European Psychiatry 27 (2012) 445–450

Available online at
ScienceDirect
www.sciencedirect.com

Elsevier Masson France
EM|consulte
www.em-consulte.com

Original article

A European network for the investigation of gender incongruence: The ENIGI initiative

B.P.C. Kreukels [a], I.R. Haraldsen [b], G. De Cuypere [c], H. Richter-Appelt [d], L. Gijs [a], P.T. Cohen-Kettenis [a,*]

[a] Department of Medical Psychology, VU University Medical Centre, P.O. Box 7057, 1007 MB, Amsterdam, The Netherlands
[b] Department of Neuropsychiatry and Psychosomatic Medicine, Rikshospitalet, 0027 Oslo, Norway
[c] Department of Sexology and Gender problems, University Hospital Ghent, De Pintelaan 185, 9000 Ghent, Belgium
[d] Department of Sex Research and Forensic Psychiatry, University Medical Centre, Hamburg-Eppendorf, 20246 Hamburg, Germany

ARTICLE INFO

Article history:
Received 4 January 2010
Received in revised form 13 April 2010
Accepted 22 April 2010
Available online 9 July 2010

Keywords:
Transsexualism
Gender identity disorder
Gender incongruence
Transgenderism
Gender dysphoria
Cultural differences

ABSTRACT

Studies on diagnostic subtypes of gender identity disorder (GID) or gender incongruence (GI), comorbidity and treatment outcome show considerable variability in results. Clinic/country specific factors may account for the contradictory results, but these factors have never been studied. This article is the first of a series reporting on a unique collaborative study of four European gender identity clinics (the European network for the investigation of gender incongruence [ENIGI]). Here, we present the diagnostic procedures of the four clinics (Amsterdam, Ghent, Hamburg, and Oslo), the standard battery of instruments, and the first results regarding applicants with GI who seek treatment. Applicants in the four clinics did not differ in living situation, employment status, sexual orientation, and age of onset of GI feelings. However, the Amsterdam and Ghent clinic were visited by a majority of natal males, whereas Hamburg and Oslo see more natal females. Male applicants were older than female applicants within each country, but female applicants in one country were sometimes older than male applicants in another country. Also, educational level differed between applicants of the four clinics. These data indicate that certain sociodemographic and/or cultural characteristics of applicants have to be taken into account in future studies.

1. Introduction

"Gender incongruence" refers to the incongruence between one's experienced/expressed gender on the one hand, and one's assigned gender and/or one's congenital primary and secondary sex characteristics on the other hand. [25]. Individuals with GI form a heterogeneous group. In the literature they are known under various names: transsexuals, gender queer, gender variant, transgender individuals, individuals with gender dysphoria, or individuals with gender identity disorder. The last term is the name of the current DSM-IV-TR [1] diagnosis and refers, like transsexualism (ICD-10) [31], to extreme gender dysphoria only. In this paper, we will use the term GID only when we refer to the clinical diagnosis. GI will be used when we refer to those who were seeking help because of gender identity issues, but have not yet been diagnosed.

As a result of the debate on psychological health and GI, many studies have been conducted to assess the relationship between psychological functioning/psychiatric comorbidity and various forms of GI. Between studies, results vary widely. Some report a high prevalence of psychiatric comorbidity among transsexuals [8,19], whereas in other studies, psychological functioning of transsexuals was in the non-clinical range [16,17].

To assess the effectiveness of gender reassignment, a large number of follow-up studies have been conducted (see Pfäfflin & Junge [26], for studies until 1990, and Gijs & Brewaeys [14], for studies between 1990–2007) and showed that postsurgical outcome was relatively poor in some studies, and intermediate or satisfactory in other studies.

The Standards of Care of the World Professional Association for Transgender Health (WPATH) are, in most centres, used as guidelines for the clinical management of GID/transsexualism [18]. In these guidelines, the DSM and ICD are used to classify the diagnoses of GID (DSM-IV-TR) [1] and Transsexualism (ICD-10) [31]. However, there is still a lack of clarity with respect to the way clinicians weigh diagnostic indicators to come to a diagnosis of GID/transsexualism. The previously mentioned inconsistencies in findings regarding psychological functioning and treatment outcome may well result from differences in the way clinicians

* Corresponding author. Tel.: +31 20 4442550; fax: +31 20 4443077.
E-mail address: pt.cohen-kettenis@vumc.nl (P.T. Cohen-Kettenis).

0924-9338/$ – see front matter © 2010 Elsevier Masson SAS. All rights reserved.
doi:10.1016/j.eurpsy.2010.04.009

make their diagnoses or from differences between clinics in diagnostic procedures. Unfortunately, with regard to reliability, no research exists.

Besides differences in diagnostics, other factors, such as country/clinic differences in type of referrals (e.g., with respect to age of GI onset or sexual orientation), or in the attitude towards GI and concomitant differences in stigmatization may also play a role in the variability of study results. In single clinic studies, the influence of such factors on the study results cannot easily be determined.

