, low self-esteem and feeling of not being loved); *Withdrawal and depression* (evaluates social closure, tendency to isolate, shyness and discretion); *Somatic complaints* (evaluates the tendency to express anxiety and concern through physical disorders as nausea, stomach pain and headache); *Social problems* (evaluates the difficulty within the relationships with peers as being teased and not getting along with peers); *Problems of thought* (evaluates the presence of thoughts and perceptions that are not reflected in reality); *Problems of attention* (evaluates the difficulty to maintain the concentration and the tendency to hyperactive behaviour such as impulsivity, irritability and motor restlessness); *Rule transgression behaviour* (evaluates the tendency to assume delinquent behaviours such as stealing, lying, setting fires and using alcohol or drugs); *Aggressive behaviour* (evaluates the presence of aggressive, provocative and destructive behaviours towards people or property). Moreover, it is possible to evaluate

behaviour through the three general following scales: *Internalising*, *Externalising* and the *Total Problem Scale*. Finally, it is possible to identify 6 scales which are based on the categorical DSM-4-TR classification: *Affective problems* (dysthymia and major depression), *Anxiety problems* (generalised anxiety, separation anxiety and phobias), *Somatic problems* (somatisations and somatoform disorders), *Attention problems and hyperactivity*, *Oppositional-provoking problems* and *Behavioural problems*. The test score provides a profile of the child's competences, syndrome scales, general scales and *DSM oriented scales*. Regarding psychometric properties, Achenbach et al. (2008) can be consulted<sup>29</sup>.

The CGAS<sup>30</sup> is one of the most widely used clinician rated scales for evaluation of the severity of disorders in young people. This is a one-dimensional measure of social and psychiatric functioning of children and adolescents aged between 4 and 16 years on a scale from 1 to 100. The CGAS is based on the adaptation of the *Global Assessment Scale* (GAS) for adults to children and adolescents, and can be used as an indicator of the need for activation of clinical services, as a marker of the impact of treatment, or as a single index of impairment within epidemiological studies.

The main objectives of the second part of the assessment are to specifically evaluate GD<sup>7</sup>. In particular, the following psychometric instruments are administrated:

- the *Gender Interview for Adolescents and Adults*<sup>31</sup>; this is a structured interview consisting of 27 items that explores gender identity and GD in the last 12 months in adolescents and adults. Specifically, gender identity and GD are conceptualised along a continuum, characterised by male and female poles, which includes various degrees of GD and gender uncertainty. For psychometric properties, the reader can consult Deogracias et al. (2007)<sup>31</sup>;
- the *Utrecht Gender Dysphoria Scale* (UGDS) (Steensma et al. in press); this instrument consists of 12 items answered on a 5-point Likert scale, which specifically measures GD and the distress perceived by the individual in relation to daily confrontation with his/her gender. Higher scores indicate more severe GD. For the specific psychometric properties, Cohen-Kettenis and van Goozen (1997)<sup>32</sup> can be consulted (Steensma et al. in press);
- *Recalled Childhood Gender Identity Scale*<sup>33</sup>; this is a retrospective questionnaire which consists of 23 items designed to measure recalled gender-typed behaviours and relative closeness to parents during child-

<sup>\*</sup> All the instruments used in the protocol of the AGIR research group in Amsterdam are currently being translated, adapted and validated by the authors of the present contribution, who form the reference research group for this protocol in Italy, and are part of the multicentre international research project managed by the Amsterdam group.

hood. For the specific psychometric properties, see Zucker et al. (2006)<sup>33</sup>;

- *Body Image Scale* (BIS)<sup>34</sup>; this is a questionnaire that measures the satisfaction with one's body parts and is composed of 30 items divided into three subscales: primary, secondary and neutral. Higher scores correspond to higher levels of dissatisfaction with one's body. For the specific psychometric properties, see Lindgren and Pauly (1975)<sup>34</sup>.

## Conclusions

GD in adolescence is a complex phenomenon, whose origins are most likely multifactorial, that requires further study. Considering the growing demand for specialised services for GD in adolescence, it is important that mental health professionals who deal with these issues use assessment protocols that are comparable, both nationally and internationally, and increasingly based on empirical research. In this regard, the Dutch Approach, now largely included in the WPATH's SOC, and the AGIR project, provide an opportunity to perform comparative research between clinics<sup>8</sup>.

Currently, mental health professionals are in a delicate and difficult situation when it comes to clinical decisions. They may intervene in the case of false positives, thus causing damage, or choose not to intervene, and as a consequence not alleviate the suffering of transgender adolescents who actually need these interventions. Lately, the age of the adolescents who come to the attention of specialists and require a GR has decreased considerably. It is not unusual, in fact, that adolescents 12 years old have an explicit request for a medical/surgical GR. Of course, this raises ethical and clinical issues with no easy solution<sup>6-25</sup>.

In response to the criticism that has been formulated against the early treatment of adolescents starting with puberty suppression<sup>5</sup>, the Dutch team underlines the importance of considering the consequences of non-treatment. Non-treatment does not represent a neutral option and, in some cases, can lead to negative consequences in the long-term for those people who have to wait until after puberty to begin hormone treatment. For example, individuals could be pushed to behave in an irresponsible and dangerous manner to have access to hormone therapy, confidence in professional help could be undermined and, finally, developmental processes and psychological functioning could be impaired. The philosophy *in dubio abstinere* could therefore be harmful<sup>20</sup>.

Structured guidelines for the assessment and treatment of gender dysphoric adolescents will assist professionals to help in resolving the adolescents' acute sense of unhappiness and developing the resources to live peacefully with their families and peers<sup>4</sup>. The Dutch Approach, taking into account all aspects of adolescent psychosocial

functioning, not only aims to solve gender dysphoria, and eliminating it, but also to strengthen the resources of the person to ensure optimal psychological development and a good quality of life.

### Conflict of interests

The authors have not received grants.

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