In order to obtain more transparency in diagnostics and treatment of GI, four major West European gender identity clinics have initiated a collaboration in the "European network for the investigation of gender incongruence" (ENIGI). To facilitate cross-country and cross-clinic comparisons, the participating gender identity clinics (Amsterdam, Ghent, Hamburg, and Oslo) now have one diagnostic protocol and use the same assessment battery. The intention is to also develop a common hormone treatment protocol in the near future. By using similar instruments and procedures, the collaborating clinics aim to gain better insight in the phenomenon of GI and its treatment effectiveness, and to explain some of the contradicting findings in the literature. A further advantage of this collaboration is that data can be collected faster in this rare condition than when each centre would work separately.

The research topics that will be addressed in this collaborative project regard:

1. A description of applicants for treatment of GI in the four clinics.
2. The outcome of the diagnostic process in the four clinics.
3. Psychological functioning/psychiatric comorbidity of applicants for treatment of GI.
4. GI subtypes.
5. Factors predicting post-treatment outcome.

The aims of this first article are to present the procedures and instruments that will be used in this collaborative study, and to describe the first 271 applicants for treatment of GI in the four participating gender identity clinics.

2. Materials and methods

2.1. Subjects

In Ghent, Hamburg, and Oslo all applicants with GI of 16 years and older were asked to participate in this study. In the Netherlands, only GI applicants of 17 years and older were asked to participate, as 16-year-olds already participated in another study. Applicants with insufficient command of the respective languages, applicants who already had undergone some form of medical treatment (hormones or surgery), and applicants who were clearly psychotic when seen at first entrance were not invited.

2.2. Procedure

The principle researchers first agreed upon a diagnostic procedure that would be as similar as possible among the three institutions. Due to the specific clinical context at individual institutions, this was not possible in all respects. Subsequently, a number of instruments were selected that measured the main concepts for this study that were feasible for all centres to use in their respective clinical settings.

The ethics committees of all four collaborating clinics approved the study. Written informed consent was obtained from study participants according to institutional guidelines.

3. Instruments

Considering the main research questions, the following instruments have been chosen:

GID symptoms and background variables:

- A *background data interview* (MtF and FtM version). This is an adjusted version of the Dutch BVT (*Biografische Vragenlijst Transseksualiteit,* in English: Biographic Questionnaire on Transsexualism) [29] with questions about sociodemographic characteristics, social contacts, psychological and physical problems, family problems, gender development, cross-dressing, sexuality, and desired treatment. For many years, this instrument has been used as a part of the diagnostic procedure in the Amsterdam and Ghent clinics.
- The *Utrecht Gender Dysphoria Scale* (UGDS). This scale consists of 12 questions to measure the degree of experienced gender dysphoria [6].
- The *Body Image Scale* for evaluating transsexuals. This scale consists of 30 items to determine satisfaction with various body parts [24].
- The *Gender Identity Questionnaire*. This questionnaire has 22 items and four scales (male gender identity, female gender identity, 'certainty to belong to a gender,' and transgender identity) [27].
- The *Gender Identity/Gender Dysphoria Questionnaire for adolescents and adults*. This instrument consists of 27 questions regarding gender identification during the last 12 months [10].
- The *Hamburg Drawing Body Scale*. This scale measures the satisfaction with different body-parts with the help of a schematic drawing [3].

Psychological functioning/psychiatric comorbidity of applicants:

- The *SCL-90-R, Symptom Checklist*, assessing self-reported psychological burden on nine symptom scales: somatisation, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoneuroticism [11].
- The *MINI-PLUS* interview assessing DSM axis I disorders [28].
- The *SCID-II* interview assessing DSM axis II disorders [13]
- The Global Assessment of Functioning (*GAF*) assessing DSM axis V [12].

Measures also to be used for assessing postoperative outcome:

- The *SF-36*, measuring health-related quality of life on eight dimensions: physical functioning, role-physical, bodily pain, general health, vitality, social functioning, role-emotional, and mental health [30].
- Two scales measuring aspects of general quality of life: "*Life as a whole,*" [4] measuring general satisfaction with one's life, and the *Social Readjustment Rating Scale* [20], a rating scale with 43 social and life events that may have happened in the last six months.
- The *physical appearance scale*. This is a rating scale for the subjective appraisal by an observer of a person's gender (in-)compatibility in physical appearance [29].

Use of symptoms to come to GID/GID related diagnoses:

- A self-constructed score-sheet with 23 items based on the DSM-IV-TR symptoms and diagnostic criteria to be filled out by the clinicians after they have made a diagnosis.

Potential predictors of outcome:

- A short self-developed list of potential risk factors, according to the clinicians, to be filled out at the moment of referral for hormone treatment.

4. Clinical procedures of the four clinics

4.1. VU University Medical Centre, Amsterdam, The Netherlands

The multidisciplinary Amsterdam team started to provide diagnosis and comprehensive treatment (psychological/psychiat-